Alzheimer's Disease International

The global voice on dementia

World Alzheimer Report 2020

Design, Dignity, Dementia:
Dementia-related design and the built environment

Volume I

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ADI and the report authors extend their appreciation to all of the people who nominated buildings and spaces, who contributed to case studies and offered their design experiences and insights. Inclusion in the report is not an endorsement of operations and reflects a sample of the current diverse range of establishments and operations globally.

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Richard Fleming trained as a clinical psychologist and worked in aged care homes in London and the back wards of a large psychiatric hospital in Australia where he learned a great deal about what should not be done to people living with dementia. This experience has been of great value to him in his efforts to develop better environments and services for, and with, them.

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Author of I'm Still Here: a new philosophy of Alzheimer's care, Dr. Zeisel is Founder of The Hearthstone institute and the I'm Still Here Foundation. A sociologist with a background in design, John champions nonpharmacological "ecopsychosocial" interventions in dementia care with an emphasis on the impact of the physical environment and engagement on improving quality of life and reducing reactive behaviours.

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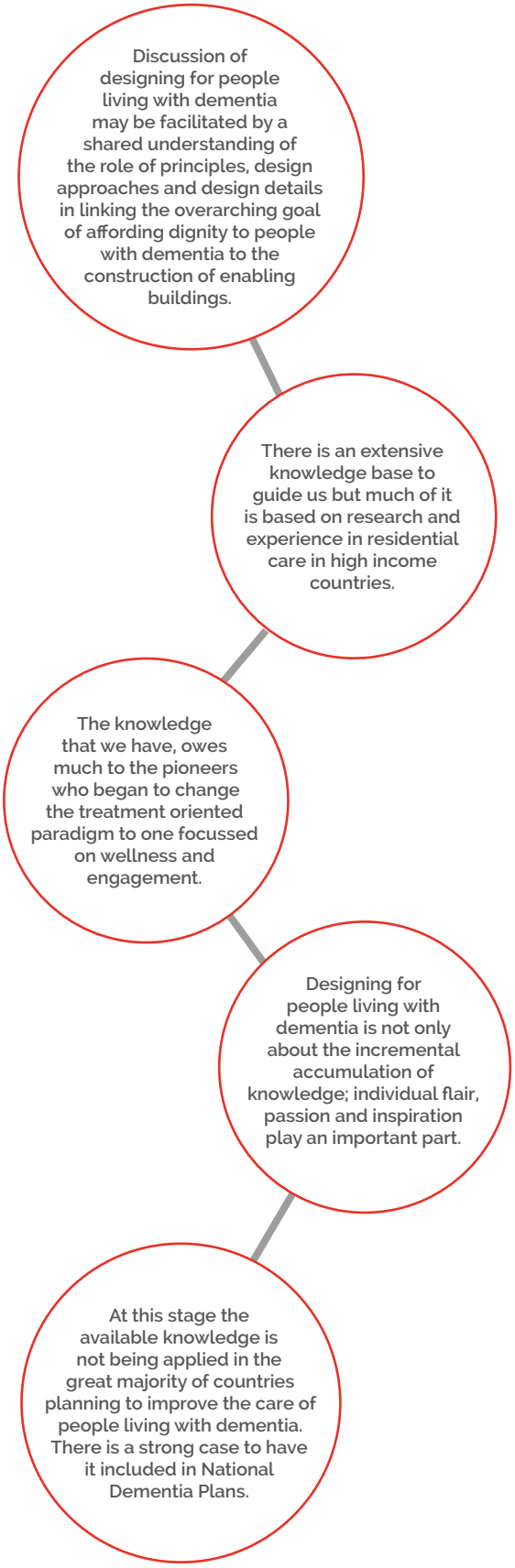
The story



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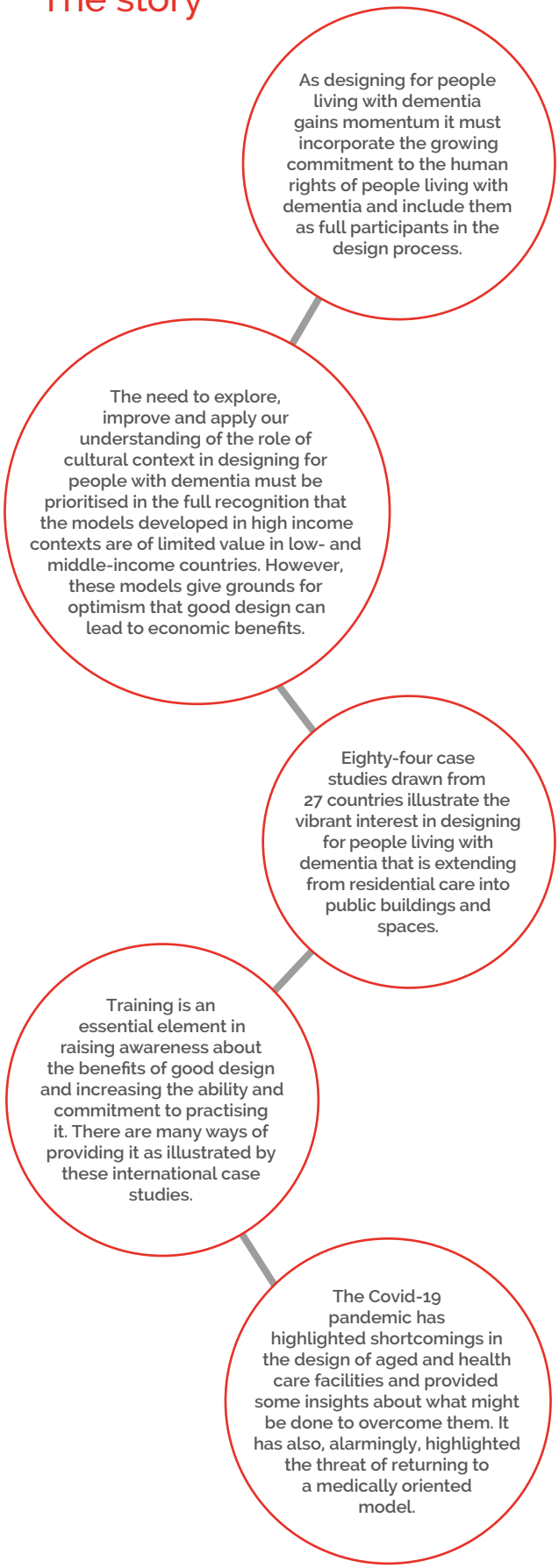
The story



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Foreword

Foreword

Paola Barbarino, Chief Executive Officer, Alzheimer's Disease International

The first time I realised the importance of good design for people living with dementia was during a site inspection of a venue for a conference. The person accompanying us pointed out how black areas on colourful carpets could look like holes in the floor and that people living with dementia might walk around them as they would be worried of falling into them. As a long term, short-sighted person I realised, at that moment, I have always had that problem too and wondered why don't we ask designers for better carpets that would make many people's lives easier.

The second time, visiting a beautifully designed model home in South Korea – showing how interiors could be adapted for people with dementia – Li-Yu Tang of TADA, one of ADI's members, pointed out how the designers had made the basic mistake of leaving mirrors on the wall. This would not work in a real setting as people with dementia can be disoriented by seeing their own reflection, especially at night.

The third time, I was in India and Meera Pattabiraman, of ARDSI, another ADI member, showed me a much more modest model home with simple interventions to help a person living with dementia live in their home for longer. Things like a clear indication of where the toilet is or a large clockface. It was then I realised good design did not have to cost the earth and simple principles could be applied in any context.

Speaking to Birgitta Martensson, one of ADI's Board members about my interest in design, she took me to listen to a lecture on the topic and it was then that I started to realise that all this common sense about people with dementia needing better design was not implemented due to two major obstacles. These were:

- stigma, that made society perceive people with dementia as marginalised rather than integrated in their community and
- lack of education. Most of the interventions needed to improve an environment can be made cost effectively and they can work very well even at large scale. However, they need to be integrated in the early stages of planning to really work. Many educational establishments still do not include this element in their curriculum, so it is no surprise that architects and designers don't think about it.

As you recall, in last year's World Alzheimer Report, we tackled the topic of stigma in all of its facets. We are still working on it (and will be for a long time) but we did make some big steps forward. This report tackles the topic of lack of education. We hope that by demonstrating practically, culturally, societally, economically and ergonomically that designing well for people with dementia makes sense in any context, more people will come on board and we will end up with a better world for people living with dementia and their families.

All of this can be underpinned by a solid human rights basis. We now perceive the rights to access for the physically disabled as a fundamental tenet of our society. When I was in my first job, I remember people saying that accessible lifts and ramps were impossible to install in old buildings – but look at it now! So, if we can cater for those with visible disabilities why do we refuse to cater for those with invisible disabilities?

But the report is more subtle than that. A great quote from Dennis Frost states "*Our expectations as we age should be to age in the community we choose, not to be consigned to a 'specialised' micro-community of homogeneous population*". This opens the big issue of isolation and confinement versus acceptance and integration. Many dementia advocates rightly opine, in a nutshell, that a splendid isolation is still isolation. How can we promote integration? There are many wonderful examples in this report that will persuade the most sceptical that not only it is possible – but it is really the only way to go. And that, by the way,

includes integrating people living with dementia and end users into design planning, importantly explored in this report.

While stating throughout the importance of a safe environment, the report also focuses on beautiful as well as practical design. As we are publishing the report online this year, we have been able to add some video interviews for the first time. In one of them you will find this great quote from Allen Kong, "I want to create buildings you can 'cuddle' and buildings that 'cuddle you'". This, I think, says more than any essay could. But let's not forget design is also a non-pharmacological intervention. When done well its results are akin to miracles, it can reduce agitation, anxiety, conflict, confusion and depression while improving orientation, pleasure, mobility and all activities of daily living.

The report also looks critically at the topic of this year: COVID-19. It looks at how restrictions implemented based on a need to protect residents in long term care may have resulted in interventions that could have accelerated physical and cognitive decline and/or indirectly contributed to the deaths of some residents. It also explores, how better design could help lower the spread of the virus. I would urge any policymaker reading this to go straight to that chapter. We are now receiving the terrible statistics that show that over a quarter of people who died in the first wave of COVID-19 had dementia. It is our collective job to ensure that never happens again.

And for those of us that think change is not possible in lower- and middle-income countries there are great essays in this report that pragmatically review the challenges but also the opportunities. This great quote from Monica Sanches Yassuda from Brazil is enlightening.

"*The hospital [in 2000] looked like a sanatorium, a real insane asylum for older people. It was awful and too old. I felt as if I were in a prison. Then the place went into an amazing renovation process, an incredible work with colour, glass, and natural lighting. The wards all have different colours and colourful lanes. It looks incredible. One can imagine the impact of this on the patients. Even for [those of us] who worked there as researchers we [felt that we were] in a modern place. It cheered our hearts*".

Such is the power of design and it is achievable everywhere, but we need to be realistic. In the words of Ishtar Govia: "*Embedded in discussions about design for dementia are assumptions about choice. The word choice is frequently noted in the presentation of the design principles. Yet, 'choice' is related to power. Power is related to resources. And low resourced contexts are often constrained in the choices available. Even in the midst of such constraint, however, there are examples of remarkable resilience and adaptation*"

I would like to conclude this foreword with a final quote from the report, from Japan "*there is the AHA! moment among people when they learn about dementia design. […] knowing the meaning of design makes people realise that there are different perspectives. Design can be inclusive, can be both functional and aesthetic and can change people's lives for the better.*"

So, this is what happened to me, I had the AHA! moment. The difference is that I am lucky to work for a very special organisation where we can translate insight into action and into communication. Here I need to thank two key people who have been with me throughout the genesis of this report, Glenn Rees, the Chair of ADI, who supported the idea throughout and introduced us to Prof Richard Fleming, our main author and Chris Lynch, ADI's Deputy CEO, who when at Alzheimer Scotland had witnessed first-hand a lot of design excellence and who took this idea and transformed it into the amazing report in your hands. He is also the person who – having worked in the travel and catering industry – told me an obvious truth vis-a-vis swirly carpets with black spots "venue managers love them because they don't show the dirt". And, indeed they don't, but don't we as a society need to find a better solution for this problem rather than just perpetuating it? It's great to be able to transform conversations into actions.

In conclusion, the report speaks of dignity but another word I would like you to alight on is compassion. As the numbers of people living with dementia rise, and young onset is becoming increasingly an issue, we need to build a world for people living with dementia and their families that we can all be proud of. The report is here, now and in your hands. There is no conceivable excuse anymore for any planner not to implement its recommendations but planners, architects, designers and policymakers won't implement its recommendations unless they see them. It is crucial that this report lands in as many hands as possible. I count on you all to help us with that.

Paola Barbarino
Chief Executive Officer

Overview

Design Dignity Dementia

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In the beginning this report was going to be called "Dementia and the Built Environment". In the final stages of pulling it together, having read, edited and discussed the 120,000 plus words written by international experts and having struggled with understanding where principles of design fit in the grand scheme of things, "Dementia and the Built Environment" no longer seemed adequate on its own. Too static, too dementia focussed.

A direction had emerged from the words, the purpose of designing well for people living with dementia is to support them to reach their full potential as human beings. Once said, this seems obvious, but readers of the chapter on the Early Years will see that this has not always been so.

The phrase 'reach their full potential as human beings' covers a lot of ground. The chapters on human rights, inclusive design and cultural influences delve into many aspects of what this means within the field of design. The chapter on principles of design bridges the overarching goal of enjoying human rights and the detailed tasks of design, such as selecting floor finishes. This is a huge concept, if concepts have size, and there is a focus to it, dignity.[i]

So the title evolved. Following the example of Tom Kitwood, dementia was put last. Design first, because that is the topic of the report. Dignity in prime focus, the middle, because that is what we are all trying to achieve in working with people living with dementia to provide enabling buildings.

While this report contains independent contributions from 58 named authors from 17 countries there is a narrative to it. The next few pages will outline that narrative and provide a scaffold to support the reader who wants to jump from point of interest to point of interest.

Principles

In comparison with many other fields, designing for people living with dementia does not have a large knowledge base. Nevertheless, there is a sufficient range of views and isolated 'facts' that writing a report on the field would be made much easier if the contributors could, by and large, agree to use a small set of principles of design to structure their thoughts and writing. The first chapter introduces the reader to a set of principles and carefully sets out an argument for accepting them as a useful tool in structuring the contributions to this report. Happily, where the use of principles was relevant to the topic, the contributors have used those described in Chapter 1 to structure their writing, conceivably laying a foundation for future systematic discussions about designing for people living with dementia.

This chapter also endeavours to explain the function of principles as a link in the chain that connects the high order goal of reaching the full potential of a human being with the basic, but essential tasks involved in designing the fine details of the built environment, even down to choosing door knobs.

i Pointed out by Jan Golembiewski during one of our discussions.

In a nutshell, this chapter puts forward, for the first time, a picture of how designing for people living with dementia is a journey that must start and finish with dignity, as we move from knowing why we design to how we design.

The principles of designing for people living with dementia

Unobtrusively reduce risks
People living with dementia require an internal and external environment that is safe and easy to move around if they are to continue to pursue their way of life and make the most of their abilities. Potential risks such as steps must be removed. All safety features must be unobtrusive as obvious safety features, such as fences or locked doors, can lead to frustration, agitation and anger or apathy and depression.

Provide a human scale
The scale of a building can affect the behaviour and feelings of a person living with dementia. The experience of scale is influenced by three key factors; the number of people that the person encounters, the overall size of the building and the size of the individual components (such as doors, rooms and corridors). A person should not be intimidated by the size of the surroundings or confronted with a multitude of interactions and choices. Rather the scale should encourage a sense of wellbeing and enhance the competence of a person.

Allow people to see and be seen
The provision of an easily understood environment will help to minimise confusion. It is particularly important for people living with dementia to be able to recognise where they are, where they have come from and where they can go. When a person can see key places, such as a lounge room, dining room, their bedroom, kitchen and an outdoor area they are more able to make choices and see where they want to go. Buildings that provide these opportunities are said to have good visual access. Good visual access opens up opportunities for engagement and gives the person living with dementia the confidence to explore their environment. It also enables staff to see residents. This reduces staff anxiety about the residents' welfare and reassures the residents.

Reduce unhelpful stimulation
Because dementia reduces the ability to filter stimulation and attend to only those things that are important, a person living with dementia becomes stressed by prolonged exposure to large amounts of stimulation. The environment should be designed to minimise exposure to stimuli that are not specifically helpful to the resident, such as unnecessary or competing noises and the sight of signs, posters, spaces and clutter that are of no use to the resident. The full range of senses must be considered. Too much visual stimulation is as stressful as too much auditory stimulation.

Optimise helpful stimulation
Enabling the person living with dementia to see, hear and smell things that give them cues about where they are and what they can do, can help minimise their confusion and uncertainty. Consideration needs to be given to providing redundant cueing i.e. providing a number of cues to the same thing, recognizing that what is meaningful to one person will not necessarily be meaningful to another. Using text and image in signs is a simple way to do this. Encouraging a person to recognize their bedroom through the presence of furniture, the colour of the walls, the design of a light fitting and/or the bedspread is a more complex one. Cues need to be carefully designed so that they do not add to clutter and become over stimulating.

Support movement and engagement
Purposeful movement can increase engagement and maintain a person's health and wellbeing. It is encouraged by providing a well-defined pathway, free of obstacles and complex decision points, that guides people past points of interest and opportunities to engage in activities or social interaction. The pathway should be both internal and external, providing an opportunity and reason to go outside when the weather permits.

Create a familiar place
A person living with dementia is more able to use and enjoy places and objects that are familiar to them. The use of familiar building design (internal and external), furniture, fittings and colours environment affords them the opportunity to maintain their competence. The personal backgrounds of the residents need to be reflected in the environment. The involvement of the person living with dementia in personalising the environment with their familiar objects should be encouraged.

Provide opportunities to be alone or with others
People living with dementia need to be able to choose to be on their own or spend time with others. This requires a variety of spaces in the unit, some for quiet conversation and some for larger groups, as well as spaces where people can be by themselves. When the internal and external spaces have a variety of characters, e.g. a place for reading, looking out of the window or talking, this cues the person to engage in relevant activity and stimulates different emotional responses.

Link to the community
Without constant reminders of who they are, a person living with dementia loses their sense of identity. Frequent interaction with friends and relatives can help to maintain that identity. The more the environment enables visitors to drop in easily and enjoy being in places that encourage interaction, the more this sense of identity is reinforced. Such places need to be attractive and comfortable to encourage visitors to come and spend time.

Design in response to vision for way of life
The choice of lifestyle, or philosophy of care, will vary between facilities. Some will choose to focus on engagement with the ordinary activities of daily living and have fully functioning kitchens. Others will focus on the ideas of full service and recreation, while still others will emphasise a healthy life-style or, perhaps, spiritual reflection. The way of life offered needs to be clearly stated and the building designed both to support it and to make it evident to the residents and staff. When the building embodies the philosophy of care, it constantly reminds the staff of the values and practices that are required while providing them with the tools they need to do their job.

The literature

Having established the usefulness of principles of design as an organising framework the report goes on to review the literature. The contributors to this section address the areas identified by ADI as being the foci of the report: residential care, hospital care, domestic homes, day care and public buildings.

Stephanie Harrison in *Design and the built environment for people living with dementia in residential aged care* offers a thoughtful critique of the application of the principles. While she points out the weakness of much of the research, she nonetheless is of the opinion that "there is sufficient evidence to suggest that the quality of the built environment in residential aged care can positively impact meaningful activity, behaviour and quality of life for residents. Enabling residential aged care environments which help facilitate residents to engage in indoor and outdoor activities and offer a variety of spaces whilst creating a familiar environment for the residents, are associated with better quality of life".

Tom Grey observes that

many hospitals are not designed to care for people with dementia,

not least because "Designing at a human scale is challenging in the context of large-scale and complex acute hospitals." He describes dementia-friendly design as an inclusive approach which pays attention to cognitive impairment alongside the age-related changes such as physical frailty, mobility, visual impairments, hearing loss, and circadian rhythm difficulties. These cognitive, physical, sensory and age-related issues underpin dementia-friendly design. He is encouraged by how dementia-attuned research and design is contributing to the developing knowledge base and will contribute the support of a wide range of patients, visitors and staff of all ages, sizes, abilities and disabilities as well as people living with dementia.

He highlights the contributions made by the Universal Design approach and salutogenic design. He notes that seeking the sense of coherence aimed for in salutogenic design through meaningfulness, manageability, and comprehensibility provides a valuable design framework for healthcare architecture. Establishing a context for the recognition of the therapeutic impact of natural things, like sunlight, on stress and pain leading to reductions in analgesic medication use.

Residential and hospital care for people living with dementia are never seen as preferred options. There is a growing body of evidence on the beneficial effects of designing, or more usually, modifying peoples own homes to make them more supportive. Ash Osborne – *Home modifications to support people living with dementia* – observes that "The vision that drives home modifications is, quite simply, to keep things as they have been for as long as possible. To enable the person with dementia to enjoy their relationship with their past life, as embodied in their home, despite the problems introduced to their life by dementia".

The current literature supports the conclusion that home modification is a strategy that can optimise safety, comfort and independence for a person living with dementia and enhance the quality of care while reducing caregiver burden.

By providing appropriate housing options in the community, in combination with home and social care, people living with dementia can be supported to age in place and avoid or defer a move into residential care.

Day care centres are one aspect of the social care necessary to support people with dementia living at home. The case studies in volume 2 of this report demonstrate the international acceptance of the value of day care centres and their relevance to the delivery of support in low and middle-income countries.

Jason Burton – *Day Care Centre Design* – provides a review of the current knowledge on day care centre design along with a great deal of practical advice on how to use the principles to design a successful centre. He emphasises the need to understand the role and outcomes the day centre service is seeking to achieve. When there is a clear vision of these the philosophy of care, model of service delivery, staff competency and skill set, and the design of the physical environment can be developed to complement each other to achieve the goals of the service and its users. He observes that misalignment of the physical environment and the service model often makes achieving service goals difficult. A service model focused on rehabilitation and physical wellness, for example, may not work well in a small house design and a model aiming to achieve wellbeing and strengthening of personhood through

meaningful engagement may be difficult to achieve in a large scale building set up to deliver large group or passive entertainment activities.

He sees the day care centre as a hub of community activity providing opportunities for inter-generational programmes and purposeful activities that support community connection. He recommends systematic application of the principles of design to, for example, unobtrusively reduce risks to both protect attendees from harm and to give staff confidence to support maximum freedom of choice and movement. As day centres can be very noisy and active places he recommends that the design carefully manages stimuli in the environment and ensures good line of sight exists for transition through the day centre and out to the gardens. This is essential to assist purposeful movement and reduce a sense of ill-being.

The role of public buildings and spaces in the life of people living with dementia and, potentially at least, in supporting them to live in the community, is relatively unexplored. There is a small body of literature and its influence is beginning to be felt, particularly in the context of the promotion of dementia friendly towns and cities.

Dennis Frost is a person with dementia living in a town on the south coast of New South Wales, Australia. He has provided a response to four key articles on the design of public buildings and spaces and contributed to the field by offering a three dimensional matrix approach to dealing with the relationships between the World Health Organisation's Domains of Age Friendly Cities, the domains of dementia friendly design (derived from the principles) and the variations in the experience of spaces with time. It has become clear to Dennis that his experience of a place is heavily determined by seasonal, weekly and diurnal variations, for example in levels of illumination, activity and temperature, and that these are very rarely accounted for in the literature.

Dennis holds the view that

> 'Our expectations as we age should be to age in the community we choose, not to be consigned to a 'specialised' micro-community of a perceived homogeneous population.'

He is looking forward to the expansion of the knowledge on how to design enabling and accessible public buildings so that people living with dementia have the opportunity to make that choice.

In summary, there is a useful knowledge base that can be applied to designing for people with dementia. It is strongest in the residential care field and needs accelerated development in the other areas.

The next section explores how we come to have that knowledge base.

The early years

Prior to 1980 the care of people living with dementia in high income countries was characterised by a focus on the medical aspects of the condition and a consequent institutional approach to treatment. John Zeisel – Dementia Care Design: Groundbreakers and Lessons Learned describes the paradigm shifting efforts of the pioneers who reacted against this model during the 1980's and 90's. Their innovative buildings were more the result of inspiration and trial and error than the systematic application of research findings but in building them they provided a context for research. The research was almost always small in scale, based in residential care and focussed on particular interventions such as the introduction of 'shadow boxes' to assist residents to identify the door to their room. But, the research, design and operation of the residential care centres were all heading in the direction of supporting the emergence of the provision of more home-like buildings. They all demonstrated that, given the right conditions, people with dementia can lead fulfilling lives with a much greater level of autonomy than was afforded to them in the old system.

The pioneers were not only struggling with the limitations of the available knowledge, they were also faced with

> the challenge of convincing regulators of the benefits of breaking conventional rules about the design of residential buildings

where people with dementia were to live, rather than to be treated. These battles were often fought over the inclusion of kitchens, because of the perceived risks of people with dementia being engaged in cooking. Another innovation involved ensuring that people living with dementia continued to be linked to their communities, at least by being able to look through a

window into the street, but sometimes in much more profound ways, such as shopping or living with people who did not have dementia. The foundations for our current conviction that people living with dementia should have the opportunity to live in their own homes as full citizens were laid during these early years.

Pioneers and innovators

Readers who have got to this point in the report will have worked through some weighty chapters. They will have been invited to consider how the concept of principles of design enables us to link the overarching goal of dignity for people living with dementia to the choice of door knobs and to systematise discussions on designing for people living with dementia; then to recognise the strengths and the weaknesses of the evidence base that supports our efforts in the design of residential care centres, day care centres, hospitals, public buildings and domestic homes. Leading to the acknowledgement that while much is known, much more needs to be outside of residential care if the knowledge base is to be useful in a world that is increasingly focussed on providing care in people's own homes.

They will also have been introduced to, or reminded of, the pioneers of designing for people with dementia and the challenges they faced.

The next section provides a rest from such heavy reading as it links to a set of video interviews with two pioneers (Maggie Calkins and Clare Cooper-Marcus), three innovative architects (Allen Kong, Peter Phippen and Michael Murphy) and three paradigm shifters (Jannette Spiering, Wilhelmina Hoffman and Alan Dilani).

While these people are unique, they share a sustained passion for pushing boundaries, trying to find something that works better and then putting it into practice. They are also happiest when they are sharing their knowledge.

Rights and inclusion[ii]

The passion for improving design shown in the interviews is reflected on the international stage in the growing awareness of the role that human rights conventions must play in affording people living with dementia the dignity that is their right.

A central aim of this report is to place designing for people with dementia in the context of the growing movement that views dementia through the lens of both human and disability rights.

In the chapter *Human Rights, design and dementia: moving towards an inclusive approach* Kevin Charras reinforces the principle that Human Rights apply to every human being, and no exceptions should be made for people living with cognitive disabilities such as dementia.

> The broadening of the scope of environmental design from a medical model to a more socially inclusive and rights-based framework is central to realising the rights of people with dementia.

Design can play a key role in embracing the diverse characteristics of people with dementia – neurological, psychological, cognitive, behavioural, social and cultural. Inclusive design – as distinct from universal and accessible design – encourages a focus on maximising abilities, know-how, and aptitudes for skill development, rather than on compensating for disabilities. Kate Swaffer – *Disability Rights, Enabling Design and Dementia* – reinforces this message by drawing a comparison between the progress made in environmental modifications carried out for people with a physical disability and those that are being made for people living with dementia.

Using experiences in Germany as an example Anne Fahsold and colleagues give us a critical reflection on the tendency of high income countries to foster segregation as the default mode of providing residential services to people living with dementia – *Segregation and integration of people with dementia in long-term care environments* – critical reflection on living concepts and possibilities of social inclusion. The chapter outlines that living environments are implemented very differently across the world, based on both differing care

ii The assistance of Dr. Lyn Phillipson in summarising and editing this section is gratefully acknowledged.

concepts and the perceived benefits and limitations for individual residents with dementia. Common though, are environmental design features such as orientation aids, stimulating features and environment safety features (e.g. locked doors or high fences) that can offer both challenges and opportunities for autonomy. The chapter presents a compelling argument for the identification of barriers to participation and taking action to create environments which support the person with dementia to operate as a full member of society. Residents must be given the choice to decide where they stay and when they meet with other people. In this light, it is critical that the perspectives of people with dementia be central to ongoing debates on integrative and segregative housing concepts in long-term care environments.

Niels Hendriks and Andrea Wilkinson in their chapter – *The involvement of people with dementia in the design process: a (political) choice to make* – emphasise the centrality of involving people living with dementia in rights-based design. They explore the political and pragmatic reasons for the involvement of people with dementia as full participants in the design process and describe a participatory design process that offers an approach that not only promotes better design solutions but also supports the agency of people with dementia. Participatory design provides opportunities to 'design for one' by prioritising the relationship between the designer and the person with dementia.

This requires designers from all design related professions, to embed themselves in the context of the person living with dementia,

attending to both the past and the present, to facilitate explicit and implicit decision making from the person with dementia.

The application of participatory design on a community scale is illustrated in the chapter by Martin Quirke and his co-researchers – *Citizen audits: Developing a participatory, place-based approach to dementia-enabling neighbourhoods*. This team successfully used games, theatre techniques, craft activities, poems, diaries, touch and proximity, personal objects and even songs and dance to engage people with dementia in the work of designing together. These techniques come together in a case study from a participatory project based in Stirling (Scotland) which aimed to create dementia-enabling public spaces. Practical strategies used within this citizen-led project aimed to overcome limitations in traditional methods by focusing on the experiential dimensions of place. The central strategy involved weekly citizen-led observational walks through the city. The participatory approach illuminated the embodied and sensory experience by the person with dementia of the built environment. Engaging local citizens living with dementia also provided opportunities to draw upon their knowledge of the sites being evaluated. Through this the project team and local council learned about the significance of sharing place-based memories and stories as a way of connecting for people with dementia. These experiences provide insights into the fact that socially supportive environments and problem-solving approaches can help to compensate for less supportive physical environments.

Overall, the authors in this section argue that, from a rights based perspective, inclusive design goes beyond giving opportunities to people with dementia. Rather

it encourages proactive behaviour and empowers people to take decisions concerning their own life, to take control over their environment and to live freely, independently and with dignity.

Implications for national planning

The effort to create national dementia plans has been part of an international commitment to improve the lives of people with dementia as well as those of their carers and families. The importance of these plans was emphasised by the World Health Organisation (WHO) when they adopted the *Global action plan on the public health response to dementia 2017–2025*. However, plans may focus on any aspect of dementia – typically topics include the legal framework for the care of people with dementia and the financial responsibility for the care. Regional or sub-national plans sometimes pre-date national plans or focus more specifically on key actions. Jan Golembiewski explores the extent to which plans address the topic of designing for people with dementia in the chapter *Dementia related design in the national dementia plans*. He analysed the contents of 31 national plans accessed via the ADI website and found that

National Dementia Plans are broad and diverse documents that rarely focus on the physical context of people living with dementia.

However, sometimes the plans state that the current standards are very low, implying an interest in better models of design. There are exceptions, Austria, Bavaria, Denmark, Gibraltar and Norway all see designing for people with dementia as pivotal to their approach to minimise the impact of dementia. They recognise it as a key tool for reducing symptomatology, helping people with dementia to remain integrated, meaningful and purposeful in society.

The analysis also revealed interests in providing support for people living with dementia in a very wide range of settings including home-based-care, day-care, respite-care, hospital-care, public buildings, urban settings, rural settings, residential homes, green spaces and palliative care. Accentuating the urgency to extend our knowledge base beyond the residential care setting. Carrying out this work will strengthen the claim that designing for people with dementia should be considered in every plan. At the moment only 29 out of the 194 WHO Member States have national dementia plans at all, a fraction of the WHO target of 75% coverage (i.e. 146 national dementia plans) by 2025. The analysis of these plans available through the ADI website shows that only about 25% of these provide strong support for the inclusion of designing for people with dementia. There is a clear need to raise awareness of its potential benefits in the minds of the policy makers and planners responsible for these plans. However, as the next section demonstrates so well, the adoption of the current knowledge into practice in countries and cultures that are different to those where the knowledge base was developed, is fraught with dangers.

Culture and costs

Kirsty Bennett begins the consideration of the need to understand cultural context in *Designing for culture and context* where she describes the long, and active, process of listening to those who carry the culture. In this case the indigenous Australians living in the Tjilpiku Pampaku Ngura (TPN). She explains, with great practicality, that the designers of the aged care home that was built on these lands had to ask themselves:

> ‘Who can we talk to?
> ‘Do we understand what we are hearing?’
> ‘Do we understand what we are seeing?’
> ‘Are people saying what they want us to hear, or what they really think? Or what they are able to tell us?’

These are not trivial questions. They require the designer to find a calmness that allows them to open up to the context they have been asked to work in. They also require the person, or agency, that has asked them to work there to afford them the opportunity and resources to listen.

Kirsty Bennett’s description of the effort required to bring the TPN project to a successful conclusion provides a useful yardstick for measuring the size of the challenges posed by Ishtar Govia and her co-authors – *Dementia, design and development: approaches and recommendations from STRiDE countries*. STRiDE (Strengthening Responses to Dementia in Developing Countries) is a multi-country, multidisciplinary research project which aims to improve the lives of persons living with dementia and their loved ones through effective, affordable, appropriate and equitable care. This chapter brings the experience of the STRiDE Research Engagement and Impact Leads from Brazil, India, Indonesia, Jamaica, Kenya, Mexico and South Africa to bear on the fundamental question of how much of the knowledge base that has been generated in high income countries can be applied in low and middle-income countries.

The authors used the principles as a framework for addressing this question and found them useful but before applying them to the question they were obliged to describe the differences between the health and aged care structures in high income countries (HICs) and low and middle-income countries (LMICs). It is well known that there are great differences in the extent to which the services taken for granted in HICs are available in LMICs but this common sense should not lead to the conclusion that LMICs wish to copy the structures found in HICs. The relevance of residential care facilities, for example, is wide open to question. As much of the designing for people living with dementia knowledge is based on research in residential care it is immediately apparent that we should be very cautious about our enthusiasm to spread the HICs ideas of

good practice to the LMICs. While they may well be applicable to the design of facilities for the well off in LMICs careful consideration, based on research and evaluation, is required before we rush into spreading the good word. Kirsty Bennett's questions are well worth keeping in mind in this context and,

> if we are serious about supporting people living with dementia in LMICs the effort must be put in to find that calm place where systematic reflection can take place on what is ready to be shared and what needs to be developed within the unique cultural contexts in the LMICs.

As it is, the STRiDE authors describe a situation where "*environmental design for dementia has not been explicitly applied to the extent to which it has in HICs. Spatial and environmental considerations are understood to be important particularly related to safety and wandering. However, among the vast majority of the population, there is considerably less focus on aesthetics, architectural and environmental design specific to dementia care. Instead, common sense contextual design takes precedent. Facilities and families do what they can with the resources they have available in the spaces in which they are based.*"

They go on to observe that embedded in discussions about design for dementia are assumptions about choice.

> "Yet, 'choice' is related to power. Power is related to resources. And low resourced contexts are often constrained in the choices available."

Which sets the scene for the next chapter where Tiffany Easton and Julie Ratcliffe discuss *The health economics of the built environment for people living with dementia*. This is a practical chapter explaining ways in which economic evaluations are relevant to designing for people living with dementia and illustrating how they have been applied in four case studies. While it is fair to say that the economic analysis of the impact of designing for people living with dementia is at an early stage of its application, the tools are available and the results so far lend support to those who claim that

> good design is no more expensive than bad design and there are substantial operational and quality of life benefits to be gained from it.

This is reassuring to those of us who have been promoting good design for many years but, more importantly, it is a message that should be shared with LMICs so that they are assisted to allocate scarce resources for the benefit of people living with dementia.

Survey and case studies

The extent to which designing specifically for people living with dementia is taking place around the world has not, to this point, been explored. The writing of this report provided an opportunity to begin this exploration and resulted in 84 case studies from 27 countries being identified. These case studies are provided in full in Volume 2. This chapter – *Case studies: survey and overview* – describes the ways in which the case studies were collected and overviews the findings from the survey.

The survey shows that there is a vibrant interest in designing for people living with dementia across the world. Unfortunately, it took place during a time when the great majority of aged care providers were very pre-occupied with surviving the COVID-19 pandemic. This had an obvious impact on the number of responses to the survey. Those people who made the time to respond deserve particular thanks and acknowledgement for their contributions.

The responses to the survey indicate that most examples of designing specifically for people living with dementia are to be found in residential care. Which is not surprising. However, day care centres were also very well represented and there were five, very interesting, examples of public buildings or spaces being designed with people with dementia in mind. There was only one completed response from a hospital unit.

The numbers of case studies in these categories and average age of the buildings in the categories suggest that the lessons originally learned in residential care are slowly making their way into the design day care centres, public buildings and hospitals. While no claim can be made for the representativeness of the sample,

the fact that only one hospital responded almost certainly reflects the need for an acceleration of efforts to design well for people living with dementia who require hospital care.

The survey also shows that when the principles are used as the framework for collecting information interesting comparisons can be made between categories of building and between findings from research and their application in practice. It suggests that the principles are a useful tool for ordering discussions that might otherwise be difficult to focus.

Training and education

The narrative so far has illustrated the progress that has been made in designing for people living with dementia. It has been a 40-year journey, starting with some pioneers who set out to shift the paradigms of the times towards the vision of the person living with dementia enjoying a full and satisfying life. They started with little more than their own inspiration, fuelled by the belief that there had to be a better way. It is clear that we have moved beyond that stage. There is now an established body of knowledge that is capable of guiding the design of the built environment so that it supports people living with dementia. However, this report illustrates that the knowledge has not yet been adopted into practice in many parts of the world and that it should not be taken for granted that knowledge gained in high income countries can be applied, or is even relevant to, the challenges faced in low or middle income countries. The chapters in this section showcase well developed approaches to education and training that are effective within their high-income contexts but may appear to be impractical, or even irrelevant, in contexts that do not have the same availability of long-term care options. The chapter written by Ishtar Govia and her colleagues explores the issues faced in low- and middle-income countries. It challenges all of us who are dedicated to improving the lives of people with dementia to recognise that

> education and training do not stand alone, they must take their place within a systematic commitment to research, the involvement of people with dementia in devising educational programmes and the implementation of the human and disability rights that have been offered.

Perhaps one way to facilitate the inclusion of training in these activities is to recognise that they are all engaged in knowledge translation. Researchers and practitioners continue to add to the knowledge base but,

> perhaps, rather than focussing on adding to knowledge the most pressing task today is translating the knowledge we have into practice.

There are many things that have to be done to complete this translation. Most of them fit into four basic stages of knowledge translation – raising awareness that there is new knowledge, coming to an agreement that this knowledge is relevant to the task at hand, working out how it can be adopted into practice and then building the newly developed practice into policies, guidelines, handbooks, standards or even legislation to ensure that it becomes business as usual. This can be summarised as the four As of knowledge translation – Awareness, Agreement, Adoption and Adherence.

While knowledge translation (KT) requires a range of activities as different from one another as advertising campaigns and standards development, training and education are central to all successful KT.

In general terms education and training contribute to increasing the quality of life of people living with dementia (and those who interact with them) by:

- raising awareness of the importance of design in the care and support of people living with dementia
- raising awareness of the importance of the use of the environment in the care and support of people living with dementia, and those who work with them (from nursing staff to gardeners, occupational therapists to cleaners)
- providing a forum for negotiation about the relevance and applicability of the knowledge about design to particular situations and contexts
- teaching design professionals working in this field how to apply the knowledge in practice
- teaching the users of the buildings how to use them to get the outcomes that they desire
- furthering the evolution of a design literacy that can be applied with rigour in an innovative and evolving way, ensuring the continued development of the field

In this section the specifics of these

aspects of training, and more, are explored in case studies from Australia. Canada, Great Britain, Japan, Singapore and the USA. It is heartening to see such a variety of successful approaches.

However, notwithstanding the availability of these programmes, it is clear there is still much to be done if the design of environments for people living with dementia is to be included in key areas of influence, such as

- precinct planning
- course curricula for design and health professionals
- statutory guidelines and regulations
- government policy
- national dementia plans

The major challenge, of course, is to develop and provide this training in culturally sensitive ways that take into account the movement towards a holistic, values driven approach to care.

COVID-19 and Designing for People with Dementia

No report written in 2020 on any aspect of care for people living with dementia would be complete without consideration of the impact of COVID-19. Alison Dawson and her co-authors – *Long term care and the coronavirus pandemic: a new role for environmental design in a changing context* – present an argument that the

restrictions imposed to minimise the risk of harm to residents resulting from COVID-19 have accelerated physical and cognitive declines and/or indirectly contributed to the deaths of some residents.

While they have been imposed with the best of intentions in an emergency situation, a continued emphasis on them will be a great threat to the strengths based models of care that have been developed in recent years. It is likely that they will lead to cognitive decline due to lack of stimulation or meaningful programming; physical deconditioning due to lack of ability to exercise and loneliness due to isolation.

They note that beyond the obvious impact of sharing rooms with multiple other residents,

little has been said by designers and researchers about how environmental design may have influenced the impact of COVID-19 in long term care to date or how it might contribute to reducing negative impacts in future.

They call on researchers to urgently address this gap in our knowledge so that we can better understand how environmental design can be a positive force in improving infection control within a strengths based approach. They specifically call for action to develop evidence-based modifications and designing long term care facilities which:

- reduce the risk of COVID-19 disease transmission and/or improve infection control for residents, staff and visitors – where possible without excessive negative impact on other areas of resident wellbeing
- incorporate dementia design principles to support and enable long-term care residents to maintain existing capabilities and enjoy their best possible lived experience of care; and
- are capable of being adapted to rapidly changing levels of threat from coronavirus and/or other future emerging infectious agents in ways which, in every configuration, maintain the opportunities for stimulation through activity and social interaction that are critical to residents' wellbeing and quality of life

Their conclusion brings us back to the beginning of this report:

> The principles of environmental design for dementia set out in the 1980s and 90s remain revolutionary and relevant. They have been greatly instrumental in shaping the physical, technical, caring and social environments of long-term care in ways which contribute positively to resident wellbeing and quality of life and to staff job satisfaction. These principles should not and *must not* be abandoned or made totally subservient to the needs of infection control.

Design principles and their use in this report

Discussion of designing for people living with dementia may be facilitated by a shared understanding of the role of principles, design approaches and design details, in linking the overarching goal of affording dignity to people with dementia to the construction of enabling buildings.

Environmental design principles and their use in this report

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Structure is important in conversations. Imagine trying to describe a daffodil to someone who has never seen one. You might start with the colour but, by itself that wouldn't be enough. You might go on to describe the height of the plant, still not enough. Adding information about when it flowers, whether it grows from seed or a bulb would fill out the picture. Describing the shape of the flower, particularly in the case of a daffodil, would probably get you pretty close to helping the person you are talking to to get a good idea of the type of flower you are talking about. Just as importantly you are helping them compare the daffodil with other plants. How have you achieved this? I suggest that you have made a list of what seems to you to be the key attributes of the plant and you have carefully gone through that list to describe the daffodil.

Pulling together a global description of the state of the art of designing environments for people living with dementia is a bit like describing a daffodil – it is made easier by having a set of key attributes around which to organise the description.

Fleming – Bennett design principles

The information and views expressed in this report have been organised around a set of environmental design principles first described in a paper published in 1987 [1], added to in 2000 [2] and 2003 [3], and further developed and expanded over the next decade.

Between 1986 and the early 1990s these principles guided the design of the first large scale effort in Australia to provide homelike accommodation for people living with dementia who would otherwise have been hospitalised [1, 4]; in 1995 the principles guided design of the Meadows, HammondCare's first dementia specific facility which continues to influence designs [5]; they have been used for the last decade to organize education programmes on designing for people living with dementia delivered across Australia by the Government funded training organisation Dementia Training Study Centres and their replacement, Dementia Training Australia [6]; in 2015 they were adopted by New South Wales Health as the key principles for improving healthcare environments for people living with dementia [7]; in 2016 they were included in the Australasian Health Facility Guidelines for application to the design of mental health facilities for older people [8]; in 2018 they became the standard by which the Australian Aged Care Quality and Safety Commission judges design, and are currently used to judge the quality of design of facilities being proposed for inclusion in the Australian Health Department's Specialist Dementia Programme. The principles have been used as the foundation for environmental assessment tools developed in Australia, Chinese Taipei, Germany, Japan, Singapore, and the US.

The following is a brief description of them. A full description and a comprehensive review of the literature that supports them can be found in the educational material provided by Dementia Training Australia https://dta.com.au/resources/environmental-design-resources-introduction/.

UNOBTRUSIVELY REDUCE RISKS

People living with dementia require an internal and external environment that is safe and easy to move around if they are to continue to pursue their way of life and make the most of their abilities. Potential risks such as steps must be removed. All safety features must be unobtrusive as obvious safety features, such as fences or locked doors, can lead to frustration, agitation and anger or apathy and depression.

PROVIDE A HUMAN SCALE

The scale of a building can affect the behaviour and feelings of a person living with dementia. The experience of scale is influenced by three key factors; the number of people that the person encounters, the overall size of the building and the size of the individual components (such as doors, rooms and corridors). A person should not be intimidated by the size of the surroundings or confronted with a multitude of interactions and choices. Rather the scale should encourage a sense of wellbeing and enhance the competence of a person.

ALLOW PEOPLE TO SEE AND BE SEEN

The provision of an easily understood environment will help to minimise confusion. It is particularly important for people living with dementia to be able to recognise where they are, where they have come from and where they can go. When a person can see key places, such as a lounge room, dining room, their bedroom, kitchen and an outdoor area they are more able to make choices and see where they want to go. Buildings that provide these opportunities are said to have good visual access. Good visual access opens up opportunities for engagement and gives the person living with dementia the confidence to explore their environment. It also enables staff to see residents. This reduces staff anxiety about the residents' welfare and reassures the residents.

REDUCE UNHELPFUL STIMULATION

Because dementia reduces the ability to filter stimulation and attend to only those things that are important, a person living with dementia often becomes stressed by prolonged exposure to large amounts of stimulation. The environment should be designed to minimise exposure to stimuli that are not specifically helpful to the resident, such as unnecessary or competing noises and the sight of signs, posters, spaces and clutter that are of no use to the resident. The full range of senses must be considered. Too much visual stimulation is as stressful as too much auditory stimulation.

OPTIMISE HELPFUL STIMULATION

Enabling the person living with dementia to see, hear and smell things that give them cues about where they are and what they can do, can help minimise their confusion and uncertainty. Consideration needs to be given to providing redundant cueing i.e. providing a number of cues to the same thing, recognizing that what is meaningful to one person will not necessarily be meaningful to another. Using text and image in signs is a simple way to do this. Encouraging a person to recognize their bedroom through the presence of furniture, the colour of the walls, the design of a light fitting and/or the bedspread is a more complex one. Cues need to be carefully designed so that they do not add to clutter and become over stimulating.

SUPPORT MOVEMENT AND ENGAGEMENT

Purposeful movement can increase engagement and maintain a person's health and wellbeing. It is encouraged by providing a well-defined pathway, free of obstacles and complex decision points, that guides people past points of interest and opportunities to engage in activities or social interaction. The pathway should be both internal and external, providing an opportunity and reason to go outside when the weather permits.

CREATE A FAMILIAR PLACE

A person living with dementia is more able to use and enjoy places and objects that are familiar to them. The use of familiar building design (internal and external), furniture, fittings and colours environment affords them the opportunity to maintain their competence. The personal backgrounds of the residents need to be reflected in the environment. The involvement of the person living with dementia in personalising the environment with their familiar objects should be encouraged.

PROVIDE OPPORTUNITIES TO BE ALONE OR WITH OTHERS

People living with dementia need to be able to choose to be on their own or spend time with others. This requires a variety of spaces in the unit, some for quiet conversation and some for larger groups, as well as spaces where people can be by themselves. When the internal and external spaces have a variety of characters, e.g. a place for reading, looking out of the window or talking, this cues the person to engage in relevant activity and stimulates different emotional responses.

LINK TO THE COMMUNITY

Without constant reminders of who they are, a person living with dementia loses their sense of identity. Frequent interaction with friends and relatives can help to maintain that identity. The more the environment enables visitors to drop in easily and enjoy being in places that encourage interaction, the more this sense of identity is reinforced. Such places need to be attractive and comfortable to encourage visitors to come and spend time.

Stigma remains a problem for people living with dementia. If the unit is designed to blend with the surrounding community and not stand out as a 'special' unit, stigma is reduced. It is also reduced when a 'bridge' is included to connect the unit and the community, such as a coffee shop or restaurant that is used by both the community and people living with dementia.

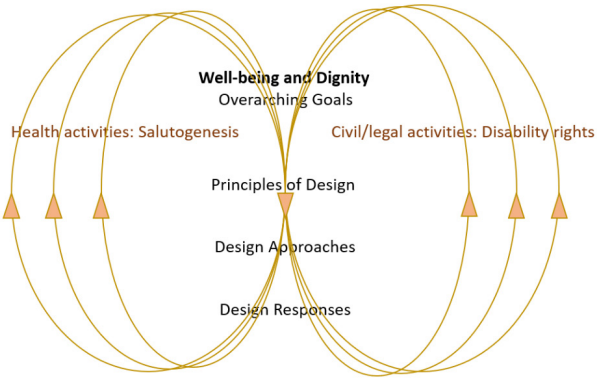
Where the unit is a part of a larger site, easy access around the whole site enables people living with dementia, their families and friends to interact with others who live there.

DESIGN IN RESPONSE TO VISION FOR WAY OF LIFE

The choice of lifestyle, or philosophy of care, will vary between facilities. Some will choose to focus on engagement with the ordinary activities of daily living and have fully functioning kitchens. Others will focus on the ideas of full service and recreation, while still others will emphasise a healthy life- style or, perhaps, spiritual reflection. The way of life offered needs to be clearly stated and the building designed both to support it and to make it evident to the residents and staff. When the building embodies the philosophy of care, it constantly reminds the staff of the values and practices that are required while providing them with the tools they need to do their job.

Where do environmental design principles fit?

Design principles are not the beginning or the end of the story. They do not tell us about the values they are intended to operationalise, nor do they specify in detail what needs to be done to operationalise them.



Design principles are one part of a broader schema which can be described in terms of four key domains. Each domain has an increasing level of specificity and detail, and relates to the other domains which precede and/or follow it. The four key domains are:

- Overarching goals
- Design principles
- Design approaches
- Design responses

Overarching goals take us from understanding why we do things to exactly what to do in practice. As we consider them it becomes apparent that they are not simply starting points or destinations but have to be in mind at every stage of the design process. They provide the direction and the energy for the activity.

Four Key Domains

OVERARCHING GOALS: WELL-BEING AND DIGNITY

This domain has a high order focus on overarching goals.

The achievement of these goals is attempted through a variety of mechanisms including, but not limited to, political, legal, civil and health related activities.

The interests of people living with dementia are being pursued through all of these mechanisms and they are all relevant to designing for people living with dementia. However, this chapter will only explore health and the civil and legal activities in the form of the relevant international conventions. This is done only to

establish the link between the principles of design and the overarching goals, as other chapters go into these issues in more detail.

HEALTH ACTIVITIES: SALUTOGENESIS

In simple terms the activities that take place under the heading of 'health' can be divided into two categories, the pathogenic and the salutogenic. Pathogenic activities are focussed on discovering and eliminating the sources of ill health, salutogenic activities are focussed on discovering and supporting the sources of health. The goal of achieving health, and thereby contributing to the overarching aims of achieving well-being and dignity, requires success in both activities and both pathogenic and salutogenic approaches can be seen in the activities of designers. The authors of this chapter are of the opinion that the last forty years of activity has been characterised by a gradual expansion of the field from concerns about the pathogenic elements of design, e.g. those that cause confusion and agitation, like complexity and over-stimulation, to putting greater emphasis on those that engage with the concerns of salutogenesis, e.g. how to create environments that support well-being. This is often presented as a move away from the medical model towards a more holistic eco-psycho-social model [9] – and this is where the authors see the link between the principles of design and the goal of achieving well-being for people living with dementia.

Salutogenesis, as described by Antonovsky (10, 11) focusses on assets, strengths, and motivation as a way to maintain and improve the movement toward health. Antonovsky's essential argument is that salutogenesis depends on experiencing a strong 'sense of coherence' and his research demonstrated that a sense of coherence predicts positive health outcomes. A sense of coherence has three components: comprehensibility, manageability and meaningfulness. According to Antonovsky, the third element is the most important because without a sense of meaning there is no reason to persist and survive and confront challenges and there is no sense of meaning, then the person will have no motivation to comprehend and manage events.

The elements of Salutogenesis

Adapted from Golembiewski [12]

'Comprehensibility' refers to providing an environment that enables a person to make sense of their life narrative, context and current circumstances. Without this fundamental understanding, people have little capacity to make the most of circumstances or to negotiate life's challenges.

'Manageability' refers to providing an environment that assists people to manage day-to-day physical realities, like working efficiently and comfortably, paying bills, staying warm, dry, clean, rested and nourished and other maintenance of their physical lives.

'Meaningfulness' is the foundation of the desire to live. It is meaningfulness that gives life forward thrust—the will to resist the entropy of illness and death's inevitability, and as such it is possibly the most important of the salutogenic resources. Meaningfulness is also the most elusive because meaning is difficult to define and is highly personal. Meaningfulness is found in the intensity of personal connections, engagement with responsibilities and the pursuit of desires.

CIVIL/LEGAL ACTIVITIES: DISABILITY RIGHTS

Attention has recently been paid to the rights of people living with dementia in the context of the Convention on the Rights of Persons with Disabilities and its Optional Protocol (CRPD) [13] and dementia rights advocates are increasingly using the CRPD to frame their demands for equality [14]. The World Health Organisation (WHO) clearly states that dementia "is one of the major causes of disability and dependency among older people worldwide" [15] and following the Mental Health Gap Action Program Forum in Geneva in 2016, the WHO added a fourth sub-category for dementia: cognitive disabilities. Kate Swaffer, Chair, CEO and Co-founder of Dementia Alliance International, writes: "Now that dementia is being described in UN documents as a cognitive disability, we ask that everyone is reminded… that people with dementia are fully recognised by the UN as rights bearers under the CRPD treaty." [15]

The CRPD is the first comprehensive human rights treaty of the 21st century. It follows decades of work by the United Nations to change attitudes and approaches to persons with disabilities and is intended as a human rights instrument with an explicit, social development dimension [16]. It reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms. Steele et al [14], quoting Cahill, notes, the CRPD 'allows for a new and exciting dialogue to emerge, where the framing of dementia is no longer characterized by stigma, fear and exclusion, but rather, where the individual with dementia is viewed as a legitimate part of mainstream society'.

The WHO Global Dementia Action Plan for a Public Health Response to Dementia identifies human rights (and specifically the CRPD) as one of three 'cross-cutting principles' [15]. In the chapter 'Human Rights – Design and Dementia' by Kevin Charras the human rights of people living with dementia are explored further.

The principles included in the Convention on the Rights of Persons with Disabilities and its Optional Protocol (CRPD) are:

(a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;

(b) Non-discrimination;

(c) Full and effective participation and inclusion in society;

(d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;

(e) Equality of opportunity;

(f) Accessibility;

(g) Equality between men and women;

(h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities. [16]

DESIGN PRINCIPLES

Design principles guide a design, but do not stipulate the way a design is to be realised. They allow for a variety of design approaches and responses.

> The use of principles allows a design to respond in different ways to people's needs, preferences, lifestyles, cultural and socio-economic backgrounds, as well as the local climate and geography.

Design principles respond to overarching goals.

Designing environments so people are able to make decisions and do things independently are key aspects of the ten principles. Each principle has something to say about what needs to be done to create environments where people can participate fully in society and be included in community life, rather than being shut away. Respect is more likely to be given when a person is able to use their skills and abilities, and all the principles focus on enabling a person to be at their best. Applying all the design principles can also lead to equality of opportunity as people are able to live well when stimulation is managed and opportunities are created for people to move around with a sense of well-being and confidence.

If we use the principles to enable people living with dementia to do meaningful things, in familiar places, with people they wish to be with, as they live the life they choose, we can reduce discrimination. People can practice their faith, have relationships with men or women, and continue their cultural practices.

Equality between men and women will be aided if the environment offers choices and places that reflect people's backgrounds and priorities. If an environment reduces risk, manages stimulation, supports movement and links to the community, it will be accessible.

PRINCIPLES, SALUTOGENESIS AND THE CRPD

The proposition is that there is a growing sense that the purpose of supporting people living with dementia is best driven by aiming at maximising their well-being and dignity. It is not about their physical health, keeping them safe and secure, making sure that they are clean and well-fed, but supporting them to lead as full a life as is possible under their, and their carers', circumstances.

It is also that designing for people living with dementia is one of the ways in which these over-arching goals can be achieved. In particular, good design can contribute to the establishment of the salutogenic conditions necessary for well-being and to the civil and legal activities that support their dignity.

The question is: 'How do we link salutogenic conditions, civic/legal activities and design?' One way is to see principles of design as the link between the how to design and the why to design and to map the principles on to the salutogenic conditions and the CRPD principles.

TABLE 1: PRINCIPLES, SALUTOGENESIS AND THE CRPD

Salutogenic conditions				Convention on the Rights of Persons with Disabilities						
Manageable	Comprehensible	Meaningful	Design Principles	Dignity, individual autonomy	Non-discrimi-nation	Full participation and inclusion	Respect	Equality of opportunity	Accessibility	Equality between men and women
x			Unobtrusively reduce risks	x	x	x	x	x	x	
x			Provide a human scale	x		x	x	x		
	x		Allow people to see and be seen	x		x	x	x	x	
x			Reduce unhelpful stimulation	x		x	x	x	x	
x			Optimise helpful stimulation	x		x	x	x	x	
		x	Support movement and engagement	x	x	x	x	x	x	x
	x		Create a familiar place	x	x	x	x	x		x
x			Provide opportunities to be alone or with others	x	x	x	x	x		x
		x	Link to the community	x	x	x	x	x	x	x
		x	Design in response to vision for way of life	x	x	x	x	x	x	x

This illustrates, for example, that optimising helpful stimulation contributes to achieving the overarching goals by contributing to the salutogenic condition of manageability and the CRPD principles of individual autonomy, full participation and inclusion, respect, equality of opportunity and accessibility. More links between the principles and the CRPD are illustrated in Table 2.

TABLE 2: FLEMING-BENNETT PRINCIPLES & CPRD

Fleming-Bennett principles	The environment …	CPRD reference
1. **Unobtrusively reduce risks**	- enables a person to continue to pursue way of life - enables a person to make the most of her/his abilities - is easy to move around internal and external built environment - has any potential risks made unobtrusive	a) Dignity, individual autonomy b) Non-discrimination c) Full participation and inclusion d) Respect e) Equality of opportunity f) Accessibility
2. **Provide a human scale**	- has positive affect on a person's responses and feelings - does not intimidate people - encourages a sense of well being - enhances a person's competence	a) Dignity, individual autonomy c) Full participation and inclusion d) Respect e) Equality of opportunity
3. **Allow people to see and be seen**	- enables a person to make choices - minimises confusion - offers opportunities for engagement - enables a person to be confident to explore the built environment	a) Dignity, individual autonomy c) Full participation and inclusion d) Respect e) Equality of opportunity f) Accessibility
4. **Reduce unhelpful stimulation**	- reduces causes of stress such as competing noises, visual clutter - avoids prolonged exposure to large amounts of stimulation - minimises a person's exposure to stimuli that are not specifically helpful to her/him	a) Dignity, individual autonomy c) Full participation and inclusion d) Respect e) Equality of opportunity f) Accessibility
5. **Optimise helpful stimulation**	- enables a person to see, hear, touch and smell cues - gives a person cues about where she/he is - gives a person cues about what she/he can do - minimises a person's confusion and uncertainty	a) Dignity, individual autonomy c) Full participation and inclusion d) Respect e) Equality of opportunity f) Accessibility
6. **Support movement and engagement**	- increases a person's engagement - maintains a person's health and wellbeing - has paths free of obstacles - includes points of interest - provides opportunities for activities and/or social interaction	a) Dignity, individual autonomy b) Non-discrimination c) Full participation and inclusion d) Respect e) Equality of opportunity f) Accessibility g) Equality between men and women

TABLE 2: CONTINUED

Fleming-Bennett principles	The environment …	CPRD reference
7. Create a familiar place	- has places a person can use and enjoy - reflects a person's personal background - involves a person in personalising the built environment	a) Dignity, individual autonomy b) Non-discrimination c) Full participation and inclusion d) Respect e) Equality of opportunity g) Equality between men and women
8. Provide opportunities to be alone or with others	- enables a person to choose to be with others or on their own - enables a person to engage in relevant activity - has a variety of places which have different characters (e.g. place for reading, place for chatting) - includes internal and external settings - stimulates different emotional responses	a) Dignity, individual autonomy b) Non-discrimination c) Full participation and inclusion d) Respect e) Equality of opportunity g) Equality between men and women
9. Link to the community	- reminds a person who she/he is and maintains her/his sense of identity - includes places that are shared by the wider community and people living with dementia - has easy access to these places and around a site	a) Dignity, individual autonomy b) Non-discrimination c) Full participation and inclusion d) Respect e) Equality of opportunity f) Accessibility g) Equality between men and women
10. Design in response to vision for way of life	- supports the chosen lifestyle - has a way of life that is clearly evident to everyone - in aged care, reminds staff of values and practices that are required and gives them the tools to do their job	a) Dignity, individual autonomy b) Non-discrimination c) Full participation and inclusion d) Respect e) Equality of opportunity f) Accessibility g) Equality between men and women

DESIGN APPROACHES

While the design principles guide the designer towards ways to contribute to the well-being and dignity of the person living with dementia,

design approaches identify a *design direction*, without giving the design detail. They indicate ways to apply design principles.

The creation of walking paths and outdoor access are two examples of design approaches. They relate to the principles of 'Support movement and engagement' and 'Create a familiar place'. There are many ways these approaches can be implemented, and the number of design responses to these approaches is almost limitless. The placement of a raised garden bed, for example, along a level walking path so that it provides a destination which can be clearly seen will encourage people to discover it. The careful detailing of the garden bed will ensure that someone can recognise it and is able to use it.

A number of authors and researchers have identified approaches that will ensure that the built environment supports people living with dementia. Amongst these is John Zeisel who proposes that the following elements are key to the provision of an environment that supports well-being and dignity:

- exit controls
- walking paths
- common spaces
- unit privacy
- outdoor access
- homelikeness
- sensory comprehension and
- independence support [17].

The relationship between design principles and approaches is key if high quality designs for people living with dementia are to be realised. These two domains are the 'engine room' of designing for people living with dementia. It is in these conversations that ideas and concepts move to design directions which elicit specific detailed responses. While proposing a four-tiered multi-layered schema for this discussion, the boundaries between categories are somewhat porous, and there is some overlap.

There is a strong interrelationship between the Fleming-Bennett principles and the Zeisel approaches, despite them having been developed independently from one another. These connections can be clearly seen in Table 3 which indicates how multiple Zeisel approaches correspond to each of the F-B principles, and in Table 4, which describes each approach and shows it relates to a number of F-B principles.

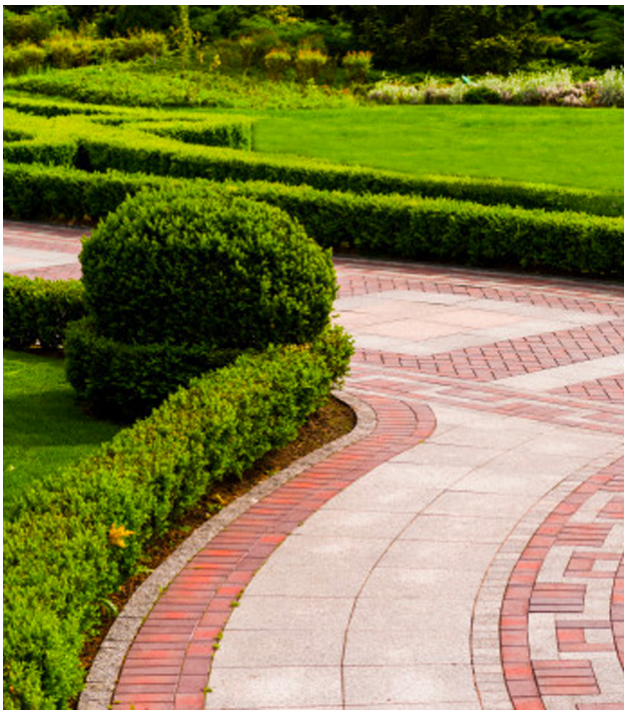


TABLE 3: INTERRELATIONSHIP BETWEEN FLEMING-BENNETT PRINCIPLES & *ZEISEL APPROACHES*

	Exit control	Walking paths	Common spaces	Unit privacy	Outdoor access	Homelike	Sensory comprehension	Independence support
1. Unobtrusively reduce risks	x		x		x	x	x	x
2. Provide a human scale			x	x		x		
3. Allow people to see and be seen	x	x						
4. Reduce unhelpful stimulation	x	x	x			x	x	
5. Optimise helpful stimulation	x	x	x	x	x	x	x	
6. Support movement and engagement	x	x		x	x	x		x
7. Create a familiar place		x	x	x		x	x	
8. Provide opportunities to be alone or with others		x	x	x	x			
9. Link to the community						x		
10. Design in response to vision for way of life	x	x	x	x	x	x	x	x

TABLE 4: ZEISEL APPROACHES VS FLEMING-BENNETT PRINCIPLES

Zeisel approaches	Key points [17]	Fleming-Bennett principles
Exit control	- Controlled exits allow for independence - Doors to dangerous places to be less inviting and as invisible as possible or camouflaged - Doors to safe places (e.g. interior courtyard) to be as inviting as possible - Use doors with see through panes to invite view to safe places - Windows whose openings need to be controlled to be less inviting and as invisible as possible or camouflaged - Fences around gardens to be as invisible as possible or camouflaged - Well designed exit controls on doors, windows and garden fences encourage resident independence - Provide meaningful and creative activities within circumscribed world	1. Unobtrusively reduce risks 3. Allow people to see and be seen 4. Reduce unhelpful stimulation 5. Optimise helpful stimulation 6. Support movement and engagement 10. Design in response to vision for way of life
Walking paths	- Clear walking paths clarify destinations - People can see where they are going - Avoid circular paths which prevent seeing a destination - Include objects that are familiar to people - Provide evident destinations - Use landmarks to mark key points along the journey - Provide places along paths to enable purposeful walking	3. Allow people to see and be seen 4. Reduce unhelpful stimulation 5. Optimise helpful stimulation 6. Support movement and engagement 7. Create a familiar place 8. Provide opportunities to be alone or with others 10. Design in response to vision for way of life
Common spaces	- Room purposes indicators improve behaviour - Rooms reflect different intended uses - Provide clearly understood environmental cues - Pay attention to scale of space, furniture, features and fixtures	1. Unobtrusively reduce risks 2. Provide a human scale 4. Reduce unhelpful stimulation 5. Optimise helpful stimulation 7. Create a familiar place 8. Provide opportunities to be alone or with others 10. Design in response to vision for way of life
Unit privacy	- Bedroom needs to be a sanctuary - Bedroom needs to offer privacy - People need to be able to personalise their bedroom - Personal cues and hints as to a person's past should surround resident - Encourage a person to express their wishes and desires directly	2. Provide a human scale 5. Optimise helpful stimulation 6. Support movement and engagement 7. Create a familiar place 8. Provide opportunities to be alone or with others 10. Design in response to vision for way of life
Outdoor access	- Gardens must be safe and easily accessible - Outdoor areas need to be safe, have engaging elements, walking path and be secure from potential public danger beyond the garden - Gardens are another common area - Create an outdoor people can use independently	1. Unobtrusively reduce risks 5. Optimise helpful stimulation 6. Support movement and engagement 8. Provide opportunities to be alone or with others 10. Design in response to vision for way of life

TABLE 4: CONTINUED

Zeisel approaches	Key points [17]	Fleming-Bennett principles
Homelike	- A sense of home is key to comfort for residents and family - People can display their own objects and mementos - Rooms are the scale of those in a house - Needs to look like a home from outside - A person can find things to do - Residential furnishings and design features	1. Unobtrusively reduce risks 2. Provide a human scale 4. Reduce unhelpful stimulation 5. Optimise helpful stimulation 6. Support movement and engagement 7. Create a familiar place 9. Link to the community 10. Design in response to vision for way of life
Sensory comprehension	- Residents take cues from sensory details they comprehend - What residents see, hear and touch must be comprehensible to them - Environmental messages need to be coherent to all the sense at once - Use the environment to help people develop a coherent picture of their life	1. Unobtrusively reduce risks 4. Reduce unhelpful stimulation 5. Optimise helpful stimulation 7. Create a familiar place 10. Design in response to vision for way of life
Independence support	- Supporting independence helps retain it - Support each individual to use the capacity they have	1. Unobtrusively reduce risks 6. Support movement and engagement 10. Design in response to vision for way of life

DESIGN RESPONSES

The detailed design solution in a project may be described as a design response.

> A design response is project specific and responds to the context and needs of the particular people who live and work there.

For example, briefing for the project may identify that cooking food is important to the people who will live there, and that they love to prepare food themselves. Including a place to cook is therefore important. The response to this design approach could be to provide a domestic kitchen, if that is where people are used to preparing food. Or it could be that the people who will live there are used to preparing food over a campfire. The approach to the principle is the same (provide a place that is homelike and supports people to be independent by including a place to cook), but the design response in each case will be quite different.

The relationship between the principles, approaches and responses is summarised in the examples given in Table 5.

TABLE 5 EXAMPLES OF RELATIONSHIPS BETWEEN PRINCIPLES, APPROACHES AND RESPONSES.

Design principle	Design approach	Design response
- Support movement and engagement - Create a familiar place	- Walking paths - Outdoor access	- Raised garden bed as destination, accessed by step free path
- Design in response to vision for way of life	- Homelike - Independence support	- Domestic style kitchen
- Design in response to vision for way of life	- Homelike - Independence support	- Campfire

This multi-layered approach to environmental design has been used by others too. Marshall in Design for Dementia [5] identifies the consensus that has been reached on principles and design features. Regnier in Design for Assisted Living Guidelines for housing the physically and mentally frail [18] lists eight frameworks from the work of practitioners and researchers in terms of goals, objectives and concepts, noting that they describe a hierarchy of considerations. (A number of these are frameworks for evaluating environments for older people, not specifically people living with dementia.)

WHAT IS THE JUSTIFICATION FOR USING THE FLEMING – BENNETT PRINCIPLES TO ORGANISE THIS REPORT?

The centrality of design principles as organising concepts in our understanding of how to design to reach our over-arching aims of maximising well-being and dignity for people living with dementia has been explored in the previous section. The principles used in this exploration were those of Fleming and Bennett. This begs the question, is there any justification for using these principles rather than those put forward by other authors.

The real-life answer to this is that if other authors had written this report they may well have chosen other principles, or even other organising concepts. Nevertheless, it would be arrogant not to offer some justification for the selection of principles, at least to show that they are consistent with those of other authors.

KEY PUBLICATIONS DESCRIBING DESIGN PRINCIPLES

A short survey of books on environmental design and peer reviewed articles was undertaken to identify what has been written regarding design principles. In addition to the search methodologies described below, the authors' knowledge of the literature was used to identify potential books and articles that discussed design principles.

BOOKS

Books that showcased environmental design for people living with dementia in acute health care settings, residential aged care/supported residential accommodation, and day centres were sought. In particular, the focus of this search were books which identified and/or discussed design principles.

As a starting point, a review of amazon.com.au identified 443 results for 'design for dementia' and amazon.com produced 986 results for 'dementia design'. A google search was used to identify additional references, and key websites (such as the DSDC Stirling's portal) were also searched for publications.

The publications were then searched to determine if they included a reference to design principles or included case studies of design. This resulted in a list of 48 references, from which a convenience sample

of ten were selected for more detailed review. The ten key books that have been selected as the focus for this discussion represent a range of building types, authors, countries and publication dates. The key criteria for selection was a discussion or identification of design principles.

ARTICLES

A similar approach was taken for articles. Potential peer reviewed articles were identified by combining the reference lists of five major systematic reviews of the dementia design literature, resulting in a list of 409 references. These sources were initially reviewed by scanning titles and abstracts resulting in the identification of 157 articles that were judged to be likely to contain sets of principles. These 'short listed' sources were then reviewed in detail resulting in a final selection of seven articles. The seven articles have been chosen to represent a range of building types, authors, countries and publication dates

DESIGN PRINCIPLES IN KEY PUBLICATIONS

Design principles are discussed in a range of ways as authors use a variety of terms to describe their ideas and concepts. Principles are a focus of literature reviews and are used as a key part of post occupancy evaluation. The authors of this report have also published in this field (2, 19–23).

BOOKS

Calkins [24] describes environment centred goals and environment behaviour issues. *Cohen and Weisman* [25] begin with therapeutic goals and then discuss principles for planning and design. They identify general attributes of the environment and describe these, along with building organisation and activity areas, in some detail. *Brawley* [26] takes Cohen and Weisman's therapeutic goals and adds one additional goal of her own. *Marshall* [5] identifies eight principles of design and twelve design features which summarise the international consensus at that time. One of Marshall's co-editors *Judd* identifies five recurring design themes and *Phippen*, the other, uses the concept of home to discuss key design characteristics that need to be considered. *Regnier* [18] includes a chapter on conceptual frameworks in which he outlines the work of a number of researchers and practitioners. This includes twelve environment-behaviour principles that he first described with Pynoos in 1992.

Moore, Geboy and *Weisman* [27] use eleven attributes of place experience to analyse adult and dementia day services centres. *Cooper Marcus* and *Sachs* [28] identify a number of design guidelines for gardens in residential and day facilities for people living with dementia. *Fung* [29] draws on Marshall's schema, asking that contextual and sociocultural factors be taken into account, in particular that the understanding of small scale and domestic be considered differently in urban environments (such as Singapore). *Fung's* dementia design palette gives a quick visual guide to design topics and design elements, as well as disabilities associated with dementia and/or ageing. *Halsall and McDonald* [30] describe six key integrated design principles that guide their practice, whether in the context of specialist care, housing design or planning the wider environment. The guidelines prepared by *Grey, Pierce, Cahill* and *Dyer* [31] name eight design issues which should be considered when designing dementia friendly dwellings.

ARTICLES

In their article which focusses on a model for post occupancy evaluation, Lawton, Fulcomer and Kleban [32] describe five specific goals of the Weiss Institute. These were primarily performance goals and derived from Lawton's conception of 'the good life'. Hyde [33] reviews eight nursing home units for people living with dementia and uses seven goals as the framework for her evaluation. Schiff [34] proposes that planning and design of environments should be based on five basic principles which are derived from concepts of good care. Gitlin, Liebman and Winter [35] identifies four general environmental principles in her synthesis of research findings regarding the effects of environmental interventions on the wellbeing of people living with dementia. In their article on environments that facilitate wayfinding, Marquardt and Schmieg [36] identify five significant criteria based on their review of publications. Chaudbury, Cooke, Cowie and Razaghi [37] provide an overview of recent empirical research and show how five unit/facility environmental characteristics relate to seven therapeutic goals. Calkins includes a table of environmental therapeutic goals for people living with dementia which captures the work of six authors, and goes on to suggest five person centred practice recommendations, each of which addresses a number of specific design strategies.

COMPARISONS WITH FLEMING-BENNETT (F-B) PRINCIPLES

Each of these texts was analysed with reference to the F-B principles. Similarities and differences in the content were identified as each item was considered to determine if, and how, it aligned with the F-B principles. Another key task was to identify any items that were not included in the F-B principles. What would be missed if the F-B principles were to be used as a framework to organise this ADI World Report?

Tables 6 & 7 (below) summarise the outcome of this analysis. Key topics discussed by the authors have been placed against one (or more) of the F-B principles. The key question being asked when undertaking this analysis was 'Can the topic described in this publication be captured by using the F-B principles?" Some topics could have been placed against a number of F-B principles. Those that did not readily coincide with the F-B principles, such as spirituality and participatory design are listed in the last row of the table.

It is apparent that there is great variety in the terminology used and in the way concepts and ideas are described. The need to be treated with dignity and respect, for example, is identified by some authors as a design principle. Others describe a design solution, such as a walking path, as a principle or a therapeutic goal. Some identified items that relate to operation quite specifically, such as care for staff.

The authors of the publications may have placed an item under a different F-B principle to the one shown here. In the limited time available for this analysis, the focus was to determine if topics could be aligned with one or more principles. A more detailed review to determine the best correlation is beyond the scope of this chapter. It does, however, suggest an opportunity for further discussion and investigation.

TABLE 6: COMPARISON OF F-B PRINCIPLES WITH PRINCIPLES DESCRIBED IN TEN KEY BOOKS

Fleming Bennett Principle	Calkins 1988	Cohen & Weisman 1991	Brawley 1997	Marshall (Marshall) 1998	Judd (Marshall) 1998	Phippen (Marshall) 1998	Regnier & Pynoos (Regnier) 2002
1. Unobtrusively reduce risks	- Maximise independence in ADL - Wayfinding/Orientation - Safety and Security - Competence in Daily Activities - Prosthetic support	- Ensure safety and security - Maximise autonomy and control - Adapt to changing needs	- Ensure safety and security - Maximise autonomy and control - Adapt to changing needs	- Compensate for disability - Maximise independence - Enhance self-esteem & confidence	- Self-esteem, autonomy and individuality - Safety	- Domestic characteris-tics-kitchens	- Control, Choice/ Autonomy - Safety/Security - Accessibility and Functioning - Adaptability
2. Provide a human scale	- Spaces for groups - Wayfinding/Orientation	- Establish links to the healthy and familiar - Protect the need for privacy	- Establish links to the healthy and familiar - Protect the need for privacy	- Reinforce personal identity	- Small	- Domestic characteris-tics-entrances, dining arrangements - Interior planning and design	- Familiarity - Aesthetics and Appearance
3. Allow people to see and be seen	- Wayfinding/Orientation	- Maximise awareness and orientation	- Maximise awareness and orientation	- Enhancement of visual access	- Legible	- Night-time cover and servicing	- Orientation/Wayfinding
4. Reduce unhelpful stimulation	- Control noxious stimuli - Wayfinding/Orientation	- Maximise awareness and orientation	- Maximise awareness and orientation	- Control of stimuli	- Legible	- Night-time cover and servicing	- Orientation/Wayfinding - Sensory Aspects
5. Optimise helpful stimulation	- Compensate for sensory losses - Wayfinding/Orientation - Personalisation	- Provide opportunities for stimulation and change - Maximise awareness and orientation	- Provide opportunities for stimulation and change - Maximise awareness and orientation	- Orientating and understandable - Control of stimuli	- Legible	- Night-time cover and servicing - Cueing	- Orientation/Wayfinding - Stimulation/Challenge - Sensory Aspects
6. Support movement and engagement	- Natural outlets (exercise, fresh air) - Wayfinding/Orientation - Privacy and Socialization - Safety and Security	- Support functional ability through meaningful activity - Maximise awareness and orientation	- Support functional ability through meaningful activity - Maximise awareness and orientation	- Maximise independence	- Self-esteem, autonomy and individuali-ty-Safety	- Outside spaces	- Stimulation/Challenge
7. Create a familiar place	- Cues props to connect to past - Personalisation	- Establish links to the healthy and familiar	- Establish links to the healthy and familiar - Encourage family involvement	- Reinforce personal identity	- Familiar	- Domestic characteris-tics-personal space - Interior planning and design	- Familiarity - Aesthetics and Appearance - Personalization
8. Provide opportunities to be alone or with others	- Interact with families and friends - Privacy and Socialization	- Provide opportunities for stimulation and change - Provide opportunities for socialization - Protect the need for privacy	- Provide opportunities for stimulation and change - Provide opportunities for socialization - Protect the need for privacy - Encourage family involvement	- Welcome relatives and the local community	- Self-esteem, autonomy and individuality	- Domestic characteris-tics-provision of shared spaces	- Privacy - Social Interaction
9. Link to the community		- Establish links to the healthy and familiar	- Establish links to the healthy and familiar - Encourage family involvement	- Welcome relatives and the local community	- Self-esteem, autonomy and individuality	- Domestic characteris-tics-siting	- Aesthetics and Appearance
10. Design in response to vision for way of life	- Cues props to connect to past - Personalisation - Competence in Daily Activities	- Support functional ability through meaningful activity - Maximise autonomy and control	- Support functional ability through meaningful activity - Maximise autonomy and control - Encourage family involvement	- Maximise independence - Enhance self-esteem & confidence	- Self-esteem, autonomy and individuality	- Domestic characteris-tics-kitchens	- Privacy - Control, Choice/ Autonomy - Personalization
Not part of 1–10	Nil	Nil	Nil	- Care for staff	Nil	Nil	- Adaptability

TABLE 6: CONTINUED

Fleming Bennett Principle	Moore Geboy & Weisman 2006	Cooper Marcus & Sachs 2014	Fung 2015	Grey, Pierce, Cahill & Dyer 2015	Halsall & McDonald 20??
1. Unobtrusively reduce risks	- Safety and security - Functional independence - Meaningful activity - Continuity of the self	- Address attitudes of residents to nature and outdoors - Ensure garden is attractive and well maintained - Building edge encloses garden or boundary provides complete (screened)enclosure	- Wayfinding - Mobility - Safety & Security - Fall avoidance	- Personalisation - Unobtrusive safety measures and appropriate technology - Safe and accessible outdoor spaces	- Distinctive Environments - Accessibility - Safety
2. Provide a human scale	- Orientation		- Placemaking	- Familiar design	- Comfortable and Stimulating Environments
3. Allow people to see and be seen	- Orientation	- Garden to be clearly visible from inside the building - Visual contact from a staff area - All parts of garden visible - Clear garden layout	- Space and programme	- Good visual access	- Legibility - Safety
4. Reduce unhelpful stimulation	- Sensory stimulation	- Locate garden so only shadow is large from building (not trees)	- Human factors - Visual perception - Environmental stressors	- An environment that is easy to interpret and calm	- Comfortable and Stimulating Environments
5. Optimise helpful stimulation	- Orientation - Sensory stimulation - Architectural delight	- Provide features that might evoke memories	- Placemaking - Wayfinding - Visual perception - Sensory stimuli	- Familiar design - An environment that is easy to interpret and calm - Distinct places	- Distinctive Environments - Legibility - Comfortable and Stimulating Environments - Familiarity
6. Support movement and engagement	- Personal control - Architectural delight	- All parts of garden visible - Address attitudes of residents to nature and outdoors - Locate garden for optimal morning use - Locate garden so only shadow is large from building (not trees) - Provide shade - Clear garden layout - Appropriate destination points	- Wayfinding - Outdoor spaces - Placemaking - Fall avoidance	- Distinct spaces - Safe and accessible outdoor spaces	- Distinctive Environments - Legibility - Comfortable and Stimulating Environments - Safety - Safe and accessible outdoor spaces
7. Create a familiar place	- Privacy - Continuity of the self	- Provide features that might evoke memories - Look like a domestic garden	- Placemaking	- Familiar design - Personalisation - Distinct spaces	- Familiarity - Distinctive Environments
8. Provide opportunities to be alone or with others	- Orientation - Social interaction - Privacy - Personal control - Architectural delight	- Appropriate destination points - Garden spaces at front and back of building	- Placemaking - Space and programme	- Distinct spaces	- Distinctive Environments - Comfortable and Stimulating Environments - Safety
9. Link to the community	- Continuity of the self		- Mobility - Outdoor spaces	- Familiar design	- Distinctive Environments
10. Design in response to vision for way of life	- Meaningful activity - Social interaction - Personal control - Continuity of the self	- Address attitudes of residents to nature and outdoors - Provide plenty of choice	- Mobility	- Distinct spaces - Safe and accessible outdoor spaces	- Distinctive Environments
Not part of 1–10	- Spirituality	- Involve management and staff in design of garden - Address attitudes of residents to nature and outdoors	Nil	- Participatory design	Nil

TABLE 7: COMPARISON OF F-B PRINCIPLES WITH PRINCIPLES DESCRIBED IN SEVEN KEY ARTICLES

Fleming Bennett Principle	Lawton, Fulcomer & Kleban 1984	Hyde 1989	Schiff 1990	Gitlin, Liebman & Winter 2003
1. Unobtrusively reduce risks	- Increase autonomy in performing ADL's - To increase meaningful use of time	- Compensate for cognitive and sensory deficits - sense of mastery within the environment and in the basic activities of daily living - Maintain physical health and safety	- Be stable and familiar - Support reality orientation	- Reduce complexity by relaxing rules and expectations and minimising distractions
2. Provide a human scale		- Enhance the quality of life, including the use of leisure time, and interpersonal relationships - Reduce tension, agitation, and problem behaviours	- Be clear and well structured - Be stable and familiar	- Provide predictability, familiarity and structure
3. Allow people to see and be seen		- Compensate for cognitive and sensory deficits - Sense of mastery within the environment and in the basic activities of daily living	- Be clear and well structured - Serve as a cue to memory	- Increase orientation and awareness
4. Reduce unhelpful stimulation	- Enhance sensory functioning - Enhance cognitive functions-specifically memory orientation	- Compensate for cognitive and sensory deficits - Sense of mastery within the environment and in the basic activities of daily living - Reduce tension, agitation, and problem behaviours	- Be clear and well structured - Serve as a cue to memory	- Reduce complexity by relaxing rules and expectations and minimising distractions - Increase orientation and awareness - Create a low stimulus, comfortable environment
5. Optimise helpful stimulation	- Enhance sensory functioning - Enhance cognitive functions-specifically memory orientation	- Compensate for cognitive and sensory deficits - Sense of mastery within the environment and in the basic activities of daily living - Reduce tension, agitation, and problem behaviours	- Serve as a cue to memory	- Increase orientation and awareness - create a low stimulus, comfortable environment
6. Support movement and engagement	- Enhance cognitive functions-specifically memory orientation - To increase meaningful use of time	- Compensate for cognitive and sensory deficits - Sense of mastery within the environment and in the basic activities of daily living - Enhance the quality of life, including the use of leisure time, and interpersonal relationships - Reduce tension, agitation, and problem behaviours - Maintain physical health and safety	- Be clear and well structured	- Reduce complexity by relaxing rules and expectations and minimising distractions - Increase orientation and awareness
7. Create a familiar place	- To increase meaningful use of time	- Enhance the quality of life, including the use of leisure time, and interpersonal relationships	- Be stable and familiar - Serve as a cue to behaviour - Serve as a cue to memory	- Increase orientation and awareness - Provide predictability, familiarity and structure
8. Provide opportunities to be alone or with others	- To increase meaningful use of time - To increase social interactive behaviour	- enhance the quality of life, including the use of leisure time, and interpersonal relationships - Reduce tension, agitation, and problem behaviours	- Be clear and well structured - Serve as a cue to behaviour	- Provide predictability, familiarity and structure
9. Link to the community	- Enhance the sense of self			
10. Design in response to vision for way of life	- Increase autonomy in performing ADL's - To increase meaningful use of time - enhance the sense of self	- Sense of mastery within the environment and in the basic activities of daily living - Enhance the quality of life, including the use of leisure time, and interpersonal relationships	- Be stable and familiar - Serve as a cue to behaviour - Support reality orientation	- Provide predictability, familiarity and structure
Not part of 1–10		- Create an environment that allows staff to work competently and communicate effectively with patients, family, and each other - Meet state and federal life safety and other codes	Nil	

TABLE 7: CONTINUED

Fleming Bennett Principle	Marquardt & Schmieg 2009	Chaudbury 2017	Calkins 2018
1. Unobtrusively reduce risks	- Autonomy	- Maximise safety and security - Support functional abilities	- Support courtesy, concern and safety
2. Provide a human scale	- Legibility - Familiarity	- Provision of privacy	- Create a sense of community - Enhance comfort and dignity - Opportunities for meaningful engagement
3. Allow people to see and be seen	- Autonomy	- Maximise awareness and orientation	- Enhance comfort and dignity - Support courtesy, concern and safety
4. Reduce unhelpful stimulation	- Autonomy - Sensory stimulation	- Maximise awareness and orientation - Regulation and quality of stimulation	- Create a sense of community - Enhance comfort and dignity
5. Optimise helpful stimulation	- Legibility - Autonomy - Sensory stimulation	- Maximise awareness and orientation - Regulation and quality of stimulation	- Create a sense of community - Enhance comfort and dignity
6. Support movement and engagement	- Legibility - Autonomy - Sensory stimulation	- Support functional abilities	- Enhance comfort and dignity - Support courtesy, concern and safety - Provide opportunities for choice - Opportunities for meaningful engagement
7. Create a familiar place	- Legibility - Familiarity - Social interaction	- Provision of privacy - Opportunities for personal control	- Enhance comfort and dignity
8. Provide opportunities to be alone or with others	- Legibility - Familiarity - Social interaction	- Facilitation of social contact - Provision of privacy	- Create a sense of community - Provide opportunities for choice - Opportunities for meaningful engagement
9. Link to the community	- Social interaction	- Facilitation of social contact	- Create a sense of community - Provide opportunities for choice
10. Design in response to vision for way of life	- Legibility - Familiarity - Social interaction	- Support functional abilities	- Enhance comfort and dignity - Support courtesy, concern and safety - Provide opportunities for choice - Opportunities for meaningful engagement
Not part of 1–10			

Conclusion

There is broad agreement about what makes a good environment for people living with dementia, although the terms that are used and the way concepts and ideas are framed may differ.

There is a strong interrelationship between the F-B principles and Zeisel approaches. This body of work has many similarities, and each expands and complements the other.

There is a sound basis for using the principles developed by Fleming-Bennett as the higher order organising framework:

- to discuss the design of the environments for people living with dementia
- to review the literature on designing for people living with dementia
- as the basis for a survey to gather information about examples of best practice design across the world.

The Zeisel approaches provide invaluable ways to apply the principles and assist us to delve more deeply into what the principles can mean.

The use of this set of principles and approaches provides a comprehensive way of designing for people living with dementia, which places it in the context of human rights and provides for limitless detailed project specific design responses.

The high order goals which centre around the dignity of a person tell us why we should do something, they reflect our values and our vision for life. The principles of design are the first, highest order, step towards describing how to achieve these goals. Design approaches and design details make our goals and principles a reality at a specific time and place, so that the environments we create are meaningful for people living with dementia.

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Literature review

There is an extensive knowledge base to guide us but much of it is based on research and experience in residential care in high income countries.

Design and the built environment for people living with dementia in residential aged care

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Introduction

Residential aged care refers to accommodation and 24-hour care provided to older people who can no longer live independently in their own homes. Internationally, residential aged care may be referred to as nursing homes or care homes. There is a high prevalence of people living with dementia in residential aged care worldwide. Accurate estimates of the prevalence of dementia for people living in residential aged care are difficult to determine due to lack of available data about people living in residential aged care and undiagnosed dementia. Estimates available indicate that 48% of residents in the United States (US), 69% of residents in the United Kingdom (UK) and 47% of residents in Australian residential aged care are living with dementia [1–3].

There is a growing interest internationally in improving care and treatment for people living in residential aged care to optimise health and quality of life. Moving to residential aged care may be distressing for new residents because of the change in surroundings, reduced contact with family and friends, and the requirement to adapt to a new lifestyle and routine [4]. This may be particularly distressing for residents who are living with dementia and new residents may experience agitation, depression, and sleep disturbances [5]. Of particular concern for people living with dementia is the potential increase in the use of psychotropic medicines after moving to residential aged care in response to changed behaviours [6].

Careful consideration of the built environment in residential aged care for people with dementia has the potential to provide an effective way of easing the transition to residential aged care for new residents. It is difficult to conduct high-quality research about design for people with dementia in residential aged care. As shown in this report, much of the evidence-base is studies which have included only one or small numbers of facilities, are observational and/or cross-sectional in design and evidence is based on heterogeneous interventions which makes comparison difficult and causality cannot be inferred. However, there is sufficient evidence to suggest that the quality of the built environment in residential aged care can positively impact meaningful activity, behaviour and quality of life for residents. Enabling residential aged care environments which help facilitate residents to engage in indoor and outdoor activities and offer a variety of spaces whilst creating a familiar environment for the residents, are associated with better quality of life [7]. Here we report an overview of the current available evidence for design in residential aged care in line with Fleming and Bennett's principles for design for people with dementia.

UNOBTRUSIVELY REDUCE RISKS

Security measures to increase safety for people with dementia in residential aged care have been considered in studies. In a cross-sectional study of 427 residents in 15 special care units for people with dementia, residents living in facilities with camouflaged exits and silent electronic locks had lower levels of depression compared to residents in facilities with non-camouflaged exits and alarms [8]. In the 1980s, special care units were developed in nursing homes in the US specifically for people with dementia. The authors hypothesised that the provision of these features would lead to staff considering these environments safer and in turn giving residents greater independence resulting in positive behaviour outcomes for the residents. It should be noted here that there is limited evidence to suggest separation of people with dementia to special care units overall have any benefit over other models of care; however, there is no set definition for a special care unit [9]. Special care units usually incorporate specific design features and differences in staff training. Some longitudinal studies have suggested poorer behavioural outcomes for residents in special care units [10].

Other relatively older studies have also suggested security measures may positively benefit residents' behaviour [11–13], but studies have mainly evaluated security measures as part of large-scale changes to a whole model of care or as part of special care units, so it is difficult to quantify the benefit solely attributed to security measures. In contrast, more recent cross-sectional evidence has suggested security features may be associated with more harmful behaviours for people with dementia [14] and prioritisation of health and safety rather than activity in residential aged care may associate with poorer quality of life [15].

Increased time spent outdoors may improve behaviours and quality of life for people with dementia [16]; therefore, restricting access to gardens and other outdoor spaces may have unintended negative consequences. Gardens may create a relaxing environment for the residents and encourage activity [16]. Overall, the benefits of security measures must be balanced against potential harms of people with dementia feeling they are segregated or restrained in a secure environment, and sufficient opportunities to use outdoor spaces should be optimised.

Falls are a particular safety consideration for people with dementia in residential aged care. Research studies have examined environment or assistive technologies including bed or chair alarms or the use of low beds. Alarms may be considered as a safety measure, but there is a lack of evidence to suggest alarms reduce falls in residential aged care [17] and alarms may be perceived as intrusive [18]. Environmental assessments and appropriate modifications are encouraged to reduce risk of falls such as improved lighting and minimising environmental hazards [19, 20]. However, the environment is only one factor to consider when planning methods to reduce risk of falls. Consideration of the underlying reasons for falls including conditions such as urinary tract infections and adverse events from medications are important [19].

It should be noted here that there is limited evidence to suggest separation of people with dementia to special care units overall have any benefit over other models of care.

PROVIDE A HUMAN SCALE

There has been interest in the benefits of smaller scale residential aged care settings for residents compared to larger-scale settings. Yet, the adoption of smaller scale environments for residential aged care is usually part of changes to the whole model of care. These small-scale environments not only differ in size to more traditional residential aged care settings, but also have different approaches to staffing and activities in an aim to provide a more home-like environment. Therefore, determining the benefits of reducing the size of the facility separately to all other modifications which accompany these smaller environments is not possible.

The Green House model developed in the US builds residential care facilities with units for 10–12 residents. Other design features include private rooms and attached bath, a shared central living space with an open kitchen, dining, and living area; and access to outdoor space [21]. This is accompanied by non-environmental features including a consistent work team, control over mealtimes for residents and 'spontaneity and risk' are supported [21]. A longitudinal study comparing 15 Green House homes and 223 matched non-Green House homes suggested the

Green House model was associated with lower rehospitalizations and some improvements in quality of care measures [22]. Some studies have reported difficulties in implementing features of the Green House model such as variation in actioning resident choice [21], but implementing the design features of the Green House model have been more consistent. Further longitudinal research is needed to examine the effects of the Green House model on resident outcomes.

A cross-sectional study of 541 residents in 17 residential aged care facilities suggested a small-scale home-like model of care where people live in clusters associates with fewer hospitalisations, better quality of life, lower use of potentially inappropriate medications and better consumer-rated quality of care without an increase in whole of system costs. [23–25]

In Australia, a cross-sectional study of 541 residents in 17 residential aged care facilities suggested a small-scale home-like model of care where people live in clusters associates with fewer hospitalisations, better quality of life, lower use of potentially inappropriate medications and better consumer-rated quality of care without an increase in whole of system costs [23–25]. However, initial capital costs of new small-scale facilities were not included in these estimates and would be substantial if re-designing larger-scale facilities. In the Netherlands, a longitudinal study of 259 residents over 12-months comparing small-scale living facilities to psychogeriatric nursing home wards did not find any significant effect for quality of life or behaviour for residents [26]. It is unlikely that a randomised controlled trial (RCT) of small-scale living compared to larger settings would be feasible and benefits seen in some studies of small-scale living are likely to be due to overall changes in the entire model of care which may be facilitated by the small-scale design. Whether implementing a design of small-scale design change without considering other changes to the model of care would have any benefits to residents is unknown.

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ALLOW PEOPLE TO SEE AND BE SEEN

People living with dementia often walk with purpose and it is important to have an environment to support safe wayfinding i.e. finding their way from one place to the next. This may become particularly challenging when individuals with dementia are moved to a new environment. If this is a permanent change, such as a move to residential aged care, then there is a particular need to support people with dementia to become familiar with their new environment. Despite the importance of walking with purpose for people with dementia, very little research has been conducted to compare different cues or designs which improve wayfinding in residential aged care. The building structure and environmental cues may be helpful to improve the orientation of residents including use of signs, colours, lighting and furniture [27].

Features of the building structure such as long corridors, repetitive elements and lack of distinction between different areas of the building may cause confusion in wayfinding, whereas smaller-scale buildings with direct visual access may improve wayfinding [27, 28]. A non-randomised study of over 100 residents compared a corridor design to a L-shaped, H-shaped or square design within group living units of up to 8 residents [29]. The study found a decline in depressive symptoms for people in the square design but did not find any differences in ten other behaviour domains investigated. Minimisation of corridors has been one of the key design features considered to facilitate a home-like environment when developing small-scale living environments [30]. In a comparison of 30 nursing homes, a straight layout without changes in direction supported orientation for residents with mild to severe cognitive impairment [31].

Open-plan environments in smaller-size facilities may allow for better visual access for residents and support orientation and social engagement and also may improve visual access for staff so they can see the residents in living areas [30].

Opportunities to participate in domestic and other activities can be facilitated by improvements in environmental design. Staff should engage with residents to determine activities they would like to participate in, but visual access to potential activities may also stimulate residents to engage in new activities. An example of this is using visually stimulating sensory or enabling gardens to encourage residents to engage in gardening activities.

REDUCE UNHELPFUL STIMULATION

High levels of stimulation/sensory input may be overwhelming for some people with dementia. A cross-sectional study with 427 residents in 15 special care units showed in environments which were deemed to have more understandable sensory input, residents had lower levels of verbal aggression [8]. Modifications such as designated quiet rooms, elimination of unnecessary clutter and alarms have been recommended to help reduce overstimulation; however, recommendations are primarily based on experiences of designers or care providers as research studies focusing on this aspect of design are lacking.

Small-scale facilities with fewer residents may help reduce overstimulation as noise would be likely reduced, but there is no evidence to suggest noise levels are lower in small-scale facilities and research to determine if less noise improves outcomes for residents has been conflicting. High noise levels were associated with lower levels of social interaction in a study of residents with severe dementia [32], whereas moderate noise levels have been associated with higher levels of engagement [33]. Noise has been identified as an important factor influencing behaviour and quality of life of residents from focus groups with family members and staff [34]. Temperature of bedrooms and living areas should also be considered. A small study of 21 residents in one facility found agitation levels were higher when temperatures were above 26˚C and lower than 20˚C [35], and uncomfortable room temperatures have been associated with poorer quality of life [32].

Busy entry doors may result in overstimulation and may draw the attention of residents to the exits and encourage them to leave. Therefore, the stimulation from entry and exit doors should be minimised [7]. Methods to reduce overstimulation such as adding internal partitions to larger group spaces was conducted in some of the facilities investigated in a recent cluster RCT as part of multicomponent refurbishment interventions, but it is unclear if this change specifically helped improve outcomes for residents [36]. Care providers need to find a careful balance between reducing unhelpful stimulation and optimising helpful stimulation. People with dementia should not be deprived of activities, information or helpful design features for fear of overstimulation, instead a person-centred approach should be taken. The provision of a quiet room in case of noise problems should be considered so that people have an alternative quiet area to their bedrooms.

OPTIMISE HELPFUL STIMULATION

Environmental stimulation in residential aged care which is individually tailored and promotes engagement can reduce apathy for residents [37]. In addition to personal items placed on resident doors to facilitate wayfinding to bedrooms, signs may be useful in other areas, but signs may not be as efficient as allowing visual access.

Signs, colours, lighting and furniture may be relatively inexpensive methods of improving wayfinding for residents [27]. Memory boxes, signs or pictures on bedroom doors may help residents to recognise their own rooms, but little research is available to determine if one particular method is more useful than another [38]. A person-centred approach may be preferred, i.e. to place cues on the resident's bedroom door which are easily recognisable to the individual. Contrasting colours without patterns may help with the identification of different rooms or objects and spatial awareness. However, bold floor patterns can disorient people with dementia and cause anxiety [39] and dark surfaces can appear as holes [40]. There has been little research specifically focusing on use of colours in residential aged care and what colours may work best for wayfinding are unclear. However, the use colours and objects to improve wayfinding and feelings of familiarity have been considered as part of multicomponent refurbishment interventions in a cluster RCT in residential aged care with improvements in agitation and quality of life [36]. However, which components of the design intervention may have improved outcomes for residents is unclear. Signs used in residential aged care should be purposeful and separate to all other stimuli, so the residents can easily identify and distinguish signs from other information [27].

A small study of 20 aged care residents suggested visual and auditory stimulation can positively help residents to recognise mealtimes [41]. The study used simple cues including tablecloths and flowers on tables accompanied by background music. This builds on previous reviews which have suggested stimulation of many senses is needed to improve wayfinding [27]. Other studies which have examined multicomponent environmental changes in residential aged care have also included changes to individualise resident rooms and dining room changes such as tablecloths and centrepieces. One longitudinal study over two years of over 100 residents examined the impact of refurbishment to care homes to include these design changes alongside an increase in person-centred care [42]. The study reported a reduction in physical agitation and forceful behaviours for residents in the refurbished settings, but it is difficult to quantify the environmental design contribution to these positive changes observed.

Additional studies have also focused on changes to the mealtime environment in residential aged care [43, 44]. These studies have used similar small design changes accompanied by other changes, such as how the food is displayed and changes to mealtime routines e.g. distinct times from other activities and increased staffing levels during mealtimes. Two cluster RCTs have examined the impact of changes to the mealtime environment for residents. Although these studies are still subject to bias considerations and small numbers of facilities involved, both studies reported improvements in quality of life for residents with the dining room changes [43, 44].

Mealtimes are an integral part of life in residential aged care [45], therefore, simple approaches to improve recognition of mealtimes, dining room design and the mealtime experience may be beneficial to residents.

Appropriate timing and intensity of lighting in residential aged care may improve circadian rhythms and mood for residents. Studies of residential aged care facilities have shown facilities often have dim lighting during the day or insufficient lighting to meet the visual needs of residents [46]. A study of 80 residents in seven residential aged care facilities investigated the effect of blue-enriched lighting in communal rooms, but the study found mixed results. Positive effects were shown for increased daytime activity and reduced anxiety, but negative effects such as increased night-time activity, reduced sleep efficiency and quality were also shown [47]. Whereas, a RCT of 189 residents in 12 facilities in the Netherlands suggested simply increasing the level of illumination by providing whole-day bright light (fluorescent tubes) in the common living room did not have adverse effects and improved mood, behaviour, functional abilities, and sleep for residents [48]. This adds to evidence of previous studies which indicated exposure to whole-day brighter light is associated with better outcomes for residents with and without dementia [49, 50]. Providing higher levels of lighting in communal areas is likely preferred to light-box bright light therapy methods where residents with dementia may have to be in the same sitting position for long periods of time [49]. Seasonal differences in light exposure should also be considered as higher lighting levels may be necessary during the winter months.

SUPPORT MOVEMENT AND ENGAGEMENT

Research studies have suggested physical and social inactivity are a major concern in residential aged care settings, and the majority of residents spend most of their time sedentary and inactively sitting or lying alone [51, 52].

This is of particular concern for people living with dementia as a study suggested individuals living with dementia in residential aged care had over 23% lower daily physical activity levels compared to people with dementia living in their own homes [52]. Physical inactivity and long periods of remaining sedentary have negative impacts on health and quality of life, and is the fourth leading cause of death worldwide [53]. Physical inactivity is associated with loneliness and one third of older adults may experience loneliness [54, 55]. Loneliness or social isolation may have detrimental effects on mental health and also increases the risk of morbidity and mortality [56, 57]. There is a lack of research about loneliness for people in residential aged care, but The National Institute for Health and Care Excellence (NICE) quality standards calls for older people in care homes to be provided with 'opportunities during their day to participate in meaningful activity that promotes their health and wellbeing' [58]. Design of residential aged care settings may help to facilitate engagement in activities for residents.

The design of indoor spaces should encourage purposeful movement and social engagement. Well-defined pathways and sufficient access to pathways have the potential to encourage a person living with dementia to actively engage in activities. A mixed-methods study examined the impact of pathways and their use for walking in retirement communities [59]. The study concluded pathways which are selected for recreational walking tended to be longer, were well-connected, did not have steps and had attractive views [59]. A review of 12 studies examining environmental influences of physical inactivity for older individuals in residential aged care suggested the environment's compatibility with abilities of the residents, the presence of equipment (e.g. handrails), accessibility (e.g. greater corridor width, accessibility of activity rooms), security, comfort and aesthetics of the environment and corridors (e.g. artwork, plants and windows) were important factors influencing physical inactivity [60]. Staffing levels are also important to facilitate movement for residents, facilities with higher staffing levels have been associated with less time spent in bed during the daytime compared to residents of facilities with lower staffing levels (three hours in bed vs. five hours in bed) [61].

The design of outdoor spaces should also encourage purposeful movement and social engagement. However, it is difficult to determine causality of the effects of exposure to garden spaces and outcomes for residents, as those who spend more time outdoors are likely to be residents with less health conditions, but current evidence suggests positive impacts on agitation for residents with dementia [16]. A qualitative study with focus groups of residential aged care staff suggested creating outdoor environments which have an 'inspiring design' which stimulates senses whilst creating a comfortable setting in which residents want to spend time in [62]. A study which designed a therapeutic garden in a residential aged care setting specifically for people with dementia included memory boxes, wandering paths, scented plants and viewing platforms. This study reported qualitative and quantitative findings of improvements in quality of life, agitation and depression and reduced stress for staff and family members [63]. However, this only compared one residential aged care facility before and after the implementation of the garden. Other studies of garden design in residential aged care, not specifically for people with dementia, have examined varied approaches including raised flower or vegetable beds, benches, gazebos, patios, bird baths, provision of shaded areas and linking conservatories or sun rooms to the garden [16]. A review of qualitative studies of residents, staff or family members suggested gardens with seasonal plants, all-weather outdoor seating, manageable doors with accessible thresholds, planned outdoor activities and appropriate clothing were all important enablers to facilitate residents to use outdoor spaces; whereas staff and organisation concerns regarding safety and visual accessibility of residents were barriers [64]. Changes to garden design could address safety and visual access concerns of staff and should be considered in parallel to the model of care and organisational culture of the facility for enabling access to the outdoors. In addition to a stimulating garden, facilities must consider if residents can access the garden unaccompanied and if not, active measures should be put in place to ensure residents are receiving adequate support to use outdoor spaces.

CREATE A FAMILIAR PLACE

People with dementia have reported that moving to residential aged care may challenge their sense of belonging and they may not feel part of their new environment [65]. Many carers and people with dementia want their care settings to have a 'homely feel' [66]. People with and without dementia living in residential aged care should have the opportunity to personalise their environment by bringing with them their own belongings to create a familiar place. Photographs, paintings, and pieces of furniture are objects with sentimental value [67].

The built environment, in addition to psychological factors and social factors, influences the 'sense of home' experienced by residents [69].

Introducing new technologies to people with dementia is possible, but technologies should not replace caregiver contact and residents of aged care facilities have reported preferences for receiving help from a care professional rather than technologies [70]. Technologies may be helpful to help residents feel connected to their families and to alert care professionals, but technologies should be presented in a way which is understandable to all residents regardless of their levels of cognitive functioning [66]. Whilst physical inactivity is a concern for residents of aged care facilities, residents have reported that televisions are the most valued item in their private rooms and are important to help residents feel at-home [67].

Cultural diversity in residential aged care settings has increased in many developed nations [71]. Cultural heritage of residents should be considered and the

environment should be adapted accordingly, for instance by providing spaces for culturally-based activities [72].

As described in the context of the provision of a human scale, home-like models of residential aged care have been introduced in multiple countries to create an environment which looks and feels more like a home. These environments usually involve small-scale buildings and a focus on meaningful activities where staff have integrated tasks, and some features, such as kitchens, are incorporated in the buildings to help residents feel more at-home and provide opportunities to participate in domestic tasks [73]. The Eden Alternative is an example of developing a home-like environment in residential aged care without changes to the scale of the building. The Eden Alternative focuses on smaller changes such as the introduction of plants, animals and children to develop a more home-like environment and more person-centred care [74]. A study which compared one Eden Alternative nursing home with a control site which had not adopted the Eden Alternative concluded no beneficial effects in terms of cognition, functional status, survival, infection rate, or cost of care after one-year [75]. However, qualitative observations indicated that the Eden Alternative was positive for many staff as well as residents, and a survey of family members suggested the Eden Alternative provided many opportunities for family involvement [74].

Several research studies have found associations between personalising the environment for the individual resident and positive outcomes including maintenance of activities of daily living, reduction in behavioural measures including aggression, anxiety and depression and higher levels of quality of life [8, 34, 68].

When examining the Eden Alternative and other home-like models of care, it is difficult to differentiate potential benefits by environmental changes from benefits brought by an increase in person-centred care. A cluster RCT which examined multicomponent refurbishment interventions in residential aged care found improvements in quality of life for people who received person-centred care and a person-centred environment compared to no intervention, but did not find that implementing both person-centred care and a person-centred environment further improved quality of life [36]. However, there were difficulties in implementing this person-centred environment intervention in this study.

PROVIDE A VARIETY OF PLACES TO BE ALONE OR WITH OTHERS

People with dementia living in residential aged care should have the opportunity to spend time alone and time with others.

A study of 35 Australian residential aged care facilities examined the Environmental Audit Tool (EAT) which is based on the ten design principles featured in this review [7, 76]. The study showed the provision of spaces for privacy and social interaction significantly contributed to self-reported quality of life. Other important contributors were provision of alternatives to wandering, familiarity and provision of opportunities for engagement in domestic activities [7]. A cross-sectional study of 38 residential aged care facilities suggested more gradation of space (the extent to which the building provides a range of private, semiprivate and public spaces) is associated with better resident quality of life [77].

A cross-sectional study of 11 residential aged care facilities concluded that shared bedrooms were associated with uncooperative behaviour [14]. However, the study also noted that there is no single environment suited to all residents, and some residents may prefer shared rooms [14]. Overall, evidence suggests a strong preference amongst residents and staff for private bedrooms [78]. Shared bedrooms may also result in arguments between residents about the use of the shared room [79].

PROVIDE LINKS TO THE COMMUNITY

After moving to residential aged care, residents may feel disconnected from their friends, families and neighbours [80]. Being able to maintain contact with family and maintain familiar activities have been identified as highly important for people with dementia after moving to residential aged care [65]. Research has suggested that family members often continue to provide critical support to relatives after they move to residential aged care [81–83]. The environment may help people with dementia maintain social relationships

with people in the community. There is some evidence to suggest small-scale residential aged care environments provide greater opportunity for family and friends to be involved in the group life [84].

Residents should have access to spaces where they can interact with family members separate to their bedrooms. There is a lack of research regarding potential advantages of facilitating easy access for residents to the local community. Research has mainly focused on the advantages of residents going outside within the grounds of their residential aged care facility rather than to the surrounding community [85].

In small-scale settings family members have reported being treated more as group members rather than visitors and were able to join at meal times. This encouraged family members to visit their relatives more frequently [84]

DESIGN IN RESPONSE TO VISION FOR WAY OF LIFE

The influence of designing to support a vision for a way of life on the well-being of people with dementia is hard to determine, not least because there are many visions for a way of life and these are often quite hard to define. The most common vision for a way of life involves providing a home-like environment. As previously described, there has been increasing interest in how to provide 'home-like' environments for people with dementia in residential aged care, or how to create a 'sense of home' [69, 73]. Home-like models of care differ in their approach, but many have included involving residents in domestic activities such as cooking. However, there has been some consideration that residents vary in the type of opportunities for meaningful activities they would want to engage with for example physical activities, musical activities, intergenerational activities, reminiscence and cognitive stimulation [86]. There have been variations worldwide in how the home-like model of care has been implemented in residential aged care. The home-like model usually involves encouraging residents to participate in domestic activities by providing access to facilities, such as a kitchen and encouraging residents to use the spaces offered [23].

Overall, it is difficult to differentiate the impact of environmental characteristics of home-like models in particular and vision driven designs in general because the environmental aspects of the model are inextricably linked to other aspects of the model, i.e. staffing structures, staff training, staff selection, financial model etc. However,

the role of the vision for a model of care as the driving and unifying force behind the adoption of all of the aspects of the chosen model deserves greater attention.

CONCLUSIONS

Optimising the built environment in residential aged care is important to facilitate activities, engagement and help residents feel at-home to minimise the impact of transitioning to residential aged care from living in their own homes. Studies which have investigated environmental design in residential aged care have usually been prone to a high-risk of bias as described in a Cochrane review on the evidence for environmental design in residential aged care expected to be published this year [87]. Residential aged care providers should consider using environmental assessment tools and identifying features which could be improved. Improvements do not necessarily have to involve complete restructuring of buildings to be beneficial. Environmental design changes in residential aged care should be made in conjunction with considerations regarding the model of care offered by the provider and the needs and preferences of the residents.

Design and the built environment to support patients living with dementia and accompanying persons in acute hospitals

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Introduction

Acute general hospitals provide time-sensitive acute curative services, typically in a short time frame. This distinguishes them from other healthcare settings such as primary health care centres (i.e. primarily for short daytime appointments) or community hospitals (i.e. typically for long term residential care or rehabilitation) [88, 89].

With global demographic ageing, acute hospitals are treating a growing percentage of older people; for instance, in Ireland in 2015, people over 65 years accounted for 54% of the total hospital inpatient bed days and approximately 37% of day case bed days [90]. Correspondingly, the percentage of hospital patients with dementia is increasing, with some research indicating that up to 30% of all inpatients in acute hospitals have a dementia [91, 92], others suggest these figures may be higher [93] Furthermore, people with dementia will often spend longer in hospital than average [94], illustrated in Australia, where a patient with dementia will have an average stay of 22 days compared to an average of six days for all hospital stays [95].

Unfortunately, for many of these patients the unfamiliar, busy, complex, large-scale, and austere hospital setting can be disorientating, stressful, alienating, and have a detrimental impact [96, 97] resulting in adverse outcomes, and increased complications and mortality rates [94]. Moreover, if a patient is hospitalised without their dementia being correctly diagnosed, this may lead to further problems such as injuries, malnutrition, over or under medication [98].

Moyle et al [99] argue that many hospitals are not designed to care for people with dementia, pointing out that this not only undermines care and health outcomes (see Galvin), but also adds to the burden of care for the staff. In addition, they highlight the important supporting role played by family members and caregivers, a role which is often hard to maintain within the hospital setting [100].

Many hospitals are not designed to care for people with dementia

In response to these challenges and growing awareness about the negative impact of many hospital environments, a range of dementia-friendly hospital design goals and principles have been developed and advocated by various organisations [101–104]. These approaches are based on well-established literature relating to diverse healthcare environments

[101, 105–107], including a strong focus on residential aged care design [108–111]. Some of the key features of these dementia-friendly hospital design goals and principles include careful management of risk, attention to building scale, visual access, sensory stimulation, mobility and social engagement, and familiarity.

Acute hospitals are typically large-scale facilities with multiple departments providing outpatient and inpatient care in specialised and non-specialised wards, emergency services, rehabilitation and day clinics, visitor amenities, and myriad health and social care services [88].

The dementia-friendly design themes investigated here are largely applicable across the full spectrum of the hospital, where there are issues specific to a certain part of the hospital these will be identified. They have been organised in line with Fleming and Bennett's principles for design for people with dementia

UNOBTRUSIVELY REDUCE RISK

Managing risk in the acute setting accounts for multiple factors including infection control, clinical errors, falls prevention, staff injury and burn-out, and a range of other challenges. Programmes such as Lean Sigma Six for Healthcare [112], the Product Ward initiative [113], and infection prevention and control guidelines [e.g. 114] provide evidence based recommendations for mitigating risk and protecting patient and staff wellbeing. Patients with dementia will benefit from standard design measures to support and protect patients who are ill, frail or recovering from surgery including non-slip and shock-absorbent floors [115], sufficient handrails or grab bars [116, 117], minimum distances between bathroom and patent beds, or adequate lighting [118].

Specific dementia-related safety features commonly used in residential settings are often employed in hospitals. Concealing staff only doors or exits by painting them the same colour as the background [103] or using murals may enhance patient safety. While the former is straightforward, the latter requires careful consideration to avoid unintended disorientation or distress [119].

Technology to detect patients getting out of bed [120] or exiting the ward can help with staff supervision. Monitoring equipment is available to alert staff when patients go beyond predetermined boundaries or exit points, but associated alarms should be passive and should discreetly alert staff through a pager or similar, rather than flashing lights or an alarm sounder both of which could be distressing for patients.

PROVIDE A HUMAN SCALE

Less institutional and more home-like design is typically more of a consideration for residential aged care settings [105–107], however, it is increasingly an issue in the hospital context where the focus is on creating a less clinical and more human scale environment [121, 122]. In this regard Fleming and Bennett ([101]) argue that the experience of scale is firstly determined by the number of people a person encounters, secondly by the overall size of the building, and thirdly by the size of the building components, for example corridors, rooms, or door. To avoid an overbearing scale, a patient should not be daunted by the size of the setting or overwhelmed by excessive interactions or choices.

> Designing at a human scale is challenging in the context of large-scale and complex acute hospitals.

However, a case study of selected contemporary international hospitals [123] illustrates how many large hospitals manage their scale and complexity through careful massing of accommodation blocks, establishing a hierarchy of scale, and by providing clear legible circulation strategies within the building. These complexes are often designed as a collection of buildings, bound together by a shared internal public realm such as an atrium, central 'street' or concourse from where visitors to the building can orientate themselves. Setola and Borgianni [124] argue that successful public space within the hospital is crucial to the humanization of the hospital environment. They identify 'visibility', 'accessibility', 'proximity' (a closeness to the citizen and community), 'intelligibility' (understanding of the layout and building), and 'relationability' (relationships, social fabric and culture in the hospital) as core public space concepts that underpin supportive and humane hospitals.

ALLOW PEOPLE TO SEE AND BE SEEN

To improve spatial cognition, the environment should balance differentiation of appearance (size, shape, colour, or architectural style); visual access (the visibility of one part of a building or space from various locations); and layout complexity (i.e. level of spatial articulation, number of separate spaces etc.) [125, 126].

Wayfinding has been recognised as a problem in the healthcare environment, resulting in stress, feelings of helplessness, raised blood pressure, and fatigue

[127]. To achieve better wayfinding for people with dementia in a complex environment such as a hospital, Passini et al [128] point to the importance of a 'spatial organisation' with a simple layout that minimises memory and inference-based decisions and allows a person to move between decision points without too much forward planning. This reduces dependence on cognitive mapping by providing good visual access and clearly communicating the overall structure of the space. 'Environmental communication', can be achieved by clearly articulating key features and functional zones, and by expressing the circulation strategy, creating spaces with distinct character, introducing key landmarks, and at a more detailed level the use of signage and graphic information.

Huelat's [129] promotes the concept of 'progressive disclosure' in large-scale complex environments, an approach that provides visitors with just enough information to get them to the next decision-making point. This avoids information overload and confusion and helps to simplify the navigation of a building.

Research shows that when toilets are visible [130] and easy to find from the bedroom [131] incontinence and falls may be reduced for people with dementia. Following on from this, many hospital guidelines promote inpatient rooms with a direct line of vision to the toilet entrance from the bed, toilet doors with distinct and clear colour contrast, good clearly visible and legible signage, and toilet fittings that visually contrast with the background [e.g. 97, 104].

Visual access also enables staff to see and monitor patients, while visibility of staff can provide reassurance for patients [101].

In some studies, decentralised nurses' stations placing staff nearer to patients contributed to a reduction in falls [132] while other reports suggest that greater staff visibility through decentralised stations reassures patients, reduces nurse calls, and improves staff satisfaction [97]

REDUCE UNHELPFUL STIMULATION

Negative sensory stimulation is a major concern for people with dementia. Noise will disrupt sleep and have adverse effects such as raising blood pressure [133]. This is a concern in hospital settings where noise [134] and poor acoustic conditions [135] undermine patient recovery.

In a study involving intensive care units and high dependency units, MacKenzie and Galbrun [136] found that 34% of noise was totally avoidable

(e.g. rubbish bins, chair scraping), 28% are partially avoidable (e.g. alarms, trolleys), and that design related noise control solutions such as the installation of appropriate absorbent materials (e.g. acoustic ceiling tiles) and appropriate room geometries (e.g. avoid very large volumes) would help reduce background noise and improve speech intelligibility.

A person with dementia may experience visual spatial cognition difficulties that lead to problems with depth perception, disorientation, anxiety or discomfort. In this context, glare and reflections can cause visual discomfort and cause disorientation [103, 137, 138]. Reflections from glossy surfaces may also be problematic if they are perceived as water, for instance, a light reflection from a glossy floor can be misinterpreted as being wet and slippery, and consequently may cause a person with dementia to alter their gait or step over the perceived wet patch, possibly resulting in a fall

Furthermore, significant contrasts in floor colour tones can be perceived as a step or hole by a person living with dementia [139]Similarly blocks of contrasting colour tone or high contrasting floor patterns may be perceived as objects on the floor, that result in stepping over [140], sidestepping, or veering [141].

OPTIMISE HELPFUL STIMULATION

For many hospitalised people with dementia, cognitive challenges and disorientation are compounded by the size, busyness, and unfamiliarity of the hospital. Consequently, the promotion of visual orientation is recommended in hospital guidelines including: artwork to reflect seasons, calendars, large face clocks, natural light, photographs of local scenes, views of nature, and visible staff [142].

Ulrich et al (2008), identify the therapeutic value of providing patient rooms with good levels of natural light and views to nature.

The therapeutic impact of sunlight in hospital rooms has been shown in relation to decreased stress, pain, and analgesic medication use [143].

There is also a correlation between daylight exposure and reduced depression and mortality rates in acute settings [144, 145]. This is significant for people with dementia who may often suffer from sleep disturbance [146], and increased agitation levels [147]. Research shows how exposure to light strengthens circadian rhythms and thus improves sleep (van Hoof et al., 2010), while exposure to morning bright light can alleviate symptoms of agitation [148].

Ulrich et al [149] describe studies where views of nature from both non-healthcare and healthcare environments (e.g. patient rooms) have been shown to reduce pain, stress, and length of stay, while also offering restorative effects such as positive emotional, psychological, and physiological changes. For many people with dementia whose mobility or ability to go outside is restricted, external views may be one of the few ways they have to experience the outdoors and contact with nature [150].

Hospital buildings that facilitate contact with nature are receiving more attention through the concept of biophilia [151], which is the innate emotional affiliation that human beings have with nature [152]. In this regard biophilic design is a framework to ensure that the built environment supports and promotes contact with nature as part of a healthful design approach [153].

Other positive sensory stimuli such as music [154] or artwork [154, 155] is advocated in the clinical setting to provide a calming effect and to support meaningful activity, orientation and wayfinding [97].

SUPPORT MOVEMENT AND ENGAGEMENT

The Royal College of Psychiatrists [156] recommend that space and resources are important for patient activity, as they argue that inactivity can lead to a "lack of attention, lack of stimulation and boredom for patients". In this regard many of the hospital design guidelines call for day rooms or adequate space within single and multi-bed patient rooms to support patient activity [157] [102].

Certain behaviours exhibited by many people with dementia, labelled as challenging or inappropriate are often the result of unmet needs. A review of various interventions to alleviate inappropriate behaviours conducted by Cohen-Mansfield [158] include stimulating or relaxing interventions (e.g. music), social contact, activities, and environmental interventions (e.g. walking areas or reduced stimulation environments).

Providing areas for activity, engagement, and safe walking spaces areas has been recognised in a number of guidelines

In the hospital context providing areas for activity, engagement, and safe walking spaces areas has been recognised in a number of guidelines [156, 159].

Outdoor spaces in hospitals can alleviate certain challenging behaviours such as pacing or wandering, they also provide a change of scene [105], reduce stress [160], provide exposure to natural light and regulate circadian rhythms [161], act as a restorative environment [162], and provide a space for physical exercise [163]. Given these benefits, it is not surprising that many dementia-friendly hospital guidelines promote secure, accessible and usable, and calm outdoor space for patients, accompanying persons and visitors. To minimise risk to patients various guidelines recommend: level access thresholds; solid, non-slip, non-reflective surfaces; continuous or looping paths; non-toxic plants; and secure boundaries that use plants to screen wall or fences.

CREATE A FAMILIAR PLACE

Recommendations for familiar or domestic style largely refers to residential settings. Familiarity in this way is difficult to achieve in the modern hospital context and therefore it is important to examine familiarity in a way that can be accomplished in more subtle way in hospitals.

Catkins et al [106] argue that the Universal Design principle 'Simple and intuitive' [164] promotes design that meets users' expectations and thus in some ways supports the principle of familiarity. Maki and Topo [165] refer to the 'Simple and Intuitive' principle as one that eliminates unnecessary complexity and promotes understanding regardless of the users' knowledge, experience, language skill or current concentration levels.

At a smaller scale, or at the level of finishes, artwork or furniture, a sense of familiarity can be created through images or photographs of local scenes [142]. Bed spaces can be personalised with personal belongings

to reinforce identity and help with orientation. Reinforcing personal identity or the continuity of self is an important goal in designing for people living with dementia [107, 110].

Finally, while the scale and complexity of acute hospitals will make a familiar and home-like environment difficult, there may be other ways to create calm and supportive spaces for patients with dementia. Edvardsson et al [166] investigate supportive care settings (including geriatric and acute wards) where patients sense an atmosphere of ease. They describe

five key factors including: experiencing welcoming; recognizing oneself in the environment; creating and maintaining social relations; experiencing a willingness to serve; and experiencing safety.

'Atmosphere' is an important environmental quality in care settings and is receiving greater attention [167, 168]. Referring to the size of typical hospitals, Martin et at [169] argue that scale is secondary to atmosphere, and it is more important to consider "the feel of medical spaces, and their potentialities for different types of caring practice."

PROVIDE A VARIETY OF PLACES TO BE ALONE OR WITH OTHERS IN THE HOSPITAL

Acute hospitals contain a range of public (e.g. external campus spaces, cafes etc), semi-public (e.g. family or day rooms on inpatient wards) and private spaces (e.g. patient rooms). Depending on the quality of these spaces, they can potentially provide valuable places for solitude, social interaction, rest or activity [104]. The benefits attributed to the gradation of public to private space in residential settings [170] are also relevant in hospitals [124] and this diversity and graduation of spaces should be carefully considered.

Family or day rooms provide a retreat space where a person can withdraw when they feel overwhelmed [106, 157]. This is important in multi-bed wards where it will not always be possible to maintain calm. Providing a retreat space or a space for one-to-one communication or activities will be beneficial [171]. Day rooms also facilitate activities, dining, or engaging with visitors or other patients [103, 171], this may be particularly important for patients in single rooms who may feel isolated. These rooms may also serve as an overnight facility for an accompanying person if there is not enough space within the patient room [103, 171].

For residential care Marshall (1998) [107] recommends single rooms with enough space for personal belongings; this helps with familiarity and personalisation. In the hospital context a single room has advantages for patients including privacy, less noise, and better quality of sleep [149, 172]. A single room may also be more supportive for the accompanying person where a reclining chair, fold-away bed or couch can be provided [103].

However, it should be noted that some [122, 173] advise against eliminating all multiple rooms, and suggest that a hybrid approach combining single and multiple rooms may be worth considering. Possible benefits associated with multiple-bed rooms include greater patient safety [174, 175] and social interaction [173, 176], while on the other hand single-bed rooms may increase building size and associated construction costs [173, 177].

Outdoor spaces and gardens provide valuable opportunities for social interaction. In this regard Cooper Marcus [178] promotes a variety of seating options for single people, couples, and small groups.

PROVIDE LINKS TO THE COMMUNITY

The hospital's engagement with the broader community is a multi-faceted issue that spans a number of spatial scales within the hospital. At the macro level the hospital must be located and sufficiently accessible to facilitate the community links and engagement of family or friends promoted by Fleming and Bennett [101].

In the US, Rosenbaum [179] discusses how some hospitals are becoming "health hubs" for the local community. While in the UK, the Commission for Architecture and the Built Environment (CABE, now part of the UK Design Council) argues for the integration of healthcare buildings with the local community through ease of access and integration of public transport, and the creation of public open space that ties the facility into the community [180].

The hospital must be located and sufficiently accessible to facilitate the community links and engagement of family or friends.

DESIGN IN RESPONSE TO VISION FOR WAY OF LIFE

Carpman et al. (2016) [127] refer to the 'symbolic meaning' of the hospital environment and argue that the physical environment transmits a meaning and that this must send a positive message to patients and visitors as part of supporting their emotional and psychological wellbeing. In this regard, hospital design must move beyond merely mitigating the negative effects of the typical hospital environment, and provide a more active healthful approach as advocated by Ulrich's concept of supportive design [172] or the Health-Promoting Hospitals initiative [181, 182].

In this context, the theory of 'Salutogenics' is gaining traction [183, 184]. Golembiewski [185] argues that

> Salutogenic design and the sense of coherence it seeks to creates through meaningfulness, manageability, and comprehensibility is a valuable design framework for healthcare architecture.

Universal design [164, 186], due to the inclusive and participatory nature of its approach, provides a good framework for supporting people with dementia. By placing the individual at the centre of the design process, it ensures that the concerns, inputs and needs of that individual are reflected in the built environment.

The inclusive approach promoted by universal design is supported by age-friendly hospital movement [187, 188] that promotes a more responsive hospital environment for older people.

The themes and design principles described in the previous sections must be synthesised to create a dementia-friendly hospital. If this synthesis is framed through concepts such as health-promoting hospitals, salutogenic design, universal design, and age-friendly hospitals, then hospital architecture will support and promote the vision of hospitals as healthful, therapeutic, and age-friendly [187] places for people of all ages and abilities.

CONCLUSIONS

Designing for dementia takes account of cognitive impairment which is common among older patients within hospitals [189] and can arise from syndromes ranging from intellectual disability, or acquired brain injury to delirium. Dementia-friendly design is an inclusive approach which pays attention to cognitive impairment while addressing many of the comorbidities that commonly accompany dementia and delirium [190].

It is also important to consider age-related changes such as physical frailty, mobility, visual impairments, hearing loss, and circadian rhythm difficulties [103]. Cognitive, physical, sensory and age-related issues underpin dementia-friendly design and therefore represents a convergence with universal design and some best practice contemporary hospital design [123]. This is encouraging and illustrates how

> dementia-attuned research and design can contribute to the developing knowledge base and evidence around good hospital design.

This will support a wide and diverse range of patients, visitors and staff of all ages, sizes, abilities and disabilities, while also helping hospitals to fulfil their role as caregiving and healing facilities.

Home modifications to support people living with dementia

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Introduction

A person's home and possessions represent a lifetime of accomplishment and can contribute to a good quality of life into older age [191]. A home can also allow for the expression and maintenance of a person's identity and lifestyle choices [192, 193] and can be a place with significant personal meaning [194]. As we age, being in a familiar space may also enable us to maintain our capacities and independence [195]. This is no different for a person who is living with dementia.

The vast majority of people with dementia live at home and wish to remain there [191]. In Australia it is estimated 70% of people with dementia live at home in the community [196]. In the UK the number of people with dementia living in the community is estimated at 60% [197], in the US 80% [198] and in Canada over 93% [199]. Although many of these people are living with others, in Australia evidence suggests about one third of community dwelling older people living with dementia live alone [196, 200].

Appropriate housing options can not only provide comfort, functional support, social stimulation and independence for people living with dementia, but can also assist formal and informal carers to deal with the changing needs of the person they support over time [191, 201]. A well designed or appropriately modified home can support and enhance both the quality of care and the quality of life for both people living with dementia, and those who support them.

> Environmental interventions that create a safe, enabling and predictable home environment are considered key to improving the lived experiences of people living with dementia and their carers [191, 201–203].

In light of the recognised impact of housing on people living with dementia and those who may support them, it should be acknowledged that not all housing will provide an optimal supportive environment. Some housing adjustments or 'Home Modifications' may need to be undertaken to reduce stressors that can cause distress and disability and may affect functional capacity in a person with dementia [204].

So what exactly is meant by the term 'Home Modifications'?

The Australian Housing and Urban Research Institute [193] provides the following definition:

Home Modification is a term that refers to services that are designed to maintain or modify the dwellings of people in later life in order to enhance their safety, independence, identity and lifestyle.

These modifications can include structural modifications to the fabric of the home (such as door and corridor widening and bathroom or kitchen remodelling); non-structural changes to fixtures and fittings (such as ramps and grab rail installation); repairs and improvements (such as changing floor finishes or lighting) and ongoing maintenance work to maintain the function and amenity of the home and its surrounds [193].

Home modifications are an important means of enhancing the range of options available to people as they age by helping to support housing and living arrangements that meet the individuals needs and also importantly, reflect their lifestyle choices and identity. (Jones et al, 2008). Home modification should harness the strengths of the individual and be chosen to improve independence in activities of daily living (ADLs such as eating, dressing, bathing and mobility), increase safety in performing these activities, and reduce caregiver burden [205].

Making changes to the home environment can provide a strategy to optimise safety, comfort and independence for a person living with dementia [192, 201] and can boost confidence while protecting dignity [201]. Modifying an existing home can reduce dependency on caregivers for activities of daily living and reduce caregiver burden [192, 206, 207].

Many older people living with dementia also cope with the same age related health problems as other older adults, therefore, any environmental changes made should also consider the needs of older people in general [191, 195]. These common age-related disabilities may include mobility difficulties, visual and auditory difficulties, sleep disturbance and aged related cognitive decline. A number of studies looking at the type of home modifications undertaken for people with dementia found that many home modifications were undertaken to compensate for general age related disability such as physical disability rather than specifically dementia-related cognitive deficits [201, 208].

Additionally, if the person living with dementia is being supported by an informal carer, this person may also have age related health problems and/or sensory impairments that need to be considered if changes to the home are to be undertaken [209]. Caution should be taken that any changes to meet the need of one resident does not create problems for another [210, 211]. There is a need to recognise that the needs of person living with dementia and their carers may not always be the same [191, 201, 212].

It should also be recognised that home modifications constitute only a small part of supporting a person living with dementia to remain independent [191]. In combination with appropriate 'at home' care and social support, home modifications can help enable a person to remain in their home for longer [191, 213]. However, as Olsen [214] remarked, even a sensitively design or beautifully finished home cannot compensate for lack of appropriate, well delivered and personalised care.

When considering home modifications for a person living with dementia it should be remembered that

no single design solution will work in all situations nor for all individuals. Different people will need different solutions and personalised approaches will be required [191, 195, 208, 209].

The individuals cultural background should be considered during the home modification process, to allow for example, for accommodation of culturally based activities [209, 215].

For a person living with dementia home modification can be an ongoing process as the needs of the person will change over time as their disease and its associated disabilities, progress. However, as dementia is a progressive condition, whilst remaining in their own home has advantages for a person during the mild and moderate stages of dementia, as a person moves into the late stages of dementia, these advantages may be lost as the physical environment is no longer able to accommodate increasing disability [195]. Even with home modifications the increased care needs of the person living with dementia may necessitate a move into residential care [195].

A number of researchers in this area have suggested that home modifications are best completed in the early stages of dementia at which time they can have positive effects on levels of confusion and support successful ageing in place [192, 216–218]. Modifications attended later in the disease process may cause confusion and impact negatively on the person living with dementia [192]. It should be recognised that a participatory design approach should be utilised to ensure that the person living with dementia has their needs and preferences understood during the home modification process [191, 205, 209, 211, 219].

With growing awareness of the impact of housing on people living with dementia, a range of dementia specific home modification guides, recommendations and principles have been developed [196, 197, 203, 220–223]. The area of home modification design shares a body of knowledge with the areas of residential care and hospital design. This will be explored in the following sections using the relevant Fleming and Bennett principles as an organising framework.

UNOBTRUSIVELY REDUCE RISK

Home modifications for the person living with dementia should promote safety for the individual and peace of mind for the caregiver. However, these should occur in the least restrictive environment possible [224]. An unobtrusively safe environment allows a person living with dementia to function best [202, 225].

Van Hoof [191] notes that home modification developments in the field of safety and security currently received most attention in the research literature. In a scoping study of articles on home modifications for people with Alzheimer's disease, Struckmeyer & Pickens [226] found that the majority of physical environmental problems were specifically related to safety. Common safety related concerns included 'wandering', falls risks, and risks related to cooking and use of appliances. Other issues identified were trip hazard from rugs, access to sharp knives, stove tops and hot water, and the need for door locks. A range of safety interventions related to physical disability were also included in dementia home modification (such as installation of grab rails, non-slip surfaces, shower chairs and raised toilet seats) [195, 224].

Technologies and assistive devices to address management of risk are often used to bridge the gap between functional status and environmental demands. These include assistive devices and equipment to address physical/mobility difficulties (e.g., grab rails and hoists) or cognitive deficiencies (e.g., sensors and alarms) [201]. A number of authors reported on the successful use of technological solutions to manage risk [226, 227]. However, while there are numerous assistive technologies promoted for dementia, a number of papers reported use of these technologies tended to be low [228, 229] and a number of challenges to their use were identified including usability, effectiveness, cost-effectiveness, and ethics [230].

Decluttering and simplifying the environment is a home modification strategy used by carers to make a home more practical and safer for a person living with dementia. This includes removing trip hazards such as rugs and slippers, walkers with brakes and removing small pieces of furniture. [191, 201, 228, 231]. A number of authors have identified a range of more formal home modifications that have been shown to reduce falls risk substantially, including the removal of environmental hazards such as loose rugs, the removal of clutter that may pose a trip hazard and the installation of grab rails, stair railings and additional lighting [232, 233].

Van Hoof [191] reported on a possible unintended consequence of this type of risk reduction in creating an under stimulating space that may lead to sensory deprivation, disorientation and a loss of familiarity through excessive decluttering and simplification of spaces. Care should be taken that prioritising accessibility, functionality and safety, that the social and personal meaning of home isn't diminished [195]. When undertaking home modifications targeted at risk reduction, consideration should be given to the impact on these changes for the person with dementia. Tanner et al [194] noted:

> "The experience of home can be diminished when the physical aspects of accessibility and functionality are emphasized and the personal and social meanings of home held by the home dweller are neglected or discarded."

Falls prevention is the most common risk prevention activity associated with home modifications for the elderly and those living with dementia, and as such, provides the strongest experimental evidence [234–238]. Steps, both inside and outside the home have been identified as a common physical obstacle contributing to increased falls risk [218]. A number of authors suggested locating a bathroom and bedroom on the ground floor where possible to avoid the need for stair climbing [191, 209, 222]. In a systematic review Stark [237] found strong evidence for home modifications provided by occupational therapists being effective in reducing falls risks among high risk older adults as part of a multicomponent intervention.

The progressive nature of dementia resulting in the needs of the people living with dementia changing over time must be borne in mind,

> home modifications should be implemented in step with the changing needs [214, 224, 239].

PROVIDE A HUMAN SCALE

In a study looking at the impact of the physical home environment for family carers of people with dementia, Soilemezi et al [201] identified scale as a key theme which could either promote or hinder the caring role. Some carers reported that having more space made life easier by increasing safety, improving accessibility and providing for storage of equipment such as wheelchairs, hoists and other 'gadgets'. A separate carer bedroom or 'escape space' also allowed carers to relax and spend time alone, away from the carer role [191, 201, 214].

On the other hand, Soilemezi [201] also reports that some carers felt a smaller scale environment was more manageable requiring less maintenance and housework. A single storey dwelling with no stairs improved accessibility and supervision of the person living with dementia and removes a falls risk [214, 218, 222]. Multi-storey homes with stairs may be a reason to consider relocation [201]. Locating the master bedroom and bathroom on ground floor is a feature rated positively by carers [214].

ALLOW PEOPLE TO SEE AND BE SEEN

An open plan home layout can allow for easier supervision by carers through visual and acoustic access [191, 201, 214, 222]. However, Marquardt et al [218] observed that people living with dementia in a home with high proportions of open spaces such as circulation spaces and interconnected rooms were more dependent on others for assistance with their activities of daily living. The authors hypothesized that this was due to the fact that these more open spaces did not provide clearly legible meaning and function that might provide cues that would prompt individuals to engage in basic activities of daily living but recognised this was an area requiring further investigation [218].

The location and proximity of rooms within the home can also have an impact on the home's functionality for both the person living with dementia and a carer, if present [201]. For the person living with dementia, easy access to a bathroom can be beneficial, while for a carer using a separate bedroom; having this bedroom well located to enable supervision, especially at night, is important [201, 222].

Improving the lighting has been shown to compensate, at least in part, for visual deterioration (functional or cognitive). Improved lighting also makes a contribution to safety [240]. Home Modifications related to lighting in the literature include adding additional lighting, increasing light levels or simply adjusting existing lighting such as leaving a light on in the corridor [201, 241].

REDUCE UNHELPFUL STIMULATION

Because dementia reduces the ability to filter stimulation and attend to only those things that are important, a person with dementia becomes sensitive to over stimulation and may be stressed [201]. Reducing environmental stressors can improve behaviours [202].

A good acoustic environment is essential for people living with dementia [201, 222, 242]. This is consistent with previous research which suggests that "noise is for people with dementia is what stairs are for people in wheelchairs" [243]. A safe, calm and predictable environment allows people living with dementia to function best [202]. Grey et al [222] recommends creating peaceful spaces (such as bedrooms) away from sources of unpleasant external noise, and recognising the impact of domestic appliances and systems (including air-conditioners, washing machines and dishwashers) that may have a detrimental impact on those living with dementia.

OPTIMISE HELPFUL STIMULATION

As dementia progresses a person is likely to depend on perceptual cues such as hearing, smell, vision and touch to compensate for memory problems [201]. An under stimulating environment may not provide the cues that they need.

Hearing and visual cues can provide reminders to complete a task [201, 222, 244]. These include the use of notes, calendars and message boards [201]. Other, more technologically advanced, assistive devices may prove beneficial however it is important to carefully assess the individual needs and abilities of the person living with dementia when considering their use [195].

Large windows that bring in natural light and afford a pleasing view can provide sensory enrichment for the person with dementia; listening to music can provide company and be used to improve the mood of the person with dementia and also the carer, if present [201, 222, 225, 241].

A common way to optimise helpful stimulation is to provide visual cues, such as signs, to help wayfinding to key locations such as the bathroom [191].

SUPPORT MOVEMENT AND ENGAGEMENT

Spatial disorientation and concerns about getting lost are an important consideration when creating supportive home environments for people living with dementia but they should not prevent to support movement and

engagement inside and outside of the home. Access to appropriate places to walk can provide exercise and may contribute to better sleep at night [245].

Helping a person living with dementia to stay active and engaged can help her or him to stay motivated, increase self-esteem and reduce boredom and anxiety.

Meaningful, enjoyable activities can assist in staying active [246], with some limited research showing maintenance or even improvement in mobility and a reduction in falls when people living with dementia are kept engaged [247]. However, it must be recognised that as dementia progresses the ability to walk independently outside of the home and to return home declines [218], so home modifications to support movement and engagement must be carried out in a timely way.

Access to outdoor spaces has consistently been shown to be good for everyone and this is no different for a person living with dementia [209, 248–250]. Facilitating access to a safe outdoor space can give the person living with dementia the freedom to go outside as they please, support social contact, enjoyment of fresh air and sunshine and can allow the person to have a break from the confines of the home [214]. While there is a range of literature on the benefits and desirable features of dementia friendly outdoor spaces, there has been little discussion of outdoor spaces in the home modification literature. The literature that makes mention of home modifications related to outdoor spaces is primarily concerned with safety and security such as step free access to reduce trip hazards [211], 'exit control' on external doors [228], and securing outdoor spaces with gates or fences [214].

'Exit control' as a home modification needs to be considered in the context of supporting movement and engagement in a way that also recognises choice, human rights and dignity. Marquardt, [228] noted that exit control seemed to become important in the moderate stages of dementia when many caregivers locked the doors or used some kind of auditory alert (such as a door exit alarm), however in the later stages when mobility is more impaired, exit control becomes less of a concern as the person often no longer wants to leave the home.

CREATE A FAMILIAR PLACE

A person's home and possessions represent a lifetime of accomplishment and the familiarity of it can have a positive impact on quality of life [191]. Being in a familiar space may also enable a person to maintain their capacities and independence [195] as well as contribute to maintenance of identity [192].

When undertaking home modifications to support a person living with dementia care must be taken to avoid negative impacts on the 'familiarity' of the home.

Pierce et al [209] explore how the principle of creating a familiar space to enable a person living with dementia to maximise their independence could be supported through the use of universal design principles during the home modification process. If making change to the environment, ensuring the Universal Design principle of 'simple and intuitive' is used to eliminate unnecessary complexity and help reduce stress and confusion in an 'unfamiliar' environment that may be created during the home modification process [209, 222].

Personal items and photographs are an important strategy to enrich the environment and support familiarity [201]. They can provide comfort, a sense of continuity and connectedness with their families. Family carers have identified the use of these items as a useful strategy if moving with the person living with dementia into a new home [201] and may help compensate for changes in the home during the home modification process [191]. The bedroom, in particular, should be a familiar and pleasant sleeping environment [191, 222].

PROVIDE LINKS TO THE COMMUNITY

The role of home modifications in enabling older people in general and people with dementia in particular, to stay in their homes and remain engaged in existing social networks and everyday activities has been well recognised [209, 251]. The maintenance of these social relationships is highly valued by the person living with dementia [211] and seen by some researchers as an essential part of maintaining the sense of identity of the person living with dementia [252, 253]. Modifying a home so that the person with dementia can wave to someone through a window may have a significant effect on their sense of connection to their neighbourhood [254].

DESIGN IN RESPONSE TO A VISION FOR WAY OF LIFE

It could be argued that most homes are not designed, they are created over many years by the interaction of the individual with the spaces; the adding and subtraction of objects; the changes in the furniture, fittings and décor; the laying down of memories of experiences, relationships, hopes and dreams that at one time or another were contained within the physical place called home. The aim of the interventions explored above has always been to maintain the contact between the person with dementia and this creation.

> The vision that drives home modifications is, quite simply, to keep things as they have been for as long as possible. To enable the person with dementia to enjoy their relationship with their past life, as embodied in their home, despite the problems introduced to their life by dementia.

It is clear that the meaning of home is complex, however we know that feeling 'at home' can help increase an older person's sense of autonomy, security and wellbeing [255]. This has been one of the reasons for the focus on the concept of Ageing in Place by a variety of policy and practice institutions around the world [221, 239, 256–258].

Ageing in Place means that as people get older they can remain living in their home rather than having to move into residential care. To support this concept the person must be able to achieve some degree of ability to live independently even as the impacts of old age affect physical, sensory and cognitive abilities. The benefits of this include having some control over the space one lives in and the maintenance of connections to the community they are used to. It should also be acknowledged that this may necessitate modification of an existing home or a move to an alternative living place, but ideally not into residential care [259].

This idea of 'in place' is expanded by the World Health Organisation [256] to include the older persons social connections to their chosen community. This aligns with one of the main priorities of the UN Convention on the Rights of Persons with Disabilities [260] stating that people with functional limitations have the right to live and be included in their community.

At the International Technical Meeting on Aging in Place, Québec, [256], the following statement was made: *The notion of "healthy aging" is central ..... It is based on the WHO definition of healthy aging as being a "process of developing and maintaining the functional ability that enables well-being in older age." This functional ability is determined by the intrinsic capacity of the person, the environments he or she inhabits, and the interaction between these.*

In combination with appropriate at home care and social support, home modifications can help enable Ageing in Place and support the vision of enabling people living with dementia to remain in their homes for longer [191, 213]. Universal Design is a model that recognises the changing needs of a person with dementia and the individualised approach required to achieve this vision [209, 261, 262].

As stated previously, home can have an intensely personal meaning for the occupant [191, 192]. A home can be an expression of one's history, identity and way of life [193]. When undertaking any home modifications an awareness of the meaning of home for that particular person should be embedded in the policy and practices guiding these modifications [194]. To this end a participatory design approach should be utilised to ensure the voice of the person living with dementia is heard [191, 205, 209, 211, 219].

The adoption of a participatory approach to design might allay some of the scepticism that some carers have about the potential for home modifications to compensate in any way for the problems caused by dementia [201, 228, 229]. It might also contribute to mitigating the view that making changes and utilising equipment or devices are costly symbols of disability and abnormality [263].

Conclusion

Home modification is a strategy that can optimise safety, comfort and independence for a person living with dementia, can enhance both quality of care and quality of life and reduce caregiver burden. By providing appropriate housing options in the community, in combination with suitable home and social care as required, people living with dementia can be supported to age in place and avoid or defer a move into residential care.

It is important to consider other age related cognitive, sensory and physical disabilities the person with dementia is experiencing and ensure that any home modifications that are made meet the individual needs of that specific individual. There is no 'one size fits all' model of home modification. As dementia is a progressive condition the need for and appropriateness of home modifications should be assessed over time and implemented as needed.

Finally, any changes made to a person's home should be done using a participatory design approach where possible to ensure that the social and personal meaning of 'home' is not compromised by prioritising accessibility, functionality and safety during the home modification process.

Day care centre design

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Introduction

Out of home care services for people living with dementia provided in a day or short stay centre/house setting have been an established community care service type for many years. With government policy increasingly moving to support people to remain at home for as long as possible there is an increasing focus on community care services, and demand for centre type services continues to grow strongly. Day centre settings vary considerably in their design, scale and building type. The role of the day centre is varied and intended outcomes of attendance include:

- Respite for the carer [264]
- Social connection and reduced loneliness [265]
- Meaningful engagement and occupation [266]
- Entertainment and pleasure
- Improving physical function and activities of daily living [267]
- Enhancing wellbeing and personhood [268]

Care centres can play a critical role in supporting people living with dementia to remain living at home for as long as possible. Wellbeing, function and the impact of the disabilities of dementia can all be influenced significantly by the built environment [269].

DAY CENTRE MODELS AND SETTINGS

Day care centres vary significantly in their models of delivery, care philosophy and physical environment. In Australia physical environments range from large community halls, to single rooms in larger buildings, through to purpose built cottage style accommodation.

The models of day care can be generally split into two main types; community centre large group models and smaller scale house models. The physical environments are often reflective of the model of service delivery.

Community centre models often have larger groups of attendees and have a social and entertainment focus to their programs. Meals are usually prepared and served to attendees by staff or volunteers, and activities are planned and scheduled based around larger group activities such as crafts, singing or quizzes. The community centre model may cater for 30–100 attendees a day and takes place in larger venues. These venues may be purpose built or in shared purpose buildings. They are designed to cater for large groups and often feature a combination of large halls/activity spaces with smaller rooms for more intimate group gatherings. Dining tends to be in large dining room spaces and meals are prepared and served by staff or volunteers in commercial style kitchens.

House model day centres are smaller scale and are often delivered in a more domestic home designed environment. This may be a purpose-built larger scale house design to cater for larger living spaces, or converted domestic housing. Group sizes are smaller and the house may have 10–20 people attend a day. Activities are individualised and often include meaningful engagement opportunities relating to the running of the household, such as gardening and preparing meals [271]. Meals are prepared and served with the involvement of group members in more familiar domestic style dining environments, and a strong emphasis is placed on social connection.

Attendance at day centres varies greatly and may range from attendance for three to four hours once a week, up to full day attendance five days a week. There is an increasing availability of cottage style centres providing both day and short stay overnight respite services. This overnight respite service model provides advantages in giving the person living with dementia a greater sense of familiarity with the environment and staff, and therefore more willingness to accept a respite stay at the cottage rather than in an environment that is unknown to them [272]. This style of overnight respite may be more acceptable and better able to meet needs of the person living with dementia than a traditional respite service in a residential care home. Staff know the client well from their attendance at the day centre and this familiarity supports delivery of a more person centred service. Day centres with short stay respite facilities usually offer two to six bedrooms.

CREATING ENABLING DAY CENTRE ENVIRONMENTS

Despite the two models of day centre respite service, community and house, being quite different in the buildings and physical environment they take place in, the application of dementia enabling design principles [273] can be applied cross both environments. These principles are used to organise the description of interventions and evidence provided below. Many of the interventions have been applied in the design of the Alzheimer's Association WA's Hawthorne House which is described in the case study section of this report. Reference to the case study will help readers to see how these interventions can be applied in practice.

> Unobtrusively reducing risks in a day centre setting is an important consideration to both protect attendees from harm, and also to give staff confidence to support maximum autonomy and freedom of choice and movement.

An environment with excessive or obvious security features can prove to be frustrating or belittling for the person living with dementia [274]. Simple design features such as disguising hazardous areas so there is no obvious access, reducing risk of the person accidently leaving the building and being unable to find their way back, and storage of hazardous material in suitable locked areas can be designed into the environment to unobtrusively reduce risk. As the centre may be unfamiliar to the person good wayfinding and clear purpose of rooms with adequate dementia specific signage can help improve orientation and a sense of wellbeing [275]. Many day centres do not have locked doors and reduce the risk this can create through good design, clear observation, use of technology and by creating an engaging care environment that the person is happy to stay in. A balance between dignity of risk and duty of care is required with the physical environment reflecting this balance by unobtrusively reducing risk while still providing opportunity for autonomy, choice and meaningful engagement.

The day centre house model provides a more familiar scale and domestic feel to the person attending than a traditional community centre environment. The design of the centre in this model provides a 'home away from home' [276] and operates in a way that reflects a more domestic home. While the house model's physical environment lends itself to a more human scale, breaking down the large spaces of a community centre environment is possible. Creating smaller group meeting spaces, activity areas and dining spaces can provide a more manageable scale for a person living with dementia. Operable walls can provide greater flexibility for large or small group activities. Smaller scale environments have been shown to have better outcomes for people living with dementia in residential care and this may be mirrored in day centre settings [277]. Smaller scale environments can also provide stronger social relationships, increased wellbeing and greater engagement [278].

Designing the day centre to aid wayfinding through good line of sight orientation is critical [279]. With the person living with dementia attending infrequently it may take some time for the person to become orientated and familiar with the environment. Clear line of sight with easy and logical transition from one area to another can increase autonomy and reduce frustration. Day centre design with toilets that are easy to see from main activity spaces, inter-connection between activity rooms and a close relationship in room location to avoid long hallways or dead end location points makes wayfinding easier. Accessing outdoor spaces can be beneficial for people living with dementia [16] and having clear visual access to the garden area from the main lounge and activity rooms will increase usage of outdoor spaces as well as provide clear observation for staff and volunteers [280]. Designing the centre to have clear observation lines across the main indoor and outdoor spaces from where staff spend most time supports unobtrusive monitoring and increases staff confidence to support autonomy and freedom of movement.

Day centres can be very noisy and active places, so it is important that the design carefully manages stimuli in the environment.

Often walls and windows are adorned with visual items created by day centre participants, health and safety notices as well as staff and user information. This can create a mass of visual clutter that can be overwhelming for the person living with dementia and reduce their ability to pick out key information such as orientation signage, aesthetically pleasing paintings or items that create a sense of familiarity.

Consider carefully what is placed on walls and if it assists a person or causes difficulties. Noise in day centres can be loud and constant. Use of acoustic treatments, carpets, soft furnishings and appropriate ceilings to absorb sound and reduce overall volume of noise should be used [281]. The breaking down of large areas into smaller group size spaces can also help reduce unwanted audio stimulation, particularly when activities are being run that require concentration or conversation. Operable walls can be useful in providing more flexibility to space usage and to provide acoustic barriers. Consideration needs to be given to kitchen location and operation. If groups are running in the morning the operations and noise of the kitchen nearby can prove very distracting and make it difficult for the person to concentrate. Location of the kitchen may depend on the function and style, for example large scale commercial or domestic homelike. A large scale commercial kitchen is better suited away from the group and lounge spaces where as a domestic accessible kitchen is better located in close relationship to the main activity spaces, but with the ability to reduce the noise permeating into activity spaces.

One of the key roles a day care centre can play is to support meaningful engagement and activity to improve quality of life [282]. Opportunities for self-initiation of activities should be created that are easy to reach, clear to find and obvious in purpose. Setting up spaces and leaving out items for activity can support autonomy and choice. Ensuring items are easy to see and are of familiar design can aid usage. Setting up areas for reading the paper, doing a jigsaw or having tools available for tending a raised garden bed can promote self-activation of spaces and activities. Using clear signage to showcase a room's purpose, or an items usage, with multiple cues such as words and pictures can maximise effectiveness. The use of sensory stimulation to trigger orientation or enjoyment can add to the pleasure of being in an environment. Bringing in cut flowers from the garden, enjoying the smell of lunch cooking from the kitchen or a pot of coffee brewing on the sideboard, while familiar and meaningful music plays in the background removes the institutional feel of an environment and creates a more familiar setting. Use of colour to identify different locations and room purpose, as well as aid spatial perception, should be carefully considered [283]. The use of contrasting coloured furniture from flooring, contrasting colour door frames to identify exit and entry points and coloured doors to identify key destination places such as the toilets can aid spatial differentiation and improve orientation [284].

Ensuring good line of sight exists for transition through the day centre and out to the gardens is essential to assist purposeful movement and reduce a sense of ill-being [285].

Setting up the garden area to create obvious entry and exit points, with pathways that connect the two with minimal directional decision points, encourages walking and access to the outdoor spaces. The creation of seating within line of sight of the garden entrance from the building can provide a safe space for a person to sit outside while still being able to observe the inside of the centre, giving a sense of reassurance. Avoiding dead ends to hallways and reducing obvious access to office spaces or store areas that clients may not wish to be in should be considered in the overall design. Clear signage that uses words and pictures, has good contrast, is placed in sequential locations, or in line of sight positions, can assist greatly in wayfinding and supporting movement [286].

The design of the day centre should provide a sense of familiarity to the clients. Use of decoration that reflects centre attendee identity, local history or places that would be familiar to them can assist with a greater sense of ownership of the space. Using photos of day centre clients in sideboard photo frames, creating memory walls of events or moments at the centre and having objects that have meaning to the attendees can help foster a sense of familiarity and ownership of the space. Furniture should be homely and non-institutional. Use of wood and cloth for furniture materials rather than plastic and vinyl provides a more domestic feel. Colours should be warm and welcoming and help define the space. If clients are staying for overnight respite bedrooms should be able

to be personalised and clients encouraged to bring in meaningful personal items to decorate their room during their stay.

The opportunity to care for gardens or animals can provide a sense of ownership of an environment for the centre user and incorporating these activity opportunities in the environment can assist with a sense of home and familiarity [287].

Day centres provide social interaction opportunities that can reduce isolation and loneliness. Rooms should be set up to encourage social interaction with small social groups of chairs in circles and shared dining tables. Spaces should be flexible and furniture moveable so larger spaces can be created for big group activities such as a choir or cinema time. Having one large room and a number of different sized smaller spaces provides greater flexibility for different group activities and purposes. The day centre can be a tiring place with all of the activity and social interaction taking place. The person living with dementia may need space to enjoy some solitude or to partake in an individual activity. Small individual sitting areas away from the main activity areas should be available to have a rest, to read a book or listen to some music. These can be set up both indoors and outdoors. Setting up these spaces with a newspaper, a comfortable lounge chair and a small side table will encourage 'spontaneous personal enjoyment' [131], relaxation and rest.

Feeling part of a community and maintaining connections can play a significant role in changing the lived experience of dementia [288].

Day centres can provide a hub of community activity by providing opportunities for inter-generational programmes and purposeful activities that support community connection.

Inter-generational programmes have been shown to have beneficial outcomes for some people living with dementia [289]. Hosting children's playgroups or linking the centre with the local school to have schoolchildren spend regular time at the centre can add to the day centre environment. The design of the centre should encourage children's play and provide opportunities for larger group interactions, as well as spaces for people who may find the stimuli too overwhelming and need to be in a quieter area. Linking the day centre with charities and utilising the activities or spaces within the centre to support worthwhile causes can give the person living with dementia a sense of purpose and meaning in helping others. External groups such as community choirs or arts groups can be invited to utilise the day centre to increase community connection and reduce stigma. The addition of a large workshop for men's shed groups or inviting local gardening groups to tend the gardens with centre attendees can help reduce the stigma of dementia and strengthen connection between the centre and the community. Volunteering befriending programmes that bring members of the local community together with people living with dementia to create one-on-one companionship can provide a meaningful way to reduce loneliness for both attendees and members of the community [290]. The day centre physical environment should be large enough to be able to accommodate community groups or volunteers to spend time at the day centre.

Conclusion

It is important to understand the role and outcomes the day centre service is seeking to achieve. Through this understanding

the philosophy of care, model of service delivery, staff competency and skill set, and physical environment can be developed to complement each other and achieve the goals of the service and its users.

Misalignment of the physical environment and the service model will make achieving service goals difficult, for example a service model focused on rehabilitation and physical wellness may not work well in a small house design. Likewise, a model aiming to achieve wellbeing and strengthening of personhood through meaningful engagement may be difficult to achieve in a large scale building set up to deliver large group or passive entertainment activities. Through aligning philosophy, practice and physical environment we can ensure maximum outcomes for people living with dementia attending the day centre and maximise autonomy and wellbeing through an enabling environment.

Moving toward a more dementia friendly world

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Introduction

The literature on designing to meet the needs of people living with dementia is substantial but certainly not huge. There is a great deal of overlap between evidence bases for good design in residential care, hospitals, day centres and home. Rather than interrogate the evidence for guidance on the design of public buildings and spaces, which would inevitably repeat much of the discussion contained in the chapters on residential care, hospitals, day centres and home modifications, it was decided to present four significant articles to a person living with dementia and ask him to respond to them.

FOUR SIGNIFICANT ARTICLES

The first of the articles describes the seminal work of Mitchell and Burton [291] who recognised that unless people living with dementia are able to use their local neighbourhoods safely they are likely to be effectively housebound and deprived of the benefits to health, well-being and independence afforded by access to the outdoors.

> Their research, groundbreaking in its use of 'walking interviews' with people living with dementia, defined dementia-friendly neighbourhoods as welcoming, safe, easy and enjoyable for people with dementia and others to access, visit, use and find their way around.

They identified six principles to guide the design of dementia-friendly environments; familiarity, legibility, distinctiveness, accessibility, comfort and safety. They applied these principles in making 17 recommendations that included providing; small blocks laid out on an irregular grid with minimal crossroads (legibility), a hierarchy of familiar types of street, including high streets and residential side streets (familiarity), buildings/facilities designed to reflect uses (familiarity and legibility), obvious entrances to buildings (legibility and accessibility) and landmarks and visual cues (legibility and distinctiveness).

The second article, in terms of date of publication, explores the transferability of design ideas and principles originating in health care settings to the enhancement of well-being through design in community settings [292]. Boex and Boex highlighted the usefulness of 'touch points' in the journeys taken by people with dementia. Touch points are the times and places where the individual interacts with the physical and social environment of the building and provide a framework through which to explore the use of space. They explore the feelings and issues experienced by a person with dementia as they navigate a journey that starts in a car park, approach an entrance, enter through that entrance, the path to a destination (often along a corridor) and ends in a place where the person engages in a task or activity. They use this experience as a platform for making recommendations about the design of the spaces being passed through and conclude that the design thinking originating in health care settings can offer fresh perspectives to those designing buildings in a community setting.

The third article was published a decade later than the first and illustrates the progress made in understanding the relationship between place and identity [254]. Ward and colleagues showed that the participants in their research defined themselves according to the places they lived and spent time in using the material environment as a means to articulate aspects of identity and selfhood such as their values, beliefs, and sense of belonging. They provide a compelling argument for greater environmental awareness within dementia care, not simply to compensate for the symptoms and problems associated with dementia but as a resource in person-centred practice, a resource that is largely unused.

The fourth article expanded the focus to the broad field of making cities age-friendly [293]. van Hoof and colleagues address the challenges of creating inclusive neighbourhoods and see the use of technology as one of the ways to achieve this. The technology includes health monitoring and emergency response systems, wandering detection technology, and the automated assessment of the need for assistance in activities of daily living. These technologies rely on Big Data analytics and the Internet of Things, which includes the diffusion of sensors and wireless sensor networks in the city with the capability of real-time data gathering. These developments will require all public and many private partners to work together in the redesign of the public space, healthcare and welfare services, and the design of new housing concepts and technologies.

These articles provoked a thoughtful and innovative response:

COMMUNITY AND THE PUBLIC ENVIRONMENT

Much work has had a narrow focused on public buildings such as hospitals but much needs to be done to address the range of venues and locations that form the broader community. A holistic approach needs to be taken when assessing a building regarding its "Dementia Friendliness" as no one building exists in isolation. We need to consider its place in the community both physically and socially. Most of this work outside of clinical settings also focusses on challenges faced by an aging population rather than challenges faced by people living with dementia and does not acknowledge the age diversity of people living with dementia. Another aspect of community that appears to be downplayed, is people's previous connections and experience in their community. For example, there appears to be no reference to how long people have lived within a community prior to their diagnosis, or attempts to identify how and why their engagement with the broader community has changed (both for the positive and the negative) since their diagnosis.

There is an argument around whether a city environment or a rural environment is a better place to live in if you are living with dementia or simply aging in place. Cities dominate this argument because of the higher populations and economic incentives to live in a city. The emphasis should be on identifying the aspects of the environment that enable us to continue to live in the community. The principles are likely the same in rural and urban environments, for our private homes, for the community streetscape and for all public assessable buildings. The emphasis should be around preserving and optimising dementia friendly environments across all environments, from our homes, though the local community and across the nations.

> It is also important to understand what we mean by dementia friendly. It encompasses many things from social attitudes around dementia and aging, to environmental features and modifications that help enable a person with dementia to interact within that environment without discrimination or fear, without disadvantaging others.

It is also important to note that cultural differences exist and are a rich part of our normal lives, and as such should be reflected in their communities. Taking a design feature that works in one environment, such as Scotland and transporting into another area that may be culturally similar such as some areas of Australia with strong ties to Scotland, are unlikely to work as well, without a lot of re-interpretation.

There is a consensus of opinion in many communities, that by making more of the community dementia friendly, we make it more assessable to all people.

The World Health Organisation (WHO) has identified eight domains of age friendly cities.

- Outdoor Spaces and Buildings
- Transportation
- Housing
- Civic participation and employment
- Respect and Social Inclusion
- Social Participation
- Communication and Information
- Community Support and Health services

These domains offer a starting point to help orient discussion around making communities more dementia friendly, but they lack an understanding of the needs of people living with dementia and the perspective of people living with dementia in the community.

To progress the understanding of Dementia Friendly communities these age friendly domains need to be viewed though the principles of Dementia Friendly Design

i.e.

- Safety
- Seeing and Being Seen
- Familiarity
- Size
- Variety of Spaces
- Movement and Engagement
- Stimulus Reduction
- Stimulus Enhancement

Much work has been done in these two areas but they remain largely separate as efforts to combine them are rare. Sometimes the results of studies appear to be counter intuitive. For example, Mitchell and Burton [291] suggest that for street layout, an irregular grid pattern is most legible for people with dementia. This maybe because this type of layout may create more unique wayfinding points than a regular grid. They also suggest a 500m radius for primary services and an 800m radius for secondary services from the home. If these figures are taken at face value they may result in a detriment to the community as a whole. The straight-line distance ignores the physical route and general accessibility of those services. The picture is far more complex than just one physical measurement.

Another point to consider is time. When we consider any aspect of the environment, built or otherwise, we must be aware of the many time related changes that will influence it. For example, a streetscape will likely appear different as the sun progresses overhead, likewise this light-scape will likely vary seasonally as do other aspects of the environment. We can expect physical environmental changes that reflect seasonal weather. Likewise, social patterns are likely to vary in accord with seasonal activities and all these factors can combine to affect how a person living with dementia may be able to assess and interact with the broader community.

Perhaps the best way to approach understanding how the public space can be improved not only for people with dementia but all its citizens is to take a matrix approach to these two domain principles. One axis would be the eight domains of age friendly principles and the perpendicular axis would be the principles of Dementia Friendly Design. This would result in each of the age friendly principles being assessed against Dementia Friendly principles and better validated.

This matrix approach appears complex at first viewing, but essentially only formalises much of what would already be done and can help identify small changes that could result in large impacts.

Ideally this two-dimensional matrix could then be transformed into three dimensions, with the third dimension being time. Then deeper insights could emerge. Thus, not only benefitting people living with Dementia, but all people in the broader community.

To illustrate this point, take the area of Outdoor Spaces and consider a public park. It could be assessed against the eight domains of Dementia Friendly Design at a particular time and found to meet all the requirements. If this assessment was repeated at a different time of day, the natural lighting would be different and may produce large areas of deep shade or bright sunlight that could compromise safety or make it harder or easier for people to be seen and to see the environment around them. Likewise, these changes could be more pronounced as seasons change and as other people

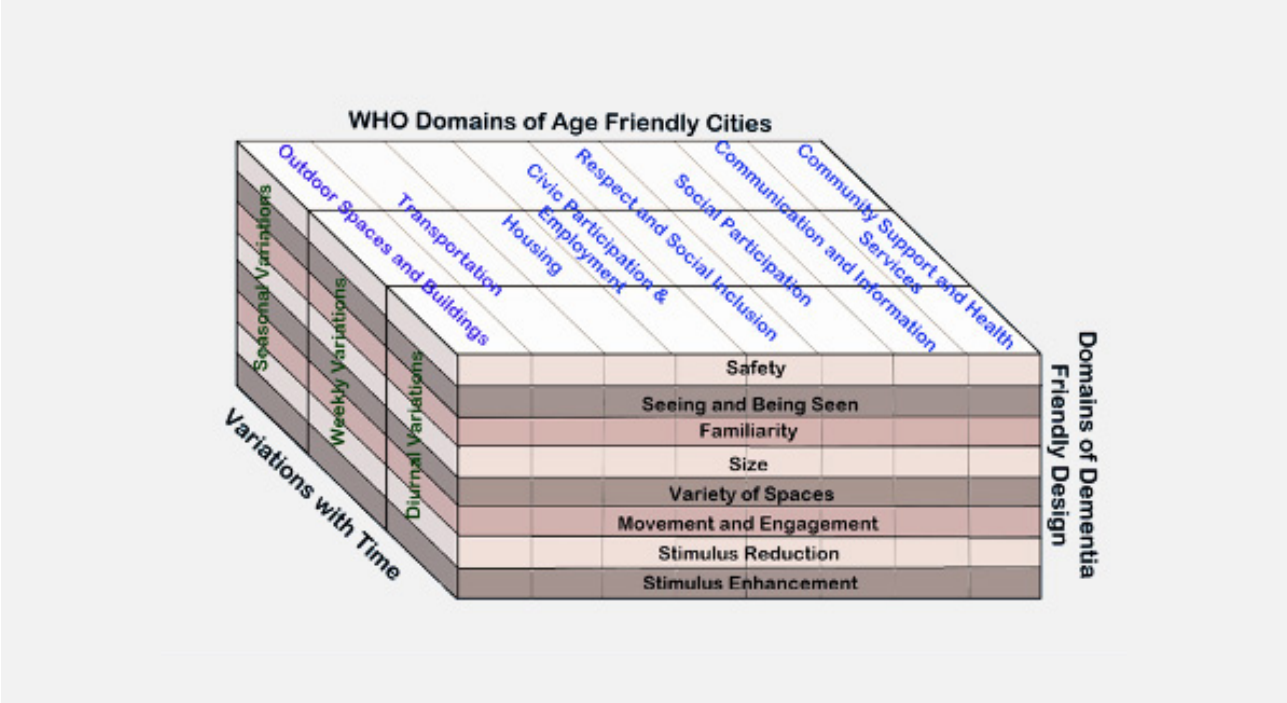

Figure. 1 Introducing time into design domains

engage with the park. It could emerge that the usage of the park varies over a number of scales, over the duration of a single day, over the duration of a week and then seasonally over a year.

It is also important to involve as many people living with dementia as possible in the assessment process as possible. This will ensure a more realistic assessment that could lead to more fruitful and beneficial changes.

An overarching methodology is suggested that throughout this process seeks to firstly identify the aspects of the existing environment that are salutogenic with the aim of preserving these aspects, then to identifying the aspects that can be changed to improve the environment. Preservation may be better than re-creation.

Another aspect to consider in designing better environments is segregation.

> Our expectations as we age should be to age in the community we choose, not to be consigned to a 'specialised' micro-community of a perceived homogeneous population.

This is often reflected in the areas being studied being selected for a cultural uniformity. Many communities reflect many different cultural backgrounds that result in practices from one culture being adopted across other culturally diverse groups in a community. This mix would likely be different in each community and would shift or expand over time. Nevertheless, there are likely practices that may be common across many different communities and scales of community, such as the observance of specific events or holidays.

Change will naturally occur in all communities in response to many causes. There are many agents causing this change. They include such diverse elements as climate change, changes in population demographics, economic change. It is also important to realise that these changes while affecting any given community are dynamic and on global scale their interplay is different in each community.

One consequence of this dynamic is that a solution that works in one community may not work elsewhere. What may work is the methodology that derives an approach and solution that is applicable to the community where it is used.

Finally, it is important to realise the need to have as many people living with dementia involved in all aspects of assessing an environment and designing change. Without the involvement of the lived experience, change risks being tokenistic.

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The early years

The knowledge that we have owes much to the pioneers who began to change the treatment oriented paradigm to one focussed on wellness and engagement.

Dementia care design: Groundbreakers and lessons learned

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In 1975 – 45 years ago – Alzheimer's Disease was hardly recognized by health care professions as a major concern. Doctors learned hardly anything about Alzheimer's in medical school and seldom saw patients who presented with Alzheimer's disease. What has come today to be known as Alzheimer's Disease, was then generally called "senility" and "hardening of the arteries". If someone did present to a doctor at an early stage of Alzheimer's, they were told to wait and come back if things got worse; if they were later in the progression of Alzheimer's they might have been sent to a nursing home for care. Once one or more drugs were developed to somehow control the "behaviors" that care givers and the medical profession associated with Alzheimer's, doctors started to prescribe these medications at the same time as telling patients to "come back in a year" to have their condition re-assessed.

That same year, Folstein et al [1] developed an early "test" for dementia, the Mini Mental State Exam (MMSE), a 10-minute 30-question test that doctors could use to identify the "stage" of Alzheimer's the patient was in at that time. Repeated use of the MMSE over time – re-testing the person – was considered a way to identify the "downward progress" of the person's cognitive function.

Anther clinical step forward took place in 1982, when Barry Reisberg and colleagues developed the Global Deterioration Scale (GDS) known as the "Reisberg Scale" to describe in more functional and behavioural terms what they saw as the downward spiral of the disease – the person's *deterioration* [2]. The scale defined 7 behavioural stages of Alzheimer's. The first three stages which the scale indicates might last anywhere from two to seven years are labelled "no dementia", although today we might include them in Mild Cognitive impairment (MCI). A person in the 4th stage, called Early Stage Dementia and which might last two years, shows evident signs of memory loss, wayfinding difficulties, and executive function problems. People living in Stages 5 and 6, Mid-Stage dementia, are living with severe behavioural problems, speech problems, incontinence, and require assistance with all activities of daily living (ADL's). The 7th stage is late stage dementia

These approaches to the measurement of dementia tell us much about the way in which people with dementia were viewed at that time. Few general practitioners and clinicians in the 1980's were aware of the future place Alzheimer's disease would hold in the health care arena; at the same time, few architects, landscape architects, and interior designers saw the importance of the field of designing for dementia.

However, in the psychological and social sciences, and among a small group in the design professions, a new field called Environmental Psychology or Environment-Behaviour (E-B) Studies was evolving. Harold Proshansky and colleagues at the City University of New York, published a textbook – "*Environmental Psychology*" [3] based on the work of earlier theorists and thinkers, including Edward Hall, Erving Goffman, Robert Sommer, Robert Merton, and others. It included chapters by psychologists, anthropologists, sociologists, architects, and other designers – all making the point that the physical environment has a direct influence on people and the way they behave – at work, in health care, at leisure, and at home. This book was followed by several others and heralded the creation of the Environmental Design Research Association (EDRA) whose message was the same with a slight twist – EDRA stressed the importance of carrying out research on the built environment to create an evidence base defining more precisely the relationship between environment and behaviour – including not only physical behaviour, but

also perception and attitudes. Academic departments in psychology and design around the globe began to include this subject matter in their curricula.

> This was the start of the field of design for dementia – innovative buildings, in situ experimentation, research approaches, trial and error buildings, training, and consultancy practices.

Researchers including Margaret Calkins, Gerry Weisman, Uriel Cohen, Lori Hyatt, Brian Kidd, and the authors of this report – Richard Fleming, John Zeisel, and practitioner Kirsty Bennett developed methodologies for studying the use of space by persons with dementia, worked in the private and public sector to influence residential as well as health care building design for persons living with dementia, and carefully studied these paradigm shifting buildings to identify and catalogue the most person-centred and supportive environmental conditions. In the research and design literature, the term "Alzheimer's" eventually became replaced with Alzheimer's Disease and Related Disorders (ADARD), and eventually just by the term "Dementia". This research became the basis for a rich design-related literature that includes evidence-based descriptions of intentional paradigm shifting environments, research findings, and both design principles and specific design approaches to guide the design of future environments for persons living with dementia.

This report centres around a set of such principles developed during these years by Fleming and Bennett (4, 5) and a closely aligned set of design approaches developed by Zeisel [6]. While psychological and social scientists and research-oriented architects and designers were identifying conceptual frameworks for design for dementia, creative, thoughtful, and adventuresome operators, developers, public bodies, and designers of all stripes, were beginning to design, build, occupy, and use residential environments that reflected what was being learned about dementia-friendly and supportive design.

This chapter honours those innovative teams and the buildings and communities they developed. Each of the following 10 projects are what the authors of this report are calling "paradigm-shifting" environments. In its own way, each building contributed to knowledge of environmental design for dementia, as did psychological and social science research at the time.

The following project descriptions briefly explain some of the contributions in design and operations made by designers and operators using what little evidence existed at that time.

> Drawing creatively on a mix of empathy, common sense, and evidence they made the best decisions they could. We owe them a debt of gratitude.

Groundbreaking Paradigm Shifters	Principles & approaches the designers / operators explored in this environment
Adards, Tasmania	Homelike, accordion design to switch between "family" & "community" scale", lively garden
Aldersgate, Felixstowe SA	Process innovation; non-institutional quality; redundant cuing
Anton Pieckhofje, Haarlem NL	'Family scale", central services, differentiated style management
Le Cantou, France	Separate small apartment in larger building, continued family involvement
Hasselknuten, Sweden	In town location, common areas open to the public, normalised life for all,
Hearthstone, Marlborough, Massachusetts USA,	"Community scale," central garden, engagement activities at "family" scale
Himawari, Ofenatu Japan	First "family scale" in Japan
Moorside, Winchester UK	Choice through design, unobtrusive care, seeing and being seen
Pepper Tree Lodge, Queanbeyan, Australia	Unit for the Confused and Disturbed Elderly (CADE) broke Australia's institutional model
Woodside Place, Oakmont, PA	Neighbourhoods with joint common space, family scale gardens, innovative details

Plans and photos of several of these buildings are available in the book *Design for Dementia* [7], which served as a source for some of the descriptions, now available for free download on the HammondCare Dementia Centre web site.

A note on scale: Family, Extended Family, Community

Studying the design and operations of each groundbreaking paradigm-shifting residence, one element stands out – scale. Together these projects address three levels of scale each in a slightly different way:

- 6 to 8 person "family scale"
- 12 to 15 person "extended family scale"
- 27 to 36 person "community scale"

Scale has been a bone of contention between design-for-dementia experts since the dawn of environment-behaviour studies

You argue that "community scale" is most important because it provides residents with a lively group of people with whom to interact. I support "family scale" because its familiarity helps residents with dementia be more at ease; its small size does not challenge their cognitive abilities. Our colleague feels "extended family scale" is best for people with dementia because "family scale" is not stimulating enough, while "community scale" can be confusing, and anyway don't we all actually live in an extended family with brothers, sisters, grandparents, grandchildren, nieces, and nephews!

This debate has been raging for decades with no apparent resolution; each expert citing their own evidence and personal experience to support their point of view. Studying the paradigm-shifters provides an "either-and" rather than "either-or" way out – all three scales, it turns out, are relevant all the time in dementia design. In many cases all three are addressed either through design or operational decisions within individual projects.

One programme provides *family scale* during the day and accordions out to *community scale* at night. Other residences provide *family scale* one part of the day, connect to another family scale unit at mealtimes, leading to *extended family scale* at those times. *Community scale* is achieved in some cases through operations in which several smaller scale units are treated together for staffing efficiency and service provision. In other cases, *community scale* liveliness is achieved by making available to neighbours and other outsiders a bistro or hair salon within the building. In one paradigm shifting residence, while the setting is designed at *community scale*, daily engagement activities subdivide residents into *family scale* and *extended family scale* groups during the day.

The answer to which scale is most important in designing for dementia: all three scales at different times are important and all three can be achieved in different ways in the same project. Scale can be conceived as an Escher drawing in which depending how you look at the drawing, the subjects appear to be moving to different destinations – up and down at the same time, usually ending up where he began.

I urge the reader, as he or she reads the brief descriptions of each paradigm-shifting project, to keep this multi-scale image in mind and consider how each addresses the significant question of scale.

Ten paradigm-shifting designs

ADARDS, WARRANE, TASMANIA

Accordion design supports 8-person "family" scale residences during the day that transform into an efficient 32-person "community" scale programme at night.

The straightforward name Adards derives from the original term for Alzheimer's – Alzheimer's Disease and Related Disorders. Developed in the late 1980's, Adards opened in 1991 as a nursing home specifically for persons living with dementia who do not need a wheelchair, and who no other residence could "manage".

Adards was inspired by the leadership of State Mental Health Commissioner in Tasmania Dr J.S.H Tooth who lectured extensively about his work throughout Canada at that time, and geriatrician Dr Sam Ginsberg. In addition to the many design features listed below that reflect the Fleming-Bennett principles and Zeisel approaches, Adards resolved and pioneered a critical challenge all residential dementia programmes face – the need for smaller family and extended family scale to provide residents an understandable and engaging way of life, yet the need for larger scale, especially overnight, to achieve cost effective staffing while maintaining safety and care surveillance when most residents are asleep.

Adards resolved this dilemma in what might be called an "accordion" design – each 8-person house is independent during the day, yet the entire programme operates as a 32-bed unit at night. Four autonomous fully equipped 8-person homes surround a farmhouse garden with chickens and an aviary, which all residents and their families can walk around as well as enjoy sitting on their home's front porch to watching its animal life. At night, all four homes open their connecting door to a night attendant desk and lounge, creating a single 32-person easily surveilled setting that reduces night-time staffing and makes the entire programme cost effective.

Adards includes many siting and design features that reflect the principles and approaches identified in this report: the domestic character of the buildings that fit into the surrounding neighbourhood, interior design and homelike colours, the absence of dead-end corridors that frustrate residents, each living room furnished with a virtual "hearth" – an imitation log fireplace. Outdoors there is a garden that contains not only chickens laying eggs like the laying chickens many residents were used to, along with birds, cats, and dogs, but also an old car that "the guys" can shine and take care of.

Two unique elements were included, one of which is an excellent idea that has been little implemented in more recent designs for dementia and another which was never meant to be adopted by others but has been – worldwide.

The first is that right inside each resident's room on the wall visible from the hallway when the door is even slightly open, is a hook on which the resident's dressing gown hangs. Each unique dressing gown clearly indicates to that resident that he or she lives there. It is reported that, and I can attest from personal experience at Adards, that doing this promotes wayfinding more effectively than personalised "memory boxes" outside a person's room or even a picture or colour-coding. In other settings the hook might hold an outer coat, a dress jacket, or any other piece of clothing unique to that person. This is seldom done today.

> The element that has been copied widely; Dr. Tooth wished hadn't been copied – a bus stop shelter on the edge of the garden.

He recounted to me that he installed the bus shelter to accommodate one particular resident for whom this was a calming element– and that few other residents ever used it. In fact, he said, he felt it frustrated those who occasionally did sit there waiting for a bus that never arrived.

ALDERSGATE VILLAGE, FELIXSTOWE, SOUTH AUSTRALIA (SA)

Process lessons include confronting regulations and being open to learning from critiques and feedback from an earlier stage of design in a multi-stage project

Aldersgate, planned and developed in the mid-1980's solely for persons living with dementia, includes three 9-person "family" scale houses, making a 27-person "community" scale grouping; ensuite single bedrooms for each resident, a gas log "hearth" fireplace in each common living room to convey homeliness and as a gathering point, a central large open common area to reduce the perception of lengthy corridors, and most important a secure enclosed rear garden that provides a significant "outdoors" common space to prevent residents feeling cooped up and imprisoned. A major paradigm shift is the way the designers thought about the building aiding wayfinding – namely what they didn't do – they avoided confusing "decision points" in the layout. To them a simple non-confusing design assists people living with dementia to find their way. Today we realise this presaged what is called "natural mapping" – where all the information a person needs to know to use that object or environment correctly is embedded by design in the environmental itself – no set of instructions needed. Finally the designers employed redundant cueing – the use of more than one sensory indicator of places to go or places to turn, in order to accommodate individual's different sensory tendencies – visual information, touch via tactile experiences, lighting intensity, and sounds. Even smells such as odours coming from a meal being cooked in the kitchen can be a useful sensory cue.

All these innovations were not common in the mid 1980's (stage 1 1984; stage 2 1987). Home regulations were strict and limiting – not at all dementia-friendly or even dementia-aware.

> To change this design paradigm for dementia meant convincing regulators that design innovation and breaking conventional design principles for nursing homes predominant at that time, would benefit residents.

This was only made possible because of the commitment of both CEO Tim Horsnell and Architect Brian Kidd to challenge the status quo. Among the most important of these at Aldersgate Village were residential quality of the entire environment vs. institutional quality, private 1-person ensuite bedrooms instead of multi-person bedrooms with a toilet and shower room shared by 4 residents, common at that time, carpeting resident bedrooms along with rapid response maintenance instead of the common practice of using vinyl flooring, and providing staff with rolldown desks in a small nook instead of nursing stations. The operators did lose one confrontation. Under pressure from the local licensing authority, they installed a staff call system the operators felt residents living with dementia would not be able to operate. It became redundant.

Aldersgate's owners, and Brian Kidd, also embraced another important design process approach – they learned from critiques to modify the environment in positive ways. Each 8-person "house" originally included a formal dining room intended for family parties and dinners. It wasn't used. They converted it to another bedroom. Front doors to each "house" were originally inside the community not visible from the street. In phase two each "house" has its own street address and letterbox – a face on the street like other houses around it. Phase two included an air handling and heating system that residents could manipulate to their own comfort level instead of the earlier central system with no individual controls. All in all feedback from users greatly influenced the design process and product.

ANTON PIECKHOFJE, HAARLEM, THE NETHERLANDS

Six autonomous 6-person "family scale" apartment homes, constituting a 36-person "community scale" programme served by a central nursing and service staff, reflect a traditional Dutch church-attached care setting – the Hofje.

Located in an urban setting on the edge of the city of Haarlem, Anton Pieckhofje, an early paradigm shifter from 1989**,** is a 36-person "community scale" residential care setting divided into six homelike apartments of 6 persons each, with each apartment front door opening onto a corridor surrounding a central open courtyard. Some services are provided to all residents centrally, while meals are prepared in each apartment.

Common to all six apartments is a large kitchen window – overlooking the courtyard and public street providing residents with connection to people riding their bikes and walking past – to daily life.

Unique to each dwelling is the way it is run and the way it feels– one might be perfectly organised and neat and clean, the other more relaxed with washing sitting in a basket on the dining room table and a ritual each evening of drinking hot chocolate together.

Care is provided by a small staff in each building. At night if the one staff person in each household has difficulty, which seldom happens – perhaps twice a year – they can call a nearby on-call back-up to come and help. Anton Pieckhofje provides an early example of small "family units" as the organising principle for design, with the overall building at the "community" scale in which services are provided most efficiently. In the same building above these units are private apartments for the general public. The Netherlands is a natural context for this scale of innovation because of its long tradition of church-related "hofjes" – small groupings of apartments providing shelter for those in need in the community, surrounding a courtyard usually located next to a church, separated from the street by a fence and gate.

LE CANTOU, RUEIL-MALMAISON, FRANCE

Individual 12-person "extended family" scale apartments situated in normalised apartment building settings, where both cognitively challenged and non-challenged elders live together, helping each other, and families remain closely involved.

The term Cantou, is a French Provencal term for fireside corner, hearth, or a seldom used term "inglenook". It reflects a clear "vision" of a way of life in a large shared apartment for people living with dementia, located in a normal apartment building, where the apartment reflects homeliness, family, and cosiness. Under a different term – such small "extended family"-scale apartments are today included in many French residential care homes / assisted living residences called in French – EHPAD (Etablissement d'Hebergement Pour Personnes Agée Dépendentes). Although originally a term reflecting homeliness and

family as described above, the term has been re-verse-acronymised in French as: CANTOU (Centre d'Animation Naturel Tiré d'Occupations Utiles).

The first "Cantou" – whose name continues for this type of dwelling in Belgium – was developed by Georges Caussanel at the end of the 1970s in the Parisian suburb Rueil-Malmaison.

> The groundbreaking purpose of the 12-person shared apartment was for elders with cognitive challenges to live and engage together in daily life tasks with those with fewer challenges, thus stimulating and preserving the independence and autonomy of those with dementia.

The concept includes a homelike environment where residents and their families living in the community can carry out daily tasks – peeling vegetables, setting the table, doing the dishes, folding laundry – as they always had, but together in a group. Thus, the intention was not only to support residents but assist their "burdened" families as well.

A condition of living in a Cantou was that residents' families commit to maintaining responsibility for the person and continue to provide emotional support. The commitment includes participating in monthly meetings with the other families.

Each autonomous Cantou unit includes 12 individual bedrooms with, for each, a bathroom with sink, toilet, and shower, together with a common room in which daily tasks, including preparing and having meals, takes place. Each Cantou includes living quarters for care managers and a universal worker staff person who supports residents with tasks they have difficulty performing.

Family members furnish and decorate bedrooms according to the tastes and needs of the residents.

HASSELKNUTEN, STENUNGSUND, SWEDEN

An in-town, shared "family scale" apartment in the Swedish culturally appropriate shared apartment plan called Gruppenboende, that by fitting into its residential neighbourhood, communicates to those who live there and to their families the normal acceptable nature of residents' lives.

The Hasselknuten shared apartment is located near the town centre of Stenungsund Commune, giving it a sense of being at the centre of town life – a boon for families of residents Six persons living with dementia live in a "family scale" ground floor apartment designed and renovated specially for their use. The design in 1998 pioneered the principle of 'seeing and being seen'. At the centre of the apartment, with ensuite bedrooms on each side, is a grouping of common spaces each with different character reflecting the approach that differentiated common spaces offer insight to their use. These spaces are visually connected through glass doors and screens – large family room on one side, "farmhouse" eat-in kitchen accommodating all 6 residents on the other. Just inside the apartment entrance are a set of storage closets for outer wear and to leave boots, common in many Swedish homes where snowy winters are common.

> The vision in Hasselknuten is that residents are treated as persons in their own right, as a group they support each other, and the small staff is specially trained not to intervene in a person's life, rather support them to maintain individual competence and quality of life.

To get to this shared apartment, family members, staff, and other support personnel use the building's front door as do all other residents of this two-story 12-apartment building – normalising the entire setting in everyone's eyes.

Hasselknuten reflects Swedish cultural influences that further normalise life for residents and their families. Group homes – "Gruppenboende" – like Hasselknuten are a Swedish concept with many examples in the country, of which Hasselknuten is only one.

HEARTHSTONE ALZHEIMER CARE, MARLBOROUGH, MASSACHUSETTS

A "community scale" 35-apartment dementia residence with carefully planned residentially enclosed therapeutic garden, in which "family" and "extended family" scale are achieved through daytime engagement programmes geared to different levels of resident competence.

Hearthstone represents a paradigm shift to community scale and centrality of outdoor space in a renovated building. Occupied in the mid-1990's the Dementia Community houses 35 residents at "community scale" on three floors. The first floor is all common spaces – living room, dining room, plus offices open to these spaces on the same floor so that staff members are part of the life of the community, not hidden away. Two upper residential floors also include their own kitchen-dining areas where breakfast is prepared "to order" – eggs, waffles, cereal – when residents get up at their leisure as they did the rest of their lives. Care and support are provided at three levels of need, the highest care of which, Serenity, has its own space at one end of an upper floor where quieter and more sensory engagements are provided such as foot baths and hand-massages. Engagement opportunities – music and movement, reading clubs, garden clubs, seated aerobics, and other evidence-based engagement opportunities developed by the organisation's Research Division – are offered in common spaces on all three floors.

Residents move between these spaces as engagement options change during the day – a purposeful procedure to urge residents to walk and therefore get more exercise than they would if everything to do was provided in one or two places nearby each other.

A large safe garden space surrounded by a residential fence designed by Landscape Architect Martha Tyson and employing Kevin Lynch [8] space principles of pathways, districts, boundaries, nodes, and landmarks, is open to all residents. The therapeutic garden is fully visible to other residents and to staff inside, making natural surveillance easy from the interior kitchen, dining room, and living room. The garden can be seen as well from half the resident bedrooms and each common space on upper floors to assist residents with orientation and a sense of place. The setting is clearly "community scale" – 35 bedrooms – larger than the "family scale" of Anton Pieckhofje and the extended family scale of Le Cantou. Family scale, so critical to residents feeling comfortable and in control, is achieved through engagement activities at both small family and extended family scales. The major paradigm addition this community provides is the tight link between the physical design and the "vision" of care based on the I'm Still Here Engagement Replacement Method [9].

HIMAWARE, OFENATU, JAPAN

One of the very first group homes in Japan built specifically to accommodate people living with dementia; it set the stage for further development of "family scale" settings for people living with dementia in Japan.

Opened in 1996, Himaware was one of the very first group homes in Japan built specifically to accommodate people living with dementia. Nine people – large "family scale" – live in Himaware, each with her or his own bedroom. The building is a simple plan with bedrooms arranged along a double loaded corridor leading to an open plan kitchen and dining area. The philosophy of care focuses on engaging residents in ordinary activities of daily living, which in this rural area includes growing their own vegetables and catching their own fish. Residents are encouraged to go to the local supermarket with staff to shop for food and are actively engaged in preparing meals in the fully functional kitchen.

Himaware's homelike design enabled its founder, Dr. Noriya Kikawada, to demonstrate the ability of people with dementia to 'live their own lives', to continue to be responsible for many activities of daily living and, in fact, to show 'life-long development'.

Dr. Kikawada used this experience in his Presidency of the Japanese Group Homes Association to guide the development of group homes as a key part of the Japanese long term care insurance strategy which resulted in the growth of the number of groups homes from less than 10 in 1996 to more than 8,000 by 2006.

MOORSIDE, WINCHESTER, UK

Moorside is a nursing home in which a great deal has been done by design to maintain a home-like feeling –separating, almost hiding, service and staff areas, employing easily cleaned carpeting instead of institutional flooring, and providing abundant choices for residents so that they feel in control of themselves and their surroundings.

Moorside's is a 1997 "community scale" building of 27 beds, with 3 "family scale" apartments of 8 and 7 people each, plus a small respite area. While Moorside is a nursing home, its designer took great pains to make sure that the nursing and care staff could work unobtrusively within the building in order to maintain as residential a feeling as possible.

The apartments themselves contribute to resident well-being in several ways, one of which is to maximise choice for residents. One set of apartments faces a busy street, the other a quiet garden. A dining room overlooks one view: a living room the other. Residents choose the room to occupy and the view they want. They choose where and how to spend their time between their private ensuite rooms and the large common rooms; the sunny or shady side of the apartment. Bedrooms are all located so each has sunlight at one time of day – morning or evening. The principle of seeing and being seen is reflected in the central location on both sides of the corridor of the large common rooms that provide a view from one side of the apartment to the other – making every approach and movement in those rooms visible to those in the rooms.

Homeliness is a major design goal – reinforced by each apartment door being designed like a house front door, recessed off the corridor, with domestic carpet in all resident areas chosen for its appearance and effect rather than ease of maintenance. To reduce the sense of Moorside being an institution, the exterior is constructed of local materials, fits into the neighbourhood in terms of style, and is only a short walk to the town centre with its shops, swimming pool, and bingo hall which, accompanied, residents can visit.

PEPPER TREE LODGE, QUEANBEYAN, NEW SOUTH WALES, AUSTRALIA

Opened in 1987 Pepper Tree Lodge was the first of Australia's Confused and Disturbed Elderly (CADE) units built in New South Wales during the late 1980s and early 1990s.

CADE units – domestic in scale and situated in local communities – were established to confront and replace the dominant paradigm at the time – centralised, institutional care of people with dementia in the back wards of New South Wales psychiatric hospitals. Design of the CADE units is heavily influenced by the principle of seeing and being seen – good visual access of all spaces for residents – enabling residents to see their bedroom door, kitchen, dining room, sitting room, exit to the garden, and a toilet from almost everywhere within the unit. Each CADE unit accommodates an "extended family" scale of 16 people in two "family scale" 8-person cottages sharing a common staff room. Emphasis is placed on reducing unnecessary stimulation and using visual cues, such as colour contrast, to highlight things and places that residents need to find often during the day.

> The fully-functional kitchens match the philosophy of care focused on engagement with ordinary activities of daily living

– a stark contrast to the medical model that the residents admitted from the psychiatric hospitals were used to. The nine CADE units built by the NSW Health Department, were early demonstrations of the viability of a person-centred and capacity-based model of care. Their influence on the design of aged and health care facilities in Australia can still be seen today.

WOODSIDE PLACE, OAKMONT, PENNSYLVANIA, USA

This community was one of, if not the, first in the US, to focus design-for-dementia based on available evidence from planning decisions to layout, down to details of shelving over the bed and bedroom door design. This groundbreaker reflects decisions in all of the domains addressed in this report – goals, principles, approaches, and design details.

Designed in 1991 by architect David Hoglund of Perkins Eastman Architects, Woodside Place established a "family" scale model in several important ways. Woodside Place provides private bedrooms in three 12-person "family scaled" houses connected to common areas used by all 36 residents. The three individual houses each have a living room, dining area and kitchen along with staff support areas. Each has an entryway fronting on an indoor path that strings together craft areas, TV room, café, and a fireplace sitting area. Artwork, colour, and materials based on shaker quilt patterns -- green tree, red schoolhouse, blue star –provide each house with its own identity. Each has its own secure "house" garden that connects to a larger "community scale" garden all residents share.

Innovations at Woodside Place include

> interior design elements aimed at providing residents with opportunities for self-expression – a built-in shelf on the wall over each bed for personal photos and mementoes, and a "shadow box" at the door to each bedroom

in which each resident or their family places items that are important to the resident's identity. Another "experimental element", which over time has been adopted by some but not many designers, (perhaps to avoid accusations of passive restraint or to maintain fire ratings) was also included in the design – "barn doors" on each room with the bottom half and top half separately lockable. This door system enabled staff to close the bottom half to avoid residents rummaging in other's rooms while leaving the top half open for visible wayfinding and light.

Woodside Place challenged other operators and designers by setting a high bar for its organisation and details. It was one of the first programmes in the US to actually set a goal to be responsive to the needs of its residents with dementia, their care partners, and family members.

Still Breaking Ground and Shifting the Paradigm

The paradigm shifting projects of the 1980's and 1990's described above did an excellent job given the limited know-how available. These pioneers met many of the implicit criteria available to provide a positive, capacity based, person-centred way of life for their residents living with dementia. Each team had to invent its own way through the forest of regulations, common practices, and design conventions to achieve this. We owe these operators, designers, architects, officials, and residents and their families a huge debt of gratitude.

Design innovation, however, does not stop with establishing design principles and approaches and applying them to groundbreaking projects. The following more recent examples represent designs and programmes that build creatively on these paradigm shifters while at the same time continuing to innovate and move the Design for Dementia goalposts ahead.

DE HOGEWEYK, THE FIRST "DEMENTIA VILLAGE"

Hogeweyk is a self-contained Dutch dementia nursing home that through creative design, planning, and operations, enlarges the concept of scale beyond family, extended family, and community, to "village scale".

Since 2009 when De Hogeweyk opened its doors in the town of Weesp, the Netherlands, a dynamic concept has been growing and continues to grow – a "dementia village". It is not so much an actual "village" as much as a secure inwardly turned community with a single controlled entrance, much like a castle in the middle ages with its single drawbridge entrance where 167 people live with dementia in "family scale" 6-person households. Household apartments in which support of daily life and care is provided to residents by a stable two-person team, are grouped in "community scale" clusters around small open spaces onto which the households' front doors open. The community's open spaces are for use by all, and care is coordinated at the scale of the entire 167 person "village".

Incorporating lessons from evidence, other paradigm shifters, and an earlier version of De Hogeweyk, its innovative operational and design features include:

- Each household is a self-contained family unit of 6 to 7 residents with entry way for coats and boots, a living room, dining area, kitchen, and individual bedrooms with bathrooms shared by three residents
- Meals are prepared and care provided in each household by two aids who generally spend from 7.30 am till 10.30 pm with those 6 to 7 residents – sometimes inside neatening up, preparing meals, and providing care, at other times sitting outside with residents in front of their front door
- Because the entire community is securely walled and there is a concierge at the entry, the outdoor courtyards are not secured enabling residents to walk wherever they please within De Hogeweyk
- In the "village square" that you walk through when you enter De Hogeweyk's main entrance, there is a theatre, a central square fountain, a restaurant, and a pub
- Unique to De Hogeweyk is that the restaurant and the pub are available not only to residents, their families, and the entire staff who provide care and support, but also to residents of the surrounding neighbourhood. A menu board sits outside the entrance inviting neighbours to come in for a meal
- A unique feature which takes advantage of the "village" scale of De Hogeweyk is the number of what seem to outsiders and insiders alike to be public shops and stores located on De Hogeweyk's

Resident and an aid preparing dinner together

The Village Square

"main street" and in its large atrium. The secret is that the "hardware store" is actually the maintenance office for the village; the "travel agency" actually the office of the activities coordinator who also arranges trips to the theatre and opera in Amsterdam for residents; the "super market", laid out and designed as a public "market" is actually the storeroom which household staff, often accompanied by residents, visit daily using a prepaid "credit card" at the checkout counter to "shop" for the raw foodstuffs for residents' meals and everything else needed to run a household.

- The market also sells special beauty and other products family members might want to purchase for a resident
- The strong visual image these "shops" present – next to the restaurant and pub which actually function as public places – is striking. They give residents the feeling of being free and independent – vital for persons living with dementia in what otherwise would be an institutional nursing home. It also conveys to care partners working and volunteering there, that they are serving residents in their own household and home

De Hogeweyk is clearly a present-day paradigm shifter. The concept has already inspired others to replicate the concept, if not the physical characteristics, in France, Italy, Australia, the US, and other countries. However, the success of De Hogeweyk is as much about the vision, the planning, the programming, and the operational model as it is about the building, and these are much more complicated to replicate.

BELONG, ATHERTON, UK

Belong Atherton, a 72-unit building in Lancashire, UK, built in 2011, comprises a great many evidence-based lessons taught by its predecessors. It presents us a chance to learn how a comprehensive model of care and design that innovates at every scale, can contribute to the lives of those living with dementia.

Belong's "goals" are lofty. As Judd et al in *Design for Dementia* [7] *describe them:*

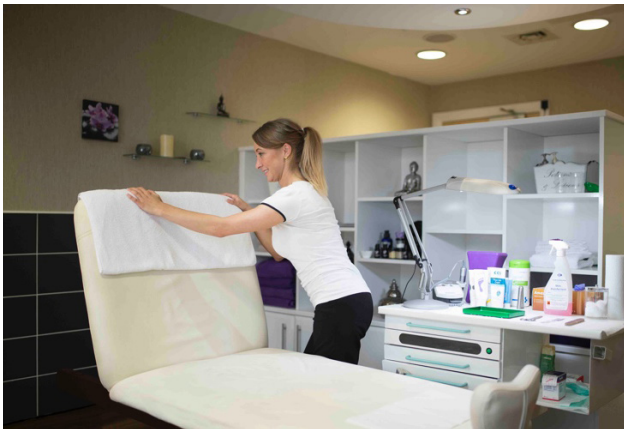
> "Good design for dementia should compensate for impairments, maximize independence, and enhance self-esteem and confidence. It should also demonstrate care for staff, be orienting and understandable, reinforce personal identity, welcome relatives and the local community, and allow control of stimuli."

At the "community scale", constructed of local materials and sited close to the town centre of the Victorian mill town of Atherton, Belong fits in physically and visually. Socially it fits in to the town as well. Its common areas – bistro, hair salon, and internet café – are all open and inviting to town residents.

Community-based alternative health practitioners – massage, aroma therapy – are invited to use the well-being suite. Belong, in a real sense is a member of the larger community.

Life and care at Belong take place in "extended family" scale households – there are six 12-person group neighbourhoods with dining and living rooms where residents live their lives and receive the care they require – supported by care partners expertly trained to support Belong's goals to prevent isolation and maintain each person's independence. The environment at the smallest scale is also adapted to the needs and abilities of persons with dementia: glass-fronted kitchen cabinets, service doors that are camouflaged, familiar fixtures, and memory boxes.

The Bistro open to the community



The well-being suite in use

The benefits of outdoors – garden on the ground floor and large balconies for each household on upper floors – has not been overlooked. Everyone can go outdoors safely.

At the "individual scale" Belong's operators and designers decided to provide larger than required one-person ensuite bedrooms where residents can bring their own belongings to remind them of their self – always present even in advanced dementia [10]. From the head of the bed, when the bathroom door is open, residents can see the toilet and be more independent when they get up at night. These bedrooms can be combined into larger full one-bedroom apartments if the needs of this community change.

Belong can be thought of as a design and operation that puts it all together, presenting a model to review, to test, and to learn from. Photographs and a plan of Belong Atherton can be seen in Volume 2 of this report.

GLENNER TOWN SQUARE®, CHULA VISTA, CALIFORNIA

Located in an industrial warehouse in Chula Vista, California, seven miles south of San Diego, Town Square® is an elaborate day programme environment that breaks the mould of what a day programme centre looks and feels like. (Note: Wherever the term "Town Square" is written in this description, it represents a registered trademark term).

One enters Town Square through a large welcoming door into a public foyer, much like a theatre lobby. Passing through the next large door, visitors come face to face with what looks like a 1950's theatre or opera set with a small diner with tables to eat at, a pub with a pool table in the centre, an old car at a gas station pump, a "department store", a barber shop,

Shooting pool in the pub

a town hall with administration offices, a mini-museum with local displays, a pet store, a medical suite with a nurse's office and place for a participant to lie down, and a movie theatre that seats 20 people. All of these surround the mini Town Square park with benches.

Set designers of the San Diego Opera Scenic Studio designed and constructed the facade of each of the town's "buildings". Lunch is served daily in the restaurant and pub. Engagement programmes are conducted daily in all the "shops" including the theatre, museum, pet store, and department store — breaking the larger community scale number of participants into smaller family and extended family groupings.

Town Square's 1950's Gas Station

Behind the scenes, because Town Square itself does not completely fill up the warehouse, are service delivery and service areas unseen by participants.

Whatever the evidence and intuition behind this 2018 programme, and whether the 1950's town décor directly affects participants' cognitive abilities, Town Square is definitely an innovative paradigm-shifting environment and programme which is likely to teach us many important lessons about the design and operation of dementia day programs.

ABE'S GARDEN

Abe's Garden assisted living community in Nashville, Tennessee, is a non-profit community providing services since 2015 for persons with dementia. Abe's Garden's mission is to

> foster positive change and share best practices in evidence-based, person-centred care through design, engagement, management, and training.

The "community scale" 42-person home environment, surrounding a lively therapeutic garden, is divided into three interconnected 12 to 17 person "extended family" households, each of which has a unique programme feel and different common area design. The themes of the three households are music and movement; connection to nature; and art and lifelong learning. The music household includes a performance space that supports concerts and plays.

Front door to the Nature House inside the central garden

A working greenhouse exiting into the outdoor vegetable and flower garden is the main feature in the nature household.

The art household centres around an art studio. From the central therapeutic garden each household has a "front door" leading into the household dining room.

The community's best practice health programme is delivered in cooperation with Nashville-based Vanderbilt University. Trained team members implement the I'm Still Here Engagement Replacement approach [9] – engaging residents in interesting and meaningful adult activities that replace and reduce reactive behaviours such as agitation, anxiety, and aggression commonly associated with dementia. Part of the Abe's Garden mission is to offer best-practice training to other dementia-specific communities.

Unique to Abe's Garden is not only its evidence-based operations and design for dementia, but also its best-practice dissemination mission.

In sum, we owe a debt of gratitude to those operators and designers who 30 to 40 years ago broke the mould of dementia care enabling us to learn significant design and operational lessons. These have led to a much better understanding of principles of design, design approaches, and design responses; as well as to the critical understanding of how these relate to the overarching aim of striving for the well-being and dignity of people living with dementia. At the same time, in order to continue to build our knowledge base, to grow and learn, we must keep a careful eye on today's groundbreakers who have a great deal to teach us still.

The working greenhouse

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Pioneers and innovators

Designing for people living with dementia is not only about the incremental accumulation of knowledge; individual flair, passion and inspiration play an important part.

Eight interviews with pioneers and innovators

John Zeisel PhD, Hon D.Sc. Founder of The Hearthstone institute and the I'm Still Here Foundation.

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Introduction

Portraying individual flair, passion and creativity is a difficult thing to do in a textual report but, in this day and age there is no reason to be confined to text. The voices and faces of the pioneers, innovators, architects, and researchers can be made available through links to videos to add a colourful and insightful dimension to this report.

Having some experience with this medium (see YouTube Public TV interview series: *Hopeful Aging with Dr. John Zeisel*) it was decided that I would conduct the online interviews. I am based in Boston while the interviewees were located in Australia, the Netherlands, Sweden, the UK, and in the US in California, Ohio, and Maine.

It was necessary to find a way to conduct the interviews that overcame the problems of distance and COVID-19 restrictions on travel. Advice from a videographer led me to appreciate the value of the mobile phone as the source of high-quality video and the need for this to be supplemented with a tripod to provide a stable base for it, along with a lapel microphone to ensure high quality sound. So, a mini-tripod and lapel microphone were sourced in each of the countries and dispatched to

- Margaret Calkins – architect, pioneer researcher
- Jannette Spiering – serial innovator
- Clare Coper-Marcus – pioneer garden guru
- Michel Murphy – international design thinker
- Allen Kong – multi-cultural architect
- Wilhelmina Hoffman -geriatrician, designer, innovator
- Alan Dilani – salutogenic champion
- Peter Phippen – groundbreaking architect, influencer

While we identified a host of topics for discussion, we also decided to limit the interviews to 20 minutes – necessitating choices of topics for each interview.

The full list of topics includes:

- The interviewee themselves: background, unique vision, what excites them about design for dementia
- The role of a vision for a fulfilling life for people living with dementia in guiding design and operations
- Basic assumptions / philosophy: fit between users and settings, role in design of human principles, user needs, and the setting itself
- Design principles: user principles, physical design principles, general user principles, principles aimed at dementia
- The design process including programming, briefing, and construction
- User involvement: who to include, clients, residents, staff, operators
- The role of research and a research expert in the design process
- The role of aesthetics and the person's definition of aesthetics
- Creating new futures and how to reconcile them with present user needs

The interviews focused on identifying what was most important to each interviewee. A pre-interview video conversation identified major concepts and focus, notes were taken, written up, organised into topics / questions for the interview, and sent to the interviewee. Then a 20-minute interview was conducted.

The time limit restricted each interview to two or three of the major topics. Altogether, however, the interviews together paint a fascinating picture of the past and present of design, dignity, and dementia.

The following pages provide a very brief summary of the interviews, enough I hope, to encourage you to view them at ww.alz.co.uk/research/world-report-2020

Margaret Calkins – architect, pioneer researcher

Dr Margaret Calkins, Board Chair, IDEAS Institute – Innovative Design & Environments for an Aging Society. Known to her colleagues as Maggie, her 1988 book, *Design for Dementia: Planning Environments for the Elderly and the Confused*, remains a significant publication shining light on the importance of environmental design principles and approaches to the lives of people living with dementia.

Although Maggie gives a great deal of credit to her mentor M.Powell Lawton and his environmental press model, developed with Lucille Nehemow, Maggie herself is a giant in the field.

While working in the Corinne Dolan Center at Heather Hill between her Masters and PhD, Maggie contributed to the field in fundamental ways by systematically testing a set of hypotheses, for example, that people living with dementia could find their toilet at night if it was visible from their bed, and that access to a garden makes residents feel more respected and valued. She studied the effects carefully with observations, behaviour tracking, and interviews. These design approaches – which today are common sense and accepted widely – began their evidence-based life with her design and research efforts.

Maggie defines Person Centred Care in compelling terms, and describes her "wow" moment, when in the midst of a design research project she realized that the predominant deficit thinking about dementia had to be replaced with strength-based thinking, if the human rights of this growing group of individuals were going to be respected and supported in society.

She champions the personhood of those living with dementia, pointing out that they, just like everyone, require privacy, orientation, engagement, and meaningful relationships to achieve well-being, quality of life, and joy. "We all need to experience joy every day", she tells us.

Jannette Spiering – serial innovator

Jannette Spiering is founder of the Hogeweyk®, the first "dementia village" located in Weesp, the Netherlands, Part of Vivium Sorggroop, and senior managing advisor of **be**, a consultancy for those interested in learning about he Hogeweyk and how to achieve their own innovative responses to dementia.

In 1993 when Spiering became part of the Hogeweyk planning team she had little health care training. Hers was training and experience in hospitality – hotel management. She calls herself a pragmatist, rather than a theorist. She feels she and the planning team had an advantage in terms of innovation – they were rather "naïve".

They asked simple questions like what makes people tick and what would a "normal life with dementia" look like.

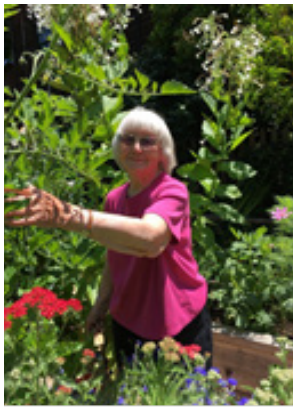
Spiering's personal and professional insights on innovations that resulted in the novel concept of De Hogeweyk – the original "Dementia Village" – are significant in the history of design for dementia. Her ideas about the next innovative leap, equally worthy of attention.

Spiering discusses the team process they employed, asserting that innovation is not an act, but rather a process. She emphasizes that having a clear shared

vision of the type of place an organization wants to achieve is critical to being able to work with architects on the design of that place. She describes how the Hogeweyk team was not afraid to say: "that doesn't work, let's try something else to use and test in practice."

Each organization must go through the process themselves – there is no way to just take over another's vision and make it your own, she asserts. Jannette believes that the next big shift will be the "emancipation" of people living with dementia: with their own home, in society, and embraced by society.

Clare Cooper-Marcus - pioneer garden guru



Clare Cooper Marcus, Professor Emerita of Architecture and Landscape Architecture, University of California at Berkeley is co-author of *Therapeutic Landscapes: An Evidence-Based Approach to Designing Healing Gardens and Restorative Outdoor Spaces* (Hoboken NJ: John Wiley and Sons, 2014) written with Naomi Sachs.

Clare is a passionate champion for the benefits of nature and is presently writing a book about the transformation of her back garden which has supported her through raising children, teaching, writing as an adult, and now in her later years.

There is ample research that being in nature has many beneficial effects for all human beings, Cooper-Marcus maintains, including: decreased agitation and aggressive behaviour, better sleep patterns, improved hormone balance, and increased production of vitamin D enhancing bone density. Nature, Cooper-Marcus continues, reduces stress hormones and improves immune function. Along with its beneficial physiological effects, nature imparts spiritual benefits.

If people are in confinement, such as in prison or a residential care setting, access to nature in the form of a garden is essential to maintain their well-being.

An example, she gives, of a wonderful garden for people living with dementia is The Living Garden at the Family Life Center, Grand Rapids, Michigan, designed by Martha Tyson of Douglas Hills Associates, Evanston, Illinois.

Clare's long-term perspective enables her to make simple observations that actually have profound implications, such as that plants go through phases of popularity – like the length of dresses and the width of neckties. Today dahlias which used to be much prized, are out of fashion. She suggests that to determine which plants and flowers might have been in fashion in the era familiar to the people dementia gardens are designed for, search through old plant catalogues

Clare offers a wealth of advice on therapeutic garden design.

Michael Murphy – international design thinker

Michael Murphy, Int FRIBA, is Founding Principal and Executive Director of MASS Design Group, an architecture and design collective that leverages buildings, as well as the design and construction process, to become catalysts for economic growth, social change, and justice. The firm's award-winning work in over a dozen countries encompasses healthcare, education, housing, and urban development. Michael's TED Talk has reached over a million views. He has taught at the Harvard Graduate School of Design, University of Michigan, and Columbia University's Graduate School of Architecture Planning and Preservation.

The biggest problem to Michael regarding housing designed for people living with dementia – as well as other housing for older people – is what he calls "The Architecture of Institutions", built manifestations of the intersection of public need (the State), and such settings as nursing homes, hospitals, and prisons. To Michael, this intersection leads to the worst un-humanized institutional architecture.

Buildings become institutions, according to Michael, because the dominant business model sees buildings as a necessary part of business strategy. When people are forced into institutions everything is lost. People who are dying get institutionalized. Communities of colour are forced into institutions, he asserts. The big problem is that in the business model, a building's shape determines the care program, rather than the care programme shaping the building.

Working in other cultures, for example in Rwanda, Michael learned important lessons that can be applied to design for dementia. One is that the designer needs to be immersed in the community. The other is that the pressures to build on an institutional scale must be resisted.

To Michael, it is essential that architecture provide its users with both fun and dignity.

If Michael designed a poster to hang on the wall about dementia design which designers, operators, developers will read daily, it would say what he learned from his colleague John Cary:

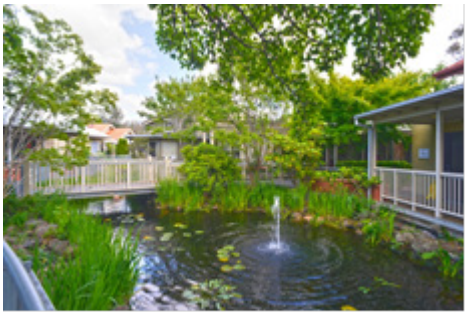
"What Health is to Medicine, Justice is to Law, Dignity is to Design."

Allen Kong – multi-cultural architect

Allen Kong is the Director of his own architectural firm in Melbourne, Australia. He has designed housing for people living with dementia for many years.

Allen's indigenous Australian, Chinese, Scottish, and English, background has influenced his conceptual framework for designing for people living with dementia, and for the practical application of his theories.

His work fits into its context in both its physical appearance and its natural context as can be seen in the fountain photo from his Gilgunya community design



Allen's building's aesthetic is quite simple – in words – it can be called "an old shoe aesthetic". He describes the way he wants his buildings to feel to its users as if they were wearing comfortable worn-in shoes, not like the shoes you wear to a wedding. "I want to create buildings you can "cuddle; and buildings that "cuddle" you" he says.

On the other hand, in material design this aesthetic is complex: It is essential to Allen's "old shoe" aesthetic, that the feel of what you want to achieve be present right at the start of a design project.

Allen's work goes beyond this aesthetic. In all his projects he takes account of the fundamental evidence basis for design decisions, including what is known about users' psychological responses to the built environment and the larger issue of environmental sustainability.

As a Feng Shui practitioner, Allen works with "energy" – Chi – managing the way spaces direct the chi of the project. He uses the materiality of bricks, wood, colours, trees, gardens to 'dress' the building and give it its feel – a feel that must be present in the mind of the architect at the beginning of the project. "To me, beauty comes in the softness / tactile materials / the window handle you just want to hold onto even if you don't want to open the window. Visually I want you to feel like you want to have a cup of tea there." "My design aesthetic", he explains, "is to bring the people in the building in line with the environment."

Allen has some specific advice for young architects getting into the arena of designing for people living with dementia.

Wilhelmina Hoffman – geriatrician, designer, innovator

Wilhelmina Hoffman, CEO and Headmaster of Sweden's Silviahemmet, Queen Silvia's Foundation, and President of the Swedish Dementia Centre is a geriatrician specializing in the care of people living with dementia.

In her role at Silviahemmet, Dr. Hoffman has been deeply involved in an exciting design and building project aimed to support people living with dementia that began in 2017 when IKEA's founder, Ingvar Kamprad, a man of the people, went to tea with Queen Silvia and asked her what she would like to do. The answer: "I would like an apartment for people (with dementia) to live together a little longer before moving to a care setting." This began the multi-year collaboration between Silviahemmet, Ikea, and the construction company Skanska.

The goal is to provide a high quality of life to people living with dementia and their families, by providing purpose designed buildings with apartments, that would support all elders, including those with disabilities but especially those with cognitive challenges.

An apartment in one house acts as a showroom to demonstrate the many innovations – a place to disseminate knowledge and inspire others locally and internationally.

Over 100 innovations are built into the apartments. According to Dr. Hoffman It is important, that the innovations are physical so you can see and touch them – not conceptual and abstract.

Alan Dilani – salutogenic champion

Dr. Alan Dilani, is Professor of Architecture/Public Health, and Founder of the International Academy for Design & Health

Dr. Dilani's design approach reflects Aaron Antonovsky's Salutogenic theory, which posits that life's experiences – understood as more or less comprehensible, manageable and meaningful – shape one's sense of coherence which in turn helps each person successfully mobilize resources to cope with life's stressors and manage life's tension – leading to health.

Dilani asserts that this definition of health and the "theory of health" that underlies it, lead to a coherent design method and approach. He describes how design *un*informed by salutogenic theory causes unnecessary stress, while emphasizing the importance of a stress-prevention design approach for dementia.

His Salutogenic Design Theory is an ecological, health promoting design method for dementia. He presents not only theory but practice examples that demonstrate the significant role that natural building materials and nature play in salutogenic design, as well as the psychological impact of views and choice and personal growth.

Dilani brings to the conversation on dementia design his experience of founding a multi-disciplinary international sharing and learning organization. He has brought together scientists, policy makers, industry experts as well as designers and building owners from across the globe to discuss principles and application of ecological and salutogenic design approaches in support of sustainable development in a healthy post corona society. By combining a theoretical understanding of ecological and salutogenic design with practical case studies of its successful application in healthcare, education, workplace, and urban settings, he is moving this important, health promoting approach forward.

Peter Phippen – groundbreaking architect, influencer

The Author of *Design for Dementia*, together with Mary Marshall and Steven Judd, a late 1990's volume of descriptive and numerical data on designs for dementia around the world.

Peter reflects on the major lessons he learned during his extensive research into designing for people living with dementia. The big three, for him, are that dwellings should be small scale and comprehensible to all residents, sited close to urban centres so that there are amenities residents can enjoy and have culturally appropriate home-like designs from the organization of spaces down to the shape of the taps on the sink.

He says, hominess is the key to designing for dementia, which is easy to say but quite complex to achieve. Not least because hominess varies with cultural context. One cultural difference he points out is in the acoustic environment of home. In the UK, homes are full of sound-absorbing carpets, wall coverings, and window dressings, so the expectation of UK residents with dementia is that "home" is quiet. In France and other Mediterranean cultures accustomed to hard surface floors and windows, home can include more and louder sounds.

Another key is what Peter calls the environment's "legibility" – seeing everything that you need and want so that you can read the environment easily. His conversation touches on what used to be called "wandering paths" that just encourage people living with dementia to keep walking in circles. He prefers destinations at the end of hallways that enable those living there to know where they are going – to walk purposefully rather than wander aimlessly.

Peter has advice for younger architects and designers getting into the field of design for dementia, spend time with those who might live in what you design – not necessarily the precise people but those whose needs and wants you need to take into account. Speaking with, observing, and getting to know your potential users is critical to designing to meet their needs and desires.

When asked to put his message in a single poster that he hopes everyone in the dementia design industry would read every day, he offered:

"The more like home it is, the happier people will be."

National plans

At this stage the available knowledge is not being applied in the great majority of countries planning to improve the care of people living with dementia. There is a strong case to have it included in National Dementia Plans.

Dementia-related design in the national dementia plans

Jan Golembiewski PhD, Director of Psychological Design, Australia and Associate Professor of Interior Architecture and Environmental Design, Bilkent University, Turkey.

Corresponding author Jan Golembiewski greenmanunk@gmail.com

The effort to create national dementia plans has been part of an international commitment to improve the lives of people with dementia as well as those of their carers and families. These plans set a national vision for the future and a strategic framework to reduce the burden of dementia [1]. The national dementia plans are based on situational evidence and are geared toward the priorities established by the key stakeholders of the countries they are written [1]. They represent an insight into the operational imperatives, the national challenges and the approaches that are considered to be of key importance by those with the administrative responsibility to care for people with dementia. As such, these documents provide valuable insight into the relative importance of dementia-related design (DRD) in the minds of the policy makers and planners when set against all other imperatives. However, this isn't to suggest that DRD is often a main theme of a plan: the

> national plan may focus on any aspect of dementia – typically, the legal framework for the care of people with dementia or the financial responsibility for the care, in practice they rarely focus on the granular details of their individual living situations, such as the design of accommodation or support facilities.

To gain an understanding of the position of DRD in the national dementia plans the ADI website was used to access them. It attempts to provide links to 25 national-level dementia plans and national action strategies, as well as several subnational (provincial) plans and some non-governmental strategies. In some cases, such as Japan, Macau, Chinese Taipei and Wales, the links to the plans did not provide specific access to them. Where they existed, the national plans were accessed, and where they didn't exist, the subnational (provincial) plans were accessed in their place when they were available. (6 of them). Subnational plans were not accessed where national ones existed (such as in Switzerland, USA and Australia), and non-governmental resources were also ignored. In total, 31 plans were reviewed. Of these, 15 were in English. Translations were obtained for 5 using official translators or native speakers with a knowledge of dementia-related topics. The remaining 11 were translated using Google Translate or an equivalent.

The national plans were analysed by the author, an architect and academic who specialises in applying the salutogenic approach of Antonovsky (2, 3) to the design of buildings used for the care of people with mental health problems and dementia. In the first instance the analysis focussed simply on the prominence of DRD in the national plan; whether it was mentioned at all, supported, recommended or considered to be essential.

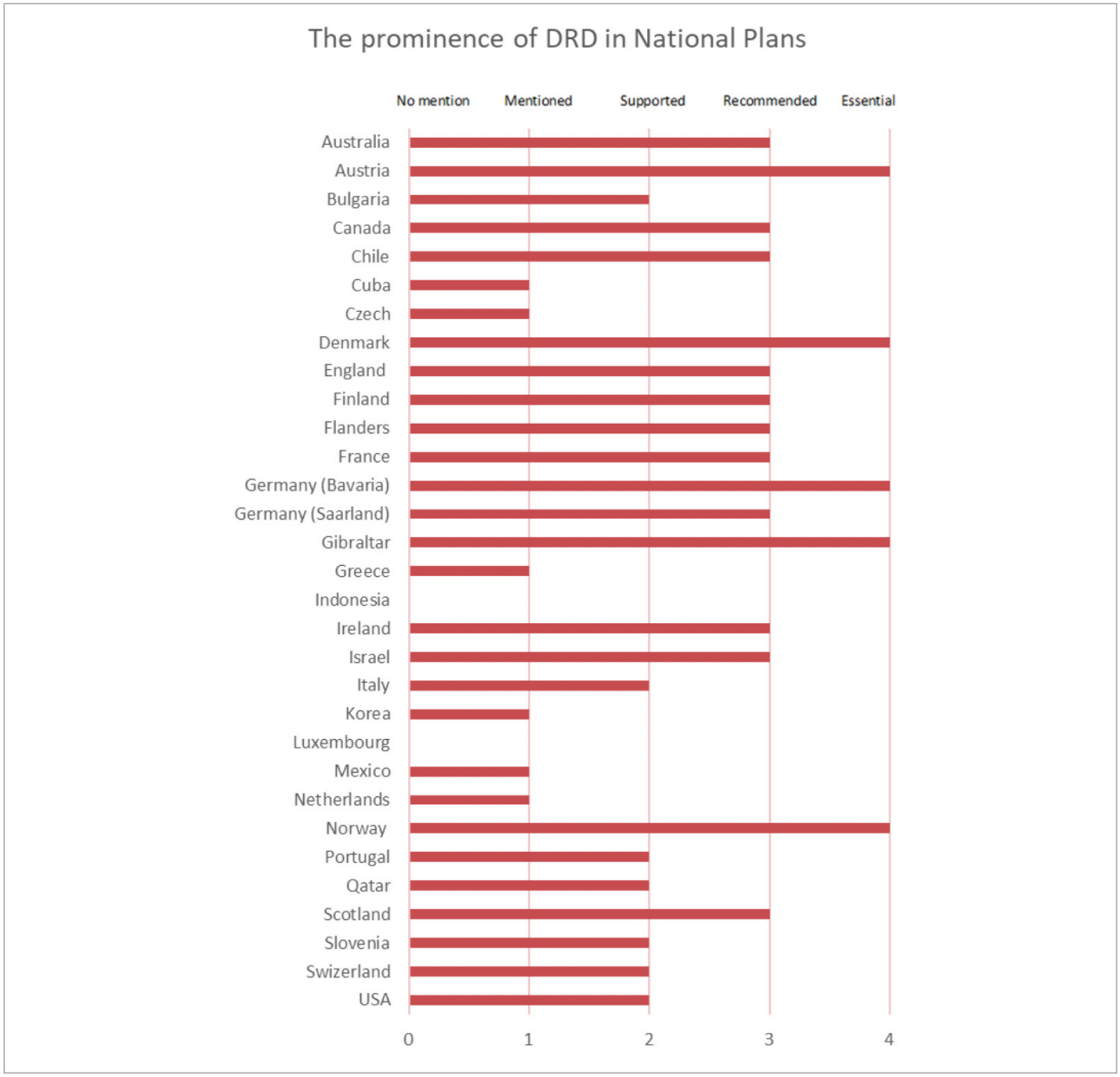


Figure 1. The prominence of DRD in national dementia plans

The analysis revealed that national dementia plans are broad and diverse documents that rarely focus on the physical context of people living with dementia.

Sometimes, as in Qatar's case, the authorities are passionate about DRD,[i] yet the detail in their plan is very light. On the other hand, in other cases (such as in Cuba's plan), it appears that the lack of focus on the physical environment reflect a lack of knowledge about the benefits of DRD. However, the fact that most national plans don't speak directly to the design of the built environment may have little to do with the level of interest or knowledge but simply reflect the fact that, in most cases, national authorities have no direct jurisdiction over physical infrastructure (this is commonly the responsibility of lower-levels of

i The author worked with Hamad Medical Corporation (HMC), the principle public healthcare provider in Qatar to design a national dementia facility between 2014–16. HMC also compiled the national dementia plan.

government such as those of individual states, local areas, even individual service suppliers, and of course individuals themselves in their own homes).

In their plans, nations seek to create value in whatever way they feel is appropriate for their circumstances.

Sometimes ignoring DRD is explicit, coming with apologies for areas outside of the current national priorities. Even so, as Figure 1 illustrates, there is a general interest in, if not a specific focus on, DRD in the plans.

Some countries, such as Bulgaria, Indonesia and Luxembourg make little or no mention of the built environment for dementia at all. These countries appear to be focussed on developing a basic framework for dealing with dementia – on finding budgets, streamlining diagnoses and medical treatments, identifying key responsibilities or legal frameworks, etc.

In some cases, the frameworks put forward are thorough and appear to provide support for downstream DRD implementation but the plans themselves are too high-level to directly engage with approaches to the design of facilities. The Indonesian plan for instance, attempts to ensure that enough insurance policies will include payments for dementia care and other such measures, and leaves open the possibility of supporting DRD as part of a loose objective to '5: to develop long-term accommodation for people with dementia' [4]. Similarly, Switzerland's plan is focused on prevention – marshalling anti-smoking and other cardio-vascular health campaigns and various pharmacological and non-pharmacological approaches that excluded DRD.

Other countries including Cuba, Greece, Israel, Korea, Mexico and Portugal mention how facilities, urban plans or other typologies can be an impediment to services and should be adapted or designed for dementia, but otherwise consider these matters to be lower-order issues, to be considered by municipalities, private enterprises or other areas of government.

Sometimes the plans state that the current standards are very low, thereby implying an interest in better models of design.

Korea's plan, for instance sets out a vision for reduced use of physical restraints and seclusion. Switzerland's plan acknowledges how institutional architecture will need to adapt to the needs of people with dementia – to become more need oriented, but neither of these national plans give guidance about how or where this should occur. Saarland (a province of Germany) also acknowledges how the environment can make matters worse by triggering 'so called challenging behaviours, restlessness, aggressiveness and hallucinations.' [5]

Australia, Czech Republic, England, France, Italy and Scotland give DRD more prominence, with an understanding that the built environment plays a role in the improvement of care for people with dementia, often suggesting it plays a role in the reduction of stigma and in helping reduce the problem of dementia in the first place. Most of these plans include ideas and objectives for the creation of specialised accommodation for people living with dementia, but whether it is envisaged that this accommodation will be in buildings specifically designed to meet the needs of people living with dementia is left unstated.

Canada, Finland, Flanders and to a lesser extent, the USA all approach the subject of design for dementia by openly seeking better health promotion in all spheres of human life, and by inviting research organisations, universities, other institutes of higher education and businesses to produce information on best practices to use as a basis for developing services that will deliver excellence.

Ireland goes a step further by clearly acknowledging the impact of design – suggesting that all design efforts should be tailored to be person-centred, flexible and responsive to maximise the overall quality and integration of the typology, and that care should always be given in the most appropriate of settings. A particular focus is given to the urban scale, which should be transformed into better places to live for people with dementia but also on other scales – although it doesn't direct readers in how they might do this.

Austria, Bavaria, Denmark, Gibraltar and Norway all see DRD as pivotal to their approach to minimise the impact of dementia, recognising DRD as a key tool for reducing symptomatology, helping people with dementia cope, manage and therefore remain integrated, meaningful and purposeful in society.

These national dementia plans all link DRD to better outcomes and poor design with worse ones. Where Austria and Gibraltar are making an effort to design for dementia now and promise guidelines in the future, Bavaria, Denmark and Norway flesh the DRD objectives out with examples and guidelines in the national plan itself, with a few key themes: that homes should be small, manageable, recognizable; homes must be richly decorated with well-considered lighting, sound design and other aesthetic factors; that homes should be customisable to reflect a person's individuality and individual needs; that there are good opportunities to get outdoors and in contact with daylight and the natural environment (6, 7).

Perhaps the most developed approach to DRD is in the Norwegian plan, which asserts that environments must not only compensate for functional decline but build on a person's own resources and strengths. The Norwegian National Dementia Plan describes environments that do these things in a way that is enjoyable for both the person with dementia and also for their carers – one model they describe is 'Green Care Farms,' which are traditional farms that open up to the community members with dementia. In these facilities, people with dementia come to chop wood, work in the kitchens, gardens or orchards, eat together and go for walks while their regular carers take some respite. The Norway plan also proclaims the benefits of small homes, which are easier to manage and negotiate [7].

Only the Danish and Norwegian plans offered resources to guide DRD for example. Norway mentions the following texts: Dalsbø, Kirkehei [8], Gonzalez and Marit [9], Haugan, Woods [10], Landmark, Kirkehei [11], Strandli [12], Taranrød [13] and promise that by 2020 further tools will have been developed for involving people in the design of their physical, social, cultural and spiritual spaces and activities. The Danish plan directs readers to the Statens Byggeforskningsinstitut at Aalborg University for further guidance – and to Sigbrand, Bredmose [14] in particular. The other national plans don't provide specific guidance.

Of all the national dementia plans that fully recognise DRD, only Bavaria's and Norway's give specific approaches. The Norway Plan points to:

- A salutogenic approach. Although it isn't mentioned by name (or in the reference list), all the basic principles of salutogenesis are promoted. The idea of salutogenesis is that efforts to improve health don't have to focus on the specificity of disease, but on coping and even thriving. Salutogenesis divides supportive factors into the physical domain 'manageability;' the intellectual domain, 'comprehensibility;' and the emotional domain; meaningfulness. The need to promote all of these to improve peoples' ability to cope is a central thrust of the Norwegian National Dementia Plan
- Milieu Therapy
- Green Care: Dementia Farms where people can work in the kitchen, the orchard, chop wood, cook meals and eat together [15]
- The Small is Beautiful housing movement (Landmark et al. 2009; Gonzalez & Kirkevold 2014, Haugen 2015)

The Bavarian plan implicitly references the principles pioneered by Zeisel, Hyde [16] such as good access to outdoors with enhanced wayfinding, circular pathways in dementia gardens and familiar objects to trigger memories and improve a sense of place.

Because DRD must always be understood within context, and because it isn't always mentioned explicitly in the plans, the attention given to related concerns, all of which have DRD implications, was also assessed.

The analysis revealed various levels of interest in promoting the interests of people with dementia in home-based-care, day-care, respite-care, hospital-care, public buildings, urban settings, rural settings, residential homes, green spaces and palliative care settings.

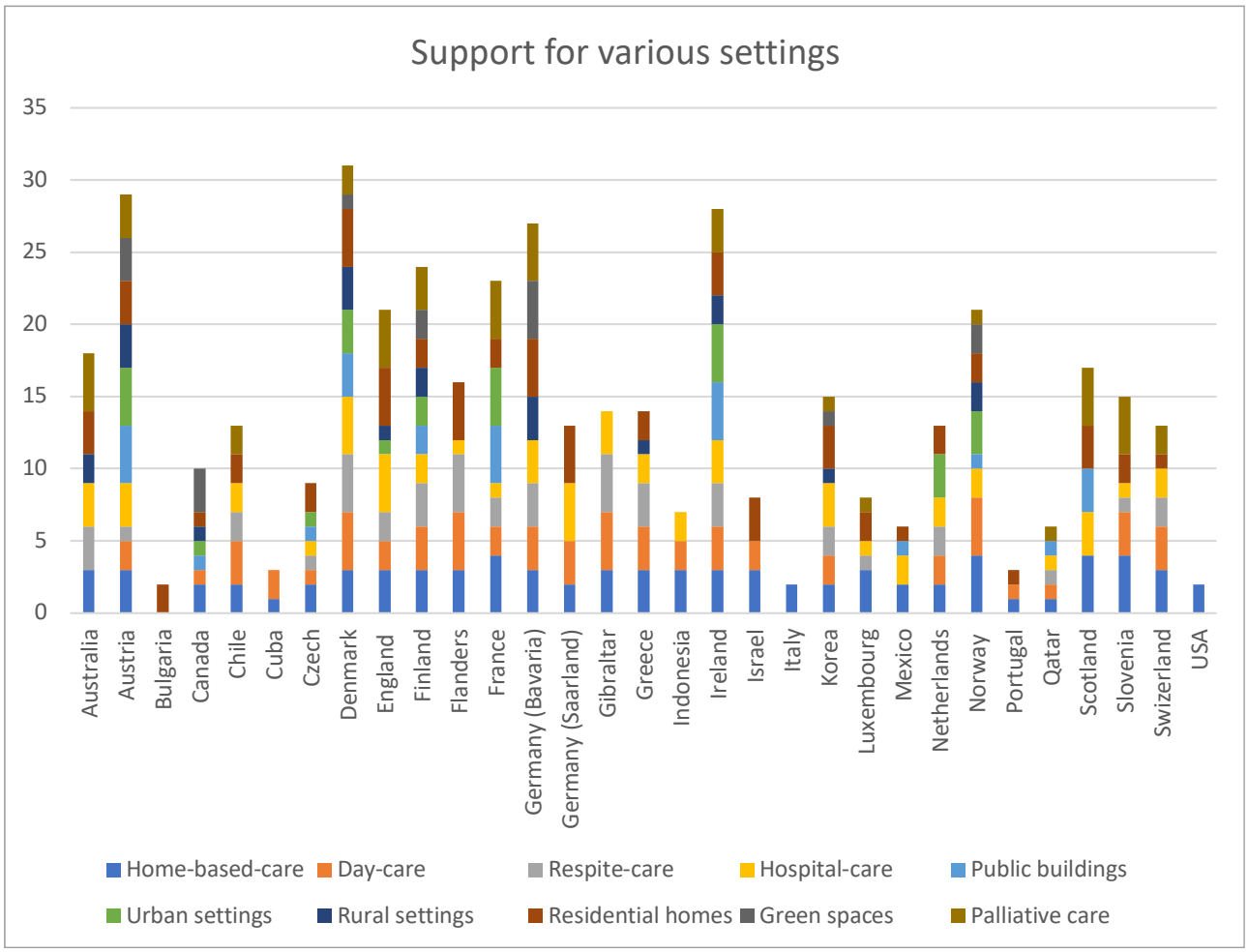


Chart 1: Plan support for various settings

All of these settings lend themselves to improvement through consideration of designing for people living with dementia. The chart summarises how important these settings are to the overall plans, and in as much as DRD is thought to be important, we assume that it is intended for these settings.

Of all the dementia-related typologies, the broadest interest is in promoting home-based care, a topic that is mentioned in almost all national dementia plans – and in many cases it's a top priority.

The exemplary precedents set by the few plans that already focus on the value of DRD, when combined with the argument forwarded by this publication present a compelling case for including DRD in the development of plans going forward.

The development of national dementia plans is already a priority for the World Health Organisation, but currently only 29 out of the 194 WHO Member States have them, and of these. This is a fraction of the WHO target of 75% coverage (i.e. 146 national dementia plans) by 2025. But there is still time and thus an opportunity to include design for people living with dementia in the new generation of plans and the reiteration of existing ones.

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Inclusive design

As designing for people living with dementia gains momentum it must incorporate the growing commitment to the human rights of people living with dementia and include them as full participants in the design process.

Human Rights, design and dementia: moving towards an inclusive approach

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Introduction

Human Rights apply to every human being whatever condition they face and context they live in, and there is no exception for people living with disabilities. Such rights also apply to people with cognitive disabilities, such as dementia, living at home and/or in institutional facilities. However, Steele and colleagues [3] point out that there is a common belief that people with dementia should be confined in secured care units for their own sake and safety. These authors argue that the conditions of people with dementia living in such care facilities are closer to segregation than is admitted by Human Rights. Goffman [4] also stresses that institutional settings often restrict the freedoms of residents and tend to become totalitarian. To illustrate this assertion Steele and colleagues [3] "focus on the rights to non-discrimination (Article 5), liberty and security of the person (Article 14), equality before the law (Article 12), accessibility (Article 9), and independent living and community inclusion (Article 19)" (p.1). These rights apply to care agendas and practices as well as care settings themselves.

Although some institutional settings are restrictive, others contribute to promote care practices respectful of rights of people that are taken care of [5]. There are several approaches to designing environments for people with dementia and all of them, without exception, refer to humanist approaches and target quality of life of people with dementia [5]. In addition, they support the view that design of settings should embrace the characteristics of the person – neurological, psychological, cognitive, behavioral, social and cultural – and directly compensate for them through architectural planning.

How design compensates physical disabilities seems obvious (i.e. ramps for wheelchairs, handrails, levelled furniture) but it is not so evident for psycho-social disabilities

> Like all disability, dementia needs to be addressed from a holistic perspective.

People living with dementia are also concerned with ageing problems, sometimes involving physical and sensory disabilities as well as altered cognitive functioning that can be worsened by neurological damage caused by dementia. Consequently, architectural design can address these problems using concrete physical solutions like signage, contrasts, walking paths, lighting, length of corridors, spatial and temporal orientation, sensory cues, etc. Cognitive and psycho-social outcomes of dementia, on the other hand, jeopardise independent living and affect inner life, social health and rights [3, 6, 7] which interrogates social, philosophical, semantic, and symbolic characteristics of environmental design whether institutional or not.

DESIGN FOR PEOPLE WITH DEMENTIA

Design approaches for people with dementia have taken multiple paths. Environmental design is considered as part of non-pharmacological treatments for people with dementia [7]. With a dominant medical model, environmental models mainly focused on how design could alleviate dementia symptoms. Major advances were made in this field bringing proof that *therapeutic design* reduced dementia symptoms such as wandering, agitation, aggressive behaviours, or psychotic symptoms [9]. Approximatively at the same time, *dementia friendly design* gained its stripes with person centred care [6]. Dementia friendly design reduces environmental stressors by ergonomically fit design principles based on scientific knowledge of how aging and dementia alters

senses, cognition and physical abilities [10, 11]. Dementia friendly design raises awareness of the potentially malignant impact of environment to promote disabilities and contributes by integrating dementia within the social model of disability, thus targeting competences rather than deficiencies. From that point, research in architecture and design started focusing on *enabling environments* which related to affordances, and how use of space activated behavioural and social schemes and promoted independent living [5, 12]. Researchers, architects, clinicians and policy makers sought to understand how environment and care that people with dementia benefit from enables them to exercise their rights and their aspirations.

FITTING DESIGN CONCEPTS WITH HUMAN RIGHTS

In 2010 and 2011, an international group of experts agreed that "the physical environment has little purpose outside of a value system" and that Human Rights are "a starting point for a discussion of the purpose of designing environments for people with dementia that is not linked to a disease model and aims to be of value to people from many cultures"[13](p.7). The 1948 Universal Declaration of Human Rights demonstrate that all design principles whether for people with dementia or any other group of people share the goal of promoting: Dignity; Liberty; Security; Privacy; Freedom of movement; Access to own property; Access to participation in cultural life of the community; and Standard of living adequate for health and well-being [5].

The PANEL human rights-based approach conceptualized by the World Health Organisation [14] addresses specific design principles for people with dementia. The approach "provides a framework with important elements … to promote the respect for the rights of people living with dementia". The PANEL acronym designates: Participation, Accountability, Non-discrimination and equality, Empowerment, and Legality. Accordingly, design of care settings for people with dementia should:

- facilitate participation of people with dementia in decisions concerning their own life and access to community services and facilities
- encourage and enable people with dementia to exercise their rights and freedoms in all aspects of their daily lives
- contribute to be free from discrimination and raise awareness of the condition of dementia
- empower the person to claim their rights and to preserve their autonomy and independent living by creating dementia-friendly environments
- refer to human rights standards to conceive environments targeted for people with dementia

According to the PANEL approach, design should promote independent living of people with dementia within a frame respectful of rights. These dimensions have been partly implemented and experimented by each of the design approaches cited above, by encouraging residential design, by promoting autonomy, by addressing Human Rights principles (respect, dignity, choice and freedom), by designing legible environments, or by enhancing control over one's life.

Nonetheless, the creation of dementia specific environments can be argued is stigmatising in essence, and so

> the next step of architectural design must rely on inclusive principles, for which people feel valued, differences are respected and accepted, and basic needs are met to support dignity.

SOCIAL AND SPATIAL INCLUSION

Social inclusion is a widely used concept to raise awareness about rights of people with particular social, physical or psychological conditions. It has mainly been studied and implemented according to concerns about integration of migrants in western societies. The European Commission defines social inclusion as a process and an outcome "which ensures that those at risk of poverty and social exclusion gain the opportunities and resources necessary to participate fully in economic, social and cultural life, and to enjoy a standard of living and well-being that is considered normal in the society in which they live. It ensures that they have greater participation in decision-making, which affects their lives and access to fundamental rights (as defined in the Charter of Fundamental Rights of the European Union)"[15] (p.8). Moreover, UNESCO emphasises that "Public spaces can play a key role in improving … inclusion by acting as places for … dialogue and exchange ", suggesting that architectural and urban planning are also responsible for promoting social inclusion. Thus, *spatial inclusion* implies that "segregated areas can be opened up thanks to careful

physical planning interventions … adequate housing, well-connected public transport and accessible public buildings for cultural and religious needs".[i]

In addition, a person-centred approach seems particularly indicated to promote social inclusion through space since users are beneficiaries of design as well as agents who can improve their own lives. Moreover, citizenship and personhood are an ethical imperative in caring for people with dementia [16]. According to the Raoul Wallenberg Institute inclusive societies should empower members "who have been subjected to discrimination and whose rights have been violated as a result of social and political processes that disregard the right to participation"[ii]

INCLUSIVE DESIGN AND EMPOWERMENT

Recent academic and scientific literature converges towards the need for inclusive properties of space and design processes for people with dementia [17, 18].

> Inclusive design goes beyond giving opportunities to people with dementia. It encourages proactive behaviours and empowers people to take decisions concerning their own life, to take control over their environment and to live independently.

While salutogenic architecture mainly focused on health issues and how to support healthy behaviours, inclusive design takes its roots from spontaneously expressed needs in order to respond to user requirements promoting social and spatial inclusion.

Empowering people with dementia by promoting capabilities necessitates unconditional acceptance and accreditation of their condition and involving a diversity of physical, psychological, social and sensory abilities. In practice, inclusive design is based on the premise that one can live well with a disabling chronic illness or disability and that it can provide an opportunity to adapt the environment to one's own abilities and to develop new skills. Inclusive design is different from universal design and accessibility design because it is not built according to disabilities in order to compensate for them, but on abilities, know-how and interpersonal aptitudes in order to develop new skills. Such skills rely on person-environment interrelations as well as experience of space, and lead to development of solutions that will be used in daily life to establish equitable living conditions. For people with dementia, this may involve, for example, paying close attention to the layout and structure of space so that it is legible and serves its intended purpose.

Inclusive design entirely relies on groups of individuals and on each of the individuals. It is initiated by their motivation to build society according to their abilities, aspirations and needs in a perspective of empowerment and independence. Beyond simple participation of people with dementia, this approach is based on the principle that projects, whether societal, architectural or urban, are initiated by people directly affected by them, in order to meet the needs they have identified and to enable them to express others. Needs can relate to accessible physical or cognitive design changes as well as raising awareness about a condition.

Inclusive design thus contributes to preserve self and reduce stigma by normalising the environment as much as possible and by promoting capabilities of its users. It focuses on social and societal issues enabling people to exercise rights and live amongst and like others in a non-discriminative way. Physical, intellectual, psychological and sensory accessibility of the environment are also key issues of inclusive design. Spatial inclusion supports peculiarities of users of an environment to promote equitable access to places, services and people. Beyond the dimensions of the PANEL approach, implementation of inclusive design for people with dementia must contribute to social health by enabling them to: fulfil their obligations and exercise their rights; manage their daily lives with a degree of independence; and promote participation in social activities and community [7].

EXPANDING BOUNDARIES OF INCLUSIVE DESIGN

Ageing in place is not only about housing. It also applies to neighbourhood and areas surrounding the person's habitat. As suggested earlier, accessibility of places, services and people play an important role for social and spatial inclusion, as well as for freedom and choice. Thus, urbanistic and landscape design are also essential properties of an inclusive society for reducing segregation of people with dementia within a given environment.

i http://www.unesco.org/new/en/social-and-human-sciences/themes/urban-development/migrants-inclusion-in-cities/good-practices/inclusion-through-access-to-public-space/

ii https://rwi.lu.se/what-we-do/focus-areas/inclusive-societies/

Urbanism, for example, will provide recommendations regarding public transports, accessible environments, services that are required in each place, or environmental cues that will ease orientation for people with dementia. For instance, although it may seem trivial, identifiable toilet facilities, "you are here" maps and receptionists can reveal essential information to give the opportunity to people with dementia to participate in public spaces. On similar grounds landscapes, gardens and parks also enhance the quality of life of people with dementia. Restoring effects of nature are well known and have proven to be effective to some degree for people with dementia [19–21]. It is inconceivable nowadays to consider architecture without referring to outdoor spaces and landscape design. The presence of outdoor spaces encourages people to get out and recalls the existence of environments outside of home. People with dementia must feel secure, attracted and interested enough to want to access outdoor environments. Outdoor environments and spaces can be public or private. They provide opportunities for social relationships and to connect with nature and the outside world.

CHALLENGES OF INCLUSIVE DESIGN FOR PEOPLE WITH DEMENTIA

An inclusive approach of design for people with dementia constitutes a real challenge and requires person-environment transactions to take place efficiently.

> Inclusive design cannot fully be implemented unless society changes the way it views dementia and people with dementia.

Conversely, it will contribute to the way we approach dementia and people with dementia. Social and spatial inclusion produced by inclusive design of places, settings and facilities that are used by people with dementia will also contribute to reduce in situ and tacit segregation. However, although such an approach is certainly beneficial in terms of quality of life, social health and mental health, inclusive is not without risk for people with dementia (i.e. getting lost, falling, and feeling distressed or confused) and should be implemented to carefully expose and balance benefits and risks with the people concerned. Nonetheless, inclusive design for people with dementia appears to be an exciting perspective regarding human rights that would certainly move person-centred care a step forward towards supporting empowerment of people with dementia.

Disability rights, enabling design and dementia

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Accepting that dementia is a major cause of disability and dependence in older persons worldwide [22] is essential and is a critical reason why it is so important that the built environment for people with dementia is accessible, in the same way we provide wheelchair access. With the rise of a disability rights movement for disabilities caused by any type of dementia, predominantly being led by people with dementia globally [23–26] we have come to understand the problem is not with the person with dementia, but about the environment being made accessible. This of course, includes the physical and built environments.

The environment's influence in creating disability or in increasing it has been well established and is seen as integral to the definition of disability [27]. Disability arises out of the interaction between a person with a health condition, and the environment in which they live and work. A health condition causing disability can include a stroke or a diagnosis of dementia, a long-term health condition such as mental illness, or through losing a limb or another physical function due to an accident. If the environment changes, then the experience of someone living with a disability will also change.

Rights is an important next step in the discussion of the built environment for people with dementia. The United Nations Universal Declaration of Human Rights is a milestone document in the history of human rights, although to date, even though people with dementia still retain the same rights as anyone else in society, including human rights and disability rights, there has been little change in the realisation of these rights. For example, the Australian Aged care and Disability Royal Commissions, and now COVID-19 have highlighted just how often abuse, neglect and the violations of rights is occurring. This has placed dementia and aged care into the spotlight more than ever before.

The Convention on the Rights of Persons with Disabilities (CRPD)[43] is particularly relevant to persons with dementia because it defines persons with disabilities as including 'those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.' There can be little doubt that persons with dementia are addressed by this definition and are hence intended beneficiaries of the Convention.

> A human rights-based approach is about making people aware of their rights, whilst increasing the accountability of individuals and institutions who are responsible for respecting, protecting and fulfilling rights.

This Charter also reflects the standards already set by the United Nations Universal Declaration of Human Rights and other international instruments. The CRPD adopts a social model of disability but does not offer a specific definition. Its preamble explains that the Convention recognises:

"*...disability is an evolving concept and that disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,*"

In Handicap Law [29] Stone states that in America, in spite of an obvious need to provide access for persons with disabilities, their rights were not recognized by the law courts until the 1970's. Jackson [30] says that even in the 21st century with the advent of the CRPD, the existing built environments fail the 'neighbourhood accessibility' of people with disabilities. Jackson was

not talking about people with disabilities caused by dementia, which therefore makes it likely community access for this cohort is non-existent.

The paradigm change introduced many decades ago by the disability rights movement has made modifying the built environment for accessibility commonplace and, in most countries, legislated. We are all so familiar with accommodations for physical disabilities that it is rarely an issue, as accessible bathrooms, guide-dogs, assistive listening systems, or wheelchair ramps are available almost everywhere.

People with physical disabilities have made major progress as substantial, influential members of society. Yet people with dementia are still being left behind, not only in terms of health and social care, but in terms of recognition of dementia as a condition causing disability

and therefore of legislated disability support, and of enabling and accessible communities. What this means is that people with cognitive disabilities caused by dementia are still being denied the most basic access to live independently in their communities.

Aside from access through dementia-enabling built environments, people with dementia have a right to communication and other cognitive disability access, none of which are provided through a dementia friendly initiatives (DFIs) or a Sunflower lanyard scheme. The Sunflower lanyard [31] is a hidden disability sunflower on a lanyard specifically meant to 'discreetly indicate to people around the wearer including staff, colleagues and health professionals that they need additional support, help or a little more time' [32]. People with invisible disabilities caused by dementia will not necessarily benefit from more time, if their communities are not accessible and enabling. And whilst the DFI's may help raise awareness, and provide significant funding for organisations, they don't tackle the real issue of equitable inclusion for people with dementia through dementia enabling and accessible communities. Equal inclusion means disability access for everyone, including people with cognitive disabilities. The Sunflower lanyard scheme, like the DFI's, may indirectly do harm through further stigmatising and labelling of people with disability.

What this means is that programmes such as the SCOPE Communication Access [33], just one type of cognitive ramping, alongside Community Based Rehabilitation (CBR) programmes need to be embedded, alongside improving built environments. People with dementia need cognitive ramps, in the same way people in wheelchairs are afforded wheelchair ramps. Through improving the built environments with dementia enabling strategies, we are more likely to provide substantial and improved opportunities for people with dementia to be supported to live independently in their homes and in their communities.

Segregation and integration of people with dementia in long-term care environments – critical reflection on living concepts and possibilities of social inclusion

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Introduction

As nurse researchers in the field of dementia-specific health care research, we are often concerned with questions regarding living concepts for residents with dementia in long-term care environments. Living concepts encompass several different approaches such as "Green Care Farms [34]", "CADE units [35]" or "Dementia Special Care Units [36]". These concepts can be divided into integrative and segregative approaches, which means that people with dementia either live together with people with or without dementia. However, in order to provide a suitable living concept for persons with dementia, it is essential to critically reflect on what integration and segregation in the context of long-term care environments actually implies. It is also important to understand the benefits of both living concepts and how they promote the inclusion of people with dementia in society.

THE ROLE OF LONG-TERM CARE ENVIRONMENTS IN DEMENTIA CARE

Most people with dementia wish to be cared for at home until they pass away [37]. However, particularly when dementia-specific symptoms become severe and the associated need for support in daily living is increasing, this often leads to the demand for nursing home care. Although alternative care environments to the traditional nursing home have been developed, in many countries worldwide the traditional nursing home is still the predominant place for professional care when services at home are no longer sufficient.

Based on the assumption that the majority of residents in nursing homes show symptoms of a dementia, one has to decide if residents with and without cognitive impairments should live together and share common areas such as living and dining rooms or if they should be separated. This decision has many implications – for the nursing home provider, the staff and of course for the residents and their relatives.

WHAT DO "INTEGRATION", "SEGREGATION" AND "SOCIAL INCLUSION" MEAN?

Before introducing the concepts, it is important to briefly describe how we define the terms integration, segregation and social inclusion. The social debate on integration and segregation is mainly based on sociology. So we will focus on the sociological definition of those terms.

"Integration" can be defined as "the merging of individuals and groups into a more or less homogeneous community [38]". In the context of long-term care environments, this relates to the fact that residents with and without dementia live in a nursing home or living unit regardless of their conditions and the symptoms associated with them. Accordingly, they interact in everyday living, take part in group activities and have meals together. In this way they form a social group.

"Segregation" can be defined with the term separation [3] – meaning the physical and/or social separation of people with certain characteristics of a particular social group. In the context of long-term care environments

this is defined as certain residents with dementia living in a group apart from other residents without dementia-related symptoms by means of a segregated living concept.

"Inclusion" pursues the aim of treating heterogeneous groups individually. An inclusive group is characterized by its diversity in terms of different characteristics e.g. gender, functional or cognitive abilities. An inclusive group consists of various majorities and minorities. Each member of the group is treated individually according to his or her abilities [39]. "Social inclusion" can be seen from two points of view. On the one hand it can be an approach that looks at the rights of people as members of a society. On the other hand the approach defines itself as an "opportunity to participate in key functions or activities of the society"[40]. In this context, social inclusion can be seen as a prerequisite for successful dementia-specific long-term care. Social contact can help people to use their remaining abilities, for example, by having conversations with housemates, meeting around the nursing home or participating in familiar activities with family or friends outside the facility. Furthermore, social interaction is crucial in order to be and remain a part of society [41]. For this reason, like some researchers in this field (e.g. O´Donnell et al., 2018 [42]),

we see social inclusion as an outcome that needs to be achieved especially through, or despite, the character of long-term care environments.

When talking about social inclusion and people with dementia in long-term care environments, the main focus is on what barriers exist to experiencing participation and what actions need to be taken to create an environment in which they can once again be members of society.

RELEVANCE TO SUPPORT SOCIAL INCLUSION IN LONG-TERM CARE ENVIRONMENTS

The effort to maintain or re-establish the social inclusion of people with dementia is not only based on sociological theories, but also on social policies. People with dementia, like other people with disabilities, need particular support in achieving this inclusion.

On an international level this is determined by the United Convention on the Rights of Persons with Disabilities (CRPD). Concerning the issues at stake in different living concepts in long-term care environments, we can refer to the articles 'non-discrimination' (Article 5), 'accessibility' (Article 9) and 'independent living and community inclusion' (Article 19)[43]. However, when implementing these policies, it must be taken into account that the degree of social inclusion can vary according to the wishes and also the disease-specific situation of a particular resident. The main aim is to integrate residents with dementia into society, i.e. the community of the neighbourhood or town or to support them so that they can continue to be a part of this group. At a lower level, and where a resident's dementia may already have progressed significantly, this overall goal can no longer be achieved. In this case, the actions for social inclusion of a person are those aimed at ensuring that he or she remains part of a smaller group. For example, a woman with mild dementia may wish to continue to play her role in the church community even after moving to a nursing home, while a man with severe dementia may have positive emotions during the common singing group in the living unit, but may be overwhelmed by large crowds and the noises outside the nursing home and feel uncomfortable.

Maybe you can already guess that residents in integrative living units have different possibilities to achieve social inclusion independently than those in segregative ones. But it can be supported in both living concepts, even if the efforts are different. For example, a well-designed physical environment can help to create social interactions between residents or people inside and outside the nursing home. The design can facilitate inclusion when there is enough private space and a sufficient level of access to communal space for people living with dementia and others [44]. Challenges can arise when additional environmental safety features prevent a person from being included into a larger social group in the nursing home or the community. Mainly these features are intended to protect residents from the dangers they may face outside and aim to reduce the risk of falling outside or wandering off [3]. To overcome these features and to interact with other people outside the living environment residents need staff to accompany them when they go outside. They therefore need personal assistance to achieve any degree of social inclusion.

PRACTICE OF INTEGRATIVE AND SEGREGATIVE LIVING CONCEPTS

How integrative and segregative living concepts are implemented and organized in practice varies widely. Figure 1 gives a brief insight into their implementation

in long-term care environments and illustrates how distinctive this integration or segregation of people with and without dementia can be.

For instance, entire nursing homes can be segregative and only admit residents with dementia or certain dementia-specific symptoms. They thus offer highly specialised care for people with dementia throughout the entire nursing home. As another option, nursing homes may have one or more segregated care units, where residents with certain symptoms of dementia are cared for, but where other residents with and without dementia also live in the building. It should be noted that segregative long-term care environments are associated with a special care concept and a particularly dementia-sensitive physical environment which should be looked at carefully to understand the underlying principles. For people with dementia and their care partners who are searching for a nursing home place, however, it is not always visible from the outside whether a nursing home is integrated or segregated [36]. If residents with dementia live together in a nursing home or a living unit in a nursing home, the physical and social environment can more easily be adapted to their needs. It is often assumed by nursing staff that residents with dementia can behave more autonomously because their housemates with dementia may not feel hampered by this in the same way as residents without dementia. Therefore the dementia-specific behaviour need not be suppressed and fewer conflicts emerge as a result. But in fact, we do not know if residents with dementia really feel well or better when they interact with other people with dementia.

The other side of the spectrum are integrative living concepts, which usually consist of admitting residents to a living unit regardless of their disease and symptoms. The number of residents with and without dementia depends more on the care needs of the individual residents. The groups vary according to the needs of the residents and their remaining abilities to manage daily living.

Living concepts, regardless of their integrative or segregative character, can be accompanied by certain environmental aspects and these are important because of their impact on the possibility for social inclusion.

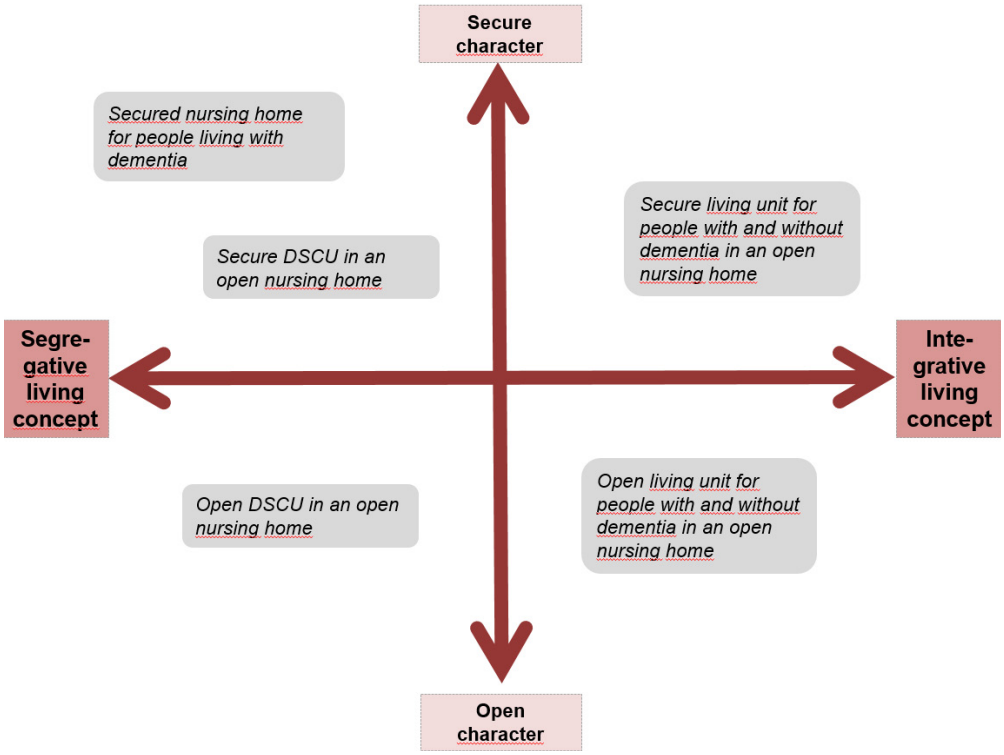

Figure 1: Possibilities for integrative and segregative living concepts (DSCU = Dementia Special Care Units)

Orientation aids or stimulating features are incorporated into almost all living concepts, but the concepts can also be accompanied by environmental safety features. These include, for example, locked doors in the living unit or high fences around the garden or the entire nursing home.

THE DIVERSITY OF SOCIAL INCLUSION IN INTEGRATED AND SEGREGATED LIVING CONCEPTS, TAKING GERMANY AS AN EXAMPLE

When looking at living concepts and their possibilities for social inclusion for people with dementia, it is questionable that one living concept has clear advantages over the other.

On the one hand, the benefits of a living concept always depend on the individual resident and his or her condition. On the other hand, integrative and segregative concepts are implemented very differently across the world, and these are based on a variety of care concepts. As researchers in Germany, we have a good insight into the national healthcare system and yet we would like to have a more detailed view of the variety of integrative and segregative living concepts in Germany. This would give us an insight as to how actions on social inclusion in both concepts is taken.

Looking at the demand for different long-term care environments in Germany it has to be stated that of the approximately 83 million inhabitants in Germany, about 3.4 million people are in care dependency [45]. Approximately 1.7 million people are living with dementia [46]. As with the general need for care, the majority of them live at home and are supported in their daily lives by relatives and/or by professional care services (70%). About 818,289 people are cared for in residential long-term care environments [45]. About 51% of residents are diagnosed with dementia, but it is estimated that more residents show dementia-specific symptoms [47].

The organisation of long-term care environments and thus also of integrative and segregative living concepts is very diverse. You may find overlaps between the living concepts described here and the residential long-term care environments in your country or maybe you understand something completely different by the concepts described here:

Traditional living units

Traditional living units represent the majority of long-term care environments in Germany. They can vary in size (up to approximately 30 residents) and are part of integrative living concepts. The aim is to provide traditional long-term care, to address residents' need for care and to provide social services. In many cases, the organisation of everyday life is not carried out by the nurses themselves, but by social staff and assistants.

With regard to the opportunities for social inclusion, this living concept offers many possibilities: Residents with and without dementia meet each other in their everyday routine and can thus also enter into sustainable relationships. The open-environment design of the living units also allows people with mild or moderate dementia to interact socially with other people outside the nursing home independently or with a low level of personal assistance. However, the concept can also create barriers – e.g. where residents without dementia cannot understand the behaviour of a housemate with dementia and are unable to react in an empathic manner, living together is likely to be prone to conflict and social isolation may result.

House community models

House communities are small living units in which up to 12 people live together, as far as possible, independently. The main focus of the concept is the shared organisation of normal everyday life, in which every resident contributes to the household according to his or her abilities. This means, for example, that residents help to prepare lunch or do the laundry together with the staff. By turning away from institutionalised daily and organisational routines that often characterize traditional nursing homes, a familiar character is to be created. The aim of the concept, which is based on the principle of normality, is to promote the self-determination and quality of life of the residents [34, 35]. House communities are not especially aimed at people with dementia and at an integrative living concept in this form.

The most significant aspect of social inclusion is that the residents form a stable social group as a household community in which the abilities of the individuals can be taken into account.

Dementia Special Care Units (DSCU)

DSCUs were created in the 1980s to respond more appropriately to the responsive behaviour of residents with dementia and have evolved in many ways over the past forty years. About 30% of living units in Germany are categorised as DSCUs, but many residential areas offer dementia-specific care without this being recorded in a structural way [36]. Admission to a DSCU is regulated by different criteria that mostly include the medical diagnosis of dementia or a certain score on the Mini Mental State Examination, a high level of mobility and the occurrence of responsive behaviour. The residents are cared for in a dementia-sensitive physical environment and the staff is highly specialized in dementia-specific needs and a person-centred approach. It has been shown in different studies that care in a DSCU could be associated with positive effects such as decreasing the use of psychotropic drugs, feeding tubes and physical restriction [21].

For the possibility of social inclusion these effects go along with enabling the regaining of capabilities to manage everyday life. For example, residents with certain responsive behaviour can use their skills to integrate into the group of residents and to make contact with other residents and staff. The special living concept is open to their behaviour and tries to support integration in spite of this. It needs to be said that the concept of DSCUs is not necessarily accompanied by a complete physical separation by means of environmental safety features such as locked doors or fences in the outdoor area. These features are sometimes used to prevent residents from leaving the nursing home or even the living unit, but are not necessarily part of the concepts of dementia-specific care. Their existence has a further influence on the possibilities for social inclusion within the institution and in the community.

"Care Havens" – Shared-room concept for people with dementia

In "care havens", a small group of residents (about 6 to 10 persons) live together in a large group room in which nurses are continuously present. The whole life takes place in this room. All residents have a permanent place in the room where their bed and personal belongings are situated. The target group of this segregative living concept are residents with severe dementia, a very high need for care, reduced communication skills and a need for assistance in all activities of daily living. The care concept of "care havens" includes a specific spatial layout with access to the outside (balcony or terrace), a palliative qualification of the staff as well as sense-based interventions. These aspects and the continuous presence of staff is designed to contribute to increasing the quality of life of residents with severe dementia at the end of their life [50].

Since the residents are bedridden and communication can often only take place non-verbally, the possibilities for social inclusion are limited. Nevertheless, social interaction can take place through the constant presence of the staff as well as the residents in the room. For example, when residents react to each other or when nurses address the group during interventions [2]. Interaction with people outside the care haven usually takes place only through visits from relatives, but not through interaction with residents of other living units in the nursing home.

Milieu-therapeutic dementia living groups

Milieu-therapeutic dementia living groups are small living environments (10–15 residents) integrated into the larger living units but structurally separated from each other. They focus on mobile residents with mild to severe dementia. The key idea of this living concept is the provision of dementia-special care with milieu-therapeutic orientation which aims to increase the well-being of the residents by adapting the environment and taking individual needs into account [2]. The change of social milieu stands at the centre of the concept. For this purpose, residents are selected for the living concept on the basis of defined criteria. The selection can be made on the basis of different biographical aspects. The homogeneity of the group focused in this manner can help to activate social interaction between the residents and thus contribute to social inclusion.

Regarding the accommodation of people in one of the listed living concepts, which has a secure character, another aspect has to be considered, which is related to the CRPD and also to social inclusion – the legal regulations. The legal regulation of accommodation in a closed residential area is strictly regulated in Germany, regardless of whether it is integrative or segregative. Nurses and other health care professionals are not entitled to decide where a person with dementia is accommodated if they are no longer able to take the decision themselves. Relatives, even if they have taken over guardianship for the person, cannot decide alone that someone should live in a closed residential area. However, if a person is no longer able to decide where they live – because they show symptoms of self-endangerment or loss of reality – they must be relieved of this decision. In this case, a (guardianship) court decides that the person can no longer decide on matters concerning his or her place of residence and instead takes the decision that accommodation in a closed residential area is necessary. However, this decision is regularly reviewed by the court to determine whether the person's symptoms still make the closed accommodation necessary.

WHAT DO PEOPLE WITH DEMENTIA WISH FOR WHEN THEY LIVE IN LONG-TERM CARE ENVIRONMENTS?

Finding out the desires of people with dementia in respect of long-term care environments can be quite tricky. Of course, it is the utmost goal of almost every person to stay at home in their familiar surroundings and with their relatives for as long as possible, even if help is needed in everyday life. Nevertheless,

it is essential to listen to and include the perspective of people with dementia and their wishes into the discussion about integrative and segregative living concepts in long-term care environments.

The most relevant question that arises is the following: "Where do people with dementia want to live when it comes to moving into a long-term care environment?" One of the most well-known dementia advocates, Kate Swaffer, comments that the most important point is that the healthcare system provides meaningful alternatives and appropriate support to make choices from a range of alternative residences [3].

With regard to the maintenance and promotion of social inclusion in long-term care environments, regardless of whether they pursue an integrative or segregative living concept, residents should be given the opportunity to decide independently where they stay and when they meet other people.

Where environmental safety features are installed, social interactions could be facilitated, for example, by providing residents with their own keys for the doors if they have the capacity to use them. If this action is not possible, people with dementia at least wish for the absence of barriers and walls to create an environment that eases social interaction [51].

The relevance of being included in decisions concerning accommodation in long-term care environments is also addressed by other representatives of interest groups such as working groups of people with dementia

including Scotland and Chinese Taipei, plus regional groups in Europe and the UK. They consider it to be essential to include them in all decisions concerning them as they are affected and from this they derive the slogan "Nothing about us without us" for all activities in the field of dementia-specific care and the development of new care concepts [52].

HOW CAN WE DEVELOP FUTURE IDEAS FOR SOCIAL INCLUSION IN BOTH LIVING CONCEPTS?

The diversity of the integrative and segregative concepts presented here shows that they are accompanied by very different opportunities but also challenges with regard to the social inclusion of residents with dementia. Some already offer good opportunities for the person to continue participating in social activities, but are not suitable for people who experience severe cognitive impairment because they require a certain level of abilities in daily living and independence. Others focus on the safety and integrity of residents by means of additional environmental safety features, while at the same time preventing moments of interaction between people with and without dementia and residents of the nursing home and the surrounding neighbourhood. For further discussion regarding the practical implementation and further development of living concepts, people with dementia should be more involved. Their views should guide the professional and political debate on integrative and segregative housing concepts in long-term care environments. One way of doing this might be to ensure that the ideas are heard by dementia advocates and dementia-specific interest groups at the point where decisions are taken on the practical implementation or when legislation is introduced. Also, people who need a place in a nursing home should have the choice of which living environment they want to live in. National healthcare systems should offer choices and structures to help people make these choices, but should not make decisions for the person and their care partners right from the beginning. But we as researchers and health care professionals should consider that the development and practical implementation of living concepts in nursing homes should link people in need of care to the other residents and community and other people and should provide the basis for having valuable connections again. As a result, conditions such as generally locked doors in nursing homes or other environmental safety features, which are basically installed where residents with dementia live, should be critically reviewed and discussed. We should question wherever they are necessary to give certain residents the opportunity to use their remaining everyday skills in a low-stimulus environment in safety. But we should also ask whenever they are more of an obstacle to social inclusion, preventing people from interacting with the community, other residents and their families. Furthermore, we as a society should ask ourselves how we can contribute to nursing homes being seen and used as part of the community, for example, in which cafés or community rooms are shared by both the surrounding neighbourhood and the residents.

For this reason, we would like to conclude by asking you, the reader, to three questions to keep in mind:

1. How are integrative and segregative living concepts implemented in long-term care environments in your country?

2. Which actions are undertaken in your country to promote the social inclusion of residents with dementia with other residents of a nursing home but also with the community?

3. How would you like to see actions to promote social inclusion if you were a person living in a segregative long-term care environment?

The involvement of people with dementia in the design process: a (political) choice to make

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> "Design practices are not neutral – there are always critical-political issues, others, alternatives and futures involved." [53]

This quote from Ramia Mazé, who specializes in critical approaches to design, indicates that every design implies a political consequence – or is the outcome of a specific political context. Every design choice one makes holds a consequence for (groups within) society. If one looks at the design practices surrounding dementia, there are many designers, developers and architects who design tools, products and environments for people with dementia. The intention of their work is to renovate outdated elderly care infrastructure to support autonomy [54]; to stimulate conversation, instigate playfulness, to build connections through the use of sounds [55] or to use technology such as virtual reality as part of meaningful leisure activities for people with dementia [56]. This chapter is however less concerned with the actual design outcomes. Rather it is more focused on the way designers, developers and architects set up the design process and the ways people with dementia are involved in making design decisions, as this holds a political consequence.

Despite the good intentions of stigma reduction campaigns like the Belgian "Onthou mens, vergeet dementie" ("Remember the human being, forget about dementia") or the Irish "Forget the Stigma" (using "I have dementia. I am still me." as a slogan), few designers, developers and architects involve people with dementia as collaborators in their design processes. This was also observed by Span and colleagues in 2014 [57] in their systematic review which highlighted that only 2 out of 26 research and design projects had involved a person living with dementia as an equal partner (or co-designer). Most of these design projects 'used' people with dementia merely as an informant or, even worse, as an object of study. More recently, Suijkerbuijk et al.[58] and Wang et al.[59] found that this is changing and that there are now more projects that facilitate collaboration with people with dementia with designers, developers and architects. This has included not only people with mild to moderate dementia, but also people in more advanced stages. Despite these positive evolutions, both Wang and Suijkerbuijk mention that the number of design projects that (document how they) involve people with dementia is still limited.

WHY ARE DESIGNERS, DEVELOPERS AND ARCHITECTS NOT INVOLVING PEOPLE WITH DEMENTIA

There are a number of reasons why involvement in design by people with dementia does not happen. Some designers, developers and architects experience the practical, social, physical, and cognitive limitations associated with dementia as prohibiting collaboration [60, 61]. Others experience designing together with people with physical and cognitive decline as too difficult or too much of a challenge [60]. Additionally, some projects experience a lack of resources, time or funding to collaborate with people with dementia. Finally, some designers feel they lack the skills, tools or methods and thus refrain from doing so [62]. Potentially as a consequence of that, some designers are hesitant to involve people with dementia due to fear or even a feeling of pity [61, 63].

Whilst all of the above mentioned obstacles to participation may hinder involvement, one must almost reflect on, as Mazé indicated, the political choices or consequences of refraining from involving on the political choices or consequences.

Colouring books designed specifically for people with dementia as a means to initiate intergenerational conversations and as a leisure activity [1]

> If one agrees that a person with dementia must be recognized as a person with thoughts, emotions and wishes then this person should – like anyone else – be included as a person who can and should actively be included in research and design.

This leaves us with the question, who are we, as designers, developers or architects to choose not to involve in the process those we design and create for? Why is it that we spend so much time designing leisure activities, buildings or digital apps for people with dementia, but so few support people with dementia to be part of this process and value them as contributors? By not doing so, designers, developers and architects strip people with dementia of their agency and disempower them; by not allowing them or seeing them as able to be 'full' participants.

WHY YOU SHOULD INVOLVE PEOPLE WITH DEMENTIA

We have outlined good political or moral reasons to involve people with dementia, but are there also other, more pragmatic reasons to facilitate this involvement?

Carrol and Rosson [64] indicate that involving those one designs for will lead to better designs (taking into account the wishes, dislikes and needs of those involved right from the start, results in less problems or unwanted features afterwards). Next to this, involving people with dementia and learning how to design for and with them is something that fits well within the role design can play as a sector wishing to respond to societal challenges [60]. The industrialisation and growing consumerism at the beginning of the 20th century helped support standardisation and production for the masses as one of the features of design. Standardisation and production for the masses was the designers' response to a changed society. Similarly, after the second World War, there was a belief that the world needed rebuilding differently from the present. In response, designers were urged to abandon the modernist styles in favour of more open and democratic ways of designing. The rise of Scandinavian Design can be seen as an example of this.

Likewise, the exponential growth of the numbers of people living with dementia, combined with the socialisation of care and community-based care has generated a social shift. This includes understanding that the control and responsibility for wellbeing should lie in the hands of family and the people with dementia themselves. This shift requires a response from the design industry at large and more specifically, it requires individual designers to respond. This will lead not only to more tools to support ageing in place and community-based care, but also more ways to facilitate this 'taking of control' by people with dementia over how tools and environments of care and living will be designed. Facilitating this involvement by designers, developers and architects thus seems a necessity.

HOW TO INVOLVE PEOPLE WITH DEMENTIA?

Participatory design (PD) is one approach that has answered the question of involvement from a strong political stance. PD originated in Scandinavia in the '70s. Originally this design approach aimed to provide tools, techniques, methods and practices to empower workers and collaboratively shape the role computers would play at the workplace [65]. With more technology coming into the workplace and changing work practices and processes, workers were dis-abled and unable to take control of the design and implementation of tools in their workspaces. They were either not heard or not enabled to raise their concerns or desires about these changes. In 50 years, PD has shifted from a political interest through democratic systems development in the workplace, to a more encompassing notion of accountability in design. Participatory design has been applied in various domains such as urban development to the design of spaces and furniture. It has moved away from a specific focus on workers to that of reflecting the variety of people our society consists of.

In this sense, much like the workers were dis-abled in taking control of the way their work environment was designed, so is this the case with people with dementia within design.

One of the founders of PD, Michael Muller, wrote an article defining participatory design as happening in a third or hybrid space [66]. In this hybrid space the border between who is a designer and who is not a designer gets blurred. While both are using a verbal, visual or a non-verbal language that both master and thus facilitates them to work together, a series of PD tools, techniques, methods and practices support (the creation of) these hybrid spaces. These tools, techniques, methods and practices can be as varied as games [67], theatre techniques [68] or simple craft materials [69] such as pens, crayons, and scissors.

These traditional PD tools, techniques, methods and practices, however, do not always work well when working with people with dementia. Part of the reason lies in the fact that having a background in work-related contexts, traditional PD techniques focus on productivity and work and assume that each participant is cognitively able, which is not the case when working with persons with dementia [60]. Various PD techniques also use verbal and visual cues and this too, is not always evident for people with dementia. As a consequence of this, designers, developers and architects have experimented with new ways to work together with people with dementia as varied as using poems and diaries [70], touch and proximity [71], a variety of personal objects like jewellery [72] or songs and dance [73].

HOW TO PUT PARTICIPATION INTO PRACTICE

The tools, techniques, methods and practices for including people with dementia in the design process are very diverse; there is no one-size-fits-all tool or technique (as there is no one way someone will be affected by dementia). This section, however, sums up a series of guiding principles that form the start of facilitating collaboration together with people with dementia. The knowledge, experience and expertise a designer, developer or architect will gain from following these guiding principles will help to select, adapt and employ tools, techniques, methods and practices that facilitate working together as a designer, developer and architect together with people with dementia. Most of these insights here have been gathered over the years working with a team of designers together with carers, family and most of all, people with dementia, under the name Dementia Lab Research (see www.dementialabresearch.com).

The most fundamental principle begins from the building-up of a relationship between a designer, developer or architect and a person with dementia.

As the way dementia affects daily life is different for each person, our approach does not favour working in large groups, but rather proceeds from the individual's experience of dementia. In general, what we try to do is adapt our ways of working to the lived experience and the condition of the person with dementia. Looking at the past, processing biographical information coming from family, friends, and a partner – all of this can be of use. Questions that play on several levels are important: what were the person's hobbies, their professional activities? Did they have kids and how many were there? What were defining events in the course of their life and what were the rituals of everyday? Looking at the way the person with dementia experiences the now takes into account their subjective interpretation of the world, with their own ways of behaving, meaning-giving, rituals, set of beliefs, etc. that might be rooted in the past but get interpreted in the present. Acquiring an understanding of the subjective interpretation of the present can happen through repeated encounters with the person with dementia. These encounters can be functional or goal driven (i.e. directly related to the design process), but will more often be non-functional: just being there, joining them in the dementia choir, visiting the hairdresser together, helping out during mealtime, etc. all for the sake of trying to build a rapport with the person with dementia. Both the past and the present will inform the designer, developer and architect about potential handles that can be used to involve the person living with dementia in the design process.

Consequently, such an approach favours a process where a designer is designing for one person with dementia, over designers, developers or architects working with multiple people with dementia. This radically rethinks the vision of most design work that starts from generalisation ("design something for all children between 6 and 10"). As indicated in the section on the reasons why designers, developers and architects are not involving people with dementia, there can be a strong hesitation (or even fear) in doing so. We believe that this distance between a person with dementia and a designer, developer or architect cannot

be bridged when working with larger groups but needs a one-to-one approach, one designer, developer or architect working with one person with dementia. Working in such a personal way not only asks for a rethinking of the 'standard' tools for designing (for example, being good at computer modelling vs good communication skills) and the mindset one should have (for example, a very methodical way of working vs. flexibility in the situation).

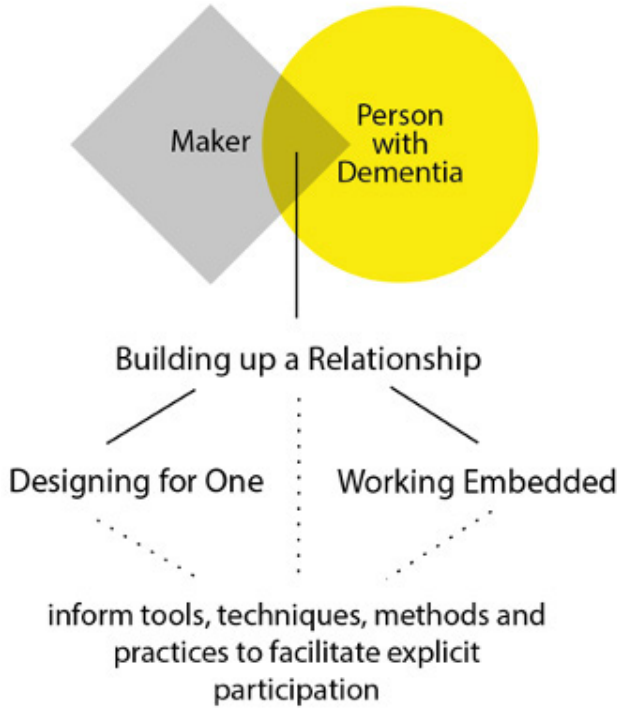

Figure 2: Design Participation in Practice: guiding principles for a collaboration between a designer and person with dementia. Copyright Dementia Lab Research 2020.

To put it simply, designers, developers and architects should approach the context as humans first,

then as designers, developers and architects and in this way connect on a personal level, responding to the person and their individual context as a human being.

Building on this idea of context, as a way to facilitate the personal approach and this designing for one, it is a necessary precondition to be embedded in the work. This embeddedness involves being physically present in the care and living environment of people with dementia for a long duration. This can be a common living room or the personal bedroom of a residential care facility or the kitchen, garden or shed when a person with dementia lives at home. This embeddedness is a choice that the designer makes; a choice against the use of relying on time-restricted, well-planned design setups which have clear roles and goals. In practice, we have installed our workshops and ateliers next to the dementia ward of a care facility, or, when people lived at home, we, for example, visited them weekly. Being present redefines the role of the designer, developer or architect from an external actor to an insider; from a distant other to 'one of us': the researcher is no more a mere passer-by but is 'part' of the care and living environment. Such an approach facilitates an empathic and personal way of working, reminiscent of the person-centred care principles, one of the ruling care principles in dementia care.

We discovered in studying and engaging in these personal relations that to involve people with dementia directly, means that there is a need to articulate both explicit and implicit shared decision making through participatory design. Explicit decision making happens when the designer facilitates that the person with dementia explicitly states her wants, needs, longings, etc. and this facilitating can happen through prototyping together, singing, dancing, etc. or other ways of doing this. What type of tool, technique, method or practice to choose is based on your knowledge of the person with dementia you are collaborating with. However, explicit decision making is not always possible with people with dementia. Therefore, implicit decision making should be part of the design process. Implicit decision making means that designers take design decisions based on the interpretation of implicit forms of interaction (like body language etc.) or based on the knowledge the designer, developer or architect has from the relationship he builds with the person with dementia. The implicit form of participation, which often predominates when working with people in more advanced stages of dementia, is present in more subtle cues such as bodily movements and physical responses (e.g. smiles, nods, muscle tension, being focused or not, tears etc.) and understanding these in the context (tears could, for example, not indicate a negative emotion, but maybe as an indication of contentment or even joy). Next to these, designers can derive certain design decisions implicitly through the creation of the life story of the past and the present of a person with dementia. Of course, explicitly involving people with dementia in the design process should be the starting point and the goal of each design process, however, if that does not work, this implicit form of participation should be second best.

Embedding design education in a dementia ward. Copyright Dementia Lab Research 2020.

CONSEQUENCES OF A PARTICIPATORY APPROACH

This final section can be seen as a call for action as it wishes to make explicit how different sectors can support a participatory approach in design. More specifically this section looks at the creative industry (architectural bureaus, design agencies, production companies, etc.), design in academic contexts of research and education, policy makers and the care domain.

For 'making' industries, the challenge lies in effectively opening up their processes for people with dementia. While collaborating with people with dementia early on in the design phase will not always guarantee a better result, chances are that the time and money invested in conceptualising and creating a design, app or environment will be better suited to the needs and wants of the target audience when they have been on board from the start.

In the same way that most (digital) design making made the switch from a 'design by default' approach towards a more user-centred approach, so too 'making' industries must put more effort in involving people with dementia

(and their partners and carers). There are thresholds that still exist and are understandable: a more personal approach is heralded in academic design contexts but is often met with criticism in industry (for avoiding generalisability, which is needed to upscale a design, and for being too time consuming). However, the academic design sector is collectively working to create handover tools to support the transfer of these personal

experiences to a larger context by trying to answer how a design result coming out of an individual experience can be translated to a larger group (but not all) people with dementia. Next to this, a consumer (be it a carer, a relative or a person with dementia) can potentially not discern what qualitative products for people with dementia are. As a result, the 'making' industries cannot rely on ways to indicate to 'the market' that their product is a qualitative one. They should initiate and support the creation of certification procedures (leading to a mark) that indicates when a product meets certain quality standards. On a European level, these initiatives have already been taken (see amongst others the Certification-D-project [74]).

For design with and for people with dementia done in academic contexts and education the message is quite clear: do not be afraid to get your hands dirty. Take your classes, ateliers and workshops into the living rooms, garages and common rooms of people's homes and residential care centres. As indicated above, this embeddedness is a first step to work towards a new skill set for designers, developers and architects. This skill set will need to integrate a valuation of implicit decision making and the build-up of relational expertise. Next to that, setting up ways to facilitate knowledge sharing on design for and with people with dementia is needed. This knowledge sharing starts with being open to make explicit the methodology and evaluation of people with dementia's involvement in a design project (as Suijkerbuijk indicates). Next to that, there are only a few events that focus solely on design and dementia where these types of results can be shared. The MiND conference and The Dementia Lab Conference are examples of this. Next to that, networks of designers, developers, architects and academics sharing their experiences in designing together and with people with dementia should come into existence. Both these networks and the events should work as go-to places for new designers, developers and architects (both for networking and to get the basic knowledge needed) and facilitate long lasting collaborations with the make industry, the care sector and people with dementia.

Lastly, a strong call to action is aimed at those setting research agendas (in design academies, architecture faculties, etc.). More often than once, design for and with people with dementia is a topic that is not taken up as a lasting research topic. This has led many promising researchers in design and architecture to abandon this field once a specific research project has ended or a PhD research is finished.

This leads to a lack of a strong body of research, much needed to advance the design for and with people with dementia. Research agendas that take on (and allocate budget and staff to) designing for and together with people with dementia as an ongoing topic are what is needed. This ever growing group in society is searching for better living environments, designs and digital tools and there are many topics still to tackle. What are good tools to transfer individual experiences (of one person with dementia working with one designer, developer, and architect) to a larger group with dementia? How can the tools to facilitate collaboration be improved? What are ways to define good design for such a diverse group and how can we design tools and environments that are responsive and adaptable when a disease progresses (and abilities change)?

For policy makers, the challenge lies in supporting, facilitating and enforcing participation of people with dementia. This can be done by promoting and championing participation when opening calls for research or design grants. Whenever 'something' is designed for people with dementia clear methods of involvement should be defined. And, this involvement should go beyond 'tokenism' where involvement is done to tick a box on a research proposal (and mostly means validating what a designer, developer or architect has already decided upon). Next to this, participation should be enforced whenever the make industry is bidding to design urban environments (like a town hall or cultural centre) and when makers are being asked to create tools (such as a digital shopping guide) or products (such as street furniture). While it is the main responsibility of the designers, developers and

architects to involve people with dementia in the design process, it should be the policymakers' responsibility to both demand, expect and value their inclusion.

Lastly, we ask the care domain to welcome designers, developers and architects to use the location of care (and living) of people with dementia as the main location of (participatory) design (and research) despite all the hurdles (ethical approval, workload on care staff, etc.) this might bring. However, do make sure that the care domain does not become a mere test location, but claim authorship over the set-up of the (participatory) design processes and crucial design decisions to be made. Without these, the risk for tokenism exists. Be critical towards the designs created or participatory design process proposed: often we unfortunately see a type of 'thankfulness' towards 'any' design created or design process set up, without looking at its viability. Finally, look at design (be it architecture or product design) from a systemic point of view: make sure that participatory design experiments and its outcomes not only work on a product level ("does it function?"; "does it feel ok?") but look at how this design alters or confirm the existing 'system'. In order to do so, a design should be critically looked at, questioning its sustainability ("can we fix it when it breaks down?"; "will this product last for a longer period of time?"); its integration in the routines of daily life and care and the care ideology of the care organisation; and the way a certain design might question those routines, practices and ideology.

CONCLUDING REMARKS

Design can bring support in daily life and care by conceptualising and creating new leisure activities, tools to re-think family relations and support communication or environments that stimulate interaction.

> Through participation in the design process people with dementia are valued for who they are and were: individuals with wants, needs, things to love and to detest, wishes and ambitions.

As a make industry, being designers, developers and architects, it is a political choice (our duty) to involve people with dementia in the design process. As research and educational organisations, we need to train designers, developers and architects to become empathic and engaged human beings. As policy makers it is your duty to support, facilitate and enforce the involvement of people with dementia in the 'set-up' of buildings (from elderly care centres to public squares) and the creations of artefacts that 'occupy' these places and spaces. As a care domain you will both welcome and at the same time be critical towards participatory approaches in design.

Participation should be the thread throughout all design work, even if the attempts to collaborate with a person with dementia turn out to be enormously challenging or even might fail, it shows a vision on society (a political choice), namely that one needs to give a person with dementia a voice, however hard this might be, and, that it should be worth to invest time and effort in facilitating this.

Citizen audits: Developing a participatory, place-based approach to dementia-enabling neighbourhoods

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Introduction

In the wake of COVID-19, cities, towns and villages around the world are engaged in dialogue over the need to re-think the allocation and use of public space. Pavements are being widened, cycle lanes introduced, and greater use made of green and open spaces. Yet the rapid pace of change runs a risk of reinforcing, even amplifying, place-related inequalities. We need to ensure that age and dementia-friendly design considerations are integral to the programme of changes being made. One way to achieve this is through directly engaging people living with dementia and their care partners in helping to enhance the inclusivity of public space, and here we share one approach to doing so. In this chapter we reflect on the experience of a participatory project aimed at helping to create dementia-enabling public spaces. Commissioned by Stirling Council (Scotland), the project was undertaken by 'Our Connected Neighbourhoods' (OCN)[i] a community-development partnership involving people living with dementia, unpaid carers, a team of volunteers, a network of third sector provider organisations, and the University of Stirling. The commission offered a unique opportunity to facilitate a dialogue between people living with dementia and the local council, with the intention of investing in changes to council venues and facilities and the wider city centre.

The project has allowed us to reflect on the meaning of 'enabling neighbourhoods' and consider the implications for a broader global agenda for dementia-friendly communities.[ii]

Background

THE CHALLENGE OF IMPROVING PUBLIC SPACES

Funded by the Life Changes Trust,[iii] Our Connected Neighbourhoods is an experimental community-development project working in the Stirlingshire region

i For further details see our website: https://ourconnectedneighbourhoods.org.uk/
ii https://www.alz.co.uk/dementia-friendly-communities
iii https://www.lifechangestrust.org.uk/our-dementia-programme

of Scotland. Premised on a knowledge partnership, we aim to integrate research evidence, practice-based learning from provider organisations, and expertise by experience of people living with dementia and their care partners to help foster dementia-enabling neighbourhoods. A focus on the environment is a core strand of the project; Neighbourhoods need to be inclusive of those living with dementia for the 'dementia-friendly communities' agenda to progress. OCN was recently commissioned by Stirling Council to guide a programme of renovation and refurbishment to council buildings, improving accessibility for people with dementia while also considering the routes and pathways through the city that connected these different venues. With finite funds available our challenge was to find an effective way of identifying and prioritising changes the Council could make to enhance their public-facing buildings and surrounding areas for access and use by people living with dementia.

One option available was to make use of an environmental audit tool (EAT). EATs take the form of a framework that collates existing evidence of dementia and design, highlighting examples of good practice, and enabling the user to score or evaluate a particular setting against a series of design criteria. While these tools were originally developed to guide design and retro-fitting of specialist dementia environments such as hospital units and care homes,[iv] the format has been adapted to a diverse range of settings including gardens, outdoor and public spaces.[v] Many of the tools encourage users to involve colleagues and people living with dementia and to embed the audit process in a dialogue about the setting at hand.

We wanted to expand upon the conventional audit process, for example by attending to the social atmosphere and other less tangible or visible dimensions that are still crucial to a person's experience of place. Existing approaches to conducting environmental audits have tended to dichotomise social space and the built environment, often by approaching the latter as largely fixed and static. Meanwhile, the social aspects of a venue or space, including the resources and capital it offers are treated independently. In our view, this is an artificial division that fails to reflect the lived experience of people with dementia and as such we were keen to experiment with new methods and media to build in a more experiential dimension to the auditing process. Conventional EATs can also reinforce a deficit approach to dementia, treating the environment as a resource to compensate for losses incurred through dementia and finding ways to assuage certain symptoms. From this perspective dementia is treated as an abstract set of characteristics, driven by the assumption that making a series of pre-determined design changes will have a commonly shared impact upon the people with dementia who occupy that particular environment. Our own experience of working closely with people living with dementia has suggested otherwise. Many have highlighted the unpredictable nature of their relationship with even the most familiar places in their neighbourhood.

Developing a participatory place-based approach

The project team included people living with dementia (one who was a wheelchair user), unpaid carers, an architect with in-depth knowledge of design for dementia, the chief executive of a regional arts organisation with expertise in arts-based and creative methods for engagement, a community engagement worker from Alzheimer Scotland and the project worker for OCN. In line with the broader ethos of OCN our aim was to enable people living with dementia to lead the process and take the decisions that guided progress.

> Our view is that living with dementia gives people a unique experience of place and a particular kind of expertise that provides insights into public spaces that are inaccessible to others.

THE DEVELOPMENT PROCESS

The project began with a series of workshops, involving people living with dementia and carers in prioritising routes and venues for inclusion in the project, developing methods for data-gathering and designing suitable tools. We created a menu of activities that allowed participants to decide the level and extent of their involvement. We initially shared examples of existing EATs designed for public venues, but these were rejected on grounds of pre-determining what we would look for in too much detail, being largely word and text-based and too narrowly focused on the

iv A good example is the tool offered by the King's Fund: https://www.kingsfund.org.uk/sites/default/files/EHE-dementia-assessment-tool.pdf

v Examples include, the Dementia Friendly Communities EAT: https://www.enablingenvironments.com.au/uploads/5/0/4/5/50459523/alzheimers_enviro_assess_tool_a4-signoff.pdf and a selection of tools from the Dementia Enabling Environments Project (Australia) https://www.enablingenvironments.com.au/audit-tools-and-services.html

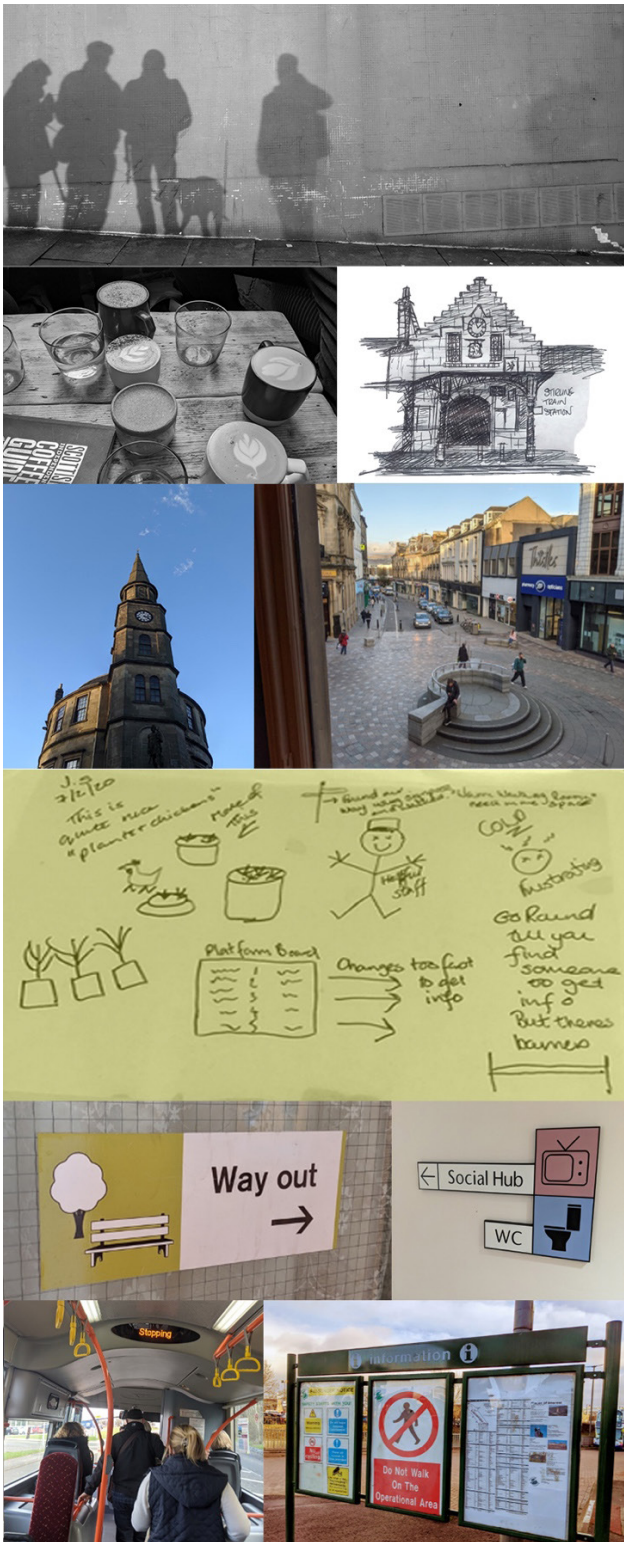
built environment. The workshops allowed us to try out different types of technology and other creative methods for data-gathering. We quickly recognised the value of generating audio and visual data, as a way to support people with dementia to participate in the analysis and arrive at a set of priorities. We focused on accessible and affordable technology including the recording and filming facilities on smartphones, Go-Pro cameras, and even selfie-sticks, that didn't require specialist technical know-how.

During these early workshops it was quickly concluded that we were interested in more than the physical environment and wanted to engage with the broader experience of 'place'. This meant looking at the social as well as material properties of the environment and considering the feel or 'affective' aspects of each setting. Workshop participants talked of the importance of a sense of comfort and of the atmosphere of different kinds of public space.

Discussions led to the creation of two tools for capturing place-based experiences. The first was a Recording Sheet with questions linked to a numbered scale focusing on participants' affective response to the setting under scrutiny. The second tool allowed for note-taking and/or sketching under a series of headings that combined attention to the material, social and embodied experience of place. The tools were intended to structure and facilitate dialogue rather than being a focus for the audit, and participants were encouraged to select and use tools as suited the conversation. We decided to use walking interviews and other forms of mobile discussion as a way to tap into the situated insights of participants. This approach shifted the emphasis from recall and memory onto observation and live encounters. We used Google Street View to provide visual cues while planning a series of walks and held a series of debriefing video conferences between the walks, as a chance to reflect on what we had learned.

Fieldwork

Fieldwork involved a series of weekly gatherings. Arriving at a venue, we would begin by discussing our respective journeys there. We then took an observational walk around while discussing the uses of the venue, the facilities and access using the recording sheets, video, audio-recordings and notetaking or sketching. Citizen auditors often led the conversations with staff at the venues, asking questions linked to the audit but also focussing on their own concerns. Stories and memories of the venue were shared and design solutions proposed. The second half of the session would follow an agreed route, often stopping off at a coffee shop,



Capturing experiences of place: Stirling city centre

sometimes one of the team would divert the route to take in something important. Social opportunities occurred spontaneously as we bumped into friends, and neighbours. The informal social aspects of the audits proved important for generating discussion, testing theories and ideas and sustaining interest.

As the project progressed our level of comfort and familiarity with the process increased, people's confidence appeared to build, evidenced by sustained and increased engagement and participation. Their observations began to refer to comparable examples from other routes, patterns and themes emerged, prompted by the tools and gradually a shared language and priorities evolved amongst the team.

The Audit Journey Sketch and Scribble Sheet: One of two tools co-created during the project

The perspective of a citizen auditor / person living with dementia (Vibeke):

Vibeke began the project feeling a little uncertain, but after participating in the workshops and being an integral part of the team, she felt she grew into the role of citizen auditor. She had been a little reticent at recording her feedback through sketches and notes, so appreciated the opportunity to verbalise her views instead, and feels that offering a flexible approach with a range of data-gathering methods was vital to the overall process. Vibeke has a dream 'that something will happen' as a result of her input to the project. She talked of sometimes feeling ignored following her diagnosis with dementia, but the experience of the participatory audit led her to a view that this type of involvement should extend to ongoing representation in council business for people living with dementia. She found it particularly fulfilling to be involved in a project with tangible outcomes and the possibility that, in the months to come, there will be changes made around the city that she "had seen the birth of". Vibeke continued: "I really, really hope something will come out of it". On reflection, the audits have helped Vibeke to see parts of Stirling in a new light. Areas she previously under-appreciated or simply passed through en route to other destinations have been given new meaning. She also better appreciates the importance of design, continuing to actively note spaces and settings that will benefit her peers.

The perspective of a citizen auditor / care partner (Margaret):

I role-played my friend [with dementia] as we did the audits and reflected on what her experience would be like with each route and venue we visited. When we go out together, I'll look at planning on the route, right down to the toilets being accessible. During the audits I particularly enjoyed asking the tourists the best way to the shops – one pointed towards the bus station, while the other pointed away in another direction. While it was quite funny, it shows that we need better signage. And of course, if I was taking my friend up to the shops I would check if the route was comfortable for her and if not, I would need to head another, more manageable way. As part of the audit process I was thinking about how important it is for people to feel confident and reduce anxiety as they navigate, for example having someone to hold onto, places to rest, to grab hold of and things that reassure them. It is also important for people to be able to see what's coming next, who is around to feel safe and comfortable when they feel anxiety, wherever they are waiting. I have really enjoyed this project, and it has widened my experience of working with people living with dementia. You really have to walk in their shoes to see the world as they see it.

The perspective of a citizen auditor / CEO of Artlink Central (Kevin)

We were all learning from one another, and over a number of weeks began to understand how someone living with dementia managed wayfinding and barriers, how they put strategies in place to find assistance or information, and we began to see opportunities to support improved design. We were emboldened and empowered by the people with dementia in the team. Whereas we could be quite hesitant, the citizen auditors felt little concern about approaching train station staff or stopping tourists to test their perspectives on wayfinding or access. This led to some of the most important revelations of the project. For instance, tourists, many with limited English, often felt very similar disorientation navigating the city centre. Not only this, but they employed similar strategies for resolving these issues, from asking for help to navigating using landmarks and looking for decision-making points. As a team we explored the aesthetics of public spaces, the distinctiveness and heritage, considered the walkability and active travel and also the coherence of the travel systems and wayfinding as a whole.

Learning and reflections on process

Learning from the project fell into three categories: practical knowledge of the cityscape and priorities for change; insights into the value of a participatory methodology; and a more in-depth understanding of place-based barriers and resources that people encounter in the course of their day-to-day lives.

> Taking a participatory approach taught us about the embodied and sensory experience of the built environment that was vital in shaping how people moved about the urban landscape.

The citizen auditors frequently noted the absence of suitable seating and inaccessibility of toilet facilities which demonstrated an overlap with existing age-friendly work on urban design.[vi] For us, this highlighted the need for much closer dialogue and co-ordination between the age-friendly cities movement and the emerging dementia-friendly communities agenda.

The project was confirmatory of existing research into dementia-inclusive design[vii] concerning the legibility and navigability of public spaces. We learned of the value of landmarks for orientation and route-marking but also identified key points where new landmarks could easily be introduced, perhaps in the form of public art or an installation that told the story of a particular site. Discussion of what the city could look like underlined the power of imagination that people were able to draw upon when envisaging future spaces. Engaging local citizens living with dementia provided opportunities to draw upon their situated knowledge of the sites we were evaluating, through this we learned about the significance of sharing place-based memories and stories as a way of connecting, but also how past experiences of a particular place can shape a person's view of it in the present.

Through the course of a series of walks we also encountered the unpredictability of the neighbourhood. Sudden changes in the Scottish weather could alter the walkability of a route, change the appearance of surfaces and pavements, and darken previously sunlit passageways. Different times

vi https://www.ageing-better.org.uk/outdoor-spaces-and-buildings
vii https://www.idgo.ac.uk/about_idgo/docs/NfL-FL.pdf

One of the group's proposals: a tartan themed way finding system for the city

of day were significant for variations in traffic (vehicular and pedestrian) and the overall feel or atmosphere of a place. Such on-going change underlined the limitations to approaching place as fixed or stable, and how reliance on abstract measures and criteria could mean struggling to engage with the dynamism of place. As such, we would argue that the participatory approach took us to a new level of knowledge and learning, by enabling citizen auditors to engage with the neighbourhood as a living breathing place.

While conventional EATs tend to disaggregate features of the environment, a participatory approach showed how different properties of place can interact. For example, intrusive noise (sensory), a hectic presence of other visitors (social) and narrow walkways or tables positioned closely together (physical) could combine to create a sense of discomfort and possibly even a degree of anxiety (affective). An important insight was that a socially supportive environment can help to compensate for a less supportive physical environment; but the reverse may prove more difficult to judge. As a case in point, the least popular venue for the project group, was simultaneously assessed as being the technically most supportive physical environment, in terms of design. We also witnessed the problem-solving approach of the citizen auditors, finding social solutions to challenges posed by the material environment; for example, seeking the assistance of a passer-by when faced with unreadable bus schedules. A related point of learning concerns the obvious resonance between the experience and challenges faced by many people living with dementia and of visitors and newcomers to the city. It was clear that many adjustments to enhance navigability and the aesthetic of the city could benefit the tourist experience with implications for the visitor economy.

Overall, the project provides us with grounds to argue for the benefits of a 'citizen-led' approach to auditing public spaces. Perhaps this approach could be combined with an EAT tool, although we suggest that direct engagement between people and places not only leads to different insights and learning but more fundamentally an alternative understanding of place itself. Indeed, we have learned that it is as much a question of how someone living with dementia engages with place that matters to its enabling potential, as any intrinsic properties of the place itself.

Bin screen graphics (top to bottom): Tolbooth Stirling (historic photo); Robert Burns by contemporary artist Michael Corr; Zurich Improvisations VIIby Alan Davie (1920–2014) c/o University of Stirling Art Collection

Recommendations for policy and practice

We end by highlighting key messages and recommendations for policy and practice.

Our approach demonstrates the value of direct dialogue between local citizens living with dementia and those responsible for introducing changes to the built environment.

Indeed, there is scope within our methods for direct participation from town planners, civic architects and local councillors with powers to push forward certain changes.

- The project highlighted the potential for place-based alliances and affiliations. For instance, there were clear overlaps with age-friendly and disability agendas as well as benefits for the visitor economy. Future projects could consider bringing together representatives from different groups to better understand the shared interests surrounding changes to the environment, and for identifying priorities of greatest benefit in a context of finite funding or resources
- The most impactful aspect of our approach was through the visibility of people living with dementia in the places selected for audit. By announcing ourselves and our purpose we were able to challenge assumptions and show how embodied and cognitive diversity is so routinely overlooked in public spaces. In some cases, our visits provided a first step for a venue and its staff to consider new ways of working, interacting with diverse visitors on a path to more lasting change
- Finally, our mobile methods showed the cumulative benefits of moving from place to place, benefitting from the resources present in different types of setting. Rather than focusing narrowly on changes to discrete sites and spaces in the neighbourhood, this illustrated the need for joined-up policy that enables free movement and access across the neighbourhood, and beyond

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Designing for culture and context

The need to explore, improve and apply our understanding of the role of cultural context in designing for people with dementia must be prioritised in the full recognition that the models developed in high income contexts are of limited value in low- and middle-income countries. However, these models give grounds for optimism that good design can lead to economic benefits.

Designing for culture and context

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Whenever we look at environments in different parts of the world, or in different parts of our own country, we need to be conscious of our own cultural bias. We need to be wary of assuming that what is great in one culture will be best in another, that what is important in one setting will be equally valued in another. We need to be mindful of our own world view, of our own lens through which we look at things. We need to remember to delve deeply to understand what we are looking at, to hear from the people who know a place, and understand why it is the way it is. We need to take time to understand what we are looking at. We need to listen carefully.

Context is everything. The story is vital. Local knowledge is essential.

As I have worked in different parts of Australia over the years I have been struck again and again by how similar, and how different we are. We are a large continent. Some of us live in homes with a 6 metre street frontage. Others live on 1000sq kilometres of land. Some have access to services, and others face hours of driving to get to a shop. For some a medical centre is around the corner, for others the doctor arrives in a small plane. Understanding context is vital if environments are to respond to people in a meaningful way.

A significant part of my recent work has been working on the development and application of a set of design principles with Richard Fleming [1]. These have been described in some detail in the earlier chapter on principles and will simply be referred to as the Fleming-Bennett principles here. One of the reasons I am passionate about design principles is because they can be applied in so many ways. In my architectural practice I have seen that it is possible to use the same principle in different contexts and see completely different built responses arise. What is familiar in Brunswick, Victoria where I live, for example, will not necessarily be familiar to someone whose home is in Broome, Western Australia. The principles are the start of a conversation. By using a principles-based approach to design, we can ensure that we respond to culture and context, and design well, regardless of where we are.

This has been my experience working in many different parts of Australia, but was perhaps most striking for me at Tjilpiku Pampaku Ngura (TPN) in central Australia where I worked with Paul Pholeros, Adrian Welke and Maureen Arch. Paul, an architect and project coordinator, brought together three architects and a health professional to work on the TPN project, each with different expertise. Paul had a strong relationship with Nganampa Health Council and extensive knowledge of the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands built up over many years of working in design, construction and environmental health projects. Adrian, co-founder of Troppo Architects, was a remote area specialist with experience in remote settings across Australia and all the complexities that are involved in getting a building constructed in remote locations. Maureen, a nurse and gerontologist who was then an aged care worker employed by Nganampa Health living on the APY Lands was involved in all stages of the project. Having worked in practice designing aged care for many years in different parts of Australia, volunteered as a care giver, and studied gerontology, I joined Paul, Adrian and Maureen as an aged care design specialist.

The TPN project was led by the Nganampa Health Council (NHC), an Anangu controlled health organisation experienced in providing health care across the Lands. NHC not only identified a means of funding and designing a building, but more importantly, developed a strategy for the ongoing operation of TPN upon its completion. There had been concern for some years about the inadequacy of services for older Anangu which meant that people had to move hours away from traditional lands and family to receive care. NHC identified the needs of older Anangu through a census, and then in response to its findings established an Aged Care and Disability Care programme which included the building of a residential care facility for older Anangu [2].

TPN on the APY Lands

Being able to fund and staff the operation of a facility for older people with high health care needs that is located 500km's on a dirt road from the nearest town is a significant challenge, and managing these factors was crucial if respite and long term care were to be provided successfully on the APY Lands. The detailed and comprehensive approach taken by NHC was fundamental to TPN's success.

TPN was designed to accommodate up to 16 Anangu for respite or longer-term residential care. The Fleming-Bennett principles played a big part in the design of TPN, and the form the environment took there in response to the principles is very different to that of other aged care facilities.

Designing TPN did not only result in the building of a place for older Anangu on the APY Lands; it taught the design team a lot and provided an opportunity for others to learn as well:

- While we came with knowledge, built up over many years, we also came to learn. We learned by listening
- Having listened, a project was conceived and realised. TPN was created
- And as a result of this project, Paul Pholeros was commissioned by the Commonwealth Government of Australia to write an Indigenous Aged Care Design Guide

Listening and Understanding

As architects, one of the most important things we can do is listen to our clients. It is their building, their project. We are helping them realise their dream. We need to ask ourselves:

'Who can we talk to?' 'Do we understand what we are hearing?' 'Do we understand what we are seeing?' 'Are people saying what they want us to hear, or what they really think? Or what they are able to tell us?'

'WHO CAN WE TALK TO?'

I remember the briefing for the TPN project. There were Anangu aged care workers and non-Anangu aged care workers, such as Maureen. I spoke to Maureen. Maureen spoke to the Anangu worker. It was not appropriate for me to speak directly to her – I was an outsider.

'DO WE UNDERSTAND WHAT WE ARE HEARING?'

I remember hearing about the importance of fire for Anangu when on the APY Lands. And I thought to myself: 'Well this at last is a topic I am familiar with, I know something about fire. I have cooked barbecues, I have successfully set a fire in the open fireplace in my living room.' But as the conversation progressed I realised that the discussion was about the type of wood that one needed for a particular type of fire, that the use of the fire was critical to the wood that was selected. Is it

for food? Or for decorating timber to make artefacts? Or for warmth? And the location of the fire was critical too, and varied according to the season, the time of day, and the weather as people may wish to catch a breeze or the sun as they sit and use it. And I realised…

I knew nothing about fire in this context.

DO WE UNDERSTAND WHAT WE ARE SEEING?

I remember driving past a newly constructed fence outside a Town Camp in Alice Springs when I was doing some work there. My colleague, a local architect, exclaimed:

> 'What a great fence!' I was taken aback. I had seen a barrier, a means of control, and a separation from the street and from the community (all of which were negative). My colleague on the other hand, saw a statement of ownership.

This was Indigenous land. These people were determining who came and went in this place. It was theirs. Without that conversation I would have left with an opinion about the environment which completely missed the point, that only local context and knowledge could provide.

ARE PEOPLE SAYING WHAT THEY WANT US TO HEAR, OR WHAT THEY REALLY THINK? OR WHAT THEY ARE ABLE TO TELL US?

It is also vital that conversations and consultation are meaningful. I remember running sessions for older people at a senior citizens centre in Darwin NT Australia many years ago in preparation for a project there. My task was to find out what people wanted, what was important to them in residential aged care. As I explored this topic with the senior citizens lots of different stories and ideas came up. We spoke about having a place to sit, a place to make a cuppa, access to outdoors. I have never forgotten one woman's response: 'But if you made it like that then we wouldn't be allowed to live there'.

There will be things when working with Indigenous communities that, as non-Indigenous people, we are not told. There will be a reason for something being the way it is that can't be shared with us, or that we do not understand. It does not mean that there is no explanation, or that it is as simple as we are told. Gender and skin groups will determine who can talk to whom among Indigenous and non-Indigenous people. The way consultations are held will be particularly important, and cultural matters will influence where meetings are held and who is present. It will also impact on the time needed to make decisions and the way decisions are made.

Anangu sitting in a wiltja at TPN

Creating Tjilpi Pampaku Ngura (TPN)

The listening for TPN took many years and included an extensive process of visiting all parts of the Lands to talk through the issues. An Aged Care Steering committee comprising NHC, the NPY Women's Council and the AP Council was established and consultation was undertaken over six months with older people, their carers, clinic staff, community councils and women's centres. Up to 50 Anangu attended, travelling hundreds of kilometres to participate in steering committee meetings.

Site selection was a key. The selection of the site and its cultural and spiritual significance were seen as much more important than the design of the facility itself. It was important that the site was a place where all Anangu could feel welcome, recognizing that people will come from all parts of the Lands (which cover approx. 105,000 square kilometres) and so for many people TPN will be on someone else's country. The consultation also included making an inventory of all the things that were required to make the facility work in each community, such as good power supply, good water supply, access to a health clinic, staff, good roads, a (food) store and an airstrip [2].

The team led by Paul Pholeros worked with Anangu to create a place that would be meaningful for them. Having met with Anangu and APY Lands based aged care workers and explored what the design principles could mean in that place, the architects designed in response to these people in this context. The first thing to consider were questions which focused on what older Anangu want to do, what is important to them, their experiences, what they are able to do and their expectations. Anangu said that they wanted to participate in cultural business, travel, hunt and gather, teach young Anangu, visit their traditional country, attend funerals and conduct sorry business. They wished to maintain family and community links, socialize, practice traditional arts (such as making artefacts, basket weaving and painting), sing, dance and tell stories, and sit by the fire with other Anangu. They said that it was important that they have shelter from the elements (of extreme heat, extreme cold, dust and rain), have sheltered shady places to sit with a view, have good food including bush tucker, feel safe and have secure storage for their belongings.

As we listened, we learned that Anangu expect to go outside no matter how sick they are and be able to lie near fires and live close to or on the ground. Anangu can live happily with very few belongings. While everything and everyone comes and goes from the building, it is not the focus but rather a place for storing things and retreating to in times of bad weather. It is important that there can be separation between men and women and that family/social relationships which require distance between people can be respected. It is also necessary to be able to make a sorry camp, a place where people can move to and from when a person dies. It was apparent that while Anangu are more agile than other frail older people (seen for example in the way they climb into the back of vehicles and sit on the ground for hours) they are chronically ill with diseases such as diabetes, kidney, respiratory, skin, eye and heart disease and mobility problems.

Having gained a greater understanding of these 'big picture' questions, it was important to determine which aspects of the Fleming-Bennett design principles (highlighted in italics below) were most relevant when designing for older people on the APY Lands, and what the most appropriate response to these principles was.

Providing a fence around the site was an important part of *unobtrusively reducing risk*. Fences are seen as a positive thing on the APY Lands, perhaps in a similar way people from other cultures may view the wall of a living room. The fence prevents residents at TPN leaving and non-residents coming to TPN uninvited. It also identifies this place as the older person's place, thereby offering them peace and security. Anangu have an interesting appreciation of *scale* as they live with the vastness of the landscape and the smallness of a wiltja (traditional outdoor shelter). TPN is a small facility that has then been broken up into a number of small buildings. The buildings are designed to be small objects in a vast landscape, rather than be a significant presence. Anangu have a *clear view* of the places that are of interest and importance to them and so can choose where they wish to go. *Stimulation* is managed. There are two circulation systems: a 'front of house' way for residents and a 'back of house' route for staff. This allows residents to be undisturbed by the servicing and operation of the building, and instead to focus on the areas that are of interest to them such as a bedroom unit and the living/dining room. For many Anangu it will be the outdoor environment which will offer the most meaningful stimulation and cues. Rocks, views, mountains and fire are all likely to assist wayfinding and orientation.

As a person *moves around* TPN there are constant views and *engagement* with the outdoor environment. The outdoor environment is deliberately free from paths, and instead remains in a more natural state so people are able to move about outside following their own routes and creating new ways as appropriate. For Anangu, outdoor shelters (wiltjas) are a very *familiar* part of their lives. The outdoor environment was designed for these to be introduced and removed as appropriate over time. Rooms were designed to be of

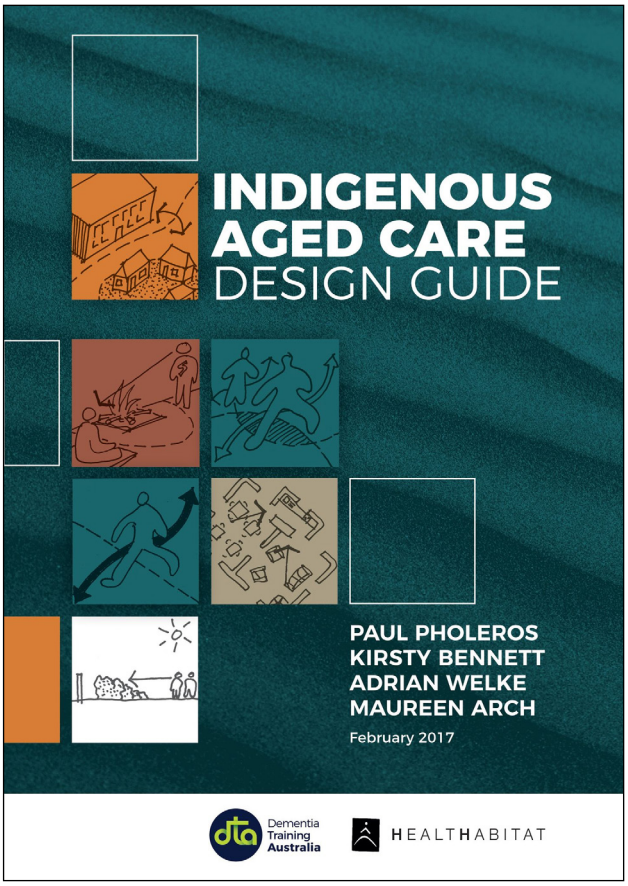
One of the small buildings of TPN

a size that is *familiar* to Anangu, recognizing that they are used to being inside in a small space or outside in big country. The ensuite layout is similar to the layout of bathrooms in houses on the Lands. There are many ways people can *be with others or alone* at TPN. This recognised that much of life in Indigenous communities is lived in public. On the other hand, privacy between different skin groups and genders is very important. The *relationship between TPN and the community* is best reflected in the selection of the site itself. Despite older Anangu's strong desire to take part in the life of the Lands, it was seen as very important that older people were given a quiet place to live, away from the noise and humbug (or bother) of the community. For Anangu *supporting movement and engagement* means having easy access to the outdoors and being able to sit around, eat outside, sleep outside, and see the surrounding country with adequate shade and shelter. It means having access to fire to make a cup of tea, make a spear, to cook, to make artefacts, to keep spirits away, to provide warmth and to dance and sing. It means having a fire that can be moved during the day to suit the sun and wind.

Indigenous Aged Care Design Guide

Some years after completing Tjilpi Pampaku Ngura TPN, Paul Pholeros was commissioned by the Commonwealth Government to write an Indigenous Aged Care Design Guide (referred to hereafter as 'the Guide'). Paul gathered the team who had worked on TPN together to create the Guide to assist in the design, construction, ongoing assessment and maintenance of aged care facilities for Aboriginal and Torres Strait Islander peoples. Paul's work on the National Indigenous Housing Guide, in his role as Manager of Healthabitat, was fundamental to his appointment, as was the successful creation of TPN. The team (Paul Pholeros, Kirsty Bennett, Adrian Welke and Maureen Arch) made a key decision early in the project to organise the Indigenous Aged Care Design Guide around the Fleming-Bennett design principles [3]. These principles were chosen because they are evidence based, and widely accepted in 'mainstream' aged care. The focus on evidence that informed the principles resonated strongly with the Paul's work on the National Indigenous Housing Guide [4] and the use of these principles also encouraged connections to be made with the aged care sector as a whole, rather than treating Indigenous aged care as a completely separate field.

While the Fleming-Bennett principles were articulated to help respond to the needs of people living with dementia, it was recognised that a building designed according to these principles provides a positive environment for all older people, staff and visitors.



Front Cover of the Indigenous Aged Care Design Guide

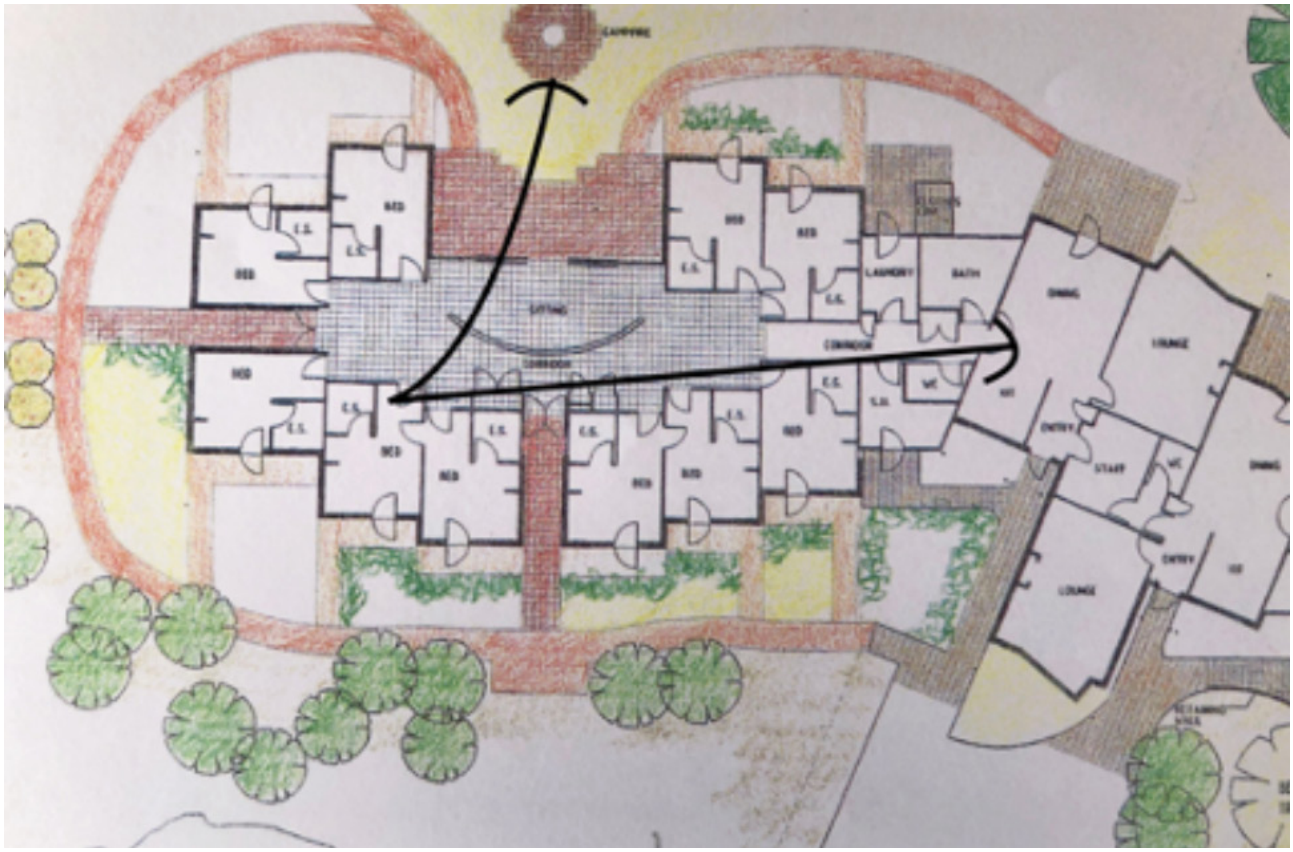
The team identified that for the Guide to be most effective, it should assist people to create environments according to the design principles, rather than present ready-made solutions. This is significant. It is not a guide that assists designers and operators to replicate TPN. TPN is a particular design response, for a particular community, geographical context, and time. The Guide provides information to help users apply the principles in a range of settings and communities. By taking a principles based approach, it was possible to produce a guide which could be used amidst the incredible diversity of Indigenous communities, in different contexts across Australia, from the central desert, to suburbia, inner city and the Gulf of Carpentaria.

I had seen the strength of a principles based approach (rather than a solution driven one) when I worked on a project in Alice Springs, NT in the mid 1990s. I was told by the client that every part of the building was to be suitable for an Indigenous or non-Indigenous older person. At the start of the project, I spent months consulting with a range of people in and around Alice Springs. I visited Town Camps, met with local Indigenous Councils, senior citizens, and the older people who were already living in cottages on the site. One thing that came up repeatedly was the importance of cooking in people's lives. While cooking was a common theme, the way people cooked was, however, quite different. For some people, a domestic kitchen was what they looked for. For others, it was a campfire, a chance to be outside and gather around. So we provided both.

When the time came for government approvals, I met with local departmental representatives from Territory Health to answer some questions. One related to the placement of the kitchen in the design. They argued it was well known that a kitchen needed to be the hub of aged care, and so they were concerned that it did not occupy a central position in our design. My response was to go back to the design principles. I explained that the reason a kitchen was important was because cooking was a priority in a *person's way of life*, and so it needed to be *familiar*, and *support engagement* if it was to be meaningful. Placing the kitchen centrally in the building would work for some people, but not everyone. The thing the residents would have in common was food preparation. The way they did it, what they ate, and where they liked to eat would vary greatly according to culture and lifestyle.

And so in our design when residents left their bedrooms they had a choice: 'Do I go outside to the campfire?' or 'Do I go along the short corridor to the kitchen?'. Both were *easy to see*. The residents could choose where they wanted to go and what they wanted to do. The design responded to the principles, rather than turning to a solution that had been successful elsewhere, in a different culture and context.

In addition to providing design guidance, the Guide also includes an assessment tool. An Environmental Assessment Tool (EAT) had been created by Richard Fleming, Ian Forbes and Kirsty Bennett some years before to support the use and application of the principles in a systematic way [5]. Using that tool as a starting point, the team looked to create a tool that responded specifically to Indigenous older people's needs. The Indigenous EAT is organised around the Fleming-Bennett principles. Existing EAT questions were reviewed. Questions were adapted where appropriate, and new ones were introduced to respond to particular needs and foci that were identified [3].



Linear plan with kitchen and campfire

Applying the principles in different cultures and contexts

The influence of culture and context on the application of key design principles is clearly seen in the Indigenous Aged Care Design Guide and the Indigenous EAT. For the Guide to be useful, attention needed to be paid not just to the content, but to the means of conveying it. The use of illustrations and the choice of language within the Guide are significant. The language used in the Guide was given careful consideration to minimize the likelihood of misinterpretation. (For many aged care workers who use the tool English may be a third or fourth language). For many of the questions, illustrations have also been used as these can convey an idea simply and successfully, particularly for people who are used to visual information.

The Guide provides design information that is relevant to each of the questions in the Indigenous EAT. For example, under the principle of *unobtrusively reducing risk*, there are a number of additional questions which address the importance of designing for health in many Indigenous settings. Healthabitat had identified that as a result of the failures of health hardware [4] in Indigenous housing (almost always due to poor initial construction or lack of routine maintenance), Indigenous people do not have the ability to carry out the most basic healthy living practices (such as the ability to wash people, wash clothes and bedding, remove waste safely from the house and immediate living environment, and improve nutrition) [4] Aged care facilities in remote locations are also likely to face difficulties in providing functioning health hardware due to the harshness of the environment, lack of available tradespeople and poor design and maintenance. In this context it was therefore important that the Indigenous EAT includes a number of additional questions to determine whether kitchens, toilets, bathrooms and ensuites are functioning in the aged care facility.

As another example, questions under the principle '*Doing what you want to do*' include a number of things that would be specifically appropriate and desirable for Indigenous residents to be involved in, depending on their lifestyle and location.

These include having access to good clean sand for sitting and dancing, being able to enjoy views to country, sleeping or resting in a cool (or warm) place outside and being able to make spears, create artefacts, or brew a cup of tea. As the Indigenous EAT is designed to be

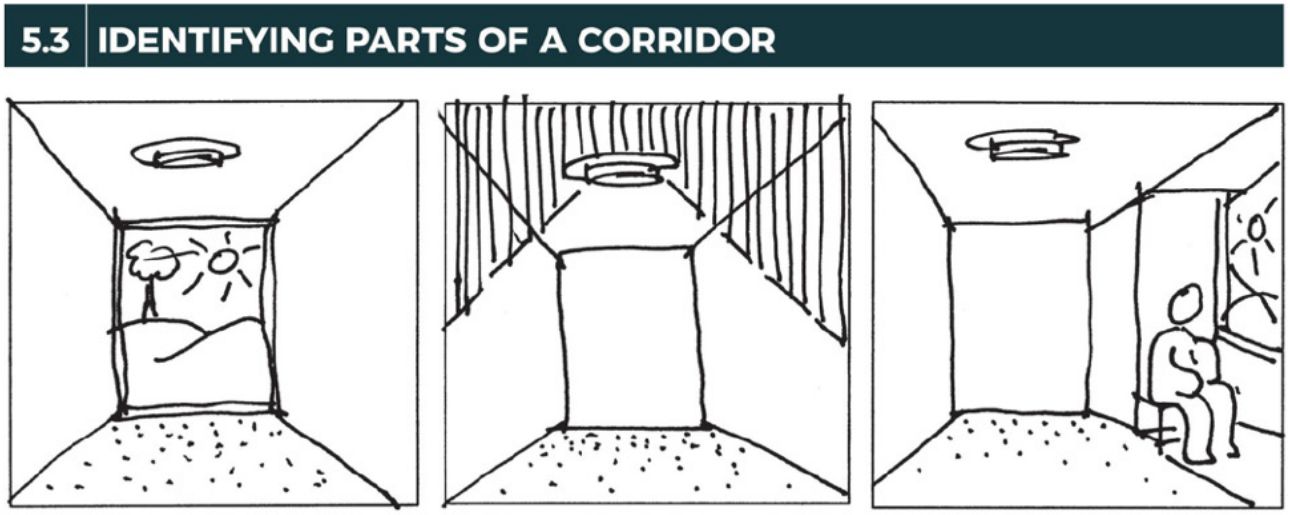
used in Indigenous settings across Australia in locations as geographically, climatically and culturally different as Borroloola, Brunswick and Pukatja, the range of items included under this principle is extensive. The questions also recognize that Indigenous people are likely to want to be outside no matter how frail they are.

Reflection and Learning

The Indigenous Aged Care Design Guide provides a valuable example of the way key design principles can be used to guide design in very different cultures and contexts, and also of the way different cultures can inform and teach each other. Tjilpi Pampaku Ngura, home for up to 16 Anangu in central Australia, is an illustration of putting principles into practice in a different cultural context, after much listening. The way of listening and the years spent in conversation were crucial to realising the project.

It can be hard to take a step back and see the world differently, to accept that something we may value deeply can be meaningless to someone else. It can be challenging to understand that someone values things that we would never have imagined could be important. It can be difficult to recognise that we know a lot about where we are, something of places we are invited into, and very little about other places that we look at from the outside. A resource like the Guide can help us approach this challenge

There are many examples of projects in this report from all around the world. It is important to remember as we read about them, that like TPN they have all been informed by their own particular cultures and contexts. Understanding each of these environments in its context and culture will be essential if we are to learn from them and gain from the richness they have to offer.



Illustrations used to convey ideas

Dementia, design and development: approaches and recommendations from STRiDE Countries

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STRiDE (Strengthening Responses to Dementia in Developing Countries) is a multi-country, multidisciplinary research project which aims to improve the lives of persons living with dementia and their loved ones through effective, affordable, appropriate and equitable care. It is led by the London School of Economics and Political Science and is funded by the Global Challenges Research Fund, UK. ADI is a proud partner of this progressive project.

STRiDE targets seven middle-income countries: Brazil, India, Indonesia, Jamaica, Kenya, Mexico and South Africa. These countries represent diverse regions of the world, with project teams spanning several languages, cultures, backgrounds and areas of expertise. The project merges the academic rigour of designated educational institutions in each country with community-based expertise from non-governmental organization (NGO) representation. This ensures holistic, realistic and strategic approaches to building capacity for dementia awareness, research, and care in these countries. The Research Engagement and Impact Leads from the STRiDE countries have co-authored this chapter. As the representatives of our countries' Alzheimer's association and as liaisons with other NGOs and stakeholders, our mandate is to ensure that the research being produced benefits its end-users: persons living with dementia and their carers. While many of us are current or former carers of loved ones living with dementia, we acknowledge that persons living with dementia are not represented in the authorship of the chapter or explicitly in many of published resources we drew upon in writing this chapter. This is not an oversight on our part, but a reflection of the stigma in many low- and middle-income countries (LMICs) related to identifying as someone living with dementia, particularly during the earlier stages of dementia.

The STRiDE countries, like many low- and middle-income countries (LMICs), are very diverse (e.g. population size, land mass, languages, ethnicities, GDP sector compositions). Indonesia has approximately 6,000 inhabited islands, and over 11,000 uninhabited

ones. In India, there are 22 recognized languages; in South Africa there are 11 official languages. In Brazil, which is almost the size of the whole of Europe, there are more than 160 languages and dialects spoken by indigenous peoples. In all countries, some older persons live long, healthy lives and have little need for care, while others may need full time care for decades. Some segments of older persons in LMICs are wealthy; others perhaps are the only family members with consistent income via pensions, and so they support their families well into their 80s. Some may continue to work until their 70s in order to earn an income or remain active. Others may be wholly financially dependent on their loved ones. It is therefore important that when we think of environmental design for dementia, we are mindful that there are diverse needs in the population of persons living with dementia [6].

Environmental design for dementia may look different in different individual, family and community contexts, within and across LMICs.

It may look different depending on factors related, but not limited to, economic and social position.

While it is important to address elements of standard care home designs, such as those described in other chapters of this report, this chapter focuses on the average older person in LMICs who does not belong to high income groups and who therefore likely lives with their families, lives alone, or lives in an unregulated facility. It presents the principles of design for dementia used in high-income countries (HICs) in terms of how they may or may not apply to LMICs, draws on real world experiences, highlights areas for further research and advocacy, and makes recommendations for LMIC contexts.

Designing for dementia; Designing for long-term care

Persons with dementia often become recipients of long-term care (LTC). LTC refers to holistic care for persons who cannot look after themselves on a day-to-day basis over a period of time. Such care may be provided in personal homes or in private or public LTC facilities.

As dementia advocates, we lobby for LTC to be a core component of health and social care services and systems. Yet, we do so in countries in which LTC is often fragmented, inconsistent, insufficient and poorly regulated.

In some countries, like India, Indonesia, Jamaica, and Kenya, care homes are not very common, and most persons prefer to care for their loved ones themselves at home. In countries like Indonesia historically when community members see that a family has placed a loved one in a care home, they judge the family members as not responsible, capable, or caring enough to take care of their loved ones. They see such a placement as a type of abandonment or neglect. There have, however, been gradual shifts in these cultural perceptions. As more senior living facilities targeting higher income groups are built and funded by the private sector, placing family members in these facilities is being regarded as an acceptable option. Other countries, like Brazil, Mexico, and South Africa, have vast LTC sectors since demand for paid care has increased with life expectancy, rural to urban migration, and changing family structures. Even in those contexts, however, most long-term care facilities (LTCF) are privately owned and are very expensive. The average older person in a LMIC who does not belong to a high-income group is therefore likely to live with their families, live alone, or live in a largely unregulated and privately owned LTCF.

Palliative care, geriatrics or nursing homes are familiar terms in many LMICs. However, they are not always identified as LTC services or given adequate public health care priority due to competing demands on government funding and attention. The population segment of persons 65 and older is rapidly growing in developing countries. Despite the economic and social consequences of this population ageing, care services and systems are not adequately prepared to manage the current and future needs of older persons and their carers. The services and infrastructure of many developing countries are only just coming to terms with the impact and challenges of an ageing population, including increasing demand for LTC. Because the demand is outstripping supply in many developing countries, where public healthcare facilities are already overburdened, a largely unregulated private LTC industry has emerged.

An example of a higher-end facility in Atlixco, Mexico is pictured below.

The COVID-19 pandemic has forced many stakeholders in LMICs to pay attention to older persons and their carers in LTC facilities. In many countries, this is the first time these facilities have received such targeted and sustained attention. It has given rise to many conversations about the importance of industry regulation against elder abuse, neglect, and fraud, as well as the management of infectious diseases.

Diversity in LMICs: Working without stereotypes and assumptions

Although most care homes in LMICs may be under-regulated and even perhaps not recognized by law there also exists a segment of the market that aims to meet the needs of a higher-income demographic. Urban, more elite facilities which incorporate some principles of design for dementia certainly exist in LMICs. Some of these, such as the RUKUN Senior Care Facility in Indonesia, are featured in the case studies of this report.

The facility is built on all one level for easy accessibility and designed to allow residents to take advantage of the tropical climate and outdoor space. The grounds include a pool, to help residents remain active. These are elements of standard care home designs that can be found across both HICs and LMICs.

The impact of policy (or lack thereof) on design in LMICs

In contexts where there are few to no regulations for care homes, design is often not a major concern. For example, in Jamaica, of the 185 known private nursing homes, only 14 are registered with the Standards and Regulation Division at the Ministry of Health and Wellness [7]. While this division has issued mandatory guidelines for care homes, including some related to design that can benefit persons with dementia, the known implementation rate is lower than 10%. In Mexico, it is estimated that 80% of LTCF are unregulated and are simply private, adapted residences.

> In Kenya, dementia has traditionally not been viewed as a serious health condition; design for dementia therefore has not been a priority.

However, designing for persons with disability has been a priority, as 1.3 million persons with disability are prevented from accessing public buildings due to narrow corridors, step-only access, and similar able-bodied design assumptions. Advocacy efforts resulted in property owners being asked to retrofit their buildings in 2014 [8]. But the out-of-pocket

cost to redesign buildings resulted in unwillingness of many property owners to make the changes such as installation of ramps. In 2019, there was an amendment to the bill for persons with disabilities [9] and recommendations are ongoing of how to make buildings more accessible for people living with disabilities. This has been an opportunity for the STRiDE team in Kenya to lobby for the consideration of persons with dementia within disability rights.

In Brazil, over 14% of its 200 million population is aged 60 and over [10]. This spurred the Brazilian Ministry of Health in 2018 to issue the Strategic Age-Friendly Cities programme, based on the WHO Global Age-Friendly Cities with the aim to adapt cities' physical, social and political environments in order to better facilitate active and healthy aging. In 2019, the Elderly Care Department in the Ministry of Health in Brazil, together with UNESCO, designed an initiative to map those good practices. A total of 177 experiences (initiatives) were sent by 124 Age-Friendly Cities and grouped under eight different dimensions: respect and social inclusion; support, health and care; learning opportunities; participation; communication and information; buildings and outdoor spaces; transportation and urban mobility; and housing [11]. Only four initiatives (approx. 2%) were about public spaces and buildings designed to be welcoming, safe and accessible. There were no initiatives about adapting housing. And

there is no evidence of experiences designed specifically for persons living with dementia.

Despite the country's progressive approach to policy inclusion of older persons, little (if any) attention is given to the need for persons to 'age in place' or to be accommodated in their own homes.

Relevance of the 10 principles of design for dementia in LMICs

The year 2020 has brought about major shifts in the way that we think about healthcare, social care, our environment, our relationships, relationships between traditionally privileged and underprivileged groups and future needs. The recommendations on designing for persons with dementia are based on HIC perspectives and experiences, yet nearly 70% of persons with dementia will live in LMICs countries within the next three decades [12]. The 10 principles of design for dementia [13] have been informed by the desire to use physical space as a part of person-centred, creative care management for persons with dementia (13, 14).

Yet, not all of these principles are applicable to some of the diverse contexts in LMICs.

PRINCIPLE 1 UNOBTRUSIVELY REDUCE RISK & PRINCIPLE 6 SUPPORT MOVEMENT AND ENGAGEMENT: SAFETY AS THE MAIN PRIORITY

Safety is the number one priority for designing for dementia in LMICs. The combined effects of low awareness of dementia as a health and social care issue and the few dementia care support resources in family homes and the wider community make safety within and outside of the living space a central concern. Reducing risk in the lived and built environment and supporting independent movement is key to protecting persons with dementia and facilitating their living as long as possible with minimal constant supervision (15, 16).

To do this, those who care for loved ones at home must balance the safety-related adaptations to the home space with how accepting the person living with dementia is to those changes. The person living with dementia may experience changes as an invasion to his/her privacy and strategies meant to keep their movements restricted [17]. In addition, the homes often continue to be the home spaces of other household members whose needs and preferences must also be respected.

BOX 1. WHAT EXACTLY *IS* DESIGN FOR DEMENTIA?

"I used to think about environmental design as something restricted to public spaces and outdoor areas. For me, the housing safety itself was more like something each individual would have to think about and be responsible for, independent of its external surrounding and the social, political and historical relations. My Mom´s diagnosis has changed my perception of what it means to live in a place designed to be safe and accessible. When faced with Alzheimer´s, the place she´s lived for the last 41 years became unsafe and uneasy. I realised the house was cluttered with portraits, rugs and furniture, the neighbourhood was excessively noisy and not supportive of any kind of engagement, and the public spaces were hostile to people living with dementia. Moving out was not an option for many reasons. Me, my Dad, my sister and my Mom herself were then left with the task of having to adapt everything we could and to balance her wellbeing while keeping her sense of belonging and identity."
Elaine Mateus, STRiDE Brazil Research Impact and Engagement Lead

Over time, the balance, vision, depth perception, and physical mobility of persons with dementia are affected. Some major safety concerns for persons with dementia in LMICs (and in HICs) include:

Falls: Older persons with dementia fall twice as often as their counterparts, and are at higher rates of morbidity, mortality and hospitalization when they do fall [18]. In most of the STRiDE countries, Fall Prevention Clinics are either non-existent or very few in number. These clinics help prevent and treat persons recovering from falls. In many countries, this resource is largely unheard of even among healthcare professionals. In LMICs, the onus is therefore on the caregivers, whether paid or unpaid, to protect their loved one with dementia from falls and to help with rehabilitation if they do fall.

Kitchen injuries: Burns from the stove, mistakenly ingesting cleaning products, cuts from sharp objects or accidental gas leaks are all common concerns when persons living with dementia are living on their own or being cared for at home. According to one caregiver,

'every little corner of the house needed some kind of change and adaptation as the disease progressed, and still does, despite the [stage of dementia]'.

Injury caused by disorientation: When persons with dementia are unable to successfully navigate their surroundings, for example, to find the toilet or to exit a space, they become disoriented, often experience related panic, frustration or missteps, and may therefore hurt themselves or others unintentionally. In these cases, awareness of unpredictable symptoms of dementia like aggression and how to best manage these is important.

Wandering: This can occur especially at night as part of sundowning symptoms – when persons with dementia become disoriented. They may try to find their way to a more familiar place. Unfortunately, in LMICs where police officers and members of the wider community are not sensitized to recognizing symptoms of dementia, incorrectly believe that dementia is a normal part of ageing, or where there is a lot of stigma around dementia, persons with dementia who wander off are often ignored or dismissed and therefore locating them becomes even more challenging. In some instances, persons with dementia who were disoriented and lost and displayed aggressive symptoms are at risk of experiencing dangerous and fatal encounters.

Simple design solutions for reducing the risk of these safety concerns while supporting movement have been suggested and implemented in both HICs and LMICs for decades.

For example, in Kenya and South Africa, families are often advised to make the following changes to their home:

- Install walk-in showers where there is not already a walk-in shower to help prevent falls
- Add grab bars to the shower or tub to support independence and safe movement
- Add textured stickers to slippery surfaces and apply adhesives to keep throw rugs and carpeting in place to help prevent falls
- Use night lights in hallways, bedrooms and bathrooms to help prevent disorientation or symptoms of sundowning
- Have a photo of the toilet or a sign written legibly at the door to help prevent disorientation
- Construct ramps and remove stairs to help prevent falls or to facilitate wheelchairs where needed
- Install a safety valve / child lock for the gas cylinder to help prevent gas leaks

- Incorporate pleasant and comforting colours and tones in the space to enhance the aesthetics
- Incorporate elements of nature where possible

Simple changes such as removing a mat that can cause anyone to trip, decluttering pathways, removing mirrors and startling paintings, or improving lighting are often recommended by Alzheimer's associations around the world. These measures and interventions address issues that have been identified in research [14]. They are cost effective, do not require professional services, and can be done fairly quickly and easily.

Community mobilization is also a type of environmental design. In some countries, rapid response interventions are recent innovations that offer people in crisis care at home [15]. While such adaptation is not prevalent in many LMICs, there are a few encouraging initiatives. In Indonesia, for example, the regional government of Jakarta collaborated with the local Alzheimer association, Alzheimer's Indonesia, to establish the Purple Troops. This is a network of social workers who have been trained in communication with persons living with dementia and who become first responders when a missing older person is found in the city.

PRINCIPLE 4 REDUCE UNHELPFUL STIMULATION AND PRINCIPLE 5 OPTIMISE HELPFUL STIMULATION: EDUCATION AND AWARENESS RAISING AS FUNDAMENTAL

Reducing unhelpful stimulation is another universally feasible principle. The culture of respect for older persons that many in LMICs have means that families are often sensitive to the needs of their older relatives. In addition, in a number of LMICs one of the most frequently occurring living arrangements of persons 65 and older is the multigenerational household [19]. While this arrangement can help with awareness of the needs of older persons, this is not always the case. In many LMICs there is also a considerable proportion of seniors who live on their own and whose care needs are not visible to or known by many.

These realities are likely more acute for persons living with dementia. In LMIC contexts, where dementia is still a taboo condition, many family members, unpaid carers, and even paid carers are not aware of what stimulation persons with dementia may find helpful. Thus, this might result in isolation and a lack of stimulation in their own homes.

These two principles must therefore be underpinned by educating individuals, families, and the community

in general about how dementia progression affects the senses, what under- and over-stimulation may look like in persons living with dementia, how to ensure living spaces and relationships are as harmonious and conflict free as possible, and how to manage behaviours when the person with dementia is either under- or over-stimulated (Barrett et al., 2019).

BOX 2. TRANSFORMING SPACES EQUALS TRANSFORMING EXPERIENCES

> "The hospital [in the early 2000s] looked like a sanatorium, a real insane asylum for older people. It was awful and too old. I felt as if I were in a prison. Then the place went into an amazing renovation process, an incredible work with colours, glass, and natural lighting. The wards all have different colours and colourful lanes. It looks incredible. One can imagine the impact of this on the patients. Even for [those of] us who worked there as researchers – we [felt that we were] in a modern place. It cheered our hearts. *Monica Sanches Yassuda, Psychologist and Professor, Brazil*

Individual, family and community level stigma, shame, and awareness of the disease must be addressed if appropriate strategies for under or over stimulation are to be created. This is the case particularly during the COVID-19 pandemic. The need to protect older persons by practicing physical distance, especially with those at greater risk, such as persons with dementia, may increase the likelihood of the isolation of people living with dementia. Family and community members do not visit or assist as often. This neglect has left many of them feeling scared and alone.

STRiDE Research Impact and Engagement Leads have led or participated in a variety of efforts in their local contexts that encourage alternative means of connecting with persons with dementia and their carers. In Indonesia, for example, the Alzheimer's association has reached out to persons with dementia for chats, for video calls for dancing, and to share resources with carers. In Jamaica, telephone and video calls for dementia care management consultations have provided family members and loved ones with customized and practical tips and strategies for improving the quality of life of both the carer and the person with dementia by reducing potential stressors

in the environment and instead making the space and the relationships as peaceful as possible. Similarly, Alzheimer's Indonesia recently initiated a Care Navigator Programme for families of persons living with dementia to access online consultation with professionals or experts by experience such as current or former carers. The consultations are meant to provide practical advice including about affordable home modifications to support persons living with dementia. In South Africa, the Alzheimer's association personnel provide people living with dementia, family members, and carers with support and counseling through video calls (e.g. Zoom) and text messaging (e.g. WhatsApp). The association's personnel have also received virtual training to deal with COVID-19 related challenges among those they serve.

PRINCIPLE 2 PROVIDE A HUMAN SCALE, PRINCIPLE 3 ALLOW PEOPLE TO SEE AND BE SEEN, & PRINCIPLE 8 PROVIDE A VARIETY OF PLACES TO BE ALONE OR WITH OTHERS IN THE UNIT: THE NEED TO WORK WITH THE CONTEXT

These principles are about empowering persons with dementia to manage everyday interactions and navigate their everyday environment. This is done by ensuring that only a few people are in their space on a regular basis and by ensuring that the size of the building and its elements (like doors and corridors) are not intimidating (14, 20). Advising on the scale of the physical space is more applicable to built-to-purpose LTCFs. However, in LMICs, most LTCFs are set up in existing structures that have been re-purposed, such as family homes. Many of the owners of these facilities find it impractical or prohibitively expensive to retrofit the spaces. In such cases, the spatial layouts may inadvertently reduce the competent functioning of the persons living with dementia.

> Managing the scale of the crowd in homes can be challenging.

In a number of the STRiDE countries, there are informal settlements and communities. In such communities there is high unemployment; the living space is characterized by close quarters bordered by zinc fences; between five to ten family members are housed in small, makeshift structures with shared bathrooms; and running and potable water is not consistently available if available at all. These communities are often close-knit, with neighbours regularly traversing each other's yards and homes. A "human scale" in these settings is therefore quite different and perhaps less alterable than what is presumed in HICs.

BOX 3. THE REALITIES OF LIVING SPACES IN POOR COMMUNITIES

"A neighbourhood is a set of rooms with the minimum necessary. They share basic services such as bathroom and laundry area. In general, they are two-story buildings and very, very old and very fragile. In these spaces there is no space or way to modify anything in the environment in favour of the person with dementia. They live on average [in spaces with] 5 to 7 people including adults, children, [and] adolescents. If everyone has to go to work and / or school, they will leave the [person with dementia] tied or locked in the room. Sometimes…the neighbours will go to feed or help [the person with dementia] drink, often in exchange for a payment that does not include the hygiene or cleaning of the person with dementia". *Nurse Maite, Mexico*

In addition, in both residential and commercial care homes in LMICs it may be impractical or quite challenging to manage the crowds and human traffic. In Jamaica, for example, due to urban density, crowding occurs in both low-income communities and in upscale areas in Jamaica's capital city of Kingston. In these communities, many condominiums create small communities with high turnover of short-term renting residents. In formal care facilities, the governing standards and regulations allow up to four residents per bedroom, though beds must be at least four feet apart, and provisions must be made for each resident to feel like they have a space of their own within the room. However – pre-COVID-19 – the turnover among residents, interactions with staff and visits from loved ones, health or social care professionals often led to a lot of daily traffic. Time will tell about how physical distancing has supported this principle in care homes, or whether it has led to more adverse consequences like isolation or neglect.

Principle 3 refers to the need to provide good visual access to different rooms and other persons within the space. This

> visual access is meant to facilitate the person with dementia making choices,

seeing where she or he wants to go, and enabling carers to see those they are caring for. It assumes that persons with dementia have a choice when navigating their physical and social spaces. While it is important to provide opportunities for persons living with dementia

[21], given the conditions described earlier, even for persons with dementia who are in the early stages and are capable of navigating their space,

there may not be much choice available.

In poor communities a lack of distinct rooms or a designated primary caregiver may mean that a person with dementia is dependent on a daily basis on whatever circumstances arise within the home. A priority in this context should instead focus on supporting persons with dementia in such environments and requires adapting to daily individual variations and resources.

Principle 8 again speaks about choice – the need for the person with dementia to be able to choose to be on their own or to spend time with others. Often persons with dementia in these contexts rely on help from others for their basic daily needs (food, toileting, cleaning). These needs and the realities of living in close quarters with others mean that there are often few options for different spaces for different activities.

Working with the specific contexts in creative ways is essential in such cases.

PRINCIPLE 7 CREATE A FAMILIAR PLACE: CONSIDER THE PERSON'S CULTURAL IDENTITY

Design for dementia must incorporate what is familiar to the person – this must happen at both the individual level and the cultural level. Individually, memory boxes, which hold mementos from the life of a person living with dementia and harken to earlier periods of their life, is a design device often used in LTCFs in HICs and LMICs.

BOX 4. THE BALANCE BETWEEN NORMS AND NEEDS

"The challenge is not only to know what to do, but to understand the particularities of each context. The rug that gets in the way and brings danger of falls is the same rug that represents memories and awakens good feelings. The decision to remove that piece or to find other ways to keep it safely depends on a reflection of what it deeply means." *Maria Luisa Trinidade Bastetti, Architect and Professor of Geriatrics, Brazil*

Mementos also extend to the external surroundings. One of the few care homes in Kenya asks family members of new residents about details of the resident's previous home which they can incorporate into the residence's built environment. They incorporate details such as placing the resident's previous house number on their bedroom door (where applicable); they paint the walls of the resident's bedroom in the colour of their previous home; and, where possible, they furnish and decorate the resident's room and the general living space with smaller items of furniture and photos from the resident's life before the care facility. Similarly, in South Africa, some care homes encourage families to furnish the room of the person living with dementia with personal furniture and to include personal paintings and photos to decorate the room.

It is also important to ensure that the LTCF is culturally appropriate in design and layout

(14, 20). When "best practices" in design from HICs are adopted in LMICs, it is important to modify and customise as appropriate. In India, dementia care in institutional settings is relatively new; people with dementia are still mostly cared for at home by immediate family members. In urban locations there are a few care homes that have been constructed specifically for people living with dementia in mind, whose designs are inspired from care settings in HICs like Australia and the Netherlands. In these spaces, the local cultural contexts are merged with these HIC designs. An Indian flair is visible in several ways: the common corridor/pathways fitted with Indian tiles/stones; dedicated places for worship; dedicated spaces for residents to stroll; local varieties of trees and plants in the vicinity of the home; furniture and spatial décor such as swings and traditional cane furniture; walls painted soberly; incense sticks lit throughout the space. India lies in the tropical region, with relatively warm climate most of the months. The rooms are therefore very well ventilated, with provisions for daylight permeating the room. In the evenings, the rooms are well lit. While

some exclusive care homes are able to incorporate local culture in international design in an intimate residential way,

others also maintain Indian cultural elements but are largely based on a hospital setting where the facility is divided in floors with large rooms, segregated by

partitions to accommodate people with dementia and with large shared bathrooms and toilets. The residents are generally grouped based on the severity of the disease condition and are strategically accommodated in different floors. They have specific activity schedules including different therapies and such places are designed with relevant Indian elements to help stimulate the residents cognitively.

These types of modifications and considerations are of paramount importance. In cultures where LTCF has not traditionally been the norm, when a person living with dementia is moved into a LTCF, they can experience it as an abrupt stripping of whatever remaining sense of identity they may have.

BOX 5. LTCF AS CONTRIBUTING TO GREATER LOSS AND IDENTITY EROSION

"One can perceive that the care homes try to do the best job they can, but that´s not always possible. [Older persons] start the losing process the minute they leave their homes. They usually have a number of meaningful objects, things they've kept for a lifetime, but they can take only a few of them. When they arrive at the LTC institution, not everything can [come along]. This is an eroding process that ends up with the older person losing his/her identity." *Nadir Aparecida Menezes Estevam da Silva, Social Assistant, Brazil*

PRINCIPLE 9 PROVIDE LINKS TO THE COMMUNITY: THE NEED TO LINK BOTH THE FAMILY *AND* THE COMMUNITY TO THE LTCF

This principle focuses on frequent interactions with family members and the broader community for the person with dementia to maintain their sense of independence for as long as possible. These interactions and connections have traditionally occurred in person. In contexts where the care environment is the family home, interactions may occur in spaces referenced earlier: spaces where they can see and communicate with household members and neighbours. Remaining in their households and communities often means benefitting from services rendered by places of worship, senior citizen groups and other community-based organisations.

BOX 6. FAMILIES AND COMMUNITIES ARE ESSENTIAL FOR GOOD QUALITY OF LIFE

"Two key [issues] have to be addressed: (1) the integration of the families with the LTC facilities, and (2) the integration of the LTC facilities with their surroundings and the whole community or neighbourhood. The families want to place their older relatives into the institutions and forget about the existence of that world. There´s a lot of prejudice and stigma. [Older persons] are infantilized in the LTC facilities, especially the ones living with dementia. The families distance themselves from the LTC facilities and the LTC facilities distance themselves from the families. This is a taboo subject…nobody wants to talk about it. The LTC institutions prevent themselves from doing this critical job of taking care of the older persons and of their families. When we say that the older person needs to bring what is meaningful to him/her, nothing compares to the meaning of the family. And older people live in the communities [that the LTC facilities are situated in]. They cannot be kept confined within the LTC facility walls. They should be able to keep walking around the neighbourhood, going to the church etc. Even if the person lives with Alzheimer´s, she or he should be able to hang out and to connect with the community." *Nadir Aparecida Menezes, Social Assistant, Brazil*

During the COVID-19 pandemic, those who are being cared for in their homes may have experienced less of an abrupt change in their connections than those who are cared for in LTCF. Those in LTCF have experienced great change in the frequency of physical contact with family members as well as staff and volunteers are the facilities. The COVID-19 experience highlights the need for greater integration of health and social care particularly in public and private paid care.

The assumption is often that in unpaid care contexts, linking with the community is expected and easy. However, it is frequently a challenge. Family and community members who rotate care responsibilities have different schedules. Carers are juggling multiple responsibilities and are stretched. In some contexts, family care arrangements have evolved to address these and other care management issues. In close-knit communities and densely populated areas, neighbours also play a role in looking after persons living with dementia. For example, in Jakarta, Indonesia, a carer recounted her neighbour's help in preventing her father from wandering and getting lost by greeting him and asking him to come home with them when she saw him walking out of the neighbourhood.

In a number of LMICs traditionally three generations of family members live under the same roof. Such living arrangements are undergoing changes over the past decades (United Nations, 2019). In India, for example,

with urbanisation and job-related migration, nuclear families have become more common and so many older persons are often by themselves

either as couples or alone. If such persons develop dementia, adult children sometimes feel obligated to care for their parents and relocate to where the parents are living. However, they do not move into the same house; they live close by, either in the same apartment complex or another house in the vicinity. This type of arrangement facilitates both the independent living of the parents and the nuclear family life of the adult children who may have families of their own. Adult children live close enough to drop in on a daily basis and help with errands and needs such as trips to doctor.

Grandchildren get to spend quality time with their grandparents, and since the time spent is scheduled and routine, this has benefitted the intergenerational relationship and bonding.

However, it is important to keep in mind that this option is available to those with the resources to make this kind of move and adjustment.

PRINCIPLE 10 DESIGN IN RESPONSE TO VISION FOR LIFE: BE CLEAR ABOUT WHOSE PHILOSOPHY OF CARE IS BEING PRACTISED

This principle speaks to the need for environmental designs to reflect the care facility's philosophy of care. Aesthetics is considered by some to be a key element to the philosophy of care. For many, it is believed that

the aesthetics of the space in which a person with dementia lives can have a major impact on their sense of wellbeing and mood as well as that of their caregivers.

Along these lines, there is often a push for LTCF to consider the aesthetics of their buildings and the impact this can have on patients and staff. In addition, LTCFs are encouraged to incorporate an appreciation of aesthetics as they ensure the design has appropriate spatial modifications. For those who are caring for persons with dementia in family homes, spatial modifications, however, often impinge on their own aesthetics and what they have grown accustomed to with their home layout. Resistance to spatial modifications can come from both the person living with dementia *and* from other family members. Stigma surrounding dementia leads persons to not want to have any visible indicators that their lives have changed or that their living space has been modified to accommodate disability. Such modifications are seen as sources of embarrassment for the family. Stigma and a lack of awareness also mean that many people do not see cognitive impairments as disabilities.

In other cases, creating comforting and pleasant aesthetics simply may not be achievable and is certainly not a priority.

Low-income communities generally do not have the option of adapting lighting, colours, or surroundings.

In fact, many low-income communities live in areas with high levels of noise, pollution, and crime. Their environments may compromise the health and well-being of these persons over the course of their lives.

BOX 7. A TRICKY BALANCE: MOVEMENT NEEDS & SECURITY CONCERNS

"The more affordable LTCF are overcrowded and residents stay in dormitory like rooms. Their movements are restricted, and privacy is almost non-existent. Some of these LTCF may have a small garden, but the doors to the garden are locked with the intention of ensuring the safety of residents. However, this suggests that they are in fact not dementia friendly environments. On the other hand, as South Africa is a country with a high crime rate, security is of utmost importance for LTCF as well as private residences. Most LTCF have security measures in place, entrances are equipped with security gates and some LTCF have security guards to ensure the safety of residents and personnel. Most private homes also are equipped with fences, burglar proof and security gates." *Loraine Schirlinger, volunteer and former Regional Manager, Alzheimer's South Africa*

Just as physical environment can be adapted for positive intervention, pre-existing environmental conditions can also lead to barriers to adequate care in dementia. In Mexico, for example, according to data from the 2015 Intercensal Survey, 18% of homes with older persons still use firewood or coal as the main source of fuel; 6.4% do not have drainage, 4.8% do not have piped water, and 3.8% have a dirt floor.

Design in response to vision for life is a principle that therefore needs to be rooted in an appreciation of whose philosophy of care is being advocated and emulated.

A blind adoption of spatial layout and modifications from HICs to the care contexts of the average older person in an LMIC will likely exclude those who are integral in the day-to-day care network such as domestic workers and visiting community members.

Conclusion

In many LMICs while there are efforts to promote dementia inclusive communities, environmental design for dementia has not been explicitly applied to the extent to which it has in HICs. Spatial and environmental considerations are understood to be important particularly related to safety and wandering. However, among the vast majority of the population, there is considerably less focus on aesthetics, architectural and environmental design specific to dementia care. Instead, common sense contextual design takes precedent. Facilities and families do what they can with the resources they have available in the spaces in which they are based.

Embedded in discussions about design for dementia are assumptions about choice.

The word choice is frequently noted in the presentation of the design principles [21]. Yet, 'choice' is related to power. Power is related to resources. And low resourced contexts are often constrained in the choices available. Even in the midst of such constraint, however, there are examples of remarkable resilience and adaptation.

The economics of design

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Introduction

The physical environment has the potential to affect the behaviour, function, well-being, social abilities, orientation, and care outcomes of a person living with dementia [22]. It is therefore highly worthwhile for all decision-makers, from governments and policy makers through to property developers, designers and architects to consider both the costs and the positive and negative health consequences of dementia-specific design initiatives. This chapter will provide an overview of the relevant aspects in the field of health economics, as well as methodological challenges specific to dementia and the built environment. We have included four case studies from the international literature exploring the application of economic evaluation to the built environment, and to dementia-specific design in particular. Implications for researchers and policy makers will be discussed and recommendations provided for future research.

GLOBAL ECONOMIC IMPACT OF DEMENTIA

Dementia has a substantial and growing economic impact worldwide. The most up-to-date global estimate, published in the 2015 World Alzheimer Report, indicates that the global cost of dementia of exceeded US$818 billion, an annual cost today in excess of US$1trillion and forecast to double by 2030 and continues to rise [23]. To place this in context, this makes the global costs of dementia similar in magnitude to the Gross Domestic Product (GDP) of countries like the Netherlands and Saudi Arabia, the 17th and 18th largest economies in the world [24, 25].

The costs of caring for people with dementia are higher in higher income countries. This is disproportionate relative to disease prevalence. The 2015 World Alzheimer Report estimated that 58% of all people with dementia live in countries currently classified by the World Bank as low or middle income countries, whereas 90% of dementia care costs occur in high income countries (23.) This pattern is consistent with other leading chronic diseases such as cardiovascular disease, diabetes and respiratory ailments [26].

Much of the burden of caring for people with dementia falls on families rather than on healthcare systems. The costs associated with dementia fall into three broad categories: direct health costs, social care costs, and informal family care costs. Direct health costs account for a modest one fifth of global dementia costs [23] In high-income countries, informal care and formal social care each account for roughly 40% of costs [23]. As country income level declines, the contribution of informal care increases – in low-income and lower-middle-income countries, the dominant cost relates to unpaid care provided by the family with approximately 94% of people with dementia living at home [23].

Robust evidence to promote efficiency in the design and delivery of dementia care is crucial to ensure the best outcomes for people with dementia and their families. Economic evaluation provides a systematic and transparent framework with which the costs and benefits of dementia care initiatives can be appraised. In an environment of increasing budgetary constraints, economic evaluation evidence is becoming more important within dementia care and across health and social care settings more broadly to help inform the optimal allocation of limited resources.

OVERVIEW OF ECONOMIC EVALUATION

Economic principals and techniques have been applied in a healthcare setting for quite some time, to help guide the use of health resources and to facilitate rational, consistent decision-making. At a fundamental level, the economic principles of scarcity including budgetary and resource constraints mean that all decisions result in opportunity costs. This means that by choosing to allocate resources to a particular use, we give up the opportunity to use them for a different purpose. Intuitively this makes sense. We have a finite amount of resources, whether that be land, labour, or capital, and we must make decisions about their use.

> Economic evaluation is the most prevalent form of health economic analysis, and provides a framework to identify and display the factors involved in a decision to commit resources to one use instead of another.[27]

These factors are comprised of costs and consequences. Relevant costs may arise from several different categories, including resources consumed across a variety of sectors:

- in the Healthcare sector: these would consist of items such as medications, hospitalisations, general physician or specialist visits, and equipment such as wheelchairs or walkers
- in other sectors: in the context of dementia these may relate to community services or long-term care facilities, or in the context of the built environment these may relate to architecture, design, or property development and construction costs
- by the individual consumer or their family: these consist of out-of-pocket expenses as well as time receiving treatments (by the individual) or time providing informal care (by the family). To the extent the work time of individuals or family members is consumed, there may also be associated productivity costs to consider

Relevant consequences may also arise from several different categories including:

- the impact upon the individual's health and quality of life
- other value, not necessarily linked to the individual's health state, such as the value of information or reassurance about one's health, or value derived from the process of receiving care, independent of the outcome
- resources saved in each of the cost categories previously listed, for instance fewer hospitalisations or a reduction in the level of care required

In the context of dementia and the built environment, there are four main types of economic evaluation that can be applied: cost-effectiveness; cost-utility; cost-benefit; and cost-consequence. Economic evaluation is defined as the comparative analysis of two or more alternative interventions in terms of both their costs and outcomes [27]. The calculation of costs is broadly consistent across all four types of economic evaluation, whereas the measure of effectiveness (the outcome) differs between each type.

- **Cost-utility analysis** presents outcomes in terms of the life-years gained, with each life-year adjusted by a utility weight representing the quality of those years, as determined by societal preferences for different health states. The outcome is the Quality Adjusted Life Year (QALY)
- **Cost-effectiveness analysis** differs from a cost-utility analysis in that the outcome is reported in natural or clinical units, such as life-years gained or unit improvement in cognitive functioning. The choice of outcome will depend on the particular field and must have relevance to the patient or individual
- **Cost-consequence analysis** is a variation of cost-effectiveness analysis, in which an array of outcomes are presented in their natural units. Cost-consequence analysis may be appropriate where a single outcome measure cannot capture the full profile of effects and requires the decision maker to form their own view of the relative importance of each of the presented outcomes
- **Cost-benefit analysis** values all benefits in monetary terms, including health and quality of life outcomes. This allows the calculation of the net benefit ratio whereby the costs and benefits of a programme are directly compared using monetary values

Health economic evaluation has typically been used to evaluate health care treatments and technologies. However, the methodology can also usefully be applied to other health and quality of life promoting measures, including environmental design. Indeed, cost-benefit analysis is a well-accepted method for prioritising infrastructure investment decisions often utilised by government departments and other decision-making bodies. In moving forward to explore the application of health economic evaluation to dementia and the built environment, this chapter draws on the principles of

health economics to address choices which influence health and quality of life and to ensure these choices are made efficiently to maximise health and quality of life benefits from the available resources.

MEASURING AND VALUING OUTCOMES FOR PEOPLE WITH DEMENTIA

This section considers relevant outcomes for people with dementia, and the potential measurement issues arising in this population. We focus in particular on the measurement of an individual's health status.

An individual's health status may be captured by clinical measures as is the case in cost-effectiveness and cost-consequence analyses, or in terms of their quality of life as is the case in a cost-utility analysis. The clinical measures of health that are typically collected for people with dementia pertain to cognition, function, behaviour and psychological symptoms, depression, and overall dementia severity [28]. These are the domains most commonly affected by dementia. There are numerous assessment scales available in each of these domains. Scales should be well-validated (e.g. questions are relevant and important, the scale measures the construct it was designed to measure, and the scale performs well in comparison with expert clinical assessment or gold standard assessments) and reliable (e.g. two people using the scale to rate the same individual would come up with the same result). The changes in a scale measured at defined time intervals before and after an intervention can then be used to assess the effectiveness of an intervention and incorporated into a cost-effectiveness or cost-consequence analysis. Researchers have already compiled information on the validity and reliability of different assessment scales for people with dementia, and these data are widely available for use [28].

It is important to keep in mind, however, that dementia is characterised by the progressive loss of mental and physical functioning in affected individuals. There is currently no cure, and no treatments have been found to stop or slow it's progressive course [29]. The practical implications of this is that collecting information on a particular domain, such as cognition, at multiple points in time for a given service or intervention may not show improvements. Indeed,

> the main objective in providing dementia support and care is to improve the quality of life of people with dementia and their carers and families [29].

In health economics, researchers have developed instruments to measure and quantify an individual's quality of life [30]. Quality of life is represented on a scale anchored at 0 and 1, with 0 representing being dead and 1 representing full health. Health states considered worse than death would have negative values, and health states considered better than death, but less than full health would have values between 0 and 1. Quality of life instruments suitable for economic evaluation (meaning they enable the calculation of quality-adjusted life years) consist of two components: a descriptive system in the form of a questionnaire to capture and describe an individual's health state, and a preference based scoring algorithm that assigns a weight to each health state based on preferences elicited from the general population for one health state over another. These instruments are known as 'preference-based' measures.

Quality of life instruments capture a multi-dimensional perspective which includes domains such as emotional well-being and social relationships in addition to health-related outcomes. Quality of life is a key component of cost-utility analyses and is also integral for quality assessment in built environments such as nursing homes and assisted living facilities. Beyond the individual with dementia, it is often pertinent to consider the quality of life of family and friends who take on an informal carer role for the person with dementia [31].

Quality of life measures can have either a generic (designed for use across different conditions) or a condition-specific focus (designed for a particular condition or disease) [30]. Both generic and dementia-specific preference-based measures have been used in previous studies for people with dementia [32]. Generic measures commonly used and validated in this population include the EuroQol-5-Dimensions (EQ-5D), the Health Utilities Index, and the Quality of Well-Being scale [32, 33]. There are two condition-specific measures currently available for dementia, the DEMQOL-U [34] and the AD-5D [35]. Generic instruments are beneficial for comparing between different conditions and groups, whereas condition-specific instruments are thought to be more sensitive to changes in disease-specific domains that would not be included in a generic instrument. There is currently research underway to develop a preference-based quality of life instrument designed specifically for older people receiving aged care services [36]. The preferences of older people, including those with mild cognitive impairment and dementia, will be incorporated in the development, validation and valuation of the new instrument [36].

Conventionally, measuring quality of life is a subjective assessment and should ideally be undertaken by the individual themselves wherever possible.

Research has shown that people with mild and moderate dementia are able to reliably report their own quality of life [37]

though researchers should be cognisant of the burden of data collection to ensure it is manageable. For example, being mindful of the length of questionnaires, the number of different questionnaires an individual is being asked to complete, and perhaps breaking up the data collection over several sessions if needed, may increase the feasibility of self-rated responses for participants with dementia. As cognitive decline progresses, however, loss of insight, reduced capacity to make judgements, and reduced ability to form new memories are characteristic symptoms of dementia, as well as reduced verbal fluency and ability to read and respond to written questions. The validity of self-rated responses thus becomes uncertain as cognition declines (38–40). For people with severe dementia, proxy responses may be sought from a family member, friend, or carer as an alternative to self-assessment.

When choosing to use proxy responses, research suggests that these be treated as a complementary perspective, rather than a substitute for self-rated responses (41, 42). When collecting proxy responses, there are a number of issues to be aware of and it is important for researchers and decision makers to interpret these data with caution. Firstly, proxies may be asked to respond from one of two perspectives: 'Proxy-proxy' report in which responses reflect the proxy's perception of the person with dementia's quality of life; or 'proxy-patient' report in which responses reflect the answer the they believe the person with dementia would give if they were able to answer themselves [43]. Responses from each perspective may not result in the same quality of life score, and thus caution should be used in interpreting these scores. Research has indicated that proxies tend to give lower quality of life ratings than the individual themselves would give (44–46). Proxy responses have also been found to be more reflective of physical symptoms such as dependency and behavioural disturbances, while self-rated responses are more reflective of subjective attributes such as mood [47]. Proxies have been found to have difficulty accurately identifying an individual's pain and emotional wellbeing, while being highly influenced from their own care burden [48].

A growing body of evidence emphasizes that people with mild to moderate dementia can participate in the assessment of their own quality of life, and this input provides valuable information that can be incorporated into the evaluation of services and interventions for people with dementia. Proxy responses can be sought for individuals with severe dementia who are unable to self-report, but researchers should be aware of the potential for proxy bias and use caution in the interpretation of results.

APPLICATION TO DEMENTIA AND THE BUILT ENVIRONMENT

The body of evidence examining the impact of the physical environment on people with dementia has been well documented, and environmental design interventions have been shown to affect behaviour, function, well-being, social abilities, orientation, and care outcomes [22].

However,

economic evaluations of environmental characteristics and dementia-specific designs are scant

[49]. The economic evidence available indicates that environmental modifications often come at an additional cost but they may be associated with better outcomes in the form of reduced agitation and improved social interactions [49]. There is a paucity of research investigating whether incorporating dementia-specific design principals from the outset would incur additional costs above and beyond non-dementia-specific design. It is important for future studies investigating the effectiveness of a particular environmental intervention or design principal to conduct an economic evaluation simultaneously in order to build a more robust evidence base surrounding the value of investing in specialised designs.

The remainder of this section will examine four different research papers which have applied a form of economic evaluation to the built environment. These case studies will provide real examples of how the techniques discussed in this chapter can be applied to different environments from a variety of perspectives, and the relevant costs and outcomes incorporated in each scenario.

CASE STUDY 1: THE COST-EFFECTIVENESS OF A HOME HAZARD REDUCTION PROGRAMME TO REDUCE FALLS AMONG OLDER PERSONS [50].

In our first case study, we focused upon a cost-effectiveness analysis conducted alongside a randomised controlled trial in which an occupational therapist assessed homes for environmental hazards and supervised the necessary modifications. This study was conducted with 530 community-dwelling people aged 65 or older in one Australian state. People with cognitive impairment were included if they lived with someone who was able to give informed consent and who could report on falls during the follow-up. Participants were randomly assigned to either the intervention or control group. For participants allocated to the intervention group, an occupational therapist would assess their home for environmental hazards and then supervise the necessary modifications. Control group participants received routine care that did not include an occupational therapist. The study was conducted over one year, and the primary outcome of interest was the number of falls that could be prevented through this home hazard reduction program. The most common home modifications included the removal of rugs or mats, the use of a non-slip bathmat, and the installation of rails to external stairs. Less common modifications included repairs to pathways, stairs, gates and flooring, installation of rails in the bathroom/toilet, and installation of better lighting. Costs were collected from a societal perspective. Hence, costs to the healthcare sector, other sectors, and to the individual and their family were considered. Costs were collected for a subsample of study participants (n=212/530) and then extrapolated for all 530 participants. Specifically, costs were included for:

- Hospitalisations
- Other health services (including general practitioners, specialists, nurses, allied health professionals, outpatient clinics, and other health professionals such as chiropractor or acupuncture)
- Informal care (including any help received in or around the home such as cleaning or gardening)
- Home modifications (calculated as the market price of the good plus cost of labour to complete modification)
- Occupational therapist salary

An incremental cost-effectiveness ratio was calculated by dividing the difference in total costs incurred by the control and intervention groups by the difference in the number of falls prevented between the two groups.

This study provides an excellent example of a well-conducted, straightforward cost-effectiveness evaluation in which two alternatives were compared in terms of the incremental cost per fall prevented. A broad (societal) perspective means the study is relevant to a wider audience including people with dementia and their families. Given the substantial use of informal care for people with dementia worldwide, it is very important to include these costs in studies particularly in a home or community setting. The study was inclusive of people living with dementia, allowing a family member or carer residing at the same address to report the fall outcomes if the participant was unable due to cognitive impairment.

Ideally, costs would have been collected for all participants, however this is not always possible in practice. It is worth noting that no measure of well-being or quality of life for participants was collected. The stated aim of the study, and relevant outcome of interest was to reduce falls. However, there would certainly be value in knowing whether any quality of life improvements were achieved and whether aspects such as a person's functional ability and orientation improved. Did the home modifications improve the ability of study participants to move around and complete various activities of daily living with increased ease, regardless of whether they reported a fall? Did well-being or quality of life improve? While these questions are outside the scope of this particular study, future researchers may wish to consider these broader areas of potential benefit to ensure that all costs and benefits can be considered in resource allocation decisions and the benefits of a particular intervention are not underestimated.

CASE STUDY 2: CAN BETTER OUTDOOR ENVIRONMENTS LEAD TO COST BENEFITS IN ASSISTED LIVING FACILITIES THROUGH INCREASED WORD-OF-MOUTH REFERRALS? [51].

In our second case study, we focused upon a partial cost benefit analysis of outdoor spaces at assisted living facilities. This study surveyed 1140 residents from 68 assisted living facilities across 3 states in the United States. There was no intervention, rather the study comprised a cross-sectional survey of environmental features related to outdoor satisfaction. Key outcomes of interest were resident satisfaction with outdoor areas, feeling better after being outdoors, and the amount of time spent outdoors. Monetary costs and benefits were assessed separately but were not combined for a true cost-benefit analysis. Costs were evaluated from the perspective of the owners/operators of assisted living facilities, in other words from an institutional perspective. Costs were estimated for improvements to four features most often described as problematic: doorways, unsafe walkways, inadequate seating, and lack of shade. Results from statistical analysis of survey responses were used to construct a business case for

the financial benefits of improving outdoor spaces. Links were drawn between a resident's satisfaction with the outdoor spaces, their wellbeing, and their willingness to refer others to the facility. Financial benefits were then calculated for increased annual income for the facility resulting from increased revenue from new referred residents and decreased spending on the marketing budget.

This study illustrates how different costs and benefits may be relevant to different stakeholders. Taking the perspective of the facility owners and operators, the authors show a financial benefit to the bottom line of a facility's operating budget and suggest that investing in improvements to the outdoor environment is likely to result in a net profit. Relevant costs pertain to the modifications themselves, and relevant outcomes pertain to increased occupancy, increased revenue, and decreased marketing costs. We note this is vastly different from the societal perspective taken in our first case study, which included health care costs to the individuals as well as informal care provided. While a narrower perspective, the institutional perspective is an important viewpoint to consider.

Financial viability in the dementia and aged care sectors is imperative to ensure the necessary care and service environments can be provided on a sustained and long-term basis.

As with our previous case study, this study focused on a very particular outcome. Again, there are numerous pathways by which the environment and environmental design could provide benefits. This study did not consider the impact of modifications on the incidence and severity of falls, health care utilisation, or any potential impact on staff. As in the previous example, no validated quality of life measure was included. Financial viability is indeed a critical factor, but so too is the health and wellbeing of residents, and there would certainly be value in collecting these data with validated measurement tools.

CASE STUDY 3: PERCEN: A CLUSTER RCT OF PERSON-CENTRED RESIDENTIAL CARE AND ENVIRONMENT FOR PEOPLE WITH DEMENTIA [52].

In our third case study, we focus upon a cost-consequence analysis of person-centred care and person-centred environments conducted alongside a cluster randomised controlled trial in residential aged care homes (also frequently referred to as nursing homes). This study recruited 601 participants aged over 60 and living with dementia at one of 38 residential aged care homes in one Australian state. Participating facilities were randomly allocated to receive one of three interventions or to the control group. The interventions included implementing person-centred care (PCC), person-centred environmental modifications (PCE), or both PCC and PCE. Facilities allocated to the control group continued with care as usual. The study was conducted over a period of 8 months, and the primary outcomes collected were resident agitation, emotional responses in care, quality of life, depression, and care interaction quality. Implementation costs for each of the interventions were collected. PCC costs included the costs of trainers, replacement staff attendees, training materials, site visits, and telephone support. For PCE, facility improvements were targeted at the safety, accessibility and utility of outdoor spaces, a greater variety of social spaces, and using colour and objects for orientation and to improve feelings of familiarity. Data were collected for the planned total cost of the recommended changes as well as the actual cost of implemented changes, as not all recommendations were implemented. Changes in each of the 5 outcome measures were compared for residents before and after the interventions and reported separately to costs. To capture quality of life, a non-preference-based dementia-specific measure was used (the DEMQOL and DEMQOL-Proxy questionnaires) [53]. The results indicated significant improvement in quality of life and a reduction in agitation.

This study is an excellent example of how dementia-specific outcomes can be incorporated into environmental interventions. This is also the first case we identified in which all study participants had a dementia diagnosis. All five of the outcome measures collected were validated tools to measure specific aspects affected by dementia as well as a dementia-specific measure of quality of life. While utility values were not presented in this study, it is worth noting that there is now an algorithm to convert DEMQOL and DEMQOL-Proxy responses to a preference-based utility score (DEMQOL-U and DEMQOL-Proxy-U), and thus it would be possible to do so [34].

As with our second case study, this study was also conducted from the perspective of the facility. In this case, however, the focus was on resident outcomes and financial viability or the potential for increased occupancy or revenue from changes to the care environment were not considered. Both financial viability and resident outcomes would be valuable data for the owners and operators of aged care facilities

to consider simultaneously. Other potential benefits that may have been overlooked include reductions in health care utilisation such as hospital admissions and medication use, or reductions in the incidence and severity of falls.

CASE STUDY 4: CLUSTERED DOMESTIC RESIDENTIAL AGED CARE IN AUSTRALIA: FEWER HOSPITALISATIONS AND BETTER QUALITY OF LIFE [54].

In our final case study, we focus on a second cost-consequence analysis conducted in an Australian residential aged care setting. This study recruited 541 residents residing in 17 facilities across 4 Australian states. Designed as a cross-sectional, observational study, resident outcomes including quality of life, medical service use, health and residential care costs were compared between facilities with a smaller, home-like model of care and those with larger, more traditional designs. The small home-like facilities were all owned by the same provider and designated as dementia-specific facilities in which all residents were living with cognitive impairment or dementia. Each unit had 15 or fewer residents, easy access to outdoor spaces, and its own kitchen to facilitate resident participation in meal prep, meals cooked in the unit, and self-service of meals. Of the study participants residing in larger traditional facilities, 79% were living with cognitive impairment or dementia. Two years of running costs were collected for each facility. Health care use for each participant for the 12 months prior to data collection were obtained from federal and state data custodians. Both generic and dementia-specific quality of life measures were collected using the EQ-5D, DEMQOL, and DEMQOL-Proxy instruments. Multilevel random effect linear models were used to compare costs and outcomes between settings and results were presented as an array of outcomes. The study found running costs to be similar between the two models of care but reported higher quality of life (EQ-5D) and lower rates of hospitalisation and emergency department presentation in the small home-like facilities compared to larger, more traditional facilities. A second paper from the same study found the facilities with smaller, home-like environments to be cost-saving by reducing the use of potentially inappropriate medications [55].

This study illustrates the importance of capturing cross-sectoral benefits. Most of the positive benefits reported related to health care use, including hospitalisations, emergency department presentations and pharmaceutical use. This study also collected utility values and a range of dementia-specific outcomes, which is important as most participants had some degree of cognitive impairment or a diagnosis of dementia. Another key strength is the collection of facility running costs in addition to resident-specific costs and outcomes so that both financial viability and resident impact could be considered. Ideally where possible, data would be collected at multiple points in time to allow for a longitudinal analysis. Cross-sectional designs, as in this study, do not allow for conclusions about the causality of associations.

Together, these case studies have demonstrated how the physical environment has the potential to impact a wide array of outcomes for people with dementia and the care services they are receiving. From healthcare utilisation, to formal and informal care needs, to quality of life, and even the financial viability of service providers.

> There is good reason to believe that any additional costs involved in the outlay of good dementia design would be offset by the benefits and cost-savings gained.

It has been argued that re-design of the aged care environment is key to improving care quality and cost-effective reform of the aged and health care sectors [56]. Researching and documenting the full extent of costs and benefits will provide valuable information to the many stakeholders involved in the design and delivery of dementia care. This has important implications for researchers and policy makers.

IMPLICATIONS FOR RESEARCHERS AND POLICY MAKERS

As dementia-specific design continues to progress and expand around the world, examining the full array of costs and benefits will provide valuable information to decisionmakers and stakeholders. A strong economic evidence base will help promote dementia-specific design by building both the business and human case for good design. It is increasingly important for future studies investigating the effectiveness of aspects of the built environment for people with dementia to conduct economic evaluations alongside in order to build a more robust evidence base surrounding the value of investing in specialised designs. Health economists should be consulted in the early stages of research when designing studies to ensure appropriate data to conduct a solid economic evaluation are collected.

Appropriate outcomes should be considered in light of the aim of the evaluation and the relevant decision maker. It is important to keep in mind how far-reaching the impacts may be. A particular challenge in applying economic evaluation to a degenerative disease such as dementia, is that long-term effects may be hard to capture due to the progressive deterioration of an individual's condition. It may be worthwhile to consider a social context as well as a health context when considering outcomes as broader quality of life outcomes such as dignity, independence, and having control over their daily lives are important contributors to quality of life for people living with dementia.(49, 57, 58) It is also important to consider the broader impact beyond the person with dementia, such as the effect on family members and carers, both formal and informal.

We do not yet have the robust evidence base needed to adequately promote the economic benefits of specialised dementia design in the built environment. However, we do have the necessary tools and information to build this evidence base into the future.

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Survey and case studies

Eighty four case studies drawn from 27 countries illustrate the vibrant interest in designing for people living with dementia that is extending from residential care into public buildings and spaces.

Case studies: Survey and overview

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Introduction

This chapter introduces the 84 case studies contained in Volume 2 of this report.

Identifying the case studies

The case studies in this report originated from four primary sources:

1. An email sent to the associations affiliated with Alzheimer's Disease International (ADI) inviting them to nominate examples of good design in day care, residential care, public buildings and hospitals.

2. An invitation to members of Dementia Alliance International to nominate examples of good design in the same categories.

3. An open invitation issued by ADI via newsletter and announcements to everyone interested in good design for people with dementia to nominate building

4. Specific invitations sent to organisations known to the authors to have buildings of interest.

All nominations were followed up with an email to the contact person identified inviting them to complete an on-line survey. Where no contact person was identified strenuous efforts were made to identify such a person by searching web-sites and contacting third parties who might have a contact in the target organisation.

Results

The call for nominations was responded to by 113 people who identified 141 buildings – 50 day care centres, 61 residential care centres, 4 hospitals and 16 public buildings.

The 84 case studies in this volume were the result of the efforts to contact key people in the organisations responsible for these buildings and their willingness complete the on-line survey. The survey took place from March to July 2020, a time when the aged care sectors in every country were under extreme threat from COVID-19. The willingness of the respondents to find the time and the energy to complete the survey deserves recognition. It is a testimony to their pride in their buildings and their dedication to improving the care of people living with dementia by sharing their experience. There is no doubt that in normal circumstances the number of case studies in this volume would have been even higher but dealing with COVID-19 had to take priority for many people.

The case studies came from 27 countries and span the high- middle- and low-income groups.

Australia	Ireland	P. R. of China
Canada	Israel	Poland
Costa Rica	Italy	Singapore
Dominican Republic	Japan	Sri Lanka
Estonia	Malaysia	Sweden
France	Mexico	Chinese Taipei
Greece	Netherlands	Thailand
India	Nigeria	United Kingdom
Iran	Norway	USA

Table 1. Respondent countries

They include 20 day care centre, 57 residential care centres, 1 hospital and 5 public buildings. Australia, the UK and the USA are over-represented in the residential care centre category with 31 of the 57 buildings coming from these countries. Volume 2 of this report contains all of the case studies and the contents list provides a clear breakdown of the representation of each country in each building category.

The average age of the buildings varied by category with the residential care buildings being the oldest and the public buildings the youngest (Table 1).

	Average age (years)
Day Care	5.3
Residential Care	7.6
Hospital	5
Public Buildings	3

Table 2. Average age of buildings

The majority of day and residential care buildings were purpose designed (Table 2).

	Purpose designed	Renovated
Day Care	11	9
Residential Care	37	21
Hospital		1
Public Buildings	2	4

Table 3. Purpose designed or renovated

The average number of places in residential care centres is not able to be captured in a single number because some of the centres are in fact micro-towns (de Hogeweyk and Newdirections, for example) while other centres are stand-alone units. The four largest residential care centres provide accommodation to more than 150 people each, the average number of places in the smaller units is 22, with the smallest case study describing a two person house designed for a married couple (Résidence Puijalon et Zaccaria in Canada).

Day care centres are similar but to a lesser extent with only one major outlier providing between 100 and 149 places while the average number of people attending daily in the other centres is 22.

Survey respondents were asked to describe the vision that had informed the design of the building. The flavour of the visions has been captured in the following word clouds, generated by https://www.wordclouds.com.

The frequency of word usage in the day care centre visions suggest a focus on family, community, care, people, professionalism, the environment, activities, caregivers, life, staff and enabling.

When asked how well their environments support their vision two thirds of the respondents reported that it supported their vision 'extremely well' and the remainder said that it supported them 'very well'

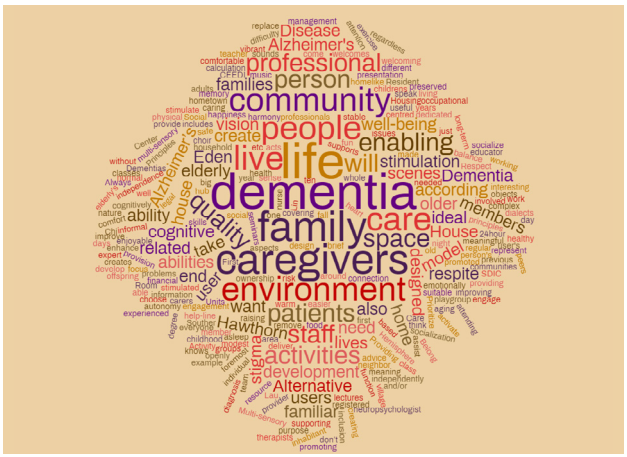

Figure 1. Day Care Centre word cloud

The word cloud for residential care centre visions suggests a slightly different emphasis. The primary focus appears to be on the provision of care to the residents, perhaps unsurprisingly, but there is a very satisfying emphasis on life, living, quality, people, design, environment, community, garden, wellbeing and the person.

The great majority of respondents (68%) reported that the building supported their vision 'extremely well' with a further 16% saying that it did this 'very well' and 7% 'well'. There were no negative responses but 9% of respondents did not answer this survey question.

Figure 2. Residential Care Centre word cloud

Two of the five public buildings (an area in a shopping mall in Malaysia and a library in Norway) were described as supporting the vision 'extremely well'. They are both adaptations of existing buildings. One was described as supporting it 'very well' and one 'well'. The remaining building was not rated on this survey item.

The small sample makes interpretation risky but it is tempting to take the most common words at their face value, 'vision and design improving therapeutic space for the inclusion and well being of people with dementia'.

As there is only one hospital represented in the survey responses no word cloud has been produced for hospitals. The vision for the hospital is reported in the case study, as are all of the visions provided for the individual case studies.

Figure 3. Public Buildings word cloud

Information on the perceived importance of the principles of design that have been described in Volume 1 of this report was gathered during the survey. Each respondent was asked to identify which of the examples of the implementation of the principles was very important.

The chart in Figure 4 shows the difference in emphasis between the categories of buildings.

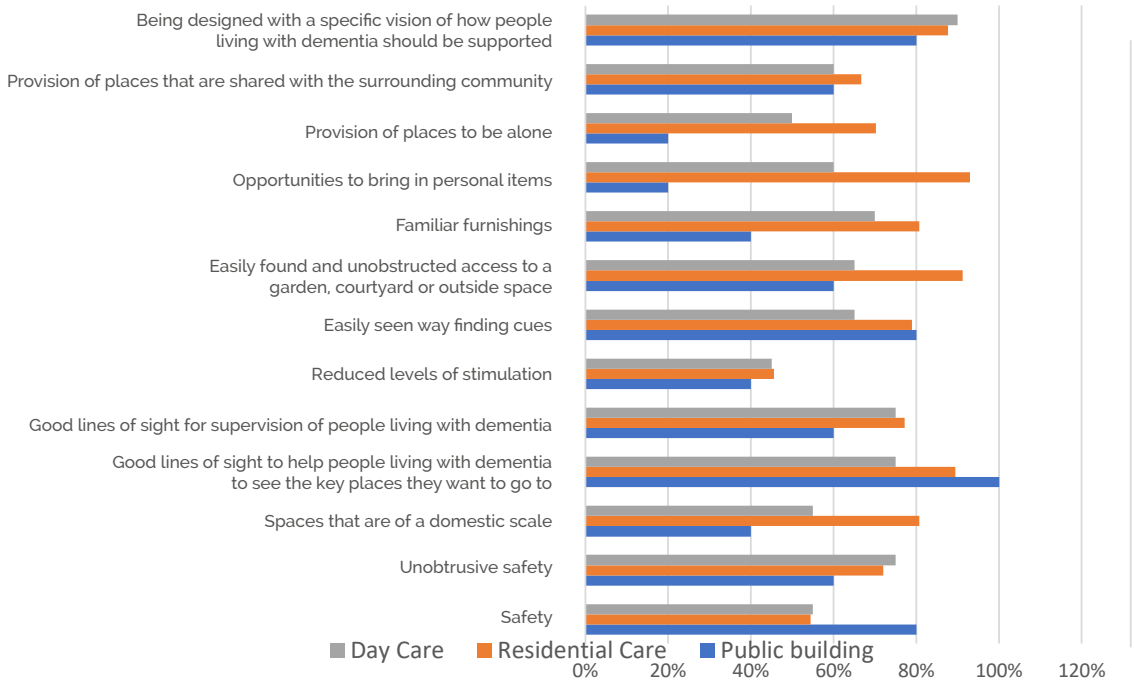

Figure 4.Relative importance of examples of design principles

Discussion

While it has already been said, it is worth repeating that the people who provided case studies by responding to the survey, did so at a time when there were many, very urgent, calls on their time and energy. The representativeness of the sample of buildings that they have described is entirely unknown. There has never been an international attempt to systematically collect data on the nature of buildings used in the service of people with dementia so there is nothing to compare this sample with. What is known is that

the data have been collected on a sample of buildings regarded by their nominees as representing good design. We can be sure, therefore, that they do not represent the typical building used by, and for, people living with dementia.

No attempt has been made to evaluate these buildings. There are three main reasons for that,

1. The data presented is based on the self-report of the respondent and is therefore subject to many unknown biases.

2. The case studies are drawn from a very wide variety of cultures, demographies and geographies. Several chapters in Volume 1 have alerted us to the dangers of making cross-cultural comparisons. While it is anticipated that interest in designing for people living with dementia will eventually lead to a common language of design, making comparisons possible, we are a long way from there yet. The principles of design used to structure this report have proven useful to a point but not to the point where they can be used to say that a design in Poland is better than a design Sri Lanka. However, they may be useful to begin to tease out the similarities and the differences.

3. It is not the purpose of this report to evaluate the individual efforts being made to design well for people living with dementia. It is to try, for the first time, to get a grip on what is going on in this field across the world.

The data that have been collected may offer us some glimpses of trends. For example, the average age of the sample of residential care buildings is 5 years greater than that of the public buildings, suggesting that designing for people with dementia has been around longer in residential care than in the design of public buildings, and indeed in day care design. This may also be reflected in the higher proportion of purpose designed residential care buildings.

These findings suggest that one of the areas for future work is to take what we have learned in residential care and, while carefully evaluating our knowledge for its relevance to new fields, apply it more energetically in day care, public buildings and hospital settings. The fact that there is only one hospital represented is a stark reminder of the need to apply our knowledge in this area.

The data on the number of places in residential and aged care centre illustrate the wide variety of models currently being implemented across the world. There are examples of carefully designed homes for couples through to substantial micro-towns but there is a hint that the actual living unit in these well designed buildings is quite small. There are no examples of large, dormitory style accommodation.

While falling short of a thorough thematic analysis the word clouds suggest that there are differences in the visions that guide the various categories of buildings. The residential care buildings emphasis on care, which can sometimes lead to a medicalised environment, is balanced with the emphasis on community, gardens, life and wellbeing. Day care centres focus on family reflects their broader mission to support the carers of people living with dementia and the frequency of words like activities and enabling give a sense of how they do it. The vision guiding the development of public buildings emphasises independence, inclusiveness, improvement, engagement and dignity.

Words that inspire aspirations to have a society where people living with dementia do not have to rely as heavily on day care centres and residential care because the buildings that they use in their everyday lives support them.

The analysis of the relative importance of the examples of the implementation of the principles does not include the hospital data as it is restricted to one hospital. It is interesting to see that the examples are, by and large, rated as more important by the residential care respondents, then by the day care and then public

buildings. Reflecting either the lag in adoption of the principles in the latter categories or their lesser relevance, or both. The call to action here is to increase awareness of the knowledge summarised by the principles in the minds of the designers of day care centres and public buildings (not to mention hospitals) while, at the same time, evaluating the relevance of these principles to these categories of buildings. Other chapters in this report will remind the reader that this needs to be done in collaboration with people living with dementia.

The data suggest that there is a common understanding of the need to have a clear vision of how the building is to support people living with dementia. This is a welcome finding, but it is probably an artefact of this sample of buildings that have been nominated as being well designed. Experience has shown that the majority of buildings used to support people with dementia have been designed with other priorities in mind, such as efficiency of operations and a narrow view of cost effectiveness.

The data also show some contrasts. In comparison with the day care and public buildings, the responders to the residential care survey place more emphasis on providing a familiar, domestic scale environment with a variety of places to be alone or with others. The public buildings and spaces prioritise good way finding cues, good lines of sight that support way finding and discrete monitoring and basic safety measures. While the day care centre respondents emphasise, relative to the others, the provision of safety in a way that does not inhibit the feeling of autonomy.

These variations in priorities are understandable in these different contexts. Clearly there is little need for public buildings to provide opportunities to bring in personal items or to provide places for the person with dementia to be by themselves while they are very important in a residential setting. The fact that these differences become easily apparent when viewed through the lens of the principles strengthens the argument for the use of a set of principles as a common foundation for discussions about designing for people living with dementia. Such use provides opportunities for asking whether the design of an individual building is similar to that of its peers or to other categories of buildings and, if it is very different, whether that difference is likely to lead to a good outcome. They also invite questions like 'Why is there such little emphasis on reducing levels of stimulation when there is good evidence to suggest that this help people living with dementia to cope with their surroundings?'. The ability to compare and contrast in this systematic way could only help the development of designing for people living with dementia.

Conclusion

The response to the survey reflects and indicates that there is an enthusiasm for designing well for people living with dementia in at least 26 countries and it is believed that the difficult circumstances in which the survey was carried out have masked an even greater interest. The enthusiasm is apparent across the range of high to low income countries.

The adoption of a set of principles for the collection of the survey data has enabled comparisons between categories of buildings and suggests that there is an opportunity to use this approach as the basis for future discussions about the strengths and weaknesses of designs for people living with dementia.

The challenges identified by the survey are twofold; to expand the knowledge that has been gained in residential care into the day care, public buildings and, especially, the hospital categories, and to carry out this expansion with due regard for improving the relevance of the existing knowledge to the new categories.

Education and training

Training is an essential element in raising awareness about the benefits of good design and increasing the ability and commitment to practising it. There are many ways of providing training as illustrated by these international case studies.

Australia: The Dementia Centre's Design Schools – reaching the influencers of quality of life in residential aged care

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THE IMPACT OF DESIGN ON QUALITY OF LIFE.

People diagnosed with dementia account for 52% of all residents in Australian residential aged care facilities [2] There is considerable and increasing evidence on what makes an enabling environment for someone with dementia (3, 4). We know that not only is a person with dementia's quality of life and behaviour strongly determined by the design of their environment, but they are more dependent upon it *and* less able to regulate it than a person without dementia [5].

It is a challenge to design an environment that meets the needs of everyone. People with dementia are individuals with very different life experiences, personalities, levels of physical and mental health and may be at different stages of the condition. Designing residential aged care facilities which are truly enabling must be one of the most complex design challenges that exists.

THE INCREASED RESPONSIBILITY OF THOSE INVOLVED IN THE DESIGN PROCESS

The difference design makes to quality of life is found at every level. From the siting and plan of the building, its relationship to the outdoor space, to the number of bedrooms in a grouping, and the length of corridors – these all can all impact on a person's ability to function. The building's operational model – how and where food is cooked, or how waste and linen is managed – must be optimised by design too. And crucially, the philosophy or model of care underpins both what the building looks like and how it operates.

This puts more significance on the role of those involved in the design of these environments – those who;

- Lead care home services, shaping models or philosophies of care and mission statements
- Commission buildings, write briefs, purchase sites or buildings, who allocate budget and select design teams
- Design and construct buildings, their interiors, systems and outdoor spaces
- Procure furniture and fittings
- Manage and maintain buildings and surroundings

If these people have a common understanding about the aims and purposes of the building, and the bearing that design decisions have on the building user, it is more likely that good outcomes for that user will result.

These professionals are the target audience of *The Dementia Centre's International Design School*; a diverse group with the capacity to make change happen in and through their organisations.

THE KNOWLEDGE GAPS

This group are often talented in their area of specialisation but may lack the knowledge and experience of either dementia itself (often the designers, manufacturers) or the ability of good design to support processes and quality of life (managers and clinicians).

Many non-designers would not be conscious of the practical and emotional impact of design on their daily lives. And very few undergraduate professional courses cover design for people with dementia; architects and lighting engineers often have no dementia education at all.

> There is still a preoccupation with designing for the Vitruvian man – able- bodied, and *compos mentis*.

This bias arguably is echoed in medical degrees – where typically students will receive little education on old age psychiatry (four lectures out of a five-year course [6]) despite the likelihood of their contact with patients with dementia. It's an unglamorous subject, reminding us of our own frailty. In the case of medicine, dementia is not 'fixable', an affront to a profession that prides itself on its competency [7].

And neither is design a cure, but it can be transformational. Our focus in the School is to open people's minds to the complexity of the experience of dementia, the amazing capability of design to make a difference, and to inspire them to make change happen in their sphere of influence.

Method

FORMAT, STRUCTURE, SIZE.

The *Dementia Centre's International Design School* has been running for over ten years. It is a two-day course for between 15 and 25 people. Courses have taken place in Australia, New Zealand, Singapore and the UK.

Schools are also often commissioned by groups of professionals or individual providers and as such are commonly used as part of an extended briefing process. HammondCare's capital works division also utilises this model as standard part of its concept briefing and project commissioning for new projects. The relatively small number of delegates is key to providing the opportunity for the programme to be responsive to the needs of the participants. The facilitators can vary their approach to enable learning while building on the specific knowledge and skills of delegates. This facilitates cross-disciplinary discussion and teamworking and helps apply this to real world design processes.

Delegates are assigned to teams of around five, ensuring a blend of designers, clinicians and managers in each team. An emphasis on group interaction and co-operation is encouraged so participants share their knowledge and perspective. A light-hearted competitive element between teams helps them gel and incentivises group working. Creating opportunities for discussion in groups also helps participants model the discussions they might have with their own organisations and to hear different views.

Putting Principles into practice in a design exercise

Over the decade of the School's existence, the format, style and content has developed to suit the changing needs of the consumer and to maximise the delegate experience. Feedback over the years identified the collaborative parts of the School as having the most impact and so the programme has become increasingly interactive, with short TED-style talks, workshop elements and activities. It is an intimate and focused programme, designed to be as informative and enjoyable as possible, paced to support participants in maintaining focus and attention. Different types of activities match different participants'' learning styles, ensuring a positive learning experience.

Some activities provide participants with new factual or theoretical information. Others require participants to reflect on their practice to help them relate to the content of the programme and open their minds to a new way of thinking. The opportunity to put theory into practice is provided in a safe environment where participants are encouraged to try new things. They are encouraged to look to the future, to their personal situations, identifying the ways in which they may put their new learning into practice.

We have found team-based design exercises particularly effective allowing participants to apply immediately the knowledge they have learned.

Participants work together to find solutions and present their project to the class. This allows gaps in understanding to be worked out as a group.

We find humour and collaboration encourages and motivates participation in the learning process.

Simple activities, which allow people to experience sensory deficit, or a sense of increased cognitive load (e.g. completing a task under time-pressure in an overstimulating/negative environment) help build empathy and understanding around the client group.

USE OF VR

The inclusion of Virtual Reality allows participants to explore a real environment designed for people living with dementia. Participants reflect on how certain spaces make them feel, making the learning experience more memorable.

Filmed in a HammondCare cottage built in 2019, the experience is a tour of the building taken at a pace which allows discussion as a group. It is valuable to see aspects of the design which can otherwise be hard to visualise, such as the visual access from the kitchen to the bedroom corridors, or the domestic scale. Using VR maximises the learning from a live space, while protecting the dignity of the people who now use it. Participants can see how the design principles can be applied to work together in practice.

ENVIRONMENT

While Schools have taken place in many different venues, a quiet, spacious, well-lit, well-ventilated room with breakout space is ideal. Using alternative spaces for different activities is refreshing for delegates and the bonus of an available outdoor space gives people a complete break, privacy and fresh air. Often in break times people have their most meaningful conversations and connections.

These different spaces also help delegates put into practice what they are learning about reading environments. We test the theory using light and sound meters and critically consider these spaces from a design perspective. We use an assessment tool [8] specifically developed to demonstrate the application of our design principles at a detailed level. Designed with the user in mind, this offers a framework to promote and support good decision-making by executive and financial decision makers. It enables all stakeholders to have a shared understanding of common objectives and goals, and in this way, echoes the goals of the Design School itself.

MULTIDISCIPLINARY EDUCATORS

The programme benefits from having facilitators from different professional backgrounds. Appropriate backgrounds commonly include people living with dementia who can talk about their experience, Architects, Occupational Therapists and Registered Nurses, Social Workers,

but this list is not exhaustive. This provides participants with different perspectives and models how effective multidisciplinary collaboration can enhance outcomes.

There are two main facilitators, one with a design background and one with an Occupational Therapy (OT), social work or nursing background, both with dementia experience and expertise. These two set the tone for the school – they model the quality and manner of engagement. They are present throughout the two days, building relationships with delegates, ensuring that content flows seamlessly and reading the room. It is essential they have the knowledge and experience to answer and facilitate discussion about any aspect of dementia and design. A third speaker, normally an external architect or engineer who is a dementia specialist, often delivers content, and contributes to discussions.

Design School in Hobart, Tasmania.

ENDING WELL

Managing expectations when there is an audience of diverse disciplines can be challenging. Starting with naming these expectations and following up across the days can address this. However, there are always topics that participants would like to spend more time on. During breaks facilitators can link these participants to other resources or programs.

This feedback highlighted the need for Masterclasses – bolt-on sessions where topics can be addressed in more detail. Sessions on interiors, lighting, finishes and product design are available for smaller groups of five to 10 participants. These one-day sessions drill down on a topic and apply it to the specific needs of the group. For example, our Lighting Masterclass builds on the technical detail laid down in the general School and applies this to a client's project in a workshop format, putting the theory into solid practice.

SCHOOL VARIANTS

The idea of a School for people living with dementia was first discussed at our International Dementia Conference in Australia in 2016. So often we noticed people with dementia missing out on the learning and design debates that were taking place; seen as passive recipients of design created by others. And yet people living with dementia have often found personal solutions to, and experienced the emotional impact of, living with environmental challenges that everyone can learn from.

This combination of dementia experience, design knowledge, disability design, human rights and equality found a home in our *DeMEntia Design School* – the first of its kind anywhere in the world.

The school, which took place in the UK in 2018, enabled people with dementia and design experts to share experiences and build a rich repository of knowledge to inform architects, planners, developers and service providers and to explore gaps in current research and policy.

Following this event graduates have continued in an advisory group role, created mentoring opportunities and produced a peer reviewed journal paper on accessible design and dementia as an equality issue [9]

Other special focus Schools have been developed for individual providers or consultancy groups, with emphases on different areas such as working with existing buildings or using outdoor spaces.

Content

To ensure the robustness of the course content we draw on a variety of sources, including the experience and commentary from people living with dementia, up to date literature and empirical evidence, current press and trends, case studies, and experience from our own team working in and with residential services. Experts in their fields, such as Dr. Meredith Gresham, architects Ricky and Annie Pollock, Prof. Mary Marshall, lighting specialist David McNair and Dr. Stephen Judd have all contributed their expertise at design schools.

The content of the School does not assume pre-knowledge of dementia or design and as such follows a structure designed to take participants on a journey starting with unpacking the experience of living with dementia, and the interplay with the environment. What dementia is, is not, and the ways it can affect the experience of the world is addressed first. From there a range of topics are covered such as:

- The prosthetic capacity of design; the extent to which a supportive environment can reduce the excess disability that a person experiences
- The link between a stressful or negative environment and the way that people feel and behave. We reference both delegates' personal experiences and case studies from Dementia Support Australia data.[i] We look at case studies where referred behaviour has been linked to a poor environment
- The negative impact of poor design – the impact on quality of life, illness, use of antipsychotics, carer stress, depression
- The importance of the language we use – the impact it has on our own and others' attitudes, on perpetuating or reducing stigma
- Commonly agreed design principles and features and their application in different settings, their history and the evidence behind them. This includes for example, the basics of what makes a good layout, creating visual access, supporting a good dining experience, managing stimulation

- Detailed aspects of design such as the use of colour and finishes, lighting, acoustics and circadian health. We review practical tips to implement good practice in both new and existing buildings, highlighting the simple interventions that give maximum impact
- The way design can support positive relationships between a person living with dementia and the people they spend time with such as friends/family, other residents and staff
- How to critically assess emerging technology and the opportunities and risks it presents
- How to unpack an organisation's model of care, understand the way that such a philosophy impacts design decisions and what happens when these are misaligned
- Finally, making change happen – establishing organisational drivers, using the right language and measuring success

Continuous Improvement

The evaluation process after each School includes a yearly analysis to capture trends, helping us update content and identifying the need for new resources.

Capturing the impact that the School has on practice has not always been easy. With the implementation of follow up evaluations six- and twelve-months post event aims to establish what delegates have been able to put into practice and what the barriers have been to implementation.

Over recent years an increase in delegate knowledge about dementia has been apparent. There are, however, often common misunderstandings about behaviour, and about the appropriateness of certain design interventions. Common mistakes have seen the Dementia Centre develop resources like Toilet Talk [10] and Talking Murals [11] to bust myths and address gaps in knowledge.

Schools often lead to requests for further input, for example additional bespoke Schools, environmental reviews of existing buildings, or building plan reviews. In that way the School can act as a solid platform for a team from an organisation to consolidate their approach to a new build or programme of works.

Some feedback has been about the increased confidence to direct and encourage change on the ground. Delegates have said, one year on, they are more able to critically assess environments that are disabling and have been able to introduce practical improvements such as better lighting or reducing glare. They are more aware of the need to consult with the users of the space to establish what is and what isn't working for them.

One senior executive remarked on how attending the School helped strengthen their drive to create a home-like environment for a new dementia-specific facility. They commented on the improved wellbeing of their residents, the smoothness of the transition to the new environment, and a reduction in the behaviours they had been seeing in the original facility.

> When we ask delegates about the barriers to putting principles into practice we hear about a lack of knowledge at top level management, and a desire to create a competitive difference through apparently luxury aesthetics, rather than design, which enables people with dementia living in the facility.

One described the 'hotel/resort feel' their CEO wants – which has led to significant expressed behaviour from residents. In contrast where small changes were made, there was a measurable difference in residents' sense of purpose and engagement.

> There are signs that the climate is shifting, in part due to legislators acknowledging the role of the environment.

This is reflected in the 2019 update to the Australian Aged Care Quality Standards, which require the environment to support quality of life as well as a person's functional ability.

The use of assistive technology has also been put forward by the Australian Royal Commission into Aged Care Quality and Safety as essential for residential aged care's sustainability.

More care providers are starting to acknowledge that supportive environments are not just a nice extra, or 'just for some', but are a necessary component integral to providing high quality care. This motivates, not just the provider who genuinely wishes to deliver good care, but those who are striving for distinctiveness in an increasingly competitive market.

THE FUTURE

The future for the Design School could take many forms. The COVID-19 pandemic is driving our thinking about safeguarding future learning experiences by making more content available remotely. In the UK, because of social distancing, our in-person schools for people with dementia are now going online with a Dementia Centre PA to support each participant. The first '*Talking Sense*' in Stirling, Scotland, is due to start before the end of 2020. *Talking Sense* is a new School focused on sensory changes and dementia developed from Churchill Fellow Agnes Houston's work in this field. There is currently a book of the same name, and an audio book in development. The programme brings together the best of the *DeMEntia Design School* format and the book, to reach a wider audience, promote co-productions and deliver impact in local communities.

CONCLUSION

There is no doubt that design as a non-pharmacological intervention can improve quality of life.

It is a source of continual frustration that, even where the research makes it clear that the principles are relevant, we do not see these long and well-established principles being put into practice.

Instead we see new large institutions thinly veneered with hotel aesthetics. Homes which have no place for someone to express their taste, or carry out simple domestic activities, units where twenty or more people live in one space and where simply going outside is considered too risky. Places where people are commonly lost, frustrated and angry at the environment they find themselves in, through no fault of their own, but from the basic inadequacy of design, and yet are unable to do anything about it. The ongoing human cost of this is shameful.

The Design School and programmes like it, must seize the opportunity not only to inform and enthuse (which only goes so far) but to locate the barriers to change that exist in the room and disarm them, equipping and encouraging those around us to do the same.

It's a process that requires intellect, guts and optimism and above all, a team effort.

Australia: Dementia Training Australia – designing for people with dementia, a practical education service

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Introduction

I was standing with a group of residential aged care staff in a corridor and I asked the question: 'Where is Jean's room?' Then I queried 'Which way is the dining room from here?' They looked in one direction and then in the other and exclaimed 'Oh dear! We never realised that before. The corridors look the same!'

Figure 1: Corridor views in a residential aged care facility

I have had many exchanges such as this over my eight years as the founding manager of the Designing for People with Dementia (DPD) service run by Dementia Training Australia. In a simple way, this exchange captures much of the story of the DPD service:

- We went on site
- We concentrated on offering education to staff
- We took a systematic approach to applying evidence-based design principles
- We focussed on the experience of the person living with dementia
- We gave staff knowledge, resources and problem-solving skills
- We asked what can be done to improve the environment

The DPD service was established in 2011 to improve the quality of environments for people living with dementia. At that time, despite the evidence showing that a person living with dementia will have greater capacity in a well-designed environment (and less in a poorly designed one), it was apparent that established design principles were not being widely applied in residential aged care in Australia. A lack of knowledge translation (KT) was identified as a key obstacle [12] and in response to this the DPD service focussed on providing education which was grounded in Pathman's knowledge translation approach [1]

Pathman identifies four elements that are needed for knowledge to become practice: awareness, agreement, adoption, and adherence. The key components of the DPD service: on site education, walking around the unit with staff, using an assessment tool, identifying proposed for works, and changing policy, all responded to this KT framework.

The DPD service delivered public workshops across the country, education to design professionals in a range of universities and professional associations, and engaged with various community groups.

The cornerstone of the DPD service was on-site education which was a key instrument of change and improving the quality of environments for people living with dementia [13].This paper will focus on this practical education service during my time as manager (Sept 2011-March 2020).

BACKGROUND

The DPD service was created as part of an Australian Government initiative to establish a national network of Dementia Training Study Centres (DTSC). The New South Wales/Australian Capital Territory DTSC was given the responsibility for environmental design, and the DPD service became a key part of this centre as it grew in scope and reach. A team of consultants was engaged on a part time basis. I was appointed as Manager of the service and Senior Consultant in Victoria by the Director of the DTSC, Richard Fleming, who provided consultancy in NSW. Additional consultants were appointed in Perth (Western Australia), Melbourne (Victoria), Brisbane (Queensland), and Adelaide (South Australia) as the service developed.

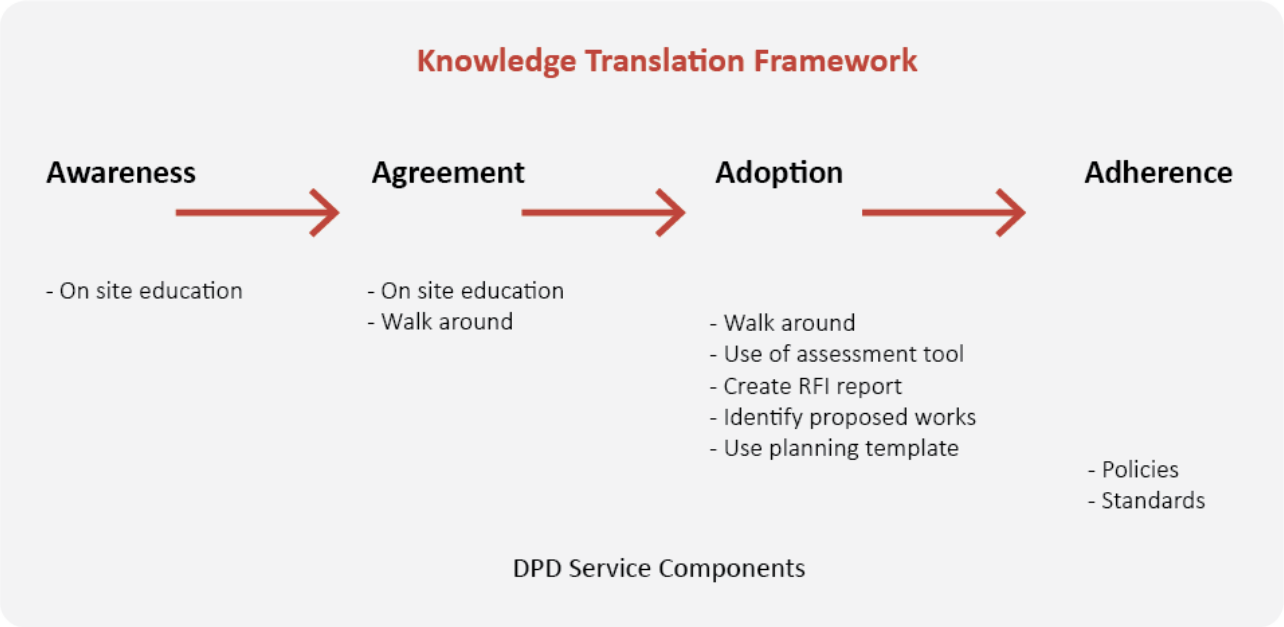


Figure 2: Knowledge Translation in the DPD service

The appointment of these consultants enabled the service to be delivered on site in every state and territory in Australia.

The team offered expertise in a range of disciplines, including architecture, psychology, landscape architecture, nursing, work health and safety, acute health and residential aged care management.

In 2016 the Australian Government Department of Health transformed the state-based Dementia Training Study Centres into a single, nation-wide service which became known as Dementia Training Australia (DTA). The DPD service became a key part of the service offered by this new entity In March 2020, the DPD service changed to 'DTA-Environments' to recognise a new phase of the service. Under different leadership, DTA-Environments now builds on the strong track record of the DPD service as it continues to work with organisations to improve environments for people living with dementia.

WE WENT ON SITE

The DPD team offered an on-site education service, which at that time was the only service of this type in Australia. The on-site component allowed the consultant to spend time with staff where they work, and to walk around their environment with them. It also ensured that staff needed a minimum time away from work to attend an education session, something which is particularly important in a setting on the outskirts of a rural town or in a distant location. For these staff, travel distance often prevents their attendance due to the cost and time required for travel, and the difficulty in backfilling their positions. In some locations staff are simply not available to replace colleagues who are attending education off site.

Walking around the unit on site with staff enabled a number of changes to be made to the environment immediately, such as removing notices and objects which were causing clutter, rearranging furniture, opening curtains, turning lights off or on, and opening doors to encourage access to rooms and gardens. It also allowed the DPD consultant to observe the way the environment was used first-hand and ask staff to respond to situations on the spot, thereby putting the knowledge gained from the preceding education session into immediate practice.

This move from awareness and agreement (which was provided by the education and accompanying conversation) to agreement and adoption (in the walk around and subsequent change to the environment) was a central means of translating knowledge into practice that was made possible by being on site.

The DPD service operated across Australia. It began in 2011 by offering on-site education in residential aged care, expanding in 2013 to include acute health settings, and in 2018 community settings. It has reached many and varied locations, from inner urban sites to very remote ones.

Funding was provided based on data which showed the number of residential aged care building projects that were planned in any year, with a goal of providing education to a significant number of these organisations. In a typical year, approximately 80 site visits were undertaken, with a spread of visits across

Figure 3: The difference in driving to site visits in Victoria and the Northern Territory

states/territories. As expected, the majority of visits (75%) were in the larger states (NSW, Victoria and Queensland). As there are relatively few aged care and acute health settings in the smaller states and territories (Tasmania, the Northern Territory and the Australian Capital Territory) only a small number of visits were made to these locations.

As a national service the DPD service was not big city (metropolitan) focussed, although that would have made the logistics simpler and reduced travel costs. Ensuring the reach of the service across each state and territory, and in metropolitan, regional, rural, remote and very remote locations has been a focus from the outset and reflected the Government's equity KPI. In a typical year 53% of visits were made to regional, rural and remote locations.

The map demonstrates the significant reach of the DPD service and shows the spread of locations visited. (NB The vast majority of the Australian population lives on or near the coast, and most people live in the eastern states.)

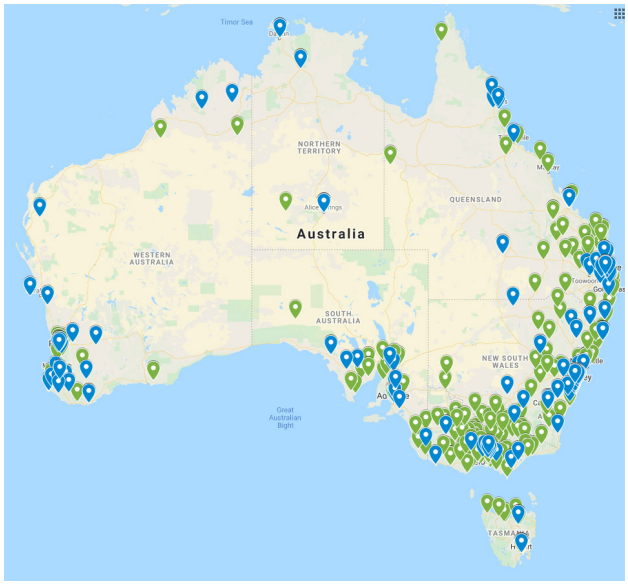


Figure 4: Distribution of DPD service on-site consultations 2011–2020 (Green flag indicates residential care, blue flag hospital)

Services were provided following web-based enquiries, word of mouth, presentations at conferences or in response to marketing. After receiving an enquiry, a consultant had a phone conversation with the site to learn more about the likelihood of achieving change at that location.

Readiness for change was a key factor in the decision to offer a site visit.

The focus was not on a site having a new project, or a building budget, but rather was on the organisation's desire to actively use the environment to support people living with dementia, and to do more. The resources of the DPD service were limited and Australia is a large country. Experience has shown that some requests for the service come from enthusiastic, even passionate, individuals who want to improve the quality of life of people living with dementia and see improving the physical environment as a significant part of that process. However, these individuals may not always be in a position to influence the organisation that they work in, so unfortunately, responding to their request for assistance would be unlikely to bring about significant change. Choices needed to be made whether to deploy limited resources to respond to a request such as this, or to apply them to other organisations where a strong, organisation wide commitment to improvement could be obtained.

Screening was done over the phone using a simple set of questions to guide the initial conversation between the DPD consultant and the service representative. This ensured consistency of the readiness assessment and the information gained was placed in a proforma table that could be used by the DPD service and DTSC/DTA. Key topics covered included reasons for contacting DPD, issues of concern, details of the facility/ organisation, the organisation's plans for change, timeframe for change, and expectations of DPD service.

WE CONCENTRATED ON OFFERING EDUCATION TO STAFF

The foundational focus of the service was design education, rather than design consultancy, or specific design advice. The goal was to go on site and engage the staff and management in a conversation about the role of the environment in supporting people living with dementia, introduce them to evidence based key design principles, share resources, and help them to turn this knowledge in their practice.

The service's focus on knowledge translation gave staff a framework that could be used to identify why change may (or may not) have been successful in the past, and highlighted how change could be achieved in the future. Rearranging furniture was a common topic of discussion and serves as an example of this approach.

Why is it so hard to change the way furniture is arranged in a room?

The KT approach provides a straightforward way to respond to this question:

- Does everyone know why it is arranged the way it is? **Awareness**
- Does everyone agree with arranging it this way? **Agreement**
- Who is going to arrange it this way and keep an eye on it? **Adoption**
- Is this focus on creating small scale settings written into policies and induction materials? **Adherence**

The DPD service recognised the key role that staff play in providing a supportive environment for people living with dementia. While it did offer group-based education sessions to architects, the focus of the on-site service was on the day to day staff who use the environment. From nurses, managers, therapists and carers to cleaners, cooks, orderlies, laundry staff, gardeners, and maintenance personnel; they all interact with the environment in the course of their work. If they have a greater understanding of how they may impact negatively on the environment (for example by wheeling a noisy linen trolley through the middle of a lounge room), and how they can use the environment to support someone (for example by opening the curtains and placing a chair with a view to the garden and with ready access to a magazine), the therapeutic strengths of an environment can be used more effectively.

WE TOOK A SYSTEMATIC APPROACH TO APPLYING EVIDENCE BASED DESIGN PRINCIPLES

The service consisted of a site visit which contained three key components:

- an introduction to the evidence based key design principles
- an introduction to Environmental Assessment Tools
- a walk around the unit or ward looking at the ways in which the environment already does, and could, respond to the principles.

This three-stage approach enables changes to be made to the environment in a systematic and targeted way rather than an ad hoc one, as staff increase their knowledge and awareness of the areas that have potential for improvement and the reasons for this. The assessment tool was used to capture objective information about the environment and the planning template that was used later provided a structure to record ideas for change.

The standard approach of the service was to invite a group of between 6 and 12 staff with a range of expertise to attend the education. If building works were proposed the architect or designer was invited to be present too. While the service typically focused on one unit, staff from different parts of a facility were also encouraged to attend. (We know that applying the principles of dementia friendly design across a facility will be of benefit as people living with dementia live in all parts of residential aged care.)

Environmental Assessment Tools were introduced to the participants. The tools are principles based and provide a systematic way of looking at the environment with questions under each of the design principles. Tools were either completed on site with participants or left with them for their completion at a later date. The latter approach was a good way to encourage staff to reconvene after the education and have another conversation about the environment.

A key focus of the education (and the walk around) was facilitating a conversation both with and between staff. Often staff have little opportunity to work with others from different disciplines and so aren't aware of the expertise and knowledge that is already available in the facility. The DPD service recognised this wealth of experience and sought to draw out and add to this knowledge. A hallmark of the DPD service was its ability to bring people from different parts of a facility together. This enabled staff to make contact with each other and draw on resources within the facility itself, as staff meet and became aware of each other's skills and interests. It also encouraged staff to take ownership of the changes that were made, rather than feeling they are being told what to do and have little opportunity to influence decisions.

WE FOCUSSED ON THE EXPERIENCE OF THE PERSON LIVING WITH DEMENTIA

We talked about the people we knew and supported who were living with dementia. We asked participants to think about what this person likes to do, what is important to them, what they is able to do. In some settings, people living with dementia joined us. The importance of knowing the person who is being supported was emphasised, as is the need to support a person to continue to do what is important to them. We encouraged participants to explore how a well-designed environment can reduce a person's agitation, anxiety, conflict, confusion and depression, and improve a person's wayfinding, eating, motor functions, pleasure, mobility, and other activities of daily living.

We asked participants to try to put themselves in the shoes of a person living with dementia. This means thinking about a person's lifestyle, their values and their cultural background.

WE GAVE STAFF KNOWLEDGE, RESOURCES AND PROBLEM-SOLVING SKILLS

A set of key evidence-based principles developed by Richard Fleming and Kirsty Bennett [14] were the foundation of the DPD education service.

The *Environmental Design Education Resources* by Richard Fleming and Kirsty Bennett were created to improve environments for people living with dementia. The resources introduce the reader to a systematic way of looking at the built environment and provide tools which can be used to create change. Resource 1 discusses the prevalence and impact of dementia, and reviews the literature on the design of aged and acute health care buildings used by people living with dementia. Resource 2 describes how assessment tools can be used to identify the strengths and weaknesses of the environment. Resources 3, 4 and 5 introduce environmental assessment tools that have been developed for the assessment of environments where most people are mobile, higher care environments (where people may or may not be mobile), and public and commercial buildings. Resource 6 is an aged care design guide for Indigenous people. The listing of these resources as the key reference in the Australian Government's Aged Care Quality Standards in 2018 recognises their practical value and evidence-based reliability.

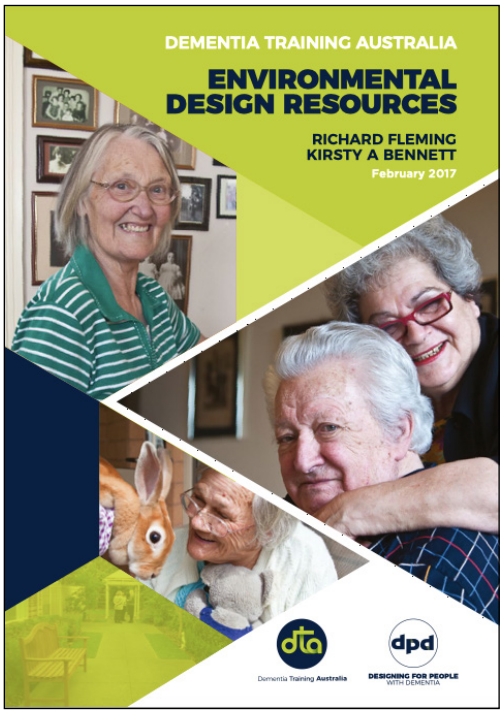


Figure 5 Environmental design resources available from https://dta.com.au/resources/environmental-design-resources-introduction/

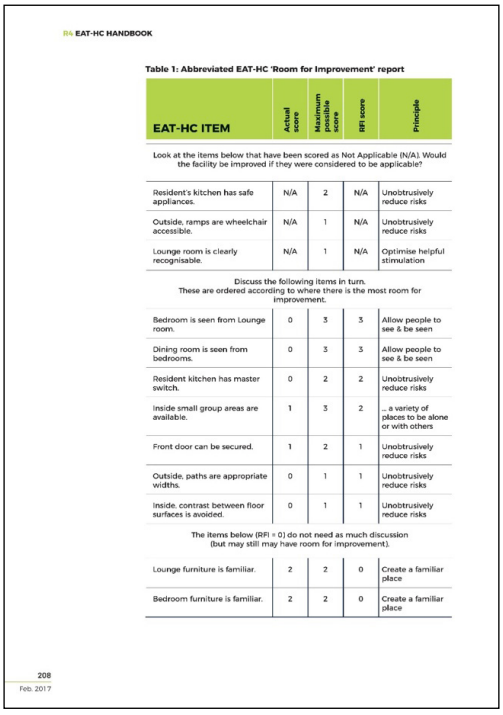
The DPD service used the Environmental Design Resources to introduce aged care staff to a new way of thinking which recognises the therapeutic difference an environment can make to a person's life. The education and subsequent walk around on site provided an opportunity for staff to discuss their context in detail and focus on the application of key design principles. This gave staff and management knowledge and problem solving resources that they could apply to a range of people and environments, rather than providing 'quick fixes' which can be successful with one person, but irrelevant or detrimental to others. Providing an image on a bedroom door relating to a resident's professional background, for example, may reinforce identity and purpose for one person, but be insignificant if this background was not a focus in a person's life. Cane furniture was added successfully at a NSW site to create a light and breezy sunroom feel. The same furniture, when introduced at a Melbourne facility for Vietnam veterans, sparked anger and stress as it reminded these residents of their war service in the tropics. The walk around (as well as the use of the assessment tool and planning template) was a key component of moving from awareness and agreement to the adoption phase of the KT framework.

We asked what can be done to improve the environment

During the walk around, we asked staff to focus on some simple targeted questions:

'How are you able to use the environment to respond to the needs of person living with dementia? What can you do to use the environment to support her or him?' Staff were asked to complete an Environmental Assessment Tool. This was done using a hard copy of the assessment tool, or a smartphone app, the BEAT-D which can be found at https://dta.com.au/resources/beat-d-app/

The BEAT-D App (Built Environmental Assessment Tools – Dementia) offers the option of two assessment tools; the EAT (Environmental Assessment Tool), or the more recent EAT-HC (Environmental Assessment Tool – Higher Care) for buildings accommodating less mobile people living with dementia. The BEAT-D app generates a Room for Improvement report which includes a ranking of the responses prioritised according to the most room for improvement in relation to the key design principles. The focus is on the opportunities for improvement rather than on attaining a specific score.



R4 EAT-HC HANDBOOK

Table 1: Abbreviated EAT-HC 'Room for Improvement' report

EAT-HC ITEM	Actual score	Maximum possible score	RFI score	Principle
Look at the items below that have been scored as Not Applicable (N/A). Would the facility be improved if they were considered to be applicable?				
Resident's kitchen has safe appliances.	N/A	2	N/A	Unobtrusively reduce risks
Outside, ramps are wheelchair accessible.	N/A	1	N/A	Unobtrusively reduce risks
Lounge room is clearly recognisable.	N/A	1	N/A	Optimise helpful stimulation
Discuss the following items in turn. These are ordered according to where there is the most room for improvement.				
Bedroom is seen from Lounge room.	0	3	3	Allow people to see & be seen
Dining room is seen from bedrooms.	0	3	3	Allow people to see & be seen
Resident kitchen has master switch.	0	2	2	Unobtrusively reduce risks
Inside small group areas are available.	1	3	2	... a variety of places to be alone or with others
Front door can be secured.	1	2	1	Unobtrusively reduce risks
Outside, paths are appropriate widths.	0	1	1	Unobtrusively reduce risks
Inside, contrast between floor surfaces is avoided.	0	1	1	Unobtrusively reduce risks
The items below (RFI = 0) do not need as much discussion (but may still may have room for improvement).				
Lounge furniture is familiar.	2	2	0	Create a familiar place
Bedroom furniture is familiar.	2	2	0	Create a familiar place

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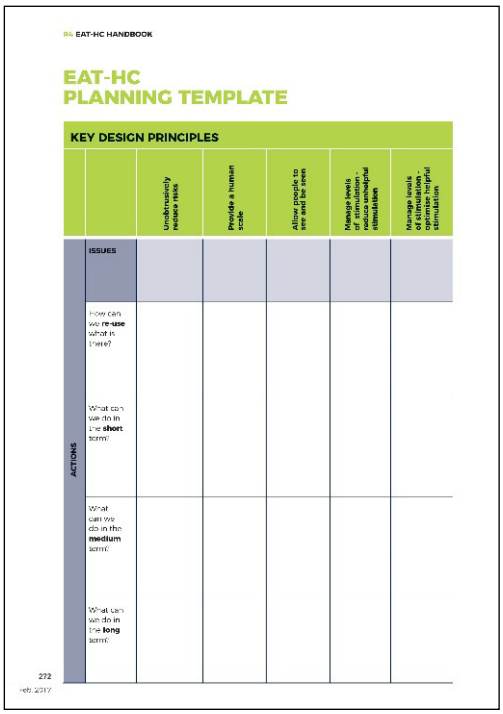
Figure 6: Room For Improvement report

A key question we asked was: 'What are the strengths and weaknesses of the environment?' There is always something positive in an environment, and there is always more that can be improved.

> Using an assessment tool to systematically look at the environment and the way it responds to the key design principles allows the strengths and weaknesses of the environment to be highlighted.

The Room for Improvement report encourages the organisation to set priorities. This was done in conjunction with a discussion about timing. We asked participants to consider: 'How can you reuse what is there? What can be done in the short term? In the medium term? In the long term?' This allows staff to balance what needs to be addressed with what is possible so that achievable goals can be set. It may be, for example, that an outdoor shelter is identified as a priority. This is likely to require fundraising and a building permit (making it a medium to long term project), whereas an umbrella can provide shade (in the short term) until the shelter can be built. A planning template was used to assist staff to record what needed to be done, identify which design principles these items related to, and give a timeframe for the works.



R4 EAT-HC HANDBOOK

EAT-HC
PLANNING TEMPLATE

		KEY DESIGN PRINCIPLES				
		Unobtrusively reduce risks	Provide a human scale	Allow people to see and be seen	Manage levels of stimulation - reduce unhelpful stimulation	Manage levels of stimulation - optimise helpful stimulation
ACTIONS	ISSUES					
	How can we re-use what is there?					
	What can we do in the short term?					
	What can we do in the medium term?					
	What can we do in the long term?					

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Figure 7: Planning template

These conversations also placed great emphasis on the experience of staff and their knowledge of the people who lived in a facility and the context. The DPD team was there for a short time and so only had a glimpse of the situation. While an outside and fresh view is valuable, it needs to be balanced with experience so that any changes can be implemented successfully. Discussions with staff were always the focus, and attention was paid to ensuring that the priorities that they set would both meet their objectives and be achievable in their context.

CONCLUSION

The DPD education service enabled participants to

- increase their knowledge of the role of the environment in supporting people with dementia
- gain skills to enable the ongoing use of the environment as a tool in the care of a person living with dementia
- make changes to the environment in a systematic and targeted way to ensure environments can be enabling for a person living with dementia
- receive resources which could help them improve the environment and engage more fully in briefing and design conversations with architects and project managers
- connect with other members of their organisation with expertise that can complement their own
- maintain contact with DPD service for follow up and advice

From inception, the DPD service focussed on giving staff the knowledge to understand why and how the environment makes a difference to people living with dementia, and the resources to learn more about this. It did this with a focus on turning knowledge into practice as staff moved from awareness to agreement, adoption and adherence.

Recognising that staff have a key role to play in creating, using and maintaining environments that are supportive for people living with dementia was significant. It acknowledged that the initial design of an environment was only one component of designing for people with dementia. While an architect needs knowledge and skill to design well,

> the best environment can only be successful if the people who manage and use it on a day to day basis are also aware of its potential and therapeutic value.

This focus on increasing staff's knowledge of how to modify and use the environment enabled them to continue to use the environment well, long after the DPD team had left and as each new resident arrived with their individual needs. In this way, these environments really can be enabling and empowering for people living with dementia.

ACKNOWLEDGEMENTS

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Canada: Supportive environments for people with dementia in long-term care: Education and training methods

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Introduction

As part of the programme curriculum in the Department of Gerontology at Simon Fraser University, we offer a course on institutional environments for older adults. This course focuses on the long-term care facility with particular emphasis on the built environment of the care setting. Students taking this course are expected to examine the relevant theoretical frameworks, peer-reviewed empirical research and conduct a term project on built environmental assessment with standardized measures, behavioural observations and spatial-photo analysis. The pedagogical strategy is to engage the students in experiential learning in care settings utilizing various tools and methods with the goal of gaining first-hand understanding of the importance of the built environment on residents' functioning, autonomy, mobility, daily activities, social interaction and well-being. The course description: "Organizational policies, staff training, staff culture, care practices and physical environment -- all contribute in shaping the everyday life of older adults living in a long-term care (LTC) facility. This course explores theory, research and practice in institutional living environments with special focus on the role of the physical or built environment in the residents' quality of life as well as quality of staff care practices. We will focus on the physical environmental design from a multi-faceted perspective taking into account the residents' socio-psychological situation, staffing issues and organizational context. The term project will engage the students to conduct environmental assessment of a selected long-term care home. Students are expected to actively participate in the discussions and critique the readings."

EDUCATIONAL GOALS

- Understand the key theoretical approaches, substantive research findings and applied issues in long-term facilities
- Identify the major environmental design principles relevant for creation of a supportive physical environment in long-term care facilities
- Develop techniques and skills in conducting built environmental assessment of care homes using a multi-method approach

Term Project Description: Environmental Evaluation of a Long-Term Care facility for People with Dementia

This is a two-student group project, which includes four components. Although there are overlaps or connections across these components, they need to be considered as distinct methodological approaches. Each student group identifies a residential care facility in the Vancouver metro area. The group contacts the administrator and introduces themselves as Gerontology students at Simon Fraser University and communicate the purpose and methods of the class project. After securing permission from the facility administration to conduct the study at the site, they utilize the following methods:

EVALUATION OF THE ENVIRONMENT WITH STANDARDIZED EVALUATION TOOLS:

The Professional Environmental Assessment Protocol (PEAP) [15] and the Therapeutic Environment Screening Survey for Nursing Homes (TESS-NH) [16] are validated instruments used to evaluate the built environment of dementia care settings. Students are trained on using these tools before they use them to evaluate the selected care facility. TESS-NH was designed for use by persons with relatively modest levels of training in person-environment theories. It focuses predominately on the physical environment and contains 13 sections, under which specific physical features are defined. Observers rate these features using a simple point system (e.g. Yes [1] or No [0]). At the end of this tool, observers are also asked to provide a global rating of the facility's physical environment out of 10; 1 being very unpleasant, and 10 being quite pleasant. PEAP differs from TESS-NH in several important ways. It examines the overall environment of the care unit in physical, sensory, social, and policy terms in eight global sections. In each section, the observer is asked to rate the facility on a scale of 1 to 5, 1 being very poor and 5 being very good. Overall, it provides a much more detailed look at the various environmental aspects of the facility with which a resident may interact, requiring the user to be familiar with person-environment theories. Using these two instruments in a care facility provides the students a solid first-hand understanding of the various important physical environmental features. The discussion of the relevant environmental issues and features of a care setting based on readings in the classroom provides the requisite knowledge.

Using the assessment tools to observe a real physical setting and making informed judgment is extremely helpful for the students to connect that knowledge with reality of the field.

BEHAVIOURAL OBSERVATIONS

A few key questions to be answered in this project are: how is the common space(s) (e.g., dining space, activity area, hallways) in a care home utilized, who are the users, how many people are using the spaces, in what ways and when. These data are collected with the technique of "behavioural mapping." This method involves systematic direct observations of common spaces in a care setting. Objectives of this technique are: a) How often are various activity and dining spaces in the facility used? b) Who are the users of those spaces? and c) What are the patterns of social engagement in those spaces? Students conduct observations in the shared or common spaces, i.e., dining/activity space, and lounge areas. Private areas, e.g., residents' rooms, rest rooms and tub-rooms, are excluded from behavioural observations. Frequency counts are calculated for the number of residents, staff, volunteers and family members using the different spaces, as well as the types of behaviours they are engaged in.

TOOLS USED:

- Behavioural Checklist
- Basic floor plan of the activity/dining space showing location of door(s), window(s) and existing furniture.
- Photographs: The students take photographs of the activity/dining area from different angles of the space considering the following: institutional/ homelike quality of the space, quality of the furniture, furniture layout and social groupings, location of windows and views through the windows, visual connections with adjacent spaces, quality of lighting, floor finishes, wall hangings, etc
- Field notes: During the behavioural observations, students take qualitative notes on relevance of the activities for residents, usage of furniture (preference for locations, types or arrangements, interpretation of the environmental ambience, interpretation of the social ambience)

DATA COLLECTION:

- The students ask the administrator of the facility if there is any easily accessible floor plan of the care facility. Alternatively, they can draw the plan of the selected activity or dining space
- They draw the furniture layout (as best as possible) of the activity/dining area on an enlarged plan and make multiple copies of it
- They conduct observations in the activity room to record the type of users, social engagement level of the residents and staff using the "Behavioural Checklist." The floor plan is used to record spatial locations of the observed activities, preferences in use of furniture, movement within and in/out of the space, etc
- Observations take place over 30–40 minute periods at different times of the day and week to capture activity variance. Total time for observations should be 3–4 hours per group member

AFTER DATA COLLECTION:

- Frequency counts of different levels of social engagement are added and graphically presented to show different activity levels across different times, types of users (residents, staff, visitors)
- A floor plan of the activity space is annotated based on an analysis of the positive and negative aspects.

Based on the analysis of the data collected with the multiple methods and design guidelines, the students generate recommendations for low to medium cost environmental modifications for the space. Issues to consider include: spatial layout (subdividing large spaces), treatment of exit doors, furniture arrangement (supportive of small group interaction), furniture type (appropriate for frail older adults and homelike in appearance), quality and quantity lighting, floor finishes, opportunities for display of residents' memorabilia, etc.

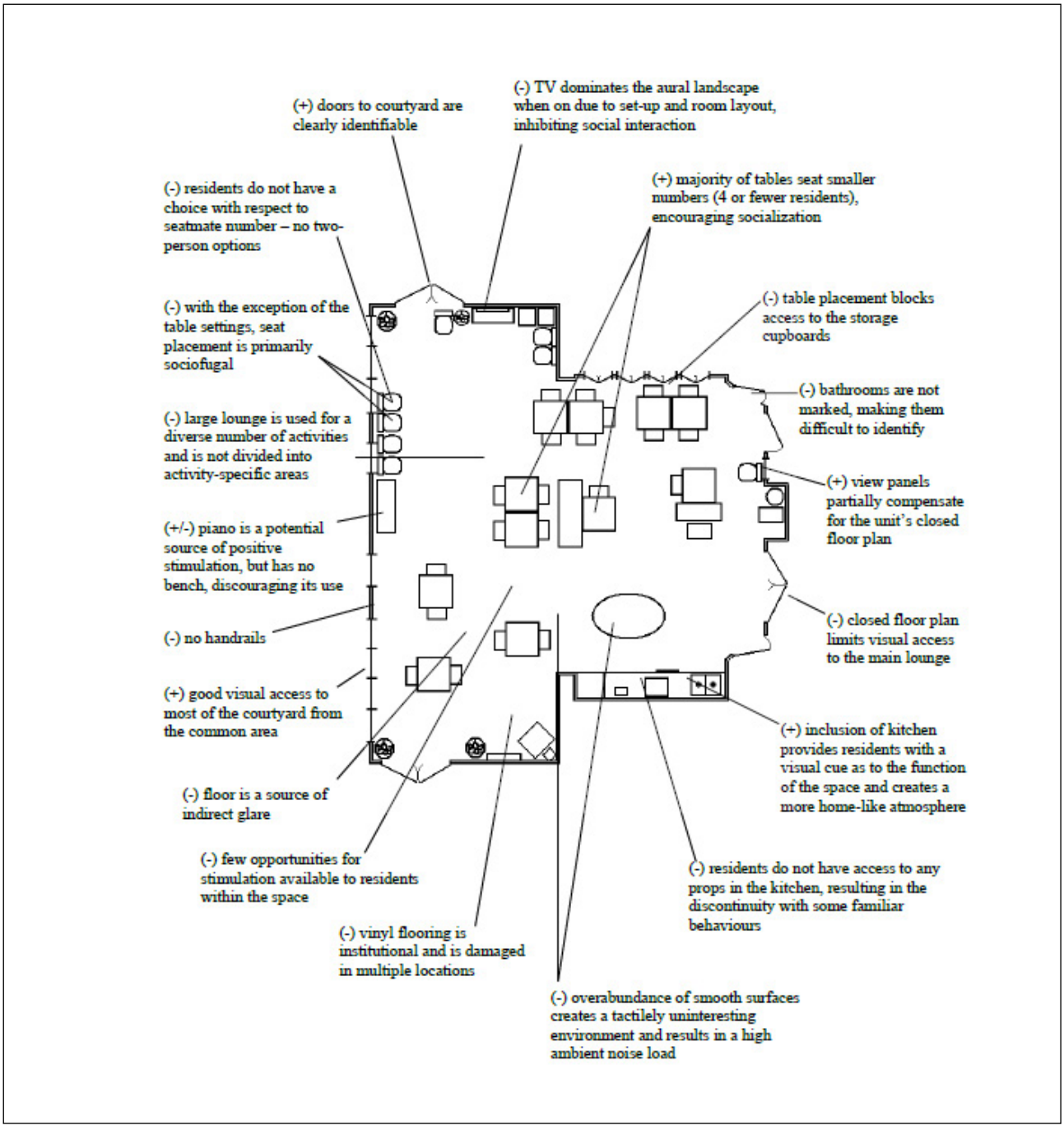


Figure 1: Example annotated plan showing positive and negative built environmental features in a dining space of a care facility

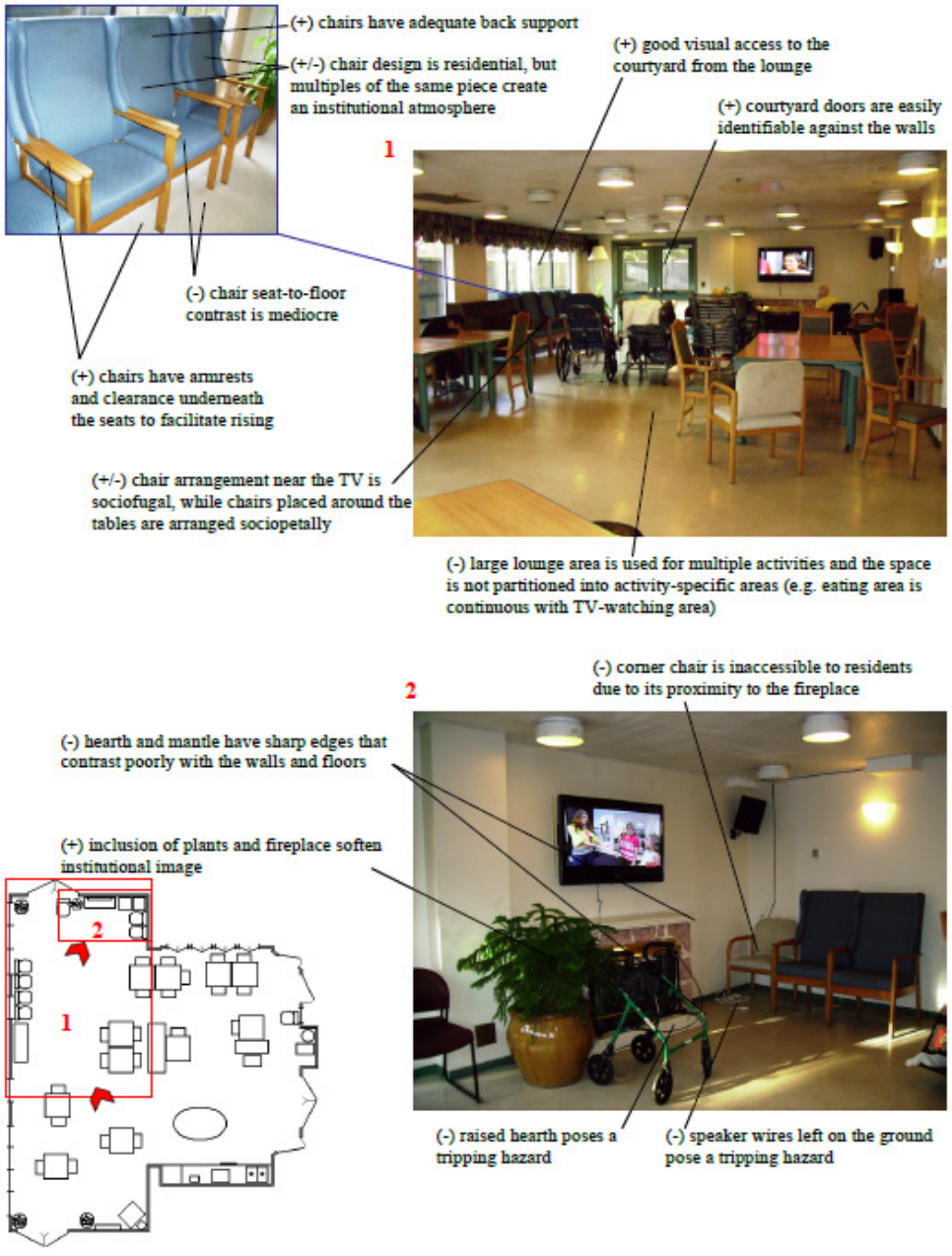


Figure 2: Example photographic analysis showing positive and negative built environmental features in a dining space of a care facility.

Flooring

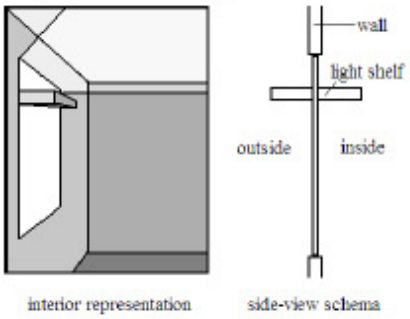
- Replace the current flooring in the unit's lounge with laminate. Ensure the floor has a matte finish to reduce the likelihood of glare, and that the colour contrasts well with the walls so that residents may easily discern the wall-floor boundary. The baseboard moulding should also contrast well with the floor.
- Embed any metal doorframe strips in the floor itself to minimize transition height and eliminate any tripping hazard this may pose. Ideally, any floor transitions should not exceed 1 mm in height (Brawley, 2006; Briller et al., 2001)

Lighting

- Install recessed lighting around the periphery of the space to provide even, diffuse, indirect lighting.
- Replace the current ceiling-mounted fixtures with more home-like shielded fixtures such as light bowls to augment the peripheral lighting. Additional task-specific lighting can be installed over areas such as the kitchen where objects must be easily discernible from their surroundings.

Wall, Ceiling, and Window Treatment

- Install handrails on the walls around the space to facilitate ambulation. Handrails should be easily accessible to residents (e.g. not blocked by furniture)
- Repair any damage to the walls and ensure good wall-to-floor contrast. To maximize light distribution, the ceiling should be lighter than the walls, and the walls lighter than the floor (Briller et al., 2001).
- Install light shelves on the exterior windows. These shelves redirect natural light up towards the ceiling, allowing it to be refracted back in a diffuse fashion to reduce glare without impeding visual access to the exterior environment. Shelves should be installed 30-50 cm from the top of the windows (Brawley, 2006). Sunshades can be installed on the bottom portion of the shelves so that during times of intense glare, the shades can be drawn while still permitting some natural light to filter in through the top portion.



interior representation | side-view schema

- Apply an acoustic spray treatment to the ceilings to help reduce the ambient noise load. Such treatments can also mimic the texture of residential ceilings.
- Put up fabric wall hangings to absorb sound and provide tactile stimulation
- Install a power-assist system for the courtyard doors to increase accessibility
- Identify the public toilets. For example, a large (30 cm x 20 cm) picture of a toilet can be put on the outside of the door with the word "Toilet" or "Bathroom".

Figure 3: Example design recommendations for a dining space of a care facility

Environmental Design Workshop for Long-Term Care Professionals and Administrators:

The primary goal of this workshop is to equip long-term care facility administrators, care staff, facility planners and design professionals with the knowledge base to understand the importance of a responsive physical environment in person-centred dementia care. After the workshop, participants are equipped to make informed decisions in making small-scale environmental changes, as well as plan for medium to major renovations that would optimize residents' quality of life in a care facility.

Figure 4: Workshop is a combination of didactive and interactive sessions

The objectives are:

a. To identify typical problems in the physical environments of typical care homes for people with dementia

b. To understand and recognize the role of therapeutic goals and environmental design principles in dementia care

c. To make informed decisions in planning and design for renovations in existing care facilities or planning and design of new care facilities.

APPROACH:

The workshop consists of didactive (lectures) with larger groups (30–25 persons) and interactive (hands-on exercises) sessions in small groups (5–6 persons/group). The lectures cover various substantive and process-oriented topics including; conceptual issues in environmental design for people with dementia, therapeutic goals and design principles in dementia care facilities, interior design issues. In the hands-on exercise, there are two case studies. Case study 1 is based on the short film Ex Memoria about a person with dementia living in a care home. In this case study, participants identify the impact of environmental design aspects and features on the resident's functioning and well-being, as depicted in the film. Case study 2 is based on a care facility that is planning renovations. In this case study, participants have the opportunity to develop a physical and social designs (functional and architectural programs) and design schematics by applying design principles in the context of a case study care facility. In sum, the workshop provides participants with research-based knowledge and skills in evaluating, planning and designing physical environments that support the cognitive status and functioning of people living with dementia.

COMPONENTS OF WORKSHOP:

- Introduction to Content and Process of Workshop
- Conceptual Issues on Physical Environment and People with Dementia
- Environmental Design Principles and Illustrations
- Interior Design Considerations
- Using Standardized Assessment Protocols: Person Oriented Environment Tool (POET) and Dining Environment Audit Protocol (DEAP)
- Case Study 1: Life in a Care Home through the Eyes of Eva
- Case Study 2: Social and Physical Design (Programming) of a Care Facility
- Programming Exercise (Small-Group Activity)
- Review of Programming Exercise
- Environmental Design Exercise (Small-Group Activity)
- Review of Design Solutions

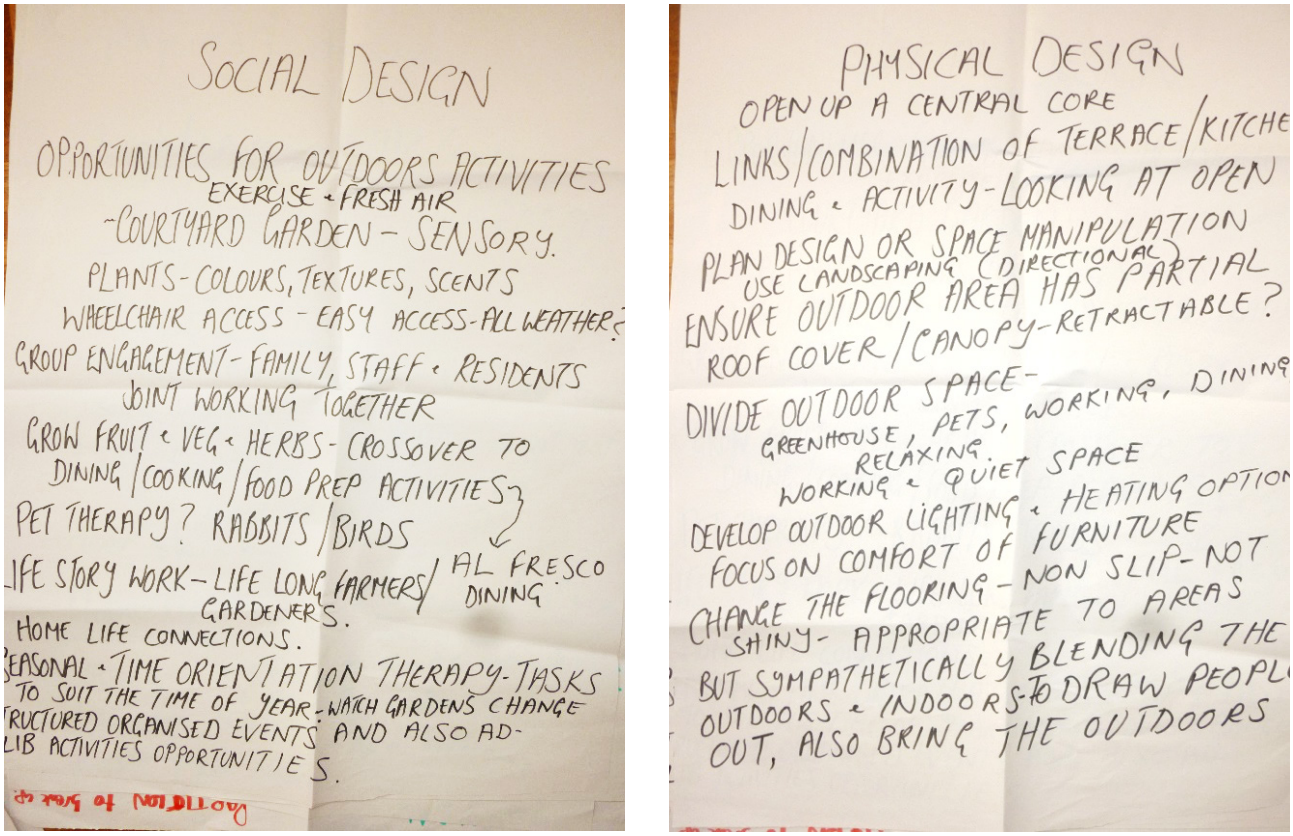


Figure 5: Example of participant generated physical and social designs.

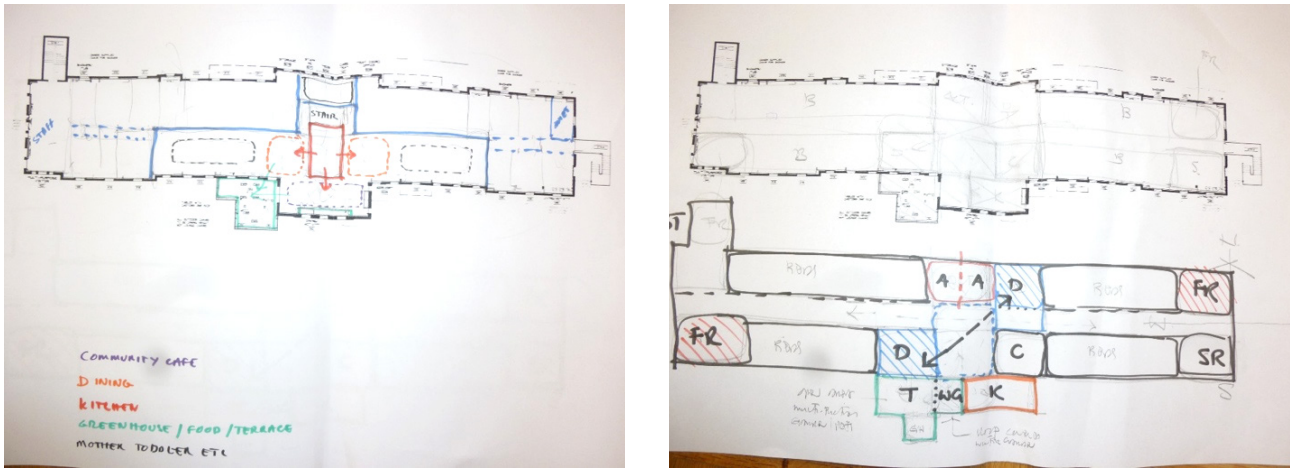


Figure 6: Examples of participants' schematic design outputs

Brief Description of the Standardized Environmental Assessment Tools:

PERSON ORIENTED ENVIRONMENT TOOL (POET)

The physical environment is a critical component of a supportive residential care setting for people with dementia. There is substantial evidence that has identified the effect of unsupportive physical environments that contribute to common challenging behaviours in people with dementia, e.g., spatial disorientation, anxiety, agitation, social withdrawal, etc. Unsupportive environmental features in residential care settings contribute to spatial disorientation, anxiety and agitation among residents with dementia [17–20]. These environments include features such as long hallways, large dining rooms, shared bedrooms, high noise levels and institutional lighting, etc. Conversely, a well-designed supportive physical environment has been shown to foster positive behaviours, such as reduced agitation, increase in social contact less dependence in conducting activities of daily living, etc. [17]. Supportive environmental features include small household, homelike kitchen, cluster design with no hallways and positively designed outdoor spaces, etc.

There is a need for the development of assessment tools to systematically measure the physical environmental features supporting the quality of life for people with dementia in long-term care facilities.

We have developed a physical environmental assessment instrument, named *Person Oriented Environment Tool* (POET), to assess the quality of physical environmental features in the long-term care setting that are supportive/unsupportive of residents' behaviours and social interactions. There are two components of the research tool: a) *Module 1*: used for a walk-through environmental evaluation (e.g., noise, lighting, furnishing, decor) of the care unit, and b) *Module 2*: used for documenting physical environmental features and behavioural observations (data on residents' behaviours are collected with a researcher/observer chosen instrument) of *current residents* with dementia in the common areas of the care unit (i.e., dining room, activity area, lounge).

POET Module 1 involves walk-through assessment based on observation of the physical environmental features (e.g., noise level, furniture type and arrangement, lighting, floor finishes, visual access) only in the various spaces of the care facility. In use of Module 1, there is no observation of any resident or staff member who might be present during the walk-through observation. The walk-through observation takes approximately 1–1.5 hours. This Module includes both discrete features of the built environment (e.g., quality of furniture, lighting) and their expected influence on residents' behavioural outcomes (e.g., social contact, wandering).

POET Module 2 is unique as it is used to document the physical environmental features along with the current residents' social behaviours (e.g., participation in planned activities, sitting, walking, eating). This includes environmental and behavioural observations of the residents conducted for 6 hours over a two-week period. All observations for Module 2 are conducted only in the common spaces of the units. These include dining and activity spaces, hallways and lounges. The goal of Module 2 is to collect data on environmental features that are associated with individual resident's behaviours, and in turn, inform the care staff to make targeted environmental changes that would be responsive to the current residents' needs.

Dining Environment Audit Protocol (*DEAP*) is used to collect data on environmental features in dining areas of the care homes. It is one of the few very recently developed and validated new tools for environmental assessment of long-term care settings [21, 22] Dining is often one of the early care practices and environmental areas that are modified as a care community seeks to adopt more person-centred values and practices. The original version of the DEAP included 32 items grouped into seven domains (functional ability, orientation, safety and security, familiarity and homelikeness, optimal sensory stimulation, social interaction, and privacy and personal control). The revised version (psychometrics reported here) includes 24 descriptive items, seven discrete items (adequacy of lighting, glare, personal control, clutter, support in staff supervision, restraint use, and seating arrangement option for social interaction) and two scale questions that rate the overall homelikeness and functionality of the dining room, with a scoring range from 0 to 8. The higher number represents a higher quality of the observed dining environment [21].

DEAP was validated in a sample of 10 dining rooms in three care communities that were part of the same parent organization (dining rooms were empty at the time of the assessment). Seven of the ten dining rooms assessed were dementia-specific and three were "general population". Average interrater reliability was 0.7 (range 0.2 to 1.0). Overall "homelikeness" was based on key physical environmental features including size of the space, institutional/homelike furniture, quality of

lighting and absence/presence of homelike artefacts, etc. Overall "functionality" was related to entry/exist conditions, contrast between table and plates, posted menu, server, lighting intensity, glare, etc. The construct validity of DEAP is supported with several correlation measures and theoretical relations with homelikeness and functionality of the dining rooms in a study based on data from 82 dining rooms in 32 care homes [22]. The homelikeness scale was positively associated with a view of the garden/green space, presence of a clock and a posted menu, while functionality scale was positively associated with number of chairs and lighting ($p<0.05$). The interrater reliability and construct validity of DEAP suggest that the tool's use in future studies to quantitatively measure the physical environmental quality of dining rooms.

Case Study: Life in a Care Home through the Eyes of Eva: A Video-based Exercise

Ex Memoria – a short film (15 minutes) portrays daily life experience of Eva – a woman with dementia living in a care home – through her perspective. A collaboration between Bradford Dementia Group (BDG), writer/director Josh Appignanesi, and producer Mia Bays. In this exercise, the video is used to relate to Eva's experiences in a care facility and identify the physical environmental features that are challenging for her. After viewing the video, the participants are asked to read descriptions of selected scenes, respond to a set of questions and raise new ones.

Here are a few excerpts from the descriptions, example questions and suggested answers:

The physical environment – examples from the film ***Ex Memoria***

Home-like décor

In the opening shot of the nursing home, we see Eva seated in a lounge that is furnished much as we might furnish our own home. There are comfortable armchairs, arranged in a conversational pattern, bookshelves, table lamps, coffee tables, and a fireplace with knick knacks on the mantle. While the larger common area where Eva's family first appears still has paintings on the wall, a piano, plants, and bookshelves, it has a slightly different feel. What might contribute to this feeling? In both the lounge and the common area, there is very little for Eva to touch or pick up. What familiar day-to-day objects could be incorporated into these areas?

A variety of personal possessions are on display in Eva's bedroom. Framed photographs and knick knacks sit on top of a chest of drawers. There are flowers in a vase, paintings on the wall and family photographs and letters on the bulletin board. Eva's visual and physical access to some of these objects is limited. What changes could be made to improve her access to such objects? How could staff use such possessions to foster meaningful interaction with Eva?

In contrast to the living areas, the relatively large toilet area with its tiled walls seems very stark and institutional. How could the bathroom be made to feel more residential and the residents at ease?

Orientation & use of space

Eva is wheeled out of the lounge into a long hallway. At Eva's eye level, there is very little visual stimulation. The institutional appearance of the hallway stands in contrast to a residential home. The brick walls are painted the same white as the bedroom doors, and in places the hallway is quite dark. In the first half of the hallway, there is no handrail along the wall, which could make it difficult for residents to move independently from the lounge to the bedrooms. What could be done to make the hallway more visually engaging? What features could be added to assist residents in finding their way? As Eva requires assistance to move around, she has limited choice as to where she spends her time. How could her physical access to the common areas and her own room be improved?

Eva's physical positioning also impacts her visual access. While she is seated and relatively immobile, staff are standing and moving around. Her visual access is further compromised when she is repeatedly positioned with her back to the action. How could staff help Eva to feel more socially included? What changes to the physical environment could be made to improve her visual access?

Eva's interactions with her family take place in the common area and her bedroom. While the common area provides little privacy for visiting, it is unclear if there is seating in Eva's bedroom for her family to sit and visit. What environmental features could help improve the quality of Eva's visits with her family?

HOME-LIKE DÉCOR – SAMPLE OF SUGGESTED ANSWERS:

What might contribute to this feeling?

Institutional furnishing, flooring and lighting are the most common elements that contribute to an institutional environmental ambience. Use of reflective vinyl in upholstery and flooring is helpful in terms of maintenance but creates a non-residential atmosphere. High quantity of overhead fluorescent lighting, lack of residential lighting fixtures and total reliance on one type of lighting create an ambient lighting condition that is both institutional and negatively stimulating over time.

What familiar day-to-day objects could be incorporated into these areas?

Photo-frames, books, magazines, art objects, and plants are examples of everyday objects that can be found in people's homes. These and similar objects are familiar to most residents and can help create a home-like décor and provide prompts for interaction.

What changes could be made to improve her access to such objects?

Horizontal surfaces in the rooms that can be easily reached from a seated position (either on a chair or a wheelchair) provide the environmental context for object placement. A bay-window sill, a low wall shelf, and a bedside table would all be appropriate examples.

The full-day workshop has been offered in various countries including the U.K., Spain, Hong Kong, Singapore, Canada and U.S. Typically they are attended by long-term care facility administrators, frontline staff, architects and interior designers. Overall, the participants' evaluation of the workshop indicate that the training provides them with a strong foundation in understanding the importance of the built environmental features on residents' behaviour and well-being, equip them with skills and ideas to develop small to medium to large scale environmental interventions and empower them to advocate for environmental changes.

One of the most important impacts of the workshop has been the recognition that even low-cost small changes in the environment can also bring about meaningful effect on residents' functioning, wayfinding behaviour, anxiety and engagement levels.

United Kingdom: The Association for Dementia Studies, University of Worcester

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Background

The Association for Dementia Studies was established in 2009 by Professor Dawn Brooker as a Research Centre at The University of Worcester, England. It has established a national reputation as a centre of innovation and excellence in dementia research, education and policy advice developing strong partnerships with health and care providers, commissioners, charities, government departments and other Higher Education Institutions (HEIs). The Research Centre contributes to UK national and international programmes for the delivery of education and research worldwide including Europe, Scandinavia, Australia, South Africa, Japan and India. Its research and education portfolio are aligned to The Dementia Training Standards Framework and working towards making a substantial contribution to building evidence based practical ways to enable people living with dementia and their families to live well [23].

The Association for Dementia Studies recognised that the environment in which people living with dementia (those with a clinical diagnosis of dementia) and those affected by dementia (people living with dementia, and their family or carers), live, is critical to their quality of life. Creating an optimal environment maximises the opportunity for their engagement and well-being whilst ameliorating some of the challenges associated with dementia. The environment is approached in its broadest sense to capture, not only buildings and design, but to develop an understanding of how a building is used; how it can support a person-centred care culture to thrive the importance of keeping people connected with nature; how connection with local communities can be promoted; and how social engagement can be enhanced – all with the aim of improving health, wellbeing and care outcomes. The development of the environments specialism and educational offer within the Association for Dementia Studies aligned with an increased national focus on the importance of dementia friendly design through the National Dementia Action Alliance [24]. Synergies between work by the Kings Fund on the *Enhancing the Health Environment Programme* and the aims of the Association for Dementia Studies coalesced at a time of growing interest in the environment to support the needs of people living with dementia. National conferences formed part of a structured dissemination path which led to a range of organisations interested in improving the care and support of people affected by dementia seeking consultancy, training and education to inform their practices. Working directly with experts at the forefront of healthcare, social care and housing design, the education offer was tailored through a reciprocal learning cycle blending knowledge with practitioner insights in a continually evolving dynamic exchange. The journey below charts the path taken by the Association for Dementia Studies in harnessing national change to create a powerful programme of education and influencing environmental and organisational development.

THE KING'S FUND'S ENHANCING THE HEALING ENVIRONMENT PROGRAMME

Patients and carers were at the centre of The King's Fund's *Enhancing the Healing Environment* (EHE) programme launched by the charity in 2000 [25] The programme supported over 250 multidisciplinary teams to improve care quality and support service change through high quality, innovative, value for

money environmental improvements. From 2009 the programme focused on Developing Supportive Design for People with Dementia [26].

The EHE programme consisted of two main elements which linked education and practice: a development plan for a multidisciplinary team drawn from the participating organisation and a grant for the team to carry out a project to improve the patient environment. Teams were clinically led, and included managerial and estates staff, arts coordinators and critically service users and carers who learned and worked together to achieve defined project outcomes. This multidisciplinary mix brought challenges but was a critical factor in the success of the individual projects in acute and community hospitals, mental health units, hospices and prisons in England.

The educational element consisted of short residential courses, seminars and visits over a period of six months. All team members received training in design principles, the use of colour, light and art, presentation skills, consultation methodologies and project management.

As a clinical team leader commented "It's more than the building. It's a tool to change people's attitudes".

Projects typically took from one to two years to complete, with The King's Fund providing continuing support during this period. This allowed team members to gain in confidence and develop their skills in project management and leadership. To receive the project grant, teams were required to gain local approval from their service users and, to ensure cross organisational support, from their governing board.

DEVELOPING SUPPORTIVE DESIGN FOR PEOPLE LIVING WITH DEMENTIA

In 2009 the Department of Health (DH) commissioned and funded a specific EHE programme for hospitals in England to support the publication of Living Well with Dementia: a national dementia strategy [27]. Through this programme 26 projects were completed in acute, community and mental health settings. The projects were chosen to provide exemplars capable of wide replication, with local adaptation, across the service. However, evaluation showed that many of the high impact changes in staff attitudes and behaviours towards people living with dementia occurred as a consequence of the initial residential training before teams had started to plan their projects. In the words of one of the estates staff it is "*not just about the colour of the paint*". Carers were welcomed as full and active members of each team, some finding EHE a life changing experience: "*The extra learning taken on as part of the project has completely changed future plans for my work*". During the course of the programme there were identifiable improvements in staff metrics in the areas where projects were being undertaken, with reductions in sickness and absence rates and better recruitment and retention compared to other areas of the hospital.

One of the more surprising findings of the educational programme was that,

even amongst dementia specialists, there was a significant knowledge gap about the critical role that relatively straightforward and inexpensive improvements to the built environment can play in improving care and supporting the well-being of people living with dementia.

It was also very difficult at that time for key staff including care assistants, administration, support and estates staff to access specific training in the care of people living with dementia.

"*Despite my background as a dementia nurse, I have to admit that I had very little understanding of how the environment can affect people with dementia. This has been the greatest lesson and now I am equipped with the evidence and ability to highlight the benefits to others.*" A Dementia Specialist Nurse

Drawing on the outcomes from the programme, research evidence and best practice The King's Fund developed a set of overarching dementia friendly design principles and a set of environmental assessment tools [28] (The King's Fund, 2014). EHE team members and people affected by dementia, were instrumental in the development of the practical and easy to use tools which were, unlike other tools available at that time, specifically designed for use by people affected by dementia as well as staff. The tools focus on those aspects of the physical environment known to impact on people with dementia and assess not only the physical environment, such as floor coverings and use of paint colours, but also the way that the environment encourages people

to behave and interact. Evaluations of the tools have shown that they have been instrumental in prioritising areas for improvement but also proved to be a vehicle for educating staff, thereby helping to change attitudes and improving care delivery [29]. All five tools for wards, hospitals, care homes, housing and health centres remain free to download [30]. The tools were adapted with the help of people affected by dementia, and user groups to develop 'Making Your Home Dementia Friendly' [31].

The King's Fund built on the learning from this dementia care programme and developed a two-day residential educational programme for those interested in designing environments for people living with dementia. The programme included contributions from experts in dementia, design, lighting, colour and arts in health as well as case studies from teams who had participated in the EHE programme. Participants included architects, designers, health and care staff, estates and building managers, arts practitioners, academics and teachers, researchers, dementia specialists and service user representatives.

In 2015 to ensure that the knowledge gained from The King's Fund's work on dementia friendly environments could continue to be developed and disseminated, a collaborative partnership was formed with the Association for Dementia Studies which was capable of integrating dementia design within its overall portfolio and which possessed the appropriate networks to ensure that the EHE work continued to develop and thrive.

MOVING FORWARD

The learning from the EHE programme has now been successfully adapted and expanded, enabling the Association for Dementia Studies to offer a range of educational support to a wide variety of organisations to increase understanding of the importance of the environment to the well-being of people living with dementia and those that care for them. The underlying principle of the EHE programme and the work of the Association for Dementia Studies is that through targeted and engaging educational experiences, coupled with workplace interventions,

it is possible to effect sustainable improvements in the physical and social environment by changing staff attitudes and behaviours towards those affected by dementia.

This was founded on the premise that when people gain an understanding of why the environment was a key factor in the maintenance of well-being of people affected by dementia, they would be challenged to effect change. One of the most powerful factors in achieving this has been the use of case studies. These have demonstrated how their peers in similar circumstances have achieved remarkable results and have ensured a long-term impact by, for example, encouraging their organisation to adopt dementia friendly design principles in all capital schemes and refurbishments. Programme evaluations have confirmed that an understanding of dementia, the impact of the environment and what makes good design for people living with dementia has enabled a wide range of staff, not only those in leadership positions, to effect change.

This ethos of gaining understanding and the acquisition of practical knowledge has translated into the portfolio of educational and development programmes provided by the Association for Dementia Studies. These include one day Masterclasses hosted at the University and the provision of on-site dementia friendly workshops together with dementia friendly environmental reviews. The Association for Dementia Studies has also been commissioned by a range of housing, health and care organisations, local authorities and charities to support and enable them to use a co-production approach to develop their own dementia friendly design standards and bespoke assessment tools.

CASE STUDY 1: THE DEVELOPMENT OF DEMENTIA FRIENDLY DESIGN STANDARDS FOR A CARE HOME GROUP

The Association for Dementia Studies was commissioned by a large care home group to collaborate on dementia friendly design standards for all their care homes. This initiative was led by the Director of Care Operations and the organisation's Dementia Working Party which included care home managers, key training staff, and those responsible for procurement. The organisation was developing a dementia strategy and the design standards were seen as an integral part of this work and the organisation's new design manual.

A consultative approach underpinned by educational input was taken, with members of the Working Party being invited to a series of seminars and workshops to inform the development of the standards. Key to the work was agreement on the balance of core standards across the organisation, for example the colour of paint to be used for all toilet doors, and the elements

that could properly be left to a local home manager's discretion, for example artworks that reflected local landmarks.

In addition, a rationale was developed so that staff could understand the reason behind each of the standards.

As with The King's Fund's dementia friendly assessment tools, the rationales have proven to be an excellent educational tool for staff. The group's new design manual for its care homes now incorporates both the design standards and details on suggested schemes for each area of the home, together with a range of dementia friendly furniture and fittings to inform refurbishments and new builds.

An eLearning package was developed to support the implementation of the standards, with all staff expected to successfully undertake this training. The Association for Dementia Studies was already providing advanced practice and specialist level education programmes for the organisation and many participants chose to undertake environmental projects including bathroom and toilet refurbishments, improvements to the dining experience and the provision of activity areas as part of this programme.

Integral to the Association for Dementia Studies education-led and consultative approach to dementia friendly standards development, is formal approval of the standards by the board to ensure top level commitment across the organisation and sustainability. This methodology has been successfully adapted for use in NHS Trusts and with providers of assisted housing with care.

CASE STUDY 2: THE DEVELOPMENT OF A BESPOKE DEMENTIA FRIENDLY ENVIRONMENTAL ASSESSMENT TOOL WITH A ROYAL COLLEGE FOR HEALTHCARE PROFESSIONALS

In the UK there are a number of Royal Colleges for the healthcare professions, each having a different remit with regard to education, practice and research for their profession. The Association for Dementia Studies was approached by one of the Royal Colleges to develop a bespoke dementia friendly environmental assessment tool for its members, in recognition of the increasing number of people affected by dementia that were being treated by the profession. A reference group was formed to guide the project with membership drawn from the College, practitioners and representatives from the lay partnership group. An initial workshop was held for the group which explored the background to, and positive impacts associated with, dementia friendly design. A number of key decisions about the design of the prototype for the tool were made to inform its development. It was agreed that the tool should, with appropriate adaptation and revised wording, follow The King's Fund's model with the importance of the rationale in educating the profession confirmed. However, the scoring system needed to be more flexible to take into account the range of premises from single clinics to multidisciplinary health centres in which practitioners worked.

It was also agreed that an introductory guide should be produced to accompany the tool to educate members about the importance and impact of the environment on the well-being of people living with dementia. The reference group were involved in the drafting of the guide and tool providing critical professional insights during their development. Two rounds of testing were undertaken each with a different group of College practitioners from across the UK, with changes being made following each round on the advice of the reference group. To disseminate the knowledge acquired during the development of the tool, a presentation on the work was given at the Annual General Meeting prior to the launch of the tool, and an introductory guide was made freely available to College Members. Results drawn from the environmental assessments will become an integral part of the Royal College's future quality assurance process.

CASE STUDY 3: SUPPORT TO COMMUNITY INITIATIVES

Village Halls

The Association for Dementia Studies continues to develop bespoke assessment tools for housing, health and care settings and most recently has worked with a community charity to produce a short dementia friendly guide and checklist for those organising events in village and community halls as part of a pilot programme. In England voluntary committees are responsible for the management of village halls which are used for a variety of community activities and can provide space for rural post offices and general practitioner (GP) services. An educational briefing was arranged for committee chairman who had indicated that they were happy to support the development of the guide and checklist. Materials were drafted and site visits made, with the support of an expert by experience, to test and refine the checklist and guide before publication. This work formed part of the charity's initiatives to tackle loneliness and isolation

by encouraging all the community, including those affected by dementia, to access and engage in the activities provide in their local community halls and is now in use across two rural counties in England.

Dementia Dwelling Grant

In recognition that the majority of people living with dementia live in their own homes, a pilot grants programme was offered through a group of five local councils across a rural county in England. The programme was funded through the Better Care Fund and provided minor aids and adaptations to people with a clinical diagnosis of dementia living in their own homes, rented accommodation or social housing, and was not means tested [32]. The grant was not means tested. The Association for Dementia Studies was commissioned to provide education to shape the programme and to work with the expert multidisciplinary group drawn from health and social care, local dementia support providers and council representatives who were involved in the pilot. This group informed the development of a standard list of products, capable of adaptation to meet individual need, that were to be offered to grant recipients. Subsequent training assessments were undertaken by dementia advisors as part of initial home visits following diagnosis and the required aids were delivered from stock. The commission also included the opportunity to evaluate the programme to explore the benefits these could make to the wellbeing of people living with dementia and their carers. Findings from the pilot evaluation showed that

relatively inexpensive aids can contribute to the maintenance of wellbeing for people living with dementia in domestic settings.

In addition, it increased the skills and confidence of the dementia advisors. The dwelling grants have continued to be funded by local authorities across the county.

CASE STUDY 4: WELSH LOCAL AUTHORITIES

Local council authorities within the United Kingdom are responsible for utilising public funds to support the unique profile of their populations. As a result of conference presentations, a local authority in Wales became aware of the importance of the environment to support its residents who were affected by dementia. The operations manager for a Social Services Department was successful in obtaining funds from the Welsh Government to make environmental adaptations to two of the authorities care homes and commissioned The Association for Dementia Studies to provide education to staff from the homes and estates and other council staff so that they were equipped to plan an manage the environmental changes and to underpin the rationale for change.

The education package comprised initial visits to both care homes to meet with staff and residents to explore areas of change using the Kings Fund Assessment Tool. In addition to the operations manager and care home managers, an architect from the council was also able to attend, residents were able to offer opinions and other staff were observed using the spaces. This inside knowledge was incorporated into a workshop held the following day to support staff to understand the applied principles of environmental change in relation to their own provisions. Staff were able to explore the outcomes from the assessments to scaffold their understanding of the needs of people living with dementia visualising how environmental change could enhance quality of life. Working groups were tasked with creating action plans to consolidate ideas and move forward to implementation.

Following project completion the Association for Dementia Studies revisited each of the homes where the impact of change was evident; signage had improved which assisted wayfinding; clutter had been removed so that materials for engaging activities could be easily identified; artworks had been commissioned depicting local areas of interest to engage residents in discussion and provide cues to assist navigation; mirrors had been removed; busy décor had been replaced with calming colours. Staff at both provisions were extremely proud of their achievements, a factor borne out by discussions with residents who '*loved their new home*'.

Importantly, these improvements did not require structural change or vast sums of money.

Through education, clear direction and applied principles, bespoke to the unique challenges faced by each care home they were enabled to make small changes, which had a big impact.

As a result of the success of this educational intervention the Association for Dementia Studies supported work to improve environments in further supported living, residential homes and hospitals in Wales.

Distance Learning: new times and new challenges pave the way for education. The need for education to be accessible in flexible ways to meet the needs of different audiences drove The Association for Dementia Studies to seek new ways of reaching learners. A fully online Post Graduate qualification in Dementia Studies was launched in January 2020. Comprised within this programme is a 12-week module focusing on the importance of the environment to support people living with dementia. Already the programme has met with success, reaching leaders and practitioners from a wide range of disciplines.

Conclusion

The work of the Association for Dementia Studies demonstrates the critical importance of education in enabling public, private and voluntary organisations to effect sustainable improvements in the lives of people living with dementia and those that care for them through environmental change. Without an understanding of the specific needs of people living with dementia, their potential co-morbidities and, in the majority of cases, the effects of ageing, it is not possible for staff to appreciate how difficult and anxiety provoking health and care settings can be. However, as illustrated by the case studies, through tailored educational programmes and the development of associated guides, checklists and assessment tools, staff can be enabled to effect sustainable changes not only to the environment but also to attitudes and behaviours so as to better support people affected by dementia.

The relationship between those who create the environment and those who experience that environment is key to developing spaces which maximise the opportunities for people whose needs have largely been ignored. Education provides the vehicle to drive this knowledge and understanding. It is crucial that all professional, administrative and support staff including volunteers working to support people living with dementia across all health and care settings are involved in this learning cycle.

Developing a new paradigm takes time; education is the key to this new paradigm.

A new paradigm where the needs of people living with dementia and those who work to support them have a mutual understanding of the symbiotic relationship fostered by the environment; we are a part of our environment not apart from our environment.

The Association for Dementia Studies, University of Worcester UK, continues to develop its research and educational programmes to ensure that sustained and systematic improvements can continue to be made to improve the quality of life for those affected by dementia.

United Kingdom: Environmental design education in a changing world

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Introduction

We argue that developments in other spheres of life have left environmental design less than fully fit for purpose. Dementia is a global issue. Evidence-based environmental design *should* be part of the solution in every country and in all cultures. However, research evidence reflects and reproduces the contexts in which it was created, and environmental design education has too frequently been insufficiently critical of both the quality of the evidence base and its generalisability to other contexts. We provide examples drawn from our experience of the challenges to its delivery in different parts of the world before calling for a new, more nuanced approach to environmental design education which we call 'Designing for context'.

In this chapter we first explore what we mean by environmental design education ('EDE'), present and discuss key aspects of EDE and introduce sensitivity to context. We then present a way to examine differences in the context of EDE before presenting a series of timelines identifying key trends from which we draw examples to highlight ways in which EDE reflects and reproduces context. As an illustrative example, we consider the changing provision of EDE by the University of Stirling's Dementia Services Development Centre (DSDC) which, since 1989, has been at the forefront of critical thinking with respect to architectural built environments for people living with dementia.

Informed by experience, we explore challenges to delivery of EDE in a global context, considering issues around how knowledge which informs EDE is created, translated and and shared, inviting readers to discuss and debate this topic with us. Finally, we ask whether it is time for a new paradigm in dementia design capable of addressing identified issues.

WHAT DO WE MEAN BY 'EDE'?

We start by clarifying our understanding of 'environmental design' (ED) and 'education' respectively. There is no agreed meaning of ED. Definitions range from the short and literal to those which encompass details of both methodology and goals:

'*environmental design* [*is an activity which*] *focuses on using holistic, human-centered, and interdisciplinary approaches to create and enable a sustainable life/space ecosystem, including experiences, communication, and places that optimize the interactions of humans with their surroundings*' [33].

We favour definitions of environmental design as necessarily interdisciplinary, extending beyond the physical, and concerned with interaction between person and environment after physical structures are in place. In addition, here we are talking about evidence-based activities which incorporate dementia design, a non-pharmacological approach to maintaining quality of life and addressing some behavioural symptoms with the goal of optimising interactions of people living with dementia with their surroundings. For the purposes of EDE we define 'education' simply and broadly as 'an enlightening experience'.

KEY ASPECTS OF EDE

We consider four key aspects of EDE, as set out in Table 1, which provide an aid to thinking about the ways in which EDE is sensitive to wider environmental influences, for example prevailing social norms around the support of people living with dementia, the focus or aim of ED at different points in time and space, advances in information and communications technology, and so on.

Table 1. Key aspects of environmental design education

Aspect	Significance
Who ('the educators')	The identity of the educator, i.e. the provider or facilitator of EDE, reflects which organisations or groups of people in society are perceived to have valued knowledge or understanding of ED at any point in time
What	The content of EDE can point to what knowledge educators perceive as able to bring enlightenment to others, important to share to further their aims or objectives, or perceived as likely to be valued by those to be educated
To/for whom ('the educated')	The identity of the recipients of EDE reflects categories of people or organisations which the educator believes will benefit from 'enlightenment' and/or the categories of people or organisations that consider they or others will benefit from that enlightenment.
How	The methods and media of delivery of EDE reflect and reproduce prevailing norms about how ED knowledge and understanding can and should be imparted (for example, through academic journals, training events, 'grey' literature, completed works such as art and architecture etc).

In the next section we illustrate EDE's sensitivity to context by thinking of context as consisting of multiple dimensions, examination of which provides a means for understanding geographic, cultural, social, and temporal differences in EDE.

KEY TRENDS: HOW EDE REFLECTS AND REPRODUCES CONTEXT

We do not have space here for a full description so to illustrate our concept of context and how it helps to explain differences in EDE over time and space we provide timelines (see Figure 1) and identify key trends influencing EDE across three influential dimensions; understandings of disability; dementia-specific policy; and development of information and communications technologies.

SOCIAL UNDERSTANDING OF DISABILITY

EDE reflects and reproduces prevailing wider social understandings of disability.

Jewson [34] suggests that the 'medical model of disability', in which disability resides in the person and is addressed by 'fixing' their impairment, became the dominant paradigm in the late 19th century. The medical model impacts significantly on the identity of EDE providers by restricting the perceived validity of expertise to medical domains to the exclusion of those living with illness or impairment. As Simon Brisenden wrote in 1986:

'*Our opinions, as disabled people, on the subject of disability are not generally rewarded with the same validity as the opinions of* '*experts*', *particularly medical experts*' [35].

Building on pioneering work which began in the 1970s [36], by the 1980s a new 'social model of disability' had begun to supplant the medical model.

According to the social model, disability is defined as the disadvantage that results from the failure of society to take the impairments that some people have into account and is addressed by fixing social barriers and not the person. The social model of disability informed the Disability Discrimination Act 1998, a landmark piece of UK legislation which introduced a mandatory requirement to provide 'accessible' environments and which had a profound impact on the built environment. Neither the social model of disability nor the Act explicitly accounted for cognitive disability, but both influenced dementia-related thinking. Authors such as Gilliard, Means [37] have subsequently explored the social model of disability as a framework for thinking about dementia. General acceptance of the social model of disability prompted expansion in academic interest in dementia-related knowledge creation and changed foci across disciplines, both of which feed into the content of EDE.

More recently the 'social relational model of disability' has influenced both thinking around dementia and the content of EDE. The social relational model sees disability as 'a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional wellbeing' [38] and draws a distinction between 'impairment effects' and the socially imposed restrictions which constitute disability. Shakespeare, Zeilig [39] draw parallels between influence of the environment on the experiences of people living with dementia and of those living with physical disabilities before asserting that 'a relational model of dementia lays the basis for a human rights approach to the condition'.

The development of Dementia-specific journals provides evidence of the impact of the changing social understanding of disability on EDE. As Table 2 illustrates, the earliest listed, Alzheimer Disease and Associated Disorders, is established in 1987 when the medical model is dominant and this is reflected in the journal's focus on diagnosis and treatment, inhibiting the development of ED. The change from medical to social model as the dominant paradigm sparks interest in dementia from other academic disciplines, and journals established in the 1990s stress the multidisciplinary nature of their content. Later journals service nascent academic communities of interest in non-medical aspects of dementia-related research and, consistent with the social relational model, focus on research exploring lived experiences of dementia.

Table 2. Dates of first publication and purpose at establishment of selected journals

Journal title	Date of first publication	Stated purpose at first publication
Alzheimer Disease and Associated Disorders	1987	'An international forum for reports of new research findings and new approaches to diagnosis and treatment'.
Journal of Dementia Care	1993	'A multidisciplinary journal for all professional staff working with people with dementia, in hospitals, nursing and residential care homes, day units and the community.'
Journal of Alzheimer's Disease	1998	'An international multidisciplinary journal to facilitate progress in understanding the etiology, pathogenesis, epidemiology, genetics, behavior, treatment and psychology of Alzheimer's disease'.
Dementia: The International Journal of Social Research and Practice'	2002	'An international peer reviewed journal that acts as a major forum for social research of direct relevance to improving the quality of life and quality of care for people with dementia and their families'.
Alzheimer's & Dementia: Journal of the Alzheimer's Association	2005	'To bridge the knowledge gaps across a wide range of bench-to-bedside investigation'.

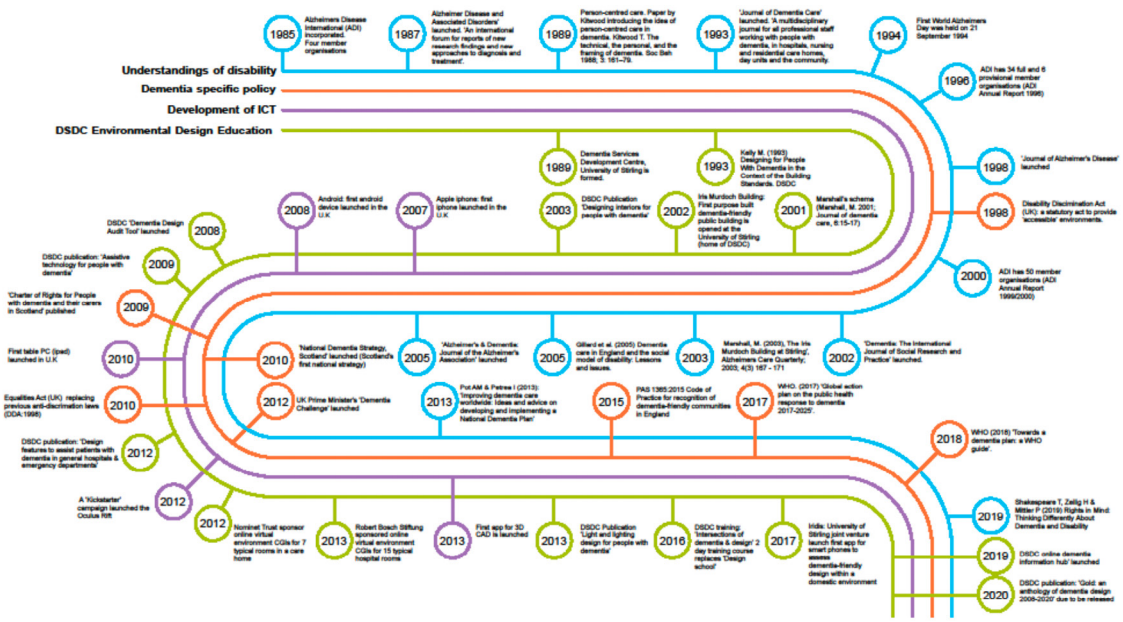

Figure. 1: Timeline

Dominant models of disability are also reflected in the language which organisations use to describe themselves, their remit, or their beneficiaries and in EDE itself. For example, terms reflecting the medical model such as 'Alzheimer's victims' and 'dementia sufferers' that were used in the 1980s have since been replaced by those such as 'people living with dementia' which are consistent with social and relational models.

NATIONAL DEMENTIA PLANS

In May 2017, the Seventieth World Health Assembly adopted the WHO 'Global action plan on the public health response to dementia 2017–2025' [40]. The ambition of the Global action plan is 'to improve the lives of people with dementia, their carers and families, while decreasing the impact of dementia on communities and countries' and it sets out seven key areas for action. 'Area 1, Dementia as a public health priority', calls on countries to act on dementia. Dementia action plans reflect awareness and commitment to act to improve the lives of people living with dementia, including in relation to ED.

Sensitivity to context is stressed by Pot and Petrea [41], who suggest that

> national dementia action plans, which often detail actions to be taken in relation to ED, 'need to be based on the country-specific situation and context and methods' and to take into account amongst other things 'the needs of people living with dementia and their care-givers,…the services provided by healthcare professionals, and cultural and socio-economic factors'.

By 2019, 31 such plans had been adopted, primarily in higher income countries [42]. Other countries are being actively encouraged to adopt dementia plans by the World Health Organization [43].

'Dementia awareness and friendliness', Area 2 of the WHO Global action plan, has the greatest direct bearing on EDE. Proposed actions for member states in this area include:

'Support changing all aspects of the social and built environments, including the provision of amenities, goods and services, in order to make them more inclusive and age- and dementia-friendly, promoting respect and acceptance in a manner that meets the needs of people with dementia and their carers and enables participation, safety and inclusion' [40].

The Global action plan also sets out complementary actions for the WHO secretariat relevant to EDE in relation to Area 2, which include building on the resources of the WHO Global Network of Age-friendly Cities and Communities in order to:

'integrate and link dementia-friendly initiatives by documenting and evaluating existing dementia-friendly initiatives in order to identify evidence of what works in different contexts and disseminate this information' [40].

DEVELOPMENT OF INFORMATION AND COMMUNICATIONS TECHNOLOGIES

The technological context of EDE has seen rapid change in relation to information and communication technologies ('ICTs'), especially the development and uptake of internet-enabled devices (e.g. personal computers, tablet computers for mobile computing, and smartphones). These developments influence the delivery of EDE and the identities of EDE providers and recipients.

Internet-enabled devices are a relatively recent innovation. Computers for consumer use became available in the 1970s, but the 'world wide web' was not introduced until 1991 and Internet use did not expand significantly until late 1993 [44]. Mobile internet-enabled devices are more recent still, with smartphones really only taking off after the first mass market touchscreen phones were launched: iPhone in 2007 and the first Android device in 2008 [45]. The launch of iPad in 2010 is similarly regarded as the catalyst for subsequent growth in the market for tablet computers [46].

> Increasing processing power, sophisticated computer software programmes and mobile applications ('apps') and cloud-based data storage and retrieval systems now allow for new ways of delivering or facilitating EDE,

which in turn influence the identity of educators and recipients. The ability to be able to participate remotely, often at a time and pace convenient to the EDE recipient, provides the potential for educators to offer EDE to recipients irrespective of geographical location and to provide EDE at costs which make EDE attractive to individuals whose interest is personal in addition to those with professional interests in ED. Internet-enabled devices still allow EDE to be delivered as old style direct instruction distance learning, but also facilitate a shift away from face to face and uni-directional modes of learning and dissemination into digitally enabled and (arguably) richer modes of education such as 'flipped classrooms', more dynamic and interactive EDE experiences from virtual or augmented reality, and bi-/multi-directional EDE and learning through collaborative design and co-creation processes.

An illustrative example: The University of Stirling's Dementia Services Development Centre (DSDC)

INTRODUCTION TO DEMENTIA SERVICES DEVELOPMENT CENTRE (DSDC)

The Dementia Services Development Centre (DSDC) sits within the Faculty of Social Sciences at the University of Stirling. It is an international centre for knowledge exchange which for more than thirty years has worked with individuals and organisations to: improve the lives for people living with dementia through design; make communities dementia-friendly and increasingly dementia-supportive and enabling; and influence policy to improve services for people with dementia. DSDC's EDE offering is used to illustrate the effects of changes in selected dimensions of context over time.

FORMATION AND MISSION

DSDC was formed in 1989 with support from the Dementia Services Development Trust (DSDT), a Scottish charitable organisation established a year earlier, to further DSDT's charitable mission. DSDC reflects and works to achieve the aims of DSDT, re-stated with updated language in line with the contemporary context in a 2016 vision statement as:

'To improve the lives of those living with dementia' and its mission as 'To promote the best practice in the development of services of care and support of all those living with dementia and their carers.' [47]

In the beginning there was an emphasis on raising awareness of dementia among health and social care staff, but DSDC now provides 'training, consultancy, undergraduate and postgraduate education and information on dementia for professionals and carers around the world' [48].

EDE AT AND THROUGH DSDC: REFLECTING CHANGES IN SCOTTISH AND UK CONTEXT

Then Director of DSDC Mary Marshall noted in 2003 that 'From its inception in 1989 the numbers of requests for help with design to assist people with dementia have been considerable' [49], and EDE is now explicitly acknowledged as a major element in the work of DSDC. The Centre has a dedicated environmental design team comprising of architects, landscape architect, interior and product designers and services engineers supported by registered mental health nurses and social care practitioners.

In the 1980s the main focus of ED research, literature and design guidance was on institutional care environments and DSDC's early EDE offerings reflected that. The late 1980s saw significant changes in the context within which DSDC was operating. DSDC responded to growing interest in ED with conference presentations and consultancy, and in the early 1990s DSDC offered design expertise through short books published in-house on aspects of ED including: group living for people with dementia [50]; design in the context of UK building standards [51]; and small scale, domestic style, long stay accommodation [52]. The development of 'person-centred care' (53, 54) as a new approach to caring and the Disability Discrimination Act 1998 passing into UK law forced the ED community to focus on issues of accessibility. DSDC's EDE offerings were reconsidered in this context and expanded, with the first 'DSDC Design School' three-day training events held in the late 1990s. The choice of 'Design School' as the descriptor for these events speaks to the primary method of EDE delivery, which was through direct instruction, a method familiar to both educators and recipients which allowed for significant volumes of unfamiliar material to be introduced 'en bloc'.

Increasingly seeing ED as a core part of their educational offering, DSDC were also aware of the differing needs of EDE recipients. Discussing the Iris Murdoch Building ('IMB'), the UK's first purpose-built dementia friendly public building, shortly after its construction in 2002, Mary Marshall wrote that 'Most of our work targets people working in dementia care rather than architects. While the latter can visualize

design features from a plan or description, others really struggle' [49]. DSDC badly needed office space at that time, but the need to provide alternative but complementary ways to communicate EDE for non-architect EDE recipients was also a key driver, and DSDC recognised that the IMB 'presented an opportunity to demonstrate dementia-friendly design'.

IMB has continued to provide a practical example of dementia friendly design, but changes in context over nearly two decades, including working time poverty of professional participants and increased expectations of participant-centred and peer group learning, interactivity, and technology mediated course content, prompted radical re-thinking of the 'Design School' model of EDE delivery. In 2016 DSDC replaced 'Design School' with 'Intersections of dementia & design', a new 2-day training course incorporating a mix of learning activities intended 'to redress the balance between dementia care and dementia design by focussing on the complex combination of the individual, dementia and the built environment'.

Key developments in the availability and use of information and communications technologies (ICTs) and the expansion of EDE recipients from primarily professional recipients to a far more varied population which includes informal carers and people living with dementia have driven changes in the delivery of EDE at DSDC. For example, in 2012 the Nominet Trust sponsored the development of online virtual environment CGIs for 7 typical rooms in a care home and a year later the Robert Bosch Stiftung sponsored online virtual environment CGIs for 15 typical hospital rooms. Both sets of virtual environments are accessible to all via the DSDC website. In 2017, the University of Stirling were partners in the development of Iridis, an iterative built environment application for mobile devices which allows homeowners and professional users to assess the built environment against the DSDC's Dementia Design Audit Tool [55] and upload results to enable 'practice informed research'.

Most recently, in 2019 DSDC has launched the 'DSDC online dementia information hub' [56] The hub was developed to complement a series of free, 4-hour informal educational workshops delivered as part of a project with local partner organisations designed 'to address a notable gap in the provision of dementia education for both informal carers and those in volunteering roles'. Both the workshops and the online information hub provide EDE.

The dimensions of context explored in section 2 and illustrated in relation to EDE provided by DSDC in section 3 have led to a

framing of people living with dementia as individuals with the same rights to participation in society as anyone else but subject to a range of socially imposed restrictions to activity which limit their ability to exercise those rights.

At the same time, dementia is now firmly established as a global priority and one to which nations are increasingly responding with action plans which impact on EDE. Added to this, the widespread availability and use of ICTs has allowed a widening population of professional and informal consumers of EDE around the world to access and act on available digital content. Section 4 reviews the challenges to delivery of EDE which this presents.

CHALLENGES TO THE DELIVERY OF EDE IN A GLOBAL CONTEXT

Much of the ED design guidance currently available has been developed in and/or is underpinned by research undertaken in developed countries and informed by Occidental culture. This can present challenges to the delivery of EDE in a global context and from our experience of working with international clients, including in India, Japan and Nigeria, we outline the key challenges. These evidence

a pressing need for critical discussion of the research evidence base and its global generalisability and encouragement of new research reflecting global diversity.

LANGUAGE

At first this may seem an obvious challenge which could easily be overcome, for example by employing the services of a translator. However, used here 'language' relates to both linguistic systems and to abstract concepts influenced by emotion, time and social context. Changing contexts have led to abandonment of certain words (senile, demented, patient, sufferer etc.) and adoption of other more inclusive terms in some places, but this is not uniform across cultural contexts.

In addition to the cultural sensitivity of the terms used to describe dementia, ED incorporates several professions which are technical in nature and involve

domain-specific terminology. EDE needs to be culturally sensitive and able to adopt industry specific terminology. This requires a close working relationship with international partners to ensure language is both culturally and technically appropriate and the EDE is relevant to the wider context.

LOCAL VERNACULAR

EDE is itself a product of globalization. In many countries, memory shelves, contrasting toilet seats and applied signage are all too familiar. However, one only has to view the building orientation, form, elevations and use of materials to see how the local vernacular (climate, density, availability of materials and cultural practices) influence the overall design.

The local vernacular and technical codes which govern ED vary and are not always compatible to the geographic origins or age of research evidence. This is self-evident when considering a global context but can also be true within federalised countries or across member states of larger unions. Therefore, it is essential to understand the design context and to be sensitive to how differences in context shape the application of core dementia design principles. For example, within the United Kingdom statutory regulations and regulatory bodies for care vary between member countries, prompting DSDC to publish guidance identifying conflicting regulations and providing recommendations.

To address this,

we have found that global EDE is more effective when distilled to design principles as opposed to descriptive technical requirements.

This in itself can be challenging for the provider because recipients of EDE are often seeking technical solutions to everyday situations. The use of precedent examples is helpful, but care is needed to ensure that the EDE recipient does not assume this to be the definitive solution, ignoring local context. Where EDE provider and recipient work collaboratively a design solution can be developed which acknowledges the research evidence base (the core principles) and is fit for purpose (designed to the local context).

EDE is and should be a critical practice and we advocate for an approach similar to that of critical regionalism [57]: inspired by and responding to the local context whilst maintaining a discrete recourse to globalization, and the global evidence base. Such an approach facilitates innovation and creativity and ensures the solution is designed for context.

A DESIRE FOR DETAIL

Over the past 30 years considerable ED research has been undertaken. Early research focussed on and assessed general aspects of ED such as scale of care setting, safety features, wayfinding and orientation, visual access, colour and outdoor space. Key trends in research foci are reflected in DSDC's EDE content, enabling changes to be tracked (refer 'Key Trends' timeline). For example, in 2003 DSDC EDE reflected research focus on design of interiors. Since then we have witnessed an increasing demand for EDE to provide greater certainty, quantitative outcomes and detailed explanation of their application, and more recent publications on 'light and lighting design' (2014) and 'air quality' (2016) reflect increasing EDE recipient demand for and thus research concern with depth and detail.

Recent foci for research interest, such as the effects of bright light interventions, ambient assistive technologies, smart buildings and artificial intelligence, reflect deeper awareness of the interdisciplinary nature of ED but also speak to a turn towards the use of innovative technologies in ED. This presents a challenge because the speed with which society demands information in this hyper-connected, digitised world is not always compatible with the time needed to design, implement, analyse and publish research and the evolution of EDE is reliant on a suitable 'pipe-line' of quality research.

DOMINANT ENVIRONMENT

Research into the impact of the built environment on people with dementia has favoured care environments with less research undertaken in hospitals, public buildings or people's own homes.

Studies tend to prioritise certain research designs or to focus on specific rooms or areas within the environment [58] and these tend to reflect key trends in global attitudes towards dementia. This has led to the emergence of a dominant environment in EDE (the care environment) and a gap in environmental design research.

The Iris Murdoch Building was recognised as the UK's first purpose-built dementia-friendly public building (c.2002). At the time Marshall acknowledged the need for a design exemplar which could:

'show dementia design features for any age, cohort, any cultural background, and any level of disability.' [49]

However, in the UK increased interest for wider adoption of dementia-design principles into public buildings, work environments, leisure and community buildings was not apparent until 2012, following the launch of the UK Prime Minister's 'Challenge on Dementia'. It was not until 2019 that DSDC awarded its internationally recognised accreditation for dementia-friendly building design to the UK's second purpose-built dementia-friendly public building (Great Sankey Neighbourhood Hub in Warrington, UK, designed by Walker Simpson Architects for Livewire CIC).

PHYSICAL VERSUS PSYCHO-SOCIAL ENVIRONMENT

Physical and psycho-social environments are intricately interrelated and therefore EDE must also acknowledge the care relationship / care model. Fleming highlights the challenge of undertaking ED research in care settings, stating that:

'It is the difficulty of teasing out the relative contribution of the physical environment and the staff-resident interactions which is most central to the problem' [59].

This point is reinforced by Bowes and Dawson, who note:

'The research on care homes highlights the importance of the approach to care, and the difficulties of separating out the impact of design features from that of the model of care delivery on the quality of care' [58].

As noted, research into the impact of the environment on people living with dementia has predominately been undertaken in Occidental cultures where similar person-centred care models dominate. This increases the complexity of providing EDE in countries where the care model is different and has the potential to conflict with person-centred environmental approaches to ED.

TIME FOR A NEW PARADIGM IN DEMENTIA DESIGN? AN OPEN INVITATION TO DEBATE

In starting this discussion, we set out our definition of ED as a human-centred, interdisciplinary approach to creating a sustainable ecosystem which encourages interactions between humans and their surroundings informed by an evidence-based focus on design for dementia and we adopted a broad and inclusive definition of 'education' as an 'enlightening experience'. In mapping the methods and media of EDE as informed by three dimensions (social understanding of disability; dementia action plans; and development of ICTs) across a 30-year period we have illustrated EDE's sensitivity to wider context and outlined some of the challenges of EDE on a global stage.

We posit that EDE and the evidence base which underpins it, reflect and reproduce the contexts of production and that to date, this has privileged certain environments and cultures. It is not optimal to replicate EDE for people with significantly different context-dependant lived experiences. A nuanced understanding of context is critical to designing for people living with dementia in different international contexts, suggesting a need for

a new paradigm in ED; one which reflects emerging human rights-based perspectives, is critical in its practice and embraces global diversity in its application.

We refer to this approach as 'Designing for Context'.

'Designing for context' recognises the multi-faceted needs of people with dementia and rejects an assumed homogenisation in favour of considering the needs of one person with dementia as being unique to the needs of another individual, and represents a starting point in the development of a more context-sensitive approach to ED and EDE. It takes into account the different political, economic, socio-cultural, technological and legal environments which make up country specific contexts around the world and which influence design and human behaviour.

We welcome robust discussion and debate on the detail of this approach.

Japan: Experience of dementia design and education in Japan

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Introduction

Dementia design can make a significant impact on people in different ways. This is what we have learnt from the past projects. The benefits of dementia design and education are diverse. It has a potential to help people with dementia to live their lives to their full potential. It helps people to live their lives as they were, even with dementia. We have witnessed people with dementia who are incontinent at home to be able to go to the toilet on their own in the environment where dementia design is implemented.

It also has a potential to help people living or working with people with dementia to think about things from a point of view of people with dementia. Dementia design teaches us the power of the environment and what design can do to help, why certain design features are helpful and how we can accommodate the environment for people whom we care. It can prompt us to think about the meaning of challenging behaviours of people with dementia from different perspective.

This section introduces three cases in relation to dementia-friendly design projects with particular focus on design as a means of learning and education. Dementia-friendly design projects discussed in this section are based on the implementation of dementia design principles through the collaboration between the Dementia Services Development Centre (DSDC) at the University of Stirling in the UK and Mediva Inc., a Japanese consulting firm specialising in healthcare. We have been collaboratively working together since 2015. The three cases introduced here are with our Clients – a private land developer, a non-profit medical institution and a local government.

WHY DEMENTIA DESIGN AND EDUCATION IN JAPAN?

Japan has gone through a rapid demographic change from a relatively young population to one of the oldest populations over several decades. It is now experiencing a number of issues in relation to the ageing society at the first hand. The increase in the number of people living with dementia is one of the urgent issues that Japan is facing.

In Japan, it was estimated that there were 4.6 million older people with dementia in 2012, a number which will increase to 7 million by 2025, based on a long term cohort study [60]. Due to the sheer number of people with dementia and the urgency of the issue, people in Japan, whether in the public or private sector, have been trying various ways to deal with the issues. There have been many successes as well as failures in dementia care in Japan. These experiences can be used to learn the lessons, to develop better ways to deal with the dementia issues and to provide an opportunity for other countries to prepare themselves for the future.

There were mainly three reasons why the collaboration with the DSDC was initiated. First,

dementia-friendly design was, and still is, a novel concept in Japan.

Dementia care in Japan traditionally tended to focus more on social environment such as care models and support for people with dementia and their caregivers, and less on the built-environment and space. People were not widely aware that the physical environment was able to contribute to the lives of people with dementia and those of people who lived or worked with people with dementia.

Second, where there were some good examples of dementia care in Japan, both social and physical environments were implemented, there were not many, and those which did exist tended to be localised and were not accessible for people living away from these areas. As the number of people with dementia were growing, it was important that people whenever they lived could have access to good dementia care, wherever they lived.

Third, the concept of most physical environments in relation to dementia care was largely experience-based and subjective, and less based on objective evidence. Dementia design developed by DSDC is one of those based on research and international good practice. It is a set of standards and has been reviewed using the latest scientific literature. It has the potential to be implemented in different parts of the country or across other countries.

CASE 1. SETAGAYA NAKAMACHI PROJECT

Setagaya Nakamachi Project was the re-development project in Tokyo by Tokyu Land Corporation with the size of 34,000 square metres. The project consisted of 252 residential flats, a nursery school, a community culture centre, a small-scale nursing care centre and Grancreer Setagaya Nakamachi (176 independent living senior housing and 75-roomed care home) as a senior living complex.

The project aimed to create a multi-generational community where people from different generations lived and engaged with each other. It was initiated to put forward a possible solution to Japan's current and future issues, such as an ageing population with declining birth-rate, the extension of life expectancy, an increase in the number of people with dementia, the high rate of turnover in care professionals, a shortage of nurse school places and the disappearance of community networks.

Dementia design guided by DSDC has been implemented in Grancreer's nursing home and the small-scale nursing care centre. They were the first cases where DSDC's dementia design was implemented in Japan. The two facilities are operated by different organisations, a private company and a non-profit medical institution. Dementia design was implemented as one project, but education and training have been provided separately. It is, therefore, discussed in separate sections later.

The dementia design planning and implementation phase started in 2015. It included an introductory lecture on dementia design and regular meetings with DSDC. A close collaborative working relationship was built among those involved in the project through the process of design planning and implementation. In retrospect it is clear that it was the first phase of the design education.

Not many people in Japan knew about dementia design at that time. Having just an introductory lecture was not enough. The deep understanding of dementia design came when people faced certain issues which needed to be overcome. There were in-depth discussions based on concrete examples, which helped people to understand what dementia design is and how it could be applied. People realised that it was not just colour or signs to follow but understanding the issues facing the people with dementia and knowing how they perceived the environment.

In addition, there was a two-way learning process to understand cultural differences between the UK and Japan, such as familiar materials and furniture, meaning of space and colour, and particular architectural features. Ideas were tested and the most suitable and practical solutions were implemented. What was learnt in this phase was that there was no single perfect answer to everything. The application of dementia design is much more flexible and adaptable depending on the needs of people with dementia, and their families and caregivers.

Dementia design offered something people had not thought previously. It was more than just living space. Understanding the meanings of dementia design, based on evidence and good practice, was empowering. Without excessive additional cost, it was possible to create environments that were both functional and aesthetic as well as to address the needs of people with dementia.

The second phase of education was to pass the knowledge and experience of dementia design to the frontline staff and to enable them to apply to their daily practice. A one-day seminar was organised and care professionals were invited to attend. The contents of the seminar included the concept of dementia design and person-centred care.

The final phase of education happened after the two facilities opened and continues to happen when the staff are faced with issues and difficulties in their daily practice This phase has conducted differently in the two facilities.

CASE 1–1. GRANCREER SETAGAYA NAKAMACHI

Grancreer Setagaya Nakamachi is a senior housing complex, built and operated by Tokyu Land Corporation, with 176 independent living flats and a 75-roomed nursing home. Dementia design was implemented into the nursing home section. The responses on dementia design from the residents and their families has been mostly positive.

In terms of education, the seminar prior to the opening did help, but was not enough. Learning really started once the residents moved in. The care staff faced the issues and tried to solve them based on their experience and what they had learnt. Having dementia design in place helped as design was always visible and raised awareness of dementia care among them. It stimulated voluntary discussion and ideas to try in practice.

> Design acted as a constant reminder for the care staff that there was something they could use to make their care better.

It also inspired the organisation to develop their own dementia care method. The method is a combination of person-centred care, other dementia care methods, and advice from the experts in this field, in conjunction with dementia design. Design played a powerful part in the creation of this method. Being in the environment with dementia design empowered the care staff to reflect and improve their care for people with dementia.

CASE 1–2. NURSE CARE LIVING SETAGAYA NAKAMACHI (NCLSN)

NCLSN, operated by Sakura-Shinmachi Urban Clinic, Platunus Medical Corporation is a type of small-scale nursing care centre which is formally called "Small-scale multifunctional at-home nursing care" and provides the service under Japan's Long-term Care Insurance. The team supports people who require nursing and social care while continuing to live in their local community. It acts as a one-stop service providing different functions: home visit by nurse or by the caregiver, day care centre and respite care. People who are registered with the service can use any function provided by the same team according to their conditions and their needs. This type of service has been implemented throughout Japan with 390 facilities as of 2017 [61]. Dementia is the most common disease among the users in this type of care, accounting for about 60% [62].

The manager of NCLSN was instrumental in the implementation of dementia design into the facility. She visited Europe and experienced how design could change the healthcare environment. The risk of hospital admission for people with dementia has been higher than for other people (63, 64). The negative impact of hospital admission has been more significant for people with dementia than others. Dementia design could have a potential to change people's lives positively. In Japan, many people recognised the importance of universal design for people with physical disability, but not many people recognised that the design could assist people with dementia.

> Design could be helpful and make people, regardless of their abilities, live better.

This was the key driver for the implementation of dementia design into this facility. NCLSN incorporated their dementia design education within the induction programme and their monthly in-service training sessions. The dementia design environment also helps staff to experience behavioural changes in people with dementia, for example, people with dementia with difficulty going to the toilet at home could go to the toilet on their own or those who were unstable on the feet could hold and use a handrail without a prompt.

The application of dementia design does not stop within the facility. For example, one gentleman with dementia was often wandering at night at home. He walked up and downstairs, went to the kitchen and living room, opened a number of doors, but never settled. At first the staff did not know the reason and tried a variety of interventions. One was putting a toilet sign with the pictogram of the toilet on the toilet door. This simple intervention made a significant difference to the lives of this man and his family. He started to go to the toilet and stopped wandering at night. This is just one example, but dementia design can prompt people to think about how the environment can affect people with dementia and give insights into how we can act. It facilitates people's understanding of challenging behaviours and widens a range of interventions that people can apply to meet the needs of people with dementia.

CASE 2. CREER RESIDENCE YOKOHAMA TOKAICHIBA

Tokaichiba project is the second project by the same private land developer, as Setagaya Nakamachi project, Tokyu Land Corporation. The project was different from the previous project as it was publicly led by Yokohama City, a local government near Tokyo, whereas the previous project was privately led. The city authority was acutely aware of the issues that the area with public housing complexes in the suburb of Tokyo were having. Like other similar public housing complexes, the area was developed several decades ago. It had an ageing population with a shrinking younger population. The city wanted to regenerate the area. A new lifestyle model was proposed by Tokyu Land Corporation. The idea was an extension of Setagaya Nakamachi project, developing a multi-generational community in the area.

The project consisted of 312 residential flats, a shop, a community space, a nursery school, a community café, a community nursing office, a day care centre, and a variety of senior housing including 8 houses, 32 rented flats, 90 independent living housing and a 90-roomed nursing home.

Dementia design was implemented in the nursing home. The nursing home was not built in isolation and was intentionally located within a senior housing complex. It allowed the residents to meet other residents and local people.

Dementia design education was planned more carefully this time which reflected the lessons learnt from Setagaya Nakamachi project. The transition phase from an implementation team to the frontline staff was identified as an important period enabling them to understand the implications of dementia design and to apply them to their daily practice. The core team of frontline staff was assembled a couple of months prior to the opening. A series of discussion meetings with DSDC and a workshop were organised and provided by DSDC. The core team was actively involved in the development of the contents of the workshop. The meetings with DSDC helped them to learn dementia design, to think how they could apply dementia design to their daily practice and create the contents which maximized their colleagues' learning in the workshop. The workshop was conducted in a multidisciplinary way with care workers and nurses as well as the management team and sales representatives. Dementia design was one of their added values. The values were not only for the residents, but also for the staff.

CASE 3. FUKUOKA CITY

Fukuoka City has developed their inclusive design guideline focusing on people with dementia, called "Fukuoka City friendly design guideline for people with dementia". It is a part of their strategy to make Fukuoka City a dementia friendly city. It aimed to raise awareness of dementia friendly design among the general public and to encourage people with dementia and those involved to work together and co-create a better environment.

Fukuoka City is located in Kyushu region, the southern part of Japan, one of the four main islands of Japan. The population is about 1.5 million, the fifth largest city in Japan. The city faces the same demographic challenge as the rest of Japan with population ageing and with a declining birth-rate. Its older population accounts for 23.4% [65].

Fukuoka City's demographic changes meant that there would be much more diverse and increased demands for their healthcare and social care in the near future. As people age, people's healthcare and social needs increase due to comorbidities, frailty, reduced physical and cognitive functions, which in turn increases healthcare and social care expenditures. Fukuoka City has acknowledged these challenges and demonstrated an awareness that city's public sector alone would not be able to cope with all the demands.

Fukuoka City developed a healthcare and social care strategy, called "Fukuoka City Advanced Health City Strategy" in 2017, to address their future health related challenges. It aimed to realise a sustainably healthy society without too much burden on the younger population. It set out "Fukuoka 100" which was a mid-term goal to create 100 initiatives by 2025. A dementia-friendly city has been chosen as one of the themes in "Fukuoka 100".

Within the framework of becoming a dementia-friendly city, there had been several projects already running prior to the dementia design guideline project, such as rolling out a training programme on a dementia care approach, promoting the development of "Dementia Café", and implementing a watch-and-care system using GPS for people with dementia.

The project for developing a dementia-friendly design guideline started in 2018. Fukuoka City formed a committee which consisted of university academics in design, architecture and town planning, a physician in dementia care and representatives from care providers and Alzheimer's Association Japan. The benefits of having this type of multidisciplinary committee not only enabled the committee members to discuss the issues in a multidisciplinary way, but also provided opportunities for the committee members to learn more about dementia, design and issues that people were facing and to find out better solutions through design.

Along with developing the guidelines the committee implemented dementia design in one of the city's public community centres as a testing site. It was a refurbishment project and dementia design was implemented on the ground floor of the two-story centre. This particular centre was selected as it provided regular dementia cafe for local people. The refurbishment was completed in the summer of 2019. A survey on the users was subsequently conducted. The results of the survey showed that design implemented into the centre was well received and supported by local people. People with dementia were also interviewed when they used the centre and provided positive feedback on the design. One person,

Before

After

Before

After

for example, mentioned that she usually had difficulty finding a toilet in public spaces, but it was much easier to find it in the centre.

The aims of the development of the guidelines were two-fold. Firstly, it enables people to become aware that there are ways to improve their own built environment even when there is only a small budget available. Over the two years, the committee has discussed various issues, particularly localisation of design in order to meet local people's needs. Most research on dementia design have been conducted either in Europe or America.

The committee has ensured that the concept and design are acceptable to local people and suited to their lifestyle, culture and tradition.

In the guideline, 30 helpful points have been identified based on research, good practice and local culture. The guidance helps people to choose what they can implement depending on their needs, space and budget.

Secondly, it provides an opportunity for people to think about dementia and people with dementia. It encourages all stakeholders to discuss what would be the best environment for people who live there regardless of their dementia status. Although awareness is growing, dementia is still largely stigmatised. Dementia is, though it becomes less and less, still some stigma attached. It can be a difficult subject to discuss. Design, however, can enable people to discuss this important subject from a user's point of view. There are three key drivers enabling Fukuoka City is able to invest in the development of the dementia-friendly design guideline. First, there is strong leadership in the city. The mayor is determined to tackle the issues with vision and to move the city towards their goals. Second, there are genuine concerns for the future such as population ageing, an expected increase in healthcare and social

care expenditures and potentially unable to meet those increased demands by Fukuoka City alone. People in Fukuoka City are aware that they need to take actions now for the future. There is urgency for change. Third, there have been other initiatives on dementia already implemented prior to the development

Conclusion

Our cases suggest there are three key factors why people invest in dementia design and education.

Firstly there are pressing and serious issues. Issues can be social, such as population ageing, can be personal such as the needs of people with dementia and caregivers, or can be organizational such as recruitment and retention of staff. People or organisations that initiated the dementia projects were aware that the issues were an urgent matter and dementia design could address at least some of the issues.

Secondly, there is the "AHA!" moment among people when they learn about dementia design. Dementia design features are based on evidence and good practice and explain why particular design is used.

Knowing the meanings of design makes people realise there are different perspectives. Design can be inclusive, can be both functional and aesthetic and can change people's lives for better.

Thirdly,

dementia design and education do not require significant human, material or financial resources. At the same time, the return on investment is visible.

It makes the environment better for people with dementia as well as for those who live and work with them. It facilitates people to understand the implications of dementia, empowers them that they can make a difference and rewards them at various levels (such as the benefits to people with dementia, to the caregivers such as job satisfaction, and to organisations such as recruitment and retention). It is hoped that lessons we learnt in Japan will help other countries to find better solutions for people with dementia.

Singapore: Cultivating empathy for ageing and dementia through environmental and design education

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Introduction

A perennial challenge faced by environmental educators teaching topics on ageing and dementia is the age- and generational-gap between the younger people and older people whom they are studying. For students and instructors alike, the absence of first-person experience of the physical and psychological effects of ageing makes it necessary for any educational approach to adopt various methods in simulating and representing those actual phenomena. Needless to say, these are at best a proxy for the complex realities of ageing but nonetheless necessary inventions in order to cultivate deep empathy in our young minds. Cognitive impairment such as dementia further compounds the already immense challenges of teaching environmental gerontology and the nurturing of skillsets for evidence-based design.

Hence, it may be surmised that accurate representation of the multifaceted nature of ageing and dementia undergirds the fundamental pedagogy of environmental and design education in most universities. Here is where theories and models are given form—a concrete manifestation of real-world conditions. Without the tireless efforts of observing, understanding, defining, interpreting and representing the nuanced occurrences and effects of ageing and dementia, any knowledge gained is restricted to an abstract construct rather than useful insights.

> Young people reading literature on the subjects could possibly comprehend the arguments contained therein but without direct real-world correlation; the insights are likely to be incomplete and unanchored.

The importance of approximating the direct visceral experiences of ageing and their concomitant behavioural effects cannot be understated. Undoubtedly, no single method of representation can accurately or fully capture the phenomena of ageing in its entirety, even less so for the greater complexities of dementia where there are large knowledge gaps. Notwithstanding such a limitation, it is imperative that in re-presenting the actualities and effects for educational purposes, the correspondence to reality should be as close as is practically possible.

This report is an account of efforts by the School of Design and Environment (SDE) at the National University of Singapore (NUS) to foster the desired values and skillsets for understanding ageing and dementia beyond theories and conceptual models

from academic literature. While it does not offer a comprehensive discussion of pedagogical practices, this essay aims to unpack the opportunities and challenges of cultivating empathy for ageing and dementia through environmental and design education. Here, dementia is taught as a special case within the broader ambit of ageing and any discussion of the latter would typically encompass the former to varying degrees. The hope is that a dedicated course on dementia would eventually be developed. For the past decade and more, interest of faculty and students in topics on ageing and health has been steadily rising in SDE. However, efforts during the nascent period were mostly sporadic and uncoordinated. A more concerted approach was adopted with the establishment of the Centre for Ageing Research in the Environment (CARE) in 2015 as part of SDE's contribution to the campus-wide focus on ageing research. Since then, salient developments in environmental and design education include funded research, establishment of a graduate-level elective for Masters students, PhD dissertations, design-led research through architectural design studios, workshops and lectures, among others. Topics commonly found in environmental gerontology courses were coupled with design education to offer a comprehensive understanding of ageing from the perspective of integrating theory and praxis. Having only embarked on this pedagogical focus on ageing recently, much more is envisaged in the near future.

A primary direction at SDE that shapes the environmental and design education on ageing is a continuing and conscious effort in contextualising research, teaching and learning to Singapore's own circumstances of population ageing, and often relating to the immediate regional situation. This necessitates a constant adaptation and reframing of knowledge gained from global studies.

Contextualisation

Singapore is an urban city-state that is unique in many ways. A notable and commonly known characteristic is that 80% of her population resides in high-rise, high-density public housing developed by the government. The island's gross population density stands at approximately 7,800 persons per square kilometre, one of the highest in the world. While different housing options are available for seniors, the majority are apartments sold to citizens for a lease period. Owners are permitted to resell their unit after a minimum initial occupation period, resulting in an active resale market because many people seek to upgrade or right-size their housing as spatial needs change. This poses a strong counterpoint to the national imperative that encourages seniors to age-in-place because many older people would have relocated their place of residence several times throughout their life-course. Place familiarity in old age becomes a challenge especially for people with dementia. Another equally known phenomenon is Singapore's multi-racial, multi-cultural and multi-religious pluralistic society. This diversity is deemed a strength, while simultaneously imposing certain limitations on social behaviour for the greater good of national cohesiveness. Singapore is also constrained by its land size of approximately 720 square kilometres, as well as a lack of natural resources.

Collectively, the above conditions engendered a unique context for the country and its people. Educational imperatives consequently have to be cognisant of these contextual factors while endeavouring to respond to the emerging interconnected global problems of population ageing, climate change, scarcity of natural resources, geo-economic contestations, civil activism and health epidemic, among other existential challenges.

One immediate and necessary difference lies in the framing of Singapore's unique context against the places where excellent studies were conducted globally and published in literature. Insofar as research in ageing and dementia is concerned, it may be true that many of the outstanding works and best practices pertain mainly to countries or cities where the population and physical densities are low or at best, medium, when compared to Singapore. Furthermore, most of these studies were conducted in low-rise or medium-rise environments.

While established principles and concepts may still be broadly relevant, specific applications are not directly transportable to the high-rise, high-density urban context of Singapore.

A case in point—wayfinding studies were primarily based on low-rise horizontal movement whereas in Singapore and many vertical Asian cities, it has also to address the vertical movement, making navigation a complex three-dimensional jigsaw puzzle. This simple contextual difference is especially crucial when designing for people with dementia or other forms of cognitive impairment.

Cultural and social differences add a further complexity to any attempt in applying lessons learnt from the established overseas studies. Such divergence similarly requires a re-examination of what could otherwise be accepted as established concepts, even while still being contested by scholars. For instance, the notion of 'neighbourhood' invites a wide plethora of definitions and interpretations resulting in diverse planning typologies, each with its own socio-cultural, political and economic implications. In the case of Singapore, public housing estates and neighbourhoods were derived from first principles based on prevailing needs rather than the direct adoption of any established conceptual model. The practice here is to achieve an integrated planning solution, where housing does not stand in isolation but rather is integrated with and supported by amenities and common facilities within easy reach of the residents. Such a top-down planning approach engendered compact high-rise, high-density neighbourhoods with little or no opportunities for residents to appropriate public spaces for unstructured activities. Amenities to support ageing are part of the forward planning from the outset, often imposing limitations on how such facilities are to be used, resulting in an asymmetry between design intent and actual usage based on needs.

The above narrative briefly highlights the sort of contextual considerations that are often raised and discussed in environmental and design education under the ambit of the Department of Architecture at NUS, comprising its architecture, urban planning, urban design and landscape courses. These local issues are equally, if not more crucially, pertinent to the teaching and research on topics related to ageing and dementia in Singapore.

PEDAGOGY

The overarching pedagogical objective of environmental and design education is to inculcate a sense of empathy among our young people for the multifaceted issues and challenges of ageing and dementia. Concurrently,

the knowledge transfer is driven by a higher agenda to create real-world impact through evidence-based, design-led research

or 'design-research' in short. This practical application of knowledge is quintessential to the Singaporean's ethos and is manifested in almost all the country's endeavours and across different societal sectors. One might argue that such pragmatism undergirds the country's acknowledgement that judicious use of resources is critical to national survival. Notwithstanding its origin, the broad societal milieu of favouring utility over form has influenced Singapore's education in general with an unwavering focus on translation of research and application of knowledge for the greater good of the country. The advancement of basic theoretical knowledge is not neglected at all, just simply augmented by broader societal needs.

Aligned with the national imperative, the environmental and design education at NUS promotes problem solving of the diverse unmet needs arising from ageing and dementia. Thus, the cultivation of empathy could be described as inculcating values, insights and skillsets through related educational tasks. First, students are exposed to actual conditions of ageing and dementia to facilitate evidence-based understanding of the prevailing conditions. Second, through critical thinking, students identify, and frame problem statements based on their insights. These two aspects contribute to critical analysis and discourse as is common to most academic courses, but where appropriate they are further augmented by design-led research. Third, in design-research, students ideate potential opportunities for mitigating problems through design as the platform of investigation. In design studios, students explore various design options that address or respond to the identified problem and learn to communicate their research and designs.

Efforts were made to align research and teaching so that the latter would benefit from real-world insights to augment the theoretic and conceptual knowledge from literature. This cross-referencing engenders an enriched model of teaching and learning practices. Especially for the topics of ageing and dementia, where problems

are mainly practical and verifiable, the translation of knowledge into potentially actionable principles and strategies is an invaluable aspiration for our young students training to be architects and designers, who will eventually contribute to society eventually. Attaining a close correspondence in the research-teaching binary is crucial to environmental and design education.

Notably, the desired process of cultivating empathy for ageing and dementia works on establishing connections between the abstract constructs of literature research, insights from case studies and field works, then through to design thinking towards applicable outcomes.

This aspiration to connect the dots is still very much a work-in-progress at NUS but

it is a timely offering as many young people are keenly interested in the wide spectrum of social and environmental issues that could be mitigated or resolved through design.

METHODOLOGY

Given the complex multifaceted nature of ageing and dementia, the study of these domains unsurprisingly employs a wide range of commonly available methods. Quantitative, qualitative and mixed methods were adopted for research to acquire knowledge, including literature and evidence-based field works.

Theoretical and conceptual underpinnings from extant literature on ageing and dementia were taught in a graduate-level elective for students attending the Masters courses. The elective introduces contextual aspects that are specific to Singapore, such as public housing arrangements for seniors, ageing-related policies and programmes, and care practices and environments. Concurrently, students taking the elective participate in study visits to aged care facilities such as nursing homes, senior day care centres, community café, etc. Dementia is taught as a key topic in the elective, where students were introduced to salient medical, aged care, social and environmental concepts. Assignments in the elective module include critical essays, case studies, as well as design ideation exercises.

A common method in environmental education is the use of an empathy workshop, where students learn about the difficulties faced by seniors and people with cognitive impairment. This entails the use of simple equipment to simulate the physical challenges of ageing: weights for a sense of frailty from loss of strength, tinted goggles for impaired vision, taped fingers to restrict movement to effect loss of dexterity or sense of touch, ear-plugs for reduced hearing, etc. Students are also exposed to the difficulty of manoeuvring a wheelchair, including on-site experiences of overcoming obstacles like kerbs and steep slopes. These are known methods used in generating empathy for ageing and its disabling effects.

Beyond the simulation exercises, one crucial aspect in environmental education is exposure to real-world conditions. This entails study visits to aged care facilities such as nursing homes, seniors day care centres, physiotherapy gym and community café. There are tremendous educational values in using a time-tested method to enlighten our young minds as they can observe first-hand the nuances of ageing and dementia in real-world settings. Such practices achieve several educational objectives: direct knowledge of the environmental conditions including restrictions imposed on seniors, actual routines, activities and workflows, different personas and behaviours, etc. More importantly, the exposure would invoke a sense of social responsibility, igniting proactive self-initiated actions such as volunteering, community engagement, participatory activities, etc.

A further benefit is to motivate the young people to embark on the greater good of educating their families and friends to avert social stigmatisation of ageing and dementia.

At the higher level of graduate education, Master and PhD students conduct independent research for dissertations on diverse topics related to ageing and

dementia. Students adopt and apply both quantitative and qualitative methods involving literature and field work to produce a critical discourse. Graduate students sometimes self-initiate participation in community actions to deepen their insights, for example, volunteering at seniors care centres and the Alzheimer's Disease Association. Such extra-curricular activities offer another dimension to deepen their understanding of ageing and dementia. Furthermore, for Master of Architecture students undertaking a thesis, the initial research is translated through a design-research project.

Design is a platform for investigating problems and opportunities identified by the critical research.

The outcome illustrates and unpacks the issues and challenges arising from a design idea and points toward potential mitigation and resolution. While design-research outcomes are prospective, there is often embedded in many projects a good potential for implementation due to the rigour of research, even offering indicative evidence for policy direction. Design-research from graduate-level studios is often included as a scope of formal research projects, especially where there is a stipulated requirement for translational outcomes. This manifestation where initial research contributes to teaching-learning, and then back to inform basic research is inherent in the environmental and design education as practised in NUS. An example of a research project that incorporated design-research on ageing is a planning and urban design study of future housing typologies in Singapore. The project included two graduate-level design studios contributing ideas to the formal research. Another is an ongoing research to derive evidence-based design principles for person-centric care in future nursing homes, which were used to guide design-research by professional architects in developing pilot projects. Both the research projects were commissioned and funded by the Singapore government. The close iterative process and relationship between research and design-research is a key capability of the School of Design and Environment at NUS.

Design-research studios were also introduced at the undergraduate level of the architecture programme to bring into early focus the issues of ageing and dementia, so that our young minds are introduced to the prevailing situation and societal concerns. Although the investigation at undergraduate level is less robust, a design studio on ageing- or dementia-related topics nonetheless serves the important goal of raising awareness of an ageing population, including the rising cases of dementia in Singapore. This will motivate undergraduate students to take up rigorous research during their graduate-level studies. Significantly, an early introduction to ageing and dementia allows fertile young minds to imagine and re-imagine potential innovations to improve the wellbeing and quality of life of the seniors in our communities. Nurturing this aspiration and capacity for creative imagination is quintessential to architectural design education.

Technology plays an increasingly important role in environmental and design education. The immediate availability of virtual reality (VR) and augmented reality (AR) is readily assimilated in existing technologies such as three-dimensional computer modelling and visualisation, which are traditionally an indispensable aspect of contemporary design education.

This synergy offers students a 'preview' simulation of what the disabilities of ageing and dementia might entail. The use of VR/AR headsets for educational purposes to simulate the effects of disorientation due to dementia is fairly recent. However, there is insufficient evidence on the validity and benefits of such technological representation. Even less so are the purported benefits of using such technologies for therapy and rehabilitation of people with dementia. Inherent in such virtual technologies and user experience is the challenge of verifying authenticity in the re-presentation of reality. Still, it is undeniable that further advent in technology will increasingly help to bridge the gap between reality and a simulated re-presentation of it. From an educational perspective, what is useful is always to augment the use of technology with real-world insights from direct observations and human interaction with seniors and people with dementia.

Conclusion

Similar to the many research gaps in environmental gerontology in general and dementia in particular, the educational opportunities and challenges in teaching and learning are equally immense. It is of paramount importance that environmental and design education constantly refreshes itself through a process of re-examination of the core pedagogy and its underlying values. New methods of research and teaching will continue to emerge but it is of paramount importance to keep in sight the ultimate purpose of environmental and design education. There is an urgency to impress upon our young minds, the crucial need to understand and to address the multiplicity of issues related to ageing and dementia. Education is merely a first step towards the deep contributions of improving the wellbeing of seniors and people with dementia in the real-world conditions.

United States: Hearthstone Institute's I'm Still Here® Dementia Training

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Since 2012 the Hearthstone Institute has trained over 7,000 managers, family care partners, and professional caregivers in the *I'm Still Here*® approach. The physical environment and its design implications are included in the training, not as a training for designers on how to plan environments to support people living with dementia, but rather how the physical environment enhances the *I'm Still Here*® vision and its particular caregiving actions. These are in turn considerations that designers must consider when working on an actual project – design programming / briefing and design itself.

> This comprehensive training focuses on the entire care partnering process – one element of which is using the environment to support the lives of people living with dementia.

This brief explanation of the Hearthstone Institute's I*'m Still Here*® Dementia Training describes the major training modules and important physical environmental considerations for each.

The following descriptions of each module are followed by the physical environmental implications taught to care partners within each module.

Each of the basic modules in this training reflect the unique *I'm Still Here*® vision:

- Overview of the *I'm Still Here*® Approach
- Communication Techniques
- Dining Experience
- Managing Reactive Behaviours
- Personal Care Experience
- Activity Experience

MODULE 1: OVERVIEW OF THE I'M STILL HERE® APPROACH

The *I'm Still Here*® approach focuses on discovering and utilizing skills that remain in a person living with any stage of dementia and is grounded in a philosophy of respect and dignity for the individual. The approach emphasizes the use of abilities that are still available to persons with dementia and the creation of meaningful social roles to increase purposeful living.

This module provides a basic understanding of Alzheimer's and related dementias and how to integrate this knowledge into a plan-of-care incorporating the *I'm Still Here*® methodology.

Topics: I'm Still Here® Overview

- Understanding dementia
- Learning in persons with dementia, and how to capitalize on that capability to improve quality of care and quality of life
- Common symptoms of dementia
- Successful strategies for adaptive interventions at each stage of the disease

PHYSICAL DESIGN IMPLICATIONS

The following are included in this training module:

- The physical environment is described that reflects the *I'm Still Here*® vision and supports the positive dignified approach to care and how each space and the way it is presented adds or detracts from the goals of the approach. Each space communicates as much through its design as might verbal and pictorial instructions

The training emphasizes the importance of utilizing the environment to cue and understand behaviours.

For example, a resident will often behave differently if seated in a living room setting (conversation, relaxation) versus a dining room setting (eating). For this reason we instruct care partners of people in the later stages of dementia not to offer a paper cup filled with paint during an activity in the dining room, because the environment will cue them that this is something to drink. The same object given in a craft room would be much more likely to be used appropriately.

MODULE 2: I'M STILL HERE® COMMUNICATION TECHNIQUES

This highly interactive module teaches effective verbal and nonverbal techniques for successfully communicating with persons experiencing all stages of memory loss. Strategies for handling commonly challenging situations are discussed and practiced, including how to prevent or decrease anger, agitation, and fear.

Topics: I'm Still Here® Communication

- Application of the *I'm Still Here*® principles to communication
- Verbal communication (invitations, offering choices, breaking tasks into steps)
- Communication adaptations
- Non-Verbal Communication techniques
- Sensory communication
- The use of templates and external memory cues to facilitate communication
- Successful communication adaptations for persons in each stage of the disease process

PHYSICAL DESIGN IMPLICATIONS

The following are included in this training module:

- The need to choose (feel in control) – the environment must be designed to present simple choices of where to go, what spaces to use; how to go in and out of the garden – a single option if possible or two at the most. This provides residents with the greatest feeling of choice
- Sharing information without using words – pictures or pictorial representations tested with residents with dementia are excellent ways to orient such users to their physical environment
- Use of templates and external cues – templates provide instructions that indicate to users how to engage with an event, a place, or something physical. Templates in the physical environment are critical to communicating with people living with dementia. Templates consist of simple words and pictures, individualized for participants
- Making eye contact at the person's level; get in their field of vision – the height of chairs and the relationship between seating and tables both impact the ability of care partners to "get down to" the level of the resident's eyes – a foundational principle of *I'm Still Here*®. The floor covering is also a consideration for care partners' knees as is the sturdiness of both tables and chairs to push themselves up
- Pictures can be used to communicate instead of words – the use of pictures and/or physical objects is a significant tool in successfully communicating with those living with dementia
- Senses: Taking advantage of opportunities to communicate using all the senses: smell, sight, taste, hearing, and touch – in order for senses to be used in communication the more sense objects there are in the environment, the better. Selection of textures and materials on the floor, furniture, walls, and in resident rooms all create opportunities to create sensory experiences. Colours and views within a residence as well as outside in a garden can also provide visual sensory stimulation. Smells and sounds are part of the home in the kitchen, laundry, and in the garden. Providing residents with a safe kitchen and dining area where they can cook, taste, and share food adds to taste sensations
- Residents helping with daily tasks – the more furniture is in place that can be used as guides for activities, the easier it is to conduct engagement activities. For example, if dining tables are four-sided and easy to reach, a resident can easily be invited to place a placemat – plates, glasses, or whatever – on each side of the table
- Finding their room – residents being able to find their rooms at home or in a residence designed for people living with dementia is extremely important in promoting independence and feelings of confidence. The layout of the residence, the door design and colours, as well as the ability to add signage or personal identifying elements on or next to the door (templates) all contribute to wayfinding ability
- Memory boxes at every entry help everyone know about the resident including what a resident likes to be called – memory boxes outside each person's room with personal objects and information are one

way to use the physical environment to help people find where they live as well as to introduce the resident to others
- Distractions must be minimized – visual or auditory distractions may prevent a person from hearing or understanding caregiver intentions. Over stimulation and noise is often a hindrance to engagement programmes in settings for people living with dementia and can increase anxiety and agitation. In the training, participants are asked to carry out a task together. When the instructor turns on a vacuum cleaner and starts vacuuming the floor, participants experience how noise can disrupt daily life
- The inverse is also true in the environment – a quiet environment with minimal distractions can support activity engagement, but in an environment that is too quiet everyone is disturbed because they can hear a pin drop

MODULE 3: THE I'M STILL HERE® DINING EXPERIENCE

> The Dining Experience can be a wonderful opportunity for social interaction and cognitive stimulation.

In this module, participants learn how to provide a pleasant and meaningful dining experience for persons with memory loss.

Topics: I'm Still Here® Dining Experience

- Creating a restaurant style dining experience
- Successfully inviting a person to dine
- Menu choices
- Presentation of food choices
- Adaptation of food to promote independence
- The use of templates and visual cues in the dining experience
- The use of cues to signal beginning / end of mealtime
- Encouraging social interaction during meals

PHYSICAL DESIGN IMPLICATIONS

The following are included in this training module:

- Comfort, Relaxation, Socialization, Nutrition – the training demonstrates how a healthy dining experience for people living with dementia requires comfort and the ability to relax, digest the meal, and the opportunity to socialize with others. This requires a well-designed dining room
- Ample personal space at the table (not crowded) is most dignified. Square feet allocated to the dining room per resident must consider space for walkers and wheelchairs and space for wheelchair transfers
- Relaxing music for dining – relaxing background music, such as classical or soft jazz, with the volume low to avoid over stimulation, can enhance the dining experience. Loud or high-energy music can cause agitation, especially for persons in the later stages
- A home-like dining area is important to promote healthy eating. Team members wanting to create a homelike dining experience might dine with the residents – even with those who do not need assistance. If that is the case, there needs to be enough physical space for tables and chairs to accommodate staff members dining, as well as residents
- Family members joining the dining experience contributes to a positive resident experience. To accommodate this, there needs to be enough space planned in the dining room
- Visual clutter in the dining room and on the table, can disorient people living with dementia, especially persons in the later stages. The dining room must be kept visually uncluttered – by including such things as cupboards where random objects can be kept out of sight. Tables and table settings – including accoutrements such as salt and pepper – must be able to be arranged with the least amount of visual clutter

- Contrast – plates should be of a contrasting colour to placemats, tabletops, and/or tablecloths so that residents can easily identify their food

MODULE 4: MANAGING REACTIVE BEHAVIOURS USING THE I'M STILL HERE® APPROACH

This training module, based on over 25 years of experience with the *I'm Still Here*® approach, presents evidence-based real-world nonpharmacological strategies and interventions to manage the prevalence of common dementia-related behaviours such as agitation, aggression, and repetitive question asking. Case studies as well as real experiences from the trainees are utilized to illustrate the efficacy of this method.

Topics: I'm Still Here® Approach to Managing Reactive Behaviours

- Common challenging behaviours associated with dementia
- Behaviours have meaning – what might the person be trying to communicate?
- How to identify an underlying need that may be causing a behaviour

- Caregiver actions that may accidentally cause behaviours
- Approaches that may reduce behavioural "triggers"
- Strategies for creating successful therapeutic interventions
- The P.O.W.E.R.™ method of analysing potential behavioural triggers
- Creativity in problem solving

PHYSICAL DESIGN IMPLICATIONS

The following are included in this training module:

- Identifying the triggers for each person's behaviour using P.O.W.E.R.™ analysis: Instructors present a system for deciding what triggers might be at work generating reactive behaviours. The acronym identifies the first set of triggers as "P" for physical causes. Physical Causes include:
  - Is the room too hot or too cold? Air handling systems are important as is heat gain through windows, because when the ambient temperature is too hot or too cold, some people with dementia develop agitated reactions
  - Strong sunlight or glare can cause agitation
  - Exit doors to areas dangerous to residents act as magnets for exit-seeking. It is important to design such exit doors to be as little evident to residents as possible, through type of door, choice of hardware, the colour of the door, and contrast with surrounding walls
  - Sensory input can be confusing. Lighting, HVAC, and other systems must be designed to be both simple to operate and their effects must reduce confusion
- Natural Mapping to turn "wandering" into "walking" – A major design approach to support resident independence and reduce aimless wandering is natural mapping of the entire environment.

Natural mapping is achieved when the layout and design of the environment itself indicates to users all the information necessary to find their way around.

This includes all potential destinations being as visible as possible, and all spaces appointed in ways that indicate their use.

Optimal stimulation – sometimes reactive behaviours occur because a person is over or under stimulated. The same as in communication, environments that are over or under stimulating – a design issue – can have major effects.

Anxiety – some residents repeatedly ask, "Where is my room?" Placing an external cue on a resident's door (template) – a physical intervention that design can assist with – can make this easy or difficult. Templates allow staff to orient the person and assist in wayfinding by saying: "Henry, your room is the one with the picture of a violin on the door."

MODULE 5: THE I'M STILL HERE® PERSONAL CARE EXPERIENCE

This module applies the *I'm Still Here*® principles to one of the care partner's most challenging tasks: providing personal care to a person living with dementia – bathing, assistance in using the restroom, and dressing. Specific techniques to successfully facilitate these tasks are described and practiced, including the use of templates and signs to improve independence and encourage the person to maintain control of their personal care.

Topics: I'm Still Here® Personal Care

- Application of the *I'm Still Here*® principles to Personal Care
- Understanding each resident's individual needs
- Adaptation of the *I'm Still Here*® methodology and techniques to all levels of care
- Use of templates and visual cues to empower residents to remain independent
- Problem solving around common personal care challenges

PHYSICAL DESIGN IMPLICATIONS

The following are included in this training module:

- Some residents prefer a shower, others a bath. Generally, showers are the preferred mode of bathing for elders, especially for those with dementia because of safety concerns as well as because of the ease for staff to help the person shower thoroughly and safely. Showers designed into each person's private bathroom achieve this. Design must also include the opportunity for residents who prefer to take a bath to be allowed to do so
- Assistive Devices can promote independence – this is achieved by including such items in design specifications as raised toilet seats, grab bars, urinals, and accessible commodes which must be designed in and specified
- A spa-like environment can assist residents who are resistant to care to enjoy and benefit from bathing. This can be created by designing systems that provide familiar scents and soothing music, among other spa-like sensory experiences

MODULE 6: THE I'M STILL HERE® ACTIVITY EXPERIENCE

The *I'm Still Here*® approach to activity programming focuses on discovering ways to create a high level of meaningful engagement for people living with dementia despite the severity of their memory loss. This module is designed to develop care partners' proficiency and confidence in presenting basic activities to residents individually and in small groups.

Topics: *I'm Still Here*® Activity Program

- The top 10 *I'm Still Here*® principles for presenting activities
- Introduction to the basic *I'm Still Here*® Evidence-Based Activities through demonstration and role playing
- Practice in the use of positive communication during all activities
- Use of a 24/7 activity table to optimize engagement

PHYSICAL DESIGN IMPLICATIONS

The following are included in this training module:

- For those in advanced stages of dementia, a multi-sensory environment can be extremely soothing. To include such an environment requires the space in plan for such a room as well as the required electrical outlets, ventilation, noise reduction, and ability to adjust lighting.
- Engagement Supplies – where there is an emphasis on engagement activities, as there is in all *I'm Still Here*® settings, it is important that all staff have easy access to prepared activity supplies and set-ups. This requires that secure storage areas be planned convenient to where activities take place
- To increase engagement and opportunities for individualisation, small group activities are a foundational principle of the *I'm Still Here*® approach. Therefore, the environment must be designed to accommodate multiple small groups simultaneously (versus one or two large activity spaces) in quiet, comfortable areas that reduce distractions.

In sum, the Hearthstone Institute's *I'm Still Here*® Dementia Training programme is based on the principle that the designed environment for any type of building for people living with dementia – in this case residential care – must reflect a clear and explicit vision of the building's use – in this case a vision of a care approach – before, not after, the building is designed, and completed.

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Designing for people with dementia and COVID-19

The COVID-19 pandemic has highlighted shortcomings in the design of aged and health care facilities and provided some insights into what might be done to overcome them. It has also, alarmingly, highlighted the threat of returning to a medically oriented model.

Long term care and the coronavirus pandemic: a new role for environmental design in a changing context

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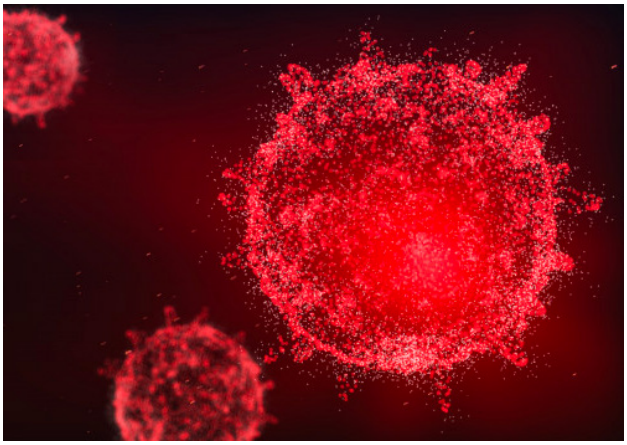
Introduction

It took more than three decades of championing the principles of environmental design for dementia and developing the research evidence base on how the physical environment can support the independence and wellbeing of people with dementia to reach a point where cognitively supportive design should be the default requirement for new and existing long term residential care facilities. It has taken a fraction of that time for an emerging coronavirus to displace concern with residents' lived experience in favour of strict transmission and infection control measures, forcing a return to more institutionalised and medicalised environments and care practices.

We urgently need to consider the impact of COVID-19 on the aspirations of environmental design for long term care and to re-evaluate its future role in this changed context.

As the coronavirus pandemic has developed globally, recommended infection control precautions (ICPs) based on the best evidence available have been swiftly implemented by long term care providers anxious to protect those that they care for. These ICPs are designed to minimise transmission of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the virus which causes COVID-19. In some cases, this is achieved by restricting residents' opportunities for physical activity and social interaction (e.g. remaining



in and receiving meals/care only in their bedroom, no outside visitor policies). Evidence is starting to emerge that these measures have had ongoing detrimental effects on the overall health and wellbeing of residents.

Restrictions imposed to minimise the risk of harm to residents resulting from COVID-19 are suspected to have accelerated physical and cognitive declines and/or indirectly contributed to the deaths of some residents.

In this chapter, we argue that environmental designers, care providers and care managers all urgently need to respond to the changing context of long term care precipitated by COVID-19, and that the challenge in future will be to design settings which can be dynamically adapted to respond to novel infectious agents and aid infection control whilst also providing the levels of stimulus, activity and interaction necessary to allow residents to live well.

In the remainder of this chapter we briefly set out and consider the aims of pre-COVID guiding principles for environmental design of long-term residential environments which, we would argue, must remain a core part of future long term care design solutions. We then consider pre-COVID infection risk and control in long term care, drawing attention to infectious agents which have historically presented risks to residents' health and to the measures which have routinely been deployed to manage them. Following on from that, we explain why COVID-19 potentially presents additional challenges for infection control and why supporting infection control must also be a core element in future environmental designs. Finally, we summarise the direct and indirect impacts of COVID-19 on long term care residents, drawing on evidence of the latter to support our contention that in future the role of environmental design will be to take into account and balance competing needs for infection control and maximising residents 'effective capacities' to live well.

PRE-COVID ENVIRONMENTAL DESIGN CONSIDERATIONS

The primary aim of environmental design prior to the coronavirus pandemic was the creation or reconfiguration of long-term care facilities to provide settings which support and enable residents to live their best possible lives. It has long been suggested that environmental design can improve the quality of life for residents with dementia and there is increasing support in the academic literature for a variety of different environmental design interventions which deliver beneficial outcomes for residents, even if significant gaps remain in the evidence base (1, 2).

In 1998 Mary Marshall set out a series of key design principles for residential environments which would support and enable people living with dementia. Her principles are expressed in terms of outcomes, both for people living with dementia and for care staff working in residential environments, but actioned via evidence-based environmental design [3]. Drawing on a 1987 statement of principles [4], Fleming, Forbes and Bennett [5] set out ten design principles for such settings, broadly consistent with Marshall's in terms of impact, but described in terms of environmental characteristics. Table 1 sets out both sets of environmental design principles.

Principles set out by Marshall [3]	Principles set out by Fleming et al. [5]
Design of care environments should:	Care environments for people living with dementia should:
• Compensate for disability • Maximise independence • Enhance self-esteem and confidence • Demonstrate care for staff • Be orientating and understandable • Reinforce personal identity • Welcome relatives and the local community • Allow for the control of stimuli	• Be safe and secure • Be small • Be simple and provide good 'visual access' • Reduce unwanted stimulation • Highlight helpful stimuli • Provide for planned wandering • Be familiar • Provide a variety of spaces with opportunities for both privacy and community • Provide links to the community • Be domestic and homelike

The principles set out by Marshall and Fleming et al. have proven hugely influential in environmental design and each formed the basis of tools for auditing or assessing care environments. However, more recently Barrett, Sharma [1] have made the case for a dementia 'holistic evidence and design' (HEAD) model. The HEAD model takes its lead from Marshall's earlier concern with compensating for the reduced capabilities of the person living with dementia, incorporating three top-down design principles: manageable cognitive load; clear sequencing; and appropriate level of stimulation.

These principles, when applied to personal spaces and to shared spaces / wayfinding respectively, link to a series of evidence-based practical design parameters which speak to Fleming et al.'s ten principles. Barrett et al. argue that the 'effective capacity' of a person to live well with dementia at any point in time is the product of that individual's current capacity plus gains derived from enabling physical and technical environments, supportive caring and social environments, and pharmacological treatments.

This approach to thinking about maximising effective capacity helps to highlight the need to consider how the social and environmental measures taken to reduce transmission of COVID-19 and control infection impact negatively on other broad matters of health and wellbeing for residents with dementia

and the frontline staff who care for them and how they impact on care based models in which social activity and interaction are critical components, e.g. 'Eden Alternative' and 'Gentle Care'.

CONTROLLING INFECTIONS IN LONG TERM CARE

Long term care residents have always been vulnerable to a range of bacterial, viral, fungal, and other infectious agents with risks of infection often exacerbated by age, functional impairment, multimorbidities and use of indwelling devices. Urinary tract, respiratory and skin and soft tissue infections are common in long term care [7]. Facilities may also experience outbreaks of communicable diseases including influenza [8] and gastroenteritis caused by norovirus [9]. A review of reports by Utsumi, Makimoto [10] identified 37 infectious agents associated with 206 outbreaks. Many infections can present serious risks to health but respiratory infections in particular can have high hospitalisation and fatality rates for long term care residents, for which reason long term care providers routinely employ a range of measures to reduce the risks of infection.

The risks of transmission of infectious agents are minimised through the implementation of a combination of standard infection control precautions (SICPs) and transmission-based precautions (TBPs). SICPs are the basic infection prevention and control measures necessary to reduce the risk of transmission of infectious agents from both recognised and unrecognised sources such as bodily fluids or secretions, equipment and other items in the care environment [11]. Examples of SICPs include: good hand hygiene; covering the mouth and nose whilst coughing, sneezing or blowing the nose; using personal protective equipment (PPE), such as aprons, face masks and gloves; regular cleaning / decontamination of the care environment and equipment within it; segregating people known or suspected to be infected, e.g. in negative pressure isolation facilities or single rooms; and restricting or suspending visits to those in care. TBPs are additional more targeted precautions which are applied when a person is known or suspected to be infected by a specific infectious agent and SICPs alone are insufficient to prevent cross transmission [11]. TBPs are categorised by identified transmission types: contact, droplet, or airborne, and a combination of these types of precautions should be implemented based on the route(s) of transmission of the specific infectious agent.

WHAT IS DIFFERENT ABOUT COVID-19?

Characteristics of the SARS-CoV-2 virus and, following infection, of COVID-19 mean that it presents a greater risk to long term care facilities and residents than more familiar infections.

Petersen, Koopmans [12] compare transmissibility, hospitalisation, and mortality rates for SARS-CoV-2 with other epidemic coronaviruses and with 1918 and 2009 pandemic influenza viruses. They find that SARS-CoV-2 has the highest average transmissibility, longest incubation period and shortest interval between

symptom onset and maximum infectivity of the viruses compared, making outbreaks difficult to contain. The high proportion of people who experience only mild symptoms makes COVID-19 outbreaks more difficult to detect. Petersen et al. note that a 'key difference between SARS-CoV-2 and pandemic influenza is the age distribution of patients who are severely ill'. SARS-CoV-2 infections are experienced as severe mainly by older people, whereas influenza is experienced by people across all age groups. Whilst similarly small proportions of individuals with 2009 pandemic influenza and SARS-CoV-2 infections require hospitalisation, Petersen et al. estimate that more than five times as many people with COVID-19 than with influenza in 2009 require intensive care (1 in 16,000 compared to 1 in 104,000).

There are significant issues around the collection and reporting of data available for comparative analyses, but evidence suggests that COVID-19 represents a more significant threat to life than infections such as influenza, particularly for older people. Based on weekly counted deaths in the USA from COVID-19 in April 2020 compared to mean counted deaths from influenza for the same week (normally the peak week for counted deaths from influenza) from 2013–2020, Faust and del Rio [13] estimate that on average there were more than 20 times as many deaths from COVID-19 in the weeks examined than from influenza in those weeks in other years. WHO [14] suggest that COVID-19 infection fatality ratios (IFR), estimates of the proportion of deaths among all infected individuals, are hard to accurately determine due to issues including attributing and/or reporting deaths from COVID-19. However, Faust and del Rio [13] estimate a case fatality rate (the proportion of deaths in confirmed cases of COVID-19) of 0.5% based on age-adjusted data from the Diamond Princess cruise ship outbreak which, they suggest, would still be five times greater than the case fatality rate normally suggested for adult seasonal influenza.

In addition, airborne transmission may play a greater part in the spread of SARS-CoV-2 than in the transmission of other infectious agents such as influenza. This may be a characteristic of the virus that long term care environments are not currently well equipped to deal with as most other viral disease risks in care settings can be controlled through contact and droplet TBPs. Transmission was initially thought to be primarily via respiratory droplets expelled when a person infected by SARS-CoV-2 coughs or by contact with surfaces where infected respiratory droplets came to rest, and recommended infection prevention and control measures are primarily based on a combination of SICPs and TBPs for droplet and surface transmission, e.g. maintaining minimum physical distances between individuals, regularly disinfecting surfaces, and maintaining good hand hygiene. Airborne transmission, in which pathogens in smaller 'microdroplets' can remain in the air for long periods and be transmitted over greater distances, was thought to be confined to settings and procedures which generate aerosols (WHO 2020). However, the potential for airborne transmission has been a concern within the research community since the start of the COVID-19 pandemic. Research prior to the pandemic found that respiratory droplets could evaporate to form smaller 'droplet nuclei', and that indoor humidity and air turbulence influence droplet nuclei size and dispersion [15]. In a commentary published on 6 July 2020 and signed by 239 other scientists, Morawska and Milton [16] set out the research evidence for the potential for airborne spread of COVID-19 and advocated the use of preventive measures to mitigate this.

Lack of scientific agreement over the risks posed by infected aerosol-like particles, a resulting lack guidance on possible precautions, and/or inability to address these risks throughout the care setting, but especially in 'high traffic', less well ventilated areas, could potentially have contributed to the rapid spread of COVID-19 in some settings.

THE IMPACT OF COVID-19 IN LONG-TERM CARE

A grim picture has emerged of the direct impact of COVID-19 in long term care.

Disproportionate numbers of deaths due to COVID-19 have been recorded in long term care facilities in many countries around the world, although there is significant international variation. Comas-Herrera, Zalakaín [17] report that, as of 26 June 2020, some countries (Hong Kong, Jordan and Malta) had reported no COVID-19 infections or deaths in care homes whereas in others (Canada, Slovenia) more than 80% of the country's COVID-19 deaths were care home residents. Based on data from 26 countries excluding those who reported no deaths, Comas-Herrera et al. found that on average 47% of people who died from COVID-19 in those countries were care home residents. They also found that, for 18 countries for which these data were available, the proportion of all care home residents who have died and whose deaths are known to be linked to COVID-19 ranges from 0.04% (New Zealand) to 6.1% (Spain), with these proportions strongly correlated with the severity of the coronavirus pandemic nationally as expressed in COVID-19 deaths per million population.

The indirect impact of COVID-19 in long term care is less clear. Evidence appears to be emerging that responses to COVID-19 which were designed to minimise disease transmission and control infection, such as prohibiting visitors to care facilities in all but life and death situations and encouraging residents to remain in their rooms, may have accelerated the physical and cognitive declines and/or indirectly contributed to the deaths of some residents. In the UK, figures from the Office for National Statistics [18] suggest that in England and Wales for a three-month period from 15 March 2020, only two-thirds of the nearly 30,000 'excess deaths' over the same period in 2019 could be directly attributed to COVID-19. It has been suggested that COVID-19 may be indirectly responsible for many of the remaining excess deaths, including via adverse consequences resulting from 'the impact of changes to normal routines for vulnerable care home residents following lockdown' [19].

Such adverse consequences include but are not limited to: cognitive decline due to lack of stimulation or meaningful programming; physical deconditioning due to lack of ability to exercise; loneliness.

Whilst research is not yet available to substantiate the extent of resident decline following measures taken to improve infection control in long term care during the pandemic, there is significant anecdotal evidence. For example, in oral evidence given on 12 August 2020 to the All-Party Parliamentary Group on Coronavirus, an informal cross-party group of UK Members of Parliament and the House of Lords convened to learn lessons from the UK's handling of the coronavirus pandemic, Helen Wildbore, Director of the Relatives and Residents Association, commenting on the effects of visitor restrictions and isolation within care homes said (at p7):

'We hear daily from our helpline callers about how their relatives in care are deteriorating, not just their mental health but also the knock on impact on the physical health of older people losing weight, losing speech, losing their memory, no longer being able to recognise their family members and there's one relative put it to us that they're losing the will to live,…' [20]

A NEW ROLE FOR ENVIRONMENTAL DESIGN

In this chapter we have set out why COVID-19 presents new challenges to long term care providers who already routinely safeguard residents against infectious agents. A range of explanations have been offered for levels of COVID-19 transmission to and within long term care settings, for example focusing on issues of low-paid staff, poor training around infection control, the availability or adequacy of personal protective equipment (PPE) for staff, and/or the risks of disease transmission posed by those visiting residents in professional (e.g. physicians, nurses) or personal capacities and research is underway in many countries to examine these and other potential causes of disease transmission.

Beyond the obvious impact of sharing rooms with multiple other residents, little has been said about how environmental design may have directly or indirectly influenced the impact of COVID-19 in long term care to date or how it might contribute to reducing negative impacts in future.

This research gap urgently needs to be addressed. We need to learn all possible lessons and better understand how environmental design can contribute positively to improved infection control.

We have also suggested that whilst reducing the risk of COVID-19 outbreaks, infection control measures which isolate residents of long term care from external visitors and restrict opportunities for meaningful activities and/or social interaction within facilities may have serious negative outcomes for some residents.

The principles of environmental design for dementia set out in the 1980s and 90s remain revolutionary and relevant. They have been greatly instrumental in shaping the physical, technical, caring and social environments of long-term care in ways which contribute positively to resident wellbeing and quality of life and to staff job satisfaction. These principles should not and *must not* be abandoned or made totally subservient to the needs of infection control as long terms care providers seek to establish a 'new normal'

Since the start of the pandemic, in order to protect the most vulnerable residents, long term care providers have been forced to make sometimes deep moral and ethical decisions to implement measures which have costs to all residents in terms of loss of opportunities for activity and interaction and to balance such decisions against the negative health and well-being outcomes which flow from such measures. Much research effort is currently focused on the development of an effective vaccine against COVID-19, but we cannot know if or when such a vaccine will be found and what its efficacy might prove to be for different age groups / health contexts. In its absence, long term care providers will be faced repeatedly with having to weigh the risks of COVID-19 infection and transmission to staff and residents against the risks to those same groups of losing, even temporarily, access to activities or practices which support and enable residents to have the best possible lived experience of care.

The new role of environmental design needs to be maximising the benefits to all by supporting providers in maintaining a balance between these competing risks. Architects, designers, academics, long term care providers, residents and their supporters in the wider community need to come together and take up the challenge of developing evidence-based modifications and designing long term care facilities which:

- reduce the risk of COVID-19 disease transmission and/or improve infection control for residents, staff and visitors – where possible without excessive negative impact on other areas of resident wellbeing
- incorporate dementia design principles to support and enable long-term care residents to maintain existing capabilities and enjoy their best possible lived experience of care; and
- are capable of being adapted to rapidly changing levels of threat from coronavirus and/or other future emerging infectious agents in ways which, in every configuration, maintain the opportunities for stimulation through activity and social interaction that are critical to residents' wellbeing and quality of life

To succeed we will need to work together, recognising different expertise and valuing every contribution. We must rise to this challenge: until we do every day that passes more lives will be lost and more loved ones will become lost to us. The stakes could not be higher.

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Recommendations

There has been progress but much remains to be done and it needs to be done with careful consideration of context and the over-arching goal of affording dignity to people living with dementia.

One of the benefits of compiling a report like this is that it provides perspective on what might have seemed common sense or obvious. This report shows that what was common sense at one time was challenged by innovators and became outdated, and the efforts of those innovators became common sense, which then came under challenge and began to change. In other words, things change over time as new challenges emerge.

The challenges to the idea of good design for people living with dementia are, perhaps, becoming clearer. They are emerging from the human and disability rights arenas, the pressure to include people living with dementia in the design process, the economic and numerical scale of the provision of services and, of course in 2020, the realisation that a highly contagious virus can wreak havoc with plans that have been made with the best of intentions.

There is also the challenge of translating knowledge across cultures. There is a great temptation to believe that what has been 'proven' to be useful in one culture can be translated into action in another in an effort to speed up the development of services for people living with dementia. Those who have read this report carefully, and watched the videos that accompany it – particularly the interviews with Michael Murphy and Jannette Spiering – will be aware of the benefits of taking careful account of the organisational and cultural contexts of the project and inventing a wheel that works in them, rather than buying a wheel from someone else.

There are some big ideas providing context to designing for people living with dementia that should also be challenged before they continue into the next generation of innovations or across into other cultures. Perhaps the most obvious, but hidden in plain sight, is the idea that putting a lot of older people together in one place is a good idea. This simplistic idea is at the foundation of most services for people living with dementia in the western world, yet its failings are made obvious by the levels of depression and low quality of life often found in these places. It is such a big idea, so deeply and expensively ingrained in these services, that it might be thought to be too big to fail. But will it survive the scrutiny that is taking place as COVID-19 exposes the profound weaknesses of this approach? Can it continue in the face of the calls for change from those who wish to see our elders enjoying a continuation of their lives as full citizens and community members until they die?

These considerations must lead to a sense of humility in the offering of any recommendations. The passage of time, changes in cultural context and unexpected events can, and will, make the recommendations of here and now irrelevant in the future. We must be very careful to avoid being content with making recommendations that are useful for making things better within a poor paradigm when we should be putting our efforts into creating a better paradigm.

However, with these caveats in mind, the following, high level recommendations are offered.

Recommendations

1. ADI will facilitate discussions on the development and adoption of a common set of design principles that will be used to structure the exploration of designing well for people living with dementia and the formulation of future recommendations.
2. A call for more overt and considered inclusion of dementia-related design as a non-pharmacological intervention, to be included in national dementia plans, in response to the WHO Global action plan on the public health response to dementia 2017–2025.
3. ADI, alongside partner Dementia Alliance International, and other advocacy groups, will work to give prominence to the arguments contained in the Convention on the Rights of Persons with Disabilities (CRPD) for the recognition of dementia as a disability and the consequent need to apply design guidelines for people living with dementia in the same way as design guidelines are provided for people living with a physical disability.
4. A call to all educators about the need to include designing for people living with dementia in the curricula of schools of architecture and design.
5. Encourage health economists to engage with the field of designing for people living with dementia to clearly establish the cost benefit of investment in dementia-related design translating to savings in health and care costs by facilitating people to live in their own homes and their communities for as long as possible.
6. ADI will encourage governments and academic institutions to engage researchers to translate knowledge on designing for people living with dementia. This knowledge, often gained in high income countries, can support and service development in low- and middle- income countries.
7. ADI will encourage National Dementia Associations to better inform themselves about the available knowledge on designing for people living with dementia, consider its relevance to their contexts and priorities, and advocate for relevant knowledge to be implemented by planners, designers, architects, care operators and developers.
8. ADI will encourage governments and the international community to proactively engage designers, architects, developers, operators and innovators, in the construction and IT sectors, in designing for people living with dementia.

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