

Considering the move to a long-term care home

This information is for you if you are caring for someone living with dementia and you are considering moving them to a long-term care home. We know this may be one of the most difficult decisions you will ever have to make. This information sheet covers things to think about, including some checklists and hands-on tips.

Long-term care homes are places where adults can live, receive help with their daily activities and have access to 24-hour nursing and personal care. A long-term care home provides more nursing and personal care than a retirement home or supportive housing. Alzheimer's disease and other dementias are progressive and degenerative, which means that the person's symptoms will gradually get worse. There may come a time when you can no longer provide care in an individual's own home.

As a caregiver you should not consider a move as a failure or selfishness. Recognize that it is a very common step in the overall progression of dementia. In fact, in 2020, 61.6% of seniors living in a long-term care home had a diagnosis of dementia.¹

As you consider a move, you may experience a broad range of emotions. For example, you may feel guilt, loss, sadness, anger, shame and resentment, as well as a sense of defeat. You may also feel relieved that you now share the responsibility for providing care with others. You may even have second thoughts about your decision.

It is important to understand that these are all normal reactions and help is available throughout the process. Contact your local Alzheimer Society for help, visit alzheimer.ca/helpnearlyou.



A note about the terms we use:

- "Caregiver" refers to anyone involved in caring for or providing support to someone with dementia.
- "Dementia" refers to Alzheimer's disease and other dementias.
- "Long-term care home" and "home" refer to a "nursing home". The terms for nursing home vary across Canada; we use "long-term care home" or "home" for easier reading.

Reasons for considering a move

There are no rules guiding when you will decide that a move is necessary.

You may consider a move for a variety of reasons:

- The condition of the person living with dementia has worsened. They may have been in hospital and their needs may be becoming more complex so they require more help on a day-to-day basis.
- You are concerned about the person's safety.
- You no longer feel able to provide the full-time care that the person requires to enjoy the highest possible quality of life.
- Your health and abilities have changed or you are exhausted or are in crisis.

Your well-being

When considering how best to meet the needs of the person living with dementia, you need to remember to balance their needs with your own well-being. Use the checklist on the next page to help assess how stress may be affecting your life.

"Everyone said, 'It's time for your mom to move to a long-term care home. You've done enough, it's taking a toll.' I had a lot of guilt. You almost feel like a failure, but you're trying to do the impossible." – Caregiver

"All residents are different and come with different styles and backgrounds. Some love watching TV and yes, even falling asleep in front of the TV. It is about making the family member the happiest and the most comfortable. My aunt couldn't fall asleep without the TV and whenever she was at home, her TV was always on." – Caregiver



Caregiver stress assessment checklist

Answer the following questions by selecting “never,” “sometimes” or “often.”

Questions	Never	Sometimes	Often
Do you have difficulty falling asleep?			
Do you wake up in the middle of the night?			
Do you have stressful dreams?			
Are you anxious or do you have panic attacks?			
Have you gained or lost weight recently without meaning to?			
Do you get sick more often than you used to (e.g. frequent colds or the flu)?			
Have you developed chronic health problems (e.g. backaches, headaches, high blood pressure)?			
Do minor upsets make you cry, become angry or get unusually agitated?			
Do you find it difficult to control your temper?			
Do you feel pressure to hold things together?			
Are you feeling hopeless about your situation?			
Have you given up hobbies or interests that you enjoy?			
Are you spending less time with others?			
Is caregiving affecting your career?			

If you answered “sometimes” or “often” to many of these questions, you may need help balancing care for the person living with dementia and care for your own well-being. No matter how close you are to the person, you may want to consider including others in the caregiving role. Caregiving involves a range of responsibilities. Sharing these responsibilities will help you and the person living with dementia have a better quality of life. Staff at your local Alzheimer Society can help evaluate options for sharing care in various settings.

Finding the right long-term care home

To help make the best decision, familiarize yourself with the long-term care homes in your area. Ask questions about the services, policies and costs so you are ready to make a decision quickly when a space becomes available.

In addition, you may find it useful to ask someone to come with you for input and support. It is also helpful to talk to residents who live in the home and their caregivers. Some long-term care homes provide tours that are led by people who have faced similar decisions to yours, giving you a chance to ask questions.

Pay attention to your feelings; these can be very helpful in determining whether a particular LTC home is appropriate for the person you are caring for.

When a space becomes available in a long-term care home that you have applied to, the home often requires that you decide quickly whether you would like to take it or not. If you decide not to take the space you may be put at the bottom of the waiting list.

About waiting lists

Your position on the waiting list, wait times and the number of available spaces vary from one home to another and are constantly changing. Space availability is based on priority needs such as the individual's condition, how much support the person currently has and your condition as a caregiver.

If you urgently need to relocate the person living with dementia to a LTC home, a space may become available that is not your first choice. In this case, you can stay on the waiting list of the place that is your first choice and transfer the person living with dementia as soon as a space becomes available.

However, once an individual moves into a LTC home, it is important to think about the advantages and disadvantages of another move for both the person and yourself. If you have any questions, contact your local health-care team.

Helpful tips

To help find a care home, follow these tips:

- Consider what your priorities and expectations are in a long-term care home. It is important to know that there are differences between private and publicly funded homes. Sometimes you don't get what you pay for; a more expensive home does not necessarily mean that the person will get better care.
- Contact your local health-care team for information about the long-term care application process in your area. Some communities have a number of homes to choose from. Make a list of long-term care home options and then narrow the list down to ones you would like to visit.
- Visit each home on your list to see what they have to offer. Bring your list of priorities and expectations and any important questions you may have. Some long-term care homes allow the person living with dementia to visit the home and become familiar with it by attending day programs or other services.
- Even after an extensive search, you may not find everything you want in a single place. Try to be flexible and consider whether you could work with staff to meet the needs of the person living with dementia.

Use the checklist on the following page to help make the best decision.



Long-term care home checklist

Make a copy of this checklist to use as you research and visit each long-term care home.

Long-term care home name: _____

Privately funded Publicly funded

Visit date: _____

Things to check before visiting the home	Yes	No	Notes
The person living with dementia has the choice between a private room or a shared room.			
The person living with dementia is able to live here as their dementia progresses.			
The home tells me the cost of care and whether there are additional costs for extra services as dementia progresses.			If there are additional costs, what are they for? How much will they cost?
The home offers tours and I know how to book one.			
There is a waiting list.			If so, how long is it?
There are rules about waiting lists (e.g. people in crisis situations are given priority).			
The home is accredited and inspected regularly.			Ask the LTC home for a copy of a recent inspection report. Or search for a provincial/territorial inspection-reporting website.

Things to check while visiting the home	Yes	No	Notes
Physical setup			
The location is convenient and easy for me to visit.			How long is the commute? Is it accessible by public transit? Is there free parking?
The home is clean and tidy without seeming institutional and sterile.			Are there unpleasant odours?
Laundry is done on site.			Are there any fees associated with these services?

Things to check while visiting the home	Yes	No	Notes
Physical setup...cont'd			
There are quiet areas for visitors to spend time with residents.			
Residents can walk safely and easily indoors and outdoors.			
The bathrooms are clean with safety devices like grab bars.			Do they easily accommodate mobility aids like walkers?
There are clear signs throughout the home to help residents get around (e.g. a picture of a toilet on the bathroom door).			
Resident care and staff training			
There are consistent staff assigned to each resident so staff and residents can get to know each other.			Is there a rotation of many staff assigned to each resident?
All staff are trained to care for residents living with dementia.			How frequently do staff attend refresher courses?
I see staff talking to residents in a personable manner, clearly showing that they know each resident as a unique individual.			
I see staff trying to understand what residents are trying to communicate through their actions.			
Caregivers are invited to attend regular care planning meetings (a care plan is a standard document for each resident that includes everything about the resident's care).			How do caregivers request a care meeting?
With consent, the home shares information about the resident readily and routinely with caregivers.			How does the LTC home share the information? If I have concerns, who would be my main contact?
There is a doctor on call.			Can a resident keep their family doctor if they like? What are the pros and cons of this decision?
The home has access to other services (e.g. opticians, dentists, physiotherapists, chiropodists (foot care) and hairdressers).			Are there costs for these services? Who accompanies residents to their appointments? Are there fees associated with this service?

Things to check while visiting the home	Yes	No	Notes
Resident care and staff training...cont'd			
Staff try non-pharmacological approaches before prescribing medications. The LTC home has a clearly stated policy on the use of physical, chemical and environmental restraints.			Ask to see the home's policy on the use of physical, chemical and environmental restraints.
Medical emergencies are handled appropriately.			How are medical emergencies handled? Under what circumstances are residents transferred to hospital?
Staff is able to provide palliative care (to reduce distress and provide enhanced comfort, dignity and pain control at end of life).			
Daily life			
Each resident has a flexible daily routine (e.g. home can accommodate a resident who is used to having breakfast at 11 a.m.).			
The menu is good in all important ways (e.g. varied, appealing, nutritious and can accommodate special dietary needs).			
The LTC home considers different cultural, religious and spiritual needs.			Do I have specific cultural, religious or spiritual issues to ask about?
There are a variety of meaningful activities for groups and individuals.			What are they? Are they available during evenings and weekends? Ask for a program schedule. Is there a volunteer visiting program for additional one-on-one support?
Do I see signs of inactivity (e.g. residents falling asleep in front of the television)?			
The visitors policy suits the needs of the person living with dementia and my needs as a visitor.			What is the policy regarding visits? What are the visiting hours? Can a caregiver or friend sleep over to comfort and assist a sick resident?
The home allows visitors to join the resident for meals.			Is there a cost?

Your overall impression:

Rate the long-term care home on the following scale:

1 2 3 4 5 6 7 8 9 10

I would never consider moving the person living with dementia to this home.

I would consider this long-term care home as one of the best options.

Comments:

ⁱCanadian Institute for Health Information. (2020). *Profile of residents in residential and hospital-based continuing care, 2019–2020 - Quick Stats*. Ottawa, ON: CIHI.

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