

# Meaningful Engagement of People with Dementia

A Resource Guide





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**Note:** *the term family used in the guide includes anyone in the supportive network of people with dementia.*

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## 1. INTRODUCTION

### Purpose of the Resource Guide

People living with dementia tell us, “Nothing about us, without us”. They also tell us that their experience in working with organizations— regardless of where they live in Canada— is sometimes “uneven”, meaning that they are not always included in ways they believe would be beneficial for the organization or that are satisfying for them. People with dementia have a right to be involved in organizations that represent their interests. With this in mind, this Resource Guide has been developed to provide tools, resources and strategies to assist organizations in promoting meaningful engagement with people who have dementia.

This Resource Guide is designed to:

- Foster relationship building between staff and leadership volunteers and people with dementia.
- Promote the value-added potential of including the “voices of those with dementia”.
- Improve the experience of meaningful engagement for both the organization and the person with dementia.
- Build capacity within organizations to collaboratively address the needs of persons with dementia.

**“We need to inspire local communities, organisations and businesses to become more aware and understanding of dementia, and more inclusive. And we need to support the collective engagement of people with dementia, so their voice is heard more clearly in this debate, and so they have more confidence and capacity to influence attitudes, policies and practice.”**

*– (Dementia without Walls, DEEP Dementia Engagement and Empowerment project, November 2014)*

### Target audience

This Resource Guide was created for staff and leadership volunteers of all organizations in which people with dementia are involved. The Resource Guide is a living document which will be adapted and changed over time as needs arise.

### How to use this Resource Guide

This Resource Guide is a reference which provides a framework of principles that underpins the statement of commitment to people with dementia. These principles include the promotion of well-being, choice, privacy and confidentiality, autonomy, honesty, transparency and open communication which are foundational to meaningful engagement with persons with dementia.

Assessment tools are included in the Resource Guide so that staff and volunteers can assess how well they are meaningfully engaging people with dementia in their work. There are also practical strategies

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and resources that they can use to enhance their process of engagement. It is recognized that many implementation strategies will require changes in skill levels, organizational capacity, and organizational culture, and may need education, practice, and time to mature.

### Philosophy/Approach

The content in this Resource Guide supports the philosophy of person-centered engagement which recognizes that individuals have unique values, personal history and personality and that each person has an equal right to dignity, respect, and to participate fully in their environment. When we use the term, “person-centered” throughout this Resource Guide, we are recognizing that, in order to provide person-centred engagement, relationships and the principles of authentic partnerships are embodied within this approach. The importance of including people with dementia in all aspects, as appropriate, in the work of the organization is the basis for the development of this Resource Guide.

## 2. MEANINGFUL ENGAGEMENT

**To me, “meaningful engagement” means being able to actively participate. Whether it is acting as the “Honorary Chair for the Walk for Memories”, being on the committees developing toolkits for various programs, speaking at meetings, or with the press or simply attending a support group meeting; it is the personal involvement and interaction with others that I find to be most satisfying. – (Person with dementia)**

What is meaningful engagement?

Meaningful engagement is a person-centred approach which encourages and invites people with dementia to purposefully participate in the work of an organization to which they belong. Participation includes actively contributing ideas, skills and abilities, while recognizing that individual participation will vary, depending on abilities, personal histories and available opportunities.

Meaningful engagement requires:

- A welcoming, encouraging attitude from staff and volunteers.
- Having staff that are knowledgeable about the effects of dementia on the person.
- A participatory approach, “nothing about me without me”.
- Encouraging persons with dementia to speak for themselves.
- Active listening and engagement in dialogue.
- An open expression of opinions without fear of being judged or dismissed.
- Being able to influence what happens and make decisions that matter.
- Recognition of skills and abilities.
- Meaningful and useful participation.
- Being listened to and understood and having views respected and heard.



### Meaningful engagement is based on an Ethical Framework

The involvement of people with dementia should be founded on the values of personhood, relationship and social citizenship and on the principles of ethical practice. Personhood includes “knowing the person” and drawing on his/her biography and life experiences; meaningful relationships and authentic partnerships are ones that are based on equality, understanding, sharing, participation, collaboration, dignity, trust and respect; and social citizenship implies that all citizens – including persons with dementia- have entitlement, power, status, and responsibilities. The ethical principles of autonomy, beneficence, justice, and non-maleficence underpin meaningful engagement practice.

### Ways to promote a culture shift

The following supports a culture shift in how people with dementia are viewed and integrated into the work of an organization:

1. **Staff and volunteer training:** opportunities for staff and volunteers to receive ongoing education on how to engage, types of meaningful engagement, examples and strategies to try, with evaluation processes in place to measure success.
2. **Policy development and Position Statements:** policies are written that reflect the inherent human right of people with dementia to be involved in the work of the organization that reflects their interests and abilities. Policies should reflect the organization’s commitment to meaningful engagement. Position statements should acknowledge that people with dementia are viewed as able, willing and passionate about advocating and working on their own behalf. This commitment should be made public by including policies and strategies in Strategic Plans, Annual Reports, media and public speaking events, and when reviewing aims and objectives in board and committee meetings. (Sample policy under Tools and Resources section)
3. **Resource allocation:** funds need to be allocated from annual budgets to facilitate training of staff and leadership volunteers in how to meaningfully engage people with dementia, designate staffing resources to provide support and training for persons with dementia in the work and activities they are undertaking, and offset any expenses to be reimbursed to people with dementia.

### Benefits of meaningful engagement for the person with dementia include:

- Being listened to as an equal.
- A sense of purpose and routine.
- Being offered an appropriate outlet for skills and experiences.
- An increase in self-esteem and sense of accomplishment.
- Being able to address issues related to living with dementia.
- Being offered opportunities to influence policies and programs which can improve quality of life.
- Being able to provide the perspective of the person with dementia and affect decision making.

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### Benefits of meaningful engagement for the organization include:

- Credibility and legitimacy that the organization does, in fact, represent and act as a voice for the needs and interests of people with dementia, their families and care partners.
- Increased capacity by capitalizing on skills and abilities of persons with dementia.
- Doing work that is increasingly relevant.
- Informed decision-making.
- Ability to identify gaps in services from individuals and families\*\* who may benefit from them.
- Provision of appropriate information and services that address real concerns.
- Adding depth to the organization and dispelling myths and stereotypes.
- Staff positively supporting the cause of a better quality of life for people with dementia and their caregivers.

*Note: The benefits listed are contained within the articles and reports found in the References Section of this Resource Guide.*

### Questions for Reflection

**Organizational culture:** Does your organization have an attitude and approach that ensures that people with dementia have a voice and an opportunity to participate, as they are able, in the work of every department of your organization? If so, how do you know this practice is consistently applied by all staff and leader volunteers in all situations? What happens if it is not?

**Philosophy:** Is the active and meaningful engagement of persons with dementia in the work of your organization clearly reflected in mission statements? Does your organization actively and routinely reach out to people with dementia to participate in the work of the organization, focusing on their strengths and abilities? How do you do this? How are persons with dementia supported in their partnership work with your organization?

**Policies:** Does your organization have policies in place which provide guiding principles for the inclusion of people with dementia in the work of the organization?

**Staff and volunteer training:** Does your organization provide ongoing information, opportunities for assessment/reflection and training to staff and leader volunteers on the application of ethical principles guiding the participation of people with dementia in the work of the organization? For example, are staff encouraged to reflect on whether they are being overly protective of people with dementia?

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\*\*The term family includes anyone in the supportive network of people with dementia.



### 3. GETTING STARTED

**“Involving people with dementia should not be regarded as a “project” or one-off activity. If involvement is to be effective it must be thought of as an ongoing and evolving process that becomes embedded in the organisation’s culture and day-to-day practice.” – (Listen to Us. Involving people with Dementia in Planning and Developing Services.UK, 2005 p.22)**

- 1. Create an organizational culture of person-centred engagement through training and awareness for all levels of the organization:** In order to meaningfully engage people with dementia in the work of an organization, the first step is to embrace this culture throughout the organization. This means that it is not enough to provide opportunities for “consulting” and to be a “voice” for the organization. Staff and leadership volunteers need to work in partnership with people with dementia so that in working together, the planning and implementation of all aspects of the work of the organization can occur. This philosophy should be visible so that it is obvious to anyone who connects with the organization that participation by people with dementia is welcomed at all levels. (Sample position statement under Tools and Resources section)
- 2. Actively and routinely invite people to participate:** Consideration of the involvement of people with dementia is embedded into every facet of the organization’s work. Opportunities for involvement should be presented and options provided. How each potential participant will be approached and invited to take part will depend upon a range of factors, including: how well they are known to the staff; their cognitive and communication abilities; their cultural and social circumstances. Recruitment strategies may include word of mouth, advertisements in newsletters, personal invitations to current and former clients as well as those of other community organizations such as memory clinics, websites, radio announcements, newsletters, consumer mail-outs, early stage support groups, local action groups. (Sample advertisement under Tools and Resources section)
- 3. Screen:** Each person with dementia will need to be screened in order to better understand how their skills, interests and availabilities may fit with the type of opportunities available. This discussion should be a conversation that includes identifying individual strengths, abilities, background experiences, current situation, relationships and interests, and any support the person with dementia may need in order to participate. (Sample screening tool under Tools and Resources section)
- 4. Develop clear roles and responsibilities:** In order to meet the goal of meaningful and useful participation, people with dementia need to know the purpose of the work and their role in helping to achieve success and desired outcomes. Information about the amount of time required, location of activity, length and nature of the involvement needs to be provided. This should be discussed and written down so that the individual can refer to this information as needed. (Sample job description under Tools and Resources section)
- 5. Collaborate with families:** Family members can play an important role in facilitating the participation of people with dementia. They will have information that can help staff understand the support that is needed and available. It is important to keep in mind that in some situations, family members

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can adversely affect the involvement of persons with dementia by speaking on their behalf or not understanding the continued abilities of the person with dementia. In these situations, skill will be required to work together and separately with the person with dementia and family members to be sure that the needs and concerns of each are being addressed.

- 6. Support and respond to changing abilities:** Staff support is required to make sure that the engagement is meaningful and helpful for both the individual and the organization. At the beginning of the engagement, agreement should be reached as to the course of action when changing abilities hinder meaningful engagement. Encourage self-monitoring throughout the process of engagement. Does the person with dementia feel they can continue to participate in the same capacity? As abilities change, it is important to explore other ways for persons with dementia to be engaged. It is also important to remember, however, that the organization is in the business of fulfilling an important mandate. Clear and respectful messages about the organization's commitment to the individual as their needs change must be shared as early as possible with the individual as well as with any family caregivers, with the individual's consent.

**“When people are first diagnosed, they may not be ready to become involved in the work of the Alzheimer Society. You need to keep the doors open and encourage people by example.”**

*– (Prioritizing the Involvement of people with Dementia in the Work of the Alzheimer Society, ASC 2011, Person with dementia p.11.)*

### Enabling factors: Keys to success

- 1. A clear, meaningful purpose for participation:** Involvement in the work of the organization needs to be purposeful, not an act of “tokenism”; participation of people with dementia needs to be embraced by all involved. What is the organization trying to achieve and how will the individual play a role in helping reach that goal?
- 2. A person-centred approach:** The approach needs to embrace effective partnerships which value personhood, recognize the importance of interdependency and reciprocity, and have a commitment to empower and provide as much choice and control as possible. The reciprocal act of sharing experiences and being listened to with a view to decision-making together provides real involvement and empowerment for the individual and will enrich the outcome for both the individual and the work itself.
- 3. Safe environment:** The environment which promotes successful engagement is one that respects diversity of opinion and recognizes that diversity typically leads to a richer experience and more successful outcome, where it is all right to disagree and express opinions, and one in which feelings of mutual trust and respect are nurtured.
- 4. Facilitation:** The attitude of staff in facilitating the engagement of persons with dementia is important and should be based on respect for the person as a “whole person”, genuineness, and a positive attitude. Recognizing the value of the individual with strengths and abilities as an equal partner in the work undertaken is required throughout the facilitation process.

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- 5. Open communication:** A two-way process of communication needs to occur, comprised of active listening, empathy and engagement in dialogue between all team members. Open communication enables all individuals to express their ideas freely with confidence that all communication will be valued. (Tips for how to “actively listen” are in the Tools and Strategies section)
- 6. Regular reflection:** On-going assessment of and reflection on the process is essential for everyone involved, including a willingness to improve and adapt as necessary. Check in on a regular basis to find out how the person is doing.
- 7. Recognition:** Find out how individuals wish to have their contributions recognized then create ways to acknowledge the work of persons with dementia in the organization (awards and certificates, public acknowledgement in newsletters, handwritten thank you notes, small gifts, ceremonies, etc.) It is also important to recognize staff who are promoting meaningful engagement within your organization.

*Note: Many of these enabling factors are derived from the Authentic Partnership model. Please see the References Section.*

### Questions for Reflection

#### Assessment and Reflection: At the present time does your organization:

- Ensure that people with dementia have a voice and meaningful opportunities to regularly (or routinely) participate in every department of the organization? How specifically do you do this?
- Avoid tokenism by ensuring involvement is meaningful for both the person with dementia and the organization? How specifically do you do this?
- Act as a catalyst by increasing awareness and assisting in creating dementia friendly communities where all people with dementia are viewed as full citizens and persons with autonomy? How specifically do you do this?
- Value and respect the involvement of persons with dementia in the work of the organization and provide recognition and appreciation in meaningful ways? How specifically do you do this?

#### Challenges/opportunities/lessons learned from persons with dementia include:

- Attitude:** ‘Protectionist’ attitudes of professionals or caregivers do not encourage people with dementia to make their own choices. Do you really convey that the person with dementia is a partner in the work or do you believe that you “know best”?
- Break the work down into manageable pieces:** For staff and persons with dementia alike, when a project is very large it can be daunting. Think about it one step at a time.

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- **Consider health:** Health issues can be a barrier to involvement and should be planned for (e.g. hospital admissions).
- **The best time to work:** Meeting times are sometimes a challenge when they are not at a person's "best time of day".
- **Give time to respond:** Pauses in conversation are important to allow a person with dementia to respond, otherwise their thought can 'pass out of mind' rather quickly.
- **Ask about comfort level:** They may be anxious about public speaking and traveling to and from unknown venues. Ask if specific support might help or if this is the right opportunity for them.
- **Rest:** Time to rest and recuperate after travelling to a meeting or speaking engagement is important as tiredness and losing concentration happen easily for some. Adjustments to the pace and length of meetings, inclusion of travel companions, and being able to say no to requests are important to consider when participating in the work of the organization.
- **Accommodation:** Enlarged print reading materials, easy to follow agendas and time to reflect may all be helpful.(Sample agenda under Tools and Resources)

### Challenges/opportunities/lessons learned from the organization include:

- **Capacity:** Staff need to have the skills and attitude necessary for the successful engagement of people with dementia. Resources need to be dedicated to provide adequate support to all staff.
- **Dedicated staff:** It is important to have staff dedicated to support the participation of people with dementia.
- **Policies:** It is beneficial to have policies in place which facilitate the work of the person with dementia and may include support arrangements and funding allocation.
- **Self- monitoring approach:** Encourage people with dementia to honestly and regularly reflect on how the work is going from their perspective and to share their experience with others. Do they feel they are able to continue their involvement in the same way or has something changed?
- **Process consent:** Sometimes ongoing explanation about the nature and purpose of the consultation or involvement activity is helpful along with ongoing negotiation to determine if the person continues to understand the project and their role in it and remains willing to offer their expertise and opinions.
- **Relinquishing control:** Be prepared to 'give up' some control over priorities, the process and speed of getting there. Often the result is better than what one could have imagined when time is taken to take everyone's feedback into account.
- **Be flexible:** People with dementia need to be treated as autonomous and competent people who have unique skills and abilities that can be helpful. They may, however, benefit from some accommodation for any challenges they may be facing due to fluctuating abilities.

*Note: The challenges/opportunities/lessons learned listed are contained within the articles and reports found in the References Section of this Resource Guide.*

### 4. TYPES OF ENGAGEMENT

**“People want something meaningful to do. I don’t want to stuff envelopes (although some people might). It’s about ‘fit’ between the person’s skills and interests and the needs of the organization.” – (Person with dementia)**

People with dementia have the right to be involved in the organization that represents their interests. The term ‘involvement’ is purposefully broad and describes the whole range of practical ways in which persons with dementia can participate in the organization’s activities. Here are some ideas:

- Participating in decision-making (e.g. membership on Boards, Committees and Advisory groups)
- Promoting advocacy (e.g. speaking engagements, being a media spokesperson, participating in pre-election activities, organizing a public awareness event)
- Working in programs (e.g. peer mentorship, group leadership or facilitation, participating in fundraising activities, developing volunteer training materials)
- Reviewing materials (e.g. reviewing drafts of publications)
- Assisting with the operation of the organization (e.g. participating on a staff hiring team, facilitating a component of new staff orientation and ongoing staff training, helping with office tasks)

**“There is no ‘one way’ of involving people with dementia in the work of an organization. It is best to have discussions with people with dementia and develop guidelines based on conversation and experience - having a set of guidelines developed with people with dementia is important and should be referred to on a regular basis.” – (Prioritizing the Involvement of people with Dementia in the Work of the Alzheimer Society, ASC 2011, Person with dementia p.16) Coordinator, Northeast, College and Association of Registered Nurses of Alberta**

### 5. TIPS AND STRATEGIES FOR FACILITATING MEANINGFUL ENGAGEMENT

The involvement of people with dementia within the organization should be founded on values of personhood, relationship-centered and authentic partnerships, and citizenship, and on the principles of ethical practice. Involving people with dementia should not be regarded as a “project” or one-time activity. If involvement is to be effective it must be thought of as an ongoing and evolving process that becomes embedded in the organization’s culture and day-to-day practice. It will take time to create an organizational culture of person-centered engagement and will require training and awareness at all levels of the organization.

The role of staff providing support and facilitating the engagement process is critical to achieving success.

It starts with an effective leader who will:

- Constantly challenge yourself and those you work with to ensure that the level and type of engagement is optimal and meaningful.
- Engage staff and harness staff commitment.
- Celebrate and regularly recognize staff who embody authentic partnership principles and practices.
- Link with leading edge practice (best practices based on evidence based research).
- Provide information and training about methods and techniques of involving people with dementia.
- Demonstrate, and help staff to test out, ways of working.
- Be a role model for staff.
- Provide advice and encouragement.
- Provide a framework to keep staff focused on objectives and timelines.
- Provide prompt feedback and encourage reflection on practice.
- Co-ordinate activity and promote networking with a view of mutual support, shared learning and reduced duplication of effort.

Next, a staff member with the following attributes should be selected as a support person/facilitator:

- Expertise and experience in dementia.
- Good communication skills with people with dementia, caregivers, staff and managers.
- Tenacity, enthusiasm, and an ability to inspire enthusiasm in others.
- Commitment.
- Openness to new possibilities.
- Humility with a willingness to learn.
- Clarity of thought and purpose.
- Good organizational abilities.
- Respectful.
- Sense of humour.



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Strategies for successful facilitation include:

- Providing opportunities for people with dementia to choose whether or not to participate. Attending a meeting and having a sense of being part of something can be more important to some people than playing a more active role. All contributions should be valued no matter how small.
- Being sensitive to people's differing levels of awareness and understanding.
- Encouraging people to participate in whatever way they feel comfortable.
- Making time to complete preparatory work outside the group events. This includes visiting potential participants to be sure that they understand what will be involved.
- Creating a relaxed, informal atmosphere where people can feel safe and able to express themselves without fear of judgement or recrimination.
- Working at the pace of the participants with dementia, not of the staff.
- Making use of smaller discussion groups rather than having everything covered in larger group meetings.
- Ensuring that staff do not take the discussion into areas that are not a priority for the participants.
- Checking out meanings and interpretations with the group regularly and sensitively.
- Ensuring sufficient staff support is available for tasks such as note taking, assisting the chairperson during the meetings, etc. without detracting from supporting participants.
- Ensuring that participants are told that their expert contribution is valued and that they are thanked for it.

## SECTION 2 – Tips and Strategies Reference Sheets

Within this section there are five (5) Reference Sheets. Within each Reference Sheet there are many strategies that are common to each. However, each Reference Sheet is intended to be used as a stand-alone document for ease of use.

### FACE-TO-FACE MEETINGS

#### Before the meeting:

- If possible, select a meeting space that is dementia friendly: easy to find, easy to get into, welcoming atmosphere, no large mirrors, no highly reflective floors, close to washroom if possible, etc.
- Work with individuals to determine the best time to hold the meeting. Try to conduct meetings between the hours of 11am-2pm. Although individuals vary, many people with dementia are not at their best early in the morning and some people have lowered energy levels in the late afternoon. Experience suggests that it is best to arrange meetings that start around midday.
- Identify a support person from your organization who will be the point of contact for the individual. This person should be available on the day of the meeting.
- Both people with dementia and staff usually like plenty of time to prepare. Send out meeting materials at least two weeks in advance, if possible. Ask the individual if they would like the materials sent by email or by mail. Suggest to the individual that they:
  - ✓ Read the notes from the last meeting (if applicable).
  - ✓ Review the agenda and make a note of anything they want to be sure to ask or suggest, including new agenda items.
  - ✓ Consider having a notepad and pen with them during the meeting. This way they can write down any ideas they may have as the discussion takes place.
- The agenda needs to be easy to follow, broken down into sections with the purpose of each agenda item stated as well as the speaker identified.
- Use tent cards to identify each participant around the table and write the participant's name on both sides of their card.
- The identified support person should contact the individual and arrange a time to discuss the meeting materials. The best time to discuss the meeting materials is the day before the meeting, if it can be arranged. The individual may have questions, need clarification etc. At this time, the support person would go over the agenda items to see if there are any questions.
- Consider transportation to the meeting. Can the individual get to the meeting by himself/herself or is assistance required?
- The support person should be available to meet the individual at the front door, the day of the meeting, in advance of the meeting start time.
- Orientate the person with dementia to the environment, including where the washrooms and guest quiet room are located. Consider having these rooms labelled and location signs posted.

### FACE-TO-FACE MEETINGS *CONTINUED*

#### During the meeting:

- Take time at the beginning of the meeting to:
  - ✓ Allow group members to introduce themselves
  - ✓ Introduce the agenda
  - ✓ Remind members of the purpose of the meeting
  - ✓ Verbally summarize the work done to date
- Try to slow the pace of the conversation. Give plenty of time for people with dementia to speak and respond. Time should be taken with each agenda item to stop the discussion and ask for feedback from the individual. Checking in with all participants after each agenda item can reduce anxiety and ensure the pace of conversation is acceptable.
- Use visual cues such as name labels and flip charts.
- Summarize and reflect on previous decisions.
- Use a blend of closed and open-ended questions. Close-ended questions are those which can be answered by a simple “yes” or “no,” while open-ended questions are those which require more thought and more than a simple one-word answer.
- Consider taking breaks during the meeting depending on the length.
- Have a room or space available that persons with dementia use if they want time away from the meeting. This should be close to the meeting room.

#### After the meeting:

- In a few days following the event, contact the individual to thank them again for their contribution. Individuals should feel valued for the contribution they have made to the success of the meeting.
- Ask if they have any questions or comments about the meeting. Ask them if they have any suggestions to add to the meeting discussion or what might make it easier for them in future (e.g. breaks, presentation of written material, lighting, and sound levels).
- Ensure that any expenses are paid quickly.

### MEETINGS BY TELECONFERENCE

#### Before the meeting:

- Work with the individual to determine the best time to hold the meeting. Although individuals vary, many people with dementia are not at their best early in the morning and some people have lowered energy levels in the late afternoon. Experience suggests that it is best to arrange meetings that start around midday.
- Identify a support person from your organization that will be the point of contact for the individual. This person should be available on the day of the meeting.
- People usually like plenty of time to prepare. Send out meeting materials at least two weeks in advance, if possible. Ask the individual if they would like the materials sent by email or by mail. Suggest to the individual that they:
  - ✓ Read the notes from the last meeting (if applicable).
  - ✓ Review the agenda and make a note of anything they want to be sure to ask or suggest, including new agenda items.
  - ✓ Consider having a notepad and pen with them during the call. This way they can write down any ideas they may have as the discussion takes place.
- The agenda needs to be easy to follow, broken down into sections with the purpose of each agenda item stated as well as the speaker identified. Provide a “virtual table”, pictures of each of the participants with their names written clearly underneath each picture so that a person with dementia is able to visualize who is talking and therefore more easily follow the flow of conversation.
- The identified support person should contact the individual and arrange a time to discuss the meeting materials. The best time to discuss the meeting materials is the day before the meeting, if it can be arranged. The individual may have questions, need clarification etc. At this time, the support person would go over the agenda items to see if there are any questions.

#### During the meeting:

- At the beginning of the meeting, time should be taken to;
  - ✓ Allow group members to introduce themselves.
  - ✓ Introduce the agenda.
  - ✓ Remind members of the purpose of the meeting.
  - ✓ Verbally summarize the work done to date.
- Time should be taken with each agenda item to stop the discussion and ask for feedback from the individual. Checking in with all participants after each agenda item can reduce anxiety and ensure the pace of conversation is acceptable.

### MEETINGS BY TELECONFERENCE *CONTINUED*

- Each member should say their name before speaking.
- Summarize and reflect on previous decisions.
- Use more closed-ended questions rather than open-ended questions. This can be useful if a person is having difficulty following a conversation.
- Try to keep meetings short with most important agenda items at the beginning.

#### After the meeting:

- After the meeting, check-in with the person with dementia i.e. Are they okay? How are they feeling?
- In the couple of days following the event, contact the individual to thank them again for their contribution. Individuals should feel valued for the contribution they have made to the success of the meeting.
- Ask if they have any questions or comments about the meeting.
- Ensure that any expenses are paid quickly.

### SPEAKING ENGAGEMENTS

People with dementia are increasingly being asked to speak about their lived experience at public policy, educational and fundraising events. In addition, interviews with media are becoming more commonplace. Here are some tips and strategies to help make these speaking engagements more successful for both the person with dementia and the organization.

#### Matching the person with dementia with the best speaking opportunity:

**Have a discussion with the person to determine their preferences, strengths and abilities. For example, the person may prefer:**

- Speaking at public policy type events compared to speaking at fundraising events.
- A one-on-one interview compared to speaking behind a microphone.
- An interview over the phone rather than in person.
- A pre-taped interview rather than a live interview.
- Radio or print interviews rather than television.
- Speaking as part of a panel.

**Be clear about what you are wanting:**

- For speaking engagements, do you want a formal presentation? How much time is available? Can you offer them a time slot that suits them?
- Do you want the person to focus on anything in particular in their presentation or in their interview? You may need to provide prompt questions to help them prepare.

It is a good idea to provide this information in writing so that the person can refer to it when needed. Include the date, time, and location of the speaking engagement as well.

Paperwork may need to be completed for this speaking engagement. This should be done ahead of time. For example, if this is a media event, there will probably be a consent form for the person to sign regarding the disclosure of personal information.

**Ensure there is enough planning time before the event:**

People usually like plenty of time to prepare their presentation or speaking notes. However, the pressure of organising an event sometimes means that they are asked very late in the day to be involved. People who are experienced at public speaking may be fine with this but it can be very stressful. Time pressures may also mean that you can't give as much support as you might like to the person with dementia.

Remind the person that the audience is a sympathetic audience. Although this cannot be guaranteed, most audiences are present for a reason – whether to donate money to the cause or become more educated about dementia.

**Determine what support will be needed:**

You will want the speaking engagement to be a good experience for people with dementia. It is important to remember, though, that participating in an event like this might be very new to them. They may feel nervous or not very confident about giving a presentation. Being able to reassure them by being supportive from the beginning is essential. Ask the person what support measures would help



### SPEAKING ENGAGEMENTS *CONTINUED*

them to be more successful in their speaking engagement. Consider asking family members what support will be needed to help facilitate the participation of the person with dementia.

- Identify a support person from your organization who will be the point of contact for the person with dementia. This support person should be someone that the person with dementia knows.
- The support person should be present on the day of the speaking engagement and the person with dementia should be given an option of having the support person beside him/her during the speaking engagement or interview.
- Consider transportation to the engagement. Can the person get to the location by himself or is assistance required?
- The support person should be available to meet the person with dementia at the location of the speaking engagement, in advance of when the speech is to be given.
- Following the speaking engagement, there may be an opportunity for questions from the audience. Establish how the person would like to handle this and provide support as needed.

#### **Keep in touch:**

As the event approaches, keep in touch with the person with dementia.

- Are they feeling anxious? Do they have any worries? How can you ease these concerns?
- Have they prepared their presentation? How can you support them in preparing for their presentation?
- Would the person with dementia like you to proof read their written comments?
- Would the person with dementia like to go over their presentation with you face-to-face?

With the person's permission, talk to his/her care partner to answer any questions they may have about the speaking engagement.

The day before the speaking engagement, contact the person to see if they have any questions or concerns that need to be addressed.

#### **After the event:**

The support person from your organization should be available to the person with dementia during and after the event.

- ✓ After the event, check-in with the person with dementia i.e. Are they okay? How are they feeling? Ask the person with dementia if they require an escort to the bus, taxi or car.
- ✓ Ask them what their experience was like and how you might better support them in the future.
- ✓ Let the person know when the "interview" will be aired if not immediately.
- ✓ In a few days following the event, contact the person to thank them again for their contribution. Individuals should feel valued for the contribution they have made. A thank-you letter or card goes a long way.
- ✓ Share feedback with them about the audience response to their presentation.
- ✓ Ask if they have any questions or comments about the speaking engagement.
- ✓ Ensure that any expenses are paid quickly.

## SECTION 2 – Tips and Strategies Reference Sheets

### REVIEWING DOCUMENTS

People with dementia are in a unique position to share what it is like to live with dementia. They will have unique insights into issues and can contribute their knowledge and expertise. Through involving people with dementia in the review of documents, the organization can ensure that they are providing appropriate support and services.

Reviewing documents can be done individually or in a group setting.

#### **Preparation:**

When inviting people to review documents, be clear on what you are asking them to do. Use a job description format that identifies:

- Purpose of the review and intended outcome.
- Timeline for the review.
- How the feedback will be collected, either individually or in a group setting.
- Who the contact person is in the organization for questions etc.
- That all feedback will be considered but not all feedback may be used.

#### **Presentation of the text:**

- It may be difficult for the person to read a long document. If so, write a summary of the document or provide the document in sections.
- It will be easier to review the document if it is presented as large clear type with lots of white space to write comments. Courier New font may be easier to read for persons with dementia.
- Ask the person how they would like the document delivered to them, by email or mail.

#### **Gathering feedback:**

- It will be important for the person to know how their feedback will be used. They may wish to remain anonymous and have their views presented as part of a group response. If you wish to use their individual feedback as quotes, then you will need their consent.
- If the person will be part of a group when discussing their feedback, then a staff person can facilitate the discussion and take notes, but the discussion and agenda should be in the control of the individuals. The notes should be circulated back to the participants to ensure their accuracy. Develop clear questions to be discussed during the feedback session and share those questions with people with dementia before the session.
- If you are working with an individual then it might be easier to set up a meeting time or telephone call to obtain their comments.

### REVIEWING DOCUMENTS *CONTINUED*

#### After the review:

- ✓ Thank the person for their contribution. Individuals should feel valued for the contribution they have made.
- ✓ Let the person know how their feedback will be used and what the results and outcomes are of the review process.
- ✓ Ask if they have any questions or comments about the review process.
- ✓ Ensure that any expenses are paid quickly.
- ✓ Consider sending them a copy of the finalized document with a thank you card.

(Source: Deep Guide: Collecting the views of people with dementia. <http://dementivoices.org.uk/resources/deep-guides/>).

### WRITING DOCUMENTS INTENDED FOR PERSONS WITH DEMENTIA

People with dementia are in a unique position to share what it is like to live with dementia. They will have unique insights into issues and can contribute their knowledge and expertise. Through involving people with dementia in the writing of documents, the organization can ensure that they are providing appropriate support and services.

Most organizations produce documents at a program level such as brochures, booklets, tip sheets, newsletters, content for a website etc. Writing documents can be done individually or in a group setting. If a person with dementia is writing a document, it will be important that a staff person facilitate this project so that a process can be followed which is beneficial to the person as well as the organization.

#### Preparation:

When inviting people to contribute to written documents, be clear on what you are asking them to do. Use a job description format that identifies:

- Purpose of the document and its intended outcome.
- Timeline for the development.
- The process on how views on content will be collected, either individually or in a group setting.
- Who the contact person is in the organization for questions etc.
- That all feedback will be considered but not all feedback may be used.

#### Obtaining views on content:

Organising a separate discussion event on a subject can provide a focused way in which people with dementia can give their views.

- An existing “early stage” group within the organization could be approached for this project or an ad hoc group could be formed with interested persons attending. Invitations could be extended throughout the organization and the general community.
- The purpose of the group needs to be clearly outlined with specifics on how the writing of the document will take place. Once the views of the group are collected, the writing could be done by a person in the group, or by a staff person.
- Have a clear timetable for the group session, with refreshments available at set times.
- If the group is being run by people with dementia:
  - ✓ Ensure that staff do not interrupt, interject or ‘take over’.
  - ✓ Encourage participants to share tasks around the group, with support as necessary, to avoid too much work for one or two group members.
  - ✓ If a person with dementia is chairing the meeting, the facilitator should discuss with them in advance what assistance they might need and how they would like it to be provided.
- Take plenty of time for pauses and reflection on what is being discussed. It may take longer for people with dementia to process what is being said and formulate a response. Don’t overwhelm people with too much information.

### WRITING DOCUMENTS INTENDED FOR PERSONS WITH DEMENTIA

#### CONTINUED

- Avoid overstimulation with visual aids. If using flip charts, capture key points; underline key themes that will help them to stand out.
- Ask members how they want to handle a situation when group members need clarification during the discussion. (Are they comfortable speaking up for themselves if they need clarification?)
- Watch the non-verbal cues to see if all members understand the discussion. If you think there is confusion, ask them and see if everyone is on the same page.
- Don't call on individuals to speak as this can cause anxiety.
- To stimulate discussion, ask a few questions about a particular issue to get them started. Plan enough time for discussion so it is not rushed.
- Be prepared to rephrase or reframe questions that are not understood.
- Gauge energy levels in the room. Work with the group to determine the ideal duration of meetings.

#### After the discussion:

- Group members appreciate acknowledgement of their time and contribution to your work. A thank-you letter or card goes a long way.
- Let group members know what will happen with the information they have given you.
- Ask them if they have any questions or comments about the discussion.
- If a document is published later, be sure to let the group know. Send a copy or share a website link. If they helped write the content, they need to be acknowledged as a contributor.

#### Writing the document:

Here are a few tips that may be of help when writing dementia-friendly documents:

- Try to keep the information short and to the point.
- Visuals can be helpful; however, too many images can be confusing.
- Present information clearly, concisely, and in a positive manner.
- Colours can be used to differentiate between different sections of information.
- Use bullet points, bold text, titles and headings to separate information.
- Put information that you want to stand out in boxes.
- One column is easier for the eye to read than two columns.
- A font size of at least 12pt is good. 14pt is ideal. If Courier New font is used 11pt works well. White space around text is good.
- Avoid italics, which is much more difficult to read.

(Source available in English: Deep Guide: Writing dementia friendly information <http://dementivoices.org.uk/resources/deep-guides/>).

## SECTION 3 – Tools and Resources

Within this section there are nine (9) Tools and Resources. The “Checks and Balances” forms are intended to be used as a guide to track your progress from one time period to another. The sample tools and tip sheets are intended to guide your work as you develop meaningful engagement strategies. The “tools” may be modified to meet your needs.

### MEANINGFUL ENGAGEMENT OF PEOPLE WITH DEMENTIA Checks & Balances: Leadership Guide

Date: \_\_\_\_\_

In order to track your progress over time, please indicate how much you agree or disagree with the following statements.

	Strongly Agree	Agree	Undecided or Neutral	Disagree	Strongly Disagree	Notes and Examples
<p><b>Organizational culture:</b> Our organization has an attitude and approach that ensures that persons with dementia have the opportunity to be included, as they are able, in the work of every department of our organization.</p>						
<p><b>Philosophy:</b> Our organization actively reaches out to persons with dementia to become involved in the work of the organization, focusing on their strengths and abilities.</p>						
<p><b>Policies:</b> Our organization has a policy statement and goals that reflect the commitment we make to the involvement of persons with dementia in the work of the organization.</p>						



**Checks & Balances: Leadership Guide** *CONTINUED*

	Strongly Agree	Agree	Undecided or Neutral	Disagree	Strongly Disagree	Notes and Examples
<p><b>Support and training:</b> Our organization provides support and training for staff and volunteers on how to meaningfully engage persons with dementia in order to develop organizational capacity.</p>						
<p><b>Resource allocation:</b> Our organization has strategies and appropriate resources in place to ensure effective participation of persons with dementia in its activities.</p>						
<p><b>Environment:</b> Our organization provides a safe environment that embraces the participation of persons with dementia in the work of our organization.</p>						
<p><b>Valuing:</b> Our organization fosters a sense of belonging for the person with dementia and appropriately recognizes and honours their participation.</p>						

## SECTION 3 – Tools and Resources

### MEANINGFUL ENGAGEMENT OF PEOPLE WITH DEMENTIA Checks & Balances: For people with dementia

Date: \_\_\_\_\_

In order to track our progress over time, please place a (√) under the appropriate column regarding the following statements.

	Strongly Agree	Agree	Undecided or Neutral	Disagree
I feel that I am included in the organization and have been provided with opportunities to participate in the work of the organization..				
I feel that I can address issues and make suggestions which are important to me and relevant to others with a diagnosis of dementia.				
I feel that my skills and experience are respected and put to good use. My participation is helping to make a difference.				
I feel supported by staff and volunteers in the organization who are trained in the skills of working collaboratively with people living with dementia.				
I feel safe and comfortable in participating in the work of the organization. Staff and volunteers are supportive and recognize both my abilities and limitations.				
I feel that I am appropriately recognized and honoured for my participation in the work of the organization.				

Comments: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Thank-you for completing this evaluation!

### SAMPLE POLICY

#### Meaningful Engagement Policy

The XXXX actively promotes the meaningful engagement of persons with dementia in the work of its organization. The XXXX will provide an environment in which people with dementia are invited to actively contribute ideas, skills and abilities, recognizing that individual participation will vary, depending on abilities, personal histories and available opportunities.

#### Procedures

##### Introduction to the organization

The individual will be provided information about opportunities for participation when they become clients and throughout the course of their journey with the XXXX.

##### Valuing diversity

A collaborative, partnership approach will be used to meaningfully engage persons with dementia. There are many different types of engagement opportunities available within the organization and it is recognized that all individuals have differing skills and abilities. The XXXX will embrace this diversity and aim to create meaningful engagement opportunities which best suit the needs of the individual as well as the organization.

##### Person-centered

A person-centered engagement process will be used which recognizes the individual needs, skills and abilities of the person with dementia. Support will be provided to the person with dementia in their volunteer role with XXXX in order to ensure that the engagement process is purposeful and empowering for the individual.

##### Staff

The Meaningful Engagement Policy of the XXXX forms an important aspect for hiring staff within the organization. Upon commencement of employment, all staff will be made aware of the organization's philosophy and its importance. When possible, staff and volunteers will attend training sessions on meaningful engagement strategies of persons with dementia.

Date adopted:

---

At meeting of:

---

Signed:

---

Reviewed:

---

## SECTION 3 – Tools and Resources

### SAMPLE POSITION STATEMENT

#### Our Core Values and Beliefs

The XXXX values collaboration, partnerships, accountability, respect and excellence and promotes a person centered approach for persons who have dementia. The XXXX believes that individuals have unique values, personal history and personality and that each person has an equal right to participate in the work of the organization to the fullest extent possible.

#### Our Shared Organizational Responsibility

People living with dementia tell us, “Nothing about us, without us”. They have a right to be involved in the organization that represents their interests. With this in mind, the XXXX has the opportunity to enhance its credibility, reach and relevance by ensuring that the voices of people with dementia are heard in all aspects of our work. This means that we must all work together to build both organizational capacity and individual capacity to shape and cultivate a supportive environment for successful meaningful engagement opportunities within the work of the XXXX.

#### Our Unique Position to provide Leadership

The XXXX mandate is to provide support for persons with dementia and those who care for them. Within this mandate is a commitment to promote and improve quality of life for persons with dementia and to ensure that people with dementia are engaged in relationships which are based on equality, understanding, sharing, participation, collaboration, dignity, trust and respect. The XXXX will provide resources needed to develop the knowledge, skill and competence of staff and volunteers in order to promote meaningful engagement opportunities for persons with dementia in the work of our organization.

#### Our Call to Action

This statement has been approved by the Board of Directors of the XXXX. An action plan has been developed to ensure that this statement is supported by clear and definitive actions by the XXXX. XXXX will periodically evaluate its efforts and will update its action plan annually to confirm that its commitment is sustained.

### SAMPLE ADVERTISEMENT

A clear statement such as the one below could be placed on print and media based sites. Its purpose is to let the general public know that the XXXX encourages individuals with dementia to purposefully participate in the work of the XXXX.

“The XXXX embeds meaningful participation in its work by inviting persons with dementia to actively contribute their ideas, skills and abilities, recognizing that individual participation will vary, depending on abilities, personal histories and available opportunities.”

### Sample Screening Tool

When screening people living with dementia for involvement in the organization, it is important to have an interview process (like for other volunteers) to determine interests, skill set and availability and to ensure the work proposed will be meaningful for both the individual and the organization. It is also important to explore the supports needed for the individual’s success.

### Sample Interview Questions:

1. Can you tell me about your past history including work, employment, and skills that you have acquired?
2. What are your interests now?
3. How has the diagnosis of dementia affected you, physically and emotionally?
4. Here are the opportunities for involvement that are available. Is there a particular opportunity that is of interest to you?
5. What is your availability during the week?
6. Will you require assistance with carrying out your volunteer role and responsibilities? If so, what do you think will help you be successful?

### Tips on Interviewing:

- Treat the person with dementia like any other interviewee. Act naturally, greet them with a handshake, and avoid patronising or over-praising.
- Interviewing a person with dementia may require patience. If necessary, allow more time for answers and repeat questions if required.
- Be clear and precise when seeking information on the person’s experiences and ask only one concisely phrased question at a time.
- Often the person with dementia will reply to questions with short, concise answers rather than longer comprehensive ones, so be prepared to move on to the next point or topic.
- If you do not understand the answer you receive, ask for clarification, or repeat what you have understood for confirmation.

## SECTION 3 – Tools and Resources

From the interview responses, develop a Strengths and Strategies profile.

### SAMPLE STRENGTHS AND STRATEGIES PROFILE

This form can be used as a communication tool for staff and volunteers in order to identify the strengths, gifts, interests of an individual as well as strategies that will help to make the engagement a success.

#### Sample: Bob Smith

Strengths, gifts, interests	Supportive strategies for success
<ul style="list-style-type: none"> <li>• Previous employment as CEO of an advertising company</li> <li>• Skills in management, conducting meetings, recruitment, writing reports etc.</li> <li>• Lives in Sandy Creek, Saskatchewan</li> <li>• Married with children and grandchildren</li> <li>• Wants to be involved with management aspects of organization.</li> <li>• Can travel to meetings out of town, if provided with transportation.</li> <li>• Has a computer and can work through email and teleconference calls.</li> <li>• Enjoys public speaking and will talk about personal experiences with dementia.</li> </ul> <p>Meaningful engagement opportunities at XXXX:</p> <ul style="list-style-type: none"> <li>• Board member</li> <li>• Committee member</li> <li>• Advisory capacity</li> <li>• Media spokesperson and/or member of Speakers' Bureau</li> </ul>	<ul style="list-style-type: none"> <li>• For meetings in town, provide a taxi chit. Bob likes to be accompanied to where the taxi is located.</li> <li>• If meeting is out of town, plan a hotel room for the night before. (Appreciates time to relax before a meeting).</li> <li>• If out of town meeting, may prefer to have a travel companion but may feel uncomfortable asking because of expense.</li> <li>• Send meeting materials well in advance of meeting. (Likes to receive 2 weeks in advance)</li> <li>• Let Bob know which staff person will be available to assist him if needed.</li> <li>• Discuss agendas and meeting materials with Bob the day before the meeting for clarification and also input.</li> <li>• Meet Bob 1 hour before face-to-face meeting starts.</li> <li>• Provide a quiet area for Bob to relax during breaks.</li> <li>• Likes to have written remarks and written reports proof-read before presentations.</li> </ul>

**"I felt meaningfully engaged when I was asked my opinion and when my skills and expertise were being utilized for the benefit of the Society and all its members."** – *(Person with dementia)*

### SAMPLE JOB DESCRIPTION

When presenting options for involvement, it is important to be specific. Job descriptions are appropriate and helpful in defining roles and responsibilities.

**Position Title:** Committee Member on Research Panel

**Purpose:** To assist in determining successful fundable research grant applications and provide input into needs of research in the field of dementia.

**Location:** Meetings will be held at the XXXX office located at: 32 Circle Rd., Sandy Lane, Sask.

**Key Responsibilities:** As a Committee member you will be required to:

- Attend Research Committee meetings
- Participate in discussions
- Review each grant application against set criteria
- Identify your recommendations and give reasons for doing so
- Provide input on research needs in the field of dementia.

**Reports to:** The Chair of the Research Committee

**Length of Appointment:** 1 year

**Time Commitment:** 4 meetings are held in the 1 year period; meetings are held during the day, and one meeting generally last 4 hours.

**Support provided:** Orientation for this position is provided. In addition, the Program Director will be available for questions and assistance during your appointment to this Committee.

## SECTION 3 – Tools and Resources

### TIPS ON “HOW TO ACTIVELY LISTEN”

Active listening is making a conscious effort to hear not only the words that another person is saying but, more importantly, trying to understand the message that is being sent. It is all about building rapport, understanding, and trust.

#### 1. Pay attention

- Give the person your undivided attention, and acknowledge the message. Remember that non-verbal communication also “speaks” loudly.
- Look at the person directly.
- Put aside distracting thoughts.
- Don’t mentally prepare a rebuttal!
- Avoid being distracted by environmental factors, such as, side conversations.
- “Listen” to the person’s body language.

#### 2. Show that you are listening

- Use your own body language and gestures to convey your attention.
- Nod occasionally.
- Smile and use other facial expressions.
- Note your posture and make sure it is open and inviting.
- Encourage the person to continue with short verbal comments like “yes”, “go on”, “I understand”, etc.

#### 3. Provide Feedback

- Listen with an open mind. Our personal filters, assumptions, judgments, and beliefs can distort what we hear.
- Ask questions if you are not sure what is being said.
- Use the “I” language for reflecting back. For example, “I can see that you are upset”.
- Listen carefully to confirm what you think you are hearing.

#### 4. Defer making assumptions

- Interrupting is a waste of time. It frustrates the person and limits full understanding of the message.
- Allow the person to finish each point before asking questions.
- Allow for silence. It will give the person time to think as well as talk.

#### 5. Respond Appropriately

- Active listening is a model for respect and understanding. You are gaining information and perspective.
- Be honest and respectful in your response.

Remember: Effective listening involves observing body language and noticing inconsistencies between verbal and non-verbal messages. (Resource: Information sheet on communication: [www.alzheimer.ca/~media/Files/national/brochures-day-to-day/day\\_to\\_day\\_communications\\_e.pdf](http://www.alzheimer.ca/~media/Files/national/brochures-day-to-day/day_to_day_communications_e.pdf))



### TIPS FOR DEVELOPING A PROCESS FOR REFLECTION

Regular reflection about the engagement process with a view to improving and adapting as necessary is an important step in meaningful engagement. The following are some questions to guide your thinking. It is a good idea to write notes of your reflections as you go along so that you can refer to your notes when you meet as a team to discuss the involvement of persons with dementia in the work of the organization.

- How did you recruit persons with dementia? Did they approach you? Did you advertise? If so, was this a successful process?
- Was the screening process effective? Did you feel that an appropriate match could be made between the person with dementia and the available opportunities for involvement?
- What were the practical, social and emotional areas in which the people with dementia needed support to be involved?
- Were there areas in which you think more could have been done to enable people to be more fully involved?
- What were the issues on which people with dementia expressed views?
- Has anything changed for the people with dementia as a result of their involvement?
- Has anything changed for staff and leader volunteers as a result of the involvement work?
- What support did you need as a facilitator? What would make it easier for you?
- What went well and why?
- What, with hindsight, would you have done differently?

## SECTION 3 – Tools and Resources

### CHECKLIST: IMPLEMENTING MEANINGFUL ENGAGEMENT

<b>Setting the stage</b>	✓
Have you had a presentation or discussion with all staff and volunteers about Meaningful Engagement of People with Dementia: A Resource Guide and its implications for implementation within your organization?	
Are all staff and volunteers willing to embrace the philosophy that people with dementia are not just “clients” requiring service but are citizens in their own right with an equal right to participate in the work of the organization, as they are able?	
Does your organization have policies in place that reflect procedures which direct the commitment being made to meaningfully engage people with dementia?	
Have you publicly posted a Position Statement acknowledging that people with dementia, as appropriate, are encouraged to participate in the work of the organization?	
Have you scheduled staff and volunteer education on planning and implementation strategies for meaningful engagement of people with dementia which includes strategies on how to engage, types of meaningful engagement, examples and strategies to try, with evaluation processes in place to measure success?	
Has your organization committed staff resources and an appropriate budget to support the work that people with dementia will be doing in your organization?	
<b>Invitation to participate</b>	
Do you routinely invite people with dementia to participate in the work of the organization, as they are able?	
Have you purposefully recruited people with dementia, both within your organization and within the community, to become meaningfully engaged in your work?	
Have you developed a list of available opportunities of meaningful engagement which are not just “consultation” opportunities but are opportunities that encompass every department of the organization?	
<b>Screening for success</b>	
Have you developed a screening tool for interviewing people with dementia to identify the strengths of the individual as well as strategies needed for successful engagement?	
Have you developed job descriptions for available opportunities for meaningful engagement in your organization?	
Have you collaborated with the family, with the individual’s consent, to share information regarding the proposed engagement opportunity and the involvement of the person with dementia?	

### CHECKLIST: IMPLEMENTING MEANINGFUL ENGAGEMENT *CONTINUED*

Screening for success	
Have you had a discussion with the individual regarding self-monitoring and agreed to a course of action when changing abilities hinder meaningful engagement?	
Do you provide skills development education for your staff and leader volunteers in meaningfully engaging people with dementia in the work of the organization?	
Have you put a recognition plan in place for acknowledging and honouring the work of people with dementia?	
Do you regularly assess and reflect on the process of engagement with a view to improving and adapting as necessary?	

*Note: The term family includes anyone in the supportive network of people with dementia.*

### Background on the Alzheimer Society's Development of the Resource Guide

Historically, the Alzheimer Society has focused on providing support and education programs for caregivers of people living with dementia. However, with a growing understanding of the importance of an earlier diagnosis, people with dementia in the early stages are now themselves reaching out to the Society for information and support. Learning about a person-centred approach to providing services to people with dementia and their families has helped Alzheimer Society staff to recognize the importance of hearing “their voices” as we promote awareness of dementia and enlist the help of persons with dementia in our work. There is also a growing demand to expand the ways in which people with dementia can and want to contribute to all aspects of the Society's operations, from decision-making and setting standards to providing input into dementia awareness strategies, programs and services, advocacy efforts, and systemic change.

There are many benefits of engaging people with dementia in work that directly impacts them:

- It provides the opportunity for people with dementia to give input into decisions that directly affect them which in turn contributes to a sense of personal worth.
- It increases understanding of the issues and promotes communication among people with dementia, Alzheimer Society staff and researchers.
- It provides legitimacy, credibility and accountability to the organization in the planning and implementation process.

The following Alzheimer Society activities led to the development of this Resource Guide:

- **“Engaging People with Early Stage Alzheimer's Disease in the Work of the Alzheimer Society, A Research Report” (Imagine 2006):** A study commissioned by the Alzheimer Society of Canada to identify strategies to promote the active participation of people with early stage dementia in the work of the Society, particularly policy, research and service delivery. The report recommended that the Alzheimer Society “develop a strategic direction, policy statements and goals for consumer inclusion” (p. 24).
- **“Prioritizing the involvement of people with dementia in the work of the Alzheimer Society: A Call to Action Report”, Oct 2011:** A further study commissioned by the Alzheimer Society of Canada was undertaken to obtain specific recommendations on the steps needed for successful engagement of people with dementia in the work of the Alzheimer Society. This study included an international scan of the literature as well as information on various international approaches.
- **Formation of an Alzheimer Society Dementia Advisory Group 2012 comprised of persons with dementia from six provinces:** The group's mandate is to advise and share their perspectives on how the Alzheimer Society currently engages people with dementia in their work and what needs to be done to make the engagement of people with dementia more meaningful and fulfilling for both them and the Alzheimer Society. One of the group's key actions was the development of an “Ethical Framework on Engaging People with Dementia” (2013) that guided the Alzheimer Societies' future work in this area. The Advisory Group has overseen the development of this Resource Guide.

## APPENDIX: Background Information and References

The Ethical Framework contains four ethical principles which enhance the experience of people with dementia throughout their involvement with the Alzheimer Society. These ethical principles include:

- **Autonomy:** Respect the rights, views and decisions of each individual.
- **Beneficence:** Do good and take positive actions to help others.
- **Justice:** Treat individuals with dementia fairly and morally.
- **Non-Maleficence:** Do no harm.

Please see complete Ethical Framework on page 41.

- **Connecting with current researchers in relevant fields:** Conversations have taken place with Drs. Carrie McAiney, Elizabeth Kelson, and Elaine Wiersma, key leaders in “meaningful engagement” research, to obtain their insights and comments regarding how best to integrate research into practice in this Resource. Most notably, the research “Meaningfully engaging with people living with dementia in the development of programs and services: What Works” by Dr. Elaine Wiersma, et al (Lakehead University, 2013) has provided insights into this field of enquiry and is foundational to meaningful engagement of people with dementia in all settings. In addition, the stellar work that has been done by Dr. Sherry Dupuis on Authentic Partnerships in dementia care has paved the way for inclusion of people with dementia as partners in decision-making in Canada.
- **ASC’s focus on a person-centred approach:** In 2012, the Alzheimer Society of Canada embarked upon a “Culture Change Initiative” in Long Term Care. Its aim was to improve the experience of long-term care for people with dementia and their families, and work with others to provide useful strategies, tools and tips that can help put the principles of person-centred care into practice. The PC P.E.A.R.L.S.<sup>®</sup> are seven key elements that were identified through the “Culture Change Initiative”, and if implemented, can begin and sustain a culture change to provide person-centered engagement and care.

## APPENDIX: Background Information and References

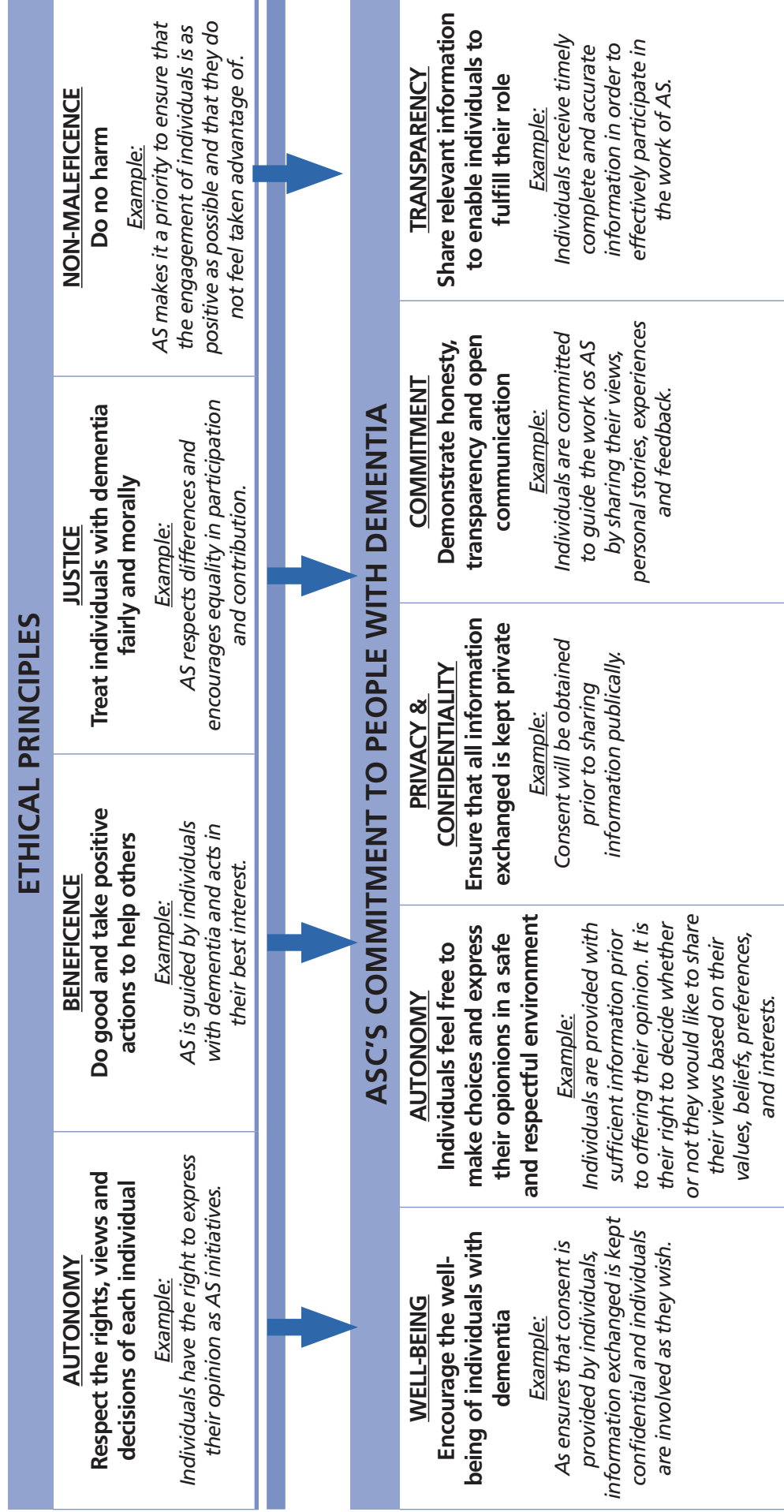
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# Alzheimer Society

## ETHICAL FRAMEWORK - ENGAGING PEOPLE WITH DEMENTIA

Goal: To develop a common approach that will guide and enhance the engagement of individuals with dementia, during their involvement with the Alzheimer Society.





# Alzheimer *Society*

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