

Decision-Making: Respecting Individual Choice

The Alzheimer Society of Canada's "Conversations" series was created to help people with dementia, caregivers, and healthcare providers have conversations about complex and sensitive topics related to living with dementia. This sheet provides information on things to consider when having conversations about decision-making. To read other issues in the Conversations series, please visit www.alzheimer.ca/brochures.

People with dementia, caregivers and healthcare providers are encouraged to have conversations about all of the topics in this series early and throughout the progression of the disease. Even though talking about these topics can be difficult, it is only by having open conversations that it will be possible to be better prepared for the challenges that often come with the disease.

Dementia and decision-making

Dementia is an overall term for a set of symptoms that is caused by disorders affecting the brain. Symptoms may include memory loss and difficulties with thinking, problem-solving or language, severe enough to reduce a person's ability to perform everyday activities. A person with dementia may also experience changes in mood and behaviour. These dementia symptoms are irreversible, which means that any loss of abilities cannot come back.

It should not be assumed that just because someone has dementia, they are not able to make their own decisions. However, as the disease progresses, the person's decision-making abilities will change and they will need support in making decisions on important issues such as finances, accommodation and care.

Decision-making and capacity

The ability of a person to make their own decisions is called having capacity. Having capacity means the person is able to make "informed decisions." A person is said to have capacity when they:

- Understand all of the information relevant to the decision they are making.
- Understand the possible consequences of their actions.

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Dementia can affect parts of the brain responsible for helping us remember, understand and process information, which can impact the person's ability to make decisions. Because dementia is progressive, the person's capacity to make informed decisions will reduce over time. When this happens, whoever makes decisions on behalf of the person with dementia should always use the person's known wishes to guide the decision.

It is important to note that the capacity to make decisions should not be confused with judgement. The issue is not whether a person is making a "good" decision, but whether they are able to make an informed decision after carefully weighing the pros and cons of the options available.

Assessment of abilities

Assessing whether or not the person with dementia has capacity to make informed decisions can be difficult. Before making a decision on the person's behalf, consider the following:

- Memory problems do not automatically make the person with dementia incapable of making informed decisions.
- If the person is having difficulty remembering things, aids such as voice recorders or written notes could be used to support their memory and to record their decisions.
- A person with dementia has the right to be supported to make their own decisions until they are deemed incapable.
- A decision should not be made on a person's behalf until they have been provided with different types of support without success.
- If necessary, an assessment by a healthcare provider may be required to determine the person's capacity to make informed decisions. Regulations governing competency assessments can vary from province to province. Contact your local Alzheimer Society for information about the relevant regulations in your province.

Note: *Recognizing that people with dementia can be vulnerable to decisions made on their behalf, a group of people with dementia worked with the Alzheimer Society of Canada to create the Canadian Charter of Rights for People with Dementia. The Charter is meant to help people with dementia, and those who support them, understand and advocate for their human rights. Read the Charter at www.alzheimer.ca/charter*

Supporting the person with dementia to make decisions

The person with dementia has the right to be supported to communicate their views and wishes. To support the person to make their own decisions, consider the following:

- A person with dementia may need more time to think about their decision. Be patient and give the person the time they need to think it through.
- Some decisions do not need to be made in one sitting. Decision-making is a process that can happen over a period of time. Encourage the person to think about the decision from time to time and ask them to write down any thoughts that occur to them.

- Communicate all relevant information in simple terms, using clear language. Consider using props, such as photos, to help you with this. For more information on communicating with a person with dementia, please visit www.alzheimer.ca/communication
- Provide step-by-step guidance.
- Find a time when the person is most alert.
- Eliminate distractions and noise, such as turning off the TV.
- If the person needs assistive devices such as glasses and hearing aids, check that they are working.
- If the person is in pain, discomfort, or taking medications which cause drowsiness, their ability to make decisions may be affected.
- Reduce the number of options. For example, ask, “Would you like to have your bath now or later?” rather than, “When do you want a bath?”
- Listen and be sensitive to the person’s facial expression, tone of voice and body language.

Note: *Being unable to make some decisions (such as where to live) does not necessarily mean the person cannot make any decisions (such as what to wear or whether or not they want to participate in a program). As the abilities of the person with dementia change, those who provide care and support need to ensure that the person continues to be involved in making as many decisions as possible.*

Planning ahead

It is recommended that the person with dementia start thinking about issues relating to future healthcare, personal care and financial decisions soon after their diagnosis.

It is important for the person with dementia to select a **substitute decision-maker**. A substitute decision-maker is a person (or in some cases, multiple people) who makes decisions for the person with dementia when they are no longer able to do so. They make decisions about:

- Living arrangements
- Medical treatments
- Finances

When choosing a substitute decision-maker, the person with dementia should consider their:

- Availability to take on the role
- Understanding and respect for the values and wishes of the person with dementia
- Ability to work with others, including when under stress
- Ability to resolve conflicts

Even though talking about these topics can be difficult, it is only by having open conversations with their designated substitute decision-maker that the person’s wishes can be honoured.

It is important to keep in mind that:

- The person with dementia and the substitute decision-maker should have open, on-going conversations about the wishes of the person.
- Wherever possible, legal paperwork should be completed to ensure that the wishes of the person with dementia are recorded and a substitute decision-maker is named. Laws about advance directives and substitute decision-making can vary from province to province.

The person's values and wishes can be written down in an **advance directive**. This is a document that records a person's wishes about their future care. Laws about advance directives can vary from province to province. Contact your local Alzheimer Society for more information.

Things to consider when having discussions about future care

Some people may find it difficult to have conversations about personal values, finances, living arrangements and end-of-life care. However, if the person does not have open and honest conversations with their family and/or future substitute decision-maker, they may be denied the opportunity to express and realize their wishes about their own care. When making decisions on the person's behalf, family members and substitute decisions-makers should be aware of what the person values and how the person defines quality of life.

Note: *It may be helpful for the person to fill out the "All About Me" booklet. This is a resource from the Alzheimer Society that people with dementia can use to tell others about themselves (such as their healthcare providers, caregivers and substitute decision makers). To access the booklet, please visit www.alzheimer.ca/allaboutme. For more information about quality of life and dementia, please visit www.alzheimer.ca/qualityoflife*

Some topics for discussion about future care may include:



Future healthcare

- What kind of treatment would the person want for other major health problems, such as heart disease or cancer?
- What medical interventions, if any, such as cardiopulmonary resuscitation (CPR) or feeding tubes, would the person want?
- What effect would the treatment have on the person's physical and cognitive health?



End-of-life care

- If given a choice, would the person prefer to die where they are living, in a hospice or in the hospital?
- Does the person have any special wishes at the time of death, such as family and friends nearby, music playing, or specific faith or cultural rituals?
- For more information about dementia and end of life, please visit www.alzheimer.ca/endoflife

Conversations About Decision-Making



Finances

- Has someone been named to look after the person's financial interests? This may or may not be the same person responsible for decisions relating to health and personal care.
- Are financial and legal documents, such as wills, insurance policies and bank accounts gathered together in a safe location?
- Have financial priorities been set? For example, a person with dementia might indicate that their top priority is their own comfort and wellbeing.



Personal Care

- What language should be used in communicating with the person with dementia?
- Is there a specific type of diet the person wishes to follow? (e.g. vegetarian, kosher).
- Is keeping well-groomed important? Are there specific routines that the person wishes to be followed? (e.g. hair dyeing, beard trimming).
- Are there specific clothes the person wants to dress in? (e.g. a favourite sweater, prayer shawl, turban).
- Are there daily habits to be followed? Is the person a morning person or a night person? (e.g. having tea before breakfast, watching the news every evening).
- Are there any health practices that the person wishes to continue? (e.g. taking daily vitamins, special dental care).
- Does the person want to continue to pursue certain activities? (e.g. daily walks, watching golf on tv, quilting, listening to a specific type of music).
- Is there anything the person is especially afraid of? (e.g. dogs, storms, loud noises, spiders).
- Does the person have any allergies?
- If living at home is not possible or safe, what type of long-term care home would the person prefer? (e.g. small, large, culturally-specific). For more information about moving to long-term care, please visit www.alzheimer.ca/longtermcare

Strategies for the substitute decision-maker

When the substitute decision-maker has to make decisions on behalf of the person with dementia, the expressed wishes of the person must be followed whenever possible. The job of the substitute decision-maker is to put into action the person with dementia's wishes, not their own. If conflict develops, or, if the person's wishes are not known, are unclear or are impossible to follow, there should be a review of the decision based on:

- the values of the person with dementia
- the weighing of risks and benefits of the decision for the person, caregivers, family members and others who may be affected
- the effect on the physical and emotional well-being of the person
- the effect on the quality of life of the person

If there is disagreement between the needs and wishes of the individual and those expressed by family members, caregivers or healthcare professionals, an impartial, trusted third party should be consulted to assist in resolving the issue. With some decisions, a resolution may take some time.

Useful Resources:

Contact your local Alzheimer Society for information, support and education. They can provide you with province-specific information on:

- Substitute decision-making for healthcare and finances
- Advance directives
- Competency assessment

You can find your local Alzheimer Society by visiting www.alzheimer.ca/helpnearyou

Visit www.alzheimer.ca/brochures for more information about:

- Quality of life
- Living alone
- Driving
- Intimacy and sexuality
- Communication

For information about moving to long-term care, please visit www.alzheimer.ca/longtermcare

For information about dementia and end of life, please visit www.alzheimer.ca/endoflife

To access the All About Me booklet, please visit www.alzheimer.ca/allaboutme

View the Canadian Charter of Rights for People with Dementia at www.alzheimer.ca/charter

For more information on advance care planning, check out the Speak Up campaign at www.advancecareplanning.ca

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