Dementia and End-of-Life Care

Alzheimer Society

Part I: What decisions do I need to make?

About this resource

The needs of people with dementia at the **end of life*** are unique and require special considerations. This resource is for you – a **family** member supporting a person with dementia – to help prepare for end of life, make some of the difficult decisions you may face, and cope with the grief and loss you might experience.

This resource is part of a four-piece series on dementia and end of life care. A description of the other resources in this series is available at the end of this booklet.

It can be hard to read a lot of information about end of life all at once; think about the issues you are most concerned about and read that section first. There is no "correct order" to reading this information. However, if you are at a turning point and need to make some decisions quickly, reading the most appropriate section may help.

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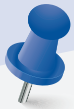

Other Resources in this Series and Glossary of Terms found on pages 8-10.

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*All **bolded** words are found in the Glossary of Terms located at the back of this document.

The importance of planning ahead

Due to the progression of Alzheimer's disease [alzheimer.ca/stages] and other dementias, the person with dementia will eventually become unable to express their wishes. **Family** members and health-care professionals often have to make difficult decisions on behalf of the person with dementia. Families can benefit greatly from knowing the person's wishes in advance.

It's human nature to try to avoid talking about sad and difficult topics like **end of life**. But by taking an active role in preparing for this stage, individuals and families can get on with their day to day lives knowing they have taken important steps to ensure that the care provided at the end of life will reflect the person's wishes, beliefs and values.

Most of us want to die in a peaceful, dignified and pain-free way, close to the people who are important to us and with our wishes, beliefs and values respected. Research indicates that discussing goals and preferences regarding end of life care early on increases the likelihood that a person with dementia will be comfortable at the end of life.

> **"Have you talked to your parents about the kind of care they would want? Don't be scared to look ahead and figure out what the options are. You'll be better prepared to make informed decisions when the time comes, without the accompanying emotional stress."**
>
> *– Barbara Dylla, a former caregiver in Montreal*

Advance care planning

Advance care planning is the process of planning for a person's future health-care based on conversations about their values and beliefs. Developing a clear plan in advance can reduce **family** distress and help ensure that the person receives the **end of life** care that they want.

> **"The window of opportunity to include the person in end of life decisions is well before they are gone. I started having these discussions with my parents as they were aging and getting more frail. I asked, 'what would you like us to do?' I believe in being proactive because it helps in the end."**
>
> *– Rachael Mierke, a caregiver in Winnipeg*

What should be discussed?

It is important that everyone involved in the conversation understands the progression of the disease and the typical needs near end of life so that you are able to talk about these issues early on.

Some questions you might want to think about and discuss are:

- If given a choice, would the person prefer to die where they are living (e.g. at home or in a long-term care home), in a **hospice** or in the hospital?
- What **medical interventions**, if any, such as **cardiopulmonary resuscitation (CPR)** or **feeding tubes**, would the person want?
- 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?

A person's verbal wishes can be just as valid as a legal document, such as a **living will** or **advance health directive**, although it is still a good idea for the person to write down their wishes. A written **advance care plan** can name someone to be a **substitute decision-maker** when the person with dementia is no longer able to express their wishes for health and personal care decisions.

> **"Choose a person you can trust who will follow your direction."**
>
> *– Rachael Mierke, a caregiver in Winnipeg*

For more information on the types of planning to consider, please see Planning for the future at www.alzheimer.ca.

ADDITIONAL RESOURCES

- Tips for talking about end of life on page 10
- "Speak Up" advance care planning workbook by the Canadian Hospice Palliative Care Association found at www.advancecareplanning.ca
- Decision-Making: Respecting Individual Choice in the Alzheimer Society's Tough Issues series found at www.alzheimer.ca

Appointing substitute decision-maker(s)

The **Substitute Decision-Maker (SDM)** is the person chosen to make personal care decisions, including medical decisions, for the person with dementia when they are no longer considered capable of making them alone. The laws regarding substitute decision-makers vary from province to province across Canada. You can read more about the laws in your province at [www.advancecareplanning.ca/resource-library/#resource-librarylcategory:your-province-or-territory].

Who should this person be?

The substitute decision-maker should be someone whom the person with dementia trusts to carry out their wishes, such as a family member or a close friend. If the person with dementia does not appoint a substitute decision-maker, most provinces and territories have a priority list, usually starting with family members. It is important to understand that the people in the list will be asked in priority sequence to act on behalf of the person, regardless of how close their relationship is to the person.

Making decisions

In making decisions about **end of life** care, guidance can be found in written documents, known as **advance directives**, and conversations in which the person expressed their wishes. If the person's wishes have not been written down or expressed verbally, decisions will need to be made based on the person's lifelong desires and values and what you think the person would want. You may have to weigh the risks and benefits of the decision, and assess how it will affect the person's quality of life and well-being.

Medical care decisions

It's also important for the **substitute decision-maker** to seek advice in advance and work with the **health-care team**. Understanding and discussing medical treatment options at **end of life** in advance can be very helpful in making the appropriate decisions when the time comes.

Decisions around aggressive medical care

The **substitute decision-maker** needs to know the person's wishes regarding the use of **aggressive medical care** to help keep them alive. The following are some of the measures that commonly arise:

- **Antibiotics** may be prescribed to treat common infections.
- **Cardiopulmonary resuscitation (CPR)** is an emergency lifesaving procedure that is done when someone's breathing or heartbeat has stopped (heart attack). A **Do not resuscitate (DNR)** or Do not attempt resuscitation (DNAR) order tells the medical professionals not to perform CPR if the person's breathing or heartbeat stops.
- **Feeding tubes** are sometimes suggested if a person has a difficult time eating or swallowing.
- **Intravenous (IV) hydration** is liquid administered to a person through a needle in a vein in the hand or another part of the body.
- A **ventilator** may be used to assist with breathing if the person cannot breathe on their own.

What types of medical care decisions will need to be made?

It is important to ask and learn what choices the person with dementia would make with respect to issues such as **resuscitation**, **artificial hydration**, **feeding tubes**, **ventilators** and **emergency hospitalization**.

- Would the person want to undergo medical treatments that may be somewhat invasive as death approaches?
- What personalized **comfort care** do they want?
- At the end of life, would the person want to be **transferred to a hospital** knowing that a change in environment may be frightening and disorienting?
- Would the person want to remain in the familiar environment of their home or long-term care home if possible?

Palliative care

Aggressive treatments and procedures that may cause fear or discomfort may not be in the person's best interests. However, deciding not to use extreme measures to keep the person alive does not mean withholding all treatments. The goal of **palliative care** is to reduce distress, provide enhanced comfort, quality of life, dignity and pain control.

Palliative care does not mean stopping all treatments. The person may continue to receive medications for chronic conditions such as diabetes or high blood pressure, as well as treatments that reduce pain and discomfort.

A **palliative approach** to dementia care should be applied as early in the disease as possible. Research indicates that a palliative approach to care is essential for good-quality end-of-life care and dying well with dementia. Ongoing discussions should be had with the **health-care team** to ensure the best **comfort care** for the person at all times.

Here are some questions you may wish to ask the doctor before making decisions about medical treatment:

1. Which health conditions of the person are treatable? Which are not?
2. Will the proposed treatment bring physical comfort?
3. Are there side effects to the treatment? If so, what are they?
4. How can symptoms be safely and effectively managed?
5. Will the proposed treatment require time in the hospital? If so, for how long?
6. Is the proposed treatment painful for the person?
7. What can be expected to happen in the coming days or weeks?
8. What can we expect if we choose not to have any treatment?

Practical things to consider

- If the death is likely to occur in a long-term care home or hospital:
    - Talk with the staff in advance if your faith, cultural or ethnic background requires any special customs or rituals after death, so that they can plan with you.
    - Ask about end-of-life programs such as a guest room for privacy, comfort baskets and dignity robes to prepare the body for final viewing.
    - The long-term care home may also have a respectful ritual to honour the person and family when the body is removed.
- If the death is likely to occur at home:
    - Communicate with health-care providers (such as home care nurses) who need to be contacted at the time of death. As soon as possible after the person dies, an appropriate medical professional such as a doctor or nurse must be contacted to pronounce death. It may not be appropriate to call the emergency services if aggressive treatment is not in keeping with the person's wishes, since ambulance crews are required by law to provide aggressive life-saving treatment unless a "**Do not resuscitate**" order is in place.
- Write a newspaper obituary.
- Make decisions about gifts to charity. Include the information in the obituary.
- Keep a record of cards, visitors and donations so these can be acknowledged later.
- When planning the timing of the funeral, consider the schedules of people coming from out of town.
- Some people record the service so the words can be replayed anytime and be sent to those who could not attend the service.

> **"I wanted to do my mom's eulogy. That was the end of the journey together through Alzheimer's. My niece wrote a poem for mom and read it at the funeral. Mom had a lot of the arrangements pre-planned, which was a huge relief for me."**
>
> *– Debbie George, a caregiver in Halifax*

Brain donation and/or autopsy

Since much of the research into Alzheimer's disease and other dementias relies on studying brain tissues that have been donated after the person has died, many individuals and families feel that brain donation is one way to increase the likelihood that we will one day cure this condition.

If brain donation is something you wish to consider, it must occur as soon as possible after death. As this is naturally a difficult time, it is important to discuss brain tissue donation in advance and to learn about the options available in your area. For more information about donating brain tissue for research in Canada, read our page on Brain donation [www.alzheimer.ca/en/Research/brain-donation].

Funeral/memorial arrangements

In the early stages of the disease, you can help the person with dementia choose to make all or most of their arrangements in advance of death, such as the planning and pre-payment for a funeral or memorial service, and burial or cremation. The advantages of doing this early on are that the person with dementia is able to make their wishes known and you not requested to make many difficult decisions or arrangements.

Even if you haven't done a great deal of **advance planning**, it is very helpful to make some preliminary plans in advance regarding the choice of **funeral director**, the type of service and where it will be held, who will officiate, whether you want music or readings, and whether a burial or cremation is preferred.

> **"Pre-planning the funeral while my mom still had her faculties was a huge help. I couldn't imagine having to go through all that without her direction."**
>
> *– Debbie George, a caregiver in Halifax*

For other people, however, making arrangements in advance may seem too final an action or too emotionally difficult. Whatever the degree of planning that has been done, it is important to know about the arrangements that need to be made after death.

ADDITIONAL RESOURCES

- Information on making funeral/memorial arrangements from Funeral Service Association of Canada visit www.fsac.ca
- Planning for a funeral found at www.virtualhospice.ca

Glossary of Terms

Advance care planning: Process of planning for a person's future health-care where the person has conversations with close family and friends about their values and beliefs.

Advance health directive: Set of documents containing instructions that consent to, or refuse, specified medical treatments and that states the care and lifestyle preferences in anticipating possible future circumstances.

Aggressive medical care: Intensive medical treatment designed to preserve and prolong life.

Ambiguous loss: Type of loss you feel when a person with dementia is physically here, but may not be mentally or emotionally present in the same way as before.

Antibiotics: Medication used to treat bacterial infections.

Artificial / Intravenous hydration: Liquid administered to a person through a needle in a vein in the person's hand or another part of the body.

Bereavement services: Services provided to anyone who has experienced a loss including the process of healing from the loss.

Cardiopulmonary resuscitation (CPR): Treatment used in emergencies to restore function when a person's heart and/or breathing stop working (heart attack).

Care or support of a family member: This means that you provide psychological or emotional support; or arrange care by a third party; or directly provide or participate in the care.

Comorbidity: When two or more chronic conditions exist at the same time.

Compassionate care benefits: Benefits paid to people who have to be away from work temporarily to provide care or support to a family member who is gravely ill with a significant risk of death.

Do not resuscitate (DNR) / Do not attempt resuscitation (DNAR): Legal order to withhold cardiopulmonary resuscitation (CPR) in respect of the person's wishes.

Emergency hospitalization: When a person is admitted to a hospital without warning.

End of life: Stage of life where a person is living with and impaired by a condition.

Family: Includes anyone in the supportive network of the person with dementia.

Feeding tube: Medical device used to provide nutrition to a person who has a difficult time eating or swallowing.

Funeral director: Also known as a mortician or undertaker, a funeral director is responsible for conducting funeral rites. This person often performs the embalming and burial or cremation of the dead, as well as the planning and arrangement of the actual funeral ceremony.

Geriatrician: A physician who specializes in the diagnosis, treatment and prevention of disease in older people and the problems specific to aging.

Health-care team: A team of medical professionals that often includes a physician, nurse, pharmacist, clinical nutritionist, social worker and other support staff.

Hospice: A comprehensive service provided to people living with and dying from a fatal condition. This may include medical care, respite care and end of life care for people who are unable to die at home.

Living will: Legal document detailing a person's desires regarding their medical treatment in the event that they become incapable of communicating their wishes on their own.

Medical intervention: Treatment undertaken to improve health or help with a particular problem.

Opioids: Medications that relieve pain.

Palliative approach: An approach to care that aims to improve the quality of life for individuals with a fatal condition and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, psychological, social, cultural and spiritual needs.

Palliative / Comfort care: Type of health care for patients and families facing life-threatening illness. Palliative care helps patients to achieve the best possible quality of life right up until the end of life. Palliative care is also called end-of-life, or comfort care (Canadian Virtual Hospice).

Person-centred care: A philosophy that 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.

Psychological family: People you naturally turn to in times of crisis and celebration; the people in your life who are there for you in good times and bad.

Substitute decision-maker: A person who makes medical decisions and provides consent for treatment or withdrawal of treatment on behalf of another person who is incapable of communicating their wishes on their own.

Transfers to the hospital: Moving a person from home or the long-term care home to the hospital by ambulance.

Ventilator: A machine used to assist with breathing if a person cannot breathe independently.

Tips for talking about end of life

Talking about **end of life** can be difficult for everyone but you may even find some relief in having the subject out in the open. Talking about it early on can help you face your worries together. You don't have to talk about everything at once and there is no right or wrong way to approach this subject. Here are some suggestions that might help:

- Choose a time and place where you both feel safe and comfortable.
- Feel free to acknowledge the difficulty of talking about end of life. Using humour, when appropriate, may relieve pressure.
- If the other person refuses to talk or changes the subject, try saying "That is okay, we don't have to talk about it right now but it is something I would like to talk about soon. I want to be sure I know your wishes so I can act on them when the time comes."
- It is okay to express your emotions, including your sadness. Talking about a person's end of life can be upsetting.
- If you find the discussion overwhelming, suggest continuing the conversation at another time. You do not have to talk about everything all at once.
- This is a conversation about you and the person you support, so encourage the person with dementia to be involved in it as much as they are able.

Other Resources in this Series:

Part II: What do I need to know about caring for the person?

- Physical changes at end of life
- Caring at home
- Care in a long-term care home or hospital
- Importance of palliative care
- Understanding pain management
- Comforting the person

Part III: How do I care for myself and my family?

- Tips for self-care
- Getting the support you need
- Supporting children and teens
- Grief and loss
- Moving on
- Tips for coping with your grief

Part IV: What practical information should I know?

- Compassionate care benefits
- Government benefits after death
- Important documents and questions checklist

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