

Dementia and End-of-Life Care

Part IV: What practical information should I know?

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 5-7.

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

Compassionate care benefits

You may be eligible to receive **Employment Insurance (EI) compassionate care benefits** if you are absent from work to provide **care or support** to a gravely ill family member at risk of dying within a number of weeks. If you are self-employed, you may apply for special EI benefits if you are registered for access to the EI program.

For more information about compassionate care benefits, you may contact the EI Telephone Information Service at 1-800-206-7218 or refer to Service Canada – Employment Insurance Compassionate Care Benefits at www.servicecanada.gc.ca

Government benefits after death

When your parent, spouse or common-law partner dies, you may be eligible for certain government benefits:

- Allowance for the Survivor provides a monthly non-taxable benefit to widowed spouses with a low income who are not yet eligible for the Old Age Security pension.
- Death benefit provides a one-time payment to (or on behalf of) the estate of a deceased Canada Pension Plan contributor.
- Survivor's pension offers a monthly pension paid to the spouse or common-law partner of a deceased Canada Pension Plan contributor.
- Children's benefit provides a monthly benefit for dependent children (under age 18, or between 18 and 25 and attending school) of a deceased Canada Pension Plan contributor.
- The Aboriginal Affairs and Northern Development Canada – Decedent Estates Program manages the estate of a deceased First Nation individual who lived on a reserve before their death.
- International benefits provide survivor benefits to eligible individuals who have lived or worked in another country.

For more information about government benefits after a death please see Service Canada – Benefits After A Death at www.servicecanada.gc.ca

Important documents and questions checklist

Handling the administrative tasks after a death can seem overwhelming, but the following checklist and list of questions can help.

Print this page and use it as a checklist to make sure that you have all of the documents that you need:

Document	✓
Death certificates (10 - 15 certified copies)	
Social insurance number, driver's license, medical coverage card	
Marriage certificate	
Birth certificate of person, if applicable	
Insurance policies	
Deed and titles to property	
Will, if available	
Stock certificates	
Bank books	
Honourable discharge papers for a veteran and/or Veteran Affairs claim number	
Recent income tax forms	
Automobile title and registration papers	
Loan documents or contracts	
List of contacts of family and friends	
List of health, home, and community services used (such as dentist, family doctor and/or specialists, meal-on-wheels, home care services, utility companies, telecommunication services, MedicAlert® Safely Home® and social services – such as the local Alzheimer Society)	

Also consider the following important questions:

- 1. Were the funeral arrangements already made?** If so, where is the documentation? If not, contact your local funeral home to discuss the next steps.
- 2. Did the person express any specific wishes about their funeral?** If not, think about how the person would want their death marked and their life celebrated.
- 3. Do I need a burial permit in my province?** Is there a specific process for this? Consult the [Canadian Consumer Handbook \[www.consumerhandbook.ca\]](http://www.consumerhandbook.ca) to find funeral service regulators for your province.
- 4. Did the person have a will? Where is this document?** If the person does not have a will or substitute decision-maker, you may need to speak to a lawyer or consult the Public Guardian and Trustee about next steps.
- 5. Has the person been receiving government pension and benefits?** Be sure to notify the Canada Revenue Agency (CRA) of the death by phone at 1-800-959-8281 or online [www.cra-arc.gc.ca].
- 6. Do I qualify for government benefits?** For more information about government benefits after a death, please see our pages on Compassionate Care Benefits and government benefits after death.
- 7. Do I need to file a tax return for someone who has died?** Consult the Canada Revenue Agency page: [What to do when someone has died \[www.cra-arc.gc.ca/deceased/\]](http://www.cra-arc.gc.ca/deceased/).
- 8. Is there anyone else I need to notify about the death outside of friends and family?** Was the person a member of a social club, faith group, or organization such as the Alzheimer Society? Were they receiving community services such as Meals on Wheels? If so, contact these organizations.
- 9. What should I do with the person's belongings and other items not covered in the will?** Consider giving them away to close friends and family who will appreciate the items, or donate them to local charities.

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.

Other Resources in this Series:

Part I: What decisions will I need to make?

- The importance of planning ahead
- Advance care planning
- Appointing substitute decision-maker(s)
- Medical care decisions
- Practical things to consider
- Tips for talking about end of life

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

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