Dementia and End-of-Life Care

Alzheimer Society

Part III: How do I care for myself - as a caregiver - and my family?

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.

Table of Contents

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

---

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

Tips for self-care

The **end of life** stage can be particularly challenging for **family** caregivers. To provide care and support for the person with dementia, you need to remember to take care of your own physical and emotional health too.

Here are some suggestions to help care for yourself and boost your resilience:

- Accept your need to grieve and feel your loss before and after the person dies.
- Take breaks from caring for the person. Consider if there is someone you trust to spend time with your family member while you get some rest.
- Don't assume people know what you need. Let family and friends know how they can help.
- Access local services in your community for help and support with daily care.
- Take time alone for yourself when you need it.
- Share your feelings with people you trust who are good listeners.
- Consider joining a support group or seek professional help if your feelings become overwhelming.
- Eat well, exercise and get lots of rest. Do something nice for yourself each day.
- Make time to do some of the things you enjoy.
- Caring for someone can easily become the main focus in your life. Try to maintain or rebuild relationships with good friends and be open to making some new ones.
- Express your grief and loss in creative ways through writing, painting, photography or other art forms.
- Recognize and value your growth as a person, which has resulted from caring for someone with dementia. You may have learned new skills, such as handling finances or delegating care tasks, become more compassionate, or developed an inner strength and resilience you didn't realize you had.

> **"The support group allowed me to vent my frustrations and realize that others faced similar hurdles and fears. I went regularly to the meetings to ask questions about things that worried or angered me and, as my parents' conditions deteriorated, guide the newer members of the group by sharing some of my hard-earned knowledge. Remember, don't do it all yourself. Rely on others to help you."**
>
> *– Barbara Dylla, a former caregiver in Montreal*

ADDITIONAL RESOURCES

- Read **Looking after you, the carer** on page 38 in Dementia information for carers, families and friends of people with severe and end stage dementia by the University of Western Sydney.

Getting the support you need

Seeking out support is one of the most important steps you can take to come to terms with the feelings of loss and grief that are part of caring for a person. However, building and nurturing relationships takes time and energy- two things that caregivers often have in short supply. While providing care may have become the primary focus of your life, supportive relationships can make a positive difference throughout the caregiving experience and as you prepare for the person's **end of life**.

Try to take some time to rebuild and maintain the connections that are important to you. Your circle of support may go beyond your biological family. It's important to reach out to individuals in your life who are your "**psychological family**," a term that means the people you naturally turn to in times of crisis and celebration. Identify the people in your life who are there for you in good times and bad. These are individuals who may be able to understand the losses and grief you experience, acknowledge your remarkable efforts and successes, and give vital support. Your psychological family can be a diverse group. It might include friends, neighbours, co-workers, and those family members who understand you. The staff at an adult day program or care home, a **geriatrician**, or a family doctor can also become part of your circle of support. You don't have to be alone and, as busy as you may be now providing care to the person with dementia, some of these individuals may become even more important to you when the person passes away.

Suggestions for maintaining supportive relationships

- Set up a schedule with a friend for a phone chat and make this a routine for yourself by writing it in your calendar.
- Set up regular lunch meetings with a couple of friends.
- Participate in social outings such as a community nature walk or movie night with a group of friends.
- Invite friends for an informal gathering, such as a pot luck dinner.
- Join online discussion forums.
- Contact and join support groups in your local area.
- Look for volunteer opportunities. Not only will you be contributing to your community, but you can also help others who are in need.
- Pursue activities that you enjoy and inspire you. Start a new hobby.
- Join local groups with similar interests such as walking, reading, sports, singing, knitting, etc. Find out what's available through your local community centre.
- Count your blessings everyday no matter how small. Keep a journal to write them down.
- Show appreciation to your friends. It can be as simple as saying thank you or sending them a greeting card.
- Demonstrate your support to other family members by being a good listener. Take the time to really hear what they are saying.
- Use social media or cell phone apps to keep in touch with friends or simply send them an email.
- Don`t be afraid to reach out to people. People often want to help but don't know how.

Supporting children and teens

When you are caring for someone in their final months, you can support your children or teens by communicating openly with them about the situation and the person's illness. There are a number of ways that you can support your child or teen during the late stage of dementia and at **end of life**:

Communicate openly

Support your child or teen by communicating openly with them about the situation and the person's illness. It's important not to try to spare children or teens from knowing that a parent, grandparent, aunt or uncle is dying; they will sense the truth. Silence or whispered conversations could make them imagine situations that are worse than the reality. Give your child or teen information about what to expect and opportunities to ask questions and to express their feelings. Be as open as possible with whatever questions and emotions that may come up, and answer their questions truthfully in words they understand. Also consider some of the excellent books that are available to help you talk about serious illness and dying with your children.

> **"We left my son with his grandfather after his death. That was my son's first experience of death and we gave him his private time. I've always encouraged people to say what they want to say before the person dies or after the person is gone. That's going to be their last time with the person in the physical sense."**
>
> *– Rachael Mierke, a caregiver in Winnipeg*

Involve them in what's happening

In the final months, continue to include children and teens in activities with the person who is ill, if your child or teen is willing and open to this. Remember to keep visits short for small children. After death, involve your child in family rituals such as the funeral. An older child or teen may want to have a role in the final remembrance activities which could involve gathering and arranging photographs for display or reading a meaningful passage at the funeral. Your child may also want to choose special mementos from the possessions of the person who has died.

Include them in your grieving process

As a parent, you may be coping with your own grief at the same time as your child or teen needs support with theirs. Reserve time for your children and consider that they may benefit from being included in your grieving process.

How a parent grieves affects the way a child grieves. Adults who acknowledge and express their feelings and cry with their children help them to accept and understand death. When adults who are sad don't acknowledge or show their feelings, this may confuse children. Tell your children that you love them as much as ever during your time of grief.

Suggest outlets for their grief

Explain to your child or teen that their thoughts and feelings of grief are normal and that it is okay to cry. Encourage them to express feelings by talking, painting, writing a poem, or playing music. They may enjoy writing or talking about things that they learned from the person, for example, or sharing funny memories.

Keep the school informed

Make sure that your child's teachers and school counsellors are aware of the illness in your family and consider the possible effects on school or performance in other activities. Try to maintain the child's usual routine as much as possible.

After the person with dementia dies, help your child with the transition back to school by going over the routine. Let teachers and school counsellors know about the loss your family has experienced. Talk with your child about what they may wish to share with friends or classmates. They may be apprehensive and be tempted to keep the loss secret because it will make them feel different. Encourage your child to talk about their grief with friends or classmates they trust, which creates opportunities for them to be supportive.

ADDITIONAL RESOURCES

- Our Resource list for children and teens includes recommended books to help support children and teens of different ages found at www.alzheimer.ca
- Talking with Children and Youth about Serious Illness by Canadian Virtual Hospice found at www.virtualhospice.ca

Grieving in the final stages of dementia

When the person with dementia reaches the final stages, they may no longer be able to recognize or communicate with you, which can be very painful. You are aware that the relationship between you is almost over, yet you can't mourn the person fully because she/he is still alive. Recognizing your feelings and understanding the concept of **ambiguous loss** can help.

At this time, you may find that just sitting together holding hands or placing an arm around the person may give both of you comfort. It may also help to remember all that you have done to support the person.

Find ways to stay connected to the person with dementia as they are today, but also adapt to the losses in that relationship by maintaining and nurturing relationships with friends and family, and making new friends too.

Though it is often difficult, it is important to be realistic about how the disease will affect the person over time, and you need to plan for a life on your own after the person with dementia is gone.

Grief and loss after a person with dementia dies

Some caregivers of a person with dementia find that they have grieved the loss of the person for such a long time that they don't have strong feelings of grief when the person dies. Others do experience a range of emotional reactions which may include feeling numb, denial of the situation, shock and pain, relief, guilt, sadness, feelings of isolation, or a sense of lack of purpose. If you have been caring for someone with dementia for years, you may feel a huge void in your life when the person is gone.

It is normal for some people to experience these feelings of grief for a long time. Even if you are generally coping well, you may find that there are times when you feel especially sad or upset, such as the first Christmas, birthday or Mother's day without them.

During the months following the person's death, try to avoid making any major decisions, when you are still feeling shocked or vulnerable. Speak to your family physician if you need help with anxiety or depression.

ADDITIONAL RESOURCES

- Ambiguous loss and grief: A resource for individuals and families can be found at www.alzheimer.ca
- Our Grieving page includes tips for coping with grief and additional information on grieving in the final stages of dementia found at www.alzheimer.ca
- The Grief section on page 125 of A caregiver`s guide: A handbook about end of life care provides more information on how grief can affect you physically, mentally, emotionally, spiritually and socially.

Moving on

Moving on with your life may not be easy; how each person copes with the changes and emotions varies from individual to individual. Even if you feel you are coping well, there may still be times when you get upset. Give yourself time and do not try to go through this process alone.

Where to get support

- **Bereavement services** provide a number of services including counselling, support groups and informational sessions on topics such as coping strategies.
- Family support groups help you share your feelings with others who have experienced similar losses. A support group gives you an opportunity to share your own experiences and help you manage stress and feel less isolated.
- Turn to friends and family and accept the assistance that is offered. Often people want to help but don`t know how, so tell them what you need –whether it`s helping out with funeral arrangements or lending a shoulder to cry on.
- The Alzheimer Society is there to help – contact your local Alzheimer Society [www.alzheimer.ca/en/provincial-office-directory]
- Private grief counselling may help you work through intense emotions and overcome obstacles to your grieving. Not everyone is comfortable participating in a group. Sometimes, talking one-on-one can be helpful.
- You may draw comfort from spiritual guidance.

Tips for coping with your grief

- Keep a journal. A journal is a private place where anything can be written including unfulfilled wishes, guilt, anger and any other thoughts and feelings. A journal is a place where you can explore your frustrations and express your thoughts and ideas without interruption.
- Express your feelings in a creative way by drawing, painting, making a scrapbook or photo album celebrating the person's life, or crafting some other form of artwork.
- Cry. Tears can be therapeutic. Let them cleanse and relieve the pain inside. Relieve tension through shouting or punching a cushion.
- Learn to laugh again. Rediscover your sense of humour. Watch a funny movie, read the comics, or spend time with a friend who makes you laugh. Finding joy in life can be one way of honouring the happy times you used to share with the person with dementia.
- Plan ahead for possible 'triggers' such as holidays or anniversaries by talking to the people in your supportive network. Ask them for support or help in ways to honour the person.
- Find comfort. Different people have different ways of finding comfort. For many there is comfort in rituals, such as prayer, meditation or other activities.
- Remember that it is okay to express your feelings. Unresolved grief can lead to complications such as depression, anxiety or other health problems.
- Do not push yourself to overcome your emotions. There is no "right" or "wrong" way to grieve; each person`s grief is unique to them.
- Be kind to yourself. Be patient with yourself and your feelings. Find a balance between the happy and sad person, the angry and peaceful, and the guilty and glad self.
- Take one day at a time, respecting your needs and limitations.

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.

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 IV: What practical information should I know?

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

Alzheimer Society

Alzheimer Society of Canada
20 Eglinton Avenue West, 16th Floor, Toronto, Ontario M4R 1K8
Tel: 416-488-8772   1-800-616-8816   Fax: 416-322-6656
E-mail: info@alzheimer.ca   Website: www.alzheimer.ca
Facebook : www.facebook.com/AlzheimerSociety   Twitter : www.twitter.com/AlzSociety