Alzheimer Society

SUPPORTING CLIENTS THROUGH AMBIGUOUS LOSS AND GRIEF

Strategies for health-care providers

"All family caregivers will be grieving. It's important to address and name grief so people can talk about it and understand it. When people understand what's happening, they may be less likely to blame themselves and see themselves as a failure, and that's empowering."

The Alzheimer Society is Canada's leading nationwide health charity for people living with Alzheimer's disease and other dementias. Active in communities right across Canada, the Society

- Offers information, support and education programs for people with dementia, their families and caregivers
- Funds research to find a cure and improve the care of people with dementia
- Promotes public education and awareness of Alzheimer's disease and other dementias to ensure people know where to turn for help
- Influences policy and decision-making to address the needs of people with dementia and their caregivers.

For more information, contact your local Alzheimer Society or visit our website at alzheimer.ca.

Help for Today. *Hope for Tomorrow…*®

Created: 2013. Last reviewed: 2024. Next review due: 2025.

Alzheimer *Society*

Supporting clients through ambiguous loss and grief: Strategies for health-care providers

The issue of loss and grief is one of the most significant issues when supporting people with dementia and their caregivers. Losses and grieving occur in different ways at all stages of the dementia caregiving journey.

Caregivers can experience and grieve the loss of:

- Their dreams and expected plans for the future.
- A confidant and a partner.
- Shared roles and responsibilities.
- The progressive losses in the life of the person with dementia.

The ambiguous loss and grief that a caregiver may experience adds another layer of complexity that can make coping more difficult through the progression of dementia. These issues of loss and grief are often not recognized or well understood by caregivers or the health-care providers with whom they interact.

People with dementia are also likely to experience feelings of loss and grief over their diagnosis and throughout the progression of their dementia as their own abilities gradually change. Caregivers, health-care providers and Alzheimer Society staff can support them in living with these losses in various ways.

This document is intended to help health-care providers, Alzheimer Society staff and volunteers gain a better understanding of how loss and grief affect people with dementia and their caregivers. It will provide useful strategies to help families.

- Deal with their multiple losses and grief.
- Stay connected with the person with dementia.
- Build their own strength and resilience through the progression of dementia.

Acknowledgement: A sincere "thank you" goes to the caregivers, health-care providers and people with dementia whose lived experience is reflected in the case studies and quotes used throughout this booklet. Please note that the names included in the case studies have been changed.

Strategies for health-care providers

"The word 'ambiguous' helped me understand what was going on. I'm still married to my wife. I love her, but I don't live with her. I've always been crazy about her and still am. She's looked after, but it is a huge loss for me. The ambiguity is exactly how I feel."

What is ambiguous loss?

Ambiguous loss is a type of loss that happens when a person with dementia is physically present, but at times psychologically absent. A family member caring for a person with dementia may experience ongoing stress and grief due to the ambiguous loss of having a spouse or parent still there, but not present in the same way as before.

This is very different from the loss and grief of sudden death, for example, where the bereaved knows clearly that the person is gone, is often likely to receive support from family and friends, and may eventually find closure through the natural grieving process.

Ambiguous loss complicates grief. It's often hard for a caregiver to know whether or how to grieve when parts of the person with dementia are lost, but aspects remain.

Ambiguous loss can confuse relationships and prevent moving on. For example, a spouse may feel as if they are no longer in a marital relationship if their partner no longer knows who they are. They may feel like they are living in a state of uncertainty, unable to fully grieve or resolve the losses that have already occurred while anticipating other losses that are ahead.

Ambiguous loss is unlike any other grief process, but it may be common for family and friends caring for a person with dementia. Understanding this concept is an important first step that can help to ease its effects. Strategies and guidance can be provided to help caregivers learn how to live with ambiguous loss, and remain healthy and resilient.

Naming, normalizing and validating grief

The unique kinds of losses and grief experienced by family and friends caring for a person with dementia are often not recognized, acknowledged or understood by the people around them or even themselves.

When grief is not acknowledged or validated, this is known as **disenfranchised grief** and its effects on the caregiver may become more challenging. The lack of acknowldgement makes the grief worse because the person can be in danger of feeling more alone.

Naming the ambiguous loss and grief caregivers feel is a useful first step in the coping and healing process. Healthcare providers and Alzheimer Society staff can help caregivers recognize and understand the source of their grief, and see that it is a normal and valid response for anyone in their situation. Caregivers may no longer feel so alone, knowing that someone is listening to their concerns. Learning strategies about how to live with loss can allow caregivers to grieve as a part of the process of adjusting to loss.

It is helpful for caregivers to talk with professionals and peers, who can acknowledge and validate their losses as well as provide support. This can allow caregivers to start coping, grieving and moving forward in life. Caregivers can then make effective care decisions for the person with dementia, while also taking care of themselves.

"Baring my soul in front of strangers felt right. It was absolutely incredible. All the other people in the support group were going through exactly the same emotions as I was. I could see the grief in their faces and it was just like me."

The many faces of grief

"While there are some commonalities in how people experience grief, there are also many factors that make each individual's experience of grief unique. Sadness is often considered to be the most normal and appropriate expression of grief. But anger, situational depression, irritability, annoyance, intolerance and frustration are also common reactions.

What grieving people need most is permission to grieve in their own style and their own time without being fixed or "hurried" along. They need access to support and honest, accurate information about healthy grief so that they can seek help if they become stuck or overwhelmed."

Strategies for health-care providers

Helping the person with dementia live with losses and grief

A person in the early stages of dementia will likely experience grief over their diagnosis and losses associated with their symptoms. The person also may experience grief over the anticipated losses in:

- Memory
- Cognitive and functional abilities
- Personal independence
- Relationships with others

As their dementia progresses, the person may lose the cognitive ability to understand the losses and grief, but can still have a feeling that something is wrong. These feelings may be expressed through behaviours that suggest inner pain, such as agitation or anxiety.

Caregivers can help and support the person with dementia in dealing with these losses in many different ways, such as:

By focusing on what the person can do at each stage of their dementia, rather than the abilities that have been lost.

By acknowledging the grief and sense of loss felt by the person with dementia. The caregiver can listen with empathy and offer comfort and reassurance without denying or discounting the feelings expressed.

By looking for ways to make meaningful connections with the person each day. Referring caregivers to the Alzheimer Society's information sheet *5 communication tips for conversations with people living with dementia*, available at alzheimer.ca/communication. The sheet will provide them with strategies for how to connect with the person with dementia at every stage.

By sharing their intimate knowledge of the person with dementia – personality, needs, interests, likes, dislikes, favourite activities and life history – with health-care providers so they are better able to support and connect with that person as a unique individual. Encourage the caregiver and the person with dementia to complete the Alzheimer Society's *All About Me* booklet, available at alzheimer.ca/allaboutme. This booklet can be used as a tool for others to get to know the person with dementia better.

CASE STUDY

A support group intervention for caregivers

Support groups can provide caregivers with an opportunity to explore loss and grief issues, identify tools and strategies to help them manage their grief, adapt to changes and build personal strengths and resilience.

"It's important to address grief because it's such a big part of the dementia caregiving picture. If we don't name grief, people can't deal with it. When we name it, the feeling moves to the left side of the brain and people can talk about and process it," says one caregiver grief educator.

When *Satya began attending a support group in her community, she didn't understand that her way of dealing with her mother's dementia was a grief reaction. "I kept thinking I could fix my mother and make her better. I was losing her and trying to find her. I experienced a lot of depression and didn't know why. I had no idea it was grief," she says.

Listening to others in the group, Satya realized she was grieving and came to accept that she could not bring her mother back. "I understood it all a little better. Physically she was my mother, but mentally she was gone. I learned you have to grieve each one of the losses, feel the loss and move on. I decided to let it go and just be with my mother," she says.

Support groups can help caregivers like Satya recognize, understand and deal with their grief, cope with the losses and take better care of their own needs. "It's about hearing the stories, recognizing loss and encouraging exploration of that. People also get to know each other and a strong bond develops. The feedback we get from groups is that the information and support has made them feel powerful."

An evaluation of the effectiveness of one support group, offered by a local Alzheimer Society, found that it significantly reduced caregivers' levels of grief, and increased their ability to cope, sense of empowerment and resilience. It was also found that similar grief coaching interventions delivered individually face-to-face, individually by telephone, in a telephone group and in an online group were just as effective as well.

**The names in this case study have been changed.*

Strategies for health-care providers

Grieving styles and grief reactions

Each person grieves in their own way. But researchers have also observed that caregivers tend to have two distinct grieving styles, known as intuitive grieving and instrumental grieving. Some caregivers may show both styles of grieving. Intuitive grievers "feel" the grief, while instrumental grievers "do" the grief:

Intuitive grievers experience their grief as waves of feeling. They cope by taking time to grieve and sharing their feelings with others. They are more likely to experience and express their grief through:

- Feelings of sadness
- Intense inner pain
- Helplessness
- Hopelessness
- Loneliness
- Guilt
- Anger
- Depression
- Low physical energy
- Tears

Helpful ways to support intuitive grievers include:

- Active listening
- Encouraging them to explore and express their feelings
- Providing insights
- Providing opportunities to connect and share with others in group settings

Instrumental grievers are more likely to experience grief intellectually and physically. They are action-oriented problem-solvers who mentally process what's happening and may be reluctant to talk about their feelings. They may show their grief through:

- Anxiety
- Agitation
- Becoming hyperenergetic
- Immersing themselves in tasks and projects

Effective ways to support instrumental grievers include:

- Giving them practical information
- Encouraging involvement in activities and projects
- Memorializing who and what has been lost
- Talking about the impact of the changes in their situation

Many caregivers blend both of these grieving styles and could benefit from any or all of these supports.

Grieving styles and grief reactions

It's also important to understand that caregivers may show their grief reactions in many different ways. Examples include:

- Sadness
- Anger
- Ambivalence
- Guilt
- Helplessness
- Denial
- Feeling overwhelmed
- Changes in sleeping and eating patterns
- Fatigue
- Anxiety

By recognizing and being sensitive to these varying grief responses, health-care providers and Alzheimer Society staff can more readily offer the support needed when caregivers reach out for help.

Strategies for health-care providers

Grieving the losses at different stages: Healing and support

Grief is a normal and healing response; it is an ongoing process for caregivers throughout the progression of dementia. Caregivers must continually adapt to new events or changes that occur at different stages of dementia and as part of their caregiving role.

It is helpful for caregivers and those who support them to recognize that feelings of loss and grief often become more intense in response to key changes and events. Some common ones that may increase feelings of grief are:

- Noticing symptoms
- Diagnosis of dementia
- Increasing loss of memory and cognitive functioning
- Loss of driving ability and driver's license
- Person with dementia can no longer go out alone
- Person with dementia can no longer be left alone
- Changes in social circle (loss of friendships)
- Changing perceptions of how others view or treat the person
- Need for help with personal care of the person
- Need for outside help in the home
- Need for respite from the caregiving role
- Incontinence of the person
- Moving the person to a long-term care home
- Changes in behaviours
- Increased risk of falls and/or lack of mobility of the person
- Caregiver no longer being recognized by the person with dementia
- Declining health, including increased infections, decreased nutritional intake and/or difficulty swallowing
- Palliative care, the dying process and death
- Period of bereavement and mourning
- Adjustment to the loss of the caregiving role

Health-care providers and Alzheimer Society staff can help caregivers identify, acknowledge and experience these losses, and pay attention to and express their grief in response to these changes. Healing happens when caregivers allow themselves to feel the pain and grieve the losses along the way, rather than avoiding or denying their grief.

"I was losing my mother and trying to find her. The biggest loss was when I realized I could not bring her back. Physically she was my mother, but mentally she was gone. You have to grieve each one of the losses. Just feel the loss and move on."

The psychological family

Many family members can be helpful and offer meaningful support to one another in coping with the losses and grief experienced when caring for a person with dementia. If some people in a caregiver's family aren't able to do that, it may be because they are going through their own grief and loss reactions.

Psychological family is a term you may hear that simply means the people you would turn to in times of crisis and celebration. It's a circle of support that goes beyond someone's biological family.

Consider asking each caregiver to identify the people in their lives who are there for them in good times and bad. These may be individuals who are able to understand the losses and grief the caregiver experiences, acknowledge their remarkable efforts and successes and give vital support.

A caregiver's psychological family can be a diverse group. It might include:

- Friends
- Neighbours
- Co-workers
- Faith leaders
- Family members who "get it"
- Staff at an adult day program, long-term care home or the Alzheimer Society
- A family physician or other health-care provider
- Peers in a support group

Prompting caregivers to think and talk about the people in their psychological family may help them to discover and seek out important sources of support they might not have recognized before. This could start the process for a person who feels like they have little or no support from their biological family to find other ways to get the support they need.

"Talking about the concept of a 'psychological family' helped some group members, who felt they had no support, recognize they had valuable formal supports. One caregiver who thought she had no support discovered she considered the staff at an adult day program an important support. People also talked about the usefulness of the group and included it as part of their psychological family."

Strategies for health-care providers

Paradoxical thinking

The ambiguous loss a caregiver feels is rooted in a deep and painful paradox, an apparent contradiction that is nevertheless true.

Paradoxical thinking (which can also be referred to as "both/and" thinking) is a way for caregivers to explore, and learn to tolerate or live with, the many uncomfortable uncertainties that are a result of dementia. Using paradoxical thinking as a tool can help caregivers begin to make sense of what is happening and their complex feelings. The goal is for them to learn how to hold the paradox and accept two opposing or seemingly contradictory ideas at the same time.

Helping the caregiver practice paradoxical thinking

Instead of believing that their thoughts about loss are either correct or incorrect, encourage the caregiver to accept that many differing thoughts occurring at the same time can still accurately reflect the losses they are feeling.

To make this mindshift, the caregiver can practice thinking about their losses differently by replacing "either/or" thoughts with "both/and" thoughts.

For example, the caregiver can learn to make the shift from thinking that the person with dementia is either alive or has passed away, to realizing that they are both present and not present at the same time. Refer to the chart below for other examples of how a caregiver can practice thinking about their losses differently:

Instead of "either/or"…	**Try "both/and"…**
I can either take care of the person with dementia or myself.	I can take care of both myself and the person with dementia.
I am either the person with dementia's daughter or their caregiver.	I am both the person with dementia's daughter and their caregiver.
I either love the person with dementia exactly as they are now or I miss how they used to be.	I both love the person with dementia exactly as they are now and miss how they used to be.

While supporting families and individuals in grieving the losses and changes dementia brings, Alzheimer Society staff and health-care providers can help them find ways to connect with the person with dementia in a meaningful way.

CASE STUDY

Living with ambiguous loss: A grief support group intervention for caregivers

A counsellor with a local Alzheimer Society office piloted and led a four-week support group that gave caregivers the opportunity to explore their feelings of loss and grief, understand how ambiguous loss differs from ordinary loss, and learn how to ease its effects. "It helped to emphasize that their loss is unlike any other grief process" said the counsellor. "Caregivers were able to get a better understanding of what was going on and feel they were not alone in this. That's the power of the support group dynamic."

"It was helpful to have a diverse group [who were caring for people] at different stages of the [condition]. They could compare their experiences and see different perspectives. People shared the lessons they had already learned and different ways they coped with the changes," the counsellor continued.

Discussing the concept of the "psychological family" helped some group members who felt they had no support recognize they had valuable formal supports, such as staff at an adult day program or the grief support group itself.

Putting the name "ambiguous loss" to what he was feeling was tremendously helpful for a male caregiver in the group. "The word 'ambiguous' helped me understand what was going on. It's a huge loss. I'm still married to my wife. I love her and have depended on her company for 50 years, but she lives somewhere else," he says. "It's terribly lonely when you are by yourself. To be able to talk to other people about it is a godsend."

A daughter was inspired to find other ways to connect with her mother after the group talked about paradoxical thinking in the very first meeting. "I realized that something is lost, but something is not lost. I started to look for things that were still part of my mom. My mom still has her quirky sense of humour – it's just quirkier than it used to be. My goal when I visit her is to get my mom in a good mood and keep her laughing. I can still share a laugh with her and it's made a difference," she says.

Strategies for health-care providers

"I came to the realization that the person I knew, loved and married was gone. I had to accept that and I was left in the role of caregiver. Regardless of what I did, the disease was going to run its course. I had to maintain my physical and mental health through all that. If I allowed myself to be a total wreck, I couldn't provide anything for my wife anymore."

Grieving and caregiving: Easing the stress of a double load

Until recently, health-care providers and researchers have focused mainly on the stress experienced by caregivers in relation to their responsibilities of caring for a person with dementia. Less attention has been paid to the losses and grief felt by caregivers and the potentially negative effects on their health and ability to function.

The evidence clearly indicates, however, that loss and grief are an important part of caregiver stress. Studies also suggest coping with loss and grief may be more challenging and complex than coping with the demands of providing care.

So, it's useful and helpful to distinguish between caregiver grief for the many and ongoing losses, and the stresses felt by caregivers from the demands of caregiving.

Grieving takes energy and caregiving takes energy. Someone caring for a person with dementia is carrying a double load. Caregivers can benefit greatly by addressing and attending to both issues, so neither one is neglected — in doing so, they can relieve some stress.

For example, caregivers are often so involved in their caregiving duties that they may not have an opportunity to grieve their own losses and the losses of the person with dementia, or recognize the need to do so. If that grief isn't acknowledged, expressed or dealt with, it adds to the stresses of caregiving and may eventually affect their ability to care effectively for the person with dementia.

Caregivers should be encouraged to find ways to renew their energy on a regular basis to lessen the risk of burnout and serious stress-related illnesses. Health-care providers and Alzheimer Society staff may help them understand the need to balance the caring role with a life of their own, while also providing support for their losses and grief through an empathetic listening ear, counselling or peer support groups.

Strategies for living positively with ambiguous loss and grief

There are many steps caregivers can take to live positively with their losses and grief while caring for a person with dementia. Educating and informing caregivers about some of these strategies and options may help them cope, adapt and choose how best to live with the reality of dementia:

- ☐ **Reflect** on the losses that occur in the life of the person with dementia and their own lives as well. Acknowledge, express and share the grief they feel in response to those losses with a person or people who will understand and be supportive.
- ☐ **Stay connected** to family and friends, enhance existing relationships, and be open to building new relationships with others who can be supportive and enhance their lives during the loss and grief.
- ☐ **Look after their own needs.** Stay physically active, eat as well as possible and do what they need to do to relieve stress. Take breaks from care. It's vital for their health and morale, and will help them to make better decisions and be more effective as caregivers.
- ☐ **Let their family and friends know how they can help**, rather than assuming people know what they need.
- ☐ **Seek out information about dementia and what to expect.** Talk to others who are caregivers at different stages of the journey. This knowledge gives caregivers more ideas and information about how best to cope with dementia and plan for the future.
- ☐ **Seek out support** from family and friends, professional organizations such as the Alzheimer Society, other professionals and/or support groups.
- ☐ **Share advice** from their own experience and contribute by helping others in a similar situation. Become a volunteer or advocate for people with dementia and their caregivers.
- ☐ **Express grief in creative ways** through writing, painting, photography or other art forms.
- ☐ **Recognize and value their growth as a person**, which resulted from caring for someone with dementia. A caregiver may have learned new skills, such as handling finances, become more compassionate or developed an inner strength and resilience they didn't realize they had.

"My way of dealing with the disease is looking at the cup half full rather than half empty. I look at what my mother can do, instead of what she can't do. I focus on the skills she still has and accept whatever she is able to do."

Strategies for health-care providers

Building resilience, personal strengths and hope

Ambiguous loss and grief are integral parts of the dementia caregiving experience. Understanding and getting support for their grief allows caregivers to move forward by making informed choices and taking actions to build resilience, personal strengths and hope that life can continue in a new way.

To restore energy and balance, despite limited time and resources, caregivers can make a variety of positive self-care choices, such as:

- Staying physically active and eating healthily.
- Remaining mentally active and socially involved.
- Engaging in stress management and relaxation activities.
- Working with their doctor to treat conditions, such as depression.
- Tending to their spiritual health.
- Listening to positive feedback and comments on their personal strengths from supportive friends and family, health-care providers, Alzheimer Society staff or peers in a support group.

Hope can be renewed each time a caregiver makes a positive adjustment to the challenges and changes experienced by the person with dementia and themselves. Caregivers may experience tremendous personal growth by taking on new roles and responsibilities, acquiring new skills and knowledge, building new support networks and finding different ways to connect with the person with dementia.

The profound transformations that occur during loss and grief can give new hope, purpose and meaning to the lives of caregivers.

"Group support and listening to other people's stories is the best type of support. You know you're not alone and you can just let the fears go."

Planning for a life in the future

It is common for caregivers to be so involved in caring for a person with dementia that their own needs are neglected and their lives are put on hold. But if that pattern continues for very long, the caregiver's own health and well-being may suffer, and they may be less able to care for the person with dementia.

One reason for caregivers to regularly make time for themselves is to replenish energy and gain strength to continue the caring role and preserve their own health. It's also important, though often difficult, for caregivers to be realistic about how the condition will affect the person over time and plan for a life on their own after the person with dementia is gone.

Caregivers can be helped in preparing and planning for their future personal and emotional well-being. In addition to legal, estate and financial planning, and making future health and personal care decisions for the person with dementia, caregivers can be encouraged to maintain meaningful relationships with others throughout and beyond the care journey.

If a caregiver loses touch with friends or family while looking after a person with dementia for many years, it may be difficult to restore those relationships and they may feel a huge void long after the person is gone.

Caregivers can be encouraged to reach out and spend time with friends and family, and make new friends through the different losses and stages of dementia. These vital social and human connections will help them to be more resilient and lay the foundation for life to continue in a fulfilling new way in the future.

"If you spend all your time with that person and neglect your own life, there is going to be a void when she's gone."

Ambiguous Loss and Grief

What you can do to help caregivers cope: Tips and strategies

- ☐ **Help caregivers find creative ways to engage** with the person with dementia, despite their grief. Every person, regardless of their abilities, maintains a core of self that can be reached.
- ☐ **Help caregivers understand** how the ambiguous loss and grief they may experience in caring for a person with dementia is different than the loss and grief of death.
- ☐ **Name, normalize and validate their grief,** which is often not acknowledged or supported.
- ☐ **Educate and engage caregivers** in effective ways of managing loss and grief through discussion, resource materials, workshops and referrals to support services.
- ☐ **Support caregivers** by gently probing and inviting them to talk about loss and grief issues once a rapport has been established.
- ☐ **Look for opportunities in peer support groups** to introduce and explore loss and grief experiences as a difficult, but critical issue for caregivers.
- ☐ **Set up a dedicated peer support group** with a local Alzheimer Society office to help caregivers live with ambiguous loss and grief.
- ☐ **Ask caregivers to identify** the people in their life who are there for them in good times and bad, and encourage them to reach out to their circle of family or friends for support.
- ☐ **Encourage caregivers to ease the double load** of caregiving and grieving by getting breaks from care and taking time for grieving.
- ☐ **Offer suggestions** to help caregivers look after their own needs and wellness by staying physically active, eating well, relieving stress, drawing on their spirituality and taking breaks from care.
- ☐ **Be aware of different grieving styles,** such as intuitive and instrumental, and help caregivers see that each family member or friend may have their own grieving style.
- ☐ **Be sensitive to a wide range of caregiver grief reactions,** including sadness, anger, anxiety, ambivalence, guilt, denial and helplessness.
- ☐ **Help caregivers understand** that certain events and stages, such as moving a person with dementia to a long-term care home or the person not being able to recognize family members, often trigger more intense grief.
- ☐ **Acknowledge and affirm caregivers' strengths,** success and resilience in coping with losses and adapting to changes.
- ☐ **Encourage caregivers to think about preparing and planning** for a life in the future by nurturing meaningful relationships and making new connections.

Resources

Adams, K. B., & Sanders, S. (2004). Alzheimer's caregiver differences in experience of loss, grief reactions and depressive symptoms across stage of disease: A mixed-method analysis. Dementia (London, England), 3(2), 195–210. https://doi.org/10.1177/1471301204042337

BrainXchange. (2013, Nov 6). Ambiguous loss and grief [Video]. https://vimeo.com/78838766

Boss, Pauline. (2000). Ambiguous loss: Learning to live with unresolved grief. Harvard University Press.

Boss, Pauline. (2006). Loss, trauma and resilience. W.W. Norton & Company.

Boss, Pauline. (2011). Loving someone who has dementia: How to find hope while coping with stress and grief. John Wiley & Sons.

Schlegel-UW Research Institute for Aging. Living and transforming with loss & grief: An inspirational guide for persons with early stage memory loss and their partners in care. A By Us For Us Guide. https://the-ria.ca/resources/by-us-for-us-guides/

Horst, Glen. (2017). Grief in times of celebration: The empty spot. Canadian Virtual Hospice. www.virtualhospice.ca/griefintimesofcelebration

Meuser, T. M., & Meuser S. J. (2001). A comprehensive, stage-sensitive model of grief in dementia caregiving. The Gerontologist, 41(5), 658-670. https://doi.org/10.1093/geront/41.5.658

Noyes, B. B., Hill, R. D., Hicken, B. L., Luptak, M., Rupper, R., Dailey, N. K., & Bair, B. D. (2010). Review: The Role of Grief in Dementia Caregiving. American Journal of Alzheimer's Disease & Other Dementias, 25(1), 9–17. https://doi.org/10.1177/1533317509333902

Island Health. Dementia. https://www.islandhealth.ca/learn-about-health/seniors/dementia

Where can I get further information?

Please refer to the following resources available from your local Alzheimer Society and alzheimer.ca.

Progression series:

Overview
Early stage
Middle stage
Late stage
End of life

Day-to-day series:

Communication
Personal care
Meal times
Moving to long-term care series

Conversations About:

Decision-making
Living alone
Intimacy and sexuality
Driving

Other helpful resources:

All about me
Ambiguous loss and grief in dementia: A resource for individuals and families
Dementia and staff grief

Note: This publication provides guidance but is not intended to replace the advice of a health-care provider. Consult your health-care provider about changes in the person's condition, or if you have questions or concerns.

Alzheimer *Society*

Alzheimer Society of Canada
20 Eglinton Avenue West, 16th Floor Toronto, Ontario M4R 1K8
National Office: 1-800-616-8816 Information and Referrals: 1-855-705-4636 (INFO)
info@alzheimer.ca alzheimer.ca
@AlzheimerCanada @AlzCanada @AlzheimerCanada

Charitable registration number: 11878 4925 RR0001