Alzheimer Society

AMBIGUOUS LOSS AND GRIEF IN DEMENTIA

A resource for individuals and families

"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."

The Alzheimer Society is the 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 www.alzheimer.ca

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Alzheimer *Society*

Ambiguous loss and grief in dementia: A resource for individuals and families

This resource is meant primarily to help you, as a caregiver, gain a better understanding of how loss and grief can affect you and the person with dementia. It also provides valuable information to help people with dementia deal with their own losses and grief, and live as well as possible with the disease. In addition, you will find useful strategies and tips to:

- Help you cope with multiple losses and grief
- Stay connected to the person with dementia
- Remain healthy and resilient through the progression of the disease

Loss and grief are among the most significant and challenging issues you will face as a caregiver when supporting a person with dementia. Dementia is a fatal, progressive and degenerative disease that destroys brain cells. Whether you are caring for your spouse, your parent or a friend with dementia, you may experience losses and grief in different ways at all stages in the dementia caregiving journey.

As a caregiver, you may grieve:

- The loss of your dreams and plans for the future
- The loss of a confidant and partner
- The loss of shared roles and responsibilities
- The progressive losses in the life of the person with dementia

The ambiguous loss that you may feel caring for a person with dementia can make the caregiving experience even harder. Fortunately, understanding loss and grief can help to ease the effects of the disease.

Acknowledgement: A sincere “thank you” goes to the caregivers and people with dementia whose lived experience is reflected in the stories and quotes used throughout this booklet. Please note that the names included in the stories have been changed.

Ambiguous loss & grief in dementia

What is ambiguous loss? Why is it important?

Ambiguous loss is a 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.

This is very different from the loss and grief of sudden death, as an example, where you clearly know that the person is gone. With a death, you are more likely to get support from family and friends, and may eventually find closure through traditional mourning rituals and the natural grieving process.

Ambiguous loss complicates grief. It may be hard for you to recognize this grief or know how to grieve when the abilities of the person with dementia have changed.

Grief can be frozen and it can put your life on hold. If you don't allow yourself to grieve or resume some of your regular activities, coping may be harder as the disease progresses.

Ambiguous loss also confuses relationships and can prevent moving on. For example, you may feel as if you are no longer in a marital relationship if your spouse no longer knows who you are. Yet your spouse, regardless of their abilities, is still a whole person who can be reached at all stages of the disease.

Recognizing these feelings and understanding the concept of ambiguous loss can help to ease the effects. With guidance and support, you can work through these feelings, begin to grieve the losses and stay connected to the person with dementia while also building your own strength and resilience.

Normalizing and acceptance

Whether you are caring for your spouse, your parent or a friend with dementia, the unique kinds of losses and grief you may feel are often not recognized, acknowledged or understood by the people around you. If your grief isn't acknowledged or understood by others, it only adds to your grief and you can feel more alone.

Naming your feelings and talking about them with healthcare providers, Alzheimer Society staff or other caregivers can help you understand your losses and grief, and see that this is a normal and valid response to a disease that changes the person over a period of time.

You may no longer feel so alone knowing someone is truly listening to and acknowledging your concerns. Talking with knowledgeable professionals, or peers in a support group going through a similar experience, gives you opportunities to learn strategies for coping and living with the losses.

Reaching out for support in these ways can also help both the caregiver and the person with dementia to grieve. Adjusting to loss and accepting the disease can help both of you move forward to make the changes needed to live as well as possible with dementia.

"My husband has been open about his disease all along, so everybody knows. Because he's open about it, I tell people too and that helps me. If you think about Alzheimer's like any other disease, there shouldn't be a stigma. I had breast cancer. He has Alzheimer's disease and we're dealing with it. He decided he could either accept it or get in a funk."

"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."

*André’s story

Living with losses: sharing makes it easier for a person with dementia

André felt as if his world had ended when he was first diagnosed with dementia. “In one hour, you can go from being independent to feeling very dependent,” he says. But his conversations with a supportive geriatric nurse helped André to see the future more positively.

“A diagnosis is not the end of things. I didn’t like the idea of giving up and I decided that wasn’t going to happen. There is life after dementia and I’m living as productive a life as possible. I enjoy gardening and taking the dog for long walks alone, which was a concern for my family,” says André, who now carries a phone with a GPS tracker so he can continue one of his favourite activities independently and safely.

Joining an Alzheimer Society support group also helped André to cope with his feelings of loss and grief. “You have to adapt and accept the changes in your life, which is hard. Those group meetings helped me through some rough patches. We need one another for support. Sharing with other people makes it easier and we can build on each other’s knowledge,” he says.

It is normal to feel a sense of loss and grief when you are diagnosed with dementia. There is also ambiguity and uncertainty about how the disease will progress, whether slowly or quickly, and how it will affect your relationships with family and friends, your daily life and plans for the future.

Talking openly with family, friends, healthcare providers, Alzheimer Society staff or peers in a support group about your fears, feelings and concerns is a useful first step that can help to normalize the feelings people have about the disease.

**The names in this story have been changed*

Helping the person with dementia live with losses and grief

A person in the early stages of dementia will likely experience their own range of emotions, including grief over the diagnosis and the losses associated with their symptoms. The person may grieve the anticipated:

- Losses in memory
- Problems with thinking
- Changes in their ability to do things
- Loss of personal independence
- Changes in their relationships with others

In the early stages, encourage the person to talk openly about their fears and express their wishes about how they would like to live well with dementia. Planning for the future, while the person is still able to express their wishes and desires, gives the person with dementia some control over their life at a time when they might be feeling helpless.

Knowing the person's wishes will also help you later to make decisions on their behalf that reflect their values, beliefs and preferences. For more information about how to support the person with dementia in decision-making, refer to the Alzheimer Society's information sheet *Decision-Making: Respecting Individual Choice*, available at www.alzheimer.ca/brochures.

Strategies to help the person with dementia live with losses and grief

As the disease progresses, the person with dementia may not be able to understand or express the losses and grief they are experiencing but still may have a general feeling that something is wrong. Their grief may be expressed through feelings of being anxious or agitated.

You can support the person with dementia in dealing with these losses in many different ways:

Focus on what the person can do at each stage of the disease, rather than the abilities that have been lost.

Acknowledge their grief. Listen with empathy and offer comfort and reassurance without denying or discounting their expressed feelings.

Look for ways to make meaningful connections with the person each day. For tips on connecting with the person at every stage of the disease, see the Alzheimer Society's information sheet on *Communication*, available at www.alzheimer.ca/communication.

Share your intimate knowledge of the person with dementia – personality, needs, interests, likes, dislikes, favourite activities and life history – with any staff providing care so they are better able to support and connect with that person as a unique individual. The Alzheimer Society's *All About Me* booklet, available at www.alzheimer.ca/allaboutme, is a helpful resource for recording this information.

Grieving the losses along the way

Grieving is a normal and healing response to loss.

The loss and grief you experience caring for a person with dementia is ongoing: not a one-time trauma, like the sudden death of a family member or friend. As changes occur, it can be helpful to identify and acknowledge the losses, and turn to your circle of support to talk about your grief in response to these events. Some changes that may lead to feelings of grief might include:

- Losses in memory and cognitive function
- Loss of a driver's license
- The loss of being able to travel together
- The need for outside help in the home
- The move to a long-term care home
- Palliative care, dying process and death
- Adjustment to the loss of the caregiving role

Healing happens when you allow yourself to feel the pain and grieve the losses along the way, rather than avoiding or denying your grief. You can then move on and adapt to these losses by making positive changes to enhance the quality of life for the person with dementia while taking care of your own needs too.

> **"I miss my best friend. My wife has always been my best friend. We used to be able to share our joys, our concerns, our hopes and our dreams with each other. We were great sounding boards for each other as we dealt with our jobs, our children and our lives. Now I have no one with whom to share my concerns – yes, I can talk to the children, and some of my friends, but it's not the same as talking something over with someone you know as intimately as your spouse."**

*Satya's story:

When Satya began attending a grief 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.

**The names in this story have been changed*

Grieving styles

Each person grieves losses in their own way. Some caregivers are more likely to experience and express their grief through feelings like:

- Sadness
- Hopelessness
- Loneliness
- Anger
- Guilt

If your style of grieving is "**feeling**" it may help to:

- Share your feelings with a supportive audience
- Join a peer support group

Other caregivers are more likely to experience and express grief through their thoughts and actions. If your style of grieving is "**doing**" it may help to:

- Get practical information
- Find solutions to problems
- Do things for yourself and the person with dementia

Many caregivers blend these "feeling" and "doing" grieving styles, and can benefit from any or all of these strategies for coping and adapting to losses.

> **"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."**

*Kurt and *June's story:

Making changes and adapting to the losses

When Kurt was diagnosed with young onset Alzheimer's disease, he and his wife June talked about the changes they should be making in their lives. Although Kurt was still able to drive, they decided to sell their house and move to a condominium in the city before he had to give up his license. "Even though I do drive, I don't like to and I'm also aging. We moved before he started to decline and now live in an area where we can walk almost anywhere. It's been a godsend," she says.

June and Kurt fulfilled their retirement dream of travelling to Europe, even though it was a different kind of trip than she had envisioned. "Travelling wasn't easy. We would have split the responsibilities in the past. I had to take care of everything and keep track of him. But we did it," she says.

They still exercise together, go to social groups with old friends, and host a drop-in brunch every week for their children and grandchildren. "I keep as much of the old relationship alive as I can by doing some of the things we always did. The connection between us is changed, but I keep it going," says June.

She also recognizes the importance of balancing care for her husband and herself. "I try to keep a life for myself. I go curling one day a week in the winter. I sing in a choir and I go to lunch with friends," says June. "We have had some wonderful years since Kurt's been diagnosed and we're living our lives as fully with Alzheimer's as we can."

**The names in this story have been changed*

Reaching out to your circle of support

Seeking out support is one of the most positive and powerful ways of dealing with the feelings of ambiguous loss and grief that come with caring for your spouse, your parent or a friend with dementia. There are many ways to do this.

Many families are able to help and offer meaningful support to one another to cope with their losses and share their grief. Sometimes, however, they are going through their own grief and loss reactions and are not able to provide support to others.

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 the individuals who may be able to understand the losses and grief you are experiencing, 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
- Faith leaders
- Family members who "get it"
- Staff at an adult day program, long-term care home or your local Alzheimer Society
- A geriatrician, family doctor or other healthcare provider

Joining a peer support group gives you a unique opportunity to talk about feelings of ambiguous loss and grief, and share lessons learned with people going through many of the same experiences as you.

Getting one-on-one counselling and support from Alzheimer Society staff or healthcare providers can also help you understand and grieve the losses, and learn how to ease their effects.

"My husband and I go regularly to a young onset support group. The huge benefit is you make connections with other people like you. We've made friends in the group and we get together with them socially. That's the best support."

Ambiguous loss & grief in dementia

Try thinking about your losses differently

With ambiguous loss, it is common to have what may seem like contradictory thoughts about the losses you are experiencing. This can be stressful because these thoughts often stir up mixed feelings and highlight the many uncertainties that surround dementia. Fortunately, to help cope with ambiguous loss, you can learn how to handle thoughts about loss that seem contradictory.

Try this tip

Recognize that what may at first seem like contradictory thoughts about loss are not necessarily contradictory. Do this by shifting the way you think about ambiguous loss.

Instead of believing that your thoughts about loss are either correct or incorrect, accept that many differing thoughts can occur at the same time and still accurately reflect the losses you are feeling. This shift in thinking can help you continue to connect to the person with dementia in a meaningful way.

To make this mindshift, practice changing how you view the losses you are experiencing by replacing "either/or" thoughts with "both/and" thoughts (this is sometimes referred to as "paradoxical thinking"). For example:

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.

Check out this tip in action

Here's how a daughter taking care of her mom started to look at ambiguous loss differently:

> **"Something is lost, but something is not lost. So I started to look for things that were still part of my mom. She still has a sense of humour and I can still share a laugh with her. She still has an emotional part of her, so I zero in on the emotion of the event because it's on a level where she gets it."**

Next steps

Work with Alzheimer Society staff, healthcare providers or others in your support network to practice this shift in thinking.

Building resilience and planning for the future

Resilience is the remarkable quality that helps an individual to adapt positively to challenges and changes in life, and the losses and grief experienced in caring for a person with dementia.

There are many things you can do to boost your resilience:

- Reach out for support and work with your doctor to treat conditions such as depression.
- Stay physically active and eat a healthy diet.
- Remain mentally active and socially involved.
- Try stress management and relaxation activities like yoga, meditation or Tai Chi.
- Take regular breaks from caregiving responsibilities.
- Listen to positive feedback on your personal strengths from supportive friends and family, healthcare providers, Alzheimer Society staff or peers in a support group.
- Find ways to stay connected to the person with dementia as they are today.
- Maintain and nurture meaningful relationships with friends and family, and make new friends too.
- Though it is difficult, it is also important to be realistic about how the disease will affect the person over time. You need to plan for a life on your own after the person with dementia is gone.

> **"I knew this was happening and I knew it wasn't going to change. You have to figure out what you need and what gets you through things. I'll go to the market and have tea with a friend.**
>
> **Other people have lost friends through this process. I know how much I will need friends later."**

Strategies for living positively with ambiguous loss and grief

There are many steps you can take to live positively with your losses and grief while caring for someone with dementia:

☑ **Reflect** on the losses that occur in the life of the person with dementia and your own life too. Acknowledge, express and share the grief you feel in response to those losses with a person or people whom you know will understand and be supportive.

☑ **Normalize** and begin to accept your feelings of ambiguous loss and grief by talking to other caregivers who feel the same emotions and go through a similar experience, as well as Alzheimer Society staff who support people with dementia and their caregivers.

☑ **Stay connected** to family and friends. Strengthen existing relationships, and be open to building new relationships with others who can be supportive and enhance your life amid the loss and grief.

☑ **Look after your own needs.** Stay physically active, eat as well as possible, and do what you need to relieve stress. Take breaks from care. These things will boost your health and morale, and help you to make better decisions and be more effective as a caregiver.

☑ **Let your family and friends know how they can help**, rather than assuming people know what you 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 you more ideas and information about how best to cope with the disease and plan for the future.

☑ **Seek out support** from family and friends, professional organizations such as the Alzheimer Society, a professional counsellor, and/or participate in support groups.

☑ **Share** your own experience and contribute by helping others in a similar situation.

☑ **Get involved and volunteer** with your local Alzheimer Society. Learn how to advocate for your own needs and the needs of your family member or friend with the disease.

☑ **Express grief in creative ways** through writing, painting, photography or other art forms.

☑ **Recognize and value your growth as a person**, which resulted from caring for a family member with dementia. You may have learned new skills, such as handling finances, become more compassionate, or developed an inner strength and resilience you didn't realize you 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."

Resources

1. Alzheimer Society of Canada, *Grieving*. Available at www.alzheimer.ca/grief
2. Alzheimer Society, *Ambiguous Loss and Grief: A resource for healthcare providers.* Available at www.alzheimer.ca/brochures
3. Boss, Pauline, *Ambiguous Loss: Learning to live with unresolved grief.* Harvard University Press, 2000. Book.
4. Boss, Pauline, *Loving Someone Who Has Dementia: How to find hope while coping with stress and grief.* John Wiley & Sons, 2011. Book.
5. Boss, Pauline, *The Ambiguous Loss of Dementia: Finding meaning and hope.* 2009. DVD.
6. Murray Alzheimer Research and Education Program, *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. Available at www.the-ria.ca/by-us-for-us-guides
7. Horst, Glen. *Grief in times of celebration: The empty spot.* 2017. Available at www.virtualhospice.ca/griefintimesofcelebration
8. Vancouver Island Health Authority, *Grief, Loss and Dementia: Caregivers share their journeys.* DVD, 2011 and supporting documents CD (Workbook for Dementia Caregivers, A Quick Guide for Family Caregivers, and A Quick Guide for Professional Caregivers).
9. www.mygrief.ca - a website developed by grief experts designed to help users understand and work through their grief.

Where can I get further information?

Please refer to the following resources available from your local Alzheimer Society and also at www.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
All about me: A conversation starter

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

Alzheimer *Society*

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Charitable registration number: 11878 4925 RR0001