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."
– A male caregiver in Toronto

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.

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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 provides valuable information as well 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 the multiple losses and grief, and stay connected to the person with dementia while remaining 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, and 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.

People with dementia are likely to have feelings of loss and grief too. This can be a result of their diagnosis and through the progression of the disease, as their own abilities gradually change. In this information sheet, you will learn how you can support them in living with these losses in various ways.

Ambiguous loss is different from the loss and grief of death because closure is not possible and your grief cannot be fully resolved while the person with dementia is alive. But this ambiguity and the mixed feelings that it can stir up are a common and expected experience for caregivers of people with dementia. Fortunately, understanding loss and grief can help to ease the effects of the disease.

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. Family and friends may not recognize your need to grieve the many losses you experience at different stages of the disease and therefore not provide you with the support you need in your ongoing caregiver role.

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

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

While it may be common for family members caring for a person with dementia to experience ambiguous loss, this type of grief is often not recognized or well understood by family caregivers.

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.

"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." *– A male caregiver in Toronto*

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 health-care providers, Alzheimer Society staff or other caregivers can help you to understand your losses and grief, and see that this is a normal and valid response.

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.

"Fred 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. Fred decided he could either accept this or get in a funk." – *Ann West, a caregiver in Halifax*

"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." – *M., a female caregiver in Toronto*

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

Wayne Eaker felt as if his world had ended when he was first diagnosed with dementia at 64. "In one hour, you can go from being independent to feeling very dependent," he says. But his conversations with a supportive geriatric nurse helped Wayne 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 wife and kids," says Wayne, 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 for men with dementia in Edmonton also helped Wayne 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 and natural 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, health care 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. Knowing you're not alone – and that caring people are listening -- makes acceptance easier. You can then move forward and make plans for the future, expressing your wishes about the life you want to lead with dementia.

Helping the person with dementia live with losses and grief

A person in the early stages of dementia will likely experience his own range of emotions including grief over the diagnosis and the losses associated with his symptoms. The person also may grieve the anticipated losses in memory, thinking, and ability to do things, personal independence and relationships with others.

In the early stages, encourage the person to talk openly about his fears and express his wishes about how he would like to live well with dementia. Planning for the future, while the person is still able to express his wishes and desires, gives the person with dementia some control over his life at a time when he might be feeling helpless. Knowing the person's wishes will also help you later to make decisions on his behalf that reflect his values, beliefs and preferences.

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

You can help and support the person with dementia in dealing with these losses in many different ways. First, focus on what the person can do at each stage of the disease, rather than the abilities that have been lost. Encouraging and allowing the person to do what he enjoys and is able to do – whether it be helping to prepare a meal, painting, telling stories or playing with children – can help keep the person engaged in daily activities and ease his sense of loss, contributing to his quality of life.

When supporting someone with dementia, show you understand the feelings of loss the person may express about declining abilities. You can listen with empathy, and offer comfort and reassurance without denying or discounting his expressed feelings. The person with dementia may need to have his grieving acknowledged by others and expressed just as you do.

Look for ways to make meaningful connections with the person each day. Focus on today rather than trying to find or bring back the person he was before the disease. Staying connected gives the person meaningful support that can ease his distress. As the symptoms progress over time, the person will be less able to express his thoughts and concerns. There are still ways to connect to the person and show your support, such as holding his hands, using a reassuring tone of voice.

It's also important to 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.

"You have to put the person you knew behind you and make a relationship with the person who is in front of you." – *Prue Teagle, a caregiver in Toronto*

"I try to keep as much of the old relationship alive as I can by doing some things together that we always did. But I also have to direct the relationship because my husband is less able to initiate things. The connection between us is changed, but I keep it going." – *Ann West, a caregiver in Halifax*

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. From the time you first notice symptoms the person with dementia will experience many losses and changes to her abilities. (Please see page 8 in "Ambiguous loss and grief: a resource for health-care providers" at **http://www.alzheimer.ca/~/media/Files/national/For-HCP/for_hcp_ambiguous_loss_e.ashx** for more information on common changes that may stir up grief.)

As these changes occur – losses in memory and thinking ability, loss of a driver's license, the loss of being able to travel together, the need for outside help in the home and the move to a care home – 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.

Paradoxically, 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.

Each person grieves a loss or losses in her own way. Some caregivers are more likely to experience and express their grief through feelings like sadness, hopelessness, loneliness, anger, and guilt. Sharing and airing these emotions with a supportive audience can be especially helpful if your style of grieving is "feeling."

Other caregivers are more likely to experience and express grief through their thoughts and actions. Getting practical information, finding solutions to problems and doing things for yourself and the person with dementia can be particularly helpful if your style of grieving is "doing."

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. *– Katherine Murray, hospice palliative care nurse educator and thanatologist with Life and Death Matters in British Columbia*

"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." *– A caregiver in British Columbia*

Case Study

Making changes and adapting to the losses

When Fred West was diagnosed with early onset Alzheimer's disease, he and his wife Ann talked about the changes they should be making in their lives. Although Fred was still able to drive, they decided to sell their house and move to a condominium in the centre of Halifax 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.

Ann and Fred fulfilled their retirement dream of travelling to Italy, 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 a wine group with old friends, and host a drop-in brunch every Sunday 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 Ann.

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 Anne. "We have had some wonderful years since Fred's been diagnosed and we're living our lives as fully with Alzheimer's as we can."

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. Those 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, faith leaders, and those family members who "get it." 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 through various stages of the journey.

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. The Alzheimer Society of Toronto, for example, has held support groups for caregivers focused specifically on ambiguous loss.

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

No matter what your family situation may be, you don't have to be alone. Your circle of support can help to give you the motivation and resilience for coping with the many losses felt as the disease progresses and moving forward.

Case Study

When Marilyn Preston began attending the Coping with Transitions Support Group*, 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 Marilyn 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.

** This pilot project for the Alzheimer Society of B.C. was funded by the Vancouver Island Health Authority and the Alzheimer Society Grant to Improve Dementia Care in B.C., provided by the Ministry of Health Services.*

"My husband and I go regularly to an early 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." – *Tanis Eaker, a care partner in Edmonton*

Paradoxical Thinking

The ambiguous loss you may feel as a caregiver is rooted in a profound and painful paradox, an apparent contradiction that is true. The person with dementia is physically present, but often psychologically absent. Your spouse, parent, sibling or friend with the disease is here, but unable to understand, respond or react in the same way as before. You miss and grieve their ability to connect in this moment and time.

Paradoxical thinking is a way for you to explore and learn to live with the many ambiguities of the disease. You may feel married and not married to your spouse with dementia. Even though a parent is always a parent, you can feel like both a daughter and a parent to your father.

You may love the family member with dementia deeply and feel hurt that he doesn't seem to know who you are. You want the person with dementia to live as long as possible, yet wish for his pain to end. These ambiguities are normal for the disease but can cause confusion, stir up mixed emotions and make you feel uncomfortable.

Using paradoxical thinking as a tool can help you begin to make sense of what is happening and these complex feelings. Your goal is to learn how to recognize and understand the paradox, and accept two opposing or seemingly contradictory ideas at the same time.

As the abilities of the person with dementia change with the progression of the disease, your roles and responsibilities as caregiver also change. Instead of holding onto the past, it is better to acknowledge the present and adapt to the changing needs of your spouse, parent or friend with dementia.

Learning to live with these ambiguities is a balancing act. You can shift from thinking that the person with dementia is either alive or has passed away to realizing that he is both present and not present at the same time. Instead of believing and feeling that either the needs of the person with dementia or your needs must be put first, you see that both sets of needs are important.

Every person with dementia is a whole person and, regardless of his abilities, connecting with the person is still possible at all stages of the disease. What a person says or does and how a person behaves has meaning. But dementia affects his ability to communicate with us in a way that we can always understand.

Alzheimer Society staff and health care providers can support you in grieving the losses and changes the disease brings, and also help you find ways to connect with the core of self in the person with dementia that can still be reached.

"It's a paradox. Something is lost, but something is not lost. So I started to look for things that were still part of my mom. My mom 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. She may forget my name, but she knows who I am."
– M., a female caregiver in Toronto

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 in a healthy way. 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, health-care providers, Alzheimer Society staff, or peers in a support group. This can be a powerful confidence and morale booster.
- Find ways to stay connected to the person with dementia as she is today. Adapt to the losses in that relationship by maintaining and nurturing meaningful relationships with friends and family, and make new friends too. It's also important, though often difficult, 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.
- Vital social and human connections will help you to be stronger, more resilient and hopeful through the different losses and stages of the disease. They help 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." – *M., a female caregiver in Toronto*

"Fred and I do yoga routines five days a week when we get up. We go to Elder Aerobics at the Y, which is social and keeps your brain healthy. We stay in touch with old friends and have a bunch of little adventures in life. It makes us feel like we're still alive and not just sitting around waiting to die." – *Ann West, a caregiver in Halifax*

"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." – *Tanis Eaker, a care partner in Edmonton*

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 visual 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." – *Sharon, a caregiver in Toronto*

Resources

In addition to the resources below, this publication on Ambiguous Loss and Grief includes information from health and social care providers, people with dementia, and caregivers of people with dementia.

1. Alzheimer Society of Canada, "Grieving," **http://www.alzheimer.ca/en/Living-with-dementia/Grieving**.
2. Alzheimer Society, "Ambiguous Loss and Grief: A resource for health-care providers," **http://www.alzheimer.ca/~/media/Files/national/For-HCP/for_hcp_ambiguous_loss_e.ashx**.
3. Alzheimer Society Toronto, "The Ambiguous Loss of Dementia: Finding Meaning and Hope," Pauline Boss, September 2009, DVD.
4. Boss, Pauline, "The trauma and complicated grief of ambiguous loss," *Pastoral Psychology*," vol 59, 2010, 137-145.
5. By Us for Us Guide, *Living and Transforming with Loss & Grief: An inspirational guide for persons with early-stage memory loss and their partners in care,* Murray Alzheimer Research and Education Program, University of Waterloo, 2009.
6. Horst, Glen, Canadian Virtual Hospice, "Grief in times of celebration: the empty spot," **http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Emotional+Health/Grief+in+Times+of+Celebration_+The+Empty+Spot.aspx**.
7. 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).

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

Other dementias:

Creutzfeldt-Jakob disease
Lewy body dementia and Pick's disease
Frontotemporal dementia
Vascular dementia
Down syndrome

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

Alzheimer *Society*

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