



AMBIGUOUS LOSS AND GRIEF

A resource 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." – Betty Anderson, caregiver grief educator and developer of "Coping with Transitions in Dementia Caregiving" education series and support group

Ambiguous loss and grief: a resource 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 in the dementia caregiving journey.

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

Family caregivers also experience and grieve the loss of their dreams and expected plans for the future, the loss of a confidant and a partner, the loss of shared roles and responsibilities, and 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 add to the confusion and make coping more difficult through the progression of the disease.

Ambiguous loss differs from the loss and grief of death because closure is not possible and grief cannot be fully resolved until the person with dementia dies. The person with dementia is present, but not as before. Yet that person, regardless of their abilities, still maintains a core of self that can be reached at all stages of the disease.

These issues of loss and grief are often not recognized or well understood by family caregivers, or the health-care providers with whom they interact.

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 family caregivers. It will also give them useful strategies to assist families with their multiple losses and grief, and help caregivers to stay connected with the person with dementia while also building their own strength and resilience through the progression of the disease.

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 here, but not present in the same way as before.

This is very different from the loss and grief of sudden death, as an 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 aspects of the person with dementia are lost, but aspects remain. Family and friends may not recognize the caregiver's need to grieve the many losses at different stages of the disease and receive support while the person with dementia is alive.

Ambiguous loss confuses relationships and prevents moving on. A spouse may feel as if they are no longer in a marital relationship if their partner no longer knows who they are. Caregivers may feel like they are living in a limbo of uncertainty, unable to fully grieve or resolve the losses that have already occurred while anticipating other losses that lie ahead.

So it is important to help families and individuals recognize and understand the feelings of ambiguous loss and work through them with the help of Alzheimer Society staff or other health-care providers, and to help caregivers find creative ways to engage with the person with dementia.

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

"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

Ambiguous loss & grief

Naming, normalizing and validating grief

The unique kinds of losses and grief experienced by family members caring for a person with dementia are often not recognized, acknowledged or understood by the people around them or even the caregivers themselves. When the grief is not acknowledged or validated, this is known as “disenfranchised grief” and its effects on the caregiver may become more debilitating. The lack of acknowledgement compounds the grief because the person is 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. Health care providers and Alzheimer Society staff can in this way help caregivers to recognize and understand the source of their distress, 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, others go through a similar experience and can learn strategies for living with the losses, allowing themselves to grieve as part of the process of adjusting to loss.

Talking with professionals and peers who can acknowledge and validate their losses, and provide support, allows family caregivers to begin the process of coping, grieving and moving forward to make the changes needed to provide effective care for their family member 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.” - M., a female caregiver in Toronto

The many faces of grief

“Grief is a natural, subjective and often complex response to a person’s perceived loss. 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 that may be exacerbated by sleep deprivation, ongoing changes in lifestyle and roles, the challenges of caregiving, and/or the fear of separation and the unknown.

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

Helping the person with dementia live with losses and grief

A person in the early stages of dementia will likely experience grief over the diagnosis and losses associated with the symptoms. The person also may experience grief over the losses anticipated to come in memory, cognitive and functional abilities, personal independence and relationships with others.

As the disease progresses, the person may lose the cognitive ability to understand the losses and grief but still have a generalized feeling that something is wrong. These feelings may be expressed through behaviours that indicate 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. First, it is important for caregivers to focus in a positive way on what the person can do at each stage of the disease, as opposed to the abilities that have been lost. Encouraging and allowing the person to do what they enjoy and are able to do – whether it be helping to prepare a meal, painting, telling stories or playing with children – can make a world of difference in alleviating the sense of loss. This adds to the person’s quality of life each day, and helps the person to maintain confidence and a sense of self.

When supporting someone with dementia, it’s also important to validate feelings of loss the person may express about declining abilities. The caregiver can listen with empathy, and offer comfort and reassurance without denying or discounting the feelings expressed. The person with dementia may need to have their grieving acknowledged and expressed just as the caregiver does.

Caregivers can look for ways to connect with the person as they are today, rather than trying to find or bring back the person they were before the disease. Staying connected gives the person meaningful support that can alleviate distress. As verbal communication declines in the middle and later stages, caregivers can use non-verbal means, such as holding the person’s hand or using the sound and tone of their voice, to connect and allow the person to feel their affection and reassurance.

Family caregivers can also share their intimate knowledge of the person with dementia – personality, needs, interests, likes, dislikes, favourite activities and life histories – with professional caregivers in care homes and day programs so they are better able to support and connect with that person as a unique individual.

Case Study

Coping with Transitions in Dementia Caregiving: Dimensions of Loss and Grief

A support group intervention for family caregivers

All family caregivers will be grieving the losses experienced by the person with dementia and in their own lives. But many caregivers may not be aware they are grieving or may not know how to cope with the losses and deal with their grief reactions in response to these changes.

Coping with Transitions in Dementia Caregiving: Dimensions of Loss and Grief is a six-part education series and support group intervention offered to family caregivers by the Alzheimer Society of B.C. in Victoria and Nanaimo on Vancouver Island. This innovative program gives caregivers an opportunity to explore loss and grief issues, and 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 caregiver grief educator Betty Anderson, who developed *Coping with Transitions* as a pilot project* for the Alzheimer Society of B.C. in 2009 and has led 16 of these groups.

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.

The *Coping with Transitions* support group has helped caregivers like Marilyn to recognize, understand and deal with their grief, cope with the losses and take better care of their own needs. “Each group has a life of its own and magic happens. It’s about hearing the stories, recognizing loss and encouraging exploration of that. The feedback we get from groups is that the information and support has made them feel powerful,” says Betty. “Of the 16 groups I’ve been involved with, 15 have gone on to continue meeting on their own. People get to know each other and a strong bond develops.”

An evaluation of the support group intervention’s effectiveness by University of Victoria and Vancouver Island Health Authority researchers found that it significantly reduced caregivers’ levels of grief, and increased their ability to cope, sense of empowerment and resilience. The researchers 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 as effective as well.

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

Grieving styles and grief reactions

Each person grieves a loss or losses 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. And some caregivers may show both styles of grieving.

Intuitive grievers experience their grief as waves of feeling. They are more likely to experience and express feelings of sadness, intense inner pain, helplessness, hopelessness and loneliness. Guilt, anger, depression, low physical energy and tears are also some of the ways they show their grief. They cope by taking time to grieve and sharing feelings with others.

- Helpful ways to support intuitive grievers are through active listening, encouraging them to explore and express their feelings, providing insights, and opportunities to connect and share with others in groups.

Instrumental grievers are more likely to experience grief intellectually and physically. They are action-oriented, problem-solvers, who mentally process what's happening and are reluctant to talk about their feelings. They may show their grief by becoming anxious, agitated or hyperenergetic, rather than depressed and listless, and immerse themselves in tasks and projects.

- Effective ways to support instrumental grievers are by giving them practical information, encouraging involvement in activities and projects, memorializing who and what has been lost, and talking about the impact of the changes in their situation.

Intuitive grievers “feel” the grief, while instrumental grievers “do” the grief.

These are guidelines only and many caregivers could benefit from any or all of these supports.

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 and 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 family caregivers reach out for help.

Ambiguous loss & grief

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 the disease. Family caregivers must continually adapt to new events or changes that occur at different stages of the disease 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 stir up 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 no longer can go out alone
- Person can no longer be left alone
- Change in social circle (loss of friendships)
- Perception of how others view or treat the person living with dementia
- Help with personal care needed
- Need for outside help in the home
- Need for respite
- Incontinence
- Move to a care home
- Aggressive or embarrassing behaviours
- Increased risk of falls, lack of mobility
- Caregiver no longer recognized by the person with dementia
- Declining health including more infections, less nutritional intake, difficulty swallowing
- Palliative care, 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 family caregivers to identify, acknowledge and experience these losses, and pay attention to and express their grief in response to these changes. Paradoxically, 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." - Marilyn Preston, a caregiver in Victoria

The Psychological Family

Many families are able to be helpful and offer meaningful support to one another in coping with the losses and grief experienced in caring for a person with dementia. If some people in a caregiver's family aren't able to do that, it may be that 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 the caregiver's biological family.

Consider asking each caregiver to identify the people in their lives who are there for them in good times and bad. Those individuals who may be 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, and those family members who "get it." Health and social care providers at an adult day program, care home, a family physician, peers in a support group, or Alzheimer Society staff can also become part of the caregiver's psychological family through various stages of the journey.

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 be the catalyst 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.

No matter what a caregiver's family situation may be, the person need not be alone. Everyone has someone they can turn to, if they reflect on it and are encouraged to reach out. The psychological family can help provide caregivers with the motivation and resilience for coping with the many losses felt as the disease progresses. This is a vital resource caregivers can turn to for support in grieving and moving forward.

"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." - Christine Leskovar, Alzheimer Society of Toronto counsellor and leader of a Living with Ambiguous Loss support group

Ambiguous loss & grief

Paradoxical Thinking

The ambiguous loss a family caregiver feels is rooted in a profound and painful paradox. The person with dementia is physically present, but often psychologically absent. The spouse, parent, sibling or friend with the disease is here, but not present in the same way as before.

Paradoxical thinking is a way for caregivers to explore, and learn to tolerate or live with, the many uncomfortable ambiguities that arise out of the disease. The caregiving spouse may feel married and not married to her husband. The caregiver daughter can feel like both a daughter and a parent to her father – even though a parent is always a parent.

The person with dementia has needs and the family member caring for that person has needs. The caregiver may love the family member with dementia deeply and that person doesn't appear to know who the caregiver is. The caregiver wants the person to live as long as possible, yet wants the pain to end.

Using paradoxical thinking as a tool can help family members 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.

For example, the caregiver learns to make the shift from thinking that the person with dementia is either alive or has passed away to realizing that the person 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 the needs of the caregiver must take priority, the caregiver sees that both sets of needs are important.

Every person with dementia is a whole person and, regardless of their 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; however, dementia affects their ability to communicate with us in a way that we can always understand.

While supporting families and individuals in grieving the losses and changes the disease brings, Alzheimer Society staff and health-care providers can help them find ways to connect with a core of self in the person with dementia that can 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

Case Study

Living with Ambiguous Loss

A grief support group intervention for family caregivers

Family members caring for a person with dementia may experience ongoing stress and grief due to the ambiguous loss of having a family member physically present, but often psychologically absent.

Christine Leskovar, a counsellor with the Alzheimer Society of Toronto, piloted and led a four-week support group that gave family caregivers the opportunity to explore their feelings, 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. 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," says Christine.

The group included spouses and children of people with dementia, and both male and female caregivers. "It was helpful to have a diverse group at different stages of the disease. 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," explains Christine.

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 quirrier 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.

Ambiguous loss & grief

Grieving and caregiving: easing the stress of a double load

Until recently, health care providers and researchers have focused mainly on the stresses and burden experienced by family 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 family caregivers and the potentially debilitating 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 actually 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. A family member 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, and in doing so will relieve some stress.

For example, family members are often so involved in their caregiving duties that they may not have an opportunity or recognize the need to grieve their own losses and the losses of the person with dementia. 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.

Family caregivers should be encouraged to find ways to replenish 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 giving caregivers support for their losses and grief through an empathetic listening ear, counselling or peer support groups.

"I came to the realization that the Karen 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 Karen anymore." - Ernie Morgan, a caregiver in Prince Albert, Saskatchewan

How caregivers can benefit from understanding and managing grief

The ambiguous losses and grief that family caregivers experience along the dementia journey are different and in many ways more challenging than the grief felt when the person dies. Because the person with dementia is physically here, but aspects of the person are lost, the grief is more complicated.

The caregiver may not receive the acknowledgement or support for their grief expected from family and friends, or in some cases realize that they are grieving. There is not the finality or closure of death, and some caregivers may be unable to address or express their grief while looking after the person and anticipating other losses that lie ahead.

Pauline Boss, the author of *Ambiguous Loss*, calls this a state of “frozen grief.” When a caregiver’s grief isn’t acknowledged, supported or expressed, grief becomes disabling and its effects may worsen with each successive loss. The caregiver may become immobilized, confused, at risk for physical and mental health problems, and less able to support the person with dementia or function effectively in daily life.

By naming, exploring, understanding, expressing and getting support for their grief, caregivers are better able to cope with and adapt to their own losses and the losses of the person with dementia. Addressing and dealing with their grief makes it more manageable and less frightening.

Caregivers learn to accept that grieving is part of the healing process, and that allowing themselves to feel the pain is healthier in the long run than trying to deny the fear, anger, sadness, resentment, loneliness or other emotions they may be experiencing in reaction to the losses.

Sharing their grief and connecting with others helps caregivers find the strength and resilience to continue providing care while taking care of their own health too. They realize they’re not alone and can turn to others for help when they need it.

After grieving the losses, caregivers may be more accepting of the changes that have occurred and look for ways to connect with the person with dementia as they are today instead of trying to bring back the person as she was before the disease.

Change, loss and grief are all part of the dementia caregiving journey. Helping family caregivers to understand and manage loss and grief issues is essential for their future health and well-being.

“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.” - Betty Anderson, caregiver grief educator and developer of “Coping with Transitions in Dementia Caregiving” education series and support group

Ambiguous loss & grief

Strategies for living positively with ambiguous loss and grief

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

- **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 whom they know 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 amid the loss and grief.
- **Look after their own needs.** Stay physically active, eat as well as possible, and do what they need 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 the disease and plan for the future.
- **Seek out support** from family and friends, professional organizations such as the Alzheimer Society, other professionals, and/or participate in 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 a family member with dementia. A caregiver may have learned new skills, such as handling finances, become more compassionate, or developed an inner strength and resilience the person didn't realize she 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

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 and changes. Stay physically active and eat healthily. Remain mentally active and socially involved. Engage in stress management and relaxation activities. Work with their doctor to treat conditions such as depression, and tend to their spiritual health. Any one or even better a combination of these elements can have a major impact in boosting the caregiver's overall wellness and resilience.

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 also can be a powerful confidence and morale booster.

Hope can be renewed each time a caregiver makes a positive adjustment to the challenges and changes in the person with dementia and their own situation. 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 a person with dementia.

The profound transformations that occur amid the losses and grief can give rise to new hope, purpose and meaning in 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.” - Marilyn Preston, a caregiver in Victoria

Ambiguous loss & grief

Planning for a life in the future

It is common for family caregivers to be so involved in caring for a person with dementia that their own needs are neglected and their lives 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. But it's also important, though difficult, for caregivers to be realistic about how the disease will affect the person over time and plan for a life on their own after the person with dementia is gone.

Family 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 choices relating to future health and personal care decisions for the person with dementia, caregivers can be encouraged to find ways to maintain and nurture meaningful relationships with the people in their lives through and beyond the care journey.

If, during the continuum, a caregiver loses touch with friends or family while looking after a person with dementia for many years, it may be difficult to rekindle 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 the disease. 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." - M., a female caregiver in Toronto

Ambiguous Loss and Grief

What you can do to help family caregivers cope: tips and strategies

- Help family 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 family caregivers** in effective ways of managing loss and grief through discussion, with resource materials, workshops and referrals to support services.
- Encourage caregivers to stay connected** to family and friends, and be open to building new relationships with others who can be supportive.
- 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** to help family caregivers live with ambiguous loss and grief in a local Alzheimer Society chapter.
- 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 attending to both, getting breaks from care and taking time for grieving.
- Offer suggestions** to help caregivers to look after their own needs and wellness by staying physically active, eating well, relieving stress, drawing on their spirituality, and taking breaks from care.
- Encourage caregivers to connect** with the person with dementia as they are today. Staying connected can ease distress for both the caregiver and the person with dementia.
- Be aware of different grieving styles**, such as intuitive and instrumental, and help caregivers see that each family member 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 care home or 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** a life in the future, by nurturing meaningful relationships and making new connections.

Ambiguous loss & grief

Resources

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

1. Adams, Kathryn, Sanders, Sara, "Alzheimer's caregiver differences in experience of loss, grief reactions and depressive symptoms across stage of disease," *Dementia*, vol 3(2), 2004, 195-210.
2. Alzheimer Society of Canada, "Grieving," www.alzheimer.ca/en/Living-with-dementia/Grieving.
3. Alzheimer Society of Toronto, "The Ambiguous Loss of Dementia: Finding Meaning and Hope," Pauline Boss, September 2009, DVD.
4. Betz, Gabrielle, Thorngren, Jill, "Ambiguous loss and the family grieving process," *The Family Journal: Counseling and Therapy for Couples and Families*, vol 14(4), October 2006, 359-365.
5. Boss, Pauline, *Ambiguous Loss: Learning to live with unresolved grief*, Harvard University Press, 1999.
6. Boss, Pauline, "Ambiguous loss: living with frozen grief," *The Harvard Mental Health Letter*, November 1999, 4-6.
7. Boss, Pauline, *Loss, Trauma and Resilience*, W.W. Norton & Company, 2006.
8. Boss, Pauline, "The trauma and complicated grief of ambiguous loss," *Pastoral Psychology*, vol 59, 2010, 137-145.
9. 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.
10. Doka, Kenneth, Grief, multiple loss and dementia, *Bereavement Care*, vol 29 (3), 2010, 15-20.
11. Frank, Jacquelyn, "Evidence for grief as the major barrier faced by Alzheimer caregivers: a qualitative analysis," *American Journal of Alzheimer's Disease and Other Dementias*, vol 22, December 2007/January 2008, 516-527.
12. Grief, Cindy, Myran, David, "Bereavement in cognitively impaired older adults: case series and clinical considerations," *Journal of Geriatric Psychiatric Neurology*, vol 19, 2006, 209-215.
13. Haley, William, Bergman, Elizabeth, Roth, David, McVie Theresa, Gaugler, Joseph, Mittelman, Mary, "Long-term effects of bereavement and caregiver intervention on dementia caregiver depressive symptoms," *The Gerontologist*, vol 48 (6), 732-740.
14. Horst, Glen, Canadian Virtual Hospice, "Grief in times of celebration: the empty spot," www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Emotional+Health/Grief+in+Times+of+Celebration_+The+Empty+Spot.aspx.
15. Meuser, Thomas, Marwit, Samuel, "A comprehensive, stage-sensitive model of grief in dementia caregiving," *The Gerontologist*, vol 41, October 2001, 658-670.

16. Noyes, Brigg, Hill, Robert, Hicken, Bret, Luptak, Marilyn, Rupper, Randall, Dailey, Nancy, Blair, Byron, "The role of grief in dementia caregiving," *American Journal of Alzheimer's Disease and Other Dementias*, vol 25 (1), February 2010, 9-17.
17. Rentz, Clarissa, Krikorian, Robert, Keys, Michael, "Grief and mourning from the perspective of the person with a dementing illness: beginning the dialogue," *Omega*, vol 50(3) 2004-2005, 165-179.
18. Silverberg, Eleanor, "Applying the 3-A grief intervention approach to nursing home placement: Acknowledge, Assess and Assist," *Canadian Nursing Home*, vol 22 (2), June 2011, 22-25.
19. Silverberg, Eleanor, "Introducing the 3-A grief intervention model for dementia caregivers: acknowledge, assess and assist," *Omega*, vol 54(3) 2006-2007, 215-235.
20. 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.

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