



DEMENTIA AND STAFF GRIEF

A resource for healthcare providers

"The residents are very active in programs, we have a lot of fun together and a special bond develops. When a resident passes away, it gets stuck in my mind for a while. If I want to cry, I'm going to cry."

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*

About this booklet

Grief and loss support for staff in dementia care: A resource for health and social care providers

This resource is meant to help you and your organization gain a better understanding of:

- The multiple losses experienced by staff caring for people with dementia across the continuum of care
- How staff members can be effectively supported in managing their loss and grief when clients¹ are dying and after their deaths, transitioning out of a program or to another level of care

In this booklet, you will find:



Information about grief, how it can affect staff and care, and how to manage it



Useful **ideas and strategies** that can be put into practice to support staff in coping with loss and grief



Positive self-care strategies and **tips**

Acknowledgement: We would like to extend a sincere “thank you” to the researchers and healthcare providers, including staff from Bloomington Cove Care Community, the Alzheimer Society of York Region, Broadmead Care and Bethammi Nursing Home, who informed this resource and whose lived experience is reflected in the case studies and quotes used throughout this booklet. Please note that the names included in the booklet’s case studies have been changed.

¹ The term “client” is used to refer to all persons served, regardless of setting.

Dementia and staff grief

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What is grief?

Grief is the emotional, psychological and physical reaction to death or loss. It is a healthy, natural reaction.

When a client in the community or in a long-term care home moves or dies, staff members feel the loss of the relationship they had with that person. They also frequently experience a loss of the relationship with that person's family and friends.

Everyone experiences grief differently and each staff member may have a different reaction to the loss or death of the person. This grief may cause a range of emotions. Some common emotions include:

- Anger
- Sadness
- Depression
- Loneliness
- Hopelessness
- Numbness

Why is the issue of staff loss and grief important?

Staff often form close attachments to the clients they care for, as well as the families² they support. Yet it is sometimes assumed that somehow healthcare providers are immune to grief – and that the impact of death and their grief reactions will lessen as they witness death more frequently.

However, when grief is not acknowledged, expressed or supported, the effects of grief add up rather than lessen with each accumulated loss.

As staff face multiple deaths and losses, it is crucial for employers to provide them with education and support in managing their grief. The benefits that result can include:

- Improved quality and consistency of care for clients and their families
- Increased staff retention
- Higher staff morale and cohesiveness

“Grief is not only around death. It’s around the changes that staff see in clients. Loss is a huge thing and they feel it when a client leaves a day program and goes into long-term care.”

² The term “family” includes anyone in the supportive network of people with dementia.

Dementia and staff grief

The impact of unattended grief on staff and quality of care

Grief is often felt by healthcare providers when a client with dementia dies. However, the loss and grief experienced by healthcare providers is frequently not recognized, acknowledged or supported.

This **unattended grief** and a lack of support in managing grief can take a heavy toll on caregiving staff, leading to **compassion fatigue**. When there are multiple losses and grief is not addressed, the risk of compassion fatigue and staff burnout increases.

Healthcare providers can experience **disenfranchised grief** in the workplace. Staff may feel it is inappropriate or unprofessional to express their own emotional response to a client's death. Yet they are called upon to support the families and friends of the person who has died with no acknowledgement that the death is a loss for them as well.

Unattended grief: unresolved grief that has never been given a chance to heal.

Compassion fatigue: physical, emotional and spiritual exhaustion that can affect the ability to feel and care for others.

Disenfranchised grief: a loss that is not openly acknowledged, socially validated or publicly observed.³

What are the potential consequences of unattended grief?

The costs to employers can be steep if they do not provide support for staff to manage and acknowledge their grief when a client dies. Unattended grief can:

- Negatively affect the efficiency and quality of care provided
- Increase staff turnover and absences
- Reduce staff morale and teamwork
- Result in staff shortages
- Compromise the long-term physical and emotional health of staff members

The organizational culture and environment also influence how staff experience loss and grief when a client dies. When the process of dying and death is not acknowledged in appropriate ways and there is a silent culture around dying, the lack of openness can impact end-of-life care and how staff and families respond to grief.

What are the potential benefits of acknowledging and supporting staff grief?

It's important for organizations to "enfranchise" the normal grieving process for healthcare providers caring for people with dementia by allowing them the space to grieve openly. Long-term care homes and community agencies need to let staff know that it is "okay" to appropriately express their personal and professional response to the death of a client.

By providing grief support to staff, management may:

- Promote healthy behaviours and attitudes towards dying
- Improve the quality of palliative and end-of-life care
- Boost staff morale
- Increase staff retention
- Decrease staff shortages

³ Doka, Kenneth, *Disenfranchised grief – Recognizing hidden sorrow*, Lexington Books, 1989.

Grief support for staff is essential to person-centred care

What is person-centred care?

Person-centred care means recognizing that individuals have unique:

- Values
- Personal history
- Strengths and abilities
- Personality

Person-centred care recognizes that each person has an equal right to:

- Dignity
- Participate fully in their environment
- Respect

The ultimate goal of person-centred care is to create partnerships among people with dementia, staff and families that will lead to the best outcomes and enhance the quality of life and the quality of care for the person with the disease.

Refer to the following Alzheimer Society resources for more information on person-centred care:

- PC P.E.A.R.L.S.® – available at www.alzheimer.ca/pcpearls
- Guidelines for Care – available at www.alzheimer.ca/guidelinesforcare

Why grief support matters in person-centred care

By treating staff in the person-centred way they hope will be used in client care, leaders in long-term care and community agencies can model a person-centred approach.

It is essential for employers to recognize and acknowledge the emotional impact that a client's death can have on staff members. Education and supportive strategies can help staff to manage their grief and find closure after a client dies. Examples of supportive strategies can include:

- Formal or informal debriefings
- Peer support gatherings
- A pause for reflection and reminiscing
- Counselling
- Memorial rituals or services

“Staff need to know it’s okay to grieve. All you are revealing is that you’re human. Families are often moved when they see from staff that their loved one is cared for deeply.”

Dementia and staff grief

The impact of unattended grief on person-centred care

How can person-centred care affect the grief experience?

When providing person-centred care, staff often develop close relationships with clients and their families. With caring, comes the pain of loss. Staff need emotional support as they experience their own emotional reactions to the decline of clients and their eventual death.

Below, a staff member speaks to how they struggled with their grief when a resident they had a close relationship with died:

“I remember one of my favourite residents had died and the next day that I worked, another man was in his bed. I had such a hard time knowing he would not be there, let alone looking at someone else in that bed. These people become like family to us; and with some, it’s as if we just lost a grandparent or parent. Then it was like he did not even exist. Not a fingerprint left.”

What impact can this have on staff?

If a death is not acknowledged in an appropriate way and staff haven’t been prepared for loss, staff members are left to cope individually with their losses and may suppress their natural grief reactions after a client dies. As a coping mechanism, staff may learn to emotionally distance themselves from clients when a client is dying or a death occurs, without grieving their loss or finding closure. The reality of their work is they have to continue to provide quality care to other clients, often without the advantage of taking the time to grieve.

Avoidance of pain is a normal human self-protection mechanism; if care hurts and there is no relief or support, the danger is that staff may consciously or unconsciously put up emotional barriers to maintain distance from the other clients they are caring for.

What can be done to address unattended grief?

Staff education in palliative and end-of-life care, along with support to manage their loss and grief, can improve staff morale and workplace wellness. Staff who feel supported are more likely to develop the emotional resilience needed to provide person-centred care to clients, and their families, at all stages of the disease.

Refer to the following pages of this booklet to learn more about strategies you can use to support staff in their grief.

“Death can happen in spurts and these periods are much more difficult for staff. They want to put up an emotional barrier, knowing they are affected. When you’re trying to shut down emotionally, it can have an impact on the care you give.”

Educating staff in a palliative approach enhances care and supports their emotional health

Dementia is recognized as a life-limiting condition. Education and training in palliative and end-of-life care can give staff from multiple disciplines increased understanding and the confidence needed to provide person-centred care to people with dementia through the end of life.

A palliative approach to care

The goal of palliative care is to provide clients with:

- Comfort
- Quality of life
- Dignity
- Pain control

Palliative care is a holistic approach which can be adopted as early as possible in the course of the disease and is not limited to the very last days or weeks of life.

Education and training in palliative and end-of-life care teach staff what they can do to improve the quality of living and dying for people with dementia and to minimize unnecessary pain and suffering. Staff learn strategies and skills to facilitate a comfortable death by providing:

- Effective pain and symptom management
- Hands-on care to alleviate distress and discomfort
- Psychological, emotional, spiritual and cultural support for clients and their families

Please see the End of life information sheet in the *Progression* series at www.alzheimer.ca/stages for more information on some common changes and possible strategies for end-of-life care.

Introduce end-of-life education early

Job orientation is a good time to prepare new staff in long-term care homes and community agencies with the knowledge that death is common and that grief is a normal response to loss. It's also important to give staff information about the support and resources available to them when experiencing grief after a client dies, including employee assistance programs (EAP) or local counselling services.

The benefits of palliative and end-of-life education for staff

Education in a person-centred, palliative approach to care should also prepare staff to deal with the stress and feelings of loss and grief they may experience while the person is dying and after death, emphasizing the importance and value of taking time to grieve and caring for their own needs.

Providing care and support that makes a real difference in the quality of living and dying for clients with dementia and their families can also help staff members to accept their feelings of loss and achieve meaningful closure.

"If you have more education, it will help get you prepared for the resident's death. The experience is more positive for you when you can provide the end-of-life care the resident and family want."

CASE STUDY

A palliative approach to caring for people with late-stage dementia

The *Canary Lodge, a long-term care home where about 225 residents live, was inspired to develop an innovative staff education program by noting the recent changes in both the characteristics of residents and the care environment. The proportion of residents with dementia has increased, the average length of stay has shortened and a greater number of residents with dementia are dying in the home each year.

"We recognized that while people are coming to Canary Lodge to live, they are also coming here to die. The goal of the program is to increase the capacity of our staff to provide excellent care through to death by applying palliative principles and focusing on issues that are unique to caring for people who are dying with dementia," says *Yulia, a social worker and facilitator of the workshop.

More than 150 staff members have taken this specialized training in palliative and end-of-life care for clients with dementia. An evaluation of the program's effectiveness found that staff members reported an increased understanding and acceptance of the dying process and death, which has translated into reduced stress both for themselves and family members.

As a result of the training program, there is more discussion of advanced care planning with family members during the admission process and more care conferences are called for clients who are in their last days, weeks or months. Staff members feel increased pride in doing a good job as a team when supporting residents and their family members during the dying process, so that residents in their care experience comfort, dignity and warmth in their final days.

**While this case study is based on an actual Canadian long-term care home, the names included have been changed.*

Valuing what you do in end-of-life care

Valuing what you do in caring for a client with dementia and supporting family members is an important strategy for making sense and finding meaning out of loss. It allows you to step back and gain perspective on your role and vital contributions.

This process of affirmation, through personal reflection or sharing with your peers, can help to reduce the stress and resolve the grief you may experience after a client you have cared for dies. Some strategies may include:

- **Recognize** the contributions you made to enhance the person's experience, comfort, dignity, warmth and feelings of being at home while dying.
- **Value** the compassionate care you provided to reduce pain, alleviate distress and discomfort, and offer that person social, emotional and spiritual support.
- **Acknowledge** your contributions in helping the family to make important decisions about and participate in the care of the person, supporting family members during the dying process, and helping the family to say goodbye.
- **Reflect** on the rewards you received through caring for that person over many weeks, months or years, adding quality to that individual's life, sharing the person's past and being a valuable part of the person's "present".

As you experience the pain of loss, you may gain strength by finding meaning and satisfaction in your role and contributions as a healthcare provider. What you do makes a difference in giving each client with dementia the best day possible through the end of life, and in remembering the person after they are gone.

"I do the personal and daily care. You get to know how the residents feel and you try to comfort the person the best that you can. There are times when they want you to sit on the bed and give them a hug. It feels good to do that. You feel you are doing something special for that person."

"We have a role to play in contributing to a good death. What we do now in the person's final days lives on in the memories of the families, which is powerful. Appreciating that we do make a difference can help with the feelings of loss."

Dementia and staff grief

Honouring and remembering the person after death

How an organization chooses to recognize the death of a client — or does not, if death is not appropriately acknowledged and a silent culture exists around dying — can make a huge difference in supporting staff loss and grief.

A workplace culture that recognizes and actively supports staff grief establishes meaningful rituals and protocols that are activated during the dying process and after the client dies. These activities give staff opportunities to honour and remember that person.

Here are a number of strategies that have been successfully implemented in a variety of settings to help staff manage their loss and grief. Consider some options that may be right for you and your organization:

- **Perform** a ritual when the person dies such as placing a silk rose on the bed, opening the window, or coming together in the room to say a prayer or blessing.
- **Institute** a ritual to honour the body. For example, place a special Dignity Quilt over the stretcher just before the body is removed from the room. Some residents and family members, management, staff and volunteers could form an honour guard which accompanies the body to the front door, where a moment of silence or a short prayer is offered, before the body leaves the home.
- **Put** a placemat with a blue butterfly symbol at the table setting of a deceased resident for three meals after the person's death, which acknowledges to others that the person will be missed and is in our thoughts.
- **Recognize** the loss of each client by placing a photograph of the person or flowers in an appropriate place in the long-term care home or community program.
- **Provide** "grief boxes" with relaxation or spiritual CDs, literature, photos, and sympathy cards, which staff and residents can sign and then send to families.
- **Support** the attendance of staff who wish to go to the funeral or memorial service, subject to permission from the family.
- **Hold** regular memorial services, or celebrations of life, that are open to families, friends, residents and staff who wish to attend.
- **Create** a memory book and honour those who have died with photos, letters or notes from staff, residents, family members and friends who want to contribute a message of remembrance.
- **Invite** a staff member who was particularly close to that person to write a paragraph or an article for a staff newsletter.
- **Display** a memory tree, with branches where the names of deceased clients can be printed on leaves, in an area visible to staff and residents.

"When Evelyn died, I did not attend the funeral. Her son brought in a basket of plants to thank the staff. I brought home a plant and it's grown into a tree. That was 14 years ago. It's a memento of that particular lady. She has a soft spot in my heart."

What employers can do to support staff in managing loss and grief

There are a number of strategies long-term care homes and agencies in the community can adopt to support staff in managing their loss and grief after a client dies. Many of these strategies are effective and inexpensive, and can apply to small or large organizations:



Formal and informal grief support programs and initiatives provide staff with the opportunity to openly discuss and work through their feelings of loss with support from their peers.



Job orientation can prepare new staff with knowledge about death in the workplace, normal and expected emotional responses to clients dying, and the grief support available to them.



Specialized education and training enable staff to increase their skills and gain confidence in providing the best possible palliative and end-of-life care for clients and their families, and can assist staff in managing their own loss and grief in healthy ways.



Rituals and ceremonies to honour and remember the person who has died are other important ways in which employers can support staff grief and provide a meaningful opportunity for staff to acknowledge their loss and find closure.

Examples of best practices for each of these strategies will be outlined and described in the sections that follow.

“It is important for management to acknowledge the impact a resident’s death has on staff members. Checking in with the staff who were working at the time of the death to see if they are alright and asking if they need grief support is a supportive measure staff recognize and appreciate.”

Dementia and staff grief

Peer support strategies to help manage grief and improve care

Peer support can be a powerful and effective way for staff to manage loss and grief after a client dies. Staff members often look to one another for support. The opportunity to talk amongst one another as a group — sharing stories and memories of the person, and thoughts or feelings of loss — can be comforting and provide a healthy emotional release.

Healthcare providers who participate in **bereavement debriefing sessions** are better able to manage their grief and this type of support can reduce staff turnover. Peer-led debriefings have been used effectively for grief support in hospices and long-term care homes. Routine peer-led debriefings can improve overall workplace wellness, and reduce staff stress and absenteeism.

Examples of peer support strategies can include:

Informal peer support:

- This can be as simple as the opportunity for staff to recount stories and feelings of loss during a daily team huddle.
- Co-workers from an adult day program might talk in the kitchen, reminiscing and expressing feelings of sadness after a client with dementia has died.

The organizational culture:

- Leaders can support the healthy grieving process amongst peers by allowing and encouraging staff to gather after the death of a client, and asking staff members how they are doing.
- Staff members need to feel comfortable talking openly about death and their emotional reactions in a supportive, non-judgmental way.

Peer-led debriefings, also known as sharing circles:

- This is one way to formalize a peer support process for staff members after a client dies.
- These sessions can be led by a staff member who provides direct care for clients, such as a personal support worker. Their personal experience and training, related to workplace grief, can help guide peers through the grief process.
- Ideally, the sharing circle leader is someone who is widely respected by their peers, not in a supervisory role, and sensitive to the needs of all group members.
- Sharing circles give staff members an opportunity to reflect on their thoughts and feelings about that person through a guided process involving questions and discussion.

“Staff say the most beneficial form of support often comes from their own peers. The relationships established with co-workers can be comforting and there is credibility in the experience of peers who have been working in the long-term care setting for a long time. Having an opportunity to reminisce amongst one another about a resident who has died gives staff an opportunity for closure.”

“Each shift has a team huddle every day and everyone goes to the huddle. That is a built-in forum for staff to talk about their feelings for a resident who has passed away in an atmosphere where grief is acknowledged and supported. People will express their feelings more readily in an informal setting than in a formal one. All homes could very easily do this.”

- Staff members are encouraged to recount details, emotions and reactions to the person's death, share information, and through this process, gain validation for their feelings.
- These sessions also help the staff by allowing for a review of what went well in the provision of end-of-life care and what could be improved upon.

CASE STUDY

*Oakwood Valley Long-Term Care Home

Peer-led debriefings offer meaningful grief support for direct care staff

*Nala, a personal support worker at Oakwood Valley Long-Term Care Home, remembers how difficult it was for staff emotionally when a resident died and there was no organized process in place to support their grief.

"Most of us did not have much taught to us about death or the dying process. Our perception of death was just give the care, give them your time, your love, watch them die, and move on to the next person. There was no time to stop and talk about the person. No time to grieve and no way to say goodbye," she says.

That is not how it is today.

For the past two years, Nala has led and been a champion of debriefings for staff – also known as sharing circles or celebrations of life – after a resident dies. These gatherings are usually held within a few hours of the person's death and towards the end of a shift, when most tasks have already been completed. Staff members from all disciplines and roles are welcome to attend.

Debriefing is a time for staff to reflect and support each other. "We gather in a quiet room and we talk about the resident, wondering if we were able to help them attain all their wishes. We reminisce about the person and what they meant to us. We all have our stories and special moments to share," says Nala. "Having the support of management is crucial to making this work. They understand the importance of having closure for staff."

The peer-led debriefings were developed and implemented as a result of Oakwood Valley's participation in a long-term research project with a local university.

"It's been very powerful to see how the staff support each other after the loss of a resident. The debriefings have also given the front-line staff at Oakwood Valley increased confidence they are doing good work at the end of life," says the research project manager.

The training that personal support worker *Jayan received through the project to become a debriefing facilitator changed his perspective on caring for people who are dying. "I came to understand in a deeper way the importance of end-of-life care. The care the residents receive in their final days becomes more significant than anything else," he says.

Jayan calls the debriefings he leads at Oakwood Valley celebrations of life. "When a resident passes, we all come together. Some people are quiet, some shed tears, and there is also laughter, as we share comical memories. Even though you're just talking to your fellow workers, it's therapeutic and this has a positive effect on the team bond," says Jayan.

**While this case study is based on an actual Canadian long-term care home, the names included have been changed.*











Dementia and staff grief

Strategies to support grief and loss in the workplace

Self-care strategies for staff: Taking the time to look after yourself

Using self-care strategies to help cope with your loss and grief can positively contribute to your physical and emotional well-being. These strategies can also help renew or strengthen your capacity to function effectively in your role as a caregiver, and your ability to invest in relationships with new clients and their families.












What you can do:

-  **Acknowledge your grief** and recognize that it is a normal reaction to loss. Pay attention to your feelings and be aware of how you are responding to the loss.
-  **Talk informally to the co-workers** you feel most comfortable with to share your grief experience. Reminiscing about the client who has died and expressing your feelings can help you resolve grief.
-  **Seek out support** by asking for a formal debriefing session with a supervisor or a team of co-workers, or by meeting with a professional counsellor. Reach out to others, especially if you provide care in the community and tend to work in isolation. Ask for and seek out opportunities to meet with your peers to talk through your feelings and be listened to without judgement.
-  **Practice relaxation techniques**, such as tai chi, yoga or meditation, which can provide the mind and body with restfulness, calmness and a sense of well-being. Go for a long walk outside or listen to a relaxation CD.
-  **Exercise, eat well**, and do what you need to relieve stress. These basic self-care strategies can boost your health, mood and energy level.
-  **Take time out** for yourself from work, if needed, to help resolve grief. By preventing even greater symptoms of distress, this can help you return to your normal capacity sooner.
-  **Advocate and suggest ideas** for developing a peer support program, or other staff grief support initiatives, at the agency or long-term care home where you work.
-  **Ask to attend the funeral** or memorial service, if you feel you would like to and the family gives permission.
-  **Contribute to a book of memories** or write an article for a staff newsletter remembering the client.
-  **Recognize your positive contributions** to the quality of life of the client who has died, that person's family and your team of co-workers. Reflect on the rewards that you received through caring for that person.

Strategies to support grief and loss in the workplace - *continued*

Employer strategies: Supporting staff effectively

There are many steps that employers can take to support staff in managing the loss and grief experienced when a client dies:

-  **Orient** new staff with the knowledge that death is common in long-term care and community agency settings, and provide information on the grief support programs and resources available to them.
-  **Educate** and train staff in the palliative approach to care, including strategies and skills to provide pain control and emotional support to clients through the end of life.
-  **Support** staff participation in peer led debriefings, or sharing circles, after the loss of a client, which could be held near the end of a shift when tasks have been completed.
-  **Ensure** there are procedures in place to inform off duty staff that a client they have been caring for has died.
-  **Check in** with staff members who were working at the time of death to see how they are doing, if they need grief support and what type of support would be most helpful.
-  **Post** information on grief support offered through employee assistance programs (EAPs) or local counselling resources in the staff room and in other appropriate spots in the long-term care home or community agency.
-  **Provide opportunities** for home care workers to meet with their peers, or managers, to talk through their feelings, and to attend funerals or memorial services.
-  **Encourage** open discussion, reflection and sharing of information in staff meetings about best practices in caring for clients during the dying process.
-  **Convene care conferences** involving staff and family members for clients who are actively dying, to clarify the optimal goals of care in keeping with the person's wishes.
-  **Say "goodbye"** through rituals such as the placing of a silk rose on the bed, the use of dignity robes instead of a shroud, or an honour guard to accompany the deceased person's body through the front door upon leaving the home.
-  **Honour and remember** each client who has died by creating a book of memories or a memory tree. Hold regular memorial services open to families, residents and staff who wish to attend.

Dementia and staff grief

Additional Resources

www.alzheimer.ca/ambiguousloss - this resource explores the concept of ambiguous loss – a type of loss that happens when the person with dementia is physically present, but not in the same way as before. The resource is intended to help healthcare providers gain a better understanding of how loss and grief affect people with dementia and their families.

www.alzheimer.ca/grief - visit this page for further information on dementia and grieving, tips for coping with grief and additional resources.

www.alzheimer.ca/endoflife - this resource is for family members supporting a person with dementia. It can help them prepare for end of life, make some of the difficult decisions they may face, and cope with the loss and grief they might experience.

www.palliativealliance.ca – this website provides an overview of a project called “Improving Quality of Life for People Dying in Long-Term Care Homes” and includes practical resources, such as a toolkit that long-term care homes can use to help guide the creation of their own palliative care programs.

Webinar – “Acknowledging staff grief: When working with dementia, it is vital”. www.vimeo.com/119876282 – This webinar discusses how grief impacts staff who work with people with dementia in both community and long-term care settings. Watch this webinar for more information on key ingredients for a successful debriefing, facilitation strategies and self-care techniques.

Where can I get further information?

Please refer to the following resources available at www.alzheimer.ca or from your local Alzheimer Society.

Please refer to your local Alzheimer Society for education, information and support. You can find your local Society at www.alzheimer.ca/helpnearyou.

Grief and loss series:

Strategies for healthcare providers supporting clients through ambiguous loss and grief

Ambiguous loss and grief: A resource for individuals and families

Progression of Alzheimer's disease:

Overview

Early stage

Middle stage

Late stage

End of life

Living with Alzheimer's disease and other dementias - Day-to-day series:

Communication

Personal care

Meal times

Person-centred care:

PC P.E.A.R.L.S.®

Guidelines for care: Person-centred care of people with dementia living in long-term care homes

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