

# Taking the lead: Supporting staff in coping with grief and loss in dementia care

Mary Schulz, MSW, CSW<sup>1</sup>

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## Abstract

Healthcare providers working with people living with dementia often experience a profound sense of grief when the person they support dies or moves to an alternative level of care. Unattended staff grief can impact healthcare leaders by reducing quality of care, increasing staff turnover and absenteeism, lowering morale, and creating a greater risk of long-term staff health problems. Organizational and self-care strategies can mitigate these challenges.

## Introduction

Healthcare providers working with people having dementia often experience a profound sense of grief when a person dies. In long-term care, it is estimated that up to 39% of residents are anticipated to die each year by the year 2020.<sup>1</sup> The staff in these settings experience the death of a client on a regular basis, yet few initiatives exist to address their grief and loss.<sup>2,3</sup> Similarly, in community-based settings, loss not only can result from client deaths but also transition to other levels of care.<sup>4</sup>

In 2014, the Alzheimer Society conducted a research review of the literature on staff grief in healthcare workplaces and interviewed healthcare providers working with people having dementia in settings across Canada where death is omnipresent. The initial goals of the research were two-fold: to learn more about the impact of staff grief on staff turnover, absenteeism, and morale and the provision of quality care for clients and to identify promising, innovative, and effective organizational initiatives to support staff grief and assess their positive benefits.

Healthcare providers in dementia care told the Society that the resources it had developed on coping with ambiguous loss and grief are valuable and useful in supporting clients and their families. But what about my grief? What help can you offer me?

As a result, the Society developed *Dementia and Staff Grief: A Resource for Healthcare Providers*<sup>5</sup> (available at [http://www.alzheimer.ca/~media/Files/national/For-HCP/staff\\_grief\\_e.pdf](http://www.alzheimer.ca/~media/Files/national/For-HCP/staff_grief_e.pdf)). This practical, evidence-based resource is designed to help healthcare providers and organizations gain a better understanding of the multiple losses experienced by staff caring for people with dementia. The resource offers strategies and examples of best practices in supporting staff loss and grief when clients are dying and after their deaths, transitioning out of a program, or moving to another level of care. Organizational leaders can use this resource as a tool to support and empower their staff at all levels to cope with their grief and loss in the workplace. By providing effective grief support to staff, leaders can promote healthy behaviours and attitudes toward dying, improve the quality of person-centred palliative and end-of-life care for people with dementia and their families,

boost staff morale, increase staff retention, and reduce staff shortages.

## Impact of unattended grief on staff and quality of dementia care

Healthcare providers often form close attachments to the clients with dementia they care for, including the families they support. 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 and also often experience a loss of the relationship with the person's family and friends.

Yet the loss and grief experienced by healthcare providers are frequently not recognized, acknowledged, or supported.<sup>6-8</sup> Direct care staff may receive no training or scant training on grief and bereavement as well, despite witnessing and experiencing death so regularly.<sup>7</sup> It is sometimes assumed that the impact of death and grief reactions of staff will diminish as they witness and experience death more frequently, but the burden of unattended grief is cumulative.<sup>7,8</sup> Unattended grief is unresolved grief that has never had a chance to heal. Studies of direct care staff in high-mortality settings—long-term care homes, oncology units, and Intensive Care Units (ICUs)—have found that when their grief is not acknowledged, expressed, or supported, the effects of unattended grief add up rather than lessen with each accumulated loss.<sup>6-9</sup>

What are the costs to an organization of unattended grief and not providing support for staff to manage and acknowledge their grief and loss when a client with dementia dies?

Lack of support for staff grief and bereavement can reduce the ability of staff to deliver compassionate and quality care for clients with dementia and to facilitate a “good death” for clients with dementia.<sup>2,3</sup> When healthcare providers try to suppress the feelings associated with the death of a client, this can lead to emotional distancing and compassion fatigue, a form of

<sup>1</sup> Alzheimer Society of Canada, Toronto, Ontario, Canada.

## Corresponding author:

Mary Schulz, Alzheimer Society of Canada, Toronto, Ontario, Canada.  
E-mail: [mschulz@alzheimer.ca](mailto:mschulz@alzheimer.ca)

physical, emotional, and spiritual exhaustion that can affect the ability to feel and care for others.<sup>6,7</sup> In addition, the long-term physical health of healthcare providers can be compromised as a result of the chronic suppression of feelings associated with client deaths and compassion fatigue.<sup>6</sup>

Unattended staff grief also has been shown to contribute to increased staff turnover and absenteeism, low morale, and poor staff retention, leading to staff shortages and the extra costs of recruiting and orienting new staff.<sup>3,6,10</sup> This can negatively impact the organization by reducing the continuity, consistency, and efficiency of care and service delivered by staff to clients and their families, resulting in increased client and family dissatisfaction.<sup>6,10</sup>

### **Key findings on strategies to support staff grief and loss**

A wide range of practical strategies and initiatives can be adopted by long-term care homes, hospitals, and community agencies to support staff in managing loss and grief after a client dies or transitions to an alternative level of care. Self-care strategies help staff manage loss and grief in healthy ways. The recommendations for these support strategies were based on findings in the research literature and interviews with healthcare leaders and staff at all levels in dementia care settings across Canada.

Doka defined the grief experienced by individuals—including professional caregivers—that is not openly acknowledged, socially validated, or publicly observed as “disenfranchised grief.” Staff caring for people with dementia may experience this when grieving over the death of a client is not part of the culture of their workplace.<sup>4,6</sup> Organizations need to “enfranchise” the normal grieving process for healthcare providers caring for people with dementia by letting staff know that it is “okay” to appropriately express their personal and professional response to the death of a client.<sup>7</sup>

Some long-term care homes have traditionally had a culture where death is hidden from residents and direct care staff, which can be a major barrier to healthy grieving.<sup>3</sup> Changing the culture of silence around death and dying in long-term care settings is essential in promoting healthy ways for staff to acknowledge, express, and resolve their grief, which enhances their ability to continue providing compassionate and quality care. Sharing knowledge of a client’s death in a timely way with all staff through e-mail or bulletin boards and implementing organizational strategies and rituals to acknowledge and honour the memory of all clients who died are examples of practices that give staff the opportunity to process and move through their grief.<sup>3</sup>

### **Orientation, education, grief support, and self-care strategies**

Job orientation can prepare new staff with knowledge that death is common in long-term care settings, as well as information about normal and expected responses to clients dying.<sup>3</sup>

It is important to also give staff in community agencies, hospitals, long-term care homes, and hospices information about the grief support programs and resources available to them, including employee assistance programs or local counselling services.

Specialized education and training enable healthcare providers to increase their skills and gain confidence in providing the best possible person-centred palliative and end-of-life care to people with dementia.<sup>2</sup> This education should also prepare them to deal with the feelings of stress and loss they may experience while the person is dying and after death and highlight the importance and value of taking time to grieve and care for their own needs.<sup>2,3</sup> The Dementia Difference program, which provides specialized training workshops in palliative and end-of-life care, is an example of an innovative initiative that led to increased understanding and acceptance of the dying process and death for staff participants at the Lodge at Broadmead in Victoria.<sup>11,12</sup> Staff also paid increased attention to self-care, which includes “permission” to grieve the losses they experience.

Formal and informal grief support programs and initiatives are particularly important and effective ways for organizations to support staff in managing their loss and grief after a client dies. The need for grief support programs has been identified for staff working across many healthcare settings including ICUs, transplant units, and long-term care homes.<sup>6,10,13</sup> They have been used effectively in long-term care homes and hospices to improve overall workplace wellness, reduce staff stress and absenteeism, and may contribute to staff satisfaction and retention.<sup>3,9,14</sup>

Leaders can support a healthy grieving process among peers by allowing and encouraging staff to gather after the death of a client either informally or through a formal grief support program. Informal grief support can be easily integrated into existing and routine processes in long-term care homes, such as a regular team huddle on each shift. It is a built-in forum that gives staff a meaningful opportunity to recount stories about and feelings of loss for a client who has died in an atmosphere where grief is acknowledged and supported. Co-workers from an adult day program might gather informally to talk, reminisce, and express feelings of sadness after a long-time client with dementia has died. Managers can also acknowledge the impact a client’s death has on direct care by checking in with those who were working at the time of death to ask how they are doing or if they need grief support.

Peer-led debriefing is another example of an innovative, formal grief support program. Known as “sharing circles,” these sessions are usually 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. Peer-led debriefings were developed and implemented at Bethammi Nursing Home in Thunder Bay as a result of the home’s participation in a long-term research project with Lakehead University and the Quality Palliative Care in Long Term Care Alliance. These sessions give healthcare providers an opportunity to reflect on their

thoughts and feelings about that person through a guided process involving questions and discussion. Staff participants, peer debriefing leaders, and researchers reported that having an organized process to support grief was therapeutic for staff, had a positive effect on team bonds, provided closure after death, and gave frontline staff increased confidence they were doing good work at the end of life.<sup>3,5</sup>

Grief teams and grief support groups guided by professionals with specialized expertise are other examples of formal grief support programs shown to be effective in long-term care homes and other high-mortality settings.<sup>6,9</sup>

How organization leaders choose to recognize the death of a client can have a substantial and very positive impact in supporting staff loss and grief. Rituals and ceremonies to honour and remember the person who has died provide meaningful opportunities for healthcare providers to acknowledge the loss they experience and find closure.<sup>3,8,10</sup>

Although workplaces need to support grief and loss processes across the organization, individual staff members are also empowered by practicing their own self-care strategies. The importance of self-care in coping with grief has been highlighted in numerous studies of healthcare providers working in ICUs, oncology units, and long-term care homes where client deaths occur regularly.<sup>2,6,7,11</sup> Self-care strategies can range from paying attention to feelings of loss and talking informally with co-workers, to relaxation techniques, exercise, meeting with a professional counsellor, and contributing to a book of memories.

### How leaders can better support staff grief

Leaders of community agencies, hospitals, long-term care homes, and hospices can help their organizations and staff members cope with the loss and grief experienced by healthcare providers when a person with dementia dies or transitions to an alternative level of care.

The organizational review could identify both areas of strength and specific target areas for improvement in grief support practices. Practical ideas and strategies can be pilot tested and put into practice to fit the specific needs, culture, and size of the organization and its healthcare staff. Many of these strategies are effective and inexpensive and can apply to small or large organizations. It is important for leaders to seek the input and involvement of healthcare staff at all levels and from different disciplines in choosing and implementing the most appropriate grief support initiatives and strategies for their organization. A grief support project team, led by workplace champions, could take on the task of evaluating, piloting, and implementing these strategies.

As these initiatives are piloted and implemented, organizations can assess their effectiveness and benefits in contributing to staff morale and cohesiveness, reducing staff turnover and increasing retention, and improving quality and consistency of person-centred care for clients and their families.

### Conclusions

Leaders of community agencies, hospitals, and long-term care homes need to support person-centred care of people with dementia by treating staff in the way they want staff to treat people with dementia, their families, and co-workers. When providing person-centred care, staff members often develop close relationships with clients and their families. With caring comes the pain of loss. As staff working in dementia care face multiple losses and death, it is crucial for these organizations to provide them with education and support to manage their grief and loss. The Alzheimer Society of Canada's Dementia and Staff Grief: A Resource for Healthcare Providers provides practical, evidenced-based ideas, initiatives, and strategies that organizations can use to support staff in coping with loss and grief in the workplace. The benefits that result may include improved quality and consistency of care for clients and their families, increased staff retention, and higher staff morale and cohesiveness.

Initiatives to support staff grief are urgently needed within provincial healthcare systems across Canada to ensure that all organizations providing dementia care have effective programs and practices in place to support healthcare staff in managing the loss and grief they experience when a client dies or transitions to an alternative level of care. Leaders of organizations in the field can and should take the lead on this vital issue by implementing and championing such practices in their own workplaces. They should also advocate for government and industry policies to promote, encourage, and require practices and processes to support staff grief and loss within all organizations in Canada that provide dementia care.

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