

## Strengthening Bereavement Care

in Long-Term Care Settings



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## Bereavement in Long-Term Care

- One of the least acknowledged and most important shared experiences within long-term care is bereavement. In many Canadian longterm care homes, more than 1 in 4 residents will die each year.<sup>1</sup>
- When a resident dies, the death touches everyone in the long-term care community.<sup>2</sup> Yet, the resulting grief can take different forms for different people. Family caregivers, who often feel intense guilt about not being able to manage care at home, may have been experiencing anticipatory grief, or sadness over the changes that unfold during the course of a life limiting illness. As many as 1 in 5 family caregivers also experience complicated grief, meaning that after a death, grief is strong and persistent, and extra support may be needed to navigate the experience of loss.<sup>3</sup> And, even though their bonds with residents are newer, other residents and staff members can also experience strong grief reactions. For them, bereavement overload can occur after multiple losses.
- It can feel difficult to adequately support one another's grief. For families (including
  chosen family or supporting friends), the strength and stability of the relationships
  they formed in long-term care may suddenly feel very uncertain. Other residents may
  be too frail to attend a funeral outside the home, while staff may not be able to put
  aside their work to do so.
- Strengthening bereavement care in long-term care settings is a very important way to ease the grief response of all long-term care community members. This booklet explores a range of in-house bereavement ceremonies and practices recommended by long-term care homes and family caregivers. These take many forms, ranging from meaningful ways of communicating that a resident has died to coordinating funerals and other special gatherings. Each ceremony provides an opportunity for residents, family members, volunteers, and staff to share memories and support each other through the grieving process.
- As you read through each of the ceremonies described in the booklet, remember that
  each culture and religion has its own special approach for remembering the dead
  and supporting those who live. If you are thinking about introducing one or more of
  these ceremonies, consider consulting with families, spiritual care providers, or others
  who understand the cultures represented in your long-term care home to help you
  identify the best approach.



### Dignity walk and quilt

- Even when it is not possible for all members of the long-term care community to take part in a wake, funeral, or burial, it can be very meaningful to gather those present soon after a resident has died.
- The dignity walk is a short ceremony that can have a profound effect on the expression of grief and care for each other while strengthening a sense of community.
- In a dignity walk ceremony, available residents, family members, friends, staff, and volunteers form a large honour guard by lining the halls as the resident's body is accompanied on a stretcher to the front door by some of those present.<sup>5</sup> A short prayer, reading, or song may be offered, or a moment of silence may be taken, before the body leaves the home.<sup>6</sup>
- It is a good idea to consider using a dignity quilt during dignity walk ceremonies. A dignity quilt is specially made for dignity walks.<sup>7,8</sup> It is often made by a family member, staff member, or volunteer associated with the long-term care home. Alternatively, resident and family council members, staff, and volunteers work together to help to design the quilt, which is then created by a quilter.

Memory tree

 A "memory tree" is a form of memorial in which residents, volunteers, and staff are invited to express positive memories of the person who has died by writing a message and adding it as a leaf

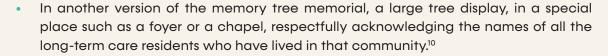
on the tree.

As people write, they may read what each other has written, sensing the impact of the loss on everyone in the community, and feeling less alone in their grief.

 This provides a convenient way to engage more members of the long-term care community.

 The tree, or the messages left on it, can later be shared with the family (including chosen family or supporting friends), as an expression of the community's shared grief, and their care for the deceased resident and the family.

There are many ways to create a memory tree. It can be a live tree, potted indoors or planted outdoors. It can also be a false tree created from a branch or creatively with art supplies. In either case, the key is to identify a way to hang messages from the branches on small cards.<sup>9,10</sup>



 No matter the format, memorials provide a meaningful place for residents, staff, and volunteers to respectfully remember someone who has died, and to express their support to the resident's family.





#### Room blessing

- When a resident has been part of a long-term care community for several months or years, it can be difficult to feel as though there is time to respectfully say good-bye while others urgently await the supports provided in this setting.
- To help staff and other residents to mark the loss, while also acknowledging that a new resident will be coming soon, a brief room blessing ceremony is led by a spiritual care provider<sup>11</sup> or a willing staff member. This ceremony is held in the deceased resident's room.
- During the ceremony, prayers are said to honour the resident who has died and to bless the incoming resident. This sets a respectful tone for good-byes and welcomes and helps residents and staff to feel more at peace with changes.<sup>11</sup>

#### Preparing the room

- Whether a resident has lived in long-term care for several weeks or several years, it is important to acknowledge that others within the community share the family's sadness at the loss.
- A meaningful way to express care for the family (including chosen family or supporting friends) is to pay careful attention to the space where the resident lived.
- After the body leaves the home and before the family arrives to take home the resident's possessions, long-term care staff prepare the room by opening a window,<sup>10</sup> placing a special quilt on the bed, and/or placing a silk rose, rose petals, or other flowers on the quilt.<sup>6,8</sup> They may also leave a sympathy card for the family.
- Preparing the room sets a respectful tone for good-byes. Taking the time to make these changes also helps staff and volunteers to feel more at peace with change, and more ready to welcome others who will soon need their care.



## Sharing memories during the family's last visit to the resident's room

- The time during which family members (including chosen family or supporting friends) gather the resident's belongings is a very sensitive time.
- Given the number of tasks the family will need to coordinate around this time, the window of time allowed for this should be as long as feasible.
- After the death happens, or as soon as the family asks, provide a reminder of the home's process, including amount of time available for gathering belongings. The tone should be supportive, acknowledging that there are many things to do, sharing what other families have found helpful, and inquiring how the home can best help. This is a very significant time to provide bereavement support. It may help to remember that providing needed information is an important part of bereavement care.
- If the family is present at the time of death, they may choose to stay and pack the belongings at this time. If not, invite them to identify a time when they can return to pack the belongings. Encourage them to bring whoever would like to help, and to support each other by spending some time sharing the memories attached to sentimental belongings or objects.
- If your home has a spiritual care provider, and if the family is interested, this time may begin with a prayer; otherwise, it can begin with a welcome, expressions of condolence, and offers of help.<sup>12</sup>

As appropriate to the family's needs and wishes, encourage others, including residents, families, volunteers, and staff, to spend a few minutes offering condolences and sharing memories.<sup>12</sup>

• If you are asked to pack up a resident's belongings on behalf of the family, do this with great care, and an awareness that how the belongings are packed may be seen as a sign of the level of care and respect for the resident and family. Consider attaching a sympathy card signed by residents, volunteers, and staff.



## Making residents aware of the death

- Residents often become close friends, and even residents with moderate to advanced cognitive impairment feel losses deeply. It is very important to them to know when a resident who is close to them has passed away, and to be supported through the loss.<sup>8</sup>
- There are several ways to acknowledge that another resident has died and will be missed. Some examples include:
  - placing a butterfly symbol at the table where the resident used to sit<sup>6</sup> or on their closed door.<sup>12</sup>
  - placing flowers, a picture of the deceased resident, or a candle memorial in an appropriate place in the LTC home.<sup>6, 13</sup>
  - coordinating a "huddle" or a series of individualized communications to share that someone has died, and inviting residents to share their memories during these conversations.
  - inviting residents to attend a funeral, dignity walk, or other memorial.



# Making volunteers and staff members aware of the death

- Staff members<sup>14</sup> and volunteers in long-term care homes often develop strong attachment relationships with residents. They sometimes describe this as a sense of friendship or kinship.
- When staff members or volunteers are not at work when a resident dies, they often
  prefer to be notified of the death of a resident before they arrive to begin their next shift.
- Notifying staff members and volunteers of the death of a person they care for acknowledges their grief at the loss of relationship and it allows them to begin processing the loss before arriving to work.<sup>15</sup> It can be very upsetting to find out about the death by walking into a room to find the deceased resident's bed empty or already filled.<sup>16</sup>
- Consider providing a brief phone call, text message, or email to notify staff members
  or volunteers of a death, or placing memorial cards and notices in a prominent place,
  so people entering the building have the opportunity to see them.



## Reflective debriefing for staff

- Peer-led reflective debriefing sessions combine staff support with quality improvement planning, making them a sound practice for long-term care communities seeking to strengthen a palliative approach to care.
- Reflective debriefing sessions ideally include care team members of all occupations, encouraging the growth of an interdisciplinary team approach to palliative care.
- After each resident death, staff members who worked closely with a deceased resident are invited to share their reflections on how things went at the end of life.
- As staff members share their thoughts and feelings openly, they are caring for each other, emphasizing strong practices, and acknowledging where they need more support.<sup>8,13</sup>
- Sessions are led by a staff member who is familiar with the format, and who ideally knew the resident or knows the staff participants.<sup>13</sup>



## Friendship boxes for families

- Sometimes, resident's family members (including chosen family or supporting friends) develop a sense that they are part of a small community within the longterm care home.
- When a resident dies, the family's grief may be compounded by the sense that
  they have also suddenly lost these newer connections. It can help to know that
  other members of the long-term care community continue to think of them and to
  remember the resident who died.
- To reach out to family members who recently experienced a loss, some long-term care homes offer "friendship boxes" containing items such as relaxation or spiritual CDs, books, photos, and sympathy cards signed by staff and residents.<sup>6</sup> Other long-term care homes have different ways to reach out in the days and weeks after a loss, such as by telephone, or by extending invitations to special events.
- Even if your long-term care home does not yet have a strong sense of community, this practice may provide an important opportunity for community growth.

## Funeral or memorial service

 Many people who have experienced or attended a funeral in a long-term care home say it is a very special experience to be supported by people who understand their caregiving journey and have walked with them through the resident's final days.

When a long-term care home hosts a funeral, this also makes it more feasible for residents, volunteers and staff members to attend.<sup>7</sup>

Funeral services are more likely to be hosted by long-term care homes with large chapels and dedicated spiritual care providers. Even so, most long-term care homes are likely to be considered suitable locations for funerals because of their supportive atmosphere, large indoor and outdoor public areas, and the availability of food service.

Some long-term care homes coordinate periodic (monthly, quarterly, or annual) memorials for multiple residents who have recently died.¹ This practice is also well-received by many families, especially within close-knit long-term care communities, where this can be a powerful way for caregivers who have all recently experienced a loss to recognize and support each other's losses.

• If your long-term care home has opted for a periodic memorial service, it will also be important to find ways to express support for bereaved family members, friends, residents, volunteers, and staff immediately following the loss.



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