

A GRIEF & BEREAVEMENT GUIDE FOR NURSING HOMES

In the face of the COVID-19 pandemic,

our nation's nursing homes experienced an overwhelming loss of life as never seen before. From the first massive wave of death early in 2020, homes have lost 200,000 residents and at least 2,500 staff to COVID-19. Loss of this scale has triggered a tsunami of mental health crises in the form of anxiety, depression, and Post Traumatic Stress Disorder (PTSD). Mental health services provided throughout 2022 were utilized at 39% more than pre-pandemic. We have learned that social isolation, loneliness, grief, and bereavement are conditions that, left unattended, cost the economy millions of dollars and tear away at the health and well-being of those living and working in nursing homes. We recognize two of the most negative mental health outcomes in nursing homes today: grief and bereavement.

In 2022, with a grant from *The Michigan Health Endowment Fund*, Altarum created a Learning and Action Network (LAN) for Michigan nursing homes with the intent of improving the mental health of staff and residents. The LAN provides a forum for the participating nursing homes to learn from each other by sharing best practices for reducing the impact of grief and bereavement, and social isolation and loneliness. In 2023, Altarum held two roundtable discussions – one with nursing home staff and one with State and national subject matter experts – to discuss the state of grief and bereavement in Michigan nursing homes.

The collaboration brought to light both practical solutions homes are using as well as gaps that need addressing.

In this guide, we will cover what grief may look like in residents, their family and friends, and the professional caregivers serving in nursing home communities, as well as what happens when it goes unaddressed. We will also provide evidenced-based solutions to support the bereaved in your daily practice.



What are Grief and Bereavement?

Grief is our response to irreversible loss. Grief can be strong enough to drown us in dread, anxiety, and disbelief. It can be the catalyst for depression, dementia, and chronic illness. Grief can leave us exhausted, isolated, disoriented, and numb. Grief exists at the core of bereavement.

Bereavement is the way in which we live with our grief. Bereavement is the long road back to our daily lives. It is a journey back to our foreverchanged selves. Bereavement, like grief, is different for each of us, and its timeline is its own.





How a Resident May Experience Grief and Bereavement

A resident entering a nursing home is no stranger to grief. Grief is loss; often, by the time an individual arrives to their room with the "Welcome" sign on the door, you can expect they have experienced loss.

Common Losses Experienced by Those Entering a Nursing Home:

- Health
- Vision and hearing
- Confidence in their independence
- Home
- Lifestyle
- Pets

- Friends
- Mementos and personal items
- Spouse
- Family
- Trusted caregiver
- Hope

INVOLVING THE RESIDENT CAN BRIDGE THE GAP FROM RESISTANCE TO ACCEPTANCE

- Focus on the resident's goals and strengths
- Focus care plans on keeping hope alive
- · Help families approach difficult conversation and share support
- Include the individual in the planning
- Encourage individuals to visit prior to admission, share a meal or activity, and meet staff to build trust

For others coming into a nursing home with support for their choices and the opportunity to participate in their admission, grief may look a bit different, but it is there and may appear as:

- **Sadness** expressions of loss, tearfulness, inability to sleep at night, loss of appetite, lack of energy, confusion, decline in personal appearance.
- **Self-Isolation** spending most of the time in the room, declining group activities, passive independent activities like watching TV most of the day, declining outings, visits, or phone calls with family/friends, requesting all meals in the room, disinterest in getting to know the staff or other residents.

What might grief look like for a resident coming into long-term care for the first time when this resident was not included in the choice?

- Anger demanding to go home, demanding to be left alone, refusing care, frequent calls to family or friends to come right away, even contacting 911.
- Loss of Control demeaning the staff, refusing medications, threatening/calling police, inaccurate concerns about lost items, their room is too hot or too cold, self-medicating, dissatisfaction with meals and alternate meal options.
- Fear refusing to get out of bed, not wanting to leave the room, concerns about other residents or staff coming by, wanting the lights off and the blinds closed all the time, not speaking to others.

These situations prevent a resident from settling in and being able to focus on their own care goals. It also prevents caregivers from connecting with the resident meaningfully to begin building trust. It is exhausting and dissatisfying for all.

Grief is uncomfortable, but it is a natural response to loss. Unsupported grief, however, can lead to depression. The diagnosis of Depression is significant, should be assessed, and treated clinically with interventions that support physical and mental health.

Grief impacts the ability to make meaningful connections but with consistent support from the interdisciplinary team, individuals can begin establishing relationships. Supportive practices that can help with this are:

Guardian Angels are team members voluntarily assigned specifically to a resident when they arrive, to watch over them and check in with them frequently. Guardian Angels can answer residents' questions, introduce them to other residents and staff, eat a meal with them, attend an activity with them, and actively engage in connecting the new residents with the rhythm of daily life within the home.

Peer Ambassadors are resident volunteers who assist a new resident in the same way the Guardian Angel would. Peer ambassadors create the win-win essential to person-centered care. This relationship empowers both of the residents within it.





OTHER WAYS TO HELP RESIDENTS WITH THEIR GRIEF

Take time to talk with them about it. They may welcome the opportunity for self-expression in a calm and safe space.

Take time to talk with individuals about their own end-of-life wishes. Many individuals are comfortable speaking about their own end-of-life wishes but may resist speaking to their family or friends for fear of sadness. Staff are helpful in asking about an individual's life plans; in doing so, they provide the opportunity for individuals to express themselves freely. Residents may feel comforted and empowered with the assurance that their end-of-life wishes are communicated clearly to the staff.

Peer support groups consistently gather those who recognize the benefit of sharing together. These may be completely resident-led or facilitated by a trusted staff person or family/community member.

Individual therapy, while not something that all residents might want, should be available.

Creative activities with the Life Enrichment Team can provide a resident with many personal opportunities for creative self-expression, social support, and healing.

Rituals help the living both by providing comfort when there is a death but also lets the residents know what will happen when they die. They show that people are not forgotten, and death is not hidden. Some examples of rituals:

- Honorable departing.
- · Memorials.
- Legacy activities (for example writing or contributing to their obituary).
- Memory boards and Memory trees.
- Placing a special quilt/blanket and a rose across the now empty bed of the deceased to acknowledge the loss to the community.

Residents can participate in the planning of their departure from the building by doing one or more of the following:

- Legacy planning activities like obituary writing.
- Making a guilt that will cover their body.
- Choosing the song that will play overhead as they leave the building for the final time.
- Choosing the prayer, recitation, poem, etc. that will be read as they depart the building or at their memorial service.
- Utilizing community support from Veteran's support groups, Hospice, and community churches.

How Family and Friends May Experience Grief and Bereavement

Upon admission, families experience many emotions when considering nursing home placement for their loved one:

- Helpless and out of control
- Mental and physical exhaustion
- Guilt, Disappointment, and Worry
- Fear, Anger, and Anxiety

How these emotions can manifest: HYPERVIGILANT

Family may seek a sense of control by being extra alert, making a lot of requests, and criticizing care.

What To Do:

- Staff will need backup and support from managers to listen to and accommodate requests and criticisms by these family members.
- Social workers can support families to help them build trust and focus on reasonable expectations of quality care.
- Increased communication can help manage grief that comes across as anger.
- Responding kindly, repeating the points of concern they express to clarify their expectation.
- Tell them what you can and cannot do and follow through on the next steps to completion.
- Asking open ended questions during times of calm, applying active listening techniques to help understand the driving force of the grief.
- Respect the roles that families play in the lives of their loved ones.
- Life Enrichment may provide suggestions for meaningful activities that families can do together to help family members that are unsure how they can remain active in their loved one's life.





How these emotions can manifest: HYPOVIGILANT

Others may shift to the other extreme and will gloss over care concerns, saying that all aspects of care are simply perfect, and nothing could be better.

What To Do:

- Those with this mindset may be avoiding the feeling of guilt and loss by denying them completely. Glossing over feelings of grief or denying a resident their own voice of grief is unhealthy and unsafe.
- While denial is a common defense mechanism used to protect oneself from
 the hardship of considering an upsetting reality, things that can help people
 to get through and move past the denial are to examine their fears, consider
 the consequences of not taking action, keeping a journal, and talking with
 loved ones.

Smooth Transitions Can Lessen Grief

- Keeping the resident clean and comfortable and in a calm and comforting environment is important.
- Providing a transitioning room, a single accommodation with extra seating for family and friends who may be keeping vigil.
- Making hospitality trays with coffee, water, and snacks available to visitors.
- Encouraging staff to come in and spend some time with the transitioning resident.
- Ensuring staff know what the resident's Advanced Directive/POLST specify can help staff to feel better during/at the time of death because they are honoring their wishes.
- Upon death, after notifying the physician, it helps if the family can remain for a reasonable time if needed before calling the funeral home.

UPON DEATH

Anger upon the death of a loved one in the nursing home may be expressed as remorse that more was not done to sustain life or sadness that the loved one was unable to get better and go home as all had hoped and promised. Guilt from self-doubt asks, "Were all the right choices made?" or because they feel a sense of relief that a time of difficulty is over. Remember that families need to be:

- Listened to/allowed to share their feelings around grief without judgment.
- Encouraged to remain active in the Family Council.
- Reminded that they can return and visit as volunteers.
- Encouraged to take advantage of the bereavement support offered by hospice.



OTHER WAYS TO HELP

Family Councils can help new families connect with those who have had a similar experience. Being able to navigate the nursing home can help families alleviate fear and guilt and focus on building new relationships with their care partners.

Pre-Admission Support to families and friends play a vital role in helping their loved ones navigate an unfamiliar environment. Their support begins well before the day of admission. In the days and weeks leading up to a planned admission, families may avoid talking with their loved one about coming to the nursing home.

Homes can provide tips on how and what to discuss prior to admission.

Admission Conferences are where a staff member meets with the family and resident in the first few days to listen and share key details for the resident's care that have been shown to build trust and support those who are grieving.



Hospice Involvement Does Not Alleviate the Grief of Home Employees

While hospice staff are involved in managing and caring for residents who are closer to death than others, the home staff still deliver most daily nursing care and maintain supportive relationships just as they did before the resident entered hospice care. Consistent assignments foster supportive relationships which benefit the individual's quality of life and the staff's quality of work.

CNAs providing postmortem care for the resident and the nurses who make the final phone call can all experience grief. Staff care about those they care for and when they regularly experience residents' deaths, the impact may become cumulative and take many forms.

The Need for Ongoing Training was Identified

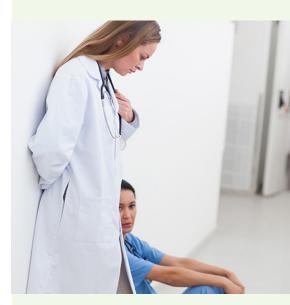
In-service training and other opportunities for mental health support should be considered by leadership. Current certification training is limited to care for the dying resident but provides little if any training on how to do self-care or recognize and support a grieving resident or coworker. The curriculum doesn't address bereavement coping skills even though CNAs will face this in the workplace routinely. Because of this leadership should consider building opportunities for mental health support and self-care training into existing training and new staff orientation. Grief and bereavement topics could also be included in other training topics such as dementia. Other opportunities for mental health support are offering Mental Health First Aid for supervisors; implementing a Grief & Bereavement or Mental Health Employee Resource Group (ERG) and/or employee G&B support group; and implementing grief and bereavement support groups for residents if there is interest. Groups could be facilitated by the social worker or an outside professional, but resident-led groups (supported by staff) are ideal.

Relationships with hospice and hospice contracts should be reviewed annually. Homes should consider including annual education/in-service on the philosophy and mechanics of hospice care. Special note: hospice staff contracted with your home are already required to provide bereavement support to family members of departed residents. In addition to this, leverage your relationship with hospice to potentially add bereavement support and education for your staff, as well.

Conclusion

Through the *WellbeingTREE* Learning Collaborative and roundtable sessions we have learned that the post-pandemic effects of grief have been compounded by failure to recognize and treat the symptoms. Grief has had a significant adverse effect on nursing home residents, staff, and their families and friends. While loss is inevitable in the nursing home setting, poor mental health due to unaddressed grief and bereavement does not have to be. How homes approach bereavement among employees and residents has a direct impact on their wellbeing. Homes that can fully address bereavement can minimize its impact by creating a culture of care. Supported employees feel more secure, provide better care, and are more likely to stay. Supported residents have better quality of life, maintain independence longer, and are easier to care for. This in turn can raise morale, cement loyalty, facilitate recruitment, improve quality metrics, and lower costs.

Special thanks to *The Michigan Health Endowment Fund*. <u>Altarum.org/WellbeingTREE</u>



THINGS THAT CAN HELP

- Allowing staff an opportunity to take time for a beside visit
- Share kind words with their family and friends
- Standardized notification process to let staff know BEFORE a death occurs
- EAP and Chaplains

BE AWARE

- Staff may tamp down grief to stay focused on daily tasks because of the fast paced, demanding environment
- Staff may not have time to express feelings of loss until a later time.
- Staff may experience compassion fatigue that can prevent them from performing their roles with empathy
- Signs of unaddressed grief are increased absenteeism as well as presenteeism that can result in greater risk of occupational injury, diminished productivity, decreased motivation, brain fog, and decrease in the quality of care to residents.

It is important for leadership in the homes to acknowledge the stress and emotion that is intrinsic to care for a dying resident and provide time and space for the caregivers to express what they have experienced.



Additional Resources for You

Title	Audience	Description	Link	Category
Altarum WellbeingTREE Nursing Home Collaborative Learning Series	All	Videos and materials from <i>The WellbeingTREE</i> collaborative learning series on tackling grief and bereavement, and social isolation in Michigan nursing homes	Altarum.org/WellbeingTREE	Education & Training
Altarum WellbeingTREE Best Practice Bereavement Rituals	All	A list of actionable, low or no cost rituals Michigan homes are using to help residents and staff process grief	Altarum.org/WellbeingTREE	Tools
Altarum WellbeingTREE Best Practices in Grief & Bereavement Policies	All	Best practices in grief and bereavement policies and procedures with additional resources	Altarum.org/WellbeingTREE	Tools
Altarum WellbeingTREE Grief & Bereavement Roundtables: Summary Report of Findings & Recommendations	All	Summary report of findings and subsequent recommendations from two roundtable discussions with Michigan nursing home staff and State and national subject matter experts on the status of grief and bereavement support in nursing homes	Altarum.org/WellbeingTREE	Report
Hospice of Michigan	All	Offering face-to-face and virtual grief support groups.	Grief Support Groups hom.org	Support Group
Mental Health First Aid Training for Adults	All	A skills-based training that teaches people how to identify and respond to signs and symptoms of a mental health or substance use challenge in adults ages 18 and over.	The National Council for Mental Wellbeing and MSU Extension	Training
Grief Work for Healthcare Providers	LTC Staff/ Managers	This self-guided course is open to all nurses, doctors, residence, health care staff, and those on the frontlines of care.	The Institute for the Study of Birth, Breath and Death birthbreathanddeath.com	Training
Center for Loss and Life Transition Seminars	LTC Staff/ Managers	The Center for Loss and Life Transition is known for providing quality bereavement care training.	Trainings - Center for Loss & Life Transition www.centerforloss.com	Training
Grief Support Specialist Program	LTC Staff/ Managers	An 8-week, non-credit certificate program through Continuing Education and Workforce Development at NMU.	Continuing Education and Workforce Development nmu.edu	Training
End-of-Life Doula Training	LTC Staff/ Managers	Training course that teaches the foundations of doula work and support for the dying. You will practice techniques, role play situations, and explore scenarios that end-of-life doulas may encounter.	NELDA End of Life Doula Training nedalliance.org	Training
Grief Support for Staff	LTC Staff/ Managers	This resource was created to provide LTC homes with ideas and strategies on how to acknowledge the grief and loss experienced by staff working in LTC.	Grief Toolkit (PDF) palliativealliance.ca	Tools
Grief Speaks	LTC Staff/ Managers & Residents	Presentations, workshops, keynotes, and counseling for adults, teens, and children	Seniors griefspeaks.com	Tools
Long-Term Care Staff: Honoring Grief and Increasing Resiliency	LTC Staff/ Managers	A workbook for LTC staff experiencing grief	LTC Staff Grief and Resilience Workbook (PDF) clri-ltc.ca	Tools

