

The background features a complex geometric pattern of overlapping triangles and polygons. The top half is primarily light gray and white, while the bottom half is dominated by a large teal shape on the left and a yellow shape on the right, both with a 3D effect. The text is centered in the upper portion of the image.

BEST PRACTICES IN BEREAVEMENT CARE

INTRODUCTION

Long-term care facilities blend the concept of home with skilled medical care. Initially, staff and other residents are strangers, but eventually they become familiar. Relationships formed in this setting shape the day to day experience and are critical to the overall well-being of residents.

In long-term care and retirement facilities, death is an expected part of the environment, but not everybody comes in with a life-threatening illness. In fact, some residents enter skilled nursing for short-term rehabilitation. Those residents may also suffer from grief over changes in their environment and their social network, declining health, or some other loss.

More than sixty hours of interviews with members of nine long-term care facilities in middle Georgia led to the development of this guide, which we hope will promote change in the culture of dying and grieving in the nursing home setting. Participants identified practices used to support residents, families, and staff during critical end of life transitions. They also identified areas of need for improved care. Their insights reflect their experiences with advance care planning and bereavement care.

ACKNOWLEDGEMENTS

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BEREAVEMENT CARE

CAUSES OF GRIEF

Grief has many causes. When a loved one has a debilitating illness, grief often begins long before death. Although the needs of the dying person are most important, persons around the bed are also harmed by the process of dying.

Grief may be caused by events other than death. For example, when residents first enter the facility, they may be grieving the loss of caregivers, pets, or the comforts of home. They may also undergo losses while they are in the facility.

People express grief in different ways. While some respond with sorrow, others respond with emotions such as anger or denial.

A man here watched his wife die about three months after they had arrived. He was crying and crying and crying for weeks. There's nobody to talk to. People are just left here. There is no one to sit down with and no group to talk to.

— Resident



One dear friend developed dementia. I guess she's the one that I've been closest to in the facility. When she died, it was expected, and in an interesting sort of way it was a relief.

— Resident

When my husband died, I was angry. I was angry that I couldn't get him to lead a better lifestyle and take care of himself. He was a very smart man, and there's a piece of me that was mad.

— Resident

When I arrived, I knew no one and while everyone was kind, my grief was invisible.

— Resident



A lot of our residents come in first for rehab, and then transition. We see that a lot of anger or disappointment or grief comes after this failure to be able to go home from therapy. There is anger involved because family members are telling folks “Nope, sorry. You worked hard but you still can’t go home.”

— Admissions Director

A few years ago, I lost some keepsakes that had a lot of sentimental value to me. Some of them had been inherited from family, and others were items that I collected over my life. I don’t think that it is reasonable to grieve over physical objects, but I did. I started crying and I couldn’t stop.

— Resident





I have known residents to grieve when they are forced to part with a pet. Sometimes, when we move residents from independent living to skilled nursing, we have to find a sitter for the pets. A pet owner's biggest worry is often the well-being of the pet, and sometimes they miss their pets so much that we have to arrange for visits so that the person can maintain a relationship with the pet. Otherwise, separation from the pet is too traumatic.

— Staff

I am not from this area, and coming here was a real hard adjustment to me. I did not fit in, and I really missed my old home. I gained a lot of weight in the beginning.

— Resident





When my wife became needful of assisted living, we had to separate. One of my hardest memories is that when I went to the door to leave her room, she was hurting. And I was hurting, and she said to me, “We’ll never be able to stay together again.” I closed the door and left. That was hard. That was the beginning of the end.

— Resident

This isn’t the same person I married. He isn’t the person to whom I used to say “Oh why don’t you listen to this. I read something really interesting in this book.”

— Resident



Residents:

You may feel grief for any number of reasons, and your grief could take many different forms. Your feelings may not even seem rational to you. Understand that these feelings are common among people who experience these stresses in their lives. It is important that you recognize and address your feelings of grief.

Families:

Be aware of the triggers of grief from which your family member may be suffering. Offer as much support as possible, and encourage your family member to take advantage of available resources.

SUPPORT FOR GRIEF

TALKING ABOUT GRIEF

Each person experiences grief differently. Individuals have unique needs; not every practice works for everyone. For example, some residents have expressed a preference for support groups, while others would prefer one-on-one conversations.



When a neighbor dies, and I see the family come in, I try to sympathize, but I never say, “I know just how you feel.” I really hate when people say that. Everyone experiences death differently. I also try not to say, “she’s in a better place” or anything else that’s religious, because you never know what other people believe.

— Resident

I would have liked somebody who had been through a similar circumstance to assure me that someday it’s going to be over. I wish someone had said, “I see you’re working hard at it, I can’t really tell you what will work for you but I can tell you if you keep looking you’ll find it, and I will be here to talk to you about it all the way.”

— Resident

At my church, I had some grief counseling. I thought I didn’t need it, but I was so wrong. It was really helpful. There were people in there who had lost a brother or sister; there were people who had lost a spouse ten years before. There was somebody who had lost a spouse at the same time as I had. What I learned, what I took away from it when I left is that love never dies.

— Resident



There were support groups that I didn't take full advantage of; I didn't take much advantage at all actually. I lost a parent to Alzheimer's in '97, and of course a lot of things have improved, and the Alzheimer's Association has grown since then. It offers so much that I wasn't aware of. But when I finally took advantage of the support groups, they were really good.

— Resident

Some family members have cared for a relative with Alzheimer's for years. They might take advantage of a support group, because they are so battle weary and fatigued. They have fallen into this routine that has become so rigid for them, and all of a sudden everything changes and they really don't know how to put their lives back together. So they are the ones that often seek counseling.

— Chaplain



Residents:

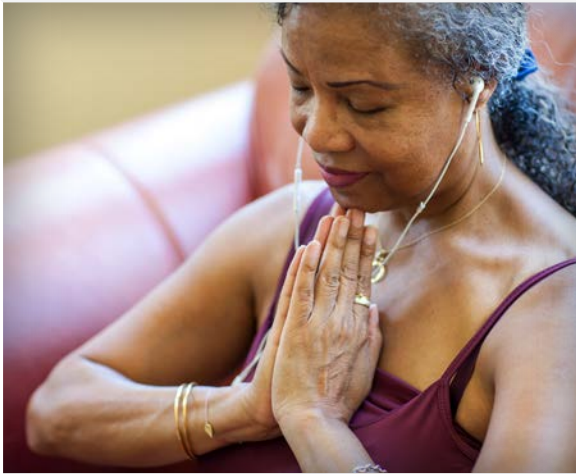
If you are grieving, think about what might help you cope and discuss it with staff members. Consider talking to a therapist, social worker, or chaplain if they are available. It may also be helpful to discuss your feelings with the administrator, admissions director, or a trusted friend.

Families:

You may find that you need more help than you realize. Consider joining a support group or talking to a therapist or chaplain, or a friend who has experienced similar grief.

CAREGIVER SELF-CARE

Caregivers juggle many tasks and responsibilities. Often they forget to take care of themselves. If they do not take time to maintain their own physical and mental health, it negatively impacts the care that they give.



As he experienced more and more cognitive abilities decreasing, we talked about it more. And our understanding with each other was that if one of us began to experience those kinds of things, the other spouse was not to stop living life.

— Resident

Residents and Families:

If you are a caregiver, always remember that it is necessary to care for yourself. Allow yourself restorative breaks from time to time. Make sure you recognize and address your own feelings of grief.

As a caregiver, you have to take care of yourself first. In an airplane, they tell you to put on your own mask before you help other people with theirs. Or, if you think about a pitcher of water, you cannot continuously pour from it without refilling it.

— Family Member and Caregiver

SPENDING TIME WITH LOVED ONES

Caring for a sick relative can be extremely stressful. Watching a loved one become increasingly sick or lose the ability to engage with you or even talk to you can be devastating.

We have one resident whose favorite song is the fight song for Georgia Tech. If you want to get her to respond, sing that song. She will sing it with you. Her brothers went to Georgia Tech, and they would sit around the piano and sing it when she was little.

— Staff



I remember walking through the dementia unit to visit my wife and seeing several patients just sitting silently. Then I saw a CNA pick up a puzzle, set it up, and start to work on it. Patients came up and asked her what she was doing, and she invited them to help her. This was a great way to get them involved in an activity.

— Resident

Families:

When you visit an ill family member, especially one with decreased cognitive abilities, it may help to have an activity to do together. For example, you could do a puzzle or read a book, even a children's book. You may also consider playing music that your family member used to enjoy.

MEMORIALS

Memorials honor the lives of those who have passed and those who have cared for them. In long-term care facilities, memorials provide an opportunity for families to honor their loved ones with the staff and residents who have cared for them and lived with them at the end of their lives.



This past year we did a memorial service for everybody that had passed away during that year. We had it out on the front lawn. The activities director read a little passage, I read a poem. One of the secretaries sang and the head chef played the guitar. At the end, we released a butterfly for every resident that passed away. So it was really, really sweet, and it seemed very appreciated.

— Social Services Director

My friend was diagnosed with terminal cancer and she gave herself a farewell party in the grand room and invited everybody in the place. Had her son play the piano. She gave me an example to follow; she did it beautifully.

— Resident

Residents:

Consider attending any memorial service offered for your fellow residents. It may be your only opportunity publicly to honor and celebrate the lives of your neighbors and friends.

Families:

If your loved one's long-term care facility offers a memorial, it may be helpful for you to participate. The memorial is designed to help everyone address feelings of grief and loss. It will give you a chance to honor your loved one with those in the facility who knew and cared for them.

END OF LIFE PLANNING

EXPRESSING END OF LIFE WISHES

Death is a natural and inevitable part of the aging process. Today, due to advances in technology, there are many decisions that surround the process of aging and dying. Some adults would like to die a natural death, whereas others would prefer to be resuscitated and kept alive for as long as possible. End-of-life planning can help older adults ensure that their wishes are respected and that their values are reflected in their care.



I had a friend that died. Her kidneys failed, everything went wrong. She died in a hospital in horrible shape, terrible breathing; everything was awful. Her children were there, and she kept saying “I just want to die. Will they just let me die?” She was alive enough to say “I want to die, let me die. Take all these things off of me and let me die.” And finally the children said okay. But it took weeks. She was in too much pain; she was in agony.

— Resident

I’ve said it in jest sometimes, but it’s true. We all came here to die, and we have to accept our condition. It helps me deal with grief when I accept my condition and say to myself, “things are not going to be what they used to be.”

— Resident

Residents:

End of life planning can ensure that your wishes are respected. A written record of your wishes lets staff members know how you would like them to care for you if you become unable to tell them yourself. For example, your document can show whether you would prefer a natural death or life support. Planning can also reduce the stress that your family members would face making difficult decisions on your behalf.

My wife had dementia, and she was staying in a skilled nursing unit. I walked into her room and found that she had died. Of course, she needed attention and cleaning, so I walked down to the nursing station and told them and they hurried down, but I knew that she had already died. I told the nurse that we did not want resuscitation, and she said that she knew that. It was a relief to me. I would rather have my wife die than live on like that.

— Resident

Families:

Older adults are often ready and willing to discuss their wishes for care. While you might find it challenging, it is important to talk about their wishes. Documenting those wishes can ensure that when the time comes, they are respected, and it may also reduce the burden of decisions that need to be made later.



ADVANCE CARE PLANNING (ACP)

On January 1, 2016, the Centers for Medicare & Medicaid Services (CMS) began reimbursing physicians for time spent discussing and documenting patients' wishes and preferences for future care. This is called Advance Care Planning (ACP). It can occur in the outpatient setting, the hospital, or within a long-term care facility.

Residents:

If you have discussed advance care planning with your personal physician, let staff know. Also, let staff know if you or your doctor have put your wishes in writing. It will help improve care.



Families:

If you know that your family member has discussed advance care planning with a physician or completed any document related to end of life care, let staff know that. It will help the staff honor your family member's wishes and support both you and your family member.

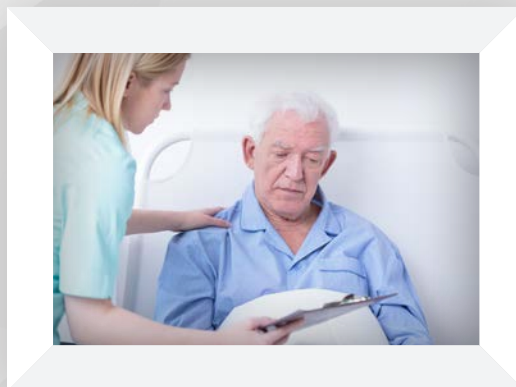
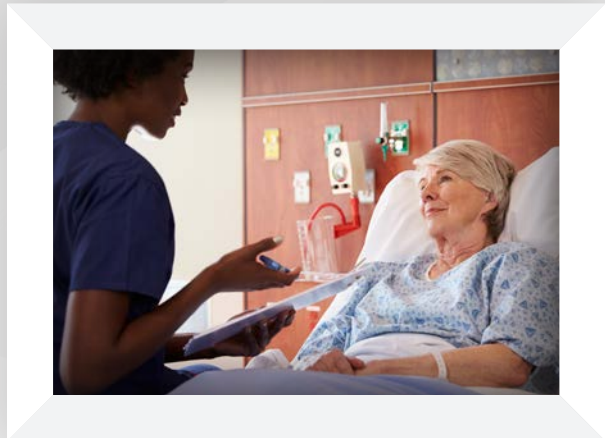


PHYSICIAN ORDERS FOR LIFE SUSTAINING TREATMENT (POLST)

The POLST form may be helpful near the end of life. It is signed by the both a doctor and a patient, and it serves as a physician's orders. It indicates whether someone wants a ventilator, a feeding tube, or other measures to extend life. It is a single sheet of paper that can stay with the patient as the patient is transferred between facilities.

POLSTs are not for everyone. They were designed for persons with serious illnesses or frailty whose current health indicates the need for standing orders for medical care.

For healthier persons, an advance directive is an appropriate tool for making future end of life care wishes known to family.



Residents:

If you feel that the POLST may be right for you, bring it up with senior staff at your facility. Discuss it with a physician, admissions director, therapist, social services director, social worker, administrator, or director of nursing.

Families:

If you feel that the POLST may be appropriate for a family member, try to talk to that individual about it. Consider asking a social worker or therapist at the facility for help with the conversation.

You may have to make decisions on behalf of a family member who is no longer capable of expressing those wishes. The admissions director can help you fill out a POLST. Just ask.

**MDHHS-5836, MICHIGAN PHYSICIAN ORDERS
FOR SCOPE OF TREATMENT (MI-POST)**

Michigan Department of Health and Human Services (MDHHS)
(Revised 8-22)

HIPAA permits disclosure of MI-POST to other Health Care Professionals, as necessary. This MI-POST form is void if Part 1 or Section D are blank. Leaving blank any section of the medical orders (Sections A, B, or C) does not void the form and is interpreted as full treatment for that section.

PART 1 – PATIENT INFORMATION

Patient Last Name	Patient First Name	Patient Middle Initial
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Date of Birth (mm/dd/yyyy)	Date Form Prepared (mm/dd/yyyy)
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Diagnosis supporting use of MI-POST

This form is a Physician Order sheet based on the medical conditions and decisions of the person identified on this form. Paper copies, facsimiles, and digital images are valid and should be followed as if an original copy. This form is for adults with an advanced illness. It is not for healthy adults.

PART 2 – MEDICAL ORDERS

Section A – Cardiopulmonary Resuscitation (CPR)

Person has no pulse and is not breathing. See MDHHS-5837 for further details.

- Attempt Resuscitation/CPR (Must choose Full Treatment in Section B).
 - DO NOT attempt Resuscitation/CPR (No CPR, allow Natural Death).
-

Section B – Medical Interventions

Person has pulse and/or is breathing. See MDHHS-5837 for further details on medical interventions.

- Comfort-Focused Treatment**
Primary goal of maximizing comfort. May include pain relief through use of medication, positioning, wound care, food and water by mouth, and non-invasive respiratory assistance.
 - Selective Treatment**
Primary goal of treating medical conditions while avoiding burdensome measures. May include IV fluids, cardiac monitoring including cardioversion, and non-invasive airway support.
 - Full Treatment**
Primary goal of prolonging life by all medically effective means. May include intubation, advanced invasive airway interventions, mechanical ventilation, other advanced interventions.
-

Section C – Additional Orders (optional)

Medical orders for whether or when to start, withhold, or stop a specific treatment. Treatments may include but are not limited to dialysis, medically assisted provisions of nutrition, long-term life-support, medications, and blood products.

Send form with Patient whenever transferred or discharged.

Section D – Signature of Attending Health Professional

My signature below indicates that these orders are medically appropriate given the patient's current medical condition, reflect to the best of my knowledge the patient's goals for care, and that the patient (or the patient representative) has received the information sheet.

Print Name

Date

Signature

Phone Number

Print Name of Collaborating Physician

Phone Number

Section E – Signature of Patient or Patient Representative

My signature indicates I have discussed, understand, and voluntarily consent to the medical orders on this MI-POST form. I acknowledge that if I am signing as the patient's representative, these decisions are consistent with the patient's wishes to the best of my knowledge.

 Patient Patient Advocate/Durable Power of Attorney for Health Care (DPOAHC) Court-Appointed Guardian

Print Name of Patient

Print Name of Patient Representative

Signature

Date

Information of Legally Authorized Representative

Complete this section if this MI-POST form was signed by a Patient Advocate/DPOAHC or Court-Appointed Guardian.

Address

City

State

Zip Code

Phone Number

Alternate Phone Number

Section F – Individual Assisting with Completion of MI-POST Form

Print Preparer's Name

Title

Date

Preparer's Signature

Organization

Phone Number

Section G – To Reaffirm or Revoke this Form

This MI-POST form can be reaffirmed or revoked at any time, verbally or in writing. See MDHHS-5837 for further details on reaffirmation or revocation. **If this document is revoked or is not reaffirmed, and a new form is not completed, full treatment and resuscitation will be provided.**

Healthcare Provider Name/Collaborative Physician (if applicable)

Healthcare Provider Signature

Patient/Representative Name

Patient/Representative Signature

Reaffirmation Date

Send form with Patient whenever transferred or discharged.

HIPAA permits disclosure of MI-POST to other Health Care Professionals, as necessary.

The Michigan Department of Health and Human Services will not exclude from participation in, deny benefits of, or discriminate against any individual or group because of race, sex, religion, age, national origin, color, height, weight, marital status, partisan considerations, or a disability or genetic information that is unrelated to the person's eligibility.

CONCLUSION

Many older adults have chronic illnesses and need extensive care for a long time before they die. This can be very difficult for patients and caregivers. Bereavement care promotes healing for everyone involved.

Planning for the end of life is an important part of bereavement care. It ensures that treatment corresponds to patients' wishes and values. Planning can reduce stress on family members who may face heart wrenching decisions about care. Today there are tools such as POLST forms and advance directives to help with this process.

We recognize that thinking and talking about illness, death, and grief can be challenging. We hope that this booklet offers you some guidance for considering how to approach these challenges. It is important to have conversations with healthcare professionals and other people you trust about planning, decision making, and coping with grief.

I think care facilities and caregivers need to embrace the idea of grief. If you have physical deterioration, you've usually got a grief issue. Patients grieve because they're not the same people they used to be. I think grief needs to be part of the overall caregiving plan. I always picture care as person-centered; I picture the person there and then these things that need to be taken care of all around them. Grief needs to be one of those things.

— Family Member and Caregiver

RECOMMENDATIONS

This booklet is designed to help residents and their families acknowledge grief and to encourage use of readily available resources. Although each person's experience of grief is unique, we offer the following general recommendations.

ADDRESSING ONE'S OWN GRIEF

1. Every facility has different available resources. If you are experiencing grief, ask an admissions director or other senior staff member what resources are available to you.
2. When people offer support, take them up on it. Remember that people often get joy out of helping others. Do not worry about being a burden.
3. Remember that any loss you grieve (people, animals, things) is a real and valid loss.
4. Although talking isn't the only way to express and process emotions, it may help to talk to someone who has walked in your shoes. Sharing your experience with someone who has gone (or is going) through something similar can help you feel less alone and confused.
5. It can be very beneficial to talk with trusted and skilled professionals about your grief. Many facilities offer therapists, social workers, chaplains, or other staff trained to help with grief.
6. Remember that grief comes in many forms. What is important is to notice your own habits and the extent to which grief affects or changes them.
7. Be active. Walk or exercise your body and pursue activities that engage your mind as well.
8. It can take time and effort to locate and engage the right supports. We encourage you to keep trying different options until you find a good fit.
9. If you are a caregiver, make time for restorative breaks. Make a list of specific things that you would welcome other people doing to help you. This way, when someone asks if they can help, you can make clear and specific suggestions as to how.
10. Attend and participate in memorial services. If your facility does not hold these regularly, you may want to encourage the facility to do so.

HELPING OTHERS WITH THEIR GRIEF

1. Let the grieving person know you care. Even if that person may not want to see anyone for a while, a simple note or phone call saying you are thinking about them can have a positive effect.
2. Share activities and experiences together.
3. Avoid phrases like "I know how you feel" or "You need to get over it." Simply saying "I'm sorry for your loss" is better.
4. Offer to do something specific for a grieving person, like "may I bring coffee tomorrow at 10?"
5. Consider forming a group of volunteers who are responsible for checking in on those who are grieving. Volunteers who have had similar grief experiences can be especially helpful.

PLANNING

1. Keep formal written records of your wishes and instructions for your care.
2. Talk with a doctor or planning assistant (admissions director, social worker) to determine which forms and formats are appropriate for you.
3. If possible, discuss your wishes and specific instructions with your appointed health care proxy.

ADDITIONAL RESOURCES

1. Alzheimer's Association: <http://www.alz.org>
2. National Hospice and Palliative Care Organization: <http://www.nhpc.org>
3. National POLST Paradigm: <http://www.polst.org>

Next Steps:

WHAT ARE YOUR THOUGHTS ABOUT GRIEF AND COPING MECHANISMS?

ARE THERE HELPFUL RESOURCES AVAILABLE TO YOU? IF NOT, WHAT COULD BE PROVIDED TO HELP YOU?

NOTES

Appendix: Background Research on the Impact of Grief on Health

1. *The Impact of Mid- and Late-Life Loss on Insomnia: 2010 HRS Cohort.* Simpson et al (2014). Family & Community Health, 37(4): 317-326.

This study examines insomnia after loss of a loved one. Insomnia is responsible for \$6.6 billion in healthcare-related costs each year. It also increases one's risk for heart disease, diabetes, anxiety, and depression. Adults who have lost a spouse, child, or more than one family member are the most likely to suffer insomnia. The highest rates of insomnia after loss occur in women aged 50 to 59 years and men aged 65 to 70 years. Any kind of physical activity - like walking - reduces this risk by one-third.

2. *In a Longevity Society, Loss and grief are Emerging Risk Factors for Health Care Use: 2010 HRS Cohort Aged 50 to 70 years.* Miles et al. (2016). American Journal of Hospice & Palliative Medicine, 33(1): 41-46.

This study examines the risk for being hospitalized after death of a parent, spouse, sibling, or child among persons aged 50 to 70 years. Loss is associated with a 20-30 % increased risk for an overnight hospital stay.

3. *Population-level impact of loss on survivor mortality risk.* Allegra et al. (2015). Quality of Life Research, 24(6): 2959-2961.

This study shows that the loss of close relative (parent, spouse, sibling, or child) is an independent contributor to risk for mortality of the bereaved. It also suggests that physical activities – like walking - “strongly reverses” the risk.

4. *Refusing to Admit Defeat: Physicians' Reluctance to Discuss End of Life Care.* Brown & Miles. (2016). Palliative Medicine & Care, 2(1): 1-2.

This is a thoughtful piece derived from an interview with a retired surgeon who is also a nursing home resident. He suggests that physicians' reluctance to have frank end of life discussions with patients stem from a need to avoid 'failure'. His commentary and the reports of others suggest a broader range of views within the physician community about end of life care. His discussion has implications for the use of POLST as a therapeutic tool and training future physicians.

5. *Indicators of resilience and healthcare outcomes: 2010 HRS Cohort.* Ezeamama et al. (2016). Quality of Life Research, 25: 1007-1015.

The other studies in this list indicate that there is an increased risk of insomnia, hospitalization, or death after the loss of a parent, spouse, or adult child. There are factors, however, that clearly show the positive effects that prior experience with adversity can have to build resilience. Persons aged 50 to 70 years draw on this experience to buffer the negative health impact of loss. Once again, mild physical activity – like walking - was shown to have a consistently protective effect on health outcomes.



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