

End-of-Life Care, Memorial Services and Moving On

By Kathy Laenhue, M.A.

Introduction

Norman Cousins said, “Death is not the ultimate tragedy. The ultimate tragedy is depersonalisation – dying in an alien and sterile arena, separated from the spiritual nourishment that comes from being able to reach out a loving hand...”

There was a time not so long ago where the death of residents in residential care settings was hidden. The final illness of the person was not mentioned to other residents, and when death occurred, not only was the dying resident often left alone, but the other residents were sent to their rooms or a ‘safe place’ so that the removal of the body would not be seen. That removal often consisted of a body bag on a wheeled stretcher hastily pushed through a back door. Often residents and staff were not even told of funeral plans, never mind being given opportunities to attend.



Thankfully, we now embrace far better alternatives. This course will talk about:

- Creating a good death in residential care settings
- Supporting families and staff as the end of life nears
- Ways to honour the life of the person who died
- Moving on

*It's not that I'm afraid to die.
I just don't want to be there when it happens.*
Woody Allen

Creating a good death

Defining a 'good death' has multiple elements. They include:

- Making the dying person comfortable and at ease; and as much as possible, honouring the dying person's wishes related to where they will die
- Helping the family and friends cope
- Supporting the staff

A dignified death – hospice principles

An increasing number of older adults choose to remain at home during their end-of-life care, and 'home' for them often means a nursing home or assisted living residence. With the help of hospice organisations that offer palliative care, they are generally able to be kept comfortable and relatively pain free.

In 1990, Hank Dunn, then a chaplain for Hospice of Northern Virginia, USA, wrote a booklet called *Hard Choices for Loving People*. According to Mr Dunn, 'hospice' was a medieval term related to 'hospital' and 'hospitality' that described a place of rest and shelter for sick or weary travellers. It was "first applied to specialised care for dying patients in 1967, when Dr Cicely Saunders established St Christopher's Hospice in a residential suburb of London."



Hospices are aimed at relieving pain and providing comfort. People who choose hospice care have usually made the decision to forego further diagnostic testing, along with treatment (eg chemotherapy), and life-prolonging measures, such as feeding tubes. (Mr Dunn does a masterful job of explaining how CPR and other 'life-prolonging' measures can actually increase the suffering of frail older adults and those with dementia. But that is a topic for another course.)

What the hospice patients do receive are 'comfort measures' which may include oxygen to make breathing easier, aspirin or paracetamol to reduce a fever, and pain medication. Most importantly, both patients and families are surrounded by loving and dedicated nurses, assistants, social workers and counsellors. 'Treatment' may also include additional elements such as music, gentle touch, soft fabrics, pleasing food, and whatever helps the person 'live well' as far as possible in their final days. As we will note later in this course, the goal is to make the end of life as pleasant as possible, with joy and laughter playing an integral part. It's important to remember that many of the comforts a hospice can offer can be put in place by residential care staff at any time.

Think about it . . .

Have you ever witnessed the death of an older adult? If so, what was the experience like? Would you call what you witnessed a 'good death'?

Whether or not you have witnessed anyone dying, how would you define a 'good death'? What are the elements that would make it 'good'?

Summary . . .

A hundred years ago, people frequently died at home, often peacefully, but over the years, as more and more technological devices and medicines have allowed lives to be prolonged, it has become common for people to die in a hospital, often surrounded more intimately by tubes and medical equipment than their loved ones. Now more and more people are choosing to die in more natural circumstances.

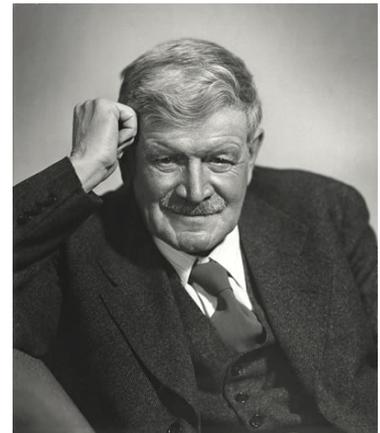
The principles of a hospice, a term that has its roots in shelter and hospitality, have grown increasingly popular over the last 40 years. Hospices are aimed at relieving pain and providing comfort. People who choose hospice care have usually made the decision to forego further diagnostic testing, along with treatment and life-prolonging measures. The 'comfort measures' they receive instead may include oxygen to make breathing easier, aspirin or paracetamol to reduce a fever, and pain medication. Most importantly, both patients and families are surrounded by loving and dedicated nurses, assistants, social workers and counsellors. 'Treatment' may also include additional elements such as music, gentle touch and whatever helps the person 'live well' as far as possible in their final days.

*I detest life-insurance agents.
They always argue that I shall someday die, which is not so.*
Stephen Leacock

Creating comfort

Part-time humourist Stephen Leacock might have wished otherwise, but we all must die someday. (He actually died in 1944 at the age of 74.) The goal is to live a full, joyous, and meaningful life for as long as we can. Ideally, that's until the day we die, but when that's not possible, there is still much we can do to make life comfortable for the dying.

This course uses ideas from Joyce Simard's book, *The End-of-Life Namaste Care Program* (see Resources section), and takes inspiration from her work. Throughout the course we will focus on people who are truly at the end of their lives. Many people who are living with serious illnesses may be able to be much more actively involved with family, friends, and caregivers. Those who do not have dementia are likely to be clearer in expressing their needs and desires than people with dementia who often lose the ability to speak more than a few words at the end of their lives.



This course is not intended to cover medical or nutritional concerns related to the end of life or to give advice on activities of daily living, such as bathing and continence care. Instead, it focuses on creating feelings of comfort and nurture among the dying. The key to this kind of care is *gentleness*. People are gently awakened, gently cared for, gently touched.

A word about slow gentleness with people who have dementia: When people have dementia, gentleness can be especially important, because the deterioration that occurs affects many parts of the brain. While people with Alzheimer’s disease vary widely in the progression of their symptoms, most will eventually lose their ability to walk, sit up and even hold their heads up, and by then they become highly sensitive to motion of any kind. When you want to move them for a shower, for instance, they may flail their arms and protest. People in the latest stage of dementia often flail because they have little control over the movement of their limbs, so if you are hit by them, it is usually a result of the flailing, not an intentional action. (They may also be frightened by *your* movement as you walk towards them at what you consider a normal pace.) Interestingly, many people with dementia near the end of their lives tend to have long periods of sleep during the day followed by a period of restlessness. Their bodies seem to need to move, but they can't control the movement well. As noted below, the range of motion exercises practiced with this group of people is intended to give some structure to restlessness.



In Joyce Simard’s programme, most of the care takes place in a dedicated, carefully designed room. After waking, breakfast and basic grooming, participants are brought to the room where they usually spend the morning in a lounge chair. They leave for lunch and sometimes for an afternoon nap, then come back for more afternoon programming.

Attention is paid to positioning people where they choose within the room (eg near a window, among a group of friends) and to making the room sensually appealing – incorporating soft music, pleasing scents, bright colours, and some natural, but always non-glaring, light. Each participant is always individually welcomed with a smile and called by their preferred name.

As people are moved from wheelchair to lounge chair (remember that these people are too weak to ambulate on their own), they are covered in a colourful blanket, or lighter throw in summer, which has the comforting effect of feeling like swaddling. Older adults are frequently cold, and the blankets keep them warm and cosy. Pillows and other comforting items are placed around them. These comforting items may include a photo of a loved one, a treasured ornament, or various other objects personalised to that individual.

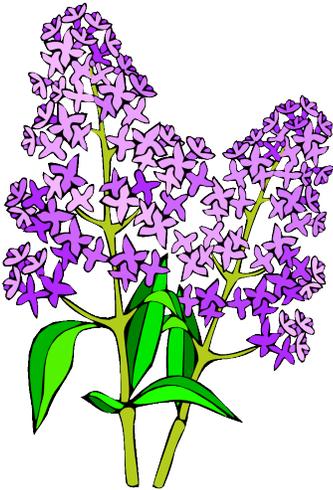
They are provided with a variety of snacks throughout the day – many enjoy sucking on lollipops. Each person must be individually evaluated, of course, but the flavour and moisture in the mouth is pleasurable, there is no need to bite down, and the stick prevents the lolly from being swallowed or choked on.



Morning activities might include:

- Hand washing, followed by a gentle hand massage with lotion – can also be done with face and feet
- Brushing/styling hair
- Manicures
- Shaving (for men)
- Music activities (more detail below)

- Sensory activities – using wind chimes, rain sticks, and humorous items like wind-up chattering teeth. Staff might also make use of touchable fabrics or second-hand clothing made of silk, satin, velvet, fur, flannel, and so on.
- ‘Scent activities’ – some groups use essential oils and lotions, but having fresh, scented flowers such as lilacs filling the room is generally preferable. Sometimes someone will bring in a box of freshly mown grass, and frequently they bake bread in the room.



In the afternoon the staff are more likely to assist the participants with passive range-of-motion exercises taught to them by physical therapists. They might also make use of realistic stuffed animals, balloons or soft balls, and various sports equipment for sharing and discussion.

Among those who are non-verbal, participants are watched carefully for facial expressions and body language that indicates pain, having had enough, needing a rest, or simply finding an activity unappealing.

At the end of life, almost anything a person does takes enormous effort, and therefore they (deservedly) tend to sleep a great deal. However, when you need to get their attention, you can sometimes do so in amusing, individualised ways. If a person’s sense of smell is intact (it may not be in many older adults), peppermint, spearmint and eucalyptus might wake them up. There are lots of little rubber toys (eg rubber ducks) that give out a little puff of air when squeezed. Aim that puff of air at a cheek to cause someone’s eyes to open. Also consider past occupations and sounds they may find rousing, such as a teacher hearing a school bell.

Music is an endless topic, but the chief rule is again to pay attention to personal preferences. People have a tendency to have a lifelong love affair with the music that was popular in their teen years and early 20s, but many people like a variety of types, such as:

- Jazz
- Classical
- Broadway tunes
- Big bands and/or crooners
- Hymns
- Music representing one’s cultural background



Music can be used to energise or calm people, to lift a mood or soothe it. It can serve different purposes throughout the day. One of the most universally appealing types of music when one is near death is a woman’s voice singing softly without accompaniment, like a mother singing a lullaby to her baby. (People who are religious are often calmed by prayers like *The Lord’s Prayer* or a simple blessing.)

With today’s earphones, you can have a room with a dozen people all listening to separate iPods that are playing individually appealing music. Or you could lead a singalong if everyone wants to join in together.

Some of the other listening possibilities include:

- Recordings of the participant’s family members providing greetings, good wishes or reading a favourite story aloud.
- Nature sounds – birds singing, crickets chirping, or a stream babbling can all have enormous appeal.
- A radio recording of an old sports event featuring the soothing voice of a familiar radio announcer.



Think about it . . .

When you are ill and in pain, what do you find comforting?

Have you had success in bringing comfort to someone who was near the end of their life? What did you do?

Do the suggestions above give you ideas for new things to try with specific people you care for? What will you do and with whom?

Summary . . .

The essence of providing comfort care is to move slowly and gently and be attentive to the individual needs and interests of the people you are caring for. They need to be both physically and emotionally at ease.

While people at the end of life may not be able to take an active part in many activities, their quality of life can be maintained by providing an environment that is pleasing and stimulating in just the right amount. Among the activities you might try with them are:

- Daily care (grooming, manicures, applying lotion)
- Sensory (pleasant fabrics and other touchable objects, wind chimes, stuffed animals)
- Scents (pleasing smells from baking and nature)
- Music (based on personal preferences)
- Those related to life stories and personal interests (sports, hobbies, families, etc)

The role of humour and laughter

I have always set personal boundaries of what is funny and what is not.

I have been quoted as saying,

“There are just some things you don’t poke fun at.”

I was wrong.

Laughter rises out of tragedy when you need it the most and rewards you for your courage.

Erma Bombeck

Erma Bombeck was a humourist who died at the age of 69 following complications from a kidney transplant. Humourist Allen Klein used the above quote to open the first chapter of his book *The Courage to Laugh*. He wrote, “I am not advocating that humour should cover up grief or that laughter need replace tears... What I am saying is that laughter and tears are both valid in the dying and grieving process.”

In that same chapter, he listed some of the main points the book would cover. They included the following:

- Death itself is not funny. Things that happen around it are.
- Those who work in the death-and-dying arena understand the need for humour; those who do not, may not.
- Most people who are dying don't want survivors to be morose when they die.
- You can laugh and cry at a loss. Both are appropriate.
- No matter how serious a situation is, humour can help us get through the day.

Humour provides hope and diversion

He goes on to quote Peter Weingold, MD:

“Finding humour in a tragic situation is an extremely healthy step. It is a way of looking toward the future and of saying that this suffering can be put behind us. Humour is something to strive for and embrace. It's a way of saying, ‘The tragedy has *happened* to us, but it does not *define* us.’”

Humour diverts us from both physical and emotional pain and lifts our spirits. It restores our equilibrium when we are off balance.

*Laughter gives buoyancy
so you don't sink to the bottom.
Like a life preserver, it helps
keep your head above water
so you can still breathe...
Laughter is like a breath of fresh air
that you desperately need.*
Patty Wooten

When we enter the room of someone who is gravely ill, we have a tendency to treat the occasion seriously, and may in fact harbour feelings of sadness, anger, anxiety, helplessness, and even repulsion. But now imagine that you are the person lying in the bed, and everyone who comes to visit is expressing some combination of those solemn feelings. Would you want visitors?

Bringing light and cheer

Our role is to bring light. We can't change the circumstances, but we can control how we treat the person going through those circumstances. That doesn't mean we have to tell jokes (unless you're good at it and the person is looking forward to your latest offering), but it does mean that we can bring our smiles and a cheering word.

Interestingly, the cheering word can sometimes be pointing out what's awful. A lot of joking is about pointing out what we have in common that we would rather we didn't. For example, stress management courses often begin with the leader asking three questions:

- How many of you are feeling a little stressed today?
- How many of you are feeling VERY stressed?
- For how many of you is 'stressed' part of your job description?

By the third question people are usually laughing about how stressful their lives are; in other words, they are laughing about their misery.

It works in healthcare settings, too. We can joke about the circumstances people find themselves in, such as visiting someone in traction and saying as we enter, “No, don’t get up.” Jokes like this are what Erma Bombeck might once have said were ‘off limits’, but what they do is say to the person we are visiting, “I know these aren’t ideal circumstances, but I am glad to be here anyway.” Making that clear is one of the best gifts we can give.

As described above, however, we can often do more. Perhaps we can:

- play some music
- sing a song
- take the person for a wheelchair walk outdoors
- read aloud
- bring some chocolate

But most important is the fact that we show up. We make time to be present in the moment with the person. Families need to know this, and so does every member of the staff.

Opening doors

Another benefit of laughter is its ability to open closed doors. In his book *The Courage to Laugh*, Allen Klein tells the story of a woman named Laura who was being treated for 4th stage ovarian cancer, which can be summarised like this:

Laura had worked hard over the oven and stove to prepare a tasty meal for her family, and things seemed to be going well. Just before dessert, she left them for a moment to go to the bathroom. When she saw herself in the mirror, she gasped. The entire front of her wig was ‘a solid melted glob of plastic fibres’ – the result of getting too close to the oven when basting the bird. She looked ridiculous, but NO ONE in her family had said a word all through dinner. As she walked back to the table, she started laughing uproariously over their ability to keep a straight face, and soon everyone else was laughing too. That laughter then opened up the first heart-to-heart conversation the family had had since her diagnosis. Sharing laughter helped them to share their pain and fears.



Many people in caring professions have found humour is the key to unlocking the door that has kept a person’s fear, anger, sadness, denial, and frustration hidden. Shared laughter suggests friendship and trust that leads to deeper relationships.

Think about it . . .

How do you use humour to cope with difficult circumstances?

Have you ever used humour or laughed at a time that seemed inappropriate? What happened? Did it turn out okay?

Summary . . .

Humour and laughter give us hope in the midst of difficult circumstances.

Humour brings:

- A bit of diversion, and therefore respite from emotional (and often physical) pain
- Light and cheer into dark circumstances
- A way to open doors into deeper discussions

In reality, we don't have to be clowns or joke-tellers to bring cheer. We simply have to be present and make clear that we are where we want to be.

What is odd about humour is that, often, it is not about jokes or something funny happening, but about the absurdity or frustrations of the situation we find ourselves in.

When comedian Steve Allen was hospitalised during a serious illness, he overheard a nurse say that his condition was critical.

In his mind he agreed: "I'm critical of the food, of the nurses, of the doctors..." and he had to smile.

Laughter is a super-sized pill that is easy to swallow.

Helping the family cope

A 'good death' as we have defined it here is focused on the needs and desires of the person who is dying, but you can be certain that family members are likely to have their own definitions that may vary widely among siblings, parents and other parties.

- One daughter may want their mother to die at the family home.
- The son may be frightened by the prospect of making mistakes in their mother's medical treatment at home and wants her to stay in the nursing home.
- Another daughter who has long been estranged and has unfinished business with their mother may want treatment that prolongs her life.
- Perhaps the husband is still alive, but has dementia. He may or may not be upset by his wife's final illness, but now there are concerns about his care needs too.

In her book, *Talking about Death*, Virginia Morris says that what most of us mean by a 'good death' is that in a year or two, or 10 or 20 years from now, we will be able to look back and say, "That was as easy as it was possible to make it." We want the person to be comfortable, pain-free (if possible), serene, valued and uplifted by people who love and care for them. Virginia says that usually happens when family members are urged to ask themselves "What would *they* want me to do?" rather than "What do I think should be done?"

When we are talking about people who are in the late stages of Alzheimer's disease, their seeming lack of responsiveness towards family members can be particularly disheartening for the family. The first thing to note is that people with dementia always know who loves them. They may not know a person's name, but they often recognise and treasure their loved ones' voices, and they can still be

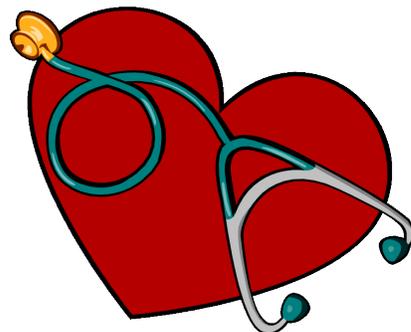
comforted by their loved one's presence. Furthermore, music, touch, smiles and laughter usually provide comfort until the very end of life.

Staff can help these family members by attuning them to subtle signs. People in the last stage of Alzheimer's disease take a long time to track and respond. If pain and stiffness are not a factor for the dying person, particularly for a bedridden person, the family members can lie down next to the person on the bed, give them a hug, or hold and stroke a hand. They can talk soothingly or even sing softly, and give the person time to react. If smiles or return hugs are no longer forthcoming, they can look for the little things:

- Does he follow you with his eyes?
- Do her hands flutter or does her rate of breathing increase?
- Does he make eye contact, or do his eyes flicker or moisten?
- Do her eyes roll beneath her eyelids?

All these are tiny signs of recognition.

Family members have a variety of needs that may need to be addressed, but often the best thing staff can do is simply listen to them. Listening is something there is far too little of in this world, and we all want to be heard.



Supporting the staff

When a person has been living in your residential care community for months or years, and particularly if they have had increasing care needs that require direct involvement of staff, chances are that some people will deeply mourn the person's passing. They will have developed a close relationship with them and be genuinely saddened by their death. Sometimes a person dies suddenly of a heart attack or other catastrophic illness, but most residents increase in frailty over time, and they can become quite close to the staff members who assist them.

You obviously can't offer bereavement leave to staff every time a resident dies, but it's important to treat the grieving of staff seriously. They need time to talk about and mourn the resident, not just at the time of the resident's death, but in the months that follow. Some may need formal grief counselling, but most will be helped if the person continues to be talked about in daily life:

Wouldn't Mary have loved this?

I wish Mary were here to give us her ideas. She was always so creative.

As noted elsewhere, talking in front of other residents about residents who have died is also reassuring to them, allowing them to see that the ripple effect of their life will live on too.



Think about it . . .

What do you do in your community to support families who are dealing with the dying of a loved one? Do you have ideas for things you might do better?

How are staff supported through their grief in your community? How would you like them to be supported?

Summary . . .

We can help families cope with the dying of a loved one by, first and foremost, being a good listener. We can also show them ways to engage with their loved one and to be attuned to subtle signs that show their loved one is aware of their presence.

We can help staff cope by recognising that they are likely to mourn the loss of people they care for too. We can provide counselling, if needed, and we can honour the person by continuing to talk about them and the things we miss about them.

Honouring a person's life and death

If you have done a good job as a residential care community, you will have shown how much each resident is valued throughout each of their lives. But the post-life honouring begins at the moment of death.

As noted above, the person should be surrounded by people who value them at the time of death. A caveat to this is that hospice workers and others who have witnessed many deaths will tell you that people choose their moment of death, and some people choose to die alone, when others are out of the room, or when the dying person is sure that a beloved relative has the support of another trusted friend nearby.



Sometimes family members want to be alone with their loved one at the time of their death. At other times, they are grateful for the presence of staff, hospice workers, and/or other residents. Take your cue from the family.

Once a person has died, some family members want to leave immediately; others choose to linger for reasons of their own. When they do leave, it's important to make sure they do not leave alone – other family members, friends, clergy or a member of your staff should accompany them at this difficult time, particularly if the next of kin is a frail spouse.

If the person has died without family around, family members need to be notified as quickly as possible. It's good practice for staff members to wash the body and dress it in fresh pyjamas or a nightgown in preparation for the arrival of family after the person's death – that is, if they have not been there at the time of death, and assuming they will be arriving soon. Removing medical equipment, playing soft music and keeping the lights low can also make the family's adjustment to their loved one's death a bit easier.



If family members live far away and are not present at the time of death, it is still a kindness to wash the body and re clothe it before the funeral home staff or medical personnel (for autopsy) arrive.

It can also be meaningful for other residents and staff to have an opportunity to visit the body before it is taken away, but if that is not feasible, leaving the room unoccupied with the bed covered by a blanket and with a single rose lying across it can create a pleasant place for everyone to say goodbye over the next 24 hours.

It can be fitting to accompany the body out of the residential care community as it is removed into the funeral hearse or other transport. Draping a flag or blanket over the trolley holding the body adds dignity, and family (if they desire), friends, and staff could also walk with the trolley from the resident's room to the hearse. Sometimes a prayer is said before the body is placed in the hearse. Sometimes there is a final laying on of hands over the blanket or flag. Sometimes those accompanying the body even spontaneously wave as the hearse drives away. It may seem absurd, but it can be strangely comforting.

The reality is that many absurd things happen when we are dealing with death, and again humour is an important coping mechanism. In his earlier book, *The Healing Power of Humor*, Allen Klein included a story told by humourist Art Gliner who was called to the hospital after his father died:

For some reason the nurse handed me a plastic container that held my father's [false] teeth. I had carried that container around with me for fifteen or twenty minutes to different parts of the hospital before I realised what I was holding. As I saw the absurdity in this, I turned to my brother-in-law and remarked, "I never go anywhere without my father's teeth."



Laughter can be the first step toward healing.

Think about it . . .

How is a person's death handled in your residential care community?
Do you have ideas about how to make it a meaningful ritual?

Summary . . .

We can begin to honour a person's life right from the moment of death, when we treat the passing with kindness towards all who are present and prepare the body with dignity. We can also provide reassurance to other residents when we show respect for the person who has died and give everyone a chance to say their farewells.

Funeral services

In most cases, funeral services will not take place at your residential care setting. This usually means that residents and staff who may wish to attend may find it difficult to do so. If possible, however, do provide opportunities for staff members and residents who felt especially close to the resident to be present. (Be aware that the member of staff who feels closest may be a housekeeper, part of the dining staff or a direct care assistant. You send an important message about your community when you give them the same opportunity to attend as the executive director, who may, in reality, have known the person less well.) This serves several purposes:

- It tells the family that the resident was important to the residential community where they lived.
- It is cathartic for the residents and staff who wish to honour the resident in this way.
- It is reassuring to residents that the people they care about (staff and fellow residents) will likely be at their own funeral when it comes. For some, this is important.

*They say such nice things about people at their funerals
that it makes me sad to realise
I'm going to miss mine by just a few days.*

Garrison Keillor

Memorial services

Within a week of the death of a resident, plan a memorial service within your residential community, whether or not family members choose to attend. This gives all the residents and staff who wish to remember the person another opportunity to do so. Depending upon the person's religious preferences, a member of the clergy may or may not be the leader, and prayers and hymns may or may not be said and sung. The primary purposes of the memorial service are to honour the person who has died, and to assure the other residents that they, too, will be remembered when they die.

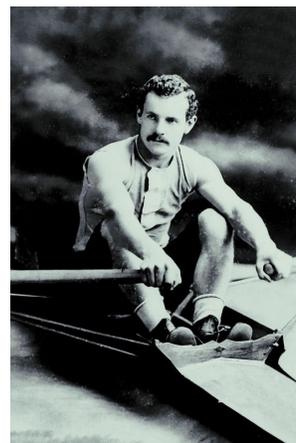
Whether or not family members ultimately decide to attend or be part of your home's memorial service for a resident, they should be invited to help plan it. Give them an opportunity to suggest elements in-keeping with their loved one's desires, such as a favourite hymn or scripture reading. Perhaps they will also be willing to share feelings, stories or photographs during the service.

Other suggestions for preparing a memorial service include the following:

- Try to schedule the service at a time when staff members who had the most contact with the resident can attend.
- Place a picture of the deceased resident next to the notice of when the service will take place.
- Invite all residents, family members and staff to attend (as well as friends and hospice workers who may have been involved).
- Recruit an appropriate member of the clergy or a layperson to lead the service.
- Set up the room with chairs in a semi-circle so that attendees partially face each other – this facilitates group interaction and provides a stronger feeling of connectedness.

And some suggestions for during the service:

- Pass a recent, clear photograph of the deceased around the room, to help residents remember them.
- Provide a brief, written life history of the deceased based on their participation in activities and your own memories of the resident. If they had a particular hobby such as painting, quilt-making or woodcarving, samples might also be displayed for everyone to see.
- Encourage participants to express their feelings and memories – don't be afraid to laugh or cry as a group or individually. Sometimes people do not want to speak in front of others, but are willing to have their written thoughts read aloud by someone else.
- Be sensitive to others' emotions and feelings. Note where follow-up may be appropriate.
- The 'main event' is a time when anyone present can stand up and share memories of the person. Often these evoke laughter, even when the remembrance isn't overtly funny. Saying something like, "Mary certainly loved correcting our mistakes," is likely to make people smile, even though it may have been frustrating at times.



Generally, even residents with dementia are able to participate in such a service, as long as it is kept relatively short.

If a good death is one in which a person dies peacefully surrounded by family and friends, a good funeral or memorial service might be described as one at which the person is remembered fondly for

both their accomplishments and their quirks. Author and columnist Calvin Trillin said, “The most remarkable thing about my mother is that for thirty years she served the family nothing but leftovers. The original meal has never been found.” If you had a mother like that, the memory makes you both laugh and cry – a perfect funeral tribute.

Allow everyone to have their say, if they want to. Then serve light refreshments.

Think about it . . .

Have you ever attended a ‘good’ funeral or memorial service? What made it good?

Have you ever seen how laughter can help people cope with the loss of a loved one? What was said or done that was funny?

Summary . . .

Funeral and memorial services are a way for us to honour the person who has died by showing everyone how they live on in our memories. We all hope others will remember us fondly, so it is important to include everyone who was close to the person who died in the invitation to the service.

Expressing sympathy

Many people – residents and staff – may not want to get up and speak at a memorial service but still want to express their condolences to the family. People can send individual notes or you can write a group note composed at a staff meeting or as an activity with residents. Many of us are awkward and don’t know what to say when someone is grieving, so offering staff a training class about this topic could also be helpful.

What not to say: Edna Ballard, in her (now out of print) booklet, *Managing Grief and Bereavement*, suggested that listening in non-judgmental silence is often the best thing we can do for the grieving person. Here are some of the things she said NOT to say:

- **It’s time to get on with your life.** What right do you have to say how long another person should take to work through their grief?
- **It’s God’s will. . . At least he’s/she’s not suffering anymore.** Where is the comfort for the grieving person in those statements?
- **You have to be strong. . . or You are holding up well.** This means the grieving person won’t feel able to lean on you for support, or show you their weaker moments.
- **You don’t mean that. . . or You shouldn’t say that.** When someone is grieving, they may say a great many things that they wouldn’t normally say in less stressful times. Give them a chance to rant.
- **Oh, I know how you feel; when Fred was dying, I. . .** Sharing what you went through demotes the other person’s loss. The exception to this is sharing embarrassing moments – many of us have made fools of ourselves in grief and this can provide an opportunity to laugh together. When your friend expresses their embarrassment over bursting into tears at an inopportune moment, and you can top it, do so. Laughter is an effective lubricant for the passage through grief.

- **Frank, how are you doing? Did you see the golf at the weekend? How about that hole in one?** Don't avoid using the name of the person who is deceased or acknowledging the continuing grief of family and friends. Don't change the subject. The bereaved person not only has a need to validate their loss by talking about the person who is gone, but will appreciate you remembering that their loss will be especially painful during holidays and on special dates (anniversaries, birthdays, etc). Don't be afraid of reminding the person of their loss; they are already thinking about it.

*I didn't go to his funeral, but I sent a nice letter
saying I approved of it.*
Mark Twain

Send a note: When a carer is mourning in 'anticipatory grief', there are various appropriate greeting cards to do with coping or providing encouragement, and when a person has died, every shop offers a choice of sympathy cards. But never send a card with just your signature. Add at least a line or two in your own words, even if it's just, *I don't know what to say at this difficult time, but this card expresses my feelings for you.*

Brevity is not a shortcoming. A pretty notecard on which you have scrawled only, *I am so sorry for all that you are going through. Please know that my thoughts (and prayers, if religious) are with you,* is far more welcome than you might imagine. You are staying connected through your words.

When a person has died, a personal note is especially important, but keep in mind the purpose. You can't fix a death, so you don't have to offer solutions; you simply have to acknowledge the loss to yourself (when appropriate) and to the mourner (in all cases). Be as specific as you can be.

- Describe what traits, characteristics, or interests you enjoyed about the person who has died. Mourners want to know that others thought as highly of the deceased person as they did. You don't have to go overboard though.
Your father was stubborn and opinionated, but he was also a man of integrity and intelligence and passionate beliefs. I admired him.
- Describe specific events that may stir up fond memories in the mourner.
*I remember our trip to the Lake District, or
I remember his hilarious stories of visiting his uncle's farm and being terrified of the cows, or
I remember how she loved to play the saxophone.*
- Describe the person's career or community accomplishments.
*The art auction will never be the same without him, or
She will always be my favourite teacher.*
- Describe the person's love of the mourner.
*I know your mother was proud of how you raised your children under such difficult circumstances, or
Your father loved to talk about his son, the journalist.*



- Even if you never knew the person who has died, you can sympathise with the loss of the person left behind.

I know these last years have been difficult for you and that you feel uncertain about the future. Know that I think of you every day and send my thoughts of love and support.

To live in hearts we leave behind is not to die.

Thomas Campbell

Memorial gifts

Sometimes families are extremely grateful to the staff and residents for the support provided in the last years of their loved one's life and want to leave a lasting memorial. This is a matter that must be handled with delicacy, of course, because it would be inappropriate to ever hint that such a gift was expected.

At the same time, if a family member brings up the suggestion, be prepared with a 'wish list' of possibilities that reflect knowledge of the individual.

- If a person loved to sit outdoors under a tree, a gift of a memorial bench or the planting of another tree (possibly with plaques identifying the gift) might be appropriate.
- The family of a woman who loved art might give art supplies.
- The family of a man who loved woodcarving might provide some woodworking equipment.
- The family of someone who loved visits from musicians might make a contribution to the entertainment fund.

As delicately as possible, determine how much the family wishes to spend, because what can be done with £20 is far different from what can be accomplished with much larger sums, but no family member should ever be made to feel that a gift offered is too small.

Where a tree or a bench is gifted, always invite the family to a dedication ceremony. If money is given for an event, such as a concert, invite the family to come along. If art or craft supplies or equipment is gifted, send a thank-you note accompanied by related photos of finished artworks or woodworking projects by the residents. The planting of a tree might even be incorporated into a memorial service, but other gifts might require more time to arrange.



Note that it is also possible that residents and staff might want to give a gift in honour of a resident who has died as well. In that case, the money is usually best given to a fund for a particular purpose. No one should ever be coerced to give, and the amount raised should not be revealed, in order to avoid competition between deceased residents. You do not want anyone saying things like, "I will gladly contribute to Mary's memorial fund, but George was a cantankerous old soul who doesn't deserve my money."

Moving on

We all hope that our lives have a ripple effect. We want to live on in the memories of others after we've died.

When appropriate – when it comes up naturally – it is good to verbally express how much the deceased person is missed.

- Both residents and staff might comment on how much the person would have enjoyed a particular activity, or how everyone laughed over something they once said, or how everyone admired a talent of theirs. It not only feels good to remember the person for their own sake, but because we all (residents especially) hope that others will continue to think about us when we are gone.

Family members may pull away from your residential community after their loved one dies, but many who have made friends with staff and other residents find that staying involved helps fill the void in their lives and enhance the person's memory. Look for ways to keep family members involved.

- They might befriend a resident who has no local family.
- A family member might offer a special talent such as accompanying a singalong with their piano playing.
- Others might provide support to another family going through the end-of-life process.



Some family members need time off for their own healing, but if you stay in contact with them – send a 'thinking of you' card signed by staff three months after the funeral, for example, and again at six months – you may find that you can nurture invaluable volunteers, who are grateful to continue to be needed.

If the family has provided a memorial gift, it is also a nice gesture to call attention to it now and then with residents.

- A garden bench dedicated to a past resident might be a good place to gather for small group outdoor reminiscence sessions.
- Hanging birdhouses from a memorial tree might then provide a perfect place to host an activity on recognising birdsong.
- If a memorial gift was used for art supplies, the resident art teacher might occasionally note how lucky the group is to have quality paints and brushes, thanks to the resident's family.

Think about it . . .

How is sympathy expressed to families in your residential care community?

Do you stay in touch with former residents' families over time? How?

What opportunities do families have for memorial gifts in your community?

Summary . . .

Many of us feel awkward when it comes to expressing sympathy in person or by notecard, but it is always better to acknowledge those awkward feelings than to say nothing at all. Often, we are doing better than others when we at least bring up the deceased person's name, because the person who is mourning is eager to talk about them, and grateful if we simply listen.

When we are at a loss for words, it can be helpful to express anything you remember about that person – their personality, interests, skills – or any shared memories you have about them. It is also helpful to the person in mourning to hear how much the deceased person is missed among residents and staff, or the kind words they said about the person who is mourning.

Another way that a person can live on is through memorial gifts and by keeping the family of the person who has died involved in your residential care community. Some families and friends need time away to heal, but may be drawn back in time, particularly if they can be made to feel useful and needed.

The highest tribute to the dead is not grief but gratitude.

Thornton Wilder

Additional resources

NHS Hospice Care website

<https://www.nhs.uk/conditions/end-of-life-care/hospice-care/>

The End-of-Life Namaste Care Program for People with Dementia written by Joyce Simard

<https://amzn.to/3AwJ6zm>