

At the end of life:

Comfort care provides a peaceful death

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One of the biggest, most difficult, challenges for caregivers, is caring for elders when death is near.

It's a difficult time for everyone.

But it can be especially difficult for caregivers because they have the additional responsibilities of not only caring for the needs of the dying elder, but also taking care of the needs of many relatives and friends who want to be with the elder as death approaches.

This means that frontline caregivers are often an important, central, factor in the dying experience, for everyone involved.

To make it even more challenging, there are also varying opinions among friends, relatives, and the elders themselves about how a dying elder should be cared for.

Some believe that the elder should be given all possible medical help and resuscitation to extend life as long as possible.

And others believe that the elder should be allowed to die a peaceful, natural, death with as little mechanical and medical help as possible.

Alzheimer's makes it difficult

And if the elder has Alzheimer's, all this is made even more difficult.

That's because the Alzheimer's elder cannot be involved in any of the decision-making about their death.

It can be very difficult for caregivers to know how to care for them, because they're not able to tell them about problems they're having.

“Comfort care is the special, compassionate care that's given to elders when death is near”

New caregivers can find the experience especially difficult.

But you'll get better at this very important caregiving task with more experience.

And you will eventually find that your own personal caregiving can help both elders and friends and relatives approach the death experience as well as possible.

Knowledgeable caregivers are, without a doubt, a huge beneficial asset for the care of those elders who are dying.

Comfort care

First off, you need to know about “comfort care”... sometimes called “palliative care”... the peaceful, natural approach to dying.

Most experts recommend this approach, especially when it is certain that death is inevitable.

Comfort care is the special, compassionate care that's given to elders when death is near, to allow them to have a peaceful death which comes naturally, without the use of medical techniques that can artificially extend their life.

Your own personal caregiving can help your elders approach the death experience as well as possible.

End-of-life care is a very important part of the longterm caregiver's job. And it's also one of the most challenging of all caregiver tasks.

Needs improvement

The World Health Organization has extensively researched end-of-life care, and considers it a major medical problem worldwide, where improvements are badly needed.

The agency recommends a peaceful, natural death through palliative/comfort care procedures, and says this:

"Palliative care is an approach that improves the quality of life of patients and their families... through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."

NIA recommendations

The National Institute on Aging (NIA) recommends similar peaceful death procedures.

"Comfort care is an essential part of medical care at the end of life. It is care that helps or soothes a person who is dying.

The goal is to prevent or relieve suffering as much as possible while respecting the dying person's wishes."

So, you can see that throughout the world, caregivers are increasingly being advised to improve their level of end-of-life care so that the elder dies a peaceful, natural death as free from stress and pain as possible.

"Comfort care" is what it's all about, and CNAs are often right at the very center of providing this.

"Comfort care is an essential part of medical care at the end of life of life"

"Comfort Care is an essential part of medical care at the end of life. It is care that helps or soothes a person who is dying."



Better communication

A National Institutes of Health (NIH) panel that studied end-of-life care said that much more needs to be done to improve caregiving in this area.

The panel found that, for many Americans, a lack of continuity of care, and poor communication between healthcare practitioners, elders, and family members make the end-of-life period a "struggle" for everyone.

One of their early recommendations is that better communication among elders, families, and caregivers "is crucial to high-quality end-of-life care."

It's often a difficult and emotional time for everyone involved.

And, since caregivers are often at the center of it all, they often find themselves not only needing to work compassionately with the elder, but also with family and friends.

Having good communications skills at this time can make a huge positive difference in the end-of-life process.

Each is different

One thing to keep in mind, is that each elder approaches the time of death differently, with their own unique family, spiritual, psychological and medical needs.

And one of your jobs as a caregiver is to do all you can to make sure those unique needs are met for the elder.

To do this properly, you need to learn as much as you can about their individual needs and desires.

Find out about the elder's spiritual needs and wishes, whether or not there's an advance directive that spells out what is to be done relative to resuscitation and life support, and so on.

**Be prepared to listen.
Being a good listener is always an important part of caregiving**



Some things you can do

Caregivers can be a very important factor in providing compassionate care for the elder at this time.

Because of the frequency with which they see their elders, they can actually become one of the most important persons to the elder, at this stage.

So, you need to take this part of your caregiving duties very seriously, and do the best you can. Here are some suggestions that may help:

- **Keep the elder company as much as you can:** chat with them, watch movies or TV with them, read books or newspapers, or just be with the elder. This can also be accomplished by caregivers, family or compassionate volunteers.

- **Allow the elder to express fears and concerns about dying,** such as leaving family and friends behind.

Be prepared to listen. Being a good listener is always an important part of caregiving, and the end of an elder's life is no exception.

- **Be willing to reminisce about the person's life with them.** Reminiscing about the past is often a favorite activity of elders. They love doing it, and it's important in that it gives meaning and importance to their life-well-lived. Being a good listener and a supporter is very important at this time.

- **Ask a few questions** during your conversation with the elder... including topics you may be interested in... and you'll often find it to be an interesting and rewarding time for yourself, as well.

Sometimes, even if the elder is unconscious, researchers believe they can hear what is being said... so don't forget to converse with them, or encourage visitors to do this, even if the elder seems unresponsive.

- **Use comfort touch.** Touch can bring a great deal of comfort to an elder as death nears.

This includes something as simple as holding their hand, possibly gently rubbing the back of it. Or just a hand on the shoulder as you're talking to them.

You can also encourage visitors to use comfort touch as much as they'd like to.

“Better communication among elders, families, and caregivers “is crucial to high-quality end-of-life care.”

Researchers believe that even elders in the later stages of Alzheimer's respond very favorably to this compassionate touch.

- **Reassure the elder that you will honor advance directives,** such as living wills, and any other desires that they may have.

- **Ask if there is anything you can do.**

- **Respect the elder's need for privacy.**

Dignity therapy

Previous research on end-of-life issues has shown that dying patients face enormous psychological distress.

In some instances, this may be even more difficult to bear than physical pain, and may lead to severe depression and suicidal thoughts.

“You need to learn as much as you can about their individual needs and desires.”

A new caregiving program has been developed within a joint study between the University of Manitoba, Manitoba, Canada, and Edith Cowan University, Perth, Australia, which lessens the emotional suffering of your dying elders, and also enhances the quality of their remaining life.

This is something that any caregiver can do, and which can have great benefits for your dying elder... plus their friends and relatives, as well.

The new program is called “dignity therapy,” and consists of giving the terminally ill elder the opportunity to record their thoughts and feelings, and discuss issues that are most important to them.

The recordings, or written transcripts of the recorded sessions, can then be given to the elders for them to share with their loved ones.

One hundred patients took part in the study, whose results were published in the *Journal of Clinical Oncology* by Dr. Harvey Max Chochinov and colleagues.

“The taped sessions, which lasted between 30 and 60 minutes, began with the question, ‘Tell me a little about your life history, particularly the parts that you either remember most or think were most important,’” explained the researchers.

This question helped the caregivers to develop the interview in the most appropriate way, depending on the interest and response of the elder.

Other examples of appropriate questions, as used in the study, included:

- What would you like to be remembered for?
- What are your most important achievements?
- Is there something in particular that you would like to say to your loved ones?
- Are there things you wish for your family?
- Have you any particular advice that you would like to offer them for the future?

“It is also interesting to note that 81% of patients felt that dignity therapy had helped, or would be of help to, their families,” point out Chochhinov and colleagues.

“This distinguishes dignity therapy as a unique end-of-life care intervention in that it benefits the patients and their family members—with real potential for multigenerational impact.”

Importantly, compared to before the intervention, patients showed a significant reduction in suffering and depression.

An elderly woman dying of cancer who participated in the study said:

“This experience has helped me to delve within myself and see more meaning to my life.”

“I really look forward to sharing it with my family. I have no doubt that it will be enlightening to them.”

Note: This activity is only useful with those elders who are not seriously cognitively impaired, such as those in the later stages of Alzheimer’s disease.

Watch for signs of pain. Many elders are in unnecessary pain and suffering.

Watch for signs of pain

The issue of pain at this time is a major consideration that all caregivers need to be alert for.

This is because researchers tell us that many elders are in unnecessary pain and suffering at the end of life. And it’s especially challenging for those with Alzheimer’s, who cannot report their pain and suffering to you.

You don’t want your dying elders to be in pain, or suffering, so you need to do the best you can in determining what type of help they may need.

Dignity Therapy.

In Dignity Therapy, an elder’s answer to questions about his life are recorded, and later written out for friends and relatives to read.

In research tests, dying elders responded very well to this activity.

“This experience has helped me to delve within myself and see more meaning to my life,” said one.

“I really look forward to sharing it with my family. I have no doubt that it will be enlightening to them.”



The National Cancer Institute (NCI) suggests that if you notice any of the following symptoms, the elder may require additional professional care, and that your supervisors should be notified about the situation:

- The elder is in pain that is not relieved by the prescribed dose of pain medication;
- The elder shows discomfort, such as grimacing or moaning;
- The elder is having trouble breathing and seems upset;
- The elder is unable to urinate or empty the bowels;
- The elder has fallen;
- The elder is very depressed or talking about committing suicide.

Experts believe that care for someone who is dying should focus on relieving pain without worrying about possible long-term problems of drug dependence or abuse.

So, be very alert for signs of pain, and if you think pain is not being adequately controlled, tell your supervisor.

Breathing problems

Shortness of breath or the feeling that breathing is difficult is a common experience at the end of life. It’s called dyspnea (disp-NEE-uh).

The National Institute on Aging has some possible solutions to breathing problems: Try raising the head of the bed, opening a window, using a vaporizer, or having a fan circulating air in the room.

Sometimes, medical personnel may suggest extra oxygen, given directly through the nose, to help with this problem.

People very near death might have noisy breathing called a death rattle.

This is caused by fluids collecting in the throat or by the throat muscles relaxing. It might help to try turning the person to rest on one side.

But note that not all noisy breathing is a death rattle.

And, it may helpful to know that this noisy breathing is usually not upsetting to the person dying, even if it is to family and friends.

Skin irritation

Skin problems can be very uncomfortable for the elder.

The problem is, with age, skin becomes drier and more fragile, so it is important for you to help take care of the elder’s skin problems, especially as death approaches in the elder is unable to do so.

Keep a “caregiver’s eye” out for skin problems, such as dryness of the lips and eyes (which are common in near death) and so on.

Always keep your dying elder dry frequently repositioned, to prevent the development of pressure ulcers.

What about eating?

If an elder near death wants to eat, but is too tired or weak, you can help with feeding, says the NIA.

If loss of appetite is a problem, encourage eating by gently offering favorite foods in small amounts. Or try serving frequent, smaller meals rather than three big ones.

But, the agency says that you should not force an elder to eat. Going without food and/or water is generally not painful, and eating can add to discomfort.

Losing one’s appetite is a common and normal part of dying. A conscious decision to give up food can be part of a person’s acceptance that death is near.

Temperature sensitivity

Elders who are dying may not be able to tell you that they are too hot or too cold, so watch for symptoms.

For example, someone who is too warm might repeatedly try to remove a blanket.

You can take off the blanket and try a cool cloth on his or her head. If a person is hunching his or her shoulders, pulling the covers up, or even shivering—those could be signs of cold.

Make sure there is no draft, raise the heat, and add another blanket, but avoid electric blankets because they can get too hot.

Fatigue

It is common for people nearing the end of life to feel tired and have little or no energy, says the NIA. Keep activities simple.

This is a time when family and friends can be of great help in giving comfort. Grandchildren can let their grandfather know how much he has meant to them. Friends can relate how they value years of support and companionship.

For example, a bedside commode can be used instead of walking to the bathroom. A shower stool can save a person’s energy, as can switching to sponging off in bed.

Experts suggest that moving someone to a different place, like a hospital, close to the time of death, should be avoided if possible.

Providing emotional support

Providing emotional support as death nears, is as important as medical support.

And this is where caregivers can also become very highly involved, and be of great comfort and support to the elder, and all concerned

First off, it’s important to realize that each elder will have different emotional and spiritual needs as death approaches, and you need to find out all you can about these preferences ahead of time.

And then, do what you can to comply with them as closely as possible.

Religious and cultural needs

One thing you’ll need to find out, is if there are any special cultural or religious needs that everyone needs to be especially aware of at this time.

Some of these things, in some cultures, may directly impact how you work with the elder at the end of life.

You can ask the elder about their wishes and preferences, plus family, friends, or clergy.

Praying, talking with someone from one’s religious community (such as a minister, priest, rabbi, or Muslim cleric), reading religious text, or listening to religious music may bring comfort to the elder, so do what you can to arrange these visits, if the elder or family desires.

Emotional support, as death nears, is as important as medical support

Family and friends

This is also a time when family and friends can be of great help in giving comfort. They can talk to the elder about how important they were in their lives.

Grandchildren can let their grandfather know how much he has meant to them.

Friends can relate how they value years of support and companionship.

Family and friends who can’t be present can send a recording of what they would like to say or a letter to be read out loud by the caregiver, or family.

Caregivers are often the ones who helped arrange for these very important visits, and give all participants information and encouragement on how to proceed.

It’s an important part of your job, at this time.

What are the signs that death is approaching?

Certain signs and symptoms can help a caregiver anticipate when death is near.

It is important to remember that not every elder experiences each of the signs and symptoms.

In addition, the presence of one or more of these symptoms does not necessarily indicate that the elder is close to death. They're guidelines only.

Here are some signs, from the NCI, that can indicate that perhaps death is approaching:

- Drowsiness, increased sleep, and/or unresponsiveness (caused by changes in the elder's metabolism).

What to do: The caregiver and family members can plan visits and activities for times when the elder is alert.

It is important to speak directly to the elder and talk as if the person can hear, even if there is no response.

Most elders are still able to hear after they are no longer able to speak.

Elders should not be shaken if they do not respond.

- Confusion about time, place, and/or identity of loved ones; restlessness; visions of people and places that are not present; pulling at bed linens or clothing (caused in part by changes in the elder's metabolism).

What to do: Gently remind the elder of the time, date, and people who are with them.

If the elder is agitated, do not attempt to restrain the elder.

Be calm and reassuring. Speaking calmly may help to reorient the elder.

“Giving the elder permission to “let go” can be helpful.”

It is important to speak directly to the elder and talk as if the person can hear, even if there is no response

- Decreased socialization and withdrawal (caused by decreased oxygen to the brain, decreased blood flow, and mental preparation for dying).

What to do: Speak to the elder directly. Let the elder know you are there for them. The elder may be aware and able to hear, but unable to respond.

Professionals advise that giving the elder permission to “let go” can be helpful.

- Decreased need for food and fluids, and loss of appetite (caused by the body's need to conserve energy and its decreasing ability to use food and fluids properly).

What to do: Allow the elder to choose if and when to eat or drink.

Ice chips, water, or juice may be refreshing if the elder can swallow.

Keep the elder's mouth and lips moist with products such as glycerin swabs and lip balm.

If the elder does not want to eat, don't force them... a reduction in appetite is a natural part of the dying process.

- Loss of bladder or bowel control (caused by the relaxing of muscles in the pelvic area).

What to do: Keep the elder as clean, dry, and comfortable as possible. Place disposable pads on the bed beneath the elder and remove them when they become soiled.

- Darkened urine or decreased amount of urine (caused by slowing of kidney function and/or decreased fluid intake).

What to do: Caregivers can consult a member of the elder's health care team about the need to insert a catheter to avoid blockage.

- Skin becomes cool to the touch, particularly the hands and feet; skin may become bluish in color, especially on the underside of the body (caused by decreased circulation to the extremities).

What to do: Blankets can be used to warm the elder. Although the skin may be cool, elders are usually not aware of feeling cold. Caregivers should avoid warming the elder with electric blankets or heating pads, which can cause burns.

- Rattling or gurgling sounds while breathing, which may be loud; breathing that is irregular and shallow; decreased number of breaths per minute; breathing that alternates between rapid and slow (caused by congestion from decreased fluid consumption, a buildup of waste products in the body, and/or a decrease in circulation to the organs).

What to do: Breathing may be easier if the elder's body is turned to the side, and pillows are placed beneath the head and behind the back.

Although labored breathing can sound very distressing to the caregiver, gurgling and rattling sounds do not cause discomfort to the elder.

An external source of oxygen may benefit some elders. If the elder is able to swallow, ice chips also may help.

In addition, a cool mist humidifier may help make the elder's breathing more comfortable.

- The elder turns their head toward a light source (caused by decreasing vision).

What to do: Leave soft, indirect lights on in the room.

- Increased difficulty controlling pain (caused by progression of the disease).

What to do: It is important to provide pain medications as the elder's doctor has prescribed. The caregiver should contact the doctor if the prescribed dose does not seem adequate. With the help of the health care team, caregivers can also explore methods such as massage and relaxation techniques to help with pain.

What are the signs that the elder has died?

- There is no breathing or pulse.
- The eyes do not move or blink, and the pupils are dilated (enlarged). The eyelids may be slightly open.
- The jaw is relaxed and the mouth is slightly open.
- The body releases the bowel and bladder contents.
- The elder does not respond to being touched or spoken to.

Note: After the elder has passed away, there is no need to hurry with arrangements.

Family members and caregivers may wish to sit with the elder, talk, or pray.

When the elder's family is ready, call other family members, friends, and clergy.

Provide or obtain emotional support for family members and friends to cope with their loss.

If the elder does not want to eat, don't force them

Alzheimer's elders love the taste of ice cream. Feeding tubes can interfere with this kind of compassionate caregiving



The special problems for those with Alzheimer's

For elders with Alzheimer's, the final stages of dying can be very difficult for family and friends.

Dr. Stephen Post, professor in the department of bioethics at Case Western University School of Medicine, says that:

“Late-stage AD is characterized by the inability to communicate by speech or recognize family members, the inability to move about without assistance, incontinence, loss of appetite, and loss of the ability to swallow, with death usually resulting from aspiration pneumonia, infection, or coronary arrest.”

Aggressive medical interventions are not recommended for those in the late stages of Alzheimer's disease

Post says that aggressive medical interventions are not recommended for those in the late stages of Alzheimer's disease.

“Many family members are not aware that no longer eating and drinking is part of the dying process, and it is normal,” says Post.

“Cessation of food intake results in the release of endorphins, which reduce pain.”

Feeding tubes block the release of endorphins and can result in weeks of “unnecessary suffering,” Post says, with elders “uremic and bloated and unable to clear mucus from their lungs.”

“Cessation of food intake results in the release of endorphins, which reduce pain.”

Also, feeding tubes interfere with compassionate caregiving at the end of life.

For example, experts advise that “Alzheimer's elders love sweets... even in the later stages... things like milk shakes and ice cream.”

Feeding tubes will prevent caregivers and family from giving their dying elder these types of treats... and the compassion that goes with this kind of thoughtful caregiving at the end of life. **END**

Inservice Quiz

Comfort Care at the end of life

Caregiving Objectives:

1. To understand the very important role that frontline caregivers have in the dying experience.
2. To learn the special, successful, caregiving techniques for dying elders.
3. To learn how to successfully and compassionately attend to the needs of friends and relatives.

1. **True, False.** “Comfort Care” is end of life caregiving that allows the elder to die a peaceful death, with the least possible suffering.
2. **True, False.** Good communication among caregivers, friends, relatives, and also the dying elder is important for compassionate end of life caregiving.
3. **True, False.** Caregivers should not touch a dying elder unless absolutely necessary, as it may frighten them.
4. **True, False.** Caregivers should be good listeners, letting the elder talk about their concerns and wishes.
5. **Which is true about “Dignity Therapy?”** (Check all that are correct.)
 - a. It’s a method of reminiscence, whereby a dying elder records their most important remembrances about their life.
 - b. It’s not only beneficial to elders, but also their friends and relatives.
 - c. In studies, most elders reported feeling much better after their Dignity Therapy experience.
6. **True, False.** Research shows that many elders are suffering with undiscovered pain.
7. **True, False.** Caregivers should arrange as many visits as possible with friends, relatives... including grandchildren... with the dying elder.
8. **True, False.** Most experts do not recommend aggressive medical interventions for dying elders who have Alzheimer’s disease.
9. **True, False.** Not wanting to eat much is normal for a dying elder.
10. **True, False.** Frontline caregivers are often a very important central factor in making the dying experience as successful as possible for all concerned, including the elder, and friends and relatives.

Name _____ Date _____ Score _____

Answers to quiz
Comfort Care

- | | |
|-------|----------|
| 1. T | 5. a,b,c |
| 2. T | 4. T |
| 3. F | 3. F |
| 4. T | 2. T |
| 5. T | 1. T |
| 6. T | |
| 7. T | |
| 8. T | |
| 9. T | |
| 10. T | |