END · OF · LIFE

Helping With Comfort and Care

NATIONAL INSTITUTE ON AGING ■ ✦ ✶ ✹ NATIONAL INSTITUTES OF HEALTH

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End of Life

Helping With Comfort and Care

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Empty-handed I entered the world,
Barefoot I leave it.
My coming, my going
Two simple happenings
That got entangled.

— Kozan Ichikyo (d. 1360)

Introduction

At the end of life, each story is different. Death comes suddenly, or a person lingers, gradually failing. For some older people, the body weakens while the mind stays alert. Others remain physically strong, and cognitive losses take a huge toll. But for everyone, death is inevitable, and each loss is personally felt by those close to the one who has died.

End-of-life care is the term used to describe the support and medical care given during the time surrounding death. Such care does not happen just in the moments before breathing finally stops and a heart ceases to beat. An older person is often living, and dying, with one or more chronic illnesses and needs a lot of care for days, weeks, and sometimes even months.

End of Life: Helping With Comfort and Care hopes to make the unfamiliar territory of death slightly more comfortable for everyone involved. This publication is based on research, such as that supported by the National Institute on Aging, part of the National Institutes of Health. This research base is augmented with suggestions from practitioners with expertise in

helping individuals and families through this difficult time. Throughout the booklet, the terms comfort care, supportive care, and palliative care are used to describe individualized care that can provide a dying person the best quality of life until the end. Most of the stories in this booklet are fictitious, but they depict situations that reflect common experiences at the end of life.

When a doctor says something like, "I'm afraid the news is not good. There are no other treatments for us to try. I'm sorry," it may close the door to the possibility of a cure, but it does not end the need for medical support. Nor does it end the involvement of family and friends. There are many places and a variety of ways to provide care for an older person who is dying. Such care often involves a team. If you are reading this, then you might be part of such a team.

Helping With Comfort and Care provides an overview of issues commonly facing people caring for someone nearing the end of life. It can help you to work with health care providers to complement their medical and caregiving efforts. The booklet does not replace the personal and specific advice of the doctor, but it can help you make sense of what is happening and give you a framework for making care decisions.

Providing Comfort

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

You are probably reading this because someone close to you is dying. Is it a parent or grandparent, your husband or wife, a favorite aunt or uncle, your best friend? You wonder what will happen. You want to know how to give comfort, what to say, what to do. At the same time, you're possibly unsure about what is needed, worried about doing the wrong thing, or afraid of being there—or not being there—at the moment of death.

You might be giving day-to-day care to the dying person, chosen to make health care decisions, or a close family member or friend who wants to help. You would like to know how to make dying easier—how to help ensure a "good death," with treatment consistent with the dying person's wishes.

A "good death" might mean something different to you than to someone else. Your sister might want to know when death is near so she can have a few last words with the people she loves and take care of personal matters. Your husband might want to die quickly and not linger. Perhaps your mother has said she would like to be at home when she dies, while your father wants to be in a hospital where he can receive treatment for his illness until the very end. Some people want to be surrounded by family and friends; others want to be alone. Of course, often one doesn't get to choose, but having your end-of-life wishes followed, whatever they are, and being treated with respect while dying are common hopes.

Generally speaking, people who are dying need care in four areas—physical comfort, mental and emotional needs, spiritual issues, and practical tasks. In this chapter you will find a number of ways you can be of help to someone who is dying. Always remember to check with the health care team to make sure these suggestions are appropriate.

Comfort needs near the end of life:

- Physical Comfort
- Mental and Emotional Needs
- Spiritual Issues
- Practical Tasks

Physical Comfort

There are ways to make a person who is dying more comfortable. Discomfort can come from a variety of problems. For each there are things you or a health care provider can do, depending on the cause. For example, a dying person can be uncomfortable because of:

- Pain
- Breathing problems
- Skin irritation
- Digestive problems
- Temperature sensitivity
- Fatigue

Pain. Watching someone you love die is hard enough, but thinking that person is also in pain makes it worse. Not everyone who is dying experiences pain, but there are things you can do to help someone who does. 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. Don't be afraid of giving as much pain medicine as is prescribed by the doctor. Pain is easier to prevent than to relieve, and overwhelming pain is hard to manage. Try to make sure that the level of pain does not "get ahead" of pain-relieving medicines. If the pain is not controlled, ask the doctor or nurse to arrange for consultation with a pain management specialist.

Struggling with severe pain can be draining. It can make it hard for families to be together in a meaningful way. Pain can affect mood—being in pain can make someone seem angry or short-tempered. Although

What about morphine?

Morphine is an opiate, a strong drug used to treat serious pain. Sometimes, morphine is also given to ease the feeling of shortness of breath. You might have heard that giving morphine leads to a quicker death. Is that true? Most experts think this is unlikely, especially if increasing the dose is done carefully. Successfully reducing pain and/or concerns about breathing can provide needed comfort to someone who is close to dying.

understandable, irritability resulting from pain might make it hard to talk, hard to share thoughts and feelings.

Breathing problems. Shortness of breath or the feeling that breathing is difficult is a common experience at the end of life. The doctor might call this *dyspnea (disp-NEE-uh)*. Worrying about the next breath can make it hard for important conversations or connections. Try raising the head of the bed, opening a window, using a vaporizer, or having a fan circulating air in the room. Sometimes, the doctor suggests 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. There is also medicine that can be prescribed to help clear this up. But not all noisy breathing is a death rattle. And, it may help 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. With age, skin becomes drier and more fragile naturally, so it is important to take extra care with an older person's skin. Gently applying alcohol-free lotion can relieve dry skin as well as be soothing.

Dryness on parts of the face, such as the lips and eyes, can be a common cause of discomfort near death. A lip balm could keep this from getting worse. A damp cloth placed over closed eyes might relieve dryness. If the inside of the mouth seems dry, giving ice chips, if the person is conscious, or wiping the inside of the mouth with a damp cloth, cotton ball, or a specially-treated swab might help.

Sitting or lying in one position puts constant pressure on sensitive skin, which can lead to painful bed sores (sometimes called pressure ulcers). When a bed sore first forms, the skin gets discolored or darker. Watch carefully for these discolored spots, especially on the heels, hips, lower back, and back of the head. Turning the person from side to back and to the other side every few hours may help prevent bed sores. Or try putting a foam pad under an area like a heel or elbow to raise it off the bed and reduce pressure. A special mattress or chair cushion might also help. Keeping the skin clean and moisturized is always important. A bed sore that won't heal probably needs treatment by a wound specialist.

Digestive problems. Nausea, vomiting, constipation, and loss of appetite are common end-of-life complaints. The causes and treatments for these symptoms are varied, so talk to a doctor or nurse right away. There are medicines that can control nausea or vomiting or relieve constipation.

If someone near death wants to eat, but is too tired or weak, you can help with feeding. 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, don't force a person 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. People who are dying may not be able to tell you that they are too hot or too cold, so watch for clues. 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. Keep activities simple. 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.

Medical tests and treatments can be uncomfortable and can drain the strength of a person who is dying. Some may no longer be necessary and can be stopped, as one woman's family learned. At eighty, Catherine had already been in a nursing home for two years since her stroke. Her health began to fail quickly, and she was no longer able to communicate her wishes. Her physician, Dr. Jones, told her family she was dying. He said that medical

tests, physical therapy, and IVs (intravenous tubes inserted into a vein with a needle to give medicine or fluids) were no longer really needed and should be stopped since they might be causing Catherine discomfort. Dr. Jones also said that checking vital signs (pulse, blood pressure, temperature, and breathing rate) was interrupting her rest and would no longer be done regularly.

Then Catherine developed pneumonia. Her family asked about moving her to the hospital. The doctor explained that Catherine could get the same treatment—antibiotics, if chosen, and oxygen—in the familiar surroundings of her nursing home. Besides, he said a move could disturb and confuse her. The family agreed to leave Catherine in the nursing home, and she died two days later surrounded by those close to her. Experts suggest that moving someone to a different place, like a hospital, close to the time of death, should be avoided if possible.

Mental and Emotional Needs

Complete end-of-life care also includes helping the dying person manage any mental and emotional distress. Someone nearing the end of life who is alert might understandably feel depressed or anxious. Encouraging conversations about feelings might be beneficial. You might want to contact a counselor, possibly one familiar with end-of-life issues. If the depression or anxiety is severe, medicine might provide relief.

A dying person might also have some specific fears and concerns. He or she may fear the unknown or worry about those left behind. Some people are afraid of being alone at the very end. This feeling can be made worse by the understandable reactions of family, friends, and even the medical team. For example, when family and friends do not know how to help

or what to say, sometimes they stop visiting. Or, someone who is already beginning to grieve may withdraw. Doctors may become discouraged because they can't cure their patient and feel helpless. Some seem to avoid a dying patient. This can add to a dying person's sense of isolation. If this appears to be happening, try to discuss your concerns with the family, friends, or the doctor.

The simple act of physical contact—holding hands, a touch, or a gentle massage—can make a person feel connected to those he or she loves. It can be very soothing. Warm your hands by rubbing them together or running them under warm water.

Try to set the kind of mood that is most comforting for the dying person. What has he or she always enjoyed? For example, Bill loved a party, so it was natural for him to want to be surrounded by family and friends when he was dying. Ellen always preferred spending quiet moments with one or two people at a time, so she was most comfortable with just a few visitors. Some experts suggest that when death is very near, music at low volume and soft lighting are soothing. In fact, near the end of life, music therapy might improve mood, help with relaxation, and lessen pain. Listening to music might also evoke memories those present can share. For some people, keeping distracting noises like televisions and radios to a minimum is important.

Spiritual Issues

People nearing the end of life may have spiritual needs as compelling as their physical concerns. Spiritual needs involve finding meaning in one's life and ending disagreements with others, if possible. The dying person

might find peace by resolving unsettled issues with friends or family. Visits from a social worker or a counselor may also help. Many people find solace in their faith. 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.

Family and friends can talk to the dying person about the importance of their relationship. For example, adult children can share how their father has influenced the course of 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 could send a recording of what they would like to say or a letter to be read out loud.

Sharing memories of good times is another way some people find peace near death. This can be comforting for everyone. Some doctors think it is possible that even if a patient is unconscious, he or she might still be able to hear; it is probably never too late to say how you feel or to talk about fond memories.

Always talk to, not about, the person who is dying. When you come into the room, it is a good idea to identify yourself, saying something like "Hi, Bob. It's Mary, and I've come to see you." Another good idea is to have someone write down some of the things said at this time—both by and to the one dying. In time, these words might serve as a source of comfort to family and friends. People who are looking for ways to help may welcome the chance to aid the family by writing down what is said.

There may come a time when a dying person who has been confused suddenly seems clear-thinking. Take advantage of these moments, but understand that they might be only temporary, not necessarily a sign he or she is getting better.

Practical Tasks

There are many practical jobs that need to be done at the end of life—both to relieve the dying person and to support the caregiver. Everyday tasks can be a source of worry for someone who is dying, and they can overwhelm a caregiver. Taking over small daily chores around the house—such as answering the door, picking up the mail or newspaper, writing down phone messages, doing a load of laundry, feeding the family pet, taking children to soccer practice, picking medicine up from the pharmacy—can provide a much needed break for caregivers.

A dying person might be worried about who will take care of things when he or she is gone. Offering reassurance—"I'll make sure your African violets are watered," "Jessica has promised to take care of Bandit," "Dad, we want Mom to live with us from now on"—might provide a measure of peace. Reminding the dying person that his or her personal affairs are in good hands can also bring comfort.

Everyone may be asking the family "What can I do for you?" It helps to make a specific offer. Say to the family "Let me help with …" and suggest something like bringing meals for the caregivers, paying bills, walking the dog, or babysitting. If you're not sure what to offer, talk to someone who has been through a similar situation. Find out what kind of help was useful. If you want to help, but can't get away from your own home, you could schedule other friends or family to help with small jobs or to bring in meals. This can allow the immediate family to give their full attention to the dying person.

If you are the primary caregiver, try to ask for help when you need it. Don't hesitate to suggest a specific task to someone who offers to help.

Friends and family are probably anxious to do something for you and/or the person who is dying, but they may be reluctant to repeatedly offer when you are so busy.

Setting up a phone tree or computer *listserv* for the family to contact friends and other relatives can reduce the number of calls to the house. A listserv is a way to send the same message to a large group of people through email. Some families set up a website where they can share news, thoughts, and wishes. These can all save close family members from the emotional burden of answering frequent questions about how their loved one is doing.

Questions to Ask

This section has described what family and friends can do to provide comfort and ease to someone nearing the end of life. Here are some questions to help you learn more about what you might do.

Ask the doctor in charge:

1. Since there is no cure, what will happen next?
2. Why are you suggesting this test or treatment?
3. Will the treatment bring physical comfort?
4. Will the treatment speed up or slow down the dying process?
5. What can we expect to happen in the coming days or weeks?

Ask the caregiver:

1. How are you doing? Do you need someone to talk with?
2. Would you like to go out for an hour or two? I could stay here while you are away.

3. Who has offered to help you? Do you want me to work with them to coordinate our efforts?
4. Can I help, maybe … walk the dog, answer the phone, go to the drug store or the grocery store, or watch the children (for example)…for you?

To Learn More

About Comfort Care:

- *For more detailed information:*
  Caring Connections (National Hospice and Palliative Care Organization)
  www.caringinfo.org ◆ 1-800-658-8898 (toll-free)

- *For information about caring for wounds:*
  American Academy of Wound Management
  www.aawm.org ◆ 1-202-457-8408

- *For "Patient/Family Teaching Sheets" with caregiving tips:*
  Hospice and Palliative Nurses Association
  www.hpna.org ◆ 1-412-787-9301

- *For a music therapist:*
  American Music Therapy Association
  www.musictherapy.org ◆ 1-301-589-3300

- *For information about managing pain:*
  American Academy of Pain Medicine
  www.painmed.org ◆ 1-847-375-4731

Death does not sound a trumpet.

— African proverb

Finding Care

at the End ◆ of ◆ Life

Decades ago, most people died at home, but medical advances have changed that. Today, most Americans are in hospitals or nursing homes at the end of their lives. Some people enter the hospital to get treated for an illness. Some may already be living in a nursing home. Increasingly, people are choosing hospice care at the end of life.

There is no "right" place to die. And, of course, where we die is not usually something we get to decide. But, if given the choice, each person and/or his or her family should consider which type of care makes the most sense, where that kind of care can be provided, whether family and friends are available to help, and, of course, how they will manage the cost.

Hospitals and Nursing Homes

George is sixty-four and has a history of congestive heart failure. One night he is taken to the hospital with chest pain. George and those closest to him had previously decided that, no matter what, the doctor should try to do everything medically possible to extend George's life. So, when

George needed care, he went to a hospital, where doctors and nurses are available around-the-clock. Hospitals offer a full range of treatment choices, tests, and other medical care. If George's heart continues to fail, the hospital intensive care unit (ICU) or coronary care unit (CCU) is right there. Although hospitals have rules, they can sometimes be flexible. If George's doctor thinks he is not responding to treatment and is dying, the family can ask for relaxed visiting hours. If George's family wants to bring personal items from home, they can ask the staff if there are space limitations or if disinfection is needed. Whether George is in the ICU, CCU, or a two-bed room, his family can ask for more privacy.

Who pays for care at the end of life?

How to pay for care at the end of life depends on the type and place of care and the kind of insurance. Medicare, Medicaid, private medical insurance, long-term care insurance, Veterans Health Administration (if VA-eligible), or the patient and his or her family are common sources of payment.

See *To Learn More* at the end of this section for links and telephone numbers for services that are Federal government programs.

In a hospital setting, there is always medical staff available who know what needs to be done for someone who is dying. This can be very reassuring for that person, as well as for family and friends.

More and more people are in nursing homes at the end of life. In a nursing home, nursing staff is also always present. A nursing home, sometimes

The doctor wants to move my relative to the ICU. What can we expect?

The ICU (intensive care unit) and CCU (coronary care unit) are types of critical care units; that is, they are parts of a hospital where more seriously ill patients can benefit from specially-trained staff that have quick access to advanced equipment. The medical staff in ICUs and CCUs closely monitor and care for a small number of patients. Doctors who work in these units are called *intensivists.*

Patients in the ICU or CCU are often connected to monitors that check breathing, heart rate, pulse, blood pressure, and oxygen levels. An IV (intravenous) tube may supply medicines, fluids, and/or nutrition. Another tube called a Foley catheter may take urine out of the body; a tube through the nose or stomach area may provide nutrition and remove unwanted fluids. A breathing tube through the mouth or trachea (windpipe) may be attached to a ventilator or respirator to help with breathing. Often these external supports—designed to be used for a short time—will maintain vital functions while the body heals.

But sometimes, even with intensive care, the body can't heal, and organs start to fail. When this happens, survival is unlikely. In this case, the health care team might talk to the family—and the patient if he or she is conscious—about considering whether or not to continue intensive treatment.

called a skilled nursing facility, has advantages and disadvantages for end-of-life care. Unlike a hospital, a doctor is not in the nursing home all the time. But, plans for end-of-life care can be arranged ahead of time, so that when the time comes, care can be provided as needed without first consulting a doctor. If the dying person has lived in the facility for a while, the staff and family have probably already established a relationship. This can make the care feel more personalized than in a hospital. As in a hospital, privacy may be an issue. You can ask if arrangements can be made to give your family more time alone when needed.

Home

Home is likely the most familiar setting for someone who needs end-of-life care. Family and friends can come and go freely. Care at home can be a big job for family and friends—physically, emotionally, and financially. But, there are benefits too, and it is often a job they are willing to take on. Hiring a home nurse is an option for people who need additional help.

In order to make comfort care available at home, you will have to arrange for services (such as visiting nurses) and special equipment (like a hospital bed or bedside commode). Health insurance might only cover these services or equipment if they have been ordered by a doctor. Work with the doctor to decide what is needed to support comfort care at home. If the dying person is returning home from the hospital, sometimes a hospital discharge planner, often a social worker, can help with the planning. Your local Area Agency on Aging might be able to recommend other sources of help (see page 30 to learn how to contact your Area Agency on Aging).

A doctor has to be available to oversee the patient's care at home—he or she will arrange for new services, adjust treatment, and order medicines as needed. It is important to follow the doctor's plan in order to make the dying person as comfortable as possible. Talk with the doctor if you think a treatment is no longer helping.

Palliative Care and Hospice

Doctors can provide treatment to seriously ill patients in the hopes of a cure for as long as possible. These patients also receive symptom care or *palliative care.* For example, in time George developed anemia along with his heart failure. Managing the anemia can improve some of the symptoms troubling George. It might also make it easier for him to do things like get dressed or bathe on his own. Treating his anemia is part of palliative care.

Recently, the term palliative care has come to mean more than just treating symptoms. In the United States, palliative care now often refers to a comprehensive approach to improving the quality of life for people who are living with potentially fatal diseases. It provides support for family members, very similar to the more familiar concept of hospice care.

In a palliative care program, a multidisciplinary health care team works with both the patient and family to provide any support—medical, social, and emotional—needed to live with a possibly fatal illness. The health care team may be made up of doctors, nurses, therapists, counselors, social workers, and others as needed.

Who can benefit from palliative care?

Palliative care is not just for people who might die soon. It is a resource for anyone with a long-term disease that will, in time, probably cause their death. These include heart failure, chronic obstructive pulmonary disease, or Parkinson's disease. The organized services available through palliative care could also be helpful to any older person having a lot of general discomfort and disability very late in life.

Palliative care can be provided in hospitals, nursing homes, outpatient palliative care clinics, certain other specialized clinics, or at home. Medicare covers some of the treatments and medicine. Veterans may be eligible for palliative care through the Department of Veterans Affairs. Private health insurance might pay for some services. Health insurance providers can answer questions about what they will cover.

In palliative care, you aren't asked to make a choice between treatment that might cure a terminal disease and comfort care. In time, if the doctor believes the patient is not responding to treatment and is likely to die within 6 months, there are two possibilities. Palliative care could transition to hospice care. Or, the palliative care could continue, with increasing emphasis on comfort care and less focus on medical treatment aimed at a cure.

That is what happened with Jack, retired from the U.S. Air Force, who was diagnosed with chronic obstructive pulmonary disease at age seventy. As the disease progressed and breathing became more difficult, Jack wanted to explore experimental treatments to slow the disease. Through the palliative care provided by the Veterans Health Administration, while receiving treatment for his pulmonary disease, Jack was also able to receive the comfort care and emotional support he needed to cope with his health problems. The palliative care program also provided help around the house and other support for Jack's wife, making it easier for her to care for Jack at home.

At some point, curative medical treatment may no longer make sense—it might not help or may actually make the patient more uncomfortable. *Hospice* is designed for this situation. The patient beginning hospice care understands that his or her illness is not responding to medical attempts to cure it or to slow the disease's progress. The hospice approach to end-of-life care is similar to palliative care, in that it provides comprehensive comfort care to the dying person as well as support to his or her family, but, in hospice, attempts to cure the person's illness are stopped.

Hospice is an approach to care, and so it is not tied to a specific place. It can be offered in two types of settings—at home or in a facility such as a nursing home, hospital, or even in a separate hospice center. Hospice care brings together a team of people with special skills—among them nurses, doctors, social workers, spiritual advisors, and trained volunteers. Everyone works together with the person who is dying, the caregiver,

and/or the family to provide the medical, emotional, and spiritual support needed. A member of the hospice team visits regularly and is always available by phone—24 hours a day, 7 days a week.

It is important to remember that stopping treatment specifically aimed at curing an illness does not mean discontinuing all treatment. A good example is an older person with cancer. If the doctor determines that the cancer is not responding to chemotherapy and the patient chooses to enter into hospice care, then the chemotherapy will stop, but other medical care may continue. For example, if the person has high blood pressure, he or she will still get medicine for that.

Choosing hospice does not have to be a permanent decision. For example, Delores was eighty-two when she learned that her kidneys were failing. She thought that she had lived a long, good life and didn't want to go through dialysis, so Delores began hospice care. A week later she learned that her granddaughter was pregnant. Delores changed her mind about using hospice care and left to begin dialysis in the hopes of one day holding her first great-grandchild.

Similar to Delores, real-life humorist and *Washington Post* columnist Art Buchwald, age eighty-one, decided against the kidney dialysis suggested by his doctor. Buchwald entered hospice in February 2006, expecting to die of kidney disease within a few weeks. It was big news when his condition stabilized. When it became clear death was not imminent, Buchwald left hospice. He spent the summer in Martha's Vineyard and died in January 2007.

Some Differences Between Palliative Care and Hospice

	PALLIATIVE CARE	HOSPICE
Who can be treated?	Anyone with a serious illness	Anyone with a serious illness whom doctors think has only a short time to live, often less than 6 months
Will my symptoms be relieved?	Yes, as much as possible	Yes, as much as possible
Can I continue to receive treatments to cure my illness?	Yes, if you wish	No, only symptom relief will be provided
Will Medicare pay?	It depends on your benefits and treatment plan	Yes, it pays all hospice charges
Does private insurance pay?	It depends on the plan	It depends on the plan
How long will I be cared for?	This depends on what care you need and your insurance plan	As long as you meet the hospice's criteria of an illness with a life expectancy of months, not years
Where will I receive this care?	◆ Home ◆ Assisted living facility ◆ Nursing home ◆ Hospital	◆ Home ◆ Assisted living facility ◆ Nursing home ◆ Hospice facility ◆ Hospital

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Art Buchwald on leaving the hospice:

- I maintained everyone has to die—I still do. The hospice gives a person the opportunity to die with dignity. It provides care, help, and as much comfort as possible.
- In spite of the fact that I've been staying in a hospice, I'm not going to heaven immediately. My doctor informs me that I can stop over on Martha's Vineyard on the way there.

Art Buchwald, *Too Soon to Say Goodbye,* (New York: Random House, 2006).

Eighty-year-old Annie had advanced lung cancer and asked for help through a hospice program, so she could stay in the home she had lived in for more than 40 years. A hospice team helped her family and friends with caregiving and everyday activities. They arranged *respite care* for Annie's family—once she went into a facility for a few days to give her husband a break. Respite care can be for as short as a few hours or for as long as several weeks. After Annie died, hospice continued to support her family offering bereavement counseling for a year.

Hospice care was a relief for Annie who didn't want to be a burden to her relatives in her last days. Hospice services also greatly reduced the stress of caregiving for Annie's family. In fact, a widow or widower is less likely to die within 18 months after the death of a spouse if that spouse received hospice services. This was true for Annie's husband who weathered the sadness of her loss without having his health decline. Families of people who received care through a hospice program are also more satisfied with

What does the hospice "6-month requirement" mean?

Some people misinterpret their doctor's suggestion to consider hospice. They think it means death is very near. But that's not always the case. Sometimes people don't begin hospice care soon enough to take full advantage of the help it offers. Perhaps they wait too long to begin hospice; they are too close to death. Or, some people are not eligible for hospice care soon enough to receive its full benefit. In the United States, older people can receive hospice care through Medicare if their health care provider thinks they have less than 6 months to live. Doctors have a hard time predicting how long an older, frail person will live. Health often declines slowly, and some people might need a lot of help with daily living for more than 6 months before they die. Talk to the doctor if you think a hospice program might be helpful. If he or she agrees, but thinks it is too soon for Medicare to cover the services, then you can investigate how to pay for the services that are needed.

What happens if someone under hospice care lives longer than 6 months? If the doctor continues to certify that that person is still close to dying, Medicare can continue to pay for hospice services. It is also possible to leave hospice care for a while and then later return if the health care provider still believes that the patient has less than 6 months to live.

end-of-life care than are those of people who did not have hospice services. Hospice recipients are more likely to have their pain controlled and less likely to undergo tests or be given medicines they don't need than people who don't use hospice care.

Before Annie died, she chose to receive hospice care and agreed to give up treatment, such as chemotherapy and radiation, to try to cure her lung cancer. But she continued to receive comfort care and counseling. If Annie had changed her mind, she could have left hospice care and received treatment for her cancer.

Questions to Ask

Choosing among the different options for care at the end of life can be difficult. Here are some questions that might help you determine what is best for you and your family.

1. How long is this person expected to live?
2. What kind of end-of-life care is needed?
3. Is the most likely caregiver able to give that kind of care?
4. Where would the person who is dying want to have this end-of-life care—a facility or at home, for example?
5. What is the best place to get the type of care he or she wants?
6. Who will pay for this care?
7. Can children, grandchildren, friends, pet, etc., visit whenever they want?
8. Is there a good chance that treatment in an intensive care unit will reverse the dying process, or instead draw it out?

To Learn More

About Hospice or Palliative Care:

- American Hospice Foundation
  www.americanhospice.org ◆ **1-800-347-1413 (toll-free)**

- Center to Advance Palliative Care
  www.getpalliativecare.org ◆ **1-212-201-2670**

- Centers for Medicare & Medicaid Services
  www.medicare.gov ◆ **1-800-633-4227 (toll-free)**

- Department of Veterans Affairs
  www.va.gov ◆ **1-877-222-8387 (toll-free)**

- National Hospice and Palliative Care Organization
  www.nhpco.org ◆ **1-800-658-8898 (toll-free)**

- Visiting Nurse Associations of America
  www.vnaa.org ◆ **1-202-384-1420**

To contact your Area Agency on Aging:

- Eldercare Locator
  www.eldercare.gov ◆ **1-800-677-1116 (toll-free)**

While I thought that I was learning how to live,
I have been learning how to die.

— Leonardo da Vinci (1452-1519)

Dementia

at the End ◆ of ◆ Life

As they reach the end of life, people suffering from conditions like Alzheimer's disease (AD) or Parkinson's disease can present special problems for caregivers. People live with these diseases for years, becoming increasingly disabled. Because they do not die soon after they are diagnosed, it can be hard to think of these as terminal diseases. But they do contribute to death.

Illnesses like Alzheimer's disease make it difficult for those who want to provide supportive care at the end of life to know what is needed. Because people with advanced dementia can no longer communicate, they cannot share their concerns. Is Uncle Bert refusing food because he is not hungry or because he's confused? Why does Grandma Ruth seem agitated? Is she in pain and needs medication to relieve it, but can't tell you?

As these conditions progress, they also obstruct efforts to provide emotional or spiritual comfort. How can you let Grandpa know how much his life has meant to you? How do you make peace with your mother if she no longer knows who you are? Someone who has severe memory loss might not take spiritual comfort from sharing family memories or understand when others express what an important part of their life this person has

been. Palliative care or hospice can be helpful in many ways to families of people with dementia.

Sensory connections—targeting someone's senses, like hearing, touch, or sight—can bring comfort to people with Alzheimer's disease. Being touched or massaged and listening to music, "white" noise, or sounds from nature seem to soothe some people and lessen their agitation.

When an illness like Alzheimer's disease is first diagnosed, if everyone understands that there is no cure, then plans for the end of life can be made before thinking and speaking abilities fail and people can no longer legally complete documents like advance directives. That didn't happen in Ethel's family. She had been forgetful for years, but even after her family knew that AD was the cause of her forgetfulness, they never talked about what the future would bring. As time passed and the disease eroded Ethel's memory and her ability to think and speak, she became less and less able to share her concerns and desires with those close to her. This made it hard for her daughter Barbara to know what Ethel needed or wanted. Barbara's decisions, therefore, had to be based on what she knew about her mom's values and priorities, rather than on what Ethel actually said she would like.

Quality of life is an important issue when making health care decisions for people with Alzheimer's disease. For example, there are medicines available that might slow the progression of this devastating disease for a short time in some patients, generally early in the illness. However, in more advanced AD, some caregivers might not want these drugs prescribed. They may believe that the quality of life is already so diminished and that the medicine is unlikely to make a difference. If the drug has serious side effects, they are even more likely to decide against it.

End-of-life care decisions are more complicated for caregivers if the dying person has not expressed the kind of end-of-life care he or she would prefer. Someone newly diagnosed with Alzheimer's disease might not be able to imagine the later stages of the disease. Ethel was like that. She and Barbara never talked about things like feeding tubes, machines that help with breathing, antibiotics for pneumonia, or transfers to the hospital. So when doctors raised some of these questions, Barbara didn't know how to best reflect her mother's wishes. When making care decisions for someone else near the end of life, it is important to consider how a treatment will benefit the person and what the side effects and risks might be. Sometimes you might decide to try the health care team's suggestion for a short time. Other times you might decide that the best choice is to do nothing.

Alzheimer's disease and similar conditions often progress slowly and unpredictably. Experts suggest that signs of the final stage of Alzheimer's disease include some of the following:

- Being unable to move around on one's own
- Being unable to speak or make oneself understood
- Needing help with most, if not all, daily activities
- Eating problems such as difficulty swallowing or no appetite

Because of their unique experience with what happens at the end of life, hospice and palliative care experts might also be of help identifying when someone in the final stage of Alzheimer's disease is beginning to die.

Caring for people with Alzheimer's disease at home can be demanding and stressful for the family caregiver. Depression is a problem for some family caregivers, as is fatigue, because many feel they are always "on call."

More than half of one group of family caregivers reported cutting back on work hours or giving up their jobs because of the demands of caregiving. Most of those family members taking care of dying Alzheimer's disease patients at home expressed relief when death happened—for themselves and for the person who died. It is important to realize such feelings are normal. Hospice—whether used at home or in a facility—gives family caregivers needed support near the end of life, as well as help with their grief, both before and after their family member dies.

Questions to Ask

You will want to understand how the available medical options presented by the health care team fit into your family's particular needs. You might want to ask questions such as:

1. How will the approach the doctor is suggesting affect your relative's quality of life? Will it make a difference?
2. If considering hospice for your relative with Alzheimer's disease, does the facility have special experience with people with dementia?

To Learn More

About Dementia and Caregiving for People With Dementia:

- Alzheimer's Disease Education and Referral Center
  www.nia.nih.gov/Alzheimers ◆ **1-800-438-4380 (toll-free)**
- Alzheimer's Association
  www.alz.org ◆ **1-800-272-3900 (toll-free)**

Understanding Health Care Decisions

It can be overwhelming to be asked to make health care decisions for someone who is dying and no longer able to make his or her own decisions. It is even more difficult if you do not have written or even verbal guidance (see pages 58-61). How do you decide what type of care is right for someone? Even when you have written documents, some decisions still might not be clear.

Two approaches might be useful. One is to put yourself in the place of the person who is dying and try to choose as he or she would. That is called *substituted judgment.* Sheila's ninety-year-old mother, Esther, was in a coma after having a major stroke. The doctor said damage to Esther's brain was widespread and she needed to be put on a breathing machine (ventilator) or she would probably die. The doctor asked Sheila if she wanted that to be done. Sheila remembered how her mother disapproved when an elderly neighbor was put on a similar machine after a stroke. She decided to say no, and her mother died peacefully a few hours later. Some experts believe that decisions should be based on substituted judgment whenever possible, but decision-makers sometimes combine that with another method.

The other approach, known as *best interests,* is to decide what would be best for the dying person. Jim's father, Sam, is eighty and has lung cancer, as well as advanced Parkinson's disease. He is in a nursing facility and doesn't seem to recognize Jim when he visits. Sam's doctor suggested that surgery to remove part of a lung might slow down the course of the cancer and give Sam more time. But, Jim thought, "What kind of time? What would that time do for Dad?" Jim decided that putting his dad through surgery and recovery was not in Sam's best interests.

If you are making decisions for someone at the end of life and trying to use one of these approaches, it may be helpful to think about the following:

- Has the dying person ever talked about what he or she would want at the end of life?
- Has he or she expressed an opinion about how someone else was being treated?
- What were his or her values in life? What gave meaning to life? Maybe it was being close to family—watching them grow and making memories together. Perhaps just being alive was the most important thing.

As a decision-maker without specific guidance from the dying person, you need as much information as possible on which to base your actions. You might ask the doctor:

- What can we expect to happen in the next few hours, days, or weeks?
- Why is this new test being suggested?
- Will it change the current treatment plan?
- Will a new treatment help my relative get better?

- How would the new treatment change his or her quality of life?
- Will it give more quality time with family and friends?
- How long will this treatment take to make a difference?
- If we choose to try this treatment, can we stop it at any time? For any reason?
- What are the side effects of the approach you are suggesting?
- If we try this new treatment and it doesn't work, what then?
- If we don't try this treatment, what will happen?
- Is the improvement we saw today an overall positive sign or just something temporary?

It is a good idea to have someone with you when discussing these issues with medical staff. Having someone take notes or remember details can be very useful during this emotional time. If you are unclear about something you are told, don't be afraid to ask the doctor or nurse to repeat it or to say it another way that does make sense to you. Do not be reluctant to keep asking questions until you have all the information you need to make decisions. Make sure you know how to contact a member of the medical team if you have a question or if the dying person needs something. You may want to get pager numbers, email, or cell phone numbers.

Sometimes the whole family wants to be involved in every decision. Maybe that is the family's cultural tradition. Or, maybe the person dying did not pick one person to make health care choices before becoming unable to do so. That is not unusual, but it is probably a good idea to choose one person to be the spokesperson and the contact person when dealing with medical staff. The doctor and nurses will appreciate answering questions from only one person. Even if one family member is named as

the decision-maker, it is a good idea, as much as possible, to have family agreement about the care plan. If you can't agree on a care plan, a decision-maker, or even a spokesperson, the family might need to hire a mediator, someone trained to bring people with different opinions to a common decision. (See *To Learn More* on page 46.) In any case, as soon as possible after the doctor says the patient is dying, the family should try to discuss with the medical team what approach to end-of-life care they want for their family member. That way, decision making for crucial situations can be planned and does not have to be done quickly.

Issues You May Face

Maybe you are now faced with making end-of-life choices for someone close to you. You've thought about that person's values and opinions, and you've asked the health care team to explain the treatment plan and what you can expect to happen. But there are other issues that you need to understand in case they arise. What if the dying person starts to have trouble breathing and a doctor says a ventilator might be needed? Maybe one family member wants the health care team to "do everything" to keep this relative alive. What does that involve? Or, what if family members can't agree on end-of-life care, or they disagree with the doctor? What happens then?

Here are some common end-of-life issues like those—they will give you a general understanding and may help in your conversations with the doctors.

If we say "do everything," what does that mean? This means that if someone is dying, all measures that might keep vital organs working will be tried—for example, using a machine to help with breathing (ventilator)

or starting dialysis for failing kidneys. Such life support can sometimes be a temporary measure that allows the body to heal itself and begin to work normally again. It is not intended to be used indefinitely in someone who is dying. "Doing everything" does not include medical treatments intended to cure a medical condition, such as surgery or chemotherapy.

What can be done if someone's heart stops beating (cardiac arrest)? CPR (cardiopulmonary resuscitation) can sometimes restart a stopped heart. It is most effective in people who were generally healthy before their heart stopped. In CPR, the doctor repeatedly pushes on the chest with great force and periodically puts air into the lungs. Electric shocks (called defibrillation) may also be used to restart the heart, and some medicines might also be given. Although not usually shown on television, the force required for CPR can cause broken ribs or a collapsed lung. Often, CPR does not succeed, especially in an elderly person who is already failing.

What if someone needs help breathing or completely stops breathing (respiratory arrest)? Sometimes doctors suggest using a ventilator (a respirator or breathing machine)—the machine forces the lungs to work. Initially, this involves *intubation,* putting a tube attached to a ventilator down the throat into the trachea or windpipe. Because this tube can be quite uncomfortable, people are often sedated. If the person needs ventilator support for more than a few days, the doctor will probably suggest a *tracheotomy,* sometimes called a "trach" (rhymes with "make"). This tube is then attached to the ventilator. This is more comfortable than a tube down the throat and may not require sedation. Inserting the tube into the trachea is a bedside surgery. A tracheotomy can carry risks, including collapsed lung, plugged tracheotomy tube, or bleeding.

How can I be sure the medical staff knows that we don't want efforts to restore a heart beat or breathing? As soon as the decision that medical staff should not do CPR or other life-support procedures is made by the patient or the person making health care decisions, the doctor-in-charge should be told of this choice. The doctor will then write this on the patient's chart using terms such as DNR (Do Not Resuscitate), DNAR (Do Not Attempt to Resuscitate), or DNI (Do Not Intubate). If end-of-life care is given at home, a special "non-hospital DNR," signed by a doctor, is needed. This ensures that if emergency medical technicians (EMTs) are called to the house, they will respect your wishes. Without a non-hospital DNR, in many places EMTs are required to perform CPR and similar techniques when called to a home. Hospice staff can help determine whether a medical condition is part of the normal dying process or something that needs the attention of EMTs. DNR orders do not stop all treatment. They only mean that CPR and a ventilator will not be used. These orders are not permanent—they can be changed if the situation changes.

What about pacemakers (or similar devices)—should they be turned off? A pacemaker is a device implanted under the skin on the chest that keeps a heartbeat regular. It will not keep a dying person alive. Some people have an implantable cardioverter defibrillator (ICD) under the skin. This is a pacemaker that also shocks the heart back into regular beats when needed. The ICD should be turned off at the point when life support is no longer wanted. This can be done without surgery.

What if the doctor suggests a feeding tube? If a patient can't or won't eat or drink, even when spoon fed, the doctor might suggest a feeding tube. While recovering from an illness, a feeding tube can be helpful. But

at the end of life, a feeding tube might cause more discomfort than not eating. As death approaches, loss of appetite is common. Body systems start shutting down, and fluids and food are not needed as before. Some experts believe that at this point few nutrients are absorbed from any type of nutrition, including that received through a feeding tube.

If tube feeding is going to be tried, there are two methods that can be used. In the first, a feeding tube, known as a nasogastric or NG tube, is threaded through the nose down to the stomach to give nutrition for a short time. Sometimes the tube is uncomfortable. If so, the doctor might try a smaller, child-sized tube. Someone with an NG tube might try to remove it. This usually means the person has to be restrained, which could mean binding his or her hands to the bed. If tube feeding is required for an extended time, then a gastric or G tube is put directly into the stomach through an opening made in the side or abdomen. This second method is also called a PEG tube for percutaneous endoscopic gastrostomy tube. These carry risks of infection, pneumonia, and nausea.

Some people try tube feeding for a short time to see if it makes a difference, while keeping open the option of removing the tube if there is no improvement. Talk to the doctor about how the feeding tube could help and how long it makes sense to try it.

Refusing food might be a conscious decision—a part of the dying person's understanding that death is near. The decision-maker should think carefully about doing something that might be against the dying person's wishes.

Should someone dying be sedated? Sometimes very near the end of life, the doctor might suggest sedation to manage symptoms that are not

responding to treatment and still make the patient uncomfortable. This means using medicines to put the patient in a sleep-like state. Sedation doesn't cause a person to die more quickly. Many doctors suggest continuing to use comfort care measures like pain medicine even if the dying person is sedated. Sedatives can be stopped at any time. A person who is sedated may still be able to hear what you are saying—so try to keep speaking directly to, not about, him or her. Do not say things you would not want the patient to hear.

What about antibiotics? Antibiotics are medicines that fight infections caused by bacteria. Lower respiratory infections, such as pneumonia, are often caused by bacteria and are common in older people who are dying. If someone is already dying when the infection began, giving antibiotics is probably not going to prevent death but might make the person feel more comfortable. Tom was eighty-three and had lived in a nursing home for several years with advanced Parkinson's disease when he choked on some food causing him to inhale a small amount into his lungs. As a result, Tom developed aspiration pneumonia. The doctors assured his wife that they could keep Tom comfortable without antibiotics, but she wanted them to try treating his pneumonia. He died a few days later despite their efforts.

Is refusing treatment legal? Choosing to stop treatment that is not curing or controlling an illness or deciding not to start a new treatment is completely legal—whether the choice is made by someone who is dying or by the one making health care decisions. Some people think this is like allowing death to happen. The law does not consider refusing such treatment to be either suicide or euthanasia, sometimes called "mercy killing."

What happens if the doctor and I have different opinions about care for someone who is dying? Sometimes medical staff, the patient, and family members disagree about a medical care decision. This can especially be a problem when the dying person can't tell the doctors what kind of end-of-life care he or she wants. For example, the family might want more active treatment, like chemotherapy, than the doctors think will be helpful. If there is an advance directive (see page 58) explaining the patient's preferences, those guidelines should determine care. Without the guidance of an advance directive, if there is disagreement about medical care, it may be necessary to get a second opinion from a different doctor or to consult the ethics committee or patient representative, also known as an ombudsman, of the hospital or facility. An arbitrator (mediator) can sometimes assist people with different views to agree on a plan. (See *To Learn More* on page 46.)

The doctor does not seem familiar with our family's views about dying. What should we do? America is a rich melting pot of religions, races, and cultures. Ingrained in each tradition are expectations about what should happen as a life nears its end. It is important for everyone involved in a patient's care to understand how each family background may alter expectations, needs, and choices. You may come from a different background than the doctor you are working with. You might be used to a different approach to talking about what is happening or making health care decisions at the end of life than the medical staff is. For example, many health care providers look to a single person—the dying person or his or her chosen representative—for important health care decisions at the end of life. But, in some cultures the entire immediate family takes on that role, something American doctors might not expect. It is helpful to

discuss your personal and family traditions with your doctors and nurses. Don't be reluctant to say what you want. Each person—each family—is entitled to the end-of-life care that best matches their beliefs and rituals. Make sure you understand how the available medical options presented by the health care team fit into your family's desires for end-of-life care.

If there are religious or cultural customs surrounding death that are important to you, tell the health care providers with whom you are working. Knowing that these practices will be honored could ease the dying person. Telling the medical staff ahead of time may also help avoid confusion and misunderstanding when death occurs.

Questions to Ask

Here are some examples of the kinds of questions you might want to ask the medical staff caring for the dying person:

1. What is the care plan?
2. If we try using the ventilator to help with breathing and decide to stop, how will that be done?
3. If we try the treatment plan you are suggesting and then decide to stop, what will happen?
4. If my family member is dying, why does he or she have to be connected to all those tubes and machines? Why do we need more tests?
5. What is the best way for our family to work with the care staff?
6. How can I make sure I get a daily update on my family member's condition?
7. Will you call me if there is a change in his or her condition?

Things to Share

Make sure the health care team knows what is important to your family surrounding the end of life. You might say:

1. In my religion, we … (then describe your religious traditions regarding death).
2. Where we come from … (tell what customs are important to you at the time of death).
3. In our family when someone is dying, we prefer … (describe what you hope to have happen).

To Learn More

About Decisions You Might Need to Make:

- Society of Critical Care Medicine
  www.myicucare.org ◆ 1-847-827-6869

- Family Caregiver Alliance
  www.caregiver.org ◆ 1-800-445-8106 (toll-free)

About Family Mediation:

- Association for Conflict Resolution
  www.acrnet.org

We understand death for the first time when
he puts his hand upon one whom we love.

— Madame deStael (1766-1817)

What Happens

When Someone Dies

When death comes suddenly, there is little time to prepare. On the other hand, watching an older person become increasingly frail may mean that it's hard to know when the end of life begins because changes can happen so slowly. But if you do know death is approaching and understand what will happen, then you do have a chance to plan. Listen carefully to what doctors and nurses are saying. They may be suggesting that death could be soon.

Just as each life is unique, so is each death. But, there are some common experiences very near the end:

- Shortness of breath, known as *dyspnea*
- Depression
- Anxiety
- Tiredness and sleepiness
- Mental confusion
- Constipation or incontinence
- Nausea
- Refusal to eat or drink

Each of these symptoms, taken alone, is not a sign that someone is dying. But, for someone with a serious illness or declining health, these might suggest that that person is nearing the end of life.

In addition, closer to death, the hands, arms, feet, or legs may be cool to the touch. Some parts of the body may become darker or blue-colored. Breathing and heart rates may slow. In fact, there may be times when the person doesn't breathe for many seconds, known as *Cheyne-Stokes breathing.* Some people hear a death rattle. That is noisy breathing that makes a gurgling or rattling sound. Finally, the chest stops moving, no air comes out of the nose, and there is no pulse. Eyes that are open can seem glassy.

Should there always be someone in the room with a dying person?

Staying close to someone who is dying is often called "keeping a vigil." It can be comforting for the caregiver to always be there, but it can also be tiring and stressful. Unless your cultural or religious traditions require it, do not feel that you must stay with the person all the time. You need to eat and rest. If there are other family members or friends around, try taking turns sitting in the room. Some people almost seem to "prefer" to die alone. They appear to slip away just when visitors leave. Of course, experts have no way to prove that's what happened.

After death, there may still be a few shudders or movements of the arms or legs. There could even be an uncontrolled cry because of muscle movement in the voice box. Sometimes there will be a release of urine or stool, but usually only a small amount since so little has probably been eaten in the last days of life.

Calling 911 or not?

When there is a medical emergency, such as a heart attack, stroke, or serious accident, we know to call 911. But if a person is dying at home and does not want CPR, calling 911 is not necessary. In fact, a call to 911 could cause confusion. Many places require EMTs (emergency medical technicians) who respond to 911 calls to perform CPR if someone's heart has stopped. Consider having a "non-hospital DNR" (see page 41) if the person is dying at home.

Things to Do

After Someone Dies

Immediately following death, nothing has to be done. Take the time you need to start the grieving process. Some people want to stay in the room with the body; others prefer to leave. You might want to have someone make sure the body is lying flat before the joints become stiff and cannot be moved. This *rigor mortis* begins sometime during the first hours after death.

After the death, how long you can stay with the body may depend on where death happens. If it is at home, there is no need to move the body right away. If your religious, ethnic, or cultural background requires any special customs soon after death, there should be time for that now. If the death is likely to happen in a facility, such as a hospital or nursing home, discuss any important customs or rituals with the staff early on, if possible. That will allow them to plan so that you can have the appropriate time with the body.

Some families want time to sit quietly with the body, console each other, and maybe share memories. You could ask a member of your religious

community or a spiritual counselor to come. If you have a list of people to notify, this is the time to call those who might want to come and see the body before it is moved.

As soon as possible, the death must be "pronounced" by someone in authority like a doctor in a hospital or nursing facility or a hospice nurse. This person also fills out the forms certifying the cause, time, and place of death. These steps will make it possible for an official death certificate to be prepared. This legal form is necessary for many reasons, including life insurance and financial and property issues. If hospice is helping, a plan for what happens after death is already in place. If death happens at home without hospice, try to talk with the doctor, local medical examiner (coroner), your local health department, or a funeral home representative in advance about how to proceed.

Arrangements should be made to pick up the body as soon as the family is ready. Usually this is done by a funeral home. The hospital or nursing facility, if that is where death takes place, may call the funeral home for you. If at home, you will need to contact the funeral home directly or ask a friend or family member to do that for you.

The doctor may ask if you want an *autopsy.* This is a medical procedure conducted by a specially-trained physician to learn more about what caused death. For example, if the person who died was believed to have Alzheimer's disease, a brain autopsy will allow for a definitive diagnosis. If your religion or culture objects to autopsies, talk to the doctor. Some people planning a funeral with a viewing worry about having an autopsy, but the physical signs of an autopsy are usually hidden by clothing.

What about organ donation?

At some time before death or right after it, the doctor may ask about donating organs such as the heart, lungs, pancreas, kidneys, cornea, liver, and skin. Organ donation allows healthy organs from someone who dies to be transplanted into living people who need them. People of any age can be an organ donor. The person who is dying may have already indicated they would like to be an organ donor. Some states include it on the driver's license. If not, the decision has to be made quickly. There is no cost to the donor's family for this "gift of life." If the person has requested a do-not-resuscitate (DNR) order, but wants to donate organs, he or she might have to indicate that the desire to donate supersedes the DNR. That is because it might be necessary to use machines to keep the heart beating until the medical staff is ready to use the donated organs.

To Learn More

About Funerals:

- AARP
  www.aarp.org ◆ **1-888-687-2277 (toll-free)**
- Federal Trade Commission
  www.ftc.gov/bcp/menus/consumer/shop/funerals.shtm
  ◆ **1-877-382-4357 (toll-free)**

About Organ Donation:

- Donate Life America
  www.shareyourlife.org ◆ **1-804-782-4920**
- Living Bank
  www.livingbank.org ◆ **1-800-528-2971 (toll-free)**

Getting Help

for Your Grief

Losing someone close to you can make you feel sad, lost, alone, and maybe even angry. You greatly miss the person who has died—you want them back. You might have also been so busy with caregiving that it now seems you have nothing to do. This can add to your feelings of loss. This is all part of grieving, a normal reaction to the loss of someone you love.

There are many ways to grieve and to learn to accept this loss. Try not to ignore your grief. Support may be available until you can manage your grief on your own. It is especially important to get help with your loss if you feel overwhelmed, consumed, or very depressed by it.

Family and friends can be a great support. They are grieving too, and some people find that sharing memories is one way you can help each other. Feel free to talk about the one who is gone. Sometimes people hesitate to bring up the loss or mention the dead person's name as they worry this can be hurtful. But everyone may find it helpful to talk directly about their loss. Shortly after Carol's husband Doug died, her friends started coming over with dinners as well as memories to share. They would sit around Carol's dining table for hours remembering Doug's humor and

kindness. Soon Doug's friends were joining them with their own recollections. It was so like old times that it almost seemed Doug had just stepped out of the room. Those evenings together helped Carol, as well as the others, start to heal after their loss.

Sometimes people find grief counseling makes it easier to work through their sorrow. There are grief counselors who will talk with you one-on-one. Regular talk therapy can help people learn to accept a death and, in time, create a new life. There are also support groups where grieving people help each other. These groups can be specialized—parents who have lost children or people who have lost spouses, for example—or they can be just generally for anyone learning to manage grief. Check with religious groups, a local hospital, hospice groups, or your doctor to find support groups in your area.

An essential part of hospice is providing grief counseling to the family of someone who was under their care. Even if hospice was not used before the death, you can ask hospice workers for bereavement support at this time. If the death happened at a nursing home or hospital, there is often a social worker you can ask for resources that can help. The funeral home might also be able to suggest where you can find counseling.

Remember to take good care of yourself. You might know that grief affects how you feel emotionally, but you may not realize that it can also have physical effects. The stress of the death and your grief could even make you sick. Eat well, exercise, get enough sleep, and get back to doing things you used to enjoy, like going to the movies, walking, or reading. Accept offers of help or companionship from friends and family. It's good for you and for them.

Let major decisions wait, if possible.

Try to delay major life decisions until you are feeling better. You don't want to decide to make a big change like selling your home or leaving your job when you are grieving and perhaps not thinking clearly.

To Learn More

About Dealing With Grief:

- AARP
  www.aarp.org ◆ **1-888-687-2277 (toll-free)**

- American Hospice Foundation
  www.americanhospice.org ◆ **1-800-347-1413 (toll-free)**

Planning for

End-of-Life Care Decisions

Because of advances in medicine, each of us, as well as our families and friends, may face many decisions about the dying process. As hard as it might be to face the idea of your own death, you might take time to consider how your individual values relate to your idea of a good death. By deciding what end-of-life care best suits your needs when you are healthy, you can help those close to you make the right choices when the time comes. This not only respects your values, but also allows those closest to you the comfort of feeling as though they can be helpful.

There are several ways to make sure others know the kind of care you want when dying.

Talking About End-of-Life Wishes

The simplest, but not always the easiest, way is to talk about end-of-life care before an illness. Discussing your thoughts, values, and desires will help people who are close to you to know what end-of-life care you want.

For example, you could discuss how you feel about using life-prolonging measures or where you would like to be cared for. For some people, it makes sense to bring this up at a small family gathering. Others may find that telling their family they have made a will (or updated an existing one) provides an opportunity to bring up this subject with other family members. Doctors should be told about these wishes as well. As hard as it might be to talk about your end-of-life wishes, knowing your preferences ahead of time can make decision making easier for your family. You may also have some comfort knowing that your family can choose what you want.

On the other hand, if your parents are aging and you are concerned about what they want, you might introduce the subject. You can try to explain that having this conversation will help you care for them and do what they want. You might start by talking about what you think their values are, instead of talking about specific treatments. Try saying something like, "when Uncle Walt had a stroke and died, I thought you seemed upset that his kids wanted to put him on a respirator." Or, "I've always wondered why Grandpa didn't die at home. Do you know?" Encourage your parents to share the type of care they would choose to have at the end of life, rather than what they don't want. There is no right or wrong plan, only what they would like. If they are reluctant to have this conversation, don't force it, but try to bring it up again at a later time.

Advance Directives and Other Documents

Written instructions letting others know the type of care you want if you are seriously ill or dying are called *advance directives.* These include a living will and health care power of attorney. A *living will* records your

end-of-life care wishes in case you are no longer able to speak for yourself. You might want to talk with your doctor or other health care provider before preparing a living will. That way you will have a better understanding of what types of decisions might need to be made. Make sure your doctor and family have seen your living will and understand your instructions.

Because a living will cannot give guidance for every possible situation, you probably want to name someone to make care decisions for you if you are unable to do so for yourself. You might choose a family member, friend, lawyer, or someone in your religious community. You can do this either in the advance directives or through a *durable power of attorney for health care* that names a *health care proxy*, who is also called a *representative, surrogate, agent,* or *attorney-in-fact.* "Durable" means it remains in effect even if you are unable to make decisions. A durable power of attorney for health care is useful if you don't want to be specific—if you would rather let the health care proxy evaluate each situation or treatment option independently. A durable power of attorney for health care is also important if your health care proxy, the person you want to make choices for you, is not a legal member of your family. Of course, you should make sure the person and alternate(s) you have named understand your views about end-of-life care. If you don't name someone, the state you live in probably has an order of priority based on family relationships to determine who decides for you. A few states let people name a health care proxy by telling their doctor, without paperwork.

Don't confuse a durable power of attorney for health care with a *durable power of attorney.* The first is limited to decisions related to health care, while the latter covers decisions regarding property or financial matters.

A lawyer can prepare these papers, or you can do them yourself. Forms are available from your local or State government, from private groups, or on the Internet. (See *To Learn More* on page 61.) Often these forms need to be *witnessed.* That means that people who are not related to you watch as you sign and date the paperwork and then sign and date it themselves as proof that the signature is indeed yours. Make sure you give copies to your primary doctor and your health care proxy. Have copies in your files as well. Hospitals might ask for a copy when you are admitted, even if you are not seriously ill.

Sometimes people change their mind as they get older or after they become ill. Review the decisions in your advance directives from time to time and make changes if your views or your health needs have changed. Be sure to discuss these changes with your health care proxy and your doctor. Replace all copies of the older version with the updated ones, witnessed and signed if appropriate.

You should also give permission to your doctors and insurance companies to share your personal information with your health care proxy. This lets that person discuss your case with your doctor and handle insurance issues that may come up.

Do you live in one state, but spend a lot of time in another? Maybe you live in the north and spend winter months in a southern state. Or possibly your children and grandchildren live in a different state and you visit them often. Because states' rules and regulations may differ, make sure your forms are legal in both your home state and the state you travel to often. If not, make an advanced directive with copies for that state also. And make sure your family there has a copy.

To Learn More

About Advance Directives and Living Wills:

- American Bar Association
  www.abanet.org ◆ 1-800-285-2221 (toll-free)

- Caring Connections (National Hospice and Palliative Care Organization)
  www.caringinfo.org ◆ 1-800-658-8898 (toll-free)

- Medlineplus.gov
  www.medlineplus.gov, go to: Advance Directives

- National Cancer Institute
  www.cancer.gov ◆ 1-800-422-6237 (toll-free)

They are not dead who live in the hearts they leave behind.

— Tuscarora saying

Closing Thoughts

Many Americans have little experience with someone who is dying. But, when the time comes, unless the death is unexpected and quick, there are choices to be made. These may not be easy. But planning ahead and working with the health care team can help you provide needed comfort.

You will probably remember for a long time what you do for someone who is dying. Realize that this is a difficult time for you too. Caring for someone at the end of life can be physically and emotionally exhausting. In the end, accept that there may be no perfect death, just the best you can do for the one you love. And the pain of losing someone close to you may be softened a little because, when they needed you, you did what you could.

Resources

If you are interested in learning more about any of the topics in this booklet, here are some other resources for you to explore. Some of these are also listed in the *To Learn More* section found at the end of most chapters.

AARP
601 E Street, NW
Washington, DC 20049
1-888-687-2277 (toll-free)
www.aarp.org

Aging with Dignity
Box 1661
Tallahassee, FL 32302
1-888-594-7437 (toll-free)
www.agingwithdignity.org

Alzheimer's Association
225 N. Michigan Avenue, Floor 17
Chicago, IL 60601
1-800-272-3900 (toll-free)
www.alz.org

American Academy of Pain Medicine
4700 W. Lake
Glenview, IL 60025
1-847-375-4731
www.painmed.org

American Academy of Wound Management
1155 15th Street, NW, Suite 500
Washington, DC 20005
1-202-457-8408
www.aawm.org

American Bar Association
321 N. Clark Street
Chicago, IL 60654
1-800-285-2221 (toll-free)
www.abanet.org

American Geriatrics Society Foundation for Health in Aging
Empire State Building
350 Fifth Avenue, Suite 801
New York, NY 10118
1-800-563-4916 (toll-free)
www.healthinaging.org

American Hospice Foundation
2120 L Street, NW, Suite 200
Washington, DC 20037
1-800-347-1413 (toll-free)
www.americanhospice.org

American Music Therapy Association
8455 Colesville Road, Suite 1000
Silver Spring, MD 20910
1-301-589-3300
www.musictherapy.org

Association for Conflict Resolution
12100 Sunset Hills Road
Suite 130
Reston, VA 20190
www.acrnet.org

Beth Israel Medical Center
Department of Pain Medicine
and Palliative Care
First Avenue at 16th Street
New York, NY 10003
1-877-620-9999 (toll-free)
www.stoppain.org

Caring Connections
(See National Hospice and Palliative Care Organization)

Centers for Medicare and Medicaid Services
1-800-633-4227 (toll-free)
www.medicare.gov

Center for Practical Bioethics
Harzfeld Building
1111 Main Street, Suite 500
Kansas City, MO 64105
1-800-344-3829 (toll-free)
www.practicalbioethics.org

Center to Advance Palliative Care
1255 Fifth Avenue, Suite C-2
New York, NY 10029
1-212-201-2670
www.getpalliativecare.org

Compassion and Choices
Box 101810
Denver, CO 80250
1-800-247-7421 (toll-free)
www.compassionandchoices.org

Department of Veterans Affairs
Veterans Benefits Administration
Veterans Health Administration
810 Vermont Avenue, NW
Washington, DC 20420
VA benefits:
1-800-827-1000 (toll-free)
To speak with a health care benefits counselor:
1-877-222-8387 (toll-free)
www.va.gov

Donate Life America
700 North 4th Street
Richmond, VA 23219
1-804-782-4920
www.shareyourlife.org

Eldercare Locator
1-800-677-1116 (toll-free)
www.eldercare.gov

Family Caregiver Alliance
180 Montgomery Street, Suite 1100
San Francisco, CA 94104
1-800-445-8106 (toll-free)
www.caregiver.org

Federal Trade Commission
CRC-240
600 Pennsylvania Avenue, NW
Washington, DC 20580
1-877-382-4357 (toll-free)
www.ftc.gov

Growth House
2261 Market Street, Number 199A
San Francisco, CA 94114
www.growthhouse.org

Hospice and Palliative Nurses Association
One Penn Center West, Suite 229
Pittsburgh, PA 15276
1-412-787-9301
www.hpna.org

Hospice Association of America
228 Seventh Street, SE
Washington, DC 20003
1-202-546-4759
www.nahc.org/HAA

Hospice Foundation of America
1710 Rhode Island Avenue, NW
Suite 400
Washington, DC 20036
1-800-854-3402 (toll-free)
www.hospicefoundation.org
www.hospicedirectory.org

Hospice Net
401 Bowling Avenue, Suite 51
Nashville, TN 37205
www.hospicenet.org

Living Bank
Box 6725
Houston, TX 77265
1-800-528-2971 (toll-free)
www.livingbank.org

National Alliance for Hispanic Health Cuidando con Cariño/ Compassionate Care HelpLine
1501 Sixteenth Street, NW
Washington, DC 20036
1-866-783-2645 (toll-free)
www.hispanichealth.org

National Cancer Institute
Public Inquiries Office
6116 Executive Boulevard
Room 3036A
Bethesda, MD 20892
1-800-422-6237 (toll-free)
www.cancer.gov

National Hospice and Palliative Care Organization
1731 King Street, Suite 100
Alexandria, VA 22314
1-800-658-8898 (toll-free)
www.caringinfo.org
www.nhpco.org

National Institute of Nursing Research
31 Center Drive, Rm. 5B-10
Bethesda, MD 20892
1-866-910-3804 (toll-free)
www.ninr.nih.gov

National Library of Medicine
www.medlineplus.gov
Health Topics
Search for:
"Advance Directives"
"Bereavement"
"End-of-Life Issues"
"Hospice Care"
"Organ Donation"
"Pain"

Palliative Care Policy Center
www.medicaring.org

Robert Wood Johnson Foundation
Box 2316
College Road East and Route 1
Princeton, NJ 08543
1-877-843-7953 (toll-free)
www.lastacts.org

Society of Critical Care Medicine
500 Midway Drive
Mt. Prospect, IL 60056
1-847-827-6869
www.myicucare.org

Visiting Nurse Associations of America
900 19th Street, NW, Suite 200
Washington, DC 20006
1-202-384-1420
www.vnaa.org

Well Spouse Association
63 West Main Street, Suite H
Freehold, NJ 07728
1-800-838-0879 (toll-free)
www.wellspouse.org

The National Institute on Aging (NIA) is part of the nation's principal medical research agency, the National Institutes of Health. NIA promotes healthy aging by conducting and supporting biomedical, social, and behavioral research and public education.

Visit NIHSeniorHealth (www.nihseniorhealth.gov), a senior-friendly website from the National Institute on Aging and the National Library of Medicine. This website has health information for older adults. Special features make it simple to use. For example, you can click on a button to have the text read out loud or to make the type larger.

To learn more about Alzheimer's disease, contact NIA's ADEAR Center at:

Alzheimer's Disease Education and Referral (ADEAR) Center
Box 8250
Silver Spring, MD 20907-8250
1-800-438-4380 (toll-free)
www.nia.nih.gov/Alzheimers

For more information on health and aging, contact:

National Institute on Aging Information Center
Box 8057
Gaithersburg, MD 20898-8057
1-800-222-2225 (toll-free)
1-800-222-4225 (TTY/toll-free)
www.nia.nih.gov
www.nia.nih.gov/Espanol

To sign up for regular email alerts about new publications and other information from the NIA, go to:

www.nia.nih.gov/HealthInformation

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