



END OF LIFE

Helping with Comfort and Care



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3	INTRODUCTION
5	PROVIDING COMFORT AT THE END OF LIFE
19	CARE OPTIONS AT THE END OF LIFE
34	DEMENTIA AT THE END OF LIFE
39	UNDERSTANDING HEALTHCARE DECISIONS
51	WHAT HAPPENS WHEN SOMEONE DIES
54	THINGS TO DO AFTER SOMEONE DIES
58	GETTING HELP FOR YOUR GRIEF
61	PLANNING FOR END-OF-LIFE CARE DECISIONS
68	CLOSING THOUGHTS
69	RESOURCES



*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 fading. For some older people, the body weakens while the mind stays alert. Others remain physically strong, but cognitive losses take a huge toll. Although everyone dies, 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 only in the moments before breathing ceases and the heart stops beating. Older people often live with one or more chronic illnesses and need a lot of care for days, weeks, and even months before death.

The goal of *End of Life: Helping with Comfort and Care* is to provide guidance and help in understanding the unfamiliar territory of death. This information is based on research, such as that supported by the National Institute on Aging (NIA), along with other parts of the National Institutes of Health. It also includes suggestions from healthcare providers with expertise in helping individuals and families through this difficult

time. Most of the stories included are examples of 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 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.

End of Life: Helping with Comfort and Care provides an overview of issues often faced by people caring for someone nearing the end of life. The information provided here does not replace the personal and specific advice of the doctor or other experts, but it can help you make sense of what is happening and give you a framework for making care decisions. A sampling of resources related to end-of-life care are provided if you are looking for more information.

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 goals are to prevent or relieve suffering as much as possible and to improve quality of life while respecting the dying person's wishes.

You are probably reading this because someone close to you is dying. You wonder what will happen. You want to know how to give comfort, what to say, what to do. You might like to know how to make dying easier—how to help ensure a peaceful death, with treatment consistent with the dying person's wishes.

A peaceful 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, avoiding

suffering, having your end-of-life wishes followed, 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. Their families need support as well. In this section, you will find a number of ways you can help someone who is dying. Always remember to check with the healthcare team to make sure these suggestions are appropriate for your situation.

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 healthcare 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 severe pain is hard to manage. Try to make sure that the level of pain does not get ahead of pain-relieving medicines. Tell the doctor or nurse if the pain is not controlled. Medicines can be increased or changed. If this doesn't help, then ask for consultation with a palliative medical specialist who has experience in pain management for seriously ill patients (see *Palliative Care*, page 20).

What about morphine and other painkillers?

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. Pain medication can make people confused or drowsy. 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.

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 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 humidifier, or having a fan circulating air in the room. Sometimes, morphine or other pain medications can help relieve the sense of breathlessness.

People very near death might have noisy breathing, sometimes 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 that may help clear this up. Not all noisy breathing is a death rattle. It may help to know that this noisy breathing is usually not upsetting to the dying person, even if it is to family and friends.

Skin irritation. Skin problems can be very uncomfortable. With age, skin naturally becomes drier and more fragile, so it is important to take extra care with an older person's skin. Gently applying alcohol-free lotion can relieve dry skin and 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 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. Try putting a foam pad under an area like a heel or elbow to raise it off the bed and reduce pressure. Ask if a special mattress or chair cushion might also help. Keeping the skin clean and moisturized is always important.

Digestive problems. Nausea, vomiting, constipation, and loss of appetite are common issues at the end of life. 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, a common side effect of strong pain medications.

If someone near death wants to eat but is too tired or weak, you can help with feeding. To address loss of appetite, try gently offering favorite foods in small amounts. Or, try serving frequent, smaller meals rather than three big ones.

You don't have to 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. Swallowing may also be

a problem, especially for people with dementia. 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. 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.

Meena's Story

At 80, Meena had been in a nursing home for 2 years after a stroke, when her health declined, and she was no longer able to communicate her wishes. Meena's physician, Dr. Torres, told her family she was dying. She said that medical tests, physical therapy, and intravenous treatments were no longer really needed and should be stopped because they might be causing Meena discomfort. Dr. Torres 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, Meena developed pneumonia. Her family asked about moving her to the hospital. Dr. Torres explained that Meena could get the same care in the familiar surroundings of her nursing home. Besides, the doctor said, a move could disturb and confuse her. The family agreed to leave Meena in the nursing home, and she died 2 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 mental and emotional distress. Someone who is alert near the end of life might understandably feel depressed or anxious. It is important to treat emotional pain and suffering. Encouraging conversations about feelings might help. You might want to contact a counselor, possibly one familiar with end-of-life issues. If the depression or anxiety is severe, medicine may help.

A dying person may 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 feel helpless because they can't cure their patient. Some seem to avoid a dying patient. This can add to a dying person's sense

of isolation. If this is happening, 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 a comforting mood. Remember that listening and being present can make a difference. For example, Gordon loved a party, so it was natural for him to want to be around family and friends when he was dying. Ellen always liked 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 a 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.

Often, just being present with a dying person is enough. It may not be necessary to fill the time with talking or activity. Your quiet presence can be a simple and profound gift for a dying family member or friend.

SPIRITUAL ISSUES

People nearing the end of life may have spiritual needs as important as their physical concerns. Spiritual needs include 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. Others may struggle with their faith or spiritual beliefs. Praying, talking with someone from one's religious community (such as a minister, priest, rabbi, or imam), reading religious texts, 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, Juan. 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 person who is 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. Sometimes, a dying person may appear to see or talk to someone who is not there. Try to resist the temptation to interrupt or say they are imagining things. Give the dying person the space to experience their own reality.

PRACTICAL TASKS

Many practical jobs need to be done at the end of life—both to relieve the person who is dying 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 picking up the mail or newspaper, writing down phone messages, doing a load of laundry, feeding the family pet, taking children to soccer practice, or picking up medicine from the pharmacy—can provide a much-needed break for caregivers.

A person who is dying 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 person who is dying.

If you are the primary caregiver, ask for help when you need it and accept help when it's offered. 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.

Keeping close friends and family informed can feel overwhelming. Setting up an outgoing voicemail message, a blog, an email list, a private Facebook page, or even a phone tree can reduce the number of calls you have to make. Some families create a blog or website to share news, thoughts, and wishes. See *To Learn More about Comfort Care*, page 17, for organizations that make setting up such webpages easy and secure. Or, you can assign a close family member or friend to make the updates for you. These can all help reduce the emotional burden of answering frequent questions.

Questions to Ask about Providing Comfort

Family and friends can provide comfort and ease to someone nearing the end of life. Here are some questions to help you learn more.

Ask the doctor in charge:

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

Ask the caregiver:

- How are you doing? Do you need someone to talk with?
- Would you like to go out for an hour or two? I could stay here while you are away.
- Who has offered to help you? Do you want me to work with them to coordinate our efforts?
- 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

Some resources to help you learn more about comfort care:

American Academy of Pain Medicine

www.painmed.org | 1-847-375-4731 | info@painmed.org (email)

American Music Therapy Association

www.musictherapy.org | 1-301-589-3300

info@musictherapy.org (email)

CaringBridge

www.CaringBridge.org

CaringInfo (National Hospice and Palliative Care Organization)

www.caringinfo.org | 1-800-658-8898 (toll-free)

caringinfo@nhpco.org (email)

Hospice and Palliative Nurses Association

www.hpna.org | 1-412-787-9301 | hpna@hpna.org (email)

National Alliance for Caregiving

www.caregiving.org/resources | 1-301-718-8444

info@caregiving.org (email)

PostHope

www.posthope.org

What Matters Now

www.whatmattersnow.org



Death does not sound a trumpet.

— AFRICAN PROVERB

CARE OPTIONS

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. Hospice can be provided in any setting—home, nursing home, assisted living facility, or inpatient hospital (see *Hospice*, page 22).

There is no right place to die. And, of course, where we die is not always 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 how they will pay for it. In this section, we explain some of the care options available to people at the end of life.

PALLIATIVE CARE

Doctors can provide treatment to seriously ill patients in the hopes of a cure for as long as possible. These patients may also receive medical care for their symptoms, or palliative care, along with curative treatment.

Who can benefit from palliative care?

Palliative care is a resource for anyone living with a serious illness, such as heart failure, chronic obstructive pulmonary disease, cancer, dementia, Parkinson's disease, and many others. Palliative care can be helpful at any stage of illness and is best provided from the point of diagnosis.

In addition to improving quality of life and helping with symptoms, palliative care can help patients understand their choices for medical treatment. The organized services available through palliative care may be helpful to any older person having a lot of general discomfort and disability very late in life. Palliative care can be provided along with curative treatment and does not depend on prognosis.

A palliative care consultation team is a multidisciplinary team that works with the patient, family, and the patient's other doctors to provide medical, social, emotional, and practical support. The team is made of palliative care specialist doctors and nurses, and includes others such as social workers, nutritionists, and chaplains.

Palliative care can be provided in hospitals, nursing homes, outpatient palliative care clinics and certain other specialized clinics, or at home. Medicare, Medicaid, and insurance policies may cover palliative care. 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. Check to see if insurance will cover your particular situation.

Adriana's Story

Adriana developed anemia while she was being treated for breast cancer. A palliative care specialist suggested she get a blood transfusion to manage the anemia and relieve some of the fatigue she was experiencing. Controlling her symptoms helped Adriana to continue her curative chemotherapy treatment. Treating her anemia is part of palliative care.

In palliative care, you do not have to give up treatment that might cure a serious illness. Palliative care can be provided along with curative treatment and may begin at the time of diagnosis. Over time, if the doctor or the palliative care team believes ongoing treatment is no longer helping, there are two possibilities. Palliative care could transition to hospice care if the doctor believes the person is likely to die within 6 months (see *What does the hospice 6-month requirement mean?*, page 26, for more about this timeframe). Or, the palliative care team could continue to help with increasing emphasis on comfort care.

HOSPICE

Tom's Story

Tom, who retired from the U.S. Air Force, was diagnosed with lung cancer at age 70. As his disease progressed and breathing became more difficult, he wanted to explore experimental treatments to slow the disease. Through the palliative care provided by the Veterans Health Administration, Tom got treatment for his disease and was able to receive the care and emotional support he needed to cope with his health problems. The palliative care program also helped arrange for assistance around the house and other support for Tom's wife, making it easier for her to care for him at home. When the experimental treatments were no longer helping, Tom enrolled in hospice. He died comfortably at home 3 months later.

At some point, it may not be possible to cure a serious illness, or a patient may choose not to undergo certain treatments. 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.

Like palliative care, hospice provides comprehensive comfort care as well as support for the family, but, in hospice, attempts to cure the person's illness are stopped. Hospice is provided for a person with a terminal illness whose doctor believes he or she has 6 months or less to live if the illness runs its natural course.

Hospice is an approach to care, 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 someone is always available by phone—24 hours a day, 7 days a week. Hospice may be covered by Medicare and other insurance companies; check to see if insurance will cover your particular situation.

Dolores' Story

Choosing hospice does not have to be a permanent decision. For example, Dolores was 82 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 Dolores began hospice care. A week later, she learned that her granddaughter was pregnant. After talking with her husband, Dolores changed her mind about using hospice care and left to begin dialysis, hoping to one day hold her first great-grandchild. Shortly after the baby was born, the doctors said Dolores' blood pressure was too low. At that point, she decided to re-enroll in hospice.

It is important to remember that stopping treatment 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. Other medical care may continue as long as it is helpful. For example, if the person has high blood pressure, he or she will still get medicine for that.

Some Differences between Palliative Care and Hospice

	PALLIATIVE CARE	HOSPICE
Who can be treated?	Anyone with a serious illness at any stage of their disease	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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Although hospice provides a lot of support, the day-to-day care of a person dying at home is provided by family and friends. The hospice team coaches family members on how to care for the dying person and even provides respite care when caregivers need a break. Respite care can be for as short as a few hours or for as long as several weeks.

Annie and Maria's Story

Eighty-year-old Annie had advanced metastatic melanoma and asked for help through a hospice program so she could stay in the home she had lived in for more than 40 years. After Annie died, hospice continued to support her family, offering bereavement counseling for a year. Hospice services greatly reduced the stress of caregiving for Annie's family. This was especially true for Annie's wife, Maria, who weathered the sadness of her loss without her own health declining.

Families of people who received care through a hospice program are more satisfied with end-of-life care than are those of people who did not have hospice services. Also, hospice recipients are more likely to have their pain controlled and less likely to undergo tests or be given medicines they don't need, compared with people who don't use hospice care.

What does the hospice 6-month requirement mean?

Some people misinterpret their doctors' 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, people enrolled in Medicare can receive hospice care if their healthcare provider thinks they have less than 6 months to live should the disease take its usual course. Doctors have a hard time predicting how long an older, sick 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 healthcare provider still believes that the patient has less than 6 months to live.

HOSPITALS

Omar's Story

Omar is 64, lives at home, and has a history of congestive heart failure. He has decided that no matter what, he wants the doctor to do everything medically possible to extend his life. Those closest to Omar agree. One night, Omar wakes up with chest pain and is taken to the hospital, where doctors and nurses are available around-the-clock. Hospitals offer a full range of treatment choices, tests, and other medical care. If Omar's heart continues to fail, he can receive care in the intensive care unit (ICU) or coronary care unit (CCU).

Although hospitals have rules, they can sometimes be flexible. If Omar's doctor thinks he is not responding to treatment and is dying, the family can ask for relaxed visiting hours. If Omar's family wants to bring personal items from home, they can ask the staff if there are space limitations or if disinfection is needed.

In a hospital setting, medical professionals are available who know what needs to be done for someone who is dying. This can be very reassuring. In addition to the regular care team, some hospitals may have palliative care teams (see *Palliative Care*, page 20) that can assist with managing uncomfortable symptoms and making medical decisions for patients who may or may not be at the end of life.

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. These units are parts of a hospital where seriously ill patients can benefit from specially trained staff who 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 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 healthcare team might talk to the family—and the patient if he or she is conscious—about considering whether or not to continue intensive treatment.

NURSING HOMES

More and more people are in nursing homes at the end of life. In a nursing home, nursing staff are always present. Unlike a hospital, a doctor is not in the facility all the time, but may be available by phone. Plans for end-of-life care can be arranged ahead of time, so when the time comes, care can be provided as needed without first consulting a doctor.

If the person has lived in the nursing home for a while, the staff and family probably already have a relationship. This can make the care feel more personalized than in a hospital. Additionally, if the person is enrolled in hospice (see *Hospice*, page 22), the hospice team will be available to assist nursing facility staff with end-of-life care.

As in a hospital, privacy may be an issue in nursing homes. 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 caregivers are willing to take on. Hiring a home nurse is an option for people who need additional help and have the financial resources.

Talk with your healthcare provider about the kind of care needed. Frequently, this care does not require a nurse but can be provided by nursing assistants or family and friends without medical training.

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 about Care Options at the End of Life*, page 32, for links and telephone numbers for Federal Government services and programs.

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; make sure you check with your insurance company before ordering.

Work with the doctor to decide what is needed to support comfort care at home. If the seriously ill 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 *To Learn More about Care Options at the End of Life*, page 32, to find out 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. Hospice is frequently used to care for people who are home at the end of life.

Questions to Ask about End-of-Life Decisions

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.

- If we continue the current course of treatment, what do you expect will happen next?
- What kind of end-of-life care is needed?
- Is the most likely caregiver able to give that kind of care?
- Where would the person who is dying want to have this end-of-life care—a facility or at home, for example?
- What is the best place to get the type of care he or she wants?
- Who will pay for this care?
- Can we get help paying for respite care?
- 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 Care Options at the End of Life

Some resources to help you learn more about care options at the end of life:

Center to Advance Palliative Care

www.getpalliativecare.org | 1-212-201-2670 | capc@mssm.edu (email)

Centers for Medicare & Medicaid Services

www.medicare.gov/Pubs/pdf/02154.pdf | 1-800-633-4227 (toll-free)

Department of Veterans Affairs

www.va.gov | 1-877-222-8387 (toll-free)

Hospice Foundation of America

www.hospicefoundation.org/End-of-Life-Support-and-Resources
1-800-854-3402 (toll-free) | info@hospicefoundation.org (email)

CaringInfo (National Hospice and Palliative Care Organization)

www.caringinfo.org | 1-800-658-8898 (toll-free)
caringinfo@nhpco.org (email)

Visiting Nurse Associations of America

www.vnaa.org | 1-888-866-8773 (toll-free) | vnaa@vnaa.org (email)

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 dementia can present special challenges for caregivers. People can live with diseases such as Alzheimer's or Parkinson's dementia for years, so it can be hard to think of these as terminal diseases. But, they do cause death.

HARD DECISIONS

Dementia causes the gradual loss of thinking, remembering, and reasoning abilities, making 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 clearly, they cannot share their concerns. Is Uncle Bert refusing food because he's not hungry or because he's confused? Why does Grandma Sakura seem agitated? Is she in pain and needs medication to relieve it, but can't tell you?

As these conditions progress, caregivers may find it hard 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 (see *Care Options at the End of Life*, starting on page 19) 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. Being touched or massaged can be soothing. Listening to music, white noise, or sounds from nature seem to relax some people and lessen their agitation.

When a dementia 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 the person with Alzheimer’s can no longer legally complete documents like advance directives (see *Prepare Advance Directives and Other Documents*, page 63).

End-of-life care decisions are more complicated for caregivers if the dying person has not expressed the kind of 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.

Alma and Silvia’s Story

Alma had been forgetful for years, but even after her family knew that Alzheimer’s disease was the cause of her forgetfulness, they never talked about what the future would bring. As time passed and the disease eroded Alma’s memory and ability to think and speak, she became less and less able to share her concerns and wishes with those close to her.

This made it hard for her daughter Silvia to know what Alma needed or wanted. When the doctors asked about feeding tubes or antibiotics to treat pneumonia, Silvia didn’t know how to best reflect her mother’s wishes. Her decisions had to be based on what she knew about her mom’s values, rather than on what Alma actually said she wanted.

WEIGHING CARE CHOICES

Quality of life is an important issue when making healthcare decisions for people with dementia. For example, medicines are available that may delay or keep symptoms from becoming worse for a little while. Medicines also may help control some behavioral symptoms in people with mild to moderate Alzheimer's disease.

However, some caregivers might not want drugs prescribed for people in the later stages of Alzheimer's. They may believe that the person's quality of life is already so poor that the medicine is unlikely to make a difference. If the drug has serious side effects, they may be even more likely to decide against it.

When making care decisions for someone else near the end of life, consider the goals of care and weigh the benefits, risks, and side effects of the treatment. You may have to make a treatment decision based on the person's comfort at one end of the spectrum and extending life or maintaining abilities for a little longer at the other.

With dementia, a person's body may continue to be physically healthy while his or her thinking and memory are deteriorating. This means that caregivers and family members may be faced with very difficult decisions about how treatments that maintain physical health, such as installing a pacemaker, fit within the care goals.

DEMENTIA'S UNPREDICTABLE PROGRESSION

Dementia often progresses 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, such as eating and self-care
- Eating problems such as difficulty swallowing

Because of their unique experience with what happens at the end of life, hospice and palliative care experts might be able to help identify when someone in the final stage of Alzheimer's disease is in the last days or weeks of life (see *Care Options at the End of Life*, starting on page 19).

CAREGIVER SUPPORT

Caring for people with Alzheimer's or other dementias 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. Family caregivers may have to cut back on work hours or leave work altogether because of their caregiving responsibilities.

Many family members taking care of a person with advanced dementia at home feel relief when death happens—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 (such as a nursing home)—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 about Dementia Care

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

- How will the approach the doctor is suggesting affect your relative's quality of life? Will it make a difference in comfort and well-being?
- If considering home hospice for your relative with dementia, what will be needed to care for him or her? Does the facility have special experience with people with dementia?
- What can I expect as the disease gets worse?

To Learn More about Dementia and End-of-Life Care

Some resources to help you learn more about dementia and end-of-life care:

Alzheimer's Disease Education and Referral Center

www.nia.nih.gov/alzheimers | 1-800-438-4380 (toll-free)

1-800-222-4225 (TTY/toll-free) | adeaar@nia.nih.gov (email)

Alzheimer's Association

www.alz.org | 1-800-272-3900 (toll-free)

1-866-403-3073 (TTY/toll-free) | info@alz.org (email)

Alzheimer's Foundation of America

www.alzfdn.org | 1-866-232-8484 (toll-free)

info@alzfdn.org (email)

U.S. Department of Health and Human Services

www.alzheimers.gov

UNDERSTANDING HEALTHCARE DECISIONS

It can be overwhelming to be asked to make healthcare decisions for someone who is dying and is no longer able to make his or her own decisions. It is even more difficult if you do not have written or verbal guidance (see *Prepare Advance Directives and Other Documents*, page 63). 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 since the documents may not address every situation you could face.

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. This is called substituted judgment. Some experts believe that decisions should be based on substituted judgment whenever possible.

Joseph and Leilani's Story

Joseph's 90-year-old mother, Leilani, was in a coma after having a major stroke. The doctor said damage to Leilani's brain was widespread and she needed to be put on a breathing machine (ventilator) or she would probably die. The doctor asked Joseph if he wanted that to be done. Joseph remembered how his mother disapproved when an elderly neighbor was put on a similar machine after a stroke. He decided to say no, and his mother died peacefully a few hours later.

Another approach, known as best interests, is to decide what would be best for the dying person. This is sometimes combined with substituted judgment.

Ali and Wadi's Story

Ali's father, Wadi, is 80 and has lung cancer, as well as advanced Parkinson's disease. He is in a nursing facility and doesn't seem to recognize Ali when he visits. Wadi's doctor suggested that surgery to remove part of a lung might slow down the course of the cancer and give Wadi more time. But, Ali thought, "What kind of time? What would that time do for Dad?" Ali decided that putting his dad through surgery and recovery was not in Wadi's best interests. After talking with Wadi's doctors, Ali believed that surgery would not improve his father's quality of life but would cause him pain and discomfort.

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

- 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 might we expect to happen in the next few hours, days, or weeks if we continue our current course of treatment?
- 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 helpful. 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. 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.

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 healthcare choices before becoming unable to do so. That is not unusual, but it makes sense to choose one person to be the contact when dealing with medical staff. The doctors and nurses will appreciate having to phone 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 consider a mediator, someone trained to bring people with different opinions to a common decision (see *To Learn More about Making Healthcare Decisions*, page 49).

In any case, as soon as it is clear that the patient is nearing the end of life, the family should try to discuss with the medical team which end-of-life care approach they want for their family member. That way, decision making for crucial situations can be planned and may feel less rushed.

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 healthcare team to explain the treatment plan and what you can expect to happen.

But, there are other issues that are important 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 healthcare team to do everything possible 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 other common end-of-life issues. They will give you a general understanding and may help your conversations with the doctors.

If we say do everything possible, 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 ventilator to support breathing 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.

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. During 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 correct an abnormal heart rhythm, 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 in older adults who have multiple chronic illnesses or who are already frail.

What if someone needs help breathing or completely stops breathing (respiratory arrest)? If a patient has very severe breathing problems or has stopped breathing, a ventilator may be needed. A ventilator 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 with very strong intravenous medicines. Restraints may be used to prevent them from pulling out the tube. If the person needs ventilator support for more than a few days, the doctor might 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 a collapsed lung, a plugged tracheotomy tube, or bleeding.

How can I be sure the medical staff knows that we don't want efforts to restore a heartbeat or breathing? Tell the doctor in charge as soon as the patient or person making healthcare decisions decides that CPR or other life-support procedures should not be performed. 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), AND (Allow Natural Death), or DNI (Do Not Intubate). DNR forms vary by State and are usually available online.

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. Make sure it is kept in a prominent place so EMTs can see it. Without a non-hospital DNR, in many States EMTs are required to perform CPR and similar techniques. 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. An ICD shocks the heart back into regular rhythm when

needed. The ICD should be turned off at the point when life support is no longer wanted. This can be done at the bedside without surgery.

What if the doctor suggests a feeding tube? If a patient can't or won't eat or drink, the doctor might suggest a feeding tube. While a patient recovers from an illness, getting nutrition temporarily through a feeding tube can be helpful. But, at the end of life, a feeding tube might cause more discomfort than not eating. For people with dementia, tube feeding does not prolong life or prevent aspiration.

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 those received through a feeding tube. Further, after a feeding tube is inserted, the family might need to make a difficult decision about when, or if, to remove it.

If tube feeding will be tried, there are two methods that could 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. 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 sometimes called a PEG (percutaneous endoscopic gastrostomy) tube. It carries risks of infection, pneumonia, and nausea.

Hand feeding (sometimes called assisted oral feeding) is an alternative to tube feeding. This approach may have fewer risks, especially for people with dementia.

Should someone who is dying be sedated? Sometimes, for patients very near the end of life, the doctor might suggest sedation to manage symptoms that are not responding to other treatments and are still making the patient uncomfortable. This means using medicines to put the patient in a sleep-like state. 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) and urinary tract infections are often caused by bacteria and are common in older people who are dying. Many antibiotics have side effects, so the value of trying to treat an infection in a dying person should be weighed against any unpleasant side effects. 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.

Diego's Story

Diego was 83 and had lived in a nursing home for several years with advanced Parkinson's disease. One day, he choked on some food, causing him to inhale a small amount into his lungs. As a result, Diego developed aspiration pneumonia. The doctors assured his wife that they could keep Diego 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 the person who is dying or by the person making healthcare 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 be especially problematic 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 explaining the patient's preferences, those guidelines should determine care (see *Prepare Advance Directives and Other Documents*, page 63).

Without the guidance of an advance directive, if there is a 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. Palliative care consultation may also be helpful. An arbitrator (mediator) can sometimes assist people with different views to agree on a plan (see *To Learn More about Making Healthcare Decisions*, page 49).

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 influence expectations, needs, and choices.

Your background may be different from that of the doctor with whom you are working. Or, you might be used to a different approach to making healthcare decisions at the end of life than your medical team. For example, many healthcare providers look to a single person—the dying person or his or her chosen representative—for important healthcare decisions at the end of life. But, in some cultures, the entire immediate family takes on that role.

It is helpful to discuss your personal and family traditions with your doctors and nurses. If there are religious or cultural customs surrounding death that are important to you, make sure to tell your healthcare providers.

Knowing that these practices will be honored could comfort the dying person. Telling the medical staff ahead of time may also help avoid confusion and misunderstanding when death occurs. Make sure you understand how the available medical options presented by the healthcare team fit into your family's desires for end-of-life care.

Questions to Ask about Healthcare Decisions

Here are some questions you might want to ask the medical staff:

- What is the care plan? What are the benefits and risks?
- How often should we reassess the care plan?
- If we try using the ventilator to help with breathing and decide to stop, how will that be done?
- 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?
- What is the best way for our family to work with the care staff?

- How can I make sure I get a daily update on my family member's condition?
- Will you call me if there is a change in his or her condition?

Thoughts to Share

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

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

To Learn More about Making Healthcare Decisions

Some resources to help you learn more about making healthcare decisions:

Association for Conflict Resolution

www.acrnet.org | 1-202-780-5999 | admin@acrnet.org (email)

Family Caregiver Alliance

www.caregiver.org | 1-800-445-8106 (toll-free)
info@caregiver.org (email)

Society of Critical Care Medicine

www.myicucare.org | 1-847-827-6869 | info@sccm.org (email)



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

— MADAME DE STAEL (1766-1817)

WHAT HAPPENS WHEN SOMEONE DIES

When death comes suddenly, there is little time to prepare. In contrast, 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. You might also ask—how much time do you think my loved one has left, based on your experience with other patients in this condition?

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 or reduced alertness
- Refusal to eat or drink

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

In addition, when a person is 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's breathing becomes abnormal, known as Cheyne-Stokes breathing. Some people hear a death rattle, noisy breathing that makes a gurgling or rattling sound. 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. 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 after visitors leave.

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.

Call 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 (cardiopulmonary resuscitation), 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 (Do Not Resuscitate order) if the person is dying at home. Ask your doctor or the hospice care team who you should call at the time of death.

THINGS TO DO

AFTER SOMEONE DIES

Nothing has to be done immediately after a person's death. Take the time you need. 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 happens at home, there is no need to move the body right away. This is the time for any special religious, ethnic, or cultural customs that are performed soon after death.

If the death seems 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 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 officially 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 and according to local laws. Usually this is done by a funeral home. The hospital or nursing facility, if that is where the death took 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 the 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 died to be transplanted into living people who need them. People of any age can be organ donors.

The person who is dying may have already said that he or she would like to be an organ donor. Some States list this information 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 remove the donated organs.

For more information, read NIA's *Organ Donation and Transplantation for Older Donors and Recipients* (online-only at www.nia.nih.gov/health/publication/organ-donation-and-transplantation).

To Learn More about What to Do When Someone Dies

Some resources to help you learn more about what to do when someone dies:

AARP

www.aarp.org/home-family/caregiving/grief-and-loss

1-888-687-2277 (toll-free) | 1-877-342-2277 (español/ línea gratis)

1-877-434-7598 (TTY/toll-free) | member@aarp.org (email)

Donate Life America

www.donatelife.net | 1-804-377-3580

donatelifeamerica@donatelife.net (email)

Federal Trade Commission

www.ftc.gov/bcp/edu/pubs/consumer/products/pro19.shtm

1-877-382-4357 (toll-free)

The Living Bank

www.livingbank.org | 1-800-528-2971 (toll-free)

info@livingbank.org (email)

Social Security Administration

www.socialsecurity.gov | 1-800-772-1213 (toll-free)

1-800-325-0778 (TTY/toll-free)

GETTING HELP

FOR YOUR GRIEF

Losing someone close to you may leave you feeling sad, lost, alone, or even angry. You may miss the person who has died—you want him or her 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 mourning, a normal reaction to the loss of someone you've cared for.

There are many ways to grieve and to learn to accept 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 or very depressed by it.

Family and compassionate friends can be a great support. They are grieving, too, and some people find that sharing memories is one way to help each other. Feel free to share stories about the one who is gone. Sometimes people hesitate to bring up the loss or mention the dead person's name because they worry this can be hurtful. But, people may find it helpful to talk directly about their loss. You are all coping with the death of someone you cared for.

Charlie and Doug's Story

Shortly after Charlie's husband Doug died, his friends started coming over with dinners and memories to share. They would sit around Charlie'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 Charlie, as well as the others, start to heal after their loss.

GRIEF COUNSELING

Sometimes people find grief counseling makes it easier to work through their sorrow. Grief counselors can talk with you one-on-one. Regular talk therapy can help people learn to accept a death and, in time, start 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 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. You can ask hospice workers for bereavement support at this time, even if hospice was not used before the death. Nursing homes and hospitals often have social workers who have helpful resources. 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

Some resources to help you learn more about dealing with grief:

AARP

www.aarp.org/home-family/caregiving/grief-and-loss

1-888-687-2277 (toll-free) | 1-877-342-2277 (español/línea gratis)

1-877-434-7598 (TTY/toll-free) | member@aarp.org (email)

Hospice Foundation of America

[http://hospicefoundation.org/End-of-Life-Support-and-Resources/](http://hospicefoundation.org/End-of-Life-Support-and-Resources/Grief-Support.aspx)

Grief-Support.aspx | 1-800-854-3402 (toll-free)

info@hospicefoundation.org (email)

National Library of Medicine

www.medlineplus.gov/bereavement.html

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 wishes for end-of-life care.

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 may give your loved ones comfort.

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

TALK 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 about end-of-life care before you become sick will help people who are

close to you to know what care you want. You could discuss how you feel about using life-prolonging measures (for example, CPR or a ventilator) or where you would like to be cared for (for example, home or nursing home). Doctors should be told about these wishes as well.

For some people, it makes sense to bring this up at a small family gathering. Some 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. 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 (or another close relative or friend) are aging and you are unsure 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 Isaiah had a stroke, 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.

PREPARE 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 healthcare power of attorney. A living will records your end-of-life care wishes in case you are no longer able to speak or make decisions for yourself.

You might want to talk with your doctor or other healthcare provider before preparing a living will. This will help you 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. Of course, you should make sure the person you have named (and alternates) understand your views about end-of-life care and are willing to make those decisions on your behalf. You can do this either in the advance directives or through a durable power of attorney for health care that names a healthcare 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 a useful document if you don't want to be specific—if you'd rather let a proxy evaluate each situation or treatment option independently. This document is particularly important if your healthcare proxy—the person you want to make choices for you—is not a legal member of your family.

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.

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 about Advance Directives and Living Wills*, page 66.) 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 healthcare 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.

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

Sometimes people change their minds 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 healthcare proxy and your doctor. Replace all copies of the older version with the updated ones, witnessed and signed if appropriate.

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, perhaps 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 advance directive with copies for that State, too, and be sure your family there has a copy.

What are POLST and MOLST?

A number of States use an advance care planning form known as POLST (Physician Orders for Life-Sustaining Treatment) or MOLST (Medical Orders for Life-Sustaining Treatment). This form provides more detailed guidance about your medical care preferences.

The form is filled out by your doctor, or sometimes a nurse practitioner or physician's assistant, after discussing your wishes with you and your family. Once signed by your doctor, this form has the same authority as any other medical order.

To Learn More about Advance Directives and Living Wills

Some resources to help you learn more about advance directives and living wills:

Aging with Dignity

www.agingwithdignity.org/five-wishes | 1-888-594-7437 (toll-free)

fivewishes@agingwithdignity.org (email)

American Bar Association

www.americanbar.org | 1-800-285-2221 (toll-free)

www.americanbar.org/contactus (email form)

CaringInfo (National Hospice and Palliative Care Organization)

www.caringinfo.org | 1-800-658-8898 (toll-free)

caringinfo@nhpco.org (email)

National Library of Medicine

www.medlineplus.gov, *Search for: Advance Directives*

National Cancer Institute

www.cancer.gov/about-cancer/managing-care/advance-directives

1-800-422-6237 (toll-free) | cancergovstaff@mail.nih.gov (email)

Physician Orders for Life-Sustaining Treatment Paradigm (POLST)

www.polst.org | 1-503-494-4463 | info@polst.org (email)

PREPARE

www.prepareforyourcare.org | 1-415-735-1106

info@prepareforyourcare.org (email)



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

— TUSCARORA SAYING

CLOSING THOUGHTS

Caring for someone who is dying can be hard. And, unless the death is unexpected and quick, there are choices to be made when the time comes. These may not be easy. Planning ahead and working with the healthcare 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. Being a caregiver 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 you were needed, you did what you could.

RESOURCES

If you are interested in learning more, here is a sampling of resources. Some of these are also listed at the end of most chapters.

AARP

1-888-687-2277 (toll-free)
1-877-342-2277 (español/línea gratis)
1-877-434-7598 (TTY/toll-free)
member@aarp.org (email)
www.aarp.org

Aging with Dignity

1-888-594-7437 (toll-free)
fivewishes@agingwithdignity.org
(email)
www.agingwithdignity.org

Alzheimer's Association

1-800-272-3900 (toll-free)
1-866-403-3073 (TTY/toll-free)
info@alz.org (email)
www.alz.org

Alzheimer's Foundation of America

1-866-232-8484 (toll-free)
info@alzfdn.org (email)
www.alzfdn.org

American Academy of Hospice and Palliative Medicine

info@aaahpm.org (email)
www.palliativedoctors.org

American Academy of Pain Medicine

1-847-375-4731
info@painmed.org (email)
www.painmed.org

American Bar Association

1-800-285-2221 (toll-free)
www.americanbar.org/contactus
(email form)
www.americanbar.org

RESOURCES

American Board of Wound Management

1-202-457-8408

info@abwmcertified.org (email)

www.aawm.org

American Geriatrics Society

Health in Aging Foundation

1-800-563-4916 (toll-free)

info@healthinaging.org (email)

www.healthinaging.org

American Music Therapy Association

1-301-589-3300

info@musictherapy.org (email)

www.musictherapy.org

Association for Conflict Resolution

1-202-780-5999

admin@acrnet.org (email)

www.acrnet.org

CaringBridge

www.CaringBridge.org

CaringInfo

(See National Hospice and Palliative Care Organization)

Center for Elder Care and Advanced Illness

Altarum Institute

1-202-776-5100

eldercare@altarum.org (email)

www.altarum.org/cecai

Center for Practical Bioethics

1-800-344-3829 (toll-free)

info@practicalbioethics.org (email)

www.practicalbioethics.org

Centers for Medicare and Medicaid Services

1-800-633-4227 (toll-free)

1-877-486-2048 (TTY/toll-free)

www.medicare.gov

Center to Advance Palliative Care

1-212-201-2670

capc@mssm.edu (email)

www.getpalliativecare.org

Department of Veterans Affairs

Veterans Benefits Administration

Veterans Health Administration

VA benefits:

1-800-827-1000 (toll-free)

To speak with a healthcare benefits counselor:

1-877-222-8387 (toll-free)

www.va.gov

Donate Life America

1-804-377-3580

donatelifeamerica@donatelife.net

(email)

www.donatelife.net

Education in Palliative and End-of-life Care (EPEC)

1-312-503-3732

info@epec.net (email)

www.epec.net

Eldercare Locator

1-800-677-1116 (toll-free)

www.eldercare.gov

Family Caregiver Alliance

1-800-445-8106 (toll-free)

info@caregiver.org (email)

www.caregiver.org

Federal Trade Commission

1-877-382-4357 (toll-free)

www.ftc.gov

Growth House

1-415-863-3045

info@growthhouse.org (email)

www.growthhouse.org

Hospice Association of America

National Association for Home
Care and Hospice

1-202-546-4759

www.nahc.org/

**Hospice and Palliative Nurses
Association**

1-412-787-9301

hpna@hpna.org (email)

<http://hpna.advancingexpertcare.org>

Hospice Foundation of America

1-800-854-3402 (toll-free)

info@hospicefoundation.org (email)

www.hospicefoundation.org

www.hospicedirectory.org

Hospice Net

info@hospicenet.org (email)

www.hospicenet.org

The Living Bank

1-800-528-2971 (toll-free)

info@livingbank.org (email)

www.livingbank.org

National Alliance for Caregiving

1-301-718-8444

info@caregiving.org (email)

www.caregiving.org

**National Alliance for
Hispanic Health**

1-866-783-2645 (English and
Spanish; toll-free)

membership@healthyamericas.org
(email)

www.hispanichealth.org

National Cancer Institute

1-800-422-6237 (toll-free)

cancergovstaff@mail.nih.gov (email)

www.cancer.gov

[www.cancer.gov/cancertopics/
factsheet/support/end-of-life-care](http://www.cancer.gov/cancertopics/factsheet/support/end-of-life-care)

**National Hospice and Palliative
Care Organization**

1-800-658-8898 (toll-free)

caringinfo@nhpco.org (email)

www.caringinfo.org

www.nhpco.org

**National Institute of Nursing
Research**

1-301-496-0207

info@nintr.nih.gov (email)

www.nintr.nih.gov

National Library of Medicine

www.medlineplus.gov

Search for:

“Advance Directives”

“Bereavement”

“End-of-Life Issues”

“Hospice Care”

“Organ Donation”

“Pain”

OrganDonor.gov

Health Resources and Services
Administration

U.S. Department of Health and
Human Services

donation@hrsa.gov (email)

www.organdonor.gov

**Physician Orders for Life-Sustaining
Treatment Paradigm (POLST)**

1-503-494-4463

info@polst.org (email)

www.polst.org

RESOURCES

PostHope

<http://posthope.org>

PREPARE

1-415-735-1106

info@prepareforyourcare.org (email)

www.prepareforyourcare.org

Society of Critical Care Medicine

1-847-827-6869

info@sccm.org (email)

www.mycucare.org/Pages/default.aspx

Social Security Administration

1-800-772-1213 (toll-free)

1-800-325-0778 (TTY/toll-free)

www.socialsecurity.gov

U.S. Department of Health and Human Services

www.alzheimers.gov

Visiting Nurse Associations of America

1-888-866-8773 (toll-free)

vnaa@vnaa.org (email)

www.vnaa.org

Well Spouse Association

1-800-838-0879 (toll-free)

info@wellspouse.org (email)

www.wellspouse.org

What Matters Now

www.whatmattersnow.org

For more information on health and aging, contact:

National Institute on Aging Information Center

P.O. Box 8057

Gaithersburg, MD 20898-8057

1-800-222-2225 (toll-free)

1-800-222-4225 (TTY/toll-free)

niaic@nia.nih.gov (email)

www.nia.nih.gov

To order publications (in English or Spanish) or sign up for regular email alerts about new publications and other information from the NIA, go to www.nia.nih.gov/health.

Visit www.nihseniorhealth.gov, a senior-friendly website from the National Institute on Aging and the National Library of Medicine. This website has health and wellness information for older adults, including information about end of life care. Special features make it simple to use. For example, you can click on a button 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

1-800-438-4380 (toll-free)

adear@nia.nih.gov (email)

www.nia.nih.gov/alzheimers



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Page 73—Stock photo, MediaBakery.com, Santa Barbara, CA

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