



## Preparing for End-of-Life Decisions

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Time seems to freeze when you learn that someone you love has a life-threatening illness. Maybe you instinctively pushed the news away. Or perhaps you cried, or swung into action. No matter what happened that day, time and life go on after the diagnosis is made — regardless of whether you feel ready to cope.

You and your loved one may have pursued promising treatments and perhaps enjoyed a respite from encroaching illness. At some point, however, the illness may become terminal, and gradually the end draws closer. Once further treatments are unlikely to be successful, there is a great deal you can do to muster support for both of you.

Some of the support you need is emotional. The fears and feelings that surface now are better aired than ignored. Some of the support you need concerns practical details. End-of-life care needs to be arranged and funeral plans need to be considered. Legal and financial matters must be addressed now or in the days after the death. This article can help guide you through some of these steps and suggest additional sources of support for you to draw on.

### Dealing with anticipatory grief

Often, people feel anticipatory grief when they know someone they care about is seriously ill. Anticipatory grief means grappling with and grieving a loss before it completely unfolds.

When someone has a serious illness, there are many losses to grieve long before the person becomes terminally ill — for the person who is dying as well as for family and friends. Blows to independence and security, impaired abilities, and truncated visions of the future are just a few examples of devastating losses.

Just as with grief after a death, family and friends may feel a multitude of different emotions as they adjust to the new landscape of their lives. Typical emotions at this time include:

- sorrow
- anxiety
- anger
- acceptance
- depression
- denial

Depending on the type of illness and the relationship you share, you may feel closer and determined to make the time you have left count. Perhaps you are terribly anxious about what's to come or so firmly focused on last-resort treatments that you continue to push away any thoughts of the end. Possibly you long for release or feel guilty and conflicted.

Although not everyone experiences anticipatory grief, all of these feelings are normal for those who do. You may find the following steps comforting:

- Talk with sympathetic friends or family members, especially those who have weathered similar situations.
- Join a support group online or in person.
- Read books or listen to tapes designed for caregivers.

#### Making time to say goodbye

#### Key Points

- When a loved one develops a serious illness, it's normal to go through an emotional experience akin to grieving.
- If the illness is life-threatening, it's important to talk about death and plan for the end of life.
- These conversations can be difficult, but there are ways to make them easier.

Although painful in so many ways, a terminal illness offers you time to say “I love you,” to share your appreciation, and to make amends when necessary. When death occurs unexpectedly, people often regret not having had a chance to do these things.

Ira Byock, author of *Dying Well* and a longtime hospice advocate, suggests that dying people and their families exchange these words with each other:

- I love you
- I forgive you
- Forgive me
- Thank you
- Goodbye.

Sometimes, dying people hold on to life because they sense that others aren’t ready to let them go. Tell your loved one it’s all right to let go when he or she is ready to do so. The assurance that you will be able to carry on — perhaps to help children grow or to fulfill another shared dream — may offer enormous relief.

## How to talk about death

Talking about death is often difficult. Possibly you worry that you’ll undercut your spouse’s will to continue or swamp your friend in fear. Speaking about death may seem like a form of abandonment because it suggests you’ve given up on the lingering promise of a cure. Your own anxiety, sadness, and discomfort may make the words choke in your throat.

But clinicians who work with people with a terminal illness point out the following:

- **Some crave reassurance.** Some people at the end of life are comforted by the thought that they will be embraced, not abandoned, no matter what happens.
- **Some want to talk.** They may tire of keeping up a good front or talking around a topic that looms so large that every other conversation strikes false notes.
- **Some are afraid-and want empathy.** They may be stifling their own numerous fears: leaving loved ones, losing control, becoming a burden, and leaving tasks and plans unfinished. Many people dread a painful death or the reflected fears of others. Sharing such fears and expressing beliefs about death can help people feel less overwhelmed and alone. It can also diminish physical pain, which is aggravated by fear.

### Approaching this difficult conversation

Clearly, not everyone who is terminally ill is ready to talk about death. So how will you know when to talk and what to say? Below are some words that may help you. Your task in this difficult time is merely to open the door to this conversation and promise to stay for it if the person you care for wishes to talk.

**Look for openings.** A sermon or song you heard, a book you read, or the way someone else’s illness and death unfolded can be an opportunity for remarks that open the door. By commenting, you signal that you’re ready to talk and needn’t be protected.

**Broach the topic gently.** Elisabeth Kübler-Ross, psychiatrist and author of the book *On Death and Dying*, describes conversations that start with the simplest question: “How sick are you?”

While you may be too close to reasonably make that inquiry, there are other questions you can ask:

- What do you worry about?
- How can I help?
- Is there anything you want to talk about?

Try not to rebuff tentatively expressed fears with hearty assurances, such as:

- That’s a long way off.
- Of course you’re not a burden.

It might help instead to ask specific questions. Depending on your loved one’s comfort level and receptiveness to the topics, questions you could ask include:

- What are you thinking about?
- What would be a good death?

- What would be a good death.

Sharing your own thoughts on the nature of a good death may help.

**Seek spiritual counsel.** Talk with your religious leader or counselor. Priests, rabbis, and other religious leaders can offer real comfort to believers. Even people who do not regularly attend religious services may turn toward their faith as an illness progresses.

**Ask advice about hospice.** Hospice workers and hospital social workers can also help you and the person who is ill grapple with the issues surrounding death. Even if you have chosen not to use a full range of hospice services, some resources are often available.

**Ask a doctor to help.** A doctor's reassurance about how physical symptoms might unfold and how pain will be handled can be invaluable. Some doctors can ask gently about fears, as well. Realize, though, that it's not unusual for doctors (and nurses) to shy away from talking about death. Some feel determined to try everything and view death as a failure. Being human, they have their own fears and discomfort to deal with, too.

**Let it go.** Kübler-Ross noted that people slip into and out of denial during the course of illness and even during a single conversation. Sometimes it's too hard to think or talk about death. Let your loved one end conversations that feel too difficult. Allow him or her to hold on to comforting thoughts and fantasies.

### How medical staff can help families

When families of terminally ill patients have an opportunity to speak at length with medical staff about their fears, concerns, and questions, they may be better able to cope with their loved one's death.

A 2007 *New England Journal of Medicine* study reported that longer, more empathetic end-of-life conferences eased stress, anxiety, and depression in family members of people who died in intensive care units (ICUs). Conducted in 22 ICUs in France, this randomized trial divided families of 126 patients into two groups; those in one group had short, standard conferences, and those in the other engaged in longer sessions and received a brochure on bereavement. During the longer sessions, staff focused on listening, acknowledging and valuing feelings, encouraging and responding to questions, and gaining an understanding of the patient as a person.

When the researchers contacted a representative in each family 90 days later, they found that those who attended longer end-of-life conferences had significantly lower scores on measures of stress, anxiety, and depression than did family representatives from the control group.

## The practical aspect of end-of-life planning

Few of us wish to think about practical matters at difficult times. But it's easier, although not always possible, to consider many of these issues before they become pressing.

The sections below address the topics of advance care directives (which set forth how a person hopes to be treated medically toward the end of life), hospice services, and organ donation.

### Advance care directives

An advance care directive helps ensure that a person's health care wishes and end-of-life concerns are known and respected. These documents address how aggressively doctors should pursue life-sustaining measures and whether quality of life or comfort should be paramount concerns.

Two common advance directives are:

- **Living will.** This sets forth medical wishes that will guide health care if a person becomes mentally or physically unable to make decisions
- **Health care power of attorney or health care proxy.** These forms designate a person to act on an ill person's behalf when necessary.

State laws vary, so it is important to make sure any advance directive complies with local regulations. A local hospital, hospice, or seniors' organization may have staff members who can help prepare an advance directive. Or have your loved one discuss this with a lawyer qualified in elder law. (It's wise for everyone to have advance directives, so you should also consider preparing them for yourself as well.)

One flaw of advance directives is the impossibility of knowing the exact circumstances under which they will be invoked, what medical options will be available, and how a person's feelings might change. Rather than sidestepping this difficult issue, though, consider that mulling over wishes for end-of-life care can help people sort out values and feelings about medical measures often taken at the end of life.

A frank talk with a doctor about possible medical scenarios can provide guidance. It may help to know that if the person who wrote the advance directive has a change of heart at any time while under medical care, his or her spoken wishes override any written ones.

These wishes should be communicated fully with everyone involved. Make sure you or your loved one takes the following steps:

- **Make a copy.** Anyone named as proxy in a durable power of attorney for health care should have a copy of the document and know the goals for medical care. The proxy, a family member, and a lawyer, if any, should know where additional copies of the form are kept.
- **Talk with medical staff.** Talk with the doctors to be sure the wishes are understood and can be followed. Ask them to place a copy of the advance directive in the person's permanent medical record.
- **Inform family members.** Discuss wishes for end-of-life medical care with family members. Acknowledge that this is a difficult topic. It may help to begin by talking about a recent case in the news or the treatment of someone you know.
- **Repeat periodically.** Have discussions with family and medical staff more than once to be sure wishes are understood. This is especially important as circumstances change.

### Do-not-resuscitate orders

A do-not-resuscitate order (DNR) tells health care professionals not to attempt cardiopulmonary resuscitation (CPR) or defibrillation if the person's heart stops beating. This document is written only when these measures are unlikely to revive a dying person or to prolong meaningful life. Generally, during the last stage of a terminal illness, CPR is not very likely to result in successful resuscitation.

Here is some advice about making the best use of DNR documents:

- **Decide when a DNR is needed.** Discuss the need for a DNR with your loved one and the doctors. There are different types of DNR orders, and forms and laws vary from state to state, so it's important to discuss this issue with your loved one's physician.
- **Understand that medical care will still be available.** It may be reassuring to know that even with a DNR, the patient will continue to receive appropriate medical care to treat short-term illnesses or injuries and relieve pain or other troubling symptoms. Emergency service personnel called to a person's home can still give oxygen, medications, and fluids and transport the patient to a hospital, if necessary.
- **Know why putting it in writing matters.** It's worth noting that health care and emergency personnel are required to attempt CPR if there is no DNR, even if the patient has asked family members to request that they forgo this measure.
- **Keep the originals handy.** Generally, only originals are valid, so it's wise to have several originals of a DNR form. Always keep one original handy in the person's home; the other should be carried by the patient or a caregiver at all times.
- **Have some on file.** In hospitals and nursing homes, the DNR is kept on file and noted in a patient's chart. Mistakes do occur, so ask if this has been done.

### Other decisions to make

It is difficult to predict these things in advance, but it's worth considering whether you will or won't want the following life support options:

- **Mechanical ventilation:** A machine called a ventilator or respirator forces air into the lungs for people who are unable to breathe under their own power.
- **Intravenous hydration:** A tube inserted into a vein supplies a solution of water, sugar, and minerals for people who are unable to swallow.
- **Artificial nutrition (tube feeding):** A tube inserted through the nose into the stomach supplies nutrients and fluids for people who are unable to swallow.
- **Hemodialysis:** Blood is circulated through a machine to maintain the balance of fluids and essential

- **Hemodialysis:** Blood is circulated through a machine to maintain the balance of fluids and essential minerals and clear waste from the bloodstream for people whose kidneys are unable to perform this function.

## Hospice comfort and care

Once a word that evoked shelter for tired and ill religious pilgrims, the term hospice has come to describe a concept of end-of-life care centered on quality of life. Hospice care — which encompasses physical, emotional, and spiritual needs — may take place at home or at a nursing home, assisted living center, or hospice residence. When a cure is not possible and aggressive treatment isn't desired, hospice care offers symptom relief, pain control, and a great deal of support.

The hospice team works with the patient to develop a personal plan of care. Family, partners, and close friends may be invited to help in many ways, such as by assisting with daily tasks like feeding and bathing and offering comfort by reading, sharing music, holding hands, and simply being present.

Hospice programs vary greatly but generally share certain characteristics:

- **Range of services.** Hospice staff can administer pain medications, provide nursing care, and offer emotional support. Before and after a death, emotional support is extended to caregivers, too. Many programs offer bereavement counseling for a year after a death.
- **A multidisciplinary team.** The hospice team typically includes specially trained doctors, nurses, aides, social workers, counselors, therapists, people who offer spiritual care, and volunteers, according to the Hospice Foundation of America.
- **Licensing, certification, and accreditation.** Hospices must be licensed in most states. Those providing services covered by Medicare or Medicaid must be certified by the Centers for Medicare and Medicaid Services. Hospice programs may also be accredited by the Joint Commission or the Community Health Accreditation Program, but there is no national requirement for this.
- **Insurance coverage.** Hospice services are covered nationwide under Medicare and in at least 45 states and the District of Columbia under Medicaid for anyone who has a prognosis of six months or less to live. Many private insurers and health maintenance organizations also offer coverage.

As you consider hospice programs, the Hospice Foundation of America suggests you ask whether each is licensed and Medicare- or Medicaid-certified, or certified by other organizations. Find out what services are available, whether insurance or Medicare or Medicaid covers these costs, and what out-of-pocket expenses are typical. Sometimes a sliding-scale payment plan is available for services that insurance will not cover.

It is wise to investigate hospice programs well in advance, as there may be a waiting list for some facilities. Consider what will be expected of you and whether the hospice's philosophy of care — including use of antibiotics, resuscitation, and hydration — matches that of your loved one and other family members. And ask about support programs for caregivers and availability of inpatient services.

### Locating a hospice program near you

To locate a hospice program near you, ask a doctor for a referral or contact:

The Hospice Foundation of America  
800-854-3402 (toll-free in the U.S.)  
[www.hospicefoundation.org](http://www.hospicefoundation.org)

The National Hospice and Palliative Care Organization  
800-658-8898 (toll-free in the U.S.)  
[www.nhpco.org](http://www.nhpco.org)

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