

Section 10

End-of-Life Issues



Starting the Conversation About End-Of-Life Wishes

You can help the person you care for, and yourself, by initiating a conversation about his or her wishes regarding end-of-life care. Although it is often difficult to speak honestly and openly about death and dying, it can be even more uncomfortable to have to make end-of-life decisions concerning a loved one without having had such a discussion. The majority of people who die from an illness, as opposed to a car accident or some other sudden means of death, will go through a period of days or weeks when they move in and out of consciousness and are unable to talk. This is why it is important to talk, while you still can, about the person's wishes for life sustaining treatment.

Barriers to Talking

Most families find that bringing up the topic is the hardest part. Once everyone gets past the initial discomfort, many find themselves relieved to have the issues out into the open. If the time does come when the person who is being cared for can no longer speak for him/herself, family members who know their loved one's wishes are spared the guilt and anxiety of trying to make difficult life-support decisions without previous guidance. As a potential decision maker, you may find it is in your best interest to start the quality of life conversation and encourage the person you care for to write down his or her wishes in an advance directive.

While 80% of Americans say they wish to die at home, only 20% do. And although 75% of Americans say they are in favor of advance directives, only 30-35% of them actually write one. The biggest barrier is procrastination-not getting around to it. In an ideal world, every adult would have an advance directive, no matter his or her age. Sudden accidents or illnesses occur all too frequently and often take us off guard. Within the context of a serious illness, there may be no time to put this decision off. If you need help in thinking about or discussing these issues, contact the Community Partnership for End of Life Care (a program of Hospice & Palliative CareCenter) or call 336-768-6157, ext. 622.

Conversation Starters

The American Bar Association tool kit is an excellent and very accessible resource to help patients and their families discuss matters concerning end of life care. The kit's articles address topics such as weighing the odds of survival, your personal priorities and spiritual values, how to select a health care representative, and how to be a health care representative.

There probably is no right time or right way to start a discussion about dying. Unless there is a story in the news that provides a good opening, you may want to begin with an indirect reference. For instance, you can talk about a friend who had problems when her parent died because the parent had not spoken with family members or written an advance directive. By expressing the personal distress you would feel if you were in that situation, you then can shift to asking the person you care for what he or she would like to have done "just in case." Many people who are sick care very deeply about not causing their family members pain or anguish. Once they realize that not talking about the situation will make it harder on the ones they love, they often can get past their resistance. Some are even relieved because they had wanted to talk about it but didn't know how to bring up the subject!

Sometimes it helps to open the conversation by acknowledging how awkward you feel: "I have something on my mind that is really uncomfortable to talk about, but I feel we need to. I wouldn't be a

good [son/daughter/wife] if I didn't find out about your wishes for care if you get to the point at which you can't express them yourself."

Alternatively, if you know that the person you care for is very particular about how things are done, you might want to start the conversation by emphasizing his or her ability to remain in control, even at the end, through an advance directive. People with a serious illness often feel powerless about their disease and their situation. By planning ahead for their care, they will at least be able to direct those things that are still within their power to control.

Some people say their attorney advised them to have the conversation: "My attorney was talking to me about my need for an advance directive, and I realized I don't know much about you and your wishes." Others might start the conversation by noting something about famous people. For instance, "Neither Richard Nixon nor Jackie Kennedy was on life support when they died. I wonder if they had an advance directive."

You may want to look at a guide called *Isn't It Time We Talk*. It outlines several basic concepts you may want to cover in your discussion. In addition, this guide can be used to help the person you care for identify what it is he or she wants and values before going on to complete an official advance directive form. Our article about quality of life is also helpful in this regard. For factual information about commonly used life-support measures (e.g., the effectiveness and experience of CPR, tube feeding, the use of antibiotics, etc.), go to www.hospicecarecenter.org.

When Family Members Disagree

The person who is ill may have very clear thoughts about what he or she wants in terms of care at the end of life, but family members may not agree. This situation can make things very difficult for the professionals involved. They are legally and ethically bound to follow the patient's wishes. If all the paperwork is complete and available, then there is no question about what will be done.

Professionals recommend that you keep several copies and distribute them liberally so they are not difficult to find when they are needed. For instance, a safe deposit box is OK, but your doctor and lawyer should have copies, as should your health representative and your local hospital. Some even suggest keeping a copy in the glove compartment of your car and at home in your desk. If the person you care for is homebound, you may want to keep a copy in a drawer by the bedside so it is readily available for emergency medical personnel in case there is a call to 911.

To facilitate access to the advance directive, in many states you may have it registered electronically. This enables hospitals and health providers from around the country to have access to your advance directive 24 hours a day, 7 days a week. Check with your state attorney general; in some states a fee is involved, while other states are now offering this service for free.

With all the paperwork in place, your care receiver will have his or her wishes honored. However, that does not mean the situation will be a comfortable one if there is disagreement within the family. If a relative has strong feelings that are contrary to the wishes of the patient (whichever direction they lean), you would do well to resolve the conflict as soon as possible. Bringing in a professional such as a counselor, social worker, chaplain, or other spiritual advisor can help immeasurably. These professionals can help the patient express his or her feelings about quality of life in a safe environment. They can

also provide opportunities for the dissenting family members to not only be heard, but also be guided to an understanding and acceptance of the patient's decision. Time and resources spent gaining family consensus before the death will be a good investment for helping everyone constructively process events after their loved one has died.

Responding to Resistance

Here are a few of the ways people often respond when someone brings up the subject of advance directives and end of life decisions:

"It'll be okay. I'll beat this thing. We don't need to discuss life support."

Denial is one of many ways we cope with problems that seem overwhelming. Although it is frustrating for family members, it can be a very important strategy for the person who is confronting mortality. However, it doesn't relieve you of the need to have the conversation. Rather than force the person you care about to accept the terminal nature of the disease, you can frame your need for a conversation in the context of "just in case." In a gesture of unity, you could also decide to make an advance directive yourself and suggest that the two of you do it together. This helps prevent the person who is ill from feeling marginalized and set apart. As a side benefit, it can provide you with an advance directive. People with terminal illnesses are not the only ones who need such a document. Accidents happen all the time, and those who may have to care for you would likely appreciate having a directive to help them make decisions on your behalf.

"It's all in God's hands."

Those who are religious or have strong life philosophies believe the moment of death is out of our control. Whether or not you agree with these beliefs, you can affirm your loved one's conviction and still point out that "a Higher Power has given us the responsibility to determine how we live up until death." You can communicate your need to know more about the person's wishes in case he or she is unable to describe those wishes when they are needed.

"It's too painful to talk about. Besides, talking about it is bad luck. It will only make it happen."

Rather than challenge your care receiver's beliefs about a premature demise, focus instead on the pain it will cause you if you don't have the discussion. You can first acknowledge his or her pain and discomfort with the subject. You can then share that you too, are in anguish at the prospect of making tough decisions and living with the guilt of making a decision that is different than what he or she would have wanted. You can also acknowledge discomfort by not insisting on an immediate conversation. Instead you can ask to set up a specific time in the next few days when the two of you can get together and talk. Sometimes spending a little time with the idea can make it easier to address later.

"There's no need to talk. You know me. I don't want any heroics."

Although this is a simple, straightforward response, unfortunately end-of-life decisions are not always about heroic measures. For instance, from what this person has said, one could reasonably assume that he or she would not want cardiopulmonary resuscitation (CPR), but what about antibiotics in the case of an infection with pneumonia? Or what about tube feeding if he was no longer taking in food or water? Our article about planning for healthcare decisions includes information about the medical and quality-of-life considerations that typically must be faced for each of the life-support measures.

Source: Hospice & Palliative Care Center, 2002-2014, www.hospicecarecenter.org

Advanced Illness: Holding On and Letting Go

Introduction

Our culture tells us that we should fight hard against age, illness and death: “Do not go gentle into that good night,” Dylan Thomas wrote. And holding on to life, to our loved ones, is indeed a basic human instinct. However, as an illness advances, “raging against the dying of the light” often begins to cause undue suffering, and “letting go” may instead feel like the next stage.

This fact sheet discusses the normal shifting emotions and considerations involved in holding on and letting go. Exploring these issues ahead of time will allow a person with a chronic illness to have some choice or control over his or her care, help families with the process of making difficult decisions, and may make this profound transition a little easier for everyone concerned.

The opinions of the dying person are important, and it is often impossible to know what those beliefs are unless we discuss the issues ahead of time. In caring for someone with memory loss, it is important to have the conversations as soon as possible, while he/she is still able to have an informed opinion and share it. Planning ahead gives the caregiver and loved ones choices in care and is most considerate to the person who will have to make decisions.

This fact sheet presents principal concerns, then discusses planning ahead, and some of the related matters that come up during chronic illness. Finally, it presents ideas on how to go about making the decisions when the time comes. All along the way, there are few, if any, right or wrong choices. This is a time to seek the answers that most respect the person experiencing advanced stages of an illness.

Holding On

Humans have an instinctive desire to go on living. We experience this as desires for food, activity, learning, etc. We feel attachments to loved ones, such as family members and friends, and even to pets, and we do not want to leave them. We do not so much decide to go on living, as find ourselves doing it automatically. Robert Frost said, “In three words I can sum up everything I have learned about life: It goes on.” Even in difficult times, it is our nature to hold on for better times.

When we realize that the end of life may be approaching, other thoughts and feelings arise. The person who is ill will want to be with loved ones, and may also feel a sense of responsibility towards them, not wanting to fail them nor cause them grief. He/she may have unfinished business. For example, the person may or may not want to reconcile with estranged family members or friends. Fears arise, and may be so strong that they are hard to think about or even admit to: fear of change, of the dying process, of what happens after death, of losing control, of dependency and more. Both the person who is ill and the caregiver might also experience resentment, guilt, sadness and anger at having to do what neither wants to do, namely face death and dying.

Even in facing death, hope remains. The object of hope may change. As death comes closer, the family may hope for a restful night, or another visit with a particular friend, or just a quiet passing from this life to whatever we hope follows it. Often, as an illness progresses to an advanced stage, two seemingly incompatible ideas may arise in our minds. The Jewish prayer of the gravely ill puts it well for both the person who is ill and the loved ones caring for him/her: "I do not choose to die. May it come to pass that I may be healed. But if death is my fate, then I accept it with dignity."

Letting Go

As death nears, many people feel a lessening of their desire to live longer. This is different from depression or thoughts of suicide. Instead, they sense it is time to let go. Perhaps, as in other times in life, it's a sense that it's time for a major change like one might feel when moving away from home, getting married, divorcing or changing to a new job. Some people describe a profound tiredness, a tiredness that no longer goes away with rest. Others may reach a point where they feel they have struggled as much as they have been called upon to do and will struggle no more. Refusing to let go can prolong dying, but it cannot prevent it. Dying, thus prolonged, can become more a time of suffering than of living.

Family members and friends who love the dying person may experience a similar change. At first, one may adjust to managing a chronic illness, then learn to accept a life limiting illness, and then accept the possibility of a loved one dying. Some may refuse to accept the inevitability of death. Lastly, one may see that dying is the better of two choices, and be ready to give the loved one permission to die. As mentioned, the dying may be distressed at causing grief for those who love them, and, receiving permission to die can relieve their distress. There is a time for this to happen. Before that, it feels wrong to accept a loss, but after that it can be an act of great kindness to say, "You may go when you feel it is time. I will be okay."

Other Concerns

Letting go gets mixed up in our minds with a person wanting to die, although these are really separate situations. There are various reasons a person may want to die, reasons quite separate from those for letting go. Depression is one response to finding life too painful in some way. Some people cannot tolerate losing control, so they want to take control of dying. It can be unpleasant to be disabled, or in a place one does not want to be, or isolated from the important people and things in one's life. Very often, a severely ill person feels like a burden to family and friends, and may wish to die rather than let this continue. Fears of the future, even of dying, may be so great that a person wants to die to get away from that fear. Inadequately controlled pain or other symptoms can make life seem unbearable.

For many of these situations the right sort of help can make a great improvement, and replace the desire to die with a willingness to live out this last part of one's life. At this time, professionals such as mental health providers, a hospice team evaluation, or pain-management specialist, may be called upon for consultation.

Chronic Illness

So far, this fact sheet has been about the very end of life. Many, or even most, people go through a period of chronic illness before they die. Along the way there are numerous choices to make. Caregivers and people they care for have to decide whether or not to get a particular treatment or procedure. How long can one keep trying to do usual activities, including work, and when does it seem time for one

to face that that phase of life is over? Most of us have things we have dreamed of doing, but never got around to. Now may be the time to do that thing, no matter how difficult, or it may be time to let it be just a beautiful dream. Chronic illness brings up one situation after another where caregivers and care receivers must do their best to communicate about beliefs and options, and then decide either to hold on or to let go.

Planning Ahead

Planning ahead means thinking about what is important, and what is not. It also means talking about this with those close to us. Even though we think we know what someone else thinks and believes, we really do not know until we ask. You cannot read other people's minds.

When we think about the last part of our own or someone else's life, consider these questions:

- What makes life worth living?
- What would make life definitely not worth living?
- What might at first seem like too much to put up with, but then might seem manageable after getting used to the situation and learning how to deal with it?
- If I knew life was coming to an end, what would be comforting and make dying feel safe?
- What, in that situation, would I most want to avoid?

Knowing what really matters to you is worth considering. How important is being able to talk with people, engaging in daily activities, physical comfort or general alertness to you? What comes to mind when you think about the burden of care on others, being at home, or not being there? How much distress is it worth in order to live another month? And what medical procedures are not worth enduring? From your perspective, what is the best way for a person to die, and how important is it to you to be in control of how you live and how you die? Whose opinion should be sought in making choices about the care received when an illness has progressed to an advanced stage?

One especially important matter is to complete the Advance Health Care Directive for both the person who is ill and the caregiver, so that there is an official spokesperson when one is too sick or too confused to speak for him/herself.

If, as caregivers, we haven't had the necessary conversations—whether due to reluctance, dementia, or a crisis—we might have to think about the issues raised above without a lot of information.

Some questions that might help in thinking about this are:

- What has that person actually told me?
- How can I find out for sure about her or his wishes?
- Turning now to myself as the caregiver, what would be important to me?
- What would I especially like to know about that person's wishes?
- What would be the limits of what I could do?
- Could I take time off work? How much? What are my financial constraints?
- What physical limitations do I have?
- What kinds of care would be just too much emotionally for me?

- Might I provide more comfort if I let go of some of the daily hands-on caregiving, and allow someone else, even a paid caregiver, to assume this role?
- Am I willing to accept the responsibility of being someone's official spokesperson?
- If that person has relatives who would be especially difficult to deal with, how would I manage being the official maker of decisions?

All of these questions may sound very difficult to discuss now, when the time for decisions is still in the future. However, they are harder to discuss when someone is really sick, emotions are high, and decisions must be made quickly. Chronic pain, frailty, and cognitive decline may take away the ability to discuss complicated issues. The earlier everyone sits down to talk, the better. The best way to start is simply to start. Arrange a time to talk. You may say you want to talk about things that might happen in the future, in case of serious illness. Have some ideas to bring up. Be prepared to listen a lot, and to ask questions. Do your best not to criticize what the other person says. If you know the other person will not want to talk much about this topic, have just one or two important things to say or to ask about. Be prepared to break off the conversation, and to come back to it another time. Write down the important things people say. Eventually, you can use your notes to prepare a statement of wishes and make this statement part of an "advance directive" about health care decisions, whether or not the formal document has been completed.

Many families find it is easier to have such a critical discussion with the presence and guidance of an impartial facilitator. Some social workers, case managers, or faith-leaders are skilled in providing this support (see added resources). Asking for a professional to assist with the discussion may relieve individual family members from the burden of having to take on this role.

It is also important to talk with your physician about treatment choices. You may ask the doctor to complete a POLST, or Physician's Orders for Life Sustaining Treatment. (Visit www.polst.org to find out if your state offers a POLST program, or in states without POLST, ask the doctor about a DNR order - Do Not Resuscitate). This form is a set of medical orders, similar to the DNR (allow natural death to occur). On this form one can state that he/she does or does not want to be resuscitated, and whether or not one would want a feeding tube, ventilator and other treatments. Decisions to provide or withhold life support are based on personal values, beliefs and consideration for what a person might have wanted. Such decisions are painful. Family members should give themselves ample time to cope with these life and death decisions and to process feelings of doubt, guilt or blame that may surface.

POLST is not for everyone. Only individuals with serious, progressive, chronic illnesses should have a POLST form. For these patients, their current health status indicates the need for standing medical orders. For healthy individuals, an Advance Directive is an appropriate tool for making future end-of-life care wishes known to loved ones. Professionals in medical offices, hospitals, community-based services, and hospice teams are skilled at assisting individuals or family groups at working with these very normal, but painful, emotions.

Making the Decision

Is it time to let go? Or time to give a loved one permission to die? There are three ways to help decide.

First, look at the medical situation. Has the illness really reached its final stages? When it has, the body is usually moving on its own toward dying, with strength declining, appetite poor, and often the mind becoming sleepier and more confused. Treatments are no longer working as well as before, and everyday activities are becoming more and more burdensome. In a sense, life is disappearing. Consult with your physician; ask for clarity on the prognosis, or likely course of the illness or stages of dying.

Closer to death, there may be dramatic changes in the dying person's moods, behaviors, desire to take food or water, and capacity to verbalize wishes. All of this may be a normal part of his or her letting go. At this time, safety and comfort care are of utmost concern.

Second, talk with people you trust. Discuss the situation with the family members and friends who seem to be able to see things as they are. You might also talk with people who are not personally involved. Most importantly, consider what the dying person has expressed or you know to be his or her desires.

Third, listen to your heart. Try to see beyond your fears and wishes, to what love and caring are saying to you. What is really best for the one who is dying, and for the others around? Given that death is unavoidable, what is the kindest thing to do? It might be holding on. It might be letting go.

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Palliative Care Frequently Asked Questions

What is palliative care?

Palliative care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain and stress of a serious illness - whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

How do I know if palliative care is right for me?

Palliative care may be right for you if you are experiencing pain, stress and other symptoms due to a serious illness. Serious illnesses include but are not limited to: cancer, cardiac disease, respiratory disease, kidney failure, Alzheimer's, AIDS, amyotrophic lateral sclerosis (ALS) and multiple sclerosis. Palliative care is appropriate at any stage of a serious illness and you can get it along with treatment meant to cure you.

What does palliative care do?

- **Pain and symptom control:** Your palliative care team will identify your sources of pain and discomfort. These may include problems with breathing, fatigue, depression, insomnia, or bowel or bladder. Then the team will provide treatments that can offer relief. These might include medication, along with massage therapy or relaxation techniques.
- **Communication and coordination:** Palliative care teams are extremely good communicators. They put great importance on communication between you, your family and your doctors in order to ensure that your needs are fully met. These include establishing goals for your care, help with decision-making and coordination of care.
- **Emotional support:** Palliative care focuses on the entire person, not just the illness. The team members caring for you will address any social, psychological, emotional or spiritual needs you may have.
- **Family/caregiver support:** Caregivers bear a great deal of stress too, so the palliative care team supports them as well. This focused attention helps ease some of the strain and can help you with your decision making.

What can I expect?

You can expect to have more control over your care and a comfortable and supportive atmosphere that reduces anxiety and stress. Your plan of care is reviewed each day by the palliative care team and discussed with you to make sure your needs and wishes are being met and that your treatments are in line with your goals. You can also expect relief from symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping. Palliative care addresses the whole person. It helps you carry on with your daily life. It improves your ability to go through medical treatments. And it helps you better understand your condition and your choices for medical care. In short, you can expect the best possible quality of life.

Will my insurance cover palliative care?

Most insurance plans cover all or part of the palliative care treatment you receive, just as with other hospital and medical services. This is also true of Medicare and Medicaid. If costs concern you, a social worker or financial consultant from the palliative care team can help you with payment options.

Do I have to give up my own doctor?

The palliative care team provides an extra layer of support and works in partnership with your primary doctor. Your primary doctor will continue to direct your care and play an active role in your treatment.

Can I have curative treatment together with palliative care?

Absolutely. Your treatment choices are up to you. You can get palliative care at the same time as treatment meant to cure you.

Who else, besides the patient, can benefit?

Everyone involved! Patients as well as family caregivers are the special focus of palliative care. Your doctors and nurses benefit too, because they know they are meeting your needs by providing care and treatment that reduces your suffering and improves your quality of life.

Where do I get palliative care?

Palliative care can be available in a number of places. These include hospitals, outpatient clinics, long-term-care facilities, hospices or home.

Who provides palliative care?

Usually a team of specialists, including palliative care doctors, nurses and social workers, provide this type of care. Massage therapists, pharmacists, nutritionists and others might also be part of the team. Generally, each hospital has its own type of team.

Can I get palliative care if I am at home?

After discharge from the hospital, you, your doctor and the palliative care team can discuss outpatient palliative care. Some hospitals also offer outpatient palliative care even if you have not been in the hospital. Check with your doctor.

What is the difference between hospice and palliative care?

Palliative care is for anyone with a serious illness. You can have it at any age and any stage of an illness, and you can have it along with curative treatment. It is not dependent on prognosis. Hospice is an important Medicare benefit that provides palliative care for terminally ill patients who may have only months to live. People who receive hospice are also no longer receiving curative treatment for their underlying disease.

How do I get palliative care?

Ask for it! Start by talking with your doctor or nurse.

Source: www.GetPalliativeCare.org

Hospice FAQs

Helping older relatives or friends make more informed choices about end of life decisions.

Frequently Asked Questions about Hospice

At the end of a life limiting illness, there may come a time when a person chooses to stop receiving aggressive treatment efforts. In your role as a caregiver, this may be an appropriate time to discuss the option of hospice care with your loved one.

What is Hospice and Palliative Care?

The hospice approach to care focuses on comfort and dignity for the dying patient and the patient's family. The focus is on caring, not curing. This approach is called palliative care and aims for pain relief and symptom control rather than cure.

Hospice services are provided by a team of physicians, nurses, social workers, counselors, certified nursing assistants, clergy, and volunteers. Hospice care is available to anyone with a terminal illness who is expected to pass away within six months if the illness follows its normal course. Unfortunately, many patients receive hospice services for only their last few weeks of life when they actually could have benefitted from hospice services for several months.

The basic principles of hospice care are:

- **Death with dignity.** Provide end-of-life care that eases both physical and emotional pain.
- **Palliative care.** Help the patient experience quality of life through relief of suffering and control of symptoms.
- **Individual control over life.** Involve the patient in all aspects of care and respect the choices the patient makes.
- **Ongoing support for the patient, family and friends.** Ensure the patient and the patient's family feel understood, reassured, and validated during this difficult time.
- **Importance of family.** Family and friends are fundamental to the well-being of the patient and should be as involved as the patient would like them to be.

Does hospice provide any services for the family of the dying patient?

Hospice understands that those who are close to a dying person experience the dual pains of shared suffering and anticipated loss. Hospice provides continuing support for caregivers for at least one year following the death of a loved one and sponsors bereavement groups and grief support groups.

What kind of services does hospice provide?

Hospice provides medical and nursing care, medical equipment and supplies, medication therapy for pain and symptom control, homemaker services, social work services, counseling, respite care, religious support and the coordination of all services needed by the patient and family. Respect for the individual's ethnicity, cultural beliefs, and sexual orientation are reflected in the services and program of hospice care.



Dispelling Myths About Hospice

Myth – Hospice is just a place to send people when they are dying.

Hospice is not a place, but a way of caring for people and their families who are facing their final six months or so of life. Hospice helps them remain as comfortable, functional and dignified as possible, providing physical, emotional and spiritual support. With the support of the hospice team, most people are able to remain in their own homes, surrounded by the people and things they love.

Myth – Choosing hospice is giving up

Hospice affirms life and helps people live as fully and comfortably as possible when cure is no longer possible. It is a way to realistically and humanely manage the final stage of life and an opportunity to redefine and experience hope and healing.

Myth – Hospice is only for those who are near death

Hospice accepts those people who are in their final six months of life, allowing time for support, education, to allay fears and live fully the remainder of their days.

Myth – Once hospice is chosen, the person is no longer in control of their care.

The terminally ill person and their family remain in control of their care. The job of hospice is to support them in a way that respects their value and goals. The person always has the right to change their mind about the selection of hospice care, the provider of hospice care, and may choose to cancel hospice at any time should they again seek aggressive curative treatment.

Myth – Hospice is the same as euthanasia

Hospice neither hastens death nor prolongs dying. The honor both life and the natural process of dying, assuring as much comfort and function as possible within the limits of the disease.

Myth – Hospice care is expensive

Under Medicare and most insurance companies, hospice care is **covered 100%**, relieving families of many financial burdens. Covered services include nursing visits, social workers, bereavement counselors, spiritual counselors, home health aides, volunteers, physical and speech therapy, all working under the direction of your physician. Medication and equipment and many personal supplies necessary for the comfort and safety are also covered and delivered to your home, as well as short-term inpatient stays for symptom management or respite. No one is refused because of their inability to pay.

Hospice frequent visits, comprehensive support and 24-hour availability helps the person avoid costly and unnecessary hospitalization and trips to the ER.

Myth – Hospice is just for people who have cancer

Hospice cares for anyone facing a terminal disease or natural end of their lives. This includes old age, dementia, heart and lung disease, neurological disorders, and more.

Myth – Hospice stops all medications and treatments

Hospice is very aggressive in providing excellent comfort care. This includes medication, oxygen and other treatments necessary to enhance quality of life. They will work with your physician to determine the best possible plan of care to assure your comfort.

Myth – Hospice is depressing

While it is always sad to realize someone you care about is facing the end of their life, hospice helps that person and family discover ways to create meaning, find healing, share stories and leave a legacy and make the most of the days and months that remain. This is life affirming and can be as filled with laughter as it can with tears. Hospice is a guide for the journey to lessen fear and promote communication and quality of life.

Did you know this about hospice?

- Services are available 24 hours a day, 7 days a week with intermittent visits by the hospice team.
- Your doctor remains in charge of your care unless you choose otherwise or if he or she feels you will get the best care with a physician who specializes in comfort care.
- The majority of people are able to remain in their own homes until death.
- Two studies show that people actually live longer under hospice care due to good symptom control and decreased aggressive treatment that may occasionally hasten the end of life.
- A number of people improve so much under the hospice team's ability to manage symptoms that they are discharged because the doctor feels they are no longer in a terminal phase (the last six months)
- Your right to choose never ends. You can:
 - Decide to try curative treatment again and sign out of hospice. If you get better, we are thrilled for you. If treatment fails, the person is welcomed back to resume hospice support and care.
 - Change hospice programs if one isn't meeting your needs
- No one has a crystal ball. A six-month prognosis is our best educated guess based on your disease. Hospice will continue to provide care after 6 months as long as your health status and goals still meet criteria for care.

Advanced Illnesses: CPR & DNR

Introduction

Big issues - and big decisions - confront us when we think about the imminent death of a terminally ill loved one in our care. Among the emotional, legal and financial considerations are also questions regarding the type of medical assistance your loved one should receive as their illness advances. For example, if your loved one suddenly has difficulty breathing, will you allow a paramedic or an emergency room technician to administer CPR? And if CPR revives your loved one, yet he or she still can no longer breathe on his or her own, should you allow a machine - a respirator - to breathe for him or her? A better understanding of cardiopulmonary resuscitation, or CPR, can be helpful when it comes to making this difficult choice before a crisis occurs. This Fact Sheet specifically addresses the process of CPR and describes the DNR (Do Not Resuscitate) form, the legal document used to indicate to medical professionals your - or your loved one's - wishes. (For a more detailed discussion of the other issues involved in planning for the end of life, see the Family Caregiver Alliance fact sheets, End-of-Life Care Planning: Decision Making, and Advanced Care: Feeding Tubes and Ventilators).

CPR (Cardiopulmonary Resuscitation)

Consider the following scenario:

Nancy's husband has had Alzheimer's disease for eight years, and is now in the final stages of the illness. After a discussion of end-of-life issues with her family, Nancy has decided to "let nature take its course" if anything of an urgent medical nature happens to her husband. In other words, she does not want him to be put on life support. She has told her doctor of this decision, and he has concurred.

One night, Nancy wakes up to find her husband having trouble breathing. Reflexively, without thinking, she calls 911. By the time the paramedics arrive, her husband has stopped breathing completely. The paramedics leap to do their job: they immediately administer CPR and take him to the hospital. By the time Nancy arrives at the hospital, her husband is connected to a ventilator and numerous IVs. Unfortunately, this is exactly what she did not want for him.

Definition

Fully understanding Nancy's scenario requires a deeper understanding of cardiopulmonary resuscitation. Simply put, CPR is the process of restarting the heartbeat and breathing after one or both has stopped. The first step involves creating an artificial heartbeat by pushing on the chest, and attempting to restore breathing by blowing into the person's mouth. A medical professional will then insert a tube through the mouth and down the airway to make the artificial breathing more efficient. Electric shocks may be given to the heart, and various drugs may be given through an intravenous line. If the heartbeat starts again but breathing is still not adequate, a machine called a ventilator may be employed to move air in and out of the person's lungs indefinitely.

On television, CPR is often depicted as the ultimate life-saving technique. However, television does not show this process quite accurately - in real life the process is more brutal. Pushing the center of the chest down about one and one-half inches, 100 times a minute for several minutes, causes pain, and may even break ribs, damage the liver, or create other significant problems. CPR produces a barely adequate heartbeat, and doing it more gently is not sufficient to circulate enough blood. Electric shocks and a tube in the throat are also harsh treatments, but may be essential to resuscitate someone.

CPR frequently can save a person's life, particularly in the case of some kinds of heart attacks and accidents an otherwise healthy person may experience. CPR is also most successful when the failure of heartbeat and breathing occurs in the hospital, in the Cardiac Care Unit (CCU). Nurses in the unit will instantly recognize the problem and begin sophisticated care.

However, when a person is in failing health from a serious and progressive illness, the heart and breathing will ultimately fail as a result of that illness. In such a circumstance, there is little chance that CPR will succeed at all. Any success will be temporary at best, because the person's weakened condition will soon cause the heartbeat and breathing to fail again.

Another possibility is that CPR may be only partially successful. If the heartbeat is restored but a person is still too weak to breathe on his or her own and remains too weak to do so, he or she may be on a ventilator for days, weeks, months or longer. Moreover, when breathing or heartbeat fails, the brain is rapidly deprived of oxygen. As a result, within seconds, the brain begins to fail (one loses consciousness), and within a very few minutes permanent damage to the brain occurs. If it takes more than those very few minutes to start effective CPR, the person will not fully recover. The brain damage may mean anything from some mental slowing and loss of memory to complete and permanent unconsciousness and dependency on a ventilator and sophisticated medical life support.

The Role of Emergency Help (Calling 911)

A call to 911 is a request for emergency help; the goal of those who respond to 911 calls is to protect life and property, and the people who respond expect to go to work doing what they are trained to do to accomplish that goal. If your house is on fire, the firefighters don't ask for permission to cut a hole in your roof and spray water all over your living room - they just do what is necessary to stop the fire from destroying your home.

Similarly, when a person's heartbeat and breathing have failed, the 911 responders are not prepared to have a long talk with you about the person's condition and what you think might be best to do. They know that any delay could mean brain damage, so they immediately start CPR and then take the person to the hospital. With one exception, which we will discuss in the next section, their rules require this, and it makes sense if you think about the purpose of the 911 system.

When Nancy called 911 in our scenario, the paramedics simply did what they are trained to do - they revived her husband. However, if Nancy and her doctor had completed a DNR form and kept it in the home, her husband would not have been resuscitated and/or connected to machines when he got to the hospital.

The Do Not Resuscitate (DNR) Form

The Emergency Medical Systems Prehospital Do Not Resuscitate (DNR) Form is a legal document that gives the 911 responders permission not to perform CPR. The DNR form is prepared in advance of any situation and kept at home. This prehospital DNR form lists the name of the person to whom it applies, and is signed by that person (or whoever represents that person if he or she is too ill to make medical decisions on his or her own behalf). It is also signed by the person's doctor. Please note this is very important: the form is not valid until the doctor signs it, as it is a medical order. There is a new form which can replace or be a supplement to the traditional DNR order called a POLST (Physician Orders for Life Sustaining Treatment). See Fact Sheet: Advanced Medical Directives for more information on POLST.

The DNR or POLST is the only form that affects 911 responders; other documents, such as a Durable Power of Attorney for Health Care or some other Advanced Directives, do not. If emergency personnel arrive to find a person whose heartbeat and breathing have failed or are failing, they will perform CPR unless they see a correctly completed DNR/POLST.

In light of this, the DNR/POLST form should be kept near the ill person's bed, perhaps on the wall, so it will be easy to find in case of emergency. When 911 responders see this form, they will still do anything they can to make the sick person comfortable, but they will not perform CPR. In the absence of a DNR/POLST form, they must do CPR. The DNR/POLST is the only form that gives you control over what they may do. (Note: A DNR may be reversed if you so desire.)

Choices

Why would one choose to prepare a DNR? Because, as we've discussed above, there are times when it may not make sense to perform CPR. As an illness progresses, there usually comes a time when continued treatment will no longer reduce symptoms nor heal the person and he/she is in an end stage of the disease. (When a person is becoming more and more sick, doctors may try various treatments to stop the illness, but eventually it may become clear that treatments are not having the desired effect. Other treatments might provide comfort, and might even partly control the disease, but a point may be reached where nothing will stop the person's decline.) Under these circumstances, you might feel there is little reason to attempt CPR, as it (At this point, CPR) may only prolong dying. This allows natural death to occur. In fact, the original name of the DNR form was "DNAR" for "Do Not Attempt Resuscitation." This name recognized the fact that the form instructed the 911 responders not to undertake something that, despite the best efforts, would not work effectively in the long run. At most, the effort might put the sick person in the hospital, in pain and distress, for the last days of his or her life. Having a DNR prepared may also relieve the caregiver of making a decision to turn off a machine, which can be an even more difficult decision psychologically.

(See the FCA fact sheets, End-of-Life Choices: Holding On and Letting Go and End-of-Life Decision Making for more discussions about this issue).

Conclusion

When someone is suffering from a chronic illness, as opposed to an acute illness (the kind that usually requires a hospital visit or stay), the decline is often gradual. As a result, both caregivers and those in their care often forget to talk about the choices the chronically ill person would like to make regarding his or her health care. If you decide that you do not want CPR and are concerned about this decision, it

might help to talk with your physician and clergy person. It is normal, instinctive, to try to save life no matter what, and some people are concerned that not doing everything possible to preserve life is the same as “killing” someone. But it can also simply mean respecting the end stage of a disease as the body shuts down and death naturally occurs.

There are no right and wrong answers to these questions, and until we face a situation like this, it is difficult to anticipate the kinds of choices we’d make. As we change throughout the course of an illness, our choices might also change. However, the more thoroughly family members have discussed these issues in advance of the need to make a critical decision, the easier it will be on both the person who is ill and those responsible for that person’s care. It is never too soon to start the conversation. Hospice care can relieve suffering and provide support to patients and families facing these crises.

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Death at Home

Helping older relatives or friends make more informed choices about end of life decisions.

Reaching the end of your caregiver journey can be a very emotional time that demands courage and compassion. You may want to “be there” for your relative, providing support and making sure his or her wishes are carried out. Often, we foresee the death of our family member as we witness gradual declines in his or her health and functioning, but sometimes death comes suddenly.

Frequently Asked Questions about a Death at Home

How do we begin to prepare for this time?

The first step in preparing for a death at home is to gather the facts.

- Learn about the disease or condition that affects your relative by talking with the health professionals providing care. Ask about symptoms, changes in health or behavior that may occur and the “normal” course of the disease and/or condition.
- Contact organizations or foundations that are likely to have information on what you can expect, such as the Alzheimer’s Association, the American Heart Association, the American Cancer Society, the Parkinson’s Association, etc.
- If your relative has a terminal illness, you may want to become familiar with the services and benefits offered by hospice care. The hospice approach to care focuses on comfort and dignity for the dying patient and his or her loved ones. All efforts are made to allow the person the comfort of dying at home. Your relative should feel free to discuss hospice care with his or her physician at any time.

My relative is seriously ill and I’m afraid if she dies I won’t know what to do. Where can I turn for guidance?

It is frightening to face this situation without the resources you need. Having information and resources, as well as knowing your relative’s preferences, will help you manage this difficult time.

If your relative does not want to receive CPR or other advanced life support efforts in the event his or her heart stops beating or breathing ceases, he or she can complete a “Prehospital Medical Care Directive” form, also known as an “orange form” because it must be printed on orange paper to have legal effect. These forms can be obtained from PCOA at (520) 790-7262.

Funeral Consumers Alliance has a wealth of information on getting one’s affairs in order, what to expect when death occurs, and planning for burial or cremation. They can be reached at (520) 721-0230 or www.funerals.org. There are also several agencies that accept body and organ donations for research. Most of these agencies cover the costs of transportation and cremation of the body. Call PCOA for a list (520)790-7262.

Passages is a local Tucson agency that provides support and education in end-of-life issues. They can be reached at (520) 400-0274 or www.passageseducation.org.

What can you expect if your relative dies at home?

If your relative is enrolled in a hospice program, you will be instructed to call the hospice emergency number **instead** of 911. Hospice staff are highly trained professionals and will know exactly what to do. Staff will come to the home, assist with details and offer support.

If your relative is not in a hospice program it will be necessary to call 911 immediately to report the situation. After you have called 911 or the hospice team, **consider calling a friend or support person to come and stay with you while you wait**. When the 911 team responds, they will—as a matter of procedure—notify the Police or Sheriff’s Department. The primary doctor of the deceased will be contacted to determine if the death is expected and to determine if the physician is willing to sign the death certificate. If the physician indicates that it is an expected event (such as with a terminal illness) then arrangements will be made to take the deceased person to the designated mortuary or funeral home.

If the cause of death is questionable, and/or your relative’s doctor is unwilling to sign the death certificate, law enforcement will have the body transported to the medical examiner’s office. The body of the deceased person will be released after the medical examiner determines the cause of death. This usually creates a delay of a few days or less, depending on the circumstances.

Is there always an autopsy?

No, the office of the medical examiner only conducts an investigation or autopsy if there is enough information to indicate a crime may have been committed. They are well trained in cultural and religious differences and make every effort to honor the beliefs of those who object to an autopsy. However when necessary, it is part of the procedure.

How long will the whole process take?

Depending on the circumstances, the process of removing the body can be very time consuming and may span several hours. Losing a loved one is very difficult even when anticipated, and perhaps more so if the death is sudden. It is important that you try to stay calm, and that you not disturb the situation until the 911 team and law enforcement arrives.

What kind of questions will be asked?

Primarily, responders will ask questions about your relative’s past medical history, medications taken and for what conditions, treatments being administered, as well as the names and contact numbers of treating physicians. They may ask about your relative’s overall well-being, how much assistance he or she needed to conduct daily activities and other routine questions to clarify the circumstances surrounding the death.

Resources

For a list of Grief Support Groups, contact:

Pima Council on Aging at (520) 790-7262 or TMC Hospice at (520) 324-2438.

Pathfinder: Death at Home FAQs - Revised 06/2014

Grief and Loss

Introduction

Grief is a natural process, an intense fundamental emotion, a universal experience which makes us human. It is a process that entails extremely hard work over a period of many painful months or years. People grieve because they are deprived of a loved one; the sense of loss is profound. The loss of a spouse, child or parent affects our very identities - the way we define ourselves as a husband, wife, parent or offspring. Moreover, grief can arise from the survivor's sudden change in circumstances after a death and the fear of not knowing what lies ahead.

The death of someone close can be a life-changing experience. If you are the primary caregiver of someone you love, this experience can affect every aspect of your life for some time. It is natural to grieve the death of a loved one before, during and after the actual time of their passing. The process of accepting the unacceptable is what grieving is all about.

Anticipatory Grief

If someone has had a prolonged illness or serious memory impairment, family members may begin grieving the loss of the person's "former self" long before the time of death. This is sometimes referred to as "anticipatory grief." Anticipating the loss, knowing what is coming, can be just as painful as losing a life. Family members may experience guilt or shame for "wishing it were over" or seeing their loved one as already "gone" intellectually. It is important to recognize these feelings as normal. Ultimately, anticipatory grief is a way of allowing us to prepare emotionally for the inevitable. Preparing for the death of a loved one can allow family members to contemplate and clear unresolved issues and seek out the support of spiritual advisors, family and friends. And, depending on the impaired person's intellectual capacity, this can be a time to identify your loved one's wishes for burial and funeral arrangements.

Sudden Loss

A death that happens suddenly, unexpectedly, is an immeasurable tragedy. This type of loss often generates shock and confusion for loved ones left behind. Incidents such as a fatal accident, heart attack, or suicide can leave family members perplexed and searching for answers. In these cases, family members may be left with unresolved issues, such as feelings of guilt that can haunt and overwhelm a grieving person. These feelings may seem to take over your life at first. But over time it is possible to get past these thoughts and forgive yourself and your loved one. Give yourself plenty of time; it's virtually impossible to make yourself "move on" before you're ready. People experiencing the sudden loss of a loved one have a particular need for support to get through the initial devastating shock, pain and anger. Family members, close friends, and clergy can be vital lifelines for the griever.

How Long Does Grieving Last?

Grief impacts each individual differently. Recent research has shown that intense grieving lasts from three months to a year and many people continue experiencing profound grief for two years or more. Others' response to this extended grieving process may sometimes cause people to feel there is something wrong with them or they are behaving abnormally. This is not the case. The grieving process depends on the individual's belief system, religion, life experiences, and the type of loss suffered. Prolonged bereavement is not unusual. Many people find solace in seeking out other grievers or trusted friends. However, if feelings of being overwhelmed continue over time, professional support should be sought.

Symptoms of Grief

Grief can provoke both physical and emotional symptoms, as well as spiritual insights and turmoil.

Physical symptoms include low energy or exhaustion, headaches or upset stomach. Some people will sleep excessively, others may find they are pushing themselves to extremes at work. These activity changes may make an individual more prone to illness. It is important to take care of yourself during this period of bereavement by maintaining a proper diet, exercise and rest. Taking care of your body can help heal the rest of you, even if you do not feel inclined to do so.

Emotional symptoms include memory gaps, distraction or preoccupation, irritability, depression, euphoria, wailing rages and passive resignation. Some people identify strongly with the person who died and his/her feelings. If you have experienced a loss and are hurting it is reasonable that your responses may seem "unreasonable." Nonetheless, it is important not to judge yourself too harshly as you experience conflicting and overwhelming emotions.

Like grief itself, people's coping strategies vary. Some people cope best through quiet reflection, others seek exercise or other distractions. Some have a tendency to engage in reckless or self-destructive activities (e.g., excessive drinking). It is vital to obtain support in order to regain some sense of control and to work through your feelings. A trained counselor, support group, or trusted friend can help you sort through feelings such as anxiety, loss, anger, guilt, and sadness. If depression or anxiety persist, a doctor or psychiatrist may prescribe antidepressant drugs to help alleviate feelings of hopelessness.

Spirituality: you may feel closer to God and more open to religious experiences than ever before. Conversely, many people express anger or outrage at God. You may feel cut off from God or from your own soul altogether—a temporary paralysis of the spirit. If you are a person of faith, you may question your faith in God, in yourself, in others or in life. A member of the clergy or spiritual advisor can help you examine the feelings you are experiencing. Learning to deal with grief is learning to live again.

Stages of Grief

Often portrayed as a grief "wheel," these stages do not necessarily follow a set order. Some stages may be revisited many times as an individual goes through a grieving period:

- Shock
- Emotional release
- Depression, loneliness and a sense of isolation
- Physical symptoms of distress

- Feelings of panic
- A sense of guilt
- Anger or rage
- Inability to return to usual activities
- The gradual regaining of hope
- Acceptance as we adjust our lives to reality

Most people who have lost someone close go through all or some of these stages, although not necessarily in this specific order. This kind of healthy grieving can help a person move through a significant loss with minimal harm to self, either physical or mental.

Ethical Issues

Often family members and caregivers are faced with the decision to allow someone to die naturally or to prolong their death and maintain life through artificial means. Physician training, hospital and nursing home policies often dictate the use of “heroic means” to sustain life. “Reviving” a very ill person after a stroke or using a respirator for someone deemed medically “brain dead” are standard procedures used in many hospitals.

If at all possible, it is important to learn and document a person’s wishes about using artificial life support before any crisis arises. A living will or durable power of attorney for health care (DPAHC) expresses a person’s wishes when he or she can no longer speak for him/herself. These documents can help instruct hospitals or nursing homes on an appropriate course of action to be taken at a critical moment. By law, all hospitals must now inform patients about their right to fill out these documents.

When a person is confused, or otherwise unable to express preferences, family members are often put in the position of becoming surrogate decision makers. Such decisions present a thorny array of medical, legal, and moral questions. Decisions to provide or withhold life support are based on personal values, beliefs, and consideration for what the person might have wanted. Such decisions are painful. Family members should give themselves ample time to cope with these life and death decisions and to process feelings of doubt or blame which may surface.

Tips for Helping the Bereaved

- Be available. Offer support in an unobtrusive but persistent manner.
- Listen without giving advice.
- Do not offer stories of your own. This can have the effect of dismissing the grieving person’s pain.
- Allow the grieving person to use expressions of anger or bitterness, including such expressions against God. This may be normal behavior in an attempt to find meaning in what has happened.
- Realize that no one can replace or undo the loss. To heal, the individual must endure the grief process. Allow him/her to feel the pain.
- Be patient, kind and understanding without being patronizing. Don’t claim to “know” what the other person is feeling.

- Don't force the individual to share feelings if he/she doesn't want to.
- Physical and emotional touch can bring great comfort to the bereaved. Don't hesitate to share a hug or handclasp when appropriate.
- Be there later, when friends and family have all gone back to their routines.
- Remember holidays, birthdays, and anniversaries which have important meaning for the bereaved. Offer support during this time. Don't be afraid of reminding the person of the loss; he/she is already thinking about it.

Practical Assistance for the Bereaved

Things a person can do without asking:

- Send a card or flowers.
- Bring food.
- Water or mow their lawn.
- Donate blood.
- Contribute to a cause which is meaningful to your friend or family member.

Things a person can do to help but should ask first:

- Offer to stay in the home to take phone calls, receive food and guests.
- Offer child care on a specific date.
- Offer to care for pets.
- Offer transportation.

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www.caregiver.org/grief-and-loss

