Section 10
End of Life Issues

CAREGIVER CONSORTIUM
WHERE TO FIND MY IMPORTANT PAPERS

Name: ___________________________ Social Security #: __________________
Spouse/Partner name: ___________________________ Social Security #: __________________
Address: ____________________________________________
Date prepared: ___________ Copies given to: ____________________________

My valuable papers are stored in these LOCATIONS (address or where to look):

A: Residence: ____________________________________________
B: Safe Deposit Box: ____________________________________________
C: Other: ____________________________________________

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Clergy: ____________________________________________
Attorney: ____________________________________________
Accountant: ____________________________________________
Insurance agent/policy #(s): ____________________________
Other contacts: ____________________________________________

Modified with permission of Passages Caregiver Resource Center (formerly Mountain Caregiver Resource Center).
Family Caregiver Alliance and Passages CRC are part of California’s statewide system of Caregiver Resource Centers.

Rev: 170807
End of Life Care – Making a Plan

Why is planning for your end of life care important?

- By planning, you make decisions that reflect your wishes for end of life care and create a guide for loved ones and health care professionals to follow.
- By not planning, you allow others to make decisions for you.
- By planning, you provide your loved ones with peace of mind because they will know what you want and will not be left guessing.

How do I make a plan?

- Think about what is important to you and what care you want at the end of your life. Professionals, family members or friends can help you with this and many resources are available to guide you.
- Document your wishes by creating an advance directive.

What is an advance directive?

- Instructions about what kind of care you want and don’t want and who can speak for you if you are not able to express your wishes.
- Living will: the kind of care you wish to receive.
- Health care power of attorney and mental health care power of attorney: who you designate to speak on your behalf if you are not able to speak for yourself.
- Once you complete an advance directive in Arizona, you must have one person at least 18 years old who does not provide your health care, is not related to you by blood, marriage, or adoption, is not your representative or a beneficiary in your will, witness your signature.

What do I do with my plan?

- Communicate your wishes to family members, friends and health care professionals by sharing copies of your advance directives. Note: If life circumstances change, plans can be changed.
- Register your documents with the Arizona Advance Directive Registry - a free registry to electronically store and access your medical directives. The secure and confidential program grants peace of mind to registrants and their families, and easy access to all health care providers. www.azsos.gov/services/advance-directives

Call PCOA's Helpline for assistance and information:
(520) 790-7262
End of Life Care – Making a Plan

Where can I get forms or planning documents?

The official State of AZ forms are available from the AZ Attorney General’s website, are free of charge and comply with Arizona law. However, please note that advance directives do not require any particular form, and information and forms are also available from medical, religious, aging assistance, and legal organizations.

Five Wishes: [agingwithdignity.org](https://agingwithdignity.org)
Available from Aging with Dignity, Five Wishes is written in everyday language and helps people express their wishes in areas that matter most — the personal and spiritual in addition to the medical and legal. It also helps start and guide family conversations about care in times of serious illness.

The Conversation Project: [theconversationproject.org/starter-kits](https://thecommunicationproject.org/starter-kits)
The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

A comprehensive user-friendly workbook that covers why you need to think about future health care decisions, what you want done for you if you couldn’t speak for yourself, your beliefs and values, choices about death and dying, and the legal and ethical issues of advance care planning.

Compassion and Choices: [www.compassionandchoices.org/eolc-tools](https://www.compassionandchoices.org/eolc-tools)
Tools to help you manage end-of-life care including assessing what is important to you, speaking with loved ones, putting your plan together, and taking charge of your healthcare.

Call PCOA’s Helpline for assistance and information:
(520) 790-7262

9-2017
Talking About Your Wishes for End-of-Life Care

By Mara Levin, Interfaith Community Services

One of the most important parts of advance care planning is talking about your wishes with relatives or friends who might be called on to direct your care if you can no longer do so yourself. Caregivers need to have these conversations as well as care receivers, no matter what age or state of health they may be in. Why talk about advance directives? Think about it as a two-fold opportunity: you can reflect on what is important to you and have your wishes honored; and you can give your loved ones the gift of understanding what you want, thereby relieving them of uncertainty during a difficult time.

There isn’t one right way, “right time”, or even right place to talk to others about your preferences. Maybe you can have a discussion at your home or at a favorite coffee shop. Or perhaps you could bring up the subject while taking a walk in the park. Ideally, you can have more than one conversation about it, once you’ve broken the ice.

You might encounter some resistance to bringing up the topic—most people, especially our family members, find it an uncomfortable one. Don’t be surprised if your loved ones respond with statements like, “I don’t want to talk about that—I have too many other things to worry about”; “Let’s not focus on dying—I’d rather think about positive things”; or “Oh, gosh, Mom, you’re going to live for a long time—we don’t need to discuss this now!” But once the conversation gets past the initial awkwardness, you may find that feelings of relief and satisfaction will follow. Loved ones may even admit that they have wanted to discuss this with you before but didn’t know how to bring it up.

Take time to reflect on your values and wishes for care planning before you have the family conversations. The more clear and thorough you are about your preferences, the easier it will be for your designated people—and medical professionals—to understand what you want and do the right thing if called upon.

In the case of helping individuals you are caring for talk about their wishes, encourage them to reflect on their own values and what kind of care they would want in specific scenarios. Talking with their doctors can also help them understand how their illness might progress and inform their decisions regarding each of the specific types of life-support measures.

Getting Started in Your Conversation

One way to introduce the topic is to tell your loved one(s) about reading this article, and how it got you thinking about end-of-life care planning. Another possible starting point is to bring up a healthcare situation or medical emergency that a friend or relative experienced, and how that made you aware of the need to do your own advance care planning. If you can’t come up with a friend or relative’s experience, maybe there is a recent news story about someone who faced a difficult end-of-life scenario that you could...
discuss. However you choose to start, you can let your loved ones know that while this is an uncomfortable topic, it is very important to you to talk with them about it.

Examples of conversation starters for talking about your own care planning:

- “I just went to a workshop about advance directives and completed a booklet called the Five Wishes. I’d really like you to look over what my wishes are in case anything happens.”
- “Did you see the [TV show/article] about the woman [on a ventilator]....? It was so difficult for the family, and it made me think about what I do and don’t want if something like that happens to me. I need to make sure you know what my wishes are, so that you could support me if that happened. When can we talk?”
- “I know it’s not easy to talk about this; still, it’s important to me and it seems a lot better than waiting until a crisis hits. Let’s talk about it now, while we can.”
- “Talking about this will make things easier for you, because you’ll have a better understanding of what I want and don’t want.”

Examples for bringing up the topic with the person for whom you provide care:

- “I just went to a workshop about advance directives and filled out my own documents about what I want and don’t want.....Thinking about what my preferences are made me realize that I don’t know what your wishes are. I’d really like to set up a time when we can talk about this.”
- “Did you see the [TV show/movie] about the woman [on life support and her family didn’t know what to do]....? It was so agonizing for the family to make decisions about her care, and it made me think about what you might want if something like that happened to you. I would want to honor your wishes if that happened. When can we talk?”
- “I can imagine that this illness might make you feel pretty powerless over what’s happening.... Writing down your wishes for care and telling us what you do and don’t want is a way for you to have some sense of control even at the end of your life.”

To learn more about this topic, attend a free two-hour workshop or schedule an individual session through the Interfaith Community Services End-of-Life Program: (520) 526-9309.

Advanced Illness: Holding On and Letting Go

Introduction

By the Family Caregiver Alliance

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 (see fact sheet on Advanced Health Care Directives). 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.

Resources
Family Caregiver Alliance
National Center on Caregiving
(415) 434-3388 | (800) 445-8106
Website: www.caregiver.org Email: info@caregiver.org
Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers. For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer’s disease, stroke, head injury, Parkinson’s and other debilitating disorders that strike adults.

**Other Organizations and Links**

Aging Life Care Association (formerly National Association of Professional Geriatric Care Managers). This professional group offers a listing of care managers nationwide.
www.aginglifecare.org

Compassion & Choices
www.compassionandchoices.org

National Hospice and Palliative Care Organization
www.nhpco.org

Hospice Foundation of America
www.hospicefoundation.org

Five Wishes Aging with Dignity
www.agingwithdignity.org

Five Wishes is a document that helps you express how you want to be treated in the event you become seriously ill and unable to speak for yourself.

POLST
Objective information provided about this advanced care planning tool. Offers a current POLST program map by state and a downloadable POLST form.
www.polst.org

Prepared by Family Caregiver Alliance. Reviewed by Beth MacLeod, LCSW, Care Consultations and Therapy, San Francisco, CA. © 2013 Family Caregiver Alliance. All Rights Reserved.

*Source: Family Caregiver Alliance, Advanced Illness—Holding On ad Letting Go,*
www.caregiver.org.
Advanced Illness: CPR and DNR Introduction

By the Family Caregiver Alliance

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: Decision Making, and Advanced Illness: Feeding Tubes and Ventilators). [Note: Fact sheet titles are being changed from "End-of-Life" to "Advanced Illness" as we revise and update them. -6/2013]

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 Advance Health Care Directives and 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.
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 clergyperson. 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.

Credits


Other Organizations and Links
Alzheimer's Association
www.alz.org
(800) 272-3900
Compassion & Choices  800-247-7421  www.compassionandcare.org

Improving Care for the Dying:
http://www.growthhouse.org/educate/flash/mortals/mor11107.html

National Hospice and Palliative Care Organization  (703) 837-1500  www.nhpco.org

Palliative Excellence in Alzheimer's Care Efforts (PEACE)  5841 South Maryland Ave. Chicago, IL 60637  (773) 702-0102

Dying Unafraid Fran Johns Synergistic Press  (415) 387-8180  www.synergisticbooks.com

Center for Health Care Decisions  3400 Data Drive Rancho Cordova, CA 95670  (916) 851-2828  http://chcd.org/what-endoflife.htm

Five Wishes Aging with Dignity  (888) 5-WISHES  http://www.agingwithdignity.org/5wishes.html
Five Wishes is a document that helps you express how you want to be treated in the event you become seriously ill and unable to speak for yourself.

Handbook for Mortals  Joanne Lynn, MD and Joan Harrold, MD; Americans for Better Care of the Dying  (202) 895-2660  http://www.abcd-caring.org


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Source: Advance Illness—CPR and DNR, Family Caregiver Alliance:  https://www.caregiver.org/advanced-illness-cpr-dnr
Advanced Illness: Feeding Tubes and Ventilators Introduction

By the Family Caregiver Alliance

Families caring for a chronically ill loved one may eventually face very difficult decisions regarding medical treatment for the person in their care. The progression of many conditions—Alzheimer's disease, Parkinson's disease, Amyotrophic Lateral Sclerosis or post-stroke, for example—may lead to two of the most common such decisions: whether to use feeding tubes when a chronically ill person can no longer chew and swallow his or her food, and whether to use a ventilator when someone can no longer breathe on his or her own. Given that a person with a chronic illness may be ill for many years, caregivers might put off discussing and thinking about medical complications that are likely to happen in the future. When decline from an illness is gradual, it is easy not to notice the early warning signs of an impending medical crisis. But understanding and discussing these issues ahead of time can help avoid the need to make urgent decisions during a crisis.

Nutritional Supplement and Hydration

As many types of neurological illnesses progress, the muscles of the throat gradually cease to work properly. This can cause swallowing difficulties, gagging, choking, trouble coughing, loss of voice, or difficulty catching one's breath. Receiving proper nutrition is difficult if someone is having trouble swallowing, which is usually accompanied by eating less. The danger of choking while swallowing is that the food can "go down the wrong pipe"—in other words, the food is aspirated into the lungs. Gagging can also cause vomiting, which may cause some of the stomach contents to enter the lungs. All of these possibilities can lead to an illness called aspiration pneumonia, which occurs when bacteria causes infection in the lungs which have been damaged by food or stomach material. Treating aspiration pneumonia usually requires a hospital stay and a course of antibiotics.

Patients may be fed during hospitalization with an NG Tube (naso-gastric tube, inserted through the nose and down the esophagus to the stomach), which allows the patient to receive liquid nutrition. If swallowing difficulties continue, physicians may discuss the use of a G-tube (gastric tube) with the family. Surgery is required to insert a tube directly through the front of the belly into the stomach and the patient then receives all or most of his/her nutrition via frequent "feedings" during the day and/or night. This feeding can be done by hand using a syringe or by using a machine that will drip the liquid through the tube into the stomach. Either way, the patient must be sedentary for a period of time in order to receive the food.

With or without feeding tubes, patients can learn swallowing techniques to reduce the likelihood of aspirating. Caregivers can also help by preparing "thick liquid" diets (thin cream of wheat, mashed potatoes, thickened broths for example), that are easier to swallow, and by avoiding thin liquids and things that require chewing. Some people can
enjoy eating small amounts this way, even when they are receiving their primary nutrition through a tube.

In many cases, feeding tubes help prevent illness and prolong life. In diseases like ALS, feeding tubes can be a normal part of treatment, as swallowing may be compromised before a person is in the end stages of the disease.

If someone has trouble swallowing and continues to eat or drink, the possibility of repeated incidences of aspiration pneumonia is high. The decision then becomes how to treat the resulting pneumonias (see "ventilators" below). Some patients truly miss the taste and experience of eating and find normal eating hard to give up. Patients with dementia and/or severe agitation may pull at the tube and/or pull it out, which might require sedation or restraints. And remaining sedentary for the time required to receive the feedings may be difficult.

There is some debate, for example, about whether feeding tubes actually extend life in end-stage Alzheimer's disease. For many, this is a quality of life issue, and they would prefer to not to live this way. Depending on the situation, people receiving tube feedings may not be able to avail themselves of hospice services.

If the family chooses not to insert a feeding tube, the patient and family may have decided that this person is in the final stages of the illness, and that they are now willing to allow death to occur. If the person is totally unable to eat and does not use a feeding tube, the body will slowly shut down over a period of one to two weeks. Comfort measures are given, so the patient does not suffer, and hospice care can help the patient and family.

Intravenous hydration is the process of giving fluids using a tube in the veins. In the past, IV hydration was used to prevent death from dehydration, which was considered a painful way to die. We now know that gradual dehydration is not painful; rather, it brings a lessening of awareness about discomfort, so that the person slides naturally toward death. If the body is shutting down, it cannot rid itself of the excess fluids given by IV and thus the fluid builds up in the lungs and leads to shortness of breath. Dry mouth is treated more effectively with good mouth care than by IV fluids. With hospice care, it has been the practice not to give IV hydration when someone is close to death. Naturally, pain and other symptoms are still treated as they occur. As with a feeding tube in the advanced stages of an illness, IV hydration can prolong dying rather than prolong living.

**How Does One Make These Decisions?**

When a person is diagnosed with a chronic and degenerative illness, it is important for the patient and family members to discuss these topics early in the illness, while the patient is still in a position to let family members know what his/her wishes are regarding these decisions—it is much more difficult to make a decision under the pressure of an acute episode. If the ill person has begun to choke when swallowing, it is a good time for the family, the patient, and, if possible, the physician, to discuss the "what ifs," and how to think about the choices, keeping in mind the patient's values. Consultation with clergy may also be helpful. (It is important that our loved ones know how we would come to a decision, remembering that decisions can be changed, if needed, as none of us knows what
we will really want until the time comes. Unfortunately, these decisions most often need to be made at a time when we can no longer state our preferences.

**Pneumonia and Ventilators**

One of the other choices a patient or family member faces is how to treat pneumonia. Many years ago, pneumonia was called "the old man's friend," as many people suffering from chronic illnesses ultimately died of it. This is no longer true, due to modern medicine's techniques to prevent and treat pneumonias.

Pneumonia, an infection involving the lungs, makes it difficult to breathe, causes pain, confusion and progressive weakness. There are two kinds of pneumonia—bacterial and viral. Bacterial pneumonia can be treated by antibiotics; viral pneumonia cannot, but people can now get a vaccination to prevent many kinds of viral pneumonia. Aspiration pneumonia, the kind that can result from difficulty swallowing, is a bacterial pneumonia.

After a stroke or heart attack, or when a patient is in the final stages of an illness such as Alzheimer's disease, family members and the patient can choose not to treat pneumonia if it occurs. In this case, comfort measures to reduce pain and the distress of labored breathing would be offered, but antibiotics would not be given. Some people recover spontaneously under these circumstances; others die within a week or two.

With bacterial or viral pneumonia, as with initial treatment for a stroke or heart attack or when breathing is compromised by illness, one of the possible treatments involves a ventilator, a machine that helps the person breathe. A ventilator requires a tube down a person's throat or through a tracheotomy (hole in the throat), also called intubating. When a person is put on a ventilator, it is not always known ahead of time whether it will be for the short or long term. Often a ventilator is used for a short time in treating pneumonia; the patient is then "weaned" off the machine and is able to breathe again on his/her own. Sometimes, however, people are too weak or their illness is so progressed that they will never be able to breathe again on their own. The patient then faces the possibility of remaining on the machine for the rest of his/her life. Even people who have not discussed end-of-life issues may have expressed the desire to not be kept alive "on a machine;" generally, it is a ventilator they are referring to when they say this.

When someone cannot regain the ability to breathe on his/her own, the patient and family may have to decide whether or not to continue using the ventilator. The decision to stop is very difficult to make, particularly emotionally, and, in making it, you may feel as if you have chosen to "kill" the person, although it is, in fact, accepting the natural process of dying. However, like the use of nutritional supplements, use of a ventilator is also a quality of life decision. For some people, staying alive under these circumstances is not acceptable. One way patients and family members can ease the difficulty of this decision is to choose not to use a ventilator as treatment in the first place. Patients can make their wishes known about this through Advanced Directives and discussions with their physicians and family members.

Even with the best advanced planning, patients and family members often must make decisions in a crisis situation. It is natural, even reflexive, to make decisions to prolong life.
However, quality of life measures are also important considerations. Each illness has a different course, and being well informed about a loved one's particular illness can help with the decision-making process. When you know what the choices and consequences are, you can make a decision consistent with a loved one's wishes and values.

Credits


Dementia Care Practice Recommendations, Phase 3: End of Life Care, Alzheimer's Association, www.alz.org


Bioethics, Thomas Shannon, ed. Paulist Press, 2009


Casebook on the Termination of Life Sustaining Treatment and the Care of the Dying, Cynthia Cohen, ed. The Hastings Center, 2005. www.thehastingscenter.org


The Feeding Tube Dilemma, The Center for Bioethics and Human Dignity, 1/27/06, cbhd.org

Handbood for Mortals: Tube Feeding www.growthhouse.org


Resources

Family Caregiver Alliance National Center on Caregiving (415) 434-3388 (800) | 445-8106
Website: www.caregiver.org E-mail: info@caregiver.org
FCA CareJourney: www.caregiver.org/carejourney
Family Care Navigator: www.caregiver.org/family-care-navigator
Palliative Care (pronounced pal-lee-uh-tiv) is specialized medical care for people with serious illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

Palliative care is provided by a specially-trained 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 it can be provided along with curative treatment.

1. WHERE DO I RECEIVE PALLIATIVE CARE?
Palliative care can be provided in a variety of settings including the hospital, outpatient clinic and at home.

2. DOES MY INSURANCE PAY FOR PALLIATIVE CARE?
Most insurance plans, including Medicare and Medicaid, cover palliative care. If costs concern you, a social worker from the palliative care team can help you.

3. HOW DO I KNOW IF PALLIATIVE CARE IS RIGHT FOR ME?
Palliative care may be right for you if you suffer from pain, stress or other symptoms due to a serious illness. Serious illnesses may include cancer, heart disease, lung disease, kidney disease, Alzheimer’s, HIV/AIDS, amyotrophic lateral sclerosis (ALS), multiple sclerosis, Parkinson’s and more. Palliative care can be provided at any stage of illness and along with treatment meant to cure you.

4. WHAT CAN I EXPECT FROM PALLIATIVE CARE?
You can expect relief from symptoms such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping. Palliative care helps you carry on with your daily life. It improves your ability to go through medical treatments. It helps you better understand your condition and your choices for medical care. In short, you can expect the best possible quality of life.

5. WHO PROVIDES PALLIATIVE CARE?
Palliative care is provided by a team including palliative care doctors, nurses and other specialists.

6. HOW DOES PALLIATIVE CARE WORK WITH MY OWN DOCTOR?
The palliative care team works in partnership with your own doctor to provide an extra layer of support for you and your family. The team provides expert symptom management, extra time for communication about your goals and treatment options and help navigating the health system.

7. HOW DO I GET PALLIATIVE CARE?
You have to ask for it! Just tell your doctors and nurses that you would like to see the palliative care team.
Understanding Palliative/Supportive Care: What Every Caregiver Should Know

By Family Caregiver Alliance

Palliative care, also increasingly known as Supportive Care, may be one of the most misunderstood terms in healthcare. Many people believe it’s the same as hospice care and it means the end of life. But palliative care is different from hospice, and when put in place, palliative care can bring hope, control, and a chance at a better quality of life for seriously ill patients and their caregivers.

This Fact Sheet will summarize key features of palliative care, describe how it differs from hospice, and clarify some of the misconceptions that prevent people from considering palliative care for themselves or for loved ones.

What is palliative care and how can my family member benefit?
For individuals living with serious illness, and for their caregiving family and friends, palliative care offers medical and related treatment towards living as well and as fully as possible.

Healthcare professionals embrace a patient’s values, goals, and wishes when considering disease management and burden relief from pain, anxiety, fear, and other symptoms. The patients’ plans and wishes are shared with family and friends who provide care, and support is provided to help relieve burdens.

Most importantly, this patient/family-centered care is appropriate at any age and at any stage in a serious or chronic illness. For example, a person with cancer may be treated for unrelenting pain and appetite loss concurrent with curative treatment; a person living with Alzheimer’s disease may be treated for anxiety and sleeplessness. Care may be offered in the hospital, long-term care facility, at home, or in outpatient clinics.

First used in the 15th century, the term palliative today means to remedy or lessen without curing. Although in the past palliative care and hospice care were bound together, now they can be considered two related approaches that respond to serious illness, depending on the patient’s condition and wishes. They share similar philosophies, and a person in palliative care may transition to hospice care if they are approaching the end of life.

Looking deeper into the concept, the National Consensus Project on Palliative Care describes it this way: “Palliative care is both a philosophy of care and an organized, highly structured system for delivering care. The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. Palliative care expands traditional disease-model medical treatments to include the goals of enhancing quality of life for patients and family members, helping with decision making, and providing opportunities for personal growth. Palliative care can be rendered along with life-prolonging treatment or as the main focus of care.”
What is the “organized, highly structured system,” and how did it come to be so widespread now in healthcare? First, palliative care takes a collaborative, interdisciplinary team (IDT) approach. In addition to the patient and family, the specially trained team can consist of: doctors, registered nurses, social workers, chaplains, dieticians, pharmacists, licensed mental health professionals, physical and occupational therapists, music therapists, massage therapists, and others.

The most common health conditions addressed in palliative care include:

- Cancer
- Congestive heart failure (CHF)
- Kidney failure
- Liver failure
- Chronic obstructive pulmonary disease (COPD) or other lung diseases
- HIV/AIDS
- Spinal cord injuries
- Brain diseases such as stroke, ALS, or Parkinson’s
- Multiple sclerosis (MS)
- Alzheimer’s and other dementias

When patients choose to begin palliative care, they receive a formal assessment of their health early in the process. Symptoms most commonly addressed include:

- Pain or discomfort
- Shortness of breath
- Fatigue
- Anxiety
- Depression
- Lack of appetite
- Nausea
- Constipation
- Adjusting to and living with the diagnosis of a serious health condition
- Sleep problems

There will be discussions about the need for an Advance Directive and preferences about with- holding or withdrawing life-sustaining treatments (POLST). (See Making End-of-Life Decisions: What Are Your Important Papers?)

The palliative approach focuses not just on difficult symptoms of an illness, but on the overall benefits and/or side effects of potential treatments, and the emotional, physical, and financial stresses for someone dealing with a serious, perhaps life-threatening, disease. Ensuring patients’ dignity, coordinating care, and shared decision-making are critical components.
Palliative care is more likely to be suggested when there are:

- Frequent emergency room visits
- Three or more admissions to the hospital with the same symptoms within a year
- Serious side effects from treatments like chemotherapy
- Eating problems caused by serious illness

This is a dramatically different approach to healthcare from the fragmented care we sometimes see in standard medical practice, where treatment is not always well coordinated among primary doctors and specialists, and where time limitations and funding don’t allow for an in-depth look at patients.

Physicians are trained to focus on fixing a problem(s) and charging specific fees for specific services, not necessarily offering comfort measures to patients or treating the whole person, including his or her emotional issues. Additionally, unlike a palliative program, healthcare practices too often neglect to recognize the family as part of the team, even though the family is, of course, greatly impacted by a loved one’s chronic or serious illness, and is usually providing significant amounts of care.

History

The philosophy of palliative care in the US has evolved over time. It began in the hospice movement, in which a more patient-centered approach was offered when death was imminent, and where comfort, peace, pain relief, and dignity were the goals, and cure not a possibility.

Although palliative care is a natural practice in many cultures worldwide, the advancement of life-sustaining technology had charted a more cure-focused path in the United States. Life-prolonging measures such as a pacemaker early on in a condition, or a feeding tube or respirator as a disease progresses, are often assumed to be part of the treatment plan of care. Patients and their caregiver(s) can question these assumptions, opting for a plan of care that recognizes and acts on their preferences.

Palliative care became a recognized medical sub-specialty in the US fairly recently, in 2006. As with other medical specialties, physicians can become board certified in palliative care, and there is training and certification for other healthcare staff as well. Now about 80% of large US hospitals offer palliative care programs. The palliative philosophy of support, comfort, peace, and dignity is offered at any stage—even early in the diagnosis—of a chronic or serious illness that ultimately may or may not be life-threatening.

Medical professionals who practice palliative care are committed to communication, to compassion, to seeing the “whole” person, and to including the family as part of the healthcare team. Studies have indicated the benefits of palliative care:

- Better quality of life for patient and caregivers
- Help getting through difficult medical treatments
- Reductions in hospitalizations and readmissions
- At times faster recovery and longer survival rates
It’s easy to understand, for example, that patients are better able to function when their pain is well managed and substantially reduced. But not all patients have access to palliative care. Hospital staff may not have the right training. A doctor may feel it would not be beneficial in a specific case. Or, because it is more time-consuming than standard medical care, facilities may have concerns about reimbursement of costs.

Paying for palliative care and hospice care
Most insurance will cover palliative services as it covers other healthcare procedures and medications, although there may be co-payments. Medicare and Medicaid (Medi-Cal in California) will likewise cover many of the costs. If questions about coverage remain, a social worker or consultant from the health care team may be able to clarify pay provisions for the service.

Comprehensive hospice coverage is available for patients with Medicare Part A. This benefit is broader than the coverage for palliative care: most services are free. This may include medical equipment such as wheelchairs and hospital beds, medications, professional fees, counseling, and more. Most private insurance programs pay for hospice programs, and state Medicaid programs cover costs as well.

How are palliative care and hospice care different?
Hospice is a specific kind of palliative care for patients approaching the end of life and focuses on death with dignity, not on seeking cure. While both palliative and hospice care deal with serious disease and offer a team approach, hospice becomes an option when there are no further treatments available, or the treatments’ side effects, pain, and suffering are overwhelming and will not contribute to a cure. In contrast, palliative care can start at any stage of a serious disease, and curative treatments can continue.

With Advance Directives in place, families and healthcare professionals know that when someone is in hospice care, painful or intrusive treatments, admission to intensive care units, or frightening ambulance trips to emergency rooms, for example, may not be wanted or accepted. In fact, if a patient has a medical emergency, families or caregivers are instructed to call the hospice provider rather than 911.

Patients become eligible for hospice care when doctors have determined that they are likely to have six months or less to live. Hospice is always a voluntary program, and patients may continue in hospice if they survive longer, may be discharged from hospice if their condition improves, or may withdraw. Hospice staff are available for consultation 24 hours a day. In hospice, as in palliative care, the focus is on comfort and dignity, and spiritual concerns are addressed. Hospice also offers grief therapy and support for families, even after the death of a loved one.

How can patients access palliative and hospice care?
If it hasn’t been offered, ask for it. Not all hospitals provide the services, but most do. The patient’s primary physician should be able to refer families, or check the directory at https://getpalliativecare.org/. There are different types of local hospice organizations—
large and small, and nonprofit and for-profit. Care can be provided in the home, in assisted living or nursing home, hospital, or in a special hospice residence.

In both palliative and hospice care, patients and families are gently supported as they are asked to do deep soul-searching about their values and beliefs during a very challenging time. There is no question that the decisions are complicated and can be wrenching. Yet while most doctors are trained to do everything possible to prevent death even if treatment is painful or futile, with palliative and hospice services in place, patients have the final say.

Resources
Family Caregiver Alliance National Center on Caregiving
785 Market Street, Suite 750 San Francisco, CA 94103
(415) 434-3388 | (800) 445-8106
Website: www.caregiver.org
E-mail: info@caregiver.org
Family Care Navigator: www.caregiver.org/family-care-navigator

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research, and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy, and caregiving issues and provides assistance in the development of public and private programs for caregivers. For residents of the greater San Francisco Bay Area, FCA provides direct support services for caregivers of those with Alzheimer’s disease, stroke, traumatic brain injury, Parkinson’s, and other debilitating health conditions that strike adults.

Prepared by Family Caregiver Alliance. Reviewed by Helene Martel, MA, Director, Elder Care and Palliative Care, Care Management Institute, Kaiser Permanente. Funded by California Department of Health Care Services. © 2016 Family Caregiver Alliance. All rights reserved.

Hospice FAQs

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

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.

**Can my loved one remain at home and receive hospice care?**
All efforts are made to allow the patient the comfort of dying at home if that is his or her wish. The hospice care team delivers services to the majority of patients in their personal residences. However, hospice care can also be provided in a nursing home, assisted living community, or assisted living home. In certain circumstances, a patient may also be cared for in a freestanding hospice facility.

**Is the cost of hospice care covered by insurance?**
Hospice coverage is widely available and is covered by Medicare, Medicaid (ALTCS) and by most private insurance providers. To be sure of coverage, check with the health insurance provider or ALTCS/AHCCCS. Most hospices will provide care for patients who cannot pay by using money raised from the community, memorials and/or foundations.

**If my relative is covered by Medicare, will there be any additional expenses?**
Medicare covers all services and supplies for the hospice patient related to the terminal illness. Some hospices may require the patient to pay a small co-payment for medications and for respite care. Ask about co-payment when selecting a hospice.

**How do I know if my loved one is eligible for hospice care?**
The criteria for acceptance into hospice include:

- The patient must have a diagnosis of a terminal illness and have a prognosis of six months or less if the illness follows its normal course.
- The patient has chosen not to pursue, or to discontinue, aggressive treatment for his or her illness.
- The patient has in-home caregivers or resides in a care facility if he or she can’t be left alone.

The patient and patient’s family should feel free to discuss hospice care with the patient’s physician at any time during a life limiting illness. At the end of a loved one’s life, while caregivers may feel pain and sadness, they have the opportunity to grow stronger and more courageous with the support provided by a caring hospice program. Hospice is not about death, but the quality of life as it nears its end, for all concerned—the patient, relatives and friends.

*Source: Pima Council on Aging, Pathfinder: Hospice FAQs; www.pcoa.org*
Dispelling Myths About Hospice

By Pathways

Myth – Hospice is a place to send people when they are dying.
Hospice is not a place, but a way of caring for people add 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 accept and 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 emergency room.
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, kidney 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.
- 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 teams 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 are welcomed back to resume hospice support and care.
  - You can 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.

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

Source: Pima Council on Aging, Pathfinder: Death at Home FAQs; www.pcoa.org
Funeral Planning Checklist: A list of all of the issues to consider when planning a funeral

Planning a funeral is a complicated process, which is made even more difficult by the emotional stress that accompanies the death of a loved one. Fortunately, many of the arrangements can be made ahead of time, which will decrease the burden on those left behind. Use the checklist below when discussing funeral plans with your loved one, to make sure that his or her final wishes are carried out.

<table>
<thead>
<tr>
<th>Pre-Planning</th>
<th>Final Arrangements</th>
</tr>
</thead>
<tbody>
<tr>
<td>All of these items can be arranged in advance of a person’s death.</td>
<td>The following items cannot be arranged beforehand.</td>
</tr>
<tr>
<td><strong>General Preparations</strong></td>
<td>Ambulance transfer from place of death</td>
</tr>
<tr>
<td>Assemble personal information for obituary</td>
<td>Apply for death certificates</td>
</tr>
<tr>
<td>Choose a charity to direct donations to</td>
<td>Apply for a burial permit</td>
</tr>
<tr>
<td>Decide if jewelry is to remain or be returned</td>
<td>Set a time and date for the service</td>
</tr>
<tr>
<td>Choose a funeral home</td>
<td>Request preparation and embalming</td>
</tr>
<tr>
<td><strong>Funeral Home Services</strong></td>
<td>Compose and submit obituary</td>
</tr>
<tr>
<td>Choose burial or cremation</td>
<td>Arrange location and food for the reception</td>
</tr>
<tr>
<td>Select a casket or cremation container</td>
<td>©Copyright FamilyCare America, Inc. All Rights Reserved.</td>
</tr>
<tr>
<td>Select a burial vault or cremation urn</td>
<td>For additional tools for caregiving or aging, visit <a href="http://www.CaregiversLibrary.org">www.CaregiversLibrary.org</a></td>
</tr>
<tr>
<td>Choose the location/type of service</td>
<td>Source: Caregivers Library. This checklist reprinted with permission. For additional resources, please visit <a href="http://www.CaregiversLibrary.org">www.CaregiversLibrary.org</a></td>
</tr>
<tr>
<td>Choose family viewing or visitation</td>
<td></td>
</tr>
<tr>
<td>Choose a floral arrangement</td>
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</tr>
<tr>
<td>Select a photograph to be displayed</td>
<td></td>
</tr>
<tr>
<td>Decide which religious or fraternal items are to be displayed</td>
<td></td>
</tr>
<tr>
<td>Decide what the deceased will wear</td>
<td></td>
</tr>
<tr>
<td>Select music, hymns, and solos</td>
<td></td>
</tr>
<tr>
<td>Select scripture or literature to be read</td>
<td></td>
</tr>
<tr>
<td>Select a memorial register</td>
<td></td>
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<tr>
<td>Select memorial folders and acknowledgement cards</td>
<td></td>
</tr>
<tr>
<td><strong>Funeral Home Services: Transportation</strong></td>
<td></td>
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<tr>
<td><strong>Participants</strong></td>
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<tr>
<td>Choose clergy or officiant</td>
<td></td>
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<tr>
<td>Choose organist or other musical participants</td>
<td></td>
</tr>
<tr>
<td>Select pallbearers</td>
<td></td>
</tr>
<tr>
<td>Select family member or friend to perform the eulogy</td>
<td></td>
</tr>
<tr>
<td>Select family member or friend to read scripture or literature</td>
<td></td>
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<tr>
<td><strong>Cemetery Selections</strong></td>
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<tr>
<td>Choose a cemetery</td>
<td></td>
</tr>
<tr>
<td>Select a burial or cremation plot</td>
<td></td>
</tr>
<tr>
<td>Decide whether above or below ground</td>
<td></td>
</tr>
<tr>
<td>Select a memorial or grave marker and inscription</td>
<td></td>
</tr>
</tbody>
</table>

For additional tools for caregiving or aging, visit www.CaregiversLibrary.org

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Grief and Loss Introduction

By the Family Caregiver Alliance

We generally think of grief as a reaction to a death. But there is another grief that comes from loss while someone is still living. This grief is often experienced when caring for someone with a chronic illness. Chronic illness, and particularly any illness that impairs a person’s cognitive ability, causes caregivers and loved ones to experience grief and loss right now. In this fact sheet, we will discuss the grief related to death and dying, and grief associated with chronic illness. 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.

Chronic Illness and Loss

Over time, with most chronic illnesses, there are changes in a person’s abilities. Whether it is someone living with Parkinson’s disease who can no longer button a shirt, or someone coping with diabetes who has to follow a special diet, or someone with Alzheimer’s disease who can’t remember who you are, caregivers have to adjust to the needs of the care receiver. Caregivers may experience many kinds of losses: loss of independence; loss of control; loss of the future as it had been imagined; loss of financial security; loss of the relationship as it once was; loss of freedom, sleep, and family harmony; loss of someone to share chores and other tasks with; or simply the loss of someone to talk things over with. Persons with chronic illnesses also have to adjust to many of the same losses, but also—loss of dignity, mobility, a carefully planned future or retirement, a loss of roles that were played, or the loss of a sense of worth (all depending on what disability is associated with the illness).

It is easy to ignore these losses and just keep doing the things that need to be done. However, these losses lead to grief, and grief can lead to sadness, depression, anger, guilt, sleeplessness, and other physical and emotional problems. It is important to identify our losses, identify our feelings, and let ourselves grieve the changes that have happened in our lives. When we can do this, our feelings will less often erupt as angry outbursts weighed down by guilt, or creep over us as depression and hopelessness; they instead can more easily be expressed as a shared loss of something treasured—which family and friends close to the situation can likely empathize with, leading to deeper communication and stronger relationships with those going through the loss with you.

Writing in a journal can help you to name and express your feelings about these losses. You can combine it with a gratitude journal—things that you are thankful for. Prayer, meditation, relaxation exercises, attending a support group (or simply talking with a friend or counselor), or creating a ritual can help you to let go of the intensity of the feelings so that you can grieve but also heal.
Ambiguous Loss
Ambiguous loss is what we experience when someone is still “there” but also not “there.” This is mainly experienced when someone has a cognitive impairment from dementia, a traumatic brain injury, or a stroke. We also experience ambiguous loss when someone with dementia has “moments of lucidity,” when he/she is clear and makes sense for a short period of time. It is hard not to think that if they can do this every once in a while, they ought to be able to do it all of the time. When they return to their confused state, we often experience anger, frustration, and disappointment—renewed grief.

Anticipatory Grief
When caring for someone over time, we may start to grieve that person long before they die, we grieve the loss of the person’s “former self.” Experiencing loss on a daily basis, as well as anticipating the loss at the end of life, knowing what is coming, can be just as painful as the loss associated with a death. Caregivers may experience guilt or shame for “wishing it were over” or thinking of their loved one as already “gone” (particularly when someone has a cognitive impairment). 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, make end of life plans for funeral and burial, and experience their pain in stages. Sometimes, when someone has grieved a death over a long period, there is less grief when the person dies; sometimes there is more pain when a person dies.

Grief at Death
Grief is a natural emotion, a universal experience that makes us human. Because it is intense and uncomfortable to feel, we often try to find ways to avoid experiencing the immensity of the emotion—through distraction and busyness. We grieve because we are deprived of a loved one; the sense of loss is profound, the change in roles is confounding, and we may become uncertain of our identity. Often caregivers are in the situation of having to make changes in their circumstances—where to live, financial concerns, relationships—along with fear of not knowing what lies ahead.

Grief lasts a long time. 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. Our society expects us to be “doing fine” in about two weeks. It is common to think there is something wrong with us if our grief “lasts too long.” The grieving process depends on our belief system, religion, life experiences, and the type of loss suffered. Many faiths and cultures have rituals for recognizing grief and loss during at least the first year after a death. We also expect other family members to show their grief in the same way we do, even when we can say that everyone grieves differently. There is no right or wrong way to grieve; grief is an individual process. Many people find solace in sharing their grief with family and friends; others find solace by attending grief support groups offered in every community through their local hospice (even if you did not have hospice services). If you are feeling overwhelmed and concerned about your own grief process over time, seek professional help.
When someone dies suddenly, our first response is often denial, then shock, confusion, and pain. Fatal heart attacks and strokes, car accidents, and suicide can leave family members troubled and searching for answers. In these cases, family members may be left with unresolved issues, such as guilt, anger, anxiety, despair, and feelings of emptiness.

Sometimes we have to learn to forgive ourselves and our loved one who died. It can take longer to heal from this loss and it is important to give yourself time to grieve before pushing yourself to “move on.” Getting support from family, clergy, friends, and grief groups can help.

**Symptoms of Grief**

Grief affects our whole being—physically, socially, emotionally, and spiritually. Each of us will have different symptoms. If you have had a previous loss, you may experience grief this time in a similar or different way, depending on the situation, your relationship with the deceased, and other significant emotional factors in your life at the time. Culture, religion, and social norms influence what we are comfortable showing to others and even what we are comfortable admitting to ourselves.

- **Physical**
  - Crying
  - Sighing
  - Low energy/exhaustion/weakness/fatigue
  - Headaches
  - Stomach aches, loss of appetite
  - Eating too much, particularly comfort foods
  - Sleep disturbance—too much or too little, disturbed dreams
  - Feelings of heaviness, aches, pains
  - Being super busy, pushing yourself to do too much
  - Reckless, self-destructive activities such as drinking too much

- **Social**
  - Feeling alone
  - Wanting to isolate yourself from socializing, finding it hard to pretend to feel OK, being pushed to be social by others
  - Feeling detached from others
  - Angry that others’ lives are going on as usual and yours isn’t
  - Not wanting to be alone, feeling needy and clingy

- **Emotional**
  - Sadness, crying spells
  - Anger/frustration/rage
  - Confusion/overwhelmed
  - Guilt
- Worry/anxiety/panic
- Yearning
- Edginess/irritability
- Memory problems, feeling distracted, preoccupied
- Depression
- Euphoria
- Passive resignation
- Fluctuating emotions
- Sense of lack of control
- Others might see you as “unreasonable” or “overreacting”

**Spiritual**
- Questioning your faith/meaning of life/suffering
- Questioning reason for the death/disease
- Anger at God
- Coming closer to faith/God for solace

**Stages of Grief**
There is no road map for dealing with grief. There are stages that most people go through, but they are not a linear progression from stage 1 to stage 2, etc. We “visit” these stages at different times during the grieving process, depending on what is happening in our lives, for instance, special occasions, like anniversaries and birthdays. And we might go back to a stage years later, such as loneliness and isolation or depression. Although Elizabeth Kübler-Ross defined the five stages below, many clinicians think there are more or different stages.

- **Shock/denial**
  - Trouble accepting the fact of death, diagnosis or new reality, numbness
  - Inability to do usual activities

- **Anger**
  - Anger at yourself, others, professionals (particularly doctors), God, life
  - Feeling helpless and powerless, abandoned

- **Bargaining**
  - Making “deals” with God or friends hoping to change the situation
  - Thinking about “what could have been” or “should have done differently”

- **Depression**
  - Feeling overwhelmed with loss and change, sadness, regret, fear, anxiety
  - Lonely, isolated, self-pity, empty, lost
Acceptance
- Adjusting to the new reality, starting to move on
- Sense of hope, healing, and integration

Helping Those Who Are Grieving
We often feel uncomfortable when approaching someone we know who is grieving. It is hard to know what to say or do. Here are some tips:

- Be available. Offer support in an unobtrusive but persistent manner.
- Listen without giving advice.
- Do not offer stories of your own experiences with grief. 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 that 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. Share stories and memories of the deceased.
- Send cards, flowers, deliver a meal, offer to do chores, donate to a cause that is important to the person who died or who is grieving.

Taking Care of YOU
Taking care of yourself in difficult times is hard. Trusting your own process will help you to do what you need to do in order to best take care of yourself. Acknowledging your feelings—good and bad—will help you to cope better with whatever is happening. Read, journal, get support, cocoon, or do whatever is nurturing for you.

Resources
Family Caregiver Alliance National Center on Caregiving (415) 434-3388 | (800) 445-8106
Website: www.caregiver.org Email: info@caregiver.org
FCA CareJourney: www.caregiver.org/carejourney
Family Care Navigator: www.caregiver.org/family-care-navigator
Other Organizations and Links
Center for Loss and Life Transition
www.centerforloss.com

National Hospice and Palliative Care Organization
www.nhpco.org

Hospice Foundation of America
www.hospicefoundation.org

The Fisher Center for Alzheimer’s Research Foundation
www.alzinfo.org

Recommended Readings


This fact sheet was prepared by Family Caregiver Alliance, revised and updated in 2013, and reviewed by Rabbi Jon Sommer, Professional Grief Caregivers’ Network, October 2013. Copyright © 1996, 2013 Family Caregiver Alliance. All rights reserved.

Source: Family Caregiver Alliance, Grief and Loss, www.caregiver.org