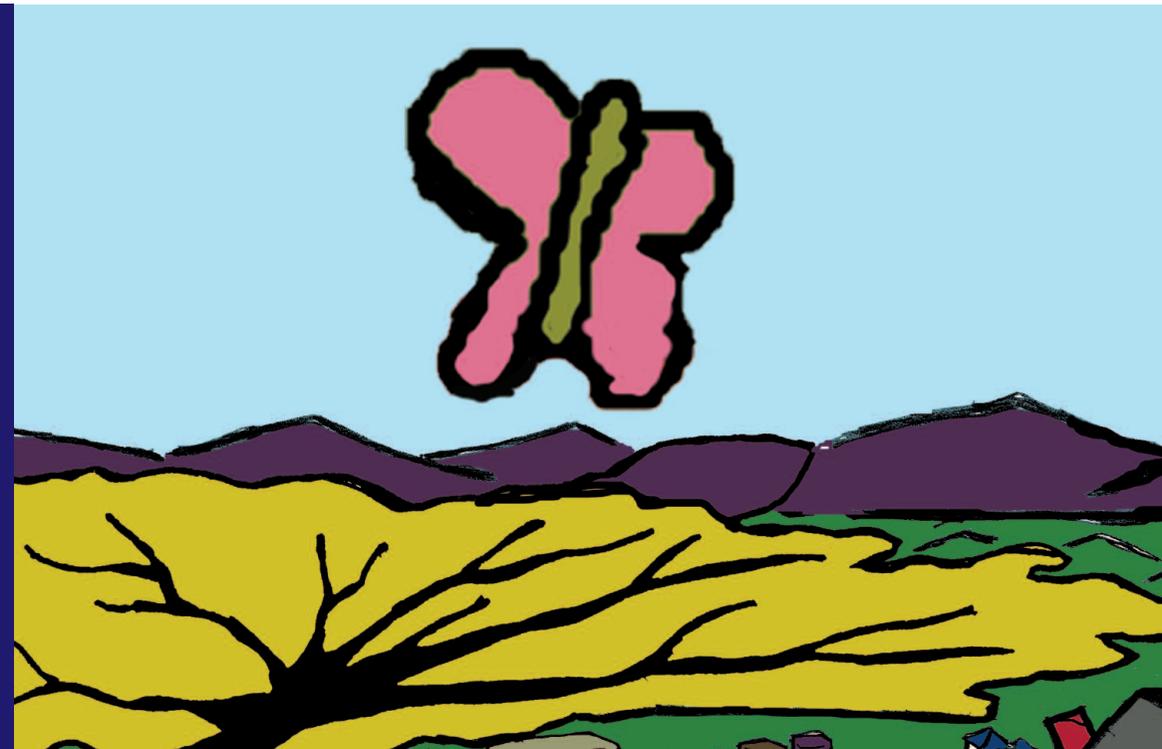


End of Life Issues

Including Advance Directives



INTRODUCTION

Talking about end-of-life issues with your family and healthcare providers can be a daunting task. Family members may avoid this topic, because it may be too painful for them to contemplate the loss of their loved one. Many healthcare providers feel uncomfortable discussing this topic as well, because their energy is focused on finding cures and restoring health. Many times, when people ask questions about death, they are often encouraged by others to "think positively" and not to "give up hope." Even though all of us will eventually die, for many people, talking about death feels like admitting defeat.

While these attitudes are understandable, being told to "think positively" does not really help you to answer the important questions you might have or plan for your death. Not knowing where to turn to get the answers you need can lead to feelings of frustration and hopelessness.

Getting some answers

It is not "giving up" or being overly anxious to ask questions about your end-of-life concerns. A few of the most commonly asked questions include:

- "What treatment options are available?"
- "What will happen to me as I die?"
- "Will it be painful?"
- "What can I do to be sure that my wishes are followed?"

While this brochure cannot possibly answer all of the questions you might have, here is some general information to help you and your family begin to think about these important and difficult questions.

MAKING END-OF-LIFE PLANS

Most of us do not plan for serious illness and death, however, being better prepared for the end-of-life can let you live more fully and comfortably in your final days. People and their family members need time to think about the illness, the prognosis, and options for treatment. If no discussion occurs until you are admitted to the hospital for an acute episode, you may be too ill to make your wishes known, and the decision-making will fall on the shoulders of your family members or doctor. This places a large burden on these people and may lead to their making a decision you would not have wanted.

In particular, you should discuss with your doctor and your family your preferences for hospitalization and the use of ventilators and cardiopulmonary resuscitation (CPR). Many advisers suggest having these types of discussions more than once, because often people find their priorities and preferences may change over time. To make sure your wishes are known, you should consider preparing "Advance Directives" or written documents you can make available to your healthcare provider and emergency personnel. In addition, some people make their wishes known by wearing a medical alert bracelet containing the message "do not resuscitate" and/or posting a similar message on their refrigerator where it can be easily located by emergency personnel who might be called to your residence.

ADVANCE DIRECTIVES

Advance directives are a variety of documents that allow you to control your medical care and let your wishes be known ahead of time. Advance directives can inform caregivers about your wishes and plans, even if you cannot communicate them at the time because of serious illness. End-of-life decisions are the most common use of these documents and this information.

Advance directives usually take the form of one or more documents:

- A living will
- A durable medical power of attorney
- A resuscitation directive

You can write advance directives in several ways. Special forms for advance directives can be obtained from your physician or local medical facility. An attorney can also prepare these documents for you. Many well-respected healthcare and legal organizations, such as the American Medical Association, American Academy of Family Physicians, the American Bar Association, AARP,

and the American Cancer Society, provide information on preparing advance directives and free forms or links to on-line resources for forms. On-line sites such as the U.S. Living Will Registry allows you to register your documents on-line and provides links to individual states where you can obtain the forms that meet the legal requirements for your state. Also, there are many on-line legal services where you can prepare your own legal documents for a small fee. However, advance directives do not have to be complicated legal documents. They can be short, simple statements about what you want done or not done if you can't speak for yourself. If you choose to simply write your wishes down, you may want to have what you have written reviewed by your doctor or a lawyer to make sure your directives are understood exactly as you intended. When you are satisfied with your directives, the orders should be notarized if possible and copies should be given to your family and your doctor.

Most important is the verbal communication to family members and healthcare professionals that must accompany any of these documents. The documents can stand alone and, in the absence of these documents, your communication with family and physicians can stand alone, but the best way to make sure your wishes are followed is to combine documents with communication.



KEY LEARNING: The best way to make sure your end-of-life wishes are followed is to combine advance directive documents with verbal communications to family members and healthcare professionals.

LIVING WILL

With respect to end-of-life medical issues, a living will is a document that specifically says what you do and do not want done during a medical situation in which you are not able to communicate your wishes directly. A living will often contains information about the type of extraordinary life-sustaining measures you do or do not want in those situations. For example, it may state that if you are in a situation in which it is determined that you will not be able to regain consciousness, or will not be able to regain use of your body in a meaningful way, that you do not want to have mechanical ventilation continued, or you do not want to be fed through a feeding tube or intravenous line, or you do not want to have medications continued that maintain blood pressure. Alternatively, a living will can be used to make it clear that you specifically wish all measures be taken to sustain your life when such medical situations exist.





REMEMBER: A living will is a document that specifically says what you do and do not want done during a medical situation in which you are not able to communicate your wishes directly.

The living will can be a very specific document (if this, then that; if this other event, then these other wishes; etc.) or it can be a relatively broad statement of things you do or do not want done. This document is then used to guide the care you are given in an end-of-life situation, and helps your relatives understand your wishes as they are asked to help in decision-making.

DURABLE MEDICAL POWER OF ATTORNEY

A Durable Medical Power of Attorney (also known as a Durable Power of Attorney for Healthcare) is critical, because it allows a trusted agent to make healthcare decisions on your behalf. Few hospitals wish to take on the responsibility of determining your healthcare decisions for you, especially in this litigious society.



IT'S A FACT: Few hospitals wish to take on the responsibility of determining your healthcare decisions for you. A Durable Medical Power of Attorney allows a trusted agent to make healthcare decisions on your behalf.

The Durable Medical Power of Attorney helps your doctors determine when life-supporting measures should be stopped. If your wish is to not use life-sustaining measures, you can convey this to the person you have named, and they will be able to fulfill wishes on your behalf. The person designated in your Durable Medical Power of Attorney only has the responsibility to make healthcare decisions on your behalf, and this document does not authorize this person to make financial or other decisions on your behalf.

RESUSCITATION DIRECTIVES

When your heart stops functioning or your breathing stops in a medical situation, cardiopulmonary resuscitation (CPR) is begun, if trained personnel are present. Under certain circumstances you may choose that CPR be prevented. Such circumstances usually include when you are terminally ill with no chance of recovery, or when it is clear that the quality of your life prior to resuscitation is so limited that sustaining one's life may not be warranted. If you choose to avoid resuscitation under these circumstances, you can create a document asking that you be considered DNR (Do Not Resuscitate). In patients with severe lung disease, such a document can specify a desire to avoid intubation or mechanical ventilation.



KEY LEARNING: If you choose to avoid resuscitation under certain circumstances, you can create a document asking that you be considered DNR (Do Not Resuscitate).

It is important to note that the documents you prepare may not be recognized by states other than the one in which they were prepared. If you travel routinely between states or are scheduled for a medical procedure such as an organ transplant in a state other than your own, you will need to be sure that you have documents that are recognized.

COMFORT MEASURES

In addition to concerns surrounding advance planning for end-of-life decision making, most people express deep concern that they or their loved one “not suffer pain” and be “made as comfortable as possible” as the end-of-life approaches. Certainly the goal of your healthcare provider during this time will be to ensure all measures will be taken to promote your comfort.

While there are many terminal conditions that do not necessarily require pain control, such as end-stage lung disease, many people are concerned about pain relief when discussing end-of-life issues. To this end, there are many different types of medications available to control pain and provide comfort at the end of life. You may have already taken non-prescription over-the-counter medicines such as aspirin, acetaminophen, ibuprofen, or similar medications. These are the same medications your healthcare provider may suggest for you to alleviate mild pain.



If these medications are not working, your doctor will want to know more about the type of pain you are experiencing. How you describe your pain can help to determine its cause or location in the body. Does your pain come and go, or do you have pain all the time? Your answers will help determine which type of medication is right for you: long-acting, short-acting, or a combination of the two. The intensity of your pain: mild, moderate, severe, or excruciating, will help determine the dose you may need to control your pain.

Pain medications come in many forms and a variety of strengths. Usually, your healthcare provider will suggest a pill, capsule, or liquid formulation. If this form is difficult for you to swallow, or if it does not appear to provide adequate relief, some medications can be administered by a patch applied to the skin. Other medications can be given by injection, or small battery-operated pumps through a small needle placed under the skin.

Many people are worried about addiction to pain medicine, but you should not deny yourself the medication you need to control pain.

Medications are very useful for controlling pain, but there are other methods you might want to consider in addition to taking medications. You may want to ask your healthcare provider if some of these comfort measures might be right for you:

- Meditation
- Relaxation
- Imagery
- Hypnosis
- Support groups
- Pastoral and spiritual support

This is a stage of life when individuals may wish to especially visit with close friends and family members. Others do not want to spend time with too many visitors, and you should feel free to let your wishes be known in this regard. Many people want to spend this time with a spiritual advisor who can help add meaning to this period of your life, and provide guidance and comfort for family members as well.

Since no one can predict with certainty when your life will end, you should not feel you have to put off discussing any of these topics until the end is near. So you can be assured you have allowed yourself and your family enough time to talk about your wishes and concerns, you may want to initiate a discussion of these matters well in advance of having to make final decisions.

FINDING HELP FOR END-OF-LIFE CARE

Your physician can help you and your family members discuss and consider your desires about where you wish to be during this stage of life: in a hospice setting, a hospital, or at home. To help you make this decision, ask your healthcare provider or hospice adviser how the treatments you might require can be affected by your choice of setting.

Hospice is not a place, but a concept of care. Many people do not know the majority of hospice care is provided in the home, and these services have been a fully reimbursable Medicare Part A benefit option for beneficiaries and providers since 1983. Hospice care is also covered by Medicaid in many states.

Covered services include:

- Medical and nursing care
- Medical equipment (such as wheelchairs, walkers, supplemental oxygen)
- Pharmaceutical therapy for pain relief and symptom control
- Home health aide and homemaker services
- Social work services
- Physical and occupational therapy
- Speech therapy
- Diet counseling
- Bereavement and other counseling services
- Case management



CROSS REFERENCE: For more information about hospice services, contact the organizations listed in the Additional Resources section in the Big Fat Reference Guide™ at www.alphanet.org

WHAT DOES IT ALL MEAN?

The way you view your life might be similar to the way you answer that age-old question "Is the glass half-empty, or half-full?"

For many people, the final stage of their life is a time to do many of the things they put off for "someday," even though their activities may be restricted to the unpredictability of good days and bad days. Some people describe this time of life as a happy period when family and friends come together and share their love for one another. For some, this stage offers them the opportunity to obtain resolutions to long-held problems. Many people see this stage of their life as an opportunity to reach-out and share what they have learned in order to help others. Other people seem to find solace in spending more time alone.

Throughout history, humans have explored the meaning of life and death. There are beautiful passages in the texts of the world's great religions, in poetry, in music, in humor, and in philosophical essays ... all of which try to provide us with a deeper appreciation for life and its meaning. The way we discover what is meaningful may be different for each of us and can often come in surprising "packages". Ultimately, it seems we must each answer life's persistent questions for ourselves.



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AlphaNet is a not-for-profit organization providing disease management services and support to individuals affected by Alpha-1 through a staff of medical professionals and specially trained AlphaNet Patient Services Coordinators, available 24 hours a day, 7 days a week. To learn more about ADMAP or to find the AlphaNet Coordinator nearest you, visit our website (www.alphanet.org).