

***ADVANCE
MEDICAL
DIRECTIVES***

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TABLE OF CONTENTS

Considering Life and Death.....	3
Your Faith and Advance Directives.....	4
What are “Advance Directives”?.....	5
Myths.....	6
Talking About Your Choices.....	10
Discussion Questions.....	17
How to Get Started.....	18
Glossary.....	19
Resources.....	20

*Much of this material is adapted from “Making Your Wishes Known,”
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Considering Life and Death

Most people in our society – including physicians, patients, and the general public – are in favor of advance medical directives. Yet, few have completed documents. Physicians and families are afraid to talk about death. Death, however, is an inevitable and natural part of the life cycle. Completing advance medical directives greatly increase the chance terminal patients can die as they and their family would choose.

- Willard Krabill, M.D.

If you were near death and unable to give directions for your own health care, how would doctors and nurses provide the treatment you want? How would you care for your family and act with integrity if you were unable to speak?

Making Choices

Susan Beachy*, 75, prepared for death. Through a workshop on advance medical directives, she realized that she wanted to die peacefully without artificial life support. She talked to her children, expressed her preferences, and began the process of completing her living will. One week later, she suffered a stroke and remained unconscious. The family unanimously decided to disconnect her from artificial life support as she wished. They were with her a day later when she died.

Arthur Janzen* knew he was dying and had the opportunity to plan for his future need. He refused, however, to talk about death to his wife or family. After a long illness, which exhausted his health insurance, doctors prolonged his life even when his family begged to discontinue treatment because death was near. Arthur's three extra months of life left his family with a medical bill of \$150,000, enough to cause a financial crisis and hardship for many years to come.

These stories show the necessity of preparing for your health care in the event that you become unable to express your wishes. Most people want to die a quiet, peaceful death. That reasonable wish, however, is often not fulfilled.

Medical treatment can now delay the moment of death for weeks, months, or even years, and has created the following realities:

- Nearly 80 percent of all North Americans die in hospitals or long-term care institutions.
- Over 50 percent of all North Americans die after a decision to stop life-sustaining treatment in a hospital.
- About 85 percent of the average living person's lifetime medical expenditures are spent in the last two years of life.
- An average family without adequate health insurance is only one serious accident or extended illness from financial ruin. Hospitalization which includes assisted breathing or other artificial life support costs at least \$1,000 a day.

- Large numbers of Americans will someday face a life-and-death decision in a hospital setting.

*names have been changed

Your Faith & Advance Directives

The decisions you make concerning an advance directive could be among the most personal, complicate, and emotionally-charges decisions you will ever make. They may result in permanent and irreversible medical, ethical, and legal applications. Therefore, your faith perspective and your wishes for treatment if you become terminally ill should be discussed with your spouse, children, close friends, pastor, and members of your Sunday school class or small group.

Life is a gift of God.

Our faith community believes that human beings are created in the image of God, and as a result, human life reflects the very life of God. This means all human life is precious, including the lives of the people who are terminally ill, mentally disables, or dependent in any other way.

“Then God said, ‘Let us make humankind in our image, according to our likeness...’” (Genesis 1:26-27)

“Then the Lord God formed man from the dust of the ground, and breathed into his nostrils the breath of life; and the man became a living thing” (Genesis 2:7)

Euthanasia and mercy killing. Because human life is a gift of God, none of us has the right to take a life. Killing another human being summarily interrupts a life given by God and therefore takes into human hands what rightfully belongs only to God.

“Whoever sheds the blood of a human, by a human shall that person’s blood be shed; for in his own image God made humankind” (Genesis 9:6)

The commandment, *“You shall not murder,” (Exodus (20:13)* is not limited to outright acts of murder. It also includes intentionally causing the death of another human being through commissions, such as administering a legal drug, and omissions, such as withholding care that is available, beneficial, and not excessively costly. As such, most people in our faith community believe that euthanasia, assisted suicide, or other forms of “mercy killing” are unacceptable.

Completing the dying process. A differentiation needs to be made between intentionally taking the life of another and withholding treatment to permit a person to complete the dying process. Because the dying person can be stopped does not necessarily mean that it should be stopped. We can love, respect, and revere persons both in prolonging life and in permitting dying.

However, the line of demarcation between who is and who is not terminally ill is not always easy to determine, and physicians often do not agree on the prognosis of patients who are near death and unable to communicate. For example, in certain situations in which patients are in a coma and on life support, it is very difficult or impossible for physicians to predict if or when the patient may come out of a coma and what degree of function they might have if they recover.

The need to be considerate of others in the way we live and die. While we affirm the sanctity of life, we also believe that it is necessary to be good stewards of resources, including those that pertain to medical care. We realize that economic, social, and medical resources are limited and inequitably distributed within the U.S. and elsewhere in the world. As a result, many in our faith community consider the impact the expense of their medical care may have on others.

This commitment to stewardship affects the decisions we make with regard to the way we live and die. For instance, Christian patients who are terminally ill may be reluctant to insist on heroic means in the hope that by refusing such treatments, others might be able to avail themselves of scarce medical resources. Additionally, Christians may decide to forgo a medical treatment in order to be more alert while dying, even if it means that he or she will die a bit earlier than would otherwise be the case.

What are “Advance Directives?”

They are about respecting and protecting your own choices about your health care!

Advance directives can be verbal or written statements about how you want your healthcare decisions made if you cannot make them yourself. *The two most common types of written directives are the Living Will and the Health Care Power of Attorney.* Attached are the actual legal forms for use in the State of Indiana. *They can be filed at our hospital at no cost to you!* You are not obligated to file them—the choice is yours. Completing one/both now does not necessarily mean they will be needed in any particular hospital stay. However, talking this over with your family now can be helpful in educating them about your specific wishes “just in case.” These directives can also be changed or updated any time you choose!

A Living Will documents your choices about how you want to be cared for by medical persons during the “end-stage” of your life. It is called a *living* will since it takes effect while the person is *still alive* (in contrast to a “regular” will, which deals with one’s wishes about distribution of property and finances *after* death.) *It is a good thing to have if you do not want your life to be sustained artificially. It takes effect*

when your doctor determines the following conditions all coexist: When 1) you definitely have a terminal illness or injury and 2) you are unlikely to recover, and 3) artificial life support would only prolong the natural dying process. There are various options you may choose on most Living Will forms.

The Health Care Power of Attorney form includes an "Appointment of a Health Care Representative" and is a written, *notarized* document. Its purpose is to *appoint any person of your choice to temporarily make medical decisions, or to consult with medical staff on your behalf, whenever you are unable to communicate or are in a condition where you are unable to make appropriate decisions for yourself.* This also helps prevent uncertainty or delay if conflicting interests are involved when hard decisions need to be made about your care and you are unable to participate! For married competent persons, spouses often name each other. This form is also useful for appointing a successor (back-up), just in case the first person named is unable or unavailable at the time of need. In Indiana an HCPOA *must be notarized* to be valid!

Ten Legal Myths About Advance Medical Directives

by Charles P. Sabatino, J.D.

Myth 1: Everyone should have a Living Will.

A Living Will, without more, is not the document most people need. As a threshold goal, most people should have a Health Care Power of Attorney (or Health Care Proxy) that names a trusted person as agent or proxy. A still better alternative is to execute both documents or a single, combined "Advance Directive" that names a proxy and provides guidance about one's wishes.

Unfortunately, because of statutory restrictions or inconsistencies within state law, many practicing attorneys advise clients to execute separate rather than combined documents. The reason for the primary importance of the proxy appointment is simple. Most standardized living will forms are quite limited in what they can accomplish and what conditions they cover.

For example, most provide instructions that apply only if the individual is in a terminal condition or permanently unconscious, yet the majority of health care decisions that need to be made for patients lacking capacity concern questions about day-to-day care, placement options, and treatment options short of "pulling the plug."

Moreover, most boilerplate instructions express fairly general sentiments about not wanting treatments that serve only prolong the dying process. Relatively few people disagree with this sentiment. However,

applying it to a particular set of facts is more difficult than at first meets the eye. Virtually no interventions only prolong the dying process. Any intervention can produce multiple consequences, some predictable, some not so predictable. If an aggressive and possibly painful course of treatment will give the patient a 1 in 3 chance of recovering to the point of being able to converse again with loved ones for a least a few more months, is that hope enough to treat aggressively? What if the odds were 1 in 25?

Living will instructions always need interpretation, even when the terminal nature of an illness is clear. An agent or proxy under a health care power of attorney can do precisely that. The proxy, who should know the patient's values intimately, can respond to the actual facts and variables known when an actual health care decision needs to be made. Short of possessing a crystal ball, no one can anticipate the specific and often complicated circumstances fate will place them in. The proxy acts not only as legal decision maker, but also as spokesperson, analyzer, interpreter, and advocate.

Myth 2: Written Advance Directives are not legal in every state.

False. Every state recognizes both the proxy and living will type advance directives, although the laws of each state vary considerably in terminology, the scope of decision making addressed, restrictions, and the formalities required for making an advance directive.

A more frequently raised question is whether an advance directive written in one state will be recognized in other states. In other words, is the directive portable across state lines. Many states expressly recognize out-of-state advance directives if the directive meets either the legal requirements of the state where executed or the state where the treatment decision arises.

Myth 3: Just telling my doctor what I want is no longer legally effective.

False. While it is better to have a written Advance Directive, oral statements remain important both on their own and as supplements to written directives.

Myth 4: An Advance Directive means “Don’t treat.”

False. While it is true that most people use Advance Directives to avoid being kept alive against their wishes when death is near, it is a mistake to assume that the existence of an advance directive means, “Don’t treat.” Advance directives are also used to say that the individual wants all possible treatments within the range of generally accepted medical standards. What is said depends upon one’s particular wishes and values. Moreover, even when an advance directive eschews all life-sustaining treatments, one should always assume (and insist upon) continuing pain control, comfort care and respect for one’s dignity.

Myth 5: When I name a proxy in my Advance Directive, I give up some control and flexibility.

False. An individual gives up no authority or choice by doing an Advance Directive. As long as the person remains able to make decisions, his or her consent must be obtained for medical treatment. Health care providers cannot legally ignore the patient in favor of one's agent or written instruction. Indeed, in most states, health care advance directives are "springing."

That is, they have no legal effect unless and until the patient lacks the capacity to make a health care decision. In a minority of states, immediately effective directives are permissible, but the maker always retains a right to override the proxy or revoke the directive.

Myth 6: I must use a prescribed Advance Directive form for my state.

Usually false. In most states, you do not have to use a specific form. About 37 state statutes include forms for appointing proxies or for creating comprehensive advance directives. In the majority of these, the forms are optional. In about 18 states, the forms must be "substantially followed" or certain information disclosure language must be included in the form. Even with these requirements, changes and additions to standard language are permissible. Indeed, any form can and should be personalized to reflect the individual's particular values, priorities, and wishes. If you do not agree with language contained in an approved form, change the language.

If changing the language creates any doubt about the validity of the form, then further legal consultation is in order. Above all, it is a mistake to pick up an "official" form and just sign it unchanged, without first being sure that it truly reflects one's specific wishes.

Myth 7: I need a lawyer to do an Advance Directive.

No, a lawyer is not needed. Yes, a lawyer is a helpful resource, but not the only resource, nor necessarily the best resource for all persons. Advance directives are not difficult to complete, but they require a few steps to do well. Try these steps for yourself, even if you already have an advance directive.

First, obtain an "official" or generally accepted form for your state, plus at least one or two additional advance directive forms from other sources. See the attached resource list for forms.

This helps you see the variations in topics different advance directives cover and the alternative instructions they provide. The form-publishing business may be burgeoning, but most are inadequate in one respect or another. Even with the best drafting, there is no perfect form for everyone. People are different.

Second, discuss the contents of the forms with your physician, close family, and the person you may name as proxy. Most people find these discussions difficult to initiate, but they are extremely important.

Third, complete the form you choose, being sure to add or modify language to reflect your wishes more accurately. Be sure to follow the witnessing instructions for your state exactly.

Myth 8: Doctors and other health care providers are not legally obligated to follow my Advance Directive.

Legally false, but as in many endeavors, reality muddies the waters. As a matter of law, it is clear that medical providers cannot treat an individual against his or her wishes. Consequently, if a physician acts contrary to a patient's clear instruction directive or contrary to the decision of the patient's authorized proxy, the physician risks the same liability he or she would face if the physician were to ignore a refusal of treatment by a fully competent patient. Treatment would constitute a battery. However, a few factors complicate the situation.

First, the doctor or health facility sometimes do not know about the existence of an advance directive. While federal law requires hospitals, nursing homes, and home health agencies to ask about and to document your Advance Directive, the document often does not make it into the appropriate record. It is up to the patient and those close to the patient you to ensure that everyone who might need a copy of the directive in fact has a copy.

Second, as noted earlier, people often do not express their wishes very clearly or precisely in advance directives. Simply using general language that rejects "heroic measures" or "treatment that only prolongs the dying process" does not give much guidance. Therefore, interpretation problems may arise. Giving a proxy broad authority to interpret one's wishes will help avoid this problem, except that sometimes proxies themselves are not quite sure what the patient would want done. This fact underscores the importance of discussing one's wishes and values with the intended proxy.

Third, in most states, if a physician or facility objects to an Advance Directive based on reasons of conscience, state law permits the physician or facility to refuse to honor it. However, facilities must notify the patient of their policies regarding advance directives at the time of admission.

If a refusal occurs, the physician and facility should provide assistance in transferring the patient to a provider that will comply with the directive.

Fourth, persons who are dying, but living in the community, may face problems in having an advance directive followed if a crisis occurs and emergency medical services (EMS) are called (for example, by calling "911"). EMS personnel are generally required to resuscitate

and stabilize patients until they are brought safely to a hospital. States are beginning to address this situation by creating procedures that allow EMS personnel to refrain from resuscitating terminally ill patients who are certified as having a "do not resuscitate order" and who have an approved identifier (such as a special bracelet).

Myth 9: If I do not have an Advance Directive, I can rely on my family to make my health care decisions when I am unable to make decisions for myself.

This is only partly true. If an individual does not have an advance directive naming a health decisions agent or proxy, several states expressly designate default "surrogates," typically family members in order of kinship, to make some or all health care decisions. Only a few of these statutes authorize a "close friend" to make decisions, and then normally only when family members are unavailable.

Even without such statutes, most doctors and health facilities routinely rely on family involvement in decision making, as long as there are close family members available and there is no disagreement. However, problems can arise because family members may not know what the patient would want in a given situation, or they may disagree about the best course of action.

Disagreement can easily undermine family consent. A hospital physician or specialist who does not know you well may become the default decision maker. In these situations, patients risk having decisions made contrary to their wishes or by persons whom they would not choose. Moreover, family members and persons close to patients experience needless agony in being forced to make life and death decisions without the patient's clear guidance. It is far better to make one's wishes known and to appoint a proxy ahead of time through an Advance Directive.

Myth 10: Advance Directives are a legal tool for old people.

False. Don't think of this as an "old" people's issue. It may be natural to link death and dying issues with old age, but that is a mistake when it comes to advance directives. Consider that perhaps the most well known landmark court cases those of Nancy Cruzan and Karen Ann Quinlan involved individuals in their 20's. The stakes are actually higher for younger persons in that, if tragedy strikes, they might be kept alive for decades in a condition they would not want. An Advance Directive is an important legal planning tool for all adults.

Talking About Your Choices

It's all about talking

This booklet introduces you and your loved ones to the issues surrounding end-of-life decision making. It's all about *talking*- talking to your loved ones about your health care preferences; talking to your doctor about your options so that you can make informed decisions. Talking *before* a crisis can help you and your loved ones prepare for any difficult decisions related to health care at the end of life.

Exploring your thoughts and talking about your choices is an ongoing process. Start by planning for your end-of-life care.

Contact us at Partnership for Caring: America's Voices for the Dying if you have any questions. And refer to the resource list for other agencies and organizations that might be helpful to you.

Advance Care Planning

You can prepare for a potential medical crisis by taking steps *today* that ensure your participation in future health care decisions:

- **GATHER** the information you need to make the right choices for you.
- **TALK** about end-of-life decisions with your family, friends, doctor, the clergy and any others close to you to help determine what quality of life and which decisions are important to you.
- **PREPARE** and sign advance directives that accurately reflect your decisions and comply with your state's law.
- **INFORM** your loved ones and doctor about your preferences and give them copies of your advance directives.

Talking about the issues

The following questions may help you discuss these issues with family, loved ones and an agent:

- How do you want to be treated at the end of your life?
- Are there treatments you particularly want to receive or refuse?
- What are you afraid might happen if you can't make decisions for yourself?
- Do you have any particular fears or concerns about the medical treatments that you might receive? Under what circumstances?
- What makes those things frightening?
- What do phrases like *no heroic measures* or *dying with dignity* actually mean to you? (People often use these expressions with different meanings)

Talking with family and friends

Decisions about end-of-life medical treatments are deeply personal and should be based on your values and beliefs. Because it is

impossible to foresee every type of circumstance or illness, it is essential to think in general about the quality of life that is important to you. You should consider your:

- Overall attitude toward life, including the activities you enjoy and situations you fear;
- Attitude about independence and control, and how you feel about losing them;
- Religious beliefs and moral convictions, and how they affect your attitude toward serious illness;
- Attitude toward health, illness, dying and death; and
- Feelings toward doctors and other caregivers.

Other factors may be important, such as considering the impact of decisions on family and friends and determining whether loved ones will support your decisions concerning end-of-life treatments. Bring your family and friends into the process. Talk with them. They might need to advocate on your behalf if the medical condition prevents your active participation in decision-making.

Discussions with loved ones are a vital foundation for making end-of-life decisions. Conversations that focus on decisions and why you are making them will relieve loved ones and health care providers from the need to guess what *you* would want.

Talking with your doctor

Do not wait until a crisis occurs before discussing concerns about end-of-life treatments with your doctor. Chances are that he or she is waiting for you to start the conversation. When you discuss your concerns and choices:

- Let your doctor know that you are completing directives.
- Ask your doctor to explain treatments and procedures that may seem confusing before you complete your directives.
- Make sure your doctor knows the quality of life that is important to you.
- Make sure your doctor is willing to follow your directives. The law does not force physicians to follow directives if they disagree with your wishes for moral or ethical reasons.
- Give your doctor a copy of your completed directives. Make sure your doctor knows the name and telephone number of your appointed health care agent.
- Assure your doctor that your family and your appointed health care agent know your wishes.

One final point: reassess your decisions over time. They might change as circumstances in your life change.

Preparing the right advance directive

Talking with loved ones, friends and others close to you helps determine your preferences concerning end-of-life treatments. Make certain that those preferences will be respected even if you lose the ability to participate in your health care decisions: sign an advance directive.

“Advance directives” is a general term that describes two types of legal documents that “speak” for you in the event of incapacity: 1) A living will allows you to document your wishes concerning medical treatments at the end of life. 2) A medical power of attorney (or health care proxy) allows you to appoint a person you trust as your health care agent, who is authorized to make medical decisions on your behalf.

Advance directives are legally valid throughout the United States. The laws governing advance directives vary from state to state, so sign advance directives that comply with your state’s law. Also, advance directives can have different titles in different states. Call Partnership for Caring: America’s Voices for the Dying for information about appropriate documents for your state.

Talking with your health care agent

Your agent should be a person whom you trust, who knows your wishes about medical treatment and who is willing to take responsibility to ensure your wishes are followed. Appointing an agent or accepting such an appointment can raise questions you might never have considered. you may reach a deepened understanding of yourself and your relationship with the person you appoint or who appoints you. Taking time to talk about the issues can be a rewarding experience in itself.

SELECTING AN AGENT:

- Select someone whom you trust and who understands your decisions.
- Because you are asking your agent to accept significant responsibility, be certain to ask your agent if he or she is willing to act on your behalf. Not everyone is able to be an effective agent.
- Talk to your agent about your wishes regarding end-of-life medical treatment. Even family members may not know how much treatment a loved one would be willing to accept near the end of life. Talking clarifies what you want and diminishes an agent’s potential guilt and anguish over whether he or she is doing *the right thing*.
- Prepare and sign the appropriate forms for your state. Keep the original and give copies to your agent and alternate agents, family and doctors and have it placed in your medical record.

BENEFITS OF HAVING AN AGENT:

- The agent knows you and understands your wishes about medical treatments. He or she can make decisions in situations you might not have anticipated.

- An agent has flexibility. He or she can talk with your physicians about your changing medical condition and authorize treatment or have it withdrawn as circumstances change.
- If you have prepared a living will, your agent can interpret it in situations that were not foreseen. Be sure to make clear in your living will that your agent should make decisions on how to interpret it or when to apply it.
- Your agent can advocate for you. If health care providers resist following your wishes, your agent can negotiate with them and take any other necessary steps to see that your wishes are honored.
- In most states, your agent can make decisions any time you lose the ability to make a medical decision, not just decisions about the end of life.

Acting as a health care agent

Providers and patients (or their agents) don't talk enough. As an agent, you will be responsible for working with providers to ensure that your loved one's wishes, including preferences about end-of-life treatments, are honored. If you become the decision maker for a loved one, take the following steps:

- Establish open communication with the doctor. Identify the attending physician. Make an appointment to speak about your loved one's care. Be assertive in expressing your wishes. Clearly state the reasons behind your requests without being hostile.
- Ask questions. To be effective and to make informed decisions, learn as much as possible about your loved one's condition and prognosis. If you don't ask, the physician might not tell you everything you need to know to make an informed decision. Ask about the goals of the treatment plan- often, a physician's definition of *recovery* can be different from what is acceptable to you or your loved one. Some providers may have a hard time withholding or withdrawing treatments.
- Seek the assistance of a social worker or patient representative. Such professionals can help improve communication between you and the physician if necessary.
- Don't be afraid to speak to the facility's administration. If the physician is unresponsive, go directly to his or her superiors, including the chief of medicine, risk manager, hospital lawyer or administrator.

Understanding life-support measures

Life support replaces or supports a failing bodily function. When patients have curable or treatable conditions, life support is used temporarily until the illness or disease can be stabilized and the body can resume normal functioning. At times, the body never regains the ability to function without life support.

When making decisions about specific forms of life support, gather the facts you need to make informed decisions. In particular, understand the benefit as well as the burden. The treatment will offer you or your loved one. A treatment may be beneficial if it relieves suffering, restores functioning or enhances the quality of life. The same treatment can be considered burdensome if it causes pain, prolongs the dying process without offering benefit or adds to the perception of a diminished quality of life.

A person's decision to forgo life support is deeply personal. When gathering information about specific treatments, understand why the treatment is being offered and how it will benefit your care.

COMMONLY USED LIFE-SUPPORT MEASURES:

Artificial nutrition and hydration: artificial nutrition and hydration (or tube feeding) supplements or replaces ordinary eating and drinking by giving a chemically balanced mix of nutrients and fluids through a tube placed directly into the stomach, the upper intestine or a vein. Artificial nutrition and hydration can save lives when used until the body heals. Long-term artificial nutrition and hydration may be given to people with serious intestinal disorders that impair their ability to digest food, thereby helping them to enjoy a quality of life that is important to them. But long-term use of the tube feeding frequently is given to people with irreversible and end-stage conditions. Often, the treatment will not reverse the course of the disease itself or improve the quality of life. Some health care facilities and physicians may not agree with stopping or withdrawing tube feeding. Therefore, explore this issue with your loved ones and physician and clearly state your wishes about artificial nutrition and hydration in your advance directive.

Cardiopulmonary resuscitation: Cardiopulmonary resuscitation (CPR) is a group of treatments used when someone's heart and/or breathing stops. CPR is used in an attempt to restart the heart and breathing. It may consist only of mouth-to-mouth breathing or it can include pressing on the chest to mimic the heart's function and cause blood to circulate. Electric shock and drugs also are used frequently to stimulate the heart. When used quickly in response to a sudden event like a heart attack or drowning, CPR can be life saving. But the success rate is extremely low for people who are at the end of a terminal disease process. Critically ill patients who receive CPR have a small chance of recovering and leaving the hospital. If you do not wish to receive CPR under certain circumstances, and you are in the hospital, your doctor must write a separate do-not-resuscitate (DNR) order on the chart. If you are at home, some states allow for a non-hospital DNR order. This order is written by a physician and directs emergency workers not to start CPR.

Mechanical ventilation: Mechanical ventilation is used to support or replace the function of the lungs. A machine called a ventilator (or

respirator) forces air into the lungs. The ventilator is attached to a tube inserted in the nose or mouth and down into the windpipe (or trachea). Mechanical ventilation often is used to assist a person through a short-term problem or for prolonged periods in which irreversible respiratory failure exists due to injuries to the upper spinal cord or a progressive neurological disease. Some people on long-term mechanical ventilation are able to enjoy themselves and live a quality of life that is important to them. For the dying patient, however, mechanical ventilation often merely prolongs the dying process until some other body system fails. It may supply oxygen, but it cannot improve the underlying condition. When discussing end-of-life wishes, make clear to loved ones and your physician whether you would want mechanical ventilation if you would never regain the ability to breathe on your own or return to a quality of life acceptable to you.

ADDITIONAL ISSUES:

The distinction often is made between not starting treatment and stopping treatment. However, no legal or ethical difference exists between withholding and withdrawing a medical treatment in accordance with a patient's wishes. If such a distinction existed in the clinical setting, a patient might forgo treatment that could be beneficial out of fear that once started it could not be stopped. It is legally and ethically appropriate to discontinue medical treatments that no longer are beneficial. It is the underlying disease, not the act of withdrawing treatment that causes death.

Learning about pain management

A common fear of both terminally ill persons and their loved ones is that the dying person will experience great suffering and pain. Many of us are more afraid of dying in pain than of death itself. Pain should be treated as seriously as the disease. Pain can significantly impair the quality of life of individuals, even causing them to give up on living. A plan to manage pain should be as concrete as a plan to manage the disease.

In most cases, severe pain and physical discomfort can be managed through effective use of pain management and palliative care (symptom control). This can be accomplished through medical means, such as medications (narcotics and non-narcotics), surgery and nerve blocks, and non-medical means, such as relaxation therapies, biofeedback, massage and good nursing care.

Reasons that many terminally ill patients experience a great deal of pain and suffering include:

- Failure to tell others about their pain;
- Failure of providers and family to accept patients' reporting about the severity of their pain;

- Failure of providers to consider pain as seriously as other aspects of a patient's illness;
- Lack of knowledge among health care providers about the effective and
- appropriate use of medications and other tools to control pain;
- Fear that providing or taking adequate narcotics will lead to addiction;
- Lack of access to sufficient quantities of medications for patients on very high doses of narcotics; and
- Fear of causing death by providing aggressive pain management.

People with terminal illness may require extremely large doses of narcotics to control their pain. Despite the fact that clinical experience has shown that those who take narcotics for pain management rarely become psychologically addicted, myths about addiction from the use of narcotics are a serious barrier to effective pain management. Fears of causing death are similarly misplaced. It is important to recognize that the disease is causing death, not the medications and procedures used to control pain. Pain management is provided simply to keep the dying person comfortable.

WAYS TO ENSURE GOOD PAIN MANAGEMENT:

- Ask your doctor how he or she will manage any pain that might result from your illness. Different types of illness might require different approaches. The doctor should have a plan in mind or see that you have access to appropriate pain specialists.
- Consider what trade-offs you are willing to make for pain management. Some people would rather endure more pain if it meant they would be more alert.
- Don't be afraid to let your caregivers know when you are in pain. You should expect to have your pain taken seriously.
- Describe your pain as specifically as possible. Let the doctor know how it is affecting your ability to do specific things; when it is better or worse; where it falls on a scale of 1 to 10.
- When a pain management plan is implemented, follow the plan! The goal of good pain management is to keep you from experiencing pain. Once you are in pain it requires much more medication to bring the pain under control.

Discussion Questions

The following questions can be used to discuss issues pertaining to advance directives in your class or group.

1. What do you believe about life after death, and how do these beliefs affect your views on advance directives?

2. To what degree do you accept the use of medical resources as a stewardship offer, and under what circumstances would you be prepared to refuse treatments because of the expenses involved?
3. In what ways can Christians express their faith through advance directives?
4. What are some of the barriers to discussing advance directives with your spouse or close family members, and how can these barriers be overcome?
5. Have you ever been personally involved in a situation where an advance directive was used? What was the event like, and what were the positive and negative effects of advance directives?
6. Have you ever been personally involved in a situation in which there was disagreement over treatment options of someone who was terminally ill and an advance directive could have helped?
7. Who would you select as a proxy to help physicians make decisions regarding your care if you were terminally ill and unable to communicate? What are some practical implications of naming a proxy?

How to Get Started

Advance directive checklist: The following checklist is designed to help you complete your advance medical directive. As you work through the checklist, you may find that you need to give more thought to some of the issues presented or that you need to consult with others. Complete as much of the checklist as you can, referring to other sections of this booklet as necessary. Then, use the checklist as a guide in gathering the rest of the information needed.

- I am 18 years of age or older.
- I have considered my wishes in acute medical situations in which I could not communicate (permanent coma, brain damage, terminal illness, etc.).
- I have considered what I want to accomplish (or avoid) with advance directives.
- I have discussed my wishes with the important people in my life.
- I have read sample living wills and durable power of attorney forms
- I have talked with my physician or a local hospital representative about the advance directive guidelines in my home state.
- I have completed a living will by writing my advance directive as precisely and specifically as I can.
 - Including the purpose of the document.
 - Dating and signing the document.
 - Having two witnesses* observe my signing the living will and having them also sign the document.
- I have chosen to name and record a person to act as my health care representative (proxy) in a durable power of attorney document.
 - My proxy agrees to make necessary health care decisions based on my written directions if I am unable to communicate.
 - I have discussed my views about life, death, and faith with my proxy thoroughly so he or she understands my health care preferences.
 - I have completed the document.

- I have named a second or third health care representative who will be consulted if my first choices are not available when critical decisions have to be made.
- I have signed and dated the document in the presence of appropriate witness/es*. (Some states require a notary public as witness).
- I have made at least five copies of my advance directive plus a copy for each of my children and myself. I have given copies to my:
 - spouse or closest friend
 - physician
 - lawyer
 - local hospital (to file)
 - pastor
 - children
- I have completed a wallet card indicating that I have advance directives, and I am carrying the card with me.
- I will review my advance directive annually and will date and initial each review.

* Two witnesses must be people who will not inherit any of your estate nor will they stand to gain otherwise by your death (e.g., Life insurance or estate beneficiary). Many states have specific witness requirements. Consult the instruction booklet for your state.

Glossary

Advance directive: A general term that describes two kinds of legal documents, living wills and medical powers of attorney. These documents allow a person to give instructions about future medical care should he or she be unable to participate in medical decisions due to serious illness or incapacity. Each state regulates the use of advance directives differently.

Assisted suicide: Providing someone the means to commit suicide, such as a supply of drugs or a weapon, knowing the person will use these to end his or her life.

Brain death: The irreversible loss of all brain function. Most states legally define death to include brain death.

Capacity: In relation to end-of-life decision-making, a patient has medical decision-making capacity if he or she has the ability to understand the medical problem and the risks and benefits of the available treatment options. The patient's ability to understand other unrelated concepts is not relevant. The term is frequently used interchangeably with competency but is not the same. Competency is a legal status imposed by the Court.

Do-not-resuscitate order: A DNR order is a physician's written order instructing health care providers not to attempt cardiopulmonary resuscitation (CPR) in case of cardiac or respiratory arrest. A person with a valid DNR order will not be given CPR under these circumstances. Although the DNR order is written at the request of a person or his or her family, it must be signed by a physician to be valid. A non-hospital DNR order is written for individuals who are at home and do not want to receive CPR.

Hospice care: A program model for delivering palliative care to individuals who are in the final stages of terminal illness. In addition to providing palliative care and personal support to the patient, hospice includes support for the patient's family while the patient is dying, as well as support to the family during their bereavement.

Living will: A type of advance directive in which an individual documents his or her wishes about medical treatment should he or she be at the end of life and unable to communicate. It may also be called a “directive to physicians”, “health care declaration,” or “medical directive.” The purpose of a living will is to guide family members and doctors in deciding how aggressively to use medical treatments to delay death.

Medical power of attorney: A document that allows an individual to appoint someone else to make decisions about his or her medical care if he or she is unable to communicate. This type of advance directive may also be called a health care proxy, durable power of attorney for health care or appointment of a health care agent. The person appointed may be called a health care agent, surrogate, attorney-in-fact or proxy.

Palliative care: A comprehensive approach to treating serious illness that focuses on the physical, psychological, spiritual, and existential needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering, by controlling pain and symptoms, and by enabling the patient to achieve maximum functional capacity. Respect for the patient’s culture, beliefs, and values are an essential component. Palliative care is sometimes called “comfort care” or “hospice-type care.”

Surrogate decision-making: Surrogate decision-making laws allow an individual or group of individuals (usually family members) to make decisions about medical treatments for a patient who has lost decision-making capacity and did not prepare an advance directive. A majority of states have passed statutes that permit surrogate decision making for patients without advance directives.

Withholding or withdrawing treatment: Forgoing life-sustaining measures or discontinuing them after they have been used for a certain period of time.

Resources

Partnership for Caring: America’s Voices for the Dying; National Office 1035 30th St. NW; Washington, DC 20007; Tel: 800-989-9455; Fax: 202-338-0242; e-mail: pfc@partnershipforcaring.org; Website: www.partnershipforcaring.org

Advocates for the rights of dying patients, provides legal and educational information about end-of-life decisions, and operates a counseling service for people with questions and concerns related to the implementation of advance directives and other end-of-life issues.

Commission on Legal Problems of the Elderly; American Bar Association; 740 15th St. NW, Washington, DC 20005-1022; Tel: 202-662-8690; Fax: 202-662-8698; e-mail: abaelderly@abanet.org

Graydon F. Snyder, *Tough Choices*, Brethren Press, 1988.

Willard S. Krabill, David Schroeder, and Jesse H. Ziegler in *Medical Ethics, Human Choices, A Christian Perspective*, Herald Press, 1988

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