

# DECISIONS

## The Changing Role of Medicine Our Changing View of Death

**T**he practice of medicine is a delicate weaving of art and science and of ethics and philosophy. Now that medical technology offers so many more ways of keeping us alive, dying can be a prolonged process.

Some people near death opt to allow machines to keep them alive, while others bypass heroic efforts, preferring to go at their natural time. Because of all the choices available today, we've prepared this bulletin (the first of six) to help guide you through the process of making your own end-of-life decisions.

### A Crash Course in Modern Medicine

In the late 1800s, scientists developed anesthesia and antiseptic surgery. In the twenties, modern antibiotics arrived with the first sulfa drugs and the discovery of penicillin. During World War II, refined penicillin and blood-transfusion techniques saved thousands of lives. The '40s brought more effective medicines, antibiotics and chemotherapy. In the '50s, polio led to more sophisticated breathing machines and the first intensive care units (ICUs). CPR has saved countless lives since its arrival in the '60s. And over the past 40 years, we've benefited from high-tech advances in surgical procedures, dialysis and organ transplants.

### The First in a Series of Six Bulletins

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- 1 The changing role of medicine and our changing view of death**
- 2. Quality of life**
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- 4. Tools of communication**
- 5. Building a partnership with your doctor**
- 6. Living and dying in a caring community**

## Progress Brings Dilemmas

Long ago, patients had few opportunities to make decisions about their health care. In most cases, they had a very limited selection of treatments, if any at all.

There's no question that medical advances save thousands of lives every day. But this progress also brings questions about the process of dying. High-tech equipment that once was reserved for accident victims or patients recovering from major surgery or illness is now used routinely in a way that may prolong the dying process.

The fact is, the ethics and philosophy of health care—including decision-making—must now catch up with the science of medicine.

## The American Way

America prides itself on individualism, ingenuity and independent choice. Some researchers say the American spirit is reflected in our attitude about death, which may explain why we rely on intensive care units and valiant medical treatments. Many say that Americans view death as the ultimate defeat, rather than a natural part of the life cycle.

## It's Time to Question

Today, many Americans question old attitudes as they search for new ways that fulfill psychological and spiritual needs, as well as physical ones.

The hospice movement that began in England in 1949, for example, has spread across our nation, bringing solace and support to incurably ill patients and their families.

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**The goal of *Decisions* is to help you make decisions about your medical treatment when you near the end of life. Because you never know when it will happen, it's never too early to start thinking about your own views on death and dying.**

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Researchers and authors such as Elisabeth Kübler-Ross, a pioneer in working with patients at the end of life, have helped demystify the stages of dying and reduced the fear surrounding them. Rev. Frederick W. Reklau talks about our society's struggle between the emphasis on

“curing” and the dying person’s need for “healing.” He explains that healing “embraces the whole, may occur without cure, and includes death among the outcomes of care.”\*

Our health care system’s inconsistent approach to caring for dying patients is highlighted by the debate surrounding physician-assisted suicide. In its 1997 ruling against a constitutional right to assisted suicide, the U.S. Supreme Court suggested that the desire for aid in dying often is driven by people’s fears that medical care at the end of life may not bring relief from severe pain, anxiety or suffering. This attention has heightened the public’s awareness of these issues and may result in improved care for dying patients.

The past few decades have brought us greater patient involvement in decision-making—both in the treatment phase and at the end of life. With more information, patients and their families can feel better about the many choices they have—and the decisions they have to make.

\* *Health Ministries Connection, 1997.*

## Next Bulletin: **2** *Quality of Life*

Evaluating your beliefs and values so you can live the final days of your life the way you want.

*Written by a diverse group of healthcare professionals and clergy dedicated to informing the public about end-of-life decisions.*

# Quality of Life

**I**f you're like most people, you probably don't spend much time thinking about how you'd like to live the last days of your life. For many of us, death is an uncomfortable subject—perhaps because it reminds us of our own mortality. Yet it's a subject that deserves your attention, particularly in light of advances in medical technology over the past few decades.

## No One Can Define Your Quality of Life But You

Today, a variety of medical treatment options are available if you're seriously ill or injured. The choices you and your doctor make about treatment may result in a completely different lifestyle than you had before. That's where quality-of-life issues come into play.

Fact is, each person has an idea of what constitutes quality of life based on beliefs and values like family, independence, spirituality, mobility and mental capacity. It's important to consider how *you* define quality of life for *yourself* should the need arise to choose medical treatment and make end-of-life decisions.

The following cases may help you examine your own quality-of-life values.

### Case #1: Mrs. Lee

Mrs. Lee, a 48-year-old wife and mother, was admitted to the intensive care unit with pain in her right side. She also had trouble breathing.

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**The way you define quality of life can determine the choices you may have to make regarding your own end of life.**

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Her doctors found she had a recurrence of lung cancer that was incurable. As Mrs. Lee's breathing got worse, the physicians talked with her about treatment options.

With no further treatment, her breathing problems would hasten her death. She could leave the hospital and receive supportive care at home. Or she could be attached to a breathing machine, an option that would let her live several days or weeks longer even though she'd be completely dependent on the ventilator. With both options, her doctors promised to help her breathe and ease her pain with medication.

Mrs. Lee decided to use the ventilator, knowing that she would live her last days in the hospital and eventually die with a breathing tube in place as the cancer progressed.

Imagine yourself in Mrs. Lee's position. What treatment choice would you make? What values influenced your decision? Would you rather remain in the hospital or receive supportive care at home? If you were unable to speak for yourself, would a family member or a close friend know what decision to make for you?

## **Case #2: Mr. Miller**

Mr. Miller, a very active 62 year old, had sudden and severe abdominal pain while golfing. He was rushed to the hospital where doctors found a large blood vessel had ruptured, causing internal bleeding. Mr. Miller was admitted to the ICU. Over the next several days, complications from his initial loss of

blood and extremely low blood pressure resulted in kidney damage and loss of circulation to his left leg.

Mr. Miller was unconscious and remained on a breathing machine.

His doctors talked with his wife about her husband's poor potential for full recovery. They felt Mr. Miller could eventually breathe on his own. But because there was minimal blood flow to his brain before the emergency surgery and he continued to be unresponsive, they could not say for sure that he would regain full mental functioning. The doctors also informed Mrs. Miller that her husband would have to undergo amputation of his left leg and kidney dialysis two or three times a week.

If you were Mr. Miller, how would you feel about your dramatically changed lifestyle? What effect would losing a limb, undergoing regular dialysis or having reduced mental functioning have on your lifestyle? Given your values about quality of life, what treatment would you choose? Would your family or a close friend know what medical decision you'd want made if you were incapacitated like Mr. Miller? What should Mrs. Miller do?

Consider now how you define quality of life.

## **Next Bulletin: 3** ***How to communicate your values***

Telling your loved ones about your end-of-life decisions.

*Written by a diverse group of healthcare professionals and clergy dedicated to informing the public about end-of-life decisions.*

# DECISIONS

## How to Communicate Your End-of-Life Decision

*Pat, something's on my mind*

*How can I help?*

*Well, it's one of those subjects that's kind of hard to get into...*

*Come on, Leslie. You can talk to me about anything.*

*Okay. Here goes: I'd like to talk about what would happen if I were in an accident and unable to make medical decisions. I know what I would want for myself. And I want us all to be prepared should that time come.*

**I**n the previous *Decision* bulletins, we talked about medical progress and quality of life—and how they influence the choices we make about how we want to live our remaining days. If you've identified your values about the quality of your life, the next step is for you to communicate your wishes. The following guidelines can help.

### Choose the Right Person

First things first...select the person you feel is best able to speak for you should you ever be unable to do so yourself. This person is sometimes referred to as your surrogate (substitute) decision-maker. No matter whom you choose, make sure that person clearly understands your values and beliefs—and is willing and able to speak on your behalf. It's best *not to assume* that your closest companion feels the same way you do. For example, if your spouse or partner is not comfortable with carrying out your preferences, consider a mature child, sibling, extended family member or close friend.

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## Talk about Your Values and Choices

What's the best way to communicate? Just start talking—in the car, in the kitchen, at a restaurant, in the park or on the phone... whatever feels right for you.

Talk in a way your spokesperson can understand about the medical choices you'd make if you were seriously ill or injured. Be specific. Think about what it would be like to narrowly survive a disease or accident—and how you would prefer to live out your remaining days.

- Do you feel comfortable receiving help to bathe, dress, eat and get around?
- How do you feel about spending your final days in the hospital?
- What if you had trouble talking with others?
- What if you were permanently dependent on life support machines?
- Do you want to stay alive even if you'd never regain consciousness?

Tough questions, we admit. But your answers form the basis of your end-of-life decisions.

### Make the Time

The old adage goes, "You never find time, you make time." Here's how to make time to communicate your values about the end of life.

*Discuss the issue now—while you're healthy.* There is no way to anticipate what might happen to you. Expressing your preferences ahead of time—in anticipation instead of by necessity—assures that you will be heard.

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### Use movies and news stories

to open opportunities to discuss, "if that happened to me, here's what I'd do."

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What's more, you'll have peace of mind that your family knows what you want.

Plus if you talk about it when you're feeling full of vigor, your conversation is more apt to be objective and focused.

*Use current events as a springboard.* Every day, the media serve up thought-provoking and conversation-stimulating topics. Let movies and news stories open opportunities to discuss "if that happened to me, here's what I'd do or want done for me."

It is never too early to begin these discussions. Your life experiences may change your views and values and affect the decisions you make. If you have a change of heart, make it known by talking with your chosen surrogate decision-maker. One family finds it helpful to set aside a time each year for such a discussion.

### The Important Thing is to Communicate

There's no right or wrong way to communicate—as long as you do communicate. Perhaps you want to put your feelings down in writing rather than have a face-to-face conversation. Maybe you'd feel better in neutral territory such as a car or restaurant. Whatever works for you is the best way to communicate your personal values and decisions.

### Next Bulletin: The tools of communication

The legal tools available to help make your wishes known.

*Written by a diverse group of healthcare professionals and clergy dedicated to informing the public about end-of-life decisions.*

## Tools of Communication

*I heard something today at the office. You know, it made me think. Maybe we should discuss it. Is this a good time?*

*Of course. What is it?*

*Well, Sally says her uncle isn't responding well in the ICU. And her family just doesn't know what to do.*

*You mean there wasn't an advance directive in his file?*

*She didn't say. Uh, honey?*

*Yes?*

*What's an advance directive?*

**T**he previous *Decisions* bulletins discussed medical progress, quality of life, making end-of-life decisions and communicating your preferences to a trusted spokesperson.

Now we'll look at advance directives—legal communication tools designed to make your feelings known.

### Using Advance Directives

If you're ever in a position where you cannot make medical treatment decisions for yourself, your doctor will most likely ask your closest available relative or friend to help decide what's best for you. For many people that works fine. But sometimes not everyone agrees about what to do.

How can you help prevent this dilemma? Discussing your values about end-of-life care with your family and physician is the first and most important step. Completing an advance directive document can also be helpful by describing in writing what is important to you. In the future, if you cannot speak for yourself, this tool can affirm the conversations already held with loved ones and your doctor.

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## Understanding Advance Directives

Advance directives can help communicate your wishes when you no longer can. They can help your loved ones by reducing confusion and disagreement over your choices. Any adult who is able to make decisions can establish an advance directive. Generally speaking, there are two types of advance directives:

### Medical Power of Attorney

A Medical Power of Attorney *lets you name someone to make your health care decisions when you can't*. This type of advance directive may also be called a "health care proxy" or "appointment of a health care agent." The person you appoint may be called your health care agent, surrogate, attorney-in-fact or proxy. Most states allow this person to speak for you in any health care decision, not just those at the end of life.

### Living Will

Living wills are written instructions that tell doctors your wishes for medical treatment should you become permanently unconscious or suffer from a terminal illness. They're called "living" wills because they take effect while you are still alive but unable to speak for yourself. Some states define when the living will goes into effect and limit the treatment to which it applies.

California allows for the designation of your surrogate and/or instructions for your medical care in one advance directive.

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**The most wonderful gift you can give yourself and your loved ones is peace of mind. Make your wishes known now.**

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Advance directive forms are often available in hospitals and nursing homes. For more information about advance directives and copies of forms for different states, contact:

National Hospice & Palliative Care Organization  
website: [www.caringinfo.org](http://www.caringinfo.org)  
e-mail: [caringinfo@nhpco.org](mailto:caringinfo@nhpco.org)  
helpline: 1-800-658-8898

Keep the original advance directive document and give copies to those who need it, such as your doctor, family members, and/or a close friend. You can change or cancel the form at any time. Keep the document close at hand (not in a safe deposit box.) If you are admitted to the hospital, bring a copy of your advance directive.

## Part of the Communication Process

Communicating your wishes to your loved ones and doctor is essential. Completing the advance directive may bring you an added sense of security. By communicating your desires, you take responsibility for decisions about your life and death and help your family and friends move on with peace of mind.

### Next Bulletin: **5** *Building a partnership with your doctor*

Discussing end-of-life issues with your physician.

*Written by a diverse group of healthcare professionals and clergy dedicated to informing the public about end-of-life decisions.*

# Building a Partnership with Your Doctor

*Doctor, I brought you something today.*

*Well, thank you. What is it?*

*An advance directive. I've been meaning to talk to you about my end-of-life choices for some time now. And I decided there's no better time than during my check-up.*

*That's great, Mrs. Andrews. It's a smart thing to do when you're healthy. I wish all my patients made their health care decisions known. It sure would make it easier on me—and on their families.*

**I**n the previous *Decisions* bulletins, we reviewed medical progress, quality of life, communicating end-of-life decisions and completing advance directives. Now we'll look at discussing these issues with your physician.

## **A Healthy Doctor-Patient Relationship**

There is never a more important time to have a good talk with your physician than when reviewing decisions about the end of your life. For patients, families and physicians alike, this subject is probably one of the most difficult to tackle. It's only natural to put off talking about death—especially when we're feeling healthy.

When it comes to your values, health care choices and end-of-life decisions, you're the expert. And when it comes to your medical condition, your doctor is the authority. It's easy to see then why building a partnership between patient and physician is vital—even if you don't have a personal physician and are being treated by the doctor for the first time.

So what's the key to developing a strong relationship with your doctor. Good communication, pure and simple.

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## When You're Healthy

One of the most important times to discuss your feelings with your physician is when you're healthy and have given some thought to your beliefs and values.

Doctors want to know your attitudes toward aggressive treatments that may be used should you become very ill. These treatments include ventilators that help you breathe, shocking the heart, CPR and other potentially life-prolonging treatments.

For some people, the possible benefit to receiving aggressive care near the end of life may not be worth the prospect of spending their last days in a high-tech environment. Physicians who understand their patients' views, values and priorities are best able to assist patients and families at the time when treatment decisions must be made.

## If You're Not Healthy

Physicians should always speak with their patients about their wishes before asking anyone else—unless the patient is too ill to speak. Keep in mind that you may not feel the same about treatment when you're ill as when you're healthy.

Remember, no decision you made before is written in stone—even documents like the Medical Power of Attorney and the Living Will. If you do change your mind, be sure to inform your doctor.

## The Gray Area

Your doctor—or team of doctors as is usually the case—should fully explain your condition, expected outcome and the benefits and burdens of available treatment options. But sometimes that's easier said than done. Fact is, each patient responds to treatment differently. So there are many gray areas about what is occurring medically and what might happen in the future.

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### What's the key to developing a relationship with your doctor?

**Good communication, pure and simple.**

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Ask your physicians just how certain they are about your situation and make decisions accordingly.

## Clarifying Your Wishes

Patients often say they want their doctor to “do everything” or they “don't want to be a vegetable.” But these vague and subjective statements do little to help the physician. A better solution is to state your goals.

“I really want to travel to my grandchild's wedding.” “Talking with my family is what's important to me.” These are two examples of what you could say to help your doctor determine how likely you are to achieve your goals.

## Making a Difficult Choice Easier

One subject that may arise is when to withdraw medical support if there seems to be little chance of reversing the disease or injury. This is a gut-wrenching time for everyone—including doctors.

Here again, by making your family and doctor aware of your goals, values and beliefs, you can help ease their distress if they need to decide whether to allow the natural process of death to take place.

A partnership between you and your doctor—together with good communication about your medical condition, personal values and goals—can make your final days easier on you and your loved ones.

## Next Bulletin: **6** *Living and dying in a caring community*

Receiving care and comfort at the end of life.

*Written by a diverse group of healthcare professionals and clergy dedicated to informing the public about end-of-life decisions.*

# Living and Dying in a Caring Community

*Jamie just told me about the wonderful hospice care Terry's getting now.*

*It's terrific! Sounds like everyone is just so caring. It makes me wonder how the hospice people can give so much day in and day out.*

*They probably feel like they're getting back much more than they give.*

*You know, if I'm ever in a similar situation, that's the kind of thing I'd want.*

*How about you?*

**I**n the previous *Decisions* bulletins, we reviewed medical progress, quality of life, end-of-life decisions, advance directives and patient-doctor relationships. This issue looks at giving and receiving care.

## Loving Company

Each of us is born into a community of family, friends and perhaps fellow worshippers. It's probably safe to say that most of us would also hope to die in the loving company of those who care deeply about us.

The faith community activates their compassion and spirituality by easing pain and touching wounds in the simple but all important *ministry of presence*.

## A Ministry of Presence

Our hands—as the loving hands of God—reach out to others in times of joy and success, as well as in time of need. The late priest and author Henri J.M. Nouwen relates his experience of working with Adam, a severely

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handicapped 25-year-old man who could not speak and was totally dependent on others.

“As my fears of entering Adam’s unfamiliar world gradually decreased,” Nouwen writes, “I began to feel a profound tenderness and affection toward him. Before this, I had come to believe that what makes us human is our mind. But Adam keeps showing me that what makes us human is our heart...where God has hidden trust, hope and love.” He concludes, “If Adam wants anything of me, it is that I simply be with him.”\*

This example shows us that a ministry of presence is an opportunity to touch the lives of others with an expression of caring, spiritual renewal, comfort and hope.

### **Spiritual Support. Day-to-day Care.**

Loved ones, extended family members and friends can offer a special dimension of caring and assistance to those nearing life’s end. Also standing ready to offer both spiritual support and daily assistance are spiritual leaders, caring ministries and communities of faith, which more and more are receiving training in end-of-life matters and grief counseling and support.

There is also a growing interest in congregational-based health ministries. Some communities of faith focus on the health and healing of the mind and body—along with a strong emphasis on spiritual well-being.

A nurse or health practitioner may serve individual congregation members as the coordinator of health education activities, a resource for medical and psychological services, and a link between the medical and spiritual care communities.

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Hospice care also is important in the caring community, specifically for those in the latter stages of terminal

illness. In a delicate and personalized way, hospice helps patients and their families cope with the physical, emotional and spiritual aspects of dying. Through hospice, patients can receive comprehensive services at home, where they can be close to their families, friends and favorite surroundings. Services include pain management and symptom control, advanced nursing care, referrals to community resources and bereavement counseling for the family.

### **Giving and Receiving**

Living and dying in a caring community offers a twofold life experience—for those in need of receiving care and for those called on to give care. Theologian and ethicist Richard John Neuhaus writes, “To entrust ourselves to the care of others is to abandon preoccupation with our own dignity and to allow others the greatest human dignity, which is caring for those who have no claim upon us other than the claim of human need.”†

In this mutual relationship of serving and being served, of caring and accepting care, we can truly experience faith in action.

\* *Reader’s Digest*; January, 1990

† *The Religion and Society Report* 5; August, 1988

***This concludes the Decisions series. We hope this series makes you more aware about end-of-life matters and opens the lines of communication between you and your family and doctors.***

*Written by a diverse group of healthcare professionals and clergy dedicated to informing the public about end-of-life decisions.*