

A FRED FRIENDLY SEMINAR

Before I Die

medical care and personal choices

Viewer's Guide

A production of Seminars, Inc.
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in New York.
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What's in this Viewer's Guide

This Guide is meant to help you think about and talk about the issues raised in the Fred Friendly Seminar "Before I Die: Medical Care and Personal Choices."

In these pages you'll find:

- Five brief essays that place the major themes and issues in context and provide some background to aid you in your discussions.
- Thought-provoking discussion questions, keyed to each essay.
- Key information about advance planning, hospice and "comfort" care,

end-of-life medical treatments, financial and legal issues.

- A glossary of key terms.
- An up-to-date Resource and Reference Section to help you learn more about the issues that concern you the most, including suggestions for further reading, addresses and phone numbers of relevant organizations, and web sites.
- Suggestions on how to use this Guide, after viewing the program, to stimulate an informed discussion about end-of-life issues.

How to use this Viewer's Guide

Getting people to talk about dying is not easy. That is one of the main messages of the program "Before I Die: Medical Care and Personal Choices." But given time and encouragement, most people are not only willing to address end-of-life issues; they are grateful for the chance to explore ideas, feelings and courses of action related to the unavoidable facts of death and dying.

There is no "right" way to get a discussion going. You might hold a special meeting of an organization that you belong to, conduct a pre-arranged discussion with friends, organize a seminar or conference, include a series of these topics at regular monthly meetings of clubs, or link up with local organizations that may be willing to sponsor such activities (e.g., hospices, hospitals, libraries, churches, community colleges, community centers, senior citizens groups, civic organizations or other groups). You may wish to bring in a

local speaker (e.g., doctor, hospice staff person, critical care nurse, bioethicist) to help answer questions and provide additional information.

Perhaps most valuable of all, you may find that this program and Guide will help initiate discussions about hopes, wishes, fears and preferences at the end of life with your family and friends. Almost everyone has had some personal experience with the death of a family member, friend or co-worker. Asking people to talk about these experiences is one way to begin.

Discussions can be free-form or focussed around specific issues raised in the program or in the essays. You may want to ask different people in the group to respond to one or more of the discussion questions. You might end the discussion by asking people to suggest at least one positive step they can take to reduce their own or their loved ones' fears and anxieties about death and dying.

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To help you get the most out of "Before I Die: Medical Care and Personal Choices," you are invited to:

- **Make copies of all or part of this Guide.**
- **Access and download the Guide and other materials on the "Before I Die" website at <http://www.wnet.org/bid> or <http://www.pbs.org/bid>.**

"Before I Die: Medical Care and Personal Choices" is one of a series of Fred Friendly Seminars that uses a Socratic dialogue format, dramatic role playing, hypothetical situations and a roving inquisitor to compel panelists to confront complicated situations where the "right" choice is not clear.

Dying Well

Dear Viewer:

When you picture a dying person, you may imagine someone in pain, in a hospital, hooked up to machines and quite possibly alone. And, in fact, this is true of how many people die today, but I believe this image will soon be largely a thing of the past. Early in my career, I found there was little coordination among the various entities involved in providing end-of-life care, so my colleagues in social work, nursing and pastoral care, and I held a weekly meeting to coordinate the care of people with terminal illness. By keeping people from feeling abandoned and by making sure that their pain was treated, remarkable things were occurring: occasionally a family would describe the last month as 'the best time we've ever had together.' Or a patient who was within a week or so from death – and knew it – emanated a sense of genuine contentment and peace. It became clear that these patients were in fact "dying well."

I believe our system of end-of-life care is broken. The roots of the crisis extend deeper than misguided insurance policies, prescription laws that inhibit prescribing of adequate pain medications, and problems in medical education. The core problem is cultural; it is our inability to imagine what 'success' at the end of life might look like.

While medicine defines dying as a set of problems to be solved, dying is not fundamentally medical – its nature is personal. Medical care often ignores what people may have left undone in their lives, finding a sense of completion, providing pleasure, tenderness and truly loving care – precisely what is needed to complement the technical aspects of end-of-life care. Often the calm, caring presence of another person can soothe a dying person's anguish, as they can be read to, prayed with, or gifted with gentle song.

One way to solve the current problem is to understand how doctors can intervene and help people through the dying process, which requires more than simply treating pain and other symptoms. Another component of the solution is to raise expectations about the dying experience so that patients and families expect – and insist on – better care. Consumer pressure can change medical practice, as it did thirty years ago, when people said that doctors would never allow women to go through labor without anesthesia, and that you could never get surgeons to meet an ambulance in the emergency room. These are now fully accepted medical practices, and they changed because patients demanded that they change.

Participating in discussions, sharing stories and identifying or developing new volunteer services to improve the lives of people with terminal illness and their families, can help communities cope with death and bereavement. Doctors, lawyers and journalists too often approach dying as a choice between suffering and suicide. As a nation, we need an option where people can live with the assurance of relative comfort, support and caring that preserves personal dignity and human potential through the end of life. What is missing from the debate about death is the concept that people can be "well" even while dying. My goal is to ignite people's imagination with the notion that this can become a reality for those they love, and ultimately for themselves.

Ira R. Byock, MD, panelist

Director, The Palliative Care Service
President, American Academy of Hospice
and Palliative Medicine

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Before I Die: Medical Care and Personal Choices

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Off air taping rights of **Before I Die: Medical Care
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for one year following each broadcast.

Ordering Information

Before I Die: Medical Care and Personal Choices

(*broadcast version*) along with copies of the
Viewers Guide, is available from
PBS Home Video, 1320 Braddock Place,
Alexandria, VA 22314
Phone toll-free 1-800-424-7963
Fax (703) 739-5269

Also available: a special edition of the program
segmented for discussion purposes, and additional
support materials for outreach and professional
development use. See the Resource and Reference
Section to order.

Program Schedule:

PBS Premiere Broadcast: April 22, 1997
**Please check local listings for broadcast times
and any scheduling changes.**

“There is no death...
There is only...
me...me...who is
going to die...”

André Malraux (1901-76)

Before I Die

None of us doubt our own mortality. We all know that nothing is as certain as death. But as long as we are healthy, it's easy to put death out of mind. And why not? With modern medicine to keep us healthy, why worry about something so far off, so unpleasant, so painful?

Then, with the urgency of a siren in the night, it's upon us. Not swift death but a medically prolonged, often agonized dying. And whether it is our own end that we must face or that of someone dear to us, we find ourselves without the tools to deal with it.

The truth is, death in today's America is rarely swift. Studies show that most of us will live for weeks, months, even years with the disease that eventually kills us. Even when modern medicine cannot cure, it can keep the vital functions of heart and lungs going almost indefinitely.

This means that dying is no longer just the last moment of life. For most of us, dying has become the last chapter of our life-story, a time fraught with new challenges and hard decisions.

Some of the hardest decisions have to do with medication, legal matters and

money. As many as one third of all families in America will suffer serious financial hardships as the result of coping with a loved one's prolonged dying. Nothing can erase the anguish of loss. But thinking ahead about the inevitable – and starting now to confront end-of-life issues – can save everyone involved unnecessary pain and suffering.

It all begins with communication: Talking about death and dying with your doctor, your family, yourself.

“We all die at some point in our lives, and we should have a say about it when we're well, and it's not a threat, and we can have some thoughts about how we would like that to happen.”

Claudia Fegan, MD., panelist

Discussion Questions

- If you have had a relative or close friend die, would you describe it as a “good death” or a “bad death”? Why? Could it have been better? How?
- If you could have your choice, who would you choose to care for you at the end of your life? What considerations count most in your mind: your own needs and comfort, your family's well-being, the precepts of your religion or community?
- What is your greatest fear about dying? What kinds of information or support from other people do you think would ease your fears?
- If you had to make life-or-death decisions about medical treatment, who would you turn to for advice and counsel? Your doctor, family members, friends, clergy?
- Do you feel that healthy people can dwell too much on death? How much time and effort should a person in the prime of life spend preparing for the inevitable?

“Oh Lord, grant
each his own, his
death indeed...”

Rainer Maria Rilke (1875-1926)

Learning About Dying

It's been said that the greatest fear is fear of the unknown. When a critical illness strikes, feelings of anxiety, helplessness, embarrassment and despair can make a grave situation even worse.

You can't anticipate everything. But learning about the options and choices in advance can give patients and family a sense of control in a time of crisis and the power to choose a death with dignity.

The business of the medical profession is to save lives. For any caring doctor, death can feel like a failure. As a result, many physicians are as reluctant to talk about dying as their patients are. Yet the process of coping with the inevitable is best begun through a candid conversation between doctor and patient.

The outcome of this conversation can be an Advance Directive, such as a Living Will – a legal document telling medical personnel what to do and what not to do if illness or accident prevents you from speaking for yourself.

But a Living Will by itself is no guarantee that your wishes will be followed in a busy emergency room or intensive care unit, or that your instructions will be appropriate to the actual medical situation. For this reason, perhaps the single most important thing you can do is name a Medical Care Proxy — a family member or friend who will speak for you when decisions must be made about aggressive procedures like resuscitation and the insertion or removal of breathing and feeding tubes.

Because it is so hard to foresee every complication, you may want to fill out a Values History — a document explaining your views about life and death and your end-of-life priorities in ways that can help your doctor and your proxy interpret your wishes no matter what happens.

What are your feelings about dying? About the appropriate medical measures to take at different stages? About balancing pain relief with mental alertness? Just sitting down to talk to your doctor and your chosen proxy can

help clarify your thoughts about such basic matters. This in turn will make it easier to bring up the subject with other family members and friends.

Not everyone is ready to engage in a dialogue about dying. But the more completely you understand your own feelings, the easier it will be to engage the support of people you love in achieving your ultimate goal: to bring as much peace and meaning as possible to the end of your life.

Key Facts: Advanced Planning

Advance planning typically includes consideration of the following options:

Values History:

- A comprehensive document that prompts you to put down in writing your thoughts and feelings about life, your attitude toward illness, dying and death, and your preferences about end-of-life care.
- For use by your doctor, family and friends if you are unable to make decisions about medical treatment.

Advance Directives:

- Include documents you can fill out and sign to express specific preferences for care in the event you are unable to speak for yourself later.

Two types of Advance Directives are:

1. Durable Powers of Attorney for health care, which appoint a friend or loved one as your medical care Proxy for making medical treatment decisions.
 2. Living Wills, spelling out your end-of-life preferences as guidelines for medical treatment.
- All 50 states and the District of Columbia have laws recognizing the use of Advance Directives, although each state has different guidelines.
 - A state-specific Advance Directive may be obtained through an attorney or an organization such as Choice in Dying, 1-800-989-WILL.

Medical Care Proxy:

- Proxies are often called upon to help interpret your Advance Directive and decide what you would have wanted to do when faced with unforeseen circumstances, such as an unwanted resuscitation.

For a list of organizations that can provide more information about Values Histories, Advance Directives and Medical Care Proxies, see the Resource and Reference Section.

“I think we have to make death acceptable. We have to tame it.” *Nancy Neveloff Dubler, LLB., panelist*

Discussion Questions

- Have you ever had a conversation about death and dying with a critically ill person? How did you approach the subject? If you could, what would you do or say differently today?
- How much detail would you want your doctor to give you about end-of-life options and the choices available? What kinds of instructions would you want to put into an Advance Directive? How much leeway would you want to leave your doctor and proxy in dealing with unforeseen situations?
- If you were to become terminally ill, who would you want to be informed? Your spouse, parents, children, closest friends, co-workers? Who would you want to tell them? Yourself? Someone else? What would you want them to be told?
- Do you think there is an acceptable way to talk about death and dying to children? What, if anything, would you say to teen-aged children? To children under ten? Under five?
- If the next-of-kin or closest friend of a terminally ill patient refuses to talk about what is happening, how would you deal with this refusal?

“Be careful then, and
be gentle about death.
For it is hard to die,
it is difficult to go
through the door, even
when it opens.”

D.H. Lawrence (1885-1930)

Learning to Listen

The hardest thing for many people to do is to listen well. This is especially true when the subject is death. Coping with the prospect of death — or helping someone else cope with it — is a skill that few are born with. Fortunately, it can be learned.

Some people in the helping professions have observed that many patients, together with their loved ones, go through a similar series of reactions in the days, weeks or months following the diagnosis of a terminal illness. These can be roughly divided into four stages.

Typically, the first stage is strong denial: *This can't be happening. There must be a mistake.* After denial, anger is common: *Why me? I have so much*

to do, so much to give. It's not fair. It's someone else's fault. Anger is often followed by a stage known as bargaining: *If I do everything I'm told, maybe things will be all right. If I can just have another week (or month or year), I can handle this.* When these reactions are exhausted the terminally ill may suffer deep depression. A patient may be overwhelmed by a sense of numbing loss, a "preparatory grief" so great it can raise a barrier between the dying person and those who try to help.

While thinking in terms of stages may help us understand our own and other people's behavior, no one can predict how any individual will react in the face of death. Whatever the circumstances, doctors, nurses, pastors, relatives and friends can help ease suffering

by learning to listen when patients express their feelings. With enough time, a patient may pass beyond the so-called four stages of dying to a fifth stage, which some refer to as acceptance.

Having mourned the impending loss of life, the patient may now find peace in what remains: Visits from a few chosen loved ones. The wordless comforts of solitude. What one patient called "the final rest before the long journey." While the experience of dying varies enormously from patient to patient and institution to institution, the sensitivity of people who come into contact with the critically ill can make a significant difference.

"Dying is more than a set of medical problems to be solved. Dying is a part of living, and it's a part of the life of every individual, every family, every community. I would submit that the real solution is not medical, it's cultural." *Ira Byock, MD., panelist*

Discussion Questions

- What can a person do to become a better listener? What can you do to encourage someone to talk about a painful subject?
- Do you think that dividing a person's end-of-life experiences into separate "stages" makes sense? In what ways do you think that knowing about these stages might help you cope with your own dying or that of a loved one?
- What kinds of clues — such as tone of voice, physical gestures and posture — reveal what people are feeling? What clues might you look for to help you understand what a dying person is going through? How would you deal with someone whose body-language seems to contradict what he or she is saying?
- If you feel strongly that a terminally ill patient is behaving in a way that is hurtful to both patient and family, should you share your feelings with the patient? The family? How would you go about it?

Key Facts: End-of-Life Preferences

SUPPORT, an eight-year study involving 10,000 terminally ill people, found that doctors often did not know their patients' end-of-life preferences.

- Nearly one-third of patients preferred to forego resuscitation, yet their doctors knew about this preference in only one-third of the cases.
- Nearly half of do-not-resuscitate (DNR) orders were written within a day or two before death, suggesting lack of advance planning in terminal illness.
- Many doctors fear that suggesting a DNR or referring a patient to a hospice will be seen as giving up rather than appropriate care at that stage of disease. Yet of patients who had not discussed their end-of-life preferences with doctors, more than two out of five said that they wanted to have that discussion.
- Half the patients able to communicate in the last three days of life said they were in severe pain.
- Other studies confirm that attempts to alleviate pain in dying people are inadequate in a large number of cases, including outpatients, hospital patients and nursing home patients.

For a list of organizations that can provide more information about end-of-life options, see the Resource and Reference Section.

“I’m not afraid to die. I just don’t want to be there when it happens.”

Woody Allen (b. 1935)

Managing End-of-Life Issues: Pain and Money

According to conventional wisdom, everyone dies alone. But today's medically prolonged dying has become a complex and expensive public event. At a time when you most desire to be alone or with loved ones, you find yourself surrounded by unfeeling machines and by people who, despite their best intentions, have no intimate knowledge of who you are or what you want. This can lead to unnecessary pain and anxiety.

Experts tell us that with modern medications, no one need suffer debilitating pain during a terminal illness. Yet the largest clinical study of the sick and dying revealed that more than a third of terminally ill hospital patients die in pain. Why?

Sometimes the fault lies in inadequate patient-physician communication. Making your wishes known can be difficult. Often doctors lack training

in pain control. Some fear being reprimanded or even sued for prescribing "high" doses of painkillers. In some institutions, pain management has a low priority compared to treating more "serious" symptoms, even in terminally ill patients.

Few medical practitioners today are taught how to deal with dying patients and their families. Medical textbooks rarely address the subject. Only 5 of 126 medical schools in the U.S. have a separate, required course about death.

The high cost of dying adds to the suffering of patients and families. Even with medical insurance, nearly a third of terminally ill patients use up most or all of their savings to cover uninsured expenses like home care. After the anguish of caring for and then losing loved ones, many families find themselves literally impoverished.

Under our present system, prolonged dying is a huge drain on the national budget as well. Over a quarter of all hospital costs in the U.S. go to caring for patients – many of them terminally ill – in the nation's 78,000 intensive-care beds.

One alternative is hospice care. Like the natural-childbirth advocates in the 1960s who successfully challenged the medical model of birth with a more patient-oriented approach, hospice advocates believe that people should be able to determine the circumstances of their dying. Hospice care may be available at home, in a special hospital wing or in a separate hospice facility. It typically offers sophisticated pain control, comfortable surroundings and psychological and social support to terminally ill patients who are willing to forego "aggressive" medical intervention, such as resuscitation and machine-assisted breathing.

" Pain is such a narrow part of the experience. It's physical, it's emotional, it's spiritual. It can even be financial. And hospice teams are prepared to look at all parts of the suffering..." *Constance Holden, RN, MSN, panelist*

Discussion Questions

- Had you heard of hospice care before viewing this program? Would you want hospice care for yourself or for someone you love?
- What aspects of hospice care appeal to you? What aspects of hospice care worry you?
- How important do you think pain control should be in treating terminally ill patients? Who should make decisions about the level of pain-killers used: The patient, family, doctor, hospital staff?
- If the high cost of medically prolonged dying takes money away from other socially desirable goals – such as better child care, education, and disease prevention – should government curtail Medicare and Medicaid spending on end-of-life treatments? Who should make this decision? On what grounds?
- What changes would you make in our current health care system to increase your own chances of ending life with a "good death"?

Key Facts: Financial and Legal

- Nearly one-third of terminally ill patients use most or all of their savings to cover uninsured medical expenses like homecare.
- One-third of terminally ill patients require substantial caregiving assistance from a family member, who often must quit work or take time off to provide the needed care.
- In one of ten families the stress of dealing with a terminally ill relative led to serious health problems in other family members.
- The average savings derived from not resuscitating a dying patient whose heart had stopped was almost \$14,000.
- One-third of Medicare payments go to people in their final year of life.
- According to the National Health Council, all patients have a series of rights and responsibilities. For more information contact the National Health Council.

For a list of organizations that can provide more information about financial and legal issues affecting end-of-life options, see the Resource and Reference Section.

“Of all the wonders that
I yet have heard, it
seems to me most
strange that men should
fear, seeing that death,
a necessary end, will
come when it will come.”

William Shakespeare, *Julius Caesar*

Death and Life

For over a century, medical science has been rewriting the rules of living and dying. We live longer than ever before. Without rejecting what we have gained, perhaps the time has come to take a close look at the personal and social costs of treating death as a purely medical issue.

Consider the serious psychological and ethical questions that are raised by a dying person's decision to do without life-prolonging medical treatment – whether expressed in a living will, through a proxy, or by opting for hospice care.

Is a patient's decision to stop resisting death a form of "quitting?" Do other family members have a right to contest the patient's choice? Is there a moral distinction to be made between foregoing mechanical life-supports entirely and "pulling the plug" later on?

No one can decide for anyone else the proper way to die. For some, religious teachings are paramount; for others, the impact on family and friends; for still others, purely personal considerations such as weighing pain control against loss of self-control. Yet everyone has some idea of what a "good death" means.

What seems clear is that the kind of care we give to the dying is a reflection of our own fears, our hopes, our priorities, our deepest values. If the issue of physician-assisted suicide looms so large in our society, it may be because so few people are aware that other alternatives exist to the high-tech, high-cost option of dying in a hospital.

There are now 2,700 hospice organizations nationally, most of them created in the last decade. If the way we die says something about the way we live,

the growth of the hospice-care movement says something about the resolve of terminally ill patients to take control of the last act of life, and invest it with dignity and meaning.

"The way to ameliorate the sting of death...is by teaching people how to live with meaning and therefore die with meaning. How to understand that death is not the ugly specter that we had painted it, that we're afraid of." *Rabbi Maurice Lamm, panelist*

Discussion Questions

- Who should ultimately make decisions about death? You? Your doctor? God?
- What are your beliefs regarding an afterlife? Do these beliefs bring you comfort when you consider your own death?
- What does the phrase "the meaning of life" mean to you? In what ways can dying and death be said to have "meaning"?
- If you were going to die next week, what would remain undone in your life? How would you want to spend

your remaining time? Would you find comfort in leaving behind a letter or a videotape for your loved ones? What would you include in such a last statement?

- In what ways do you think your life has been changed by watching this program and discussing it in a group? Would you want other people you know and love to share this experience? Is there anything you can do now to help them clarify their thoughts and feelings about death and dying?

Key Facts: Comfort Care/Hospice Care

Comfort care is the type of care provided to patients in a hospice setting. (The medical term is "palliative" care.) The guidelines for this type of care call for:

- Symptom control for the patient.
 - Allowing patients to spend their last days at home or in a home-like setting among the people and things they love.
 - Coordinated support for patients and their families by a team of medical, spiritual, legal, economic and psychological service providers.
 - Respect for patient lifestyles, wishes and philosophies.
 - Continuing self-determination and decision making by patient.
 - Communication among family, patient and caregivers.
 - Bereavement counseling and care for survivors.
- In treating the physical, emotional and spiritual needs of patients, hospice teams are committed to:
- Using the latest medications and devices for pain relief.
 - Keeping patients pain-free but alert.
 - Assisting patients in being as mobile and self-sufficient as possible.
 - Using resources such as music, art, massage therapists and religious counselors to maintain patients as comfortably as possible.
 - Providing counseling for family members during a patient's care and for at least a year following the patient's death.

For a list of organizations that can provide more information about hospice care, see the Resource and Reference Section.

Moderator

Arthur R. Miller

Arthur R. Miller is the Bruce Bromley Professor of Law at Harvard Law School. Professor Miller appears regularly on ABC's *Good Morning America* program and COURT TV. He is nationally known for his work on court procedure, copyright and unfair competition, and the right of privacy.

Panelists

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Executive Director,
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Rabbi Maurice Lamm

Chair, Professional Rabbis,
Yeshiva University
Author, *The Jewish Way in Death and Mourning*

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Author, *How We Die*

Richard Payne, MD

Professor of Medicine (Neurology) and Chief, Section of Pain & Symptom Management
Department of Neuro-Oncology, University of Texas/M.D. Anderson Cancer Center

Anna Quindlen

Novelist and Pulitzer Prize-winning columnist,
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Director of Educational Programs,
AIDS Pastoral Care Network

Katherine E. Slaughter, RN, MSN, CCRN

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University Hospitals of Cleveland

Karen Stanley, RN, MSN, AOCN

Clinical Nurse Specialist, Pain and Symptom Management, Kaiser Permanente

Resources and References

Further Reading

Dying Well:

The Prospect for Growth at the End of Life

Ira Byock, M.D., President, American Academy of Hospice and Palliative Medicine
Riverhead Books
Copyright 1997

How We Die:

Reflections on Life's Final Chapter

Sherwin B. Nuland, M.D.
Vintage Books
Copyright 1993

Helping Yourself Help Others:

A Book for Caregivers

Rosalynn Carter with Susan K. Golant
Time Books, a division of Random House
Copyright 1994

Last Acts Resource Directory

Barksdale Ballard & Co.
703-827-8771

Organizations

The following organizations may provide or refer you to important information about end-of-life care:

Alzheimer's Association

919 N. Michigan Avenue, Suite 1000
Chicago, IL 60611-1676
1-800-272-3900
advance planning, receiving a Values History, Alzheimer's disease information and support

American Geriatrics Society

770 Lexington Avenue, Suite 300
New York, NY 10021
212-308-1414
referrals, health care and older adults, principles for quality care at the end of life

Center to Improve Care of the Dying

The George Washington University
1001 22nd Street, NW, Suite 820
Washington, D.C. 20037
202-467-2222
expert care for dying people, speaker

Choice In Dying

200 Varick Street
New York, NY 10014-4810
212-366-5540
advance directives, end-of-life issues in general, speaker

Health Care Financing Administration

7500 Security Blvd.
Baltimore, MD 21244-1850
800-638-6833 - Medicare Hotline
Medicare, Medicare hospice benefit

Hospice Association of America

519 C Street, NE
Washington, D.C. 20002
202-546-3540
referrals to local hospices

Hospice Foundation of America

2001 S Street, NW, Suite 300
Washington, D.C. 20009
202-638-5419
referrals to local hospices

Leukemia Society of America

600 Third Avenue
New York, NY 10016
212-573-8484
patient information and support

Midwest Bioethics Center

1100 Pennsylvania Avenue, Suite 4041
Kansas City, MO 64105
816-221-2002
end-of-life related ethical issues (DNRs, advance directives, withdrawal of treatment), speaker

National Association of People with AIDS

1413 K Street, NW
Washington, D.C. 20005
202-898-0414
patient support and information

National Family Caregivers Association

9621 East Bexhill Drive
Kensington, MD 20895-3104
301-942-6430
membership, caregiver support, speaker

National Health Council

1730 M Street, NW, Suite 500
Washington, D.C. 20036-4505
202-785-3910
referrals to voluntary health agencies, patient rights and responsibilities, speaker

National Hospice Organization

1901 N. Moore Street, Suite 901
Arlington, VA 22209
1-800-658-8898
referrals to local hospices

Websites

PBS - "Before I Die: Medical Care and Personal Choices"

<http://www.pbs.org/bid> OR
<http://www.wnet.org/bid>

The Robert Wood Johnson Foundation

<http://www.rwjf.org> OR www.lastacts.org

Alzheimer's Association

<http://www.alz.org>

American Association of Retired Persons

<http://www.aarp.org>

American Cancer Society

<http://www.cancer.org>

American Diabetes Association

<http://www.diabetes.org>

American Medical Association

<http://www.ama-assn.org>

American Red Cross

<http://www.corpweb.redcross.org/>

Amyotrophic Lateral Sclerosis Association

<http://www.alsa.org>

Choice In Dying

<http://www.choices.org>

Hospice Foundation of America

<http://www.hospicefoundation.org>

National Coalition of Hispanic Health and Human Service Organizations

<http://www.cossmho.org>

National Family Caregivers Association

<http://www.ravens-nest.com/nfca>

National Hospice Organization

<http://www.nho.org>

To order the special segmented edition of **Before I Die: Medical Care and Personal Choices** please contact:

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Barksdale Ballard & Co.
8027 Leesburg Pike, Suite 200
Vienna, VA 22182
Telephone (703) 827-8771
Fax (703) 827-0783

Glossary

Advance Directive

A document in which you:

1. Name someone to make health care decisions for you if you cannot make them for yourself, and
2. Write down the medical care you would or would not want in the future, based on your beliefs and what is important to you.

Advocate/Proxy

A written document in which the individual appoints an agent such as a Medical Care Proxy close relative or friend to act as a decision maker for the medical care in the event that the person is unable or unwilling to make and/or communicate decisions.

The individual may also give specific instructions to the advocate/proxy concerning the decisions that he/she may make.

DNR (Do Not Resuscitate) Order

A document that instructs medical personnel to forgo cardiopulmonary resuscitation if a patient's heart stops beating.

Euthanasia

The act of killing a person painlessly to relieve suffering. Euthanasia is against the law in most Western countries. Euthanasia is distinct from nonintervention, which is the physician's recognition that, if a patient has an advanced or incurable disease, he or she has a right to refuse medical treatment that would simply prolong the process of dying.

Hospice

When cure is no longer possible, hospice provides state-of-the-art comfort by combining the best in medical, nursing, emotional, and spiritual care in the home, a hospital or hospice facility. At the center of hospice philosophy is respect for the decisions of patients.

Informed Consent

Whether the medical treatment is surgery, drugs, dialysis, ventilator support or tube feeding, consent for the procedure must be given before it begins by the patient or his/her guardian or proxy. Once given, this consent can be withdrawn at any time, whether or not the patient is terminally ill and whether or not the treatment is necessary for the patient's survival.

Living Will

A written declaration, signed by an adult person of sound mind, that instructs his or her physicians to withhold or withdraw life-sustaining treatment if the person suffers from an incurable and terminal condition. Although the terms and provisions of the laws vary from state to state, in general they require the physician and the hospital to honor the patient's living will or to transfer the care of the patient to another physician who will honor the living will. The law also provides legal immunity from liability for the physician and the hospital honoring the patient's wishes expressed in his or her living will.

Medicaid

A federal program that provides funds to support state programs of medical assistance to people receiving or eligible for welfare. Medicaid eligibility and benefits vary from state to state.

Medicare

A federal program that provides basic health insurance for Americans age 65 and over and for some younger disabled persons.

Palliative Care

Therapy or care that relieves the symptoms of a disorder but does not cure it. Patients will receive necessary medication and medical procedures to provide hygiene, comfort care and alleviate pain.

Physician-Assisted Suicide

When the physician has an active role in ending the life of the patient. Such as writing a prescription or injecting drugs. It is not the same as the constitutional and common law right of all patients to refuse any medical treatment if they are able to make such a decision on their own.

Prognosis

A medical assessment of the likely course and outcome of a disease.

Viatical

The proceeds from the sale of a life insurance policy to a third party by a settlement to a terminally ill individual. The money can then be used to pay for living expenses and care at the end of life.