Talking About Your Choices
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*The Robert Wood Johnson Foundation*

**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 directive” is a general term that describes two types of legal documents that “speak” for you in the event of incapacity:

- A living will allows you to document your wishes concerning medical treatments at the end of life.
- 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.

**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**
**AIDS Hotline**
1-800-342-AIDS (2437)
Operated by the Centers for Disease Control and Prevention. Provides general information about AIDS and HIV, as well as referrals to HIV testing facilities, medical services, counseling, and support groups. There is someone available to answer calls 24 hours a day and they maintain a national database of AIDS resources.

**ALS Association**
2101 Ventura Boulevard
Suite 321
Woodland, CA 91364
1-800-782-4747
Provides information and educational materials about ALS (Lou Gehrig’s Disease). They will provide referrals to physicians, support groups, and drug trials.

**Alzheimer’s Disease and Related Disorders Association**
919 N. Michigan Avenue
Suite 100
Chicago, IL 60611
1-800-272-3900
Provides general information on the disease and referrals to over 200 local association chapters for specific services.

**American Academy of Hospice and Palliative Medicine**
11250 Roger Bacon Drive, Suite 8
Reston, VA 20190-5202
703-787-7718
Fax: 703-435-5490
aahpm@aahpm.org
http://www.aahpm.org
Can provide referrals in many parts of the country to physicians who specialize in palliative care. Can also direct professionals to training programs for palliative care.

**American Association of Retired Persons**
601 E Street NW
Washington, DC 20049
1-800-424-3410
or 202-434-2277
Provides a wide range of services including counseling, advocacy, benefits, and entitlement information; activities and assistance to people who are homebound.

**American Pain Society**
5700 Old Orchard Road
First Floor Skokie,
IL 60077
847-375-4715
Association of pain physicians. Provides referrals to pain facilities, physicians, and support groups.

Cancer Care,
Inc. 1180 Avenue of the Americas
New York, NY
10036
1-800-813-HOPE (4673)
In New York, 212-302-2400
cancercare@aol.com
http://www.cancercareinc.org
Provides support groups, educational programs, and workshops for cancer patients and their families. They operate a national referral service, and counselors on staff provide assistance to callers. Cancer Care also publishes Helping Hand, a useful resource guide for cancer patients and others.

Cancer Information Service
1-800-4-CANCER (422-6237)
Has 19 offices across the country. Answers any question related to cancer and Cancer treatment. Provides referrals to hospice, home care, and support groups.

Genetic Alliance
(formerly The Alliance of Genetic Support Groups)
4301 Connecticut Avenue,
NW Suite 404 Washington, DC
20008
1-800-338-GENE (4363)
or 202-966-5557
Fax: 202-966-8553
info@geneticalliance.org
http://www.geneticalliance.org
A nonprofit coalition of support groups, consumers, and professionals dedicated to promoting the common interests of children and adults with, or at risk for, genetic disorders. Specializes in linking people interested in genetic conditions with organizations that can provide support and information.

Partnership for Caring:
America’s Voices for the Dying
National Office 1035 30th Street,
NW Washington, DC 20007
1-800-989-9455
Fax: 202-338-0242
pfc@partnershipforcaring.org
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.

**Hospicelink**  
1-800-331-1620  
Provides general information on hospice care and referrals to hospices across the country.

**National Hospice and Palliative Care Organization**  
1901 N. Moore Street, Suite 901  
Arlington, VA 22209  
1-800-658-8898 (hospice referral)  
703-243-5900 (other questions)  
[http://www.nho.org](http://www.nho.org)  
Offers information, patient advocacy, professional education, and referrals to hospice programs throughout the country.

**National Self-Help Clearinghouse**  
25 W. 43rd Street,  
Room 620 New York,  
NY 10036  
212-642-2944  
[www.selfhelpweb.org](http://www.selfhelpweb.org)  
Part of a country wide affiliation of clearinghouses. Provides referrals to self-help organizations; mutual-support groups; and other national, state, local and community resources.

**Visiting Nurse Association of America**  
11 Beacon Street,  
Suite 910 Boston,  
MA 02108  
1-888-866-8773 or  
617-523-4042  
Fax: 617-227-4843  
Provides referrals to visiting nurse agencies nationwide and supports visiting nurse agencies in their commitment to provide the most effective, innovative, and personalized community-based care.

**Call Partnership for Caring: America's Voices for the Dying**  
We have trained counselors who can help you navigate the health care system and sort through the information you are receiving from health care providers about end-of-life treatment decisions. If you hear something that is confusing or that just doesn’t seem right, call Partnership for Caring at (800) 989-9455. We can help you understand the issues important to your situation.