

Booklets in the Complete Life series were developed under grant #90-CG-2548 from the National Family Caregiver Support Program, U.S. Administration on Aging.

*True love is not a feeling
by which we are overwhelmed.
It is a committed,
thoughtful decision.*

—M. Scott Peck

ADVANCE CARE PLANNING



Making Choices Known

© 2002, 2004 Center on Aging
John A. Burns School of Medicine
University of Hawaii
www.hawaii.edu/aging

THE COMPLETE LIFE SERIES

Advance Care Planning: Making Choices Known is the first in a series of five booklets on end-of-life planning and care. The booklets in the Complete Life series are:

Booklet 1 - Advance Care Planning: Making Choices Known. *A workbook to document the kind of care you want if you are unable to make decisions for yourself. Includes web addresses to find your state's forms.*

Booklet 2 - Planning Ahead: Funeral and Memorial Services. *A workbook to document your funeral or memorial service preferences ahead of time. Includes tips for consumers.*

Booklet 3 - Preparing to Say Good-bye: Care for the Dying. *Learn about common symptoms experienced by dying people and what you can do to make the dying person more comfortable.*

Booklet 4 - When Death Occurs: What to Do When a Loved One Dies. *A guide to help you get through the hours, days, and weeks following a loved one's death.*

Booklet 5 - Help for the Bereaved: The Healing Journey. *Learn about the common expressions of grief, the healing process, and when to get help.*

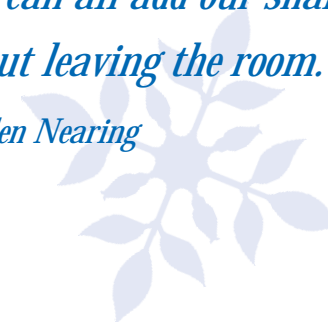
All five booklets can be downloaded from www.hawaii.edu/aging

TABLE OF CONTENTS

Your advance directive for health care.....	5
Benefits of advance directives	6
Talking about it.....	7
Understanding life-sustaining treatments.....	9
Documenting your wishes	12
Checklist	17

*Everyone can love in the place
where they are. We can all add our share
of love without leaving the room.*

-Helen Nearing



ADVANCE CARE PLANNING

We like to think that we will always be healthy and able to make decisions for ourselves. But if you develop a sudden illness or serious condition or are involved in an accident, you might not be able to make decisions for yourself.

Making your wishes known while you are still healthy is a good idea. Sharing your healthcare decisions with others is the best way to make sure they are respected.

Your family and loved ones will benefit from your advance planning. Knowing your wishes will help ease their burden and reduce their uncertainty if they ever have to make medical decisions on your behalf.

In this booklet, you will learn about the types of decisions you can make ahead of time and how to let others know what you want.



*Plans are useless,
but planning is invaluable.*

–Winston Churchill



YOUR ADVANCE DIRECTIVE FOR HEALTH CARE


An advance directive is a written or spoken statement about your future medical care. The advance directive lets your doctor, family, and others know how you want to be treated if you are unable to tell them. The two main types of advance directives are the "Living Will" and the "Power of Attorney for Health Care."


Planning in advance for health care decisions is the best way to make sure your voice is heard and your wishes are respected.


In your advance directive you may share your wishes about:

- The kind of medical treatment you want or don't want
- The person you want to make health care decisions for you when you can not
- What you wish to have for comfort care (care that focuses on reducing pain and suffering when a cure is no longer possible)
- Ethical, religious, and spiritual instructions
- Anything else about your health care preferences that you want your loved ones and your health care providers to know

BENEFITS OF ADVANCE DIRECTIVES


 **They Help People Know What to Do.** Your written advance directive is a gift to your family and friends. By documenting your wishes, others won't have to guess what you want if you can no longer speak for yourself. If your family has to guess, they may disagree and argue. That makes it hard for the doctor to honor your wishes. An advance directive is the best way to make sure that your wishes are carried out. Even if you currently have a living will, new laws enacted in your state may be more comprehensive and may give you more choices.

 **Health Care Decisions Will Not Be Left to Chance.** You make choices every day about your work, your home, and your life. Why leave health care decisions to chance? Now is the time to decide about the kind of care you want. Now is the time to share your thoughts.

 **They Let Others Know Your Values.** Advanced technology makes it possible for patients with little or no hope of recovery to be kept alive for months or even years. This makes it even more important for you to think and talk about what kind of care you would want if you were unable to make your own decisions.




TALKING ABOUT IT

 **Talking Now Is a Gift You Give to Those Close to You.** In the event you become so ill that you can no longer speak for yourself, advance planning will help those close to you make the decisions you would want. Surviving family members of people who died without advance directives tell us that they struggled over their decisions and always wondered if they did the right thing.


Destiny is not a matter or chance, it is a matter of choice. It is not a thing to be waited for, it is a thing to be achieved.

–William Jennings Bryan

 **Use an Example of Someone You Know.** Many people, including some doctors, are uncomfortable talking about care at the end of life. You can start the discussion by talking about someone else's experience. For example, you could ask:

- Do you remember when our neighbor was in the hospital before she died? What did you think about the treatment she received?

Then describe what you would want if you were ever in this condition. Or ask your family members what they would want. Enlist the help of your family or loved ones in making sure that, if this happens to you, they will respect your wishes. It also is important to discuss your concerns and wishes with your doctor.

 **Getting Help.** Sometimes you may need the help of a friend, counselor, social worker, or clergy person to start talking with your family about the end of life. There are people from all walks of life and religious groups who have the experience to help.

Let your heart find a voice.

Celebrate life with those you love.

UNDERSTANDING LIFE-SUSTAINING TREATMENTS


The following are examples of some of the common medical treatments used to extend or sustain life in terminal conditions. It is good to become familiar with them, as you may be asked to consider them for yourself or a loved one.


Always discuss the risks and benefits of all surgeries and other medical treatment decisions with your doctor.

Nutrition (Food) and Hydration (Fluids).

Advance directives commonly include instructions to carry out or to stop life-sustaining treatments such as artificial nutrition (food) and hydration (fluids). People in a terminal condition will generally receive artificial nutrition and hydration, unless they have stated their wishes against this means of prolonging life.

Forcing food when a person is dying and not hungry can increase pain, cause the person to choke (aspirate), and worsen the condition. Forcing fluids may also aggravate the situation. Even intravenous feeding (IVs) at this time can cause complications, such as swelling and congestive heart failure.

 **Blood Transfusion.** This includes whole blood or blood products. Some people do not want whole blood, but will accept plasma. There comes a point at which blood transfusions no longer improve the quality of the terminally ill person's life.

 **Surgery.** Before a surgery is considered, you should understand the risks and benefits of the surgery. Will it provide comfort and relieve suffering, or merely extend life? In terminal conditions, some surgical procedures are performed to reduce pain and increase comfort and are not meant to be curative. Are there other, less invasive procedures that can increase comfort and reduce pain?

Cardiopulmonary Resuscitation (CPR).

Normally, when someone suffers a heart attack, also known as a cardiac arrest, a "code" is called and cardiopulmonary resuscitation (CPR) is initiated. An attempt is made to "jump-start" the heart with an electrical impulse, and manual compressions are applied to the chest in an effort to restore the heart to its normal rhythm. In specific medical crises, CPR can help to save a person's life. However, in persons with terminal or life-limiting illnesses, CPR is rarely helpful. In a hospital or health care facility, unless there is a written order NOT to resuscitate, CPR will be given. If cardiac arrest occurs and 911 is called, CPR will always be initiated unless the person is terminally ill and wearing a "comfort care only" bracelet or necklace ordered by a doctor. Comfort Care bracelets or necklaces, however, may not be available in all states. Those who receive CPR are often put on mechanical ventilators, or breathing machines.

Mechanical Ventilation. When people can no longer breathe on their own and wish to have their lives prolonged, they are “vented” or placed on mechanical ventilators. These are machines that breathe for them, forcing air into the lungs.

In emergency situations, such as cardiac arrest, mechanical ventilation is common. Persons who are “brain dead” can no longer breathe on their own, and they can be kept physically alive only through mechanical ventilation. Once it has begun, withdrawing mechanical ventilation is usually a difficult decision for family members, as they may feel responsible for the death. Be assured that the dying process that began before mechanical ventilation is now being allowed to take its natural course.

Antibiotics. Antibiotics have become a cornerstone of modern medicine. They are commonly given to treat many different infections. However, the use of antibiotics should be carefully considered in terminal conditions. For example, pneumonia used to be called “the old person’s friend.” Today, it can be effectively treated. But if a person is close to death, is the use of antibiotics the best thing to do? For persons nearing the end of life, symptoms of an infection may be effectively managed without the use of antibiotics.

DOCUMENTING YOUR WISHES

Think about the kind of care you would want (or not want) if you were seriously ill, and talk about it with your loved ones and your health care provider.

Even though oral (spoken) instructions regarding your health care are considered legal, it is best to write down your wishes in an advance directive.

In the U.S., every state has a law about how advance directives can be completed. These laws also require doctors and health care facilities to honor advance directives.

Advance directive forms often are available from your health care provider or local legal aid society. Advance directive forms are also available on the Internet.

State-specific forms may be downloaded from www.partnershipforcaring.org (1-800-989-9455).



Most advance directives allow you to document your answers to these questions:

1. What kind of care do I want if I can no longer make decisions for myself and I have little or no chance of recovery?

You can specify whether or not you want your life prolonged indefinitely, if you want to be fed through tubes if you can not feed yourself, and if you want treatment for pain. This information can be documented on a "living will," also called a health care directive.

A. CHOICE TO PROLONG OR NOT TO PROLONG LIFE

___ YES, I do want to have my life prolonged as long as possible within the limits of generally accepted health care standards that apply to my condition.

OR

___ NO, I do not want my life prolonged.

B. ARTIFICIAL NUTRITION AND HYDRATION

(FOOD AND FLUIDS) BY TUBE INTO STOMACH OR VEIN

___ YES, I do want artificial nutrition and hydration.

OR

___ NO, I do not want artificial nutrition and hydration.

C. RELIEF FROM PAIN

___ YES, I do want treatment to relieve my pain or discomfort, even if it hastens my death.

OR

___ NO, I do not want treatment to relieve my pain or discomfort.

2. Who will make decisions for me if I can't make them for myself?

You can specify someone as your "agent" to make health care decisions for you if you are unable. This type of directive is called a "Power of Attorney for Health Care" in most states. Your agent can be your spouse, an adult child, a friend, or any other trusted person but can not be an employee of a health care facility where you are receiving care (unless related to you by blood or marriage).

People who could serve as my agent are:

Name	Relationship
------	--------------

Name	Relationship
------	--------------

Name	Relationship
------	--------------

3. Do I want to donate my organs or tissues after my death?

Anyone over the age of 18 can become an organ and tissue donor. Those under 18 years of age need parental consent. Donor cards and additional information may be obtained from www.organdonor.gov or by calling 1-800-DONORS-1.

Most states allow you to indicate on your driver's license if you are an organ donor. Some states also allow you to indicate your decision in your advance directive. Find out more at www.donatelife.net.

SAMPLE FAMILY NOTIFICATION CARD

I would like to become an organ and tissue donor.
I want you to know my decision now because you will be consulted before donation can take place.

I wish to donate the following:

Any needed organs and tissues

Only the following organs and tissues:

Signature: _____

4. Do I want to donate my body to medical science?

Some states allow you to donate your body to medical science. For rules about body donation in your state, visit www.med.ufl.edu/anatbd/usprograms.html

5. Does my advance directive need to be notarized?

Your state may require that your advance directive be witnessed or notarized. The witnesses can not be the same people listed as your agent(s). One of them can not be related to you by blood, marriage, or adoption.

People who could witness my advance directive are:

Name Relationship

Name Relationship

Once you have completed your advance directive, give copies to your family members, your doctor, and your clergy person or temple leader. Bring a copy with you if you are hospitalized. Do not leave copies in a safe deposit box where they will be found too late to do any good.

People I will give my advance directive to are:

Family members: _____

Physician: _____

Lawyer: _____

Church/Temple: _____

CHECKLIST

- Talk with your spouse, adult children, family, friends, spiritual advisors, and doctors** about the type of care that is important to you.
- Ask someone you trust to be your health care agent.** Discuss your wishes with this person.
- Complete an advance directive.** State-specific advance directive documents and instructions may be downloaded free of charge by visiting www.partnershipforcaring.org/. A printed set of documents may be ordered for \$10.00 by calling 1-800-989-9455.
- Finalize your advance directive.** You must comply with your state's witness and signature requirements. All states require you to date your advance directive. All states require that your signature be witnessed by at least one adult not related by blood, marriage, or adoption. Some states require two witnesses. Advance directives may also be notarized. Most states give you the right to revoke or change your advance directive at any time, orally or in writing.
- Tell your family, friends, and doctors that you have an advance directive.** Keep them informed about your current wishes.
- Give copies of the advance directive** to your doctors to put in your medical record. Also, give copies to your family, close friends, spiritual advisors, and other individuals who might be involved in your care.
- Review your advance directive regularly.** It is a good idea to review your advance directive each year, as your situation may change. When you update your advance directive, the old one is no longer valid. Let people know if you change your wishes. Make sure your doctor puts the new document in your medical record.
- Keep a copy in an easy-to-find place in your home.** Do not put it in a safe deposit box. Let others know where it is.
- Carry your organ donor card, or indicate on your driver's license that you are an organ donor.** Donor cards may be obtained by visiting www.organdonor.gov or by calling 1-800-DONORS-1.
- If you wish to donate your body to medical science,** tell your family and fill out the necessary documents ahead of time.