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Talking to Your Family and Doctor About
DIFFICULT HEALTH CARE DECISIONS



OREGON STATE UNIVERSITY EXTENSION SERVICE

EC 1386
October 1991

Jan Hare, Extension family life specialist, Department
of Human Development and Family Sciences, Oregon
State University.

This publication was partially supported by a grant
from Oregon State University Research Council,
NIH Biomedical Research RR07079.

Talking to Your Family and Doctor About **DIFFICULT HEALTH CARE DECISIONS**

No adult is too young or old to think about the difficult medical decisions required when a serious illness or injury occurs. This publication is designed to help you discuss your thoughts and feelings about these important issues with your family and doctor.

Hospitals and nursing home professionals know how important it is that people begin to talk about what they might want in case of a health crisis. Most health care facilities that receive Medicare or Medicaid funds are now required to advise adult patients of their rights under state law to document their wishes concerning health care. This means that if you are admitted to a hospital or nursing home, someone will ask you if you have completed an “advance directive.” Advance directive refers to a formal plan for end-of-life medical decisions such as a Power of Attorney for Health Care or a Living Will. Although you are not required to complete an advance directive you must be advised of your right to do so. If you would like more information about advance directives, see “For More Information” on page 14.

In this publication the word *family* is used broadly to mean those people who share deep and personal connections with you. Sometimes those who know you best are

not related by blood or marriage. These are the people who receive and provide support especially in times of need.

Try To Imagine How You'd Feel If...

You have advanced cancer that is not responding to treatment. Because the cancer has made you weak and sometimes confused, you are no longer able to make decisions for yourself. Your family is asked if you should be resuscitated if your heart should stop.

You are 89 years old and in the late stages of Alzheimer's disease. You now have pneumonia. Your grown children are asked if antibiotics should be given to treat the pneumonia or only medications to keep you comfortable while you die.

You were in a car accident several years ago and have been in a coma ever since. The doctors say you will almost surely never again be aware of your surroundings. A feeding tube that provides food and water could help keep you alive for many more years. Your family must decide whether the feeding tube should be continued.

Medical machines and procedures generally help people stay alive while treatment is given a chance to work. In such cases, this technology helps restore people to health so they can live long and happy lives. Sometimes, however, technology simply postpones death. It is important to think about how much suffering the treatment imposes as opposed to how much good is achieved. These are difficult decisions, especially when the person who is ill is unable to help make the decision. The family is often asked what the patient would want. Many families must face these treatment decisions in ignorance and uncertainty about their loved one's wishes.



What If You Could Not Make Decisions for Yourself?

If you cannot speak for yourself, someone else must make decisions for you. The person speaking on your behalf is acting as your *proxy*. The job of a proxy is to provide *substituted judgement* by figuratively standing in your shoes and deciding as you would decide for yourself.

Recent studies show that proxies who are family members are correct about the

patient's preferences only about 70 percent of the time and that doctors are even less aware of the patient's wishes.

It's not surprising that families are often not aware of your wishes since most families rarely talk about these issues. It's not easy or comfortable to talk about illness, death, or losing somebody you love. Your family needs your help to make appropriate decisions on your behalf. Nobody knows better than you how you want to be cared for if you are not able to recover from a serious illness or injury.

Most people say they want a family member to make decisions for them if they cannot speak for themselves. Few people want their doctors to make these decisions.

Who would you want to be your proxy decision-maker?

Tell your family what you think.

Life-Sustaining Procedures

The most difficult medical decisions faced by families are about the use of life-sustaining procedures. Following is a description of the most common procedures.

Respirator

A respirator is also known as a ventilator or a breathing machine. It can either totally or partially take over breathing if you are unable to breathe well enough on your own. A tube is placed down the throat and into the windpipe. The tube is usually as big around as your little finger. To ease discomfort, medication is sometimes used to relax the muscles or for general sedation. This may make you feel more comfortable and help the respirator work better.

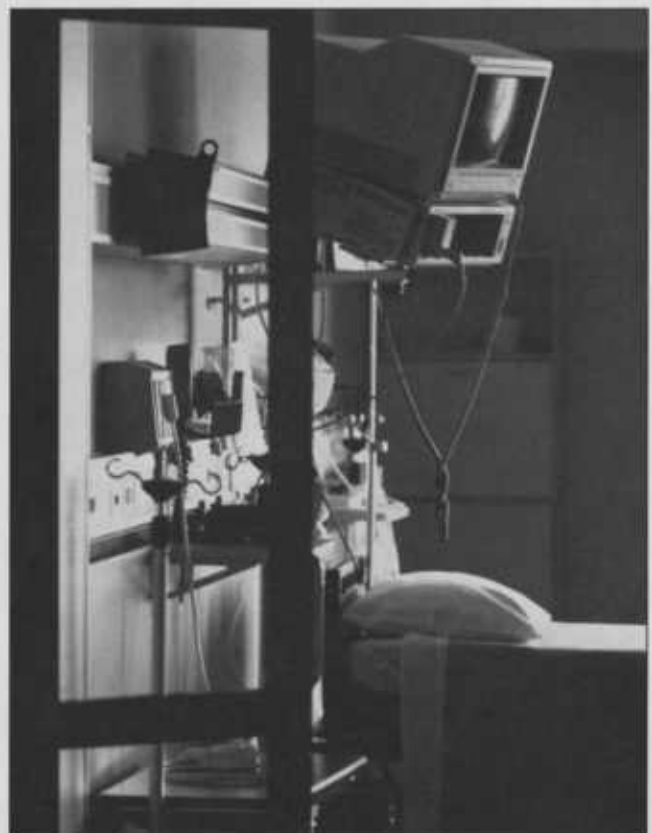
It isn't possible to talk or eat while on a respirator so artificial feeding is often needed. Tape attaches the breathing tube to the upper lip and around the head. Another small tube is used to suction out fluid that may accumulate in the lungs.

Artificial Feeding

A person who cannot eat is usually fed using a nasogastric (NG) tube. This tube is placed down the nose and through the esophagus into the stomach. It is smaller than a respirator tube. Although it is possible to talk, the tube in the throat can make talking and swallowing uncomfortable. High calorie liquid foods are delivered through the tube. Other types of artificial feeding methods include IVs (intravenous tubes) or a tube placed through the belly wall into the stomach.

Cardiopulmonary Resuscitation (CPR)

If your heart or breathing stops while in the hospital, an emergency team begins CPR to start your heart and lungs. CPR is tried unless you and your doctor have previously given orders not to have this done.



For CPR, a crash cart with equipment and drugs to revive the heart and lungs is quickly brought into the room. Paddles that supply electric current through the chest to the heart and intravenous medications may be used to start the heart beating again. If this does not work, the emergency team starts pumping on the chest and using artificial respiration. The forceful pumping may cause pain later. Attempts to revive the heart continue until the heart starts beating again or the doctor believes additional effort is useless.

Sometimes CPR can last over an hour. The longer CPR is given, the less likely it will be successful. It is possible for very ill patients to have CPR administered several times in one day. After the heart starts beating again, patients often need to be on a respirator for a few hours or days.

Antibiotics

Serious infections, such as some kinds of pneumonia, are sometimes referred to as "the old person's friend." Untreated, they can bring a fairly comfortable death within a short time. Massive doses of antibiotics can cure a serious infection, but the underlying health problems are not affected. Discomfort resulting from a serious infection may be eased by a cooling blanket for fever, oxygen for shortness of breath and medications for fever or pain.

Dialysis

If your kidneys fail or function poorly, your doctor may recommend dialysis. Dialysis consists of inserting large IVs, usually into the arm or groin, and attaching them to a portable machine that cleanses the blood of toxins and removes excess fluid the kidneys are not able to flush.

This is a procedure that can be either short- or long-term. While dialysis does not cure the underlying condition, it can assume kidney function for the body while the kidneys have time to recover. If kidney function returns, dialysis can be discontinued. If the kidneys do not recover, the patient may always need to rely on dialysis. Dialysis generally takes two or three hours and may be needed three times a week or as often as every day.



Treatment Questions to Ask Yourself

1. Are there some basic functions which you believe that you must have in order to feel that you would want to continue to live? (For example, to be able to recognize your loved ones or to respond to others.)
2. Do you have certain spiritual or religious beliefs that affect your attitudes toward a terminal illness, treatment decisions, or death and dying? (For example, some people believe that life-sustaining treatment should never be withdrawn. Others believe that when there is no hope of recovery, death should be allowed to occur.)
3. Are there specific kinds of life-sustaining treatment you would want to have if you were diagnosed with a terminal condition? (For example, some people feel that if they could not eat or drink, they would want a feeding tube under all circumstances.
- Other people say they would want it tried for a short period of time.)
4. Are there specific kinds of life-sustaining treatment you would not want to have if you were diagnosed with a terminal condition? (Unlike the example above, other people would choose to forego a feeding tube if they could not eat or drink.)
5. Is there a particular doctor you want to help your family make decisions about your care?
6. Is there a particular person you want as your proxy for decision making? (A proxy cannot be your doctor or nurse.)
7. Is there anyone you do not want involved in your health care decisions? (For example, specific family members, friends, or professionals?)
8. If given a choice, where would you prefer to die? (For example, home, the hospital, a nursing home?)

Talking With Others About Medical Decisions

Talking about the possibility of losing your health is never easy. Because it can be so uncomfortable, some people make broad statements like:

- If I get too sick to take care of myself, then just take me behind the barn and shoot me.
- I don't want to live like a vegetable.
- No heroics.

Statements like these do not really help your family or doctor know your feelings about specific treatments and procedures if you were in a terminal condition. For example, would you want CPR, tube feedings, or antibiotics. Even you may find it difficult to know what you would want without actually being in the situation. How, then, can you help your family understand your preferences?

Although you might not be able to give them the exact answer to specific treatment decisions, it is possible for you to talk generally about your values, beliefs, and wishes.

Such knowledge could help guide decisions your family might someday need to make. Think through your answers to the questions in the box on page 7.

Beginning the Conversation

Sometimes when a person tries to initiate a serious conversation about health care decisions, other people become afraid. For example, if an older parent starts such a conversation, the adult son or daughter might say, "Oh Mom, we don't need to talk about this. You're going to outlive us all."

It's important to begin your conversation in a way that lets other people know that you want to be taken seriously. Perhaps you could start by saying something like, "I want to talk to you about something that is important to me. I hope you will be able to listen."

If you know of a specific situation you can discuss, such as a friend who was terminally ill, you might talk about what you would have wanted if you had been that person. For example, "Remember what happened to Mary after her third stroke. If that ever happens to me, I would want . . ."

When there is a health crisis in a family, communication with the nurses and doctors can become complicated and confusing. It's helpful to have a specific family member who is responsible for most of the communication with the medical team. This can prevent serious miscommunication. Talk to the person you think would best know your wishes. Ask the person to be your proxy. It

is a good idea to name an alternate person in case the first is unable to be your proxy. It is critical that you designate your legal proxy for health care decisions in writing. You can do this by completing a Power of Attorney for Health Care document, available from your doctor or local hospital. (Refer to OSU Extension Circular 1375 *Planning in Advance for Health Care Decisions* for further information.)

After you have chosen a proxy, talk with your family about your wishes and tell them whom you have chosen as your proxy. Explain that this is the person you want to be responsible for helping the medical team understand your wishes regarding terminal care. If you express your feelings to all members of your family, conflict will be less likely to arise later.

Consider making a video or audio tape in which you talk about your feelings concerning end-of-life health care. If you are not comfortable making a tape, write a personal letter addressed to your family and friends. Tangible expressions of your wishes are comforting to families during times of crisis.

What If You Don't Have a Close Family Member or Friend?

You may feel that you have no one close enough to make decisions for you, or perhaps you have outlived the most important people in your life.

If this is the case, think carefully about those around you. Is there a neighbor, a clergy member, or a distant relative you



could ask to be a proxy for you? Because you may not know this person well, you must express your wishes carefully. It is particularly important to document your wishes in writing or record them on tape.

It is possible to designate a public guardian or conservator to serve as your health care proxy. Some people choose to have

their attorney serve as their guardian when they can no longer make decisions. Should the need arise, designate in advance whom you want the court to appoint as your guardian or conservator. There are expenses associated with a professional conservator. Ask your attorney for more information.

Talking To Your Doctor

In addition to family, it is crucial that you talk to your doctor about your feelings concerning life support in the event of a terminal illness or injury. Because of the numerous medical specialties, many people no longer have just one doctor. Your primary care doctor is the one who provides most of your medical care and your routine checkups and is the one you should speak to about these issues.

It is a good idea to make a special appointment with your doctor to discuss your wishes concerning medical treatment if you should become seriously ill. When you call for an appointment, simply say that you want to have a consultation with your doctor about advance directives. You can have a general conversation with your

doctor about your values concerning end-of-life medical treatments or your doctor may be able to anticipate what treatment decisions might arise based on your particular medical history. It is probably a good idea to go over the Power of Attorney for Health Care and Living Will document before this appointment and talk to your doctor about how you would like to fill it out.

As well as requesting reasonable medical treatment, you have a right to decide against medical treatment. Your doctor will be able to tell you whether or not your wishes are medically reasonable. For example, to ask for a liver transplant because you have a malignant tumor in your liver is not medically reasonable; or to ask your doctor to provide you with a lethal dose of morphine is not legal.



Good Samaritan Hospital Ethics Committee, Corvallis, OR.

It is also important to talk with your doctor because your values could be in conflict. For example, you might not want to have tube feedings (a medically reasonable request), if you were in a terminal condition. Your doctor, on the other hand, may have personal beliefs that would prevent her or him from withholding or withdrawing tube feedings. In that case, your doctor must refer you to another doctor who would be able to honor your wishes.

Remember that no matter what your medical condition, health care professionals will always do their best to keep you comfortable.

Ethics Committees Can Help Resolve Conflicts

Most hospitals and nursing homes have an Ethics Committee which offers help to patients, families, and staff. Occasionally there is disagreement inside a family or conflict between a family and medical team about a patient's care. In such cases, it is wise to ask for help from an Ethics Committee.

An ethics committee is composed of different people from the hospital or nursing home and the community. Each has experience in helping to think through difficult medical situations.

You have the right to ask the Ethics Committee for an opinion about your case or the case of a family member. To do this, ask the

staff member responsible for your care how to contact the ethics committee. In reviewing a case, the committee usually talks to the patient (if possible), family members, and the staff who are providing care for the patient.

Cases involving end-of-life treatment issues are not the only concern of the Ethics Committee. The committee can also consider cases such as:

- ❑ A depressed woman has lost her best friend and now refuses to eat.
- ❑ A nursing home resident wants to visit friends outside the facility each day and wants meals served at odd times.
- ❑ Two residents in a nursing home have fallen in love and wish to room together. The family of one of the residents objects.

The patient, family, or doctors are not obligated to follow the advice of the Committee. However, the most helpful part of an Ethics Committee consultation can be that it improves communication among involved persons. Consequently, decisions can be made more easily.

Planning in advance for a health crisis helps you control circumstances that might otherwise be out of your control. In addition, you will be giving your family the guidance they need to get through a difficult time.

Keep in Mind

- No adult is too young or old to plan for future health care.
- Health care decisions are based primarily upon your personal values and beliefs.
- You are the best decision-maker for these issues.
- No time is better for planning than the present.

What to Do

1. Select one or two proxies who are willing to base decisions upon what you would choose for yourself.
2. Sign a Power of Attorney for Health Care which names your proxy decision-makers. Give copies to the proxies, your doctor, and keep a copy in an easy to find place, like your desk drawer.
3. Tell your family whom you have chosen as your primary and alternate proxy.
4. Become familiar with life-sustaining procedures and the circumstances you would and would not want them used.
5. Make an appointment with your doctor to discuss your preferences for end-of-life health care.
6. Explain your preferences in a letter or on an audio or video tape. Give copies to the following people:
 - your primary and alternate proxies
 - your doctor
 - close family members

Remember that the choices are yours when you plan ahead.

Definition of Terms

Advance directives

Legal documents that help people retain control over their health care decisions when they are no longer able to speak for themselves. A Living Will and Power of Attorney for Health Care are the most common examples.

Competency

You are considered medically competent to make a treatment decision if you understand information about the medical problem and the consequences of treatment and no treatment.

Power of Attorney for Health Care

A legal document that appoints another person to make health-related decisions for you in case you are unable to make them for yourself. This is not the same as a simple Power of Attorney although the same person could have both jobs.

Guardianship

If you are declared incompetent to make your own decisions, the court can appoint a guardian to make a variety of decisions, including that of health care.

Life-prolonging treatment

Treatment that is likely only to prolong the natural process of dying when there is no significant hope of recovery. Examples could include resuscitation or artificially administered nutrition.

Living will

Legal document on which you can state your wishes and instructions, about desired medical treatment in case of a terminal illness or irreversible injury, when you are not able to make medical decisions

Substituted judgement

Making treatment decisions for someone else based on what that person would want.

Proxy

A person legally named to make substituted judgements for another.

Chronic health problem

Usually a long term illness that worsens over time and is not reversible. Common examples are arthritis, diabetes, or many types of heart disease.

Terminal illness

A terminal condition is an incurable or irreversible condition for which medical treatment only prolongs the dying process.

Will

A legal document written to control what happens to your property and assets after you die, does not involve health care decisions.

For More Information

These resources may help you make decisions consistent with your beliefs. They provide specifics about advance directive documents and emphasize the importance of family communication about health care decisions.

Making Health Care Decisions: When You Can't Speak for Yourself, \$5.00
Oregon Health Decisions
Suite 723
921 SW Washington
Portland, OR 97205
1-800-422-4805

The Medical Directive, \$1.00
Harvard Medical School Health Letter
164 Longwood Avenue
4th Floor
Boston, MA. 02115

This publication uses four medical situations to allow you to think through and document the treatment you would want in each case. It guides you through the process of making decisions before completing an advance directive. While it has no legal power, it may be helpful to attach it to your advance directive document to further clarify your wishes.

Health Care Decision-Making for Oregon Families
This Oregon State University Extension program introduces the Oregon Power of Attorney for Health Care and the Living Will. The primary focus is on family communication about difficult health care decisions. Call your local county office of the OSU Extension Service and ask for the home economics agent. Offices are listed under county government in your telephone directory.

Taking Control of Life and Death Health Care Decisions, \$15.00
University of Minnesota
Distribution Center
3 Coffey Hall
1420 Eckles Avenue
St. Paul, MN 55108-1030

This is a University of Minnesota Extension Service self-study packet. It is designed to help people ask the right questions and think through the implications of the options. The self-study format allows people to work on their own or with others and at their own pace.

Concern for Dying
250 West 57th Street
New York, NY 10107
(212) 246-6962

This is an educational council created to improve the care of dying patients. It educates the general public and health care professionals about issues surrounding terminal care decision-making.

OSU Extension Service Publications

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Mail your order to Publications Orders, Agricultural Communications, Oregon State University, Administrative Services A422, Corvallis, OR 97331-2119.

- EC 1221, *Families and Aging: A Guide to Legal Concerns*, \$1.25
- EC 1243, *When Death Comes: Funerals & Alternative Arrangements*, \$1.25
- EC 1372, *Building Community Support for Families of People With AIDS*, 25¢
- EC 1375, *Planning in Advance for Health Care Decisions*, 25¢
- PNW 88, *Death—A Family Crisis*, 25¢
- PNW 196, *Growing Older: Sensory Changes*, \$1.00 (also available in Spanish as PNW 196-S, *Avanzando en Edad: Cambios Sensorios*, no charge)
- PNW 246, *Aging Parents: Helping When Health Fails*, 50¢
- PNW 314, *Helping Memory-Impaired Elders: A Guide for Caregivers*, 50¢
- PNW 315, *Coping with Caregiving: How to Manage Stress When Caring for Elderly Relatives*, 75¢
- PNW 318, *Living Arrangements in Later Life*, \$1.00
- PNW 342, *Alcohol Problems in Later Life*, 75¢
- PNW 344, *Helping Your Older Family Member Handle Finances*, 50¢
- PNW 345, *Financing Health Care in Later Life*, \$1.00
- PNW 347, *Depression in Later Life: Recognition and Treatment*, \$1.50



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