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Planning in Advance

FOR HEALTH CARE DECISIONS

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Imagine yourself seriously ill and unable to speak for yourself. Who would know what treatment choices you would make if you were able?

When is the last time you talked with your family about what you would want, or not want, if you were ever in a terminal or comatose condition? These conversations can be very difficult. When they do occur, they may include unclear statements such as "Don't ever let me live like a vegetable" or "I don't want to be hooked up to all kinds of machines. No heroics."

Unfortunately, statements such as these are not helpful when decisions must be made for someone in a terminal condition who is unable to speak for himself or herself (perhaps because of a coma or severe pain). For example, if you say that you don't want to be hooked up to machines, does that mean you don't want a respirator? Does it also mean you don't want to be fed artificially

by tube or to receive intravenous antibiotics? Medical technology is complicated. Therefore, in order to make your wishes clear, it's important for you to know as much as possible about different treatments often used in a terminal condition. Some ordinary treat-

ments such as antibiotic therapy may be considered "heroic measures" in certain situations.

Oregonians who are concerned with planning for future health care for possible events such as the two listed below have the "Advance Directive" document available to

What is a terminal condition?

Terminal condition means any condition of your health which is incurable or cannot be improved. Medical treatment for this type of condition would serve only to prolong the dying process. Imagine yourself in these situations:

- *You are 82 years old and have had a small stroke. You are in the hospital being treated by your family physician and you are expected to recover. However, on the third day of your hospitalization, you suffer a massive stroke which leaves you unconscious and in critical condition. Doctors agree it's unlikely you will regain consciousness. Your family is asked whether the doctors should try to resuscitate your heart should it stop. What should they do?*
- *You are 25 years old and have been hit by an automobile as you were crossing the street. You have severe brain damage and have been in a deep coma for 5 months. The doctors say your brain has almost no chance of recovery. Only the part of your brain which makes your heart beat and your lungs breathe is working. Yet, a feeding tube through your nose to your stomach may keep you alive for many more years. Should that feeding tube continue to be used or should it be withdrawn so that you are allowed to die?*

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them. You don't need to hire an attorney in order to complete this document.

A federal law took effect December 1991 which requires health care facilities (which receive Medicare or Medicaid funds) to advise all adult patients of their right to complete an Advance Directive document.

The Advance Directive

The purpose of the "Advance Directive" is to allow you to control important decisions about your health care if ever you are unable to speak for yourself. Completing the Advance Directive is your choice. You do not have to have such a form if you don't want one. The Advance Directive is a legal document that includes: "Appointment of a Health Care Representative" and "Health Care Instructions." You can fill out both parts or just one. Consider what each will allow you to do.

Appointing a health care representative

In this part, you may name a person to direct your health care when you cannot do so. This person is called your "health care representative." Your representative must agree to serve in this role for you and must sign the form. Your representative should be someone you trust and who knows you well. He or she should be able to make health care decisions for you based on your values and beliefs. In other words, your representative should be able to separate his or her own desires from what you would want to have done in a certain situation. This is called using substituted judgment. If your representative does not know your treatment preferences, then she or he should decide what is in your best interest.

It's important to talk with your representative about your wishes regarding health care treatments.

You can select any adult to be your representative, except: 1) your doctor, 2) an owner, operator, or employee of your health care facility, unless that person is related to you by blood, marriage, or adoption or that person was appointed before your admission into the facility. Your representative cannot act for you unless you become unable to make your own decisions. You also may choose an

It's a good idea to evaluate your document periodically to see if you would like to make any changes.

alternate representative. Divorce revokes the appointment of a spouse, unless you indicate in writing that you still want this person to continue to be your representative. Your representative does not have to pay your medical bills.

You must make two specific decisions about what your representative can do for you. The first is that you must indicate whether your representative can decide about life support for you. If you don't initial your consent in the space provided on the form, then your representative may not decide about life support. The second is that you must indicate whether your representative can decide about tube feeding. Tube feeding is food and water supplied artificially by a medical device. If you do not initiate your consent,

then your representative may not decide about tube feeding. You also may set any other limits you wish.

If you have initialed consent, your appointed representative can make decisions about life support if you are in one of four medical conditions: 1) terminal illness when death is imminent regardless of treatment; 2) permanent unconsciousness, including irreversible persistent vegetative state; 3) advanced progressive debilitating fatal illness where you have permanently lost the ability to interact with others (for example, late-stage Alzheimer's Disease); and 4) conditions where life support itself would cause extraordinary pain. No matter what choices you make, you will always receive care for your comfort and cleanliness.

Health care instructions

In this part of the Advance Directive, you may give instructions for health care providers to follow if you are unable to direct your care. The form gives you an opportunity to give very specific instructions about each of the four medical conditions described earlier or to give one general instruction.

Witnessing the document

Your Advance Directive must be signed by you in the presence of two witnesses. Neither witness can be appointed as your health care representative or alternate representative. Neither witness can be your attending physician. At least one witness must not be a relative by blood, marriage, or adoption. That witness also must not be entitled to any portion of your estate upon death. That witness also must not own, operate, or be employed at a health care facility where you are a patient or resident.

What if you have a document you signed under Oregon's earlier law?

The Advance Directive described in this bulletin came into effect November 3, 1993. If you completed one of Oregon's earlier documents, The Power of Attorney for Health Care or the Directive to Physicians, it still is valid under the new law. However, the Power of Attorney for Health Care form expires after 7 years and the Directive to Physicians covers only a few situations. Consider replacing your old form with the Advance Directive created by the 1993 law.

What to do with the completed documents

You can ask your doctor or local hospital for a copy of the Advance Directive. The document has instructions telling you how to complete the form. Keep the signed original in a readily accessible place. Do not put it in your safe deposit box where it is not immediately available to those people who will need it. In addition, give signed copies to your representative, doctor, family and other loved ones, home care nurses, minister, priest or rabbi, and anyone else you think should know how you feel. Take a

copy with you if you are admitted to a health care facility. It's a good idea to evaluate your document periodically to see if you would like to make any changes. If you have not written an expiration date on your Advance Directive, it will not expire. However, you can revoke it at any time and in any manner. The best way to revoke is to notify all people who have a copy of your form.

The health care decisions discussed in this bulletin are difficult ones. Remember, no one can make them better than you can.

Why is a written document so important?

Putting your health care wishes in writing became particularly significant after a June 25, 1990, U.S. Supreme Court decision on the first "right to die" case to come before it. The Court's opinion on this case is significant for patients in a terminal condition, their families, and health care providers.

The case involved Nancy Cruzan, a young woman in Missouri, who had lived in a persistent vegetative state as a result of a 1983 car accident. She was not brain dead; the lower part of her brain which enabled her heart to beat and her lungs to breathe continued to function. She did not need a ventilator to survive. Because she could do nothing for herself, however, she was artificially fed and hydrated with a feeding tube.

Nancy's parents, believing she would not want to have tube feeding under her circumstances, requested it be discontinued. They based this belief on what they knew about their daughter and in part on her own earlier statement that she would not want to live if she could not be, in her own words, "at least halfway normal."

The U.S. Supreme Court did state that 1) competent patients can refuse life-sustaining treatment and 2) artificial feeding and hydration should be treated the same as any other medical treatment. However, it also stated that Missouri could require the continued

treatment of a patient in a persistent vegetative state unless there was "clear and convincing evidence" that he or she had explicitly authorized the termination of treatment before losing the capacity to make decisions. In other words, the parents' request to remove the feeding tube was denied because Missouri did not view the judgment of Nancy's parents as clear and convincing evidence. It's important to note that while the U.S. Supreme Court upheld Missouri's decision, it did not require that other states adopt Missouri's rigorous standing of proof.

Still, it now appears that if you wish to set limits concerning treatment you would be more certain your wishes will be followed if you put those wishes in writing before a health crisis occurs.

A postscript to the Cruzan case: After the U.S. Supreme Court decision, Nancy's parents returned to the scene of their first legal proceeding in Missouri. They brought with them two women who had worked with Nancy at a school for blind and deaf children. These women testified that while Nancy was feeding a severely disabled child, she expressed the sentiment that if she became impaired to the point where she was a "vegetable," she would not want to be force-fed or kept alive on machines. The Missouri Court reversed its original decision. The tube feeding for Nancy was discontinued, and 12 days later, on December 26, 1990, she died.

Resources to help you with the decision

Most people are not trained in health care issues and find it confusing to think through what choices they would make in the event of a health crisis. Without adequate information about life-sustaining procedures and what it's like to have them used in your care, it's difficult to make informed decisions. Listed below are additional resources to help you think through certain health care issues and make decisions consistent with your beliefs.

Health Care Decision-Making for Oregon Families

This is an OSU Extension program that introduces the Advance Directive. Primary focus is upon communication among family members concerning difficult health care decisions. Contact your county home economics Extension agent for further information.

Talking to Your Family and Doctor About Difficult Health Care Decisions

This Oregon State University Extension publication (EC 1386) will help you consider the important

issues you should discuss with your family and doctor. It also describes the various treatments that can be used for a patient in a terminal condition. Contact your county Extension agent or Agricultural Communications at Oregon State University, (503) 737-2513.

If you have questions about Oregon's Advance Directive, call Oregon Health Decisions (a private, non-profit corporation) at 1-800-422-4805. You also may wish to consult an attorney.

Oregon State University Extension Service publications

The publications listed below may be available in the office of the OSU Extension Service that serves your county. Check with the office for current prices. You also may call Agricultural Communications at Oregon State University, (503) 737-2513, for availability and current prices of the publications.

- EC 1221, *Families and Aging: A Guide to Legal Concerns*, \$1.25
- EC 1243, *When Death Comes: Funerals and Alternative Arrangements*, \$1.75

- EC 1386, *Talking to Your Family and Doctor About Difficult Health Care Decisions*, \$1.25
- PNW 196, *Sensory Changes in Later Life*, \$1.00
- PNW 246, *Aging Parents: Helping When Health Fails*, 50¢
- PNW 314, *Helping Memory-Impaired Elders: A Guide for Caregivers*, \$1.00
- 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*, \$1.00
- PNW 344, *Helping Your Older Family Member Handle Finances*, 50¢
- PNW 347, *Depression in Later Life: Recognition and Treatment*, \$1.50
- PNW 438, *Coping With Your Loss and Grief*, \$1.00
- PNW 439, *Loss and Grief in Later Life*, \$1.00



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