

ADVANCE DIRECTIVES AND LIVING WILLS

More than ever before, people with cancer and their families are being asked to take part in decisions about end-of-life care. Yet, most people still do not discuss end-of-life care at all, even if they are seriously ill. As a cancer survivor, this may be an issue that was addressed with your oncologist or family during treatment. You may or may not have come to any decisions during your treatment, but it is important to also think about these topics during times of wellness. This fact sheet provides survivors with an outline for thinking about these issues and some guidelines for discussion with their doctors, families, and loved ones. This fact sheet is also designed to help survivors understand the medical, legal, and personal choices they may face in the future.

WHAT RIGHTS DO PATIENTS HAVE REGARDING THEIR MEDICAL TREATMENT?

Patients are entitled to complete information about their illness and how it, or its treatment may affect their lives, and they have the right to share or withhold that information from others. People who have had cancer should also be informed about any follow-up care that is planned, the benefits and risks, and any alternatives that may be available. Patients may be asked to sign an “informed consent” form, which includes this information. Before signing such a form, they should read it carefully and ask the doctor any questions they might have.

All individuals have the right to make decisions about their own medical treatment and care. These decisions may change over time. In the face of worsening disease, some patients may want to try every available drug or treatment in the hope that something will be effective. Other patients may choose to forgo aggressive medical treatment. Many patients turn to family members, friends, or caregivers for advice. But it is the patient's decision how much or how little treatment to have. Sometimes a patient is unable to make this decision, due to severe illness or a change in mental condition. That is why it is important for people with cancer to make their wishes known in advance, while they are healthy.

WHAT IS END-OF-LIFE CARE? WHAT ARE ADVANCE DIRECTIVES?

End-of-life care is a general term that refers to the medical and psychosocial care given in the advanced or terminal stages of illness. Advance directives are the legal documents, such as the living will, durable power of attorney and health care proxy, which allow people to convey their decisions about end-of-life care ahead of time. Advance directives provide a way for patients

to communicate their wishes to family, friends, and health care professionals and to avoid confusion later on, should they become unable to do so.

Ideally, the process of discussing and writing advance directives should be ongoing, rather than a single event. Advance directives can be modified as a patient's situation changes. Even after advance directives have been signed, patients can change their minds at any time.

WHY ARE ADVANCE DIRECTIVES IMPORTANT?

Complex choices about end-of-life care are difficult even when people are well. If a person is seriously ill, these decisions can seem overwhelming. But patients should keep in mind that avoiding these decisions when they are well will only place a heavier burden on them and their loved ones later on. Communicating wishes about end-of-life care will ensure that people with cancer face the end of their lives with dignity and with the same values by which they have lived.

WHY IS IT IMPORTANT TO WRITE A WILL?

A will is important so that patients can give instructions about distribution of their money and property when they die. Patients can name a trusted family member, friend, or professional to handle their personal affairs (also known as an Executor). It is advisable to seek the expert advice of a lawyer in drawing up a will so that the decisions made about taxes, beneficiaries, and asset distribution will be legally binding. This process can relieve a patient's family and friends of an enormous burden in case of disputes or questions about allocation of the patient's assets.

WHAT IS A LIVING WILL?

A living will is a set of instructions documenting a person's wishes about medical care intended to sustain life. It is used if a patient becomes terminally ill, incapacitated, or unable to communicate or make decisions. Everyone has the right to accept or refuse medical care. A living will protects the patient's rights and removes the burden for making decisions from family, friends, and physicians.

There are many types of life-sustaining care that should be taken into consideration when drafting a living will. These include:

- the use of life-sustaining equipment (dialysis machines, ventilators, and respirators)
- “do not resuscitate” orders; that is, instructions not to use CPR if breathing or heartbeat stops
- artificial hydration and nutrition (tube feeding)
- withholding of food and fluids
- palliative/comfort care; and
- organ and tissue donation

It is also important to understand that a decision not to receive “aggressive

medical treatment” is not the same as withholding all medical care. A patient can still receive antibiotics, nutrition, pain medication, radiation therapy, and other interventions when the goal of treatment becomes comfort rather than cure. This is called palliative care, and its primary focus is helping the patient remain as comfortable as possible. Patients can change their minds and ask to resume more aggressive treatment. If the type of treatment a patient would like to receive changes, however, it is important to be aware that such a decision may raise insurance issues that will need to be explored with the patient's health care plan. Any changes in the type of treatment a patient wants to receive should be reflected in the patient's living will.

Once a living will has been drawn up, patients may want to talk about their decisions with the people who matter most to them, explaining the values underlying their decisions. Most states require that the document be witnessed. Then it is advisable to make copies of the document, place the original in a safe, accessible place, and give copies to the patient's doctor, hospital, and next of kin. Patients may also want to consider keeping a card in their wallet declaring that they have a living will and where it can be found.

WHAT IS A HEALTH CARE PROXY AND DURABLE POWER OF ATTORNEY FOR HEALTH CARE?

A health care proxy is an agent (a person) appointed to make a patient's medical decisions if the patient is unable to do so. Generally, people assign someone they know well and trust to represent their preferences when they can no longer do so. Patients should be sure to ask this person for agreement to act as their agent. An agent may have to exercise judgment in the event of a medical decision for which the patient's wishes are not known.

The durable power of attorney for health care is the legal document that names a patient's health care proxy. Once written, it should be signed, dated, witnessed, notarized, copied, distributed, and incorporated into the patient's medical record.

Patients may also want to appoint someone to manage their financial affairs if they cannot. This is called a durable power of attorney for finances, and is a separate legal document from the durable power of attorney for health care. Patients may choose the same person or someone different from their health care proxy to act as their agent in financial matters.

WHERE CAN PEOPLE WHO HAVE HAD CANCER GET ASSISTANCE WITH THEIR ADVANCE DIRECTIVES?

If survivors need help making the decisions discussed in this fact sheet, they should not hesitate to call upon family, friends, and other loved ones. Survivors can also call an organization such as Cancer Care, Inc., for help with this process. Cancer Care, Inc., provides free, professional assistance to people with any type of cancer, at any stage of illness, and to their families. Patients and their families may write to Cancer Care, Inc., 275 Seventh

Avenue, New York, NY 10001; call 1-800-813-HOPE (1-800-813-4673); or visit their Web site at <http://www.cancer.org> on the Internet.

Although a lawyer is not needed to complete advance directives, it is important to be aware that each state has its own laws for creating advance directives. Because these laws can vary in important details, special care should be taken to adhere to the laws of the state a patient lives in or is treated in. It is possible that a living will or durable power of attorney signed in one state may not be recognized in another. Appropriate forms can be obtained from health care providers, legal offices, Offices on Aging, and state health departments.

This fact sheet was adapted with permission from Cancer Care, Inc., a nonprofit social service agency whose mission is to help people with cancer and their families. Cancer Care's toll-free telephone number is 1-800-813-HOPE. The National Cancer Institute and Cancer Care, Inc., are in partnership to increase awareness of the psychosocial issues faced by cancer patients and to provide resources to cancer patients and their families.

FOR MORE HELP, CONTACT:

NCI's Cancer Information Service

Telephone (toll-free): 1-800-4-CANCER (1-800-422-6237)

TTY (toll-free): 1-800-332-8615

LiveHelp® online chat: <https://cissecure.nci.nih.gov/livehelp/welcome.asp>

Other Resources

Tennessee Department of Health

<http://health.state.tn.us/AdvanceDirectives/index.htm>

Works cited:

National Cancer Institute Fact Sheet 8.12, Advance Directives (www.cancer.gov)