

Advance Directives

"Advance directive" is a general term that refers to your spoken and written instructions about your future medical care, in the event that you become unable to speak for yourself. These instructions play an important part in the way patients and families make decisions about end-of-life care, the range of medical and psychological services patients receive in the advanced or terminal stages of their illness. An advance directive consists of two specific legal documents that provide a way for patients to communicate their wishes to family, friends, and healthcare professionals, should they become unable to do so:

- **Living Will:** This is a legal document in which you spell out your desire for care in case you have a terminal medical condition or in case you become unconscious and are not expected to recover. In these situations, your medical care team will act according to instructions set forth in your living will only when you become incapable of making and expressing your wishes related to healthcare decisions or when your doctor determines that you are unable to make medical decisions. You may identify a specific person in your living will to make healthcare decisions on your behalf. That person is called a surrogate.
- **Durable Power of Attorney for Healthcare Decisions:** This is a legal document in which you appoint someone to make decisions for you, should you become unable of doing so on your own. The person you authorize to make decisions for you is often called your "agent" or "proxy." Both a surrogate and a durable power of attorney for healthcare decisions can make decisions for you in matters related to your living will. A durable power of attorney for healthcare decisions can also make decisions for you in matters of your care not covered by your living will, or if you do not have a living will.

Admission Process and Advance Directives

Giving patients the option to complete an advance directive is a part of the Fox Chase admissions process. If you are admitted to Fox Chase's Hospital or Home Health Services, you will go through the following steps in relation to advance directives:

- Your nurse will ask if you have completed any advanced directives.
- If so, you should give a copy of your living will or durable power of attorney for healthcare decisions to your nurse to include in your medical record.
- If you do not have a living will and would like help in creating one, ask your nurse for a referral to Social Work.
- If you wish to make changes to your living will, please let your nurses or doctors know.

While the option to complete an advance directive is given to all patients, patients are not required to sign an advance directive to be admitted to the hospital or to Fox Chase Home Health Services.

DICTIONARY OF TERMS

There are several terms you may need to understand as you prepare an advance directive. The definitions below should help you understand some of the forms of medical treatment you will be making choices about:

Brain death

Complete stopping of all function of the brain that cannot be reversed. A brain-dead person is not in a coma, but is, in fact, dead.

Cardiopulmonary resuscitation (CPR)

A method used to restore stopped breathing and/or heartbeat.

Do Not Resuscitate (DNR)

A doctor's order that alerts other healthcare givers that the patient or family—in consultation with the doctor—does not want the patient to be given cardiopulmonary resuscitation or CPR.

Feeding Tubes

Tubes inserted through the nose, mouth, stomach, or other areas of the body to feed patients who are no longer capable of eating normally.

Incompetent

The lack of sufficient capacity for a person to make or communicate decisions concerning himself or herself due to physical or mental impairment.

Intravenous therapy (IV therapy)

Treatment that provides nutrition, water, and/or medication through a thin tube placed in a vein.

Life-sustaining treatment

A medical intervention given to a patient that prolongs life and delays death.

Permanently unconscious

A condition in which a patient is determined to be in a state of total loss of consciousness that cannot be reversed.

Respirators

Machines used to assist or keep a patient breathing.

Surrogate

The appointment of another person to act on your behalf. May also be referred to as an agent.

Terminal condition

An incurable and irreversible medical condition in an advanced state that will result in death.

Emergency Treatment Policy and Advance Directives

Advance directives may affect the type of treatment you receive in an emergency. Please review the following Emergency Treatment Policy to better understand the role advance directives play in emergency treatment at Fox Chase's Hospital and Home Health Service:

- You will be given full emergency treatment, should your breathing or heartbeat suddenly stop.
 - If you do not want this done, please tell your doctors and nurses when you are admitted. Your doctor should recommend types of emergency treatment would be in your best interest in certain situations.
 - Your choice to limit the amount or emergency treatment you receive will not limit the type of care that you receive for other medical problems. Comfort measures to relieve your physical symptoms and reduce your emotional distress will always be offered to you.
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Frequently Asked Questions About Advance Directives**What is an advance directive?**

Advance directives are a means for you to tell your healthcare givers about the care you wish to receive—or not receive—should you ever become unable to tell them of your wishes. There are two forms of advance directives. One is called a living will. The other is called a “durable power of attorney for healthcare decisions” or may also be called “appointment of a surrogate for healthcare decisions.”

Why should I consider having an advance directive?

By law, healthcare providers must provide necessary medical care to all individuals within their care. They are relieved of this duty only if they can demonstrate that the care goes against a person's wishes. If you have preferences about the healthcare you want to receive in the event you are not able to express your wishes, you may want to write a living will, a power of attorney for healthcare decisions, or both.

Where can I get the forms to complete an advance directive?

Examples of advance directives may be available from Fox Chase's Department of Social Work Services. Other examples may also be available from local groups such as the offices of the American Association of Retired Persons (AARP), the local Bar Association, or the offices of the County Area Agency on Aging.

Are there times when my advance directive may not be followed?

Pennsylvania law generally does not permit a doctor or other healthcare provider to honor the living will of a pregnant woman who has directed that she not be kept alive. However, if you are pregnant, your living will may be honored if your doctor has determined that life-sustaining treatment will: (1) not maintain you in a manner that will allow for the continued development and birth of your unborn child; (2) physically harm you; or (3) cause you pain that cannot be relieved by medication. If your living will is not honored because you are pregnant, the Commonwealth of Pennsylvania must pay for your care.

What should I put in my advance directive?

The most important thing is to express your wishes or give permission to your agent to make decisions for you about receiving or not receiving certain forms of medical treatment that would keep you alive. You may also wish to indicate your wishes regarding organ and tissue donation.

May I name certain treatments that I do not want to have?

Yes, you can name certain treatments you do not wish to have. For example, one treatment that is very important for you to make your wishes known about is the use of feeding tubes. If you do not wish to be placed on feeding tubes, you should include such a statement in your advance directive.

What does my doctor have to tell me about my care and treatment?

Your doctor should tell you about the risks and benefits of any medical procedure or course of treatment that he or she is recommending. You also should be told about possible side effects or any alternatives to the proposed procedure or course of treatment. You may accept or reject your doctor's advice, and you may seek a second opinion.

Where should I keep my advance directive and who should know about it?

Give a copy of your advance directive to your family doctor, lawyer, family, and to those people you have named to make decisions for you if you are unable to make them. You also should bring a copy with you when you are being admitted to a hospital, nursing home, or other healthcare facility. Make sure that when there are changes to your advance directive, all old copies are destroyed.

Do I need an advance directive to be admitted to a hospital?

No. You do not have to sign an advanced directive to be admitted to a hospital or other healthcare facility.

If I choose not to make an advance directive, who makes treatment decisions for me?

As long as you are able, you and your doctor together will decide about your care. If you are unable to communicate your wishes or to make decisions, your doctor will discuss this with your family. If you have no family, a court order may be required to decide your care.

I spend several months a year in one state and several months in another. Do I need an advance directive for each state?

You should know the law in each state in which you live. It may be necessary to have more than one advance directive to meet the legal rules in each state.

What if I change my mind about my advance directive?

An advance directive is only effective when you are unable to express your wishes. It may be changed or cancelled by you at any time. It is a good idea to review your advance directive periodically to make sure it is still in agreement with your wishes.

What if a person I name to make decisions for me dies before I do?

It is always a good idea to name a second person to make decisions in case your first choice is not available, for whatever reason.

What if my doctor does not want to follow my advance directive?

It is very important that you talk to your doctor about this question while you are able to do so. If he or she indicates a problem in following your wishes, you have the right to change doctors.

What if I have expressed my wishes about treatment orally but have not put my wishes in writing?

Oral directions that you have given to your physician or to your family will sometimes be followed by healthcare providers, depending on how detailed and recent these instructions were. If you want to be certain your wishes are followed, it is best to put them in writing.

What types of questions should I consider when planning out my advance directive?

There are many issues that need to be considered when planning out your advance directive. Some of the more pressing ones may include:

- Where do you want to be cared for?
- Whom do you want to take care of you?
- What are your options financially?
- What will your insurance cover?
- If you have children, how will you prepare for their future?
- What do you want done with your money, your house, and your other possessions?
- What religious rituals are important to you?
- Do you want to join clinical trials on medications or devices that have not yet proven safe and effective, but that may provide some improvement to your condition?
- Do you want to be an organ donor?

What should I do once I've signed my advance directive?

Once you have signed your advance directive, you should keep the originals in a secure place. Give copies to your agent, any alternative agents, and your family. Also give copies to your doctors to place in your medical record. Take copies to the hospital whenever you go there for either inpatient or outpatient care.

Do I need to have both a living will and a power of attorney for healthcare decisions?

While it may be a good idea to have both a living will and a power of attorney for healthcare decisions, you do not need to have either of these documents, or you may have one or the other. If you want to designate specific treatment that you do or do not want, you may want to write a living will, even if you have named an agent to make decisions for you. Pennsylvania courts have not decided if the law permits an agent to refuse treatment on your behalf.

What is a living will?

A living will is a legal document in which you spell out your desire for care. A living will goes into effect only if you have a terminal medical condition or are in a state of permanent unconsciousness, and your doctor determines you are incompetent to make medical decisions.

Are living wills legal in all states?

Most states have laws that say living wills are legal. Most of these laws contain a form that you can use. Many doctors will honor living wills even in a state without a living-will law.

Is a living will the same thing as last will and testament?

A living will is not a last will and testament. A last will and testament tells your survivors what to do with your property after you die. A living will is a document that spells out your desire for care, should you have a terminal medical condition or fall into a state of permanent unconsciousness.

What is a power of attorney for healthcare decisions?

A power of attorney for healthcare decisions is a legal document that allows you to say who can make decisions about your care if you are not able to make such decisions yourself. The person you authorize to make decisions is called your "agent." All powers of attorney are presumed to be durable, unless specifically provided otherwise.

Does a power of attorney for healthcare decisions mean I have to appoint a lawyer to make healthcare decisions for me?

No. You are allowed to appoint anyone you wish. You should appoint someone you know, trust, and with whom you can talk over your wishes.

Legal Background on Advance Directives

Both federal and state laws govern the use of advance directives. The Patient Self-Determination Act of 1990 (PDSA) requires all healthcare facilities that receive Medicaid and Medicare funds to provide written information for ensuring a patient's rights to make healthcare decisions. This law also requires such facilities to offer patients help with creating advance directives. All 50 states and the District of Columbia have laws recognizing the use of advance directives. For questions pertaining to creating an advance directive, please consult Fox Chase's Department of Social Work.

Palliative Care and Advance Directives

Palliative care is cancer care that focuses on comfort in the final stages of life, rather than finding a cure through surgery, chemotherapy, or radiation therapy. When a person fills out a living will or advance directive, he or she is essentially saying that they do not want to receive any more aggressive treatment, but instead want to be made comfortable and pain free. In this way, palliative care offers patients comfort measures to relieve physical symptoms and to reduce emotional and spiritual distress. Palliative care does not limit the type of care that one receives for other medical problems.

The Palliative Care Service of Fox Chase Cancer Center offers supportive in-home services to adult cancer patients and their families through a team of medically supervised, skilled health professionals, all of whom have special training and sensitivity to terminally ill cancer patients. Palliative Care at Fox Chase includes the following services:

- **Nursing Care**
Registered nurses who specialize in cancer and hospice care coordinate all palliative care services. Nursing services include pain management and relief from other symptoms caused by illness. Nursing support is available 24 hours a day, seven days a week.
- **Social Work**

A social worker with expertise in the medical aspects of terminal illness evaluates the emotional and practical needs of patients and their caregivers. Counseling is given to help patients and their families adjust to illness and to help secure resources that allow patients to remain in the company of family and friends.

- **Pastoral Counseling**
A specially trained interfaith chaplain provides services aimed at strengthening or reinforcing patients' spiritual comfort throughout their illness.
- **Home Health Aides**
Trained, supervised assistants provide personal-care services, such as bathing, feeding, toileting, and skin care.
- **Medical Equipment and Supplies**
Medical items, such as dressings, equipment, and hospital beds, may be provided directly through Fox Chase's palliative care service or arranged through an outside supplier.

Insurance for Palliative Care

The following insurance companies cover palliative care services in the home:

- Medicare
- Major medical
- Commercial insurance
- Blue Cross

Patients without insurance coverage may also arrange for palliative care services. Fox Chase Cancer Center makes every effort to accommodate individual patient needs.

Referrals for Palliative Care

Inquiries, requests, and referrals for Palliative Care Service may be initiated by physicians, other healthcare professionals, patients, or their families. Patients are accepted for care upon approval from their attending physicians and upon meeting the following criteria:

- Patients must be in the terminal stages of their disease.
- Patients must reside in Philadelphia County, Eastern Montgomery County, or Southern Bucks County.

Pastoral Care and Advance Directives

Fox Chase's Pastoral Care Service provides patients and their families with a diverse, interfaith staff of chaplains and healthcare professionals who offer spiritual and faith-based support during all stages of the cancer process. Chaplains can be particularly helpful with living wills and advance directives, since they bring considerable experience working with individuals and families to address end-of-life issues. Other services offered by Pastoral Care include:

- Offering inpatients at least one visit during hospitalization
- Responding to referrals from staff
- Providing weekly and special holiday prayer services for patients, families, and staff
- Providing a Quiet Room (or chapel) for prayer and meditation
- Maintaining a spiritual library for patients
- Participating in a network of churches that supports the Fox Chase community

The Department of Pastoral Care also serves as a liaison between the hospital and a variety of local interfaith clergy who can be contacted at a patient's request.

Sample Living Will

PENNSYLVANIA LIVING WILL DECLARATION

I, _____, being of sound mind, willfully and voluntarily make this declaration to be followed if I become incompetent. This declaration reflects my firm and settled commitment to refuse life-sustaining treatment under the circumstances indicated below.

I direct my attending physician to withhold or withdraw life-sustaining treatment that serves only to prolong the process of dying, if I should be in a terminal condition or in a state of permanent unconsciousness.

I direct that treatment be limited to measures to keep me comfortable and to relieve pain, including any pain that might occur by withholding or withdrawing life-sustaining treatment.

In addition, if I am in the condition described above, I feel especially strong about the following forms of treatment:

- I () do () do not want cardiac resuscitation.
- I () do () do not want mechanical respiration.
- I () do () do not want tube feeding or any other artificial or invasive form of nutrition/food or hydration/water.
- I () do () do not want blood or blood products.
- I () do () do not want any form of surgery or invasive diagnostic tests.
- I () do () do not want kidney dialysis.
- I () do () do not want antibiotics.

I realize that if I do not specifically indicate my preference regarding any of the forms of treatment listed above, I may receive that form of treatment.

Other instructions:

SURROGATE DESIGNATION

I () do () do not want to designate another person as my surrogate to make medical treatment decisions for me if I should be incompetent and be in a terminal condition or in a state of permanent unconsciousness.

Name and address of surrogate (if applicable):

Name and address of substitute surrogate (if surrogate designated above is unable to serve):

ANATOMICAL GIFT DONATION

I () do () do not want to make a gift of my corneas. In general, organs other than corneas are not accepted for transplant from patients with cancer.

DECLARANT SIGNATURE

I made this declaration on the _____ day of _____ (month, year).

Declarant's signature: _____

Declarant's address: _____

WITNESS SIGNATURES

The declaration of the person on behalf of and at the direction of the declarant knowingly and voluntarily signed this writing by signature or mark in my presence.

Witness signature: _____

Witness address: _____

Witness signature: _____

Witness address: _____

Adopted 1/98

Fox Chase Social Work Services and Advance Directives

The Department of Social Work Services at Fox Chase offers professional counseling and support for patients and families coping with cancer at all stages of diagnosis and treatment. Fox Chase social workers can be particularly helpful to patients who need assistance with creating advance directives. Support related to advance directives may consist of the following:

- Providing patients with information on advance planning, legal documents and pain management
- Helping patients explore, discuss, articulate, and document their preferences for end-of-life care
- Enlisting the support and participation of family members and friends
- Helping patients keep track of important items throughout the planning process
- Serving as a liaison between patients and their physicians to discuss end-of-life care
- Helping patients deal with anxiety, fear, and other powerful emotions
- Helping patients and their families with practical problems such as nursing-home placement, insurance, and financial concerns

Patients who use these resources offered by the Department of Social Work Services frequently save themselves the emotional energy of going to multiple places to get the support they need during this critical time in their care.

Useful Links

- **Cancer Care**
www.cancercare.org
 Cancer Care is the nation's largest social service agency dedicated solely to providing free emotional support, information, and practical assistance to people with cancer, their loved ones, and caregivers. The agency is staffed by master's-level social workers who provide counseling and support over the telephone, over the Internet, or at regional offices. Cancer Care's services are available to people of all ages, with all types of cancer, at any stage of their disease. The website includes a referral service for health professionals as well as a section for media professionals who wish to learn more about cancer.
- **Partnership for Caring**
http://www.partnershipforcaring.org/Advance/talking_set.html
 Partnership for Caring is a national, nonprofit organization devoted to raising consumer expectations for excellent end-of-life care and increasing demand for such care. The website offers resources for counseling services, educational services, legal services, and state-specific information on advance directives.
- **Ageing With Dignity**
<http://www.agingwithdignity.org/>
 Ageing With Dignity is a nonprofit agency that provides patients with practical information, advice, and legal tools to ensure that their wishes concerning end-of-life care are respected. The website offers a free preview of a popular advance-directive tool called *Five Wishes* that helps patients express how they would like to be treated if they become seriously ill and unable to speak for themselves. The Five Wishes document is legal in Pennsylvania and in most states.