

Patient Information Packet

What Are Advanced Directives?

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Definitions

Advance Directive

A document in which a person makes provision for health care decisions in the event that, in the future, he/she becomes unable to make and/or communicate those decisions. Examples of Advance Directives include Living Wills, Health Care (Medical) Powers of Attorney, and other directives.

Agent

An adult who has the authority through a Health Care (Medical) Power of Attorney or through law to make health care treatment decisions for another person, referred to as the principal. Any authorized surrogate is the patient's Agent.

Artificial nutrition and hydration

When food and water are fed to a person through a tube, such as an intravenous tube (IV) or a feeding tube placed in the stomach.

Best Interest

When the person's "probable wishes" are unknown, the surrogate has an obligation to do what seems best for the person; e.g. what is in the "best interests" of the patient.

Comfort care

Care that helps to keep a person comfortable. Bathing, turning and keeping a person's lips moist are types of comfort care. CPR (cardiopulmonary resuscitation) Treatment to try to restart a person's breathing or heartbeat. CPR may be done by pushing on the chest, by putting a tube down the throat or by other treatment.

Guardian

A person appointed by a court of law for the express purpose of making health care treatment decisions on behalf of a patient who is unable to do so. Obtaining a legal guardianship usually takes time and may be costly.

Health Care (Medical) Power of Attorney (MPOA)

A written designation of an agent (surrogate) to make health care decisions while the person is unable to do so. When signed by the person writing the directive, the document is witnessed or notarized by at least one adult who is not related to the principal by blood, marriage, or adoption; not a beneficiary in the principal's estate, and is not providing health care to the person.

Life-sustaining treatment

Any medical treatment that is used to keep a person from dying. A breathing machine, CPR, and artificial nutrition and hydration are examples of life-sustaining treatments.

Living Will

The Living Will blank form is a particular form of Advance Directive intended to guide or controls the health care treatment decisions that can be made on a person's behalf. A Living Will often includes the phrase, "if I am in a terminal condition", and therefore limits its applicability.

Organ and tissue donation

When a person permits his/her organs (such as the eyes or kidneys) and other parts of the body (such as the skin) to be removed after death to be transplanted for use by another person or to be used for experimental purposes.

Persistent vegetative state

When a person is unconscious with no real hope of regaining consciousness even with medical treatment. The body may move and the eyes may be open, but as far as anyone can tell, the person can't think or respond.

Principal

The person who designates a Health Care (Medical) Power of Attorney or other Advance Directive such as a living will blank form.

Substituted Judgment

A decision about medical interventions that the person would most likely make if he/she were able to communicate with the health care team. This is sometimes called the "probable wishes" standard. (See Best Interests)

Surrogate

A person authorized to make health care decisions for a patient in the following order of authority:

1. Guardian
2. Health Care (Medical) Power of Attorney
3. Surrogate
 - a. The patient's **spouse**, unless legally separated
 - b. An **adult child** of the patient, or a majority of adult children
 - c. A **parent** of the patient
 - d. The patient's **domestic partner** if the patient is unmarried
 - e. A **brother or sister** of the patient
 - f. A **close friend** of the patient (an adult who has shown special concern for the patient, is familiar with the patient's desires and who is willing and able to become involved in the patient's health care, acting in the patient's best interests.)
 - g. The patient's **physician**, when none of the above persons can be located. The physician may make health care decisions after consulting with the institutional ethics committee, or with a second physician if an ethics committee is unavailable.

Terminal condition

An ongoing condition caused by injury or illness that has no cure and from which doctors expect the person to die even with medical treatment. Life-sustaining treatments will only prolong the dying process if the person is suffering from a terminal condition.

What Is An Advance Directive?

An Advance Directive is a document in which you give instructions about your health care, what you want done or not done, if you can't speak for yourself.

Advance directives are not complicated. They can be short, simple statements expressing your values and choices.

Examples of Advance Directives include Health Care Directives, Living Wills, Health Care (Medical) Powers of Attorney, and other personalized directives.

Health Care Directive

A Health Care Directive is a type of Advance Directive that tells your doctor and your family members what kind of care you would like to have if you become unable to make medical decisions. It's called an "advance directive" because you choose your medical care before you become seriously ill.

Unlike most Living Wills, a Health Care Directive is not limited to cases of "terminal illness." If you cannot make or communicate decisions because of a temporary or permanent illness or injury, a Health Care Directive helps you keep control over health care decisions that are important to you. In your Health Care Directive, you state your wishes about any aspect of your health care, including decisions about life-sustaining treatment.

Living Will

A Living Will is one form of Advance Directive. It usually only comes into effect if you are terminally ill. Being terminally ill generally means that you have less than six months to live. In a Living Will, you can say what kind of treatment you want in certain situations, but its use may be limited to situations when you are determined to be terminally ill.

Health Care (Medical) Power of Attorney

A Health Care (Medical) Power of Attorney lets you name someone to make medical decisions for you if you are unconscious or unable to make medical decisions for yourself for any reason. A Health Care (Medical) Power of Attorney can be part of another advance directive form, such as a Health Care Directive or Living Will, or may be a separate document. The person you appoint to make decisions for you when you cannot are called an "agent".

Appointing an agent is particularly important. At the time a decision needs to be made, your agent can participate in discussions and weigh the pros and cons of treatment decisions based on your wishes. Your agent can decide for you wherever you cannot decide for yourself, even if your decision-making ability is only temporarily affected.

Who Should Complete An Advance Directive?

Less than 25 percent of Americans have expressed their thoughts in writing about how they wish to be cared for if they become seriously ill or unable to communicate their choices for medical care. Most people avoid the subject. Each of us should discuss these issues so we can make reasoned choices in advance, easing the stress our families, friends and other loved ones.

If I am healthy, why should I complete an Advance Directive? When you are healthy, it's hard to think about the care you will want if you become ill or are facing the end of your life. But it may be the best time to make these decisions. An accident or serious illness can happen at any time. Talking with your family and physician now gives you a chance to ask questions and talk about your concerns. If you do this when you're healthy, you'll be thinking clearly as you talk about this important topic.

Aren't Advance Directives a legal tool for old people?

Not at all. Don't think of this as an "old" people's issue. It may be natural to link serious illness with old age, but that is a mistake when it comes to advance directives. Consider that perhaps the most well known landmark court cases, those of Nancy Cruzan and Karen Ann Quinlan, involved individuals in their 20's. The stakes are actually higher for younger persons in that, if tragedy strikes, they might be kept alive for decades in a condition they would not want. An Advance Directive is an important legal planning tool for all adults.

Don't all Advance Directives mean "Don't treat"?

All Advance Directives do not mean "Don't treat." While it is true that most people use Advance Directives to avoid being kept alive against their wishes when death is near, it is a mistake to assume that the existence of an advance directive means, "Don't treat."

Advance directives are also used to say that an individual wants all possible treatments. An Advance Directive is an opportunity to express your personal values and wishes for your future health care. Even when an advance directive limits life-sustaining medical treatments, you should always receive continuing pain control, comfort care and respect for your dignity.

Who Do They Affect?

You and your family

If you have completed any form of Advance Directive, you still remain in control of your health care decisions as long as you are able to communicate your wishes. An Advance Directive, including a Health Care (Medical) Power of Attorney, has no legal effect unless and until you lack the capacity to make health care decisions or to give consent for care.

If you are no longer able to make decisions for yourself, an Advance Directive can often relieve your family's stress. By expressing your wishes in advance, you help family or friends who might otherwise struggle to decide on their own what you would want done. Talking to your family and friends about your values and healthcare decisions is of critical importance.

Your Doctors

Whether you are in good health, or experiencing a chronic medical condition, each of your doctors should be your partner in developing an Advance Directive. Good health care decision-making requires good communication among all interested parties, and your physician is a key component of your health care plans.

The contents of your written Advance Directive should reflect a continuing conversation between yourself, your doctor, family, and close friends.

Hospitals and other Healthcare Facilities

When you are admitted to a hospital or other healthcare facility, the staff must provide you with information about advance directives, offer you an opportunity to complete one, or collect copies of your previously completed Advance Directive.

Doctors and other health care providers are legally obligated to follow your Advance Directive.

However, in order to honor an Advance Directive, the physician or healthcare institution must be aware of it and what it says. It is up to you and those close to you to ensure that everyone who might need a copy of your Advance Directive in fact has a copy.

Emergency Medical Services - "911"

People who are very ill, but living in the community, may face a challenge in having an Advance Directive followed if a crisis occurs and the emergency medical services (EMS) are called (for example, by calling "911").

EMS personnel are generally required to resuscitate and stabilize patients until they are brought safely to a hospital. If needed, you may receive cardiopulmonary resuscitation (CPR), which is treatment to try to restart a person's breathing or heartbeat. CPR may be done by pushing on the chest, by putting a tube down the throat or by other treatment.

If you do not wish to have cardiopulmonary resuscitation (CPR) if your heart stops or if you stop breathing, you must complete a special Advance Directive document called a "Pre-Hospital Directive". This document must be on printed on bright orange paper and signed by you as well as by your physician or other healthcare provider.

When Should I Complete One?

The best time to complete an Advance Directive is in ADVANCE of a medical crisis situation.

Although many advance directives are written by older people or by people who are seriously ill, a healthy young person can easily complete one. In case of an unexpected accident or illness, problems can arise because family members may not know what that person would want in a given situation. They may disagree about the best course of action. Disagreement can easily undermine family consent. A hospital physician or specialist who does not know you well may become your decision-maker, or a court proceeding may be necessary to resolve a disagreement.

What Happens If I Do Not Have An Advance Directive?

If you do not have an advance directive and you cannot make health care decisions, Kansas State law give decision-making power to default decision-makers or "surrogates." These surrogates, who are primarily family members in order of kinship, can make some or all health care decisions.

In these situations, individuals risk having decisions made contrary to their wishes or by persons whom they would not choose. Moreover, family members and loved ones may experience needless agony in being forced to make life and death decisions without

your clear guidance. It is far better to make your wishes known and to appoint a Health Care (Medical) Power of Attorney ahead of time through an Advance Directive.

How Do I Complete An Advance Directive?

Who Can Help Me Create A Health Care Advance Directive?

You do not need a lawyer to make an Advance Directive.

Start by talking to someone who knows you well and can help you state your values and wishes considering your family and medical history.

Your doctor is an important participant in creating your Advance Directive. Discuss the kinds of medical problems you may face, based on your current health and health history. Your doctor can help you understand the treatment choices your agent may face. Share your ideas for instructions with your doctor to make sure medical care providers can understand them.

What Do I Need To Consider Before Making A Health Care Advance Directive?

There are some important questions to ask yourself:

What Are My Goals for Medical Treatment?

The Health Care Directive may determine what happens to you over a period of disability or at the very final stage of your life. You can help others respect your wishes if you take some steps now to make your treatment preferences clear.

While it is impossible to anticipate all of the different medical decisions that may come up, you can make your preferences clear by stating your goals for medical treatment.

What do you want treatment to accomplish? Would you want to receive treatment to prolong your life, whatever your quality of life? Or, if life-sustaining treatment could not restore you to a level of quality of life you find acceptable, would you want to stop treatment?

Once you have identified the quality of life you find acceptable, your family and physicians can make medical decisions for you on the basis of these values. If treatment would help achieve one of your goals, the treatment would be provided. If treatment would not help achieve one of your goals, the treatment would not be provided.

Who Should Be My Agent?

Choosing your agent is the most important part of this process. Your agent will have great power over your health and personal care if you cannot make your own decisions.

You may have several close relatives or friends who would be willing to become your Health Care (Medical) Power of Attorney or agent. Who would be able to make tough decisions? Who would be able to speak up in a crisis situation? Who understands your values and desires and could speak for you when you are unable to speak for yourself? It may not be a family member or loved one that you feel the closest to that is the best agent. Pick someone who will really listen to your feelings and values. Your agent should be someone you trust. Make sure that person is willing to assume the responsibility of being your representative.

Choose just one person to serve as your agent and you may avoid disagreements. If you appoint two or more agents to serve together and they disagree, your medical caregivers will have no clear direction. If possible, appoint at least one alternate agent in case your primary agent is not available.

Speak to the person (and alternate agents) you wish to appoint beforehand to explain your desires. Confirm their willingness to act for you and their understanding of your wishes.

Are There Medical Treatments That I Do Not Want Under Any Circumstances?

If you have specific wishes or preferences, it is important to spell them out in the document itself. You may have a certain medical condition or have had experience with a particular medical treatment and know that you want to avoid a particular type of medical care.

Discuss these decisions with your agent and health care providers. These discussions will help ensure that your wishes, values and preferences will be respected.

Where Do I Get A Form?

Is There an Advance Directive I Must Use?

You do not have to use a specific form. Although there is a sample form in the Kansas law, you may use any form, as long as it conforms to the law and is properly witnessed.

Any form can and should be personalized to reflect your individual values, priorities, and wishes. If you do not agree with language contained in a standard form, change the language. It is a mistake to pick up an "official" form and just sign it unchanged, without first being sure that it truly reflects your specific wishes.

Do I Need a Lawyer to Complete an Advance Directive?

You do not need a lawyer to make an Advance Directive.

Can I Write My Wishes Down in My Own Words?

Yes. You do not need to use a particular form or format to express your wishes. Your agent or surrogate decision-maker, as well as your physician and healthcare providers will be obligated to follow your wishes as long as they comply with the law. However, if you decide to write your wishes down in your own words, your wishes can only be followed if they are clearly understood by others. It is very important to discuss these wishes with your decision-maker, your family and your doctor.

What Do I Do Once I've completed an Advance Directive?

Sign Your Advance Directive with a Witness Present

To assure that the wishes expressed in your Advance Directive, sign the document in the presence of a qualified witness. A witness may NOT be the individual you have named as your agent, someone related to you by blood, marriage or adoption, someone who will benefit from your estate, or your healthcare provider. An unrelated friend, a neighbor, or a minister can make an ideal witness. Witnessing requirements vary from state to state.

Talk to Your Family and Friends

You can help others respect your wishes if you take some steps now to make your treatment preferences clear. Since you cannot predict every possible future medical situation, discuss the values and beliefs about life's quality that help you make your decisions. What do you want treatment to accomplish? Would you want to receive treatment to prolong your life, whatever your quality of life? Or, if life-sustaining treatment could not restore you to a level of quality of life you find acceptable, would you want to stop treatment?

Once you have identified the quality of life you find acceptable, your family and physicians can make medical decisions for you on the basis of these values. If treatment would help achieve one of your goals, the treatment would be provided. If treatment would not help achieve one of your goals, the treatment would not be provided.

Talk to Your Doctors

Your doctor is an important participant in creating your Advance Directive. Discuss the kinds of medical problems you may face, based on your current health and health history. Your doctor can help you understand the treatment choices your agent may face. Share your ideas for instructions with your doctor to make sure medical care providers can understand them.

The contents of the written Advance Directive should reflect a continuing conversation between you, your physician, family, and close friends. Discuss the kinds of care you want, the kinds of care you don't want, and the your values related to an acceptable quality of life.

Make Copies of Your Advance Directives

Doctors and other health care providers are legally obligated to follow your Advance Directive. However, in order to honor an Advance Directive, the physician or healthcare institution must be aware of it and what it says. It is up to you and those close to you to ensure that everyone who might need a copy of your Advance Directive in fact has a copy. Keep copies handy in your home, in your car, in your wallet or purse. Give a copy to your appointed Health Care (Medical) Power of Attorney or agent. Give a copy to each of your doctors. Give a copy to other health care personnel, at the Emergency Room, Outpatient Clinic, or Hospital.

What if I Change My Mind?

You can cancel or change any Advance Directive by telling your agent or health care provider in writing of your decision to do so. Destroying all copies of the old one and creating a new one is the best way. However, the Advance Directive with the most recent date is the legal one that will be followed. Make sure you give a copy of the new one to your physician and anyone else who received the old one.

If you do not have time to put your changes in writing, you can make them known verbally. Tell your doctor and any family or friends present exactly what you want to happen. Wishes that are made in person will be followed in place of the ones made earlier in writing. Be sure your instructions are clearly understood by everyone you have told.

How do I get more information - RESOURCES

www.kansashealthethics.org/index.php?topic=advdirect
<http://www.kansascity.va.gov/patients/advance.asp>
www.ksbar.org/public/public_resources/pamphlets/living_wills.shtml
www.agingkansas.org/Publications/Other/hcbsfeyourrightsrespon5_2000.htm

Kansas Resources

Elder Law Hotline (800) 353-5337 www.kansaslegalservices.org/Home/PublicWeb/GetHelp
Kansas Department on Aging (800) 432-3535 www.agingkansas.org
Kansas Health Ethics (316) 684-1991 www.kansashealthethics.org
Kansas Legal Services (888) 353-5337 www.kansaslegalservices.org
Life Project Helpline: (888) 202-5433 www.lifeproject.org

Kansas Resources with Downloadable Forms

Kansas Bar Association (785) 234-5696 www.ksbar.org or ksbar.lawinfo.com (page with forms)

The University of Kansas Hospital (offers forms in Spanish) www.kumed.com/bodyside.cfm?id=2120

National Resources

Caring Connections Helpline: (800) 658-8898 Spanish Helpline: (877) 658-8896 www.caringinfo.org

National Library of Medicine and the National Institutes of Health:

MedlinePlus www.nlm.nih.gov/medlineplus/advancedirectives.html

LawHelp.org www.lawhelp.org