

*Circle Of Life: Cancer Education and Wellness
for American Indian and Alaska Native Communities*



American Cancer Society Circle Of LifeSM
Cancer Education and Wellness for American Indian and Alaska Native Communities

**Wellness along the Cancer Journey:
Nearing the End Of Life**

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Chapter 10: Appendices

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Appendices

Appendix A: Frequently Asked Questions about Advance Directives

Some people have questions about advance directives. This list has key questions that will help a person understand the information they need to help make decisions about their treatment.

What is a terminal condition?

A terminal condition is an irreversible illness that in the near future will result in death. It may also be a state of permanent unconsciousness from which the person is not likely to recover. Examples of terminal conditions include advanced cancers, multiple organ failures, or massive heart attacks and strokes. In many states, a terminal illness is defined as one in which the person will die “shortly” whether or not medical treatment is given. These definitions can complicate or delay the use of a living will.

What is a life-sustaining medical treatment?

In most cases *life-sustaining medical treatment* is a mechanical or artificial means that sustains, restores, or substitutes for a vital body function. Life-sustaining treatment can prolong the dying process for a terminally ill person. States have different definitions, so it is important to check state laws. Life-sustaining medical treatment may include the following:

- Cardiopulmonary resuscitation (CPR)
- Artificial respiration (includes mouth-to-mouth breathing, manual ventilation, or a ventilator or respirator – a machine that pushes air into the lungs)
- Medicines to help with blood pressure and heart function
- Artificial nutrition or hydration (liquid food or fluids given through a tube to the stomach or into a vein)
- Dialysis (a process that does the job the kidneys normally do)
- Certain surgical procedures (such as amputation, feeding tube placement, tumor removal, or organ transplant)

Nutrition and hydration (food and water) are not usually defined as life sustaining unless they are given through a feeding tube or into the vein (IV). Comfort measures, which are medicines or procedures needed to provide comfort or ease

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pain, are not usually defined as life sustaining. In some states, tube feedings and IV fluids are considered comfort measures.

When should I make an advance health care directive?

The best time to make an advance directive is before one is needed! In other words, before a person becomes too sick to make their own decisions about what medical care they want to take or refuse. Young people as well as older people should think about making an advance directive. Advance directives can be changed or revoked (taken back) at any time. They should be reviewed and updated if a person is found to have a serious illness.

It's very important that loved ones know that a person has written an advance directive and what medical care they want in certain situations. But even the most detailed living will can't possibly describe every medical event that could happen. That's why some people write two advance directives – a medical power of attorney along with a living will or Five Wishes form. But a person can use any kind of advance directive as a starting point to discuss difficult subjects like illness and dying.

That is why a person may want to use an advance directive as a chance to discuss difficult subjects like illness and dying. Through open talks with loved ones, a person can explain what is important to them and what kind of treatments they do and do not want done. This is a good thing to do at any age. It can save loved ones from a lot of guilt, uncertainty, and conflict in the event they must decide about a person's care. A person's loved ones can help make sure that their wishes are followed, but first they must know and understand what the person would want.

What happens when I have an advance health care directive?

If a person cannot make their own medical decisions, these decisions will be made for them. But if they have an advance directive, the decisions will be guided by what the person said they wanted. Decisions will be listed in the living will or made by the person they chose as their agent or proxy (substitute decision maker). It is important to make sure that the family, health care providers, and

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others who might be contacted know that a person has an advance directive and what is in it. These people also need to have a copy of the most recent advance directive so that it can be used in medical treatment. It is better to have extra copies so that loved ones can find the directive quickly.

A person should talk to all of their family about their advance directive. They should be sure that their family is clear about who their agent and back-up agent will be, and what a person has told them about their wishes. There may be problems if everyone in the family does not know about or does not support the choices a person has outlined in their advance directive. Arguments, family conflicts, and emotional objections can sometimes lead health care providers and hospitals to the “safest” route of care – aggressive treatment that can prolong death for a long time. This may not what a person would want.

How will my health care provider know that I have an advance health care directive?

If a person has any type of advance directive, they should tell people close to them that they have one and where it is kept. The person should give copies of the advance directive to the proxy or agent (who will make decisions for them), the back-up agent, family members, and friends who would be contacted if they become ill. A person can talk it over with their doctor, but keep in mind that the doctor’s office records are not likely to be available to a hospital or facility where the person is admitted.

Do not keep an advance directive locked up where no one can find it or get to it. Have extra copies where they are easy to find. It is up to the person, their agent, or a family member to give a copy of an advance directive to their health care provider and hospital when it’s needed.

Federal law requires that hospitals, nursing homes, and other health care agencies ask at the time of admission whether or not a person has an advance directive. If they are unable to answer the question or if the advance directive is not available, it may not be included in their medical record. In that case, the advance directive may not be used to guide care according to the person’s wishes.

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Does the health care provider have to follow my advance health care directive?

There are some times that a health care provider may reject a medical decision made by someone or their agent based on their advance directive. For instance:

- When the decision goes against the health care provider's conscience
- When the decision is against the health care institution's policy
- if the decision violates accepted health care standards

In such cases, the health care provider or facility must tell the person or the person's agent right away. The person may be transferred to another facility that will honor their decision.

Will my advance health care directive be used if I am taken to an emergency room?

An advance directive is valid in an emergency room only if the health care providers there know about it and have a copy. In serious emergencies, it may not be possible for health care workers to find out that someone has an advance directive before medical care begins. If a loved one calls emergency medical services (911) at a time a person cannot speak for themselves, the advance directive may not be honored. This is another reason why a person's family should know their wishes before such a situation happens.

What happens if I do not have an advance health care directive?

It is estimated that about one in four adults in the United States have advance directives. If a person does not have an advance directive, they may get medical care that they do not want. If there is no advance directive, the health care provider may ask a person's family about their treatment. Some state laws require that the spouse (unless legally separated) must be asked first, followed by adult children, parents, and adult brothers and sisters. But some states do not have laws that require health care providers to check with family members. And it is common for family members (especially those who aren't close to the person) to not know what a person would want. Family members may disagree on certain aspects of a person's care, which may cause delays or them not getting the care they want. For example, It's unlikely that a trusted friend or unmarried partner

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will be consulted without an advance directive naming that person as an agent or proxy.

In some cases, a court may appoint a legal guardian to make health care decisions if a person does not have an advance directive. This is why it is important for a person to express their wishes in a written advance directive ahead of time. It is also helpful to discuss their wishes with their health care provider, agent, and those close to them.

Do I need a lawyer to write my advance health care directive?

Although a lawyer can be helpful, a person does not need a lawyer to write their advance directive. Some states have forms that a person must use, and each state has certain requirements. Visit caringinfo.org for sample forms and directives that meet each state's requirements.

Can I have an advance health care directive in more than one state?

Most states have their own rules about what they will accept as a valid advance health care directive. Some states accept an out-of-state directive if it meets the legal requirements of the state in which the person wants to use it. Some experts suggest having an advance directive for each state in which a person spends a lot of time. If a person wants to use an advance directive in a state other than that in which they signed it, it is a good idea to check with a lawyer in order to avoid potential problems.

Does having an advance health care directive affect my life insurance?

No. No one, including health insurance companies, can require a person to have or prevent them from having an advance directive. Having an advance directive will not affect any terms of a person's life insurance.

Does having an advance health care directive affect my health care?

Having an advance directive does not mean someone has given up their right to make any decisions about their care as long as they are able to do so. Having or not having an advance directive will not affect the quality of someone's care while

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they can make their own decisions. Treatment and comfort measures are still offered.

The advance directive only takes effect when a person cannot speak for themselves. At that point, certain treatments or cure measures may be withheld if that is what the person requested. Any person who is mentally able can change or revoke (take back) his or her advance health care directive at any time.

Can I have both a living will and a power of attorney for health care?

Yes. A person can have a living will and a durable power of attorney for health care at the same time. In most cases, a person can also provide extra instructions in another type of advance directive for situations not covered by the living will.

If a person has more than one kind of advance directive, be sure that the person named as the agent or proxy in the power of attorney for health care has copies of the living will and any other advance directive. The agent or proxy must clearly understand what you want.

It's also very important to be sure that these documents don't conflict with each other, so that there will be no confusion about a person's wishes if they can't speak for themselves.

Some states allow a person to have a single, combined advance directive/living will document. But it is important to check state requirements to find out what the state legally accepts.

Can I change my mind about what is written in my advance health care directive?

Yes. Once a person makes an advance directive, they may change or revoke it (take it back) at any time while they are mentally able to do so. Changes should be signed, dated, and witnessed. A person should tell their proxy or agent, loved ones, and health care provider if they change or cancel their advance directive.

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If they are writing a new advance directive, they should destroy all copies of the old advance directive so there is no confusion on the part of their agent or their family. Some states require that a person notify their health care provider in writing when they make changes to their advance directive or write a new one.

Is my advance health care directive valid if I am at home?

Someone who is dying but who is not in a health care facility may face problems in having an advance directive honored in an emergency. Some states have addressed this issue. A few states allow 911 emergency medical services to refrain from trying to revive terminally ill persons who have a “do not resuscitate” order written by a health care provider. As part of this, those states require that people who wish to die at home post a special orange DNAR form or wear a special bracelet labeled “do not resuscitate.” Each state is different. This is something that a person should ask their local health care provider and EMS about.

What is a “do not resuscitate” order?

Do not resuscitate, or DNR, is a medical order written by a health care provider for a person in a hospital. It tells the health care team taking care of a person that CPR is not to be used if their heart or breathing stops. Each time a person who does not want CPR is admitted to a hospital or facility, they should be sure that their health care provider knows CPR is not wanted.

The in-hospital DNR orders do not help people once they go home. Advance directives often include instructions not to start CPR. This may not help in emergencies when no one knows that they have an advance directive. But if family and loved ones know, they may be able to avoid an emergency treatment situation.

What are “end-of-life decisions?”

End-of-life decisions are choices a person can make about how they wish to be treated when they are dying. End-of-life decisions can include whether to accept or refuse treatments that prolong life. An advance directive is one way to let others know about a person’s decisions based on what is important to them. Again, it helps if everyone close to the person fully understands what they want at

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this time of their life. This makes it as easy as possible for loved ones to carry out the person's wishes.

What is "euthanasia?"

The word euthanasia comes from a Greek phrase meaning "a gentle and easy death." It is defined as any action or omission that causes death with the purpose of ending suffering due to illness. This means there are two major types of euthanasia: active and passive.

Active euthanasia is when someone other than the person takes active measures to end their life, such as personally giving a deadly dose of a drug. This is illegal in the United States, even if the person asks for it.

Passive euthanasia is defined as stopping treatment that prolongs life, such as breathing machines or feeding tubes. This allows a terminally ill person to die naturally, and does not further prolong death.

What is assisted suicide?

Assisted suicide is different from active or passive euthanasia. Assisted suicide is giving someone the means to take their own life. For instance, a health care provider may write a prescription for deadly dose of drugs that the person may choose to take when they are ready.

As of mid-2015, only the states of Oregon, Montana, and Washington allow health care providers to prescribe a lethal dose of medicine for terminally ill people who wish to end their lives. Those states' Death with Dignity Acts forbid active euthanasia; that is to say, no one else can give the lethal dose of medicine. The person must do that for themselves. These laws contain many requirements that must be met before a person is given the means to hasten death. (The Montana Supreme Court ruled in 2009 that assisted suicide is not illegal in the state, but there's no specific law that allows it.) Even then, not all health care providers in those states will write such prescriptions even for people who meet all the requirements. Health care providers can refuse to prescribe these drugs based on conscience.

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All of these states have laws that prohibit active euthanasia; that means no one else can give the lethal dose of medicine. The patient must do that for themselves.