

*Circle Of Life: Cancer Education and Wellness*

*for American Indian and Alaska Native Communities*



American Cancer Society Circle Of Life<sup>SM</sup>  
*Cancer Education and Wellness for American Indian and Alaska Native Communities*

Wellness along the Cancer Journey:  
Nearing the End Of Life

Revised October 2015

Chapter 5: Advanced Directives



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#### Advance Directives Overview

| Group Discussion   |      |       |          |
|--|------|-------|----------|
|  | True | False | Not Sure |
| 1. A person's health care wishes can be honored through legal means. |      |       |          |
| 2. Advance directives require patients to have treatment.            |      |       |          |
| 3. There is only one type of advance directive.                      |      |       |          |

An *advance health care directive* or *advance directive* is a kind of legal document that tells a health care provider a person's wishes about their health care. Advance directives are only for times that a person can't speak for themselves. They do not affect a person's type or quality of health care while a person can voice their own decisions. Advance directives take effect when a person can no longer speak for themselves.

There are several types of advance directives. They can be general, with very few directions about care, such as a basic *power of attorney for health care*. This kind of directive usually just names a substitute person (agent or proxy) to make decisions for a person who is unable to do so.

Advance directives can also be very detailed. Some *living wills* clearly outline the different types of life-sustaining treatments a person would accept or refuse in certain situations. There are other types of advance directives that are limited to certain situations, such as organ or tissue donations or your wishes not to be revived if your heart or breathing stops.

No matter which kind of directives a person uses, **no one will be able to control their money or other property** based on an advance health care directive. It may

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also help to know that a person can also change or revoke (take back) their directives at any time.

#### **Advance Directives and Informed Consent**

Adults have the right to control their medical treatment as long as they are mentally able to do so. They can choose which course of treatment they would like from those the health care provider offers. They can choose the kind of treatment (aggressive, comfort care, or even none), and can refuse any treatment that they do not want. This right is generally called *informed consent*.

Informed consent means that the doctor or nurse explains the purpose, benefits, risks, and alternatives of the treatment before a person decides whether to get it. In most cases, treatment can be given only if the patient agrees to it. Still, this right is not absolute. For example, if a person needs immediate or emergency care, a health care provider may go ahead with treatment even if the person can't take in information and agree (consent) to be treated at that moment.

It's also generally accepted that a competent (mentally able) adult may refuse medical testing or treatment if they understand the likely outcomes of refusing. This is sometimes called *informed refusal*. A competent adult patient may also ask that treatment be stopped, even if it means they will die as a result.

Sometimes, family members make medical decisions for spouses, parents, or adult children who cannot speak for themselves. Whether this type of informal arrangement is allowed depends on the medical provider and which state you live in. Many states have passed laws that say which family members (in a listed order of priority) may act on behalf of a person who cannot speak for themselves. But if there is any disagreement between family members it can complicate and delay decision making.

Even though others may be able to make health care decisions without an advance directive, these documents can give a person more control. An advance directive offers a better chance that a person's wishes will be carried out at a time when they can't speak for themselves.

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#### **Types of Advance Health Care Directives**

General information about different advance health care directives, like living wills, durable powers of attorney, letters of instruction, and others like these will be reviewed here. They apply only to health care decisions and do not affect financial or money matters. Because the laws vary by state, it helps to find out about what a state requires. Please see Appendix A for frequently asked questions about advanced directives.

The types of advance health care directives vary based on state laws and a person's preferences within these states' legal requirements. The two most common types of advance directives are the *living will* and the *durable power of attorney for health care*, which is sometimes called the *health care power of attorney* or *health care proxy*.

- The living will covers a list of health care decisions when a person is *permanently unconscious* or is *terminally ill* or and can no longer voice decisions.
- The durable power of attorney for health care allows a person to name an agent or proxy (substitute person) to make their health care decisions if the time comes when they are unable to do so.

Advance health care directives can also include extra guidance about making health care decisions. For instance, a directive lets a person say when they do not want to be *resuscitated* or if they want to donate organs or tissue. (Resuscitation means an attempt by medical staff to re-start the heart and breathing, such as CPR. In some cases it may also include devices that try to prolong life, such as breathing machines.)

Advance directives usually let a person include instructions for other situations, too, such as when they may be unconscious for a short time. Some advance directives allow instructions if the person is impaired by Alzheimer's disease or something like it.

If a person does not have written advance directives, some states recognize spoken (oral) advance directives as legal. A person may make a properly witnessed statement that must then be written by someone who heard it.

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If a person expects problems with mental illness, an advance directive can be used to outline their health care wishes. The directive can be used if they later become seriously mentally ill and can't make health care decisions. This is called a *mental health care directive* or *psychiatric care directive*.

#### ***Living Will***

A *living will* is a document designed to control future health care decisions only when a person becomes unable to make decisions on their own. State laws vary, but most allow health care providers to stop trying to prolong life in the case of terminal illness or permanent unconsciousness. If a person has hope of recovery, the living will generally does not apply.

A living will describes the conditions in which an attempt to prolong life should be started or stopped. It further lists the type of medical treatment the person would want in these situations. This applies to treatments such as dialysis, tube feedings, or artificial life support.

The living will is a formal legal document that must be written and signed by the person. Some state laws contain a model form. For most states the form is not required, but others require that their form be used. Most laws require the living will to be witnessed and notarized. Usually, the witnesses cannot be spouses, potential heirs, an attending physician, or employees of the patient's health care facility.

There are many things to think about when writing a living will. These include:

- The use of equipment such as dialysis (kidney) machines or ventilators (breathing machines)
- "Do not resuscitate" orders (instructions to not use CPR if breathing or heartbeat stops)
- Whether to have fluids by vein and/or nutrition (tube feeding into the stomach) if someone cannot eat or drink.
- Whether to have food and fluids even if the person is not able to make other decisions

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- Whether to have treatment for pain and nausea or other symptoms, even if the person is not able to make other decisions (this may be called "comfort care" or "palliative care")
- Whether a person wishes to donate organs or other body tissues after death

It is also important to know that choosing not to have "aggressive medical treatment" is different from refusing all medical care. A person can still get antibiotics, nutrition, pain medicines, and other treatments, even if they have chosen not to have "aggressive medical treatment." It's just that the goal of treatment is comfort rather than trying to cure the cancer. It's important that a person make it clear exactly what they want and don't want.

A person may revoke (end or take back) a living will (or any other type of advance directive) at any time. It is important to know that a few states will automatically void the living will after a certain number of years.

There is no general agreement for recognizing living wills from other states. If a person spends time in more than one state, they should create separate living wills. Some people may find a way to be sure that their living will meets the requirements of all the states they spend a lot of time in.

A living will is more limited than a health care power of attorney (discussed later). The living will generally applies only when a person is terminally ill or permanently unconscious and unable to make their wishes known. It also only gives written instructions about certain things that might happen and does not cover every health care situation that could come up. With most types of living wills, a person can't choose an agent or proxy to make decisions for them, and no one is appointed to be sure that their wishes are carried out. That's why most people need a health care power of attorney also (discussed below).

#### ***Durable Power of Attorney for Health Care***

A durable power of attorney for health care is also called a health care power of attorney. It is a legal document in which a person chooses an agent (who may also be called a proxy or substitute) to make all health care decisions if they become unable to do so. If a person names an agent, that person can speak with health

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care providers and other caregivers and make decisions on your behalf. The agent or proxy decides which treatments or procedures to do or not do. If a person's wishes in a certain situation are not known, the agent will decide based on what they think would be wanted and what they consider to be the person's wishes. But some states do restrict the ability of the agent to carry out some requests. For example, a few states do not allow an agent to stop artificial nutrition (feeding) and giving fluids.

The person named as the proxy or agent should be someone who can be trusted to carry out a person's final wishes. It's also important to choose a person who knows the patient well. Most people choose their spouse or a close friend or family member who knows their situation and has a good idea of what they would want. If needed, the agent must be able to do this in a time of great stress, uncertainty, and sadness. Talk to them and be sure that they're comfortable in this role. Be sure to discuss your wishes in detail with that person. It is also a good idea to name a back-up person to be the agent in case the first choice becomes unable or unwilling to do their job. (Some states ask for this back-up agent, or successor, on the health care power of attorney form.) The law does not allow the agent to be a health care provider, or other person providing health care, unless that person is a close relative.

State laws that let a person choose a proxy or agent usually require that the request be in writing, signed by the person choosing the agent, and witnessed. In many cases, the agent also signs the document. Some states have a special form for this.

Just like with living wills, state laws vary. For instance, some states will automatically void a health care power of attorney in certain cases when marital status changes. It is important that a person get the information that applies to their state, and any forms that the state requires.

#### ***The Five Wishes and Directives Like It***

Advance directives vary a lot by state, but many states let a person include instructions for certain situations. For example, the Five Wishes form, which is legally recognized in 42 states as of 2015, asks whom a person would want to make their health care decisions if they could not. It also asks about their choice

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of medical treatment, how they want to be treated, instructions on comfort care, and final expressions or wishes for family and friends. Visit [agingwithdignity.org](http://agingwithdignity.org) for Five Wishes forms and others. Make sure the state accepts the form if you want it to be legally binding. In order to be sure the information is helpful to family and loved ones, be sure that the form outlines the exact wishes and choices. Even if it isn't legally binding in a particular state, it might help family and loved ones make decisions the way the person wants.

#### ***Do Not Resuscitate Orders***

If a person is in the hospital, they can ask their health care provider to add a Do Not Resuscitate or DNR order to their medical record. They would ask for this if they didn't want the hospital staff to try to revive them if their heart or breathing stopped. But remember that an inpatient DNR order is only good while a person is in the hospital. Outside the hospital, it's a little more difficult.

Some states have an advance directive that is called a *Do Not Attempt Resuscitation (DNAR)* or special *Do Not Resuscitate (DNR)* order for use outside the hospital. The non-hospital DNR or DNAR is intended for emergency medical service (EMS) teams that answer 911 calls. EMS teams are usually required to try to revive and prolong life in every way they can. Even though families expecting a death are advised to call other sources for help when the person with cancer worsens, a moment of uncertainty sometimes results in a 911 call. This can mean unwanted measures that prolong death. The non-hospital DNR or DNAR order offers a way for people to refuse the full resuscitation effort in advance, even if EMS is called. It must be signed by both the person with cancer and the health care provider.

#### **Keeping Advance Directives Available**

All these important documents should be kept in handy, easy-to-find places so that someone else can find it if a person is in the hospital and needs it. Make sure that family members have copies and that others know where the advance directive is kept. Be sure it is clearly marked.

See Appendix B for a list of instructions on how to write an advance directive.



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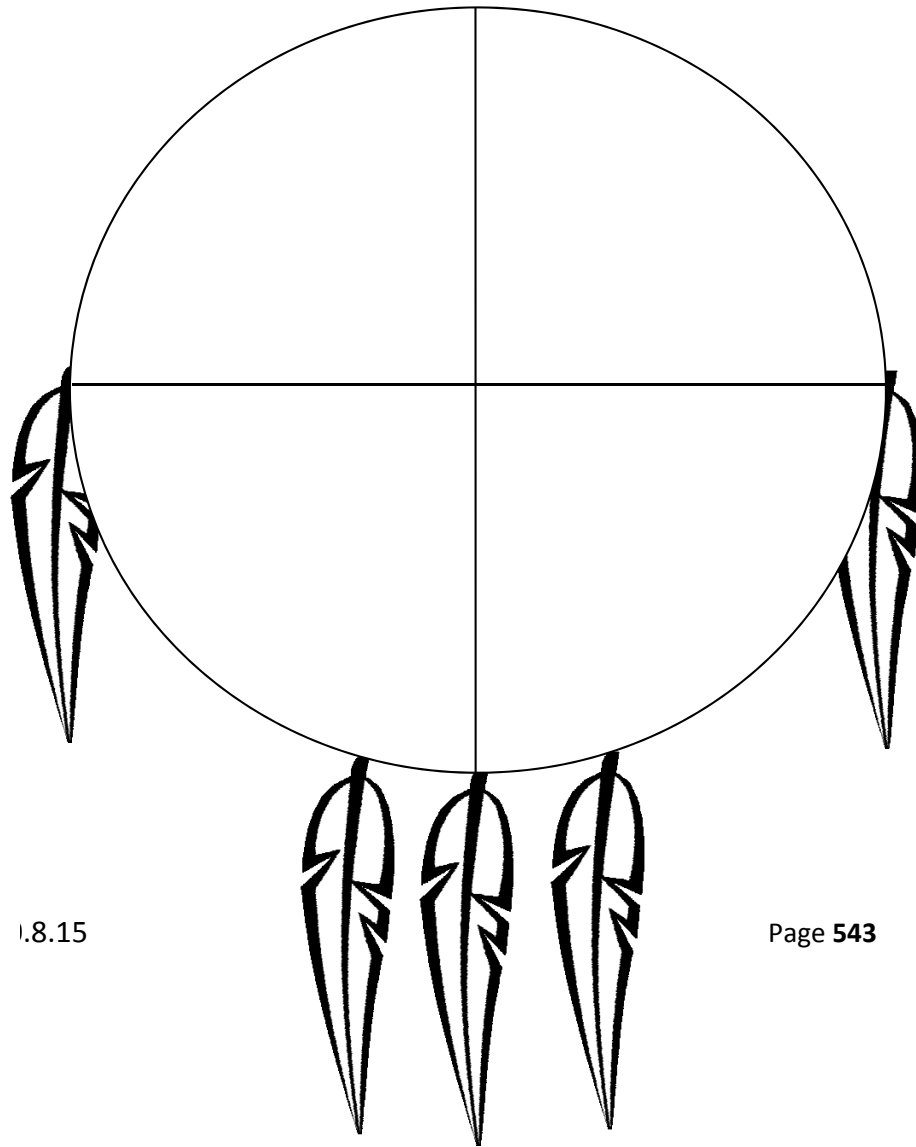
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**Activity**

Consider each question below and when you are ready, write your answers as best as you know them at this time in each section of the shield.

**Who do you want to make decisions for you when you are no longer able to?**

**What measures do you want to try and prolong your life?**



**As you reach the end of your life, do you want to die at home? Would you like hospice care?**

1.8.15

**After you die, are you willing or unwilling to donate your organs or tissues to others who need them to live?**

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### Story of Hope



*“I think at some point you’ve gotta reconcile that death is possible, of course death is inevitable for all of us down the road but when you get a diagnosis of cancer I think you’ve gotta really decide, do you really want to fight this, because if you decide you don’t wanna fight it, I think you really can die faster but I determined somewhere early on that I really wanted to live and I was I believe about 43 at that time, and you know they say, life begins at 40 a lot of interesting things were going on in my life.”*

– Angela Russell, Crow Breast Cancer Survivor

(Clark, R., (Producer) & Russell, A. (Artist). (2007). *Survivor Video Vignettes: Perceptions of Death*. [Web]. Retrieved from <http://www.natamcancer.org/vignettes/angela-palliative.html>)

### Key Messages

- An advance directive allows a person to state what they want to happen if they become unable to make their own medical decisions.
- The time to create a living will or durable power of attorney is before one is needed!
- A person should make sure family members and trusted friends know their end-of-life wishes and where they keep all legal documents that state these wishes. Advance health care directives should not be locked up in a safe.