

## Advance Health Care Directive (AHCD) Companion Document Consider the Medical Care You Want

An AHCD can be used as a starting point for you, the patient, to put in writing your health care decisions in case there is a time when you are unable to make such decisions yourself.

Some state laws provides guidance for people to use when creating their AHCD. The Advanced Directive accompanying this explanatory document authorizes a trusted family member or friend to make medical decisions for you when you are unable.

### Is an AHCD required?

No, an AHCD is not required by law.

### Is an AHCD necessary?

Yes, if you want a specific person to make decisions for you when you are unable.

### What is the purpose of an AHCD?

The purpose of an AHCD is to authorize another person to make medical decisions for you when you are incapacitated (i.e. unable to make decisions for yourself; either temporarily or permanently, for example, because you are in a coma). This type of document is known as a **durable power of attorney** for health care.

If you do not designate an agent and you become unable to make your own medical decisions, some state laws, California for example, allows your physician to select the person the physician believes is best suited to make such decisions. It could happen that the physician chooses the same person you would, but there is also the risk that the physician might choose someone who doesn't know or agree with your values, or is uncomfortable advocating for you in a stressful situation. Authorizing your preferred agent in an AHCD eliminates any chance of mistake.

### But I am young—why would I need an AHCD?

Accidents can happen to anyone. If a thirty-three year-old father of 3 were incapacitated temporarily, his wife might not legally be allowed (depending on the state) even to look at his medical records if he had not named her his Agent through something like an AHCD. We all know someone, either directly or indirectly, who has been in such an accident.

## Why use a durable power of attorney instead of writing out a list of procedures and treatments I do not want?

It can happen that a procedure or treatment that seems unthinkable suddenly becomes preferable when a real-life decision arises. For example, many persons who acquired a permanent disability due to a disease or an accident had said they could not have anticipated a good quality of life if it required using a feeding tube, oxygen machine (ventilator), or wheelchair. However, after the initial shock of the disability recedes, they were deeply grateful that they or their agent decided to pursue the treatment.

Moreover, creating a list of treatments you do not want ahead of time can have the effect of taking options off the table for your agent. Eliminating options before a concrete situation arises means that your agent is not free to choose a treatment that could lead to a good quality of life; one that you would choose if you were able, given the circumstances of a particular situation.

## Consider Your Treatment Preferences: Think Outside the Box

### What is ‘overtreatment’ and ‘undertreatment’?

Overtreatment occurs when a person is **subjected to medical interventions they do not want**, or would not want their health care agent to authorize. Undertreatment is when a person **does not receive the medical care they want**, usually because the medical provider (i.e. physician, hospital) or insurance company thinks the intervention is unnecessary or futile.

While there may have been a time when overtreatment was more likely, in today’s health care system undertreatment should be carefully guarded against.

For example, a car accident severs a person’s spinal cord. The person’s health care agent is told that even if surgery to save the life of the person is successful it is doubtful the person will ever regain the use of her arms and legs. After the surgery she will need to undergo months of rehabilitation and may have to use a ventilator to breathe.

**This situation happened to Terrie Lincoln when she was nineteen years old.** Her parents were pressured repeatedly to “let her go” and “pull the plug” rather than see their daughter live with what the physicians described as a less fulfilling quality of life. Terrie’s parents demanded treatment for her and several months later, Terrie was able to wheel into the hospital by herself. She didn’t need a ventilator for life and today is a working mother.

Like others who become people with disabilities after an accident or disease, Terrie experienced an almost lethal form of discrimination. The physicians speaking to Terrie’s parents (who were also her health care agents) did not think the time, money, and effort required to heal Terrie would result in a life worth living. Thankfully, Terrie’s parents were adamant that Terrie receive the care she needed.

Please follow the link to read more about [Terrie's experience](#).

### **Seniors can be especially vulnerable to discrimination from health care providers.**

A 2015 study found,

- o “One out of five adults over the age of 50 years experiences discrimination in healthcare settings.
- o One in 17 experience frequent healthcare discrimination, and this is associated with new or worsened disability by 4 years.”

The most common reasons for experiencing discrimination were age, gender, and financial status. Seniors and their health care agents need to be prepared for subtle forms of discrimination when medical providers reference life expectancy, quality of life, and potential burdens on the patient and caretakers.

Please follow the link to read more about [this study](#).

## **How do I know which medical interventions to tell my agent to pursue?**

As Terrie Lincoln's experience shows, it can be difficult to know definitively which treatments to pursue or prohibit before a specific situation presents itself.

Some people may think they would never want to live with a ventilator, feeding tube, colonoscopy bag, wheelchair, etc. But it may be the case that eliminating one or more of these possibilities upfront could remove an option that may be:

- (1) only temporary, or
- (2) an adjustment to life that can be made with time.

**Consider the example of military servicemembers** who lost limbs to an Improvised Explosive Device (IED) while serving in Iraq and Afghanistan. One moment they are on patrol, the next moment they wake up in a hospital without an arm or leg. Almost all of these new amputees report struggling with depression; some even consider suicide.

Though no military amputee wanted to live without a limb, many have resolved to use the experience to give and get more out of life. Some have become competitive athletes while others are motivational speakers. **In the advance directive context, the characteristic that is perhaps most helpful is the optimism that guides their perspective.** Rather than see the surgeries, treatments, rehabilitation, and prosthetics as hindrances to a quality life, they view them as tools for making a worthwhile life possible.

Seeing someone navigate a disability successfully can be very helpful. As reported by the Amputee Coalition, “I remember thinking that living life with one leg was worse than not living at all. I really, honestly did... [Then] a young boy with an artificial leg came into my hospital room for a visit. I don't remember what he said. I don't remember what he looked like. I was so transfixed with his prosthesis as he walked into my room. That's all I needed to give me the personal strength to go on...”

Please follow the link to read more about the [Amputee Coalition](#):

## Determining Brain Death and Persistent Vegetative State

The American Academy of Neurology (AAN), a professional association of medical experts, provides voluntary protocols for determining brain death and persistent vegetative state (the latter it now calls disorders of consciousness). These protocols are updated periodically to reflect recent research. Summaries of the protocols are available for patients to read. Both can be shared with a future health care agent and physician.

The purpose of the protocols is to provide a **clear medical standard for determining life and death matters**. For brain death, the AAN recommends confirming three clinical findings: coma (with a known cause), absence of brainstem reflexes (e.g. not responding to light in the eyes or cold water in the ears), and apnea (not breathing on one's own). This protocol can be a concrete way for your health care agent to establish benchmarks with the medical team treating you.

[Link to AAN Brain Death resources](#)

[Link to AAN Disorders of Consciousness resources](#)

## Consider Your Agent(s): Who Will Understand

### Whom should I choose to be my Agent?

You should choose someone who understands your personal values and will apply them to treatment decisions.

- o The person should be assertive in stressful situations, so that your wishes are communicated to your medical team;
- o It is not necessary for your agent to agree with all aspects of your personal values, but it is important that the agent understand and apply your values in relevant situations.

Because of this, most people choose a trusted family member or friend to be their agent for health care decisions. In order for an agent to apply accurately a person's values, **it is important to speak candidly and consistently with your agent**.

You can go over specific scenarios the agent might encounter; and how you would want the agent to respond. In every case, it is critical to share your principles and reasoning so that your agent becomes familiar with your way of thinking.

Other factors to consider when choosing an agent include:

- o How close the agent lives to you;
- o Whether the agent will be available if needed (e.g. travels frequently or is deployed overseas);
- o Whether the agent suffers from any physical, mental, or social impairment. For example, is the potential agent comfortable enough with medical terminology to advocate for your values?

## Should I select Alternate Agents?

It is a common practice to select alternate agents in case the first choice for an agent is unable or unwilling to serve when needed. You should select alternate agents using the same criteria, taking care to be candid and consistent in communicating your values when it comes to medical decisions. This version of the AHCD provides space for two alternate agents. All agents should have a copy of the executed AHCD.

## Are there any limitations on my Agent's authority?

In this version of the AHCD, your agent is prohibited from authorizing **“any action or omission that is intended to cause or hasten my death.”** In other words, this AHCD prohibits euthanasia, assisted suicide, medical aid-in-dying, death with dignity, and similar acts or omissions.

Your agent is required to pursue “all ordinary medical treatments available,” including:

- o “treatment for alleviation of pain or discomfort;”
- o “food and fluids... by [any] means... unless nutrition and hydration stops benefiting my health;”
- o “basic nursing care and procedures designed to provide comfort care.”

## Consider Officiating Details

## What do I need to do to make my AHCD effective?

To be effective, you may follow the directions in the state-specific form after consulting a local attorney.

## What if I change my mind after my AHCD becomes effective?

You may revoke your AHCD at any time. A simple way to revoke an existing AHCD is to execute a new AHCD that names a new agent and alternate agents. This method preserves the safeguards of the AHCD, while ensuring that your wishes regarding your preferred agent(s) remain current.

## When should I complete my AHCD, select, and educate my agent?

As soon as possible. **Every adult** needs to have these pieces in place in the unfortunate event that life takes a sudden and dramatic turn.

