

Advance Directives

Nobody likes to think about it, but it can happen: through a sudden, catastrophic illness or an accident, you become unable to make decisions about your health care.

An *advance directive* speaks for you when you can't speak for yourself. An advance directive is a written statement that tells a doctor or other health care provider what medical interventions you'd want if you could speak for yourself. You make decisions about your health care, but before you need to. An advance directive can also name someone to make health care decisions for you.

Most people don't have an advance directive because they don't want to think about becoming incapacitated or they just haven't gotten around to it. They might also mistakenly believe that advance directives are only for the elderly.

However, it's much better to think about these issues when you're well than to wait until you're sick and under stress. The best time to create an advance directive is when you're in good health, so avoid procrastinating. Accidents can happen to anyone.

Creating an advance directive is a loving gesture for your family. It spares them from having to make difficult decisions that can potentially create guilt or disagreements between family members. If you don't specify your wishes, others will have to make the decisions for you. No matter how much someone loves you, this is a heavy burden. Also, it's unwise to assume that because someone loves you they will know what you'd want. They might make choices very different than the ones you'd prefer.

You don't need an attorney to help implement an advance directive. You can do it yourself with a form that you can obtain from your family doctor, health care advocate, attorney, health department, hospital, or even AARP. You do, however, need a witness to sign your advance directive.

Your advance directive will include a living will. This is a written statement allowing you to decline life-sustaining treatment if you're terminally ill or in a persistent vegetative state (no higher brain functions with no hope for recovery).

You may also choose to complete a durable power of attorney for health care. This written document designates a person of your choice to make health care decisions for you in the event that you cannot make them for yourself. Rest assured that a durable power of attorney for health care doesn't pertain to financial decisions in any way. Your authorization only applies to health care decision-making.

The person with your durable power of attorney for health care, also known as your 'health care proxy,' is supposed to carry out *your* decisions. So be sure the person you choose is willing to do what you want—even if it conflicts with what he or she would choose for you or for him- or herself. Also make sure to discuss your wishes with this

person so he or she understands them fully. Your doctor cannot serve as your health care proxy; you must choose someone else.

However, you would ideally discuss your wishes with your doctor before formalizing them in a written document. Your doctor can help you understand the implications of different treatments at the end of life. He or she is also likely to have a good understanding of your priorities for your health and what kinds of end-of-life care are most consistent with them.

Advance directives always delineate your wishes about life-sustaining therapies. These include ventilators to help you breathe, feeding tubes, and intravenous (IV) fluids. These therapies may not cure you but they can temporarily prolong your life. There are no right or wrong choices about life-sustaining therapies; they are a matter of personal preference. You just choose to accept or reject them if you have a life-threatening condition and are unable to speak for yourself.

With an advance directive, if doctors start life-sustaining therapies, your health care proxy can have them stopped. An example of this might be if you arrive in an emergency room with catastrophic injuries and are placed on a ventilator before your agent arrives. Your doctors can also discontinue life-sustaining therapy based on your wishes as detailed in a living will.

A living will is valid until you revoke it, but it only applies if you are unable to speak for yourself. If you have a living will in place when you go to the hospital but you can communicate and are coherent, your desires at the time override your advance directive. For instance, even if your advance directive prohibits intubation, you can still choose it.

You or your designated power of attorney for health care may wonder if stopping life-sustaining treatment is the same as committing suicide or killing someone. Absolutely not. When a patient is terminally ill or in a persistent vegetative state, it is the disease or condition that's taking their life. Interventions such as intubation simply delay death. Stopping a life-sustaining therapy is the same as not starting it in the first place—both just allow the natural process of dying to occur without intervention.

Futile therapy is medical interventions that have no medical benefit at all as determined by your physician. Doctors may disagree about whether care is futile, but they are legally able to refuse to provide care they believe is futile. If a patient or a patient's agent disagrees, they may transfer care to another doctor. How would you like your health care agent to respond if your doctors believe your care is futile? Be sure that your agent knows what your wishes are.

Another issue to consider is cardiopulmonary resuscitation, or CPR. This refers to a group of interventions aimed at restarting a person's heart or lungs if they've stopped functioning. CPR can include defibrillation (using electric paddles to stimulate the heart muscle), manually compressing the chest, intubation (inserting a breathing tube in the

lungs and hooking it up to a ventilator), and/or using IV medicines to make the heart beat properly.

CPR can have unwanted side effects, including broken ribs from manual compressions, electrical burns of the chest from defibrillation, and pain. More importantly, if CPR is only partially successful, the patient may be left brain-damaged and unable to communicate. If the chance of full recovery is small (for example, in someone with end stage disease of the heart or another organ), the risk might not be worth the tiny chance of benefit. Weighing the pros and cons of CPR is an excellent reason to discuss your individual circumstances and choices with your doctor.

In addition to thinking about issues like CPR, intubation and ventilation, food and fluids, and dialysis, consider the following questions.

- Which statement do you agree with more?
I want to live as long as possible regardless of my quality of life
OR
I want a good quality of life even if I may not live quite as long
- How important to you is the ability to communicate?
- How important to you is the ability to think clearly?
- How much do you worry about being a burden to your family?

Writing down your answers to these questions and discussing them with your health care proxy can provide direction in situations where a living will might be less clear. For example, your living will might decline IV fluids if you have a terminal illness, such as end stage cancer. However, what if you have cancer but aren't near death and get in a car accident? Your living will declines fluids, but your doctors believe that, with some temporary aggressive treatment, they can restore your health to where you were before the accident. What should they do?

Clearly communicating—in writing and with your health care proxy—your values and priorities will help your doctors and proxy know how to follow your wishes. You might include a general statement along these lines:

If my doctors think I can be restored to a state where I could speak, walk, and enjoy my family, then I want more aggressive treatment. If they believe treatment will only prolong my death, I don't want it.

An advance directive form called 'The Five Wishes' leaves more space for explaining priorities. You can order it at www.agingwithdignity.org or you can use another advance directive form and attach a paragraph explaining your values and priorities

Be sure to discuss your advance directive with multiple members of your family. This decreases potential family conflict and stress if your advance directive is used and protects you in the event that your health care proxy is incapacitated, too. For instance, if your spouse is your proxy and you're both injured in the same accident, informing other family members ensures that your wishes will still be followed.

Preparing an advance directive may not be fun, but it's important. When you can no longer speak, it reminds your family that you loved them enough to prepare for the worst.

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