



Other Issues Related to Hepatitis C

# End-of-Life Issues and Hepatitis C

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The development of new antiviral drugs means it is easier than ever to cure hepatitis C virus (HCV). Despite this, the number of people who are dying from hep C is increasing, and will continue to rise unless we diagnose and treat the millions of people who still don't know they are infected.

Even if we treat everyone who has hepatitis C, some will still develop cirrhosis and be at risk for liver cancer, and death may feel all too close. As a result, they may not know how to or be afraid to talk about it.

We plan our careers, vacations, weddings and retirement; we even plan our hepatitis C treatment. Despite the fact that we all die eventually, most of us don't make plans for the end of our lives. We often leave it to others to make important decisions surrounding our health care, dying and after-death arrangements.

It is easy to procrastinate on end-of-life issues. We don't think about it when we are feeling well, and when we are sick, we don't have the energy to give the issue the consideration it deserves. But it is better for us, and for those we leave behind, if we take the time to plan ahead.

Making decisions from estate planning to health care, from how we want our lives celebrated to how we want our body disposed of, can be overwhelming. The information in this section pertains to health care advance planning, and provides resources to help you with some of the other aspects of end-of-life planning. Take one step at a time and, eventually, you will complete your plan. Then you can sit back, enjoy life and appreciate the fact that you have made your wishes known.

## Health Care Advance Planning

Advance directives are documents that you set up before you need them that state your wishes if you are at the end of life and unable to communicate. There are various types of advance directives, and this section describes two: the living will and the durable power of attorney for health care (DPAHC).

Many of us say that we do not want prolonged or painful deaths, but the majority of us do not take the time to document our wishes by having advance directives. A good way to convey this information to your health care agent is through a living will. This document lists particular interventions that you may or may not want under certain medical conditions. You can specify in the living will how you feel about ventilators, feeding tubes, resuscitation, pain medication, organ

donation and various other medical interventions. Educate yourself about some of the possibilities and be as specific as you can in your directives.

The DPAHC is a document declaring that you have appointed someone to act as your agent, in order to make your wishes known in the event that you cannot. This is someone you trust and is willing to act as your agent. Your agent doesn't decide if, how or when you are going to die; your agent's job is to carry out your wishes, so it is important that you communicate to your agent what you want.

Advance directive forms are available online. Hospitals and medical offices usually offer them as well. Make sure you use a form that meets your state's requirements. Some organizations, such as the U.S. Living Will Registry, offer nationwide electronic registration of your documents. A list of resources is provided at the end of this section.

Here is more information about advance directives:

- Each state has its own laws governing advance directives, so it is important to seek advice specific to your state. In some cases, the power of attorney and the living will are combined into one document called the Advance Health Care Directive.
- Advance directives only go into effect if you have a terminal condition and you lose your ability to make health care decisions. For instance, if you are unconscious but expected to live, then the advance directives don't go into effect. If you have a terminal condition but regain the ability to decide for yourself, then the agent no longer acts on your behalf.
- The most effective strategy for insuring that your wishes are followed is to make your preferences known to as many people as possible. Storing a written copy of your advance directives in a safe deposit box won't be helpful in an emergency. Give a copy of your advanced directives to your appointed agent. Inform as many people as possible that you have advance directives and where they are located.
- Give copies of your advance directives to your physician and your medical facility, and ask them to make it part of your permanent medical record.
- Keep a small card in your purse or wallet noting that you have advance directives, where they are located and the name of your agent, if you have one.
- Under federal law, when you enter a medical facility that receives reimbursement from Medicare or Medicaid, you should be asked whether you have advance directives. If you do, the

facility will request that you provide a copy to be placed in your permanent medical records.

- Review your advance directives on a regular basis. Choose an anniversary date to help you remember when to conduct this review. Update your directives after a major life-changing event, such as divorce, death of a loved one or a change in your health. Be sure to let your designated agent, medical team, family and other close ones know of any changes to your advance directives.

## Resources

### Aging with Dignity

For a small fee, you can purchase a form called “Five Wishes” that explores many aspects of dying.

[agingwithdignity.org](http://agingwithdignity.org)

### American Bar Association

Excellent information and tools about advance directives.

[americanbar.org](http://americanbar.org)

Caring Connections–Information and forms about hospice and end-of-life issues.

[caringinfo.org](http://caringinfo.org)

### Funeral Consumers Alliance

In addition to after-life planning, this nonprofit organization provides information about many aspects of death.

[funerals.org](http://funerals.org)

### U.S. Living Will Registry

The Living Will Registry is a privately-held electronic registry that offer a wide range of educational resources.

[uslivingwillregistry.com](http://uslivingwillregistry.com)

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