

Final Steps with HCV: An HCSP Guide on *Death* and *Dying*



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Alan Franciscus
Executive Director
Editor-in-Chief, HCSP
Publications

Author
Lucinda K. Porter, RN

Managing Editor / Webmaster
CD Mazoff, PhD

Contact Information
Hepatitis C Support Project
PO Box 427037
San Francisco, CA 94142-7037
alanfranciscus@hcvadvocate.org

The information in this guide is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV.

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Foreword

The vast majority of those with hepatitis C (HCV) will die **with** it and not **of** HCV. However, we are all going to die from something at some point. Death is a subject many of us are uncomfortable with, despite its inevitability. Death is frightening.

Ethnicity and religion influence our attitudes about death. In some cultures, death is celebrated. In others, death is not discussed. Some cultures have incorporated death into every day life. In the United States, death usually occurs in a hospital. Because of this, death is a nearly invisible process, making it even more mysterious and unapproachable.

Ignoring death does not change the outcome. Experts in the field of death suggest bringing this topic into the open. Confronting death may help us realize how alive we are. Coming to terms with death may help our loved ones and us.

We plan vacations, projects, career changes, weddings and HCV treatment. However, issues around death and dying may be left for others to decide for us. It is easy to procrastinate planning for this event. We think it isn't going to happen for a long time, so why think about it now. Besides, once we are gone, it won't matter what we think.

The problem is, death isn't predictable. A good example is Terry Schiavo¹. She did not write clear information about how to handle her last days of life. As a result, the end of Ms. Schiavo's life was a media event, tearing apart her family and the nation.

It has been said, "None of us gets out of life alive." Being human is a life-threatening condition. This guide discusses issues surrounding death and dying. I hope this creates an opportunity to think and talk about both life and death.

Lucinda Porter, RN

Writer, Hepatitis C Support Project and *HCV Advocate*

¹*Terri Schiavo, suffered severe brain damage in 1990 following a heart attack. The brain damage left her unable to care for herself and living in a constant vegetative state. Her husband believed that Ms. Schiavo would not want to live this way and took steps to stop nutrition, hydration and life support. Her parents disagreed and Ms. Schiavo's life became a legal, moral and political debate. Ms. Schiavo died on March 31, 2005.*

1. Advance Directives

The debate over the life of Terri Schiavo could have been avoided if she had done some planning before her heart attack. This is called an *advance directive*. Health care advance directives are documents that address medical issues in the event that you are unable to speak for yourself.

Health care advance directives provide information about your preferences in the event that you are unable to make a decision about your medical care. An advance directive is a gift you give to others because you are making your wishes known rather than asking others to guess what your decisions might have been.

A health care advance directive consists of two documents: a *living will* and a *durable power of attorney for health care* (DPAHC). The living will is a written document describing specific health care interventions that you may or may not want under certain medical conditions. The DPAHC is a document attesting that you have appointed someone you trust to act on your behalf in order to make your wishes known in the event that you may be unable to do so yourself. That person is known as your *agent* or *proxy*.

Federal law states that medical, home health and hospice facilities serving persons covered by either Medicare or Medicaid must inform you about Advance Directives. The facility is required to inform you about your legal right to have an Advance Directive and your right to refuse any medical care you do not want.

Each state has specific legal guidelines for advance directives. For instance, in California, the *Health Care Decisions Law* combines the power of attorney and the living will into one document called the *Advance Health Care Directive*. You do not need a lawyer to write health care advance directives, although some attorneys specialize in this area. Find out if your state requires witnesses or notarization of your advance directive.

Advance directive forms are available on the Internet. Hospitals, medical offices, and community health libraries sometimes have these forms. Make sure you use a form that meets your state's requirements. The *Resource* section of this guide provides information that may help you find the proper forms for your state.

After completing your advance directives, it is important that you talk to those who are closest to you, such as family, partners or close friends. Unfortunately, family members can behave in unpredictable ways when under stress. To avoid this, let them know in advance what your wishes are and who your proxy is.

Give copies of your health care advance directive to your proxy and alternate proxy. Give copies to your medical provider(s) and those closest to you. Keep a copy for yourself and tell others where you keep it. Put documents in a place that is easy to find. Do not put end-of-life documents in a safety deposit box.

Take a copy of your advance directives with you every time you are hospitalized. Carry a wallet card notifying others that you have advanced directives.

Regularly review your directives. Pick an easy to remember date for an annual review, such as the day after you send in your taxes (death and taxes are unavoidable). Review your directives after a major life-changing event, such as divorce, death of a loved one, or a change in your health.

If you want to change your advance directives, it is best to complete a new document. A new document takes precedence over older directives. If you wish to revoke your advance directives without writing a new document, let your fam-

“The fear of death is worse than death.” – Robert Burton

ily, friends, medical provider and hospital know, preferably in writing.

2. Durable Power of Attorney for Health Care

The DPAHC is a document attesting that you have appointed a proxy to act as your agent in order to make your wishes known in the event that you may be unable to do so yourself. Your physician cannot be appointed to make these decisions. Choose someone you trust and ask that person if he/she would be willing to act as your agent.

Communicating with your agent is the most important part of this process. It may be more important than writing your living will. Tell this person as much as you can about how you want the quality and details of your medical care to be handled.

Sometimes people are reluctant to appoint someone to act as their agent, not wanting them to have to make life and death decisions. Actually, it is the other way around. If you do not appoint an agent, you are forcing your loved ones to make decisions about you. When you have a DPAHC, you are asking them to follow your instructions. It is a good idea to appoint an alternate in case your original proxy is unable to fulfill his/her obligations.

Note: Since your agent is representing you, Health Insurance Portability and Accountability Act (HIPAA) regulations do not interfere with your agent's ability to receive medical information about you.

3. Living Wills

A living will is a document that gives specific instructions about your health care preferences should you become incapable of communicating. This is the appropriate place to specify how one

feels about breathing machines, feeding tubes, resuscitation, pain medication, and other various medical interventions. If you do not want prolonged or painful death this is the opportunity to document your wishes.

Living wills reflect your values. You may believe that every measure should be taken to prolong life. You may have strong opinions on keeping people alive who suffered massive brain injuries but who are otherwise living in a comatose state. Start by educating yourself about some of the issues and possibilities that may occur towards the end of life. Write down your wishes. Be as clear and specific as you can.

Assuming that death was imminent, consider the following:

- What sorts of medical intervention would you want or not want?
- If you could no longer eat or drink fluids, would you want to be fed by a tube in your stomach?
- Would you want intravenous fluids?
- How do you feel about the use of breathing machines to keep you alive?
- If you had severe pain, would you want your pain to be controlled even if it meant you would be sedated?
- Would you want to be kept alive no matter what?
- Would you prefer to die at home or in a medical facility?
- How do you feel if being kept alive meant spending the rest of your life in a hospital or skilled nursing facility?
- How do you feel if being kept alive placed a huge financial and emotional burden on your family?

These are only a few of the issues to think about. A good way to proceed is to use a template as a starting place. Forms and tools are available to help you with this. Your doctor or hospital may be able to help you with this. The organization

Aging with Dignity has a form called *Five Wishes*. It is popular, works in most states, and costs five dollars. See Resources to obtain information and help.

4. End-of-Life Medical Care

You can expect to receive good medical care at all stages of life, even towards the end. Lifesaving medical care will be provided as long as there is reason to believe it will help. Medical treatment that provides comfort but is not lifesaving is called *palliative care*. Palliative care relieves symptoms but does not cure an illness.

Some people receive end-of-life care through *hospice*. Hospice provides comfort and support for a patient and family facing death. Hospice care can be given in a home or hospital.

If death is imminent and you do not want to be revived, talk to your medical provider about *do-not-resuscitate orders*. These orders can only be given by a doctor. In many states, if emergency personnel are called, they are required to provide cardiopulmonary resuscitation (CPR) if it is needed. If you are dying and do not want CPR, ask your doctor to write *non-hospital do-not-resuscitate orders*.

5. Death from HCV

The vast majority of people with HCV will die *with* it, not *of* HCV. It is estimated that between 8,000 and 12,000 people will die from HCV-related complications. Some patients with advanced cirrhosis want to know what to expect when facing death.

Just like birth, stories about death vary, so no two deaths are alike. Typically, a patient with

advanced cirrhosis will begin to *decompensate*. This means that the liver has hardly any function left. In cases where HCV is the cause, liver failure is usually very slow and gradual. This may be a faster process if alcohol or another disease is involved.

Typically, someone with liver failure will have jaundice. Eyes and skin will be yellow. Urine is usually the color of tea, stools the color of grayish clay. Intense body itching is common. The person is usually extremely bloated. This is from *ascites* or fluid accumulation in the abdomen. Mental confusion, known as *hepatic encephalopathy* may occur in end stage liver disease. Bruising and vomiting blood are other signs. Loss of appetite, extreme fatigue, and infection may occur during end stage liver disease. People with end stage liver disease often slip into a coma before death.

“Death is more universal than life; everyone dies but not everyone lives.” – A. Sachs

Note: People with HCV often complain about feeling foggy or confused. Patients refer to this as “brain fog.”

This is very different from the confusion that is caused by hepatic encephalopathy.

6. Facing Death

It is both common and normal to have strong thoughts and feelings about death. Dwelling or acting on them is not. The following are a few suggestions to consider if you find yourself wrestling with issues about death.

- *Talk about it.* Tell someone your fears and thoughts. Sometimes the act of saying the unspoken can be very powerful.
- *Get the facts.* Talk to your doctor about your particular situation. Be specific with your questions. Should you be concerned about the fact that you cannot remember things like you used to? What are your chances of dying from HCV? If you have an unfavorable prognosis, how much

time do you have left? Your physician may not know the answers to these questions, but should take you seriously. You have the right to not be dismissed or made to feel uncomfortable about your concerns.

- *Compare notes.* The key here is to talk to other people *without* HCV. Choose people close to your age and lifestyle. Ask them how they feel. You might be surprised to learn that many people without HCV are also feeling tired, achy, and find their memory slipping.
- *Get support.* The key here is to talk to people *with* HCV. In spite of what was said in the previous paragraph, people with HCV do have more health complaints than those without HCV. They also have ways to cope with these complaints. They know the best and the worst doctors. They can recommend web sites and literature. Best of all, when you are at a support group, you do not have to try to look or act your best.
- *Control what you can control.* You may not have control over the fact that HCV has taken up residence in your liver, but you do have control over whether or not you risk further harm by using alcohol. Look at your lifestyle. Do you smoke, drive without a seatbelt, or misuse drugs? Do you exercise and are you careful about what you eat? Do you get 7 to 9 hours of sleep every night? How is your attitude? You can control these areas. One caveat – permanent change does not happen instantly. If you find yourself wanting to make changes, learn how to do this successfully.
- *Plan your death.* Everyone needs to think about this. How do you feel about pain medication, tube feeding, and mechanical life support?
- *Grieve.* Grief is a part of death. Many of us know people who have died from complications

“There is no cure for birth and death save to enjoy the interval.” – George Santayana

related to HCV. Patients talk about friends from their youth, people they grew up with, who are now dead. Experiencing grief is the only way to get through it.

- *Live while you are alive.* Focus on the present, not the future. Until you stop breathing, you are still alive. How are you going to spend today and the rest of your life?

7. Transplantation/Organ Donation

The majority of those who are chronically infected with HCV will never have to face the complexities surrounding liver transplantation. Statistical odds and good health practices (particularly curbing or abstaining from alcohol use) minimize the need for a transplant.

Currently there are approximately 90,000 people waiting for an organ transplant in the United States. Every day, nearly 75 people will be organ recipients. Every day, 10 people die waiting for an organ. It is estimated that 12,000 people annually meet the criteria to become donors, but only one-third of them actually donate their organs.

Many of us believe that simply noting on our driver’s license that we want to donate our organs insures this will automatically happen when the time comes. However, this is not the best way to achieve donation. People are encouraged to talk to their family members as well as their care-providers. The decision to donate organs falls upon the family members. Make your wishes known to them, loudly, clearly, and frequently. Encourage them to do the same.

Some states have organ transplant registries. Organ registries remove the decision-making process from your loved ones. However, it is always a good idea to discuss your wishes with them. If your state has one, register your wishes. Carry a donor card with you.

8. Making Medical Decisions for Others

If you are asked to make decisions for another person, it is best to talk to them *before* the need exists. Find out what their preferences are and if they have any written documents describing their wishes. It would be helpful if you can get an advance copy of the document. Review the advance directives on an annual basis or anytime there is a major change in that person's life or health.

Remember, you are to help carry out *someone else's* wishes, which may be different than decisions you would make for yourself. Make sure you are very clear about what you are being asked to do.

Should you find yourself in this role for an event in which there was no prior planning, ask yourself, "What do I think this person would want?" You may want to ask others who are close to the individual. Ask yourself, what is in this person's best interest?

These questions can only be answered after you have gathered sufficient information. Some information you need to know is:

- What are the options?
- What are the risks and benefits of each option?
- Is this person suffering?
- What is the quality of life with or without an intervention?
- What are the risks involved with or without an intervention?
- What are the wishes of those close to the patient?
- What do the doctors recommend?
- If this person is active in a religious community, what is the recommendation of the leader of that community?

9. Resources

1. AARP – www.aarp.org/families/end_life (888) 687-2277 Also known as the American Association of Retired People, AARP offers excellent resources for end of life planning
2. Aging with Dignity – www.agingwithdignity.org (888) 5-WISHES/(888) 594-7437 For five dollars, you can purchase a popular form called "Five Wishes"
3. American Bar Association – www.abanet.org/aging/toolkit (800) 285-2221 Very good information and tools about advance directives
4. Americans for Better Care of the Dying – www.abcd-caring.org This activist organization sells excellent books on the issues of death and dying
5. American Medical Association (AMA) – www.ama-assn.org (800) 621-8335 You can access information specific to your state by visiting the links to local AMA chapter; look for end-of-life planning resources in the MEDEM medical library section: www.medem.com/MedLB/sub_detaillb.cfm?parent_id=384&act=disp
6. Caring Connections – www.caringinfo.org (800) 658-8898 Information and forms about hospice and end-of-life issues
7. Center for Practical Bioethics – www.practical-bioethics.org (800) 344-3829 Practical information and tools to help make difficult decisions
8. Coalition on Donation – www.donatelife.net Information about organ donation
9. Compassion and Choices – www.compassionandchoices.org (800) 247-7421 Provides information about compassion and end-of-life choices
10. Family doctor – <http://familydoctor.org/003.xml#6> Information about advance directives and do not resuscitate orders
11. Hospice Foundation of America – www.hospicefoundation.org (305) 981-2522 Information about hospice and related issues

12. National Academy of Elder Law Attorneys – <http://naela.org> (520) 881-4005 Legal information for older adults
13. National Cancer Institute – www.cancer.gov/cancertopics/factsheet/support/hospice (800) 4-CANCER/(800) 422-6237 End-of-life information and resources presented by the National Institutes of Health
14. National Hospice and Palliative Care Organization – www.nhpco.org (703) 837-1500 Provides information on many aspects of death and dying, such as advance directives, hospice, and grieving
15. National Funeral Directors Association – www.nfda.org Information about funerals and celebrating life
16. National Right to Life’s “Will to Live” – www.nrlc.org/euthanasia/willtolive/StatesList.html (202) 626-8800 This organization discusses options that are meant to use medical interventions to keep those alive who prefer this option
17. Neptune Society – www.neptunesociety.com This organization provides cremation services
18. United Network for Organ Sharing (UNOS) – www.unos.org Information about organ donation
19. U.S. Department of Health and Human Services – www.organdonor.gov/donatelife.htm Information about organ donation
20. U.S. Living Will Registry – www.uslivingwillregistry.com (800) LIV-WILL/(800)548-9455 This website is totally devoted to the issue of advance directives
21. *Your Life Your Choices – Planning for Future Medical decisions: How to Prepare a Personalized Living Will*, by Robert Pearlman, et al and the Veterans Administration Medical Center, Seattle, WA – www1.va.gov/hsrd/publications/ylyc.pdf A 52-page workbook focusing on death and dying issues

HCSP GUIDES

The Hepatitis C Support Project has published various publications in our “Guide” series. The Guides are available on our Web site www.hcvadvocate.org

A Guide to Understanding and Managing Fatigue – this Guide provides a comprehensive overview of the causes of fatigue as well as simple tips to help manage this often debilitating symptom of HCV.

Management of Hepatitis C by the Primary Care Provider: Monitoring Guidelines. This Guide gives the medical provider with the necessary information to help identify and manage hepatitis C positive individuals. (Available in English and Spanish.)

A Guide to Hepatitis and Disability is one of the most comprehensive documents available on how to prepare and file for social security disability. There is additional information on commercial disability insurance, and health insurance.

First Steps for the Newly Diagnosed is an HCSP guide designed to help the person who is newly diagnosed with the medical aspects of HCV including a lab tracker, questions to ask your medical provider and more.

Women and Hepatitis C: An HCSP Guide, by Lucinda Porter, RN, discusses the issues around hepatitis C and how they differ in women.

The Guides are downloadable in copy-ready format. Permission to reprint is granted and encouraged with credit to the hepatitis C Support Project.