

Stigma and Hepatitis C

Lucinda K. Porter, RN



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

Author
Lucinda Porter, RN

Managing Editor, Webmaster
C.D. 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.

Version 1.0 April, 2006
© 2006 Hepatitis C Support Project



Table of Contents

Foreword	2
Stigma	3
Effects of Stigma	3
Living with the Labels of Others	4
Breaking Free from Our Own Labels	4
Acting Responsibly	6
Topics for Thought or Discussion	7
Resources	8

Foreword

Millions of Americans live with the hepatitis C virus (HCV). Although potentially life threatening, the vast majority of those with HCV will die **with it** and **not of** HCV. In most cases, HCV is manageable and treatable. However, HCV may test the physical, emotional and spiritual health of those with it. HCV touches the homes, workplace and communities of all those within its reach.

An often overlooked and painful component of HCV is stigma. Although invisible, stigma is a harsh reality. For some, the stigma of HCV hurts more than HCV itself. This guide discusses the ways in which HCV is stigmatized and provides tools for confronting and living with HCV's senseless labels. Stigmas hurt all of us. We may not all have HCV, but we all live with it. Living without stigmas and with compassion is just plain good sense.

Stigma

According to the Oxford Dictionary, the definition of stigma is *"a mark of disgrace associated with a particular circumstance, quality or person."* The Greek and Latin roots of stigma mean "to mark, brand or tattoo." The dictionary Encarta, defines stigma as *"a sign of social unacceptability: the shame or disgrace attached to something regarded as socially unacceptable."* Merriam-Webster's descriptions of stigma include *"a mark of shame or discredit; an identifying mark or characteristic; a specific diagnostic sign of a disease."*

Sadly, hepatitis C does carry a stigma. This may be for several reasons. First, HCV is potentially infectious. Although not easily transmitted, people are nevertheless fearful and shun those who have the disease. Fear and ignorance have cost patients their jobs, friendships and marriages. Hugs and kisses cease. Sexual relationships stop or are never initiated. In the extreme, even marriages have been challenged.

Another stigma associated with HCV is connected in a

**"PREJUDICE IS
THE CHILD OF
IGNORANCE."**

**– WILLIAM
HAZLITT**

“FEAR IS A DISEASE THAT EATS AWAY AT LOGIC AND MAKES MAN INHUMAN.”

– MARIAN ANDERSON

more general way. Some people do not like to be around people who are “sick.” The disease itself does not seem to matter. It does not have to be an infectious disease, nor one with obvious symptoms. This is probably due to fear. Some people are afraid of illness and death. They may be uncomfortable around others who have a disease or illness. Consciously or unconsciously, this discomfort may cause them to avoid those with diseases. They may also be afraid that someone they care for will die, so they reject that person rather than risk the loss.

A third stigma connected to hepatitis C is from its association with injection drug use. Misinformed people sometimes assume that all hepatitis C patients have a history of injection drug use in spite of the many ways hepatitis C can be acquired. Our society lacks compassion and understanding about injection drug use. Those who never used injection drugs do not want to carry that label. Former injection drug users feel haunted by their past and want to avoid this label. Active injection drug users carry the burden of having two stigmatized diseases – addiction and hepatitis C.

Effects of Stigma

The potentially damaging effects of stigma are elegantly described in *Stigma: Hepatitis C and Drug Abuse*, by Astone-Twerell, Strauss, and Munoz-Plaza.¹ The authors report some of these effects as: “reduced self-esteem, diminished mental health, less access to medical care, and fear of disclosing a positive status.” Fear of disclosure may lead to reduced social support and reluctance by medical providers to care for HCV-positive patients. In particular, injection drug users have trouble accessing medical care and other humane services.

In the January 2006 issue of *Hepatitis* magazine, the staff conducted an informal web poll about stigma and viral hepatitis (Vol. 8, No. 1, p. 53). The article reported both good and bad news. First the good news: 42% of the participants felt they had not faced any stigma due to living with hepatitis B (HBV) or hepatitis C (HCV). Now the bad news: 20% felt they had experienced job discrimination due to HBV or HCV; 13% reported hepatitis-related social stigma; 13% had been alienated from family and friends because of viral hepatitis. The most remarkable report was that 8% of those in this informal survey felt that medical professionals had denied service to them because of HBV or HCV.

It is tragic to witness this unnecessary and avoidable ostracism. Those struggling to live with a chronic disease need more support, not less. To some, the isolation is worse than the virus. This is distressing, especially when patients are newly diagnosed and need the most support.

Living with the Labels of Others

How you acquired HCV is nobody's business. You do not need to tell anyone you have hepatitis C. However, HCV is a community problem that needs a community response. It is time to look at solutions rather than problems. Dropping the stigma is a good place to start.

What can we do about this? First, start with yourself. Do you label yourself? Do you expect to be shunned? Do you fear that others will reject you in some way? Do you have your own fears about having HCV? If so, talk about this. The best place to discuss these feelings is at an HCV support group. Learn how others live with HCV.

Do you feel like you deserve HCV as a consequence for current or past behavior? If so, there is something you need to know – no one deserves HCV. It does not matter how you acquired HCV. This virus is not a punishment or natural consequence – it is an unfortunate but unintended outcome. Guilt and remorse will not improve your health and may have a negative effect. If you struggle with negative emotions, talk to your medical provider. You may need some counseling. **Important Note: If you have thoughts of suicide or of hurting yourself or others, seek immediate professional help.**

Breaking Free from Our Own Labels

We live in a label-conscious society. Clothes, sports apparel, handbags, even our eyewear dons some sort of label. But what happens if **you** label yourself? What would you say if you were asked, "Who are you?" Take a moment and answer that question. Make a list of everything you are. You might answer, "I am a mother or a father; a spouse, a partner, or a friend; a Buddhist, a Methodist, a Jew; a carpenter; a dentist; a hepatitis C patient. If you labeled yourself as a hepatitis C patient, this section is for you.

Labels define us. They tell others who we are. They tell us about our values and beliefs. Some labels describe our relationships and identify the people in our lives. Some labels describe what we do, such as an occupation or hobby. Declaring our religious preferences gives insight into our spiritual beliefs. However, being a hepatitis C patient is quite different from being a parent or a nurse. Saying, "I am a hepatitis C patient" defines me. It says, "I am sick." It ties me to a state of disease rather than to a state of health.

It is easy to identify with an illness. Hepatitis C (HCV) can be all encompassing at times. Sometimes it is in the foreground; other times in the background. Nevertheless, it is always there. However, living with HCV is not the same as being an HCV patient.

"OUR ENTIRE LIFE... CONSISTS ULTIMATELY IN ACCEPTING OURSELVES AS WE ARE."

– JEAN ANOUILH

This may seem like hair splitting. Before dismissing this idea, try an experiment. If you imagine or describe yourself as an HCV patient, try substituting more powerful images and words. Imagine yourself as strong and calm. Say to yourself, “I am living with hepatitis C, but I am much more than this.” How does this feel as compared to “I am a hepatitis C patient”?

There is a healthy side of identifying with an illness. We can't let go of something without first accepting it. An important part of moving through HCV is to acknowledge it, reflect on it and recognize its meaning. In *Man's Search for Meaning*, Viktor Frankl notes, “seriously ill people are often not given the opportunity to suffer bravely, and thereby retain some dignity.” He goes on to say that when we tell people to cheer up and be optimistic, the ill are made to feel ashamed of their pain and unhappiness.

Frankl is imminently qualified to speak about the human search for meaning. His contributions to modern psychotherapy were forged by his experiences as a Holocaust survivor. Frankl spent three years in Nazi death camps, including Auschwitz. The Nazis slaughtered his family. Frankl endured more than most of us. He did not let pain, torture, or grief interfere with living a life filled with compassion and integrity.

The problem occurs when a line is crossed between finding the meaning in the illness versus letting the illness define you. What does having HCV mean to you? Does it mean a lifetime of fatigue? Loss of opportunity? Perhaps HCV is a wake-up call, motivating you to make lifestyle choices that bring renewed vigor. Maybe you appreciate life more because of HCV.



A Buddhist principle is that our energy follows our attention. If we focus on illness, that is where our energy will go. Illness can take over, robbing meaning and joy from our lives. The entire self is defined by illness.

If this rings true for you, consider an attitude adjustment. Try to live in the positive rather than the negative side of life. Optimism is not wishful thinking. If an earthquake is rocking the world, it is foolhardy to act as if you are on steady ground. The wise thing is to protect yourself and others, and to try to minimize the damage. Once the shaking stops, evaluate the damage and make a recovery plan. The optimist looks at what is left and plans around this. The pessimist looks only at what is gone and in doing so, lives in the loss and pain.

Tips for Developing a Healthy Attitude

- Be honest and realistic. Do not base your attitude on thinking things are worse than they are or better than they are.
- Make sure you know the truth. Get accurate information about HCV. Some people think that HCV is an automatic death sentence. This is not true. The majority will die **with** HCV, **not of** HCV.
- Stay in the present. Don't make things worse by imagining a future with pain, disability or loss.
- Accept your situation, but don't overly identify with it. HCV may be a part of your life, but that doesn't mean it should control your life.
- Maintain your perspective. Focus your attention on something that brings peace, joy, laughter and meaning.
- Watch your words. If you hear yourself talking negatively, substitute positive phrases. Say, "I will find a way to live with HCV" rather than "HCV is ruining my life."
- Try to relax. Tell yourself that difficult moments will pass.
- Visualize health, not illness. Visualization is a powerful tool for self-transformation.
- Practice gratitude. Make it a habit to find things for which you are grateful.
- Learn what you can control and what you cannot. There are things you cannot control, such as the fact that you have HCV. However, there are things you can control, such as your attitude and what you say to yourself about having HCV.
- Learn from HCV. Ask yourself what HCV can teach you about living.
- Get support. Being with others who are dealing with the same issues can bring encouragement and hope. See if there is an HCV support group in your area.
- Help others. When it comes to stepping outside of ourselves, probably nothing works as well as reaching out to others who are also struggling.

In *Minding the Body, Mending the Mind*, Joan Borysenko writes, "Adversity is the crucible in which the spirit is forged." A similar expression is "that which does not kill us, makes us stronger." Hepatitis C is an invitation to cherish each day, to live fearlessly and fully. It is the opportunity to wear a new label.

Acting Responsibly

You are not legally required to disclose your hepatitis C status. However, there are certain moral responsibilities that come with having a potentially infectious virus. First, do not attempt to donate blood, tissue or organs without complete and honest

disclosure about your health. There are certain conditions in which donation is appropriate, such as for research purposes. Hepatitis C-positive organs are used in certain circumstances. Educate yourself about ways you can reduce your risk of HCV transmission to others. Act from a place of responsibility rather than a place of fear.

One final thought for reflection – there is another definition of stigma. In botany, the stigma is the part of a plant where bees deposit pollen. The stigma bears the fragrant sweet solution that attracts bees. It is a place of fertilization. For those with HCV, it may be the place where shame blossoms into hope. It is time to bring hepatitis C out of the closet and into the sunshine.

Topics for Thought or Discussion

- Do you tell others that you have hepatitis C? Whom do you tell and whom do you not tell? What are the reasons for withholding this information?
- Have you ever felt that others are uncomfortable because you have hepatitis C? If so, why do you think that is?
- Do you believe that hepatitis C carries a stigma? Why do you think this is?
- Have you ever felt uncomfortable around others who have an illness? If so, what makes you uncomfortable?
- What are your feelings about having HCV? What label(s) do you give yourself? Do you see yourself as a victim of HCV? Do you feel like you are “dirty” or a risk to others? Do you feel like your health and future have been ruined?
- Do you feel like you deserve HCV as a consequence for current or past behavior?
- Has hepatitis C influenced your life in any positive ways?
- Is there anything you can do to address the stigma of hepatitis C?
- What do you want others to know about your life with HCV?
- What are some actions that you might take if you felt a medical provider behaved improperly because your HCV status?
- What are your thoughts on this statement: “I deserve HCV because I used injection drugs 20 years ago.”
- Do you have any advice for those who are newly diagnosed with HCV?

➔ **Coping with Stigma**

- **Educate yourself and others. Inaccurate information can perpetuate stereotypes.**
- **Get support. We can achieve together what we may not be able to do alone.**
- **Laugh at yourself and with others who have HCV. Laughing with those who share our experiences can lighten the load of HCV.**
- **Speak the truth, but don't criticize or blame others. Stigma comes from ignorance and fear. Educating others may be all that is needed in order to break through stigma.**
- **Join a patient advocacy group.**
- **Tell the media or other agencies if you are offended by how HCV is portrayed. There was a tasteless and misinformed comment about hepatitis C in the film Bewitched. A letter to the movie producers is a proactive response to this stereotyping.**
- **Challenge stereotypes. If you do not like how marketers portray people with hepatitis C, let them know.**
- **Take action. Send letters, emails, faxes and phone calls to legislators, policy-makers and agencies. These are powerful tools for political and social change.**
- **Think globally, act locally. See if your community has an HCV task force and become a member.**
- **Maintain your focus and resolve. Margaret Mead said, “Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.”**

Resources

- Hepatitis C Support Project
- www.hcvadvocate.org
- Hepatitis C Advocacy Coalition
- www.hepcadvocacy.org
- Hepatitis C Advocate Network
- www.hepcan.org
- Hepatitis C Harm Reduction Project
- www.hepcproject.org
- National Hepatitis C Advocacy Council
- www.hepcnetwork.org
- United States Government's Official Web Portal
- www.firstgov.gov (800) FED INFO (800) 333-4636
Information and links to all federal, state and local officials and agencies

Notes

¹“Stigma: Hepatitis C and Drug Abuse”, by Jannetta Astone-Twerell, Ph. D., Shiela M. Strauss, Ph.D., and Corrine Munoz-Plaza, M.PH. National Development and Research Institutes, Inc. (2006) This article can be found under “Medical Writers’ Circle” at www.hcvadvocate.org.

➔ **HCSP Guides**

The following HCSP Guides are available at www.hcvadvocate.org in pdf format and may be downloaded and printed.

- A Guide to Hepatitis and Disability
- A Guide to Hepatitis C: Making Treatment Decisions
- A Guide to Hepatitis C: Treatment Side Effect Management
- A Guide to Understanding and Managing Fatigue
- A Guide to Understanding Clinical Trials and Medical Research in Hepatitis C
- A Guide to Understanding Hepatitis C
- A Guide to Understanding Hepatitis C Basics
- Aging and Hepatitis C: An HCSP Guide
- Easy C - A Guide to Understanding Hepatitis
- Final Steps with HCV: An HCSP Guide on Death and Dying
- First Steps with HCV for the Newly Diagnosed
- Hepatitis C Support Group Manual
- Management of Hepatitis C by the Primary Care Provider: Monitoring Guidelines
- Women and Hepatitis C: An HCSP Guide

➔ **Additional**

- HCSP Find a Physician Locator
http://linux.hcvadvocate.org/cgi-bin/doctor_lookup1.cgi
- HCSP Support Group Locator
http://linux.hcvadvocate.org/cgi-bin/sg_lookup1.cgi
- Ottawa Health Research Institute - <http://www.ohri.ca/DecisionAid> This website offers several excellent tools that can help with decision-making.