

FOR FAMILY AND FRIENDS: **CARING FOR SOMEONE WITH HEPATITIS C**

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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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A publication of the Hepatitis C Support Project

TABLE OF CONTENTS

Introduction 1

Common Reactions of Caregivers 2

How to Cope 2

Caregiver Stress Danger Signs 3

Protect Yourself from HCV Infection 4

Sexual Transmission 4

The HCV Patient During Treatment 5

Depression, Anxiety, Irritability and Mania 5

Resources 6

• *Introduction*

In a presentation to the American Association for the Study of Liver Diseases (AASLD), Brian Edlin from Cornell University's Weill Medical College reported that 5 million people in the United States have been infected with HCV. HCV primarily affects the liver. Usually it takes a long time to do any damage, especially if the person who has it does not drink alcohol and lives a healthy lifestyle. Sometimes the damage is so minimal that people will go through their entire lives without knowing they have HCV. However, HCV may cause extensive damage to the liver and health of an individual. A small percentage of people will experience liver cancer, liver failure and death resulting from HCV.

Important note: *Most people will die **with** HCV and **not of** HCV. Out of 100 people who have hepatitis C, 3 or fewer will die an HCV-related death. Unfortunately, it is not known who will and who will not have serious disease progression. For this reason, everyone with hepatitis C needs to be regularly monitored by a medical provider.*

HCV symptoms are vague because they are similar to many other medical conditions. Some people have little or no symptoms. The most commonly reported one is fatigue. Body aches, flu-like symptoms, depression, and abdominal discomfort are also symptoms of HCV. Some patients report difficulty concentrating or that their thinking feels cloudy. Although not an official medical term, many refer to this as "brain fog."

You may have a loved one or friend who tested positive for the hepatitis C virus (HCV). Whether this person is asymptomatic or struggling with multiple HCV symptoms, their disease may affect you. Since HCV is not passed casually, it is unlikely that you will acquire HCV.

Caregivers are at high risk for health problems. According to the Family Caregiver Alliance, caregivers have a higher risk of mental and physical health problems than non-caregivers do. They experience depression, pain, loneliness, isolation, abandonment, loss, and grief. They experience fear – of the unknown, of death and of change. Caregivers may feel insecure about their ability to give adequate support. They may worry about the security of their future, the risk of acquiring HCV, or of being a single parent or sole financial provider. The likelihood of any of this happening is low. However, it is normal to feel and think about these possibilities.

Lucinda Porter, RN

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COMMON REACTIONS OF CAREGIVERS

Guilt is a common feeling among caregivers. If you find yourself saying the word "should," this is associated with guilt. Examples are "I should do more," "be more understanding," "be more loving." Guilt helps no one. It robs us of our self-esteem. Try to let go of guilt.

Anger is another emotion reported by caregivers. The HCV patient may be getting sympathy and attention, while you are striving to keep your family afloat. You may feel resentful that no one notices how overworked and exhausted you are.

Many caregivers feel afraid. You may fear what the future holds for you and your loved one. You may wonder if you are going to be strong enough to handle the future.

Grief is common. Your life has changed. You may feel that your dreams are gone. Your loved one may be wrapped up in his or her illness and you may feel lonely because of this. You may need to mourn the loss of the person you once knew and the dreams you once held.

HOW TO COPE

The best way you can help your loved one is to take care of yourself first. In the event of a pressure drop on an airplane, we are advised to put on our own oxygen mask first before assisting others. This concept applies to caregivers. If you put the needs of your loved one before your own, you serve no one.

- Make a commitment to your own health. Do not neglect your sleep, diet, exercise and other health-promoting habits. Get a flu shot and regular health care.
- Do not throw away inner peace by reacting to everything you hear. Get the facts first. That way, if you are going to be upset about something, at least it is about something accurate.
- Take time to process new information. You may hear "bad news" or be bombarded by data. This is not a good position from which to make decisions. Take a break. Give yourself time to digest new details.

- Accept your feelings and talk about them.
- Get support. Find out if there is a caregiver's support group in your community.
- Every day, do something you enjoy.
- Maintain social contacts. Ask a friend out for coffee, a movie or a walk. Use the phone or email to stay in touch.
- Ask for help. You aren't Superman or Superwoman. Be specific about the help you need.
- Take a break from care giving. See a friend, go for a walk, read, go to a movie, take a nap – anything that revitalizes you. It is all right to go away for a day, a weekend, or longer if this is what you need.
- Set limits for yourself. Remember the word "no" is a complete sentence.
- Focus on the positive.
- Find ways to laugh. Laughter can relieve all sorts of complaints and has no side effects.

CAREGIVER STRESS DANGER SIGNS

Caregiver stress must be taken seriously. If left unmanaged, caregiver stress can be life threatening. Some danger signs are:

- Uncontrollable anger or resentment
- Depression or suicidal thoughts
- Thoughts of harming another or physical abuse
- Misuse of alcohol or drugs
- Sleep problems
- Overeating or loss of appetite
- Physical complaints, such as headaches or stomach problems. Some of these may be serious and may affect your blood pressure or heart.

PROTECT YOURSELF FROM HCV INFECTION

HCV transmission between household members is rare. HCV is contagious, but mostly only through blood-to-blood contact. HCV is not transmitted by hugging, kissing, sneezing, coughing, sharing eating utensils or glasses, or by casual contact. Although the risks are low, it is recommended that family members be tested, especially children of women who may have had HCV at the same time they were pregnant.

In the August 2006 issue of *Hepatology*, Hwang and associates reported findings of a large study indicating no increased risk of HCV transmission based solely on history of body piercing, tattooing, or intranasal drug use. Although the risk of acquiring HCV is low, we recommend that you do not share razors, toothbrushes and other tools that may be exposed to blood. A common source of infection is through the sharing of contaminated injection drug utensils. If you use drugs with an HCV-positive person, learn how to do this safely.

SEXUAL TRANSMISSION

The risk of sexual transmission between monogamous heterosexual partners is low. The Centers for Disease Control (CDC) does not recommend any changes in sexual practices between monogamous, long-term partners. Sexual transmission rates increase with multiple sexual partners. It is important to get accurate information about sexual transmission of HCV.

Sex is a basic part of life. If your partner is HCV-positive and you have any concerns about transmission, talk to your partner about this. Honesty and openness are important. Be honest with yourself and your partner(s). If you are uncomfortable with the current sexual practices in your relationship, it is your right to express and change this. If you want to practice safer sex, it is your right to do so.

“So many gods, so many creeds, So many paths that wind and wind, While just the art of being kind is all the sad world needs.”

— Ella Wheeler Wilcox

THE HCV PATIENT DURING TREATMENT

The HCV patient in your life may be symptom-free or have symptoms of the disease. The decision to undergo treatment is a complicated one and not based solely on the presence of symptoms. Current HCV treatment uses a combination of medications. Peginterferon is an injection, usually given once weekly. Ribavirin is a pill, usually taken twice daily.

HCV medications may cause many side effects. Some common ones are fatigue, irritability, depression, anxiety, difficulty concentrating, insomnia, itching, rashes, stomach upsets, headaches, fevers, and body aches. Patients sometimes report decreased sex drive (libido) during treatment. The social and psychological side effects are usually harder to deal with than the physical ones, especially for family and friends of HCV patients. These side effects are temporary and they will reverse with time after HCV treatment is stopped.

Patients often “look good” during treatment. This can create problems, especially if the patient feels awful and assumes everyone around her can see this. Open communication is the best way to find out how your loved one feels. However, do not expect too much from the person undergoing HCV therapy, especially if he was not a good communicator before treatment. Some patients do not want to talk about their experiences. Others want to talk about them a great deal. The two best things you can do for your loved one are to encourage him or her to join a support group and to take care of your own health.

DEPRESSION, ANXIETY, IRRITABILITY AND MANIA

Psychiatric problems commonly occur during HCV treatment. Watching a loved one experience these may leave you feeling frightened and helpless. Encourage him or her to speak to a doctor. Appropriate diagnosis and treatment are essential. Treatment for depression may take anywhere from two to eight weeks to become fully effective. Encourage your friend or family member to stick with it until the medications start to work, or to talk to his or her doctor about alternatives if there seems to be no improvement.

If there are any hepatitis C support groups available in your area, encourage your

loved one to attend. You may offer to drive her to the group. If the group is open to everyone, perhaps volunteer to attend together. Respect the wishes of your loved one if he does not want you to attend.

Encourage the depressed person to go for a walk, go to the movies, or engage in other activities that previously gave pleasure. However, if the offer is refused, do not push it. It may be enough to just sit and listen to the radio or watch TV together. Some patients have difficulty reading during treatment, so perhaps listening to an audio book might interest you both.

People with hepatitis C are sometimes irritable during treatment. Try not to take this personally. Keep your expectations to a minimum. Do not expect a depressed HCV patient to “snap out of it” or to be able to turn his or her mood around through positive thinking. Medication-induced depression is influenced by physical factors, and all the willpower in the world won’t make it go away.

Important Note: Do not ignore remarks about suicide or hurting oneself or others. Report these immediately to the patient’s doctor or other professional. If a suicide attempt is imminent, call 911. If you feel the patient could physically harm you, get immediate help. Do not put yourself in harm’s way.

HCV affects many people besides patients. Educating yourself about the disease and the side effects of HCV therapy may help you understand some of the issues your loved one is confronting. Above all else, get support for yourself. Remember to put your oxygen mask on first before assisting others.

RESOURCES

- Hepatitis C Support Project
www.hcvadvocate.org
- Family Caregiver Alliance
www.caregiver.org

“Be gentle with yourself.”
- Max Erhmann

- National Alliance for Caregiving
www.caregiving.org
- National Family Caregivers Association
www.thefamilycaregiver.org
- Rosalynn Carter Institute for Caregiving
<http://rci.gsw.edu>
- Wellspouse Association
www.wellspouse.org
- Roche Pharmaceuticals Hepatitis C: A Guide for Family and Friends
www.pegasys.com/pdf/patient4.pdf
- Schering Corporation See "For Family Members"
www.hep-help.com

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➔ **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
- Coping with Depression and Hepatitis C
- 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
- Side Effect Management: HCV Treatment and Depression – For Family and Friends
- 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.

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Version 2.0, January 2009
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