

# **HCSP TRAINING MANUAL**

## *SECTION VII: GENERAL HCV MANAGEMENT*

Alan Franciscus, Editor-in-Chief



**T**he 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.

*Permission to reprint this document is granted and encouraged with credit to the author and the Hepatitis C Support Project.*

***A publication of the Hepatitis C Support Project***

# GENERAL HCV MANAGEMENT

## Objectives:

- *Be able to discuss various measures to manage HCV and maintain good overall health*
- *Be able to list substances that can be harmful to the liver*
- *Be able to describe a healthy diet for people with chronic hepatitis C*
- *Be able to describe stress reduction and time-management techniques*
- *Be able to discuss the potential risks of disclosing HCV status*
- *Be able to discuss the benefits of professional therapy and support groups for people with HCV*

## General HCV Management

### General HCV Management: Key Points

- *People with HCV can take several measures to improve their health and quality of life.*
- *People with HCV should avoid alcohol and be cautious about using prescription and over-the-counter medications, recreational drugs, herbal remedies, and nutritional supplements.*
- *A healthy, well-balanced diet is important for people with hepatitis C.*
- *People with HCV should limit over-consumption of vitamin A, vitamin D, iron, and niacin unless prescribed by a medical provider.*
- *People with HCV should avoid raw or undercooked shellfish.*
- *If possible people with HCV should avoid preserved foods, vegetables and fruits treated with pesticides.*
- *Caffeine and chocolate consumption should be light to moderate.*
- *Regular moderate exercise can improve overall fitness and help reduce fatigue, stress, and depression.*
- *People with HCV should consult their doctors before starting a new diet or beginning an exercise program.*
- *Stress management, time management, and meditation can help improve quality of life.*
- *People with HCV may experience many fears and anxieties related to living with a chronic disease.*
- *People should think carefully about disclosing their HCV status.*
- *People with HCV may benefit from professional counseling and from informational and emotional support groups.*

## **General HCV Management:**

### ***General Information***

HCV can be a difficult disease to manage, in part because of the overall limited treatment options. However, lifestyle plays an important role in HCV disease management, and can help improve overall health and quality of life. A healthy diet, exercise, and stress management are all critical to maintaining good health. In addition, it is important to avoid alcohol and drugs, environmental toxins, and other substances that can be harmful to the liver.

### ***Good Health Care***

It is important for people with HCV to get good, regular medical monitoring. Once HCV is diagnosed, people are generally referred to an experienced specialist, usually a hepatologist (liver disease specialist) or a gastroenterologist (digestive disease specialist). People coinfecting with HCV and HIV should see both a liver disease specialist and an infectious disease specialist, preferably one who has experience treating both diseases. Whether or not a person is receiving treatment for HCV, liver enzyme levels should be monitored regularly; liver biopsies are also useful for determining liver health. Many physicians, especially those who do not often see people with HCV, are not fully educated about chronic hepatitis C, and HCV-positive people should educate themselves and their healthcare providers. Herbalists and other alternative practitioners who work with HCV-positive people should also have experience treating people with HCV. If a person finds it difficult to work with his or her current health-care provider, he or she should consider seeking a new one; friends, family, and agencies that serve people with HCV may be good sources of referrals.

### ***HAV and HBV Vaccination***

*It is strongly recommended* that people with hepatitis C get vaccinated against hepatitis A virus (HAV) and hepatitis B virus (HBV) if they have not been previously infected. Hepatitis A and hepatitis B can be much more severe in people with existing liver damage due to HCV. A combination HAV/HBV vaccine (Twinrix) is available. HAV and HBV vaccines are discussed in more detail in **Section III: An Introduction to the Viral Hepatitis Alphabet.**

### ***Avoiding Harmful Substances***

As discussed in **Section II: The Liver**, nearly everything a person eats, drinks, breathes, or absorbs through the skin must be processed by the liver, and the liver is prone to damage from a variety of toxic substances. Avoiding these substances can help reduce the risk of liver disease progression and have a positive effect on overall liver health.

Many studies have shown that heavy consumption of alcohol can accelerate HCV disease progression. One study showed that 58% of a group of heavy drinkers with HCV (more than five drinks per day) progressed to cirrhosis, compared to only 10% of a group of non-drinking people with HCV. It is not yet known how harmful light or moderate alcohol consumption are to the liver, but most experts recommend that people with HCV – especially those with liver cirrhosis – not drink alcohol at all. Be aware that many liquid medications and herbal tinctures contain alcohol.

### **What we know about alcohol consumption and HCV to date:**

- Heavy alcohol use (more than 50 g daily) worsens fibrosis
- Increases risk of cirrhosis
- Contributes to fatty liver
- Contributes to the accumulation of iron in the liver
- Increases the mutation rate of the virus leading to more quasi-species
- Increases risk of HCC (liver cancer)
- Lower levels of alcohol intake apply to women
- Heavy (regular or binge) alcohol intake may lead to a lower treatment response rate to antiviral therapy
- Cessation of heavy alcohol intake improves response to antiviral therapy
- Alcoholic patients may be able to complete therapy but seem less responsive
- Abstinence from alcohol is recommended during therapy

Most drugs are processed by the liver. Certain prescription and over-the-counter medications, recreational drugs, herbal remedies, and vitamin and mineral supplements can be toxic to the liver (*hepatotoxic*), especially when combined. Even some seemingly harmless over-the-counter drugs like acetaminophen (Tylenol) and ibuprofen (Advil) have been known to cause liver damage when taken in large doses or by people with existing serious liver disease. People with HCV should tell their healthcare providers about any drugs they are taking. In addition to alcohol and drugs, chemicals a person breathes or absorbs through the skin must also be filtered by the liver. As much as possible, avoid fumes from paint thinners, solvents, pesticides, and aerosol sprays. People who cannot avoid exposure to toxic chemicals should wear a face mask or respirator and protect their skin with gloves and work in a well-ventilated area. In addition, exposure to tobacco smoke may accelerate disease progression, worsen cirrhosis and increase the risk of developing liver cancer.

## Good Nutrition

It is important that people with HCV eat a healthy, well-balanced diet. A diet that follows the general guidelines for good nutrition based on the new MyPlate at [www.choosemyplate.gov](http://www.choosemyplate.gov) is generally recommended.

The number of servings listed in USDA's MyPlate may seem like a lot of food, but what counts as a serving is usually smaller than most people think (for example, a piece of meat the size of a deck of cards,  $\frac{1}{2}$  cup of nuts, 1 cup of raw leafy vegetables,  $\frac{1}{2}$  to  $\frac{3}{4}$  cup of fruit juice,  $\frac{1}{2}$  bagel, or  $\frac{1}{2}$  cup of cooked rice or pasta). A healthy diet is low in fat, cholesterol, and sodium (salt), high in complex carbohydrates, and has adequate protein. Drinking enough fluid is also important; experts typically recommend eight glasses of water per day. Most people can obtain adequate nutrients through eating a well-balanced diet. Some people with HCV find various nutritional supplements beneficial (see **Section IX: Alternative and Complementary Therapies**). However, certain vitamins and minerals (e.g., vitamin A, vitamin D, iron, and niacin) can be harmful to the liver in high doses. People with hepatitis C should consult their healthcare provider – and perhaps also a trained dietitian or nutritionist – before starting any new diet or taking vitamins and minerals



People with hepatitis C can experience loss of appetite (anorexia), nausea, and diarrhea; these may also occur as side effects of drugs used to treat HCV. Many people find it helpful to eat small, frequent meals or snacks rather than three large meals each day. Soft or liquid foods and foods at room temperature (neither hot nor cold) may be easier to tolerate, while spicy or fatty foods may worsen nausea. If a person is very ill and unable to obtain enough nutrients by eating normally, liquid nutritional supplements (such as Advera, Ensure, or Sustacal), tube feeding, or intravenous nutrition are options.

The following is speculative, but is nutritionally sound: Because the liver processes and detoxifies everything a person eats, avoiding certain foods may help reduce the liver's work load. Some experts recommend that people with HCV avoid consumption of raw or undercooked shellfish (which can contain hepatitis A and other viruses and bacteria). Certain fishes may be contaminated with heavy metals. Processed foods may contain chemical additives, so people with HCV may benefit from limiting consumption of canned, frozen, or preserved foods, as well as fast food. Organic fruits and vegetables are grown without pesticides and fertilizers that can potentially harm the liver; all fruits

and vegetables should be washed thoroughly to remove harmful residues. People with HCV should read food labels and familiarize themselves with ingredients. It is often recommended that people with HCV should try to avoid foods high in fat, salt, or sugar. Some people with HCV find it difficult to tolerate dairy products; if this is the case, soy milk or rice milk may be good substitutes.

In the past, diet modification was seen as an important part of liver disease management; this is less true today. However, the latest research is finding many conditions that can be caused by poor nutrition, such as metabolic syndrome, steatosis, insulin resistance, and diabetes, which all negatively affect HCV disease progression and treatment outcome.

People with cirrhosis may have difficulty properly utilizing large amounts of protein. When the diet contains more protein than the liver can process, toxins can build up in the blood and interfere with cognitive functioning (and in severe cases, lead to hepatic coma). However, adequate protein is important for body tissue maintenance and repair, and most experts today recommend that people with cirrhosis eat protein that is derived from plant sources. Too much animal-based protein intake should be only be limited if a person shows signs of encephalopathy (brain damage) such as confusion or difficulty in thinking. In addition, people with advanced liver disease may have problems with fluid retention (ascites, edema), which can be exacerbated by heavy salt consumption.

## **Exercise**

Regular exercise is an important part of a healthy lifestyle. It can help improve overall fitness and endurance, and can play a role in reducing fatigue, tension, stress, and depression and in improving memory. Most people with chronic hepatitis C can safely engage in moderate exercise. Some people prefer a formal exercise program that includes regular workouts at the gym, while others enjoy outdoor activities or team sports. Regular daily activities such as walking or gardening can be highly beneficial; simple measures like taking the stairs instead of the elevator or parking further from your destination can be easy ways to get more exercise without spending a lot of time or effort.

There are two basic types of exercise. *Aerobic* exercise works out the heart and lungs; running, bicycling, and swimming are examples of aerobic exercise. Aerobic exercise improves cardiovascular fitness, increases endurance, and burns fat. Most experts recommend at least 20 to 30 minutes of sustained aerobic exercise every day. *Anaerobic* exercise focuses on building and strengthening muscles; weight training is an example of anaerobic exercise and should be included in any exercise program to maintain

overall health. Stretching is also an important part of any exercise routine; it warms up the muscles, improves flexibility, and helps reduce the risk of injury during exercise.

People should start slowly with easy exercises and work up to a level that feels comfortable for them. Fatigue is one of the most common symptoms associated with HCV and the drugs used to treat it. Although people experiencing fatigue may not feel like doing anything active, many find that regular exercise actually helps them feel less tired and more energetic. Even easy exercises done for a short period of time (for example, a ten minute walk each day) can be beneficial.

Some people with HCV find that overly strenuous exercise can lead to a “flare up” (worsening) of disease symptoms. If this happens, people should do more moderate exercise, light stretching or skip exercising until symptoms subside. People with arthritis should choose low impact exercise (such as swimming) that puts minimal strain on the joints. People with portal hypertension (high blood pressure in the vessels that carry blood to the liver) should be cautious about exercising. People with HCV, especially those with cirrhosis should check with their doctor before starting any exercise program.

### ***Managing Stress and Fatigue***

Living with a chronic disease can be stressful. Stress management, good time management, and measures to reduce fatigue can all help improve a person’s quality of life. Anecdotally, many people report symptom “flare ups” following episodes of stress. People with chronic hepatitis C should be aware of their limits and not overexert themselves. It is important that people understand the severity of their illness, maintain a realistic picture of their health, and find an appropriate level of activity. It may be necessary to learn to say “no” to family and friends who have unrealistic expectations. Many people with HCV find it helpful to use a daily planner to make activity schedules. People should try to alternate strenuous activities with more restful ones. Remember to schedule time for rest during the day, if necessary, and to get adequate sleep at night. Some people with HCV find that meditation – a method of relaxation and clearing and focusing the mind – helps reduce their levels of stress. Many spiritual traditions include meditation; there are several different techniques (for example, prayer, transcendental meditation, vipassana, certain types of yoga, t’ai chi), some of which are simple and easy to learn.

### ***Psychosocial Issues***

When a person is diagnosed with a life-threatening disease such as hepatitis C, many issues and anxieties may come up.

Common fears include:

- fear of rejection by family and friends
- fear of infecting loved ones
- fear of disclosure in the work environment and of losing employment
- fear of having HCV listed in one's medical records
- fear of being denied health and life insurance
- fear of being viewed as a disease rather than as a person
- fear of being unable to continue daily activities
- fear of disability and losing control over bodily functions
- fear of death

Patients should be reassured that most of these fears are unlikely to come true in the majority of people with HCV. Many of these fears can be alleviated by talking with a trained medical professional or with peers in a supportive setting. Some people with HCV benefit from therapy with a person who has professional training, for example a psychiatrist, psychologist, or social worker. Family, friends, or an agency that works with people with HCV may have good recommendations. There are many different types of individual and group therapy. It is important that a person feel comfortable with both the type of therapy and the individual therapist in order for therapy to succeed. Family members learning that a loved one has HCV may also benefit from professional therapy.

### ***Disclosure***

Hepatitis C is a highly stigmatized disease, in part because it is associated with injection drug use. But HCV can be transmitted in many ways, and an estimated 1 in 10 people with HCV have no apparent risk factors and do not know how they contracted the virus. While many people find it a relief to disclose that they have HCV, people should be careful who and what they tell due to potential consequences in their personal and professional life. People newly diagnosed with HCV are encouraged to seek professional help and support from peers before disclosing information about their disease.

Telling family and friends about having HCV is important, but people should wait until they are emotionally ready before divulging their status. Most likely the first person one tells will be his or her spouse or significant other, because of both the need for emotional support and the potential risk of exposure. Telling loved ones can be a traumatic experience for both the person with HCV and the person receiving the news. Family members or loved ones may need emotional support that the newly diagnosed person may not

be able to provide. People with HCV should have enough information – about HCV in general and about their own condition in particular – before they tell others. It can be helpful to have printed materials or other resources available to share.

Disclosing one's HCV status in an employment environment should be carefully considered. The Americans with Disability Act (ADA) offers many legal protections for people with disabilities. The ADA defines "disability" as a physical or mental impairment that substantially limits one or more major life activities. A person who is designated as disabled is entitled to certain workplace protections that can affect wages, benefits, job assignments, promotions, etc. Employers with **15 or more employees** must provide "reasonable accommodations" (those that do not cause undue hardship to the employer), which might include time off for medical appointments, unpaid leave, job restructuring, or a flexible work schedule. One cannot be terminated from employment simply because he or she has HCV. People with symptomatic hepatitis C may find it beneficial to talk with their employer about their HCV status so that the employer can make accommodations. This may be particularly important when a person is considering treatment, because they may experience side effects that could require a change in work schedule or job responsibilities. Employees who feel that they are facing discrimination or are not being given reasonable accommodations can start a grievance process. For more information about the ADA, and what protections a person is entitled to, call 1-800-949-4232. However, people are not automatically entitled to special benefits and protections simply because they have HCV; people with asymptomatic HCV may not be covered, although they may be if they are experiencing treatment-related side effects. People with HCV should also take into account discrimination that may not be so obvious. For example, persons with HCV could be passed over for job promotion because they are perceived as being chronically fatigued. Or coworkers may avoid an HCV-positive employee because they fear exposure. In situations like this, education about hepatitis C may be helpful.

Questions to ask when considering disclosing HCV status at work include:

- How will disclosure affect the day-to-day working environment?
- How will disclosure affect future promotions?
- How will disclosure affect working relationships with coworkers?
- Is it really necessary to disclose at this time?

### ***Support Groups***

Many people with HCV feel isolated and find it difficult to cope with the effects of living with a chronic illness. A support group can offer a safe space to discuss the emotional and

practical issues surrounding HCV. In addition, the information shared by peer members can be helpful in making decisions about a wide variety of issues. Family members may also need help when they learn that a loved one has a potentially life-threatening disease, and should seek support; there may be also be support groups available for them.

In the past few years many peer-led support groups have begun to emerge to address the need for support and education in the HCV and HIV/HCV coinfecting populations. Support groups can be divided into two basic types: informational (or educational) and emotional. Most support groups provide aspects of both, but focus on one area or the other. Informational support group meetings typically have a lecture format and may include guest speakers. All group members should be involved in the process of researching information and selecting speakers so that information is not unduly influenced by particular individual biases.

Emotional support groups typically have one or two facilitators who lead the group in discussions with the help of a specific structure or guidelines. (See HCSP's guidelines for starting and leading a support group on our website: [www.hcvadvocate.org/hepatitis/factsheets\\_pdf/Support%20Group%20Manual%202011.pdf](http://www.hcvadvocate.org/hepatitis/factsheets_pdf/Support%20Group%20Manual%202011.pdf)) A variety of different people may attend support groups. People who have been recently diagnosed with HCV are usually interested in educating themselves about the disease and talking to others living with chronic hepatitis C. People considering HCV therapy can receive help with their decision-making process and talk with others about what to expect and how to prepare for treatment. People currently undergoing HCV therapy can receive emotional support and learn coping strategies to help them deal with the physical and psychological side effects of treatment. Finally, people with symptomatic HCV can benefit from the emotional support and the chance to discuss the various issues that surround living with a chronic illness.

Some support groups are led by medical providers, and counselors, but the majority of groups are led by people with HCV who have not been professionally trained as therapists or counselors. People seeking a support group should explore more than one (if available) to make sure that the group is a good fit and that facilitators are well informed. HCV-positive friends and acquaintances, healthcare providers, and agencies that work with people with HCV may all be good resources for finding a local support group. Unfortunately, some people may not have a local support group in their area. These people may find Internet resources and online mailing lists or discussion groups beneficial.

To find a support group in your area, you can use the Support Group locator at [www.hcvadvocate.org/community/Groups.asp](http://www.hcvadvocate.org/community/Groups.asp)

# HCSP TRAINING MANUAL

## SECTION VII: GENERAL HCV MANAGEMENT

Alan Franciscus, Editor-in-Chief



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

Author  
Alan Franciscus, Editor-in-Chief

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 10, October 2011  
© 2011 Hepatitis C Support Project