

A publication of the Hepatitis C Support Project

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.



NEXT STEPS: WHEN TREATMENT ISN'T WORKING

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INTRODUCTION

Hepatitis C virus (HCV) is the most common blood borne virus infection in the United States. According to the Centers for Disease Control and Prevention (CDC), 3.2 million are chronically infected. The standard treatment for HCV infection is antiviral therapy, currently a combination of two or three medications. The primary goal of antiviral therapy is to eliminate HCV from the body. Unfortunately, complete and permanent eradication of HCV is not guaranteed. Approximately 5 to 20% of patients who are treated with currently available medications will remain infected with HCV.

HCV therapy can be difficult. Patients usually enter into treatment with the desire, the hope, or even the expectation of a favorable outcome. It may be a huge disappointment to hear words such as, "You did not respond to therapy," "You are still positive for HCV," "The virus has come back," or "Your HCV treatment did not work." Reactions to this outcome may differ, but the questions are frequently the same. Patients often ask, "What do I do now?" You may be among those wondering what to do next. The purpose of this guide is to provide tools for patients who underwent antiviral therapy, still have HCV, and are asking, "What's next?"



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RESULTS AND REACTIONS

The medical term for a “successful” HCV treatment outcome is sustained viral response (SVR). SVR is defined as the maintenance of undetectable HCV for six or more months after the end of treatment. Undetectable HCV means that hepatitis C is no longer present in the blood. Patients who fit in this category are sometimes referred to as sustained responders. In general, patients who have an SVR are very pleased with this outcome. Unfortunately, sometimes the virus remains detectable, and this is usually unwelcome news.

The chance of achieving an SVR is influenced by the type of treatment, HCV genotype (or sub-type), viral load (the amount of HCV), and other factors such as body mass, age and race. There are different ways in which treatment may fail to produce a sustained response. For instance, HCV therapy may be discontinued before completion. This can occur for a variety of reasons, such as problems with side effects or lab abnormalities. Patients who do not respond at all to HCV treatment are described as non-responders. Sometimes patients complete an entire course of therapy and their HCV viral load becomes undetectable for a time, but then the virus comes back after treatment ends. Such patients are described as relapsers. A less common variation of this is when there is an initial complete response, but HCV reappears during treatment. This is known as a breakthrough response. A partial response occurs when patients experience a large drop in the amount of HCV in their blood, but their viral load remains detectable throughout treatment. The phrases

“*Although I still have HCV, my treatment was successful. Before treatment, I had moderate liver damage. After treatment I had no liver damage. This feels like success to me.*”

treatment failure or failure to respond, are the medical terms used to describe treatment that does not work. From the patient’s perspective, this is an unfortunate choice of words. Any effort is a success, even if the results are disappointing. In fact, research shows that even therapy that does not completely eradicate HCV can still help slow – or even reverse – the progression of liver damage.

Reactions to unfavorable results can vary. Hearing that you still have HCV after you have spent anywhere from 12 to 48 weeks, coping with uncomfortable side effects can be discouraging.

If you are given undesirable results while you are still taking antiviral medication, you may be experiencing some side effects. This leaves you more vulnerable to the impact of this information. The same is true if you have recently completed treatment. Although some patients report that it takes six months or more before all side effects are completely gone, most patients experience a noticeable improvement between two and 12 weeks after treatment ends. This is important to keep in mind, because coping with unwanted news can be more difficult before you are feeling better.

It is reasonable to have an emotional reaction if the outcome of HCV treatment does not turn out the way you hoped. Feelings can vary, and some people experience more than one response. Here are some common reactions patients report when told that HCV therapy did not work:

- **Depression**

Patients express feeling disappointed, depressed, or even devastated after an unsuccessful treatment outcome. Prolonged depression, or depression that interferes with your well-being, may require medical intervention such as antidepressant drugs or psychotherapy. Thoughts of self-harm or suicide are urgent medical events that require immediate help.

- ***Guilt and Blame***

These two responses come in many forms. Guilt and blame can be recognized when we say to ourselves, "I should have, I would have, I could have, or I ought to have." Self-recriminations can be relentless, brutal, and painful. It can be hard enough to endure treatment, receive unwanted results, and still experience side effects or symptoms of HCV, but adding the pain of guilt and blame only magnifies the situation. It can feel like an act of self-imprisonment.

- ***Anger and Rage***

Some people feel angry after being told that HCV treatment didn't work. Anger can be expressed inwardly or outwardly. Anger may be specific or non-specific and may be expressed in rational or irrational terms. A patient might be angry because he felt his physician "talked him into" treatment which wasted his time. Someone who did not take her medication regularly might feel angry at herself. Unresolved anger can turn into rage. Rage is uncontrolled or violent anger and is a serious matter.

- ***Anxiety and Fear***

Responses to adverse medical information may include anxiety and fear. Anxiety is a general reaction that can leave you feeling ill-at-ease or apprehensive. Fear is often more specific, such as fear of suffering or dying. These two feelings can crop up expectedly or may be provoked by seemingly unrelated events. Stress can provoke or intensify feelings of anxiety. Unresolved or extreme anxiety can be quite uncomfortable and can negatively influence a person's health and quality of life.

- ***Denial***

Denial is a common and interesting emotional defense mechanism. People who are "in denial" may do this in order to avoid painful feelings and issues. A little denial can be useful, but left unchecked, it can be harmful. An example is patients who deny having chronic medical

problems, act as if they are indestructible, and compound their problems with frequent alcohol use.

- ***Sadness and Grief***

Two different degrees of basically the same emotion, sadness and grief are common. The reality of living with a chronic illness such as HCV can differ from person to person, but it often involves feelings of loss. This could be loss of health, loss of certain relationships, loss of the future, and loss of the freedom that comes with being virus-free. Perhaps the most devastating is when hope is lost. Sadness and grief are usually healthy responses and necessary emotional ingredients that lead to the process of acceptance. Prolonged sadness and grief can lead to depression and may require professional intervention.

- ***Acceptance***

Acceptance is a willingness to accept the present situation. It is the absence of the feelings mentioned previously, such as anger, fear, and grief. Acceptance means giving up the struggle. It is not resignation. Acceptance does not imply happiness, although contentment may accompany it. It is a feeling of peace. Acceptance comes easily to some, while others may struggle with the concept.

COPING WITH YOUR REACTIONS

The way patients cope with ongoing hepatitis C can be negatively influenced by various

“Of course there is no formula for success except perhaps an unconditional acceptance of life and what it brings.”

—Arthur Rubinstein

factors. Insufficient medical insurance or financial resources, communication difficulties with healthcare providers, and depression or cognitive problems are a few examples. To cope effectively, a useful starting point is to obtain reliable information. It is easy to be misled by misinformation. Fortunately, you don't need medical training to understand the important issues pertinent to your condition. All you need is a willingness to learn, an open mind, and reliable resources. These elements will help you build a firm foundation of knowledge. You are already an expert – an expert on the subject of you. Since you have already experienced HCV treatment, you know a whole lot more than most. Round out your expertise with more knowledge about HCV, and you may find yourself easily navigating the medical landscape.

If the only goal of HCV therapy was to achieve a sustained virologic response, then it is accurate to state that the outcome was not successful. However, there are a number of other important goals of therapy. There is strong evidence that patients who respond to treatment but later relapse – and perhaps even those who never achieve a complete response – can still experience histological improvement. This means that the liver may be healthier than it was before treatment. Interferon therapy may help slow or stop the progression of liver fibrosis. Additionally, some patients report that even though they didn't completely eradicate the virus, they feel noticeably better than they did before starting treatment. Improvement in quality of life can be a huge success.

There also may be some subjective benefits to treatment, regardless of how it turned out. Ask yourself what you learned during this process. Perhaps you discovered unrecognized strengths and weaknesses in yourself. You did not waste your time! There is a benefit to knowing that you made the effort. If you had not tried HCV treatment, the future might have had a different outcome. By making the effort now, you may avoid future regret.

You may wonder if you contributed to an unfavorable outcome because you missed some doses of medication, or if you could have done more to optimize your chances of success. If this is the case, get some facts. Questioning whether you did everything you could have or should have done is only useful if you use the information to help you. It can be destructive if you use it to blame yourself. The past cannot be changed. But it can be useful to analyze the past to change the present or the future. Just skip the guilt and blame.

Do not expect yourself to bounce back immediately from this experience. Acknowledge the feelings attached to the disappointment, but don't dwell on them. Be patient and generous with yourself. Have you told yourself how proud you are that you made the effort? It takes courage to go through HCV treatment. This may be the perfect occasion to tell yourself how strong and brave you are, especially when you felt weak and afraid.

WHAT DOES THIS MEAN?

The outcome of your treatment may mean you have to make choices and changes. Start by talking to your medical providers. Ask for an opinion about the future of your health. Are there any specific recommendations to consider, such as other medications or lifestyle changes? Does your physician advise further HCV treatment? Are there any available clinical trials you could join? What kind of follow-up care should you receive?

• *Cirrhosis, Cancer and Other Complications*

Most people with chronic hepatitis C lead relatively normal lives. But in 5 to 20% of people, the disease progresses to cirrhosis over the course of 20 to 30 years. Chronic HCV infection can lead to liver damage, the development of fibrous tissue in the liver (fibrosis), fat deposits in the liver (steatosis), liver scarring (cirrhosis),

and a type of liver cancer called hepatocellular carcinoma. In severe cases, individual persons may require a liver transplant.

Cirrhosis is a process in which liver cells are damaged or killed and replaced with scar tissue. Extensive scar tissue prevents the flow of blood through the liver, causing a loss of liver function. Compensated cirrhosis means the liver is heavily scarred but can still function relatively normally; people with compensated cirrhosis exhibit few or no symptoms. Decompensated cirrhosis means the liver is unable to function as it should. People with decompensated cirrhosis may develop complications such as stretched and weakened blood vessels (varices) in the esophagus and stomach, internal bleeding, fluid accumulation in the abdomen (ascites), and other potentially life-threatening conditions. They may also experience reversible mental confusion. Liver cancer usually develops at later stages of HCV infection, typically after 25 to 30 years.

• *Diagnostic Tests*

Most physicians recommend regular follow-up lab tests for patients with hepatitis C. These usually include a complete blood count (CBC) and liver function tests (LFTs), including ALT, bilirubin, and albumin levels. There is no need to conduct further viral load tests unless HCV treatment is started again or your medical provider wants to confirm the presence of HCV. The amount of HCV in the blood does not correlate with disease progression. A viral load that is higher or lower than a previous measurement does not mean that your condition is worsening or improving. Sometimes a viral load will “spike” to what may seem to be alarmingly high numbers, especially after antiviral treatment is stopped. This is common and not medically significant.

“*You may be disappointed if you fail,
but you are doomed if you don’t try.*”
—*Beverly Sills*

In general, after a diagnosis is confirmed, the information gained from regular viral load tests serves no useful purpose unless you are being treated for HCV. For this reason, a sensible approach is to refrain from retesting the viral load outside of HCV treatment context. This approach will reduce false reassurance and anxiety, as well as save time and money.

Your doctor may order a prothrombin time (PT) test. This test measures the speed of your blood’s clotting ability. The liver makes proteins that enable the blood to clot. If your PT is prolonged (or elevated), this may indicate that your liver is having difficulty manufacturing clotting factors.

People with cirrhosis should also be monitored for liver cancer (hepatocellular carcinoma). To do this, an alpha-fetoprotein (AFP) test may be included with your blood tests. This protein is produced by fetal tissue, tumors, and the liver. Patients with hepatocellular carcinoma can have abnormally high AFP levels. An AFP test usually is not ordered for HCV patients with mild to moderate liver disease, since hepatocellular carcinoma rarely occurs unless patients have cirrhosis.

Your doctor may want you to have an abdominal ultrasound exam. This painless, noninvasive procedure uses sound waves to create a picture of the liver and other abdominal organs. An ultrasound is primarily used for patients who have advanced fibrosis or cirrhosis. This exam can detect liver cancer. Ultrasound can sometimes identify signs of cirrhosis, but this needs to be confirmed with further testing.

The liver biopsy is another diagnostic test that your doctor may request. Liver biopsies are performed for a variety of reasons. There are no universal standards on if, when, and how often a liver biopsy should be performed. If you have never had a biopsy, your doctor may want you to have one in order to assess the condition of your liver.

There are different types of liver biopsies. One common type involves insertion of a thin needle with a hollow core into a numbed area between the ribs on the right side of the abdomen. About one-third of those who have this procedure report some pain. Compared to other invasive procedures, medical professionals consider liver biopsies to be fairly straightforward with little risk of complications or death. However, patients may have some anxiety about undergoing a biopsy, and may need medications to help them relax during the procedure. Less invasive procedures are being tested, such as blood tests to measure liver fibrosis. The usefulness of these tests varies and they have not yet replaced biopsies.

Abnormal lab results do not necessarily signify a dire situation. Sometimes test results are incorrect. Also, normal ranges can vary from lab to lab, which can create the illusion that there has been a major change. Drugs (prescription, over-the-counter, or recreational) can alter lab results. The same is true for alcohol and low carbohydrate or high protein diets. Seek an expert opinion before assuming an abnormal lab value is cause for concern. This is hard to do, but pays off by reducing anxiety.

There is no single standard of follow-up care for patients who do not respond to HCV treatment, but there are some general recommendations.

- ***Mild-to-Moderate Disease***

It is common for physicians to recommend annual or semi-annual follow-up visits and blood testing for patients who have minimal liver disease.

Opinions vary regarding follow-up biopsy recommendations. Some doctors advise liver biopsies every 5 years, or sooner if there is an indication that the disease process is advancing faster than normal. Longer intervals for follow-up biopsies are sometimes recommended.

- ***Advanced Disease***

Follow-up recommendations for patients with advanced fibrosis or cirrhosis depend on the severity of their liver disease and whether there are other medical concerns. It is important for your medical provider to follow your healthcare very carefully when you reach this stage of hepatitis C.

Some common guidelines are:

- Follow-up visits every three to six months, with blood tests including prothombin time and alpha-fetoprotein
- Ultrasound testing every six months
- Liver biopsies are usually not done because there is a greater risk of complications for patients in this group, and the information gained from the procedure is generally not useful.

FURTHER TREATMENT

The American Association for the Study of Liver Diseases (AASLD) is the U.S. organization that makes evidence-based recommendations regarding the diagnosis, management, and treatment of hepatitis C. The most recent practice guidelines were published in 2011. They are available on the HCV Advocate Website Fact Sheet page in the "Treatment Issues" section: www.hcvadvocate.org/hepatitis/factsheets.asp#treat-gd

Guidelines are updated as new information and treatment becomes available from the AASLD at www.aasld.org

“*This thing that we call ‘failure’ is not the falling down, but the staying down.*”

—Mary Pickford

The National Institutes of Health (NIH) Consensus Conference was published in June 2002. Since the NIH guidelines are so old, it is best to look for more current information. Presumably the NIH will be re-examining their current guidelines.

Currently there are no standards for HCV retreatment. New HCV medications are rapidly being developed. Medical providers tailor their treatment recommendations based on the latest solid research. This is known as evidence-based medicine. Providers may request early access to use these medications for their sickest patients before the drugs are approved. Additionally, providers may use medications off-label which means they may suggest using a combination of drugs that hasn't been FDA approved.

When considering HCV retreatment, it is essential to identify the possible reason(s) why you might not have responded to previous treatment. Here are some factors to take into account:

- If prior treatment used older HCV generations of medications, discuss retreatment options with your medical provider.
- What was the duration of the previous treatment? Patients whose treatment was shortened are less likely to have an SVR. This is particularly true of genotype 1 patients who receive interferon or interferon and ribavirin.
- Were there dose reductions during treatment? Patients who remain on the maximum dose for the maximum duration have a better chance for an SVR than those whose dose was reduced.
- Why were there dose reductions or discontinuation of treatment? If side effects or other adverse reactions were the cause, these may be managed in a different way. For instance, if depression was the reason for discontinuation, then perhaps antidepressant

medications can be prescribed a month before restarting treatment. If medication dosages must be reduced, it is better to decrease in small intervals. Dose reduction occurring after reaching nondetectable HCV is preferable to dose reduction with detectable HCV RNA. Naturally, patient safety is the top priority.

- Did you receive the correct dose for your weight, genotype and viral load?
- Were medications taken properly? Were there many missed doses? Was the drug stored properly?
- Did you use alcohol, herbs, dietary supplements or non-prescribed drugs during treatment? A complete honest assessment may provide insight on how to maximize future chances for an SVR.
- Does your medical provider feel you are a candidate for off-label use of any HCV medications, such as maintenance therapy or a longer course of treatment using pegylated interferon with or without ribavirin?
- How difficult was treatment? If you had a hard time and ended up taking multiple drugs to manage side effects, you may not feel ready for a second or extended treatment.
- How advanced is your HCV? Do you have extensive damage to your liver or unmanageable side effects? Conversely, do you have minimal damage and no HCV symptoms?
- How old are you? What is going on in your life? Is this a good time for retreatment?

Patients who did not have sufficient reduction in HCV RNA according to the protocol guidelines for the antiviral regimen that they are on are unlikely to respond to further treatment with a similar antiviral. However, new medications are worth considering. Furthermore, those who

are taking direct-acting antivirals who don't meet the guidelines, must discontinue treatment to prevent the development of a resistant strain of HCV. The bottom line is this – work closely with your medical provider to explore the appropriate options for your situation.

If you do continue with more HCV treatment, fortify your decision by learning all you can to either avoid another relapse or to maintain adherence to the prescribed dose of medication for as long as your doctor advises. Here are some suggestions:

- Remember to take all of your medications as directed. If memory is a problem, use tools to remind yourself, such as daily pill containers, timers, Post-It notes, or messages to yourself on your computer or phone message system.
- Learn how to manage side effects so you are better able to tolerate treatment. The earlier you report a side effect, the easier it is for your doctor to treat it. If you wait, you risk your health and your ability to stay on treatment.
- Get accurate information and support. These may help you get through difficult treatment intervals.
- Avoid alcohol, herbs, drugs and any other substances that have not been prescribed by your medical provider.

• *Clinical Trials*

A clinical trial is a study designed to answer specific questions about a potential new therapy or new uses of an established therapy. Patients

“Concentrate on what you want to become, not what you are trying to overcome.”

—*Author Unknown*

participate in clinical trials for various reasons. Those who have tried all existing FDA-approved options may explore the realm of clinical research to gain access to new experimental medications. Insufficient health insurance coverage or inability to pay for health care may motivate other patients to take part in clinical trials. Some become involved for intellectual or humanitarian reasons. Regardless, clinical research has potential risks and benefits.

Potential risks:

- The possibility of not receiving the new study drug in a placebo-controlled trial
- The possibility that the treatment will not be effective
- The risks of foreseeable and unforeseen adverse reactions or side effects
- The extra time involved in appointments and record-keeping

Potential Benefits:

- The possibility of receiving early access to an effective new treatment (this is not guaranteed)
- The possibility of receiving free medication
- The possibility of free or less expensive medical care (this is not always offered)
- More time spent with the health-care team, including close monitoring and follow-up

The decision to participate in a clinical trial should be careful and informed. Obtain information about the specific trial that interests you as well as the general subject of clinical research (see Resources).

MAINTAINING YOUR HEALTH

Living with a chronic illness can be demanding -- physically, mentally, emotionally, spiritually, and socially. Hepatitis C is complex because

symptoms can occur in organs other than the liver. Signs and symptoms vary among individuals; some people have no symptoms or only a few mild symptoms, while others have more severe symptoms. Symptoms associated with HCV may also be caused by a variety of other common conditions, making it difficult to sort out and diagnose additional medical problems. For example, although HCV patients frequently report fatigue, it is virtually impossible to say with certainty that HCV is to blame, since fatigue can have many causes. The human body is a complex organism with many components. Since mental, physical, and spiritual conditions are interrelated, it is usually wise to tend to all these aspects.

MENTAL HEALTH

• *Emotional Concerns*

It is reasonable to have an emotional reaction if HCV treatment does not turn out the way you hoped. The expression of these feelings in a healthy way should be encouraged. However, some people complain of problems that affect their overall sense of well-being and ability to function. Patients may experience depression, irritability, insomnia, difficulty concentrating, and even mental confusion. If any of these problems occur, discuss them with your doctor. It is important to rule out other causes for these complaints.

If you are diagnosed with depression, effective treatment is available. Your doctor may prescribe an antidepressant or other medication. Antidepressant medications may take up to six weeks to begin working. Occasionally, you

will need to try a few different medications before you find the one that is most effective for you. Your doctor may also recommend psychotherapy. Some patients seek the opinion of a psychiatrist (a physician whose specialty is mental illness) for diagnosis and treatment of depression.

If your health-care provider prescribes an antidepressant, you should not stop taking the medication without expert guidance. This is particularly true for the class of medications called selective serotonin reuptake inhibitors (SSRIs). Since it can be harmful to stop these medications abruptly, your doctor can provide guidelines on how to safely stop taking antidepressants.

The following coping tools can be used if you are having normal emotional responses such as sadness and loss or other transient moods. If you are diagnosed with depression, these tools may be helpful in conjunction with medication and/or psychotherapy.

- Get informed. There are some excellent resources on the subject of depression and other types of mental illness.
- Talk about what's bothering you.
- Get support. Support groups can be extremely helpful and can provide valuable information.
- Avoid isolation.
- Get adequate sleep.
- Engage in moderate exercise.
- Maintain a healthy diet.
- Practice stress reduction techniques such as meditation, tai chi, qigong, or yoga.
- Abstain from alcohol and substance use. Seek help if quitting is difficult for you.
- Go outside every day, especially when it's sunny. (Use sun protection.)
- Do not neglect your recreational needs.
- Cultivate positive thinking.

Note: *If you have thoughts of hurting yourself or others, get immediate help.*

- Find ways to laugh. Humor has no side effects except perhaps a few laughs.

- **Cognitive Issues**

Patients with chronic hepatitis C occasionally report mental or cognitive impairment. Patients sometimes refer to this as “brain fog.” There are many factors that can have an impact on mental acuity, including stress, depression, and fatigue. If you are experiencing “brain fog,” try to analyze your situation. Are you experiencing stress? Do you have insomnia or other sleep issues? Are you depressed? Do you have any other medical problems or take medications that could cause cognitive impairment? If your answer is “no” and your physician has ruled out other causes of impaired cognition, here are some tools to try:

- Be organized. Keep lists.
- Always put your keys and eyeglasses in the same place.
- Challenge your brain. Do arithmetic in your head or on paper rather than use a calculator.
- Play games, such as crossword puzzles and other word games.
- Keep learning.
- Learn to laugh at yourself.

PHYSICAL HEALTH

HCV is a complicated disease that affects the entire body.; it is important to take care of your liver and to learn how to manage the symptoms of HCV. Health is a package deal, and taking care of your whole body just makes sense. The majority of deaths in the U.S. are largely preventable, with tobacco, obesity, and other lifestyle factors topping of the list of leading causes. The number of preventable deaths from other causes is overwhelming compared to HCV-related deaths. For instance, more than 800,000 people in the U.S. die annually from heart diseases compared to 15,000 deaths from

HCV. Tobacco use leads to more than 400,000 deaths a year. The bottom line: you can optimize your chances of living well and living longer if you take preventive health measures.

- **Nutrition**

Try to eat a balanced diet and maintain a healthy weight. Obesity can have a negative impact on the liver, heart, and overall health. People living with chronic HCV may have additional reasons to be concerned about body weight. Research shows that obesity is a risk factor for cirrhosis-related death and may increase the risk for fibrosis. In addition, obesity is associated with a poor response to HCV therapy. Unless your doctor has advised you otherwise, a basic healthy heart diet is a good choice for individuals with chronic hepatitis C.

- **Physical Fitness**

One of the essential ingredients for good health is regular exercise. Exercise is known to have a positive effect on a number of medical problems including arthritis, osteoporosis (bone loss), back pain, diabetes, depression, and cardiovascular disease. Certain fitness programs can improve flexibility, balance, tone, strength, and stamina. Being physically active may improve sleep, reduce stress, and enhance your immune system. Exercise also reduces food cravings, burns calories, and can improve your energy level.

Gardening, walking, hiking, swimming, dancing, bicycling, yoga, and weightlifting are some common recreational activities. Physical fitness is more likely to be successful if it can be done anywhere, does not depend on the weather, and fits any budget. Staying fit does not have to be an “all or nothing” proposition and can fit into the busiest schedules. Any opportunity to be active may be beneficial.

Be sensible about exercise. First and foremost, discuss any physical fitness plan with your health-

care provider. Start a new exercise program gradually. Remember to drink water, apply sunscreen, and avoid injuries. Pain is not gain. However, sore muscles may occur. Heat, cold packs, and stretching may be beneficial. Consult your doctor should you have any injuries, and do not exercise if you are feeling ill.

• *Sleep*

Get enough sleep. The function of sleep is to restore our bodies. Insufficient sleep can negatively affect daily performance and immune function, and has been linked to traffic accidents. Inadequate or poor quality sleep can lead to daytime tiredness. The National Sleep Foundation states that the average adult needs 7-9 hours of sleep per night. If you believe that insufficient sleep is contributing to your fatigue, gather more information. Sleep problems are well understood, and much can be done to improve the quality of sleep.

• *Substance Use*

Alcohol consumption can accelerate liver disease progression. It can also reduce the effectiveness of HCV therapy. Heavy drinking is associated with cirrhosis of the liver. It is not yet known for certain whether light or moderate alcohol consumption is harmful to the liver, but most experts recommend that people with HCV

“*Sometimes a wound is the place where we encounter life for the first time, where we come to know its powers and its ways. Wounded, we may find a wisdom that will enable us to live better than any knowledge, and glimpse a view of ourselves and of life that is both true and unexpected.*”

—Rachel Naomi Remen

should avoid alcohol. People with HCV should also avoid recreational drugs and tobacco use. If you have difficulty abstaining from alcohol, drugs, or tobacco, talk to your doctor or use one of the resources listed at the end of this brochure.

• *Vaccines*

Be sure you are up to date on all immunizations. Both the NIH and Centers for Disease Control and Prevention (CDC) recommend that all people with hepatitis C should be vaccinated against hepatitis A (HAV) and hepatitis B (HBV) if they are not already immune. Coinfection with hepatitis A or B can lead to severe liver disease in people who already have HCV. The hepatitis A vaccine consists of two doses within a six-month period, and the hepatitis B vaccine requires three doses within a six-month period. Both vaccines are considered safe and effective. A combination HAV/HBV vaccine is also available.

• *Spiritual Health*

Spirituality can mean different things to different people. It can include prayer, meditation, walking in the woods, or belonging to a religious group. Spiritual practices such as prayer and meditation have been found to have a positive effect on people with chronic illnesses. The subject of spiritual health is deeply personal and often overlooked. If this is something that interests you, try to include regular spiritual practice in your life.

COMPLEMENTARY MEDICINE

The term “complementary medicine” is often used to describe less conventional medical practices. The terms alternative or holistic medicine are also used when describing a variety of approaches that support health using therapies or tools along with or instead of typical Western-based therapies.

- ***Herbs, Vitamins, and Other Dietary Supplements***

Although herbs and other supplements may seem appealing, a number of herbs can cause harm. Discuss herb and supplement use with your health-care provider. Tell your doctor about all the herbs and supplements you take, even if you think he or she might disapprove. Drugs, herbs, and supplements can interact with each other, and may affect various health conditions. Vitamin and mineral supplements that exceed the Recommended Daily Allowance (RDA) can cause liver and nerve damage. If you are taking a multivitamin, avoid additional vitamin A and iron. Vitamin A in high doses can cause liver injury. Large doses of any supplement are strongly discouraged. More is not better.

Some herbs are known to have potentially carcinogenic (cancer-causing) properties, and some can cause neurological damage. While some herbal remedies such as milk thistle and licorice root may be beneficial to the liver, others can harm the liver, potentially causing liver failure and death. Because herbs can cause hepatotoxicity (poisoning of the liver), people with HCV should avoid herbs or use them cautiously with the advice of a health-care provider. Herbs should never be used by people with decompensated cirrhosis.

If you do use dietary supplements, get informed and be sure your information is current. Before you take an herb or supplement, find out if it is compatible with other drugs or supplements you are taking. Verify that the supplement is not contraindicated for any other condition you may have. Apply the same commonsense approach you would to any drug. If you are cautious about taking prescription or over-the-counter drugs, be equally cautious about herbs and supplements.

- ***Other Forms of Complementary Medicine***

Dietary supplements and herbs are not the only forms of complementary medicine. There is a

huge menu of health practices, many of which do not involve ingesting anything that passes through the liver. Some choices are Ayurveda, biofeedback, Chinese medicine, chiropractic, holistic medicine, homeopathy, naturopathic medicine, osteopathic manipulation, and therapeutic massage. If you have health insurance, check your policy to see if any of these therapies are covered. Some insurance companies have contracts with individual practitioners who will provide a discounted fee for service. Some employers also have arrangements with specific providers, so check your company benefit package.

ACTIVISM AND ADVOCACY

- ***Advocacy for Yourself and Others***

An important part of taking care of your health is to become better equipped as a patient and self-advocate. Start by evaluating your current medical providers. How you feel about your doctors, nurses, and other health professionals is key. Perhaps you like your doctor, but also want a second opinion. A good physician will support your decision to seek other advice. She or he may even provide you with referrals. You can also ask family, friends, co-workers, and medical plan networks for recommendations. Here are some suggestions on how to maximize the time spent with a medical provider:

- Be prepared. Take the time before your appointment to write down all of your medications, supplements, pertinent allergies, a brief medical history, and your chief health complaints. It can also be helpful to include the names, addresses, and phone numbers of your primary care provider and specialists who might be linked to your current medical issue. Also, write down any questions you wish to ask.
- Maintain your own health records. It can really help expedite matters if you bring copies of your most recent pertinent laboratory and biopsy results.

- Prioritize your health issues and be brief but clear. Start with the most important details, and if there is time you can add the less important information at the end.
- When describing your symptoms, begin with the general picture and end with the specifics. Example: "My stomach hurts. I feel nauseous in the morning."
- Relate the impact the problem has on your life. Example: "I am so tired I am unable to exercise."
- Ask for clarification. If your doctor uses words or explanations you do not understand, ask her to clarify or simplify her words.
- Take notes. If your doctor makes suggestions, write them down. Ask him to spell any words you might want to refer to later, such as a diagnosis, medication, or procedure.
- Take a friend. This is especially important for appointments that may be long, complicated, or not routine. Ask your companion to take notes for you.
- Express your reservations. If your doctor suggests a treatment plan that you have some concerns about, let her know. Sometimes these concerns can be easily addressed.
- Ask if there are any alternatives. If your doctor makes a treatment suggestion that you are not prepared to follow, ask about what else you might consider instead.
- Keep an open mind. This can be your strongest ally. It is amazing how many people will not try a medication because of their fear of side effects, only to find out later that the reality was nowhere near their imagination.

“*Be an organ donor. You can donate your organs upon death to HCV patients who would otherwise die.*”

• *Patients' Rights*

Occasionally conflict or confusion can arise between patients and their health-care team. If this should happen, identify resources for conflict resolution. Many private and public health-care settings have formal patients' rights guidelines. For more than a few years, the U.S. Congress has unsuccessfully tried to pass legislation that will provide a universal Patients' Bill of Rights. A bill of rights exists for federal employees, as well as Medicare and Medicaid patients. Some states have patients' rights bills. The Health Insurance Portability and Accountability Act (HIPAA) went into full effect in 2003. These federal regulations give patients more privacy and access to their medical records. Some physicians voluntarily follow patients' rights guidelines set by the Association of American Physicians and Surgeons (AAPS). Ask if your medical provider follows any specific patients' rights guidelines (see Resources).

• *Support Groups*

Support groups can provide valuable information and resources to patients. There are different types of support groups. Some are more informational in nature, while others offer opportunities for feedback and support. Some are closed, requiring more commitment, while others operate on a drop-in basis. When looking for a support group, try to find the type of group that meets your needs. If there is no support group in your area, consider starting one. It is not difficult to do; people seem quite willing to help and the rewards are immeasurable.

THE FUTURE

The understanding and treatment of hepatitis C has an optimistic future. HCV therapies are in various stages of development. A variety of drugs are in different stages of testing. Check with HCV Advocate's Drug Pipeline for the latest developments:

www.hcvadvocate.org/hepatitis/hepC/HCVDrugs.html.

Studies evaluating innovative treatment strategies such as varying doses and durations of therapy, as well as improved delivery systems such as an oral interferon are also in progress. Along with nonresponders, researchers are studying treatment for people with advanced liver disease and other "hard to treat" groups. There are also a few studies looking at the role of vitamins, herbs, and other supplements. Finally, research is being conducted on noninvasive blood tests being developed to evaluate liver tissue health. If successful, this could reduce or eliminate the need for liver biopsies to measure HCV disease progression.

Although drug research is encouraging, it is a complicated process. According to the FDA, only about 1 in 5000 compounds advances to human testing and only 1 in 5 of these makes it to the market. So do not base your hopes on a magic cure that will fix your problem. The future depends on the present. You may still have HCV, but you also have choices and tools to help you now. What are you doing to take care of yourself today? What are your next steps going to be? Investing in your health today is an investment in your future.

RESOURCES:

- Hepatitis C Support Project
www.hcvadvocate.org

This website has in-depth information about most of the topics discussed in this guide. Start here for information on any issue relating to HCV.

• *Clinical Trials*

- ClinicalTrials.gov www.clinicaltrials.gov
Includes a section on "Understanding Clinical Trials," as well as a listing

of open trials for all diseases and conditions.

- CenterWatch: www.centerwatch.com

• *Complementary and Alternative Medicine*

- Alternative Medicine Foundation: www.amfoundation.org
- National Center for Complementary and Alternative Medicine: www.nccam.nih.gov
- University of Maryland Medical Center: www.umm.edu/altmed

• *Diagnostic Tests*

- Labs On-Line: www.labtestsonline.org

• *Healthy Living*

- Aetna Intellihealth: www.intelihealth.com
- Office of Disease Prevention and Health Promotion: www.healthypeople.gov
- Shape Up America: www.shapeup.org
- HealthFinder: www.healthfinder.gov
- Nutrition: Choose My Plate: www.choosemyplate.gov

• *Herbs and Supplements*

- ConsumerLab.com: www.consumerlab.com
Some free information - the annual fee to access the entire website is worth it.
- Memorial Sloan-Kettering Cancer Center: www.mskcc.org/aboutherbs
- National Institutes of Health Office of Dietary Supplements: www.ods.od.nih.gov

• *Mental Health*

- National Alliance for the Mentally Ill (NAMI): www.nami.org
(800) 950-NAMI (6264)
- National Institute of Mental Health: www.nimh.nih.gov (866) 615-6464
- National Mental Health Information Center: <https://infocenter.nimh.nih.gov>
(800) 789-2647

- **Sleep**

- The National Sleep Foundation:
www.sleepfoundation.org

- **Stress Reduction**

- The American Institute of Stress:
www.stress.org
- Laughter Heals Foundation:
www.laughterheals.org

- **Substance Use and Smoking Cessation:**

- Alcoholic Anonymous (AA): www.aa.org
To find an AA group near you, look for "Alcoholics Anonymous" in any telephone directory or contact AA World Service; (212) 870-3400
- Centers for Disease Control and Prevention (CDC): www.cdc.gov/tobacco (800) CDC-INFO (232-4636)

- Narcotic Anonymous (NA): www.na.org
To find an NA group near you, look in your local telephone directory or contact NA World Services (818)773-9999

- **General Resources:**

- Centers for Disease Control and Prevention
www.cdc.gov
- Help4Hep: www.help4hep.org (877) HELP4HEP (877) 435-7443
- National Institutes of Health (NIH):
www.nih.gov

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TREATMENT ISSUES

HCSP GUIDES

*A publication of the
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A GUIDE TO: PREPARING FOR TREATMENT



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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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