



When HCV Treatment Isn't Working



{ Next Steps }



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Introduction

The National Institutes of Health (NIH)

2002 Consensus Statement on the Management of Hepatitis C estimates that at least 4 million people living in the United States have been infected with hepatitis C (HCV). It is believed nearly 3 million are chronically infected. The standard treatment for HCV infection is antiviral therapy, currently a combination of pegylated interferon plus ribavirin. The primary goal of antiviral therapy is to eliminate HCV from the body. Unfortunately, complete eradication of HCV is not guaranteed. Approximately 40-50% of patients who are treated with the currently available drug regimens will remain infected with HCV.

HCV therapy can be difficult. Patients usually enter into treatment with the desire, the hope, or even the expectation that the outcome will be favorable. It can 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?"

THE MEDICAL TERM FOR A “successful” HCV treatment outcome is *sustained virological response* (SVR). SVR is defined as the maintenance of undetectable HCV for 6 or more months after the end of treatment. Undetectable HCV means that hepatitis C is no longer present in your 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 subtype), viral load (the amount of HCV in your blood), and other factors such as age and race. There are different ways in which treatment can 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



Good people are good because they've come to wisdom through failure.

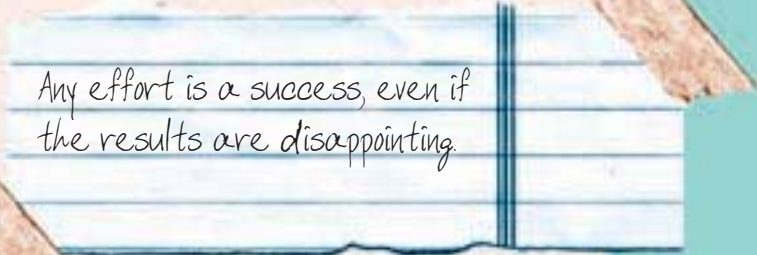
—William Saroyan

HCV re-appears 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 “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 “unsuccessful” therapy that does not completely eradicate HCV can still help slow—or even reverse—the progression of liver damage.

Reactions to undesirable results can vary. Hearing that you still have HCV after you have spent anywhere from 12 to 48 weeks (and sometimes longer) 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 6 months or more before all side effects are completely gone, most patients experience a noticeable improvement between 2 and 12 weeks after the end of



Any effort is a success, even if the results are disappointing.

treatment. This is important to keep in mind, because coping with unwanted news can be more difficult until 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 report that an “unsuccessful” treatment outcome can be disappointing, depressing, or even devastating. 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 become angry after being told that HCV treatment didn’t

work. Anger can be expressed inwardly or outwardly. Anger can be very specific or non-specific, and may be expressed in rational as well as irrational terms. A patient might be angry because he feels his physician “talked him into” treatment and he wasted his time. Someone who did not take her medication regularly might feel angry at herself. Unresolved anger can turn into rage. Rage is an uncontrolled or violent anger, and is a serious matter.

ANXIETY AND FEAR

Responses to adverse medical information can 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 unexpectedly 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.

This thing that we call 'failure' is not the falling down, but the staying down.

—Mary Pickford

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 quite 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 a feeling 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 feelings mentioned previously, such as anger, fear, and grief. Acceptance means giving up the struggle. But it is not resignation. Acceptance does not imply happiness, although contentment can accompany it. Acceptance comes easily to some, while others may struggle with the concept.

It is a feeling of peace



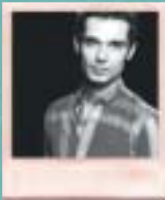
coping with your reactions

Coping with Your Reactions

THE WAY PATIENTS COPE WITH

ongoing hepatitis C can be negatively influenced by various factors. Insufficient medical insurance or financial resources, communication problems 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. But, 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 virological 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



**Success is the ability to go
from one failure to another with
no loss of enthusiasm.**

—Sir Winston Churchill

treatment. Interferon therapy may help slow or stop the progression of liver fibrosis. Additionally, some patients report that even though therapy 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, perhaps you avoided 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. For instance, if you missed some ribavirin doses but overall took at least 80% of your medication, the data are reassuring. Patients who fall below the 80% threshold may have reduced their overall chances of achieving a sustained response. Questioning whether you did everything you could have or should have done is only useful if you can use it positively. 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've been, especially when you felt weak and afraid.

what does this mean?

What Does This Mean?



THE OUTCOME OF YOUR treatment may mean you have to make choices and changes. Start by talking to your healthcare 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 10 to 25% of individuals, the disease progresses over the course of 10 to 40 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, individuals 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 a

range of symptoms, sometimes none at all. 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 care 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 viral load will “spike” to what may seem to be alarmingly high levels, especially after antiviral treatment is stopped. This is common and not medically significant. In general, the information gained from regular viral

A viral load that is higher or lower than a previous measurement does not mean that your condition is worsening or improving.

load tests serves no useful purpose unless you are being treated for HCV. For this reason, a sensible approach is to refrain from re-testing viral load except when undergoing HCV treatment. 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 blood’s ability to clot. 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. To do this, an **alpha-fetoprotein (AFP)** test might 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, non-invasive 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 also 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 people 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.

Keep in mind that 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,

**You may be disappointed
if you fail, but you are
doomed if you don't try.**

—Beverly Sills

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 liver disease is advancing faster than normal. Longer intervals for follow-up biopsies are also 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 prothrombin 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

Further Treatment



My treatment wasn't a failure! I learned so much about myself. I'm a fighter, I don't give up...there's always hope!

UNFORTUNATELY FOR PATIENTS who do not respond to current HCV therapy, there is insufficient research regarding re-treatment. Consequently, there are no general guidelines or approaches for managing people who have not responded to a previous course of therapy.

Although there is little re-treatment data, the issue is being discussed and studied. The general opinion seems to favor not re-treating patients with little or no fibrosis who did not respond to therapy with pegylated interferon plus ribavirin. The issue becomes more complicated when considering patients who have a reduced quality of life, those who did not respond to standard interferon monotherapy without ribavirin, and those with late stage fibrosis or cirrhosis. Research shows that HCV treatment may have

some benefit even if there is no SVR. Patients who did not respond to a previous course of treatment with pegylated interferon plus ribavirin, who have genotype 1 HCV, and who have high HCV viral loads have a very low chance of

achieving an SVR if they are treated again. Conversely, those most likely to achieve an SVR when re-treated are those with genotype 2 or 3 HCV and those who relapsed after standard interferon monotherapy.

**Breathe in, breathe out.
Forget this and enlightenment
is unobtainable.**

—Author unknown

Current clinical trials are examining various re-treatment options. These include longer durations of therapy, increased dosing, combinations of experimental and/or existing drugs, and maintenance therapy. Maintenance therapy refers to the continuous use of a medication, often at lower doses, for a long period of time. The rationale behind maintenance therapy is that it might suppress viral activity and prevent future liver damage. The Hepatitis C Long-Term Treatment Against Cirrhosis (HALT-C) trial is the most well-known study currently evaluating maintenance therapy. The HALT-C trial is a long-term project looking at the use of Pegasys plus ribavirin in patients who have advanced HCV-related liver disease. Initial data has been released and looks promising. Similar studies using other types of interferon and other regimens are also encouraging.

In addition, re-treatment with other drugs not usually used as first-line HCV therapy is also attracting attention. Interferon alphacon-1

(Infergen or consensus interferon) was the first (and technically the only) type of interferon to be FDA-approved for patients who relapsed or did not respond to previous HCV therapy. Data from the original Infergen re-treatment studies were encouraging, especially at a time when HCV treatment was limited to interferon monotherapy and initial response rates were low. Re-treatment with Infergen plus ribavirin is now being studied. If the results are as favorable as preliminary data suggest, this may provide an option for patients who did not respond to prior therapy. Another combination under study is Infergen plus ribavirin plus interferon gamma-1b (Actimmune). New maintenance regimens and new investigational drugs provide reasons to remain optimistic.

If you do continue with more HCV treatment, fortify your decision by learning all you can to avoid another relapse and 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 you, 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. Talk with your doctor about ways to minimize and manage your side effects.

Get accurate information and support. These may help you get through difficult treatment intervals.

THE NIH ADVISES

“Selected patients who fail to achieve an SVR may benefit from re-treatment with pegylated interferon-based regimens. Decisions regarding re-treatment should be based on (1) previous type of response, (2) the previous therapy and the difference in potency of the new therapy, (3) the severity of the underlying liver disease, (4) viral genotype and other predictive factors for response, and (5) tolerance of previous therapy and adherence... Patients with advanced fibrosis or cirrhosis have an increased risk of hepatic decompensation and should be considered for re-treatment, especially if they were originally treated with interferon monotherapy. For the re-treatment of patients with intermediate degrees of fibrosis (bridging fibrosis or cirrhosis with minimal disease activity), clinicians should consider the factors enumerated above in determining whether or not to re-treat.”

(Management of Hepatitis C: 2002. NIH Consensus Development Conference Statement. June 2002.)

ADVICE FROM THE NIH



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 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 healthcare 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.

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*).

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 healthcare team, including close monitoring and follow-up.

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.

I was afraid I would be just another number, but I was surprised at the high level of care and support I received while participating in a clinical trial.

maintaining your health

Maintaining Your Health



LIVING WITH A CHRONIC illness can be very 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. Many symptoms associated with HCV can 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



The secret of life is enjoying the passing of time.

—James Thurber

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 psychiatric illnesses) for diagnosis and treatment of depression. If you have thoughts of hurting yourself or others, get immediate help.

If your healthcare 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 re-uptake 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 feelings of 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:

Be informed. There are some excellent resources on the subject of depression and other types of mental illness (see *Resources*).

Talk about what's bothering you.

Seek 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 this is difficult for you.

Get outside every day, especially when it's sunny (use sun protection). Do not neglect your recreational needs.

Cultivate positive thinking

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 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. For example, do arithmetic in your head or on paper, rather than using a calculator.

Play games, such as crossword puzzles and other word games.

Keep learning.

Learn to laugh at yourself.

PHYSICAL HEALTH

The majority of people will die **with** HCV, not **of** HCV. Naturally, it is important to take care of your liver and to learn how to manage the symptoms of HCV. But 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 the list of leading causes. The number of preventable deaths from other causes is overwhelming, compared to HCV-related deaths. For instance, more than 700,000 people in the U.S. die annually from heart disease, compared to 8,000 to 12,000 deaths from HCV. Tobacco use

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.

—Author unknown

contributes to 440,000 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.

Being physically active may improve sleep, reduce stress, and enhance your immune system.

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 healthcare 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 your body. Insufficient sleep can negatively impact 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 to 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 whether light or moderate alcohol consumption is harmful to the liver, but most experts recommend that people with HCV should avoid



alcohol. People with HCV should also avoid recreational drugs and smoking cigarettes. If you have difficulty abstaining from alcohol, drugs, or tobacco, talk to your doctor

or consult one of the resources listed at the end of this brochure.

VACCINES

Both the NIH and Centers for Disease Control and Prevention (CDC) recommend that all people with hepatitis C should be vaccinated against hepatitis A virus (HAV) and hepatitis B virus (HBV) if they are not already

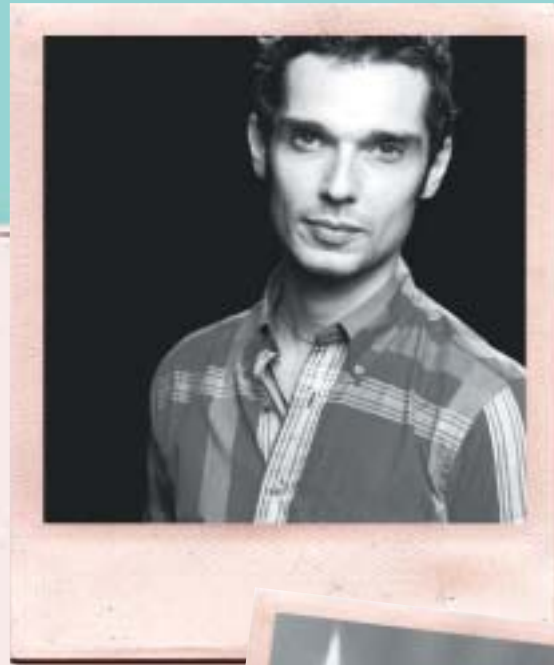
**Health is the consummation
of a love affair of all the
organs of the body.**

– Plato

immune. Coinfection with hepatitis A or B can lead to more 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.



THE TERM “COMPLEMENTARY” medicine is often used to describe less conventional medical practices. The terms “alternative” or “integrative” medicine are also used when describing a variety of approaches that support health, using therapies or tools along with, or instead of, typical Western therapies.

HERBS, VITAMINS, AND OTHER DIETARY SUPPLEMENTS

Although herbs and other supplements may seem appealing, certain herbs and herbal supplements can cause harm. Discuss herb and supplement use with your healthcare provider. Tell your doctor about all the herbs and supplements you are taking, 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, D, and iron. Most people can get enough vitamin D with a multivitamin, a balanced diet, and exposure to sunlight. 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

Life, if thou knowest
how to use it, is long
enough.

—Lucius Seneca

some can cause neurological damage. While some herbal remedies such as milk thistle and licorice root may be beneficial to the liver, others can cause hepatotoxicity (liver poisoning), potentially causing liver failure and death. 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.

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 any-

Before you take an herb or supplement, find out if it is compatible with other drugs or supplements you are taking.

thing that passes through the liver.

Some choices are Ayurveda, biofeedback, Chinese medicine, chiropractic, holistic medicine,

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 common-sense approach you would to any drug. If you are

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 benefits package.

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

- *Be prepared.
- *Maintain your own health records.
- *Prioritize your health issues.
- *When describing your symptoms, begin with the general picture and end with the specifics.
- *Relate the impact the problem has on your life.
- *Ask for clarification.
- *Take a friend.
- *Express your reservations.
- *Ask if there are any alternatives.
- *Keep an open mind.



of your most recent 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 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.

*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.*

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 what they imagined.

PATIENTS' RIGHTS

Occasionally conflict or confusion can arise between patients and their

...never, never, never, never, in nothing great or small, large or petty, never give in except to convictions of honour and good sense. Never yield to force; never yield to the apparently overwhelming might of the enemy.

—Sir Winston Churchill

healthcare team. If this should happen, identify resources for conflict resolution. Many private and public healthcare settings have formal patients' rights guidelines. For more than a few years, the U.S. Congress has unsuccessfully tried to pass legislation that would 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



From the moment I was diagnosed I realized that in order to receive the best possible medical care I would have to take charge of my own health. Now I consider that to effectively manage my health a real partnership must exist between myself and my medical providers.

(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 not a support group in your area, consider starting one. It is not difficult to do; people seem quite willing to help and the rewards can be immeasurable.

The Future

the future

THE UNDERSTANDING AND treatment of hepatitis C has an optimistic future. There are many HCV therapies in various stages of development, including updated versions of drugs and agents such as protease inhibitors that fight the virus using entirely new mechanisms. Studies are currently evaluating innovative treatment strategies such as varying doses and durations of therapy, as well as improved delivery systems, such as an oral form of interferon. Along with non-responders, 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 non-invasive blood tests to evaluate liver tissue health. If successful, this could reduce or eliminate the need for liver biopsies to measure the 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. 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

*All you need is a willingness to learn,
an open mind, and reliable resources.*

Hepatitis C Support Project

www.hcvadvocate.org

This website has more 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

Hepatitis C Long-Term Treatment Against Cirrhosis (HALT-C) trial

www.haltctrial.org

Complementary and Alternative Medicine **National Center for Complementary and Alternative Medicine**

<http://nccam.nih.gov>

888-644-6226

Dr. Weil.com

www.drweil.com

Alternative Medicine Foundation

www.amfoundation.org

Diagnostic Tests

Labs On-Line

www.labtestsonline.org

Herbs and Supplements

American Botanical Council

www.herbalgram.org

512-926-4900

American Herbal Products Association

www.ahpa.org

ConsumerLab.com

www.consumerlab.com

FDA Dietary Supplement website

vm.cfsan.fda.gov/~dms/supplmnt.html

Memorial Sloan-Kettering Cancer Center

www.mskcc.org/about/herbs

Mental Health

National Foundation For Depressive Illness, Inc

www.depression.org

P.O. Box 2257 New York,
NY 10116
800-239-1265

National Institute of Mental Health

www.nimh.nih.gov

Information Resources and Inquiries

Branch 6001 Executive Boulevard
Room 8184, MSC 9663 Bethesda, MD
20892-9663
301-443-4513



**National Alliance for the Mentally Ill
(NAMI)**

www.nami.org

Colonial Place Three
2107 Wilson Blvd., Suite 300
Arlington, VA 22201;
800-950-NAMI (6264) or
703-524-7600

Nutrition and Physical Fitness

American Heart Association

www.amhrt.org

**The President's Council on Physical
Fitness and Sports**

www.fitness.gov

U.S. government nutrition information

www.nutrition.gov

Vegetarian Resource Group

www.vrg.org

Sleep

The National Sleep Foundation

www.sleepfoundation.org

729 15th St., NW, 4th Floor
Washington, D.C. 20005

*Substance Use and
Smoking Cessation:*

Alcoholic Anonymous (AA)

www.alcoholics-anonymous.org

To find an AA group near you, look for "Alcoholics Anonymous" in any telephone directory or contact AA World Service, PO Box 459, New York, NY 10163; 212-870-3400



**Centers for Disease Control
and Prevention:**

[www.cdc.gov/tobacco/
how2quit.htm](http://www.cdc.gov/tobacco/how2quit.htm)

Narcotic Anonymous (NA)

www.na.org

To find an NA group near you, look
in your local telephone directory or
contact

NA World Services,
PO Box 9999,
Van Nuys, CA 91409
818-773-9999

General Resources

National Institutes of Health (NIH)

www.nih.gov.

This website covers general informa-
tion about many health-related top-
ics. Issues specific to liver diseases are
incorporated into the website of the

**National Institute of Diabetes &
Digestive & Kidney Diseases (NIDDK)**

www.niddk.nih.gov/index.htm

**NIH Consensus Development Confer-
ence Statement on Management of
Hepatitis C. June 2002**

[http://consensus.nih.gov/cons/116/
091202116cdc_statement.htm](http://consensus.nih.gov/cons/116/091202116cdc_statement.htm)



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This information is provided by the Hepatitis C Support Project. The mission of the project is to offer support to those affected by HCV. The project provides information, education, and support groups, and seeks to serve the HCV community as well as the general public.