

AFTER HCV TREATMENT: AN HCSP GUIDE

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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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- *Foreword*

Congratulations. You made it through hepatitis C (HCV) treatment. Give yourself a pat on the back. It does not matter if you had an easy or difficult course of treatment, the fact that you finished is enough to feel proud. Now that you are done, you may have questions about what happens next.

The post-treatment period is largely a recovery time. Patients are tired and anxious to return to a normal life. The post-treatment period is also a time of waiting for results. Patients want to know if they are free of HCV. They want to know if their efforts paid off.

This guide addresses common questions and concerns that arise during the six-month period following treatment. At the Hepatitis C Support Project, we understand HCV post-treatment issues, both personally and professionally. We want to provide practical information as well encouragement. We also want to celebrate your victory. You have succeeded in completing treatment. No matter what the outcome is, you have reached a milestone.

At the end of this six-month post-treatment time, you will be either HCV-negative or HCV-positive. If you test positive for HCV, we suggest reading HCSP's *Next Steps: When Treatment Isn't Working*. If HCV is non-detectable, then we recommend *HCV Negative: A Guide for Healthy Living without HCV*.

Positive or negative, take some time to appreciate your health. Sometimes it takes a crisis or loss of health to realize how important health is. With or without HCV, do whatever you can to maximize your health. There is no better investment.

Lucinda Porter, RN
Writer, Hepatitis C Support Project
and *HCV Advocate*

*"If you don't do what's best for your body, you're the one who comes up on the short end."
– Julius Erving*

WHAT TO EXPECT

Do not expect the treatment side effects to disappear over-night. HCV medications linger in your body a little while. Even after they are out of your system, it takes some time before your body returns to its pre-treatment function level.

You may start to feel better in a week or two. You will probably notice a significant change in about a month. Most patients notice that they are back to normal by two or three months. However, there are patients who report that it took 6 months or a year before all the side effects were completely gone.

IMPORTANT ISSUES

There are important guidelines that you need to observe following treatment. Pregnancy needs to be avoided during the six-month period after treatment. Female patients and female partners of male patients should continue to use two reliable forms of birth control for six months following the date of their last HCV medication dose.

If pregnancy occurs during this follow-up time, immediately inform your medical provider. Also, report it to the Ribavirin Pregnancy Registry. You or your doctor can do this. This is confidential, free, and important. (See Resource Section)

Return all used needles and syringes to your pharmacy or medical provider's office. Never discard used needles or syringes in the garbage. These items should be disposed of in special puncture-proof containers called sharps containers. Ask your medical provider what to do with any left over medication or unopened syringes.

MEDICAL FOLLOW-UP

Your medical specialist will have his or her own follow-up guidelines. You may have had some treatment side effects that need special monitoring. Most specialists see their patients six months after their last dose of medication. Lab tests are performed, including

*"Take care of your body. It's the only place you have to live."
— Jim Rohn*

an HCV viral load.

If all of the tests are normal but the viral load is positive for HCV, then your specialist will make recommendations. These may include maintenance therapy or another round of treatment or waiting for new HCV treatments to be approved. If treatment is reattempted, it is usually varied in some way. Maintenance therapy is usually peginterferon without ribavirin and may be at a lower dose.

If all of the tests are normal but the viral load is negative for HCV, then your specialist will tell you what happens next. Some specialists recheck the virus in 6 months or a year. If the virus is still negative, your liver enzymes are normal and you have no other liver disease, your specialist may say there is no reason to come back. A letter may be sent to your primary care provider reporting that HCV was eliminated and that this is usually permanent. It may be suggested that you have an annual complete blood count (CBC) and liver panel but no further viral load testing.

If you have cirrhosis or other liver complications, your specialist will continue to follow you. This will include regular ultrasound and lab tests. If you acquired a thyroid problem during treatment, this will need to be monitored by your primary care provider.

ANTIDEPRESSANT AND OTHER MEDICATIONS

Do not stop taking antidepressants or other medications to manage side effects of HCV treatment. The abrupt stopping of antidepressants is especially risky. If you want to stop taking these or other medications, talk to your medical provider about how to do this safely.

STRENGTHENING YOUR HEALTH

Now that treatment is over, use this time to get in shape. Just by enduring treatment, sometimes patients discover hidden strengths. They are able to carry these into their lives after treatment.

*“No time for your health today, will result in no health for your time tomorrow.”
– Irish Proverb*

Identify any areas that you would like to change. If you are a smoker, you may want to quit smoking. Perhaps you want to focus on getting more sleep. Stress reduction may be your primary issue. Perhaps you are thinking of eating more vegetables. Whatever it is, change only one thing at a time. Formulate a plan for success and get some support.

You may have been overweight before treatment, lost weight during treatment, and want to keep it off. It is likely that when your appetite returns, if you eat as you used to, the weight will return. The best way to prevent this from happening is to watch what you eat and start or increase your physical activity.

Exercise has many benefits. Inactivity during treatment may have left you feeling weaker and flabbier. You also may have lost your endurance. You may need a combination aerobics, strengthening and stretching program. Discuss any physical fitness plan with your medical provider. If you are ready to take this on, start slowly. Be sensible about exercise. Remember to drink water, apply sunscreen and avoid injuries.

To avoid weight gain, do not eat more calories than you use. Unless your doctor has advised you otherwise, a basic healthy heart diet is a good choice. Strive for a diet that is low in saturated fat and cholesterol. Avoid trans fats. Eat generous amounts of fresh fruit and vegetables. Opt for grains that are whole rather than processed. Choose plant-based proteins, such as beans, nuts, and seeds. When eating animal protein choose fish and poultry rather than red meat. Minimize intake of foods with added sugar. Do not exceed sodium (salt) levels that are recommended for your health condition. Processed foods often have high sodium levels. Drink 6-8 glasses of water daily.

For more information on this subject, see *A Guide to Healthy Living with HCV*.

ALCOHOL USE

Most medical providers advise their HCV patients to avoid alcohol. However if the virus is gone, it is reasonable to wonder, "is it safe to drink alcohol?" We do not know the answer. There is no adequate research to answer this. You must decide what is best for yourself. We have provided some insights and suggestions for you to consider.

Try to avoid alcohol during the six-month post-treatment period. If your viral load was non-detectable at the end of treatment, there is still a chance that HCV will return. This chance is greatest during the first 6 months after stopping medication. It makes sense to protect the investment you put into getting through treatment by waiting for at least 6

months before drinking alcohol. If you do this and your six-month post-treatment HCV viral load is positive, you will know that alcohol had nothing to do with the results. For most, this peace of mind outweighs any temporary pleasure that alcohol may bring.

After six months post-treatment if you want to drink alcohol, discuss this with your medical provider. There may be reasons why it is best to avoid alcohol, such as advanced liver disease or other factors. If you do decide to drink, try to limit your alcohol consumption to amounts recommended for those without liver disease – one drink daily for women; two drinks daily for men. Never combine alcohol with acetaminophen (Tylenol). Acetaminophen is a common ingredient in cold medicines, pain relievers and other drugs.

For some patients, the decision not to drink is simple and easy. In support groups, some patients state that they do not intend to return to alcohol use. They worked hard to clear the virus and they know that excess alcohol can damage the liver. They found that they do not miss alcohol and enjoy the freedom of not having to think about it. If you find yourself regularly drinking more than what is recommended, ask yourself if you have a problem. If so, stop, cut back or get some help for your drinking.

TRANSMISSION

Act as if you still have HCV. Act responsibly around blood and bodily fluids. Cover all cuts or wounds. Do not share personal hygiene instruments, such as razors, cuticle scissors, nail clippers, toothbrushes or other items that might be exposed to blood. Properly discard all feminine hygiene products. Use good judgment when getting tattoos or piercings. Although HCV is not classified as a sexually transmitted disease, practice safer sex when appropriate.

Act as if you can still acquire HCV and other diseases. HCV treatment does not protect you from getting HCV again. HCV antibodies do not provide immunity. There are other viruses and sexually transmitted diseases to guard against. This is a good time to take the best care of yourself that you are able to provide.

You still cannot donate blood to a blood bank. However, virus or no virus, you may donate your organs and tissues after death. Consider giving this ultimate gift.

*“Hold on; hold fast; hold out. Patience is genius.”
– Georges-Louis Leclerc, count de Buffon*

RESUMING RESPONSIBILITIES

You may be anxious to get back to resuming activities that you had to curtail or modify during treatment. Do this slowly, especially for activities that are physically demanding. Although you may be feeling better, jump in gradually. Remember that your body has been through a lot. Respect your limits and eventually you will be back up to speed.

If you were on medical leave or had a medically ordered modified work plan, then you will need to be cleared by your medical provider before you can return to full work duties. If you were on complete disability, a gradual return to work may be more sensible than returning to work full-time.

FINAL WORDS

The six-month post-treatment period is a time of mixed emotions. You may feel happy that HCV treatment is over but nervous about the future. Apprehension about the outcome is natural. It is uncomfortable to wait for six months to see if you are HCV negative or HCV positive. No one likes to wait for medical test results.

You are not alone. Nearly every HCV patient who has been through treatment feels this way at this point. Probably the best thing you can do is attend a support group. Express your feelings and concerns. It can be healing knowing that others have been through what you are going through. By sharing your story, you may provide comfort, strength and insight to others.

RESOURCES

Ribavirin: Pregnancy Registry 1-800-593-2214; 1-910-509-4991 (Call collect)
www.ribavirinpregnancyregistry.com

- Easy C Facts: *HCV and Hygiene Items*

"The greatest power is often simple patience."

– E. Joseph Cossman

- *Easy C Facts: HCV and Needle Exchange*
- *Easy C Facts: HCV and Piercing*
- *Easy C Facts: Hep C and Tattoos*
- *HCSP Fact Sheet: Alcohol and HCV*
- *HCSP Fact Sheet: Alcohol and the Liver*
- *HCSP Fact Sheet: HCV and Tattoos*
- *HCSP Fact Sheet: Occupational Exposure to Hepatitis C*
- *HCSP Fact Sheet: Preventing HCV Transmission in Personal Care Settings*
- *HCSP Fact Sheet: Sexual Transmission of Hepatitis C*
- *Hep C Basics: Sexual Transmission of Hepatitis C*
- *A Guide to Healthy Living with HCV*
- *Next Steps: When Treatment Isn't Working*
- *HCV Negative: A Guide for Healthy Living without HCV*

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