

HCV NEGATIVE: A GUIDE FOR HEALTHY LIVING *WITHOUT* HEPATITIS C

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The information in this guide is designed to help you understand and manage HCV and is not intended as medical advice. All persons with HCV should consult a medical practitioner for diagnosis and treatment of HCV.

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• *Foreword*

The ideal outcome for hepatitis C (HCV) treatment is to have a sustained viral response (SVR). This means that HCV is non-detectable in the blood for at least six months after the last treatment dose. Approximately one-half of those who complete treatment will have this best possible outcome – a life free of hepatitis C (HCV). If you are reading this, presumably you were told that your HCV viral load was non-detectable. Congratulations. This is wonderful news.

Although your body is virus-free, you may still have questions and concerns about HCV. You may wonder, does this mean you are cured? Are you in remission? Does this mean you cannot infect anyone else? Can hepatitis C come back? Does this mean you can drink alcohol? What happens next?

This guide addresses these and other common issues following a sustained viral response to treatment. Keep in mind that the study of HCV is still relatively new. Even less is known about what happens to those who have a sustained response to HCV treatment. We cannot provide concrete answers to all of your questions. We can pass along what we have learned from the experiences of others and ourselves. We hope it will provide a platform for you to build this next exciting stage of your life.

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

REMISSION OR CURED?

If six months after your last dose of HCV medications, your HCV viral load was non-detectable, then you had a sustained viral response (SVR). This means that the virus is gone – probably permanently.

The word probably is not totally reassuring, but in fact, HCV is very unlikely to return on its own. It is rare that someone with an SVR after 6 months will later have detectable HCV – rarer still after one year of living virus-free. So rare, that many medical providers stop checking for the presence of HCV after this point.

Because of this small amount of uncertainty, many avoid using the word cure. Some medical professionals use the word cure, since an SVR is so close to curing HCV, that there is no better way to describe it. The word remission is sometimes used, but the term falls short of describing the usual permanence of an SVR.

It may take you time to find a term that best describes the relationship between you and HCV. Whether you say you had an SVR, are HCV-negative, virus-free, cured or whatever, it all comes down to this – living without hepatitis C.

LIVING WITHOUT HEPATITIS C

After living with HCV, it would seem that living without it would be comfortable and straightforward. However, there is an emotional side to living with a chronic disease. Just because HCV is gone, does not mean that emotions go away. There is a process that accompanies disease recovery.

First, there is the issue of believability. You may ask the following: Is this real? Are the test results accurate? How do I know that my lab tests weren't mixed up with someone else's? These questions are normal. The most reassuring way to trust lab results is to have the viral load tests repeated. Do this a few times over a period of one to two years. Tell your medical provider that you want the most sensitive viral load test. The qualitative

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

viral load is generally more sensitive than a quantitative version.

Second, there is the issue of permanence. You may not believe that HCV is gone. However, after a year or two of negative viral loads, it is likely you will trust that HCV is truly gone.

Another issue that some face is an identity crisis. If being a hepatitis C patient has been your identity, what happens when you are HCV-negative? The answer will come with time. Seize the opportunity to make healthy choices and soon you will have a new identity.

SUPPORT GROUPS

If you were an active member of a hepatitis C support group, you may wonder if you still fit in. In general, people who have had an SVR have several reactions. Some continue to attend support groups. They share their stories and inspire others to persevere through the challenges of living with HCV. These patients often say that they want to give back some of what they received.

Stopping group attendance is another common reaction following an SVR. Some people want to put distance between them and hepatitis C. If you feel this, do not feel guilty. It is a normal and healthy response.

Some people feel a mild form of survivor guilt. They wonder why they had an SVR when other patients did not. Survivor guilt is destructive to the self and to others. If you feel guilty, talk about it. Acceptance and gratitude can transform guilt. You will help other patients more if you learn to live with the gift of an SVR, rather than with guilt.

MEDICAL FOLLOW-UP

If all of your lab tests are normal, then your medical provider will tell you what happens next. Some providers recheck the virus in 6 months to a year after the six-month post-

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

treatment period. If the virus is still negative, your liver enzymes are normal, and you have no other liver disease, your medical specialist may say there is no reason to come back. He or she may send a letter to your primary care provider stating that HCV was eliminated and that this is usually permanent. He or she may suggest 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, your primary care provider will monitor this.

From time to time, people have elevated liver enzymes. There are many causes of this, such as drugs, alcohol, fatty liver, toxins, etc. When elevated enzymes occur in patients who have cleared HCV, the initial reaction may be to wonder if the virus is back.

This is unlikely and may be ruled out with an HCV viral load test. Your medical provider will need to diagnose the cause of the elevated enzymes.

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.

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, or lost weight during treatment and want to keep it off. It is likely that when your appetite returns, if you eat like 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

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.

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.

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

TRANSMISSION

Although you do not have HCV, you still need to act responsibly around blood and bodily fluids. 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.

Although it is very unlikely that HCV will return, continue to take precautions. Although HCV is not classified as a sexually transmitted disease, practice safer sex when appropriate. 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.

You still cannot donate blood to a blood bank. However, you may donate your organs and tissues after death. Consider giving this ultimate gift.

INSURANCE

If you were denied medical or life insurance because you were positive for hepatitis C, you may want to apply for insurance again. Ask your medical provider to write a letter on your behalf. A simple and concrete letter is best. Even if the person reading the letter is medically trained, he or she may not understand that the presence of HCV antibody does not mean you have HCV. Ask your medical provider to spell this out.

FINAL WORDS

You are beginning a new phase of your life. Most likely, you cherish this new stage of health. Keep in mind that good health is something that has to be worked at every day.

"The greatest power is often simple patience."

– E. Joseph Cossman

You can only get back what you put into it. Unfortunately, there are no guarantees. Age and life may make unexpected demands. However, experience is a good teacher. The lessons learned by living and surviving hepatitis C may shed light on many of life's darker moments.

RESOURCES

- Easy C Facts: *HCV and Hygiene Items*
- 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 Setting*
- HCSP Fact Sheet: *Sexual Transmission of Hepatitis C*
- Hep C Basics: *Sexual Transmission of Hepatitis C*
- *A Guide to Healthy Living with HCV*

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