

HCV Treatment

A Guide to Help You Stay on Treatment



HEPATITIS C
SUPPORT PROJECT

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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

If you have already started HCV treatment, congratulations. It takes courage to undertake treatment. The hardest part is making the decision to start, so you are already over one of the biggest hurdles. The majority of patients who start HCV treatment also finish it.

This does not mean that the rest is easy. You may have some rough times ahead. In the over 10 years of working with HCV patients, combined with our personal experiences, we have come to believe this generality: if you are brave enough to begin treatment, then barring major problems, you will likely make it to the end.

Your chances of eliminating HCV are directly related to your ability to complete the entire course of treatment at the maximum prescribed dose. For a variety of reasons, not everyone is able to do this. For some, it may be simply because they do not have enough tools and support to help them.

The purpose of this guide is to offer some tips to help you stay the course. It is a companion guide to HCSP's *A Guide to Hepatitis C: Preparing for Treatment*. We recommend that you read that guide first, even if you have already started treatment.

We hope this information is useful. Mostly we want you to know what thousands of us have learned – that you can make it through treatment.

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1. Maximizing This Information

The best way to use this guide is first to read HC-SP's *A Guide to Hepatitis C: Preparing for Treatment*. That guide covers topics such as support, resources and workplace issues. *Preparing for Treatment* discusses ways to get ready physically, mentally, emotionally and financially for HCV treatment. Much of the information that may help in the preparation process may be useful during treatment.

2. Support

If you have not already done so, build a support system. If you are the strong independent type that does not like to ask for help, consider this: asking for help is one of the greatest gifts we can give. It is an act of unselfishness. It requires that we put our trust in others. Those close to us may feel scared or helpless when we are on treatment. Family and friends want to help but do not know how to. Let those around you know how to help you.

Patients derive many benefits from support groups. It can be a relief to be among people who share the same experiences. Support groups are the places we can be ourselves. It is where we do not have to explain how treatment feels because everyone else who is or has been on treatment already knows how this feels. Support groups are where we meet the true experts – the ones who live with HCV.

3. Maintain Your Health

Take especially good care of yourself during HCV treatment. Here are some suggestions:

- Drink at least 8 glasses of water daily
- Eat a healthy, balanced diet
- On a daily basis, engage in light to moderate exercise, such as walking and stretching
- Strive for 7 to 9 hours of sleep every night
- Take care of your teeth and gums
- Pursue pleasure, especially if it makes you laugh
- Maintain social contacts and **do not** isolate yourself
- Take care of your personal appearance
- If you believe in it, continue or cultivate a spiritual practice

4. Medical Emergencies

HCV treatment has many side effects. You may find it reassuring to know what might be an emergency and what might not be. The following list provides some general guidelines. Prior to starting treatment, review this list with your medical provider and ask if he or she would add or remove anything from the list. Some of these symptoms may actually not be emergencies. For instance, you do not need to call 911 if you are pregnant or have worsening psoriasis. These should be reported as soon as possible, but can wait until during regular office hours.

- Mania (periods of very high moods followed by very low moods), severe depression, thoughts of harming yourself or others are potentially life-threatening emergencies.
- Chest pain: there are many causes of chest pain, but this is something only a professional should evaluate.
- Difficulty breathing: shortness of breath with exertion is common with therapy but breathing difficulties are potentially life-threatening emergencies.
- A persistent fever or fever that continues to elevate: fever is a common side effect of treatment and not necessarily an urgent event. Your medical provider will tell you when fever is cause for alarm.
- Loss of or blurry vision: HCV treatment causes dry eyes and blurry vision. These are reversible side effects. However, your medical provider should rule out more serious eye problems.
- Worsening of psoriasis (an autoimmune disease that primarily affects skin)
- Bloody diarrhea
- Unusual bleeding or bruising
- Severe stomach or lower back pain: mild back and stomach aches are common treatment side effects, but severe pain is cause for concern.
- You or your female partner becomes pregnant
- Excessive fatigue that prevents you from getting out of bed
- Any symptom that might be potentially life-threatening or causes you excessive anxiety

5. Medical Appointments

You will need to see your medical provider during HCV treatment. It is a good idea to bring along a family member, friend or advocate to your appointments. A second set of eyes and ears has many advantages, especially after the appointment when our memories fade. Medical appointments are a necessary and important part of managing treatment. Make every effort to keep your appointments.

Your provider is likely to order regular laboratory tests, tailored for your medical condition. For more tools to help with lab tests, see *Appendix: HCV Lab Tracker*. Some providers prefer to review lab results at the time of your appointment, while others order tests after your appointment. Discuss this with your provider. It may be your responsibility to keep track of your lab schedule. Make a copy of your lab orders and mark the dates on your calendar. Also, discuss with your provider how to handle communication of lab results if there is a gap between your lab tests and appointments.

Review your side effects with your provider. Start with the ones that bother you the most. Some patients are reluctant to discuss side effects, concerned that their treatment will be discontinued. However, it is easier to manage side effects in the early stages, so your medical provider may encourage you to report all side effects. A form to help you with this is at the end of this guide. See *Appendix: Side Effect Log*.

Talk to your medical provider about depression, mania, anxiety, anger, irritability, rage, insomnia, feelings of hopelessness, etc. If you feel like harming yourself or others, discuss this with your medical provider immediately. If you are not taking antidepressant medication, your provider may prescribe this. If you are taking antidepressants, the dose may need to be increased or you may need a new or additional medication. Antidepressants may help alleviate a number of treatment-induced side effects, such as fatigue, anxiety, insomnia and depression.

Your provider may prescribe medication for side effects. Be sure you understand the medication instructions and potential side effects. If your provider wants to reduce the dose of either of your HCV medications, discuss if there are other alternatives. In order to avoid dose reduction, some providers use other medications to combat side effects.

Alcohol use is ill-advised for all liver disease patients, but especially during HCV treatment. If alcohol

or substance use is an issue for you, discuss this with your provider.

Discuss work issues with your provider. If you are having a hard time at work, mention this. You may not need to make any changes in your work, but should you need to later, early documentation may help.

If you are having sexual or relational problems, tell your provider. Medication can cause or alleviate sexual problems. Your doctor or nurse may offer non-medication suggestions for these issues.

Before you leave your provider's office, schedule a follow-up appointment and ask for an appointment reminder card. Make sure you know when you are expected to have regular follow-up lab tests.

6. HCV Medications

Ribavirin

Unless otherwise instructed, your ribavirin dose (Copegus, Rebetol, Ribasphere) should be taken in the morning and evening hours with food. If you miss a dose of ribavirin, take the dose as soon as you remember as long as the doses are not close together. *Do not double the dose.*

Peginterferon

Each vial/syringe/ready pen of interferon (Pegasys, PegIntron, Infergen) is a single dose of medication. The manufacturer's instructions advise discarding any remaining solution after injection.

If you miss a dose of peginterferon find out what your doctor or nurse wants you to do. Usually, if it is within 2 days of your usual injection day, it is all right to give yourself an injection as soon as you remember. Call your doctor's office if more than 2 days have passed.

Dispose of used syringes in "sharps container." These containers can be returned to your drug store or to the clinic.

Be sure to notify all other medical and dental providers that you are on HCV medications.

7. Side Effect Management

Important Note: Report all side effects to a medical provider as soon as possible. Treatment side effects should be evaluated and managed by healthcare professionals.

Completion of treatment goes hand in hand with

good side effect management. Most side effects can be managed **with early intervention**. Understandably, patients are sometimes reluctant to tell their medical providers about their side effects because they are afraid that treatment will be stopped. However, when side effects get worse, it is sometimes too late for successful intervention. So, the sooner you report side effects, the better.

Patients may not report side effects because they do not want to take any more medications. If this is how you feel, tell your provider. Some side effects can be managed without medications.

Keep an open mind. You may be reluctant to take a medication that may be the difference between tolerability and suffering. Talk to other patients about their experiences. A good example is antidepressant medications. Even patients who resisted antidepressants are frequently happy they agreed to take them.

Be patient. Not all drugs work the same way on everyone. You may take medication that has uncomfortable side effects. Don't let this stand in the way of trying a different type of medication. The second or third try might make a huge difference.

Some patients fear bothering their medical providers with every detail. Medical appointment time is short. Prioritize your health issues. 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. If you have any fears or feelings, discuss them. It can be reassuring to learn that your symptoms have nothing to do with some disease you have been dreading. Sometimes it is helpful to bring a friend or loved one with you. They may be better equipped to convey information or severity of side effects than you can articulate. Your advocate can take notes to remind you of any important details that you need to know.

Remember that treatment outcome is associated with your ability to stay on the prescribed dose for the duration of treatment. Good side effect management can help you reach this goal.

8. Emotional Issues

Patients commonly report emotional issues during their HCV treatment. These can include depression, mania, irritability, insomnia, difficulty concentrating and even some confusion. If any of these problems occur, discuss them with your doctor. It is important to rule out other causes for these complaints. *Thoughts or feelings of wanting to hurt yourself or someone else*

is always an urgent situation and should be reported immediately.

During treatment, many of the neuropsychiatric symptoms are caused by the HCV medications. Since these are chemically induced, sometimes the best way to counteract them is with medication. Willpower and determination, although fine attributes, are unlikely to alleviate the strong emotions that arise during HCV therapy. Seek professional help for these symptoms. Although your medical provider may be able to help you, consulting with a psychiatrist or psychopharmacologist may be particularly valuable. Keep in mind that, in time, you will return to your old self after you complete treatment.

Stress has a tendency to make life harder, particularly during treatment. Feelings of stress may be reduced with various stress management techniques. You can learn how to manage stress through books and classes. Light exercise may help, such as walking, Tai Chi, Qigong, or Yoga. Some people are helped by meditation. Reserve your "best times" for activities that require the most concentration. Do not neglect your recreational needs. Find ways to laugh. Humor has no side effects except perhaps a few laughs.

9. Social and Sexual Issues

Some of the treatment side effects, such as fatigue and depression can lead to isolation. Make every attempt to avoid isolation. The value of support, particularly in the form of an HCV support group, cannot be overstated. Patients can be experts of a very special kind. They are true authorities on how to live with this disease. Learning how to cope can make all the difference in the world. As the saying goes, "pain is inevitable; suffering is optional."

Some patients remark that they have a decreased *libido* (desire for sex) during treatment. Patients who are taking certain antidepressants are especially prone to sexual difficulties. Some women have problems with orgasm and arousal; some men have problems maintaining an erection or attaining orgasm. Talk to your medical provider about any sexual concerns. Sometimes there are solutions for these problems.

Vaginal dryness can be a problem for women, especially if they are post-menopausal. This may lead to uncomfortable intercourse. Lubricants may provide relief. If you rely on condoms for protection, never use an oil-based product, such as Vaseline. Oil-based products can break down condoms.

If sex is a problem for you, talk to your partner. Assure your partner that this is a temporary situation and will gradually return to normal after treatment is completed. Find alternative ways to be intimate. Share a romantic evening watching a sunset or exchanging massages.

It is essential that female patients as well as female partners of male patients engaging in sexual activity during HCV therapy practice effective contraception. This needs to be consistently followed up to 6 months after the last dose of ribavirin. If you need information about this, contact your local public health department, Planned Parenthood, or medical provider.

10. *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.

11. *Other Medications and Vaccines*

During this time, it is important that you continue your regular medical care. Inform all people involved in your health care about the regular use of prescription and nonprescription drugs, as well as herbs and supplements that exceed the Recommended Daily Allowance (RDA). If another health care practitioner orders other medications you may take these without calling your hepatologist. Nucleoside Reverse Transcriptase Inhibitors (NRTI), such as zidovudine, stavudine, and lamivudine, should be used cautiously. Do not take didanosine with ribavirin. Patients taking theophylline or methadone need to use extra caution.

It is a common myth that HCV patients cannot take acetaminophen (Tylenol). Ask your medical provider about his or her preferences. In general, hepatologists recommend taking acetaminophen (Tylenol) according to the package insert, not exceeding 3000 mg of acetaminophen (Tylenol) daily. The maximum dosages may be lower for those with advanced liver disease or for transplant patients. Be aware that many prescription and nonprescription medications may include

acetaminophen in the formula. Never mix acetaminophen and alcohol.

It is okay to have a flu shot, hepatitis A, hepatitis B or other type of immunization if your health care practitioner orders this for you while you are undergoing HCV treatment.

12. *Complementary and Alternative Medicine*

No herbs, supplements, or alternative treatments have been adequately tested with current HCV medications. Some herbs can be harmful and even lethal. Consult with a professional prior to taking any herbs or supplements during HCV treatment. Some herbs or supplements may mask certain lab test results. Be informed before taking any supplement. Some people have experienced health improvement from acupuncture, acupressure, meditation, Tai Chi, Yoga and other complementary health practices.

13. *Cognitive Tips*

Some patients have problems with forgetfulness and mental fog during treatment. Staying organized is the best way to minimize this. Here are some tips to help you stay organized:

- Put your pills in a weekly pill container. The best one is a container that has morning and evening slots for each day. Alternatively, you can buy two weekly ones and mark one for AM and one for PM.
- Keep records of you injections and appointments on a calendar.
- Maintain a log of side effects and questions to ask your medical provider (*see Appendix: Side Effect Log*).
- Near your phone, put the names and phone numbers of all your medical providers, pharmacy, and medical insurance; carry this information in your wallet.
- Be organized. Keep lists of what you need to do, buy, or remember.
- Put paper and pencils where you need them – by the phone, in the kitchen, in your car, by your bed, etc.
- Always put your keys and eyeglasses in the same place.

- Use sticky paper to post notes to yourself. If you have a hard time remembering to take your medication, stick a reminder note to a mirror, TV or computer screen.
- Call yourself and leave messages on your answering machine or voicemail.
- Set alarms on clocks and watches to remind you to take your medication.
- Learn to laugh at yourself.

14. Workplace Issues

At this point, you probably have a sense if HCV treatment is affecting your work. This issue is discussed in HCSP's *A Guide to Hepatitis C: Preparing for Treatment*. In addition, Jacques Chamber, CLU has written many articles on disability, insurance, benefits and other workplace issues. His articles may be found at www.hcvadvocate.org. Click on the "BENEFITS column" button on the right-hand side of the home page.

15. Cultivate a Positive Attitude

Last, but probably most important, is the power of a positive attitude. Maintaining a positive attitude while undergoing treatment may be difficult, but it can be done. There is no scientific data at this time to support the notion that a positive attitude will have an impact on hepatitis C or treatment outcomes. However, many patients report that attitude was an important part of staying on therapy.

Good attitude is important, but balance it with reality. The physical and emotional side effects of HCV treatment are real. Do not let being positive interfere with expressing your feelings. It is unhealthy to ignore any physical or mental problems that you have. Acknowledge discomfort and feelings. Communicate these with your loved ones and medical providers. Sometimes the fastest way to a good attitude is by letting your feelings out.

Strive to maintain a positive attitude, but be realistic. No one can achieve perfection 100% of the time. A positive attitude is a process and not a final goal. Do not set yourself up for failure. This is a time to be gentle with yourself.

16. Resources

Look for these and other patient brochures at the Hepatitis C Support Project's website www.hcvadvocate.org. Just click on either the "hcsp FACT SHEETS" or the "hcsp GUIDES" buttons on the right-hand side of the home page.

- *A Guide to Hepatitis C: Preparing for Treatment*
- *A Guide to Hepatitis C and Disability*
- *A Guide to HCV Disclosure*
- *A Guide to Hepatitis C Treatment Side Effect Management*
- *A Guide to Understanding and Managing Fatigue*
- *Coping with Depression and Hepatitis C*
- HCSP Factsheet: *A Patient Guide to Finding an HCV Support Group*
- HCSP Factsheet: *Being an Effective Healthcare Consumer: Calling your Healthcare Provider*
- HCSP Factsheet: *Being an Effective Healthcare Consumer: Getting Organized for the Health of It*
- HCSP Factsheet: *Being an Effective Healthcare Consumer: Maximizing Your Medical Appointments*
- HCSP Factsheet: *Being an Effective Healthcare Consumer: Medical Appointments*
- HCSP Factsheet: *Being an Effective Healthcare Consumer: Medication Guidelines*
- *Women and HCV: An HCSP Guide*
- HCSP Factsheet: *HCV and Complementary Medicine: Herbal Dietary Supplement Glossary*
- HCSP Factsheet: *HCV and Complementary Medicine: Herbs and Dietary Supplements – Making Safer and Wiser Choices*
- Hoffman-La Roche (Pegasys and Cogenus) www.pegasys.com 1(877) PEGASYS or 1(877) 734-2797
- Schering Plough (PegIntron and Rebetol) www.pegintron.com 1(888) HEP-2608 or 1(888) 437-2608
- Three Rivers Pharmaceuticals (Ribasphere) www.3riverspharma.com 1(800) 405-8506
- Valeant Pharmaceuticals (Infergen) www.infergenaspire.com 1(888) MOVE-FWD or 1(888) 668-3393

