A Guide to

Preparing for Treatment

Lucinda K. Porter, RN Alan Franciscus, Editor-in-Chief, HCSP Publications



he 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.

Permission to reprint this document is granted and encouraged with credit to the author and the Hepatitis C Support Project.

A publication of the Hepatitis C Support Project

This document is used in its entirety with permission from the authors Lucinda K. Porter, RN and Alan Franciscus, Editor-in-Chief, HCSP Publications, and HCV Advocate.

TABLE OF CONTENTS

Foreword	1
Support and Resources	2
Financial Preparations	3
Medical Preparations	6
Medication Preparations	7
Side Effect Management	9
Preparing Your Body	
Cognitive Tools	1
Goals	1
Attitude	2
Parting Words	3
Resources	3
Appendices:	
Black Box Warning	4
Birth Control and Breastfeeding	5
Tips for Lowering Prescription Drug Costs	7
Medical Provider Information	8

• Foreword

Living with chronic hepatitis C virus (HCV) infection is like a journey. It is not a straightline voyage, but more like an expedition with stops and turns along the way. HCV treatment is one of those stops. Not everyone wants or undergoes treatment; however, those that do usually find themselves engaged in a process of self-discovery. Some uncover strengths that they never knew existed and feel empowered by the treatment process.

If you have no idea what to expect, HCV treatment may seem like a frightening prospect. Scarier still is if you speculate about the process by reading the long list of potential side effects. Yet many people have gone through treatment, some two or more times.

The Hepatitis C Support Project has been educating and supporting HCV patients snce 1998. We have observed that, in general, the anticipation of treatment is a high-anxiety stage of the process. In hindsight, patients usually report that their imagination of what would occur was worse than the actual treatment. This is so common that it is rare to hear the reverse – that treatment was worse than anticipated – although that does happen.

This is not to say that HCV treatment is easy. Some people report having an easy treatment, but, for most it is a challenging experience. The majority of patients who undergo HCV treatment complete it. The dropout rate due to side effects is roughly 10% to 16%.

Patients who are able to complete the entire course of treatment at the maximum prescribed dose are the most likely to reach a virus-free finish line. This means that your chances of eliminating HCV directly relate to your ability to endure the treatment.

The purpose of this guide is to provide tools to help prepare you for HCV treatment. Tools may help you get over the bumps in the road. You may never need some of these. On a daily basis, we do not get flat tires, but most of us carry a spare. We hope that the tools in this guide will be like carrying around a spare tire and a jack – tools you will not need but are important to have for peace of mind.

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

Alan Franciscus Executive Director, Hepatitis C Support Project Editor-in-Chief, HCV Advocate

1. SUPPORT AND RESOURCES

The first step is to find support. The support of your family, friends and other significant people may make a huge difference during this time. Clear communication with close ones is important. Good communication before you begin treatment will pay off during treatment.

HCV support groups are ideal places to gather support and information. Although reading about treatment is useful, there is probably no better way to learn about it than by meeting people who are going through or who have completed treatment. Patients are HCV experts. Support groups are good places to pick up treatment survival tips. In time, you will become an expert and can pass along tips to others.

Preparing for HCV treatment involves identifying and collecting resources. Start with your medical provider. Ask your doctor, nurse or other provider if he/she has literature or other resources to help you during treatment.

Find out if your medical provider offers resources. Some medical groups and health maintenance organizations (HMOs) maintain libraries and web-based resources. Kaiser Permanente has excellent books and resources for their members. Some hospitals maintain community libraries. Your public library may carry medical books and reference materials.

Your community may provide resources. Some areas have support groups open to anyone with any chronic disease. Look for listings about these in your local newspaper or library. Some cities and counties offer community resource guides.

There are commercial resources too. Most pharmaceutical companies offer consumer support and information. Your pharmacy, either local or mail order, may provide services for their customers. Employers and insurance companies frequently offer health-related services.

Note: Some communities offer support groups for family and friends of HCV patients. If there is one in your area, encourage your loved ones to attend.

"It's not the load that breaks you down, it's the way you carry it." — Lena Horne

2. FINANCIAL PREPARATIONS

Whether you are dealing with your pharmacy, insurance company, or medical provider, be prepared to provide the following information:

- Patient's name
- Patient's address
- Patient's phone number
- Patient's date of birth
- Identifying number such as social security, account or membership number

Note: Every time you call your insurance company or medical office, keep notes of dates, names and issues that you discussed. If you have email records, keep these.

• Insurance

Before starting HCV treatment, verify that you have prescription coverage. If you do not, find out how much you will have to pay for HCV medications, as these drugs are very expensive. Additionally there are the costs of medical appointments, lab tests, or drugs to manage side effects. If you do not have prescription coverage and cannot afford to pay for your medications, you may qualify for patient assistance.

Even if you do have prescription coverage, verify what your out-of-pocket costs will be. Some insurance plans separate oral medications from injectable ones. The drugs taken orally, such as ribavirin or a protease inhibitor, may be covered and you might just have to pay the standard co-pay amount. Because peginterferon is administered by injection, your insurance may pay for that under the medical portion of your plan. For some this is good news; for others it is not. For instance, a 30% co-pay means shelling out more than \$300 every month just for the peginterferon.

Before you start treatment, try to get answers to the following questions:

- Do you have prescription coverage?
- If so, what will your out-of-pocket costs be?
- Do you have any reason to think your medical insurance will stop during treatment, such as a probable job lay off?
- If you do not have prescription coverage, what is the cost of HCV treatment?
- How often will you have lab tests done and what is the co-pay?

- How often will you need to see your medical provider and what is the co-pay?
- Insurance or not, can you afford the costs associated with HCV treatment?

• The Workplace

A common myth is that patients are unable to work during HCV treatment. This is simply not true; many people report that continuing to work in some capacity actually helped them through treatment. Although some patients are unable to work, the majority work during some or all of treatment. However, treatment may have an enormous impact on workplace issues and it is wise to look at these before they occur.

Treatment is usually easier to tolerate in the beginning. For this reason, planned time-off does not make any sense until you are further along in treatment. Some people make the mistake of taking time off for their first week or two of treatment, only to find that they feel fine. If they use this sick leave when they do not need it, there may be less leave time later when they are more likely to need it.

Fear of the worst is common and most of us worry that we will be instantly disabled, starting with the first injection. Experience is the only reassurance and until that happens, it is difficult to make time-off plans. One way around this issue is to plan your first injection during a vacation or long weekend.

Workplace disclosure is a delicate issue. The trick is to know the answers to the following: whether to tell, what to tell, when to tell, and how to tell. The answers to these will vary and none are one-size-fits all. You may work in a close-knit, supportive environment and feel you have little to lose if you disclose early. Conversely, you may work in a hostile aggressive place and feel that disclosure will put you at risk. Maybe your job is mentally and physically easy. Perhaps you work at a demanding or dangerous job.

• Medical Leave and Disability

Everyone should know the details of their medical benefits. Here are some questions to ask:

- What is your employer's sick leave policy?
- Is your sick leave paid or unpaid?
- If you have accumulated sick leave, how much do you have?
- Are you allowed to use vacation or personal time for sick leave? If so, what are the rules for doing this?
- Will you have difficulty taking time off for medical and lab appointments?

- If you need to take a medical leave of absence, what is your employer's policy about this?
- What are the terms of short-term and long-term disability?
- Do you qualify to take time off under the Family and Medical Leave Act (FMLA)?
- Does your state or labor union offer better provisions than the FMLA?
- If you take a medical leave of absence, who is responsible for paying for your medical insurance?
- Who pays for other types of insurance, such as life and disability?
- What are the procedures for returning to work?
- Will time-off create a financial burden?
- Will work create a health burden?

Many patients find that treatment is not easy but quite doable. They have good days and hard days. The best strategy is to negotiate a workplace compromise. You may not need to make any changes, but thinking about these things before treatment may help you see that work is not always an all or nothing proposition.

Some examples of these changes are:

ė

- Work less, such as a four-day workweek. You may want to take Fridays off and schedule your weekly medication injections on Thursday nights.
- Adjust working hours to accommodate your best hours. You may feel great in the mornings and want to work 6 am to 2 pm rather than 9 am to 5 pm.
- Telecommute. Some patients are able to work from home.
- Request a change in responsibility. Perhaps you have a project that demands too much of you, and work would be easier if you did not have this one responsibility.
- Take breaks. Perhaps you can take a nap in the employee lounge or in your car.

At some point, you may wonder if you need partial or full disability; discuss this with your medical providers. Good communication with your medical providers is important since they are an integral part of this decision. Some patients state that treatment was easier because they worked. Some state the opposite. Take some time with this

Important Note: For more in-depth coverage of this subject, Jacques Chambers, CLU has written many articles on disability, insurance, benefits and other workplace issues. His articles may be found at www.hcvadvocate.org. Just click on the "BENEFITS column" button on the right-hand side of the home page. decision. Do not rush to a decision based on a few hard days. These may pass. If they do not, talk this over with people you trust and then decide whether disability is worth pursuing.

3. MEDICAL PREPARATIONS

Your medical provider is likely to order laboratory tests before you begin treatment. If it has been awhile since you have had lab work done, some of these tests may be repeats of previous ones. Here are some common and important lab tests that are done before treatment begins:

Pregnancy test – Your medical provider should verify that you are not pregnant immediately before you start treatment. This means taking a pregnancy test. This also holds true if you are the female partner of a man planning to undergo HCV treatment.

_____Viral load – This test confirms that you have chronic HCV infection. Tragically, patients have been treated on the sole basis of a positive HCV antibody test. Approximately 20% of those exposed to HCV carry HCV antibodies but are HCV-negative. In addition, it needs to be ruled out that this is not an acute infection (occurring in the past 6 months). Acute infections are handled differently than chronic ones (infections longer than 6 months). Sometimes the viral load is used to decide which pegylated interferon to use and to estimate your chances of a favorable response.

Genotype – This test determines your strain of HCV and affects the duration and dose of your treatment. The test can help you predict your potential for a favorable response.

Baseline diagnostic tests – These may be used to decide which medicine to use and to estimate your potential for a favorable response. Common tests include a complete blood count (CBC), liver or hepatic panel, and tests to rule out the presence of other diseases, such as diabetes, thyroid or autoimmune conditions. Men over 40 years, women over 50 years and anyone with a history or risk factors for heart disease need a cardiac evaluation prior to HCV treatment.

<u>Liver biopsy results</u> – You may or may not have this information. Some doctors perform routine liver biopsies, while others only do a biopsy on certain patients. Liver biopsy results may be used to decide which pegylated interferon to use and to estimate your potential for a favorable response.

Eye Exam – Although the risk for serious eye problems is low, it is advisable to have a baseline eye exam prior to treatment.

<u>Medical and dental procedures</u> – If you were already planning on undergoing elective medical or dental procedures, you may want to do these before you start treatment. You can do these during treatment but may find that healing time is quicker before you begin treatment. Have a complete dental exam and teeth cleaning before you start treatment.

Immunizations – Patients who are undergoing HCV treatment may be immunized during treatment. This is a good time to be sure you are up to date on your immunizations. Do not delay this since immunization is the best protection against certain diseases.

_____ Talk to your medical provider about antidepressant use during treatment. Some providers initiate antidepressant medication about a month prior to treatment. Some providers recommend waiting to see if antidepressants are needed. Antidepressants may help alleviate a number of treatment-induced side effects, such as fatigue, anxiety, insomnia and depression. Be sure to tell your provider if you are taking antidepressants or have a history of depression. Your provider may want you to have a baseline psychiatric consultation prior to treatment.

____ Schedule a follow-up appointment with your doctor. Make sure you know when you are expected to have regular follow-up lab tests.

_____ Find out how you can reach your provider during evenings, weekends and holidays. Does your medical provider share off-hour service with other providers? If so, with whom?

4. MEDICATION PREPARATIONS

HCV medications are not like common medications. Here is some important information:

- 1. Peginterferon is given by self-injection. Find out who is going to teach you how to do this.
- 2. The medication may need refrigeration depending on what is prescribed for you, so a refrigerator may be necessary.
- 3. Find out if you should begin your ribavirin and protease inhibitor, if prescribed, on the same day or on the morning after your first injection.
- 4. Unless your provider wants you to have your first injection in the office, plan to begin your therapy with an evening injection. Some people choose Friday evenings for their first injection, leaving the weekend open in case there are uncomfortable side effects. Not everyone has side effects after the first injection.
- 5. If you live a long distance from your pharmacy, bring a cooler and ice pack with you when you pick up your prescription. This is not necessary to do if your pharmacy is a reasonable distance. However, never leave your medication in direct sun or a hot car.

- 6. Each pharmaceutical company provides starter kits. These kits are packed with useful information and tools, such as videos, coolers, ice packs, and pill containers. Find out how you can obtain one of these.
- 7. If you travel, ask your medical provider or pharmacist about safe ways to transport needles and refrigerated medication. Carry a copy of your prescription.
- 8. Usually you do not just walk into your local pharmacy and leave fifteen minutes later with a filled prescription. Some pharmacies need at least 24 hours notice in order to fill HCV prescriptions.
- 9. Many insurance companies require "prior authorization" before they will agree to cover the cost of the medication. This could take days or weeks to obtain.
- 10. Your insurance company may require you to purchase all prescriptions at contracted pharmacies. Occasionally insurance companies will only supply HCV medications through a mail order or specialty pharmacy.
- 11. Used syringes need to be disposed of safely. Be sure your pharmacy or medical provider provides you with a "sharps container." These containers can be returned to your drug store or provider's office.
- 12. Pharmacists have a wealth of knowledge about side effects and drug interactions – use their knowledge and experience.

If it is your choice whether to use a regular pharmacy or mail order/specialty pharmacy, consider this:

Advantages to using a specialty pharmacy:

- Medication is shipped directly to you via overnight delivery, saving time and energy.
- Most of these services offer additional support by way of nurses, websites, and other information to help manage your therapy.
- Most of these services will notify you when you need to re-order the medicines.

Advantages to using a regular pharmacy:

- If it is your regular pharmacy, all of your medication records are in one central location.
- You control where and when you pick up medications.
- Some regular pharmacies offer support services for HCV patients.

5. SIDE EFFECT MANAGEMENT

A favorable treatment outcome is associated with your ability to stay on the prescribed dose for the duration of treatment. Completion of treatment goes hand in hand with good side effect management. Good side effect management can help you reach this goal. The key to managing side effects is to treat them as soon as possible, before they become worse. Keep on hand information about side effect management. You may not need most of it, but it is good to have available. For more information, see the Resources section of this guide.

The side effects are usually temporary and should gradually fade away after treatment is stopped. This may take weeks or months; rarely up to a year. The exception is thyroid problems, which may be permanent. Obviously, death is not reversible. Death occurred in less than 1% of study patients. Product information for one of the HCV drugs stated that of the five deaths, two were from suicide, one from suicide/murder, one from a motor vehicle accident, and one from sudden death. Information from the other peginterferon manufacturer stated that the most common potentially life-threatening or fatal events were bacterial infections, depression, suicide, drug overdose or relapse. HCV medications may have induced or aggravated these events.

Nearly everyone has one or more side effects during HCV treatment, ranging in frequency and severity. Most side effects are tolerable. Overall, neuropsychiatric problems occurred in approximately three out of four patients. As well, two out of three patients reported fatigue and headache.

6. PREPARING YOUR BODY

• 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. Although the jury is not in on whether light or moderate alcohol consumption is harmful to the liver, most experts recommend that people with HCV should avoid alcohol. People with HCV should also avoid recreational drugs. Cigarette smoking has been negatively associated with liver disease. If you have difficulty abstaining from alcohol, drugs, or tobacco, talk to your doctor or speak to a chemical dependency professional.

HCV treatment may aggravate chemical dependency problems. Most experts recommend at least 6 months of drug or alcohol abstinence for patients with dependency issues. Prior to treatment, arrange a good support system to help you through this time.

• Weight

Obesity is a negative-predictor for response to HCV therapy. Obesity is a risk factor for cirrhosis-related death and may increase the risk for fibrosis. Obesity is also associated with the increased risk of developing or worsening a number of medical conditions including heart disease, stroke, high blood pressure, arthritis, sleep apnea, type 2 diabetes, gall bladder disease and depression. Overweight individuals are prone to **non-alcoholic** *fatty liver disease* (NAFLD). NAFLD is a spectrum of fat-related liver conditions, ranging from simple *steatosis* (fatty liver cells) to a more severe form, *non-alcoholic steatohepatitis* (NASH). NAFLD is the most common liver disease in the United States.

Body weight determines the dosages for some HCV treatment medications. You may be able to take a lower dose of medication if you lose weight.

Patients with NAFLD, with or without HCV, are likely to improve their health after losing weight and/or body fat. Simple healthy changes in diet and light exercise may produce significant changes for the better. Research showed improvements in lab results, liver biopsy reports and quality of life measurements. If you are overweight, with or without HCV, consider making some changes. Skip "all or nothing" thinking – even a small weight loss may benefit your health.

• Physical Fitness

Many patients find that light to moderate exercise alleviates some of the common side effects of HCV treatment, such as fatigue, anxiety, depression, and body aches. It is best to start this before you begin treatment. Better still, make an exercise commitment to yourself regardless of any external circumstances in your life. Your body will appreciate it.

Sometimes a successful fitness program is just a matter of finding the right one. Fortunately, there are many from which to choose. Examples are: walking, swimming, dancing, Yoga, Tai Chi, Pilates, gardening and playing with children.

Talk to your medical provider before starting any new physical fitness program. For those new to exercise, a reasonable beginning regimen might be to walk a few minutes, stretch, and stop for the day. Always allow a day of rest between weight training workouts. Some fitness trainers recommend a day of active rest every week. Active rest means taking a break from a regular fitness regimen but does not mean spending it on the couch.

Start small and gradually work up to a goal. If the long-term goal is to walk 30 minutes five days a week, then start with 5 minute walks 3 days a week until you can do this effortlessly. Do not overdo it. Too much exercise may lower your immune function.

Be sensible about exercise. 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. Remember to consult a doctor for injuries and discuss a back-up fitness plan for common injuries. Avoid exercise when ill.

• Birth Control

It is essential to avoid pregnancy throughout treatment and for six months after treatment has ended. The guidelines are to **use two reliable forms of birth control**. Reliable means using medically accepted contraceptive methods and using them correctly. Whatever you choose, know how to use the method correctly. Also, notice the word **two**. This means that if you use two forms of birth control and one fails, then you have back-up protection. If you or your partner need information about birth control, talk to your medical provider or family planning center.

7. COGNITIVE TOOLS

Some patients have problems with forgetfulness and mental fogginess during treatment. The trick is to stay organized. You can help train your memory by building good habits before you even begin treatment. Always put keys, wallet, purse, checkbook, and other important items, in the same place. Have the following on hand:

- Weekly pill container, preferably one 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
- Calendar

8. GOALS

Before you start treatment, it is a good idea to define your goals. Write these down and post them where you can see them every day. This may help you if you ever have a day when you doubt your decision to undergo treatment.

The main goal for most patients is to eliminate HCV, completely and permanently. This is called a sustained virologic response (SVR). Roughly three out of four people who complete treatment will reach this goal.

It is a good idea to have some back-up goals. This way you may experience success even if you do not have an SVR. One goal that everyone can reach is just trying treatment. The person who starts treatment and quits in a week has accomplished much more than someone who is too afraid to try it.

There is strong evidence that patients who respond to treatment but later relapse – and perhaps even those who never achieve a complete response – can still experience histological improvement. This means that the liver may be healthier than it was before treatment. Interferon therapy may help slow or stop the progression of liver fibrosis.

Some patients report that even though they did not 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 may be some subjective benefits to treatment, regardless of how it turns out. You may learn a great deal about yourself. You may discover unrecognized strengths and weaknesses in yourself. There is a benefit to making an effort. If you do not try HCV treatment, the future may have a different outcome. By making the effort now, perhaps you will avoid future regret. Regardless of the outcome, treatment is never a waste of time.

9. ATTITUDE

Sometimes, the difference between happiness and misery is attitude. When life gets hard, a good attitude can lighten the load. This is especially important during treatment. HCV drugs can sap your body, mind, and soul, making it harder to maintain a positive attitude. However, this is when you need it the most.

You can prepare for treatment by preparing your attitude. Take steps to build a support network. Surround yourself with positive people. Collect a library of inspiring or humorous literature, videos and websites. Wallpaper your environment with uplifting sayings. Post encouraging words on your computer screensaver, cell phone and mirror. When you need it most, sometimes the smallest details make a difference.

Good attitude is important, but don't let it interfere with expressing your feelings. It is unhealthy to ignore any physical or mental problems that you have. Sometimes the fastest way to a good attitude is by letting your feelings out.

10. PARTING WORDS

It is possible to over prepare for impending HCV treatment. Although this may be unnecessary, it is not harmful unless anxiety is causing this. Some patients report making themselves sick with worry during the treatment-planning phase. They may be involved in a minor accident or come down with a cold. Our bodies can handle only so much distraction. It is hard to concentrate on other tasks when we are consumed by anxiety about treatment. Try to stay in the present. Taking care of yourself today usually pays off tomorrow.

11. RESOURCES

Look for these and other patient brochures at the Hepatitis C Support Project's website www.hcvadvocate.org

- A Guide to Hepatitis C: Making Treatment Desicions
- A Guide to Hepatitis 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: Getting Organized for the Health of It
- Women and HCV: An HCSP Guide
- Genentech (Member of the Roche Group): 1-877-PEGASYS (1-877-734-2797) www.genentechaccesssolutions.com/portal/site/AS/
- Merck (includes Schering-Plough subsidiary): 1-866-939-HEPC (4372) www.merck-cares.com

- Kadmon Pharmaceuticals (formerly 3 Rivers Pharmaceuticals: 1-800-405-8506 www.3riverspharma.com
- Vertex: 1-888-552-2494 Patient Assistance: www.vrtx.com/patients.html

APPENDIX: BLACK BOX WARNING

The Food and Drug Administration requires the manufacturers of ribavirin and peginterferon to label these products with strong warnings. Read the product information before taking any medication, especially the following:

Use of VICTRELIS with Ribavirin and Peginterferon alfa:

- Ribavirin may cause birth defects and fetal death; avoid pregnancy in female patients and female partners of male patients. Patients must have a negative pregnancy test prior to therapy; use two or more forms of contraception, and have monthly pregnancy tests.
- Anemia The addition of VICTRELIS to peginterferon alfa and ribavirin is associated with an additional decrease in hemoglobin concentrations compared with peginter-feron alfa and ribavirin alone.
- Neutropenia The addition of VICTRELIS to peginterferon alfa and ribavirin may result in worsening of neutropenia associated with peginterferon alfa and ribavirin therapy alone.

Use of Incivek with Ribavirin and Peginterferon alfa:

- Pregnancy: Use with Ribavirin and Peginterferon alfa: Ribavirin may cause birth defects and fetal death; avoid pregnancy in female patients and female partners of male patients. Patients must have a negative pregnancy test prior to initiating therapy, use at least 2 effective methods of contraception, and undergo monthly pregnancy tests.
- Serious Skin Reactions: Serious skin reactions including Drug Rash with Eosinophilia and Systemic Symptoms and Stevens-Johnson Syndrome have been reported. For serious skin reactions, all components of INCIVEK combination treatment should be discontinued immediately.
- Rash: Patients with mild to moderate rash should be monitored for progression. If rash progresses and becomes severe, INCIVEK should be discontinued.
- Anemia: Monitor hemoglobin prior to and at regular intervals during INCIVEK combination treatment. Follow dose modifications for ribavirin; discontinue INCIVEK if required.

APPENDIX: BIRTH CONTROL AND BREASTFEEDING

Breastfeeding: Nursing mothers who want to undergo HCV treatment must choose between breastfeeding or treatment. They should not do both at the same time.

Birth Control: Your medical provider should verify that you are not pregnant immediately **before** you start treatment. This means taking a pregnancy test. This also holds true if you are the female partner of a man planning to undergo HCV treatment.

Assuming pregnancy is ruled out, then the goal is to avoid pregnancy throughout treatment and for six months after treatment has been stopped. Use **two reliable** forms of birth control. Birth control should be used in situations where pregnancy is even remotely possible. This includes women who have had tubal sterilizations and men have had vasectomies. The only conditions in which pregnancy is technically impossible occur in women who are post-menopausal or post-hysterectomy. Menopause is defined as the permanent end of fertility marked by the absence of any menstrual bleeding for one year (assuming there are no other causes).

Reliable birth control means using medically accepted contraceptive methods and using them correctly. Whatever you choose, make sure you are well-informed on how to use the method correctly. Also, notice the word **two.** This means that if you use two forms of birth control and one fails, then you have back-up protection.

If pregnancy occurs during or six months after treatment has stopped, report this immediately. Tell your medical provider. All pregnancies should be reported to the Ribavirin Pregnancy Registry. You or your doctor can do this. This is confidential, free, and important.

- Ribavirin Pregnancy Registry: www.ribavirinpregnancyregistry.com 1 (800) 593-2214
 Toll Free or 1 (910) 509-4991 Collect calls accepted
- Merck (includes Schering-Plough subsidiary): 1-866-939-HEPC (4372) www.merckcares.com
- Vertex: www.vrtx.com/patients.html
- For information about emergency contraception, talk to your medical provider or contact Planned Parenthood www.plannedparenthood.org 1(800) 230-PLAN or 1(800) 230-7526

Types of Birth Control (The higher percentage is with perfect use)

- Abstinence 100% reliable, but since it's impractical, include a back-up method
- Tubal Sterilization 99.5-99.9% reliable
- Vasectomy 99.5-99.9% reliable
- Condom 85-98%-reliable, nearly 100% with withdrawal
- Female condom 79 95% reliable
- Spermicide 71-85% reliable
- Diaphragm 84-94% reliable
- The "Pill" 92-98% reliable
- The "Patch" 92->99% reliable
- The "Ring" 92->99% reliable
- The "Shot" 97-99.7% reliable
- IUDs 99% reliable
- Fertility Awareness 75-99% reliable when using a back-up method for fertile days
- Withdrawal 73-96% reliable

Here are examples of two reliable forms of contraception:

- A man with a vasectomy whose post-procedure infertility has been confirmed plus a correctly used condom.
- A woman who underwent tubal sterilization whose partner uses a condom correctly.
- A man who correctly uses a condom with a spermicidal.
- A woman who correctly uses a diaphragm with a spermicidal.
- A man with a vasectomy and a woman with a tubal ligation.
- A woman who correctly uses birth control pills and a man who uses a condom.

Important Points

- Rule out pregnancy prior to starting HCV treatment.
- Use two reliable forms of birth control during and six months after treatment.
- Whatever method you choose, know how to use it correctly.
- Report any pregnancy immediately.
- Do not breastfeed while taking interferon or ribavirin.

APPENDIX: TIPS FOR LOWERING PRESCRIPTION DRUG COSTS

Prescription drug costs are increasing. Do not be embarrassed if you cannot afford a medication. Nearly everyone has been hit by rising healthcare prices. The following are some cost-saving tips to consider:

- Ask your doctor if there is a cheaper version of your medication, such as a generic form.
- Inquire about free samples.
- See if you qualify for a pharmaceutical patient assistance program. For more information contact **Partnership for Prescription Assistance** www.pparx.org or **Needy Meds** www. needymeds.com
- Shop for the best drug price, such as through Costco, wholesale, or reliable Internetbased pharmacies.
- Look for discounted drug prices, such as through your insurance plan, or AARP. You can save money by using insurance pharmacy mail order plans.
- If it is a drug you are confident you will be taking for some time and at a steady dose, and if you can afford it, see if a 90-day supply costs less than a 30-day supply.
- Some pharmaceutical companies offer discounted drug prices for everyone without prescription drug coverage. For more about this, look for information at the website of the pharmaceutical company that sells the medication you are taking.
- Join a discount pharmacy program. These programs offer discounted drug prices for an annual membership fee. If you are interested in this option, make sure the membership fee is reasonable and that the program carries the medications you are taking.
- Compare the price of different strengths of the drug. Ask your doctor if the pill can be
 prescribed at a higher dose and safely divided in half. For instance, if you are supposed
 to take a 5 mg dose of a medication every day, it may be cost effective to purchase a
 30-day supply of a 10 mg dose and divide it in two. This would stretch the medication
 over a 60-day period. Some pills should not be cut without first clearing this with your
 doctor. A word of caution this may violate the rules of your insurance company and
 may not be permitted.
- For more information about Medicare programs, call Medicare at 1(800) MEDI-CARE/1(800)633-4227 or go to www.medicare.gov/MedicareReform. Kaiser Family Foundation provides information about this program and other health topics at www.kff.org
- Locate clinical trials in your area using the drug treatment that you need.
- Look for coupons in magazines or on drug manufacturers' websites
- Purchasing prescription drugs in Canada, Mexico, or overseas is controversial. In some cases, this is legal and other cases it is not. The laws about this vary, depending on the medication and how it is being used. Medication from another country is not always the same or safe and not necessarily cheaper. However, sometimes it can be the same drug, priced at a substantial savings.

APPENDIX: MEDICAL PROVIDER INFORMATION

Provider's Name	Phone Number	Address	Notes
Primary Care Provider:			
Nurse(s):			
Cara si ali a			

Specialists GI/Hepatology:

Nurse(s):

Pharmacist:

Other:

Preparing for Treatment

Lucinda K. Porter, RN & Alan Franciscus, Editor-in-Chief, HCSP Publications



Alan Franciscus Executive Director Editor-in-Chief, HCSP Publications

Authors Lucinda K. Porter, RN Alan Franciscus, Editor-in-Chief, HCSP Publications

Managing Editor, Webmaster C.D. Mazoff, PhD

Contact Information Hepatitis C Support Project PO Box 427037 San Francisco, CA 94142-7037 alanfranciscus@hcvadvocate.org

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.

Version 3 June 2011 © 2011 Hepatitis C Support Project