

# A publication of the Hepatitis C Support Project

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.



## A GUIDE TO: TREATMENT SIDE EFFECT MANAGEMENT

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## FOREWORD

Hepatitis C (HCV) treatment has dramatically improved with the introduction of direct-acting antivirals (DAAs). Current treatment for chronic hepatitis C virus infection (HCV) can cure up to 95% of patients who undergo antiviral therapy. However, HCV medications have troublesome side effects, which can lead to dose reduction or discontinuation of therapy.

The incidence of side effects listed in this guide are taken from FDA package inserts of HCV antiviral therapy and presentations and reports given on the new combination therapies using DAAs, pegylated interferon and ribavirin.

According to the National Institutes of Health Consensus statement on HCV infection, successful HCV treatment requires staying on the prescribed dose of medications for the prescribed period of time. The importance of taking all of the HCV direct-acting antivirals is even more important in increasing the response rates and preventing the development of resistance to the new DAAs. Side effects that interfere with quality of life can hamper this goal, so it's important to manage side effects early, aggressively, and appropriately. The good news is that the management of treatment-related side effects has also dramatically improved, thus making treatment easier to tolerate.

Fortunately, there are many simple and practical steps you can take to avoid or reduce serious side effects. *A Guide to Hepatitis C Treatment Side Effect Management* provides useful tips to help handle the side effects of HCV therapy. One of the most important strategies is to manage any side effects before they become serious.

It is important to remember that not everyone experiences the same side effects, nor are all side effects necessarily severe. In fact, some people may experience few or no side effects. However, it is important to be prepared for the worst, and hopefully your symptoms will be less severe and easier to manage.

Another important component of successful side effect management is to establish a good support system prior to starting HCV therapy. Peer support groups, family, and friends can help most people get through the most difficult times during HCV therapy.

Many people have completed therapy and remain free of HCV. Just completing treatment is a success in and of itself. I hope that this guide will help give you the tools to make a difference in your life.



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

## 1. Maintaining a Positive Attitude

Maintaining a positive attitude while undergoing treatment may be difficult, but it is essential, and should be at the top of your list for side effect management. 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. 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 when you need to be gentle with yourself.

### • Attitude

How do you maintain a positive attitude? There are many steps you can take. For example, before beginning therapy, make a list of the reasons why you are receiving treatment and read the list often.

### Reasons to undergo therapy include:

- To improve your health
- To live longer
- To feel that you have done all that you can do
- To be alive for your children, grandchildren, and loved ones
- To experience life and all it has to offer
- To simply get rid of the virus
- To put hepatitis C and its treatment behind you

- To have children
- To reduce symptoms and increase your quality of life
- To prevent liver cirrhosis and liver cancer
- To help you reach personal and professional goals
- To avoid being a burden to others

Starting the day off with a positive attitude is half the battle. When you wake up in the morning, try to think of something you are grateful for in your life. For example:

- I am grateful that I have the opportunity to take this treatment
- I am grateful for the people in my life
- I am grateful I have a roof over my head and a bed to sleep in at night

Try restructuring your thought processes. Substitute positive thoughts for negative ones. Repeat them to yourself even if you do not believe them at first.

- Instead of thinking, "I'm overwhelmed," say, "I am doing the best I can"
- Instead of thinking, "I'm tired," substitute, "This will eventually pass"
- Instead of saying, "I can't do this," try saying, "I can do this because it is only temporary"

In the evening when you are going to sleep, look back on your day and define what made you feel better and what made you feel worse. Congratulate yourself for getting through the day! Remind yourself that you are one more day closer to your goal of completing treatment.

### • Support

Staying positive while on therapy would be difficult if a person did not have an established support system in place well before starting treatment. It is important to get support from as many areas as possible. Support can come from many sources, including family, friends, co-

workers, healthcare providers, and peers found in support groups. If you do not already attend a hepatitis C support group, consider joining one before starting therapy.

### • *Personal Appearance*

Keeping a positive attitude is easier when you take good care of your body, including your appearance. When you look good, you generally feel better. If you wake up in the morning feeling achy and out of sorts, you may feel better if you take the steps to stay well groomed. Starting your day off feeling fresh will have a positive influence on your emotions for the entire day.

#### Try these strategies:

- Shower or bathe daily; spoil yourself with bath products that smell and feel good
- Light a candle and listen to soothing music
- Take care of your hands and nails
- Moisturize, moisturize, moisturize
- Consider getting a different hairstyle that is attractive, easy to take care of, and would be flattering in case you experience hair loss
- Brush and floss your teeth regularly
- Men: shave or trim facial hair
- Women: if you regularly use make-up, continue while on treatment
- Get dressed even if you will be lying on the couch; choose comfortable clothing
- Wear colors that make you feel good

### • *Exercise*

Exercise is one of the most important components of health maintenance, and this remains true during therapy. Physical activity helps you stay positive and focused and improves your general well-being. Moderation is the key to physical activity. Exercise comes in many forms. You do not have to spend an enormous amount of money or run a marathon to stay fit. Try low-impact activities such as:

- Stretching
- Walking
- Hula-hooping
- Swimming
- Dancing
- Gardening
- Yoga
- Pilates
- T'ai chi or qigong

### • *Relaxation*

Being on HCV treatment can be stressful. Many people feel overwhelmed by trying to remember to take their medications, dealing with side effects, continuing to work at a job, and handling family responsibilities. It is important to build in time for relaxation. Try some of these strategies to help you relax:

- Meditation: try saying "May I be well" while you inhale deeply, and saying, "May others be well" as you exhale
- Prayer: practice your preferred spiritual or religious observance at least once a day
- Light a candle and listen to music
- Instead of holding your breath when you feel stressed out, try breathing in and out gently and slowly
- Sit or walk in a place of natural beauty, such as a beach, forest, garden, or park

### • *Social Events*

Treatment-related side effects and the everyday demands of life can create some uncertainty. Maintain a social life, but be realistic when scheduling dates or appointments. The surest way to become depressed is to isolate yourself from family and friends. However, it is important to talk with family and friends before starting treatment so that they can understand and be supportive if you need to cancel or adjust your plans. Sometimes just the knowledge that you

can cancel or leave a social activity early may help reduce stress. Try to relax and enjoy the time spent with friends and loved ones.

### • *Other Daily Strategies*

Engage in activities that make you laugh. Choose comedies rather than movies with painful themes. Read the comics, watch sitcoms, or do something else you enjoy. Use humor during difficult moments to get a better sense of perspective. Laughter may not be “the best medicine,” but it sure helps. Indulge in a favorite hobby. Most of all, learn to pamper yourself, and let others pamper you, too.

## 2. Side Effects that Need Urgent Attention

Although they are uncommon, it is important to know the symptoms of the most serious side effects. Call your doctor immediately if you experience any of the following:

- Severe depression
- Thoughts of harming yourself or others
- Chest pain
- Persistent fever or fever that continues to increase
- Loss of vision or blurry vision
- Difficulty breathing (shortness of breath with exertion is common with therapy)
- Moderate to severe rash; worsening of psoriasis
- Bloody diarrhea
- Unusual bleeding or bruising
- Severe abdominal or lower back pain
- You or your female partner becomes pregnant
- Any symptom that might be potentially life-threatening
- Any symptoms that cause excessive anxiety

## 3. Aches and Pains

### • *Flu-Like Symptoms*

Interferon is a natural chemical produced by our immune systems. When we fight a cold or flu, we feel the effects of our own internal interferon: fever, chills, malaise, body aches, and headaches. Manufactured interferon causes the same effects. Most people feel these symptoms for several hours or days after their first interferon injection. These flu-like symptoms generally last for a few hours, but may extend into the next day. Some people have flu-like symptoms after every injection, while others have seemingly random symptoms that do not follow a regular pattern. However, some patients never have flu-like symptoms, or might have them only after their first injection. Although infrequent, some patients experience many of these side effects throughout the course of their HCV treatment.

### Tips for managing flu-like symptoms:

- Schedule injections for just before bedtime
- Do not schedule the first injection the night before a major event, such as your wedding
- Ask your medical provider if it is all right to pre-medicate with regular strength (650mg) or one extra strength (500 mg) acetaminophen (Tylenol)
- Drink sufficient water throughout the day before your injection and throughout treatment
- Put layers of blankets and clothes at your bedside to manage chills
- If your teeth chatter, remove dentures or other breakable dental appliances
- To reduce fever, stay cool, but do not get chilled. Acetaminophen, removing layers of blankets and clothing, and lukewarm sponge baths can provide relief
- Get plenty of rest
- Remember that these initial reactions are only temporary (typically lasting four to eight hours) and that losing a good night's sleep is

not the end of the world. Don't forget, you are investing in your future

### • **Body Aches**

Muscle, joint, and body aches are common side effects of interferon treatment. Some people feel these effects just after their first injection. Others experience body aches throughout treatment, either intermittently or continuously. There are several self-help measures you can try. First, get a proper diagnosis for the cause of pain before beginning a self-help regimen. Many conditions can cause body aches, so a proper diagnosis is the first and most important step in good medical care.

#### **Tips for managing body aches:**

- Ask your physician about the use of prescription and non-prescription medications to help with pain
- Try gentle stretching exercises
- Avoid prolonged periods of inactivity
- Apply heat or ice packs
- Try warm or hot baths. Spoil yourself with a bubble bath. (Beware: hot baths can dry the skin)
- Massage may be helpful

Some dietary supplements are purported to relieve inflammation and arthritis. If this interests you, discuss the issue with your medical provider.

### • **Headaches**

Many patients experience headaches while on HCV therapy. Although in some cases the headaches associated with HCV treatment can be debilitating, most people find that they have mild headaches that come and go. If you experience a persistent or ongoing headache for more than 24 hours, contact your healthcare provider immediately.

There are many strategies to help relieve the

headache pain. First, it is important to rule out any causes other than treatment side effects that may be causing or contributing to a headache. Stress, insomnia, and diet can all induce headaches. After ruling out other possible causes, there are some simple steps that may help prevent the occurrence or reduce the severity of a headache.

#### **Tips for preventing headaches:**

- Limit caffeine intake by avoiding caffeinated coffee, teas, and/or sodas, especially in the late afternoon or evening
- Drink lots of water or other clear fluids
- Avoid loud noises, bright lights, and strong odors
- Try to go to sleep and wake up at the same time each day
- Eat all meals, especially breakfast, at roughly the same time each day
- Pamper yourself during stressful times
- Get moderate exercise regularly, at least three times per week
- Don't forget to play, relax, and enjoy life
- Try to find a pattern or the reason for the headache, such as food, stress, or other trigger factors

Ask your medical provider for a list of over-the-counter or prescription medications. Never self-medicate—this can be a recipe for disaster! If you take certain types of pain medication, you may develop rebound headaches, which could be as bad as or worse than the original headache.

Once a headache has started, the same strategies that prevent headaches can also help ease the pain.

#### **Tips for relieving headaches:**

- Depending on the type of headache, a cool damp cloth (or frozen peas) applied to the

back of the neck or forehead may provide some relief

- Some headaches respond to warm compresses
- Place a lavender-scented aromatherapy pillow on your eyes while you rest. Learn acupressure points for headache relief
- Try relaxation techniques such as biofeedback, prayer, or meditation to help with the pain and stress that come with a headache
- Occasionally headaches respond to small amounts of caffeine. Black tea, coffee, cola drinks, and Excedrin all contain caffeine. Try this only occasionally, since caffeine can also cause headaches. Also, do not try in the late afternoon or evening, since caffeine can keep you awake at night

## 4. FATIGUE & SLEEP

### • *Fatigue*

Fatigue is another common side effect of HCV treatment, and of hepatitis C itself. In clinical trials of pegylated interferon, ribavirin and a DAA the majority of patients reported fatigue. Talk to your medical provider if this is a concern. Other medical conditions that lead to fatigue may occur during HCV treatment. Anemia, depression, insomnia, and hypothyroidism are side effects of HCV therapy associated with feelings of exhaustion. These can all be treated.

Assuming you have already consulted your doctor, examine three important factors that influence energy levels: sleep, nutrition, and exercise. Inadequate or poor quality sleep can lead to feelings of daytime tiredness. Make sure you are getting sufficient sleep. The National Sleep Foundation states that the average adult needs seven to nine hours of sleep per night.

Be sure to eat foods with high nutritional value. Fruits and nuts are good choices. Eat small,

frequent meals. Make sure you are getting sufficient quantities of vitamins and minerals. Stay well hydrated by drinking plenty of water. For the average adult, this means drinking a half to a whole gallon of water daily.

Light exercise is probably the single most effective antidote for fatigue. This can be hard to believe, especially if just getting out of bed is an ordeal. When you do not feel like moving, move anyway. As a popular advertisement says, "Just do it." Try exercising for 10 to 15 minute intervals, two to three times daily. If you are not accustomed to physical activity, start slowly and for shorter, less frequent periods. Some activities to try are walking, biking, swimming, dancing, gardening, yoga, tai chi, qigong, and Pilates.

### Tips for managing fatigue:

- Stress can be draining. Learn relaxation techniques
- Unmanageable pain can be exhausting—seek help
- Vary your activities—do not sit too long or stand too long
- Balance rest with activity. Try to rest before you get too fatigued
- Rest even if you are not tired. This may help you avoid future fatigue
- Take short naps—no more than 20 minutes and not close to bedtime
- Take a shower. Alternate water temperatures from hot to cold
- Practice good posture
- Stretch
- Avoid alcohol, tobacco, and recreational drugs
- Make sure your indoor space is sunny or well lit
- Ask for help with chores and other activities
- Create short cuts

- Organize your work areas so you can work more efficiently
- Schedule your most demanding tasks for the times of the day when you are usually at your best
- Take “mini vacations.” Spend an afternoon doing something you really enjoy
- Rub your earlobes for at least seven seconds
- Find ways to laugh
- Practice deep breathing for a minute whenever you feel tired
- Try Chinese medicine or hypnosis

Attitude cannot cure fatigue, but it can be a powerful ally. Watch the negative “self-talk.”

When all else fails, laugh. There is no doubt about it: fatigue puts a damper on life. However, fatigue accompanied by humor is more tolerable than fatigue accompanied by misery. The choice is yours.

There are also herbs, supplements, and vitamins that may help relieve fatigue. However, there has not been much research on the use of herbs, supplements, and vitamins during HCV therapy. The best advice is to avoid these substances during therapy, or discuss their use with your medical providers before trying them.

#### • *Insomnia*

Insomnia, or having trouble getting to sleep and staying asleep, is one of the most common side effects of HCV treatment. Anyone who has ever suffered from insomnia can attest to the fact that it can make you miserable. It may even make the other side effects of treatment worse.

Start by talking to your doctor. A variety of medical issues can cause sleep problems. One example is sleep apnea. Sleep apnea interferes with breathing during sleep and can cause serious health problems. People with sleep apnea often do not know they have it. Fortunately,

sleep apnea can be treated.

Tell your healthcare providers about all the dietary supplements and drugs you are taking (over-the-counter, prescription, or recreational). Some of these may be contributing to your sleep problems. For instance, ginseng and certain cold medicines can keep people awake.

Getting too stirred up before bedtime can also make it hard to fall asleep. Worrying can cause us to toss and turn. Watching the news or exercising before bedtime can be overly stimulating. Sleep experts recommend leaving the TV out of the bedroom. Turn off the TV and your computer an hour or two before bedtime.

#### **The following can interfere with a good night’s sleep:**

- Caffeine in coffee, sodas, tea, chocolate
- Tobacco
- A room that is too hot or too cold
- Light
- Noise
- An uncomfortable bed
- Using alcohol before bedtime
- Being hungry
- Eating a large meal close to bedtime
- Drinking too many liquids before sleep
- A snoring bed partner
- A pet in the bedroom

#### **Tips for promoting sleep:**

- Make eight hours of sleep a regular habit. Sleeping less during the week and trying to catch up on the weekend doesn’t work
- Try to go to bed at the same time every night
- If you have a clock that is always lit, turn it so you can’t see the time
- Exercise every day

- If you nap, keep it short and early in the day
- Try reading before bedtime, but use a low-watt bulb
- Do not eat during the few hours before bedtime, but don't go to bed hungry. If you eat something, choose food that is light and nutritious. Avoid spicy or greasy foods
- Take a hot bath before retiring
- If you feel you need to worry, tell yourself that you will only worry in the daytime. Make your bedroom a fret-free zone. Learn relaxation techniques to reduce stress and worrying
- Listen to relaxation tapes before retiring
- Do not lay awake in bed for more than 20 to 30 minutes. Get up, do something boring for a little while, and then go back to bed
- Your bed is for sleep and sex. If you are not doing either of these, stay out of bed

Some herbal teas can be used to aid relaxation. Chamomile tea is one of the more widely used herbs for sleep promotion. The downside of herbal teas is that some people are awakened during the night by the need to urinate. The scent of lavender on linens or near the bed is thought to promote relaxation. If you use herbs to aid sleep, be very cautious. People with hepatitis C should avoid some herbs, especially while undergoing HCV treatment.

If sleep problems persist, your medical provider may want to prescribe medication to help you sleep. Both prescription and over-the-counter drugs can be very effective. Some medications can be habit-forming, so it's important to tell your provider if you have a history of substance abuse. With sufficient and accurate information, your medical provider is likely to find a medication that is suited to your needs. If the medication you try does not work well for you, report this to your provider. There are many drugs to treat insomnia, and sometimes it is a matter of trial and error to find a good fit.

Insomnia can be a drain on your quality of life—a life already affected by other treatment side effects. Do not lay awake thinking about it. Get some help!

## 5. MENTAL & PSYCHIATRIC SYMPTOMS

**Important Note:** The diagnosis and treatment of psychiatric and other medical disorders requires a trained medical professional. Information contained in this guide is intended for educational purposes only. It should not be used as a substitute for professional diagnosis and treatment of any mental or psychiatric disorder. Please consult a medical professional if the information here leads you to believe you or someone you know may have a psychiatric or other mental illness.

### • *Cognitive Changes and Difficulty Concentrating*

Loss of concentration, memory, and the ability to think clearly are frequent side effects of HCV treatment. But not everyone has these symptoms, and those who do have a wide range of experiences. If this is a problem for you, start by talking to your medical provider. Many factors can cause cognitive changes. Medication can help alleviate some cognitive problems.

### Tips for managing concentration and cognition problems:

- Be physically active on a daily basis. A combination of stretching, strength training, and aerobic activity is an ideal approach
- Eat a nutritional diet. Fruits and vegetables, along with other high-value foods, can provide nourishment for your brain. Do not skip meals
- Drink sufficient water
- Manage stress. Meditation and relaxation techniques can help you think more clearly

- Avoid alcohol and unhealthy substance use
- Get sufficient sleep. The average adult needs seven to nine hours of sleep each night
- Breathe – oxygen is essential to our brains
- Stay mentally active

As for forgetfulness, there are techniques you can use to improve your memory. Libraries usually have books on memory improvement.

#### Tips for improving memory:

- Use daily or weekly pill containers
- Use a calendar or journal to record when you are scheduled to take medications as well as when you have taken them. You can also use this to keep track of your medical appointments
- Use post-it notes to remind yourself of medical appointments and medication schedules
- Set the alarms on your wristwatch, alarm clock, electronic organizer, or computer to remind you about medication and appointment times
- Get yourself organized
- Create habits and daily routines
- Write things down and keep your lists in the same place
- Do one task at a time, rather than multi-tasking
- Pay attention to what you want to remember
- Visualize what you wish to recall
- Use repetition to fasten something in your memory bank

#### • *Depression, Anxiety, Mania, and Other Mood Changes*

The prescribing information that accompanies pegylated interferon and ribavirin lists depression, psychosis, and suicide among the potential side effects. Agitation, mood alteration, aggres-

sive behavior, difficulty concentrating, mania, and bipolar disorder have also been reported. In clinical trials, irritability, anxiety, and nervousness were reported by a third of patients. Insomnia occurred in about 1/3 of patients and about 2/3 experienced fatigue. Insomnia and fatigue are both symptoms of depression, and can also cause or worsen depression and anxiety. Nervousness, insomnia, and fatigue may also be symptoms of other underlying disorders, such as thyroid abnormalities, substance abuse, or medication problems. This section will describe some of the neuropsychiatric side effects of HCV medications so you can discuss them with your healthcare provider.

***Important Note:*** Interferon may cause or aggravate life-threatening neuropsychiatric disorders. If you have thoughts of suicide or hurting yourself or others, seek immediate professional help.

#### • *Anxiety and Depression*

Depression is one of the most common side effects of HCV therapy. Depression may range from mild to severe. In trials, 1% to 2% of patients reported suicidal thoughts or attempts, and 2% stopped treatment prematurely due to depression.

Most people think that anxiety and depression are opposite sides of the coin, but in fact, they often occur together. Anxiety accompanies depression in close to half of all depressed patients. Sometimes referred to as agitated depression, such patients may have feelings of irritability, anger, restlessness, or being “on edge.” Some people may report an increase in worrying or have obsessive thoughts.

#### • *Symptoms of Depression*

The symptoms of HCV treatment-induced depression are often similar to those seen in

regular depression, and may include:

- Feeling sad, “down,” or “blue”
- Fatigue or low energy
- Irritability or anger
- Agitation or restlessness
- Feeling “on edge”
- Mood swings
- Feeling apathetic or “empty”
- Inability to concentrate
- Excessive worry
- Change in appetite
- Thoughts of self-harm or suicide

For patients with a history of depression, interferon-induced depression may be experienced differently than previous episodes. For example, a patient who previously felt withdrawn when depressed might experience feelings of anger and irritability during treatment. This is important to know, because if what you are experiencing now does not feel like previous episodes of depression, you may be less likely to report it.

#### • *Help for Anxiety and Depression*

If you are considering HCV treatment, tell your healthcare provider if you have a current or past history of depression or psychiatric illness. It is especially important to report severe depression, hospitalization for any psychiatric illness, or any suicide attempts.

Sometimes antidepressant medications are used in conjunction with HCV treatment. Many patients say that antidepressants made a huge difference in their quality of life while undergoing HCV treatment. Depression does not always start immediately after beginning HCV therapy. Often, patients do not notice depression until four to twelve weeks – or even longer – into treatment. If you notice any fatigue or mood changes such as irritability, lack of pleasure, or signs of depression after starting interferon, talk to your doctor.

It takes time for antidepressant medications to take effect, so do not expect immediate results. While some people may notice improvement after a week or two, antidepressants typically must be taken regularly for six to eight weeks before their full effect is felt. Starting antidepressants before beginning interferon can help prevent depression or lessen its severity. Since antidepressants can help with other medical complaints, such as fatigue and insomnia, some doctors routinely start patients on these medications prior to initiating HCV treatment. Talk with your doctor about whether you should start antidepressants prior to HCV therapy or start interferon first and then see whether you think you need treatment for depression.

There are many different types of antidepressant medication. Antidepressants themselves can cause side effects, but they are usually mild. However, some side effects can be serious; tell your doctor about any side effects that are unusual, annoying, or affect your activities or quality of life. Common antidepressant side effects include drowsiness, headaches, nausea, feeling agitated or jittery, and sexual problems. Sometimes a drug’s side effects can actually work in a positive way. Insomnia, for example, may be alleviated by an antidepressant that is slightly sedating. Antidepressants can interact with certain drugs; inform your doctor about any over-the-counter or prescription medications, recreational drugs, herbs, or supplements you are using, since these may affect how your antidepressant works.

**Important Note:** Avoid alcohol, since it can worsen depression and may interact with antidepressants and reduce their effectiveness.

When it is time to stop taking antidepressant medications, patients need to taper off slowly. Never stop a medication without first talking

with your doctor. The symptoms of interferon-induced depression and anxiety will gradually fade away after your HCV therapy has ended. Usually people wait a month or more after completing HCV treatment before they feel ready to stop taking antidepressants. You may notice increased anxiety and depression after discontinuing antidepressants. It may take time before you feel life has “returned to normal.” Patience and support will serve you well.

### • *Bipolar Disorder*

Bipolar disorder, formerly known as manic-depressive illness, is a brain condition characterized by mood swings. Most of us have normal ups and downs. However, the symptoms of bipolar disorder are much more intense and can be extremely severe. The “down” phase of bipolar is depression, while the “up” phase is called mania. Occasionally, a bipolar patient will have symptoms of depression, but not have any obvious symptoms of mania. However, the symptoms of mania may become apparent after starting medication for the treatment of depression. If you notice symptoms of mania after starting antidepressants, report these immediately. Like simple depression, bipolar disorder can be treated.

### • *Symptoms of Mania*

According to the National Institute of Mental Health, symptoms of mania include:

- Increased energy, activity, and restlessness
- Excessively “high,” overly good, euphoric mood
- Extreme irritability
- Racing thoughts and jumping from one idea to another
- Talking very fast
- Distractibility, unable to concentrate well
- Little need for sleep
- Unrealistic beliefs about one’s abilities and powers

- Poor judgment
- Spending sprees
- A prolonged period of behavior that is different from usual
- Increased sexual drive
- Abuse of drugs, particularly cocaine, alcohol, or sleeping medications
- Provocative, intrusive, or aggressive behavior
- Denial that anything is wrong

### • *Self-Help for Mood Changes*

The mind and the body are not separate or independent from one another. Your body affects your mind, and your mind affects your body. Stress can weaken the immune system and make it harder to resist diseases. Feeling unwell can lead to increased fatigue and more depression. Breaking the cycle of depression may require a mind-body approach. There are a number of ways you can help yourself. The following suggestions are not intended to replace medical care, but may enhance your quality of life.

#### Tips for managing mood changes:

- Get support. Look for a support group, either for hepatitis C or for depression. Ask your family and friends for support; avoid isolation
- Avoid or reduce stress. Try stress management techniques such as yoga and meditation, or take a stress management class
- Try to be physically active every day. Even if you do not like to exercise, find a way to move your body
- Get at least eight hours of sleep each night
- Avoid alcohol, tobacco, excess caffeine, and recreational drugs, which can cause or worsen depression and anxiety
- Eat a healthy low-fat, high-fiber diet that includes fruits, vegetables, and whole grains
- Balance rest and activity; pace yourself, take

breaks, plan ahead, and delegate.

- Practice positive thinking; try to replace negative thoughts with messages of hope and affirmation
- Find ways to laugh and amuse yourself; try to pick at least one pleasurable activity and find the time to do it often

## 6. SYMPTOMS RELATED TO EATING & NUTRITION

**Note:** Ribavirin, boceprevir (Victrelis), simeprevir (Olysio) and telaprevir (Incivek) are to be taken with food; the instructions for telaprevir are very specific. For more information, see HCSP's Fact Sheet Incivek (Telaprevir): 20 Grams of Fat. Sofosbuvir (Sovaldi) can be taken with or without food.

### • Nausea

Nausea can be a symptom of hepatitis C itself, as well as HCV therapy. It can also be caused by many other factors, such as stress, headaches, other viruses or bacteria, alcohol, lack of food and drink, or overindulgence in food and drink. Regardless of the cause, nausea can have a serious impact on a person's well-being and quality of life. It can also affect how you take your medications and even whether you will stay on therapy.

Nausea is typically described as feeling sick to the stomach, and can range from general queasiness to a strong urge to vomit. Although vomiting is not a common treatment side effect, bloody or persistent vomiting requires urgent medical care.

It is important to find out what is causing nausea so that appropriate steps can be taken to control

it. Try to figure out what triggers your nausea. The solution may be as simple as altering your eating and drinking habits.

### Tips for controlling nausea:

- If morning nausea is a problem, eat some dry crackers when you first wake up, and get out of bed slowly
- Avoid foods and odors that trigger nausea
- Pass on spicy, greasy, and deep-fried foods
- Eat small amounts of food every few hours rather than two or three large meals per day
- During periods of nausea, avoid acidic juices (orange, grapefruit, pineapple); instead, try clear juices, ginger ale, chicken broth, herbal tea, or sports drinks
- Drink and eat slowly
- Consume foods at room temperature (neither very hot nor very cold)
- Take over-the-counter medication for nausea as recommended by your healthcare provider
- Use peppermint, chamomile, or ginger tea to help calm your stomach
- Try raw or cooked ginger
- Suck on ginger candy or lollipops (available at most health food and maternity stores)
- Try relaxation techniques
- Exercise lightly, such as walking or yoga
- Try acupuncture or acupressure
- Wear acupressure wristbands

If nausea improves to the point where you feel able to eat, choose bland, easily digestible foods, such as bananas, rice, applesauce, toast, and tea (the BRATT diet).

If nausea interferes with your ability to take your medications, does not lessen, or becomes worse, contact your healthcare provider. There are many prescription medicines to help treat nausea. It is important to be as proactive as

possible so that you can focus on staying on treatment. Some of the simplest tips can make a huge difference in how you feel.

- **Diarrhea**

Diarrhea is defined as loose or watery stools that occur three or more times per day. In addition to being a potential side effect of interferon and ribavirin treatment, many factors can cause diarrhea, including bacterial and viral infections, drugs, certain foods or beverages, and anxiety.

As with nausea, diarrhea can greatly affect your overall health and adherence to treatment, so it is important to treat diarrhea as soon as symptoms appear. Diarrhea can lead to dehydration and reduced quality of life, as well as contribute to nutrient deficiencies. Notify your medical provider if you experience any of the following:

- Severe diarrhea that lasts longer than two days
- Dramatic weight loss (five pounds or more) that occurs in one day
- Blood in the stool or around the anal area
- Uncontrolled fever, fever higher than 100.6°F, or fever that lasts more than 24 hours
- Severe stomach or intestinal cramping

**Tips for controlling diarrhea:**

- Drink plenty of clear fluids, such as water, weak tea, or broth (vegetable, chicken, or beef)
- Eat Popsicles or gelatin
- Eat small frequent meals
- Keep track of bowel movements
- Consume foods that are high in potassium, such as bananas and potatoes
- Stay away from high-fiber foods, such as whole-grain breads and cereals
- Avoid spicy, fried, and greasy foods
- Stay away from very hot or very cold foods

- Abstain from alcohol, caffeinated drinks, and tobacco products
- Choose bland, easily digestible foods, such as bananas, rice, applesauce, toast, and tea (the BRATT diet)

Diarrhea can dry, chafe, and irritate the anal area. After a bowel movement, wash and rinse the area with warm soapy water or baby wipes and pat dry with a soft tissue or cloth. Apply a water-repellent cream around the anal area to help relieve pain and irritation. A warm sitz bath (sitting in a bathtub filled with warm water) may relieve pain and discomfort, as well as help you relax.

Report severe diarrhea to your healthcare provider immediately. Your doctor may recommend over-the-counter medication like Imodium or a prescription drug to treat diarrhea. Do not self-medicate. Controlling diarrhea is an important part of taking care of yourself. It will ensure that you stay healthy and feel better, and will help optimize your HCV treatment outcome.

- **Weight Loss**

Severe weight loss can be a serious problem during hepatitis C treatment. Getting proper nutrition from a healthy diet is an important part of maintaining your overall health during this time. A majority of people undergoing HCV therapy report mild to moderate weight loss. Unfortunately, the weight loss associated with HCV treatment may be a combination of regular weight loss and a reduction in body muscle mass. For this reason, including fluid and food as part of your medical regimen will help maintain good health. Exercise is also important, since it increases muscle mass, stimulates the appetite, helps keep the immune system strong, and combats depression and anxiety. Besides HCV therapy itself, many factors can contribute to weight loss, including taste changes, nausea, vomiting, diarrhea, depression, or an overactive thyroid. To determine the underlying causes, weight loss should be evaluated by a medical provider.

**Tips for preventing weight loss:**

- Consult with a dietician or nutritionist for information on healthy food choices
- Choose foods that are high in calories and protein
- Drink clear juices in addition to water for extra calories
- Add powdered milk to regular milk, milkshakes, casseroles, soups, eggs, mashed potatoes, hot cereal, and puddings
- Spread peanut butter on bread, tortillas, waffles, pancakes, fruit, and celery
- Add cooked beans or hard-boiled eggs to soups, casseroles, and pasta that already contains cheese or meat
- Try products designed to promote weight gain, such as nutritional supplements, canned formulas, protein powders, instant breakfast drinks, power bars, and high-calorie puddings

If you continue to lose weight despite such strategies, talk to your healthcare provider about medications to help with this. Some antidepressants can stimulate appetite while helping with other medical issues. If you have severe weight loss (five pounds or more in a week), shortness of breath, or dizziness, consult with a medical provider immediately.

**• Dehydration**

The importance of drinking an adequate amount of water during HCV treatment cannot be overstated. Many of the side effects associated with interferon-based therapy can be greatly reduced simply by drinking water. Can you drink too much water? Yes. Drinking excessive amounts of water can affect the body's electrolyte balance, which could lead to serious health problems. Therefore, it is important to check with your healthcare provider before dramatically increasing the amount you drink every day.

The positive effect of drinking water on side effect management is quite substantial. Many people taking HCV therapy report that they experience a marked decrease in side effects on days when they drink plenty of water, compared to days when they drink little or no water. It is recommended that you drink water right before and right after self-injection and stay well hydrated throughout the week.

**The benefits of drinking water include:**

- Flushes out wastes and transports nutrients
- Regulates body temperature
- Hydrates the skin, which helps reduce the dry skin syndrome caused by HCV medications
- Lubricates the respiratory tract, which helps relieve the cough some people get while using ribavirin
- Aids the digestive system, helping to prevent constipation and other problems
- Replaces fluids lost during a bout of vomiting or diarrhea
- Counters the reduced natural saliva production caused by HCV medication, which can increase the risk of dental cavities and diseases
- Keeps your gums hydrated and rinses away harmful bacteria in the mouth

**Tips for drinking enough water:**

- Drink water before you feel thirsty. This will help you to stay well hydrated, since thirst is a sign of dehydration
- Drink water instead of caffeinated beverages such as sodas, tea, and coffee. Caffeinated beverages deplete the body of fluids, which necessitates drinking even more water
- Keep water in places you frequent – at home, in the office, and in the car
- Add a slice of lemon, lime, mint, ginger, or cucumber to add flavor to the water
- Sip water throughout the day instead of gulping it, to give your body more time to absorb it

### How Much Water?

There are many ways to calculate a healthy person's minimum daily water needs. While on HCV therapy, you should drink at least the daily requirement and possibly more, depending on your healthcare provider's advice. One method of calculating your minimum daily water requirement is to divide your body weight in pounds by two. That number represents the total number of ounces you should strive to consume each day. For instance, a person who weighs 150 pounds will need to drink 75 ounces of water per day (nine 8 oz glasses, or slightly more than two quarts or two liters per day).

Additional information on converting measurements is available at [www.easysurf.cc/cnver13.htm](http://www.easysurf.cc/cnver13.htm).

**Note:** When you compute the daily amount of fluid needed remember that the food you eat and other liquids you consume count towards your daily total.

### How Can You Keep Track?

Numerous studies have measured the amount of water people drink daily. It has been shown that the amount of water most people drink each day is much less than they need to stay healthy and well hydrated. Also, people usually drink less water than they think they do, because most people do not keep track of their daily consumption. For this reason, it is important to keep a record of how much you drink.

#### Tips for keeping track of water intake:

- Fill a bottle with fresh water. Write down the volume of water the bottle holds and how many times you refill it throughout the day.
- Buy commercial water bottles that list the fluid content. Fill up or buy enough bottles to meet your daily requirement. Set the bottles in plain view to help you remember to drink all the bottles.

### • Taste Changes

Changes in the way foods and beverages taste is a real problem for many people on HCV therapy. Patients usually describe this as having a metallic taste in the mouth. Medical terms for taste changes are phantogeusia ("phantom" or false tastes), dysgeusia (unpleasant tastes), and para-geusia (abnormal tastes). Other medical conditions, such as a zinc or vitamin B12 deficiency, can cause phantogeusia. Report taste changes to your medical provider and dentist so they can rule out other causes. Taste changes can affect many areas of life, since food is such an integral part of our social lives and overall health. To sustain wellness, it is important to maintain a healthy diet throughout treatment. Treat food as part of your medical regimen.

#### Tips for managing taste changes:

- Drink plenty of water
- Eat with plastic, wooden, or porcelain utensils instead of metal ones
- Use non-metallic cookware, such as glass
- Add tart flavorings such as vinegar, lemon, lime, or orange juice to your food
- Eat cold foods rather than hot ones
- Marinate meats to enhance or disguise flavors
- Avoid strong foods and odors
- Try foods that are high in protein, such as eggs, tofu, chicken, fish, or nuts
- Sample various dairy products, such as cheese, yogurt, cottage cheese, or ice cream
- Sorbet, sherbets, frozen fruit bars, and smoothies may taste better to you
- Flavor your food with horseradish or mustard
- Avoid canned foods, especially those with low or no sodium (Watch your sodium intake if you are on a sodium-restricted diet)
- If a food does not taste good to you, take a break from it for a while
- Try a new food or one that you did not like

in the past. You might find that you enjoy it while you are going through HCV treatment

- Eat crisp, cold foods, such as jicama, bell pepper, and apples
- Before eating, rinse your mouth with club soda, warm salt water, or a mouthwash made of ½ teaspoon salt and ½ teaspoon baking soda in 1 cup of warm water
- Do not eat or drink flavored foods, especially citrus, immediately before or after brushing your teeth
- Take good care of your teeth – brush, floss, and receive regular dental check-ups
- Ask your healthcare provider if zinc sulfate would be worth a try; a typical dose is 220 mg twice daily
- Remember, your sense of taste will return after you have completed HCV treatment
- Some people report that eating just a small piece of chocolate helps to eliminate the metallic taste

### • **Mouth Sores**

During HCV treatment, some patients complain of mouth soreness. This may include sores or ulcers on the gums, cheeks, and tongue, possibly accompanied by redness. Mouth sores are sometimes called canker sores. The medical term is aphthous ulcers. Before treating mouth sores, consult your healthcare provider to obtain a proper diagnosis. Many factors can cause mouth sores, and it is important to understand what caused the problem before it can be fixed.

How do you cure canker sores? The answer is, you probably can't. There are remedies that can make them less painful or hasten their healing, but – as with the common cold – there is no reliable cure for the common canker sore. The exception is if your particular variety of canker sores is caused by an underlying condition that can be remedied. Canker sores that are associated with food sensitivities, medications,

nutritional deficiencies, or the use of sodium lauryl sulfate can be treated if these conditions are resolved.

There are several home remedies you can try. Talk to your healthcare provider about these suggestions, particularly prior to using any herbs or supplements.

### **Tips for preventing and relieving mouth sores:**

- Maintain oral hygiene. Be gentle when brushing your teeth, but don't skip it
- Avoid dental products that contain sodium lauryl sulfate
- Use a soft bristle toothbrush.
- Drink lots of water. Adequate hydration is important for health maintenance, particularly during HCV treatment
- Do not drink liquids that are excessively hot. Ice or frozen juice bars may soothe mouth sores
- Try over-the-counter products that numb canker sores. Products that contain benzocaine, benzoin tincture, lidocaine, camphor, or phenol can provide temporary relief from the pain of mouth sores (Orabase and Zilactac-B are two examples)
- Apply a protective barrier to the lesion. There are over-the-counter products that form a film to cover mouth lesions, making them less vulnerable to irritation
- Maintain good nutrition by eating well. Discuss with your doctor whether you should take a multivitamin or other dietary supplement. (Some people suck on zinc lozenges, but there is no data to support the effectiveness of this remedy)
- Avoid foods that are hard, crunchy, spicy, salty, or acidic
- Reduce stress
- Keep a food diary to see if a particular food is causing mouth sores. Try eliminating suspected foods

- Swish, then spit or swallow a teaspoonful of an antacid such as milk of magnesia (magnesium hydroxide) or Mylanta (aluminum and magnesium hydroxides) with a teaspoonful of liquid Benadryl (diphenhydramine) four to six times daily
- Try tea. Black and some herbal teas are high in tannin. A used tea bag placed on a canker sore may provide relief
- Consider taking an anti-inflammatory medication such as ibuprofen. Be careful because this medication can also cause aphthous ulcers, and not everyone can or should take ibuprofen
- Acetaminophen (Tylenol) may help reduce pain. Do not exceed recommended dosages, since this drug can potentially harm your liver
- Infuse sage and chamomile in water, and use as a mouthwash four to six times daily
- Try raspberry, peppermint, and licorice
- Try taking lactobacillus. These harmless bacteria, sometimes called probiotics, are part of the natural intestinal flora. There are many brands of lactobacillus, such as Lactinex. (Although relatively safe, it is not recommended if you have a prosthetic heart valve or valvular heart disease, asthma, an allergy to dairy products, or are pregnant, trying to get pregnant, or breast-feeding)
- Lysine may be beneficial for herpes-related mouth sores. The general recommendation is 500 mg one to three times daily

**Important Note:** Echinacea may speed mouth sore healing, but should be avoided during HCV treatment, if you are HIV-positive, or if you have an autoimmune condition.

#### • Medication

If non-prescription remedies do not provide sufficient relief from mouth soreness, talk to your

doctor about prescription drugs. Depending on your particular condition, there are a number of different choices. Aphthasol is a relatively new medication that forms a protective barrier when applied over mouth ulcers. Corticosteroids mixed into Orabase are sometimes used. Your doctor may prescribe a liquid antibiotic mouth rinse. Thalidomide is sometimes prescribed for HIV-positive patients suffering from severe aphthous ulcers, but this drug should not be used by HIV-negative people or by women who are pregnant or trying to get pregnant. If a herpes virus causes your mouth sores, talk to your medical provider, they may prescribe acyclovir (Zovirax) or other prescription medication to prevent or lessen the duration and severity of outbreaks.

Your doctor may prescribe a solution of viscous lidocaine, magnesium hydroxide antacid, and diphenhydramine to be swished and either swallowed or spit out, depending on your particular condition. Viscous lidocaine alone may be applied to mouth sores for temporary relief. If your doctor prescribes a medication that must be applied directly to the canker sore, do the following. Dry the sore by gently dabbing it with a tissue. Put the medicine on a clean cotton swab and dab the sore with the swab. Do not eat or drink until the medication has had a chance to dry and form a barrier. Use all medications for the length of time your doctor advises.

Mouth sores can be agonizing and can interfere with your ability to eat and your overall quality of life. Do not ignore mouth ulcers that are very painful or large, or sores that recur, do not heal, or appear in clusters. Canker sores may not seem to be a big deal, but those who have suffered through them know just how painful they can be. Reducing pain and controlling recurrences can help immensely and improve your quality of life.

#### • Dental Hygiene

Poor dental hygiene can lead to tooth decay, gum disease, mouth blisters, and other prob-

lems. It is generally recommended that a dental exam be completed before beginning HCV therapy. People are also encouraged to have procedures such as dental fillings, gum surgery, or root canals well before starting HCV treatment. During HCV therapy, natural saliva production is decreased, which can lead to increased risk for dental problems such as tooth decay and infection.

#### Tips for maintaining good dental health:

- Brush teeth regularly (before and after meals) with a soft bristle toothbrush
- Floss on a regular basis, but be gentle so that your gums are not injured
- Use saliva substitute products if necessary
- Self-examine your teeth, gums, and all areas of the mouth frequently
- Rinse out your mouth often, especially after meals
- Suck on sugar free candies, such as peppermint, to produce more saliva
- If you can afford it, schedule an additional teeth cleaning during HCV treatment. If you regularly see your dentist twice a year, consider going three times

## 7. SKIN \* HAIR \* NAILS \* EYES

### • *Skin Rashes and Itching*

It seems like almost every patient undergoing HCV treatment develops some type of skin problem. The most common skin problems are rashes caused by ribavirin and telaprevir. Skin problems are usually not serious, but can be very annoying; however, there are some rashes associated with telaprevir (Incivek) that can be extremely serious and potentially life-threatening. Consult with your healthcare provider or a dermatologist (skin specialist) if you develop skin problems during treatment. Do this as soon as you notice skin problems since it is much easier to get a mild rash under control than it is to try

to manage a severe rash. If there is any redness, swelling, or accumulation of fluid or pus, this could indicate an infection, so report it to your provider.

In general, HCV therapy can cause dry skin, so it is not surprising that most people suffer from this side effect during treatment. Symptoms may range from mild dry flaky skin to severe skin irritation including bumps and blisters. The itching associated with rashes is usually mildly annoying. At its extreme, itching can be so irritating that it interferes with quality of life. Itching tends to be worse in the evening and may interfere with sleep.

Avoid scratching; if you must scratch, never use your fingernails or sharp objects, since this can lead to infection. This is especially important for people on therapy, since interferon can lower the white blood cell count, which, in theory, can lead to a greater chance of infection.

#### Tips for combating dry skin and itching:

- Avoid soap. Use a non-soap cleanser such as Cetaphil or a similar substitute
- Try rubbing, vibration, or applying pressure instead of scratching. A good thing to "scratch" with is an ice cube
- Drink plenty of water or other clear fluids to keep your entire body hydrated
- Apply moisturizer immediately after a shower or bath – before drying off with a towel
- Creams are more effective moisturizers than lotions
- Apply moisturizer at least twice a day. Effective moisturizers include Vaseline, Aveeno, Eucerin, and Lubriderm brands
- Use only non-perfumed, mild bath and personal care products
- Avoid extremely hot showers and baths
- Take an oatmeal bath to relieve itching and help with relaxation

- Try baking soda or unscented bath oils for bathing
- Apply cold packs (wrapped in a towel) to the skin
- Whenever possible, wear loose fitting clothes made from natural fabrics that breathe
- Protect your skin from the sun – wear sunscreen
- Look after your lips – use lip balm with sunscreen
- Get plenty of rest
- Keep rooms ventilated and at a temperature of 60 to 70 degrees
- Make sure that the area to be injected is clean and sterile
- Apply alcohol and let it dry for 10 to 20 seconds before injecting
- The easiest and least painful areas to inject include the abdomen and thighs; avoid injecting into the waistline or too close to the navel
- The size of the needle is important; check with a physician or pharmacist for recommendations and a prescription if needed
- Position the needle with the bevel up when you inject
- Inject at a 90-degree angle
- Do not massage the injection site
- After injecting, cover the site with a bandage
- Clothing can irritate the injection site, so wear loose natural fabrics
- Topical creams can help with minor irritations
- Rotate injection sites—use a different place each time you inject. Some people alternate between the stomach and the thigh to make sure they do not accidentally inject in the same spot twice in a row

For mild itching or rashes, ask your medical provider if you can use an over-the-counter topical hydrocortisone cream. Do not use hydrocortisone on your face or for prolonged periods unless directed to do so by your doctor. Oral antihistamines such as diphenhydramine (Benadryl) or hydroxyzine (Atarax) can relieve itching and also help with sleep problems.

### • *Injection Site Reactions*

Some people experience a generalized skin reaction in the area where they inject interferon. If you experience continued pain, swelling, irritation, or infection at the injection site, consult a medical provider immediately. Fortunately, the most common injection site reactions are mild and more of a nuisance than a serious problem. However, it is important to follow the necessary steps to ensure that you are using the correct injection technique.

#### **Tips for safe injection:**

- Review injection techniques found in the medication package insert
- Wash your hands with soap and water before injecting to prevent infection
- Make sure the medication is at room temperature

If you want to wear a bathing suit that exposes your thighs or a top that shows your midriff, make a choice of one or the other. Injection site redness is common, and you may not want to walk around exposing red blotches on your skin. For instance, if you are a woman planning a beach vacation where you want to wear a one-piece bathing suit, confine your injections to your abdomen starting about four weeks prior to the event. Start rotating your sites again after you return.

Needles and syringes should never be reused, and used injection equipment should be placed in a puncture-proof disposable “sharps” container (available through your pharmacy or healthcare provider). Do not throw the full

container into your household trash. Dispose of it as instructed by your medical provider or pharmacist.

### • **Nail Changes**

HCV therapy can affect your fingernails and, to a lesser extent, toenails. Nails may become dry and brittle. They may also develop ridges and may break easily.

#### **Tips for taking care of your nails:**

- Keep nails short
- Use hand lotions and creams as often as possible, especially after your hands have been in water
- Wear gloves to protect your hands when doing chores such as dishwashing, cleaning, gardening, or using chemicals
- At bedtime, apply oils or thick creams (such as Aveeno or Eucerin) to your hands. Smear extra on your nails. Wear cotton gloves while you sleep to protect your sheets and clothing
- If you polish your nails, use gentle polish removers
- Better yet, avoid nail polish and other harsh nail products altogether
- Use nail strengtheners and try buffing to bring out a shine

**Important Note:** If you have your nails professionally manicured, know how to keep others as well as yourself safe from blood-borne viruses. Tools that can break the skin or that may come into contact with blood should be used on only one person or thoroughly cleaned between clients. Consider buying your own personal care tools to take with you to keep it safe.

### • **Hair Loss**

Some hair loss is common for healthy people. In fact, the average person loses between 50 and 150 hairs each day. Hair loss can be caused by many different factors, including heredity, harsh hair treatments, and various medical conditions. Interferon therapy can cause excessive hair loss (alopecia) and changes in hair texture. Such changes may occur all over the body, not just on the head. It is rare for a person on interferon to lose all of his or her hair or go bald, but many people notice that their hair is thinning, or that it is becoming brittle and breaking off. Hair color may become dull and hair texture may change during therapy curly hair may even become straight or vice-versa.

Treatment-related hair loss and changes in texture may affect body image and mood, so it is highly recommended that people seek professional psychological support or help from a peer-led support group. The good news is that hair loss and changes in hair texture are only temporary. The hair will usually grow back after treatment is completed. Some people even report that their hair grows back fuller and thicker than before.

It is important to know that minoxidil (Rogaine) will not work to counteract interferon-induced hair loss. In fact, minoxidil should be avoided because it can irritate and dry out the scalp. A newer drug, finasteride (Propecia) is also unlikely to provide any benefit. Approved only for male-pattern baldness, virtually nothing is known about the use of this drug for interferon-induced hair loss. Additionally, most people will be done with HCV treatment about the time it takes for finasteride to work.

#### **Tips to reduce hair loss and related problems:**

- Do not wash your hair too frequently
- Avoid the chemicals found in dyes and permanents – use natural products. If you

do use chemicals on your hair, choose the mildest products available

- A short, layered haircut will make hair look thicker and fuller
- Keep your hair conditioned; use moisturizers and detangling products.
- Use hair products that add body and texture or that create the appearance of depth
- Avoid hair dryers, rollers, and curling irons
- Comb and brush your hair less; choose a soft brush or wide-tooth comb
- Do not “tease” or “back-comb” your hair
- Use a sunscreen, hat, or scarf to protect your scalp and hair from sun damage. Splurge on hats and scarves that accentuate your best features
- Avoid hairstyles that could strain your hair, such as hair weaves or braiding
- Sleep on a satin pillow
- Wear a hair-piece or wig

### • **Eye Problems**

Some rare but serious eye problems can occur during HCV treatment, so early diagnosis and intervention is essential. Only a medical provider or eye specialist is qualified to evaluate any vision or eye problems.

**Important Note:** A loss or decrease of vision requires immediate medical attention.

Some common eye problems are not immediately serious. Dryness is one of these. Talk to your medical provider about the use of preservative-free non-prescription artificial tears. Some people report that the quality of their eyesight diminishes during HCV treatment. This may be due to dry eyes, fatigue, normal aging, or medication. Again, talk to your medical provider if this is a concern.

A baseline eye exam before you start HCV treatment is recommended. Your eyes should return

to normal in the weeks and months following the end of therapy. Exceptions to this are changes due to normal aging and possibly some rare or untreated medical problems.

## 8. BLOOD DEFICIENCIES

### • **Hemolytic Anemia**

Red blood cells carry oxygen to body tissues, providing fuel the body needs to stay alive and healthy. The normal average life span of a red blood cell is about 120 days; after red blood cells have worn out, the spleen removes them from circulation. Hemolytic anemia is a condition in which red blood cells are destroyed faster than the body can make enough new ones to replace them. Ribavirin, boceprevir and to a lesser extent telaprevir are the main causes of anemia.

### Symptoms

The most common symptoms of anemia include shortness of breath, fatigue, pale skin, chills, rapid heart rate, depression, and reduced quality of life. If left unchecked, hemolytic anemia can lead to jaundice, dark urine, and an enlarged spleen. In severe cases, it can lead to heart attacks. For this reason, people should have a physical exam to rule out any potential heart problems before starting HCV treatment.

### Diagnosis

A simple blood test called a complete blood count (CBC) measures various components of the blood including red cells, white cells, and platelets. Anemia is diagnosed using two tests that measure red blood cells and their oxygen-carrying capacity: hemoglobin and hematocrit. A low hemoglobin or hematocrit indicates anemia.

### Normal Ranges

	Adult Male	Adult Female
<b>Hemoglobin</b>	13.5-17.5 g/dL	12.0-16.0 g/dL
<b>Hematocrit</b>	42.0-52.0 %	37-47 %

Source: [www.rush.edu](http://www.rush.edu)

## Treatment

There are two approaches to treating hemolytic anemia: ribavirin dose reduction and use of a growth factor hormone (erythropoietin) to promote red blood cell production. Ribavirin-induced hemolytic anemia cannot be treated by eating iron rich foods or taking iron. Ask your medical provider if you should take B12 during HCV treatment.

In general, ribavirin dose reduction or the use of red blood cell growth factors are recommended when the hemoglobin level goes below 10 g/dL or if there is a significant drop in hemoglobin level over a short period of time. People with heart disease should be monitored very carefully when their hemoglobin level starts to drop. Ribavirin may have to be discontinued if the drop in hemoglobin level is substantial. The general recommendation is to stop taking ribavirin or HCV therapy altogether if the hemoglobin level drops below 8.5 g/dL.

Some medical experts believe that ribavirin dose reductions should be avoided, especially during the first 12 weeks of therapy, since an adequate ribavirin dose helps prevent relapse and improves the chances of achieving sustained virological response (SVR).

Erythropoietin alfa (EPO; brand name Epogen or Procrit) and Darbepoetin alfa (Aranesp) promote red blood cell production in the bone marrow. Clinical studies using EPO to treat HCV treatment-induced hemolytic anemia have shown an average increase in hemoglobin levels of 2.0 g/dL and improvement in patients' quality of life. EPO is FDA-approved for chronic kidney failure, cancer chemotherapy, HIV therapy, and use before elective surgery. Although EPO is commonly used to treat ribavirin-induced hemolytic anemia, it has not been approved by the FDA for this purpose, so obtaining insurance coverage or reimbursement may be difficult.

A warning has been added to the EPO product

package insert about serious and life-threatening complications that may be related to the use of EPO. To minimize these risks it is recommended that only the lowest dose needed is used for a limited amount of time.

It is important to notify and work closely with your medical provider if you notice any symptoms of anemia, in order to ensure that your HCV treatment will be as successful as possible.

- **Neutropenia**

The primary function of white blood cells is to fight infection. There are many different types of white blood cells, such as neutrophils, lymphocytes, monocytes, eosinophils, and basophils. Neutropenia is a condition characterized by an abnormally low number of neutrophils.

Neutropenia occurs in some healthy people and seems to be more prevalent in certain populations, for example Blacks and Yemenite Jews. Decreased production or destruction of white blood cells can also cause neutropenia. Some diseases can cause neutropenia, including viral infections, tuberculosis, typhoid fever, and some bone marrow disorders.

Interferon and other medications can also cause neutropenia. Neutropenia is a common side effect of conventional and pegylated interferon with or without ribavirin. Clinical studies have shown that as many as 95% of people on HCV treatment using interferon experience some reduction in neutrophil count below the normal range. People taking pegylated interferon are especially at risk, with about 20% of patients developing significant neutropenia.

Generally speaking, interferon boosts the immune system. The vast majority of people who develop interferon-induced neutropenia do not seem to develop any serious infections. However, even though the risk of a serious infection is low, it is still very important that patients be closely monitored to prevent severe neutropenia.

Neutropenia is usually managed by interferon dose reduction according to the specific product labeling found in the drug manufacturers package insert. About one-fifth of people treated with pegylated interferon plus ribavirin require dose reduction due to neutropenia. Since dose reduction is usually effective, complete treatment discontinuation is rarely necessary.

Since maintaining the maximum dose of interferon improves the chances of achieving SVR, some medical providers prescribe granulocyte colony-stimulating factor (G-CSF, or filgrastim; brand name Neupogen) to manage severe neutropenia. However, G-CSF has not been well studied for interferon-induced neutropenia, and is not FDA-approved for this purpose. The decision about how to manage neutropenia is a complicated process that requires expert guidance from a medical provider.

#### Tips for avoiding infection:

- Avoid crowds and sick people
- Get a flu shot and other vaccines to protect against infections
- Practice good hygiene – wash your hands frequently
- Use your elbows, shoulders, or hips when touching common public objects such as doors and elevator buttons
- Stay away from raw or undercooked eggs, poultry, and shellfish

## 9. MISCELLANEOUS

### • *Anal Burning and Itching*

Anal burning and itching are common side effects of telaprevir (Incivek). Diarrhea may intensify this problem, so start by controlling loose stool problems.

- For mild-to-moderate itching, try over-the-counter (OTC) creams or ointments that

contain hydrocortisone. Use these sparingly and as directed.

- Apply zinc oxide cream such as Desitin or other protective ointment to the anal region. Calamine lotion may also help.
- There are many products that provide relief for anorectal problems. Preparation H offers a variety; look for one that suits your needs.
- If these measures don't work, your medical provider may prescribe a cream or ointment and/or an antihistamine.
- Prevention of anal itching mainly involves washing properly and avoiding irritants.

#### If you already have anal itching, try these self-care measures:

- Keep the anal area clean. Gently cleanse with a soft wet cloth, paper towel, unscented wipe, or squeezable water bottle.
- Be sure the area is dry. Pat dry with toilet paper or soft paper towel. A hair dryer at a low setting is a good way to dry the area. Cornstarch, talc or baby powder may keep the area dry.
- Avoid irritants, such as bubble bath, perfumes, scented soaps, etc. Use unbleached, unscented toilet paper.
- Don't apply greasy products such as Vaseline, which keeps the area moist and prone to itching.
- Try not to scratch, as this increases the itch, further irritates the skin and can lead to other problems. Sitz baths and cold compresses may help relieve itching.
- Wear natural fiber underwear and loose clothing. Avoid panty hose and tight-fitting clothes.

### • *Libido Changes*

Patients commonly report decreased sexual interest during HCV treatment. Additionally, certain antidepressant medications may decrease

libido (sexual drive) and sexual performance. Depression and fatigue may also dampen interest in sex. Men may have difficulty achieving or maintaining an erection. Women may find that intercourse is uncomfortable due to vaginal dryness caused by interferon. Both men and women report feeling less attractive during HCV treatment.

Start by talking with your healthcare provider. Many factors can contribute to sexual problems – such as low thyroid hormone levels, other hormonal imbalances, or side effects from other medications – so it is important to start with an accurate diagnosis. Medications are available to treat erection problems (Viagra, Levitra, Cialis). If you are taking an antidepressant, your doctor might switch you to a different medication that is less likely to affect your libido. If sexual problems do not improve, ask for a referral to a gynecologist, urologist or sex specialist.

**Note:** Patients should never stop taking medications without speaking to their healthcare provider first.

#### Tips for maintaining libido:

- Use a water-soluble vaginal lubricant. Do not use petroleum-based products for vaginal dryness
- Talk to your partner about the changes you are experiencing. Your partner may be relieved to know that your current condition is a medical rather than an interpersonal problem
- Find ways other than sex to give and receive physical and emotional pleasure
- Get adequate rest throughout the day
- Find ways to pamper yourself and feel good about yourself
- Check out books and videos that address sexual issues
- Remember that this is a temporary condi-

tion. Your body will return to normal after stopping HCV treatment and antidepressant medications

**Important Note:** Ribavirin is associated with birth defects. It is essential that female patients, as well as female partners of male patients, receiving ribavirin avoid pregnancy during treatment and for six months after ribavirin is discontinued. Even if you or your partner has had a sterilization procedure (i.e., vasectomy or tubal ligation), it is recommended that you use an additional form of contraception, as there have been documented cases of pregnancy post-sterilization.

#### • *Menstrual and Menopausal Irregularities*

The effect of HCV therapy on the menstrual cycle and menopause is an area that has not been well studied. Some women report menstrual irregularities during HCV treatment. These may include heavier or lighter periods, fewer or more frequent periods, more or less premenstrual syndrome (PMS), and so forth. There is no one single predictable course of menstrual irregularities while on HCV therapy.

Women who are approaching menopause also report changes. Some have more hot flashes, while others have fewer. Some women report more bleeding; others say their periods are shorter, fewer, or lighter.

After menopause, women are at higher risk for bone loss. Abnormal bone loss is called osteopenia. Osteoporosis means the bone loss is significant enough to create a risk of fracture. A number of factors increase this risk, including smoking and family history. Small studies have linked ribavirin to bone loss, but not enough is known to draw firm conclusions.

It is known that inactivity can also increase bone loss. While undergoing HCV treatment, people who are normally physically active may find themselves cutting back on the intensity, frequency, or duration of their normal fitness routines. This may leave them with one less tool for bone loss prevention. Calcium, magnesium, vitamin D, and other nutrients are necessary for good bone health. Talk to your medical provider or a dietician about which dosages are suitable for you.

## 10. WORDS FOR FAMILY AND FRIENDS

HCV treatment affects many people besides patients. This may be a stressful and challenging time for you. Educating yourself about the side effects of HCV therapy may help you understand some of the issues your loved one is confronting. Patients often “look good” during treatment. This can create problems, especially if the patient feels awful and assumes everyone around him can see this. Open communication is the best way to find out how your loved one feels. But don’t expect too much from the person undergoing HCV therapy, especially if he or she was not a good communicator before treatment. Some patients do not want to talk about their experiences. Others want to talk about them a great deal. The two best things you can do for your loved one are to encourage him or her to join a support group and to take care of your own health.

### • *Depression, Anxiety, and Irritability*

Depression is a common side effect of pegylated interferon. Watching a loved one experience depression can be frightening. Feeling helpless is a common reaction to someone else’s depression. If you are a friend or family member, you are already helping by reading this. By gaining information and tools, you can be a great source of power and support.

The experience of undergoing HCV therapy is somewhat unique, and patients frequently state that the only people who understand them are other hepatitis C patients with treatment experience. Although you may not be able to empathize completely, you still can be supportive by showing compassion and patience.

It may be helpful to find support if your loved one is depressed. Encourage him or her to speak to a doctor. Appropriate diagnosis and treatment are essential. Treatment for depression may take anywhere from two to eight weeks to become fully effective. You can encourage your friend or family member to stick with it until the medications start to work, or to talk to his or her doctor about alternatives if there seems to be no improvement.

**Important Note:** Do not ignore remarks about suicide or hurting oneself or others. Report these immediately to the patient’s doctor or other professional. If a suicide attempt is imminent, call 911. If you feel the patient could physically harm you, get immediate help. Do not put yourself in harm’s way.

If there are any hepatitis C support groups available in your area, encourage your loved one to attend. You may offer to drive him or her to the group. If the group is open to everyone, perhaps volunteer to attend together.

You may want to encourage the depressed person to go for a walk, go to the movies, or engage in other activities that previously gave pleasure. However, if the offer is refused, do not push it. It may be enough to just sit and listen to the radio or watch TV together. Some patients have difficulty reading during treatment, so perhaps listening to an audio book might interest you both.

People with hepatitis C are sometimes irritable during treatment. Try not to take this personally. Keep your expectations to a minimum. Do not expect a depressed HCV patient to “snap out of it” or to be able to turn his or her mood around through positive thinking. Medication-induced depression is influenced by physical factors, and all the willpower in the world won’t make it go away.

### • **Sexuality**

Patients commonly report decreased interest in sex during HCV treatment. Some antidepressant medications can also cause decreased libido. This will return to normal after HCV therapy is completed and antidepressant medications are stopped. Nevertheless, patients should never stop medications without speaking to their doctors first.

Maintain as much sexual, physical, and emotional intimacy as possible. Be open-minded and creative while finding ways to obtain pleasure and fulfillment. Do not take it personally if your partner turns down invitations for sexual or emotional intimacy.

While your loved one is undergoing HCV therapy, make sure you take care of yourself. It is not necessary for you to ignore your own needs during this time. If you need to, find someone you can talk with, and who will support you. Engage in activities that give you pleasure. If your sex life is impacted, try to find other ways to give and receive physical affection with your loved one. Remember that HCV treatment does not last forever. It will end, and so will the side effects.

We are always looking for strategies to help people manage side effects. If you know of any tips that you would like to share, or if you have any information that would help to improve this guide, please contact [alanfranciscus@hcvadvocate.org](mailto:alanfranciscus@hcvadvocate.org).

## 11. RESOURCES

*To find a support group in your area please go to:*

[www.hcvadvocate.org/community/groups.asp](http://www.hcvadvocate.org/community/groups.asp)

Be sure to check out the following Support Group Guides and Handbooks, which can be downloaded from our website:

- *HCSP’s A Patient Guide to Finding an HCV Support Group:*  
[www.hcvadvocate.org/hepatitis/factsheets\\_pdf/Finding\\_a\\_support\\_group.pdf](http://www.hcvadvocate.org/hepatitis/factsheets_pdf/Finding_a_support_group.pdf)
- *HCSP Support Group Handbook*  
[www.hcvadvocate.org/hepatitis/factsheets\\_pdf/Support\\_Group\\_Handbook.pdf](http://www.hcvadvocate.org/hepatitis/factsheets_pdf/Support_Group_Handbook.pdf)
- *HCSP Support Group Lessons*  
[www.hcvadvocate.org/hepatitis/factsheets\\_pdf/Support\\_Group\\_Lessons.pdf](http://www.hcvadvocate.org/hepatitis/factsheets_pdf/Support_Group_Lessons.pdf)

Also, Pharmaceutical companies that make HCV drugs offer excellent supportive services for people taking their medications:

- Genentech: 1-877-PEGASYS (1-877-734-2797)  
[www.genentechaccesssolutions.com/portal/site/AS/](http://www.genentechaccesssolutions.com/portal/site/AS/)
- Gilead Sciences: 1-855-7-MYPATH (1-855-769-7284) [www.sovaldi.com](http://www.sovaldi.com)
- Janssen: 1-855-5-OLYSIO (1-855-565-9746)  
[www.olsio.com](http://www.olsio.com)
- Kadmon Pharmaceuticals: 1-800-405-8506
- Merck: 1-866-939-HEPC (4372)  
[www.merck.com/merckhelps/act-program/](http://www.merck.com/merckhelps/act-program/)
- Vertex: 1-888-552-2494 Patient Assistance:  
[www.vrtx.com/our-medicines/financial-assistance-and-patient-support-program](http://www.vrtx.com/our-medicines/financial-assistance-and-patient-support-program)

**Be Sure to Check Out These Other HCSP Guides:**

To view and download Guides, go to [www.hcvadvocate.org/hepatitis/factsheets.asp#Guides](http://www.hcvadvocate.org/hepatitis/factsheets.asp#Guides)

- *A Guide to Understanding Hepatitis C*
- *Easy C - A Guide to Understanding Hepatitis C*
- *Management of Hepatitis C by the Primary Care Provider: Monitoring Guidelines*
- *A Guide to Hepatitis and Disability*
- *Hepatitis C Support Group Manual*

**Treatment Side Effect Management Fact Sheets (Series)**

[www.hcvadvocate.org/hepatitis/factsheets.asp#SEM](http://www.hcvadvocate.org/hepatitis/factsheets.asp#SEM)

**Suggested Reading**

- *Healing Hepatitis C*, by Christopher-Kennedy-Lawford and Diana Sylvestre.
- *Free from Hepatitis C: Your Complete Guide to Healing Hepatitis C*, by Lucinda K. Porter, RN.
- *Hepatitis C Treatment One Step at a Time*, by Lucinda K. Porter, RN

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# TREATMENT ISSUES

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## HCSP GUIDES

*A publication of the  
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### A GUIDE TO: TREATMENT SIDE EFFECT MANAGEMENT

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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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