



Colorado Department
of Public Health
and Environment



LIVING WITH HEPATITIS

Take control.

Learn more.

Be sure.



It is estimated that 3.9 million Americans are currently living with hepatitis C. If you have been diagnosed, take an active role in your health care. You can make choices that promote the best health for you and those around you.

This booklet provides information that will help you understand and manage your illness.



Hep Cconnection



TABLE OF CONTENTS

Introduction 1

Understanding the Basic Facts

About Hepatitis C 2

- ◆ What is hepatitis C? 2
- ◆ How is hepatitis C spread? 2
- ◆ How serious is hepatitis C? 4

Living With Hepatitis:

Keeping Your Liver Healthy 5

- ◆ What are the symptoms of hepatitis C? 5
- ◆ What can I do to lessen the symptoms of hepatitis C? 6
- ◆ What does my liver do? 7
- ◆ How can I take care of my liver? 7
- ◆ Can I be re-infected with hepatitis C? 9

Testing and Diagnosis 11

- ◆ Antibody Tests 11
- ◆ PCR 11
- ◆ Liver Function Tests 12
- ◆ Genotype 12
- ◆ Liver Biopsy 12

Treatment 13

- ◆ What kinds of treatment are available for hepatitis C? 13
- ◆ Is it necessary to be treated right away? 13
- ◆ Are there side effects of treatment? 14
- ◆ How long does treatment last? 15
- ◆ Are there other treatments available? 15

HIV/Hepatitis C Co-Infection..... 17

- ◆ How does my HIV status affect my hepatitis C status? 17
- ◆ How do HIV medications affect hepatitis C medications? ... 17
- ◆ Should I have separate health care providers for HIV and hepatitis C? 18

Other Helpful Information 18

- ◆ How do I establish family and social support?..... 18
- ◆ Can I become pregnant if I have hepatitis C? 19
- ◆ What can I do if I don't have health insurance or if I am not working? 19
- ◆ How do I make sure my health care providers are working together? 19
- ◆ How do I cope with my feelings? 20

Additional Resources and Support Organizations..... 21

Taking Control— Asking the Right Questions..... 22

Writing it Down..... 29

Glossary..... 30

Revised and adapted by the Colorado Department of Public Health and Environment and the Hep C Connection. Original version developed by the Massachusetts Department of Public Health.

Portions of this booklet were provided by the Multnomah County Health Department, Portland, Oregon. "Double Jeopardy: The HIV/HCV Co-Infection Handbook," by the Community Prescription Service, NYC (1999)

INTRODUCTION

If you have recently been diagnosed with hepatitis C, you may feel scared, angry, or confused. You are not alone. More than 3 million Americans are living with hepatitis C infection; about 56,600 live in Colorado. You can take an active role in decisions affecting your health and your life. You can make choices that promote the best health for you and those around you. Getting good medical care is the first step. In this booklet you will find information that will help you understand your illness and help you get the proper care. You can lead the life you want and still cope with your illness. Take control, learn more, and be sure.

Take control.

Learn more.

Be sure.

**It is estimated that 3.9 million Americans
are living with hepatitis C infection;
about 77,000 live in Colorado.**

What is hepatitis C?

Hepatitis means “inflammation of the liver.” Hepatitis C is a virus that can cause the liver to become inflamed.

At this time there are five hepatitis viruses known to affect the liver: A, B, C, D, and E. These viruses, which may cause similar symptoms, are very different. The hepatitis C virus is found in the blood and liver of persons who have the infection. While there are vaccines for hepatitis A and B, there is no vaccine for hepatitis C.

How is hepatitis C spread?

Hepatitis C is spread through blood and is the most common blood-borne infection in the U.S. In the past, many people were infected with hepatitis C through blood transfusions, clotting factors, or organ transplants. Before 1992, there was no test available for hepatitis C. As a result, donated blood could not be screened for the virus. This is why people who received blood products and/or an organ transplant before 1992 may be infected. Transfusions and transplants are not a source of hepatitis C now because the blood supply is screened for hepatitis C.

Today, hepatitis C is spread primarily through sharing needles and equipment (e.g. water, cotton, cookers/spoons and ties) used to inject illegal drugs. Anyone who has injected drugs, **even once many years ago**, should be tested.



Health care workers may be at risk for hepatitis C through needlestick injuries. The virus can also be spread through items contaminated with blood, including unsanitary tattooing and piercing equipment, razors, manicure tools, and toothbrushes. Although hepatitis C can be spread through sex, sexual contact is much less likely to lead to infection than direct exposure to blood. Sometimes a pregnant woman can pass hepatitis C to her infant during childbirth.

The hepatitis C virus is not spread by casual contact like hugging, sneezing, coughing, or sharing food or drinks. It is also not spread by breastfeeding.

To prevent the spread of hepatitis C to others:

- ◆ If you are using drugs, ask your health care provider about drug treatment and harm reduction programs. It is important not to share any drug injection equipment. This includes not using a common syringe to measure drugs. Be sure to use sterile equipment or bleach your works.
- ◆ If you are in a sexual relationship, talk to your partner (and ask your health care provider) about whether he/she should be tested for hepatitis C. If you have multiple sex partners, use a condom or barrier method every time you have sex. Using condoms will help protect both you and your partners from many other sexually transmitted diseases, including HIV.
- ◆ Do not share razors, toothbrushes, or other personal items that can be contaminated with blood.
- ◆ Do not expose others to your blood. Cover cuts and sores, and do not attempt to donate your blood.

The hepatitis C virus is not spread by casual contact like hugging, sneezing, coughing, or sharing food or drinks. It is also not spread by breastfeeding.

Hepatitis C is not caused by or spread by drinking alcohol.

But drinking alcohol will worsen damage to the liver once you already have hepatitis C infection.

How serious is hepatitis C?

Hepatitis C infection can be very serious for some people but not others. Some people (15-25%) who have hepatitis C will clear the virus from their bodies within a few months of being infected, without treatment. But most people who are infected will carry the virus for the rest of their life (chronic infection).

The good news is that most people who have chronic hepatitis C infection feel well and remain healthy for many years, perhaps even decades. They may never have serious liver problems. Others will develop liver inflammation and/or scar tissue (fibrosis). A small number will go on to develop serious liver disease including cirrhosis (widespread scarring), liver cancer, and/or liver failure.

Although it is not clear who will develop serious liver disease, how you take care of your liver plays an important role in how slowly or quickly hepatitis C will progress. Moderate lifestyle changes and available treatment options are key to living long and living well with this illness. Drinking alcohol, using illegal drugs, eating a poor diet, and having other diseases such as HIV may contribute to faster liver disease progression.



What are the symptoms of hepatitis C?

If you have hepatitis C you may have no symptoms at all. But even if you feel fine, the virus could be hurting your liver, and you could be spreading the disease to others.

Soon after getting hepatitis C, some people may feel as if they have the flu. Symptoms may include tiredness, fever, muscle and joint aches, and nausea. Some people with hepatitis C may notice that their urine has become a darker color, and their skin and eyes have a yellowish tint, called jaundice. These symptoms usually go away without any treatment.

After many years of hepatitis C infection, the liver can become scarred and damaged. As scar tissue takes the place of healthy cells, the liver may not work properly and a person may begin to feel symptoms: fatigue, nausea, and loss of appetite. About 20% of people with chronic hepatitis C will develop cirrhosis, which is widespread scarring of the liver that results in permanent damage. People with more advanced disease can experience severe itching, ascites (fluid build-up in the abdomen), bleeding problems, and liver cancer or liver failure.

If you have hepatitis C you may have no symptoms at all. But even if you feel fine, the virus could be hurting your liver, and you could be spreading the disease to others.

What can I do to lessen the symptoms of hepatitis C?

There are things you can do to help lessen some of the symptoms of hepatitis C liver disease.

Tiredness:

- ◆ Getting exercise can help lessen the tiredness that you may be feeling. If you were not exercising before, this may be a good time to start. Start slowly. You should do only as much activity as you feel you are able to handle.
- ◆ When you rest, your liver rests. Getting a full night's sleep every night of the week is one way you can get the rest you and your liver need. It may be helpful to take a short nap during the day on the days you are feeling particularly tired.
- ◆ Be sure to talk to your health care provider if you are having trouble sleeping.

Nausea and Loss of Appetite:

- ◆ Many different things can trigger nausea, including smells, tastes, empty stomach, or sudden movement.
- ◆ Some people who have nausea find it easier to eat their largest meal in the morning, and eat several smaller meals throughout the day. Foods like crackers, rice, potatoes, toast, gelatin, ginger ale, or ice pops may be tolerated better than others.
- ◆ It is very important to drink plenty of fluids. Drink 8 to 10 glasses of water or juice each day to avoid dehydration.
- ◆ If you are vomiting persistently, be sure to contact your health care provider.



What does my liver do?

The liver is vital to good health—you can't live without it. It is the largest internal organ in the body. It is roughly the size of a football and is tucked up under the ribs on the right side of the body. Blood leaving the stomach and intestines passes through the liver before reaching the rest of the body. The liver's job is to change nutrients and drugs into forms that are easier for the body to use. The liver does many important things for your body. It:

- ◆ Helps digest food and absorb nutrients;
- ◆ Helps control bleeding by making clotting factors;
- ◆ Makes body chemicals such as fats, cholesterol, and protein;
- ◆ Stores sugar and vitamins for our bodies to use when needed; and
- ◆ Takes toxins and alcohol out of the blood and turns them into substances that can easily be eliminated from the body.

How can I take care of my liver?

Your liver depends on you to take care of it. In turn, it will take care of you. Your liver is your body's power plant, working constantly as your body's engine, refinery, and warehouse. It is also a silent partner. When it is injured it does not complain until the damage is advanced. You do have some control over your liver disease, and moderate behavior changes can help you live a longer, healthier life.

You do have some control over your liver disease, and moderate behavior changes can help you live a longer, healthier life.

Don't Drink Alcohol

The most commonly abused drug in the U.S. is alcohol. People with hepatitis C need to reduce or eliminate even small amounts of alcohol from their lives. Alcohol on its own can hurt your liver. Alcohol and hepatitis C are a deadly combination, leading to serious liver disease. Large amounts of alcohol over time cause liver cells to become scarred or die, leading to many liver problems from fatty liver to cirrhosis. Talk to your health care provider about your alcohol use. If you need help, ask for it so that you can take steps toward stopping drinking. There are programs available to help you eliminate alcohol. Even if you can't access them right away, limit the amount of alcohol you drink starting today.

Talk To Your Health Care Provider Before Taking Medications

Because many prescription and over-the-counter drugs may affect the liver, it is important to talk to a health care provider before taking any medication. The same is true for some vitamins, minerals, and dietary supplements. When you are first diagnosed with hepatitis C, be sure to tell your health care provider about all medications and supplements you are taking.

Get Vaccinated for Hepatitis A and B

Hepatitis A and B are two other viruses that can affect the liver and cause damage, especially in people who have hepatitis C. But unlike hepatitis C, they can be prevented by vaccine. Talk to your health care provider about being vaccinated against hepatitis A and B.

Don't Use Illegal Drugs

Using illegal drugs is harmful to your overall health. Drug use affects your body, and can affect the decisions you make after being diagnosed with hepatitis C. Sharing needles or other injection equipment may put you at risk for getting HIV or another type of hepatitis, and may put others at risk for getting hepatitis C. If you decide to seek treatment for your illness, the use of illegal drugs may affect how well the treatment will work. Eliminating or decreasing illegal drug use is the best action to take. If you need help, ask for it so that you can take steps toward stopping drug use. There are programs available to help you quit using illegal drugs. If you are not ready to stop, be sure to avoid sharing needles, syringes, straws, or any other paraphernalia used for injecting or snorting drugs.



Eat A Healthy Diet

The liver helps to digest food, absorb important nutrients from the foods we eat, and change foods into the energy our bodies need to live. Eating a nutritious diet and maintaining a healthy weight can help keep the liver healthy. Generally, people with hepatitis C who do not have advanced liver disease should develop a consistent diet with plenty of nutrients and avoid fad diets. If you have cirrhosis or advanced liver disease, you may need to follow a more specialized diet and work with your health care providers to ensure that you are eating and drinking the foods that best manage your symptoms.

Choosing the proper beverages to drink will also help you keep your liver healthy. Try to drink about 8 glasses of non alcoholic liquids each day. Water is best. Drinking too much juice may cause or aggravate diarrhea; if this happens, drink smaller amounts or try diluting the juice with water. Caffeinated drinks such as cola, coffee, and tea increase urine output and may cause you to become dehydrated.

Can I be re-infected with hepatitis C?

People who are treated for hepatitis C and get rid of the virus can become infected again. Most people who have hepatitis C will have the infection for a long time. Hepatitis C causes the body to make antibodies (proteins in the blood that help fight infections). These antibodies try to destroy the virus, but are not successful. There are also different types of hepatitis C (see the Testing and Diagnosis section on page 11), and it is possible that people with one type can be infected with another type. It is important to do everything possible to prevent contact with blood so that you do not become re-infected.

People who are treated for hepatitis C and get rid of the virus can become infected again.

In Summary – Take Charge of Your Liver Health:

1. If you have hepatitis C and you stop drinking alcohol, you are doing the best thing for your liver and yourself. If you need help, ask for it. If you cannot stop completely, reduce the amount you drink to the smallest amount possible.
2. Get vaccinated against hepatitis A and hepatitis B. They can both cause serious liver damage but can be prevented.
3. Eat a healthful diet: fresh fruits, vegetables, lean protein, and whole grains. Try to limit or reduce high fat foods, including most choices in fast food restaurants.
4. Drink plenty of non alcoholic liquids: at least 8 glasses a day. Water is best.
5. Take vitamins and supplements only as recommended by your health care provider.
6. Talk to your health care provider before starting any new medicines (over-the-counter or prescription), or herbal therapies. Take only recommended doses.



TESTING AND DIAGNOSIS

There are several tests that your health care provider will do to diagnose hepatitis C, monitor the condition of your liver, and determine if you should consider treatment. Understanding the tests and what the results mean will help you become an active partner in managing your illness.

Antibody Tests

The first test usually done for hepatitis C is an antibody test such as an EIA. A reactive (positive) result means that, at some time in your life, you were exposed to hepatitis C and your body produced antibodies to fight off the virus. If the EIA test is reactive (positive), a second antibody test called the RIBA (which is more accurate) may be used to confirm the result. Most people who test reactive (positive) to both antibody tests are chronic carriers, meaning they carry the virus in their blood and can pass the virus on to others. However, some people (about 15-25%) who have a reactive (positive) result can clear the virus on their own without treatment. Further testing should be done to determine if you are chronically infected.

PCR

A PCR is a viral load test that detects the presence of hepatitis C in the blood. If the PCR is positive, you are infected with the hepatitis C virus, and are probably a chronic carrier. If you undergo treatment for hepatitis C, this test helps to monitor whether the medicines are working.

Understanding the tests and what the results mean will help you become an active partner in managing your illness.

Liver Function Tests

Liver function tests (LFTs) help your health care provider determine whether your liver is working properly. These blood tests measure the levels of enzymes and other substances in your liver. When the liver is inflamed or damaged, certain enzymes will be released or the level of some substances will change. Some common LFTs include albumin, total protein, the enzymes ALT and AST, alkaline phosphatase, and bilirubin. Learn what your numbers mean and talk to your health care provider about how often the tests should be done.

Genotype

Genotype refers to the particular type of hepatitis C. There are at least six genotypes of hepatitis C. Most people (75%) in the U.S. have genotype 1. Genotypes 2 and 3 are the next most common. If you are infected with one genotype it is possible to become infected with another type. Therefore, it is important not to expose yourself to the blood of others. If you decide to be treated for your hepatitis C infection, knowing your genotype will help determine how you may respond to treatment, and how long your treatment will be. Your health care provider can find out your genotype by testing your blood.

Liver Biopsy

Your health care provider may want to do a liver biopsy. To do a biopsy, the provider takes a small piece of your liver to check for inflammation and scarring. It is a way for your health care provider to help you decide if and when you should begin treatment and what type of treatment you should receive. A biopsy is the only way to truly know the stage of liver disease. As with any medical procedure, there is a small risk associated with a biopsy, so be sure to ask your health care provider about the risks and what to expect before you decide to have a biopsy.



What kinds of treatment are available for hepatitis C?

Medications are available to treat chronic hepatitis C. If successful, they reduce the amount of virus to a level that is undetectable by the PCR test. If the virus levels remain undetectable for at least 24 weeks after a person stops taking the medications, the individual is considered to have a “sustained response” and may be cured of the disease. Currently, treatment consists of taking two medications: injections of a drug called *pegylated interferon* and pills called *ribavirin*. This is called *combination therapy*. A usual treatment scheduled involves injecting interferon once a week and taking the ribavirin pills on a daily basis.

Is it necessary to be treated right away?

For most people with hepatitis C, getting treatment is not an emergency. You do not have to rush into a decision. Treatment can decrease the risk of liver damage and even reverse liver damage in some people. It is important for you to weigh the pros and cons so that you make the best decision for yourself. Be sure to talk to your health care provider about when you should think about treatment, and about what type of treatment would be best for you.

New treatments are on the horizon and are designed to be used in combination with the weekly interferon shots and daily ribavirin pills. *Triple therapy* has been shown in studies to greatly increase the “sustained response” and is an exciting prospect for individuals living with hepatitis C.

**For most people with hepatitis C,
getting treatment is not an emergency.
You do not have to rush into a decision.**

Are there side effects of treatment?

There may be side effects from hepatitis C medications. Some people have severe side effects, while others experience few effects at all. When they occur, they can disrupt your life and day-to-day activities. But there are ways to cope and treat side effects. In fact, many side effects of treatment are similar to the symptoms of hepatitis C, and can be dealt with in the same manner. Common side effects include muscle aches, tiredness, nausea, diarrhea, and loss of appetite (see the *Living With Hepatitis C: Keeping Your Liver Healthy* section on page 5).

Strategies for managing side effects may include:

- ◆ Drinking 8 to 10 glasses of water and juices each day to avoid dehydration;
- ◆ Talking to your health care provider about the use of pain relievers;
- ◆ Eating small frequent meals, and avoiding greasy or spicy foods;
- ◆ Getting enough rest by keeping a regular sleep schedule and taking a nap, if necessary; and
- ◆ Using your support systems by talking to family and friends about how you are feeling, or considering joining a support group.



One possible side effect of interferon is depression and anxiety, which can be severe in some people. If you have a history of depression, make sure you tell your health care provider. Anti-depressant medication can help lessen the symptoms, and talking to family and friends is important.

Ribavirin can cause birth defects, so appropriate birth control is essential for both men and women being treated for hepatitis C, both during treatment and for 6 months after.

If you or your partner are considering antiviral treatment, and either of you is pregnant or considering becoming pregnant, be sure to talk to your doctor or health care provider immediately.

How long does treatment last?

The length of treatment is 6 to 12 months depending on your genotype (see the *Testing and Diagnosis* section on page 11). People with genotype 2 or 3 tend to respond much better to treatment. A person with genotype 1 may need treatment for a full 12 months, while someone with genotype 2 or 3 may need only 6 months of treatment.

Are there other treatments available?

Complementary therapies are used together with conventional medicine to treat many illnesses, including hepatitis C and the side effects of treatment. Complementary treatment attempts to use the body's natural self-healing abilities to bring the body back into balance. See box at right for a short description of some complementary therapies.

It is estimated that over one million people in the U.S. are infected with HIV.

If you have a history of depression, make sure you tell your health care provider.

Acupuncture

Acupuncture is part of traditional Chinese medicine, and has been practiced for over 3,000 years. It is used to stimulate the immune system and may strengthen your body's ability to fight the virus. Side effects of prescribed medications like nausea, muscle pain, headaches, fatigue, flu-like symptoms, skin problems, insomnia (difficulty sleeping) and depression may be reduced by acupuncture treatment.

Chinese Herbal Medicine

Chinese herbal medicine has been practiced as a form of treatment for illness for over 5,000 years. Chinese herbal medicine uses herbs, minerals, and animal products to treat illnesses. Herbal remedies are used to make the immune system stronger and reduce symptoms of disease.

The use of Chinese herbal medicine or any herbs should only be done under the supervision of a trained herbalist who has experience treating hepatitis C. If not chosen carefully, Chinese herbs and other herbs may interact in a harmful way with medications such as interferon, ribavirin, and other herbs and vitamins.

Massage Therapy

Massage therapy is provided by a trained therapist using his/her hands to manipulate muscles and soft tissues of the body to help reduce tension, stimulate or soothe the nervous system, improve blood circulation, and increase joint movement.

Yoga

Yoga is an ancient Indian system that is based on the togetherness of body, mind, and spirit. Yoga is a gentle form of exercise that involves physical postures and breathing techniques.

Qi Gong and Tai Chi

Qi Gong and Tai Chi are martial arts that use physical exercises or movements that focus on healing and inner awareness. They combine aerobic conditioning, meditation, and relaxation.

Meditation

Meditation is a mental practice that is meant to bring about relaxation, inner peace, and increased awareness. There are many different types of meditation; they all work to quiet the mind and help you feel more peaceful and relaxed.



All the information in this booklet applies to you if you are co-infected with hepatitis C and HIV, but you may have some additional needs to consider.

How does my HIV status affect my hepatitis C status?

HIV affects your immune system. This means that having HIV lessens your body's ability to fight the hepatitis C virus. HIV may also speed up the rate of liver damage caused by hepatitis C. This means that having both HIV and hepatitis C may put you at higher risk for developing more advanced forms of liver disease such as cirrhosis (scarring), liver cancer, or liver failure when compared to people who have only hepatitis C. Although both illnesses are serious, they can be treated. To get the best care possible, talk to your health care provider about all your treatment and illness management options.

How do HIV medications affect hepatitis C medications?

The medications used to treat hepatitis C in a person co-infected with hepatitis C and HIV are the same medications used to treat people with hepatitis C only (see the *Treatment* section on page 13). Because the liver processes the medications used to treat HIV, treatment for people who are co-infected can be complicated.

Having both HIV and hepatitis C may put you at higher risk for developing more advanced forms of liver disease when compared to people who have only hepatitis C.

Should I have separate health care providers for HIV and hepatitis C?

Finding a health care provider who is knowledgeable about both HIV and hepatitis C can help ensure that you will receive the best care, treatment, and management of both illnesses. If your current health care provider does not specialize in both illnesses, it may be helpful to ask him/her to work with or refer you to a provider experienced in treating both hepatitis C and HIV.

OTHER HELPFUL INFORMATION

How do I establish family and social support?

Hearing for the first time that you have been diagnosed with hepatitis C can be a very difficult and frightening experience, not only for yourself, but also for others who play an important role in your life. It may be helpful for you to discuss your diagnosis with those who are close to you. Should you decide to talk to your family or other people close to you about your diagnosis with hepatitis C, it may not be easy. But once they know, they may be able to provide you with the help and support you need to manage your illness in the best way possible. You may want to:

- ◆ Explain what hepatitis C is and how it is spread.
- ◆ Talk about ways you can help protect them and how they can protect themselves from getting hepatitis C.
- ◆ Share information with your children that is appropriate for their age. Give them only the information they need.
- ◆ Have a friend or family member go with you to your medical appointments.



Can I become pregnant if I have hepatitis C?

Women who have hepatitis C do not need to avoid pregnancy or breastfeeding. Hepatitis C can be passed on to an infant during the birthing process. This happens in about 5 to 6% of cases. The passing of the virus to the infant is more likely to happen in women who are co-infected with HIV.

You or your partner should not become pregnant while being treated for hepatitis C with ribavirin. Ribavirin can cause severe birth defects (similar to thalidomide). If you or your partner are considering antiviral treatment, and either of you is pregnant or considering becoming pregnant, be sure to talk to your health care provider immediately.

What can I do if I don't have health insurance or if I am not working?

If you are not working, or if you do not have health insurance, you may be able to receive assistance through the Colorado Indigent Care Program. Call the Hepatitis Help Line at 1-800-522-HEPC for more information. You may even be eligible for free clinical trials of new medications. Ask your health care provider for additional information.

How do I make sure my health care providers are working together?

Being diagnosed with hepatitis C can be a frightening and confusing experience—especially when it comes to getting the best health care. Part of taking control of your illness includes getting the best care available to you. If you have not already done so, it may be helpful for

A team of trusted health care professionals can help you meet your physical and mental health care needs by working together to manage your care.

you to develop a health care team to help manage your illness. A team of trusted health care professionals can help you meet your physical and mental health care needs by working together to manage your care. Depending on your specific needs, your health care team may include any number of the following professionals:

- ◆ Primary care physician
- ◆ Hepatologist or infectious disease specialist
- ◆ Psychiatrist
- ◆ Registered Dietitian
- ◆ Case Manager
- ◆ Social Worker/Counselor/Therapist
- ◆ Complementary or alternative care provider

How do I cope with my feelings?

Being diagnosed with an illness like hepatitis C can be an overwhelming experience. You may feel scared, sad, angry, tired, or even empty inside. You may lose interest in things that are important to you. These feelings are quite common, and can fade with time, treatment, and support from others. When these feelings do not go away, become stronger, or keep you from doing your daily activities, you may be experiencing signs of a more serious condition called depression. Try talking about your sad and angry feelings to your family members and friends. And let your health care provider know about these feelings so that you get the help you may need.



ADDITIONAL RESOURCES

AND SUPPORT ORGANIZATIONS

The following is a list of resources that you may find useful as you learn more about hepatitis C.

- ◆ Call the Hep C Connection Hepatitis Help Line at 800-522-HEPC (4372) or visit the website at www.hepc-connection.org. Hep C Connection also provides an extensive resource directory that can be found on their website or they can mail you a free copy.
- ◆ Call the Colorado Department of Public Health and Environment Viral Hepatitis Line at 303-692-2780 or visit the website at www.HepatitisColorado.Info.
- ◆ Visit the National Institute of Health website at www.health.nih.gov/topic/HepatitisC
- ◆ Visit the National Digestive Diseases Information Clearinghouse (NDDIC) at www.digestive.niddk.nih.gov
- ◆ Visit the Centers for Disease Control and Prevention (CDC) website at www.cdc.gov/hepatitis or call 800-CDC-INFO (232-4636)
- ◆ Visit the American Liver Foundation website at www.liverfoundation.org or call 800-GO-LIVER (465-4837)
- ◆ Visit the American Dietetic Association website at www.eatright.org or call 800-877-1600
- ◆ Visit the Alcoholics Anonymous World Services (AA) website at www.aa.org
- ◆ Visit the Narcotics Anonymous website at www.na.org
- ◆ Visit the National Center for Complementary & Alternative Medicine Information Clearinghouse website at www.nccam.nih.gov or call 888-644-6226



ASKING THE RIGHT QUESTIONS

The questions in this section may help you communicate with your health care providers and manage your illness. Some questions may not apply to your specific situation, or some questions may be appropriate to ask at a later time. These questions are not a complete list, and are meant only to guide you in your discussions with your providers. You may find it helpful to take this booklet with you to your appointment and record answers to the questions you ask.

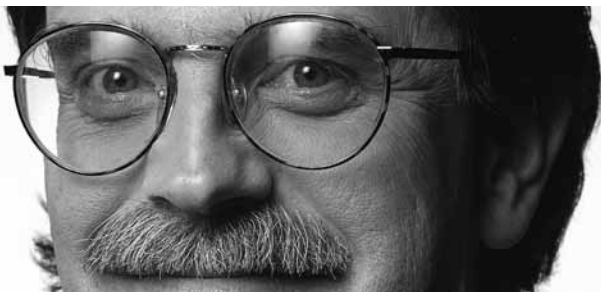
Questions About a Health Care Provider's Experience with Hepatitis C:

- ◆ Do you have many other patients with hepatitis C?
- ◆ Do you feel up-to-date on all the latest changes and advancements in hepatitis C treatment?
- ◆ Do you think I should be referred to a liver specialist for my care?

Questions About Testing:

The following questions relate to routine and one-time liver tests:

- ◆ What is my hepatitis C viral load?
 - (If you have already gotten a viral load test)
What are the test results?
 - How often should I have my viral load checked?
 - May I have a copy of the test results for my records?



- ◆ What is my hepatitis C genotype? (This is a one-time liver test)
 - (If you have already gotten a genotype test) What are the test results?
 - How does my genotype affect my illness and possible treatment?
 - May I have a copy of the test results for my records?

- ◆ What are my liver function test levels? (Liver function tests are ALT/AST,ALP, and SGTP, bilirubin, albumin, and prothrombin time)
 - (If you have already gotten liver function tests) What are the test results? How do they compare with normal levels?
 - How often should I have liver function tests done?
 - May I have a copy of the test results for my records?

- ◆ Do you recommend I have a liver biopsy?
 - If yes, why? If no, why not?
 - What is involved in getting a biopsy?
 - What are the risks?
 - How is the procedure performed?
 - How long does the procedure take?
 - What experience do you have, or does the doctor performing the procedure have in doing liver biopsies? (The more experience they have, the better.)
 - If a liver biopsy shows that I have fibrosis or cirrhosis (scarring), how does that affect my treatment options?
 - (If you have already gotten a biopsy) What are the results of my liver biopsy and what does it mean? Will the result affect my treatment?
 - May I have a copy of the biopsy report for my records?



Questions About Medical Treatment (if you are on treatment or thinking about treatment):

- ◆ Do you feel I am a good candidate for interferon and ribavirin combination therapy? What about pegylated (peg-a-lated) interferon therapy?
 - If so, why?
 - If not, why?
 - What will happen if I decide to wait to start treatment?
- ◆ What are the pros and cons of beginning treatment?
 - What are the potential side effects of the interferon and ribavirin, or pegylated interferon?
 - How long do you think I will have to be on therapy?
 - How is the treatment taken?
 - How may the treatment affect my life and my lifestyle?
 - What is the likelihood that the treatment will be successful?
 - Do I have to change how or when I eat if I choose to be treated?
 - Should my partner or I take birth control pills while on the medications?
 - Can my partner (or I) get pregnant safely while I am on the medications?
- ◆ If I have a history of mental health issues (depression/anxiety), will I be a candidate for hepatitis C treatment?
 - How will my mental health be managed?
 - What will be done if my mental health gets worse?



- ◆ If I am on methadone, how will this affect my eligibility for hepatitis C treatment?
 - How do you feel about treatment for hepatitis C while a person is on methadone?
 - Will you work together with my dispensing/treatment agency to coordinate my care?
- ◆ Do you exclude patients from interferon/ribavirin or pegylated interferon treatment if they have advanced liver scarring?
- ◆ Are there new therapies that will soon be available, and do you think I should wait for them?

Questions About Alternative and Complementary Treatment (if you are receiving treatment or thinking about treatment):

Before beginning any type of complementary treatment for hepatitis C, ask your health care provider the following:

- ◆ How do you feel about complementary and alternative medicine such as Chinese herbs, supplements, and acupuncture to help treat my hepatitis C?
- ◆ Have you read any research on the benefits of herbs and other complementary or alternative therapies for hepatitis C?
- ◆ Will you work together (share medical information) with my complementary care provider should I choose to have one?
- ◆ Can you refer me to a good complementary and alternative medicine provider in my area?



When choosing a complementary practitioner you should use as much care as when you choose your health care provider. Here are some useful questions to ask:

- ◆ What is your treatment philosophy or treatment style?
- ◆ How did you become a complementary treatment practitioner? Do you have specific credentials as a practitioner?
- ◆ What is your experience in treating someone with hepatitis C?
- ◆ Is this therapy safe and/or effective in treating hepatitis C?
- ◆ Are there any side effects from this therapy?
- ◆ How long will treatment last?
- ◆ Can I do this treatment while being treated with the standard medications (interferon and ribavirin, or pegylated interferon)?
- ◆ What is the cost of this treatment, and is it covered by health insurance?
- ◆ Will you work together (share medical information) with my primary care provider, and/or my liver specialist?



Hepatitis C Self Care:

- ◆ How does my diet affect the hepatitis C virus?
 - Do I have to change how and when I eat now that I have hepatitis C?
 - May I be referred to a dietitian or nutritionist for help with my dietary needs?
- ◆ How do my social habits (drinking alcohol, using drugs, smoking) affect my liver or the hepatitis C virus?
- ◆ Do I need to stop drinking alcohol completely?
- ◆ If I want to stop using alcohol and/or other drugs, can you refer me to an alcohol and drug counselor?
- ◆ If I want to stop smoking, can you refer me to someone to help me quit?
- ◆ Do I have to change my sexual practices? Should my partner(s) and children be tested?
- ◆ What kinds of symptoms/signs can I expect now that I have been diagnosed with hepatitis C?
- ◆ What if I feel fine? Does that mean my liver is not damaged?
- ◆ Do you recommend that I have tests done to see about the condition of my liver? If yes, which tests?
- ◆ Do you recommend that I begin treatment for hepatitis C? If yes, which treatment do you recommend and why?
- ◆ Is there a support group in the area that I can attend?

Other Infections:

- ◆ Do I need to be tested to see if I am immune to hepatitis A and/or hepatitis B?
- ◆ Am I immune to hepatitis A and/or hepatitis B? If not, do you recommend I be vaccinated for either or both hepatitis A and B viruses?
- ◆ Should I be tested for HIV or other infections?

Questions About Hepatitis C and HIV Co-Infection

(If you have been diagnosed with both hepatitis C and HIV, you may want to ask these questions in addition to the other questions provided):

- ◆ Do you provide care or work with many patients with both HIV and hepatitis C?
- ◆ Do you feel up-to-date on all the latest treatments for HIV and hepatitis C?
 - If not, can you refer me to a health care provider who treats co-infected clients?
- ◆ Do I need to treat my hepatitis C before I start on HIV medications?
- ◆ If I am already on HIV medications, do you recommend treatment for hepatitis C?
 - How long will I need to take medications?
 - What side effects can I expect from taking HIV and hepatitis C medications together?
 - Are there certain combinations of medications that are better tolerated or easier to take than others?
 - Do I have to change how and when I eat if I choose to have treatment for the HIV and/or hepatitis C?

Questions About Follow-Up Care:

- ◆ How often should I return for follow-up?
- ◆ Can I schedule an appointment now?
- ◆ What should I do if my health gets worse between now and the next time I see you?
 - Can I call your office and make an earlier appointment?
- ◆ Are you available by phone and/or email?



WRITING IT DOWN

Keeping a journal that includes all your daily activities, thoughts, and feelings can be a great way to help yourself and your health care provider understand your special needs. Helpful things to write down may include:

- ◆ When you visit your health care providers, and what you discuss;
- ◆ When and what you eat and drink, smoke, or inject;
- ◆ When you have bowel movements and urinate (be sure to note any changes in color, smell, or consistency);
- ◆ When and how often you exercise;
- ◆ When and how often you experience side effects; and
- ◆ What you are feeling or thinking about each day.

GLOSSARY

Antibodies – Proteins made by the body's immune system in response to foreign substances and germs.

Antiviral Medication – A medicine used to treat viral infections.

Ascites – Fluid buildup in the abdomen that is a possible symptom of advanced liver disease.

Asymptomatic – Having no symptoms of disease or illness.

Carbohydrates – One of three types of nutrients that supply the body with calories (energy) and are essential for life. They are sugars and starches found in breads, cereals, fruits, and vegetables.

Cirrhosis – Widespread scarring of the liver.

Co-infection – Being infected with more than one germ at a time.

Combination Therapy – Two or more drugs used together as treatment.

Complementary Therapies – Healing practices that are used to promote the body's natural self-healing abilities.

Conventional Medicine – Commonly used healthcare practices and treatment.

Chronic Hepatitis – Generally defined as inflammation of the liver lasting more than six months.

Dehydrated – Lack of water in the body.

EIA – A blood test to screen for infection by looking for antibodies.

Fats – One of three types of nutrients, that provides the body with calories (energy). Small amounts are needed to keep the body functioning normally.

Fibrosis – The development of scar tissue.

Genotype – Refers to the particular genetic type of a virus. There are at least 6 genotypes of hepatitis C.

Harm Reduction – Approaches for reducing the physical and social harms associated with risk-taking behavior.

Hepatitis – Inflammation of the liver caused by viruses, chemicals or drugs.

Hepatitis A – A type of hepatitis caused by a virus. The virus is found in feces (stool) of infected people, and is spread person to person through close contact, or by ingesting contaminated food or water. It is preventable with a vaccine.



Hepatitis B – A type of hepatitis caused by a virus. The virus is spread through blood and body fluids, such as semen and vaginal secretions. It is preventable with a vaccine.

Hepatitis C – A type of hepatitis caused by a virus. It is spread mainly through contact with infected blood. It usually causes chronic (long-term) infection and is NOT preventable with a vaccine.

HIV – Human Immunodeficiency Virus; a virus that weakens the immune system and is the cause of AIDS (Acquired Immunodeficiency Syndrome).

Immune System – The body's defense against viruses and other disease-causing germs.

Insomnia – Inadequate or poor quality sleep.

Interferon – A drug that is sometimes used to treat hepatitis C infection.

Jaundice – Yellowing of the skin or eyes that may indicate liver disease.

Liver – The largest internal organ of the body that performs hundreds of functions essential for life.

Liver Biopsy – A procedure in which a small piece of the liver is examined for inflammation and liver damage.

Liver Function Tests (LFTs) – A series of blood tests (such as ALT) that help to see whether the liver is working properly.

PCR – A viral load test that detects the presence of virus in the blood.

Pegylated Interferon – A slow-release form of interferon that is injected once a week.

Protein – One of three types of nutrients that provide the body with calories (energy). They build muscle and tissues in the body, and are necessary for life. Foods such as meats, beans, and tofu are good sources of protein.

RIBA – A blood test that detects antibodies and is used to confirm a positive EIA test. RIBA stands for Recombinant ImmunoBlot Assay.

Ribavirin – An antiviral drug that is sometimes used to treat hepatitis C infection.

Sustained Viral Response (SVR) – Continued lack of detectable HCV RNA six months after the completion of treatment.

Vaccine – A substance introduced into the body to stimulate resistance to infectious diseases, thereby protecting the body from viruses and bacteria.

Viral Load – The amount of virus in the blood.





Colorado Department
of Public Health
and Environment

www.HepatitisColorado.Info

Hep C Connection

Hep C Connection Hepatitis HelpLine

1-800-522-HEPC (4372)

www.hepc-connection.org