HEPATITIS C SUPPORT GROUP

Lessons
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Introduction

Thank you for your interest in starting—or running—a support group for people with hepatitis C.

Support groups are important because they provide people with the knowledge that they do not have to face challenges alone. They offer members both helpful information and companionship. And they provide the people who run them—people like you—with valuable experience that can come in handy in every area of life.

The following 12 lessons (or “modules”) are designed to help you organize and lead a new hepatitis C support group. We hope you find it to be a helpful guide for your group’s meetings.

The people who come to your group meetings will have many questions. They need to understand what hepatitis C is and how it will affect them. They may want to be able to talk about it with their friends, family, employers, and other people. Your support group can help them.

Naturally, there is a lot of information out there. Some group members will come to your meetings already knowing some basic facts. Other people may have wrong ideas about hepatitis C. Still, others might know nothing at all about the virus.

There are 3 basic types of support groups: educational, thoughtful, and a combination of both. They approach support from different angles, but can be used together to provide the best of both worlds for your members:

- If your group is the educational kind, you may want to read from each lesson exactly as it is written
- If you are running a thoughtful support group, you may just want to use a few of the topics from each lesson as conversation starters
- If your group is a combination of both types, you can use a blend of the 2 approaches as you see fit

We will explore each of these formats in more detail later in this manual. So feel free to use this series of lessons about hepatitis C in any way that works best for you.

As the leader of the group, it’s totally up to you.

At the end of each lesson, there is a handout sheet that you can print or copy. Hand them out to everyone in your group, so they can review what was discussed at the meeting on their own. Each handout sheet contains a reminder of the key points from the lesson, along with some reliable resources for learning more. The information we suggest is very basic, so you might want to ask a healthcare professional and/or a patient advocacy group to suggest other brochures or printed materials that you can also share with your group.

We hope this material makes your job a little easier and your meetings more helpful for all of your group members.

Thanks again for taking on the role of team leader.

**Purpose:** To provide people in your community some basic facts about hepatitis C, and to educate them about the liver in general; to teach them how the liver works, why it is a very important organ, and how the liver can be damaged by hepatitis C.

**Facts: Hepatitis C in the United States**

The members of your group may be feeling alone, but the fact is, that is far from true. They may be surprised when you tell them the numbers:

- Around 5 million people in the United States are infected with the hepatitis C virus
- Approximately 75% of infected people don’t even know they have hepatitis C
- Left untreated, up to 85% of people who have hepatitis C will have it for the rest of their lives. This is called chronic hepatitis C. People with hepatitis C can be cured or can “clear the virus.” This is also known as a “sustained virologic response” (SVR). This happens when the virus does not show up in the blood 6 months after you have finished taking treatment
- Hepatitis C is most common among people who were born from 1945 through 1965. This is because of the high rates of infection in the 1960s, 1970s, and 1980s
- Up to 12,000 people die from problems due to hepatitis C each year
- Hepatitis C is the leading cause of liver cancer, and the main reason for liver transplants

Here are some sample questions and answers you can use as you like during your meeting:

**What is hepatitis?**

Hepatitis is inflammation (swelling) of the liver. When a virus causes inflammation of the liver, it is called viral hepatitis. There are many types of viral hepatitis. In the United States, the most common types are hepatitis A, hepatitis B, and hepatitis C.
All 3 viruses can be spread from one person to another. But how they spread, how long the illness lasts, and how they are treated are different for each virus.

- **Hepatitis A** is usually spread through contact with contaminated surfaces or foods. For instance, touching someone who has not properly washed his or her hands after using the bathroom, or eating food that is infected with the virus, can spread the disease.
- **Hepatitis B and hepatitis C** are each spread when blood from an infected person gets into someone else’s blood.
- **Hepatitis C** can be spread in many ways:
  - Receiving blood transfusions or organ transplants before 1992
  - Sharing drug needles or cocaine straws
  - Using unclean surgical, tattooing, or piercing equipment

The hepatitis C virus is found in the blood and the liver of people infected with hepatitis C. This virus can multiply (replicate) quickly and infect liver cells. After many years, the liver can become damaged and may not be able to do all the things it needs to do.

### Are there different types of hepatitis C?

There are at least 6 different types of hepatitis C, called genotypes, and they are numbered from 1 to 6:

- **Genotype 1**, which is the most common in the United States, and the hardest to treat
- **Genotypes 2 and 3**; fewer people in the United States have these 2 genotypes
- **Genotypes 4, 5, and 6**, which are not very common in the United States

Understanding genotypes is important because the course of treatment works better on some genotypes than on others. That’s why people with hepatitis C need to get tested and learn which genotype they have. This ensures that they will get the best possible treatment. The genotype test is usually conducted only once, because a person’s genotype doesn’t change unless they are reinfected. If this happens, the person should get retested.

### Acute and chronic hepatitis C: What’s the difference?

The first 6 months of being infected with the hepatitis C virus is called acute hepatitis C. During this time, most people who are infected with hepatitis C may have mild symptoms, if any at all. If they do have symptoms, they may feel like they have the flu.

If someone still has the virus after 6 months, it is called chronic (long-lasting) hepatitis C. Most hepatitis C infections become chronic. Some people can get rid of it on their own, but most people—up to 85%—cannot.
What are the signs and symptoms of hepatitis C?
As chronic hepatitis C progresses, people with the virus may not feel any symptoms, or only a few. Some people have only mild symptoms that come and go. Symptoms can include:

- Fatigue (feeling tired)
- Feeling like they have a mild case of the flu (fever, headache, muscle and joint pain)
- Confusion or “brain fog”
- Itchiness
- Pain in the area of the liver (on the right side of the abdomen, behind the lower ribs)
- Insomnia (trouble sleeping)
- Upset stomach
- Diarrhea
- Lack of interest in food or sex
- Depression (hopelessness, sadness, or irritability)

How does hepatitis C harm the liver?
When hepatitis C is in the liver, it causes inflammation (swelling) and kills cells. Over a long period of time, the inflammation can cause a buildup of dead cells in the liver called scarring. This scarring can slow blood flow to the liver and, as a result, the liver can’t do what it needs to do to keep you healthy.

Healthcare providers divide scarring into 2 levels:

- Mild scarring is called fibrosis (fi-BRO-sis)
- A large amount of scarring is called cirrhosis (si-RO-sis). Cirrhosis causes the liver to begin to shrink, harden, and stop working. This is a serious problem

A liver that is damaged with cirrhosis can lead to:

- Liver cancer
- Liver failure
- A liver transplant

How does someone get and then pass on hepatitis C?
The hepatitis C virus is spread when the blood of someone with hepatitis C mixes with the blood (or body fluids that contain blood) of someone else.

Some of the ways the hepatitis C virus was spread before 1992 were through:

- Blood transfusions
- Blood products
- Transplanted organs
Before 1992, blood products sometimes contained the hepatitis C virus. Since then, blood products are tested for the virus, so now it's rare for people to get hepatitis C in this manner.

Today, people typically get the hepatitis C virus by:

- Sharing a dirty needle or other drug equipment (“works”). They can also get it by sharing straws for inhaling cocaine
- Using dirty tattooing needles and ink
- Using dirty body-piercing needles
- Using dirty acupuncture needles
- Using a dialysis (kidney) machine that wasn’t clean and has someone else’s blood in it
- Accidentally getting pricked by unsterilized medical equipment and instruments that have been in contact with blood (health and emergency workers could be at risk for this happening)
- Sharing razors, toothbrushes, or manicure and pedicure tools that have traces of infected blood

Although it doesn’t happen often, pregnant women with hepatitis C can sometimes pass on the virus to their unborn children.

As a general rule, anything shared that has blood on it can pass on the hepatitis C virus. This includes blood from cuts, nosebleeds, and even a woman’s period.

There’s no vaccine to prevent hepatitis C. But there are many ways to protect yourself and others from getting it. If you know how hepatitis C spreads, then you can tell others how to avoid getting it.

**What does NOT cause the spread of hepatitis C?**

Hepatitis C cannot be spread by:

- Holding someone’s hand or shaking hands
- Ordinary touching, such as hugging, or kissing
- Being coughed on or sneezed on
- Eating food or drinking water
- Sharing eating utensils, plates, or drinking glasses
- Breast-feeding
- Using a swimming pool
Additional Hepatitis C Information:

American Liver Foundation
1-800-GO-LIVER (1-800-465-4837)
www.liverfoundation.org
Information on liver diseases, including hepatitis C

Caring Ambassadors Hepatitis C Program
1-503-632-9032
www.hepcchallenge.org
Hepatitis C Choices book (free PDF); information and awareness

Centers for Disease Control and Prevention (CDC)
1-800-CDC-INFO (1-800-232-4636)
www.cdc.gov/hepatitis
Fact sheets and answers to frequently asked questions about hepatitis

Hepatitis Education Project
www.hepeducation.org
A website for people with hepatitis C and their friends, family members, and healthcare providers. It has hepatitis information about advocacy and support, as well as other resources

Hep C Connection
1-800-522-HEPC (1-800-522-4372)
www.hepc-connection.org
Resources and support for people affected by the hepatitis C virus

Hepatitis C Support Project
www.hcvadvocate.org
Provides resources for and information on hepatitis C that range from clinical information to alternative treatments and complementary therapies

Hepatitis Foundation International
1-800-891-0707
www.hepfi.org
Information on liver disease and viral hepatitis
Review Points

• Around 5 million people in the United States are infected with the hepatitis C virus.

• About 75% of infected people don’t even know they have hepatitis C.

• Left untreated, up to 85% of people who have hepatitis C will have it for the rest of their lives. This is called chronic hepatitis C. People with hepatitis C can be cured or can “clear the virus.” This is also known as a “sustained virologic response” (SVR). This happens when the virus does not show up in the blood 6 months after you have finished taking treatment.

• Hepatitis C is most common among people who were born from 1945 through 1965. This is because of the high rates of infection in the 1960s, 1970s, and 1980s.

• There are at least 6 types of hepatitis C, called genotypes, numbered from 1 to 6. Genotype 1 is the most common in the US. It is also the hardest to cure or clear from someone’s body.

• Hepatitis C causes inflammation (swelling) of the liver. Over time, inflammation can cause dead liver cells to build up and cause scarring. This scarring can slow blood flow to the liver and, as a result, the liver can’t work right to keep you healthy.
• Mild scarring is called fibrosis. A large amount of scarring is called cirrhosis. Cirrhosis causes the liver to begin shrinking and hardening.

• Discuss the timing of your treatment with your healthcare provider.

• General rule: Anything shared that has blood on it can pass on the hepatitis C virus. This includes blood from cuts, nosebleeds, and even a woman's period.
2: Hepatitis C Basics, Part 2: Monitoring and Watching Hepatitis C

**Purpose:** To help the people in your group better understand how the hepatitis C virus is affecting their health. By knowing what's happening to their bodies, they can work better with their healthcare providers—whether they decide to take medicine for the virus or not.

**Facts to help reduce future damage**

It’s a good idea to talk with the group about certain lifestyle changes that could help reduce additional liver damage.

**Lifestyle and dietary changes:**
- Stay away from drugs and alcohol
- Eat right (more fruits, vegetables, and fiber; less fatty, fried, or junk foods)
- Exercise regularly. Talk to your healthcare provider before starting any exercise program
- Stop smoking

Be on the lookout for signs that something isn’t right. If you have hepatitis C and notice changes, tell your healthcare provider if:
- You feel differently than you usually do
- You are more tired than usual
- Your eyes or skin tone look different

**Here are some sample questions and answers you can use as you like during your meeting:**

**What tests do healthcare providers order?**

Healthcare providers will often perform blood tests to monitor the virus and the overall health of people with hepatitis C:

- These tests measure the amount of hepatitis C virus in the blood (viral load) and the amount of the liver enzymes ALT and AST. (ALT stands for alanine aminotransferase. It is a liver enzyme that helps build and take apart protein. AST stands for aspartate aminotransferase. It is an enzyme that is found in the liver, heart muscle, and red blood cells.)
Other blood tests may include:

- A complete blood count (CBC)
- Tests for liver cancer, such as an alpha-fetoprotein test (AFP)
- A test to measure blood clotting called prothrombin time (PT)

Once people with hepatitis C have had a blood test, they can ask their healthcare providers about the results and what they mean. Many even bring a notebook to write down the answers. They can also ask for a copy of the results to keep in a special folder or binder.

When people have their own copies, they can refer to these results whenever they need. The law says they are entitled to the results, but some healthcare providers’ offices may charge a fee for the copying.

What are liver enzymes and viral loads?

A high or low amount of the hepatitis C virus in the blood (viral load) does not show the amount of damage to the liver. The same is true for blood tests that show higher liver enzymes, such as ALT and AST. Those are the 2 liver enzymes healthcare providers look for. Measuring these enzymes helps healthcare providers plan for or manage treatment.

The virus and the amount of liver enzymes often change often change over time for no particular reason. This is because hepatitis C may be unpredictable.

Once you are diagnosed with the hepatitis C virus, the viral load is only measured:

- When starting treatment
- During treatment
- 6 months after the end of treatment

These tests will help healthcare providers assess whether or not treatment is working.

What is a liver biopsy?

Today, a liver biopsy is still the most common way to determine if someone with hepatitis C has liver damage. During a liver biopsy, a healthcare provider puts a needle into your liver and takes out a small sample of liver tissue to examine. Then, your healthcare provider will study it to see if there is fibrosis or cirrhosis (scarring of the liver).

After the biopsy, the liver tissue will be sent to a lab. There, it will be looked at through a microscope, and the results will be put into a report about the health of your liver. Remember to ask when your results will be back from the lab. It can take several days to 2 weeks.

Some healthcare providers are starting to try new ways to get the same information without having to do a biopsy. Some of these tests measure blood chemicals, others take pictures—such as CT scans, X-rays, and ultrasounds—to check on liver disease. For now, though, the liver biopsy is still the most common test.
How fast does the virus grow?

The hepatitis C virus is constantly making copies of itself. This is called viral replication (or growth). Hepatitis C has an extremely high replication rate. It is estimated that the hepatitis C virus makes approximately 1 trillion copies of itself each day in a single person infected with hepatitis C.

What are fibrosis and cirrhosis?

The presence of hepatitis C in the liver causes inflammation (swelling). Over time, this constant swelling causes a buildup of dead cells in the liver that hardens and thickens the liver (scarring). This scarring is called fibrosis.

The way to measure fibrosis is by having a liver biopsy. There are several systems for rating how much fibrosis there is in the liver. Different labs use different measurements. But for all of the rating systems, the higher the number, the worse the damage:

- **Stage 0:** No scarring
- **Stage 1:** A small amount of scarring
- **Stage 2:** A little more scarring
- **Stage 3:** A lot of scarring
- **Stage 4:** Cirrhosis

If you have a liver biopsy, ask your healthcare provider what stage of fibrosis your liver has.

The worst stage is cirrhosis. It causes the liver to shrink and harden. Cirrhosis can slow blood flow to the liver, which can cause the liver to stop working.

There is no way of knowing exactly who is going to get cirrhosis. It does not happen right away. In fact, some people who have cirrhosis for a long period may not show any signs of it. But people with hepatitis C need to talk to their healthcare provider about cirrhosis because it can do serious damage. And the virus can start damaging the liver without any symptoms.

There are 2 different stages of cirrhosis:

- Compensated cirrhosis means that the liver has a large amount of scarring (dead tissue), but can still function. People with compensated cirrhosis may show few signs of the disease. In fact, a person may live many years with cirrhosis without being aware that his or her liver is scarred
- Decompensated cirrhosis means that the liver has a lot of scarring (dead tissue), which keeps the blood it needs from flowing through it. As a result, the liver is unable to work like it’s supposed to. Compensated cirrhosis can become decompensated in a short period of time, so it is important to monitor the liver carefully

You can see the signs of decompensated cirrhosis. Some of these symptoms may include:

- Too much fluid in the abdomen, or belly (ascites)
- Bleeding (internal bleeding, such as bleeding in the esophagus, or food pipe)
- Vomiting
• Dark urine or not being able to urinate at all
• A yellow coloring in the skin and eyes (jaundice)
• Feeling confused
• Dark, tarry bowel movements
• Easy bruising of the skin
• High blood pressure in branches of the blood vein called the portal vein, which brings blood from the intestine to the liver (portal hypertension). Cirrhosis is the leading cause of portal hypertension in Western countries

Another serious complication of cirrhosis is liver cancer.

By themselves, these symptoms do not mean you have hepatitis C. If you have 1 or more of these symptoms, talk to your healthcare provider about them at your next visit.
Does drinking alcohol cause liver disease?

Alcoholic liver disease is one of the most common types of liver disease in the United States. Since alcohol can speed up cirrhosis, people with hepatitis C should avoid it. This means everything from wine and beer to hard liquor.

What is fatty liver?

Fatty liver (also called fatty liver disease or steatosis) is when there is too much fat in the liver cells. It is the most common type of liver disease in the United States.

Drinking too much alcohol is one cause of fatty liver. But it can also happen to people who hardly ever drink. People have a greater chance of getting fatty liver if they:

- Have diabetes
- Are overweight
- Have too much fat (cholesterol) in their diet
- Don’t exercise enough

The amount of fat in the liver might go down when overweight people lose weight, when a diabetic’s blood sugar is under control, or when levels of cholesterol are lowered.

Can hepatitis C hurt anything else besides the liver?

The main target of the hepatitis C virus is the liver. But when the virus gets in your bloodstream, it can also cause health problems in other parts of your body.

Some people notice joint and muscle pain, different skin conditions, dry eyes and mouth, or itching. But these problems are not that common, and hepatitis C affects everyone differently.

Review Points

1. It is important to have your hepatitis C monitored.
2. Work closely with your healthcare provider.
3. Do what is necessary to avoid more damage to your liver. This includes:
   - Stop drinking alcohol and taking drugs
     - If you can’t do it on your own, ask your healthcare provider or a counselor for help
   - Eat right (more fruits, vegetables, and fiber; less fatty, fried, or junk foods)
   - Exercise regularly. Talk to your healthcare provider before starting any exercise program
   - Stop smoking
**3: The Stigma of Hepatitis C: Bias and Prejudice**

**Purpose:** Helping members of your group realize they are not at fault for getting hepatitis C. Letting your group know that people who don’t have hepatitis C may be scared by it. Understanding that there may be a stigma, but that it can be overcome.

**What is a stigma?**
A social stigma is when people who don’t know better think negatively about another group or another person.

When people think this way about others, they typically have a wrong view of that person or group.

More often than not, their notions are based on ignorance, or not knowing.

Remind everyone in your group that how or why they got infected is not important. People outside the group may ask, but people in the group do not have to answer.

Here are some sample questions and answers you may want to use during your meeting:

**Why does hepatitis C carry a stigma?**
Any condition can be stigmatized from a lack of compassion, a lack of understanding, or fear. Many people are biased or prejudiced against things they don’t understand.

Hepatitis C may carry a stigma for several reasons:

- **Fear of catching the virus:** Hepatitis C is contagious and can be spread to others through contact with blood. This alone may make some people avoid those who have the disease.

- **Fear of illness in general:** Some people do not like to be around “sick” people, even if the “sick” person does not have an infectious disease, or one with noticeable symptoms.

- **Blame:** No matter how you got hepatitis C, no one should be blamed.

- **Ignorance:** Anyone can get infected with hepatitis C. While it is true that some people who have hepatitis C got it from sharing drug needles with someone who had hepatitis C, that could have been decades ago. Many other people were infected by blood from transfusions or improperly cleaned medical, tattooing, or piercing equipment.
What are the effects of a stigma?
The potentially damaging effects of a stigma can affect many areas of life:

- **Relationships**: Friendships and marriages may suffer because of fear and ignorance
- **Jobs**: Some people are treated unfairly at work, and some have been denied promotions
- **Access to medical care**: Disclosing a disease may lead to reduced social support and less access to medical care. Injection drug users particularly have trouble accessing medical care
- **Personal**: Feeling excluded may lead to reduced self-esteem and self-respect

No one deserves hepatitis C. People with hepatitis C should focus their energy on staying healthy and helping to educate others about hepatitis C.

Did you know your attitude can help reduce the sting of stigma?
How anyone was infected with hepatitis C is private. No one needs to tell another person. People with hepatitis C should not blame themselves for things that happened in the past; instead, they should focus on what they need to do in the present. Doing something for your liver can be as simple as eating healthy food or taking a walk to get exercise.

Can educating others help break the stigma?
Stigma comes from ignorance and fear. Most people know very little about hepatitis C. They don't know how it spreads or how many people have it. Simply explaining these facts may be all you need to do to break through the stigma.

So, always be honest and factual about hepatitis C. Try not to criticize or blame others for their misunderstanding or lack of knowledge.

Did you know some people may feel like hepatitis C is a punishment for current or past behavior?
Please remember that:

- **No one deserves hepatitis C**
- **It does not matter how anyone got hepatitis C**
- **Guilt and shame will not improve health. They waste energy—the very energy that people with hepatitis C need to fight the disease**

If anyone with the virus struggles with negative emotions, he or she should talk to a healthcare provider. Counseling is available. Seek professional help immediately if you have negative thoughts, such as thoughts about suicide or of hurting yourself.
Should your group discuss these questions?

• What can each person in the group do to address the stigma of hepatitis C?

• Do you tell other people that you have hepatitis C? Who would you tell and why? Why would you not tell some people?

• Have you ever felt that other people are uncomfortable because they found out you have hepatitis C? If so, how do you think you can make them more at ease?

• Do you believe that hepatitis C carries a stigma? Why do you think this is?

• Have you ever felt uncomfortable around other people who have an illness? If so, what makes you ill at ease?

• When telling other people, have they felt uncomfortable? If so, why? How might you help them feel more comfortable?

• What are your feelings about having hepatitis C? Do you see yourself as a victim?

• Do you feel like you are “dirty” or a risk to other people?

• Do you feel like your health and future have been ruined?

• Do you feel like you deserve hepatitis C because of something you did?

• What do you want others to know about your life with hepatitis C?

• Have you missed meetings or healthcare provider visits because you were afraid of being seen in a place for people with hepatitis C?

• Have you told anyone at work? If so, have you felt that other people have treated you differently?
Should you be ashamed of having hepatitis C?

No, you shouldn’t. Being told that you have hepatitis C can be frightening. It is normal to feel overwhelmed, but it’s nothing to be ashamed of. So don’t punish yourself. You are still you; you are not the disease. But feeling this way is very understandable.

Realize that around 5 million Americans have hepatitis C. That means people with all sorts of jobs—teachers, firefighters, healthcare workers, lawyers—can and do have hepatitis C. You are not alone.

Take the time to read all you can about hepatitis C. The more you know, the better chance you have of making healthy decisions and living a healthy life. When you know the facts, you can help other people learn what’s true and what’s false about hepatitis C.

Review Points

- Do you believe that hepatitis C carries a stigma? Why do you think this is?
- Is there anything you can do to address the stigma of hepatitis C?
- Do you tell other people that you have hepatitis C? Who would you tell and why? Why would you not tell some people?
- Have you ever felt that other people are uncomfortable because they found out you have hepatitis C? If so, why do you think that is?
- Have you ever felt uncomfortable around other people who have an illness? If so, what makes you uncomfortable?
- When telling other people, have they felt uncomfortable and, if so, why? How might you help them to feel more comfortable?
- What are your feelings about having hepatitis C? Do you see yourself as a victim?
- Do you feel like you are “dirty,” or a risk to other people?
- Do you feel like your health and future have been ruined?
- Do you feel like you deserve hepatitis C because of something you did?
- What do you want others to know about your life with hepatitis C?
Adopting a healthy attitude

• Focus on today, not the past. And think positively about a future, when you’re cured and clear of the virus

• Get accurate information about hepatitis C from your healthcare provider or support group

• Be honest and realistic

• Accept your situation, but don’t let it label you. Hepatitis C may be a part of your life, but that doesn’t mean it should control your life

• Maintain your perspective on the big picture. Focus your attention on things that bring peace, joy, laughter, and meaning

• Be aware of the words you use. Say positive phrases. Instead of saying, “Hepatitis C is ruining my life,” say, “I can find a way to live with hepatitis C.” Or even better, “I can beat it”

• Learn what you can and cannot control. For example, you cannot control the fact that you got hepatitis C. You can control your attitude and what you say to yourself about having the virus. And, if you choose, you can control your commitment to defeating it

• In your mind, picture yourself in good health, not sick with hepatitis C. Look at your life in a more hopeful, positive way. Visualization is a powerful tool for changing the way you—and other people—see you. You’re making a change for the better. Be proud of your accomplishments, and there will be many more to come

• Help others. Reaching out to those who are also struggling can be another way to help yourself
4: Telling Others You Have Hepatitis C

Purpose: To help group members understand who they should tell and who they may want to tell about their condition. Also includes strategies for telling people.

Facts about telling people you have hepatitis C

It’s not easy telling anyone that you have hepatitis C. But it’s vital that you tell anyone who you think you may have exposed to the virus. It’s a good idea to have the support group practice with each other.

There are 2 reasons why you must tell anyone you may have exposed to the virus:

- They can get tested
- They can avoid passing the virus to others, if they are also infected

Other than these people, you do not have to tell anyone that you have hepatitis C, unless you want to.

You may want to encourage people in your group to role-play with these sample questions and answers:

Should you tell other people about your infection?

You should tell anyone you may have exposed to hepatitis C, such as:

- Anyone you’ve recently shared a needle or cocaine/crank straw or crack pipe with
- Your medical healthcare providers and your dentist

It is important that people with hepatitis C tell anyone they may have exposed to the virus as soon as possible. That way, the people they have come in contact with can get tested and avoid passing on the virus to others.

If someone with hepatitis C can’t tell someone who they may have exposed to the virus, most city or county health departments will inform the person of the potential exposure. The health department does not need to reveal names.
Other than those who may have been exposed, people with hepatitis C don’t have to say they have
the virus, unless they want to. This is a very important and personal decision that needs a great deal
of thought.

When people with the virus reveal they are infected, they need to be prepared. A lot of people have
little or no information about hepatitis C. Or even worse, they may have wrong information.

• Many people tell others that they have hepatitis C as soon as they find out. But others wait to
reveal it because they need a little time to deal with the shock, or they need time to learn more
about the virus

• Telling people close to you can be upsetting for you and them

What should you tell other people?
If you decide to tell people that you have hepatitis C, you may want to start simply. Telling people
when and how you found out that you have the virus is probably a good place to start. You might
want to tell them the basic facts about how the virus is spread and how it isn’t spread. Tell them that
it causes a liver disease brought on by the hepatitis C virus.

Tell them that hepatitis C spreads only when one person’s blood mixes with another person’s blood,
and that hepatitis C is not easy to get. Tell them that hepatitis C is not spread through ordinary
contact, such as hugging, shaking hands, or sharing a meal.

What is denial?
Often when people learn they have hepatitis C, they go into denial. Denial is the act of refusing to
believe or accept bad news.

If you’ve just been told you have hepatitis C, who could blame you for refusing to believe or accept
it? After all, this isn’t the kind of news that anyone wants to hear.

So if you’ve been told you have hepatitis C, realize that going into denial is a normal reaction. Then,
move beyond denial because it can keep you from getting the medical care you need and from
doing the things that can help you become healthy. So after you go through denial, you have to
accept what’s real.

What do you tell your employer and coworkers?
Some employers are very understanding and will do what they can to help you balance work with
treatment. Unfortunately, others may not be as understanding.

The good thing is that you cannot be fired just because you have hepatitis C. The Americans with
Disabilities Act (ADA) protects you from being treated unfairly at work because of your disease. Get
in touch with the people who enforce this law to learn more. You can reach them about the ADA at
1-800-514-0301 or visit them online at www.eeoc.gov.
How do you tell your loved ones you have hepatitis C?
Telling the people close to you that you have hepatitis C can be difficult. Here are 2 suggestions for how to let certain people in your life know:

Telling a young child you have hepatitis C
You may want to give just enough information so that your children know you are sick. It is important to tell a child that this doesn’t mean you’re going to die. When you believe they are ready for more information, start with, “Remember when I told you I was sick? Well, I would like to talk about it a little more to make sure you understand. My liver is sick with something called hepatitis C. Don’t worry. You cannot catch it from me. It’s not like a cold or sore throat. It is only in my liver and blood. To make sure you don’t get sick, it’s important that you don’t use any of my things that could have my blood on them, my toothbrush for instance.”

If you are going to have treatment, you may want to add, “I will need to take some medicine the doctor gave me. There may be times when it makes me feel sick. I will try very hard to be healthy. Sometimes, I may be sick to my stomach and throw up. Other times, I may just be tired and have to rest. I will be trying very hard to get better.”

Telling a partner or spouse you have hepatitis C
This may not be an easy conversation. You may need to share things you never wanted to, such as choices you made in your past. Being open and honest is important because it allows your partner or spouse to be supportive.

You can begin with, “I need to talk to you about my visit to the doctor. I have hepatitis C. It means my liver may be damaged and I could have some symptoms, like pain or tiredness. Or I could be fine for a long time.”

Even if you’re not 100% sure, you owe it to your partner or spouse to try to explain how you got the virus: “I am not sure how I got it. The virus is transmitted by coming into contact with infected blood. This means at one point in my life, I may have gotten the virus by sharing a needle for drugs.” Another person may say, “It’s possible that it was transmitted through infected blood from dirty piercings or tattooing.” A third person might explain, “It could have happened through a blood transfusion or getting an organ, because they didn’t screen for hepatitis C before 1992.” Each person’s situation will be different.

Show that you want your partner to be safe, too: “You will have to get tested. There could be a chance that you have it, too. The important thing is that we never share things that might have traces of blood on them, like razors and toothbrushes. I have to be careful about anyone coming into contact with my blood. Right now, there is no vaccine for hepatitis C.”
If you are considering having treatment, you may want to add, “I have been talking to my doctor about treatment for hepatitis C. It is very difficult to go through treatment, and it may last as long as a year. If I do the treatment, I will need shots and need to take pills as my healthcare provider prescribes. They have some side effects. Treatment could help me, but I will definitely need your help to get through it.”

**Review Points**

1. Should you tell other people about your virus?
2. What should you tell others?
3. What do you tell your employer and coworkers?
5: Understanding and Caring for Your Liver

Purpose: By knowing how the liver works, people in your group can learn how to take better care of themselves as they live with the virus.

Facts about liver function
Discuss within the group the importance of the liver and what it does. You can talk about how it helps your body stay healthy in many ways, including:

- Cleaning bacteria from your blood
- Controlling hormones and chemical levels in your blood
- Storing and releasing vitamins, minerals, and sugar as needed

Here are some sample questions and answers you can use as you like during your meeting:

What is the liver?
The liver is one of the largest organs in the body. It is also one of the most important. You simply cannot live without your liver.

It has 2 main sections called lobes. It is located on the right side of your abdomen (belly), behind your lower ribs, which help protect it.

What does it do?
We can survive only a short while if the liver stops working. If it fails, your body will fail, too. Here are some of the important things your liver does for you:

- It helps clean your blood. It gets rid of waste products, drugs (prescription, over-the-counter, and street or illegal drugs), alcohol, and other toxins (poisons)
- It helps control your body’s hormones
- It helps control most chemical levels in your blood

Discussion Topics
What is the liver?
What does the liver do?
What are liver enzymes?
Where can liver damage come from?
How do you stay healthy and protect your liver?
Handout
How do you stay healthy and protect your liver?
• It produces bile, a yellow-green fluid that helps digest food. Bile also helps carry away waste when you urinate and move your bowels
• It makes the proteins that help stop bleeding, so injuries can heal
• It helps remove bacteria from your bloodstream to fight infections
• It stores vitamins, sugar, hormones, and important minerals like iron. As your body needs them, your liver lets them go into your bloodstream

What are liver enzymes?
Liver enzymes are proteins, called AST and ALT, that the liver makes. They help the liver do some of its important tasks. We all have some of these enzymes in our blood. But if the liver is damaged or sick, you can have too many liver enzymes in your blood.

Blood tests can measure these liver enzymes. When your healthcare provider looks at the results, AST and ALT numbers may be higher than normal if the liver is damaged (keep in mind that the liver can be damaged and the AST and ALT numbers may be normal). Numbers for both tend to change, so you may have to have a lot of blood tests. This lets the healthcare provider know what is going on in your body.

Because each person is different, your healthcare provider will tell you what the normal levels are for you.

What can hurt the liver?
The liver can become damaged in many ways:
• Viruses, such as hepatitis
• Alcohol—especially if you drink a lot of it
• Prescription drugs, street or illegal drugs, or over-the-counter drugs, such as acetaminophen (Tylenol® (acetaminophen), McNEILL-PPC, Inc)* and certain herbal supplements, especially if you take too much. Large doses sometimes cause liver failure
• Injuries to your liver
• Tobacco

Always check with the healthcare provider before taking any drugs—prescription or over-the-counter—as well as any supplements, including homeopathic drugs, that you may be taking.

The most common type of liver disease in the United States is fatty liver. It happens when there is too much fat in the liver cells. People have more of a chance of getting fatty liver if they drink alcohol, have diabetes, or are overweight.

How do you stay healthy and protect your liver?
For people with hepatitis C, it’s very important that the liver be as healthy as possible. The liver processes everything that we eat and drink. Also, any chemicals we are exposed to can have an effect on the liver.

*Trademarks used herein are the property of their respective owners.
• Eat healthy foods, including vegetables and fruits
• Drink water to help remove toxins (poisons) and help process nutrients
• Avoid alcohol because it can hurt your liver. This means everything from hard liquor to wine and beer
• Newer studies say that drinking coffee may slow liver disease; however, caffeine is also a chemical that your liver has to process. You may want to go easy on coffee, tea, and soda—moderation is the key
• Stay away from undercooked shellfish. It can carry hepatitis A and a bug called vibrio vulnificus, which is very dangerous to people with hepatitis C
• Avoid too much sugar, salt, fatty foods, and deep-fried foods
• Get vaccinated for hepatitis A and B (if your healthcare provider recommends them)
• Exercise regularly but make sure you tell your healthcare provider before starting a new exercise program
• Get plenty of rest
How can you protect your liver even if you have hepatitis C?

Remember that the liver processes everything we eat and drink. Also, any chemicals we are exposed to can have an effect on the liver.

- Eat healthy foods, including vegetables, fruits, and lean meat
- Drink plenty of clear fluids, such as water, to help remove toxins (poisons) and help process nutrients
- Avoid hard liquor, wine, and beer because alcohol can hurt your liver
- Ask your healthcare provider if you should avoid caffeine
- Stay away from undercooked shellfish. It can carry hepatitis A and other illnesses, which can be very dangerous to people with hepatitis C
- Avoid too much sugar, salt, fatty foods, and fried foods
- Get vaccinated for hepatitis A and B (if your healthcare provider recommends them)
- Exercise regularly. Talk to your healthcare provider before starting a new exercise program
- Get plenty of rest
- Try to reduce stress

Protect your liver from drugs and medicines.

- Do not use tobacco or recreational drugs
- Drugs like acetaminophen (Tylenol®) can be harmful if you take too much
- Be very careful when mixing alcohol with drugs. Never mix acetaminophen and alcohol
- Always check with your healthcare provider before taking any drugs—prescription or over-the-counter—as well as any supplements
Review Points

Q. Your liver does over 500 things for you. Can you name 3?
1. 
2. 
3. 

Q. Your liver is protected by:

__Your ribs
__Not drinking alcohol or smoking
__Your heart

Q. Name 3 foods, beverages, or habits that are good for you and your liver:
1. 
2. 
3. 

Q. Name 3 foods, beverages, or habits that are harmful for your liver:
1. 
2. 
3.
6: Living With Hepatitis C

**Purpose:** To teach people in your group what they can do to care for and protect their livers.

**Facts**
A good conversation to have with your group is how to take an active role in caring for the liver, such as:

- Choosing healthy foods and drinks
- Keeping the air where you live and work free from chemicals
- Reaching and keeping a healthy weight
- Making time for the rest you need
- Being careful about taking medicines
- Trying to keep stress down
- Drinking a healthy amount of water every day

**Discussion Topics**
- What kind of medical care will you need?
- What do you need to learn about hepatitis C?
- What do you need to do about your overall health?
- Why should you reach out to people for support?

**Handout**
- How do you stay healthy with hepatitis C and also protect your liver?

**Here are some sample questions and answers you can use as you like during your meeting:**

**What kind of medical care will you need?**
Hepatitis C is a serious disease. As someone with the virus, you need to see your healthcare provider regularly for checkups. Once you schedule an appointment, be sure not to miss it.

During your appointment, you may want to discuss the following topics with your healthcare provider and your healthcare team:

- Symptoms you have had since your last visit
- Hepatitis C treatment
- How you can live a more healthy life
- If you need to be vaccinated for hepatitis A and/or hepatitis B
- Answers to a prepared list of questions. Ask for places to get more information
- Your commitment to getting better
- Any over-the-counter medicines, vitamins, or supplements you are taking
What do you need to learn about hepatitis C?
Knowing more about hepatitis C can help you make healthy choices. You can find out about the virus by:

- Asking people who know what you are going through, including your healthcare provider and your support group
- Contacting your Veterans Affairs health office if you are a veteran. Ask them for information on hepatitis C, or visit www.hepatitis.va.gov
- Checking out government educational groups or nonprofit groups that deal with hepatitis C (these websites typically end in .gov, .org, or .edu)
- Seeing if your healthcare provider's office has a book or pamphlet about hepatitis C
- Talking to healthcare workers who may suggest reading materials

Did you know better overall health could help you deal with hepatitis C?

- Eat a healthy diet with lots of vegetables, fruits, and lean meats. They can help your liver
- Avoid too much sugar, salt, and fatty foods. They can lead to liver problems
- Don't drink alcohol. That means everything from wine and beer to hard liquor. Some healthcare providers won't treat people who still drink any alcohol
- Don't smoke
- Don't use street or illegal drugs if you have hepatitis C. You could become reinfected
- Exercise regularly. It may make you feel less tired. Walking is great exercise
- Get plenty of rest. Try to take a nap during the day, or at least take some time to just relax
- Try meditation, prayer, or anything that helps you cut down on stress

Read the handout section called, “Living With Hepatitis C.”

Why reach out to people?
Don’t forget you can confide in people you trust—family, friends, coworkers, and people you meet through a support group. Talking with people can be good for your health.
Living healthily with hepatitis C and protecting your liver may require some changes. Ask yourself these questions:

### Do you need to change what you eat and drink?

- **Hard liquor, beer, and wine can hurt your liver. The best thing you can do is stop drinking alcohol, but if you can’t stop, cut down and try to get some help to quit**
- **Try not to have too much sugar, salt, or fatty foods. They can make you gain weight**
- **Cut down on junk food (cookies and chips), fast food (pizza and cheeseburgers), and deep-fried food**
- **Try not to have too much food that’s made with white flour or white sugar. Try to eat multigrain food that has vitamins and fiber your body needs**
- **Stay away from food that’s overcooked or over-processed. It doesn’t have the nutritious parts your body needs**
- **Avoid raw or undercooked shellfish (this includes oysters, clams, lobster, shrimp, and mussels). Raw shellfish sometimes contains a virus that causes a different kind of hepatitis (hepatitis A), and a bug called vibrio vulnificus, which can be dangerous for people with hepatitis C. Talk to your healthcare provider about getting vaccinated for hepatitis A and B before starting treatment for hepatitis C**
- **Caffeine is also a chemical that your liver has to process. You may want to go easy on all caffeinated drinks**
- **Although newer studies say that drinking small amounts of coffee may slow liver disease, you should check with your healthcare provider to see what is right for you**
- **Avoid large-dose or mega-potency multivitamins, including those with iron. They can overwork your liver**

### Do you need to change your surroundings?

It's important to avoid substances that might harm your liver:

- **Smoking damages your liver. If you smoke, you should stop. Smoking also makes your liver work harder to remove toxins (poisons) from your body. If you stop smoking, your liver can go back to working as if you weren’t smoking**
• Handle chemicals carefully, whether you are home or at work. Everything you breathe or absorb through your skin can affect your liver:
  o If you have to use chemicals, protect yourself
  o Make sure your work area has plenty of fresh air
  o Cover your skin. Wear long sleeves, long pants, gloves, and a protective face mask
  o If you work around strong chemicals, you may also need to wear protective breathing equipment
• Fumes from paint thinners, cleaning supplies, pesticides, and aerosol sprays can also damage your liver. Avoid them if you possibly can

What can you do to reach and keep your body at a healthy weight?
• Exercise can help keep you physically and emotionally healthy. Regular exercise is best, such as walking, stretching, yoga, or aerobics. Talk to your healthcare provider before you start any exercise routine
• Having and keeping a healthy weight can also help keep your liver healthy
• Write down what you eat. It will help you keep track and lose weight
• Check out weight control programs

Are you getting the rest you need?
• Rest when you are tired. Try to take a short nap during the day. Or find a time when you can just relax
• Get enough sleep. Most people need 7 to 9 hours of sleep every night
• Try to do things to help cut down on stress, such as meditation or yoga. Prayer may also help you reduce stress

What medicines do you need to be careful about taking?
• Do not use tobacco and street or illegal drugs
• Drugs like acetaminophen (Tylenol®) can be harmful if you take too much. Large doses sometimes cause liver failure
• Always check with your healthcare provider before taking any drugs—prescription medicine, over-the-counter drugs, or supplements
Review Points

How soon can you start making these positive changes?

• Eat a healthy, balanced diet with lots of vegetables (especially green vegetables) and fruits

• Eat food that has fiber. Fruits, vegetables, and grains all have a lot of fiber

• Have different types of protein. You probably know about animal proteins found in meat, poultry, fish, milk, cheese, and eggs. But there are also vegetable proteins, found in beans, nuts, seeds, tofu, and soy products

• Drink lots of water. Water helps to remove toxins (poisons) and process important nutrients

Do you know about this food resource guide?

MyPlate, from the US Department of Agriculture, can help you choose the right food and the right amount of food. You’ll find it online at www.choosemyplate.gov.
Purpose: To get the members of your group ready for their healthcare provider appointments. By planning ahead before a visit, people can get more of what they want from conversations with their healthcare providers.

Tips for having a successful appointment with your healthcare provider

Appointments with a healthcare provider can be pretty stressful. It’s a good idea to go over with your group different ways to prepare for your visits.

- Write out questions to avoid having to remember them at the appointment
- Know how long the appointment is. This helps to keep the purpose of your appointment in focus
- Share important health information

It is a good idea to become an active partner in your treatment.

- Asking for clarification shows the healthcare provider that you care about your health
- Taking notes tells the healthcare provider you can follow through with treatment
- Bring someone with you to help you write notes and remember what was discussed

Discussion Topics

What kind of healthcare provider should you see?
How do you get ready for your healthcare provider visit?
What information should you share with your healthcare provider?
Why partner with the healthcare provider?
How do you make sure you are working as a team?
How do you make a good impression at your appointment?
What should you expect from the appointment itself?
Do you know what the Patient’s Bill of Rights is?
How is health information protected?
What rights does the Privacy Rule give for health information?

Handout

Suggested questions to ask your healthcare provider
Understanding the Patient’s Bill of Rights
Here are some sample questions and answers you can use as you like during your meeting:

**What kind of healthcare provider should you see?**
If someone is diagnosed with hepatitis C, the healthcare provider might recommend seeing one of these specialists:

- A gastroenterologist is an expert on the digestive system, which includes the stomach, intestines, and liver
- A hepatologist is a gastroenterologist who’s an expert in treating people with liver diseases, such as hepatitis C
- An infectious diseases doctor is a medical doctor who specializes in specific diseases, including those caused by viruses or bacteria. You would want to work with one who specifically treats hepatitis C

**Ready for your visit to the healthcare provider?**
To have a successful healthcare provider’s appointment, it helps to prepare. With a little planning, you can have a productive appointment.

Things to do *before* the visit:

- When making the appointment, ask if there is anything needed beforehand
- Ask the healthcare provider’s office to mail any paperwork they will need for the appointment. Fill it out ahead of time so you don’t have to do it at the healthcare provider’s office
- Write down questions and list them in the order of their importance. Writing down what to ask the healthcare provider means not having to rely on remembering

**What information should you share with the healthcare provider?**
You have to give your healthcare provider information about yourself. It is the only way your healthcare provider can give you the treatment that is right for you.

Some things healthcare providers will need to know from people with hepatitis C:

- Most healthcare provider offices will ask for a medical history, including a list of:
  - Illnesses
  - Surgeries
  - Symptoms
  - Life changes
  - Important stressors in your life
• Also write down:
  - If you work with or around harmful substances
  - How much alcohol you drink
  - Any and all drug use in the past 10 years
• Be sure to list all the prescription and over-the-counter medicines, vitamins, herbs, and food supplements that you are taking. Include the dose, amount, and how often you take each one

Why partner with the healthcare provider? How do you make sure you are working as a team?

Healthcare providers want to help. When people with hepatitis C work with their healthcare providers towards the same goal, they can help each other achieve that goal.

What the healthcare provider says is just as important as what you say to the healthcare provider. Working with the healthcare provider gives you a greater chance of being satisfied with the healthcare you receive.

Here are some tips for being a good partner with the healthcare provider:

• Tell the healthcare provider that you want to work together in your treatment. Make eye contact when talking to the healthcare provider

• Understand that as you talk, the healthcare provider will be planning the best chance for treatment success

What makes a good impression at the appointment?

Making a good impression on the healthcare provider is more important than most people realize. Show commitment to staying with treatment. Here’s how:

• Arrive on time for the appointment

• Be alert and pay attention

• Dress as if you are going to an important meeting

• Take notes. Some people have said the cost of a notebook was the best investment they made. A notebook with pockets is a good way to keep all the medical information in one place

• Bring a friend or family member to take notes. A companion may also help by giving you emotional support

What should you do at the appointment with the healthcare provider?

• Ask the questions that you wrote down before your appointment. Talk about your most important health issues first. Try to be brief, but clear. You can bring up the less important issues if there’s time later

• Listen carefully to what the healthcare provider says. If the healthcare provider’s instructions are unclear, ask to have them explained
• Take notes. If the healthcare provider makes suggestions, write them down. Ask the healthcare provider to spell any difficult words

• Speak up if the healthcare provider’s instructions about the treatment are not clear. Ask to have things explained in more detail

Do you know what the Patient’s Bill of Rights is?
Everyone who receives medical care has certain rights. They are all listed in “A Patient’s Bill of Rights,” written by the American Hospital Association. Even though it is not a law, it has been widely accepted by the healthcare industry.

During your treatment for hepatitis C, there will be times when you should remember that the Patient’s Bill of Rights might help you out. You should ask to find out if your healthcare provider follows the Patient’s Bill of Rights. If your healthcare provider does, it could help you in a number of ways:

1. You have the right to receive medical care that takes your wishes, needs, and feelings into consideration.

2. You have the right to get all the information about your diagnosis from your healthcare provider.

3. You have the right to what’s called informed consent. This means that the healthcare provider must give you enough information about a treatment or procedure so that you can decide whether or not to have it.

4. You have the right to refuse treatment (if allowed by law).

5. You have the right to privacy concerning your own medical care.

6. You have the right to expect that all information and records about your care will be private.

Other patient rights have to do with staying in a hospital. If you are hospitalized, ask to see the Patient’s Bill of Rights for that hospital.

How is health information protected?
A federal law called the Privacy Rule (a part of HIPAA, Health Insurance Portability and Accountability Act) protects information about your health. It limits who is allowed to look at your health records.

The Privacy Rule applies to all forms of information about your health, whether it’s written, electronic (on a computer or database), or spoken.

Another federal law, called the Security Rule, is just for your electronic health records. The Security Rule requires organizations to guarantee that your records will be protected, and that they are secure enough so that no one can gain access to them.
What rights does the Privacy Rule give for health information?

The federal government requires health insurers and providers to uphold your right to:

- Get a copy of your health records
- Get in writing how information about your health may be used and shared
- Decide if you want to allow your health information to be used or shared for certain purposes, such as for advertising
- Get a report on when and why your health information was shared for certain purposes
- Check with your local health department, because some states have additional rights and protections

If you believe that your rights are being denied, or that your health records aren’t being protected, you can file a complaint with your health insurance provider. You can also file a complaint with the US government.
Part of your appointment should include asking your healthcare provider questions.

- By writing your questions down, you can be sure you don’t forget to ask them
- Write down what you want to know about your disease and treatment
- List your most important questions first

You can get answers to a lot of your questions by asking nurses or physicians’ assistants. They are usually easy to talk to and they know a lot about treatment. Most will go out of their way to make sure you get the information you need as quickly as possible.

**Suggested questions to ask**

**Questions about hepatitis C:**

- Has the hepatitis C virus damaged my liver?
- What is my virus load and genotype? What do these results mean?
- What tests will you perform to find out more about my health and the effect that hepatitis C is having on me?
- Do I need a liver biopsy?
- Should I be vaccinated against hepatitis A and B?
- Now that I have hepatitis C, how should I address my other health problems?
- (If you’re a woman) How does this affect pregnancy?
  (For both partners) How can we protect each other from infection?
- If my spouse has hepatitis C, how will I be affected?

**Questions about treatment:**

- Do I need treatment for hepatitis C?
- What are my treatment options?
- What are the benefits of each treatment option?
- What are the potential risks of each treatment option?
- How long will my treatment last?
- Do I have any other conditions that will make treatment harder for me?
• How often will you need to see me?
• What tests will I need during treatment?
• What about pregnancy and birth control?

Questions for your healthcare provider:
• How much experience do you have treating people with hepatitis C?
• Should I see a specialist?
• Can I reach you by phone?
• Should I contact you directly?

Related questions (some can be answered by the healthcare provider):
• Should my family be tested for hepatitis C?
• Is it possible for me to spread hepatitis C to others?
• How can I protect the people around me from getting hepatitis C?
• Do you have any brochures or other printed materials that I can take with me? What are some reputable websites where I can learn more about hepatitis C?
• Who should I tell that I have hepatitis C?
• Are there some daily habits I should change in order to help me stay healthy?
• Do I need to make any changes to my diet?

Be sure to share any worries or concerns with your healthcare provider. Don’t hold anything back. If you don’t understand an answer, ask your healthcare provider to explain it in a simpler way.

**Review points**

• Dress as if you are going to an important meeting
• Arrive on time for your appointment
• Be alert and pay attention
• Find out how much time the healthcare provider has for questions. Respect these limits
• Ask the questions that you wrote down before your appointment and address the most important questions first
• Take notes
• Listen carefully to what your healthcare provider says
• Speak up if you are not clear about your treatment
A Patient’s Bill of Rights

Everyone who receives medical care has certain rights. The American Hospital Association wrote the Patient’s Bill of Rights. Even though it is not a law, it has been widely accepted by the healthcare industry.

During your treatment for hepatitis C, there will be times when you should remember that the Patient’s Bill of Rights might help you out, depending on your healthcare provider’s policy. The Patient’s Bill of Rights may help you in a couple of ways:

1. You have the right to receive medical care that takes your wishes, needs, and feelings into consideration.

2. You have the right to get all the information about your diagnosis from your healthcare provider.

3. You have the right to what’s called informed consent. This means that the healthcare provider must give you enough information about a treatment or procedure so that you can decide whether or not you want it.

4. You have the right to refuse treatment (if allowed by law).

5. You have the right to privacy concerning your own medical care.

6. You have the right to expect that all information and records about your care will be private.

Other patient rights have to do with staying in a hospital. If you are hospitalized, ask to see the Patient’s Bill of Rights for that hospital.
8: Next Steps

Purpose: To help people in your group understand that they have choices and how to have an informed talk with their healthcare provider.

Facts
Each person’s path moving forward is based on what they and their healthcare provider agree to. The choice is to either treat the virus or to watch and wait.

Anyone considering treatment needs to talk with their doctor to find out about all their options.

Treatment for hepatitis C may include 3 prescription medicines:

- Direct-acting antiviral (DAA) pills that you take each day
- A weekly injection of pegylated interferon alfa
- Ribavirin pills that you take as your healthcare provider prescribes

DAAs directly target the hepatitis C virus and interfere with the virus as it multiplies. DAAs do not work alone and must be taken with peginterferon alfa and ribavirin.

Interferon is something that your body can make naturally. It works by interfering with the growth of a virus. Your body makes interferon if you are sick with the flu, for example. Man-made interferon is given as an injection. It’s been used to treat hepatitis C since 1991. Peg is short for “pegylated.” That helps keep the interferon in the body longer.

Ribavirin is a medicine that helps fight the hepatitis C virus together with peginterferon alfa. How ribavirin works is not completely known. Ribavirin is a pill you swallow with food. The amount of ribavirin you take depends on your weight. The more you weigh, the more ribavirin you may need to take.

Discussion Topics
Why is hepatitis C treatment important to you?
Why commit to treatment?
Why do you think some people decide not to get treated for the virus?
What might happen if you do nothing?
What are some lifestyle changes you can make?
How long can treatment take?
Do you know other people who have hepatitis C?

Handout
If you and your healthcare provider are thinking about treatment, what should you plan for?
Here are some sample questions and answers you can use as you like during your support group meeting:

**Why is it important to consider hepatitis C treatment?**
People with hepatitis C may be tempted to postpone talking with their healthcare provider. Symptoms do not always appear, so it can be easy to ignore. Here are some good reasons why you should consider talking with your healthcare provider sooner, instead of later, about your next step:

- Hepatitis C is the leading cause of liver cancer
- Hepatitis C can shorten your life by 8 to 12 years

**How successful is treatment?**
Successful treatment depends on many factors, such as genotype, age, and stage of liver disease, for example. Your doctor can explain what your chances for treatment success may be.

**When is a good time to get treated for the virus?**
Some people wait until they begin to notice signs of the disease. But even though there may not be any symptoms, hepatitis C could be harming the liver. There is no way of knowing if the disease will become serious or how fast it will progress.

**Why commit to treatment?**
Treatment for hepatitis C takes time, energy, and planning. But as tough as it can be, you can be tougher. Think about these important facts:

- We know more about hepatitis C today than we ever have before
- There are more treatment options than in the past

**What if hepatitis C is left untreated?**

- While treatment gives you a chance to get the virus out of your body, without treatment, the virus will stay in your body
- Studies from the National Institutes of Health (NIH) show that about 20% of people with hepatitis C can get serious liver disease, such as cirrhosis
- There’s no way of knowing who will get serious liver disease, but it becomes more likely as people get older
What if treatment is not an option?
Instead of starting drug treatment, the healthcare provider might suggest making lifestyle changes. These may include following a healthier diet, giving up alcohol, and monitoring (your healthcare provider keeping an eye on your condition). Monitoring doesn’t mean doing nothing. It means keeping a close eye on how the liver is doing. It will help the healthcare provider decide on the next step. You may need to have a liver biopsy every 5 to 7 years. Even though you and your healthcare provider should work as partners, and it’s important to listen to your healthcare provider’s opinion, you should always remember the decisions about your body are up to you.

How long will treatment last?
It depends on the genotype (the individual type of hepatitis C virus). There are 6 different genotypes, but genotypes 1, 2, and 3 are the most common in the United States. People in the United States who have hepatitis C mainly have genotype 1. It is the hardest to treat. The treatment time is different for each genotype:

- **Genotype 1:** Up to 48 weeks, depending on your previous treatment history and how your body responds to treatment
- **Genotypes 2 and 3:** 24 weeks

If the treatment is not working, or if there are issues with side effects, the healthcare provider might stop the treatment.

What makes a difference in the results?
Not everyone will have the same success from hepatitis C treatment. There are many factors, some of which are out of your control, that can have an impact. Having a healthy lifestyle can help. Talk with your healthcare provider about actions you can take.

What are the potential side effects of therapy?
Most people have some side effects from treatment. Talk to your healthcare provider to:

- Learn about the side effects
- Know how to manage the side effects

You should also read the Medication Guides that come with the medicines. These guides can help you understand what side effects you may have.

Are there many other people with hepatitis C?
Yes, about 5 million people in the US are infected with the hepatitis C virus. Most people with the virus were born from 1945 through 1965. Many people were infected with hepatitis C in the 1960s, 1970s, and 1980s without even knowing it. They may now have been carrying the virus for over 30 years. They are getting older, and the disease may be doing serious harm to their livers.

According to recent research, over the next 20 years there will likely be a big increase in new cases of cirrhosis (severe liver scarring) and the problems it can cause. This means that more and more people will become sick if they choose not to get treated.
Should you plan for treatment?
You probably don’t want to make any big decisions hours or days after you’ve been told you have hepatitis C. Obviously, you need to time to clear your head. When you’re ready, answering these questions can help you decide what is your best next step:

• Can you afford the cost of hepatitis C treatment? Even with insurance, it may be expensive. Check with your insurance company to see what will be covered. Also, make sure you can handle the out-of-pocket costs (the part of the costs that your insurance doesn’t cover)
  ○ You may qualify for a prescription assistance program (PAP). Visit www.pparx.org for more information about the programs

• Does your schedule allow you to have treatment for up to 48 weeks? You may need to make changes:
  ○ At work. You may need to take sick days or work fewer hours if you are feeling sick during your treatment
  ○ In your life. For example, if you are male, your partner must not get pregnant while you are being treated and for 6 months after treatment ends. Similarly, if you are a female, you must not get pregnant while you are being treated and for 6 months after treatment ends

• Are you mentally prepared? This includes having a plan, goals, and people you can rely on so you can be as healthy as possible:
  ○ If you have emotional problems or a history of depression, discuss them with your healthcare provider
  ○ If you have a problem with alcohol or drugs, you need to deal with it before you can begin treatment
  ○ Discuss with your healthcare provider any medical or emotional issues you have

One more thing: Don’t make your decision alone. Talk with family members, close friends, and of course, your healthcare providers. Share what you’re thinking and feeling. Have them share what they’re thinking and feeling. It will make a big difference.

Review Points
• What is my genotype? What are my chances for a cure, or clearing the hepatitis C virus?
• What are some of the side effects of treatment that most people get?
• How should I plan for treatment?
• What should I take care of before I start treatment?
9: Getting Organized for Treatment

**Purpose:** To help the people in your group prepare mentally, physically, and financially, for treatment. This lesson also has detailed suggestions to help them get organized before starting treatment.

**Facts for scheduling treatment**
People in your group need to plan their lives for treatment. At the very least, they will need to be:

- Prepared mentally
- Ready to pay medical bills not covered by insurance
- Financially organized so they know what money they have to live on during treatment
- Keeping routines that can help them stay on their treatment schedules
- Living healthy lifestyles

**Here are some sample questions and answers you can use as you like during your meeting:**

**Have you defined your goals?**
First, you need to get into the right frame of mind. It helps to spell out your goals and know exactly what you want to accomplish with treatment, such as:

- Beating the virus
- Keeping the disease away
- Feeling free of the burden of disease
- Looking forward to a healthy future for you and your family

**Discussion Topics**
How can you prepare mentally and define your goals?
How do you prepare your finances?
With or without insurance, can you afford the costs of hepatitis C treatment?
Will you be able to take days off if you are sick?
Will taking days off affect your income?
Can you receive disability payments?
Can you use the Family and Medical Leave Act?
Should you keep a diary?
Should you keep a wall calendar?
How can you stay organized?

**Handout**
Areas to help prepare mentally
What if you can’t afford your medicine?
Have you written down your goals?
Once you define goals, write them on paper. Then, you can put that piece of paper where you can see it every day. There are going to be times when you will have doubts about treatment. These lists will be powerful reminders of why you made your decisions.

The ultimate goal for most people is to be cured, or clear their body of hepatitis C, completely and permanently. That happens when the virus is not detectable for 6 months after treatment is finished. It is also called a sustained virologic response (SVR).

Have you prepared your finances?
Part of being ready for hepatitis C treatment is being ready financially. This means having a plan in place to:

- Pay for doctor visits and lab tests
- Cover the cost of medicines
- Deal with the possibility of lost pay due to time off from work

What about affording the costs of hepatitis C treatment?
Treatment for hepatitis C is expensive. Medicine alone for a 48-week course of treatment can be costly if you don’t have insurance that covers the cost. Even with medical insurance, you may have to pay a portion of the treatment costs depending on your coverage. And that doesn’t include the costs of medical appointments, lab tests, and drugs to manage side effects. It is important to know how much people will need to pay for each part of treatment.

In order to be prepared, people will need to double-check the amount of coverage in their medical insurance plans.

Before starting treatment, try to get answers to the following questions:

- Does your insurance cover prescription drugs? Call the insurance company and find out
- If so, what will the out-of-pocket costs be (the amount of your own money you have to pay)? Ask the insurance company about these out-of-pocket costs
- If you don’t have prescription drug coverage, how much will hepatitis C treatment cost? Talk to pharmacists in your neighborhood. Check online to find out about the costs of medicines purchased through mail order pharmacies
- How often will you have lab tests done, and what is the co-pay (the part you have to pay yourself)? Call the insurance company. Ask what would be covered
- How often will you need to see the healthcare provider, and what is the co-pay? Talk to the healthcare provider and the insurance company

Even if you have prescription coverage, you need to know what your out-of-pocket costs will be. Some insurance plans separate medicines that are taken orally (by mouth) from ones that are injected (by needle).
Will you be able to take days off if you are sick? Will taking days off affect your income?

People being treated for hepatitis C may need to take time off from work. Here are some questions to think about:

- Can you afford to miss any work? Ask your human resources representative or supervisor if you have flexibility for sick days and if your pay will be affected if you miss additional days because you are sick.

- Will you have trouble taking time off for healthcare provider visits and lab tests? Check in with your healthcare provider or other people who have hepatitis C to find out how many visits patients needed with their healthcare providers. You may want to talk to your human resources representative or supervisor.

What about receiving disability payments?

If you have hepatitis C and are unable to work, you may be able to file a disability claim to receive money that covers you while you are out on medical leave. Healthcare providers can help you with this. It’s another reason why good communication with the healthcare provider is so important. In addition, you should:

- See if your employer provides disability insurance and find out what the requirements are.

- Check eligibility for the Social Security Disability Insurance program. Be aware that it takes time to qualify for benefit payments. You can get information at the website www.ssa.gov.

- Find out whether your state has its own disability program.

Will the Family and Medical Leave Act help?

The Family and Medical Leave Act is a federal law. It guarantees up to 12 weeks of unpaid medical leave for many people who are sick or who are taking care of other family members who are sick. It has restrictions. It is not automatic and it is not for everyone. For example, this act is for a person who has worked full-time for at least a year for a company of 50 or more employees.

- For additional information, visit the US Department of Labor at www.dol.gov.

- Many states have laws that provide similar protection, so check with your state’s Department of Labor.

Why not use a calendar to help remember?

An important part of being ready for hepatitis C treatment is planning ahead. Many people write down dates on a wall calendar.

- One big advantage of a wall calendar is that it serves as a constant reminder of treatment progress. A wall calendar can’t get lost or misplaced. It’s right there in front of you, just asking to be looked at.
• Keeping an organized calendar will help plan for the next healthcare provider’s appointment

• Some of the medicines need to be taken at very specific times. It’s very important that people who are in treatment stick to the schedule. For that reason, many people mark their calendars with those dates and times

• People being treated for hepatitis C also need to have a number of lab tests. It is important to schedule them into your days. The results of those tests help the healthcare provider assess how well the treatment is working

To remind themselves when it is time to take their medicines, many people use the calendar alarms on their wristwatches, computers, cell phones, or other mobile devices.

Sticking to a strict schedule and routine makes things less confusing and easier to stay on track. Keeping a good, organized calendar helps plan for the next healthcare provider’s appointment, and helps with taking medicine at the right time. During treatment, medicine must be taken at very specific times.

• Knowing you’ve planned ahead can make the treatment less stressful

• Using a daily or weekly pillbox can help keep medicines organized

**Why keep a diary to record how treatment is going?**

When someone is ready to begin treatment, the companies that make the medicines may give out a patient treatment diary. People on treatment can make their own using notebooks, if they prefer. The important thing is that they make note of:

• Healthcare provider visits and lab work

• Their latest injection site

• Their last dose of medicine

• Side effects

• Their general mood on a certain day

• Their overall mood during the past week

• Any over-the-counter medicines, including vitamins, herbs, and supplements

• Things to ask the healthcare provider

Keeping a diary can help the healthcare provider get a picture of the physical symptoms, see if anything is out of the ordinary, and notice a problem that needs to be checked.
Why stick to a routine?
Try to create and stick to both a daily and weekly schedule. Treatment will be a busy time with a lot going on. Having regular habits will help manage your time and treatment.

Planning ahead can help treatment fit into the day, even when you may be:

- Too tired to keep up an active lifestyle
- Needing more rest and occasional naps
- Not feeling as mentally sharp as you were before

What's a good way to stay organized?
Some people have problems with forgetfulness during treatment. Being well organized will help. For example, always put your keys, wallet, purse, checkbook, and other important items in the same place. Storing the medicine bottles in the same cupboard can also help. Some people find that pill organizers help them keep track of their medicine schedule.

Teach yourself good habits for everything, and stick to these habits so they become a routine.
Areas to help you prepare mentally:

- Build a relationship with your healthcare providers. People who were cured, or successfully cleared the virus, say that their relationship with their healthcare providers were key in helping them through treatment.

- Support network. You can’t do it alone. Support from family and friends can be another important part of completing treatment, so surround yourself with positive people.

- Find the right support group for you. A support group will give you some tips to make treatment easier. You can learn more about the virus and talk to people who are going through treatment. Your healthcare provider’s office should be able to suggest a nearby group for you.

- Prepare to make lifestyle changes. If you want the best possible outcome for your treatment, you may have to make a few changes; specifically, you should give up all alcohol and improve your diet. And if you smoke or do drugs, you should try to stop immediately. If you need help to stop smoking or to get off drugs, talk to your healthcare provider.

- Think positive thoughts. When things get tough, the right attitude can make all the difference. Thinking positively may help with your perspective. You can prepare for treatment by trying to be as optimistic as possible.

What if you can’t afford your medicine?

If you don’t have prescription coverage and can’t afford to pay for your medicine, you might qualify for patient assistance from drug companies. You will have to work closely with your healthcare provider to apply for these programs. Here is an example of one:

- Partnership for Prescription Assistance: 1-888-477-2669 or www.pparx.org

Review Points

1. What steps will you take to get organized for treatment?

2. What are your goals for treatment?
10: How to Help Yourself

**Purpose:** To help the people in your group prepare for treatment by putting together the support they will need from many different people. Helping people in your group to get better can also help the people they care about.

**Facts**
Support takes many forms. Getting support is a big help to people going through hepatitis C treatment. This includes help from:

- **Family**
- **Friends**
- **Support groups**

**Discussion Topics**
- What kind of support do you have? Is it enough?
- Do you have family, friends, and coworkers who care about you and can support you?
- How will you support yourself?
- How do you help educate those who support you?
- What are your childcare/family-care options?
- How do you prepare your family?
- Who will do what?

**Handout**
How to help yourself

**Here are some sample questions and answers you can use as you like during your meeting:**

**What kind of support is there and is it enough?**
Every person with hepatitis C reacts differently to the diagnosis. Some get angry. Some worry or get sad. Having people around who will let you express your feelings to them before, during, and after treatment can be a comfort.

It is important to have friends, family, coworkers, and peers in a support group to lean on while going through treatment.

Think about who you can rely on for support. Although some people may try to go through treatment without support, for most it’s not a good idea to do it alone.

**Do you have family support?**
When you speak to family members, it’s important to explain:

- What your family can do to help you get through treatment
- What they should expect from you in terms of mood, side effects, medicine schedules, healthcare provider visits, and lab tests
Your family should know that you must keep to the schedule and not miss taking any medicine or miss any lab test appointments. Tell your family that you will also be trying to eat and sleep on a strict schedule.

You might also ask a family member to be a “gatekeeper.” That will allow your family member to discuss any serious problems you are having with the medical team.

**How can people getting treatment for hepatitis C support themselves?**

People being treated for hepatitis C need support from others. Sometimes, the most important support will come from a support network.

Here are some ways you can help yourself:

- **Rest, eat well, and exercise regularly.** You should talk to your healthcare provider before starting any exercise program.
- **Try setting aside time for hobbies you enjoy or that help you relax.** It could be something as simple as reading or listening to music.
- **Learn as much as you can about hepatitis C.** Ask your healthcare provider to suggest some reliable websites, literature, and other resources to help before and during treatment.

**Would it help to educate supporters?**

Once people being treated for hepatitis C inform friends and family, it can help to educate them about hepatitis C. When family and friends understand, it can make them feel more comfortable being around you. Here is what you should do:

- **Let them know that hepatitis C is a disease of the liver.**
- **Tell them that hepatitis C is not spread by casual contact.**
- **Explain that the disease can only be spread through blood-to-blood contact, so people with hepatitis C must be extra careful about exposing others to their blood.**
- **Let family and friends know that you can’t—and won’t—share a toothbrush or any personal item that could contain even a tiny trace of blood.**

**Do you have childcare/family-care options?**

After you start hepatitis C treatment, you will probably need help caring for your children or family. Since treatment could last for 48 weeks, you need to plan ahead. With everything you will be going through, you don’t want the added worry of having to find babysitters, or finding out that your children have no way of going to or coming home from school.

**How can you plan for your childcare needs?**

- **You should ask yourself, who could help if you suddenly become sick and can’t care for your children or family?**
- **Who can you call if there’s an emergency and everyone else is too busy to help?**
Find a close friend, family member, or babysitter to help. But what if it’s too much work for one person to handle? If that’s the case, there are local agencies, support groups, and drop-in childcare services that can help. Try to get as much help as you can. And don’t be shy about asking for it.

Once you have a plan in place, you should share it with your children’s schools.

**How can you prepare your family?**

- Tell your family that you’re starting a treatment program, and that there’s a good chance it will cause changes in the household
- Tell them that your treatment is important and that you will need their help and support
- Explain to them you’re trying to get better because you want to be there for them in the future. But right now, you need them to be there for you

**Who will do what?**

Everyone in the family should have a role in helping, even with the household chores.

You may need someone who can make things easier on you, such as someone to:

- Help prepare meals
- Do chores
- Run errands
- Give you a ride to work

Again, if you are unable to afford these resources, social services may be able to help. Ask what services are available, such as a Meals On Wheels® program. You will most likely need support during your treatment, so set up help in advance.
Additional support

Here are some other organizations where you may find answers and support:

**American Liver Foundation**
1-800-GO-LIVER (1-800-465-4837)
www.liverfoundation.org

**Caring Ambassadors Hepatitis C Program**
1-503-632-9032
www.hepcchallenge.org

**Hepatitis C Support Project**
www.hcvadvocate.org

**National Hepatitis C Coalition, Inc**
1-951-766-8238
www.nationalhepatitis-c.org

**United States Department of Veterans Affairs (VA)**
www.hepatitis.va.gov

**Drug company support**

The drug companies that make the approved medicines for hepatitis C treatment provide free support programs to help you cope. They also offer educational brochures and pamphlets. They even have healthcare providers who will answer your questions over the telephone.

**Review Points**

1. Who will be helping you with the support you need? (list names and phone numbers):
   - **Family:**
   - **Friends:**
   - **Support group:**
   - **Childcare:**

2. What else do you need help with during treatment?
   - **Getting to and from your healthcare provider’s office.**
   - **Household chores.**
11: Getting Your Medicine

**Purpose:** To help simplify where, when, and how the people in your group get their treatments. This can be complicated, so this lesson is designed to make it easier for them.

**Facts:**
Your group members need to know about the 3 kinds of pharmacies.
- Specialty pharmacy
- Local/national chain pharmacy
- Discount pharmacy

Patients also have rights regarding their health when it comes to getting their medicines.
- Rights about treatment
- Rights about privacy

**Here are some sample questions and answers you can use as you like during your meeting:**

**Where should you order your medicine?**
To order hepatitis C medicines, it is important to plan in advance:
- Some pharmacies need at least 24 hours’ notice to fill hepatitis C prescriptions
- Many insurance companies require prior authorization (approval ahead of time) before they will agree to pay the medicine’s cost. This could take days or even weeks
- The insurance company may have the person getting treatment for hepatitis C buy prescriptions through a mail order or specialty pharmacy

People being treated for hepatitis C can choose their own type of pharmacy. They should know that each has its strengths.
Specialty pharmacy:

- Medicine is shipped by overnight delivery directly, saving time and energy
- They can explain how to use the combination therapy
- They will provide websites and other information to help you manage your treatment
- Most will reach out when you need to reorder your medicines

Local/national chain pharmacy:

- They keep a record of all the medicine you bought from them in one place: their store
- This allows you to decide where and when you pick up your medicine
- Sometimes, these pharmacies also offer support services for hepatitis C patients

Discount pharmacy:

- People getting treatment can receive offers that reduce the cost of a medicine, but you need to sign up for an annual membership and pay a fee
- They may have a delivery service for medicines

**How do you care for your medicine?**

- Peginterferon alfa needs to be kept in a refrigerator
- If it is a long distance from the pharmacy to your house, bring a cooler and an ice pack to pick up the prescription. And never leave the medicine in direct sunlight or in a hot car
- If you travel, ask your healthcare provider or pharmacist about safe ways to transport needles and refrigerated medicines. If you are traveling by plane, carry a copy of your prescription, for when the airport security asks to see it

**Do you have a Starter Kit?**

Each drug company provides Starter Kits for people getting treatment for hepatitis C. These kits are packed with useful information and tools, such as:

- Videos
- Coolers
- Ice packs
- Pill containers

Contact the company that makes the prescription medicine to receive a Starter Kit.
Do you know the Patient’s Bill of Rights?

Everyone receiving medical care has certain rights. They are all listed in “A Patient’s Bill of Rights,” written by the American Hospital Association. Although this is not a law, it has been widely accepted by the healthcare industry.

During treatment for hepatitis C, there will be times to remember these rights:

• You have the right to receive medical care that takes your wishes, needs, and feelings into consideration
• You have the right to get all the information about your diagnosis from your healthcare provider
• You have the right to what’s called informed consent. This means that the healthcare provider must give you enough information about a treatment or procedure so that you can decide whether or not to have it
• You have the right to refuse treatment (if allowed by law)
• You have the right to privacy concerning your own medical care
• You have the right to expect that all information and records about your care will be private

Other patient rights have to do with staying in a hospital. If you are hospitalized, ask to see the Patient’s Bill of Rights for that hospital.

How is health information protected by federal law?

A federal law called the Privacy Rule protects information about your health. It limits who is allowed to look at your health records.

The Privacy Rule applies to all forms of information about your health, whether it’s written, electronic (on a computer or database), or spoken.

Another federal law, called the Security Rule, is just for your electronic health records. The Security Rule requires organizations to guarantee that your records will be protected, and that they are secure enough so that no one can gain access to them.

What rights does the Privacy Rule give me over my health information?

The federal government requires health insurers and providers to uphold your right to:

• Get a copy of your health records
• Get in writing how information about your health may be used and shared
• Decide if you want to allow your health information to be used or shared for certain purposes, such as for advertising
• Get a report on when and why your health information was shared for certain purposes

If you believe that your rights are being denied, or that your health records aren’t being protected, you can file a complaint with your health insurance provider. You can also file a complaint with the US government.
What if you cannot afford your medicine?
If your health insurance does not include prescription coverage, or you can’t afford to pay for your medicines, you might qualify for patient assistance from the company that makes your medicines. You will have to work closely with your healthcare providers to apply for these programs. One example is:

• **Partnership for Prescription Assistance:** 1-888-477-2669 or www.pparx.org

A Patient’s Bill of Rights
The American Hospital Association wrote the Patient’s Bill of Rights. Even though it is not a law, it has been accepted by the healthcare industry.

During your treatment for hepatitis C, there will be times when you may want to remember you have these rights:

1. You have the right to receive medical care that takes your wishes, needs, and feelings into consideration.

2. You have the right to get all the information about your diagnosis from your healthcare provider.

3. You have the right to what’s called informed consent. This means that the healthcare provider must give you enough information about a treatment or procedure so that you can decide whether you want it or not.

4. You have the right to refuse treatment (if allowed by law).

5. You have the right to expect that all information and records about your care will be private.

Other patient rights have to do with staying in a hospital. If you are hospitalized, ask to see the Patient’s Bill of Rights for that hospital.

Review Points

• Where should you order your medicine?
  - Specialty pharmacy
  - Local/national chain pharmacy
  - Discount pharmacy

• What are some things that are protected by the Patient’s Bill of Rights?
12: Before, During, and After Treatment

**Purpose:** To help people in your group understand all parts of treatment. Members of your group who have tried treatment may want to share what their treatment was like.

**Facts**
Does everyone in your group know what drugs may be used to treat hepatitis C? Remind them that they could include:

- **Direct-acting antiviral (DAA) pills that you take each day**
- **A weekly injection of pegylated interferon alfa**
- **Ribavirin pills that you take as your healthcare provider prescribes**

Using 2 or more medicines together is called combination therapy.

**Here are some sample questions and answers you can use as you like during your meeting:**

**Why is hepatitis C treatment important?**
Unless your body cures itself or clears the virus by itself, treatment is the only way to get rid of it and stop the disease from progressing. Treatment success depends on different things, such as genotype, age, and stage of liver disease.

Your doctor can explain what your treatment success may be.

**What are side effects, and what if you have them?**
Side effects are reactions that might happen in the body because of the treatment. Some are mild and make people feel a little differently than normal. Other side effects are serious and can make someone on treatment feel sick. And other side effects can be life-threatening.

**Discussion Topics**
- Why is hepatitis C treatment important?
- Where can I learn about potential side effects?
- Why is it important to be able to identify side effects?
- What if symptoms continue even after treatment?
- When are treatment results final?
- What if treatment doesn’t cure or doesn’t clear the virus from the blood?
- What else should you know about treatment?

**Handout**
Questions to ask your healthcare provider
There are even some side effects that people may not feel at all, but that a healthcare provider may notice from lab tests or physical examinations.

Having side effects doesn’t always mean that people who are on treatment need to stop taking their medicines. In fact, if you do experience any side effects, do not stop treatment, but let your healthcare provider know about them right away.

Your healthcare provider can help to manage some side effects. For example, the healthcare provider might give you another medicine that makes your side effects better or easier to deal with.

**What are the common side effects of hepatitis C therapy?**

Most people have some side effects from treatment. There are a wide variety of physical and mental side effects that people may experience on a daily basis. Before starting treatment, you should talk to your healthcare providers or pharmacist.

**What should you expect while on treatment?**

When someone who is being treated has trouble adjusting because of the side effects, it can lead to:

- **Difficulties dealing with people at home and at work**
- **Feeling anxious and feelings of being burdensome and worthless**
- **Needing to use other medicines to help reduce your side effects as your healthcare provider recommends**

For some people, the side effects from treatment make it hard to stay on treatment. Their healthcare providers may reduce their medicine doses, reduce the length of the regimens, or decide to stop treatment.

**What if symptoms continue even after treatment?**

Sometimes, the side effects continue even after you stop therapy. Be sure to talk to your healthcare providers about any side effect that continues after treatment ends.

Hepatitis C treatment can be a long process. It may take even longer to feel completely “back to normal” after treatment is over.

**When are treatment results final?**

At the end of treatment, and again 6 months later, the healthcare provider will measure the viral load (the amount of the virus in the blood) to see if the virus is present or not. The time spent waiting to learn if you’re cured, or have truly cleared the virus, and achieved sustained virologic response (SVR) can be filled with anxiety.

After completing treatment, it is possible for the hepatitis C virus to return. If the virus comes back 6 months after treatment, it is called a relapse. This outcome can be very disappointing. It can be difficult for people in this situation to decide how to move forward. Talking to your healthcare provider is a good start to figuring out your next step.
What if treatment doesn’t clear the virus from the blood?
If you have finished treatment but you are not cured—the treatment did not clear the hepatitis C virus from the blood—you may want to take a break from treatment for a while. But have a conversation with your healthcare provider first to figure out what is your best next step.
Talk to your healthcare provider to figure out a plan.

What else is there to know about treatment?
Everyone has a slightly different experience with hepatitis C treatment. Side effects are different for everyone, so the healthcare provider can’t predict how well treatment will work for any one person. But doing everything that can be done can increase the odds that treatment will work, like staying healthy by eating well, getting plenty of rest, doing moderate exercise, and by not using alcohol or drugs that can damage the liver.

At all stages—before, during, and after treatment—stay in touch with your healthcare providers to learn as much as possible. Your healthcare provider will give you advice on your next steps after treatment is finished.

What if treatment isn’t right for me?
Your healthcare provider might suggest lifestyle adjustments. These may include:

• Following a healthy diet
• Giving up alcohol
• Monitoring your condition

When a healthcare provider is monitoring your condition, it means he or she is keeping a close eye on how your liver is doing. This helps the healthcare provider decide on the next step. You may need to have a liver biopsy every 5 to 7 years. Even though you and your healthcare provider should work as partners, it’s important to listen to your healthcare provider.
Start the conversation

Here are some questions you may want to ask your healthcare provider. This can include your doctor, nurse, or pharmacist. There is also room for other questions you may want to write down to ask. Once you ask your question, write down the answers you get so you don’t have to remember what was said.

1. Why should I consider treatment?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

2. What is the name of this medicine? How do you spell it?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

3. What is it supposed to do?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

4. What are the side effects?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
5. How do I take this medicine? 


6. Will this medicine work safely with the other medicines I am taking? 


7. Should I avoid certain foods, alcohol, dietary supplements, or driving while taking this medicine? 


8. Are there non-prescription medicines I can take instead of this medicine? 


9. Why is this the right medicine for my condition, age, and gender? 


10. Are there other options that I can consider?

11. Should I call if I have side effects?

12. When will I know if this medicine is or is not working?

13. When do I stop taking this medicine?

14. When is my next visit?
15. What should I do if another healthcare provider tells me to stop taking this medicine?

(Other questions)
13: Resources and Glossary

Spend time with these resources to continue to learn more and share what you’ve learned.

**Hepatitis C Resources**

**American Liver Foundation**  
1-800-GO-LIVER (1-800-465-4837)  
www.liverfoundation.org  
Information on liver disease, including hepatitis C

**Caring Ambassadors Hepatitis C Program**  
www.hepcchallenge.org  
Hepatitis C Choices book (free PDF); information and awareness

**Centers for Disease Control and Prevention (CDC)**  
1-800-CDC-INFO (1-800-232-4636)  
www.cdc.gov/hepatitis/index.htm  
Fact sheets and answers to frequently asked questions about hepatitis

**Hepatitis Education Project**  
www.hepeducation.org  
A website for people with hepatitis C and their friends, family members, and healthcare providers. Information, advocacy, support, and other resources

**Hep C Connection**  
1-800-522-HEPC (1-800-522-4372)  
www.hepc-connection.org  
Resources, education, and support for people affected by the hepatitis C virus

**Hepatitis C Support Project**  
www.hcvadvocate.org  
Provides resources and information on hepatitis C, from clinical trials to alternative treatments. Also includes complementary therapies and information about living well with hepatitis C

**Hepatitis Foundation International**  
1-800-891-0707  
www.hepfi.org  
Information on viral hepatitis and liver disease
13: Resources and Glossary

**Mayo Clinic**
www.mayoclinic.com
Up-to-date information and tools that reflect the expertise and standards of the Mayo Clinic

**MedicineNet (owned by WebMD)**
www.medicinenet.com/hepatitis_C
Medical information on hepatitis C

**MedlinePlus Health Information**
An extensive health information website that includes a medical dictionary, information on prescription and nonprescription drugs, and an overview of hepatitis C

**National AIDS Treatment Advocacy Project (NATAP)**
www.natap.org
Educates people about HIV and hepatitis treatments, and advocates for those with these conditions. Provides hepatitis C news and conference coverage

**National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)**
www.niddk.nih.gov
Contains a database of educational materials and a discussion of hepatitis C

**National Institutes of Health (NIH)**
www.nih.gov
Comprehensive health website with links to health publications and current research

**United States Department of Veterans Affairs (VA)**
www.hepatitis.va.gov
Information, brochures, and handbooks on hepatitis C

**Drug Manufacturers and Other Resources**

**Better To Know C Program**
Vertex Pharmaceuticals
1-888-552-2494
www.BetterToKnowC.com

**Partnership for Prescription Assistance**
1-888-4PPA-NOW (1-888-477-2669)
www.pparx.org

**All About Hep C**
Schering/Merck
www.AllAboutHepC.com

**Tune In To Hep C**
Schering/Merck
www.TuneInToHepC.com
**Other Resources**

Rules and regulations regarding medical conditions and the workplace can be obtained from:

- **Americans with Disabilities Act (ADA)**
  www.ada.gov

- **Federal Equal Employment Opportunity Commission (EEOC)**
  www.eeoc.gov/facts/qanda.html

- **Federal Family and Medical Leave Act of 1993 (FMLA)**
  www.afm.ars.usda.gov/hrd/payleave/family/FMLAentitlements.htm

New privacy laws about medical information and records can be found at:

- **US Department of Health and Human Services (HHS)**
  Health Insurance Portability and Accountability Act (HIPAA)
  www.hhs.gov/ocr/privacy
GLOSSARY

**Acetaminophen:** The generic name for over-the-counter pain and fever relievers, such as Tylenol®. Large doses can cause liver failure. Ask your healthcare provider if you can take acetaminophen. It should never be taken with alcohol.

**Acute:** A term used to describe disease symptoms of a short period of time.

**Acute hepatitis C:** A short-term illness that usually occurs within the first 6 months after someone is exposed to the hepatitis C virus. About 75% to 85% of people who become infected with the hepatitis C virus will develop chronic, or long-term, hepatitis C.

**Adverse event:** An unwanted reaction you get from taking a medicine.

**Alanine aminotransferase (ALT):** A liver enzyme that plays a role in building up and breaking down protein. Healthcare providers check the serum level as part of a liver function test. If your liver cells are damaged, the serum levels of ALT may be high. Hepatitis C can cause your ALT level to go up.

**Anemia:** A condition in which your blood has a lower-than-normal number of red blood cells. Symptoms include feeling tired, having a shortness of breath, having a headache, and having your heart beat too fast or too slow for no reason.

**Antiviral drug:** A medicine that fights a virus.

**Aspartate aminotransferase (AST):** An enzyme normally present in liver, heart muscle, and red blood cells. It is released into the blood when you’ve been injured (including getting infected with the hepatitis C virus). Higher levels of AST in your blood may mean you have the hepatitis C virus.

**Blood transfusion:** The transfer of blood from one person into the bloodstream of another person. Before July 1992, people were at risk of getting infected with the hepatitis C virus through blood transfusions. Since then, blood is screened more carefully.

**Blood-borne virus:** A virus in your blood that can infect someone else through blood-to-blood contact (through shared needles when blood is exchanged, for example).

**Body mass index (BMI):** A measurement of body fat. It is calculated by the weight of your body and your height. Your healthcare provider can use it to help find out if you are overweight.

**Chronic:** A permanent or reoccurring disease or condition.

**Chronic hepatitis C (CHC):** A serious condition that inflames and damages the liver. It can lead to potentially fatal liver diseases, such as cirrhosis, liver failure, and liver cancer. About 75% to 85% of the people who are infected with the hepatitis C virus will develop chronic, or long-term, hepatitis C.

**Cirrhosis:** The late stage of liver disease. It’s when the liver has scar tissue that has replaced normal liver tissue. As a result, the liver does not have enough blood flowing through it.

The liver has fibrosis (scar tissue that has replaced normal liver tissue), and has a bumpy surface from new growth. There are 2 types of cirrhosis—compensated and decompensated:

- **Compensated cirrhosis means that the liver is very scarred but can still do what it is supposed to do. People who have compensated cirrhosis can be treated with hepatitis C medicines**
• Decompensated cirrhosis (also known as end-stage liver disease) means that the liver is so scarred that it can’t work properly. The liver can no longer keep the person healthy. Decompensated cirrhosis is a life-threatening condition.

Clearing the virus (or being cured of the virus): Describes the best result after treating hepatitis C. You are cleared of the virus, or cured of the virus, when no virus is detected in your blood 6 months after you finish all treatment. This is also called a Sustained Virologic Response (SVR).

Combination therapy: 2 or more drugs used at the same time to treat a disease or condition.

Direct-acting antiviral (DAA): A type of medicine used in combination with other medicines to treat hepatitis C. It is a class of medicine that you swallow as a pill. DAAs directly target the hepatitis C virus as it multiplies.

Depression: A state of being when you may have problems concentrating, lose interest in things you once enjoyed, feel guilty or hopeless, or have thoughts about death or suicide.

End-stage liver disease: The last stage of liver disease. It happens when the liver is not getting enough blood flowing through it, when the liver has fibrosis (scar tissue that has replaced normal liver tissue), and when it has a bumpy surface from new growth. This disease is also known as decompensated cirrhosis, and it can cause death.

Fatty liver: Too much fat in the liver cells. It is the most common type of liver disease in the United States. Having diabetes, being overweight, and eating a diet with too much cholesterol (fat in food), all increase chances for getting fatty liver disease.

Fibrosis: Scar tissue that replaces healthy liver tissue. It can lead to cirrhosis, liver cancer, and even death.

Gastroenterologist: A medical doctor who is an expert on the digestive system, which includes the stomach, intestines, and liver.

Genotype: A virus type that has a special genetic makeup. There are at least 6 genotypes for hepatitis C. In the United States, genotype 1 is the most common: genotypes 2 and 3 are found in a smaller number of people with hepatitis C. Genotypes 4, 5, and 6 are not common in the United States.

Genotype 1: The most common type of the hepatitis C virus in the United States.

Hepatic portal vein: The main vein that carries nutrients from the digestive tract to the liver where the nutrients are processed. Liver disease, such as cirrhosis, increases blood pressure in the portal vein, which can lead to complications and even death.

Hepatitis: Inflammation (swelling) of the liver.

Hepatitis C disease: A liver disease caused by the hepatitis C virus. The hepatitis C virus lives in a person’s blood. It inflames and can damage the liver, sometimes without any symptoms. It can only be transmitted through blood-to-blood contact. Hepatitis C is a major public health problem and the leading cause of chronic liver disease in the United States. It is also called hep C or HCV.

Hepatitis C virus: A virus that lives in a person’s blood. It inflames and can damage the liver, sometimes without any symptoms. It can only be transmitted through blood-to-blood contact.
Hepatitis C is a major public health problem and the leading cause of chronic liver disease. It is also called hep C or HCV.

**Hepatologist:** A gastroenterologist who is an expert in treating people with liver diseases, such as hepatitis C.

**Interferons:** Proteins that our immune system makes to fight viruses and other inflammatory diseases. Interferon can also be a synthetic (man-made) medicine. It is an injection and is part of the treatment for hepatitis.

One type of interferon is called peginterferon alfa that is often combined with the drug ribavirin. They are both used together to treat hepatitis C, genotypes 2 and 3. Those 2 medicines are also used with another medicine, a DAA (direct-acting antiviral), to treat people who have genotype 1.

**Jaundice:** A yellow coloring of the skin and eyes. Jaundice can appear when the liver is not working normally. It is also one of the signs of end-stage liver disease.

**Liver biopsy:** A procedure where a small piece of liver tissue is taken out of the body by a long needle. Healthcare providers then study the tissue under a microscope to see if it is diseased.

**Liver cancer:** Develops when a cell or group of cells becomes damaged and begins growing in an unusual way. It often causes liver tumors (lumps of tissue). People with hepatitis C are at a higher risk of getting liver cancer. Between 1 and 5 people out of every 100 get liver cancer after having cirrhosis. Liver cancer is also called hepatocellular carcinoma (HCC).

**Liver enzymes:** These are proteins that the liver makes to help do some important tasks. We all have some enzymes in our blood, but too many enzymes may be a sign that the liver is damaged or sick.

**Peginterferon:** A type of synthetic interferon. It is given as a weekly injection.

**Polymerase inhibitor:** A class of compounds that work to inhibit (stop) the polymerase enzyme from working, in order to prevent a virus from multiplying.

**Protease inhibitor:** A class of compounds that is still being studied. They work to inhibit (stop) the protease enzyme from working, in order to prevent a virus from multiplying.

**Prothrombin time (PT):** A test that measures blood clotting.

**Rapid virological response (RVR):** A term used for blood test results after 4 weeks of treatment that shows that the hepatitis C virus can no longer be detected.

**Relapse:** An instance in which illness symptoms of a disease return after showing improvement. A relapse of hepatitis C can happen after reducing the virus or after stopping therapy.

**Ribavirin (RBV):** A medicine used in combination with peginterferon alfa to treat hepatitis C. When used alone, it is not effective in the treatment of hepatitis C.

**Ribonucleic acid (RNA):** Genetic material. Hepatitis C virus RNA can be detected in the blood within 2 to 3 weeks after a person is infected. After treatment, if a blood test shows no hepatitis C virus RNA, the person is considered clear of the virus.

**Support group:** Small meetings of people who have hepatitis C. The people share information and help each other deal with the challenges of life and having hepatitis C.
Sustained virologic response (SVR): A term used when the hepatitis C virus does not show up in blood tests taken 24 weeks after treatment has stopped. SVR is also called “a cure,” or “clearing the virus.”

Undetectable: When the virus can’t be detected or found in viral blood tests.

Viral load: A measure of the amount of hepatitis C virus in the blood. Test results are usually written in international units per milliliter (IU/mL).

Virus: A tiny infectious “agent” or “germ” that causes diseases.