Your Guide to Hepatitis C

What You Need to Know About Managing Your Health
Getting Started

If you've been diagnosed with hepatitis C virus, you may have a lot of questions. Whether you were just diagnosed recently or many years ago, there is a lot to learn. It is important for you to know that over 95% of hepatitis C cases can be cured. Medicines work much better and are easier to take than in the past. Also, if you weren't able to get treatment when you were first diagnosed, you may be able to get it now. Use this guidebook with your healthcare professional to learn more and to develop a plan for treating and managing your hepatitis C.
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About Hepatitis C

What Is Hepatitis C?

- Hepatitis C is a virus that affects the liver and sometimes other parts of the body. Many people have hepatitis C and don’t even know it.
- If you have hepatitis C and don’t get treatment for a long time, it can cause serious damage to your liver.
- Your liver is a very important organ. It clears toxins out of your blood like a filter. It also helps you digest food and use it for energy in your body.
What Are the Signs and Symptoms of Hepatitis C?

- Most people who are infected with hepatitis C do not have any symptoms.
- Some may have body pain, joint pain, loss of appetite, jaundice (yellow eyes or skin), or feel very tired.
- Other parts of your body can be affected, too. For example, some people get a rash on their skin.
- In rare cases, toxins can build up in the body and affect your brain. This can cause confusion, slurred speech, or changes in behavior.
- It can take years for you to feel sick after you have been infected. Many people don’t know they have the virus at all.
How Did I Get Hepatitis C?

Hepatitis C can be spread through blood and some other body fluids. The most common ways people get hepatitis C is by:

- Having a blood transfusion before 1992 that was infected with hepatitis C virus
- Injection drug use or sharing "works," which can include cookers, cotton, or water
- Getting tattoos or piercings in places other than licensed shops ("street" tattoos/piercings)
- Having sex without condoms with someone who has hepatitis C
- Having a history of kidney dialysis
- Being born to a mother with hepatitis C
- Being a healthcare worker who is stuck by a needle infected with hepatitis C
Getting Diagnosed

A blood test can tell your healthcare professional if you have hepatitis C. After you are diagnosed, it is important to work with a healthcare professional who has experience in treating patients with hepatitis C. He or she will order some blood tests to learn about your hepatitis C. The blood tests will help your healthcare professional decide:

- If you need a hepatitis A or B vaccine.
- If you should be tested for HIV. HIV and hepatitis C can be passed in the same way, so sometimes people may have both.
- If your liver has any damage. To learn more, you might also get pictures taken of your liver and a physical exam.
  - Hepatitis C affects the way your liver works. This can put you at risk for liver cancer. If tests show that you have bad scarring on your liver, you will need to get an ultrasound every 6 months, even after your hepatitis C is cured.
- If you need an upper endoscopy, a test where a very small instrument with a camera is put into your body. This will help your healthcare professional get a better idea of what your liver looks like.

Have follow-up conversations with your healthcare professional so that you can work together to choose the path that's right for you.

Hepatitis C can be cured! You can get treatment whether you have had it for years or have just been diagnosed.
Your Emotional Health

Getting diagnosed with hepatitis C can make you feel sad, ashamed, and alone. These feelings are normal. But it’s important to remember that you are not alone, and that there is a cure. Millions of people have hepatitis C. More and more of them are being cured every day.

It can be helpful for you, your family, or your loved ones to go to a support group. At a support group, you can meet others living with hepatitis C and talk about your experiences. Ask your healthcare professional or local public health department about groups in your area. There also may be online support groups that you can join. Use Google and social media sites like Facebook or Twitter to find a support group.

Many people start to feel better when they learn more about hepatitis C. When you arm yourself with knowledge, you are in control!

For More Support

If you are struggling with your mental health or substance or alcohol abuse and would like to receive help, talk with your healthcare professional. There may be programs available in your area to help you. See page 31 for some websites that may be helpful.
About Hepatitis C

Working With Your Healthcare Team

Your healthcare team may include:

- Doctors
- Nurses
- Nurse practitioners
- Physician assistants
- Pharmacists
- Nutritionists
- Social workers or case managers
- Counselors or therapists
- Healthcare navigators

These are people who can work with you to develop a treatment plan, help you make decisions, and answer your questions. They can also help you stay "in the know" about where you are in the treatment process.

YOU are the most important part of the team! If you have questions or concerns, don’t be afraid to speak up. Your family members or loved ones can also be a part of your team. They can come with you to your appointments to ask questions and help you remember things.
What Is Liver Damage?

Your liver can be seriously damaged when you have hepatitis C. There are four stages of liver damage. They are:

a. **Inflammation.** Your liver becomes irritated and may become bigger.

b. **Fibrosis.** If you don’t get treatment, your liver can begin to scar and develop scar tissue. Scar tissue takes over and replaces healthy tissue. This causes the liver to not work as well.

c. **Cirrhosis.** When the scarring becomes very bad, it is called cirrhosis. At this point, your liver cannot function normally and cannot heal itself. Cirrhosis can, but does not always, lead to liver cancer and/or liver failure.

d. **Liver failure.** Liver failure means that your liver is so damaged that it can no longer do its job. This is a life-threatening condition that may cause you to need a liver transplant.

**Stages of Liver Damage**

<table>
<thead>
<tr>
<th>Healthy Liver</th>
<th>Inflamed Liver</th>
<th>Fibrosis</th>
<th>Cirrhosis</th>
</tr>
</thead>
</table>

Hepatitis C and Your Liver
Will I Have Symptoms of Liver Damage?

It is very common to have no symptoms of liver damage. But over time, you may start to have such symptoms as:

- Discomfort or pain in the upper-right part of your abdomen (stomach area)
- Feeling very tired
- Having trouble sleeping
- Weight loss
- Skin rashes

What Will Make My Liver Damage Worse?

Some things will make your liver become more damaged faster. These can include:

- Drinking alcohol
- Having another health condition, like HIV or hepatitis B
- Having obesity
- Having a fatty liver
- Drug toxicity. This might happen if you take too much of certain types of medicines, or medicines that were not prescribed for you.
Cirrhosis means that your liver is very damaged or scarred. If you have cirrhosis, it can be compensated or decompensated.

- **Compensated cirrhosis** means that your body still works pretty well, even though you have scarring on your liver. You may have very few or no symptoms at all.
- **Decompensated cirrhosis** means that the scarring has become so severe that it affects the way your body functions. This can result in severe symptoms, such as:
  - Ascites. This happens when fluid builds up in your belly. It causes your belly to swell and stick out.
  - Icterus, also called jaundice. This causes your eyes or skin to be yellow.
  - Feeling confused.

![Healthy Liver and Liver with Cirrhosis](image-url)
Old Medicines vs. New Medicines

There have been a lot of changes in the way hepatitis C is treated. It’s much different today than it was in the past. A medicine called interferon had many side effects, had to be taken for a long time, and sometimes didn’t work. New medicines can cure hepatitis C almost all of the time.

If your insurance did not cover hepatitis C treatment in the past, it might now. Talk with your healthcare professional about whether you can receive treatment.
Health Insurance and Costs

Getting treatment for hepatitis C can sometimes be a long process. Getting access to hepatitis C medicines may depend on your health insurance. Your healthcare professional might need to ask you questions about your insurance. This will help them find out what medicines your insurance will or will not cover.

The new medicines that are available might need approval, sometimes called "prior authorization," from your health insurance company. This process can take some time. Many insurance plans, including Medicare and Medicaid, pay for the medicines. Some insurance plans might pay for some, but not all, of the costs. You might have a "copayment" or "copay" for some medicines. This means you share some of the cost of the medicine with your insurance plan.

If you can't afford your medicines, there may be programs to help you. Talk with your healthcare professional about all of your options.
Staying Healthy While Waiting for Treatment

Even though you might have to wait a while for treatment, you can keep your liver and the rest of your body healthy by:

- Eating a healthy diet. This includes fresh fruits, fresh vegetables, whole grains, and lean proteins.
- Getting enough sleep. Most adults need at least 7 hours a night.
- Stopping or lowering your use of alcohol.
- Stopping or lowering your use of injection drugs. If you do still inject drugs, make sure you are using clean "works." This means clean water, tourniquet, and cotton. Do not reuse or share needles.
- Protect sexual partners from becoming infected by always using condoms.
Stick It Out!

Once you are approved for the medicine, treatment will take about 2-3 months. During this time, you will see your healthcare team a lot. While the process might be long, it’s worth it. It’s very important to go to the appointments that you schedule with your healthcare team. It’s also important to stop or limit alcohol or drug use. This will help you stay healthy, safe, and on the road to being cured.

The medicines for hepatitis C available now can cure it. "Cure" means that the hepatitis C is no longer in your body 3 months after you are finished with your medicines. If your liver is damaged, or if you are living with other infections, you might need to get more treatment.
Appointment Planner

While you are taking your medicines, you will need to see your healthcare team often. This might mean once a week or once a month. It's very important to stick to these appointments. Write them down here so you remember important dates.

The date I started taking my medicine(s) is: ____________________________

The date I will finish taking my medicine(s) is: _________________________

The date I will take a blood test to see if I am cured is: ________________

I have an appointment at the lab located at _____________________________ on these days: (location, address)  

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

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________________________________________________________________________

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________________________________________________________________________

________________________________________________________________________
I am seeing ____________________________ (healthcare professional) at ____________________________ on these days:

(location, address)

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I am seeing ____________________________ (healthcare professional) at ____________________________ on these days:

(location, address)

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________________________________________________________________________
Treatment for Hepatitis C

My Important Numbers

My healthcare professional's number: _____________________________

Number for the lab: ___________________________________________

Number for the pharmacy: ______________________________________

My emergency contact's number: _________________________________

If I can't get a ride to my appointment, I will call: (Ask your healthcare professional if he or she knows a service you can use.)

________________________________________________________________________
Medicines

There are many different medicines to treat hepatitis C. Talk with your healthcare professional about which medicines might be right for you. You will not have to take these medicines for the rest of your life. Most people only need to take a few pills a day for a few months.

Most people don't have major side effects from the newer hepatitis C medicines. Some people have minor side effects like a headache, upset stomach, or feeling tired. If you have any side effects that concern you, call or visit your healthcare professional.

You might have to use a special pharmacy to get your medicines. You can contact this pharmacy with any questions you have while taking your medicines.
Taking Your Medicines

It's very important that you take your medicines every day. You will need to take your medicines every day for a few months. Try to stick with a medicine routine. Keep your medicines in the same place and take them at the same time every day. To help stick to a routine, you can:

- Use a medicine tracker (see pages 22 and 23)
- Use a pill organizer
- Set an alarm on your cell phone

Some medicines can interact with your hepatitis C medicines and cause problems. Tell your healthcare professional about all the medicines you take, even vitamins, herbals, supplements, or other things you buy over-the-counter. Call your healthcare professional if you start taking a new medicine.

Planning Ahead

Things can come up in day-to-day life that affect how you take your medicine. Make sure that you are able to bring your medicines with you for both planned (vacation) and unplanned (going to the hospital) life events. If you have a situation that causes you to be unable to take your medicines, talk to your healthcare professional immediately. They may be able to help.
<table>
<thead>
<tr>
<th>Name of Medicine</th>
<th>Dosage</th>
<th>Size, Shape, Color</th>
<th>How Much</th>
<th>When to Take/How to Use</th>
<th>What I Use It For</th>
<th>Start/Stop Date</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>sofosbuvir</td>
<td>400mg</td>
<td>small, oval, yellow color</td>
<td>1 pill</td>
<td>Take by mouth every morning</td>
<td>hepatitis C</td>
<td>4/1/2018</td>
<td>Don't skip doses</td>
</tr>
</tbody>
</table>

Example:
<table>
<thead>
<tr>
<th>Name of Medicine</th>
<th>Dosage</th>
<th>Size, Shape, &amp; Color</th>
<th>How Much</th>
<th>When to Take/How to Use</th>
<th>What I Use It For</th>
<th>Start/Stop Date</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Example: Vitamin C</td>
<td>500 mg</td>
<td>Big, round, orange</td>
<td>1 pill</td>
<td>Take by mouth, every morning</td>
<td>Daily vitamin</td>
<td>2/5/12-</td>
<td></td>
</tr>
</tbody>
</table>
A Patient's Story

My name is Sherry, and I am 61 years old. I am a devoted wife, mother of three wonderful boys, and a retired master teacher of elementary education for 30 years. At age 50, I was devastated to learn I had HCV, even though I had been in good health and had no symptoms. My liver quickly began to fail and my only option was a transplant.

When first diagnosed, my doctor prescribed a weekly injection of interferon and daily pill therapy. It was a difficult experience, and I felt afraid, confused, depressed, angry, and sad. Due to fluid build-up in my stomach, I made weekly trips to the hospital to remove the fluid and relieve pain.

During this time, I made sure that my diet was healthy, that I drank a lot of water, took my medicines on time, and rested as much as possible. I cut out all processed foods, began daily juicing of fruits and vegetables, and watched my salt and sugar intake. I followed the treatment plan my doctor and I created.

While I was waiting for a transplant I had bad leg cramps, itching that wouldn't stop, and more fluid build-up. The HCV also caused toxins in my blood to start to affect my brain. I went into three comas. After many hospital stays, I finally received the call I had been praying for—they found a new liver for me.

However, even with my new liver in place, HCV was still in my body. Finally, in 2015, I was able to take a new medicine for my HCV type, and was clear of the virus in 4 days with no side effects! I was overjoyed.
After You Are Cured

Anyone who has been diagnosed with HCV needs to seek treatment. Even if you do not have symptoms, the virus is not going to just disappear. The great news is, HCV is curable! My team of healthcare professionals helped me at every step of my treatment journey. They made sure I received the information I needed about the virus and lifestyle changes I should make. They also gave me great resources for support.

Thanks to my team and my donor family, I now have a second chance at life, so that I can live longer, enjoy my family and friends, attend important life events, and dedicate time to supporting and helping others fighting HCV.

Sherry with her family
After You Are Cured

Keep Your Appointments

Even though you are cured of hepatitis C, you still need to keep your scheduled appointments. This includes having blood taken and doctor’s appointments. This is how you can be sure you are cured, and it can also help you stay healthy in the long run.

It is possible that your hepatitis C is cured, but your liver is still damaged. If your liver was damaged before you started treatment, your healthcare professional may ask you to make an appointment to be screened for liver cancer. It is very important to come back for this test. If your liver is very damaged, you might need a liver transplant. Continue to follow up with your healthcare professional to track your liver health over time.
Prevent Reinfection and Infecting Others

Hepatitis C is spread to others through body fluids, such as blood or semen. It is NOT spread through saliva or tears. It is also possible to become reinfected with hepatitis C after you are cured. There are steps you can take to prevent spreading hepatitis C and getting it again.

- Do not share razor blades or nail clippers.
- Do not share toothbrushes if your gums are bleeding.
- Use sterile tattoo and piercing equipment.

If you use injection drugs and are not ready to stop:

- Do not reuse needles (if you must reuse needles, mark your name on them so you know they’re your own)
- Do not share needles (if you must share needles, clean them with bleach and water)
- See if your town has a needle exchange program—you may be able to get new, clean needles for low or no cost

Hepatitis C is not spread through kissing or hugging. It is also not spread through normal household contact, like sharing cups, forks, or plates.
Hepatitis C and Sex

The risk of getting hepatitis C from a sexual partner is low. But to be completely safe, you should always use condoms. Condoms also help prevent the spread of other diseases, like HIV. In rare cases, your doctor might suggest that your partner be tested for hepatitis C.

Getting hepatitis C through sex is more likely if you have sex that might cause bleeding. Some examples of this might be:

- Anal sex
- Rough sex

Hepatitis C and Pregnancy

- If you are pregnant and have hepatitis C, there is a small chance that you could spread it to your baby. Your chance of this is higher if you have a co-infection, such as HIV.
- You cannot take hepatitis C medicines while you are pregnant. If you are considering getting pregnant, talk to your healthcare professional about your options.
Healthy You, Healthy Liver

Trying to stay healthy can keep your body working at its best. This can also help prevent any more damage to your liver. To stay healthy, try to:

- Eat healthy. This includes eating lots of fresh fruits, fresh vegetables, and whole grains. This also includes eating lean proteins like chicken, turkey, fish, or tofu.
- If you have diabetes, control your blood sugar.
- Exercise, if you are able. Do something you enjoy. This can be as simple as taking a walk with a friend.
- Stay at a healthy weight. If you have obesity or excess weight, work with your healthcare professional to come up with a plan to get to a healthy weight.
- Sleep well. Most adults need at least 7 hours of sleep every night. Create a bedtime routine, like reading or stretching before bed, and stick to it!
- Stop or limit using alcohol and/or street drugs. There are resources that can help you. Ask your healthcare professional for more information.
- Make sure you are up to date with your vaccinations. Talk with your healthcare professional about which vaccines are right for you.

“I was diagnosed 27 years ago. I always made my doctor's appointments and filled my prescriptions. I've been a vegetarian for 10 years and I eat organic foods. I go to support groups. No substance use. We call it 'right living.' That's how I did it!”

— Mike, 64 years old
1. Do I have too much liver damage to be treated for hepatitis C?
2. How has treatment for hepatitis C changed?
3. Am I eligible for hepatitis C treatment? If not, what can I do?
4. I can't afford to pay for treatment. Are there programs that can help me?
5. Will my insurance plan pay for my medicines?
6. What can I do for my health while I wait for treatment?
7. Will any of the medicines I'm currently taking interact with my hepatitis C medicines?
8. Why do I have to go to a specialty pharmacy?
9. What if I have HIV/hepatitis A/hepatitis B or another chronic condition?
10. Can I still have sex?
11. Should my partner get tested?
12. Can I still get treatment even if I’m a substance user?
For More Information About Hepatitis C, Visit:

The Liver Foundation
http://hepc.liverfoundation.org/

The HCV Advocate
http://hcvadvocate.org/

For Information About Programs That Can Help You Stop Using Alcohol or Drugs, Visit:

Alcoholics Anonymous
https://www.aa.org/

Narcotics Anonymous
https://www.na.org/
Acknowledgments

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