



HEPATITIS C LESSONS • PART 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.

- *Direct-acting antiviral (DAA) pills that you take each day*
- *Ribavirin pills that you take as your healthcare provider prescribes*

Treatment for hepatitis C may include different prescription medicines:

DISCUSSION TOPICS

Why is hepatitis C treatment important to you?

What are some lifestyle changes you can make?

Why commit to treatment?

How long can treatment take?

Why do you think some people decide not to get treated for the virus?

Do you know other people who have hepatitis C?

What might happen if you do nothing?

Handout: If you and your healthcare provider are thinking about treatment, what should you plan for?

FACTS (CONT'D)

DAA's directly target the hepatitis C virus and interfere with the virus as it multiplies.

Ribavirin is a medicine that helps fight the hepatitis C virus together with and

without 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.

NOTES

Here are some sample questions and answers you can use as you like during your 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*
- *Hepatitis C causes many symptoms and diseases such as fatigue, brain fog, muscle joint pain, certain extrahepatic manifestations (conditions and diseases outside of the liver), depression, and more*

How successful is treatment?

It depends on your genotype. The majority of people who are treated can be cured of hepatitis C (up to 100%). Talk to your medical provider about your chances.

When is a good time to get treated for the virus?

There is no way of knowing if the disease will become serious or how fast it will progress. The medicines to treat hepatitis C have very high cure rates and minimal side effects so now is the right time to get treated.

NOTES

Why commit to treatment?

Treatment for hepatitis C takes time, energy, and planning. Think about these important facts:

- *We know more about hepatitis C today than we ever have before*
- *There are more treatment options with very high cure rates, shorter treatment durations and few side effects than in the past*

Why commit to treatment?

- *While treatment gives you a chance to get the virus out of your body, without treatment, the virus will stay in your body causing more damage*
- *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 and the longer you have hepatitis C*

NOTES

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 test to find out how much liver damage the hepatitis C virus has caused. 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 7 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 24 weeks, depending on your previous treatment history and how much your liver is damaged (cirrhosis) and responds to treatment*
- **Genotype 2:** *12 weeks*
- **Genotype 3:** *24 weeks*

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

NOTES

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.

NOTES

Are there many other people with hepatitis C?

Yes, more than 3 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 and bodies.

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.

Remember: There have been many important advances in the treatment of hepatitis C so it is important talk with your medical provider about your choices.

NOTES

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 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 http://hcvadvocate.org/hepatitis/factsheets_pdf/Patient_Assistance.pdf for more information about the programs
- *Does your schedule allow you to have treatment for up to 24 weeks? You may need to make changes:*
 - At work. Most people can work through treatment. But it is always a good idea to plan ahead if you need to take some time off for medical appointments or if you are having days when you don't feel well enough to 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, people taking ribavirin: 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, your medical provider may require that you 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?*

Suggested Reading:

HCV Treatment: FDA-Approved Medications

Genotype 1 Treatment: Harvoni (Sofosbuvir & Ledipasvir)
http://www.hcvadvocate.org/hepatitis/easyfacts/Harvoni_e.pdf

Genotype1: Harvoni Therapy
http://www.hcvadvocate.org/hepatitis/factsheets_pdf/GT1_Harvoni.pdf

Genotype 1 Treatment: VIEKIRA PAK
http://www.hcvadvocate.org/hepatitis/easyfacts/Viekira_e.pdf

Genotype1: VIEKIRA PAK Therapy
http://www.hcvadvocate.org/hepatitis/factsheets_pdf/GT1_Viekira.pdf

Genotype 1: Sovaldi (Sofosbuvir) Triple Therapy
www.hcvadvocate.org/hepatitis/factsheets_pdf/Sovaldi_GT1.pdf

Genotypes 2 & 3: Sovaldi (Sofosbuvir) Plus Ribavirin
www.hcvadvocate.org/hepatitis/factsheets_pdf/Sovaldi_GT2-3.pdf

HCV Treatment: Patient Assistance Programs

Help with Medicines (Patient Assistance)
www.hcvadvocate.org/hepatitis/easyfacts/e_Patient_Assistance.pdf

Patient Assistance Programs
www.hcvadvocate.org/hepatitis/factsheets_pdf/Patient_Assistance.pdf