What You Need to Know about Hepatitis C

What is hepatitis C?

Hepatitis C is a liver disease. "Hepatitis" means inflammation of the liver. Hepatitis C is caused by the hepatitis C virus, or HCV.

Who gets hepatitis C?

Anyone can get hepatitis C, but some people are at higher risk:

- People who were born to a mother with hepatitis C
- People who have had more than one sex partner in the last 6 months or have a history of sexually transmitted disease
- People who had a blood transfusion or organ transplant before July 1992
- People with hemophilia who got blood products before 1987
- People who have used illegal injection drugs.

How could I get hepatitis C?

You can get hepatitis C through contact with an infected person's blood. For example, you could get hepatitis C by:

- Being born to a mother with hepatitis C
- Having sex with an infected person
- Being tattooed or pierced with tools that were not sterilized after being used on an infected person
- Getting an accidental needle stick with a needle that was used on an infected person

- Using an infected person's razor or toothbrush
- Sharing drug needles with an infected person.

You cannot get hepatitis C from:

- Shaking hands with an infected person
- Hugging an infected person
- Sitting next to an infected person.

What are the symptoms of hepatitis C?

Most people have no symptoms unless the virus becomes chronic and causes liver damage. This can take 10 or more years to happen.

What is chronic hepatitis C?

"Chronic" means long or persistent. Hepatitis C is chronic when the body can't get rid of the hepatitis C virus. Although some people clear the virus from their bodies in a few months, most of these infections become chronic. Without treatment, chronic hepatitis C can cause scarring of the liver (cirrhosis), liver cancer and liver failure.

Symptoms of cirrhosis and chronic hepatitis C include:

- Yellowish eyes and skin (jaundice)
- A longer than usual amount of time for bleeding to stop
- Swollen stomach or ankles
- Tiredness or weakness

- Upset stomach (nausea) or loss of appetite
- Weight loss
- Easy bruising
- Fever
- Diarrhea (loose stools)
- Light-colored stools
- Dark yellow urine
- Spider web-like blood vessels, called spider angiomas, that develop on the skin.

How is hepatitis C diagnosed?

Hepatitis C is diagnosed through blood tests. These tests can show if you have chronic hepatitis C or another type. Your doctor may suggest a liver biopsy if he or she suspects chronic hepatitis. A liver biopsy is a test for liver damage. The doctor uses a needle to remove a tiny piece of liver, which is then looked at with a microscope.

How is hepatitis C treated?

Hepatitis C is not treated unless it becomes chronic. Chronic hepatitis C is treated with drugs that slow or stop the virus from damaging the liver.

Chronic hepatitis C is most often treated with two drugs—peginterferon (Pegasys or Peg-Intron) and ribavirin. Peginterferon is taken through weekly shots, and ribavirin is taken daily by mouth. Treatment usually lasts from 24 to 48 weeks.

A liver transplant may be needed if chronic hepatitis C causes liver failure. Liver transplant surgery replaces a failed liver with a healthy one from a donor. Drug treatment for the virus is usually given after the transplant, because hepatitis C usually comes back after surgery.

What happens if I am diagnosed with hepatitis C?

If you are diagnosed with hepatitis C, you will have blood tests. These will help us decide how best to treat you. Blood tests can also help us prevent side effects and let us know if your medicine is working.

Because your therapy can lower certain blood counts, your doctor will check the hemoglobin, white blood cells and platelets in your blood. Your doctor may also check how well your liver and thyroid are working. It is very important to have these tests done, so keep your lab appointments.

What kinds of blood tests will I get?

If you have hepatitis C, you will likely have two kinds of blood tests: **genotype** and **HCV viral load**.

Genotype

This blood test can tell your doctor what type of hepatitis C virus you have. There are at least six types, called genotypes.

In the United States, about seven out of ten people with hepatitis C have genotype 1. Most of those who do not have genotype 1 have genotype 2 or 3.

Knowing your genotype helps your doctor decide how long to treat you. In most cases, people with genotype 1 or 4 will need to take

medicine for 48 weeks (a little less than a year) to kill off the virus. People with genotype 2 and 3 may need medicine for only half that long (24 weeks).

HCV viral load

Knowing how much hepatitis C virus is in your blood helps your doctor treat you. The blood test that measures how much of the virus is in your blood is called an HCV viral load test. Your doctor will tell you if your results are high or low. If no hepatitis C virus is found in your blood, your doctor will say that the virus is "undetectable."

Your doctor will use this test before, during and after your treatment.

• Before treatment

The test helps your doctor predict how successful your treatment will be. The less virus you have, the more likely you are to get rid of it.

• During treatment

The test helps your doctor see how well your treatment is working. If the amount of virus in your blood does not go down over time, your treatment is not working. For many patients, the doctor can tell if the treatment is working after 12 weeks. If your treatment is working, the test helps your doctor decide how long you should take your medicine.

• After treatment

The goal is for the virus to become undetectable and to stay undetectable for six months after treatment.

How do I get the best results from my treatment?

To get the best results from your treatment, you need to take your medicine as prescribed by your doctor. People who take their medicine as prescribed have a greater chance of getting their virus to stay undetectable for 6 months after treatment. (When your virus is undetectable for 6 months after treatment, we say that you have a sustained virologic response.)

Taking hepatitis C medicine is not always easy. The following simple tips may help:

- Before starting therapy, talk with your doctor about possible side effects and ways to manage them. (See page 9 for ways to cope with the side effects.)
- Write down your side effects in a diary or journal. Take this with you to your clinic visits. Be sure to tell your doctor about any side effects that bother you or won't go away.
- Use a pill box to track and remember to take your ribavirin.
- Use a calendar to track your peginterferon (Pegasys or Peg-Intron) injections. Pick a day and time for your shot and stick to it every week.
- Ask your family and friends for help.
- Drink plenty of water or clear liquids without caffeine or alcohol.
- Eat a healthy, balanced diet.
- If you cannot afford your medicine, call Fairview Specialty Pharmacy and ask to speak a patient financial advocate. The

companies that make your medicine may also offer financial help.

- —For help paying for Pegasys, call 1-877-734-2797, or go to www.pegassist.com.
- —For help paying for Peg-Intron, call 1-800-521-7157, or go to www.beincharge.com.

Will my hepatitis C medicine cause side effects?

Everyone reacts differently to hepatitis C medicine. Common side effects include:

- Flu-like symptoms (aches, pains and chills)
- Muscle pain
- Tiredness or weakness
- Nausea (feeling sick in your stomach)
- Weight loss
- Headaches
- Insomnia (trouble falling or staying asleep)
- Trouble concentrating
- Hair loss
- A reaction where you inject your medicine (usually, the first shot is the hardest)

- Cough
- A rash or dry, itchy skin.

Often, there will be fewer side effects, or they will become less severe, after the first few weeks of treatment.

How do I cope with the side effects of my medicine?

To help lessen the side effects, try taking your medicine at bedtime. If you work and are taking shots, you may want to take your shot on a Friday evening, so that you have the weekend to recover.

Here are some more tips for coping with the side effects of your hepatitis C medicine.

Flu-like symptoms

Most people will get flu-like symptoms. These symptoms include aches, pains and chills. To cope with these symptoms:

- Take your shot 2 to 3 hours before you go to bed.
- Ask your doctor if you can take acetaminophen (Tylenol), ibuprofen (Advil or Motrin) or another type of painkiller. Do not take these if you have cirrhosis (liver disease).
- Drink plenty of fluids. Avoid caffeine (coffee, tea, cola) and alcohol.
- Use warm blankets if you have chills.

Muscle pain

To cope with muscle pain:

- Drink plenty of fluids. Avoid caffeine (coffee, tea, cola).
- Soak in warm water or use warm compresses.
- Take a painkiller, such as acetaminophen (Tylenol) or ibuprofen (Advil or Motrin), if your doctor says it's okay.
- Gently rub or massage your muscles.
- Walk or do other mild exercise.

Tiredness or weakness

If you feel tired or weak, tell your doctor at your next clinic visit. You might have another problem besides hepatitis C.

To cope with tiredness or weakness:

- Keep doing your daily activities as best you can.
- Walk or do other mild exercise.
- Take breaks whenever you can.
- Take one or two naps during the day.
- Let others help you when possible.
- Eat at regular times so you have enough energy.
- Do your most important tasks first.

Nausea (feeling sick in your stomach)

To cope with nausea:

- Drink plenty of cool, clear fluids (water, apple juice or flat ginger ale, for example). Avoid caffeine (coffee, tea, cola) and alcohol.
- Avoid acidic, spicy, sweet or fatty foods.
- Eat several small meals a day.
- Eat dry foods such as toast or crackers.
- Avoid unpleasant sights, tastes or smells.

If nothing seems to help, ask your doctor for nausea medicine.

Weight loss

If you are losing weight:

- Eat several small meals a day.
- Eat a larger meal in the morning, if your appetite is better.
- Get plenty of rest and sleep.
- Try eating chicken, fish, beans or peanut butter if red meat tastes bitter.
- Increase your calories by drinking instant breakfast or fruit smoothies mixed with protein powder.

Headaches

To cope with headaches:

- Avoid alcohol.
- Drink plenty of fluids. Avoid caffeine (coffee, tea, cola).
- Take acetaminophen (Tylenol).

If you still have headaches, call your doctor.

Insomnia (trouble falling or staying asleep)

Tell your doctor or pharmacist if you cannot fall asleep or stay asleep. This may make a difference in what they suggest for you.

To sleep better:

- Stay awake during the day.
- Go to bed at the same time each night.
- Do mild exercise during the day. Do not exercise within 4 hours of bedtime.
- Drink a glass of warm milk or take a warm bath before you go to bed.
- Think about using a mild sedative (medicine to help you sleep), if your doctor says it's okay.
- Tell your doctor or pharmacist about all the medicines you are taking. Some medicines can keep you from sleeping well.
- Avoid eating or exercising late in the day.

Trouble concentrating

Problems with concentration (mental focus) do not usually last long. If you have trouble concentrating:

- Ask a family member or friend for help.
- Keep a diary or write notes to yourself.
- Take shorts naps.
- Tell your doctor or pharmacist about all the medicines you are taking. Some medicines can affect your memory.

Hair loss

- Use a mild shampoo (baby shampoo, for example) and conditioner to wash your hair.
- Do not wash your hair too often. Every two or three days may be better than every day.
- If you comb your hair, use a wide-tooth comb.
- Avoid using sticky hair products, hair dryers, curling irons, hot rollers and harsh chemicals (perms, dyes).

A reaction where you inject your medicine

If you have soreness, redness or swelling where you give yourself a shot:

• Make sure you are giving the shot the right way: Give it at a 90-degree angle (straight up from the skin). Inject the medicine, count to 3, then pull out the needle.

- Put ice on your skin to numb it before the shot.
- Make sure your medicine is at room temperature before you give yourself a shot.
- Let the alcohol dry on your skin after you swab it.
- Give the shots in different places. Do not use the same spot two weeks in a row.
- Do not rub or massage the place where you gave the shot.

Cough

If you have a cough, tell your doctor at your next clinic visit. A cough can be caused by an infection or allergy. Ribavirin can also cause coughing. If you have a cough and are taking ribavirin, talk to your doctor. To cope with a cough:

- Use a humidifier.
- Suck on hard candy.
- Quit smoking (if you smoke).

If your cough gets worse, call your doctor.

Rash or dry, itchy skin

Ribavirin can cause itching. If you have itchy skin and are taking ribavirin, you may need to take less of it. To cope with a rash or dry, itchy skin:

 Take warm (not hot) showers or baths. Pat (don't rub) your skin dry.

- Moisturize your skin. Use soap with lotion, sunscreens and products for sensitive skin.
- Use an anti-itching cream, such as pramoxine. Avoid or use very little hydrocortisone cream.
- Take an oatmeal bath.
- See a skin doctor (dermatologist) if you have a rash that won't go away.

Call your doctor if you:

- Feel very depressed or think about hurting yourself or others.
- Have severe pain in your chest, stomach or lower back.
- Have trouble breathing.
- Have changes in your vision.
- Become pregnant.
- Have unusual bleeding or bruising.
- Have a high fever or a fever that won't go away.
- Have bloody diarrhea (loose, watery stools that contain blood).
- Have psoriasis (a skin disorder) that gets worse while taking peginterferon (Pegasys or Peg-Intron).

More information

Fairview Specialty Pharmacy: 1-800-595-7140

HCV Advocate: www.hcvadvocate.org

National Institutes of Health:

http://digestive.niddk.nih.gov/ddiseases/pubs/hepc_ez

Clinical trials: Go to www.clinicaltrials.gov, select "Search for Clinical Trials," then type in HCV.



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