

QUIK **FAQs**
for Hepatitis C
Educators

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Introduction

Over the years our clinic has become a big advocate of HCV support groups for one simple reason: they have allowed us to successfully treat hepatitis C in persons who are supposedly untreatable. We take care of drug users, people with mental illness, homeless persons, and the marginalized. They come to our hepatitis C groups and get treated right alongside everyone else, and our data suggests that a person's background, behaviors, and financial status have nothing to do with whether the treatment will work or not.

Our HCV group leaders offer warm welcomes to newcomers filled with dread and misinformation and they destigmatize HCV and its treatment by sharing their experiences for good and for bad. By example, they are able to convince newcomers that there really is a reason to deal with this hep C thing.

That is why our hepatitis C groups are not an offshoot of our medical clinic, they are its foundation. Our one-stop-shopping hepatitis C model incorporates support, education, testing, and treatment, all within a weekly group session. The groups don't add to our work, they subtract from it. Because of our groups, we can offer concentrated and highly efficient HCV care. Plus, believe it or not, the groups are also great fun.

We try to encourage every setting that offers HCV services to establish a support group. But a good group requires a good leader. It is not just about being super empathetic or highly knowledgeable. It is about learning to get people to interact and empowering them to take control of their own particular situation. That is the real value of a support group and the main challenge for its leaders.

We have created this manual to help others develop their own strategy for support. There is no one single model that works, and so we have outlined our own methodology as one good way of doing things. You can adapt whatever is relevant to your own site.

This manual is organized into two sections. The first section contains information about our own support group model and how we structure our interventions. The second section contains factual information about hepatitis C that mirrors and expands upon our "Get the Facts!" workbook.

Don't worry if you're new at this – you don't have to be an expert to pull it off. It's really just a matter of figuring out what might work best in your setting and giving it a try. If something doesn't go well just try again. People will be grateful for your efforts and over time, you will get better and better and before you know it, you'll be an expert too!

*Diana Sylvestre, MD
OASIS Clinic
November, 2012*

Starting a Support Group

We didn't start our hepatitis C work with a grand vision. It was a simple practicality: we were overwhelmed with hepatitis C patients and needed to do something about it. The majority of our patients were long-term injection drug users and over 90% had been exposed to HCV. Nobody else was willing to deal with it, so HCV treatment was left to us.

We faced many hurdles. The main one was that we didn't know much about hepatitis C! Our clinic's area of expertise was addiction medicine, not hepatology, and we had never prescribed interferon and ribavirin. In addition, we were a small clinic with limited resources. On the other hand, we weren't the kind of place to ignore unmet medical needs, particularly when they could lead to serious debility or death. At some point, you've just gotta jump in.

So we started small, selecting a handful of reliable patients that were willing to work with us as we learned how to manage HCV: so many blood tests and so many side effects! In truth, though, it seemed easier to treat than addiction, a chronic illness with limited treatment options. When it came to hep C, which could actually be cured, it was mostly just some more new stuff to learn.

After success with our first patients, word started getting out that we were offering HCV services and with thousands of patients we knew we would soon be overwhelmed. We weren't so much worried about treatment, because most of our patients didn't need it. We were mostly concerned that we were too small to handle the education and screening of so many people.

Finding ourselves repeating the same information over and over again to each individual patient, we figured that we might save time by gathering a small group. So we asked some of our best early patients if they would help us out by coming to the clinic at the same time so we could educate them together; this would also allow them to pick up tips about side effect management from each other.

At that point, since they were already at the clinic, we figured we might as well just draw whatever blood tests they needed that day. And with things going well, we decided that other patients would benefit from hearing from the real experts, our patients, and so gradually we began inviting them to the group, too. Peers became educators and educated new peers, slowly but surely increasing our reach into our underserved community.

The rest, as they say, is history. From a small group that met every other week, we became one of the largest programs for treating addiction-related HCV in the country. Our data contributed to the 2002 NIH Consensus Statement on HCV, which finally recognized that drug users could be successfully treated for HCV. We are proud of that. But there are still many needy HCV patients still out there, and we hope that you will

consider organizing something at your own facility to join our fight against HCV.

Starting something like this probably sounds hard. You will face similar challenges: money, staffing, time, and energy, to name a few: another activity to take away from your already stretched schedule. However, there are advantages that may not be apparent. The group format is an efficient way to educate and peers help engage people that are fearful of doctors. The time it takes will be more than compensated for by improved compliance and outcomes. Peers help with appointment compliance and facilitate the initiation of mental health and addiction treatment. It really works.

The Advantages of Peer-Based Education

Let's face it: most doctors aren't that great at educating. They have a tendency to make things complicated and dull and either they talk too long or they don't talk enough. Plus, they can scare the pants off people, and it's hard to consolidate information when you have the jitters.

This is where peer educators come in. Over the years we have noticed how much they help with our more challenging patients, such as those with addictions or mental illness. Said simply, many patients with hepatitis C don't naturally trust authority figures. It doesn't matter to them who has the most education: it is experience that counts.

Knowledgeable peer educators make things more understandable. Doctors open their mouths and what comes out sounds like gibberish. Peer educators make things simpler and more concrete and are less threatening to boot.

Peers are more empathetic. They've been there, done that, and know how hard it was and what it took to deal with testing, biopsies, and treatment. When you've hit bottom on treatment, it's nice to hear that others had the same experience and that they pulled through and here's how. Only peers can credibly offer that kind of support, and it is that kind of support that makes all the difference.

We recognize that peer groups are not for everyone. Plenty of people dislike groups. They don't like to share. They are shy. They are embarrassed. They don't have time. Their schedule isn't flexible. There are many reasons why there need to be alternatives. But for many patients with HCV who lack access to services, peer groups are invaluable.

The O.A.S.I.S. HCV Model

Over the years, our peer-group HCV model came to integrate three key components: support, education, and medical treatment. Together, these are structured into a weekly hourly session that is open to all comers on a walk in basis. When people show up, they sign in so we can keep track of who needs to be seen. Groups always

start on time so as not to punish the prompt, and stragglers are only allowed a 15 minute grace period so the disruptions of continual in's and out's are minimized. There is something to eat, usually pizza as it is easy and relatively cheap. The word is, people initially show up for the pizza, but eventually, they stay for the group.

Introductions: The Foundation of Support

Our groups start with introductions, and with 25-50 people showing up, intros take up about half of the allotted hour or sometimes a bit more. A peer leader begins by introducing him or herself, lays out the ground rules (confidentiality, no crosstalk, etc.) and then summarizes his or her hep C experiences. Our educators speak freely about their drug use histories, starting the process of destigmatizing topics that newcomers are afraid to discuss. The speaking baton is then passed from person to person until everyone has a chance to introduce themselves.

We encourage attendees to share experiences both for good and for bad, but we have learned to be strategic in how we allow the introductions to unfold. That is because a lot of negativity at the beginning can deflate the entire rest of the session. Simply said, we want to make sure newcomers get enough positive messages to keep their brains from shutting down in fear.

Therefore, a group of experienced peers sits near the front and introduces themselves early on. Right from the beginning, you hear about successful HCV struggles and cures. That way, when the hard stuff comes out, it is more digestible. This helps with group cohesion, fosters camaraderie, takes anxieties down to a manageable level and sets the stage for the next part of the group, the education session.

Education

Finding out you have hepatitis C is scary and confusing. There is a lot of misinformation out there, and sometimes it even comes from doctors. That is why we center our groups around education, to give our patients the information they need to advocate for themselves. Hepatitis C is also a lot less alarming once you understand what is going on.

Most support groups educate, but fewer are structured to incorporate straight-on learning time. Ours does, but we don't do it in the traditional way.

When most people think of teaching, they envision "I talk and you listen" lectures. We try to avoid this format. Part of the reason is that unless you are a fabulous lecturer, you risk boring the group: a sure recipe for shrinking its size. But in addition, prepared lecture topics eventually become redundant for regular attendees, and groups will dwindle as the regulars stop benefiting from the experience and stop attending. This will be a big loss for the fresh faces who really benefit from experienced long-termers.

Instead, our groups use the Socratic method of educating. With this method, questions are answered with questions; the leader's task is to shape the response and allow the group to come up with the correct answer. Done correctly, this question-based instruction format is challenging and fun. It makes for a lot of interaction and is a really good way to improve knowledge.

Here's an example of how this process might go at our clinic. The topic for discussion won't be predetermined, it will be chosen based on issues that have come up during introductions. Say, someone in the group just got good results from a liver biopsy, and there are a couple of newcomers that obviously know little about HCV. This would be a nice time to talk about who needs treatment, and how liver biopsies can help with that decision.

The leader might ask, "So, just what is a liver biopsy?" In an experienced group, you can expect a number of people to give the answer you are looking for, which is: they numb up a spot over the liver and take out a small piece with a hollow needle. Then the leader can say, "Ouch! That must hurt a lot!!!" This, of course, is a common misconception. But most of those who have had one will protest that worrying was worse than the biopsy. When newcomers hear that from experienced peers, they are much more likely to believe it than if the info came from a lecturer. With that kind of buy in, the leader can move forward with more questioning, such as, "So what do they do with that piece of liver?" "What exactly is fibrosis?" "What is the difference between fibrosis and cirrhosis?" "How much fibrosis do you need to get treated?" The list is infinite, and the discussion can drift with the interests, knowledge level, and relevance to the group on that particular day.

In short, the leader's goal isn't to lecture, but instead to manage a participatory discussion in which participants can answer their own questions and steer the topics for discussion. This might seem intimidating, because an unstructured discussion requires the group leader to think on the fly. It takes practice, and as questions get more sophisticated you'll sometimes get stumped. But that's ok, just admit it and then look it up for the next time: you will gain credibility with this honesty! For many, the interactions foster cohesion and make the group seem like a family. This kind of experience is what keeps participants coming back for more.

Contemporaneous Medical Care

It's not easy to get to medical appointments, particularly if you have a lot of them: travel is expensive, time is short, and if you don't feel well, who wants to get out of bed? That is why we let our group patients get their medical needs addressed while our weekly group is in session.

When people arrive they are asked to sign in, and they can check a box if they

would like to see one of our staff. That might be for a hep C screening test, an interferon shot, or treatment-related testing. Then, during the session, one of our staff pulls them from the group into an exam room to do screening or blood testing or whatever. Straightforward needs like venipuncture are completed by a medical assistant; more complicated needs, such as a treatment-related side effect requiring intervention, will be addressed by a doctor or mid-level provider.

In a small clinic like ours, there often isn't enough time to complete everything in a single one hour session, particularly if we have a lot of people on treatment. For that reason we often schedule a bit of free time before and after the group to accommodate these additional needs.

Additional Tips on Running a Group

Be positive. There will always be participants with negative attitudes who only feel better when others feel worse. Don't let them set the tone for the group. Get one or two of your regulars to chat with Mr. or Ms. Negativity so they can see the positive side of HCV. Make sure you are offering enough so your successful patients keep coming keep back. Peer interactions and pressure will drive a discernible shift toward positive attitudes.

Make it fun. People don't see how you can have fun in a group that addresses a chronic and potentially fatal illness. But the truth is that HCV will still be chronic and potentially fatal whether you decide to have fun or not, so you might as well try to enjoy the ride even if you sometimes get thrown off. How do you do this? Use your imagination. Consider using games, having little ridiculous contests with prizes, that sort of thing.

Use humor. Ditto what is written above: gloom will not change things for the better. A good chuckle is good medicine: it helps people momentarily forget their suffering and maintain their motivation to cope with the hepatitis C testing and treatment process. Try not to be dour.

Respect emotions. Anger, fear, guilt and the like are common and perfectly normal; negative emotions in a group setting are fine as long as they aren't disruptive. If things are getting out of hand, an offer discuss things privately after the group is over might be in order, and supportive peers can also be recruited to come to the rescue.

Set firm ground rules. Occasional conflicts and behavior problems are inevitable, but getting pissed off during the group really doesn't help. So be prepared and set the ground rules for these problems ahead of time. If participants are acting out, don't get angry. Just have an experienced peer escort them from the group for a time out before

things get crazy.

Foster honesty and don't judge. There are problems that people with hepatitis C need to talk about, like depression or the use of drugs and alcohol. Beware of group members who are convinced that abstinence is the only route to success, as this is not supported by data. In particular, misinformed beliefs about substitution therapy and psychiatric medications can lead peer leaders to be unknowingly judgmental. Don't let this happen: help your peers understand that there is no single road to success and that honesty is the first step toward meaningful behavior change. Foster groups that are accepting and based on evidence, not dogma.

Admit your limitations. Guiding a question-based discussion can (and should) lead you to the point at which you reach the limits of your knowledge. Let other members know when you don't know something: it's ok! Then look it up for them and report back. Stay on topic. There are many roads leading away from hepatitis C, and diversions are inevitable and often useful. But remember that the focus of the group is hepatitis C, and don't get endlessly involved in discussions of irrelevant side issues. Your group's newcomers will be grateful.

Reward participation. Interaction and involvement is more important than getting the right answers. When people volunteer a wrong answer, be encouraging: use phrases like "Close!", "Good thought!", "Not quite!", or "Keep guessing!" to make sure they continue to be involved.

Food always helps. This luxury may not be available, but having something to munch on is a really good thing. See what you can work out. It gets a lot of people in the door, and then it keeps them coming back.

Be Prepared for the Challenging Patients

The Narcissist. The Narcissist continually focuses on his or her own issues and asks a lot of personal questions that may not be related to the current topic of discussion. This can be disruptive and irritating to others in the group. If the Narcissist is introducing too many off topic questions you may need to set limits. This might include an offer to discuss a particular issue at a later group or to meet with them privately.

The Distraught Patient. Obviously it is difficult to conduct an group when someone is sobbing. This WILL happen at some point, because patients are often fearful when first diagnosed. Usually, the cohesiveness of the group will settle things down, but if the

emotionality is problematic or disruptive, be prepared to gently escort the distraught patient from the group into a quiet setting. If you can, have a group leader talk them down, privately.

The Doctor Patient. Some patients come to think they know more than they actually do; many have spent too much time on the Internet. As long as they don't misstate the facts or irritate other group members, this is fine. But beware of patients spouting unproven nonsense or incorrect information. Keep topics fact-based; usually a few gentle corrections will keep Dr. Patient in check.

The Negative Patient. Negative patients know everything, and everything is bad. One advantage to a peer group is that it minimizes the Negative Patient's impact. We usually let them vent during introductions; they usually quiet down when they don't get sympathetic feedback. If the negativity becomes disruptive, however, it should be addressed privately and limits should be defined. If that fails to alleviate the problem, then the Negative Patient will need to seek support elsewhere.

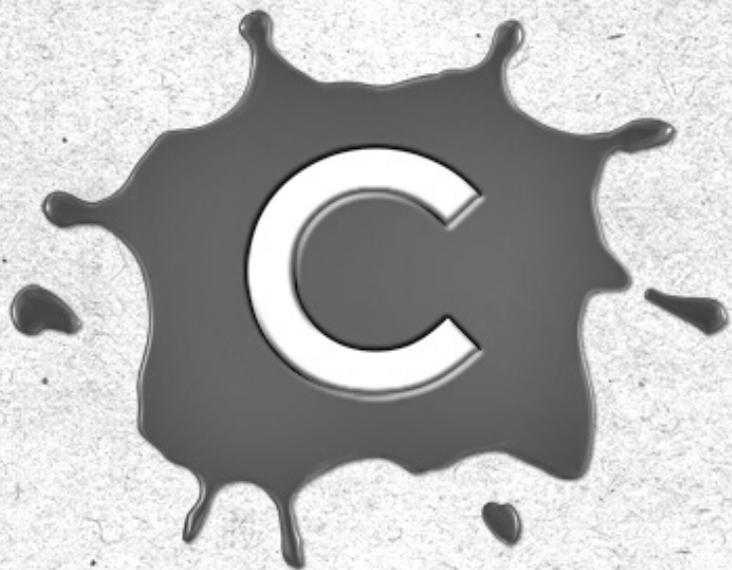
The Just Plain Disruptive Patient. This one is easy. Disruptions can be intentional or unintentional, such as persons who cannot control their chatting; in any case, disruptions must not be tolerated. This is one of our pre-group ground rules. If participants are disruptive, we give one warning. If they continue, we ask them to leave.

The New Guy. New members joining an established HCV group often feel lost, and they may keep interrupting to ask questions. Some of this is ok, but sometimes it gets disruptive. Make sure that new participants understand that everyone is flummoxed at first, and that it takes time to understand so much information. Encourage them to listen carefully, and to keep coming back.

The OASIS HCV Curriculum

We have tailored this manual to mirror our workbook and videos entitled "Hepatitis C: Get the Facts!" You will find that almost all the information is presented in a question-and-answer format, because that is how we teach it. This is not meant to be exhaustive in content or a final authority on hepatitis C: it is a guide to educate you about the many issues that will arise in your leadership role. We suggest that you also consider using our videos which are peer-based and fun to watch. They can be found on our YouTube channel: [hepcvideos](#).

HEPATITIS



GET THE FACTS

What is hepatitis?

"Hepa"
means
liver

and

"itis"
means
inflammation



So "hepatitis" just means **INFLAMMATION**
of the **LIVER**. Like "appendicitis" means
inflammation of the appendix.

Pg. 1. What is hepatitis?

Much like tonsillitis (inflammation of the tonsils) and appendicitis (inflammation of the appendix), the word **HEPATITIS** is just a general term for *inflammation of the liver*: hepa- (liver) and -itis (inflammation).

Common misconceptions:

Many people think hepatitis is a virus. Although hepatitis can be **CAUSED** by a virus, it is actually a generic term for inflammation of the liver.

Related questions:

Q. What is the most common cause of hepatitis in the U.S.?

A. Fatty liver disease, estimated to affect 10-20% of people in the U.S., or something like 50 million people! This compares with about 4 million people who have been exposed to HCV. Too much fat in the liver can lead to inflammation and scarring; it doesn't usually cause cirrhosis but it can. People who are overweight or those who have diabetes are at increased risk, but anyone can actually have it as it runs in families.

Alcohol is the second most common cause. About 18 million Americans are at risk for hepatitis caused by alcohol, which is far more likely to lead to cirrhosis, particularly in people who have hepatitis C.

Q. About how many causes of hepatitis are there?

A. Over 100! The list of things that can cause inflammation of the liver is very long! In addition to the hepatitis viruses, the list includes other infections, medications, alcohol, autoimmune conditions (where the body reacts against itself), hemochromatosis (too much iron in the liver), too much copper (Wilson's Disease), and too much fat in the liver (NAFLD: Non-Alcoholic Fatty Liver Disease or NASH: Non-Alcoholic SteatoHepatitis).

Q. When the word "hepatitis" is followed by a letter, what does it mean?

A. It means that the hepatitis is caused by a virus. The viruses that cause hepatitis are named by putting a letter after the word hepatitis; e.g., hepatitis A, hepatitis B, or hepatitis C.

Q. How many hepatitis viruses are there?

A. There are five so far: hepatitis A, B, C, D, and E. They were named in the order of their discovery. Two others were thought to be hepatitis viruses: hepatitis F and hepatitis G. However, hepatitis F was a laboratory error and doesn't exist, and hepatitis G was originally thought to cause liver damage, but it doesn't and has been renamed GB virus C.

Q. Are the hepatitis viruses related?

A. No. They are actually very different, even though they can cause similar symptoms and prefer to infect the same organ. They differ in how they are transmitted, how they are treated, and their tendency to remain in the body.

Q. Can my own body clear hepatitis viruses?

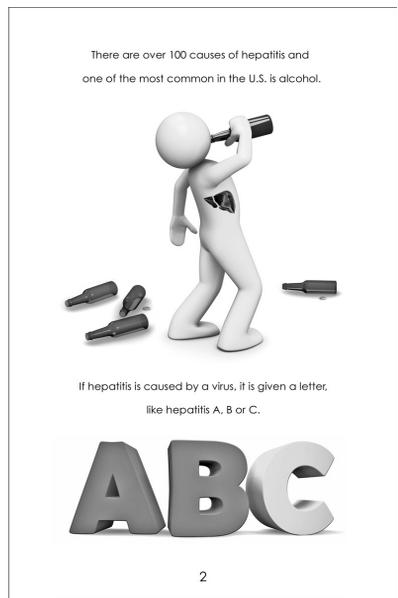
A. Yes, but it depends upon which of the different hepatitis viruses you are talking about. For instance, your body ALWAYS clears hepatitis A—it never stays in your body. You get it, get sick, and then get well. Similarly, over 90% of the people who get hepatitis B as an adult will clear it. However, the situation with hepatitis C is different. Only about one in four people who get hepatitis C clear the infection without treatment.

Q. What do acute hepatitis and chronic hepatitis mean?

A. "Acute hepatitis" means you got infected in the last 6 months; if it doesn't go away after the acute period, you have "chronic hepatitis." It is important to understand the difference, because if you are going to clear one of the hepatitis virus infections, you do it within the first 6 months. After about 6 months, the virus is unlikely to go away without treatment.

Q. Can I have more than one cause of hepatitis at the same time?

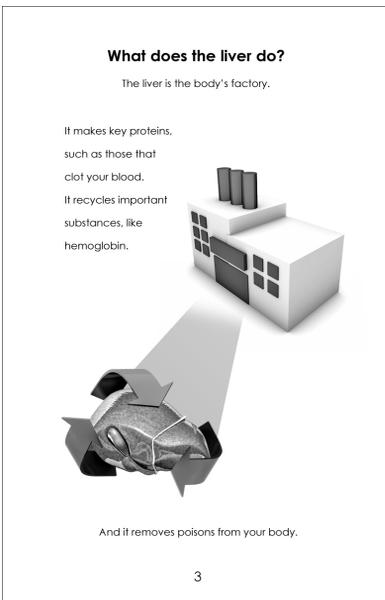
A. Sure! One of the most common causes of hepatitis is alcohol; if you drink alcohol you can have both alcoholic hepatitis and HCV at the same time. People with HCV can also be "coinfected" with hepatitis B, and when two different causes of hepatitis are damaging the liver at the same time, liver scarring can occur at a faster pace. That is why alcohol and HCV are such a bad combination: the two types of damage add together and are much more likely to lead to serious liver problems.



	HEP A	HEP B	HEP C	HEP D	HEP E
Transmission	Fecal-Oral	Sex > Needles	Needles >> Sex	Needles > Sex	Fecal-Oral
Chronic?	Never	Rare (6%)	Common (75%)	With HBV	Almost never
Vaccine?	Yes	Yes	No	Yes (HBV)	No

Pg. 3. What does the liver do?

The liver, the largest internal organ in the body, is a metabolic factory. It processes almost everything that enters the body. It recycles food into nutrients, stores vitamins, minerals, and sugars, and breaks down toxins, like alcohol and drugs. One of the unique features of the liver is that it can regenerate.



Common misconceptions:

Most people believe that the liver is too complicated to understand. Not true! The liver's functions are pretty straightforward. When teaching people about liver functions, keep it simple. Because the liver ordinarily does its job so silently, you can help illustrate what the liver does by using someone whose liver is failing as an example. Many people with HCV know of someone who has had severe cirrhosis and are familiar with the swelling, jaundice, bleeding problems, and mental confusion that go along with it.

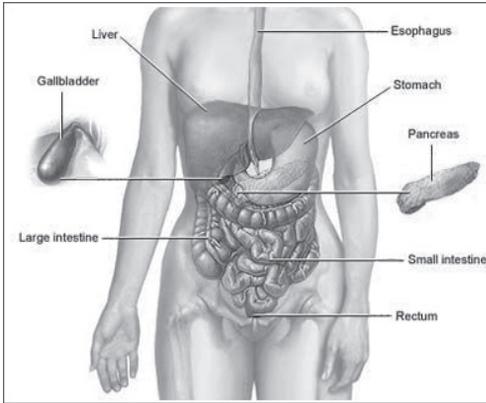
Related questions:

Q. What is the largest organ in the body?

A. The skin. The liver is the largest **internal** organ. It weighs about 3 pounds, and is about the size of a football.

Q. Does the liver feel pain?

A. Not directly. Some people with hepatitis C say they have a sore liver, but it is not actually the liver that is causing it. Like some other organs, the liver has a skin around



it, called a **capsule**, which causes discomfort when stretched. So if a liver becomes swollen for any reason, like from an infection with hepatitis C or heavy alcohol ingestion, it can stretch the capsule and lead to discomfort.

Q. What are some of the things the liver makes?

A. It makes **albumin**, the most common protein in the blood. Albumin is like a molecular sponge, holding onto water

molecules so they stay inside the blood vessels. When a damaged liver can't produce enough albumin, the liquid part of the blood seeps through the blood vessel walls into the tissues, causing swelling throughout the body. This is called **edema** when it occurs in the skin and **ascites** (uh-SITE-eez) if the fluid collects in the abdominal cavity.

The liver also makes **blood clotting proteins**. People with bad livers have bleeding problems partly because the liver doesn't make enough proteins to clot the blood. It also makes **bile**, the yellowish-green substance stored in the gallbladder that breaks down fatty meals. Bile is yellow because it contains **bilirubin**, created when the red blood cell pigment hemoglobin is broken down – the same thing that happens in your skin as a bruise heals. The liver gathers up the bilirubin and either recycles it or directs it to the bile.

Another thing the liver makes is **glycogen**. Glycogen is a chain of sugar molecules that is stored in the liver as a quick supply of energy.

Q. How does the liver deal with drugs and alcohol?

A. It is the liver's responsibility to filter the blood and help remove any toxins it finds there. It has an amazing arsenal of enzymes, proteins that help degrade and recycle just about everything that enters the body. Alcohol and most drugs are filtered out by the liver, broken down, and either recycled or excreted from the body. But the liver can't process everything it finds. For instance, heroin that is injected often contains particles like talc that the liver can't degrade. Things like this can stay in the liver for **many years**.

Q. How does alcohol damage the liver?

A. Surprisingly, we are not entirely sure. Alcohol is absorbed quickly from the gut and passes directly to the liver. Alcohol seems to cause the release of chemical irritants from

the stomach and the liver that can lead to the development of scar tissue. Some people seem to be more susceptible to this damage, but again, we don't know exactly why.

Q. Can the liver regenerate?

A. Yes. It is one of the most wonderful aspects of the liver. In fact, if half the liver is removed from a healthy person, it will be completely regrown in a month or two! That is why some people donate part of their liver for family members that need a liver transplant, although it is still a risky operation. However, if the liver has a lot of scar tissue, the healthy tissue can't regrow through the fibers. A liver with cirrhosis can't regenerate.

Pg. 4. Where is the liver located?

It is under the ribs on the upper right side of the abdomen. Most people's liver edge

Where is the liver located?

The liver is located under your ribs, on the right side of your abdomen. The liver about the size of a football.



The liver's partner is the **spleen**, located on the other side of the stomach, on the upper left of the abdomen.

4

extends slightly below the ribs and can be felt on a physical exam. A good way to help people remember the location of the liver is to ask them to raise their right hand and take a pledge to protect the liver; they can then lower their hand to the upper right abdomen where the liver is located.

Common misconceptions:

People may confused about which side of the abdomen holds the liver. Also, few understand that a small and shrunken liver (cirrhosis) is usually worse than one that is enlarged.

Related questions:

Q. What does the liver feel like?

A. A normal liver is soft and smooth and is usually not tender when it is pushed on. A baby's liver feels kind of like a piece of Jello floating in a bowl of milk. In an adult, the liver span is about 8 inches or so from top to bottom and its edge usually sticks out about an inch below the ribs; the edge feels smooth, flexible, and a little firmer than a baby's. A liver with cirrhosis feels different from a normal liver: it is small, lumpy, and firm. Doctors try to feel the liver during the physical exam to see if it is tender and enlarged, or firm and cirrhotic.

Q. Is a big liver bad?

A. Actually, a liver with **cirrhosis** is **smaller**, not larger, than a normal liver, because the scar tissue causes it to retract and shrink. A liver that is bigger than normal can mean that it is inflamed and swollen and it may also be tender during a physical examination. A lot of things can cause this, including alcohol, hepatitis B, hepatitis C, and others. If the inflammation continues, scar tissue can start developing, and the liver will gradually go from large and inflamed to small and shrunken. So, while a big liver can indicate illness, a small liver can be worse than a big one.

Q. Can I get an X-ray to check my liver?

A. The liver doesn't really show up on an X-ray, but an ultrasound can be used to visualize the liver. This procedure uses sound waves that reflect from the liver's surfaces, and is the same technique that is used to look at babies before they are born. An ultrasound can assess the size and shape of the liver and can also visualize gallstones. Unfortunately, it is not particularly good at detecting scar tissue unless the liver is deformed by cirrhosis. CT scans and MRI's can also be used to look at the liver, particularly if there are concerns about cancer.

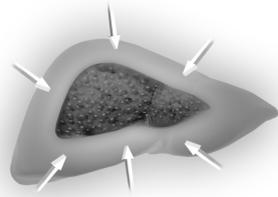
Q. What is a gallbladder?

A. The gallbladder is a little sac attached to the underside of the liver. It stores the bile. If you eat a fatty meal, hormones are released that cause the gallbladder to contract and release the bile that will break down the fats. Unfortunately, the gallbladder has a tendency to develop stones, called gallstones. If these cause problems by blocking the outflow of bile, then the gallbladder is usually removed surgically.

Q. What is a spleen?

A. The spleen is the liver's partner organ, and it helps the liver cleanse the blood. It is located in the upper left side of the abdomen under the ribs, opposite the liver. The liver and spleen share a blood supply, called the portal circulation, which flows slowly and gently through these organs to let them do their important filtration work. The spleen pulls out the old blood cells and the liver recycles their used products back into new ones. If the liver gets cirrhosis, or a lot of scar tissue, the blood can't percolate through

Some people with hep C may get a swollen liver that feels sore, but that doesn't always happen.



The liver gets larger when it is inflamed, but if more seriously damaged, it shrinks and can become small and firm.

the liver as easily anymore, and the pressure builds up in the portal system like a finger blocking water coming through a hose. The high pressure backs up into the spleen and it enlarges, one of the signs of liver damage.

Pg. 6. What is cirrhosis?

What is cirrhosis?

Cirrhosis just the medical word for a lot of scarring in the liver.

Unlike a smooth reddish healthy liver,
a liver with cirrhosis is firm, yellowish and bumpy.



Because much of it has been replaced with scar, it can feel like rubber! Not surprisingly, if you have cirrhosis there is less healthy tissue to do its work, and that is why people with cirrhosis can become ill. If you have SOME scar tissue but not a lot, that is called **FIBROSIS**.

If you catch it early, your liver damage can be reversed.



The liver can regenerate!

6

Cirrhosis is the medical term for a lot of scar tissue in the liver. Scar tissue in the liver starts as thin fibrous strands; these strands can eventually coalesce into large sheets that completely encircle healthier areas of liver. Once this happens, the scar tissue makes the normally smooth reddish liver look yellowish and bumpy and feel hard, like gristle. This is called cirrhosis. The healthy liver tissue can't grow beyond the boundaries of the fibrous sheets, so once cirrhosis develops the liver cannot fully regenerate.

Common misconceptions:

Few people understand what cirrhosis actually is, even though many know someone with it.

Because treatment for HCV should ideally occur prior to the development of cirrhosis, it is useful to teach how liver damage from HCV (and other diseases) develops progressively and can lead to irreversible cirrhosis.

Related questions:

Q. What is fibrosis?

A. Fibrosis is just a medical term for scar tissue. When the liver starts getting damaged by something, be it hep C, hepatitis B, alcohol, or whatever, the scar tissue is called FIBROSIS. Fibrosis starts gradually as isolated strands of scar tissue throughout the liver. When there are small amounts of it, it is called **fibrosis**; when large intersecting sheets form it is called **cirrhosis**.

Q. Will I die if I get cirrhosis?

A. Not usually. You can lead a long, healthy life if you have cirrhosis and take good care of yourself, as long as there is enough healthy liver left to take care of the body's functions. But if too much of the normal liver is replaced by scar tissue, then there might

not be enough liver to perform vital functions. Cirrhosis also increases the risk for liver cancer.

Q. Why do people with cirrhosis turn yellow?

A. Red blood cells get old after about 120 days and need to be recycled. The red pigment in them, called hemoglobin, is chopped up into a yellowish pigment called bilirubin; this process also occurs in a bruise, and that is why an old bruise looks yellow. One function of the liver is to gather bilirubin and reuse it, either recycling it back into more hemoglobin or excreting it into bile. A liver with cirrhosis may not have enough healthy tissue to process the yellow bilirubin back into new molecules, and so it builds up in the blood and leaks out into the tissues. When this happens, people take on a yellowish hue, called **jaundice**.

Q. Why do people with cirrhosis have bleeding problems?

A. Two reasons. The first is that the liver makes the proteins that clot the blood; a liver with cirrhosis may not be able to make enough clotting proteins. This increases the risk of bleeding. The second reason is that the platelet count can go down. Cirrhosis can cause the liver's partner organ the spleen to enlarge; all that scar tissue increases the pressure in the spleen like a finger on a hose. The tiny blood cells called platelets get hung up in the enlarged spleen and don't get out into the circulation. Since platelets function by sticking to injured tissue to help form a clot, the risk for bleeding goes up with a low platelet count.

Q. What are varices?

A. Varices are enlarged blood vessels in the esophagus, or swallowing tube. The liver, spleen, and gut form an important separate circulation called the portal circulation, which is responsible for absorbing nutrients and filtering the blood. The scar tissue from cirrhosis prevents the blood from passing through the liver easily, and the pressure in the portal circulation builds up, kind of like putting a finger on a hose. The high pressure causes everything connected to it to swell, including the spleen and the blood vessels of the portal circulation, some of which are part of the esophagus. These get big and knobby and have very thin walls, kind of like hemorrhoids. This makes them prone to rupture, and since they are under high pressure and are located in an area that you can't put direct pressure on, the bleeding can be profuse. This is one of the ways that people with cirrhosis may die.

Q. Why do people with cirrhosis get confused and forgetful?

A. Usually because there is a buildup of ammonia. Proteins in the diet are broken down

into their building blocks and recycled; ammonia is one of the byproducts of this protein breakdown. The liver then gathers this ammonia and recycles it into new proteins. When the liver has cirrhosis there isn't enough healthy tissue to do it and so ammonia builds up in the blood. Ammonia is toxic to nerves, and when levels build up, the nerves in the body don't work right: people get confused, forgetful, and shaky.

Q. Why do people with cirrhosis get big stomachs?

A. Mostly, because there isn't enough healthy liver to make the protein **albumin**, which acts like a molecular sponge to keep the liquid inside the blood vessels. When there isn't enough albumin, the liquid leaks out of the blood vessels into the tissues. If a person has cirrhosis, the pressure in the blood vessels in the abdomen is also relatively high because the blood can't pass through the liver very easily, and that increases the leakage into the abdominal cavity. This fluid collection is called ascites.

Q. Are there other risks with cirrhosis?

A. Yes. Liver cirrhosis also increases the risk of liver cancer. Liver cancer hardly ever occurs in people with HCV unless they get cirrhosis, and that is another good reason to deal with HCV before the damage gets too severe. Another complication is an increased risk of infections, because people with cirrhosis may not make enough opsonins (AWP-sun-ins), proteins that bind infectious particles and allow them to be removed from the body.

Q. Can the liver regenerate?

A: Yes! The liver has a remarkable ability to regenerate. In a healthy liver or one with only a little damage, a liver can completely regenerate in a month or two, even if cut in half. However, when you have cirrhosis, there is enough scar tissue to completely encircle the healthy islands of liver, and the liver cells can't get through the fibrous scar tissue and can't regenerate.

Q. Can I just have the cirrhosis cut away to let my liver regrow?

A: Unfortunately, no. Liver scarring occurs pretty evenly throughout the entire liver, and so you can't cut out a piece of it to make it go away.

A Mini-History of HCV

1970's Non-A, non-B virus (NANB) receives a name

1988: The hepatitis C virus is identified and named

1990 The first antibody test is developed

1992 The blood supply is tested

Pg. 7. How do you get hepatitis C?

Think BLOOD. The majority of the 4 million cases of HCV in the US, about 60%, are related to injecting drugs, and about 10% got it from a blood transfusion before 1992. Sexual transmission is relatively uncommon; fewer than 1 in 20 steady sexual partners of persons with HCV become infected. Hepatitis C is not transmitted by casual contact, such as hugging, kissing, or eating utensils.

Common misconceptions:

Although most people know that hep C is transmitted by blood, they may be confused (and worried) about sexual transmission and the risk of getting HCV with noninjecting drug use and by casual contact. Be sure you understand how HCV is and isn't transmitted.

Related questions:

About 60 out of 100 with hep C got it from **NEEDLES**.



About 15 out of 100 people got it from **SEX**.



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How do you get hepatitis C?

THINK
BLOOD!



7

Q. Who should be tested?

A. Testing should be based on age and risk factors. If you were born between 1945 and 1965 you should be tested, and the same is true if you were EVER exposed to someone else's blood or secretions and they might have had hepatitis C. Regular blood tests don't check for hepatitis C, so you need to ask for the test.

Q. Can I get hepatitis C from a blood transfusion?

A. Nowadays it is extremely rare, because all donated blood is tested for HCV. Transfusions before 1992 had about a 10% risk per unit of blood of transmitting HCV. There have been only a handful of cases of transfusion-related HCV since testing began in July, 1992.

10 out of 100
got it from a
**BLOOD
TRANSFUSION.**



5%

5 out of 100
have a different
risk factor, like a
NEEDLESTICK INJURY.

In 10 out of 100
cases of hep C,
the risk factor is
UNKNOWN.

10% ?

Q. I never used needles, but I snorted drugs. Should I be tested?

A. Transmission by noninjecting drug use is uncommon but possible, related to contact with someone else's blood. Nasal membranes are fragile and prone to bleeding, and when the straws used for snorting drugs are inserted into the nose they cause a tiny amount of bleeding. If the same straw is shared, blood to blood transmission can occur even though the amount of contaminating blood is miniscule. Similarly, the use of crack cocaine may lead to dry, bleeding lips, and the blood on the crack pipes may be a potential risk if they are shared.

Q. I only used needles once or twice, many years ago.

A. Hepatitis C has been around for a lot longer than we have been testing for it. Even sharing injection equipment once, many decades ago, puts you at risk for hepatitis C. You should definitely be tested.

Q. Can I get HCV from tattoos or body piercing?

A. It's possible. If the tattoo needles, piercing needles or ink are shared and not sterile, such as usually happens in prison, then one person may transmit HCV to another person. Reputable tattoo and piercing parlors are usually careful about sterilizing their equipment, but to be safe you should always ask.

Q. Do men who have sex with men have a higher risk of getting hepatitis C?

A. It appears so, perhaps related to sexual practices that increase the risk of blood to blood exposure.

Q. Who is more likely to get HCV from an infected sex partner: men or women?

A. Similar to what is seen with HIV, women are slightly more at risk for getting HCV from sex than are men, perhaps because there are small numbers of virus particles in the semen.

Q. Which is easier to get with a needlestick injury: hepatitis C, hepatitis B, or HIV?

A. The risk from needlestick injury is highest with HBV (30%), intermediate with HCV

(2%), and lowest with HIV (0.3%).

Q. Why is hepatitis C so contagious?

A. Probably a few reasons, but it's not entirely clear. HCV is a very small virus and it is stable outside the body for up to 4 days or maybe even longer. In addition, the number of virus particles in the blood is usually very high.

Q. How long does hepatitis C live outside the body?

A. Probably somewhere between 18 hours and 4 days.

Q. Which virus lives longer outside the body, hepatitis C or HIV?

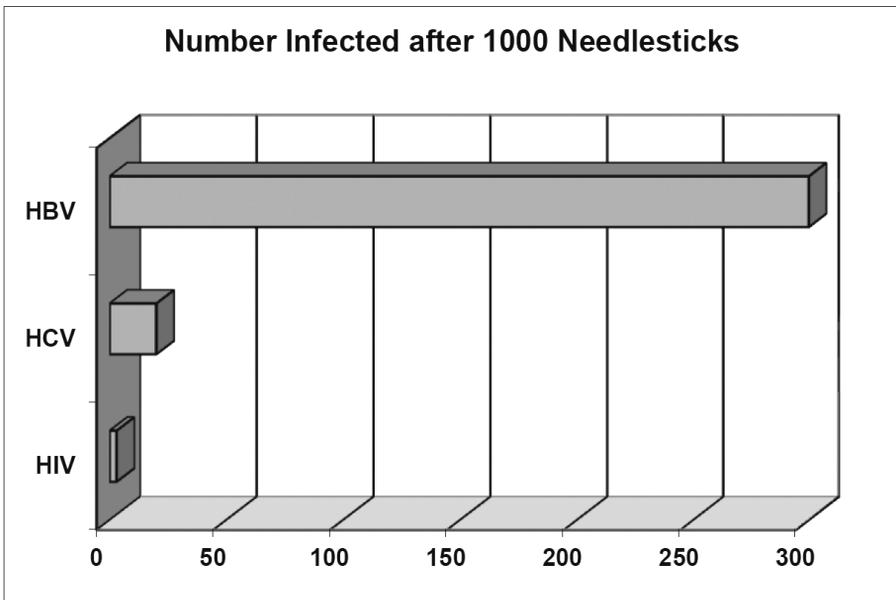
A. HCV. It lives outside the body for up to 4 days. HIV dies in a day or less.

Q. Which is more infectious: hepatitis C or HIV?

A. It depends. Hepatitis C is 10 times more infectious than HIV by direct blood-to-blood contact. This explains the higher rates of HCV infection among injection drug users. However, HIV is more transmissible than HCV between sexual partners and from mother to infant.

Q. Why is HCV so common in drug users?

A. Overall, about 70% of injecting drug users have been exposed to HCV. Hepatitis C



lives for up to 4 days outside the body, and there are large numbers of virus particles in the blood. So HCV is transmitted very easily by injection drug use: sharing ANY of the paraphernalia, including needles, syringes, cottons, cookers, and rinsewater, can lead to spread. So after a short period of time, the majority of injecting drug users become exposed.

Q. What are the chances of becoming infected in the first year of using needles?

A. Somewhere around 50% overall in the US. It depends upon a lot of things, like how common hepatitis C is in the community. However, about half of new injection drug users are exposed to hepatitis C after using needles for a year.

Q. What are the chances of getting exposed to HCV after injecting drugs for 5 years?

A. Again, it depends. But overall, up to 90% of needle users are exposed to hepatitis C after injecting for 5 years.

Q. I never shared needles or syringes. Am I ok?

A. Not necessarily. HCV is spread by ANY of the injection equipment, not just needles and syringes. Sharing cottons, cookers, rinsewater, and even tourniquets can also lead to infection. That is why everyone who used drugs by injection, even if only once, should be tested.

Q. I still inject drugs. What is the best way to clean an outfit?

A. No way is 100% effective. The problem isn't just that small amounts of blood can transmit HCV, but more importantly that killing the virus takes time. Therefore, the very best strategy is to use a new outfit for every injection, and not to share ANYTHING: needles, syringes, cottons, cookers, rinsewater, or even tourniquets. However, that being said, here is the best way to bleach syringes. There are 3 steps:

- **Step 1: Water.** Rinse the syringe with water. Fill it with clean water by pulling back on the plunger, then shake it and squirt the water out. Repeat this two more times with new water.
- **Step 2. Bleach.** Fill the syringe with full strength bleach and shake it. Leave it for at least 30 seconds—use a watch and don't cheat. Squirt the bleach out, and repeat with new bleach 2 more times, 30 seconds each time.
- **Step 3. Water.** Rinse the syringe 3 more times with clean water. Use separate water from the water you will use to prepare drugs.

Once you get used to bleaching this way, it only takes a couple of minutes. Practice beforehand when you aren't sick so that you can get good at it.

Pg. 10. Is there a treatment for hepatitis C?

Yes. Today's treatment consists of interferon injections and ribavirin pills taken for 6-12 months, and some people will also take another pill called a protease inhibitor for part of the treatment. Outcomes have improved dramatically: from 10% response rates in the early 1990's to about 70% response rates today, and we believe that most of these are cures.

Common misconceptions:

Although awareness is increasing, many people know little about HCV treatment, what it is, what it entails, and how effective it is. The word "cure" is now acceptable, because the viral response is durable in the vast majority of people who develop a sustained virologic response to treatment.

Related questions:

Q. What is a sustained response?

A. What you want! It's actually a definition. If there is no detectable HCV virus in the blood 6 months after the treatment is over, you have had a "**sustained response.**" A sustained response is important, because if the virus hasn't come back 6 months after the treatment is over, is usually doesn't come back. That is why the word "cure" is usually used.

Q. What is interferon?

A. Interferon is a protein that interferes with a virus's ability to infect cells. It was first approved for HCV treatment in 1991. It belongs to a family of molecules that are produced by the body's white blood cells. When a virus invades the body, interferons put the body's defense mechanisms on high alert so that the infection will be cleared. This is why interferon is taken as a part of HCV treatment: it improves the body's ability to clear the hepatitis C virus. Unfortunately, interferons are also responsible for some of the

Is there a treatment for hep C?

Yes!

Hepatitis C treatment consists of weekly injections of **INTERFERON**. Interferon helps your body kill the hepatitis C virus.

And daily pills called **RIBAVIRIN**. Ribavirin helps interferon do its job.

They are usually taken for 6-12 months

And for some people with hep C there are new medicines called **PROTEASE INHIBITORS**. They are taken with **INTERFERON** and **RIBAVIRIN** and can make the treatment even more effective.

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fever, chills, and muscle aches that are associated with viral infections. Because of that, many people who start HCV treatment can feel like they have the flu.

Q. How is interferon administered?

A. By injection under the skin, it can't be taken by mouth.

Q. Is there more than one kind of interferon for HCV?

A. Yes. There are short-acting interferons that are injected three times a week or even daily, and long-acting "pegylated" interferons that can be taken once weekly. There are also other interferons like beta, gamma, and lambda interferon, which are taken for other conditions or are currently in hep C treatment studies.

Q. What is pegylated interferon?

A. The name that is used for the long-acting interferons. PEG- stands for polyethylene glycol. It is a large, sugar-like molecule that wraps around the smaller interferon molecule, protecting it from being degraded and slowing down its absorption. That is why pegylated interferon only needs to be taken once a week.

Q. What is ribavirin?

A. Ribavirin is an antiviral medicine called a nucleoside analogue, similar to some HIV medications. It is taken by mouth as a pill. Although it doesn't have any effect against HIV, it doubles the response rates of interferon against hepatitis C.

Q. I don't like shots. Can I just take the ribavirin?

A. No. Ribavirin doesn't work by itself.

Q. Can I just take interferon?

A. Yes, interferon will work alone. But it is about twice as effective when taken in combination with ribavirin.

Q. How long do I need to be treated for?

A. Most people are treated for 6-12 months. It depends on your genotype and how quickly you respond to the treatment. People with genotype 2 or 3 and those whose viruses disappear rapidly only need to be treated for 6 months. The rest are usually treated for a full year to maximize treatment outcomes.

Q. How will I know if I am responding to treatment?

A. Your doctor will do blood tests for virus periodically throughout treatment to see if the

virus is gone. The early viral load tests are particularly important to predict how well the treatment is going. If the virus is not responding as hoped, your treatment may be stopped early because you have virtually no chance of cure with the treatment you are currently taking.

Q. Can I stop treatment early if I am responding?

A. No! Even though the virus isn't detected in the blood, it could still be hiding in the liver. You will need to complete the full course of treatment even if the blood tests show that you are responding nicely.

Q. Is it really a cure, or is the virus just in remission?

A. If you have a sustained response then it is probably a cure, and here's why. The way viruses can hide undetected for long periods in your body is by inserting themselves into your own DNA. HIV and herpes viruses are examples of this: they can be gone for long periods and then show up again. But hepatitis C doesn't have the ability to get into your own DNA, and so it can't hide very well. So the longer it's been missing, the less likely it is to come back. Most sustained responders, the people who don't show hepatitis C virus in their blood 6 months after treatment is over, still won't have virus in their blood 10 years later. So it's probably completely gone, or cured.

Q. How effective is the treatment for hepatitis C?

A. Over all, about 70% of people who undergo treatment will have a sustained response and are probably cured. The genotype is one important predictor of response. For instance, persons with genotype 2 have cure rates approaching 90% with just peg-interferon and ribavirin for 6 months. Genotype 3 is a little less responsive, but overall quite similar. Genotype 1 is more tenacious but outcomes are improving rapidly. Using peg-interferon, ribavirin, and one of the new protease inhibitors, about 70% will be cured after 6-12 months of treatment.

Q. Does everyone respond the same?

A. No. In addition to genotype, there are other things that can reduce your chances of responding. People with cirrhosis don't respond as well, nor do people who are overweight or people over the age of 40. Females are more likely to respond than males, but this may be because they tend to be smaller. And African-Americans have somewhat lower response rates than Caucasians, but the reasons for this are not known yet. One other thing that can affect the response is the presence of HIV virus. People with HIV and HCV have about half the response as people with HCV alone.

Q. Are there any other benefits of treatment?

A. Perhaps. In some people, interferon seems to help reduce the amount of scar tissue, even though it may not get rid of virus. Interferon may also help protect against the development of liver cancer, but studies of these issues are ongoing and somewhat controversial.

A Mini-History of HCV Treatment

1991 Alfa interferon treatment is approved for HCV

1998 Interferon/ribavirin combination treatment is approved

2000 Pegylated interferon is approved

2001 Pegylated interferon/ribavirin combination is approved

2011 HCV protease inhibitors approved

Q. What are the risks of HCV treatment?

A. HCV treatment is difficult and should not be taken lightly. It is like being on chemotherapy for 6-12 months, and can cause lots of problems. It lowers the blood counts and can cause depression that may be severe. It can cause many different side effects, like fatigue and flu-like symptoms. And there are plenty of others. Although most of the problems are manageable, you will need to be followed closely by your doctor while you are on treatment.

Q. Can persons who are coinfectd with HIV and HCV be treated for hepatitis C?

A. Sure. It is important to evaluate all HIV/HCV coinfectd patients for HCV treatment. Survival has increased so dramatically with newer HIV medications that HCV-mediated liver disease is emerging as one of the biggest problems in people with HIV. A general approach is to treat HIV first in order to stabilize the immune system, and treat the HCV afterwards. HCV treatment can be more challenging in coinfectd patients because of additional problems introduced by the extra set of medications, but most people can complete the treatment successfully. Unfortunately, response rates are still somewhat lower, but the new medications are showing great promise in improving outcomes.

Q. How much does HCV treatment cost?

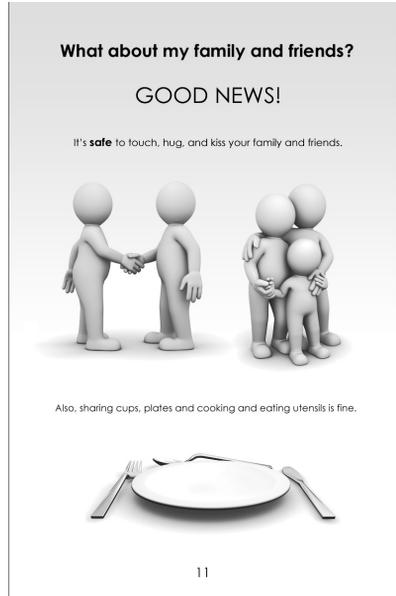
A. A lot: over \$50,000 for a typical treatment course! That is one reason why a decision to take the treatment is not made lightly.

Pg. 11. What about my family and friends?

Fortunately, you can stop worrying about your friends and family members! Casual contact, such as hugging, kissing, coughing, sneezing, or sharing eating, cooking utensils, or drinking glasses, does NOT spread hepatitis C. Sexual transmission occurs in only about 1 in 50 steady monogamous relationships, and mothers pass it to their unborn children around 5% of the time. Simple measures that limit exposure to contaminated blood are sufficient to prevent the spread of HCV.

Common misconceptions:

For the most part HCV is not particularly contagious, but many worry that they have infected their sexual partners and children. Blood to blood transmission, such as sharing injection equipment, is the only efficient way that HCV is spread.



Related Questions:

Q. How should I protect my family?

A. Simple. Remember that only your blood transmits HCV. If you cut yourself, cover it up, and if you bleed, clean up the blood immediately with a 1:10 solution of bleach and water. Don't share razors, toothbrushes, or nail clippers; even though it is highly unlikely that they will transmit HCV they could contain small amounts of blood.

Q. Can I spread HCV if I don't have any symptoms?

A. Yes. Symptoms have nothing to do with how much virus is in your blood, which is the main predictor of whether you can spread HCV to someone else.

Q. Should my sexual partner be tested?

A. Yes. Although sexual transmission is relatively uncommon, it can occur. Because HCV usually doesn't cause symptoms, the only way verify exposure is to be tested.

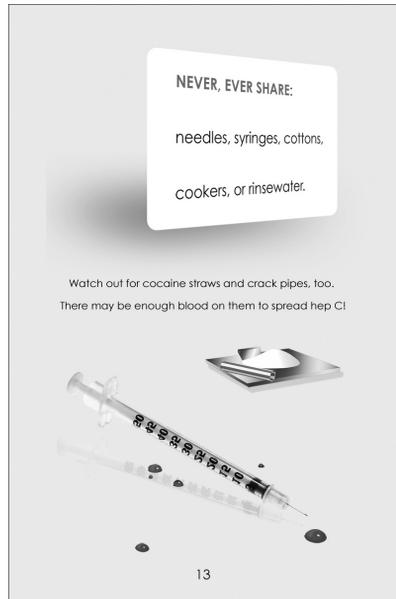
Q. When should I use condoms?

The risk of sexual transmission increases with multiple sexual partners and sexually transmitted diseases. Using latex condoms in these circumstances is advisable, and condoms should also be used early in the course of any relationship. Remember that there are other reasons to use condoms, such as HIV and hepatitis B. However, people in mutually monogamous relationships that have lasted a year or more don't need to use condoms.

Q. Should I have my kids tested?

A. Fathers don't pass HCV to their children through their sperm, but transmission from mother to baby occurs in around 5% of births.

However, these rates are as high as 20% if the mother also has HIV. It is recommended that children of mothers with HCV be tested after they are at least one year old, after the mother's antibodies have faded from the baby's bloodstream.



Hepatitis C Prevention Tips

- Don't share anything: needles, syringes, cottons, cookers, rinsewater, or ties.
- Cover cuts and sores.
- Use latex condoms and tell your partners you are HCV positive.
- Don't share razors, toothbrushes, or other personal items that could have blood on them.
- Don't share drug straws.

Q. What about breast feeding?

A. Breast feeding is fine if you have HCV. If you have HIV/HCV coinfection, you should not breastfeed as the HIV virus can be spread by breast milk and may also increase the risk of transmitting HCV.

Q. I work in a restaurant. Is that OK?

A. Yes. HCV is not transmitted through food.

Q. I can't be an organ donor, can I?

A. Maybe! Under some circumstances, your healthy organs may be valuable to someone else who already has HCV. For instance, if you have a healthy liver, it could be offered to one of the 10,000 people who die of HCV-related liver disease each year. It is better to sign up: you might save a life!

Q. If I get rid of the hepatitis C virus, can I donate blood?

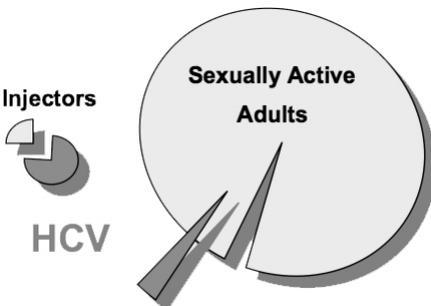
A. No. Once you have been exposed to HCV, you can no longer be a donor, even if you don't have the virus in your body.

Pg. 14. What about sex?

Sexual transmission is relatively rare with HCV, and only about 2% of people in mutually monogamous relationships pass it to their partner. Sexually transmitted diseases and multiple partners increase the risk, though. If you have HCV and have been in a stable relationship for a year or more there is no need to use condoms. Others should use discretion, not only for HCV but to prevent the transmission of other infections.

Common misconceptions:

There is a lot of misinformation about HCV sexual transmission, mostly fed by the fact that about 15% of people with HCV got it from sex. The bottom line is this: HCV is usually NOT passed on by sex, and people in a long term relationship do not need to use condoms to prevent its spread.



What about sex?

Use **CONDOMS** if you have more than one sex partner or aren't in a stable relationship.



If you are in a long-term monogamous relationship, your chances of passing it on are very low!



If you're not sure, talk to your partner. BE SAFE!

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Q. If HCV is hardly ever passed on sexually, then why does it cause 15% of cases?

A. Because sexual activity is much

more common than injecting drugs! Although there are about a million drug injectors in the US, there are over 200 million adults. Even if only a small percentage of them get HCV from sexual transmission, the numbers add up quickly. In other words, sexual transmission may be a small slice, but it's a very big pie.

Pg. 15. Is hepatitis C common?

Yes. Hepatitis C is the most common bloodborne infection in the US. Over 4 million people in the US and about 170 million people worldwide have been exposed.

Is hepatitis C common?
YES!

In the United States, over 4 million people have been exposed. There are 170 million cases worldwide.

There are **5 times** as many cases of hepatitis C as HIV in the US.

Nearly 2 out of every 100 people in the US have been exposed.

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Common misconceptions:

Few people are aware of the high prevalence of HCV, and that it is much more common than other conditions that get a lot of attention, like HIV.

Related questions:

Q. What percent of the US population has been exposed to HCV?

A. About 2%, or one out of every 50 people. About 4 million people in the US have been exposed, and about 2.7 million are chronically infected.

The rest cleared the virus on the own. And these

numbers are considered to be underestimates, because incarcerated and homeless persons were not included in the count. The real number of people exposed may be closer to 5 million.

Q. Does the US have more HCV than other countries?

A. No. Although the US doesn't have the lowest rate, the rates of HCV in the US are much lower than some other countries. In Egypt, for example, a program to eradicate a disease called schistosomiasis using multiple injections of tartaric acid has left about **15%** of the population with exposure to HCV.

Q. What about hepatitis C in prisons?

A. HCV is very common in prisons. There are 1.8 million persons incarcerated in the US, and the rates of HCV range from 14% in New York to 42% in California. The reasons for this relate to policies that treat drug use with incarceration, and also to unsafe

tattooing, needle sharing, and sexual practices.

Q. Are there any racial differences?

A. Yes. African-Americans have about twice the prevalence of hepatitis C that Caucasians have, and Latinos are somewhere in between. No one exactly knows why. In fact, almost 10% of African-American men between the ages of 45 and 55 have been exposed to HCV.

Q. What age group has the highest rates of HCV?

A. Persons aged 40-59. Because of this, the CDC recently recommended that all baby boomers born between the years 1945 and 1965 get tested at least once, regardless of risk factors.

Q. How many people die from hepatitis C?

Currently, about 8,000-10,000 people die from HCV each year in the US. The number of deaths from HCV is expected to rise to 30,000 per year by 2015.

Q. How many people with hepatitis C also have HIV?

A. There are about 240,000 people coinfecting with HCV and HIV in the US. As many as 25-30% of HIV positive people in the US are coinfecting with HCV and up to 10% of HCV positive persons are HIV infected. In urban areas of the US, up to 90% of persons who acquired HIV from IDU also have HCV.

Pg. 16. How much time have I got?

Probably a lot longer than you think! For the majority of people, HCV is a mild illness, leading to cirrhosis in fewer than one in five people after more than two decades of exposure. Most people will die WITH hepatitis C, not of it.

Common misconceptions:

Many people still think of HCV as a uniformly fatal illness, and are surprised that it is benign most of the time.

**Give it to me straight:
How much time have I got?**



Relax! For most people, hep C is a pretty mild disease.



Even after 20 years, only 1 out of 5 people
will have cirrhosis!

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Related questions:

Q. How long does it take to get liver damage from hepatitis C?

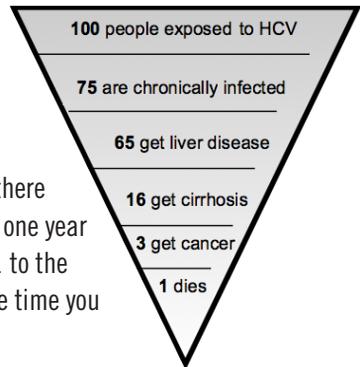
A. Usually, quite a few years. Hepatitis C generally advances slowly and gradually. After 20 years of infection, fewer than 20% will have cirrhosis.

Q. What are my chances of having cirrhosis?

A. Part of the answer depends upon how long you've had the virus. In general, after having HCV for 20 years, the chances of having cirrhosis are less than 1 in 5. The majority of people with HCV have healthy livers. But there are some things that can increase your chances of cirrhosis, like a history of heavy alcohol use. Also, having HIV or hepatitis B at the same time as HCV can accelerate the development of scar tissue in the liver, and even cigarettes and marijuana may be a problem. There may also be genetic differences in the tendency to develop scarring, but there is no real way to predict cirrhosis accurately without testing.

Q. How long have I been infected?

A. For most people, there is no way to tell for sure. However, if you got hepatitis C from injecting drugs, there is about a 50% chance that you were infected within one year of starting needle use. So a good estimate is to add 1 to the age you first used a needle: that is probably about the time you were infected.



Q. Do most people with hepatitis C die from it?

A. No. Death from HCV is rare! Of 100 people who are exposed to the hepatitis C virus, about a quarter will clear the virus spontaneously. Of the remaining 75 who are chronically infected, about 65 will get chronic liver disease from hepatitis C, but only 16 will ultimately end up with cirrhosis after being infected for 20-30 years. Of those, approximately 3 will develop liver cancer and 1 will die from the consequences of long-term infection: either cirrhosis or liver cancer.

Pg 17. What can make hep C worse?

A. The number one thing is alcohol: alcohol and hep C are like gasoline and fire. Having HIV and hep B at the same time can make the liver disease get worse more quickly, and even cigarettes and marijuana have been shown to contribute to liver damage when you have hep C.

Common misconceptions:

The fact that alcohol can contribute to liver damage isn't usually a surprise, but the fact that cigarettes and marijuana can cause problems is less widely known. Use this information to motivate people to cut down or quit!

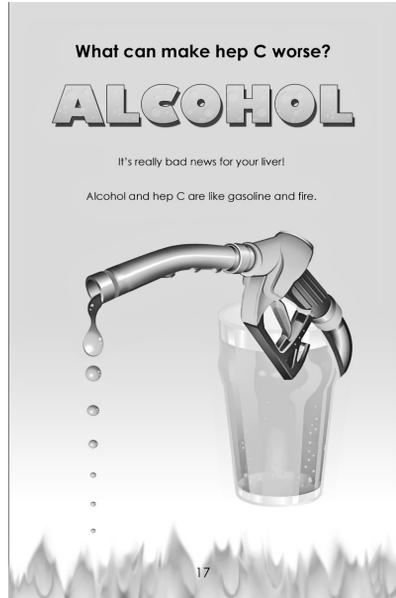
Related questions

Q. Are people with HCV more sensitive to alcohol?

A. Alcohol is a big problem when you have hepatitis C. As few as 1-2 drinks a day may damage the liver. It is important to try to avoid alcohol to keep your liver healthy.

Q. Is there anything I can do to protect myself?

A. Yes. Don't drink alcohol, because it magnifies HCV's damaging effects on the liver. Get vaccinated for hepatitis A and B if you haven't been exposed. And there is some evidence that cigarette and marijuana smoking may make HCV worse, yet another reason to quit. But there is no need to eat a special diet or take any vitamins.



Other things that can make hep C worse:



HIV

HEPATITIS B



CIGARETTES

MARIJUANA



So take good care of yourself, and get regular medical attention.

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Q. Should I eat a special diet?

A. No, not usually. A healthy balanced diet is all you really need.

Q. How about vitamins?

A. A better way to get your nutrition is through a healthy diet. If you want, you can take a daily multivitamin, but be careful of taking too much iron. It can build up in some people's liver and cause scarring. Check with your doctor to be sure.

Q. What about herbs?

A. Although no complementary or alternative therapies have been scientifically proven to cure HCV, many people try holistic remedies such as milk thistle, dandelion, and licorice root to treat

or control their symptoms. Milk thistle (silymarin) has not been shown to be harmful and some people report that it helps reduce fatigue and other symptoms, but it does NOT clear the virus. So be careful. All substances, including herbs, can have dangerous side effects and impact the dosing of other drugs. And some herbs, such as kava kava, can lead to liver failure.

Q. Can I take Tylenol or ibuprofen if I have hepatitis C?

A. Usually. Taking small amounts of these medications is not usually risky if you have hepatitis C. You should check with your doctor, just to be sure.

Q. Does having HIV make hepatitis C worse?

A. Yes. HCV appears to progress more rapidly in persons with both viruses, perhaps as much as 4 times faster.

Q. Does hepatitis C make HIV worse?

A. Probably not. Hepatitis C does not appear to impact upon the progression of HIV. However, having HCV can cause problems with some of the medications used for HIV, and vice versa.

Pg. 19. Does everyone need treatment?

Does everyone with hepatitis C need treatment?

NO

Many people live for years without developing much liver damage from hep C. The decision about whether you need treatment should be made by you and your doctor, together.

may 3rd
start treatment

19

Fortunately, no. In fact, most people don't need treatment because HCV is usually a benign disease. Treatment is only needed if it is causing significant damage to the liver or causing severe symptoms.

Common misconceptions:

A lot of people think that everyone with HCV should be treated. For those who have heard about how difficult HCV treatment can be, it can be a primary reason they avoid medical intervention.

Related questions:

Q. Why shouldn't everyone get treated?

A. Because HCV treatment is still very difficult, and the most people don't develop serious liver damage from HCV. If there were a simple

treatment, like a short course of antibiotics, more people would be treated. But until HCV treatment becomes easier, only people who have developed scarring in their liver or are having problems related to the HCV infection need to be treated for it.

Q. How can I tell if I need treatment?

A. It is hard to give a general answer. If hepatitis C isn't causing much damage to the liver then treatment is not needed. This is most accurately assessed by a liver biopsy, but there is more and more use of indirect markers like Fibrosure and Fibrotest. Sometimes there are also clues in the regular blood tests, such as a low platelet count, that indicate more significant damage. Also, some people have intolerable symptoms from hepatitis C like severe fatigue, and others get related conditions like vasculitis or cryoglobulinemia that won't go away unless the virus is treated. Another issue that factors into the decision is the chance of treatment success. Treatment is more likely to be offered to those with genotypes 2 and 3, because of the high response rates and shorter duration of therapy.

Q. Shouldn't I wait until I am very sick from HCV before I get treated?

A. No. People with very advanced liver disease may not be eligible for HCV treatment. HCV medications allow the immune system to attack and kill infected liver cells. If there is very little healthy liver to start, then there may not be enough tissue to perform the body's necessary functions during treatment, and this could lead to liver failure. When liver disease is severe, the best option is liver transplantation.

Q. Are there other reasons that HCV treatment should be avoided?

A. Yes. Although the only absolute contraindication to hep C treatment is pregnancy, because ribavirin causes birth defects, hep C treatment can be problematic or even potentially dangerous in a number of other circumstances. HCV treatment can worsen autoimmune conditions like lupus, rheumatoid arthritis, and psoriasis. It can also cause anemia, which reduces the body's ability to transport oxygen, potentially causing problems in people with heart and lung disease. The risk of birth defects is increased, for men as well as women, DURING treatment and for 6 MONTHS afterward. There are more: check with your doctor.

Q. Can people with cirrhosis be treated?

A. Yes, although treatment is more risky and is not as effective. However, if the cirrhosis is severe HCV treatment may be unsafe, and transplantation may be the best option.

Q. What if I just got hep C?

A. Most people who think they just got hep C are wrong: they have actually had it a long time but the infection was silent. But if you really DID just get infected, you need to see a doctor right away. Treating hep c within the first 6 months of exposure has very high rate of success, with over 90% developing a sustained response to treatment!

Pg. 20. What are the symptoms of HCV?

The most common symptom is nothing at all: most people with HCV don't know they are infected because they do not have symptoms.

What are the symptoms of hepatitis C?



A lot of people don't have any, but the most common symptom is **FATIGUE**.

Some people have **FEVER** or muscle and joint aches.

Or vomiting, **NAUSEA**, loss of appetite, or stomach pains.

You can have bad symptoms, and still be healthy!

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However, many report fatigue, muscle and joint aches, nausea, and other nonspecific complaints, and these may be a byproduct of body's immune response to the virus. Symptoms are not a good way to predict the presence of hep C and don't relate to the amount of liver damage you have.

Common misconceptions:

Many people don't know that symptoms don't help predict disease activity or liver damage, and they need to be encouraged to proceed with an evaluation regardless of how they feel.

Related questions:

Q. I am very tired. Is that my hepatitis C?

A. Maybe. However, studies have shown that patients without hep C report fatigue just as often as those who have it, and that just finding out about a diagnosis of hep C increases fatigue-related symptoms! There are also many other causes of fatigue, like thyroid disease and: just getting old!

Q. Don't most people with hepatitis C turn yellow?

A. No. The majority of people who get hepatitis C don't even know it. They don't turn yellow and the majority don't even get sick.

Q. I have pains in my stomach. Is that hepatitis C?

A. Possibly. Although HCV shouldn't cause pain in the stomach itself, people with hepatitis C can have a tender, swollen liver in the upper right side of their abdomen that they refer to as "stomach pain". This pain results from swelling of the skin around the

liver, called the liver capsule. However, there are many other causes of abdominal pain, and it is usually worth getting them checked out by your doctor.

Q. My ankles are getting swollen. Is that hep C?

A. Maybe. If the liver is damaged enough from hep C, it may not make enough of the protein albumin to keep you from getting swollen. But there are many other causes of ankle swelling, and one of the main ones is eating too much salt.

Q. Can hepatitis C cause a rash?

A. Yes. HCV is associated with several skin conditions. The most recognized one is **porphyria cutanea tarda**, a blistering rash that occurs in sun exposed areas, especially the back of the hands. Another one is **lichen planus**, which causes small reddish flat-topped lesions on the body. Another condition that HCV can cause is **vasculitis**. This is an autoimmune condition, one in which the body reacts against itself, and it can lead to a red bumpy rash that is often on the legs but can be more widespread.

Q. My fingers and toes are numb. Is that HCV?

A. Could be. Sometimes HCV infection leads to a condition called cryoglobulinemia, where antibodies stick to other antibodies and clog up the small blood vessels when the blood gets cool, as it does in the fingers and toes. But numb fingers and toes may also be related to serious conditions like diabetes and vitamin deficiencies, and should be investigated by your doctor.

I feel fine!
Doesn't that mean my liver's okay?

Not always. You **CANT JUDGE** hepatitis C by how you feel.



Although you are probably healthy, some people develop cirrhosis from hepatitis C before they have any symptoms. Hepatitis C can be sneaky. Why risk it? Get checked!

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Pg. 21. I feel fine. Does that mean my liver's ok?

Not necessarily. Once again, many people have no symptoms from hep C. Just because you feel fine doesn't mean that the virus isn't active and damaging the liver. Sometimes there are no symptoms at all until the liver damage is quite advanced, and at that point treatment can be much more difficult. That is why a biopsy is so important: It is the best way to diagnose the amount of damage that has been caused by HCV.

Common misconceptions:

Most people believe that if HCV is damaging their liver they will feel ill. That is not true. It is

important to help people realize that the hep C virus may be damaging their liver, even though they don't feel or look sick.

Related questions:

Q. I am so tired I can hardly get out of bed. Does that mean my liver is in bad shape?

A. No. Just as HCV can damage the liver without making people feel ill, it can also cause someone with a perfectly healthy liver to feel awful. Symptoms don't predict liver damage.

Q. Will my symptoms go away if I get treated?

A. Possibly. The problem is, it can be hard to tell for sure if the symptoms are actually due to HCV or to something else. Fatigue is a good example: many people complain about fatigue even though they don't have HCV. But if the symptoms are related to HCV infection, they usually improve or disappear if the treatment is successful.

Q. I don't have any symptoms at all. Why should I get tested?

A. As far as hep C goes, symptoms are pretty useless. In fact, you can develop serious liver damage and feel fine the whole time – then it's too late to be treated. If you have a risk factor or were born between 1945 and 1965, then it's worth getting tested. It also will help you know whether you can transmit the disease to others, or whether you can just relax!



Q. Do people who feel fine tend to have healthier livers than people who feel sick?

A. No. Once again, symptoms are not useful for assessing the amount of liver damage. You can feel quite normal even though your liver is developing a lot of scarring.

Pg. 22. My blood tests are normal. Can I forget about hepatitis C?

Unfortunately, no. Over a third of people with HCV have blood tests of the liver that are completely and persistently normal, even though the virus is actively dividing in the liver. The good news is that people with normal blood tests are more likely to have healthy livers, but that is not

always the case. The only way to tell if the hepatitis C virus is active is to check for virus in the blood.

Common misconceptions:

Many people (and even doctors!) are not aware that completely normal liver enzymes are perfectly consistent with active hep C. This can sometimes lead to the mistaken assumption that the hep C infection is inactive, even though the virus is actually causing problems in the liver.

Related questions:

Q. What are liver function tests?

A. Liver function tests (LFTs) are blood tests that measure the level of liver enzymes. Liver enzymes are leak into the blood as a normal part of liver function. When the liver is working hard or is damaged, enzyme levels in the blood go up. Two common liver enzymes are ALT and AST.

Q. What is an ALT test?

A. ALT is an abbreviation for alanine aminotransferase, one of the main enzymes in the liver. When the liver is inflamed, the ALT in the blood can become elevated. AST (aspartate aminotransferase) is another liver enzyme test that is commonly tested.

Q. My doctor said my liver enzymes are very high. Should I worry?

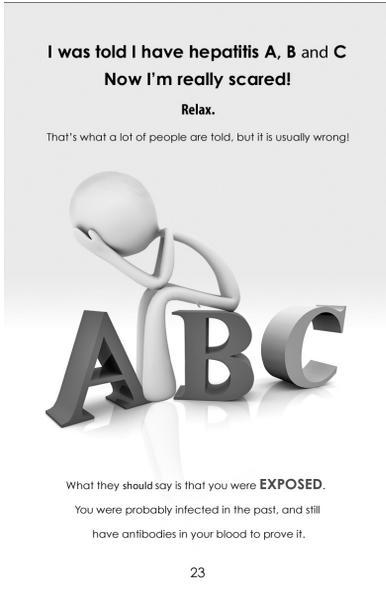
A. Not necessarily. When the liver enzymes are high, it indicates that there is a lot of inflammation in the liver. There are many causes other than HCV, including alcohol, of course, and many medications. When there is lot of inflammation, the risk of developing scar tissue or damage to the liver may be higher, so most doctors will be concerned and will work to determine the cause. If you have very high liver enzymes because of HCV, it may mean that your body is fighting aggressively to clear the virus from your body. But it could also mean that you have an additional reason for liver inflammation; these issues will need to be sorted out.

Q. Is it possible to get liver cirrhosis even though my liver enzymes are normal?

A. Yes. Although people with normal enzymes are less likely to end up with cirrhosis, it does happen on occasion. About 1 in 20 or so of people with persistently normal liver enzymes can still have cirrhosis.

Pg. 23. I was told I have hepatitis A, B, and C!

Probably not. Although scientifically possible, it would be extremely unlikely. Most people who say this have been EXPOSED to the 3 viruses but are not actively INFECTED with all



of them. Hepatitis A is never chronic, meaning it leaves the body after the initial infection. You only HAVE hepatitis A for several months after you get it. The virus disappears from the body but hepatitis A **antibodies** stay around to protect against another infection. Similarly, most people who are exposed to hepatitis B as adults clear the virus and only have **antibodies** to it. Of the 3, only hep C has a good chance of staying around after the initial infection.

Therefore, it would be incredibly rare to have all 3 viruses in the body at the same time. People who think this are probably confusing hepatitis A and B antibodies with hepatitis A and B viruses. But they are very different. Antibodies indicate prior exposure, either by infection or vaccination, but say nothing about whether a person is currently ill. Having antibodies isn't the same as being infected.

Common misconceptions:

Many people don't know the difference between prior exposure to virus and active infection. In addition, there is confusion about the differences between the hepatitis viruses, and hardly anyone knows hepatitis B is a sexually transmitted disease. Be sure to spend enough time on these important issues.

Related questions:

Q. How do you get hepatitis A?

A. HAV is usually transmitted through what is called **fecal-oral transmission**, during household contact with an infected person or by eating food, raw shellfish such as clams, or drinking contaminated water. People who are infected with hep A shed lots of the virus in their feces. If food comes in contact with the virus, perhaps when handled by an infected person who didn't carefully wash their hands, then it can cause hep A infection in the person who eats it. There are other ways of getting hep A, like changing the diapers of an infected child, sexual contact, or sharing needles, but these are less

common.

Q. I can never remember how you get hepatitis A.

A. Here's how we remember it: if it's one of the VOWELS, it comes from the BOWELS! So both hep A and hep E come from fecal-oral transmission.

Q. What does a positive hepatitis A test mean?

A. It depends, because there are different tests. If your doctor was testing you because you have hepatitis C, she was probably sending the test to find out if you need to be vaccinated. That test is called the **hepatitis A total antibody** (or IgG) test, because it looks for the presence of the antibodies we all develop after an infection. If you have these antibodies, there is no need to be vaccinated: you are already protected. But there is another hepatitis A test, the **hepatitis A IgM antibody test**, which is used to detect a recent infection. The body makes a bunch of different kinds of antibodies, IgM, IgG, IgM, IgD and IgE. IgG is the most common antibody, but IgM is the one that forms most quickly in the body. So if there is **IgM** antibody, it means the infection was recent; if there is IgG, it happened further in the past. So if a **hepatitis A IgM test** is positive, you may still have hepatitis A in your body. If your hepatitis A IgG test is positive, then the infection is probably gone.

Q. That was confusing. What I really want to know is, do I still have hepatitis A?

A. Probably not. Hep A never takes up permanent residence in the body. People who get hep A get sick for a month or two but then they recover. At that point the virus is completely gone and will never return. The only clue that it ever happened will be the hepatitis A antibodies that will be left in the blood.

Q. My doctor wants to vaccinate me for hepatitis A. Why?

A. Although most people don't get seriously ill when they get hep A, people with hep C already have one virus causing problems in the liver. If another one invades, the illness can be much more severe. Said simply, people who have hep C are more likely to die from hep A, and vaccination prevents this from happening.



Blood tests can stay **POSITIVE** long after an infection is gone.

So most people with a positive hep B test don't have hep B anymore. They were exposed in the past. Ask your doctor, so you can be sure.



It is important to know about your hep A and B tests.

If you haven't been exposed, then you should be vaccinated!

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Q. What are the hepatitis A shots like?

A. It usually takes two shots to protect against hep A. The shots are administered in the muscle of your shoulder, and they are given about 6 - 18 months apart. However, there is a new combination vaccination for both hep A and B together, and this requires 3 shots.

Q. What is serum hepatitis?

A. Usually it is a term used for hepatitis B.

Q. How do you get hepatitis B (HBV)?

A. Most of the time, HBV is transmitted sexually through exposure to blood, semen, vaginal secretions, and open sores; only about 15% of cases of HBV are related to injecting drug use. **Hep B** is primarily a **sexually transmitted disease!** About 40% of new cases are related to high risk heterosexual practices—more than one partner in the prior six months, or a history of other sexually transmitted diseases (STDs)—and another 18% are associated with same-sex activity. Unlike hep A, hep B is NOT spread casually.

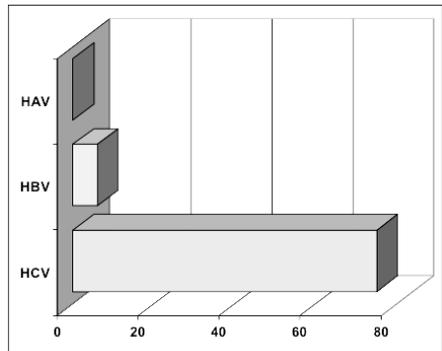
Q. How am I supposed to remember that one?

A. Remember the **2 B's** of hepatitis B: **body fluids** and **blood**. You get it from sex, and you get it from needles.

Q. Does hepatitis B cause a chronic infection (i.e., remain in your body)?

A. Sometimes. Mostly, it depends upon how old you are when you were exposed. When adults are exposed to hep B, they usually clear the infection—almost 95% of the time. But unlike hep A, hep B can become permanent. That happens in about 1 out of 20 adults who are exposed, and this is called a chronic infection, or chronic hepatitis B.

Percent cases that become chronic



Q. What if you get hepatitis B when you are a child?

A. The younger you are when you get exposed to hep B, the more likely you are to develop a chronic infection. Babies that are exposed at the time they are born almost never clear the infection. The good news is that hepatitis B can be prevented with vaccination. And that is why hepatitis B vaccinations are given to newborns in the US, and are also

required for all school age children.

Q. Why should I get vaccinated for hepatitis B?

A. People with hep C already have one virus in the liver, and an infection with a second virus can tip the balance and cause severe illness or even death. Hep B is worse than hep A, because it causes a more severe illness and can lead to chronic infection. And over time, the presence of 2 chronic viral infections increases the risk of cirrhosis, liver failure, and liver cancer.

Q. What do the shots consist of?

A. Three shots over a period of 6-12 months are usually required for hep B, and they are given in the arm. You get a booster about 1 month after the first shot, and then another booster 6 months after the first shot.

Q. Can I get hepatitis B more than once?

A. No. Hepatitis B infection confers immunity, and you can't get it again.

Q. Do hep A and B always cause severe symptoms?

A. No. People with these infections may not have symptoms at all, or may just feel like they have the flu.

Q. What is non-A, non-B hepatitis?

A. Most of those cases have turned out to be hepatitis C. Non-A, non-B hepatitis was the term used before the hep C virus was discovered in 1988. Now that the hep C virus has been identified and we can test for it, we know that those infections were mostly caused by HCV.

Q. Does hepatitis C stay in your body?

A. Yes! Hep C has a 75% chance of becoming chronic, which means that it stays in your body. Only about 1 in 4 people will clear the hepatitis C virus after they are exposed. That compares to 5% of exposed adults who develop chronic infection after being exposed to hep B, and 0% of chronic infections after hep A exposure.

Q. Is there a vaccine for hepatitis C?

A. No. Hepatitis C is a very tricky virus. So far, even though this is a very active area of research, attempts to develop a vaccine for HCV have not been successful.

Q. If I am exposed to hepatitis C, will gamma globulin shots prevent the infection?

A. No. Gamma globulin shots can prevent hep A and hep B when they are given within 2 weeks of exposure, but they won't prevent hep C.

Q. In the US, which has the most new cases each year: hepatitis A, B, or C?

A. Hepatitis B. The CDC estimated that the number of new HBV infections in 2010 was 38,000. This compares with 17,000 new infections each for HAV and HCV.

Q. What is hepatitis D?

A. An incomplete virus, sometimes called the Delta agent or Delta hepatitis, which can only be active in someone with hepatitis B. Coinfection with hepatitis B and hepatitis D is more serious than having just HBV alone. Vaccinating for hepatitis B will prevent infection with hepatitis D.

Q. What is hepatitis E?

A. An infection that is a lot like hepatitis A, but is uncommon in the US. It is passed by fecal-oral contamination, and hardly ever becomes chronic.

So how do I find out if I have hep C?

The screening test is called an **ANTIBODY TEST**. It looks for the **FOOTPRINTS** of hep C in your blood. If the test is positive, it doesn't mean you have hep C! You could have cleared the infection on your own!

An antibody test can only tell you whether the virus was in your body at some point, **NOT** whether the infection is still there **NOW**.

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Pg. 25. How do I find out if I have hep C?

The first test you need is a screening test to find out if you have been exposed. This is also called an antibody test or an EIA, and it can even be done with a fingerstick. This test **WON'T** tell you if you have hep C, it will tell you if you have ever been **EXPOSED**. It looks for the antibody footprints in your body and is highly accurate. In order to find if you actually **HAVE** hep C once your screening test is positive, you will need a viral load test. If your screening test is positive, your chance of having hep C is about 75%: you have a 1 in 4 chance of clearing the hep C virus on your own.

Common Misconceptions:

Most people think a positive screening test means they have hep C but this is not true. It only tells you that you have been exposed in the past.

Related questions:

Q. What kind of test is the fingerstick test for hep C?

A. An antibody test. If your fingerstick test was positive, you were exposed to hep C in the past. Your chances of having hep C are about 75%. You will need a viral load test to determine this.

Q. Why do a hep C test that doesn't tell me I have it?

A. Because this test is sensitive, accurate, and inexpensive. The viral test costs about 10 times as much and is harder to do. So the antibody test is used as a first test, then followed by virus testing if it is positive.

*Q. What is an **EIA** test?*

A. It stands for enzyme immunoassay. It is just another term for the antibody screening test.

*Q. What is a **RIBA**?*

A. It stands for recombinant immunoblot assay. RIBA is a more specific kind of antibody test, but it is expensive and hardly ever used any more.

Q. How long after getting exposed to HCV does it take to develop antibodies?

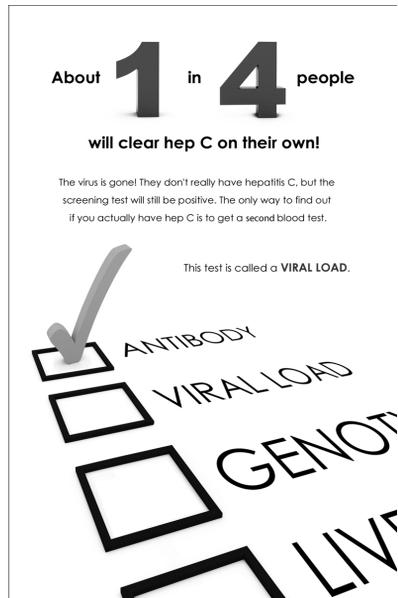
A. About 6-7 weeks on average. After 3 months, more than 90% of people who are infected will test positive for HCV antibodies.

Q. How can I tell whether I had the antibody test or a test for virus?

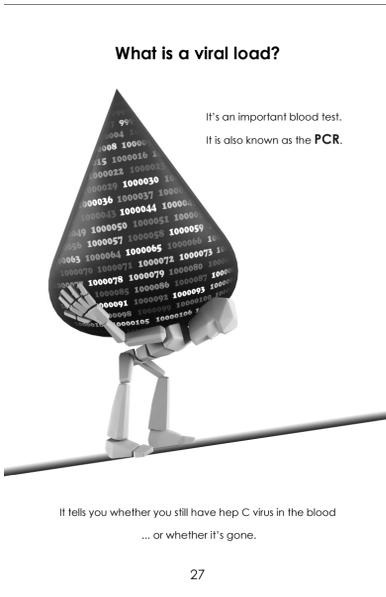
A. One way, of course, is to ask. But sometimes you can also tell by the way the results are reported. A lot of antibody tests are reported as “positive” or “repeatably positive” or “negative.” Virus tests frequently give you a number (that usually looks pretty high), or says “detected” or “not detected.”

Q. Is the antibody test ever wrong?

A. Not usually. The newer antibody tests are very sensitive and accurate, but rarely someone with an immune disorder like HIV will be negative but still have hep C. The test is also sometimes positive when it shouldn't be, or **falsely positive**. This happens most



commonly in autoimmune conditions like lupus. Overall, however, the test is extremely accurate, and is a great screening test.



Pg. 27. What is a viral load?

Also commonly called a PCR (polymerase chain reaction), this is one of the blood tests for hepatitis C VIRUS. As opposed to the antibody screening test which just indicates prior exposure, this test tells if there is **virus in the blood**, and indicates whether the person is **actively infected**. Virus numbers in the millions are common, but high virus numbers don't mean there is worse liver disease.

Common misconceptions:

The PCR, or viral load test, detects something completely different from the antibody screening test. Most people incorrectly assume that a

positive result on an antibody screening test means they are infected with hep C, but it is the PCR test, or viral load, that actually makes a diagnosis of active hepatitis C infection. If the PCR doesn't detect virus, you don't have HCV.

Related questions:

Q. One doctor told me I have hep C, and then another told me I didn't. I'm confused!

A. And probably so is one of your doctors. Find out what tests were done. Only a test that looks for virus (like the PCR test) can tell you if you actually have a hep C infection; the screening antibody test tells you if you were ever **exposed** to HCV. Be sure to know the difference. Once your screening test is positive it will stay that way, even if you are cured with treatment. It is useless to repeat a screening test once it's positive, but some doctors do it anyway. Don't let anyone else confuse you: you are infected with HCV only if your viral load test is positive, the screening antibody test doesn't tell you that.

Q. How long after getting exposed to HCV before virus can be detected in the blood?

A. The virus can be detected as early as 1-2 weeks after exposure.

Q. If the viral load is such an important test, how come everyone doesn't get one?

A. Because it is much more expensive than the antibody test. It costs over 10 times as

much, and so it isn't used to screen for hepatitis C.

Q. My doctor said I don't need a viral load test because my liver enzymes are normal.

A. You can still have active HCV even with normal blood tests, so you do need the viral test. In addition to giving you information about whether you might need treatment, this test tells you if you can pass the virus on to other people. A negative test is a big relief, and you can probably stop seeing the doctor for hep C!

Q. My viral load is over a million! How bad is that?

A. The number has nothing to do with how much liver damage you have. Numbers in the millions are common even with healthy livers; conversely, people with cirrhosis can have low viral loads. If your viral load is very high then it will be slightly harder to get rid of it with treatment, but in general the number is not useful. The importance of the test is in telling you whether you still have virus or not. The actual number of virus particles hardly matters.

Q. My hep C screening test was positive, but my viral load was undetectable. What does that mean?

A. It means that you are one of the lucky one in four people who clear the virus on their own. The term for this is **spontaneous remission**. Even though you don't have virus and probably never will, your screening test may stay positive for the rest of your life, even though the virus test will always be negative.

Q. If I clear the hep C infection, will my antibody screening test become negative?

A. No. Once you have been exposed to HCV, the antibodies will stay around for a long time, possibly for the rest of your life. There is no reason to get another antibody screening test after one is positive, because the results will stay the same.

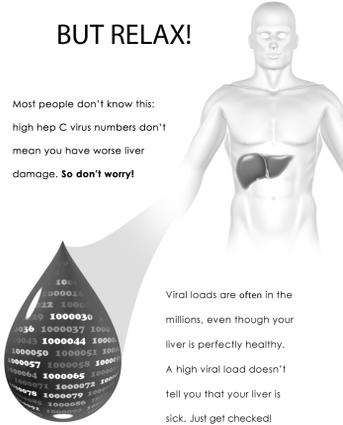
Q. Do different races have the same chance of having active HCV?

A. No. African-Americans are slightly less likely to clear their initial HCV infection. In other words, they are more likely to develop a chronic infection after being exposed. We don't know why.

**A lot of people have virus numbers
in the MILLIONS.**

BUT RELAX!

Most people don't know this:
high hep C virus numbers don't
mean you have worse liver
damage. **So don't worry!**



Viral loads are often in the
millions, even though your
liver is perfectly healthy.
A high viral load doesn't
tell you that your liver is
sick. Just get checked!

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Q. Is the virus gone or is it just hiding?

A. If your virus test is negative and you were never treated for hep C, then it is probably gone forever. If you protect yourself from new exposures, then you should never have to worry about hep C again.

Q. What is the difference between a “qualitative” and a “quantitative” PCR?

A. A qualitative PCR tells you if the virus is detected or undetectable, kind of a yes or no test. **Quantitative** PCR gives you the number of virus particles in the blood (like the word **quantity**). The **qualitative** test is more sensitive than some of the PCR tests - it can detect fewer numbers of virus particles – and sometimes a bit less expensive. That is often why it is used.

Q. How high is a high viral load?

A. It depends upon the measure. Tests used in the past measured **copies/mL**: the number of virus copies in one milliliter of blood (one mL is the same as one cc.) The cutoff between high and low viral loads was **2 million copies/mL**. Imagine: a viral count of 1.9 million copies/mL was considered low! More recently, the tests have been standardized across the world, and the viral loads are now reported as International Units per milliliter, or IU/mL. There is no automatic ratio between copies/mL and IU/ml, but 2 million copies/mL is **approximately** the same as **400,000 IU/ml**.

Q. How high does my viral load need to be before I need treatment?

A. Unlike HIV and hep B, the HCV viral load can't be used to tell if treatment is needed. Most people will have fairly stable virus numbers over time; the number doesn't go up as you get sicker. Don't forget that hep C virus loads can be very high, so numbers in the millions are common and shouldn't worry you. The number of virus particles in your blood is largely determined by how aggressively your body attacks it. Some people's immune systems keep the virus at a low level, but other people's immune systems are not much bothered by the virus and mostly leave it alone. They can have many millions of virus particles but still have healthy livers.

Q. How come high numbers of hepatitis C virus particles don't cause worse liver damage?

A. Because the problem isn't the hep C virus, it is your own immune system! The virus itself doesn't damage the liver; it will live there peacefully if your body will let it. But the immune system usually is not happy with the infection and tries to clear the infected cells from the liver. It attacks and kills the infected liver cells, causing inflammation and scar tissue. It doesn't matter how much hep C virus is around, it only matters how

pissed off your body is that your liver is infected.

Q. How many new hep C virus particles are produced each day in the body?

A. Up to a trillion! Now you know why you are tired!

What is a genotype?
Another important blood test.

Genotypes are like different **strains** of the hep C virus. All genotypes have the same effect on the liver, but some are easier to get rid of than others.



In the United States, **GENOTYPE 1** is the most common, and the hardest to treat.

Almost everyone else has **GENOTYPE 2** or **GENOTYPE 3**. If you have these genotypes, treatment is usually more successful.



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Pg. 29. What is a genotype?

An important blood test. A genotype is kind of like a “strain” of HCV, and there are 6 of them: genotypes 1, 2, 3, 4, 5 and 6. All genotypes cause the same amount of liver damage, but some of them are easier to get rid of with treatment, and so if you are contemplating treatment you should know your genotype.

Common misconceptions:

Many people don't know their genotype or they believe that the genotypes that are more difficult to treat cause the worst liver damage. They also don't know how genotype affects response rates, treatment regimen, and the length of treatment.

Related questions:

Q. I don't get the genotype thing.

A. Think of the genotype as you would different breeds of dog. Some are obedient and do as told, but others are more difficult to handle. Similarly, some genotypes usually disappear obediently when you take the treatment but others are more stubborn. The genotype just gives you more information about what you can expect when you get treated for hep C.

Q. What is the most common genotype?

A. In the US, genotype 1 is the most common: about 76% of people have genotype 1. Almost everyone else has either genotype 2 or 3, but a few have one of the other genotypes. Naturally,

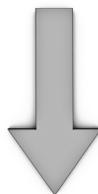
GENOTYPE 1 needs 6-12 months of treatment. With the new medicines, almost 3 out of 4 people will clear the virus!



GENOTYPE 2 and **GENOTYPE 3** usually only need treatment for 6 months, and about 80% clear the virus.



IMPORTANT:
ALL genotypes cause the same amount of liver damage.



You are no more likely to get cirrhosis by having genotype 1, 2 or 3.

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the most common genotype, genotype 1, is the hardest to get rid of with treatment.

Q. Why does my genotype have a little letter after it?

A. The letters indicate small genetic differences that may predict treatment success. For instance, genotype 1b is more responsive to triple therapy with protease inhibitors than genotype 1a.

Q. Which genotype causes the worst liver damage?

A. They all cause the same amount of liver damage.

Q. Which genotypes are the easiest to treat?

A. Genotypes 2 and 3 are the easiest and genotype 3 is not far behind. Over 80% of people with genotypes 2 and 3 can expect to clear their infection with 6 months of treatment. Nowadays, about 70% of people will clear genotype 1, but this requires 3 medications and up to a year of treatment.

Q. How come we hardly ever talk about genotypes 4, 5, and 6?

A. Because they are relatively uncommon in the US. Genotype 4 is common in certain areas of the world, like the Middle East. It behaves a lot like genotype 1. We know even less about genotypes 5 and 6.

Q. Do genotypes change?

A. Usually, no. Unless you are re-exposed to another virus, your genotype will stay the same. However, if you are exposed to a different genotype, you may change from one to the next. There is no real way to predict which genotype will predominate.

Q. Do people have more than one genotype?

A. Sometimes. Most people will show only one genotype in their blood, but some people do have more than one.

Q. Do genotypes differ by race?

A. Yes. Although about 75% of people overall in the US have genotype 1, genotype 1 is much more common in African-Americans: over 90% of African Americans have this genotype. The reasons for this are not entirely clear.

Pg. 31. How can I tell if my liver is being damaged?

It's not easy. Blood tests can give you a clue, but they can also be wrong. Sometimes they are normal even though the liver is being damaged, and sometimes they are very

abnormal even with a healthy liver. Your doctor's physical exam may contain some clues about the health of your liver, but usually only tells you about the liver's size. Tests like ultrasound, CT scans, and MRI only give limited information. Certain tests, like Fibroscan and Fibrosure are being used more and more, but the most accurate way to tell what is going on in the liver is still to get a **liver biopsy**.

Common Misconceptions:

Most people think that blood tests are a good measure of the amount of liver damage.

Related questions:

Q. Won't I feel sick if my liver is being damaged?

A. Not necessarily: symptoms are a poor indicator of the health of the liver. Sometimes hep C doesn't cause any symptoms at all until the liver damage is very advanced. At this point treatment can be difficult, and so it is important to get evaluated even though you might feel perfectly fine.

Q. Can't the doctor tell by examining me how healthy my liver is?

A. To some extent, yes. In most people, the physical exam can give some estimate of the size of the liver and texture of the liver. There are also other clues about more severe liver damage, like an enlarged spleen, or swelling in the legs, or enlarged blood vessels on the chest. But it is not easy to accurately predict the amount of scar tissue in the liver by physical findings.

Q. How about an ultrasound?

A. An ultrasound is very good at assessing the size of the liver. It can also provide some useful information in people with severe liver damage, such as whether the liver is shrunken and knobby with cirrhosis, or if the spleen is enlarged, or if there is ascites fluid in the abdomen. But since scar tissue looks a lot like regular liver tissue on an ultrasound, it is not an accurate way to measure how much fibrosis there is.

Q. Anything else? CAT scan? MRI?

A. Nope. Again, fibrous scar tissue in the liver appears very much like regular liver tissue

How can I tell if my liver is being damaged?

You can't always tell from the blood tests!



Blood tests only give you a general outline of how healthy your liver is, not if you need treatment.

And since these tests are on the blood and not the liver, they can sometimes fool you!



A biopsy is the MOST accurate way to see if the hep C virus is causing scarring of your liver.

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with these tests. When the liver has more serious damage there are certain findings on these tests, but the goal is to catch the liver damage before it gets that advanced.

Q. Do drug users get more liver damage from hepatitis C than people who got it another way, say from a transfusion?

A. No. Interestingly, after correcting for the amount of alcohol use, drug users in general appear to have less liver damage! It may be related to exposure at a younger age or infection with a lower number of virus particles, but no one knows for sure.

Q. My doctor is recommending a test called Fibrosure. What is that?

A. The Fibrosure test is a blood test in which a variety of individual measures of liver health are combined into a formula to estimate the amount of scar tissue. It can be helpful when a liver biopsy is not available or is contraindicated, but it is still not FDA approved.

Q. What about a Fibroscan test? Can that tell me how healthy my liver is?

A. The Fibroscan gives you a measure of how soft and pliant your liver is, using a similar probe to the one used in an ultrasound. The idea is, a healthy liver is very soft and squishy, but a liver with cirrhosis is firm and rubbery. The Fibroscan tells you about the texture of your liver as an estimate of how much scar tissue there is. It is still not FDA approved in the U.S. and is not as accurate as a liver biopsy.

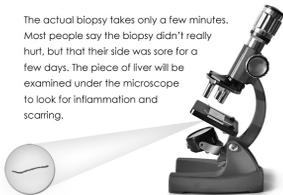
Liver biopsy? Ouch!



Most people say that worrying about the biopsy was the worst part! A liver biopsy is done by passing a small needle through your skin and into the liver and removing a tiny piece.

Don't worry: your skin will be numbed first!

The actual biopsy takes only a few minutes. Most people say the biopsy didn't really hurt, but that their side was sore for a few days. The piece of liver will be examined under the microscope to look for inflammation and scarring.



But not everyone needs a liver biopsy! You should discuss with your doctor whether this test is necessary for you.

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Pg. 32. Liver biopsy!

The dreaded liver biopsy is still the most accurate way to determine how much scar tissue is in the liver. Despite its scary reputation, it is actually a simple outpatient procedure. The area over the liver is numbed up, and then a needle is inserted through the skin into the liver. A small sample is removed and examined under the microscope. The biopsy actually only takes a few minutes, although it will require several hours of observation to make sure there is no bleeding. And is it painful? Occasionally. But most people say that worrying was the worst part.

Common misconceptions:

Although some find it painful, most people are

surprised at how little pain they experience. Many people complain that the biopsy was boring, because they had to lie flat for several hours afterwards.

Related questions:

Q. Does everybody need a liver biopsy?

A. No. Although the liver biopsy is the best way to assess the amount of scar tissue in the liver, it is only needed if it will affect a decision about whether or not to undergo treatment. For people who don't want to be treated but are willing to do so if there is enough liver damage, it is good to know that delaying treatment is a reasonable option. But if the results of a biopsy won't change anything, there is no good rationale for doing one. In short, because a liver biopsy is expensive and has some risks, it is only performed when there is a good reason.

Q. Are there any risks?

A. Yes. The main risk is bleeding. If the biopsy needle passes through a blood vessel, there may be bleeding into the liver, and on rare occasions the bleeding can be severe. Therefore, a liver biopsy is only done when it is needed.

Q. How bad does it hurt?

A. Most people say that the biopsy didn't hurt at all, but that their side was sore for a few days. However, occasionally the liver biopsy is more painful than that, especially in people with cirrhosis. Probably this is because the liver is so firm that it is harder to insert the needle into the liver.

Q. Can't I be put to sleep?

A. No. The reason is that you will need to help the doctor by taking a deep breath and holding it while the biopsy is done. The deep breath pulls the edge of the liver down far enough to make it easier to biopsy. Otherwise, there is a much higher risk of the needle passing into the lung space, which could be a big problem, or causing bleeding in the liver.

Q. What information will I get from the biopsy?

A. There are two things that will be assessed: inflammation and fibrosis. If you get a cut in your skin, it will get red, irritated and then develop a scar. The same thing can happen in your liver when you have hepatitis C, and the medical words for the irritation and scar tissue are **inflammation** and **fibrosis**. The doctor looks for inflammation and fibrosis when he or she examines your liver under the microscope, and gives each one a

score. Although there are different scoring systems, one that is often used scores both inflammation and fibrosis on a scale of 0-4. Zero means none, and 4 means advanced. Someone with stage 4 fibrosis in this scale has cirrhosis.

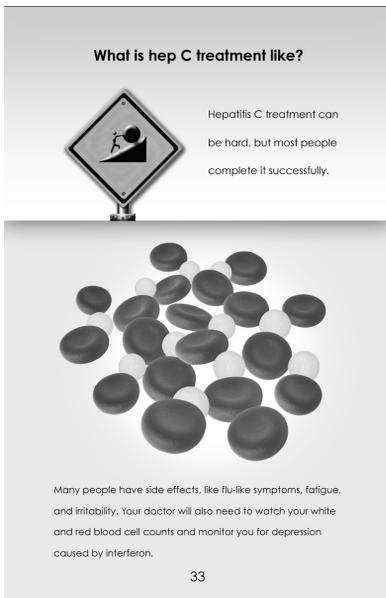
Q. If fibrosis is so important, why do we also look at inflammation?

A. Because if the liver is more inflamed it is more likely over time to develop additional scar tissue, or fibrosis. In other words, the amount of liver inflammation helps predict how fast the scar tissue, or fibrosis, will develop. If there isn't much inflammation, then the scar tissue will probably develop slowly. But if the liver is very inflamed, it will probably develop fibrosis much faster.

Q. How often do I need a biopsy?

A. Not very often: hepatitis C advances slowly! Most people who have a biopsy only have it once. However, if a biopsy is going to be used to follow the amount of liver damage that is developing from hepatitis C, then it is usually not done more frequently than every 3-5 years.

Pg. 33. What is hep C treatment like?



What is hep C treatment like?

Hepatitis C treatment can be hard, but most people complete it successfully.

Many people have side effects, like flu-like symptoms, fatigue, and irritability. Your doctor will also need to watch your white and red blood cell counts and monitor you for depression caused by interferon.

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It consists of interferon shots and ribavirin pills taken for 6-12 months, and some people will also take another kind of pills called protease inhibitors for part of that time. The medications can have lots of side effects, including flu-like symptoms, fatigue, depression, and irritability. You will need to see your doctor regularly during treatment to monitor your blood and to help manage your side effects. Despite this, the majority of people are able to finish the treatment, and about 70% can expect to clear the virus permanently.

Common Misconceptions:

They abound. Interestingly, most people seem to be worried most about minor things such as going bald (no), but are less concerned about

significant treatment-limiting problems like severe anemia.

Related Questions:

Q. How do you take interferon?

A. Interferon is taken as an injection under the skin, similar to how insulin is used. Pegylated interferon is usually taken once a week, and regular interferon is taken 3x weekly.

Q. How do you take ribavirin?

A. Ribavirin comes in capsules or pills, and you can expect to take between 4 and 7 pills a day total, depending on your genotype and how much you weigh.

Q. What are these new medicines called protease inhibitors?

A. The protease inhibitors are a new class of HCV medicines that directly attack the virus itself. They are currently used for people who have genotype 1, and are combined with interferon and ribavirin to improve treatment response rates.

Q. How long will the treatment last?

A. For the most part, it depends upon your genotype. Genotypes 2 and 3 are easier to get rid of, so people with genotypes 2 and 3 usually are treated for 6 months. If you have genotype 1, your treatment will last between 6 and 12 months, depending on how quickly your virus responds to treatment.

Q. How often do I need blood tests?

A. About every 4-6 weeks. However, early in the treatment the blood is taken more frequently until the blood counts (and you!) stabilize.

Q. Will I feel like I have the flu the whole time?

A. No. Flu-like symptoms like fevers, chills, and aches are worst at the very beginning of treatment, but they tend to wear off after a few shots. After that, many people won't feel as well for the day or two after they take the interferon shot, but mostly they just feel kind of tired and run down.

Q. I heard pregnancy is a problem.

A. True. Ribavirin causes birth defects. Therefore, women need be very careful not to get pregnant during HCV treatment and for 6 months afterward. Men are also at risk, and should not get a woman pregnant while taking ribavirin and for 6 months thereafter.

Q. What do I take if I feel like I have the flu?

A. The most important thing that you can do to manage the side effects of HCV treatment is to drink lots of water. The optimal amount is 15-20 8-ounce glasses per day, or about a gallon. It's quite a bit of water to get used to, so it's best if you start drinking extra water even before you get started on treatment. Many people will try to cut down on this amount because they get tired of drinking so much water, but it is so effective at helping with the symptoms that they go right back up. In addition, many people take Tylenol or ibuprofen to help with these symptoms; these should be taken under the direction of your doctor.

Q. What will happen to my blood counts?

A. They will go down, and that is one of the main reasons that you need regular blood testing. Interferon lowers the platelet counts and makes you more prone to bleeding, and it also lowers the white blood counts, which can put you at risk for infections. Ribavirin can cause the red blood cells to break up; this is called hemolytic anemia and can make you feel short of breath. The protease inhibitors can add to the blood count problems, especially the anemia. If these problems become significant, you may need to reduce the amount of medications you take. Alternatively, some doctors will prescribe additional medications like erythropoietin or G-CSF to counteract the problems.

Q. I heard that the treatment can make you depressed.

A. True, and occasionally the depression can be so severe as to lead to **suicide**. It is very important to keep your doctor informed about your mood and to involve someone else in your care who can keep an eye on you. The mood problems include **irritability**, which is very common, severe **depression**, and severe **mania**—an unstable and potentially dangerous mood elevation. The mood problems tend to have their peak at about 3 months after starting treatment. Although there are plenty of medications to address these side effects, they can take several weeks in order to work. The earlier you get help for them, the better.

Q. I don't want to take any nut pills.

A. A lot of people avoid antidepressants because they worry about the side effects. However, many of the newer medications are extremely effective and cause very few problems. They can also make the hep C treatment go MUCH easier. There is nothing wrong with you if you need to take these medications; they are simply being used to help manage those tough side effects. The goal isn't to make you a robot, it's just to keep you going until the treatment is done.

Q. What is “brain fog”?

A. A lot of people have trouble concentrating and thinking while they are on HCV treatment. Many people also complain that they can't remember anything. The slang term that many people use for this is **brain fog**, for obvious reasons!

Q. Will I go bald?

A. No, although many people's hair gets thinner and dry. It grows back after the treatment.

Q. What if I can't sleep?

A. Insomnia is pretty common. Mild medications like Benadryl often help, but if the problem is more severe then your doctor may need to give you sleeping pills.

Q. Does treatment affect your thyroid?

A. It can, and sometimes the changes are permanent. Your doctor will monitor you for thyroid problems, and if needed, additional medications may be prescribed.

Q. I heard pregnancy is a problem.

A. True. Ribavirin causes birth defects. You must use careful birth control during treatment and for 6 months thereafter. This is true for both men AND women, because ribavirin is present in the semen.

Q. Should I come off of methadone before I start treatment?

A. Probably not. Methadone doesn't harm the liver, and it may help keep your side effects and cravings tolerable during HCV treatment. In fact, many people who are on treatment increase their dose a little when they are treated for HCV, to help with side effects. Detoxing from methadone might also increase your risk of relapse.

Q. What happens if I drink alcohol while on HCV treatment?

A. There is good evidence that people who drink alcohol while they are being treated for HCV have lower response rates. Since it appears that alcohol can neutralize the HCV medications, don't compromise your treatment by drinking alcohol!

Q. Can I work while I am on treatment?

A. It depends. People who do hard physical labor may find it difficult to keep pace, and people whose jobs require memory and concentration will also find it hard. The majority of people are able to continue working, but won't be at full capacity.

How can I tell if the treatment is working?

Your doctor will do regular blood tests during treatment to see if the virus is responding.



It will take about 1 MONTH before you'll know if the hepatitis C treatment is working.



If the virus isn't responding the treatment may be stopped early.

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Q. How long will it take me to feel normal again?

A. It varies from person to person, but most people start feeling better a few weeks or after they finish treatment, and most are back to normal after a few months.

Pg. 34. How can I tell if the treatment is working?

Mostly, by the blood tests you will have during treatment. In addition to monitoring the blood counts, thyroid levels, and other things, your doctor will be checking your viral load on a regular basis to see if it is responding.

Common misconceptions:

Probably the most common one is that treatment can be discontinued when the virus is no longer

detectable. This is a big mistake! Although the virus may not be detectable in the blood, it may still be hiding in the liver. Therefore, if the virus is undetectable it means that you need to be EXTRA sure to complete treatment as planned, as your chances of responding are very good.

Related questions:

Q. My virus went down really low but my doctor stopped treatment early. Why was this?

A. If the virus does not respond quickly enough, this means that the medications are not working. Treatment should be stopped under these circumstances, because there is a risk of the virus becoming resistant to the medications. With all the new hep C medications in the pipeline, you need to preserve your chances of success in the future.

But if the virus does respond, it's even more important to finish the whole treatment, because that will give you

THE BEST CHANCE

of getting rid of the virus for good.



Even if you don't clear the virus forever, your liver can get healthier just from going through the treatment!

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Pg. 36. I heard there's new treatments for hep C.

That's true! In 2011, a new class of medications called protease inhibitors was approved by the FDA. These are added to interferon and ribavirin to improve treatment outcomes in people who have genotype 1, the hardest one to get rid of.

Common misconceptions:

Knowledge about the protease inhibitors has lagged behind their availability. In particular, many people think that the new medications can be taken without interferon, which isn't true.

Related questions:

Q. I don't want to take interferon because of the side effects. Can I take one of these new medicines instead?

A. No. The new medications must be ADDED to interferon treatment in order to work. Otherwise, the hep C virus will become resistant to them.

Q. What are the new protease inhibitors called, and how are they taken?

A. Their names are telaprevir and boceprevir. Both are pills, and current recommendations are that they be taken three times daily, every 7- 9 hours.

Q. How well do they work?

A. When taken correctly, the protease inhibitors improve genotype 1 response rates from about 45% with pegylated interferon and ribavirin, to about 70% with triple therapy.

Q. How long do I take them for?

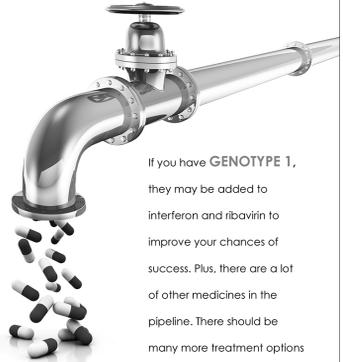
A. It depends upon which one you are taking. Telaprevir is taken just for the first 12 weeks of treatment. Boceprevir is started after the 4th week of treatment and is taken for 24 – 44 more weeks, depending of factors like your response to treatment, whether you have been treated before, and how much liver damage you have.

Q. With these protease inhibitors working so well, can I stop treatment early?

A. Sometimes. About half the people who take them respond quickly, and their treatment course can be as short as 6 months.

I heard that there's new treatments for hepatitis C.

That's true! They're called **PROTEASE INHIBITORS**.



If you have **GENOTYPE 1**, they may be added to interferon and ribavirin to improve your chances of success. Plus, there are a lot of other medicines in the pipeline. There should be many more treatment options in the coming years!

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Q. Do the protease inhibitors have any side effects?

A. Yes. Although the side effects differ between the two medicines, the most common one is anemia. They also can cause rashes, rectal pain, weird taste changes, and others.

Pg. 37. How do the protease inhibitors work?

These new medicines act by attacking the hep C virus directly. This is very different from interferon and ribavirin, which work by enhancing the immune response to the hep C virus.

Common misconceptions:

The main one is that the protease inhibitors can be taken as monotherapy. In addition, many are unaware that the new medications bring with them a new set of side effects!

Related questions:

Q. Are there any risks associated with the protease inhibitors?

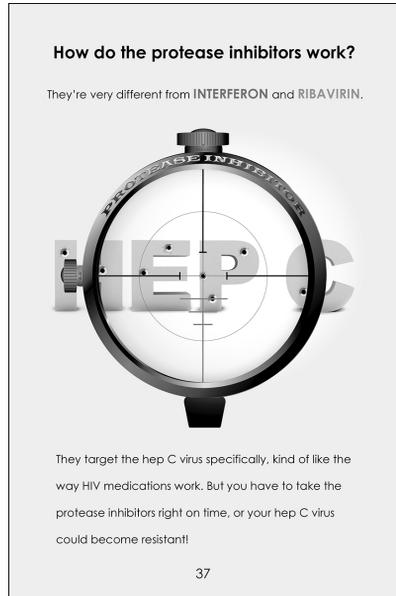
A. Of course – there are risks with any medication! The protease inhibitors have their own set of side effects, and these can add to the considerable side effects of interferon and ribavirin. In particular, they can make the anemia from hep C treatment even worse, and telaprevir can cause a rash that may be life threatening. In addition, if they are not taken correctly, you can develop resistance – and your virus may stop responding to other protease inhibitors as well!

Q. Can I take them on an empty stomach?

A. No. Telaprevir must be taken with 20 grams of fat, and boceprevir must be taken with a light snack, such as crackers.

Q. If the side effects are bad, can I take a lower dose?

A. No. This would put you at risk for developing a resistant virus. If you do not tolerate the protease inhibitors, then they must be stopped completely.



Q. If I don't respond to one of the two protease inhibitors, can I take the other one?

A. No. These medications work on similar targets, so if one of them doesn't work the other one won't either.

Pg. 38. Can hepatitis C be cured?

Probably! Ten years after people have a sustained response to interferon, well over 90% are still virus-free. Since HCV is not the kind of virus that has the ability to hide, it means that the treatment probably can lead to more than a remission. If it is successful, HCV treatment can probably lead to a cure.

Common misconceptions:

There is still some debate about whether using the word “cure” is appropriate, but based on the evidence it is becoming much more common. Patients will often get mixed messages about this, but there is every reason to be cautiously optimistic.

Related Questions:

Q. What is a sustained response?

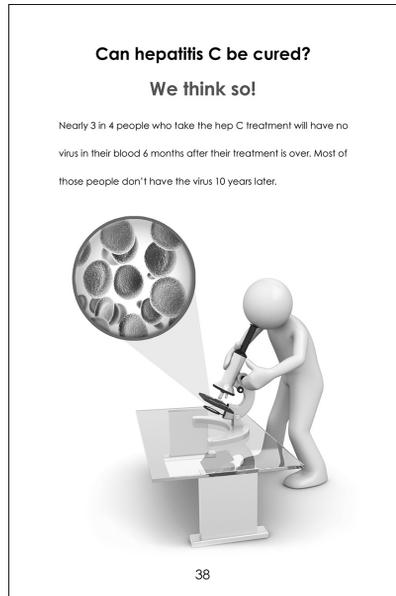
A. It is the term used when there is no detectable HCV in the blood 6 months after treatment is over. It is the thing you want to happen when you get treated.

Q. What are my chances of a sustained response?

A. Overall, about 70% of people are sustained responders—no virus in the blood 6 months after treatment is over. A sustained response is what you hope for, because >90% of sustained responders will still be virus-free over 10 years later, and are probably cured.

Q. I heard that my genotype is important.

A. True. The chance of having a sustained response is about 80% after 6 months of treatment in people with genotypes 2 and 3. Genotype 1, the most common genotype in the US, is harder to treat. Using triple therapy with interferon, ribavirin, and a protease inhibitor, the sustained response rate of genotype 1 is about 70% and many people



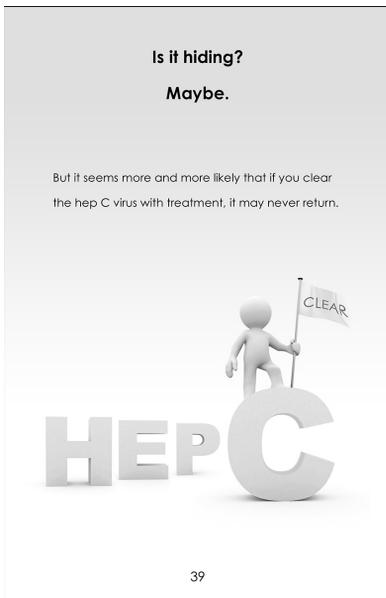
require a full year of treatment.

Q. Are there any other ways to predict if I will respond?

A. To some extent. Although genotype is by far the most important, there are other factors that have a lesser impact on treatment outcomes. People who have lower numbers of virus particles in their blood are slightly more likely to clear virus. Thin people respond better than people who are obese, and so do people younger than age 40 and premenopausal women. The amount of scarring in the liver is also important, because response rates are lower in people with cirrhosis or advanced fibrosis.

Q. What if I don't clear the virus?

A. If this happens, the next steps should be discussed with your doctor. Sometimes treatment is undertaken again if the liver is not healthy enough to wait for several years until new treatments become available.



Q. If the virus comes back, was treatment a waste?

A. No. Interferon may help keep the liver healthy during treatment. During interferon treatment some of the scar tissue may reverse, even though the virus is not eliminated.

Q. Do I have to go through the entire treatment before I know if it will work?

A. For the most part, yes. However, if the virus is not gone after 3 months of treatment or if the virus load hasn't gone down by at least 100-fold, then the chances of a sustained response are very low, about 2%. Many people will elect to stop

treatment at this point. People who achieve the 12-week benchmark have a somewhat improved chance of a sustained response, but still need to complete the full course of HCV treatment.

Q. If the treatment doesn't work, can I do it again?

A. Yes. Some people are retreated, but response rates are much lower. Sometimes people are treated for longer periods of time, or with higher doses of medications. But we don't know yet whether any of these new strategies are valuable.

Q. If I get a liver transplant, will it cure my hepatitis C?

A. No. Even though the infected liver is removed, the residual virus in the blood will infect your new liver. That is why it is good to try to get rid of the HCV virus with treatment before you get a liver transplant, although it is often not successful.

Q. Can I be reinfected?

A. Probably. There are a few documented cases of reinfection after HCV treatment. A prior infection probably does not confer immunity, and so if you clear virus you will need to be especially careful to protect yourself from another exposure.



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