HIV, Hepatitis C and You

A GUIDE FOR COINFECTED PEOPLE

THE BODY®
The Complete HIV/AIDS Resource

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Consult your doctor! The only purpose of this booklet is to educate and inform. It is no substitute for professional care by a doctor or other medical professionals. TheBody.com neither endorses nor opposes any particular treatment option discussed in this booklet. Instead, we encourage you to discuss all of your options with a health care provider who specializes in treating HIV/hepatitis coinfection.

We wish to warmly thank Lynn Taylor, M.D., for her care and generosity in providing a meticulous medical review of this booklet to help ensure its clinical accuracy. Our deepest gratitude also goes out to Bob Munk and Heidi Nass, who were kind enough to offer assistance and feedback on early drafts. Last, but far from least, endless thanks to the people whose names and quotes appear within this booklet: By sharing your personal stories and your wisdom, you made it a thousand times more useful and meaningful.

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GILEAD

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Introduction

As if dealing with one dangerous virus in your life wasn't enough!

If you're reading this booklet, it means you're not just living with HIV; you're also living with hepatitis C, which can cause a whole other set of health problems.

Well over a million people in the U.S. are living with HIV. Hundreds of thousands of them also have hep C. So you're not alone in this.

But we won't lie: There's a lot to learn when it comes to HIV/hepatitis C coinfection. There's plenty of important info you need to know about how hep C works, how it might threaten your health, and what your treatment options are.

In this booklet, we'll give you a rundown of all of that, as of the information we have in late 2011. We'll also share the stories of a few people who are living with HIV/hep C coinfection right now, and talk about what they're doing to cope with their two infections and keep themselves healthy.

This booklet can never replace some very important conversations you need to have with your health care providers, case manager, support group and loved ones. But we hope it'll provide you with a quick reference to help you learn the basics.

So let's get started!

George Burgess

Age: 57
From: Atlanta, Ga.
Diagnosed With HIV: 1995
Diagnosed With Hep C: 1995
HIV Viral Load: 100,000
CD4 Count: 20

“A friend of mine took me into an abandoned building, reached into the wall and pulled out a dirty needle. It was dirtier than the Hudson River,” George Burgess recalls. “But my addiction said, ‘Use that needle anyway.’”

It may well have been that needle that gave George both HIV and hepatitis C. Then again, considering he was addicted to heroin for 27 years, he may have been infected at any time in the 1980s or early 1990s.

Regardless, 1995 was the year everything changed for George: He was diagnosed with HIV and hep C, told he had a CD4 count of 43, and given four months to live.

So much for that grim prediction. In 2011, George celebrated 16 years of life since those twin diagnoses. He’s alive, off drugs and sober, and has long since left behind a life marked by crime and violence.

In an ironic twist, George credits his infection with the two life-threatening viruses as having changed his life for the better. “I think the hepatitis C and HIV diagnoses keep my recovery in place,” George says. “Why risk your life?”

Another key to George’s recovery was finding care providers who truly care about his well-being. His current, longtime doctor disagreed with the one who told him he’d be dead within four months. They’ve worked together to keep George healthy. “She was really good for me, and she’s still good for me,” George says. “We’re a great team.”

George feels the same way about his social worker, who he’s also worked with for more than a decade and who he calls his “earth angel.”

Still, George realizes that staying healthy involves keeping a delicate balance. “I try not to do anything to jeopardize [my health]. … I know that being coinfected, I have to work—not work extra hard—I just have to be a little more careful.”

George also strives to keep himself not just healthy, but *happy* as well. “Quality of life is the most important thing,” he explains. “Enjoy your life, and educate other folks.”

George has learned a lot of powerful lessons over the past 16 years; and in his work as an HIV treatment educator, he’s had many chances to pass those lessons on to others. “I look at AIDS as an acronym: Always In Divine Service; Always In Divine Space,” he says. “I like being of service.”

Here are some of the major things you should know about hep C. We’ll go into more depth on all of these topics as we move through this booklet.

You’re Not Alone

At least one out of every four people with HIV in the United States has hep C as well. That’s more than 300,000 people.

Having hep C is not something to be ashamed of. Neither is having HIV. The stigma of living with these viruses is still high in much of the U.S., but you are *not* a bad person for having them, and you do *not* deserve to be judged or discriminated against because of them. (In fact, there are laws against such discrimination.)

> “Get more information and don’t panic. There are treatments for both HIV and hep C. And for hep C, the treatments can eradicate that virus from the liver completely. The treatment [may be] difficult to endure; however, there is light at the end of the tunnel if you get those great results.”
>
> – Sherri Lewis, diagnosed with hep C in 1972

How You Get It

Hep C is transmitted when blood from a person who is infected with hep C comes into direct contact with another person’s bloodstream. The most common way this happens is by sharing injection drug equipment—needles, syringes, cotton, cookers—or by sharing straws used when snorting drugs such as cocaine. Similarly, reusing tattooing instruments can pose a risk, as can sharing any other tools that may have a person's blood on them.

Hep C can also be transmitted through sex, since many types of sexual activity can make people bleed. Blood in even small amounts can potentially transmit hep C. This means that unprotected sex (especially rough sex and bareback anal sex) and activities such as fisting can be a danger. Keep in mind that this form of hep C transmission has been seen mostly among HIV-positive men who have sex with men.

There is no vaccine that can protect a person from getting hep C.

What It Does

Hep C damages your liver. Usually this damage occurs slowly, over time. You can live with hep C for 10 or 20 years (or more) before you feel any symptoms—in fact, 80% of people living with hep C have no idea they're infected. This makes the virus especially dangerous, since it can do its damage without you or your doctor realizing it until it's almost too late.

The liver is an extremely important organ, serving a few functions that are critical to your health. The more damaged it gets, the more your health is at risk. Hep C causes your liver to scar, turning healthy cells into useless cells that make it more difficult for your liver to do its job. Without proper treatment and close monitoring, hep C can ultimately cause your liver to fail completely.

Hep C Infection Can Be Cured

Unlike HIV, hep C *is* curable. Hep C treatment usually involves taking medications every day for several months without missing doses, while sometimes dealing with side effects that can be hard to handle. But when it works, it completely wipes out all of the hep C in your body.

However, treatment doesn't always work: Many different factors can affect whether hep C meds will work for you. We'll get into some of those factors later in this booklet.

Regardless of the odds, hep C meds are the best option available to prevent serious liver damage, illness and even death due to the virus. Remember that, if you have trouble with the treatment, you always have the option to stop. You can try the treatment again another time—or, if your health allows, you can wait for new meds to be developed that you may find easier to handle.

How Hep C Causes Harm

After it enters your bloodstream, the hep C virus (HCV) attaches to your liver cells. Once inside the cells, hep C forces them to create copies of itself. Those hep C copies then jump to other, nearby cells in your liver, infecting them one at a time. Your body's immune system tries to contain the infected cells by making scar tissue, which is almost like wrapping the infected liver cells in a bandage. "Fibrosis" is the medical term for scarring.

Over time, fibrosis damages your liver. Doctors may also use the word "cirrhosis" to describe scarring that's especially severe and won't go away. Extensive liver scarring can eventually lead to severe health problems, and may put your life at risk. (Cirrhosis, for instance, can lead to cancer.)

Sometimes It Stays, Sometimes It Goes

Not everybody who has hep C will develop liver damage. In fact, at least 15% of all people who are infected with hep C will "clear" the virus from their body within the first few weeks of infection (meaning there will be no sign of the virus at all)—without medical treatment! The likelihood may have something to do with genetics. It appears less likely to happen in men, as well as people with HIV.

Most people do not clear the virus. If after 12 to 24 weeks the hep C hasn't gone away, they are said to have "chronic infection," which means the virus has set up shop in their liver, infecting cells and turning them into factories that make more hep C. If you're chronically infected with hep C, you may be at risk for developing liver damage—and you need to consider hep C treatment if that damage occurs.

Keeping Track of Your Liver Health

You and your health care provider—ideally a person who specializes in hepatitis C—will want to monitor your hep C regularly to see whether it's damaging your liver. Hep C usually does its damage very slowly, but it's unpredictable: The virus can seem to leave your liver alone for many years, and then suddenly it may begin causing severe damage within the span of a few months. This is why it's important to have regular checkups with a hep C specialist every six months or so, even if your last checkup showed no cause for concern.

> "People who have fibrosis may not even know it because the liver is what is called a 'non-complaining organ,' so it's important to get checked by your doctor."
>
> – Sherri Lewis, diagnosed with hep C in 1972

Hep C can do a lot of damage to your liver without you experiencing a single symptom, so how you feel is not a reliable measure of your health. By the time you do start to feel symptoms of liver disease, it may mean you have severe liver damage that needs immediate medical attention.

To check up on your hep C infection and your liver, your health care provider may take one or more of the following steps.

Check your liver enzymes.

Enzymes (especially two enzymes called ALT and AST) help your liver do its job. A damaged liver can cause the enzymes to spill out of your liver and into your bloodstream. Your enzyme levels alone aren't a reliable measure of your liver health (you can have normal enzyme levels despite having liver disease). But by measuring how those levels change over time, your health care provider can begin to get a better picture of how your liver is doing.

Possible Symptoms of Liver Disease

- yellowing of your skin or the whites of your eyes
- dark urine
- pain in your belly
- swollen ankles or belly

Check your liver function.

There are a number of tests that can be done on your blood to look for "markers" of how well your liver is doing its job. These include testing your levels of platelets, albumin, bilirubin and something called prothrombin time (PT), which is a measure of how well your blood is able to clot when it needs to (for instance, to heal a cut on your skin).

Check your hep C viral load.

A simple blood test will measure the amount of hep C virus in your bloodstream and determine whether your liver cells are still producing copies of hep C. (It can also determine whether your infection is recent or chronic.) A high hep C viral load *does not* mean your disease is getting worse, but it may make your hep C harder to treat (although newer meds in development may help with this problem). Regardless, a high hep C viral load may also increase your risk of passing hep C to somebody else. People who are infected with both HIV and hep C tend to have a higher hep C viral load than people with hep C alone.

Determine your hep C viral "strain."

Your health care provider will perform a "viral genotype test" on a sample of your blood to determine what strain, or type, of hep C you have.

There are at least six strains of hep C. They're called "genotype 1," "genotype 2" and so on. Most HIV-positive people in the U.S. have type 1, which is the hardest to treat with currently available medications, but is still curable in many cases. Some good news, though: New meds are being developed that may have more success against type 1 virus.

> "My liver specialist continues to monitor once a year with a sonogram [aka an ultrasound]. It's very important to keep up with your hep C condition."
>
> – Sherri Lewis, diagnosed with hep C in 1972

Consider a genetic test.

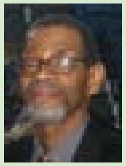
In recent years, we've learned that a specific mutation within a gene called IL28B can have an impact on the odds that one of the traditional hep C medications (called "interferons") will work. African Americans and Latinos are more likely to have a variation of the IL28B gene that may make hep C treatment less likely to succeed. Anyone can have this gene variation, though, which is why genetic testing is important.

On the plus side, researchers are working to develop new meds that may be able to work around the IL28B gene issue. Fingers crossed!

Consider a liver biopsy.

This is a routine medical procedure in which your skin is numbed, you're given meds to help you relax, and a small needle is very briefly inserted into your liver. The needle removes a tiny piece of your liver, about the size of a long, narrow postage stamp. Doctors then do tests on the sample to see how damaged your liver is.

You stay awake during the procedure, which is very quick; your doctor can fill you in on the details and address any fears you might have. (Keep in mind you don't have to have a biopsy in order to begin hep C treatment.)



> "I'm celebrating 16 years clean and sober; I think the hepatitis C and HIV diagnoses keep my recovery in place. Why risk your life?"
>
> – George Burgess, diagnosed with hep C in 1995

How HIV and Hep C Interact

Hep C is a big deal on its own, but when you've got hep C *and* HIV at the same time, things can get more complicated. This is because:

- Coinfected people tend to develop liver damage more quickly.
- Coinfected people tend to have a higher hep C viral load.
- The side effects of hep C treatment may be more common and severe in coinfected people.
- Taking hep C treatment alongside HIV treatment means more pills to manage and more drug interactions to watch out for.

We know this all may sound pretty grim, but the important thing to remember is that hep C infection *can* be cured. You've already taken an important step toward looking after your health by reading this booklet. The next step is to figure out, with your health care provider, where to go from here.

Keeping Your Liver Healthy

Preventing liver damage is about much more than taking hep C medications: There are many extremely important things you can do to ensure you're not putting your liver health at further risk. That means:

Don't drink alcohol.

There's no such thing as a "safe amount" of alcohol to drink when you're at risk for liver disease. Your liver filters the alcohol out of your blood, and the less you drink, the easier its job is and the less likely it is to get damaged. So if you're a big drinker now or you binge drink, every little bit less you drink can make a difference. Obviously, cutting out alcohol entirely would help the most, but it's usually best to take things one step at a time. Keep in mind that your health care provider may be able to connect you with medicines, counseling and other help you may need to cut down on alcohol.

Remember: Beer and wine count just as much as the hard stuff!

Quit smoking cigarettes.

We know, you don't need another reminder about why it's bad to smoke. But we'd be irresponsible if we didn't mention this: Smoking increases your liver cancer risk, and it hurts your organs and immune system in other ways that can lead to serious long-term damage. Just as with alcohol, even cutting down on the amount you smoke can help.

Get help to beat drug addiction.

If you use injection drugs or snort cocaine, remember not to share any equipment—you don't want to accidentally infect others or become infected with a new strain of hep C (or HIV!). If you think you might be addicted to drugs or alcohol, get help at your local HIV organization or clinic, or talk to your case worker if you have one. There are many forms of addiction treatment, some of which are perfectly safe to take alongside HIV or hep C treatment.

Avoid taking meds that can cause liver damage.

This won't always be possible, because some important meds have some liver risk. Be sure to look at the warning labels of over-the-counter medicines, and check with your doctor or pharmacist to make sure specific meds are safe. This also goes for anything else you take: herbal treatments, vitamins, you name it! Even things you might think are not an issue can cause huge problems, so it's better to be safe and check with a doctor first.

Eat healthy, wholesome foods.

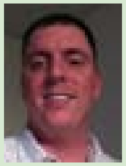
The healthier you eat, the less work your liver has to do to clear out toxins. Use good judgment when deciding what to eat and how much of it to eat; avoid crazy diets and try to stay away from junk food. Certain supplements can also be good for liver health (pure milk thistle is one example), but as we noted above, be sure to get your doctor's OK before you start taking them.

Exercise and reduce your stress.

Obesity can be especially dangerous if you're living with hep C: The extra fat can make its way into your liver and accelerate scarring. Meanwhile, stress may be an unavoidable part of life (especially when you're living with two chronic illnesses!), but counseling, support and staying active can help you reduce the odds that stress will begin to hurt your immune system. There are so many different ways to exercise and reduce stress; talk with others for tips and keep searching for a solution that works for you.

Keep your HIV in check.

You’ve got two viruses to manage, and it’s important to pay attention to both of them. Keeping your HIV under control (by taking HIV meds and sticking to your treatment regimen) helps keep your immune system healthy and your CD4 count up. The stronger your immune system is, the better able your body will be to fight hep C and ensure the success of some hep C treatment regimens.



“Fear, hopelessness and fatigue diminish the spirit. To combat these feelings: Take a walk around the block. Smile more. Call an old friend. Make a new friend. Laugh more. Volunteer. Eat well. Rest. Take your meds. Meditate. Take a few deep breaths. Begin to design the life you always imagined.”

– Kevin Maloney, diagnosed with hep C in 2010

Get regular hep C checkups.

As we mentioned earlier, hep C can go from doing no damage at all to doing a lot of damage, without you feeling any symptoms. Meanwhile, our knowledge of hep C and how to treat it is rapidly improving. So it’s important to check in with a hep C specialist every six months or so to make sure your liver is OK and you’re up to date on the latest info.

Kay D.

Age: 60
From: Colorado
Diagnosed With HIV: 1992
Diagnosed With Hep C: 1995
HIV Viral Load: undetectable
HCV Viral Load: 130
CD4 Count: 562

“A lot of people think: ‘I’m not feeling anything from hepatitis C, so I don’t have any problems,’” says Kay D. “But hepatitis C brought on a lot of the problems that I experience physically, more so than HIV.” In the early ‘90s, Kay married a man who happened to have an AIDS diagnosis. Their relationship wasn’t working well, but rather than end it, Kay began injecting drugs with her husband. “It eased the tension,” Kay remembers.

In 1992, a condom broke during sex and Kay became HIV positive. She concentrated on caring for her husband until he passed away in 1993. After that, Kay began using heroin daily—in part to numb the shock of her HIV diagnosis. “It was before the good drug combinations came out; things were kind of hopeless.”

Kay was diagnosed with hep C in 1995. “I ignored it,” she recalls. She was taking the medications available at the time to control HIV; in the meantime, hep C was wreaking havoc on her liver. Twice she underwent treatment for hep C—first with interferon and ribavirin, the longtime standard of care; then with Pegasys (pegylated interferon) and ribavirin. Neither course was successful.

“I wasn’t ready to start the treatment and let it be as effective as it could have been,” Kay recognizes in hindsight. “I was trying to work and take care of my mother, who was very ill. I stopped the treatment the first time. The second time, I stayed on it for nine months. I was just exhausted. I lost a lot of weight. My platelets were very low. I had to have transfusions. Ultimately, they took out my gallbladder, and I ended up on disability. At that time, a liver biopsy showed that I was in stage 4 cirrhosis.”

Ever since then, Kay has been on a transplant list for a new liver. She’s doing well, taking effective HIV meds, and she’s had the same great doctor for many years. She’s also been drug free for 14 years. “I had wonderful support, people who were there for me, when I was ready to take control of my life again,” she says.

Kay stays as healthy as possible by following a few guidelines: “Eating right, meditation, knowing my physical limits, spirituality, service, and surrounding myself with positive people”—including her sister, two daughters and two teenage grandchildren, not to mention a number of rescued dogs.

Kay encourages those recently diagnosed with HIV and hep C to seek out support groups. “Experienced members will arm you with words of wisdom and contacts, and share experiences that may well be something *you’re* struggling with,” she’s observed. “There are more people in the community with hep C—everyday people in all walks of life—than I could’ve ever imagined.”

When to Start

The answer to the question, "When should I start hepatitis C treatment?" is a lot like the answer to the question, "When should I start HIV treatment?" In both cases, most experts tend to agree that earlier is better: The sooner you can get the virus under control, the less likely it is to cause long-term damage.

In the case of hepatitis C, starting treatment may be more urgent if you have liver damage, especially if that liver damage is getting worse. The type of hep C you have can also play a role, as we noted on page 9.

Regardless, the choice to start treatment is one that you and your health care provider should reach together. It's important that you understand all of the benefits and risks before starting treatment, so you'll know what to expect when you begin. You'll also need to be sure you're ready to commit to treatment, since taking every dose is crucial.

Treatment Timeline

When you start HIV treatment, it's usually a lifetime commitment, because HIV meds can't cure HIV. But hep C treatment is different: It always has a beginning and an end. Doctors usually prescribe a single "course" of hep C treatment for anywhere between six and 18 months, depending on how quickly the treatment works against the hep C virus in your body. (In the future, newer, more powerful meds may help shorten the time you need to be on treatment.)

While you're on hep C treatment, you'll get periodic blood tests to check your hep C viral load. The goal is to get your hep C viral load to "undetectable" (meaning your hep C viral load is so low that our current tests aren't able to spot the hep C in your blood) as quickly as possible, and then keep it there. Keep in mind that it may take longer for people coinfected with HIV and hep C to be cured of hep C compared to people living with hep C alone.

Three months into your hep C treatment, you and your health care provider should have a pretty good sense of how well it's working. If it seems to be going well, you'll continue treatment for at least another three months (for a total of six months), and possibly for several months longer depending on your hep C viral load.

Once you've completed your course of hep C treatment, you'll want to keep getting checkups to see whether your hep C viral load remains undetectable. If six months pass with no sign of hep C in your body, you'll be told you have a "sustained virological response." This means there's no hep C left, and you're cured.

Keep in mind that, even if you're cured of hep C, you may still have leftover liver damage that will make it important to lead a liver-healthy lifestyle from here on out. And be sure to visit with your hep C specialist at least once a year, especially if you're still engaging in any activity that puts you at risk for hep C. It is possible to be infected with hep C again even though you've been cured of an infection in the past, so continue to get tested! (Remember: If you become infected again, you will probably feel no symptoms.)

Take ***Every*** Dose!

The most important thing to remember about hep C treatment is that you should never miss a single dose. This can be hard, especially because the side effects can sometimes be very difficult to handle (more on that in a moment).

The strength of hep C meds begins to drop very quickly if you don't take every dose. That increases the risk that your treatment will stop working, or that your hep C will become resistant to it.

So stay focused! Take every pill and every injection on time. If you don't think you'll be able to do it, now may not be the right time for you to be on hep C meds. Know your limits, be honest with yourself and your health care provider, and seek out whatever help you need to get to a place where you can handle the commitment.

Treatment Regimens

As of late 2011, there's basically one type of hep C treatment regimen for people coinfected with HIV and hep C. A single course of treatment usually involves taking these three different types of medications for six to 18 months:

Peginterferon alfa (also called "pegylated interferon," "interferon" or just "peg").

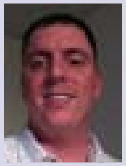
It must be injected under the skin with a tiny needle once a week. (This isn't like getting a flu shot or getting blood drawn; it's just a small prick into the skin that you can give yourself.) Two different companies make and sell peg drugs; one drug is called Pegasys, the other is called PEG-Intron.

Ribavirin.

This is a pill you take by mouth twice a day. Many companies make ribavirin, so it can be known by any number of brand names, including Copegus, Rebetol, Ribasphere, Vilona and Virazole.

Protease inhibitors (or "PIs").

Approved in 2011 specifically for people with hep C type 1, these are pills you take by mouth three times a day. There are two PIs approved specifically to fight hep C: Incivek (also known as telaprevir) and Victrelis (also known as boceprevir). PIs for hep C are different from the PIs you might take to treat HIV, so a PI you take for hep C *will not* be able to fight HIV, and HIV meds don't work against hep C.



> "The hep C treatment was not a walk in the park, but it was also *not* as bad as I read about online."
>
> – Kevin Maloney, diagnosed with hep C in 2010

Since PIs for hep C are still pretty new, we're still learning about their effectiveness and safety in people with HIV. So talk closely with your health care provider before considering them.

Side Effects

One of the most frustrating things about hep C treatment is that it may cause uncomfortable side effects. Some of these side effects can really disrupt your life. Unfortunately, we have few treatment options for hep C right now (though many are now in development), and the alternative is not much of an alternative: If left untreated, hep C may eventually cause life-threatening liver disease, which would be worse than the possible side effects of treatment. So be sure to talk with your health care provider and prepare yourself!

Common side effects of hep C treatment may include:

- Bone marrow suppression, which can result in certain blood disorders, such as anemia (which can make you feel tired)
- Depression, negative feelings or anxiousness
- Fatigue
- Flu-like symptoms (including headache and nausea)

Most of the time, these side effects can be treated and managed. But if they're just too much to handle, you can always talk to your health care provider about stopping treatment completely. Don't skip doses, because that'll just reduce the chances of your treatment working. And don't completely stop your treatment without first discussing the matter with your health care provider. Instead, work with your health care provider to come up with a plan to stop your hep C treatment and try again in the future.

Pregnancy Concerns (for Women *and* Men)

Don't take hep C treatment if you *or your partner* are pregnant! Ribavirin can cause severe birth defects, and interferon can cause loss of pregnancy. Tell your health care provider if you are:

- a woman who is pregnant, or if you think you might get pregnant within the next six to 12 months
- a man who is about to become a father, or if you think you might get a woman pregnant within the next 12 months
- a man who may have sex with a pregnant woman within 12 months

> "It's very, very important that people not get pregnant during their treatment for hepatitis C, because the ribavirin is such a powerful producer of birth defects."
>
> – Dr. Kathleen Clanon, Clinical Director, Pacific AIDS Education and Training Center

Your health care provider will either adjust your treatment regimen or hold off on hep C treatment entirely until after the baby is born, depending on how healthy your liver is.

The risks of a woman passing hep C to her baby during birth are small. However, it's riskier among women coinfected with HIV and hep C than among women with hep C alone. This doesn't mean it's automatically a good or bad idea to have a baby; it just means you should be sure to talk with your health care provider beforehand, because having a baby when you're both HIV positive and hep C positive is a big deal and requires careful planning.

Drug Interactions

Hep C meds can interact with other medications that you may be taking. This is especially true for many HIV medications. If two drugs interact, it can cause one drug not to work as well as it should, or it can cause potentially dangerous side effects.

In addition, these older HIV medications are not safe to take if you're on hep C treatment that includes an interferon or ribavirin:

- Retrovir (also known as AZT or zidovudine)
- Combivir (which contains Retrovir)
- Trizivir (which contains Retrovir)
- Videx (also known as ddI or didanosine)
- Zerit (also known as d4T or stavudine)

For this reason, you and your health care provider will want to carefully plan out your treatment. Be sure to tell her or him about *every* drug you're taking, whether it's from a prescription or it's bought over-the-counter (like painkillers). The same goes for vitamins and supplements. This will help your health care provider make any adjustments she or he needs to make to keep you healthy, and to keep both your HIV and hep C at bay.

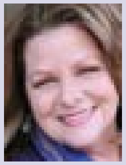
What If Treatment Doesn't Work?

Sometimes, despite all your efforts to keep your liver healthy, and even though you may have taken a full course of your hep C meds without missing a dose, hep C treatment may not be able to cure you of your hep C infection.

If this happens to you, remember: It is *not* the end of the line. You may be able to wait until new hep C meds are approved, or even join a clinical trial that is studying a medication in development. A number of such meds are now in the pipeline, and may be approved over the next few years.

Depending on why your treatment didn't work, you may be able to try the same regimen again. The most common reasons for this may be that the side effects were too hard to handle the first time around, or you just weren't ready to have hep C treatment be a part of your life (and thus you missed doses).

In the worst-case scenario (advanced cirrhosis or liver cancer), your doctor will ask you to consider a liver transplant. This is a major surgery that would only be used as a last-ditch effort if you have life-threatening liver damage. It would not cure you of hep C. (The waiting list for such transplants is very long, so there's no guarantee you'd be able to get one.)



"If I'd been able to take care of myself and focus on my own health, rather than trying to have all these other balls in the air, I think the two courses of hep C treatment would've been a lot more successful."

– Kay D., diagnosed with hep C in 1995

Although this booklet focuses on hepatitis C coinfection, it's not the only type of hepatitis that can be a danger for people living with HIV. Here's a quick look at two other forms of hepatitis to be aware of.

Hepatitis A

Hep A is a different virus from hep C. People usually get it by eating or drinking food that contains a microscopic amount of fecal matter (poop) that's infected with the hep A virus. Hep A is one of the big reasons that chefs, cooks, waiters and other people who serve food are told to wash their hands thoroughly after using the bathroom. You can also get hep A through anal sex (especially oral-anal sex) or through sharing unsterilized injection drug equipment.

Not everyone who is infected with hep A has symptoms, but for those who do, it's often a lot like having the flu, and diarrhea is common. Symptoms usually last anywhere from a few days to several weeks.

There's no treatment for hep A; much like the common cold or most forms of the flu, your body will eventually wipe out the virus on its own. In rare cases, though, the virus can cause liver damage. If you have hep C, the risk of liver damage can be higher, which makes it even more important to protect yourself.

There is a widely available vaccine you can get to protect yourself from hep A. Ask your health care provider to hook you up!

Hepatitis B

Hep B is also a different virus from hep C. The virus gets passed from one person to another in much the same way HIV is transmitted, such as unprotected sex, sharing injection drug equipment, and mother-to-child transmission during birth or breastfeeding.

Hep B is pretty common, especially among people with HIV. More than 350 million people worldwide are believed to be living with hep B, and about 10% of people living with HIV are believed to have hep B as well.

Almost every adult who catches hep B clears the virus naturally—in fact, they may never even know they were infected unless they get a blood test to see if they were once hep B positive. However, people with HIV may have a harder time clearing hep B.

This may especially be the case if the person isn't on HIV treatment, since that means HIV may be actively hurting their immune system.

If your hep B infection doesn't clear, you become "chronically infected," and you'll need to talk with your health care provider about your treatment options. Left untreated, hep B can cause the same sorts of problems that hep C can cause: liver damage and possibly liver cancer.

Just as with hep A, however (and unlike with hep C), a vaccine can protect you from hep B, and is recommended for just about everyone. If you haven't been vaccinated against hep B yet, be sure to talk to your health care provider.

Kevin Maloney

Age: 33
From: Upstate New York
Diagnosed With HIV: 2010
Diagnosed With Hep C: 2010
HIV Viral Load: undetectable
HCV Viral Load: undetectable
CD4 Count: 384

“Although I did have a substance abuse issue, I never put a needle in my arm,” says Kevin Maloney. Though it’s not the most common mode of hep C transmission, Kevin likely came into contact with hep C in the same way he did HIV: through unprotected sex. He was diagnosed with both viruses in 2010, not long after he’d been infected.

Kevin’s diagnoses were a much-needed wake-up call, and he immediately sought treatment for his drug addiction as well as the viruses. He spent time at an addiction recovery center and began attending Crystal Meth Anonymous meetings. He also started taking HIV meds. At the time his CD4 count was 285; once it reached 500, Kevin began taking Pegasys and ribavirin for hep C.

He’d been told he had hep C genotype 1A, which is considered the most difficult strain of the virus to treat. However, because Kevin was diagnosed within six months of infection, his doctor felt comfortable prescribing 24 weeks of hep C treatment instead of the usual 48-week course. He was also optimistic that Kevin’s treatment would work.

Ribavirin was six pills per day; Pegasys was a shot in the stomach Kevin gave himself weekly. “The doctor did the first shot, and after that I was on my own,” Kevin recalls. He adds that the shot didn’t hurt once he got the hang of it. His 7 million-copy hep C viral load dropped to undetectable by week 5 and stayed there—but his most challenging side effects didn’t start until *after* three months on treatment.

By the end of 24 weeks he’d lost 25 pounds and dealt with low energy and all-over body aches. But he found the psychological side effects hardest to deal with: “Increased anxiety, decreased concentration, racing thoughts, making rash decisions, with sleeplessness and decreased appetite mixed in,” he remembers. In part because of these effects, Kevin believes it’s a good idea to start talking to a therapist—and even considering meds for depression or anxiety—*before* starting treatment. Many doctors treating hep C recommend the same.

Six months after he completed hep C treatment, Kevin’s doctor declared him cured. “I could never have completed treatment if it wasn’t for the constant communication between my doctor and me,” he stresses. “He stayed on top of my health, as did I.”

Nowadays, Kevin gives back to his community by speaking about his treatment experiences and writing about them in an online blog. “Seek medical help as soon as possible,” Kevin advises those newly diagnosed with HIV and hepatitis C. “Educate yourself. Find a talk therapist. Be patient with yourself and with the process. Ask questions. Reach out to a friend when you’re in need. Don’t try to do this all on your own.”

Paying for Your Hep C Treatment

Like HIV treatment, hep C treatment can be extremely expensive. Fortunately, most health insurance programs will cover hep C meds and other medical costs. But what if you don’t have insurance?

- Federal and state programs, including AIDS Drug Assistance Programs (ADAPs), may be able to help. Talk with your case manager or health care provider about how to find out.
- If you’re on Medicare or Medicaid, they may be able to help cover your treatment costs as well.
- The companies that make and sell hep C meds often have special assistance programs for low-income people. Your case manager or health care provider should be able to help you apply.
- Other HIV and hepatitis service organizations may be able to lend a hand—not only with your treatment, but with other parts of your mental and physical health. Be sure to talk to your case manager or health care provider about finding support, or visit TheBody.com on the Internet to find a service organization near you.

Be Safe!

There are a couple of important things to remember when it comes to making sure you don't transmit hep C to another person:

Keep those needles clean.

Dirty injection drug equipment is still the main way that hep C is passed from person to person. So if you inject drugs, don't share your works—needles, cotton, cooker, water, any of it. Or at least make sure your equipment has been completely, thoroughly sterilized before somebody else uses it.

Be as safe as possible during sex.

Recent studies have shown that hep C *can* be transmitted through sex, especially unprotected anal sex between HIV-positive men who have sex with men. Transmission is most likely to occur when your blood comes into contact with theirs. So if you're a man or a woman and you're thinking of having unprotected anal sex, rough sex or fisting with someone of unknown hep C status, please reconsider. Condoms are good things!

Taking It Day by Day

Remember: You are not alone! Millions of Americans are living with hep C, and hundreds of thousands of them are estimated to have HIV as well.

Seek out your local HIV organization or clinic, and talk to the people there about how you can connect with other people in the same boat as you. Many organizations host support groups for people with HIV and hep C.

You can also look online at TheBody.com, where our bulletin boards, blogs, personal stories and organization listings can bring you closer to other people living with HIV/hep C coinfection.

TheBody.com is also home to a huge library of articles that can provide you with more information about living, and thriving, with HIV and hep C. We even have an online expert in our "Ask the Experts" forums who's available to answer your questions about HIV/hepatitis coinfection!

You’re living with HIV and hepatitis C.

What do you do next?

- Begin with your health care professional
- Use this booklet
- Then visit TheBody.com for more information

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The Complete HIV/AIDS Resource

Founded in 1995, TheBody.com is the most comprehensive HIV/AIDS resource on the Internet, serving more than one million visitors every month.