



HEP C STORIES

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INTRODUCTION

Finding out you have hepatitis C can be overwhelming. If you don't know much about the disease, it can be the start of a learning journey—albeit one you didn't sign up for. You might have questions, such as: What is hepatitis C? How did I get it? Can it be cured? What can I do to stay healthy? What should I expect down the road? In these pages, we provide you with some basic information to help answer these questions.

Having hep C is about more than a blood-borne virus or the pills in your medicine cabinet. It affects many facets of your life and *you* as a person!

The seven people you'll meet here all know what it's like to have this liver disease. Some of them are living with it and waiting to start treatment; others have taken treatment and are now gratefully hep-C-free. They all speak candidly about their journeys and share their insights and advice. Hearing about their experiences and how they cope will hopefully help make your hep C journey a little smoother.

The great news is that hepatitis C can now be cured. New drugs—called direct-acting antivirals (or DAAs)—are highly effective, unlike some of the older medications that only worked some of the time. And unlike the older hep C treatments, which caused unpleasant and sometimes debilitating side effects, the new treatments cause few side effects and are much easier to tolerate. Treatment is also becoming more accessible in Canada.

While it's true that hep C disproportionately affects certain groups—for example, people who use injection drugs, people who had unsafe medical procedures in other countries, and people born between 1945 and 1965—there is no one “kind of person” who gets hep C. This disease can affect people of all ages and backgrounds. The more we put human faces to the disease, the more we can challenge stereotypes and chip away at the stigma. If you would like to add your story to Hep C Stories online, email us at: myhepcstory@catie.ca.

Millions of people around the world have this infectious disease yet most don't know they have it! By getting tested and diagnosed, you've taken the first—essential—step to being cured. And by picking up this resource, you're arming yourself with valuable knowledge. Wherever you are on your journey, know that you are not alone. Many have travelled the path to health and wellness after being diagnosed with hepatitis C.

ALEXANDRA DE KIEWIT, 38 & ERIC PLOURDE, 40
Montreal, Quebec

Alexandra: Eric and I started dating in 2008. We met at work—at *L'injecteur*, a magazine by and for people who use injection drugs. I was working as the coordinator and Eric was an *infoman*, a writer/journalist who brings their lived experience to the job.



Eric: A couple of years before Alex and I met, when my ex-girlfriend and I went into detox and started methadone, we learned that we had hepatitis C. I felt more tired than usual and as a bike courier hadn't been performing as well, but I didn't know I was sick until I got my diagnosis.

My ex-girlfriend and I split up shortly afterwards so I was alone when I started treatment. By that time, I had cirrhosis [scarring of the liver]. I had no choice: I had to start treatment because my fibrosis was so advanced—stage 3. Treatment at that time was pretty rough, and it lasted six months.

Alexandra: I first tested positive for hep C in 1998, but a nurse later told me I had cleared the virus on my own. Then, in 2007, I learned that I had tested positive again. I was so mad at myself that day! I knew it was from a syringe I had borrowed from my friend to shoot heroin.

After Eric and I started seeing each other, we went for counselling together at our local clinic, Clinique l'Actuel, to learn how to manage my HIV and hep C co-infection (I had been diagnosed with HIV a year earlier). I was anxious to start hep C treatment but it was a super long time before my request for drug coverage was approved because my liver wasn't yet too badly affected.

Eric: My medication was rougher physically than Alex's but I had a pretty good setup. I was living in rent-controlled housing at the time, so my living expenses were manageable. After my weekly interferon injection, my father would come get me at the doctor's office in Montreal and we would drive to my parents' house in the country, in Verchères, where I would stay for three or four days.

They had a hot tub there, my mother would bring me food and pastries, I could play PlayStation, the whole shebang.

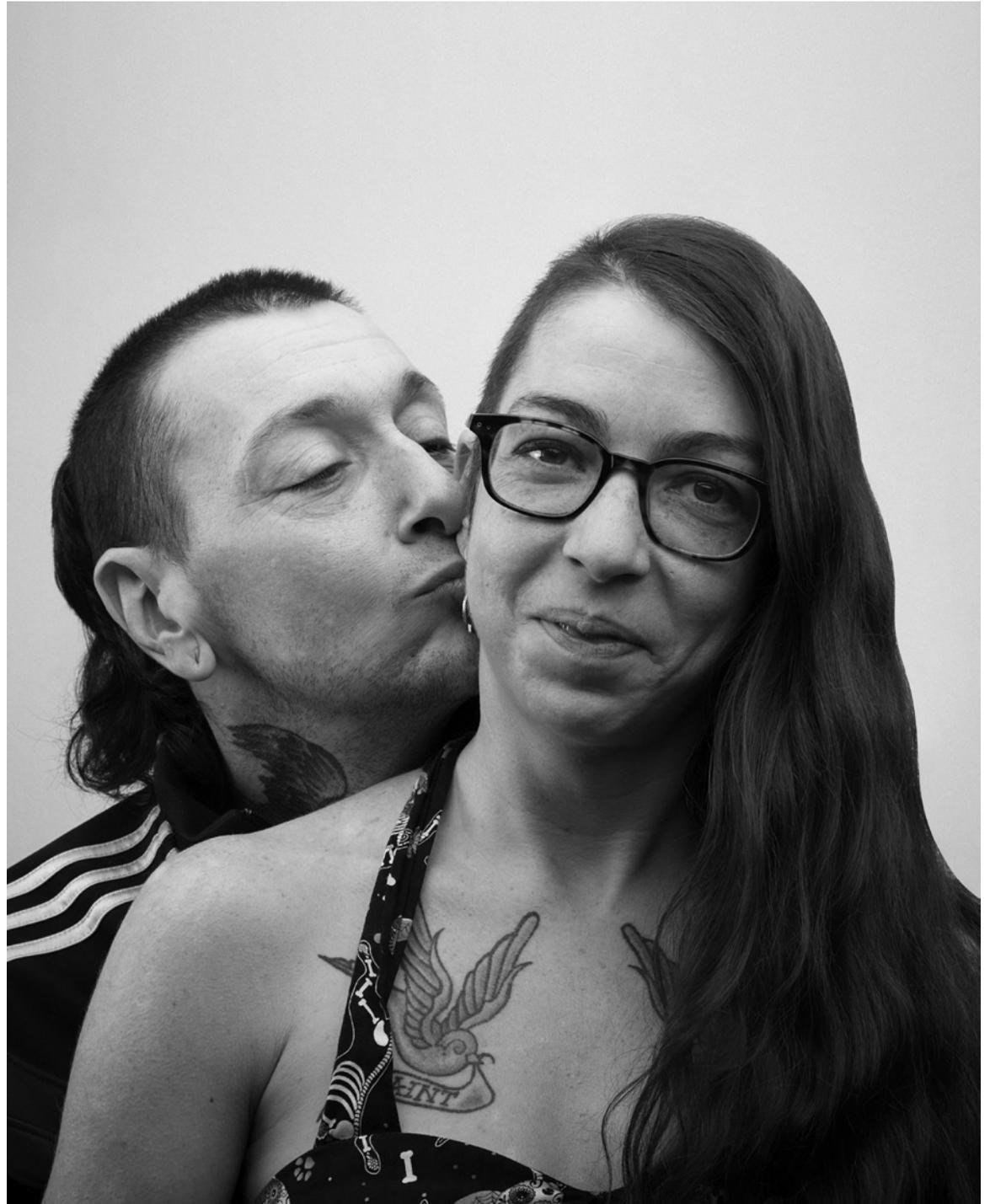
Alexandra: I took hep C medication (simeprevir and sofosbuvir) for just three months. I managed to keep working while on it. Some days I felt tired but it generally went well.

Eric and I had been trying to have a baby. What I found the toughest was that I had to get a shot of Depo-Provera to prevent pregnancy before starting my hep C treatment [because some medications used to treat hep C can harm the fetus]. That really got to me. I was already 37 years old and time was passing quickly.

The day I got the Depo-Provera shot, I cried like a baby at my doctor's office. I didn't

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After Eric and I started seeing each other, we went for counselling together at our local clinic, Clinique l'Actuel, to learn how to manage my HIV and hep C co-infection.



What is hepatitis C?

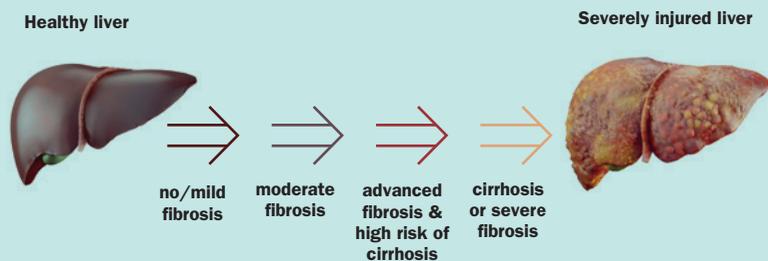
Hepatitis C (hep C) is a virus that harms the liver. The liver is an organ that does many important jobs, such as changing food into energy, cleaning out toxins from the body and storing vitamins.

The only way to know if you have hepatitis C is to get tested.

Most people who get hep C go on to develop a long-term (or chronic) infection. About one in four people with hep C clears the virus on their own, without treatment; the rest can be cured of hep C by taking medication.

Many people with hepatitis C feel well and do not experience any symptoms for years, but the virus can still be injuring the liver.

Over time the liver can become scarred—this is called fibrosis. If hepatitis C is left untreated and the liver becomes more damaged, a person is more likely to experience symptoms, such as swelling in the legs or yellowing of the eyes or skin (jaundice). When the liver becomes more severely injured and scarred, this is called cirrhosis. After many years a person may develop liver cancer or their liver could stop working.



There are six strains, or genotypes, of the hepatitis C virus—genotypes 1, 2, 3, 4, 5 and 6.

There is no vaccine for hepatitis C.

know anything about it, and it scared me. The hep C treatment didn't bother me much, but the Depo-Provera did—it put me in such a bad mood. And instead of stopping my periods, it made me bleed 25 days a month. It was not cool!

Eric: Before I started treatment, my life had not been going well. I had stopped working and had been feeling depressed. Although the side effects of the older treatment that I took were rough, that time brought positive things to my life. It brought me closer to my parents.

My parents helped me out a lot! So did one of the nurses at my clinic. She was a childhood friend who came from the same village as me. She wasn't my attending nurse but I knew she was there for me, both in Montreal and when I visited my parents, which coincided with her time off.

Alexandra: My family helped a lot. My mom really encouraged me. And then there was Eric, who was there day-to-day and had already been through treatment tougher than mine. I knew I could talk to him. He was a major support.

My colleagues supported me too—as harm reduction workers, they understood why I was sometimes tired or grumpy.

I had a really great nurse, Pierre-Luc. No need to hide anything or beat around the

bush with him, I could tell him everything. I knew he wouldn't judge me. You need to have someone on your medical team you can trust. Some people feel they need to hide their substance use, but it's better not to if you can be open about it. If you really want to get the help you need, it's best to be honest. With Pierre-Luc, I could say, "Yes, I'm using but I can still take care of myself."

Eric: We did our treatment at the same place but at different times. It was just a year and a half apart, yet they were two different eras because the treatment evolved so quickly.

Alexandra: Before treatment, I felt weighed down. It always took extra effort to take a shower, do housecleaning and basic chores. I just didn't feel up to doing anything. Now I have more energy—when I have something to do, I'm happy to do it.

Because of my hep C treatment, I had to change my HIV medications and start taking them morning and night, which disrupted the routine I had gotten used to. But my CD4 counts had never been so high as they were after my hep C treatment. They reached 900, which is great.

Eric: I'm one of the very lucky ones. Miraculously, my liver regenerated.

Alexandra: We'd still like to have a kid, but we don't know if it's in the cards....

What I went through made me who I am today. I have a life experience that makes it possible for me to support my peers, to understand and teach them. I do street work. I'm a liaison officer with Stella, an organization that works to improve the quality of work and life for sex workers. I'm a member of the CATIE board, which I'm really happy about. I've always loved writing and being able to tell people that

life goes on even if you have hepatitis C or HIV.

A hep C diagnosis can be heavy, but research and medical advancements have made it possible for us to have a good life. We just have to learn to take care of ourselves. It doesn't mean you have to become a saint. I do drugs, I drink, but I'm able to take care of myself. My rent is paid, I have a stable job, I'm making something of myself. I'm proud of what I've become and I love what I do. ■

ALEX AND ERIC'S ADVICE FOR OTHERS

Alexandra: See a doctor—it's super important because hepatitis C can be cured. Be honest with them. If you can bring along someone you trust, do. If possible, go to a specialized clinic. If you're in a stable place and you have support, you generally won't have problems with treatment.

Eric: Hep C isn't a death sentence. The treatments are so much better than they used to be. Hep C treatment can be a great opportunity to re-evaluate things, take a break or chill out—or if you want to stop using, to stop. I learned that I had hep C after 15 years of drug use. It happened at a good time for me to reflect and think about things.

SAJAD HUSSAIN, 44
Toronto, Ontario

I immigrated to Canada from Pakistan in August 2015. Shortly after arriving, I wasn't feeling very well. Initially, I thought maybe I was just having trouble adapting to my new life in Toronto. I had all kinds of symptoms—an upset stomach, dizziness, depression. My plan was to see a doctor and get checked out once I got my health card.



At first I couldn't figure out how I got it. Finally, it came to me: It must have been from a dental procedure I had in Pakistan.

So I waited three months—that's about how long it takes for a newcomer to Ontario to get a health [OHIP] card. Immediately after I got my card, I went to a walk-in clinic and told the doctor about my symptoms. He said, "You look fine but let's do a complete checkup." He recommended various tests and discovered that I have hep C.

I didn't know anything about this illness, so when I got home I looked it up online. I learned that it can kill you. I was shocked and dismayed. I didn't understand how this could have happened. The doctor told me and I read online that the virus is transmitted through blood-to-blood contact. At first I couldn't figure out how I got it. Finally, it came to me: It must have been from a dental procedure I had in Pakistan right before coming to Canada.

I told my roommate at the time because I was alarmed and wanted to let him know so that no harm would come to him from my condition. He is my friend. I know him from Islamabad. His father had suffered from the same illness, so he was not as fearful about it as someone else might have been.

The doctor told me that I shouldn't have sex, which made me feel like a pariah.

I wasn't dating anyone at that time, but I had met one or two people and was hoping to date more. He also told me that I would soon get a call from public health. I worried I might be quarantined. I felt scared and sad and depressed.

I called my closest friends—one in Pakistan and the other in the UK—and told them about it. I didn't tell my parents because they're old and ill and I worried about the impact it would have on them. I told my brother in Toronto, and then my three other siblings. It was difficult for all of them, especially my two sisters, but they have all been supportive.

When I met my liver specialist, I felt great relief. He reassured me that at my stage of liver damage, the state of my health wasn't as serious as I had thought. They did more tests to determine what strain of hep C I have. I found out that it's genotype 3, which is more common among South Asians.

Initially I was very disturbed by the fact that I had hepatitis C, but I have grown more comfortable and stoic about it. I've also started taking antidepressants, and I feel better—less stressed, less gloomy and more motivated about work and my future plans.

In fact, there are days when I totally forget that I even have it. I try to not focus too much on it because until I start treatment, there's not much I can do about it.

Late last summer they tested me again and determined that I probably have stage 2 liver disease. Now I'm in line for drug coverage through Ontario's Trillium Drug Program. I'm hoping I'll be able to start the medication soon.

I wish these new treatments were not so expensive. I had to do a lot of paperwork to apply for coverage and I am still waiting for final approval. It seems like all will be fine once I start the medication. I must get this treatment. I'm taking medicine for other health problems, so I'm quite used to being

careful about taking medicines on time. My body is already kind of a chemical lab.

The biggest challenge has been working a minimum-wage job, as a security guard, for which I have to exert myself physically and stay mentally alert for long hours while suffering from brain fog. I think my persistence to get treatment has helped me and despite all the paperwork and the long wait, I have been able to get the best out of Canada's medical system.

In the meantime, I was told not to drink too much alcohol, so for months now I haven't been drinking. The nurse also advised me to change my diet and eat more vegetables. It's hard for a meat eater to be totally vegetarian, but I'm trying to eat more vegetables.

I don't have many people in my life here. My brother who lives here is always busy; we mostly talk on the telephone. And since my roommate moved out, I've been living alone. I haven't made many friends.

Although I'm usually very friendly and I have plenty of friends in Pakistan, here I find it difficult. If you didn't grow up or go to school here, it's pretty hard to meet people. People are polite but not very chatty. Also, I work night shifts so even at work I don't get to interact much with people. It is kind of a lonely life: You go to work, you come back, you sleep, you eat, and then you go back to work again.

As a newcomer, you have to start from scratch. My old roommate told me that the first year is especially hard for immigrants. ■

SAJAD'S ADVICE FOR OTHERS

There are many different kinds of hep C medications available now. One's chances of getting them hinges in part on how much one knows about these things. That's why it's important to keep an eye out for the latest developments. These days it is not difficult to get the latest news about hep C and hep C treatment.

Is there treatment?

Yes! And the new medications, called direct acting antivirals (DAAs), can cure the vast majority of people!

Hepatitis C treatment has improved dramatically. It used to involve getting injections of a drug called peg-interferon, which caused difficult side effects and often didn't cure people.

New treatments involve taking pills, which cause far fewer side effects that are mostly mild. New treatments often last only two to three months and are far more effective.

Hep C treatment is expensive but there are programs that help people cover the cost. If you are interested in learning more about hepatitis C treatment or how you can get financial assistance, speak to a doctor or nurse.

Being cured of hepatitis C can improve a person's liver health and quality of life.

If you have been cured of hepatitis C, it is still possible to get it again.

JOAN KING, 70
Surrey, British Columbia

I woke up one morning in 1990 and noticed that, as usual, I was achy all over and my stomach hurt. I figured, I'm old—of course I'm achy. But this time, perhaps thanks to the body awareness classes I'd been doing, I started wondering about the aches and pains. So I made an appointment with the doctor. I told her to check everything. A few days later, my lab tests came back and my doctor called me.



“Everything looks great. See you next year,” she said. “Oh, by the way, your liver enzymes are a teeny bit high, but nothing to worry about.”

“Oh, good,” I answered. “See you next... wait a minute. What do high liver enzymes mean?”

“It’s nothing to worry about. Anything can do it, like if you had a drink the night before.”

I replied, “Doctor, I don’t drink.”

Then I heard her say, “Oh, maybe we’d better test you again.”

She ordered more blood tests. When the results came in, she called me to her office and told me I had tested positive for hepatitis C antibodies. She said she would have the test redone, along with a more specific one to see if I had chronic hepatitis C infection.

She went over what I now know to be a list of risk factors to determine how I might have gotten it. Yes I had received a transfusion, “but that was back in 1970,” I protested. She said it didn’t matter how long ago it was—people can get hep C from a transfusion and not show symptoms until much later. She looked worried.

I remembered my blood transfusion in Mexico. I had had an ectopic pregnancy,

for which I needed an emergency operation that required a transfusion. When I was asked to sign a consent letter, I asked the doctor what for.

“You will get hepatitis from the blood.” (Not “might,” but “will.”)

“But it will go away, won’t it? There’s a cure, right?”

“No.”

“Will it kill me?”

“Yes.”

“In how long?”

“About 20 years.”

I thought to myself, “At least I’ll have time to raise my son.” But something in me just refused to accept that news.

I received three units of blood that day—very probably infected with hepatitis C. And then I forgot about it. I guess I was in denial. As the years passed, I slowly began to feel symptoms, like weakness, achy joints and fatigue. I started experiencing dizziness and vertigo.

Fast-forward to 1990 when I went to see the liver specialist. By then the diagnosis first made by my doctor had been verified.

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Hepatitis C gave me purpose in life and a chance to develop other capabilities that I wouldn't have discovered otherwise.



Transmission

How does a person get hepatitis C?

Hepatitis C is a blood-borne disease. It can be passed when the blood of a person with hepatitis C gets into another person's bloodstream. Blood can be passed even when the amount of blood is too small to see.

In Canada, hepatitis C is most commonly passed through sharing equipment to inject drugs. A person can also get hepatitis C from:

- getting a tattoo or piercing with reused or unsterilized equipment
- sharing crack pipes or straws for snorting drugs
- having anal sex without a condom (the risk is higher if you have rough sex, HIV or other sexually transmitted infections)
- sharing personal items, such as razors, toothbrushes or nail clippers

It is possible to get hepatitis C from a medical procedure with unsterilized equipment. This can occur in countries where there is limited access to new needles and sterilized medical or dental equipment.

It is rare for hepatitis C to be passed during pregnancy. Hepatitis C can be passed to an infant through breastfeeding if the mother's nipples are cracked and bleeding.

Hepatitis C is NOT passed through most day-to-day activities. It cannot be passed by handshakes, hugs, kisses, coughs, swimming pools, toilet seats or sharing forks, cups, food and towels.

How can you avoid passing hepatitis C?

If you inject drugs, use your own equipment every time you use—including new needles, cookers, filters, vitamin C powder or citric acid, water and alcohol swabs. If you use new equipment every time, there is no chance of getting or passing hepatitis C or other infections like HIV.

If you smoke or snort drugs, use your own pipe or straw.

If you are getting a tattoo or piercing, the artist should use a sterile tattooing machine or piercing equipment, new needles, new ink and ink pots and new gloves. In a professional studio they should have an autoclave to sterilize equipment.

Use a condom when having sex, especially if you might be having rough sex or if you or your partner has HIV or another sexually transmitted infection (STI).

Avoid sharing toothbrushes, razors, nail clippers and other personal items.

"Hepatitis C! Best kind to have!" he declared almost jovially. "There's a cure called interferon, but you're not sick enough. Your enzymes are next to normal! Do you have any symptoms?"

"Well, yes," I replied. "My stomach hurts and I ache all over."

He blamed it on something I had eaten and on getting older. "You don't want a biopsy, do you?"

I imagined anesthesia, operating rooms, knives.... "Uh, no thanks."

"Good. Come back in six months."

I told my husband and my two kids right away. My son was 21 and my daughter was 17 at the time. They were very supportive. I took precautions, like cleaning up any blood spills right away and not sharing razors with my daughter, so they wouldn't get infected.

Little by little, I told some friends and more relatives. All were supportive except my neighbour across the street and my sister. They refused to see me after that. I was devastated that they reacted that way. I spoke to my sister on the phone when I was in her area once, but she still wouldn't see me. She has since passed away.

I've had my share of health problems. In 2003 I was diagnosed with breast cancer. (I did all the treatments offered to me—surgery, chemotherapy and radiation. I still get yearly checkups for

breast cancer.) I had a fall and had to have my shoulder replaced. I've been diagnosed with osteoporosis and have had two hip replacements.

I have taken hep C treatment several times, thanks to a biopsy that proved I had stage 2 fibrosis—in spite of low enzymes! I tried interferon four times without being cured. I had lots of side effects but felt better with the side effects than with the symptoms. Then in 2013, I took asunaprevir/daclatasvir for six months as part of a clinical trial. NO side effects. And it worked!!!

It was hard to believe that only six months of treatment could be effective. At the time, some of my friends had been taking interferon-based treatments for up to two years. I had seen the results of clinical trials with the newer direct-acting antivirals (DAAs) and my treatment was one of the best, so I had hope. My first test, after just one or two weeks of being on treatment, showed that the virus was gone...and it never came back.

It wasn't easy to continue working (I played violin with the Victoria Symphony) during the interferon-based treatments, but it helped that I loved my work dearly and that most people were supportive and understanding.

In my pre-treatment days, I felt weak—I couldn't even raise my arms. And I was itchy! I found it hard to walk around

Butchart Gardens. Now I can hike 10 km without even thinking about it.

I like to say that I had been looking for a cause—and it found me. I bought a computer and founded an online group called the HEPV-L list. We support people who are living with chronic hepatitis and share our experiences of clinical trials and treatments with one another. I got involved with the Hepatitis C Society of Canada and later helped start HepCBC. I made lots of friends, online and in person. I also started a newsletter, the hepc.bull (hepcbc.ca) so people could be aware of what was going on and feel a sense of community.

Hep C gave me a chance to have a more tangible purpose in life and develop capabilities that I wouldn't have

discovered otherwise. There is little that gives me as much pleasure as hearing from someone that they are cured!

Post-treatment, my life is pretty much the same as it was before, but with less pain and more energy. I've retired but still play violin in community orchestras and teach a few students. I love babysitting my grandchildren. I have a wonderful partner. I hope to travel more when my partner retires.

My dog, Marty, has been there for me faithfully. He makes sure I get my walks and stay healthy (and he guards me from evil delivery people). Life is good! I'm so glad to be around to experience it. ■

JOAN'S ADVICE FOR OTHERS

Get informed. Get treated. The treatments are almost 100% effective now and don't involve injections. Some take only eight weeks. Be sure to take your meds on time. Set your alarm and take the meds with you if you go out.

If you try complementary or alternative treatments, know that they won't cure you. Some might even make you sicker. Also, acetaminophen (Tylenol) will take away your joint pains but it can destroy a delicate liver. Let your doctor know about all the medications you're taking and have blood tests regularly.

LAUREN CARDINAL CHARLES, 32
Sturgeon Lake First Nation, Prince Albert, Saskatchewan

I was 16 years old and pregnant with my first son when I found out I had hepatitis C. That was in 2000. I was at Access Place, a clinic in Prince Albert, for a prenatal checkup. They pulled my file and told me I had contracted the hepatitis C virus. At that time I didn't really know what it was. It came as a shock. It was almost like being told I had cancer.



Testing

Two blood tests are done to determine whether or not you have hepatitis C.

The first test is called the hepatitis C antibody test. It tests to see if you have ever had hepatitis C.

If that test comes back positive, a second test is done to see if the hepatitis C virus is currently in the body. (Some people have the antibody but no longer have the virus.) This test is done using either the hepatitis C RNA test or the core antigen test.

If a person tests positive for both the hepatitis C antibody test AND either the hepatitis C RNA test or the core antigen test, it means they have hepatitis C. You can get tested for hepatitis C by a nurse or doctor at a clinic, hospital or community health centre.

The nurse was really caring. She explained what hep C was and how it can be passed. I felt afraid for myself and my baby but the nurses were reassuring.

I got a lot of support from my family. My dad had hep C too. He was very understanding. He told me, “You and the baby will be OK. You just need to take care of your liver.”

My older brothers, Cory and Todd, liked to joke and laugh—that was their way of making me feel OK, that I didn’t have to worry.

I had my baby two days after I turned 17. While my son was an infant, my dad was sick with diabetes and dying. I was trying to take care of him, be a mother to my son and be with my son’s dad. This time was hard for me. There was so much happening that I wasn’t really able to focus on the fact that I had hepatitis C.

Around this time my baby’s father got curious about drugs, so we tried Dilaudid (an opioid). That’s how the addiction started. We started doing a little more and a little more and then it got to be too much and I knew I couldn’t handle everything.

We had to go to my in-laws and ask them to take care of our son because our

addiction was taking over and I didn’t want him going into foster care. My brothers and I had been in foster care until we were 18 and I didn’t want my son to experience that.

In 2003, my dad, Roddy Cardinal Sr., passed and my life fell apart. My addiction took over. The goal of getting a home for my son melted away.

I ended up seeing another man and we robbed someone to get money for drugs. We were found guilty and I was sentenced to three years in a federal penitentiary.

The day I got back to the provincial jail from court, I got called into the nursing station. The nurse told me that I had tested positive for HIV. I went into shock.

I was scared and overwhelmed. The first thing I did was ask for all the information she had on HIV. She grabbed a folder and pulled everything they had about it. It felt like a life sentence had been added on to my three-year prison term. That’s when life got serious for me.

Barb, a support worker, and Shelly, a nurse from Access Place, came to see me the day after my HIV diagnosis. I remember Barb saying, “You’re going to be OK. We

are looking forward to working with you when you get out.” That really meant something to me.

After being transferred to the penitentiary I made a decision: “I’m going to stay healthy and deal with this the best way I can. I’ve got to be there for my son.”

When I was in the Pen I took every program they had—a violence prevention program, an employment program and I worked on getting my high school diploma. I did everything I could to make sure when I got out of jail this time, I was not going back to that life on the streets again.

One day, the nurse in the Pen told me, “I really think you should take this course in infectious diseases that I’m going to be offering.” I took the course and at the end of it, I got a job supporting and sharing knowledge with new inmates about hep C, HIV and sexually transmitted infections. I was the first peer support worker at Edmonton’s penitentiary for women.

I did that job for two years. It was a really good thing for me. I think it helped me deal with my co-infection. I tried turning my co-infection into a positive thing. If I could give information to just one person or get through to somebody and stop them from contracting any of these diseases, I’d be happy.

I really got into my Aboriginal culture in the Pen. I earned my medicine bundle and I was given teachings by the elders about different medicines, like sweetgrass and sage. I also earned my drum. I was taught how to make the drum and take care of it and I started learning songs. Sweats and an Aboriginal prayer and healing ceremony helped with my physical and mental health. I let go of a lot of grief, resentment, anger and pain during the sweats. I knew I couldn’t move forward unless I let go of that stuff.

In 2010, while I was in the Pen I found out that my brother Todd had died. He was

How can you take care of your health if you have hepatitis C?

Get connected to a doctor or nurse and have your liver checked regularly. Talk to a nurse, doctor or community worker about your hepatitis C treatment options.

Take care of your health as much as you can. Try to:

- Drink plenty of water.
- Get plenty of sleep.
- Eat as well as you can.
- Talk to someone about how you are feeling.
- Get some exercise, like walking or swimming.

There are things you can do to take care of your liver, for example:

- If you drink alcohol, try to drink less or stop drinking.
- If you smoke cigarettes, try to smoke less or stop smoking.
- If you take pain medications, ask your doctor which ones are safe for the liver.

Trying to cut back or quit drinking alcohol or smoking can be hard. You may want to ask your doctor or nurse how you can get support if you are trying to make these changes.

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Sweats and
an Aboriginal prayer
and healing ceremony
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physical and mental
health.



only 28. That was really hard on me. That's when I said to myself, "that's not going to be me." I got out of the Pen with a totally different perspective on my life and myself.

While I was in the Pen, I got approved for hepatitis C treatment (peg-interferon and ribavirin for 18 months). There were nine of us on this treatment. They housed us all in the same house. That time was excruciating—physically, mentally and emotionally—because of the side effects of peg-interferon and because I was living with other people who were also dealing with these side effects.

After I finished treatment, my hepatitis C test result came back negative for six or seven months, and then it came back positive. It was hard to take. I cried and got upset.

Shelly, the hep C nurse, said, "It's OK, Lauren, we can always look at getting you treatment again." At that time new treatments were coming out.

I've been getting my liver function checked and my liver is still healthy but I don't want to wait until I have stage 2 liver fibrosis to get treated. I want to start sooner than that. My son, Aidan, who is now 16, has been my little man the whole time. He was my

reason to keep going. Now I have two boys. My baby, Dakota, is four years old. He tested negative for both HIV and hepatitis C. He is healthy and happy.

When I got out of the Pen, I became a peer mentor after Barb and Shelly suggested it one day. It's making me stronger because it drives me to better

myself and to help others. Like today I ran into an old using friend of mine who just quit using. He said, "It's good to see you doing what you do." It felt really good to know that I'm setting a good example for people, especially the younger generation and the people I used to use with. It made me aware that I'm making a difference. ■

LAUREN'S ADVICE FOR OTHERS

Your life isn't over. You can still be happy and healthy. There is treatment out there.

Take your hepatitis C seriously. Understand that your liver is a vital organ—it's like your heart. You need to take care of it.

Know that you are not alone, that others are living with hep C or have had it.

You still have a good life ahead of you and hepatitis C doesn't have to hold you back from anything.

WILLIAM HART, 22
Wolfville, Nova Scotia

I was in treatment for addiction at a rehab centre and decided to get tested for hepatitis C, HIV and a bunch of other things while I was there. I had been tested for hep C months before and that test came back negative. I had no symptoms when I got tested (and I still don't), but I'd been using needles—including some used ones—to inject opiates since I took the first test. I figured it was best to get it checked out while I was in rehab, where there was support.



Hep C by the numbers*

- An estimated **71 million** people worldwide have chronic hepatitis C infection. Hepatitis C is a major global health problem, yet it receives relatively little attention and funding, both in Canada and internationally.
- **80-90%** of people who are infected with hepatitis C experience no symptoms whatsoever. This is why many people are unaware that they have hep C. Getting tested is key!
- Approximately **1 in 4** people with hep C spontaneously clear the infection. **3 in 4** people develop chronic infection and require treatment.
- Sharing injection drug equipment is the **#1** way hepatitis C is passed in Canada.
- Unlike the old hep C treatments, the success rates of the newer treatments is higher than **95%**.
- Many new treatments require taking just **1 pill** a day and cause few side effects.
- **6-18 months** is the length of time that people had to take older hep C treatments.
- **2-3 months** is the length of time a person needs to take most newer hepatitis C treatments. Treatment is much shorter than it used to be and it will likely get even shorter in the future.

*These numbers are estimates, based on the best available data at the time of publication. For more hep C numbers, please visit www.catie.ca/hepcstories.

A couple of weeks after those blood tests, I got a call from a doctor who works at the rehab. He told me I had tested positive for hepatitis C (and negative for HIV). I wasn't too shocked. I'd been trying to prepare myself for a positive result. But it was pretty upsetting to find out over the phone.

The doctor kept interrupting me and wasn't very supportive. Initially, I was more concerned about how he was treating me than with the actual test result. It sounded like he was driving and he clearly wasn't invested in making sure I was OK with the news.

Thankfully there were other people around at the time of the call who were very supportive. My grandfather was visiting me, so I told him immediately. I also told some of the rehab staff. My grandfather's view was that it was no big deal—I'd be fine and we could get rid of it, no problem. I tried to make it seem like I was fine because I didn't want him to worry.

Soon after, I told my parents when they came to visit. I had to explain a lot about hep C to them after I learned more about it, so they wouldn't panic. I tried to answer all of their questions.

My roommate and everybody who's close to me knows about my hep C at this point. Most of them have dealt with an addiction or know someone who has, so everybody



It doesn't make much sense to me to put financial gain in front of people's well-being.

is pretty understanding or has known someone who has hep C. I've met a few people at the rehab who either had or still have hep C. Most of them haven't suffered too much from it. There have been some odd questions though, mostly about how hep C is transmitted. Nobody seems to know that it's only transferred through blood-to-blood contact.

At the rehab I do various odd jobs, like helping with minor renovations and speaking with family members of clients to let them hear what it's like being an addict. I also started volunteering with the Hepatitis Outreach Society of Nova Scotia (Hep NS). I've already gotten to talk to students at a community college as part of a presentation Hep NS gave about hepatitis and HIV. I told them my story about how I ended up with hep C and how I'm trying to move forward.

I got a referral to a liver specialist in Halifax, so I'm going to have to drive about an hour each way. I plan on seeking treatment.

I hope to get medical coverage for direct-acting antivirals (DAAs) because otherwise I won't be able to afford it. But from what I've heard you still have to be in pretty bad shape to get medical coverage for it, and I'm not sick enough yet. I've spoken to a few people with many more symptoms than I have and they haven't received the DAAs so I doubt that I will.

I've only had hepatitis C for a year and that's not typically long enough for the disease to have progressed a whole lot. Hopefully, access will improve in the years to come. I understand that several organizations are pushing to make treatment more accessible and affordable. *[Editor's note: Access to treatment is changing rapidly. Medications used to treat hepatitis C are becoming more accessible in Canada's provinces and territories.]*

In the meantime, I intend to do everything I can to take care of my liver and keep myself up to date on the state of my health with regular checkups with my family doctor. I've been told a few simple things that can help keep my liver well, such as avoiding cigarettes and unhealthy foods. Also, acetaminophen (Tylenol) is quite

harmful for the liver if you take it too often, so I avoid it. Being in recovery, I abstain from alcohol and drugs—alcohol is a big one for keeping the liver well. And I'll just keep going to the specialist to make sure that if my liver health gets worse, I know about it immediately so I can try to do something about it.

I'm trying to stay optimistic. I feel healthy and I'm not too worried about the state of my liver. I'm a little discouraged with the healthcare system and how difficult it is to get coverage for treatment. It doesn't make much sense to me that they would put financial gain in front of people's well-being. ■

WILLIAM'S ADVICE FOR OTHERS

Don't delay—seek medical help immediately. Find out if you are eligible for treatment and then go from there. Find somebody you can trust to talk to about your diagnosis, somebody who can answer your questions and offer emotional support. Reaching out for help is a lot better than going through it alone.

If you tell your family or loved ones, make sure to do it face to face (if you can). Assure them that it's not the end of the world and that there is a cure, and try to answer whatever questions they might have.

LAUREL GLOSLEE, 49
Victoria, British Columbia

I found out I had hep C in the early '90s. I was an intravenous drug user back then. We didn't know not to share drug equipment like the spoons, filters and water. I had overdosed and my family doctor called me back in the next day to tell me that my hep C blood test had come back positive. I had hepatitis C and there wasn't anything they could do about it. I was still using, so I didn't really care.



It took me three tries to stop using. My son was my motivation. His father is also an addict and my son needed one of us to come back to reality. I finally got clean in 1997—that's when I sort of woke up.

For the first few years I was afraid to tell people I had hep C. I wanted to protect the people around me from me. The stigma of having a blood-borne illness kept my mouth shut.

When I finally told my parents, my mom cried. I was very close to her. My mom and dad were my biggest supports.

When we told the rest of the family, my mom's side of the family walked away. My mom passed away 10 years ago, and to this day the only contact I have with them is Christmas cards. Their silence shows their lack of knowledge and continued judgment. I feel guilty for the way my parents were also pushed out.

I'm the "little junkie" in the family...still. I haven't used for almost 20 years, but I still have that label hanging over me.

In 2001 my doctor offered me hepatitis C treatment. But I wasn't feeling really sick at the time and I wanted to focus on my studies—I had gone back to university for

my social work degree—so I put it off. In 2006, my health crashed, so I agreed to start treatment.

I have done three treatment regimens in total. I started my first one in 2006: pegylated interferon and ribavirin. It was awful. I lost my hair, puked nonstop, couldn't sleep and was in pain. Injuries from years earlier got worse. I had had a car accident in my teens and my lower back started to kill me. The headaches, insomnia and pain under my ribs were the worst of it. My hep C treatment was supposed to last for 48 weeks, but when my viral load started to climb after 28 weeks, I stopped taking it. *[Editor's note: This treatment has been replaced with newer, far more effective medications that are easier to take.]*

My life was awful during that time. Between 2006 and 2012, I walked out of a 10-year relationship, my mom died and my first hep C treatment failed. I was also diagnosed with diabetes. My life fell apart. I became agoraphobic—I didn't want to go out, I was afraid of people and their germs, and I was scared that I would make somebody else sick.

My doctor just kept prescribing painkillers. While taking a lot of Demerol each day, I somehow got straight As and managed to finish my social work degree.

In 2012, I was sent to a community health centre in Victoria called the Cool Aid Clinic, where they have counsellors, dietitians, acupuncturists, hepatitis C support groups and more. I started my second regimen: interferon, ribavirin, telaprevir and boceprevir. It was hell for another six and a half months. When that treatment failed, I didn't know what to do. There wasn't another treatment available. A new medication called Harvoni was coming, but not soon enough. That's when I found out I had liver cirrhosis. My hep C was progressing, and fast.

My son has known about my hep C for 20 years, since he was eight. He really kept me going through it all. He would get groceries, clean the house, and do other chores. I tried to hide from him how poorly I was feeling—the physical side effects and the brain fog—so I could get him to school and to his activities. But it was hard on him, especially during the first two treatments. He used to look at me like I was about to die. I felt extremely sad and guilty about this.

After my second treatment failed, I started volunteering at AIDS Vancouver Island (AVI), working at the front desk. That made me gain self-confidence and feel like I was part of society again.

Because of my cirrhosis I was eligible for free treatment with the new medications through a pharmaceutical company, on compassionate grounds. For my third round I took simeprevir, sofosbuvir and ribavirin. I had some side effects—a lot of scratching, headaches and fatigue—but nothing close to the previous two rounds.

Six months after finishing treatment I found out that I was finally cured.

When I found out that the meds had worked, I was—strange as it may sound—scared. I had been fully prepared to die. I wasn't at all prepared to live. I had to see a counsellor to help me understand that, yes, I do get to have a rest of my life.

My son is still scared to hope because my previous treatments had failed. But I think

he can see how healthy I am—I'm looking healthier now than I have for most of his life.

During those years when my treatment efforts failed, I did things to try and keep my liver healthy. A lot of it involved diet. I saw a nutritionist several times. I went for acupuncture, which reduced my lower back pain, so I continue to do that. I still drink warm water with lemon in it every morning because it's good for your liver.

Having hep C made me stronger. I am self-reliant but I've learned that I need to ask for help when I need it. Hep C has taught me to walk through fear—to take the first step, because you never know what's going to happen after you do.

I got so used to minimizing what I was going through that it's almost a relief to sit in support groups and hear others share their stories. I still go to those groups to show people that there is life after hep C. People were there for me when I needed support, so I try to be there for others. I talk about my hep C journey every chance I get.

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Hep C has taught me to walk through fear—to take the first step, because you never know what’s going to happen after you do.



Now I am the hep C peer educator at AVI. It's awesome. I get to go out into the community and talk about hep C and ways to promote a healthier liver, especially if you're not sick enough to qualify for treatment coverage. I think it's absolutely asinine that you have to get sick to qualify for treatment, though that is now changing. We should be treating people as soon as they're diagnosed.

I recently joined the board of HepCBC [a non-profit organization by and for people affected by hep C] because I want to push for a national hep C strategy. I also go into a stabilization and detox program twice a month to talk about liver health and hep C. I love doing that. It's such an honour to serve people in this way.

It's been two years since I finished my treatment. Life is still difficult in many ways. Physically, it's taken me what seems like forever to get healthy. But now I can exercise again. The brain fog is finally starting to lift. My energy level is improving, but I still have trouble sleeping. And stress is a struggle.

When I left my relationship 10 years ago, I worried that I had passed the virus to my partner, and I really didn't want to have another relationship until the hep C was gone. Although the risk of sexual transmission is extremely low, I didn't want to worry about that. Now I have friends who are bugging me to date. I remain open to the possibility. ■

LAUREL'S ADVICE FOR OTHERS

Seek support! You don't have to be alone in this. All you have to do is take the first step, then it gets easier. And seek treatment—it has changed so much and it's so much better today. I'm especially passionate about getting women treated. Now that these drugs are so good, you can parent through treatment. Best of luck to all who are reading this and to those who help us get through it!

Where can you get more information?

If you have questions about hepatitis C:

- Speak with a nurse, doctor or community worker.
- Check out www.catie.ca.
- Call CATIE's toll-free confidential phone line at 1-800-263-1638.



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HIV and hepatitis C
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