



HONOURING OUR VOICES





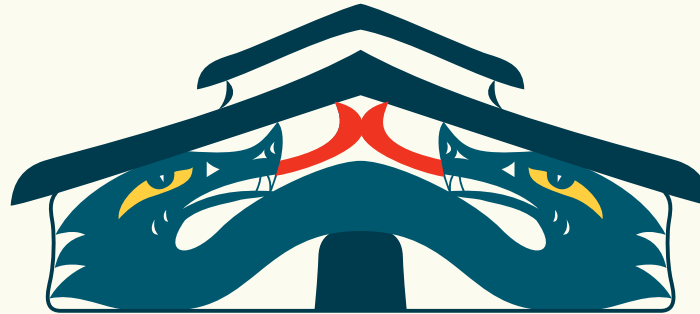
Honouring Our Voices

Personal stories about living with hepatitis C

Dedications

This book is respectfully dedicated to the participants who graciously shared their time and stories so that others impacted by hepatitis C, their families and their communities may draw from their courage and strength.

We share these stories to support their journey.



Introduction

In BC, there are high rates of hepatitis C (Hep C) within the Aboriginal population. The explanation for this is complex and is rooted in the overall effects of colonization on aboriginal people and communities. The loss experienced through that process has resulted in Aboriginal people being vulnerable to Hep C. However, the resilience that lies within Aboriginal people and communities will help to heal the hurt and trauma that has been experienced and help improve the overall health and wellness of individuals and communities.

Hep C impacts individuals in different ways, physically, mentally, emotionally and spiritually. It is important for individuals, families and communities to gain knowledge that will help support people and families in their journey with the disease.

In March 2015, five aboriginal people from across BC who are affected by Hep C gathered for a day of sharing hosted by Chee Mamuk, Aboriginal Program, from the BC Centre for Disease Control. The participants shared personal stories about their journey with Hep C. This booklet captures those stories using the words of those who shared.

Chee Mamuk puts our hands up to the brave warriors who shared their stories so openly and honestly.

The purpose of this resource is to provide information on Hep C in hopes that it creates a greater awareness of how Hep C impacts Aboriginal people, families and communities. Our hope is that these stories and information will create conversation, allowing for knowledge to be shared that will reduce stigma and misinformation about Hep C. Doing so will create more supportive communities for individuals living with Hep C and their families who are also affected.

We invite you to read these stories and to share the teachings with others in your family and community.

*– Chee Mamuk, Aboriginal Program,
BC Centre for Disease Control*



James Quatell / Quageelagee

James is from Campbell River Reserve, Wei Wai Kum First Nation. He describes himself as a “Roaming Elder.” He was diagnosed with Hep C in 2001. With treatment he was able to clear the virus by 2002. Now in good health, he says, “For 65 I’m doing damn good!”

I WAS DIAGNOSED with a gallstone so I made arrangements with my doctor in my community to get the operation which required blood work. Then my wife called and told me the doctor wanted to see both of us. I thought maybe he just wants to tell us what I’m going to have to go through for the operation. When I got to his office, he was quite serious. He said, “We’ve got your blood work back. You’ve tested positive with the Hep C virus.”

I said, “What are you telling me?” I wasn’t aware of what Hep C was. The part that I took seriously was when he said that Hep C is a virus that affects the liver, and can lead to liver cancer. What I thought I heard him say was that I was dying. Because my brother was diagnosed with Hep C, and he did pass away.



I thought maybe there was a mix up. I went back to my doctor in Campbell River and asked to do the test again, but he told me no, it’s positive. I really wanted to know for sure that I had the virus. So I fired my doctor and I got another doctor and asked him the same question. And he told me that he could arrange an appointment with the liver specialist down at Vancouver General. So I went there and got the test, and he sent the results to my doctor in Campbell River. I got the results back, and they were positive.

What is hepatitis?

Hepatitis is a medical term that means inflammation of the liver. If inflammation is left untreated for a long period of time, it can cause damage to the liver and prevent the liver from working properly.

There are many different types of hepatitis. Three of the most common types found in Canada are hepatitis A, B and C.

HEPATITIS A is passed through eating food or drinking water that has been contaminated with the Hep A virus. Hep A is more common in areas with poor sanitation and can be serious but will go away on its own.

HEPATITIS B is passed through contact with blood or bodily fluids that contain the Hep B virus. It can lead to serious health issues such as liver scarring (cirrhosis) and liver cancer if left untreated for a long period of time.

THE ONLY WAY to find out if you have hepatitis is through a blood test.

There ARE vaccines to prevent hepatitis A and B.

There is NO vaccine for hepatitis C.



I went home feeling sorry for myself. My first instinct was to fade away, let it take its toll. I was browsing through my TV, and there was a woman giving her testimony about clearing Hep C, and I thought, holy smokes, what a coincidence. I was meant to hear that. I replayed what the doctor had said, and realized his words to me were not that bad. He said: *“If it gets to that point, it could make you sick.”* And so even though I had the virus in me, it hadn’t affected my liver yet. I went back to my doctor and asked him, “what can we do?”

He told me that the treatment was quite expensive, but with some paperwork I could get it for free. The nurse sent the paperwork to Health Canada where it was approved. Next thing I knew I got a call from the pharmacy in my community to say that my kit was there. I said, “My kit?” It had needles and medication in it. I took it to my doctor. At that time I had to give myself an injection of the medicine. And the nurses helped show me how.

I was on this Hep C treatment for six months and that was a journey itself. Because that medication takes a toll on you. The nurses kept real good tabs on me.

**“ I went back
to my doctor and
asked him,
what can
we do? ”**

One day a nurse called me down to her office. Crap, I thought, here it comes. But it wasn't. She was so shocked. She said, "James, whatever you're doing, just keep it up."

**“ From my experience,
once you're told you
have this, don't let
them put you down.
Stand up,
be strong. ”**

So I thought I'm not going to die and I'm not going to let this kill me. I was already one step ahead of everything. My liver was strong because I don't drink, I don't smoke. And that's one of things I had in my favour.

By the time I was finished my treatment the nurse said, "There's nothing. It's gone." It was one of the best things I ever heard!

Once you're told you have this, don't let them put you down. Get on a journey and be active and know that you don't have to be ashamed. Stand up, be strong.

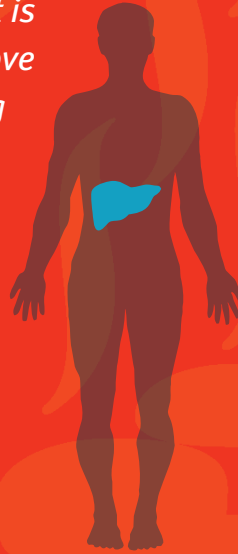
In the beginning, I would never have shared my story. My wife knew and that was it. I didn't want anybody else to know. Why? I was really deep inside of my spirit, ashamed. Because of this idea of being branded 'nothing but a dirty Indian.' It is one of the harshest things to try to live within yourself, and then try to survive in your community.



What does a healthy liver do?

The liver is necessary for a healthy life. It is located on the right side of the body above the waist. The liver deals with everything we put into and on to our body. It makes sure our bodies remain healthy.

- *The liver helps digest and filter food and drinks*
- *It helps filter lotions and creams that are applied to our skin*
- *It filters out chemicals and other substances from our blood*
- *It stores vitamins, nutrients and energy from the food we eat*
- *It makes proteins that help stop bleeding from a cut or injury*



Now I think one of the best things about this is that I can talk in my community – I sit on boards and I’m available under many departments there. I work with the Ministry and I do a lot of work with the hospital where I’m an Elder Advisor. I’m able to stand up to them and say, you know what? I’m a human being.

These are the things that need to be told and shared because there’s going to be somebody else that faces a similar situation. So if somebody reads or hears my story, they’ll know there’s a better way. Strive for something better because you are better than any virus, any disease.

I’m no longer a victim or a survivor. I am a voice.

— James Quatell



**“ I’m no
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Denise Mundy

Denise is from Ucluelet First Nation. She is a mother of two boys, 22 and 28. She's been co-infected with HIV and Hep C for twenty years. It was very important for her to get information and support from local AIDS support groups as well as family.

I DIDN'T THINK I'D BE HERE twenty years later, and I'm still here. Cleaning up and getting off the streets, taking care of myself and trying to be an example for my children. I try to educate them as much as I can and I still take medication.

I was living in Nanaimo. They look at AIDS and HIV as a street disease, a sexual disease, but I was in the church when I got HIV and Hep C. I was in the church doing good and just out of the blue, I find out my youngest one's dad did something and I got co-infected with HIV and Hep C from him. I was petrified.



**“ You’ve got to
have faith.
Trust yourself. ”**

What is Hepatitis C?

Hepatitis C is a virus that affects the liver. A virus is a tiny organism that uses the cells of the human body to duplicate and make more copies of itself.

Antibiotics have no effect on viruses.

Hep C enters the body through blood and, over time, causes swelling of the liver.

If left untreated over years, Hep C can cause scarring in the liver (cirrhosis) leading to liver cancer and other serious complications.



“I’m grateful that I’ve made it this far.”

I really didn’t think it was that bad until I moved home to a small community to find judgmental attitudes about being HIV positive. When I first found out, I thought I was going to have to give my kids up for adoption. I was afraid of going to an organization for support. I couldn’t do it because there was such stigma. I stayed in that little hole for a while saying, poor me.

This disease may seem like it’s an endless battle but it’s not. You’ve got to have faith. Trust yourself. Ask questions. It’s the only way you’re going to get what you need.

I’m grateful that I’ve made it this far. Just accept it. Love yourself. Be strong. Be proud. And ask for help. Personally, I say if you’ve got the opportunity to go on the medication, do it because it extends your life.

It took my doctors quite a while to find the right cocktail for me and finally they have found it. I’m down to two pills a day instead of twenty pills a day. I’m glad I’m feeling better. I no longer have the side effects I had at the very beginning of my illness. I ended up with neuropathy nerve problems in my feet with the first pills that they gave me,

and then I ended up with pancreatitis with the next set of pills, and I ended up in the hospital. It just takes patience and consistency, going to the doctor and stating your health issues and what concerns you. He can’t help you unless you say, look, I’m concerned about my HIV. I’m concerned about my Hep C. What can I do?

There’s all kinds of places that you can go to for support. I got support from a local AIDS organization that really helped me with my adjustment and learning to live and cope with being HIV and Hep C positive. It took a lot of energy and time but if I can make it, anybody can.

Line up those supports. Get somebody to go with you to the doctor when you’re getting your results. That’s what I did. It was very important for me to educate my children even though they were young. To this day, I still bring them with me to appointments. It’s really important to have someone with you when you go to the doctors, when you’re kind of foggy in the head, you’re tired. My oldest one comes with me a lot. He asks questions. He takes care of me.



Hep C is not passed through:

Sneezing or coughing

Sharing food or drinks

Sharing clothes

Hugging, kissing or shaking hands

Sweats, smudging, dancing, or singing

Mosquito bites

It is okay to show affection and share in ceremonies such as sweats, smudging and dancing.

I don't like being labelled and I say so. It's not just another disease but it is. People don't give up because they have cancer. We just have other situations with our blood. Our blood is infected.

My biggest thing now is to educate my family about HIV and Hep C, because I've had numerous close calls. My boys are educated. I try to educate my father, my brothers and sisters.

I feel that I am an example to my children that I don't give up.

Accept the things that you can't change, and change what you can. Because that's how we stay healthy. Communicating, being open, honest, taking your pills, stay with your regular doctor, follow up with all your appointments. That's what I've done. That's what helps me a lot.

You can let the disease defeat you or you can cherish your life and fight for it.

“Cherish your
life and
fight for it.”

I've ended up with a few more physical conditions but it's nothing I can't get over. I accept that now. It'll pass, I'm just sick for a while but it'll pass. Really take that time to take care of yourself and love yourself.

Take it one step at a time and be yourself. Be a support person. That's what I'm doing. Being a living example in my community. Stepping out and saying, yeah, I'm HIV positive and I'm Hep C positive. I'm comfortable saying that now, I've accepted it. I can't change it so I've accepted it. I get my gratification from being able to share what I know and make HIV/AIDS and Hep C a little less scary.

— Denise Mundy



Sheldon Joseph

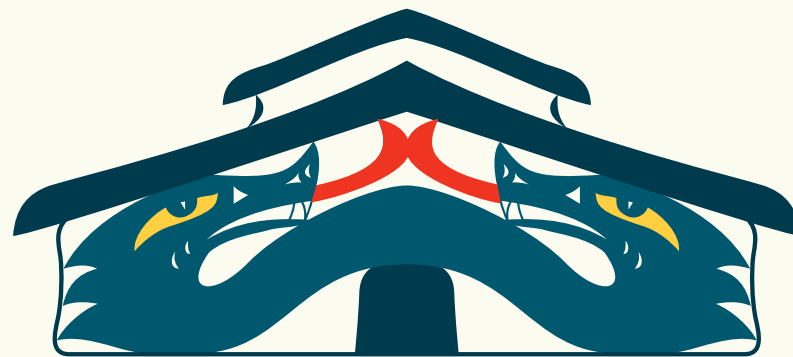




Sheldon is from Tl'azt'en Nation in Tachie near Ft. St James, a member of the Frog clan Sicilou. Within the same week he was infected with Hep C and HIV. He was able to clear Hep C without medication.

BACK IN 2007, I was on the street in Prince George. I was hanging around with this one fella and we worked every day panhandling, scrounging, borrowing – anything we could for money – to get high and keep drunk.

One particular night at four in the morning, I remember it was minus 15 degrees, he had asked me to doctor him, to the hand. I couldn't hit him for the life of me. *(To 'hit' means to inject drugs, and to 'doctor' someone means to inject drugs into a person for them.)*



We'd been at it for six or seven days straight so I'd been awake for six or seven days. I remember trying to hit him in the hand and next thing I knew, I went on a nod – I was literally asleep with the needle in my hand. The funny thing is, he hit the nod at the same time I did so we both fell asleep. I woke up, it seemed like forever but it was two or three seconds. Without even thinking, I saw the needle in my hand and I hit it. When I shared that needle, I got Hep C.



Christmas 2007 I started getting sick. I hadn't thought about it at the time but I had also had unprotected sex with a woman who said she had the flu. It turns out she was HIV positive. And I got HIV. Within a week, Hep C and HIV.

I thought I was going to die. I was co-infected. I didn't know anything about HIV, let alone Hep C or the combination of the two. I contemplated suicide.

My daughter called me up two months after I was diagnosed with HIV and Hep C. She said, "You're going to be a grandpa." That was a turning point in my life. I decided to live with my disease rather than die with it.

I think after the third month, I knew more about HIV and Hep C than 90% of the health care workers in Canada. It's my disease and I have a responsibility to understand it.

Within a year, I went to a conference in Prince George. I was living in Ontario at the time. They flew me to the conference in Prince George and I met up with a man who had also been co-infected. And I'd heard stories that he had cleared Hep C on his own. He says, oh, you'll get rid of it. Like it was nothing to him. But it was everything to me. I quit drinking.

I quit using. I quit smoking. I exercised. I ate healthy. Within seven or eight months, my Hep C was gone.

Keep your head up and talk to somebody who's had it or who's going through it. I can guarantee they'll give you some pointers as to how to get rid of it on your own. They say First Nations and some minority people can get rid of it on their own. I'm saying this for everybody.

“ *My daughter called me and said, you're going to be a grandpa. **That was a turning point.** I decided to live with my disease rather than die with it.* ”

Transmission

How Does Someone Get the Hep C Virus ?

In order to get Hep C, three things are needed. If any one is missing, Hep C cannot be passed.

1 BLOOD THAT HAS HEP C IN IT

+

2 DIRECT OPENING INTO THE BODY

Any open wound, sore, cut or needle stick on the body

+

3 ACTIVITY *any activity that moves infected blood into a direct opening into the body*

1+2+3=

**POSSIBILITY OF HEP C
TRANSMISSION**

**HEP C IS PASSED THROUGH
BLOOD TO BLOOD CONTACT
SUCH AS:**

Sharing injection equipment

Sharing drug snorting equipment

**HEP C IS SOMETIMES PASSED
THROUGH ACTIVITIES SUCH AS:**

Piercing and tattooing

Sharing razors, toothbrushes or nail clippers

Unprotected sex when blood is present

Needle stick injury

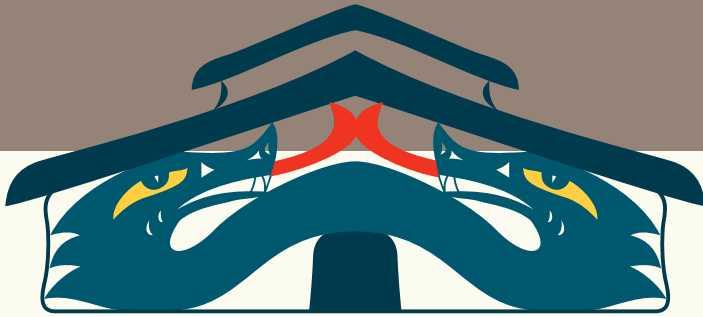
Child birth – mom to baby

Find somebody who's there who's gone through it, who's going through it. Learn about it. Hep C is finicky. It does damage to different people in different ways. There's no template to what it can do. The end game of course is liver failure.

Get help. Take care of yourself. First and foremost, you're not going to die.

If you follow those steps – quit drinking, quit using, eat healthy and exercise – First Nations or not, I strongly believe you can get rid of it.

**“ Find your peace.
Believe in yourself,
number one. ”**



Of course, I still have HIV. I did get rid of my Hep C. I struggle with my HIV. I don't know a person who doesn't. I'm very happy about the Hep C being gone.

It sounds ironic but I was lucky that I got sick. Otherwise I could be a carrier and passing Hep C and not knowing it. Even before I was diagnosed, I got tested because I was in a high risk situation. Every four months. My doctor got tired of me but he still did the test. I got sick. I was very lucky.

Find your peace. Believe in yourself, number one.

— *Sheldon Joseph*





Charlotte Brooks



Charlotte is from the Tsimshian Nation near Prince Rupert BC. She had already been diagnosed with HIV when she found out she had Hep C a few years later.

I WAS GOING TO MY SPECIALIST and they were doing all kinds of blood work, and one of my tests came back positive for hepatitis C. I never really shared too much because of the lifestyle I had – drinking, using drugs, stuff like that. It was kind of embarrassing, kind of shameful.

People who are living with hepatitis C are human. We're all human. We have feelings. One of my messages is that it doesn't matter, it shouldn't matter, how the person got infected.

My hepatitis C went away on its own. My body fought it off so it's gone. I'm pretty excited about that.

The message is always harm reduction and prevention for everything. Hepatitis C is one of the viruses that can live a long time outside the body, so precautions like wearing gloves should be taken if there is blood. It is also recommended not to share nail clippers, razors or toothbrushes and stuff like that where there might be blood present.

“ People living with hepatitis C are human. We're all human. We have feelings. It shouldn't matter how a person got infected. ”



A lot of people think you can get it through sex. It's very low risk sexually. It's mainly through sharing drug equipment.

If you're newly diagnosed, learn everything you can about it. The best way to accept a diagnosis is to go through all the emotions. Go through everything you need to go through. If you need to cry, cry. If you need to be mad and angry, get angry. It's a very emotional rollercoaster ride. But once you get over that ride and it stops, you accept what you have and learn everything you can about it.

“ You can sit in the same chair. You can hug the person, you can hold hands. *It's really important* to feel the affection of our family, our friends. ”

Yeah there's stigma, there's myths and there's discrimination. Hepatitis C could affect anyone, it could be your mother, your father, your brother, your sister, your niece, your nephew, even maybe your grandparent. That person needs your unconditional love.

If somebody is going to be out there saying things behind somebody's back because they have hepatitis C, then stand up for them and say, "That's my brother. That's my mom. That's my sister."

There are so many ways out there that people can find love and support. If you're not getting it from your main family, find a support group. If there's one or even a handful of people in your life who can tell you how special you are, how much you're loved, how much you mean to them, that changes everything.

This is where you learn who your real family and friends are. You also find out your inner strengths. You find out everything about yourself. It's pretty amazing. We need to have a positive outlook on life.

Signs and Symptoms of Hepatitis C:

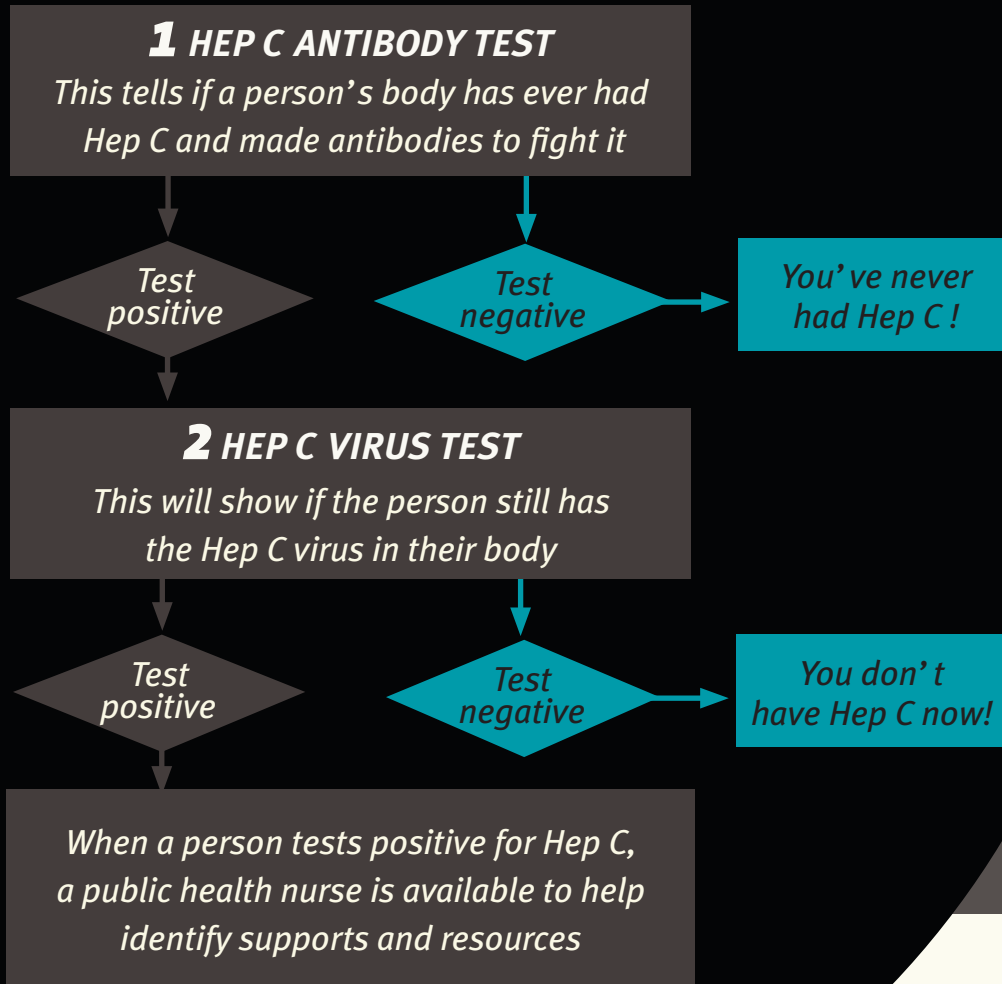
People who have Hep C often do not develop symptoms right away. Many people feel well, have no symptoms and don't know they have the Hep C virus in their blood. It may not be until after the liver has been damaged over several years that symptoms develop.

Hep C affects each person differently. Early on most people will have no or few symptoms. Over time some people may experience:

- **Fatigue** (feeling tired for no reason or a lack of energy)
- **Anxiety**
- **Muscle pain**
- **Abdominal pain** in and around the liver
- **Joint pain**
- **Brain fog** (having a hard time concentrating and suffering from memory lapses)
- **Headaches**
- **Itchy skin**
- **Depression**

Testing

The only way someone can know if they have the hepatitis C virus is through two separate blood tests.



WINDOW PERIOD

It can take **2 weeks to 3 months** for Hep C to show up through a **blood test**. The window period is the time between when a person is initially infected with hep C and the time it takes for antibodies to be detected in the body through a blood test.

RESILIENCE

Some Aboriginal people naturally clear the Hep C virus at a greater rate than others. However, this does not mean that Aboriginal people are naturally protected from Hep C.

You're number one. You'll always be number one. Even if you don't feel like it, just pretend until you feel like it. I've been doing that for years and it's hard! It's hard on me. Because of the things I've been through.

And I'm happy I'm a part of these learning resources. It takes a lot to do this and if you decide to have a voice, to come and do this, do it. It really makes a difference.

— Charlotte Brooks

**“ Love somebody.
Whether they have
hepatitis C or both
HIV and hepatitis.
Encourage them. ”**



Randy Tait



Randy is from the Nisga'a Gitksan Nation. He was born in Prince Rupert, BC, and is currently living in Vancouver.

I'M A FIRST NATIONS ARTIST. I'm a traditional dancer. I'm a storyteller. I do energy work with people. I go to my sweatlodge ceremonies. Anything to help me stay on track and stay away from the use of alcohol and drugs.

I found out that I had hepatitis C over fourteen years ago. I don't know how I got it. My lifestyle was very dark. I was using a lot of drugs, pharmaceutical drugs. I was shooting up cocaine. I lived a very risky lifestyle growing up. Somewhere along my journey, I picked up Hep C.

I didn't know what Hep C was. I was traumatized a bit. I was bothered by the fact that I was carrying a disease. I didn't know what it was all about so I ended up just living with it, day by day, and forgetting that I had it. I had many, many partners over the years. When I was drinking and doing the drugs again. I didn't really seem to care about my life at the time. I was living on this path of destruction.

When I decided to do something about my Hep C, at first I felt disappointed by my family doctor because he discouraged me to take the medication due to the side effects. But I advocated strongly for myself because I wanted to take my life back. So I worked with my doctor to get on treatment and was able to clear Hep C from my body.

I was always tired and fatigue would set in very easily, and depression – all mixed feelings. When I sobered up – I have over ten years of sobriety – my life changed. I finally took my life back and wanted to work on the hepatitis C virus I had. I finally went on the Hep C program and I did have all the side effects, the flu-like symptoms, from the medications I was taking. I was depressed and part of the way through, around the beginning, I wanted to give up on the treatments.



**“ My daughter
walked in. She said, “Dad,
I heard you wanted to
give up ” I said, “Yes, I do.”
She said, “Well,
*I want you
to live longer.*
I love you Dad.”
She gave me a big hug
and that was it. ”**



**“ I’m a First Nations artist. I’m a traditional dancer.
I’m a storyteller. I do energy work with people.
I go to my sweatlodge ceremonies.
Anything to help me stay on track.”**

I was laying in bed feeling sorry for myself and my daughter walked in. She said, “Dad, I heard you wanted to give up. I said, “Yes, I do. I don’t feel good. I don’t like the way I’m feeling right now.” She said, “Well, I want you to live longer. I love you Dad.” She gave me a big hug and that was it.

Today I’m happy where I’m at in my life.

I was reluctant at first to go on the hepatitis C medication but they’ve got some great drugs out there that will help with it. It’s changing every year. It’s getting stronger and better than what I had to go through.

This is a journey that I have been on for a long time.

Treatment

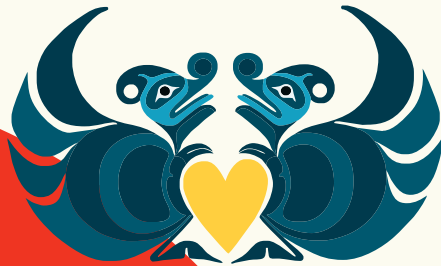
There are many things to consider in choosing the best approach for treatment. The health care provider will work with each individual to develop a personal treatment plan that will fit into their life.

New treatments are becoming available that require a shorter length of time and have less side effects. The current Hep C treatment is complex and can have side effects, which may include flu-like symptoms such as tiredness and difficulty sleeping.

- *Treatment needs to be fully finished to completely get rid of the virus*
- *Treatment is available to individuals who use substances and have other health issues such as HIV or diabetes*
- *Hep C positive women can have healthy babies*
- *Good nutrition, rest, exercise and other stress relievers can help with the treatment process*
- *After treatment a person can get re-infected*

Co-infection is a term that describes when there are two viruses in the body, such as hepatitis C and HIV.

“ *It’s getting better every year. They’re coming out with better drugs that help you heal.* ”



Prevention

Hep C is preventable

- *Get tested*
- *Know your Hep C status*
- *Use new drug injecting equipment every time (new needles and syringes)*
- *Use your own drug equipment every time (personal straws for snorting)*
- *Use your own personal care products (razors, toothbrushes and nail clippers)*

I feel really good today about going to any length to get my needs met. If you find out you have hepatitis C, see a doctor right away and see what medications are out there.

Take your life back. You don’t know how long you’re going to live for. It’s important that you take your power back, your life back, and move forward in life. Enjoy life the best way you know how. Life will get difficult at times. Just keep it simple. Life is very precious and you have a lot of loved ones out there that care about you. Thank you. All my relations.

— *Randy Tait*



**“ I reach out to people
that will help me on my
journey. And life
gets better. ”**



***Chee Mamuk is grateful to all those
who helped make this publication possible.***

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