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The baby boomers' stealth killer: hepatitis C

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Back in her hippie days, Elizabeth Rains was hitchhiking through Arizona in the rear of a truck when the drunk at the wheel crashed into a boulder. Rains needed close to 50 stitches in her head and may have had a blood transfusion.

Two years later, in 1971, she received blood in a Montreal hospital to treat hemorrhaging after the birth of her second child. A year after that, she moved to Vancouver and endured rough sex with a drug-addicted boyfriend.

Any of these events could have infected her with hepatitis C. But more than 40 years passed before Rains discovered she had the liver-scarring disease. Her quest to track down the cause of her illness and understand its nature gave rise to her new book, *Demon in my Blood: My Fight with Hep C – and a Miracle Cure*.

In Canada, about 75 per cent of people with hepatitis C are baby boomers, born between 1947 and 1966. Despite the disease's association with intravenous drug use, the majority of infections can be attributed to contaminated medical equipment, such as reusable glass syringes, B.C. researchers reported last year in the Lancet medical journal. After analyzing genetic mutations in the virus over time, they concluded that the spread of hepatitis C reached its peak in the early 1950s, when boomers were children.

Hepatitis C can inflame the liver for decades without triggering symptoms. By the time Rains was diagnosed in April 2014, she was on the verge of cirrhosis – a deep scarring that turns the mushy organ into the texture of hardened leather. Left untreated, the virus shuts down the liver's ability to filter blood and manufacture proteins that protect against infection.

Up until three years ago, the only option for treating hepatitis C was interferon medication, which cleared up the virus in just half of patients. Side effects ranged from flu-like symptoms to vomiting, diarrhea and severe depression.

Fortunately for Rains, Health Canada approved a new treatment less than a week before her diagnosis. She received $115,000 worth of direct-acting anti-viral medication, fully covered by insurers. Within 48 weeks, her disease was gone.

On the line from her home on B.C.'s Sunshine Coast, Rains explained what it's like to have hepatitis C, and why all boomers should get tested.

Your book reads like a whodunit. Did the unknown cause of your illness torment you?

When you get a diagnosis, you start racking your brain. You say, "Where did this come from, how did this happen?" But the cause didn't torment me – the disease tormented me. When I was researching and writing, I felt better. But if I wasn't writing, I kept having this creepy feeling about the disease, especially knowing I had had it for so long.

Symptoms of hepatitis C include fatigue, joint pain, weight loss. What were yours like?

I can't really put a finger on it. It was all very vague and so gradual. It's like if you see a child every day, you don't see them grow. There was brain fog, but I was able to work – I taught, I wrote. There were aches and pains, which I still have, but more of them then. Six months before I was diagnosed, I did lose a lot of weight. I'm normally 120 pounds and I went down to 108 or 110. I was happy – I didn't know it was from hep C.

In the book, you describe a friend who turned her back on you and a family member who feared contagion. What is the stigma of hep C?

Some people think it's highly contagious, and it's not. It takes direct blood-to-blood contact. Hep C is seen as a shady disease. You might picture rough characters dealing hard drugs. But if someone understands what hepatitis C is, what it's about, what it does, how curable it is and that it can happen to anyone, then you're usually okay.

What keeps people from getting tested?

I had the same doctor for years and she didn't test me. Many people just trust their doctor. When I moved to the Sunshine Coast, I got a new doctor and she does the blood test as a matter of routine. That's how I found out. The United States recommends testing all boomers. Canada recommends testing based on risk factors.

In my case, a lot of my experiences were long in the past, forgotten until I actually hunted through my memory. So now I say to everyone, "just get tested."

What was it like to revisit your flower child days, knowing your daughters would read about how vulnerable you were as a young mother?

I agonized a little bit over that, or maybe a lot, but I wanted to tell this story. And I really couldn't say, "I probably got hep C from this," without saying, "I might have got it from that." And that required details. One thought led to the next.

You wrote about a friend who manages hepatitis C with alternative remedies. Were you tempted to follow her path?

I do have a friend who swears by it, but she's a lot younger than me, and the progression of hep C tends to happen when you get older. She did have some very good health and diet advice, so I'm not saying I believe nothing of that. I just didn't believe it's a cure. I read a lot of studies and some were on attempts to use natural products. I never found any convincing results.

What would have happened to you if you hadn't received immediate treatment?

I could be dead now. There are four levels of liver damage and the fourth level is cirrhosis. I was right on the borderline of cirrhosis. If you're not diagnosed, cirrhosis can advance suddenly and it will become too late. If you're past a certain point, you're not going to be a candidate for a liver transplant.

What was the hardest part of your "hepatitis summer" of 2014?

I was heavily in shock and fear. I was very squeamish about having blood tests. And I had huge payment stress at first, because I didn't know if the treatment would be covered by my medical plan. But I was really lucky because I was teaching at a college and the drug plan covered all prescription drugs. I was reading and researching a lot, and seeing the results of the clinical trials [on the new direct-acting anti-viral drugs], and I did become confident fairly quickly. I was very careful to take the pills at exactly the same time of day; I did everything my doctor said. I forced myself to get my blood tested, and within a few weeks, the virus was disappearing.

How is your liver now?

My doctor says my liver now is just like his, and he's such a healthy guy. The liver repairs itself, like a starfish. It's amazing – the rest of the body doesn't do that. Now I'll have a glass of wine at dinner, maybe three times a week.

Have you become an advocate for people with hep C?

Well, I've got a blog called Hepboomers.net, because most people infected are baby boomers. I have other projects I'm working on, but I do keep in touch.

You had $115,000 worth of treatment. What kind of payment maze do patients face today?

The new pill-a-day treatment costs between $45,000 and $100,000, depending on the drug. The exact cost is a private negotiation between the provinces and the drug companies. The patient's [cost] has to do with your income, and every province has a different drug plan. You're not going to pay more than maybe $4,000, but if you have a low income, you won't pay much. Until recently, the provinces have restricted the drugs covered under the provincial plans to people who have liver damage up to about stage 2. But now B.C. and Ontario have stated that within a year, they will cover the drugs for anybody with hepatitis C, even if the liver is only slightly damaged.

What would it take to eradicate hep C?

The World Health Organization has set a goal of eradication by 2030, but it could be done much faster through testing and making the [new] drugs widely available. Testing should be routine at a doctor's checkup, maybe when you hit age 50. In the book I mentioned a very simple, non-invasive saliva test that has been approved by Health Canada. It's not widespread yet, but I think we'll see it a lot in the future.