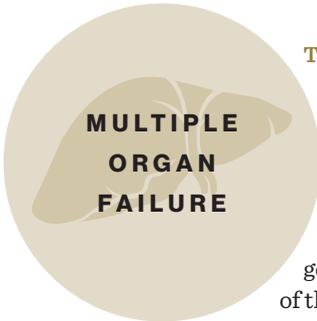

the boomers' disease

Liver disease may affect as many as a quarter of Canadians – and it's on the rise. One of the most common forms is Hepatitis C – the so-called Boomers' Disease because of its high rate of prevalence in this cohort. Here's what you need to know to protect yourself.

by CAITLIN AGNEW



**MULTIPLE
ORGAN
FAILURE**

THIS WAS THE OFFICIAL CAUSE OF DEATH WHEN MY FATHER passed away in 2006, just two days after his 56th birthday. While several of his organs had shut down by that point, the source of his complicated illness can be traced back to a single one: his liver.

Liver disease may affect as many as one in four Canadians. I use the word “may” because many affected are unaware that they even have the disease. The symptoms are so stealthy that decades could go by before developing any telltale signs, like jaundice, a yellowing of the skin and whites of the eyes that occurs when the liver is unable to properly secrete bile. In the case of hepatitis C, between 40 and 70 percent of those affected are undiagnosed. Of those who have been diagnosed, between two-thirds and three-quarters are baby boomers. One of them was my dad.

Like your home's electricity or plumbing, the liver is not something we typically give much thought to when it does its job. Located in the upper right area of the abdomen, this organ performs about 500 vital life functions, including processing what we eat, drink, breathe or rub onto our skin. It cleanses our blood; regulates glucose, hormones, cholesterol, vitamins and minerals; and produces



illustration by TIM ZELTNER

the bile needed to eliminate toxins and aid with digestion. It's a powerful workhorse that doesn't get as much public attention as the heart or brain due, in no small part, to the stigma of alcohol and drug abuse that has long been associated with liver disease. "Societally, there's a stigma and a lack of awareness at the provider level, and those two things together drive a lot of the vast under-diagnosis of liver disease," says Dr. Hemant Shah, clinical practice director at the Francis Family Liver Clinic and assistant professor at the University of Toronto. Liver disease is by no means a death sentence, but being too uncomfortable to talk about it can have fatal consequences: Approximately 5,000 Canadians die of liver disease every year.

"The liver is the chemical factory of the body," explains Dr. Morris Sherman, chairperson of the Canadian Liver Foundation and a now retired hepatologist at Toronto General Hospital. "It takes whatever you eat that comes through the digestive tract into the liver, transforms those nutrients into chemicals that the body needs – proteins, sugars, fats and so on – and then sends them out to the bloodstream." It's also, he says, the major detoxifying organ of the body. "Environmentally, we're exposed to all kinds of potential toxins," he says. "It's not just a recent phenomenon – historically, that's the case – and the liver has mechanisms to deal with that so these toxins don't hurt us."

The diseases that can affect this sophisticated organ are complex, and liver disease can take on more than 100 forms. These are the ones that are most commonly found in Canada.

NON-ALCOHOLIC FATTY LIVER DISEASE (NAFLD)

This affects more than seven million Canadians. It's mainly caused by obesity and an overload of fat in the body that ends up being stored in the liver. While NAFLD defines fat accumulation in the liver that occurs without excessive alcohol consumption, this, too, can have similar complications. Consistently drinking too much can alter and destroy liver cells, resulting in fat deposits called fatty liver or, more seriously, liver inflammation, which is known as alcoholic hepatitis and cirrhosis (permanent scarring of the liver). For women, the Canadian Centre on Substance Use and Addiction says that's exceeding two drinks a day, or 10 drinks a week.

NON-ALCOHOLIC STEATOHEPATITIS (NASH)

This more severe form of NAFLD is associated with ongoing liver damage and usually suspected in people who are overweight or obese. It's estimated that 20 percent of Canadians have NAFLD, which progresses to NASH in about four percent of the population.

HEPATITIS

This virus-based includes the following types:

HEPATITIS A

One of the three most common forms of viral hepatitis, it affects thousands of Canadians and is typically caused by contaminated food or drinking water.

HEPATITIS B

This type is spread through blood and bodily fluids via unprotected sexual contact, injection drugs or unsterilized tattoo equipment and affects thousands of Canadians.

HEPATITIS C

This type is spread through blood-to-blood contact. It affects an estimated 170 million people worldwide and may not present any symptoms for 20, 30 or even 40 years. It's also a leading cause of liver cirrhosis, the need for a liver transplant and liver cancer.

LIVER CANCER

Often an outcome of liver disease, it's one of the fastest rising and deadliest cancers in the country. It's rare to find liver cancer in someone who doesn't already have chronic liver disease. The major causes of this cancer are alcohol use, NASH and chronic hepatitis B and C.

No matter what type of initial liver disease, the end result is the same: inflammation. "Inflammation leads to scar tissue, which accumulates over time and, eventually, when you have enough scar tissue, that's the condition of cirrhosis," explains Dr. Sherman. Even at this stage, the liver may still work perfectly well, but as scar tissue continues to accumulate, it eventually replaces enough normal-functioning liver cells and liver failure develops.

In a perfect world, we would get to the problem faster, but that's not the current reality. Awareness surrounding the importance of liver testing

for those at a higher risk of liver disease is lacking in both the medical community and in the population at large. “It should never happen that a patient’s liver disease is diagnosed for the first time when they present with cancer or liver failure, but that still takes place very frequently,” says Dr. Sherman, pointing out that there have probably been years or even decades of abnormalities present before reaching this stage. “Ideally, we should know about it before from testing,” he says.

Guidelines for liver disease testing vary in Canada. In 2017, the Canadian Task Force on Preventive Health Care advised screening only people at high risk for hepatitis C infection, no matter what their age. But it is often difficult to identify people who are at high risk, as the list includes those who have engaged in intravenous drug use with shared needles, had unprotected sex with multiple partners and received blood transfusions, blood products or organ transplants before 1992. Patients may be unaware of – or have simply forgotten – past instances of risk, and calling them out rather than targeting a larger group leads to further stigmatization. To better diagnose those who may be infected, in June 2018, the Canadian Association for the Study of the Liver recommended age-based testing, specifically for those born between 1945 and 1975. The guidelines reached doctors across the country when they were published in the *Canadian Medical Association Journal*, and it’s up to them to implement them in their practices.

Dr. Shah is co-author of the study and says there are many different ways to test the liver but a blood test is the first step to assess inflammation. “Blood tests are very easy to perform and can be ordered by any doctor,” he says. “The hep-

atitis C screening test is a simple blood test, recommended for all people born between 1945 and 1975, that can be ordered by your primary care provider.”

Even though specialists are certainly aware of the urgency for testing, it’s not always top of mind at your regular check-up. Dr. Shah says this is due to the fact that most chronic liver disease has no symptoms and because of its association with alcohol and drug abuse. “Because of that stigma, there’s a lack of awareness and reluctance to be tested,” he says. “It’s the fear that if you’re diagnosed with hepatitis C, everyone is going to think you’re a drug user.” As a result, sometimes it’s just a matter of chance that testing happens at all. That was my father’s case. He discovered he had hepatitis C in the early 1990s, when he happened to take part in a medical test group run by his employer and a blood test was ordered.

For Elizabeth Rains, it was a move to a new doctor that gave her a diagnosis. As luck would have it, her new doctor was from the Philippines, a country with a high incidence of hepatitis. She was adamant about testing, even when Rains, who was in her 60s at the time, wasn’t. “You don’t voluntarily go to the dentist and say ‘Maybe something’s wrong. Would you drill my tooth?’” Rains says with a laugh. Although the thought of a blood test made her squeamish, she went through with it. “And then suddenly, I got the shocker of my life,” she says.

In her 2017 book, *Demon in My Blood: My Fight with Hep C – and a Miracle Cure*, Rains faces the difficult realization that she has been infected with the virus for years and may never know for sure when and how it happened. She describes her youth in the 1960s and ’70s – a time in her life that included wild parties, rough sex, a blood transfusion after childbirth and a horrific accident. It’s not exactly what we would call “clean living.” “In the hippie era, when I probably acquired the virus, no one talked about promiscuity; they called it free love,” she writes. “‘Make love, not war’ was the mantra.”

Perhaps the most tragic barrier to testing is the stigma associated with liver disease. Dr. Sherman says that there are two reasons for this. “In most people’s minds, liver disease equals alcoholism,” he says. “Actually, alcohol is only fourth on the list of common causes of liver disease. The second thing is that, when hepatitis C became well known, it was a disease of injection

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– Dr. Hemant Shah

drug users.” Although we now know that this is not true (hepatitis C was commonly spread through poorly sterilized medical equipment and blood transfusions, none of which were tested for the disease until 1992 in Canada), that stigma lingers. Given the serious consequences of cirrhosis, forgoing testing out of ignorance or ego could cost you your life.

I still find it difficult to tell others about my father’s illness. Unlike cancer or stroke, hepatitis is very misunderstood by many, and the negative connotations that come with it are none that I want associated with my dad, who was a quietly funny chemical engineer who gave me and my brother the most loving, nurturing upbringing.

It’s a social judgment that affected Rains deeply when she revealed that she had the illness to her circle of friends. “There was one friend that I pretty much stopped communicating with because her reaction really bothered me,” she says. While it’s important to relay your diagnosis to your family so that they can be tested in the small chance that they’ve also been infected, Rains didn’t find it necessary to explain her illness to everyone in her life. “You’re dealing with your own disease, and you might not want to take on the task of being the educator right then,” she says.

Another barrier to testing is the fact that, until recently, therapy was extremely difficult and not always effective. For hepatitis A and B, there is a vaccine, but treating hepatitis C often involved a notoriously difficult 48-week program of injections with interferon, a protein with aggressive side effects and a dismal success rate that only worked about half the time. It’s what my dad was prescribed, but treatment-related complications took his life before he could complete it.

Rains’s diagnosis came in 2014, just a few days after a new treatment was approved by Health Canada. Known as direct-acting antiviral medication, these pills are taken once a day and offer a 95 percent cure rate for hepatitis C, with minimal side effects and shorter treatment durations. They work by attacking the virus and preventing it from multiplying. In some provinces, like Ontario and British Columbia, the \$45,000 to \$100,000 cost of the drugs is covered by the government. Growing up with someone who lived with what we thought of as an incurable disease, I found it amazing to see that treatment has evolved so quickly that the World Health Organization has set a goal of eliminating hepatitis B and C by 2030. Since her treatment, Rains says that her

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liver has fully recovered. “The liver is like magic,” she says. “It heals itself like a starfish.”

In some cases, it’s simply a matter of adopting a healthy lifestyle. The American Association for the Study of Liver Diseases found a significant improvement in NAFLD when patients lose as little as five percent of their body weight and recommends adopting a healthy diet, combined with an increase in physical activity. “As I like to tell my patients, ‘What is good for the heart is good for the liver,’” says Dr. Shah.

You can’t be cured, though, if you don’t open up to your doctor first. “It’s always important to discuss anything that you’re taking or doing with your health care provider to ensure that it’s safe for you,” says Dr. Shah. Be truthful about your lifestyle choices, past and present, including alcohol consumption, your diet and any other factors or experiences that may put you at higher risk of liver disease. Patients who would like to get tested can simply ask their doctors.

Even when medical intervention is required, it’s better to find out sooner rather than later. Dr. Shah likens living with liver disease to looking at the horizon while walking toward a cliff. “You don’t see that the ground is going to give out from under you,” he says. “Everything is fine, and then suddenly you’re plunging off the cliff.” He adds that now is the time when many undiagnosed individuals are getting dangerously close to the edge of this cliff. “The hope is that they are offered the test and get diagnosed before they fall because we can treat and cure them reliably now,” says Dr. Shah. “It’s just a matter of identifying them.” It’s a hope that Rains shares: “There are a lot of undiscovered cases [of hepatitis C], so if you’re a baby boomer, it may be you.” *hr*