Journey to a Cure

How to get and stay healthy before, during and after treatment

August 31, 2015 By Casey Halter

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In October 2014, Sheila Dewey—mother of six, yoga enthusiast and railroad worker from just outside Sacramento, California—was among the first wave of people to be cured of hepatitis C virus (HCV) using the latest highly effective, interferon-free medications.

However, her 18-year journey from diagnosis to treatment was far from easy. Dewey was diagnosed with hep C at age 37 in 1996, at the first comprehensive physical she'd had since becoming an injection drug user (IDU) in her teens.

"I went totally the opposite of what I was taught, and spent a lot of years just beating myself up," says the preacher's daughter, who split with her Christian faith during adolescence. She married at 19, had children and developed a drug habit, and as a result was in and out of jail for much of her young adult life.

Despite her past, Dewey left her addiction behind, getting healthy while waiting for HCV treatment. "There is hope," Dewey laughs. "Make the right choices and get the right people to help you." Here, she outlines the steps she took to start and keep living a healthy life.

Step 1: Overcome Addiction

Dewey says that her hep C diagnosis was the beginning of her journey to a cure. "I wanted to change. I realized I've got one body and I've got to start taking care of it," she recalls.

In that respect, Dewey's story is not unique. Today, injection drug use is the most common means of HCV transmission in the United States. The U.S. Centers for Disease Control and Prevention estimates that hep C prevalence is approximately 70 to 90 percent among older users like Dewey. The high incidence is largely attributed to needle-sharing during the 1970s and 1980s, before anyone knew the risks of HCV and other blood-borne viruses.

"When I first got diagnosed with hep C, [my doctors] were like, 'Oh yeah, you're an addict, most addicts get it,' and that's all they told me," Dewey says. "But I kept seeing so many of my friends

pass from overdosing and just bad health in general that I wanted to change."

So, throughout the late '90s, Dewey did everything she could to abstain. She attended an outpatient program, reconnected with her faith and started attending peer support programs, eventually launching a Christian 12-step program at her father's church. Dewey didn't know that much about hep C at the time, but she believed the first step to building back her health was to kick her drug habit.

That's the best first move you can make as an IDU with hep C, says Judith Feinberg, MD, associate chair of medicine at the University of Cincinnati, who has devoted much of her career to researching the links between heroin, hep C and HIV/AIDS. In fact, it's the No. 1 prerequisite many doctors have for patients to be eligible for HCV treatment.

"It makes no sense to fix one liver toxin if you're not going to stop the other toxin," says Feinberg. It's an easy link to understand, since the liver's main job is to filter out all the poisons from the body and the bloodstream.

Even early on, hep C interferes with this toxin-filtering process and is a big risk to the health of HCV-positive IDUs, says Feinberg. In its later stages, the virus can even affect the body's ability to metabolize drugs, potentially increasing overdose risk and causing liver-destroying chemicals to remain in the bloodstream far longer than in HCV-negative people.

Guidelines from the American Association for the Study of Liver Disease advise doctors not to treat people who have hep C until they kick their injection drug use. The same goes for alcohol abuse.

Experts across the board say that living with hep C is like having simmering coals in your liver, and that drinking alcohol is tantamount to pouring lighter fluid on them. Alcohol causes swelling in the liver and higher hep C viral loads, and it increases the chance of developing cirrhosis (scarring of the liver). It also ups a person's risk for developing HCV-related liver cancer, transplants and even death.

So Dewey quit drugs and alcohol and set herself on the road to a new life. However, post-addiction, she realized that she needed to make a few more changes.

Step 2: Get Healthy

"I did no cigarettes and no drinking, and I also tried to knock out a lot of the sugars from my diet," says Dewey. Long gone were her days of cream-and-sugar coffee; "I switched to creamer only," she says. She did so at the advice of her doctor, a hepatologist referred to her by Dewey's primary care provider.

What may seem like a trivial dietary cutback is far from it, say liver disease experts. Several studies show that high blood sugar can actually speed the progression to cirrhosis in people living with hep C. At the same time, cirrhosis tends to increase the body's insulin levels, a fact that's especially important to people who are also living with diabetes.

As for Dewey's creamer-only coffee, there are now several studies showing that she was on the right track—drinking coffee, whether decaf or regular, can actually have a protective effect on the liver.

Dewey also swears by her cucumber-ginger shakes and has switched to a diet full of fruits and vegetables. She also tries to avoid fatty, high-calorie meals and processed foods as much as possible.

However, aside from eating well, doctors say there isn't much you can do in the way of quick medical fixes to avoid hep C progression.

"Milk thistle, licorice, multivitamins—I don't think these things work. This kind of 'voodoo medicine' is not good for the liver," warns Feinberg, when asked about alternative therapies or diets to consider while waiting for hep C treatment.

Milk thistle, the most popular herbal remedy for hep C, is often thought to reduce liver inflammation and possibly have an antiviral effect. However, a 2008 study conducted by the European Association for the Study of Liver Disease found no direct improvements in people who took it.

As for licorice root, a 2002 study found that compounds within the plant could help prevent liver cancer from developing in chronic hep C patients. However, the herb was only effective when taken intravenously, not in supplement form—and it also caused high blood pressure, which increases liver disease risk.

Regarding multivitamins, doctors like Feinberg generally advise against them. In particular, HCV-positive people are advised to avoid iron supplements, since iron can speed up liver scarring. However, doctors do recommend low-iron children's vitamins for those who are truly adamant about mineral deficiencies.

After switching up what she regularly ate, Dewey had one more not-so-secret trick up her sleeve: "I work out a lot," she says. Studies show that people who are of a healthy weight have far slower liver disease progression than those who aren't, proving Dewey once again put herself on the right track.

Dewey had been a cross-country runner in high school, so she already knew the drive and determination it takes to get in shape. She started working out four times a week ("body pumps and a cardio core," Dewey says) through a gym membership paid for by her job. She also takes Bikram yoga classes, sweating out vinyasas and power flows in 105-degree heat three times a week.

"I see a lot of people my age saying, 'My back! My legs!' So I try to keep it moving," Dewey says. She's also motivated by the fact that she's required to lift 75-pound packages on a regular basis at her job as a supply clerk at the Union Pacific Railroad in Elk Grove, California.

Despite getting healthy, Dewey still had concerns. “If you have hepatitis C, it puts you more at risk of getting liver cancer, so I didn’t want to keep waiting,” she says.

Step 3: Find Treatment

Since being diagnosed with hep C nearly two decades ago, Dewey made sure she kept up on annual appointments with her hepatologist, getting tested every year for liver function numbers and viral load counts to make sure she was not in danger of a major health crisis.

Luckily for Dewey, hepatic inflammation generally doesn’t start until 10 to 20 years after an initial hep C infection. What’s more, since she had been taking such good care of her health, Dewey didn’t have a lot of the liver damage that often results from the virus, or any of the comorbidities like heart disease or obesity that can make HCV worsen faster.

“I don’t have high blood pressure, I don’t have diabetes, so I felt blessed,” she recalls. “Because I was living a healthier life, I could wait for better medication.”

“Dewey’s story is not rare,” Feinberg says. “A lot of people who got hep C didn’t go on treatment [right away]. Interferon didn’t work that well and was very toxic. Plus, for the last five years or so, people have known that better things were coming.”

In fact, by the time the 2000s hit, Dewey’s doctors started telling her about HCV drugs that were in the pipeline. These new cures were expected to be much more successful and have far fewer side effects than previous interferon-based cures. So Dewey, with the help of her medical team, kept waiting.

Starting in 2013, those treatments finally made their way through approval by the U.S Food and Drug Administration. The first was Gilead Sciences’ Sovaldi (sofosbuvir), an all-oral cure. By early 2014, folks like Dewey were finally getting cured, at rates upward of 90 percent and with few side effects.

Because she had never been treated before, had been living with hep C for such a long time and was in good health otherwise, Dewey’s doctors got her in a clinical trial to access one of these breakthrough new treatments.

In July 2014, Dewey started an experimental drug regimen through Merck, called MK-5172/MK-8742.

Throughout treatment, Dewey kept going to work every day, continued her weekly workouts and kept up with the busy lives of all her kids and grandkids. “I didn’t stop anything,” she says. Plus, she got paid for the trial.

Finally, after 12 weeks of treatment, in October 2014, Dewey’s doctors and research team told her she was cured. She underwent eight weeks of post-trial follow-up. Today, she is living a life free of both addiction and HCV.

Step 4: Live Life

Thanks to HCV treatment, Dewey has lowered her risk for liver cancer by up to 70 percent and the risk of liver-related death or a transplant by 90 percent. Now, she's all about helping injection drug users through their own journeys to health and a hep C cure.

"I really believe in reaching back and giving others hope," says Dewey. "So many people think, 'How can I ever stop using?' and I say, 'If I can stop, anyone can stop.'"

Dewey is still running her Christian 12-step program, reaching out about hep C to her church community and volunteering at a group home in her spare time. She also regularly talks with her friends who are still struggling with addiction.

Next up for Dewey on her hep C treatment advocacy journey is a deeply personal step—her husband of 34 years is going to start HCV treatment soon.

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