I’m Still Standing

With a proper diet, exercise and a great care team, Houstonian Terri Milton is determined not to let advanced fatty liver disease get the best of her.

March 2, 2020 By Tim Murphy

Terri Milton loves life. The 56-year-old Houstonian of Mexican descent, a former realty executive and school bus driver, blisses out on singing with her church group, baking cookies with her grandkids and traveling throughout the United States with her husband, Doug.

“You have to have things to look forward to,” she says. “Because sometimes the ‘right now’ sucks!”

She should know. For 20 years, Milton has lived with complications from non-alcoholic steatohepatitis (NASH), an advanced form of fatty liver disease that affects roughly 20 million Americans and, because of a mix of genetics and lifestyle, impacts Latinos at a higher rate.

Milton’s NASH journey began when routine blood tests revealed that her liver enzymes were high. Her primary care provider sent her to a liver specialist, who told her, “You have fatty liver, but don’t worry about it—everyone does.” So Milton didn’t worry and went on with her life.

But by 2015, she was having regular abdominal pain, which was diagnosed as irritable bowel syndrome. Two years later, while in an emergency room for severe pain, she was told she had a gallstone. Surgery to remove it revealed that her liver was rough and nodular with scar tissue, rather than smooth, as a healthy liver should be. Three biopsies later, she was told she had NASH as well as cirrhosis (severe liver scarring).

That, says Milton, is when all hell broke loose. “Suddenly, I went from not having any symptoms to gaining 30 pounds in a week.” The weight gain was the result of ascites, a buildup of fluid caused by advanced liver disease. She ended up in the hospital again. “I was sopping wet all the time,” she recalls. “I continued to drain two to three liters of fluid daily for almost two weeks. I thought, I didn’t sign up for this. What in the world is going on?”

Soon after, she ended up in an ER again, this time with hepatic encephalopathy, a condition that develops when a damaged liver can no longer filter out toxins and they make their way to the brain, impairing cognition. “The one thing I was afraid of was losing my ability to think and speak, and now I wasn’t able to,” she recalls.

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Medications quelled the ascites. But Milton and her care team decided it was time to consider a liver transplant. The first evaluation for the procedure required 17 vials of blood. On top of all this, Milton had type 2 diabetes, which was causing gastroparesis, a painful condition that renders the stomach unable to digest food at a normal rate.

“I felt like I was playing Whac-A-Mole, one problem after another,” says Milton. A further defeat: Her MELD score, used to prioritize people for liver transplants, was too low. “It was crazy that my liver was still functioning so well that it didn’t affect my score.”

Amid all this, she had lost her appetite for life. “I was sleeping 14 hours a night. I’d gone from being a very social, active person to someone who wanted to cry at the thought of leaving the house.”

Then, on top of all that, she found out in May 2018 that she had hepatocellular carcinoma—yes, liver cancer. Two months later, she had radiofrequency ablation to destroy the tumor. In August, a scan showed that the cancer was gone, but in November, another showed that it had come back.

Early in 2019, she had a TACE—transarterial chemoembolization—a procedure that delivered chemotherapy beads to the tumor via a catheter threaded through a vein in her groin. Despite side effects such as pain, severe nausea and some hair loss, Milton said the treatment was “not that bad overall—it’s a miracle treatment.”

So this is where Milton is today, living daily with complications of NASH. That means, in her words, “trying as hard as I can to be active. Part of cirrhosis is muscle wasting, so the more you move, the stronger you are.” She got herself a smart watch to track her daily steps. “Some days I get in 500 steps, others 2,000.”

Then there are the meds. She’s on two different diuretics to avoid fluid buildup. She’s taking one med for irritable bowel syndrome, another to treat her high blood pressure, another to treat blood clots, 5,000 IU of vitamin D-3 “because my liver can’t process vitamin D,” two different kinds of insulin for her diabetes and a daily antacid “to keep everything calm.”

As for diet, she has to keep her sodium to below 2,000 milligrams a day as well as watch her sugar and carbohydrates to control her blood sugar, so she leans heavily on eggs with homemade salsa; steel-cut oatmeal with no added sugar; fresh fruit; nuts; salads; lean proteins, like fish, chicken and turkey; and wild rice and quinoa.

She admits that her story conveys a strong message about preventing NASH, diabetes and high blood pressure—all of which are influenced by genetic factors and obesity. “It’s not about going on a crash diet,” she says. “It’s a permanent lifestyle, what you eat and what you do. Sodas, muffins, cake, cookies—all the things that make you smile? Save them for small portions on special occasions.”

As for exercise, says Milton, “You have to start where you are. If you want to run a marathon but you haven’t walked a block, that’s not realistic. Today, get up and walk to the end of your street and back, and build on that.” She also suggests counting steps with a smartphone app, Apple Watch, Fitbit or similar device.

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For those already dealing with NASH, Milton says, “You need a team of doctors you can trust, and you need to be your own advocate and learn the language.” She recommends starting at the website of the Global Liver Institute (GLI), an organization she has become involved with, as well as the Facebook group she co-moderates, Cirrhosis and Liver Disease Support Group: Helping Each Other!

Milton is determined to make the best of her holding pattern. She wants to go back to school to become a social worker to help people living with chronic disease, and she and Doug are determined to travel to the roughly 10 states they’ve not yet visited, including Alaska and Hawaii.

Yet despite all she has endured with NASH, “I’m smiling,” she says, “because this journey has given me an opportunity to meet some of the most amazing people on earth—lawyers, caregivers, patients and people like [GLI founder] Donna Cryer. I’ve traveled to New York City to speak to researchers, and I’m part of the process of looking for a cure.”

That’s what keeps her spirits up. “I have days where I cry because it’s so overwhelming,” she says. “But the people I’ve met along the way are incredible, and that’s what I love.”