

Playing With Cancer

When Jim Plotkin was diagnosed with chronic lymphocytic leukemia, his sports hobbies helped him through the rough patches.

June 10, 2024 By Jennifer Cook

Like many people's cancer stories, Jim Plotkin's started with a seemingly innocuous symptom: bumps on his neck. His doctor felt them in early 2018 and sent Plotkin to an ear, nose and throat doctor, who said they weren't big enough to biopsy and told him to return in a few months. He went back twice, but she never biopsied the bumps.

It was an auspicious year for Plotkin. After a decade-long hiatus from golf—during which he and his wife had two kids—the 63-year-old former pro golfer returned to the game and qualified for “the biggest senior amateur tournament in the U.S. sponsored by the USGA,” he says. “They only had 156 people out of the whole world” at the August tournament in Eugene, Oregon. And more competitions were coming up. Living in Carlsbad, California, meant he could practice, play and compete year-round.

That fall, however, he wasn't feeling well. "I started to feel bad every other day, just kind of lethargic and foggy-headed, blah," he says. "I remember thinking, I need to go see a doctor." At an appointment in September, blood tests revealed low thyroid hormone levels; when the tests were repeated in October, his white blood cell count was high, and he was referred to a hematologist-oncologist for more testing. She told Plotkin that he probably had CLL, or chronic lymphocytic leukemia. CLL is a usually incurable cancer that starts in lymphocytes, a type of white blood cell, and can eventually spread to the lymph nodes, spleen, liver and elsewhere in the body.

But the year-end holidays were coming up, and Plotkin would have to wait an entire month to receive his test results. He spent time "stumbling around" the internet and getting scared by his findings. "The first thing you think about is, I can't die now—my kids are too young. And then you think, I gotta see my kids get married. And then you think, I gotta see my grandkids," he says.

In January 2019, Plotkin learned that the hematologist-oncologist had been right: He did have CLL. A CT scan that showed swollen lymph nodes and a swollen spleen confirmed the diagnosis. "You have the good kind of cancer," a young nurse in the doctor's office told him. But all he could feel was disbelief and shock. The average age of people who are diagnosed with CLL is roughly 70, and he was only 57.

Keeping Things on the Down Low

Plotkin didn't want to tell anyone about his cancer diagnosis, although he's not sure why. "I don't know—maybe I was embarrassed," he says. He told his wife but waited seven months to tell his teenage son and daughter so that the news wouldn't disrupt their school year. As it was, when his daughter descended the stairs at home and saw her dad and mom looking serious, knowing that they wanted to talk, she said, "Don't tell me you have cancer," at which point both parents started to cry.

People living with CLL who see minimal changes in their blood counts and experience no symptoms usually don't require immediate treatment but instead can be put on a watch-and-wait program of regular medical exams and blood work, sometimes indefinitely. But Plotkin's cancer was more advanced, and the hematologist-oncologist started him on two drugs right away—an oral targeted therapy combined with a monoclonal antibody given intravenously.

The side effects—starting with bleeding—began almost immediately. During the day, when he walked, he would find blood in his saliva if he spit; at night, his ears would bleed, leaving bloodstains on his pillow that he would discover in the morning. During the first month, he also developed atrial fibrillation, a heart rhythm disorder that required a couple of different

medications, which he still takes. He was seeing the doctor so often that he had to cut back to part-time work at the employee testing business he owns and runs.

“I felt like my whole body was falling apart,” Plotkin says. “I had one thing after another going wrong. There were a few other things besides the side effects. It was a horrible year.

“Plus, it took me a year to accept I had CLL” he adds. “I would say to myself, like every day, you have CLL. But I just couldn’t get past thinking about it, thinking, I’m gonna die right away if I don’t get lucky.”

A Change in Meds—and Outlook

After eight or nine months, feeling worn down by side effects, Plotkin switched doctors and saw Michael Choi, MD, a CLL specialist at Moores Cancer Center at the University of San Diego, a National Cancer Institute–designated comprehensive cancer center. It was a fortuitous time to do so. In May 2019, the Food and Drug Administration had approved another targeted therapy for people with CLL, and Choi, a hematologist and medical oncologist, had been on the team researching this use of the drug.

Stay focused on doing your normal life.

Choi started Plotkin on this med along with a new monoclonal antibody. The difference was striking: With only mild, manageable side effects (cramps and diarrhea), he was able to remain on the drugs for the full course of treatment, which ended in September 2020.

What’s more, the change helped shift Plotkin’s perspective. Instead of thinking death was imminent, he acknowledged to himself that he had a chronic illness that could be managed. That, in turn, engendered a return to a kind of normalcy. “You have to stay focused on doing your normal life,” he says, and because “the medicines out there for CLL patients are great now,” that’s more doable than ever.

Plotkin had played and practiced golf throughout his treatments and realized that CLL was a boon to his game. Golfers often fixate on their last bad shot, which can be a game-losing distraction. But Plotkin would think, Well, you have CLL, who cares if you hit a bad shot into the water? It’s not that important; go get it, and hit another one. “Golf is so hard, you’re gonna hit bad shots,” he says. “Tiger Woods hits bad shots. Everybody hits bad shots.”

His game improved as a result of his new attitude. “I’ve won five individual and three team tournaments, and some of them are considered noteworthy wins,” he says, including the Northern California Golf Association Senior Championship in 2022, which he won by three shots—the only golfer to finish the tournament under par. At one point, he was ranked in the top 15 in the United States in the amateur golf senior division. His goal now is to stay competitive for the next five or six years, so he keeps taking lessons and practicing.

He also returned to surfing, a sport he had taken up at age 36 when he moved to Southern California. During treatment, “I was pretty weak. And when I paddled out and there was a decent amount of waves, I couldn’t make it, so I wouldn’t even try,” he says. Now, he gets out on the water regularly.

“Surfing and golf are different types of hobbies,” Plotkin says. With surfing, “I’m not keeping score. It doesn’t matter how bad I do—or only a little bit. And it’s kind of a Zen sport. When you’re out there, you rarely think about work. Riding a wave is a great feeling. After you’re done, the endorphins make you feel really good. I rode two great waves today, and I’ll remember those for a long time.”

On the other hand, “golf, to me, is work,” he adds. “People might not admit it, but it is. It’s very fulfilling because when you achieve your goal of doing well, you feel great. But if you’re playing tournament golf, you’re grinding out there. It’s not like surfing—surfing’s fun. It’s the greatest sport I’ve ever done.”

“I Have Time”

Plotkin has been in remission now for nearly four years. Last October, plagued with infections, he started getting an infusion of intravenous immunoglobulin once a month to boost his immune system. He also goes in for blood work every four to six months.

The benefit of the treatment combination Plotkin had been on was estimated to last two to five years, Choi told him. “It’s likely I’ll make it four and a half years, so the drug is doing better than they expected,” Plotkin says. Earlier in the year, Choi told him that in the worst-case scenario, he’d have to start treatment again as soon as in nine to 12 months “and, if I didn’t misunderstand him, he also thought I’d only have to go on medicine [that one additional round] before I hit the 10-year mark.”

Thinking about the next round of treatment, Plotkin says, “I’m getting a little worried, but I

probably shouldn't be because I'm gonna have to go through it again.

"It's the unknown, really. That's what it is. You can't predict what's gonna happen. But I'm not gonna die tomorrow. This summer, I'm gonna see my kids and play some golf tournaments. I have time."

SIDEBAR:

How to Survive and Thrive With CLL

Jim Plotkin offers the following tips to anyone diagnosed with chronic lymphocytic leukemia (CLL). They are things he wishes he'd known or done as well as advice from his own life experiences.

- Look for a CLL specialist. One of Plotkin's regrets is that his first hematologist-oncologist didn't specialize in CLL. He recommends seeing a CLL specialist, even if it's only for a consultation and even if you have to fly to the appointment. "They're experts on CLL," he says. "That's all they do." And that means they'll be well versed in all of the latest treatments.
- Use only the best internet sources. "There's a lot of bad information out there," he says, as well as outdated data—for example, there are no long-term studies yet of some of the newest drugs. To gather fact-based information, Plotkin recommends the CLL Society, a nonprofit that focuses on education, support and research; The Leukemia & Lymphoma Society, a leader in the fight against blood cancers; and Patient Power, which is devoted to supporting cancer patients and caregivers.
- Don't give up your hobbies. Even if you have to cut back for a while, your passions can help you get through your treatments and buoy your spirits.
- Stay active. "Maybe some days you don't feel good, but you can at least go for a walk, even if it's a short walk," he says. "Do something at a minimum. It will help you get back to living the

way you did.”

- Listen to your doctor’s advice and instructions. Plotkin notes that basketball great Kareem Abdul-Jabbar, who has chronic myeloid leukemia, said it best in an interview: “Many people have the chance to beat this cancer, if you do it the right way and follow the instructions of your doctors—they’re seeing really good results with new drugs.” The same can be said for CLL.