OUR JOURNEY WITH CUTANEOUS LYMPHOMA: BECOMING EMPOWERED

Shared by Lisa K. - Care Partner

When Mike was first diagnosed with cutaneous T-cell lymphoma, more specifically, Sézary syndrome, he was just 41 years old. He was an otherwise healthy guy, who loved to play racquetball, watch football, spend time with family and friends. He never complained. He could tough out just about anything, and believe me, he did. He had no idea how to be a patient.

Sézary syndrome is an aggressive, leukemic form of cutaneous lymphoma. It is rare and it is scary. The good news is that medicine continues to make advances and there are new therapies coming out all the time. Unfortunately, most of the current treatments have limited success rates. For over a year, we tried a variety of treatments and drugs, hoping every time that this one would be the answer.

Navigating the System

In 2015, Mike was scheduled to have a stem cell transplant (SCT). Part of the standard regimen to prepare for transplant is full-body radiation, which our clinic did not offer. We were scheduled to go to a health care center in another state for the treatment.

Because of the way the health insurance system works in the US, we were required to switch over to the care of the out-of-state doctor for this process. There was some confusion and Mike ended up being scheduled for radiation treatments, but did not get scheduled to see the doctor that we had been referred to.

The radiation gave Mike a rash, most likely due to a drug he had been on prior to radiation. The thing is, Mike did not speak up for himself when the rash first started. Unfortunately, because his appointment with the doctor was not scheduled in a timely manner and he did not speak up for himself and insist on seeing the doctor, the rash got so bad that he ended up in a sauna suit for six weeks.

Patients are often out there on their own, floundering through the healthcare system, trying to figure out diseases, treatments and medications that are getting more complex by the day. I consider Mike and me to be pretty smart and savvy. But this experience was truly overwhelming and frightening. At times there seemed to be an unreasonable amount of expectations placed on the patient to keep track of everything.

During the transplant process, we saw a different doctor every four weeks. While we appreciated the benefit of multiple opinions, again, there was a lot of burden on Mike as the patient and me as the caregiver to keep track of what was happening.

Some days, there was nothing I could do except run up and down the stairs. Which I did…repeatedly. And be hyper-vigilant about what was happening so I could be a good advocate for Mike. He was such a trooper thru the whole ordeal. I didn't want him to have to suffer one minute more than necessary. There were several times when I felt like if I hadn't been paying attention, things would have gotten missed. There were clearly times when I had to push for what Mike needed because his needs were getting lost in the shuffle of all the various members of the team. Each focused on their specific part of the process and not specifically on the patient's experience.

Shared Advice from Experience

If I could share two pieces of advice with anyone going thru this ordeal, first, I would encourage patients and their caregivers to ask a lot of questions and take a lot of notes. **You are driving your care.** You need to fully understand what the process is, what the timing is, what symptoms to expect, what doctors to see, and what to do if you have issues.

Secondly, it wasn't in Mike's nature to complain. So as a result he may have suffered more than he needed to. If you are a patient, be sure to let your team know what is happening with you. **You are not complaining, you are giving the doctors the information they need to help you.**

Caregivers, ask questions. Ask how today's symptoms are different than yesterday's. Ask how long they have been going on. Help your loved one learn to talk about their illness…and take lots of notes.

Cancer, especially Sézary syndrome like Mike had, is rare and unpredictable. It's not that the doctors are not super smart or the nurses are not working as hard as they can. It's just that when you have a rare disease, the patient and caregiver bring a unique perspective based on what they are experiencing and it's important that they feel empowered to participate in the process.