Cancer Survivorship Requires One More “Ologist”

After cancer treatment, many of us need a specialist trained in oncology and survivorship who can coordinate care and improve outcomes.

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After staring down Stage IV non-Hodgkin lymphoma in 2016, I AM HERE, and I am grateful beyond measure. However, I am learning that the treatments that saved my life came at a high cost, and that in its own way survivorship is the hardest part of what I and my family now call, “the adventure.” The adventure is certainly never what we imagined it would be.

We were living the American dream. I married my college sweetheart, Michael, and we have an awesome son, Ethan. Mike and I have run a successful small business for more than 25 years. I love being active and studied martial arts and in April 2015, I achieved a third-degree black belt in karate. Things changed in February of 2016 when I started experiencing pain in my left shoulder blade that grew increasingly worse and spread to my head, down my arm, and into my back. I went to my doctor, then several others, and was told my ribs were likely cracked. When I didn’t improve, I was told my shoulder was injured. Almost three months later, I coughed and felt pain like lightning bolts in my legs and suddenly, my legs weren’t working properly.

We were stunned when I was diagnosed with aggressive, stage IV, non-Hodgkin lymphoma that spread to my chest and spinal column.

I went from running the business with Mike and studying for my fourth-degree black belt to needing a walker. I did over five months of intense chemotherapy. By intense, I mean every three weeks I underwent 96 continuous hours of chemo, as well as multiple injections to get chemo to my spine. This treatment was followed by high dose, high risk inpatient chemo and then almost a month of radiation. When completed, I was pronounced in remission.

I AM HERE.

It wasn’t until almost a year after finishing treatment, when I was complaining to my oncologist, Dr. Shah, about what I felt to be my slow recovery, that he told me just how close we had come to

losing everything. My file was dropped on his desk one day at 8:30 am and at 8:45 am, he and his partners met to discuss my situation. By 9:00 am, they were on the phone telling me to immediately come into the office with an overnight bag to be admitted to the hospital. They said, “We have to begin chemo today. We have to try and save your spinal cord and your life.” At noon, I was in the hospital. I cycled through a heart study, lung study, blood work, PICC line placement, and, by late afternoon, I was on chemotherapy.

Our heads were spinning but the speed was crucial because the consensus was that I was a week to ten days from being completely paralyzed and three weeks from dying. Dr. Shah said, at that moment in his career, I was his full-blown emergency.

I AM HERE.

On our 30th wedding anniversary, I was here to play with Michael in Disney World like two kids, just like we did on our honeymoon. In May of 2022, I got to dance, truly dance, with our son at his wedding. What a gift!

One of the biggest lessons I’ve had to learn can be summed up in a great meme, “just because my hair has grown back doesn’t mean everything is okay now.” Cancer marketing includes pretty scarves and big smiles. There’s no sign of the relentless pain, the fear of recurrence, and the daily struggle as you work to repair your body or swallow more pills than you thought possible. I thought if I followed through with treatment, no matter how rigorous, I would take a few months to put myself back together and return to my life as I knew it before diagnosis, with “the adventure” solidly and completely in the rear-view mirror.

It did not work out that way, not for me. This part of “the adventure” is more challenging than I ever imagined. I remember telling myself, “I just have to get through the initial chemo.” Then, “I just have to get through the high dose chemo.” And finally, “I just have to get through radiation.” The reality is it may never end. The aftermath of non-Hodgkin lymphoma is a chronic medical condition that will continue to evolve with new needs and realities for the rest of my life. The chronic pain, neuropathy, PTSD, muscle weakness, balance challenges, ongoing health issues, and a myriad of monitoring tests are my “souvenirs.” But where is the field general to manage this dizzying array of medical challenges, each requiring its own specialist?

I AM HERE. BUT WHAT’S NEXT?

My care team are incredibly dedicated, knowledgeable professionals, but it also feels like they do not fully understand what survivorship truly means. When I was in active treatment, care was coordinated; all the doctors and members of my care team consulted with each other about the path forward and came to consensus when they didn’t agree.

However, after treatment (the part of “the adventure” you want to last the longest), care is suddenly fragmented. My doctors no longer consulted with each other as they did during active

treatment. This resulted in my need to become even more actively involved, pushing them together, and getting consensus on what was next for me, when I am not the one with the medical degree. For example, when trying to cope with chronic pain, I started with a neurosurgeon because it felt like nerve pain, but another physician working with me disagreed with the neurosurgeon's recommendations. I spent time, money, angst, had tests done and prescriptions filled, and then was told, "No, you shouldn't be doing that!"

WHO SHOULD I LISTEN TO? WHO'S RIGHT?

How can survivorship that includes coordinated care and support that improves patients' lives and outcomes happen within an overtaxed health care system with its myriad of health insurance requirements and parameters? Survivorship needs to be a core part of oncology practices and patient care from the beginning.

One way to think about this would be to consider the field of gerontology and geriatrics. Those specialties did not exist 60 to 70 years ago as they do today, simply because the patient population did not exist. There are now more than 17 million cancer survivors in the U.S. alone. We are a new patient population. And as more of us survive, we don't want to just survive, we want to live our best lives.

One possible solution is to add an "ologist" to the health care team: an expert in oncology and survivorship. A new kind of specialist who supports patients and caregivers in navigating life after cancer treatment—a survivorship-ologist. This specialist would be part of the oncology team that works with patients from the moment of diagnosis. They would serve as the post-treatment team lead supporting the comprehensive care survivors require. They would be trained in survivorship with all its challenges and nuances. In addition, if relapse happens, the transition within the team to additional treatment is seamless because they are a member of the patient's treatment team.

Surviving cancer is a completely different beast than treating cancer, with its own unique needs, challenges, and knowledge base required. We need a survivorship-ologist.

Onward!

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