Chapter 13: Ruminations from a Patient to Future Provider: Cancer as a Lifelong Journey

Bridgette Merriman

A Boston College alumna, Bridgette Merriman, now medical student, describes her journey with cancer in early childhood—from the early symptoms to the diagnosis, and then to chemotherapy. Cancer is a lifelong journey. It continues to impact one’s life, even being a survivor. In her case, it can ultimately lead to acquire the needed training and dedicate herself to caring for people, even children, struggling with cancer.

“Is This Normal?”

Life in fifth grade was great. I participated in my first competitive sports leagues, had a blast playing in the neighborhood, and absolutely loved learning in school. What could be better? But that fall, I began to notice some nondescript symptoms.

It was tough to catch my breath at swim practice. You are still adjusting to this new breathing pattern I told myself. My doctor suggested an inhaler for exercise-induced asthma. I later developed a cough. The deep, vibratory, kind. But who doesn’t have one of those? I also found a large lymph node on my neck. “Mom, is this normal?” I stared at myself in the bathroom mirror, seeing the uneven bulge where my neck met my shoulders. A provider believed the large lump I originally found, and more palpable masses, to be backed up glands. Given my chronic cough, the time of year, and the fact that they were ‘squishy,’ she said to keep an eye on them and come back in a few weeks if they persist. The lumps were solid as marbles.

At the same time, I had been losing a few pounds. But I was a “robust” child, and we attributed my changing body composition to swimming. These things seemed normal.
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By February 2009, the little symptoms that we attributed to this or that were enough to make the diagnosis, but we weren’t seeing it. Things culminated to a point that was impossible to ignore. I was absolutely exhausted at my championship swim meet—I barely made it through my 30-second race. *What is happening? My times are going in the wrong direction.*

“It looks like you’re gasping for air,” my dad joked. *It felt like I was!*

“My times are going in the wrong direction. It felt like I was! Yet my bathing suit that had once fit like a glove was baggy in places it should not have been.*

More strange occurrences followed on our family vacation to Florida. While the rest of my family developed a warm sun-kissed glow, I seemed to be paler than when we arrived. And that cough? It continued nonstop. I even slept in my own area, propped up with pillows, a cup next to me into which I spit the phlegm, but there was no relief. “Just get it out!,” my parents called out at night. *I am, but I can’t stop.*

**“Must Be Mono”**

Back from vacation, we decided to return to the doctors’ office before school resumed. We were relieved to secure an appointment with our pediatrician. *He will know what’s going on.* While only a month had passed since I was last seen, much had changed. I lost another ten pounds, and the lymph nodes had grown in both size and number. My doctor had a strange presence about him; moving between my chart and me, examining my lymph nodes, even taking a measuring tape out to assess their size. *I was right, they don’t move.*

As he was writing lab and imaging orders, my mom noticed him write *STAT* across the sheet. She broke the silence. “Man, it must be mono or pneumonia, right?”
My doctor just looked at us, “Mmm... we will run some tests and see. I will call you tonight.” It’s Friday afternoon, how “stat” must it be?

Another oddity at the x-ray appointment; the technician kept going back and forth in front of my changing area, bringing different folks with her to review my image, before letting my mom and me go. “She must be new,” we muttered to ourselves. If only we knew what that poor woman saw.

Then the Phone Call Came
I heard the telephone ring around 9:00 p.m. My mom cried, ran down the stairs, and shouted for my dad. Just that afternoon, he was at our neighbors’ house explaining all that had transpired. They are both providers at our local hospital and were putting two and two together as my dad spoke to them. “Go home, be with your family, call us when they call you.” They knew.

My parents told me to pack a bag because we were going to the hospital. When I asked if we would be there long, they just said to bring a book. I guess that means yes? I never had to go to the hospital for me, what was going on?

The hospital was a whirlwind. Walking past folks sitting in the waiting room and lining the halls, hearing the beeps of machines and moans of pain and concern, I felt so out of place. We checked in at the pediatric desk and were practically swarmed upon arrival. Within minutes, I was ushered into a room, IV placed, whisked to do another x-ray, and this time, I experienced a new test, a CT scan. These will become your new normal.

Moments from this night are seared into my memory with such detail that, as I close my eyes writing this, I’m transported back.

My reflection in the ceiling mirror stared back at me as I was wheeled down the hall; I am wearing my favorite Red Sox shirt, jeans, and gaudy pink glasses I thought were stylish. The nurse held my arm as contrast went in. I felt it spread through my body. I
Everyone around me was acting as if I was incredibly sick, but I felt fine. *What was going on?* Later, I sat on the emergency room bed, and a man ushered my parents into the hallway. They returned visibly upset; it was the first time I’d seen my dad cry. The man walked to my bedside and stood eye-to-eye with me. Though I did not understand what was happening, at that moment, the one thing I did understand was that this person was here for *me*. He introduced himself as my oncologist and then said the words that no one should ever have to hear.

“Bridgette,” he said, “you have cancer. It’s Hodgkin’s Lymphoma. But it’s curable.” I was relieved; hearing “curable” wiped away the fear that had risen inside of me. I think that moment determined how the rest of my journey would play out. From the very beginning, my oncologist, I, and by nature everyone else in my life focused on the silver linings; *curable* was always center stage. The scary terms of *stage four, high-risk, metastasized*, were afterthoughts, so much so that it took years before I fully grasped the gravity of my situation.

He briefly explained the “game plan” to me: biopsy the next morning, PET scan after, inpatient stay until chemotherapy began. My oncologist then asked what questions I had. I had been nodding along. Though these words did not make complete sense to me, I knew that I was sick, and there was a plan to make me better. What more did I need to know? I asked the only thing that was on my mind. “Will my parents be okay?”

I never thought about death. I never thought about the potential bad outcomes. Maybe it was childhood innocence, maybe it was optimism, maybe it was faith. Who knows what it was, but what I did know, is that everything would be okay.

**Entering the Twilight Zone**

I kept track of my journey through CaringBridge, an online blog forum, describing everything in detail to friends and family that subscribed to my page. I envisioned myself as the spunky, witty, teenage protagonists in the
books that I obsessed over, creating her viral blog posts practically daily. I loved it! I wrote about my procedures, described how the local anesthetic felt, explained what needle sizes were. I even included pictures of some devices and equipment! I guess the future doctor in me was blossoming.

Later, I received the bad news. For the semi-permanent IV, I couldn’t get the one that is surgically put in. I needed the one that goes in halfway up my arm, and a tube travels up my arm, around my shoulder, and across my collar bone. Oh, and that tube is inside one of my veins—not arteries, veins. I was so scared because this is done while you are awake, and even though there is numbing cream, there are still four needles going into you, and that makes me queasy. When the lady who would be doing it to me came in, the numbing cream on my arm already worked its magic. Before she started anything else, we had to wait for my nurse, Kristin, to get the relaxing medicine. When it went into my IV (it was on my hand), it burned!!!! It felt like my hand and as the medicine traveled up my arm, the rest of my arm was on fire! Then, Shery, the lady doing my big IV started to work. First, she gave me a shot of numbing medicine to numb under my skin. For 10 seconds, I got that same burning sensation, only she gave it to me fast, so the fire burned even stronger than before. While she fed the wire into my vein, she would squeeze every once in a while, and what I felt was almost a crunch. That also hurt. Finally, Shery was done putting in my IV after 4 numbing fire shots. That was one of the bad things that happened.

After the wrapping was put on to keep the wire in place, I started bleeding. A lot. The shirt that I had on was all red on the sleeve. To prevent more bleeding, Kristin (my nurse) put gauze on my arm. Later, my arm started to turn purple, and I was afraid because that is a sign that the IV wasn’t put in right. That means it would have to be taken out and put back in again! The nurses came to make sure that I definitely needed it put in again. One thought the gauze was put on too tight, and asked me to take it off. It
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turned out the gauze was put on too tight. My arm turned back to normal soon. That gave me a scare, and that is one of the reasons why my day was horrible.

I also got the IV that was on my hand, and making it swell, out. Kristin let me take it out because of all the tape around it, and the part inside me was like a piece of floss. Soft and stringy. That part of my day was like hallelujah.¹

Chemo came, and my hair went. As it started to fall, I got a shorter cut. Makes the transition more palatable, people told me. I was excited for a new ’do.

“Make it look like Alice from Twilight” and I showed my hairdresser movie scenes for inspiration. While showering a few days later, my hair fell out in such big clumps that it grossed me out more than made me sad. I knew it was time to shave it.

So I did. And my cousin gave the sweetest act of kindness I’ve ever received; he shaved his head with me. We are best friends to this day.

“What Does It Feel Like?”
What does it feel like to have cancer? To go through chemotherapy and radiation? I have always struggled to describe these experiences to others because they are feelings that are incredibly niche and unique to each patient. As with many things in healthcare and beyond, cancer is more of a “one size fits one” than a “one size fits all.” Yet, ironically, uttering a single word such as “neupogen,” can elicit the same moans, bitter laughter, and sensation descriptions, from almost every patient. At the same time, I am a firm believer that, sometimes, our brains prevent us from fully understanding and internalizing the experiences of others, in order to protect and shield ourselves from that trauma. So even if there was a perfect way to describe what cancer feels like, is it fair of me to invite those who

have not gone through it themselves to share those feelings? Is it even possible? I did not think so, until I got my COVID vaccine.

The night following my vaccine I could not stop crying, and it was not just because of the physical pain I felt. I anticipated the soreness and exhaustion that usually comes with vaccines, so I could not understand why I was literally brought to my knees from the sensation that flooded my body. Then it hit me: the only other time in my life I had that specific feeling was during chemo.

The deep bone aches in my back, hips, and femurs, pulsed through my skeleton. The ebb and flow of my bone marrow working hard and preparing my immune system was the same pain I felt during chemo. It was the same pain that woke me in the middle of the night in 2009, when the neupogen shots finally kicked in, signaling my marrow springing back to life. It was the same pain that came from my rapidly dividing cells, collateral damage from the chemo. I recognize how lucky and blessed I am for my treatment experience. I did not have many of the side effects that people warned me about, that I prepared myself to experience, never threw up, had a cold sore, or lost my appetite. Just intense fatigue and hair loss. My gratitude and appreciation for my body’s response to chemotherapy grows each year as I learn more about what the chemotherapy medicines were actually doing to my body. As I witness friends and family members navigate their own cancer journeys, I am pained to see them go through things that I should have experienced. Survivor’s guilt shows itself in insidious ways.

I now understand how horrible chemotherapy is. I didn’t when I was sick. Maybe ignorance was bliss. Chemotherapy is poison. It is toxic ammunition. We dump it into an incredibly sick person; a person betrayed by their own body, being eaten by a monster growing inside of them, over which they have no control. We fill a person with poison, hoping their body is strong enough to withstand it and for the poison to win before the cancer does. I realize that my experience only scratches the surface of what cancer and its treatment can do to a person and their loved ones.
Life Beyond Me
My cancer journey was also my first introduction to global health and health equity. One infusion day, I met a doctor from Ethiopia who was visiting my oncologist. I learned that they are members of an organization whose aim is to establish sustainable pediatric and adolescent oncology care systems in low-resource countries. They explained to me that children in other countries also get cancer, but many elements beyond the molecular biology of cancer contribute to the child’s ability to beat their disease. Factors such as distance from a care center, access to specialists and patient-to-provider ratios, affordable treatment and care, all impact a child’s ability to survive. I thought to myself, How is it that, just by luck of the draw, I was born with this hospital right in my city? We are all children with similar illnesses, yet such different healthcare opportunities determine our ability to survive and thrive?

I have continued to keep health equity and accessibility as a passion since then. Advocacy for justice in all realms of life underlies the service, organizations, and movements to which I dedicate my time. I do not feel compelled in this pursuit, as if I am indebted to something. Rather, it is a desire to make a difference and promote positive change that fills me with a sense of purpose and meaning. Some groups holding a special place in my heart include my local hospital and a camp for children and families affected by cancer and other life challenges. I have worked with these organizations since 2009 and will continue for many years to come. During college, I was devoted to Dance Marathon and raising support for Boston Children’s Hospital and its patients. Today, I lead student service and advocacy groups whose missions aim to serve adolescent parents and their children, folks obtaining gynecologic procedures, and oncology patients. Advocating for equity and justice is an integral part of my being and will continue as such in my education, future career, and personal life.

My New Normal
By July of 2009, I was in remission. Focus shifted from curing me, to making sure I stayed healthy. The complexities of follow-up care quickly
became routine: CT scans, chest x-rays, blood work, echocardiograms, EKGs, screenings for secondary cancers, ultrasounds, genetic screening, and the list continues.

While this was done to protect my physical health, I learned that there are complexities to survivorship; cancer is more than getting sick and getting better. What about the fears that instantly consume my thoughts when I feel a lump or a bump? When I got mono and immediately assumed the worst? Survivor’s guilt I feel when I learn about someone’s death, why did I survive? Do I have to do something spectacular to make my life “count”? Can I have a family? What if I get cancer again, and this time it wins?

Cancer is a life event. I explored the ways in which cancer continues to impact young adult survivors for my thesis throughout my senior year of college. Some folks hold being a survivor at the very core of their identity, and others keep it in the past. Some remember their treatment experience, and others were just babies at the time of their illness. But no matter the age at diagnosis, specific cancer, treatment length, or how often one thinks about their cancer journey, the same underlying questions and fears unite us all.

These uncertainties do not necessarily develop over years; sometimes they are implanted the moment a child receives their diagnosis. These uncertainties are constant reminders that being different from other people can be isolating, both during treatment and for years to come. I was fortunate to learn about Camp Good Days and Special Times, a camp where I’d be surrounded by kids like me, kids with cancer. My parents signed me up that very day. That summer, I rode the bus in eager anticipation; I had preconceived ideas based on what my friends told me about their camps, but I would soon learn that Camp Good Days is different. Counselors dressed in fun costumes greeted the bus, hugging each of us as we stepped off. The week was filled with activities beyond my wildest dreams: archery, scuba diving, magic shows, and hot air balloons! But best of all, for the first time in months, I was normal. No more wearing a bandana or an itchy wig to cover my bald head, no more explaining the
“funky tube” in my arm, no more sad looks from adults. I was just Bridgette.

My favorite weeks of the year are the ones I spend there, once as a camper, now as a counselor. I love connecting with my campers and watching them come out of their shell, seeing their smiles as they are finally able to participate in “normal kid” activities. But they, too, share the same “survivor fears.” Several years ago, a camper asked me why, if all campers had cancer, does it seem that none of the counselors had cancer? Her unspoken question stung my heart: *is there life after being a pediatric cancer patient?*

Being a survivor is not necessarily tattooed across our foreheads, and it is scary not knowing what happens next. The intensity of care dedicated to “beating the cancer” sometimes seems to outweigh “life after cancer.” Her face lit up once I showed her a picture of my first year at camp, when I was bald. Another camper’s confusion shifted into the biggest smile when I told her that we share the same oncologist, and another friend and I joke that we are “cancer buddies.” I find myself repeating this saying often, but its repetition does not make it any less true; while I am not happy that other people experience some of these hardships, it is comforting to know that I am not the only one.

Just as much as there is hope and courage at Camp Good Days, there is also some sadness. I say goodbye to campers every year. Sometimes, it is a goodbye forever. The opening ceremony is one of my favorite traditions at camp; campers and counselors take time to reflect on our past, those who supported us, those who are with us, and those who can no longer join us. There are many names that I write on my remembrance rock, and the list grows each year.

I have known in my heart for as long as I have wanted to pursue medicine that I was going to be a pediatric oncologist. Although I am fascinated with each specialty in medicine, nothing fills me with the same awe and gratitude as pediatric oncology. I cannot wait to follow my oncologist’s footsteps, being just as patient centered and family focused as he is, for my future patients, for children like my campers, for kids like me.
“Am I Lucky?”
Am I fortunate that I had cancer? In a weird way, yes. My experience has directed my vision and understanding of not only medicine, but what it means to embrace the fragility of human connection. My life is an extension of my cancer journey: career goals, service, and advocacy work. I work hard to become a pediatric oncologist, always seeking opportunities to learn and grow. I have a genuine and deep-rooted desire to give back; it’s my purpose. I began to learn about equity and justice because of my cancer, and today, advocacy and justice consume my thoughts just as much, and maybe even a little bit more, than studying.

For what seemed like forever, my dream of becoming a doctor was in the far-off distance. Now, all of a sudden, it’s becoming a reality. The email that made me cry of happiness even more than my first medical school acceptance, was the one I got from my doctor, signed “your colleague.” I still tear up reading it.

I am currently a second-year medical student, and every day I love medicine more, love my patients more, and am more excited to be their provider. I am where I’m meant to be, I cannot imagine any other life circumstance that would have brought me here.

My peers from Boston College may remember our school’s invitation to ask ourselves these questions, and answer them honestly: what brings you joy, what are you good at, and what does the world need you to do? My life journey helps me to answer those questions with confidence. From patient to future provider, my cancer journey helped develop who I am and who I want to be. I can’t wait until the day I’m a doctor, helping kids battle their diseases. I believe that challenges aren’t meant to break people but rather help them recognize their passions and shape their future. For better or for worse, in sickness and in health, till death do us part, cancer is part of me.

So bye bye!! Oh, this most likely will be my last CaringBridge update. If it is, I hope that you have enjoyed it as much as I have. Thank you and I love you all.
One more thing, I will attach new pictures later tonight so you can see some of the fun I had this summer and my new hair-do. I LOVE the way my hair grew back. It is soft and curly and really blonde.

- Bridgette :)

Bridgette Merriman is a second-year medical student at Boston University School of Medicine, pursuing her dream career of becoming a pediatric oncologist. At medical school, she leads several student organizations, including the Student Oncology Society; conducts research on the impact of COVID-19 on pregnant and parenting adolescents; and assists providers in the Teen and Tot clinic, caring for adolescent parents and their children.

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