

My Myeloma Journey

By Catherine Suzanne

In the year 2000 I was single, fit and an outdoor enthusiast. As an avid hiker I had organized many a day hike and back packing trip with friends. I had also taken part in university excursions cycling, heli –hiking, or kayaking the wonders of British Columbia as well as learning to sail in the British Virgin Islands. All of these adventures had reinforced my love of nature and life itself.

The millennium brought about a new work setting for me. After nursing in many areas, my love of cancer care had been confirmed and I set my sites on the Tom Baker Cancer Centre. I was hired on a casual basis in the radiation and outpatient departments. As a single person this was a financial risk. It was, however, one I was willing to take in hopes of eventually securing a position in a setting I felt I was “meant to be in”. The truth in that belief became apparent in more ways than I had imagined.

By the fall of 2001 I began experiencing abnormal fatigue and night sweats. I assumed these were simply a reflection of work stress. I consulted my family physician and blood tests indicated I was mildly anaemic. Subsequent investigations were inconclusive. Months passed and my blood counts became significantly depressed before finally receiving a diagnosis, one I had by this time strongly suspected. On Labour Day 2002 I received the phone call confirming I had Stage III Multiple Myeloma. The good news? I had no bone lesions or kidney involvement. The bad news? I was single, the owner of a new home and mortgage, without disability or health benefits, sick and facing a battle with an incurable cancer.

My myeloma journey began nine years ago but there were indications early on that I was destined to experience rather unique health challenges. It began with a breech birth; yes, I came into this world butt first, an omen perhaps of the difficulties that lay ahead.

After an unremarkable childhood I began to suffer from fatigue and migraines during my first year of university studies. Eventually I was diagnosed with a

large, left sided acoustic neuroma, a benign brain tumour of unknown origin usually presenting beyond the age of fifty. GO FIGURE !

My friend's father of Jamaican descent said it best in his thick accent – “She has too much brains and they have to take some out “. And so they did. I survived the surgery only to experience a recurrence of this tumour fourteen years later. BEATS ME! This second smaller tumour was removed without complications.

The call confirming my cancer diagnosis had not been a surprise. Despite this, I did experience a considerable numbness to the news. I somehow found a way of telling others and getting myself to the Tom Baker a week later to start chemotherapy. What followed was a blur of consultations with various members of the transplant team. Even as an oncology nurse, the information was overwhelming. I tried to research myeloma and inform myself of its treatments, complications and outcomes. Three to five year survival rate? OMG!

As treatment related fatigue set in I was extremely grateful for my experience as a staff member of the Tom Baker. I was confident of the quality of care I was receiving and trusted my caregivers. I knew how to navigate the center's maze of halls only now I would walk them as a patient.

VAD, a tough combination of chemo drugs, was a standard pre-transplant protocol in 2002. While receiving this regimen my only sibling was identified as a perfectly matched stem cell donor, an occurrence in only 25 % of all tested siblings. My transplant plan changed from an autologous one to an allogeneic. My sister's cells were harvested and banked in hopes that, once infused, they could potentially cure me of myeloma. Research since then has not supported any evidence of the curative effect of allo transplants. Furthermore, high risks of rejection in the form of graft vs. host disease have made them a rarely used first line treatment.

Fortunately, my body did not reject my sister's cells. I had survived the transplant and was recovering faster than anticipated. I was on a high. Perhaps I would be the one who would be cured. You never know. It could happen. So what if my monoclonal cells were still eleven. I was feeling great.

Unfortunately, my savings were quickly dwindling. Nursing with a weakened immune system was no longer a great fit. I started feeling considerable anxiety over my finances when a friend suggested I dog walk for her. Before I knew it I was at the off leash every weekday with not only her dog but several others, including my newly acquired one. I was walking with my “buds” by day and taking dog training classes with my “boy” in the evenings. I was having the time of my life. I had even incorporated my bone density treatments into my work schedule. Once a month, to the dismay of my fellow dog walkers, I could be found at the park with my dogs and a “baby bottle” of pamidronate hanging from my waste, infusing by gravity until completed, whereupon I would simply discontinue the I.V. Genius! This was my new normal and it was o.k.

Inevitably with time came the reality check. My “m” counts were rising. My myeloma was back. In reality, it had never really left. Now, it was here to stay. As I started my chemo once again, I experienced a dark period of grief and anger. The velcade and dexamethasone regime was difficult to tolerate. Healthy veins were getting harder to find. All of this was seriously interfering with my dog walking. I hit a wall. That was it. There had to be a better way. I wasn't doing this anymore. I took a hiatus from anything myeloma related; I basically had a hissy fit and, like an ostrich, stuck my head in the sand. I carried on with my dogs. I took a trip to Mexico. I learned to scuba dive. I avoided discussing “the counts” as much as possible until I could no longer.

Now, my myeloma was raging. At least the chemo this time, Thalidomide, was oral. No more intravenous pin cushion sessions. Fourteen cycles later, however, my platelets took a sudden dive, a rare side effect known as ITP with only one other known thalidomide related case. My condition was stabilized with steroids and my chemo was put on hold. I enjoyed almost a full year of stable disease before needing to start Revlimid to manage my once again rising “m” counts. An onset of back pain at that time was found to be due to a compressed and fractured vertebra. A relatively new surgical procedure known as Kyphoplasty was performed and my back pain substantially reduced.

I was feeling like a new person. I started to resume some of my usual activities only to have a sudden fall a week later fracture five more vertebrae. A second Kyphoplasty was performed. My back was stabilized but chronic pain

necessitated the use of regular analgesics. My suspicions were confirmed. My myeloma was weakening my back and pelvic bones. I lost three inches in height in my lumbar spine. For the first time in my life I had a Muffin Top! Unbelievable! Needless to say, I received little empathy from my dieting friends.

Shortly after my second surgery my myeloma became resistant to Revlimid. As my chemo options decreased my anxiety increased. Velcade was tried once again with cyclophosphamide added to it. With the side effects better managed this time I have been able to tolerate the drug and keep my “m” counts stable. A port-a-cath has facilitated infusions of Zometa to maintain my bone density. Steady as she goes.

Throughout my cancer journey I have had to readjust to constantly changing situations in my body and adapt my expectations to things out of my control. It's been like a fast paced ball game; curve balls are constantly being thrown at you. You need to duck them and then step up to the plate again and again. Only thing is, you don't know how many innings you get to play. It takes energy, resilience and courage to carry on with what myeloma has now become: a chronic incurable cancer. I have had to teach myself not only to reach out and ask for support but also learn to receive it graciously.

Support can come in many forms: friends, family, the myeloma support group, spiritual care, and the many health care professionals at the Tom Baker. Wellspring also has a wide variety of free programs to assist cancer patients and their caregivers in their recovery. Personally the Southern Alberta Myeloma Patient Society has been a tremendous resource in my life. Talking to people who are similarly on this myeloma journey has enabled me to feel normal and understood. The work with its steering committee as well as volunteer work at Wellspring has given me a sense of purpose and connection while working with others on a greater good.

During my darkest moments after fracturing my spine I struggled to find my new normal again. Bone pain and the risk of fractures ruled out many activities I previously enjoyed. What COULD my body tolerate? I took up deep water running with a couple other “myelomics” on a regular basis. This has been my best ally in strengthening my spine and body, as well as managing my pain and promoting my mental well being.

Walking this myeloma path has taught me many things about myself and what is truly important in my life. There have been many perceived losses along the way: career aspirations, financial dreams, travel plans, finding a partner, fitness goals. They are however just that...perceptions. All those hopes still exist in my life; they simply need to be reframed to today’s new normal. Again and again.

Early on I came to the realization that there rarely are any answers to the “Why Me” question. Quite frankly, it doesn’t matter. Nothing I did or did not do brought about my health challenges. It sucks but it simply is. As my good friend Carol Westberg often says “You get to choose every morning to get up and make the best of your day”, or not. Every one in this room has a unique and wonderful life story. Myeloma is only the context of the plot, not its final chapter.

To adjust to changes and maintain equilibrium in life requires a loss of fear. Fear can be paralyzing. One of the best ways I have found to release my fear is to do what brings me joy. Whether it’s something as simple as buying flowers, seeing a live musical performance, travel, whatever it is you love....just do it. Now is the time to be kind to yourself.

Today, I have seen name tags with many stars on them. These are a testament to the great care we receive and the resilience of every person in this room. Patients, caregivers and health professionals alike, you are all amazing warriors on this myeloma journey. You make our future look bright.

I know I will die one day sooner than most. I hope when that day comes that I lived life fully and laughed a lot along the way. No matter what happens, I know I will be all right.

Thank you

