Don’t Sweat the Small Stuff

A new chapter each week – a 4 minute read!

Chapter 5 - Cancer School

Cancer School

The first visit to the cancer centre is a strange experience. It is a separate part of the hospital and the décor is bright and upbeat. As we looked around the waiting room there was a table with a half completed jig saw puzzle, coffee, cookies and some couches. I had been in this hospital at least a hundred times and have never seen this area. Aside from the physical environment the number of people in the waiting room was surprising – there was easily 30-40 people. Quickly I realized that there are hundreds of people going through the same battle that we were. It is hard to explain but a camaraderie quickly forms between cancer patients. Patients willingly share their experiences, their highs and lows and their next steps on the journey. Carol had become part of a community bound together by a common struggle and uncertain future for all its’ members.

Small Stuff #4 – Not sure there is any way to prepare for this but dealing with the start of your cancer treatment is truly challenging. Never mind that your world has been turned upside down and for the next several months your plans, schedules and agenda are simply thrown out. You are on a journey you did not choose, with a tour guide and itinerary that was predetermined for you and your family. It is simply “all consuming”. We attended “Cancer School”. This is the point where they inform you about everything that is going to take place – the good and the bad – there will be side effects, you will likely feel ill, the need to monitor your temperature and how to circumvent the ER if you have a problem. Your will lose your hair, your appetite and weight and at the end of the day you may not survive so relish every moment you have. We left our stint at Cancer School and Carol was in tears – mostly because of the unknown nature of what lay ahead. I realize that there is no way to make cancer school less frightening or intimidating. My only suggestion would be to prepare the family and caregivers that this is a critical moment in the process. There is much that is unknown and within a few months you will have some idea whether you are getting better or in some cases not responding to treatment. This is the point where the unknown haunts your every thought.

We met Dr. Faghih who was going to be the oncologist managing Carol’s care. He is a soft spoken calm individual and his demeanour was comforting to both of us. He explained that the lab results indicated that Carol had Large B cell Non-Hodgkins lymphoma and her chemotherapy treatment would start the next week. He explained that Carol would receive 5 different drugs – CHOP-R. They would be administered to her as an outpatient in the cancer centre and would take the better part of a day once every three weeks. This regimen would be repeated six to eight times and would start almost immediately. The next four to six months were now fully scheduled and followed a very predictable pattern. Treatment day followed by a week of side effects and laying low. The second week was better and the third week Carol felt normal.

Small Stuff #5 - This very quick movement to treatment may well be the reason that Carol survived. Carol's biopsy and pathology report done at TBRHSC was accurate but it was incomplete. Carol had a rare form of lymphoma known as triple hit lymphoma. We didn't find this out for almost a year. It was discovered when Carol was referred to Princess Margaret to determine if she was a candidate for a stem cell transplant after her first round of chemo had not been successful. The lab at Princess Margaret reviewed her biopsy specimen. This is a very aggressive form of lymphoma with relatively poor outcomes and delays in treatment allow the cancer to grow quickly. (Life expectancy for triple hit lymphoma was 4 months – a fact I inadvertently learned and did not share with anyone except my friends Justerini and Brooks). For whatever reason the very short time interval between Carol's diagnosis and the start of chemotherapy may have significantly improved her chances of survival. Someone at Princess Margaret told me that this is why they do their own pathology – they implied that they did not trust the work done elsewhere. This seemed a little cavalier and judgmental. After all when someone is referred to Princess Margaret their initial course of action has not been successful and there must be an underlying reason. While we appreciated the clarity around Carol's situation it wasn't fair to intimate that Thunder Bay had missed something.

I had the opportunity to talk to the head of the pathology department in Thunder Bay. I wondered after the fact why they did not completely identify the type of cancer that Carol had. He indicated that in his 8+ years at TBRHSC, he had only seen one other case of triple hit lymphoma out of several hundred lymphoma cases. It was truly very rare and not something that they would normally screen for. It is not routinely screened for elsewhere and it is rare enough that they could not even conduct studies on triple hit as there were too few cases. By the time Carol got to Princess Margaret, her previous treatments had not been totally successful so they were looking for an answer as to why. As stated before the fact she survived to find this out was probably thanks to the immediate chemo she received in Thunder Bay that slowed the cancer down. Delayed access to care which has become a problem since covid could potentially be a death sentence for some.

Small Stuff #6 - There is another aspect to this story which can be embraced or discarded as people see fit. Carol is a quiet individual but she had an incredible inner strength that kept her moving forward and fighting on. Someone suggested the book "The Power" which gave her comfort and strength. She also had a deep faith that she would persevere. A friend gave her a "comfort bird" that was made locally. A little wooden bird that she could hold and use as a touch stone during her thoughts and prayers about what was happening. Carol has given these birds to others who are facing the cancer battle. Whether you are religious or not your individual attitude towards your cancer fight seems to have an impact on outcomes. We certainly felt that Carol's tenacity and faith helped her deal with the battle she was fighting in a very positive way.

We were now fully engaged in our "new life" of fighting cancer. Everything else takes a back seat and I appreciated that the people I worked with at The Northwest Health Alliance and in

Sioux Lookout who picked up the slack and allowed me to be available to support Carol as we moved forward. We also will be forever indebted to family and friends who joined Carol during her chemotherapy sessions and kept her spirits and attitude amazingly positive. The cancer had provided a bonding experience that was quite unexpected but instrumental in our struggle.

Next week – Crash Time