

~~Don't~~ Sweat the Small Stuff

A new chapter each week – a 4 minute read!

Chapter 7 – Ready to Rumble – On to Round Two

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Our cancer treatment world revolved around three week episodes. As previously stated there was chemotherapy followed by a week of tiredness, some stomach upset, nausea and bowel issues. Most of Carol's time was spent on the couch or in bed. The second week after treatment was considerably better and the third week, things seemed normal, (as normal as life good be!).

A nurse arrived to provide a neupogen shot each afternoon at 2. Neupogen is a drug that stimulates white blood cell growth. The ongoing measurement of white blood cells is a key component of ongoing cancer treatment. If your white blood cell count is too low, your treatment will be postponed until the count increases. There is a particular drama to the process. You arrive at the cancer centre ready for your treatment but then you have your bloodwork done. Now it is a waiting game to find out if your white cell count is high enough for you to have your treatment. Obviously any delays in treatment are not a good thing. We were fortunate that although Carol had lower white blood cell counts that at times were marginal they never were low enough to postpone treatment.

The nurse who arrived at our house to provide the neupogen shots was dispatched by the local CCAC. This referral happened smoothly and the nurse made it clear that he would train Carol to do her own injections. The home care system in Ontario has gone through a lot of changes over the past 25 years and it continues to be the "orphan" of the health care system. It is a sector that has so much potential but the Ministry and successive governments have never been able to figure out how to use the CCAC or home care sector effectively. (There will be a chapter on this later.)

Interestingly the CCACs represent the only true border to border service in Ontario. There were 236 offices all using the same integrated software, and while there were originally 43 CCACs, subsequently reduced to 14 to align with LHIN geography, the Ministry never leveraged the potential of the CCACs to play an impactful role in primary care, seniors care or post hospital care. Every ten years or so there is a complete reorganization and renaming of the home care sector and we are due for a further update. Hopefully the current Ministry and government will get it right this time.

We met with Carol's oncologist and he indicated that we would only go through six cycles of the CHOP-R instead of eight. Evidence showed that there was no beneficial impact beyond the six cycles of CHOP-R.

Small Stuff #9 – Timing Matters! - Prior to Christmas Carol had some additional scans and fortunately we had our own “back door” radiologist who called to let us know on December 19th that the tumour was smaller so things were going the right direction. Getting this information helped us to have a Christmas where we were not continually worrying about the future and the fight we were in. We did not get the information from the formal system until Carol went for her next scheduled appointment with her oncologist in early January. We were fortunate to know earlier and it made a difference to us and our family over the Christmas period.

We concluded the six rounds of chemo on February 9th and rang the bell at the cancer centre to signify that we were done. (We declined future opportunities to “ring the bell” - as the cancer had other plans for us and as crazy as it seems ringing the bell seemed to spite our cancer foe and created in that foe a resolve to bring us to our knees.)

Small Stuff # 10 – Where to next and more importantly – when ? - We were finished but not finished. Our initial diagnosis and the immediate start of treatment gave us a focus and a strong hope for a successful resolution. Round one of chemo was done in February and during March there were more tests and scans completed. It was clear that we were not finished with cancer yet. This was the most trying time of the process as we realized that we still had more to do to deal with Carol’s cancer but we did not know exactly what the next steps were going to be. There was a delay in getting a PET scan but it was done mid-April, two months after Carol’s treatments had ended. On April 21, we met with Dr. Faghih and he indicated that the PET scan showed results that we did not want to see. There were 2 spots on Carol’s colon. Dr Faghih indicated that Carol needed a colonoscopy to determine what we were dealing with. He also wanted a biopsy so the best path forward could be determined. He indicated that he would make a referral to a local surgeon but due to a lack of surgeons it would probably take at least three weeks to be seen and a scope would be scheduled after that. This seemed like an awfully long time. We had already been two months since the last treatment – we knew there was still something going on inside Carol’s body and we really wanted to get on with the next steps, whatever they were going to be.

Sitting in Dr. Faghih’s office on that Friday when he told us the results of the PET scan I emailed the surgeon we knew in Sioux Lookout (back door again!) – Dr. Eric Touzin. I told him of Carol’s situation and he responded immediately saying to come to Sioux Lookout and they would figure out how to get Carol in for the scope she needed. Less than 48 hours later, on Sunday, we were on our way to Sioux Lookout. The back door once again provided us with timely access the system could not. Knowing we had to move forward but having no clear path ahead was troubling and created a sense of dread. We were going to get a scope done but really had no idea where the path forward was going to lead us. H.P. Lovecraft said it best – “The oldest and strongest emotion of mankind is fear, and the oldest and strongest kind of fear is fear of the unknown.” That is the fear we had.

Next chapter – Where to from here??