

Don't Sweat the Small Stuff

A new chapter each week – a 4 minute read!

Chapter 9 – Not Smooth Sailing – But Making Headway!

Waiting to determine the next steps was difficult as we knew more had to be done. As pointed out in the previous chapter this was the most difficult period of our battle. The uncertainty created by the knowledge that we knew there was a fast growing cancer and the unavoidable delays made each and every week difficult as the unknown was truly the greatest fear we faced.

Even though there was not a definitive diagnosis, thankfully, our oncologists in Thunder Bay started a new treatment regimen. This may have seemed as a bit of a “Hail Mary pass” to us, but we can never forget that we are drawing on years of experience of the cancer team. The goal of this treatment was not to eradicate the cancer but to slow it down enough that a stem cell transplant might be considered as the next crucial step in our battle. We were incredibly relieved when the second round of treatment began – we were once again in the fight – no longer a bystander.

As indicated we were put in touch with Princess Margaret and went through a number of virtual meetings to assess Carol's suitability for the procedure. Carol was 60 at the time so well within the age range. Stem cell is usually not undertaken with patients over 70. The biggest deciding factor was evidence that the current treatment was having an effect on the cancer. It had to be demonstrated that the treatment was shrinking the tumours. If treatment wasn't positive enough, the transplant was off the table as it would not have the desired effect. Simply put - no stem cell transplant, no chemotherapy, radiation or surgery that could cure the lymphoma meant Carol would be classified as “terminal”.

This underscored the importance of the current chemo and the need for it to be somewhat successful in slowing the cancer and shrinking the tumours that had been growing in Carol's body. After three rounds Carol had another PET scan. We were relieved when our radiologist let us know that the tumours were in fact shrinking. This was truly a red letter day for us!

Small Stuff #13 - Special Delivery

We were happy with the news from our radiologist and the Thunder Bay based radiologist but it had to be confirmed with Princess Margaret before they would accept Carol into the program. I was a little surprised that TBRHSC needed to burn a disc of the PET scan and courier it to Toronto. In past chapters I had complained about TBRHSC's reliance on mail to notify and arrange appointments and how antiquated it seemed. At the other end of this spectrum, TBRHSC operated as the provider to the twelve hospitals across the north west by providing a unified EHR (Electronic Health Record). This meant that if a patient moved between hospitals across the region their hospital medical record was available at any of the twelve facilities. There was also a shared PACS (Picture Archiving and Communication System) which allowed the

hospitals to electronically share images across all twelve hospitals. This had been in place for a decade and worked incredibly well. The fact that Thunder Bay could not share images with Toronto electronically was a surprise to say the least.

Thunder Bay burned the PET scan images on a disk and couriered them to Toronto. Two days later, on Thursday we had a call from PMH indicating they did not have the PET scan. We were obviously anxious and on Friday a second disk was sent via courier. Monday morning we received another phone call - still no scan. (Not sure where the problem was – cannot overlook that Princess Margaret is part of University Health Network, the largest system in Canada with over 18,000 staff and dozens of locations. Not hard to imagine things going astray!) On Monday I went to medical records and asked for another copy of the PET scan to be burned. I picked it up Monday afternoon and early Tuesday I took a 2 hour Porter flight to Toronto, took a cab to PMH and hand delivered the disk to the oncologist's office. A return cab to the downtown airport and I was back in Thunder Bay by mid - afternoon. The cost and time involved are trivial in the overall scheme of things but it highlights the lengths we had to go to in order to fill a system shortcoming.

Small Stuff # 14 – Heros everywhere!

I am happy to report that this situation has been rectified. I had got to know Andrea Tait when I worked with the CCACs in Ontario. The CCACs shared a common electronic program to operate the home care sector. This represented the only part of the health care system where the entire province was on a common system and could share information border to border to border. At the time 234 CCAC offices used the same software. This was no small feat as it took years for all of the CCACs to migrate to a common system. Andrea's team at the Ministry was responsible for the system and its development. The costs were shared between the individual CCACs and the Ministry so there was a strong working relationship between the Ministry and the CCAC sector over several years. Andrea and I got along well and worked together to support a common approach to this software development.

A few months after my in-person delivery I got a phone call on the Monday of a long weekend. It was Andrea. She had heard about my need to courier images from Thunder Bay to Toronto. She told me that her team that she now worked with at the Ministry had been working all weekend to implement the final phase of a project that would allow for electronic sharing of scans, data and images all across Ontario. She was proud of her team and wanted me to be the first to know. The phone call left me appreciative of the fact that Andrea would take the time to make me aware of this, but also the fact that her team had given up a long weekend to make this happen. It becomes easy to find the faults in the system and sometimes we lose sight of the fact that at its core we have a system of incredibly dedicated professionals who want to do their very best. There are many heroes in our system!

The results were as hoped for, and we were informed that Carol was a candidate for a stem cell transplant. First we would need to travel to Toronto to meet with the PMH team. Finally the

path forward was much clearer and we knew that we had a better chance at a positive outcome.

Next Chapter – Our First Visit to the “Big Smoke”