

Don't Sweat the Small Stuff

A new chapter each week – a 4 minute read!

Chapter 12 - The Process Starts

Hope as Part of Healthcare

We travelled to Toronto and settled into our condominium. We were *hopeful* about what lay ahead. Hope is an interesting phenomenon. When I was at Sioux Lookout I was leaving the hospital and there was a young native patient smoking by the door. I said to him “you know you can't smoke here” and he started walking to the designated smoking area which was by the parking lot I was going to. I said to him “we have programs to help you stop smoking” – no response. I pressed on – “you know those things are bad for your health”. He turned and looked at me and asked “why should I care about my health?”. It was obvious that being healthy, living a long and prosperous life were not part of his vision of the future – his seemed to be one of hopelessness.

Hope has been shown to improve clinical outcomes and has shown to be effective in dealing with mental health treatments. Hope is not “wishing” – like I hope to win the lottery – that is a wish. Hope is a feeling or an attitude that creates an expectation and desire for something to happen and this leads to working toward such an expectation both consciously and subconsciously. My wife Carol is one of the most hopeful individuals you will ever meet. She was always optimistic about the future although she could get frustrated with delays when she thought the path forward was clear. Whether you believe in a higher power or not the presence of hope in your daily life seems to provide a steadying influence and the ability to “Keep Calm and Carry On”! (War time Britain was stirred by the hope of victory and better days ahead by Churchill – he used hope as a weapon to strengthen the nation's resolve.)

During our first visit to Dr. Kuruvilla we were given a calendar that outlined each step in the process. As mentioned there were several steps in the process. Broadly they fell into four groups. First there was extensive testing to make sure that Carol was in the right condition to go forward with the transplant. The next stage was the harvesting of cells for the transplant. The third stage was the delivery of an intense chemotherapy that killed everything in your body to provide a clean start for the stem cells. The last step was the reintroduction of stem cells into your body and the follow up care from that.

We went through several days of testing and were in constant contact with Dr. K's office. Carol was in generally good health although she was tired a lot of the time and spent a lot of time sleeping. We had plenty of time on our hands and even got to catch an afternoon Blue Jays game on our anniversary.

Small Stuff # 18 – Even the best designed systems can fail!

We needed to go to the Community Care Access Centre office in downtown Toronto to register Carol so she could receive care at the condominium. As I had pointed out the CCACs had a system right across the province that allowed for patients to be transferred between CCACs. The vast majority of transfers begin in Toronto and result in a patient accessing home care services somewhere else in Ontario. Our situation was a little different as we were transferring to Toronto for service.

Carol did not require much care but I received a call from the nurse. I said I would be right down to the lobby to let her in. She said she knocked on the door and nobody was home – I asked where she was and it turned out she was standing on our driveway in Thunder Bay 1500 km away. Carol was still registered as a Thunder Bay patient even though we had visited the Toronto office. We ended up getting the minor procedure that was required at Princess Margaret. Once the testing was complete, we then moved to the harvesting of Carol's stem cells. This process can take up to five days. It is very similar to dialysis. Carol was seated in a chair and blood was withdrawn and it went through a machine that separates the stem cells from the blood and returns the blood back to the body. Each day requires the patient to sit with the drawing and harvesting of cells for five hours. This process started at ten and ran till three. The number of times you need to go through the process is dependent on your body's ability to "manufacture" stem cells. We were told that on occasion a person could complete the harvesting process within one day. At the other extreme some required more than five days. Carol took three days to stockpile the necessary stem cells.

Making new friends - a silver lining!

On Carol's first day I accompanied her for routine blood work and then we reported for the stem cell harvesting. The room is set up in a "U" shape with about 15 stations for patients to hook up to the harvesting machine. In the middle there was equipment, nursing stations and other supplies. Once Carol was hooked up and started the process I went back to our condominium to work. At around two I went back to the hospital and Carol was having a conversation with a woman. Carol introduced me to Rhonda, who, like Carol, had been a teacher. She said I should go to the other side of the room and meet Rhonda's husband – he was a retired hospital CEO so we probably had a lot in common. I went around and Rhonda introduced me to her husband who was also undergoing the harvesting process. It was Dr. Rueben Devlin. I had not met Rueben before but certainly knew who he was.

Rueben was well known in Ontario health care circles as the CEO of Humber River Hospital. Rueben was an orthopaedic surgeon who left clinical practice to become the CEO of Humber River Hospital. We got chatting about all sorts of things and we hit it off with the two of them. Later in the week Rhonda and Rueben invited us out for dinner – something we would do on occasion over the next twelve months. Rueben had already fought cancer but eight years later it returned and a stem cell transplant was his best hope. Rueben went on to lead the Premier's Council to End Hallway Medicine. Unfortunately Rueben passed away during Covid and the work that he was doing through the council was never truly completed.

Once through the harvesting process we needed to prepare for the most difficult step of the process – the intensive and powerful chemotherapy that would kill the cancer cells. Unfortunately, it kills healthy blood cells as well. There were many side effects from nausea, diarrhea, dehydration and tiredness. One practitioner explained they use the high dose chemotherapy to wipe out your existing immune system so they can start fresh. It certainly confined Carol to bed as her body dealt with the therapy.

Next week - The Best Laid Plans