

## **Don't Sweat the Small Stuff**

*A new chapter each week – a 4 minute read!*

### **Chapter 14 – We finally meet NED!**

We returned from Toronto and got Carol admitted to Thunder Bay Regional. She spent the next ten days in isolation at the hospital and she seemed to spend most of her time sleeping. The system had done a truly amazing job of treating Carol including the stem cell transplant. It was now a bit of a waiting game to ensure that the transplant worked.

Although I have had many small complaints about our system it is necessary to point out that Thunder Bay Regional Oncology program intervened in Carol's cancer quickly by having her start chemotherapy only ten days after she had presented at the emergency department. This decisive approach likely held the cancer from spreading to other areas of her body and laid the groundwork for a successful resolution of her situation. We continue to hold the cancer team at TBRHSC in the highest esteem. The cancer centre had a long history and under the guidance of Dr. Dhali Dhaliwal the base was built for a truly excellent service. The creation of Cancer Care Ontario managed to bring together the many cancer centres across the province and ensure standardization of approaches, providing adequate resources, comprehensive screening and building what is arguably one of the best cancer programs in the world. Cancer Care Ontario serves as a true success of our public health care system. Dr. Dhaliwal went on to have a distinguished career heading up Cancer Care Manitoba.

As mentioned we were now in a waiting game – the system had done everything it could for Carol and now it was time to see if the stem cells were grafting as expected. There are times when the grafts do not work and the oncologists may wish to repeat the stem cell transplant. Carol spent most of her time sleeping as extreme tiredness was the main side effect she felt. After a month it was clear that she was recovering.

She was referred to a radiation oncologist who felt that Carol might benefit from radiation therapy to ensure the tumour was irradiated. Given the past experiences Carol opted for the radiation treatment. This would be a cycle of four weeks with five treatments a week. She would receive the treatment starting in November and finishing on December 6<sup>th</sup>. Aside from some side effects such as tiredness and impacts on her bathroom schedule the treatments went smoothly. Treatments did not take very long. The longest part of the process was ensuring that she was in the right position. They had tattooed markers on her body so the radiation rays would hit the exact same spot throughout each treatment. The machines use more than a single beam in order that they do not damage the healthy sites around the tumour. When the multiple beams meet at the tumour site they combine to create a much larger absorbed dose that effectively targets the tumour while not damaging the surrounding area.

Prior to beginning radiation Carol had gone for additional screens. She was told the results would be forthcoming. That never happened. She waited for the results but they did not arrive. This created a lot of consternation on her part. The day of her first radiation treatment her oncologist visited her in the radiation bunker. Carol asked about her results. The oncologist was surprised that she had not received them yet and went to get the results. She came back with the pathology report that was extremely encouraging. Things were “unremarkable” which is what you want to see and the oncologist pointed out the letters NED at the bottom of the report. She indicated this was a good sign as NED stood for No Evidence of Disease. No one likes to use the cure word as it can be seen as tempting fate, however this was the best news we received in our battle. The delay in getting Carol’s results was explained by the fact that they will share poor results first and the better or more positive results can wait.

For those of a certain age you may remember that “charm” bracelets were all the rage. These were bracelets that you added charms to. A long time ago women use to wear their bracelets as they recounted the key events in one’s life – graduations, weddings, children’s births, trips and so much more. Carol’s sister Joan had provided Carol with a charm bracelet with the instructions she could not take it off until she was done with her battle. It was a plain bracelet that Carol wore throughout the entire journey. I decided to get her a charm for Christmas with NED on it. We had to get her sister’s permission to add this to the bracelet. She was agreeable and I don’t know many people named NED but this name became a special name to us. When I picked up the charm I handed my credit card to the salesperson. She looked at the name and she said – I thought you would be named NED. I recounted why NED was on the charm as it marked a significant turning point in our struggle. The poor sales person when hearing my story started to cry. When a complete stranger can share in such a moment you realize the incredible support that we have had from family, friends, practitioners and others involved in this journey. To all of them we will be forever thankful. We visited Toronto for one of Carol’s annual checkups at Princess Margaret. They keep their stem cell patients on the program and between Thunder Bay Regional and Princess Margaret, the follow ups went from every three months to every six months to annual.

While in Toronto for a check up we went out to a well know restaurant – Barberian’s on Elm Street. We had gone to Barberian’s with Rueben and Rhonda Devlin, as well as Carol’s sister Joan and her husband John. I arranged for the waiter to deliver a note from NED to our table after we sat down. The note from NED indicated that he could not join us for our meal, but wanted us to know that he would be with us forever. NED provided a bottle of wine for us to enjoy the evening.

This completes the story of our journey through Carol’s treatment. We are deeply thankful but also stop to remember the many people we met throughout the process who didn’t have successful outcomes. We realize that you cannot figure out why or why not but simply be thankful for the outcome we achieved.

I will be sending out a few more chapters outlining some of the challenges we face in the Ontario health care system. All in all this has gone out to almost 500 people in Ontario each week and the interest has been exceptional. Hopefully there will be a constructive will to bring about the changes we need to ensure that our public system continues as a truly viable system of health care provision that can deliver the results and quality the residents of Ontario should expect and deserve. We need to strive to move our system from good to great!

**Next week – Epilogue**