~~Don't~~ Sweat the Small Stuff

A new chapter each week – a 4 minute read!

Chapter 8 – Where to from here?

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We are half way through recounting our battle with cancer and we are surprised at the number of people who have reached out to share their stories and offered insights into the health care system. Thank you for your continued interest and feedback. We finished our first round of chemotherapy and while it showed some effectiveness it did not result in the outcome we had hoped for. The next few months were truly challenging.

When we started, the path forward seemed quite clear. The oncologist in the ED on day one figured it was some type of lymphoma. Tests proved him right and the course of action was well known – CHOP-R. This was a path the practitioners have seen many times and prescribed on countless occasions. Their decisiveness and quick action were both comforting and reassuring. When we got to the end of the first phase of treatment and realized that we were not finished we looked for the next steps, as though there was some sort of playbook the oncologist pulled out to determine where we should be going in our battle. At this juncture we learned that the next steps were not necessarily well defined as there were a lot of unknowns. Before we could move forward there had to be more questions answered which required a number of further tests, scopes and our oncologist really wanted a biopsy to specifically identify what we were dealing with.

Our surgeon friend indicated that the scoping was not all that successful as there was some sort of blockage. He suggested that there not be a biopsy as the recovery time from doing the biopsy could delay the next round of therapy as there would need to be recovery time taken into account. Weeks dragged on and then it became two months. The only facts we knew was that there were more growths and they were growing relatively quickly. We were desperate to move forward but there was no clear indication of exactly what path we should be taking. Our oncologist did indicate that Carol might be a candidate for stem cell transplantation, but there would be a number of steps required before that would be possible.

Small Stuff # 11 – Oops!

In the midst of our working to find out a path forward, we spent the long weekend in May at our cottage on Rainy Lake. On the Monday we called Eric Touzin, our surgeon friend in Sioux Lookout to see about a further scope and if there was some way we might be able to do the biopsy. Eric got on the phone with us and indicated that he had the latest pathology report in front of him. Carol was all clear – no signs of cancer – Congratulations! We were ecstatic – we drove the four hours back to Thunder Bay giddy with happiness that we were finally done with this life altering situation. We returned to Thunder Bay planning how we would restart our lives and get on with things. I phoned our radiologist friend to offer our thanks for all of the timely advice over the past eight months. The message was somber – “David not sure where you got this information from but I am looking at the scans right now and Carol still has growths that are getting larger.” Turned out that the pathology report was a mistake and our oncologist had identified it was an error within 24 hours of when it was offered, but the incorrect report continued to create part of Carol’s record. Over a week later when we went to see a surgeon in Thunder Bay and he asked why we were there as he had a report that there was nothing wrong with Carol. We explained that the report was in error. He concurred with Eric that a biopsy could create more problems than solutions. The PET scan did show additional growths and that they were getting larger rather quickly. We were now in discussions with Princess Margaret about the possibility of a stem cell transplant but there was a large and looming caveat – the tumours had to respond to treatment or a cell transplant was off the table. It was a difficult discussion we had with the Dr. Kurvella from Princess Margaret as he pointed out that if the tumours did not respond to a second round of chemo and the transplant was off the table Carol’s prospects were grim.

Dealing with Princess Margaret which is part of UHN gave us amazing access to Carol’s medical records, appointments, scans and specialist reports. Carol didn’t bother to look at her MyUHN record. I did and noted that when Princess Margaret reviewed the pathology and reanalyzed the sample that Carol had the rare “triple hit” lymphoma that is a lymphoma with three genetic mutations. The report concluded prognosis – poor – usual life expectancy 17 weeks. As stated earlier I did not share this with Carol, she had enough on her plate to deal with.

Small Stuff #11 – Can you spare $10,000? Carol finally started on a second round of chemo – GDP plus rituximab. At our own cost of $3400 per treatment we added the rituximab. It had been used in the first round but Ontario and Alberta will not cover the drug for a second round of treatment. Upon the recommendation of our oncologists we paid for the treatments ourselves. Apparently there is not enough evidence to show that rituximab is effective beyond the first course of treatment but it is widely used across Canada and the US in subsequent rounds of chemotherapy. Whether it had a positive impact on Carol’s outcome is impossible to definitively prove, but we were fortunate that we had the resources to pay for the treatment and obviously credit it to some degree with Carol’s positive outcome. We were happy that we were entering another phase of chemotherapy and hoping for the best. We desperately wanted to explore the stem cell transplant route and were hopeful that this round of chemo would open the door for us to pursue the transplant at Princess Maragaret.

Next chapter – Not smooth sailing but making headway!