

Don't Sweat the Small Stuff

A new chapter each week – a 4 minute read!

Chapter 11 - A Month in TO – The best of the best!

We now knew we would be heading to Toronto for an entire month. We were filled with hope and appreciate the health care system in Toronto and everything the city has to offer. The stem cell transplant process has many steps to it and Princess Margaret provides you with a calendar outlining what will be happening over the four weeks. As we concluded our first trip to Toronto we needed to start planning for our return visit for the stem cell transplant.

Small Stuff # 16 - Getting There and Staying There - Has anyone seen Ronald McDonald ? (Staying) and Who has a Ticket to Ride? (Getting There)

Ronald McDonald House

McDonalds famously operates Ronald McDonald Houses for children patients and their families. Toronto's is literally steps away from the Princess Margaret back entrance. This offers a much needed service and the positive public relations to McDonalds (a \$ 35 billion corporation) is huge. It would be great if some other national corporation would do the same but with a focus on adult patients.

Knowing that we needed to stay in downtown Toronto for a month we looked for a place to stay. The Northern Travel Grant offered a maximum of \$100 for room and board regardless of length of stay. (This has since been increased modestly). Hotels were a possibility and several downtown properties offer reduced rates for people travelling for health purposes. Even at their reduced rates the cost of lodging for a month would be over \$6500 out of pocket.

I visited the Princess Margaret Lodge which was about twelve blocks away from the hospital. It was an older structure located on Church street. It was built as some sort of dormitory and it had not been updated in at least 50 years. I was given a tour - the rooms were all the same – quite sparse, just two single beds – no TV or other amenities you might see in a hotel room. Bathrooms were shared amongst several rooms. There was a dining area and a living room area with a television and sofas. While such accommodations were fine for a short stay they were not ideal for a long stay. The real kicker for us was that I could pay a nominal fee to share a room with Carol, but if the bed was needed by a cancer patient I would need to find alternative accommodations for myself. The residence is currently closed and being updated.

The Early Bird!

I am a very early riser (gets worse with age!). On our last day in the Toronto area I was up and on my computer by five and started investigating short term condo rentals in the area. I went to

Kijijii and noted that someone had just posted 20 minutes earlier that he had a condo for rent for the month we needed and it was close to Princess Margaret. I responded immediately and he quickly got back to me. He was leaving the country for three months and had his condo rented for two of the three months. It was located on Carlton street next to Maple Leaf Gardens - just a five to ten-minute walk to Princess Margaret.

On our way to catch our flight we stopped to see the condo. It was a one bedroom and small but was available for less than \$3,000 for the month. We signed up immediately. Things seemed to be falling into place and we hoped this was a harbinger of things to come. As with the \$10,000 we spent on the Rituximab out of our own pockets we were fortunate we had the resources pay our own room and board. Not everyone is so lucky and while the Northern Travel Grant tends to cover transportation costs not everyone in Ontario has access to such funding – in some ways being from the north has its benefits.

Small Stuff # 17 – Need a Ticket to Ride – Getting to the care you need!

We sat in many waiting rooms while Carol waited for her various appointments. In the waiting room at TGH a woman beside us started a conversation. While our situation was challenging her story made me aware that others struggled more than we did. Her husband had multiple myeloma and was supposed to get daily treatment for a stem cell transplant at Princess Margaret. They lived in Orillia which is about 150 kilometres north of Toronto. His treatment was similar to Carol's and required them to be available on a daily basis for four weeks. They could not afford to stay in Toronto for the duration of the treatment. Her husband was too ill to drive so she had to do the driving but that was not an option for daily treatment. The option was to become an inpatient so he could be in a hospital bed and take his daily treatments. Now they were faced with a really difficult decision – if they waited for an inpatient bed the wait could be several months – treatment delayed by months often severely reduced the efficacy of the treatment. To have to make such a decision over the ability to physically access the care that was needed seemed arbitrary and unfair. The care they received was excellent but the access to that care put up such a barrier that staying home and delaying needed care was the option they were forced to choose. Ours was a brief encounter - probably 15 or 20 minutes. I never knew their names but just the fact that someone who was so close to some of the worlds' best care would make the decision to delay that care for months because of what should be a small thing, like getting to that care proved to be so difficult.

Next week – The Process Starts