

The Topic of Cancer

By Ruth Merkis-Hunt
&
Adam Hunt



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with epic apologies to Henry Miller

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The Topic of Cancer

with epic apologies to Henry Miller

by Ruth Merkis-Hunt

With a diagnosis of cancer comes a flood of emotions. Anything from confusion to terror, even to relief, you're going to have those feelings...and it's all okay. I know this because I went through it all when I received my own diagnosis of cancer.

This came on Friday April 13th, 2012, just as we were still trying to come to terms with my sister's sudden death only a couple of months earlier. Even at her funeral, I had a very strong suspicion that I had cancer...cervical cancer...locally advanced cervical cancer it would turn out to be.

My story begins rather suddenly back in November, 2011 when I developed an odd symptom. There was no pain or anything that caused me any particular worry...until a couple of months into things when this particular symptom had not gone away. So, I went to see my doctor who ordered some tests. I wound up, over the course of a couple of months, consulting with not one, but two gynecologists, one of whom examined things and decided to take a biopsy, as he didn't like what he saw. A week or so later, the doctor, one in a series of medical specialists I would soon see, cautiously but firmly told me that the results of the biopsy confirmed cancer.

I actually felt both relief and a bit of vindication. Yay, I was right and now that we had a definitive diagnosis, we could take the next step...and the one after that...and the one after that.... Not a single one of those steps would be easy but they were, and

remain, necessary if I wanted to have my health back – and even wanted to live. I was on the cusp of turning 48 and already had about 13 years' experience dealing with fragile and uncertain health as I already had been living with multiple sclerosis. I already had experience dealing with endless medical tests, procedures, appointments and follow-ups.

Separation of self

At the risk of sounding heartless or else mired in a denial of some kind, doing well with a diagnosis of cancer (or any other illness actually) requires you to extract yourself from it. This goes for family and other loved ones who will be helping you with your treatment. Cancer is something you “have” not something you “are”. At the same time, it is we ourselves whose health, livelihood and even very lives that is under threat. How can you just “detach” the diagnosis from the person who, literally, embodies the disease process itself? That isn't easy and even if you are successful, there is no guarantee that success will remain. This is where the up and down and all over the place emotions come into play.

I know that in my own case, once the doctor told me I had cancer, I immediately wanted to know what would happen next to both me and to my body. I recall not reacting with any kind of emotional upset – that came a few weeks earlier when I was dealing with the one and only symptom and not knowing what was going on. However, the diagnosis was there and we could now proceed to the next step; the parade of doctors and tests.

About 6 hours after I got the diagnosis of cancer, the phone rang and rang as clinics, doctors offices and other medical institutions phoned to set up the many appointments for me. Yes, I did sometimes feel as though I were merely a patient number or a slab

of meat but, know what, I **am** a patient number or a slab of meat. So are you. So are they. So is everyone so it's important not to take anything too personally. I found the only way I could successfully navigate the whole endless-tests-and-appointments cycle was to remember that it's not about me and that I am but one of many many others who are also facing similar things. Extract the self from the process and things will work a lot easier.

That's not to say deny the very real personal aspect to cancer but it is to say not to get too attached to that sense of self. It's around here where you will encounter a significant contradiction: your cancer diagnosis and treatment are about you but it's not about you either. That's a tough one to navigate so I found it worked better for me to not bother too much about it. I had a whole bunch of tests and imaging to go through.

What follows next is the set of newsletters I wrote and sent out to family and friends.

I did hear back from friends and family in response to my newsletters and the notes were always so positive. It's important for cancer patients to engage in as much of a “normal” conversation with loved ones and I was very blessed to have retained that aspect. It's not all about me and I enjoyed hearing from others about their lives.

This is the journal of events of my cancer treatment. I did try to write a little something each day. A few themes, phrases or ideas may repeat themselves in my notes but it doesn't happen too often.

Ruth
Ottawa, October 2012

Forward to the Second Edition

by Adam Hunt

Back when Ruth and I met in October 1996 she said we would one day write a book together. As we spent more time together she told me that the book that we would write would be story of the love and kindness that we shared, about how good relationships can really be. We thought it would be uplifting and hopefully inspiring.

While this book does tell something about love and kindness, this is not the book we had hoped to write at all. This is, instead, the story of Ruth's death from cancer on 30 January 2014 at age 49, far too young an age to go.

Adam
Ottawa, January 2014

Part I

Initial Treatment

April-September 2012

By Ruth Merkis-Hunt

Tuesday, April 24th, 2012

CT scan morning.

Hi everyone,

As we don't really have the means to make the videos of me as I undergo treatment for cancer, we figured the next best thing was to make a newsletter with pictures instead.



Well, we are still at the imaging phase of my cancer treatment. This morning's appointment was for a CT scan of my pelvis.

In preparation for this scan, I had to drink 8 glasses of water throughout the day yesterday. That translated to roughly 3 1/2 fillings of my new NCF water bottle. I also knew that I would have to have both a contrasting fluid injected intravenously and to drink some contrasting fluid as well. The picture above gives you as clue as to how this nightmare from a chem lab tasted.

The liquid I had to drink is designed to provide sufficient contrast so that the radiologist can easily see my various internal organs. Now, I don't and never expect medicine like this to be particularly tasty (clear raspberry delight or lovely lemonade) but this dreadful glop smelled and tasted like chlorinated pool water into

which something like hair spray or nail polish remover had been added. The picture above was my absolute, genuine reaction after the first (inhales deeply), “sip”.

The whole experience was made only slightly more tolerable by the technician's very generous offering of one of those extra large mint life-saver candies. That's not to say it made the drink fantastic – just that it made it only slightly less disgusting.

I didn't wash my hair this morning as is evident in both pictures from today, but then, I'm not trying to look like a model anyway.

There are many things that got me through all this, including my word search puzzle book.



Next appointment is on May 1st and it will be to meet with Dr. E, the radiological oncologist at the General Hospital.

Tuesday, May 1st, 2012

More tests but we have a plan too...

If there is one thing I've learned about having a cancer diagnosis is that the reams and acres of tests, examinations and consultations I've undergone to date would test the patience of a

Buddhist monk. However, you also wind up meeting some of the kindest, warmest and most helpful people out there and yesterday (I'm writing this on the 2nd) I met a lot.

My first trip to the cancer centre actually came after a quick detour to get a chest x-ray. Apparently, cervical cancer seems to really like spreading to the lungs, hence the need for a chest x-ray and that's where the news was really good. My lungs are in good shape and there is no sign of any metastases.



We went to the Ottawa Hospital, General Campus and wound our way to the aptly named module “X” for my chest x-ray. What do you think of the colour of the all-too-familiar hospital gown I wore for the chest x-ray? The “Crest toothpaste blue” is kinda neat but not really my favourite. I registered at the desk (something I do rather a lot lately) for the x-ray and, twenty minutes later, was having my picture taken

by the technician. The picture Adam took here was afterwards while I was getting ready to get dressed again.

That done, we went to the first floor, found ourselves a table and chairs and then ate a bit of lunch before my appointment to meet, and be subsequently examined by, the radiation oncologist, Dr. E. I also saw a few other doctors, including the chemotherapy doctor Dr. Weberpals. She came to talk with me about the chemo itself. The chemo will come after the radiation therapy, so I was told.

Overall, the experience was very positive but really busy, too. I

lost count of the number of nurses, technicians, doctors and physician residents I have seen since this all started.

At this point, I am looking at beginning the external beam radiation therapy within the next couple of weeks. I will be going in for that Mondays to Fridays over a 5 week period for a total of 25 treatments. The internal treatment, known as brachytherapy, will be next. I believe I am having three treatments there and then the chemotherapy (Cisplatin) will follow. We are also very lucky in that Rachael, my daughter, is up here for awhile to help out. She wants to come with me to my treatments and has been really hungry to learn about all of this.

By the time I was released from the myriad of consultations, tests (chest x-ray and yet more blood tests) and other procedures, it was getting late. I have been given a lot of take-home information sheets and pamphlets and so am even more prepared to start treatment. Hopefully, that will all take place within the next few weeks.

The next step, however, is a trip to the Ottawa Hospital Civic campus for an MRI. That'll be tomorrow early in the day so I'll write about that. *(Edit: I didn't actually write anything on May 2nd but that's because they changed my MRI appointment to May 14th. It happens now and again.)*

Wednesday May 9th, 2012 – No PETs found

In my darker moments, I can argue that they lied. By that I mean that I didn't expect that yesterday's test (I'm writing this on the 10th) would be a double whammy of sorts.

When I saw Dr. E, and his colleagues, one of the many people I

also saw was a research associate who was helping prospective participants sign up for a study to determine whether cancer patients who obtain a PET scan have improved outcomes over patients who don't obtain a PET scan. Being the dull science type, I eagerly signed up for a PET scan. They're not currently covered by OHIP and so if the scientists can demonstrate to the Ontario government that PET scans can significantly improve cancer treatment outcomes for patients then it would be in everyone's best interests to include PET scans as a funded procedure. Our health care system is set up so that medically necessary procedures are funded by taxpayers so, long story short, depending on what the study finds, PET scans may soon be added to the other medically necessary procedures that are covered.

Eager to help out, I was pleased to learn that I was placed in the group that would receive a PET scan. Yay! So, yesterday, Rachael and I went to the hospital and I got ready for the scan.

PET stands for Positron Emission Tomography and it's, fundamentally, another form of imaging. I knew I would be receiving the chemical, Flurodeoxyglucose₁₈ by IV infusion.

However, as I sat with yet another IV stuck in my left arm (they couldn't find a large enough vein in my right arm) I was surprised when the technician also brought to me a large cup of that horrible swill I managed to choke back for my CT scan I had had on April 24th. This, I was informed, was for my CT scan which I would be having along with my PET scan...hence my thought that I had been lied to.

So, I would be having a second CT scan along with my PET scan and that meant I would get to savour the same – um – side effects from the earlier 1-point-something litres of pool chemicals flavoured with nail polish remover that I bravely drank. The things I do for science.

So, while treatment has not actually begun, I like to think it has to start soon. I only have an MRI left to do on the 14th but as I have had MRIs before at least know what to expect.

No, nobody actually “lied” to me – but it's hard to not think someone somewhere is having a good laugh at my expense while I try to soothe an already upset stomach.

The Final Imaging Test...YAYYYY!, May 14, 2012

I have had MRIs before so I didn't have any qualms whatsoever about this, my final imaging test that has been ordered to date. What I hadn't counted on, however, was that I would have to be injected with yet another contrasting fluid. At least, though, I wouldn't have to drink the horrid stuff.

This would also mark the very first time I had gone to the Ottawa Hospital Civic Campus on Carling Avenue. That “branch” of the Ottawa Hospital is amazing in its sheer labyrinthine character. I had been told to enter via the “Main Entrance”. So, I foolishly assumed that would be a simple enough act to do.

No.

There are quite a number of entrances to the Civic campus, none of which were really the best one to use. But, the three of us (meaning Adam, my 21 year old daughter, Rachael, and I) shuffled through anyway and were almost instantly met by a puzzling maze of corridors, wheelchair accessible ramps leading to somewhere-we-didn't-need-to-be and all of these “streets” festooned with luggage shops, medical equipment stores and even a few coffee shops. So, we gingerly made our way through and

came to an information desk. The staff and volunteers at the civic campus seem to be spring-loaded towards asking people if they need help with something so we were very pleased to have got a lot of help. Eventually, we did find our way towards the “C” elevator which would take us up to the first floor – completely overlooking the assumption that the main floor of any given building would already be the first floor.

No.

Rachael found the “C” elevator and so we got in only to discover that there is no “door close” button. We would have to wait until, I don't know, the egg timer was up before the doors would close. A quick zip up an entire floor later (no, we couldn't find the stairs nor was there really any time to look) and the doors opened to near total silence. I had been instructed to follow the red dots on the floor, what Rachael humorously called the blood spatters, until they ended. Then we were to follow the purple dots until we got to the end and, presto, the MRI section would magically emerge from the haze of this rabbit warren of a hospital.

No.

Instead, there were green dots next to the red dots and then a solid wall. If it hadn't been for the sign on the wall pointing us to the MRI clinic, we would probably still be there wandering aimlessly and looking for the place. I did find the MRI clinic, filled in all the requisite forms and, in short order, found myself dressing yet again into one of those hospital gowns.

The waiting room right by the entrance to the scanner itself was its requisite ice cold. They all are, aren't they? I had known I would have to have a contrasting fluid injected into me via yet another IV so I was well prepared for that.

Shortly afterwards, the technician lead me into the room, had me hop onto an ironing board which would then slide into the scanner itself. I was fitted with headphones and gently instructed to lie perfectly still. I usually meditate when this happens – what else am I going to do, right?

If you've never had an MRI before, it's an interesting experience. There is no pain at all whatsoever but the scanner itself is LOUD. The whole experience can be a little intimidating, too, when you consider that there are those large yellow warning triangles informing you that magnets are in use all the time. The doors leading to the scanner form what appears to be a Faraday cage so that any magnetic zaps stay inside there...where you yourself are going to be spending the next half hour.

The first scan, lasting about 2 minutes, always startles the (insert colourful noun here) out of me and I elicit the startle reflex like a pro...until I quickly learned that any scan is preceded by a couple of heavy taps (I told others so that they wouldn't jump when their scans start). But, YIKES, MRI scans are loud. Imagine sitting next to a jackhammer being amplified by a live concert of Jethro Tull's *Locomotive Breath* on repeat and you get the idea of what an MRI is all about.

Yet, I didn't have to drink any horrid awful stuff so that made this morning's experience so much better.

Now, the imaging is all done (it better be) and so the next phone call I get should be from the Cancer Clinic informing me of when my external beam radiation should start. If I hear nothing by, say, this Friday then I will start making my own phone calls.



Cancer is serious, even if it's treatable and curable as mine is. However, I am not very good at adopting too dire a posture. There is a certain Kafkaesque absurdity to all this which actually makes me laugh.

Of course, with Rachael here, she has been not just an immense and magnificent help to me but has said some of the funniest, most ridiculous things to me.

Adam has been a perfectly marvellous and breathtakingly beautiful husband to me throughout all this. My cancer affects him, too, and I would just not be able to even think about going through all this and keeping my spirits high if it weren't for him.

This wayward wheelchair (above) proved to be too much of a temptation for the likes of me and so I had to demonstrate how to do the Heimlich maneuver on myself while sitting in a wheelchair. The alternative was for me to lie down under an ambulance and to stick my feet out the back but there were no ambulances within easy reach. Besides,



Rachael said “No, Mom, that's stupid and dangerous.”

More than all that, though, is that I glean so much from seeing all the other cancer patients. The courage and the beauty within shines through in ways I can barely describe. I am infinitely honoured and privileged to share in the love and courage of others.

The other picture from today is proof positive that Rachael was wearing my shirt in case anyone ever doubted.

Friday, May 18th, 2012 – more liquid goop and some tattoos, too!

I was very happy when I got not one but two phone calls from the cancer clinic. They both took place on May 16th, two days after my MRI. The first was from Dr. E's secretary, Michelle. She phoned to tell me that I was to come in for my “simulation” (aiming point prep, really) of a radiation treatment. This is the appointment where I get placed on yet



another ironing board and slid into the machine that will – essentially – nuke me. It was also the appointment where I got not one but three tattoos, none of which are flower festooned banners with things like “LOL” or “Carpe Diem” written inside. The tattoos I have are three tiny black dots where the radiation beam will be aimed. They’re permanent and the application therein marked the last non-treatment appointment. By the way, there was a pun in that last sentence and it was only partly intended. (*Edit: The little pun is that the appointment “marked” just like the tattoo “marked”...*)

Michelle also said I would have to – ugh – drink contrasting fluid but she promised me it wouldn’t be the wretched horror of CT scans past. Instead, I got to drink three large glasses of what tasted like plasticated water...and to not visit the ladies room. I guess life isn’t challenging enough without having to spend time with an overfull bladder to make things more – uh – challenging. Apparently, of all the radiation oncologists at the hospital, only Dr. E requires patients to be stunningly uncomfortable with a very full bladder. The picture from this day shows me getting ready to finish the third of three drinks of what Rachael calls “Trenton water”. However, the wonderful technicians there (bless them all) performed the scan as quickly as possible and then let me zip off to the washroom. Upon my return, I was placed once again on the ironing board and the permanent tattoos applied. The areas still sting a tiny bit but I am assured that will subside.

The second phone call I got was from Alicia from the chemotherapy section. It turns out that I will be having chemo while also undergoing radiation. By that, I mean this will all take place over the same 5 some odd weeks and not that I will be hooked up to a cisplatin delivering device while also being cooked from within. I will start both radiation and chemo on the 24th of May, some 5 and a bit weeks after having been diagnosed.

I mention that to emphasize how quickly our health care system hops into gear whenever the word “cancer” appears anywhere on any medical report. This is why I never complain about paying taxes.

Thursdays will be my chemo day and I will get one dose per week for the next 5 weeks. Although I start radiation this Thursday, with a second dose the next day, I will not be receiving any radiation over the weekends. That means two things. Firstly, I get the weekends off and can, possibly, partake in such goodies as the Sunday Bike Day. It also means that the hospital does not run the radiation machine over the weekends. I only mention this second thing because, apparently, MRIs run 7 days a week so there are **some** diagnostics being done.

The vast majority of yesterday's venture was spent with me and Rachael sitting in one of the spacious and open waiting areas and watching me sip plastic water which, TRUST ME, was infinitely easier to drink than the CT scan nonsense. There were other cancer patients, of course, and the overall mood there seemed to be one of community and general bonhomie, despite the tendency for some patients to delve into astoundingly over-detailed information about their treatments. However, there was one little boy there whose sheer courage brought me to tears.

He must have been around 6 years of age. Emaciated, bald and being held lovingly on his very brave mother's lap, this small child looked and was exhausted. Yet, through all that, he still smiled and very happily took the free candies the Cancer Society volunteers were offering. It wasn't that little boy's cancer that so moved me but his very ordinariness in happily reaching for free candies that had me in (quiet) tears. Luckily for me (VERY luckily for me) I had Rachael with me and she held me and rubbed my back while I worked through my mild weepiness. Dr.

E's secretary, Michelle, was also there and very much understood my reaction. When this small boy started walking with his mother, presumably on his way to treatment, I reached out, touched his skinny little arm and told both him and his mother to hang in there and that he was doing great. His mother looked at me and reassured me that he was doing really well and that he was kicking butt. I know it's a lot of courage and optimism and while I'm sure he would do well, as a mother myself, it physically sickens me to see children suffer like that. I have no doubt in my mind that this boy's mother is feeling the horrifying nightmare of having a very sick child. I had Rachael holding me and reassuring me so I was extremely lucky. Wow. I have awesome children.

I have also totally given up. By that, I mean I am no longer going to try and force myself to refrain from laughing at the ridiculously hilarious things Rachael and Adam tell me. Except for radiation treatment, where I have to lie perfectly still, I intend on laughing as much as I can. I have no idea what kinds of side-effects I, personally, will experience but I'm ready for them...I think.

Afterwards, it was lunch time and so Rachael and I went to the common eating area in the lobby of the hospital. There, we found a number of empty tables (think cafeteria) and promptly parked ourselves there. She then went off to Tim Horton's to get us both a couple of iced lattes to complement our lunch of cantaloupe and cheesy sandwich somethings (with mine on tomato basil rice cakes which are gluten free). It was only after she left that I saw the sign on the wall that said a "Second Cup" was coming soon. She and I didn't even notice it when we first sat down and I only saw it after she got up. When she got back, I directed her attention to the sign.

YAY for froofy overpriced coffee thingies.

So, now we know where and when my treatments will begin. It is not my intention to write to you all every single day about each individual radiation treatment but I will write about my first treatment of radiation and chemo. After that, just put “ibid” and you'll get the gist of things. *(Edit: I did write a little something each day as it turned out. The best laid plans of mice and cancer patients, eh?)*

Thursday, May 24th, 2012 - Intro to Chemo & Radiation... Part I

Rachael and I got to the hospital around 7:40 this morning. I was supposed to be at the chemo day clinic by 8:00 but the bus connections were such that we got there early. That gave us an extra few minutes for Rach to get some coffee for herself. Plus, we had to find the day clinic itself. We knew it was on the 8th floor but, not wanting to wander aimlessly through the place and in a half-panic in case we were getting late and not finding it, we chose to show up early. If that meant waiting then so be it.

The elevator doors opened on the 8th floor revealing, in large letters, very clear directions to the various obstetrical wards. It was only the kind directions of a nurse who just happened to be walking past the elevator that had me and Rach heading in the right direction.

We found the chemo day clinic and not half a minute later was I seated in the big comfy chair. The day clinic ward is a small room with 4 beds. I had been directed to a bed but chose a chair instead. As this was my first day of chemo, I wasn't sure whether I would need a bed or not but one was there if I did need one.

The nurse came in, confirmed I was the right person to be set up

and then went to get the necessary IV implements. As usual, the left arm was used as, apparently, the veins on my right arm are way too tiny for any easy insertion of the needle. The nurse was very gentle and I felt only the tiniest prick when she installed the IV needle and bandaged it to my now well-used left arm. Rachael adjusted the pillow under my forearm and, once the nurse set up the saline solution and got the drip going, we were off to the races.

I also got a pill given to me to help stave off the nausea typical for chemotherapy. In particular, I would be given the drug cisplatin which is, we learned, notorious for causing nausea and vomiting. The pill, Zofran (aka decadron) is a steroid whose side-effects include insomnia and a sense of “being wired”. I don't know about the insomnia but I certainly don't feel especially jumpy or energetic. I feel tired, but then, it's been a rather rough time so far this year.

Then, the nurse took my temperature and blood pressure. Temperature = 36.7C (no sign of fever or, by inference, infection); blood pressure (yes, they found it this time) = 93/60, which is normal for me.

I also got a steroid med (“a cousin of prednisone”, the nurse called it) also by IV but that part of today's treatment didn't go on for too long.

Then, another nurse came in about an hour after all this started and brought the cisplatin bag. *This*, I thought with a quiet smile, *is the reason I'm in this room in the first place*. I watched, breathing easily, as the nurse hooked me up. Rachael and I watched, smiling the whole time while the half-dose cisplatin (dissolved in likely another saline solution) dripped its cytotoxicity into my willing vein. The real irony here is that

cisplatin, technically a poison, is also a healing agent. Originally known as Peyrone's salt, this miracle drug synthesized in the 19th century, has been used as a chemotherapeutic agent since the late 1970s. It is notorious for causing the stereotypical nausea, vomiting and other visual side-effects we so commonly associate with cancer.

Cisplatin damages the DNA of rapidly dividing cells, preventing further replication and resulting in cell death. Cancer cells are the intended target and they do die off from exposure to cisplatin. However, because cisplatin cannot discriminate between the rapidly dividing cells of cancer and the normally rapidly dividing cells of, say, the stomach lining, intestinal lining and of hair follicles the (too) common consequences of nausea, vomiting, diarrhea and hair loss are seen.

I am assured I will notice virtually none of those things.

Yet, I also received quite a number of prescriptions for anti-nausea meds as the paradigm in cancer treatments is prevention rather than response – a sort of “nip this one in the bud”.

Rachael was, and still is, her usual fantastic and awesome help. The IV tower used to deliver my meds through my vein runs on electricity but, once the plug is removed from the wall, a battery kicks in so that I can wheel my way to the washroom. Hey, when they're pumping in 'x' litres of fluid one is bound to need to visit the washroom at least once, right?

So, Rachael unplugged the unit and helped to get me to the washroom which was in the room. She came in with me – she had to go, too – and we helped each other to make sure neither of us ran into any problems, not that either of us was expecting any.

About 90 minutes after I was first connected, I was done. Now, we had to wait in the patient lounge to speak with the pharmacist who wanted to explain my prescribed meds to me. All of the medications I saw I was familiar with...but there was one with which I was quite familiar – and I was a little disturbed seeing it on my list of prescriptions.

I used to work as a mental health professional in private practice and am pretty familiar with the medications used to treat the various mental disorders. I quite vividly recall having had a client who was taking a medication called olanzapine. That, I well knew, is an antipsychotic drug prescribed for people who have schizophrenia. It's used there because it's fairly fast acting so when I asked the pharmacist why I was given a prescription for an antipsychotic drug, was told that olanzapine is also a very good anti-emetic medication. I questioned the need for such a powerful drug for me, especially when I had been assured that I wouldn't likely experience much in the way of either nausea or vomiting. She said that would be an absolute last resort medication. Long story short, I did have all my anti-barfing drugs filled at our pharmacy but, at this stage, have no intention of picking up olanzapine.

I did not go to my first radiation treatment because the doctor wanted one more day to consult with another doctor (so I was told) before starting. So, tomorrow, Rach and I will once more brave the forecast heat and humidity so I can lie on an ironing board and be nuked.

I am feeling a few mild side-effects from my first chemo (or is it the Zofran the nurse gave to me this morning?). I am feeling kinda tired, but then, I've been awake thanks to the cardinals again since about 5:30 this morning so that's gotta play a role here.

Friday, May 25th, 2012 radiation treatment 1/25

There is a (famous?) scene from one of the Star Trek movies in which Captain Kirk attempts to free Spock from some horrible plight involving vicious radiation. As Kirk reaches for the handle to yank the door open, Dr. McCoy grabs Kirk and yells (something like), “Don't, you'll flood the whole compartment!” Spock died from acute and utterly heart-wrenching instant radiation poisoning. Then the music swelled up as people in the audience stifled snuffles watching Spock's body slump to the floor.

Radiation treatment is exactly, precisely nothing like that at all.

Today, I was given a briefing on the effects of radiation treatment

and nowhere was the horrifying fear of flooding any compartment ever mentioned. No one slumped to the floor and died. Instead, I was told that I could use Glaxal Base to keep the treated areas of my skin from drying too much from the treatments. I was even told what brand of soap is best for my skin. No doctor prevented me from opening any door. It was fine – even the nice music (I think it was Grapes of Wrath) – was a welcome feature of this



otherwise uneventful time. I was laid on the ubiquitous ironing board while the three young and extremely professional technicians wriggled my prone form into position. More temporary marks were scribbled on me which I was advised to try and not wash off.

The actual procedure, 7 beams of high powered x-rays, took about 11 minutes once I was fully positioned. I am assured the next treatment, on Monday, won't take nearly as long. I am also supposed to be meeting with the surgeon next week to set things up with my brachytherapy. Should be fun. My newsletters will also become a once-a-week update, otherwise, Monday's expected radiation treatment will read exactly the same as tomorrow's. Just, as I said, place the word "ibid" or just plain ol' "ditto".

Monday, May 28 – Friday, June 01, 2012

Week one of radiation and chemo #2

Monday, May 28, I had my second radiation treatment and the start of my first full week of treatment for cancer. As anticipated, radiation treatments take a very short time and I was prone on the table for probably a total of about 15 minutes, 3 or 4 of which were spent with the technicians positioning me so that the high energy X-rays would zap me in the right place. The music of the day featured a few ditties by the Irish Rovers. No, I am not making this up.

One of the more – um – curious side effects I've noticed is that I feel a sort of pulling or stretching sensation in my right side. How much of that is psychologically mediated remains to be seen.

Tuesday, May 29th, 2012.

It's early, 06:36 to be precise. A weak thunderstorm rumbled through here about an hour ago and I've been awake since then. My radiation time today is for 12:55 but I then have an appointment with the surgeon at 13:40. Will write more then.

Today's appointment featured music by the Archies. It's a good thing I wasn't feeling too grim, especially since I also heard bits of the song "Stand By Your Man" sung by some warbling creature. If I had to listen to "you are my candy girl" for much longer, someone's music box would have been trashed by me.

Otherwise, now am I really starting to feel the side-effects to the radiation. I actually napped late this afternoon and I suspect that will not interfere with me getting any sleep tonight.

Adam took me today and we also met – it turns out for no real reason – one of the oncological surgeons. Although the appointment had been made in error (it happens), we did glean some useful information from him.

The internal treatment (brachytherapy) will take place around the end of June, right after my external beam radiation is done. The surgical procedure will be done under heavy sedation (I would prefer general, myself) and individual treatments will take place on 3 Thursdays in a row. So, by that reckoning, I should be actually really done all this by the second or third week of July. Then, the recovery from all this can begin.

Wednesday, May 30th, 2012

My radiation appointment today is at 1:55 pm. Then, I am supposed to meet with Dr. Samant, as Dr. E is away this week. Dr.

Samant is the lead scientist who is running the PET scan experiment. Essentially, that experiment seeks to learn whether patient outcomes are improved by adding a PET scan to the regular imaging regime. Currently, our health care system (OHIP here in Ontario) doesn't cover the cost of a PET scan. However, if it can be shown that there is a statistical improvement in outcomes with the use of PET scans, that may – um - “inspire” the government to both include that as a regular imaging procedure as well as fund it. After all, why do we pay taxes into our universal health care system in the first place?

It is 7:34 and I'm actually feeling pretty good. I figure I have “recovered” from the first dose of chemotherapy so today will be my “honeymoon” day before Rachael and I head up to the hospital tomorrow for chemo day #2. However, I have my ondansetron and my dexamethasone to at least work to keep any nausea at bay. The nausea hasn't actually been too bad – mostly it's that my appetite is virtually gone. I am 109 pounds as of this morning but that was before I had some leftover rice for breakfast this morning. Mostly, it's that I have to keep eating even if it's a little nibble here and there. I am so scared of throwing up especially since once it starts it's impossible to stop. I need my nourishment but even that's hard when I don't have an appetite. So, I'm stuck between wanting to nourish myself, not wanting to barf, having no appetite and having a wide variety of good, calorie dense foods all around me. It's a tricky balancing act, to be sure.

Later: My fourth radiation procedure went very well, according to the technicians. The music was some tinny sounding goop from the 1960s, so I merely meditated instead.

After the treatment, I saw Dr. Samant, one of the radiation oncologists and the lead scientist on this PET scan procedure I

had done during the imaging phase of this. The awesomely good news is that he had the results of the PET scan and they showed no distant metastases. In other words, I have no other cancers and the one I'm getting treated has not spread anywhere. This is, of course, awesomely great news. Tomorrow, I have chemo at 8:00, radiation dose #5 at 12:30 and a meeting with the dietitian right afterwards. I am having a tough time maintaining 110 pounds so I am going to be getting some advice there.

Thursday, May 31, 2012 – chemo day #2

It's 6:12 in the morning and I will be having some breakfast shortly. Yes, I actually feel up to eating some food and, even more interesting, I will forgo my morning cuppa until I am hooked up to the IV drip.

MUCH later, as in 5:25pm later.

Rachael and I got home around 2 hours ago after a busy but very productive day. As usual, she was incredibly helpful, wonderful and so totally awesome that today's treatments were – well – fun. The silly stories and other conversations she and I had while the cisplatin dripped into my vein, quite literally, left me both speechless and doubled over in that silent, gasping laughter that had nurses peering in to see if I was okay. She is now quite well known to the chemo nurses and I was warmed by their kind and very considerate treatment of her. The nurses would just as easily inform Rachael of what they were setting up on my IV stand as they would tell me and they were very happily cooperative when Rachael wanted to double-check to make sure that what bag the nurses were hanging had my name on it.

Chemo done, we went down to the cafeteria to get something to

eat. Yes, I was actually hungry for food which is a good thing as, since this past April, I had lost about 6 pounds (I was 116 when treatment started and was now down to 110) and so really needed the calories. I am not a high fat eater but, this morning, I wanted hash browns (actually, I wanted french fries but it was too early) and a couple of slices of – gasp – bacon. So, we went to the cafeteria and we got some food. We sat and we ate and we talked and then we laughed about I-don't-know-but-it-was-pretty-dumb.

Then, we moseyed to the radiation therapy section at the cancer clinic and played hangman on a blank piece of paper while we awaited my turn on the radiation treatment table. As usual, Rachael and I found ourselves doubled over in gasping, breathless laughter and we found a number of the other patients smiling broadly at our evident fun, even if they had no clue what we were laughing at.

Radiation today actually started a little late as the technicians were behind schedule a bit, but we were done there in short order. Then we went to the dietitian (not my idea) and we wound up with a whole whack of free samples of calorie laden meal replacements.

I got the advice the radiation nurse felt I needed and, not surprisingly (to me), learned that as long as I ate very small but frequent meals



throughout the day that I would obtain the calories and nourishment I require without having to contend with the spectre of nausea.

At this time, 8:16pm, I am just working through a bit of mild nausea but, really, it isn't bad. I credit this to the Zofran pill I took this morning about half an hour before the chemo nurse hung the IV equivalent for me. As much fun as even mild nausea isn't, admittedly, it just isn't that bad for me. It's tolerable and even my appetite has improved slightly. Last entry tomorrow when I go for my next radiation treatment.

Friday, June 1st, 2012 – hooray, it's Friday

Typical for post-chemo nausea, it tends to “hit” the day afterwards and I have it. It's not too awful but that doesn't mean it's fun either. Oh well, I'm so armed with anti-nausea meds so I am not worried.

Today's radiation won't take place until 5:40 this afternoon and likely during the really good rain we have coming this way (it's needed). I will also get to use my very first monthly bus pass. Ever since we moved to Ottawa back in December 2000, I have never had an actual bus pass as I never really needed one. Now I have one and so have any and all transit for me paid for this month. Wow, if that's what counts for excitement then, man, am I ever a dull person. We are planning to get the new Presto cards which will be available starting June 10th so that may be the absolute highlight for us as far as transit use goes.

I feel pretty good, despite the nausea. It actually isn't all that bad and, best of all, it tends to resolve fairly quickly and does not involve throwing up. My radiation and chemo schedule for next

week is now known. My chemo remains on Thursday and for 8:00 am but my radiation treatments are all for mid-late afternoon which actually works better for me as the wait times tend to be short and I often get in a little earlier than “scheduled”.

I cannot overemphasize just how marvellous Rachael and Adam have been with me. They have a rota of who does what and when worked out to a very smooth schedule and no one is saddled with having to do too much. Make no mistake, I am not unable to do things. It is simply that there is a LOT I can't do that I normally do and it's almost exclusively because of the fatigue from radiation. Plus, I have a fair amount of indigestion and other side-effects that so wipe me out. I can shuffle about and get a few things done. I can walk from here to the bus stop and can manage transit stations and hospital corridors as well as anyone; I'm just slow on the stairs and need to sit down a lot.

So, I have 3 more chemo sessions to go and 19 more radiation treatments to go. So far, the intended effect has been notable and strong so I have absolutely no complaints. Sure, the nausea and fatigue are not fun but, as a nurse said to me earlier this week, it's a small price to pay for a cure and I very wholeheartedly agree.

I remain in absolute awe of cancer patients, many, MANY of whom have it a lot worse than me. While mine is still pretty serious, it is nothing compared to the cancer that other people have. The strength, determination and humour so many of us face is tempered by the soft self-care, grace and good humour with which we tolerate things. The indignity of examinations some cancer patients face, the seemingly endless barrage of imaging scans, appointments, prescriptions and paperwork can only ever be faced squarely and with a sort of humility that cancer patients have. For me, and this may sound odd, it's been a lesson in dealing with the impermanence of life and in learning to truly

embrace the day to day joys that make life the rich and worthwhile experience it is.

I have what I think will be some really lovely tiger lilies in my back yard, my orange mint bush has a really thick and healthy crop of green leaves (yay), my daylilies in my front yard also look to be doing well and I have seen and heard a rich variety of small birds flitting about this year. I have a beautiful and kind family and such a marvelously fantastic bunch of friends who have been so supportive and so kind to me that I cannot help but be moved to a sort of sublime humility that informs my every waking moment. What else is life about but for these moments? I thank all of you from the bottom of my heart. There will be cookies for all, gluten-free for some.

Friday, June 1st, 2012 – later

I was the last patient for radiation treatment today, yet the clinic was running a bit behind. The machinery on unit #05 had some small issues earlier in the day and the technicians had to be called in a couple of times throughout the day, so I had been told. Nevertheless, treatment for me did take place and, as has happened so regularly, I was entertained by some quiet Irish folk songs throughout being zapped.

So, I have finished my first full week of chemoradiation and lived to tell the tale. As I have emphasized, the treatments aren't all that horrible despite my fears that it would be – nausea and vomiting are the very worst fears of mine, anything else associated with cancer I can pretty much put up with. In all fairness, I have nausea, though it is mild. However, I have anti-nausea medication I take to treat that and it has been such a powerful lifesaver for me. The reason nausea and vomiting are a genuine concern for the

doctors and nurses is that recovering from cancer requires calories and lots of them. But, if you're feeling nauseated and/or are barfing your guts up, the last thing on your mind is eating even though eating is exactly what you need to do. It's hard to muster up even the tiniest shred of interest in even a single mouthful when you're convinced (rightly or otherwise) that it'll only come right back up.

No matter, next week begins week two and so I am on a much desired weekend off having to go to the hospital.

Week two – June 4th - 8th, 2012

Monday, June 4th

So, it's Monday in early June. Yet, it's cloudy, very cool and quite breezy outside. I only have radiation treatment today and even that's not until much later. This works well as I very foolishly decided to do a 30 kilometre trike trip yesterday and now I am paying the price.

LESSON #1: when your health care team tells you to not overdo things, they're not kidding. Actually, there is another lesson in there as well and one I did learn. Just because I think I can do something doesn't mean I'm right. I mean, good grief, I wound up having to use the elevator at the Smythe transit station; how lame is that? The music played at this evening's treatment session sounded like Elvis screaming into a bowl of unflavoured gelatin; I'd rather listen to the sound of a street sweeper with a faulty muffler system or maybe a dial-up modem from the mid 1990s.

I had always heard that the real side-effects of achiness and fatigue from chemoradiation don't really “hit” until the second

week into things...I think they're right. So, we'll just have to see how long it takes for me to recover. Also, they changed my Friday session time to 8:15 in the morning which, given my new and crushing fatigue, works better for me, as I tend to be much more alert in the morning.

Tuesday, June 5th, 2012

So, here it is, Tuesday morning and, after a good night's sleep and sleeping in until 6:45 this morning, I actually feel pretty good. I have radiation later today at 5:25pm so that leaves me the whole day to 'carpe diem' and all that. I am planning to go out for a trike trip with Rachael on the bike but it will NOT be anything long or onerous. I enjoy getting exercise and don't really idle well (ask Adam about that one) but I have promised both of them not to go much beyond, say, 8 or 9 kilometres.

Later that morning: I walked down the stairs, twice in fact, and nearly collapsed in sheer exhaustion. I am, thus, going to have to idle and not head out anywhere today other than for radiation.

Later still: We got to the hospital just in the nick of time for my scheduled appointment thanks to the late arrival of one of the buses. However, I wasn't too worried as the radiation clinic was behind schedule anyway so Adam and I did have a bit of a wait. I was quite tired and am actually finding it a bit of a strange matter to get used to being exhausted merely from walking from the bus stop at the hospital itself to the radiation clinic a few hundred metres away. More than a couple of times did I recall the fatigue I felt back in '99 when I had my first MS "episode" and even that wasn't nearly as draining. This felt differently and I was (and still am) grateful not only for having had Adam's physical support as he helped me get to the clinic but also for the fact that it was

sunny, warm and quite a pleasant late day to be outside.

So, the treatment for the day done, we went home and wound up enjoying a very lovely slow saunter from the bus stop back to our place. The weather was perfect, the early evening air still sun warmed and even the slowly clouding skies not a problem by any measure. Tomorrow's day will include blood work, my weekly appointment with the radiation oncologist, Dr. E and a (hopefully) on-time radiation treatment. Rachael will be coming with me today, giving Adam a badly needed break from things.

Wednesday, June 6th, 2012

Part of my treatment regimen is a weekly consultation with the radiation oncologist, Dr. E which took place today. Today, I got in a little bit of poo poo from him for doing a 30 kilometre trike trip last Sunday and then collapsing into an exhausted heap when I'm supposed to be healing from the treatments. So, while he understood and appreciated my desire to remain physically active throughout my treatment regimen has, essentially, asked me to stop. That doesn't mean I cannot go out for a little walk here and there (I head out daily for treatment of some kind) but it does mean I have to lay off the Sunday bike days until at least August.

Ugh! That'll be a tough one.

He also ordered me to eat more calories which I am still trying to do. I can maintain 110 pounds but he shook his head and said it wasn't enough. He also said he would be booking the day surgery for my brachytherapy portion of my treatment. Brachytherapy is the internal radiation phase and it involves surgically implanting devices so that directed radiation can be placed right at and/or directly inside what's now left of the offending cancerous bits. He

said this would involve general anaesthetic to which I heartily agreed. They're going to implant and suture into place some hard plastic and metal bits into certain body parts that don't normally have such objects. I do NOT want to be awake for that, thank you kindly. He smiled and nodded in full understanding. It'll be day surgery so I get to miss the joy of an overnight stay (works for me). He said this would likely take place during my last week of external radiation which won't be until the last week of June. Brachytherapy will be a once a week venture for 3 weeks and then that should be it. A follow-up will take place 4 to 6 weeks post treatment and then regular follow-ups every 3 months for 2 years. That also works for me.

I also had my weekly bloodwork done which went very well and then Rachael and I sat and waited for my radiation treatment. I almost never get the same technicians more than, say, three days in a row but what I can say is that every single one of those marvelous people are utterly wonderful. The music was something I can't readily recall but suffice it to say that it was not loud enough to interfere with my radiation meditation so that's a bonus.

Tomorrow's adventures will begin with anti-nausea meds before my weekly chemo. I wonder what horribly funny jokes Rachael will have me cracking up over. I guess we'll find out...

Thursday, June 7th, 2012

We were going to bring the camera with us so that Rachael could take a picture of me being hooked up to the IV fusion pump at the chemo day ward but we forgot to bring it with us. In hindsight, it was just as well because the room was busy. In fact, for a good while there, Rachael was relegated to sitting on one of those little

roll-away stools that the nurses normally use when they're inserting the IVs.

In other words, it was crowded in the room.

She and I talked with a couple of the other cancer patients, one of whom was getting daily chemo for her cancer that had metastasized to her small intestine. Her spirits were bright and she, her chemo companion and Rachael and I wound up sharing many good laughs about things. It also really brought home to me how easy I've got it.

Yet, I am using my cane each time I go because I get so tired so easily and that's primarily from the radiation treatments. No matter, it actually gives me a bit more endurance and a sense of relief knowing I can just stop and lean on ye ol' cane when needed. I am assuming that once this is all done, that I can regain my strength and will no longer need the cane quite so much. I've still got about 193 some odd kilometres to do this triking season in order for me to meet my goal of doing 300 kilometres for the year. We are very lucky to have a long triking season so I have very few concerns there.

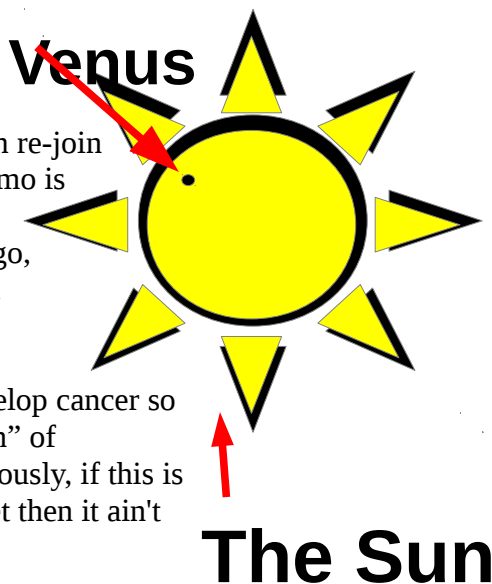
Chemo was done for me by 10:25 but my radiation wasn't scheduled until 4:20. The chemotherapy nurses informed that, ideally, I should be having my radiation within 4 hours of chemo and not the 6 hours that faced me. She advised me to get something to eat and then to saunter to the radiation department to see about getting me in earlier than 4:20. While I try not to be demanding, did admit that this would be a good idea as I really do not enjoy sitting around for hours in the waiting room. Long story short, I got my radiation treatment done a good 3 hours earlier than scheduled so that was a bonus.

Tomorrow's treatment, the last for this week, happens at 8:15am. If Rachael and I time things right, we can be out and back on one bus transfer. Then, I get to rest and recover from things until Monday.

I got next week's chemo and radiation schedule. They've moved my times more towards the mornings which really works better for me overall. With MS, I am much more alert and far less likely to succumb to the fatigue that plagues me by mid-late afternoon so having appointments earlier in the day makes so much more sense for me in my case.

Because I seem to be responding very well to the regimen and even that my side-effects, though annoying and periodically embarrassing in some respects, there is a sense with the nurses, technicians and even the doctors that we can start talking about post-treatment procedures. In short, there is a light at the end of this really-it's-not-*that*-bad-of-a-tunnel and I am starting to sense that it won't be that much longer before I can re-join the human race. My chemo is 60% done. I only have two more treatments to go, so that can't be too grim.

Not that I would ever recommend anyone develop cancer so they can enjoy the "phun" of chemoradiation but, seriously, if this is the worst it's going to get then it ain't all that bad.



Since I don't have a picture of me at chemo for this week's newsletter, may I, instead, offer my version of the recent transit of the planet Venus across the surface of the sun.

Friday, June 8th, 2012

Another early appointment for me (and Rachael), but that also meant an early return home so that's a good thing. The radiation tech team must be getting used to me by now as it is taking less than 30 seconds to position me just so, as opposed to the nearly two minutes it used to take. As much as I'm a fast learner about how to hold perfectly still and how to not startle when the table is adjusted remotely a millimetre here or there, they're learning quickly how to set things up or at least to find those microscopically tiny tattoos on my hips and abdomen.

A very odd side-effect I am noticing from the chemoradiation is that my ability to digest gluten containing foods is restored. This means I can eat bread once again and have done so. That has allowed me to have that much more stamina though I'm not exactly walking at a spritely pace and singing silly ditties about birds, sunshine and warm weather.

Today's treatment music featured Roy Orbison and his high pitched wobbly crooning but, hey, as treatments only take about 10 minutes and the volume of the songs was low at least I didn't have to endure that nonsense for too long.

I am now only awaiting one more phone call from the day surgery people as Dr. E has said I should be getting my brachytherapy treatment by the end of the month. It's Friday and they may phone but, if they don't, that's fine, I will learn of the date and time in due course.

-Peace to one and all

June 11-15th, 2012

Monday, June 11th.

Right now, under blazingly sunny skies, it's a little after 8:00 am and already the day promises to be that powdery warm so common for June.

Today's appointment is just for radiation and that's a good thing. The cumulative effects of even short duration but high frequency radiation are just not any fun, not that I ever expected them to be. Admittedly, I am increasingly tired, shaky and just want to curl up and sleep – but at least I can still read the news on the Internet, do my email and write these little newsletters. I can still hear what sounds like a couple of American goldfinches yelling at each other just outside and I can definitely feel the deep warmth of a very late spring morning.

Curiously, I don't miss my regular exercise routine. I know I'll be able to get back to triking and just going out for walks later on this summer. I thought it would bother me that I couldn't go with Adam to do the Sunday bike day but I really am okay with just staying in and resting.

Tuesday, June 12th, 2012

Now I am really feeling the cumulative effects of radiation and chemo. From the bus stop at the hospital, I could no longer walk and so Adam placed me against a very large concrete garbage can

and then ran off to get a wheelchair. It made all the difference, actually, between being able to get to the clinic and not. I am assured that the fatigue will pretty much continue like this so I will be seeing many more wheelchairs between now and the end...

...and there is the end in sight. Part way through this morning's external beam radiation represented the precise half-way point for me. As of today, I have fewer appointments scheduled than have already been experienced. I also got to meet up with the nurses who run the brachytherapy clinic for an initial "this-is-brachytherapy-and-it'll-be-so-much-fun". I was given all the details about what to expect.

The first treatment, scheduled for June 28th, will require me to be at the hospital by 7:00 am. Adam and Rachael will be coming with me, perhaps to make sure I don't chicken out at the last minute (as though this were the sort of thing I'm likely to do, right?). Then, there will be a fair amount of prep done for both the general anaesthetic and the procedure itself. The procedure should then take place some time between (I was told) 8:00-9:00 am. The surgical team will install what is called a Smit Sleeve so that the internal radiation seeds can be very precisely placed. Yes, all those imaging tests I went through in late April-early-to-mid-May were good practice for the yet more imaging that takes place. Precision and efficiency are the key issues here and, trust me, you want that. Especially when dealing with something like cancer and DEFINITELY when dealing with radiation, "close enough" won't work.

Once the Smit Sleeve is correctly in place, then, later and after I'm stabilized from the general anaesthetic, the first brachy treatment will happen. I am assured that I will feel very tired afterwards which, to be honest, isn't going to be any different from the fatigue I feel right now anyway.

I was also told that, if I were to get hungry at any point, that a ready supply of such things as cookies and cheese'n'crackers would be available. Once I heard that this morning, I actually felt hungry and informed both the nurse and Adam. This is a change as my appetite has been, at best, random and mostly absent.

I continue to respond very well to the treatments but, yikes, the side-effects are brutal and I'm only undergoing half dose chemotherapy. Still, I do see the end in sight and know I will make it...wheelchair or no.

Wednesday, June 13th, 2012

Today is **much** cooler. A cold front passed through which pushed the stifling humidity away from here. Yes, weather plays a role in how well I can handle physical activity – even the comparatively simple act of walking from here to the bus stop and back.

Today's appointments will consist of not just radiation but my weekly visit with Dr. E and my weekly blood test. As far as I can tell, my bloodwork has come back with no concerns so that's got to be a good thing. It's also a good sign for me when Lucy, the brachytherapy nurse I saw yesterday, spoke with me indicating that, once external radiation and chemo are done that my care would be transferred to the brachy unit. It may sound like such a small point but, to me, it represented a shift in gears from the beginning/middle to the end of treatments. That's not to say once my brachy is done that I can just go home and all is done. All won't be done as the follow-up process will then begin. I still face the possibility of needing more chemoradiation than the originally prescribed amount but, today, I'm just not thinking in those terms.

Today also marks a tiny shift in who takes me to the hospital. This week, it would have been Adam who comes with me but, this time, it'll be Rachael. Adam will be taking me to chemo tomorrow instead of Rachael. It's as much to give her a break from the stunningly dull task of sitting with me while cisplatin gets drizzled into my vein as to give Adam the chance to "enjoy" sitting with me for the 2 some odd hours it takes to "do chemo".

Unlike yesterday, today's radiation isn't scheduled until 12:55 but, as I have blood tests and a weekly visit to Dr. E, Rach and I won't be back until later on. At least it's cool enough that I should do better walking from the bus stop to the clinic – though I suppose we'll find out. Push comes to shove and it'll be wheelchair time once again.

Today's radiation treatment featured Cat Stevens' music. "Ooohh baby baby it's a wild world..." drifted into my happy ears and it was hard to refrain from dancing and singing right along even as the beams were being directed into me. No matter, it really helped to pass the time.

Next was the weekly blood test and visit with Dr. E. "Calories, calories and, oh, did I mention calories?" It seems to be a common refrain. Otherwise, he seemed very satisfied with my progress. The one thing I did mention was the crushing fatigue that has put me in a wheelchair for these hospital ventures. It isn't that I cannot walk (how else do I get to and from the bus stop?) but that even the slightest venture so wipes me that I wind up resembling mobile tofu.

Tomorrow's trip will be with Adam and will be my penultimate chemo day. Chemo at 9:00 followed by radiation at 12:15. I will also have to get my radiation/chemo schedule for next week.

Thursday, June 14th, 2012

Yes, today is “chemo day” but it's the second to last session so that's a good sign. In fact, even with the brachytherapy set to start later this month, all of my cancer treatments will be DONE in a month with my last brachy treatment scheduled for July 12th.

Today, chemo is at 9:00 and it will be Adam that comes with me this week. Radiation is for 12:15 and then we can come home to enjoy the rest of the day.

Later:

The chemo session went relatively well. The infusion pump had a tough time delivering the meds to me through the oft-used vein in my left arm. The automated infusion pump kept bleeping “alarm” to the point where it just couldn't do the job it was set up to do. The nurse wound up removing the IV needle and – somehow – managed to find a vein in my right arm instead. This is very interesting as I, apparently, have **very** tiny veins in my right arm and it is difficult for nurses and doctors to



find anything useful. Nevertheless, the nurse successfully found a vein in my right arm and so we were able to carry on with the delivery of the chemo. This is the comfy chair I get to sit in while the cisplatin is pumped into my vein. The other picture is the infusion pump. Phun, eh?

I also told one of the nurses about the problems with extraordinary fatigue I had been feeling. She checked the latest blood test results from yesterday and – long story short – my hemoglobin count is very very low. So, tomorrow, after radiation, I have to visit the lab once more to have my blood type

determined
and all of
that is in
preparation
for the –
yes – blood
transfusion
I have to
have on
Monday
morning. It
will, so I
am assured,
help me
with my
crushing



fatigue so that I can get around more easily and not require being plunked into a wheelchair. Because I am having both chemo and radiation, my bone marrow is taking an awful beating and the nurses told me that my situation is very common. Admittedly, it is not what I wanted to have to face, but if it's a choice between having a blood transfusion so I can move around more easily without experiencing such wilting, crushing fatigue and not

having a transfusion and having to be virtually carried everywhere then I'll take the former.

Friday, June 15th, 2012

The problems that have been plaguing the radiation therapy unit in the hospital persist as appointments were behind by about 45 minutes. This meant that Rachael and I had to spend a bit more time waiting than either of us wanted. Yet, I did get in and had my 16th treatment without any serious problems. Afterwards, Rachael wheeled me to the lab. I had to go and have my blood type and cross checked so that I get the proper type of blood on Monday. Hopefully, after Monday's transfusion, I won't be so completely wiped out exhausted. I am assured that I will start to feel a lot better within half an hour after the transfusion.

Today also represents the end of week 3 of this treatment regimen. I am scheduled for my brachytherapy surgery on the 28th but that phase of treatment will consist of a single appointment once a week for 3 weeks.

The picture is of the room in which I will have the brachy surgery and not a hair salon.

Then, it'll be follow up time 4 to 6 weeks afterwards.



While it will still involve regular trips to the clinic, at least they won't be every single day which gets tedious, tiring and quite boring after awhile.

Next week's weather is supposed to be stinking hot and humid so that will definitely not help things at all...but, I'm more than half way through everything now so that is a comfort to me.

Monday, June 18 - Friday, June 22nd, 2012

Monday, June 18th

It's a few days from the "official" start of summer but we already have the air conditioning on. We have a substantial heat wave forecast to drift into the area over the next few days so we're trying to keep the house cool although not refrigerated. This week, Rachael and I decided to give Adam the next 5 days off having to bring me anywhere so she will be accompanying me this morning.

Today, I will be receiving a blood transfusion of, I believe, 2 units of blood. This past Friday, I went to get my blood typed and cross-matched and so I assume this has all been done. I had been told to come in this morning for 9:00 so I'm guessing things will be ready by then.

My blood type is A+, meaning blood type 'A', Rhesus factor positive. I don't know what kindhearted and generous person donated blood so that I may have it but, whoever you are, you have my unending thanks, especially as my red blood cell count went from an anemic 102 to a much healthier 129. I am still very fatigued from this whole thing but at least I can walk up a flight of stairs without fainting. Thank you so much blood donor; your

generosity is very much appreciated. I don't know precisely how long the transfusion will take but I do know that I have my 17th external beam radiation appointment at 12:30. However, I may be a bit late depending on how the transfusion goes. I'm not worried, though, as the techs down at radiation know what's going on.

It's here where I should really mention how tightly coordinated all of my different appointments are. When I sign myself in (read: scan my little passbook) for any reason, the clinic units I am supposed to go and see are all alerted. In other words, not only are the external radiation technicians alerted to my presence in one of the waiting



rooms, but if I have to see anyone else (eg, Dr. E on Wednesdays or the dietitian at random times), then his or her office located in the north section of the cancer clinic (which is, itself, a pretty large area) is also alerted. It's the same when I need to go to the

chemotherapy day clinic on the 8th floor. The appointment the nurses there set up for me is coordinated with the radiation people on the other side of the hospital complex. It is a very efficient system that's really designed to cut down the risk of scheduling conflicts and/or the hours of unnecessary waiting between appointments – though the recent equipment problems with the external radiation machinery has put a bit of a monkey wrench into the works. However, overall, the system for getting cancer

patients in for their various treatments and appointments is an excellent one – at least from my experience.



In the image here, if I look tired it's because I am. However, unbeknownst to either me or Rachael, I was served lunch during my transfusion and ate the most wonderful beef barley soup. I have never ever had a “problem” with hospital food. There is always something worth eating on the tray. I gave the tea to Rachael as she loves orange pekoe tea while I don't

like tea at all.

Tuesday, June 19th and Wednesday June 20th, 2012

It's actually Wednesday as I write this. Tuesday's venture turned into something a lot longer than either Rachael or I wanted. I wound up requiring re-hydration (yes, another IV lasting for 3 hours) and 3 Imodium tablets so that wasn't fun. In fact, this morning, Wednesday, June 20th, I still have the "port-a-cath" in my arm in case I require more hydration later today when Rach and I head out for my 1:20 radiation appointment.

I should also mention that my brother, Witold, and my sister-in-law, Vicki, have loaned us a car for our use getting me to and from hospital appointments. For that, we are extremely grateful to have that option. It is especially welcome when the weather is just so hot and humid. I can wait for buses but it's, admittedly, more taxing than I like when the dewpoint is in the 20s and the temperature in the 30s. Heat and humidity make for uncomfortable days for many but especially for people who have health problems. Thank you, dear brother and sister-in-law. I hope you know there are cookies in the deal.

I also have more blood work and my weekly appointment with Dr. E today but it'll all be in air conditioned comfort so that's a good thing. Here in Ottawa, today is supposed to be the hottest day so far, with a forecast humidex of 46C...that's "plus" 46. Hmm...sounds like Iced Coffee (note the proper noun status) to me.

The radiation treatment went its usual well. The music featured the song "Happy Together..." by The Turtles so that was a special bonus as I really like that song.

Next came the weekly blood test and it's about this time that most people start to feel like a pincushion. The good news is that, for about the third time in my life, someone was able to find a usable

vein in my right arm. This is good as my poor left arm is already replete with small bruises. I believe next Wednesday marks the last time I will need blood testing for this portion of the cancer treatment. I say "this portion" because I don't know what will be needed for the brachytherapy and I know that I will be having blood tests as part of the follow up process – in other words, for the next 2-5 years.

My appointment with Dr. E was exactly the way I like: short, direct and informative. My progress with cancer treatment is very good and Dr. E seems pleased with how I am responding to it all. He asked how I was doing after this past Tuesday's events and seemed satisfied with how things were going with me. He reiterated the need for rest, calories and that I would see him next Wednesday and Thursday just before brachy therapy.

Wednesday was a good day. It was also the day that the sun reached its northernmost point in its annual path across the sky – in other words, summer in the northern hemisphere began at precisely 7:09pm, eastern daylight time.

Thursday, June 21st, 2012

This morning, I received my LAST CHEMOTHERAPY treatment. YAY! I still feel like a pincushion but at least this portion of my cancer treatment is over and I genuinely feel as though I can start to recover from all this. The medication that's been dripping into my vein once a week for the past 5 weeks is cisplatin. Once they remove the IV, it isn't as though the medication stops doing its bit. I am informed that it'll take a few weeks before its effect is gone and its job is done. I know I still have a little ways to go before I will feel like a human being but, with chemo now done, I can start the process of recovering. I

thanked the nurses for their awesome care. Despite how busy they are and that I, personally, feel such places are understaffed, each of the nurses took the time to answer questions and to help make me and Rachael-or-Adam comfortable.

But, by far, the most wonderful people in the chemo day ward are the other patients. Each week, we see these sick and courageous people show up for their treatments. I have heard tell of just how viciously ill the chemo makes them feel – and yet each week each and every one of them smiles and laughs even as these poisonous chemicals are dripping into their veins. I find inspiration and an immense sense of gratitude to share these few hours with them.

When chemotherapy begins, it is common for the nurses and other health care professionals to “break the bad news” that patients will lose their hair, yet every patient I have ever spoken to has indicated that they don't care about such things. We can put up with losing hair and there are really good meds out there to help with things like nausea and even fatigue. Mostly, we just want to be either cured or to at least not be in any pain. I am extremely lucky in that I feel virtually no pain whatsoever. Stranger still, is that my chemo doc, Dr. Weberpals, who had told me my hair could thin a bit had prepared me for that possibility – yet my hair has actually thickened a bit and both Rachael and Adam have commented on how nice and healthy it feels. I have lost a bit of the kink or curl but that's nothing at all. Who would have guessed I would experience something like that?

Food is tasting a tiny little bit differently to me – mostly that some foods taste a bit like a cross between sunscreen and tin foil but, once again, it's nothing at all to be even concerned about. Besides, that will all change once this whole summer of cancer treatment is done.

Between the chemo and the radiation, Rachael and I wound up encountering Lucie, the brachytherapy nurse with whom Adam and I had met. As we were early for the radiation, and as it will be Rachael who will be at the hospital with me next Thursday, I thought it might be a good chance for her to see the surgery suite and to talk with the nurse. Lucie thought that was an excellent idea so, lucky lucky Rach, we got to take a quick tour of the facility. Rachael had some questions for the nurse (she is getting really good at asking good questions) and Lucie indicated that Rachael can leave her cell phone number with the nurses who will phone or send her a text message to let her know when she can see me after waking up. That was a very kind and thoughtful touch. Lucie is one of those people who is a total sweetheart AND a nurse.

I have heard from a few other cancer patients who have said the treatment is worse than the disease. I can understand that but, at the same time, I feel their experiences were very likely a lot worse than mine. I only had “chemo light” (meaning half dose) and I only had cisplatin. While cisplatin is highly emetogenic (meaning it invariably results in nausea and vomiting compared to other meds) There are many many other nasty horrible drugs that are used in cancer treatments. If those other drugs (carboplatin, cystoxin, imatinib, vincristine and any other polysyllabic, difficult to pronounce, awesome Scrabble words you care to toss into the pot) were prescribed for me, I would be in a lot worse shape than I am. As it is, I am just extremely fatigued.

I also have to admit that this is all starting to weigh me down. It's getting – well – boring going in day after day but I endure and remind myself not just that I have it really good but that each day done is a day closer to the finish line.

I will walk away from this, I am assured, and still expect to

complete my goal of 300 kilometres on my trike in one season.

Friday, June 22nd, 2012

Well, today's visit will be for just external radiation. It will also mark the end of week 4 for me. Next week will consist of external radiation every day except Thursday when I am having the start of my brachytherapy treatment. Monday, the 25th, I have to meet with the anaesthesiologist to discuss, well, anaesthetic and what the general procedure for the surgery will be. The last time I had a general anaesthetic was 16 years ago and I had no problems then. I will assume (as dangerous as that may be) that this time around will be equally problem-free.

In the meantime, life is good. I have actually re-gained about 2 pounds, bringing my weight up to 112 pounds. While still, technically, underweight, at least I'm not losing any more weight and that's important.

I also smile at the fact that I will have a lot of cookies to bake for a lot of wonderful people. As of today, I have 6 more external radiation treatments to go and 3 brachy treatments to do. July 12th marks the last trip to the hospital. July 13th marks the first day of partying.

Know what I miss the most? I really miss vegetable stir fries and salads. As long as I am still treating the cancer, I have to stay away from any high fibre foods. I know I will be able to resume following a sane and normal diet soon...so it'll be stir fry and salad for dinner on July 12th!

YAYNESS!

-Peace to everyone and I will write again next week.

Monday, June 25th - Friday, June 29th, 2012

I can tell I'm impatient by my incessant need to get back to doing things. Yesterday, Sunday, I thought I could handle a simple 900 metre walk around the neighbourhood but that proved to be impossible.

Now, today, I am paying for pushing myself beyond what I can actually do. Yes, I had been well warned against doing things. Yes, I did it anyway. Yes, I am stupid.

Mea culpa.

Monday, June 25th, 2012

Today is very cool – as in, it-feels-like-autumn cool. I like that as the cooler temperatures just make it easier to deal with the side-effects. I am assuming the chemo side-effects will continue to diminish over time; at least, I hope they do!

Today's appointments include meeting with the anesthesiologist in preparation for my brachy surgery this coming Thursday. Today is also the first day of my last week of external beam radiation. After this Friday, I will not have to go to the hospital every day.

Later: Well, it turns out that I had been given the wrong time for today's external radiation. Last Friday, I had been told my appointment today would be at 5:25 pm but it turned out to not be the case. No matter, my appointment with the anaesthesiologist went very well (deemed fit enough to go under on Thursday) as

did radiation.

It's very chilly and windy outside; in fact, it feels more like October than late June. Yet, I rather like it, actually.

Tuesday, June 26th, 2012

I can tell things are settling down towards the first finish line – nothing scheduled beyond external radiation which is scheduled for this morning at 8:50.

The question of what I will do this Friday when the last of the external radiation treatments are done has been raised. There is a tradition whereby patients who have completed a course of radiation treatment ring a loud bell whose tone resonates throughout the whole clinic. Presumably, it's meant to indicate some kind of achievement to all and sundry and there seems to be this tacit assumption that all cancer patients – including I myself – would happily participate in this ritual.

My answer is, and will be, a gentle but firm “no, thank you”.

For me, I decide fully who knows what about my cancer journey. I write these weekly newsletters for family and friends – not for strangers who have their own family and friends. Last week after I finished my last chemotherapy, I thanked the nurses and the other patients in the room. We all wished each other well and left it at that. I am, by nature, a private person but especially when it comes to such deeply personal matters as health I see no need at all whatsoever to alert half the civilized population that I have completed a course of treatments. Friends, family and other loved ones? Sure, why not? But that's as far as it goes as far as I'm concerned.

I fully recognize and totally respect that other people want to share their achievement with others and I wholeheartedly support their choice. I make a different choice. *(Edit: I decided later to write about my experiences for anyone else who may be even remotely interested but, at the time, I didn't want to advertise anything – I just wanted to be done with it all.)*

This morning's radiation went smoothly. Interestingly, and I'm sure it's purely psychological in nature, but when I was being helped off the table in the radiation room, I felt the first stirrings of feeling almost human again. Maybe it was also to do with the fact that we could find no wheelchair (those tend to go quickly in the morning, we learned awhile ago) and so I shuffled along with my cane. Autonomy and a sense of self-efficacy go a long way.

Yet, here Rachael and I were, walking, carefully, gingerly but walking nonetheless. I was able to lift my cane and – gasp – walk unassisted. Once outside on this fresh, cool, sunny but windy Tuesday morning, Rachael phoned Adam for a pick-up and we spent about 15 minutes sitting atop a stone wall. I got up there without any problems and, again, I felt almost human.

To be sure, I am still exhausted but it felt glorious watching the shreds of bright white clouds drifting along an otherwise pure blue sky. Yes, it was (and still is) chilly but in the sun it felt warm and so wonderful.

Wednesday, June 27th, 2012

This is the day before brachy surgery so, indeed, I plan on enjoying it. The guide the hospital gave to me included phrases like, “last meal” and “final” so the prospect of general anesthetic

coupled with those ominous sounding words leaves me with a sense that things are, at long last, coming to some kind of conclusion.

Today's appointment is the 24th of 25 external treatments so this Friday will be – whew – the last of the external treatments and, better yet, the last of daily forays to the hospital.

The side-effects continue to bother me periodically but at least food is rapidly reacquiring its proper taste. Not that everything tasted like tin foil but a few things did and I am very happy to note that peanut butter sandwiches now taste like peanut butter sandwiches. This is especially good as I really like peanut butter sandwiches.

LATER:

Well, I had my 24th of 25 external treatments, the usual weekly bloodwork and visit with Dr. E. I am very happy – not to mention utterly relieved – to report that I am doing very well and that my prognosis remains excellent. He is pleased with my latest blood report and did not appear to have any major concerns about things. I am well prepared for the brachy procedure tomorrow.

Friday's external treatment, my absolute LAST one is scheduled for 4:45 pm although I will still have to coordinate with the brachy nurse(s) who want(s) to see me on Friday for a quick follow-up. Mostly it's that daily forays to the hospital will END very soon and that's a good thing. I was finding them to be a mind-numbingly grinding bore.

Thursday, June 28th, 2012

The anesthesiologist, a sandy-haired tall man with what must be the biggest teeth I have ever seen on a human being, quietly said,

“Okay, Ruth, I'm just starting a mild sedative drip here.”

“Okay,” I replied already feeling the gentle settling in me. I was already on the table, supine and in no position to argue anything, really. Suddenly, the anesthesiologist resident quietly said she was going to put an oxygen mask on me and that I only need breathe in deeply.

Oxygen.

Right.

The next thing I knew, someone was calling my name and me out of a rather vivid dream I was having about, of all things, apples and peaches.

“We're almost done here, Ruth, so just relax.”

I opened my eyes and saw Dr. E doing a few things, mostly removing the myriad of devices they had installed in me. The surgical procedure AND the first brachy treatment are now done.

Dr. E did meet up with me after I was able to prove myself able to walk (wobble upright, really) to the washroom. I asked him how things looked and he replied that everything was looking very well. I am successfully “fighting” this cancer and he even said I will have no problem with my goal of triking 300 kilometres this season (actually, I only have 163.0 left to go but that's another story) (*Edit: I met and even exceeded my goal on September 2nd*). The point is that I will get my life back in fairly short order. To describe me as happy and relieved at hearing this would be an understatement of epic proportions.

Now, at home, I remain groggy but I did get more sleep and am

actually eating some food. I can even taste the food which is a bonus.

Tomorrow's appointment will be my LAST external beam radiation...then, it's forced rest until next Thursday. I also have to have – yes – more bloodwork done but that can be taken care of at our nearby blood lab which is a whole 400 metres from here. Mostly, I am just so relieved that my daily slogs to the hospital are almost done! I know I've said that many times but it's just such a relief to me that I repeat it for emphasis.

YAYNESS!

Friday, June 29th, 2012

I am awake and feeling not too badly this morning. At least I can walk upright and not worry about falling over. Yesterday's anesthetic was, indeed, a short-acting one.

I am not scheduled to go for my last external beam until way later today at 4:45. That leaves me most of today to continue recovering from the anesthetic and procedure from yesterday.

The end of this difficult period is coming.

LATER: All done external beam. I made it clear to the technicians that I had no intention of ringing that silly “hooray-I'm-done” bell. They were not only really okay with that but had told me that they really didn't like that part of patient treatment. I can't blame 'em. Cancer treatment is a deeply personal and uniquely experienced process...so Adam, Rachael and I celebrated by going out for dinner instead. Best of all was that I was not only hungry but actually feeling up to going out somewhere that was nothing

to do with anything medical.

We had originally planned to take Rachael to *The Works* for her birthday, which is later this summer, but the opportunity to go out now had us heading there today. It felt good to be out and enjoying a meal, in that I actually felt like eating something. It was the first time for Rachael to experience *The Works* and she and I learned later that the restaurant is expanding to cities outside Ottawa. Places like Peterborough, Oakville, Waterloo and The Beaches in Toronto can expect to see this awesome little gem of a place gracing their neighbourhoods. We only go there once a year but today's was as good a time as any to do it.

So, we did.

And now this portion of my cancer treatment is done. No more lying on a rock hard table watching paddles slowly rotate around me as high energy x-rays emanate (in 2 or 3 second bursts of course, it's not a constant thing) from a device sporting stickers of hockey teams, puppy dogs and other logos. All that is left is brachy treatments 2 and 3 and they don't resume until next Thursday. So, NO MORE daily outings when I am barely well enough to stand upright. I did it. We did it, though I'm not entirely sure how.

I still have to have blood work done but that's next Tuesday anytime and at the lab close to home here.

Thursday, July 5th, 2012

I had my second of three brachy treatments. This involved being moderately well sedated and I was actually too drowsy/dopey to shuffle myself into the treatment room. So, I was wheeled into the

room, smiling and giggling like an idiot as I was, accompanied by the endless chimes and bongs of computers which were, to my dismay and mild alarm, all running Windows.

I wound up spending a lot of time in quiet contemplation while the doctor and the physicist set out to plan my treatment. I can understand the need to plan, especially when dealing with something like radioactive elements. I'm just not entirely sure why it would take close to an hour; yet I'm glad the medical team takes its time. I'd rather they take the time and get things right than to rush through and risk not getting things right.

I was also informed that the radiation will continue to exert its effects on the cancer for around 4-6 weeks after the treatments are all done. The radiation oncologist who did the treatment this week was Dr. Samant as Dr. E is away this week. I am also told that there are 3 radiation oncologists who "take turns" performing the brachy treatment; my first was with Dr. E, this week was with Dr. Samant so next week should see Dr. Lupe (pronounced LOO-pay and not LOOP) finish things off.

In the meantime, I'm still dealing with the side-effects but they are not nearly as difficult as they had been and - even then - they weren't all that bad for the most part. I'm still desperately tired but, increasingly, my naps are leaving me more refreshed and better able to do a few more things, like walk up a flight of stairs without falling into an exhausted pile. Can resuming my trike trips be far behind? Well, yes, they are far behind...but they're s-l-o-w-l-y catching up and that's a good thing as far as I'm concerned.

I am grateful for the air conditioning even though we don't use it continuously. Hot, humid air wears everyone out but, for me this

year, it actually makes me feel quite sick. That will change (everything changes) over time so I'm not worried.

Next week will be my last update so you can all not worry about me bugging you guys every week (LOL).

**Friday, July 13th,
2012– the day after
the end!**

Yesterday was my last venture to the hospital, at least for now. I had my last brachy treatment and, glory be, the oncologist-of-the-week removed the smit sleeve. The actual procedure is always a gentle undertaking as much from the moderate level of sedation as the simple fact that it doesn't hurt although



I suspect the two may be related. In fact, I spend a lot of time alone while the medical staff are on the other side of the door. This is the reality when dealing with radioactivity. Tremendous caution is exercised to protect the medical staff from being exposed to radioactive substances...but I get to lie there and receive it full force.

There are and will be the inevitable follow-up appointments but, at this point anyway, I can just rest and let the healing continue. I say “continue” and not, “begin” because the healing has been going on since all this started at the end of May. Admittedly, my skin where I received the 25 external beam treatments is still a bit sore but it's nothing that some good moisturizing cream can't fix.

I even managed to put on about a pound so my current weight is 113. No danger of me plummeting to 80 pounds, not that there ever really was.

The picture is one Rach took with her cellphone. The sedative meds the nurses gave to me had only just started to take effect thus gluing the silly grin on my face.

No matter, my body is healing and I'm even finding my energy reserves building if only a little bit. Cancer treatment will completely wipe out any energy you have (yes it will!) and it takes both time and patience to rebuild. I am very happy to report that I am doing all that. Things are healing and I feel better rested each morning. I'm not going to push myself to get “right back at 'er” although at least I can get around without my cane.

One

Small

Step

At

A

Time...and no giant leaps for the foreseeable future.

I can't begin to express my gratitude to so many people who have helped me throughout this – um – challenging time. There is nothing whatsoever nice about cancer nor is the treatment for it any less grim. However, I couldn't have got through this with my sense of humour and perspective intact without the kind help from others. I couldn't possibly list each and every single person who has helped me weather my cancer treatment but there are a few who come to mind.

My radiation oncologist, Dr. E. Ever serious, I have managed to make him smile when I referred to Montreal smoked meat as a biohazard.

My beautiful kids (snort, 'kids' – good grief they're all adults). I talk to my youngest, Nicholas, once a week on the phone as he reminds me to eat food or else....

Matt, my eldest, regularly sends me some of the funniest comics and stories from the Internet (think autocorrect jokes). His small 'stuff-I-send-during-my-coffee-break' offerings always make me smile and laugh and to help put it allllll into perspective. He and his beautiful girlfriend, Katia, have even taken time from their over-busy lives to come down here to visit with me. Better yet, they brought a gift of the most amazing banana muffins I've ever tasted. How else can I not feel grateful to them both?

My daughter, Rachael, I cannot thank strongly enough. She came up here on May 1st, specifically to help get me to my countless medical appointments thus relieving Adam from this – essentially – boring task. She was the one who helped me when I had an – um - “accident” at a transit station. She is the one who got the nurses to help me, to find and bring to me a wheelchair when I just couldn't hold myself upright. She has brought meals to me

and has made me laugh so hard during the grim experience of chemotherapy that the nurses would periodically peer inside the room to make sure I was okay. She has kept me company, has given me some of the most amazing foot massages to help relieve the burning sensation so common with chemotherapy. She has taken the initiative to ask questions about my treatments and has held my hand when the pain of getting yet another IV or blood test rears its silly head. Her goofy impersonations, reminiscent of a 5 year old Carol Channing on helium, have reduced me to gasping laughter. I will miss her when she returns to school in Hamilton this fall.

My beautiful husband, Adam. This has affected him, too. Yet he has put up with the uncertainties and difficulties with grace, good humour and an unending supply of simple love for me. His kindness and breathtaking love have reduced me to tears at times. He has held me tightly while I try to not vomit or when the searing pain of the side-effects of radiation have been too much to bear alone. Every night I anxiously await for him to read to me. I love our bedtime stories.

My brother, Witold, and his family deserve more than the cookies I keep threatening them with. They know we live a car-free life which, in nearly all facets of our lives, works well for us...except for hospital appointments for cancer treatments when buses aren't always timely and walking is impossible. Yet, they loaned to us a car which was not only useful but actually saved my stupid self that Sunday I thought I could walk from here to the drug store and back without collapsing.

I can't possibly list all of my friends and family who have graciously tolerated my weekly newsletters. Just knowing that you care is enough for me to make it through. Thank you all. Really. I appreciate everything you've all done for me, everything

you have shared with me. This is the joy of humanity and what fills me with a renewed faith in people – simple, human love. No, I do not want anyone to name a phone booth after me.

Undergoing cancer treatment has provided me with a perfect opportunity to practice Buddhism. The realities of impermanence have played out well here (while my life is not permanent, neither is cancer treatment) and the support and care I have received from my fellow Buddhists have humbled me greatly.

Okay, I'm done now. We can get back to our regularly scheduled programs already in progress.

May you all be well
with love
Ruth person

>>>roll end credits and horrible music<<<

Post treatment follow ups

Tuesday, August 14th, 2012

I had my first follow-up appointment with Dr. E and the oncology resident-of-the-week. So far so good. I will have to go for another MRI to compare things now with the way things looked at my last MRI (May 14th) but both doctors told me that things are looking very good. At this time, the doctors are not anticipating me needing any more chemoradiation but we'll know more in about 4 to 6 weeks.

In the interim, we are still hanging in there.

Tuesday, September 18th, 2012

On this rainy morning we headed out to see Dr. E for my second follow-up examination. The news remains good although it also remains provisional. After going through the last MRI I had on August 31st and after having examined me, Dr. E was not able to feel any sign of the cancer.

That's not to say necessarily that it is completely gone but comparing the initial MRI in May with this last one I had in late August, the cancer had shrunk by a significant amount. Once again, the doctor used words like, "normal tissue" and "looking good". I am scheduled to see him again in a couple of months for follow-up number 3.



While we don't have an absolute declaration that I am cancer-free, Dr. E seemed to be confident that things are good. He did say the cancer had a "100% response" to the chemoradiation so that's always good to hear. Adam took this picture of me just outside the cancer clinic. The fact that I'm wearing my black monsoon coat should be evidence enough that it's pouring with rain here.

Love to all and may you all be well

Ruth person

Part II

Follow-up Treatment

November 2012 –
January 2014

By Adam Hunt

Introduction

Ruth's initial treatment sequence in 2012 was not successful in eliminating the cancer. She asked me to take over writing the diary of her follow-up treatment, since she planned, at that time, to concentrate on a new book about Buddhism instead. As her illness progressed very quickly she was not able to write much of the new book, however and never completed it.

Tuesday, November 20th, 2012

Today Ruth had a follow-up appointment with the ever-succinct Dr E at Module A in the Cancer Centre of the Ottawa General Hospital.

After a physical examination, he said that there was still some thickening in the area. He seemed fairly certain that it was just scar tissue, but wanted to schedule an examination and biopsy under anesthetic, just to be sure.

All of us, including Dr E, felt confident that things were working out well and that the biopsy would confirm that.

Monday, December 3rd, 2012

Today was a full day at the General Hospital. I went with Ruth and spent the day in various waiting rooms while she went through what she calls “catch and release” to get her biopsy done.

I got to see her after she came out of recovery and she was in good spirits. In an hour or two they said she could go home and cross examined us to make sure that we would be taking a taxi home.

I brought her a wheelchair and took her down to the cafeteria for a bite to eat. Even though it was dinner time the place was almost empty, like a great, echoing, over-lit mausoleum. By the time she had eaten a bit Ruth was feeling energetic and not much like taking a cab.

Taxis in Ottawa are dangerous. Most cab drivers drive like complete maniacs and accidents involving them are very common events here. We decided to take the bus home instead, cheaper and a lot safer as well.

Tuesday, December 11th, 2012

The biopsy results were back and this, of course, required another consultation to see what they said and then what needed to be done, if anything. We were naturally hoping to hear that the results were negative and that Ruth would be just put on routine follow-up in three months.

In an examination room on Module A, at the Cancer Centre, Dr E presented the news, the biopsies had come back positive for cancer.

He indicated that Ruth had already received the maximum dosage of radiation and, since he was a radiation specialist, he would be passing her onto another physician for possible surgery or chemotherapy as next options. He ordered a CT scan, as he explained, to see if the cancer had spread or not.

Usually very calm and concise, Dr E seemed a bit annoyed and cagey that day. That had me concerned, though Ruth shrugged it off. I just thought, "how could there even be a risk of the cancer spreading when the PET scan done on May 8th 2012 had shown only one tumour and since then it has been under radiation and

chemo bombardment?” I didn't understand Dr E's sense of agitation.

Friday, December 21st, 2012

Since the CT scan is a routine procedure and fell on a Friday, which is an NCF volunteer day for me, I let Ruth go to the Riverside Hospital on her own. The trip for her by bus was easy – just one bus there and back as Riverside is on the southern transitway.

Ruth's CT scan was at lunchtime, so she showed up early, as she always does, got processed quickly and drank all the disgusting contrasting fluid. I had bought her some commercial drink flavour crystals, as the nurses had recommended, but she found that the fluid wasn't that bad and she didn't use them.

The weather was bad with a snow storm raging, and that seemed to keep some out-of-town patients away, so Ruth was done earlier and was home by mid-afternoon.

Tuesday, January 8th, 2013

With Christmas and New Years upon us it took a bit of time to get a new appointment to hear the results of the CT scan and find out what the new treatment plan would be. We weren't totally sure who we would be seeing, but the appointment turned out to be with Dr Hopkins, whom we had seen in April, 2012. She remembered Ruth by face, if not by name.

She brought two interns with her, two rather nervous young women, who stood by the door in the consulting room.

Dr Hopkins explained that the CT scan showed that the cancer

had moved into the lymph system. She stated that the best imaging that currently exists, CT scan, PET and MRI, cannot detect tumours smaller than 1 cm and so these tumours in the lymph were probably there from the start and were just not seen until they grew big enough to detect.

Since the cancer could not be treated with surgery the plan would be to use chemotherapy, Carboplatin and Taxol, to try to reduce and control the cancer. It would involve five sessions, three weeks apart, probably starting later in January and running until the end of April. Her winter might be a bit challenging, but her summer should be good as she will have recovered from the chemo by then.

We both caught the implications of all this right away, that the cancer is not curable, and asked a lot of questions. Dr Hopkins and her interns seemed amazed at how calm we were. Ruth explained it was her Buddhism and the rehearsals we had done of all possible outcomes.

When we asked the right questions Dr Hopkins did explain that the median time of survival with this condition is two years and the 100% percentile point comes in about four years. The bottom line is that she has one to four years left.

We asked about not doing any further treatment, but Dr Hopkins stressed that was not a good choice. As she put it, “you don't want to die from cancer in the abdomen as it causes all kinds of digestive tract problems.” She indicated the planned treatment was intended to force the cancer to grow up into the chest, which was preferable.

We asked more questions and in the end Dr Hopkins thanked us for being so calm. We both explained that we didn't think that

would help her do her job if we got upset and, besides that, all those stress hormones wouldn't help Ruth either. Dr Hopkins actually hugged Ruth, something I don't think she regularly does with patients.

We left the hospital, walked, talked and cried a bit out in the cold January air and the gathering darkness.

We went to Best Buy and got Ruth a new Sony Walkman. The Walkman name was introduced in the early 1980s as a cassette tape player, but today the name refers to an MP3 player. Ruth wanted one to be able to play her Buddhist dharma lessons on.

We went for coffee at Starbucks and talked a lot more. With only a 50% chance of being alive in January 2015 we had to do some planning.

Ruth thought about it and decided to tell no one about the prognosis. She didn't want to be deceptive, but she didn't want to worry anybody excessively or have them change their plans for her, especially not her kids. She decided that she would tell everyone that she was going for chemo next and that we would see how that turned out.

Ruth also decided to write a new book about Buddhism instead of continuing this diary, as a better and more positive use of her time. I asked her if I could continue this as a "second edition" and she agreed, on the promise that I wouldn't post it until she was gone.

Later that day Ruth sent out a email update to everyone to let them know that she is going for chemo next and many people wrote back to offer her good wishes.

Ruth's daughter, Rachael, who was such a help in the summer of 2012, is graduating from Mohawk College, in Hamilton, in the field of Early Childhood Education (ECE) in April and has been considering whether to stay in Hamilton to find work, or to come to Ottawa. When Ruth told her that she was starting more chemo the two of them agreed that it would be a good plan if Rachael came to Ottawa to live with us when her classes are done. For her part Rachael was very enthusiastic about the plan, she will have a place to live, the chance to find work here in the city and the opportunity to help take care of her mom. Ruth didn't want her to know the short timeline involved, so that Rachael wouldn't worry too much while finishing her last three months of school.

Ruth also regularly talks to both her sons, Matt and Nick, and we will probably have both of them here for visits between now and April. Nick has agreed to deliver Rachael and her belongings here with his truck, in the end of April.

By the time Rachael gets here Ruth will have just about finished her chemo. I'll be getting her to her appointments on my own this time, but the good news is that the three of us should have a great summer together. Rachael is already excited that we will do bike trips, hikes and picnics together, like last summer. I think it will turn out to be a great summer.

Wednesday, January 9th, 2013

Since this round of chemotherapy will cause Ruth to lose her hair she decided to have me give her a crew cut today, to get ready for it. She didn't want to look like she had an attack of mange once the chemo starts. So I got the clippers out and cut her hair down to one inch in length. She liked the results.



Since May 2012 I have been growing my hair at Ruth's request. It actually fits in well with my volunteer job at NCF, as everyone thinks I must be an IT guru, because of the hair! I offered to

have it cut short too, but Ruth thought about it and decided that she wanted me to keep it long.

Tuesday, January 22nd, 2013

Today we had an appointment with Dr Hopkins at the Ottawa General Cancer Centre to sort out the final preparations for chemo to start. Ruth had her height and weight taken and we were briefed on chemo side effects. As usual Dr Hopkins was really great, very thoughtful and helpful. She was on her way to surgery as well. We won't see her again until the chemo is done and two more CT scans are completed. There will be one CT scan after three chemo sessions to see if the dose needs adjusting and one afterwards to see what was accomplished.

The chemo will start on Wednesday 30 January with the installation of a PICC (Peripherally Inserted Central Catheter) line that Ruth will retain until the chemo sessions are all done. Our best guess is that the last chemo session will be on her birthday, 15 May 2013.

Ruth has been talking quite a bit this week about her short time left, probably about 24 months on average. She seems very calm about it. She does her Buddhist meditation and yoga everyday, which I think contributes greatly. After the session with Dr Hopkins we went out for lunch at Kelsey's at South Keys (thank you Ian and Alex!) and had a good talk about it all. Ruth admitted that her worst fear in life was living with MS for another 30 years, with the inevitable growing disability, wheelchairs, loss of ability to go out much, go skiing and cycling and losing cognitive functioning as well, too. She really seems to see an early death as a much better alternative than growing disability slowly sucking the life out of her. As she put it, "I would rather leave at the top of my game".

In some respects she is right, there are a lot of advantages to skipping getting old, not having to deal with things like Alzheimer's, osteoporosis, nursing homes and everything else. There is no choice in this matter for Ruth, but at least she seems to be taking the most positive spin on the hand she has been dealt. She is determined to make the most of the time she has left and I can only do what I can to help her do that.

An Account of the First Chemotherapy Treatment by Ruth



**Wednesday, January
30th, 2013**

Today began very early for us as we shuffled along the half melted half frozen and totally lethal sidewalks to catch one of two buses

to get to the hospital. Adam got to test his newly acquired Presto transit card and, lo and behold, the damned thing worked. So, it was worth the 40+ minutes I spent online dealing with slow-as-molasses servers and trying to get one of the 10,000 free trial Presto cards the city gave to the lucky few who managed to get one.

I don't have a Presto card but when we got on the #97 this morning, I wound up with a day pass the driver gave to me even though I only paid my single fare. I didn't argue and I was able to use the day pass, well, all day.

So, once at the hospital, we wound our way down to Module "X" for my PICC line insertion. PICC stands for *Peripherally Inserted Central Catheter* and it's an increasingly common procedure for those patients who are receiving chemotherapy, especially over a prolonged period of time. A specially trained registered nurse is one who does the procedure.

The PICC line insertion is a very painless and safe procedure in which a very thin and very flexible catheter is threaded through a vein in my upper arm and ending in the superior vena cava near my heart. This is a retained catheter allowing nurses to both hook me up to any number of IV meds and for allowing for a blood



draw. This, effectively, eliminates the need to be constantly looking for a usable vein to insert an IV. It also drastically reduces the likelihood of my arm becoming a battle-weary collection of multi-coloured bruises.

The nurse who installed the PICC did a fantastic job, too. I didn't even feel the needle that would inject a local anesthetic. The whole insertion, including the requisite ultrasound to see what vein would be best and the measuring of the distance between my upper arm and my superior vena cava (an estimate but, hey, you gotta start somewhere), took about 25 minutes.

Then, I had to go for a chest x-ray to make sure the catheter had been placed correctly. It turned out that the estimate was off by about 2 cm and so I had to return to the PICC room to allow the nurse to pull out the catheter by about 2cm. Again, it's totally painless and I felt nothing at all. Finally, we could get up to the chemo day ward for what would turn out to be about 5 hours there. Besides the requisite antinausea meds, I was given Benadryl (yes, that makes you high as a kite!!) and Zantac to stave off any possible allergic reactions to the Taxol I would be given. There was a 2-4% chance I would have a reaction to the med but, hey, nothing unpleasant happened. The Benadryl did make me a bit drowsy and I did doze for a bit but I did not sleep and I was even able to play a Scrabble game with Adam

At last, the Taxol was brought to me. I was hooked up (very easily thanks to the PICC line) and was otherwise left to sit up, talk, play Scrabble and otherwise enjoy the 3 1/2 hours of that telltale clickety-clickety-clickety of the IV infusion pump.

The carboplatin, drug #2, came later and it only required about 30 minutes to drip in.

Finally, I was done and felt energetic enough to walk from the hospital to the Riverside transit station. Getting home was a piece of cake with my day pass, although I confess that today's record warm temperatures did help there.

Adam and I parted directions at Riverside. I got on the bus and he continued to walk home for the exercise. He wanted to drop off my collection of prescription meds for anti-nauseants.

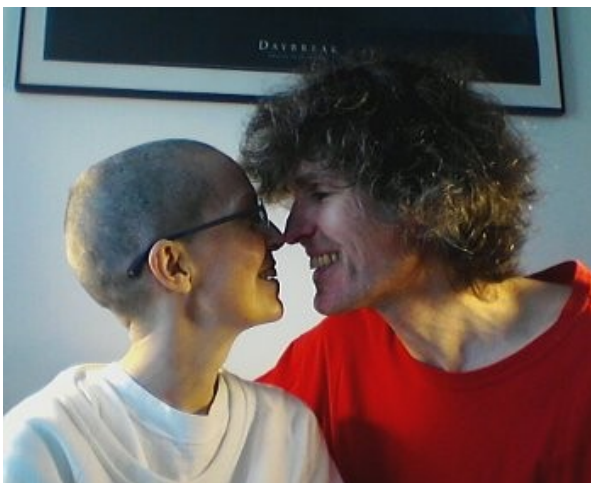
The PICC line I have is covered in a neat dressing but it will need to be changed weekly by a nurse who will visit us here in the house. The nurse will also be able to draw some blood as I must have a blood test two days before my next chemo day in 3 weeks.

As for side-effects, well, carboplatin will mean I lose all my hair, which I so don't care about. The only other side-effect to be on the lookout for is fatigue but as I have MS, I am already familiar with that one. Otherwise, I shouldn't have too nasty a time with this regimen.

I am singularly fortunate in having such access to fantastic resources. This isn't fun, but it provides a perfect opportunity for Buddhist practices of contemplating things like impermanence. Nothing is "forever" (well, except for potholes and shawarma shops) and so I will get through this. No, really, it's true.

**Friday, February
1st, 2013**

Today the Champlain Community Care Access Centre sent an RN around to check Ruth's PICC line and go over what services the home care



nurse will provide.

It seems that one of the nurses will come once a week to check the PICC and change the dressing. They will also come once every three weeks to take a blood sample, which I will then take to the lab for analysis.

CCAC also administers Ruth's provincial drug plan coverage which covers the cost of the cancer drugs she needs at home. That is reassuring.

It sounds pretty straightforward and it worked well last summer.

Saturday, February 2nd, 2013

Ruth decided today was the day to get ahead of the upcoming hair loss and have me clip her hair down to 1/16”.

It didn't take long with the clippers. It looks a bit drastic, but Ruth is pleased with the results. Her haircut is the shortest she has ever had it and that contrasts with my hair, which is the longest that I have ever had it! I suspect in the next week what hair Ruth has left will fall out, but at least it won't be a big change and it won't make for a lot of vacuuming, either. She is being very practical.

One thing Ruth did learn quickly is, at this time of year with a haircut like that, your head gets cold even indoors, so she has taken up wearing a toque around the house. Again a practical approach!

Sunday, February 10th, 2013

As the chemotherapy has taken effect Ruth has felt a lot more tired than normal and has noticed a bit of “chemo-brain” the muddled thinking that often goes with taking the drugs. She has promised not to go outdoors alone, which is a good idea!



That said, with a reasonable snowfall on Friday, February 8th, 2013, Ruth really wanted to get out skiing at least one last time before winter ends and the chemo really knocks out her ability to do that much exercise. So yesterday I went out to the Sawmill Creek Constructed Wetlands and laid down new ski tracks in the fresh snow to make it as easy as possible for her and today Ruth went skiing.



She was a bit slower than normal, but paced herself well enough. It didn't last long, though and after a total of 1 km she had had

enough. It was 500 m out and the same distance back. She made it home okay, pretty tired, but happy that she had been able to get out and ski.

It is actually good that she did get out skiing as the forecast is for temperatures above zero and melting conditions. It is likely that we won't have good skiing conditions again for a while!

Thursday, February 21st, 2013

Today completed Ruth's first chemo cycle with our second visit to the hospital chemo day ward and her second dose of the chemo drugs.

Overall the cycle went reasonably well, compared to expectations. Mostly she has been very tired during the past three weeks and has largely stayed home except for a few short walks and the one short ski trip. The last few days before the chemo session she was very tired, but she has rested a lot and we made the trip to the hospital and back by bus without any problems. She even wanted to walk part way home, from the hospital as far as Riverside



transitway station before catching a bus from there home.

Her spirits have been pretty good all this time, mostly buoyed by knowing that her

daughter Rachael will be coming up to live with us in the end of April. Ruth does her Buddhist meditation practice every day and does Buddhist readings as well and that seems to help her a lot. Otherwise she tries to occupy herself with crochet projects and watching humorous programs and cartoons. It all seems to work for her.

In the last few days her hair has really started falling out a lot and she seems predictably unconcerned about this, wearing scarves or toques when needed, although around the house she usually eschews them due to the itchiness caused by the ongoing hair loss.

I am sure that this second dose of chemo will leave her more tired than the first cycle did, as the effects add up. We'll have to see how she is doing by the end of this cycle.

Wednesday, March 13th, 2013

Today was the third chemo session and thus marks the middle of the regimen of six treatments. The actual day at the hospital went well, we were organized and played two games of Scrabble while there, just to pass the time while the medicine dripped. Ruth even slept a bit.

Ruth has lost pretty much all her hair now, or at least it has really hasn't grown back in since I clipped it for her. Her head feels like a peach. While outdoors she wears toques and indoors she wears either a toque or a scarf most of the time. Some times she is too hot and goes without any head covering, though.

Like last cycle this time she was sick from about the third to the tenth days after the chemo and then got better until a few days before the next chemo treatment and then started to feel worse

again. It seems to be a pattern.

We have the mid-chemo CAT scan coming up in two weeks, to see how the treatment progress is going. I will be surprised if much changes, but you never know. The consultation with the oncologist about the CAT scan will be just after the fourth chemo session, on April 5th, so we should know more about how the treatment is going then.

Until then it will be a lot of meals in bed and days spent on the couch for Ruth, too sick to go out or do much. She is maintaining her spirits and sense of humour most of the time, just hoping that the treatment will end and give her a good summer to enjoy some life again, including riding her trike and getting out for picnics and similar adventures.

Tuesday, March 26th, 2013

Today was Ruth's mid-chemo program CAT scan. This test was anticipated when she started chemo as a sort of halfway-through check-up on how the chemo is going.

As usual the scan itself is nothing to get concerned about, she just had to lie on a table for a minute or two. It is the preparation that is time consuming and nasty. As in



the past, the doctor had ordered "contrasting fluid" to fill the digestive tract and this meant Ruth had to drink three large plastic cups of what she describes as "a mixture of nail polish remover and swimming pool water". Also she cannot just down it like it was a "shooter" and have it over with, as each cup is graduated by time in half hour increments and so the three cups have to be consumed slowly over 90 minutes, right before the scan takes place.



We were at the Civic Hospital for this test, using their under-utilized emergency room CAT scanner and so we repaired to the nearby cafeteria to sit and play scrabble while Ruth sipped the required stuff.

Ninety minutes later Ruth had taken the last sip, made the last grimace at the taste of the stuff and was ushered in by a

very pleasant technician for the test. Ten minutes later she was all done and we headed home via the O-Train. Now she just has three or four days of gut disturbances from the stuff she drank.

We will get the results from the CAT scan on 9 April 2013 when

we see Dr Hopkins at the Cancer Centre. I am not sure what news we will hear then, but I am not expecting anything dramatic. The chemo should be keeping the cancer at bay, you would think, although the many years of Ruth taking immuno-suppressants/modulators may have a long-lasting effect. I guess we will find out on the 9th.

Wednesday, April 3rd, 2013

Today did not go as planned, but it still worked out all right in the end.

This was supposed to be the day of Ruth's fourth chemo session and so we got on the road very early and arrived at the hospital equally early. The nursing staff looked at her and asked, "what are you doing here?" Not a good sign.

In fact we had been given six dates for six chemo treatments, but orders had only been signed for three treatments, pending the results of the recent CAT scan. While the scan itself had fallen in between the dates for the third and fourth chemo sessions the consultation had not and so we had no order for a fourth chemo



session.

It looked like our trip might be wasted, when I decided to ask about the results of Ruth's most recent blood test, taken just the day before. The nurse checked the database and it was in, and indicated that she needed a blood transfusion due to a low red cell count. That didn't surprise either of us, as Ruth had been feeling very, very tired the past week or so. Chemo can be very hard on the bone marrow, where red cell production is supposed to occur.

So we spent a very long day at the hospital in the end, just getting done by the time the chemo day ward closed at 1700 hours. It took time to do a blood match, discover Ruth had a new antibody in her blood and then locate two matching units of blood and send them up. We played three games of Scrabble and Ruth notably started feeling better as the day wore on, winning two of our three games!

Friday, April 5th, 2013

Today was certainly a low point in the process. It was my volunteer day at NCF and so I made sure Ruth was feeling okay before leaving her on her own for the day. She hid how badly she was feeling and told me she was fine when she wasn't and I just wasn't attentive enough to notice.

I was just in the middle of a very busy morning at the office when I got an email from her indicating she was feeling very depressed and suicidal, had talked to the hospital staff and was going to take herself to emergency. I immediately phoned home, but there was no answer.

She specifically asked me not to leave work, but of course I did anyway and headed home right away. When I got there it was

apparent that she had taken some bus tickets and already left. I brought some supplies and caught up with her at the General Hospital's emergency ward, where I found her in tears, cold and sitting alone in an examination room with a few crackers and some peanut butter. She had been seen by a nurse and doctor and was waiting to be sent to the psych emergency ward next. I was not impressed that they had just left her there alone, for almost two hours. Not very smart.

We talked and I held her a lot. She told me that she had been feeling very depressed for weeks, but that she had not wanted me to know how bad it had become.

In the psych emergency ward she was assessed by a resident, while I was interviewed separately by a social worker and assessed as "burnt out". Then we all met with the psychiatrist, Dr Mann. She determined that Ruth was suffering from a major depressive episode, was at risk and needed to be admitted either voluntarily or involuntarily, her choice. Ruth chose to stay voluntarily and thus got to keep her clothes and have in-and-out privileges on the ward.

We sat together for hours waiting for the bed to become available. I went to the cafeteria and got her an ice cream, which she ate.

Once she was settled on the ward, in bed and comfortable, I packed up the personal items that she didn't need, kissed her good night and went home. I think we were both completely exhausted.

She made me promise to get some rest and not to come back and see her too soon. She was afraid that I would exhaust myself going to the hospital every day. I have planned to go back on Monday, read to her, play some Scrabble with her and bring her some books and things.

The plan is to treat the depression with Celexa and keep her for at least a week, perhaps longer. The ward psychiatrist indicated that she felt this was brought on by the past 14 years of accumulated and increasing illness and disability stress.

At this point I just want her to get better, so she can enjoy the time she has. I recognize that I am burnt out from taking care of her without a break for many years and so I am using these days to try to rest and recover, too.

Monday, April 8th, 2013

I have been visiting Ruth pretty much each day since she was admitted and she seems to be improving steadily. The psychiatrist she saw says that she will stay there until April 19th, a total of two weeks. They don't want to send her home too early, before she is stabilized on the medication and before all the home supports are in place.

That date works out well as it is the day that Rachael and Nick arrive. So that means that I will have help here taking care of Ruth.

In the meantime I go and visit her as often as I can, bring her books and cookies and play scrabble with her. That seems to brighten her mood up considerably.

For me the key thing is to get her through this difficult period, get her chemo done and give her a chance to recover from it and have a good summer here when she can get out triking and doing the things she loves doing.

Tuesday, April 16th, 2013

Ruth has now been in the hospital for twelve days and is still scheduled to come home on April 19th as previously noted.

The antidepressants she has been given are working well and she is recovering from the depths that she had previously experienced. These days her biggest problem is the other patients on the psych disturbing her. It is tough mostly feeling okay on a ward where there are lots of psychotic people yelling all the time.

I have been at the hospital visiting Ruth most days. By last Friday I had totally burnt myself out doing it and ended up completely exhausted. It wasn't good that Ruth had to console me, but at least that shows that she is doing better. I took the weekend to recover and saw her again on Monday, April 15th.

We played Scrabble and went for a walk outside the ward, around the inside corridors of the hospital, just to give Ruth some exercise. Lying in bed has caused her to lose some muscle tone and resulted in back and leg pain. Walking is the best treatment for that.

On her own Ruth has signed up for occupational therapy and has mostly spent the classes doing painting, which gives her a good creative outlet.

Friday she will return home and that is also the day that Rachael arrives, long with Nick, Matt and Katia, so we will have a full house for the upcoming weekend. On Saturday Ruth's brother Witold and his wife Vicki and some of their kids will be coming over for bunch and I have planned to cook pancakes, so it will be a busy time, too. Hopefully that will all make Ruth feel happy to be home again.

By the time the dust settles on Sunday Rachael will be all moved in and everyone else will have headed home. The doctors don't want Ruth left alone for a couple of months, until she is clearly feeling better and over the depression, so Rachael and I will take turns being with her, taking her out and such. It will be great to have Rachael's help in that regard.

We did get to consult with Dr Hopkins, Ruth's chemo oncologist, this past week after a number of missed appointments and found out that the CAT scan results were pretty good, showing that the tumour seems to have stabilized. There is some minor lymph involvement higher up, but the doctor is not concerned and indicates that further radiation maybe called for.

Ruth was happy with the consultation results and it lifted her spirits considerably to have some actual good news for once.

The new treatment plan therefore is just to continue her last three chemo sessions as an outpatient. The first one will be on Wednesday April 24th. That would mean that the second one should fall on Wednesday May 15th, Ruth's birthday and the last one on June 5th. Given her experiences recovering from the last three chemo sessions it will be reasonable to think that she will be feeling fairly good and able to get out much more by Canada Day, giving her at least most of the summer to enjoy.

After the last session is done there will be another CAT scan and a further consultation to see if the treatment goals have been met. Judging by what we know now it is likely that Ruth won't need more treatment until the wintertime and can enjoy a good summer and autumn.

Wednesday, April 24th, 2013

Ruth was released from the hospital on schedule on Friday, April 19th. I met her there in the morning and brought her home again. It was a busy day as she quickly finished a crocheted bedspread that she had been making for Rachael and had it done before Rachael arrived.

Rachael and Nick actually made it to Ottawa for dinner time, followed not long afterwards by Matt and Katia, coming from Montreal.

On Saturday we had Ruth's brother, Witold and his wife Vicki, plus Alexander and Liz and Ellie here for brunch as well, a total of eleven of us. It made for a busy day, but Ruth certainly had a good homecoming celebration!

Since then Rachael has been moving in and settling into Ottawa. On Sunday, April 21st we even went downtown to a play and out for some supper in the



Byward Market. Having not had chemo in six weeks Ruth was starting to feel more energetic at last.

The lack of chemo, the antidepressants she is now taking, plus all the family support seem to have had the desired effect and she is

feeling a good deal better.

Of course chemo started again today, the first of three more sessions, which will be three weeks apart. The last session should now happen on June 5th, 2013. Given her recovery speed this time around, she should be back on her feet in early July, in time to enjoy the summer and get in some triking.

She actually got her trike out yesterday and rode it in the street . I wanted to join her, but a bad shoulder injury from hauling supplies for her to the hospital has kept me sidelined from many activities.

One bonus with Rachael living with us now is that she will take her mom to the next three chemo sessions, giving me a break from that routine and spreading the care-work out. There is no doubt that after 14 years of caring for Ruth I am very tired. Rachael is my break and I am very glad she is here.

Sunday, May 12th, 2013

Things have been changing rapidly recently.

On Tuesday May 7th I went with Ruth to emergency (ER) at the Ottawa Hospital General Campus as she had a slight fever of 38.1C, just into the criteria for some attention. The night before she had had a fever of 40.0C, but had refused to go to the hospital. We had been at the Cancer Centre on the morning of May 7th for a PET scan science survey follow-up and they had checked her out carefully at that time, found her temperature was normal and sent her home. Ruth thought the fever was due to a slight bladder infection, which the ER doctor later confirmed. Ruth had already started taking her own antibiotics for it at home, which was the recommended treatment.

While in the ER they did complete blood testing and found that her red cell count was quite low at 61, due to the chemo and so kept her in over night for three units of blood and some magnesium as well. By the next day she was feeling quite perky and close to her old self. She came home at noon.

During the discussion on the evening of May 7th between Ruth, Rachael and me about how to get Ruth to the hospital, Rachael had decided to unilaterally call a relative for a ride, a decision that resulted in a long delay in getting Ruth there. That didn't affect Ruth's treatment, as it was not an emergency, but it did result in a very late night for both Ruth and and me, which wasn't optimal. Rachael had stayed home and went to bed.

The next day Rachael asked me if that was the wrong decision. I had intended to have a short debrief on how we might get Ruth to the hospital more efficiently the next time, but when I said "yes" she immediately slammed out of the house in a snit. Later on she phoned her mom from the new iPhone we had just bought her and launched into what Ruth described as “a hysterical and incomprehensible tantrum”. This left Ruth very angry and not a little bit disappointed. Rachael only returned to get her possessions and then moved to London, Ontario to live with her late father's wife.

I had started work on contract at NCF, but the job was more demanding than I had hoped and, combined with Rachael's change in plans, meant that I had to terminate work to stay home and take care of Ruth.

Saturday, May 18th, 2013

Ruth had her fifth round of chemotherapy in this series on

Wednesday, May 15th, which was also her 49th birthday. That sounds like a whole bunch of "no-fun", but we always make the best of these days as far as possible. That means we bring a picnic lunch and play Scrabble during the five hour process. In this case Ruth beat me in both Scrabble games we played, which is a suitable way to celebrate one's birthday, I think!

As usual Ruth felt pretty good on the day of the chemo and the next day, but had the side effects hit her yesterday, on Friday. She was fairly ill, although she was cheered up by a visit from her two sons, Matt and Nick. Nick was driving to Montreal for the Victoria Day weekend and Matt decided to come to Ottawa by train and then drive back with Nick. That gave them a few hours in Ottawa to see their mom, which worked out well, as by the time they were ready to leave town Ruth was tired and ready for bed.

Today Ruth was quite sick with the chemo side effects, in fact sicker than I have seen her before. She was tired right out and had some hip pain from it as well. She had no fever or any other cause to take her to the hospital, so I gave her some pain relievers, finally got her to eat a bit. She stayed in bed and slept a good part of the day away, which is probably the best way to deal with it.

I think the stress dumped on her last week by Rachael has had a negative result, as might be expected and has made the side effects worse this time around. Hopefully she will feel better in a few days from now. In the meantime all I can do is ensure she gets enough rest.

Saturday, May 25th, 2013

Today Ruth baked bread, something she hasn't done in a long time. This is a good sign, as she has recovered from the last

chemo treatment sufficiently to feel ambitious enough to take on projects like this.

Baking bread is something she once loved to do, but in recent years has stopped doing. This was probably for two reasons: lack of energy from the MS and cancer and also because she developed a gluten intolerance, which meant she couldn't eat the bread once it was baked.

The chemo has had at least one positive effect, it has suppressed her immune system and along with that the gluten intolerance as well, meaning she can eat bread once again.

As we usually do, this bread-baking was a team effort, with Ruth doing the baking and me doing the clean-up. The four loaves of bread turned



out really well, too! They were good enough that we made a gift for some friends of one loaf, the rest we kept to eat ourselves.

Tuesday, June 11th, 2013

This past week has been an eventful one and not in a good way.

June 5th was a chemo day for Ruth, her last scheduled one. It went reasonably well and we were both home by mid-afternoon. Ruth's blood report had shown a need for yet another transfusion, her fourth one, and so we had to come back the next day for that. Even that wasn't too bad as she had a psychiatrist appointment anyway and would have had to be at the hospital that day regardless. We managed to get both appointments done, with the psychiatric appointment in between the two units of blood delivered. The PICC line proved handy for that, as the chemo day care ward nursing staff just unplugged her and I took Ruth downstairs to the psychosocial oncology department for her consultation. Then we went back upstairs and plugged her back in again for the second unit of blood.

By the time we got home mid afternoon I was getting very sick and at that time I thought that I had caught a dose of the flu in the hospital the previous day. It turned out to be very bad and it came on just as Ruth's chemo side effects arrived, leaving me unable to care for her in any useful way. For the next four days we just muddled through as best we could, stayed hydrated and slept as much as possible. When either one of us was up to it we brought some food to bed. The flu-like symptoms had mostly passed by Monday June 10th and I was able to go out and get some groceries for us, as we had run out of milk.

This was the worst illness I have experienced in the past 27 years; it was truly awful. The worst part was not being able to take proper care of Ruth as she struggled with her side effects and for the most part she took care of me, as she was not as sick as I was. For much of the four days we just lay in bed, held hands and dozed a bit; it was all we could do.

Tomorrow is Ruth's next scheduled CAT scan, which will be followed with a consultation with Dr Hopkins on June 21st to find

out the results of the six sessions. At this point the best answer will be that the treatment went well and no further chemo will be needed until the fall or next winter. The worst case will probably be that more chemo sessions are needed right away. Ruth has said she will accept and comply with whatever recommendations she is given, but the latter will be very hard on both of us as Ruth will end up laid up for the rest of the summer.

Sunday, June 23rd, 2013

Friday was Ruth's consultation as a follow-up to the CAT scan she had the week before. The timing was good as I was just freshly released from the hospital after four days there with a urinary tract infection. I had previously thought I was coming down with the flu, but it turned out to be this one infection that knocked me out of action for two weeks in total. The worst part was that I was in no shape to take care of Ruth while I was sick. Ruth ended up on her own for three nights, but coped okay.

For this consultation we saw a new physician, Dr Barnes, and she briefed us on the results.

She indicated that the main tumour seemed to be under control and, in fact, the centre of it seemed necrotic, which is very good news! The left lymph node in the lower back has a small mass that may be cancer and it has increased from 8 mm to 10 mm in size, but is not currently a cause for concern. There is pressure on the left ureter, but that is being monitored.

The good news is that everything is stable enough for now that Ruth will only need an ultrasound as a next imaging procedure and that will come at the end of August. The ultrasound will be much easier to deal with than the CAT scan with its disgusting contrasting fluid. That has left Ruth with gastrointestinal upset for

a week after drinking it.

As an added bonus, with no more treatment scheduled, Ruth was able to have her PICC line removed, allowing her to get back to normal activities, like showering instead of bathing. That was a great relief for her!

So to celebrate both of us doing much better now and some



actually good weather after a month of rain here in Ottawa, we went out by trike up near Dow's Lake for a picnic lunch. It was a nice trip and we cycled 21 km round trip, a good start on us both regaining some fitness.

Wednesday, July 3rd, 2013

Ruth is back in the hospital and has been there since last Thursday.

On that Thursday she was running a fever of 39.3C, so we packed up some items: a change of clothes, a book, toothbrush and a jacket for the usually cold emergency room. I took her by taxi to the Ottawa General's emergency ward. The taxi showed up very quickly at our house, only about six minutes after I called it. The taxi turned out to be surprisingly clean as well. Once at the

hospital I reported to the duty nurse and they took her right away, ahead of about thirty other people, so they judged her situation to be a definite priority.

Once at the hospital her fever was still there and she was in a lot of pain in her back and left side. She said it was the worst pain she had ever experienced. They did imaging and determined that she has a kidney infection, as a result of that blockage in the ureter, causing fluid to back up. The lack of kidney drainage was addressed with a nephrostomy, a tube that directly drains the kidney.

The infectious agent turned out to be *e coli* once the test results came back. That is not significant by itself, as it is a common infection and always present in the human body.

She was quickly shifted from emergency to the observation ward and from there to the 7th floor, where a bed was available. A day later she was moved to the cancer ward on the 8th floor, right next door to the chemo day care ward, where we have spent so much time over the past year. She is getting good care there, including IV antibiotics and painkillers. Later on they shifted her to oral antibiotics and painkillers and on July 2nd took out her IV in preparation to send her home. Her condition seemed to have stabilized and she had had passed 24 hours without a fever, a precondition to going home. Then this morning she called saying the fever had returned and the doctors aren't sure why. They are keeping her there, of course, and doing more tests to see why the fever is back.

As much as I want Ruth home again, I am glad that she is being kept at the General until she is well and truly better. The last thing I would want is to have her come home and then have her run another fever and have to take her right back again. At least she is

getting the best care possible there. I have been visiting her every day, except today, bringing her food, clean clothes and other items she has asked for, like chocolate bars and carrots.

Ruth was in the hospital over the Canada Day long weekend, but that did have some benefits. Her son, Matt, and his girlfriend, Katia, came to town from their home in Montreal to stay with me and see some friends as well. While in town they went to visit Ruth three times, which was good for her morale.

Thursday, July 11th, 2013

Ruth was finally released from the hospital on Sunday July 7th after eleven day's stay there. She had been treated very well, but was happy to be home, needless to say. I was at the hospital with her every day of her stay, but one.

The infectious diseases team decided that she had an additional bladder infection which was causing the persistent fever and prescribed Flagil, a broad spectrum antibiotic, for it. That seemed to address the problem and her fever abated as a result.

Since she has been home now for four days she has had some pain and weakness, but the large number of drugs prescribed have kept things under control. We have even been out of a house a bit, including a short walk and a bus trip to Westboro today and she seems to be slowly regaining her strength.

Ruth now has a permanent nephrostomy in her left kidney, which is to say that the kidney directly drains into an external bag via a tube. She will have visits twice weekly from home care nurses to help take care of the equipment.

At first Ruth found the nephrostomy a depressing prospect, but

she seems to have developed a more pragmatic approach since she got home and has been trying to figure out how to make the bag's impact minimal as possible. I think in many ways she is braver than I am about things like that.

Because the tube exits in her back with a small plastic stopcock, this has made sleeping on her left side difficult. It may also make riding her Catrike difficult, too, she hasn't had a chance to try sitting on it yet.

We have an consultation with three different physicians on July 16th, including Dr E, the radiation oncologist, and hopefully a plan can be devised to shrink the tumour that is pressing on her ureter, which would allow her to get off the bag. We will see next week.

Tuesday, July 16th, 2013

Today we had three doctor's appointments, all at the Ottawa General Hospital and back-to-back.

The first was a pain management session with Dr Barnes, the very soft-spoken, 8th floor cancer ward doctor. That went reasonably well and well and we have a few adjustments to the pain medication now in place, plus Ruth will keep a medication diary to track what she is taking and when.

The second consultation with an oncology resident was pretty much pointless. She just told us what we already knew.

The third consultation was with Dr E and he had a solid plan for us. He will treat Ruth's tumour metastasis, the ones that are pressing on her ureter, with radiation. This has a 50-50 chance that it will shrink the tumours there enough to get her off the bag,

so it is statistically worth trying. Regardless of whether it does achieve that or not, it will shrink the tumours which is worthwhile.

This is virtually a duplicate of last summer's routine, so it is very familiar. The program consists of one CAT scan to image the tumour for planning and aiming purposes, followed by a radiation aiming point determination session (they term this "a simulation"), followed by 20 or 25 radiation sessions. These will be five days a week for five weeks on an out-patient basis. As we found last time the process each day is about half an hour long, but the daily times booked will vary greatly, between 8 am and 6 pm, depending on time slots available, with no two days the same time. This will be followed by another CAT scan at the end to see how it worked and a consultation to discuss that. So the total number of trips to the hospital will be about 29 over about eight weeks.

The exact weekly schedule is yet to be determined, but the plan is to start later this week or early next week with the CAT scan. This will take the whole process right through August and past Labour Day into early September. The lack of a "fixed daily time" for treatment makes establishing any routine impossible and so this tends to be pretty disruptive to daily life. The radiation will make Ruth very fatigued and unable to care for herself.

On the chemotherapy front, the plan stands unchanged and depends on imaging to be done just after Labour Day. The most likely scenario is another CAT scan right after Labour Day, followed by weekly chemo starting in mid September and lasting for six weeks. This will take it to just after Halloween and mean that she will be very sick and unable to care for herself until at least New Years time. There is a chance that Ruth will be sick enough that they may be talked into admitting her as an in-patient

for this part, but that is unlikely.

Ruth's nephrostomy home care provided by CCAC and *We Care* will continue through this period with two, half hour nursing visits a week.

Now we just need a schedule so we can plan this whole thing out. That should start with a phone call to give us the CAT scan booking.

Monday, July 29th, 2013

Today Ruth started radiation, the first of 20 sessions, five days a week. She decided that she felt good enough, being eight weeks post-chemo and having regained some strength, that she wanted to take herself to the first session by bus and give me the day off. I appreciated her kind thought as I have been very worn out lately and on Friday hit an “exhaustion wall”. I have cancelled everything for the last few days to recover and get some sleep. I was really counting on having a break this summer and her not needing even more treatment right away on top of the chemo.

By the time this radiation is done we will have been doing cancer treatment and recovery for 16 months straight. This isn't the way it is supposed to work, she is supposed to have a break to enjoy some of what time she has left, but it doesn't seem to be happening. It is looking like endless treatment until the end. I am not sure what the point of that is.

With the immune-system-suppressing chemo leaving her body Ruth is now showing signs that her MS is returning, which is not a surprise. She has been getting bouts of hiccups, which was a previous MS symptom. That is caused by the MS affecting the nerves controlling the diaphragm. She is also starting to have

cognitive problems as well, where she doesn't always make sense and can't explain what she was saying. That all adds up to me having to get myself rested up and back on the job of taking care of her full time as fast as possible, as she really shouldn't be out alone when having those sorts of problems.

She also tried out sitting in her Catrike Trail recumbent tricycle yesterday so we could try to figure out where we could position the nephrostomy bag so it is below her kidney and thus will drain while she is riding. We couldn't figure out a solution that works, as the reclined seating position results in the bag always being too high, unless it is dragging on the ground. On the plus side she will be able to ride the quadracycle, so perhaps I will get her out in that. This is actually all for the best as she isn't strong enough right now to ride on her own and with the return of her cognitive problems, shouldn't be riding solo anyway.



**Wednesday,
August 7th,
2013**

At this point in time Ruth has now had seven radiation treatments, with another 13 scheduled.

Ruth is not doing too

badly to far, with just some nausea and fatigue, but still fine with travelling to the hospital daily by bus. She has set up an account with the Cancer Society ride program in case she needs it, but at

present she feels okay on the bus. We are both getting good use out of our OC Transpo Presto cards.

Last week on Thursday August 1st she was again running a fever and tests done on urine from both her bladder and nephrostomy bag both showed similar results: some blood, high white cell count and the lab, for both samples, was unable to grow any cultures. It doesn't add up to a very clear picture, but perhaps it was a viral infection? We saw Dr E and he prescribed antibiotics, but her fever persisted for four days before abating. All a bit of a mystery, really, but at least it is gone now.

Like in 2012, the radiation treatments vary in time of day, with some at 0800 hours and some later in the day, depending on when there are time slots available. Her treatment is at Unit 10 in Radiation North, which is a new unit and has a brand new radiation machine. As Ruth termed it "it still has that new radiation machine smell". It also broke down once already, yesterday, but was fixed and back on line in 45 minutes, so it didn't create huge treatment delays. At least it is still under warranty!

I am naturally anticipating that she will get more and more fatigued in the next week or so, as in 2012, and that the rest of August and all of September she will be largely too sick to do much at all except rest.

On the plus side Ruth is excited that her hair is slowly growing back in. The radiation doesn't affect that, as hair loss is a chemo effect. At this point she essentially has a short crewcut and the hair is coming in mostly darker than her hair used to be, almost black, in fact.

In the recent past it seems that I have been too optimistic about

Ruth's prospects for even a short period without treatment or being in recovery from treatment. So at this point I will assume that she will be constantly ill and in need of 24 hour a day care until she goes to the palliative care ward. This assumption at least helps me eliminate any thoughts of us having a break together, being able to take a vacation or go anywhere at all, even day trips in the city. Those may happen yet, but it will be a pleasant surprise, not something planned for, nor anticipated. The forecast future is just endless treatment now.

At this point we know that the doctors are thinking she will need more chemotherapy at some point, we just don't know when. As we have learned, when it restarts it will wipe out about seven months in a row, when Ruth will be too sick to do anything but sleep.

Thursday, August 8th, 2013

I took Ruth for her radiation appointment today and noted on the bus there that she seemed to feel too warm. Once at the hospital I asked the nurse to take her temperature and she was running a fever of 39.3C. A blood test showed a red



cell count of just 74 and so she needed another blood transfusion. As a result they decided to admit her once again.

She spent most of the day sleeping on a stretcher in the Radiation North stretcher bay, while waiting for a bed to become free, which was a good idea. I brought her lunch from the cafeteria, a hot dog and fries, with some onion rings, which was what she asked for.

By evening she was in a single room with an expansive view to the northwest up on the 8th floor cancer ward. Time will tell how long this stay will last, but I have a feeling it will be a longer stay this time.

The essential problem here is that she has had an intermittent fever for six weeks now. The antibiotics they have given her, two series of Cipro and one of Flagil, seem to have suppressed, but not cured, the infection. The doctors seem to agree that it really is a medical mystery at this point in time. I am hoping they will keep her there until this is resolved as I can't do much for her in this state here at home, other than keep her warm, fed and read her stories.

This was also the date that I had a follow-up appointment with Dr Saltel, the urologist at the Civic Hospital. He gave me the rundown on my previous urinary tract infection and pronounced it cleared it up, which is good news, of course. The less-than-good-news is that he thinks the infection was caused by abdominal muscular tension forcing urine back up the prostate into the sperm duct where the infection was found. He was clear that meant my problem was stress-related. I know I am under a high degree of stress with everything that is going on now and that it has been going on for a very long time. I have been changing how I deal with events, stopped hoping for any kind of future at all for us,

but the only real cure in the long run is to reduce the amount of stress that I am under.

Saturday, August 10th, 2013

Ruth remains in the hospital on IV antibiotics. Her spirits are good and she naturally feels better after her recent blood transfusion. She has been moved out of her single room and into a double with an even better view straight to the north, which includes the Peace Tower, downtown Ottawa and Gatineau Park. She is hoping to see some northern lights while she is there. I brought her our compact binoculars from home and she watched the Parliament Hill light-show from her bed.

The doctors seem to agree that we will probably not have any luck identifying the source of the fever. Dr Hopkins thinks it may be related to dehydration causing irritation, but all tests to date showed very little other than a high white cell count.

She did get some attention this afternoon when her nephrostomy tube started showing pretty close to straight blood flowing down it. That brought in the nursing staff and the resident physician, a very young oncologist, Dr Jordan Sim. He consulted with a urologist and they decided that it is most likely due to the nephrostomy tube itself, so that will be replaced on Monday.

I must say the nursing staff have been superb as usual. Ruth's one nurse, Marie-Claude Brunet, had the job of getting a new IV into Ruth, not an easy task with her small and slippery veins. Despite setbacks Marie-Claude tackled the job with a degree of steely determination that was truly inspiring to watch and I told her so. We later nominated her for an award.

With all the medical stuff going on I did manage to bring Ruth a

latte from Second Cup, paint her toenails dark purple and even beat her at Scrabble by just one point in a very tight game.

Right now it looks unlikely that Ruth will be home before Wednesday.

I should note that Ruth has now decided to tell friends and relatives that her cancer is terminal. Everyone has been really good so far and her concern that people would be upset hasn't been an issue. For her sake that is a good thing, as it would have added to her stress.

Wednesday, August 14th, 2013

Ruth has now been in hospital for seven days. She had a CAT scan on Monday and this yielded some useful results. In consulting with Dr Carine Lapointe-Pilon she indicated that they have definitely located the source of the infection, the primary tumour.

It seems that, as Dr Hopkins had previously indicated, the primary tumour has been damaged by the chemo, basically killing the centre of it, leaving necrotic tissue there and the remaining tumour a “donut” shape. The doctor thinks that dead tissue has become infected and that is causing the fevers Ruth has been experiencing.

The problem cannot be addressed by draining the area or with surgery, so that leaves treating it with antibiotics, so she is on Cipro and Flagil once again. I did point out that these weren't successful last time, but did suppress it for a while. Dr Lapointe-Pilon indicated that, this time, they will make it a longer treatment, perhaps even ongoing indefinitely, if need be.

Dr Lapointe-Pilon also indicated that she wanted to do some more imaging to figure out where the infection came from. She is concerned that the tumour may have “bowel involvement”, meaning that the bowel may have become perforated and leaked the infectious agent into the tumour area. Hopefully they will carry the imaging out before Ruth comes home, as it will save making yet another trip to the hospital later.

Other than the imaging, Dr Lapointe-Pilon says Ruth can go home once she has been switched from IV to oral antibiotics and then goes 24 hours without a fever, indicating that they are working. That may mean she will be able to come home as early as tomorrow, but more likely Friday or Saturday. Personally, even though it is some work visiting her in the hospital, I would rather she stay there as long as needed, rather than come home too soon and have to go back again in a few days. They can take better care of her there than I can here and that is worth the daily travel time.

In talking to Ruth, this looks like it will be our routine for the foreseeable future, some days at home with Ruth on the couch unable to go out much, interspersed with time in hospital. The hospital time will likely proportionally increase over time until she is finally admitted for palliative care. Even then she can still come home for visits, if she is well enough to do so.

This past spring I had made the mistake of working at too fast a pace based on Ruth being done chemo this summer and then having some time off to recover, a period when we could perhaps get out and do some limited things together or even take a holiday away for a few days. I basically completely ran out of energy when they announced that she was going straight into a month of radiation right away. What I have learned is that you can't do that, can't count on any breaks, ever. Doing so builds up the expectation of a break, a vacation, that isn't going to happen. So

now, after talking to Ruth, I have just decided to forget about the future entirely, pace each day to deal with just that specific day and not count on anything beyond that, except that each day will be just like the last one. This will work better for Ruth as she needs me there every day and not exhausted from working too hard on the bet that I will get a break to recover. I won't and neither will she.

Thursday, August 15th, 2013

Ruth was released from hospital today and is now home!

First the good news: The doctors of the infectious diseases team decided that Ruth likely doesn't have an infection at all and that that the last seven day's worth of antibiotics probably didn't accomplish much. Based on a CAT scan done on Monday 12 August 2013, they decided that the fevers have been simply caused by tissue dying off in the primary tumour from the chemo and radiation treatments. That in itself is good news, because the treatment is supposed to kill off the tumour.

So that all meant that that she could come home today, won't have to have any follow-up IV treatment at home and can continue her radiation series. It also means that in future she won't have to go back to the hospital if she is just running a fever, unless there is some secondary sign that it is a problem, such as pain, diarrhea or similar.

All that is good news.

The bad news is that the CAT scan shows that the cancer has spread into the L4 vertebrae and that that individual vertebrae is also fractured. Dr Sim confirmed that is most likely from the cancer rather than any other reason; an injury in the last ten weeks

that was sufficient crack a vertebrae would have been memorable. This is also likely the cause of the nerve pain in her left leg, as a nerve that runs along the left leg inserts through L4. Dr Chan recommended a new pain control regimen, designed to deal with the pain. We also confirmed that the current radiation regimen is indeed addressing that area with the radiological oncologist, Dr E, during his consultation today.

The bone cancer means that I expect Ruth will run into mobility limits in walking, including even sitting up, in the not too distant future.

Sunday, August 18th, 2013



On Sunday 18 August 2013 even though Ruth was in the middle of her radiation treatment she felt well enough to get out for a short 6 km quadracycle trip. She really enjoyed

getting a bit of exercise, as well as some sunshine. She didn't do much pedaling, but it was a nice break for her from being on the couch or in bed and seemed help her leg pain to some degree.

Saturday, August 24th, 2013

This past week has been busy with five radiation appointments one physician consultation and two imaging appointments. The imaging appointments were on Friday and at the Civic Hospital instead of the General. That didn't work out too badly as after Ruth's early morning radiation session we took the hospital's inter-campus shuttle bus over to the Civic for her chest x-ray and pelvic ultrasound.

The results from the ultrasound will determine whether the radiation has shrunk the tumour pressing on the ureter so that Ruth can get rid of the nephrostomy and the bag that goes with it.



I did manage to accomplish one useful thing this week and that was getting two appointments for Ruth cancelled. They had booked her for a physician

consultation on 10 September and then a CAT scan on 12 September. Aside from the fact that it makes more sense to have the imaging and *then* the consultation to find out what the CAT scan said, in fact both of these had been booked back in early July and essentially overtaken by the imaging and consultations done during Ruth's recent hospital stay. I just had to talk to one receptionist and one nurse to get both of those cancelled. Ruth was very pleased as it means two fewer trips to the hospital and

best of all, no contrasting fluid to drink. That stuff upsets Ruth's GI tract for up to ten days afterwards, so she was happy to be able to skip it.

Next week we have two final radiation treatments on Monday and Tuesday and then no more medical appointments for a month! I expect, as the radiation's delayed effects take hold, that month will mostly be spent in bed or on the couch, but it is a bonus not to have to go out to appointments while feeling ill. The unspoken fact the schedule says is that Ruth won't be starting any more treatment for a while, which is good. She has been beaten up enough by the chemo and radiation and really needs a break from it all.

Tuesday, August 27th, 2013

Today was Ruth's last radiation treatment and we made the round trip by bus on a single transfer, which saved us a second fare each. The nurse briefed us on post treatment procedures, mostly a list of who to call, if problems arise.

We are both exhausted after a bad few nights' sleep. The lack of running to the hospital five days a week will help, but we just both need to get some better sleep now.

For the last few weeks Ruth has been bumming cigarettes from a friend of ours who smokes. Ruth smoked for a few years when she was a teenager, but quit more than 30 years ago. This week she bought her own package of cigarettes. I asked her why she had taken this up again and she indicated that basically she has "nothing to lose" at this point. I have told her that I am not happy about it, but there is little else I can really say. I can't cite her health as a reason as, at this point, she is not going to live a lot longer, not long enough to develop cancer from smoking anyway.

One thing I did point out is that soon she will be hospitalized again and you can't smoke there, but she just indicated she will deal with that issue when she gets there. Right now she seems to be smoking 4-5 cigarettes a day.

Saturday, August 30th, 2013

Ruth's radiation treatment is now starting to hit home and she has very little energy and lots of intestinal problems, made worse by the Hydromorphone pain killers. As usual she thinks she can do more than she really can and gets exhausted easily. Yesterday she tried a short walk outdoors, but the bowel and fatigue problems ended it prematurely. I am finding it is best to leave her in bed all day and just bring her what little food she will eat. She often isn't able to play Scrabble or even to listen to being read to. She does respond well to being cuddled and held, though.

Because her intestines are so noisy at night we are now sleeping in separate beds. That seems like a new stage in this process of losing her.

I am not sure if it is the painkillers, or an MS episode, or a combination of both, but she is having cognitive problems, both remembering things and hallucinating. She often asks me about events that never happened or people we don't know. She is taking a break from the Hydromorphone today, so we will see if that effect diminishes or not.

Needless to say I am very reluctant to leave her alone for any period of time as I don't know what she will do. The only thing that allows me to get out and get groceries and do other errands is that mostly she is too tired to get out of bed, thus reducing the risk of something unexpected happening.

Based on our past experiences I expect her radiation effects to get worse over the next three weeks and thus not really start to reduce until into October. I anticipate that by Halloween she will be feeling a bit better, unless the medical people want to start some other treatment before then.

Monday, September 1st, 2013

The radiation effects really seem to be taking hold now as Ruth woke me up at 0400 hours, sweating and quite cold and then at 0500 had diarrhea. I got her cleaned up and got her back to bed with extra blankets to keep her warm and then cleaned up the mess later on, in the morning. She hasn't eaten much, but at least she got back to sleep again.

I am going to have to keep a closer count on her medication, too. Ruth has mostly been managing her own pills, but she hasn't been keeping on top of the counts and today she ran out of the Hydromorphone 1 mg top-up pills she uses to control pain. She has a refill on those available, but today is Labour Day and the pharmacy is closed. She will have to make do with the long-term release ones and use Acetaminophen for any breakthrough pain that she has, at least until I can get the prescription refilled tomorrow. I did a count on her long-term release pills and she doesn't have enough to last until the next doctor's appointment either, so that needs addressing, too.

She had a lot of diarrhea this afternoon, more radiation effects, and I had to give her Imodium for that until it stopped. Of course there are disadvantages to that medicine as well, in that her bowels won't work for the next several days

We will have to see how the next week or so goes, right now her care requirements are high and getting higher all the time. In the

last 24 hours I have been starting to think that she would be better off in hospital where her medication never runs out and where they can keep up with her increasing needs. I am sure that she will land in hospital soon enough due to some infection or other similar problem and the assessment will then have to be made as to whether she would be better off staying there for a while, at least until the radiation-induced sickness has abated.

Tuesday, September 2nd, 2013

Ruth landed back in the hospital again today.

The last week since her final radiation treatment has not been very good. Radiation produces delayed effects and this time has left her with diarrhea, vomiting and loss of appetite. She has also had increasing amounts of abdominal and leg pain. Just after she threw up lunch today I made her get on a bathroom scale and discovered that she had lost 19 lbs in the last ten days, which was about 1/5 of her body weight. She was down to about 96 lbs, from 115 lbs only last week.

I called the Radiation North unit since they are our support for up to two weeks after her treatment, but couldn't get anyone on the phone there, so, with afternoon wearing on, I just called a cab and took her in. I figured if they didn't want us there that I could just take her to emergency instead, right upstairs.

Her radiological oncologist, Dr E, examined her and decided to admit her. They are going to try to get her eating, probably through a tube. He also thinks that her current condition is probably more than can be handled in a home environment, so they are going to look at whether she will be coming home at all or moved to a more appropriate care facility instead.

I have to admit, looking at this incident, I have to conclude that Dr E is right. I haven't been able get her to eat anything, feeding her at home has been a real struggle. Every day I make her nice food that she normally likes and she refuses it or just eats a small amount. She has been only getting maybe 200 or 300 calories a day. I knew she was looking thin and not eating enough this week, but I was shocked when she got on the scale and her weight was that low. Ruth was surprised also, as she had been avoiding the scale. As soon as I saw the reading I knew that if she stayed home she wouldn't live long.

We will have to see how long they keep her in this time and what they decide should be done for her. I have been hoping that she would recover from the radiation treatment there in hospital, put on some weight and then come home again, but we will have to see.

For her part Ruth says she can't stand the constant pain anymore. In the Radiation North stretcher bay she told Dr E she had had enough and was ready to die today. I am hoping still that they can give her some time, even a few months without pain or treatment to recover from, to come home, to ride her trike this fall and maybe go skiing this winter, all the things that she loves doing.

Wednesday, September 4th, 2013

I had a chance to speak with two of Ruth's physicians today and here is what they are saying at this point. First, that while her sudden weight loss is a concern they think it is relatively normal for cancer patients and aren't willing to do more than give her some steroids to improve her appetite. They don't want to put her on a feeding tube right now.

Her red blood cell count was down again to 81 and so she got two

more units of blood, her sixth transfusion since last summer. That made her feel quite a bit better alone.

They have re-assessed her pain situation and decided to make some changes there, as she was not getting proper pain control this past week with the existing medication and dosages.

I brought her some high-fat food (chips) and some fruit, but as usual she is being obstinate and not keen on eating too much. I did get her to eat most of the dinner that was brought to her, though. I also helped her shower and change her clothes.

As far as later care goes I was basically told that there are no care facilities for people in her situation. The hospital is "acute care", meaning that you only get short stays there. Ruth isn't sick enough to qualify for longer term care yet, although she may be sent to the Elisabeth Bruyere Hospital downtown for pain management if required later on. So that means she will be coming home, probably early next week, so I am getting the place cleaned up and laundry done for that.

Here is something new: Ruth has actually agreed that I can bring her laptop in while I am there tomorrow (there is no ability to secure valuables there so I will bring it home when I leave) but she will be on the internet in the afternoon/early evening and will reply to any e-mails that she gets. We will see how that works out!

Thursday, September 5th, 2013

The good news is that Ruth is doing better today and is likely to be home again early next week.

The pain specialist has decided that she should be moved from the

General Hospital to the Elisabeth Bruyere Hospital in downtown Ottawa. This facility has a specialized pain program and they should be able to give Ruth better pain control. I expect that she will be transferred there tomorrow or Saturday, but I am still waiting to find out exactly when that will be. They will transfer her by Ontario Patient Transfer (OPT) ambulance so she will have an easy trip of it.

The Bruyere is also the only dedicated palliative care hospital in Ottawa so it is likely that she will end up there in the long run as this cancer progresses, so it wouldn't hurt to become familiar with

the place and the staff there.



I took Ruth her laptop so she could answer her email, but unfortunately the hospital switched the patient internet wireless from a secure network to an insecure, open network recently and that meant Ruth wasn't going to chance having her passwords stolen by signing into any services like GMail. That was a drag, but at

least she got to check the news and the weather, one of her

favourite things.

Friday, September 6th, 2013

Ruth has been moved to the Elisabeth Bruyere Hospital in the Byward Market area of Ottawa, room 514B. They are going to be starting her on a new pain control regimen using Methadone and she will probably be there a week, so I am looking at her coming home about next Friday or so, depending on how things go.

She is on the palliative care floor, so it has very comfortable rooms, attentive staff and better food than the General. Ruth can get ice cream 24/7 in the kitchen near her room!

Monday, September 9th, 2013

Ruth has now started on the Methadone treatment. It is too early to tell how effective it will be, but it doesn't look like she is having any adverse reaction to the drug, which is good.

I am relatively pleased at how this hospital is handling her pain management, but less so over the other reason she was brought in: weight loss.

At the General Hospital, Dr E was very concerned about her weight loss of 19 lbs in ten days and recommended a feeding tube. The 8th floor doctors were less concerned and I was told that losing weight during cancer treatment is normal.

Now that she is at the Bruyere I don't think that the weight loss issue is being taken seriously. They are aware of it, as we have discussed the issue and they have prescribed a steroid to increase her appetite, but that is all they have done. They did not weigh her when she arrived and haven't weighed her since. They also have

not been monitoring what she is eating and many days it isn't much.

She was supposed to have a dietitian consultation, but, even though she has been there for four days now, that hasn't happened. She is on the default standard diet there and it sometimes clashes with her rather fussy food preferences. One day for supper they gave everyone tuna casserole, which she refused to touch and ate nothing at all. I did feed her some chips and ice cream, otherwise she would have been happy to go hungry rather than eat something she doesn't like.

I have been bringing her chips, pop and chocolates, which she asked me to do, but she hasn't been consuming much of them. I am concerned that with her daily calorie burn, regenerating tissue from the radiation and chemo damage, that she is still under-eating every day and losing weight, but it is hard to tell. I took her for a short walk this evening and she is very frail and weak. I am going to have to check her weight, since no one else is doing that and try to find a scale and weigh her. I don't want to bring her home and have to take her back to the hospital a few days later. The worst case would be if Bruyere staff won't do their job and release her having lost weight, I may have to take her straight to the General's emergency from there.

Tuesday, September 10th, 2013

I am pleased to report that Ruth finally had her dietitian consultation today and they are now feeding her a higher-calorie diet made up of food that she will actually eat. I also found a scale and asked her to stand on it, which she happily did. The good news there is that after a week in hospital she has gained three pounds and now weighs 46.5 kg (102.5 lbs). I am just happy that her weight is going up and not down. I have to add that this

should be a nursing function to monitor her weight and not my job there.

Ruth also met with a physiotherapist, although it is not clear why she was referred. The interview did not go well and the physiotherapist kept berating her for “not being good to her body” for doing things like yoga. The woman reportedly admitted that the things she was saying were not very professional. The whole thing was somewhat distressing to Ruth, so I suggested that she just not meet with the physiotherapist any further, as she doesn't seem to have anything of value to offer.

Overall, the experience at the Bruyere has not been as good as I had hoped. The physical surroundings are generally nice, the physicians seem good, but the nurses are understaffed and harried, it took five days to get a dietitian consultation for someone admitted with severe weight loss who was never weighed at all and now a self-admittedly non-professional physiotherapist. The place is also dirty and disorganized. I feel like I need to keep a closer eye on what is going on there than a patient's spouse should have to.

Friday, September 13th, 2013

Today we had a conference with Ruth's physicians today, Drs Lawler and Hernandez.

The methadone regimen seems to be working well and they have her



100% switched over to that for baseline pain control. They need to spend another few days getting the dosage slowly right, by increasing it a bit at a time and then transition to using it for any breakthrough pain that she experiences.

At this point they are still thinking she will be home by the middle of next week, as previously indicated.

With some careful planning we managed to surprise Ruth with a visit from her son from Montreal, Matt, and her son from Burlington, Nick, who were in town to move some furniture to from Ottawa to Matt's new apartment in Montreal. In both cases she was duly and pleasantly surprised!

This week Ruth has had lot's of visits from friends and now relatives and the outpouring of affection for her seems to have aided her recovery and the maintenance of her good spirits. She even had some flowers!

Monday, September 16th, 2013



I just got some good news from Ruth: she will be coming home on Wednesday! The key items will be the follow-ups: making sure she has

enough medicine and an easy way to renew her prescription, plus a home palliative care physician as well. We can't take a risk on not being able to get her Methadone, as you can't go missing doses of that once you start on it.

I also want to be sure we have a good method of getting Ruth back into the Bruyere Hospital directly the next time she needs it. I am assured that the visiting palliative care physician will be able to admit her directly and that will save us from having to go via the General's emergency room and the 8th floor.

During her time in the hospital Ruth has had lots of visitors including her brother, Witold and his wife Vicki, who took the photo of the two of us in the lounge area.

Wednesday, September 18th, 2013

Ruth was supposed to come home from the Bruyere hospital today, but we are still in the middle of administrative issues, mostly finding a physician who is authorized to prescribe her new pain medicine, before she can be allowed to go home. There really isn't any point in sending her home if she can't continue on her medication!

It turns out that the visiting palliative care physician program rejected her as "not sick enough" for home care, which ironically meant that she had to stay in the hospital. It makes no sense to me either. We are hoping to have this sorted out tomorrow and have her home by lunch time, but we will see!

Ruth is keen to come home, but not in a big hurry and we would both rather do it right, rather than do it fast and have it all messed up.

Saturday, September 21st, 2013

Ruth finally did come home on Thursday, but the discharge was disorganized and she still doesn't have a prescribing physician for the methadone. We are supposed to have two doctors appointments coming up to sort that out. In the meantime she has a good supply that was delivered to her from a pharmacy that does handle it.

Ruth seems to be doing well since she came home. The methadone is controlling her pain and she is eating okay, with a combination of regular food and meal replacement shakes giving her enough calories to maintain her weight for now. The aim is still for her to gain some weight for the risk of later weight loss.

Today was rainy, but she did get out for a short walk with the walker that CCAC lent her on Thursday. If the rain stops we will try to get her out again and start rebuilding her muscles after all this time in hospital and lying down at home.

Monday, September 23rd, 2013

Today Ruth had an appointment at the General to get her nephrosomy tube changed, which is a minor outpatient surgical procedure.

She was really at a low ebb today, not feeling well at all, very tired and unable to walk much, even with her cane. I put her in a wheelchair during the time at the hospital and that helped.

Ruth wasn't thinking clearly and she kept reminding everyone that we met that she needed her methadone at 2 o'clock: nurses, clerks, porters, everyone. Most people kept telling her that wasn't their job. I had her pills and I kept promising that she would get her

dose on time, and she did. At one point she sent a nurse to track me down in the waiting room to make sure I still had her dose. The nurse asked me if she was addicted and I had to admit that she was; after all it is an opioid.

I am also very, very tired today and not feeling well at all, just exhausted mostly. Ruth and I didn't get along well today, she was difficult, didn't eat much and often didn't make sense when she said things. She seems to be having cognitive problems, but I am unsure whether these are due to MS or to the pain killers. I am hoping that we can both get better quality sleep this week and that things will run more smoothly between us, like they usually do.

Tomorrow we have to go back again to the General for a consultation with Dr Hopkins. At least that is what the appointment says, but you never know who you will see there. Ruth has said that she doesn't want any more treatment right now, that she is too exhausted from all the chemo and radiation. I have to agree, the treatment is getting quite pointless and is just doing more damage to her time left, than it is good.

Tuesday, September 24th, 2013

This morning, as part of preparation for Ruth's appointment with Dr Hopkins I had her once again stand on the scale and it read 102.0 lbs. This means that her weight has remained essentially the same over the past two and a half weeks, so she is just barely eating enough to maintain her weight. I figure she is consuming about 1800 cal/day, so that shows what her body is burning. The odd thing is that in the ten days prior to her hospital admission she lost 19 lbs while eating about 200 cal/day. That indicates a calorie deficit of about 6650 cal/day, or a total daily burn of 6850 cal/day. That means that in the intervening period something has changed, either the body repairs from the chemo and radiation

have slowed down or the cancer has.

Regardless of which it is, Ruth is not gaining any weight and if it gets back up to the burn rate it was at, at her current food intake she will start losing 1.4 lbs/day and land back in the hospital in a week or two.

We discussed this and she insists that she can't eat any more than she is doing. Mostly she eats so slowly, for instance taking an hour to eat a sandwich. If the cancer ramps up its growth and burns more calories then she will very soon lose so much muscle mass that she will be unable to stand up or walk and that means she goes back to the hospital. As we saw in the Bruyere, they never seem very concerned there, but maybe that fits their mandate of a palliative care facility anyway. Perhaps it makes sense to die faster, rather than more slowly and drag the whole thing out.

I was hoping that Ruth would regain some strength and weight and we could do some things together, but that seems to be unrealistic. Looking at the numbers it looks far more likely that she will just be here at home on the sofa until the cancer speeds up a bit again and her weight starts dropping once again and then she will just go back to the hospital for the final time.

Later that same day

Today we had an appointment with Dr Hopkins, Ruth's primary care oncologist at the Cancer Centre of the Ottawa General Hospital. She reviewed the 12 August 2013 CAT scan imaging and recent history from Ruth's stay at the Bruyere Hospital and was able to give us some news.

First off Ruth won't be getting anymore chemotherapy or

radiation, which is good, as she is still too sick from the last sessions of those. Dr. Hopkins also said we would be contacted for a home care physician this week.

Ruth also asked her directly how long she could expect to live and the doctor stated "about three months", which would be Christmas time. Naturally that will be plus or minus a bit, but at least it gives us an updated time frame to work with. As a rough guess that means Ruth will be returning to the Bruyere Hospital probably near the end of November for the final time, all other things being equal.

In an odd moment the doctor hugged Ruth and told Ruth that she loved her. She shook my hand as well and indicated that we probably wouldn't see her again as the treatment from here on in will be strictly for pain control.

We are both very tired and totally worn out today and just need to get some sleep.

Friday, September 27th, 2013

Today we had a visit from Dr Bill Splinter, the home care physician. He came to our house and spent almost an hour with us going over the case. He seems like a good doctor for work with and we are happy to not have to worry about finding someone who can prescribe Ruth's methadone now, as he can do that.

We went over the rough plan and he agreed that all other things being equal that Ruth would be home for another month or two and then would be most likely to move into a care facility when she can no longer stand or walk by herself. He explained that there are three facilities available: the Elisabeth Bruyere Hospital again, the Hospice at May Court near Billings Bridge and the

Embassy West, a converted hotel at Highway 417 and Carling Avenue. May Court is the closest to here and probably the nicest as well. Ruth doesn't seem to have any preference and where she ends up will depend on where space is available when the time comes.

We are supposed to see Dr Splinter again midweek.

Wednesday, October 2nd, 2013

Dr Splinter carried out a telephone consultation with Ruth yesterday afternoon. She has been having trouble urinating and he was concerned that she may have metastasis that are interfering with that. He ordered a catheter installed and *We Care* sent a nurse to do that in the evening. As a result Ruth now has her left kidney draining into a bag directly and her right kidney draining into a bag via her bladder.

The doctor also changed her methadone dosage from 7.5 mg three times a day to 15 mg at bedtime and 10 mg in the morning. The bedtime dosage left her hallucinating before she fell asleep. She is also starting to have problems with nausea for the first time since starting methadone, although it is unlikely the drug that is causing that.

Even Ruth has noted that her condition is deteriorating quite quickly right now, although she doesn't want to discuss it. This is new as we always used to talk about everything together.

She hasn't been away from the house since the first day back from the Bruyere, as she hasn't felt up to going past the back garden swing to smoke cigarettes. Given Dr Hopkins' prediction of three months and her quick deterioration lately, I am now wondering if that number won't turn out to be an overestimate once again, like

the 1-4 years we were given in January. Due to Ruth's decade long MS immuno-suppressant medication everything seems to be happening faster than anyone seems willing to guess.

Ruth is supposed to go to Montreal this weekend to visit Matt and Katia and I am concerned that, even in those two days, something might go wrong and she will need medical care. We will have to see how she is doing on Friday to make that call though.

Thursday, October 3rd, 2013

This week Ruth has stopped doing almost anything for herself, like even putting her toothbrush away when done with it, or picking up her clothes when she takes them off. She just drops things on the floor, which is very out of character for her. It seems she is unable to take care of even the most minor details for herself.

We have had some friends over for lunch this week and it seems to really wear her out interacting with anyone for more than an hour or so.

She is also now not able to sit down in a chair, she has to recline or else it hurts her hips. She spends all day lying on the couch with lots of cushions, but at least she is comfortable there. She often sleeps in the middle of the mornings and afternoons.

One thing that has become very noticeable this past week is that the house is starting to smell of death all the time. It is becoming very strong, is literally eye-watering and almost unbearable. This is quickly getting worse and is due to cancer tissue necrosis. Fortunately it has been warm enough to keep the windows open, as well as the fans running and that has reduced the problem.

All of these factors add up to my thought that time is shorter than anyone thinks it is.

We had a visit from her CCAC home care coordinator, Kelli Cross, today. She carried out an assessment of Ruth and went over some of the services that they offer.

Dr Splinter phoned to check up on her yesterday and again today, as he is going on holidays to Australia for two weeks. We will still be able to contact Dr Coulombe while he is away, if needed, though.

Friday, October 4th, 2013

Today Ruth is scheduled to go with her son Matt for two nights at Matt and Katia's new apartment in Montreal. I am staying home to catch up on laundry and sleep before "the final push" starts here. Unfortunately it looks like it will be a rainy weekend, which will keep me at home working and not out taking a break, biking.

I hope the visit goes well and that Ruth doesn't have any medical "urgent matters". Last night she had a nephro leak from the site, which soaked her dressing. The waterproof bed pad that Matt and Katia bought for Ruth saved the bed from getting wet. I washed and dried it so she can take it on her trip today, along with her high-calorie drinks, medicine and other supplies. We collected together her crocheting supplies as she is giving them all away to Katia, having taught Katia to crochet earlier this year. Ruth also wants to give away her much loved Catrike Trail tricycle to either Matt or Katia. She knows that these things have to be done and soon.

I think this will be Ruth's last trip anywhere, as she is getting quite weak, tired and sleeping most of the time. Right now she

sleeps from 2100-0400 each night and then again from 1000-1200 and 1400-1600 or so. This is being caused partly at least by the Methadone and partly, I am sure, by the energy that the cancer is sapping out of her.

For my part I have been going over our finances, making sure all the “designated beneficences” are all in place so there will be no need to probate the will. I have also been looking into Ruth's coverage provisions under my life insurance, as well as cremation options and pricing. This is really no fun at all.

Monday, October 7th, 2013



Ruth completed her trip to Montreal without any medical emergencies, although she contacted me on Saturday morning to indicate that she wanted to come home due to pain and fatigue. I did point out to her

that if she came home that she would just end up lying on the couch at our home instead of the couch and Matt and Katia's home. She saw the logic in that and decided to stay there until Sunday morning.

Overall her visit went okay, although it wasn't possible to go out anywhere and she just spent the weekend lying on their couch.

The car ride both ways left her hurting as she cannot sit in a chair anymore without pain and has to be in a reclined position. I don't think she will be going anywhere very far afield anymore.

Dr Coulombe called today to see how Ruth was doing, while Dr Splinter is away in Australia for two weeks. Ruth described the trip to Montreal, all the other visits she has had lately and her state of fatigue. Dr Coulombe told her to cancel all further visits for the balance of the week and just rest. Given how quickly Ruth's health is sliding I suspect that will be the state of affairs next week as well.

I would like to be able to report that while Ruth was away that I got some serious rest, but that wasn't the case. She was only away about 40 hours and I spent most of it trying to get the house cleaned up, doing laundry and some grocery shopping. The weekend weather was better than originally forecast and so I did ride my mountain bike up to Pink Lake in Gatineau Park, which was a nice break.

This upcoming week looked excessively busy, but now, with all visits canceled, it is looking a bit more manageable. We are both really showing the signs of long-term fatigue from this ordeal, but for both of us there are no real breaks available. Fewer visitors will help a lot this week, as they add significantly to the requirements for cooking meals, grocery shopping and doing dishes. It had been suggested last week by Dr Splinter that Ruth apply for the day program at May Court, but right now she is too tired to go and participate in any meaningful way, she would just end up sleeping there all day.

This afternoon we are waiting for a *We Care* nurse to come and do a dressing change on Ruth's nephro dressing. She woke up at 0400 with it soaking wet, along with the pad she sleeps on once

again. Fortunately the pad held the leak and so the bed did not get soaked this time. It was just good luck that this happened here where we can deal with a dressing change, instead of in Montreal over the weekend. Events like this at 0400 hours just add to the fatigue for us both, however.

I am trying to keep Ruth here at home as long as possible. Right now, with the supplies we have, like the bed pads and such, along with canceling most visits, I think we can handle being at home for a bit longer. Ruth will end up in a care facility sooner or later, but I would prefer it to be as later as possible.

I decided to get Ruth a spare bed pad at Shoppers Drug Mart so she has something to sit on when the other one is drying out after washing it.

Tuesday, October 8th, 2013

The stress of the past 18 months of cancer treatment, as well as the last 14 years of Ruth's illness, have been catching up with both of us lately. We are both having trouble with insomnia, gastro-intestinal problems and I have been developing skin rashes and having nightmares as well. The stress of dealing with all of this is continuous, always-increasing and there are no easy solutions within the present medical system. Ruth isn't sick enough for hospital or hospice care yet, but taking care of her at home is very hard, with constant nephro leaks at 0400 hrs and similar problems making the days exhausting. Trying to keep the home calm and harmonious is a challenge when no one is sleeping very much.

Due to insomnia we both found ourselves in the living room at 0300 after hours of being awake and unable to sleep. This whole experience has been grueling and we are nowhere near the end of

it yet.

Wednesday, October 9th, 2013

Ruth grows weaker and less steady on her feet each day. She also has pretty much stopped eating once again. Her calorie count for yesterday from actual food was about 450. She did drink four of the meal replacement shakes, which add up to 1420 calories, so those are really the only factor that is keeping her from losing weight right now.

I gave up trying to get her to eat some weeks ago, she is stubborn, intransigent and refuses to eat unless she feels hungry, which she almost never does these days. It seems the steroids that she has been taking, with the intention of increasing appetite, are no longer working. She is unhappy whenever I try to get her to eat and has asked me to stop mentioning it.

At this point there is little more I can do. If the cancer ramps up again she will lose weight rapidly, but for now her body weight seems to be staying even at about 102 lbs.

Saturday, October 12th, 2013

Ruth has seriously cut down on her calorie intake. Yesterday she ate very little, complaining that she wasn't hungry, etc, and only drank two of the meal replacement shakes. Trying to get her to eat is a waste of time as she just puts up a fight and always has a reason why she won't. I can't make her eat.

Today her catheter is not draining, the bag was empty this morning when she woke up, which I found alarming. That urine has to be going somewhere unless her left kidney has stopped working. She also has blood and urine in her nephro dressing, so

I called *We Care* and asked them to send a nurse around to change the dressing and assess the catheter. I hadn't checked her nephro dressing yesterday so I have no idea how long it has been contaminated. Ruth says it was fine when she got up this morning, but the blood is dried and brown, so that is not correct. I feel that I am always missing what is going on, always one step behind the next crisis.

The *We Care* nurse came and the lack of urine in the catheter bag was due to a tube blockage so she had to change the catheter. It looks like Ruth has a urinary tract infection going, so is taking Cipro for that. The nephro dressing was urine soaked and was changed also.

I washed her incontinence pads three times today and could barely keep up with getting her a clean one, as they have to air dry.

Hopefully the next few days will be quieter.

Sunday, October 13th, 2013

I got Ruth to stand on the bathroom scale this morning and she is 103 lbs, so at least she hasn't lost any weight since coming home from the Bruyere on 19 September 2013.

Monday, October 14th, 2013

We had another *We Care* home care nurse in again today as once again Ruth's catheter didn't drain overnight. The nurse flushed the catheter and this time that cleared it and drained it.

Ruth is still dealing with a urinary tract infection, which is probably at least partly responsible for the catheter problems. She

is taking antibiotics for that but has run out (on a holiday, too) and so Dr Coulombe, the home care physician, has arranged a delivery of more of them.

Once again Ruth is tired, not hungry and isn't eating. The nurse indicated that she was dehydrated and needs to drink a lot more fluid. I have given her more drinks, but she won't drink much at all and prefers to sleep instead.

Tuesday, October 15th, 2013

Ruth's sleeping habits have become quite disrupted. Last night she went to bed at 1930 hrs and got up at 0130, saying that she was hungry and wanted to get something to eat. In the morning I found her lying on the couch, dozing and watching cat videos, still hungry. She hadn't got herself anything to eat, despite being only a couple of feet from the kitchen where I have lots of food ready for her. When I found her I got her some breakfast cereal and then she went to sleep on the couch for a bit.

In hindsight I guess what I should have done was got up at 0130 and fed her or at least made sure she got something to eat. She hardly ate anything at all yesterday as it was, refusing food all day long.

Her nephro dressing was once again urine soaked and needed changing.

Wednesday, October 16th, 2013

Ruth was still refusing to eat anything substantial today. She says she won't eat because she is not hungry.

Our friend Gwen was over for dinner last night and she was quite

startled that, while I made us all a good dinner, Ruth refused all food as usual. She ate about 300 calories all day yesterday by my count.

Ruth has become quite militant and very difficult about not eating. I asked her to explain why she has stopped eating and she just lashed out at me and told me to stop asking her. She has eaten about 100 calories today. This was exactly the same issue that landed her in the Bruyere a month ago, but the physicians and nurses all seem pretty unconcerned there. I can't seem to get anyone's attention on this, especially Ruth's. Maybe it is just not important and I am just delaying the inevitable.

Again today Ruth's nephro dressing was urine soaking and needed changing, and her catheter was once again not draining. The *We Care* nurse came mid-afternoon, changed the dressing and flushed the catheter again. While the nurse was here Ruth had an enormous series of bladder spasms that were frightening to watch, almost like a seizure. Even the nurse said they looked like labour pains. All I can say is that it was a good thing she had an adult diaper on as that contained most of what resulted. I suggested that Ruth needed to go to the hospital but the nurse said no, she is fine at home.

Ruth slept much of the afternoon, but by the evening her bladder was full and the catheter still wasn't draining it at all. I did a 60 ml flush of it, as the day nurse had showed me, but only got about 3 ml in return. Ruth was in a great deal of distress, with bladder spasms, pain and then she became quite verbally incoherent. I called *We Care* again and they sent around an on-call nurse in about ten minutes. She did a catheter change, although Ruth's spasms expelled that one before it could do any good and she had to insert another one over again. This time Ruth was able to empty her bladder, but mostly past the catheter, not through it,

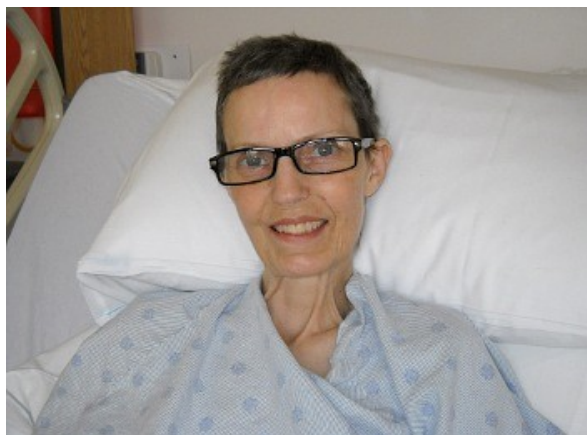
with wrenching spasms.

After her bladder was empty she was still in a lot of pain, sweating profusely, hyperventilating, experiencing constant spasms and unable to speak. I suggested we call an ambulance and the nurse agreed. The paramedic arrived first, assessed her and got her on oxygen. Once the ambulance arrived we all got her onto a stretcher, into the ambulance and off to the Ottawa General once again. I did go out to the ambulance to see that she was okay there. I didn't go to the emergency ward as I am completely exhausted. I'll catch up with her there tomorrow, as I know she is in good hands.

Today was a very hard day, when both of our levels of exhaustion, combined with Ruth's quickly escalating symptoms, to produce another crisis point in this illness. We will have to see what happens next, but I think we have exceeded the point where I can care for Ruth at home.

Thursday, October 17th, 2013

I went to the General Hospital and discovered that they had assigned her to room 8235, her old room from a previous stay



there, the one with the great sweeping views over Ottawa's downtown, Parliament Hill and the Gatineau Hills beyond. It really is a great room.

Ruth is doing quite a bit better than yesterday. She has essentially lost reliable control of her bladder and bowels due to the cancer, but she is in good spirits otherwise. I brought her her toothbrush, her reading glasses and other supplies she will need.

She told me that she recognizes, after yesterday's events, that she is no longer able to be cared for at home and so she has asked to be transferred to a palliative care facility and her doctors have agreed to that. We aren't sure which facility in Ottawa she will move to, as there are three: The Bruyere once again, May Court and the Embassy West.

Right now Ruth is thirteenth on the combined waiting list, but they tell me that this usually goes relatively fast, which is ominous all by itself. I am thinking she will be moved by early next week in all likelihood. In the meantime she is being well cared for in the Ottawa General and lacks nothing there. She has even started eating a small bit at last.

The one screw-up at the General was that she was left without any methadone for almost 24 hours, due to the lack of a physician with the proper signing authority to prescribe it when she arrived in the emergency department. Even the pain specialist was not impressed and indicated that there were other physicians who could have been called to prescribe it. They topped her up with hydromorphone as a temporary measure, but she did get some painful withdrawal symptoms later at night. That was totally unnecessary. I just wish they had called me, as I have her home methadone supplies and could have brought those in right away.

Ruth seemed much calmer today, closer to her old self now that she is in hospital again. She has asked me to not to come and visit every day as she is concerned about my level of exhaustion, just Ruth being thoughtful as always. We agreed that I would come

every second day, unless she needs me to bring her something. She tires out very easily and so she also asked me to pass onto friends and relatives who come and visit her to keep the visits short.

Saturday, October 19th, 2013

Yesterday Ruth had a pastoral visit from Ayyā Medhanandi and Sister Ahimsa, two Buddhist nuns from Sati Saraniya Hermitage. They did some meditation and chanting



and that helped Ruth a lot. Today she seemed much calmer and enjoying life more again.

I went to the hospital today and brought Ruth more supplies that she had asked for, took her outside twice for cigarettes, read to her and we had a nice time together. As usual she has been making friends with her room mate, as well as winning hearts on the nursing staff.

Ruth has had a number of visitors and has appreciated them all. Matt and Katia have indicated that they will come in from Montreal this weekend for a visit.

Tuesday, October 22nd, 2013



Ruth was feeling a bit stronger today and more her old self, even a bit feisty, which was great to see after seeming to get weaker through last week.

We got good news today, they have a bed at the Hospice May Court for her and she will be transferred there tomorrow morning. I will be going in early to help get her moved and ride in the transfer ambulance with her. The hospice should provide her with a nice setting and a good level of care. I appreciate that she will be getting the best care, but it feels so final to move into a hospice.

Wednesday, October 23rd, 2013

Today we did the transfer from the Ottawa General to the May Court Hospice. Other than the tearful goodbyes at the General it all went smoothly with Ontario Patient Transfer providing the ambulance for the ride there.

I went into the General very early this morning to pack up all her things and ride along in the transfer ambulance. Ruth was wearing the new puffin socks her niece, Christina, sent her from Newfoundland.

Once at May Court we were greeted by the care coordinator and Ruth was wheeled to Room 7.

The facility at May Court is quite large, but only has nine beds, the rest of it being taken up mostly with day programming spaces. The building is very nice, with lots of common room spaces, including a sun room near Ruth's room. The grounds are lovely and overlook the Rideau River.



We met many of the May Court staff and volunteers, and everyone is just as wonderful and helpful as you might expect in such a facility. Mostly it is quiet, calm and unfrenzied. It is

literally a good place to rest and spend the rest of your life. Needless to say Ruth is impressed and really likes it there.

Perhaps best of all they have actual secure wifi internet that is faster than what we have here at home, with 17 MB/s download and 1 MB/s upload! That means that Ruth is back on the internet with her System 76 Ubuntu laptop, which I brought to her this afternoon. She is really very pleased that she can stay in touch with friends and watch cat videos on You Tube once again.

I put Ruth in a wheelchair and we had a chance to go out in the gardens and enjoy the fresh air, she had a cigarette and even met a local cat to pet there.

I'll probably be there every day bringing Ruth clean clothes and such, since there are no hospital gowns at May Court, plus food and other supplies that she needs, while collecting up her laundry and such.

Saturday, October 26th, 2013



Ruth has been settling in well at May Court and really loves the place, the staff and volunteers and the setting.

For what it is, May Court is pretty much ideal.

Ruth has had lots of visitors and this weekend. Matt and Katia came from Montreal to visit her as well.

Ruth is weak and tires out easily, but is still largely her feisty old self, retaining her sense of calmness and her sense of humour as well. She is not eating much at all these days, but the hospice staff don't monitor food intake very closely as patients are not there to get better.

I take Ruth outdoors to the garden each day in a wheelchair and also take her around the building to admire the paintings and décor. Her visiting physician, Dr Splinter, sees her every day or two and says that she is doing very well there. As everywhere she goes, the staff and volunteers adore Ruth, as she is such an easy patient to care for. I brought the staff and volunteers some homemade chocolate chip cookies that I baked today, too.

I have been there every day so far and sometimes twice a day, as it is only 6.6 km from home, allowing an easy 55 minute walk or 20 minute mountain bike ride there, when the weather permits.

I have now brought Ruth a good supply of clothing, food, books and other things and, with her laptop there, she is very comfortable and well cared for. Basically it doesn't get any better than this.

Wednesday, October 30th, 2013

Ruth has now been at May Court for a week and she is very much settled in there. She has never been the sort of person who has problems with places and, besides that May Court is hard not to like. The staff and volunteers are nice and provide the right amount of care, mostly they don't do too much and leave you in

peace most of the time. Food is always available and they omit annoyances, like IVs and such. The location is lovely and best of all, quiet.



I have been there everyday, as have many of our friends and relatives, too. Ruth tires out easily, even just conversing, but otherwise she is doing well enough, still buoyant and positive and still enjoying life. I get her out to the garden for “a smoke” at least twice a day, in a wheelchair, although how long that will continue, with

winter on the way, who knows. Ruth is aware that the combination of getting more sick and winter may curtail her smoking habit.

The staff and volunteers naturally love Ruth as she is continuing to be happy, friendly and non-demanding.

Ruth is not eating much at all these days, probably about 300-500

calories per day. The usual reasons apply: “not hungry”, “don't feel up to it,” etc. We have talked about the subject and she has asked me to not to bug her about it. She knows that not eating properly will shorten her life, but it is her choice.

Oddly we have not met any of the other eight patients there, as they all seem to be confined to their rooms for one reason or another.

I did meet a funeral home crew yesterday coming in the front door to do a “pick-up”, so I surmise someone completed their stay there. The whole pick-up was done very quietly and Ruth wouldn't have even noticed if there hadn't been a few lit candles in the hallway. I was pleased with how low-key it all was, compared to the hullabaloo and rituals we saw at the Bruyere Hospital.

I am glad Ruth is at May Court. Having her properly cared for there, instead of struggling with things here at home has been a real change. She is doing better and so am I. I am really glad that she decided not to stay and die at home.

I have started the job of picking out a funeral home to handle the pick-up and cremation when the time comes. The natural inclination is to put this off as an unpleasant task, but I am aware that the end may come very suddenly and unexpectedly and preparations need to be made for that possibility. This is not fun, but then very little of this whole series of events has been.

Wednesday, October 30th, 2013

Today Ruth was very tired and seemed to have pulled a muscle in her abdomen as well, which didn't help her feel any better at all.

Ruth slept much of the afternoon away, while I watched her sleep. She almost canceled having Ayyā Medhanandi and Ayyā Nimmalā of Sati Saraniya Hermitage come to see her, but they came anyway and had a nice chat with Ruth and did three chants. Ruth had been studying the first chant and learned many of the Pali words to it.



The pastoral visit actually perked Ruth up quite a bit and was really worthwhile for her. Hopefully Ayyā can come again to see Ruth next

Wednesday as well, as she is teaching a class at the hospice again on that day.

I assured the sisters of our ongoing support for Sati Saraniya and that I would ask our friends and relatives to make a donation to the hermitage in lieu of flowers or other gifts at the appropriate time.

I actually made videos of the three chants done today and they are now on You Tube for everyone to hear.

Friday, November 1st, 2013

Ruth and I have settled into a bit of a routine for my daily visits,

consisting of me briefing her on what I have seen out in the big wide world, her telling me what is going on in the smaller world of the hospice, cuddling, watching videos, her sleeping while I watch her, playing Scrabble and me reading to her. Ruth really enjoys the latter a lot and I have been reading her stories since 1999, when she had her first major MS episode and couldn't see properly for several weeks. I found a book that she hasn't yet read, *Who Has Seen The Wind* by WO Mitchell, a Canadian classic first published in 1947 and set in the Great Depression. We started reading that yesterday and she is greatly enjoying it so far.

We have also been having some wonderful in-depth talks, too. One subject we have returned to several times is the subject of “kindness”. Kindness is a key aspect of the Buddhist way of living, but in all the time I have known her Ruth has always completely embodied kindness. It is her fundamental way of dealing with the world. I had always thought that it was just an inherent part of her, but she recently told me that, no, it was a decision she made at age six. Faced with a lot of meanness everywhere during childhood, she decided early on not to join that strategy of facing meanness with greater meanness and instead met it with kindness. So her kindness was really an act of rebellion! She admitted that some people don't react well to kindness, especially when they are being mean and can see themselves being mean, but it is a highly defensible way of responding, meaning no fault can be found with it. No one can “call you out” or blame you for being kind.

My questions to her about kindness came about when I noted her writing a letter, taking someone to task for their recent behaviour, that was not phrased very kindly. I thought that odd for her and after she read it to me she just deleted it, unsent. As she explained being kind is not inherent to her, as I had thought it was, but is a conscious decision that she still makes each day. It builds the sort

of world that she wants to live in, even if other people around her don't take it up. In many ways I think that makes her kindness so much greater than if it was just an inherent part of her, because then she would have no choice but to be kind, whereas because she has to work at it, it becomes an achievement each day. This approach does work, as most people react to Ruth's kindness with kindness in return and that makes the world a better place. It has a disarming effect, because it is so rare in a world of mean-spirited egotism. This is the greatest lesson that Ruth leaves behind. She inspires me.

Saturday, November 2nd, 2013

This is now the 19th month of cancer for us. Grueling would be an understatement.

Today we were both tired out. Ruth is getting weaker almost daily, now hardly able to get out of bed and into her wheelchair placed next to the bed, for a roll out to smoke a cigarette outside. She injured her back lifting her laptop computer. She thought it was a pulled muscle, but Dr Splinter indicated that her back is likely to be weak overall from the bone cancer progressing, putting a strain on the muscles and everything else there. She is getting quite physically fragile now. She asked me not to cuddle her anymore, just due to the pain from her injury. I can still hold her hand and rub her head, though.

Her mood is still good and she has not lost her sense of humour at all. One of the Ottawa Buddhist Society members is volunteering at the hospice and we all had a nice talk for a few minutes. Even short talks now wear Ruth out.

Today we had a little pizza party which our friend Gwen joined us for. We ordered a pizza for delivery to May Court and that worked

out pretty well. At least Ruth ate some of it.

We had an interesting discussion the other day. Many people describe their experiences with cancer as “a battle with cancer”. This sort of language is often used in obituaries too, as in “he died after a long and heroic battle with cancer”. Having been through it Ruth disagrees. She says it is more like “enduring cancer” and notes that it is not a battle, you don't struggle or fight it, you just lie there and it slowly kills you. I tend to agree with her, as she knows. She thinks that some family members just want to make it sounds dramatic, or more of an even contest, than it really is.

Ruth has described her experiences with cancer as being more of a Kafkaesque absurdity, than like an Old Testament style battle of good versus evil. In Kafka's *The Metamorphosis*, the main character underwent changes he didn't necessarily understand and couldn't really see why his family and friends were treating him so differently. Cancer, for Ruth, has been more like that, she says.

Monday, November 4th, 2013



Today I spent much of the afternoon at the Funeral Co-operative of Ottawa. This is a new, not-for-profit organization that just came into

being eight weeks ago. I like their philosophy of providing good services at reasonable prices with respect for people's wishes and no up-selling. I met the Funeral Director, Stephane Montpetit, there today and checked out their office. I was impressed enough to sign us both up as members. We will use their services when Ruth dies.

Arranging this has given me some peace, as it was the last thing I had to put together. Now, when Ruth does go, I have a phone number to call and things will happen, hopefully.

I spent the later part of the afternoon and early evening with Ruth at the hospice as usual. After a good couple of days over the weekend, especially on Sunday when her brother, Witold, and sister-in-law, Vicki, visited, today she was very tired and in some pain from her back as well. They have upped her methadone now to about 40-50 mg per day, including top-ups, from her start point of 15 mg. This is expected as the cancer progresses and it seems to be doing so.

In helping her to the bathroom this evening it was also pretty obvious that she has lost more weight, perhaps another ten pounds or so. My guess is that she is maybe 90 lbs now; she is very thin and frail. This is also not a surprise as she is very obstinate about only eating two tiny meals each day of maybe 300 calories in total. That is her choice, but she is fading away fast, losing her mobility quickly and is in pain with any movement of her back. She still hasn't lost her sense of humour or her wit, though. I am hoping she keeps that through to the end.

Given her lack of eating and the quick progression of her condition I think that time is getting short now, perhaps a few weeks left, but it is very hard to tell.

I am there with her everyday, bringing her clean clothes, coffee and other supplies and things, but I am always concerned that I am not doing enough. She wanted to talk to me about that today and assured me that I was doing more than enough for her. She later wrote an email and said "...please know that I love you like mad and you are the absolute best, kindest most loving, thoughtful and beautiful man I have ever ever known in my entire life. You are precious to me, Adam. You do so much to help me and all without being asked." Reading that from Ruth helps me keep on doing all I can for her.

Thursday, November 7th, 2013

I went into the hospice early today. Ruth had cancelled all her visitors yesterday, including a visit from the Buddhist nun sisters, so I knew she was tired out. She slept most of the time I was there today, but did wake up long enough to eat a bacon sandwich and have some coffee.

She mentioned to Dr Splinter during his visit that she was not sleeping well at night. He asked what was keeping her awake, wondering if it was the Pepsi she drinks, but she said it was worrying about things like NASA funding for space exploration. So she still has her sense of humour.

I stayed with her into the afternoon and read her some stories from the news and she slept some more. I thought I would be able to stay on longer, but I quite quickly I tired out just sitting there with her. So I headed home and slept for over an hour at home. I have been there every day and want to continue being there each day, but it is hard to keep it up over a long period of time.

Ruth has been away from home now over three weeks. When I have time I am slowly cleaning the house up, just reorganizing

cupboards and stuff like that. I am careful to not throw out any of her belongings, even though I know she isn't coming back here. Living alone is not much fun, but under these circumstances it is even more difficult.

It is evident that time is slipping away on Ruth. She still insists she is fine and even feeling better, but I can see she is getting weaker and thinner each day, even though she is still thoughtful, funny and considerate.



Matt and Katia are back in town this weekend, so the house will buzz with some activity and not be quite as quiet.

Sunday November 10th, 2013

It was six years ago today that my mother died of cancer.

Matt, Katia and I had a good, if short, visit with Ruth yesterday. She was tired and her back hurt a lot if she moved at all, but we did get her outside for a smoke and back into bed. She was having a tough day with lots of bowel problems and, due to the staff being tied up with other patients, I had to step in and help her in the bathroom.

In the evening I came back to the hospice to see Ruth again and read to her from *Who has seen the Wind*. She is really enjoying the book.

Today the plan was for Matt, Katia and I to go to Ruth's brother and sister in law's house in Kanata for brunch and then bring Ruth some of her favourite German pancakes for a short family visit. However this morning she sent me a message "I'm going to cancel today's visit. I overdid it yesterday and I am just too extremely weak and sick to see anyone. I'm sorry but that's the way it is today. The nurse said I ought to just take today to catch up on the sleep I lost".

I was unable to get a hold of Ruth on chat later in the day so after brunch I went to the hospice with Matt and Katia. Ruth was almost totally unconscious and not doing well. She was able to say goodbye to Matt and Katia before they left for home. Then I spent the rest of the afternoon sitting with Ruth, watching her sleep, reading to her and holding her hand. Eventually she did wake up a bit and I fed her some of Witold's pancakes. Finally she settled into watching some videos and, exhausted, I headed home.

Overall she seems to be doing quite poorly and if she doesn't recover in the next day or so then I think that we are not far from the end of this. I don't want to lose her, don't want her to go, but she is suffering with bowel and bladder problems and almost unable to interact with anyone right now. Even with all her humour and kindness mostly intact, this really is an awful way to die.

Monday, November 11th, 2013

This weekend the Sati Saraniya Hermitage hosted a meditation

retreat on death and dying entitled “Dying to be Free”. The retreat was dedicated to Ruth.

Ayyā Medhanandi wrote to me this morning and said, *“Ruth has been with us all through the retreat, breath by breath, moment by moment in the Dhamma.*

“Today as the retreat comes to a close, we will make dedications again and the shrine is lit up with the light of our silence and inner work. Throughout this process, we have constantly held you both in our hearts and continue to do so - with most tender compassion and loving-kindness.

“Wishing you both together, abiding in noble blessed peace, from all of us at Sati Saraniya Hermitage”

It is really lovely that people care so much about Ruth. It shows how she has touched and inspired so many people, although when I point this sort of thing out she just says, “I haven't done anything special.”

Ruth was doing better today than yesterday and seems to have recovered somewhat. She is still tired and weak, but at least she was conscious and had regained some of her normal level of feistiness.

Tuesday, November 12th, 2013

Ruth's energy didn't last long and today she just slept all afternoon after a short visit with Gwen when she had been awake. I spent some time talking with Gwen in the sun room, but Ruth never really woke up again and in the end I just watched her sleep there until I had to go.

Every evening I come home to our empty house, silent except for the clock ticking, the unheard echoes of Ruth's laughter slowly fading away here. The whole thing is indescribably awful.

Wednesday, November 13th, 2013

Ruth seems to be fading fast these days. Again today she dozed and slept much of the afternoon, often hallucinating. At one point, while I was reading to her, she made some odd hand gestures. When I asked her what she was doing she said she was taking some vitamins. Then she identified it as a hallucination.

At one point today she awoke from her daze and asked me to get her some French fries. The kitchen at May Court doesn't have such a thing, so I trekked up to Billings Bridge Plaza and got her some from there. She actually ate about half the order of fries, with some salt, which is more than she has eaten in days.

Lately Ruth seems to have one good day followed by one virtually unconscious day recovering. I did suggest to her that the visitors are wearing her out and she agreed. I suggested that she really can't deal with visitors two days in a row anymore and also that perhaps after this week, based on how she seems to be trending, it was probably going to be necessary to just cut off the visits entirely. She thought that made sense and will look at the schedule when she wakes up a bit.

I left her this evening with a visit from her brother, Witold, but I will be back tomorrow afternoon again. I still haven't missed a day there yet and that seems to be helping her morale.

There were two more empty beds at May Court when I got there this afternoon. By my count that is now nine in the past 12 days or so. Considering that there are only nine beds, that is a 100%

turn-over rate. Ruth is the second longest-lasting patient there right now, as she has been there 22 days. That fact has an ominous ring to it. Very few people are there at May Court for very long.

Thursday, November 14th, 2013

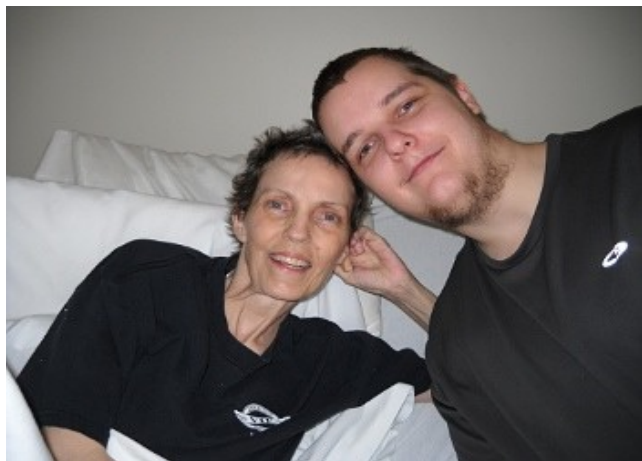
Ruth has been vomiting today and has had diarrhea and the nursing staff is not sure why. It could be related to the cancer or viral in nature. As expected she is weak and tired. She had a short visit from our friend Louis today, but indicated at lunchtime that that she wasn't up for anything else.

She later recovered and actually had a fairly lucid day, her first one in five days and was able to have a good visit with her brother, Witold. Her condition has become unpredictable now, with many days in a row of near unconsciousness followed by the odd day when she is doing well.

I have her sons both coming here this weekend and I am not sure if she will be able to see anyone at all or not.

Sunday, November 17th, 2013

Yesterday marked a month since Ruth went to the General via ambulance and then was transferred to the Hospice at



May Court. It is also a month since she was last at home.

Dr Splinter has indicated that the vomiting and diarrhea is most likely due to the progression of the cancer in the bowel and digestive tract and ordered a clear liquid diet with Restoralax, which seems to have helped relieve some of the symptoms.

Dr Splinter also indicated today that the tumour Ruth has in the bowel has eroded its way through the wall, creating a fistula. This is not a good development. They are discussing options, such as three-times daily enemas, to reduce the symptoms. The doctor also indicated that Ruth won't be able to get out to go and smoke her cigarettes at some point soon, just due to weakness.

After four days of semi-consciousness, Ruth suddenly became completely lucid, feisty and back to almost her old self again on Thursday afternoon. She has remained in that state through today so far, which is good news. She had a good visit with her son Nick and me for four hours yesterday and only tired out mid-afternoon and even then she was not dramatically tired. She will have another visit with Nick today and Matt and Katia as well who are in town again from Montreal.

The strain of being there everyday with Ruth for the past month, plus the number of visitors staying here at the house has now completely exhausted me. I now have almost complete insomnia, and am going to have to miss going to the hospice today, my first missed day. Ruth is doing well enough right now and says she is fine with me taking some days off. I also can't have any more house guests for the foreseeable future. This is by far the most stressful thing I have ever endured and after 19 months I can't keep going like this.

Ayyā Medhanandi wrote today:

“Dear Adam,

“Ruth is amazing - next to her noble qualities of kindness, wisdom and compassion are also great strong and resilience as she continues to prevail in this human realm.



“I am so touched by your message and the beautiful photo of you both - such palpable and profound love and devotion - so rare in this world, so blessed.

“If I had wings . . . I would be at Ruth's side many times these last day just to sit in silence with her - having said that, I am teaching today at the Hermitage, time is slipping by, and even with a lift offered to Ottawa tomorrow, it seems an imposition - Ruth needs to draw herself inward rather than outward at this time... and we all want to support that.

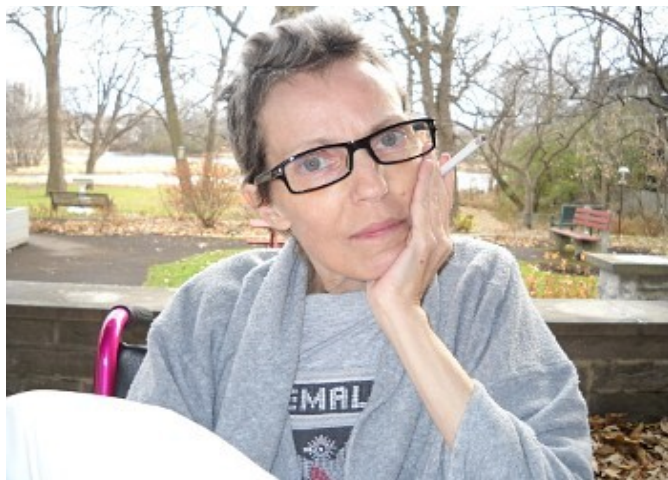
“I'm leaving for Toronto on Thursday and back next Sunday night. I will be dedicating the retreat to Ruth. Yesterday we chanted special chants for her and I gave a talk about letting go and Ruth's heroic practice... it was a truly auspicious gathering

and a few people asked about her - most of those present are also members of the Ottawa Buddhist Society.

“From afar - though very near in spirit - as you watch her resting, our hearts are there, with you both, wishing the light of loving-compassion to shine around you and uplift you moment by moment, ”

Ayya Medhanandi

Tuesday, November 19th, 2013



Ruth was quite weak and tired yesterday, very worn out from the weekend visits. I took her outdoors to the garden for a smoke and then put her back to bed and I

read to her a bit, but after that she slept most of the afternoon.

She has been having almost continuous bowel problems, due to the bowel tumours, requiring double diapers now and frequent changes. The clear liquids-only diet and Restoralax do seem to have helped a bit, but only a small bit.

Today she is even more tired out and has cancelled her two

visitors for today. She has blocked off the rest of the week as “no visitors”. She initially asked me not to come in either, but I told her that I will just watch her sleep. I don't want her to be there alone.

In the end I did take her outside for a smoke, read to her some more from *Who Has Seen the Wind* and sat with her all afternoon and she slept a couple of hours. I also walked back up to Billings Bridge Plaza to get her some vitamin drinks and some Scotch mints, which she asked for. She did drink some chicken broth today as well, but that was all.

Between the lack of food intake, the constant diarrhea and the ever-increasing fatigue I don't know how long she will last. I have to think that we are down to a matter of a week or two at this point, but you can never tell, as she has rebounded before.

Saturday, November 23rd, 2013

Today marked one whole month for Ruth at May Court, three times longer than the average stay there. Over the past week Ruth's condition has somewhat stabilized, neither getting any better, nor worse.

She cannot stand or walk, having lost most of



her muscle mass now. Her bowel problems have continued, but the regimen of daily enemas seem to have reduced the requirement for diaper changes from about two dozen per day to about five or six. The main benefit of that is that it is much easier on her skin, although it saves a lot of supplies and nursing labour as well, of course.

Ruth's energy levels have rebounded a bit after the long visits last weekend which really tired her out. This week there have been very few visits, as she has basically cut off seeing most people and, as a result, she is less tired. It certainly has been a trade-off between the benefits of seeing friends and family and the resulting fatigue. It is pretty obvious that at some point she will have to end all visits, though, just to concentrate on her illness and meditation.

Today it snowed about 1 cm, but I was still able to get Ruth out for a smoke once, bundling her up in her toque, scarf and jacket to sit in the wheelchair. With colder temperatures and higher windchills on the way for the next few days I am not sure how long she will be able to keep going outdoors. Right now she is down to one cigarette per day, just due to the cold and the logistics of getting her outside, so she has almost quit anyway!

Monday, November 25th, 2013

Ruth's condition continues to be stable this week, in fact she is doing quite well, despite the weakness and fatigue.

I did get Ruth out for a smoke today as it was a bit warmer and less windy, but she didn't go out at all yesterday due to the weather.

Today during our visit we decided to take a day off tomorrow. We

are both tired right out and need a day's break to rest. I have ensured she has a supply of her Powerade sports drinks and vitamin water that she has taken a liking too and so she will be okay for a day there on her own.

Given that Ruth's stay at May Court seems to be going on longer than either one of us first thought it might, we have mutually decided to program in one day off visiting each week, just in an attempt to deal with the intense fatigue that we are both suffering from. Right now all it takes is one bad night's sleep and I am over the edge into complete exhaustion. I have just never done anything this hard, for this long before.

Thursday, November 28th, 2013

Yesterday was a low-ebb day for Ruth as she slept all morning and most of the afternoon as well, following a poor night's sleep. I spent the afternoon watching her sleeping as it got dark there in her room.

Today she was more awake, although she did doze a bit in the afternoon. Uncharacteristically Ruth was a bit grumpy and occasionally incoherent, although it could have been medication-related, as that is out of character for her.

I did finish reading *Who Has Seen The Wind* to her, a curious book, almost devoid of a plot, but with great descriptive writing. She has decided that she she would like me to read another WO Mitchell classic to her next, *Jake and the Kid*.

Saturday, November 30th, 2013

Today we had a birthday party planned for Ruth's youngest son, Nick, who is staying in Montreal with Matt and Katia. We

intended to have cake and pizza, but we had to change plans as so often happens. In this case Katia came down with a cold and so we had to call it off. It was just as well as Ruth had overbooked herself with visitors today anyway and by the time the party time had arrived she was fast asleep and slept all afternoon.

I received this email from Ayyā Medhanandi this morning:

Dearest Ruth and Adam,

We never stop praying for you, thinking of you each day and chanting for you. We did your favourite chant today. I returned from teaching in Toronto and dedicated the entire retreat to you - also spoke to the retreatants about your incredible love, devotion, courage, practice and beautiful heart.

With all our love, kindness and compassion, the highest peace, the truest blessings,

Ayyā Medhanandi

Sunday, December 1st, 2013

Today marks the beginning of the 20th month of cancer. Ruth has now been at May Court for 40 days, plus the seven days in the General Hospital before that.

I had a good chat earlier in the week with Dr Splinter about Ruth's condition and he indicated that she is stable and that the cancer is in low-ebb right now, essentially it is sleeping. He indicated it could go on like this for as little as a few days, or for much longer and that the course is very unpredictable. Also unpredictable is what will happen once the cancer gets going again, it could be a slow decline or very, very rapid. He said that he has seen both

cases.

Ruth was a bit stronger today, able to almost stand for a second or two by herself, unsupported, while getting into her wheelchair. I took her outside for two cigarettes during my time there, the second driven by a genuine “nic-fit” that surprised even her. She was highly motivated to get out and smoke.



Given all those realities about her present condition, that this could possibly go on for a lot longer now, Ruth and I discussed how to proceed.

It is obvious that she has to stay at May Court as she can't really stand much and can't walk at all, needs 10-12 diaper changes a day, urine bag drainings, bed baths, enemas and so on, complete 24/7 nursing care. On Friday she had an explosive diarrhea event that soaked her to the neck. So, as much as I would like to have her home, even for a few days, that just isn't possible. She remains in a sort of cancer purgatory, in between truly living, being able to go out and do things and dying. We just have to wait it out and leave everything else on hold for the foreseeable future, for however long this goes on.

Both of us had been proceeding on the basis that her stay at May Court was going to be short, 30 days or less. Obviously at this point it is going to be much longer than that, perhaps even months more, yet. We agreed that the current visiting schedule needs to be reduced, as it is exhausting both of us. For now we have decided to go with shorter visits for me, of 3-4 hours a day, earlier in the day over lunchtimes and five days a week, rather than 5-6 hours, later on each day and seven days a week. This will allow Ruth more afternoon rest as well.

Monday, December 2nd, 2013

The new visiting schedule seem to be working well so far as it is leaving both of us less tired out. Today I was there from 1000-1400.

Ruth was awake enough that I cooked her some eggs, made her coffee, took her out for two cigarettes, read her a story by WO Mitchell and we even had a really good talk. When I departed mid-afternoon she was settling in to watch some videos and then take an afternoon nap.

We talked about the changes in our relationship due to the cancer, how close we have remained and also about the Buddhist concept of loving while not being attached. A couple of years ago we discussed this and I have to admit that I did not understand then how to love without attachment. Earlier in this year the idea of losing Ruth to cancer caused me a lot of pain, but as time has gone by the idea has become more familiar and more accepted. I mean what choice do we both have? We have had to accept reality. In many ways the cancer has brought us even closer together, but in getting ready to be apart it has also taught us the value of loving without the pain that attachment brings. As Ruth pointed out today, it is very freeing.

After that talk Ruth wrote today, “you both tell and show me your undying love every day. I have always been deeply, completely and passionately in love with you - but it lacks a certain terrifying uncertainty. That, my life's love, is the purest form of love and I am singularly honoured to be able to experience that with you.”

Wednesday, December 4th, 2013

After a couple of bad night's sleep Ruth was very tired out today and at low ebb once again. I was with her through the middle of the day, on our new visiting schedule of 1000-1400 hrs, five days a week and she could barely stay awake. She wasn't grumpy, just barely engaged with the day.

It was a busy time today, with two diaper changes, one enema, I made her scorched scrambled eggs (her favourite), one trip outdoors for a smoke, I read her a WO Mitchell story, we did some meditation and then refinished her toe nails, too. That was enough for one day.



Ruth's toenails hadn't been redone since she went into hospital six

weeks ago. There was virtually no damage to them, a function of being unable to stand up, but they had grown out enough that they needed redoing. So I did a bit of sanding, painting and clear coating and they look very nice now. Many of the nurses had remarked how nice they looked and were surprised to find out that I had done them for her. It is actually easy and fun to do for her, something we have always done for intimacy. The colour is called *Pat on the Black*, but, despite the name, it is a very dark shade of purple.

Thursday, December 5th, 2013



Again today Ruth was very tired. She was sleeping when I arrived at 1000 hrs and slept on for 45 more minutes before she awoke. By 1330 she was tired out

again and had to sleep all afternoon. Despite her cancer being dormant right now she does seem to be getting more tired each day.

She has also been slowly asking for more methadone in the form of additional “top-ups”. It is hard to tell if this means her pain is increasing or if this is just narcotic tolerance. Either way it is to be

expected. She still has a long way to go before she reaches a maximum dosage, as she is only taking about 55 mg per day right now.

In between her sleeps she did get two diaper changes and an enema, plus I read her a story and took her outdoors for a smoke. The weather has warmed up and so it was well above zero outside today. I also cooked her some well-scorched scrambled eggs for lunchtime.

Sunday, December 8th, 2013

Today Ruth seemed a bit more chipper through the middle of the day when I was there with her. She hadn't slept in the morning, but did snooze a bit in the afternoon. Her sleep patterns are disturbed and some days she gets only 5 or 6 hours of sleep and then other days she sleeps for up to 15 hours in total throughout the day.

As in most days we talked, cuddled a bit, she had an enema, which as usual I helped out with, warming the water and holding the bag for the nurse. After that I made her some scorched scrambled



eggs, read her a story and took her out for a smoke.

We also worked on our Christmas cards, with me addressing the envelopes and Ruth signing her name on them. It was really all she was up to. It won't be long until Christmas arrives; tomorrow is the turning on of the Christmas tree lights at the hospice by the mayor.

In the afternoons Ruth prefers to watch videos and snooze more than anything else. She always asks me to get going on my way home by 1300 or 1400 at the latest, so she can do that, instead of expending effort on conversation. Even just listening to conversation so wears her out that she indicated today that she probably won't take any more visitors except direct family members.

Dr Coulombe visited today and checked Ruth's pulse at 93 again, which is actually not bad. The doctor indicated that Ruth is doing okay and reiterated that the course of this is extremely variable.

Monday, December 9th, 2013

I managed to injure myself pretty effectively today. While returning a box of cereal to a low shelf in the kitchen here at home, I turned while standing up and cracked my head on the refrigerator, knocking myself flat out on the floor. I got an ice pack on it quickly which limited the external swelling, but I spent a good part of the rest of the day at the hospice dizzy, nauseated and very tired, so I think I gave myself a fairly effective concussion.

I'll take a day or so to rest up and recover, but I think this points out the problems with long-term fatigue: it causes errors and those can result in injuries.

Wednesday, December 11th, 2013

Today makes exactly eight weeks since Ruth went by ambulance to the Ottawa General and eight weeks since she has been home. Ruth was diagnosed with cancer on Friday, April 13th, 2012, 607 days ago.

Trying to find a good time to visit Ruth while she is awake can be challenging. She has fallen asleep on a couple of visitors lately and can't tolerate more than about ten minutes with anyone but me. She can only be counted on to be awake between about 1000-1300 and 1700-1900 daily. The rest of the time she is likely to be asleep.

I am taking a day off visiting today, trying to rest up and recover as best I can from the exhaustion I have been dealing with all year long. I do know that once the cancer flares up again that things could end quickly and I will want to be there more with her.

Thursday, December 12th, 2013

Even though the doctors say Ruth's situation is "stable" I am seeing a change over the past two weeks as she is more fatigued and less able to stay awake and engaged. I am not sure if this is due to the methadone or the cancer, or both. Her dosage has not been increased and she is still taking 50-55 mg per day right now. She doesn't even seem to require more methadone even for "tolerance", though she has been taking it for 14 weeks now. Whatever the cause, she is finding that when visitors come she is only able to spend about 5-15 minutes with them.

In response to our annual Christmas newsletter, which I sent out this week, Ayyā Medhanandi wrote:

Dear Adam,

We are deeply inspired by Ruth - and by your love and devotion for each other. I had the privilege of being with Ruth last week for a few precious moments, in silence, meditating with her, and for the fleeting seconds that she looked up and reached out to grasp palms with mine, in her limpid lovely clear eyes I saw the universe shining back at me with great compassion. I received such a gift in that moment.

You are both in our hearts every day, every mealtime, and dedicating our practice to you with the unconditional love that spins its light through all beings.

In gratitude for these boundless treasures shared,

Ayyā Medhanandi

Ruth was very deeply touched by a visit from her niece, Elli Merkis this evening.

Elli had decided to raise money to donate to the Hospice at May Court. She



sought sponsorships and ran raffles at her workplace, The Atomic Rooster Bistro, here in Ottawa. She had her hair cut off and donated it to charity and in all raised over \$800 for the hospice. Ruth was moved to tears by this act of kindness.

Ruth always seems amazed at how many people love and admire her and want to do kind things for her. It just shows how far Ruth's kindness itself has reached.

Saturday, December 14th, 2013

Dr Coulombe saw Ruth today and said that her nephrosomy had failed at the outer tube. The doctor removed it and this now allows the kidney to drain into the diaper instead. Ruth actually likes this better, as the nephro tubing and stopcock was restricting her movement over the last few months and now she can actually lie on her left side once again. The wound seems to be healing up as well.

Dr Coulombe indicated that Ruth's left kidney may go “dormant” and all function may shift to the right kidney instead.

Dr Splinter also saw Ruth this morning and she told him that she was having problems with daily morning nausea. He suggested it was because she was moving around too much in bed first thing in the morning, during her morning bath and cleaning routines. She tends to help the PSWs out by sitting herself up and rolling herself from one side to the other when the sheets are changed. She hates not being helpful. Dr Splinter wants her to remain more still and rest, to reduce the nausea.

Matt and Katia came from Montreal to visit Ruth during the mid-morning today, but she was only able to spend 15 minutes with them, as she was very tired and feeling ill. I have been warning

people who come to see her that the visits will be very short now.

Sunday, December 15th, 2013

Ayyā Medhanandi wrote again to us about our recent e-mail update on Ruth's condition:

Good morning dear Ruth and Adam,

Ruth dear sister on the Path... I respond to you both as this is for you - quoting Adam: Your unassailable kindness... non blaming-intentions making peace with all sufferings...it doesn't get better than that.

You tower above multitudes. Pure in heart, worthy of our first thoughts (let alone second!), highest regard, trust and devotion - qualities you both already manifest together. We are lucky to know you and be in touch. Thank you, truly.

I came across this verse of Indian poet, Rabindranath Tagore:

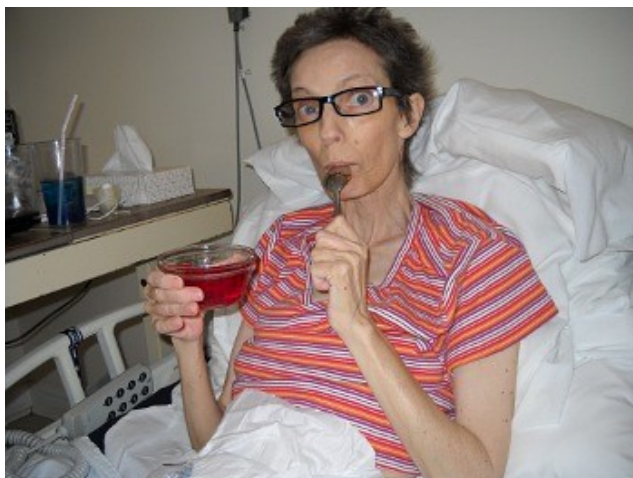
*"I slept and dreamt that life was joy.
I awoke and saw that life was service.
I acted and behold, service was joy."*

*Peace, compassion, breath
by breath
Ayyā Medhanandi*

Today I once again helped the nurse give Ruth her enema and got a good look at how she is doing. Aside from developing a small bed sore, which they have bandaged, I think she has lost weight this past week and is now probably down to something like 80 pounds. She has lost most of her muscle mass. She is also now

sleeping about 16 hours some days and fell asleep all afternoon. I stayed a couple more hours and watched her sleep, before heading home.

Ruth only ate half of a small bowl of cherry Jello today and had about half a bottle of a Powerade sports drink for a total of about 100 calories.



Ruth's spirits remain good, but she is down to the point where she has lost so much weight that she will be into organ failure soon. It is not possible to keep losing weight without repercussions sooner or later. Even Ruth herself, while not wanting to talk about the future at all, told me that I have to be ready to let her go soon. I know that and I am now ready to do that when the time comes. In the meantime I will spend what time with her that I can.

Monday, December 16th, 2013

Ruth had quite a lot of uncontrolled and very liquid diarrhea today. This is mysterious, as she has had no solid food and no bowel movements in weeks. The nurses think it may have been viral as she was running a slight fever as well. I think it is also possible that both the diarrhea and fever are related to the cancer in the bowel and tissue necrosis, but who knows. It wasn't fun for

her, regardless.

Tuesday, December 17th, 2013

I had some errands around town today on one of my “days off” seeing Ruth, but I was coming home on the bus via Billings Bridge, so I stopped in to see how she was doing. She was surprised to see me and not doing very well. She was very tired and weak and not really up for any conversation or interaction at all. I helped rearrange her pillows, got her a hot beanie bag and then left her to sleep. At least her diarrhea has stopped and that is allowing her some comfort.

Wednesday, December 18th, 2013

Today marks nine weeks since Ruth went by ambulance to the Ottawa General and eight weeks at May Court. Ruth was diagnosed with cancer 614 days ago.

Ruth was feeling a bit better today than earlier in the week, but still very tired and not up to much talking or anything. I cooked her one scrambled egg, of which she ate about half, drained her catheter bag for her twice and read her another WO Mitchell story. We have almost finished *Jake and The Kid* and Ruth has requested Mitchell's follow-up book next, *According to Jake and the Kid*.

Ruth didn't last long today, was out cold by lunchtime and slept a good amount of the afternoon. I stayed for another hour or two and watched her sleep before heading home.

I did talk to one of Ruth's regular nurses privately and she agreed that it looked like Ruth has lost five or ten pounds in the last week or so. Dr Splinter still says Ruth is doing fine every day he sees

her.

One thing Ruth has mentioned few times recently is just how amazingly dull this whole cancer experience has been. Other than learning a bit about new treatment equipment and techniques, she has found it far too slow a process and completely uninteresting. My mother died of cancer in 2007 and she found it a similarly uninteresting experience. My mother summed it up in saying, "I think I'll just go on a cruise and come back when this is all over."

Of note, for many months after her daughter Rachael departed in a hurry in mid-May Ruth had not heard from her at all. Then about early November they had some email exchanges that Ruth described as "polite, but distant". Ruth was quite open to talking with her but still very disappointed about her behaviour earlier this year and was hoping for an apology and some reconciliation. Rachael had indicated last weekend that she wanted to see her mother and Ruth agreed, but noted that she is not able to tolerate visits of more than about 15 minutes these days. This evening Ruth received an email from Rachael that she seems to indicate that she may have decided to not come and see her at all, although it isn't really clear. (Note: Rachael never communicated with her mother again after that.)

Thursday, December 19th, 2013

This morning, at about 0800 hours Ruth awoke screaming from a nightmare that became a daytime panic attack. She had quite a bit of back pain and was sweating and shaky for an hour or so. I arrived not long afterwards and she was still shaky and a bit irritable the rest of the day.

I had a chance to talk with Dr Coulombe today in the nursing office about the morning's events. She indicated that the

nightmare/panic attack was not a cause for concern and that they just gave her a methadone top-up for the pain and will monitor her. Given that this is palliative care, that makes sense to me. There really isn't anything else that can be done.

Dr Coulombe did mention that most palliative care patients don't seem to exhibit "tolerance" effects that require their dosages of methadone to be increased over time. This was something I was not aware of; I thought all narcotics resulted in tolerance over time.

Dr Coulombe also agreed that it looks like Ruth has lost weight in the past week and agreed with me that it looks like she is down to about 80 lbs or so. That means she has lost about 1/3 of her body weight so far. She indicated that the cancer was only growing slowly because Ruth is eating so little that the cancer is getting very little nutrition to feed it. She has very little fat or muscle left on her body now. Of course that also means that Ruth is losing weight as a result, too. I suggested that another two weeks of this are probably all Ruth would survive and the doctor agreed that was not an unreasonable estimate, but pointed out that these things are very hard to predict. I am finding that out!

I did get a chance to take Ruth out



for a smoke, her first one in a week, due to a break in the very cold weather we have had. I also gave her a foot rub, drained her catheter bag and read her another WO Mitchell story.

It is getting very hard to even touch Ruth, beyond holding her hands or rubbing her feet. It seems that her lack of body fat now means that every touch hurts her, especially on her legs. This makes it very hard to rub skin cream on her legs and arms. It has to be done amazingly gently to not hurt her.

Friday, December 20th, 2013

Ruth was at very low ebb today and slept most of the day. She only awoke for a few minutes at a time and even then was often incoherent and hallucinating, probably due to the methadone.

I did make her two scrambled eggs, just the way she likes them, but she ate only about a quarter of what I made. I collected up her dirty shirts and took them home to wash on my Saturday laundry day and drained her catheter bag as well. I also did manage to read her a WO Mitchell story as well, from *According to Jake and the Kid*.

After I got home I did get a couple of e-mail messages from her indicating that she had been awake a bit more in the early evening.

Sunday, December 22nd, 2013

I guess this was inevitable. Despite my best efforts, staying off the buses, using a lot of hand sanitizer, staying away from almost everyone I can, I came down with some kind of virus yesterday. It isn't bad, just a head cold it seems so far, with a sore throat, sinus congestion and general malaise, but it will keep me from visiting

Ruth at the hospice until I am better. The last thing they need there is a contagious infection in a palliative care facility. I feel very rundown and tired anyway and need the rest. One friend who just had this cold reported that it lasted two weeks.

I had run out of milk and a few other things by this morning and face a risk of getting sicker over the next few days, so, with Wal-Mart open 24 hours this week before Christmas, I decided to go out at 0630, to avoid as many other people as possible and get some groceries. The sidewalks had not been cleared and in places the snow and ice pellets from yesterday's storm were over two feet deep. It wasn't long before my boots were full of snow. I should have worn my gaiters. There were actually quite a few other customers at the store, even at that very early hour, plus the barely-awake store clerks.

On the way home the leaden, overcast sky was slowly starting to lighten a bit and suddenly the air was filled with thousands of crows, calling loudly, filling the air from horizon to horizon, flying to the northeast. It was an ominous sight.

Wednesday, December 25th, 2013

Christmas Day and I am very sick.

It is -22C with a windchill of -33 outside. The temperature is 10 degrees below the normal low for today. The forecast daytime high is nine degrees colder than normal.

This is already the worst Christmas of my life, the worst of Ruth's life as well, or at least certainly the last one, and we can't even be together.

I coughed myself awake at 0400, having hardly slept for the

second night in a row. I am still horribly sick with this cold, stuck here at home, alone for the fifth day in a row, unable to sleep, unable to go out, unable to even take care of myself anymore, unable to take care of Ruth, exhausted, out of resources.

We always took care of each other, when one of us was sick the other one made soup, read stories, brought the laptop to bed to watch cartoons, held the other one until we were better. Now we are both sick and apart. Ruth is being well-cared for by the staff and volunteers at the hospice and I am here alone.

Our friends and relatives have been good throughout Ruth's illness, but at this time of year they have their own families, they are off on vacation, skiing or gone south.

I keep getting praised by friends, relatives, nurses, for my "courage", but this is not courage; it is nothing like courage. It is merely endurance and, sick as I am here, I have run out of endurance today. I have just had enough.

Today is day five of this stupid head cold. It is 63 days since Ruth arrived at May Court, 70 days since she left home forever, 621 days since her cancer diagnosis and 5,241 days since she was diagnosed with MS. At one time I despaired that she would never get better, now I despair that this will never end. It has become an endless nightmare without sleep.

I don't know what to do about Christmas this year. Most years we would opt out of it, go skiing, make dinner, light candles, cuddle up and just be together. This Christmas we are apart for the first time ever. Now, here, at five o'clock in the morning I have been awake for an hour. I am too sick to sleep, but at least Ruth is hopefully fast asleep.

There is nothing that can be done, if there were I would have already done it. I just have to get over this stupid cold. My only fear is that Ruth will die before I get better and can see her again.

Friday, December 27th, 2013

The bad cold I have had since last Saturday has now finally abated after a full week and consequently I was able to get back to May Court this morning and see Ruth.

I arrived as they were about to do her morning enema and that gave me a good chance to see how she is doing physically. She looked quite a bit thinner than the last time I saw her. I talked to Dr Splinter today and he agreed that she has lost about ten more pounds since I last saw her a week ago. She must be down to 60-70 pounds now. Her voice is mostly gone too, although he isn't sure why that is and neither is Ruth, it could be just the dry air. She can't talk much above a whisper.

Ruth hurt her back again, she thinks she did it sitting up in bed and nodding off, stressing her spine. She is very fragile now and any little thing can hurt her. I encouraged her to make sure she is always leaning her head back against pillows and not falling asleep sitting upright. These days her bed has ten pillows on it.

I made Ruth a scrambled egg for lunch and she ate most of it. She also had a small amount of Jello, about three teaspoon's worth.

After lunch I got her into her wheelchair and out for a quick smoke outdoors.

Back inside afterwards I helped her back into bed, we talked a bit, I rubbed skin cream on her feet and legs and read her another story from WO Mitchell's *According to Jake and the Kid*, which

she really enjoyed, although she dozed as I read to her. By the end of lunchtime she was tired right out and asked me to get going and leave her to sleep.

Ruth also asked me to let all her friends and family members know that she is now unable to see any more visitors at all, including her kids. I specifically asked her about that and she insisted.

She is also unable to write much in the way of email, too, and she isn't up to on-line chats or phone calls. In the past I was infoing her on all my correspondence with friends and family, just to keep her up to date, but she asked me not to do that any more, as she hasn't the strength to read it.

Because it looks like time



is getting quite short I will be back at the hospice with Ruth every day. Tired as she is, I don't want her to be alone there.

Sunday December 29th, 2013

I sent out another email update about how Ruth is doing on Friday and heard many thoughtful responses back from our friends and relatives.

Ayyā Medhanandi wrote:

We are remembering you both again and again, day by precious day. Seeing the photos and hearing how you tenderly devote yourself to Ruth touches our hearts.

We will begin our Winter Retreat on January 2, and dedicate our practice to you both every day.

Our heartfelt blessings and tender compassion. And please take good care of yourself.

Ayyā Medhanandi

Today Ruth was feeling fairly awake and lucid, and so we had a rather long heart-to-heart talk. We both agreed that time is running short and it was really good to hear her ideas about how I should proceed after she is gone. She made me promise not to end up alone for too long and to make sure that when I find a future partner that “they are good for me”. I promised her I would do that.

Ruth has been having a lot of leg pain recently on her left side. I have been getting her hot blankets and wrapping her leg in them, which seems to help. She says it is her old nemesis, MS spasticity,

back again. That figures, after most of 2013 without much in the way of MS symptoms due to the chemo, that it would show up again in her last few days left, just to bid her farewell. Of note, even though Ruth's MS was diagnosed in August 1999, just three months after we were married, later MRI imaging showed that she had had at least one episode much earlier than that. That older scarring coincided with an anomalous episode that she had in the fall of 1994, long before I met her, and that the doctors now figure was that earliest MS event. That means that if Ruth makes it to New Years that she will be into her 20th year of MS and the subsequent cancer. That is a very long time to live with all of this.

We both realize that time is getting short and that the end may come slowly or it may come quickly and without much additional warning. Given that Ruth was so lucid today we said goodbye to each other today, just in case we don't get to do it closer to the actual time. This doesn't get a whole lot easier over time.

Monday, December 30th, 2013

The winter deep freeze returned to Ottawa today and we have cold temperatures and high windchills. The walk to the hospice this morning was fine, though, as I



was dressed for it, with my parka, long underwear, ski mask and goggles on. I arrived quite nice and warm.

For the second day in a row Ruth was quite awake and energetic today and even her voice has mostly returned. I mentioned Ruth's new level of energy to her nurse, Shannon, and she agreed that it was a notable change over last week. The nurse indicated in her experience this could be a “new normal” plateau period in the cancer or it could be a “short burst of energy” that is sometimes seen right before the end. She suggested that we will know which it is in a few days' time. Her feeling was that Ruth didn't seem too close to the end right now, but admitted that it is very hard to tell.

One thing I did note was that Ruth has now developed an external tissue protrusion at the internal fistula she has. I asked the nurse about that and she indicated she thought it was the tumour forcing parts out of the body. It doesn't seem to be causing Ruth much discomfort, but it obviously isn't a good sign.

Along with the extra energy, Ruth was even a bit hungry this morning and I made her some beef broth, although she didn't

drink much of it in the end.



I helped out giving Ruth her enema, as I have done many times before and was also enlisted to give Ruth

her bed-bath too. I had never done that before, but picked it up quickly. The trick is to get her wet, washed and then dried without getting the bed wet!

Ruth was energetic enough though the middle of the day that we played a game of Scrabble and she did quite well, too. We also talked for quite a while and I took advantage of how well she was doing today to shoot a series of webcam photos of the two of us with her laptop. I am never sure which photos of us together will be the last ones. Ruth later decided that she didn't like how she looked in the photos, as she is very gaunt and thin.

Ruth also insisted on combing my hair today. A year and a half ago, on May 13th, 2012, she last cut it and after that she had said she wanted me to grow it out to at least shoulder length, which is where it is now. She told me today that she wants me to grow it down to the bottom of my shoulder blades, which is about another 12 inches or so! That should take until about the winter of 2015-16! I agreed to do that for her and that pleased her.

Wednesday, January 1st, 2014

New Year's Day. The end of the old year and the beginning of the new, time to take stock of the big picture. In the middle of something like cancer it is too easy to get bogged down in the day-to-day details and forget how far we have come in all this time.

It has now been:

- 20 years since Ruth's first MS episode
- 15 years since Ruth was diagnosed with MS
- 26 months since Ruth's first cancer symptoms appeared
- 21 months since Ruth's cancer was diagnosed

- 11 weeks since Ruth left home for the General Hospital
- 10 weeks since Ruth arrived at the Hospice at May Court

Ruth's current actual condition is not really known, all we can do is guess. How much time she has left is also not really known, either. Reading back through this diary, certainly all my guesses have been wrong so far. Even Ruth herself thought she would be gone by Christmas, but she wasn't right about that, either. I guess she is even tougher than she thought, although she has constantly refused to talk about how she thinks she is doing since arriving at May Court and doesn't want to hear anything about her condition. That is kind of out of character for her, as she used to ask lots of questions about her cancer and researched everything in depth, but now she seems to not want to know about it or discuss the subject.

There are not many good things that can be said about such a amazingly long, slow, lingering illness like this, but one advantage is that I think I am actually ready now. I really hit bottom psychologically on Christmas Day, sick as I was that day. Since then I have been able to recover, get some good rest and find some real calmness in all of this. I have had so long to prepare, think the situation through, discuss it with Ruth, cry with Ruth, organize the cremation, write obituaries and make lists of things that will need doing afterwards, that I don't think there is a lot left unplanned, unthought or unfelt now. There are also not many excuses for feeling psychologically shocked when the end comes, either. That would just reflect a lack of adequately dealing with reality during all this lead-up time on my part.

In the early days of dealing with this cancer, especially early in 2013, when we both found out that it would be terminal, I had a real period of serious grief over having to lose Ruth. There were quite a lot of tears then. We both worked through that together

and since then the only real challenge for me has been the fatigue and exhaustion from taking care of Ruth through the many months of treatment. Ruth has made it clear that she doesn't want me losing a lot of time grieving for her after she is gone, if I don't have to. Perhaps the grief will return later on, or perhaps I have already worked through that from all our talks together, sort of "pre-grieving". I guess I will see how I do in the long run.

Today Ruth had lost her recent higher level of energy and was feeling very tired, nauseated and quite shaky while I was there. She also had some leg spasticity and pain, and wasn't up to much conversation, but she was happy to let me rub her feet and read to her. Overall her trends have fluctuated so much that it is hard to draw any conclusions as to how she is doing. Tomorrow could be another low-ebb day or she could be perky again, we won't know until tomorrow.

Thursday January 2nd, 2014

Ruth sent me an email just before midnight last night: "I am going to take today off from everything. Can I please ask you to stay home? I need a day to recover and get a lot of rest." She later added "I just feel very tired and so need today to snooze."

Ottawa is in the middle of a serious weather cold snap with daytime high temperatures running 16 degrees below normal for the date. This morning it was -27C with a windchill of -40, so a good day for me to stay in anyway.

Friday, January 3rd, 2014

Another day of high north winds and low temperatures today, with the morning -36C windchill in my face as I walked the 6.2 km up to May Court. As usual I was properly dressed, including

my ski goggles and face mask and so I was warm and comfortable, even if some other people were seriously under-dressed out there on Bank Street. It is actually quite pleasant walking in these extreme conditions when you are properly equipped for the weather.

On the way to the hospice I stopped at Shoppers Drug Mart and picked Ruth up some more of the pulp-free orange juice that she likes so much, as she had finished the last 2 litre carton of it. It is pulp-free at the request of her physician, to keep any fibre out of her bowel.

When I got to the hospice Ruth was sitting up and quite awake. I read her two WO Mitchell stories, got her some orange juice and even some chicken broth for lunch, helped her nurse, Shannon, give her her daily enema and then I conned Ruth into some photos.

Ruth has been reluctant to have any more photos taken as she thinks she looks bad. She is very thin at about 60 lbs now, but I



convinced her that as long as she doesn't try to smile that she looks fine. Toothy smiles always come out like grimaces these days, just because she has so

little fat left in her face.

I explained that I need some photos taken of her in 2014 for the website and she agreed to let me shoot some webcam photos of the two of us, with her System76 Ubuntu laptop, if I combed her hair first and promised to take no more photos after today, so I agreed. So these will be the last photos of her alive that I will have.

We took 19 photos in “burst mode”, before she tired of that. They turned out well enough so that even Ruth couldn't object and she let me post six of them on our website's 2014 page.

During Ruth's enema I had a look at the external protrusion from the internal fistula that I had first noted five days ago, on Monday. It has since then more than doubled in size to about 2 cm long, by about 1 cm in diameter. Ruth reported that it is now sensitive to touch, but otherwise isn't concerning her too much. As has been the case lately, Ruth refuses to talk about it and doesn't want to see what it looks like. I talked to both her PSW and her RN about it privately and they think that, while it looked like just a tissue protrusion due to the fistula five days ago, now it looks like a tumour protrusion and is an indication that the cancer is running away. I trust their judgment on this, as they see a lot of this sort of thing in their line of work. Shannon indicated she would get Dr Splinter to have a look at it when he is next in, although we all agreed that there was not going to be any action taken about it. It does have the potential to start bleeding, though, which could be critical if that occurs.

Saturday, January 4th, 2014

Today the cold snap in Ottawa broke and while it was -26C overnight, it reached -3C in the afternoon. That much temperature

difference makes it challenging to dress to be outdoors in.

I calculated that I have now walked well over 800 km to and from the hospice in the 73 days Ruth has been there. This certainly has been an exercise program for me.

I went to the hospice this morning and found Ruth not doing very well. She was very weak and unable to even turn herself from her side to her back and in some distress about it. She was also in a fair amount of discomfort and it took several of us to very carefully reposition her and the dozen pillows she is lying on these days to achieve any sort of comfort for her. At a couple of points she was almost panicky and a bit incoherent, when she couldn't get comfortable. This was certainly the worst I have seen her so far.

She spent most the the rest of the day dozing, too tired to even talk, although I read her a lengthy story and fed her ice chips from a teaspoon.

The nurses had Dr Coulombe authorize increasing the frequency of Ruth's methadone top-ups from four hours to two hours, which I thought was a very good idea.

Dr Splinter had also checked her tumour protrusion and noted it on the file, but that was all. I didn't expect he would recommend any action taken, but I am happy that he checked it out.

I left Ruth late in the afternoon comfortably watching some videos. I didn't want to leave her there any earlier, until she was no longer having problems.

Sunday, January 5th, 2013

Ruth seems to have rebounded somewhat and was doing quite a bit better today. She is so weak and uncoordinated that she dumped a cup of orange juice, so now she is down to using “sippy cups”.

And so it goes, with bad days and good days and no real clear trend about how she is doing. It has now been ten days since Ruth has eaten anything at all, and that was only part of one egg. Most days now all she has for food is about one cup of pulp-free orange juice, which is about 110 calories. It is apparent that she is perceptibly losing weight pretty much on a daily basis, meaning each day she looks thinner and thinner, but on a diet of almost zero calories that is not surprising. She also can't continue long like this, or at least I wouldn't think so.

On the plus side it is also ten days since she last had a cigarette, so I guess she has de facto quit smoking again, or at least lost interest in it. That was also the last time she was out of bed. She is so fragile now that any movement off her bed of pillows causes her pain, so I think the wheelchair is beyond her capabilities now.

Monday, January 6th, 2014

Today the weather was bad, we had freezing rain all night, followed by rain, high winds and then a cold front bringing a flash freeze, so everything was flooded and then iced over. I had to run an errand for Ruth and get her some mouth wash before seeing her, but the sidewalks were essentially impassable, I got my boots soaked right through in deep water and decided I had better take a bus to the hospice. Needless to say the buses were all running late as well.

Once at the hospice I set my boots to dry out and took off my socks and put them over the radiator in Ruth's room to dry out as

well. Next time we get flooded I'll dig out my Gortex socks and wear those.

At the hospice I noticed that Ruth is now looking noticeably thinner every day I see her. She had me running the whole time I was there today, getting her ice, fetching nurses and PSWs, getting her drinks, returning dishes to the kitchen, etc, and then finally reading her two stories from WO Mitchell. That is all okay, but she was acting really irritated and admitted that me just being there was irritating her and she didn't really know why. She said I was being too cheerful and upbeat. I put it down to "illness stress" on her part, but it makes taking care of her that much harder. Ruth later apologized via email for being so irritable today.

On the way home I picked up some groceries and then, with our driveway all icy from the freezing rain, had a bad fall, gashing my hand and bruising my hip, shoulder and wrist. I got some sand down on the driveway and got the bruises on ice, but I don't need these injuries right now.

Tuesday, January 7th, 2014

Ruth has been trying to get me to come and see her less often and for a shorter time each day. She says that it isn't any lack of desire to have me around, just that having anyone there with her wears her out, even if we are not talking or anything and she fears it is boring watching her fall asleep often.

I know there are these romantic movie images of spouses sitting dotingly at bedside with the endlessly sick person, but reality is very different, especially when the sick person lingers on far longer than anyone, even they, thought they would and doesn't want anyone around.

We negotiated about this and Ruth has agreed that as long as I don't mind watching her sleep that I can stay with her. I really prefer that. Right now I am there about five hours a day, five days a week.

Wednesday January 8th, 2014

Today was a non-noted anniversary. It was one year ago that Ruth's cancer was termed "terminal" and she was given 1-4 years to live. She has now crossed the one year mark.

Ruth was exceptionally weak, tired and could hardly speak today. She seems to have visibly lost more weight as well, just in the last two days. It is really disconcerting how thin she is. I spent a good deal of our visit today just rubbing her feet while she dozed. I also read her another story at her request.

Ruth's tumour protrusion has increased and is now about 3 cm in length, so the cancer is still going strong.

Of concern, her catheter bag was empty and had remained that way for almost 24 hours. The nursing staff had done two flushes but had received no return flow. They called Dr Coulombe who came in and assessed Ruth. In her estimation there wasn't much urine in her bladder, so she asked the nurse to remove the catheter and see if that helped. She was testing out whether the catheter was getting repeatedly blocked or whether something else was going on, like incipient kidney failure.

The three of us discussed the options and Ruth indicated that if it is kidney failure she would need dialysis. I am not sure why Ruth would think that, except to suggest that she wasn't thinking very clearly. Dr Coulombe had to explain that dialysis isn't an option in

her condition. Ruth then asked what would happen and Dr Coulombe explained that kidney failure leads to death in two to four days. She also added that the body will give up consciousness early on in the process and that makes it a good modality and far better than other ones, like congestive heart failure, which requires intervention.

Dr Coulombe also increased Ruth's baseline methadone dosage to 50 mg, with 25 mg in the morning and the same at night, as she was asking for enough top-ups through the day that it was indicated. This should work better, due to methadone's slow action and long half life. It also probably indicates that, under the methadone, Ruth's pain baseline is increasing, although the methadone is still controlling it well.

Ruth had the catheter removed and then we waited a couple of hours. She did eventually did produce some urine, which the PSW estimated at about 100 ml, but that was all for 24 hours and with lots of fluids consumed, too. We will have to wait a day or two to see if this was just a catheter issue or if her one remaining functional kidney is failing.

Friday, January 10th, 2014

Dr Coulombe saw Ruth today and I noted that her tumour protrusion had disappeared completely. I asked her if this is significant in any way and the doctor said “no”. Dr Coulombe suggested it probably just fell off and indicated that cancerous tumours are structurally disorganized and often have poor blood supplies, so this is not uncommon.

Ruth now seems to be producing a normal amount of urine for her intake and has no mental confusion, so Dr Coulombe concluded that there is no indication of kidney failure at this time.

As I often do, I helped the nursing staff give Ruth her enema and bed bath. I helped pick her up and shift her in the bed afterwards, too. I lifted her and was amazed how little she weighs, perhaps 55 pounds or less.

As has been the case recently she was weak and tired today, dozed a bit, but is otherwise doing generally fine. I remain amazed at how much weight she can lose and still hang in there. She is at about 45% of her normal weight.

Sunday, January 12th, 2014

Even though it hardly seems possible, today Ruth looked notably thinner than on Friday. When she is lying down you can not only see her ribs, but all the sides of her ribs, too. She can only be described now as “skeletal”. I am starting to see Ruth's wisdom in not wanting any more photos after January 3rd. She is now much thinner than she was then, only nine days ago and actually looks pretty bad now; it would truly scare some people. The staff are amazed at her tenacity, as they have indicated that not many people survive being this thin.

Ruth was also very tired today and fell asleep for the afternoon at about 1115 hrs. I did get to read her the first chapter from WO Mitchell's next book, *Roses Are Difficult Here* and then just watched her sleep.

Wednesday, January 15th, 2014

Ruth has now been at May Court 12 weeks, a total of 84 days.

Yesterday Ruth set a new record for how much methadone she needed to control her pain, a total of 65 mg. This isn't critical and

it is still working well for her, but it does indicate that her pain levels underneath the methadone are probably increasing.

Today she was again tired, sleepy and could hardly speak above a whisper. She thinks that the dry air at this time of year is a factor in that latter problem, so I brought her some cough drops. She is continuing to lose weight fairly rapidly.

At her request I cut and filed her finger nails. As usual I read to her and rubbed her feet today, there isn't a lot more I can do. I stayed later than normal today, watching her sleep though the early afternoon and then rubbing her feet some more while she watched some cake-making videos. Even her feet are starting to get quite thin now from weight loss.

I offered to take some items home for her and she agreed that I could take her outdoor clothes and the Scrabble game. She won't be going outdoors anymore and cannot stay awake enough to play Scrabble. I did mention that I can bring anything she wants back from home, if she feels better. For my part I just want to reduce the weight of things I will have to carry home when this is all done.

Thursday, January 16th, 2014

We made it to another milestone today, as this marks exactly three months since Ruth took that ambulance ride to the General and has not been home again since. It is funny as it feels much longer than three months to me. Some days it feels like forever.

I was at the hospice for over nine hours today as Ruth slept most of the middle part of the day and then, when she awoke at about 1630, asked me to stay on for a while and keep her company. She cannot really speak anymore, just a whisper now and she is quite

hard to understand.

There was some actual news as well. Dr Splinter showed up late in the afternoon and checked Ruth over. He noted her resting heart rate was only 83, which is lower than in the recent past, although he didn't think it was particularly clinically significant. He and I talked in private and he indicated that in his estimation we are very close to the end now, probably just a few days or less. He also indicated that in similar cases the end has come very quickly, with the patient going from being lucid and awake to dead in under half an hour. I told him I thought that would be a good thing, not to drag things out any longer.

Saturday, January 18th, 2013

After two days of near unconsciousness, Ruth bounced back today and was awake all afternoon watching cake-baking videos on You Tube. Dr Splinter came in to see her and noted that she was doing much better and remarked to me privately, "that's a good thing, right?"

Anticipating the end, in the last three days I have been at the hospice 26 hours and was getting close to exhaustion once again. This whole ordeal continues endlessly, and so I have to go back to carefully pacing myself. By my calculation I have now walked 930 km to and from the hospice in the 87 days Ruth has been there, so at least I am getting lots of exercise out of this.

I have noted some personality changes in Ruth over the last few months and especially in the last few weeks. She now almost totally focuses on herself and often forgets to be considerate of the other people helping her, making everyone run poorly-thought out errands for her and almost never saying thank you. She had the staff order her clear Boost juice and bugged them a lot about

it, almost obsessively, over the ten days it took to locate it, order it and get it sent across the country to the hospice. Then she refused to drink it because she didn't like it. She decided that she didn't like the water at the hospice either and asked me to haul several litres of water from home instead, but most of it is still sitting in the hospice kitchen fridge untouched and she has gone back to drinking Gatorade instead. I guess this effect is just being sick for so long that makes her oddly demanding and unappreciative like this, because it is quite out of character for her.

I did note to Dr Splinter that she refuses to talk about her illness, how she thinks she is doing, the time left, or anything to do with planning of any kind and has been this way for several months. This is also very out of character for her, as in the past we always were able to talk about anything and made jokes about subjects like this. In recent months if I bring it up with her she just says, "I don't want to talk about it". Her sense of humour has almost gone entirely and most days she just seems a bit grim and very notably detached. Dr Splinter indicated that this is very common and probably a simple defence mechanism. It seems that the illness has changed her normal behaviour in ways I wasn't completely expecting.

I haven't been coming in on Saturdays for a while, at Ruth's request and usually take that day to get the laundry done and the house cleaned up. Because we seem to be getting closer to the end I told her I would bake cookies for the staff and volunteers (this was my 11th batch for them so far) and bring them in later in the afternoon and come and see her. At about 1430 hrs, when the cookies were just out of the oven, the phone rang at home and I thought "oh-oh". It was Rochelle, one of the nurses at the hospice, but it wasn't the call I had been expecting, she just wanted let me know that Ruth wanted me to come in. I did explain that I was just packing up the cookies I had baked and was on my way down

there anyway.

When I got there, as I noted, Ruth was awake, but just wanted to watch cake baking videos. She mentioned that she really didn't feel like talking, but sent me to fetch her ice chips, Gatorade, hot blankets, hot beany-bags, more ice chips, more Gatorade, had me rub her feet and legs, apply skin cream to them and so on, while she watched her videos.

I did get out yesterday for lunch with my friend Rob, who came down, picked me up at the hospice and we went to Patty's Pub, just around the corner on Bank Street. He seemed kind of surprised when I mentioned that the last time I was out with anyone was when he and I went out for supper two months ago, on 23 November 2013. I did have two offers of dinner on Christmas eve, but I was too sick to go out then. It has even been a month now since anyone has come to our house, as well. Everyone gets busy over Christmas.

Just about everything happening now all seems to be because this has just gone on so long. Back a year ago, when we learned that Ruth's cancer was terminal, we found out that she had 1-4 years left. We were hoping then that she would have more time, not less, but it turns out that "more time" has meant a very slow, lingering death and, as I am learning, that is the worst possible scenario, for everyone concerned, the patient, the relatives, friends, everyone. No one gains by this.

Monday, January 20th, 2014

Today was another landmark: Ruth has been at May Court 90 days, nine times the average stay.

Ruth has continued to improve since Thursday and doesn't really

even seem to be losing weight anymore, although she can still only talk in a whisper. She is taking in some calories in the form of Gatorade and Jello and at her reduced body weight, plus lack of activity, that might even be enough to sustain her weight. Otherwise her condition seems to have stabilized and she could remain like this for quite a while.

For my part I have seen an increase in my stress symptoms lately, especially insomnia, which makes doing this all that much harder.

Ruth has previously described this whole period as being like a Franz Kafka novel and I have to agree. At this point the twists, turns and lack of any resolution are very much like the plot of *The Trial*.

Ruth was quite awake, relatively energetic and lucid today and so we did manage to have a good talk, despite her loss of voice. We just sat close together, so I could hear her. One thing I wanted to ask her about was, now that we know how they turned out, which cancer treatments she would have still done. She indicated that the 2012 treatments were worth trying, even though they weren't successful, because her cancer was supposed to be curable then. She also indicated that her 2013 treatments were a waste of time, as they failed to meet the palliative treatment goals and robbed her of the last year of her life because the treatment incapacitated her for almost the whole year. Hindsight is great for this sort of analysis and other cancer patients may have completely different results, of course. You never know which treatments were worthwhile until it is over.

Otherwise, I did the usual things with her today, rubbed her feet and legs, fed her Jello, Powerade and ice chips, got her hot beany bags and hot blankets and also read her a couple of chapters of WO Mitchell's *Roses are Difficult Here*. I don't think we are

going to get through the whole book, though.

Wednesday, January 22nd, 2014

The weather continues quite cold and windy, with -23C this morning and a windchill of -36. The wind was, naturally, out of the north. I actually walked downtown into the wind to a dental appointment, then back to May Court to see Ruth and then finally home in the evening, for a total of about 22 km. I was properly dressed for the weather, unlike most people I saw, and was warm and comfortable the whole way.

Yesterday Ruth's four-day long rebound seemed to come to an end. Today she was at a very low point, in fact I have not seen her this bad before today. She was quite uncomfortable in bed and we had to reposition her on her pillows several times. She was also barely conscious most of the day. Twice she asked me to read to her and then quickly fell asleep. Her voice was also pretty much gone and she was unable to even whisper audibly for most of the day. She has a pad of paper to write notes for people on, but her writing is quite bad now and she doesn't even have the energy to write much anyway.

I am starting to understand the wisdom that Ruth exhibited in cutting off visitors at Christmastime and even cut off any more photos by January 3rd. She doesn't look much at all like she used to look now, even like her January 3rd photos and is actually quite scary to see. I guess I am used to it from seeing her almost daily, but someone who hadn't seen her in a few weeks might have nightmares from seeing her now.

I had a rather lengthy counselling session with the new hospice family support social worker, Joni, in the later afternoon today and that was very helpful. One area we covered was the

“anticipatory grief” process that I have been going through since last January, when Ruth's cancer was pronounced “terminal”. In reading about this effect in the psychological literature and also drawing on Joni's experience, all I can say is that in cases like this, where there is lots of notice that someone will die, that going through the grieving process tasks before the death is very common. I didn't even realize I was going through it until about Christmastime when I started to feel like the grieving had come to an end. I thought it was all just stress, but after a year of pure grief, the absence of it was quite noticeable. In re-reading my counsellor training textbook it looks like I have completed all the grieving tasks, at least for now.

How this will impact the post-death time period seems to vary widely, with the research indicating that some people having no further grief at all, some the same amount as if they had not gone through this and some even more grief. The research evidence indicates that on average it reduces the post-death grief severity and period length. Averages like that don't really tell you anything about any one individual's response, it just tells you what the range of results is, so I guess I will see how things work out for me personally in that regard when I get there. These days I really feel like I have used up all the sadness there is.

The text also spells out that there is also a tendency, if the “anticipatory grieving” process is completed in advance of the death, due to the illness going on so long, that family members will emotionally withdraw from the patient. I sensed that could be an issue early on and have been careful not to do that to Ruth, which is why I have tried to be there so much with her.

The book does note that terminal patients also go through an “anticipatory grieving” process as well, as they are losing all their loved ones and that they will often emotionally withdraw near the

end, as part of this. This actually goes a long way to explain why Ruth doesn't want to talk about anything involving her illness, how she is doing and hasn't wanted to for a few months now. It probably also explains why she often says that she would rather have me not come in at all or just have me run errands for her, rather than sit and hold her hand and talk with her. I hope to have the opportunity to talk with Ruth about this.

Joni reminded me that I qualify for hospice counselling after Ruth is gone, if I ask for it. That is a great facet of hospice care, it is quite complete and well-thought out for the relatives, as well as the patients.

Joni was also concerned about my stress symptoms and noted that I was tired and burnt out. That is true, I was diagnosed as burnt out back in April when Ruth was admitted to the General for depression and not much has changed since then, if anything things have escalated. Joni suggested that I start coming to visit Ruth every second day, instead of five days a week, something Ruth later concurred with, when Joni asked her in person. I have to admit that there is a careful balance between caring for your dying spouse adequately and becoming a casualty yourself, especially when the time line is so long and turns out to be even much longer than expected. You don't want to start cutting back just as things get near the end, or as they at least seem to be getting near the end, although you can never be sure. It is a dilemma with no good solution.

Friday, January 24th, 2014

Ruth was very tired out today. Yesterday she did not even turn her laptop on, although today I turned it on for her and set it up for her to watch a few videos.

She can hardly whisper anymore, just a few words at a time. We had a good conversation, though, whispering and she employing head nods when she agreed. It takes a lot of concentration to see her move her head or to hear her speak, though.

I wanted to present to her what I have learned in the last while from the research about “anticipatory grieving” and she was interested to hear about that; she still loves science stuff like this. She agreed that we have both been going through that and indicated that is the reason that she doesn't want to see anyone anymore. She indicated that she has actually worked through the grief of losing everyone in her life, but she finished the process well before Christmas, not realizing the illness would last this long. She has already let everyone go. This is understandable and actually quite common, according to the research. I told her that I had worked through it all too and that, even though our paths through the grief of losing each other have been different, we have arrived at the same place at a similar time. She is ready to go and I am ready to let her go, without any pain.

Ruth and I started our time together in 1996 as friends. Today it has come full circle and I let her know that I was still there with her because we are still friends, still best friends. She understood that and agreed with that. She took my hand and it felt like she could go in peace, whenever she is ready to go.

Saturday, January 25th, 2014

With my latest email updates sent out indicating that we are getting near the end of things, I am very pleased to be able to say that our friends and relatives have really responded well. I am getting quite a number of phone calls and invitations for lunches and dinners and at this point in the events that is very helpful.

I also heard from the sisters at Sati Saraniya Hermitage today:

“Precious Ruth and Adam,

In the seclusion of our retreat, we never waiver from holding you both in our hearts. Ruth so dear and beloved, you are more radiant as the body falls away and our prayers are with you at every beat of your beautiful heart.

*with loving compassion,
your Dhamma sisters”*

Sunday, January 26th, 2014

The internet has been down at the hospice since Saturday, which probably explains why no one had had any email from Ruth. When I was there I did reboot the modem and the router and even traced the wires, but could not isolate the problem. The cable people will sort it out tomorrow, on Monday, apparently.

Ruth didn't miss her internet connection much today though, as she seems to have pretty much lost consciousness. I was there most of the day and she slept much of it, but even when awake she was almost comatose and could not speak or move very much. I confirmed she could hear me, as she was occasionally able to nod her head, although it was almost imperceptible. Most of the day I just watched her sleep or rubbed her feet, or just sat and held her hand. She seems to have some psychomotor agitation and while awake sometimes raises her hands to her face for no apparent reason, as if she has cobwebs across her face.

My predictions have all been wrong before, but this feels very final at this point. On Friday her doctor indicated that he was fairly confident that she would not finish this upcoming week.

She has rallied before, though, so I don't know where we are this time.

Monday, January 27th, 2014

Today was yet another unusually cold day, as much of this winter has been so far. A cold front brought 20 cm of snow and then high winds, causing blowing snow, something Ottawa rarely gets.

I passed a personal mark today. On the way here, walking via Bank Street I completed 1000 km of walking to and from May Court while Ruth has been there, according to my estimate.

I am writing this entry on Ruth's laptop at the hospice, having brought the book in on a USB stick to work on it. The internet at the hospice is back to working as well, although it isn't doing Ruth any good right now.

Ruth hasn't regained consciousness since yesterday morning now and today is completely unresponsive, not even head nods to my conversation with her. The nurses have asked me to keep an eye on her respiration and let them know if it stops.

Because Ruth can no longer wake up enough to take her methadone pills and because methadone is only available as pills or oral liquid she has been switched to fentanyl transdermal patches. I had discussed this about a week ago with the nurses and then Dr Splinter and this was the plan he indicated. I was concerned that when she lost consciousness that she would go through methadone withdrawal. Dr Splinter assures me that with her barely functioning excretory system that the methadone will have an effective half life of about 100 hours and the fentanyl, being faster acting, will just replace it, averting a withdrawal reaction.

All I can do is watch Ruth sleep, rub her feet and see if she is still breathing or not.

Tuesday, January 28th, 2014

Another high windchill day in Ottawa today and I am here again with Ruth at May Court, her 97th day here. Once again today she is completely unresponsive to all stimulus, but I have been talking to her on the basis that perhaps she can hear me. If she can't hear me then I am just talking to myself, but at least it won't hurt to do so. I gave her a rundown on the emails I have received from friends and relatives, plus what the weather is up to. Ruth always loves tracking the weather.

She seems to be comfortable and pain free as far as I can tell, although I took her pulse at 120 and respiration at almost 40, which is definitely higher than yesterday and shows that things are happening.

The PSWs cleaned up Ruth's room and removed a lot of the clutter that had accumulated. Today I will take her laptop computer home as well, along with a few other odds and ends that aren't needed anymore. This will help me when the end does come, as there will be less weight of stuff to haul home then.

There was a candle lit today in the residence, as another patient had died.

Wednesday, January 29th, 2014

Another cold and windy day in Ottawa again.

Ruth was again totally unresponsive today, respiration about 30

and heart rate very hard to read. Jenn, one of the nurses, couldn't even get a clear heart beat with a stethoscope and described what she heard as "thready". She made it about 122 beats per minute, but that was admittedly imprecise.

I stayed with Ruth for a while, held her hand and chatted with her cheerfully about news and weather stuff, which is to say I talked to her and I had to assume that she could hear me. If not then I was just talking to myself. I told her I love her.

By the time I left her breath seemed notably more laboured.

**Thursday,
January
30th, 2014**

I got the
phone call
from
Caroline at
the hospice
just after
0500 this
morning.
She told me
that Ruth
had died

peacefully in her sleep without regaining consciousness, at about 0045 this morning. I thanked her for her call, got up and got ready to head out.



The interesting thing is that I had woken up with a start at about 0045 hrs and couldn't get back to sleep until after 0200. I later heard from two friends who had similar experiences at the same

time. One had a dream about Ruth, that she ascended to the sky and became a night star. Another friend said that Ruth appeared to her and left her with a peaceful warm feeling. I have no explanation for any of those things.

I got up, showered and dressed. I waited until after 0700 hrs to phone Ruth's brother, Witold and her two sons, Matt and Nick and then headed to the hospice. I considered taking the bus, but decided, as a last tribute to Ruth and all the urban hikes we used to do, to walk the 6.6 km to May Court one last time. The sunrise, as I walked north on Bank Street was inspiring. The walk left me at 1041 km completed during the time that she was at May Court.

I got to May Court even before the front desk was open, went down to the residence wing and saw that they had already lit a "circle of caring" candle for Ruth. I talked to Jenn, the day nurse. She gave me a hug and told me how much of an impression Ruth had made on her and on the rest of the staff in the 99 days she was there. They all loved her and found her so positive and happy to work with.

I went in to see her and they had laid her out in bed, with a clean gown on, the bed all made neatly, with a quilt and everything. Her belongings were all packed into two paper bags and so I took them out to the nursing station and sorted them into two cloth shopping bags to take them all home. There wasn't much there, a few T-shirts, her toothbrush and the teddy bears her sister Helen had sent her. I will save the bears in case she ever has any grandchildren.

Dr Splinter had already been there before me and I got a copy of the Medical Certificate of Death from Jenn. The cause is listed as "metastatic cancer".

At 0900 I called the Funeral Cooperative of Ottawa and talked to Danielle. She asked me when Ruth had died and then asked me why I hadn't called during the night, as the funeral director has the phones forwarded to his home overnight. I told her that it wasn't an emergency and there was no need for anyone to any lose sleep. Ruth wouldn't have wanted people woken up over her death, that would have been inconsiderate! May Court had a day hospice program on today and so did not allow pick-ups until 1500 hrs, so we arranged for that time. Danielle asked me to come into their office for 1300 to do all the paperwork with Stephane.

Since there was nothing else that needed doing at that point I took a bus home and put away Ruth's belongings. I sent out the final e-mail that I had drafted so long ago, just before lunchtime, letting everyone know that Ruth was gone.

I called Ruth's brother, Witold, who had taken the day off work and he kindly spent the rest of the day with me taking me to the Funeral Coop offices to complete the paperwork, back to May Court and then finally to his house for dinner and back home again.

The paperwork at the funeral coop took quite a while, but Stephane and Danielle were very kind and helpful to us and things went smoothly there.

At May Court the funeral pick-up service crew did an excellent and very respectful job. In May Court tradition, all the nurses and PCAs on duty walked with us in a procession to the front door, behind the flag-draped body. It was shift-change time, so both shifts came with us. After the body was loaded into the Suburban, we shook hands with the funeral crew and the May Court staff all gave us hugs. Witold and I all thanked them for their care for Ruth. I told them that Ruth had loved being there and that the

May Court organization really couldn't do what they do any better, it truly is a "circle of caring". I had given the staff a "thank you" card that Ruth and I had both signed some time ago as well.

After dinner at Witold and Vicki's house, Witold took me back home. I read through all the e-mail that had come in since my notice earlier in the day and the outpouring of love and affection from all our friends and relatives was truly touching.

Tomorrow will be the first day when everyone will have to face a world without Ruth. She truly changed everyone who met her and for the better too. She made me promise to bring her message of kindness to everyone. She really thought being kind could make a better world. I think she was right. It will be harder to do without her here with us, but we will all have to try.

Lessons Learned

There are a few worthwhile lessons that can be taken away from events such as these. In cases like this, someone you love gets cancer, the treatments don't work and they die a long, lingering death and there is nothing effective that anyone can do.

Here are some of the few things we did learn:

1. The Canadian health care system is excellent. We never had any serious delays in getting Ruth treatment, never lacked for expert advice, first class facilities or care and our only costs were transportation to and from the hospitals, plus a few over-the-counter drugs. Everything else, including the cancer drugs, hospitals and the hospice care was all covered by OHIP and Trillium. Thank you Canada for getting healthcare right.
2. Taking immuno-suppressants and immuno-modulators

over a prolonged period of time, as Ruth did for her MS, is likely to give you fatal cancer.

3. The cancer treatments in existence today aren't very good.
4. Ruth's 2012 and 2013 treatments were all complete failures. The 2013 treatment series goal was to cure the cancer, which it didn't. The 2013 treatment series goal was to force the cancer to grow up into the chest and not in the abdomen, and it failed to do that. The 2013 treatment series was also supposed slow the cancer down and at least give Ruth a few months of normal life to enjoy before she died. It failed in that regard as well, and the 2013 series just robbed her of what time she would have had and made it a whole year of being sick from the treatment before she died.
5. It is hard to judge, even in hindsight, but in Ruth's specific case I think she might have been better off refusing the entire 2013 series of radiation and chemo treatments.
6. Ruth's Buddhist philosophical approach, to decide to be happy, even when dying of cancer, was quite successful. I think she proved her theory, "you may not be able to decide how events unfold, but you can always decide how you react to them and especially how you feel about it." It is certainly better to die happy than miserable, like many cancer patients we met.
7. Perhaps the greatest challenge for the friends and family members during a long and lingering illness is to remain engaged and show care without becoming casualties as well in the process. Cancer is very exhausting for everyone involved.
8. There is a tendency for everyone, including the patient, to complete the "anticipatory grief" process and, if the illness goes on long enough, then to withdraw emotionally. This is normal, but you need to be aware of it. It does help everyone to deal with the death, when it does come.

9. The Hospice at May Court is a wonderful facility with great staff and volunteers. It doesn't get much better than that as a place to spend your last days.