

On Chemotherapy

Brettel Dawson, August 2016 (updated Feb 2017)

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Because I had at least one positive lymph node, I was given the choice to do chemotherapy first and did so. I believe this is becoming standard of care. In this post, I set out how I approached chemotherapy and the various strategies I used to mitigate (or at least minimize) its effects on me.

Information is one thing. But, fear is another as you face chemotherapy. There's no doubt your body will take a hit from chemotherapy. Yet, although I had a range of side effects, the reality of chemotherapy was less frightening than I had anticipated. I had a relatively good quality of life during chemotherapy – better than I'd expected. Having time to prepare and talk with others helped me a great deal. The strategies I adopted - and set out below - came from reading and recommendations from other women who'd been through chemotherapy.

Chemotherapy: My Experience

My chemo regimen was Adriamycin and Cytotoxin (AC) every 21 days followed by Taxol weekly for 12 weeks. I was immensely fortunate that I had no nausea. I assume that this was related to improvements in the anti-nausea drugs and the steroids including in the chemotherapy infusion. My appetite remained intact and I was able to eat more or less normally. I gained weight through being less active and also from the steroids. I did not experience taste changes which can make eating difficult. My taste buds faded slowly but never completely. I lost my hair early in treatment.

My white blood counts dropped significantly raising concern about infection. One of my treatments during the AC regimen was rescheduled as a result. I was relieved that I didn't get any infections or colds during the six months of treatment. My mouth was fine; no sores. My skin was mostly fine. I had minor nosebleeds; Vaseline helped. Fatigue cumulated over the six months until at the end, I had very little 'puff' or stamina.

My ability for intense concentration was shattered. I experienced mild "chemo brain". My sleep was disturbed. I had hot flashes. Still do, thanks to Letrozole.

Near the end of the second regimen of weekly Taxol, I developed neuropathy in my fingers and toes and my body ached. In particular, my thigh (quadricep) muscles screamed when they were

nudged into movement after sitting or climbing stairs. As far as I can tell from reading, this may have been from coming off the steroids as well as being an element of the neuropathy itself.

It took some time (a long time) after chemo finished before I began to get my stamina back. The neuropathy lingered. I had to remain vigilant about my nails which had become bruised. It was a surprise to realize that while I had finished with chemo, chemo wasn't finished with me! However, it felt so good to be improving and to know that chemo was behind me.

Proactively Managing Chemo Side Effects

My first approach was attitudinal. Pragmatic and practical. Proactive and informed. Determined and disciplined. Positive. Resolutely positive. I had chosen to participate in chemotherapy. My specialists saw no reason for me not to be optimistic of a good result from my course of treatments. In the context of my life path, this was a short – if intense – period.

A second commitment was to exercise each day, primarily by walking. Friends who'd had breast cancer recommended this. And, it is a universal recommendation for cancer patients (everyone in fact!) to do between 20-30 minutes of daily exercise. I walked most days – creating a loop that took me down to the Gatineau River – about 4 km. During the final 6 weeks, even shorter variations on this walk became harder as I lost my stamina and developed some muscle aches. Going uphill became harder. I couldn't manage the full 4 km. I didn't force the issue. I chose to trust my body – if I couldn't exercise for a while, then I'd trust that my body would let me know when I could do so again. After chemo finished, I began to exercise again, very mildly.

The third line of action was to prepare for what lay ahead – learning about side effects and gathering resources to address them.

Hair: Before chemotherapy began I addressed the hair issue. Much as I loved my curly, soft gray hair, it was going to fall out with the chemo. Not much point in weeping about it. It would grow back. I chose to get a wig made ahead of time – going for the initial consultation and ordering it while I still had my hair. The wig was for others – to stabilize their comfort level by having me seem 'normal' – even a bit snazzier with the excellent colour match and updated style. This was particularly important in relation to our godchildren. We had told them I had cancer while reassuring them that we were optimistic all would be well. Shielding them a little from the shock of a bald godmother made sense to us. They rolled with the new haircut. The wig was also for me – to avoid being seen as a cancer patient when out and about. I got a 'halo' wig to put under hats during the hot summer. I was comfortable around home without my wig. As my hair came back slowly during Taxol, I became more open about leaving Delores (as I named my

wig) on the shelf when visiting with close friends. It was a sign of doing well and bouncing back from the chemo.

Nausea: As I began AC chemotherapy, I was proactive about taking anti-nausea pills after chemo even if I didn't feel nauseous. I'd been told that keeping ahead of the nausea is key. So, one pill before dinner and another overnight. I also took Pepcid overnight to prevent heartburn during the first AC regimen.

Hydration: I drank a lot of water during the AC. I already had a practice of ensuring I was well hydrated each day but drank even more water than usual.

BM: I took RestoraLax to manage occasional constipation – again being proactive.

Rest: I rested each day – what a blessed feeling of relief to lie down and to nap. During Taxol I needed less napping time but allowing myself to rest continued to be important.

PICC line: I had a PICC line inserted after the nurses had difficulty inserting the needle for the IV in each of my first two treatments. Having them 'miss the vein' was painful and led to bruising. Having a Port or PICCC line is a good idea: the drugs can damage your veins over the course of chemo. If chemo is likely to be extended (or repeated), a Port is a good idea. But it involves minor surgery to insert and remove. It also avoids some of the restrictions that come with a PICC line. This is where attitude becomes relevant. With a PICC line, you cannot shower or swim, given the need to keep the area dry -- but this is a temporary issue. As were the other motion restrictions needed in light of the risk of a blot clot: for me, no golf, no gardening (and no vacuuming). Pleasures lost for a short time. The PICC line needed to be covered and, being on my upper arm, it was visible unless I wore loose long sleeve tops. I got PICC line covers online and this helped me "wear" the PICC line in an attractive and effective manner. (Canada: www.vrrk.ca/carealine-sleeves-expanded). A PICC line has to be flushed and dressed each week but I loved my CLSC nurse and found seeing her each week reassuring. A major advantage of a PICC line to my mind, is that it can be inserted with simple surgery (local anesthetic) and it can be removed after your last chemotherapy treatment: the nurse simply pulls it out. It was less invasive and shorter-term than the alternative available in our area of Quebec a ('mini-port' in your arm). I read in many places about how many women hated their PICC lines and loved their Ports. However, I found my PICC line experience just fine.

White blood count: I had an issue with low white blood count from the chemotherapy. The chemotherapy attacks rapidly dividing cells – cancer cells. Other virtuous fast dividing cells are also hammered, including marrow cells which generate white blood colonies. If white blood

count drops you have an increased vulnerability to infection. And worse, if someone gets an infection, your ability to resist and respond to it is much reduced. Chemotherapy will be delayed or doses lowered if your white blood dips below the threshold (1.5 for AC and 1.0 for Taxol; normal starts at 2.1). **The theme here is to be careful.** Because my white blood dropped (at one point being at 0.9 during AC and 1.2 during Taxol, I had to change my activities to lower my risk of infection. No babies to visit. But more seriously - staying away from people who were sick with colds or the flu, staying away from crowds, and washing my hands frequently. I wore gloves when I attempted to garden.

Diet and white blood count: Although my counts never put me into the highest risk of neutropenia, I became careful with my diet. I avoided foods with a risk of bacteria (e.g., blue cheese; raw meats or fish; buffets or pre-cut items as with take-out sandwiches). I made efforts to support and increase my white blood count: first with injections of Neulasta prescribed by my oncologist during AC and secondly by Pasture Bone Broth (see recipe in this section). My spouse and I made it in batches. I consumed it intensively over the weekend before the next weekly blood test. It is highly nutritious, and in my case, seemed to raise my white blood count. Many thanks to Melanie for this tip.

Mouthcare: I took meticulous care of my mouth to avoid mouth sores. **The theme here is gentle.** I used an ultra-soft toothbrush and replaced it every six weeks. I used a mild toothpaste (Prevident or Biotene). I did not use floss to avoid bleeding. I used a salt and baking soda mouthwash before brushing and a mild dental rinse afterwards (Denta Rinse; Biotene). If I felt some soreness develop, I used Listerine Zero – but not for long as it is generally too strong during chemotherapy. I held in reserve the option of a prescription for ‘magic mouthwash’ – but I did not need it. And, no visits to the dentist – to avoid risk of infection. Wendy help me with this approach.

Skin care: I was conscientious with skin care. I used good hand and foot cream (Gehwol) each day. I used a calendula and comfrey salve (Hocus Pokus, available at Le Forêt Natural Store in Wakefield) along with cuticle cream or oil around my fingernails and toenails to keep them in good shape: no cracking or fissures could take hold. During Taxol, I developed a skin rash/dark blotches which threatened to become sores. I used a calendula cream to prevent the sores developing and to soothe my skin. It worked well. Consistent with the gentle theme, I used a mild soap to wash (Cetaphil).

Nails: I took meticulous care of my nails to strengthen them in advance of the Taxol which is hard on nails. I used OPI Nail Envy Nail Strengthening (clear) Nail Polish for the first 3 months and moved to the formula for Cracked and Peeling Nails (free of formaldehyde) when I began

Taxol. I applied a dark-coloured nail polish to fingernails and toenails at that point too – to block UV exposure. It helped a lot. Nail polish remover – no acetone. My nails did not crack or peel and kept growing throughout. The nurses might suggest using ice gloves during the infusion to protect your fingernails and toenails. If so, do it! I soaked hands and feet in ice water when I got home and doing so was soothing. Even so, by the end of the three months, my fingernails were bruised from the Taxol. This took a while to clear up after I completed chemo. Arnica oil helped. What I did kept the side effects in the range of mild and manageable. However, in combination with the nerve damage (neuropathy), I was quite slowed down. No washing dishes for a while (as long as I could get away with it in fact!). If that's not an option, double layers of rubber gloves are needed to protect your hands and nails.

Neuropathy: The companion issue to nails with the Taxol is neuropathy - nerve damage. The affected areas become numb, tingly and sore. Commonly, fingertips and toes are affected; mine were. In addition, the tip of my tongue. Muscle soreness and weakness in my legs also developed as I completed the last few doses. A friend in similar chemo (docetaxel every 21 days) experienced numbness in her chest. So, don't panic! My strategy of taking L-Glutamine after each chemo treatment didn't seem to help much (likely a naturopath could better plan dosage). Another friend who avoided neuropathy recommended taking magnesium daily during treatment and while effects continue. This helped when I began to take it after the neuropathy had developed. I found the calendular/comfrey salve soothed them overnight, although it didn't roll back the neuropathy. A recent study has shown that brisk walking in combination with gentle, resistance-band training at home can be very effective in reducing neuropathy in hands and feet. See: <http://meetinglibrary.asco.org/content/170470-176>

Sleep: Getting a good night's sleep became a problem during weekly Taxol and the accompanying weekly steroid dose. From my previous work life, which had included international travel, I was comfortable taking the occasional sleeping pill (immovane). Based on this experience, I was willing to take daily sleeping medication during Taxol – graduating the dose. A full pill on the day of chemo, half a pill on the second night and a quarter of a pill until the next dose of chemo etc. When I finished chemo, I stopped taking them and instead used an analgesic at night to ease the muscle discomfort to make it easier to sleep soundly.

Note: The drugs/combination in the chemotherapy regimen will differ depending on the type and stage of the cancer. Your oncologist has protocols about which regimen matches your situation. Information on various regimens and drugs is very clearly set out at <http://www.breastcancer.org/treatment/chemotherapy>.