Cancer, breast cancer-related lymphoedema and other fears: the emerging story

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I know everyone's experience of cancer is different. However, I believe it's important to hear as many of them as we can since they all add something significant to our knowledge, our ability to question and our comfort with the responses and outcomes, as well as to allay rather than potentiate fears that some may have, not only of the cancer, but its treatments, reoccurrence and the possible consequences, like lymphoedema.

I was diagnosed with breast cancer in September 2019 at 36 years of age. The only reason I found a lump is because I had dreamt that I had breast cancer the week before. It seemed so silly at the time, but I could feel a smallish lump where my dream had said the cancer was. I went to my GP the next day to see what she thought. Thankfully, despite her reassurances it wouldn't be cancer but rather a cyst or something else benign, she sent me off for a mammogram, ultrasound and fine-needle aspiration if needed.

As I sat in the waiting room a few days later, waiting for my GP to call me in, I had half-convinced myself it was nothing. I had recently finished breast feeding my second child and put it down to a blocked duct. Nevertheless, my GPs face when she called me in made my heart drop. She then uttered those dreadful words: "I'm sorry, you have breast cancer". I didn't cry for a while, just hyperventilated and swore … a lot. My GP was hugely supportive and sent me to an amazing surgeon.

I met my breast surgeon about a week later. She (yes, she!) is one of the most caring and considerate healthcare professionals I have met. She explained all the details of my cancer, the fact that it was Grade 2, Stage 2, invasive ductal carcinoma, in one lymph node and relatively small. She went on to explain my treatment options and the benefits and risks of them. She drew diagrams on paper, which I was able to take home as I had no hope of remembering everything through the tears and stress of it all. My options were either surgery, chemo, radiation or hormone blockers. She strongly advised the former so the oncologist could see how effective the chemo was on the tumour. I was mostly horrified at even needing to have chemo. The thought of nausea, hair loss and not working was terrifying. I made the decision to go with her advice and to start chemo first. A week later, I met my oncologist.

My oncologist is a caring and understanding man, who loves helping people. One of the questions I first asked him was how he handles oncology, as it seems so depressing. His answer helped my mental state. He said that most of the people he sees, he helps significantly, and they go on to live normal, long lives. He always had the right combination of seriousness and humour to help ease my anxiety of the situation. My treatment regimen was to be four doses of adriamycin and cyclophosphamide (AC) and 12 doses of taxol. Because of my underlying Crohn's disease, he opted to start me on taxol to 'ease' me into having chemo. I also opted to try the cold cap in an attempt to save my hair from falling out.

Early in October, I had my first infusion. I cried for about an hour because of what it all meant. The side effects of taxol were minimal at first — mild nausea, constipation and fatigue. The cold cap wasn't too bad either. It meant each infusion was longer than 'normal'. By the end of my 12 sessions, I started to get neuropathy in my toes. My oncologist asked me each week if it was getting worse or if it bothered me. I was lucky as it didn't get too bad and I completed the full 12 rounds of taxol. I also kept most of my hair thanks to the cold cap, although I was beginning to wonder what effects that could have on my lymphatic system. Silly, I know, but the thoughts were there. Why? Well the tingling in the toes!

To make infusions a bit less painful each time, I opted, under suggestion from my surgeon and oncologist, to get an infusaport inserted. It was a day procedure, and one of the best decisions I made. Each infusion was a simple needle inserted into the port. No searching for veins each time and no worrying my veins would collapse. All the chemo nurses said ports make their job easier and notice that it's a lot more comfortable for patients; less damage to my vascular system (and any surrounding lymphatics — good for the future, I thought!)

Right at the end of the taxol treatment programme, I caught a chest cold, which gave me a slight fever. I knew it was nothing nasty because my then 2-year-old daughter had the exact same thing the week before. It resulted in a trip to hospital and an overnight stay in ICU. The ICU nurses refused to use my port for putting in antibiotics and taking bloods, so I ended up with two very sore arms from all the needles. Why? This increased my concern about more potential vascular and maybe lymphatic damage on the arm on the at-risk side. They also inserted an arterial line to monitor my blood pressure, which was one of the most uncomfortable things to have in. Apparently, they are meant for patients who are in a coma and don't move. Any movement I did make made the monitor go off and I didn't get much sleep that night. After a 2-night stay in hospital, my temperature normalised and I went home.

My AC infusions started a few weeks after my hospital visit. The nausea was awful, but apparently I had got off lightly. I was given the strongest anti-nausea drugs that exist, plus dexamethasone and metoclopramide. After my four AC infusions, I would have nausea for about 36 hours. For me, this was really awful, and I struggled with it a fair bit. The cold cap wasn't as effective against the AC and my hair started to fall out in enormous clumps. I was devastated because I'd saved it all through taxol. I decided to shave it off and go bald. I was losing my eyebrows and eyelashes anyway, and it did look a little odd. My chemo nurses were extremely supportive and weren't surprised that it had happened.

The chemo nurses were so wonderful and took the time to explain everything and answer my crazy questions. Every time I had an appointment or surgery, I would go and visit and say hi and let them know how I was doing. They all said in their different ways that they loved hearing from patients post-chemo as most often they have no idea how people fare. I have made it my business to go and visit them, so they know the outcome of at least one patient, which I believe is very important as it completes the cycle for them knowledge-wise and allows us to recognise their efforts and thank them. Talking and sharing concerns is critical during these difficult times. It situates you back in reality, helps manage fears and calms the often irrational thoughts that arise.

Post-chemo, I had a 4-week break before surgery. I took those 4 weeks and did as much as I could, as I wasn't sure what damage having surgery would do to my arm. I looked for distractions, scanned the internet (make sure you always look at professional sites and listen to those in the business!). I also redid a full backyard renovation. I wanted some more grass for the kids to play on. This gave me some physicality and an important distraction. I gathered that activity would also help the lymphatic system work better by removing toxins and help to defend me.

I had two surgeries. The first one removed the tumour, which had shrunk significantly, plus four lymph nodes including the sentinel node. The surgery went well, in that it removed all my tumour with good margins. I also had my port removed. However, I got a call a few days later to say that three out of the four lymph nodes removed had cancer in them, so I would have to come back in for further surgery, an axillary node clearance. A second surgical intervention — I was devastated. My diagnosis went from Stage 2 to Stage 3 because of the number of lymph nodes, which in my mind was so much worse and a lot more life limiting in terms of its quantity, but also quality. I had assurances from my oncologist that the radiation and hormone blockers would finish the job off and to not think on it too much. So much easier said than done.

My first surgery came a few weeks after COVID-19 was declared a pandemic. It was petrifying. I thought there might have been a chance my surgery wouldn't happen, and the cancer would be left for goodness knows how long to do as it pleased (i.e. metastasise). Luckily it didn't come to that and my surgeries happened as planned. The care was different though. There was less contact from staff and everyone was hypercautious. My surgeon even wanted full personal protective equipment (PPE) to enter my room but was denied because of the need for PPE in COVID-19 wards.

Radiation was a walk in the park compared to chemo. Yes, it was every weekday, but it was only 15 minutes treatment time. The staff at the radiation therapy place were lovely and kind. I cried on my first visit, mainly because of the music playing — Bill Withers, Lovely Day — I certainly wasn't having a lovely day! The side effects were minimal. I didn't even feel that tired. It was only in the last week, following 6 weeks-worth of treatment, that I started to get visible burns. I have never moisturised as much as I did during radiation therapy but, again, the niggle was there — what was this also doing to my lymphatic system?

After another break, I started on hormone blockers, specifically letrozole and zoladex. Initially, the side effects weren't too bad, but they started to build. My anxiety would rise after each zoladex injection for about a week, then ease off until the next one. My joints became swollen, and I could barely walk down a flight of stairs without wincing. I also developed a pain in my hip that I was convinced was a metastasis. It turns out it was scarring from a car accident I had in 2012 tightening after being put into menopause. The insomnia was the worst. I would wake up in the middle of the night and be awake for hours, no matter what I did. In December 2020, I had my last zoladex injection. I decided to have my ovaries removed so I wouldn't have to have the injection every month for around 10 years. To me, it sounded like torture (PTSD-inducing having to go back to the chemo ward every month) and it was expensive, even with the government subsidy.

The nurse at the institution where I got my zoladex injections was so lovely and caring. She would listen to my irrational brain and give me tips and tricks to help get me through my crash into menopause, and all my other concerns. You wouldn't believe the benefits of this support to me — talking, communicating and caring — an important and critical part of my life through cancer, its treatment and possible sequelae.

A few weeks after radiation was completed, I decided to play netball again. It was only C2 Grade and there was no mid-week training. I am so glad I did it. It was so good for my mental and physical health. I still got mild cording, but nothing that has limited my range of movement long term. The effects of the zoladex and letrozole were pronounced. My knees would blow up like balloons the day after a game. Despite this, I even ended up getting Association and Club Best and Fairest. Pretty proud of myself!

In January 2021, I had my ovaries and fallopian tubes out. Everyone I spoke to in the oncology field had said it was a good idea for several reasons. Despite the ridiculously high anxiety because of the hormone drop, I am glad I had it done too. The trauma of a 2012 car accident when I was rear ended had caused my bowel to fuse into one ovary, which, when removed, also got rid of some back pain I was having. One hugely positive side effect!

I have also now had my 12-month post diagnosis mammogram and 18-month review. I currently have no evidence of disease and hope it stays that way. I am still yet to have any kind of blood test or body scan to ensure there isn't anything else elsewhere. Likewise, a check using a machine that examines my fluids and other things in my arm on the at-risk side showed no change.

The last 18 months since diagnosis have been the most challenging so far, but I'm still here and looking forward to my future life, career and family, and what a difference the continuity and quality of care makes. We must all seek this and if its not there, demand it and use it. Knowledge is power and in a way provides a form of comfort. Yes, I'm worried that the cancer may return and that I'm at risk of lymphoedema, but through quality information I know both risks are minimal, how to respond and what to do.