

I wear a silver chain around my neck, on it hangs a pendant inscribed with one word, survivor. Just above that pendant is a masterfully hidden scar from a surgery that ultimately saved my life.

In March of 2017 I noticed a swollen lump on the right side of my throat. I went to a walk in and was given antibiotics there because I'd been exposed to strep a few weeks prior. The first round of antibiotics didn't do a thing so 10 days later I was back in a clinic where they swabbed me and confirmed pretty quickly that I did not in fact have strep throat, I was prescribed another round of antibiotics and off I went. 10 day later I was back in an Urgent Care and this cycle continued until May while the infection continued to get worse with each round of antibiotics. I finally made it to my family doctor mid-April who decided more tests were needed and made a referral for a CT scan. In early May, before I'd had heard anything about the CT referrals I ended up in the ER because the infection had gone septic. It was in the ER that someone first indicated to me that what was going on might be something more serious and an ENT ordered a needle biopsy and the first of what would be 5 CTs. All of the tests came back with no significant clinical findings. I was admitted to the hospital where I spent 6 days on IV antibiotics and I stabilized. I went home with another round of oral antibiotics for good measure but within days the infection was back stronger than ever and I was again in the ER. At this point there was another biopsy, another CT and I was diagnosed with a benign Brachial Cleft Cyst, the fact that the infection seemed to be too deep for oral antibiotic to manage was a problem and my ENT scheduled surgery to have it removed. Late in June I had surgery to remove cyst. We were told that everything looked great, they'd be doing a tissue biopsy as a standard practice, and I got one last round of oral antibiotics and a surgical follow up appointment for a few weeks later.

On July 18, 2017 I went for my post-surgical follow up appointment with my ENT at the Health Sciences Center. It was one of those days you remember what the weather was like, what you wore, details you would normally forget if something about the day hadn't changed everything. I remember the doctor sitting down in the treatment chair across from me and starting to talk. Against all odds I was diagnosed with oropharyngeal cancer. It was Stage IV Squamous Cell Carcinoma, P16 positive; what this means is essentially is that I had throat cancer caused by the HPV virus. Inside of the infected cyst they had found lymph nodes that tested positive for cancer. I had heard of HPV related cervical cancer and made a practice of getting my annual pap tests. I was past the age for the Gardasil vaccine when it came out so I'd never gotten it but I'd never given it much thought. I had no idea HPV could cause cancer in your throat. As it is HPV related throat cancer isn't really common in women, it's most common in men (4x more common) with most onsets around the age of 60-70. The prognosis, we were told was really good, 80-85% chance of successful treatment and unlike other cancers the chance of recurrence is almost nil. Treatment they told us would need to be very aggressive and would

begin immediately with a seven week course of radiation treatments augmented with 3 rounds of chemotherapy.

They made no bones about telling us the treatment would be brutal; in fact, the doctors told us it was second only to a bone marrow transplant. The side effects included all the regular stuff you expect with chemo while with radiation we were told to expect burns and sore in my throat and mouth, changes in the taste of food, fatigue and weight loss. Apparently 10% of patients end up using a feeding tube because they are unable to eat and cannot keep their weight up enough to sustain treatment. They warned of potential side effects including hearing loss and tooth damage, none of which they felt they could accurately predict given my age and the fact that most patients are 20-30 years older than I was at the time of my diagnosis. I was 37 years old, a wife, a mother to two young children (5 and 3), a professional and ironically a “preferred client” to my life insurance company because I was a fit, non-smoker with a healthy lifestyle. This, they promised would not be easy but it would be worth it. I would walk away from this. And so, we began our cancer journey. I had another surgery to remove a tumor at the base of my tongue that had been identified as the primary site of the cancer. On August 21 we began what would become our routine for the next couple of months, drive downtown to Cancer Care every morning for treatment and home in the afternoons to rest. Eating quickly became a struggle and during the second round of chemo I collapsed at home and was rushed to the emergency room. I was suffering from severe dehydration, my kidneys were in really bad shape, my blood pressure had bottomed out dangerously low and I was again admitted to the hospital where I remained for the next 10 days. Just like that I became one of the 10%. The doctors decided to forego the last round of chemotherapy, prioritizing the radiation which was about to get hard.

The radiation had felt like the easy part compared to the chemotherapy up until that point but since radiation is cumulative the effects began to become really noticeable around week 4. The skin and tissue on my neck was burned and dry, the skin peeled and cracked. My hair fell out in clumps. Inside my throat was on fire, I couldn't swallow anything, I lost my voice entirely. The last few weeks of treatment are a haze of opioids and feeding schedules managed by my husband and my mom who came to stay with us to help with the kids. Friends and other family stepped up to help with everything, I don't remember much about October 2017 to be perfectly honest, maybe that's a good thing.

I officially started my recovery that fall and shortly before Christmas my first post-treatment CT gave us the first glimpse of success showing NED, no evidence of disease. We celebrated the holidays with family, grateful for the opportunity, even if I still took all of my meals through a tube and would continue to do so until March 2018. In March I had a second scan NED and my care team started to talk about my feeding tube removal. I needed to learn to swallow on my

own again before the muscles in my throat, badly damaged by the radiation atrophied. I began physiotherapy and speech exercises. I started a regimen with the dietician to balance food intake so I didn't lose more weight which was important given that I'd lost significant muscle mass during treatment. For the next few months I counted every calorie of the tasteless, mostly liquid food I consumed and finally was able to have the tube removed after successfully maintaining my body weight on my own for 30 days. On May 16, 2018 my feeding tube was removed and I was without tubes in my body for the first time in 10 months.

I'm now in remission, 22 months post treatment. I am working to re-establish myself in my new normal. I recently got hearing aids and it was like getting color back in my world. I hadn't realized that I didn't hear birds singing. I've returned to work full time. I'm working on getting back to old hobbies like running. I'm learning to explore foods a bit more and committing to social events around eating simply because it's good for my mental health; my joke is that I eat "socially". The psychological impacts are far reaching, for me and for my family. I don't know how long it will be before we feel safe enough to brush off a sore throat again, or for my kids to not worry about a doctor visit. Cancer is part of our family narrative and my kids talk about it openly, we encourage them to and hope that in helping ourselves heal we can have a positive impact for someone else somewhere. We have scars, some are visible, and others are not. We wear them proudly. How it is that saying goes? "Wrinkles mean you laughed. Grey hairs mean you cared. Scars mean you survived." And that is what we did, we are SURVIVORS.

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