Alex Soo — Doing It For His Son

Alex Soo shares how his son and others helped him through a testicular cancer journey.

January 3, 2022 By Justin Birckbichler

Welcome to the Band of Ballers! In this series on ABSOT, I'm turning over control to some other ballsy testicular cancer survivors and patients who have inspired me with their work in advocacy and awareness during and after their diagnosis. This month's feature is all about Alex Soo, who shares his journey and how others helped him persevere. Enjoy!

In 2019, when I was 33, I had a backache in my lower left rear flank for about a month. I was pretty confident that it was not related to muscular or skeletal pain, so I thought that it was a kidney stone. I saw my Primary Care Physician at Methodist Hospital and he ordered an ultrasound of the abdomen, at which point they detected a large mass wrapped around my lower aorta (about the size of a softball).

I was sent to get a CT guided biopsy, which confirmed a diagnosis of embryonal carcinoma. I remember sitting in my office at work and receiving the call from my doctor. I detected concern in his voice. I remember that he never said the word "cancer," and wondering what that meant. I wrote down a lot of notes in my work notebook, which I immediately dog-eared. I took a couple breaths and stood up next to the window and called my wife, Samjah.

At that point, I had disassociated myself from the diagnosis and went into battle planning mode.

They also found metastases to my lymph nodes, lungs and neck. My PCP recommended immediately that I contact MD Anderson for follow up.

I started VIP chemotherapy in November of 2019. V for etoposide (VP-16), I for ifosfamide and P for cisplatin/platinol. Each round of chemotherapy was inpatient at MD Anderson Hospital. After getting checked in I would go through 5 cycles of infusion of poison. Each infusion would last for about 6 hours, and then I would be hydrated for 15 hours. After 5 days of this abuse I would get discharged and recover for 2 weeks (with your typical side effects like bone pain, dehydration, nausea). That constituted a cycle. I did 4 cycles (with a little break for Christmas and New Year), ending in January of 2020. Blood tests and scans confirmed that the chemotherapy killed and significantly shrunk the cancer tumors.

I recovered from the chemo during the height of COVID, which delayed surgeries from April to June. I finally got my RPLND and orchiectomy on June 23, 2020. I was left to recover alone in the

hospital with a new 30-inch incision, but light 80 lymph nodes and a right testicle. I had to learn how to walk again.

I was discharged on June 30, 2020. I celebrated my son Theo's birthday on July 1st, 2020.

A few days later, on July 4th, 2020, I blacked out on the top floor of my home, near Theo's bedroom.

I woke up on the ground. Staring at the toys underneath his bed. I thought that it was the end. My wife called my neighbor, a doctor, and 911. The paramedics couldn't figure out what was wrong with me. I laid on the ground for a long time while they pumped me full of fluid. Every time they would try to lift me, I blacked out horribly. They couldn't read my blood pressure because it was so low.

Eventually, I was brought downstairs to the ambulance. My wife and son couldn't come with me because of COVID. I was taken to the ER where they found internal bleeding. I spent the next few days in the hospital getting blood transfusions, and monitoring to see if I would need emergency surgery. I was physically broken and terrified.

One of the things that got me through this experience was the realization that I needed to live for my son. I needed to be his daddy. So I kept on breathing and existing. I recovered and was discharged on July 7th, 2020.

After a few other bumps in the road (I tore my rotator cuff and AC joint in a bike accident and tore a finger tendon playing with TO, ooops), I was declared officially in remission in September of 2020.

I am blessed to have an incredibly strong support network.

My wife and son were constant motivations to keep going. My mom came down to stay with us for almost the entirety of the chemotherapy treatment. My three big brothers and their families all hunkered down to keep my spirits up and we started a great family group text that we keep up today. As soon as I told my boss we immediately started planning for my full time absence. If anything, I was more emotional about leaving work and my team. I am thankful that I have made such a great network of friends and mentors and coaches to turn to. I also need to emphasize the fact that my employer health insurance (CIGNA) made the entire process easier. I barely recall even seeing a bill. I know that many others do not have access to that luxury and I am thankful for my company to have invested in me.

I highly recommend a therapist or coach to help during the process, including afterwards. I utilized the internet resources quite a bit, especially r/testicularcancer at the beginning. My oncologist and MD Anderson were an incredible network who always were there to help us with any concerns. If I had found the Testicular Cancer Foundation earlier, I know that it would have been a huge benefit to have through treatment.

I generally consider the obstacles either physical or mental in nature.

Physically, the treatment is a bear. As someone who considered themselves physically fit, it deteriorated me rapidly. I made, and still have, many promises to myself to achieve a level of physical fitness beyond where I was when I was diagnosed. This goal has helped me identify other hobbies like cycling and rowing. I experienced some mild neuropathy in both my feet up to my ankles, in my hands up to my palms, and some tinnitus in both ears. I consider myself relatively lucky in how much I have recovered; even though there is still some numbness there are no complaints here.

The mental journey was hard. It is hard. The key tool I learned was how to consider the difference between an event, and our emotional reaction to an event. It's okay to feel every stab of every feeling, but what we are judged on is how we ultimately act upon our emotions. There are those who either choose to be victims, or survivors. I like to style myself as the latter.

Survivorship to me means embracing the situation that the universe has given you, and making the absolute best of it.

I've come to think of my testicular cancer as a positive experience in my life; I've made friends, learned about myself and my family, redefined what I find important, and learned how to enjoy each moment in life. I've earned an opportunity to make a difference.

Testicular cancer is unique. It's not just about a disease, it's about the very core of our masculinity and our identity. The journey we are on is by no means easy, but it can be rewarding. Each year there are more of us. Each year there are survivors. And each year some will embark on their next journey too, like our friend Andres. If we all band together as a brotherhood, an alumni of sorts, then we will all be able to support each other during whatever phase of the journey we are on.

Be sure to connect with Alex by visiting him at @lxsooshi and Facebook. Until next time, Carpe Scrotiem!

Know someone (or even yourself!) who is supporting TC awareness and would be willing to share their story? Drop their name, contact, and why they should be featured into this Google Form and I'll reach out to them and/or you!

This post originally appeared on A Ballsy Sense of Tumor on September 30, 2021. It is republished with permission.
