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Audaciously Alive

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Before I was diagnosed with cancer my husband and I had a habit of pointing out how lucky we were. As we approached our 30th birthdays we had been together and in love for nearly a decade. His career in counseling and mine in international development were on the rise and allowed us to afford our own home in downtown Washington, DC. We had fallen in love with an incredible community of friends who loved us with their whole hearts and had an ever expanding family who supported us completely. We had big dreams to travel the world, move someplace beautiful and start a family, and no reason to think they wouldn't come true.

Then, just a few months after my 30th birthday, I found it: a golf ball size lump in my right breast. I saw a doctor a few days later who sent me to a breast center. At 30 years old, in the same month my husband and I had planned to start trying for a family, I found myself alone in a hospital gown waiting with women twice my age to get my first mammogram. The rest of the day was a whirlwind. By that afternoon I had gotten a mammogram, an ultrasound, and a biopsy, had been assigned a nurse navigator, and had an appointment with a breast surgeon. Five days later I was diagnosed with Stage 2 triple negative breast cancer.

Over the next few weeks I had more tests and scans than I even knew existed, went through fertility treatments to have my embryos frozen, stood up in my best friends' wedding and started chemo. As I got used to the ups and downs of chemo I gave the days of the week new names like "Feel Crappy Sundays," and "Feel Good Wednesdays." On feel good days I would exercise, see my friends, go to

work and try to pretend like my life was normal. When my hair began to fall out I was prepared with an assortment of colorful head wraps and dangly earrings. I blogged through all of it writing pieces like “An Ode to My Hair” in which I apologized for all the bad hair days I’d complained about or “Future Baby Mama Drama,” in which I described the harrowing trials of fertility treatments.

Slowly but surely the “feel crappy days” began to feel worse and started rolling over into the “feel good days.” I got super tired of the seemingly endless assault on my body. Within just a few months I’d been to the ER for what appeared to be (but was not) a heart attack, I’d gotten a full body rash so horrifically itchy that the only relief was to sleep covered in ice packs, and I had swung violently into menopause making me want to apologize for every crazy look I’d ever given a sweaty middle-aged woman. In the 4th month I started on an extremely toxic chemo that made me sicker than I’d ever been before. For several days after each treatment I was too weak to walk. My mouth and throat stung with sores that were inches long. My eyes burned. My stomach ached incessantly. My head throbbed. I basically felt like I was dying all but a handful of days for 8 straight weeks.

It was around that time that I say my brain broke. I no longer recognized myself in the mirror. I no longer recognized my life. I had little to look forward to besides surgery, radiation and the fear of recurrence. Chemo was the worst thing that had ever happened to me and no one in my life could relate. I got looks and texts and cards overflowing with pity. I had gone from a capable, compassionate, go-getter with my whole life ahead of me to a weak, angry, miserable soul with a future already scarred with fear. I started to experience symptoms of PTSD which research has finally recognized as a very real side effect of cancer and cancer treatments. My brain, my life and my future all felt broken.

Fortunately, I survived those five months and 16 rounds of chemo. To celebrate my friends and I threw a dance party and I wore the first and only wig I ever owned: a short bob in neon pink. A few weeks later I had a double mastectomy. It was during this surgery that they discovered that the chemo had had little impact on the tumor and the cancer had already spread to nearby lymph nodes.

A few weeks later I went for a routine follow-up with my medical oncologist and discovered that because the first 5 months of chemo had been ineffective they wanted me to have 3 more months before beginning radiation. I collapsed in her office sobbing at the prospect. I was told I could think it over and when I went home that day I felt as close to suicidal as I have ever been in my life. It was ironic because

I wanted nothing more than to survive, but I didn't want to survive this way. In that moment I just wanted out of my life. I held on to a bottle of narcotics for comfort for nearly an hour before my husband made me call a prevention hotline and I made the gut-wrenching decision to get more chemo. Three long months later I celebrated yet again but this time I sat on a beach in the Caribbean for a week before I returned to start five grueling weeks of radiation.

I spent the morning of my last radiation treatment feeling triumphant. But over the course of the day my exuberance quietly turned into a foreboding fear. For a year I had been in treatments to fight my cancer. Now I was alone. I also didn't really know who I was anymore outside of cancer. The Katie I had once been was forever gone, replaced by someone who was tough-as-nails but also bitter, confused and afraid. I told my husband that the only future I could imagine was one in which cancer eventually took my life. It had already taken so much from me it just seemed like the only logical conclusion.

Fortunately, I had planned a fall filled with life-affirming activities. Up first was a trip I had planned with an organization called First Descents. First Descents provides week-long adventure trips, kayaking, surfing or rock climbing, for young adults who have or have had, cancer. Just two weeks after I finished treatment I was scheduled to go rock climbing in Moab, Utah. I arrived in Utah a ball of nervous energy but that quickly dissipated as I sat down to my first evening with my fellow fighters and survivors. We turned to stories of surgeries, chemo brain and weird pooping episodes for small talk the way most people turn to the weather. We were all desperate for understanding, for people our own age with their own chemo/radiation/surgery/doctors /pain/near-death/hair loss/menopause experiences. I knew immediately that I had found my tribe.

Out on the rock the first day I was again nervous. For a year I'd been the weakest person in the room. I didn't want to be that person anymore. I was pleasantly surprised after my first few climbs that I seemed to have some semblance of strength. It was on the second day though that I met my greatest foe of the week. I had jumped at the chance to take on what seemed like a pretty difficult climb but about 10 feet short of the top I could feel my strength fading fast. It had been an excruciating climb and my muscles were completely spent. I had been clawing, grasping, and dragging myself up, fighting for every inch. Every time I thought I might have to throw in the towel I heard a chorus of support screaming at me from above and below, unwilling to let me stop fighting. I took a moment and thought about all of the

pain I'd endured, against my will, over the last year. If I could survive that pain, I could survive this pain, I thought to myself, and I finally pushed myself far enough to reach the last hold and hoisted myself up.

It was in that moment that I found myself again. I arrived in Utah as a victim of cancer. But I was leaving a fighter, a life-embracer, someone who was tough-as-nails but also optimistic about the adventures that life had in store. My life suddenly felt big and rich and full of possibility. I spent the rest of that fall on one adventure after another. I spent a weekend wandering the streets of Rome, cheating on my diet with pizza and cappuccinos. I dove with seals and great white sharks in South Africa. I snorkeled with sea turtles in Mexico. I envisioned that fall as my cancer victory lap but little did I know cancer had much more in store for me.

In January of 2015, just a few months after treatments ended, I found yet another lump, this time near my collarbone. Within a few weeks it was confirmed that the cancer was back and had spread to a more distant lymph node. My doctor told me it was now Stage 4. She also told me that it was chemo-resistant and radiation-resistant, inoperable and unless it grew bigger or spread to my organs that I didn't qualify for any clinical trials. There was literally nothing they could do for me. I had a 1 centimeter tumor in my lymph node and I was being told that it would end my life. Unwilling to let that be the final answer I started a whirlwind tour and saw 16 different oncologists at 9 of the nation's best hospitals over the next 2 months. They all delivered the same bad news. There was nothing they could do. "Just give it a few months. It will spread quickly. Try to enjoy the time you've got," one doctor told me.

I was sad and scared and desperate. My husband and I spent long nights holding on to one another grieving the children we would never have, the vacations we would never take, the anniversaries we would never celebrate. But even in the midst of such great despair I knew I was not ready to throw in the towel. So I kept searching and eventually a good friend of mine put me in touch with her doctor, an independent oncologist in New York City.

He had a completely different approach to cancer and, unlike all of the other doctors, believed I actually had a fighting chance. He put me on a protocol that included multiple treatments, many of them cutting edge, off-label immunotherapies with few side effects. Of course, being outside the system now meant we had to pay out-of-pocket for everything but when we turned to our community of supporters for help

they stepped up like never before. After months of taking dozens of pills every day, getting injections every month, and completely transforming my diet the scans began to confirm what my doctor believed was possible. The tumor started melting away.

For nine months my cancer was slowly but surely shrinking until last November when scans showed it had popped up in additional lymph nodes.

This time I was afraid but not despairing. I had hoped to one day be rid of my cancer but with the progression it finally occurred to me that my cancer may never be gone. I may never stop paying for these insanely expensive treatments. I may never get to be the mom that I had dreamed of being all my life. I may not make it to 60 or 50 or even 40. These prospects were both terrifying and heartbreaking but they were my reality so I did the only thing I could. I dug in deep to these difficult places and battled it out with feelings of fear and grief and my own self-worth. Slowly but surely I began to find a place of acceptance. If I couldn't have a life without cancer, now or possibly ever, then I would live this life now, with cancer, and with all the love, acceptance and peace I could muster.

Since my scans last November the cancer has continued to spread and I have continued to seek out new treatment options. Slowly but surely I am getting sicker, this cancer continues to win small victories of its own over and over. But at the same time my life has not stopped being full, and rich and deeply meaningful. My relationship with my husband has never been better. We take no moments for granted and say I love you as often as possible. My life's work has become crystal clear to me: I want to be an advocate and a source of encouragement to the tens of thousands of young adults diagnosed with cancer every year in this country. To that end I wrote a book this spring called the Courage Club. It includes all of the hard-won lessons I've learned about how to survive crisis with courage and live like you mean it. My book will be published July 7, [Kickstarter underway](#).

There is a famous Buddhist monk, who, when asked about death and impermanence once said that it is important to know that the glass is already broken. He held up an unbroken glass and talked about what a wonderful glass it was. But he said, when someday, the glass inevitably breaks, his response would be, "Of course." When we see the glass as already broken we understand how precious the glass is. So my glass is neither half full, nor half empty. My glass is beautiful and it is already broken and that makes it the most precious thing in the world.