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Paying it forward: A cancer survivor and his wife share their reflections and recommendations as a patient and caregiver

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Abstract

I grew up in the north suburbs of Chicago and had a relatively normal childhood but not necessarily an easy one. Shortly after graduating from Indiana University, I moved out west and have been working in the entertainment industry ever since. My life has been a beautiful and interesting adventure with twists and turns I could have never predicted. In 2016 it seemed like everything was really coming together. I had been happily married to my wife and business partner Mary Lou Sandler since 2011, and we had been growing our photography/film production studio for as many years. I was in peak physical condition. I felt good. I thought I was ready for the next level in life. In fact, I was declaring it. I was ready! It was of great surprise to us all when on May 4, 2017 I was diagnosed with cancer in the form of a large germ cell tumor, located inside of my chest and aggressively growing into my heart and lung. It's very easy to fall into the victim role. After being diagnosed, I made a firm decision to instead be the victor... it changed everything. Through a philosophy I call "Embrace Love Free," I began to view cancer in an entirely new way. With the experience of facing an illness, one can grow and evolve in unimaginable ways. When it comes to my caregiver Mary Lou, it's a similar yet very different story. While we both were on this journey together, I had to drop everything to focus on survival. She had to drop everything to care for me. It is from our own positive experience that we want to see medical professionals improve the experience of cancer patients by incorporating things like meditation, aromatherapy, positive thinking, and healthier food choices.

Keywords

Cancer, caregiver

Introduction

My name is Justin Sandler. I grew up in the north suburbs of Chicago and had a relatively normal childhood but not necessarily an easy one. Shortly after graduating from Indiana University, I moved out west and have been working in the entertainment industry ever since. My life has been a beautiful and interesting adventure with twists and turns I could have never predicted. It certainly had not been short on its fair share of challenges...by any means.

In 2016, it seemed like everything was really coming together. I had been happily married to my wife and business partner Mary Lou Sandler since 2011, and we had been growing our photography/film production studio for as many years (www.3cubedstudios.com). I was also enjoying work simultaneously as an actor and a drummer (www.justinsandler.com). In 2015 Mary Lou and I produced our first original film together (www.welcometowhereyouvealwaysbeen.com). We toured 21 festivals and won multiple awards. The tour wrapped up in February 2017, and shortly thereafter we received distribution (ShortsTV on cable & Amazon Prime).

During this same time, I was in peak physical condition. I had joined the Gold's Gym 2017 Fitness Challenge, and

during those 12 weeks, I was also playing in a weekly flag-football league. I was in better shape than I had been in years. I felt good. I thought I was ready for the next level in life. In fact, I was declaring it. I was ready! And I was right, though not how I thought it would go. It was of great surprise to us all when on May 4, 2017 I was diagnosed with cancer in the form of a large germ cell tumor located inside of my chest and aggressively growing into my heart and lung.

When we first found the mass, I was thrown into a whirlwind of tests. For two weeks, Mary Lou and I ran to different facilities all over town so I could be poked, scanned, and surgically biopsied. Living in that world of 'knowing something is wrong but not knowing what' can be a very disorienting and scary experience. A diagnosis is almost a welcomed relief. Being that we were near the end of April, I specifically requested that my follow-up appointment be on May 4th, because... "May the 4th be with you!" So, on that day, the 4th of May, my cardiothoracic surgeon Dr. Jay Lee gave me the diagnosis. I had cancer. It was a germ cell tumor, almost 14 cm long, and it was pushing everything out of its way.

The Treatment

Dr. Lee went over his part of the treatment plan and then sent me to meet my new oncologist, Dr. Alexandra Drakaki. She specializes in genitourinary cancer (testis, bladder, etc.). A germ cell tumor is closely related to testicular cancer, so she was the expert in treating this. Now, it's bad enough I had cancer, but I had to also accept the fact that I basically had a testicle growing inside of my chest. I called it my chesticle! Anyway, Dr. D proceeded to describe the rest of the treatment plan. I thought they were both insane. They had proposed 3 different types of chemo (VIP - Etoposide, Ifosfamide, Cisplatin) to be administered 24 hours a day for a week at a time. That would be followed by a two-week break and then it was time to move back into the hospital to do it all again. Then, if all the tumor's cells were dead after four rounds, we would move to open chest surgery to remove what was left and repair any damage.

I wanted to only do natural and alternative treatments, but I couldn't. I didn't have the time to try them. The cancer wasn't directly going to kill me, but its effect on my heart would. Therefore, I had to trust my treatment plan to the incredible team at UCLA.

Within days of my diagnosis, I was moving into UCLA Hospital Santa Monica to do my first week of round-the-clock chemo. Another thing happened that week. Mary Lou found herself thrust into a role she had never expected to be in...a role she had no training for. And she also had no choice in the matter. Mary Lou was more than my caregiver; she was my muse. She inspired me from the beginning to put myself via live video on Facebook and YouTube. She saw how sharing my experience was helpful to others as well as myself.

We did videos throughout the journey to document and share everything we were going through. We knew it would potentially help others. Our mission has always been to create art with a cause, so this was no different. With Mary Lou by my side, we were ready to face this together. From the get-go, we never realized just how much this would entail for both patient and caregiver. But we did it.

I was very fortunate for all the medical professionals that I got to interact with...especially my nurses, who were some of the greatest human beings I had ever met. In addition to my medical team, I chose to be a very active participant in my treatment plan. I maintained my vegan diet (since 2011), took powerful supplements, and utilized cannabis oil. I also practiced daily personal development and observed a cocktail of spirituality which included a lot of chanting and meditation. I even listened to Solfeggio frequencies, binaural beats, and did sound baths. Mary Lou always made sure I was stocked up with alkaline water and

clean food. She even helped me set up my hospital room each stay. We brought in food, exercise equipment, musical instruments, electric candles, and even essential oils. My room was not just a place I was going ride out the chemo. We turned it into a space for growth and healing.

The Experience

I learned so much about myself and how I could be of more service to the world. It was truly beautiful. And I was able to go even deeper, thanks to a discovery Mary Lou made after my second round. The weSPARK Cancer Support Center became a source for free healing modalities such as acupuncture, Qi gong, hypnotherapy, reiki, massage, and more. We also had an incredible support system in the way of family, friends, and spiritual communities. My parents were even flying back and forth from Chicago every few weeks to help out. All the love from everyone around us was so important. We were all in this together, and I learned early on that I was going through all of this for a much bigger reason.

As my chemo went on, the suffering increased. I faced some of the most uncomfortable and painful experiences of my life. I lost all my hair and watched my body change. But despite every day getting harder, I was very blessed for a philosophy I call "Embrace Love Free" which came to me through deep Buddhist chanting. This gave me an entirely new way to view cancer. With the experience of facing an illness, one can grow and evolve in unimaginable ways. On the other hand, it's very easy to fall into the victim role...a role I knew all too well.

After being diagnosed, I made a firm decision to instead be the victor... it changed everything.

I shifted my focus to my journey, went deep within, and started making very important realizations. I realized that I had a choice. I didn't choose my cancer. But I took responsibility for it. That's not to mean I was to blame for it or was at fault in any way. I was taking responsibility for the situation I was put in and responsibility for my choices. Choices in treatment, nutrition, and spirituality. I took responsibility for my reactions...which technically were still my choices. I certainly had a choice when it came to how I would react after getting diagnosed. Ultimately, I chose to embrace my cancer, love my cancer, and free my cancer.

It's easy to get angry and to understand why one would want to hate it or fight it. I heard people's loud rally cries... "Kick its ass!" "Cancer sucks!" "F cancer!" "Go to war with it!" But... that just didn't resonate with me. I don't think violence should really be the answer to anything, and when was the last time anyone won in a war?

In my body was a growing collection of cells, just in the wrong place at the wrong time. Despite lying dormant since birth, they were awake now, and according to their watch were way behind schedule. They only knew to do their job, and just like any living thing, they only wanted to survive. I couldn't portray hatred or negative energy to something that was part of me... inside of me. I chose to accept my situation. I gave gratitude to my tumor. I told it I loved it and called it my mentor and the greatest gift I'd ever received. I was able to grow and evolve during my cancer journey in ways that I never imagined. I was more involved with my personal and spiritual development than ever before. Facing my own mortality was a rather eye-opening experience. Cancer was my greatest obstacle, but it yielded my biggest benefit.

Things continued to get harder. The side effects and all the suffering from the chemo took its toll on me. But I kept going. After the fourth round, we retested everything and indeed all the cells in my tumor were dead. But it left behind a hardened teratoma which needed to be removed. We scheduled the surgery, but due to dangerously low platelet counts, I had to be hospitalized and my surgery was postponed. Once my counts got high enough, we rescheduled the surgery.

On August 4, 2017 we arrived at UCLA Ronald Reagan Hospital early in the morning. Stress was high. It was time to go in for a near eight-hour, intense surgery. That day, Dr. Lee and his team sawed me open to remove the dead tumor. Along with it he had to remove more than one-third of my right lung, my left innominate vein, and a fifteen-centimeter piece of my heart's pericardial sac which he patched up with Gore-tex. My superior vena cava was rebuilt with bovine heart tissue and I was sealed up with titanium coil. As a long-time vegan, it was a bit shocking to find out that one has cow inside of oneself. I then wondered, "If I ever ate beef again, would I be a cannibal?"

The week in the ICU following the surgery was rough. I was in bad shape with a long way to go in my recovery. I was supposedly cancer free. But I would soon learn that I was not out of the woods yet. On December 16, my heart had unexpected complications, and I found myself being rushed into surgery as my heart was collapsing under a liter of fluid. I was suffering from cardiac tamponade (often referred to as the "widow-maker") and that day would be the closest I came to death. I remained in hospital, and a week later I went into yet another surgery to create a pericardial window and test for cancer in the heart. No additional cancer was found, although my heart and left lung had fused together from the previous surgery, so the two organs had to be surgically separated.

I was released in time for New Year's. The official lab reports in January 2018 deemed me cancer free, and it was

time to start the long road back to recovery. With no strength or stamina and a body that was beat down, hairless, thirty pounds lighter, and with newfound scars all over it, I was left to put the pieces back together. And I'm still working on that today. But I'm here. I'm alive.

When it comes to my caregiver...

Mary Lou has a similar yet very different story. While we both were on this journey together, I had to drop everything to focus on survival. She had to drop everything to care for me. And as hard as it was for me, it was an entirely different kind of hard for her. She put everything on hold. She even put her emotions in check in order to soldier forward. She was there for me around the clock. Whether it was taking me to doctor appointments, making sure I had food, or keeping the house clean, there was almost always something to do. She had to hear me complain about the pain, watch me vomit out my brains, and got to know the intimate details of my chemo-induced constipation and even the anal fissure that was surprisingly one of the most painful experiences of my life. Also, after my big surgery, she had to help me in and out of bed and empty my bedside urinal. Yes, this cancer journey was an entirely new level of sexiness. But it also brought us closer together while strengthening our relationship and our mission.

Below are some words from Mary Lou about being a caregiver:

"I did a deep dive and researched how to be a caregiver after Justin's diagnosis, as I had never cared for anyone with an illness before. I wanted to know how to deal with it emotionally, mentally, and physically. I wanted to know what to expect, how to deal with friends and family members, ward off unsolicited advice, and most of all, how to best care for my husband and myself, while living in the shock of it all.

During our cancer journey, I suggested that Justin share everything online because we know so many people, and as a performer, I know that the camera is his therapist. I, however, didn't speak much, publicly or privately. In the beginning, I was searching for resources and felt lost and overwhelmed with papers and pamphlets. I simply couldn't find much out there covering what I was experiencing while I was experiencing it. Then, when I was finally blessed with resources, I felt guilty for taking time for myself or even talking about my feelings because, in comparison, what I was experiencing was not "cancer."

So... I stuffed any feelings that I was having and kept riding the wave of adrenaline to ensure everything was okay for my love. We learned so much from cancer, as our teacher and mentor, and stayed positive throughout our

journey. If I were to face this challenge again, I would make wiser and more informed choices.

While the role of caregiver was demanding and often required selflessness, it was also extremely rewarding. I learned how to be a better friend and family member; how to be more forgiving of others and myself; and that we are all only human, trying to survive and be loved. This journey strengthened my beliefs in the magic of life and the blessings that surround us every day. Both Justin and I were so inspired by all this that we decided to put our efforts into developing a documentary film dedicated to the caregivers of cancer patients. We titled it “Caregiving Cancer: The Silent Heroes,” and we are currently fundraising while in preproduction.

In the film we’re going to provide resources that we acquired along the way, as well as go on a fact-finding mission to discover new ways to help improve the lives of patients and caregivers. The film is meant to inspire, empower, and give a voice to the often-voiceless caregiver.

My heart and soul are in this film. We are aiming to provide caregivers a sense of community in knowing they are not alone, and most of all, inspiration to continue thriving before, during, and after cancer caregiving. We plan to start shooting soon. If you would like to support the film or learn more about it, please visit: www.caregivingcancer.org Thank you.”

Embrace Love Free

By January 2018, I was officially cancer-free and “done” with my cancer journey, but the fight was far from over. I struggled a lot with the recovery phase because I was beat down with my body, a shell of its former self. A lot of old “stuff” started coming up. Depression set in. Despite that, I kept working towards my mission.

I started getting asked to speak at events. I’ve been able to share my story many times already at places like storytelling events and cancer charity benefits. In 2018, I was asked to join the Patient Family Advisory Council (PFAC) at UCLA Hospital Santa Monica. This was a great honor to be able to volunteer and help make a difference at the very hospital that saved my life. It made it even more special when a year later Mary Lou was asked to join the council as well. We have been meeting at the hospital once a month to share our ideas on how to improve the patient/family experience. And in a short time, we have accomplished big things that I am quite proud of.

In addition, the PFAC opened up an opportunity for me to speak at more events. I was bestowed the honor of being the keynote speaker at the UCLA Gold Humanism Honor Society induction ceremony in 2019. I was able to connect with some bright young minds and inspire them

to relate to their future patients on a whole new level. To me, it’s very rewarding to be able to speak knowing it’s helping others.

As a professional actor and drummer, I turned my cancer journey into a one-man show called “Embrace Love Free” that played around Los Angeles throughout 2019. I told my story through comedic characters, music, and clips of actual videos from my cancer journey. Performing the show was an incredible experience for me. One week after my final performance of 2019, Mary Lou and I flew to Chicago, picked up my parents and aunt and uncles and headed down to Illinois State University where I officially became a TEDx speaker and presented my speech “3 Steps to Overcome Any Obstacle” at TEDxNormal. This was an incredible experience for me and reinforced my desire to help others on the biggest scale possible.

Our Call to Action

One of the biggest hopes that Mary Lou and I have as a result of this journey is that hospitals and medical staff offer more information and resources for non-medical healing modalities. Doctors are often only focused on the medical world. And that is ok to an extent. But there is so much more that can be done to help. Because the doctors are so focused on the medical journey, they often don’t even think of all the different types of help that can be provided. For example, UCLA has a program called Simms-Mann which includes social workers and support groups. But after my diagnosis, we were not told about this. As a matter of fact, there was zero information available about it. Not even a stack of brochures in the oncology building. It wasn’t until after my second round of chemo, when Mary Lou asked if there was any kind of support resources, that we were introduced to the Simms-Mann organization. Furthermore, there should be information provided for outside centers like weSPARK which offer so many amazing healing modalities and support options, all free for cancer patients and their caregivers.

We’d like to also see medical professionals discuss nutrition. Our food choices have a huge impact on our health. When someone is going through cancer, eating too much sugar and processed foods can only do more harm. Medical professionals should make suggestions about the ideal diet to accompany their treatments. When I was in the hospital, most of what I saw was unhealthy food options, so I had to bring in a lot of my own food.

Also, we’d like to see more cancer doctors discussing the use of cannabis oil. There are proven results of cannabis helping shrink tumors. Even more, the cannabis was so helpful to me as I encountered the many side effects from chemotherapy. The cannabis helped with my nausea and

pain, kept my appetite up, and also helped with an overall better sense of well-being while I was going through it.

Additionally, we'd like to see essential oils in hospital rooms to help mask the smell of bleach and medicine and to create a more peaceful vibe. There are also great audio programs, from binaural beats to relaxing meditation music, to empowering podcasts.

It is from our own positive experience that we want to see medical professionals incorporate things like meditation, aromatherapy, positive thinking, and healthier food choices. Going through cancer is stressful. Stress lowers the body's immune system. Therefore, using modalities to help manage the stress of it all can only have a positive effect.

For patients and caregivers...

A big reason we are making our documentary film is so that a caregiver can watch this film as soon as their loved one is diagnosed and learn about all of the options that are available and ways in which they can be more informed about what to expect and what to do. Our desire is to have this film available for everyone going through cancer.

Other things patients and caregivers can do for themselves:

- Ask for free resources immediately
- Seek out cancer support centers in your area
- Make healthy food choices (plant based and alkaline if possible)
- Incorporate daily mediation (and other spiritual practices if they call to you)
- Use things like essential oils and salt lamps to create a calm and peaceful vibe
- Watch/listen to powerful and inspirational programming (Podcasts, TED talks, audiobooks)
- Research cannabis (even if just CBD for anxiety and such)
- Seek out the positive from the situation. What lessons can be learned? What's the silver-lining?
- Practice self-care and self-love
- Be creative! What can you do? (i.e., write, read, draw, play an instrument, etc.) Find outlets of things to do to keep your mind and soul engaged
- Share your story with others... it could be very helpful for those also going through it and surprisingly helpful for you as well
- Embrace, Love, Free

One very important resource we'd like to share with you is Meal Train (www.mealtrain.com). After my diagnosis, a

friend of ours signed us up. We set up the calendar with what we needed, from meals to help with chores, and our friends and family members signed up to help. Through this campaign, we had help cleaning the house and running errands. So many people showed up with delicious food knowing that we were tight on funds and often unable to shop or prep for meals. For those who weren't local, they were able to make donations to help with our day-to-day expenses. It's hard to ask for help sometimes, but through Meal Train, it was an easy way to share our needs with others and offer them an opportunity to help.

Specifically for caregivers...

- Take care of yourselves! Self-care is not selfish.
- Take time to replenish and refill your cup. You can't take care of another person if you're running on empty. Also, there are specific support groups and resources available just for caregivers. Find them.
- Set boundaries. People will have their opinions and may often try to push them on you. You don't have to listen to them. Create a safe space for you and your loved one. In the end, only you know what's best for you.

The philosophy of "Embrace, Love, Free" not only became my motto but also my roadmap for life. I never would have imagined that it would also become part of my mission, which is now more clearly defined than ever before. I am so passionate about sharing my message, because I want everyone to understand that we all face challenges – big and small – every day.

Sure, not all challenges are cancer, but with each challenge lies a choice. And we can choose to do whatever it takes to overcome our obstacles because we know there is a benefit on the other side. We can choose to keep going and keep growing. In my recovery, I continue to heal and grow every day and plan to go far down this road. I am grateful to be able to use my experience to help others, and it has been an honor for me and Mary Lou to share our story with you here.

In Health and with Love,
Justin & Mary Lou Sandler

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