

## Essay/Personal Reflection

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As the invited keynote speaker for a survivorship celebration at Memorial Sloan Kettering Cancer Center (MSKCC), I chose the topic of resilience and invited one of my patients to share his story. His name has been disclosed per his preference.

I'm Sam Jordan, and I'm an Allogeneic Stem Cell Transplant recipient. I'd like to first thank my doctor for giving me this opportunity, and to thank all of you for the honor of allowing me to speak to you. I am truly humbled to be here before you. And I am pleased to tell you all that I have just celebrated my 5th re-birthday this past April.

When my doctor XRC asked me to speak on the topic of resilience, I went to look it up, to be sure I am using the word correctly. Resilience is: "the capacity to recover quickly from difficulties." I wasn't sure I identified with that, so I did more research.

I looked up a few other related words: perseverance: "steadfastness in doing something despite difficulty or delay in achieving success." Determination: "firmness of purpose; resolute-ness." Tenacity: "the quality or fact of continuing to exist; persistence." To me, these spoke directly to me about who I am and what I have been through.

People fighting cancer often refer to their "journey." I have never been keen on that term. To me, this is not a journey; it's a cage match. Two go in, one comes out. And that one had to be me. Because cancer could not win this fight.

I have been asked to tell you *my* story, because I have had to bounce back from many unfortunate circumstances. Now, I say this as I look out at all of you. And I know that your challenges have been just as hard. We have all fought against overwhelming odds and achieved success. Each and every one of you: survivors, caregivers, and hospital staff. You are true fighters and I'm in awe of all your successes.

Let me start my story by giving you a little background about myself. Throughout my life, I have worked in quite many fields, including being a lifelong musician. I have been a professional stagehand; setting the stage for some of the biggest acts in the world, I have worked in the Boston tourist industry, got a degree at age 39 from the Rhode Island School of Design, worked as an Art Director, and as a Database Developer and as a Project Manager. And I'm also an Audio Engineer.

In 2003, I met the woman I was going to marry, and we married in 2006. In 2005 however, during a routine office visit with my PCP, I had an elevated platelet level, and was referred to a hematologist who confirmed that I had Myelofibrosis. When I asked him what that is, he told me simply, "it's a disease where rivers of scar tissue develop in your bone marrow. There's nothing you can do about it, so go home and try not to think about it." Well, as I'm sure everyone in this room knows, that is some terrible advice. But, I didn't know better at that point, so that is what I did.

Nothing more happened on that front until 2011, when we spoke with several top doctors in the field, and learned what we really were up against, and what we could do about it.

We prepared for the big transplant day at MSKCC, I met my psychiatrist on my first visit to the hospital, and she has been with me right through the whole battle. The transplant itself was pretty typical. The chemo was horrible, but we *all* know THAT! The ATG I was given to kill my T cells made me hallucinate.

I got Epstein Barr and Cytomegaly Virus within days of each other. I had hemorrhaging in my lungs and in both my eyes, making me blind for the next few months. Then came the biggest complication. Toxoplasmosis. Unfortunately, I had tested a false negative so I was not shored up against it, and when it happened, the doctors were not looking for that, and had a good week to take hold and feed on my brain. The result was complete loss of control of the left side of my body. Toxoplasmosis causes hemiballistic movements in the arm and leg, aptly named because of the ballistic force in which the uncontrollable movements behave. So, there I was, blind, my arm and leg thrusting uncontrollably. At some point during all of this, I was having terrible delusions and hallucinations in which I believed that the hospital staff who was trying to help me were monsters who were trying to kill me and eat me.

However, while doing this, and presumably due to the chemo brain, I would go for hours and sometimes even all day without speaking to my wife. I still didn't really know how to form complete sentences at that point, and it was about that time that she told me that she was deeply depressed and was leaving me. As my psychiatrist has said to me, "she was your advocate during your treatment but unfortunately the burden of the disease was bigger than her commitment."

This left me to deal with the rest of my recovery alone. As I could not afford our New York apartment by myself, I moved to the Washington DC area, where my father and stepmother live. They helped me in getting set up, but due to my father's old age and infirmity, when push comes to shove, I was still dealing with the day to day by myself.

In the years that followed, I was struck with a terrible depression at my situation, my loneliness, and the depth of my loss. I was so far off in my expectation of how long my recovery would take that it was crippling. I took to just lying about and didn't care about much of anything, although, still determined not to lose my music, I focused on learning to work as an audio engineer. I tried a few dating sites, but decided that I needed to get myself together before trying that. I started applying to jobs, and almost had a really good one with the State Department. They went so far as to send me an offer letter, then rescinded it when they realized it wasn't in their budget. Another disappointment. I have continued sending out résumés, but who would have thought, a 58-year-old man who hasn't worked in 7 years is not a very hot commodity on the job market! So, I had to decide. Not wanting to sit in front of a computer all day for the rest of my life, dismayed with the status of the web and social media, and with many years being out of various fields, I decided to go to community college and formalize my certification in Project Management. Being certified, even at my age, could make me a viable candidate for work.

Bottom line: I lost a lot. I lost my wife; I lost much of my music, although I staunchly refuse to give that up. I am working to find new ways to approach music, using technology as my main instrument. I lost my career path, which cost me a lot of money, as well as a secure future. I lost much of my mobility, which is an ongoing struggle to regain. The Toxoplasmosis also affected my short-term memory. In short, I feel like I went in a young man, and came out an old man. Yet, for everything I have lost, I am working and fighting and kicking and scratching my way back to doing as much as I can that I used to be able to do, having decided that it was not enough to just survive, but to thrive. Is that tenacity? Perseverance? Determination? Is it resilience? I guess that I would have to say yes to all of the above. I am bound and determined to get back to the world, as scary and alien as something that basic might feel to me now. I am up and walking as much as 7 miles a day, walking 10–20 flights of stairs, do some light weights, and I am fighting to get myself back onstage again. I simply refuse to have my voice silenced. I refuse to give up, because giving up is letting cancer win. And cancer cannot win this fight.

Which brings me back to the subject of this talk. Resilience. How resilient am I? Having thought about it, I believe that resilience is born out of determination, out of the refusal to give in, or to give up what you love; no matter what the odds. And I leave you with these simple, parting words. Life and love. That's what matters most. And that's what we fight for.

Thank you.