

## Neil Curtis' IMPACT Story

02/28/18



*As I continue to navigate this confusing frontier where nearly every decision feels dire, I feel emboldened by having The EndBrainCancer Initiative, [endbraincancer.org](http://endbraincancer.org), on my side. I know that the compassionate team there is always just an email or call away to weigh in on any problem, large or small. - Jenna Curtis Coote, daughter*

Meet Neil Curtis: My dad was always the pinnacle of good health. He was a natural athlete who worked out every day, took his vitamins, and ate lean meat. He was always keeping an eye on his cholesterol. When we received the news that he had a Grade 4 brain tumor, we were shocked. I took a break from sitting vigil at his hospital bed after a successful resection to go to a long ago planned appointment at Kleinfeld's to try on wedding dresses. My mother, aunt, cousin and I all cried as I stood before the mirror in white dress after white dress. It wasn't because the dresses were so beautiful. My fiancé and I debated pushing up our wedding which was over a year away but decided to play it by ear. My dad was tolerating chemotherapy and radiation well and ultimately, he was able to walk me down the aisle and spin me around at our father daughter dance. He even gave a hilarious speech that had our guests roaring with laughter.

Still, the day felt bittersweet. Two weeks before my wedding, we learned that his glioblastoma had recurred. Our doctor suggested we research to find a clinical trial that we wanted to participate in. My dad's wife and I started frantically making calls, and as friends and family offered to help, I made a monstrous spreadsheet to keep track of who was doing what and which studies sounded like they might be a good fit. I called several services and organizations that promised to help find clinical trials, but they sent us hundreds of pages worth of trials, much of it in medical jargon that went over my head, and some that we weren't even eligible for. I called so many hospitals that left me with the same message - have your doctor call our doctor. We relayed those messages and eagerly awaited our next appointment so that we could come up with some kind of game plan. When we entered the doctor's office, we were dismayed to learn that our doctor hadn't made any of the calls we'd asked him to make. Furthermore, his team rejected some of the studies I'd thought were promising saying that the agents being used were too toxic or that the locations of the studies weren't reputable. They offered no other solutions. I felt frustrated and upset but my father's wife felt angry. She yelled at them that we needed their help, and after a heated discussion, we devised a plan.



*Neil walking his daughter, Jenna, down the aisle*

I scheduled my dad's surgery and a week after my wedding, we all sat somberly in the waiting room at Weill Cornell. We had elected to move forward with the Tocagen clinical trial and were happy to hear that he had received the injection and that the tumor had been removed. That March, my dad and I were alone at the appointment and our regular neuro-oncologist wasn't there. I could tell by how

nervous his replacement was that the news wasn't good. The tumor had recurred in the right frontal lobe and had spread to the corpus callosum where it was inoperable. I was devastated. I stayed at my dad's apartment all weekend, my husband and I sleeping on an inflatable mattress in the living room. Armed with a new neuro-oncologist with a gentler bedside manner, my dad started a regimen of re-radiation and nivolumab. This seemed to stop the tumor from growing and my dad decided to move to Florida where he could enjoy the sunshine and go swimming every day. In the meantime, I continued researching and discovered The EndBrainCancer Initiative | Chris Elliott Fund ([www.endbraincancer.org](http://www.endbraincancer.org)) on Facebook. I saw a post about their mission to provide patients with access to advanced treatment, clinical trials, and critical care. I researched their direct connect services and kicked myself for not finding them sooner. It was exactly what I had been looking for.



*Neil Curtis celebrating life*

The tumor remained stable but my dad's physical abilities began to decline. When I saw him for Thanksgiving, he could barely make it up the flight of stairs to my apartment. I decided it was time to reach out. Their "Direct Connect" Patient Services Staff immediately emailed me and got permission to send me a packet full of vital information and inspiring stories from other brain cancer survivors. As I scanned through the pages, I felt hopeful for the first time in months. I scheduled a call with their team to walk them through the particularities and was floored by their warmth and their astuteness. They posed questions that hadn't occurred to me and offered alternatives that I hadn't heard of. They connected me with other brain cancer communities where people like me were making spreadsheets, calling hospitals, and doing everything they could to keep their loved ones alive. They even found a clinical trial out in Florida close to my father that seemed like a good match. We decided not to pursue it as my dad's tumor was still stable, but I met another neuro-oncologist and ally I could turn to and I felt safer knowing I had one more study in my back pocket. When a friend reached out to me on World Cancer Day to tell me that her mother had glioblastoma too and that it had just recurred, I sent her straight to the EndBrainCancer Initiative. "I know I'm leaving her in capable hands," I told them.



*Neil with his favorite aide*

Whenever friends reach out, asking to make a donation in support of my father, it is to this organization that I direct them to in thanks for the support that they have shown me in this time of need. If you would like to make a donation, please visit ([www.endbraincancer.org](http://www.endbraincancer.org)). It is sure to save someone like me from losing their mind making phone calls and spreadsheets and enable them to spend more time with their loved one instead.

Sincerely,  
Jenna Curtis Coote  
Loving Daughter

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