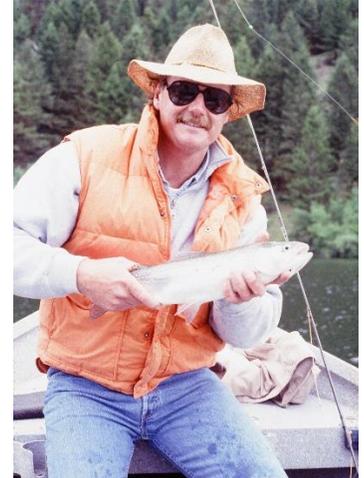


Dean Simmons IMPACT Story 12/15/16

It's hard to express the devastation of a diagnosis of Glioblastoma multiforme, a Grade 4 cancer, to anyone who has never experienced it. The day my husband, Grady Dean Simmons, was diagnosed will never be forgotten for the havoc it brought to so many of our families lives. Dean was well loved by many people and touched so many lives with his gentle, kind and humorous nature. He was a very active, high energy man that was in good physical health. One day at the age of 57, he experienced panic due to memory loss and cognitive functions. Upon diagnosis, we were immediately in a state of fear. The only direction we had was from the Neurosurgeon, Radiologist and Oncologist from within our healthcare system.

Here is the PROBLEM:

Dean's tumor at diagnosis was 5 cm and crossed the corpus callosum, and was therefore un-resectable. It took three weeks for pathology to finally send us results and by this time the tumor had grown to almost 6 cm. We immediately started standard protocol treatment and Dean quickly lost quality of life. From the start, the Radiologist team treated him like "Dead Man Walking". Even though there was only one treatment offered, it was plain that it was not a cure and was only temporarily extending life for a



Dean on a fishing trip



Dean and I dancing at my birthday

short period of time. My husband was never able to pro-actively participate in any decisions regarding his treatment plan as he was mentally unable due to the tumor. All decisions were left to me, his wife and only caregiver. Dean was the love of my life, and despite the grim prognosis, I was unable to accept his short life expectancy. **I spent hours researching all other available types of treatment, because there was NO ONE else to do this or help me do this.** When trying to discuss these ideas with his radiologist and oncologist, they were unopen to alternative care and unhelpful regarding any other programs that were not the standard protocol.

My Experience:

Unfortunately, I never found the Endbraincancer Initiative (<https://endbraincancer.org/>) online, whose Mission is dedicated to closing the GAP to advanced treatment and clinical trial participation, and to providing HOPE to brain tumor patients and their families nationally. Their daily work connects brain tumor patients, caregivers and their families immediately to advanced treatments & clinical trials. They do that by connecting brain tumor patients and their families to: 1) TOP Brain Tumor Neurosurgeons, Neuro-oncologists and Specialists in the U.S.; 2) Immunotherapy Vaccines; 3) 2nd, 3rd, 4th opinions; 4) Genomic Profiling/DNA Sequencing; 5) MGMT and Protein Testing. Because today, I believe they could have helped.

While spending my nights online looking for any alternative treatment plans, I was still managing his physical needs and trying to take care of our business and home. I was panicked over every decision. I felt isolated and alone, the only one responsible for Deans healthcare as he started to suffer from side effects of the chemo and radiation. First, he became ill with a pulmonary embolism. Not once did any of the doctors inform us of this very common side effect of the chemo and cancer. Quickly following the pulmonary embolism in his lungs, the blood thinners prescribed to fix the blood clots precipitated a brain bleed, another side effect we were not warned of. From that point, he was admitted to the ICU. While standing over him, the surgeon point blank asked me what I wanted him to save, his brain or his body. My husband, who was barely coherent in the bed, teared up and said "so that's it? I'm just going to die?" I quickly pulled the surgeon outside the room and he informed me that Dean would never walk again. He kept suggesting hospice as the best course

of action. At that point, I asked why he was even in the hospital if his prognosis was so bad, of which he said so that Dean could be monitored. I demanded that they release him that day. **Within 3 days he was standing and walking with a cane.**

The hopelessness expressed to the families in all aspects of this disease from the healthcare teams, the treatments and the support groups was astounding. I felt the entire healthcare system was broken in regards to brain cancer patients. Not only for saving lives, but also the emotional compassion from doctors to nurses while treating patients.

My Biggest Complaint:

My biggest complaint was that we were never informed of our **OPTIONS**. Options being, alternative care, quality of life decisions or clinical trials. I believe the standard care treatment took away his quality of life. After radiation, he could no longer function cognitively. He was unable to dress, feed or take care of himself. We did not know that the side effects of chemo and radiation would cause him to be in constant pain, in and out of wheelchairs the rest of his life. We were not told of the devastation of the Dexamethasone on his body and how it would deteriorate his muscles and skin.

Please Learn From Our Experience:

I believe that every brain cancer patient has individual needs. The one treatment plan fits all does not work. Doctors that do not specialize in Brain tumors should not be allowed to treat patients. Immediate alternative treatments should be discussed. All consequences of current treatment should be disclosed. All tumors should undergo genome testing immediately for research on how to best treat that particular tumor.

Dean lived 9 months after diagnosis. His particular tumor was advanced and aggressive and had we done nothing at all, he may have lived only 1 month. But it should have been our choice on how he lived that time from being well informed instead of blindly following advice that was set up to fail.

I was devastated by his death, as was his family and children. With the current treatment plan offered, he never had a chance to live. I am currently volunteering at End Brain Cancer for the organization's "Direct Connect" Program to help others afflicted with this disease and hope that with my knowledge can help them to make better informed decisions quickly that Dean never had.

Learn More About the EndBrainCancer Initiative:

Unfortunately, this story is repeated over and over again, by the many past and current brain tumor patients and families. We need to support & promote the EndBrainCancer Initiative to help newly diagnosed patients to let them know there are other options and help them before it's too late.

www.endbraincancer.org

Thank you,

Anitra Simmons



Our tenth wedding anniversary