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## From Normal to Nightmare

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Narrative Inquiry in Bioethics, Volume 4, Number 1, Spring 2014, pp. 6-9  
(Article)

Published by Johns Hopkins University Press

DOI: <https://doi.org/10.1353/nib.2014.0015>



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## Introduction

# Confronting Pediatric Brain Tumors: Parent Stories

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**Abstract.** This narrative symposium brings to light the extreme difficulties faced by parents of children diagnosed with brain tumors. NIB editorial staff and narrative symposium editors, Gigi McMillan and Christy A. Rentmeester, developed a call for stories that was distributed on several list serves and posted on Narrative Inquiry in Bioethics' website. The call asks parents to share their personal experience of diagnosis, treatment, long-term effects of treatment, social issues and the doctor-patient-parent dynamic that develops during this process. Thirteen stories are found in the print version of the journal and an additional six supplemental stories are published online only through Project MUSE. One change readers may notice is that the story authors are not listed in alphabetical order. The symposium editors had a vision for this issue that included leading readers through the timeline of this topic: *diagnosis-treatment-acute recovery-recurrence-treatment (again)-acute recovery (again)-long-term quality of life-(possibly) end of life*. Stories are arranged to help lead the reader through this timeline.

Gigi McMillan is a patient and research subject advocate, co-founder of *We Can, Pediatric Brain Tumor Network*, as well as, the mother of a child who suffered from a pediatric brain tumor. She also authored the introduction for this symposium. Christy Rentmeester is an Associate Professor of Health Policy and Ethics in the Creighton University School of Medicine. She served as a commentator for this issue. Other commentators for this issue are Michael Barraza, a clinical psychologist and board member of *We Can, Pediatric Brain Tumor Network*; Lisa Stern, a pediatrician who has diagnosed six children with brain tumors in her 20 years of practice; and Katie Rose, a pediatric brain tumor patient who shares her special insights about this world.

**Key Words.** Acute Recovery, Advocate, Diagnosis, End of Life, Long-term Quality of Life, Pediatric Brain Tumor, Problem Parents, Second Opinion, Social Support Groups, Treatment.

In 1995, my husband and I were happily following the path of our "life plan". His legal career was on track; we had two children, and with the youngest safely settled into pre-school I was using a few hours each day to write a novel. When my little boy experienced a series of headaches, vomiting and double vision, his pediatrician sent us for a CT-scan to rule out "things". I remember the casual drive to the hospital. I remember buying a chocolate bar

in the gift shop. I remember the friendly radiation technician who joked around with us and invited me into the viewing booth. A few moments into the scanning process he stopped smiling, became formal and asked me to wait in the other room.

*A Brain Tumor.*

In the subsequent weeks, my husband and I struggled to make treatment decisions and manage the grueling reality of surgery, radiation and

chemotherapy. In later months we learned to advocate for our son's medical, educational and social needs. As the years passed, we gradually stopped thinking of our son as a rehabilitating brain tumor patient and instead, as a strong and healthy survivor—albeit with physical and cognitive difficulties. These days we gratefully embrace the lovely young man who lives with us (and probably always will) and we don't spend much energy on the vague sadness in the back of our minds.

I came to see how my family's experience followed a timeline that had nothing to do with the life plan my husband and I once envisioned. The McMillan timeline was *diagnosis–treatment–acute recovery–long-term quality of life*. The journeys of other families we met along the way sometimes branched off in other directions: *recurrence–treatment (again)–acute recovery (again)* or even toward the unhappiest outcome, *end of life*. Gallimore, Bernheimer and Keogh (1999) refer to accommodation domains experienced by families with children who have disabilities. These domains (e.g. family subsistence, domestic workload, marital roles and child peer groups) require different attention at each stage of the timeline. In the world of brain tumors, frustrated parents learn that a successful plan for one segment of the journey will not necessarily work for another segment down the line. There is a constant need to problem-solve and create new, layered strategies. As parents—as primary caseworkers for our children—we are never done.

Parents like me often wonder why our hard-earned knowledge isn't put to better use. Pediatric brain tumors and treatments come in many forms and family circumstances add other variables that call for great ingenuity and perseverance. Our work on behalf of our children has us interacting with the medical world, public school districts, local, state and federal agencies and a myriad of private psycho-social support entities. With little support, we create intricate systems that work for our children but in almost every instance, we start from scratch. Once we leave the hospital there is scant guidance as we manage the complexities of our "new normal". We have learned to talk to *each other*, to support *each other* but why don't health care professionals

show more interest? We ask ourselves: Don't they want to know what we do, why it works and then learn from us?

In this issue of *Narrative Inquiry in Bioethics*, we asked for parents to share personal stories about their experiences as they cared for their children who had been diagnosed with a with a brain tumor. We sent a call for stories to regional and national support organizations, posted in online forums and list serves, and forwarded the invitation to pediatric neuro-oncologists throughout the country. We asked parents to consider their personal timeline and describe their feelings and coping mechanisms. We wanted to know how they communicated with their family members, doctors and schools. We were curious about what support systems worked for them or were lacking. We encouraged them to share how the experience has influenced them, their child and the rest of their family. In every instance, we mentioned that this was an opportunity for *their parent voices to be heard*.

We received 45 proposals and of these, only three were written by fathers. This is not altogether surprising. In my experience with parent support groups, it is usually the mother who is most comfortable expressing her feelings or even speaking factually about the child's situation. As expected, parents shared poignant stories on a variety of topics and we organized these according to timeline segments. We chose stories that best illustrated a particular issue or covered more than one aspect of pediatric brain tumors. Our goal was to present a collection of narratives that best encompassed the total experience of the journey of this disease. In the end, we selected thirteen narratives for print, six others for inclusion in the online collection and offered a heartfelt invitation to the rest to post their account on *NIB's* new website. Each story was important, relevant and generously shared. It was difficult to "choose" some over the others.

There are three points I would like to make and the first involves grief. Many years ago the son of a close friend lost his life to this disease. I confessed to my friend that while I grieved for her loss I felt ungrateful, because even though my son was still alive—I grieved for him as well. She graciously and

lovingly gave me permission to have this feeling. Ken Moses (1987) speaks eloquently about parental grief over “the loss of the dream” that one has for a child when the child is struck with a disability. This grief returns at the arrival of every milestone that is not attained. My friend pointed out that as parents, our grief begins at the point of diagnosis, and our mourning continues, no matter which direction our journey takes us.

Secondly, the path is easier if we are not alone. I cannot emphasize enough the value of peer mentoring and support groups for parents, patients and siblings. The burden is simply lighter if someone stands beside us. There is obvious value in receiving emotional support, but there is surprising and gratifying healing when in-the-trenches strategies that we construct for our own use can be helpful to others.

Thirdly, while this collection of narratives can be heart-wrenching, I don’t want the beauty of the human spirit to be lost in the drama. In each narrative, parents describe their struggle to embrace a new reality. There is grief. There is love. Unspeakable decisions must be made. In these most difficult of circumstances, pretense falls away and the world becomes very small and focused. There is great capacity for joy as adults and children learn from each other how to be their best selves.

Our first commentator is my co-editor, Dr. Christy Rentmeester. She is a professor of Health Policy and Ethics at Creighton University School of Medicine with a special interest in moral responsiveness to vulnerable populations and underserved communities. She happens to be an IRB member, too, and we met at a conference at which I was presenting on challenges faced by community members on IRBs. She sought me out after my talk to chat about a few points and we soon recognized our common interest in narrative. We kept in touch and shortly thereafter, developed the project of defining the nature and scope of what has become this issue of *NIB*. As you will see in her commentary, she draws upon her experience as a bioethicist to execute a gentle but probing analysis of ethics themes woven through these stories. Our second commentator is a general pediatrician. Most pediatricians see *one* pediatric brain tumor in the life of their practice, but Dr. Lisa Stern has diagnosed

six. Her internship in pediatric oncology before she moved to general practice has stood her good stead and my own son had the good fortune to be under her care in that crucial moment of his young life. Dr. Michael Barraza is a Clinical Psychologist who currently works with the Los Angeles County Department of Mental Health and has spent a great deal of time with families of children who have brain tumors. In the past ten years, he has moderated support groups and directed three-day family camps in English and Spanish that allow parents and children to safely express their thoughts about dealing with this disease. Last but not least is Katie Rose—a brave young woman who weathered her teen years under ambiguous diagnoses and difficult decisions but survives her ordeal with insight and strength of character that is inspiring. Her final words are a message of hope, and with the other commentaries, comprise a symposium that empowers the storytellers and enlightens the professionals who serve them.

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## Personal Narratives

### **A Bittersweet Score: A Father’s Account of His Family’s 20-Year Journey After a Pediatric Brain Tumor Diagnosis**

Christopher Riley

I hadn’t seen him for 20 years, not since the day he drilled a hole in Peter’s head and left the stainless steel drill and bloody bit on the bedside table. He figured prominently in the story I often told of that day when he, a doctor in training,

informed my wife Kathy and me that, “Wow,” our five-year-old son had “an impressive tumor” in his brain. He announced it with the admiration I reserve for a touchdown pass or stunning sunset. Since that day, he had become a venerable physician. Back then he was the resident who met us in the ER after our pediatrician told us that the MRI of Peter’s brain was “not normal,” that “there might be a growth.” As if there might not be. I imagined that Peter’s brain might simply have an unusual shape, or that the scan revealed some undiscovered fracture and the authorities only wanted to lock me up and all with my son would be well. The thrilled young doctor slew those hopes with an ice pick: “Wow, that’s an impressive tumor.” I said, “That’s the first time anyone has used the word tumor.” The doctor appeared mortified and started over.

Now 20 years later we found ourselves at the same party and I felt a compulsion to introduce myself, remind him we’d met that day in 1993, and tell him what had become of Peter and his family in the decades since he’d made that mortifying mistake, one I hoped had become for him a defining moment. To my disappointment, he didn’t seem to remember.

Peter was my red-haired boy. Fearless and whip smart, he told a stream of knock-knock jokes and performed dance routines choreographed by his 8-year-old sister Rachel. Six months of headaches, vomiting and clumsy falls led to discovery of the tumor. When I phoned my parents with the news, I couldn’t speak the words, words that felt as if they spelled my boy’s doom. My body refused to pronounce them.

The war for Peter’s life began with surgery. I sat with Kathy in the surgical waiting area, fearing every minute that I would see the surgeon approaching with his shoulders slumped in mortal defeat. I learned during those hours that fear of your child’s death is a physical pain, a constriction in the chest, a suffocation. At the end of that wait, the surgeon told us the tumor was out and Peter had survived. The pathology indicated the tumor was a medulloblastoma. Without additional treatment, including radiation, it was certain to come back. Kathy’s knees buckled. Having just endured

one life-and-death battle, we were plunged into another. To complicate matters, Peter wasn’t waking from surgery. Even after the anesthesia wore off, Peter remained groggy, unable to move or focus his eyes.

Through the following days, Peter failed to rouse or speak. Sores formed at the back of his neck where his unswallowed saliva pooled. Neurologists doubted he knew us. His doctors hoped Peter would recover but it was possible he would remain as he was indefinitely. As I sat holding his useless hand, watching his useless body, I thought I’d never loved him as much as I did now.

Peter’s doctors presented two treatment options. The first consisted of relatively high doses of daily radiation, the most effective known method for preventing the return of the cancer. But radiation wasn’t good for young brains. It “shaved IQ points,” they said in wild understatement. So they offered a second, experimental option, one that reduced radiation by a third and added months of chemotherapy. The doctors hoped this new regimen would be as effective as the old but cause less cognitive damage. They asked us to choose. It seemed impossible. We gathered the scant available data. We weighed the risks. We prayed. We took a leap. Without asking him, we made a decision for Peter we knew might cost him his life. We chose reduced radiation plus chemotherapy.

In the weeks that followed, Peter laughed at a tape recording of his friend burping. He laughed at a joke. He began swallowing his spit. His eyes focused. His right arm moved in his sleep, his hand floating like a pale butterfly above his still body.

On day 30 after surgery, we visited the neurosurgeon. He told us he’d searched the medical literature and found accounts of Peter’s mutism in other patients. Afflicted children usually recovered their speech, most often one to three months after the silence set in.

That afternoon, Peter spoke.

Kathy called me at work to let me hear Peter’s voice groan an elongated “Noooo-oooo-oooo” again and again as Rachel paid him dimes for every word. The next day, we asked him what he wanted to eat. He answered, “Nuth!” followed by

a silence so long we doubted he understood, and then finished abruptly with, “ing!”

Radiation began. Despite the daily treatments, which required Peter to receive anesthesia to lie still while his developing brain absorbed the IQ-shaving rays, his vocabulary expanded. His right arm and leg returned to his control. When his left arm and leg lagged, we spread coins across a tabletop and told him he could keep all the money he scraped into a bowl using what we called his sleepy hand.

Chemotherapy followed, eight cycles of six weeks each. His blood counts plunged. Fevers spiked. Four out of eight cycles, Peter got so sick he had to be hospitalized, medicated, hydrated, transfused. His central line became infected and had to be replaced. He lost so much weight he had to be saved by a feeding tube. During this time, Peter learned again to walk. To throw and, infrequently, catch a ball. To tell his jokes. Every step was painstaking and perilous. There were multiple emergency hospital admissions, a bloody trip-and-fall, a concussion, a drug reaction, an ambulance ride, constant tension. The outcome was always uncertain.

Through all of this, Peter’s big sister suffered. Before his surgery, Rachel had said goodbye to her best friend in the PICU. She’d gotten back a monster. She no longer knew her broken, disfigured brother. She was cared for by friends and grandparents. She saw the worry on the faces of strangers delivering casseroles. She caught parts of conversations she only vaguely understood. She seldom saw her parents. When Kathy made an appearance, Rachel said, “Mom, you’re better than a thousand grandmas.”

One rare Saturday night when all of us were home watching a movie as if we were the family we used to be, Kathy noticed that Peter felt warm. We knew his blood counts were dangerously low so we took his temperature and paged the oncologist. He told us to bring Peter to the ER. Rachel refused to be left behind so we bundled her off to the ER to witness the efforts of the medical team to keep Peter from succumbing to his cure. This was our new family night.

Rachel contracted chicken pox in the middle of Peter’s six weeks of radiation, with his immune system so weak this virus could kill him. We sent

Rachel to endure her illness at the home of friends. When she was sickest, we deprived her of the comfort of her family. We sacrificed the good of one child to save another.

It took me years to be able to confess that act aloud without weeping.

And it took years for Rachel to admit to us that during those months of Peter’s treatment, she had climbed the monkey bars more than once and thrown herself down, hoping to snap a femur, hoping for a medical crisis severe enough—more severe than chicken pox—to earn her parents’ attention.

We wish we’d known. We wish there’d been more time. We wish we’d paid more attention.

Kathy experienced all of this in her own way. I experienced it in mine. In the beginning, the differences were small. Kathy couldn’t eat. I ate cookies and ice cream, and it felt to Kathy that my anxiety, and hence my love, was less than hers. Kathy wanted to push the doctors. I was inclined to wait and see, adding to her feeling that she was fighting to save Peter alone. But at the beginning, our shared stake in the outcome of these battles, our shared anguish, overwhelmed the differences. Later the gulf grew. As Peter’s losses began to look permanent—the impaired hearing, the falling further behind in school, the inability to make friends, the loss of coordination that made it nearly impossible to catch a ball—Kathy spoke of her disappointment with an honesty I couldn’t muster. She told me she imagined what our stunted son would be like if he’d remained whole. She said she imagined him when she drove past high school football practices, handsome and smart and strong. I felt myself crawling out of my skin. She’d gone to a place I couldn’t go. Both of us felt the distance.

Kathy was grieving. Her grief wasn’t about the death of her son. It was about the death of her dreams. I was still pretending those dreams lived, that the losses weren’t real, that in the end we would see Peter’s brain cancer as a blessing in disguise.

I needed years to learn to grieve. To say out loud that a sad thing had befallen my family, a thing I hated. To admit the losses were real and lasting and that I would likely never make sense of them. To let myself feel the pain.

It created a place for Kathy and me to meet.

Kathy and I discovered we weren't the only family with a child battling a brain tumor. We met others, a hospital roommate, then a family a hospital worker introduced, then a steadily growing number of families who gathered to pool our knowledge and offer one another mutual support. From these families, Kathy and I gained perspective, a sense of our place on the long road we were traveling. We also shared comfort, a gift that can only properly be given after it has been received. We witnessed losses deeper and more total than ours, pains of a magnitude beyond ours, and we grew to respect the suffering of others, to eschew platitudes, to sit in silence and offer love in place of words. We came to see suffering as holy ground.

Peter experienced a slow, uneven recovery that included his return to school, piano lessons, a shunt malfunction, special education and all the battles and disappointments that entails. The distance in time between Peter and cancer widened. Peter's doctor told us we could discontinue his annual MRI scans. He told us Peter no longer needed the shunt that had been implanted in his brain nearly 10 years before. He told us Peter's tumor was done.

We suspected it wasn't as simple as that. We'd heard of late recurrences. We'd heard of second tumors caused by treatment for the first. We changed doctors and continued the yearly scans.

Good thing. Because even as Peter plinked his way through a piano recital and exhausted himself keeping pace in school, the radiation he'd received years before was giving back in the form of a new brain tumor, this one not cancerous but growing nonetheless. Peter called it "my small benign tumor." The neurosurgeon who removed it said now that he'd had one, he was likely to get more.

Kathy and I attended funerals of children we knew whose tumors hadn't been cured. Our daughters insisted, when we tried to protect them from it, on joining us to visit the home of a child in his last days. Peter started plugging his ears when he sensed we had news of another friend who had died.

Fifteen years after his original diagnosis, Peter managed to graduate high school. He went to his

prom. He played soccer on a team that included blind and autistic players. Sometimes I relished the fact that Peter played on a team. Sometimes I felt only grief that Peter played on *this* team.

Twenty years after diagnosis, taking one college class per semester, Peter earned a certificate in child development in hopes of a job working with children. He still tells his jokes. He wants the independence of riding the city bus. I can't let him. He forgets to look before crossing a street. No one can say how the delicate tissues of his brain will respond in the coming years to the treatment he received, the surgery, poisons and radiation. We walk with Peter into our future with gratitude for his life and these many bittersweet days, but with more questions than answers.

How could I have told any of this to the doctor at the party? All I might have had time to say was this:

"I hate brain tumors. Thieving bastards. Take your wow-that's-an-impressive-tumor enthusiasm and find a way to kill them all. But please! Remember who we are."

Of course that isn't polite party talk so I said none of it. Kathy might have. She wants to push the doctors.

I'm inclined to wait and see.



## From Normal to Nightmare

Brandi Wecks

A well check visit is usually a simple appointment to weigh and measure a baby, check for normal development and answer a parent's questions. The appointment for my 2-month-old daughter Scarlett quickly turned from normal to a nightmare thanks to brain cancer.

A few weeks prior, we noticed a bruise on her forehead—how would a newborn get a bruise? What we thought was just a bruise was a signal to the pediatrician of much more. She felt the top of Scarlett's head, with its tight, bulging fontanel, and

sent us straight to radiology for a CT scan. From there, we were sent to the ER to await an ambulance transport to the children's hospital.

It was a whirlwind. My husband and I were panicked, confused and scared. Nurses poked at Scarlett's tiny arms trying to get an IV, telling us to hold her arm tighter, twist it this way, hold tighter, as she and I cried together. Once the IV was finally in, the questioning began—we were being questioned separately, simultaneously, trying to define the source of the mystery bruise. We were asked repeatedly how it happened, and we had no answer—it just appeared. She had never fallen, been hit or shaken. I grasped at straws for an answer for the relentless steam of questions; the only possible cause of this supposed injury was weeks prior, when I had laid the baby on the bed to change my shirt. Our dog, fifteen pounds of curls and snuggles, jumped onto the bed as he always had, except this time, the baby was there, and he landed on her. She was unhurt, barely fussed. I hardly thought of it again, until I was panicked about solving the mystery of the bruise.

The bruise, with my story of the dog and a CT scan that showed abnormal bleeding in the brain, led the ER staff to call Child Protective Services (CPS). In my experience as a teacher, it may take several reports to get CPS involved with a child; for us, a social worker was sent out immediately and made it to the hospital shortly after we did.

Scarlett's ambulance ride was the first time we were separated from her. We met her in the pediatric intensive care unit (PICU), where nurses and doctors were busily attending to her. We saw her briefly before we were pulled aside to speak with the neurosurgery resident. He took us to a tiny room with two couches, and we sat nearly knee to knee as he described what he saw in the CT scan. He brought up the image on his phone as he described the giant mass in her brain as "impressive." To him, impressive was unusually large and shocking; to us, it was the first experience with what we call "doctor-ese," the vocabulary of the emotionally-detached medical professional. I know he explained more about what to expect over the next few hours, but I remember nothing after "impressive".

Minutes after being returned to Scarlett's room in a fog, we were interrupted again, this time by a social worker from the county Child Protective Services. We were taken back to the tiny room and once again asked the litany of questions about Scarlett. By this point, it was clear that we were dealing with something far beyond a bruise, but now that the investigation had begun, it was barreling on. We were asked about our education history, current employment, how we handled stress, what we did when the baby cried, and about our dog. Within 30 minutes of being told our daughter had a fist-sized brain mass, we were being questioned about how we trained our dog and if we knew it was unsafe to leave the baby alone with him. We were in such a state of shock, and the line of questioning so bizarre that we simply answered and waited for him to let us go. Before he allowed us to return to the PICU room, he asked if we would be home Tuesday so he could "stop by and check the house for dog feces." We said we didn't know, but it sounded like we would be in the hospital for a while.

The next morning, the bomb was dropped: Scarlett had a 10 cm by 7 cm tumor filling the left side of her head. It was not just in her brain; it had grown in place of most of her left hemisphere as she developed. We looked at the MRI images in awe; it was obvious that there was something severely wrong with what we were seeing. I checked and rechecked the name to make sure it was her, even though I could clearly recognize the silhouette of her chin and nose.

In our first meeting with the head of neurosurgery, we were drowned in information. It was almost certainly malignant, maybe AT/RT (Atypical Teratoid Rhabdoid Tumor) or PNET (Primitive Neuroectodermal Tumor) (meaningless then, but so familiar now). The pressure was building quickly and causing the bones of her skull to shift, which was causing the bruise. These tumors are common (more doctor-ese) in infants because their brains are growing so fast that rogue malignant cells are fueled at an alarming rate, creating a massive tumor before many effects are seen. The outcome for these babies is poor; treatments often leave them with no quality of life.

A biopsy a few days later gave it a name: congenital glioblastoma multiforme. This brain tumor

is most commonly found in older men, it killed a senator and is considered a death sentence in adults, but is exceedingly rare in children and even rarer in newborns. Now it was killing my daughter. While the neurosurgery team finished the biopsy, the department head explained their findings. He described how he observed her skull bones to be eroded where the tumor was pressing against them, and how the nickel-sized piece removed pouched out of her skull as it was excised. He then described in excruciating detail how the tumor would continue to grow, choking off her vital functions until she died. He estimated we had a few weeks, maybe a few months. We could make her comfortable with medications until the inevitable time came. Hospice would meet with us soon.

There was no discussion of further surgery. There was no mention of chemotherapy, radiation or any treatment whatsoever. That there was no possible treatment was stated as a fact, and was something we did not even consider questioning. We were sent home two days later to enjoy Scarlett's first, and apparently last, Christmas. However, before we could even catch our breath, we had to face the CPS worker once again. He called within minutes of us walking in the door at home, asking to come by as soon as possible to inspect our home. He told us he just needed to close the file, and we tried to be patient as he asked to see the bedrooms and the bassinet where Scarlett slept. He told us that the case would be marked unfounded, so there should be no problem when I wanted to apply for teaching jobs. He briefly asked how we were doing, and we had little to tell him—we just brought our daughter home to die, and here you are looking for a crime; how do you think we feel?

We tried to use his forced presence to our advantage. We asked for any services or support that might be available from the county to assist us with the now—mounting medical bills, grief and other crisis issues. He said he would get back to us after the holiday; for better or worse, we never heard from him again.

Christmas came. We forced ourselves to smile, trying to forget that we were forcing steroids down her throat to give us “quality time,” or that the toys

we had bought for her would never be played with. We tried to create memories while watching her every move for a symptom.

After the holiday weekend, we reconvened at the hospital, this time with the neuro-oncologist we had met the week before. He explained the diagnosis, the rarity, and, for the first time, the options we may have in treatment. It was all dismal: radical surgery, chemo, or both. He knew we had not been presented a surgical option by his colleagues in neurosurgery, but he was not stopping there. He suggested we meet his “friend,” a neurosurgeon at another children's hospital nearby. We were sent directly there, with biopsy reports and MRI images in hand. We arrived shortly before the surgeon was leaving on vacation.

We waited nervously in the consultation room while the doctor reviewed Scarlett's MRI. We had no reason to believe we would hear anything different than we had, so we had braced ourselves to hear the horrors all again. In just minutes, he returned and said the most hopeful words I have ever heard: “We have to try.”

Total shock. I had cried a lot in the last few days, but this was the first time I had felt any relief. I made him repeat himself because I was not sure I could trust my first reaction. I had prepared myself for many feelings, but had not considered hope. He saw a chance for Scarlett, and was not going to let her go so easily; in that brief meeting, he saved her life and mine.

He continued on, describing the long and dangerous surgery he was proposing to remove the tumor from Scarlett's brain—20 hours at least, weeks of intensive care, followed by chemotherapy. It would not be easy for any of us, but it was the only shot we had.

By the end of the week, Scarlett was admitted for observation, supplemental feeding and preparation for surgery. Then, in two 12-hour surgeries in the first weeks of the year, the tumor was removed. Scarlett battled paralysis, blood loss, seizures, a stroke and severe swelling, but came through it all. She was discharged at the end of January, a month after we were told she would die, tumor free.

We chose to continue oncology treatment with the first hospital's neuro-oncology team, but

remained at the second for neurosurgery; this meant some creative scheduling and a lot of driving between the two, but any complications were handled by the doctors. They continue to openly communicate and share information about Scarlett, and we continue to be grateful to both sides for their efforts to work together despite being at separate facilities.

Chemotherapy began in February, and lasted 12 long months. We were in and out of the hospital constantly for her first year, fighting through neutropenia, ventricular–peritoneal (VP) shunt placement (to relieve fluid pressure in the skull) and revisions, dehydration and infection. The effects of chemo made her stop eating on her own, and caused significant damage to her hearing.

As her second birthday approached, and it finally seemed that we were finding a “normal” life, a spot of new tumor growth was found on her routine MRI. She remains in treatment, but continues to make developmental progress; she is learning to walk and talk, use sign language and eat on her own. She is happy, and brings joy to everyone around her. We still have nightmares about those first harrowing days and, as so many other parents who have been through this know, the worrying never ends. Every bruise gets a second look, whether it is on her head, arm or toe. Despite the stress, worry and seemingly never-ending challenges, I will always be grateful for the second opinion that changed Scarlett’s life.



## Second Guessing

Anonymous One

**T**his is difficult for me to write because I have tremendous respect for every doctor that has been involved in my son’s care. I firmly believe that they chose and administered the highest level of care that they assessed as appropriate; that they cared for him both personally and

professionally as if he were their own child; and that he was in the care of acknowledged giants in their fields. I write this knowing that I will share this narrative with these doctors, in order that they can better understand the decisions I was faced with and the guilt I must live with feeling that I may not have made the best possible *informed* choice for my son, because of this trust and relationship.

Let me describe my oncologist. I say “my” instead of my son’s whose doctor he really is, because he is mine too in every sense of the word. He cares passionately about his work and about my son specifically; he engenders my trust because he is compassionate, brilliant, and available to me for concerns both great and small. His accomplishments have saved lives and will continue to impact his field. He became the narrow bridge I walk, that is the only thing between me and dangerous water and rocks waiting below; the balancing bar on the tightrope that is the only thing that stands to keep me from falling into the abyss and breaking my neck. And this made it difficult for me to disagree with him and seek a second opinion. Because his unspoken words were, “Don’t you trust me that I will do the best for your child?” and I could not answer then what I would answer now, “Nobody is infallible and sometimes we may miss something that someone else can see despite how much we know or care.”

It is ironic, I think, that sometimes a layperson, because of her limited knowledge, can see more clearly where a professional may not.

My son was diagnosed at age six with Grade II ependymoma in 2006. He was treated with surgery, a complete resection, and then 33 rounds of conformal radiation. He recurred in 2012, and was diagnosed with anaplastic ependymoma Grade III. He had another surgery, with the same surgeons, who pronounced it another successful total resection. This is where my story begins.

The MRI taken the next day showed a sliver of something there. My oncologist, much sought after for his diagnostic abilities in reading MRI’s showed slight concern that it may be residual tumor, but both the surgeons and the MRI report came back negative, identifying the sliver as inflammation. Six

weeks later, 3 days before we were scheduled to leave out of town to receive proton beam radiation, I insisted on another MRI. The sliver was enlarged from the post-op MRI. My oncologist said it was tumor; one surgeon said it was inflammation and the other surgeon abstained from speculation. The MRI report stated it appeared to be recurrent tumor.

Now here was my dilemma as a parent. The prognosis today of radiation on residual tumor for ependymomas is very bad, especially with a residual tumor of his size. On the other hand, my oncologist felt that going in for surgery with no guarantee of a total resection anyway, was incurring a risk of damage to my child that may impact severely on his quality of life.

My oncologist felt that for many medical reasons, inherent risks of surgery, uncertainty about status of the scan reading, quality versus quantity of life, and—I think—an understandably pessimistic view of the possibility of cure for recurrent anaplastic grade III ependymoma, he was against another surgery, and opted to continue with radiation with the tumor as is.

I am part of two support groups on line, one for parents of children with any type of brain tumor and the other specific for ependymoma parents. The clinical and anecdotal knowledge of these groups as a whole is phenomenal because, unfortunately, we have parents who have experienced and researched almost everything about this illness, in all its stages. When I was faced with this terrible situation, I posed the question to my support groups. Unanimously, the consensus was do surgery again in order to go for the cure, because, as one parent bluntly said, the children on our group who had residual tumor are no longer alive, victims of multiple recurrences, or dying.

To me the situation looked very simple. My surgeons are nationally acknowledged as giants in their field. They did surgery twice before, leaving my son intact with no deficiency except deafness in one ear; they could do it again. My oncologist is known in his field for his remarkable ability to read scans and if he said the sliver found after the surgery was tumor, then, I know it is a tumor. Ependymoma recurs over and over. Eventually, he will have to have surgery

again anyway with the same risk of surgery; so why not now, when there is a chance for a total resection and cure? The reason the resection needed to be done now was that thus far radiation for ependymoma is given maximum twice in a lifetime, and radiation is the only treatment available at this time that has the only chance for cure. If my son would undergo radiation now, with residual tumor, he would be wasting his last chance for a cure (because five years earlier he had radiation for his original diagnosis). Whatever risks surgery would hold for him then, would just happen sooner. It seemed like a no-brainer to me (no pun intended!).

But here is why I went ahead with radiation without another surgery.

I could not take the risk without my oncologist's support. The guilt in the aftermath of surgery with a bad outcome would have debilitated me emotionally.

Here is what I would have needed my oncologist to say to me, "Let's take all the scans, reports, emails, conversations about this matter and send it to this other brilliant and knowledgeable Dr. X in Facility X to have a look at it. Let's see what he says. If he does not agree with me, and feels you should undergo surgery, then we will talk then." I wanted him to say, "Don't feel rushed to make a decision just because you are scheduled for proton in three days. The difference of a week or two at this point is not as significant as the decision you need to make so you can live with your decision, whatever you decide to do. And the proton center will just have to wait."

But he didn't say that. And I did go ahead with proton radiation. And my child is now six months since radiation, with thus far no negative side effects of either surgery or radiation and the latest scan showed shrinkage of tumor. He is enjoying the quality of life my oncologist wanted for him. If he becomes the outlier and is a cancer survivor, then all is well; but if he is not, and the tumor recurs—as statistics show will occur—then the "what-if" will continue to haunt me. The difference would not necessarily have been in the final decision, nor in the outcome, had I sought a second opinion with my oncologist's blessings, but whatever my decision

would have ultimately been, whatever the outcome would have been, I would be able to cope without the guilt I live with now.



## Things Are NOT Okay

Lynne Hillard

Three doctors, each with good intentions, led us to believe that everything would be all right for our son Ben. In the fall of 2008, Ben presented with two documented seizures. We first saw a doctor from our pediatrician's office. He told us not to worry since the basic neurological physical exam showed nothing, but recommended that we see a pediatric neurologist. He gave us a list of recommended doctors, and upon leaving the examining room the doctor then said, "Don't worry. It's not a brain tumor."

We arranged a meeting with one of the pediatric neurologists who had been practicing for a long time and had worked in one of the well-respected children's hospitals before going into private practice. She was attentive and kind and spent a couple hours with us as we went over Ben's medical history. She examined Ben and found nothing unusual, in fact per her notes, "his neurological examination is better than normal." She said that she would order an EEG and a brain MRI because he had two witnessed seizures. She asked us to look into family history to see if there was anyone with a history of seizures in either one of our families. Upon leaving she said not to worry that it was probably something that he would outgrow.

After looking into family history, I found out that my older brother had had a couple of seizures when he was about twelve. He was put on phenobarbital. He eventually outgrew the seizures. Armed with this information I felt certain that Ben's issues were hereditary. It was right before Christmas 2008, so I delayed on getting the EEG and brain MRI until January of that new year. The results of the EEG

were unremarkable. The following week was the MRI. The day after the MRI, the receptionist at the neurologist's office called. She requested that we come in the next day and asked that Ben not come to the appointment.

"I am sorry to tell you, but Ben has a brain tumor." What? I couldn't even concentrate on what the doctor was saying. Ben's tumor was located in the right temporal lobe and extensively involved the right amygdala and right hippocampus.

I remember feeling completely overwhelmed with the process of choosing the individual who would ultimately perform brain surgery on our son. My husband and I interviewed three surgeons within a few weeks. On March 20 of 2009 Ben underwent surgery. The neurosurgeon was able to remove about 75 percent of the tumor. Two days after surgery Ben was released from the hospital. I remember that surreal feeling. My son had just had brain surgery and now we were going home with a list of medications and a schedule for administering the medications. I felt inept, unprepared, and yet relieved that my son had made it through; he could talk, he could move all his limbs and everything appeared to be normal. The only distinguishing feature that anything had happened was the six-inch scare on the side of his head.

The pathology report said it was a DNET tumor (Dysembryoplastic Neuroepithelial Tumor), one that should not re-grow or cause any further problems. I remember the audible sigh of relief that came out of my mouth. I remember the neurosurgeon's words: "Ben will grow up to be a fine young man, and you will dance with him at his wedding." I wanted to be happy, like I had won the lottery, but I had this feeling that there must be something more to this, it couldn't be this easy.

In his second year at preschool Ben's behavior problems became more obvious. When Ben became overwhelmed he would just sit down and not budge. Even when the director of the preschool asked us if there were any problems that were the result of his anti-seizure medication or his surgery, we said "no" because we were told "all should be good." But all along there was that nagging feeling that not all was good in Ben's world.

In kindergarten, Ben's behavior continued to decline. He started to withdraw from his peers. He would hide under his desk and refuse to participate in activities. He was angry and depressed. The school became involved. They wanted to know if something was going on at home. The school psychologist suggested a parenting class.

We realized Ben's problems were not just school-related when our family took a skiing vacation. Ben was very excited about skiing. We dropped the kids off at the ski school but two hours later I received a call from the instructor. "I am really sorry but I have tried all the tricks in the book and Ben has refused to participate. Please come get your son." I was exhausted and frustrated. What is wrong with Ben?

Even though we developed a 504 plan to accommodate to Ben's needs, school situations remained difficult. I was with him one day as he transitioned to a different classroom to learn a song. He was miserable. He couldn't participate. He put his head down and cried. I tried to encourage him to follow with his classmates who were learning the music but he just didn't know how. At the end of the practice the teacher gave each child two Skittles candies for practicing. She gave Ben nothing. One of the little girls in the group came up to Ben and shared one of the two Skittles she was given. God bless her. The sad fact was that Ben was now being labeled by his peers and the school. He became more withdrawn. My once happy go lucky son was now sullen and depressed.

A few days later, after being called to pick up Ben because he began to rage at school, I came home and went to my bathroom. I sat on the floor sobbing because I didn't know what to do. The phone rang and Ben answered it. When I finally collected myself, I got up and asked Ben who called. He said it was his neurologist. I called her back and she told me that it was time that I start acting like a parent rather than the child. She suggested my behavior was probably the cause of some of Ben's emotional problems. The neurologist and her husband, who was Ben's psychologist, questioned our home life. The school questioned our home life. I blamed myself for his behavior. Geez why not? The doctors said he was all good; the school psychologist told

me to seek a parenting class; the school principal said that she has never agreed with corporal punishment, but that Ben drove you to the point where she said she would even consider it if she had a child like him.

The neurologist did not think his medications were causing Ben's problems and the psychologist was at a loss as to what was causing so much distress. In March of his kindergarten year, Ben lashed out at his teacher, and was suspended. Ben was given a home/hospital teacher for the remainder of that year.

My husband and I were exhausted. We were struggling in our relationship. Our child's doctors were scrutinizing us; the school was scrutinizing us; my husband and I were scrutinizing each other.

Why didn't our original surgeon give us some realistic outcome related to the surgery? He made it sound like a oil change—in and out—"Ben will grow up to be a fine young man, you will dance with him at his wedding." Instead, Ben has residual problems: unpredictable emotions, rage, anger, lack of impulse control, short attention span, poor memory

That DNET brain tumor did re-grow. Ben has a new neurologist, neurosurgeon, an oncologist and new hospital. His second brain tumor resection was in May of 2012. The pathology showed that the tumor was a pilocytic astrocytoma. In September of 2012 the tumor showed significant re-growth. Ben is now undergoing eighteen months of front line chemotherapy treatment.

I have used the anger from our experiences to drive me to find the causes of my son's distress. I spend hours reading and researching. Last year, after reading an article on "right temporal lobe" injuries, I came across three words that have set us all free from the guilt and shame we have struggled with the past three years—"Acquired Brain Injury." I look at those words and it seems so obvious. Ben has an acquired brain injury. Although he has many other diagnosis—epilepsy, brain tumor, cancer, learning disabilities—it is the acquired brain injury that has been the most difficult to treat and understand. Armed with this information we are now able to get the support we need for Ben in home and at his school.

I now attend conferences on brain injury *and* brain tumors. When I meet other caregivers, one common theme is our lack of support. This is especially true in the cases where the brain tumor is considered benign and in brain injury cases where the patient has no other obvious physical problems and looks “normal.”

What can be done differently? A family dealing with a new diagnosis needs support. The peer mentorships programs that are available through support organization such as *We Can*, Pediatric Brain Tumor Support Group (a California organization) are of utmost importance. It is imperative that the doctors, hospitals, nurses, social workers know first hand about these organizations and make sure these families are given information about them. A Peer Mentor would have saved my husband and me years of frustration and heartache. At our new hospital, a volunteer from *We Can* is paired with a family who has just received the news that their son or daughter has a brain tumor. A social worker is assigned to the family. There is a resource center available in the oncology clinic that has a wealth of information, books and lists of support groups for family, patient and siblings. The main hospital also has a resource center.

More hospitals are now focusing on the need for a school transition program. If we had had better support from the professionals and a more realistic view of what to expect after someone undergoes brain surgery perhaps things would have gone more smoothly with Ben’s transition from preschool to public school. The school transition programs provide resources for the family and the school. Often a trained individual can go into the school and give a presentation to the principal, teachers and students at the school. This helps the students learn about the patient’s illness and not be afraid of the returning “sick” child. Our school district has openly admitted that they are unsure of how to proceed with a child like Ben. He is the first child in our district who has presented with so many complicated medical issues. To date Ben is still not in full time regular school. We recently had to hire an attorney to help us get the services Ben needs in school. School transition programs should have a

list of child advocates and special needs attorneys if needed.

Our current hospital continues to make improvements in the way information and support is given to families. It is my hope that no family will have to travel the road alone, especially since there are many who have gone before them who have much knowledge to share and compassion to give.



## Advocates, Not Problem Parents

Anonymous Two

**N**othing could have prepared us for the shock of hearing that our son had a brain tumor.

Rob\* was 13½, an active, healthy eighth grader, when he developed a headache so bad he couldn’t get out of bed in the morning. We saw the pediatrician three times over the next ten days. On the third visit, after ruling out problems at home, stress at school, strep throat and mono, he sent us for an MRI. When the radiology tech handed me the films and told us to drive back to the pediatrician’s office, I knew we were in trouble. Sure enough, after all the other patients had left, our long-time doctor called us into his tiny office, shut the door and fumbled with the films as he pointed to a white spot that he said was a brain tumor.

So began the experience that would change the course of our lives. We remember the diagnosis in detail and relive it in slow motion. We recall packing suitcases, driving to the hospital, waiting to be seen in the emergency room, and walking through doors marked “Pediatric Hematology/Oncology” for the first time.

We date everything “BC” (Before Cancer) or “AD” (After Diagnosis). We are grateful every day that

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\*Name changed to protect privacy.

our son is alive, but we know he is forever changed. We are changed: Our nuclear family, our extended family, everyone who knew us and supported us at the time was affected. A pediatric cancer diagnosis is a bomb that shatters your world without warning. If you're lucky, you can pick up a lot of the pieces, maybe even most of them, but the world you re-enter is never the one you inhabited before.

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Our doctor delivered the diagnosis to Rob and me at the same time. I've thought about this many times and perhaps one day will ask him: Why did he choose to do it that way? Was it a conscious decision or just happenstance? Was it kinder, in the long run—like pulling off a band-aid quickly—or terribly risky? What if I had collapsed at the news? I asked to step into the hall to use the phone. In a state of numbness, I called my husband. He knew we had had an MRI a few hours earlier. "Come quickly," I said. "There's a mass."

We chose to go to a top-ranked major medical center and were admitted that evening. A couple of days later, the discovery of tumor markers in Rob's cerebrospinal fluid and blood confirmed a central nervous system mixed germ cell tumor. We were told he would require six cycles of chemotherapy, followed by six weeks of radiation, and possibly second-look surgery and high-dose chemo with stem cell rescue on top of that. We were given a consent form listing a catalogue of short-and long-term side effects, among them the likelihood of infertility. We were urged to start treatment as soon as possible.

By sheer coincidence I had just completed a project for a small, nonprofit organization that existed to inform young adult cancer patients about their fertility rights and options. I knew that infertility concerns were usually pushed aside at diagnosis to make way for other priorities, namely the urgency of starting treatment. And that's exactly the kind of pressure we were facing.

But my husband and I were not ready to sign away our son's fertility in what felt like a no-confidence vote, a capitulation. We needed to believe

that he would survive and put this horror behind him, that he would look forward to marriage and starting a family. We were willing to cede nothing to the disease at this early stage of the game. Was this rational, naive or selfish on our part? I don't know.

The medical team seemed surprised when we asked for a delay in treatment in order to collect sperm samples. They warned that our son's condition could decline suddenly—and that postponing treatment by even several days might be dangerous. However, at our insistence, they agreed to the delay.

But how would we explain sperm banking to a 13-year-old, who could barely believe he had cancer? Would he be on board? Was it even realistic? We told Rob: "There is no room for any embarrassment. We need to be 100% honest with one another, and we need to be able to talk about EVERYTHING." He listened and agreed to the plan. We postponed treatment to collect samples over three days. The first day, we went together to the Assistive Reproductive Technologies clinic, where I signed various forms, including one designating me as legal owner of his samples should he not survive. I shuddered to think about that scenario and the decisions that would ensue.

My husband accompanied Rob on the second visit. The third visit had to be cancelled. As the doctors had warned, our son's medical condition had become worse. We rushed him to the hospital in a semi-conscious state with hydrocephalus starting to set in. He was hurried into surgery and had a shunt placed to relieve fluid and pressure in the brain. Months later, that same shunt tubing would worsen his disease and complicate his treatment by transporting tumor cells from the brain fluid into the abdomen, creating a secondary tumor site. This forced the need for tandem rounds of high dose chemotherapy with a platin drug that, in turn, destroyed the cilia in his cochlea and left him deaf.

Today Rob is an honors college student concentrating in psychology and music at a major university. He hears thanks to the miracle of cochlear implant technology. As parents, we sometimes wonder: If we had started treatment right away, would he not have required a shunt? And could he then have avoided high-dose chemo and perhaps still

have intact hearing today? All of this is speculation. What we do know is this: Our son is profoundly grateful that when the time is right to start a family, he will have backup options. Through my volunteer work, I encounter many parents who feel they were not sufficiently informed about infertility risk and fertility preservation options and who feel guilt, regret and anger about the missed opportunity.

In my experience, when you talk to brain tumor parents, no matter what the circumstances, guilt, and regret are always part of the conversation. Sadly, for us, when we reflect upon that time, some of our greatest frustration and grievance involves our experience at the hospital.

In accordance with hospital policy, the attending physician assigned to our son's case was the pediatric oncologist who just happened to be on call when we showed up in the ER. However, while technically listed as our attending, this oncologist specialized in a different type of cancer altogether and, as we would soon learn, would have no role in our son's treatment. We were immediately uncomfortable with this arrangement, as we wanted to have a direct relationship with the physician—in this case, a neuro-oncologist—who would be making decisions for our son's care. With a great deal of persistence, we finally succeeded in getting the attending relationship switched over. This was our first indication of a hospital bureaucracy that was designed to minimize the parent's access to the medical decision makers.

Even after the switchover, we found ourselves blocked from speaking directly to the neuro-oncologist due to hospital policy that all communication be passed through the fellow. While we could appreciate the importance of fellow training (and eventually came to develop a very close, trusting relationship with our fellow), we found it disturbing—especially given that our son's condition was acute and critical treatment decisions were being made—that we were prevented from having contact with the person making the tough calls.

Because we seemed to want to have more involvement with our son's medical team than they wanted to have with us, we got the clear sense we were being identified as “problem” parents. Not

only did the staff appear to feel this way about us, they also believed it was acceptable to express this opinion to our son. One two occasions, first a nurse and later one of the oncologists said to Rob (in our presence) something along the lines of: “You're not a problem, but your parents are.”

Most stressful of all was the sensitivity of seeking second and third opinions. At every major decision juncture throughout treatment—and especially after our son relapsed and fell off protocol—we felt it was important to consult with experts around the country for second and third opinions. No doubt, the poor relationship with our attending played a part in our desire to seek outside input. But even with the best of relationships, I imagine we still would have felt that our son's interests were best served by listening to what the small community of leading experts had to say. This was a rare tumor, our son's treatment was not going well, and we wanted to be sure we were getting advice from those docs who had the most experience treating it.

But seeking out a second opinion was a delicate matter. We became aware that egos are sensitive and turf battles common in pediatric oncology. Talking to a doctor outside your own institution was somehow construed as lack of confidence and an act of disloyalty. One of my most vivid memories is of an encounter where our attending “dressed me down” during rounds because I dared to raise a concern (brought to my attention by a doctor from whom I had obtained a second opinion) about our son's rising tumor marker levels. He rebuked me sternly: “Dr. \_\_\_ is not your son's doctor; I am.” It felt humiliating to be reprimanded at my son's bedside. But mainly I was terrified by my sense that Rob was failing salvage therapy (which he was) and that I had just alienated the one person most responsible for saving his life. I later summoned the courage to speak to the attending and apologized if my remarks had embarrassed him in front of his peers. He, in turn, apologized for his angry outburst; but it was a highly stressful encounter that I never quite got over, and our relationship never improved.

On top of the difficult relationship with our attending, we struggled to accept the hospital's institutional culture. While we knew that the

medical staff were hardworking, dedicated professionals intent on delivering cutting edge medical treatment, many of the hospital policies felt cold and impersonal. For example, due to concerns about respiratory syncytial virus (RSV), younger siblings were not allowed to visit the pediatric oncology patient ward. Consequently our nine-year-old son was barred from visiting his older brother for weeks, sometimes months, at a time. Surprisingly, too, there was almost no psychosocial support provided to families such as ours: There was no initial psychosocial evaluation, no personal counseling along the cancer journey, and no assistance with school re-entry. We had only one or two brief encounters with a social worker over our year and a half course of treatment because, as it was explained to us, the social workers were stretched thin and their time needed to be spent with families who were dealing with basic needs, like housing and transportation.

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We feel enormous gratitude to our attending and to the hospital for saving our son's life; but we feel anger and sadness, as well. Ultimately, this very highly ranked institution treated our son's disease but often did not treat us kindly. All in all, it was a dehumanizing experience—and there were many times when we felt as if we were in jail, being punished for a crime we did not commit.

We have experienced follow-up care in several hospital settings now, enough to know that the pediatric oncology culture varies significantly from one institution to another. I can understand that *ped-onc* must be an exceedingly stressful field for those on the front line. I can understand that maintaining professional distance and not forming emotional bonds is one strategy for avoiding professional burnout. However, I have seen hospitals where the staff extend themselves to patients and their families, where communication is encouraged, where warmth and personal relationships are the norm. I believe that families and staff are happier in those settings.

I wish our caregivers had thought of my son as more than a vehicle for cancer. I wish they had understood that, in treating our son, they were entering into a relationship with us, as parents—and that we needed to be accepted in the process, not walled off and ignored. I wish they had been encouraged to relate to us as people just like themselves—a family with hopes and dreams like any other, whose lives were horribly interrupted. Top quality care requires comprehensively and humanely caring for the patient and family; cutting-edge medical treatment alone is not enough.



## WHAT NOW?

Mike Abell

The cry broke the church's uncomfortable silence. It actually was more of a moan than a cry. It was deeper, coming from her core. I'd heard it only once before and knew it as a sound caused by a loss that will never be recovered. No one in the church had to turn to discover its source. We all knew the mother had entered to say goodbye to her 19-month-old son.

We watched as the now composed mother, along side her husband, followed the small casket—a family rendered incomplete. As they passed our pew, my wife clutched my arm and we wept tears of sympathy, guilt and fear.

Just 15 months earlier our now, 2-and ½-year-old son, Jun, had been diagnosed with a brain tumor not dissimilar from the child in the casket. The tumor has a different name, but it's equally complicated, and comparably rare and aggressive.

Over nine months, Jun endured two craniotomies, three rounds of induction chemo, three rounds of high dose chemo with stem cell rescue, 28 days of proton radiation, a sub-dural shunt placement, a port placed and removed, a broviac placed and removed and many, many blood and

platelet transfusions. As of his last scan, there was no evidence of tumor.

Jun has now been out of treatment for six months. His hair has grown back. He's stronger. The meals have stopped arriving. And we no longer are the recipients of sad eyes at playgrounds and restaurants.

In many ways we have returned to a somewhat normal life. If you didn't know Jun was in remission for a brain tumor, you wouldn't know. Despite all this, cancer still strangles us with fear.

Brain tumors often come back. Too often. We've heard a few different numbers on the likelihood. And while we've never paid too much attention to statistics, they are too scary to ignore. Especially knowing that should it recur, there is no cure. This is our day-to-day reality.

A lot of our time is spent analyzing, over analyzing and obsessing. We watch him closely. Every time he stumbles, coughs, or sleeps fifteen minutes longer than normal, we wonder if it's something more. I've called our oncologist about a 99-degree temperature. Something I wouldn't have done during treatment (I usually waited to 100). I've questioned whether hiccups are a sign of recurrence. Admittedly, I've even Googled that last one just to be sure.

All the anxiety builds the closer you get to an MRI date. My son has scans every three months so I'm beginning to recognize the cycle. It starts a couple weeks out. Normally it begins as a twinge the moment the date is set. But each day it grows, occupying more and more of my mind. This is not to say, I don't think about it everyday. I do. But the thoughts become more paranoid and frequent. Worst-case scenarios play out. It's different from the time during treatment. We always had the comfort of knowing that there is still more treatment.

By the time we reach MRI day, bring Jun back to the machine room, watch the anesthesiologist put him under, and leave him to be scanned for the next two and half hours, I feel close to nauseas. In my mind, at this point, someone knows. I know they may be a technician and are not necessarily trained to read an MRI. But they know. They've seen it before.

There usually is a waiting period between the time of the scan and the time you can meet with your oncologist or someone else qualified to read and interpret the scan. I do whatever I can to make that window as narrow as possible. I leave radiology with a disc in hand and head directly to the clinic to pass it off. I've heard of people waiting days for an appointment. That's not an option for me. There would be no eating, no sleeping, and no resting heart rate without knowing. Fortunately, our oncologist is very accommodating.

The fear peaks the moment we step into the clinic and hand off the disc. Normally, we wait in the playroom. I pace. I hear my wife or son talk to me, but I have no idea what they have said. My mind runs. Why is this taking so long? She saw something and is thinking how to break the news to us. Maybe she's wrangling the social worker for help.

I don't make eye contact when our oncologist comes out to bring us back to the examination room. I can't. I don't want to read into her body language. The image of her entrance during the initial tumor diagnosis is vivid in my mind and I know I will see her tell, real or imagined. I look down until she is with-in earshot of me, and can pass the news.

It's a cycle, repeated every three months, where the best outcome is a temporary sigh of relief.

I don't want it to be misunderstood. I'm not complaining. I feel blessed for our son, everyday. When he wakes up singing, learns something new or bursts out with a big belly laugh, I think about the parents of lost children and what they would give for just one more of those moments. That is not lost on me.

When we were invited to partake in this issue, the publication asked us to write a story about a part of the process. I chose to write about post-treatment and living with the fear of recurrence. It's partly because it's raw in my mind. But mostly, it's because no one talks about this time. I've received countless advice on managing life through treatment (all of which I'm grateful for), but there is very little when it comes to post-treatment.

In this time clinic visits are more infrequent. Doctor reassurance is spread out. The only community

that truly understands what you're experiencing has gone their separate ways. There is no returning to normal. The "normal," friends, family and colleagues associate you with is gone. There is an eternal wound that has changed me forever.

But, all that's okay. I would live everyday for the rest of my life filled with fear and angst, as long as my son is well.



## Down the Medical Rabbit Hole

Anonymous Three

*Am I alive*

*What's this pain I feel*

*Aching inside*

*Making me kneel*

*Down to the ground*

*Submissive*

*Like I've been sent*

*To Hell*

*—Anonymous*

I am making a time capsule of words. If I don't write these words now, how will I remember? It is for her. She will need these words to know who she is.

They took her at the lowest point, when she was barfing and admitting she needed to be in the emergency room (ER). And they stripped her of the ability to use her words to defend herself.

"There's really no reason for you to be here. The x-ray of your shunt tubing looks fine. The CT

of your head looks fine. You should think about going home." I start to speak, but she is speaking so I wait to hear what she will say.

"I was worried since my side hurts so bad that maybe it was my appendix and I didn't want it to burst and then have the infection go up my shunt, I know someone that that happened to, and then my head was exploding and I threw-up."

"That's when we have to come in to the ER " I say. "We've done this before. We wait until the last possible moment before coming. You've seen us here for almost 12 hours now, but we waited more than 24 hours before coming and she was just like this the whole time."

"One of the only things we can see that might be wrong is that we think she might be constipated."

"I try to stay on top of it," My 20-year-old says. "I've been taking more pain killers lately because my head is always killing me and I push myself to make it to class. But I take stuff to make it easier for me so I don't get constipated. Last Wednesday during class my head was exploding and I had to vomit. I don't think my shunt is broken. But . . ."

I interrupt, which is my job, because they are not hearing her, still she gives me hated looks, "She spends two days in bed laying basically flat so she can spend one day or even a few hours vertical the next day. This has been progressing for a while. Last May she had surgery for a CSF leak in her spine. But the headaches are different this time."

"We really think you should consider going home, the tests we've done look good."

This is the part that always happens, the part where I say you go into the twilight zone or down Alice's rabbit hole. In May I had to demand that she have the right to sit up, pain free in the hospital for two hours before leaving. And that is how they admitted her, Mother wants her to sit upright.

Here we are again 15 days before Christmas back in the ER—they, meaning the white coats, disbelieving us.

She broke then, like a piece of a falling statue, an arm or a leg or part of a shoulder busting off. "I can't go on like this, my head is exploding and I push myself so hard just to walk across campus

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*Editors' Note: This woman's child was treated for an astrocytoma at 8-years-old. The surgery included tumor resection and placement of a ventricular peritoneal shunt, which manages the flow, drainage and pressure of cerebral spinal fluid (CSF) throughout the brain and spinal column.*

and when I'm sitting in class I know I shouldn't be there, it's just so hard. I had a surgery in April last year to replace my shunt and I never really bounced back, and then they found the cyst in my back and the leak and after that surgery I just couldn't get any energy and my head still hurt."

They don't know that she never tells *anyone* any of this.

"I know you don't see anything on her scans," I say. They always look fine, but she can't go home on IV drugs. I know Diladened can make you nauseous but she was throwing up before she got here."

"It's possible she has the flu." This is said by one of the white coats. Again down Alice's rabbit hole.

I know that it isn't the flu and she knows it isn't the flu but more of her comes undone and there are tears not from the pain but from frustration. And I begin to wonder, how much suffering is enough?

"We know it's not your appendix and your blood work looks fine. There are really no other tests we can do."

Another piece of her chipped away and lost. She says it's like a house with an army outside that's supposed to protect her and when they don't she goes to the basement because another stone in the foundation has been pulled out and she says that eventually her house will fall over. The army is supposed to be the doctors.

"I never want to come to this place. But my head hurts so much and this time my side hurts too and I'm not sure if I'm constipated or not, but something is not right. We are told that if I'm vomiting we have to come here. I can't call my neurosurgeon and talk to him. I can't get an appointment in clinic right away."

The ER Doctor is not moved. He does not know that it has been years since tears welled in my eyes and threatened to spill over. The tears are there now from watching her break.

The damage has been done. The splinters fly off of her.

"I don't think I can handle this kind of pain anymore."

"Can you please ask Neurosurgery to come and see us?" I ask.

Finally she is admitted.

For three days we live in Alice's world. I call it Alice's world because in the story of Alice in Wonderland just when you think you know where you are, suddenly something else rather absurd happens that could not have been seen beforehand.

She is assigned a Gastroenterologist who tells her she has a very tiny singular gallstone but that it is in no way responsible for making her sick. She is assigned an Internist who says that she is slightly anemic and wants to start her on Iron. I decline the iron and begin the process of (1) stopping what I call chasing your tail. I ask what the side effects of giving Iron are and learn that they are a rash and constipation. Imagine, she can't get admitted to the hospital because she might very well be constipated but once admitted lets give her Iron which might actually make her constipated or add to it.

"How low on Iron is she?"

"We'll she is only very very slightly anemic."

I decline the Iron but (2) begin "in theory" embarrassing her and making them not like her and become difficult and a "decliner," which in hospital lingo means "suspect." At least this is her viewpoint, which I understand. But understand enough that I would rather piss her off than be chasing a new diagnosis based on a new drug that they had given her.

She is assigned a neurologist who wants to know if she'd taken the Nortriptyline he'd recommended and prescribed for her a few months earlier in an attempt to (1) prove she is not having migraines and (2) make her less depressed because possibly her headaches are from depression.

"I don't think I'm depressed," she says. "If I didn't have headaches and have to stay in bed I don't think I would be depressed. But everyone has bad days and sometimes I have a lot of bad days, so maybe I am depressed. I'm fake a lot. I'm fake even in front of my Mother because she wants me to be happy and even though sometimes my head is killing me I try to be fake." With this she glances at me, revealing her angry secret.

I'm am challenged both by the splitting apart of her, the drugged her who says things she might not normally say, the pain I feel for her and my gut instinct that she is only sad because she cannot live

her life. That she has been taught that it is okay to stay in bed for two days in an attempt to get enough energy to try to go to class for one “good” day baffles me.

Less than 24 hours after being admitted she starts the “push.” I call it the “push” because that’s when she starts pushing away those she loves the most and those who love her the most. This puts me and her boyfriend at the top of the list.

It can start as simply as: “I know you don’t want to be here. You don’t have to stay you know.” And escalate to “I know you hate my life and you just want me to go away. I want you to leave. I’m tired of being fake all the time and I just want to be me.”

This is more of her chipping away, changing her from whoever it was that she would have been into this person who knows only pain. “I want someone to talk to.”

And I want someone for her to talk to as well. I want a Chronic Illness specialist to see her. It’s a category I have invented. I have asked and asked but to my knowledge there is no such person.

When the nurse comes with the pain medication I tell her what we have been discussing and she puts in the request to have someone from the Psychiatric department come and talk with her.

Hours go by. It changes from day to night.

I stand outside the room, because she doesn’t want anyone in the room.

She has told me to leave and may in fact believe that I have left. But I stand like a stone outside her door. I wonder how we have come to this. I have a bit of a pity party for myself but come up with the mantra that it’s better to piss her off and advocate for her care than to listen to her PUSH me away and prolong her suffering.

By 11 p.m. she is agitated and demands someone to talk to. Someone comes and I leave for the waiting room. I need to sit at least.

I beat myself up pretty good for 10 minutes. I have certainly failed to keep her from suffering. I have not protected her. Isn’t that my job? To protect her? I am angry that she is not rational and that we are not a team. The drugs, I think, keep her awake and agitated. Slightly, slightly at this point I begin to think her personality has shifted, that she has

become what I call “her evil twin.” I know this is a symptom of a shunt failure. She knows this is a symptom. But no one else in the hospital knows that this is not the “real” her.

It makes me suspect if she kicks me out and doesn’t want me to speak on her behalf. I beat myself up pretty good with words rolling around in my head and then I get a text from her.

“He’s pathetic.” The shrink, she means is pathetic. She’d waited months to tell someone her story. “He yawned.”

That makes us a temporary team for a while; I come back to the room and though I yearn for sleep we talk through the night.

She wants to know why they won’t help her, not at all sure that they can.

“I’m guessing that since the leak at the cyst in your back was fixed and since they just did the Myelogram and can’t see anything new, I’m guessing that the valve is not correct for you now or that you are still leaking, because you always sink to the same horizontal flat position, and they tapped your shunt and you instantly got sicker, where you seem better now.”

“What does that mean?”

What does it mean? I just gave an answer that offered up several options but they all contradicted each other. I have no answers. There must be a better way.

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Six months and three surgeries after this was written we finally got our miracle! All of the CSF leaks had been stopped and an anti-siphon device was added to the VP Shunt. My daughter again re-entered the world of the upright walking population. That means that three top Neurosurgeons missed the cues and a fourth spent three years diligently working to solve the problem even though he doubted us. It was assumed that my daughter was “fine” because all of her scans were “fine” yet she couldn’t get out of bed. If I had any words of wisdom to offer they would be this: Just because a test doesn’t show *what* is wrong doesn’t mean everything is right. We have taught an army of Neurosurgery residents, ER

Doctors, and technicians that they do not need to listen to the patient or family members because a test doesn't show what is wrong. This is unacceptable.

For many years we did not know if there was a way out of the nightmare. We now know that she can be "fixed" again when her next shunt fails.



### **The Road to Understanding and Acceptance of the Late Effects of Pediatric Brain Tumors and Treatment**

Jeanne Carlson

**W**e had little warning or time to adjust to our daughter's diagnosis. A call from her third grade teacher reporting that Sarah seemed to be having vision problems rapidly led to eye exams, an MRI, and the discovery of a Germinoma brain tumor in the supratentorial region of Sarah's brain. We were terrified but began treatment feeling optimistic about the outlook for Sarah's recovery. Luckily, Sarah's treatment was relatively non-invasive and quick, chemotherapy and radiation, five months start to finish. We were thrilled to have Sarah's treatment behind us.

As any parent of a child with a life-threatening illness knows, family life is seriously disrupted by the countless doctor, lab, and hospital visits, the worry, and the financial strain that are suddenly added to the demands of everyday life. We did our best to balance our focus on both of our children as Sarah is a twin and we didn't want her brother Will to suffer as a result of his sister's illness. It wasn't easy but we found a way to schedule Will's usual play dates, baseball practice, and family time. We were all happy and relieved when Sarah's treatment was completed, yet we would later learn that we had been incredibly naïve in two ways; we thought that our brain tumor journey was over after Sarah's treatment was completed and we thought that we'd brought Will through the process without effect. We had a lot to learn.

At the time of diagnosis we knew that Sarah's memory and ability to express emotion had already been impacted by the tumor but we didn't yet know what that would mean to her quality of life. We were virtually unaware however that at age nine the chemotherapy and radiation treatments that Sarah received would result in profound late effects. Following treatment Sarah successfully completed 3<sup>rd</sup> grade and even received excellent STAR test scores (California state standardized tests). In 4<sup>th</sup> grade however, Sarah's performance began to diverge from that of her peers and she found herself struggling in school and unable to make friends. We began looking for ways to help our daughter.

What followed was a five year long journey through testing, evaluations, individualized education plans (IEPs), and therapies, which, in the end, left our family needing to accept the fact that although Sarah remains intelligent and artistically talented, she suffers from a constellation of late effects that will always affect her ability to function in the world. As a result of Sarah's tumor and treatment she struggles with Auditory Processing Disorder, word finding problems, poor executive function, inability to recognize how she feels, significant difficulty making decisions, inability to read social cues, poor memory, slow processing, an emotional age of about nine, and lots of anxiety. She is also panhypopituitary, meaning that she has no remaining pituitary function and must take replacement medications by pill and injection, has hypothalamic obesity (HO), which is primarily controlled by more medication, and Raynaud's Disease. The HO is an ongoing challenge because if Sarah does gain weight she can't lose it again and exercise is not an easy solution because, like many pediatric brain tumor survivors, Sarah is easily fatigued. Finally, although Sarah's vision improved after treatment her vision loss is significant enough to prevent her from driving. We pieced together this understanding of Sarah's challenges and disabilities slowly so it wasn't until the end of our children's middle school years that we finally accepted the magnitude of the damage caused by the tumor and treatment. Thereafter we changed our focus from what Sarah might achieve in life to how to support

her in the activities at which she still excels and how to keep her active, interested in life, and feeling good about herself.

It would have been a huge gift if we had been provided with information about the possible late effects that can result from treating the brain of a 9-year-old with chemotherapy and radiation. We know now that we were in many ways pioneers in this area and that due to the rarity of pediatric brain tumors doctors, therapists, and especially educators lack knowledge about late effects. It was a long and stressful journey to acceptance of our daughter as she is post treatment. The impact on Sarah was heartbreaking for us to watch. By nature a perfectionist, Sarah lost the ability to achieve recognition through her performance in school. Tutors and other support at school made little difference and so school changed for Sarah from a delight to torture. Friends drifted away because friendship with Sarah became hard and there were many other easier friendships to be had. We all kept trying harder because we didn't know what else to do.

As our children prepared to enter high school we were experiencing a mixture of relief and grief. Will had been admitted to his first choice of schools and seemed excited to move onto high school. Will and Sarah had been in the same classes from first through eighth grade and we were so pleased that Will would have his own school environment at last. And, after much research we discovered a wonderful school nearby for Sarah. The teachers were talented in working with kids with learning differences and the school's focus on social pragmatics allowed Sarah to form friendships for the first time in six years. Finding this school relieved so much pressure for Sarah, who could finally achieve again—earning straight A's all four years. The grief that her father and I experienced came with our greater understanding of Sarah's disabilities and the significant, lifelong, impact that they will have on the quality of her life.

Although we were aware that Sarah's struggles were having some impact on her brother, we were so focused on helping Sarah that the vigilance about keeping Will's life "normal" that we held during Sarah's treatment relaxed. Will is a stoic kid that rarely complained about what school life was like

for him and his love for his twin sister led him to internalize much of what he was feeling. It is easy for an adult to think "he shouldn't be embarrassed when his sister cries in class every day," but we weren't acknowledging that being in the same class with a sister that suffers from late effects and learning differences also made him "different." There is nothing worse for a kid than to be "different" in elementary school and middle school. His days were certainly filled with conflicting emotions varying from an impulse to defend and protect his sister to profound embarrassment about her neediness and struggles. At home, because Will is sensitive and observant, he kept much of what he felt to himself because he didn't want to add to the stress that his parents were under.

We will never know how Will's high school years would have turned out if we had a better understanding of Sarah's late effects and if we had placed her in a more suitable school sooner, but we feel certain that our constant focus on Sarah made his path toward drug addiction almost inevitable. Will may have become an addict even if he had had a fairytale childhood, but the pressure that he was under in the years leading up to high school must have helped make being high very attractive. Will's addiction took hold of him with staggering speed as we struggled, again terrified, to help him find a path to recovery. Managing Sarah's brain tumor treatment was easy by comparison!

In the end, Will chose sobriety and we feel as grateful to have him healthy, as we are grateful for Sarah's recovery. We had no control over what was happening to our son and could only show up every weekend to support him while he was in treatment. And, just as Will helped Sarah endure chemotherapy and radiation, Sarah's love was incredibly important to Will during this time of his life. During the family therapy that was part of the treatment process Will shared with us that he had many feelings of resentment about Sarah's cancer, but that he didn't resent Sarah. Thus, despite much love, and much effort to keep family life normal, Sarah's brain tumor "happened" to our entire family.

The late effects of Sarah's tumor and treatment impact nearly every aspect of Sarah's life. Sarah

will probably never live independently. She is smart and motivated and wants to go to college, but for her college would be a huge challenge and would likely not result in a self-supporting career. There are classes that she could pass, with support, but because her processing speed is about a third of normal and she is unable to compose an essay or grasp abstract subjects such as history, a degree would be difficult to achieve. Sarah is dependent on others to plan her activities and for reassurance that she is doing well. Her inability to identify her feelings makes decision making difficult and slow. She is a talented artist with a room full of art supplies, but unless she has a companion or teacher to lead her in a project Sarah can't get started. She is lonely because she can't master the social skills needed to form friendships. And finally, because Sarah remains emotionally so young she would be extremely vulnerable living in the adult world. Anyone who knows Sarah is keenly aware that her particular combination of disabilities makes it impossible for her to function independently for more than a few hours at a time. Ironically she appears to be so bright and able that convincing agencies that she is disabled and should be qualified for services is very difficult. Sarah has no single, governing disability that will fit neatly into a category on Regional Center or Social Security forms. We feel that we are also pioneers in this area because there is such a lack of understanding about the disabilities faced by survivors of pediatric brain tumors and with the lack of agency funding they are happy to deny Sarah's applications.

Sarah functions best when well supported and she usually wants that support to come from her mother. We are often amazed at what Sarah can accomplish if given the right tools and information. But these successes are of relatively short duration and then she needs help to get set up for the next task or activity. As Sarah's go to person, Mom gets little time of her own, since it is hard to take time away from such a sweet loving girl who feels safe and happy when she is spending time with her mother.

Our family is again in the midst of transition. Will is living on his own and is managing community college and a sober lifestyle independently and well.

Sarah recently graduated from high school and is starting a part-time job that she enjoys, but she remains worried about her life as an adult. Despite her disabilities she is aware of the world around her and how her life differs from that of others her age. She grieves to not be headed for college, for her lack of friends, and for her dependence on family. We are working to the fill Sarah's non-work days with activities that she enjoys and exercise to help maintain her weight. We are also working to help her celebrate her talents and strengths and to accept her disabilities. These plans are appropriate for now but as parents quickly approaching retirement age we worry about providing for Sarah's future and about how we can assure that she is safe and happy once we are gone. We are happy to be armed with the facts about Sarah's abilities and disabilities so that we can arrange for Sarah to have appropriate care when we are gone. It is distressing though that there is so little information, support, or services to help us arrange for Sarah's ongoing care. Yet, as we have always done we are asking questions and networking with others to find solutions. The journey continues.



### **Family, Friends, and Cancer: The Overwhelming Effects of Brain Cancer on a Child's Life**

Lynne Scheumann

**O**ur son was diagnosed with a medulloblastoma at the old age of 13. The "lucky" part for him was his brain was almost fully developed at this age as opposed to most "medullo" patients. While this was a benefit to him it was also one of the hardest things for him.

He went into surgery a highly intelligent, active, and left handed boy and came out unable to move his left side, could barely speak, and very much aware of what he just lost. We, as a family, were totally unprepared for how globally this would

affect the rest of his life. As we spent time in the hospital I would look at the children with other types of cancer and see them walking and talking and doing their schoolwork and God forgive me I would be jealous. The fact that the cancer was in his brain, the part of his body that makes him who he is changed everything forever.

He lost all of his friends because 13-year-old boys communicate best through physical activity and that was not an option for him. He still has the same personality and sense of humor, but he will not be the architect or engineer he once dreamed of being. Math, that was once so easy for him was now like a foreign language, never to be mastered again. He was able to graduate from High School and takes classes at our local Junior College in Computer Assisted Drafting, but he can only manage one or two classes a semester due to the fatigue he still suffers from.

What I most worry about and wish I had been forewarned about is his long-term quality of life. Physically he has come such a long way from how he was after the resection. It was a very slow process in which the first year of rehab was slowed by the fact that one of the chemo agents causes peripheral neuropathy. He developed contractures in his ankles and needed serial casting and ankle-foot orthotics (AFO) not just on the left leg, but now the right. He was able to switch his handedness fairly easily and his left hand will always be of limited usefulness because of ataxia. I would get angry at him that he gave up on his left side so quickly until it was finally explained to me years later that the ataxia would never get better.

As far as his walking ability goes he has come a long way. At first he was unable to walk and once he started rehab he went back to learning to crawl and progressed to a walker. The first time I saw him walk with the walker brought tears to my eyes. It was so much more of an event for me than when he took his first steps as a toddler. This was so much more hard fought. He never complained, just always did what was asked of him. It had to have been such hard work and also somewhat embarrassing, as he needed help to literally do everything for months. He progressed to a cane and about two years ago

decided not to use that or his AFO's. He now wears high top boots that substitute for the AFO's but don't make him appear disabled. Recently he decided there are times when he would be safer if he had his cane and purchased one that looks more like a hiking stick than a cane. I think he has come to terms with the fact that physically he is as good as he is going to get and works hard to maintain what he did regain. He has a trainer and goes to the gym on a regular basis with no prompting from us. I do not know if he realizes that as he ages things will be harder for him than the average person. I think in some way he is aware of that because he did decide to use the cane if safety is an issue.

His social life became non-existent after his diagnosis. I think adolescence is a difficult time in life as it is, and kids that age don't really know how to handle these types of mortality situations. They thought he was going to die and didn't know how to respond to that other than doing nothing. This was compounded by the fact that someone (a pediatric nurse!) in our community was spreading rumors that he was dying and that the tumor had fingers that were growing through his brain. So, he was basically abandoned by his friends because they were afraid and didn't know what to say or do with him. He couldn't play with them like he used to. Even video games were out because he could only use one hand well. And boys of that age communicate best when they are doing something physical. He also had Home-Hospital school for all of 8<sup>th</sup> grade, so that put him out of the social aspects of adolescence.

When he did return to school it was the first day of High School and he showed up with a walker and a full time aide. This for the high school crowd was totally not cool. He struggled to make inroads into a group but was not afraid to put himself out there. What happened was that his friends were the adults that came into his life after his diagnosis. I think that he could not relate to the drama that is high school. He was light years ahead of these kids on what is really important in life, and it wasn't who was dating whom. But he was also very lonely and unhappy. He still struggles with this and this is the one area that I can't fix for him. I can't make people be his friend. All of his closest friends are female because I think

they communicate better with him and have more patience. His speech can be slow at times and the more nervous he is the worse it is. He explains it as knowing what he wants to say but having trouble getting it out. He would like nothing better than to have a group of friends that call and include him in activities. Most of his relationships are now happening through technology. I don't know much about the people he talks to this way, but it seems to work for him. I know that he would love to have a girlfriend and hopes to get married and have a family. In fact this is really important for him and I hope it happens. Emotionally he is very mature, very thoughtful and in tune with other people's feelings.

Our family changed in some ways after the diagnosis. I was the one with the medical background so I handled all of that, but I had to let go of other things I normally did. And I had to except that they wouldn't be the way I did them . . . it didn't matter how the laundry was done, just so long as it got done.

Our daughter is three years older than John and I feel I missed out on her senior year of high school while caring for him. She was always independent and self-sufficient. She made it easy for us in that we didn't have to worry about her. But I feel we neglected her during that time. And she has told me that the litmus test for a husband for her is if he would be willing to have her brother live with them. I think she feels that at some point in his life, when his parents aren't around, he may need that kind of help.

I thank God every day that he survived but at the same time I constantly worry about his future and most of all his happiness.



## Over the Years

Kimberly Rocker

**M**y daughter was diagnosed with an Ependymoma brain tumor in 1986 at the age of 19 months. Our journey began when we realized that we had become concerned about

her falling. For example, we were staying at a lodge with a large stone fireplace and both my husband and myself were careful to cover the area with pillows from the couch. Then there were the sporadic "jokes" from strangers who would say, "what has she been drinking?" as she walked past with a slight stagger in her gait. We took her to the pediatrician who listened to my concerns and then watched her walk in a narrow hallway. Surprisingly, she didn't seem to stagger and she walked very "toddler-like" down the hall. We learned later that this tighter area would help compensate for my daughter's lack of balance. We were told that she simply needed to develop her gross motor skill more and that she would outgrow it and I was simply an over-concerned first time mom. Unfortunately, the pediatrician failed to recall that my daughter had been walking since she was 11 ½ months old and the current lack of coordination and balance was actually a regression in her motor skills. This negative change in her abilities should have been seen as a red flag.

I still couldn't shake the nagging feeling that something was wrong. Since our doctor had been unresponsive to my concerns, I made an appointment with another doctor. I told my husband that if the new doctor is just as unconcerned about our daughter's gross motor skills, then I would let it go. The new doctor refrained from making judgments about my parenting skills and concerns. She listened carefully as I described the situation. She examined my daughter and watched her walk in the large hospital hallway. Her next step, one that our regular doctor failed to do, was to measure her head circumference. The measurement exceeded the 100-percentile mark. They were immediately concerned and ordered a CT scan right away. The diagnosis was a brain tumor and due to the size and location, they didn't expect her to live. We called family and said our beautiful little girl was very sick and was going to die.

As a parent, we often know our children well. This can be both a help and a hindrance. Since the changes in our daughters walking skills declined gradually over several months, it was difficult for us to see just how far she had declined. We have a

video of our daughter taken just a few weeks before her diagnosis. I have only watched it a couple of times because it is difficult to see. It is painfully obvious that there is something terribly wrong. It does make me question our parenting and ability to know what is best for our child's well being. Add to that a doctor that made you feel very inadequate as a parent, it was hard to have the confidence to question the doctor. But, that small quiet voice kept getting louder, demanding to be heard.

My daughter will be 29 years old this August. One thing I remember very clearly during that first year is that I just wanted to know that somewhere there was another child who survived to live a happy, healthy life. At that time, it was difficult to find. During those first few months after our diagnosis, we met three other families who had daughters with brain tumors, Nina, Larissa and Wendy. My daughter is the only one still alive. We thank God for the gift of life He gave to our daughter but are full of sorrow for the families that suffered such a difficult loss. There were many miracles and many challenges along the way regarding her recovery. I believe our story can give hope to families as they struggle with this terrible diagnosis.

One of our first miracles was the fact that the neurosurgeons were able to remove all visible evidence of the tumor. This is rarely the case since removing the tumor can also damage healthy areas of the brain. The next one came when, through a second opinion, the oncologist suggested performing an MRI scan prior to determining follow-up treatment. His reasoning was that radiation treatment would be very damaging to the growing brain of such a young child. Since it was believed that the surgeons had successfully removed all of the tumor, he felt the best course of action would be to delay the radiation as long as possible to allow for her young brain to continue to develop normally. So, we began travelling to another state (MRI scans were new at that time and were not widely available) every three months for the scan. Eventually it became every six months, then once a year and then to only when there were some suspicious or unexplained symptoms. Again, another huge miracle, the tumor never returned.

There were challenges along the way, not the least of which was the stress that arose every time we were due for an MRI scan. Every little behavior or nuance was seen as a possible sign that the tumor had returned. We were all too aware that the odds were not in our favor. Statistically, the five-year survival rate with surgery alone was very low. The actual process of doing the MRI was also stressful. The medication used to sedate our daughter caused her behavior to be erratic and extremely fussy. It also would take a long time to take effect until she would finally give in and fall asleep for the procedure.

Prior to the surgery and the decline in her motor skills, our daughter had been walking and developing normally. After surgery, she was no longer able to sit up without support or walk. Her speech and language skills were also affected. Thus began the many appointments for physical therapy, occupational therapy and speech therapy. Her left side was significantly more affected than her right, which at least gave her the use of her right hand. At this time, we also had a newborn baby. Getting both girls in and out of the car for several appointments a week could be very exhausting. Fortunately, the fact that she was still a toddler allowed her to redevelop many of her skills just by playing and being a kid.

She did eventually relearn to walk and regained the use of her left hand. She has retained a very slight ataxic gait and was never able to ride a bike, a very small price for such a significant recovery. The speech therapy went on for several years and became quite a burden to her but she persevered.

There were also vision difficulties. She had strabismus, a condition in which the eyes don't move together properly. This puts a great deal of burden on the brain as it tries not to see double. It also made learning to read difficult and caused a lot of fatigue at the end of the day. She spent many years dealing with this when at the age of eighteen we became frustrated with her ophthalmologist and went to a neuro-ophthamologist. He suggested surgery to correct the strabismus. Only a few weeks after her surgery, she came out of her room after going to bed (which was usually around 7:30 p.m. because she was always so tired by then) and said, "I can't go to sleep because I'm not tired." If only we had sought

a second opinion earlier it would have helped her so much during her school years.

Of course there were also social difficulties, especially in the teen years. She wasn't able to play sports due to the slight ataxia and she didn't have that outgoing, talkative personality. Speech therapy both helped and hurt her in this regard. Just the fact of needing speech therapy and being slightly slower in processing information caused a certain amount of self-consciousness. She just never felt like she fit in and at times this could be lonely for her. By now, she had two sisters and a brother and our family activities helped to fill the void. Eventually she discovered Taekwondo, a form of martial arts. The benefit of this was that it wasn't a team sport so she didn't have to worry about letting her team mates down, she could progress at her own pace and it developed both the left side and right side of the brain since each move done on the right side of the body is mirrored and done with the left side. The martial arts are also very good at showing respect for others and typically are a very supportive and encouraging environment.

In 2006, she graduated from college. During this time she learned to advocate for herself for special modifications in her classes to assure her success. Since she had a slightly slower processing time, taking notes during class was difficult. She needed to focus her attention on the lecture, if she tried to take notes she would miss too much information. She was given a "note taker," another student would take notes and give her a copy. Once for a local community college she was required to take a placement exam given on the computer. Visually this was difficult for her and didn't allow her to use some of her test taking skills she had learned, such as circling important information. She did poorly on the first test. She requested to retake the test in "pencil and paper" format. After some difficulty they finally agreed and her score improved significantly. Another important modification was that she was allowed to take exams in a quiet room without a time constraint. This was very important for her especially when it came to math. It would often mean the difference between an A and B or a failing grade. This was very evident when due to

some scheduling conflicts the professor asked her to take the exam with everyone else. With all the distractions, students walking past to turn in exams and the time limit she did very poorly. Thankfully, the professor realized the situation and allowed her to retake the exam, this time very successfully.

Throughout the years we learned how important it is to be involved and informed with your child's health and education. Sometimes it means going against advice and having to search for support through other means. Sometimes it means not taking no for an answer or being assertive even when it is uncomfortable. It is also important to help your child to understand their strengths, weaknesses, and needs and that it is okay for them to demand that they be listened to. Sometimes it is a fight and sometimes, by the grace of God, what you need just comes before you.



### **Prepping for the Day You Hope Never Arrives: Facing Recurrence**

Terra Trevor

**M**y 14-year-old son was eight years past diagnosis of a brain tumor. Gone were the pristine sick days when his white hooded sweatshirt stayed spotlessly clean for weeks at a time. Each time he left a muddy footprint on the kitchen floor I rejoiced; it felt so good to have a healthy kid again. However, my son was a survivor of an anaplastic ependymoma, grade IV, brain tumor, and although I wanted to be out of the woods, I knew we were not. I'd climbed out of the space where medical problems were filed in my mind, yet I kept the door open because statics showed that the type of brain tumor he had, frequently recurred.

Still, I was determined to keep our lives as ordinary as possible. But for a brain tumor family this meant staying connected to sources of support. Parent programs, patient and sibling support groups

and camps, and we remained connected to hospital resources. Most of all we needed to have fun as a family, and we attended the cancer survivor picnics and parties our hospital hosted, where the doctors served as volunteers, grilling hamburgers and dishing up ice cream for the guest of honor patients.

My husband and I felt confident that as long as we worked as a team with our doctors and stayed connected to resources offered, we would find a way to meet any challenges that might surface.

In the end ultimately what saved us was this mosaic of support provided to us over the years from a multitude of good people and organizations offering help when we needed it most. And I had the opportunity to learn to accept help, which it turns out, is far harder than offering to help.

Shortly after my son Jay celebrated his 8<sup>th</sup> year as a brain tumor survivor, I watched him open the medicine cabinet and reach for the bottle of Advil, for the second time in a row that day. “Do you have a headache again?” I asked. He shrugged his shoulders, then hiccupped hard, and ducked his head in the toilet and threw up. Tears welled in his eyes. I sank into the deep, silent panic that made me calm.

Our primary care physician called in an authorization for an MRI. Jay hid his fear behind a mask of quiet strength. It was ten days before his fifteenth birthday.

While we waited for the MRI appointment, that week Jay was elected student of the month, and he got a lead part in the school play. My idyll of family hood continued until the MRI confirmed my worst fear—the tumor was back, and this time its fingers spread into the brainstem.

We had to decide on a plan of treatment. Surgery was scheduled. When Jay was admitted to the hospital and I requested that he be placed in the pediatric ward, an environment he was familiar with, they agreed. Although Jay was a teenager, the recurrence caused him to revert emotionally back to a younger age. It was as if he was seven-years-old again, reliving his first brain tumor experience, and he kept his childhood security item—a small teddy bear with him, tucked under the hospital covers, like he had with the first diagnosis.

Luck held. With surgery most of the tumor was resected and symptoms disappeared. Three days later, on Thanksgiving, he was feeling well enough to be excited about the Thanksgiving dinner our hospital provided us. A table and chairs were brought in, along with a feast of good food. The nurses gave Jay lavish attention, they laughed at the corny jokes he told, and made us feel like special company.

Within a week Jay was out of the hospital, recovering well. But what to do about the remaining brain tumor slivers that were inoperable? He had *already* received his lifetime dose of whole brain radiation, and chemotherapy available offered little hope of curing a recurrent tumor. But there was a small chance that stereotactic radiation might stall tumor growth. We set up a consultation.

We had to work with a new pediatric oncologist, because when Jay was five years post cancer, our insurance company decided that he didn’t need to see an oncologist anymore, and he was routed to a general practice pediatrician.

I told our new oncologist, what I knew, recounting our past eight years, my vocabulary carrying perfect medical jargon. The world of childhood brain tumors taught me to speak professional-to-professional, to shake off the happily-ever-after aspect of life. I wanted to be told the brutal facts, and I’d learned that even the slightest emotion in my voice might prevent doctors from telling me everything I wanted to know.

Meanwhile I encouraged Jay and our sixteen-year-old daughter to continue on with their ordinary routines, to live as normal as possible. I forced myself to stay in the moment so that I could help my children stay calm. Having a positive attitude was important to Jay. Although he had very low energy he attended school half-day because he loved school.

Medical treatment was slow to begin because there were numerous procedures and appointments required to get the ball rolling. A month later we were still completing preliminary procedures. Truth to tell, we knew there was little hope for long-term survival, even with the best medicine, but we didn’t know what else to do. Most of all Jay worried that

stereotactic radiation might make him so sick that what little time he had left would be wasted. While we waited we talked about calling it off and calling Hospice instead.

Jay was the one who first brought up the subject about not being sure he wanted to try stereotactic radiation because of the risk of debilitating sickness without resulting in a long-term survival. Although he maintained hope, at some level Jay seemed to recognize what he was up against and he made it easy for us to talk about it.

But it only took me about two minutes to understand that we should not talk about it with anyone within our childhood cancer and childhood brain tumor support groups. When I attempted to bring up the subject that this recurrence had a poor prognosis and held little hope for a cure, I could feel a wall go up letting me know this was not their territory.

At the winter holiday party a few days later the director of our childhood cancer support group, a group that was associated with our hospital and that we had an eight year history with, hinted that it might be time for us to seek other social avenues of support now that the tumor had recurred. Jay's best friend was also a cancer survivor in this group and he and his family did what they could to pave the way to help others accept us. But things never completely softened. Although we were never told to leave, it was clear they didn't know how to include us. A similar situation occurred within a childhood brain tumor support group we were involved with.

I could understand the support groups feared we might become too needy and drag down the social gatherings with our sorrow. Most of all, I sensed they were worried that we might drag down the other families and steal their hope of survival. Although we were sad and needy, we had the good sense not to show it, because we understood that there was not an infrastructure in place within these support groups to meet the challenges of families faced with a recurrence with a poor prognosis. Instead the support we received came from other parents we had previously befriended within the support groups whose children had also faced recurrence

and died. These other mothers and fathers walked us through the stages as they came up.

Also least expected was the amount of personal friends and co-workers who backed away from us. It was difficult for other parents to understand that Jay was living with a brain tumor, and he didn't want to be cut off and classified as dying. We were in an awkward stage where Jay felt well enough so that he didn't want to stay home in bed, but it was awkward socially to go out.

But since we had experienced a solid background of good community support keeping us strong for eight long years, we were able to emerge with the confidence we needed to carry on. Still, it was challenging for me because far too often Jay and I found ourselves alone, at our wits end, needing someone to perk us up, and I felt it was my job to keep us both from becoming too isolated.

Holding on to faith, like a rope tied from the house to the barn in a blizzard, I began to accept support from new friendships that suddenly began to emerge like miracles seemingly from nowhere. Many of the good people who offered support were doctors, nurses and social workers, but none of them were assigned to our case. Instead they were befriending us and offering to help from the goodness of their heart.

These were the people we talked with, because they let us know they were open to talking about it, and they invited us into their homes to share a meal.

Also, thankfully, a new social worker-friend arranged for a volunteer organization that provided home-cooked meals, to have fresh green salads and hearty soup delivered to our doorstep on Tuesday afternoons.

The volunteers who brought the food offered to stay for a few minutes, and asked us about our week. They didn't force conversation, but let us know they were available to talk if we wanted. Often we found something funny to laugh about too. It was becoming increasingly clear that the magic of comfort food, bringing us together with new friends, along with laughter, was a strong medicine that could carry us when all else failed.

Fortunately the sibling cancer camp our daughter had grown up attending was about to begin the

winter session. All along my daughter had preferred the sibling only sessions over the combined sibling and patient sessions because she needed a group to call her own.

Meanwhile, my son continued to feel reasonably well. He had decided that someone would be the first survivor of his type of brain tumor, and perhaps it could be him.

Jay did his best to move forward with his life. As ill as he was, he gave the impression he'd outlive all of us. But suddenly late at night his voice grew raspy. The next morning he had difficulty swallowing and his chest rattled when he breathed. We called our doctor and after a quick exam Jay was admitted to the hospital. An MRI was ordered.

The news wasn't good. The MRI showed the tumor was three times as big as it was post surgery.

I blinked in surprise. Jay knit his brow as he let the news sink in. We sat silent, frozen in the moment, while in a hushed whisper our oncologist explained that Jay's body was beginning to shut down. We had an appointment the next day to start stereo tactic radiation. But we had run out of time. I made a quick phone call to Hospice and we waited for the hospital paperwork to be completed, allowing Jay to leave. By now he could barely speak, his words were slurred. He could no longer swallow water or eat food. Yet he was completely alert and fully coherent. He wrote notes when he wanted to tell us something, and he wrote me a note that said, "How am I going to eat?"

I blinked back tears. My mouth remained open as I searched for a reply. I took a deep breath of hospital air that smelled of old wax and disinfectant.

"As your body begins to slow down, you probably won't be feeling hungry," I offered. We faced each other, not two feet apart, yet in different universes.

Jay stiffened, drew back from me, then he punched me in the arm, hard. A second later he pulled me close to him and gave me a light kiss on the cheek.

Twelve hours later Jay was settled in at home, where everything was peaceful and familiar, with his dog at his side. Hospice began, and the final piece in the mosaic of support created by a

multitude of good people and organizations offering help when we needed it most it, fell into place.



## Not the End We Planned For

Anonymous Four

In 1997, my four-year-old daughter was diagnosed with a high-risk medulablastoma. She underwent the current treatment program at that time. She suffered multiple complications from the treatment and developed seizures, which caused her to lose her sight and 80% of her hearing. These all contributed to her manifesting many behavioral issues, making her a danger to herself and others. Also during this time, she developed large amounts of brain atrophy from the maximum radiation dose she had been given. In August of 2010, Emily was still deteriorating, her seizures were uncontrollable, and her quality of life was extremely poor. A meeting to discuss how to care for my child if an acute crisis presented was held. The meeting included her parents, oncologist, endocrinologist, pediatric neurologist, social worker and the head of medical ethics. We discussed what course of action would be best for her nothing could be done to reverse her condition or prevent further deterioration. A POLST is a physician order for life sustaining treatment and is appropriate if the doctor feel that the patient has a good chance of death in the next year. The purpose of this document is to have a plan in place in case the patient has a life threatening crises. We chose to put a POLST in place with specific instructions *not* to intubate. This was a hard decision to make for a parent, but we all felt it was the best choice for her.

A few months after the POLST was entered, in November, 2010, I came home from the store and my daughter's caregivers told me she had complained of a headache different from her usual headaches. They gave her Tylenol with codeine and she went to bed about 4 p.m. When I checked her later she seemed fine, merely sleeping her headache off. We

decided to let her sleep some more. Around 8 p.m. the caregivers came and got me because they could not wake her up to go to the bathroom, which was her normal routine. I immediately went to try and wake her up but could not. I ran my thumb up the bottom of her foot and there was no reflex response. I yelled for her father that we needed to immediately go to the hospital.

We took her to the ER at the local hospital that treated her close to the house. We told them we did know what was happening with her but that there was a POLST in place in her chart. They started lines, a nasogastric tube, and sent her for a CT, which showed massive amounts of blood in her brain. I repeated again to the ER staff and physician that there was a POLST in place but no one acknowledged my statement. I asked for a different physician, one that would respect the POLST, and was told there was no one else nor was there a neurosurgeon available. The attending physician insisted she be intubated in order to be transferred to a partner hospital (more than 20 minutes away) where there was a neurosurgeon on duty. I asked him to please call her oncologist at which point he yelled at me that, "he was not calling anyone else and that she needed to be intubated and transferred to the other hospital." By this time, four hours had passed and I knew she had not gotten any medication for pain, so I told the physician to go ahead and transfer her since I knew the hospital we were at would not admit her for palliative care. She was then intubated, in violation of the POLST, and transferred to the other hospital where the neurosurgeon there told us what we already feared: That she had experienced a massive bleed in her brain. We requested she be extubated and be given palliative care to make her comfortable until she passed away.

It is tragic that our daughter's last hours involved aggressive medical treatment. As parents we hoped to avoid any additional suffering for our child, we did everything we knew to do to insure aggressive interventions would not be imposed on her, discussed this with her medical care providers, and participated in having a POLST entered. We believed the POLST would protect our child from unwanted treatment. Sadly, the POLST was ignored

and she subjected to aggressive unwanted treatment in her final hours.



## Ice Cream For Breakfast

Michelle Methven

In June of 2011, on a warm sunny day in Toronto, Canada, my partner and I brought our daughter Stella into the local hospital emergency room for what we believed would be a routine check-up. She had been exhibiting worsening clumsiness and limping for the previous two weeks and we thought it would be easier just to get her seen and have whatever it was dealt with rather than wait two months to see a specialist. My partner and I believed it was likely a severe ear infection, or maybe Lyme disease from a recent camping trip. We each called our workplaces and said we would be an hour or so late. Nothing could have prepared us for the news 22 hours after arriving at the hospital, that Stella had a cancerous mass in her brain. After a biopsy three days later to confirm the diagnosis, Stella was diagnosed with Diffuse Intrinsic Pontine Glioma (DIPG), and given less than a year to live.

Parents most often describe DIPG as "a monster." The tumour saturates the pons and shuts down nerve pathways one at a time. In no particular order, and in no particular time, sufferers (most often young children) lose the ability to walk, sit up, hold up their head, speak and see. The pons is also responsible for breathing, swallowing and regulating the heartbeat, so death can come in many forms at any given time. Though it destroys the brain's ability to command, the person continues to think and understand as the main part of the brain is untouched. Different from most cancers, chemotherapy and radiation have almost no effect on DIPG; even trials with the most toxic chemotherapies do not slow its progress.

My partner and I were shaken to the core at this diagnosis. Looking at our energetic, redheaded

mop-topped little imp, it was impossible to fathom that she had just been given a fatal diagnosis. Yet we knew the doctors at the hospital were among the best and most sought-after in the world, so denial was never a part of our mantra.

A week after Stella was diagnosed, we met with a neuro-oncologist to discuss our plans. The only treatment that is slightly effective for DIPG is focal radiation, which can stall the tumor's growth, granting what is known as a "honeymoon period" of no new symptoms. The honeymoon lasts approximately six months, but there are no guarantees. Twenty percent of children get no honeymoon whatsoever after radiation, and others get only weeks. The doctor we met with confirmed radiation would not be curative, but would "buy time". He explained that radiation involved six weeks of treatment, seven days a week. Following the six weeks of treatment, there would be a period of anywhere from one to six months in which Stella would likely be asymptomatic. However, at some point, the symptoms generally return and when they do, children deteriorate relatively quickly. Sometimes it takes a month or two, but on occasion there is as little as two weeks between progression and death.

As Stella's parents, we were not convinced that the prescribed radiation was something we wanted to subject Stella to. Because she was only two, and a very spirited and energetic child, it would have been virtually impossible to have her lie quietly on the table in hospital each day for six weeks while radiation was put behind her ear. The neuro-oncologists' solution was that Stella be sedated for each daily radiation treatment, which would make her groggy for a big part of the day and necessitate needles and IV. As parents, we were presented with an impossible gamble. Do we risk taking away six weeks of her still somewhat symptom-free life for a possible extra three to six months later? And the timing was difficult as well. It was late June. If we chose to radiate it would mean spending the entire summer shuttling her between hospital and home with no weeks at the cottage, and much less time to attend neighbourhood BBQ's, parties, trips to the park, the library, science centre and zoo. Other than a slight limp, Stella was completely asymptomatic.

After two sleepless nights of discussion, my partner and I agreed wholeheartedly that we did not want to treat Stella's tumor, "buy time", or attempt any type of cure. With full support from our family members, we decided we wanted no radiation, no chemotherapy, no steroids, no feeding tubes, no shunts. Our family would make each decision regarding treatment as needed, and only if it became a quality of life issue. For example, if the hydrocephalus in her brain began to cause extreme pain to Stella, we would consider a shunt to improve her quality of life, but we would not consider it merely for life-extension. At the end of the day, our beautiful, vibrant, smart and energetic child was going to die, and we just wanted to take Stella home, take her to the park and let her be a "normal" two-year-old for as long as possible. We wanted quality of life for Stella. We couldn't shake the fact that there were no guarantees offered with the radiation, and in some rare cases, radiation even makes the symptoms of the tumor worse with patients exhibiting partial paralysis after radiation. We wanted to spend the summer watching Stella run at the cottage, eat ice cream and visit the farm, not under sedation in a sterile hospital.

In conversations with doctors the next day, we grappled with the certainty of our decision as we were forced to repeat over and over our choice to decline radiation. In North America, deciding not to treat is akin to "giving up." When we met with the neuro-oncologist to discuss our treatment plan, he was visibly shocked that we had opted against radiation. He reiterated that radiation was the prescribed, and recommended, treatment for DIPG. His follow up notes stated three times, "Parents declined treatment" in a single page document. Partway through the meeting, when the doctor left for a moment, I remember turning to the other people in the room and saying, "Are we crazy? I feel like these doctors think we're complete lunatics. Are we making a huge mistake? Is this decision wrong?" After much support and affirmation from the family and friends attending the meeting, my partner and I were able to stick with our decision, despite the pressure we were receiving from the neuro-oncologist and his team,

some of whom were brought in to initiate further discussions with us. Faced with being told that your child will die, it is natural to want to fight and demand whatever treatments might be available. The idea of fighting a disease with 100% mortality rate is futile, yet it is for some reason more acceptable in society to “fight” the cancer, to hope, right to the very end, that your child might be the first one to beat this disease.

The neuro-oncologist finished the meeting by telling us that without radiation Stella’s life expectancy would be three to six months instead of 8 to 12 months. Still, we stuck with our decision. We didn’t want a medical honeymoon; we wanted the guarantee of having Stella with us, and not in the hospital, every day possible. Since most children with DIPG are older and typically receive radiation treatment, the doctor was unable to give much direction on how the next few weeks and months would unfold. He opined that she would probably start to be more symptomatic shortly, but could not say for certain.

We further surprised the doctors by telling them that since Stella was going to die sometime in the coming months, we wanted to be connected immediately with a palliative care team. In our mutual experience, palliative care was often brought in very near the end of someone’s life, but rather than look at palliation as end-of-life care; we wanted it to be about symptom control and comfort. Our request was granted and two weeks after Stella’s initial diagnosis we had been transferred from neuro-oncology to a palliative care team that would treat Stella from our home.

Because palliative care was with us right from the beginning, our family became very familiar with the doctors we worked with and trusted them implicitly. Stella’s two palliative care physicians visited her on a weekly basis at home, scheduling appointments between play dates and trips. The Doctors had a solid relationship with Stella and my partner and me, so when there were difficult decisions to be made, they were already familiar with our wishes and convictions and were able to offer options that met with our hopes for Stella’s life and death.

As far as we are concerned, refusing treatment for her tumour allowed Stella to win the life lottery. She never went back to the hospital, and spent 16 months *living* with her DIPG tumor. As expected, she did lose her faculties one at a time but it was a slow and steady decline as opposed to “the cliff” one neuro-oncologist described it as. In September 2011 she lost her ability to walk. In December 2011 she lost her ability to speak. In February 2012 she lost her ability to sit up. In June 2012 she could no longer hold her head up. In August 2012 she lost control of her arms and hands. In October 2012 she died.

Yet, through the entire experience, Stella remained happy and content. We adjusted together as a family to her changing physical abilities. When she could no longer dance with her legs, she danced with her arms and head. When that was taken away from her, she danced with her eyes. When she could no longer speak, she devised a way to tell us “yes” or “no” using her tongue. She smiled and swam and teased her younger brothers right to the end of her life. Her decline was very natural and organic, and she lived longer than most children who *do* undergo radiation and/or a combination of radiation and drug trials.

In our culture, hope is synonymous with cure. In this context, as parents, we have needed to live with the label that many people saddle us with as having “given up” on Stella. We didn’t fight for a cure, didn’t put Stella into any medical trials, didn’t pray for a miracle to save her. Our only hope was that Stella would have a good death, and our only wish was that she lived each day.

Looking back on our decision not to treat, and the incredible 16-months we were given with Stella, we have absolutely no regrets. Instead of being dragged back and forth to the hospital, subjected to painful treatments and put into medical trials with medications that have various side effects, Stella simply lived. She ate ice cream for breakfast, watched her favourite TV shows from the comfort of our laps, visited the farm and zoo on a weekly basis, laughed, danced, played and died peacefully in her parents’ arms with a radiant smile on her face that let us know, without a doubt, we’d made the right choice for her and our family.