



# VOICES

PERSONAL STORIES FROM THE PAGES OF NIB

## CONFRONTING PEDIATRIC BRAIN TUMORS





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PERSONAL STORIES FROM THE PAGES OF NIB

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All the authors in this issue for sharing their stories with all of us.

## Introduction

# Confronting Pediatric Brain Tumors: Parent Stories

Gigi McMillan\*, Symposium Editor

\*Correspondence concerning this article should be addressed to Gigi McMillan at 1590 Rosecrans Ave., Ste. D332, Manhattan Beach, CA 90266.

Email: gigimcmillan@gmail.com

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 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

This 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 refuses 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

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*\*Name changed to protect privacy.*

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 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 peds-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.

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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.*

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 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 Diladed 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 Nortriptoline 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

**I**n 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.



## Commentary

# Cartography of Endurance

Christy Rentmeester<sup>1,\*</sup>

1) Creighton University School of Medicine

\*Correspondence concerning this article should be addressed to Christy Rentmeester at Creighton University School of Medicine, 2500 California Plaza, Omaha, Nebraska, 68178-0409.

Email: christyrentmeester@creighton.edu

These stories are remarkable in their generosity: not only because their authors were willing to share family intimacies with the bioethically curious, but also because they were written such that the raw freshness of their losses, strivings, and vulnerabilities are so clearly rendered. As a teacher of clinicians-in-training, I appreciate such clarity, as it often facilitates teachability. My perspective is not only pedagogical, but analytical, given my background as a researcher and clinical ethics consultant, so I've considered these parents' stories with an eye toward collecting themes and lessons. I offer these reflections in hopes that the moral relevance of those themes and lessons might also be made clearer. May they be helpful in the futures of parents, children, and professionals who must navigate the clinically and ethically complex terrain of this set of illness experiences.

### Mapping for Meaning

The most prominent unifying theme among these stories is a desperate need for a "map" of what these families go through. The map metaphor is drawn upon frequently in the stories, particularly those by Christopher Riley, Anonymous Two, Jeanne Carlson, and Michelle Methven. I suggest that the project of physical, spiritual, and emotional sense-making about illness experiences is one of cartography. Maps provide travelers with a few key things: bounds for hopes and expectations, pathways to next steps, suggestions of where and where not to go, and can even offer guidance for improvising a new way among already-established trails.

Riley, for example, longed for a "sense of our place on the long road we were traveling." He and his family navigate the emotional, psychological, and spiritual tension between trying to make sense out of their son's illness and trying to accept facts out of which, perhaps, no sense can be made. In one poignant vignette, Riley mentions that his son "wants the independence of riding the city bus." Here, Riley tries to negotiate the parental terrain between expressing protective regard for his child's vulnerability and the project of creating space for his growth and development.

In another story, Carlson refers to parents of children with brain tumors as "pioneers." The authors in this collection are surveyors and cartographers of an extreme landscape of parental experience. As Methven describes, planning the death of a child is one path most parents don't have to forge. Anonymous Two also notes the need for psychosocial support along paths for which there is no map to wellness. Riley adds that exacting requirements and levying penalties unintentionally upon siblings of children with brain tumors are other experiences for which he might have liked a map.

Overall, it seems sinister and cosmically unfair that brain tumors generate symptoms that can masquerade as criteria for conditions ranging from abuse to the common cold. Riley's theme of constant striving to navigate was clear not only in his struggles with clinical uncertainty, but also in his struggles to cull clarity from metaphors, such as "shaved" IQ points. This shaving metaphor allowed prognostic humility about iatrogenic effects—harmful consequences of medical

treatment or advice—that were not often possible to predict accurately. But, metaphors should be used cautiously in clinical contexts because they effectively mask uncertainty by creating more of it. Riley, specifically, was dreadfully surprised at how much of his son’s abilities had been compromised by treating the tumor. His experience suggests that uncertainty creates need for mapping parents’ processes of making way through at least these kinds of uncertainties: discovering just how bad and how long iatrogenic effects persist; grieving losses not yet realized; and searching for hope in small signs, but not holding too fast to measures of progress that might be lost with the next treatment.

### **Transformations in Parents’ Relationships During, After, and Long After a Child’s Illness**

Children’s brain tumors seem to require changes not only to the parent–child relationship, but also to the parental partnership. Such changes are probably best conceived as journeys rather than destinations, and many are also unmapped. Perhaps loving a partner or spouse through a child’s illness is a skill set partners can cultivate together over time. Riley suggests that years might be needed to develop hindsight for distinguishing small losses from ultimate ones, and that years might be needed to grieve them all. He also suggests the need for parent–to–parent space in which couples can create and nurture the capacity to preserve a partnership.

Jeanne Carlson also recommends specific skills such as the ability to identify and become aware of one’s own responses to grief, and Riley recommends other skills, such as the ability to witness and compassionately respond to a partner’s grief. He suggests that parent–to–parent space might be occupied, in solidarity through suffering, “as holy ground” to allow for shared transformation.

Many of the stories in this collection relate specific kinds of suffering that couples might endure better together than alone. Anonymous One, for example, suggests the challenge of living with one’s parental treatment decisions. Mike Abell expresses

what it feels like to be haunted persistently by fears of tumor–recurrence. Terra Trevor counts accepting help as one of her biggest challenges. Numerous other authors cite the project of orienting oneself and one’s partner to the reality of a child’s long–term dependence and disability and also remark upon the persistence of painful comparisons, made mostly by themselves, of their child to “normal” children.

### **Points of Interest on the Map for Health Professions Education**

In this collection, parents’ relationships with the clinicians directing their children’s care are, perhaps, just as important as parents’ relationships with each other. The stories related several specific instances in which clinicians’ responses were critical and influential, sometimes positive and sometimes negative.

#### **Clinical Humility**

Brandi Wecks, Lynne Hillard, Anonymous One, Kimberly Rocker, and Anonymous Two each, for example, had poignant experiences regarding what we typically call “second opinions.” In these cases, parents took their child to different clinicians to gather additional clinical hypotheses about their children’s symptoms or to corroborate or interrogate initial diagnoses. These particular stories suggest that second opinions are not only medically, but also morally, important.

Wecks expresses ways in which a second opinion was one hallmark of her search for hope, and Hillard discusses her own explorations with different clinicians’ views as sprouting from her urge to be prepared and her need to create views of the future that include realistic outcomes. Rocker relates how several clinicians appeared to have missed cues that might have tipped off accurate diagnosis of her child’s brain tumor earlier.

Rocker’s story and the story by Anonymous One also prompt us to express respect for clinicians’ fallibility; one possible moral expression of such respect is to safeguard the value and virtue of humility. The presence of uncertainty seems to loom

as large over clinicians as it does over parents in these stories. One lesson is that a clinician of humility will welcome second opinions, not only as a way of participating in the profession and practice of medicine in a collaborative, patient-centered way, but as a concrete strategy for helping parents cope with persistent guilt over present decisions that might not turn out well and with the barrage of unknowables that might traverse the imaginations of parents later haunted by hindsight.

As Rocker relates, clinicians who are threatened by second opinions of medical colleagues undermine their own credibility and trustworthiness. Responses of anger or frustration with other clinicians' views of what's going on clinically can create the impression among parents that a clinician is more interested in being right than in getting it right. These stories suggest that clinical humility means reserving healthy dubiousness about one's own certainty and one's own habits of perception (Rentmeester & George, 2009). From a parent's point of view, it also means sparing suffering when you can, and in the case of pediatric brain tumors, that seems to require clinicians to collaborate inclusively on a child's diagnosis and care.

### Learning Curves

Patients and their loved ones' play critical roles in clinicians' educations. Clinicians owe generosity and gratitude to these folks, and the stories in this volume offer some lessons on how those virtues might be expressed. Lynne Hillard's experience suggests how the clinician-parent relationship goes wrong when clinicians pathologize—represent as abnormal or expressive of illness—a parent's involvement in a child's care. Practicing medicine with generosity in this particular case would have meant that parents are free to grieve and interrogate clinical findings. Parents are not held to standards of professionalism, but clinicians certainly are. Pathologizing parents' behavior is unhelpful to the child, and makes poor use of opportunities to recruit parents as allies in the project of caring well for the child. In cases of disagreement between parents and clinicians, it is within the scope of clinicians'

responsibilities to nourish the delicate tendrils of connection between disagreeing adults who share a common interest in a child's well-being.

Errors in clinical education and professionalization are matters of when, not if. Several stories in this collection consider different kinds of errors. Anonymous Four tells of how careful plans for implementing palliative care and a good death plan for a child became muddled by miscommunications and unwary commitment to routine rescue procedures; this is an instance of a systemic error that is a product, in part, of the acute-care-driven culture of our long-standing national healthcare enterprise.

Riley relates a different kind of error about speech and context. Specifically, habits of speech appropriate for a clinical audience can cause harm to those with personal, not just professional, stakes in the outcomes. Bad news delivery experiences are almost always painful for patients and their loved ones, but they can, perhaps, be less painful when clinicians carefully and deliberately focus on the harm their words might incur. The resident physician in the story Riley tells realizes his error of referring to his son's tumor as "impressive." But the realization comes too late, only after Riley's unwelcome surprise is evident: "That's the first time anyone has used the word *tumor*."

Trusting measurable evidence over and above a patient's or parent's experiences and self-report can also be seen as a kind of error. This kind of error is a product of cultural over-reliance on science in situations that call for active listening for the kinds of knowledge that most reliably derive from patients' experiences or the experiences of their loved ones. Anonymous Three relates how their knowledge claims, which came from long-standing direct care of the child, were undervalued relative to measurable evidence. Measurable evidence is often clinically important, but over-reliance on measurability clouds clinical moral perception and generates feelings of powerlessness and frustration among those whose knowledge claims are undervalued during clinical encounters and in clinical decision-making. When patients or their loved ones feel that their knowledge claims are not taken up as authoritative, conditions are ripe for distrust. When distrust

infiltrates a clinician–parent or clinician–patient relationship, the relationship gets damaged morally, perhaps beyond the point at which that relationship can be therapeutic to the patient.

Lynne Hillard relates another important lesson for clinicians in her story, in which she struggles with the tension between hope as a source of strength and hope as a source of painful disappointment. She seems to offer a message to clinicians about how to prognosticate: leave room for hope, but not too much. In her story, she was offered a prognosis that erred on the side of optimism. This seemed to be a well-meaning clinician’s attempt to preserve hope and provide reassurance, but optimism rang hollow when it became clear that poor outcomes were the ones that emerged in actual experience, and this prompted her to distrust her child’s clinicians, which turned out to be a painful source of anxiety. A morally relevant message we extract from Hillard’s story is that humility about good outcomes is just as important as humility about poor ones—humility can preserve trust and eliminate terrible surprises when truth wills out.

### Medical Care as a Source of Trauma

The possibility that one’s medical care can be a source of trauma from which one (or one’s loved ones) must recover is rarely, if ever, recognized as an important path on the map of an illness or injury experience. Iatrogenic suffering, for example, wrought in particular by the long-term late effects of chemo and radiation, is considered by several authors in this collection, including Brandi Weeks and Jeanne Carlson. Anonymous Three also acknowledge that personality changes and depression among children, or children who have now grown into adulthood, can be responses to traumatic illness and healthcare experiences. Lynne Hillard emphasizes ways in which the healthcare system is generally ill-equipped to help clinicians and parents help children who develop behavioral problems in response to those illness and healthcare experiences. Lynne Scheumann also suggests another traumatic result of the experience of being a patient: alienation and marginalization. An

additional lesson for clinicians and clinicians-in-training is the importance of cultivating awareness of one’s own role in making illness and healthcare experiences therapeutic rather than traumatic.

### Excavation and Revelation

The stories in this collection simultaneously call for and create maps of illness experiences. The multi-media artist, Mark Bradford (The Mark Bradford Project, 2011), uses maps as one source for cultivating collages that facilitate focused exploration of the processes by which we construct and deconstruct meaning in contemporary life. Of his work, he says, “I excavate and I build at the same time.”

These stories’ authors are similarly engaged. They use narrative to describe their own experiences, so that others might learn from them, and they use narrative to quarry new insights about those experiences, so that they might emerge from heavy pasts with lighter treads toward their futures. It’s my hope that these reflections on some of the complex moral valences of those experiences might help those of us in the enterprises of bioethics to think more powerfully about where and when professional education intersects with intimacies of illness experiences of children and parents.

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## Commentary The Right Thing

Michael Barraza<sup>1\*</sup>

1) Los Angeles County Department of Mental Health

\*Correspondence concerning this article should be addressed to Michael Barraza, Psy.D. at 17707 Steudebaker Rd., Cerritos, California 90703. Email: mibarraza@dmh.lacounty.gov

When someone we care for is seriously ill, we are sad and frustrated. The powerlessness we feel is difficult to tolerate and it impacts our ability to function. In my hospital experience working with families, parents describe being stripped of confidence and having their functioning so compromised that they are unable to process facts or initiate action in a meaningful way. Some caregivers might fully realize the severity of their child's condition, while others struggle to accept the basic concept that their child has cancer. They fear they are not up to the task. They long for answers, for hope and most of all—for guidance. These narratives offer a glimpse into the minds of these parents and two things are clear: they love their children and they want to do the right thing. The burning question: What *is* "the right thing" when your child has a brain tumor?

Before I discuss some of the themes that stood out to me in these stories, I want to paint a general picture of what happens to a family in the face of a critical or chronic illness. Managing the complex treatment and recovery of a pediatric brain tumor is a daunting task. The child's team includes physicians, therapists, psychologists, social workers, educators, and clergy as well as immediate and extended family, friends and neighbors. Team members are often asked to step out of their comfort zone to meet the needs of the child. The stress is immense and I liken the family to an engine of sorts. Each member works as a component in that engine to promote the smooth running of daily life. In the face of serious illness, the duties of all the components are rearranged. The engine sputters.

It may limp along indefinitely. It might race wildly before burning up or shudder to a cold hard stop. With a few modifications, it can run satisfactorily, but the fact is—the basic functionality of this family unit has changed, which is stressful—on top of the emotional trauma of the medical emergency.

An added difficulty is that treatment for pediatric brain tumors can last for long periods of time (months, even years) and cause significant damage even while seeking to save the child's life. Over the course of time, the family dynamic changes. What was once a novel emergency that inspired heroic coping measures becomes a tedious, energy-sapping nightmare. Visiting family members go home. Neighbors stop bringing casseroles. Vacations are postponed (again). Siblings feel neglected. The parents sometimes settle into a division of labor, where one becomes the "expert", managing the physical labor and making the majority of decisions. Robinson et al. state that as the course of treatment of a sick family member lengthens, the physical health of the primary caregiver will worsen (2001). And in the face of all this, parents are called to perform a task that is fraught with guilt, doubt, fear and tremendous responsibility: choosing the course of treatment for their child.

The first most obvious theme I can identify is the agony that these parents go through as they struggle to make life and death decisions on behalf of their children. More than just deciding between two serious and often very different treatment plans, the weight of the action seems to lie in the fact that they are deciding *for someone else*. This realization can be found in most of these narratives. Christopher Riley

writes, “We made decisions for Peter we knew might cost him his life.” Anonymous One states, “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,” offering more evidence of the difficulty in having to decide for someone else. When Anonymous Two reflects on her experience of considering the reproductive health of her child and treatment concurrently she writes that in her “experience, when you talk to brain tumor parents, no matter what the circumstance, guilt, and regret are always part of the conversation.” Many times I have heard the words, “If only it were me!”—not just referring to the heinous disease, but addressing unwillingness to accept the burden of decision-making and unknown long-term outcomes. And worse—the direct result of these treatment decisions is tangible physical harm. The child is cut (surgery), made sick (chemotherapy), exposed to radiation. Another consequence of treatment is elucidated by Christopher Riley as he witnesses how treatment compromised his son Peter and exposed him to even more risk. By eroding his defenses and making most viruses deadly as he writes Peter was “succumbing to his cure.”

This predicament makes the relationship between the parent and the medical team that much more important. One parent wrote that after their child was diagnosed with a brain tumor, much of their social support group vanished. Terra Trevor writes, “. . . least expected was the amount of personal friends and co-workers who backed away from us.” Parents must find a new support system that is relevant to their new life situation—and this revolves around the treating physicians. The leader of this support network might be the treating oncologist (not always) and the temperament and interpersonal skills of this person directly affects the quality of the group interaction. It is important to draw attention to the social-emotional dynamics that drive the relationships within this support network. Several parents wrote about the difficulty in seeking second opinions because they feared damaging the relationship with their oncologist

(Anonymous One and Anonymous Two). (Note: Most parents identify the physician as “their” oncologist, not “their child’s” oncologist, highlighting the point that this disease can be characterized as affecting not just the child, but the child-parent unit and immediate family.) With great detail and poignancy, several stories describe damaged relationships after a second opinion was sought, the feeling of being ignored, disparaged, and dismissed when trying to share facts about their child’s condition and opinions from other experts in the field. The pain, regret and even humiliation evident in these stories underscore the vulnerability of these caregivers and the responsibility of the team leaders to be more aware of parent needs. I am led to ask: Why is there a disconnect between these two parties who are both focused on the same child?

Clearly, parents are at a disadvantage because they are not medical experts or scientists with an objective grasp of their child’s situation. They are new to the world of pediatric brain tumors. They don’t know the background, the terminology, the intimate perspective or the global climate of the disease. They *do*, however, know their child—and in that regard, are the experts of note—but they find themselves in a hospital, where they are subject to a different hierarchy. The physicians on the team may have careers based on this disease and are accustomed to working in the culture of the treatment center. While some physicians may grow very close to the child, they also retain a degree of objectivity that allows them to provide the needed medical care. The physicians, however, are not the primary source of guidance and emotional support for the pediatric patient, and may not know how best to nurture a cooperative relationship with the child. In short, revolving around the sick child are two different camps of experts, often with different but intersecting agendas, who must figure out how to work with each other.

It is important to emphasize the complexity of this medical situation. In a world where many of us do not read the warnings on the over the counter medications we self-administer, how does one absorb descriptions of risks and benefits of a complex treatment plan? These parents are given thick

binders full of complications and complications to the complications to read through and discuss with their medical team. In some cases the true effects of some forms of treatment are not completely understood because no one has survived them. It has been said that a human needs to hear something three times in order to integrate it into their working knowledge (Scarborough et al., 1977.) This is not, however, a case of simply absorbing concepts and facts. At this crucial juncture where knowledge must be absorbed, these parents have received devastating news and are processing life stimuli at less than optimal levels. To put it simply, many of them are in shock.

The Diagnostic and Statistical Manual of Mental Disorders has a diagnosis for the ensuing difficulty after having experienced a specific event: Adjustment Disorder (4th ed., text rev., 2000, pp. 679–681). The impact of a pediatric brain tumor on these parents is also noted by the “flashbulb memory” many of them have of when they received the diagnosis or some other significant moment in their child’s treatment (Wecks, Carlson and Rocker). A flashbulb memory is defined by Brown & Kulik as a memory so emotionally loaded that we can clearly recall many aspects from when we experienced the specific event (1977). With a flash of a bulb, there is a searing instant of illumination followed by momentary blindness. In the case of these parents and others in my experience, the “blindness” is manifested by difficulty in absorbing often-crucial information about treatment options, the risks and benefits of enrolling in a clinical trial, and short and long-term consequences of whatever path is chosen. Because the team leader has the experience, perspective and objectivity—and is *not* the vulnerable party, this professional has the responsibility to monitor and assist the parents as they work through the onslaught of data and emotions and to foster respectful and meaningful communication between the team members,

In these narratives, we are exposed to classes of tumors and types of treatment that slowly rob children of body function and lead inexorably to death. In one circumstance, a teenager has enjoyed a tumor free life for eight years and his mother determinedly

celebrates life and whatever it may bring. He is ultimately aware that he will lose his life and follows his mother’s lead with unflinching acceptance as he has a recurrence (Trevor regarding son, Jay). Another narrative describes a two-year-old who is beginning to experience the world around her with a zest for the beauty of life, despite progressive physical limitations (Methven). In a third, a mother is determined to ensure a peaceful passing for her child but is thwarted by her treatment team at the last moment (Anonymous Three). No one of these narratives is more tragic than the other, and in each these mothers demonstrate formidable will and strength that is both gritty and graceful.

Physical death is not the outcome in all the narratives, but in every instance there is loss. The long-term quality of life issues for a brain tumor survivor are complicated, unique to each child and often a surprise to their caregivers. As one mom said to me, “We beat cancer, but where’s the party? Now we have to fight the school district to help him through the next phase of his life!” These children return to school with physical and cognitive difficulties. There may be disfigurement, but often there are disabilities that are not obvious and schools and society. For example, pediatric brain tumor survivors often experience inability to attend to verbal or written instructions; compromised processing speed, difficulty with impulse control, problems with abstract thought and executive function (Glauser & Packer, 1991). Riley, Anonymous Three, Scheumann and Carlson describe this secondary, post tumor journey. What is implied but not specifically mentioned is the need for these parents to become a new kind of expert to navigate this leg of their journey. The culture and vocabulary they learned to deal with the medical world does not necessarily apply to the world of public education, the job market and life skills for those with disabilities.

Many of these stories mention the importance of support groups (Trevor, Rocker, Blumfield, Hillard). A family may desperately want to exit the lights, sounds and smells of the hospital but find themselves overwhelmed and unprepared to deal with a G-tube. The strain of a permanently altered life begins. Loneliness comes from having to attend

social functions solo (one parent stays home with the sick child) or not bothering to leave the house at all. A sense of isolation comes from inquisitive looks and rude stares when in public with the survivor. Siblings act out or repress their feelings (Riley, Carlson). I have seen, however, the healing power of finding a group of “others like me.” When family members find others who are on a similar journey, they begin to embrace their “new normal.” The benefits of groups have been long understood by many people (Yalom, 1995; Rodgers, 1966). They provide people with a place to be validated and heard. They foster an environment where explanations are not needed about odd behaviors, certain scars, or assistance devices. Support groups create repositories of knowledge that are continually updated by experience and freely shared. Topics range from how to deal with the side effects of disease and treatment to emotional swings in the family to strategies on how to best manage daily challenges. By seeing examples of other families who are successfully managing survivorship, those new to the journey find hope.

Deepak Chopra states that we are all trying to do our best, but sometimes we let people down. When this happens, we hope that people forgive and accept us for who we are; in turn we should forgive and accept others when they let us down (2003). This thought came to mind as I reflect on the complex task before the doctors as they work with parents and difficult choices parents make on behalf of their children. These stories illustrate a range of persistence and ingenuity of heroic proportion. It is an honor to have been invited to share in their world.

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## Commentary “Grey Matters”

Katie Rose<sup>1\*</sup>

1) Author does not wish to share an affiliation and has changed her name to protect her identity.

\*Correspondence concerning this article should be addressed to the journal editorial office.

Email: narrativebioethics@gmail.com

*I*t's a tricky tumor all right: a temporal lobe ependymoma with glial-like cells and an unusually slow growth rate. It's common in *this world*, for diagnoses to be confused. This grey, oblique world is the “World of Brain Tumors” from which these narratives are written. Nobody wants to enter into *this world*, but despite my fear, when my name was called, I stood up, flooded with relief.

The diagnosis of my brain tumor was the explanation to all of our questions. Social difficulties with bullying, zigzag swimming because my left side was weaker than my right, “spacing out” during middle school, dropping grades, headaches, struggling to breath during physical education class and eventually “episodes” which we later learned to be complex-partial seizures. In an effort to deal with my social difficulties, in ninth grade I hinted at an illness to gain sympathy from my peers. Less than a year later, however, I would go to a real doctor's appointment and come back with a real diagnosis: possible clump of blood vessels, probability of tumor growth in brain. Thank God something was wrong with me! I had been begging for a key to this world for years, but had no idea of the reality, obliqueness, and fear that came with it—a fear of the unknown.

Each narrative illustrates *this world* in which everything is covered in a thick film rendering things once obvious, now unknown. Parents are asked to choose treatment plans for their children, plans that will inevitably alter their child's quality of life but in ways they cannot determine or even imagine. Parents are asked to play God. As one mother discloses, “It does make [her] question

[their] parenting and ability to know what is best for [their] child's well being” (Rocker). And when parents choose to voice their concerns, opinions, or decision to seek a second opinion they are flagged. Marked like Nathaniel Hawthorn's heroine, a large scarlet “P” for “Problem Parents.”

My own parents faced this difficult situation. They chose to follow the recommendation of our second opinion and “watch and wait” after a tangerine-sized tumor was removed from my temporal lobe. The distress, weight, and magnitude of the emotions they carried on their shoulders, going against the advisement of our treatment team is unimaginable.

However, doctors are only human and “nobody is infallible . . . sometimes we may miss something that someone else can see despite how much they know or care,” writes Anonymous One. In agreement, Anonymous Two described that, “talking to a doctor outside your own institution was somehow construed as lack of confidence and an act of disloyalty.”

I wish I could go back in time to that day in 2004 when my parents decided not to radiate my brain to reassure them and thank them in advance for saving me from additional brain trauma. This was the right path, for my unique tumor, and they were terrified when making these decisions. I trusted my parents more than my specialists, and my specialists more than other doctors. My life was in their hands, the softest yet strongest hands available. At that time, at the age of fifteen, I didn't want to know anything about the possible repercussions of my craniotomy or further treatment. I remember having

a very serious discussion with my doctor about the exact amount of hair he would be shaving off, how I would cover it, and how fast it would regrow. Half my head with a “comb over,” he called it. Luckily, I had enough to do a complete comb over with only a few prickly hairs sticking out here and there. I could hide underneath my hair, and sit back while my parents did the heavy lifting of obtaining second and third opinions about successive treatments.

One of the mothers in this collection, Jeanne Carson, was not told to seek a second opinion or given any information about the late effects of radiating a young, growing brain. “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 nine-year-old with chemotherapy and radiation” she writes. “The grief that her father and I experienced came with our greater understanding of Sarah’s disabilities and the significant lifelong impact that they [would] have on the quality of her life.” Like Sarah’s parents, my own, and most of the parents who share their stories in this collection, parents of PBT (pediatric brain tumor) patients have to walk the line. They walk the line of trying to not disrupt their relationships with their physicians, wanting the best for their child, and facing the decision to follow their gut or go with advised treatment plans.

Walking a line that is based on so many factors—intuition, research, advice, ethics, discussions, contemplation, and sometimes prayer—seems to be one of the largest burdens that accompany the appearance of pediatric brain tumors.

I was fifteen when diagnosed, so I saw the affect of my illness reflected in the eyes of my parents and my siblings. I saw the sacrifices they made, without complaint, as they scheduled their lives to accommodate to my doctors appointments, MRIs, therapy, and my need to be surrounded by family. I saw the concern provoked by my struggle with schoolwork, my extreme weight gain, my slow recall, and the side effects of my anti-epileptic drugs. With this visibility, I felt the burden of my illness in a new way: the burden carried by my parents and sister and brother. Almost every weekend for nearly two years, my 27-year-old

sister, and 29-year-old brother drove long miles to be with me. Their social lives were impacted, and to this day I wonder about my sister’s dating life and what would be different if she had had that time to socialize and expand her friendships. It’s just another “what if”—I’ll never know.

Many of the narratives written by parents include anecdotes about their other children and the effect on siblings of PBT survivors. Siblings can become secondary when a child is facing mortality. The late affects of this are like those of some secondary treatments: unknown. Jeanne Carson watched her son struggle on a completely different plane than his twin sister. “We did our best to balance our focus on both of our children as Sarah is a twin,” says Carson. “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” she continues, “but we feel certain that our constant focus on Sarah made his path toward drug addiction almost inevitable.” The intensity and repercussions of having a sibling with a life-threatening illness vary according to age, family structure, etc. but there is a common thread: the constant worry that something else could go wrong; the lack of attention no matter the intention; and the reality that the sibling might become their dependent once parents are no longer able to care for them—a heightened sense of awareness. Years after her son’s diagnosis, Lynne Scheumann learned that her younger daughter’s “litmus test for a husband is if he would be willing to have her brother live with them.” In a PBT family, the sibling(s) are the heavy crates that connect the parents—the engine—to the caboose—the child with a pediatric brain tumor. They may not carry the entire train, but all the interaction between the engine and the caboose affect them in some way. They are pushed and pulled, unsure, at risk of external factors, at times left in the dark, and must sacrifice attention while still playing their part; a very important part.

Within this chaos is the thundering roar of a train doing its best to move a large weight; it is a challenge, at the very least to see or hear anything beautiful. However, that does not mean it does not exist, even in *this* world. Your eyes become

accustomed to the grey. You start to see things in a different light than before, when light is available, and eventually you begin to create your own light.

At first, I felt completely in the dark, completely alone, in my experience with my brain tumor despite the tremendous amount of support I received from family and friends. No one really knew what it was like, or so I thought. But when I finally succumbed to attending "We Can Family Camp" for pediatric brain tumor survivors, I saw that there were other residents in this world. These residents become a form of light—as described so beautifully by Christopher Riley: "Kathy and I discovered we weren't the only family with a child battling a brain tumor. . . . We also shared comfort, a gift that can only properly be given after it has been received." When I say succumb, I mean that my teenage self did not embrace the idea of going to a camp where everyone was "sick." I was the most high-functioning person at camp and usually spent more time speaking with the parents than with the children. However, I was able to give—to speak to them from the perspective of a PBT survivor, even if my experience was not the same as their children. I could never emphasize the importance of family enough. In return, I received support and thanks. If I had not given, I would not have received.

This experience of giving and receiving is perhaps the most important part of life in *this* world. It can, however, be hard to see what has been given or received. A doctor, who has saved a life, may feel that the multitude of thanks given by the family, the genuine gratitude that will never be forgotten, is the family's way of giving back. The family, however, may never feel that their words could possibly express the gratitude towards the surgeon or the doctor who gave the second opinion that ultimately changed or perhaps saved their lives.

I still cannot accept that my gratitude is enough when it comes to the amount of sacrifice my family and friends have made on my behalf. During my two years at University of California Berkeley, I was in the emergency room every single month for a grand mal seizure. I was never alone. I had the most genuine, beautiful roommates and dear friends who ensured I was never alone and took

care of me when my seizures were small. I thank God for them, I thank them, and I still feel like all I have done is received, like no matter what I do it will never be equal to the amount they have given of themselves.

Lynne Hillard illustrated the beauty of receiving and giving through a short anecdote within her narrative where she observed her son at school. "At the end of the practice the teacher gave each child two skittles candies for practicing. She gave Ben [Lynne's son] nothing. One of the little girls in the group came up to Ben and shared one of her two skittles she was given. God Bless her." Maybe that is the best we can do—give something like a blessing after receiving and ask that a kindness be repaid in ways we may never know. Being in the position of needing support, strength, and sacrifice from others can be very hard to bear. But sometimes we make it more difficult by forgetting the joy that helping others gives us—and in needing we are receiving, but so are those who are giving. This has been one of the hardest lessons for me. It is so difficult to be on the receiving end of so much kindness and love with the knowledge or feeling that what has been given can never be repaid because the needs of the giver, may never be so vast. This, however, is our chance to pay it forward.

"We witnessed losses deeper and more total than ours, pains of a magnitude beyond ours, and we grew to eschew platitudes, to sit in silence and offer love in place of words. We came to see suffering as holy ground" (Riley).

I may never be able to run a marathon, or travel the various countries in Africa with which I have fallen in love, but the pains of a magnitude beyond mine have been as constant as the desire to lace up my sneakers and watch my heart-rate accelerate to the 160's. My personal tendency is to speak, and to use words to comfort. At the funeral of a girl who attended the Family Camp with me for a few years, I found that my presence and silence would not and could not suffice. After a family member sang a song about Savannah and how she would now be their angel from above, I stood up when the microphone was offered to the audience. I walked forward and despite the pain ripping through my body while

looking directly at her parents, I spoke. “You must know, that you were and are Savannah’s guardian angels. Parents make all the difference in the world and when we are rendered helpless to this disease, you guard us, and we thank God for our angels that he has placed on earth for us.”

Suffering as Holy Ground could mean a thousand things. I am not sure what Christopher Riley meant when he described suffering this way but it resonated very strongly with me. Those of us who are able to suffer do so because we are able to love very deeply. Those of us who have had near death experiences or have family members who are ill, suffer from feelings of loss, but as humans we cannot feel a loss if we have not once had *something*. Our appreciation is deepened to a level that is easy to recognize in *this* world, but makes it a bit harder to travel between the two worlds. Juggling jobs and responsibilities, maintaining friendships with people who do not understand the depth of suffering or the incredible appreciation that comes with PBT’s and other significant illnesses, makes it hard to walk the line of these two worlds, independent of one another but for us inextricably intertwined.

## Epilogue

One of my mentors asked that I write a few sentences to tell the readers what my life looks like at present.

I have just begun my master’s program in Social Work, after graduating from University of California Berkeley in 2011 with a B.A. in psychology. This is my way of giving back to those who have given so much to me—I’m going to do what has previously been called, “pay it forward.” I am motivated by the dedication of my parents, siblings, incredible physicians, friends, professors, and many strangers who have treated me with so much kindness, I am dedicating my life to the service of others, in part, because of them. I am also deeply in love with an amazing young man who also has a brain tumor and epilepsy. My ability to function at a high level comes with an acute awareness of my limitations and the things that I am “missing out on.” For example, he and I may not be able to have our own

biological children. We may not live in a suburban home because of the need for public transportation. But who wrote the fairy tales on which we base our hopes and dreams? My “happily ever after” will be lacking in the eyes of some, but it will not be less than that of any other—just different, with a bit more grey. And I will always cherish that grey, because it has made the colors in my life that much more vibrant, and me much more aware of their presence.

## Commentary

# Reflecting on Parental Concerns in the Treatment of Pediatric Brain Tumors: Observations From A General Pediatrician

Lisa Stern<sup>1\*</sup>

1) UCLA Medical Center, Santa Monica

\*Correspondence concerning this article should be addressed to Lisa Stern, M.D., F.A.A.P at Tenth Street Pediatric Medical Group, 1450 Tenth Street, Santa Monica, CA 90401.

Email: Drlisastern@gmail.com

## Introduction

This issue of *Narrative Inquiries in Bioethics* explores the concerns and point of view of parents who have had to confront the devastating diagnosis of a brain tumor in their child. Until the last few decades, the diagnosis of a pediatric brain tumor was a death sentence—there were few, if any, treatment options. The last forty years has seen an explosion in medical research that has helped delineate the biology of tumors and hone in on treatments. Along the way, a new field of doctors has emerged: pediatric neuro-oncologists, pediatric neuroradiologists, etc. and increasingly, there are new breed of patients: childhood survivors of pediatric brain tumors.

The stories in this journal were selected because they highlight a range of concerns expressed by parents who have been thrown into the fire and brimstone world of hospitals, doctors, and treatment protocols. Every family remembers the first time they hear those words: “Your child has a brain tumor” and in those few seconds that it takes to process that short sentence, the life of a family is turned upside down and will never be the same. These stories illustrate the journey from diagnosis to an array of outcomes, and they are difficult to read. The heartache in these tales reveals how this diagnosis touches every aspect of a family’s life: siblings, marriages, careers, and finances. My hope is that these words will provide an invaluable roadmap to families searching for guidance and that these stories will also enlighten

the physicians who are treating these desperately ill children.

## The Facts

Each year there are nearly 3,750 new diagnoses of pediatric brain tumors in the United States (Lau & Teo, 2013). The majority of these children will be sent to tertiary care centers for diagnosis, surgery, and treatment. There will be scans, surgery (either a biopsy or an attempt at resection), a waiting period for pathology reports, consultation with a radiation oncologist, and meetings with the neuro-oncology team to discuss treatment options. Parents are inundated with medical jargon, survival data, and the harsh reality that treatment almost always involves collateral damage. The extent of long-term sequelae, a condition that is the consequence of a previous disease or injury, is hard to fathom at the time of diagnosis when parents’ only concern is “Will my child survive?” The truth is that many of these children have survived: 26,000 and counting (Lau & Teo, 2013). But the collateral damage of these life-sparing treatments has left a generation of children with physical and cognitive impairment, which includes a range of learning difficulties and motor deficits (Packer, Gurney, Punyko, Donaldson, 2003). Parents, schools and the medical community are not prepared to handle the challenges of this growing population of long-term survivors.

In this collection of narratives, three children died at the time their stories were written and one

child was experiencing a late relapse. One was a mere six months off treatment. Of the eight survivors, four have severe impairment.

## Narrative Themes

The stories chosen for inclusion in this compilation each illustrate a topic that deserves a forum for discussion. But beyond the unique circumstances that surround these individual narratives, there are common threads that are important talking points.

### Detached Medical Professionals

Many families expressed frustration that their doctors were detached and they expected more compassionate care. From the families' standpoint, life-and-death decisions are being made about how to treat their child who has been diagnosed with cancer. These parents are overwhelmed, terrified and in shock. For the doctors, these occasions are routine; it's hard to imagine but *all* of their patients have life-threatening diseases. In general, oncologists are not known for their "bedside manners." Physicians drawn to the field of oncology generally are interested in research and are well schooled in the hard-core basic sciences. Their training requires at least two years of laboratory research and only one year of full-time clinical work. Oncologists are trained to be level-headed, clear thinking, and can occasionally come across as dispassionate.

Several stories mentioned "doctor-ese": the language that doctors use to explain things. One family said the doctor described the mass in his daughter's head as "impressive" (Wecks). I imagine a child having an impressive accomplishment but never a tumor. Another doctor, when discussing treatment said "it shaved IQ points" (Riley). Doctors learn this language during their training (I did) and are not taught to modify their clinical vernacular before interacting with families. The profession needs a lexicon for patient/family interaction that should be taught during the training period. In a very short period of time, parents become conversant in the language of neuroscience. It's a steep learning

curve. "In our first meeting with the head of neurosurgery, we were drowned in information. It was most certainly malignant, maybe AT/RT (Atypical Teratoid Rhabdoid Tumor) or PNET (Primitive Neuroectodermal Tumor). Meaningless then, but so familiar now" (Wecks). Parents, unless they have a background in neurosciences, should be spoon-fed information that is clear and direct during those initial meetings: "Your child has a brain tumor. It is probably malignant. We will be able to make a definitive diagnosis after a biopsy." That should be it. There will be plenty of time to get into the details about tumor type and treatment options when there is a diagnosis. It may save a family the feeling that they are being "suffocated" (Riley).

One family felt that the doctors were treating the tumor and not their child. One wrote that they wished that their son was seen as "more than a vehicle for cancer" (Anonymous Two). Another complained that doctors often don't listen or hear patients: "Just because a test doesn't show what is wrong doesn't mean that everything is right" (Anonymous Three). Reading these words made me realize that this compilation of stories should be required reading for all oncologists and surgeons who care for children with brain tumors. Health care professionals can learn something from these families; it's important for doctors to remember how desperate and scared these people are every day. One father said of his son's treatment "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" (Abell).

In stark contrast to the many detached doctors cited in these narratives is the oncologist who was described by a parent as being too enmeshed with their family. In the end, the family chose not to proceed with a second opinion and risk jeopardizing the relationship with their beloved oncologist. Describing the oncologist, the author says: "(he) cared for him (the son) both personally and professionally as if he was his own child." But when the child relapsed six years after originally diagnosed, the oncologist recommended against another surgery in favor of more radiation. The parent, through her research, had determined that another surgery

was, in her words, “a no-brainer”. But she decided she could not “take the risk (of another surgery) without her oncologist’s support. The guilt in the aftermath of surgery with a bad outcome would have debilitated me emotionally.” This parent felt the doctor should have said: “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” (Anonymous One). It takes a village of opinions to create optimal solutions for patients with hard-to-cure cancer. A corollary is that most of the best options for patients with rare cancers are drug trials and there is no actual “standard of care”. This is a fact of life that all families ought to be aware of from the outset and that all oncologists should concede without hesitation.

### Urgency of the diagnosis

When a child is diagnosed with a brain tumor there is no time to waste. No shopping around for a second opinion or trying to find ‘the best’ neurosurgeon to operate on your child’s brain. Most children are diagnosed after months of symptoms and then ‘BAM’: the situation is dire. A CT scan is obtained, the mass is seen, and the wheels are set in motion. That child and family are swiftly transferred to the nearest facility with a pediatric neurosurgeon. They are placed in the hands of a doctor they have never met and a biopsy or resection is scheduled ASAP. There is a feeling of utter helplessness and urgency; there is no time to think. Most families have no idea of the questions to ask. They just want to know if their child will survive. They are in a vulnerable position: they need to trust the doctors who have been assigned to save their child’s life but are often afraid to question that doctor’s judgment or request a second opinion. It’s hard to imagine that a person would challenge the doctor who is about to operate on his or her child’s brain. Additionally, you don’t want to be labeled a ‘problem parent’—which is what happened to one family who brought up the subject of sperm banking for their newly diagnosed 13 ½ year old son. “I knew that infertility concerns were usually pushed aside at diagnosis to make way

for other priorities, namely the urgency of starting treatment” (Anonymous Two).

From my standpoint, there is never a problem parent. The problem is the brain tumor. Stabilizing the patient must be the first priority, but after that, another opinion should be encouraged. Once a diagnosis is made, the questions should be: “Who has the most experience with this particular type of tumor? Can a phone consultation be arranged? Is it even feasible to get treatment elsewhere?”

One family, sent home to spend their first and last Christmas with their newly diagnosed two-month-old infant, was not offered a surgical option (after an initial biopsy). Following a meeting with the neuro-oncologist the next week, the family was sent to meet another neurosurgeon at a nearby children’s hospital. The second opinion was surgical resection, which is what the family opted for. “She was discharged a month after we were told she was going to die, tumor free” (Wecks). These crucial early decisions need to be made using language that is accessible and without the veil of egos or turf wars. After all, a child’s life is at stake.

### Grief and Guilt

Grief and guilt accompany a pediatric brain tumor diagnosis and remain entwined with every aspect of decision-making and treatment. From the time of initial diagnosis and postoperative hospitalization, continuing during the course of intensive treatment and finally into the period of long-term follow-up, all families experience an immense sense of loss and the grief associated with it. Everyone seems to suffer: the child who was hit by a bolt of lightning called a brain tumor, siblings who are out-placed to other family members, dreams that are put aside, often forever. One father, speaking about his wife, said it so poignantly: “Her grief wasn’t about the death of her son. It was about the death of her dreams” (Riley).

The issue of guilt starts at the time of diagnosis. Parents may have a nagging feeling that something is not right. An initial visit to the pediatrician may reassure them. Weeks or even months go by before a diagnosis is made. “It does make me question

our parenting and ability to know what is best for our child's wellbeing. Add to that a doctor who made you feel very inadequate as a parent; it was hard to have the confidence to question the doctor" (Rocker). There is guilt and grief from this time forward. Did we choose the correct treatment option? Was it the right decision to postpone radiation, which would allow a young brain more time to develop? What about a second surgery? Should a complete resection be attempted (potentially doing more damage to the brain) if a scan shows residual tumor or do you hope that the chemotherapy will take care of any tumor that was left behind? Every question implies that there is a right and wrong answer or at least an optimal decision for the best possible outcome.

Most treatment decisions are made based on studies or protocols that have looked at outcome data collected over the past forty years through the Children's Oncology Group (and its predecessors). The treatment of pediatric brain tumors is constantly evolving. The children being treated now benefit from the information gleaned from those who struggled before them. The guilt surrounding treatment options is part and parcel of this diagnosis; there is always a choice between several bad options. No one ever wants to be in this position. Ever.

There is universal guilt about the other children at home. "We sacrificed the good of one child to save another" (Riley). "I feel that we neglected her (a daughter three years older than their child with cancer) during that time" (Scheumann). "We feel certain that our constant focus on Sarah made his (her twin brother) path to drug addiction almost inevitable" (Carlson).

There is guilt if your child survives. "During those first few months after our diagnosis, we met three other families who had daughters with brain tumors. My daughter is the only one still alive" (Rocker). Doctors should be cognizant that these families find support and community with other brain tumor families. The death of other children reminds them how fragile their own child's existence is. "As they passed our pew, my wife clutched my arm and wept tears of sympathy, guilt and fear" (Abell).

## Recurrence and Hospice

Relapse, regrowth, late recurrence, this is what is on every parent's mind. Follow-up for pediatric brain tumors starts as soon as treatment ends. Initially scans are scheduled three months apart. Then clinic visits become less frequent and the duration of time between scans is increased. But as the months and years pass, every headache, stumble, fever gets analyzed. Could this be a relapse? "In many ways we have returned to a somewhat normal life. Despite this, cancer still strangles us with fear" (Abell).

Four of the children in this series experienced relapse between one to eight years after their diagnosis. Those relapse stories are even more heart-breaking. It's bad enough to put your child through treatment the first time. The second go-around is that much more difficult and the options are frequently limited. Brain radiation is given either as whole brain treatment or focused treatment to the tumor bed. Either way, there is a maximum lifetime dose of radiation (Donahue, 1992). Chemotherapeutic agents may also have maximum lifetime dosages. Prognosis following relapse is very poor. Relapse is a time to review past treatment history and determine what options are out there. It's also a time to re-consider a second opinion and look into drug trials.

When the prognosis after a recurrence is extremely poor, hospice replaces hospitalization. There is a shift from trying to prolong life to make what time is left as comfortable as possible. Hospice care is usually offered at the end of failed treatments but one brave family opted against treatment at the time of their daughter's initial diagnosis and immediately sought support through hospice. I actually thought that this was a beautiful and heroic narrative. Despite pressure from doctors, the family stuck with their decision since this tumor type had 100% mortality. "We 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" (Methven). This family had 16 months of support from a loving hospice team and they had no regrets.

## Long Term Sequelae

More than half of the survivors in this sample of stories had significant long-term sequelae ranging from educational impairment to devastating, life-altering complications. Surgery, radiation and chemotherapy offer the only hope of survival but they come with a price tag. Most families could not have comprehended the degree of impairment that their child would suffer. Although doctors cite a litany of complications: seizures, hearing loss, visual impairment and growth failure, most parents are willing to accept everything as long as their child survives the cancer. Basically there are no good options. It's human nature that we want to believe that our child will be the small percentage that breezes through this nightmare unscathed. Long-term disability happens to someone else. After reading the story of a child "still deteriorating, her seizures were uncontrollable and her quality of life was extremely poor" (Anonymous Four) thirteen years after cancer was treated or cured, I reflected on the decisions that were made that resulted in this devastating outcome. The treatment protocol in 1997 was high dose radiation to her brain although she was only four years old. That would never happen now but the fact is that there are children and families living with the side effects of those early treatment decisions. Parents and doctors make the "best" decision based on the most recent data and studies and then cross their fingers.

The list of long-term sequelae is long. A frequently mentioned problem of brain tumor survivors is fatigue. Everyday tasks like walking may be more difficult. Vision problems including strabismus can affect depth perception and may cause eye fatigue that interferes with homework and reading. Cognitive deficits require that there is an educational plan in places that addresses the issue of accommodation. One parent whose child had a 504 educational plan to accommodate his needs writes: "In March of his kindergarten year, Ben lashed out at his teachers and was suspended. He was given a home/hospital teacher for the remainder of the year" (Hilliard). It is hard to imagine that a child who was thought to be disease free could not be

supported in a classroom setting. As more children become survivors, a greater support system must be in place to cater to their specific needs.

## CONCLUSION

This issue of *Narrative Inquiries in Bioethics* addresses some of the important themes that are encountered by a growing population of pediatric brain tumor survivors. It offers a glimpse into the problems that need to be addressed by health professionals, educators, and support teams. Treatments will continue to improve and so will the numbers of long-term brain tumor survivors. These parental narratives are a first step to identify some of the challenges and they will hopefully lead to collaborative efforts to improve the quality of life for families and children that have had the misfortune to hear those words: "Your child has a brain tumor."

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Michelle Burgess, M. Chiu, Virginia Hammond, Anonymous Five, Cheryl Kilpatrick, Claire Yar

### Ethan's Gift

Michelle Burgess

Ethan was your average boy next door. He loved everything most 8-year-old boys do including playing baseball, swimming, and watching his favorite baseball team, the Philadelphia Phillies.

On December 3<sup>rd</sup> 2008, life for our family changed forever when Ethan was diagnosed with Diffuse Intrinsic Pontine Glioma, a rare inoperable brainstem tumor. DIPG is in essence a death sentence. There are no survivors and life expectancy after diagnosis is only 9–12 months. Our family was devastated.

For the next 14 months, we lived life to the fullest, never taking a single moment or day for granted. As Ethan's condition worsened, and it became clear that he was close to passing, I spoke with Ethan's doctor about my desire to be able to donate Ethan's corneas and his brain tumor for research. He informed me that because of Ethan's type of tumor that he may be a candidate for donation of other organs as well if that is something we wanted to do.

Knowing that there was nothing we could do to save Ethan, it was something that we felt we could do to help others so we decided to explore the option of donating Ethan's other organs. We were put in contact with the Gift of Life.

Two representatives from Gift of Life came to our home and discussed at length with us what would have to happen to make organ donation possible at the time of Ethan's passing. Specifically that Ethan

would have to pass away at the hospital and in the operating room. This was very different than the hospice environment that we had planned. They also had told us that Ethan was only the second young person that they had ever dealt with that the families had planned ahead of time to donate organs. The other person was a teenager who planned his own organ donation.

On January 26<sup>th</sup> 2010, Ethan's pain had become unmanageable at home and his breathing had become very labored. I spoke with his oncologist and he advised me to bring Ethan to the hospital to try and get his pain under control.

We loaded Ethan up in the car for the one-hour car ride to the hospital. On the way to the hospital Ethan fell asleep while being cuddled by me in the backseat. When we arrived at the hospital we noticed that his fingers and toes had turned purple. The nurses immediately checked his oxygen and it had fallen to only 10 %.

The doctors advised that he had slipped into a coma in the car, one that he would never awake from. He was immediately placed on life support. A scan was done and it was evident that the progressing tumor was placing pressure on the areas of the brain that controlled basic life functions such as breathing. Ethan could not recover.

The decision was made to begin to look for recipients for Ethan's organs. Because Ethan had not reached the point of brain death, his donation would have to be a post cardiac death transplant, meaning, life support would be removed, when his heart stopped beating and he passed away, the organ procurement would begin. However, he

would not be able to donate his heart. This was very sad for us, knowing how strong his little heart was, but we did understand the process.

On January 28<sup>th</sup> 2010, our family spent the day saying goodbye to Ethan. Even though he could not respond, we know that he could hear us. The nurse was wonderful, doing everything possible to accommodate our large family and despite all the tubes and machines, make it so that I could cuddle with my little boy one last time.

Ethan was moved to the operating room and with his stepfather and I on one side and his father and stepmother on the other, life support was removed. Watching my son take his last breath, while I held his hand, kissed his cheeks, told him I loved him and that it was okay to let go and go to Heaven was the hardest moment of my life.

Ethan was able to donate both of his kidneys to a 53-year-old man who had been on dialysis for eight and a half years and on the waiting list for over five years. He had been on dialysis for as long as Ethan had been alive. Ethan's corneas went to two different men, who now have the Gift of Sight. Ethan's liver went to research the effects of chemotherapy. Ethan's brain tumor was donated to Texas Children's Hospital and was one of only two samples that researchers were able to grow live cells from and they were able to create a mouse model from Ethan's tumor cells.

Just before the one-year anniversary of Ethan's passing, I received letters from Ethan's kidney recipient, his wife, and daughter. I had written them a letter a few months before and shared with them a picture of Ethan and told them about him. They were very sorry that I had to lose a child but their letters were filled with so much gratitude for the gift that they were given. They consider Ethan a member of their family now and keep his picture framed with their other family pictures. That means a lot to me. Life is so different for the recipient now and knowing that it has made such a difference is such a gift to me as well. Since then Ethan's stepfather and I have begun volunteering with the Gift of Life and I have shared my story for a video and for their newsletter. I think Ethan would be very proud of the decision that we made.

In his eight years, Ethan had such an impact on so many lives and his gifts still do.



## Life in Limbo

M. Chiu

When my son was 7 years old, he began complaining of headaches. They were frequent, but never seemed severe. "I have a headache!" was always followed by "Can I watch TV?" I didn't believe the pain was real until it woke him up in the middle of the night. I knew then that something must be wrong. I approached our pediatrician, who said it sounded like migraines, but we should order an MRI to rule anything out. The appointment was scheduled several months in advance, and I always had the urge to cancel it. I was pretty sure my son just wanted to watch TV. The pediatrician told me I might as well do the MRI. He told me that if we skipped it and something was wrong, I would never be able to live with the regret. We kept the Monday morning appointment, and went to the MRI expecting reassurance that nothing was wrong. Instead, we got a phone call later that day. They needed to see us on immediately, but wouldn't tell me why. Of course, I knew something was wrong. "Is it a tumor?" I asked. "This isn't something we can discuss on the phone" was the answer I got. An appointment was scheduled for Wednesday. Two days might be "immediately" to medical professionals, but to a parent who just heard that her child had an abnormal MRI, it was an eternity. I planned my son's funeral in those two days.

Our meeting with the Neurologist began with reviewing the MRI. "See this spot here? It shouldn't be there". A tumor. 1 ½ x 1 ½ x 2 ½ cm tumor, in the right thalamus. Small, they said. Looks like a Low Grade Glioma they said. The kind of tumor you want to have, if you have to have a brain tumor. A biopsy was scheduled for two weeks later. The

biopsy confirmed it was a Juvenile Pilocytic Astrocytoma (JPA). The neurosurgeon was confident she could remove all of the tumor. We were at one of the best Children's Hospitals in the world. We were in good hands.

A few days before the surgery, a friend who is a medical doctor suggested we get a second opinion. "It couldn't hurt, it could help", my husband said. Fortunately, he just sold a start-up company, and was planning to take a few months off from work before starting his next venture. He had time to research, talk to friends in the medical field and make phone calls.

Our second opinion from another leading hospital reviewed the MRI's with us. The neurosurgeon asked, "Did they say tumor? One?" Yes, they did. "See this here?" he said, pointing to a second spot on the MRI. He said it was possibly a second tumor, or more likely, an extension of the first. It was in inoperable location. Surgery wasn't an option. Chemo would be our best choice. Why would we cut into our son's brain to remove part of the tumor when he would need to do chemo anyway? Why not try chemo first?

I would like to say that we do not fault our original neuro-oncology team for missing this second abnormality. It is hard to notice an ant in the room when there is an elephant staring at you. People make mistakes, and tumors don't always look the same. That's what second opinions are for. That is why doctors *should* encourage patients to get second opinions.

We scheduled the surgery for port implantation, and got busy educating ourselves about chemo regimes. It was going to be a long journey. 18 months of transfusions with a pretty low success rate and a high rate of secondary complications. Unsure if we were doing the right thing, we got a third opinion. I am so grateful that my husband was between jobs and had time to devote to finding the best possible treatment for our son. We were financially stable and had great insurance. What do people do when they don't have this luxury?

By now, several months had passed since our first MRI. Our third opinion pointed out that subsequent MRI's showed that the tumor had not grown

since the first MRI. They asked "Why would we do something as drastic and risky as surgery and chemo to cure a headache?" They said it was possible that this type of tumor might never grow and never need treatment. They also pointed out that if we could push off treatment until my son was older, that radiation treatment might also be an option. They suggested we do nothing but monitor it and treat the headaches. He was put on cyproheptadine, which cured his headaches. Six months after we started the cyproheptadine, we were able to wean him off of it. Many of his headaches were probably caused by 'rebound' from too much acetaminophen.

My son is now 10 years old. Three years after our initial diagnosis, the tumor has not changed. He is a strong, smart, healthy boy with a tumor in his brain. Gradually, we extended the time between MRI's. Monthly. Three Months. Six Months. A year. Will it grow tomorrow? In five years? Never? It has left us in a very strange sort of stressful limbo. My son has a brain tumor. It is stable, but we live with the stress knowing that our situation could change at any minute. Or it might never change.

We live in a strange sort of limbo. Our closest friends know about our son's diagnosis and have stood by us through many stressful periods of pre-MRI "scanxiety." Most people do not know about his diagnosis. His school and teachers know, but we don't tell many people, because on a day-to-day basis, his tumor is not really an issue. We don't want him to be labeled "the kid with a brain tumor," because it is possible it will never need treatment. We have a son with a tumor, but we don't go to brain tumor support groups. It doesn't feel right to ask for support from others who are in more dire situations, when we are blessed with stability. We never call it "cancer." I don't want my son to compare himself to other kids who have severe symptoms. I don't want him to worry that that could be him. He knows he has a brain tumor, but he has no idea how it could impact his future. To him, having a brain tumor means that he has MRIs and more doctor appointments than other kids.

The most stressful part of our situation is that we won't know if we made the right or wrong decision until it is too late. Sometimes, I wish he was having

seizures or some other symptom that made treatment necessary; something to make a doctor take charge and make decisions for us. Instead, this life altering decision is left up to us. Do we risk surgery and the possible complications? Or do we risk a lifetime of complications from chemo? If we leave it alone, might it grow and cause irreversible damage? These are questions that no one can answer. We will never know if we are making the right decision. If he has a seizure tomorrow, will we regret our “watch and wait” decision?

I ask myself what would have happened if we lived in a small town without easy access to MRIs. The pediatrician would have said, “It sounds like migraines,” and prescribed medication for them. The medicine would have made my son feel better, and we would have been comfortable with the diagnosis. But we don’t live in a small town. We live in an area with multiple top ranking hospitals. Instead of “It sounds like migraines, take this medicine”, we heard “It sounds like migraines, let’s order an MRI to rule out anything else”. Because we live in a big city and have good health insurance, we don’t have a child with migraines. We have a child with a brain tumor. It has been stable for nearly three years. It could change tomorrow. It could never change. I ask myself if I am glad that we know about it, glad that we live in a time and place where tumors can be diagnosed, or do I wish we lived in a place where “migraines” are cured with simple medication. I still don’t know the answer to that question.



## My Lost Survivor

Virginia Hammond

I can’t remember the exact words as I brought my 7-year-8-month-old daughter Ann to the university medical center late spring for a review of her brain surgery from March 1990, but the words were something like it was a remarkable

98% resection, then the team went on to say 75% was considered successful and they were surprised since the surgery was not done at a major medical facility. I explained to the team we had three neurosurgeons in our town from major facilities out of state who were very well regarded so I opted to stay in town for her surgery, but valued the university medical center’s recommendation for radiation treatment. The next decision I had to make was where. I not only had to consider my daughter, but my toddler that I had to drag everywhere through all this as I had no family nearby to help me. I opted for a 75-mile drive.

The radiation protocol was for eight weeks of hyperfractionated radiation. I would leave the house with the both kids by 7:30 a.m. and stay until 3:30 p.m. because there were two treatments a day around six hours apart. I had thoughts that I would be able to take the kids to the zoo or children’s museum in between treatments, but Ann was much too sick for that. We spent most of our day at the playroom in the cancer patient house next to the radiation facility. We eventually got a room at the cancer home.

Even before the radiation therapy, Ann became sick and would wake up every morning vomiting very much like she would before the tumor resection. This vomiting went on for almost two years after her surgery and radiation. We were bounced around between doctors and specialist then finally a pediatric neurologist was concerned about how thin and frail she was and prescribed a medication that goes by the generic name Cyproheptadine hoping it would help her appetite. Within a couple of days, much to my surprise, the medicine stopped the morning vomiting and she began to eat and regain some strength as she approached the age of ten.

Now that Ann was no longer showing the outward physical signs of being ill, her school didn’t think it was necessary to make accommodations for Special Education, or follow the recommendations made by a neuropsychologist’s report. I was told her educational performance was average for her age and grade level. The school did discover she could not hear in her left ear and sent home a note that demanded I seek medical attention. I explained to

them her doctors were well aware of her perforation in her ear and decided they wanted more time to pass from the brain surgery before performing ear surgery.

There was one bright spot during her elementary school years. She had a teacher who went out of his way to make sure Ann was responding to what was being taught. Aware of her hearing deficit in her left ear and some of her cognitive deficits, he sat her in the classroom where she could hear at her best and placed her next to classmates who would not distract her. When she would forget to bring her homework home, he would stop by the house with it rather than write a disciplinary action against her. She responded so well to this teacher, she was one of a couple of students in her class that was sent to the countywide science competition. She thrived that year, but never again was she to have a professional teacher that made sure she got it!

When Ann was 11, the ear doctor decided it was time for her left ear perforation to be repaired and that would restore her hearing in that ear. She had the surgery, but the hearing was never restored.

Ann's ability to learn was becoming more difficult. I pulled her out of traditional public school to home school her through public charter school. I wish I had another option as she didn't always appreciate my teaching, but the classroom based public schools were frequently sending home notes to me complaining about her lack of participation in class, and her lack of physical fitness accusing me of letting her become a couch potato. They did not understand that she was still fighting the effects of the brain tumor and the radiation.

At age 16 Ann was experiencing a migraine and I noticed the crossed look in her eyes much like the double vision she experienced before the brain tumor diagnosis. I took her to the doctor and he diagnosed it as a VI Cranial Nerve Palsy and ordered a MRI to be done a couple of weeks down the road. Fearing her Medulloblastoma had returned, I didn't wait and took her to the emergency room. The radiologist did an MRI and the emergency room physician told me it was a return of her tumor. The doctor was sympathetic, and released her from the hospital with no direction.

Ann's previous surgeons were no longer practicing locally so I went to another doctor who had been consulting on her medical history. He referred us to a pediatric neurosurgeon in a nearby city who ordered an additional MRI and then consulted with a team of other doctors who identified her condition as a vascular occurrence (stroke) from radiation. Ann had muscle surgery on her left eye to give some correction to the double vision brought on by the vascular occurrence. She had additional memory loss, learning disabilities and confusion from the stroke. Ann graduated from high school reluctantly. She did not seem to fully understand she had to grow up and become an adult. She was developmentally behind her peers.

I was finally able to go with her to the community college since she was still under 18 and help her enroll. Reluctantly they classified her as being disabled and offered disability classes along with regular classes. She kept having to repeat math and shortly after turning 21, she caught a virus and suddenly lost hearing in her right ear, which was her good ear and she became deaf for all intents and purposes. The local doctor kept trying hearing aids, which did not help. Ann could not keep up with school and quit due to the additional hearing loss, further cognitive decline and a shorter school semester caused by state budget cuts to the community college system.

I tried getting Ann help transitioning to adulthood from a non-profit group. They provided Ann with an assisted listening device, which helped a little with her right ear. She was signed up with the group several years. Finally, they asked her to sign a release form saying she no longer needed their services; she complied. Truthfully, they did not know how to help someone with her cognitive disabilities.

A disability resource provider turned her down for life skills help because she did not have a disorder that was supported by State law. Another disability resource turned her down for job training because she had too many cognitive disorders. Ann was always falling through the cracks. I was unable to get help for her. All Ann ever asked is for someone to tell her what to do. The hearing loss

made that simple request much more difficult, at times almost impossible.

I got a referral for a specialty hearing place in another city. Ann spent several years with the new medical group. There were many changes to her hearing over those years with much deterioration. She went through a couple of hearing aids and several surgeries on her right ear. Nothing would work in her right ear as she kept getting infections and perforations. The doctor talked about the possibility for a cochlear implant, but needed proof her hearing loss in her left ear was from radiation therapy.

I got the medical records from Ann's primary doctor and I found what I needed to find. I found an audiogram that was done post brain tumor surgery and pre radiation treatment, which showed her hearing was fine at the time. I gave this to the surgeon and he immediately proceeded with the cochlear implant for her left ear.

The cochlear implant has been very helpful in communicating with family. However, she still cannot hear well in public settings where there is a lot of noise, or if the speaker is too far away even with amplification. Ann has difficulty processing more than a sentence or two at a time. She cannot make out music except for the old rock songs she had learned prior to her right ear hearing loss in college.

Now that the hearing has improved, the cognitive has deteriorated. I was informed by the late effects clinic the rate of deterioration can run around 10% a year. Neuropsychological tests done by multiple sources have not been helpful in providing solutions. The test results show her IQ in the 70's. Below 70 is considered disabling with permanent lifetime government assistance in our state. 90's plus is considered heading toward average IQ. The results show little, if any executive function (which includes the ability to organize and make decisions). One tester admitted she could not take care of herself and said younger relatives would have to take care of her when we are no longer alive or able. Another tester felt Ann could do volunteer work and gave Ann a long list of things she and others should do to accommodate her situation, which in reality would require her to have strong

organizational and communication skill to carry out the suggestions. Once again, that would require me doing things for her in order to accomplish the suggestions.

There is always some new medical condition or late effect that appears. A couple of weeks ago Ann began to tell me she was in pain and couldn't sleep in her bed anymore or sit in her desk chair. She got some newer furniture, which has helped, but she still has some pain. We are waiting for a call back from the doctor regarding x-rays and blood work as he suspects she has suddenly developed rheumatoid arthritis, but this is last week's news.

This week another doctor's office called and asked us to make an appointment immediately. The results of Ann's right-sided thyroid biopsy were called in and there is cancer. So we are waiting to see if she can get a referral to a university medical center with her government insurance so she can get treatment from a doctor familiar with radiation related thyroid issues rather than a local general surgeon.

When I am not focusing on Ann's medical issues, I am focusing on my fear. There is a good chance she will outlive me. What is going to happen to her when I die? I did not realize she wouldn't be able to live independently until she reached her 20's. If I die without leaving money and prearranging a caregiver, will she be out in the street homeless? I am not alone in my circumstances and she is not the only one who didn't grow up.

There is research describing the quality of life for the majority of Medulloblastoma survivors in developed countries. It goes something like this: They don't drive. They don't marry. They don't work. Their family is their world. They live with their parents until their parents pass away, and then their government is often left with the decision whether or not to institutionalize them.

I intend to locate or establish a loving, nurturing group home near me for Ann and other lost survivors. No longer will parents of Medulloblastoma, brain tumors, and cancer with cognitive disorders and chronic illness, have to ask the fearful question concerning what happens to their child when they die.



## An Encounter with the Art and Science of Medicine

Anonymous Five

“Let Nothing Upset You  
Let Nothing Frighten You  
Everything is Changing  
Only God is Changeless”  
—St. Theresa of Avila

St. Teresa’s prayer is on the front cover of each of four binders dedicated to storing insurance authorizations, studies, references, and reports about our daughter’s brain tumor treatment. They represent our experience, what we learned, the information we were given, and the information we sought out. I kept them in case our daughter ever wanted to understand how my husband and I arrived at a decision for her treatment that was in direct opposition to the strong recommendation of her primary treatment team of physicians.

On December 10, 2003, I received an urgent call from our daughter’s neurologist requesting that we meet with the doctor late that afternoon. For six months prior to that appointment, our daughter had been telling us about odd sensations with breathing, nausea, and balance. Sometimes she would seem extremely distressed for a short period of time or report that her friends told her about doing or saying things that didn’t make sense and that she didn’t remember. We consulted a series of physicians as her symptoms became steadily more intense and more prevalent. Our family practice physician referred us to an allergy specialist and a pulmonologist. There were a number of tests for allergies and lung problems. As the tests and treatments did not help, our daughter became increasingly unwilling to go to doctor’s appointments. My husband and I were confused and deeply concerned about the lack of progress. The next series of referrals included a gastroenterologist and a neurologist. The gastroenterologist suggested our daughter had

partial-complex epilepsy, concurred with our plan to see a neurologist, and mentioned she should have an MRI.

I remember the neurologist putting the MRI scans up, pointing to the large dark spot which he called a “large mass” (5 cm), that could be either a cluster of blood vessels or a neoplasm. He said his office had arranged for us to meet a neurosurgeon the following day. We all remember the same thing about that visit—the image of the large dark mass on the scan—and the neurologists flat, brisk tone. We met with the neurosurgeon the next day. Her team was kind and sympathetic—she was positive, up beat and direct. She did not think this mass was blood vessels. She thought it was a large tumor that needed to be removed right away. Our daughter’s surgery was scheduled for the following Friday—December 19, 2003. She had turned 15 on November 5.

Four and a half hours after our daughter was wheeled into the operating room, her surgeon told us they had removed 98% of the tumor. She said there was no cure, but there was a good prognosis based on the surgical outcome. Several days later, she called us and said she had more data, and it looked like the resection was closer to 90%. The first pathology report, a “first impression” directly after surgery, described our daughter’s tumor as an astrocytoma, probably high grade. Three weeks after surgery, we met with a panel of doctors—two oncologists and radiologist—who explained that based on the final pathology report, our daughter’s tumor was classified as an ependymoma, grade 2. We were dismayed. First, there had been the change in the estimated success of the resection and now a complete shift in both grade and tumor type.

The team recommended radiation to follow her surgery, which they said was standard treatment. We began to try to inform ourselves about her tumor. Her father, an agronomist, did an extensive search in PubMed to evaluate and sort through the literature on low-grade gliomas and radiation. What he could find was inconclusive and grim. Most reports in the literature suggested at best delayed mortality at five years after radiation.

Meanwhile, our daughter went through a spinal MRI and the preparatory “fitting” of the mask to immobilize her head during radiation.

I consulted with a friend who had worked as an EKG tech. She urged us to consult and request a second opinion. We talked to Katie’s neurosurgeon, who referred us to a local university hospital, one of the principal brain tumor centers in the country. Katie was examined by a neuro-oncologist, her scans were reviewed by a neuro-radiologist, and slides from the surgery were examined by a neuro-pathologist. We understood that their tumor board would review her case and make a diagnosis and recommendation for treatment.

While we waited for the second opinion results, we were asked by our daughter’s new neuro-oncologist to attend a group meeting with her, the radiologist, and the first oncologist who met with us, all part of the primary treatment team. The meeting lasted two hours. As we entered the meeting, the oncologist pulled my husband aside to speak to him privately and told him bluntly that he was sure that radiation was the only way to save our daughter’s life. During the meeting, we tried to discuss the results of a number of studies my husband had found evaluating radiation for low-grade pediatric gliomas. Here is one quote from a 2003 journal article: “There is no scientific evidence that radiotherapy prolongs life for patients with low-grade glioma”. He asked the team to speak to the lack of any data supporting a recommendation for radiotherapy for our daughter’s tumor type. The team of doctor’s told us that while, “there is no wrong choice,” they each felt radiation was the best choice because radiation would enhance her survival. They said the window of opportunity for radiation was about to close. One said, “I promise that the only impact on your daughter might be that she will have to work a little bit harder in college.” We left that meeting on a Thursday afternoon, having committed to beginning radiation the following Monday but having the same unresolved questions. We agreed that we had conceded, partly because the possibility of being wrong was too frightening, and partly because our daughter, who was present, said she was ready for radiation. Ultimately, we felt

unable to oppose the doctor’s judgment and experience on the basis of research studies.

Almost as an afterthought at the end of the meeting, I asked what had happened to the second opinion. No one knew. I went home and called the neuro-oncologist who was our contact person at the institution providing the second opinion. She said she had both faxed and sent a hard copy the week before. I asked her to fax a copy to my office. The first sentence in the pathology report was: “This is a very unusual neoplasm.” The last was, “. . . we feel that the best course of action would be close observation, with frequent surveillance MRI.” We made the decision to call and cancel the radiation appointment for Monday, saying we needed to think a bit more.

We took that time to talk more to the neuro-oncologist speaking for the second opinion team. We felt that “watch and wait” would be a reasonable approach but we wanted another look at the pathology. The pathologist we chose, a pathologist at a premier institution who reviews 3000 pathology slides a year, told us he had never seen a tumor quite like our daughters. He was very kind but not particularly hopeful about the prognosis. He did say he had never seen a tumor that was classified as malignant with such a slow growth rate. Our conversation with him supported using the “watch and wait” approach and we made that our final decision.

Our daughter’s surgery, which was her only brain tumor treatment, took place on Dec. 19, 2003. Now 24, she is about ready to schedule her yearly MRI scan. We always wonder, every time, if there will be growth. In the first few years I also wondered if I would feel we had made a mistake by not choosing radiation. During those years, I would try to remind myself that radiation would not necessarily have stopped growth. I would check with my husband, who would patiently explain again what I already knew about the results from his literature search. Now, she can thank us that she does not have to deal with late-effects from the radiation. Now, we know that the impact of radiation on young growing brains is more serious than studies were indicating at the time of our decision. Now, she will

be making her own decisions about treatment, with whatever back-up or help and support she requests from us. Now, she has had 10 years for her brain to grow and mature, which is a gift.

The relationship with our treatment team changed over time. Initially, we dealt only with the surgical team. Subsequently we dealt with an oncologist who was the head of the oncology group and a neuro-radiologist. On February 1, 2004, Katie became the first patient of a very experienced pediatric neuro-oncologist available through our medical group. All of these professionals gave us information at one time that was subsequently “revised.” Some of the revisions we understood, some we did not. Some I understand better now, because I know so much more. Some I still do not understand. I still don’t understand why the radiologist initially told us that our insurance would not cover Intensity-modulated radiation therapy (IMRT) and said there was no real difference between IMRT and conformal radiation, then reversed himself a half an hour later. I still don’t understand why the oncologist drew just my husband aside and made such an impassioned speech about the need for radiation to him alone. I still don’t understand how our medical group could have “mislaid” the second opinion document, which is what they told us. I still do not know why the neuro-oncologist, who initially favored chemotherapy, made such a strong stand for radiation.

We did decide, because there were too many things that we did not understand, to consult National Institutes of Health (NIH) when the medical group’s tumor board identified an area on one of our daughter’s MRI scans which they said was “suspicious.” The neuro-oncologist there explained the problems involved in discriminating between aging scar tissue and tissue change due to growth on an MRI scan. He told us it was reasonable to hope the tumor would not reoccur.

It would over-simplify to say, “over time we lost confidence in our doctors.” Prior to diagnosis, we had a number of experiences that had a “kindling effect” on our skepticism. We have had a 10-year relationship with our daughter’s surgeon and oncologist. We know something about their

personal lives, they know a lot more about ours. We know they have been distressed with us, puzzled by us, perhaps even offended by us at times. We have never left our treatment group. Although our daughter has explored relationships with other neurologists, she routinely sees her old oncologist for MRIs and has an on-going consulting relationship with her surgeon. She has just interviewed and chosen a new neurologist in the same neuroscience group. We have always found our doctors to be truly dedicated, very experienced, expertly trained and highly qualified. It is and has been abundantly clear that they truly care about our daughter. On the other hand, we did lose confidence in their guidance. I never stopped feeling like there was a “back story” that I would never be privy to, that there were accepted strategies and shared perspectives between our doctors that affected us but would never be explicitly acknowledged or shared. Under those circumstances, we felt that not only did we have to rely on our own capabilities and resources, but we had to question and remain skeptical.



### Roadmap Needed: How to Help Parents Navigate the Worst Day of Their Lives

Cheryl Kilpatrick

**O**n January 14, 2010, our 3-year-old daughter, Maggie, was rushed to an emergency room at a satellite medical center. I am an occupational therapist and was actually scheduled to work at a hospital that day. I was wearing my purple scrubs. Maggie had been showing “strange” symptoms all week that I thought might be a sign that she was getting a cold or the flu. She had been extremely tired, having morning headaches and ataxia (balance problems). When I dropped Maggie off at preschool the morning of January 14, 2010 she began to have trouble using her left arm. The teacher noticed that her smile was crooked. I did a quick neurological assessment and saw that her

left arm was much weaker than her right arm. I thought to myself, "My kid looks as if she is having a stroke. But she is only 3-years-old. This doesn't make any sense." The teacher gave me a look as if to say, "Are you going to take Maggie to the hospital or am I going to have to do it?" I just stood there. I suppose I was in the first stages of shock. I turned to the teacher and said, "We are going to the hospital."

As we walked toward the ER admissions desk I was surprised to see that we were the only people in the waiting area. It didn't take long before we were called into the examination room. The ER doctor did a neurological assessment on Maggie like I had done only 30 minutes earlier and said that a CAT scan was needed. He thought that we would most likely be transferred to a local children's hospital. The CAT scan revealed that Maggie had a large mass in her thalamus. I just looked at the ER doctor and said, "Just tell me what I need to do and I will do it." No tears, no screams, no emotion. I just went into "mommy mode" and made sure that my child felt safe every step of the way. My husband was on his way home from a business trip when I called to tell him the news. He had no idea what he would find when he finally got to us.

As expected, we were transported by ambulance to the local children's hospital. I remember sitting in the front seat with the driver and feeling like this was all a dream. It was all very surreal. Maggie calmly chatted with the EMS personnel in the back of the ambulance as if nothing was happening. I had no idea how our lives would change once we reached the hospital. This ride to the hospital began our journey into uncharted territory. Nothing in my life had prepared me for what was about to happen.

We arrived at the children's hospital around 11:00 a.m. As we walked into ER department, I could feel the eyes of the ER staff following us. I turned to look at them and they smiled. The look on their faces told me that something was very wrong with my daughter. I felt like we were a sideshow at the carnival. I hated those looks. I didn't want their smiles. I wanted to know what was happening. I wanted information.

My husband arrived about an hour after our arrival. He walked into the room and found his

little girl looking very spacey and unable to walk to him without falling. When Maggie and I stepped out into the hallway to find the restroom, I turned to look back into the room and saw my husband with his face in his hands. He was crying. I was not. I was still in "mommy mode" or just plain shock. I knew that my daughter was not well. But then again, neither was I. I was not crying. I was not screaming. I was numb. What I needed was someone to take my "emotional pulse."

We waited patiently in that small room watching the hours pass by as each doctor came to do their assessments. In between assessments, an MRI scan was performed and Maggie was admitted to the hospital. Maggie did not seem to be aware of what was happening to the left side of her body. Her left side continued to get weaker and weaker as the day went on. It was as if she were "melting". She had to be supervised when walking so as not to fall and cause injury to herself.

Once we got situated in our hospital room, we were told that the pediatric neurosurgeon would be in to see us sometime that day. The neurosurgeon walked into our hospital room at 7 p.m. that evening and said, "Maggie has a very serious problem." Even though my husband is a nurse and I am an occupational therapist, we had no prior education regarding brain tumors. None. We did not understand what we were dealing with and what our options might be. We had no "roadmap" for this journey.

The pediatric neurosurgeon asked my husband and I to follow him into a conference room so that he could show us the MRI film on the computer monitor. Maggie's grandparents kept her entertained and safe while we were out of the room. The pediatric neurosurgeon told us that it looked as if Maggie had a juvenile pilocytic astrocytoma in her thalamus that was causing the left-sided weakness. The tumor measured three centimeters by four centimeters and looked as if someone had put a giant walnut in her head. The surgeon explained that this would be a very difficult surgery to do because of the location of the tumor. He said a biopsy was possible too but it might be better to just remove the tumor. He said that Maggie would certainly make it through the

surgery but there were many risks including having a stroke. He said that he was quite capable of doing the surgery, but was not looking forward to it. He said that he understood if we wanted a second opinion but he would go ahead and schedule the surgery for the very next morning. It was about 8 p.m. at this point in time. It was getting late and the surgeon needed to leave us to go and prepare for our daughter's surgery that was only 12 hours away from beginning. The surgeon left us there with our thoughts. Left us there with our nightmare.

We were in shock and no other hospital staff person came to counsel us, guide us, direct us, comfort us after the neurosurgeon left the room. That was the worst night of my life. So, the decision was left up to us. Should we stay at that hospital and go ahead with this pediatric neurosurgeon who we had just met three hours ago? Should we contact some other very reputable medical institutions and see if they had any recommendations? But it was 9 p.m. at night and Maggie's left side was continuing to "melt." Was this a life-threatening situation at this very moment or did we have more time to make an educated decision? It had taken the pediatric neurosurgeon all day to come and talk to us, so it didn't seem as if this was an emergency. We were confused. We just went numb. We were paralyzed with fear. We still had a child to take care of and get through the night. Here was this huge hospital with thousands of employees and no one there to tell us how to navigate these terrifying waters. The burden was put on the shoulders of the neurosurgeon to guide us through. That was not fair to him, to us or to Maggie. It was not ethical. It didn't have to happen this way.

Since that day, I have thought long and hard about how this day could have been less traumatic for our whole family. Here is what could have helped and what you, as a practitioner, need to be aware of:

- The family you have just met is in shock. As you talk to them about their child's possible life-threatening diagnosis, please be aware that they might not even be hearing you. Take a "time-out" during your diagnosis presentation and ask them how they are doing. It would be a

good idea to write down some of the highlights of your presentation to give to the family. They may not remember anything you have said so having something in writing to give to them is very important.

- From the first time you meet the family, educate them on brain tumors. Don't use the words benign or malignant when referring to the tumor. These words are useless and the word benign is misleading when it comes to brain tumors. Be specific and explain that brain tumors are classified as low-grade or high-grade. Part of educating the family should include giving them some basic handouts on the anatomy of the brain and general information on pediatric brain tumors. The Children's Brain Tumor Foundation ([www.cbtf.org](http://www.cbtf.org)) has an excellent resource guide for parents of children with brain or spinal cord tumors. At a follow-up visit, I gave a copy of this guide to the pediatric neurosurgeon and told him that his department should order some copies to hand out to families. He seemed very appreciative to know of this resource. I wished I had a guide like this from the very beginning of our journey. It would have made a world of difference.
- The family needs to talk to someone with a counseling background immediately after they have been given the diagnosis that their child has a brain tumor. I call this person the neurosurgeon or neurologist's "wing-man." This person would provide support in many ways. They would be available to clarify what the doctor has just told the family. They could assist the family in where and how to obtain recommendations or second opinions regarding the treatment of their child's tumor. They could provide background information on the particular surgeon who may be doing surgery on their child. They could provide a list of most frequently asked questions of families who have been through the same situation. The person would also take the families "emotional pulse" by asking if they would like to talk about their fears, concerns or confusion. The family's emotional trauma must be addressed on the day of diagnosis. The family needs to know and feel that they are not alone.

Maggie made it through the surgery that next day. Unfortunately, her posterior cerebral artery was damaged during surgery and she had a stroke. Initially, she had no movement on her left side. After several months of occupational therapy and physical therapy, Maggie's left side began to "wake up."

The day that Maggie was diagnosed is still with me. It is still with my husband. I sought counseling to help deal with the trauma of that day. My husband did not. He still struggles with feelings of guilt. He feels that he didn't do enough to protect his daughter. I tell him we did the best we could.

I leave you with the words from another Maggie. In the book, *The Emperor of All Maladies*, Siddhartha Mukherjee shares an essay by Maggie Keswick Jencks. He states,

In an essay titled *A View From The Front Line*, Jencks described her experience with cancer as like being woken up mid-flight on a jumbo jet and then thrown out with a parachute into a foreign landscape without a map: "There you are, the future patient, quietly progressing with other passengers toward a distant destination when, astonishingly (Why me?) a large hole opens in the floor next to you. People in white coats appear, help you into a parachute and—no time to think—*out you go*. You descend. You hit the ground . . . but where is the enemy? *What* is the enemy? What is it up to? No road. No compass. No map. No training. Is there something you should know and don't? The white coats are far, far away, strapping others into their parachutes. Occasionally they wave but, even if you ask them, *they don't know the answers*. They are up there in the Jumbo, involved with parachutes, not map-making (p. 329).

## Reference

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## How I Hate You, Cancer

Claire Yar

**M**igraine. That's what we thought. They run in my family, so why not? My beautiful, bright, extroverted ten-year-old daughter's neurological exam was unremarkable,

but she had a bad headache and was vomiting in the early morning hours. Migraine didn't seem that much of a stretch. Our savvy pediatrician had a gut feeling that it was more than a migraine and sent her for an MRI.

We had not even left the children's hospital before I received a voicemail to call our pediatrician. When I returned the call, on our way to pick up Ellie's younger brother from school and already running late I heard the words that no parent wants to hear, "I have bad news. We found a brain tumor and it's rather large". This conversation would turn our lives into a frenzy of fear and leave unanswered (unanswerable?) questions. I was told to bring her to the ER where we would be met by a neurosurgeon and oncologist. I could not process this information. My initial fears were too scary to utter. Was she going to die? Do children survive brain surgery "intact"? Is it operable? Oncologist = scary cancer, doesn't it? Did we do something to cause it? What if our insurance doesn't cover the best treatment?

Clinging to the life I knew before—*needing* to stay in the "before," not even pulling the car over, I reached backwards, held Ellie's leg and spoke the words out loud for the first time. That's what a brain tumor diagnosis does to your family. It breaks up time into "before" and "after". Her reaction was a terrified wail and then, oddly, hysterical laughter. Is that what shock looks like? My own reaction to the call was of stunned silence. The sound of my heartbeat and the blood rushing in my ears meant I could not ask the questions I had in that moment.

Ellie has always been exceptional. She is a bright light in any room. At only ten-years-old, she spoke like a teenager; had the vocabulary of an adult. Never again would I be able to take this for granted. In every waking moment that our lives were unoccupied with the practicalities of a brain tumor diagnosis, the questions I couldn't think of or say out loud during that terrible phone call continually flooded my thoughts. Your child's brain is everything after all; it's what makes them "them."

An avid horse rider, she had been off her favorite horse's back for a few weeks saying that the bouncing hurt her neck. I had kept her off school for several days, but we had seen marked improvement in

the day or two leading up to that devastating D-Day of diagnosis, and she had been back at school doing well. Only a week before, Ellie had been dancing at a party with friends. How could she have a brain tumor?

We rushed home and hurriedly packed our bags for “at least a week”—and I recall that life seemed to be both in slow motion and traveling at the speed of light. I desperately wanted to turn the clock back to the innocence we had known a few hours before. This was way too much news to hear in one day. Even when I heard the diagnosis, I was surprised that we would have to go to the hospital that day. Now! Don't people get time to process or plan and get second opinions? We had no time to tell family and friends or ask for help. We didn't have the luxury of time. Time is another thing I no longer take for granted.

Upon arrival at the large children's hospital we felt as if we were given so much information, but looking back, I now know that these angels are trained in giving parents only what they can handle—in tiny pieces, nibble by nibble. You don't (can't) hear half of it anyway. Our families live far from us, and trying to gather and figure out a way to impart this information to them was torturous. We couldn't give them any nuggets of hope or assuage their fears; we could barely understand or comprehend what we were being told for our own information. We didn't know whether to tell them to jump on a plane immediately or await further instructions. I suppose we were in denial ourselves about how serious this monster was.

My husband, Shawn, Ellie's daddy, is a quiet man, wise and composed, a calm influence in our lives. The children and I tend toward the hysterical side—dramatic, flamboyant, loud and expressive. Ellie's diagnosis thrust us into unknown territory where calm and wise and composed are the order of the day. Shawn showed us how to be; demonstrated that my talkative and curious nature were seriously out of place in the world of cerebellums, tumor beds, ventricles, centimeters and brain surgery. For the first time in my life I was stunned into silence. I still asked questions but they were only the things I dared to say out loud. I almost felt like saying

scary things would make them happen. So I didn't say them. Instead I thought, feared and felt them. Shawn helped me to stay calm. I had to be tranquil for everyone in the family. They all relied on me, watched me for what normal looked like—a normal that had changed in a one-minute phone call.

What got us through those horrifying first days was the incredible support at the hospital and the love of our friends and family; a degree of support we had no idea existed. Our friends appeared in droves at the hospital in the two days before Ellie's hours-long brain surgery. All of them bringing gifts, food and desperately needed hugs and words of support and comfort. Before her diagnosis I would not have been so welcoming of that many people all at once. Before, I took them for granted too. I was always the one they asked for help. Always the person to be relied upon, the one who felt more comfortable giving than receiving. This was new for me. It took something this big for me to realize how many truly great friends we have. And it felt good to know that we had a stadium full of genuine and authentic people in our corner. We had chosen our life companions well.

Neurosurgeons have a reputation. They are supposed to be walking geeks, awkward with people, better with brain matter than social matters. This is what we expected when we were introduced to ours. Nothing at all could have prepared us for this doctor. Everyone wants “Dr. McDreamy.” We got him. He is truly an angel that walks the earth—he has not only what I refer to as “magic hands,” but also a manner about him that inspires instant trust. In the “after” of brain surgery, I have learned that pediatric cancer and oncology doctors are a different breed of human. They are special. I might even say chosen. They are the difference makers, the hope bringers, the game changers.

We feel the same way about Ellie's oncologist. She did everything that she could to help us settle into this new world. She patiently explained brain anatomy and what might come “after.” She chatted casually with our precious daughter, helping her to navigate the confusion she felt, the questions she had and the fear of the unknown that facing her own mortality brought. No question was too much. She

told us to email or call with any questions, silently understanding that parents don't even know what to ask in these first stages. She has seen it so many times before.

What we now refer to as "The Longest Day" arrived, and Ellie was prepared for her surgery. I had held it together for two days, and when the anesthesia finally took effect I lost my legs. Shawn and the nurses gathered me from the floor into the security of a wheelchair. At any moment I felt that I would vomit despite having barely eaten since the time of the terrible diagnosis. Those nine hours of surgery were so long, and so filled with unspeakable dread and fear that I do not now clearly recall them. What is blindingly clear in my memory, though, was how we felt when we saw her face again. Even though she was swollen, looking feverish and surrounded by machinery monitoring her heart rate, respiration and oxygenation, we saw only her eyes open, her chest rise and fall and the very essence of her. We breathed her in, grateful that she made it through the surgery, and had been delivered back to us. What I know now is that until you have had to face something of this magnitude other things like a broken tooth, a fractured foot, an infected cut or a migraine no longer seem like things to have much of a reaction to.

Except that now, when I hear of a child that has a "migraine" I worry for them. When my son has a pain anywhere, he doesn't want to see a doctor because he is afraid that he too might have a tumor, cancer. Now, when someone says "brain tumor" I wonder what grade, what kind of "-oma," what the recurrence rate is, what treatment they had, what the prognosis is. Ellie's tumor is considered relatively rare in the world of neurosurgery. A four centimeter, grade two ependymoma in the fourth ventricle. It had been pressing on her cerebellum, inhibiting cerebral spinal fluid flow, which was causing mild hydrocephalus and the headaches and vomiting. When I recently met another mother whose eleven-year-old child had exactly the same diagnosis as Ellie, the parallels in our stories were astonishing. Her daughter had a flawless surgery too, a recovery much like Ellie's, radiation for six weeks, with no discernible side effects. However,

at the one-year check up, the MRI revealed a new tumor in the original tumor bed. When she told this part of her story, I wanted to run away. The start of her journey was so like ours, but a year further out and I needed only happy endings. Her daughter had a second brain surgery and did not fare so well afterwards, now suffering vision and balance problems and an unsure future.

When I look at "before" it's hard to remember that time when I worried about money, the children's education, and what to do on weekends. It's difficult to recall a time when we did not truly appreciate our friends who now mean so much to us—a surrogate family. When I think back to the time when I didn't know about the different parts of the brain, various cancer treatments and facilities, or life before pediatric cancer and the hope it instills, it feels like an innocent life from another era. I long for that innocence for both us as parents and for our children.

The life we have "after" is different in many ways. We consider ourselves fortunate that the surgeon with the magic hands was able to remove the entire tumor. He shared that he had to literally tape her to the operating table so that he could tilt her every which way to gain access to the ugly tumor wrapped around the brain stem and that had attached itself to the bones of her spine. How can you thank a man who does this: who gives you your child back—very much alive, very much intact, with the same light and vocabulary and "Ellieness" that she was always known for? The after includes a whole lot of gratitude, expressed at every opportunity.

The after doesn't include those migraines we expected, only the always present threat of recurrence. For it is always there taunting you with its insidious grin. How I hate you, cancer.

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