

# *VOICES: Confronting Pediatric Brain Tumors*

## **A Study Guide\***

*By Gianna McMillan*

The stories referenced in this study guide can be downloaded for free. Please see the [Confronting Pediatric Brain Tumors volume of VOICES 2015](#)

Arthur Frank has written a short reflection piece on learning from narratives for *Narrative Inquiry in Bioethics*. Please see the *Narrative Inquiry in Bioethics* website to **download** the piece.

### **General Questions:**

1. How might narrative contribute to better healthcare practices?
2. What is the best way for health care providers to use the information learned from these stories? How is this different from how patients and families might use them?
3. A key theme in this symposium is the importance of good communication between patients, families and doctors. What are the main elements of good communication and how can these be practiced in health emergencies?
4. Many parents in these stories felt ill equipped to deal with their child's life threatening illness. Is it possible to prepare for these circumstances in advance? How do emotions affect a person's decision-making process?

### **Story Questions:**

#### **WHAT NOW?**

Mike Abell

1. Mike Abell describes attending the funeral of a child who has died from a brain tumor. He and his wife weep from "sympathy, guilt and fear". Why do you think they were affected in these three ways?

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\* Created to accompany *VOICES: Stories from the Pages of NIB 2015* from the original narrative symposium in *Narrative Inquiry in Bioethics* Volume 4 Issue 1, 2014.

2. Mike Abell writes about being “strangled with fear and an anxiety that builds every three months when his child has a check-up MRI. What makes him respond this way?

### **Second Guessing**

Anonymous One

1. This parent describes a close relationship with her child’s oncologist, even referring to him as “her” doctor. What are the strengths and weaknesses of this type of relationship with a healthcare provider?
2. Despite peer support and her own personal belief, this parent agrees to move forward with a treatment plan she does not agree with. How can physicians help patients feel more comfortable asking for a second opinion? What strategies might caregivers use to advocate for themselves?

### **Advocates, Not Problem Parents**

Anonymous Two

1. Anonymous Two is surprised that her teenaged son’s healthcare team questions her decision to delay his treatment a few days in order to bank sperm so that he can father children later in life. Can you think of other examples where patients and doctors might have different priorities?
2. This mother describes several instances where she and her husband challenge hospital procedures, thus earning them the label of “problem parents”. What factors contribute to the tension in the relationship between this family and their healthcare team and how might they have been avoided?

### **Down the Medical Rabbit Hole**

Anonymous Three

1. Over the years, this mother and young adult patient have learned many things about the nuances of the patient’s condition. In this story, they appear to know more than the doctors. What is the doctor’s response to this particular medical emergency?
2. This mother hints at tension between herself and her daughter. What difficulties can you imagine when chronically ill children transition to adulthood and must begin to care for themselves?

### **Not the End We Planned For**

Anonymous Four

1. A POLST (physician order for life sustaining treatment) is a plan for a patient who is likely to have a life-threatening crisis. In this story, the POLST includes instructions *not* to intubate. Why would the parents want this POLST in place?
2. A health emergency brought the child to a hospital that is unfamiliar with her medical history. Why do you think the doctors refused to honor the

POLST? In your opinion, what could have been the best outcome for this family?

### **An Encounter with the Art of Science and Medicine**

Anonymous Five

1. This parent's story begins with detailed descriptions of several medical opinions that do not agree with each other. How is it possible for experts in the same field to disagree? How can a patient best make a decision in these circumstances?
2. This mother admits that they lost confidence in their doctors, yet they have remained with the same medical team for over ten years. Why do you think this family chose to stay with these health care providers?

### **Ethan's Gift**

Michelle Burgess

1. DIPG (diffuse intrinsic pontine glioma) is a rare, inoperable brain tumor. Should research funders be responsible for investing in treatment options for diseases that affect very few people?
2. Michelle Burgess writes that the Gift of Life organization only twice dealt with the advance planning for pediatric organ donation. Why do you think this is the case?

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

Jeanne Carlson

1. Jeanne Carlson writes that her daughter's treatment was quick and relatively non-invasive, but that the entire family was affected by the long-term side effects Sarah experienced. This family felt ill informed and ill-equipped for the ongoing needs of this patient. What could have better prepared this family?
2. Why do you think Sarah's twin brother was so affected by Sarah's illness and the subsequent difficulties? What are some strategies that might help siblings in challenging situations like this?

### **Life in Limbo**

M. Chui

1. This family had access to major hospitals, financial stability, good health insurance and a stay-at-home parent who could research the disease and manage their son's care. What do you think it is like for families who do not have these resources?
2. Many of the narratives describe the distress of parents who wonder if they had made the right decision on behalf of their child. Is there an added responsibility when deciding something for someone else? Is this responsibility different when deciding for one's child?

### **My Lost Survivor**

Virginia Hammond

1. Pediatric brain tumor survivors often have cognitive and physical disabilities that affect their education. Many times there are “latent effects”, which is when side effects worsen long after treatment is finished. Describe the challenges these children and their parents might face as they navigate school systems.
2. Virginia Hammond worries about her daughter’s future when there will be no living family members left to care for her. What options are there for disabled adults in this situation?

### **Things Are NOT Okay**

Lynne Hillard

1. In Lynne Hillard’s story, optimistic prediction from several doctors were at odds with her son’s deteriorating behavior. Do you think that physicians should emphasize positive outcomes? Why or why not?
2. What actions does Lynne Hillard take that indicate her increasing ability to advocate for herself and her son? What would have happened if she had made no changes to the way she handled her son’s situation?

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

Cheryl Kirkpatrick

1. Cheryl Kirkpatrick and her husband work in the medical field. Do you think this gives them an advantage as they face their daughter’s diagnosis?
2. Comment on the three pieces of advice in this story: 1) Remember the family is in shock, 2) Educate them about the disease and 3) Refer the family to counseling. Can you think of other helpful points for this “roadmap”?

### **Ice Cream For Breakfast**

Michelle Methven

1. Michelle Methven’s young child was diagnosed with a rare and always-fatal tumor. What arguments might physicians use to encourage treatment even if it will not cure the disease? In such situations, is it appropriate for physicians to try to convince parents to agree to treatment? Why?
2. What arguments might a parent pose as grounds to refuse treatment? Which do you think is more important, “quantity” or “quality” of life?

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

Christopher Riley

1. A young neurosurgeon comments that Christopher Riley's son has "an impressive tumor". Why do you think this doctor began his conversation with Christopher Riley in this manner? What other ways might news of a serious diagnosis be delivered?
2. Christopher Riley acknowledges that he and his wife dealt with his son's life-threatening illness in different ways. How might this affect a marriage?

## **Over the Years**

Kimberly Rocker

1. Many narratives in this symposium describe parents who have a difficult time convincing others that something is wrong with their child. Why do you think this happens? To what extent should physicians accept parent information at face value?
2. Kimberly Rocker describes the physical and social difficulties her daughter experienced long after the medical emergency resolved. How do you think the age of the patient at disease onset – and treatment for the disease – affects their long-term quality of life?

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

Lynne Scheumann

1. This symposium deals with a serious pediatric disease. Most parents state that their children experienced social isolation and a lack of peer empathy. Why is this such a common occurrence and what might be done about it?
2. Lynne Scheumann tells us that her oldest daughter "made it easy" for her to care for the sick younger brother. This daughter later states that she will only marry a man who would be willing to have this brother live with them. Comment on the challenges of siblings whose younger brother or sister is permanently affected by a health issue.

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

Terra Trevor

1. Terra Trevor believes that it took a "mosaic of support" to help her family facing the recurrence of her son's tumor and the end of his life. What did she mean?
2. What do you think of the way this family communicated with their son as his condition worsened? Why might other families choose to do things differently?

## **From Normal to Nightmare**

Brandi Wecks

1. A routine check-up at the pediatrician's office ended with this family in the emergency room with their two-month old daughter. Unexplained bruises and a CT-scan that showed bleeding in the brain required investigation from Child Protection Services. Do you think the ER doctors were justified calling CPS?
2. Brandi Wecks recalls losing all hope until a second doctor insisted they "had to try" a risky treatment. Why do two experts have completely different recommendations? How can a patient or caregiver best choose between completely different suggestions?

## **How I Hate You, Cancer**

Claire Yar

1. Many parents talk about life that becomes divided into "before cancer" and "after cancer". How do you think their experience of the disease differs from that of their sick child?
2. Claire Yar talks about how her normally outgoing personality changed to the point where she did not want to talk about "scary things" in case that made them happen. Comment on how a traumatic experience can affect one's ability to handle difficult circumstances.