



Family Matters

Elizabeth Ahmann, ScD, RN and Deborah Dokken, MPA

Making Meaning after the Death Of a Child: Bereaved Parents Share Their Experiences

Deborah Dokken

You had direction as a parent. You had direction fighting your child's disease. But after your child's death, you are directionless. (P. Brown, personal communication, June 15, 2012)

Each year in the United States, over 50,000 families are faced with the tragedy of having a child who dies (Field & Behrman, 2003). This tragedy is a life-long one, forever shaping these families (Contro, Larson, Scofield, Sourkes, & Cohen, 2002). In the aftermath, whether soon or years later, some families find ways to “make meaning” or find direction after the death of a child. They may start a foundation or a support organization to help other children and families, they may turn to the arts for expression, they may even change careers. Not surprisingly, these approaches often emanate from strengths in families’ previous lives – from what is familiar or has provided comfort before. Further, for families who find their way of “making meaning,” there are various benefits. Family Matters co-editor, Deborah Dokken, herself a bereaved parent, interviewed three families who were willing to share insights about their distinctive and personal paths to making meaning.

Janelle and Jason Myers-Benner Talk about Their Daughter Nora Lynne and the Writing They Have Done since Her Death

Our second daughter, Nora Lynne, was born in October 2007, when our first daughter, Kali Jean, was 4 years old

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Note from the “Family Matters” Co-Editors: We are extremely grateful to Janelle and Jason, Vicki and Peter, and Maureen who so generously and honestly shared stories of Nora, Mattie, and Becca – and of their own paths to “finding meaning.” Hopefully, this article will be meaningful to them as well as to pediatric nurses and other clinicians who read and apply its lessons to their interactions with other families. Special thanks to Jason Myers-Benner for giving permission to include his poem, “This First Time,” in this article.

Some 50,000 families experience the death of a child each year in the United States (Field & Behrman, 2003). Over time, some bereaved families find or develop approaches for “making meaning” from the experience in ways that allow them to maintain a sense of connection to their child, keep the child’s memory alive, and help other families who may face similar circumstances. Interviews of three families demonstrate that the process of “making meaning” is individual and often builds on past strengths and interests. The stories shared by these three families demonstrate their individual approaches as well as common themes.

(see the photo “Nora and Her Family”). We were alerted to possible trouble with Nora’s health about half way through the pregnancy; however, nobody could tell us much about what might be wrong. At the moment of her birth, we had no idea whether she would live a few minutes or have a happy and healthy life of normal duration. All we knew was that she would be very small; in fact, Nora weighed three pounds and “change” at birth. She had Petty-Laxova-Wiedemann syndrome, which affects an infinitesimal percentage of children with various symptoms, most notably a failure to grow well and a prematurely aged appearance from lack of subcutaneous fat. After a month in the NICU, we were able to take our fragile baby home, and despite the worry and exhaustion, we enjoyed almost 6 months at home with her before we agreed to the placement of a feeding tube. But the surgery seemed to exacerbate Nora’s underlying condition of pulmonary hypertension. A few weeks later, in June 2008, we said goodbye to her at the Medical Center. Nora was a determined, courageous, and inquisitive baby, and although our healthy third daughter, Alida Hazel Sarina, arrived over a year ago and is keeping us very busy, we still miss Nora every day! (J. Myers-Benner, personal communication, June 20, 2012).

Both of us had made meaningful personal use of writing in the past – Jason through poetry (see Figure 1), and Janelle through journaling. It was not uncommon for us to write semi-publicly when major changes, events, or experiences came our way. Before, each of us had found writing to be a clarifying experience. Therefore, at different times in Nora’s

The **Family Matters** series focuses on issues, information, and strategies relevant to working with families of pediatric patients. To suggest topics, obtain author guidelines, or to submit queries or manuscripts, contact Elizabeth Ahmann, ScD, RN; Series Editor; *Pediatric Nursing*; East Holly Avenue/Box 56; Pitman, NJ 08071-0056; (856) 256-2300 or FAX (856) 589-7463.

Nora and Her Family



Figure 1.

This First Time

It feels so strange, this
first time.
So many days
have passed, that dust
could gather on the shelf around
her image?
Taking up a fraction
of a sock, I dab and wipe away
accumulated haze.
I lose track
of the moments as I hold her
in my blurred and aching
gaze.

And a knowledge that
this unaccustomed sight – left hand with
this framed photograph aloft,
the passing over,
under of a freshly dampened cloth – will
come to join the steady
number of my lifetime's repetitious motions
enters my sore mind like it were swallowing
a stone.

Who can tell me? Who can
tell me now what it will mean
then – when the hand that lifts
the frame is frail,
the wrinkled rag that clears the dust
moves slowly, rocks with tremor – to
remember her?

Jason Myers-Benner
September 22, 2008

life when we felt confused and distressed, we turned again to writing – and tried to express in letters what we could not quite understand. We made that writing available to anyone who wished to read it. In a way, it was an invitation to our circles of family, friends, and neighbors to be a more intimate part of our journey. Initially, we simply assembled an e-mail list, but sometime after Nora's death, we decided to convert our writing into a "blog" (<http://myersbenner.blogspot.com>) and to make it truly public on the chance that someone in need might gain solace from it. And our family now has a fairly extensive record of one of the most formative times in our collective history. We use it already, especially around anniversaries and other grieving times, and we look forward to making use of it as our other daughters, Kali and Alida, mature and develop their own interest in delving into that chapter of our past.

Vicki and Peter Brown Talk about Their Son Mattie and the Foundation They Created after His Death

Our only child, Matthew Joseph Brown, was born on April 4, 2002 (see the photo "Mattie and His Parents"). From the beginning, he was observant of everything and anything! In July 2008, after attending a tennis camp, Mattie complained of pain in his right arm. A few days later, he continued to complain of arm pain. A trip to the pediatrician and an X-ray revealed every parent's worst nightmare: Mattie had a tumor; Mattie had cancer. It was at that point when the world began to spin. Discussions about school, soccer practices, and play dates were instantaneously replaced with talk of chemotherapy, limb-salvaging surgeries, IVs, and antiemetics. Mattie endured 13 months of treatment, including chemotherapy, starting in August 2008; two limb-salvaging surgeries affecting three of his four limbs; and a sternotomy to remove tumors from his lungs; and was left wheelchair bound. In August 2009, after a series of scans and only two months off chemotherapy, we learned that the cancer had spread throughout Mattie's body. At that point, our conversations turned to palliative and end-of-life care. On September 8, 2009, at the age of 7 years, Mattie passed away in our arms at the University Hospital, his home away from home. To know Mattie was to love him. We will never forget our little boy, so full of life, so full of courage and love (paragraph modified with permission from Sardi-Brown, 2012).

After Mattie's death, we were angry, hurt, and directionless. We founded The Mattie Miracle Cancer Foundation, a 501(c)(3) public charity, in Mattie's memory to *do something* about childhood cancer. The Foundation is dedicated to finding better treatments for and building awareness of pediatric cancer. It is committed to addressing the psychosocial needs of children and families living with pediatric cancer, as well as educating health care providers about the impact of such a diagnosis. Through these initiatives, we hope to enhance the lives of other children with cancer and their families (see Figure 2).

The Foundation sponsors an annual pediatric cancer awareness walk; the third one in May 2012 attracted more than 400 participants. With money raised at the walk, we have funded a child life specialist position at Georgetown University Hospital, and we hosted a Psychosocial Symposium on Capitol Hill, held in March 2012. In February 2013, the Foundation also hosted a psychosocial "think tank" on childhood cancer at the annual conference of the American Psychosocial Oncology Society (APOS). Starting a foundation made sense for us as a couple. Peter is an entrepreneur and already knew how to set up organiza-

Mattie and His Parents



Figure 2.
Mattie Miracle Cancer Foundation

The Mattie Miracle Cancer Foundation, a 501(c)(3) public charity, was founded by Peter Brown and Victoria Sardi-Brown in loving memory of their 7-year-old son Mattie, who died in 2009 from osteosarcoma. The Foundation is committed to 1) addressing the psychosocial needs of children and families living with childhood cancer, 2) establishing a psychosocial standard of care for childhood cancer patients and their families, and 3) educating health care providers on the impact of a cancer diagnosis on children and their families. Mattie Miracle Cancer Foundation believes that through increased awareness, education and support, and advocacy, we can enhance the lives of children with cancer and their families.

For more information about the Foundation and Mattie's battle, please visit www.mattiemiracle.com and <http://mattiebear.blogspot.com>

tions; as a psychologist and educator, Vicki defined the focus of the foundation. Both of us used skills we already had in a new context: we partnered in creating the Foundation in Mattie's memory.

Maureen Lilly Talks about Her Daughter Becca and the Work She Has Done since Her Death

I was putting our second child, 10-year-old Rebecca, to bed one night when she suddenly lost the ability to speak. It was 1991, and Becca had been playing in a Memorial Day soccer tournament. Our first thought was that she had a head injury. Not only could she not speak, but she was looking at me like she had no idea who I was. We called her soccer coach before calling a doctor. Then my husband Joe and I rushed Becca to the emergency room. She nearly died there, and so began our long, hard battle with glioblastoma multiforme – the most insidious of all brain tumors. Over the next six years, Becca was in and out of hospitals, getting treatment at the cutting edge of medicine. Her care included multiple rounds of radiation, two surgeries, and eventually even gene therapy. Despite all of these efforts, Becca died at home with us in June 1997, just before her 17th birthday.

Although she endured years of aggressive treatment, Becca also lived a life full of energy, compassion, and commitment to others. She had a wide circle of friends in and out of the cancer community. She was the linchpin in our family as the second of our four children (see the photo "Becca and Her Family"). She insisted on playing in the city basketball championship game – for about 30 seconds – just months before she passed away. She also testified on Capitol Hill about the importance of funding for federal agencies like the National Cancer Institute (NCI) that work on childhood cancer research.

My professional past has included both political and nonprofit management positions. After Becca's death, I decided to apply that experience in a new direction: within organizations focusing on cancer and hospice care. It was a perfect marriage; I could combine what I knew professionally with what I knew personally. I have served as Director of Planned Giving for the National Hospice Foundation and as an administrator for the Washington Home Center

for Palliative Care Studies. Additionally, I've served on the Board of Special Love for Children with Cancer, an organization providing camps and other activities for children and their families. In 2011, I became the Executive Director of the Children's Cause for Cancer Advocacy (see Figure 3) after having served on the organization's Board since 2000. In this position, I can help increase public awareness about childhood cancer and impact policy on issues like drug development for pediatric patients and implementation of the Affordable Care Act.

My own career was not the only one in our family influenced by Becca's illness and death. Our daughter, Anne, is a pediatric hospice nurse; our son, Joe, is a police officer. And for the past 16 years, our entire family, together with friends, has organized "Becca's Run," a 5K run and 2-mile walk. The Run has donated more than \$500,000 to various organizations supporting children with cancer.

Benefits of Efforts to "Make Meaning"

In her interviews, co-editor Deborah Dokken learned that the ways Janelle and Jason, Vicki and Peter, and Maureen chose to make meaning provided benefit to them – individually and as couples.

Deborah Dokken (DD): How has your chosen "direction" to making meaning helped you?

Janelle: I blog when I want to remember Nora and stay connected. Writing is a way to solidify memories of her. After Nora's death, silence was the worst. Our writing also gave other people permission to talk about Nora, to tell stories – to add to the memories.

Peter: Although we, as a couple, talk about Mattie often, we talk about safe things. "Do you remember when Mattie did this or that?" But we don't often reflect on the pain of this loss. The Foundation gives us an avenue to talk about our feelings.

Jason: I don't write 'til there's a weight in my heart – when I've reached a point where I need to stop and straighten up my emotional space. Writing gets things organized in my mind.

Vicki: I run the Foundation, certainly, to help other children with cancer and their families, but at the heart of my motivation is Mattie. The Foundation keeps his memory alive, and it highlights his battle. Then, we use that battle to gain insights into how to help others.

Becca and Her Family



Peter: I'm someone who likes results. So much was wrong with our experience. Through the Foundation, I can do something about this disease and about its impact on families.

Maureen: When you have a (pediatric) cancer experience, you don't want it to be a total loss. You want to be able to give back to the people that supported you – those who gave their medical expertise, those who gave you trips to Disney. And you want to see improvement.

Advice to Other Families About "Making Meaning"

In her interviews, co-editor Deborah Dokken asked Janelle and Jason, Vicki and Peter, and Maureen to advise other families who are trying to "make meaning" after the death of their child.

DD: What advice would you give to other bereaved families who are looking for ways to "make meaning" after the death of their child?

Peter: Gravitate to what is appropriate *for you* – to what is familiar. It's a different process for each person.

Jason: Integrate the meaning-making with the rest of your life. Transform what you already have or do into something new. *You* are the right person to make meaning for yourself!

Figure 3. Children's Cause for Cancer Advocacy

The Children's Cause for Cancer Advocacy (CCCA), founded in 1999 as The Children's Cause, Inc., was established to take a leadership role in advocacy and training on national issues affecting childhood cancer. CCCA works to achieve access to less toxic and more effective pediatric cancer therapies, to expand resources for research and specialized care, and to address the unique needs and challenges of childhood cancer survivors and their families. CCCA leads efforts to ensure these needs and perspectives of children with cancer are integrated into the highest deliberations on health care and cancer policy at the federal level.

For more information about the organization and its legislative initiatives and programs, please visit www.childrenscause.org

Vicki: Focus on staying connected to your child in a personalized way. Your child defined you personally; do this (making meaning) personally!

Maureen: Do what feels right for you. We didn't sit down and analyze what we were going to do, but opportunities presented themselves. You can't necessarily plan, but be open to possibilities.

Janelle: If you allow your meaning-making to be part of a community, it is more resilient and enduring. Through community, your memories of your child can be broader.

Closing

After our two babies died, I didn't just wake up one day and say, "I think I'll become a family advocate." It was more in fits and starts as I realized I'd had a huge life-changing experience. I began to feel I could somehow make sense of what happened to us by helping other families. (D. Dokken)

Three families – Janelle and Jason Myers-Benner, Vicki and Peter Brown, and Maureen Lilly – who experienced the death of their children – Nora, Mattie, and Becca – at different ages and from different conditions found different ways – their own ways – to make meaning of the experience. Despite the differences among their experiences and their approaches to "making meaning," these three families each developed ways to stay connected to their child after death, to keep memories alive, and to help other children and their families through their individual approaches to "making meaning." ■

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