A PARENT'S GUIDE TO ENHANCING QUALITY OF LIFE IN CHILDREN WITH CANCER

EDITED BY
RUTH I. HOFFMAN, MPH & SANDRA E. SMITH

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With the support of



To Dr. Beth Cairney and to Dr. Kathy Warren for the personal sacrifices you have made to walk hand in hand with families of children with cancer—from diagnosis, through treatment and beyond....

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Preface

The American Childhood Cancer Organization's (ACCO) mission is to provide information and support for children and adolescents with cancer and their families; to provide grassroots leadership through advocacy and awareness; and to support research leading to a cure for all children diagnosed with this life-threatening disease.

Since ACCO's founding in 1970, the five year survival rate of childhood cancer in the U.S. has risen to approximately eighty percent. This improvement in survival brings hope to tens of thousands of families whose children are treated for cancer each year. In spite of the progress, children continue to be treated with aggressive therapies including chemotherapy, radiation and surgery. Treatment can leave the child in pain, feeling isolated and alone. The diagnosis leaves parents struggling to care and advocate for their sick children and to educate themselves about the disease while trying to maintain some sense of normalcy for their families.

Pediatric palliative care focuses on quality of life and addresses the physical and emotional needs of the patients as well as the needs of their families. Provided by an interdisciplinary team comprised of doctors, nurses, social workers, child life specialists, chaplains and psychologists, these specialists work together with the child's oncologist to provide relief from the physical symptoms and emotional stress of cancer. Pediatric palliative care ideally begins at the child's diagnosis and continues throughout the course of treatment, as needed. It is recommended for all children diagnosed with a life-threatening illness at any age and any stage, and is to be provided alongside treatments that are meant to cure.

It is our hope that this book will increase the family's understanding of the benefits of palliative care for the child diagnosed with cancer, which will lead to improved pain and symptom management and enhanced quality of life for the child and his or her family.

The Contributors

I am deeply indebted to the following professionals who gave of their time and expertise to author comprehensive chapters for this book. My deepest gratitude

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is extended to Rebecca Kirch, JD, Joanne Wolfe, MD, MPH, Deborah A. Lafond, DNP, PPCNP-BC, CPON, CHPPN, Danielle D. Leach, MPA, Melody Cunningham, MD, Daniel Mahoney, MD, Deena Levine, MD, Jennifer Snaman, MD, Joanna Lyman, MA, CCLS, Justin Baker, MD, Michaela F. Nalamliang, RN, MSN, CPNP, Debra S. Lotstein, MD, MPH, Paul M. Zeltzer, MD, Lonnie Zeltzer, MD, Lori Wiener, PhD, Barbara Sourkes, PhD, Marsha Joselow LICSW, MSW, Janet Duncan, MSN, CPNP, Rachael Menius, MSN, CPNP-AC, CPON, Christine Reilly, Barbara Jones, PhD, MSW, Farya Phillips, PhD, CCLS, Elana E. Evan, PhD, Tammy I. Kang, MD, MSCE, Jennifer Walter, MD, PhD, MS, Abby R. Rosenberg, MD, MS, Chris Feudtner, MD, PhD, MPH, Elisha Waldman, MD, Angela Punnett, MD, FRCPC, Kimberlee Spady, JD, Christine Denhup, MSN, PhD, Catherine Kelly-Langen, MD, Nancy Carst, LISW, Sarah Friebert, MD.

My thanks would not be complete without expressing my heartfelt appreciation to all of the families who took time to write and share their children's personal stories. These stories give credibility and passion to the book and emphasize why pediatric palliative care is so critically needed.

I cannot adequately express my gratitude for the time that Sandy Smith spent pulling together the parent stories and editing the book. Sandy lost her son Andrew to brain cancer and has turned her own grief into generously giving of herself to help other families navigate the cancer journey. I also want to personally thank Bonnie Woodworth, whose daughter Tatumn also died of brain cancer, for the time she spent providing a third set of eyes during the editing process. Your help is appreciated more than you will ever know. Warm thanks to Adelae Durand and Sammy Chu for providing valuable feedback, as well.

I wish to thank Jessie and Kristi Allen for sharing the picture of their daughter Olivia for the cover of this book. Olivia was diagnosed with hepatoblastoma when she was two. Olivia, seen holding her father's hand, was three years old, and six months in remission, when the picture was taken. She is now five years old and has been cancer free for two years. When I asked Kristi if ACCO could use Olivia's picture on the cover of the book she responded, "I think it is great you are writing a book about palliative care. Olivia was miserable for pretty much the entire treatment time and my regular parenting knowledge wasn't adequate to help her deal with the pain. I felt so helpless because I couldn't take it all away and it made me so sad. At times during treatment, I thought her spirit was broken and wouldn't recover. But today, she is a spunky, spirited, full of life little girl! It is amazing what our kids can endure and still be ok. But I needed other parents (who had been through what I had been through) to encourage me during Olivia's

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treatment that she would truly be ok when this was all over, so I am glad you have parent voices in the book too."

A big thank you to Marie-Dominique Verdier of MDV photo for working with ACCO to capture the photo of Olivia.

Finally, I wish to thank Joanne Wolfe for her help with the organization of the book, as well as author recommendations.

Book Composition

This book is written both for parents of children diagnosed with cancer as well as for healthcare providers. Chapters are written independently, and parents and providers are encouraged to read those chapters that most directly apply to the child's current medical needs. For example, parents whose children are experiencing pain with treatment might want to begin with chapter 4, Pain Management in Children with Cancer. Others might want to read the book from start to finish.

The book is divided into three major sections. **Part I, All About Living** provides a comprehensive understanding of the meaning of palliative care, as well as applications to symptom mananegement, pain management and ways to improve the child's, and family's, quality of life.

Part II, When Hope Changes addresses the difficult questions that some families face when it becomes clear that cure is no longer possible.

Part III, Appendices ends the book with two useful sections.

- Appendix A lists a sampling of resources—books, websites, listservs, and
 organizations that assist families of children with cancer.
- Appendix B is a compilation of journal articles that provides further reading
 opportunities for those wishing to dig deeper into specific palliative care
 topics addressed by the authors throughout the book.

Acknowledgements

This book would not be possible without financial support. I am indebted to **Rebecca Kirch**, Director of Quality of Life and Survivorship at the American Cancer Society, Inc., for her personal friendship, vision and passion to make a difference in the quality of life of children treated for cancer in this country. Thank you to the **American Cancer Society, Inc.**, for the financial support provided for the printing of this important resource.

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Ruth I. Hoffman, MPH Executive Director, American Childhood Cancer Organization

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"I don't think of all the misery, but of the beauty that still remains."

—Anne Frank

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Part I All About Living

Pediatric Palliative Care: The Family's Lifeline to Quality of Life

Rebecca Kirch, JD Joanne Wolfe, MD, MPH Blyth Lord, MEd

"It's like when you're filling in concrete. The [disease specialists] are the people who put the layer down, then [pediatric palliative care] are the people who go after and fill the holes, so the whole thing doesn't start to crumble. But if it does start to crumble, they're the people who actually go in with the hard hats and fix it." —Gwen Lorimier (11 years old)

Extra Support in Facing the Unthinkable

A cancer diagnosis shatters every sense of "normal life" for children and their families—thrusting everyone into unfamiliar terrain filled with uncertainty and anxiety. Daily activities take a sudden, unwelcome shift, being replaced by multiple subspecialty clinic visits and, oftentimes, prolonged and repeated hospital admissions that exert extraordinary psychological demands. The child's physical distress, along with the suffering of the parents and siblings, is compounded by the implications of the illness and by the separation from normal life and from other family members.

The child with cancer is forced to confront the extraordinary challenge of pursuing developmental tasks of childhood and adolescence while negotiating the illness experience, both physically and emotionally, through symptoms,

changes in appearance and body image, and the intrusion of technology and side effects of treatment. Healthy siblings also live the experience of illness and must bear

Rebecca Kirch is the Director of Quality of Life and Survivorship at the American Cancer Society, Inc. witness to its impact while trying to cope with the new and unplanned family atmosphere and its many uncertainties.

Approximately 10,450 new cases of cancer and 1,350 cancer deaths occur among children ages 0-14 each year, and an estimated 380,000 people diagnosed between the ages of 0 and 19 are now living in the United States with a history of childhood cancer. Many of these children endure severe symptoms and other suffering. Approximately two-thirds or more of children who survive cancer have treatment late effects that impact their physical, emotional, and cognitive functioning—causing significant chronic conditions that continue into adulthood. For families confronting these deeply troubling statistics and scenarios, pursuing cure or slowing disease progression understandably may be a primary clinical focus. It is important to note, however, that preserving quality of life need not ever be relegated to the backburner. A focus on quality of life and what that means to both the child and the family can be concurrent with cancer treatment. This is where pediatric palliative care comes in.

Pediatric palliative care, paired with pediatric oncology, has emerged in recent years as the new comprehensive cancer care paradigm, treating the pain, symptoms and stress (physical, psychosocial and spiritual) of cancer at the same time as treating the disease. Adding palliative care's extra layer of support, children and their families don't just survive. *They can also thrive*.

Team Based Care Focused on Meeting Family Needs

Pediatric palliative care focuses on quality of life, the well-being of individuals, and addresses the needs of infants, children, adolescents, and young adults, as well as the needs of their families. Pediatric palliative care is provided by an interdisciplinary team typically composed of doctors, nurses, social workers, child life specialists, chaplains, psychologists, and other specialists who work together with a child's oncologists and other clinicians to provide relief from the symptoms, pain and stress of cancer. Pediatric palliative care is appropriate at any age and at any stage, and can be provided along with treatments meant

to cure or to control the illness for as long as possible. Ideally, palliative care begins at the time of diagnosis, so that families have this extra layer of support continuously along their child's entire trajectory of care. It continues throughout the course of the illness—through survival for most children and families, or for a small portion,

Joanne Wolfe is the Director, Pediatric Palliative Care, Children's Hospital Boston, and the Division Chief, Pediatric Palliative Care Service Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute. through end of life and bereavement.

To support their shared role in making critical decisions, many families value having complete and honest information about what specific cancer treatments can and cannot do in terms of achieving cure or remission, the probable progression of their child's cancer, and what is known about life expectancy. Equally important, they want to know about the physical and mental symptoms and changes they might expect, the adverse effects and long term consequences associated with cancer treatments, and care strategies available to help minimize the negative impact of treatment and maintain their child's comfort and quality of life. Combining pediatric palliative care with cancer treatment helps support and guide decision making to ensure quality of life as a critical goal in the management of the child's disease. This value is especially important to parents who worry that a diagnosis of cancer means a loss of decision making authority as they enter a complex medical world. Doctors know the disease best, but families know their children best, and it is this respect for parents and family goals that palliative care puts front and center.

Pediatric palliative care is often provided by the primary interdisciplinary oncology team which consists of an oncologist, nurse and psychosocial clinician. Frequently, given the complexity of the illness experience, a subspecialty pediatric palliative care team is also invited to participate in the care of the child and family to add an extra layer of support. Pediatric palliative care teams offer highly skilled expertise in communication and care coordination, helping families contend with the unknowns of cancer while striving to preserve the integrity of the parent-child relationship throughout the care experience. Pediatric palliative care practitioners provide practical assistance that helps families ask questions and articulate their concerns, needs and wishes; they also explore the underlying themes that guide the patients and families in making decisions.

Essential Elements of Family-Centered Pediatric Palliative Care

Recognizing and respecting the pivotal role of the family in the lives of children.

Striving to support families in their caregiving roles by building upon their unique strengths as individuals and as families.

Respecting and encouraging the choices families make for their children.

Promoting normal patterns of living in the hospital, at home, and in the community.

Essential Elements of Family-Centered Pediatric Palliative Care

Promoting partnerships between families and professionals to ensure excellence at all levels of healthcare.

Experiencing Pediatric Palliative Care

Communicating with honesty and sensitivity about what to expect during and after treatment, talking directly with the child when appropriate, and preparing the parents and family for circumstances they may face due to their child's cancer, are all aspects of high quality care and priorities of palliative care. Sibling relationships are crucial within the family system, and palliative care can help to enhance children's mutual caring and devotion and ensure the importance of these relationships is not overlooked.

Palliative care is, by definition, about relationships: relationships with the child, the healthcare team and the family. While components of pediatric palliative care can be standardized, the actual human connection provided is not. Critical elements of the human connection in pediatric palliative care include the intent to relieve or prevent suffering; the use of words, silence, and presence to comfort; making an effort to respect hope while helping the child and family prepare for likely outcomes; working toward the development of clearly defined care objectives; the honoring of child and family preferences for care; and understanding the parents' absolute longing for their child.

Palliative care is individualized for each child and family and their unique circumstances, providing one of a kind human connection and information to deliver optimal care based on a therapeutic alliance between the team and the family. Providing this continuity of care throughout the illness and across the hospital, clinic and home settings is associated with fewer care related problems and reduces feelings of abandonment. With the close communication that palliative care provides, families are better able to make choices that are in line with their values, traditions and culture. This improves the well-being of the entire family and promotes emotional and spiritual healing—even if the disease persists.

Overcoming Palliative Care's Identity Problem

Pediatric palliative care teams increase overall satisfaction with care for children and their families by helping alleviate physical discomfort and tempering the

Blyth Lord is a bereaved mother and Executive Director of Courageous Parents Network.

suffering caused by the uncertainties of prognosis and outcomes of cancer treatment. Clinical studies have shown that early palliative care paired with oncology treatment may also lengthen survival. Yet pediatric palliative care does more than just extend a child's life; these teams work to insure that the extension is meaningful to the child and family.

Integrating palliative care with cancer treatment can reduce the number of days children spend in the hospital. It can also save energy—relieving pain and other symptoms. Despite the many benefits, palliative care is often misunderstood. Parents and caregivers may not be knowledgeable about palliative care, and many healthcare providers hesitate to recommend it because they mistakenly associate palliative care with hospice, "giving up hope" and the end of life. Quite the contrary, palliative care is appropriate throughout the duration of a child's illness and is not based on prognosis. In fact, most children in pediatric palliative care programs are still alive well beyond the year following initial consultation.

While nothing can prepare a family for the challenges of caring for a child with cancer, the guidance of an interdisciplinary team that can appreciate their needs is invaluable. Identifying and understanding the patient's and family's beliefs and values is an important palliative care skill that helps direct efforts toward improving the quality of care and quality of life. The interdisciplinary pediatric palliative care team considers the entire family and provides support to each member. Instead of narrowly targeting the child's cancer, palliative care treats the person beyond the disease. Questions first focus on learning about the child as a person—how he or she contributes to the family, and how the illness has affected them. This allows the child and family to disclose their worries, identify and adjust their goals, and enables shared decision making by regularly checking on what the family hopes for and finds most important to them along the changing course of illness.

Benefits of Pediatric Palliative Care

- 1. Relieves the child's disease symptoms, such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping.
- 2. Helps with communication and coordination of care between the medical team and the parents.
- 3. Helps the child and the family have the physical, emotional, and mental strength to carry on with treatments and daily life, and provides the best quality of life for the affected child and the family.

Pediatric Palliative Care is Gaining Prominence

Palliative care is a relatively young discipline, and pediatric palliative care is even younger; but the evidence base showing its benefits is growing. Recognizing this, the American Academy of Pediatrics has recommended that health systems caring for seriously and chronically ill children should provide palliative care services as an essential part of optimal care. The numbers of pediatric palliative care teams available are steadily rising in communities and major pediatric centers.

Pediatric palliative care team physicians have typically trained as specialists in fields such as oncology, but the strength of pediatric palliative care practice stems from the collaboration of multiple healthcare disciplines. Its cornerstones are clear communication, trust and non-judgmental understanding of the family's beliefs and values. As such, these teams can play a vital role in facilitating the family's adaptation, wellness, and resilience at different points in the illness trajectory as they encounter multiple care settings (hospitals, outpatient clinics, etc.) and interact with different teams of clinicians in each setting. Palliative care even makes house calls, opening an important door for understanding what life is like for patients and families at home, as well as identifying particular needs patients and families may have. Palliative care services also extend to schools and other community venues where the children continue to live their lives.

Accessing Pediatric Palliative Care: Ask about It

Early palliative care should be considered for every child and family navigating a serious illness like cancer. Team based pediatric palliative care coordinates medical, nursing, psychological, social work, and other specialties in outpatient and hospital settings, in communities and major pediatric centers. It provides direct support to children and families and is also a source of coordination of care and education for the broader pediatric community.

While pediatric palliative care teams are not yet available in every setting where children and families receive their cancer care, all pediatric clinicians are capable of addressing the palliative care needs of children with cancer and their families—either through personal knowledge and skill or by providing referral to specialized dedicated palliative care teams.

If you feel palliative care could help your child, your family or you, ask for it. Tell your child's healthcare team that you would like to add palliative care to your child's treatment plan. You can also ask your child's oncologist or other clinician to give your child a referral for palliative care services. By improving

familiarity with palliative care and building relationships with palliative care specialists, families and pediatric oncology clinicians can together help ensure that the best care possible is provided, regardless of outcome. If you want to find a hospital in your area that offers a palliative care program, you can go to the Palliative Care Provider Directory of Hospitals (http://getpalliativecare.org/providers) to search by state and city.

Glossary

Palliative Care focuses on the quality of life for the child and family. It is provided by a team of doctors, nurses and other specialists who work together with a child's oncologists and other clinicians to provide relief from the symptoms, pain and stress of cancer. Pediatric palliative care is appropriate at any stage, and can be provided along with treatments meant to cure.

Hospice is a Medicare benefit and is defined as a special way of caring for people who are terminally ill. Hospice care involves a team-oriented approach that addresses the medical, physical, social, emotional and spiritual needs of the patient. Hospice provides support to the patient's family and/or caregiver, as well. Hospice care is given by a public agency or private company approved by Medicare. It is for all age groups during a patient's final stages of life. The goal of hospice is to care for terminally ill patients and their families, not to cure the illness.

Interdisciplinary Care is an integrative and collaborative model where people from multiple disciplines work together in addressing a common challenge. Each specialty maintains its own identity while also sharing some common methodologies and assumptions with other disciplines.

Hospice and Palliative Medicine is the term used by the American Board of Medical Subspecialties to denote the physician subspecialty established in 2006.

Family Perspectives

Torin received palliative care through an agency called Stepping Stones in Seattle and it was invaluable. It took me some time to understand that they were not suggesting that he wouldn't make it by offering their services.



There are a lot of misconceptions about what palliative care means. Quality of life while in treatment should not be an afterthought or something parents have to fight for. It should be standard practice, but it is not.



Naithan's doctor was on board with our plan (and Naithan's wishes) and did everything in his power to allow Naithan to be at home as much as possible. We were immediately signed up for palliative care that provided an additional source of at-home care. Between his doctor, his nurse, and his palliative care nurse—and my willingness to be taught how to do certain things at home, Naithan was rarely at the hospital for anything more than his weekly clinic appointments. I remember one Friday afternoon Naithan was really not feeling well. Instead of needing to drive him to the clinic and spend hours there with the on-call oncologist, I called palliative care. The nurse showed up, realized he needed IV fluids and called Naithan's doctor directly. Fluids were ordered, the nurse accessed Naithan's port, and when the fluids arrived, I hooked them up and was able to easily change out the bags, every 12 hours, throughout the weekend. Naithan was able, through our combined efforts, to remain at home as he wished.



Palliative care is a scary term. I think the hospital could have reviewed palliative care earlier with me so I could have been more open to it—or maybe used some other wording like symptom management. Looking back I wish that pain and symptom management would have been reviewed as a separate issue; I feel it may have been better addressed.



We worked with a palliative care nurse to ensure our son's complete comfort and care at home.



To palliate is to make less harmful or harsh. That was of the utmost importance. The main focus was not only the treatment, but my child's well-being—to make life as normal as possible.



When my son Buddy was diagnosed with a brainstem glioma at the age of 1 we were told there was no cure. When we went to get a second opinion we were told there was some hope with a child under 3 years of age. The Children's Oncology Group had seen some success with chemotherapy on young children. We immediately went that route. After 3 months of chemo, my son's tumor progressed. It progressed so much that the MRI showed severe hydrocephalus even though he showed no symptoms. Buddy had emergency surgery and was put on high doses of steroids. We were told he would have survived for just a few days if we had not done the surgery. The steroids wreaked havoc on his body and he went from a child with limited movement to an immobile child. He was just 18 months old.

We immediately changed gears and moved towards palliative care. Our goal was to make Buddy smile every day and make him as comfortable as possible. Every decision we made was made with his happiness in mind. He loved his physical therapist and special education teacher so we continued with those therapies. He didn't like his occupational therapist so we cancelled her services. We made the hardest decision of our lives and met with a hospice service that specialized in palliative care for children. We decided to give Buddy palliative radiation in an attempt to minimize his symptoms. We had a nurse from the palliative team visit Buddy every week to check his vitals and see how he was doing. We finished the radiation and started a new chemo regimen. The goal was to wean Buddy off the steroids. The steroids gave him insomnia, an incredible appetite and caused him to gain enough weight that he was virtually unrecognizable.

After months of weaning him off the steroids, we began to see improvement beginning in January 2014. He started to move his legs and feet. He started saying some words. Now, 3 1/2 months later, he is working with

his physical therapist on standing. It is really incredible to see him doing things that I never thought he would do again. We still have the nurse from the palliative care team come every week. We still try to make every day as happy as possible for Buddy. We try to make him as comfortable as a child with brain cancer can be. That is what palliative care is all about.



I always associated palliative care with end of life. It would have been nice to have been introduced to palliative care earlier in Marleigh's treatment.



We quickly realized that although our palliative team was recommended by the children's hospital, they were not equipped to handle children or DIPG's fast decline. I wasted many hours talking to different specialists about meaningless items that were not applicable to our situation. One recommendation was an elaborate hoist system that would take weeks to install so he could be bathed. He didn't have weeks. When I asked about a wheel chair, they told us it could take about a month to get one properly fitted for him. Luckily, we had a sturdy jogging stroller that quickly became his mobility mechanism. When it came to medication, we were told what to use, but we needed to figure out the proper dose. At every turn, I felt like I had to figure things out for myself in this uncharted territory. My biggest regret is how much time I wasted looking for answers.



In a world where we are inundated with television shows, books, commercials and stories that focus on miracle cures and beating the odds, hearing from a doctor that your beautiful 2-year old child has a type of cancer with a 100% fatality rate, seems almost inconceivable. Sitting in a cold hospital room and hearing this exact news about our beloved little girl Stella, made our family feel completely hopeless and helpless. It became clear immediately that traditional curative medicine was not the right fit for our situation. We felt lost and alone. The first bit of light we got in this incredibly dark time in our lives, was meeting with members of the palliative care team. One of the first things that they said to us in that sterile hospital room became our mantra for the entire 16-months she lived—Stella is not dying of a brain tumor, she is living with a brain tumor. And that was what the holistic care we received was focused on—quality

of life over quantity of life.

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 palliative care physician visited her on a weekly or bi-weekly basis at home, scheduling appointments between play dates and trips. The doctor had a solid relationship with Stella and my partner and I, so when there were difficult decisions to be made, he was already familiar with our wishes and philosophy and was able to offer options that met with our hopes for Stella's life and death.



We did engage a palliative care nurse toward the end. It was the best decision we made to keep our son comfortable, as the prognosis became more dire.



It was at the end of radiation that we did another good thing. We were asked, and agreed, to meet with the pediatric palliative care nurse, before going home. I can say that I was in complete dread of meeting Bryce's palliative care nurse, because she was going to tell us all the terrible things that we couldn't and didn't want to even imagine yet, including how and when Bryce would die. I wasn't ready for it, didn't want to hear it. The day that my husband and I met with her I was physically sick. We walked in, and the first thing that she asked us was to tell her about Bryce, which threw me off kilter. She didn't want to know about his symptoms like every other person we had encountered. She wanted to know about him as a person, and as a child. She wanted to know what his interests were, and about our family. After being submerged in the cancer world and on "a mission" to treat him, this was somewhat shocking, and even refreshing.

She then looked at us and asked if we knew what palliative care was all about. We said yes, it was about dying. She said, yes, that was part of it, but it was also about so much more. She looked at us and told us that palliative care was about choosing to LIVE, for as long as possible, and in the best manner possible with the time that is left. It was about making each day a choice to live, not about waiting to die. And at that moment we made a choice. We decided that we would do just that. We would go home and LIVE Bryce's days with him, and make those days everything that they could be.

When Carson was diagnosed with cancer I wanted to crawl into his brain and take it on—he had fish to catch, baseballs to throw, girls to date. But the fight was his so we searched for a pediatric oncologist that we trusted. We leaned heavily on our doctor plus an extended team whom we later learned was referred to as palliative care.

Our team helped us along Carson's valiant fight for life, helping assess Carson's pain both physically and emotionally. Our team, led by Carson's oncologist, worked closely together and included pet therapists, massage therapists, music therapists, child life specialists and social workers—all with a vast array of others at their fingertips.

Then when cancer was unyielding and hospice took over, we knew that we had done everything possible to care for our boy.

The Parent's Role

Deborah A. Lafond, DNP, PPCNP-BC, CPON, CHPPN Danielle D. Leach, MPA

"Your child has cancer." These are words that no parent wants to face and no parent who has heard these words can ever forget. These words change lives in an instant and signal the beginning of the family's journey with the child's cancer. The child's role is usually fairly clear; he or she is the patient. But what is the role of the parent? Comforter. Researcher. Nurse. Spiritual advisor. Infection control specialist. Gatekeeper. Communicator. Advocate. Parents will likely play all of these roles and more; and they may struggle to find time just to be parents. This is the balancing act faced by every parent who has a child with cancer.

The Parent's Role

Parents of children with cancer face many changes. Families may experience long separations while one parent stays with the child in the hospital and the other works and/or cares for children at home. Mothers and fathers cope differently which can sometimes lead to disagreements on how to handle decision making and care. If there is a stepfamily involved, there may be added complexity with shifting family boundaries. Balancing the ill child's healthcare with work, family life, siblings, and other responsibilities, can be exhausting.

The Parent at Diagnosis: Making Difficult Decisions

Feelings of uncertainty, anxiety, depression, and even feelings similar to post-traumatic stress, are common. Parents may experience doubts that their decisions are the right ones. Fathers and mothers often experience these feelings

differently and to varying degrees. Mothers commonly report feeling higher levels of stress than fathers, usually associated with the physical effects of the child's cancer treatment. Common stressors that are reported by parents include hearing the

Deborah Lafond is a Pediatric Nurse Practitioner in Neuro-Oncology and Palliative Care at Children's National Medical Center, Washington, DC. diagnosis, worrying that their children might die with or without treatment, fear of not understanding the information given by the healthcare team, making difficult decisions, managing their own emotions, managing family responsibilities, and understanding their new roles and relationships after the diagnosis.

Increased stress may make it more difficult for parents to process all of the information the healthcare team shares with them. Stress may be complicated by the uncertainty that a diagnosis of cancer brings: uncertainty that the child will be cured, uncertainty that the family will survive intact, and perhaps uncertainty that they are making the right decisions regarding the child's care. It is okay for parents to express their emotions with the healthcare team. It is normal for parents to be worried and concerned for their child's welfare. The social worker, child life therapist and psychologist can be great supports for the entire family.

The terminology and language the healthcare team uses may be unfamiliar. Parents should not hesitate to ask for clarification. Even if parents have heard the information previously, they may have questions about what it means for their child. Some families find it helpful to have a notebook, or to use technology, to write down the questions and thoughts they want to discuss at a later time. The application iCANcer is a good way to track the child's diagnosis, treatment and questions to ask the healthcare team.

There may be occasions when it is urgent that the healthcare team shares information with parents because decisions need to be made immediately. There will be times when information is better shared in small bites so that the family can take the time they need to better understand. If parents feel overwhelmed and are having trouble comprehending information, they may ask to take a break (a few minutes or a few days depending on the urgency of the situation) and come back to the discussion later. Since there is usually a series of conversations about the child's diagnosis and treatment, parents do not need to understand everything all at once. While difficult, these conversations are an important part of the process of making sure the child receives the best possible care.

The pediatric palliative care team can offer an extra layer of support for parents in helping with communication and decision-making. Pediatric palliative care

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is a recognized medical specialty with the goal of optimizing quality of life for children with potentially life-threatening conditions, such as cancer. Palliative care focuses on anticipating, preventing and treating suffering in all of its forms. Palliative care for children provides care for the physical, emotional, social and spiritual needs of the child and family. It is an active, multidisciplinary process, involving a variety of professionals who work together to ease the burden of illness for the child and the family.

Many parents express that developing a good rapport with their child's healthcare team is important. The chapters in this book provide information on communication, coping and planning that will help parents to feel better prepared, to ask questions, to raise concerns and to know what is available to support them.

Help in Coping

Parents cope with their child's cancer diagnosis and treatment in many different ways. Strategies that work best for each family are the right ones for that family to use. In general, most people cope in cognitive, behavioral and emotional ways. There are several tasks in each of these domains that parents of children with cancer may face.

Cognitive tasks

Many families cope by gathering information and talking it over with people they trust. These conversations should include the child's healthcare team, but may also include other family members and friends, spiritual advisors and other parents of children with cancer. An important part of coping for parents is to know that the significant people in the child's life (the family's inner circle) are on the same page. It may be helpful for parents to have an open and honest conversation about what is important to the child and to the family. Knowing the impact of treatment on quality of life is crucial for parents as they make decisions and find peace with the decisions they make. If the parents, the child (as age appropriate), and the family's inner circle have the same goals, they can work together to achieve them.

Behavioral tasks

Many parents find that having home care nurses to assist with their child's medical care is helpful. Home care may be limited due to availability and/or insurance restrictions, but parents can discuss this with their child's nurse, social worker or case manager. Requesting help, from family and friends, with the activities of daily

life is another coping strategy. Parents may choose to ask for help with carpooling, grocery shopping, cooking a few meals, running errands, transportation, etc.

Emotional tasks

No one can know exactly how the parents feel, even those who are closest to the family. A child's parents may find it difficult to share their feelings with each other because they deal with their emotions differently. Men and women often cope with their emotional needs in distinct ways. It is helpful for parents to give each other permission to cope in whatever way works for each of them. Many parents find it beneficial to talk to a professional counselor and/or spiritual advisor. Others find prayer or meditation helpful, while other parents find exercise or physical activity a good way to relieve stress.

Table 1. Coping Tasks for Parents of Children with Cancer

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Learning about the child's cancer diagnosis

Learning about the treatments and side effects of cancer treatment

Defining goals of care (what is most important to the parent and the child)

Making decisions in the best interest of the child and family

Behavioral Tasks

Daily care needs of the child

Cancer-directed therapies at home

Monitoring the child for infection and other complications of therapy

Learning how to administer medications and other treatments needed at home

Teaching and helping the child to care for himself/herself, as age appropriate

Transportation to and from appointments

Maintaining daily family life obligations

Emotional Tasks

Grieving the loss of the "normal"

Addressing special needs of the child due to the illness

Accepting changes in family lifestyle

Dealing with uncertainty, anxiety, fear, anger and other emotions

Parenting the child with cancer

Parenting siblings in the context of having a child with cancer

The Parent as Advocate

A parent knows his or her child better than anyone else. As such, parents play a vital role as advocates on behalf of their children and can help the healthcare team understand their child's particular preferences and concerns. The pediatric palliative care team can also support parents and children in making those preferences known, which can be particularly important when the child or parents feel reluctant to speak up about their concerns. The healthcare team may be caring for many children with cancer and other serious illnesses. While they try to remember patient and family preferences, they may need the parent to gently remind them.

Asking for a second opinion is a good idea. A second opinion is having another specialist review the child's case, confirming the diagnosis and/or offering treatment suggestions. The child's healthcare team should not be upset if parents request a second opinion. In fact, they are likely often sought out for second opinions for other children in similar circumstances. Parents will want to have their child's case reviewed by experts who have the most experience in their child's type of cancer. Having several opinions can help parents as they make decisions in consultation with the healthcare team.

While adults make decisions for themselves, parents make decisions for their children. Being open and honest with children, in a way that is age appropriate, encourages dialogue so that parents understand children's preferences in different situations. While parents may want to protect their child from difficult conversations, when children are not included, they may imagine far worse than the reality of the situation. Parents who are honest with their children have the opportunity to ease the children's fears and correct misinformation.

After parents gather information, they will make decisions regarding their child's healthcare in a way that works well for them and for their family. Having doubts, and wondering if they are making the right decisions, is normal. All parents can do is use the information they have, consider the support that is available to them, talk the care plans over with whomever they are most comfortable, and make the decisions that are best for their child and for their family. Being an advocate is not always about the bigger treatment questions, but is also related to the daily life of the child in and out of the hospital, and may include scheduling of medications, organizing visits from family members and encouraging active participation of the child in his/her care.

The Parent as Caregiver: In the Hospital and at Home

One study of parents of children with cancer shows that parents find great comfort in being with their children in the hospital, in learning the routines of the hospital unit, and in developing relationships with the healthcare team and with other parents on the unit. While a child is in the hospital, nurses and others will likely be very involved in the child's care. However, that does not mean that parents cannot help or even provide much of the child's care themselves. The child may feel more comfortable with a parent giving oral medications, for example. Caring for the child in the hospital should be a partnership between the parent and the healthcare team. When the child goes home, the parents will need to know how to manage the child's day-to-day care; learning as much as possible, from nurses and other experts involved in the child's inpatient care, will help to make the transition from hospital to home a smooth one.

While there may be occasions when a home health nurse is available, much of the care of the child at home falls to the parent. Many parents do not feel equipped to administer injectable medications, to take care of central venous catheters, to give intravenous medications or to run tube feedings. While the healthcare team can teach parents the skills necessary to provide this care, there is also emotional work to do.

Support for caregivers

It has often been said that having a positive attitude helps any situation; however, parents may find that there are times when it is difficult to think positively. It is normal for parents of children with cancer to struggle with feeling down or alone. Families may become focused on the demands of caregiving for their children with cancer, to the exclusion of outside friends and even family. The demands of caregiving are substantial, and finding someone to trust with these feelings is often helpful.

Professionals that are part of the oncology team and/or pediatric palliative care team can offer expertise in helping parents navigate the demands of caregiving for their children with cancer. Some parents may find comfort in talking with a spiritual advisor. Finding other parents who are in similar situations may also be helpful. Social workers can provide information on area support groups and contacts for parents who are interested in networking.

Parents also need to take care of themselves. Spending time together as a couple or with other family members and friends may be helpful. Parents should take time alone to do the things that are rejuvenating, such as reading, exercise, prayer,

meditation, guided imagery, relaxation exercises, or whatever brings them peace and rest. It may seem selfish to some parents to even think about spending time away from their child, but the child needs a break too. A stressed-out parent only increases the stress of the child. Parents may want to consider requesting help from their medical social worker or other members of the healthcare team who should be able to direct the family to find support within the community.

Many families find it beneficial to have regular meetings with the healthcare team. The purpose of these meetings is to share information regarding the child's clinical condition, as well as to address the parents' fears and concerns. These fears and concerns are natural, but, left unaddressed, can lead to imagining a situation that is far worse than the reality. Regular discussions between parents and the healthcare team will encourage planning of care that best meets the needs of the child.

Having a good support system will help families to cope better with the serious illness of a child. Parents may request support from extended family members, friends, neighbors, spiritual communities, etc. Though parents may find it difficult to ask for help, there are usually people who want to do something and do not know what to do. Parents may consider assigning a family member or friend to be the organizer of community support. People may be able to help by doing laundry, picking up dry cleaning, shopping for groceries, taking siblings to school and after school activities, writing thank you notes, mowing the lawn, taking out the trash, cleaning the house, etc. Having a list of things that need to be done, and someone to coordinate logistics, may make life just a little less stressful for the family of a child with cancer. Well-meaning family members and friends may call for updates. Using social media to communicate on a regular basis with those who care about the child can save time and energy. Parents may want to consider asking a family member or close friend to take on the responsibility of posting updates and answering questions.

Parenting a child with cancer can be challenging. It is difficult to see a child go through painful procedures, suffer the side effects of treatment, change in physical appearance, and change in relationships with peers and family members. It can be tough to know when to discipline the child and when to let things go. In general, children crave normalcy and structure. If possible, parents should continue the parenting style used before the cancer diagnosis. A child who is treated normally will be less fearful and will understand that he/she is the same person as before the diagnosis.

The Parent at Relapse or Progression: Making Difficult Decisions

Unfortunately, there may come a time when the child experiences a relapse or progression of disease. Many parents find the time of relapse or tumor progression even more stressful than the initial diagnosis. Feelings of uncertainty and anticipatory grief are normal. Parents may feel that they can not talk with those around them about what their child may be facing. Families may realize that the support systems that were once plentiful seem to have faded away. Now is the time to gather those supports again.

Parents may find themselves avoiding conversations with members of their child's healthcare team because they fear bad news. However, studies have shown that avoiding these conversations may actually lead to more stress. At this point, parents have likely met other children and families dealing with similar cancer diagnoses and treatments. It is a natural tendency for parents to compare themselves with other families; however, every experience is different because every child is different. Making decisions about what course to take at this point is daunting because the journey is even more uncertain.

At the time of relapse or progression, some families choose to enroll the child with cancer in a research study or to try further treatment. Other families decide against further treatment and choose to focus only on the child's comfort and quality of life. Both of these decisions can be the right decision, depending on the circumstances and the goals of care. Decisions about goals of care may relate to how much the parents feel their child is suffering, either from the symptoms of the cancer or from the burdens of treatment. There can be a focus on comfort and quality of life while the child continues to receive cancer treatments, as well. Parents do not have to sacrifice one goal for the other. Consultation with the pediatric palliative care team can be particularly helpful to families facing these circumstances. The overall goal is to make every day the best day it can possibly be, regardless of the circumstances.

Family Perspectives

When my son was diagnosed, our oncologist told us that we only had a limited amount of energy and not to waste it on what ifs and how comes. He told us to get up every morning and figure out where you have to be that day and what you have to do; after that, find a way to make a memory and share a laugh. That advice became our way of life from that day forward. Our son is now 7 years post treatment, and we still live by those words. A positive attitude and a little laughter go a long way in the cancer world.



Once at the hospital, Etienne had a CAT scan. The pediatrician on call asked to see us shortly thereafter. She told us we had better sit down. She told us there was a tumor and Etienne had to be transferred to another hospital where neurosurgery would take the case. We rode the ambulance to the other hospital, trying to make light of the whole experience for Etienne's sake. We were in denial, sure there had been some mistake. Our beautiful ray of light, our strapping young lad. He was two months from turning 6 years old. Etienne had an MRI, and the neurosurgeon confirmed he had a tumor. A few very confusing days followed. We started sending the scans to specialists. The specialists told us there was no surgical option.



I wish I could take the cancer for my daughter and spare her from this whole ordeal.



I actually felt like I was going to throw up. I could feel the eyes on me. Watching to see if I would cry. I didn't. I felt like if I let one tear fall I would never be able to stop. I have the rest of my life to grieve and hurt. Now is my time to push on and push forward. To pull everything together to take care of the 6 of us the way a mother and wife is supposed to. The charge nurse Laura came and got me to talk again. Somehow she wasn't hardened against this whole process. I wasn't just a parent; I was Jennifer's mother. She wanted me to see every aspect of radiation to really understand and know how it works. Even see if Jennifer could possibly do it without being

under general. The answer quickly was no way. She was lying on a table with her head tilted backwards. She had to be perfectly still. The measurements are so precise to a millimeter. And then they have a mold of a blue hardened mesh made to perfectly fit her beautiful face that is placed on top of her and bolted to the table. Seeing her like that—I felt like I wanted to pass out. And run to her. Take her away and rock her again like a newborn. But I couldn't because radiation is a nonnegotiable.

Today was a longer time in radiation than it will normally be since they are still perfecting the exact measurements. So I got enough time to call my husband alone. I miss him so much. With him I am safe and I can cry; I don't have to explain anything. I told him today was hard and he was there with me—with us. I don't know how he does it. Works all day and takes my calls. Then goes home to my parents and is Dad and Mom to our boys. I am so lucky to have him.



The original diagnosis was cluster headaches, but it was actually a brain tumor. Of course we were told to immediately schedule surgery to remove it. Although we live in a fairly large city, we knew that we would want a second opinion from a major cancer center. We actually got three and even considered a fourth for other treatment options.



Our son, Naithan, was diagnosed with DIPG (an inoperable brain tumor) in September of 2012. He was 11 and an extremely active, football-playing, bug-collecting, Lego-building little boy. We were told, from the oncologists, that less than 20% of newly diagnosed DIPG children are still alive 12 months after diagnosis. There was no known cure and no definitive set of steps to start treatment. There were multiple clinical trials available and no one trial was better than the other, or even showed more success than another. Radiation treatment and chemotherapy were common recommendations. Many parents choose trials, many choose radiation only, many choose chemotherapy only, and some even choose no treatment at all. It was quickly apparent that research was a necessity for us.



Sadly but quite realistically, no one else is going to be as invested in supporting quality of life measures as the parent. The oncologist's job is

to kill cancer. My job as a mom was to ensure my son was as comfortable as possible, and to balance submitting to treatment with proactively living a life. The biggest factors for us have been positive and constant communication with the treatment team, asking for accommodations in treatment schedules when possible, and never giving up on finding solutions to nausea and pain.



Stella received her DIPG diagnosis in the middle of the night, on a sweltering Friday in June 2011. At the time, we were still blissfully unaware of how definitive and serious the diagnosis was. 24 hours later, we realized the full severity of the diagnosis and the fact that this type of tumor was fatal. With the guidance of our friend who worked for a grief center, we immediately asked to be connected with palliative care. Advocating for palliative care, it turned out, was more difficult than we thought. In today's cure-focused society, requesting palliative care and accepting a fatal diagnosis is seen as akin to giving up. The doctors at the hospital Stella was in, discouraged our request for palliative care, explaining that with radiation treatments to (temporarily) shrink the tumor, Stella could live for perhaps another year. We stated again that we wanted to be connected with palliative care. In our mutual experience, palliative care was often brought in very near the end of someone's life, but rather than look at palliative care as end of life care, we wanted it to be about symptom control and comfort. It took two meetings and a session with the hospital social worker to get our request granted, but two weeks after Stella's initial diagnosis we were transferred from neuro-oncology to a palliative care team that would treat Stella from our home.



The minute we learned our son was sick, terminal at diagnosis, my husband and I wanted to make sure there was no rock left unturned. We sent his MRI to every top neuro-oncologist in the country and to a few reputable European ones. Our hope was there was a mistake in his diagnosis. When we learned (and accepted) there was nothing we could do to save him, we immediately turned our focus to giving him as normal and as happy of a life as possible.



As parents on this journey, we have control over so little. We learned that we didn't have to accept everything that was suggested or offered. The healthcare providers wanted to treat our child but also wanted to listen to us as the parent advocates. When Tatumn was in treatment, we were able to customize some things that just didn't work for us. For example, Tatumn was receiving radiation every day for six weeks and was sedated each day. After the procedure they wanted to hold her in an adult recovery room for an extra hour after she woke. It didn't seem in her best interest when our time with her was so precious and she was anxious in a room with adults in varying degrees of recovery. So we were able to negotiate a special release that let us carry her out as soon as her vitals were stable.

Tatumn was only four years old, and some of her symptoms were difficult for her to describe. At one point she seemed to suffer from vertigo. She felt very unsteady and was distressed anytime we lifted her or put her in the car. She felt afraid she was going to fall; she wasn't walking at the time. There was no real way to manage that, but our instinct was that this was more than tumor related. We kept pushing until they found the source of her discomfort, an infection in her shunt. Much of what brought us peace and resolution during her diagnosis and treatment time was following our instincts. If I could suggest anything it would be to listen to that little voice.

We were given such a dismal prognosis that the concept of palliative care was thrust upon us as quickly as the diagnosis. Given that I couldn't wrap my head around the diagnosis, I was very resistant to the idea of bringing hospice into my home for assistance with palliative care. My husband is a nurse and convinced me that the supplies and services our hospice could provide would make our life a little bit easier while at home with Tatumn. So we took what we thought we could use (hospital bed, delivery of medications and IV fluids). And for one of the first times in my life, I was drawing lines in the sand; we used what was offered and politely declined any social work services. I wanted to strictly limit who was coming into my home in what was already a tragic disruption to our lives. My husband and I took turns and provided all of her care while she was home. We were very fortunate that he was able to work from home frequently and I was a stay at home mom.



When asked how aggressively we wanted to treat this terminal type of brain tumor, my words to the doctor were, "I do not want my daughter to suffer." Quality of life was extremely important to me as her mom. So it was important to us to keep the treatment as local as possible.



We didn't think of it as palliative care as we provided it. I think as parents our instincts kicked in and much of what we did came naturally. Our priority was keeping her comfortable and happy. For our daughter, being happy meant having her siblings around. So my other children took turns taking days off of school to spend time with their little sister. It was also comforting to my other kids to know that we valued their relationship with their sister and that we understood they were hurting in their own way.

Another issue that was important to us was treating the family as a whole. We tried to keep the siblings' lives as normal as possible. We were lucky to have many people that wanted to help, but I also knew my children felt displaced when there was too much traffic. I tried to limit it without hurting anyone's feelings. That was a challenge but I don't regret it.



I am honored so many people are seeing the beauty in our daughter and wanting to reach out. It's both heartwarming and gut-wrenching. It's all becoming real. Today it hit me. My daughter. Our first born. She has cancer. There is no cure. This is real.

I am no longer raising her to be a productive adult or a good wife. I want to give her only yeses. I am known for being pretty cheap, a bit of a coupon clipper, but we have been eating out and I actually bought her a frivolous purchase. I think that may have thrown her. It's a seat pet, a ridiculous info-mercial toy for her seat belt. She wanted one for a long time and had been having a bad day; she saw it, and I got it for her. She loved it—but soon wanted another info-mercial toy. And she has been hounding me for it. I realized this was the thing that was throwing her. She was testing me probably without knowing it. She needs me to say no for her to feel safe. And I realized just because I know our time is being cut short I can't quit parenting her.



We are real warriors aren't we! When our children are threatened we will do anything possible. When Chloe was ill I didn't have an ounce of energy to do anything more than look after her. And that was the best thing I have ever done in my life.

Symptom Management

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A child with cancer may experience symptoms as direct side effects of chemotherapy or other medications, as a result of the disease, or as a consequence of worry about the disease. This chapter is organized so that there are paragraphs defining or describing various symptoms, common presentations or ways to recognize symptoms, causes of each symptom, helpful tips to prevent or treat symptoms without medication, medications that the doctor may prescribe for specific symptoms and, finally, a section on when to call the doctor rather than try to manage at home.

In addition, complementary and alternative therapies have been included with home treatments. These complementary therapies and other home treatments are not intended as a replacement for professional medical or psychological consultation or services. Pain that is acute, severe, or associated with fever or new symptoms that the child has not previously experienced, should always be evaluated by the child's primary healthcare provider.

Gastrointestinal Symptoms

1. Nausea/Vomiting

Definition/description: Nausea is an unpleasant feeling in the stomach or chest that can lead to vomiting or throwing up. Some people describe nausea as feeling queasy or sick to the stomach. Vomiting, or throwing up, is when the stomach muscles contract and push the stomach contents out through the mouth.

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Presentation: Vomiting may be evident when the child actually throws up. Gagging or dry heaves, without actually vomiting, may also occur. Often, nausea can be recognized based on a decrease in the child's appetite or by self-report. In younger children, it may also be recognized by weakness or irritability.

Causes: Nausea and vomiting have many causes, including some chemotherapy treatments, antibiotics and pain medications. The child may have nausea and vomiting as a result of a viral infection that might be contagious and experienced by other members of the family. Also, low blood counts that lead to sores or infections in the mouth, stomach or intestines can lead to nausea and vomiting.

Home treatments: Fortunately there are several ways to treat nausea and vomiting, so the child does not need to suffer. Offering foods that are gentle to the stomach, such as dry crackers or toast, bland foods, ginger ale or hard candy, can minimize nausea and vomiting. Small amounts of food eaten more frequently so that the child's stomach is never too full or too empty may help, as well as limiting exposure to sights, smells or sounds that trigger nausea or vomiting.

For persistent nausea and/or vomiting, psychological techniques, aromatherapy (the scent of ginger or spearmint), and acupressure may be beneficial. On the middle of the inside of the wrist, about two and one half of the child's finger widths above his or her wrist crease, is a pressure point that may relieve stomachaches and nausea. Pushing on this point with a finger for 30 seconds to 1 minute may help. Using medium pressure, an adult can make small circles over this point and encourage the child to take a few deep breaths. This can be repeated every 15 minutes if the child finds it beneficial. There are also some medications called anti-emetics that can help the child feel better.

Medications: Medications which may be prescribed for nausea include omeprazole, diphenhydramine, promethazine, lorazepam, dexamethasone, metoclopramide, and scopolamine. These medicines may be used individually or in combination depending on the child's symptoms and response. Medications may be used on an as needed basis or scheduled around the clock if nausea is severe. Formulations include oral liquids, pills, patches and intravenous forms.

When to call the doctor: Danger signs for nausea and vomiting include nausea

and/or vomiting that lasts a long time, that prevents the child from doing what he/she would normally be doing, or that makes it difficult for the child to receive the cancer treatment as scheduled. If untreated, nausea and vomiting can lead to dehydration, which

Daniel Mahoney is a Pediatric Palliative Care Fellow at Le Bonheur Children's Hospital and St. Jude Children's Research Center in Memphis, TN. is when the body does not receive enough water and minerals, and is a reason to call the doctor. The child may be very lethargic or complain of being thirsty. Seeing blood or dark brown in the child's vomit is a reason to contact the doctor right away.

2. Constipation

Definition/description: Constipation can be defined as infrequent, small or hard-to-pass stools or bowel movements. Normal stooling frequency in children can range from three times a day to once every three days, and in infants from multiple stools per day to once every five days. Parents best know what is normal for their child.

Presentation: Constipation can lead to much distress for children and their parents, and may prove difficult to manage, depending on the cause. Constipation may be recognized based on self-report, decreased appetite, abdominal pain or bloating, or the child's crying or report of pain when trying to have a bowel movement. There may be some blood streaks in the stool since hard stool can cause small cuts and irritation as they pass. For this reason, it is very important to prevent constipation in patients receiving chemotherapy. When a stool is hard and causes cuts to the rectal area when a child has a bowel movement, the risk of infection from bacteria in the stool entering the bloodstream is high.

Causes: Constipation may be caused by changes in the child's eating such as a decrease in food or water intake, by a decrease in activity, and by some medications. Vincristine, a type of chemotherapy, and some pain medications called opioids or narcotics are highly likely to cause constipation.

Home treatments: The best way to start treating constipation is to try to prevent it from developing in the first place. A laxative medication (see below) definitely should be started to prevent severe constipation if the child needs scheduled or frequent opioid or narcotic pain medications. Encouraging the child to drink plenty of his or her favorite drinks, eat foods that are high in fiber, and remain as active and mobile as tolerated, will help to prevent the development of constipation. Chemotherapy, nausea and vomiting can make these non-medication strategies very difficult. It is also often easiest for children to have a bowel movement within

thirty to sixty minutes after eating a full meal due to the action of one of the body's natural reflexes.

Medications: The child's doctor may prescribe a number of medications for constipation including polyethylene glycol, magnesium

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When to call the doctor: Danger signs for constipation include severe and/or persistent abdominal pain, abdominal swelling, and blood in the stool or toilet bowl after passing a stool. If untreated, constipation can lead to the need for urgent medical evaluation.

3. Diarrhea

Definition/description: Diarrhea is the passage of frequent, loose or watery stools.

Presentation: The child may have more frequent and/or watery bowel movements. A child who is already potty trained may have accidents because diarrhea is much harder for the child to control than normal bowel movements. It is not uncommon for diarrhea to be accompanied by abdominal pain or cramping.

Causes: Diarrhea is most often acute, but if it lasts longer than three weeks it is considered chronic. Acute diarrhea can be caused by infection, too much laxative, anxiety and side effects from radiation or medications such as antibiotics or chemotherapy. Chronic diarrhea can be a sign of underlying anatomic defects, hormone imbalances, or certain types of cancer.

Home treatments: If the child has diarrhea, but not vomiting, parents should try to get their child to drink. Fluid and electrolytes (salts), lost when your child has diarrhea, need to be replaced. Pedialyte, or other drinks that the local pharmacist can recommend, will help the child to replace what has been lost. Sports drinks, which are advertised to replace lost salts, contain a lot of sugar and can make the diarrhea and dehydration worse. Additionally, juice, also high in sugar, should be avoided for the same reasons.

Sometimes milk or dairy products can make diarrhea worse, so avoiding these products may improve the child's diarrhea. One of the common side effects of

diarrhea is an irritation of the skin around the anus, which is best treated with barrier creams or zinc oxide paste.

Medications: The child's doctor may prescribe anti-diarrheal medication which may include

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When to call the doctor: Danger signs for diarrhea include dehydration, the presence of blood or mucus in the diarrhea, severe abdominal pain, abdominal swelling, or diarrhea that does not improve with treatment.

4. Anorexia

Definition/description: Anorexia is the loss of appetite or loss of interest in eating.

Presentation: The child may simply refuse to eat or drink. He or she may complain of feeling sick to his or her stomach.

Causes: Chemotherapy can cause nausea, taste changes, or mouth and throat problems that may make it difficult to eat. Radiation to the head and neck or parts of the digestive system may lead to difficulty eating and digesting. Loss of appetite, as well as weight loss, may result directly from effects of the cancer on the body's metabolism. Appetite loss may also be related to other side effects, such as depression or fatigue.

Home treatments: Similar strategies as used for nausea and vomiting, such as small amounts of food, foods that do not have strong flavors or smells and allowing the child to graze or eat when he or she asks, may help. The parent should be careful to avoid repetitive requests or demands that the child eats as this increased focus may worsen the problem. Creative strategies may entice the child's interest. For example, putting small amounts of favorite snacks (raisins, pretzels etc.) inside the multiple individual cups of a muffin tray offers both an array of choices and an interesting presentation. Children also tend to enjoy tasting foods that they had a role in preparing. If the child feels up to it, it may be a good idea to invite him or her to help bake some cookies or help mash the potatoes. Dips can also be a great way to engage the child's interest and add calories to a meal. Small amounts of peanut butter, cheese dip, ranch dressing, ketchup, or caramel sauce can be offered with snacks.

Medications: The child's doctor may prescribe medications to stimulate the child's appetite. This may include dronabinol, megestrol acetate, dexamethasone and cyproheptadine. These medications are typically oral pills or

Joanna Lyman is a Child Life Specialist and Palliative Care Program Coordinator at Le Bonheur Children's Medical Center, Memphis, TN. liquid and can be scheduled one to three times daily. If not initially effective, sometimes increasing the dose, as directed by the child's doctor, can result in improved appetite. In severe cases of anorexia, some children require intravenous fluids and/or nutrition if they are not eating and drinking enough to support their body's needs.

When to call the doctor: If the child's lack of appetite leads him/her to stop eating and drinking altogether, the doctor should be called as this could lead to dehydration and malnutrition. Signs that the child may not be getting enough fluids include dark urine, less urination, and lack of tears when crying. Weight loss and fatigue may also be signs that the child is not eating and drinking enough.

Neurologic Symptoms

1. Seizures

Definition/description: A seizure is a period of abnormal and excessive electrical activity in the brain. Seizures can be very frightening to watch, but usually resolve on their own within a few seconds to minutes.

Presentation: Seizures can be recognized by abnormal twitching or jerking movements of the face, head, arms or legs, or sometimes can involve the whole body. A parent may also notice that the child seems to be staring off into space and not responding to stimuli. After a seizure, it is common for children to be tired and confused. This post-ictal state can last minutes to hours.

Causes: Seizures have a wide variety of causes. Having a seizure does not necessarily mean that the child has epilepsy, which is defined as a tendency to have recurrent seizures over time. Seizures can be triggered by fevers, head injury, infections, some medications, electrolyte (salt) imbalances, and masses or tumors in the brain.

Home treatments: If the child has a seizure, it is important to lay the child down on the ground on their side. The parent should not try to stop the convulsions, to hold the child's tongue, or put anything into the child's mouth. It's a good idea to keep an eye on a clock or watch, as seizures that last longer than five minutes should be immediately treated.

Medications: The child's doctor may prescribe medication for seizure prevention and/or treatment. Preventative medications, also called anti-epileptics, may include a number of oral medications: levetiracetam,

Justin Baker is the Director of the Quality of Life and Palliative Care Division, and an Attending Physician for the Quality of Life Service at St. Jude Children's Research Hospital. phenytoin and carbamazepine. Medications such as lorazepam and midazolam are typically used at the time of a seizure as a rescue medication. These medications are typically formulated for quick administration and absorption in the form of nasal spray, rectal gel and oral medicine absorbed through the inside of the cheek.

When to call the doctor: If the child has never had a seizure before, the child's doctor should be called immediately. An ambulance should be called if the seizure lasts for more than five minutes. Danger signs include seizures that last longer than five minutes, serious injury during a seizure, difficulty breathing or turning blue during a seizure, or another seizure happening right after the first one.

2. Fatigue

Definition/description: Fatigue is a subjective sensation of not having enough energy to do the things that the child wants to do or the feeling of always being tired.

Presentation: Fatigue is a common symptom for children with cancer. Signs of fatigue include physical weakness, mental exhaustion, sleep problems, low energy levels and decreased play or participation in normal activities. In all children, but younger ones in particular, irritability may be the most prominent sign of fatigue.

Causes: Fatigue can be caused by the cancer itself. Pain, sleep problems, poor nutrition, low blood counts, inactivity, depression, anxiety, and fear can also cause fatigue.

Home treatments: Since fatigue can have multiple causes, it can be difficult to treat. Reviewing the child's medications and treatments with the healthcare team to identify possible sources of fatigue is a good place to start. Encouraging the child to eat balanced meals and drink enough fluids may help. Trying to maintain normal sleeping patterns and physical activity levels as much as the child is able to tolerate will also help to manage fatigue. However, the fatigue caused by cancer should not be expected to simply go away with a good night's sleep. When the child is feeling fatigued, parents may choose to engage him or her in an interesting activity that is not physically demanding, such as playing a board game or creating an arts and crafts project together. Alternatively, the child may enjoy participating in activities via the imagination. If he or she is feeling too tired to go outside and play with friends, imagining that he or she is playing soccer (or any other activity) can also be fun. Parents can encourage plenty of detail while the child creates an image in his or her mind, including how it feels to be outside, what it smells like, what he or she sees, and any other

specifics that come to mind!

Medications: The child's doctor may prescribe medication, such as caffeine or methylphenidate, to increase the child's alertness while awake. If fatigue is related to lack of a good night's sleep, sleep inducing medications (see section on insomnia) may be used to help encourage restful sleep at night and better wakefulness during the day.

When to call the doctor: Danger signs include confusion, difficulty waking or staying awake and difficulty breathing or shallow breathing.

3. Neuropathy

Definition/description: Neuropathy is a term used to describe certain types of discomfort or pain caused by damage to nerves.

Presentation: Neuropathy may be described as pain or discomfort that involves burning, tingling, numbness or weakness. The child may seem clumsy, sometimes having difficulty climbing stairs, buttoning clothes or tying shoes. This is because neuropathy typically happens symmetrically, and usually affects nerves in the hands and feet first.

Causes: Neuropathy can be caused by some chemotherapy treatments or by tumor causing damage to a nerve or nerves.

Home treatments: Sometimes pain medication or warm soaks can help with the pain from neuropathy. Gentle massage may also be helpful, although it is important to ask the child what feels good as not everyone with neuropathy experiences massage as relaxing. Guided imagery may also be beneficial. The child can be invited to imagine the location of his or her pain as a color (children often pick red or black). As the child takes deep breaths, her or she can be asked to imagine the color changing to something soft and soothing, perhaps to a color that may suggest the feeling of becoming cool such as blue or purple. Other helpful images include using paintbrushes, remote controls, or switches to shut off or alter the sensation of pain.

Medications: Medications that may be used to specifically treat neuropathic pain include gabalin and pregabalin. These medications are given orally and typically take 1-3 weeks to be effective. Other general pain medications may also help alleviate pain caused by neuropathy individually or in combination with these medicines. Amitriptyline is a medication which can be combined with other medications to treat neuropathic pain.

When to call the doctor: If the child experiences neuropathy, the child's

healthcare team should be notified.

4. Headaches

Definition/description: Headaches are a very common symptom for the child with cancer to experience. Headaches can be described as pain behind an eye, pounding in the head or forehead pain.

Presentation: Most of the time, the child will say that there is pain in his/her head. The child may also avoid bright lights or seem more irritable than normal.

Causes: Headaches have a wide variety of causes including acute febrile illness, sinus congestion, anxiety, migraines, lack of sleep, or, more rarely, increased pressure inside the skull.

Home treatments: The first approach to treating a headache is to try to identify its cause and treat that cause. The child may be more comfortable lying down in a quiet room, avoiding bright lights, and placing a cool, wet washcloth over the forehead or eyes. Over-the-counter pain medicines may be helpful, though this should be discussed with the medical team.

Children experiencing serious illness often feel stress and tension just as adults do. Massage may be helpful to relax tight muscles in the head and neck. An aromatherapy scent such as peppermint, chamomile or rosemary may also be a pleasant addition when using massage to address headache pain. There are several acupressure points that may reduce the sensation of a headache, including the point where the eye socket meets the nose, and the spot in between the eyebrows where the top of the nose and the bottom of the forehead meet. Gently pushing on this point for 30 seconds to 1 minute may be helpful. Medium pressure should be used to make small circles over this point while encouraging the child to take a few deep breaths. Repeat this every 15 minutes if beneficial. If the child is imaginative, he or she may be asked to use his or her imagination to move the headache to somewhere else in the body that is less bothersome, or to change the nature of the discomfort. For example, if he describes the headache as feeling like a hammer pounding on his head, help him to relax and imagine the hammer turning into soft fluffy clouds.

Medications: Medications that may be prescribed for headache include pain medicines such as acetaminophen, ibuprofen, morphine and other opioid medications (like morphine). Depending on the cause of the headache, there may be other medications prescribed including caffeine and sumatriptan. It is important not to give any medication for headache unless directed by the child's doctor. Over the counter medications such as acetaminophen and ibuprofen

can be harmful to the child while receiving chemotherapy

When to call the doctor: Danger signs include severe and sharp stabbing pain, pain that persists for several days or becomes worse despite trying the management techniques described above, pain accompanied by vomiting, pain that wakes the child from sleep or pain that is present immediately upon waking in the morning.

Dermatologic Symptoms

1. Pruritus

Definition/description: This is an itchy sensation, typically of the skin or scalp.

Presentation: The child may persistently rub his or her eyes or nose or frequently scratch various skin surfaces. If pruritus is caused by an allergic reaction, there may be small, raised red or pale spots on a particular part of the child's body, or they may appear all over the body. These spots are called hives, or wheals.

Causes: Pruritus is usually caused by dry skin, but can also be caused by medications (such as opioid pain medicines), metabolic problems or by an allergic reaction.

Home treatment: The first step in treating pruritus is to make sure that the child's skin is not dry. Skin moisturizers, without scent, can be applied liberally to all skin surfaces, being careful to avoid the child's eyes and mouth. Creams or lotions with alcohol should be avoided as this may also lead to excess drying. Pruritus can also be managed with tepid oatmeal baths and by avoiding clothing that is rough or irritating to the skin. If the pruritus is caused by a local allergic reaction, an anti-itch cream applied to the affected area may be of benefit. Again, these types of creams should not be applied around the eyes or mouth. It may also be helpful to use a laundry detergent that is free of perfume or dyes as these ingredients may irritate sensitive and itchy skin.

Medications: Medications that may be prescribed to alleviate itching include diphenhydramine, hydroxyzine and topical creams and ointments. Typically these medications are taken on an as needed basis, but may be scheduled around the clock if symptoms persist.

When to call the doctor: Danger signs include failure of home management options, as well as the child scratching the skin to the point of bleeding, because the skin may become infected. If the child has itching or hives accompanied by trouble breathing, the doctor should be called right away. This may be a sign of a severe allergic reaction.

Affect

1. Agitation or Anxiety: It is normal for a child who is sick to have times when he or she is afraid. However, it should not be assumed that all fear is of the illness or the possibility of dying from the illness. All children have fears, and children with cancer may experience fears that are shared by children who are not ill, such as the monster under the bed for younger children, or fear of doing poorly on an exam.

Definition/description: Anxiety is the sensation of worry or apprehension.

Presentation: Older children may be able to describe this sensation. Sometimes adolescents may be unwilling to share, however, as they are trying to maintain an independence that has diminished as a result of the cancer diagnosis and treatment which requires parental involvement to a degree that was not likely part of life prior to diagnosis. The adolescent may also not want to worry his or her parents. Anxiety may be displayed by crankiness or unusual anger. Younger children may experience agitation or anxiety and be unable to explain what they are feeling. A child who is usually calm may be extremely active, or a child who is usually active may be very quiet.

Causes: Anxiety may be caused by worry about the disease, as well as the changes in social situations caused by the cancer diagnosis. It can also be caused by worry that the disease may not be curable.

Home treatments: There are many non-medical ways to treat or prevent anxiety. Open and honest communication about the disease may ease anxiety and help the child know what to expect. Exercise, even as gentle as walking which may be all that the child has energy to do, can substantially lower anxiety and agitation. For the younger child, active play may help. Yoga, meditation and listening to soothing music may be effective for older children and adolescents. For the infant and toddler, swaddling and gentle rocking may be used. Avoiding caffeine, which is contained in chocolate, as well as the better known tea, coffee, energy drinks and sodas, will help to prevent or reduce anxiety. A child who is usually very active may also benefit from activities designed to release unpleasant feelings like anxiety. For example, the child may be invited to squeeze a stress ball or a piece of play dough while he or she thinks about the negative feeling. The child can be encouraged to imagine sending that feeling into the stress ball, and then throwing it away onto the floor or outside. The child can then be directed to take a deep breath and think about a positive feeling. Alternatively, a child who is usually calm may benefit from activities designed to help quiet unpleasant thoughts. Slowly walking along a labyrinth, or quietly tracing a

finger labyrinth while repeating a calming phrase, may alleviate some anxiety. Finger labyrinths can be found on line.

Medications: Medications that are often prescribed for anxiety include lorazepam, alprazolam, clonazepam and diazepam, also known as benzodiazepines. These medications range from short to long acting forms and can be used on an as needed basis or may be scheduled depending on symptoms and duration. The child's doctor may also prescribe an anti-depressant medication (discussed in the next section) to alleviate anxiety in combination with these medicines.

When to call the doctor: Anxiety the child may be experiencing should be discussed with the doctor, especially if the anxiety is preventing the child from performing activities of daily living. At times anxiety can manifest as panic episodes which can affect breathing and can be accompanied by chest or abdominal pain; in this circumstance it is important to contact the child's doctor immediately.

2. Depression

Definition/description: Depression is a state of feeling down or blue when it is mild. In its most severe form, the child may have thoughts of not wishing to live.

Presentation: The child may express feeling depressed. The child may also sleep much more than usual and be very irritable or withdrawn. He or she may not smile, laugh or have the same variety of emotions as usual. If the depression is very severe, the child may talk about hurting himself or herself.

Causes: Depression can be caused by the stress of the diagnosis, some of the medications, fatigue or persistent pain, or difficulty coping with significant changes in family dynamics, lifestyle or daily routines.

Home treatments: Mild depression can be improved with exercise, watching funny movies, or getting out with friends. Ensuring that the child has sufficient sleep and balanced meals, if possible, can also help. Finding meaning in one's experience can be very important to children who are seriously ill. Creating opportunities for children to express their feelings, thoughts, worries and beliefs through art, play and music can assist them to understand and cope with the feelings they are experiencing. Encouraging the child to write or draw his or her life story may also be a way to help the child to express his or her feelings in a healthy way. This process may also help parents and others to gain insight into how the child perceives the illness experience. Phone calls, Skype, Facebook, cards, email and texting may ease the sadness associated with lengthy separations from family and friends.

Medications: The child's doctor may prescribe a number of anti-depressant medications individually or in combination. These medications may include fluoxetine, sertraline, venlafaxine, amitriptyline, mirtazapine, and risperidone. Often depression and anxiety are linked to one another, and treatment can be combined with benzodiazepine medications as discussed in the previous section.

When to call the doctor: The child's doctor should be contacted if there is concern about the child's mood. Warning signs include loss of interest in activities, uncontrolled crying, and refusal to eat, drink or take medications. The child's doctor should be contacted immediately if there is a concern that the child may be a danger to himself/herself or to others as a result of his/her depression.

3. Insomnia

Definition/description: Insomnia is defined as difficulty falling to sleep, frequent waking and inability to fall back to sleep.

Presentation: Insomnia can be a significant issue during cancer treatment. This can worsen many other symptoms including depression, anxiety, fatigue and more physical symptoms. Insomnia can also make pain more difficult to treat. The child may have difficulty falling asleep or may wake frequently during the night.

Causes: Corticosteroids, which are part of many cancer treatment regimens, are a common cause of insomnia. Anxiety and pain can certainly cause, as well as worsen, insomnia.

Home treatments: Caffeine should be avoided. (Caffeine is found in energy drinks and in items such as chocolate where it may not be expected.) Developing a bedtime routine which includes quiet activities like reading a book, and avoiding video games, television and exercise in the hour prior to bedtime, will help. For older children, naps should be avoided during the day. Exercise should be encouraged, as tolerated, during the day as this will help with sleep.

Aromatherapy, particularly lavender, sweet orange and sandalwood scents, are good for relaxation and improved sleep. Taking slow, deep breaths in through the nose and out through the mouth can help the body's systems to slow and relax. Light massage and/or progressive relaxation may also be helpful. When helping the child to use progressive relaxation, the parent should invite him or her to tighten a specific group of muscles in the body (i.e., "Tighten your left leg.") Then the parent should instruct the child to relax the same muscle group. This can be done for each muscle group in the body, working from top to bottom or from bottom to top. While the child is relaxing his or her

muscles, the sensations of relaxation and sleepiness may be increased with parental encouragement, "From the top of your head to the bottom of your feet, relaxed from head to toe, you are feeling very sleepy."

Medications: Medications such as melatonin, diphenhydramine, lorazepam and zolpidem may be used to help induce sleep. These medications are taken orally and can be given on an as needed basis or scheduled nightly depending on symptom severity and duration. These medications should only be used under the guidance of the child's doctor.

When to call the doctor: Any concerns about sleep disturbances should be discussed with the child's doctor. Signs that may prompt earlier or urgent contact include lack of sleep that is distressing or that impacts the child's or family's ability to function on a daily basis.

Infection

1. Fever and Infection

Definition/description: A fever is defined as a temperature above 98.6 degrees Fahrenheit or 37.2 degrees Celsius. All children who are receiving chemotherapy are at risk of infection as the immune system, which fights infection, is impaired by chemotherapy. At times, infections may be less recognizable than when the child had a normal immune system and was not receiving chemotherapy. The doctor will give specific instructions about when to call for fever, which may seem very different from before the cancer diagnosis and chemotherapy treatment.

Presentation: Fever is one sign of infection. Since the child's immune system is not fully effective due to the disease and the treatment, other signs of infection may include chills, facial flushing, rash, and many symptoms that could also simply be side effects of chemotherapy, such as shortness of breath, vomiting, diarrhea, a swollen or red sore, a sore that does not look very red or swollen but is very tender to the touch, cough and irritability.

Causes: Fever can be due to infection or dehydration; it can also be a side effect of chemotherapy, radiation or the child's disease. This is particularly true if the child has a brain tumor or leukemia.

Home treatment: Preventing infection is not always possible due to chemotherapy's impact on the infection fighting cells of the body. However, careful cleaning of skin, mouth and hands can prevent some infections. Visitors should wash hands or use an alcohol-based gel and should not visit when they

are ill. Preventing constipation can also help the child to avoid some infections, since hard stool can cause tears in the rectal area that can allow bacteria into the bloodstream. It is also important, for this same reason, not to take a rectal temperature and to insist that a rectal temperature is not taken. Sometimes emergency departments that are not familiar with oncology patients are unaware of this. A cool cloth applied to the forehead, drinking a cool beverage, or taking a luke-warm bath may reduce the discomfort often associated with fever. However, the child's temperature should be noted before offering any of these comfort measures as they may temporarily reduce the temperature reading on the thermometer.

Medications: Medications such as acetaminophen or ibuprofen, called antipyretics, can be used to treat fever. These medications, however, should not be given without explicit instruction from the child's doctor as they can be harmful to the child.

When to call the doctor: The child's doctor should be contacted immediately in the case of fever. The fever could be an important sign of an infection that requires prompt evaluation and treatment.

Respiratory

1. Dyspnea

Definition/description: This is shortness of breath or the sensation that it is hard for the child to catch his or her breath.

Presentation: Older children may be able to describe this. Infants and younger children will be unable to verbalize shortness of breath. There may be changes in the child to indicate this problem; these changes may include flaring of the nostrils, the abdomen may move, or the head may bob. Fast or deep breathing patterns or noisy breathing may also be a sign of shortness of breath. The child may say that he or she feels like he/she has liquid in the lungs, that his/her chest feels heavy, that he/she can't stop coughing or that he/she feels dizzy with little activity. Often these symptoms come and go.

Causes: This can be caused by lung infection, extra fluid in the lungs, the heart not working efficiently or the lungs not getting oxygen to the body effectively. If the child is having trouble breathing, the body might not get enough oxygen. Either the lungs can't take in enough air, or the body can't get enough oxygen through the bloodstream. A number of different problems can cause this, including chronic lung disorders, blocked airways, pneumonia,

weak breathing muscles or obesity. Shortness of breath can also be caused by pain, immobility, poor nutrition, stress or anxiety, allergic reactions, surgery, anemia, the side effects of chemo or radiation treatment, a tumor, heart failure, and other problems.

Home treatment: Having the child sit up, propping the child up on pillows, or leaning the child over a pillow or a table may make breathing easier. Lowering the temperature of the room, opening a window or having a fan blowing in the child's face can also help.

Relaxation techniques can be beneficial, since anxiety worsens the sensation of being short of breath, and being short of breath can cause a lot of people to feel anxious. Guided imagery combined with soft music may also be quite helpful. The child may be encouraged to imagine his or her lungs relaxing and expanding while listening to calming music. It is often most helpful to practice these techniques at a time when the child is comfortable so that he or she will already know what works when he or she is short of breath.

Medications: Medications for dyspnea include opioids (ex. morphine), benzodiazepines (ex. lorazepam), inhaled bronchodilators (ex. albuterol) and inhaled oxygen. These medications may be prescribed individually or in combination and may be given on an as needed basis or scheduled depending on symptom severity and duration.

When to call the doctor: The child's doctor should be contacted immediately in the event that he/she is experiencing dyspnea or shortness of breath as this requires prompt evaluation and treatment.

Urinary

1. Dysuria

Definition/description: This is the sensation of pain with urinating.

Presentation: The child may not be able to verbalize the problem, but may simply cry while urinating, or try to hold it and not urinate because it hurts. There may be blood in the urine which may look like pink urine.

Causes: Pain with urinating can simply be caused by the urine hitting irritated or infected skin. The parent may be able to see if there is a rash that the urine is flowing over as the child urinates. This can be extremely painful. Pain with urinating can also be a sign of a urinary tract infection. If this is the case, the urine may smell and the child may need to void frequently, but only have small

amounts of urine. The bladder can spasm and cause pain with urinating. In addition, some chemotherapy can cause irritation of the bladder or cause kidney damage. This may cause the urine to change color (to orange, red, green, or yellow) or to have a strong or medicine-like odor. Radiation to the pelvis can also irritate the bladder and lead to painful or frequent urination.

Medications: Medications that may be prescribed in the setting of painful urination include phenazopyridine for bladder pain, lorazepam or oxybutinin for bladder spasms, and topical creams for genital skin irritation. Other general pain medications may also be prescribed. These medications can be given on an as needed basis or scheduled depending on symptom severity and duration.

When to call the doctor: The child's doctor should be called, if there is painful urination, to ensure prompt evaluation and treatment of the underlying cause and symptoms.

Complementary, Integrative or Alternative Therapies

In addition to the above symptom-based treatments, there is a growing field of integrative oncology—a field that focuses on the health of people with cancer by using multiple approaches, including mental, emotional, and spiritual interventions, to accompany the conventional therapies of surgery, chemotherapy, and radiation. These integrative or complementary therapies are used to treat both physical symptoms such as nausea and vomiting, and emotional-spiritual symptoms like anxiety, depression and fear.

These integrative therapies can be divided into several major categories including energy therapies, mind-body interventions, biologically based therapies, manipulative and body-based therapies, and alternative medical systems such as homeopathy, Chinese medicine, etc.

Parents should speak with the child's medical team before using any integrative therapies as it will be important to make sure they are safe and appropriate.

Energy-Based Therapies

1. Acupuncture

Description: Acupuncture is an energy-based therapy with an origin in Eastern Medicine and has received increased attention and use in Western Medicine. Acupuncture and similar approaches aim to stimulate specific areas of the skin either through insertion of hair-thin needles or by applying pressure, heat,

electricity, etc. to help balance the subtle energy qi (pronounced 'chee') in the body.

Use: The best documented evidence for acupuncture is in treating chronic pain and nausea, and it is used in addition to medications for pain and nausea to help decrease doses and side effects of these medications. There is some use of acupuncture directed at treatment of emotional and spiritual symptoms in adults, but little evidence in children.

Contraindications: Acupuncture should not be used when the child is neutropenic. Additionally, any energy-based therapy provider should be informed about special equipment and regions to avoid—central lines, PICC lines, chest tubes, etc.

2. Biofield therapies (reiki, qigong, therapeutic touch)

Description: Biofield therapy is frequently referred to as energy healing or laying on of hands and is often described as one of the oldest forms of healing. Biofield or energy healing involves the channeling of energy, from healer to patient, and the manipulation of the human body's energy fields. The energy field is an active biofield that is believed to exist within the human body. In therapies like reiki the therapist is thought to be bringing in a healing and universal energy via his or her hands. These techniques use touch and focus on the intention that energy can be used to help the patient restore balance to the natural energy systems of the body. These therapies can result in a sense of well-being in patients and may be helpful in reducing pain, promoting relaxation, managing stress, and improving healing and strengthening the immune system.

Biofield practitioners adhere to holistic philosophies that focus on the emotional, physical and spiritual states of health. Energy healing is considered useful in the treatment of general health and vitality, emotional issues, bodily functions and other healing. Reiki is one of the most widely known forms of energy healing and has emerged as an alternative treatment of increasing interest within research and clinical settings. The National Institutes of Health Center for Complementary and Alternative Medicine (NCCAM) classifies reiki as a biofield modality that involves touch or placement of the hands in or through biofield, the existence of which has not been scientifically proven.

Contraindications: Energy-based therapies work in harmony with all other kinds of treatment including medical and psychological care. There are no contraindications for its use. Research suggests that reiki and other energy-based therapies are helpful in improving sleep and in reducing both pain and nausea.

Mind-Body Interventions

1. Meditation and mindfulness therapy

Description: A mode of training the mind to allow increased perception of the present moment. Can be self-guided or lead by another person.

Use: Meditation is self-calming and provides additional tools to help with acute symptom management (shortness of breath, pain, anxiety). There is some evidence that it can be used to decrease symptoms such as anxiety, difficulty sleeping, and poor immune function.

2. Relaxation imagery and hypnosis

Description: Hypnosis has many names and may also be referred to as visualization, mental imagery, or guided imagery. Contrary to popular belief, the patient is never asleep when in a hypnotic state. In fact, a person who is engaged in a hypnotic process has complete control of his mind and body, and he is actively participating in a process of accepting or rejecting suggestions. Hypnosis is actually a highly focused mental state during which patients are taught to create an experience in their minds. Imagining a situation while calm, relaxed and focused allows the participant to realize that he or she is able to do things that he or she previously was not aware that he or she could do.

Most children find participating in hypnosis or guided imagery very easy as imagining and pretending are both natural components of play. In addition, using one's imagination helps a child to process new information and apply it to one's own life. In the inner world of the imagination, a child may alter the way he or she chooses to remember an unpleasant situation and/or recreate the same event in the way he or she would like it to be next time. The use of metaphor is also very common in hypnosis and other relaxation techniques. Like fairytales and other types of children's stories, metaphor may be used to convey an idea in an indirect way. This allows the child to consider a new way of being in a non-threatening context.

Use: Hypnosis may be used as a self-calming skill, and as an additional tool to help with acute symptom management (shortness of breath, pain, anxiety). Hypnosis and guided imagery may provide reduction in pain perception and anxiety in many potentially distressing situations, including painful and/or invasive procedures.

Contraindications: Hypnosis and guided imagery involve focused mental attention and active participation of the patient. These strategies may not be as effective for a child who has suffered significant cognitive impairments or

neurologic injuries as a result of illness or treatment. A child who has suffered severe right brain injury may not benefit from the use of therapeutic metaphor given that right brain function is needed to process subjective experience, generate imagery and process the meaning of story.

3. Prayer

Description: Prayer is a personal spiritual practice both by the patient and on behalf of the patient.

Use: Prayer can help to provide patients and families with a sense of control and meaning. Both community and hospital-based supports (chaplains and religious leaders) may provide additional psychosocial support.

Biologically-Based Therapies

1. Herbal remedies, dietary supplements

Description: The use of herbal products and dietary supplements in adults and children is very common. Herbal remedies range from simple teas to exotic plant and animal extracts from around the world. Although usually believed to be safe, herbal supplements and vitamins are not regulated or controlled by the Food and Drug Administration (FDA) and their purity, or safety, is not closely monitored.

Additionally, there are many possible drug-drug interaction and adverse reactions to these supplements.

Use: The best documented beneficial effects of dietary supplements include the use of probiotics such as Lactobacillus (found in yogurt) for the treatment and prevention of diarrhea.

Contraindications: Parents should speak with the medical team before use of any herbal remedy or dietary supplement in a child with cancer.

2. Vitamin therapy

Description: Vitamin therapy is the nutritional supplementation of vitamins in the absence of a known deficiency.

Use: Conventional supplementation of individual vitamins may be useful in cases of documented deficiency (cancer-induced anorexia). However, there is no FDA oversight of vitamins and purity could be an issue.

Contraindications: Vitamin supplementation including antioxidants (vitamin

E, etc) is usually not recommended during active cancer treatment as this may reverse or blunt the effect of chemotherapy or radiation.

3. Aromatherapy

Description: Aromatherapy is the use of naturally extracted aromatic essences from plants to help calm, provide balance, and promote overall health of mind, body, and spirit.

Use: Aromatherapy can be used in addition to therapeutic massage or as an individual therapy. Aromatherapy has been used to help in the treatment of nausea, anxiety, sleep disorders and depression, with promising results and few adverse side effects. The selection and use of aromas is best made in conjunction with a reliable practitioner.

Manipulative and Body-Based Methods

1. Massage

Description: Massage is the physical manipulation of the skin and tissue with the goal of promoting relaxation and improving lymphatic drainage and circulation.

Use: Massage is used as a relaxation technique to help with the management of anxiety, depression and poor sleep. Additionally, massage may be helpful in managing nausea and headache.

2. Chiropractic manipulation

Description: One of the more popular forms of non-allopathic medicine, chiropractic manipulation uses manipulation of the bones and connective structures to help in management of chronic pain. Chiropractic manipulation is based on the relationship of the nerve roots emerging from the spinal cord.

Use: Chiropractic manipulation is used to treat chronic pain.

Conclusion

This chapter is an attempt to provide some pharmacologic and alternative therapies to assist parents in helping their child with management of symptoms. It is by no means exhaustive or meant as a substitute for physician assessment. If at any point the child is experiencing new symptoms or seems to be reacting poorly to symptom treatment, the child's physician should be contacted. It is hoped that the information in this chapter eases the journey for children with cancer.

Family Perspectives

This morning was a hard one for my daughter. She cried a lot and was scared. She told me she didn't care if she saw double and had headaches—it's ok mommy. I told her when this all started there would be things she had control over and things she didn't. She can choose what form to take her steroid in, but going to radiation is nonnegotiable. We were taken back for radiation, and she didn't want to talk to any of the doctors. I told her that was another one of her choices. It was hard to allow her to be "rude" to an adult, but I also feel like it's important to give her some semblance of control with the things that don't really matter. But she is six, so she did eventually talk—asked if she could have a popsicle when she woke up!

The radiation charge nurse was amazing. We talked about different options and I reiterated that my husband and I are confident in their care and trust them. It's a good feeling to know you are in the best hands when you are desperate for help. So if they believed one option was best we were on board. Again my daughter cried quite a bit and was pulling at and even trying to bite my nails. It's so hard to try to explain to her what's happening in a non-scary way. I just held her and whispered that it was ok to be scared and ok to cry—that it's important to let the tears out so the smiles can come through.

They wheeled her on her bed though the hallway to the Stanford Cancer Center and we went back to the radiation room. It seemed filled with doctors and machines. I will be honest here in saying it was frightening for me, an adult not going through this. I can't imagine what it was like in her little mind. I got to pick her up and place her sitting up on the table. She leaned over into me. The nurse was right there with us—supporting me supporting her. I was telling her to dream about the time we all went to the spider park—when she and Jonathan raced to the top of the web and Nicholas just sat and ate. Jennifer was whimpering; she was genuinely scared, and although I was 100% there with Jennifer, I could still hear the nurse whispering to me. She was telling me to hold her tight, to support her head and her neck, to hold her like I did when she was a newborn. And I did. It was so easy to go back to that time with her when all she needed was me and warmth to be safe. Quickly she was asleep. I wanted to hold

her and not let go, but I laid her down on the table and whispered "I love you buggers" in her ear and walked away.



My daughter Shelby is 9yrs old and has Stage 4 Wilms' tumor. This whole deal has been very rough not only her, but on the family as well. Her tumor was misdiagnosed as severe constipation for a period of 3 years until a local emergency room doctor ran some extra tests. Her tumor is responding to the treatments remarkably well and her prognosis looks good at this time.



The first days were extremely harrowing: he did not take to hospital life very well at all. He was very angry and difficult to keep entertained. He needed to have a port-a-cath put in his chest to facilitate drug administration and blood withdrawals; he needed to have a mask fit for radiotherapy, and he needed to be examined many times a day. It was all very difficult for him. Mercifully, we were allowed to come home to our cool airy house while waiting to start radiotherapy.

We had such a hard time dealing with his bouts of anger! It seemed nothing we said or did would calm him down. Three things actually really worked: drawing pictures, going down to the lake to throw sand into the water and bubble blowing. He asked to draw all the time. That used to be his most loathed activity! The sand was also a great therapy. Sitting on the beach, playing in the mushy sand and then throwing it out into the lake calmed him down a lot.



My son developed a problem with his blood sugar, which caused issues with constant thirst and urination. We had to go the insulin route even though he almost completely cut sugar from his diet. The problem was a result of the steroids. While it was an additional issue to deal with, the insulin did help, and he was able to eat what he wanted when he wanted. That was important to him and to us.



The therapy was much easier than we thought it would be. Etienne could go to the clinic without having to be admitted. He would have blood work done; then after a couple of hours, the results would come back, giving the green light for therapy. He could take it sitting down as he drew pictures; or standing up as he played table soccer. It did not make him feel ill or lose his hair.

Etienne threw up early one morning four weeks after diagnosis and complained of a headache; he was very sleepy. He had also thrown up in the car the day before. Later that day Etienne ceased to be able to walk. He was so upset! He was crawling, trying to get to his cousins who were playing on the grass outside, and he was so upset he could not walk to them. We brought him inside and he fell asleep; after the nap he was able to walk with some support. The next morning, Etienne could not get out of bed on his own. His Dad carried him to the couch where he promptly threw up. I called the hospital, and they told me to bring him to emergency. We packed our suitcase, dropped our little girl to her aunties and drove to the hospital. Etienne was lethargic and crept in and out of consciousness. He had a CAT scan; they saw the build up of fluids, obstructed by the growing tumor. They called an ambulance to bring us to the other hospital, the one with neurosurgery. Meanwhile Etienne had said or moved very little; indeed, we could hardly tell if he was awake or sleeping because his right eyelid no longer closed all the way, even when asleep. The surgeon examined the scan and called us aside to ask us if we understood that resolving the problem of the hydrocephalous would not resolve the problem of the tumor. He asked us if we wanted to proceed anyway given the risk of any surgery and the inevitable outcome of this disease. We said we did, and he called in the pediatric surgeon. They inserted a shunt that would drain excess fluids from his brain down to his tummy. After the surgery, Etienne could not say much, nor was he moving his left leg, but he was breathing on his own. I sat vigil by his bedside. After a good sleep, Etienne woke up saying he was hungry. Then he fell asleep again. He was still not moving his left leg. I was not sure if and when he would fully awaken. He was tubed up everywhere: IV access, to pee, to eat. Etienne couldn't swallow. We were told he would need a tracheotomy in order to avoid suffocating to death. Yet again, the doctors asked us to decide if we preferred to subject our son to more surgery or let him go. We did not want to make a decision right away. We decided to wait a few hours yet to hear from the oncologist about whether or not there was any hope in radiotherapy.

The next day the decision was made for us: Etienne was amazing! All the doctors' jaws dropped when they saw him that morning. They decided he could even be fed through his mouth (for us, this was very exiting!) He ate

a yogurt. At lunch he ate mashed potatoes mixed with grated parmesan cheese and fish broth. We had a party! He still had a lot of trouble speaking because his tongue was not fully within his control, but we were so happy. He would be able to continue with therapy after all, although at that point we had no idea whether or not it would help. We were so relieved; it was such a roller coaster ride! We went from preparing for a funeral to preparing for further therapy.

Three months after the end of the last radiation session, Etienne was still experiencing headaches, vomiting, and wheelchair-bound. We didn't know what to think. Three and a half months after the end of radiation, Etienne began to feel better. He began to walk again. We hired a physiotherapist, and he started to go to the pool. Etienne, now one year and a half after the end of radiation, is doing well.



Steroids, which can be so beneficial, can have some very nasty side effects. At the beginning of Khylee's treatment she was on a very high dose, gained a lot of weight and became very depressed. Her personality was not her own, and she seemed more of an eating machine. Once we were able to wean her off the steroid, I knew I wanted to stay as far from that drug as possible. After tumor progression we held out as long as we felt we could before starting her on them again.



Talia was getting anti-nausea medicine and Dilaudid very frequently. She then began getting high fevers for which they gave her IV Tylenol because she couldn't keep anything down. When Talia started to feel some anxiety, the palliative care doctor prescribed Ativan. As the days went on, Talia told the doctor that her anxiety was getting worse, so the doctor increased her dosage.

Along with pain medications, anti-nausea and anti-anxiety meds, the hospital social worker and the palliative care doctor worked together in bringing in a specialist to help Talia learn techniques to help relieve nausea, pain and anxiety through meditation. Talia practiced the techniques, and it helped. I also brought in a licensed mental health counselor who specialized in relaxation techniques such as chanting and music therapy. I was trying everything I could think of to help ease her pain, nausea and anxiety. I also had a licensed massage therapist come in and give Talia massages with

essential oils to help calm and relieve the anxiety.



In an effort to aid in care, my son was given a sacro-cranial adjustment by a chiropractor. After a few sessions, I learned some basic body balance movements to aid in his daily care as he came to end of life. After he died, I went for a sacro-cranial adjustment and found it highly beneficial in aiding my physical response to my grief.



Mason was 3 at diagnosis, almost 4. He was a tough, rough and tumble kind of kid before diagnosis, and that remained true even after his diagnosis. He was stoic and did not scream or complain much, so when he did, you knew it had to be pretty bad. We never told him things would not hurt. We used to count to 10 during pokes and procedures. Sometimes too many times and he would say "too many 10's Mommy" But he trusted me to tell him the truth and that helped us through when things hurt or he was scared.

He was one of those active patients who threw up and kept running. It was deceptive so I think we often undertreated his pain because he did not demonstrate it much. After his second relapse, the tumor grew on the base of his spine and he dealt with incontinence and constipation. He just kept going but he had to have been in pain. The constipation and loss of urinary function actually caused a lot of problems for him and landed him the hospital few times before he died. He also hated wearing a diaper now that he was nearing 5.

Anytime we gave him the stronger meds, he was not our Mason; and he hated it. He hated being sedated. He actually did most of his radiation unsedated because he hated the feeling. He would promise to stay still for procedures and scans, and he did. I am grateful to the docs who let this 4 year old have control when they could.

Mason hated the steroids. He said he looked fat, and he would do sit-ups on the floor and run around so he would "lose weight." He hated not looking like himself. His rages and food cravings were legendary. It made those last few weeks tough as he knew he was not himself. He would kiss my nose after a rage and say, "Sorry Mommy. Love you."

Pain Management

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"I thought pain was part of having cancer.... I had to get through it. Now I know you don't have to just get through it; I don't have to be a macho man. I have cancer and I deserve not to be in pain.... It was nice to just lie in bed with my mucositis pain, not having to talk, but knowing that I wasn't alone; my family and friends in the room got me through the hardest times." —M.B., 16-year-old with leukemia, reflecting on his journey through chemotherapy and bone marrow transplantation

When parents are educated about pain in their child who is undergoing cancer treatment, they can act as advocates for the best pain prevention and management for their child. No child should suffer if there are ways to prevent or treat the causes of the suffering. It is important to emphasize that treatment of pain also means paying attention to sleep, anxiety, depression, and other symptoms, such as nausea or constipation.

Children and families undergoing cancer treatment face many emotional and stressful experiences. For many parents pain is one of the most concerning and frightening aspects of the journey. The parent's job is to learn to advocate for optimal relief of suffering for the child. When parents have a good understanding of pain management, they can help their child and the child's healthcare team to minimize the pain experience.

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Causes and Types of Cancer-Related Pain

There are at least three different types of pain that children with cancer might have.

- 1. "Somatic" pain-pain from injury to skin, bone, and muscles;
- 2. "Visceral" pain-pain related to internal organs such as the gut;
- 3. "Neuropathic" pain-pain related to damage to the nerves themselves, or to abnormalities in the way the nerves and brain are processing pain signals.

About 40% of cancer-related pain is felt to be neuropathic, and the rest is either somatic or visceral pain. These three types of pain can come from both the cancer itself or from cancer treatments. Pain coming from the disease itself might be from tumor spreading into the bones or into the liver. Cancer treatments that might cause pain include chemotherapy, radiation therapy, surgery, or procedures such as lumbar punctures and blood draws.

Somatic pain involves injury or inflammation in bones, joints, muscles and tissues; it is generally described as *aching, stabbing, throbbing*, or like a *pressure* in quality. The rapid growth of leukemia cells in bone marrow can cause this type of pain in the bones, as pressure within the bones builds. Likewise, tumor invasion into bones (as from osteosarcoma or neuroblastoma) can cause somatic pain. Pain from getting poked with a needle would be this type of pain.

Visceral pain is caused by injury to internal organs (the viscera), such as the intestines. Typically, visceral pain is felt over a larger section of the abdomen (rather than just in one spot), and children might describe this pain as *deep, squeezing, crampy*, or like a *pressure* in the abdomen. A child with visceral pain may also have nausea, vomiting, and sweating with the pain. Liver tumors, either from primary tumors such as hepatoblastoma, or from tumors that have spread such as neuroblastoma, can result in visceral pain. Also, tube-like organs, such as the intestines, ureters or fallopian tubes, can become blocked (*obstructed*), causing severe cramping pain

and vomiting.

Neuropathic pain is due to damage to nerves or to abnormal processing of pain signals that the nerves carry to the brain (where these signals are registered as pain). Nerves in the body are like electric wires that transmit pain signals from the body,

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up the spinal cord, to the brain. Thus, neuropathic pain is an *electrical* problem. Children often describe neuropathic pain as *burning*, *like a shock*, *shooting*, or *pins and needles*.

Children with neuropathic pain might have pain from things that would not normally cause pain, like a light touch on the skin. Even clothes or bed sheets may be uncomfortable. Other times, things that would only be mildly painful to someone else are extremely painful to a child with neuropathic pain. Along with neuropathic pain, a child might have other signs of nerves not working correctly, like weakness or change in reflexes. Nerves that go to blood vessels and control body temperature might not work correctly. So if a leg or arm is affected, it might be abnormally hot or cold, or it might change colors and look pale or too red.

Inflammation of a nerve due to cancer or infection can also cause neuropathic pain. Shingles, which is reactivation of the chicken-pox virus (herpes zoster) in a nerve, can cause this type of pain and can be seen in children whose immune systems are compromised due to cancer or its treatment. Vincristine, a common chemotherapy drug, can cause damage to nerves and can cause neuropathic pain, especially in the hands and feet.

Pain that a child with cancer might experience is often a combination of somatic or visceral and neuropathic pain. For example, when tumor spreads to the spine, it can cause bone pain in that area of the backbone and also neuropathic pain by putting pressure on the nerves coming into the spinal cord. Also, if a child experiences many months with undertreated pain, that child may develop a neuropathic-like hypersensitivity to pain.

Finally, it is extremely important to understand that the way nerves transmit any type of pain to the brain can be affected by other things a child may be going through. Unpleasant physical experiences, like nausea, fatigue or lack of sleep, can make pain worse. Likewise negative emotional states, such as anxiety or depression, can increase the severity of pain. Fortunately, positive emotional states, like when a child is having fun or is distracted by a video game, can lessen the experience of painful sensations.

Examples of common causes of pain in children with cancer and specific treatments are shown as follows in Table 1.

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Table 1. Common Causes of Cancer-Related Pain and Ways to Manage It

Cause of Pain	What Is It?	Ways to Manage It
Procedures	Pain from needles for blood tests, IV placement, lumbar punctures, injections; other distressing procedures such as placement of nasogastric tubes through the nose.	 Topical patches or creams applied to the skin to numb the area for an appropriate amount of time before the procedure or needle stick (e.g., topical lidocaine). Minimize number of times the child must be poked by clustering lab tests together; limiting lab tests to those truly essential to management. Take medications by mouth as much as possible. Use breathing, distraction, guided-imagery or hypnosis techniques during procedures. Take advantage of periods when child needs to be sedated to do as many invasive tests as possible. Light sedation, such as nitrous oxide or a relaxation medication called midazolam (Versed) during procedures, if it can be done safely. For more invasive procedures, such as bone marrow biopsies, use propofol and injected local anesthetic, with anesthesiologist and monitoring. Preparing in advance, often with the help of a child life specialist.

Cause of Pain	What Is It?	Ways to Manage It
Mucositis	Irritation of cells lining the digestive tract (mucosa), which could include areas from the mouth down to the rectum. Could also include bladder and urethra. Common side effect of certain chemotherapies including methotrexate and Adriamycin, as well as effects of radiation therapy.	 Continuous (a <i>drip</i> or around the clock) opioid pain medication during periods of severe irritation (rather than <i>as needed</i>). Using topical numbing medications before taking oral medications/eating. Using extra pain medication immediately before taking oral meds or eating.
Radiation Therapy	High-energy rays cause heat, swelling (inflammation) in mouth, throat or intestines; could also have skin pain related to radiation therapy to the chest or other body areas.	 Local anesthetics like lidocaine syrup. Gut rest, meaning no food by mouth, and nutrition through IVs. Topical soothing creams to the skin and topical anesthetics.
Surgery	Pain related to surgical procedures that are often needed for solid tumors.	 Continuous opioid or non-opioid pain medication (i.e., a <i>drip</i> or around the clock) for a period of time after the surgery (e.g., 1-2 days) rather than <i>as needed</i> dosing. Use long-acting numbing agents at the end of the surgical procedure. Acetaminophen around the clock, as a way to decrease opiate use. Psychological, behavioral, and complementary (e.g., acupuncture, hypnotherapy) therapies.

Cause of Pain	What Is It?	Ways to Manage It
Bone Pain	Bone marrow filled with leukemia or lymphoma cells, direct invasion by bone tumors such as osteogenic sarcoma or Ewings sarcoma, or metastatic tumor invasion, osteoporosis (thin cortex inside bones) which may be painful in themselves or be associated with spontaneous fractures.	 Opiate or non-opiate pain medications. Osteoporosis medications. Calcitonin. Vitamin D. Consider topical lidocaine patches. Psychological, behavioral, complementary therapies.

Barriers to Effective Pain Management: Myths and Facts

While no one wants any child to experience pain, at times a child's pain is not treated as effectively as it could be. There are many reasons for this: health professionals' lack of pain treatment knowledge and experience, unfounded myths about causing drug addiction, and fears about having unwanted severe side effects, such as breathing problems or sleepiness, from strong drugs. Understanding the facts behind some of these common myths, and clear communication with the child's medical team, can help assure that the child's pain will be treated as effectively and safely as possible.

At times, doctors, nurses, children and families do not understand each other when it comes to the treatment of pain. Some of the terminology (regarding pain and its treatment) is frequently misunderstood or used incorrectly. This is an important gap in communication, as the words and concepts involved are often emotionally powerful, and they can influence both the parents' willingness to

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agree to treatment and doctors' willingness to prescribe medications.

Morphine, and related drugs (oxycodone, hydromorphone, etc.) are referred to as **opiates** or **opioid** medications. These drugs are sometimes called **narcotics**. While this latter term is used commonly to mean opioids AND opiates, it is actually a

term used by law enforcement that should *not* be used in a medical context. It is preferable to avoid using the word *narcotics*, as it has negative connotations given the word's association with illicit or illegal drug use in society.

Likewise parents, doctors, nurses and other healthcare professionals often use the words *addiction* and *dependency* interchangeably. However, the terms have very different meanings.

Addiction is a psychiatric condition and refers to a person's uncontrollable craving for drugs or other substances. Individuals who are addicted to substances will use anti-social ways to obtain drugs, regardless of the negative impact on themselves, their families and society. Addiction is a common concern, but in fact, it rarely occurs in persons with cancer who take medications for pain control and is even more rare in children. The vast majority of people that take medications for pain (including opiate-type medication like morphine and hydromorphone) are able to take the medication as prescribed and do not have difficulty controlling its use.

In fact, the fear of addiction is a bigger problem than addiction itself. *Addiction fear* can cause parents not to ask for medicines for pain relief, with the result that their child must cope with the harmful physical, mental and spiritual effects of the pain itself. If parents have any concerns about addiction, they should discuss those concerns early on with their child's doctors, nurses, social workers and other care providers.

Physical dependency refers to the process that happens when a person's body gets used to a medication (like morphine). Physical dependency is a normal process that occurs with anyone taking a specific class of medications for a prolonged period of time; it occurs not only with pain medications, but also with other medications like those used to treat high blood pressure, seizures, and inflammation. If the medication is suddenly stopped, or quickly reduced in dosage, the person may experience a *withdrawal syndrome*. Withdrawal symptoms from opiate medications may include feeling sweaty, shaky, having nausea, vomiting or diarrhea. Many of the pain medications used to treat cancer pain are typically used for an extended period of time, and the child's body will undergo the normal process of adapting to these medications over time.

Consequently, a child should not suddenly stop taking any opioid pain medications (morphine, hydromorphone, oxycodone, methadone) that he/she has been taking on a regular basis for more than five days. If it's appropriate to stop one of these medications, the child's doctor will need to gradually lower the dose over time to prevent withdrawal symptoms.

It is important to note that some children may build **tolerance** to a particular pain medication. This means that the dose of the medication that worked before no longer works to relieve the pain. In that case, the dose may need to be increased to get the same amount of pain relief. At times, a different drug may need to be used. This need to increase the dose should not be seen as *drug seeking* or addiction, but rather means that the child's body has developed tolerance for that pain medication and adjustments need to be made.

Fear of addiction to opioids is common among families. Yet opioid medications are important tools that can be used to help assure that a child is comfortable. There is no evidence of an increased risk for drug addiction in children being treated for cancer.

Below are eight common fears about cancer pain, along with the facts that parents should know. Having knowledge will empower parents and children to help overcome the barriers to effective pain management.

Table 2. Fears and Facts about Pain Management in Children with Cancer

Fears	Facts	
Cancer causes severe pain that can't be relieved.	Cancer can cause pain; for some children, the pain can be severe. It is important to know that almost all cancer pain in children CAN be relieved.	
Children who take pain medicine will become addicted.	Addiction is a common concern; it rarely occurs in persons with cancer. Children who need pain medication do not become addicted.	
When a patient uses pain medicine, the body becomes used to its effects, and pretty soon it will not work.	Pain medications like morphine or hydromorphone do not stop working, even if taken for weeks, months, or longer. If the pain increases, the dose of medication can be increased as needed, or other medications can be used.	
Children or their parents might think that if they talk about the pain, they will be perceived as a complainer or weak.	Asking for pain relief is not complaining. Suffering in silence wears the child down and makes the child less able to take part in treatments/daily life.	

Fears	Facts
Talking about the child's pain may distract the doctor from working to cure the cancer.	Talking about pain will help the child's medical team provide the best care for the child and best cancer treatment. Pain gets in the way of sleep, rest, and meaningful activities; all are important to quality of life and the body's ability to fight disease.
It's easier to put up with pain than the side effects that come with pain medications.	Pain medications like morphine can cause side effects; most will go away or can be treated. Constipation is common and can be prevented/ treated. Nausea can be treated and will likely go away in few days. Itchiness can also be treated.
Pain medications will make children feel <i>out of it</i> .	Children may feel <i>drowsy</i> or <i>out of it</i> for a few days after starting pain medications like morphine. With continued use, that feeling will typically go away. If children have been sleep-deprived because of pain, they may have a period of catch-up sleep where they sleep more due to their good pain relief.
If a child's pain is relieved, it may be difficult to know if the cancer is growing or coming back.	Pain is only one symptom of cancer or its treatments. Other tests will assess the child's cancer. Pain treatment will not <i>mask</i> the cancer.

The Impact of Under-Treated Pain

There are multiple physical and psychological effects of undertreated pain that make excellent pain control even more important. If a child is in pain, he or she is more likely to not get out of bed or take part in other daily activities (socializing, reading, playing). Pain interferes with sleep, causing sleep deprivation that over time can slow healing and increase the risk of mood or cognitive issues. Uncontrolled pain causes slowing of normal intestinal function which can cause nausea, constipation or diarrhea. It can be hard for a child with pain to take deep breaths, which puts the child at risk for pneumonia. Overall, undertreated pain delays the time it takes a child to bounce back after a surgery or a round

of chemotherapy.

Children who experience weeks to months of uncontrolled pain are at risk for developing *pain hypersensitivity*. This is a condition in which the child's nervous system becomes highly reactive and what would be slightly painful triggers are felt as more severe pain. At times even light touch or bed sheets can cause pain in people with severe pain hypersensitivity.

There are psychological impacts on children who experience long or frequent episodes of uncontrolled pain. These children feel anxious, and some develop phobias of medical personnel or common procedures. Over time, children with uncontrolled pain are at risk for developing feelings of hopelessness and depression. These children can also become angry and mistrust their medical providers, or even their parents.

Unfortunately, some of the psychological and physical impacts of undertreated pain are not well understood by some medical personnel. Yet these facts should motivate parents and everyone else involved in a child's care to make excellent pain control a top priority.

How Will I Know If My Child Is In Pain?

Pain, like other any other sensation (sight or taste) is a subjective experience. Two children can have the exact same surgery or receive the same type of radiation, yet the level of pain they experience afterwards can be very different. So the medical team needs to learn how to understand a child's pain so that they can respond quickly and appropriately.

Furthermore, children of different ages understand and respond to pain differently. A child's ability to express how much pain they have is also influenced by his/her intellectual and emotional development. Table 3 provides some clues to the child's pain responses, depending upon age. It is important to note that any developmental delays a child may have could mean his or her responses will differ from those shown below.

Table 3. How Children Understand and Respond to Pain by Age

Age	Response
0-6 months	While child does not have understanding of pain, memory for pain is likely.

Age	Response
	 May show pain by kicking, movement of legs or arms, crying, grimacing. Persistent pain may cause the infant to appear withdrawn and avoid eye contact. Pain is measured by medical staff using a child's behaviors (also for older children who don't express themselves).
6-18 months	• Is fearful of past situations that were painful. Uses words like <i>owie</i> , <i>ouchie</i> , or <i>boo-boo</i> to describe pain.
18-24 months	• Uses the word <i>hurt</i> to describe pain. Child tries to avoid situations that hurt them in the past. Will seek hugs, kisses, medicine to help cope with pain.
2-5 years	• Can describe the level of pain (no pain, a little pain, lots of pain). Pain is measured using a tool with pictures of faces that show different levels of pain. Able to use distraction and play to relieve pain.
5-7 years	Can more clearly describe levels of pain. Can use coping techniques to distract self from pain.
8 years and older	• Pain can be measured using a numeric scale from 0-10, where 0 is no pain and 10 is the worst pain possible. Child can understand what is causing pain and why.

Parents may ask themselves, "What do I need to tell my child's doctors and nurses about my child's pain?" Many times, healthcare providers will directly ask a verbal child about his or her pain; however, parents' report of their child's pain adds important information. Children who are not feeling well may not talk about their pain, fearing that they may receive medications, shots or treatments that may cause further pain or discomfort. The child should be encouraged to share his or her pain experiences with the nurses and doctors. It is important to include how severe the pain is at the time. If the child is unable to speak, either due to age or other conditions (and so cannot rate his/her pain), then the parents and nurses can use a scale based on the child's behavior and movements.

The description of a child's pain will help guide the child's doctors and nurses on how best to relieve it. Parents should not worry that they are giving too much information. When it comes to a child's pain, the more details the better. This information helps the medical team develop the best plan to optimize the child's pain control.

Table 4. Questions to Help Understand A Child's Pain

Descriptor	Is the pain sharp, stabbing, dull, burning, tingling, cramping, aching, squeezing, pressure, electric shock, or shooting?
Location and Radiation	Where does the pain start and spread to?
Intensity	How severe is the pain? Depending on age and developmental stage of the child, he/she may be able to rate his/her pain with the use of scales (using either pictures or numbers).
Duration and Constancy	Is the pain steady or does it come and go?
Frequency	How often does the pain occur? Does it wake the child up at night?
Factors that Worsen or Relieve Pain	Is there anything that makes the pain better or worse? Does it change with position, movement, or other activities (e.g., eating, going to the bathroom)? Are there any changes happening with the child that seem to come before the pain? Do certain activities help reduce the child's pain, such as drawing, coloring, arts & crafts, music, reading?

Medications For Pain Management

There are multiple cancer pain management guidelines; all of them are based on the World Health Organization's (WHO) guidelines for pediatric cancer pain relief. Originally developed about 20 years ago, the guidelines were updated in 2012 to more accurately reflect the current knowledge and options in pain management.

Applying the WHO guidelines of pain management includes three important strategies: (1) by the clock, (2) by the appropriate route, and (3) by the child.

- (1) **By the clock** encourages around the clock or regular scheduling of pain medications to allow for steady blood concentrations. Around the clock scheduling of medications will allow the child to have consistent pain relief, while also minimizing the need for larger does of medicines that may be necessary to get severe bouts of pain under control. The child may still require additional doses of medication if he/she has pain that **breaks through** the scheduled doses. For example, if a child has mouth pain from chemotherapy-induced mucositis, an opioid will be scheduled either around the clock or through continuous infusion via a pain pump (PCA-patient controlled analgesia). If a child has **breakthrough pain** with eating or swallowing, then an extra as needed (known by the latin initials PRN) opioid dose can be given prior to or during meals.
- (2) **By the appropriate route** requires that children should take medications by the least painful and safest route possible. For example, taking medicines by mouth (PO) is the safest and easiest route in most circumstances, as it can be done without any painful *pokes* and can be done at home without special equipment.

If a child has trouble swallowing, is vomiting, or has some other problem with his/her digestive system, other methods of taking pain medications can be used. Typically in healthcare settings, medications can be given through a vein (through an intravenous catheter, like a peripheral IV or central line such as Broviac, or Portacath), or through the skin (via subcutaneous injections in areas of fat tissue on the skin) and into muscles (*intramuscular* injections through the muscle such as the thigh, buttock, or arms). In children with cancer, intramuscular medications are generally avoided because the injections themselves can be painful and also may be harmful to a child at risk for bleeding due to abnormal platelet cell counts. In some circumstances IV and subcutaneous medications can be used at home.

Other ways of taking pain medications besides by mouth include by the skin

(transdermal via patches applied to the skin) or with medications that dissolve and are absorbed directly through the tissues of the mouth (under the tongue) or rectum (*transmucosal*, for example as *orally disintegrating tablets*). Children with low white counts should generally not be given medications by rectum. Transdermal patches can be a good method of giving opioids for chronic, stable cancer pain, but is not recommended if a child has unstable pain, as it takes time to either increase or decrease the amount of medication the child receives.

(3) By the child refers to the need to have individualized treatment plans for pain management according to the needs of the child. Managing a child's pain involves accurate assessment of the child's needs. Although there are recommended dosages on all the opioids, a child may need more or less medication than the *standard* amount. Providing optimal pain relief, safely and effectively, based on a child's individual needs, is the goal of treatment. Ideally, a child should have a written pain management treatment plan for both hospital and home use, with specific times and instructions for what to do about different levels of pain.

Additionally, the WHO recommends using a *ladder* or tiered approach to the dispensing of pain medications, with less potent medications that can be used for more mild pain on the *lower rungs* or *tiers*, and stronger ones for more severe pain at the top of the ladder.

Table 5. Tiered Approach to Pain Medications

Tier 1: Non-Opioid Medications: For mild pain, inflammation-related pain, or as a way to help avoid the need for higher doses of opioid medicines.

Medication	Notes	Cautions	
Non-Steroidal Anti-Inflammatory Drugs (NSAIDs)	Many types, example: ibuprophen (Advil, Motrin), naprosyn, celebrex. Available PO, except Ketorolac: available IV, for no more than 5 days.	•	Can increase the risk of bleeding Can cause stomach irritation Can cause kidney problems
Acetaminophen (aka Tylenol, paracetamol)	Available PO, PR, IV.	•	At high doses can cause liver damage; may need lower doses (or do not use) if child has liver disease.

Tier 2: Weak Opioids: For moderate pain.

Medication	Notes	Cautions
Tapentadol	PO	
Tramadol	PO	• Should not use with other opiate medications.
Buprenorphine	IM or IV	• Special skills required to prescribe.

Tier 3: Strong Opioids: For severe pain.

Medication	Notes	Cautions
Oxycodone	PO only	For all strong opioid medications: Constipation Itching Sleepiness If given too quickly at too high dose - respiratory depression
Morphine	IV, SC, PO, PR forms	
Hydromorphone	IV or PO	
Fentanyl	IV or by skin patch	
Methadone	IV or PO	

Table 5 Abbreviations PO: by mouth; IV: Intravenous; SC: Subcutaneous; PR: by rectum; IM: Intramuscular

Medications and combinations no longer recommended

While still prescribed by some doctors in some hospitals, pain experts no longer recommend the use of **codeine**. Previously listed in the *weak opioid class*, codeine is now known to be unsafe and ineffective in children; therefore it is not a reliable medication for pain management. Also, medications that combine either acetaminophen or ibuprofen and another medicine like codeine or oxycodone (e.g., Vicodin, Tylenol #3) are generally not recommended, as it can be difficult to be sure the child is not getting too much (or too little) acetaminophen or ibuprofen.

Other medications that can be used for pain management

Most cancer pain can be managed with the use of opioids and other medicines like acetaminophen and ibuprofen. But when these strategies are not enough to relieve a child's pain, the medical team will need to do a careful reassessment, including looking for other factors that can increase pain, like depression, anxiety or spiritual distress. Some children may have unmanageable side effects from using higher doses of opioids, so other treatments may be used to lower the amount of opioids needed.

Table 6. Non-Opioid Medications for Pain Management

Table 0. Holl 0	proru meureacions	101 Tain Management
Treatment	What Is It?	Helpful For
Tricyclic Antide- pressants (e.g., Elavil amitripty- line)	Originally developed as an antidepressant, but at the low doses used for pain is not mood altering.	 Neuropathic pain. Chronic headaches or abdominal pain, not due to cancer.
Corticosteroids (e.g., dexametha- sone)	Anti-inflammatory medications that can reduce inflammation and swelling due to tumor.	 Bone pain due to metastatic bone disease. Neuropathic pain from infiltration or compression of neural structures. Headache due to increased intracranial pressure. Metastatic spinal cord compression, joint or muscle pain.
Alpha-2 agonists (e.g., clonidine)	Originally developed to lower blood pressure, acts directly on the brain and spinal cord to decrease nerve activity that sends pain messages. Can be given by mouth, by skin patch or by IV in certain circumstances.	 Neuropathic pain. Can reduce the body's stress response.

Treatment	What Is It?	Helpful For
Anticonvulsants (e.g., gabapentin, pregabalin)	Originally developed as anti-seizure medications; now recommended as first line treatment for neuropathic pain of various causes.	Neuropathic pain.
N-methyl-D-as- partate (NMDA) receptor antago- nists (e.g., ketamine) Bisphosphonates (e.g., pamidro-	These medications block pain signals going to the brain. Ketamine is also used for sedation and anesthesia. Medications that prevent bone damage.	 Ketamine can be helpful when opioid medications no longer are working or are causing untreatable side effects. Bone pain from tumors. Can decrease risk for
nate)	bone damage.	fractures in weakened bone.
Regional Anesthesia	Local anesthetics to a specific body area to produce pain relief by blocking nerve signals. Nerves may also be permanently blocked by medicines that stop the nerves from working. Medication is delivered by injections or catheters for as needed or continuous infusion. May be effective in cases where oral or IV medications are not working or are causing too many side effects.	 Tumor-related pain not controlled with high doses of opioids. Severe neuropathic pelvic pain, arm or leg pain, for example in metastatic neuroblastoma.

Treatment		What Is It?		Helpful For
Cannabis	•	It produces resin	•	Useful in treating side
(also known as		compounds called		effects of cancer and
marijuana)		cannabinoids.		cancer treatments, such
	•	Some cannabinoids		as pain, nausea and
		have effects on the		vomiting, decreased
		brain, and change		appetite, anxiety, and
		mood or con-		poor sleep.
		sciousness.		
	•	Main active canna-		
		binoid in cannabis		
		is delta-9-THC.		
	•	Cannabinoids		
		may relieve pain		
		and lower inflam-		
		mation without		
		causing the high of		
		delta-9-THC.		
	•	It can be taken by		
		mouth (via liquid		
		tincture or edible		
		forms) or inhaled.		
	•	By federal law, use,		
		sale, possession of		
		cannabis is illegal		
		in much of the		
		USA. Some states		
		& the District of		
		Columbia have		
		laws legalizing		
		the medical use of		
		marijuana.		
	•	Two cannabinoids		
		approved in USA are dronabinol		
		and nabilone.		
		FDA approved		
		for the treatment		
		of chemotherapy-		
		related nausea and		
		vomiting.		
		vomming.		

Non-Medication Pain Management Strategies

Pain affects the child's physical functioning; it also impacts his/her psychological, social and spiritual wellbeing. Frequent hospitalizations, loss of normal life activities like school and play, and lack of sleep, are all common in children being treated for cancer. These changes can lead to fear, isolation, anxiety and depression. Also, these cancer-related changes can at times lead to high levels of family stress and can create conflict in even the most loving families. This stress can affect a parent's relationship with the child, with his/her spouse, and relationships with other children. Worse, these psychological and social factors can in turn increase the child's pain, as his/her ability to cope is pushed to its limits.

Therefore, addressing non-physical issues like emotional states of mind is vital to lessening the impact of pain in the child's life. Occasionally parents are reluctant to treat these psychological issues and say "Just treat my child's pain, and he won't be anxious." Yet at times the anxiety itself is a major factor increasing the pain. Complete pain relief will not be possible without addressing the anxiety.

There are multiple interventions that can be used that will engage the child's mind and spirit to help ease pain and also help the child cope with his/her illness.

- Seeing a therapist for talk therapy for signs of anxiety, depression, posttraumatic stress disorder. Providers may be psychologists, social workers or other therapists.
- Addressing sleep deprivation (for example, setting a regular daily schedule, getting gentle exercise).
- Keeping the child's mind engaged in pleasant activities, such as socializing
 with friends and family (either in person or virtually) and/or other activities
 like playing games, and watching movies.
- Using humor, hugging and touching the child to comfort.

For some children, complementary and alternative (CAM) therapies may provide added pain relief when used with medications, potentially reducing the amount of medication needed for good pain control. Parents of children with cancer might pursue an alternative therapy if conventional therapy has not worked in achieving good pain control. CAM may improve a child's quality of life by relieving physical symptoms and side effects from cancer and cancer treatments and may uplift his/her spirit and mood.

CAM therapies may be outside the practices of many conventional physicians.

But their benefits are increasingly recognized in the scientific community through ongoing research. However, for some common therapies there is little research to prove effectiveness. Most doctors would not have an issue with trying one, even without scientific evidence that it works, as long as the CAM treatment does not interfere with the medical treatments a child is receiving, or otherwise have the potential for physical or psychological harm. For example, herbal alternative treatments or supplements could interact with certain cancer medications or even pose an infection risk. Intense physical manipulations or massage could be harmful if a child has areas of weakened bones or muscles. It is best to discuss any CAM treatments with a child's oncologist to be sure they are safe given the child's medical issues and treatments.

Table 7. Complementary and Alternative Medicine (CAM) Treatments for Cancer Pain

CAM Therapy	Description	
Hypnotherapy/ Guided Imagery	Helping the child to imagine being somewhere else or disconnected from the current experience; this can involve induction strategies to help narrow the focus of child's attention, deepening strategies to enhance the narrowed focus, helping the child go to a favorite place where the child can feel safe and comfortable, and then enhancing the dissociation with a variety of strategies, including pain switches, magic glove, central pain control station, etc. Post-hypnotic suggestions can be given for enhanced entry into and maintenance of a hypnotic state as needed.	
Acupuncture	The use of needles or pressure (acupressure) at key points along meridians or energy lines to enhance the flow of energy or Qi (pronounced chee).	
Massage/ Craniosacral Therapy	Bodily tactile manipulation of soft tissues with differing degrees of pressure, depending upon the type of massage.	
Meditation/ Mindful Awareness	The focus on the present, often with the help of a focus on the breath as the mind wanders to other thoughts and feelings; loving kindness meditation involves feelings of connection and well-wishes for safety, health, happiness, and living in peace for self and others. Meditation practice can help promote a feeling of relaxation that is achievable even in stressful times, and can help to promote positive feelings (such as a sense of compassion for self and others).	

CAM Therapy	Description
Iyengar Yoga	A form of yoga developed by BKS Iyengar in Puna, India, in which a selection of bodily poses (asanas) are held with the assistance of props, such as blocks, blankets, bolsters, and straps, to achieve bodily, emotional and spiritual balance. The training in this form of yoga is vigorous and studies have shown its benefits for people with chronic health conditions, especially chronic pain. Pranayama, or yogic breathing, comes later after learning and practicing specific poses in this form of yoga.
Art/Music/ Dance Therapy	The expression of emotions and thoughts through art, directed by a therapist with training in the psychodynamic understanding of human behavior and how to help children use the art medium for psychotherapeutic benefit. This form of therapy is especially useful for children who are non-verbal or have difficulty with direct verbal communication. Could be done as part of a group (e.g., drumming circles) or as an individual (instruments or voice).
Pet Therapy	The tactile sensation and connection made with specially trained animals and their trainers has been especially useful in hospital settings and in situations where children are socially isolated.
Biofeedback	The use of computers or other forms of provision of feedback on biological systems, such as muscle tension, breathing, heart rate, or skin temperature, with training in how to alter these systems to achieve a more relaxed state. Imagery and breathing techniques are often taught with the visual or other sensory feedback providing reinforcement of accomplishment.
Aroma Therapy	The use of different aromas to achieve a calming state, such as the use of lavender. For children who have developed conditioned anxiety to medical procedures or chemotherapy, pairing of calming interventions together with new aromas (e.g., oranges) can help such children to condition in a positive way to the new aroma.

CAM Therapy	Description
Reiki Energy Therapy	The balancing of energy fields around and within the body by Reiki masters who are trained to assess and
	alter the flow of such energy.

Table adapted from Zeltzer LK & Krane EJ. Pediatric Pain Management. In Kliegman RM, Behrman RE, Stanton BF, Schor N, and St. Geme J (Eds), Nelson's Textbook of Pediatrics, 19th ed. London: Elsevier, 2011: 360-375.

Putting It All Together: A Team Approach To Managing Pain

Since the child's experience of pain is influenced by so many different things (including psychological, social, spiritual, cognitive and developmental factors), it often takes many people to work on the child's pain control. Nurses, doctors, child life specialists, physical therapists, social workers and nursing assistants all play distinct roles in a child's pain management plan. The individuals that make up a child's multidisciplinary care team can share observations with the child's oncology team. This shared information will help the child's oncologists develop an individualized pain management plan for the child. For example, a child life specialist might note that a child becomes anxious when certain medical terms are used, which in turn increases his/her reports of pain. This information can be shared with the child's oncologists, and as part of the child's pain plan, words that cause anxiety can be avoided. As another example, a nursing assistant might observe that warm baths and warm packs are helpful in relieving a child's pain or discomfort. Ultimately, the goal of the team approach in managing the child's pain is optimal comfort and pain control.

The child's oncology team can also consult with pain and/or palliative care specialists when they need additional help managing difficult to control pain. Pediatric pain teams are typically made up of specialists in anesthesia. Palliative care physicians can address multiple symptoms in addition to pain, as they work to improve quality of life for children with serious illnesses such as cancer. All of these specialists can work with a child's oncology team to optimize the alleviation of distressing symptoms.

If a child has frequent pain, or is about to undergo a treatment that is known to cause pain (like a surgery or certain chemotherapies), the parent should work with the child's healthcare providers to have a pain management plan that is individualized for the child's unique needs and strengths. This could be used both at home and in the hospital. Writing this plan down can be a helpful reminder to parents or other caregivers who may not know the child well.

Table 8. Example of One Pain Management Plan

Medications	 For mild pain: acetaminophen 325 mg. every 6 hours as needed. For moderate pain: oxycodone 5 mg. every 4 hours as needed. For severe pain: morphine 2.5 mg. IV every 4 hours as needed.
Keep a daily routine in the hospital	• Up and in chair with shade up by 8 a.m.; in bed to sleep by 9:30 p.m.
Deal with anxiety about radiation	Talk with psychologist every other day; go to radiation treatments with child life staff.
Fun activities	Watch DVDs of favorite show;Call or text best friend;Make bracelets with kit.

The Special Role of Parents

Next to the child, parents are the most important experts in the child's pain management. The parents' involvement is important in helping the child's medical team understand and appropriately treat the child's pain. It is hoped that the information in this chapter will help parents to be a more effective voice for their children.

Children with cancer need their parents to advocate for their ongoing pain control. If a parent is not getting a satisfactory response from the first provider he/she speaks with, then it is that parent's job to be the *squeaky wheel* and to go 5-steps up the chain of command.

- 1. First, the parent should call the bedside nurse for help.
- 2. The parent can also ask to speak with a doctor directly. A junior member of the physician team (especially at an academic medical center) may first be called.
- 3. If the bedside nurse is not able to address the parent's concerns, the parent can speak with the Nurse Manager for the unit.
- 4. Likewise, if the first physician called to assist the child is not able to help,

it is appropriate to ask to speak with a more senior member of the medical team (usually a fellow, or ultimately, an attending physician).

5. The parent may request that experts in pain and symptom management (the pain or palliative care teams) be called to help the child.

Pediatric oncology teams want their patients to be as pain-free as possible. Parents can help to accomplish this. Keeping an open mind as to the type of intervention that may help the child is most beneficial; the child might need different types of medication or need treatment for related depression or anxiety symptoms.

Table 9. The Special Role of Parents in Healing

- 1. Parents recognize when the child is in pain. They know which medications have worked best for the child. They can also help the team recognize any factors that might be contributing to the child's pain experience (e.g., anxiety, insomnia).
- 2. Parents know their own child's pain threshold and can report changes in pain more quickly than any one else.
- 3. Parents have a special ability to distract the child from pain with comforts no one else can provide.
- Engaging in activities that brought the child joy during good times.
- Simple things: making the child laugh, talking with the child, holding the child, watching movies or listening to music.
- 4. The parents' fears and anxiety can influence the child's pain experience.
- Parents should take the child's lead in responding to his/her pain and try
 not to call extra attention to the pain. Frequently asking the child if he/she
 has pain can (unintentionally) serve to heighten the pain experience.
- Parents should try to get enough rest, take breaks if needed, seek support from friends, families or professionals who can help during the difficult times.
- 5. Children may fear reporting that they have pain as they think the treatment will hurt more or delay their going home.
- Other times children want to seem brave or like a big boy especially if they have been encouraged to do so in the past.
- Without babying the child, parents can encourage him/her to be honest about what he/she is feeling and reassure him/her that keeping pain under control is best for the mind and body.

Uncontrolled or inadequately relieved cancer pain has a profound impact on a child's quality of life. The burden of pain is not only evident through suffering, but also through impaired physical abilities, decreased activity and changes in a

child's sense of identity. A child's pain can also increase the suffering of parents, caregivers and other family members. As the child's advocate, the parent's ongoing involvement in the child's journey is crucial in helping the child's team of healthcare professionals develop the best possible plan to optimize the child's overall well-being.

Family Perspectives

Because Julia had a recurrence after 2 resections, radiation and the first round of chemo, when she went in for her 3rd resection, the skin at the incision point was very compromised. Her incision wouldn't heal, so she went for about 14 months with a small whole on the side of her head that I cared for and patched daily. I used a product called MediHoney to try and help it heal, but with the lack of blood flow, it mainly kept it infection free, which amazed everyone.

During treatment Julia had nausea and vomiting. If she vomited too hard, it would pull her incision open, so, working with the nurses, we came up with a combination of nausea meds that would keep her from vomiting. Having the dog with us was her best pain management. If she didn't feel good, she would call the dog (Pumpkin), Pumpkin would lick her face, and Julia would feel better.

During treatment she was in pain but nothing like what she's dealt with after treatment. After the 14 months of patching her head, they finally did a skin graft to close the incision. She spent almost two weeks in the hospital after surgery. The pain was unbearable, and it took some heavy duty drugs, and a lot of understanding on our part, to manage it.

Julia has had more pain now that she's out of treatment than when she was in treatment. Her back started hurting her bad enough that she was crying herself to sleep, so they did a spinal MRI to make sure the cancer didn't spread. The physician ordered physical therapy, and she is starting to have some relief. (Her body muscle structure was out of whack from being so immobile during treatment.) Next her stomach started hurting about 3 weeks before the end of school and continued for a few weeks after, so the doctor started Julia on a new stomach coat med that seems to be working.

Our new catch phrase is "No More Pain." If Julia has pain, we hunt for the reason and do whatever it takes to stop it.



My son, Jude, is 2 years old and currently going through treatment for high risk ALL. One issue that we've had is not being reminded by our providers about the pain different chemos can cause. Since Jude does not have the verbal skills to tell us when he is in pain, the only way we know he is experiencing

pain is when he becomes extremely agitated. Unfortunately, it initially took us a while (several days) to realize that the agitation was caused by pain; then we treated it with oxycodone. I wish we had known more, sooner, about the pain that chemo can cause, and also that sometimes children who don't have the verbal skills to talk about pain show it in different ways.



Andrew experienced some pain due to complications of treatment and was on morphine and dilaudid. Part of the plan to get him home was to switch him from IV to oral pain medications. We tried medical marijuana for a short time while working on this; while it helped us to decrease the dosages of his pain medications, it also flattened his personality. We did not realize how much the medical marijuana affected him until our weekend nurse came in after being away for 5 days and could see the difference. We dropped the morning dosage (of marijuana) to see if that would be a good compromise—a way to help us to continue to decrease the other pain meds while also allowing us to enjoy Andrew's bubbly personality. We eventually dropped the marijuana completely because we did not like the difference we saw in our son. It's my understanding that this really varies from child to child; I'm aware of situations in which marijuana was used with positive results.



Parents should listen to their children when they say they are in pain. Pain is subjective and we cannot feel what they are experiencing. It depends on the child's age, but as soon as they are able to comprehend what is going on, the child should be included in all decision making. I believe this gives them a sense of control and helps them not to be as scared of what is happening to them.



Pain management has been the most difficult element of my son's cancer treatment. His pain is variable and inconsistent. Since treatment began, he has experienced pain differently—it is more severe and more intense. It is very difficult to find a balance between medication and life-style changes that will allow him to have the best quality of life. There are very few pediatric pain specialists, and even fewer pain specialists in pediatric oncology. My husband and I had to figure out what causes my son's pain so that we can advocate for correct treatment to his oncology team. We sought opinions from pain specialists,

neurologists and orthopedists in other cities in order to better understand the nature of his pain. We had to learn about different types of pain medication so we could understand when to give him "as needed" meds. We learned about which types of physical activities are likely to trigger pain (even if it is not experienced for a few hours after the activity) and we chose to minimize those activities. We learned how to coach him in relaxation techniques such as visualization and deep breathing so that he can help himself to deal with pain. Most frustrating of all is that we had to learn these things by listening in on his sessions with specialists. There is no handbook for parents of children who are in pain.



More is not always better. In fact, the predicted "right" amount might not be the right amount at all.

After his osteosarcoma diagnosis at age 11, my son spent a lot of time in the hospital, both for treatments, as well as various surgeries. Partway through the chemo part of the treatment, my son had his 4th surgery, this time a thoracotomy, which required a chest tube. His post-op pain medication was prescribed based on his weight. (He has always been a big kid, and was one of the few who didn't lose weight during chemo, but actually kept putting it on at a similar rate as he had been before.) As he started to experience pain, the nurses gave him the prescribed pain medication in the amount listed, but rather than lessen the pain, it actually caused him to scream incessantly and writhe in obvious pain. The staff was shaken, and each additional person brought in had their own theory about what was going on. As parents, all we knew was that the staff looked worried, and our son on pain meds was clearly in horrible pain. In fact, he'd had limb salvage surgery just a few months before, and we had never had that kind of problem controlling his pain.

After the worst hour of my life, where nothing seemed to help, things finally started to calm down, and over the course of the night, his pain level was under control. We kept fastidious records of all that had gone on, and were able to talk with doctors after the fact, to look for patterns and figure out how to keep that from happening again. What we determined was that our son was prescribed a certain amount of pain med based on his weight. What really worked for him was about HALF that amount! He was very sensitive to pain meds, but we had no idea. We don't know the exact reason for this, but one suggestion is that our son wants as much control over things as he can have, and the amount of pain meds they first gave him caused him to feel out of control. Whether that meant

he normally had been somehow doing his own biofeedback and that amount of medicine removed that ability, or whether there was some anxiety or additional hallucinations or other problems, we may never know.

We were confident that over-medication had been the culprit and we were determined to never make that mistake again. We felt that whatever the "by weight" charts said for our son, the amount should be half that. Still it made doctors nervous to prescribe less than what they thought would be required (again, based on weight), so over the coming months and through many other surgeries, what we did was have the doctor write a range of dosage for the pain meds. For example, the top end of the range would be whatever the doctor would think would be needed based on weight. The lower end of the range would be half that amount. Then we kept a close eye on things and specified that we always want them to start with the lower end of the range, and only increase it if needed. We have also had this discussion with all pre-op anesthesiologist meetings we've had for subsequent operations.

This has worked so well that even when our son had to have the same surgery as the awful one (a year later), he came through it almost easily, with some small pain, but nothing even close to that horrible day the year before we learned his correct dosage.



Shortly before we thought we would be leaving the hospital after a lengthy stay, our son's medical team consulted the pharmacy about weaning him off methadone. We followed the plan carefully—looking forward to going home without the drug as part of his medication regimen. The day before we planned to leave the hospital, we had a special southern meal with the PICU staff. Unfortunately, our son was so uncomfortable that he could not eat—even though he had been looking forward to that meal very much. He was restless and seemed agitated. One of his physicians realized that he was suffering from symptoms of withdrawal; his body had become dependent on the methadone, and we had tried to wean him too quickly. She quickly got him back on the medication, and his symptoms disappeared.



So many of us become "experts" in our child's care that sometimes providers forget that we still need guidance at times. I think the assumption we were educated parents, and we would ask for what was necessary, prevented Mason

from getting some of the palliative care he needed. This can especially be a problem if your child is not one to show pain easily or is very active despite the prognosis. I think they waited until we would ask instead of really sitting us down and mapping out what we needed to think about to control our son's pain in the final months. Ask for a road map or a guide of when you should ask for help; create a process for continuous conversation about your child's pain management. It should always be a part of every visit, even at the beginning of treatment, but especially at the end. If there is one thing I think my husband and I regret in what we did for Mason, it's that we did not treat his pain enough.

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I found hospice did not adequately prepare me or aid me in making sure my son's pain needs were met. I say this only to help others find someone who is helpful, possibly not emotionally attached to the family, who can guide through the final weeks of life.

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On April 24, 2013, Talia went into the hospital complaining of back and chest pain. She was placed on an IV morphine pump the day after she was admitted. I had no idea what a palliative doctor was all about, but I quickly found out that he was the best thing since sliced bread. Talia remained on a morphine pump for many days. The palliative doctor came in every day and spoke with Talia and asked her about her pain. The doctor always listened to her and increased her morphine when she asked. Talia's pain became increasingly worse as the days went by. The palliative doctor switched her to dilaudid.

Talia was complaining a lot about her back and hip hurting. The palliative doctor knew that Talia had months to live and that he needed to find a long term drug to keep her comfortable. So Talia started methadone. As the days went on and turned to months, the palliative doctor would come and talk to Talia. He listened to her tell him where it hurt and how bad it hurt. She would tell him that she needed her pain medicine increased and he would listen. The doctor said that Talia was getting what she needed and that if she didn't need it, she would not be able to function. By now, she was taking methadone, dilaudid, Ativan and anti-nausea medications. But it wasn't enough to control her pain.

Talia started radiation on her right hip and neck to alleviate some of her pain. It helped; then radiation was needed on her other hip. Along with all the pain medication, Talia also wore lidocaine patches on the areas that hurt the most:

her back, hip and head. It was nearly a month after Talia had been admitted, and the pain was getting worse. Every day the palliative doctor would come and talk with Talia, and they would go over her medications, dosages and how she was feeling. The doctor felt it would be good to start Fentanyl IV. Talia stayed on that for a while and then went back to morphine. The doctor was always trying to find the right drug to keep her comfortable.



Our 9-year-old daughter kept complaining of pain, and it could not be explained during her final months, though we suspected it was tumor related pain. Her pain started in her right knee, and while at the hospital she was initially treated with heat packs and local pain patches, which never seemed to provide relief. Her pain became more intense in her right knee, and later showed up in her right elbow, and eventually her right cheek with numbness/tingling, which really concerned her. Pain management progressed to low doses of morphine, which was difficult for me, because morphine is associated with end of life and losing the battle against cancer. I wondered how pain medication affected my daughter's perception and final days. My father, a retired doctor, explained that, while hard, providing pain medication was the humane thing to do.



I often wonder if he was in more pain than he let me know. Jed loved me enough to keep his pain to himself and I often wonder if he would have been more vocal had I not been so weak. I would ask him if he was sore and he would muster up a smile and say no. I let Jed lay on my chest during those last days and I would feel his body tense up or relax. During those tense moments I would request pain medication to be delivered to me and I would drip it into his mouth. I would then let him rest his head on my chest and wait to see if he would relax again.



We knew we were losing him but he really remained pretty functional until a month before his death. My husband and I both believe we under-medicated his pain because he was so active. We think he did not want to be held back by what he was feeling so he did not show us. I also had this thing about morphine—if I gave him morphine, death was not far behind. My own hang-ups about my son dying prevented him from getting the pain relief he deserved.

I have to admit that when we were handed off to the pain and symptom management team, we were in denial. We thought that it was premature and that our child was going to come out of this. More often than not, when the disease has reached the point of requiring intense pain and symptom management, it's nearing the end of the journey. Parents do not always want to believe it is true. We were those parents. We trusted the doctors, but with heavy hesitation. As parents we sometimes try to avoid too much pain medication for fear that it may prevent our children from fully communicating and participating in every day life and conversation. We want them to be fully coherent to laugh and speak to us as though everything is normal; we don't always realize that this is the end and that we must ensure our children are pain free in those last precious days. I am extremely grateful for the team of doctors that took care of our daughter while she was dying. It is only after the fact that I realize they were doing the right thing and that my reluctance to having them prescribe full pain medication was only making her suffer.



Andrew seemed restless for a good part of the day that Tuesday. I remember feeling relieved when the rest of the family arrived. Wednesday morning he continued to seem restless. We offered pain medications repeatedly, but he refused them. While my husband and I were having a conversation with a trusted physician about end of life pain management, Andrew clearly became painful. The physician quickly intervened with a very low dose continuous Fentanyl drip, providing relief almost immediately. Our son fell asleep that afternoon and slept for the next day and a half before he took his final breath at 1:00 am on Friday, December 4, 2009.

Communication

Lori Wiener, PhD Barbara Sourkes, PhD

There are no adequate words to describe the overwhelming shock that parents experience when they learn their child's life is in jeopardy. It takes time to absorb all the information presented. Depending on a child's cognitive and emotional development, as well as parental preferences, the child may or may not be included in the initial discussion. When the child is not present, one of the greatest challenges that parents face is deciding what to tell their child.

Commonly Asked Questions

- What words should I use?
- How much should I tell my child?
- What about my other children?
- How can I tell my child that he or she has cancer without falling apart myself?

How to Talk to the Child with Cancer

Diagnosis

Ideally, when a diagnosis of cancer is confirmed, parents should present the information to their child as calmly and as honestly as possible. Euphemisms and other attempts to protect their child (and themselves) from the harsh realities of the diagnosis and the illness are not helpful. An honest approach paves the way for more open communication within the family, increases the likelihood of cooperation

with what needs to take place medically, and decreases the chance that the child senses that secrets are being held. Family stress can also be better managed once the child understands and accepts the diagnosis. Yet, every child has a different style of coping with stress and of

Dr. Lori Wiener is Co-Director of the Behavioral Science Core and Head of the Pediatric Psychosocial Support and Research Program in the Pediatric Oncology Branch of the National Cancer Institute. processing new information. When considering how much information to share or how much the child will understand, it is helpful to think about the child's age and development as well as how the child has coped with other stressful events in his or her life. This knowledge can help parents tailor the words to explain cancer to their child's specific needs and style of coping.

Parents from certain cultural backgrounds may not be comfortable with such candor with their children. It is important that parents communicate to the team how much disclosure they feel comfortable with and ask that their wishes be respected. For example, parents may not wish to tell the child the diagnosis. One compromise is that the team agrees to the parents' wishes unless the child asks a question of them directly. Most professionals feel that they must answer the child honestly, in order to maintain trust in their relationship. However, parents should be included in the discussion of how their child best hears and responds to information.

Age appropriate communication

Most children, even young children, can understand complex situations including the knowledge that they have a serious illness. The research shows that being honest with children, starting at the time of diagnosis, helps them cope better and leaves less possibility of them imagining situations that are even more frightening than the truth. A general guideline is to follow the child's lead because children question facts or implications only when they are ready to hear the answers. Proceeding step-by-step allows children to determine how much they want to hear. Offering less information and then asking whether they want to know more provides a safety gauge of control for the child.

Communication with children under the age of five needs to be simple, direct, clear and delivered in small measures. "We are going to the hospital to get medicine to help you feel better. Mommy and Daddy will be with you." This type of statement addresses a young child's concern about what will happen and who will be with him or her for protection.

Young children are very aware of physical and emotional changes in their environment, especially separation from home or their parent(s). Accordingly, parents should try to create a familiar homelike environment in the hospital or clinic. This

can include bringing the child's favorite toys, books, music and blanket. Children also sense when their parents are upset and may respond by becoming more clingy or irritable. Older children may keep their questions and emotions to themselves, in order to protect

Barbara Sourkes is a Clinical Psychologist and Director of the Palliative Care Program at Lucile Packard Children's Hospital, Stanford. their parents from further distress. It is important that parents have someone (either in their personal life or professionally), with whom they feel comfortable, to share their fears and anxieties. The calmer the parents, the calmer the child will become.

With cognitive and emotional development, specific words, such as cancer or leukemia, are important to use, as the child will be hearing these words from their medical providers and other patients and families in the hospital environment. Parents should be encouraged to use language that is both familiar and meaningful including references to stories, metaphors, or past experiences unique to the child. It is also very important that the child is provided opportunities to ask questions and that the child knows it is okay to ask questions at any time. Children this age are often concerned that they may have done something wrong to cause their illness. It is critical that such myths are dispelled early, perhaps with the assistance of the medical team.

Establishing a positive collaborative relationship between the medical team and the child is very important. This includes honesty in discussing how treatments will affect the child's body and lifestyle. It is important to help the child find strategies to cope with needle sticks, chemotherapy, radiation, and/or surgery. Child life therapists and social workers have wonderful tools to help children adapt to new or difficult treatments and invasive procedures.

Will I die?

As children gain experience in the medical system, and particularly if they experience any traumatizing events, it is not uncommon for them to ask whether they could die from their cancer. A natural tendency is to respond with a one word "No!" or quick reassurance that closes the door to communication. No matter how painful this question is, it is important that parents find a way to answer honestly. Children need to know that their parents can be trusted to tell the truth. It is strongly recommended that parents plan in advance how they might answer this question if asked. When children do ask if they could die from their cancer, it is important to ascertain why this question is being asked at this particular moment. For example, is the child asking if he will die from his cancer soon? When he is old? Does the child have a current serious infection that can be life threatening? Is the child experiencing significant pain or physical or emotional discomfort at that moment? Has the child recently learned of the death of another child with a similar cancer? Words such as, "Thank you for feeling comfortable enough to ask this question. Can you tell me more about why you are asking this now?" can help to clarify what prompted the child's current anxiety and can allow parents to fully address their child's immediate concern. No matter the reason or timing of the question, a parents' response should always use comforting language, while acknowledging that sometimes children die

of their illness. Once this information has been shared, the child's reaction should be observed. Has eye contact changed? Does the child become fidgety, run out of the room or ask his or her parents to stop talking? These signs will let parents know how anxiety-provoking the topic of death is for their child at that time. Letting the child know that he or she can always go to a parent, or to someone else whom they trust about their worries, can provide great comfort. Children, like adults, choose when and to whom they will reveal themselves. It is vitally important that parents pave a road for the child to communicate with someone, whenever he or she is ready.

Communicating with teens

Adolescence is a time of significant emotional and developmental change, when young individuals move toward gaining independence, formulating their self-identities, strengthening peer and romantic relationships, and begin to define their future roles in life. Being diagnosed with a potentially life-threatening illness at this time can challenge healthy adolescent development. Independence from parents or guardians is compromised, prolonged hospitalizations interfere with school and social interactions, sleeping and eating patterns are disrupted, and medical illness and ensuing treatment can cause many physical and emotional changes. Communication about the diagnosis and treatment needs to be straightforward and should include full medical explanations as the adolescent indicates he or she wants. This includes the treatment regimen and potential side effects. Many teens want to be involved in consent meetings so they can ask their questions directly to their primary treatment team.

Emotions such as sadness, anxiety, fear, and anger are anticipated, but can become problematic when they interfere with a teen's ability to sleep, eat, and enjoy friendships or activities. When these symptoms are present, consultation with a mental health professional is indicated. If a teen becomes non-compliant with taking medications, the medical team must be consulted immediately. For some adolescents, psychotherapy provides a safe context in which to express their fears and grief. Others are more comfortable with expressive therapies (i.e., art, music) and appreciate the opportunity to use writing techniques, such as personal narrative, poetry, music (song) or a combination approach.

During Treatment

Throughout treatment, children begin to obtain a deeper grasp of what it means to have cancer. The child's awareness of the life-threatening implications of the illness can be conceptualized along a continuum. At one end, children acknowledge being "very sick" or having a "bad disease;" however, they do not talk about dying from the illness. In the middle, the child expresses some

awareness that his or her life might be in jeopardy—an uncertainty about living—but still without a focus on death. At the far end of the continuum, the child is explicit in acknowledging that he or she could die of the illness. A child's awareness is gleaned from many sources: his or her own "wisdom of the body," knowledge of the illness; the urgency and intensity of treatment; the emotions of family and caregivers, and their encounters with other patients. Yet, even these children will fluctuate with talking about death one moment and future plans the next. This is the way they can continue to function in the world.

Communication during this time should hold the same tenets of honest, direct interactions tailored to the child's chronological age and emotional development. The child will benefit greatly from a feeling of security and trust that is only maintained when communication remains open and honest.

If Cure is Not Possible

Children generally have two main questions. The first is, "Am I going to die?" When the answer is understood to be yes, the second question is, "When?" Telling the child that cure is no longer a possibility is the most difficult message to convey. Parents find it helpful to redirect the focus from hope for a cure to hope for comfort and fulfilling other wishes. Comfort includes effective symptom management, freedom from further diagnostic or treatment procedures and being with people whom they love. Adolescents often want to be assured that they will not be restricted from being with friends. Regardless of age, all children need repeated reassurances that they will not be alone. Providing comfort also involves acknowledgment and acceptance of a range of feelings (e.g., sadness, fear, anger, confusion) that accompany progressive illness. Children should be told that parents and professionals will help them to relieve their anxiety and fears. To the extent possible, children should be encouraged to participate in normal daily routines, including attendance at school (even if part-time) and involvement in social, family and community functions. Preserving familiar behaviors and schedules also serves to minimize feelings of anxiety that accompany uncertainty.

Once discussion regarding death is initiated, children often begin to ask specific questions.

- What will death be like? Will it be painful?
- What will happen to me after I die?
- Is my cancer a punishment for "bad things" I have done or thought?

- Did I do something wrong that caused the treatment to fail?
- Will my family be okay after I die?

It is helpful for parents to be prepared for such questions so that, if asked, they know how they want to respond. The family's beliefs regarding end of life and an afterlife will likely guide the discussions and help with the language used with the child. This is a time that many parents find their faith is either reinforced or challenged. Clergy can often provide strength, clarity, and comfort to parents, their dying child, and their healthy siblings.

Some children directly acknowledge that they are dying; others keep their thoughts about death to themselves. Some children communicate awareness of their approaching death indirectly, through play, art, and/or writing. For example, the child may begin to draw angels, to ask questions about deceased family members, to talk about being very, very tired or about no longer needing things they own. These behaviors inform us that they are thinking about their future and what may be next. Developmental age, maturity, personality, family dynamics and culture and life experiences (especially regarding loss) are all factors in their openness. It is not uncommon for a child to fear that discussing their own death may hasten its occurrence or compound the emotional burden on their parents and siblings.

Mental health professionals can ascertain the child's private perceptions and concerns in order to correct distortions, dispel fantasies, and promote self-esteem through mastery of fears. Parents are often surprised to learn what has been frightening or worrying their child; it is sometimes different from what they had imagined. Parents can communicate about impending loss and separation through direct conversations and in other ways--for example, creating a photograph book together of the child's life, or reading books or stories that deal with loss. Examples of such reading materials are The Fall of Freddie the Leaf, Badger's Parting Gifts, The Dream Tree, When Dinosaurs Die, Shelter from the Storm, and Waterbugs and Dragonflies. These activities allow difficult conversations to emerge more naturally. Most crucial is the parents' repeated reassurance of their love for their child and that nothing will ever change that bond.

As death approaches, it is important for parents to remember that they have done everything in their power to treat their child's cancer. This is a time to focus on the time remaining to comfort their child. Some parents have later regretted spending time researching new possible cures when they could have spent the time talking or playing with their child. Even as the child is dying, he

or she is still very much alive. Knowing their parents are with them comforts most children. While some parents choose to participate in their child's care, or do so because there is no other option, they should be careful to protect time to just be with their child and not be preoccupied with medical or nursing duties.

Involving the child in making end of life decisions

Decision making under duress can be harrowing for both children and parents, particularly when there are complications of treatment or when the child's illness is refractory to standard therapies. Developmentally appropriate advance-care planning plays an important role in the care of seriously ill adolescents and young adults, and the absence of such jeopardizes best care efforts. The process begins with the identification of the decision makers, including the role of the child or adolescent in the process. Children fourteen years and older have been identified as the age group that needs to be routinely included in advance-care planning and end of life decision making. However, chronological age alone is not a sufficient determinant. Other considerations include the child's understanding of his or her condition, coping abilities, preference to be involved in decision making, options available, and cultural norms.

Providing children an avenue to share intimate views about how they wish to be cared for while very ill, and remembered after they are gone, promotes communication, fosters decision making, and allows dignity, independence and self-respect in the face of death. Legacy activities are extremely valuable and can be individualized for the child's interest and comfort level. Some children want to be sure that others know more about them (as if to cement future memories), and to give special messages to the people most important to them. Commercially available books (e.g., All About Me; A Keepsake Journal for Kids by Linda Kranz) can be helpful for children who demonstrate a readiness to approach the experience of dying more directly. Some children like to create their own books. Other expressive forms include creating a family quilt, drawing a family tree, painting pillowcases, writing poetry and letters, telling stories, or digital storytelling through such mediums as audio, video, songs and photography.

The advance-care planning process can also facilitate the acceptance of a more palliative approach, when disease-related treatments cease and the focus is on comfort. A research driven planning document for adolescents and young adults, Voicing My CHOiCESTM is now available, and is especially useful as a guide for parents to understand the most important issues for adolescents who are facing death. (http://www.agingwithdignity.org).

Reading materials about end of life and bereavement can be useful for some

parents at this time. Most appreciate having time allotted to address their immediate questions or concerns. Some parents want to plan ahead, so that they do not need to make any major decisions after their child dies. This includes decisions about organ donation, autopsy and funeral arrangements. Parents may wish to have a specific ritual performed after death based on their own cultural or religious preferences.

Communicating with siblings

Healthy children in the family also live the illness experience with intensity. As they adapt to this unique life stress, their own normal and expected concerns emerge. Like the patient, although in mirror image, siblings prematurely face the complexity and threat of loss.

Most of the considerations in communicating with the ill child pertain to the siblings as well; age and developmental level, readiness to hear information, and previous experience with loss are all factors to consider when deciding how and how much to disclose. With some exceptions (e.g., when the sibling is much older than the ill child), it is important that siblings not be asked to hold information secret from the patient, particularly with regard to prognosis.

Siblings often hold two views of the diagnosis: the accurate medical explanation and a more private version that may be laced with guilt (e.g., "I had a cold and I gave it to my brother and then he got cancer.") It is important to find out what explanation the siblings are carrying in order to clarify their misconceptions. Throughout the illness, parents should periodically reiterate the medical information and be vigilant for the reemergence of guilt.

A challenge for young siblings is the effect of the visibility or invisibility of the child's illness, especially right after diagnosis. An illness that leads to a dramatic physical change (e.g., amputation) provides a visible focus for explanation. In contrast, young children may be puzzled by the invisible nature of an illness like leukemia, particularly after their sibling's hair has regrown. Parents can help their healthy children understand that their brother or sister is the same person, even when he or she looks different, or that despite constancy in appearance, inner changes are making their sibling ill. Drawings and other visual aids are invaluable in providing medical explanations to children. On another level of visibility, it is important that siblings visit the hospital and clinic to become familiar with and to feel included in these aspects of the ill child's life.

As children in the same family, siblings see many similarities between themselves and their ill brother or sister and it is not uncommon for them to fear becoming ill with cancer. It is important for parents to reassure their healthy children that cancer is not contagious and that there is little likelihood that they will get the disease. Additionally, siblings may complain about physical symptoms, sleep problems and become prone to injury. These symptoms are often a manifestation of their own stress and reflect a need and means of obtaining equal attention. Health and mental health professionals can help parents in reassuring the siblings of their health while addressing the meaning behind the symptoms. An almost inevitable consequence of caring for a seriously ill child is that the siblings receive less of their parents' attention, especially when the sick child is in the hospital. Being available for the siblings can seem an impossible task. Especially during times of extended stress, what is most important for siblings is the quality of their relationship with their parents and with the ill child. Most parents find that if they can provide even a small period of individual time for the siblings, their appreciation is enormous.

With time, siblings' sense of guilt may focus on the fact that they escaped the illness. Acknowledging their relief about being healthy can trigger more intense guilt. Another source of guilt that is rarely mentioned is feeling shame that the family is different because there is a child who is ill, disfigured or dying. Parents can help children with these "unacceptable" feelings through quiet, private discussions and reassurance. Parents can help by being vigilant that the siblings' own activities are not constricted out of guilt that the patient cannot participate.

Outside of the home, siblings' concerns about the ill child can affect school and peer relationships, either positively or negatively. Their academic performance may suffer as a result of their preoccupation, or they may focus on school to feel successful in the face of their stress and helplessness. Similarly, siblings may curtail contact with their peers in their need to focus on the family, or they may turn increasingly to their friends for support. School and peers represent ongoing, normal life for the siblings, with opportunities for growth and diversion from the illness experience. Parental permission and encouragement for their healthy children to maintain these activities is essential. It is also critical that parents inform the siblings' teachers about the family situation so that they can be aware of any changes, as well as provide support.

As the child's illness progresses, siblings are thinking about all the same issues as the patient, with the same questions lurking.

- Is my brother/sister going to die?
- How and when will it happen?

When siblings do pose these questions directly, parental openness and honesty are essential. Siblings need to trust their parents will be honest with them through the course of their brother or sister's illness, and this foundation is essential as they face their life into the future. Some adolescent siblings may want to be included in discussions and decision making with the medical team. It is important that parents consider their requests respectfully, and, in some instances, take into account the wishes of the ill child. Whatever the specifics of the siblings' involvement, it is critical that their voices be heard and acknowledged.

Bereavement in the Family

There is no wrong way to grieve. Parents benefit from understanding that individual family members may express their grief differently, and that, at times, they may not be able to comfort one another. These differences are based on personality, life experiences, and beliefs. Diminishing or total lack of communication between the parents or within the family is experienced as another significant loss. Doubts, guilt and regrets over decisions about the child's treatment can linger for a long time. When left unresolved, unexposed, and unexamined, guilt is a significant psychological risk factor. Parents often express feeling very alone after their child's death. Friends may avoid talking about the child for fear of saying the wrong thing. Others do not understand the process of grieving and may think that the family should move on—as if there is a time schedule. Parents may benefit from letting friends know what might be helpful, such as going out for coffee, returning to a book club, talking or not talking about their child, or having a friend accompany them to the cemetery. Knowing where to find support during the days that parents feel most vulnerable is essential.

No one knows better than a parent who has lost a child that the death of a child is an intensely painful experience. A wide range of emotions, thoughts, behaviors, and physical symptoms may be observed, including coping with intrusive images and memories, reminiscing, seeking support and comfort, social withdrawal and even searching for the child. It is difficult to distinguish between normal and unhealthy responses during the first months of bereavement.

Bereavement support can be highly effective in helping families cope and adapt to life without their child. Some parents choose ongoing professional help (individual and family therapy) or peer support groups as they process the progression of the illness and negotiate the finality of the child's death. Many parents turn to their clergy. Others rely exclusively on the support of family

and friends. In any of these contexts, parents, siblings and grandparents benefit from the opportunity to reflect on and review the illness-dying-death experience of the child. It is particularly important for parents who appear to be stuck in their grief and protest the reality of the loss, to obtain professional help from experts in the field of loss and bereavement.

When the atmosphere of the treatment site is accepting and available, some families may return to the hospital where their child was treated either for bereavement support or just to visit staff they knew over a period of many years. This varies considerably and there is no right or wrong way to find comfort or grieve.

Bereaved Siblings

During the aftermath of the child's death, a parents' presence—simply being with the siblings—is the most important communication of all. With the familiar family structure shattered, siblings need reassurance that we are still a family. It is extremely important for parents to emphasize that we are all going through this together, thereby validating the siblings' loss of a brother or sister as well as their own loss of a child. A common occurrence after a child dies is that people focus almost entirely on the parents' loss, as if the siblings' loss is not of the same consequence. Parents can remind family and friends to include the children in their expressions of sympathy.

Children's expressions of grief may differ from that of adults; however, their experience is no less valid. As in any other life experience, developmental issues play a role in children's grieving. Their questions will emerge from their level of understanding, or not understanding, the finality of death. Young children who think that death can be reversed will often ask the parents "When is he or she coming back?" The recurrence of this question, sometimes for days, weeks and even months, is a child's way of absorbing the finality. Honest communication with the siblings is as important now as it was during the child's illness. As excruciating as it is to hear and to repeat the answer, "He or she is never coming back, and we are all very sad," children need for their parents to reiterate this fact. Whereas an adult's expression of grief is a continuous thread in the first weeks and months, young children tend to express their grief episodically. Their questions and grieving are punctuated by periods of normal play and activities. This pattern can be hard for parents to understand, and they may chastise a child for not being serious or respectful. However, this is a normal phenomenon, as if children know how much intensity of emotion they can tolerate before needing some distance from the pain. Many adolescents fear being different in

any way from their peers and feel that their friends cannot possibly understand what they are going through. As a result, some teens do not share their grief with their friends and, thus, lose out on potentially valuable sources of comfort.

While it is important to talk about the child who has died, it is also important that parents focus on the here-and-now life of the siblings. Consequently, families may find themselves living in a double world: grieving and remembering the child in the past while attempting to imagine a future. It is very important that the siblings be supported in looking forward, without feeling that they are betraying their deceased brother or sister. A valuable concept that parents can communicate to their surviving children is that even as they move on in their lives, they will always be the brother or sister of the child who died.

Conclusion

Communicating with a child who is living with cancer, and the healthy siblings, often feels like a high-wire act. What to say? How to say it? When is the right time? During a time of such uncertainty and stress, children look to parents for direction and reassurance. Guidelines based upon clinical studies and gathered from other parents' experiences are certainly valuable. However, there is no substitute for parents' knowledge of their children—their strengths, vulnerabilities, challenges and gifts.

Table 1. Developmental Considerations at Diagnosis

Age	Behavioral/ Emotional Reactions	Interventions at Diagnosis	Responses
Babies & Toddlers (ages 0-2 years)	Very aware of physical and emotional changes in their environment, especially separations from home or parent(s). Very sensitive to changes in their parents' emotional well being. Fears pain.	Stick to the child's routine as much as possible. At the hospital/clinic, try to create a familiar environment (favorite blanket, toys, clothes, books, music). Take care of yourself. Find support that allows you to express fears and anxieties to others.	"Mommy and Daddy will be with you when you go to the hospital to help make you feel better."
Pre-school & Kindergarten (ages 3-5 years)	Have a basic level of understanding of having a serious illness. May be concerned that they did something wrong (behaviors or thoughts) to cause their cancer.	Explain cancer in simple terms. Use images or analogies the child can relate to (Pac-man as medicine eating away all the cancer cells). Picture books, dolls or stuffed animals can help.	"You have an illness called cancer. The doctors are giving you some medicine to help you get better. I/we will always take care of you." "We will be going to the hospital together every day this week and you will meet some really special doctors whose job is to help you get better."

Age	Behavioral/ Emotional Reactions	Interventions at Diagnosis	Responses
Pre-school & Kindergarten (ages 3-5 years) continued	When stressed, may regress to behaviors they had previously outgrown (bed wetting, thumb sucking, baby talk, separation anxiety). Asking questions repeatedly is not uncommon. Uses the word dead but only to distinguish from something not being alive.	Assess understanding and dispel misunderstandings. Repeat information as needed Explain that cancer is not contagious. Look for books that have a positive outlook for any symptoms experienced (e.g., bad dreams, worry, cancer), especially ones with characters the child identifies with. Stick to discipline limit setting and other routines as much as possible. Prepare for changes within a day of them happening versus many days in advance or immediately before they occur.	"Let's make a special box so we can put in all your favorite things that we can take with us."

Age	Behavioral/ Emotional Reactions	Interventions at Diagnosis	Responses
Elementary & Middle School (ages 6-12 years)	Provide the name of the cancer your child has and the type of medicines that are be- ing used to treat it.	Look for changes in behavior, sleep, eating hab- its and emotional responses.	"Your body is making too many white cells which is making it hard for your other cells to do their
	If they want, a doctor or nurse can explain cancer and cancer cells (don't be surprised if they go the Internet to look up additional information). Assess their understanding of their illness and make sure they understand they did nothing wrong to cause the illness.	Prepare for hair loss or limb loss with explanations, books, introductions to others who have lost hair or a limb, and by eliciting family and peer support.	"You will be given medicines that will help take away your cancer. These medicines are very strong so they can also make you feel sick."

Age	Behavioral/ Emotional Reactions	Interventions at Diagnosis	Responses
Teenagers (ages 13-18 years)	Clear straightforward communication should include a full medical explanation as the adolescent indicates he/she wants. The full course of treatment should be described so that the teen does not feel blind-sided. Many want to be involved in consent meetings. Offer choices whenever possible (chemotherapy in the mornings or afternoons for example)	Assess for withdrawal from peers, impulsive behaviors, excessive risk taking. Watch for insomnia, nightmares. Assess for arguing, fighting, emotional vulnerability and/or refusing to talk about the cancer.	"Different people have different responses to the medicine you are being given. Most lose their hair, many experience some nausea and vomiting, and a few develop mouth sores. There are medicines that will help with the nausea, vomiting and mouth sores if they occur."

Family Perspectives

My daughter Naomi had waist long hair when she was diagnosed with AML. Brushing and braiding her hair was part of our daily routine—a routine that we both cherished. I knew that losing her hair from the chemo would be emotionally difficult for both of us as it meant that even strangers would know that my little girl was fighting cancer. Telling her that the medicines she was receiving would make her feel sick so that she could get better was relatively easy. She was in pain, so any medicine that would relieve that pain, regardless of the side effects, was a positive step forward. Telling her that the medicines would also result in her hair falling out was not something that I thought I could just come out and tell her. So instead, I read her the book by C. S. Lewis entitled The Lion, the Witch and the Wardrobe. The book is about four children who find themselves wandering in Narnia, a land of eternal winter. Animals become their friends—including Aslan, a brave, wise and magical lion who is the King of Narnia. At one point in the book Aslan is captured by the evil White Witch. The children watch as Aslan is tied up, shaved and killed (they think) by the evil witch. Aslan is at his weakest. He is without his fur, and it appears that the evil White Witch has won the battle. When the witch leaves in what she believes to be victory over Aslan, the children and numerous mice remove the ropes from his body. Instantly, Aslan reappears alive and strong with his full Lion's mane. With his regained strength, he kills the White Witch and returns the land to springtime. Using the imagery of the story I explained to my daughter that she was like Aslan. She was strong and brave like a lion, but she had to fight an evil witch called cancer. There would be times that she would feel like she was tied down and weak, and—like Aslan—she would lose all of her hair. But she, too, would defeat the evil witch and her mane of long hair would return, along with her strength. She identified with Aslan and viewed the hair loss as part of winning the battle to return her life to "spring."

"Wrong will be right, when Aslan comes in sight,

At the sound of his roar, sorrows will be no more,

When he bares his teeth, winter meets its death,

And when he shakes his mane, we shall have spring again."

After discussing the many treatment options available, my son surprised us by speaking very plainly about what he wanted. He wanted to fight, he would do anything that we wanted him to do as long as he could remain home. He did not want to travel out of state. He did not want our family to move. He did not want any treatments that required hospital stays. He wanted to always have the ability to remain with his sisters and his animals. With that in mind, we were able to find a clinical trial that we were willing to try and that was offered at the children's hospital only a short 45 minute drive from our house.



When communicating with my son there were times conversations included his siblings and both parents, but there were also times it was a one on one discussion. I found it important to initiate conversation and ask questions that would be uncomfortable as an adult to address, but might make the unknown more of a known for my child and, therefore, diminish fear. I might begin the conversation, "What were you thinking when the doctor said...?" or, "How are you feeling about being sick?" and then allow the child to lead the discussion so the conversation only encompasses details that the child is able to emotionally absorb. When my son was sick, I would regularly ask these questions. It appeared to give him a feeling of safety that a time would come when his fears, worries and stresses would have opportunity to rise to the surface and be discussed.



Every child is different, but these are some communication principles that worked for us. Honesty—we were as honest as we could be with our son and with his brother and his sister. We tried not to hide the truth, but we also tried to present information as positively as possible. We sometimes did not give many details; but we wanted the kids to know the basics of what was happening. Openness—We told our children often that they could talk to us about anything. If they were struggling with something and had questions, we wanted to try to answer those questions. We wanted to know how they were doing and feeling. Transparency—We let our children know that we were struggling. Sometimes parents put up such a front for their children that the children don't realize it's okay to be upset or to have a difficult time handling the situation.

My daughter was 7 years old when she was diagnosed with acute myelogenous leukemia. All I knew at that time was that any child having cancer had to be a bad thing, so my focus was to do whatever I could to relieve her pain and let her know that we were going to do whatever we could as a family to help her feel better. Communication was essential to her understanding of what was happening to her. Right from the diagnosis we made a pact together that we would be honest with each other. We also promised that we would help each other get through this by agreeing that if one of us was feeling down, the other would promise to pull that person up. That simple agreement was what helped to sustain us through a very difficult year of intense treatments including a bone marrow transplant.



We told Naithan and his sisters (13 and 9) almost everything. We told them about the tumor, where it was, that it could not be surgically removed, that it was cancer. We told them what the tumor could do to Naithan's body and about the different treatment options. We told them that our family life would change but we weren't sure how much. We did not tell them the statistics about survival and we did not initially share the term "DIPG". We chose not to share the statistics because they were disheartening, and we wanted our children to focus on treatment, on fighting, on life. We chose to not share the specific diagnosis because all of our children are extremely good investigators and have access to computers. We were not quite ready for them to read stories, probabilities and statistics in regards to Naithan's diagnosis. Once again, we wanted to keep them focused on living, fighting, and enjoying each other.



Chloe didn't want to talk about dying. She was only interested in living. We were very aware of the importance of giving her a chance to talk about this, and, despite the most horrific emotional pain on my part, we did try. We saw other teens die of cancer—far too many of them, and we left the door open to talk about the future. She never went through that door; instead she naturally gravitated to living in the here and now.



My daughter and I talked before bed last night that tomorrow would be our

first day of radiation. And that radiation was what all these appointments were building towards. That the doctors were going to use something called radiation to shrink her tumor. When we first found out she had a brain tumor we were geared up for a fight, ready for chemo and to be in this for the fight of our lives. I was ready to tell her that even though she didn't want to go to the doctor or take meds, she would need to—in order to save her life. But then we were told the word I will never forget—incurable. It was just like people say, like being punched in the gut. I stumbled onto Tony and screamed. I think part of me somewhere deep inside is still screaming like that every moment of every day. So last night was a moment that struck me—not being able to use the words I had rehearsed, that we are going to save you, but only saying to shrink the tumor. She was playing with her new iPad while we talked; I think it helped her to be able to absorb our conversation better. With princess sounds in the background, I explained to my daughter that the tumor in her head has a name—cancer.



Talia was told in early August 2012, that she had four months to one year to live. She was almost thirteen years old when she was given this news. We talked about what she wanted for the end of her life, and she was adamant that she wanted to die at Arnold Palmer Children's Hospital. She said she wanted to be surrounded by her nurses and doctors that she loved, and she told me that they would take care of her. Talia said to me, "I don't want to die in pain. I want to be in the hospital so if I need some pain medication, I can get it."



When Ella started to lose her ability to speak, we created a picture book with photos of all sorts of things she liked to do, things she needed to do and feelings. When we couldn't understand her speech we would pull it out and flip the pages. She had just enough strength to point to the pictures. My favorite was the "I love you" picture because I missed hearing her sweet voice say those words to me.



As the tumor grew and she lost her ability to verbalize, she devised a way to tell us "yes" or "no" by sticking her tongue out.



My son was completely paralyzed and non-verbal the few weeks before he died. His only form of communication was eye movement. I wish I had asked him if he was in any pain in those last weeks. The night before he died, I thought to ask him if he had a headache and he responded that he did.



The answer, "I don't know" is acceptable. As well as comments like, 'I'm scared too." Your child needs to know their feelings are normal and, as an adult, you have the same fears, feelings and insecurities.



Stella was so young when she was diagnosed with cancer—only 26 months old. She was exceptionally bright though, and we never hid anything from her. We, as well as the doctors, spoke openly to her about her brain tumor and imminent death. I'm not always sure that she understood exactly what we were saying, but she tended to respond appropriately, so it could be she grasped some things. Sometimes I would tell her that I would miss her after she died, and she would give me kisses and tell me that she would miss me too. One time I asked her if she knew she was going to die and she said, "Yes, and I'm going to go there," and pointed to my computer screen which had a screensaver of the night sky and all its bright, shining stars. She told me matter-of-factly that she wanted to die on the couch at home, and when we spoke about her tumor she would touch the back of her head and feel her skull under the mass of red curls, as if assuring us that she knew exactly what we were saying.



I learned that giving my kids the opportunity to talk about what was in their hearts gave them the freedom to heal. Children have immature ways of handling emotions, and if I can help my kids by listening—without criticizing or interrupting—and asking questions, it makes them feel loved and safe.



Our son's siblings were almost 9 and 11 when he was diagnosed with cancer. We asked our son's oncologist to meet with our other children to show them the scans and to explain the situation to them. She explained the medical facts clearly; she did not mention that our son would most likely die, and she did not give statistics. My 11 year old was part of the conversation; my 9 year old listened quietly and cried. We chose to tell them that their

brother may die because we did not want them to hear it from someone else.

As it became clear that death was imminent, another trusted physician talked with them about how to interact with their brother. He explained that just being there where their brother could hear them and touch them and know that they were present would be a comfort to him.



I was diagnosed with breast cancer just a few days before my son Andrew was diagnosed with DIPG. I got the call from my surgeon on a Monday afternoon, and we talked with our children that afternoon--mainly because we did not want them to hear the news from someone else. We wanted them to know they could trust us. We used the standard terminology—words like mass, cancer, etc. They knew someone who had died of cancer about 6 months earlier, so they immediately had questions—Are you going to die?, etc. We told them we didn't know, but that breast cancer is considered quite treatable. We also assured the kids that cancer is not contagious. At the time Stephen was 11, Charis was 8 and Andrew was 6. On Thursday of that same week, we ended up in the Emergency Department with our son Andrew. The physician's assistant explained, "There's a large area of swelling in the brainstem; we suspect a mass." Andrew responded, "My mom has a mass!" From then on we used the same approach—honesty along with basic words that our kids understood. We were not cruel. We did not stress the prognosis. We just explained the problem in a matter-of-fact way. This approach allowed us to continue to have open, honest discussions as things changed. If there was a new symptom, we just explained that it was the tumor—and not Andrew's fault that his speech was not clear, etc. We did not make a big deal out of it. We just rolled with the punches, and Andrew rolled right along with us. This led eventually to conversations about death. There were casual conversations, funny conversations and very serious conversations. I treasure all of them. I'm thankful that he knew he could talk with us. I'm thankful that he knew he could share his fears and that he did not have to go through this alone.

School

Barbara Jones, PhD, MSW Farya Phillips, PhD, CCLS

Return to school after a cancer diagnosis can be challenging for children, their families and the school. Children with cancer may experience many disruptions in their school attendance due to frequent hospitalizations, side effects of treatment and overall fatigue. They may not feel up to fully participating in school activities, they may feel uneasy about the physical changes in their appearance, or they may suffer learning differences as a result of treatment. Yet, despite these challenges, returning to school is a big part of feeling normal and productive for children diagnosed with cancer. Attending school can reassure the child that there is hope for the future.

This chapter provides suggestions for school personnel and parents on ways to facilitate return to school or connections with a child's school, with the help of hospital liaisons, school personnel, online technology, creative approaches with peers, and open, trusting communication between the medical staff, school and family.

Barriers to School Participation

Children with cancer frequently miss periods of school due to illness, side effects of treatment, hospitalizations and outpatient clinic appointments or procedures. Additionally there are other factors associated with lower rates of school attendance as well. These include psychosocial factors such as the parent's and child's concerns about how the child will be supported if he or she returns to school. This may be due to a lack of confidence in the school's ability to meet the health and emotional

needs of the child or worries that exposure to the school environment may exacerbate the child's condition. Parents may also have real doubts about the benefits of school when they are working so hard to focus on treatment and quality of life. Finally a perceived lack

Barbara Jones is Associate Professor and Co-Director of the Institute for Grief, Loss, and Family Survival in the School of Social Work at The University of Texas at Austin. of support and understanding from school staff may lead to a parent's desire to keep a child out of school. This is often due to challenges with communication and coordination between home, school and the hospital.

Children with cancer may express a desire to remain away from school because they are uncomfortable facing their peers due to physical, cognitive or emotional changes they have experienced. They may also not have the strength to return to school for visits or re-integration. Often children and adolescents have anxiety about illness-related stress, their peers' reactions to physical changes, and lack of confidence in their own physical and academic abilities. A child's body-image and self-concept can be affected by major physical changes he or she experiences, potentially causing distress in peer relations. Another factor contributing to children's difficulties with self-concept may be real physical limitations, such as fatigue, that impede their ability to fully participate in school activities. Thus the concern of peer teasing, and uneasiness in talking about the cancer and its progression with schoolmates and teachers, may deter a child from attending or visiting school. If the child is well enough to attend school, parents may still find it difficult to allow him or her to do so because of their real concerns about the child's medical and emotional fragility.

Ways to Help Facilitate School Re-Entry When Possible Social support

Social and community support for the family has been shown to help parents deal with the incredible stress of childhood cancer. Parents who receive support can then serve as a protective buffer for their children against the stressful impacts of cancer and treatment on their lives. Peers play a critical role in facilitating the school re-entry and adjustment of the child with cancer. Increased social support significantly impacts the positive adjustment of these children and their families. The impact of cancer on the school experience is decreased if peer support is not disrupted and feelings of isolation are reduced. However if the child or adolescent becomes socially isolated and distant from peers for a substantial amount of time, this can lead to further desire to miss school. Increasing a child's perceived social support through effective school intervention can help increase adjustment and improve quality of life. One of the most important interventions is for the school to be kept informed of how the child would like

to be supported in re-entry. Some children would like the healthcare team to create an educational session to teach their classmates about cancer, treatment and how it might affect them. Some children would prefer to

Farya Phillips is a Post-Doctoral Research Fellow in Psychosocial Oncology at the University of Texas, at Austin. stay at home and receive cards, emails, Facetime or social media support. Some children would like to have their experiences acknowledged as they re-enter, while some would prefer to blend into their school unnoticed. It is critical to help the child and family define what is right for them, and to work with the school to support that plan.

One important way to help children re-enter is to give their classmates ways to keep in contact with them:

- Cards signed by all the classmates and staff
- Email and texting
- Facetime or Skype
- Hopecam
- Monkey in My Chair
- PJammin for Kids with Cancer
- Posters and pictures for the child to decorate his or her room at home or at the hospital
- Social media such as Instagram, Facebook, etc.
- Video things happening in the child's class

School environment

Teachers and classmates ultimately have the most direct effect on the school experience of a child with cancer. Educating the school personnel about the child's ongoing school, health and socio-emotional needs, enables the teacher to help peers be more accepting and to facilitate accessing any necessary services to better assist the child and family in school re-entry.

Successful school reintegration requires an appreciation of the unique needs of each individual child and family. To ensure maximum benefit, the school must provide appropriate modifications of the environment and assist the parents to be effective advocates and communicators of their child's needs. The parents will also need to be a driving force behind the child's return to school during or after cancer treatment. The parents will play an integral part in creating a plan for their child and in making sure that the educational plan is updated as the child proceeds through treatment and beyond. An individual education plan (IEP) may be created for the child with cancer upon diagnosis. The creation of this plan often begins with an assessment of the child's current

level of school performance, the impact of the illness on his or her learning, medical precautions and special needs. This is followed by a statement of the goals of the IEP and an outline of the services/accommodations the child needs to achieve these goals. The child often benefits from a new IEP that takes into account changing educational needs due to treatment and disease progression. The school administration, teachers and the child's medical team will be there to ensure the educational plan progresses smoothly.

There are laws that help protect the rights of students with physical or learning disabilities, and they include provisions for students with educational needs resulting from cancer treatment.

• The Individuals with Disabilities Education Act (IDEA)

Protects children ages 3-21 years by ensuring that public schools provide a free and appropriate education for disabled students, just as they do for other children.

• The Rehabilitation Act of 1973-Section 504

Requires all educational institutions receiving federal funding to provide accommodations (adaptations) for students with physical or mental impairment that limits one or more major life activity.

Many childhood cancer survivors will qualify for intervention or adaptations under one of these laws. Some children will only require assistance during cancer treatment, and some may need help for years beyond treatment.

Things schools can do to support the child with cancer

Children at school often want to show their support and stay in touch with their friend with cancer but are not sure how. Teachers and administrators can provide avenues to help the patient and classmates stay involved with one another even if they will not be able to physically see each other for some time. The school can begin by keeping peers at school updated with basic information about the child as approved by the child and family. By taking an active role in establishing regular communication avenues, the school can avoid just reacting to crisis. This type of open communication limits the misinformation that is possible concerning a classmate with cancer. Without this honest information, children and adults may be inclined to respond to rumors that might be worse than the actual facts. A member of the child's healthcare team is an invaluable resource for teachers and administrators to consult on the type of information to share and how. In addition it may help to have one teacher at school that

knows the child well and can be the liaison to provide basic information to update the school community on what is happening. The child and family can work with their healthcare team to identify a school liaison. And the family can also designate one person to be the contact with the school and healthcare team about the needs of the child.

Special consideration should also be directed toward the siblings of the child with cancer and close relatives who may attend the same school or other schools in the same community, because their school performance and emotional wellbeing may also be impacted.

Using technology to bridge the gap

Technology can be used to help children with cancer maintain contact with their classmates and communicate with other children experiencing similar circumstances. In addition to Skype, Facetime and social media platforms, the following Internet sites are illustrative of the types of resources available to facilitate socialization for children with cancer and their peers:

American Childhood Cancer Organization Inspire Community

The American Childhood Cancer Organization's Support Community connects patients, families, friends and caregivers for support and inspiration.

Band-Aids and Blackboards

This site's goal is to help people understand what it's like from the perspective of the children and teens that are growing up with medical problems.

Hopecam

Hopecam uses technology to connect children undergoing treatment for cancer with their friends at school.

Kids Cancer Network

This is a website of resources and places to say thanks, share with thousands, and be creative.

Starbright World

This is the first-ever online social network for teens (13-18) with chronic and life-threatening medical conditions, and their siblings. Members are able to connect globally with others experiencing similar medical journeys.

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Free patient websites/blogs

These are secure websites—free patient blogs—that connect friends and family during a health challenge; keep family and friends up to date on health status, treatment calendar and community support calendars; and allow the setting up and sharing of photo galleries.

- CarePages
- CaringBridge
- My Life Line
- Post Hope (provides an additional tool allowing fundraising with online donations)

Resources for school personnel

• American Childhood Cancer Organization

Educating the Child with Cancer: A Guide for Parents and Teachers, 2nd Edition

Edited by Ruth I. Hoffman, MPH, this is an essential resource for families who have faced the childhood cancer diagnosis. Written by top researchers in the field, and balanced with parents' personal experiences, this 334 page book focuses on educational issues for children treated for cancer. It is intended to promote understanding and communication between parents, educators and medical professionals, so that together they can provide an appropriate education for children who have been treated for cancer.

Children's Oncology Group

This online resource provides information on talking with your classroom about cancer, medical considerations at school and more.

CureSearch for Children's Cancer

This online resource provides guidance for school personnel on how to support a child with cancer.

Programs especially for schools

• Alex's Lemonade Stand (ALSF)

The Change Childhood Cancer School Program invites any school to be a part of finding a cure for all children with cancer by participating in the coin collection program designed especially for students. Every penny, nickel, dime

and quarter counts in this effort to help fight childhood cancer. ALSF will provide students with suggestions on how to collect change and reach their goals. Educators are provided the necessary materials, including the book Alex and the Amazing Lemonade Stand, lesson plans, and activities integrated throughout the curriculum.

American Childhood Cancer Organization

PJammin for Kids with Cancer is a way that schools can join in the fight to beat childhood cancer and provide hope to those who need it most. Schools can organize a PJammin Day, and students can wear their PJs to school for a minimum donation of \$1.00 per participant. Each event creates awareness of childhood cancer issues, creates supportive communities for local families who are dealing with childhood cancer and raises funds to provide information and support materials for children currently fighting cancer.

• The Cure Starts Now Cancer Research Foundation

Monkey in My Chair is a program for preschool and elementary age children who are away from school because of a cancer diagnosis. Through the program, each child is provided with a monkey kit which includes a big stuffed monkey that takes the child's place in school when he or she is unable to be there. The kits include the monkey with a backpack, a book to help teachers explain to students the situation their classmate is facing and how it affects them, a teacher companion guide, along with other items that can be utilized by the child and/ or classmates. In addition to each monkey kit, each child will be given online access to Monkey Message. Monkey Message is an online component that allows the sharing of pictures and documents to ensure the line of communication stays open between the patient and the classroom.

Supporting the Child with Cancer Through Survivorship

The improved cancer survival rates for children have made their long term psychosocial adjustment an important factor to consider, especially with regards to school performance, absenteeism, social anxiety and isolation. The effects of cancer treatment may continue after treatment ends and these late effects may impact a child's school experience for years. Successful reintegration into the school environment is vital to the longterm success of these children. A comprehensive approach to survivorship is critical, focusing on every aspect of the child's life, not just medical needs after cancer treatment. Research suggests that children who are successfully attending and participating in school activities with peers perceive less stress from their cancer experience.

Children who are at risk for late effects from cancer treatment should complete neuropsychological testing so that the results and any recommendations may be shared with the school. According to the Leukemia and Lymphoma Society, the late effects that may affect children's thinking and memory include the following challenges:

- Organization of school materials
- Problem-solving
- Maintaining attention
- Reading comprehension
- Memorization of facts
- Speed of thinking, processing or writing
- Visual memory or copying visual information
- Understanding math concepts

Physical late effects may include the following challenges:

- Problems with hearing or eyesight
- Ongoing fatigue
- Seizures
- Numbness, weakness, or pain in hands and feet
- Need for a wheelchair or artificial arm or leg

Parents and teachers should be aware of and watch closely for the presence of any of these late effects from cancer treatment so that changes can be made to the classroom and school routine to accommodate the needs of the child. Even if the initial testing seems normal, if the child begins having trouble in school or develops any of the problems listed above, repeated testing is often recommended.

Making special education services available to children with special healthcare needs is required by federal and state law. If a problem is identified, services to help maximize students' learning potential can be requested. Examples of ways to address these needs are listed here:

• Allowing extra time for work, assignments, and test completion

- Minimizing the amount of written work
- Use of computer instead of handwriting
- Seating near front of classroom
- Tape-recorded textbooks and lectures
- Oral exams
- Easy access to facilities, elevator etc.
- Classroom aid for in-school support
- Extra time transitioning between classes
- Modified physical education requirements (sports accommodations for amputees)

The School's Adjustment to a Child's Death

The challenges of living with cancer are only magnified when a child and family face the uncertainty and progressive decline in health associated with end of life. Yet taking part in school activities is frequently one of the only elements that may continue to provide order and a sense of normalcy at this time. It is important for children to remain connected to their schools in spite of their experiences with cancer. The social and emotional support provided by attending school can be a critical element that helps the child to cope with the stress of illness. By actively participating in school activities and/or relationships, the child/ adolescent has an opportunity to experience community, support and some activities of normal living. Thus, school participation and direct support from the school community can enhance a young person's quality of life. Continuing school as a child approaches end of life provides the same hope and structure as at diagnosis, with many of the same interventions being useful. The school and family must always work together in partnership to find the best possible connections for the child. Maintaining social ties can reduce isolation and loneliness and keep children engaged with their peers.

The school community will need support coping with the child's declining health. The focus should remain on including the child in school and classroom experiences to the greatest extent possible. However the teachers and peers will need assistance with processing the emotional experience of watching their friend's deteriorating health. In the absence of a proactive communication plan, this is also commonly a time of rampant rumors and inaccurate information

that may be frightening to children. School staff can provide stability and a sense of safety by maintaining open communication between the school and family and helping to dispel myths about their friend. Each situation will be unique and should be handled in an individualized way to best meet the needs of the family, students and staff. Some children will continue to attend school sporadically until the end of life, while some children may not physically be present for several months. Either way, when a child dies, it is important to provide the school with information and support to assist in the natural process of bereavement. The teachers and staff in the school community need to be prepared to support students in their time of loss, in addition to processing their own grief. Therefore, careful consideration should be given to allowing the adults to have separate opportunities to grieve and process their emotions away from students. Teachers have the unique opportunity to model expressions of grief and reassure students who are struggling to understand death and dying for the first time. This is yet another occasion for school personnel and the healthcare team to collaborate. Members of the healthcare team who are experienced with grief and loss in children can be an excellent support to the school community during their loss. School responses such as planned memorial activities, including tree plantings, assemblies, and acts of charity in the deceased child's memory, have proven very effective. Thus school personnel and leadership have the ability to impact the collective response to loss, as well as the grief experience of individual students and even the family of the child who died.

Conclusion

When a child has cancer the school involvement continues to be imperative to the child's sense of well-being. Although completion of academic work may be less important at this time, the importance of ongoing school involvement to quality of life may actually be increasing. The most important intervention is open, honest communication with the child and family about how the school community can best support them. Children and families deserve this, and schools want to provide this support. The facilitation of communication between home, hospital and school can promote a more realistic perception of most childhood cancers as serious but treatable diseases. This will make possible the focus on normal learning and attainment of academic skills that will in turn have positive implication for children's self esteem and social relationships. Together parents, healthcare professionals and school personnel can create a compassionate environment for children with cancer and the children who care about them.

Family Perspectives

Julia had seizures in the 5th grade; some days she'd bang on her desk and scream, and others she'd run to the teacher to grab on. All this led to phone calls from the nurse to come pick her up, many visits to the neurologist, multiple seizure meds and a fast education on the local school system. It took time to get the seizures under control and for the school nurse to not call me every time Julia had one; eventually the nurse just let Julia sit in her office for 15-20 minutes and sent her back to class.

By the time Julia started the 6th grade we had seizures under control after trying a wide range of meds, and got to the point where her seizures were just a few seconds of blank stares. This is when I started learning about medication side effects and how seizure meds cause short-term memory loss and changes to attention span. At the first open house after school started, I visited her teachers starting with 1st period and worked through the day with her other teachers. As I talked with the different teachers it was apparent that Julia changed as the day went on. 1st period the teacher felt she wasn't there, didn't ask questions and did not participate in class. She improved as the day went on and also remembered more, so I did some research on her meds and learned a lot. I got together with her neurologist and we started adjusting the times and amounts of her meds, and she became a B student, then an A student by the end of the year. We also decided after getting meds changed that it would be best to put technical subjects like Math and Science first thing in the morning when she was fresh which worked out great. I also set up her first 504 meeting.

The summer between 6th and 7th grade, Julia's tumor showed growth, and the next phase of her journey began. After her pathology came back, one of my mistakes was to look at the survivor statistics for her tumor type, and my brain took off preparing for the worst. (The doctors were talking 3-6 months). After 2 resections and at the start of radiation/chemo, Julia had baseline neuropsychological testing. The testing showed she had issues with math and cognitive memory. Then it took me until she finished her 33 radiation treatments to realize that things were moving along good and school was getting ready to start up, so I needed to change gears and start hoping for the best. I headed to the school to re-set up her 504 plan.

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I had learned more about the school system during Julia's 5th and 6th grade years and took a whole new approach to this 504 meeting. I learned that each teacher was unique. Some thought they knew what was going on with Julia and didn't listen to suggestions. Some thought I was just a grandparent so I didn't know how things should work or what I was doing. All of her female teachers were more sympathetic and caring than her male teachers.

I brought 3 individuals from the Cancer Center with me to the 504 meeting—a social worker, the nursing program coordinator and the neuropsychologist. Because they all had titles after their names and provided care for Julia, everyone at the meeting was more attentive and believed what they were saying. I also researched and printed out papers written by well-known institutes (Duke University, St. Jude, Johns Hopkins, etc.) that everyone trusted on topics I knew the cancer center staff would be discussing—effects of radiation, chemo, chemo brain, cognitive issues, etc. I printed out enough copies to make a folder for everyone in attendance. When we finished the meeting there was no doubt in my mind that everyone knew what was going on and we knew what we were doing. Within days after the 504, I met with her medical homebound teacher, principal, teachers and office staff, and put a plan together.

About this time we started talking with the child life person at the cancer clinic about Make a Wish. School was starting and Julia wanted to be there with her friends in the worst way, so she decided against the traditional wishes like going to Disney. With the help of the child life group, we found the Children's International Make a Wish Foundation that would allow her to get multiple items and ended up with about \$5,000 worth of electronics. With free WiFi available everywhere we went, this allowed us to stay connected to school and helped to keep Julia occupied in our new hurry up and wait world. The hospital system also had a nice young teacher on staff to help whenever Julia was inpatient. (The hospital became our second home.) Julia ended up missing a little more then half of the 7th grade but came out with straight As and finished school on time. With the recurrence, 8th grade was a challenge because Julia spent 3 days every other week inpatient for chemo. Timing for her to get her treatments was important for school. I always made sure she went in on a Wednesday so we'd come home on Friday. Then on Saturday and Sunday we'd finish the work she'd missed to keep her caught up to the rest of the class. This made her feel good on Mondays because she didn't have to play catch up and could spend a normal day in school.

I learned early on to be nice, pleasant, calm, and truthful. I was a straight shooter, built relationships and asked tons of questions. I call this playing politics, and it works!



It was the end of Naomi's first grade at school when she started complaining about pain in her legs. She was attending a French Immersion school at the time and taking the bus each day to school. As the pain grew worse her friends would help her down the steps of the bus. I'll never forget the day when the school called frantically to say that my daughter was lying on a gym mat finding it difficult to breathe and crying in pain. They asked whether I wanted to come and get her or if I wanted them to call an ambulance. I had just seen her a few hours earlier so couldn't imagine that she would need an ambulance, so I told them I would come and get her. I was wrong. When I arrived, she was lying on the mat moaning and groaning in pain and struggling to breathe. I picked up her frail little body, carried her to my van and drove her to the hospital. It would be the last time that she attended her grade one class and months before she returned to school for a short visit prior to her bone marrow transplant. When we walked into the school that day we were surprised with the way the school showed their support for Naomi. Each child in the school had been taught how to make paper cranes, a symbol of hope for leukemia patients. Hanging in the main hall of the school were 1,000 paper cranes and a ladder for Naomi to climb so that she could touch them. Those 1,000 paper cranes gave us hope for the many difficult months ahead as she went through her bone marrow transplant. The school couldn't have done anything more inspiring for my daughter.



Khylee didn't really want to go to school, and with her being 4 at the time of diagnosis, I decided to keep her home. I took her to her preschool when she felt like visiting.



Noah's school made every effort to help any way they could. It was arranged for Noah's tutor, his English teacher, to come summers and during the school year. Noah would go to school when he was up for it. Noah's girlfriend, Kyleah, and staff and students at Gladbrook-Reinbeck High School, had many different fundraisers over the past several years. The support was amazing!

We opted not to put Peyton back in school after radiation. Instead we lived life to the fullest enjoying every last moment together. We didn't want to miss a thing and she didn't want to be away from us.



My daughter was in the first grade when she was diagnosed with cancer. It was just before summer break, so she didn't see her classmates until school started again in September. When she returned she was bald and wearing a scarf on her head. While sitting at her desk, and without warning, someone behind her pulled off the scarf. She assumed it had been the girl sitting directly behind her. The class burst out laughing. My daughter was devastated. She said she never wanted to go back to school again. Due to other circumstances she ended up going to a different school. It was years later when attending high school that she again saw the girl who she thought had pulled off her scarf. The two girls were walking toward each other in the hall. Without any other preliminary conversations the girl said to my daughter, "It wasn't me." In tears they hugged each other. Both had been carrying that huge burden for many years, so were thankful that it was finally lifted from their shoulders.



We decided to meet with the principal, the school nurse and Mikey's teacher a few weeks before school was to start. We needed to make sure everyone knew exactly what was going on. Mikey had been in treatment since he was 9 months old, and with his 3rd relapse, this was a complicated situation.

I sat alone with the principal, and we discussed Mikey's life. We talked about what kind of kid he was, what he liked to do, his favorite things and—yes—his cancer. We were very up front about everything, and we told them we were not sure if Mikey would make it through the year. I told the principal that while Mikey was being treated for cancer, he was still a little boy who loved school, ice cream, playing with friends and listening to stories. I wanted to make sure he was not "the boy with cancer." I wanted him to just be Mikey.

Next we went to see the school nurse to discuss Mikey's medical condition. He had a port, but was not going to be in school with it accessed. We discussed side effects from his chemotherapy, which at this point were minimal. He was on palliative chemo and the only thing that concerned us was occasional mouth sores. He had some hair—not much, but what he did have, he combed every morning. We also had to discuss and leave paperwork with the nurse. I am not sure how many DNRs had been filed with the school nurse, but it had to be done.

We went home and returned a few days later with Mikey. We met the principal again, the school nurse, and this time we got to meet his teacher. Knowing what the future held, the principal wanted to give serious consideration to which teacher would be Mikey's. He talked it over with all the kindergarten teachers and decided on the teacher who seemed to have the most structure in her classroom; and by the looks of things, we were in the right place. Mikey looked around the room in awe. He had been in a wonderful private pre-K school 3 days a week, but this was a whole new experience. This classroom had a computer, a reading rug, a science center, and each child had their own desk. His teacher was very engaging, and patiently followed Mikey around the room and let him touch, explore and ask as many questions as he wanted. I knew right then and there, this was going to be a great relationship.

We returned a week later for our first day of kindergarten. It was a day of orientation, and parents were welcome to spend the morning with the class. Not knowing anyone else, I took a seat in the back and just observed. The teacher explained to the students how each day was going to start, how to keep your coat cubbie neat and tidy, what they did for snack time and how to ask to go to the bathroom. One boy sat a few kids away from Mikey, but could not stop staring at him. Mikey's tumor was in his sinus cavity. When it was resected, there was some deformity with his right nostril. He had had some reconstruction done, but we didn't see the need to put Mikey through any more trauma. His favorite place on earth was school, and it seemed unfair to take any unnecessary time away from that. As long as Mikey was smiling, we were smiling.

The boy who could not stop looking at Mikey interrupted the teacher and said, "Hey. Your hair is really short." Without missing a beat, the teacher said, "Well, some people wear their hair long and put it in a ponytail. Some people wear their hair straight, some comb it to the side, and some people like to keep their hair really short." Seemed pretty simple, and the boy didn't question it; but he was still looking Mikey up and down. The teacher used this opportunity to talk about classroom behavior and how everyone in her

classroom were friends and helped each other out. Everyone was expected to help clean up, do their best work, be respectful of other children's work and belongings—and all of a sudden the boy who continued to stare stood up and said rather abruptly, "Dude! What happened to your nose?!" Before the teacher could say a word, Mikey stood up, went toe to toe with this boy and said, "I had an operation. Give me a break already." Mikey sat back down, crossed his legs and gave a little nod to the teacher, as if to say you may now continue. The teacher then asked if anyone else had a question, and no one said a word.

I imagine from our initial visit to the school until orientation, the teacher had prepared for every imaginable scenario. Her responses were carefully planned, thought out and delivered. Her response to the short hair comment showed us that things were under control and that the school was prepared and very well equipped to handle anything that would come up.

Over the course of the next months, Mikey thrived at school. The chemo he was on did not affect his immune system, so he was able to go out in public without worry. He made many friends, some who continue to send texts and Facebook messages to me from time to time. He was able to read, write many words on his own and do simple math problems on paper. He was a computer whiz and went to many birthday parties. Everything we wanted for Mikey was happening. He was up and ready for school without a fuss and greeting the bus driver with a giant hello every morning. We had regular check-ins with the teacher and she said Mikey was an amazing little boy who was embracing every day, loving life and everyone around him.

It was late January when we got the call we were all dreading. The recent CT scans showed the cancer had started to spread. After radiation mapping was complete, Mikey was to begin daily radiation treatments for 23 days. We worked out a schedule with radiation so Mikey could continue to go to school and receive treatment. But the truth of the matter was, radiation was taking a toll. He was tired, and since the radiation was targeting his face, he was suffering from mouth sores. Despite how terrible he felt, he was determined to got to school every day. Some days, the school made special allowances and let him bring ice cream for a snack. He really could not eat much else, but there he was at the snack table with all the other children, laughing, playing and—yes—cleaning up. He was, in fact, just a regular kid.

It was now late February, and CT scans revealed that Mikey's liver, lungs and spine were showing cancer activity. He could no longer walk, and he was admitted to the hospital for pain management. I called the school and let them know Mikey would not be returning. A new regimen of radiation was planned, targeting the spine, In ten days, Mikey literally ran out of the hospital and got onto a plane to Disney.

While we were at Disney, the school was preparing for the inevitable. It didn't seem real. Mikey was looking better than he had over recent weeks. The school had known for months this day would come. The principal drafted a letter he would send to every family after Mikey passed. The guidance counselors were meeting to discuss the best way to inform the students. I thought of those at that school often during our trip. I knew the school had the right people in the right places. I worried about Mikey's sweet little friends. What a hard life lesson at such a young age!

We came home from Disney, and Mikey was directly admitted to the hospital. His class sent get well cards and notes in a big envelope. He was so happy when he opened it! Over the next days, Mikey got sleepier and sleepier. I called the school and talked to the principal from time to time. Mikey passed Friday night. The principal contacted parents Monday afternoon by sending a letter home with every student in the entire school. The school had counselors ready to meet with students and parents, and Mikey's classmates were given special attention.

A month after Mikey passed, we planned an open memorial service in our town. Naturally I had been in touch with the school and let them know the arrangements. The school used this memorial service as an opportunity to let Mikey's classmates process what had happened and express what they were feeling. The teacher and guidance counselor came up with the idea to allow the children to draw pictures of their favorite memories of time they spent with Mikey. The counselor had another idea that she thought would be helpful. After talking to us, she approached the students' parents to ask if they would like their children to be part of Mikey's service. One by one, the students walked on stage and shared their photos with the crowd. Each student went to the microphone and said who they were and what their special memory was, holding the picture he or she had drawn. Those pictures were placed into a binder and presented to us as a gift from Mikey's class, and it is a cherished gift to this very day.



When our daughter, Tatumn, was diagnosed with an inoperable brain

tumor she was turning four and just starting preschool. I called to let the school know she was sick and we weren't sure if she would be back. She had only attended the first couple of weeks. I wasn't thinking about school as a priority at that time, of course, and assumed they would just take her off the roster but her school was so kind and sensitive. They sent pictures they made for her and care packages.

As Tatumn started to feel a little better I asked if she could come to school for an hour or so to visit. They were very excited and accommodating and were glad to have me stay for the visit. Our first visit to the school was after hours so she could just see her classroom and her teachers. I thought I would gauge any future visits from this one. She seemed excited to go back even though she was often tired. Kids at that age do a lot of independent play, so it wasn't awkward with the other children, as I feared it might be. Tatumn was able to do some center activities and participate in calendar and even hold the flag one day for the Pledge of Allegiance. That was probably as special for me as it was for her.

When Tatumn passed away the school put a bench in the playground and dedicated it to her with a butterfly release. It meant a lot to us that they wanted to remember our sweet girl. She had a plastic gazebo that she played with in our backyard, so we donated that to the school because we thought she would have wanted to share it with her school friends. She didn't have a very long school experience, so every picture, craft and story they shared with us meant so much. I never expected the school to embrace us they way they did.

Helping Sick Kids Be Kids

Elana E. Evan, PhD

A life-threatening illness is by no means something that can be taken lightly. However, with the amount of medical treatment, time in the hospital spent away from family, friends and everyday school life, helping kids with cancer just to be kids can sometimes outweigh the priority of the treatment itself.

Quality of Life

Quality of Life is defined as the state of complete physical, mental, and social well-being. Therefore, it is important to assess what is considered valuable or important to a child. This may change over the course of treatment depending on symptoms and circumstances.

One of the main services a pediatric palliative care program provides is helping the child, family and primary healthcare team(s) create a quality of life plan, with the intent of adapting the plan periodically when symptoms and circumstances change during the course of treatment and the child's lifespan. Tools such as the *Seattle Decision-Making Tool* and *Five Wishes* can be used to help children and teens come up with a plan that is based on their values. Parents should not feel that the situation is totally in their hands and can take comfort in knowing that nurses, physicians and social workers are well trained to help them.

Assessing what is important to a child

When children with life-threatening illnesses are surveyed about what bothers and hampers their quality of life the most, they say that the inability to perform age-appropriate daily activities (e.g., play sports, spend time with peers and family) and the loss of *normalcy* are

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what affect them the most, sometimes more than the distress caused by any physical symptom.

The following are questions that parents may want to ask in order to gain a better understanding of what quality life means for their child.

- What do you wish for/hope for?
- What activity or part of your life do you hope to keep in your life the most, despite being sick?
- What (symptom/s) bothers you the most?
- What can *you* do to help make yourself feel better?
- What can your *parent(s)* (*I/we*) do to make you feel better?
- What can the *healthcare team* do to make you feel better?

Even with answers to the questions above, children will experience life-threatening illnesses in different ways according to their age and developmental stage.

Age	Developmental Stage	To Maximize Quality of Life
0-2 years	Sensory-Motor; learning about the world and relationship with environment.	Provide physical comfort through familiar people and objects.
2-6 years	Use of magical thinking, symbolic and pretend play. Egocentric (they are the center of their own world).	Minimize parental separation; correct misperceptions that they are sick because they are being punished, ask about wishes on a more frequent basis since attention span is limited and memory is more short term.
6-12 years	Uses concrete thoughts.	Use concrete details for how you will help child achieve a better quality of life according to their wishes (e.g., "Every Friday, I will arrange playdates with your two best friends"), help them maintain their peer relationships, keep them involved in decision-making regarding treatment, allow them to achieve/master tasks and developmental milestones.

Age	Developmental Stage	To Maximize Quality of Life
12-18 years		Reinforce self-esteem, exploration and formation of identity, and the extent to which decisions regarding quality of life can be made independently.

Chart above adapted from Himmelstein, Hilden, Boldt et al, 2004.

Parents can use what they know about how well their child understands their illness and prognosis and refer to the table above for direction on how to discuss quality of life depending on the child's age and developmental stage. Families should try to maximize the value of play in the child's everyday activities in order to optimize the child's quality of life. Parents might consider the following questions as a guide.

How can you introduce activities that provide your child with recreation and joy on a daily basis? Can you also allow your child to initiate the incorporation of play into his/her own life, by him/herself? For example, if a teen girl realizes on her own that hanging out in the teen lounge with some of the other teens in the hospital, playing cards, every Tuesday, brings joy to her life, she may be empowered to feel that she can achieve a sense of control (despite trying to cope with an illness that is beyond her control), because she found a method for coping and improving her quality of life on her own.

Supporting Emotional Well-Being

The parent's versus the child's well-being

One of the most important tasks for the parent of a child with cancer is to provide the child with emotional support. It may be difficult to feel successful with this task, when often parents feel that they need just as much emotional support, but feel guilty to take the focus away from support directed toward the child. The reality is that if the parent does not practice self-care, or does not incorporate methods for accessing emotional support, it will be dually challenging for the child to feel emotionally supported by the parent. The child's anxiety increases when the child senses that the parent is anxious or distraught, making it difficult for the child to focus on improving his/her own emotional well-being and quality of life. Often children with life-threatening illnesses are more concerned about the welfare of their parents than they are concerned about themselves, and will achieve peace of mind when they know their parents are *cared* for and well supported emotionally.

Normalization

A critical element to supporting the child with cancer emotionally includes helping the child achieve some sense of normalcy in a life that has become very different from that of the child's peers. For children who have been out of school due to treatment, it is important to explore methods for slowly reintegrating them into the school environment, if possible (e.g., create a modified class schedule, attend memorable school events such as proms and graduations). To create some *normalcy* in the child's daily life, it is important to ask if the child remembers life before becoming ill.

- Does he/she feel comfortable discussing it?
- Does it make him/her happy to think about life before diagnosis?
- How do his/her peers without illnesses actually experience their lives, versus what is the child's fantasy of a normal life without cancer?

Incorporating the answers to these questions into the child's daily life can allow him/her to continue to live his/her life in the way he/she intended and feel connected to what he/she values.

Creating *normalcy*, or attempts to make the child's life like it was before cancer, is a difficult balance to achieve, primarily, because having cancer is not a normal life event; in some ways it is important to highlight this fact. In other words, by just focusing on normalizing the child's life, parents may be denying their child the right to own the hardships the child has successfully faced up until this point, as well as the potential obstacles that the child may need to face in the near future.

Coping

Coping is defined as thinking-oriented and/or action-oriented responses that individuals use to handle problematic situations or events. When it comes to coping with the stresses of an illness, there are theories that provide guidance regarding which type of coping (i.e., thinking-oriented or action-oriented) is most helpful or effective in reducing the stress at hand. Namely, these theories revolve around how much control an individual thinks he/she has in any given situation. The general rule is that if an individual has some control over the stressor in the environment, then using an *action-oriented* coping strategy is most helpful (e.g., if a child spikes a fever and is distressed by it, it makes sense to use an *action-oriented* coping strategy by calling the doctor who may be able to treat the fever). If an individual has little control over

the stress that is occurring (e.g., a child's blood count is too low and he/she needs to stay home from the school dance), it may be more effective to use a thought-oriented coping strategy which focuses on how one thinks about the stress rather than changing the environment or fixing it (e.g., since the child cannot do anything about missing the school dance because his/her blood count is too low, perhaps the parent can help the child think about things to make him/her feel better, such as the fact that there is another school dance in the spring which is usually the better attended, more fun dance of the school year).

Coping strategies are also selected by children and by parents alike not only based on the type of stressor in the environment, but also dependent on the personality of the individual (e.g., some people are more active copers who make themselves feel better by gathering information and getting together with friends, while others are more passive copers who prefer to use escapism, like watching TV). In some instances, parents may find themselves projecting their own coping strategy preferences on their child, which may be problematic if the parents' strategies differ from their child's usual strategies. Instead, parents may find it helpful to ask themselves the following questions to differentiate between what is helpful to them in coping with the stresses associated with their child's illness and what is most helpful to their child.

- What makes me feel better when I am feeling stressed? Does my child use the same strategy?
- Does my child know when I am stressed? How does he/she react?

Differentiating between what is helpful to the parent and what is helpful to the child, in regard to coping with stress, is even more relevant in the teen population. This is because a major task of adolescence is forming one's own identity.

Teen Concerns

Self-esteem and identity formation

Teens coping with cancer are not only dealing with the process of *growing up* and becoming adults, but they are also adjusting to life with a life-threatening illness. While they are learning to be independent, they likely will need the emotional and physical support from their parents more than other teens their age who are not coping with a life-threatening illness. *Self-esteem* refers to the extent to which one values or likes oneself. The development of *self* evolves through the usual

maturation process and continues to be shaped by what occurs in an individual's environment. While adolescents are deciding whether they like themselves, they are still discovering who they are—a process called identity formation. During identity formation, adolescents typically experiment with different identities, testing each one out, perhaps using their friend's identity, a parent's identity or another figure as a role model until they have actually settled on an identity that works for them. Their self-esteem becomes connected with their newly formed identity (i.e., how much I like myself depends on knowing exactly who I am). Teens with cancer may encounter certain obstacles while in the process of developing their identity and self-esteem. Cognition, or thinking, may be difficult due to chemotherapy and radiation effects and, thus, may affect how they think about their environment in relation to themselves. Other factors, such as appearance (e.g., hair loss, weight gain due to prednisone) and missed social opportunities due to medical treatment, may impact self-esteem. Thus, awareness regarding the identity formation process and coping with possible obstacles that adolescents with cancer may face during this process can ultimately help parents help their teens achieve a positive self-esteem.

One way to help build positive self-esteem in teens with cancer is to allow them to see how they have succeeded in various aspects of their lives. When teens are aware of their successes and strengths in certain areas of their lives (e.g., *I am a good listener, I have a lot of interests that I enjoy talking about*), they are more likely to develop a more global, overall positive self-esteem. Parents can link past successes to future challenges to foster positive self-esteem. For example, if a teen is feeling down about the possibility of dating because he/she keeps missing out on social opportunities due to his/her illness, and this is affecting his/her self-esteem, the parent can remind him/her that he/she has certain strengths (e.g., being a good listener, being well-rounded with many interests) which will allow him/her to make friends easily despite missing out on some social events. Mentoring other younger patients or those more newly diagnosed is a good way for teens to improve self-esteem. Additionally, being paired with a mentor, or another teen with cancer who has a positive self-esteem and can model good coping skills, is also a good strategy.

Friendships/Romantic Relationships

Interpersonal relationships play a critical role in adolescence. For teens with cancer, obstacles that may present themselves when developing interpersonal relationships may relate to body image (e.g., weight gain, surgical scars), fear to get involved with friends due to their diagnosis, as well as difficulty in initiating romantic relationships (e.g., how to flirt), due to possible cognitive impairments.

Helping teens connect with others either via social skills training groups with other teens, with or without cancer, can provide an environment for learning and practice to make up for lost time due to medical treatment. Camps, specifically designed for children and teens with cancer, are available around the country and are places where children with cancer can share new experiences and make memories with others their own age who are also experiencing serious illnesses. Teen support programs, like *Look Good Feel Better* (LGFB) are usually available at children's hospitals, local clinics and via online settings. *Look Good Feel Better* is a program specifically designed for women and teens with cancer. The main objective is to teach women and teens beauty techniques to enhance physical appearance in order to deal with the side effects related to treatment.

Creating Meaning

Kids with cancer are going through one of the most, if not the most, difficult moments in their lives. Many kids, especially teens, with cancer may find themselves asking, "Why me?", "Is there a reason why this is happening at this time in my life?" and/or "What can I do to add meaning to my life given that it may be challenging and/or shortened?"

Posttraumatic Growth

The concept of *posttraumatic growth* (PTG) refers to the feeling of an increased sense of well-being after surviving a traumatic event. The sense of meaning and *growth*, or PTG, from either enduring or surviving cancer can change the outlook a child had previous to his/her cancer diagnosis to be more optimistic about life's *little* troubles, and to be more appreciative of life. It may also lead him/her to create more memory-making and meaning-making experiences in his/her life.

Storytelling

Storytelling as a way to make meaning of one's experiences, often referred to as narrative therapy, can take many forms. A personal narrative can build upon the development of posttraumatic growth and can increase feelings of self-worth. Providing a child with opportunities for telling his/her story can be empowering as it helps him/her *own* the experience and frame it in the way the child would like it to be thought of by others. This can be done directly with others in-person, in chat rooms, or in written format, or it can be audio/ videotaped.

Role-playing/dramatic play, or acting out a particular role, can also engage kids

coping with cancer to act out scenarios with their parents and/or sibling(s) or friends in order to send a meaningful message or tell their stories in a non-threatening setting. If, for example, it is difficult for a teen to tell her father directly how much she appreciates him for helping her to get through her painful medical treatment, she can role-play a pretend discussion with her sibling where she gets to practice talking to her father. Her sibling can play the role of her father, and she can play out the scenario, while videotaping it, and then present the DVD to her father at another time. Children can also tell their stories by using photographs and scrapbooking.

Family-Building

The struggles and experiences of children and teens living with cancer affect the entire family. When a child has cancer, often roles and tasks will shift within the family. For example, if a sixteen year old boy is diagnosed with cancer and is undergoing treatment in the hospital, his younger thirteen year old sister may begin to take on some of the responsibilities of her older brother (e.g., she may become responsible for helping her parents with chores that her brother was once responsible for and may need to go to each of his teachers on a weekly basis to pick up homework assignments and bring them to him at the hospital). His parents may need to leave earlier from home and leave earlier from work to drive his sister to school—a task that their son once took care of since he would drive both he and his sister to their high school every day.

In turn, the family's reaction to the cancer and shifting of roles can have an effect on the child with cancer himself/herself. In other words, the same sixteen year old boy may begin to feel guilty now that he is putting more responsibilities onto the shoulders of his family due to his absence in the household. In the past, he took pride acting in the role of the *big brother*, driving his sister around and being the one she relied on as the older sibling. Now, because he is in treatment, he may need to rely on her instead.

To help the child with cancer to cope with changes within the family due to the illness, family members can begin to take part in certain exercises and projects, if time and energy allow for them. Creating a wish list for family members can be mutually beneficial for either a child or teen with cancer and for the other family members. Once every member of the family creates a wish list of wants for the family, then each family member shares it both in person and privately. For example, the sixteen year old teenage boy mentioned previously may put on his wish list that he hopes his family will not be angry with him for putting more responsibilities on their shoulders, his sister might put on her wish list

that she hopes her parents will not place more demands on her/expect more from her given her brother's absence, and the parents might put on their wish list that they would like more time together as a family. Then all members of the family can come together and share their wish lists in person. Often this purposeful act of openly sharing one's thoughts and hopes for the family, when a young person is diagnosed with cancer, can ease the emotional burden felt by all. If all family members are aware of each other's wishes, then more time can be spent working together as a family to achieve a satisfying home life and to ease the adjustment associated with the new roles that individual members of the family may take on. Other family-building activities may involve art projects such as family trees (using hand prints from all members of the family to resemble a tree), designing a master family album or even building a small play/treehouse in the backyard.

Memory-Making

Just like storytelling, memory-making can take on many forms as well and usually refers to creating memories that will last during a child's lifespan and beyond. Memory-making opportunities can be offered in hospitals and care centers, but can also be done at home and usually include prints or molds of the hands and feet, obtaining a lock of hair, making a memory box or book, photographing and videotaping, as well as journaling. Wish trips, such as day-long outings to an amusement park with family members and friends, or longer trips to a special location with loved ones, can also be filled with many memory-making opportunities. Organizations like *Make-A-Wish* can facilitate the coordination and funding of wish trips and other types of wishes (e.g., preparing and funding a teen to go the prom or to see a favorite baseball team play live) for children with life-threatening illnesses.

Legacy-Building

Legacy-building refers to creating something that positively represents an individual—something that can be left behind when he/she is no longer here; usually, whatever the legacy is, it tends to help or inspire others. Creating a legacy can be another way to help provide meaning or a sense of triumph to the struggles endured by children and teens with cancer. Examples of legacies include creating a special fund for other kids with cancer (e.g., funds to encourage scientists to conduct research in childhood cancer therapies, or funds to provide computers to kids that are hospitalized for long periods of time, so that they can communicate with friends and family members) or initiating a

project to help humankind and/or social welfare (e.g., if a ten year old with cancer enjoys weekly outings to the park, then perhaps he can start an initiative to help maintain cleanliness in all children's playgrounds). Legacies are created by also mentoring other children and teens with or without cancer by relaying information and lessons learned from one's own experience.

Family Perspectives

I made sure we did whatever we could to keep Julia connected with two very special friends that she had had since elementary school. While Julia was in treatment we'd have sleepovers with her best friends even if Julia wasn't feeling great. Sometimes they'd just hang out and watch TV or listen to music. Her friends would keep her up to date with stuff going on in school. They helped her feel connected with the latest gossip about teachers and students. If Julia was feeling good, I'd pick her friends up and head to the city—even if it was just to walk the river or head to Starbucks and pig out on Venti Frappuccinos while they all played on the Internet.



My daughter gained confidence, learned new skills, and developed friendships at camp. Camp provided support, a sense of normalcy and belonging. My entire family found support...at camp. Nothing was as healing as knowing that we were not alone.



Like most kids, our daughter liked to paint—especially on places she wasn't allowed to paint. Around 10 months after her DIPG diagnosis, I had her sitting on my lap. She couldn't hold anything in her hands anymore, so I was doing hand-over-hand with a paintbrush. She kept trying to eat the end of the wooden brush and I was getting frustrated. I admonished her, "We don't eat the paintbrushes!" She looked up at me and with one big "hmph" she lunged forward and grabbed the paintbrush with her teeth. She then bent over the paper and began to paint, by herself, grasping the brush in her mouth. Immediately my eyes filled with tears. Cancer had tried to take away my daughter's abilities, but she was grabbing them right back.



We were sent home and told to present ourselves the following week. I will always remember that week. We witnessed our boy begin to fade away. We slept in the tent, swam everyday, had picnics.... We wanted to make the most of our time, not knowing what therapy could entail.



Chloe loved life. Pure and simple. She had all the necessary emotional requirements to have a fabulous life—a beautiful life. These attributes didn't leave her during her cancer journey, but they certainly were challenged. Chloe had always been a popular child; she had a kind of magnetism that drew people to her. She used that to her full advantage when she was ill, and ensured that she was always surrounded by a large group of male and female friends. She put a lot of effort into her friendships and this paid off hugely. We ran an open house policy and made absolutely sure that there was never any secrecy around Chloe's treatment. We spoke openly about hair loss, port lines, injections, chemotherapy, and we made fun of some of it too. Chloe used the nurses sterile gloves to apply fake tan and we often chastised her for wasting health resources; I think she enjoyed being seen as naughty. Normalizing treatment and bringing it into our lives really helped, I feel. Her friends became part of her treatment and kind of learned along with us.



Our goal after diagnosis was to live as normally as possible. Fortunately I was able to take time off work, and we made muffins, picked berries, and traveled to many of our favorite places. We hiked, carrying Khylee in a child carrier backpack, and we went camping and got dirty, despite her doctor's warnings about germs. Once Khylee could no longer walk, I took her out in a jogging stroller.



Even in his last month of life, he still was determined to keep going. Mason scored a goal on the soccer field about two weeks before he died. He was wobbly, his face had started to fall on one side, but he was running on the soccer field, scoring a goal.



Despite Nicole's declining condition, her drive to live life as a normal 9 year old girl was as strong as ever during the final months of her life. My wife and I struggled to accept, or even acknowledge, that we were going to lose her. But Nicole did not dwell on her deterioration or what lay ahead. Instead, she lived in the present, wanting to play games, go shopping, be in school, attend her friend's parties, and go out to dinner with her family. I soon learned that I had to follow Nicole's lead and focus on supporting her so she could do these things. First, we installed a wheelchair ramp to get

her in and out of the house. When transferring Nicole from her wheelchair to the car became difficult, we found a used wheelchair van on Craigslist. This reduced the stress on her body and on ours. We worked to make accommodations so she could be at school and with her friends. Often this was as simple as asking for an event to be moved to ground level. When Nicole wanted to participate, we made it happen. Household tasks, such as lawn care, were handled by our support network, so we could spend time on this. Although it was exhausting at times, we look back with no regrets. It was the best thing we could have done for her.



Our son, Noah, age 17, loved life despite his courageous fight with Ewings Sarcoma. He fought for 2 years with strength, determination, faith and courage. He would go to his girlfriend's high school games no matter how bad of a day he had; he would not let cancer stop him from having fun. Noah loved fishing, kayaking, tubing and having campfires with friends. He also loved the outdoors. Unless Noah was very ill, or really hurting, he would not let it stop him.



Although receiving a fatal cancer diagnosis right from the beginning is, in some ways, incredibly difficult, our family feels as though it simplified our care for Stella immensely. With no reason to hope or believe that Stella would live long term (they gave her 3-6 months to live, and she died 16 months after diagnosis), our focus was on saying yes to all the things we had previously said no to. For Stella, that meant no more daycare, no more needing to brush her teeth and no more being forced to eat her veggies. Instead, her wishes and commands became our daily goals. "What do you want to do today, Stella?" we would ask. And then we would simply follow her directions until the day was over. Sometimes she was feeling adventurous and wanted to go to the zoo or farm. Sometimes she just wanted to go for a walk to get an ice cream or a hamburger. Sometimes she didn't feel like leaving the house and watched 13 hours of television a day (mostly Dora the Explorer and The Golden Girls). We filled our days by reading books, painting her nails with the gaudiest colors we could find, doing puppet shows and throwing her birthday parties every week. She ate ice cream for breakfast, doughnuts for lunch and cupcakes for dinner. We took frequent trips to an indoor water park that she loved and practically buried her under piles of toys.

We noticed that as her cancer progressed and she began to lose physical functions, her wants and needs became simpler and simpler until finally, the last few months, all she really wanted to do was be fed ice cream one spoonful at a time between long naps on the couch and sit outside under her favorite tree as we read her book after book. While we realize that not every family has the ability and luxury to do things as we did with Stella, we are happy that we were able to indulge her in the richest ways possible throughout her short life. Despite her horrific diagnosis, she was convinced that she was the luckiest girl in the world—and we completely agreed.

For anyone who has lost someone too soon, no matter who that person was, part of the pain is found in the pile of shattered dreams you had. Stella's diagnosis meant she was not going to get to do any of the things on the list that we adults invent for ourselves and our offspring. You know—the one that says, "Be born. Be cute. Go to school. Do well. Go to college. Do well. Get a good job. Get promoted. Make lots of money. Get married. Have your own children. Become a contributing member of society, and tell everyone how wonderful your parents are for shaping you into such a stellar human being." According to the doctors, Stella wasn't even going to get to go to kindergarten, let alone complete the list. I was haunted by thinking about how Stella's life was going to matter, when it was going to be so short.

We were lost. There was no parenting book, no map, no one to tell us how to parent a dying child. Luckily for us, Stella was smarter than everyone and she was willing to teach us. We took her lead. It turned out that even though she was dying, Stella just wanted what all kids wanted—ice cream for breakfast. And we gave it to her. Every day. Next she wanted to paint her fingernails and toenails with gaudy shades of purple and green. So we did it, and even added sparkles. She soon began requesting hamburgers at 6 a.m.—luckily there was a 24-hour Sobeys nearby. Whatever it was she wanted or needed, an army of people was always there ready to make it happen. As the disease began to affect her body, my family and I would wait with baited breath to see how she would adjust to her new reality. She never disappointed us. Stella always loved to dance (especially to Thank You For Being a Friend), and when DIPG took away her ability to walk, Stella learned to dance with her torso and arms. When it took away her ability to sit up unassisted, she learned to dance with her head. When it took away her ability to move her head, she danced with her eyes. No matter what, Stella danced.

Seeking Support: How, When and Why

Marsha Joselow LICSW, MSW Janet Duncan MSN, CPNP Rachael Menius, MSN, CPNP-AC, CPON Christine Reilly

You are the expert on your child, his or her illness, and the implications it has on your family. You are undoubtedly learning how to best support your child, your family and yourself through this uncertain time. We have worked with many families facing similar challenges, and while we have never walked in their shoes or yours, we've walked beside them through good times and bad. These families have given us some insight on how, when and why they seek support, and we hope to share some of this wisdom with you in this chapter.

Picking up this book and reading this chapter may be one of the first ways you have pursued support during your child's illness. Accepting support, while easy for some, may be difficult for others. One mother has indicated to us that the child is always at the center of the caregiver's decision to accept support. She recommends,

"Accept help. Not necessarily all help that's offered will be needed, but don't decline help just because it's uncomfortable for you. Think of your ill child. Think of your family. Let people help so you can focus on the health of your child and the well being of your family as a whole including other siblings."

In this chapter, we will explore what support, or help, actually means, how it

may be offered to you, and why support in many forms is so important for your child, your family and you. We are also hoping that this chapter might provide guidance for those who want to offer help but might not know how.

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What is Support?

Support can be for your child, their siblings and for you as the caregiver. It may come as social support through interactions with friends and family with the intention of being helpful, or as professional support from clinicians on your healthcare team such as doctors, nurses, social workers and psychologists. When social interactions are perceived as supportive, they can have a very positive impact on the wellbeing of your child, your family and you, and can facilitate positive coping in stressful situations. Some people or groups will show support in the very beginning, and some will be outwardly supportive for the duration of your child's illness. People will offer support emotionally, physically and logistically. Some will help you mobilize your own internal strength by facilitating coping strategies, including self-care, spirituality, exercise, and relaxation among other things. Some people will offer support by taking care of the practical aspects of daily life at home or work so you can focus on your sick child and your other family members. Practical support might include providing meals, carpooling or babysitting for other children, doing laundry, shopping, etc. Other supports may come in the form of online resources or books such as this one. One important thing to remember is that there are many ways people can help, but most parents find that it's the quality of the support rather than quantity that makes a difference. Throughout this chapter we will provide examples of what other parents have found to be helpful and supportive. We hope to guide you in thinking through what types of support will be most beneficial to your family.

Accepting Support

The impact of a sick child on a family can be very broad and deep. For some, parenting a sick child can lead to emotional challenges that you may never have experienced prior to your child's diagnosis. You may find you have to mobilize different resources than before to care for your child, their siblings and yourself. You are learning to identify opportunities and skills to be a good parent in the context of having a child with an illness. Some of these skills include making medical decisions for your child, ensuring your child is not experiencing suffering or pain, advocating for your child, and being more

physically present in a way you may not have needed to be when he or she was in preschool, daycare or school. As a caregiver, you feel the responsibility to continue to facilitate normal growth and development

Janet Duncan is the Nursing Director of the Pediatric Advanced Care Team, Dana-Farber Cancer Institute and Boston Children's Hospital. for your child and family. You are learning how to engage your child, even when he is not feeling well, and how to help your child to enjoy the normal activities of childhood and to continue to learn and grow.

Accepting support from family, friends and the healthcare team may be crucial for your whole family. You likely already have many strengths as a parent, but in times of crisis, you may find it difficult to access and draw on those strengths. Often, those offering support can help caregivers identify and harness internal attributes which, in turn, can promote resilience. Or they may be able to provide you with a break from the practical aspects of daily life so that you may spend more time identifying and developing those coping skills. Remind yourself that you have many positive attributes already; capitalize on those attributes and the strengths of your family as a whole. Accepting help is not a sign of weakness, but an acknowledgement that the challenge of caring for a child who is sick may require new and different strategies for coping.

Some parents have told us that they even feel guilty for not noticing symptoms sooner or not being able to protect their child from illness, needle sticks or having to take medicine with negative side effects. Remember that you are doing the best you can in a situation that often feels out of control. With the healthcare team, you may be able to think about some things you *can* control for your child, family and yourself, and capitalize on those things.

Support for your Child with Cancer

Being a good parent means something different to everyone. As a loving caregiver, there's no doubt that your priority will be seeking support for your child, and this will remain what is most important to you throughout his or her treatment. At different times during treatment, your child may have symptoms of physical and emotional discomfort. Initially, professional support will come from the healthcare team. You'll start to learn a new language—medications, treatments, interventions and symptoms. Asking questions of your healthcare team and learning this new language is the first way you will begin to receive support for your child. Arming yourself with accurate, clear and concise medical information about your child's medical condition and treatment options can

be a first important step in regaining some sense of control. Expecting and requesting this support from your healthcare team, through honest information sharing, can help you support your child, as well as decrease the amount of uncertainty that

Rachael Menius is the Acute Care Pediatric Nurse Practitioner for the Pediatric Advanced Care Team, Dana-Farber Cancer Institute and Boston Children's Hospital. you likely feel in this new role as the caregiver of a sick child. This is an ongoing process which can and should be revisited as medical situations change and if further understanding is needed. Some parents have expressed the value of having a trusted friend or family member with them at meetings with the healthcare team, or of keeping a journal with questions or concerns to take to the team.

The healthcare team can also support you and your child by encouraging and allowing you to participate in common parenting activities that sometimes seem challenging when your child is in the hospital, such as bathing your child, changing diapers, dressing your child, and reading to your child. These routines can be very comforting for the child and can reinforce your very important role as parent. With a teen, you may need to find a new balance of parenting, as your child will likely be more dependent on you at a time when he or she was moving toward greater independence. Parents can also find support through other parents while waiting in clinic rooms, during a hospital stay, or through websites. With this professional and parent to parent support, you will become an expert on how to best support your child.

Schools can be a source of long term support for your child. Teachers and administrators are often willing to adapt the school environment to accommodate the needs of the child and family. For the child who is hospitalized for long periods of time or whose illness prevents him or her from going to school, hospital-based tutoring and home-based school services may be requested. This can provide some much needed normalcy and social connection at a time when many other routines are disrupted. You may find it useful to ask someone on your child's healthcare team to facilitate conversations between you and your school to understand what changes will be most supportive for your child and you and your family.

Just as advocating for appropriate treatment of physical pain and suffering is vital, so is ensuring care for your child's emotional and spiritual health. Many hospitals have social workers, child psychologists, child life specialists and chaplains who are specially trained to work with children who have cancer

and other illnesses. These clinicians are also available to help with other children, particularly siblings, affected by the child's illness. There are many other ways in which you can advocate for additional emotional support for your child both in the hospital and in the community. You may choose to

Christine Reilly lives outside of Boston and is mom to Mikey Reilly who died of cancer in 1999. She has provided the parent perspective to local and national pediatric palliative care projects since 2000. advocate for your child to be involved in these therapies, and your healthcare team can assist you in identifying what is available.

The following are some examples of therapies that may be available in the hospital or community.

- Music therapy
- Pet therapy
- Expressive therapy
- Art therapy
- Hippotherapy
- Aquatherapy
- Integrative therapy for symptom management
 - o Massage
 - o Acupuncture
 - o Reiki
 - o Aromatherapy
- Mental health counseling
- Support group

Support for Siblings

As you know, it's not just your ill child who needs support, but also other children in your family. Often, siblings will need emotional as well as physical support during the illness of another family member. Many of the supports listed above may also provide services to siblings. If you do utilize any of these services, it's helpful to let therapists know that your child has siblings and to ask if they offer sibling support in addition to what they offer for the child with cancer.

If possible keeping the siblings' lives and routines as normal as possible, yet including them at specific times in hospital life or caregiving at home, may validate the relationship and love they share with the ill child. They may benefit from a "sibling week" or "sibling camp" where they can share in activities that reinforce they are not alone in their feelings, wants and needs. One father

astutely told us it is always helpful when other families invite siblings over for activities with children of the same age.

"This serves the dual purpose of helping the parents and the sibling. It gives the parents time to be together to talk or sleep or whatever [exercise, go out for coffee with a friend] in ways they couldn't with the sibling around. Also it gives the siblings a sense that they can have a bit of normalcy, or even special care, from the people around them."

Additionally, siblings may not want to burden you with questions, concerns, or worries, so it may be helpful for them to have other trusted adults to turn to who understand the situation and how you prefer information be communicated to them.

Support for Caregivers

Hope

"Hope is a response to severe distress that allows someone to adapt to a situation..." This adaptation, which allows you to balance your hopes and fears about your child's illness, is a very important one. Balancing hopefulness with medical knowledge allows you to both understand the present reality but also be open to possibilities of what the future may bring. It shapes the decisions you make throughout your child's treatment and helps you find meaning and balance in daily life. By being open to exploring the evolving meanings of your family's experience in the face of illness, it is possible to maintain hope for a positive outcome in your child's and family's life throughout your child's illness.

Grieving the loss of normalcy

Caregivers must take on the task of caring for their family while also balancing hope and the grieving process which is an expected consequence accompanying the diagnosis of childhood cancer. You may grieve your child's loss of health and missed milestones, such as starting grade school on time, learning to ride a bike at the expected time or spending time at home during holidays, etc. You can learn how to embrace and celebrate these milestones when they occur, even if it's much later than expected. Grief in this situation is normal and important; studies show that unidentified grief may contribute to depression, anxiety, and feelings of helplessness.

Who will offer support and why?

People offering support both socially and professionally recognize that caregivers

have multiple stressors—not just the child's illness, jobs, financial worries, personal relationships, marriages, and other obligations. These supporters likely understand that illness affects many practical aspects of daily life, and they want to help. They are likely not looking for repayment; just remember the best way to repay someone is to pay forward the support when you are able. People who accept help when needed will best be able to understand how to lend this support to others in the future.

You may become close with people you've never met. Some of your biggest supporters may be people you wouldn't have expected to help you. Some people you know well may not know what to say or do and may avoid saying anything at all. Some people will say or do things that you do not find particularly supportive. As one mother put it, "Some people will disappoint you, some people will surprise you." Most people find that support comes from their healthcare team, their family, their close friends, the families of their child's friends, community groups, church groups and their child's school. You may find it useful to keep in mind that everyone wants to help but may not have the understanding, skills, or resources to do so in a way you find supportive. In the following section, we will discuss how to best organize offers for help and seek support if you are not getting what you need.

Organizing offers and seeking support

There are strategies that are helpful in accepting another person's support. One mother said, "You evolve. How you see everything, how you decide something's important—it's all changed. It's changing as you find your way on a journey few people are comfortable with acknowledging you are on." After her child was diagnosed with leukemia, another mother realized the importance of normalizing her need for support and giving herself permission to need and ask for support. "Unfortunately, you can't always predict what you'll need or not need (and neither can those offering). It's a process, and flexibility is helpful." One grandmother said, "Sometimes I was at a loss as to what to ask for because I think, at times, I was in a state of shock and disbelief, just trying to do the very best I could."

Many people find it useful to designate a trusted family member or friend as the contact for others offering support or asking for updates about the child—almost like a gatekeeper. This could be one person or a small group of people who will communicate openly with each other and with you. This also removes from the family the burden of requesting assistance during a difficult time. Providing your gatekeepers with a list of things you think would be helpful, will

ensure that when someone says they want to help, but don't know how, they can receive some guidance. This list should include practical ways to help, such as housework, carpooling and child care for other children, and meals. It should also include ways that people can help financially when they aren't able to help physically. Some families use online programs, such as CaringBridge, or simply write emails to keep people updated and to seek help. As with all Internet-based communication, you should be careful in sharing information and make sure that your privacy is maintained. You may also choose to have your gatekeepers post updates or send emails on your behalf. The following list of websites may be helpful for information sharing and for finding support online.

Websites that provide support

- www.acor.org
- www.carepages.com
- www.caringbridge.org
- www.grouploop.org
- www.inspire.com/groups/american-childhood-cancer-organization

As you probably already know, when a child is newly diagnosed with cancer, there is often a huge amount of support. Some families find that this support is less present as the weeks and months go on. If you find that you truly are well supported in the beginning, you may choose to ask some people if you can keep them in mind for assistance later on, if necessary.

Here are some things to consider as you create a list for yourself or your gatekeeper. Depending on the age of your child, you may need to ask what kind of help feels acceptable to him or her. You may think a big community fundraiser sounds good, but your child may dread the attention it might bring. Most people want to help but don't know how. Friends and family will say, "I have some free time tomorrow. Can I do anything for you?" When this offer comes refer to your list and delegate a task. You should not feel uncomfortable asking for specific things; often people will appreciate the honesty, direction, and opportunity to do something that is actually very helpful to you. Many families tell us that the fact that people are even offering support is a sign of how thoughtful they are.

Ways to provide help

Chore list including grocery shopping or other errands

- House cleaning
- Laundry
- Drive siblings to school/activities
- Yard work
- Rotating meal delivery
- Frequent flyer miles so out of town family can visit
- Coworkers can donate unused time off
- Gas cards/grocery gift cards/cards to local restaurants
- Close family may offer to stay with child in hospital for a night
- Sibling care and play dates
 - o Acknowledge feelings and presence of siblings.
 - o Send them notes or emails.
- Notes, emails, and voicemails for the family with well wishes
- Help think through practical decisions
- Memory making with child and siblings

Support may not always be helpful

Allow yourself to make room for differences. Supporters may come from different cultures, religions, or backgrounds, and the types of support that would be useful may not match up with the help that is offered. Acknowledge that while most people have good intentions, not all help is helpful and, in fact, some "help" may be harmful. It's ok to not accept all offers of support. The intent of offering support is almost always to reduce stress, but it can actually create more. If you are wondering why you don't feel supported although you have so many offers of help, this is normal. Support may feel unhelpful due to inconsistency or because some who offer support may not listen or understand what is needed. Rigidity and inflexibility in offers to help, and the unintended blow to pride that may come with support, can also add stress rather than relieve it.

You can always say, "Thanks for the offer; may I get back to you?" Sometimes you'll find you just need space and it is ok to ask for that space or "family only" time. Adding a message on your voicemail which may include something like,

"We appreciate your call, however, we are having family time now," can be a strategy to address endless telephone messages which you may feel obligated to answer. Often when a child's appearance is affected by illness, it is harder to avoid questions or offers for assistance in public that may feel uncomfortable or like a violation of you or your child's privacy. Sometimes you may chose to engage with public displays of concern and support; sometimes you may not. You may answer an inquiry with, "We're hanging in there," or at a different time with a trusted friend you may say, "This is horrible!" Thinking through scenarios and having a scripted response may take away some stress of being caught off guard.

Conclusion

The job of parenting a child with a severe illness is one of the most difficult things you will likely ever do. Just as every child is beautiful and unique, every caregiver has an individualized approach to his or her child's care. As the saying goes, it takes a village to raise a child, and as a caregiver, allowing others in your village to assist you may make this difficult time just a little easier for your child, your family and you. Often, in collaboration with the healthcare team, your child's plan of care will include discovering resources and support for each member of the family. We hope that guidance from this chapter will help you to determine how, when and why support may be important during this time in your family's life.

Family Perspectives

Throughout Stella's illness, we were exceptionally lucky to have a large group of family and friends who rallied around us to help. At times, in fact, we were overwhelmed with the generosity of people who wanted to help. The things that our family found most helpful included:

- 1) Food Share—One of our friends set up a schedule for people to drop off food for us, so we didn't have to worry about grocery shopping and making meals while Stella was sick. To make it work for us, the friend made a master schedule and then had people drop off food directly to her house in a cooler she put on her front porch, which she then delivered to us every few days. It worked great because we didn't have to worry about organizing anything, and having the food dropped off at her house eliminated the need for people to be dropping by our place and interrupting the flow of our day.
- 2) Financial Support—Perhaps it's considered rude or too forward to mention money, but I think it's a challenge many families with sick children have. We need to take time off work to care for our children, yet the bills keep pouring in. Our friends set up a PayPal account for us, and people donated money, which allowed us to stay home with Stella for the duration of her illness. It meant the world to us.
- 3) Stepping Forward by Stepping Back—One thing we learned early on in the experience is that people want to physically "be there" for you. They want to visit and see your child. Sometimes visits are nice, but we were often much more appreciative of the people who just sent a quick note/email/voicemail or dropped something off on our front porch without knocking. In the times that your child is sick, it is not always convenient or fun to "entertain" even the kindest, most well-meaning friends/family, and social niceties dictate that it's considered rude or unkind to ask people to leave or tell them you don't wish to see them. We found that sometimes with so many people coming in and out, it can end up feeling like your child is a tourists' sightseeing stop. My advice is to lend support, be there when you're needed, but also understand that sometimes the best thing to do is give families some peace and privacy.



One great help was a box of organic fruit and vegetables that someone organized to be delivered to our door every week, and another was a friend who would just text me kisses/hugs (xoxoxo) every few days, or sometimes a word—nothing I had to reply to, but I knew she was thinking about me.



My daughter's diagnosis was thought to be terminal. So fairly early on in her treatment members of our church came into our house and gathered up her clothes and toys. I guess they thought that they were helping me by relieving me of a task that they thought I would eventually need to do. I vividly remember coming home from the hospital to find my daughter's things packed up. Instead of helping me, this gesture was almost more difficult to emotionally handle than the cancer diagnosis. My daughter was still alive. I had hope that she would survive. Seeing her things in big green garbage bags immediately took that hope away from me. What was intended to help ended up hurting me deeply. The memory continues to be very painful many years later.



When Etienne got sick EVERYONE wanted to help. They told us many times to let them know what they could do. Of course there was not much they could do—or so we thought.

Six things helped us a lot:

- 1. A family folded 1000 cranes for Etienne. That was such a moving and beautiful gesture; it helped us cope and feel truly supported;
- 2. My sister and parents came over to Europe from Canada, did the grocery shopping and kept the house tidy; looked after my daughter and helped her feel loved through the most difficult days, when we thought we were going to lose Etienne. They did not hang around the hospital and cry, but were strong and took action to keep us fed and to take care of day-to-day things so they would not build up on us while we were in hospital. They gave our family its space while looking after practical things;
- 3. We were stressed with money because I was not working and as a free-lancer, this affected our income a great deal. We were given thousands of Euro by an anonymous person or group of persons who left envelopes of cash with our relatives. We still don't know who they were, but removing that extra burden of financial stress really helped us focus on Etienne and pay for extra physical therapy that we are sure accelerated Etienne's

progress in walking again;

- 4. A group of friends got together to start a fundraising event in honor of Etienne. It not only helped raise money for research and for quality of life at the pediatrics area in the hospital; it also helped all those other friends who did not know how to contribute. They simply helped us by showing solidarity by coming to the event;
- 5. Etienne's aunt would come over every evening with her daughter to play with Etienne when he was at his worst. He was wheelchair bound, vomiting, suffering from headaches and very sleepy. The visits would cheer him up. They also provided us with an hour to focus on our daughter and our household chores:
- 6. Etienne's aunt and uncle would come to the hospital at mealtime to look after him so we could go home to our daughter and have a meal with her. When Etienne was in the hospital my husband and I usually took turns staying with him and rarely saw one another. When Etienne was kept company by his aunt and uncle, we were able to re-group and give a bit of TLC to our daughter.

What did not help:

Making us feel guilty because we did not try alternative medicine or did not fly all over the world in search for a cure. Even suggesting we did not do our homework on the topic, or that our doctors were incompetent, really hurt our feelings and made us second guess our choices.



Three ladies brought over a meal and brought their instruments and gave us a concert in our living room. A woman hid Easter eggs all over our house for a hunt. Someone landscaped our yard in the spring.



My nine year old son was my daughter's bone marrow donor. He felt responsible for saving his sister's life. He was a little boy but had this huge weight on his shoulders. He felt alone and frightened. It was a teacher who recognized that he too needed help during this difficult time. She reached out to him in particular by giving him a deck of cards that she made along with her phone number. Each card had a fun activity on them—things like going with her to her brother's farm; going fishing together; going to McDonald's with her. He was told to call her at any time when he wanted to use one of the cards. It's

been 27 years since that teacher helped my son ... and he still has many of the cards!



It is not easy to say which kind of help stood out in particular, each of the acts of help, support and friendship were and still are invaluable. I remember a spontaneous conversation with a woman I know when she was leaving our house after dropping off some food and we started to talk about dying and losing our Lovis in a very honest way. I remember all kinds of different people bringing gifts, games, and toys for the children (although we eventually asked to not overwhelm them anymore with "stuff" and rather give them time and attention in different ways), I remember an envelope with \$500 under our doormat (and no sign of who this came from), I remember a lot of food being brought to our house, I remember drawings by many children to decorate Lovis's hospital room, I remember her preschool teacher visiting over and over again and playing with Lovis and Solveigh so that they both felt cherished and loved by her. I remember the gentleness of some nurses towards Lovis, and the genuine interest of the Child Life lady at the hospital for Solveigh, I remember a quilt our whole community made for us when the winter came, just before Lovis died, I remember our playgroup gathering in front of our house while it was snowing, singing for our dying Lovis who listened through the open windows because she was too weak to be brought outside or close to the window. I remember our mothers coming from Germany to support us. I remember the young German girl who stayed with us a for a couple of months before Lovis was diagnosed and who stayed instead of leaving to take care of Solveigh and the house while we were at the hospital with Lovis. I remember my husband's company still sending us money although he was off work during Lovis's illness. I remember a benefit concert at the end of the summer which helped us so much financially that we didn't have to work for four months. I remember Lovis's smile when her palliative care doctor showed her a calendar with photos of her family in it. I remember how a good friend of ours made the casket for Lovis with his own hands. His wife sewed a mattress for it, filling it with all-natural gras material. They both brought it to our house, carried it into our basement and left in tears. Their courage was such an unspeakable help. I remember Lovis's and Solveigh's friends coming to a surprise princess party the Children's Wish Foundation had worked into a one-week vacation for our family. And I remember Lovis's gentleness and patience, her honest love and peaceful attitude—the greatest gift and most amazing help our family

Help can come in small and big ways, expected or unexpected, in an organized way or quite chaotic. I am and will always be grateful for each piece of it. The biggest gift we got was free time at home with our children during Lovis' illness because of all the donations and food that was given to us or brought to our home. It also gave my husband and me time for each other when we most needed it. He is my biggest help in this and I hope I can be his.

In hindsight I would say that money, food and help in and around the house were most wonderful forms of practical help, and time and attention for our children in an emotional and more indirect supportive way. Both stopped after Lovis died which was a shock to our family after all that attention and all the different ways of help we constantly received for seven months. I begin to understand why it was like that but would try not to do that myself if I was helping someone else—after their child dies.



This experience has shown me the goodness in people. We are so grateful for all the love and prayers, the monetary support and meals being delivered to my men folk back home. I am trying really hard to help Jennifer see how lucky we are and to teach her to find ways to pay it forward.



One of the things that helped us the most was when my cousin made a cookbook from recipes people that knew Courtney sent to her. She raised \$18,000 with this and we were able to use this for Courtney's funeral, tombstone, and some leftover bills. It was wonderful to not have to worry about those things after her death.



I have found over the years since my daughter's diagnosis that it was the unexpected gestures of kindness that would bring tears to my eyes. I'll never forget the kindness shown to my family by a very wealthy lady who was willing to come into my home to not only bring us food to eat but to also clean our toilets. No task was too humiliating for that gracious woman.

Practical Help

- Watch children so parents can have a date night or so that Mom can have a break.
- Meals
- Organize a work day at the family's house.
- Weekly house cleaning
- Provide paper products (plates, flatware).
- Plan a holiday event.
- Plan an event that will help the family create a memory and include a photographer.
- If you have a talent, share it.

Emotional Help

- Drop a note in the mail or send a quick email letting the family know you are thinking of them.
- Invite the family over for supper.
- Bring supper and plan to stay and eat with the family. If you are concerned you don't know them well, bring table questions or board games as ice breaker activities.
- Go on a double date with the parents.
- Listen, cry, laugh. There is nothing you can say that will make their life less painful. Know the value of your presence.

Strength. Love. Hope.

Tammy I. Kang, MD MSCE Jennifer Walter, MD PhD MS Abby R. Rosenberg, MD MS Chris Feudtner, MD PhD MPH

Strength. Love. Hope. Parents of children with cancer hold these words deep within their hearts. When a child is diagnosed with cancer, parents are devastated. They almost all cry. Some get angry. And then, after the initial shock lifts, they most often take a deep breath and say:

- "I need to be strong for my child and family."
- "I love my child more than anything."
- "I wish I were the one that was sick."
- "I have to focus on the positive, not the negative."
- "I must stay hopeful."

We have heard these statements many times from parents whose children are seriously ill, from the time of the onset of illness or diagnosis and then throughout the illness experience. And we have witnessed parents make these statements even more emphatically when cancer is advanced or the treatment-related side effects become difficult to manage.

This chapter is devoted to you, the loved one. How do you maintain these mantras in the face of the difficult journey you are navigating? How do you take care of yourself while trying to stay strong, loving, and hopeful for others? We provide some words of advice from many families we have been privileged to have in our care. While we put these words in quotation marks, we do so

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only to make clear the voice and point-of-view of the parents, not the precise words that they used. We also leave you with some concrete strategies to help guide you on the road ahead.

Strength

Sarah, a young single mother, has a daughter, Abby, who was diagnosed with a sarcoma that had metastasized to her lungs. Abby had months of chemotherapy, radiation, and surgery. Sarah had vowed during Abby's very first hospitalization that she would never cry in front of her daughter or her older brother. Sarah wanted her children to see her being strong for them, even when things were the most difficult.

Another mother, Shonda, whose young son has AML says, "I'm sick of people telling me to be strong and brave! My child is sick and suffering; how can I possibly be strong all the time? Telling me to be strong is just easier for them—so they don't have to watch me cry. I can be stronger for my child if I let things out sometimes."

What does strength mean? How do parents stay strong when faced with such difficult circumstances? Many parents think staying strong means never crying or breaking down in front of others, saving these emotions for times when they are alone or with a trusted friend or family member. For others, strength is the opposite, as being strong means giving themselves permission to let their emotions out whenever needed.

The only consensus is that finding strength is an individual journey. What works for one parent can have the opposite effect for another. This fact is so important for parents to realize for themselves, for their friends and family to recognize when trying to be supportive, and for their healthcare team to acknowledge and discuss with them. We have had so many families become overwhelmed with words of advice and recommendations based on what worked for someone else. Parents can then feel even more frustrated if the piece of trusted advice does not help them.

Two examples emphasize that everyone is different, that what helps one parent may not help another. Spirituality as a source of strength is our first example. Some families find great strength in maintaining spiritual connections. This can involve prayer, meditation, rituals or participation in religious communities.

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Religious and spiritual beliefs and practices are important to many families in the United States, and many individuals and families draw on these beliefs and practices to cope with serious illness. Furthermore, cancer and other illnesses that cause physical and emotional suffering often lead to spiritual distress or doubts about faith or other spiritual beliefs. Over the past two decades, healthcare teams have gotten better at helping families find resources if they are seeking help with spiritual questions. Most hospitals and palliative care teams either have a chaplain that can be a resource, or work with community spiritual providers. At the same time, however, we need to remember that not everyone finds strength in spiritual beliefs. Parents have expressed frustration when other people assume that they will find solace in talking to a spiritual care provider. Well-meaning supporters may find that their words have an effect the opposite of what they intend when they say things such as, "Have faith, things will be okay," "Everything happens for a reason," or "God has a plan."

Our second example involves advice to *share your story*. Some parents find sharing their story a positive way of expressing their feelings. Many parents write in journals or create blogs or other avenues of documenting their experiences and emotions. Putting feelings into words can be therapeutic, as can finding support from others who may have had similar experiences. The way in which these words are portrayed, whether in private journal or a more public forum is, again, an individual choice. Yet we have seen some families try one method only to find the task of *sharing* become burdensome. John, the father of a child with leukemia, started a social media web page to share their journey with family and friends. After a time, he said, "I realized I was spending a lot of time explaining things to people over and over. People would make comments on the page and expect a response from me. Worse was when other people would respond back to their questions with the wrong information. Finally, we got tired of dealing with all of this and removed the page."

Strength Over Time

"There were days, especially at the beginning, when I didn't know how I would get through it," says Amy, whose daughter Jessie has

osteosarcoma. "Over time, I've started to figure things out. Like, what to expect, what I'm capable of, what (and who) helps me cope, and how to deal with the uncertainty. At some point, I even became thankful. I wouldn't wish

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this experience on anyone. But, when I think back on it, I realize I have learned what really matters in life."

Strength over time, or what we will call resilience, implies an ability to withstand and bounce back, or even bounce forward, from adversity. Just like there are different notions of what being *strong* means, individual parents and families define resilience differently. Unlike being especially strong at a particular moment in time, though, parents may not recognize their own subtler strength over time until after the adversity is over, sometimes years later. What this means is that, day in and day out, parents may have a hard time feeling their own resilience, either personally or as a family, and wonder if they are, in fact, able to face the challenges that cancer has brought to their child, their family and themselves.

When asked to reflect on their cancer experience, we've found that most parents ultimately can describe a combination of factors that helped them to be resilient. These include personal resources that may have existed before the cancer, like stress-management strategies or optimism, as well as skills that developed during their child's cancer treatment, like family or community social support and the ability to *find positives within negative situations*. Almost all parents say their perspectives changed because of their child's cancer. Some simply appreciate their own strength ("I didn't know how strong we were"). Others redefine values ("I don't sweat the small stuff anymore") or goals ("I have found new meaning and purpose in life").

Love

Carmen, a three year old with neuroblastoma, is the life of the party, and her mother Maria said that her love for Carmen enabled her to get up every day and do whatever was needed to get Carmen through the next treatment cycle. "My heart is overflowing with love for Carmen, and this love provides me the endurance to keep going, even on the bad days."

Another mother, Sarah, described her commitment to caring for her 8 year old son Michael who had a bone marrow transplant for ALL. She worried, however, that she couldn't do everything her heart was pulling her to do. "My love for Michael tells me I need to stay here with him, but my heart is breaking because I rarely get to see my

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other two children or husband, and it is hard for me to show my love for them. I know they need me too."

When asked what it means to be a good parent to a seriously ill child, parents most frequently respond, "Make sure my child feels loved." Parents often feel at a loss when their child is ill and that all the choices offered to them are ones they do not want to have to choose from, including toxic medicines or significant side effects from life-saving treatments. Yet over and over, we hear from parents that they regain their compass for how to proceed by focusing on the best ways to express their love for their child. These acts of love are how they are best able to be a parent in an environment where most aspects of life feel out of control for both the children and the parents.

What parents believe they need to do to demonstrate their love for their child varies in different families and in different cultures. Certain behaviors, however, are frequently associated with demonstrations of love, and many of these have to do with attachment. The *attachment theory* of child development describes how children are born with the instinctive behaviors that help them in bonding with their parents. Because infants need so much support, they need to remain in close proximity to their parents to make sure that their needs are met and that they are kept safe. Parents learn quickly that an infant has different cries for different needs, and an attuned parent can respond to the appropriate need quickly. When children are confronted with new or frightening environments they return to their parent's side for comfort and reassurance.

While these attachment behaviors become less obvious as children grow older, situations of stress, like illness or hospitalization, may lead children and adolescents to seek reassurance from their parents, coming close for a hug or even asking for comfort. An otherwise independent 15 year old may ask mom or dad to get into bed with him or her in the hospital. Parents often respond to these requests willingly and describe them as heart-felt expressions of love for their children. Parents spend their child's lifetime offering reassurance and comfort through their physical presence or touch, and when their child is ill, many describe the need to be physically present with their child to show that they love their child.

Children's ability to learn how to regulate their own emotions is heavily influenced by the people who surround them. Our brains are divided into emotional centers and cognitive, or rational, thinking centers. These two types of centers, emotion and cognition, function independently to an astonishing degree. Children's emotional centers are partially developed at birth, and children rely upon attuned adults to help them to learn how to read the emotional world of others and

themselves correctly. We see this happening when a toddler falls and turns to the parent to see from the parent's behavior if he should cry or get back up and continue to play. The child looks to the parent to determine if the emotional response that he experiences is the one he *should* have.

How, then, can we lovingly help our children with the feeling of fear or anger that having cancer is likely to produce, to some degree? Many parents believe that they should adopt a positive emotional outlook in caring for their child with cancer, especially if that cancer is advanced. Children who have become skillful at reading their parents' emotions may sense that their parents, even though they are trying to be upbeat, are hiding negative feelings or bad news from them. These children may also want to protect their parents from feeling bad, so they may hide their own scary feelings.

To break this cycle of hiding feelings from each other, many parents have found that loving their child in these circumstances, and offering loving reassurance, includes helping the child to manage emotions like fear and worry. Parents can do this by acknowledging and talking about these scary feelings, and then being open to discussing the range of emotions that come with having cancer.

While doing this may feel very scary for parents, remember that being with your child completely, including the parts of you that are scared, may be what is most important for your child to have the reassuring attachment needed. Allowing your child to express the range of emotions that are common with serious illness will also let the child be completely with you. Because your child has relied upon you his/her whole life to validate his/her emotional interpretation of the world, your ability to validate your child's fears, disappointments and anger helps the child to work with and ultimately cope with the current, at times overwhelming, experience. We know this is not easy; hearing your child express emotions of fear or anger is so challenging. But part of the special bond you have with your child is helping him/her to understand the experience by taking it seriously. Hearing and validating the emotional world of your child can be a powerful expression of your love.

Attachment can also help you think about how to love other people in your life. You can maintain your attachment with your other children or family members with short visits and phone or video discussions. Making clear how much you love each of the other people in your life will be helpful in reassuring them that your attachment to them has not been severed even though you are not physically there with them.

You do not need to face all of these challenges alone. Additional support from

child life for your child with cancer, or for siblings, is another way to help children to process scary or overwhelming feelings.

Hope

What is hope? Defining this simple but important word would at first glance seem easy. According to Webster's Dictionary, hope is "to cherish a desire with anticipation." Yet for children with advanced cancer, the word is anything but simple, anything but look-it-up-in-a-dictionary routine.

James, an energetic 10 year old was being treated for an aggressive form of lymphoma. He was becoming more and more frustrated with being in the hospital and started refusing his medications. His father Paul thought James was starting to lose his will to treat the cancer and said, "No matter what the doctors say, we'll never give up hope. We can only think positive thoughts and keep fighting." When we asked James what he was hoping for, he replied, "Of course I hope the cancer goes away, but can't I go home for the weekend so I can go fishing with my dad?"

In our interactions with parents and family members of children with cancer, the common theme of hope is so powerful, yet it is often not discussed directly. We learn a great deal when we take the time to ask the question, "What are you hoping for?" Children and parents have the capacity to hope for many things from the very large, "I hope my child's cancer is cured," to the seemingly small, "I hope it doesn't rain so we can go fishing tomorrow." Most parents, regardless of their child's diagnosis or prognosis, hope for the best. No matter what the situation is in front of them, parents will often express *hope for a miracle*. Yet when we ask parents about all their hopes, other hopes, which may not seem as important, often also emerge—hope to spend time at home, hope to celebrate a special holiday, hope for comfort. Embracing all these hopes is important, as is giving yourself permission to be sad, frustrated or angry when one of these hopes does not come to pass, but also giving yourself permission to celebrate when other hopes do come true.

Parents also feel hopeless at times, and this feeling is normal. The journey of childhood cancer is not a straight path; there are many twists and turns that need to be navigated. Hopes of all sorts are our companions on this winding road. One brain tumor patient's mother was waiting for her son's MRI, which would determine whether he could have surgery to remove the tumor, and said, "It's so hard thinking all these different things. I go from hoping the MRI shows he can have the surgery to hoping it shows he can't so he doesn't have to

go through another operation."

Hoping for something that may not happen does not mean a parent *doesn't get it*. The ability of a parent to hold many hopes is a reflection of love and strength. At the same time that parents are hoping for the best, though, they are also likely hoping against the worst. Hope can be used during this intensely emotional time to anchor families for even the most unimaginable possibilities.

Sharie, mother to Jamal, a 14 year old with relapsed Ewing's sarcoma, arrived to a family meeting to discuss experimental treatment options. She told the team, "I will never give up hope that he will get better. I have to hope that something will work, and he wants to try anything he can. But, we have also decided some things as a family you need to know. He does not want to die in an intensive care unit or live on a machine unless he can be fixed." Sharie was able to protect her son from specific things as he got sicker by talking about their hopes with the oncology team.

Tactics and Strategies

We now share with you some of the ways in which parents have found or held onto strength, love and hope, based on what they have told us and what research studies have shown.

Give yourself permission to be angry, sad, happy or normal

"The other day, I had a normal day with my girlfriend. We went to lunch and laughed, remembering stories of when we were younger. On my way home, I had this huge wave of guilt for forgetting about the cancer for a while. I wondered if my friend thought I was a bad mom."

Taking time for normal activities can be a way of reenergizing yourself to continue to care for your child. Finding a safe space to be frustrated, angry or sad—and not getting upset with yourself because you feel that way—can be so very important. One mom of a young child with a brain tumor said, "I couldn't show my feelings about my daughter having an inoperable tumor. My family and friends were allowed to cry, scream and be upset, but I was supposed to be strong. I need to be able cry on someone's shoulder too." Expressing positive emotions in front of their child or family is a common goal for parents of children with serious illness, particularly if that illness is getting worse. Because many parents also often spend most of their time at their child's side, it doesn't leave much space for other emotions to come out. As one mother put it, "I get so mad sometimes that I end

up yelling at everyone about stupid things, like leaving dirty dishes in the sink. I just can't let myself be anything but positive in front of Maria. I don't want her to think I'm mad at her."

You may also need to give yourself permission to feel happy or *normal* (whatever that means to you) and not to feel guilty about having those feelings. John, the father of a teenager with a rare kidney tumor said, "I just need to go hang out with the guys, drink some beers, and hear about their kids sometimes. It makes me feel like things can be normal again."

Catching yourself being happy, according to families we talk to, can provoke all sorts of uncomfortable thoughts and feelings. How can parents be happy, even for a moment, when their child is so ill? Michelle, whose son has an aggressive form of brain cancer, was still working her full time job in order to provide healthcare and financial help to the family. She met with her boss who praised her good work and gave her a promotion. She was elated for a few minutes before immediately feeling guilty for being happy about something that should not be so important. Fortunately, sometimes happiness just pops up. We do not need to feel guilty about feeling happy. While going through such difficult times, with all the difficult feelings that arise, experiencing the other side of the full range of emotions, including happiness and pride, can help provide some balance. Another young mother, Angela, was distraught because her youngest child, who was healthy, had just learned to walk. She said, "I was so happy for a few minutes, watching him take his first steps. Then I remembered the cancer. And then I suddenly understood that I need to be happy sometimes, to feel some joy. I used to feel so guilty about it until I realized that my other kids need to see me smile sometimes and be happy for the things they are doing."

Stay connected to others

Studies show that connecting with other people is very important for most parents. Staying connected is particularly important when you are feeling overwhelmed by the situation. Sometimes you want to talk about things you can't talk about in front of your child or even other close family members. Sometimes you just need to spend time with friends who won't ask too many questions and just want to talk about day to day issues. Some parents find it helpful to talk to someone completely removed from the situation. Others find help in seeking out those who have had similar experiences. Some find counseling or therapy services either through their child's oncology team or in their communities.

Take care of yourself

Maria, the mother of a 5 year old little girl Breanna who was going through her second bone marrow transplant for leukemia said, "I'm tired of people telling me to take care of myself. I need to focus on Breanna now. I'll have time for myself later."

Maria's comments are common amongst parents of children with cancer, particularly those whose children have worsening disease. However, we do know that studies have shown that parents of children with cancer experience decreased quality of life, which in turn could impact their ability to be at their best. More exercise, better eating habits and higher sleep quality can lead to improvements in overall quality of life. Parents can often cope better with their feelings if they take care of their own needs. It's easy to forego things like eating, sleeping, exercising and taking breaks from caring for your child, in order to take on caregiving tasks.

Accept and ask for help

Parents who receive support will be able to cope better, experience less stress and feel less depressed than families who are isolated. Many parents feel they should be able to handle all the tasks that need to be done. More importantly, many parents feel they need to be the ones to provide care to the child who has cancer. Avoiding infections is a reason that some parents keep themselves isolated from family and friends. While this coping strategy may work for a few people, looking back on their cancer experience, most parents wish they had asked for more help. In addition, for longer illnesses, sometimes help that was present early in the diagnosis fades over time. Surrounding yourself with those who will stay with you for the long haul is important. Many parents feel they lose friends and family during a child's long illness because others *get tired of it and want to get back to their own lives*. One mother said, "I had so many people telling me to call them if I needed anything, but I didn't know what I needed, so I never called. I wish they would have just done something—mowed my lawn, brought me dinner or even just sat with me in the hospital for one of those long nights."

Extended family members often feel particularly helpless, and it can help both them and you to call upon them for some practical help with things such as childcare for siblings, errands, etc.

Recognize your resilience

We have found that parents who believe in their own resilience also have an easier time coping and caring for their families. How do you recognize your own resilience? Allowing yourself to feel your emotions, staying connected, taking

care of yourself, and accepting/asking for help is part of it. Next, think about the resources you already have. How have you previously handled difficult situations? Who supports you? How do you and your family like to communicate? How do you make decisions? Being aware of the answers to these questions will help you to advocate for yourself, your family and your child.

Finally, resilience can be learned. Studies show that certain activities enable people to adjust and cope better. These can be simple things like setting goals (having something to look forward to), learning to reframe negative thoughts (turning something bad into something good), and finding meaning or benefit from difficult experiences. "At first, all I could see was how sick he was from the chemo," said Kathy, whose 2 year old son Owen was receiving treatment for neuroblastoma. "But then, I started to think about how it was also killing the cancer. That made it easier."

Conclusion

Strength, love and hope are part of the cancer experience for children, their parents and loved ones. These qualities will be with you to help you cope and be resilient, and to guide you through this unimaginably difficult journey.

Family Perspectives

Pumpkin was Julia's therapy dog and literally went everywhere Julia went. Pumpkin was a registered volunteer with the hospital system, and the only place she couldn't go was the operating room. She'd ride the bed to the operating room door, and Pumpkin was the first one Julia wanted to see when she would wake up in the Pediatric Intensive Care Unit. Julia doesn't have any brothers or sisters, so Pumpkin became her sister. The unconditional love they had is something you'd read about in a book or see in a movie. It was amazing to watch them together! If Julia wasn't feeling good, she'd say, "Pumpkin I don't feel good," and Pumpkin would move up next to her on the hospital bed, lick her on the face and everything would feel better.



I lost so much sleep thinking that we were making a series of mistakes and that things could have been different. But this is such a cruel disease and no matter what we had done, no matter what anyone had done, Etienne would still be a very sick little boy. I often feel that any other parent would have known what to do better than I, but I can read on my online support group and see in the clinic that all parents are struggling just as we are.

We decided to have another child the day Etienne was diagnosed with cancer. It was our instinctive reaction. We had the baby a year and a few months later. We called her Katherine Lena ("Pure Light") because as soon as Etienne knew I was expecting, he began to put extra effort into walking. He seemed to have purpose. This baby gave us all a sense of purpose. I will not deny I am afraid of everything now, wondering if she will be sick too, but she brought our lives into perspective.



Shortly after Stella's diagnosis, I started to write about our journey with cancer on an online blog. Somehow, over the weeks and months, word spread about it and links were shared via Facebook and emails and over coffee at work. Strangers, family members and friends alike began to read the blog and learn about Stella. Despite her questionable behaviors and antics, I found people were genuinely drawn to my little girl. And as her

story spread, the most amazing things began to happen. People cared about her, about us. And the outpouring of love was incredible.

People baked cupcakes, cooked homemade macaroni and cheese, and one person even got an ice cream place by her house to whip up a special batch of "Stella" ice cream combining Stella's two favorite things, ice cream and avocados. Thanks to the generosity of our community, she got to go to her favorite place, Great Wolf Lodge, 5 times. And trust me, most people don't go there that often in a lifetime, let alone in a year. She was flown with my family and I to Pennsylvania where we had three days of VIP treatment at Sesame Street Land. She went to Riverdale Farm almost every week. People from all over sent her trinkets. Each day it seemed the mailbox held some present for Stella: DVDs of her favorite shows, a personalized t-shirt, hand knitted warm blankets, crayons, paints, balloons, books, dolls, toys, gift cards to Dairy Queen and Tim Hortons.

But it wasn't just "things" that people were giving us; it was actions. Once as I sat inside on the couch, holding Stella's limp body on my lap, a white car pulled up and started to unload. It was a woman we had never met, and her two young children, who had driven 2 hours and filled their car up with toys and treats for Stella, a little girl they had read about on the Internet. The two children came into our house and drew pictures and played with Stella for hours.

Acquaintances raised money to have a little playhouse in Stella's honor, called "Stella's Place," erected in a playground. An artist helped Stella create large canvases of one-of-a-kind paintings for her friends and family. Money was raised to erect a tree and bench outside Riverdale Farm in Stella's name. A young couple from Indiana drove 8 hours to bring Stella homemade ice tea and play a song they had written. Two little girls set up a lemonade stand every weekend in the summer, called it "The Joy Cafe" and donated over \$400 at the end of the summer in Stella's honor. A stranger arranged for Stella to go horseback riding at a place that specialized in allowing disabled children to ride a horse. A music therapist volunteered her time to bring dancing back into our house.

Every single day for 16 months, family and friends came over and painted Stella's toenails and fingernails with the gaudy colors she liked, created elaborate puppet shows for her, showered her with sweets and did anything—anything—to make her smile.

I don't really know when it happened, but in those gifts, those people and those actions, I began to see and feel God much more strongly than I ever had by reading the Bible or coming to Church.



My son was having a rough time with chemo while recovering from surgery, to remove necrotic tissue caused by radiation—the resection of some of his ribs and lung. One morning a social worker told him that he was eligible to attend camp and he begrudgingly agreed to go. His first day there, he was his normal grumpy self, so the other campers painted a bright yellow smiley face on his bald head, and his fellow campers, including the camp director, encouraged him to just have fun. The next day they encouraged him, too, only a little less often. By the end of camp, he needed no more encouragement and returned to the hospital a changed boy. He now knew that chemo would help him be like the rest of the kids at camp, and he accepted his remaining treatments better.

He really turned the corner when, three months after finishing chemo, he looked up at me while fishing and said, "Dad, I can feel the wind in my hair!" I wept.



In December 2006, my firstborn grandson had just been diagnosed with DIPG. Sammy was 4 and had won my heart over a million times! Dear friends who live down the block called early that Sunday morning as we were packing up our personal items, our Christmas, and our business, in a matter of a few hours, to drive straight through to St. Jude with our son, daughter in law, Sam and his 2 year old brother and 6 month old sister. We would be gone almost two months, sharing the care of our grandchildren. I had only had 20 minutes of sleep in 48hrs and was rushing to pack the last things in the car when they arrived. Still in their pajamas, with tears in their eyes and arms wide open with compassion, they shared our sorrow. Staying only a minute, my friend quickly handed my husband \$400 telling him it was all the cash he had at home and that he wanted us to use it to buy gas and food for our travels to Memphis, TN. These are the friends I call family.



Her strength was never-ending, and all the while she never lost her

personality. I brought her to Church with me on Palm Sunday about a year after her cancer diagnosis. By that point, she had lost control of almost all her bodily functions, but could still move her arms in big, jerky sweeping motions. She spent the entire service trying to hit me in the face with the palm she gripped in her right hand, giggling each time she made contact.



Our family was very blessed with community support when Tatumn was diagnosed with a brain tumor. Family, friends, our older children's schools and neighbors rallied around us. The outpouring of love was unexpected and truly appreciated, but some of my most valued support came from another mom of a child with a brain tumor. No one else could understand the gut-wrenching decisions I had to make and the worries I had for my other children.



At an early age Julia tagged along when my wife and I volunteered at various places. She loved visiting the seniors with the dog and I, but her favorite place was a local soup kitchen. If Julia felt up to it during treatment, we'd head for the soup kitchen on Fridays. She'd do what she could, and when she got tired or felt icky, she'd hang out in one of the offices. No matter how she felt, when it came time to serve drinks, she was behind the counter filling glasses and talking to everyone. This helped her forget about her cancer for a little while. She also talked about her treatment being almost better than being homeless and not having food.



I don't know how we would have survived cancer (the shock, horror and pain of watching our son endure chemo, radiation, surgeries, pain and suffering), unless we had faith to hang on to. Our precious son Noah fought cancer with strength and courage. He joined the Angels in his heavenly home just one month ago, at the age of 17. The pain and heartache is unbearable, but with faith you make it through the minutes, hours and days.



When my brother was diagnosed with cancer, my family had a decision to make. We could be constantly focused on the ultimate end and never actually live life, or we could focus on the present and make every moment count.

During this difficult time I relied heavily on my faith. I wasn't ready to think about Tatumn leaving me, but when I did think about it, I had some comfort knowing she would be in the joys of heaven and I would see her there someday.

My family is evolving in our new life without Tatumn and I am a work in progress. I try to find answers that will comfort me when I am able and advocate for childhood cancer when I can, but I am also learning my limits. Tatumn will always be a constant in our lives and while I love her from earth I will work hard so my other children can continue to grow in love and won't feel they have lost their mother.



And, while it would be lovely to stand before you today and say that Stella beat the odds, that the love and light of our community helped her battle the evil demons of cancer and she made a miraculous recovery, I can't. Stella was born in the Spring of 2009, with its promise of life and renewal. Stella died in our arms in the Fall of 2012 when the leaves were changing from green to brown and the wind carried with it a certain chill. She was 3 1/2.

Although I am battered and bruised with the pain of having to watch my vibrant and beautiful daughter be ravaged by a cruel disease, I am also grateful. It is good to be able to share my memories of Stella, and recognize and be mindful of the strength she gave me, the lessons she taught me, the love she showed me

Many people think that me talking about the life and death of my beloved daughter is sad. But it is not. My daughter's story has sad parts to it, definitely. But her story is one of hope and faith renewed. It is the story of people coming together. The story of finding comfort in the every day miracles of community and fellowship. The story of finding light in the darkness. It is a life story and it is a love story. And I am grateful to be able to share it.

Part II When Hope Changes

Expectations: Hoping for the Best, Preparing for the Worst

Elisha Waldman, MD

When a child has cancer, maintaining hope plays a major role in coping for both parent and child. There is always room for hope, and it is an important element of how families continue to function day after day despite the uncertainty inherent in a diagnosis of cancer. But what may be far more challenging, and maybe even more important, is also preparing for the worst. Nobody likes to think about worst-case scenarios, but learning how to maintain hope while still exploring all of the scary *what-ifs* is an important part of caring for the child with cancer, as well as the rest of the family.

One of the things that makes exploring the what-ifs so challenging, not just for families but for healthcare professionals as well, is that while clinicians can often make general statements about prognosis, making accurate and specific predictions about the course of a disease and what to expect can be very difficult. Different types of cancer may behave differently and lead to different complications and outcomes, often for reasons we don't fully understand. It is impossible to know when, or if, a child may develop potentially life-threatening complications in the course of his or her illness. As difficult and scary as it may be, this uncertainty is exactly why preparing for all possible outcomes is so important.

Advance Care Planning

Often, parents worry that if they discuss the what-ifs, it may signal that they have lost hope, or it may mean that the medical team will stop trying its hardest to cure the child. However, neither of these need be the case;

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on the contrary, discussing the what-ifs is actually an important way of protecting the child and the child's family. This exploration of the what-ifs is often referred to as advance care planning. Advance care planning may be as simple as having a discussion or series of discussions with the child's team about expectations and goals, or it may mean actually putting down in writing a plan for what to do in case of an emergency. Despite the difficult nature of these conversations, they often end up being very beneficial emotionally and psychologically; children and family members tend to cope better over the long term and have less long term difficulties when they have had time to think ahead and to discuss plans. Though many parents are hesitant to include their children in such discussions, studies suggest that a child from a very young age is aware of the nature of his/her illness and wishes to be involved in decision-making, even surrounding end-of-life decisions. More than that, avoiding such discussions may lead to children feeling that they cannot express their hopes and fears or ask questions, and may actually make children even more distressed. As scary as things may be, children may imagine that things are far worse than they actually are. In fact, one major study showed that when parents were asked about discussing the possibility of death with their child suffering from cancer, none of the parents who had that discussion ended up regretting it. In contrast, some of the parents who did not engage their children in a discussion later regretted that they had not. The healthcare team can guide parents as they have a conversation with their child at an age-appropriate level, and parents may want to talk with the team in advance about how to approach such discussions.

Another reason why exploring advance care planning is important is that it is a way to physically protect the child and to make sure that events unfold in a way that is consistent with the family's goals and values. Sometimes emergencies arise unexpectedly, and often, especially if the primary clinical team is not immediately available, healthcare providers may follow a set of automatic procedures unless documents are in place instructing them to do otherwise. For example, if the child were to suddenly develop trouble breathing at home during the night, it may be important for an emergency team called to the house to have written, legal instructions available on arrival that lets them know that the parents and child have discussed this in advance and that there are certain things that may or may not be in accordance with their wishes. These are very difficult decisions even in the best of circumstances, and are all the more difficult when they arise suddenly; the best way to ensure that the child is protected is to explore the possibilities in advance in the light of day, with the child's clinical team and family, hoping that these emergencies never pop up, but preparing for them just the same.

Do Not Resuscitate Orders

As a part of advance care planning, parents may be asked at some point to discuss what is commonly referred to as *Do Not Resuscitate (DNR)* orders. In some hospitals this is actually a matter of routine, where everyone, regardless of what they are being admitted for or what expectations are, is asked on arrival about what should be done in case of a sudden life-threatening event. In some settings patients or their guardians may actually be asked to sign a written document, while in others clinicians may simply explore the issue with the patient or guardians and then document that conversation in the medical record. It is important to stress that just because staff members are discussing DNR orders, it does not necessarily mean that they believe something bad is likely to happen; it is simply a safeguard intended to protect patients in case anything does happen, expected or unexpected.

In the past, the idea of DNR orders was generally understood to refer to one of two things: insertion of a breathing tube and subsequently being placed on a mechanical ventilator if the patient were to be unable to breathe independently, or attempts at getting the heart beating again if it were to stop or develop an irregular rhythm. However, because there have been so many technological advances in modern medicine, discussions about DNR orders often may require clinicians to also talk about other procedures, such as putting a needle or a tube into the chest, using medications such as drugs to maintain blood pressure, or using antibiotics. Again, these discussions should be viewed as an important part of making sure that the child receives the best care possible.

It is important to note that when parents or guardians discuss DNR orders, or even sign a document outlining those orders, they always have the right to change their minds and to change the orders. Parents should never be made to feel that anything is *written in stone*, and it is perfectly natural for a patient's and family's goals to change with time over the course of an illness.

There are a couple of reasons why the parents may find that they are asked about DNR orders on more than one occasion. This can be frustrating, but it is important to recognize the reasons behind being asked more than once. For one, the child's healthcare team will want to be sure that the family's goals have not changed over time. As noted above, often family and patient wishes change over the course of an illness, and it is important that the medical staff remain aware of those wishes to ensure that they are followed. Additionally, under certain circumstances, for example, an unexpected emergency may occur during the night and the parent may find the child being cared for by clinicians unfamiliar

with past discussions the family may have had with the child's providers. In such a case, a clinician may address the issue of DNR orders not to be cruel or to scare the family, but rather to make sure that they are providing the best possible care in accordance with the family's goals.

There are no right and wrong answers when discussing DNR orders; the *right* answer at any given time is the plan that most closely fits the family's goals and that will allow the medical staff to act accordingly should the child experience a life-threatening event.

Communication with Healthcare Professionals

DNR orders and advance care planning in general are influenced by, and in turn may themselves have an impact on, good communication with healthcare professionals. On the one hand, having clear directives set out in advance of any sudden, stressful changes helps make sure that the family's wishes are clearly conveyed to the medical team. At the same time, maintaining good, clear communication with the child's healthcare team is critical in helping the parents to think about advance planning and to understand what the different options may be.

One aspect of communication with healthcare professionals that is often very challenging for families is simply the sheer number of individuals who may be involved in their child's care. Understanding the different roles that people may play can seem incredibly confusing, especially when many of those faces are new or changing all the time. With so many different people involved, the family may end up feeling closest to and most comfortable communicating with one particular member of the child's healthcare team. Often this will be a member of the primary team, the group that the parent and child will meet with most often and that will usually be the best source of information on the child's current situation and upcoming treatment plans.

However, there are many other individuals whom the family may meet, interact with, and even feel close with throughout the course of the child's illness. These may include residents (pediatricians in training), fellows (oncologists in training), bedside nurses, technicians, chaplains and staff from other departments (e.g., psychologists, surgeons, and radiation oncologists). Healthcare professionals will do their best to approach the parents and their child in a polite, respectful manner. At times, it may seem that they are asking questions that the parents have already answered or that may make the family uncomfortable. If this is the case, or if the timing is not convenient (for example, the child has finally fallen

asleep after a long night), it is perfectly acceptable for the parents to ask if the conversation can happen at a later time. This may not always be possible, but healthcare professionals will try to accommodate the child's and family's needs first. As noted above regarding DNR orders, it is important to remember that team members are asking questions only because they are interested in making sure that the child receives the best care possible; clear communication with the team is an important element of making sure that happens.

Especially if the child is being treated at a teaching hospital, the patient and family have a wonderful opportunity to impact the development of young clinicians. Often less experienced healthcare professionals will ask questions that may seem simple, repetitive, or at times even invasive, but they are usually asking out of a genuine desire to learn and to understand. By approaching each interaction with the team as an opportunity to also teach healthcare professionals, the parent and child can have an important and lasting influence on the care of others and on how future patients and families are treated.

Role of Pediatric Hospice and the Palliative Care Team

One asset that might be available at the hospital or in the community, and that may be useful in helping with communication, is a pediatric palliative care team. These teams are increasingly being integrated into healthcare systems, and may go by several names other than palliative care (for example, advanced care team). Many people wrongly assume that these teams, or any service involving the term *palliative*, are involved only in situations where children are expected to die and that they deal primarily with end of life issues. In reality, modern palliative care services offer a much, much broader range of services, and are often consulted to help out with children and families facing potentially life-threatening illness regardless of stage of disease or prognosis. Many children who survive their illnesses greatly benefit from the support of palliative care services as part of their care. Though caring for children at end of life is indeed a part of what these teams do, they may also help in many other ways, including, among other things, symptom management, thinking about difficult decision-making, and thinking about how to care for children with complex needs over the long term. In addition, these teams may be very helpful in facilitating communication between patients, families and other services. Palliative care teams may be useful in helping parents talk to their child about expectations and decision-making, in helping them convey their concerns to the child's primary team, and in helping translate the primary team's thoughts from medical language into layman's terms.

The primary team may also discuss with the parents the availability of community-based palliative care or hospice teams. These are services that are often in fact more focused on maximizing quality of life as end of life approaches and in helping make sure that the family's goals and values are taken into account. It is important to emphasize that if the primary team suggests involving a palliative care or hospice service, it may not mean that they believe the child is imminently dying. Much as with DNR orders, the child's team may feel that a palliative care or hospice service may be useful as an extra layer of support to have in place just in case. Additionally, accepting hospice services does not mean that the patient and family have to sacrifice support for any other services. In fact, most states now have laws in place mandating that children be eligible for support for hospice care at the same time that they are receiving disease-directed therapy (such as chemotherapy). This is of course in line with the *hoping for the best, preparing for the worst* philosophy, allowing families and their healthcare teams to continue pursuing treatments while preparing for any possible outcome.

Because palliative care or hospice teams may be introduced relatively early in the course of the child's illness, the degree to which the service is involved in the child's care may vary. For example, if a palliative care service is consulted to help during a moment of crisis, and that crisis then passes, the team may not remain as actively involved and may in fact just check in from time to time to see how things are going and to make sure the parents know they are available. In short, palliative care and hospice services are an important extra layer of support that parents should be aware of and should feel comfortable utilizing to any degree that feels right to them.

Last Few Days/ Deciding Where a Child Should Die

One of the most important advantages that a community-based hospice service may provide is to give a patient and family options regarding where they would like to be at the end of life. The final days or weeks of a child's life may be a time when important memories are made, when rituals (spiritual or otherwise) meaningful to the family may be introduced, and critical conversations can happen. Anticipating the possibility of death as early as possible and planning ahead is an important part of infusing this difficult time with as much meaning as possible. Choosing, when possible, the location of a child's death is an important part of this. Some families choose to remain in the hospital as death approaches, taking comfort in the constant presence of medical staff nearby. Many hospitals now have specially designated *comfort rooms* where families

may request to be moved for the final days or hours. These rooms are located in the hospital, often in the same department where the child has been treated all along, but the rooms are often more spacious and family-friendly, allowing for loved ones to visit and spend time in comfort. Though these rooms can accommodate all of the medical support that the child may still need, often they are designed so that medical devices and technology are less intrusive, allowing families time to be with their child in a less *medicalized* environment.

Many communities also have hospice houses available as an option. These are facilities that specialize in the care of individuals approaching the end of life, and also have the advantage of medical staff support being present twenty-four hours a day. This may be important to families who no longer wish for their child to be in the hospital environment but where being at home may not be an optimal choice. Though many people imagine these facilities to be somber and sterile, families are often pleasantly surprised on visiting to find that they can be very warm and comforting environments, and are designed to provide as homelike and supportive an environment as possible.

Finally, many families feel that their child is most comfortable at home and that death would be preferable in an environment that is familiar. This can be a scary undertaking for families, and hospice services, especially if involved early, may be critical in allowing families to attain the goal of remaining at home for end of life care. Hospice providers generally do not remain at the house twenty-four hours a day; they usually visit at least once a week, if not more often, depending on the child's needs. They are always available by phone and are always able to send someone to the house regardless of the hour if the need arises for extra support.

As discussed previously, it is often very difficult to predict how the final days and hours of life may look. Children may slowly develop more labored breathing, become sleepier, and ultimately become unarousable. Depending on the nature of the illness, other, more potentially disturbing symptoms may arise, often without warning, such as pain, cough, seizures, or drooling. In order to help make sure that the child is well cared for and does not experience any suffering, hospice staff will often go over a detailed emergency plan with the parents, delineating what medications to give or actions to take should any issues arise. Along with an emergency plan, the hospice team may also provide an emergency pack of medications, so that should symptoms arise the parents can, with direction from the hospice team, help provide rapid relief.

Sometimes, despite all planning, a sudden life-ending event may occur

unexpectedly outside of the hospital. This is one other situation in which early involvement of hospice services may provide an advantage, regardless of expectations or hopes that end of life would occur elsewhere. If hospice services have already been involved, should a life-ending event occur suddenly, the parent will be able to contact them at any hour and they will send a provider to the child's home. On arrival, if the child has in fact passed away, they will pronounce the child's death and fill out a death certificate, a very important step from a legal perspective. In most states, the medical examiner must be notified of any death at home, and may choose to investigate any death that does not seem readily explained. Having home hospice services involved, especially if advance care planning has been discussed and a DNR order is in place (many states now have special documents, *comfort care forms*, which serve as DNR orders outside of the hospital setting), is one way to signal to the medical examiner that there is no need for further involvement.

If the child has one of these outpatient DNR forms, the parents may also choose to call their local emergency medical services if the child dies at home or if, as death approaches, they decide that they do in fact prefer to be in the hospital setting. Producing the form upon the arrival of medical personnel will legally allow the parents to request that they not perform any attempts at resuscitation but rather simply provide comfort and transport the parents and child to the hospital, where the team can help provide support and guide them through the steps following death.

Often families feel particularly connected with a particular clinician who played a role in their child's life, whether it be the pediatrician or a member of the oncology team. Though these individuals may not always be available twenty-four hours a day, if death is anticipated families may discuss in advance with their team whether a particular clinician would be willing to be called to the house to pronounce death; a familiar face may provide some comfort for the family, and the provider may also find some meaning in being involved in the end of life of a child for whom they cared.

After Death

Many families fear that once their child has been pronounced dead they will lose the support of their healthcare team. Ideally, healthcare providers, including the primary team as well as palliative care and hospice services if involved, remain available to help guide family members through the period after death. Additionally, these providers may also help connect family members with specialty bereavement teams, which may be hospital or community based, as

well as various types of support services and support groups. These services may be helpful in navigating some of the logistics necessary in the period immediately following death, for example returning equipment or registering the death (which is important for tax purposes), as well as in long term coping and support. Though families may maintain hope throughout their child's illness, even in the face of bad news, it is important to know in advance that these sorts of services exist and that they will be available to help should death nonetheless be the final outcome.

Family Perspectives

When Talia was first diagnosed with cancer on February 14, 2007, I said to myself, "Talia will be just fine—chemo, surgery and it will be over, and she will continue on her life." Even though the doctors told me that Talia was diagnosed with neuroblastoma and her chances of surviving for 5 more years were slim, I always kept my faith that Talia would be different and she would beat this. After three relapses and a secondary cancer, Talia's chances were zero.

It was a hard day when I talked to Talia about a DNR. She knew what that meant and she wanted a DNR. She didn't want to live in pain, and she didn't want to be on any life support. Talia was old enough at this time; she was almost 14 years old, and she had been fighting childhood cancer for 6 and a half years. She knew all too well what she had gone through and what this journey was all about. She wanted to live, but not like she was. The DNR was signed and everything changed. The monitors were stopped, and the vitals were not taken that often. That was a very sad time. But it was the reality that Talia was going to die.

Talia was still in pain—not as much, but it could be better. Now that the DNR was in place, I think the doctors and nurses felt that they could give her what she really needed without feeling that they were going to harm her. We just needed to find that right dosage and the right drugs to keep her comfortable. All of Talia's medications were increased to higher dosages and more frequently. The palliative doctor was still coming in her room everyday, as well as the other doctors and Talia's main doctor. Talia would talk to them and tell them how she was feeling, and if she needed more pain meds, anti-nausea or anti-anxiety, they listened.

Because of Talia's neuroblastoma, MDS, low counts, and radiation, she was getting blood and platelet transfusions quite frequently. Her fevers were still very high which would eat up her platelets. At the end of life, the doctors were especially diligent about making sure Talia's platelet count was high so that she wouldn't have any bleed outs.

I wanted to do anything to relieve her fears of dying, too. Talia was one to embrace all religions, so I called all the people I knew to talk to Talia

about heaven and the after life. I had a Rabbi, Priest and a Pastor come in to speak with Talia about their views on where we go after we die. Talia listened, and sometimes she asked questions. I even had someone come in and talk with her about her own experience with dying, and how she went to heaven but came back to tell what it was like. Talia was 13 years old, and that is a time that a child either has a Bat Mitzvah or Bar Mitzvah. I asked Talia if she would like to have a Bat Mitzvah, and she said yes. So, that is what we did. Talia had a beautiful ceremony in her hospital room with our Rabbi and close family and friends. I left no stone unturned; I wanted Talia to be at peace and not be afraid of dying.

I was so grateful for the doctors and especially the palliative care doctor that cared for Talia. That morning the palliative doctor was called because she was breathing heavily. The doctor ordered medicine to help her labored breathing. Talia was still talking and alert. The doctor stayed in her room the entire 2 and a half hours making sure she was comfortable and in no pain.

Talia passed away peacefully at 11:22 am on July 16, 2013.



We never wanted him to feel like he was sick with a terminal disease. We knew our son, and all he ever wanted was to be a big boy like his brother. He attended school and made many friends. He had no symptoms so we kept his diagnosis very private so he could have as normal a life as possible. He was genuinely a happy little boy for 15 months after diagnosis.

When it became apparent that he was in progression, we turned our focus to keeping him as comfortable as possible.



Recovery was easy. By the time I walked back she was almost completely awake. Later we played—just Jennifer and I. It was only a few minutes but just playing with her and coloring was wonderful. Then we got on the ipad to talk to Daddy and her brothers. It was adorable how they talked to each other. Nicholas (our 2 yr old) said I love you to her. I have never heard him say that to anybody before. (How will our boys survive all of this?) For dinner we had a picnic on the floor. We had girl talk. The kind of thing I should be doing for years to come with her. We talked about boys and told silly jokes. And we laughed—oh how we laughed! It was wonderful. And so unfair.

Mason's last days were something that makes me truly believe in the power of children to know their own body, no matter their age. After his last scan we were sitting in bed and we were talking about what was happening. He said, "I know it is all over my body Mommy." I told him we would not let him be in pain. He said, "Okay," and went to sleep. The next morning he woke up screaming that he was dying, he was done, leave him alone, etc. A full-blown tantrum. We gave him some emergency meds from hospice and he calmed down and took a bath with me, then played with my husband on the couch. He slept and waited for his brother to get home. They played stickers a bit, and he was resting his head on my shoulder; he said thanks and went to sleep. He started to actively die about 5 hours later. He was done. He let us know and let go.

It took him about 16 hours to die. It was a pretty textbook experience. I was glad we had been well prepared regarding what it would look and sound like. We had friends and family come by the house to say their goodbyes. We had a friend manage the people in our house. I never left his side and held him most of the time. We are grateful that our hospice kept him comfortable. His older brother Mateo actually packed Mason's bag for heaven with all his favorite toys and things.

At the end, he was in our bed with all of us around him. It was funny—the hospice nurse told us the time was coming soon, but his brother was not home. We called our older son Mateo to see if he wanted to see Mason before he died. He said he did not want to come home from his game. We did not force it. But Mason waited for him. Mateo walked in about 5 hours later, held Mason's hand, told him the score of the soccer game and sat next to him with us. Mason died about 5 minutes later. They say people wait for the most important person to get there, and Mason certainly did. He loved his brother more than anything and he waited for him so he could leave at peace.



The nurse that was present when he passed went into prayer after he passed. We are not religious and I felt very disrespected at a very hard time.



Khylee did not like being in the hospital, so it was important to us to have

her final days at home. With her hospice bed in the living room, we watched her favorite shows, read her favorite books, had many visitors and simply loved on her. One book we read repeatedly towards the end was There is a Party in Heaven. We never told Khylee she was going to die until the final day in which I was able to tell her, "Khylee you are going to Heaven, and Mommy, Daddy and Craigee will be there very soon."

During the last 24 hours of Khylee's life she began to build up a lot of fluid in her mouth and had difficulty breathing. I recalled a conversation I had had some days earlier with our regular hospice nurse about a medication that dries up the secretions. I asked our on-call nurse about it, and she instructed me to give Khylee the atropine which was in our care pack. If that had not been managed, I fear Khylee would have suffocated on her own saliva and not had a peaceful passing.



We knew from the first few hours after Stella's diagnosis of DIPG (malignant brain tumor), that she was going to die. I believe we were still in shock when we began to make many important decisions regarding Stella's last days. My partner and I decided immediately that we were going to take Stella home. We were in agreement that she required the highest quality of life it was possible to give her, and that this quality of life was something we would provide for her at home, not at the hospital. We also immediately agreed to a DNR. Our thought was that if she was going to die regardless, there was no reason to prolong her life needlessly if her body began to shut down. Our focus from Day 1 was around ensuring that she did not suffer. That was the thing that kept us up at night crying and worrying. We knew we could not tolerate knowing Stella was going to die if we also believed she was going to suffer. Our palliative care team was phenomenal. They asked us to tell them our greatest fears and told us that they would give us all the information we required to put our minds at ease. We spoke about the fact that if she stopped eating/drinking she would not suffer from hunger or thirst, as at this point her body would not need or want food or drink. We were told we could use a feeding tube if we wished, but to be aware that the tube itself would be uncomfortable for Stella and putting it in would require a hospital stay. Also, if her body was beginning to shut down a feeding tube would only prolong her death, not prevent it. We shared our wishes that no feeding tube be used for Stella and we stuck with that, even though it was immensely difficult when Stella did not eat or drink in the last days

of her life. We had to keep repeating to ourselves what the palliative care doctors told us, "Stella is not dying because she's not eating or drinking. Stella is not eating or drinking because she's dying."

Knowing that Stella was going to die, we were very preoccupied with the when and how aspects of it. Luckily, our palliative care doctor was incredible and patiently explained to us over and over again what we could expect. We were given a pamphlet that explained what the last few days/ hours/moments of life can look like as far as physical changes, and came up with a plan that we shared with our palliative care team and family and friends, as well as funeral service providers. This was a wonderful decision for us as everyone was aware of our wishes as Stella's life ended. We knew from asking questions that we did not have to call the Doctor to pronounce Stella's death immediately, and we took advantage of this by taking our time saying goodbye to her. Stella died at home with her family, and we invited everyone to have a few moments with her alone in the room to say a personal goodbye. We read books to her, stroked her hair and held her. When we were ready, we called the palliative care team to come to the house and pronounce her death. Once they left, when we were ready, we called the funeral home. We told them in advance that our child was not leaving our house in a body bag, and they were extremely understanding and caring. Our family and friends lined the house with candles and we all stood outside and made a human chain to witness Stella's exit from the house. We wrapped Stella in a soft white blanket, and she was carried out of the house by my partner and placed in the arms of one of the funeral directors. Stella was not put on a stretcher, but was cradled in the funeral director's arms while her colleague pulled out of our driveway in a regular black sedan, not a hearse.

After Stella's body left, we cracked open red wine and toasted our little girl by raising our glasses to the twilight sky.

Stella's death is something I'm immensely proud of. Planning for it in advance and communicating clearly our wishes with everyone involved—family, friends, caregivers, doctors and the funeral home, made us feel in control and allowed everything to happen very smoothly and organically. Her death was as full of love as her life, and the memory of it, instead of being traumatic, is actually very comforting and beautiful for us to remember and share with others.

Organ, Tissue and Tumor Tissue Donation: Giving the Gifts of Life and Hope

Angela Punnett MD, FRCPC Kimberlee Spady, JD

Organ and Tissue Donation

Some patients and their families may wish to explore the potential for organ and tissue donation following death. This is a complicated decision, and it is helpful when planning to understand the background of organ donation in the context of a cancer diagnosis; which patients may be eligible to donate; the process for donation; and implications of organ donation at the time of death. Tissue donation is a related, but somewhat different, process.

History of Organ Donation and Cancer

There are a significant number of patients awaiting solid organ transplantation at any given time, and 5-8% of these patients will die while awaiting transplant. Lack of consent to organ donation by the population at large is the main limiting factor to transplantation.

It is generally accepted that individuals with a diagnosis of cancer are not eligible to donate their organs because of the risk of transmitting cancer to the organ recipient. This risk of transmission has been documented since the early days of solid organ transplantation, with

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reports of close to half of recipients developing the donor's cancer, resulting in death.

However, not all cancers are equally likely to spread, and recognizing the need to balance a potential donor recipient's life-threatening illness with a risk of cancer following transplant, an International Consensus document was forged in 1997. The group of experts writing this document recommended consideration of donors with low grade skin tumors, very localized (in situ) uterine cancer, and primary brain tumors that very rarely spread outside of the central nervous system (CNS).

The list of potential donors with a history of cancer continues to expand as we are better able to collect data about the risk of transmission to organ recipients. However, at present the discussion for potential pediatric organ donors is most relevant for those children with primary brain tumors. Children with a history of any type of cancer may be able to donate tissue, and in particular corneal tissue, from the eye (gift of sight), and possibly heart valves, bone tissue, skin and more.

Patients with Primary Brain Tumors: Risk of Spread

Spread of a primary brain tumor outside of the CNS, or extracranial metastasis, has been considered unlikely because of anatomical and biological features of the CNS itself. The CNS is a relative sanctuary with the so-called *blood brain barrier* and has few lymphatic channels. As a brain tumor grows it invades surrounding tissue, collapses existing blood vessels, and really has nowhere else to go. However, studies have shown that brain tumor cells can grow in other types of tissue, and invasion of blood vessels and lymphatic drainage has been documented.

The most important and consistent risk factor for extracranial spread is the cell type and grade of malignancy. The tumors most likely to demonstrate extracranial spread include ependymoma at about 6% of patients, medulloblastoma at about 5% of patients, and glioblastoma at about 0.5% of patients. These numbers are based on relatively limited and older data, however, and are difficult to interpret. In addition, a number of other risk factors for extracranial spread have been proposed, including duration of disease, receipt of chemotherapy and/or radiation therapy, and history of craniotomy and/or ventriculosystemic shunt.

Donor Transmission of Primary Brain Tumors

There are a number of case reports in the literature documenting transmission of tumors from donors with primary brain tumors to their organ recipients, in

some cases causing death. Recipients of heart, lung, or liver transplants, were more likely to die from transmitted malignancy, as kidney transplant recipients could be saved with chemotherapy or removal of the transplanted kidney.

A number of transplant centers have reviewed their local experience in an attempt to understand the risk of transmission. The resulting analysis showed that donors with a history of primary brain tumor accounted for 1 to 4% of all donors. Among those donors with a history of primary brain tumor, the risk of transmitting a tumor to an organ recipient was 0 to 3%.

Larger experience is available through mandatory reporting to national organ transplant registries. In the United States, the United Network for Organ Sharing (UNOS) has published its experience, which shows donors with primary brain tumors consistently represent approximately 1% of all donors. Out of 642 transplant recipients, 3 developed a fatal tumor from one donor with glioblastoma multiforme (0.5% transmission rate). When comparing survival curves for recipients of kidney and liver transplants from donors with and without primary brain tumors, there is no difference. Donors with primary brain tumors represent 2.6%, 2%, and 1.5% of all donors in the Australia/New Zealand, Czech Republic, and United Kingdom registries respectively, with no cases of donor-derived malignancy reported.

Somewhat different data is available through the Israel Penn Tumor Registry, an international, voluntary reporting registry based in the United States that started in the very early days of transplantation. It is not possible to estimate the incidence of transmission with this registry data, but it is possible to look at risk factors for transmission. Among 62 organ recipients from 36 donors with primary brain tumors, 14 (23%) developed a tumor; almost half of the donors had glioma/glioblastoma. Risk factors for transmission from this data include the presence of ventriculosystemic shunt, extensive craniotomy, high-grade histology, and the presence of a cerebellar lesion.

When organ donation is being considered, the local organ procurement organization (OPO) and the transplant team must consider the donor's medical history in the context of the patients awaiting transplantation. The risk of transmission of a tumor from a donor with a primary brain tumor is difficult to quantify but appears to be low, with identifiable risk factors that increase the risk. It has been recommended that potential organ recipients be informed and counseled regarding the small but definite risk of transmission of malignancy, as well as the chance of survival if they choose to remain on the waiting list for their needed organs. The final decision regarding transplantation lies with the transplant team and potential recipient.

With donors considered to be higher risk, transplant teams may exclusively request certain types of tissue donation (for example, cornea, heart valves, bone, other), where the risk of transmission is practically nil.

The Process of Organ and Tissue Donation

Families of children with cancer may be considering organ and tissue donation at different times during the course of the child's illness. It is helpful to speak with the health care team sooner rather than later in order to explore options and the implications for the child's care around the time of death. The health care team will then refer the family to the local OPO, and a representative will meet with the family to discuss the donation process.

Organ donation occurs following confirmation of a donor's death with the goal of maintaining the organs in a healthy state until the time of transplantation. The process of removal of the organs from the donor is called organ retrieval. With brain death, there is confirmation of irreversible brain damage but continued heart activity, such that the organs are still perfused, or receiving their blood supply from their donor. Donors are maintained on artificial life support until organ retrieval occurs. Some hospitals will offer donation after cardiac death, after careful ethical consideration. In those situations, a donor is removed from all life support and death is confirmed by lack of heartbeat and breathing effort. Organ retrieval occurs immediately thereafter. In either case, death must occur in the hospital for donation to occur.

Current guidelines recommend careful review of a donor's medical history for the risk factors discussed above, as well as careful exploration at the time of organ retrieval to assess for metastatic disease. The areas to assess may include sites of previous surgery, related lymph nodes, and the shunt tract, including the chest, abdomen and pelvis. This surgery is like an autopsy and may be limited to specific sites in discussion with the OPO and the transplant team. In the unlikely event that spread of malignancy outside of the brain is confirmed by pathology, the transplant team will be notified immediately, and the organs retrieved will likely not be used for transplantation.

The process around tissue donation depends on the tissues being donated and will require discussion with the OPO representative. For cornea donation, for example, the tissue is less sensitive to lack of oxygen, and retrieval can take place hours after death. In this situation, there is more flexibility for families around the time of death.

Transplant teams take great care of their donors during the organ and tissue

retrieval process, and an open casket is possible with organ and tissue donation.

At the Time of Death

Every family will have their own needs and wishes for their child at the time of death, and organ and tissue donation may not be appropriate or possible for many families.

For those families who do want to pursue the opportunity to donate, it is important to understand the small possibility that the gift of organs may be denied. (This is much less likely for gifts of tissue.) It does appear that transplant teams now have better data to appreciate the absolute risk of tumor transmission in the case of donors with primary brain tumors and to counsel potential organ recipients appropriately. There is an urgent need for organ and tissue donors worldwide, and patients and their families have developed an extraordinary legacy with their gifts.

Family Resources for Organ Donation

The following resources may be beneficial to families considering organ donation.

U.S. Government Information on Organ and Tissue Donation

http://www.organdonor.gov/default.asp

Trillium Gift of Life Network

http://www.giftoflife.on.ca/en/organandtissuedonation

Tumor Tissue Donation

Sadly, there will be some families who are faced with the unthinkable during their child's cancer journey. These families will be told the options have been exhausted; there is no treatment that provides hope to extend their child's life. They will likely be devastated and thrust into a place of disbelief and fear. Yet, they will be faced with another important and perhaps difficult request to consider: if their child succumbs to cancer, will they be willing to make an ultimate, selfless gift? Will they allow the cancer to be removed for research that will provide hope for children who are diagnosed in the future?

The Lack of Available Tissue

Although many cancers present as a mass that is removed in whole or in part as an element of the treatment protocol, a significant segment of pediatric cancers do not present this way. Research regarding these cancers has historically progressed slowly due to the lack of available tissue. For example, research focused on diffuse intrinsic pontine glioma (DIPG), a near-universally fatal brain cancer, has historically been sparse due to the disease characteristics. The cancer cells are diffuse, sprinkled and dispersed within the healthy tissue of the pons; any attempt to remove the cells surgically would cause devastating damage. Sometimes (and with increasing frequency), the affected tissue is biopsied to confirm diagnosis or to assist in making treatment decisions. Biopsy samples are, however, very small; little, if any, DIPG tissue is left after analysis of a biopsy sample.

Similarly, hepatoblastoma is a rare pediatric cancer of the liver that is often completely resectable. In those cases, the five year survival rate is promising. Tumors which are not completely resectable, or which reoccur, do not carry such a positive prognosis. Researchers seek to discover the distinguishing characteristics between these situations—what is different about the disease in children who survive it and in children who do not? How does the cancer that comes back differ from the cancer that was initially removed?

Where diseased tissue is not readily available to researchers, little is known about the molecular basis of the cancer cells that comprise the tumor and

what empowers those cells to grow and thrive. When researchers lack such critical information, effective treatments cannot be developed. Clinical trials may be based not on the specific disease being targeted, but on similar diseases for which tissue can be

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studied. Adequate access to tissue is essential for researchers to perform a complete molecular analysis and identify potential targets for drug development.

The Changing Landscape in Autopsy Tissue Procurement

Even for pediatric cancers where treatment options have remained static over the course of decades, the intensity of ground-level research is increasing. More dedicated and ambitious researchers seem to be honing in on particularly challenging pediatric cancers. Worldwide access to information via the Internet, which also facilitates communication among affected families and between families and researchers, levels the plane of information across cultures. These combine to increase awareness and encourage teamwork between and among researchers and families. Efforts are being made to ensure that families at every stage of the childhood cancer journey know that researchers need tumor tissue and that invaluable knowledge is gained from every tissue donation.

Again using DIPG as an example, a worldwide *community* of families has formed via the Internet and is evidence of the impact of parent-led efforts in research. For that reason, DIPG is a particularly impressive example of the importance of autopsy tissue donation.

Increased awareness of the need for DIPG tissue coincided with and facilitated studies performed by several highly respected researchers at leading institutions. These studies analyzed DIPG samples donated via autopsy, as directed by families following the death of their children. The researchers' published findings demonstrated that new and beneficial information can be gleaned from tissue that is donated post-mortem. This tissue provides insight into the characteristics of the tumor and its genetic composition. Additionally, analysis of autopsy tissue can reveal how therapies such as radiation and chemotherapy cause changes to the tumor at the molecular level. Researchers are learning how the cancer cells adapt and change to develop resistance against therapies that were effective against the disease for a limited time.

The published confirmation of the immense value of DIPG autopsy tissue has generated excitement and increased focus on post-mortem tissue donations. More researchers are working together to develop innovative ways to share and use autopsy tissue and the information gleaned from it. Armed with new information, researchers are—for the first time in history—seeking to develop therapies that target DIPG tumor cells based on specific, known genetic characteristics.

The DIPG community's efforts and influence provide both inspiration to and a framework for others affected by pediatric cancer. Most families of children who

are taken by cancer have the opportunity to ensure that scientists have access to tissue to support their work toward finding effective treatments and cures for rare and fatal cancers.

Deciding to Donate

Parents are geared for hope. Even when faced with a devastating diagnosis and dismal prognosis, parents cling to the idea that the past does not dictate the future. While the family may understand that the child is not expected to survive, the idea of considering an autopsy donation remains almost incomprehensible. Somehow, though, some parents find a delicate balance between hope and the reality of their child's diagnosis. They consider, and even plan for, tumor tissue donation while firmly holding on to hope and believing that their child will survive.

Autopsy tissue donation is a gift to families who will be affected by cancer in the future, given by families who know well the tragedy of the disease. Donation allows a life cut short to make a long-lasting impact and often gives comfort to the deceased child's family. It is also important to some parents that the cancer ultimately be eradicated from their child's precious body. Autopsy donation achieves that and an ultimate victory over the disease, even in death.

Regardless of the motivation, autopsy tissue donation is at its base a selfless and positive step in an unspeakably difficult journey. Sadly, it is a gift that can be given only by heartbroken and grieving parents of children taken by a deadly disease. Even more than that, it is a gift that often epitomizes the very nature of children who have endured the ravages of cancer and, in a final act of bravery and generosity, desire to give hope to the families of those children who will follow them.

Physician Involvement in the Process

Just as it is difficult for parents who are in the midst of evaluating treatment decisions for their child to acknowledge the realities that accompany autopsy donation, it is difficult for physicians to initiate a discussion about the subject. The physician and parents are a team, working in tandem to discover an effective treatment for the child, holding on to hope for a long life and bright future. The idea of autopsy donation does not fit into the treatment plan. It can feel like even acknowledging the possibility or speaking the words is somehow giving up, agreeing to defeat.

There are also more pragmatic reasons that treating physicians might not be eager to discuss post-mortem tissue donation with families. Many physicians, particularly those affiliated with smaller institutions, more rural facilities, or

institutions without a focus on pediatric cancers, may not understand the value of autopsy donation. These doctors must have a broad base of day-to-day clinical knowledge as they treat children afflicted by all types of pediatric cancer. Tissue from the rarest pediatric cancers are, due simply to numbers, especially valuable for research. At the same time, the treating physician in a small center might see children affected by these rare cancers very infrequently. It is simply not reasonable to expect that such doctors will be familiar with the most current clinical information about treating the disease and also up-to-date with options to support research if treatment is ultimately ineffective.

In a similar vein, some physicians maintain an old-school approach, believing the only reason to perform an autopsy is to determine the cause of death. The idea of arranging an autopsy for the purpose of research is not familiar or comfortable to them.

Time and money are particularly practical factors that might affect the physician's perspective. Educating and counseling a family regarding autopsy donation can be time-consuming and emotionally draining. Add to that the fact that neither the treating physician (who is likely over-burdened with numerous and varied responsibilities) nor the treating institution may directly benefit from the donation, as far as furthering their own research projects or goals. Financially, an autopsy requires the use of personnel, facilities, equipment and other resources for which the physicians and institution may not be paid or reimbursed.

Whether it is for one of these or a myriad of other reasons, many physicians do not tell parents of the possibility of an autopsy tissue donation. Physicians often reveal, however, that they are relieved when a family raises the topic in their own way and in their own time. It is rare that a treating physician who is asked to arrange a donation is not eager to do so. In the unusual case where a physician is reluctant or ill-equipped to help, others stand ready to assist. Foundations and parents who believe strongly in the value of autopsy donation will work to achieve the family's wishes. Once a physician or family communicates with these volunteers, they will make the necessary contacts and develop a plan for the donation, while also seeking to protect the family from distraction and stress as much as possible. Both financial and logistical supports are available; these need not be a concern to either treating physicians or families.

Preparation and Arrangements

The timing and degree of parent involvement in arranging for a post-mortem tissue donation varies dramatically from family to family. Some parents choose

to include educating themselves on post-mortem tissue studies as part of their regular information-seeking during their child's illness. These parents want to be well-informed regarding ongoing research so they can make a deliberate decision as to which study/studies to support with their child's tissue, should the time come.

For other families, the idea of autopsy tissue donation is simply unthinkable until after their child takes his or her final breath. Most of the time, a donation can still be arranged, even with no pre-planning.

Other Considerations

This chapter is included as an effort to educate parents regarding the need for autopsy tissue donations and to provide general information regarding the process. The intent is not to persuade or convince parents who do not wish to donate to betray their convictions. On the other hand, it is important that parents understand that nearly any perceived obstacle to donation can be overcome and almost all concerns can be satisfactorily addressed.

As mentioned above, there are expenses associated with autopsy donation. That need not, however, be a factor in the decision to donate. Many institutions bear the expense of research-driven autopsies, particularly for their own patients. Even when that is not the case, or when the autopsy is performed by a third party or at a facility where the child was never treated, financial support is usually available. Specific research protocols may have funds dedicated to meet the autopsy expenses. In other situations, private funds are available; a handful of private foundations are committed to ensuring that a grieving family will never be forced to sacrifice financially in order to give the gift of tissue, and these foundations have established funds specifically to cover the expenses of such donations.

Another concern voiced by families is whether the child's final days must be spent in a hospital to accommodate a tissue donation. Many families choose to spend this time together at home, usually with the assistance of hospice. Location does not impede a family's ability to support research via post-mortem tissue donation, particularly with a little advanced planning. In fact, hospice personnel are often eager to help in these situations, as they understand the importance of the tissue donation to the family and its value in the grieving process.

Peace and comfort for the family, during a child's final days and immediately following death, is of paramount importance. Families who are committed to tissue donation are encouraged to spend as much time as they desire with their child following death, regardless of where the death occurs. While there are optimal timeframes within which an autopsy should be performed, the emotional

needs of a heartbroken family is the primary focus. At the same time, it is helpful to some families to have in mind a timeline to guide them in making decisions along the way.

The timeframes will vary depending on the type of cancer and the research protocol being supported. In general, studies requiring fresh tissue present the shortest window of time during which the autopsy must be performed. Optimal results are achieved with tissue obtained within three hours following death, but tissue retrieved up to six hours after death may be acceptable. Of course, the tissue deteriorates with the passage of time. As a result, the quantity and type of knowledge potentially garnered from it changes.

The numerous studies which do not require fresh tissue present a wider optimal timeframe for performance of the autopsy. The knowledge sought via these studies is dependably acquired from tissue obtained up to 24 hours after death. On the outer limit, an autopsy performed up to 48 hours after death may result in tissue which renders useful knowledge.

Individual scientists employ varied methods for storage and transport of autopsy tissue samples. Additionally, the technologies and protocols which guide research made possible by autopsy donations are ever evolving. A family who has chosen to spend extended time with their child following death should never assume that the time for autopsy donation has passed. More importantly, however, a grieving family should not feel hurried or distracted because of the decision to donate.

When a child dies at home, the pathologist who will perform the autopsy is contacted, and the child's body is taken to the appropriate facility. Usually, the funeral home chosen by the family comes to the home when the family is ready and transports the body to the autopsy site. (The autopsy will often be performed at the hospital where the child was treated, but might be done at another hospital or even in a funeral home, depending on the specific circumstances.) If the autopsy will be performed in a state other than where the death occurs, special permits for transporting the body over state lines must be obtained, so some specific preplanning is required in those instances.

Another inquiry shared by parents relates to the availability and condition of their child's body after the donation is complete, as this affects planning for a funeral or memorial service. It is important to many parents that their child's body is returned to them quickly and in a way that is appropriate for viewing during an open-casket service. The removal of tumor tissue should not cause concern in this regard.

The amount of time between the child's passing and the delivery of the child's body to the funeral home will vary depending on the time of death and the location of the autopsy. Hospitals generally do not perform autopsies during nights, weekends or holidays. If it seems that a child is likely to pass during a weekend or holiday, having a plan in place is helpful. Once the autopsy begins, the procedure itself usually takes about an hour. In most circumstances, the body is then transported by the funeral home personnel to the funeral home facility for preparation. Even when the tissue is removed from the brain, it is done in such a way that there is no visible evidence from most angles. It is, however, best to ensure that the pathologist who will perform the autopsy is aware of the family's plans and will be able to accommodate them.

Conclusion

Whether to donate post-mortem tissue is an intensely personal, and often painful, decision. There is no right or wrong choice. In fact, the family's plan may change from day to day. Nevertheless, any family who reaches out to a parent or organization devoted to this effort will receive the utmost respect and as much support and assistance as possible. Most volunteers are parents who have endured the heartache of the process themselves and are committed to ensuring that the family not be distracted or distressed by the details of a post-mortem donation. At the same time, these volunteers will join with the family in hoping and planning for the child's future.

Many parents, clinicians and researchers alike believe that autopsy tissue donation is key to bringing hope for children diagnosed with rare and terminal cancers. Growing numbers of treating physicians and parents are realizing that, even in death, children have the ability to influence the future. In turn, researchers are engaging in coordinated efforts to share resources and findings. New and ground-breaking studies are being made possible by post-mortem tumor tissue donations.

Family Perspectives

When my son died, we immediately offered organs and anything else they could use to save another child. We were told that they could only use his eyes. Two people have sight because my son died. We also donated tumor. The tumor was used in a study comparing original untreated tumor and tumor post treatment. It was determined from that study that the treatment causes the tumor to mutate and that the original drugs become less effective after treatment has been going on a while.



After we got over the initial shock of Stella's diagnosis, and the fact that she had just months to live, our family was very interested in donating Stella's organs after her death. We thought that if our little girl couldn't live a long life, that at least her death could help others. Disappointingly, we were told that children who have her type of brain tumor (DIPG) cannot donate their organs. It was difficult to hear this as we had hoped her death could help someone else, and it didn't make sense to us. Here was a child who had a tumor that was only in her brainstem; her heart, lungs, liver and kidneys were all perfectly healthy, yet they would not accept anything. Since we had been clinging to the thought that at least her death wouldn't be completely in vain and would save someone else's life, being told that she was not eligible for tissue or organ donation was another blow to us. Our palliative care doctor sympathetically offered us one bit of solace; he said that if we were willing to donate Stella's tumor after her death, the research they were doing might help find a cure for this horrific disease and could save others in the future. We immediately agreed and signed the tumor donation papers the next day.

We were told that donating her tumor did not change significantly the chain of events upon her death. She would die at home and when the funeral home came, instead of taking her directly to their funeral home, they would transport her to the hospital where the tumor donation team would remove her tumor and then release Stella back into the care of the funeral home. We chose direct cremation for Stella, so open casket considerations were not something that we discussed.

Recently the doctor to whom we donated Stella's tumor was given a large grant to continue her research on DIPG, and a few weeks ago her lab published an article about new molecular subgroups for DIPG that they discovered. Knowing that Stella's tumor is helping others has given us a sense of peace and softened the disappointment we felt at not being able to donate her organs.



We started to think about donation in our daughter's final days. When her oncologist visited, we decided to ask him about tissue donation. As parents, we decided we were against donating non-cancer related organs/tissues, but were fully in agreement for donating our daughter's brain tissue for the purpose of advancing research towards a cure for childhood cancer. We did not discuss this with her; perhaps we would have if we had read about it and thought to discuss it with her early on when she was able to think about it and communicate her thoughts with us. Her oncologist supported donating her brain tissue for this purpose, and explained it was a simple process. The hospital would work with the funeral home on arrangements for transport to the hospital after her passing, to obtain brain tissue within hours of her passing, and transport her back to the funeral home for her funeral preparation, at no cost to us. The hospital did great work; we would not have known she donated anything at all.



As Brendan's treatment options came to an end in May 2011, we talked about tumor donation with our medical team. They said we could donate his tumor after he died and that we could figure out the details as the end neared. They walked us through what would be involved. They had us meet with the funeral home and inform the funeral director that we would be donating the tumor.

Brendan's pediatric neuro-oncologist took the lead and worked out the logistics with the surgical team and the funeral home. The funeral home worked with the medical team to arrange for the transportation to and from the hospital. Brendan's physician came by the evening of June 17 as Brendan struggled to breathe, and we talked about what would happen as he slipped into a coma. He told us that they were prepared to handle the donation and that we would have as much time as we needed with Brendan at home to say goodbye after he stopped breathing. He explained exactly what

would happen and that we would be kept informed every step of the way.

Brendan died early in the morning on the 18th of June. The hospice worker handled the communication with the funeral home and the medical examiner's office, as his death was expected so they didn't have to come to the house after he died. She let them know what time he passed, and the official death certificate was prepared. Brendan stopped breathing that morning, and we stayed at home with his body for several hours. Later that afternoon we had the funeral home come. His body was transported to the hospital where the surgery was done. They preserved his brain and tumor tissue for future research. The funeral home called us, so we always knew where Brendan's body was every step of the process.

Months later we met with the pediatric neuro-oncologist again, so he could review the pathology report with us. Donating Brendan's tumor to medical research was the right decision for us; it was one way that we could make it just a little bit better for other children who would follow Brendan's path.



When cancer was unyielding Carson whispered words I'll never forget, "Momma, I thought I was gonna make it.... Don't let them bury me. Make sure they study those tumors. If those tumors can help some kid not die from cancer like I am, I'd like that; it's hard to have cancer."

So for us, knowing some of those tumors were studied two days after he died has been helpful as we grieve the death of our boy.

Then, knowing there is SO much research to be done, we have raised funds to study the rest of those tumors, with deep-aching hope that the study of those tumors will help some kid not die from cancer, like Carson did.



It was our teen daughter's last wish to have her tumors harvested and sent to the Children's Oncology Group for further testing and research. Our daughter believed that if she could not be spared from this horrid disease, that perhaps, by providing answers to doctors and researchers through donating her tissue, it could potentially help another child or teenager afflicted with the same disease. The more information we can gather about the disease, the better chance we have of finding a cure.



Peyton passed away on April 29th, 2014. He was originally diagnosed with stage IV alveolar rhabdomyosarcoma. We chose to donate our son Peyton's tumor tissue for many reasons. We wanted to help kids and families going forward with better treatments and hopefully a cure some day. We did not want Peyton's death to be in vain. We also knew that Peyton's case was a little unique because his primary tumor presented in a not so common location, his mid-lower spine. When his cancer returned, it returned in the brain as leptomeningeal carcinoma, when most rhabdo returns to the primary tumor site or metastasizes to the lungs. Peyton's tissue came from many places in his body as we requested they do a full autopsy to get as many samples as possible from as many different areas as possible.



Tumor donation.

Not something I ever imagined we would have to discuss in regards to one of our children.

Our daughter Jennifer was diagnosed with DIPG on her 6th birthday, Oct. 28th 2013. DIPG is a brain tumor that is terminal upon diagnosis. I couldn't believe that any of it was real. I was still in that fog 3 months later when we found out that the tumor had progressed rapidly and it was time to go on hospice.

The tumor on her brain stem had progressed to different parts of her brain and her spine. We asked if all the tumors would be helpful. The way her beloved and loving oncologist responded to that question was my first real glimpse into how important the donation of tumors is in the world of pediatric neuro-oncology. She was, well for lack of a better word, excited about telling her colleague, Dr. Michelle Monje, about our decision.

I thought it would be easy emotionally to donate. I thought I was prepared for so much in her final days. I wasn't. I had never used the words her tumor. It wasn't supposed to be in there so I never wanted to connect it with her. In those last weeks, as she suffered more as a result of those tumors, I began to hate them in earnest.

At that time I was so sure we would donate, I couldn't imagine not doing it. I thought the logistics would be the hard part, but that was easy from the beginning.

Jennifer took her last breath at our home, in my arms, 2 weeks later,

February 12th 2014. Then I got it. I understood how hard this choice really was.

Her little body had been through so much. It was finally at peace. Did I really want to put it through more? I was worried about the scars; what if I wanted to see her again? I didn't want to have to let her go—physically. I wanted to lie there with her forever.

My husband reminded me gently that this was what we wanted to do—to help her make a difference. Eventually he had to help me out of her room.

It was not easy for me, not in that moment. I think if this hadn't been our plan, that time that I had to say goodbye to her body would have been even more traumatic. If I didn't have a reason to let her go, I don't think I ever would have. The funeral parlor staff quietly came and got her.

I kissed her head and told her she had work to do. Work a 6 year old should never have to do.

It's only been 2 months since she died. Initially hearing the surgery was done I felt a sense of relief; finally those horrible tumors were out of her. I knew we would be burying her the way she was supposed to be, tumor free. I saw her afterwards and I couldn't tell that she had donated; the markings were not visible.

We have received multiple updates about her tumor cells. (We asked for them; we could have chosen not to get them.) Notice that I say her tumor cells now; about 2 weeks after she was gone, I started to feel connected to those cells, something that was once a part of her, a piece of her—the final physical piece.

We have agreed to have her cell line shared with other researchers. It's not how I wanted her to see the world, but now she will. That gives me some twisted sort of relief. To know a part of her is still fighting, still waging a war against pediatric cancer. She would like that. I do too.

Jennifer is survived by three younger siblings. When they are older I will share with them the articles that credit her cells, and the fund we started in her name, with helping researchers. Just 2 months later and I already have one saved for them.

We will also eventually give them the option of seeing the research in action. They will be proud of their big sister for making a difference. I hope they will be proud of their parents too—for making a gut wrenching choice, for making a difference by giving a gift that only we, parents of children with terminal cancer, can make.

Tumor donation.

Grief

Christine Denhup, PhD, APRN, CPNP

Loss is part of the family's experience when a child is diagnosed with cancer. Loss means that someone or something of great importance has been taken away. Loss can mean different things to different people. There are many different kinds of loss.

For the family whose child is diagnosed with cancer, completes treatment, and survives, loss occurs. It can be the loss of health and familiar surroundings when at the hospital. Being in the hospital also brings the loss of routines, school and activities with friends. For siblings, the cancer diagnosis can mean the loss of attention from family members and friends. It is natural for people to pay more attention to the sick child because they are concerned for the child's wellbeing.

Parents need to be with their sick child at the hospital and tend to the child's many needs. Parents also need to work and see to all the responsibilities of daily life. As a result, siblings experience the loss of their parents' presence. For siblings, the cancer diagnosis also brings the loss of routines and activities with friends. Additionally, there is the loss of security that everything will be all right. For parents, a child's cancer diagnosis can mean the loss of normal family life. It can mean the loss of hopes and dreams that they had for a healthy child and for their own future. Grandparents also experience loss. For grandparents, the cancer diagnosis can mean the loss of the hopes and dreams they had for their grandchild, their own child, and even themselves.

For the family whose child is diagnosed with cancer, receives treatment, and does not survive, great loss occurs when the child dies. Everyone in the family is affected in many ways.

When loss occurs, families experience grief. Grief is very individual. Each member of the family experiences grief in his or her own way. Christine Denhup is an Assistant Professor and Quality Improvement Coordinator at the Department of Nursing Southern Connecticut State University, New Haven, CT.

Grief

Response to loss

Grief is a normal and natural response to loss. Grief is a mixture of many different things. Some people experience many of those things. Other people experience just a few.

People can have different feelings. Many people feel sad. Crying is a physical release of sadness, although not everyone cries when they are feeling sad. Some people may want desperately to cry, but they cannot. Many people long for what they have lost. Some may feel angry. People often feel guilty or blame themselves for something they feel they did, or did not do, to cause the child's cancer. Some may feel lonely. Some people feel envious of other families who have not been affected by childhood cancer. People may feel shock and numbness. Some may feel a sense of helplessness or a sense of being powerless over the circumstances. Some people may feel a sense of peace or relief.

People may experience physical symptoms. Many have aches and pains. Headaches and feelings of tightness or pressure in the chest are very common. Many people feel very, very tired. People can feel so tired that it becomes very difficult to do simple things, such as getting out of bed, bathing, and getting dressed. Some may have problems eating and sleeping. People may lose interest in sex or have difficulty with sex. People can feel short of breath or shaky. Some people become more sensitive to noise.

It can be very difficult to concentrate. People may become confused. It is very common for people to feel disbelief that this has happened to them. It is common to have reoccurring thoughts about the loss. Many people search for some meaning in what has happened.

Behavior changes are also a normal part of grief. A person's performance at work can change. Some parents, for example, say they notice they make more mistakes at work. This may be a result of the combination of being very tired and having difficulty concentrating. Some people keep very, very busy while some people withdraw from others. Some seek out or carry reminders of the loss, while other people may avoid all reminders. Many want to talk to others about their loss, but some people do not want to talk to others. Some may overreact to situations. Many experience changes in relationships with friends or family members.

There is no right or wrong way to grieve. Grief varies from person to person.

Men and women's grief

Men and women often have many of the same grief responses that have already been discussed. Yet, society can influence how men and women express their grief. Society mistakenly expects men to *keep a stiff upper lip*. There is often the erroneous assumption that fathers don't grieve; therefore, fathers must be in a position to comfort the child's mother whose grief is greater. This, of course, is simply not true. Society often expects women to cry and not get angry. This is unfortunate because when fathers and mothers are confronted with great loss, their grief is real and may be expressed in a variety of ways.

Children's grief

A child's grief response depends on age and development. Infants can sense parents' stress, separation, and changes in routine. They may cry a lot, become clingy, resist cuddling, eat less, or sleep more.

Toddlers and preschoolers also sense their parents' stress. They react to separation and changes in routine. They often become clingy, have problems eating and sleeping, and have crying spells. Some may react by biting and kicking. It is also common for young children to return to behavior from an earlier age. For example, a five year old preschooler who was once toilettrained may start to wet the bed at night. This is a common reaction to stress.

School-age children may be moody or become distant and withdrawn. Some children cry when they feel sad, while others may try to hide their tears. Some may refuse to go to school, while others may have problems concentrating in school. It is common for children to have stomachaches or headaches. Some children become aggressive or have angry outbursts. Some behave very well to avoid upsetting their parents. Some children do household chores in an attempt to comfort parents.

Teenagers may feel sad, angry or guilty. Teenagers often have mood swings and may withdraw from friends. They can have problems sleeping or eating. Some teenagers take more risks. For example, they may become involved in unsafe things such as drug or alcohol use.

Grief intensity

Just as the type of grief responses vary from person to person, so too does the intensity of grief. Grief can be more intense on some days and less intense on others. Sometimes the intensity of grief increases for no known reason. It can feel like grief comes out of nowhere. Other times, the intensity of grief

may increase because of a specific trigger.

Triggers are situations that bring the loss to immediate attention in a sudden, intense way. What may be a trigger for one person may not be a trigger for someone else. Birthdays, holidays and anniversaries are examples of triggers that can increase the intensity of grief. Seeing friends of a child who died grow up and mature can be a trigger. Seeing other families do fun things with their healthy children can be a trigger. Seeing another child who looks like the child with cancer can trigger grief, and going back to the hospital or going to another hospital can trigger grief. Seeing other people for the first time since the child was diagnosed with cancer, or since the child died, can be a trigger. Watching a TV show that is like the family's experience may be a trigger. Seeing the child's favorite foods in the grocery store can trigger intense grief, as well as seeing another child do something with a parent. Other losses can trigger more intense grief. Sometimes it's just a spring day or a cold winter's day that will trigger grief.

How long does grief last?

Just as the type of responses and intensity of grief vary, so too does the time it takes to grieve. Grief does not occur in any particular order of stages. How long grief lasts is different for every person. There is no timetable to grief. Grief ebbs and flows. It lasts for as long as it lasts. For many, grief lasts a very long time. Sometimes grief can last a lifetime.

Effects of grief on family relationships

Grief can affect the relationships people have with family members. No two people experience grief in exactly the same way at exactly the same time. This is true even for people within the same family. A father may wish to attend a grief support group, but a mother may want to stay in bed in her pajamas and be sad. A father may wish to visit his son's friends, but a mother may want to stay away from them because it is too painful. A mother may want to talk about her child, but a father may avoid doing so out of concern for upsetting her. One sibling may feel more comfortable staying home alone, while another sibling may want to have fun with friends. All of this is very normal. However, it is sometimes hard to understand why people feel the way they do. This can lead to feelings of frustration and anger. It can become difficult to relate to one another.

Grief doesn't always have a negative effect on relationships. Grief can make relationships better. The members within a family share a similar loss. They may better understand one another and support one another as they grieve

together. Some families become closer after the loss of a child to cancer.

Parental Bereavement

The death of a child is devastating for the entire family. For fathers and mothers, it may be the most difficult and traumatic thing that can happen. After the death of a child, parents enter a new state of being called parental bereavement. Parental bereavement lasts a lifetime and has no end point. Suffering is part of parental bereavement. Parents continue to have a relationship with and maintain bonds with their child. In parental bereavement, parents also journey towards healing sustained by hope.

New state of being

Parental bereavement is a new state of being in which life is completely different than it was before. When parents describe what it has been like for them since their child's death, some say it is a totally different life. Some say that everything is defined as happening either before the child died or after the child's death. Many parents say life never, ever goes back to the same as it was before. Many parents say this new, totally different life is like a new state of being or a new sphere of reality.

The idea of *normal* ceases to exist. Some parents say bereavement can be compared to the after effects of a terrible storm. Often, these after effects go unnoticed by others.

Suffering

Suffering is the distress parents experience after a child's death. There is much suffering in parental bereavement because, parents say, nothing compares to the loss of a child. Only those who have experienced the death of a child can truly understand how it feels. Many parents say it is indescribable and they would not wish it on anyone.

Grief is part of bereavement. Some parents have said that, at times, their grief response was so intense that they felt out of control, and that scared them. There may be times grief can be less intense and parents are able to feel some comfort.

When parents know that their child is dying, they may begin to grieve. This is known as anticipatory grief. Parents who experience anticipatory grief may have many of the grief responses discussed previously. They also may begin to plan and prepare for the child's death. In spite of preparing, many parents have said that they felt unprepared at the actual moment of the child's death. When a parent experiences anticipatory grief, it does not mean that grief will be less intense after the child's death. For some parents this may be true; however, for many parents,

grief after the child's death is still very intense.

Continued relationship

The child's absence leaves a void that can never be filled. Parents have said it feels like something is always missing. Sometimes, a father or a mother can forget for a short time that the child has died. For many, it is hard to believe that life continues after a child has died.

Yet, in spite of the child's absence, the special bond parents have with their child continues. Parents do many different things to feel close and more connected to the child who has died. Not all parents find all of these things helpful. Parents often try different things to see what makes them most comfortable.

Many parents feel close to their child who died when they feel sad. Sometimes parents just want to stay in bed in their pajamas and feel sad because it comforts them to feel more connected to their child.

Talking helps many parents feel more connected to the child who died. Some parents talk aloud to their child. Some write letters to their child. Many parents like to talk with other people about their child.

Sometimes other people worry that talking about the child who died will make the parents feel more sad. Many parents say that not talking about the child is much worse. Talking about the child who died not only helps parents feel closer to their child, but also assures them that their child is not forgotten.

Looking at the child's picture is another way that some parents feel connected to the child who died. Some parents put pictures of their child up around the house. Some parents upload their child's picture onto their cell phone so they see their child every time the phone rings. Looking at pictures is not helpful for every parent. For some parents, looking at pictures is difficult and triggers intense grief. If this is the case, parents may choose to put their child's pictures out of immediate sight and take them out whenever they feel like seeing them.

Keeping their child's belongings is another way parents stay connected to their child who died. Some parents keep their child's bedroom the same as it was before the child died. Some parents keep their child's unlaundered clothes stored in a bag that they can open to smell their child's scent. Some keep their child's medical supplies. Some wear their child's jewelry. Some parents keep their child's special toys. Some parents display their child's favorite things in a special place inside their home. Some parents choose to keep their child's cremated remains in an urn inside their home.

Some parents try going to psychics. Parents have said they go in hope that a psychic's reading will help them feel more of a connection with their child. Some parents have said that visiting a psychic gave them comfort and was helpful. Others have said visiting a psychic was neither comforting nor helpful.

Many parents choose to remember their child in special ways. Some parents get a tattoo of their child's name. Some light candles. Some attend special events in their child's honor. Some remember their child through arts and crafts. Some celebrate their child's birthday. Some hang their child's Christmas stocking full of written letters. Many parents remember by simply continuing to love their child. Remembering helps parents feel close to the child who died. Remembering brings parents comfort. Sometimes parents worry that they may forget their child. But no matter how much time passes, parents never forget their children.

Some parents have reported that they have received comforting signs from their children, though not all parents do. Signs parents describe receiving include a peaceful feeling of the child's presence; dreaming of their child; smelling the child's scent; manipulation of electronics, such as lights, cell phone, and iPad; seeing certain animals, such as yellow birds; finding a penny engraved with the year that the child was born; and finding an object that has a lot of meaning.

Self-change

Parents are forever changed after a child's death. Some have said they are never really the same again. Many parents say they can never go back to who they were before the child died.

A parent's personality may change. A parent who was once a very confident person may experience self-doubt after a child dies. A parent who was once very quiet may be a vocal advocate for things of great importance after a child dies. It is different for every parent.

Many parents have said they sometimes need to pretend to be someone who they don't really feel like they are. Some parents pretend in order to be able to do the things they need to do. Some parents pretend in order to protect themselves from being judged by other people. Some parents pretend in order to protect others from feeling sad and upset. Parents often pretend by putting on a *happy face*. It is very tiring to pretend. Most parents can only pretend for a short time.

A parent's identity can seem to change. Sometimes parents feel like they are nobody's parent. For many parents, they know they will always be the mother or father of the child who died. Some parents say that being a bereaved parent is only part of who they are.

Parents are often left feeling that they have to reinvent who they are as a person at a time when they least want to do so. A parent may feel divided, or like part of them is frozen in time while another part journeys on in life. As parents continue their lives, they search for meaning and often redefine themselves with new goals and purposes.

When a child dies, the dreams a parent has for the child's future also die. Parents often dream of their children growing up to be adults. Some parents dream of their children graduating from high school or college. Some dream of their children being in school concerts. Some parents dream of their children getting married. Some dream of their children becoming parents. When a child dies, dreams parents had for themselves die, too. Parents' dreams for their own futures are linked to the dreams they had for their children. Some parents dream of dancing at their child's wedding. Some dream of becoming grandparents. Some parents dream of hosting their child's homecoming dance. Some dream of buying their child's first car. Parents dream of being the parents of an adult child. Some parents dream of the friendship and love their child would bring them. Dreams for the future are another loss parents experience when a child dies.

Journey towards healing

No parent gets over the death of a child, but it is possible to learn to live with the loss. That's what healing means. For most, healing is never fully complete. Learning to live with the loss of a child can last a lifetime.

The journey towards healing is very difficult. For some parents, it can feel like trying to climb out of a very deep, dark hole. Some days a parent may feel like he or she takes two steps up, only to fall back down to the bottom of the hole again. Parents take very small steps every day as they learn how to live in a world without their child.

For some parents, the journey towards healing may mean living in survival mode, or just putting one foot in front of the other and doing what needs to be done. Everything takes more effort. Some parents have said living in survival mode feels like pushing up against a brick wall that doesn't move. Parents may learn to really live again over time, and their thoughts will not always focus on the fact that their child had cancer and died.

There are many things that can help parents along their journey towards healing. When parents take good care of themselves, this can help; however, it is not always easy to do. Eating healthy foods and getting enough sleep and exercise are important. Talking with others is important. Many parents find it helpful to talk with their child's nurses and doctors. Some parents find that writing about their

grief is helpful. Taking time off from work if possible is helpful for many parents. Parents often wonder if medication would help them to feel better. Medication may or may not be helpful depending on the situation. Parents can talk with a nurse or doctor about how medication may be of help.

Along the journey towards healing, many parents search for meaning. Parents may find meaning in many different ways. Some are involved in the childhood cancer community. Some parents are on hospital committees to make the care of children and families better. Some parents do volunteer work in honor of the child who died. Some parents simply live their lives each day in honor of their child. One parent has shared, "To honor your child is to go on with living."

As parents find meaning, they contribute to their child's legacy. The child's legacy brings meaning to the child's death and gives parents a renewed sense of purpose. Some parents quickly find meaning in certain activities. For other parents, their search for meaning takes a long time.

Along the journey toward healing, many parents wrestle with why their child died. Sometimes parents blame themselves, even though there is nothing they did or didn't do to cause their child to have cancer and die. Many parents simply say that there is no reason.

Hope sustains parents along their journey towards healing. Many parents have the hope that with each passing year of bereavement, grief will lessen, suffering will ease, and life will change for the better.

What Does NOT Help When Loss Occurs

There are many things that do not help families when a loss occurs. It does not help when people try to explain the loss. These are some examples of comments that do not help.

- Everything happens for a reason.
- God knows best.
- God doesn't give you more than you can handle.
- You have other children.
- I know how you feel.
- Time will make it better.
- You'll get over it.

- When your heart is open, healing will come.
- Pick your head up and move on.

Comments like these can cause more suffering for the person who has experienced loss.

It does not help when other people avoid the person who has experienced the loss of a child to cancer. This makes the person feel even more alone. It is especially hurtful when friends walk away to avoid contact. One mother tells a story of how she was in the grocery store and saw a friend walking toward her down the grocery aisle. When the friend saw her, he turned in the opposite direction and walked down a different aisle. The mother felt that she was being treated as if she had a contagious disease. It doesn't help when people stop calling to talk, and it is hurtful when friends stop visiting. One father tells a story of how a good friend made plans to have dinner with him one evening. At the very last minute, his friend called to say he couldn't make it. This was difficult for the father to understand. It is also very hurtful when people stop talking about the child who died and about the family's well-being.

It does not help when people ask questions without true concern. These are some examples of questions that may be difficult to answer.

- How are you?
- How many children do you have?
- Do you know if your other children have cancer too?

Questions like these can be very upsetting.

It does not help when people complain about their own minor problems. When a loss occurs, it can be very upsetting to hear people complain about their healthy children's school or sports performance. It can also be difficult to handle people complaining about the stress of everyday life, the weather or minor health issues.

What DOES Help When Loss Occurs

There are many things that can help families who have experienced the loss of a child to cancer. Families are comforted when people listen to them and talk with them—especially about their child. Talking about the child shows families that others remember. It is especially helpful to say the child's name aloud.

Kind gestures bring relief and comfort, even if only for a short time. Making a phone call and sending a card are simple ways to show kindness. Helping with chores, such as cooking meals, shoveling snow, raking leaves, doing errands, or paying for gas, are some examples of kind acts. Being present is comforting to the family. Some friends back away following the death of a child to cancer. Kind acts do not have to be big. Simple gestures that show support, care, and concern, are very meaningful.

Being around others who share a similar experience is helpful. The hospital may offer support groups for families of children with cancer. There are camps for children with cancer and their siblings. Grief support groups are available in many towns and cities. Groups, such as *The Compassionate Friends* and *The Bereaved Parents of the USA*, provide support to families after a child's death. Support groups are a place for families to gather with one another. Some support groups meet weekly, and some meet monthly. Some support groups, like the Children's Brain Tumor Foundation's Loss, Grief and Bereavement Program, are offered over the phone or on-line. Many families who are part of a support group say they feel less alone and more understood; however, not everyone feels comfortable talking in a group. Some people prefer just listening to others.

Some people find individual counseling to be helpful. Counselors are available in many cities and towns. Some families find that when they talk to a knowledgeable and caring nurse or doctor, they feel understood.

Being with friends also helps many families. Friends can offer comfort and support. When a person is grieving, it is difficult to be a good friend. It may be difficult for the person who is grieving to do the things that were once fun to do. Sometimes it is impossible. This is normal. When this happens, it helps for friends to continue to show they care.

It is important to reassure children that they are loved and safe, and that nothing they did or didn't do caused the loss to happen. It is helpful to keep routines as normal as possible. It can be very helpful for children to express their feelings through art or music.

When a child is diagnosed with cancer, loss occurs if the child survives, and loss occurs if the child dies. All members of the family need ongoing support for a very long time.

Family Perspectives

How am I going to make it without her with me? We are doing so much together and I am getting even more attached every day of treatment. How is that even possible? She leans on me now before they tell her to, to get her sleepy meds. It's her least favorite thing, but she doesn't complain—she doesn't let the fear take over. She just leans in, and I talk and she breathes. (I love that sound of her breathing.) We hold hands automatically now. We share jokes and giggles and so many little moments throughout our day. She is growing up and changing through this experience—maturing so quickly.



It's been a little over 4 years since my boy Carson died. Strangely enough some days it seems like he's going to walk through the door and say, "Hey mom, I'm home." Yet some of our sweet memories are slowly dimming.

Personally I have powerful pain all 4 seasons; none stronger nor weaker—seems like just when I'm over the pain of that season, the next is looming with its bite.

Spring is baseball, and to Carson baseball was life. The kid flat out LOVED the game! Carson wrote a book <u>Carry Me</u> that was published 6 days before he died. In it he wrote, "Baseball is down deep in my soul. I loved putting on the jersey, the long socks and the pants. The whole uniform. I loved sliding in the dirt. I love the smell of my glove and the anticipation of playing the game." Then there is Mother's Day.

Summer is Carson's and my birthday. Something we shared and relished being the birthday or birthweek people! With no birthday boy to celebrate, it helps us to load up 2 limos full of cancer-fighting teens and take off to a Texas Ranger's Game in a suite with food. In our hearts we are throwing Carson a birthday party! We usually arrange a meeting with a professional player—an unforgettable outing each summer, and it feels like he is right there among us!

Fall of course is childhood cancer awareness month and emotionally charged with the annual trek to D.C. fighting for those still in the battle PLUS making sure the ones who battled just as valiantly are not forgotten.

Winter is Christmas and the beginning of the end. Christmas Eve from his hospital bed, Carson whispered words I will never forget. "Momma, I

thought I was gonna make it; don't let them bury me. Make sure they study those tumors 'cause if those tumors can help some kid not die from cancer like me, I'd like that." We left the hospital that Christmas Day on hospice care, and he started saying goodbye to his family and friends.



Many of us have faith that we will be reunited one day in Heaven, yet we crave a tangible symbol that our loved ones hear us and will deliver some kind of message that they do. This past Saturday it was an unusually warm November day here in New England; I took my daughter for a walk in the woods nearby. We came to an old wall of stones that used to be a mill on the river. I have often driven by this hundred year old structure and wondered what secrets it held. When I was young I wanted to be a geologist; I've always been fascinated by stones and the prospect of finding hidden treasures. Because the river was low this was my chance to investigate these ancient mysterious stone walls. We climbed down the riverbank and Tara went to one wall while I went to the other to investigate. I peered inside the gaps of the large stones not quite sure what I was looking for. Within moments I saw something clear and unusual; I reached in and pulled out a large diamond cut heart shaped crystal the size of my fist. I was stunned; how did this object get there and who had placed it? I called out to my daughter who rushed over, and she was equally astonished at my discovery. "Is it a real diamond?" she asked. I smiled and said I think it might be something even more valuable! The sunlight struck the crystal and sparkles of rainbow flecks danced all around us. I won't tell you exactly what sign I have been praying that Cole would send me, but this was extremely close. All of a sudden Tara shouted, "There's a book in there!" Wedged between two other large stones was a weathered, antique leather bound book. I pried it loose and handed it to her. Tara is a great lover of reading books and Cole had known that. Tara opened the leather book and it was filled with yellowed blank pages except for one page in the middle that had a flower pressed inside. Whenever I took Cole outside he always insisted on bringing back a handful of flowers for his mama and sister. Signs from above? I believe!



My existence was totally devoted to Jed's health and fighting for his life for 2 years and 11 months. After Jed passed away, a large part of me died with him. I was totally lost and felt completely alone with no purpose left. I felt like I had no soul and no life left in me. With no direction and no vigor, I

lay around grieving for my son in a hopeless downward spiral.

I eventually agreed to start taking antidepressants and sleeping pills. I was always so against this form of medication but this is how the psychologist explained it to me—"Jed had chemo to survive as long as he did. These little drugs are your life line, your chronic medication to make it through the dark days." I admit, I am weak; but I use my weakness, my pain and my hurt, three years later, to raise much needed awareness, to educate, to advocate, to raise funds and to make a difference in the lives of children who have cancer.



There was a time when I couldn't imagine life with a child. I was so young when I found out that I was pregnant and I knew I wasn't ready to be a parent, but everything changed the first time I heard his heartbeat. I knew that somehow everything would be okay. Miguel changed my life in ways that I never expected and once I knew him, I couldn't imagine life without him. Watching him grow and learn was a frightening and yet wondrous, amazing experience. Because of him, I experienced feelings that you really can only truly appreciate as a parent. And in one single heartbeat, he was gone. I had watched my son take his first breath and his last. I have experienced the most incredible happiness I have ever felt because of him and endured the most gut-wrenching, soul-shattering pain I have ever felt in his absence.

Watching him fight his battle was incredibly difficult. He spent 18 long months going through something no child should ever have to go through. When he went into remission, I was elated as I never truly thought I was going to lose him to cancer. And even when the tumor recurred, I still thought that if we fought hard enough, if I was good enough, that he would be fine. As he became weaker and weaker and the doctors said that we needed to transition to hospice, I still was too stubborn to see what was happening and accept it. I spent every waking moment with him in the end, and even as I watched him die in my arms, I didn't want to let go. He always said that if he died he hoped that I died with him so that we could be together. Knowing I couldn't go with him yet killed me inside. Knowing that I couldn't protect and save him is one of the worst feelings a parent can have. If I could have stopped time, I would have. I was inconsolable and I held on to Miguel for as long as I possibly could. When they finally took him from my arms more than five hours after he had passed, he was $still\ warm-as\ if\ he\ had\ fallen\ into\ a\ nap\ that\ he\ would\ awake\ from\ at\ any$

moment. But he never did.

The several weeks that followed are hazy. I went into an emotional cocoon that I've never really fully come out of. I began having panic attacks and became increasingly afraid that at any moment the grief I felt would consume me from the inside out. I wanted to sleep all of the time since I knew it was the only way I would be able to see Miguel, but could never clear my mind enough to drift off. When I did fall asleep and see him, it seemed so real that I would have stayed forever if I could have. Actually, I do recall one night where I slept on the sofa some time after he passed. I had been getting really bad tension knots in my neck and back, so I started using a gel filled heating pad. Just before I fell asleep that night, I put the heating pad on the sofa back just above me. I had a dream about Miguel, and at some point during the night, the heating pad fell onto my arm in the same place that he used to put his head when he would sleep. That stupid heating pad matched the warmth and weight of Miguel's head so perfectly that, in that place somewhere between here and there as I began to wake, I could have sworn he was lying next to me. I truly thought that when I opened my eyes I would be waking up from a nightmare and he would be looking back at me as if nothing had happened. The reality that was waiting for me was devastating; it was like losing him all over again. Dreaming of him is always bittersweet. I began to hate that Groundhog Day feeling where I just keep losing him over and over again so my insomnia became uncontrollable. If there is such a thing as hell on earth, I was there.

I became someone I didn't recognize. I was tired and weak. Everything that had happened was too much to deal with so, as much as I could, I suppressed my emotional distress, froze what I had left of his life and left it for another time and place where I was stronger and could face it without breaking. I know that the only reason I have any sort of resemblance to a functional human being at this point in my life is thanks to those self-preservation instincts.

Over time, the panic attacks have become nearly non-existent, I am learning how to manage my insomnia, and I have begun to reflect on my life both with and without Miguel. I am trying to let go of the sorrow and grief that has plagued me for the last five years but there is a large part of me deep down that I know never will heal. It's painful, it sucks, and I would never wish this on anyone. I know I will always have regrets and guilt. I am still a shadow of the person I once was and probably always will be. No matter

how functional I can be as a person, I will likely always feel there is a void somewhere at my core that can never be filled. I will probably always have a panic attack when I hear the song I sang to him just before he died. I will never stop missing his laughter and smile. I will always cry when I see or think of children suffering. He would have been 15 years old this coming summer and there are still days, five years later, where I feel like, at any moment, he is going to walk through the front door.

If someone had asked me 10 years ago where I thought I'd be in my life today, I never would have imagined it would be here without him. Although my own journey has seen me to incredible new places and amazing people, there isn't a moment that passes by that I don't wish things had turned out differently. I would trade everything I have just for the chance to see him again. Without hesitation, in a single heartbeat, I would have given my own life to save his. I loved that little boy with every fiber of my being, and I miss him so incredibly much. Miguel's journey in this life was too short. He deserved so much better, and I will regret each and every day, for the rest of my life, that I couldn't give him that.

People naturally want to make it better. They say words attempting to provide some comfort, but my emotions don't understand words. It's difficult to even find the words to describe the emotions I have. The words to quell the agony don't exist. The people who know me best don't attempt to console me anymore; they are just there to support and love me as I make my way through life. They know that, despite how I appear to be outwardly, I am an incredibly private and introverted person. The things that truly matter to me the most are sacred and I don't share those things willingly with anyone. Miguel was and still is an important part of my life. He was smart, funny and amazing, and it's time for me to share him. By opening Pandora's Box to write about these painful emotions and memories, I hope to begin the long journey to finding peace.

Over the last several days, as I have immersed myself in all the things of the life I once had, some long-lost, cherished memories have made their way back to me and I am so very thankful for all of those shining little gems in the sea of darkness that has surrounded them for so long. My sorrow has definitely gotten in the way of some of the good things I could have been focusing on instead. Regardless, I have never forgotten how lucky I am to have been a part of Miguel's life.

The Child's Legacy

Catherine Kelly-Langen, MD Nancy Carst, LISW Sarah Friebert, MD

"Today I spoke with another father. His son died one year ago. And now he is a member of an exclusive club—a club for parents who lost their children. So now he fights for a cause where before he spent time with his son at baseball games, doing homework or teaching him to ride a bike. In doing so, the cause has filled his life and a void. It will never replace his son, but to him it's about saving the next child. He tells me the second worst day of his life will be when everyone forgets about his son."

Brooke and Keith Desserich, Notes Left Behind, 2010

From the moment parents begin to consider giving birth to, adopting or fostering a child, dreams for that child's legacy are conceived. In addition to getting to know the child as a person, parents form relationship bonds with their child's envisioned personality, achievements and family connections. Once the child becomes part of the family, his or her personality and life experiences grow, creating legacy with the family, with extended family and friends, and with the community, thus increasing that child's interconnectedness with the world.

From the moment of a cancer diagnosis, legacy takes on a completely new meaning. Many parents share that when their child is diagnosed with cancer, they feel as though their world has stopped. Parents think about the potential for early death of their child regardless of their child's diagnosis or prognosis. Even parents of children and adolescents who survive their cancer and live with the consequences of treatment consider the possibility of a recurrence or relapse for many years. Parents

are left to consider the unimaginable horror of what it could be like to live without having their child with them anymore.

The threat of that unimaginable loss spreads like ripples in families, and in communities,

Catherine Kelly-Langen is the Palliative Care Attending Physician at the Haslinger Family Pediatric Palliative Care Center, Akron Children's Hospital, OH. as well. For brothers and sisters, the death of a sibling in childhood means not only losing a companion during childhood, but also losing the potential of a lifelong companion who offers something no one else can. Grandparents often experience compounded pain as they watch their children and grandchildren suffer. Communities are affected too, as an ill child's extended family, friends, school, sports teams and social groups struggle to make meaning out of witnessing such situations.

Based on the "Special Section: Cancer in Children & Adolescents in Cancer Facts and Figures 2014," survival rates for children ages 1-14 years were 81.3-82.0% and for adolescents ages 15-19 were 80.0-85.4% in the years 2003-2009. Corresponding to that, the mortality rates from 2006-2010 were about 22% for children and 25-35% for adolescents with cancer. These statistics are general and include all childhood cancers, but point out starkly that roughly 20 to 35 out of 100 children with cancer will not survive and will leave their parents, siblings, grandparents and communities behind to grieve their deaths and search for ways to memorialize and honor them.

"I talk about Marissa often. I don't care if it makes others uncomfortable. I'm still her mother. I invite others to share favorite stories and memories with me that never get old. I do this for me, but it is also for them so that they never forget my baby girl. My world is forever changed by her having been here and they need to know it."

Roz, mother of Marissa

During the initial experience of grief at a child's death, parents are often unable to think about much of anything besides their child and wanting him or her back. There is little ability to do anything except to go through the motions of life. Eventually many parents have a gradual awakening of a need to find purpose and meaning in their child's life and death. Often there is also a fear of the child's memory or spirit being forgotten by others, as Marissa's mother articulates so poignantly.

According to Merriam-Webster.com, legacy is a gift, especially of money or other personal property, or something transmitted by or received from an ancestor or predecessor or from the past. Other concepts of leaving a legacy refer to leaving meaning associated with the one who has died. Children may not be able to leave money or personal property as a way to be remembered, but they are certainly able

to leave many other ways to be remembered. Almost all adults want to leave this world being remembered for who they were and what they found to be meaningful and important. Children, adolescents and their

Nancy Carst is the Bereavement Specialist at the Haslinger Family Pediatric Palliative Care Center, Akron Children's Hospital, OH. parents are no different. To be remembered is to be present and alive in the hearts and minds of those left behind.

For many it may be hard to imagine how someone so young could leave a legacy after living such a tragically short life. The challenge is to broaden the definition of what a legacy is and not be limited by traditional thoughts.

Leaving a legacy, then, is a way for children and adolescents who have died to be remembered, for who they were and for the things that they found to be meaningful and important. This chapter presents practical examples of legacies left by children and adolescents, and legacies created for them by their parents, siblings, grandparents and even communities. It is worth noting that although the chapter focuses on the experiences of families whose children are dying or have died, legacy work can be equally important when children will survive but their lives will be lived differently because of cancer. In other words, the diagnosis of cancer in a child changes a family's life forever, and grieving for the life that has been changed is worthy of memorialization in legacy as well.

Lisa, mother of Madison, expresses that she wishes she had considered offering memory-making experiences to her daughter while she was alive, such as an opportunity to scrapbook some of her pictures and the family's life with her. Not having done this when she had the chance, Lisa thinks, "Madison probably laughs at my doing this because I don't have her artistic talent!"

Legacy Planning Before the End of Life

In considering creating a legacy, perhaps the most difficult hurdle is to consider the potential or probable death of the child. Even when children are diagnosed with the most curable types of cancer, most parents fear an early end of life (though this fear often goes unexpressed). Certainly there is a big difference between privately worrying about a child's death and acknowledging its probability to the point of planning for what may happen afterwards; making that leap is a devastating and terrifying prospect.

Like Madison's mother, parents rarely consider beforehand how they will honor their child after death, unless death is a certainty; and oftentimes there are no plans in place prior to the child's end of life unless the child is involved. To most parents,

the thought of having conversations about their child's death and its aftermath, with their child, is inconceivable—something too far-fetched and painful to consider, even as a hypothetical possibility. Most individuals who work with seriously ill and dying children

Sarah Friebert is the Director of Pediatric Palliative Care at the Haslinger Family Pediatric Palliative Care Center, Akron Children's Hospital, OH. know that children are far more prepared and open to talking about their death and its aftermath than the adults who surround them. Children, like adults, recognize their pending deaths far sooner than most people would imagine. In their knowing, they remain as curious as they are about everything else.

Just as adults ponder how they have made an impact on the world and how they will be remembered, children have grief work to accomplish before their deaths. Once children are able to acknowledge the possibility or certainty of their death, many of them begin planning for their legacy. If they are able to verbalize their knowledge of their death, they can plan openly with others. If they are afraid of upsetting the adults in their lives (particularly their parents) or if they aren't sure that others are aware, they may plan in private. One of the most helpful things that can be offered is the opportunity for open communication about a child's thoughts, feelings and plans. In fact, for many children, the fear of being forgotten is greater than the fear of death. Reassuring children that their lives have not been lived in vain and that they will always be remembered can provide a tremendous amount of comfort and meaning through an otherwise incomprehensibly difficult time.

During active cancer treatment, some parents consider whether to participate in research studies that further the understanding of cancer as a whole, or of their child's specific malignancy. Children themselves also can derive great satisfaction from the good that can come from participating in clinical trials. It is crucial that children and their parents understand whether any proposed research has the chance of providing direct benefit to the individual child. Even without the prospect of direct benefit for themselves, however, many children are happy and even proud to contribute to knowledge about cancer that may help another child in the future; and this helps parents feel as though their child may not have suffered in vain. Donation of tumor cells, or the tumor itself, after death can provide a way for the child's cancer journey to have meaning and importance for future children who may suffer less as a result.

In preparing a legacy ahead of time, children use many of the same typical expressions as adults. It is not uncommon for children of all ages to begin bequeathing items to others before their deaths. Some children may distribute important possessions without overtly expressing their legacy intentions; others personally give items away with direct acknowledgment of wanting the recipient to have the item after the death. For example, a 7-year-old who gives his brother his favorite t-shirt, may say, "I want you to wear this and think of me after I am gone." Personal items, toys, clothes, and favorite possessions are things that a child may give away. Some children write down their desires for others to have specific things—essentially, they have written a will. Children who are old enough may write a will and find a way to ensure that it is discovered in order that their wishes will be carried out. Creating openness for conversation about the

potential for death may allow children to share their thoughts verbally or in writing with others (parents, siblings, grandparents, close friends, trusted confidants).

Part of the work of grief for children, just like adults, is to express their feelings to others; in fact, sometimes this occurs more naturally or easily for children because they are generally less inhibited than adults about expressing emotions. A dying child may need to make sure that others know how much they are loved or how thankful the child is for that person or for that person's influence. It is not uncommon for children and teenagers to write cards and letters, to be opened before or after their deaths, that express their caring and thankfulness to family members, friends, significant others, coaches, teachers, spiritual guides, doctors, nurses, aides and therapists. Some children may even want to plan ahead and provide cards or gifts for others for future events, birthdays or holidays.

Some older children and teenagers may go so far as to develop bucket lists involving activities they would like to accomplish prior to their deaths. Popular culture has, in some ways, eased conversation around these difficult topics, through movies such as "50/50" and "Now is Good," and through books such as The Bucket List: Things To Do Before I Kick It. One young woman began a bucket list of 50 items before she died, ranging from milking a cow to attending a fashion show in New York City. Since her death, her mother has continued to cross items off the list to honor her daughter's legacy, most recently going parasailing in Florida despite her own fears of heights and flying.

Expressive therapies (art, music, drama, dance, writing, etc.) are creative ways to allow for grief work and legacy-building to be carried out prior to end of life. Trained therapists work with children through different media to explore feelings about diagnosis, treatment, prognosis, and other aspects of serious illness. In the process, a child may create a piece (drawing, painting, sculpture, lyrics, melody, poem, story) that also gives insight into how the child feels about dying—allowing the therapists and family to open up general conversation about the item. This creation also provides a practical remembrance of the child's journey with the illness. Exploration of death and dying may be planned or unplanned. For example, a 5 year old patient with a brain tumor drew a picture not long after her diagnosis. When asked, she informed her mother that the picture was of her place in a graveyard. As tough as that may have been to hear from the child, her parents have the comfort of knowing that she was aware of her ultimate outcome and had been preparing long before anyone else. Some children use journaling as their way of leaving a legacy of their thoughts to others. In writing their thoughts down, they are not only able to free themselves from their concerns by putting them out of their heads and into text, but they are also able to work through things independently. Reading a child's journal later allows

others to see the experience from the child's perspective and to get to know the child in another, sometimes deeper, way.

"During Nick's illness, keeping a CaringBridge journal and my own private journal was helpful for me. Not only did the CaringBridge journal help keep my family and friends up to date on what was happening, both journals were also places where I was able to write out what I was feeling about the day to day process of Nick's cancer treatment. Since he has been gone, I continue to write on the CaringBridge journal and in my private journal for the same reasons. I think that part of Nick's legacy is allowing others into my grieving process. I pray that my words might bring comfort and hope to others who also suffer loss."

Wendy, mother of Nick

Technology now allows us to create even more ways to build a legacy prior to death. Blogs and other kinds of social media, Internet sites and groups authored by children with cancer, or their parents, are common. These outlets allow others to be educated about the child, the illness, and the journey of the family through the illness and death of the child. Many people, both known and unknown to the family, may benefit in the long run by being exposed to the child's story and, often, by gaining compassion, sympathy, empathy and appreciation.

A search of YouTube will yield a variety of songs and videos created by young adults and children who are facing death from cancer. These postings celebrate their lives and encourage others to appreciate and do something with their own lives. By posting these legacy pieces, young adults and children who are facing cancer are able to bring their message to others.

In other settings, children are able to have private videos filmed specifically for legacy-building. When this has been done in a research setting, children have reported feeling less anxious after making videos about their lives, showing again that open communication about impending death is helpful. Once the likelihood of death was acknowledged, children were interviewed and filmed, answering questions, telling stories and giving messages to others. Copies were provided to the children to be shared with their families when and if they desired. These days, fancy technology is not necessary; legacy videos can be made quickly and easily with cell phones, offering a chance to capture in-the-moment remembrances and reflections, if more formal or elaborate productions are not possible or desired.

One of the many tragedies in the death of a child is the inability for that child to live out his goals. When acknowledged, the goals and aspirations of children can

also give rise to ways to create legacies that will live on in the hearts and lives of their families and many others. For example, one young woman's family was inspired by her passion for card-making and her life dream of having her own card shop that would allow her to donate the money earned to her church's missions. While she busily made greeting cards, unbeknownst to her, her family advertised their sale and her story. Cards were bought and sold all over the globe. Her family held a surprise event for her announcing her virtual store and presented her with a check for \$500 that she donated to her church. Another young woman's goal to be a famous artist was realized when her palliative care team needed a representation of their trademarked name. Thrilled to live out her dream, she painted her first watercolor and was paid for the painting and the rights to it. Art and music therapists allowed another child's dream to be realized. With the help of the therapists, the child learned how to play an instrument, then sang and played several of her favorite popular tunes. The recorded versions were made into CDs with cover art created by the child. To add to the excitement, a CD Release Party was held at the hospital with a poster-sized version of the cover art, door prizes, live performances and a raffle for an autographed CD.

On a smaller, more concrete level, legacies can take the form of objects made by families for and with children while they are still alive. For small children, infants and non-verbal children, parents sometimes choose to take part in the creation of paper, ink or three-dimensional clay or plaster molds of their hands and/or feet before the end of life as a way of preparing for death. These molds are tangible objects that hold memories of the child and allow families to hold some part of their child in their hands in the future; the process is also one that can include siblings, friends and other family members. Using craft clay to make impressions of the child's thumbprints is an active but subtle way to prepare a solid piece of legacy prior to death as well.

Whatever form legacy creation takes—and the possibilities are almost endless the important message is that many children and young adults have aspirations and goals and interests that can lend themselves to some sort of achievement or accomplishment prior to their death, if known and acknowledged ahead of time.

Legacy Planning After End of Life

As important and powerful as helping a child create his or her own legacy can be, not all children and their parents have an opportunity to prepare ahead of time. However, there are numerous ways children may be remembered for who they were, what they liked and what they found important.

Many forms of legacy are subtle and private, meaning that they are meant for and enjoyed by family members and close friends, not by the public as a whole.

Children themselves may be the source of some of the private forms of legacy, as mentioned above. Letters, gifts, cards, journals and even wills initiated and created by children are ways for them to be part of the lives of those close to them forever. Special items that remind others of the child, or that belonged to the child, may be tangible forms of a legacy that are given to others or displayed on shelves or in shadow boxes in honor of the child by family members. Favorite stuffed animals, trophies, awards, clothing, hobby items or sports paraphernalia are just a few of the items that can immediately bring the child back to whomever sees or holds the items. Even unique or unusual items that were favored by a child can bring back that child's presence. For example, a child who loved to hold an oven mitt will forever be remembered by the staff members who cared for him before his death, every time they see one like his.

A child's essence can also live on in expressions of that child that are created by others for the benefit of the family members and friends. Photos, professional and amateur, posed and candid, taken before or at the time of the child's death are often a startling and beautiful reminder of the child. Organizations such as Now I Lay Me Down To Sleep, for small infants, and Flashes of Hope, for children of all ages, are available in many communities, offering professional photographers for family photos at little or no cost (www.flashesofhope.org). Photos can be arranged as collages, videos or scrapbooks to honor the child, to show progression of the child's life, or to showcase sequential events like every Christmas or Halloween in chronological order.

More elaborate forms of private, personal legacy require a specific skill set. In Ohio, there is a painter who is skilled at creating portraits of children who have died. Favorite clothing or blankets can be retooled to make new items, such as stuffed animals and quilts; these special items have the added benefit of allowing family and friends to have the smells and favorite items of the child close to them at a moment's notice. Funeral homes and jewelers can also fashion beautiful and meaningful jewelry from photos, a child's thumbprint, handprint or footprint, and even from the ashes of a child who has died. It is not unusual to see a child's face, name or even his footprints or handprints tattooed on a parent, friend or relative after the child's death as a more permanent tribute.

Less recognized forms of legacy are personal expressions of a child known only in the privacy of the hearts of those close to the child. These personal expressions may be as simple as a song or a phrase, a taste or a smell, or even a specific memory. When mourning the death of a child, grief and processing takes many forms, some of which are these private testimonials of sights, sounds or smells. Through grief work in sessions, groups and camps, or in surprise moments, individuals can

call on their personal legacy with the child to guide them. Some parents feel a repeated connection with their child through natural phenomenon like rainbows, butterflies, animals or feathers, or through dreams in which they are visited by their child in some way. For instance, one family's continuing bond with their son was started by the appearance of a wolf; now their annual holiday card always has a wolf depicted on it. Others have recurring music or signs unique to their child as their own private legacy.

"After Nick died, his guitar teacher donated a sizeable amount of money to the youth group that Nick attended at our church. At first we weren't sure what to do with the money, but then it was decided that one of the Sunday School rooms at church would be turned into a café where people could gather to have meaningful conversations over a good cup of coffee, tea or hot chocolate. One of Nick's friends suggested the idea of a café since Nick loved a good cup of coffee—even in junior high school! The room was renovated and now the café is the most used room in the entire church. Soon Nick's Place Café will be hosting a semi-annual youth art show, and student art will be on display year round!"

Nick's family

Just as there are legacies enjoyed only by those close to children who have died, there are a myriad of ways for children to influence large numbers of people as their presence continues to live on for the world to see.

Most immediately, one of the many tasks that newly bereaved parents must undertake is that of writing an obituary. Published for any number of family members, friends and strangers, it is a way to memorialize the child. These words, used to describe the life of a child, serve to give others a glimpse into the uniqueness of that child and often serve as the beginning of a child's public legacy.

Traditional observances following the death of a child may contribute to the building of the child's legacy. Prayer cards, used in many Christian services, may become keepsakes for mourners to take with them. Specialized caskets, celebrating sports teams, favorite colors or characters, are available to share the unique interests or talents of children. In fact, a family whose son died of cancer chose not only to have a cartoon character-themed casket and funeral, but also to create an organization in honor of their son specializing in unique custom caskets. Headstones provide another means of memorializing a child; from simple to extremely elaborate, families often choose special symbols, photos and objects to serve as permanent reminders of their child's personality and contributions to the world.

After the funeral, families may choose other forms of ongoing tribute to their children. A few of these possibilities are listed here:

- Performing random acts of kindness in honor of the child.
- Establishing a foundation in the child's name for hospital or research support or for direct assistance to families with medical and practical expenses.
- Walks-by starting their own events or participating in others with the money raised going to research, to scholarship funds or to programs supporting children undergoing treatment.
- Establishing scholarships, awards, or commemorative activities (lectures, sports events) in the child's name.
- Making or donating specific items to hospitals or other charitable organizations in the child's name (blankets, hats, quilts, cards, crafts, toys, pillowcases).
- Volunteering in memory of the child, such as at cancer camps or at the treatment hospital.
- Donating toys or other items to holiday programs or other charitable organizations, especially charities that were important to the child.
- Contributing directly to cancer research or cancer support programs.
- Participating in community outreach/education (speaking at high schools, colleges, or nursing/medical schools about childhood cancer).
- Planting gardens and/or trees at schools, churches or other places of importance to the child.
- Authoring books, articles, blogs, or other publications pertaining to cancer, to the family's experience, or to the child.
- Creating rituals for special days (the child's birthday, anniversary of the child's death, holidays).
 - o Special balloon release;
 - o Eating the child's favorite meal or visiting the child's favorite restaurant;
 - o Making treats and bringing them to the child's school or the hospital unit where the child was treated;
 - o Taking time alone to participate in personal rituals or

commemorative activities.

- Pursuing career paths in helping professions or changing life directions because
 of child's cancer (nursing, medical assistant training, bereavement counseling,
 starting a non-profit).
- Attending annual remembrance services and religious celebrations with specific mention of the child.
- Offering one-on-one support/wisdom/mentoring to other families dealing with childhood cancer (e.g., through hospital parent advisory groups or through on-line support groups) or sharing their story with professionals to provide insight on the family's point of view in medical situations.

The Special Perspective of Siblings

"Cassidy was my best friend. Of course when she was diagnosed I used to get jealous...all us kids did. I'm told that was normal. We felt a little left out. We miss her so much! There's been times that I really needed her—just to talk to my big sister. Sometimes I watch her video from her funeral by myself in my room. My mom always tells Emily stories because Emily does not have any memories of Cassidy. Cassidy was very worried about Emily not remembering her."

Nicole, sister of Cassidy

Brothers and sisters share special bonds, and the premature separation of those bonds is uniquely traumatic for the surviving siblings. Children who lose a sibling can experience a multitude of confusing and conflicting emotions which are influenced by an equally large number of variables, including their developmental/cognitive age. During or after a sibling's death from cancer, surviving children often find their own creative ways to remember and honor their brother or sister. One younger sister has chosen a career path which will lead her to cancer research, as she states, "I really want to be a part of the cure." Another young woman enjoys speaking publicly, sharing her brother's story with youth groups to inspire other young people. She further strengthens her tribute to her brother by participating in annual fundraising walks to benefit the hospital where her brother was treated. A third surviving sibling feels a special bond to siblings who live with brothers or sisters suffering from cancer, just like she did. Recognizing that they are often left out, she supports them by making special sibling gift bags with supportive messages to encourage them.

Just as each child with cancer handles the illness, treatment and dying process

differently, siblings, too, handle the experience in unique ways. It is crucial to remember that siblings need time and space to memorialize their brother or sister in their own ways at their own pace. There are no right or wrong ways for families to create legacies; similarly, siblings should not be compelled to participate in legacy-building if they are not ready or comfortable. Many siblings gain satisfaction and peace by participating in legacy activities organized by their own families or others affected by cancer, but some need to remember their brother or sister in more private and personal ways.

The Special Perspective of Grandparents

"Madison's death left a large hole in our hearts. We remember her and the funny things she said and did. Because of her I have talked to many people going through tough times, I tell them of the faith of a six year old who knew where she was going thanks to the faith her parents instilled in her. After her death I was on a Relay for Life team formed for her for many years. I've worked on benefits for others undergoing treatment. We have a team that goes to the St. Jude Marathon in Memphis yearly. All year I make cards, favors and Hershey gift items to sell. Last year we learned that research studies Madison was involved in have resulted in discoveries that will impact treatment in the future. My mother helps me make some of the items and my brother helps sell. This gives both of them great satisfaction. I'm now more aware of Palliative Care at Children's. Because of this I have knit hats, made pillowcases and picked up stuffed toys to be handed out to children undergoing treatment. Madison loved the little treats when she came in for treatment. I have a friend who has made many quilts that I have brought in. Madison is not forgotten but lovingly remembered. It is hard to put into words or even remember all we do because of her."

Demi, grandmother of Madison

Grandparents bear a special burden—watching their own children as parents experiencing suffering, together with grieving for their grandchildren who are undergoing cancer treatment. Many grandparents have special and close relationships with their grandchildren and have even played major roles in caring for them during treatment. Some grandparents assist with transportation, some stay at the hospital during treatment so that parents can go to work, and some assist with care of siblings or with household tasks.

Grandparent grief often falls into the disenfranchised category because it isn't

recognized or supported by others. Involving grandparents in legacy creation can help validate their grief and support their needs as well. As Demi explained, there are many ways grandparents can be involved, locally and nationally, to help keep the memories and names of their beloved grandchildren alive.

The Special Perspectives of Communities

"The death of a child, any child, also has a lifelong impact on the community in which he or she would have lived. When a child dies, at any age, that community has lost part of its future.... But there is one thing that death cannot take away and that is the name of any child who has died before his or her time.... This means that whenever their name is linked with a meaningful memory, whenever they have made a difference in the life of another, whenever an act of kindness is done in their name, these children have been remembered. Their names, in being symbolic of who they were, become their primary legacy."

Living Still, Loving Always

Whenever a child is diagnosed with cancer, the entire community is touched in some way by that child's and family's journey. Church groups, sports teams, scouting troops, schools, parents' employers, other activity groups and teams—the list of people and organizations that are affected goes on. Even people who are not closely connected to the family often struggle with how to be helpful and how to remember the life of a child who has lived in their midst. Community legacy responses range from small to large, depending on the number of people and resources available. One community held a coin drive to pay for a young boy's headstone. Another community established a grade-level award to be presented at the annual graduation ceremony in the name of the child who died, honoring a child who shows a positive attitude and goes above and beyond to be helpful to other children. Some communities have erected playgrounds or special community gathering spaces in honor of a child who died. For example, one school-age child asked that her Make-A-Wish be to create a community playground with a safe, rubberized ground to replace rusted, outdated and unsafe equipment. Other communities and groups have participated in establishing scholarships or in public service campaigns (food drives, clothing drives, toy drives) in honor of the child who died.

It is helpful for the community or group to work with the family to make sure that the proposed activity meets the family's personal, religious, cultural and practical needs, especially if the plan is to generate funds to support the family directly. Some families would not appreciate large, public legacies, and their preferences should be respected. With thoughtful planning, however, a child's life can be commemorated in a respectful and lasting way, on a scale that usually helps a family feel tremendously supported and valued.

Special Considerations

Though there are no specific rights or wrongs in a family's legacy work, there are some general considerations that families have shared to help others.

- Parents should avoid compelling or forcing siblings (or friends, grandparents
 or other family members) to participate in legacy activities. Parents can avoid
 compounding grief and guilt by allowing siblings their own space and time
 to memorialize their loved one in their own way. Similarly, over-focusing on
 legacy creation at the expense of the surviving children and family members
 is unhealthy and works against honoring the deceased child.
- Children (even those who are very young) may be remembered by parents, siblings, friends and extended family in different ways. Creating legacies that recognize and integrate multiple perspectives is important so that each surviving person's memories can be honored and preserved.
- Multiple foundations and fundraising activities can actually work against
 a collaborative effort to create meaningful change or progress in childhood
 cancer research. It is important to investigate what is already available in a
 community or in cancer research, in order to work toward unified efforts to
 find a cure.
- Similarly, investigating available resources in a community before starting
 foundations that directly support other families coping with a child with
 cancer, or that support other ancillary services (such as bereavement centers,
 holistic healing spaces, educational resources, etc.) can avoid creating multiple
 individual activities. By joining with efforts available instead of starting new
 organizations, resources can be combined to effect meaningful change instead
 of fracturing what is available and making less of an impact.
- Families should be cautious about embarking on large projects that require significant time and energy; in the short term, allowing sufficient time for important grief work is crucial before diving into an initiative that will drain personal resources. Similarly, over-commitment to large projects is risky in terms of sustainability; insufficient time, money or true opportunities for success can short-circuit the best intentions, compounding a family's grief and

- guilt when initiatives in a child's name are not long-lasting. If a family must consider stopping a project that was started in the name of their child, guilt surfaces about giving up on (or letting down) the child and his or her legacy.
- In this era of social media and instant exposure, private family grieving is unlikely to remain private for long, especially if any of the child's journey has been shared online or in the community. While social media can establish an important sense of connectedness and support, one significant downside is the instant (and sometimes invasive) dissemination of personal information that can occur. One young man's death was actually publicized on Facebook weeks before it happened, prompting an outpouring of grief from schoolmates who descended on his hospital room. Correcting this misinformation was exhausting and distressing for the adolescent himself as well as for his family. Such publicity also impedes a family's ability to grieve privately; some families appreciate instant postings and communications, while others do not.
- Some of the most powerful legacy activities are the most subtle—saying the deceased child's name as often out loud as possible, keeping the memory of the child alive in ongoing family events, and letting others know the true number of children born into a family are lasting ways to honor the life lived.

Conclusion

It has been widely acknowledged that the death of a child is the most difficult occurrence for a family to endure. Despite the tragedy, legacy creation is a way to ensure that a child's life and death did not occur in vain and that the child will never be forgotten. Just as every child's journey is unique, there is no right or wrong way to create a legacy, nor is it mandatory that any type of public remembrance be created. Every person and community affected by the death of a child mourns, and every mourner is unique in his or her ability to forge a way to remember a child who has died. Just as there is beauty in the lives of the children who suffer and die from cancer, there is beauty in the ways these children live on in the hearts, minds and lives of those left behind.

Acknowledgments

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Family Perspectives

Cass is talked about all the time, almost daily. (She died 7 years ago.) We still celebrate her birthday every year by having steak and A-1 Sauce for dinner. My mom buys balloons for how old she is, and we send them off to her. And of course we get a Dairy Queen ice cream cake—her all time favorite! On the anniversary of her death, we also send balloons for each year she's been gone with notes attached.

Recently we found some of Cass' journals. I wish I knew then what I know now! She was always in so much pain but on the outside I never knew it.

When Cass was sick I started wanting to be a nurse, then I wanted to be nurse practitioner, then a doctor and up the line to a researcher. I really want to be a part of the cure. My mom keeps telling me to make sure it's in my heart and it's what I want—not to do it for anyone else. Of course Cass has a big part, but it's MY goal for me. I'm not sure if I would be a different person if she didn't die.



Losing those close to us threatens the story that we're living. There is nothing anyone can do to take away the pain of the loss that we have experienced. But then we have the importance of the legacy. Whoever it is that you've lost—they wouldn't want to see us in that bitterness. They would want us to be a part of something more, something bigger, a story that goes past the pain of what's happened. They've left a legacy for us that offers us something more than negativity and bitterness. What matters is your response to the legacy and how you will allow yourself to be transformed for the better or the worse. Choose to start writing a beautiful story in the midst of the pain. All of heaven is leaning over the rails to see what you'll do next.



One of her closest friends is now training to be a children's nurse in part as a tribute to Chloe.



Cortnie affected my life choices in a good way. If I have to go through

something painful, I think of how much she went through and it gets me through it. No matter what my sister went through she kept a smile on her face and touched so many people during her life and still nineteen years after her death.



I feel Jacob's legacy changes through the years. In the beginning, it was important to remember Jacob for everything. We built our lives around times to remember Jacob. Five years later, we have weeded down our times of remembrance to be on his birthday and death anniversary day. We still do events on these days as a family.

We had a Caring Bridge page during Jacob's cancer treatment, and when he died, others soon learned of his death and began putting postings on our page. I loved seeing pictures of Jacob's face, hearing what he meant to others, receiving their condolences and support, and knowing how much an impact Jacob had on others. It was very comforting for me.

I feel another part of Jacob's legacy is that many professionals at my place of employment ask me to assist them on how to give bad news to someone.

Jacob's class decided they wanted him to have a seat at their high school graduation. They had to petition the principal to do this when he was first diagnosed. Later they had a coin drive and raised \$3000, which was used for his headstone. A buckeye tree also was planted at his school with a plaque. The Jacob Williams award was created for a child who shows a positive attitude and goes above and beyond what is expected. This award is given to a student at the 6th grade graduation ceremony. I'm also now considering creating a scholarship for a member of Jacob's graduating class.



My sister had talked to Jennifer about going to Build a Bear to make presents a little bit ago. And today before her radiation, it is what she asked to go do. Throughout today she never asked to get something for herself. I think she found a true joy in making something for her siblings. We had only been planning on making them for her brothers, but on the way she asked if she could make one for her sister too. We said yes. This is something they can love and cuddle. When Jonathan falls and needs a hug from sissy he can run to his bear and squeeze it. Nicholas can snuggle it in the night, and for Charlotte she will know how her sister always thought of her. Jennifer was so proud to be putting all of this together. It was my moment to watch

her experience giving life the only way a 6 year old can. She even got to put a heart in each one—a gift from her for them for always. It was a really fun time for us to be together; she was so happy. It was very bittersweet for me though. She thinks she is just being a good sister. I know this will be one of the only tangible ties my kids have to their big sister. She has helped change all their diapers and given them first foods. She welcomed each one home from the hospital with cards and kisses. She is their leader and helper. I hope these animals serve as a reminder to always take care of each other—the way Jennifer does for them. I want them to never ever forget her and the way she loves them.



About seven years after Luke's death, I was experiencing severe headaches and an MRI was needed. I went to the radiology department at the hospital where Luke had been treated. My technician said, "You look familiar—how do I know you?" I shared that my brother was a former patient. The technician said that he had a picture Luke drew in his living room and would always remember him. I was amazed how Luke, a little kid, was still being remembered by this person! I know his legacy has meant something to a lot of people, many of whom I will never know.



There is no single right way to remember her, but we know that my daughter asked us to do random acts of kindness in her name when we missed her. We invite others to do the same on the anniversary of her death, her birthday and as often as they think of her.



I purchased a floral saddle to rest on Marissa's grave. It is changed with the seasons to reflect winter or summer. It is decorated in the colors of the sorority that Marissa's mother, aunt and I all belong to and which Marissa so dearly wanted to join.



We have always included my son in our conversations and activities, knowing that although he's not currently with us, he's still an integral part of the family.



We still celebrate Nick's birthday together every year. Sometimes we

have his friends over to celebrate and we'll watch old videos of Nick, or we will go out and do things that Nick would have enjoyed. Something simple but important our family does that I believe honors Nick's legacy is continuing family traditions. I know after Nick died we questioned if we should still do certain things we used to do as a family, and we realized that Nick would want us to still do these things and enjoy time together as a family making new memories. Nick would never want us to live sad, depressing lives just because he is gone, so I think we definitely honor him and his legacy by continuing to live life to the fullest.



I eventually realized that Stella's legacy wasn't to complete the items on the list; it was so much more. She was inspiring people to do good things, small acts of random kindness. She was creating everyday miracles of friendship and selflessness.



Cassidy's foundation has its ups and downs. Sometimes I just feel empty but something brings me back to my purpose. I get afraid if I give up on Cassidy's foundation, I will be quitting on Cassidy. I promised Cassidy that I would never quit.



Talia made her mark on the world by doing makeup tutorials and by speaking about her cancer journey on her You Tube channel Taliajoy18. Talia inspired millions of people to feel good about themselves, live each day to the fullest and to love themselves as they are. Makeup became Talia's passion, and she created the motto, Makeup is My Wig.

Talia saw having a You Tube channel and having millions of followers as a way to spread awareness about childhood cancer. She said many times that it wasn't fair that she got cancer. Talia wanted to grow up, get married and have kids. All that was taken away from her because there wasn't enough funding for childhood cancer research and clinical trials. Talia's wish was to find a cure for childhood cancer.

Talia started making videos and posting on her social media sites to help support events that were raising money for clinical trials and research. She took videos and pictures of the events and then posted them on her You Tube channel. She felt good that she was helping and making a difference

in this world. It was important to her to be involved in helping find a cure for childhood cancer.

It was Talia who started her own Legacy. Her bubbly personality and her love for life inspired millions! Talia wanted to leave her footprints and handprints on this world so she would never be forgotten. That is why we started the foundation Talia's Legacy.

Talia's Legacy will help to raise funds for clinical trials, research and drugs that specifically target childhood cancer, as well as assist families that are battling cancer. Talia's Legacy fundraisers and events were started and thought of by Talia.

One of the events that Talia created was Glam Wars. Talia started the first Glam Wars in 2012 where girls who were battling childhood cancer received a makeup lesson and a makeover. Now Glam Wars is a monthly event locally and will be going national. All the makeup has been graciously donated by COVERGIRL.

Talia's Legacy lives on.



My son's life and legacy greatly impact how I choose to volunteer my time. Because of my experiences, I have felt called to help others who have lost or are going to lose a child. I spend my time reaching out to those parents who are grieving through volunteering locally and on a national level. Yes, this is definitely hard but there is no one better for a grieving parent to talk to than another grieving parent who understands and can walk the journey with them.

There are times that I am overwhelmed when I look around and see the legacy that my son has left here. I always knew that he was a good kid who was kind and funny with a giant heart, but I don't think that I realized how much he really impacted those around him until after he was gone. It is not hard to tell the stories of my son's life, but to tell the story of his death over and over again is extremely difficult. However, as difficult as it can be sometimes, I know that my son would have wanted me to do it if it would help just one person.

What happened to my son has brought great perspective to my life, and now I see the world with new eyes. This new sight has enabled me to reach out and help others who are suffering. It is something that drains every last bit of me but at the same time energizes me like nothing else does.

Hard work. Dedication. Strength. Perseverance.

When I consider what I've learned from baseball and how the game has impacted who I am, these words come to mind. Baseball influences every aspect of my life, but perhaps not in the way you might expect.

I suspect my baseball story begins similarly to most others—I began playing t-ball almost as soon as I could walk and I developed a love for the game at an early age. Once my younger brother was old enough to field a ball and hold a bat, we were unstoppable. We played constantly. What a bonus for us to have built-in catch partners and ball shaggers! We were quite a team in our younger years.

We weren't very old when it became evident that Caleb had more natural baseball talent than me. Even when he was very young he had that instinct that the really great players have—he always seemed to know how the ball was going to bounce off a bad hop; he could read a batter's stance and see where the ball was going to be hit. He was a sight to watch even when he was playing t-ball and machine pitch.

Another thing he instinctively knew from early on was that talent is not enough. His love of the game combined with his dedication and passion motivated him to work hard to become better. No one in our family got to sleep in on Saturdays—we were awakened at dawn by the thump of a baseball off the roof of the house as Caleb worked on catching pop flies. He incessantly begged me to play a game of catch, hit some grounders or toss him some pitches. His play was all work!

Hard work. Dedication. Strength. Perseverance.

From the day Caleb first felt the pop of leather on leather in his hand, he exemplified these characteristics. They served him well when he was thrust into a fight for his life.

It's only fitting that the symptoms of Caleb's brain tumor first became evident on the baseball field. It was April 1, 2008 and my dad, all three of my brothers and I were enjoying a beautiful evening at the ballpark. Caleb was making uncharacteristically bad throws and he finally exclaimed "Dad, I see two of you! I don't know which one to throw to!"

The news we received a few days later was devastating. Caleb's double

vision was caused by a cancer in the pons area of his brainstem – Diffuse Intrinsic Pontine Glioma ("DIPG"). Kids with DIPG rarely live more than nine months after diagnosis. The disease is not only deadly, it is debilitating. Caleb's fine motor skills and coordination soon began to decline. His spirit did not falter, however. It was baseball season and he was determined to play. Because his reaction time and coordination were impacted by the tumor, he could no longer safely play short stop but he was in center field for his midget team.

Within a few days of his diagnosis, Caleb began a regimen of radiation to his brainstem and an experimental chemotherapy which wreaked havoc on his body. The result was unprecedented, but not as we hoped. He developed huge blisters all over his body which made it incredibly painful for him to be in the sun. He could barely hold a bat in his hands because of the pain caused by the blisters so he wrapped his hands with pre-wrap and wore padded football gloves instead of batting gloves. Our parents carried ice chests of warm and cold rags which they applied to his skin to give him some relief every time he came in from the field. He wore a patch over one eye to combat the double vision. Yet he played.

Hard work. Dedication. Strength. Perseverance.

Those of us who watched Caleb play baseball that summer witnessed these ideals in action. As the disease took his abilities and the treatments caused debilitating pain, baseball brought Caleb joy. He continued to work hard by putting in time in the cages and throwing the ball off the roof. His amazing strength and perseverance—and his love for the game of baseball—continue to inspire all who knew him.

I really struggled after Caleb passed away. I missed my best friend, catch partner, and brother, but baseball brought me comfort. When I stepped on the field, I felt like Caleb was with me. I exchanged the number I'd worn since I was five years old for number 10 in his honor. Today, I still wear number 10 and play the game in Caleb's honor. It's been five years since Caleb and I last played together, but every time I step over the chalk line I remember the hours we spent playing ball. It's like he is with me, but not in a sentimental way. His memory demands that I give my best effort every play and denies me the luxury of being lazy or having an off day.

Resources

Many resources are available to enhance quality of life for children with cancer and their families. This appendix contains a sampling of some especially helpful books, videotapes, organizations and websites.

Books

Children's Books to Communicate About Cancer

- Abrams, Annette. *My Body Needs Help.* Tenley Circle Press, 2011. A hopeful story in art and verse about a cancer patient who visualizes what's happening to her body, explains her feelings, and is strengthened by helper heroes in the effort to regain her health.
- Baker, Lynn. You and Leukemia: A Day at a Time. WB Saunders Company, Second edition, 2001. You and Leukemia is written for children, and helps to make a challenging disease easier to understand for both children and adults.
- Berglund, Rita and Tartakoff, Katy. *An Alphabet About Kids with Cancer.* The Children's Legacy, 1991. The letters of the alphabet are used to introduce various aspects of cancer in the lives of children with the disease.
- Cook, Julia. *The CAN in Cancer.* National Center for Youth Issues, 2013. Eli is a young boy who finds out that he has cancer. Not knowing how to feel, his doctor tells him... "There is a 'can' in cancer, so when your life seems kinda rough, breathe in and out and clear your head and think about better stuff." This creatively written book of hope follows Eli's journey through the eyes of a patient, parents, siblings, teachers, health care providers, and friends. A must read for all who are searching for their "CAN" in cancer.
- Dodd, Michael. *Oliver's Story, For 'Sibs' of Kids with Cancer.* American Childhood Cancer Organization, 2004. A practical book written to celebrate the ways in which siblings of children with cancer can help during this time of family crisis. Free to families of children with cancer. Available in English and Spanish.
- Foss, Karen. *The Problem with Hair: A Story for Children Who Are Learning About Cancer.* Centering Corporation, 1996. All the kids in the neighborhood, unhappy with their hair color and styles, envy Louella, who has lost her hair from undergoing medical treatment.
- Gaes, Jason. My Book for Kids with Cansur: A Child's Autobiography of Hope. Melius Publishing Corp., 1987. A young boy describes his successful two-year battle with cancer and offers advice to other cancer patients.
- Hershey, Marilyn. *Oncology, Stupology ... I Want to go Home!* Butterfly Press, 1999 (available in Spanish). Written from the perspective of a mother of a son treated for leukemia.

- Hoffman, Ruth I. *Cozy Cares Journal*. American Childhood Cancer Organization, 2010. This 122 page journal includes illustrations by Trevor Romain. The drawings of Cozy the 'Port-a-Cat' encourage children to draw strength from within themselves as well as those around them. Writing prompts throughout the book help children cope during their diagnosis and express their thoughts and feelings during this difficult time. Free to children with cancer.
- Hoffman, Ruth I. *Dance in the Rain, A Journal for Teens with Cancer.* American Childhood Cancer Organization, 2014. This 150 page journal is filled with writing prompts and doodles to help teens diagnosed with cancer express their thoughts and feelings as well as summarize their cancer journeys. Free to teens with cancer.
- Keene, Nancy. Chemo, Craziness, and Comfort: My Book About Childhood Cancer. American Childhood Cancer Organization, 2002. Provides clear explanations and practical advice for children ages 6 to 12 with cancer. Warm and funny illustrations, by Trevor Romain, help the child (and parents) make sense of cancer and its treatment. Free to children with cancer.
- Krisher, Trudy. *Kathy's Hats: A Story of Hope.* Albert Whitman & Company, 1992. Kathy's love of hats comes in handy when the chemotherapy treatments she receives for her cancer make her hair fall out.
- Leslie, Carson. *Carry Me.* DMA Publishing, 2010. A biography of a boy from Dallas who had cancer. Composed of a series of diary entries, the book sheds light on the things he goes through and how to be a friend to someone with cancer.
- Martin, Kim. *H is for Hair Fairy: An Alphabet of Encouragement and Insight for Kids with Cancer*. Trafford Publishing, 2005. This 32-page picture book employs the alphabet to feature different aspects of coping with cancer treatment. Mr. and Mrs. Hair Fairy, are a humorous pair who visit cancer patients on the day they lose their hair and leave them a gift, leaving them with words of encouragement.
- Peters, Tim. *I'm Still Me, Coping with Leukemia*. Tim Peters & Company Inc., 1997. Introduces children to leukemia through the story of Herbie, a chick who undergoes chemotherapy for treatment of the disease.
- Philipson, Sandra J., and Takatch, Robert. *Annie Loses Her Leg But Finds Her Way.* Chagin River Publishing Company, 1999. A poignant and funny story of a nine year old English Springer Spaniel who loses her front leg to cancer.
- Romain, Trevor. *Lift Me Up.* American Childhood Cancer Organization, 2008. This 24 page book with inspirational text is filled with wonderful illustrations to color. Free to children with cancer.
- Saltzman, David. *The Jester Has Lost His Jingle*. Jester Books, 1995. The Jester awakes one morning to find laughter missing in his kingdom and he and his helpmate, Pharley, set off on a quest to find it. They learn that laughter can provide the best medicine for anyone facing insurmountable obstacles.
- Trillin, Alice. *Dear Bruno*. New Press, 1996. In this letter to a friend's son who has just been diagnosed with cancer the author shares her own experience with a tumor and offers a listening heart.

School

Anderson, Winifred, Stephen Chitwood, and Deidre Hayden. *Negotiating the Special Education Maze: A Guide for Parents and Teachers.* 3rd ed. Bethesda, Maryland: Woodbine House, 1997. Well-organized text clearly explains the step-by-step process necessary to obtain help for children with special needs.

- Gliko-Braden, Majel. *Grief Comes to Class: A Teacher's Guide*. Centering Corporation, 1531 N. Saddle Creek Rd., Omaha, NE 68104. (402) 553-1200. Comprehensive guide to grief in the classroom. Includes chapters on grief responses, the bereaved student, teen grief, developmental changes, sample letter to parents, and sample teacher/parent conferences.
- Hoffman, Ruth. *Educating the Child with Cancer*. American Childhood Cancer Organization, second edition, 2011. Written by top researchers in the field, and balanced with parents' personal experiences, this 334 page resource focuses on educational issues for children treated for cancer. It is intended to promote understanding and communication between parents, educators and medical professionals so that together they can provide an appropriate education for, and enhance the quality of life of, children who have been treated for cancer. Free to families of children with cancer.
- Siegel, Lawrence. *The Complete IEP Guide: How to Advocate for Your Special Ed Child.* Harbor House Law Press, 2001. Spells out the IEP process for families and includes helpful sample letters and forms.
- The Compassionate Friends. Suggestions for Teachers and School Counselors. P.O. Box 3696, Oak Brook, IL 60522. (630) 990-0010.
- Wright, Peter and Wright, Pamela. Wrightslaw: From Emotions to Advocacy: The Special Education Survival Guide. Hartfield, VA: Harbor House Law Press, 2001. Full of information on special education law, advocacy tactics, and IEP tips.
- Wright, Peter and Wright, Pamela. Wrightslaw: *Special Education Law.* Hartfield, VA: Harbor House Law Press, 1999. Text of key laws and regulations.

Loss and Grief

- Boulden, Jim. *Saying Goodbye*. Boulden Publishing, 1992. This award winning book is widely used by hospices, schools, hospitals and mortuaries as well as by parents and therapists. It is a gentle, non-threatening presentation of death with a healing discussion of emotional issues. (Grades K-4)
- Brown, Laurie Krasny and Brown, Marc. *When Dinosaurs Die: A Guide to Understanding Death.* Little Brown and Company, New York, NY, 1996. The authors explain in simple language the feelings people may have regarding the death of a loved one and the ways to honor the memory of someone who has died.
- Buscaglia, Leo. *The Fall of Freddie the Leaf: A Story of Life for All Ages.* Slack Incorporated, 1982. This is a simple story about a leaf named Freddie and how he and his companion leaves change with the passing seasons, finally falling to the ground with winter's snow. The story illustrates the delicate balance between life and death.
- Cook, Julia. *Grief is Like a Snowflake*. National Center for Youth Issues, 2011. After the death of his father, Little Tree begins to learn how to cope with his feelings and start the healing process. With the help and support of his family and friends, Little Tree learns to cope by discovering what is really important in life, and that his father's memory will carry on.
- Cosgrove, Stephen. *The Dream Tree*. Serendipity Books, 2002. This is a story for all ages that addresses those things in life that are so hard to explain.
- Fitzgerald, Helen. *The Grieving Teen: A Guide for Teenagers and Their Friends.* Fireside, 2000. Renowned grief counselor Helen Fitzgerald turns her attention to the special needs of adolescents struggling with loss and gives them the tools they need to work through their pain and grief.

- Grollman, Earl A. Straight Talk About Death for Teenagers: How to Cope with Losing Someone You Love. Beacon Press, 1993. The award-winning author explains what to expect when you lose someone you love.
- Grootman, Marilyn. When a Friend Dies: A Book for Teens about Grieving and Healing. Free Spirit Publishing, Minneapolis, MN, 1994. Practical guide for teens that addresses and validates emotions associated with death such as guilt, fear, anger and confusion.
- Hansen, Warren. *The Next Place*. Waldman House Press, 1997. An inspirational journey of light and hope to a place where earthly hurts are left behind.
- Harvey, Diane. Why the Snowman Melts. Sandstone Publishing Saint George, UT, 2010. Twins Patty and Bobby move from Miami to Chicago when their father gets a new job. Though they are unhappy about leaving old friends, they are thrilled at the thought of building their first snowman. With the help of family and new friends, they build a wonderful snowman! But sadness rears its ugly head when the snowman starts to melt. This time, they learn valuable lessons about change and loss.
- Heckert, Connie. *Dribbles*. Clarion Books, New York, NY, 1994. Three cats find their routine disrupted by the sudden arrival in their home of a recently widowed old man and Dribbles, his elderly, antisocial feline. Gradually, through the persistence of the other cats, Dribbles is able to speak of her grief over her master's aging and the death of his wife.
- Mellonie, Bryan & Ingpen, Robert. *Lifetimes: The Beautiful Way to Explain Death to Children*. Bantam Books, 1983. This sensitive book is a useful tool in explaining to children that death is a part of life and that, eventually, all living things reach the end of their own special lifetimes.
- Mills, Joyce C. *Gentle Willow: A Story for Children About Dying.* Magination, Second edition, 2003. Written by the founders of the Centering Corporation, a non-profit bereavement resource center located in Omaha, Nebraska, this book is for newly bereaved parents needing general grief information. Inclusions: Feelings, Your Other Children, Grandparents, Friends, Single Parents and Step-Parents, Taking Care of Yourself and Searching.
- Pennells, Margaret and Smith, Susan C. *The Forgotten Mourners: Guidelines for Working with Bereaved Children*. Jessica Kingsley Publishers, second edition, 1999. Children have long been the 'forgotten mourners'. This edition expands on the original book by raising awareness of the sensitive issues involved for bereaved children and highlighting their needs and emotional and behavioural responses to bereavement.
- Romain, Trevor. What on Earth Do You Do When Someone Dies? Minneapolis, MN: Free Spirit Publishing, 1999. This simple, insightful, and straight from the heart book is for any child who has lost a loved one.
- Sims, Alicia M. *Am I Still A Sister?* Big A & Company, 1986. A sensitive, caring journal for hurting children ages 6 and up trying to understand the death of a sibling. This book was written by the author following her brother's death as she searched for answers that no adult seemed to have.
- Stickney, Doris. *Waterbugs and Dragonflies*. The Pilgrim Press, 1982. This book is a graceful fable written to explain the death of a five year old child to neighborhood children.
- Varley, Susan. *Badger's Parting Gifts*. Lothrop, Lee & Shepard Books, 1984. Badger's friends are saddened by his passing, but they come to realize that everyone lives on through their gifts of kindness and the happy memories that remain.
- White, E.B. *Charlotte's Web*. Harper & Row, 1952. Classic tale of Wilbur, the pig, who is scheduled for slaughter and the love from a little girl and spider who cleverly save his life.

- Wilhelm, Hans. *I'll Always Love You*. Crown Publishers, 1985. Elfie, a dachshund, and her special boy progress happily through life together. As the dog ages she is no longer able to play and romp with the little boy. After the dog's death, the boy vows that he will tell every pet he owns that he will always love that animal.
- Wolfelt, Alan. *Healing a Child's Grieving Heart: 100 Practical Ideas for Families, Friends and Caregivers.* Companion Press, Ft. Collins, CO, 2001. Practical guide that provides suggestions on how to help those who are grieving by offering sensitive responses on "what to say and do" and "what not to say and do."

Videotapes

- Back to School: Teens Prepare for School Re-Entry. Produced by Starbright Videos with Attitude, call (800) 315-2580. Teens who have been there share their stories and advice on how to get back into the groove of school. Also discusses how teens can get the extra help they may need to make returning to school a successful experience. http://www.starbright.org
- Cancervive Back to School Kit. A comprehensive package of materials developed to assist children and adolescents re-entering the school setting. The kit contains a "Teachers Guide for Kids with Cancer" and two award-winning documentary videos: "Emily's Story: Back to School After Cancer" and "Making the Grade: Back to School After Cancer for Teens." http://www.cancersourcekids.com/parents/schoolintro.cfm?usertypeid=3
- Drying Their Tears. Produced by CARTI. For information, call (800) 482-8561. Video and manual to help counselors, teachers, and other professionals help children deal with the grief, fear, confusion and anger that occur after the death of a loved one. Has three segments: one about training facilitators, one for children ages 5 to 8, and one for ages 9 to teens. Each section includes interviews with children and video from children's workshops. http://www.hopkinschildrens.org/tpl_rlinks_nobanner.aspx?id=828
- Paul and the Dragon. Powerful 25 minute video created to help children, siblings and friends understand the world of childhood cancer in a safe way, with humor but also with truth. Through watching Paul's battle with his dragon, children with cancer will understand that scary things will happen to them as they fight their "cancer-dragons." They will learn that the doctors, nurses and even the blue "medication-men" and purple "chemo-blobs" are there to help them beat their cancers. Available through the American Childhood Cancer Organization. http://www.acco.org
- Why, Charlie Brown, Why? Tender story of a classmate who develops leukemia. Available as a book or videotape. For video availability, call the Leukemia and Lymphoma Society, (800) 955-4572 (4LSA).

Organizations

The following is a list of organizations that provide resources to families of children with cancer on a national basis, whether financial, emotional, or informational. It is provided as a starting point to assist families, and is not to be regarded as a comprehensive list.

American Childhood Cancer Organization® (ACCO) 10920 Connecticut Ave. Suite A Kensington, MD 20895 (855) 858-2226 http://www.acco.org Founded in 1970, ACCO has more than 70,000 members. Some of the free services provided by ACCO include a toll-free information phoneline, an e-bulletin, childhood cancer books to help children with cancer and their families, diagnosis kits, local support group affiliates, and national advocacy.

American Speech-Language-Hearing Association

2200 Research Blvd. Rockville, MD 20850 (800) 638-8255; TTY: (301) 296-5650 http://www.asha.org

ASHA's mission is to ensure that all people with speech, language and hearing disorders have access to quality services to help them communicate effectively. Canadian organization can be found at http://www.caslpa.ca

Believe in Tomorrow Children's Foundation

6601 Frederick Road Baltimore, MD 21228 (800) 933-5470 http://www.believeintomorrow.org

The Believe in Tomorrow Children's Foundation provides hospital and respite housing services to critically ill children and their families.

Brain Tumor Foundation of Canada

620 Colborne Street, Suite 301 London, ON N6B 3R9 (800) 265-5106; 519-642-7755 http://www.braintumour.ca

The Brain Tumor Foundation of Canada provides up-to-date brain tumor information materials, educational events and support groups. Important brain tumor research is supported through annual grants, a fellowship and the brain tumor tissue bank.

Childhood Brain Tumor Foundation

20312 Watkins Meadow Drive Germantown, MD 20876 (877) 217-4166 http://www.childhoodbraintumor.org

Founded in 1994, the Childhood Brain Tumor Foundation funds scientific and clinical research for pediatric brain tumors, and sponsors educational conferences.

Children's Brain Tumor Foundation (CBTF)

274 Madison Ave. Suite 1004 New York, NY 10016 (866) 228-HOPE http://www.cbtf.org

Founded in 1988, the CBTF provides information, support and advocacy to children with brain tumors and their families. They fund scientific research leading to better treatments and cures of pediatric brain tumors, as well as research leading to improved quality of life.

Compassionate Friends

900 Jorie Blvd. Suite 78 Oak Brook, IL 60523 (877) 969-0010 http://www.compassionatefriends.org

Compassionate Friends provides personal comfort, hope and support through local chapters for bereaved family members experiencing the death of a child.

Make-A-Wish Foundation® of America

4742 N. 24th Street, Suite 400 Phoenix, AZ 85016 (800) 722-9474 http://www.wish.org

Founded in 1980, the Make-A-Wish Foundation has enriched the lives of children with life-threatening medical conditions, and their families, through their wish-granting program.

National Association of Hospital Hospitality Houses (NAHHH)

P.O. Box 1439 Gresham, OR 97030 (800) 542-9730 http://www.nahhh.org

NAHHH is a nation-wide association of 200 non-profit organizations that provide lodging and support services to patients and their families who are receiving medical treatment far from their home communities.

Pediatric Brain Tumor Foundation (PBTF)

302 Ridgefield Court Asheville, NC 28806 (800) 253-6530 http://www.pbtfus.org

The PBTF, founded in 1991, provides education and emotional support for children with brain tumors and their families. They seek to find the cause and cure for childhood brain tumors by supporting medical research and increasing public awareness of childhood brain tumors.

Online Support Groups

ACOR, The Association of Cancer Online Resources, Inc.

http://www.acor.org

ACOR offers access to mailing lists that provide support, information, and community to everyone affected by cancer and related disorders. It hosts numerous pediatric cancer discussion groups.

American Childhood Cancer Organization's Inpire Online Community

http://www.inspire.com/groups/american-childhood-cancer-organization

ACCO's Inspire online community connects patients, families, friends and caregivers. It provides a platform for support and inspiration from diagnosis, through treatment and beyond. Discussion topics include: newly diagnosed; treatment; emotional support for children with cancer, siblings, parents and caregivers; financial and insurance issues, and more

Apraxia-Kids Mailing List

Listserv@Listserv.syr.edu http://www.apraxia-kids.org This website and mailing list covers oral motor apraxia and related disabilities.

Cerebellar Mutism Brain Tumor Listserv Yahoogroup

http://health.groups.yahoo.com/group/cerebellarmutism

Listserv providing online support for parents and caregivers of children who suffer from cerebellar mutism and posterior fossa syndrome after brain tumor surgery/resection.

DIPG Listserv Yahoogroup

http://health.groups.yahoo.com/group/dipg

This group is primarily for parents of children diagnosed with diffuse intrinsic pontine glioma (DIPG). The membership includes parents who are in all stages of the DIPG journey.

Educating Brain Tumor Kids

http://groups.yahoo.com/group/EducatingBTKids

A group with links and files dealing with neuropsychological testing, school re-entry, school options, late effects etc. There is an associated listsery with archives.

Home Schooling Special Needs Children

http://groups.yahoo.com/group/special-needs-homeschool

This group supports parents who choose to home school their children with special needs. Most members have medically fragile children dealing with challenges in speech, motor development and learning disabilities and home school full time or part of the time.

Hydrocephalus (HYCEPH L)

http://neurosurgery.mgh.harvard.edu/pedi/hyceph-l.htm

This list is open to all people interested in hydrocephalus.

IEP Guide and Listserv Yahoogroup

http://groups.yahoo.com/group/IEP_guide

This is a very large listsery that offers special education support and has a free IEP guidebook.

Pediatric Brain Tumor Angels Listserv Yahoogroup

http://health.groups.yahoo.com/group/PBTAngels

Listserv providing online support for parents and caregivers who are facing end of life issues with a child who has a brain tumor and extended support for parents of children who have died after battling a brain tumor.

Pediatric Brain Tumor Facial Paralysis Listserv Yahoogroup

http://health.groups.yahoo.com/group/PBTFacialParalysis

Listserv providing online support for parents and caregivers to gain information and support regarding facial nerve paralysis after surgery for pediatric brain tumor surgery/resection.

Pediatric Brain Tumor Listserv Yahoogroup

www.yahoogroups.com/group/pediatricbraintumors

Listserv providing information and online support for parents and caregivers of children diagnosed with pediatric brain tumors including: astrocytoma, atypical teratoid/rhabdoid, glioblastoma multiforme, pleomorphic xanthoastrocytoma, craniopharyngioma, diffuse intrinsic pontine glioma, gangliocytoma, ganglioglioma, germinoma, glioma,

medulloblastoma, metastatic brain tumor, neurocytoma, oligodendroglioma, juvenile pilocytic astrocytoma, pineocytoma, pineoblastoma, PNET, primitive neuroectodermal tumor, teratoma, and ependymoma.

Websites

2bMe

http://www.2beme.org

A site for adolescents with cancer. Helpful information from skin to hair to fitness and friends.

Adolescents Living with Cancer

http://www.adolescentslivingwithcancer.org

Online information, social networking and critical resources to help adolescents living with cancer meet their unique life challenges.

Alex's Lemonade Stand: Change Childhood Cancer School Program

http://www.alexlemonade.org/campaign/change-childhood-cancer-school-program

Coin collection program designed especially for students to help raise funds for childhood cancer programs.

American Cancer Society Cancer Action Network

http://www.acscan.org/qualityoflife

Detailed information on what palliative care is and how it enhances patient and family quality of life; as well as associated legislative initiatives being undertaken by ACSCAN.

American Childhood Cancer Organization: PJammin for Kids with Cancer http://www.acco.org/PJammin.aspx

With a minimal donation, healthy children wear their PJ's to school in support of the thousands of children fighting cancer in their pajamas every day of the year. Fun way to raise awareness of childhood cancer and raise funding for childhood cancer research and educational programs.

Bandaids and Blackboards-When Chronic Illness Goes to School

http://www.lehman.cuny.edu/faculty/jfleitas/bandaides/contkids.html

Wonderful, fun and informative website about ill children and school.

CarePages

http://www.carepages.com

Free, patient blogs that connect friends and family during a healthcare challenge.

CaringBridge

http://www.caringbridge.org

Free, personal and private websites to help families experiencing a health crisis connect with family and friends.

Children's Hospice and Palliative Care Coalition

http://www.childrenshospice.org/coalition

Children's Hospice & Palliative Care Coalition is a social movement led by children's hospitals, hospices, home health and grassroots agencies and individuals to improve care for children with life-threatening conditions and their families.

Children's Oncology Camping Association International

http://www.cocai.org

Website listing the more than 65 children's oncology camps located across the U.S. as well as camps for children with cancer in Canada, New Zealand and Europe.

Children's Oncology Group

http://www.childrensoncologygroup.org

The Children's Oncology Group (COG) unites more than 7,500 experts in over 200 children's hospitals, universities and cancer centers into a global team dedicated to working towards a cure for all children with cancer. Includes a list of all COG treatment centers.

Children's Oncology Group Coping with Cancer Information

http://www.childrensoncologygroup.org/index.php/coping-with-cancer-293

Online resource to assist the family with coping information.

Children's Oncology Group School Support Program

http://www.childrensoncologygroup.org/index.php/school-support

Online resource to assist the teacher who is faced with a childhood cancer diagnosis.

Children's Oncology Group Survivorship Guidelines

http://www.survivorshipguidelines.org

Online resource for survivors of childhood cancer to assist with monitoring late effects of childhood cancer treatment.

Clinical Trials.gov

http://www.clinicaltrials.gov

Clinical Trials.gov is a registry and results database of federally and privately supported clinical trials conducted in the U.S. and around the world.

Courageous Parents Network

http://www.courageousparentsnetwork.org

Online forum to support parents who have a child with a life-limiting illness as the child approaches the end of his/her life. (Not childhood cancer specific)

CureSearch Guide for School Personnel

http://www.curesearch.org/Guidance-for-School-Personnel

Online resource to assist school personnel with a childhood cancer diagnosis.

Get Palliative Care

http://www.getpalliativecare.org/whatis/pediatric/

Online resource explaining what pediatric palliative care is and where to find it. Includes blog.

Grandparents in Action

http://www.grandparentsinaction.com

Informal association of grandparents directly impacted by having a grandchild between infancy and age 19 who was diagnosed with cancer, and dedicated to improving the outcomes.

HopeLab Remission-2

http://www.hopelab.org/innovative-solutions/re-mission-2/

Collection of online games that help young people with cancer fight their disease.

iCANcer Electronic Medical Record

http://itunes.apple.com/us/app/icancer/id389815342?mt=8

Personal electronic medical record created for iPhone, iPod, and/or iPad app that stores diagnosis, treatment and healthcare provider information. Manages medical information including current and past medications, side effects, lab results (graphed over time), and organizes and syncs doctor's appointments, and conveniently exports medical information to an email format for easy communication to a healthcare provider prior to an appointment.

Kids Cancer Network

http://www.kidscancernetwork.org

Kids Cancer Network provides FUNLETTER activity magazines for children with cancer online so that they can print their very own FUNLETTER at home or in the hospital.

KOA Care Camps

http://www.koacarecamps.org

Since 1984 KOA campgrounds have been providing a summer camping experience for children with cancer throughout North America. At these camps, children have the chance to experience camp with others their age who understand what they're going through. They swim, hike, sing, laugh, make new friends and create joy-filled memories, all while receiving the medical treatment they need.

Lexie's Cookbook for Kids with Cancer

http://www.donnagreen.com/Lexie.php

Written by Lexie, a pediatric brain tumor survivor, under the direction and expertise of Georgia Manzo Joachim, author of *A Taste of It All, Celebrating the Mood of Food*, this 240 page book is filled with delicious, healthy, cancer fighting recipes for kids living with cancer.

Monkey In My Chair

http://www.monkeyinmychair.org

Monkey In My Chair is a program for preschool and elementary aged children who are away from school because of a cancer diagnosis. Each child is provided with a "monkey kit" which includes a teacher's guide and classroom book, a backpack and a big stuffed monkey that takes the child's place when he/she is unable to be in school.

My Life Line

http://www.mylifeline.org

Free, private, patient websites for people affected by cancer.

My Post Hope

http://www.posthope.org

Free public or private website for patient and caregiver support & fundraising.

Starbright World

http://www.starbright.org

Online community for teens and young adults ages 13 to 20 who are dealing with a serious illness.

The National Institutes of Health Palliative Care: Conversations Matter Resources http://www.ninr.nih.gov/conversationsmatter

Online information to assist help health care professionals and patients to discuss pediatric palliative care earlier, with the goal to provide extra support in dealing with a serious illness.

Autopsy Tissue and Organ Donation

Oregon Health and Science University CCURE-FAST

http://www.ohsu.edu/xd/health/services/doernbecher/research-education/research/pape-family-pediatric-research-institute/ccure-fast.cfm

A helpful site to assist families with information about tumor tissue donation. Includes dowloadable information on tumor banking, Q&A about legacy gifting, religion and tumor banking, as well as guidelines for medical professionals.

U.S. Government Information on Organ and Tissue Donation and Transplantation http://www.organdonor.gov

Comprehensive website dedicated to providing information on organ and tissue donation and transplantation, including statistics, information on how to become an organ donor, legislation, associated research and grant opportunities.

Disabilities

Council of Educators for Students with Disabilities, Inc. (CESDI)

http://www.504idea.org/Council Of Educators/Welcome.html

CESDI provides Section 504 and special education training and resources to educators.

Family Village: A Global Community of Disability Resources

http://www.familyvillage.wisc.edu

A huge site that provides informational resources on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, health issues, disability-related media and literature.

Pacer Center Parent Advocacy Coalition for Educational Rights

http://www.pacer.org

A national coalition of parents working for educational rights.

Protection and Advocacy

http://www.disabilityrightsca.org

Group that works to advance the human and legal rights of people with disabilities. Website includes a page on assistive technologies.

Distance Learning

Talia Seidman Foundation

http://www.taliaseidman.com

An organization dedicated to using technology to bring hospitalized and homebound chronically ill children back into the classroom.

Hearing Impairment

Hard of Hearing & Deaf Students: Resource Guide to Support Classroom Teachers http://www.bced.gov.bc.ca/specialed/hearimpair/intro.htm

Homeschooling

A to Z's Cool Homeschooling

http://www.gomilpitas.com/homeschooling

Huge site with information on introduction to home schooling, curricula, home schooling laws, support groups, methods, and philosophies.

National Home Education Network

http://www.homeschool-curriculum-and-support.com/national-home-education-network.html

A source for home schooling information, support group listings, home school news, and related resources.

Nonverbal Learning Disabilities

Nonverbal Learning Disabilities

http://www.nldontheweb.org

A comprehensive site on nonverbal learning disabilities.

Siblings

Siblings of People with Disabilities

http://www.iidc.indiana.edu/index.php?pageId=2458

A list of books and videos that help siblings of people with disabilities.

Special Education Law

Americans with Disabilities Act Homepage

http://www.usdoj.gov/crt/ada/adahom1.htm

Consortium for Appropriate Dispute Resolution in Special Education (CADRE)

http://www.directionservice.org/cadre

CADRE provides support and materials that can help parents and educators implement the mediation requirements under IDEA 97.

Department of Education Information about IDEA

http://idea.ed.gov

Comprehensive information about the Individuals with Disabilities Education Act.

Educational Rights/Educational Law

http://edlaw.org/wordpress

This site provides publications and services for attorneys, advocates and parents who need to know about educational law, including a section that deals with transportation.

National Information Center for Children and Youth with Disabilities

http://www.nichcy.org

Includes helpful resource sheets for every state.

Wrights Special Education Law

http://www.wrightslaw.com

This extensive and well organized site is probably the best place to start to gather information on special education law. Includes sections on advocacy, law, books and other resources.

Speech and Language

IntelliTools

http://www.intellitools.com

This firm has a great catalog of assistive technology and communication devices.

Sports

American Hippotherapy Association

http://www.americanequestrian.com/hippotherapy.htm

Hippotherapy is therapeutic riding for those with motor disturbances.

Disabled Sports USA

http://www.dsusafw.org

An organization that gives people with physical, neuromuscular and developmental impairments the opportunity to participate in a variety of activities including water/snow skiing, camping, and whitewater rafting. Adaptive equipment information available.

North American Riding for the Handicapped

http://www.narha.org

An organization that promotes the benefits of horseback riding for those with physical, emotional or learning disabilities.

Research Articles

The following journal articles are referenced by the authors in specific chapters throughout the book. They are listed here to provide direction for additional reading for those individuals who wish to delve deeper into a specific topic.

Further Reading

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