

News & Updates

February 2025 | Volume 16 - Number 2

Upcoming Activities

April 7
Annual Drive

May 18
Virtual Awareness
Walk

About Us
Spreading Hope
Through
Psychosocial
Support SM

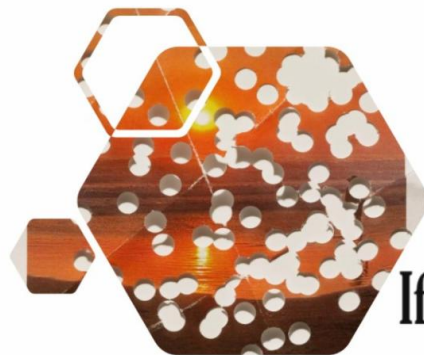
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The New York Times

OPINION
GUEST ESSAY

If My Dying Daughter Could Face Her Mortality, Why Couldn't the Rest of Us?

Quoted in The New York Times

Cancer in children is considered rare, unless you have a child diagnosed with the disease. Then for you, your child, and your family, childhood cancer becomes your all-consuming reality. Childhood cancer is the leading cause of death by disease in the United States (Siegel et al., 2024). It is estimated that, in 2024, a total of **14,910 children and adolescents, ages 0 to 19, were diagnosed with cancer** (NIH, 2024). Although the 5-year survival rates for most childhood cancers have improved in recent decades, the improvement has been notable for only a few cancers, such as acute lymphoblastic leukemia (ALL), the most common childhood cancer. In contrast, survival rates remain poor for many other cancer types, for some age groups, and for some cancers within a site.

Approximately 1,600 children and adolescents die of cancer each year in the United States, indicating that new advances and continued research to identify effective treatments are required to reduce childhood cancer mortality. It is hard enough hearing, *YOUR CHILD HAS CANCER*, but how does a family manage the other four horrific words.... **THERE IS NO CURE?** In December of 2024, the New York Times published an article by Sarah Wildman entitled, "If My Dying Daughter Could Face Her Mortality, Why Couldn't the Rest of Us?" Sarah bravely reflects on this complex and heartbreaking question from her lived experience with her daughter, Orli. Orli was

**It's not just about
the medicine!**SM



**15th Anniversary
Video**

diagnosed with hepatoblastoma, a rare liver cancer which is primarily seen in toddlers, and she died at the age of 14.

Our healthcare system is focused on aggressive medical treatment and cures. However, **when a child is dying from cancer and there are no more medical options, how is this reality conveyed?** In many cases, death can be viewed as a failure in the medical community, making it challenging for the healthcare team to help families navigate the next phase of the cancer journey, dying.

Mattie Miracle was honored to be interviewed by Sarah Wildman and included in her article. The Foundation is proud of our vision for the creation of the Psychosocial Standards of Care. These historic evidence-based Standards define what children with cancer and their families must receive to effectively support their psychosocial needs throughout the entire cancer trajectory, including end of life and bereavement care. We are grateful Sarah has called attention to the importance of end-of-life care. **Families rely on their child's healthcare team for not only the medicine, but for the support, guidance, and important conversations that are necessary to enable a child to die with dignity and for the family to build upon these conversations to honor their child's legacy.**

To access the full article, click on download.

 **DOWNLOAD**

Spreading Hope Through Psychosocial Support. SM

Family Resource

One of the many difficult tasks parents face is **speaking with their child about their prognosis**. This entails addressing issues related to the long term effects of treatment that could impact their quality of life and/or a discussion of the possibility of death.

Psychosocial providers understand how challenging such conversations can be, but at the same time recognize how beneficial it is for a child with cancer. The Courageous Parents Network (A 501c3 organization, whose mission is to empower, support, and equip families and providers caring for

Speaking with Your
Child About Prognosis



Learning Objectives

After reviewing this Guide you will be able to:

- Describe the potential benefits of speaking with your child about their prognosis
- Adopt strategies for raising conversations about prognosis with your child
- Identify resources to support you in speaking with your child

children with serious illness.) has developed a **new guide to help validate parents and caregivers' worries and to also empower them to have these conversations.**

**To access the resource,
click on download.**

 **DOWNLOAD**



Child Life Corner with Adina Levitan, CCLS

The Bonds We Build: Love, Loss, and The Heart of Child Life

February is often painted in pink and red, wrapped in candy hearts and messages of love. **But for those of us in child life, love looks different.** It is in the quiet moments—kneeling beside a child's hospital bed, tracing tiny fingers with an IV line, or offering choices when so much has already been taken away. It is in the trust built over time, in the way a child reaches for your hand before a procedure, or in the deep breath a parent takes when they see you walk through the door, knowing they are not alone.

Child life is built on connection. **We do not just meet children in the hospital; we walk beside them. We celebrate their victories—first steps after surgery, a clear scan, or a long-awaited discharge, and we bear witness to their struggles—pain, fear, exhaustion, and the weight of uncertainty.**

I am reminded of Elana, a four-year-old girl diagnosed with a large tumor just weeks after the pandemic began. She was admitted to the hospital with her father, while her pregnant mother, unable to be by her side, waited anxiously at home. Elana's dad was devastated—alone, overwhelmed, and trying to manage countless questions and decisions without his wife beside him.

I spent days with Elana in her room and the playroom, giving her as much choice and control as possible. She played through procedures and pokes, finding ways to cope even as the world around her shifted. Then, one day, I noticed her hair started to mat from days in the hospital. Gently, I asked

her father if I could brush and style it. Through tears, he agreed—feeling, in that moment, the full weight of his daughter’s mother not being there.

It is in these quiet, overwhelming moments that child life specialists see beyond the obvious. We step in not just for medical preparation, but for the small, deeply human needs that might otherwise go unnoticed.

The bonds I create with patients are both a privilege and a heartache. You don’t just know a child’s diagnosis; you know their favorite stuffed animal, the way they like their port accessed, and how to make them laugh on their hardest days. I have sat with their parents during seemingly endless hospital stays, helped siblings understand the impossible, and learned to read between the lines of exhaustion and hope.

And then, sometimes, I have to say goodbye.

No matter how much I prepare, no matter how many times I have been there before, loss never gets easier. There is no way to hold space for so much love without feeling the grief that comes when it is gone. **Child life teaches us how to help children and families cope, but there is an unspoken, “on-the-job” lesson in coping with loss that does not always make sense. How to walk into a room that used to be filled with laughter and find it empty. How to carry the weight of a goodbye that came too soon.**

But if love is what makes loss so heavy, it is also what makes this work worth it. The bonds we build, the trust we earn, and the moments we share—they matter. They bring comfort in the hardest times. They remind families that they are not alone, and long after a child is gone, the love remains.

So this February, while the world talks about love in chocolates and flowers, **I think about the kind of love that does not fit into a card. The love that sits beside a hospital bed. The love that holds a parent’s hand. The love that stays, even after goodbye.**

Keep Our Carts Rolling

In honor of Mattie's 23rd birthday, we will be hosting our **14th annual item drive**. All donated toiletries stock our Mattie Miracle Snack & Item Carts for pediatric families at MedStar Georgetown University Hospital (Washington, DC), Children’s Hospital at Sinai (Baltimore, MD), and the Clinical Center at the National Institutes of Health (Bethesda, MD).

When living in a hospital 24 hours a day, seven days a week and caring for a child with cancer or other life-threatening illness, **receiving these items can feel like a gift.** Families often rush to the hospital when their children are ill and are unable to pack basic items that are needed for their daily care. The Carts fulfill these basic psychosocial needs and **provide items free of charge to families.**



Check out our Amazon wish list below and help us keep our Mattie Miracle Carts stocked to support families caring for children with cancer. **Our Carts support over 2,500 families a year. We ask that all items be received by April 7, 2025.**

Click on the image below for our Wish List.



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MATTIE MIRACLE CANCER FOUNDATION | PO Box 6485 | Arlington, VA 22206 US

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