



NTSAD FAMILY CONNECTIONS

For Newly Diagnosed Families | Month Five

"You never know how strong you are until being strong is the only choice you have."

-Unknown

Notes From A Dragon Mom

BY EMILY RAPP BLACK, MOM TO RONAN, WITH
FORWARD BY BECKY BENSON, MOM TO MISS ELLIOTT

Parenting a child with a life limiting-illness sets us apart from other parents in so many life altering ways. We may now find it more difficult to connect to those who we once considered our peers, but whose lives now look very different from our own. Conversely, we may also find solace in those who directly understand both our immense challenges, and the victory of small wins, in whatever form they present.

When I first met Emily, her son, Ronan, was close in age to my daughter, Miss Elliott. We became fast friends, and quickly solidified our relationship as each other's grief mentors while caring for our children, who both had Infantile Tay-Sachs Disease. We further bonded over our shared love of writing and spent late nights lamenting our frustrations to each other, and confessing our fears.

In speaking about Notes From A Dragon Mom, and referring to society's expectations of what parenting looks like, Emily reiterates to me today, nearly ten years later, that this article "Speaks to the experience of parenting as a vocation with honor and purpose, meaning and joy, even when a child has a life-limiting illness."

You can read Emily's piece, [Notes From A Dragon Mom](#) in the New York Times.

Understanding Palliative Care and Hospice

BY SUSAN FINKLESTEIN, RN

There are so many questions suddenly needing to be answered when your child receives a life limiting diagnosis, including preparing for their future. Who do you turn to? You may have heard of palliative care or hospice and wondered what these each consist of. You may have associated them with end of life, death and dying, or even giving up hope. While it's true that these forms of care do shelter patients through the ends of their lives, there is so much more they can do as well. Palliative care provides medical support and symptom management to ensure your child is comfortable during their life. *Continued on page 2*

Resources:



What Are Palliative Care And Hospice?

Understanding your resources from the National Institute of Health. Click [here](#) to explore your options and learn more about the advance care planning you may want to consider for your child, including when to seek help, what type of care is provided, and where that care is provided.

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Continued from page 1

The palliative care team will coordinate with your pediatrician and other medical providers. They will recommend medications and treatments to make sure your child's symptoms are managed, and that they remain as comfortable as possible.

Hospice services are provided in any place where your child resides; whether that be in your home, or a medical facility. Hospice staff are the ones you can turn to for support. Available twenty-four-seven, they are there for both your medical questions and as a supportive ear. The services they provide include nursing, social work, spiritual and medical support, all to help you navigate issues related to your child's diagnosis. They can also help you make difficult decisions regarding your child's care. Additionally, they can provide some inpatient and home based respite services to relieve you for short periods of time.

If your medical team recommends hospice or palliative care, please don't be afraid. I encourage you to consider the benefit adding these services could provide you and your loved one. They are merely there to provide additional support during these very difficult times, and to ensure you do not have to go through them on your own.

BRIGHAM YOUNG

By the Book - Writings That Help Build Resilience

TAKEN FROM B BRAVE FOUNDATION.ORG

Everything Happens for a Reason

By Kate Bowler

What to Say When You Meet the Angel of Death at a Party

Essay by Bowler from the New York Times

Bearing the Unbearable: Love, Loss, and the Heartbreaking Path of Grief

By Joanne Cacciatore, Ph.D.

Option B: Facing Adversity, Building Resilience, and Finding Joy

By Sheryl Sandberg & Adam Grant

Man's Search for Meaning

By Viktor E. Frankl

View these titles and more at www.bravefoundation.org.

"Because, if you keep hope alive, it will
keep you alive." - Unknown