



NTSAD FAMILY CONNECTIONS

For Newly Diagnosed Families | Month One

Coping with a Life-Altering Diagnosis

BY MONICA GETTLEMAN, BROOKE'S MOM

I consider March 7, 1997 the worst day of my life.

This was the day my husband and I found out that our daughter, Brooke, had Tay-Sachs disease. She was only thirteen months old and my entire world fell apart. As a mother I felt like I had been kicked in my womb. While this may sound strange, it is where I felt the pain emanating as the ophthalmologist told us the news. For the next few weeks, I would wake up convinced it was all a bad dream. Then, the reality would hit me again like a ton of bricks. My daughter was not developmentally delayed or in need of glasses, this wasn't something we could help her overcome. She had a fatal neurological disease.

I soon learned that my husband and I had vastly different responses to Brooke's diagnosis. While his tears and pain did not stop, I had to have the emotional and physical energy to take care of Brooke and my then five-year-old son. My husband was truly inconsolable. I, too, had a myriad of emotions swirling around my head, usually leading to "why me". I quickly learned this response was neither helpful, nor could it change what would happen to Brooke. I also shed plenty of tears, but tried to maintain as much normalcy as possible in front of my son. By the end of the first month, I began to accept Tay-Sachs as our reality, and that Brooke was only going to live for a finite amount of time. I also understood that the hopes and dreams I had previously held for my daughter and her life were never going to come to fruition. My expectations, and my plan had to change. First, through acceptance, and then in moving forward, I found shifting my narrative was actually my way of coping. I couldn't change Brooke's diagnosis, but I could give her my best for as long as she lived. I knew she may not live a long life, but it could be a beautiful and meaningful life. I chose to celebrate what we had each and every day instead of focusing on what we lost.

"NEVER GIVE UP HOPE. OUR CHILDREN ARE WARRIORS."

– LESLEY GRONOW HARTLAND

"Forever I will walk this life with you in my heart."

Resources:

NTSAD Family Support

We know you're in that space of "What Now?" and "How Do I Do This?" To help you talk through the next steps, the NTSAD Family Services Team is here. Contact [Diana Pagonis](#), Director of Family Services, or [Becky Benson](#), Family Services Coordinator, to arrange a one-to-one virtual call.

Courageous Parents Network

Courageous Parents Network is a non-profit organization and educational platform that orients, empowers and accompanies families and providers caring for children with serious illness. [Click for the section: The Beginning.](#)

Contact Us:



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Disclaimer: The content of this newsletter is intended for support purposes only and not intended to be a substitute for professional medical advice, diagnosis, or treatment. Always seek the advice of your healthcare provider with any questions you may have regarding a medical condition.



After Diagnosis - What Now?

BY SARA SCAPAROTTI, JOEY'S MOM

We Are Here for You

After receiving your child's diagnosis there is an overwhelming amount of information to absorb, questions to ask, and decisions to make. We have created a new family care packet specifically to answer some of those initial questions and introduce you to what services NTSAD can offer. You are not alone in this; the entire NTSAD community is here to support you and battle these diseases together.

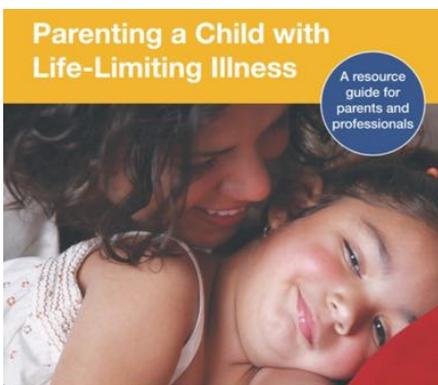
Philosophy of Care

Defining your care goals and values, or finding your philosophy of care, is often one of the most challenging decisions families need to make. These decisions are deeply personal and will enhance your communications with your health care team, including doctors, therapists and nurses. Some families find it helpful to talk to others who have already made these decisions, and we're happy to pair you with a "mentor" to provide peer support.

Philosophies occur along a spectrum from less intervention to a more technical approach. The NTSAD family is non-judgmental and supports all care philosophies regardless of where they are on the spectrum. We truly believe there are no right or wrong choices; only the ones that work best for you and your family. For more information and tips on how to find your philosophy of care, please read the "Philosophy of Care" handout included with the new family care packet, or reference the "[**Philosophy of Care**](#)" page on our website.

Resources for Newly Diagnosed Families

BY BONNIE DAVIS, ADAM'S MOM



[Watch Trailer Here](#)

We know this is all so very new and overwhelming. We encourage you to take this journey one step at a time, at your own pace. Changes to your child's health will happen gradually, and we are here to offer resources you can use to plan for your child's care, take care of yourself and your other children, and create the best memories and experiences for your family as you navigate this unknown territory.

NTSAD has many resources for you as you start to learn about your child's diagnosis. This first month, we'd like to direct you to the trailer for NTSAD's DVD "Parenting a Child with Life-Limiting Illness". **Please believe the last line of the trailer, which states, "you are capable of seeing this through and you are braver than you can ever imagine".** Copies of the full video are available upon request for you and your care team.



You Have A Decision To Make - Feeding Tube Overview

BY BONNIE DAVIS, ADAM'S MOM

The day my son, Adam, was diagnosed with Tay-Sachs disease, I vividly remember the doctors telling my husband and I that one of the most difficult decisions we would have to make was whether we would place a feeding tube for nutrition. I agree that it was extremely difficult, and many NTSAD parents agree as well. We were very thoughtful about what we wanted for our son's short life, and took the time to talk about this issue - with each other, with our medical providers, and with other parents. At the core of this discussion is the fact that you do have choices, and only the parents know what is best for their child.

We know that at some point the disease will take away our children's ability to eat by mouth. While the timing may be different for each child, there is much to consider when deciding if and when to place a feeding tube. As with most of the care choices we make for our children, it is important to educate yourself and know what your options are. Talk to your child's doctors and decide if what they are recommending aligns with your care goals for your child. Speak with other families who have cared for children both with and without feeding tubes. From these conversations, consider what resonates with you based on the philosophy of care you have developed for your child.

The reasons to place or not place a feeding tube are individual and personal. The following videos are a starting point for you to begin to think about both choices.

[This mother](#) discusses her path to placing a feeding tube for her daughter.

In [this video](#), two fathers talk about their decision of not placing feeding tubes for their children.

There is no right or wrong in this situation. Otherwise, it would be an easy decision. View more on the [decision making process](#), or read the [NTSAD supplement](#).

View the [NTSAD Care Tip video](#).

Additionally, it is okay to change your mind. As your child's condition changes, your thought processes and what you feel your child is "telling you" may change as well. Ultimately, the choice you make is the one that you know in your heart was the right decision for your child and your family at that time.

Whatever your choice, rest assured that it was made from the deep love you have for your child.

**If you would like to speak to other parents about this decision process, please contact NTSAD. We can put you in touch with parents who are willing to share their real-life experiences with you regarding feeding tubes.*