NTSAD FAMILY CONNECTIONS

For Newly Diagnosed Families | Month Six

"Kindness and Compassion are to the brain what breath is to life." - Dr. Daniel Sigel, MD

Journaling Through Anticipatory Grief

BY BONNIE DAVIS, ADAM'S MOM

Your thinking is cloudy and your thoughts are jumbled. You can't remember things from one moment to the next. Sleeping is difficult and you feel irritable and exhausted. Everyday activities seem like gargantuan tasks. You feel intense sadness and pain, and the loss of the life you expected is all you can think about right now. These are just some of the feelings you may be experiencing as you navigate life after your child's diagnosis. The ever-changing landscape of caring for a child with a life-limiting illness can feel all-consuming.

> *"Getting your thoughts and emotions on paper can help process your anticipatory grief."*

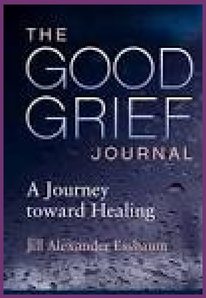
This is all part of the normal anticipatory grieving process as you adjust your expectations of the future with your child. Something that many parents have found beneficial to manage this disorganized thinking and emotional upheaval, is to write it all down. Getting your thoughts and emotions on paper can help you process this new reality. It can be cathartic, providing some emotional release. It is important to be aware that journaling may make you more emotional. Perhaps it will make you cry even more. But that's ok. Journaling is a safe, judgement-free place to explore your jumbled thoughts and feelings, possibly provide some hope, and see your progress through the process.

There are no rules to journaling. You can write free-form and just get all of your thoughts down on paper (or a computer screen). The internet has many places to find writing prompts. Perhaps you would prefer to purchase a grief journal. Other ideas might include writing a letter to your child, or creating a list of all the wonderful things you cherish about your child. Write freely about things you feel you can't share with anyone else. You don't need to filter, edit, or explain. You can be raw, authentic and explore your grief and grief responses. Journaling through life-altering experiences can help you to reflect and understand your thoughts and emotions at this difficult and painful time. Perhaps you'll consider giving it a try.

Resources:

The Good Grief Journal

In this companion journal to Good Grief, the reader is guided through exercises to: "Discover your own wisdom about your grief. Every loss deserves a fitting grief," Jill Alexander Essbaum assures us in The Good Grief Journal. From that beginning, she offers a path for those who grieve. Find both Good Grief and The Good Grief Journal, **here**.



THE GOOD GRIEF JOURNAL

A Journey toward Healing

Jill Alexander Essbaum

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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.

NTSAD leads the worldwide fight to treat and cure Tay-Sachs, Canavan, GM1, and Sandhoff diseases by driving research, forging collaboration, and fostering community.Supporting families is the center of everything we do.

Symptom Management - Seizure Overview

BY NTSAD'S FAMILY SERVICES TEAM

As Noted in the NTSAD Home-Care Manual:
"Many of our children have seizure disorders of one kind or another. Although undesirable, seizures may not be as damaging to a child as we might expect, as long as the seizure is not prolonged. A prolonged seizure can cause anoxia (loss of oxygen) to the brain. Seizures usually can be controlled with medication. The kind and amount of medication may change over time. An increase in the frequency or severity of a child's seizures may be due to a progression of the disease or may indicate that the dose of the anticonvulsant is not high enough for his or her weight. In some cases, vigorous efforts to control seizures may not be justified."

- **Presentation - What do seizures look like? What types of seizures might my child have? How will I know they are having a seizure?**
    1. Seizures can vary from child to child and from seizure to seizure.
    2. Staring or "absence seizures", laughing seizures, tonic/clonic seizures (partial seizures that involve arms and legs) and "passing out" seizures.
    3. https://www.epilepsyfoundationmn.org/resource/srr-chart/
    4. Most seizures start off mild and may progress to more "severe-looking". Most seizures require no immediate intervention.

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- **Finding the Right Doctor - Advocating for your Child and finding a doctor to listen to your concerns**
    1. Depending on circumstances, your child's seizures may be managed by your pediatrician, neurologist, or other member of your care team.
    2. Are EEGs always necessary? While it will likely be recommended, you can decide if this is something you want to have done. We know children with these diagnoses will have seizures, which can be treated without this test. Additionally, some types of seizures may be occurring, but may not show up on these tests.

- **Symptom Management - Including medications and mitigating factors when seizures present**
    1. Unfortunately this is often trial and error. Many seizure meds have side effects, especially drowsiness.
    2. The goal is to strive for a balance between your child not being too sleepy and a level of seizure activity you are comfortable with.
    3. These diseases are progressive, so seizures also progress over time. Dosages will need to be adjusted and medications are often used in combination (2-3 meds).
    4. Some medications may require blood level testing. You can consult with a physician to determine if this is something you are willing to do on a regular basis.
    5. It will be important to have emergency medications on hand, but they should be used as a last resort during prolonged seizure activity.
    6. Maintain safety, including positioning and clear airway.
    7. Monitor your child's breathing throughout each episode.
    8. Avoid precipitating factors (sudden position changes, loud noises).

You may find this article from MedicineNet helpful in distinguishing types of seizures your child may experience.

Holding on to Happiness

BY YASMINA HALIM, LILY'S MOM

After your child’s diagnosis, and once finding NTSAD, take a deep breath and know that you and your family are not alone in this anymore. Everyone in this community is either right where you are in your journey or further along. In this group you will find resources, guidance, compassion and, most of all, love.

Coming to terms with the prognosis of your child’s disease is both overwhelming and daunting. It can be hard to know how to move forward or find the resilience to do so. Our family made the decision early on to choose to find happiness, joy, and make memories together while we could.

For me, making memories means saying yes in certain situations, and no in others. I try my best to be truly present in every moment we share together. I allow myself to take all the pictures I want. They will make wonderful photo books one day. I also allow myself phone-free time with my children. Unplugging and just being together have made lasting memories I will forever cherish. Some days routine goes out the window and we have the most epic dance parties in the middle of the day!

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My advice to you is to take the walks and enjoy the scenery. Put those decorations up. Cheer as loud as you can for your warrior. Seek out the happy moments and celebrate them. We are eight months into our diagnosis and the happy memories are starting to win over the sadness. Being connected with other families of NTSAD has helped me to focus on what I can control instead of the things I cannot.

Today, tomorrow, and for as long as I can I choose to hold on to happiness and save the sadness for another day.

> "Being a caregiver can at times feel like unrelenting hard work, which can cause feelings of stress and guilt.
>
> These feelings don't mean that you're a selfish person, or that you don't love the person enough.
>
> It just means that you are human like everybody else, and that you will have good and bad days."
> -loveliveson.com