



NTSAD FAMILY CONNECTIONS

For Newly Diagnosed Families | Month Ten

Planning for a Funeral

BY HULYA D'ARRIGO, LCSW

Arranging a funeral or memorial service for your child is an overwhelming, emotionally exhausting task, and one that no parent should ever have to consider planning for. However, thinking realistically, you know you will need to make these arrangements at some point in the future. Planning a service or funeral beforehand, while you are likely to be thinking clearly, may make this process less stressful. It can be beneficial to utilize your support system to help you with this planning. You might ask a family member, close friend, spiritual advisor, or even someone on your health care team, such as a hospice or palliative care social worker to assist you in this process. If at any point you feel overwhelmed or not ready to make these arrangements, take a break and come back to it later.

There are many things to consider, such as your religious background, cultural heritage, selecting a funeral home, and service and burial arrangements. If possible, visit various sites with someone you trust to help you with these decisions. Be sure to write down questions you have before going to these appointments. Ask about expenses and make sure to get everything in writing from the funeral home so there are no surprises later. Funerals and memorial services may be held in religious settings, at the gravesite, parks, gardens, your home, or other venues.

Most importantly, listen to your heart and don't feel pressured to make a spur-of-the moment decision. Take the time to explore your options and be kind to yourself throughout this difficult process.

Resources that You May Find Helpful:

- [Grief Resources for Kids, Parents, & Supporters | Dougy Center](#)
- [The Compassionate Friends Non-Profit Organization for Grief](#)
- [Home | NHPCO](#)
- [BBrave Foundation](#)

Mindfulness and Meditation for Coping

BY MONICA GETTLEMAN, BROOKE'S MOM

I have found guided meditations on YouTube to be extremely helpful in easing anxiety. YouTube has meditations of varying lengths, but even doing the 10-minute ones are very helpful. *Continued on page 2*

"Planning is bringing the future into the present so you can do something about it now." - Alan Lakein

Resources:

Advocating for Carrier Screening

NTSAD mom to James, Shannon Miller shares her story of James' life with Tay-Sachs and advocates for carrier screening on this podcast from Grey Genetics. Listen [here](#).



Contact Us:



Diana Pangonis
Director of Family Services
diana@ntsad.org
(617) 458-9013



Becky Benson
Family Services and Conference Coordinator
becky@ntsad.org

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.



Continued from page 1

Some of my favorites include 10 Minute Meditation for Anxiety by Great Mediations. The narrator has the most peaceful and calming voice. There are other guided meditations by Goodful and The Honest Guys. Additionally, Russell Brand has a guided meditation for Anxiety which is also quite calming.

My journey in all of this started when I realized I was unable to sit or lay still without having thoughts swirl around in my mind. Listening to the narrators' voices and concentrating on what he or she is saying is much easier than attempting to meditate in complete silence.

Recently, I tried an app called Breathwrk. The free app has tutorials on how to achieve calm, sleep, awake and recharge through breathing exercises. The app instructs you how inhaling and exhaling for different amounts of time achieves each of these states. I tend to wake several times during the night and I have tried other methods of breathing exercises, unfortunately without much success. Breakwrks sleep method has truly helped me.

In speaking to other moms, they have mentioned certain podcasts on meditation that have been helpful in easing their stress and anxiety. A few that they have mentioned are The One Mind Podcast, The Mindful Minute Podcast, and I Should Be Meditating.

With various mindfulness resources and techniques, anxiety and stress can be dealt with in effective ways that help to calm worries.

Family Planning and Carrier Screening

NTSAD RESOURCES

We know that the decision to have other children can be overwhelming for parents of a child with a rare disease. NTSAD wants to help ensure that your future children do not have the same condition, and that other genetic risks are addressed before a pregnancy. To that end, thanks to the **Evan Lee Ungerleider Fund** of NTSAD, the NTSAD **New York Area Fund** and the **Canavan Foundation**, NTSAD is pleased to announce that we are now able to offer family members of an affected child or individual a discount code for comprehensive carrier screening services through **JScreen** in order to successfully and healthfully expand their families.

This special discount will offer \$100 off the cost of testing for two family members of an affected individual. With the discount, the cost of a ReproGEN test will be \$50 per person for those who provide their health insurance information, regardless of insurance coverage or deductibles (U.S. only). This means that parents of an affected child, adult siblings, aunts, uncles, or any two other family members can both be tested with an expanded carrier screening panel for a total of only \$100 out-of-pocket. For those who do not have U.S. health insurance or who choose not to use it, the special discount will take \$100 off the total cost for each individual.

To learn more and access this special family offer, please email **Diana** or **Becky** for more information.

"A wish with a plan is a goal." - Unknown