



## NTSAD FAMILY CONNECTIONS

For Newly Bereaved Families | Month One

### Common Grief Reactions

BY SARA SCAPAROTTI, JOEY'S MOM

When your child dies, it's as if a deep hole implodes inside of you. It's as if this hole, deep down in your soul, penetrates you and leaves you gasping for air. The pain is overwhelming. You may experience all kinds of difficult and unexpected emotions, from shock or anger to disbelief, numbness, guilt, and profound sadness. The pain of grief can disrupt your physical health, making it difficult to sleep, eat, or even think straight. These are normal reactions to loss—and the more significant the loss, the more intense your grief will be.

“Whatever your grief experience has been so far for you, is what was meant to be. There is no one way to grieve. There is no easy way to grieve. Grief requires energy and focus from you. It demands attention and will force you to stop and take notice of what has happened in your life. Grief and you will wrestle and struggle together. But if you are honest in the struggle, you will win and you will get your life back again.” (Living with Loss, issue 1 – for San Diego Hospice).

Life as you knew it is over. No book, encouraging words, or act of self-care can make your overwhelming loss go away. But, there can be a new normal life for you. With action and intention your healing journey can begin. It may not seem possible to you now, but have faith in yourself. Trust yourself. And, ask for help if you need it.

### Resources for Loss

BY BONNIE DAVIS, ADAM'S MOM

The death of a child has been described as the worst loss any person can endure in their lifetime. The families of NTSAD can attest to this, but we are here to help and comfort you during this time of uncertainty, pain, and often, isolation. Everyone's grief journey is unique, but you don't have to walk this road alone. Those who have gone before you and forged their own path are right beside you, and we hope you will use some of their experiences and observations to help you on your personal grief journey. Each month we will provide you with online, print, and in-person resources, to help you along the way. By far this list will not be exhaustive, rather a starting point for you when you are seeking support and connection. *Continued on page 2*

"Love is strong.  
Love lives on."

### 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 Pangonis](#), 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 Bereavement Pathway.](#)

#### Contact Us:

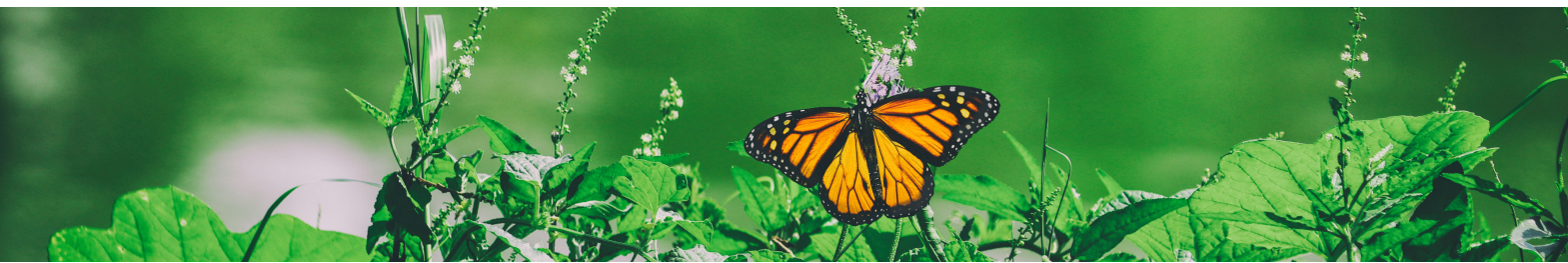


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This is all so new for you. So overwhelming. When you are ready, **please read this beautiful letter**, “**Dear Newly Bereaved Parent**” by Angela Miller and take a look around her website for many insightful and heartfelt articles, poetry and blog posts. Our hope is that you find some comfort in these words in the first weeks and months after the loss of your child.

## Navigating Your New Normal

BY MONICA GETTLEMAN, BROOKE'S MOM

My daughter, Brooke, passed away on December 24, 1998. Even though she had been hospitalized for several days and I was watching her body shut down, I was still emotionally unprepared for her death. I realize now that there is no way a parent can ever be prepared for their child to die. It was so surreal knowing she was actually gone. Through my tears and gut-wrenching pain, I kept trying to tell myself that Brooke was now free of Tay-Sachs; grasping at anything that would help alleviate the burden of this loss.

I distinctly remember getting ready for her funeral. Again, I had to ask myself, was this really happening? Since her diagnosis, I knew her passing was inevitable, but watching these events unfold was like being in a movie, as if I was watching myself through someone else's eyes. Somehow, I steeled myself and made it through the funeral, but it still felt like this couldn't possibly be my reality. How could I accept this?

In the weeks following Brooke's death and funeral, I began to experience extreme loneliness and loss of motivation and purpose. The cards and phone calls had stopped. I no longer had to physically care for my child, so my daily routine changed completely, literally overnight. I didn't know how to fill my time between when my son, Alec, would go to school and come home.

But, I knew I had to be there for Alec, for my husband, and for our unborn daughter who was due in 6 months. Alec often asked, “What is Brooke doing in heaven?” My answer actually helped comfort me as much as it did him. I would always tell him that Brooke was doing everything in heaven that she couldn't do here on Earth.

I recognize now that this was the beginning of my new normal. The first months of this new normal were filled with sadness, loneliness and learning to adjust to life no longer caring for Brooke. It took a lot of time, and I had to learn to be patient with myself to begin to gain my bearings again. Slowly, I began engaging in activities I loved again. I made an effort to take care of myself both physically and mentally by doing things like exercising and seeing friends. My advice to newly bereaved parents is to be both patient with and kind to yourself as you learn to adjust. Your deeply seeded grief is an overwhelming example of your deep love for your child, and while your grief will ebb and flow over time, that love will never change.

## What's Next?

Care and coping can be a challenge at this time. Follow **this link** to read about eight simple acts that can help you survive the overwhelming early stages of grief.

