NTSAD

NTSAD FAMILY CONNECTIONS

For Newly Bereaved Families | Month Eight

"You cannot prevent the birds of sorrow from flying over your head, but you can prevent them from building nests in your hair." - Chinese Proverb

The Physicality of Grief

TAKEN FROM THE SAN DIEGO HOSPICE SURVIVORS NEWSLETTER

While grief is often considered to be only an emotional reaction to loss of a loved one, physical symptoms are also often associated with grief. Perhaps you have noticed you have not been feeling well since the death of your loved one. Symptoms such as headaches, stomach aches, shortness of breath, dry mouth, tightness in the chest or throat, or muscle tension or weakness are common. These are symptoms of the emotional crisis you are experiencing. It's your body's way of communicating.

The fact that these symptoms are related to grief does not mean that they are all in your head. Your physical symptoms are very real and may warrant medical attention. Furthermore, grief may aggravate chronic medical conditions or cause the development of new problems. Seeing your physician can help you sort out which symptoms are physically based and which symptoms you must deal with by grieving appropriately. Studies have shown that finding meaningful, supportive relationships and appropriate outlets for the release of pain can help protect your health during bereavement.

Statistics suggest that men are particularly susceptible to health problems during the first year of bereavement. This may be related to cultural messages about manliness which makes it difficult for men to express emotion appropriately. When emotional pain is not expressed directly it may manifest itself in physical symptoms, depression, or anxiety. Recognizing our sometimes inherited prohibitions against the open expression of feeling can help us choose more effective modes of the open expression of our grief.

Sibling Perspective

BY JUSTIN UNGERLEIDER, BROTHER TO EVAN

My name is Justin Ungerleider. In 1995, my older brother, Evan, was diagnosed with Tay-Sachs Disease. One of the worst memories, forever ingrained in my mind, is hearing the doctors tell my parents that there was no hope for Evan.

The doctors said there would not be a cure or treatment for children like Evan in my parents' lifetime and that he would not live a full life.

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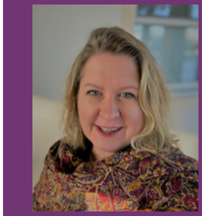
Resources:

What Siblings Want

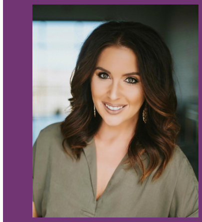
This video from Courageous Parents Network features an interview with four bereaved siblings offering insight into their lives as rare siblings, both during and after their sibling's passing. You can view the viedo, **here**.

COURAGEOUS PARENTS NETWORK

Contact Us:



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



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

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.

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No parent should ever have to hear there is no hope. From that moment on, I was determined to ensure that no other family would experience what mine did.

Several years ago at an NTSAD event, I shared my desire to pursue medicine with Miguel Sena-Esteves, PhD, who is the Principal Investigator in the Tay-Sachs Gene Therapy Consortium. Miguel offered me an internship at UMass Medical School's Gene Therapy Lab.

I was ecstatic...I couldn't believe it! Eighteen years after being told there would never be a treatment for this disease - there I was working on it! It's hard to describe the thrill of seeing the research progress—from raising money to working side-by-side with other researchers on the development of a treatment, to holding the hand of one of the first Tay-Sachs patients ever given this gene therapy!

There's always hope, and I have seen it first-hand. I am grateful to have witnessed how dedicated researchers are to ridding the world of rare diseases. I cannot stress how important it is to all the families like mine, to know that one day there will be a world where children like Evan will grow up, go to school, make friends, and simply live normal lives. This day is coming, and because of Evan, I'm working to help make that happen.

Lost In The Storm Together: Grieving Differently Than Your Partner

BY SAM SCAPAROTTI, DAD TO JOEY

Regardless of whether it was Joey's life or death, as his parents we are a team, but Sara and I handle things differently. This is painfully obvious when it comes to how we process and deal with our grief. I am naturally introverted - Sara often asks me how things are in the "mind palace". I have always been someone who daydreams, staring right through people as they talk about trivialities like the weather. However, my grief in his loss sends me to the "mind palace" more often now than before we had Joey. Cleaning out the garage by myself for hours, or working in the basement day after day without speaking to anyone, I find that I still seek to anesthetize myself with activity whenever I can. Sara is naturally extroverted, her need to verbally process is something I would consider healthy. I think it allows her to move through her grief more gracefully, not more easily, as for her, there are internal struggles that she can only deal with by talking about them.

I've read about the seven stages of grief. Shock and denial, pain and guilt, anger and bargaining, depression, the upward turn, reconstruction and working through, acceptance and hope. What I have found is that these are not linear. My grief didn't follow this prescribed path, or even resemble it. Maybe it's because I knew Joey would die more than two years before he did. I was already experiencing preemptive grief. There was a slow, defeating sorrow that gave me anger and bargaining long before pain and guilt. I can imagine this would take different forms depending on the season or circumstance.

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As a father, I also struggled with who I was supposed to be for my family - strong, wise, provider, protector. How could I pretend to be any of these things when I couldn't fix any of this? I knew that my grief had such a strong grip on me. I was very aware I was deep in grief, even so, I had a difficult time recognizing when it would hit. I could play with a little boy the same age as Joey would be, then find myself having a short temper the rest of the evening and see no cause and effect between the two. Only in hindsight did I begin to understand the way my grief was presenting itself.

Sara has not celebrated Mother's Day since Joey received his diagnosis. I understand why. What a horrible reminder of what was lost. I, on the other hand, have no issue with Father's Day. I think it's because Sara's grief really never leaves her, it's a steady dose of pain every day; consistent, with regular swells that bring tears and a small dose of relief with them. My pain, on the other hand, seems to come and go. At this point in the journey it is almost nonexistent for a couple of months at a time, then I'll experience something otherwise innocuous such as watching Disney's Coco one day and be beside myself, crying and groaning as if I have been saving all my pain up to experience at once.

We've learned that even shared grief is a solitary journey. Still, I'm grateful to have a partner to walk through it with, even if that walk is sometimes a silent one. There's no one else who could understand this type of grief the way that Sara can. We were there when Joey was born, and we were alone with him in the last moments. We continue to move through our grief together.

The Compassionate Friends
Supporting Family After a Child Dies

Find additional support for bereaved parents at
https://www.compassionatefriends.org/

"But grief is a walk alone. Others can be there, and listen. But you will walk alone down your own path, at your own pace, with your sheared-off pain, your raw wounds, your denial, anger, and bitter loss. You'll come to your own peace, hopefully, but it will be on your own, in your own time."
- Cathy Lamb, The First Day of the Rest of My Life