



NTSAD

NTSAD FAMILY CONNECTIONS

For Newly Bereaved Families | Month Three

When the Wave of Condolences Subsides

BY BECKY BENSON, MISS ELLIOTT'S MOM

When we lose a child, there are multiple factors at play compounding our already devastating loss. For many of us, caring for our medically fragile child involved a highly organized, 24-7 effort in the coordination of feedings, positioning changes, medication administration, and more.

The loss of a child can feel so lonely and isolating for grieving parents. The one thing we as parents want more than anything after our loss is for our child to be remembered. We want their life to continue to hold meaning. We want their names to continue to be spoken.

Often, in the weeks and months following a loss, after the cards, casseroles, and visitors stop coming, a stillness and quiet eventually settles in. For those of us who were used to the clamour of machines, or the seemingly unending string of appointments, this lack of highly regimented schedule and sudden quiet can be deafening. The stillness can be paralyzing.

As always, you are not alone on this journey to navigate your grief. Parents like you who have been there, understand these feelings firsthand. NTSAD parents, Oralea and Rod Marquardt, share their feelings of grief over the sudden change in the routine when their son, William, passed away. You can see the video of their discussion [here](#), on Courageous Parent's Network.

Coping with Loss of Identity

BY CARLA STECKMAN, TALIA'S MOM

Actively caring for a terminally ill child is an exceedingly rare identity that can be hard to let go of once your child is gone. The time that you would have spent caregiving is suddenly wide open. Many emotions you held at bay while caring for your child may now rush in to fill that void.

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"When we lose someone we love we must learn not to live without them, but to live with the love they left behind." - Unknown

Resources:

Option B: Facing Adversity, Building Resilience, and Finding Joy by Sheryl Sandberg and Andy Grant

In [Option B](#), Sheryl Sandberg discusses her deeply personal journey through grief. Part memoir, and part self-help, Option B motivates readers to find both meaning and purpose in their grief as they continue to live on past the death of a loved one. Sheryl shares her intimate journey through the highs and lows of mourning and perseverance as a family. She humbly encourages those living with loss to continue to navigate their journey despite the pain, and to realize that even in the midst of such trauma, life can still be beautiful.

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Be kind to yourself by respecting those emotions and know that you now have the space to feel them fully. They need to be acknowledged so that you can move through them, not get over them. Crossing the threshold from active caregiver to your child to becoming a bereaved parent can mean joining a larger group, still small but less rare. Most parents, regardless of how they lost their child, are all actively engaged in questions of how best to honor and remember their loved ones and still move forward at the same time.

Being a part of this new community can present both opportunities and challenges. You may want to reach out to other grieving parents to ask for ideas of how to honor your child's memory. Ideas like using your child's birthdate in computer passwords, or using their name for restaurant reservations are small ways to keep them present, and ways that some grieving families find helpful. Since bereavement is a lifelong condition that you don't *get over* so much as *move through*, you may find comfort in speaking with parents who are further along in their bereavement to see how they have managed their acute heart-ache over time.

While some find this outreach helpful, understanding your limitations is also a significant part of your bereavement care. It is important to remember that there is no one, right way to grieve. The key is in recognizing the enormity of your emotions and then, with time, figuring out how to harness those emotions into forward momentum toward healthy coping, and living with your loss.

The Mourner's Bill of Rights

BY ALAN D. WOLFELT, PH.D. HEALGRIEF.ORG

"Though you should reach out to others as you do the work of mourning, you should not feel obligated to accept the unhelpful responses you may receive from some people. You are the one who is grieving, and as such, you have certain "rights" no one should try to take away from you. The following list is intended both to empower you to heal, and to decide how others can and cannot help. This is not to discourage you from reaching out to others for help, but rather to assist you in distinguishing useful responses from hurtful ones."

You can read more on Dr. Wolfelt's list of the Mourner's Bill of Rights [here](#).

There is no rule book,
No time frame,
No judgement.

Grief is as individual
as a fingerprint.
Do what is right for
your soul.