



# NTSAD FAMILY CONNECTIONS

For Newly Bereaved Families | Month Nine

## Sorting Through Your Child's Belongings

BY BECKY BENSON, MISS ELLIOTT'S MOM

Sorting through your child's belongings can be a difficult and emotional task to accomplish. Knowing when it's the right time to do so, or to what extent is a deeply personal choice.

Some families see the leftover medical equipment and medications as part of the disease, and not as part of who their child was. Many families choose to remove these items fairly quickly. Other, more personal items, such as clothing, toys, and mementos tend to hold more emotional weight. Some families choose to sort through items and donate what will be helpful to others, and keep only the most treasured keepsakes, while others may not go through these items for a very long time, if at all.

Here are some examples from parents, in their own words, of how they have navigated this task.

*"The day after [my son] passed, I cleaned up everything medical. I had such a crazy urge to get rid of it all. Or at least put it away. To clear out the sadness. It was a crazy desire to get it done as fast as possible."*

*"[My son] passed on Feb 14th. I went through his things that day. It was a comfort holding everything and being reminded of how strong he was and how hard he worked. My husband had a harder time with me doing it. It kept me busy and distracted and I felt the pain when I was done."*

*"The morning [my daughter] passed I cleaned up all the medical equipment and put it in a corner out of sight. I also placed anything we had of hers in open sight upstairs in her room and shut the door. About a month and a half after she passed I decided to go through her room and clean it and get rid of some things. I thought I would be fine, but that day I had my biggest breakdown. It was so much harder than I thought. But after I was down I was happy I had done it. I put aside a few boxes of things that I wanted to keep of hers and then I donated the other things. I felt a weight lifted once I did that."*

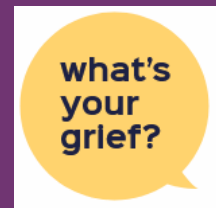
*"The day [my daughter] passed, hospice was really great (and gentle) about removing all the medical equipment. I'm really grateful for this because I hadn't even thought about it and it was really nice to just have everything removed."*

"You know the place between sleep and awake, that place where you still remember dreaming? That's where I'll always love you. That's where I'll be waiting." - Peter Pan

## Resources:

### Dealing with Stuff - Sorting Through A Loved One's Belongings

What's Your Grief offer's advice on this topic with gentle considerations for the emotional toll this act can take in this piece in their website. View the full article, [here](#).



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## New and Evolving Traditions

BY SARA SCAPAROTTI, JOEY'S MOM, AND THE NTSAD COMMUNITY

When your child dies you experience deep, soul-wrenching pain. Your life changes. You change. Everything changes. Yes, it hurts terribly. But there is nothing wrong with you. Grief is normal. It totally sucks, but it is normal.

One thing some parents find helpful is to engage in new traditions. These are actions done in purposeful ways that symbolize something much more than the acts themselves. Traditions can help us find meaningful and lasting ways to remember and honor our loved ones. They may include daily rituals, special birthday celebrations or acknowledging our loved one's continued presence in our lives. Traditions vary from family to family, are deeply personal, and they may evolve and change over time.

Here are some examples from parents of traditions they have adopted after their child died:

*"My Ellie passed away coming up to her 6th anniversary...Every night with her younger siblings we say good night to her, tell her we love her and blow a kiss. Every birthday we get her favourite ice cream cake and do all the things she loved for the entire day." – Catherine Topliff, Ellie's mom*

*"Our Shoshanna passed this year on January 8th. Not a lot of time to create traditions. But what has helped so far for us is taking her flowers every week. It allows us to feel like we can still take care of her. We also have a medium sized black and white photo of her that floats around our house - wherever we go we take it with us; it's our way of having her with us. There are many more but these are a few. I'm sure all of this will evolve over time." – Renny Drinks, Shoshanna's mom*

*"We do have the tradition of celebrating Paxton on his birthday as well as the day he died. What we do to celebrate him has evolved through time as we always just do what feels right at the time, and just being with our family (or lately just me and Graham since we can't travel to be with our family). The first year after he was gone we painted flower pots so we could each have a plant that was cut from the terrarium he made. This year for his birthday we went geocaching. We just try to do something he would've liked to celebrate his memory, that's what's important to us." – Kassie Harder, Paxton's mom*

*"Our traditions are an extension of how we remember family members who died before Cora. We build an altar to honor our deceased loved one for Día de Los Muertos. Most importantly, we talk about her whenever she comes to mind; we honor Cora by acknowledging her continued presence in our lives." – Holly McDonald, Cora's mom*

*"Dylan passed away in 2006 so our traditions have changed over the years but always remain close to our hearts in the same way of honoring his legacy. In the first few years we let balloons go on his birthday and the anniversary of his passing. Time passed and we wanted to save the environment a little so we released monarch butterflies for a few years. Whenever we see a butterfly, we always think it is Dylan reminding us that he is close to us. In recent years, we've changed to blowing bubbles on both his birthday and his anniversary. He is always close in our hearts and we often include him in family photos for any occasion." - Brian Manning, Dylan's dad*



## Musings of A Mimi: Grandparent Perspective

BY KAREN HORTON, JAMES' MIMI

For so many of us, September 11, 2001 is a day that we will never forget. In fact, most of us know exactly where we were when we heard of the terrorist attacks. February 12, 2018 holds the same weight for my family. It was Diagnosis Day. I know exactly where I was and what I was doing when I got the call that my only grandchild, Sweet Baby James, had Tay Sachs. On that day the world stopped spinning for my daughter and son-in-law with the news that this condition was terminal and there was no cure for James. Looking for answers as to why he wasn't progressing, they had been hopeful that his symptoms could be treated with dietary changes or supplements, but that wasn't the case.

While the pain of losing a child is unbearable, watching my baby lose her baby was doubly heartbreaking for me. As a parent you never want to see your child hurting. I've always told my children that I would lay down in front of a train for them. If that would have saved James, I would have done it in a heartbeat. I felt so helpless and sad, which was further compounded by guilt for passing this disease along. One that I didn't even know I was a carrier for. In the months that followed, my role became being one of James' caregivers as well as a shoulder to lean on as my daughter and her husband faced the unimaginable. Parents of seriously ill children face so many difficult decisions so I knew it was important to respect their role as parents and provide them with support as needed. Together, we all shared the same goal, to make James' life as comfortable and meaningful as possible for as long as he was with us.

Every decision his parent's made was based on James' comfort and quality of life. James went for bike rides in the fresh air, watched the birds in the yard, listened to his personalized playlist, snuggled with his dog, ate cheese grits, heard the Hungry Caterpillar at least a hundred times and never knew anything but love! While heartbreaking, it was also heartwarming to watch my daughter love her son so much and give him the best life possible. I am so proud of her.

Our time with Sweet Baby James was short, but oh so sweet. He taught us that joy and sorrow really do coexist and the importance of finding joy in the little, tiny moments, and for that we are eternally thankful.

"Whether side by side or miles apart,  
grandchildren are always close to the heart."

-Unknown