



# NTSAD FAMILY CONNECTIONS

For Newly Diagnosed Families | Month Eight

## Care for Caregivers

BY HOLLY MCDONALD, LCSW, MOM TO CORA

So many of us cringe when the topic of self-care arises. We loathe and ignore it. We often receive advice that feels trite. People tell us to take care of ourselves. They advise us to go for a run, have a manicure, or say, "let me know if you need anything". There is an art in the balance of caring for another, caring for ourselves, and in finding what steadies us and moves us forward.

The balance starts even before birth, whether we know their diagnosis or not. The first three months after birth is often referred to as the "fourth trimester"; it is exhausting and we need help. Caring for a medically complex child can feel like years of that fourth trimester. In the US, many of us are taught to value independence. For myself, much of the beauty of Cora's life came from our being cared for by family, friends, and, most surprisingly, people we met through Cora and her care. Maybe self-care is accepting help.

We can take a moment to reflect about what self-care looks like. There are many resources online that give concrete ideas, but each of us is in a different circumstance. Review these ideas at various times to see what surprises you or reminds you of a need. You may be longing to get a haircut, but to another member of our community, the same is automatic. You may find yourself delaying personal medical care or routine checkups. Maybe self-care is prioritizing basic care of our bodies.

If you've Googled your loved one's diagnosis, and you probably have, you'll find community members engaged in a wide variety of advocacy efforts: for funding of research or medical care, for prevention, or for bereavement support. Not only are the efforts widely varied, but also the needs and positions to be filled. Maybe self-care is advocating for your child or for yourself in honor of your child.

Whether newly diagnosed or newly bereaved, my encouragement to you is to look after the person you will be in five years. That starts now. The role of being a caregiver to a medically complex person can seem to engulf us with the tasks of today and what lies ahead. With the help of NTSAD and the community of people they support and organize, you don't have to walk this journey alone. We are here to help.

"You can't pour from an empty cup. Caregivers need care too."  
- Unknown.

## Resources:

### Siblings In Thier Own Words

In this video clip from Courageous Parent's Network, an NTSAD sibling discusses her feelings as a rare sibling and her connection to her brother. View the clip [here](#).



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## A Sibling's Guiding Light: Perspective and Identity

BY RUTH FELDMAN, SISTER TO AARON

In 1964, as a soon-to-be big sister, the excitement I felt about my new baby brother eventually turned into confusion and sadness. We had only had one year cuddling and playing as siblings, when my brother was diagnosed with Tay-Sachs Disease. At that time, there was very little support available for families to care for children with infantile Tay-Sachs at home, as exists today. Aaron lived out the rest of his not quite six years hospitalized while he slowly deteriorated. Family outings on Sundays when I was a little girl often meant spending time at relatives' homes so my mother and father could visit Aaron at the hospital. I wanted to see him too, but no children were allowed in the hospital back then.

During those years, my parents worked tirelessly to make a difference for other families. My dad volunteered at fundraising Bingo games on Wednesday nights, while my mom did outreach and education events, and helped organize luncheons and charity art auctions. I grew up with an unspoken cloud of sadness; I missed my brother and knew he would never come home. This sadness was balanced with a few bright moments when, thanks to my parents' hard work, I got to attend glamorous NTSAD fundraisers. Some events attracted big celebrities of the time, such as Ed Sullivan (I still treasure his autograph!), Don Rickles and Steve and Eydie Gormé.

Watching my mother and father work so tirelessly on behalf of NTSAD instilled in me the need to continue that effort. I want to make sure that advocacy, education, support and research continue, until they are no longer necessary.

Although he lived less than six years, my brother's life has greatly impacted my life. It took decades to find my own path of engagement with NTSAD so that I could make a difference of my own. As an active board member for more than ten years, I've helped with events, strategic planning, and fundraising. Recently with the support of friends and family I established Aaron's Fund to help support NTSAD's mission.

I have met families at NTSAD family conferences with both affected children and their healthy siblings, and I'm overwhelmed by their strength and fortitude. Admittedly I'm a bit jealous thinking about the experiences I missed because my brother was out of reach and is now a faint memory.

I'm an ordinary person, who is committed to doing everything I can to support other siblings living with rare circumstances. I would urge anyone reading these words to

1. know you're not alone, and
2. know that you can make a difference.

Your voice, your skills, your support and desire turned into action could have a significant impact. You might organize a lemonade stand or can drive to raise funds. You could speak and use your voice to spread awareness, or even volunteer in your sibling's memory.

I was, and will always be, a rare sister to Aaron. This has been my legacy. What will your legacy be?



## The Importance of Ongoing Physical Therapy

BY MANDY RONALDSON, MOM TO MOLLIE AND MADELYN AND HALEY ASHLEY, PT

*From Mandy:* On April 30, 2016 we received the most devastating news. Our two youngest daughters, Mollie and Madelyn, were diagnosed with Juvenile Sandhoff Disease. What we heard next, like so many others, was that there is no cure, and the only treatment is therapy and making sure they are comfortable. Those words seemed so hopeless at the time. I was left wondering if therapy would really make a difference. Regardless of those hopeless feelings, we decided we were going to go all in because we knew we wanted to do all we could for our girls.

Our current regimen with physical, occupational and speech therapy no longer leaves us feeling hopeless. We are confident that because of the services Mollie and Madelyn receive at school, and their weekly visits to their therapy clinic, they are maintaining many skills that would have been lost sooner if we weren't diligent in their therapy.

Today, the girls' therapists are like family to us. This journey would be so much harder without the love and support we receive from them. With that being said, I would like to introduce you to Mollie and Madelyn's physical therapist, Haley Ashley from Westside Children's Therapy.

*From Haley:* Going to your child's weekly therapy session (physical, occupational, speech, etc), is often the first step in helping them maintain mobility, posture, and even ambulation when applicable. The session with your provider is vitally important in understanding what your child's goals are. Whether this means improvement or simply maintenance, your provider will help assess how they are progressing in meeting those goals and adjust your therapy activities as necessary. Your therapist will go over correct stretching, positioning, handling, sitting, as well as specific exercises that your child is working on. However, this is just where the work begins.

A weekly visit for services is a great place to help guide you in learning how you can continue this care at home. Therapists assist in helping your child during their sessions and are of course on call to help with questions that parents may have. But a true testament to a life-changing therapist is being able to teach a parent, caregiver, nurse that is with your child all day every day, the exercises to do. We are fortunate in being able to instruct the exercises and check in on a weekly or daily basis, however success is seen to a great degree when the therapy is performed daily at home. Exercises, stretches, and positioning can easily be incorporated into your daily routine.

Children who have a debilitating, regressive, life-long injury are the ones who usually require the most intensive care. Their daily routine can be overwhelmingly exhausting for the parent or caregiver however, as parents we want the absolute best for our child regardless of a diagnosis, and that is the main reason why adding in one or two easy exercises a day will tremendously aid in the goals that you and your provider have set for your child.

Caregivers are truly the heroes when it comes to any area of therapy, as they are the ones that implement the exercises that are asked of them on a weekly basis. Communicating with your therapist on a weekly basis and determining the best one or two exercises that are a main focus for the week and building upon that foundation week to week. As therapist's the daily struggle, hardships and challenges is something that we may never know firsthand. This is precisely why you make the difference in your child's success. A couple of minutes a day focused on therapeutic exercise can go a long way in helping your child meet their goals.