



NTSAD FAMILY CONNECTIONS

For Newly Diagnosed Families | Month Seven

Respiratory Care

CITED FROM MULTIPLE SOURCES

Respiratory care in affected children is an important part of both managing the effects of their condition as it progresses, and offering some comfort from those effects by helping keep their airways clear. As mucus builds up in the lungs and a child's functioning slows, children have a harder time expelling it. Below we have listed some proactive ways to attend to your child's respiratory care needs.

Postural drainage uses gravity to drain the mucus build up out of the lungs through changing positions. The goal is to allow the mucus to move to the top of the lungs where it can drain out on its own, be suctioned, or allow your child to cough it up. Learn more about how to perform postural drainage, [here](#).

Another option is an Airway Clearance Vest, used as a form of respiratory therapy, as manual percussion therapy to stimulate the lungs and thereby loosens secretions. See an example of a chest vest in use in the NTSAD Care Tip video, [here](#).

Memories That Last A Lifetime

BY KRISTEN FREDERICH, AVA'S MOM

Raising special needs children is difficult. Raising children with an ultra-rare disease is even more-so. We do it with our precious Ava Rose because we weren't given a choice. It's all we know, so we just do. We do our best to make it through each day. We do our best to tend to our child's needs. When it comes to planning a trip or adventure as a family, we subscribe to the same philosophy: *we just do*.

Even the smallest and simplest experiences make the best memories, and we want to make as many memories with her as we can. The wind in her hair, sounds of a campfire crackling around her, or getting her to crack a smile in the stroller on a trail we've never been on before. These experiences are important to us. We will forever remember we shared them with her.
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"I wouldn't change you for the world, but I would change the world for you." - Unknown

Resources:

Common Respiratory Equipment

Please see some common equipment and more information on their uses via the NTSAD website, [here](#).



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Getting our children anywhere at all requires a lot of work. Some of the best advice we can give is this: plan ahead and don't be afraid of just a little more work. Trust me, all the packing, planning and lifting is worth it. As overwhelming as it might seem, we know that unfortunately this current "lifestyle" isn't forever. We feel it will be much easier to look back and wholeheartedly say that we did everything we could to engage as much as we could. By doing this I believe it will make for an easier future when all we have are our memories. There is a lot of peace in that feeling knowing it's one small thing we have agency over.

If I can leave you with one last piece of advice it's to make sure to have a good camera handy! Our daughter's smiles are quick and subtle, but sometimes I don't think they could get any bigger in those moments.

Attending to your Relationships

BY MONICA GETTLEMAN, MOM TO BROOKE

Caring for a child affected by Tay-Sachs or an allied disease is stressful and can feel all-consuming. And having an affected child in your family also affects the relationships you have with your other children and your partner. You may feel so involved in caring for your affected child that it is easy to neglect these other relationships. It is easy to lose sight of the fact that your other kids need to participate in their own activities, or your relationship with your partner needs attention.

One way to help your other children stay involved in activities is to welcome the help of their friends' parents, your coworkers, or church members. Enlist their help to take them home from activities or have a sleepover on a weekend. Being proactive in asking for help as well as accepting help from others who offer it, can have a positive impact on both you and your family. If your partner, family member, or friend can care for your affected child, your other children will certainly appreciate the alone time, as they still desire that special one-on-one time with you.

The impact of caring for an affected child most definitely adds stress to your marriage. Having scheduled date nights can help. Although it can be challenging to find a trusted person to care for your affected child, it can be beneficial to be alone together for a few hours.

As Tiffany, mom to Lilliana shares, "I'm always here to listen when they have questions, especially with Lilliana getting older, the older girls seem more concerned about her.

We spend a lot of time doing things together that includes Lilliana. We try to keep things as normal as possible. I'm the first one to volunteer for things at their school. I'm the girl scout leader for their troops and I watch them at their dance class. I also try to do things with each of the girls individually a few times a month. Kevin and I try to do something just us even if it's just running to the hardware store or grocery shopping. We try to be here for the girls and make them feel important even with a sister that needs more involvement. We also let them help with Lilliana so they feel we're all a part of caring for each other as a family."