

Support for Siblings of Children Living with a Neuromuscular Disease



When a child is diagnosed with a neuromuscular disease (NMD), the entire family is impacted, including siblings. Siblings may face challenges and emotions while learning to navigate life alongside a brother or sister with a disability. By understanding, validating, and addressing the experiences of siblings, families can foster a supportive environment that nurtures resilience and connection.



Importance of Supporting Siblings

- Siblings are not just bystanders—they are lifelong companions, potential future caregivers, and individuals deserving of our attention and care. Siblings often walk a path parallel to their parents, sharing in the triumphs and trials of living with a family member who has neuromuscular disease.
- Siblings of children with neuromuscular disease often develop important life skills such as tolerance, advocacy, and loyalty. Many siblings take pride in their sibling's perseverance and cultivate a profound appreciation for health, family, and relationships.
- Siblings may encounter various emotional and social challenges. Parents and guardians can recognize these feelings by paying attention to changes in behavior, such as withdrawal, mood swings, or expressions of frustration.
- Below are common feelings and worries that a sibling may encounter:
 - Feelings of isolation, guilt, resentment, increased caregiving responsibilities, and pressures to achieve despite their unique circumstances.
 - Feeling overshadowed by the attention their sibling receives can lead to a sense of being less important or overlooked.
 - Increased caregiving responsibilities or altered family dynamics can contribute to frustration and resentment.
 - Some siblings may feel isolated from their peers, especially if they perceive that their experiences differ greatly from those of their friends.



“...be honest but not negative with the affected and unaffected. Giving the sibling space to voice their feelings without trying to always fix it and without always shaming them.”

— Amy, MDA Ambassador Parent

Practical Strategies for Sibling Support

Families can take steps to actively support siblings, helping them cope with their emotions and build resilience.

- Remember that the single strongest factor affecting siblings' interpretation of the diagnosis is how parents interpret and manage the diagnosis.
- Provide siblings with age-appropriate, culturally responsive information about their sibling's neuromuscular condition. See the resource list below.
- Offer opportunities for siblings to meet and connect with other siblings who share similar experiences.
 - Sibshops provide opportunities for school-age siblings of children with a variety of disabilities and health concerns to meet, talk about the ups and downs of having a sibling with support needs, and play.
 - Find a Sibshop near you: sibshopsupport.org/sibshops/find-a-sibshop-near-you
- Encourage open communication with typically developing children to foster understanding and expression of their feelings. Active listening is a powerful and easy tool to achieve this. Check out the best-selling book *“How to Talk So Kids will Listen and Listen So Kids will Talk”* by Adele Faber and Elaine Mazlish.
- Learn more about the specific concerns and experiences of siblings through books, podcasts, and events that amplify sibling voices.
- Reassure children by involving them in future planning, giving them a voice and options to make choices, which can help ease their anxieties about long-term responsibilities.
- A social worker, child life specialist, school counselor, or mental health professional at your MDA Care Center may also be able to provide information and/or help to guide the discussion.



“Take it one day at a time, deal with the current situation, and try to meet everyone’s needs the best you can. Just like it is a struggle in our minds on having a child with a disability, the siblings struggle too with understanding, their friends asking questions, feeling guilty for the things they can do, or mad about the things the family doesn’t do because of the sibling with the disability. It most definitely affects the entire family but one day at a time, one moment at a time, one need at a time and you will see yourself through each day.”

— Jordan, MDA Ambassador Parent



Siblings of children with neuromuscular disease experience both challenges and opportunities that shape their growth and development. By providing emotional support, fostering open communication, and involving them in the family’s journey, we can help these siblings thrive. Their role in the family extends beyond childhood, as they often become lifelong advocates and caregivers for their siblings. Providing appropriate support now can create a stronger future for the entire family.

Resources for Families

- Sibling Support Project — siblingsupport.org
- MDA - Genetics and Neuromuscular Disease (Handout) — www.mda.org/sites/default/files/2021/07/Genetics-and-NMD.pdf
- Quest - Talking about a Diagnosis is a Personal Decision (Article) — mdaquest.org/talking-about-a-diagnosis-is-a-personal-decision
- Quest - Parent Pressure (Article) — mdaquest.org/parent-pressure
- The MDA Resource Center may be able to connect individuals and caregivers to information and resources. Call 1-833-ASK-MDA1 (833-275-6321) or email resourcecenter@mdausa.org to speak with a Resource Specialist.

Books

- *I Have Muscular Dystrophy and it's Okay!* By Dr. William M. Bauer & Mallory Bauer
- *I'll Walk with You* by Carol Lynn Pearson
- *The Abilities in Me* by Gemma Keir
- *The Diagnosis: Epic Battle with Muscular Dystrophy* by Luke Dalien



“Try to treat each child as an individual. Growing up and experiencing milestones isn’t a competition. Emphasize that each child is special in their own way and encourage the other to share in supporting and celebrating their accomplishments, whether that means winning a trophy in sports or taking those first independent steps.”

— Monica, MDA Ambassador Family

About Muscular Dystrophy Association

Muscular Dystrophy Association (MDA) is the #1 voluntary health organization in the United States for people living with muscular dystrophy, ALS, and related neuromuscular diseases. For over 70 years, MDA has led the way in accelerating research, advancing care, and advocating for the support of our families. MDA's mission is to empower the people we serve to live longer, more independent lives.

To learn more, please contact the MDA Resource Center at 1-833-ASK-MDA1 or email ResourceCenter@mdausa.org.

Acknowledgments

This document was created in collaboration with Emily Holl, Director of the Sibling Support Project. The Sibling Support Project is the first national program in the United States dedicated entirely to supporting siblings of people with developmental, health, and mental health concerns. For more information, please visit siblingsupport.org.

DISCLAIMER: This document is meant to inform and educate the community. The information presented is not intended to replace discussions with your healthcare provider and is not and should not be considered to be medical advice. Please consult with your healthcare team for information specific to you.