

Behavior Support for Children with Neuromuscular Diseases



**A Guide for
Families**

Considerations for Children with Neuromuscular Diseases



Children with neuromuscular diseases are often faced with challenges beyond the physical symptoms of their diagnosis, including emotional dysregulation, social difficulties, and cognitive impairments. Many concerning behaviors exhibited might occur beyond a typical rate, duration, and/or intensity.

Understanding and navigating these behaviors are essential for caregivers, healthcare providers, and educators in providing comprehensive support to enhance the well-being and quality of life for children with neuromuscular diseases and their families.

Neuromuscular disease and secondary diagnoses

Common secondary diagnoses associated with neuromuscular diseases are:

- ADHD
- Autism spectrum disorder
- Obsessive-compulsive disorder
- Generalized anxiety

These diagnoses can have symptoms that make it difficult for children to process information effectively, easily adapt to changes, and remain in control of their bodies and their responses.

Children with challenging behaviors thrive when supported with consistency and routine across environments. Differing values and methods between caregivers can create confusion for children and worsen behavior challenges.

Caregivers may see children exhibit behaviors that are challenging or disruptive, including:

- **Difficulty processing vocal directions.** Too much talking can be dysregulating, resulting in a child disconnecting or making unsafe choices to gain assistance or simply to stop the expectation of having to process.
- **Difficulty expressing wants or needs.** Vocal abilities may be limited, especially when emotions are triggered, resulting in children resorting to what is easiest, but not always the safest or preferred behavior, to get their needs met.
- **Inflexibility to change.** Children may have difficulty transitioning from task to task due to the varied sensory experiences and expectations across environments.
- **Extreme difficulty starting tasks or remaining on-task.** Impaired executive functioning (i.e., the ability to plan, organize, and execute tasks) and/or limited attention thresholds may make it more difficult for children to get started and remain focused for the duration of tasks.
- **Hyper- or hyposensitivity to sensory input.** When a person does not have enough input through any of their senses, or has too much, they may have difficulty maintaining a calm state. This results in behavior challenges.
- **Other challenges.** Difficulty letting go of items or thoughts, academic challenges, and lack of regard for safety, emotions, social norms, and expectations can all lead to anxiety and/or depression.



Why do behaviors of concern happen?

Behavior is communication. When a child exhibits a concerning behavior, it is most often to get their wants or needs met. Most often, this is to either:

- Gain access to something, such as an object, control, or attention
- Avoid something

On occasion, these behaviors can be meaningful to those exhibiting them because they result in a state of calm, whether that is because they are soothing or because they remove something painful.

How to Tackle Challenging Behaviors

It can be overwhelming when first considering how to help a child with challenging behaviors, and knowing where to start is not easy. Below are actionable steps parents/caregivers can take to understand and improve behaviors.

Getting started

Start by making two lists:

- **List the main behaviors you would like to see decrease in the next year.** Consider what is most meaningful to your child's social-emotional development, your home environment, and/or any other factors that are significant to you.
- **List the behaviors you would like to see increase.** Consider what will help them gain independent living skills, follow rules, name their emotions, etc.



Prioritize one to three goals from the lists above. Consider which goals are most necessary for your child and family to function harmoniously. These are the ones to tackle first. You can always add more or change the list if you need to.

Next, make a list of your child's preferences. You will use these to reinforce your family's goals. This list should include your child's favorite things and activities, such as having ice cream after dinner, going to a store, one-on-one time with a favorite person, picking music on the radio, etc. As you make this list, consider if anything stands out as a sensory preference. For example, a child who likes a lot of different crunchy foods may enjoy deep pressure in their mouth. This can be used to create new opportunities for preferences.

Find opportunities for children to be independent. This raises their confidence and decreases frustration in all aspects of their lives. Be mindful of the things a child can or could do independently. Teach and encourage them to learn life skills.

Be more proactive and less reactive

Children who exhibit challenging behaviors are likely to be easily triggered and emotionally charged. This means that only using reactive discipline techniques, such as reprimands and punishments, can hinder behavior progression and potentially make those behaviors worse. By taking a consistent, proactive approach using the six strategies below, caregivers can manage behavior more effectively.

With all these rules, consistency is key:

1. **Make a forced paired choice.** Give your child a choice between two specific ways of completing tasks, especially those that are not preferred. For example, “Do you want to clean up in 5 minutes or 10 minutes?” If they don’t make a choice, choose for them.
2. **Require your child to make a request instead of giving things to them freely.** Have them ask for what they want or give a nonverbal cue. Being able to express wants and needs is a building block for self-advocacy.
3. **Desensitize your child to waiting.** Practice telling them, “Wait” or “Hold on” in small increments (e.g., 3-5 seconds). Only practicing waiting in situations that occur naturally, which are often long, can trigger an emotional response.
4. **Manage the frustration of waiting.** If your child can’t have what they want immediately, tell them when they can have it (e.g., using a timer) or what they can have instead.
5. **Maintain a predictable daily routine when possible.** Knowing what to expect is comforting for children. In addition, a routine means you don’t have to work as hard to manage day-to-day transitions.

6. **Ensure consistent and clear expectations.** These rules are most effective when a child knows what is expected of them across all environments they are in.

Handling challenging behavior

When challenging behaviors occur, try these tips to handle them in the moment and after:

- **Use your body to calmly block or stand** between the child and anything that can cause injury, especially items that could be thrown. Move items that may make the area unsafe.
- **Avoid being reactive when dealing with tantrums or other intense behaviors.** For example, looking at, yelling at, or reprimanding the child may cause them to continue or increase the behavior, especially if the child is trying to seek attention. Remain calm, neutral, and focus on safety.
- **Co-regulate with the child by modeling ways to self-soothe.** When co-regulating, it’s important to show and not tell. For example, begin taking deep breaths instead of telling the child to breathe. This also benefits the caregiver by lowering stress in the moment.
- **Be clear and concise.** Limit the amount of talking you do or attention you give the child until they de-escalate and complete the task that was asked of them.



Teaching New Skills Using Prompts

When teaching your child new skills, prompting is key. Prompting involves using gestures or pointing, gentle physical guidance on the relevant limb, visual supports, or verbal cues to assist or encourage an individual in completing a task or activity more effectively. Prompting can be used to help you support behaviors you want to see your child develop. Prompts should be removed gradually so children can achieve independence and confidence.

Prompting examples



Visual: Leave a sticky note on the bathroom mirror to remind the child to brush their teeth before bed.



Verbal: Say to the child, "It's time to brush your teeth before bed."



Gesture: Point to the toothbrush when the child is standing at the sink before bed.

Prompting tips



Prompt silently when talking is not required. Use gestures and visual cues more often than verbal prompts.



Avoid over-prompting or doing things for your child that they can do themselves. This can be harmful to the child's behavior and mental health.



Reinforce desired behaviors by linking special privileges to your child's safe and healthy behavior choices instead of freely giving special privileges. This teaches the child that the world is better when they make safe and healthy choices.



MDA Resources

Family mental health:

- MDA's Community Education Mental Health Hub: mda.org/community-ed/mental-health-hub
- DMD and Mental Health On-Demand Webinar: youtube.com/watch?v=mb8mohB05T8
- Mental Health Challenges in Children On-Demand Webinar: youtube.com/watch?v=LeHZ5Gh50Ec
- Parenting Challenging Behaviors in Children with Neuromuscular Disease: youtube.com/watch?v=Np-lib8upnw
- Access to Coverage: Mental Health Workshop: mda.org/care/community-ed/mda-access/access-to-coverage-mental-health

K-12 education:

- Teacher's guide: mda.org/sites/default/files/2024/09/MDA-Teachers-Guide.pdf
- IEP Process handout: mda.org/sites/default/files/2021/09/The-IEP-Process-Access-To-Education-K-12.pdf
- Access to Education Workshop: mda.org/care/community-ed/mda-access/access-to-education-k-12



References

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Fisher, W. W., Piazza, C. C., & Roane, H. S. (Eds.). (2013). *Handbook of applied behavior analysis*. Guilford Publications.

About MDA

Muscular Dystrophy Association 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, contact MDA's Resource Center at **833-ASK-MDA1 (275-6321)** or **ResourceCenter@mdausa.org**. Visit **mda.org** for additional resources.

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+ To learn more about neuromuscular diseases and MDA's programs, visit mda.org.

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

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