

Muscular Dystrophy School Program Suggestions

Your child's muscle weakness should not limit their success at school. The school's educational team, including the occupational and physical therapist, can help you to assess your child's needs for school accommodations. These can then be outlined in their IEP or 504 plans. A 504 plan is set up to have modifications made to help support your child at school. An IEP is a plan for specialized education or therapy instruction for your child.

Examples of school accommodations for children with MD include:

Accessibility

- Allow for extra time to move between classes or to the cafeteria. Avoid using stairs. A ramp or an elevator is preferred.
- Your child may need a power scooter or wheelchair to move between activities or classrooms if they tire easily walking around the school campus.
- A wheelchair or scooter may also be needed to participate in school field trips or to safely access the school bus.
- Arrange help with carrying your child's lunch tray and opening food items.
- Arrange help with getting to and using the bathroom safely.
- If it is hard for your child to get up and down from the floor, they may benefit from using a chair during circle time or assemblies.
- Put a plan in place for modifications needed during a fire or emergency drill. The school should identify how your child will be helped outside during an emergency.

School work

- Use an audio recorder, have an aide, scribe or buddy take notes, or get hard copies of the teacher's notes to reduce writing fatigue.
- Encourage your child to learn keyboarding and allow the use of a tablet or laptop.
- Consider using a speech to text software program.
- Provide two sets of books – one for use at home and one for school to avoid a heavy backpack.
- Make sure the desk, lab, library, computer and lunch room tables can fit your child's supportive chair or wheelchair. Tilting the work surface may improve visibility.

To Learn More

- Occupational & Physical Therapy
206-987-2113
- Rehabilitation Medicine
206-987-2114
- Ask your child's healthcare provider
- seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line, 1-866-583-1527. Tell the interpreter the name or extension you need.

Muscular Dystrophy School Program Suggestions

- Allow flexibility and extra time with homework. This might include dictating to parents, breaking long assignments down into segments and allowing parents to prioritize in case of fatigue.
- Allow extra time for tests or no timed tests. Consider oral exams as your child's written work may not reflect their ability due to writing fatigue.
- Because of decreased endurance give frequent breaks.
- Some children with MD are at risk of having difficulties with language development, short-term memory, frustration tolerance, anxiety, social interactions and executive functions. Your child may need more reminders and more structure to learn material.
- Some children may also need advance notice before changing to another activity or before changes in daily routines in the classroom.
- Make arrangements for resource room help or extra study time when needed.
- If your child needs a lot of assistance throughout the school day, having an attendant or aide may be helpful.
- Boys with DMD taking steroids may show difficulties with mood, temperament and attention.
- A local MDA representative may be able to visit your child's school and speak with staff or classmates to provide education on your child's strengths and difficulties.
- The PPMD and MDA website also has recommendations for school participation which are listed below.

PE and Recess

- Encourage your child to take part in PE and recess as much as they can without getting over tired.
- Ask if PE activities can be adapted so your child can be actively involved. For example, the PE teacher may incorporate hamstring or heel cord stretching into the class routine.
- Depending on your child's strength and abilities, climbing and monkey bars may not be safe.
- Your child should not be expected to walk or run laps to increase endurance. Instead they should preserve their energy in order to take part in the planned game or activity for social recreation.
- Avoid weight lifting and core strengthening exercises such as sit-ups, push-ups and planks. Your child could help time or count for peers instead.
- Try a lighter weight ball when throwing, catching or kicking.
- Inform the PE teacher that jumping or hopping is often very hard.
- If there are concerns with your child falling during PE, they may need a power scooter or wheelchair to take part.
- The school physical therapist should be able to assess your child's safety and recommend the right activities for him to the PE teacher.
- In middle school, your child may benefit from taking part in other activities rather than PE class.
- Your clinic doctor and physical therapist can make additional recommendations regarding your child's participation in these activities.

Should my child have therapy at school?

Your child should be assessed by your school's therapy team to determine if there are limitations to your child's ability to access and participate in school activities. The team will determine if there are education related goals that can be addressed by physical, occupational or speech therapy at school. If your child qualifies for direct therapy services, specific goals will be outlined on their IEP. Your school should not be expected to perform your child's daily stretching routine.

If your child does not qualify for direct therapy services, the therapist should still be available to evaluate your child's ability to move around the school environment and participate with their classmates. If you have any concerns about your child's school program, we can talk to your child's teacher or therapist about their diagnosis and expectations for performance.

Web resources

Education Matters Guide

Parent Project Muscular Dystrophy (PPMD)
parentprojectmd.org

This guide helps you talk with educators about how DMD affects your child. Also includes guides for PE and classroom teachers.

A Teacher's Guide to Neuromuscular Disease

Muscular Dystrophy Association (MDA)
mda.org

Designed for your child's teacher, this manual addresses types of muscle diseases and their impact on learning ability and how a student with a muscle disease affects the classroom. It also offers additional teacher resources.

Special Education in Washington State: a handbook for parents

Washington State Special Education Services
specialeducationsupportcenter.org
www.k12.wa.us/specialEd

These websites provide more information on the IEP and 504 plan process in Washington State.