



## Diagnosis: Limb-Girdle Muscular Dystrophy (LGMD)

Limb-girdle muscular dystrophy (LGMD) is a progressive neuromuscular disease that affects the major muscle groups in the legs, arms and pelvic girdle. Due to the progressive nature of the disease, and the fact that physical fatigue in children with LGMD may impact them while in the school environment, it is imperative that educational professionals who work with students with LGMD be aware of their diagnosis, needs and abilities.

Limb-girdle muscular dystrophy is a genetic condition that does not impact the brain or intellect. It is important that school health officials understand that this disorder is not contagious and does not pose a health risk to the school. The student does, however, have an increased risk of falls and injury if he or she fatigues.

To learn more about LGMD, visit MDA's website at [mda.org/disease/limb-girdle-muscular-dystrophy](https://mda.org/disease/limb-girdle-muscular-dystrophy).

In the school setting, the following aids, interventions and supports are recommended for students with LGMD to be able to fully access their school environment and have the opportunity to excel academically and socially.

### Physical Therapy

Physical therapy enables children with limb-girdle muscular dystrophy to make maximum use of healthy muscle function, helping them maintain independence and prevent the onset of muscle contractures. This is a list of accommodations students may need during the school day:

- Stretching
- Range-of-motion exercises
- Muscle cramp massage
- Safety training (on stairs and playground)
- Hallway safety
- Accommodating activities of daily living (ADLs) to changing physical needs (toileting, lunch time/cafeteria safety, etc.)
- Adapted/modified physical education (see next section)

### Physical Education (Adapted)

Being physically active can be helpful to students with LGMD. It is recommended that students remain included in the general education classroom for physical education (PE), with modifications made to accommodate the student's needs and abilities. Modifications for most activities can be done by consulting with the physical therapist, with the goal of this student's PE curriculum being recreation, rather than competition and increased strength and endurance. It is critical that students with LGMD be restricted from eccentric (weight lifting) exercises, as these may cause muscle damage.

## Occupational Therapy

As a student with LGMD becomes physically weaker, an assistive technology evaluation will be indicated. Also, an occupational therapy consultation for body positioning, seating, and gross and fine motor function is recommended. Many students with LGMD use computers, AlphaSmart devices or have modified written assignments.

## School Accommodations

Every child is unique and has different physical needs. The following are accommodations to consider in the classroom/school environment:

- An additional set of textbooks should be provided to the student so they do not need to transport heavy textbooks to and from school (or from one classroom to another).
- If the school has multiple levels, the student should have access to an elevator.
- Whenever possible, the student's physical needs should be taken into consideration when designing their class schedule (classrooms should be close together to minimize distance walked throughout the day, etc.).
- Preferential seating in the classroom will allow a student with LGMD to safely navigate the classroom and access their class environment.
- An emergency evacuation plan should take the student's physical needs into consideration. School personnel should be assigned to accompany the student during an emergency. If the school has multiple levels, a "safe room" should be established with the local fire department.
- Field trips and school events should take into consideration the student's needs. For example, how far will students have to walk from the bus to the front door? Is the field trip destination wheelchair-accessible? Is there a wheelchair lift on the bus? Have chaperones been informed of this student's needs?

### A Message from MDA

Thank you for your commitment to your student(s) living with limb-girdle muscular dystrophy (LGMD). With your support, your student(s) will have the opportunity to achieve their academic goals while also learning to adapt to their changing physical needs. For more information about LGMD, and for additional support, contact the Muscular Dystrophy Association at **800-572-1717** and [ResourceCenter@mdausa.org](mailto:ResourceCenter@mdausa.org). Visit [mda.org](http://mda.org) for additional resources.

