Muscular Dystrophy

What is muscular dystrophy?

Muscular dystrophy is a group of genetic diseases that cause muscle wasting and weakness. The most common type is Duchenne muscular dystrophy, which is progressive and occurs only in boys.

How common is it?

- Duchenne muscular dystrophy occurs in 1 in 3,500 boys at birth. Females may be carriers.
- Myotonic dystrophy occurs at 1 in 8,000 of all births.
- Other types of muscular dystrophy are less common.

What are some common characteristics of children who have muscular dystrophy or of muscular dystrophy as children present with it?

The symptoms of Duchenne muscular dystrophy often start in the preschool age range, that is, 2 to 4 years of age. Symptoms might include being unable to get to standing from sitting and not being able to run. Children with this muscular dystrophy develop swayback, with their stomachs pushed forward, and walk on their toes. They can get leg and calf cramps and can appear clumsy. About a third of boys with Duchenne muscular dystrophy have intellectual disability; speech delay, attention-deficit/hyperactivity disorder, and specific learning disabilities are also common.

Who might be on the treatment team?

- Pediatrician/primary care provider in the medical home to coordinate specialist care
- Pediatric subspecialists that might include a neurologist, a pulmonologist, a cardiologist, and an orthopedic surgeon
- Physical and occupational therapists

What adaptations may be needed?

Medications

- Steroids such as prednisone may be used, which can affect the immune system (see Abnormal Immunity: An Overview Quick Reference Sheet [page 63]).
- All staff who will be administering medication should have medication administration training (see Chapter 6).

Dietary Considerations

Constipation can be a problem, so a diet including fiber is good. Soft-food diets may be necessary for children with more advanced disease, and feeding these children through a gastrostomy tube to prevent choking may eventually be necessary (see Gastrostomy Tubes Quick Reference Sheet [page 131]).

Physical Environment and Other Considerations

- **Equipment:** Some patients may need assisted ventilation, delivered through a mask over the nose or through a tube in the neck (tracheostomy). See Tracheostomy Quick Reference Sheet (page 193).
- **Environment:** Exposure to minor colds and respiratory illnesses can create setbacks and even hospitalization (for pneumonia).
  - All children and staff should be fully immunized, including with influenza vaccine. This step protects everyone against vaccine-preventable illnesses.
  - Children with muscular disease may miss classes because of illness, therapy, or medical appointments. Ensuring that they keep up with the lesson plans keeps them from falling behind.
  - Various types of adaptive equipment might be used, such as leg braces, wheelchairs, and communication and other devices.
  - Children with muscular disease should play to their abilities, but they may need extra rest because their muscles tire more easily.
- **Transportation considerations:** Children with adaptive equipment may need special forms of transportation.

What should be considered an emergency?

- Families should be notified immediately for any fever or difficulty breathing.
- Children who take steroids might deteriorate quickly with a mild illness; vomiting also needs to be reported to families.

Muscular Dystrophy (*continued*)

What types of trainings or policies are advised?

- Specifics of the Care Plan (eg, adaptive equipment).
- Emergency planning.
- Children with muscular dystrophy, near the end of life, might have special plans in place. Educators who understand these plans can be more supportive of the child and family and address their own feelings. See "Children With Terminal Illnesses and Do-Not-Attempt-Resuscitation Plans" box in Chapter 8.

What are some resources?

Muscular Dystrophy Association: www.mda.org, 1-800-572-1717

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