Muscular Dystrophy

Symptoms

Each form of muscular dystrophy is caused by a defect in a gene. All forms are hereditary conditions, with the genetic defect transmitted by one parent in some forms of the disease and by both parents in other types.

Many thousands of Americans suffer from muscular dystrophy. Almost 2/3 of these cases are children. Symptoms may appear any time between birth and adolescence. However, muscular dystrophy can strike anyone at any age. Some forms develop in the teens; others in the twenties, or even middle age.

About the Disorder

Duchenne Muscular Dystrophy usually develops in boys between the ages of two and six. Early signs are often overlooked. The child may have difficulty climbing stairs and rising from sitting or lying positions. There is a tendency to fall frequently. Later, the child may develop a waddling gait. Serum levels of the muscle enzyme CPK are elevated in Duchenne Muscular Dystrophy even before clinical signs of the disease appear. A distinctive characteristic of Duchenne Muscular Dystrophy is the seeming enlargement of calf muscles called pseudohypertrophy, which results from buildup of fat and connective tissue rather than muscle fiber. Progression is rapid with no remission and is marked by wasting of proximal muscles – particularly in the pelvic girdle – followed by involvement of the pectoral muscles, and finally of all muscle groups. In this, the most common and severe type of muscular dystrophy, few patients survived their early 20's decades before, but survival rates are continuing to improve due to advances in medical care and treatment. The hereditary pattern in Duchenne MD is of the recessive X-linked type, in which the mother transmits the defective gene almost exclusively to male children. There is a 50% probability that any female offspring will be a carrier of the defective gene.

Facioscapulo-Humeral Muscular Dystrophy usually occurs in early adolescence, occasionally as late as the mid-20's, and sometimes in infancy. There is marked variability in the severity and onset of symptoms from patient to patient. Initial involvement occurs in the muscles of the face and shoulder girdle. There is a resulting lack of facial mobility (difficulty closing eyes and whistling, unlined face even in middle age); difficulty in raising arms over the head, and a characteristic forward slope of the shoulders. The progression is very slow as a rule, with plateaus of significant duration. Average life span is rarely shortened, although patients may suffer considerable disability. Trunk and leg muscles may become involved, and the person may be unable to walk. Limb-Girdle Dystrophy occurs anywhere from the first to the third decade of life. It begins in either the shoulder muscles or muscles of the lower trunk and upper legs. The symptoms vary with part of the body affected. When the shoulders are affected, the individual may have difficulty raising arms and lifting objects and have drooping shoulders. If the legs and trunk are affected, the student may waddle, have frequent falls, and/or have difficulty rising from the floor, and climbing stairs. The progression of the disease varies. Life span is usually shortened.

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Myotonic Muscular Dystrophy, also known as Steinert's disease, may occur at any age, but is most frequent between the ages of 20 and 35. The first signs are weakness of the fingers, hands, forearms, feet and lower legs. Facial muscle weakness (dropping lids, jaw) may also be initially apparent. There may be stiffness in the hands and feet, especially after being chilled. There is 50% probability of incidence among offspring. Other types include Becker MD, Congenital Dystrophy, Distal MD. Becker MD is similar to Duchenne but starts later in life and is less severe. Congenital Dystrophy takes place during the fetal period and the disease is already manifested at birth. The essential features include hypotonia, muscle weakness, and contractures. Distal MD involves the small muscles of the extremities and is the rarest subgroup.

Educational Implications

- Emergency Evacuation plan in place prior to first day of school
- School therapy, access to school nurse
- Support for meeting personal needs
- Developmental Adapted PE services
- Services & support from the Physical/Health Disabilities (P/HD teacher)
- Rest periods if needed
- Physical access to school environments, such as building entry, access to multiple floors, classrooms, lunchroom, gym, recess area, restrooms, etc.
- Environmental accommodations, including automated door switches, modified door handles, elevator access, support bars and widened stalls in restroom, modified desks/chairs, preferential seating, locker access, and additional time for transitions
- Specialized instruction in areas of academic need
- Access to assistive technology such as electronic text books, devices, specialized keypads, apps and software; •Alternative notetaking methods
- Alternative test environment
- Extra time for assignments and tests
- Customized post-secondary planning

Resources

Muscular Dystrophy Association
https://www.mda.org/

Mayo Clinic: Muscular Dystrophy Overview
https://www.mayoclinic.org/diseases-conditions/muscular-dystrophy/symptoms-causes/syc-20375388

Muscular Dystrophy Information Page

National Institute of Neurological Disorders and Stroke
https://www.ninds.nih.gov/Disorders/All-Disorders/Muscular-Dystrophy-Information-Page

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