PATIENT HANDOUT

for Living With MUSCULAR DYSTROPHY



Muscular dystrophy is a group of genetic disorders that cause the body's muscles to deteriorate and weaken over time. Muscular dystrophy affects the voluntary muscles that control movement in the arms, legs, and trunk region. It also can affect involuntary muscles, such as the heart. The following tips can help if you have muscular dystrophy.

Know your options. There is no cure for muscular dystrophy and no way to stop the disease from worsening, but medications and therapy can slow the course of the disease. Supportive care, leg braces, and physiotherapy also can help with your muscular dystrophy.

Adapt your environment. Making your environment accessible to you may include having the doorways widened in your home, adding ramps, moving bedrooms to the ground level, and making changes to ensure access for wheelchairs and other devices.

Manage your weight. Reaching and maintaining a healthy weight can reduce stress on your muscles. It also can help prevent certain health conditions, such as respiratory problems.

Get physical. Low-impact physical activity, including swimming, can help improve muscle strength and your overall well-being. In some instances, especially in the early stages of your muscular dystrophy, submaximum aerobic exercise also may be recommended.

Get restful sleep. As you experience muscle weakness, it can become more difficult to find a comfortable sleeping position. Certain beds, mattresses, and pads can enhance comfort, which can improve the quality of your sleep.

Seek genetic counseling before becoming pregnant.

Genetic counseling is advised for people with a family history of muscular dystrophy. Women who have no symptoms of muscular dystrophy can still carry the gene for the disease. The odds of women with muscular dystrophy passing this disorder to their children range from 25% to 50%.

Contact your doctor. Knowing when to contact your doctor for your muscular dystrophy is important. Call your doctor if you notice worsening muscle weakness anywhere in your body. Also call if you have difficulty speaking clearly and swallowing normally.

Understand surgical options. Your doctor may recommend surgery to help maintain your functional skills and improve your quality of life. Surgical options include spinal fusion to correct scoliosis and the surgical release of contractures or tendons.

This page is part of an ongoing series of practical tips for patients with neurologic disorders. If you have compiled clinically relevant tips that you wish to share, please contact the editor at info@neurologyreviews.com.

Tips for Patients are available for download at www.neurologyreviews.com.

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