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Duchenne's Muscular Dystrophy & Occupational Therapy

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Duchenne's Muscular Dystrophy & Occupational Therapy

What caused this?

Duchenne's Muscular Dystrophy (DMD) is a genetic condition leading to weakness and degeneration of skeletal muscles and organs due to alterations in the protein dystrophin– essential to muscle strength and injury protection.

How often does this happen?

1 in every 3,500 live male births will be diagnosed with DMD by the age of 5 (NORD, et al., 2021)

How many other people have this?

In the United States, the total number of individuals with muscular dystrophies in 2021 was 250,000 (NORD, et al., 2021)

How long will this last?

There is currently no cure for DMD, but therapy can help slow down the process of this genetic condition.

What will happen because of this?

Often times individuals with DMD will see muscle wasting in the upper legs, pelvic area, upper arms, and shoulder area Commonly, there will be a delay in reaching developmental milestones, excessive falling, and decreased bone density. Most individuals with DMD will require a wheelchair by the age of 10-12 due to muscle wasting. Eventually, DMD leads to weakness and deterioration of heart muscles, rib cage muscles, and gastrointestinal muscles. (NORD, et al., 2021). Current medical advances have extended the life expectancy of of those with DMD to their early 30's, however most individuals live to their late teens or early twenties.



Will anything else happen?

Individuals with DMD may have a cognitive impairment (including learning disabilities, i.e: attention deficit disorder, autism spectrum disorder, etc.). Individuals with DMD may also experience scoliosis, decreased pulmonary function, anxiety, and depression, (NORD, et al., 2021)

How will this impact daily life?

DMD is a degenerative disease, and as such changes everyday life fairly often. DMD affects everyday mobility both at home and within the community. The ability to perform self-care tasks such as dressing and toileting, energy levels, physical activities, and socialization activities can be impacted.

What will I be able to do?

Modifying daily activities, leisure activities, and social interaction as DMD progresses can allow individuals stay as independent as possible and live fulfilling lives.

How does an occupational therapist evaluate individuals with muscular dystrophy?

An occupational therapist (OT) can use a Range of Motion (ROM) assessment to measure the mobility an individual still has and monitor the progression of DMD.

A wheelchair evaluation may also be performed to ensure the seat, back and leg rest are fitted to the individual to prevent further deformities of the spine and muscles (Ciafaloni & Moxley, 2018).

What will therapy include?

Therapy will focus on maintaining strength, mobility, and independence. When an individual is in a wheelchair the OT will focus on educating about assistive equipment, providing modification, and preventing deformity, and joint stiffness.



How will OT help an individual with muscular dystrophy?

The OT will focus on muscle strengthening exercises, gentle range of motion, and home exercise programs to slow down muscle function decline (Pendleton & Schultz-Krohn, 2018).

Transitioning into a wheelchair full time can be challenging, an OT can aid in the use of adaptive equipment by educating about proper use of wheelchair and hoist set up. Your therapist can assist with transfers from bed to wheelchair, wheelchair to hoist, and wheelchair to toilet or shower.

Splints can be provided by your OT to aid in joint mobility, grip strength, and finger motor function (Houwen-van Opstal, et al., 2020)



References

Ciafaloni E, Moxley RT. Treatment options for Duchenne muscular dystrophy. Curr Treat Options Neurol. 2018 Mar;10(2):86-93. doi: 10.1007/s11940-008-0010-4. PMID: 18334131.

Duchenne muscular dystrophy. NORD (National Organization for Rare Disorders). (2021, March 25). Retrieved March 11, 2022, from https://rarediseases.org/rare-dise ases/duchenne-muscular-dystrop hy/#:~:text=Duchenne%20muscul ar%20dystrophy%20(DMD)%20is, and%20six%20years%20of%20age

Houwen-van Opstal, S., van den Elzen, Y., Jansen, M., Willemsen, M., Cup, E., & De Groot, I. (2020). Facilitators and Barriers to Wearing Hand Orthoses by Adults with Duchenne Muscular Dystrophy: A Mixed Methods Study Design. *Journal of neuromuscular diseases*, 7(4), 467–475. https://doi.org/10.3233/JND-2005 06

Pendleton, H. M. H., & Schultz-Krohn, W. (Eds.). (2018). Pedretti's occupational therapy : practice skills for physical dysfunction (8th edition ; Eighth). Elsevier.