

Muscular Dystrophy and the Church

Muscular Dystrophy is a genetic disease that often impacts every part of a person's life, and the lives of their family members. Yet, how often do we talk about what that means at church? Find out what families of children who have Muscular Dystrophy want the church to know.

What Families Want the Church To Know

1. Learning About Muscular Dystrophy Helps - The Muscular Dystrophies are a group of diseases that cause weakness and degeneration of the skeletal muscles*. There are more than 30 types of Muscular Dystrophy and within each of these types, there are further variations. Which means Muscular Dystrophy is complex and each person's experience is a little different. Depending on which type it is, some people are diagnosed later in life and have mild symptoms, while others will be diagnosed in early childhood and have severe symptoms.

There are nine types that are pretty common. Becker, Congenital, Duchenne, Distal, Emery-Dreifuss, Facioscapulohumeral, Limb-Girdle, Myotonic, Oculopharyngeal
All types of Muscular Dystrophy are genetic, which means that it was present at birth.

The most common type to affect children is Duchenne Muscular Dystrophy. Duchenne Muscular Dystrophy is found primarily in boys, and it occurs in 1 in 3500 live male births. It causes progressive muscle weakness and damage throughout the body, becoming more severe over time. Most children are diagnosed between ages 3 and 5 when muscle weakness begins to affect walking and other activities. Wheelchair use often starts around ages 10-12, but can vary. And currently, the average life expectancy is between ages 20 and 30. Females rarely have Duchenne, but they can carry the gene and potentially pass it down. There is no cure for Duchenne, but there are promising medical trials underway.

2. Keep It Real-

The next thing that families want the church to understand is this - having a child with a progressive disease, like Duchenne Muscular Dystrophy, is hard. And sometimes all the feelings that come with it are hard too. The best way to support families is to create a safe place for them to be real with their feelings, worries, doubts and fears. Realize that sometimes well-meaning things like reciting a quick Bible verse or giving a simple encouragement like, "Just have faith", can sometimes make people feel dismissed. Instead of trying to make families "feel better", just be present and allow them to feel cared about instead. (And don't forget to ask them how you can pray for their family!)

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3. Stay Connected-

Realize that sometimes getting to church on Sunday mornings or coming to evening events can be hard for families. This can happen for a lot of reasons, such as the amount of time it takes to get their child ready to leave the house, or the threat of germs, or activities not being wheelchair friendly. If you notice that a family hasn't been around lately, reach out. See if the church can come to them or if their needs can be met in a different way. Remember that the church is not a building, it's a family. Families stay connected.

4. Inclusion and Tangible Support -

The last way that churches can support families affected by Muscular Dystrophy or other disabilities is by being intentionally inclusive and finding ways to help them with tangible support. Watch Wonderful Works Mobility Impairment and Wonderful Works Tangible Support videos for some great ideas.

Muscular Dystrophy Resources:

General Info: CDC - What is Muscular Dystrophy

Duchenne and Becker MD: Cure Duchenne

Duchenne Muscular Dystrophy: Little Hercules Foundation

Citations: www.mda.org