

Muscular Dystrophy

Have you seen the Netflix adaptation of the Broadway show “13: The Musical”? What’s special about the film is the character of Archie, who is played by Jonathan Lengel.

Lengel is an actor, singer and performer who lives with a rare form of muscular dystrophy. He uses a wheelchair just like his character in the movie.

The Rights of Persons with Disabilities Act, 2016 defines it as a group of hereditary genetic muscle disease that weakens the muscles that move the human body. It is characterized by

- Progressive skeletal muscle weakness
- Defects in muscle proteins, and the
- Death of muscle cells and tissue

The absence of the protein Dystrophin can cause problems with walking, swallowing and muscle coordination.

Muscular dystrophy can occur at any age, but most diagnoses occur in childhood. Most individuals with muscular dystrophy lose the ability to walk and eventually require a wheelchair. Living with Muscular Dystrophy also means facing varying degrees of physical and respiratory challenges.

While there are about 30 different types of muscular dystrophy, each with its unique characteristics, Duchenne Muscular Dystrophy and Becker Muscular Dystrophy are the two most common types.

The global prevalence of MD is estimated at 3.6 percent per 100,000 people. **In India, 1 in 3500 boys are likely to be affected by Muscular dystrophy.**

In the 95th episode of Mann Ki Baat, Prime Minister Narendra Modi spoke about the disease, citing a Himachal Pradesh resident who has been living with the condition since early teens.

Early diagnosis and tailored treatments can significantly improve quality of life. However, people with Muscular dystrophy often require ongoing care and support. This can include physical therapy, mobility aids, and other medical interventions.

Several people lead so-called normal lives despite the range of symptoms caused due to this condition.

Nikki Fox is one such name. She is an English presenter, broadcaster and a documentary maker who started her career with the BBC. Alfredo Ferrari, son of Enzo Ferrari, was a world famous automotive engineer who had Duchenne Muscular Dystrophy.

Awareness about Muscular Dystrophy isn't just about understanding the condition; it's about empowering communities with knowledge, advocating for research, and supporting affected individuals and families.

[The Indian Association of Muscular Dystrophy](#) has been working in this field since 1992. There is also the [Muscular Dystrophy Foundation of India](#) operating from Madurai.