

Duchenne: An overview for Educators



Duchenne muscular dystrophy is a genetic linked neuromuscular disease which causes progressive loss of muscle function and independent functioning. It results from a defective gene responsible for producing the key muscle protein, dystrophin. Children with Duchenne muscular dystrophy are usually diagnosed before the age of five. The disease leads to a loss of muscle mass, breathing difficulties and decreased heart function. Muscles are prone to extensive damage when overused and fatigued. This muscle damage causes the disease to progress faster.

Duchenne muscular dystrophy, classified as a rare or orphan disease, affects approximately one out of every 5,000 boys. Currently, there are 15,000 individuals living with Duchenne muscular dystrophy in the U.S. alone and 300,000 worldwide. About a third of individuals living with Duchenne muscular dystrophy have some degree of learning difficulty, perhaps because of dystrophin abnormalities in the brain.

Duchenne muscular dystrophy can sometimes be referred to as a “hidden” disease as its progression is not always seen with the naked eye. Often, observed behavioral changes, misconstrued as defiance, are a result of the weakened physical and mental muscle function.

Typical Progression

Early Ambulatory	Mid-Ambulatory	Late Ambulatory/Transitioning	Non-Ambulatory
Moves slower than same age peers	Increased difficulty walking	Increased fatigue	Increased breathing difficulties
Appears clumsy/falls often	Weakened trunk area	Continued progression of loss of muscle function	Decreased heart function
Enlarged appearance of calves	Awkward gait	Activities involving upper body and lower body will require assistance	Requires use of a wheelchair for mobility
Energy conservation throughout the day is important	Difficulty rising from the floor	Walking has become unsafe and cumbersome	Reliance on assistive technology and adaptive equipment
	Necessary to begin assistive technology plan		

Treatment

While there is no known cure for Duchenne muscular dystrophy, there are standards of care across the U.S. being utilized to lessen symptoms and improve quality of life. Corticosteroids are used to slow muscle loss and increase strength, however, there are side effects that may impact behavior and academic performance. Psychological effects can include but are not limited to: difficulty with concentration, sleeping and controlling emotions. Additionally, impairments in reading, thinking, and coping skills can lead to depression and/or aggression.