

Parent Project Muscular Dystrophy

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1

Education Matters for Parents and Teachers Diagnosis and Early Childhood

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Education Matters for Parents and Teachers

Diagnosis and Early Childhood

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A note to parents and teachers

If you are reading this guide, it is because you are a parent or a teacher and have a child or student living with Duchenne muscular dystrophy. Duchenne is the most common type of muscular dystrophy in children. It is a progressive disorder that causes muscles to become weaker over time. Duchenne is a complex diagnosis, and certain elements included in this guide are universal to all children living with Duchenne, while others can vary from child to child.

Children living with Duchenne may have some physical limitations, and require modifications at school, but just like any child, are eager to participate and thrive in the school environment. This guide is meant to provide you with a comprehensive overview of Duchenne along with how this diagnosis may impact your child / student's school experience. With some early planning and intervention, your child/student will have a successful school year!

—Parent Project Muscular Dystrophy

1. About Education Matters

"Education Matters" is a guide created for parents and teachers with the goal of optimizing the child's experience in a learning environment. Written by Parent Project Muscular Dystrophy (PPMD), Education Matters offers practical information on Duchenne as it relates to a child's educational experience and specific advice on achieving success in the early childhood/elementary classroom.

In this booklet, we address many areas including information about Duchenne, as well as cognition, learning, behavior and student rights. Prior to school starting parents should share this guide with their child's school administration, teachers, and support personnel. Sharing the information in this guide will help to initiate and facilitate conversation between school and home, making sure that everyone is following the same path and moving in the right direction towards an amazing school year.

In addition to this guide, PPMD has developed a living Community Resource Center that is continuously updated with resources and tools identified by all members of the Duchenne Community. The Resource Center for Education includes information on various aspects of communication, physical education, education rights and many other topics. Resources for Primary and Secondary Education can be found here: parentprojectmd.org/primary-resources

2. About Duchenne

Duchenne ("doo-shen") muscular dystrophy is one of a spectrum of muscle diseases known as *dystrophinopathies* that can range from mild to severe in presentation. Dystrophinopathies occur when the *dystrophin protein* (found in the body's muscle cells) has an altered structure or function, or is entirely absent from the body's muscle cells. Becker muscular dystrophy is also a dystrophinopathy with many similarities to Duchenne. And while Becker can be variable, depending on when symptoms first present, typically the symptoms are milder in progression compared to Duchenne. *The information in this guide extends to both Duchenne and Becker, but for simplicity we primarily refer to Duchenne.*

Duchenne affects approximately 1 out of every 5,000 live male births. About 20,000 children are diagnosed with Duchenne globally each year. Duchenne is considered a rare disease in the U.S.

Duchenne is a genetic disorder caused by a change in the DNA (or gene) that codes for dystrophin. Dystrophin acts as the "glue" that holds muscles together and the "shock absorber" that allows muscles to contract and relax without being damaged. Without dystrophin, muscles are not able to function or repair themselves properly with normal day-to-day activity. **Becker muscular dystrophy**, which is less severe than Duchenne, occurs when dystrophin is manufactured, but not in the normal form or amount.

Since the dystrophin gene is found on the X-chromosome, Duchenne primarily affects males. Females with dystrophinopathy are typically known as carriers because they have one copy of the changed gene and one copy of the functioning gene. Carrier females most often do not have outward symptoms of Duchenne. However, some carrier females can present with varying ranges of physical and/or cognitive symptoms and are usually termed “manifesting carriers,” or more recently, “females with dystrophinopathy.”

While not all children living with Duchenne have mental health issues, there are increased risks of delayed development, as well as learning and behavior issues, difficulties with social interactions and emotional adjustment. Duchenne can (but does not always) affect brain development and cause weakness in certain cognitive or problem-solving skills (parentprojectmd.org/learning-disabilities). Medication side effects, fatigue, physical limitations, family stress, and difficulty coping with the diagnosis of Duchenne can also contribute to psychosocial issues (parentprojectmd.org/coping).

Deeper Dive

There are 79 exons and 7 promoters in the gene encoding for dystrophin. This gene is found in every cell of the body, but the promoters encode for slightly different forms of dystrophin to be created in different parts of the body. The different forms of dystrophin are called “isoforms.” Many people living with Duchenne have no issues with school or learning, however a lack of dystrophin in the brain can result in cognitive, psychosocial, and emotional issues which may be accompanied by difficult to manage behaviors. Parents and teachers should work together to identify what challenges exist for the individual student, and to develop a plan together to manage these challenges. Consistent practices between the home and school will lead to much more effective learning and behavior management.

3. Physical Findings: What Does Duchenne Look Like?

Early Childhood (ages 2–5 years)

Symptoms:

Duchenne is typically diagnosed between the ages of 2 and 5, usually after delays in early milestones, such as sitting, crawling, walking, and/or talking, are noticed (parentprojectmd.org/diagnosis). Speech delay and/or the inability to keep up with peers will often be the first clear signs of this disorder.

Young children living with Duchenne will move slower or with more difficulty than their peers. They may appear clumsy and fall a lot and their calves may appear enlarged or overdeveloped (called pseudo-hypertrophy, which is replacement of the calf muscle with fat and scar tissue). Jumping from a standing position may be nearly impossible. When asked to stand up, they will usually use the *Gowers’ Maneuver* (put their rear end up in the air first and then use their arms to “walk” up their legs until they are standing). See visual.

Children at this, and every, stage of Duchenne, are generally self-aware of their energy level, and know when they are overdoing it. If children ask to rest, they are not being difficult or lazy — it’s because they know their muscles need a much-deserved break.

Young children living with Duchenne may also have issues with speech and language, learning, and behavior in addition to physical symptoms. These problems will most often require evaluation and early intervention.



THERAPIES

Physical therapy (PT) is often provided to students with Duchenne in the preschool / school setting. PT can assist with:

- Stretching
- Range of motion exercises
- Muscle cramp massage
- Safety training for navigating school, stairs, playground, bathrooms
- Hallway safety
- Accommodations for activities of daily living (toileting, lunchtime, etc.)
- Suggestions for adaptive Physical Education
- Suggestions for adapting field trips and special school events (field day, Earth Day, etc.)

The most current recommendations for physical therapy and Duchenne, as well as videos demonstrating stretching and management of young children living with Duchenne, can be found at parentprojectmd.org/physical-therapy.

It is recommended that young children with Duchenne start taking **corticosteroids** (commonly referred to as “steroids”). Steroids are prescribed due to evidence that they may slow down the progression of muscle deterioration. They are different from the anabolic steroids that are sometimes misused by athletes who want to become stronger. The two kinds that are usually prescribed are:

- **Prednisone:** usually given every day or twice a week
- **Deflazacort (Emflaza):** usually given every day or twice a week

Steroids are usually continued lifelong due to their many benefits; however, they may cause side effects that may impact functioning at school. Children taking steroids may have an increased appetite with resultant weight gain, cushingoid features (round “moon” face), and stunted growth, making them shorter than their peers. For some children, steroids cause behavior changes, which can include short tempers, impulsive behaviors, decreased inhibitions, and increased emotional lability. For children with existing challenging behaviors, it is not uncommon for steroids to heighten these behaviors.

There are a few elements of emergency care specific to Duchenne, especially for children taking daily steroids. These can be found in Section 14, Duchenne and Emergency Care.

Childhood (ages 6–9 years)

Symptoms:

As children get a little older, they typically begin to have trouble walking as the quadriceps (muscles in the front of the thighs) grow progressively weaker. This causes children to be off-balance as they attempt to shift their weight and walk. They may walk on the balls of their feet or on their toes with a slight rolling gait. In order to compensate for a weak trunk/core, they will stick their bellies out and throw their shoulders back to maintain balance as they walk. When asked to stand, they will continue to use the Gowers' Maneuver; standing up will become increasingly more difficult.

It is important to understand that some exercises or activities can actually damage muscle in Duchenne. The goal of therapy and safe exercise in Duchenne is to maintain strength, function and flexibility, rather than to improve any of these areas. Low intensity activities (i.e., biking on a flat surface, swimming, etc.) are helpful; resistive



and impact activities (i.e., jumping, biking uphill, etc.) are harmful to skeletal muscles and should be avoided. The input of a school physical therapist (PT) and adaptive physical education are critical to preserve muscle function and ensure the safety of the child. If the child fatigues easily, or has difficulty traveling far distances, mobility devices such as scooters or wheelchairs may be necessary as needed or full time.

THERAPIES

Physical therapy (PT) is often provided to students with Duchenne in the school setting. PT can assist with:

- Stretching
- Range of motion exercises
- Muscle cramp massage
- Safety training for navigating school, stairs, playground, bathrooms
- Hallway safety
- Accommodations for activities of daily living (toileting, lunchtime, etc.)
- Suggestions for adaptive Physical Education
- Suggestions for adapting field trips and special school events (field day, Earth Day, etc.)

Corticosteroids (steroids), as mentioned above should be continued lifelong as tolerated. However, taken over time, can cause bones to be fragile and easily broken (“osteoporosis”). Sadly, broken bones can result in casting or surgical intervention; time without walking, which is necessary for healing, can result in the loss of the ability to walk. At school and at home, safety and fall prevention is incredibly important. If you suspect that this child may have, or has, broken a bone, Fat Embolism Syndrome (FES) is a concern. See Section 14 for more information on FES.

Occupational Therapy and/or an Assistive Technology Evaluation is often provided to students with Duchenne in the school setting. OT and Assistive Technology can provide support with:

- Accommodating fine motor/writing concerns (slant boards, pencil grips)
- Assessments for assistive technology (laptop or dictation devices for writing assignments, etc.)

4. Learning and Academic Skills

Dystrophin is normally distributed unevenly throughout the brain causing some areas to have more dystrophin than others. Some of the areas with dystrophin are important for cognitive processing and learning. In Duchenne, those areas missing dystrophin are affected, and can result in learning and behavioral challenges. Again, it is important to remember that not every child will have issues with each of the following learning challenges. But, because some will and the incidence is higher in Duchenne, it important that both teachers and parents are aware of the signs of each.

Deeper Dive

Within the last few years, research has focused on whether the lack of dystrophin within specific regions of the dystrophin gene can be associated with cognitive and learning difficulties. Recent findings have shown that Dp71 and Dp140 are rare dystrophin isoforms important for cognition and learning. Dp140 is present in exons 45 – 79; Dp71 is present in exons 63-79. Mutations in these exons are frequently associated with cognitive delays. Evaluating and managing these issues early and consistently is necessary for a positive outcome in each area.

Intelligence (or Intelligence Quotient, IQ)

Intelligence Quotient (IQ) is often used as an overall indicator of an individual's cognitive abilities. It is calculated by averaging performances on tests that examine different kinds of thinking skills (e.g., vocabulary, pattern recognition, reasoning, processing speed). IQ tests should be administered by licensed psychologists who have specific training in the assessment and interpretation of the test scores.

Deeper Dive

In children, the Wechsler scales (Wechsler Intelligence Scale for Children (WISC); Wechsler Adult Intelligence Scale) are some of the most commonly used IQ tests. On the Wechsler scales, scores between 85-115 are considered to be average, with the majority of the population having skills that fall in this range. In those who have Duchenne, the average IQ is 80, which is considered "below average," but just as in the general population, IQs in Duchenne vary and may range from very delayed (below 70) to very advanced (130s).

There is also growing evidence that those who have Duchenne may have variable cognitive skills. In other words, some skills may be age-appropriate to advanced, while other skills may be delayed. Understanding this variability is more important than knowing an overall IQ score because everyday performances may depend on task demands. For example, there may be specific weaknesses in learning or behavior even when IQs are in the average to above average range. Additionally, understanding this variability allows for behavior plans to be developed and implemented across home and school. Below, we review some of the more common areas of concern for those who have Duchenne.

Language Development

Many people with Duchenne will have issues with language development, and may perform better on visual reasoning tasks compared to verbal reasoning. For this reason, professionals assessing cognitive and learning skills in Duchenne are encouraged to use at least one measure of nonverbal reasoning to accurately determine IQ and thinking skills. Language tasks that may be more challenging include:

- Producing speech quickly and on command
- Word finding
- Fluent speech (articulation)
- Language comprehension may be better than language expression

Those who have language delays may be at increased risk of language-based learning disabilities (dyslexia and dysgraphia).

Weaknesses in Executive Functioning

Executive functions are a group of cognitive skills required for cognitive efficiency, reasoning, planning, or organization. Some of the skills that may be impacted in Duchenne include:

- **Working memory:** Mentally monitoring and manipulating information; holding new information in short-term memory. Examples: Remembering what was just said during a lecture or while reading a paragraph to answer a teacher's question about it, or remembering to follow multi-step instructions given by a parent or teacher.
- **Cognitive flexibility:** Transitioning from one activity to another; being able to adjust your thinking in response to changes in circumstances or unexpected events. Examples: Turning off video games right away when asked, being able to tolerate when others are doing something in a way that is different than we think it should be done, accepting things and moving on when tentative plans to do something we like end up falling through.

- **Inhibitory control:** Being able to hold back behaviors or emotional responses. Examples: Not pushing to be first in line, being patient with others, refraining from talking when needed, waiting to hear all instructions given by a teacher before starting an assignment.
- **Organization, planning, and ideation:** Keeping track of possessions and schoolwork, breaking tasks down into specific steps, generating ideas/solutions ("problem-solving"), prioritizing tasks, and time-management.
- **Task initiation and perseverance:** Self-motivating and self-starting, remaining engaged when tasks are challenging or boring.
- **Self-monitoring:** Evaluating how you're behaving and whether it's appropriate for the situation, understanding how your behavior impacts others, error detection, awareness of how you're feeling and how this influences your thinking. Examples: Making sure that you're not making careless mistakes or annoying others, not blaming others for your actions/decisions.
- **Emotional Regulation:** Awareness of emotions, curbing emotions, preventing/stopping outbursts, awareness of how emotions are affecting others: difficulties in this area will affect not only learning, but also social inclusion.

Deficits in executive functioning can impact a range of activities across home/school settings.

Many times, children with executive functioning challenges can become so overwhelmed that they "shut down." This may occur, as it is often easier for the child to avoid a task all together than to be confused and frustrated by not knowing where or how to start a task, feeling that the task is too difficult, and not knowing how to ask for assistance. Executive functioning challenges can also be the cause of emotional/behavioral issues in response to task demands. Difficulties with understanding how/where to start a task or being overwhelmed by the difficulty of the task can result in anxiety, and if provoked, can cause acting out behaviors. If these issues occur at school, parents and teachers should work together to evaluate the problems and develop solutions that help support the child at home and at school.

Weakness in executive functioning are often seen in people diagnosed with attention-deficit / hyperactivity disorder (ADHD), however ADHD and issues with executive functioning can occur separately. ADHD is described in detail in section 5.

Challenges in organization and planning become more evident, and frustrating for everyone, as the student grows older and is given increasing responsibility for moderating their activities and managing their time and work. Issues that may have been minimal in the early grades may become increasingly evident.

Learning Disabilities in Reading (dyslexia)

Dyslexia refers to a specific difficulty learning to read. Dyslexia is a language-based learning disability because there are usually core weaknesses in phonological processing (e.g., identifying or matching speech sounds) and decoding (i.e., learning to match letters and sounds). Dyslexia is not specific to Duchenne but ~40% of students with Duchenne have dyslexia. Signs of dyslexia may include the following:

- **Reduced phonological awareness/processing** (difficulty generating rhyming words, identifying beginning/ending sounds of spoken words, blending sounds together to form words)
- **Difficulties learning the alphabet or identifying letters** (can't remember what the letter is or what sound it makes, confusing b, d, p, q)
- **Difficulties sounding-out words** (matching sounds to letters or letter combinations – in particular vowel sounds, remembering that letters can make multiple sounds and that different letters that make the same sound)
- **Trouble with spelling**, especially spontaneous spelling that they haven't memorized for a test

Learning Disabilities in Math (dyscalculia)

Dyscalculia is difficulty understanding quantitative relationships, calculating numbers, and learning math facts. Dyscalculia is not specific to Duchenne but ~20% of students with Duchenne have dyscalculia. Signs of dyscalculia include:

- **Giving automatic answers (guessing) to problems** (if the child has learned that $2 + 2 = 4$, they automatically answer that $2 \times 2 = 4$ because this problem also has two 2s)
- **Trouble applying new math rules** (difficulty re-learning to use numbers in different context; for example, if $4 > 2$, then $\frac{1}{4}$ must be $> \frac{1}{2}$)
- **Understanding math concepts that relate to everyday skills** (e.g., money, time)
- **Difficulty with multi-step, complex math problems** (not being able to remember parts long enough to solve the problem, missing key elements of the problem)
- **Knowing what kind of operation to use** when solving word problems
- **Difficulty remembering/memorizing basic math facts** (basic addition, subtraction, multiplication tables)

Learning Disabilities in Writing (dysgraphia)

Writing requires the integration of a number of motor and cognitive skills. The physical demands of writing may be challenging for those with Duchenne because it requires muscle strength. Fine motor dexterity and motor planning are both related to executive functioning, and may be challenging for these students. The cognitive demands may also be challenging because they require attention, executive functions, and language processing. Those who have dyslexia as well will also struggle with spelling (most will be able to spell phonetically, but they may have difficulty remembering the “rules” of spelling). Signs to look for include:

- **Poor penmanship/legibility** (problems with letter size/formation/spacing, starts writing letters in unconventional positions like starting at the bottom and drawing the line upward when writing a “t”)
- **Frequent grammatical errors** to the extent that what they wrote doesn’t make sense, and they can’t tell
- **Problems generating and sequencing ideas during unstructured writing tasks** (can’t think of what to say when asked to write about their summer vacation)

5. Emotional and Behavioral Issues in Duchenne

If you asked parents what their biggest challenge is in parenting children living with Duchenne, a many will tell you that dealing with behavioral challenges, including oppositional behaviors (talking back, arguing, etc.) and explosive outbursts (tantrums, melt-downs, etc.), is exhausting and defeating. Managing arguments that often escalate to outbursts and tantrums are, for many parents, their first and biggest concern. In the Duchenne population, it is common to see anger management issues in children with Duchenne that also suffer from anxiety (see below). Children with Duchenne are often extremely reactive in situations where they also have anxiety. This can be a stressor for both the child and the family.

Anxiety, Depression, and Obsessive-Compulsive Disorder (OCD)

In addition to learning and cognitive issues, both internalizing symptoms (anxiety, OCD, and depression) and externalizing symptoms (aggression and hyperactivity) are more common in Duchenne.

- Symptoms of **anxiety** include being worried or fearful, tense, uptight, or jittery. Anxiety can also cause physical symptoms, such as stomach aches, nausea, headaches, etc. Clinical experience suggests that some people with Duchenne have very high

anxiety, but may not “worry” in the classic sense. Instead, their anxiety is related to being easily stressed and overwhelmed. This can sometimes come out as anger. Anxiety in social situations can also be a common problem in Duchenne, causing them to “freeze up” and become silent and withdrawn (particularly when they are in a group), but it is often overlooked or just attributed to “shyness.”

- **Depression** in children often presents as reduced interest in activities that they once enjoyed. Additional mood regulation concerns are also common in Duchenne (e.g., vulnerability to temper tantrums or “meltdowns”).
- **Obsessive compulsive disorder (OCD)**, which includes intrusive and continuous worries, as well as repetitive behaviors aimed to reduce anxiety, is also more common in Duchenne.

Sensory Processing Disorder

Those with Duchenne are sometimes hypersensitive to environmental stimuli, including noise, textures (clothing and food), and light. Examples of this are socks that are never on just right or extreme sensitivity to clothing tags, or not wanting to eat foods with certain textures. There may also be increased sensory-seeking behaviors (e.g., putting things in one's mouth, pushing against walls or tables, frequently changing position in chairs). Sensory processing issues can interfere with regulating attentional and heighten emotional and behavioral concerns. Occupational therapy can be helpful in reducing interference from social sensitivities.

Social Difficulties

Difficulties with attentional regulation, executive functions, and language processing can contribute to social communication difficulties. Children may miss social cues, have difficulty expressing their ideas, or do things that unintentionally alienate other children. For those living with Duchenne, social interactions can be further impacted by difficulties keeping up with the physical activities of other children.

Autism Spectrum Disorder (ASD)

When there are severe difficulties with social communication that interfere with initiating and maintaining peer relationships, the diagnosis of an autism spectrum disorder (ASD) is considered. Many symptoms and characteristics of autism may be present in Duchenne, but do not always warrant a diagnosis. Diagnostic criteria for ASD include social and communication challenges AND the additional cluster of restricted interests, repetitive behaviors, sensory issues and/or rigidity. All of these characteristics can occur in isolation or some combination, but may not meet the criteria of ASD. It is important to have an independent psychological/neuropsychological evaluation, conducted outside the school, to make this diagnosis. People living with ASD also often have associated difficulties with attentional regulation, executive functions, language processing, motor skills, learning, anxiety, and mood regulation.

Behaviors typically seen in ASD include:

- Poor nonverbal communication (reduced eye contact or facial expressions)
- Lack of social/emotional reciprocity
- Unusual language patterns (e.g., using scripted phrases or overly formal terms)
- Lack of spontaneous make-believe play or imitative play
- Inflexible adherence to specific, nonfunctional routines
- Excessive fixation on parts of objects

- Deficits in shared or joint attention (i.e., looking where someone else is looking)
- May prefer to be alone
- May not want cuddling or touching
- Repetitive play
- Inappropriate attachment to objects
- Insistence on sameness
- Enjoyment with spinning self or objects

Attention-Deficit / Hyperactivity Disorder (ADHD), Emotional Regulation, and Social Communication

People living with Duchenne are at increased risk for having an attention-deficit disorder. The formal name for this type of condition is Attention-Deficit / Hyperactivity Disorder (ADHD). The following symptoms may indicate the presence of ADHD:

Impulsivity

- Acts or says things without thinking
- Impatient or has difficulty waiting turn
- Interrupts/intrudes on others
- Talks excessively
- Acts too silly at inappropriate times

Hyperactivity

- Fidgets, can't sit still
- Often leaves seat
- Difficulty playing quietly, overly wound up

Inattention

- Does not seem to listen
- Avoids doing things that require sustained mental effort
- Loses or misplaces important things
- Forgetful, absent-minded
- Rushes through things, makes careless errors
- Doesn't complete work or turns things in incomplete
- Easily distracted, daydreams

Types of ADHD

- Predominantly Hyperactive-Impulsive Type
- Predominantly Inattentive Type
- Combined Type

It is important to note that because of muscle weakness and physical limitations, symptoms of hyperactivity may be less obvious in boys with Duchenne. Thus, impulsivity may be the most obvious feature of ADHD for these boys. They may also have reduced sensory tolerances (see **Sensory Processing Problems**).

All types of ADHD may include weaknesses in executive functioning. Thus, children with ADHD are more likely to have problems getting started on things, and have difficulty with planning, problem-solving, and time management. A comprehensive psychiatric or neuropsychological evaluation is recommended to diagnose ADHD in Duchenne. This is important to rule out other factors that may contribute to signs and symptoms of ADHD, including language or cognitive delays.

Interventions for ADHD

There are generally 3 components to treatment and intervention:

- **The use of medication is the most effective component for many.** Medications to treat ADHD often improve one's ability to regulate attention, or to remain focused on tasks that are perceived to be difficult or uninteresting. Stimulants are the most commonly prescribed medications, and many children with Duchenne respond well to treatment with the first stimulant medication, and up to 90% respond favorably when a consecutive medication is added. However, stimulant medications should be used with extreme care in any child with heart problems, which are common in older people living with Duchenne. Thus, the doctor should closely monitor the cardiac status of patients with Duchenne who are prescribed stimulant medications. Some patients may have a minor increase in heart rate and blood pressure when taking these medications, even if they have not yet developed heart problems. It is unknown what potential impact this could have on their heart over the long run. There are non-stimulant medications that are also approved for treatment of ADHD that may be a good option, but they may also increase heart rate in some children.
- **Another component of ADHD intervention consists of psychosocial strategies.** Behavior modification therapy may be helpful in mild to moderate cases of ADHD and is most effective when focused on parent training/consultation. This can also help improve compliance and reducing arguing and temper tantrums.
- **The third component of ADHD intervention usually involves modifying or adapting the child's environment** to reduce the impact that ADHD has on their daily activities. This includes things like increasing structure and oversight during activities, implementing compensatory strategies at school or home, developing supports for memory and organizational weaknesses, and implementing routines that can be followed consistently.

Social Interactions

Although many children with Duchenne have many positive social interactions, some struggle with the development of social and communication skills. Because strong peer relationships improve quality of life and can help provide emotional support, we strongly encourage parents and teachers to play an active role in facilitating this as much as possible.

Reasons for social interaction struggles

- Cognitive deficits previously mentioned in this guide (language problems, social judgment/perspective taking, intellectual disability, ADHD, etc.) causing social difficulties
- Psychosocial factors such as anxiety or depression
- The physical limitations and fatigue caused by Duchenne making it difficult for the child to keep up with others during play activities, sports, or games.

Interventions to improve social skills

Some may benefit from participation in a social skills training program. The goal of social skills training is to teach basic skills necessary for positive social interactions. This should be in a small-group format, and should emphasize modeling and practice of very specific skills: how to enter a group appropriately, how to respond to teasing, how to ask someone about their interests, etc.

Even if it is inconvenient, go out of your way to encourage and facilitate participation in opportunities for social interaction. Examples may include modified / adapted sports, special interest clubs, summer camps, youth groups/programs, art groups, equestrian and aqua therapies, use of service dogs, nature programs, appropriate internet/chat rooms, etc.

Educating peers in a developmentally appropriate manner will often make them more inclusive and protective of a child with Duchenne. Strategies for this can be discussed between teachers and parents, as well as school counselors if needed.

6. Working Together: Connecting School and Home

First of the Year Kickoff Meeting

It is critical that parents and teachers start the school year off on the same page. Setting up a **“Kickoff Meeting”** between parents, teachers, and school staff – including the school nurse – is important to ease the child’s transition into the school/classroom.

The Kickoff Meeting is the perfect time to form a collaborative team within the school to ensure that the child’s needs are met by a supportive group – not just one individual – throughout the year. At the Kickoff Meeting, parents should candidly and openly discuss any confidentiality concerns they may have, as well as classroom accommodations required. Other topics, such as what treatments or therapies their child is receiving (or clinical trials in which they are involved, that might cause students to miss school or not feel their best) in that may impact school attendance or performance, should be discussed.

This may or may not be the first time this teacher has had a student with Duchenne in their classroom. Parents should bring information and give guidance at a level of confidentiality that they are comfortable with.

Home – School Connection

Remember, it’s important for parents to **be as open about the topic of Duchenne as they comfortably can be** and for teachers to **approach parents when they have questions or concerns**. Collaborative relationships, where everyone feels comfortable sharing questions, concerns, or observations (and vice versa!) encourage everyone to work together to meet the child’s educational needs.



7. Five Things Every Teacher and Parent Should Know About Duchenne

1. People with Duchenne often experience learning problems.

Students with Duchenne often have age-appropriate cognitive abilities. Visual skills and creativity may be areas of strength. However, children with Duchenne are also at increased risk of learning difficulties. The risk can come from weaknesses in executive functions, including working memory, processing speed, shifting, inhibitory control, planning, and organization. There may also be weaknesses in language processing, including social communication and language-based academic skills (reading and writing). An independent psychoeducational or neuropsychological evaluation, together with parent/teacher discussions, will help everyone understand the student's current abilities and particular needs.

2. Classroom accommodations and adaptive equipment can help maximize your student's physical capabilities.

Specific needs will depend on the student's age and the progression of their symptoms, however here are some practical solutions for all ages:

- **Supportive seating:** a sturdy chair with arms to support upright posture and getting up successfully (similar to the needs of an elderly person) and positioned so that feet are flat (either on the floor or on a raised support).
- **Raised desktop and slant board:** the height of the desktop should accommodate the height of the supportive chair and a slant board, and helps to prevent crouching over the desktop.
- **Special larger pencil grips and scissors:** to help control writing and cutting.
- **Changing classes/moving throughout the school:** allow extra time between classes or assign a buddy to help carry heavy books and supplies.
- **Recess:** recess can be hard and isolating for students that have difficulty keeping up with their peers. Sensitive, creative solutions can help everyone feel like they are an important part of the social scene. For great recess ideas, see section 8.
- **Extra set of materials:** to minimize transport. There should be extra books in the classroom and at home so that they do not need to be carried. To the extent possible, all materials should be available online.

3. Everybody with Duchenne is different; every child will have many things in common with typical peers.

Like all students, some with Duchenne are quiet and reserved, some are outgoing and others misbehave. Also, like all students, they should be expected to follow school rules and procedures. It's important to hold them accountable for their actions. However, an overly rigid approach to discipline may not work, and may actually escalate negative behaviors. Keep in mind that what appears to be negative behavior may be the result of a cognitive or physical weakness or a response to frustration. A practical problem-solving approach likely will be more effective than a punitive intervention.

4. Many students with Duchenne experience emotional or behavioral problems.

Specifically, they may have difficulty controlling their response to frustration and may become easily angered, irritable, or aggressive. They may also be impulsive and act without thinking. **Medications** (steroids) may heighten these behaviors. Some children with Duchenne may experience feelings of depression, anxiety, and loneliness. In addition, many may have significant social problems (i.e., making and maintaining same-sex friendships, social maturity, etc.). Having a **"safe space"** where they can spend time alone settling down can be helpful. Teachers and parents can help by communicating with each other, and being supportive, understanding, and consistent with your words and actions to the student.

5. Confidentiality is of great concern for many parents of children with Duchenne muscular dystrophy.

Parents often struggle with what, when, and how much to tell their child about their diagnosis. **It is critical that teachers make no assumptions about what this child knows.** Parents and teachers should meet together before the first day of school to discuss the parents' wishes for confidentiality and/or the child's understanding of their medical condition.

8. For Parents

Establishing Independence at Home and in the Classroom

The goal of parenting children is to help them to become well adjusted, happy, productive adults. In order to achieve that goal, children need to feel independent and capable of contributing to the family from a very early age. While Duchenne makes that a little more challenging, there are creative ways to achieve this.

Below are recommendations from parents and medical providers for establishing and supporting lifelong independence in early childhood and childhood. Five key areas specific to Duchenne are recommended to be addressed: starting early, difficult conversations, parenting styles/coping, managing transition, and bodily appearance. Included are some suggestions (in quotes) for discussion with your child.

Stage One: Early Childhood / Childhood (0–10)	
Starting Early	<ul style="list-style-type: none"> • Taking some responsibility for medical care; learning appropriate health behaviors • Assess perception and knowledge of diagnosis • Continue teaching self-care and hygiene skills • Encourage hobbies, clubs, and leisure activities • Continue to encourage decision making skills • Teach consequences of choices and behaviors • Allow child to experiences consequences of good choices and bad • Start asking about the future (“What do you want to be when you grow up?”) • Importance of how your present yourself to the world (clothing, hygiene, social skills, etc.)
Difficult Conversations	<ul style="list-style-type: none"> • Parents — accept that this is difficult and you will most likely be nervous and uncomfortable at times — this is normal! • Embrace your child’s desire to be independent! • Allow friends in and your child to go out • Start discussions about the future (school, occupation, etc.) • Encourage medical providers to have discussions with your child (directing discussion toward your child, role model for child how to manage the visit/discussions) • Begin discussions of transition • Begin dealing with gradual decreases in physical functioning • Managing anxiety related to medical needs/issues; avoiding despair, depression, anxiety • Maintaining emotional health during watershed moments • Discussions of friendships and relationships • Coping with physiology limiting career choices • Coping with career choices that may not be physically possible • Select appropriate educational/vocational goals
Patient Styles / Coping	<ul style="list-style-type: none"> • Start talking about independence, taking charge of your life • Peer acceptance of physical appearance/limitations • Coping with stigmatization (begin to identify your coping style and strategies for making decisions/being in control of your life) • Child starts to move to the front seat, parents start to move to the back seat!

Stage One: Early Childhood / Childhood (0–10)

Managing Transitions

Diagnosis

- Encourage open conversation with use of appropriate terms, conversation directed toward child and parent
- Child and parent specific resources

Steroids

- Early initiation of treatment options including timing, side effects, dosing regimen

Loss of Ambulation

- Early discussion to highlight the rationale for the interventions that we recommend
 - Bracing
 - Stretching

Respiratory Support

- Early discussion to identify signs of obstructive sleep apnea (OSA)

Emergencies

- Early discussion necessary around steroid use and anesthetics

Loss of Upper Limb Function

- Early discussion when boy becomes wheelchair dependent

Completion of education

- Start in early high school

Living Independently

- Discuss in high school

Bodily Appearance

- Gradual decreases in physical functioning, coping with body image and physical limitations
- There is always a need to check in with the child/youth/young adults to see how the body changes are impacting how they are feeling i.e.
 - Self esteem
 - Bullying/teasing
 - Depression
 - Anxiety
 - Isolation

Weight

- Educate: "Steroids increase appetite. It is important to be proactive. I want to discuss with the whole family about strategies to help minimize weight gain including food choices, portion sizes, and activity level."
- Offer dietitian/nutrition referral

Puberty (Voice change, facial hair, acne)

- Educate: "Steroids delay puberty. There is something that can be done about this if it bothers you when you are older."

Stage One: Early Childhood / Childhood (0–10)

Bodily Appearance

Height

- “Steroids make you grow slower and you will be shorter. This does not cause health issues however some people are uncomfortable with being short. The benefit of being shorter is that it is helpful with prolonging walking. ”
- “How do you feel about your height?”

Round Face

- Educate: “Most people that take steroids will have a round face.”

Getting Around / Movement (walking, falling, elevators, lifts)

- “How is school?”
- “What do you like doing at recess?”
- “Does your school have multiple floors? Where is your class?”
- “There are options that can be helpful, let us know when you are ready.”

9. For Teachers: Preschool, Pre-K, Kindergarten, Early Elementary

Duchenne in the Classroom

Setting up a Kick Off Meeting will help parents and teachers discuss the diagnosis, their observations about the child’s current level of functional ability, and possible accommodations that may need to be made during the course of the school year. All students with Duchenne will need an independent evaluation to determine eligibility for special-education services.

Classroom Challenges and Accommodations

During early childhood / childhood, students may have difficulty getting up from the floor, climbing steps, walking long distances or standing for extended periods of time. They may tire easily and get frustrated when they can't keep up with their peers. It is important to try to do everything possible to include the student in all classroom activities (including gym and recess).

- Involve your class in brainstorming and decision-making about how to include their friend with Duchenne in ALL activities.
- Ask the students for ideas on how to best involve everyone in a given classroom activity, field trip or recess. Consider it a lesson in life and problem-solving. As a result, your class will learn empathy and understanding — everybody wins.
- Friendship and inclusion are incredibly important. Programs to improve social awareness and skills maybe helpful to improve positive social interactions. Structured opportunities to interact with peers at school are often helpful, such as a teacher facilitating a school “lunch bunch” and organizing structured activities at recess to facilitate social skills and engagement with peers.

Getting up from a seated position

Ensure the student has access to the help needed to stand. Either give a hand or be sure there is something to grab onto for support, especially in the restroom. This will be necessary both in the classroom and on field trips. Because children are sometimes embarrassed to bring up subjects like this, please keep it in the back of your mind, but be sensitive and never make a big deal of it.

Getting up off the floor

Please conduct as few activities as possible on the floor. It is very difficult for a student with Duchenne to stand up from a seated position on the floor. They should be in a chair with arms and positioned so that their feet are flat. However, if you do hold sessions on the floor, it's important not to isolate the one student seated in a chair. Consider restructuring the lesson so a few people, or everyone, sits in a chair if possible.

Picking up objects off the floor, tying shoes, etc.

Remember that it's easy for your student to lose his balance. Often it seems like his legs will be pulled right out from under him when he falls. Also, as your student grows older, the ability to bend over then return upright will become increasingly more difficult. Consider assigning a buddy that sits at a nearby desk to help out if needed. As previously mentioned, safety and fall prevention are incredibly important.

Walking long distances / standing for long periods of time

Do not let students with Duchenne walk long distances. Keep walking distances to a minimum, and allow extra time and rest stops as needed. This is something to think about when planning field trips that involve a lot of walking, or if the cafeteria is far from the classroom. If extra time is needed, you can make it an honor or reward to be assigned as the child's "buddy" and get to leave class a little early or come in a little late. A wheelchair or scooter may be helpful if long distances are part of the day or the activity.

Standing for extended periods of time is dangerous as well. In addition to muscle fatigue, students may start to lose their balance and feel their legs "give out." Make sure that a chair is available and make the chair part of the group. For example, if the choir is singing, bring everyone off the stage. If one student is sitting, maybe let two or three sit. Everyone wants to be part of the group.



Arms and fingers: carrying heavy books and writing

In Duchenne, the arms begin to lose strength as well. The arms may stay strong much longer than the legs, but carrying heavy objects or carrying lighter objects long distances may be difficult. If this is necessary, assign a "buddy" to help the student with their load. Having an additional set of textbooks for the student in the room may remove the need to cart books back and forth from school.

Pencil grips and scissors with large handles often give a student better control when writing and cutting. Find out what type works best for your student and keep a few in your desk. Teachers might consider offering the entire class pencil grips. When they see one student using it, other students may suddenly "need" that pencil grip, too! If this continues to be difficult, modifying writing assignments maybe needed. In addition, "angled clipboards" can be helpful when writing — make sure these are available.

Assistive technology may be helpful to the student. An assistive technology evaluation may be needed to assess the need for such devices. Computer technology that maximizes fine motor strength or uses voice command/dictation typing systems may be useful. In addition, an occupational therapist (OT) consultation may be helpful for suggestions about proper body positioning, seating, and both gross and fine motor function.

Stairs and Emergency Evacuation Plans

If possible, students with Duchenne should avoid stairs at all ages. Stairs increase the stress on muscles and cause muscle damage. If possible, all classes should be on the same floor. If there is an elevator, it should be available to the student. If your student is using the elevator, be sure to have a plan for fire drills and other situations requiring emergency evacuation. Specific school personnel should be assigned to the student for emergency situations. The local fire department should be made aware that there is a student with Duchenne who may need assistance in the event that evacuation is needed. Along with the fire department, a “safe room” should be designated in the event that the student is unable to be removed from the building.

Recess and P.E. (climbing, balances beam, jungle gym, etc.)

Muscle weakness will make it difficult for your student to balance and climb. Ask his parents, the school’s PT, P.E. teacher, and adaptive-P.E. teacher (if one is available) to meet with you to discuss what is possible and what is not, as well as to answer any questions. Since physical capabilities may change as the school year progresses, meeting every few months and inviting all involved parties may prove helpful.

If the student is unable to go outside during recess, or unable to keep up with their peers, create a rotating buddy system of students who are allowed to stay (in) with them. Make sure there are fun things to do so that this is a special time for everyone. Here are some ideas from parents’ experiences.

- Take cars / race track outside
- Start a “coloring club”
- Play in a sandbox, preferably using a chair or raised seat
- Toy soldiers / dinosaurs / figures
- Legos / blocks / Lincoln logs / marble runs
- Jenga or other interactive games
- Sidewalk chalk, preferably using a chair or raised seat
- Start a “drawing club”
- Adaptive swings
- Kickball with a designated runner

Snack time / cooking activities

Corticosteroid medications slow the progression of muscle weakness, but side effects usually include rapid weight gain. Please ensure, for all students, that snacks are nutritious. Check with your student’s parents to find out if there are additional dietary constraints.

Behavioral Issues

Children living with Duchenne are at increased risk for having significant problems with arguing, not following directions, temper tantrums, or refusing to do what they are asked. Their oppositional and argumentative behavior may be the result of problems with mental flexibility or inability to be adaptive in their thinking. For some children, learning early, with consistent reminders that inappropriate behavior has consequences, is incredibly effective in helping them recognize and reduce their problem behaviors. However, adopting an inconsistent and overly punitive discipline style (mostly focused on punishment) with children who have these types of cognitive weaknesses usually results in escalation of conflict, power struggles, and an increase in negative behaviors. Fatigue can contribute to behavior problems in Duchenne. Steroid medication can also contribute to temper tantrums and explosive behavior.

It is important to understand that behavior problems are not always the result of parenting style, however, most negative behaviors are made worse by inconsistently imposing limits and consequences on inappropriate behavior. Recommending behavioral therapies may assist parents in identifying certain situations that are likely to trigger negative behaviors, and assist in developing alternative strategies to try to correct them.

A behavior plan, agreed on by parents and teachers that goes between school and home, is important. This can help with the child's motivation and provide a sense of consistency between their two environments.

Have regular conversations about tolerance in the classroom.

Everyone has different needs. Some students need help reading, some need help writing, and some need help following the rules. Here are some recommendations for helping young students with Duchenne in the classroom:

- **Prioritize.** You can't change everything, so focus on 1 or 2 of the biggest concerns and go from there.
- **Develop and follow a routine as much as possible.** Review what is going to happen during the day. Give advance notice of transitions, or changes in routine or expectations.
- **Try to keep calm when a child is misbehaving.** Angry parents and teachers tend to escalate the situation.
- **Focus on the positive.** Strategies that only focus on punishment do not promote positive behaviors, increase motivation, or change attitudes. Rewarding/praising/encouraging good behavior is more effective in the long run. Look for opportunities to say "yes" instead of "no." ("Yes, you can have a cookie, after you...").

Strategies for Dealing with Oppositional, Explosive, and Aggressive Behavior

Tips for Managing Behaviors

- Ignore negative behaviors when the behavior is not aggressive or destructive.
- Praise positive behavior and create opportunities for positive interactions and success.
- Reward positive behavior.
- Break directions up into small manageable steps.
- Be specific and concrete when explaining expectations.
- Use time out for aggressive behaviors (that is, remove the child from any exciting activity and put in a time-out chair alone, until calm).
- Some teachers find reward charts helpful for children aged three and up.

Behavior Modification Plan

This type of strategy has elements that are similar to the preschool strategies listed above. Essentially, the goal is to decrease negative behaviors and increase positive behaviors through the use of rewards. This type of plan assumes that a child's negative behaviors result in some kind of gain (such as getting what he wants or avoiding responsibility), or are due to low motivation or a desire to gain control.

Step 1	Identify behaviors that should be reduced (e.g., angry outbursts), and/or behaviors that should be increased (e.g., time spent on homework). Prioritize and pick only one or two to start with.
Step 2	Examine when and where these behaviors do (or don't) occur to see if there are obvious triggers, circumstances, or surroundings that need to be changed.
Step 3	<p>Set goals for change:</p> <ul style="list-style-type: none">• Expectations for behavior should be very clear and highly specific (that is, don't just say, "You need to be a good student right now.")• Develop a reward system to implement when the child meets the expectations.<ul style="list-style-type: none">– The reward should immediately follow the behavior. Long-range rewards (such as earning a prize at the end of the school year) are too abstract and distant from daily behavior and are not effective. Also, if a child does not meet expectations at the beginning of the program and loses the chance to earn the reward, there is little reason for him to keep trying.– Always give praise, but other rewards will likely be necessary. Younger children may need things like candy (not too much!), stickers, pennies, tablet time, or whatever else will motivate them. Older children are more likely to respond to points or stars that can be traded in for bigger prizes.– Avoid strategies that focus only on punishment. This type of plan does not promote positive behavior, does not change attitudes, and emphasizes failure instead of success. One example of this is to start a child with a certain number of points or on a certain "behavior level". Points are then removed or his level is downgraded when he engages in negative behavior. This type of strategy will not be effective for most children who have behavior problems.– Do not give rewards before the expected behavior occurs (such as, "I'll give you your reward now, as long as you promise to not have a temper outburst later").– Involve the child in developing the goals, expectations and rewards.– Be realistic in the amount of change you anticipate. Set small goals initially so that everyone can experience some success. For example, if a child is having a temper outburst 10 times a day, it is unrealistic to expect that he can suddenly stop. A more realistic approach might be to identify one time period during the day (such after lunch, or when he gets home from school) that the behavior should not happen.– Consistency by the parent or teacher is very important.
Step 4	Evaluate progress in meeting goals and adjust plan as needed.

Collaborative Problem-Solving Strategy

The goal of this strategy is to promote problem-solving skills. It is particularly helpful for children who are chronically rigid and inflexible in their expectations, and/or when limit-setting or punishment routinely escalate temper meltdowns. It assumes that children want to do well and get along with others if they can. They start arguing or having a temper tantrum because they have weaknesses in skills (such as controlling their frustration, taking another's perspective, generating alternatives, being flexible in their thought process, expressive language, etc.) that make it difficult for them to resolve difficult or unexpected situations. This approach attempts to improve their deficient skills, thereby resulting in more ineffective problem-solving and less negative behavior. The process is highly flexible and tailored to each child and the family/teacher, but here is a general overview.

Step 1	Empathy and Reassurance <p>Identify and understand the child's concerns and point of view (such as completion of homework, attending an event, or engaging in an activity).</p> <ul style="list-style-type: none">• Validate how the child is feeling, and tell him his concerns are important. Ask questions to help clarify why the child is upset, but avoid "Why" questions ("Why are you so mad about this?") in favor of something more along the lines of, "tell me what about [insert situation] is making you most angry." Show you are listening by paraphrasing what he is saying. Don't argue or point out how he is wrong. The goal in Step 1 is to help him learn to express himself and to "feel heard", and can be a helpful "de-escalation" tool.• Validating underlying emotions also facilitates an opportunity to model feeling identification and labeling to the child, which supports developing more diverse language they can use to describe their internal experiences.
Step 2	Define the Problem <p>Identify and explain the adult's concerns on the same issue.</p> <ul style="list-style-type: none">• Use words the child will understand. Present the adult's perspective as one point of view, not the point of view.
Step 3	Invitation <p>Brainstorm possible solutions.</p> <ul style="list-style-type: none">• Emphasize that both perspectives are important (parent/teacher and child), and that the goal is to think of a solution that addresses both sides' concerns. You are a team that will work together to solve a problem, etc. Have the child think of at least one possible option/compromise. Make a list and discuss each one. Agree on the best one and try it out. See if it works, and adjust accordingly next time. Both the adult and child work together to think of possible solutions. The goal is to come up with a plan of action that is realistic and satisfactory for both the adult and child.

10. For Teachers and Parents

Tips for Interacting with Children, Classmates, and their Parents

It is likely that classmates and their parents will have questions about Duchenne. Although there is no right or wrong way to manage discussions, the experts suggest the following:

- Talk with the child with Duchenne about addressing questions and concerns from other students and their parents.
- When a child asks questions about Duchenne, answer as honestly as you can, in terms that will be easy for them to understand.
- Remember that this child is an individual, made up of more than just a Duchenne diagnosis. Encourage others to see this also.
- Put heavy emphasis on activities and hobbies that the child can do and encourage them to do the things they want to do. Children with Duchenne, and their parents and teachers, often find creative and alternate ways to participate in activities they're interested in.
- Treat this child the same as you would, or do, other children, by providing love, support, discipline, responsibility, and love (it bears mentioning twice).
- Encourage an appropriate level of independence and try to be safe, but not overly protective.
- Create an open forum for discussions within the family and the classroom, so no one is afraid to ask questions or talk about what's on their mind.
- Rely on friends, family, aides, assistants, and your support system. That's what they're there for and they want to help. Realize that you are not in this alone.

More resources for explaining about Duchenne to early elementary school age children can be found here: parentprojectmd.org/classroom.

How to Talk About Duchenne

An easy, non-threatening way to visualize Duchenne to others is through Brain Pop's short, animated video about Duchenne that you can find on YouTube as well as a PPMD Fast Draw video describing Duchenne to young audiences. It's developed specifically to help foster a young child's understanding of Duchenne, but could be a helpful way to start a conversation with adults, too. You can find this short video at parentprojectmd.org/classroom.



In addition, PPMD has designed presentations and activities to serve as templates for interactive classroom presentations to help classmates better understand Duchenne. For these and other classroom resources, visit the PPMD classroom resource page parentprojectmd.org/classroom.

Research shows that peers are less likely to tease and more likely to defend their classmate when they are armed with accurate knowledge. Parent Project Muscular Dystrophy has compiled recommendations below to help everyone better communicate about Duchenne.

Negative adjectives and phrases to avoid	Positive adjectives and phrases to use
Suffers from	Diagnosed with / Living with
Terrible, debilitating disease	Progressive muscle disorder
Afflicted with	Affected by
Wheelchair bound / Confined to a wheelchair	Needs the assistance of a wheelchair
Disease (viral)	Disorder (genetic) / Condition
Fatal, terminal	Genetic
Crippling or crippled	Progressive muscle disorder

Ways to Raise Awareness

PPMD offers several programs that your school can host to raise awareness and educate the student body about Duchenne:

- Race to End Duchenne .1K (about the length of a football field) is a race anyone can do! PPMD provides everything you need to host in virtually any space, with any crowd of participants.
 - If your school is interested in hosting a .1K, visit join.parentprojectmd.org/racepoint1k
- Read-A-Thon is a fun, easy, and educational way to engage with classmates. Participants can pledge the number of pages or books they read and raise awareness and funds for Duchenne at the same time.
 - If you are interested in hosting an event, please email events@parentprojectmd.org

11. Education Rights for Students with Special Healthcare Needs

Schools are required to locate, identify, and support all children with disabilities. Dependent on the level of disability assessed by the school system, these services are provided for under either a 504 Plan (refers to section 504 of the Civil Rights - Rehabilitation Act of 1973) or an Individualized Educational Plan - IEP (refers to the IDEA, Individuals with Disabilities Education Act passed in 1973 that provides the foundation for special education in public schools).

Why Would My Child Need an IEP or 504?

Every child is guaranteed access to education. **504 plans** remove barriers that impact participating in a general education classroom by providing accommodations for a student. **Individual Education Plans (IEPs)** make fair and appropriate education (FAPE) in the least restrictive environment available to students that need resources and services that make that possible. The decision of which is best for your child depends on the needs of the student. As Duchenne progresses, the student's needs will change. Even though one seems best this year, re-evaluations every year are necessary to make sure that the chosen plan is still the best for the student.

Section 504

A 504 Plan prevents discrimination of persons with disabilities, ensuring that they will have access to the learning environments at

school. To qualify for a 504 Plan, a child must have a disability that interferes with the ability to learn in a general education classroom. The 504 Plan includes specific accommodations or supports for the child. The 504 Plan is reviewed each year.

Individual Education Plan (IEP)

IEPs were established through the passage of the Individuals with Disabilities Act or IDEA (<https://u.org/2yZAJB8>) The Purpose of the Law is to “ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.” While the law does not mandate that every student with Duchenne be eligible for special education, the law mandates that an evaluation must be done, using a variety of assessment tools, to accurately demonstrate the child’s specific areas of educational need. Following the assessment, a multidisciplinary team (parents, teachers, other people familiar with the child) will gather to assess whether the child qualifies for special education services. If the child is eligible, the group develops an Individual Education Program (IEP). <https://u.org/2yZAJB8>

An IEP is the guiding blueprint that delivers your child’s education program. In addition to accommodations, it may include services that are provided to your child. To qualify for an IEP, the child must have one of 13 specific disabilities (these are listed here: <https://u.org/2XGmGuM>) and that disability must affect the child’s educational performance and/or the ability to learn in a general education curriculum (thus the need for specialized instruction). The IEP will be reviewed each year in order to ensure that the changing needs of your child are met; the student is formally evaluated every 3 years to see if the IEP is still needed.

Most children with Duchenne who qualify for an IEP, qualify under the code:

- Orthopedic Impairment (OI) or
- Other Health Impaired (OHI)

STEPS TO THE IEP

The IEP process can be incredibly intimidating for parents who are new to this process. Following the steps below should help to smooth the way through this process.

- Engage with your child’s school team (in-service, meeting, etc.)
- Request is made that child be evaluated (by you, by teacher, by PT)
- Child is evaluated by multi-disciplinary team
- A “team meeting” is scheduled to review the evaluation results and to determine eligibility for services:
 - You can ask for a copy of the evaluations prior to the meeting
 - You are a member of the team; you can invite others to join you
 - Request a draft prior to the meeting
 - Come prepared with questions, concerns, ideas, and proposed goals
- If your child is found eligible for special education services, then an IEP will be written. The IEP will include:
 - A diagnosis
 - Goals or targets for learning or behavior
 - Services necessary to meet the goals
 - Accommodations that may be needed so your child can consistently access the academic environment
- You can ask for clarification and revision
- Progress measured operationally, through measurable goals (agreed upon by the team)
- IEP reviewed (at least annually)

Comparing 504 and IEP

Understanding both of these plans, and the differences between them, can be challenging. The table below should help.

504	Individual Education Plan (IEP)
A plan to achieve access to learning at school	A plan for special education services at school
Goal: remove barriers to access	Goal: fair and appropriate education in the least restrictive environment
No standard plan format or review team	Strict requirements regarding elements of plan and who may participate in IEP development
Generally, includes: <ul style="list-style-type: none"> • Specific accommodations or supports 	Generally, includes: <ul style="list-style-type: none"> • Annual measurable educational goals • Services with duration/start dates • “Present level” statement • Accommodations to school/learning environment • Modifications to academic program • Plan for standardized testing • Plan for inclusion in general education program
Parents should be notified of “significant changes,” notification does not have to be in writing	Requests for changes must be in writing
Usually reviewed annually	IEP is reviewed annually; student must be re-evaluated for service eligibility every 3 years

For more information on IDEA, 504, or IEPs, please note the suggestions in the Reference section.

For more information on Education Rights, visit this site: parentprojectmd.org/education-rights.

Sample Scenarios & Responses

This section contains difficult information for parents and teachers to read. So, take a deep breath and remember that the more prepared you both are, the more you can help your student have a wonderful school experience. Keep in mind one of the best things you can do is to work together.

You may encounter one or more of the following scenarios at your school. The corresponding responses are suggestions designed to help newly diagnosed families wrap their head around difficult situations and for teachers to understand possible situations and solutions.

The scenarios are about “sons,” even though we know that girls manifesting the symptoms of Duchenne experience many of the same scenarios.

1. Scenario: The teacher says, “Your son has started falling down frequently, and seems to be weaker and more tired at the end of the day. What should I do?”

Response: “Thanks for bringing this to my attention. My child’s diagnosis causes muscle weakness. It will get tougher to stand and move around independently. Where is he falling? How often? If he’s falling during daily activities, please ensure he remains seated and do activities at his desk as much as possible. If it’s during class changes in the hallways, please allow him extra time

to get from place to place. If the distance is too great, I may need to get a scooter or wheelchair to help his muscles to not get so tired. Also, is it possible to allow him extra time (maybe he could leave early — 3 extra minutes with a “buddy”), so he could come into the next room with the whole class? Let’s meet to further discuss classroom strategies to lessen his falling.”

2. **Scenario: The teacher says to you, “Your child’s behavior has been frustrating me. He’s stubborn, strong-willed, is compulsive about many things and has a hard time staying on the same schedule as the rest of his class.”**

Response: “Thanks for bringing this to my attention. Children with Duchenne can have behavioral or social problems as a result of cognitive weakness tied to their diagnosis. They may have problems being flexible in their thinking, and, as a result, may get stuck on an idea, appear oppositional, or have difficulties with transitions. They may have difficulty interpreting another’s perspective or reading body language. Can we meet soon so that we can discuss your concerns and help find ways for you to address them in class?”

3. **Scenario: The teacher points out that your child has a waddling gait and accidentally bumps into people at school, many of whom get frustrated because they don’t understand this is due to Duchenne muscle weakness. He often gets flustered and doesn’t know how to respond.**

Response: “My child walks this way because his muscles are weak. Children with Duchenne may walk with a wide stance and with arms stretched out because their body is naturally seeking added stability. My child is not always focused on who else is around, but is focused on trying to stay upright. Additionally, due to cognitive weakness tied to Duchenne, he may not interpret others’ frustration or realize he is supposed to say ‘I’m sorry’ if he bumps into them. Please continue to talk to me about what you observe, and let’s continue to meet about ways we can address it.”

4. **Scenario: The class is taking a field trip.**

Response: Ask the teacher, “Will any accommodations be necessary for my child to fully participate in the field trip?” For instance, even if your child doesn’t need the assistance of a wheelchair, he/she should not walk long distances on a field trip. If your child is in a wheelchair, confirm with the teacher that the field trip location and transportation are wheelchair-accessible.

5. **Scenario: A classmate calls your child ‘clumsy’ and makes fun of him for falling down so much.**

Response: “I’d like to have the opportunity to speak with the class and explain my child’s muscle weakness.” (If you don’t feel comfortable doing this, consider asking a family member or a close friend who understands the diagnosis to volunteer.) At a level you are comfortable, explain to the class that your child has weak muscles. He/she may need help standing up, walking, or picking up his pencil, for instance. By engaging the class, you raise their awareness and make them advocates, so to speak. Especially with younger students, we suggest using phrases like “Being different is okay” and “I need your help with this.” Another easy and effective way to raise the topic of Duchenne to young students is through BrainPOP’s short animated movie about Duchenne. It’s specifically written and designed to help foster a young child’s understanding of Duchenne. For more information on this video, as well as other classroom resources, visit parentprojectmd.org/classroom.

6. **Scenario: The P.E. teacher is questioning the student’s participation in P.E. class and recess.**

Response: “Due to my son’s weakening muscles, he will not be able to participate during all P.E. and recess activities. Let’s meet to find other ways he can actively participate, such as games that don’t require physical strength.” In some states, schools require adaptive-P.E. teachers so that all children can be accommodated in P.E. class. Recommendations for adapted or adaptive P.E. can be found in section 7 of this booklet.

7. **Scenario: The teacher asks, “Does your son have any learning disabilities due to Duchenne?”**

Response: “Every child with Duchenne is different. However, there are behaviors and learning issues often found in children diagnosed with Duchenne. Please keep me informed if you notice these behaviors in my child.”

Additional Helpful links providing resources for Student Rights, IDEA, IEPs and 504s can be found here: parentprojectmd.org/primary-resources.

12. Adapted or Adaptive Physical Education (P.E.)

As mentioned above, children in this stage of Duchenne will typically have movements that are slower and more labored than their peers. Standing from a seated position, especially if seated on the floor, will become increasingly difficult. Even a young child with Duchenne will find physical education challenging.

General Rules to Remember

Some general things to remember include:

- **Running and jumping are not usually possible.** The goals of P.E. are a feeling of success and inclusion, rather than improving stamina or skills.
- **Don't allow the child to exert themselves to the point of exhaustion.** Focus on keeping muscles active, to maintain flexibility.
- **Strength-building exercises can further damage weak muscles** and should be discouraged for a student with Duchenne.
- **Make sure muscles are stretched regularly.** As muscles weaken, exertion can lead to tightening of muscles and shortening of tendons, resulting ultimately in further loss of mobility. Work out a set of stretching exercises. Consider making an illustrated 'Goal Book' that will allow student to work through a set of stretches throughout the school year.
- **Avoid stairs.** It is unsafe and puts stress on the muscles. Use an elevator or a ramp instead. Better yet, choose activities that don't require students to change floors.
- **Getting up from the floor, or any seated position, is very hard** for a student with Duchenne. Have a chair or other raised seat available for use. Other students can be made responsible for making sure the seat is there when needed.
- **Please do not let your student with Duchenne walk long distances.** If extra time is needed, make it an honor or reward to be assigned as the child's 'buddy' and get to leave class a little early or come in a little late.

Since the student with Duchenne will likely be slower than his classmates, one way to make sure he's not being left behind is to assign them to be a line leader, allowing them to set the pace, or conversely, a caboose (one which must stay attached to the line).

In some cases, it might be a valuable learning experience for your other students to experience some of the challenges faced by the student with Duchenne. Suggestions on PPMD's Classroom Resources page gives suggestions for educating your classroom about Duchenne (parentprojectmd.org/classroom). Examples of Adaptive Physical Activities, and other resources, can be found here: parentprojectmd.org/primary-resources.

Suggested Activities

- Swimming is a terrific activity for the student with Duchenne; not having to fight against gravity allows your student to use more strength to propel themselves. It improves pulmonary ability and it's also a great opportunity to horse around with friends without having to worry about losing their balance.
- In earlier stages, a kick scooter or even a tricycle can be an effective way for your student to keep pace with classmates.
- A smaller field of play, a designated runner — these are adaptations that can make a big difference in the strain placed on your student with Duchenne. Baseball, soccer, kickball, etc., can all be modified to greatly reduce the distances traveled, allowing your student to compete more meaningfully.
- At each stage, try to partner your student with a rotating cast of 'buddies' to assist and keep an eye out. Many students will take to this naturally (be sure that no single student is the buddy all the time; distribute the responsibilities).

- Breaking the class into smaller teams or groups with changing membership will enable every student to have the opportunity to take part in modified and unmodified activities.
- Scooter boarding is very popular with kids. Other students can take turns pushing the student with Duchenne. Because the student's legs are weak, great care should be taken not to topple over or to be too aggressive when pushing. If your scooter boards attach, use two of them, so that the student has a place to rest his legs.
- Even after your student has reached the wheelchair stage, they should still to be able to participate. Wheelchair soccer is a terrific sport. A cage or open box may be attached to his wheelchair to capture and direct the ball. A hockey stick attached to the wheelchair can also keep your student involved and active.
- The student with Duchenne can also act as 'helper' in a variety of activities, such as freeze tag, where they can be the 'unfreezer.' Keeping score, refereeing, serving as announcer, and other non-physical roles are other ways for the student to participate. Make sure that ground rules for his authority are in place if this student is a referee. And be sure that the student feels included, not isolated, in their role, whatever it may be.

Suggested Equipment Alternatives

As long as the student with Duchenne is able to take part in modified versions of P.E. activities, alternate forms of equipment will make his involvement much more fulfilling. You can certainly come up with more ideas, but here are some that have proven to work well in the classroom. Again, be sure to encourage ideas from all of the students. You never know what they may come up with, and it invests in them the idea of responsibility to their classroom community.

- Instead of baseballs and softballs, try a whiffle ball, which is lighter, slower, and easier to spot. For volleyball, soccer, or any game that requires a larger ball, a beach ball is light, easy to throw and kick, and won't hurt if the catch is fumbled.
- In place of regular bats, whiffle ball bats, made of light plastic, may be used, as can foam bats. Foam noodles, cut down, make swinging much easier as well.
- Bowling ramps can be used, both for bowling and for pitching a kickball; these are incredibly easy to use, and are simply adjusted for aim.
- A Frisbee® can be used in place of a ball for alternate versions of soccer, baseball, bowling, golf, etc. A wide variety of sizes and weights are available; some are even made of cloth or foam.
- A ball attached to a rope that has been looped around a line stretched across an open space is an excellent adaptation for throwing and catching games. The ball travels more directly to the student, and he can throw or hit it back with more accuracy and without having to fight gravity as much.
- Using a batting tee, or suspending an object to be struck, will help the student by allowing him to take his time and really set up his swing.
- EZ Rope™ is a way to jump rope without having to actually jump in time with the swinging motion. It's simply a jump rope with the middle cut out, so that the child can swing it and jump at his own pace, or just swing it and not jump at all. His heart rate and breathing will still increase, without having to put strain on his muscles.

13. Physical Therapy (PT)

Physical therapy (PT) will be an important part of life from the time of the Duchenne diagnosis. If the student has PT provided at school, it is critical that the school, medical PT, and parents work together so that the same stretches and interventions are used by everyone. While stretching should be provided at least daily, the student should have physical therapy evaluations every 4–6 months. This way, any and all changes can be tracked overtime and needs can be addressed.

Physical therapists play an important role in:

- Minimizing contractures by introducing regular stretching into your daily routine
- Maintaining function and adapting to any loss of function
- Monitoring function over time through standard tests and measures
- Assessing for and managing compromised skin integrity
- Preventing and managing pain
- Prescribing exercise and supervising safe physical activity (i.e. aerobic exercise)
- Recommending mobility devices, adaptive seating, and other equipment
- Rehabilitation after injury or fracture

Some typical stretching exercises of particular importance to a student with Duchenne include stretching the foot and ankle (the Achilles tendon), the knees (hamstrings), and hips (IT bands). Work with the student's PT to make sure that the stretches are appropriate for this child. Further information on the specific needs of students with Duchenne can be found here at this site: parentprojectmd.org/physical-therapy.

14. Duchenne and Emergency Care

It is unlikely that a medical emergency will occur at school, but it does happen. If this does occur, and your student needs to be transported by ambulance to an Emergency Department, there are several things that is it helpful for the school to know:

- Every child with Duchenne should have medical ID and an emergency card, giving first responders information they need.
- If a student has a wheelchair, they should have a wheelchair emergency card parentprojectmd.org/support-materials.
- If there is an emergency, know where this student's parents would like their child seen for medical care.
- In the case of a medical emergency, call the parents immediately; parents will call their neuromuscular center / providers.
- Most children with Duchenne take steroids either daily or intermittently. Those taking steroids daily should not be without this medication for more than 24 hours. If a student with Duchenne is vomiting, please let the parent know when this started so that parents can monitor the need for supplemental steroid doses.



- Fat Embolism Syndrome is a particularly dangerous phenomena that can occur with fractures. If you suspect that your student may have fractured a bone, please let first responders know that this is a risk and to watch for:
 - Changes in consciousness (confusion, headache, seizures, not acting like themselves)
 - Fast breathing (tachypnea), shortness of breath, or difficulty breathing
 - Rash under the arms or on the chest
- There are specific anesthesia risks with Duchenne. Inhaled anesthesia is particularly dangerous. Let first responders know NOT to give inhaled anesthesia before calling the student's neuromuscular specialist.
- Giving oxygen to students who have Duchenne without monitoring the CO2 level can be dangerous. First responders should be aware.

Emergency Care Guidelines can be found at parentprojectmd.org/emergency.

15. Summary

Duchenne is a complex diagnosis, but not one that should prevent learning and inclusion in a learning environment. This booklet is, by no means, the final word on any of the information included. We have included references below that will provide much more depth to any of the topics that we have discussed.

By working together, parents and teachers can modify learning and the learning environment, if necessary, to help the student get the most out of their school and peers, both in and outside of school. Again, we wish for everyone a happy and productive learning year!



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Things To Know About Me

Name	
Date of Birth	
Parents' Names and Phone Numbers	
Medications	
Allergies	
Assistive Devices	
Things I Like	
Things That Upset Me	
Best Ways to Help Me Calm Down	
Other Things That Are Important to Know	

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