

Parent Project Muscular Dystrophy

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END DUCHENNE.



3

Education Matters for Parents and Teachers
Late Adolescence and Adulthood

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Late Adolescence and Adulthood

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A note to parents and teachers

If you are reading this guide, it is because you 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 and teens living with Duchenne, while others can vary from child to child.

Children and teens 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 students, parents, and teachers with the goal of optimizing the student experience in a learning environment. Written by Parent Project Muscular Dystrophy (PPMD), Education Matters offers practical information on Duchenne as it relates to a student's educational experience and specific advice on achieving success in the late high school and college classroom.

Prior to school starting, please share this guide with school administration, teachers/professors, and support personnel. Sharing this information will help initiate and facilitate conversation between the school and home life, making sure everyone is following the same path and planning for the future.

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, independent living, and many other topics. Resources for Secondary Education can be found here: parentprojectmd.org/secondary-resources. Resources for College can be found here: parentprojectmd.org/college-resources.

2. Late Adolescence and Adulthood

With advances in medical care, there is an expanding population of people living with Duchenne well into adulthood. The desire of adults living with Duchenne is the same as adults everywhere – to follow their dreams and to seek their future. The development of a transition plan will allow students, parents, and teachers to assist the student in meeting their life goals.

Transition

Successful transition to adult life requires careful and ongoing planning. By age 15, a formal plan of transition that outlines how the adolescent student will enter adulthood should be in place. This plan should include such topics as future career goals and aspirations, the importance of personal relationships, the rewards of contributing to society, as well as the need to form and pursue a set of personal goals. As these concepts become more tangible, their realization requires planning and support just as for students without disabilities. Health care providers and educators are among the best facilitators for discussions about health, education, employment, social development, and adult living. Students with Duchenne should be an active participant in these discussions, along with their family, school, and medical teams. These discussions should keep in mind the student's physical, cognitive, and learning abilities.

Every person with Duchenne should expect to be a productive member of society. Developing a formal plan, with each step outlined, will make this possible. PPMD and the Centers for Disease Control and Prevention (CDC) published A Transition Toolkit for Duchenne Muscular Dystrophy that can be used for transition planning. This supplement article, published in *Pediatrics* can be found here: parentprojectmd.org/transition.

Key Factors for this transition planning should involve the following:

- What does education/job skills training look like after high school?
- What does the living situation look like for this individual-live at home, at college, with a roommate?
- What are the options for transportation to meet the student's needs?
- What types of personal assistance is needed for this living situation to work?
- What types of personal assistance is needed for employment?
- How will they advocate for themselves and actively participate in their health care?
- What community resources are available to help?

Additional information and resources to help with transition can be found here: parentprojectmd.org/transition.

Education and Employment Planning

Older adolescents should be encouraged to identify their interests, talents, and the ways they would like to contribute to their community, with the expectation of a transition to successful adulthood. Involvement in scouting, adaptive sports, volunteer opportunities within school and the community, and involvement in other organizations can cultivate leadership skills, provide work experience, and foster a sense of purpose. The Duchenne Transition Toolkit includes a Transition Checklist that may be helpful (parentprojectmd.org/transition-checklist). This checklist includes questions that students can answer, such as what they wish to accomplish and what supports they might need to accomplish their educational and vocational goals.

Typically, during adolescence, a student's world expands and opportunities for growth begin to emerge. However, due to the progressive nature of the Duchenne, teens and adults with Duchenne live in a world that begins to shrink. Career choices will need to be tailored to current and projected physical abilities. Navigating poorly designed or inaccessible buildings and environments can hinder participation in social events and the community. The educational setting is the ideal environment for students with Duchenne to learn to use mobility supports and assistive technology (AT), which can help them overcome physical barriers and expand their access to the world. In addition, this is a perfect stage to begin to explore the student's unique interests and abilities. For example, if a student enjoys being on their tablet frequently, maybe joining a technology club that would teach coding and programming would be of interest; if they enjoy playing video games, maybe look for a gaming club. Being creative will generate both interest and skills!

Students with Duchenne should be encouraged to participate in educational planning meetings. As students move through high school, their annual educational plans should progressively involve occupational therapists, physical therapists, and AT professionals, who can recommend devices to support success in the academic and post-educational settings. The transition to adulthood should be discussed throughout high school. Schools should facilitate referrals to vocational rehabilitation centers for guidance and possible financial assistance if goals are work related.

Students who wish to pursue college should schedule a meeting with the college or university's disability services office to find what support services and accommodations are available. On most campuses, housing, parking, and medical services are all separate departments. It will be important that students contact each department separately. This will help to ensure that both the institution and the student are aware of the student's needs and how those will be best met.

Once campus departments have been contacted, and you are aware of the available resources, it will be important to contact outside agencies to fill in any gaps in care giving. Start early and be persistent – it's important to have everything organized so that there are no surprises when classes start.

Additional resources for students in secondary grades can be found at parentprojectmd.org/secondary-resources. College resources can be found here: parentprojectmd.org/college-resources.

3. 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 1 in 5,000 live male births. Approximately 20,000 children are born with Duchenne each year worldwide. 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*.

While not all people living with Duchenne have mental health issues, those diagnosed have an increased risk of delayed development, as well as possible 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.

4. Physical Findings in Duchenne

Late Adolescence and Adulthood (16+ years)

In late adolescence, most people with Duchenne are unable to walk and need to use a power wheelchair on a regular basis. They will need help or mechanical support with activities involving the legs or trunk. Fatigue (feeling tired) is quite common. Weakness in the arms can make activities of daily living more difficult. Many adolescents will begin to lose the use of their arms and fingers throughout this phase, so they will need assistance to write, eat, use a computer, and take care of their own daily needs (like brushing their hair and teeth).

Because people in this stage of diagnosis have weaker back muscles and are seated much of the day, scoliosis (too much curving the spine) may begin to develop. Scoliosis, as well as muscle cramps, may cause physical discomfort at times (parentprojectmd.org/bone). Schools and parents should discuss positioning and issues of physical discomfort/pain with physical therapists caring for / evaluating these students (parentprojectmd.org/pain).

Some exercises/therapies can actually physically damage muscle in Duchenne. The goal of therapy and movement/exercise in Duchenne is to maintain strength, function, and range of motion, rather than to improve any of these areas. Non-resistive exercises, like swimming, are helpful. The input of a school physical therapist (PT) and adapted/adaptive physical education is critical to the protection of muscle and the preservation of function.

THERAPIES

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

- Stretching
- Range of motion exercises
- Muscle cramp massage
- Safety training around the school or campus
- Hallway safety
- Accommodations for activities of daily living (toileting, lunchtime, etc.)
- Suggestions for adapted / adaptive Physical Education

Corticosteroids (“steroids”) are medications started in early childhood and taken lifelong to improve the symptoms of Duchenne and to help to delay the loss of strength and function. Steroids taken over time affect the bones, causing them to be fragile and easily broken, a condition termed “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 a student has broken a bone, Fat Embolism Syndrome (FES) is a concern. See Section 15 for more information on FES.

Occupational Therapy (OT) 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.)

Most colleges and universities offer to supply notes taken by other students. Investigate whether this is offered at your college and if it is offered for all classes or just a portion.

5. Learning and Academic Skills

Dystrophin is normally distributed unevenly throughout the brain such that some areas have more dystrophin than others. Some of the regions where there is typically more dystrophin are those important in learning.

Deeper Dive

Brain imaging (MRI) has shown a decrease in the grey matter volume (the part of the brain that is involved in muscle control, emotions, speech, sensory perception, and decision making) and altered microstructure of the white matter (responsibly for carrying nerve impulses between parts of the grey matter).

Within the last few years, research has focused on whether the lack of dystrophin within these specific regions of the gene can be associated with cognitive and learning difficulties. Dp71 and Dp140 are rare dystrophin isoforms important for cognition and learning that are missing in some genetic mutations that cause Duchenne. Recent studies have indicated that blood flow throughout the brain (“cerebral blood flow”) is decreased in patients missing Dp140. 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.

These, as well as other issues, are explained in more detail in Volume 1 of “Education Matters: Diagnosis and Early Childhood” and Volume 2 of “Education Matters: Late Childhood and Early Adolescence.”

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

The Wechsler scales (Wechsler Intelligence Scale for Children, WISC; Wechsler Adult Intelligence Scale, WAIS) 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 often 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. Below, we review some of the more common areas of concern for those who have Duchenne.

Weaknesses in Executive Functioning

Executive functions are a group of cognitive skills required important in 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. Example: remembering what was just said during a lecture or while reading a paragraph to answer a question about it, or remembering to follow multi-step instructions.
- **Cognitive flexibility:** being able to effectively shift your perspective or activity to a new perspective or activity. Example: Seeing that "A" may cause "B" or "C"; doing "A" and then shifting to "B" and then back to "A," depending on circumstances.
- **Inhibitory control:** being able to hold back behaviors or emotional responses. Example: not speaking out.
- **Organizing, planning:** developing a strategy, prioritizing, and managing time to complete a task.
- **Task initiation and perseverance:** self-motivating and self-starting, remaining engaged when tasks are challenging.
- **Self-monitoring:** evaluating self-behavior and whether it's appropriate for the situation, understanding how your behavior impacts others, error detection, awareness of feelings, and how feelings influence thinking. For example, making sure that you're not making careless mistakes, or annoying others, not blaming others for 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, students with executive functioning challenges can become so overwhelmed that they "shut down." This may occur as it is often easier for the person 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 discomfort and acting out. Students, parents, and teachers should work together to evaluate the problems and develop solutions that help support the student.

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 6.

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

Language-based learning disabilities impact a person's ability to easily acquire reading (dyslexia), math (dyscalculia), and writing (dysgraphia) skills. There is some work suggesting that these learning disabilities are more common in Duchenne. Evaluations are needed for formal diagnoses with learning disabilities, ideally at a young age so that appropriate services can be put into place. If you have been diagnosed and services are not in place, please see the section on Student's Rights and evaluations at the end of this booklet.

6. Emotional and Behavioral Issues in Duchenne

Trying to decide what behaviors are "normal" and which are "Duchenne" can be incredibly challenging. With all of the changes that happen in adolescent and young adult brains, it can be difficult to tell if behaviors are due to Duchenne or normal hormonal adolescent changes. Verbal aggression, while not pleasant, is normal adolescent behavior. Hormone changes and the desire for

more independence leads to lashing out with hurtful comments and frequent arguments. Adolescents also have low tolerance for managing frustration. While parents often bear the brunt of this, it extends to all areas of their lives. When they become frustrated, they often have difficulty controlling their impulses.

Explosive and Defiant Behavioral Challenges

If you ask parents what their biggest challenge is in parenting teens and young adults living with Duchenne, a significant number will tell you that dealing with behavioral challenges, including oppositional behaviors and explosive outbursts, is exhausting and defeating. Managing arguments that often escalate to outbursts and melt downs are, for many parents, their first and biggest concern.

Whenever there are behavioral challenges, it is important to identify underlying causes. For people living with Duchenne, there are a number of possible contributing factors:

- **Increased Awareness of Differences from Peers.** Adolescents with Duchenne tend to become more aware of their differences and limitations as they age. Although most adjust well to their condition over time, there may be times of emotional distress because of decreasing strength and abilities. Adolescence is a time of achieving independence. As they get older and require more personal assistance, young adults may resent needing help which may transcend into acting out behaviors.
- **Adjusting to the Loss of Physical Function.** Most adolescents and adults at this stage are using a wheelchair full time. While the loss of walking is significant, the loss of hand strength can impact all areas of life and lead to the need for extensive assistance. As muscle weakness progresses, they are at risk for becoming more isolated or socially withdrawn.
- **Medication Effects.** Corticosteroids (“steroids” such as prednisone or Deflazacort) are medications taken usually daily by people living with Duchenne. They are started at a young age and continued life-long. Physical limitations and disruption in physical development that may occur with prolonged use of steroids (delayed vertical growth, delayed puberty, weight gain) may make adolescence more problematic.
- **Learning Challenges or Weaknesses in Executive Functions.** As above, there may be higher rates of learning difficulties and weaknesses in executive functions in those with Duchenne. Difficulties in school, possibly together with challenges regulating attention or “seeing the big picture”, can contribute to increased emotional reactivity and the ability of the person to participate in developing a plan for their future.
- **Anxiety and Depression.** Parents and teachers should look for signs of chronic sadness, depression, or anxiety. For some adolescents, signs of emotional distress can manifest as irritability and/or oppositional behaviors (see below).

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

While most people living with Duchenne are not depressed or anxious, there is an increased chance of these psychosocial issues when compared to peers. Depression is different from normal feelings of sadness — it is more pervasive, longer lasting (weeks to months instead of a day here or there), and powerful (significantly interferes with daily activities, relationships, and goals). Adolescents may have difficulty describing their emotions or identifying the cause of their distress and, therefore, they may not always be able to identify how they are feeling or why. Here are some signs that people living with Duchenne may be experiencing depression and/or anxiety:

Signs of Depression:

- Loss of enjoyment or interest in things they would typically enjoy
- Physical symptoms (e.g. headaches, stomach aches)
- Irritability, moodiness, or aggression
- Less patience or lower frustration tolerance
- Overly sensitive or tearful
- Feelings of sadness and/or hopelessness

- Suicidal thoughts
- Poor concentration, memory, or decision making
- Changes in work habits or schoolwork
- Changes in appetite or energy level

Signs of Anxiety:

- Significantly worried or fearful
- Tense or uptight
- Jittery or trembling
- Problems separating from parents or other family members
- Experiencing chest pains, problem catching their breath, stomach aches, headache, or dizziness (though these may also be signs of a serious medical problem, so you should always notify a healthcare provider about any of these symptoms)
- Specific fears that interfere with daily activities (e.g., about leaving the house or going to doctor appointments)

There is an increased prevalence of obsessive-compulsive disorder (OCD) in teens and adults with Duchenne. In some cases, these behaviors may be due to sensory sensitivities or due to the inability to be mentally flexible or adaptive, but are not severe enough to qualify as an OCD diagnosis.

Signs of OCD:

- Intrusive or unwanted thoughts that cause significant distress (e.g., about getting sick, family members being harmed, etc.)
- Thoughts may be related to specific fears (e.g., germs, flying, death, etc.)
- Repetitive behaviors or routines that reduce the sense of anxiety (e.g., handwashing for fear of germs)
- Thoughts and behaviors cause significant distress and increase over time, although the specific content of the fears may change

Interventions for depression, anxiety, and OCD

Depression, anxiety, and OCD can be very serious conditions and should be treated by mental health professionals. Mild to moderate symptoms of depression and anxiety may respond well to psychotherapy, though more severe cases may also require psychiatric consultation and possibly medication.

Attention-Deficit / Hyperactivity Disorder (ADHD)

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 people with Duchenne. Thus, impulsivity may be the most obvious feature of ADHD. They may also have reduced sensory tolerances (see **Sensory Processing Problems**).

All types of ADHD may include weaknesses in executive functioning. Thus, teens and adults 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 three 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 with Duchenne respond well to treatment with stimulant medication. However, stimulant medications should be used with extreme care in anyone 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 people.
- **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 melt downs.

- **The third component of ADHD intervention usually involves modifying or adapting the environment** to reduce the impact that ADHD has on 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 people 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 to keep up with peers.

Interventions to improve social skills

Fostering adolescent and adult social relationships is incredibly important. During college, it is important to get out of the dorm and into the social scene. Be sure to attend as many activities as possible, meet lots of new students and get involved! Welcome events, open houses (for the campus pool, rec center, clubs), and fairs (clubs, athletics, departments, etc.) can all be great ways to see what possibilities exist. Most colleges also have “activity passes” available, giving students free access to on campus games and activities.

When individuals with Duchenne complete school, they no longer have daily interaction with their peers. It’s even more important to get out and find social resources at this time. Connecting with others through gaming, social media, etc., can be very helpful to prevent social withdrawal and isolation. Be sure to investigate the multiple options that exist in the community as well. Connecting with the Duchenne community will create a peer group where they can share common struggles and goals.

Parents at this step must also evaluate several things in regards to their child with Duchenne:

- Am I helping my teen / adult be as independent as possible within his capabilities?
- Am I helping them to develop and maintain friendships, romantic relationships, and enjoy regular interactions with peers?
- Do I find ways for my teen/adult child to contribute to the household needs (if they are living at home)?
- Do I have a plan for my teen/adult child if something should happen to me?
- What legal and financial documents do I have in place?
- Have I discussed all of this with my child?
- Do I have a plan to accommodate for their changing needs?

Sensory Processing Disorder

Those with Duchenne are sometimes hypersensitive to environmental stimuli, including noise, textures (clothing and food), and light. One example might be not wanting to eat foods with certain textures. Sensory processing issues can interfere with attentional regulation and exacerbate emotional and behavioral concerns. Occupational therapy can be helpful in reducing interference from sensory sensitivities.

Autism Spectrum Disorder (ASD)

Autism, if present, should be diagnosed and continue to be managed by this stage.

7. Working Together: Connecting School and Home

First of the Year Kickoff Meeting

It is critical that parents, students, and teachers start the school year off on the same page. Setting up a “Kickoff Meeting” between parents, students, teachers, and school staff will help to ease the student’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 student’s needs are met by a supportive group – not just one individual – throughout the year.

At the Kickoff Meeting, parents and students 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 the student is receiving or clinical trials they are involved 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 and students 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.



8. 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, people with Duchenne are also at increased risk for learning difficulties. This 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:** most students at this stage will use a motorized wheelchair for mobility. All of the student's classrooms will need a table sized appropriately to accommodate their wheelchair, as well as a room arrangement that allows for student movement.
- **Assistive devices for note taking / test taking:** writing may not be possible, students may need an aid to take notes for them or may record lectures to hear later. If writing is not possible, speech to type technology will be helpful.
- **Schedules and assignments:** be sure to develop a system of reminders for schedules and assignments. Several apps exist that can help with alerts to keep students organized.
- **Changing classes / moving throughout the school:** maneuvering a power wheelchair in a crowded hallway is nearly impossible. Allow extra time between classes or assign a friend/buddy to help carry heavy books and supplies.
- **Lunch / free time:** lunch and free time can be isolating for some students. Sensitive, creative solutions can help everyone feel like they are an important part of the social scene.

3. Everybody with Duchenne is different; every student will have traits in common with their non-Duchenne peers.

Similar to their classmates some students with Duchenne are quiet and reserved, some are outgoing, and others may act out or misbehave. In addition, students with Duchenne 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 in fact escalate negative behaviors. It is important to know that what appears to be negative behavior, may actually 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. Students with Duchenne may also be impulsive and act or speak without thinking. Medications (corticosteroids which are taken by most people living with Duchenne) may exacerbate these behaviors. Some students with Duchenne may experience feelings of depression, anxiety and loneliness. In addition, many will have significant social problems (i.e., making and maintaining same-sex friendships, social maturity, etc.). Teachers and parents can help by communicating with each other, and being supportive and understanding to provide consistent responses and interventions to the student.

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

Parents, students and teachers should meet together before the first day of school to discuss the parent's wishes for confidentiality, the student's understanding of their medical condition and their willingness to share with their peers.

9. For Parents

Establishing Independence at Home and in the Classroom

Parents will be the driving force to help their adolescent children become well adjusted, happy, and 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 these goals.

Below are recommendations from parents and medical providers for establishing and supporting lifelong independence in childhood and adolescence. Five key areas specific to Duchenne are recommended to be addressed: starting early, difficult conversations, parenting styles/coping, managing transition, and bodily appearance. The suggestions for each area start in Early Childhood and

carry over through Adulthood. Below are the suggestions for Late Adolescence through Adulthood. Included are some suggestions (in quotes) for discussion with your child.

	Stage One: Early Childhood / Childhood (0–10)	Stage Two: Late Childhood / Early Adolescence (11–17)	Stage Three: Late Adolescence / Adulthood (16+)
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.) 	<ul style="list-style-type: none"> • Increasing responsibility for medical care; begin transition to adult model of care; knowledge of diagnosis, medications, medical history, etc. • Assess perception and knowledge of diagnosis • Continue teaching self-care and health skills • Encourage diverse hobbies, clubs and leisure activities • Begin helping teen to keep records of medical history, medications, procedures, etc. • Teen spends part of medical visit alone with provider • Begin to explore health care coverage after 17 years; begin to look at SSI • Teen participate in IEP or 504 meetings • Explore possible career interests with your teen • Begin looking for an adult healthcare provider • Encourage your teen to contact campus services to request accommodations, if needed, if he/she will be attending college • Encourage your young adult to investigate services provided by the Department of Vocational Rehabilitation if he/she has not already done so • Importance of how your present yourself to the world (clothing, hygiene, social skills, etc.) 	<ul style="list-style-type: none"> • Primary responsibility for medical care; knowledge of diagnosis, medications, medical history, etc. Organize a plan to transition this responsibility • Act as a resource and support to your young adult in managing the diagnosis • Encourage diverse hobbies, clubs and leisure activities • Encourage your young adult to participate in support groups and/or relevant organizations • Finalize healthcare coverage • Finalize transfer of medical care to an adult provider • Continued contact with disabled student services as needed for accommodations • Investigate services provided by the Department of Vocational Rehabilitation if not already done so • Importance of how your present yourself to the world (clothing, hygiene, social skills, etc.)

	Stage One: Early Childhood / Childhood (0–10)	Stage Two: Late Childhood / Early Adolescence (11–17)	Stage Three: Late Adolescence / Adulthood (16+)
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 	<ul style="list-style-type: none"> • Parents — allow your children time and space away from you when they are guaranteed not to be interrupted but have the ability to call you if needed • Embrace and support your child's independence • Allow friends in and your child to go out • Continue discussions about the future • Encourage medical providers to have discussions with your child (directing discussion toward your child and spending time alone with providers; issues of confidentiality) • Begin discussions of transition and adult care • Managing anxiety related to medical needs / issues • Avoiding despair, depression, anxiety • Maintaining emotional health during critical transitions • Decisions about dating, relationships, sexuality, personal safety • Investigate social support for Duchenne issues • Lack of control over health outcomes • Select appropriate educational / vocational goals • Discuss possible stigmatization / discrimination in obtaining employment 	<ul style="list-style-type: none"> • Parents: allow your children time and space away from you when they are guaranteed not to be interrupted but have the ability to call you if needed • Balancing independence and interdependence with family and friends • Support activities, relationships and community involvement • Establish and/or maintain an occupation • Encourage your child to manage their medical visits alone with you along for support; respect confidentiality • Initiate and support transition and transfer to adult care • Managing anxiety related to medical needs / issues • Maintaining emotional/mental health; avoiding despair, depression, anxiety • Maintaining emotional health during watershed moments • Decisions about dating, relationships, sexuality, personal safety • Discussions around anxiety and depression associate with the diagnosis of Duchenne • Lack of control over health outcomes • Resolving possible loss of typical life achievements • Manage possible stigmatization / discrimination in obtaining employment

	Stage One: Early Childhood / Childhood (0–10)	Stage Two: Late Childhood / Early Adolescence (11–17)	Stage Three: Late Adolescence / Adulthood (16+)
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! 	<ul style="list-style-type: none"> • Practice independence, taking charge of your life • Decisions about dating • Increasing independence from family • Decisions about relationships / friendships / dating • Increasing independence from family • Integration of Duchenne into self; acceptance of being unique and different • Balancing independence with interdependence with family and friends • Talk with SW regarding adult plans, benefits, etc. • Parents / children need to find “the right balance” (independence, decision making) 	<ul style="list-style-type: none"> • Live as independently as possible; be in charge of your own life • Decisions regarding life partners and reproduction • Coping with loss of normative family life cycle • Finding a social groups / network • Investigate social support for Duchenne issues • Parents / children need to continue to define the balance of independence / decision making
Managing Transitions	<p>Diagnosis</p> <ul style="list-style-type: none"> • Encourage open conversation with use of appropriate terms, conversation directed toward child and parent • Child and parent specific resources <p>Steroids</p> <ul style="list-style-type: none"> • Early initiation of treatment options including timing, side effects, dosing regimen <p>Loss of Ambulation</p> <ul style="list-style-type: none"> • Early discussion to highlight the rational for the interventions that we recommend <ul style="list-style-type: none"> – Bracing – Stretching 	<p>Diagnosis</p> <ul style="list-style-type: none"> • Revisit diagnosis and associated medical conditions as child gets older to insure understanding • Child and parent specific resources <p>Steroids</p> <ul style="list-style-type: none"> • Continued discussion of steroid related issues <p>Loss of Ambulation</p> <ul style="list-style-type: none"> • Ongoing discussion, initiation of wheelchair <ul style="list-style-type: none"> – Parent sees as negative – Child may see as possible 	<p>Diagnosis</p> <ul style="list-style-type: none"> • Revisit diagnosis and associated medical conditions as child gets older to insure understanding • Age appropriate resources <p>Steroids</p> <ul style="list-style-type: none"> • Continued discussion of steroid related issues <p>Loss of Ambulation</p> <ul style="list-style-type: none"> • Ongoing discussions including discussion about loss of standing with urination

	Stage One: Early Childhood / Childhood (0–10)	Stage Two: Late Childhood / Early Adolescence (11–17)	Stage Three: Late Adolescence / Adulthood (16+)
Managing Transitions	<p>Respiratory Support</p> <ul style="list-style-type: none"> • Early discussion to identify signs of obstructive sleep apnea (OSA) <p>Emergencies</p> <ul style="list-style-type: none"> • Early discussion necessary around steroid use and anesthetics <p>Loss of Upper Limb Function</p> <ul style="list-style-type: none"> • Early discussion when boy becomes wheelchair dependent <p>Completion of education</p> <ul style="list-style-type: none"> • Start in early high school <p>Living Independently</p> <ul style="list-style-type: none"> • Discuss in high school 	<p>Respiratory Support</p> <ul style="list-style-type: none"> • Ongoing discussion about nighttime ventilation for ventilation needs, cough assist <p>Emergencies</p> <ul style="list-style-type: none"> • Anticipation of the unpredictable <ul style="list-style-type: none"> – Pneumonia – Fractures – Renal stones <p>Loss of Upper Limb Function</p> <ul style="list-style-type: none"> • Revisit discussion specifically focusing on writing, self-feeding <p>Completion of education</p> <ul style="list-style-type: none"> • Ongoing discussion in high school <ul style="list-style-type: none"> – Special focus on those not going to college <p>Living Independently</p> <ul style="list-style-type: none"> • Ongoing conversation post-graduation <p>Emergency Care</p> <ul style="list-style-type: none"> • Discussion begins in adolescence • Daytime ventilation should trigger more specific conversations 	<p>Respiratory Support</p> <ul style="list-style-type: none"> • Ongoing discussion about full-time ventilation <p>Emergencies</p> <ul style="list-style-type: none"> • Follow-up of post illness, revisit discussion <p>Loss of Upper Limb Function</p> <ul style="list-style-type: none"> • Ongoing follow-up of computer use <p>Completion of education</p> <ul style="list-style-type: none"> • Follow-up of decision making and support of plans <p>Living Independently</p> <ul style="list-style-type: none"> • Follow-up conversations to insure successful transitions or whether wishes changes <p>Emergency Care</p> <ul style="list-style-type: none"> • Ongoing discussion and support
Bodily Appearance	<ul style="list-style-type: none"> • Gradual decreases in physical functioning, coping with body image and physical limitations 	<ul style="list-style-type: none"> • Gradual decreases in physical functioning, coping with body image and physical limitations 	<ul style="list-style-type: none"> • Gradual decreases in physical functioning, coping with body image and physical limitations • Burden / complications of adult onset illnesses

	Stage One: Early Childhood / Childhood (0–10)	Stage Two: Late Childhood / Early Adolescence (11–17)	Stage Three: Late Adolescence / Adulthood (16+)
Bodily Appearance	<ul style="list-style-type: none"> • 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. <ul style="list-style-type: none"> – Self esteem – Bullying/teasing – Depression – Anxiety – Isolation <p>Weight</p> <ul style="list-style-type: none"> • 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, proportion sizes, and activity level.” • Offer dietitian/nutrition referral <p>Puberty (Voice change, facial hair, acne)</p> <ul style="list-style-type: none"> • Educate: “Steroids delay puberty. There is something that can be done about this if it bothers you when you are older.” <p>Height</p> <ul style="list-style-type: none"> • “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?” 	<ul style="list-style-type: none"> • 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. <ul style="list-style-type: none"> – Self esteem – Bullying/teasing – Depression – Anxiety – Isolation <p>Weight</p> <ul style="list-style-type: none"> • Continue same discussion. Celebrate success of weight maintenance. Add: “Increased weight makes it harder to move around and can make breathing difficult at night. What do you eat when you are with your friends or at school?” • Offer dietitian/nutrition referral <p>Puberty (Voice change, facial hair, acne, small penis)</p> <ul style="list-style-type: none"> • “Steroids delay puberty; there is something we can do about it. Some youth with Duchenne want to start going through puberty, others do not. Would you like to discuss your options?” • Offer referral to endocrinology. <p>Height</p> <ul style="list-style-type: none"> • “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?” 	<ul style="list-style-type: none"> • 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. <ul style="list-style-type: none"> – Self esteem – Bullying/teasing – Depression – Anxiety – Isolation <p>Weight</p> <ul style="list-style-type: none"> • Continue discussion. Celebrate success of weight maintenance. “What do you eat when you are with your friends or at school / work?” • Offer dietitian/nutrition referral. <p>Puberty (Voice change, facial hair, acne, penis size)</p> <ul style="list-style-type: none"> • “Steroids delay puberty; there is something we can do about it. Would you like to discuss your options?” Offer referral to endocrinology. <p>Height</p> <ul style="list-style-type: none"> • “Do you want to talk about your height? How does it make you feel?”

	Stage One: Early Childhood / Childhood (0–10)	Stage Two: Late Childhood / Early Adolescence (11–17)	Stage Three: Late Adolescence / Adulthood (16+)
Bodily Appearance	<p>Round Face</p> <ul style="list-style-type: none"> Educate: “Most people that take steroids will have a round face.” <p>Getting around / movement (walking, falling, elevators, lifts)</p> <ul style="list-style-type: none"> “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.” 	<p>Round Face</p> <ul style="list-style-type: none"> “Steroids cause a round face, is this something you would like to talk about?” <p>Getting around / movement (walking, falling, elevators, lifts)</p> <ul style="list-style-type: none"> “How is school?” What do you like to do in your free time? How are you getting around at school? How is your energy level? How is your energy at malls or with long distances? There are options that can be helpful, let us know when you are ready.” 	<p>Round Face</p> <ul style="list-style-type: none"> “Steroids cause a round face, is this something you would like to talk about?” <p>Getting around / movement (walking, falling, elevators, lifts)</p> <ul style="list-style-type: none"> “How is school?” What do you like to do in your free time? How are you getting around at school? How is your energy level? How is your energy at malls or with long distances? There are options that can be helpful, let us know when you are ready.”

Financial Planning

There are a variety of resources available for families to help organize financial planning for their children with Duchenne and other special needs. These include plans to help cover higher education and independent living.

ABLE Accounts and a Special Needs Trust (SNTs) are both accounts that allow for saving without jeopardizing federally funded benefits like Supplemental Security Income (SSI) and Medicaid. The regulations covering both are quite different. Families may wish to consult an estate attorney with experience in special needs who can review the family’s circumstances and help make the best decision. It may be beneficial for families to establish one or the other, or in some cases, both.

1. An **ABLE Account** is a tax-advantaged savings tool (similar to a 529 College Savings Plan) for individuals with disabilities and their families created as a result of the passage of the Achieving a Better Life Experience ACT of 2014, or better known as “ABLE Act.” ABLE accounts do not interfere with either Supplemental Security Income (SSI) or Medicaid. To be eligible, the individual needs must have the onset of disability before age 26 years old and must meet the SSI requirements for functional limitations due to the disability.

ABLE accounts can be created and managed by the “beneficiary,” or the person who will “benefit” from the account (the person with Duchenne). If the beneficiary needs assistance, the account can be established and/or managed by a third party (i.e. parents, guardian, etc.). Under the ABLE Act, each eligible individual can have one ABLE account. The total amount in the ABLE account must be less than \$100,000; any amount over that limit counts against SSI and Medicaid. Total lifetime contributions to the ABLE account are determined by the amount that you are able to contribute to the 529 College Savings Plan in your state. Funds in the ABLE account are available to cover all “qualified disability expenses (ADE’s),” which includes education, housing, transportation, healthcare and other disability-related expenses. Fees for ABLE accounts are generally nominal and the account growth is tax free. For more information about ABLE accounts and how to set up an account in your state, please visit ablenrc.org.

2. A **Special Needs Trust (SNT)** is a well-established savings tool that also protects both SSI and Medicaid. “First party SNT’s” are established with the beneficiary’s assets. It must be established before the beneficiary turns 65 years old. “Third party SNTs” can be established using funds from anyone except the beneficiary (parents, grandparents, etc.) and is managed by a trustee. There is no limit as to how many SNTs a person may have, or how much money is included in each SNT. SNTs must be drafted by a qualified estate attorney who has specialization in this area (please note not all estate attorneys have this knowledge). Therefore, there are typically attorney and trustee fees associated with SNTs. However a “pooled SNT,” which are managed by non-profit organizations, combine the resources of many individuals in a single account and have lesser, or no, fees associated. SNTs are subject to taxes. Estate attorneys qualified to set up SNTs can be found at these this site: specialneedsanswers.com.
3. **Supplemental Security Income (SSI)** and other Insurances can be daunting. To help families organize their thoughts around this, PPMD has developed extensive resources. These can be found at parentprojectmd.org/insurance-resources.

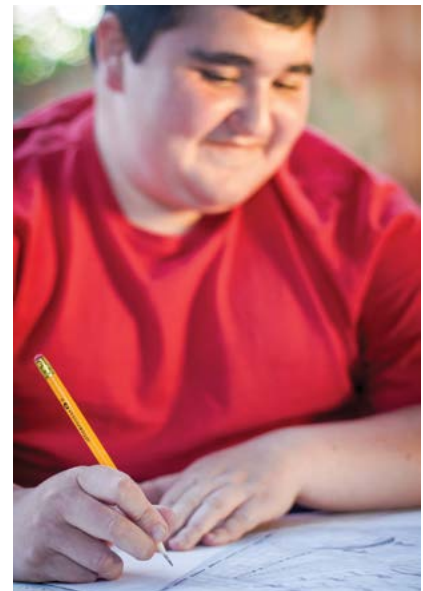
10. For Teachers: Late High School, College

Duchenne in the Classroom

By adulthood, most people living with Duchenne will have significantly reduced motor function and most likely will have decreased upper body strength and function. Gradually, they will realize reduced use of their hands and fingers. If cognitive and learning issues are present, those will persist, although by adulthood, most have devised a plan for navigating any issues present.

Common challenges for this age are the following:

- Navigating independence while still relying on parents and others for care. (i.e. becoming less physically independent in a stage when they should be more independent).
- Dealing with depression as friends leave high school for higher learning or employment, adults with Duchenne may be left behind. Also, loss of motor function and independence makes them prone to depression if they have not been prone to it before.
- Anxiety about their future and how they will be cared for with their declining health.
- Fatigue and less endurance to complete tasks of daily life which limits their participation in activities.



Positively speaking, this is also a time of opportunity for people with Duchenne. With the proper resources and support, they can find creative ways to contribute to society, find a community of friends and support, and participate in activities that make life meaningful.

The goal of this stage is to work closely with individuals with Duchenne so that they have plans and goals in place that help them find purpose in their life, relationships and work. It is important to address their mental health needs so that they live their fullest life at this stage.

Educational Considerations

Transition

As was discussed in section II a transition plan should be developed and instituted by age 14 years. The school should be aware, and supportive of, this plan and it should be included in the IEP.

Stairs and Emergency Evacuation Plans

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. For students attending college, a plan must be in place for classroom/dorm evacuations, to include fire drills, etc.

Arms and fingers: carrying heavy books and writing

At this stage, students' arms may begin to lose strength as well. In Duchenne, the arms may stay strong much longer than the legs, but lifting objects may be difficult or impossible. If this is necessary, assign a “buddy” to help the student with their load. If your school uses text books, have an additional set of textbooks for the student in the room may remove the need to cart books back and forth from school. Most schools have the option of downloading books on tablets and/or computers — be sure to investigate the options at your school.

Assistive technology may be helpful. 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, gross and fine motor function.

Considerations for Attending College/University

Navigating the higher education maze is confusing for everyone, and is incredibly confusing when considering the needs of a student with Duchenne. Here are some steps to get started.

a. Disability Services

As you begin to narrow down your choices for higher education, make an appointment with the disability office at those schools. All students with a medically documented disability are eligible to register with the school's disability services office and receive support services and reasonable accommodations. The services you receive should be tailored to your specific needs (i.e., if you are unable to write, someone should take notes, help with homework, etc.).

b. Living Options

Be sure to ask for an ADA compliant room that will meet your needs. This may be a “super single” that has a bed for you and another bed for your personal aide/assistant. Be sure the room is big enough for you to maneuver around and that the bathroom/shower options are accessible.

c. Transportation Options

Transportation will be important for getting to and from classes, getting to job or internships and hanging out with friends. Your options will be determined by your needs (i.e., do you need a wheelchair accessible option) and where you are living/attending school (i.e., are there subways available, will you need to arrange private transportation, etc.). Evaluate your needs, then do your research and know what your options are and how to access those options.

d. Learn the Landscape

Navigating a new campus can be quite an adventure. Spend some time before classes start learning the routes around your campus — where are the elevators, where are the accessible bathrooms, how can you best avoid stairs, what are the easiest paths if the weather is bad, etc.



e. **Getting Assistance**

For many, this might be your first adventure in hiring personal aides/assistants. If your parents have done this in the past, and are now passing the baton to you, be sure to ask for their help. If you know other students at your university that have travelled this path, they may be able to help as well. Your options, again, will depend on your school. First arrange a shift schedule that identifies when you need help. When you have a schedule, check with local nursing agencies to see what they might be able to offer. If those are of little help, post notices for employment opportunities on school bulletin boards: in your dorm, on school jobs board, boards in the school of nursing or physical therapy. It's best to first discuss the job by phone, narrow your pool of applicants, then hold in-person interviews. Student schedules change frequently, so it's a good idea to have a few people available as back up for sudden changes.

f. **Managing your Money**

As we all know, this area changes all the time. If you are receiving financial assistance, know how much you get, when you get it and how you are allowed to use it. This includes social security payments, Medicaid, Medicare, waivers, money in your Special Needs Trust and ABLE Account among others. After you evaluate your finances, talk to the financial aid office at your school. Given your "extenuating circumstances," they may be able to offer you additional moneys.

g. **Find Your People!**

There are MANY people who have gone to college and attended university with Duchenne. If they are on your campus, reach out and learn from their experience. There are several social media groups that include those who have attended, and plan to attend, college. In addition, many resources exist on this PPMD page: parentprojectmd.org/college-resources. This page is always being updated, so if you have additional resources to add, please let us know so that it is as up to date as possible.

Strategies for Dealing with Oppositional, Explosive, and Aggressive Behavior

For most, this section will not be necessary at this stage. However, for some families, behavior continues to be a major struggle. If it applies to your family, we hope that it is helpful.

Tips for Managing Behaviors

- Ignore negative behaviors when the behavior is not aggressive or destructive.
- Allow students to have "alone time" in a quiet place when they feel they need it.
- Praise positive behavior and create opportunities for positive interactions and success.
- Reward positive behavior as immediately as possible.
- Break directions up into small manageable steps.
- Be specific and concrete when explaining expectations.
- Suggest that the student have some time alone so that they might more easily calm down.
- Classroom management for students involves many of the techniques previously listed for home behavior management.

Behavior Modification Plan

This type of strategy has elements that are similar to the 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 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. It will be important to find a reward system that is unique to the student.– 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.– 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 student 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.– 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 that will reduce the intensity and frequency of episodes of emotional and behavioral dysregulation. It is particularly helpful for students who are chronically rigid and inflexible in their expectations, and/or when limit-setting or punishment routinely escalate temper meltdowns. This approach attempts to improve the student's 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 Identify and understand the student's concerns and point of view (such as completion of homework, attending an event, or engaging in an activity). <ul style="list-style-type: none">• Validate how the person 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 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 Identify and explain the adult's concerns on the same issue. <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 Brainstorm possible solutions. <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.

11. For Teachers and Parents

Tips for Discussing Duchenne

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

- Teachers should discuss with students how they would like to address questions and concerns about Duchenne from others.
- When a classmate asks questions about Duchenne, answer honestly, in terms that will be easy for them to understand.
- Everyone is an individual, and students with Duchenne are made up of more than just a Duchenne diagnosis. Encourage everyone to see this.
- Explore what activities and hobbies students are interested in. Find creative and alternate ways to for students with Duchenne to participate.
- Students with Duchenne 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, so no one is afraid to ask questions or talk about what's on their mind.
- Parents, remember to 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.

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.

Coach To Cure MD, presented by Werner Ladder, is a partnership between the American Football Coaches Association (AFCA), a professional organization for over 10,000 college and high school football coaches and staff, and PPMD.

- One football weekend of each season, AFCA coaches nationwide agree to promote Coach To Cure MD by wearing armbands
- If your high school or college team is interested in participating, visit CoachToCureMD.org.

12. Education Rights for Students with Special Healthcare Needs

Schools are required to locate, identify, and support all students 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 I Need an IEP or 504?

Every student 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 program is best depending 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 student 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 student. 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 students 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, OT, PT, and other people familiar with the child) will gather to assess whether the student 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 education program. In addition to accommodations, it may include services that are provided. To qualify for an IEP, the student must have on of 13 specific disabilities (these are listed at: <https://u.org/2XGmGuM>) and that disability must affect the student'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 the student are met; the student is formally evaluated every 3 years to see if the IEP is still needed. However, a parent may request an IEP meeting at any time they feel it is needed. They are not required to wait for the 3-year review.

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 those who are new to this process. Following the steps below should help to smooth the way through this process.

- Engage with your school team (in-service, meeting, etc.)
- Request an evaluation (by you, by teacher, by PT)

- Student 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 you are 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 the student 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 is directed toward parents and teachers of students across the diagnosis of Duchenne, and contains information that may be difficult to read. So, take a deep breath and remember that the more prepared you both are, the more you can help create 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, “You have been late to classes lately. How can I help?”

Response: “Yes – the halls are crowded and/or I have to go quite a distance. Would it be possible to allow me to have extra time to change classes/ get from place to place? Maybe I could leave a little early (3 extra minutes?) with a “buddy”, so he could come into the next room when the whole class enters?”

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. Students 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 class is taking a field trip.

Response: “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.

4. Scenario: Student is being bullied/isolated

Response: “I’d like to have the opportunity to speak with the class and explain my child’s muscle weakness, or to have them explain their diagnosis to their classmates. (If you don’t feel comfortable doing this, consider asking a family member or a close friend who understands the diagnosis to volunteer.) Also, my child and I would like to meet with you to discuss solutions that will help them feel more included and freer to share when inappropriate comments are made.” For more information on classroom resources, visit parentprojectmd.org/classroom.

5. Scenario: The P.E. teacher is questioning the student’s participation in P.E. Class & Recess

Response: “Due to my son’s weakening muscles, he will not be able to participate during all P.E. 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.

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

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

13. Adapted and Adaptive Physical Education (P.E.)

As mentioned above, students in late adolescence will generally have lost the ability to walk and may have limited use of their arms.

General Rules to Remember

Some general things to remember include:

- **Don't exert to the point of exhaustion.** Focus on keeping muscles active, to maintain flexibility.
- **Strength-building exercises can further damage weak muscles** and must be discouraged.
- **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 the student to work through a set of stretches throughout the school year.

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.
- 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.
- All students should still to be able to participate at some level in all activities. 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.
- 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.



14. 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 four to six 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.

15. 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 person 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.

16. Summary

Duchenne is a complex diagnosis, but not one that precludes 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 many of the topics that we have discussed.

By working together, students, 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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Important Personal Information

Name	
Date of Birth	
Emergency Contacts	
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	

Parent **JOIN THE FIGHT.**
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