

Education Matters is a guide for parents and teachers specifically about educational and other classroom-related issues for young men with Duchenne muscular dystrophy (DMD). Written by Parent Project Muscular Dystrophy (PPMD), it offers practical information on DMD as it relates to a young man's educational experience and specific advice on helping him succeed in the classroom.

**Education Matters offers parents:**

- Helpful tips on how to talk about DMD
- Issues to be aware of at school
- An Individualized Education Plan (IEP) overview
- Sample scenarios and suggested ways to respond

**Education Matters offers teachers:**

- A practical overview of DMD
- Classroom accommodations
- Suggested inclusive school activities
- What to be aware of regarding treatment/medications
- Confidentiality/sensitivity concerns



**Our Mission**

To improve the treatment, quality of life and long-term outlook for all individuals affected by Duchenne muscular dystrophy through research, education, advocacy and compassion.

**Executive Office**

1012 North University Blvd.  
Middletown, Ohio 45042  
**T.** 513-424-0696  
**F.** 513-425-9907

**Development Office**

158 Linwood Plaza, Suite 220  
Fort Lee, New Jersey 07024  
**T.** 800-714-5437  
201-944-9985  
**F.** 201-944-9987

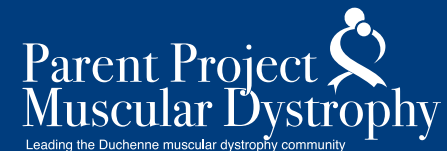
[www.parentprojectmd.org](http://www.parentprojectmd.org)

Summer/Fall 2006



# education matters

**A teacher's guide to  
Duchenne muscular dystrophy**





# education matters

**A teacher's guide to  
Duchenne muscular dystrophy**



### Our Mission

To improve the treatment, quality of life and long-term outlook for all individuals affected by Duchenne muscular dystrophy through research, education, advocacy and compassion.

Copyright © by Parent Project Muscular Dystrophy  
Version 1, June 2006

[www.parentprojectmd.org](http://www.parentprojectmd.org)

## contents

<b>Introduction by Pat Furlong</b>	<b>ii</b>
Founding President & CEO, Parent Project Muscular Dystrophy	
<b>1 Overview of Duchenne muscular dystrophy (DMD)</b>	
What is Duchenne muscular dystrophy?	<b>3</b>
Progression of DMD	<b>4</b>
Treatments for DMD	<b>6</b>
<b>2 DMD in the classroom</b>	
Important topics	<b>11</b>
Five things every teacher should know	<b>12</b>
Talking with your class about DMD	<b>14</b>
<b>3 Specific challenges and ways you can help</b>	
Pre-K, kindergarten & elementary (ages 4–7)	<b>21</b>
Elementary & middle school (ages 7–11)	<b>29</b>
Junior high & high school (ages 12+)	<b>41</b>
<b>4 The basics of working with an Individualized Education Program (IEP)</b>	
IEP team	<b>53</b>
<b>5 Summary</b>	
Why your help is so important	<b>59</b>
PPMD’s top three take-away points	<b>60</b>
<b>6 Resources for teachers</b>	
A note to my substitute	<b>65</b>
Recommended resources	<b>66</b>
About Parent Project Muscular Dystrophy	<b>68</b>

## A note to teachers & school administrators

Parents of a child with Duchenne muscular dystrophy (DMD) naturally want him to have the same educational opportunities and choices as his peers. However, newly diagnosed families often find themselves in the challenging position of having to explain to teachers and other school staff what the disorder is and how to manage it.

### **That's where we come in.**

The purpose of this guide is to help you understand Duchenne muscular dystrophy and to present practical, accurate information so you are better able to help students living with Duchenne muscular dystrophy succeed in the classroom.

### **That's where you come in.**

The best way to get familiar with your student's diagnosis and his particular needs is to meet with his parents; however, consider this booklet a resource to refer to throughout the year for guidance and advice.

Inside you'll find information on:

- Duchenne muscular dystrophy and its progression
- Physical, learning and behavioral challenges
- Classroom accommodations and activities
- Individual Education Program (IEP) issues
- Teacher tips and resources

While Duchenne muscular dystrophy slowly steals muscle function and independence, what remains strong is a child's desire to learn, grow and have fun. With your positive, informed guidance and support, you can make that a reality in the classroom every day.

Sincerely,

A handwritten signature in blue ink, reading "Pat Furlong". The signature is fluid and cursive, with a large initial "P" and "F".

Pat Furlong, Founding President & CEO  
Parent Project Muscular Dystrophy



1

**an overview of  
duchenne muscular dystrophy**



## What is Duchenne muscular dystrophy?

Duchenne muscular dystrophy (DMD) is the most common lethal genetic disorder diagnosed during childhood. It progressively causes loss of muscle function and independence, similar to other types of muscular dystrophy. However, Duchenne muscular dystrophy primarily manifests in boys because the DMD gene is found on the X chromosome. It affects all races and cultures. Although many cases are genetically inherited, approximately 35% are the result of a spontaneous genetic mutation. Duchenne muscular dystrophy affects approximately 1 in 3,500 boys and, each year, approximately 20,000 children are born with DMD worldwide. To date, it has no cure.



## Progression of Duchenne Muscular Dystrophy

Typically, Duchenne muscular dystrophy is diagnosed in boys between the ages of three and seven. Throughout the school year, your student's muscles will weaken progressively, affecting his physical capabilities. While the rate of progression and severity of symptoms are different for each student, there are four stages usually associated with DMD.

### 1 Early phase (diagnosis through age 7)

Many times, the very first signs of DMD involve a speech and language delay and other cognitive weaknesses. Physically, your student will move slower or with more difficulty than his peers. He may appear clumsy and fall a lot. His calves may appear enlarged or overdeveloped (called pseudohypertrophy). This happens because the calf muscle is replaced by other tissues (fat and fibrous). Jumping from a standing position may be nearly impossible for him. Although it may not be apparent, many boys with DMD will start to have early heart problems and may need to take medication that can cause drowsiness or lack of energy.

### 2 Transitional phase (6–12 years)

During this time, your student will typically have trouble walking because his quadriceps (muscles in the front of the thighs) have grown weaker. This causes him to be off-balance as he attempts to shift his weight and walk. He may walk on the balls of his feet or on his toes with a slight rolling gait. In order to compensate for a weak trunk, young men with DMD will stick

their bellies out and throw their shoulders back to keep their balance as they walk. When asked to stand up, he will put his rear end up in the air first and then use his arms for supports by “walking” his arms up his legs with his hands until he is standing. (The medical term for this is “Gowers Maneuver.”)

### 3 Loss of ambulation (8–14 years)

By about 12 years old, most boys with DMD need a wheelchair. Your student's weakened muscles will cause him to tire easily. The teen years bring a continuous progression of weakness. After loss of ambulation, this progression becomes more apparent. Activities involving the arms, legs, or trunk of the body will require assistance or mechanical support. Most young men will retain the use of their fingers through this phase, so they can generally still write and use a computer.

### 4 Adult stage (15+ years)

In the teen years, life-threatening heart and respiratory conditions become more prevalent. Major symptoms of heart and lung complications include shortness of breath, fluid in the lungs and swelling in the feet and lower legs (fluid retention due to congestive heart failure). Young men with DMD usually pass away due to these types of complications before their third decade of life.



## Treatments for Duchenne muscular dystrophy

When a student with Duchenne muscular dystrophy is placed in your classroom, it's important to be aware of the treatments he's undergoing, the medications he might need during the day and what side effects to expect. Although there is no cure for DMD, accepted treatments and therapies can lessen symptoms and improve a young man's quality of life.

Prednisone is currently the steroid most widely used to treat Duchenne muscular dystrophy. It slows muscle loss and dramatically improves strength. On the other hand, it often produces severe physical and psychological side effects, which may affect a student's appearance, behavior and academic performance. Physical changes include weight gain and facial changes. Psychological side effects include difficulty concentrating, sleeping and controlling emotions. There's also a chance that impairment in thinking, reading and coping skills can lead to depression or aggression.

## Checklist

To keep track of what treatments and therapies your student uses, use the checklist below. If you aren't sure, contact your student's parents.

### Therapy

- Physical therapy (PT)
- Occupational therapy (OT)
- Speech and language therapy
- Psychological counseling

### Medications

- Prednisone (see opposite page)
- Deflazacort
- Albuterol
- Nutritional supplements
- Heart medication
- Other \_\_\_\_\_

### Mobility support devices

- Leg braces
- Wheelchair or scooter

### Surgery

- To straighten spine due to scoliosis
- To treat contractures (loss of elasticity in the joints, namely the ankles, knees and hips)
- Other \_\_\_\_\_





2

**dmd in the classroom**



## Important topics

There are many things you can do for a student with Duchenne muscular dystrophy to ease his transition into your classroom. The best way to start is to have a meeting with your student's parents and all involved teachers prior to the first day of school to openly discuss his capabilities and limitations. This will also help you talk to your student and his parents throughout the year more comfortably and confidently.

This kick-off meeting is the perfect time to form a collaborative team of teachers and other professionals within your school to ensure the student's needs are met by a group—not just one individual—throughout the year.

Before we delve into specific classroom matters organized by age group (on page 19), here are a few over-arching topics applicable to all teachers—and students—affected by Duchenne muscular dystrophy.

**openly discuss your  
student's capabilities  
and limitations with  
his parents**



## Five things every teacher should know

### 1 Young men with DMD often experience learning problems.

Most learning problems are related to the amount of information your student can effectively process at one time, particularly verbal instructions. For elementary-school students, it's important to speak clearly and concisely and repeat the information to ensure he grasped it. Problems with planning and organization have also been documented. Some learning problems do not get worse, and young men often overcome them as they get older. In fact, students with DMD have above-average intelligence. Their visual skills and creativity are excellent, which is perhaps why many are good artists. Together with an independent evaluation by your school, a conversation with your student's parents will help you gain a better understanding of his current level of ability and particular needs.

### 2 Classroom accommodations and adaptive equipment can help maximize your student's physical capabilities. While some depend on the student's age and the progression of his symptoms, here are some practical solutions for all ages:

- **Supportive seating:** a sturdy chair with arms to support upright posture and getting up successfully (similar to the needs of an elderly person)
- **Raised desktop:** height should accommodate the height of the supportive chair
- **Special pencil grips:** to help control writing
- **Note-taking:** allow more time, use of a tape recorder or computer
- **Access:** allow extra time between classes or assign a buddy to help carry heavy books and supplies

3 **Duchenne muscular dystrophy has no association with a particular personality type.** Parents have suggested, however, that their sons exhibit traits similar to those associated with obsessive-compulsive disorder. For example, they may be rigid and inflexible in their thinking, they may insist that things are ordered a certain way or they may have to do things until they feel "just right." Like all students, some young men with DMD are quiet and reserved, some are outgoing and others misbehave. Also, like all students, they should be expected to follow school rules and procedures. It's important to hold them accountable for their actions. However, an overly rigid approach to discipline may not work, and may actually escalate negative behaviors. Keep in mind that what appears to be negative behavior may be the result of a cognitive weakness or a response to frustration. A practical problem-solving approach likely will be more effective than a punitive intervention.

4 **Many boys with DMD experience emotional or behavioral problems.** Specifically, they may have difficulty controlling their response to frustration and may become easily angered, irritable or aggressive. They may also be impulsive and act without thinking. Some children with DMD may experience feelings of depression, anxiety and loneliness. Other emotional issues arrive from the understandable stress that a fatal, independence-robbing disorder puts on a child and his family. As a teacher, you can help him adjust by being supportive, understanding and consistent with your words and actions.

5 **Confidentiality is of great concern for many parents of children with Duchenne muscular dystrophy.** Parents often struggle with what, when and how much to tell their son about his fatal disorder. It's critical to make no assumptions about what your student knows about his diagnosis. Meet with your student's parents before the first day of school to discuss their wishes for confidentiality.



## Talking with your class about Duchenne muscular dystrophy

Sensitivity when discussing DMD is paramount. However, be as open and engaging about the topic of DMD and disability as the family will allow. Be prepared to answer questions that may come from his peers (for example, about his changing appearance, leg braces, wheelchair or why he can't do the same things in P.E. class that everyone else does). Generally speaking, children can cope best with a medical condition and its treatment when they know as much as possible about it. Research has found that peers are less likely to tease and more likely to defend them when they are armed with accurate knowledge about DMD.

A great way to raise the topic of DMD with students (of all ages, but especially early-elementary age) is during regular conversations about tolerance in the classroom. A way to frame the conversation is to remind your students that everyone has different needs. For example, some students need help reading, some need help writing, some need help following the rules and some need their own place to work so they can concentrate, etc. You can customize this conversation in many ways and incorporate the needs of your student with DMD.



**BrainPOP animated movie about DMD:** Together, BrainPOP and PPMD developed a short animated movie to help young children understand DMD. It could be a helpful way to introduce the topic in your classroom. For more information, visit [www.parentprojectmd.org](http://www.parentprojectmd.org).



### Negative adjectives & phrases to avoid

- Suffers from
- Terrible, debilitating disease
- Afflicted with
- Wheelchair bound /  
Confined to a wheelchair
- Disease (viral)
- Fatal / terminal
- Crippling or crippled



### Positive adjectives & phrases to use

- Diagnosed with
- Progressive muscle disorder
- Affected by
- Needs the assistance  
of a wheelchair
- Disorder (genetic) / condition
- Devastating / life-limiting
- Progressive muscle disorder

#### Additional tips

- The majority of people diagnosed with Duchenne muscular dystrophy are male. Many boys will reach adulthood, and it may be appropriate to describe them as “young men” rather than as “boys” or “children.”
- Words like “normal,” “fulfilled” and “productive” should be used carefully so the sentence does not imply that those affected by Duchenne muscular dystrophy aren't “normal,” “fulfilled” or “productive.”



3

**specific challenges  
& ways you can help**

## Challenges & ways you can help

This section provides information on what to expect within the classroom. It is organized by age and the typical progression of Duchenne muscular dystrophy. Each section addresses specific physical, cognitive, behavioral and confidentiality challenges you might encounter, along with practical ways you can help.

### What grade / age group do you teach?

Pre-K, kindergarten & elementary (ages 4-7)	21
Elementary & middle school (ages 7-11)	29
Junior high & high school (ages 12+)	41



## pre-k, kindergarten & early elementary (ages 4–7)

### Physical abilities

Duchenne muscular dystrophy is typically diagnosed between the ages of three and seven. During this early phase, your student’s movements may appear slower or more labored than other students. You may notice physical changes such as enlarged calf muscles and walking on tiptoes, due to a tightening of the heel tendons. He also may start to experience difficulty standing up from a sitting position due to muscle weakness in his legs. Even the youngest students with DMD will face challenges maneuvering within the school environment.

**Involve your class in brainstorming and decision-making about how to include their friend with Duchenne muscular dystrophy in ALL activities.** Ask the student and his peers for ideas on how to best involve him in a given classroom activity, field trip or recess activities. Consider it a lesson in life and problem-solving. As a result, your class will learn empathy and understanding.



**When asked to stand up,** your student may put his rear end up in the air first and then use his arms for support by “walking” up his legs with his hands until he is standing. The medical term for this is “Cowers Maneuver.”



## Classroom challenges & how you can help

### Getting up from a seated position

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

### Getting up off the floor

Please conduct as few activities as possible on the floor. It is very difficult for a student with DMD to stand up from a seated position on the floor. He should be in a chair with arms. However, if you do hold sessions on the floor, it's important not to isolate your student by having him be the only one in a chair. Consider restructuring the lesson so a few people, or everyone, sits in a chair if possible.

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

Remember that it's easy for your student to lose his balance. Often it seems like his legs will be pulled right out from under him when he falls. Consider assigning a buddy that sits at a nearby desk to help out if needed.

### Walking long distances

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

### Stairs

To the degree possible, students with DMD should avoid stairs at all ages. Stairs increase the stress on muscles and hastens muscle damage. Use elevators or ramps instead.

### Recess & P.E. (climbing, balancing beam, jungle gym, etc.)

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

### Snack time / cooking activities

Even at a young age, your student may be undergoing steroid treatments to slow the progression of muscle weakness. Side effects include rapid weight gain, so please ensure any snack he receives is nutritious. Check with your student's parents to find out if he has any additional dietary constraints.







## Suggested classroom activities

### Connect DMD to science / human body curriculum

“Ask your students what parts of the body are affected by muscles. (Pretty much every part!) Then ask them if they know of any part that isn’t affected (brain and nerves). I explained that although Andrew’s muscles didn’t work like theirs, his brain, feelings and pain was like theirs. This really hit home.”

– Andrew’s teacher, first grade

### Play a group game

“Students stand in a big circle. One person imitates an animal using a sound or action. When someone has guessed it, the next person in the circle has to imitate an animal beginning with the last letter of the previous animal’s name. For example, after a frog—a goat; after a goat—a tadpole; and so on.”

– *The Accessible Games Book*, games for limited upper-body strength and mobility

For more information on where to find classroom activities for students with disabilities, see page 66.

## Cognitive development

Boys with DMD are at risk for difficulties with language processing. Your student may not be able to process the same amount of information or instructions as his peers. He may also have problems responding to questions or expressing himself. As a result of a weakness in language skills, boys with DMD may also struggle with learning to read. Young boys with DMD may also have problems with impulsivity, emotional control and mental flexibility/adaptability. The overall IQ of boys with DMD ranges from mild retardation to the superior. It’s important to remember that these challenges are not because of laziness, stubbornness or some other character flaw, but may be related to cognitive weaknesses. Keep parents informed about any concerns you may have.

## Accommodations

In the early stages of your student’s development, it’s best to meet with the child’s parents to chat about the diagnosis, their observations about his current level of ability and possible needs during the course of the school year. And, if it hasn’t happened already, you may refer the student for an independent evaluation to determine if he is eligible for special-education services. Schools are required to locate and identify all children with disabilities.



**Pencil grips often give a student better control when writing. Find out what type works best for your student and keep a few in your desk.** Consider offering your entire class pencil grips. When they see one student using it, you may find that many of your students will suddenly “need” that pencil grip, too!



## Behavioral issues

Physical limitations can be challenging for anyone. Physical limitations for a young man with DMD only increase over time, which can cause frustration and embarrassment, even among the youngest students. These frustrations may, for some students, be acted out through their behavior.

Some behavior problems may be the result of impulsivity, poor emotional regulation and mental inflexibility. Other students may act out because they are frustrated by learning problems.

Additionally, your student may be taking medication with strong side effects that can impact his behavior. Your sensitivity and support are critical. While students with DMD should be held accountable for following the same rules as other children, an overly rigid approach to discipline may not work and may actually escalate his frustration and behavior problems. Work with his parents to identify possible causes of and solutions to his behavior problems.



**Have regular conversations about tolerance in the classroom.** For instance, everyone has different needs. Some students need help reading, some need help writing and some need help following the rules.

## Confidentiality concerns

Because your student is newly diagnosed (and still quite young to fully understand the diagnosis), it's safe to assume that his parents may have told him only a limited amount of information, if any, about Duchenne muscular dystrophy. The only way to know for sure is to meet with the student's parents. They will be able to give you guidance regarding what or how much they'd like you to discuss with their child, his peers, other parents and other teachers.

In general, it's important to maintain open, honest and sensitive communication about DMD with your student and his parents. It will make everyone involved more comfortable to share information, ask questions and address any issues that arise.



**Here are some recommendations for helping young students with DMD in the classroom.**

- Implement routines and follow schedules as much as possible
- Give advance warning of transitions or changes in routine
- Implement a reward system
- Model/practice pro-social behaviors
- Keep parents up-to-date about their child's progress and notify them of any learning or physical concerns

## elementary & middle school (ages 7–11)

### Physical abilities

At this age, your student is considered to be in the “transitional phase” of Duchenne muscular dystrophy. (See page 4 for more information on this phase.) His leg muscles will grow weaker, and he’ll have trouble walking, standing and maintaining his balance. Most likely, he will not be able to climb any stairs and should not be encouraged to try.

As the symptoms of DMD progress, your student may face increased challenges within the classroom and school environment.

**From early on, involve your class in brainstorming and decision-making around including their friend with Duchenne muscular dystrophy in ALL activities.** Ask the student and his peers for ideas to best involve him in a given classroom activity, field trip or recess activities. Consider it a lesson in life and problem-solving. Your class will learn empathy and understanding as a result of using this strategy.



## Classroom challenges & how you can help

### Change in posture / gait

Your student's posture is changing due to his weakening pelvic muscles. This weakness throws off his center of gravity, so he compensates by redistributing his weight and changing his center of gravity. (It's common for boys with DMD to stick their bellies out, throw their shoulders back and walk on the balls of their feet.) He may need to use walls for support. Discuss this with your student and your class sensitively and honestly as comments or questions arise.

### Getting up from a chair

He will need something to grab for support as he pulls himself up. You or a classmate can give him a hand, or ensure there's something for him to grab onto, especially in restrooms—both in school and on field trips.

### Getting up off the floor

Please discourage any floor-sitting activities. Getting up from the floor will be very hard for a student with DMD. He should be in a chair with arms. However, if you do hold sessions on the floor, it's important not to isolate your student by having him be the only one in a chair. Consider restructuring the lesson so a few people, or everyone, sits in a chair, if possible.

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

Remember that it's easy for him to lose his balance. Often it seems like his legs will be pulled right out from under him when he falls. Consider assigning a buddy that sits at a nearby desk to help out if needed.

### Walking long distances

Please do not let your student walk long distances. This is something to think about for field trips that involve a lot of walking, or if the cafeteria is far from the classroom. If extra time is needed, you can make it an honor or reward to be assigned as the child's "buddy" and get to leave class a little early or come in a little late. If your student is already in a wheelchair, please ensure that field trip activities are accessible.

### Stairs

Boys with DMD should avoid using stairs. It puts stress on his weakening muscles. Use an elevator or a ramp instead. Young men of this age may begin to resist help even though they may need it. If he must use the stairs, for safety reasons, please have an adult accompany him. If he is struggling and will not use the elevator or accept help, please consult his family.

### Educating your students about DMD

It's important to involve all students in age-appropriate discussions about DMD to promote understanding, inclusion and friendships. A tool that may help is BrainPOP's short animated video about DMD, available on [www.parentprojectmd.org](http://www.parentprojectmd.org).





## Classroom challenges & how you can help (continued)

### Participation in P.E. class

Ask the student's parents what is possible and what is not. Most likely, his weakened muscles and balance will make it difficult for him to traditionally participate in P.E. classes; Consult your school district's adaptive-P.E. teacher in order to keep the student actively involved in his class with the appropriate adaptations. Since his capabilities may change as the school year progresses, meeting every few months with his parents and P.E./A.P.E. teachers would be a great idea.

### Difficulty taking notes quickly or for a long period of time

Provide a copy of notes from class, access to a computer to type or download notes, pencils with special grips, a tape recorder or the ability to copy another student's notes, if needed.

### Slowness or inability to get ready for class (lifting a book)

Allow him more time to prepare. For example, perhaps he can come in a little early for class or leave a little late. Or consider asking a classmate to carry heavy books, walk with him between classes or to the cafeteria, and pack up at day's end. Another option might be to allow the student a type of cart or rolling backpack—something another student could help move easily.

### Declining respiratory function

Breathing will be more difficult for your student and can lead to symptoms such as headaches, mental lapses and difficulty concentrating or staying awake during the day. Be understanding and mindful of symptoms (mentioned above), and, most importantly, understand that your student should be kept out of school during cold or influenza epidemics. His weakened muscles make coughing difficult, so a simple cold can quickly progress into pneumonia in a young man with DMD. Be aware that he needs to be taken to the physician if symptoms develop.

### Snack time / cooking activities

Your student may be undergoing steroid treatments to slow the progression of muscle weakness. Side effects include rapid weight gain, so please ensure any snack he receives is nutritious. Please check with your student's parents to find out if he has any additional dietary constraints.





## Suggested classroom activity

### A lesson to encourage tolerance in the classroom

Buy ankle weights from any local sports store—enough for two weights per person in your class. Talk to the kids about how Duchenne muscular dystrophy causes muscle weakness, and that they are going to find out what it feels like for their classmate with DMD.

Have your students (but not the student with DMD) wear the weights on their wrists during recess or gym class. After about half an hour, ask them to write three or four sentences on how it makes them feel (tired, sad, angry...). Then get the class together to share how they feel and how they imagine their classmate feels every day.



### Include DMD into your lesson plan

A great opportunity could be during health (the muscular system), science (how muscles work) or social studies (attitudes toward people who are different than you/people with disabilities).

**Choose classroom games or activities in which everyone can participate.** A great resource is *The Accessible Games Book* by Katie Marl. It contains games specifically adapted for mixed groups, including children with disabilities. See page 67 for more information on this book.



## Cognitive development

Boys with DMD are at risk for language processing difficulties. Your student may not be able to process the same amount of information or instructions as his peers. He may also have problems responding to questions or expressing himself. In addition, problems with organization, planning, and prioritizing may become more noticeable at this age.

The overall IQ of boys with DMD ranges from mild retardation to the superior. It's important to remember that these challenges are not laziness, stubbornness or some other character flaw, but may be related to cognitive weaknesses. It is important to keep parents informed about any concerns you may have.

## Accommodations

Chances are that your student has already undergone an independent evaluation to determine if he's eligible for special education services. It's best to meet with the child's parents to chat about his current level of ability and possible needs during the course of the school year. It may be necessary to make accommodations for test-taking and assignments. The child's Individualized Education Program (IEP) should outline what is allowed and appropriate for his situation. However, the most important thing you can do is to be as flexible as possible.



## Practical solutions

Here are a few accommodations you might consider if they apply to your student:

### Test-taking

- minimize writing, which may be taxing on the student
- allow him to take oral tests
- ask him to dictate responses into a tape recorder or to an aide

### Homework

- consider giving a condensed assignment (with less writing required)
- give extra time for assignments
- ask for a verbal report instead of a written one
- break down longer or more complex assignments into smaller segments
- provide explicit, concrete and specific instructions at the completion of each segment

### In class

- provide opportunities for creative expression
- be specific when explaining lessons and confirm your student's understanding before moving on
- provide help with math or reading
- promote active, hands-on activities
- allow computers for note-taking (typing is often easier than writing)



## Behavioral issues

After the age of 10, your student may experience symptoms such as headaches, mental lapses, difficulty concentrating or trouble staying awake during the day due to respiratory difficulties. These may affect his demeanor in class. The cause of these symptoms may be breathing problems at night. If you observe any of these symptoms, please mention them to his parents in case they have not noticed them at home.

In addition, your student will most likely be taking medications designed to slow the symptoms of DMD and improve strength. Prednisone is a widely used steroid; however it often produces severe physical and psychological side effects, which may affect a student's appearance, behavior and academic performance. (Physical changes include weight gain and facial changes. Psychological side effects include difficulty concentrating, sleeping and controlling emotions.) Dealing with all the impairments previously mentioned may lead to depression, frustration and aggressive behavior.

Boys with DMD at this age may have weak social problem-solving skills or may not be aware of the impact that their behavior has on others.

## Confidentiality concerns

At this stage, it's likely that parents have shared some degree of information about your student's diagnosis with him. However, it's best not to assume this is always the case. It's important to meet with his parents to find out what your student does and doesn't know about Duchenne muscular dystrophy.

While it's imperative to honor the parents' wishes, it's also important to maintain open, honest and sensitive communication about DMD with your student and his peers. This will help make everyone, including you, more comfortable to share information, ask questions and address any issues that arise.

**maintain open,  
honest and sensitive  
communication about  
DMD with your class**





## junior high & high school (ages 12+)

### Physical abilities

Starting at around 12 years old, a student with Duchenne muscular dystrophy typically uses a wheelchair due to significant loss of skeletal muscle strength. His muscles will continue to weaken throughout his teenage years, which is considered the adult stage of DMD.

Activities involving the arms, legs, or trunk of the body will require assistance. Most young men retain the use of their fingers through their early teens, so they can generally still write and use a computer. However, these tasks may become more difficult for an older student (15 + years).



**Involve your class in brainstorming and decision-making about how to include their friend with Duchenne muscular dystrophy in ALL activities.** Ask the student and his peers for ideas to best involve him in a given classroom activity, field trip, as well as recess activities. Consider it a lesson in life and problem-solving. Your class will learn empathy and understanding as a result.



## Classroom challenges & how you can help

### Mobility

Ensure there's enough space in your classroom for a wheelchair or scooter to comfortably maneuver. Your student will also need to travel through the halls between classes, which may be crowded and hectic. Consider allowing him to leave class a little early or a little late.

### Participation in P.E. class

For many reasons, both psychological and social, it is important for your student to actively participate in P.E. class. Ask the student and his parents what is possible and what is not. Although he will not be able to participate in P.E. class in most traditional ways, encourage him to participate in non-traditional ways. For example, give him the chance to keep time, keep score or make presentations. Since his capabilities might change as the school year progresses, meeting every few months with his parents can help.

### Difficulty taking notes quickly or for a long period of time

Provide a copy of notes from class, access to a computer to type or download notes, pencils with special grips, a tape recorder or the ability to copy another student's notes, if needed.

### Slowness or inability to get ready for class (lifting a book)

Chances are your student will have an aide helping him each day. If not, discreetly ask another student to be a helper in class to carry heavy books, walk with him between classes or to the cafeteria, for example.

### Walking long distances

Please do not let your student walk long distances, even if he is not yet using a wheelchair or scooter. This is something to think about when planning field trips that might involve a lot of walking, or if the cafeteria is far from the classroom. If extra time is needed, you can make it an honor or reward to be assigned as the child's "buddy" and get to leave class a little early or come in a little late. If your student is already in a wheelchair, please ensure that the field trip destination is totally accessible before the visit.

### Stairs

Please avoid stairs for this individual. It is unsafe and puts stress on the muscles. Use an elevator or a ramp instead. Young men of this age may resist help even though they may need it. If he is still using stairs, for safety reasons, please have an adult accompany the child. If he is struggling and will not use the elevator or accept help, it is time to consult with his family.





## Suggested classroom activities

### Grouping

Students with DMD often prefer working in mixed-ability pairs or groups to working alone or as a whole class. Most students prefer flexible rather than fixed groups selected by the teacher.

### Instructional practices \*

According to research, regardless of their age or disability status, students view the following practices as most helpful:

- giving extra time for work
- providing students with choice and opportunities for creative expression
- explaining lessons carefully
- helping with math or reading
- allowing opportunities for interpersonal interactions
- promoting active, hands-on activities

\* Excerpt from a research brief titled “Students’ Perceptions of Instruction in Inclusion Classrooms: Implications for Students with Learning Disabilities” published by Family and Advocates Partnership for Education (FAPE) and reviewed by the U.S. Office of Special Education Programs

## Cognitive development

Boys with DMD are at risk for language processing difficulties. In addition, muscle weakness is increased and fatigue might be a factor. Your student may not be able to process the same amount of information or instructions as his peers. He may also have problems responding to questions or expressing himself. Also, problems with organization, planning and prioritizing are often evident at this age.

The overall IQ of boys with DMD ranges from mild retardation to the superior. It’s important to remember that behavior challenges are not because of laziness, stubbornness or some other character flaw, but may be related to cognitive weaknesses. Keep parents informed about any concerns you may have about their son’s learning as early as possible.



## Accommodations

Chances are, your student has already undergone an independent evaluation to determine if he's eligible for special education services. It's best to meet with the child's parents to chat about his current level of ability and possible needs during the course of the school. It may be necessary to make accommodations for test-taking and assignments. The child's I.E.P. should outline what is allowed and appropriate for his situation; however the most important thing is to be flexible. If writing is a problem, he may need to take oral tests. If assignments are too taxing in terms of the amount of writing required, a condensed assignment may be given. Alternatively, a verbal report may be given instead of a written one. Computers are usually helpful and typing is often easier than writing for your student.



**Allow your student extra time for note-taking.** A tape recorder can help.

**For students who need the help of a wheelchair,** make sure there is enough room in the aisles of your classroom for him to get around easily.

**Allow a student with DMD extra time to move between classes** or get to the cafeteria, for example. To help, assign him a partner. The two students can leave class a little early or come in a little late.

## Behavioral issues

As a junior-high or high school teacher, you can attest to the challenges of adolescence. Physical, emotional and social growing pains affect all students in this vulnerable time of transitions into adulthood. It's important to remember that it's just as difficult—and arguably even more so—for a young man with Duchenne muscular dystrophy. The changes he's experiencing can be frustrating. While his friends are gaining more independence, he is facing less independence, more severe health concerns and a future cut short by something he's been living with since he was a young boy.

A teenager with DMD has a unique set of concerns that can (but not always) adversely affect his behavior in school. How he copes will be determined by the individual's personality, coping skills, and whether medications are affecting his behavior.

As his teacher, it's important to be sensitive to what your student faces every day. While maintaining school and classroom rules, be compassionate, open and honest. His parents can be your greatest ally and source of guidance. It's critical to meet with them at regular intervals throughout the year to discuss any changes in capabilities, limitations or physical ability.

## Confidentiality concerns

At this stage, it's likely that your student understands his diagnosis and its progression. However, it's best not to assume this is always the case. Meet with his parents to find out what your student does and doesn't know about Duchenne muscular dystrophy.

While it's imperative to honor the parents' wishes, it's also important to maintain open, honest and sensitive communication about DMD. This will make the student and everyone involved more comfortable sharing information, asking questions and addressing any issues that arise.

**a teenager with DMD  
faces a unique set  
of concerns**



4

**The basics of working  
with an Individualized  
Education Program (IEP)**

**you can play a  
critical role in  
developing an IEP  
for your student**

## **Introduction**

A young man with DMD may need assistance with physical activities and access only, or he may require additional accommodations and modifications to help him complete regular assignments and standardized tests, develop speech and language skills, or address specialized instruction to address learning disabilities. This is where an Individualized Education Program (IEP) comes into play.

An IEP is the blueprint that delivers your student's special education program. It's designed to help your student benefit from your classroom curriculum and participate as much as possible with his peers. This plan is developed by an IEP team, in which you can play a critical role because you will be a close observer of the student's cognitive and physical abilities.

Schools in different states may use the term PET (Pupil Evaluation Team), MDT (Multidisciplinary Team), or ARD (Admission Review and Dismissal Team) to describe the group that convenes for this purpose. In this document, the term IEP will be used.



## IEP team

An IEP team must include the child's parents or guardians, at least one regular education teacher (assuming the child will be in the regular education environment), at least one special education teacher, and a school representative who is qualified to provide or supervise special education services and who is knowledgeable about both the school's general education curriculum and the school's available resources. In addition, parents and the school are each entitled to bring others onto the team who have knowledge about the child or special expertise. At least one member of the team must be able to interpret the educational implications of the evaluations the team is to consider.

## Goals

An IEP outlines measurable goals detailing what your student is expected to learn and achieve in the coming school year. These goals must be designed to meet your student's current needs resulting from his disability to enable him to be involved in and make progress in the general education curriculum. Updates of measured progress should be provided to parents periodically through the school year, at least as often as reports are given on the progress of his peers.

The IEP is a flexible document and may be amended from time to time as necessary to help ensure appropriateness and student progress. It must be reviewed at least once each year, and the child's needs must be reevaluated at least once every three years.

## Things to consider

For most boys with DMD, the regular classroom is the Least Restrictive Environment (LRE). The LRE is considered the educational environment where a child with disabilities can receive a Free Appropriate Public Education (FAPE) designed to meet his education needs while being educated with peers without disabilities to the maximum extent appropriate. However, in some cases, an argument for additional services can be supported by pointing out to the IEP team that denying a particular service would result in the child being removed from the regular classroom.

**A student with DMD may need the following and other related services:**

- Transportation services
- Physical therapy
- Occupational therapy
- Speech therapy
- Counseling services
- Social work
- Developmental and corrective services
- Assistive technology
- Early reading intervention
- Tutoring
- Small-group instruction
- Adaptive-P.E. services (teacher or aide)

## More IEP information

The needs of a young man with DMD may be different from those of other children who receive special education. For more in-depth information on developing an IEP, and federal laws regarding special education in your state, visit our web site at [www.parentprojectmd.org/educational/states](http://www.parentprojectmd.org/educational/states).





5

summary

**you can have a  
tremendous impact  
on your student's life**

## **Why your help is so important**

When it comes to education matters with Duchenne muscular dystrophy, you can have a tremendous impact on your student's life. Whether he's starting his first day of school or heading into high school, he will need your informed guidance and support. There are many ways you can help enhance his physical capabilities, protect his muscles and encourage social interaction, especially at the start of the school year.

With your consistent support and understanding, a student with Duchenne muscular dystrophy can have a fun and rewarding school experience, which is often the highlight of his young life.

Thank you for striving to enrich the life of your student.

If you found *Education Matters* helpful or have suggestions on how we might improve it, we'd love to hear from you. Please contact Parent Project Muscular Dystrophy at [info@parentprojectmd.org](mailto:info@parentprojectmd.org) or 800-714-5437. For more information, visit [www.parentprojectmd.org](http://www.parentprojectmd.org).



## Top three take-away points

**Partner with your student's parents.** To understand your student's diagnosis and his particular needs, meet regularly with his parents. They are the best source of information for what he does and doesn't know about his diagnosis, his current level of ability and specific treatment(s) he requires during the school day.

**Involve your class in brainstorming and decision-making about how to include their friend with Duchenne muscular dystrophy.** From finding an active role for him in P.E. class to giving him extra time for note-taking, there are many things you can do for a student with Duchenne muscular dystrophy to ease his transition into your classroom.

**Be as open and engaging about the topic of Duchenne muscular dystrophy and disability as your student's family will allow.** Due to the nature and rapid progression of DMD, sensitivity and confidentiality is critical to many parents. While it's important to respect the wishes of your student's family, it's also important to have informed, open and honest discussions with your student and your class.

**your student needs  
your informed  
guidance and support**



6

**resources for teachers**

Teachers, feel free to make copies of the note on the opposite page to leave in your classroom when you are away.

## A note to my substitute

Welcome!

There's something about my class you should be aware of.

One of my students has Duchenne muscular dystrophy (DMD). His name is \_\_\_\_\_ and he's \_\_\_\_\_ years old. Because of his muscle weakness, he might need more time for taking notes and completing tests, moving between classes or getting to the cafeteria, for example.

He has a buddy/aide to help him with these things. His/her name is \_\_\_\_\_. If you plan any games or class activities, please ensure that all students in the class can participate.

I hope this helps. If you have any questions or concerns, please contact the principal.

Have a good day, and thanks for your help!

Sincerely,



## Recommended resources

### **Parent Project Muscular Dystrophy (PPMD)**

parentprojectmd.org • A national not-for-profit organization founded in 1994 by parents of children with Duchenne muscular dystrophy. For an extensive list of links to educational resources we've compiled, go directly to: [parentprojectmd.org/resources/index.html](http://parentprojectmd.org/resources/index.html)

### **Muscular Dystrophy Association (MDA)**

mdausa.org • A voluntary health agency dedicated to the partnership between scientists and concerned citizens aimed at conquering neuromuscular diseases that affect more than a million Americans.

### **U.S. Department of Education, Office of Special Education Programs and Rehabilitative Services**

[ed.gov/offices/OSERS/OSEP/index.html](http://ed.gov/offices/OSERS/OSEP/index.html)

### **National Dissemination Center for Children with Disabilities (NICHCY)**

[nichcy.org](http://nichcy.org)

### **BrainPOP**

brainpop.com • Animated award-winning online educational resource for kids, parents and teachers, which covers topics including health, science, technology, math and English.

### **Family & Advocates Partnership for Education (FAPE)**

[fape.org](http://fape.org) • Helping parents and advocates improve educational results for children with disabilities

### **Council for Exceptional Children (CEC)**

[ideapractices.org](http://ideapractices.org) • The voice and vision of special education.

### **School Zone**

[geocities.com/Heartland/Plains/6097/special.html](http://geocities.com/Heartland/Plains/6097/special.html) • A web site with an extensive list of links to special education resources.

### **Childhood Learning Disabilities**

[learning-disabilities.org](http://learning-disabilities.org) • The Internet Resources for Special Children (IRSC), global disABILITY resource.

*The Accessible Games Book*, by Katie Marl  
(available through Jessica Kingsley Publishers, [www.jkp.com](http://www.jkp.com))

*Quick-Guides to Inclusion: Ideas for Educating Students with Disabilities*, by Michael F. Giangreco (available through Paul H. Brookes Publishing Co., Baltimore: 1-800-638-3775)





## About Parent Project Muscular Dystrophy

Parent Project Muscular Dystrophy (PPMD) is a national nonprofit organization founded in 1994 by parents of children with Duchenne muscular dystrophy. Duchenne muscular dystrophy is the most common lethal genetic disorder diagnosed during early childhood, affecting approximately 1 out of every 3,500 boys, or 20,000 babies born each year worldwide. The organization's mission is to improve the treatment, quality of life and long-term outlook for all individuals affected by Duchenne muscular dystrophy through research, advocacy, education and compassion. PPMD is the largest grassroots organization in the U.S. entirely focused on Duchenne muscular dystrophy. It is headquartered in Middletown, Ohio, with offices in Fort Lee, New Jersey. For more information, visit [www.parentprojectmd.org](http://www.parentprojectmd.org).

### Pat Furlong Founding President & CEO, PPMD

Pat Furlong is the founding president and CEO of Parent Project Muscular Dystrophy. Her focus and determination have helped to grow the organization from a small group of parents, who were frustrated by the lack of investment in Duchenne muscular dystrophy (DMD) research, into one of the leading DMD authorities in the world.

In 2001, Ms. Furlong was invited to testify at a Senate Appropriations Hearing that focused on the introduction of the MD CARE ACT. Her testimony and her ability to mobilize a grassroots advocacy effort helped to speed the passage of the MD CARE ACT into law.

In February of 2002, Ms. Furlong was one of 25 individuals chosen by United Airlines as an “Everyday Hero.” This prestigious award was presented at the 2002 Olympics to honor her as a woman who carries a torch for so many families affected by DMD.

Ms. Furlong was also appointed to serve on the Muscular Dystrophy Coordinating Committee of the U.S. Department of Health and Human Services. She is one of approximately 15 committee members, appointed by the Secretary of Health and Human Services, who will develop a plan for conducting and supporting federal research and education on muscular dystrophy through the national research institutes. She also serves on the board of the Genetic Alliance.

It is through Ms. Furlong's determination that Parent Project Muscular Dystrophy continues to make strides not only in the muscular dystrophy research community, but also in the areas of care and treatment. Her goal is to help to impact this generation of boys diagnosed with DMD. And her perseverance is in honor of her two sons, Christopher and Patrick, whose own battles with DMD continue to motivate her efforts.

### Credits:

Created by Big Duck • [www.bigducknyc.com](http://www.bigducknyc.com)  
Debby Ziff-Cook, M.A.T., Education Consultant  
Ellen Mangelsdorf, M.Ed., Kindergarten Teacher

