

## To Whom It May Concern:

You are receiving this letter because you now have a student with the diagnosis of Duchenne muscular dystrophy. It is a rare condition and requires special care and consideration within the school setting. If you have not already done so, we ask that you do a quick review of what Duchenne muscular dystrophy is. You can find a helpful resource on our newly diagnosed page at: <https://www.cureduchenne.org/newly-diagnosed/>.

My name is Jennifer Wallace Valdes and I am a physical therapist who specializes in Duchenne. To help make school planning easier, we are providing you with this letter to share situations that many people affected by Duchenne will face while in school.

Duchenne causes muscle weakness and stiffness throughout the whole body which will progressively get worse. This means that he will experience and may already be showing signs of muscle degeneration. At this time, he may be doing fairly well, and it can be difficult to see that he is any different than other boys his age. It is important to understand that the activities he currently participates in will have an effect on the **future health of his muscles** and his **future functional capacity**.

## IN THE CLASSROOM

Your student will likely become **fatigued quickly** and shouldn't be pushed to "work harder" when they are already tired. This might happen with repetitious writing or other extended use of his hands. Reasonable accommodations for class notes and assignments might be:

1. Writing with easy gliding pens
2. Not asked to repeat writing a concept multiple times once proven that he understands
3. A scribe takes notes for him and writes his answers
4. The teacher or other proficient student provides him with a copy of the classroom notes
5. Assess his ability to use assistive technology such as a laptop or tablet to complete assignments.

Obstacles in the classroom like articles belonging to other students, chair and table legs should remain clear of walking paths for safety reasons. When floor time or "circle" time activities are scheduled, he should not be asked to rise from the floor until the activity is completed or should be provided a small chair to sit in while in the circle. His primary desk space should be set up with a desk approximately chest high, feet flat on the floor or on a

footrest, hips and knees at about 90 degrees with adequate back support. Arm rests are helpful as well.

## **AROUND CAMPUS/ RECESS**

It is important to not overuse muscles during activities or with the overall daily routine. Fatigue and weakness can lead to difficulty with walking, balance and safety issues. Here are some helpful tips for the school campus.

**Campus mobility:** Students with Duchenne fatigue easily which can cause muscle damage and fall risks. With energy conservation and safety in mind, it is typical that these students use a form of power mobility for independent adapted mobility around campus by the age of 7 years old.

**Cumulative daily activity level:** The daily routine should be adjusted to satisfy his needs for recovery time in between physically active times. Please request that the staff keep in mind the total physical demand of the day. A sign that the day has already been too much may be his tripping and falling due to fatigue. If this is occurring, then he may have already done too much that day and that level of activity can help guide appropriate planning for future days.

**Supervision:** This student might already or will soon have many limitations that affect his safety and participation in his school environment. If he is still young and learning to moderate his own activities, it is appropriate to have an adult supervise, guide and assist him to make better decisions during his daily school program. This includes limiting certain activities, assisting him with difficult activities and redirecting him to more appropriate choices as needed.

**Activities to avoid:** Ladders. Stairs. Running. Sit-Ups. Weight training. When he chooses to engage in spontaneous running and climbing activities, please request that the staff redirect him (and the kids that he is playing with) to a more safe and still fun activity. Always offer him alternative choices for play.

## **ADAPTED CURRICULUM/PHYICIAL EDUCATION and ADAPTED PE**

With Duchenne there will be development of shoulder and arm weakness leading to difficulty with stabilizing the shoulder during fine motor tasks (such as writing) and significantly impaired activity tolerance (fatigue) during tasks. Some students with Duchenne will also have a learning disability which should be accommodated through their educational plan as well.

**Timed Tests:** Accommodations, including assistance acquiring and setting up test materials, and additional time to complete tests, are justified for this individual and should be allowed during timed testing situations. Upper extremity weakness and fatigue can contribute to difficulty with test taking. He will need time to rest his arms and hands and stretch his fingers before continuing. If he has a power wheelchair, adjusting the seat angle to relieve pressure will also require additional time during testing. It is likely that he will require a rest break every 15-20 minutes.

**Physical Education:** Based on diagnosis, he should be exempt from typical physical education standards. Stretching routines, which are beneficial for his muscles, can be performed instead. He can also be given other duties such as assistant coach, team captain, lap timer, etc. His participation from the sideline in PE would still be appreciated so that he may learn things such as rules and strategies of games and sports.

He should not participate in activities which require the arms to push or to hold his body up, such as push-ups or many yoga poses. He should be excused from these activities or given alternatives which do not place physical demands on the arms.

## PARENT COMMUNICATION

If he experiences/expresses pain or fatigue, please allow him to rest on a chair or bench. To relieve mild muscle pain, gentle motion may help. Please notify his parents of any incidents of pain or fatigue. Also, please report any incidents of tripping or falling to his parents with detailed descriptions of the specifics surrounding the fall immediately, as **falls can lead to more serious medical issues** very easily.

Everyone's goal is that he remains strong, independent and safe for as long as possible. This requires a team approach from all who are involved in his daily routines. If you have any questions about Duchenne or need more resources, please feel free to contact me, <mailto:Jennifer@CureDuchenne.org>.

Thank you for taking such a great interest in your student's success,



Jennifer Valdes, PT  
Physical Therapist