**Instructions for using this document**

The following forms include a general overview of Duchenne muscular dystrophy for teachers and staff, emergency information, a medication list, and fatigue log. This was developed with the help of a mother who has a 12-year-old boy with Duchenne. Duchenne is a varied disease and there is no “typical” child with Duchenne. With that being said, you may need to edit some sections of this form depending on your child’s age, mutation, and other factors. Those sections are highlighted in yellow.

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Name:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

**What is Duchenne muscular dystrophy (DMD)?**

People with Duchenne are missing dystrophin, a protein that repairs muscles. Typically, when we exercise or exert ourselves, our muscles tear and dystrophin is used to make our muscles larger and stronger. They are born with all of their muscles, but lacking this essential protein means that every time they tear their muscles, instead of getting stronger, muscle tissue is replaced with fat and scar tissue, which leads to weakness. Therefore, even though some of their muscles appear large, the hard muscle is in reality fat and scar tissue. Eventually, ALL of the muscles will deteriorate in this way.

The weakness started primarily in his legs and trunk. Kids with DMD maneuver and shift their bodies to balance this weakness. Poking out their stomach and arching their back is a way to propel forward while lacking the strength you and I have to propel ourselves upright.

There are 79 exons within the dystrophin gene and there are numerous deletions, duplications and nonsense mutations throughout that gene that create Duchenne Muscular Dystrophy. Twin brothers who have inherited the exact same mutation can present and progress very differently throughout their disease. The adage within the community is that if you’ve known one individual with Duchenne, you’ve known one version of Duchenne.

**Disease Progression**

Although we work hard to increase his strength and prevent muscle degradation, Duchenne is a progressive disease and the function that he has now may not be the function he has next year or even next week. We do not know what the future holds. There are some with DMD who retain ambulation into their late teens, while there are others who by the age of 10 are already confined to a wheelchair. This uncertainty for the future exhibits how important our communication is so we are aware of and can address any losses in function or fatigue. It is our intention facilitate and foster communication so that we have a very successful and safe experience in school.

**Fall risk**

When he has a fall, it is usually when he is tired and fatigued. This means early in the year, in a new school with a new schedule is a time when fatigue and falls needs to be a concern. A fall for him typically occurs because he gets too tired to lift his foot enough to avoid an obstacle (a threshold, a curb, uneven ground) or worse, fatigue can cause his muscles to fail, and his knees just buckle, and he is on the floor before he’s aware he is falling.

**Typical fall**

He is often unaware it is coming and therefore doesn’t skin knees or hurt his hands, he hits his head. Falls can be very serious especially with other kids and desks and chairs and other hard, sharp surfaces.

If he takes a step or stair, please require him to use a rail and no hands in pockets while standing. He’s a boy and he’ll be risky, please take his arm and help him to safely engage in appropriate activities with as little damage as possible. Tell him his mom said so.

**Steroids**

As there is no cure for Duchenne muscular dystrophy, he takes a high dose of corticosteroid to reduce inflammation and increase his strength. The difference in his strength level after beginning his steroid regime was remarkable and they are the first line of defense against this disease, but they take as they give.

Long term steroid use causes a swollen look, called a cushoid appearance. Long term use of steroids can increase osteoporosis risk, so while strengthening his muscles, the steroid makes his bones weak and subject to fracture. Additionally, long term use of corticosteroids causes immune suppression, so he is at risk of greater illness and complications from illness, especially respiratory illnesses like the flu and COVID-19.

\*Please forgive this aside but before you question the wisdom of steroids with so many side effects, not taking the steroids means loss of ambulation at a much younger age (and earlier loss of cardiac and pulmonary function) and steroid use prevents organ crushing scoliosis by over 90%. I often say that with DMD treatment we are given two bad options to choose from.

**Physical therapy/stretching**

Our next line of defense for this unrelenting disease is Physical Therapy. The strength left in his muscles becomes unusable if they are too tight. Stretching is one of the most beneficial practices we can do to help him. He appreciates the stretching and requests being stretched or massaged in areas to alleviate discomfort. The more we stretch means the more strength he can access from the muscles he has and the longer he walks.

**Mobility scooter/power wheelchair**

He uses his scooter to reduce stress and fatigue on his muscles. It causes a lot of people to stare but when he gets right up out of his scooter the stares shift from curiosity to a range from perplexity to suspicion. The use of the scooter means that he has enough energy to get through his day. The longer we preserve his muscles means the longer he can walk and maintain bone, pulmonary and cardiac health.

**Comprehensive Neurological Center visits**

To manage the disease in the very best way possible, we also visit a comprehensive Neuromuscular center bi-annually and he typically misses about 3-4 days of school.

**Physical Education and Playground use**

It’s encouraged to allow access to board games and other activities that aren’t as physically taxing. He can use accessible playground equipment if it isn’t crowded. An inadvertent push from another kid can cause a disastrous fall.

**School Fatigue Prevention Strategies**

A daily fatigue log was a great way for us to track his wellbeing and it allowed us to be in communication with the school. Without tracking fatigue, we cannot adequately track his health.

**iPad**

Since he mispronounces some words at some times speech recognition software can sometimes be frustrating for him and he may need some help at such times. SnapType is an App we have used very successfully. The App costs around $5 to install. SnapType can turn any worksheet into a fillable electronic document. It is very important to us that the use of his hands go toward writing his name, drawing, coloring with markers or making art. We do not want to see him fatigued due to writing.

**Toileting help**

We encourage him to save bigger restroom jobs for home especially while he is only in school for half days but when he can’t wait, he needs help with wiping. We provided toilet wipes to the school for such times and will happily continue.

Help carrying

He will get too tired to carry heavier items such as lunch trays, heavy books, etc. and he will require help in this area. He won’t lie to get special treatment. If he asks for help, please help him.

We live it up for today, because we know tomorrow is not a certainty and we give today 100% so we can fully enjoy without regret. We have found that the best way of dealing with the grief of a progressive neuromuscular disease, is to give our all, and do our best. We feel that with this outlook gives us a full, amazing life and we are better people because of it.

We are happy to welcome you onto the team!

Sincerely,

Parent/guardian name(s):\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Phone #:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

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| **DMD Emergency Care Considerations** |
| This patient receives care at \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_Please consult \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ neurologist, regarding his care. Dr. Phone #:\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ |
|  |
| **Caution!** | **DRUG ALLERGY: Succinylcholine & inhaled anesthesia absolutely contraindicated** |
| Oxygen therapy in hypoxic individuals—need to monitor for the presence of hypercapnia |
| IV fluids due to frequency of heart failure in individuals with DMD age 10 years and older |
|  |
| **Common abnormal test results:** | Decreased LVEF; Decreased FVC% |
| CK, AST/SGOT, ALT/SGPT may all be elevated due to normal course of underlying DMD |
|  |
| **Common medical equipment:** | \*Request patient’s home cough assist device |
| Assess for trach, G-tube, ICD, VAD/port, non-invasive ventilatory support |
|  |
| **Initial Assessment:** | \*Review records: [MyID medical bracelet](https://www.cureduchenne.org/medical-id-bracelets/%22%20%5Ct%20%22_blank), test results, ECG results |
| Advance directive, determine any restrictions for resuscitation, if any. |
| History with a focus on respiratory and cardiac status, use of relevant devices and medications  |
| Consult with patient’s neuromuscular specialist and/or clinical trial contacts |
|  |
| **Breathing problems:** | \*Request patient’s home cough assist device |
| **Risk of respiratory failure! Inability to manifest increased breathing work can mask symptoms.**Important! Early noninvasive ventilatory (NIV) support and assisted coughing  |
| Considerations: pneumonia or atelectasis, untreated chronic or acute hypoventilation, pulmonary/fat embolism (in presence of recent extremity fracture), worsening heart failure, aspiration, or airway obstruction |
| Intubating individuals with DMD can be difficult. Likely avoided using NIV support. If deemed necessary, consider it high-risk. Complications: macroglossia; limited jaw motion |
| Obtain portable CXR where possible. Note: fat embolism syndrome (FES) may present as pneumonia |
| Monitor SpO2 level; mild hypoxemia concerning (SpO2 <95% room air); analyze blood gas  |
| Treat with noninvasive ventilation and frequent application of cough assistance device |
|  |
| **Cardiac problems:** | \*Obtain early consultation with a cardiologist |
| Obtain cardiac history, function & symptomsnote: Associated cardiomyopathy. Echo (LVEF declines with age) and ECG routine. |
| Monitor heart rate/rhythm. Obtain ECG (typically abnormal, Q waves may be expected) |
| Considerations: worsening cardiomyopathy, congestive heart failure, arrhythmias |
| Diuretic administration is acceptable |
|  |
| **Endocrine problems:** | \*Obtain early consultation with an endocrinologist |
| Risk of adrenal crisis! DMD patient treated with daily steroid; consider stress dosing  |
| **Critical adrenal insufficiency:** IV/intramuscular hydrocortisone (100mg for children >2yr and adults) |
| Less critical: consult [PJ Nicholoff Steroid Protocol](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5505768/) for DMD (available on PubMed) |
|  |
| **Orthopedic problems:** | \*Ambulatory: rapid weight bearing internal fixation; no cast |
| Assess for long-bone or vertebral fractures as indicated |
| **Consider FES** if dyspnea or altered mental status; seizure activity, pneumonia on CXR |
|  |
| **Disposition after discharge from emergency care:** |
| Consider hospital admission: initiate/intensify respiratory, cardiac therapy, manage fracture |
| Consider emergency transport to a neuromuscular center where possible. |

| Fatigue Log |  |  |  | Date: |
| --- | --- | --- | --- | --- |
| ACTIVITY | GOOD | REST | STOP | NOTE/REASON |
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| **Symptoms:**  | Pain  | Legs Hurting  |  Headache  | Stomach Ache  |
|  | Tired  | Hand Tired  |  Slumping  | Yawning  |
|  |  Complaining  |  Confused  |  Forgetful  |  Dizzy  |
|  | Fall  | Injury  | Extra Help  | More Breaks  |
| **Comments:** |  |  |  |  |
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| DrugMedication Table | Dose | Frequency | Reason Taking | Dates |
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