

MuscleFacts

School Resource Guide



Creating Awareness About Neuromuscular Disorders

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Foreword

With the generous support of Santhera Pharmaceuticals, Muscular Dystrophy Canada is pleased to make this information available. This guide was developed by a team in the Western Canada Region of Muscular Dystrophy Canada. It was adapted with permission from *Inclusive Education for Children with Muscular Dystrophy and other Neuromuscular Disorders*; and *Guidance for Primary and Secondary Schools* (Muscular Dystrophy Campaign – UK); *Getting to Know Us: Raising Disability Awareness in Alberta's Schools* (Alberta Committee of Citizens with Disabilities); and *A Teacher's Guide to Neuromuscular Disease* (MDA).

For further information about this guide, or any of the other services and programs available through Muscular Dystrophy Canada, please contact the office in your area or visit www.muscle.ca.

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MUSCULAR DYSTROPHY CANADA'S VISION & MISSION:

VISION

To find a cure for neuromuscular disorders in our lifetime.

MISSION

Muscular Dystrophy Canada's mission is to enhance the lives of those affected with neuromuscular disorders by continually working to provide ongoing support and resources while relentlessly searching for a cure through well funded research.

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Introduction

The MuscleFacts School Resource Guide was created to provide school administrators, staff and educators with information and practical tips on how to support students with neuromuscular disorders. Muscular Dystrophy Canada is committed to healthy and productive school environments that promote respect, dignity and fair treatment for all members of the school community. This resource was designed to increase awareness and an understanding of effective inclusion for students with physical disabilities within the school system.

The needs of most students with a neuromuscular disorder may change frequently throughout their studies as a result of deteriorating muscle strength due to the progressive nature of neuromuscular disorders. Schools must be prepared to respond appropriately to the changing needs of their students. For example, a child may be mobile and active when he/she enters the school, but over time, may require the use of a power wheelchair and assistance with toileting, eating and other personal care needs.

While being responsive to the changing needs of students with neuromuscular disorders is vital, it is equally important for educators to exhibit the same positive expectations for academic and social success as they would for other students. By doing so, this will increase the likelihood that students with neuromuscular disorders will develop positive expectations for themselves throughout their lives. It is also important to encourage independence and confidence by emphasizing the students' abilities and allowing students to participate in decision-making processes related to their school activities.

This guide provides information on the support a student with a neuromuscular disorder may require throughout the school day, both academically and socially. Throughout this resource, you will find tips on how to effectively include and accommodate for the needs of students with a neuromuscular disorder in the classroom and school. If you would like more information about neuromuscular disorders, or additional support, please contact your local Muscular Dystrophy Canada office (listed in the Foreword).

Chapter 1 – About Neuromuscular Disorders

1.1 Neuromuscular Disorders

The term “neuromuscular disorder” describes a wide range of conditions that have in common a weakness caused by an abnormality in either the nerves or muscles.

Muscular Dystrophy Canada provides information, support, equipment and other services for people living with more than 150 different types of neuromuscular disorders. Some disorders are present at birth, some manifest in childhood and others have an adult onset. Neuromuscular disorders affect both boys and girls; however, the most common form diagnosed in childhood, Duchenne muscular dystrophy, affects mainly boys. Although there is presently no cure for neuromuscular disorders, there are some medications and other treatments that may help manage the condition and slow the progressive deterioration in muscle strength. Despite these interventions, some of the more severe types of neuromuscular disorders will result in a limited life span. Heart and respiratory problems, which are secondary effects of muscle deterioration, are often the cause of death.

Many neuromuscular disorders, including muscular dystrophy and Friedreich’s ataxia, have a genetic basis, whereby a gene fails to produce one of the proteins required for normal muscle function. Other neuromuscular disorders, such as myasthenia gravis and Guillain-Barré syndrome, result from an autoimmune response, where the immune system attacks the body’s own tissues for no apparent reason.

Although muscle wasting isn’t painful, the resultant weakness can cause cramping, stiffness, joint deformities, chronic aches and pain, and sometimes the tightening and freezing of joints (called contractures).

In almost everyone with a neuromuscular disorder, bladder and bowel control are normal, although students may need help in the bathroom as their physical abilities weaken. Sexual function and skin sensation are usually normal.

For more detailed information about a specific neuromuscular disorder, please visit www.muscle.ca or call your local Muscular Dystrophy Canada office.

1.2 Diagnosis

Some students will have a diagnosis of their condition as they begin school, others will be undergoing investigations and tests and some will only be beginning to show signs and symptoms of a neuromuscular disorder while at school. Some early signs and common symptoms include: difficulty climbing stairs, walking or getting up from a seated position; poor balance and coordination; enlarged calf muscles; walking on toes instead of heels.

Once a child has been diagnosed with a neuromuscular disorder, it is important for educators, students and parents/guardians* to work together and maintain open communication. This will assist in developing proactive and effective individualized plans to meet the students’ needs. Ongoing dialogue between the parents and the school staff is essential to ensure that students with neuromuscular disorders reach their full potential within the school environment.

*For simplicity throughout this document, the term “parents” will be used to refer to both “parents” and “guardians.”

1.3 Cognitive Effects

Like other students, those with neuromuscular disorders exhibit a range of cognitive abilities, and many have higher-than-average intelligence.

However, muscle weakness and fatigue can make it difficult for students to keep up with the physical demands of handwriting, completing assignments and organizing materials, etc. In winter, the increased susceptibility to (and life-threatening consequences of) respiratory infections may cause students to miss many days of school.

A few types of neuromuscular disorders, for example Duchenne muscular dystrophy and congenital muscular dystrophy, are associated with an increased risk of learning disabilities. This may affect a student's ability to focus, verbal learning and memory, emotional interactions and ability to read and understand concepts. These students benefit from the appropriate accommodations for learning disabilities.

Students with neuromuscular disorders usually qualify for special education services based on their physical disabilities, learning disabilities or both. Throughout their school careers, most are placed in mainstream classrooms with supports. These students should have an Individual Education Plan (IEP), outlining educational goals, strategies and supports, including appropriate accommodations and program modifications.

Chapter 2 – Working Together

2.1 Working with Education Staff

Teamwork is the only way to provide an effective school response to meeting the changing needs of students with a neuromuscular disorder. Liaisons between school staff and external contacts are vital, and the identification of a “key worker” within the school is essential.

Any member of school staff can act as the key worker, but it is often the role of a special education teacher or educational assistant. The key worker helps staff plan and manage the student’s development on a daily basis, setting clear objectives to maximize independent mobility and encouraging the use of gross and fine motor skills. It ought to be a goal of the school to ensure the continued development of social skills and self-esteem.

TIPS

- ❖ Invite guest speakers from community agencies like Muscular Dystrophy Canada to staff training sessions.
- ❖ Incorporate training sessions into professional development days.

2.2 Working with Parents and the Student

Parents have a critical role to play in their child’s education. They possess unique strengths, knowledge, information, and experiences, which are vital to an overall view of their child’s needs and the plans to support them. Open, clear communication between home and school is essential for fostering an effective working relationship between educators and parents. Keep in mind that parents are asked to attend many meetings and appointments, which can be both extremely stressful as well as emotionally and physically demanding.

It is important for students to participate in and contribute to discussions about their education, particularly as they become older and more aware of their physical differences.

TIPS

- ❖ Inform parents of how to contact the key worker.
- ❖ Establish a “home/school message book” to facilitate daily, two-way communications between parents and teacher(s). This strategy can be particularly helpful when there are several teachers who work with the student, which is common in secondary school.

2.3 Working with Health Care Professionals

Often, many health care professionals will work with schools and families as a multidisciplinary team. **Occupational therapists** (OTs) advise on appropriate equipment and adaptations for maximum independence. This may include advice on seating, wheelchairs, lifting, moving and handling and the use of other specialized equipment both in school and at home. **Physiotherapists** (PTs) help children/youth reach their maximum physical potential. They aim to minimize the development of contractures and deformity through a program of stretches (and exercises, where appropriate). Physiotherapists can prescribe specialized equipment and aids such as orthopedic shoes, wheelchairs and standing frames. They can also give advice on moving and transferring issues. **Dietitians** provide advice on specialized diets, weight loss, weight gain and nutritional requirements. **Speech and language pathologists** (SLPs) assist students with speech, language and communication difficulties. They also work closely with dietitians and other therapists, and can offer advice if a child has difficulty with biting, swallowing or chewing.

TIPS

- ❖ Contact Muscular Dystrophy Canada for information about local health professionals and service providers in your community.
- ❖ Arrange multi-agency meetings as necessary.
- ❖ Coordinate meetings with external resources in the community, i.e. interdisciplinary health care professionals who can provide support to students and school staff.

Chapter 3 – Emotional and Psychological Issues

3.1 The Student's Needs

3.1.1 General Emotional and Psychological Issues

Psychological support for the student is invaluable. Professionals can provide this, but students will often seek support from those at school with whom they feel comfortable. Often, the most valuable support for a young person with a neuromuscular disorder comes from a peer with a similar condition. Liaising with staff at Muscular Dystrophy Canada or advisory teachers can provide opportunities for this type of peer support.

Understanding a student's condition is important when creating realistic expectations. It is essential to concentrate on what they can do rather than what they can no longer do, and to allow them to make their own decisions.

Working toward social integration can be difficult, and it is important to give students the opportunity to interact with their peers without adult supervision. A buddy or peer support system can be particularly helpful during breaks and lunchtimes to promote positive social interactions and independence.

3.1.2 Behavioural Challenges

Students with a neuromuscular disorder need the same structure and discipline in class as everyone else. The usual positive classroom management strategies should be employed in line with school policies. If a student is treated differently than everyone else, he/she may continue to push those boundaries and create problems within the classroom. But it is necessary to acknowledge and understand that students may have difficulty expressing complex feelings related to their condition and may behave in an angry, frustrated, stubborn or withdrawn manner.

TIPS

- ❖ Coordinate an Individual Education Plan (IEP) meeting to address the behavioural issue.
- ❖ Avoid expressing pity for the student.

3.1.3 Depression and Anxiety

Any student can experience depression and anxiety. This may become apparent in a few ways: lethargy, withdrawal, irritability, changes in appetite, changes in sleep patterns, lack of interest and poor academic performance.

For students with neuromuscular disorders in particular, these feelings are a normal reaction to their deteriorating condition. Staff should be aware of this possibility and closely monitor negative changes in performance and relationships within the school environment. If changes are sustained over a period of time, it might be wise to notify the student's parents, so that appropriate support and treatment can be sought.

3.1.4 Self-Esteem and Body Image

Some students with a neuromuscular disorder may have low self-esteem and poor body image. Lack of inclusion in school can proliferate these feelings, increasing the likelihood that these students will be bullied or tolerate poor-quality care. Research shows that people with disabilities are more likely to suffer physical, sexual or emotional abuse than their able-bodied peers.

Staff can enhance self-esteem by promoting opportunities to succeed, and by using positive role models whenever possible in teaching. Individuals with deteriorating neuromuscular disorders will be adapting constantly to a changing body image, but it is definitely possible to help students improve their confidence and develop their own individual style.

TIPS

- ❖ Utilize the following bullying-prevention strategies:
 - Find out if the student is comfortable talking about his/her disability with the class – this will reduce discomfort among his/her fellow students caused by fear of the unfamiliar.
 - Educate the class about disability awareness and etiquette (See section 3.2.5 for more information).
 - Create opportunities to integrate – avoid labelling and singling out a child.
 - Review the anti-bullying policies at your school, and encourage students to hold regular meetings to monitor and discuss rules and how to respond to bullying.

3.1.5 Sexuality and Relationships

Young people with a neuromuscular disorder will have the same anxieties and experiences as others their age, including hormonal swings. They may also wish to explore their sexuality through discussion or other means.

A young person with a neuromuscular disorder might have additional questions relating to their own physical needs and abilities, such as “Will I ever have a girlfriend/boyfriend?” or “Will anyone find me attractive with my disability?” or “Can I get married and have a family?” These questions, if asked in school, must be answered sensitively and factually.

TIPS

- ❖ When preparing sexual education classes, the teacher may want to consider:
 - What issues may arise for the student with a neuromuscular disorder?
 - Have I had a chance to speak to the student about any concerns before the lesson?
 - Would the student find it helpful for me to talk to his/her parents to follow up on issues that arose?
 - How will I deal with any questions the student may have?
 - If there are questions I can't answer, to whom can I refer the student?
 - What disability support groups exist for the student?

3.2 Support for the Community

3.2.1 Support for the Family

Coming to terms with a diagnosis is not necessarily a static situation. It is often a period of fluctuating emotions for the entire family, and this could continue for a long time. Parents handle the diagnosis of a neuromuscular disorder in a variety of ways. Where the prognosis of the condition is life limiting, there is likely to be a range of reactions, but all parents must face living with their child's deteriorating condition. Some feelings may resurface as the condition progresses and the child begins to lose specific skills.

Some families will tell their child everything about the condition, others will give their son or daughter limited information, and some will say nothing. From time to time, students with neuromuscular disorders may approach school personnel with searching questions about their condition. In these situations, it is vital for staff to refrain from providing any information on the subject in light of varying disorder outcome possibilities and parental views regarding prognosis disclosure. Instead, staff should encourage these students to redirect such inquiries to their parents. This practice will help to ensure that staff members do not provide conflicting or erroneous information.

It is important to note, however, that redirecting students back to their parents to answer searching questions may not always be successful. In these situations, it may be helpful for school staff to encourage the students to explore other avenues. This could be accomplished by simply asking, "Where else could you find this kind of information?" Schools are a place of knowledge exploration and self-discovery, so it would be quite appropriate for staff to respond in such a manner. If students decide to search out such information on their own, staff should follow up with them and encourage them to discuss with their parents any information that concerns them.

3.2.2 Support for Siblings

Many siblings can feel left out of what is going on, and may experience a range of complex feelings, including loss, jealousy, guilt and anxiety. If you are concerned about the sibling of a child with a neuromuscular disorder, you should raise the subject with the family and agree on a support plan. Siblings may benefit from having someone to talk to outside of the family, and it could be helpful for them to know that there is an identified adult in the school who can provide them with emotional support.

3.2.3 Support for School Staff

Having a child in the classroom with a deteriorating condition will have a practical, emotional and psychological impact on school staff. They will need information about the condition and the anticipated effect on the child, including how to manage this in a classroom situation.

TIPS

- ❖ Invite a community agency, such as Muscular Dystrophy Canada, or a health professional to lead an information session on neuromuscular disorders as part of a professional development workshop.

3.2.4 Support for Other Students

The school must consider the emotional and psychological needs of all students. Other students might not know the diagnosis, but ought to be made aware of general issues regarding disability. With neuromuscular disorders in particular, students should be made aware of the changing needs of their peer(s). For example, students should know that their classmate(s) might walk sometimes, but use a wheelchair or other equipment at another time. The child's close friends might require particular attention.

TIPS

- ❖ Use the following strategies to deal with the unlikely death of a student with a neuromuscular disorder:
 - Acknowledge, rather than ignore, the death – do something to mark the fact that someone has died.
 - Tell small groups before telling the whole school; be aware of any “best friends” and do some thing different for them.
 - Recognize the death as a loss for the class as well as the entire school.
 - Immediately acknowledge that the student isn't there, and avoid changing the layout of the classroom right away.
 - Allow staff and students to show their emotions and to admit that they are finding the situation difficult – give everyone permission to feel sad or to cry.

3.2.5 Disability Etiquette

Ask Before You Help

Don't assume that someone with a disability needs help. If the setting is accessible, people with disabilities can usually get around fine. Offer assistance only if the student appears to need it. If he or she wants help, ask how before you act.

Be Sensitive About Physical Contact

Avoid touching a student's wheelchair, as some people with disabilities consider equipment to be part of their personal space.

Think Before You Speak

Always speak directly to a student with a disability, not to his or her aide. Also keep in mind the terminology you choose to use. Avoid terms like handicapped, confined to a wheelchair, afflicted or suffers from. Try to use such phrases as person with a disability, wheelchair user and person born with a disability.

Don't Make Assumptions

People with disabilities are the best judge of what type of support they require. Don't make decisions for them about participating in any activity.

Chapter 4 – Health Issues

4.1 The Individual Health Care Plan

It is common practice to draw up an Individual Health Care Plan (IHCP) for students with a medical condition. The IHCP should summarize the student's condition, identify procedures for emergency situations and provide any other relevant information, examples of which are highlighted in this chapter. Schools should agree with parents regarding how frequently the IHCP will be jointly reviewed (the recommendation is at least once a year). A written agreement between the school and the parents helps clarify the roles and responsibilities, as well as establishes a basis for ongoing communication and evaluation.

Some school districts issue students “medical cards,” which can be accessed by school staff when needed, containing information about the child's condition.

TIPS

- ❖ Ensure that all staff who interact with the student, including principals, school nurses, classroom and special education teachers/assistants and substitute staff, are informed of any health-related procedures or protocols.

4.2 Common Implications of a Neuromuscular Disorder

4.2.1 Mobility

Some students with a neuromuscular disorder will be independently mobile, while others might use specialized equipment such as wheelchairs, splints, calipers or standing frames to help increase mobility. A student may alternate between walking and using a wheelchair for short periods of the day. For example, during recess or other break times, a student who is able to walk may sometimes need to use a wheelchair. As muscle strength deteriorates, he/she may need to use a wheelchair all the time, and this change could take place quickly.

TIPS

- ❖ To balance safety concerns with the student's need for independence, provide increased but non-intrusive adult supervision.
- ❖ Provide preferential seating so the student has extra room and can easily enter and exit the classroom.
- ❖ Provide extra time for transition between classes/locations in the school.
- ❖ Allow the student to go through the halls when they are less congested (slightly before or after the bell).
- ❖ Consider accessibility needs when planning field trips.

4.2.2 Falling/Losing Balance

There will be some students with a neuromuscular disorder who are able to walk but are at risk of losing their balance because of muscle weakness. This will worsen as their condition deteriorates; some of these students will then require the use of a wheelchair. A child with balance difficulties could also have problems in the playground during windy, icy and/or snowy conditions.

4.2.3 Fatigue

Fatigue is likely to be a problem for students with a neuromuscular disorder. Fatigue can affect behaviour as well as ability to concentrate, learn and take part in a full curriculum. The level of tiredness can fluctuate from day to day, and even within the day. It could become more of an issue as the child gets older.

Physical exertion, changes to routine, and health-related issues can influence fatigue. Some may also experience nocturnal hypoventilation (see Section 4.3.5), which may make the student feel lethargic and possibly lead to difficulty concentrating. Additionally, the student might have many headaches and could find it difficult to get going in the mornings.

TIPS

- ❖ Whenever possible, introduce new concepts early in the day.
- ❖ Provide the student with a place to rest during the day.
- ❖ Allow extra time to complete tasks in the afternoon, when the student may be tired.

4.2.4 Upper Limb Function

The upper limbs are often affected by a neuromuscular disorder, but this may not always be immediately apparent. For example, a child may not be able to raise his/her hand to call for the teacher's attention or respond to a question. Hand function, power and manipulation skills may also be compromised, and therefore impact a wide range of activities. A student with weakness in the upper limbs may also need help with self-care when getting changed for physical education, games, swimming or when putting on outdoor clothing.

TIPS

- ❖ Maximize hand function by paying attention to table height and seating position and by offering ergonomic pencil grips, calculators and sloping desks.
- ❖ To help students cope with the volume of written work required in class, consider introducing alternative methods of recording information, such as a student note-taker, electronic recordings and/or photocopies of the relevant materials.
- ❖ Since special arrangements may be required for exams, ensure that the student is familiar with these provisions ahead of time. Ensure that the student and/or parents are made aware if a medical letter is required for authorization of such arrangements.
- ❖ Make sure that all work tools and books are easily accessible – heavy textbooks and objects could also cause difficulties. Consider providing the student with two sets of text books, in order to eliminate the need to carry heavy books between home and school.
- ❖ Implement a communication strategy with the student to ensure his/her ability to participate in classroom discussion, i.e. establish eye contact or a designated signal if the student is unable to raise his/her hand.

4.2.5 Lower Limb Function

The lower limbs are often affected in many neuromuscular disorders. For example, a student may have difficulty getting up from the floor or from a sitting position. As the disorder progresses, the student may have trouble walking due to weakening pelvic and quadricep muscles. The student may walk on the balls of his/her feet with a slight rolling gait. In order to compensate for a weak trunk, the student may stick out his/her belly and throw his/her shoulders back in an effort to balance when walking.

TIPS

- ❖ Provide a chair as an alternative to sitting on the floor to make it easier for the student to move from a sitting to a standing position.

4.2.6 Communication Needs

Students with a neuromuscular disorder may have quiet voices due to the weakness of their respiratory and upper airway muscles. This might make them nervous about speaking in groups or in a noisy environment. Delayed language development has also been reported in some forms of muscular dystrophy. Students may have difficulties with auditory learning, causing them to struggle with retention and processing of complex spoken information.

Students with weak facial muscles may encounter language difficulties because of a lack of strength in the muscles used for articulation. Non-verbal facial expressions can also be affected by these muscle weaknesses. For example, a child with severe facial weakness may find it impossible to smile or show emotion through facial expressions.

TIPS

- ❖ To assist the child's social development, in consultation with the student and family, provide careful and sensitive explanations to other students about effects caused by the child's medical condition.
- ❖ Respect the need to wait for a response from a student with communication difficulties.
- ❖ Consider seating the student near the front of the class or having him/her use a speech amplifier to be heard more easily.
- ❖ Suggest communication devices that allow students with weak speech muscles to convey their needs and thoughts.

4.2.7 Moving and Transferring

There are likely to be moving and transferring considerations for many students with neuromuscular disorders, especially as they become unable to support some or all of their weight. First and foremost, always give consideration to the privacy, dignity, independence and views of the student. The student should be consulted for advice specific to his/her own needs. Appropriate professionals (such as physiotherapists, occupational therapists or advisory teachers) may also be able to provide valuable input. Based on this feedback, a strategy to manage moving and transferring should be developed and implemented consistently throughout the school. The strategy should be revisited regularly, as the student's body and needs may change.

4.2.8 Temperature Control

Temperature changes can affect the mobility of a person with a neuromuscular disorder. People with neuromuscular disorders may be less able to generate body heat, and are more susceptible to a cold environment both indoors and outdoors.

TIPS

- ❖ Check with the student to determine what, if anything, would help him/her to feel more comfortable within these environments.
- ❖ Encourage the student to dress appropriately for each environment.

4.2.9 Eating & Swallowing

Due to the shape of their mouths or weakness in their chewing, swallowing or upper limb muscles, some children with neuromuscular disorders have difficulty eating and swallowing. Food or drink may go down the wrong way and enter the lungs rather than the stomach (aspiration). In other cases, they may find that they can only eat very slowly. It is important to discuss with the student and parents how to manage the situation appropriately.

TIPS

- ❖ Since talking while eating may cause a higher risk of aspiration, ask the student if he/she would like to have a slightly earlier start time for lunch.
- ❖ If a student needs to use a naso-gastric (NG) tube or a gastrostomy tube (G-tube) to deliver specially prepared food directly to the stomach while at school, be prepared to discuss and include this in the Individual Health Care Plan.
- ❖ To help enable students with upper limb muscle weakness to feed themselves more effectively and maintain independence, consider the use of height-adjustable tables, mobile arm supports and adapted cutlery.

4.2.10 Washroom Use

Thought must be given to the washroom needs of any student with a disability. At a minimum, they will require an accessible toilet. A full-time wheelchair user will also need lifting facilities and sufficient space to allow safe moving and transferring on and off the toilet while being assisted by a caregiver. Students may also need more time to go to and from the toilet, and some may be unable to wait and need to use toileting facilities immediately. The type of assistance the child requires and the most appropriate person to provide it must be considered in consultation with the student and/or parents.

The majority of students with a neuromuscular disorder will not have a problem with continence. However, some will avoid going to the washroom regularly because they are self-conscious about asking for assistance. This can become more of an issue as children develop into self-aware adolescents. Staff must be sensitive while trying to establish whether this is causing difficulties.

TIPS

- ❖ Ensure that wheelchair-accessible washrooms and equipment will be available on out-of-school excursions.
- ❖ Be sensitive toward students who have to wear incontinence products.
- ❖ Allow students extra time to meet personal care needs.

4.3 Medical Treatments

4.3.1 Physiotherapy

Physiotherapy often plays a major role in managing a neuromuscular disorder. Following diagnosis, the parents will receive advice on an appropriate physiotherapy regime. This may involve stretches, exercises, hydrotherapy and advice on respiratory care. The program may sometimes need to be carried out at school. It may be incorporated into physical education lessons. Specialized equipment may be required. These requirements should be outlined in the students Individual Education Plan and the Individual Health Care Plan.

TIPS

- ❖ Recognize that a student may have physiotherapy after school, and that fatigue may affect his/her ability to complete homework assignments in the evening. Ask parents to provide information as to which days are heavily scheduled after school.

4.3.2 Medication & Steroids

Steroids may be effective in slowing the loss of muscle function and increasing muscle strength for some neuromuscular disorders, such as Duchenne muscular dystrophy. Steroids are not a cure, and they may have some undesirable side effects, such as delayed puberty, loss of bone mass, weight gain and difficulties with thinking, sleeping and controlling behaviour.

4.3.3 Orthotics, Splints and Calipers

Some students may be required to wear orthoses. The most common type are the ankle-foot orthoses (AFOs), which keep the ankle and foot in an appropriate position. Larger orthoses, such as lightweight calipers, might also be needed. These enable independent mobility, and are known as knee-ankle-foot orthoses (KAFOs).

4.3.4 Hospital Stays

Students with a neuromuscular disorder may be admitted to hospital at some point, or require certain forms of planned surgery. Most commonly, they will need orthopedic surgery on the ankles and/or feet, but they might also undergo complex surgery to correct curvature of the spine. If this is the case, more than one operation on the spine may be necessary.

TIPS

- ❖ When a student returns home after surgery, consider assigning some school work to prevent the student from falling too far behind.
- ❖ Be aware that home tutoring may be necessary with phased school re-entry as a student recovers from surgery.
- ❖ Arrange for a study buddy within the class to help the student keep up with missed work during absences from school.

4.3.5 Respiratory Complications

As some students with neuromuscular disorders have very weak respiratory muscles, health care professionals monitor them carefully. Early treatment of coughs, colds and respiratory infections is necessary as such children can become ill quite quickly.

Weak respiratory muscles may result in a student becoming unable to breathe effectively while asleep, causing a build up of carbon dioxide in the body such that the student may feel lethargic and unable to concentrate at times. Additionally, the child might have many headaches and could find it difficult to get going in the morning. Some students may benefit from the use of ventilation devices during the night, while others may be totally ventilator dependent.

TIPS

- ❖ Respiratory complications may lead to extended school absences, but may not interfere with a student's ability to do school work at home.
- ❖ Ensure that students and staff follow proper hygiene and hand-washing procedures.

4.4 Staying Healthy

4.4.1 Nutrition and Exercise

Any excessive weight gain will put an additional burden on already weakened muscles. However, it can be difficult for a child with fatigue or limited mobility to lose weight. As a general principle, encourage exercise within the student's own capabilities. Swimming provides a supported medium for movement, helping to maintain a range of movement in the joints, and is an excellent form of exercise for students with a neuromuscular disorder. However, participation in any type of activity will depend on individual abilities, and therefore any exercises should be first approved by the student's health care team and/or parents.

While some students with a neuromuscular disorder may be prone to putting on excessive weight, others may be underweight. Due to self-consciousness about the need for help when eating or because of difficulties with chewing and swallowing, he/she may not take in enough calories during the day.

TIPS

- ❖ Allow students to drink fluids throughout the day to help prevent dehydration and bladder infections.
- ❖ Adopt an inclusive approach to physical education — with the guidance of a physiotherapist, this may involve incorporating assisted stretches into the classes.
- ❖ If students appear to be having difficulty feeding themselves, privately ask if they would like any type of assistance. An occupational therapist may recommend the use of a height-adjustable table, adapted cutlery or special dishes.

4.4.2 Physical Education Classes

Some mobile students will push themselves to participate fully in physical education classes, but it's important to recognize that they may suffer from fatigue and leg cramps as a result. While moderate exercise may benefit the child, overdoing it can be very counter-effective. Try to offer alternative or adapted activities for the student (see [Appendix A](#)).

TIPS

- ❖ Try introducing your class to a wheelchair-adapted sport or activity.

4.5 Medical Emergencies

It is unlikely that a student with a neuromuscular disorder will have a medical emergency at school. However, if there is an emergency situation, it should be handled in the same manner as for any other student. The parents must be notified if the student is unwell, and an ambulance should be called for a medical emergency.

Chapter 5 – Environmental Considerations

5.1 Accessibility

5.1.1 Considerations

Any adaptations made with the goal of increasing accessibility and enabling independence should be suitable for people with a range of different needs, feature a flexible design and take into consideration the safety of caregivers.

TIPS

- ❖ When it comes to access, consider the needs of the following categories of people:
 - Students who are able to walk.
 - Students who use a wheelchair and are able to transfer out of their wheelchairs independently or with minimal help.
 - Students who use a wheelchair and are unable to transfer out of their wheelchairs independently.
- ❖ Since accessibility means different things to different people, talk to the student to make sure that appropriate accommodations are made for all of his/her extracurricular activities or out-of-school excursions.
- ❖ Find strategies to ensure full inclusion in performances and concerts.

5.1.2 The School Building

Meeting the needs of a student with a neuromuscular disorder may mean altering and adapting the school site. This is best evaluated by a site inspection of the entire school to ensure full accessibility.

TIPS

- ❖ When evaluating the accessibility of a school, check for the following:
 - Availability of ramps, elevators or step lifts as an alternative to stairs.
 - Installation of handrails on steps both inside and outside the building.
 - Removal of obstacles and hazards, such as uneven ground surfaces.
 - Adequate space for wheelchairs to pass without difficulty.
 - Provisions in place that allow students enough time to get from one area of the school to another.
- ❖ Give students with neuromuscular disorders the option to leave class a few minutes before or after their peers to avoid the rush in busy hallways.

5.1.3 Access to the Classroom

Power wheelchairs can be quite large, but they are very easy to manoeuvre and students with neuromuscular disorders will become proficient at handling them. It is important to ensure that there is clear access to the student's classrooms. This may mean rearranging classroom furniture in every area the student uses. It's also worth considering where the student is situated within the classroom. Any sensory impairment should also be considered when allocating tables/desks to students. Furthermore, during classroom activities it is important to have a proper table/tray for the student in order to maximize upper limb and hand function.

TIPS

- ❖ Encourage all students to keep classroom aisles clear of bags and coats.
- ❖ Arrange furniture to allow for a clear path into and out of the classroom.
- ❖ Consider alternate arrangements that may need to be made if classrooms are upstairs – place student in rooms on the ground floor whenever possible.

5.1.4 Elevators

Elevators may need to be installed to make the school site accessible. If elevators already exist, ensure they are suitable to accommodate the student's needs.

TIPS

- ❖ For small flights of stairs, consider step lifts as an elevator alternative.

5.1.5 Playgrounds

Consider the playground's location. Exposed north-facing sites can be windy and cold, which may cause difficulties for students with a neuromuscular disorder (see **Section 4.2.8**). Benches provide ambulatory students a chance to rest, and allow students with balance and co-ordination difficulties to sit safely with their friends. Benches also encourage social interaction for wheelchair users, enabling other students to communicate at the same eye level. Certain playground surfaces will be easier for students in wheelchairs to navigate.

TIPS

- ❖ Provide benches in playground areas for rest opportunities during break times.
- ❖ When planning for playground development or upgrades, encourage the school to purchase some wheelchair-accessible playground equipment.
- ❖ Be aware that students who usually walk may require a wheelchair during recess or other break times.
- ❖ Encourage the buddy system during breaks.

5.1.6 Storage

Students will need to store special equipment, such as standing frames, mobile arm supports and lifts, in a secure place.

TIPS

- ❖ Given that students with muscle weakness may find it tiring to carry bags full of school books, consider providing a secure locker or storage room.

5.1.7 Emergency Evacuation Procedures

If a student with a neuromuscular disorder is unable to exit the school building in the same manner as able-bodied students, then a new evacuation plan must be devised and implemented. To develop emergency evacuation procedures for students with disabilities, a complete assessment and review is recommended. All emergency exits should be checked for accessibility. Staff and students should be made aware of the evacuation procedures and encouraged to rehearse them from time to time.

TIPS

- ❖ If conducting an evacuation rehearsal for an entire classroom is too challenging, consider rehearsing with the student with a neuromuscular disorder ahead of time.

5.1.8 Accessible Transportation

Students with a neuromuscular disorder who receive transportation to and from school may require an adapted vehicle. For wheelchair users, this involves accessible vehicles with ramps/tailgate lifts, appropriate safety harnesses and an anchor system to fix the wheelchair in place. While travelling, a headrest should be attached to the wheelchair to prevent the possibility of a whiplash injury in the case of a sudden stop. Students who are able to walk may find it difficult or impossible to negotiate the steps on school buses, so special consideration for their needs is necessary. Transportation needs must be reassessed and altered as the student's muscle strength changes.

Long periods of time spent on school transportation can be exhausting for students with a neuromuscular disorder, who may tire more easily. With weakened muscles, it is difficult and strenuous to maintain postural stability in a moving vehicle. This could adversely affect their ability to concentrate while at school or to complete homework later in the day.

These points must be considered when planning school trips. Accessible transportation is required for the students to participate in and benefit from school clubs and activities.

TIPS

- ❖ Establish an appropriate drop-off/pick-up point for vehicles, and nominate a staff member to meet the student upon arrival at the school.
- ❖ Ensure the parents are informed of any changes to transportation arrangements.

5.2 Equipment

Typically, students with a neuromuscular disorder will be supported by a health care team, including an **occupational therapist** and **physiotherapist**, who may prescribe various types of equipment to meet the student's changing needs. Teachers and educational assistants may be required to receive training on proper use of equipment. Examples of some of the common types of equipment are described below.

TIPS

- ❖ Muscular Dystrophy Canada has financial support programs to help people with neuromuscular disorders obtain the equipment they require. Contact your local office for more information.

5.2.1 Wheelchairs

Some students may use a power wheelchair, while others will utilize a manual wheelchair. In the case of a manual wheelchair, staff will need basic training on collapsing it and using it safely. Extra supports can be used with a wheelchair, and it is essential that staff involved with the care of a student know how these should be positioned to help maintain good posture.

5.2.2 Special Seating

The student's seating position is important, considering that weakness of the trunk muscles can cause problems with the spine. To maximize the use of their upper limbs, some students will use a school chair that offers support and independent movement. Students who use wheelchairs may have seating inserts in their wheelchairs to provide postural support and prolong functional ability. They may also have special cushions to prevent pressure sores.

TIPS

- ❖ Be aware that reviews, adaptations and modifications to a student's seating will be needed as muscle strength deteriorates.

5.2.3 Standing Frames

A standing frame puts a person in a standing position and stretches the muscles and joints. Standing frames allow nonambulatory students to continue to bear weight on their legs, promoting healthier bones, better circulation and a straighter spine.

TIPS

- ❖ To minimize loss of teaching time and to allow for transfer, plan for the student to use a standing frame either immediately before or after breaks.
- ❖ For good hand function, place a height-adjustable table alongside a standing frame.

5.2.4 Height-adjustable Tables

The student should have access to a table of an appropriate height, which provides support for the elbows and forearms and maximizes upper limb function.

5.2.5 Mechanical Lifts/Slings

Special equipment is needed to safely transfer a student. There are two main types of lifts: mobile lifts that can be electrically or manually operated, and will require an appropriate storage space, and electrically operated tracking lifts that use a fixed tracking system.

Lifts are used in conjunction with slings. A one-piece sling for people with a neuromuscular disorder is available from most manufacturers. It supports the base of the spine to either the shoulder or crown of the head, and includes support and padding for posture and comfort.

Chapter 6 – Educational and School Policies

6.1 Students with Special Needs

TIPS

- ❖ Consider getting a special education assessment or consultation if the student:
 - Is making little or no progress, even when teaching is targeted at his/her identified area of weakness.
 - Is having trouble developing literacy and numeric skills.
 - Has persistent emotional and/or behavioural difficulties that are not resolved by the school's usual behaviour management techniques.
 - Has physical or sensory difficulties, and makes little or no progress despite the availability of specialized equipment.
 - Has communication and/or social interaction difficulties, and makes little or no progress despite the provision of a differentiated curriculum.
- ❖ When evaluating the progress of the student, please consider:
 - How the child's physical condition is affecting his/her learning/mobility.
 - How the situation is being monitored, recorded and reviewed.
 - Whether a psycho-educational assessment should be requested.
 - Arranging for a school team meeting to discuss and review the situation.

6.2 School Guidelines and Policies

All schools have policies and procedures in place to deal with a multitude of concerns, ranging from formal written policies to basic non-written protocol.

Issues of special concern when working with students with neuromuscular disorders might include a Student Protection Policy, an appropriate Discipline/Positive Behaviour Policy, strategies to deal with bullying, and a School Uniform Policy.

Please refer to your school policies and procedures in relation to all topics included in this MuscleFacts guide.

Chapter 7 – Planning for Future Pathways

The aim of transition planning should be to prepare young people for employment, training and/or further education. It should encourage them to contribute to community life and become independent. It is very important to begin transition planning early, starting at least by grade 10. Unlike other students, students with disabilities have a lot more to plan for once they turn “of age,” and the services offered to them as youth are no longer available to adults.

TIPS

- ❖ Incorporate the following activities into a transition plan:
 - Ascertain the student's views and aspirations, and ensure that they are in line with the student's curriculum.
 - Determine what information is required to help the student make informed choices and decisions.
 - Provide help and information to parents to support the student's goals.
 - Determine whether work experience is appropriate, and help facilitate a placement.
 - Provide support throughout the application and admission process for post-secondary education.

Chapter 8 – Facilitating Disability Discussions

If you have a student with a disability in your classroom, you will want to ensure ahead of time that he/she is comfortable with a class discussion on his/her disability and/or a guest presentation.

TIPS

- ❖ Follow these steps when initiating discussions about disability issues:
 - Explain the content of the lessons to the student and parents ahead of time.
 - If the student is comfortable talking to the class, invite the student to explain his/her situation and discuss activities that are challenging.
 - Choose follow-up activities that are relevant to the student's disability.
 - Invite the student's parents to join you for the lessons.
 - When speaking with the student and parents, find out if there is a sibling who would like to speak to the class.
- ❖ Consider using one of the following disability awareness activities:
 - Pair up students and have them draw themselves and their partner, noting their similarities and differences. Have the students talk about how their body parts are different from each other. Emphasize that everyone has their own unique skills and things at which they excel.
 - Facilitate a discussion about people with disabilities known to your students: grandparents, other relatives, neighbours and celebrities. Talk about some of their strengths or abilities.
- ❖ Contact Muscular Dystrophy Canada to get more information or to set up a disability awareness presentation at your school.

Chapter 9 - Summary

Muscular Dystrophy Canada's mission is to enhance the lives of those affected by neuromuscular disorders by providing ongoing support and resources while searching for a cure through research.

Please contact the Muscular Dystrophy Canada office nearest you to learn more about our programs and services, including presentations for students and educators. (Refer to the Foreword for a listing of regional offices.)

When working with students with neuromuscular disorders, remember that:

- They face physical, academic and social challenges.
- Learning disabilities are more prevalent in some neuromuscular diseases, but most have a normal range of intelligence.
- Students may need alternative methods (besides written work) of demonstrating academic comprehension.
- With imagination, almost any activity can be adapted to be accessible.
- Cooperation and open communication between the school and the family is essential.
- A team approach involving the family, the health care team and educators will help ensure that the student's needs are understood and supported.
- A positive environment in which the student is accepted and included will foster learning and development.

As you encourage your student to develop his/her strengths, remember to draw on your own strengths as a teacher: Be creative, empathetic, firm, flexible and – as much as possible – treat your student with a neuromuscular disorder like everyone else in your class.

Appendix A – Online Resources

Muscular Dystrophy Canada

Our website features disorder-specific information and details about our many services.

www.muscle.ca

Abilities

Enablelink is a unique resource with a variety of disability topics and articles.

www.abilities.ca/

Muscular Dystrophy Association

This American website contains articles and information regarding neuromuscular disorders.

www.mda.org

Sports and Recreational Activities for People with Physical Disabilities

An excellent resource for accessible activities and exercise for youth with disabilities.

www.mobility-advisor.com

The Centre for Active Living

An organization that works with practitioners, organizations and communities to improve the health and quality of life of Canadians through physical activity.

www.centre4activeliving.ca/

www.activeliving.ca

The National Center on Physical Activity and Disability

An excellent resource for accessible activities and exercise for youth with disabilities.

www.ncpad.com

The Rick Hansen Foundation

This site will give specific lesson plans around disability awareness that fit within the existing curriculum.

www.rickhansen.com

Muscular Dystrophy Canada's mission is to enhance the lives of those affected with neuromuscular disorders by continually working to provide ongoing support and resources while relentlessly searching for a cure through well funded research.



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