

# MuscleFacts™

## Teachers' Resource Guide



**Creating Awareness About  
Physical Disabilities**

# Foreword

This guide was developed by a team in the Western Canada Region of Muscular Dystrophy Canada. It in turn was adapted from the existing literature:

- *Inclusive Education for Children with Muscular Dystrophy and other Neuromuscular Disorders; Guidance for Primary and Secondary Schools*  
(Created by the UK's Muscular Dystrophy Campaign)
- *Getting to Know Us: Raising Disability Awareness in Alberta's Schools*  
(Created by the Alberta Committee of Citizens with Disabilities)

For further information about this guide, or any of the other services and programs available through Muscular Dystrophy Canada, please contact us at:

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Find your local office in **Appendix B – MDC Regional Contacts**.

## THE MISSION OF MUSCULAR DYSTROPHY CANADA IS TO:

**Support** the independence and full participation of children, youth, and adult Canadians with neuromuscular disorders.

**Assist** individuals to participate in the decisions that affect them and collaborate with others for social change.

**Fund** research to improve the quality of life of people with neuromuscular disorders and to find a cure.

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# Introduction

MuscleFacts™ was created to provide a support system for schools, teachers, parents, and students with or without a neuromuscular disorder. This resource was designed to create awareness and an understanding of the importance of effective inclusion for students with physical disabilities within the school system.

Unlike many other children with physical disabilities, the needs of most children with a neuromuscular disorder will change during their time in school, as their muscle strength deteriorates. This change could be very rapid, and schools need to be prepared to deal with every eventuality. A child may be mobile and active when they enter the school, but could be a power wheelchair user requiring assistance with toileting, eating, and other personal care by the time they leave.

While being responsive to the changing needs of students with a neuromuscular disorder is vital, the most important behaviour an educator can exhibit is to have the same level of positive expectation for their academic and social success as they would have for any of the other students. By doing so, this will increase the likelihood that these children will develop positive expectations for themselves throughout their lives. It's also important to encourage independence and confidence by emphasizing the students' strengths and allowing them to make choices and decisions.

This guide provides information on the support a student with a neuromuscular disorder might require throughout the school day, both within and beyond the curriculum. Throughout this resource, you will find tips on how to effectively include a student with a neuromuscular disorder.

# Chapter 1 – Information 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. Although there is presently no cure, medication and other treatments can help manage the condition and the progressive deterioration in muscle strength. Despite these interventions, some of the more severe forms of this condition will result in a limited life span.

Many neuromuscular disorders have a genetic basis, whereby a gene fails to produce one of the proteins required for normal muscle function. In some cases, however, these conditions result from an autoimmune response, where the immune system attacks the body’s own tissues for no apparent reason.

## **1.2 DIAGNOSIS**

Some children will have a diagnosis of their condition as they begin school, others will be having investigations and tests, and some will only be beginning to show signs and symptoms of a neuromuscular disorder.

Once a child has an identified neuromuscular condition, it is vital to discuss their health with their family. Be aware that the parents may find it difficult to pass on information, especially about their child’s future.

## **1.3 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 they do want 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 phrases like, 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 they can or cannot do. Don’t make decisions for them about participating in any activity.

# 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 each school is essential.

Any member of school staff can act as the key worker, but it should be someone who can establish a relationship with the student. 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 the primary goal of the school to ensure the continued development of social skills and self-esteem.

*\*Tip: Invite guest speakers from voluntary agencies like Muscular Dystrophy Canada to staff training sessions.*

*\*Tip: Ensure that at least three staff members are trained adequately to cover any absences.*

## 2.2 WORKING WITH PARENTS AND THE CHILD

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. Strong, clear communication between home and school is essential for an effective working relationship. 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 children to participate in and contribute to discussions about their education, particularly as they become older and more aware of their physical differences.

*\*Tip: Keep a contact diary and a central record of important contact numbers.*

*\*Tip: Inform parents of how to access the key worker.*

*\*Tip: Establish a "home/school message book" to communicate with parents.*

## 2.3 WORKING WITH HEALTH CARE PROFESSIONALS

Often, many health care professionals will work with schools and families as a multidisciplinary team.

*\*Tip: Arrange multi-agency meetings as necessary.*

# Chapter 3 – Emotional and Psychological Issues

## **3.1 THE CHILD’S NEEDS**

### **3.1.1 GENERAL EMOTIONAL AND PSYCHOLOGICAL ISSUES**

Psychological support for the child is invaluable. Professionals can provide this, but children will often seek support from those whom they feel comfortable with at school. 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.

Understanding a child’s condition is important when creating realistic expectations for them. It is essential to concentrate on what children 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 children 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**

Children with a neuromuscular condition 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, they may continue to push those boundaries and create more problems within the classroom. But it is necessary to acknowledge and understand that a student with a neuromuscular disorder may have limited ways of expressing their feelings and could behave in an angry, frustrated, stubborn, or withdrawn manner.

*\*Tip: Coordinate an IEP meeting to address the behavioural issue.*

*\*Tip: Avoid feeling sorry for or pitying the student. This assumes the disability to be a deficiency, which is not the case.*

### **3.1.3 DEPRESSION AND ANXIETY**

All children 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. Staff should be aware of this possibility and closely monitor impacts on performance and relationships within the school environment.

For children with neuromuscular disorders in particular, these feelings are a normal reaction to their deteriorating condition. However, if changes in affect are sustained over a longer period of time, it might be appropriate to discuss the possibility of seeking professional advice with the child’s parents.

### 3.1.4 SELF-ESTEEM AND BODY IMAGE

Some children with a neuromuscular condition might have low self-esteem and could also have a poor body image. Lack of inclusion in a school and low awareness levels can proliferate these feelings, increasing the likelihood that these children will be bullied or tolerate poor quality care. Schools need to be concerned about this, given the fact that children 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 conditions will constantly be readjusting to a changing body image, but it is definitely possible to help students improve their confidence and develop their own individual style.

**\*Tip:** *Ways to Prevent Bullying:*

- *Fear of the unfamiliar is often what makes kids and adults uncomfortable around children with disabilities. If the student is comfortable, have them talk about their disability to the class.*
- *Create opportunities to integrate—avoid labeling and singling out a child.*
- *Encourage students to develop rules against bullying and to hold regular meetings to monitor and discuss it.*

### 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, periods, and wet dreams. They will also wish to explore their sexuality, both physically and through discussion with peers. This should be encouraged to occur appropriately within normal social boundaries.

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?”, “Will anyone find me attractive with my disability?”, “Will I be able to have sex?”, or “Can I get married and have a family?”. Whether at school or at home, these questions must be answered sensitively and factually.

**\*Tip:** *Questions for teachers preparing sexuality education lessons:*

- *What is the nature of the student’s disability and what issues may arise for them from the content?*
- *Has the student had the chance to speak to a staff member about concerns before the lesson?*
- *Would the student find it helpful for me to talk to their parents to follow up on issues that arose for them?*
- *How will I deal with any questions the student may have?*
- *Do I know anyone I can refer the student to, if I can’t answer their question(s)?*
- *Are there any support groups for the student’s condition that I may refer them to?*

## **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 consideration of the varying disorder outcome possibilities and parent views regarding prognosis disclosure. Instead, staff should encourage these students to redirect such inquiries to their respective parents. This practice will help to ensure that staff do not provide conflicting or erroneous information that could place the school in a compromising position.

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.

In addition to the varying degrees to which a family may disclose information about their child's prognosis, families may also choose not to divulge information about all the people working with their child. If you feel that a family is not receiving appropriate support, you should discuss with them the possibility of a referral, and perhaps offer to work with the other professionals supporting them.

### **3.2.2 SUPPORT FOR SIBLINGS**

Many siblings can feel left out of what is going on, and may have feelings of loss, jealousy, guilt and anxiety. If you are concerned about the sibling of a child with a neuromuscular disorder, you should raise the subject sympathetically 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 the staff. They will need information about the condition and the anticipated effect on the child, including how to manage this in a classroom situation. The changing needs of the child must be fully understood by all staff, as they may develop a close relationship with the child and be asked searching questions.

### 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.

*\*Tip: Dealing 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 something 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 acknowledge that they are finding the situation difficult. Give everyone permission to feel sad or to cry.*

# Chapter 4 – Health Issues

## **4.1 THE INDIVIDUAL HEALTH CARE PLAN**

Students with a chronic condition require a range of support at school. To help establish the appropriate requirements for their needs, teachers must first understand the medical condition and the impact it will have on school life.

It is common practice to draw up an Individual Health Care Plan (IHCP) for every student with a medical condition. The IHCP should summarize the student's condition, identify procedures for emergency situations, and provide any other relevant information. Schools should agree with parents as to 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 for everyone involved the assistance that a school can provide and receive.

Some school districts issue students “medical cards” that are accessible to school staff when required, containing information about the child's condition. Several voluntary organizations (including Muscular Dystrophy Canada) may also produce their own medical information cards, carried by persons with the relevant condition.

*\*Tip: Ensure that all staff, including supply/visiting staff members, is informed of any procedures/protocol to be followed.*

## **4.2 COMMON IMPLICATIONS OF A NEUROMUSCULAR DISORDER**

### **4.2.1 MOBILITY**

Some children with a neuromuscular disorder will be independently mobile, but others might use specialized equipment such as wheelchairs, splints, calipers, or standing frames to help increase mobility. Children whose condition fluctuates may alternate between walking and using a wheelchair for short periods of the day. During recess or other break times, ambulatory children may sometimes need to use a wheelchair. As their muscle strength deteriorates, they may need to use a wheelchair all the time, and this change could take place quickly.

*\*Tip: Always attempt to balance health and safety concerns with the need for a child to develop independence. Advocate for increased but non-intrusive adult supervision.*

### **4.2.2 FALLING/LOSING BALANCE**

There will be some children who, while able to walk, will be at risk of losing their balance because of their muscle weakness. This will worsen as they become older and their condition deteriorates; some of these children 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 children with a neuromuscular disorder. It can affect a child's behaviour as well as their ability to concentrate, learn, and access 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/or health-related issues can influence fatigue. Some children may also experience *nocturnal hypoventilation* (see Section 4.3.5), which may make the student feel lethargic and possibly cause difficulty with concentration. Additionally, the child might have many headaches and could find it difficult to get going in the mornings.

*\*Tip: Whenever possible, introduce new concepts early in the day.*

*\*Tip: Student may need a place to rest for a while during the day.*

*\*Tip: Allow extra time to complete tasks in the afternoon, when the student may be more 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 their 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 child with weakness in the upper limbs may also need help with self-care when getting changed for P.E., games, swimming, or when putting on outdoor clothing.

*\*Tip: To maximize hand function, table height and seating position are very important. Using a variety of pencil grips, sloping desks, and calculators will be beneficial to the student as fine motor manipulations become more difficult.*

*\*Tip: Students with a neuromuscular disorder may have difficulty with the volume of written work required in class. To better assist these students, consider introducing alternative recording methods that utilize information and communication technology, and present computer-generated or photocopied worksheets where possible.*

*\*Tip: Special arrangements may be required for exams. The student should be familiar with these provisions prior to the exam.*

*\*Tip: A student might find it impossible to reach for objects in the classroom, so ensure that all work tools and books are easily accessible. Using heavy textbooks and/or objects could also cause difficulties.*

### 4.2.5 LOWER LIMB FUNCTION

The lower limbs are often affected in many neuromuscular disorders. You may notice that some students 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 their feet with a slight rolling gait. In order to compensate for a weak trunk, some children may stick out their bellies and throw their shoulders back to keep their balance as they walk.

#### 4.2.6 COMMUNICATION NEEDS

Students with neuromuscular disorders 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 children with certain forms of muscular dystrophy. Students may have difficulties with verbal memory, causing them to struggle with retention and processing of complex spoken information.

Students with specific facial weaknesses 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 in the usual way.

*\*Tip: Careful and sensitive explanations to other students are necessary to assist the child's social development.*

*\*Tip: Respect the need to wait for a response from a child with communication difficulties.*

*\*Tip: Consider seating the student near the front of the class or having them use a speech amplifier to be heard more easily.*

#### 4.2.7 MOVING AND HANDLING

There are likely to be moving and handling issues for many children 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, and independence and views of the pupil being moved. The student should be the first person consulted for advice specific to their own needs. Appropriate professionals (eg. physiotherapist, occupational therapist, or advisory teacher) may also be able to provide valuable input. Based on this feedback, a strategy to manage moving and handling 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 SEATING, STANDING, COMFORT & POSITIONING

Appropriate seating with comfortable positioning for a child with a neuromuscular disorder is very important (see **Section 5.2.2**). Solutions could include using specialist equipment. The child's therapist should assess each piece of equipment, and school staff will need training on its proper use and positioning. It is always a good idea to check with the child first to determine what, if any, equipment would work best.

*\*Tip: 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.*

*\*Tip: Provide a chair as an alternative to sitting on the floor to help the student move from a sitting to a standing position.*

#### 4.2.9 TEMPERATURE CONTROL

Staff should be aware that temperature changes could affect the mobility of children with a neuromuscular disorder. They are less able to generate body heat, and are more susceptible to a cold environment both indoors and outdoors.

*\*Tip: Check with these students to determine what, if anything would help them to feel more comfortable within these environments.*

#### 4.2.10 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 specific difficulty with 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 are only able to eat very slowly. It is important to discuss with the student and parents how to manage the situation appropriately.

*\*Tip: Talking while eating may cause a higher risk of aspiration. Starting their lunch break ahead of their classmates could reduce this risk. Brainstorm with the students to determine what would work best for them.*

*\*Tip: Students may use a naso-gastric (NG) tube or a gastrostomy tube (G-tube) to deliver specially prepared food directly to the stomach. Some children will require feeding through these tubes while at school, and this should be discussed and included in the Individual Health Care Plan.*

*\*Tip: Children with specific upper limb muscle weakness can utilize height-adjustable tables, mobile arm supports, and adapted cutlery to feed themselves and maintain independence.*

#### 4.2.11 WASHROOM USE & CONTINENCE

Thought must be given to the washroom needs of any student with a disability. As 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 handling on and off the toilet while being assisted by a caregiver. Because of their mobility needs, children may also need longer 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. The best source of information regarding these issues would be the children themselves.

The majority of children 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.

*\*Tip: Students should have a means of contacting the appropriate staff member should they require assistance while in the washroom.*

*\*Tip: Ensure that wheelchair-accessible washrooms and equipment will be available on out-of-school excursions.*

*\*Tip: Be sensitive toward students who have to wear incontinence products.*

*\*Tip: Be sure to also consider:*

- What should happen if the student needs to use the washroom, but the support assistant is not available*
- Whether students should conform to normal routines or be allowed to use the washroom upon request*
- How supply/visiting/new staff should be made aware of existing procedures*

## **4.3 MEDICAL TREATMENTS**

### **4.3.1 PHYSIOTHERAPY**

Physiotherapy often plays a major role in managing a neuromuscular condition. 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 will sometimes need to be carried out within the school. It can be incorporated into P.E. or games lessons, and specialized equipment may be required.

*\*Tip: Acknowledge that a student may have physiotherapy after school, and that fatigue may affect their ability to complete homework assignments in the evening.*

### **4.3.2 MEDICATION & STEROIDS**

Children with certain neuromuscular disorders can benefit from steroid use to stabilize or even improve muscle strength, allowing them to remain independent for longer. Steroids will not cure their condition, and not everyone responds to them. Their use also needs to be balanced against possible side effects.

### **4.3.3 ORTHOTICS, SPLINTS, AND CALIPERS**

Some children 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**

Children 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.

*\*Tip: When a child returns home after surgery, it may help them to do some schoolwork so as not to fall too far behind. Home tutoring may be necessary with phased school entry as the child becomes stronger.*

*\*Tip: 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 children 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.

Children with nocturnal hypoventilation are unable to breathe effectively while they sleep because of weak upper respiratory muscles. This causes a build-up of carbon dioxide in the body, making the student feel lethargic and possibly causing difficulty with concentration. Additionally, the child might have many headaches and could find it difficult to get going in the mornings. Some children require the use of ventilation devices during the night, while others may be totally ventilator dependent.

*\*Tip: Respiratory complications may mean that a student has to spend time away from school. Depending on the circumstances, the student may be able to continue with schoolwork at home while they are recovering.*

*\*Tip: Due to the risks that are posed by respiratory illnesses to a child with a neuromuscular disorder, it is important that staff working with the child review proper hygiene and hand-washing procedures, and are conscious of these procedures at all times.*

## **4.4 STAYING HEALTHY**

### **4.4.1 NUTRITION & 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 child'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 all children with a neuromuscular disorder. However, their participation in this type of activity would depend on their individual level of comfort with it.

While some children with a neuromuscular disorder can be prone to putting on excessive weight, others may be underweight. Due to self-consciousness about being helped to eat or because of difficulties with chewing/swallowing, they may not take in enough calories during the day.

*\*Tip: Encourage children to drink plenty of fluid throughout the day to help prevent dehydration and bladder infections.*

*\*Tip: Adopt an inclusive approach to physical education curriculum. With the guidance of a physiotherapist, you may also want to try to incorporate assisted stretches into the classes.*

## **4.5 MEDICAL EMERGENCIES**

It is unlikely that a child with a neuromuscular disorder will have a medical emergency at school. However, if there were an emergency situation, it should be handled in the same manner as for any other student. The parents must be notified if the child 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 to increase accessibility and enable independence should be suitable for people with a range of different needs, feature a flexible design, and regard the safety of caregivers.

**\*Tip:** *The needs of three disability groups must be considered:*

- *Children who are ambulatory*
- *Children who use a wheelchair and are able to transfer out of their wheelchairs independently or with minimal help*
- *Children who use a wheelchair and are unable to transfer out of their wheelchairs independently*

**\*Tip:** *Don't forget to consider the accessibility of a venue for any extracurricular activities or out-of-school excursions. Keep in mind that even though a venue may say it is accessible, it might not suit the needs of the student. Talk to the student to make sure appropriate accommodations are made.*

**\*Tip:** *Ensure full inclusion in performances and concerts.*

### 5.1.2 ACCESS TO THE SCHOOL BUILDING

Meeting the needs of a child 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.

**\*Tip:** *Areas of key concern include:*

- *Ramps and/or step lifts to provide access*
- *Handrails on steps both inside and outside the building*
- *Removal of obstacles and hazards, such as uneven ground surfaces*
- *Provisions for adequate circulation space*
- *Provisions for adequate time for students to get from one area of the school to another*

**\*Tip:** *Students with mobility difficulties can be vulnerable in crowded or congested areas. Allow students to leave class a few minutes before or after their peers to avoid the rush in busy halls.*

### 5.1.3 ACCESS TO THE CLASSROOM

Power wheelchairs provide the student with freedom and independence. They can be quite large, but they are very easy to maneuver and students become proficient at handling them. Ensure that there is clear access to all classrooms. This may mean rearranging classroom furniture in every area the student uses to access the curriculum. It's also worth considering where the student should be 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.

*\*Tip: Encourage other students to keep the aisles clear of bags and coats.*

*\*Tip: Arrange furniture to allow for a clear path into and out of the classroom.*

*\*Tip: Consider alternate arrangements that may need to be made if classrooms are upstairs—allocate rooms to the ground floor whenever possible.*

### 5.1.4 ACCESS TO THE CAFETERIA

If they are unable to eat independently, children with a neuromuscular disorder could be too embarrassed to ask for assistance or to accept help with eating in front of their friends. As a result, they may have an inadequate and/or poor diet. Some of these difficulties can be avoided if there is good access within the dining hall.

*\*Tip: A height-adjustable table as well as special adapted cutlery and dishes can help students to remain independent.*

*\*Tip: Ask the student privately about the types of assistance that would be the most desirable.*

### 5.1.5 ACCESS TO 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 4.2.9). Benches prevent fatigue in ambulant children by providing them with a chance to rest, and allow students with balance and co-ordination difficulties to sit safely with their friends. They also encourage social interaction for wheelchair users, enabling other students to communicate at the same eye level. Furthermore, keep in mind that certain playground surfaces will be easier for students to navigate through.

*\*Tip: Provide benches in playground areas for rest opportunities during break times.*

*\*Tip: Children who usually walk may require a wheelchair during recess or other break times.*

*\*Tip: 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.

*\*Tip: Children with muscle weakness may also find it tiring to carry bags full of schoolbooks around with them and would benefit from a secure locker or storage room. Such an area might be most conveniently located near the main school entrance.*

### **5.1.7 EMERGENCY EVACUATION PROCEDURES**

If a student with a neuromuscular disorder is unable to exit the school building in the same way as ambulatory 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.

### **5.1.8 ACCESSIBLE TRANSPORTATION**

Children with a neuromuscular disorder who receive transportation to and/or from school will need 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. Ambulatory students may still 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, and accessible transportation is required for the students to participate in and benefit from school clubs and activities.

*\*Tip: Establish an appropriate drop-off/pick-up point for vehicles, and nominate a staff member to meet the student upon arrival at the school.*

*\*Tip: Ensure the parents are informed if/when transportation arrangements are altered.*

### **5.1.9 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. If you have a student in a wheelchair, try to include them in different ways, perhaps as scorekeeper or referee.

*\*Tip: Try introducing your class to a wheelchair-adapted sport or activity.*

## **5.2 EQUIPMENT**

### **5.2.1 WHEELCHAIRS**

It is important to identify the type of wheelchair a student will be using. Some students may use a power wheelchair, while others will utilize a manual wheelchair. In such a case, staff will need basic training on collapsing the chair and using it safely. Extra cushions and 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. Children who are wheelchair users will have seating inserts in their wheelchairs to provide postural support and prolong functional ability. They may also have special cushions to prevent pressure problems.

*\*Tip: Reviews, adaptations, and modifications will be needed as the student grows and their muscle strength changes.*

### **5.2.3 STANDING FRAMES**

A standing frame is used to maintain a supported standing position while stretching the muscles and joints.

*\*Tip: Many standing frames have trays or can be placed adjacent to a height-adjustable table to enable good hand function.*

### **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. Children using wheelchairs will need a table that accommodates the height of their wheelchair.

*\*Tip: If students choose to work on their wheelchair tray, ensure that it is big enough for workbooks, keyboards, and recording equipment.*

### **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 their own storage space; and electrically operated tracking lifts that use a fixed tracking system.

Lifts are used in conjunction with specially designed slings. A one-piece sling for people with a neuromuscular disorder is available from most specialist 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. As a student's condition changes, different lifts/slings may be required.

### **5.2.6 ELEVATORS**

Elevators may need to be installed to make the school site accessible. If there are any already in place, ensure that they are suitable for both the student and their wheelchair.

*\*Tip: For small flights of stairs, step-lifts could be considered as an alternative.*

# Chapter 6 – Educational and School Policies

## 6.1 FORMAL RESPONSES TO STUDENTS WITH SPECIAL NEEDS

School district policies encourage a graduated approach to meet students' needs and enable full access to the curriculum. If staff is concerned that a child may have special needs, they should discuss which actions to consider. By assessing the current strategies being used to meet the child's needs, the school must determine which form of intervention is most appropriate to support the student. A critical initial action is to collect all known information about the student and anyone who may be involved with them. Such information should be compiled in the student's record in case a statutory assessment is requested in the future. This knowledge will also provide the basis for intervention planning.

*\*Tip: The school should consider getting involved if the student:*

- *Is making little or no progress, even when teaching is targeted at their identified area of weakness*
- *Is finding it difficult to develop 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*

*\*Tip: When evaluating the progress of the student, the school must understand:*

- *How the child's physical condition is affecting their learning/mobility*
- *How the situation is being monitored, recorded and reviewed*
- *If a statutory assessment should be requested*
- *That multi-agency meetings should be arranged as required*

## 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 children 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.

# Chapter 7 – Planning for Future Transitions

## 7.1 PLANNING

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 start 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 children are no longer there as adults.

*\*Tip: Checklist for transition planning:*

- *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*
- *Help parents support their child(ren) through the process.*
- *Determine whether work experience is appropriate, and help facilitate a placement*
- *Be flexible to accommodate exam arrangements and early college placement*

## Chapter 8 – Facilitating Disability Discussions

If you have a student with a disability in your classroom, you will want to ensure that they are comfortable with the lesson and/or a guest presentation ahead of time.

**\*Tip:** *Ideas for initiating discussions about disability issues:*

- *Explain the content of the lessons to the student and their parents ahead of time*
- *If the student is comfortable with talking to the class, invite the student to explain their situation and discuss the activities that they find challenging*
- *Choose follow-up activities that are relevant to the student's disability*
- *Invite the student's parents or guardians to join you for the lessons*
- *When speaking with the student and their parents, find out if there is a sibling who would like to speak to the class*

**\*Tip:** *Examples of disability awareness activities:*

- *Pair up students and have them draw themselves and their partner, noting their similarities and differences. Have the children talk about how their body parts are different from each other and how some people are better at certain things than others (ie. Johnny can run faster, while Danny can draw better)*
- *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*

# Appendix A – Online Resources

## ***Bridges to the Future***

Bridges to the Future is a program implemented in the Western Region of Muscular Dystrophy Canada that supports youth with physical disabilities in making the successful transition into adulthood.

**[www.bridgestothefuture.ca](http://www.bridgestothefuture.ca)**

## ***Enablelink***

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

**[www.enablelink.org](http://www.enablelink.org)**

## ***Muscular Dystrophy Association***

This American website contains articles and information regarding neuromuscular disorders.

**[www.mda.org](http://www.mda.org)**

## ***Muscular Dystrophy Canada***

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

**[www.muscle.ca](http://www.muscle.ca)**

## ***Sports and Recreational Activities for Children with Physical Disabilities***

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

**[www.cureourchildren.org](http://www.cureourchildren.org)**

## ***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.centreforactiveliving.ca](http://www.centreforactiveliving.ca)**

## ***The National Center on Physical Activity and Disability***

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

**[www.ncpad.com](http://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](http://www.rickhansen.com)**

## Appendix B – MDC Regional Contacts

### WESTERN CANADA

7th Floor-1401 West Broadway  
Vancouver, BC V6H 1H6  
Tel: (604) 732-8799  
1-800-366-8166  
Fax: (604) 731-6127  
Eml: infowest@muscle.ca

### ONTARIO & NUNAVUT

2345 Yonge St, Suite 901  
Toronto, ON M4P 2E5  
Tel: (416) 488-2699  
1-800-567-2873  
Fax: (416) 488-0107

### QUÉBEC

1425 boul. René-Lévesque Ouest  
Bureau 506  
Montréal, PQ H3G 1T7  
Tel: (514) 393-3522  
1-800-567-2236  
Fax: (514) 393-8113  
Eml: infoquebec@muscle.ca

### ATLANTIC

1888 Brunswick St, Suite 804  
Halifax, NS B3J 3J8  
Tel: (902) 429-6322  
1-800-884-6322  
Fax: (902) 425-4226  
Eml: infoatlantic@muscle.ca

### EDMONTON

200 Belmead Professional Centre  
8944-182 St NW  
Edmonton, AB T5T 2E3  
Tel: (780) 489-6322  
1-800-661-9312  
Fax: (780) 486-1948

### CALGARY

1024 - 10th Ave SE  
High River, AB T1V 1L3  
Tel: (403) 649-6247 (home office)  
Fax: (403) 649-6252

### SASKATOON

3-3012 Louise St  
Saskatoon, SK S7J 3L8  
Tel: (306) 221-2940 (cell)  
Fax: (306) 652-2957

### WINNIPEG

204-825 Sherbrooke St  
Winnipeg, MB R3A 1M5  
Tel: (204) 233-0022  
Fax: (204) 975-3027

### OTTAWA

150 Isabella St, Suite 215  
Ottawa, ON K1S 1V7  
Tel: (613) 232-7334/5  
1-866-337-3365  
Fax: (613) 567-2288

### LONDON

150 Dufferin Ave, Suite 702  
London, ON N6A 5N6  
Tel: (519) 850-8700  
1-877-850-8720  
Fax: (519) 850-8701

### JONQUIÈRE

Centre Hospitalier de Jonquière, C.P. 15  
2230 rue de l'Hôpital, bureau 6.17  
Jonquière, QC G7X 7X2  
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1-877-295-7911  
Fax: (418) 695-7761

### FREDERICTON

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Fredericton, NB E3C 1N8  
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1-888-647-6322  
Fax: (506) 458-2205

### SAINT JOHN

202-10 Millidge  
Saint John, NB E2K 2S1  
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1-888-696-5150  
Fax: (506) 696-8507