

MuscleFacts Parent Guide



Support for

Parents and Families

Affected by

Neuromuscular Disorders

 Muscular
Dystrophy Canada
let's make muscles move

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www.muscle.ca

Foreword

This guide was developed by a team in the Western Canada Region of Muscular Dystrophy Canada in consultation with parents of children with a neuromuscular disorder. Special acknowledgement must also be given to the following existing literature:

- *An introductory guide for families with a child newly diagnosed with muscular dystrophy or an associated neuromuscular condition*, Muscular Dystrophy Campaign – U.K. (2007)
- *Teaching Children and Youth About Sexuality*
National Information Center for Children and Youth in Washington, D.C. (1992)
- *Individual Education Planning: A Handbook for Developing and Implementing IEP's*
Ministry of Education, Citizenship and Youth – Manitoba (1998)
- Bushby K, et al. *The Diagnosis and Management of Duchenne Muscular Dystrophy, part 1: diagnosis, and pharmacological and psychosocial management*, Lancet Neurology 2010, 9 (1) 77-93.

For further information about this guide or any of our programs or services, please contact the Muscular Dystrophy Canada Office nearest you, or visit us online at 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.

Table of Contents

Foreword	1
1. About Neuromuscular Disorders	3
1.1 What is a neuromuscular disorder?.....	3
1.2 What is being done to find a cure for my child?.....	3
1.3 How can I get involved with Muscular Dystrophy Canada?.....	3
2. Coping with a Neuromuscular Disorder	4
2.1 How do parents feel when their child is diagnosed with a neuromuscular disorder?.....	4
2.2 I am finding it difficult to cope with my child’s diagnosis – whom can I talk to?.....	5
2.3 What should I tell my child regarding their disorder and when should I do it?.....	6
2.4 What should I tell my child’s sibling(s), relatives and others about the disorder?.....	6
2.5 How much does it cost to buy adaptive equipment, and who might pay for it?.....	8
2.6 How do I support my child in dealing with their need for mobility equipment?.....	9
2.7 My child has low self-esteem – how should I address this issue?.....	9
2.8 How would I know if my child were experiencing depression and/or anxiety?.....	9
2.9 How should I respond to my child’s questions about sexuality and relationships?.....	9
2.10 What words of advice can adults with neuromuscular disorders offer my child?.....	11
3. School Issues	12
3.1 My child will be going to a new school – how do I prepare the school for this?.....	12
3.2 How do I plan for my child’s education?.....	12
3.3 Other kids are teasing or bullying my child – how should I deal with this?.....	12
3.4 My child is having behavioural challenges at school – what should I do?.....	13
3.5 What can be done to help educate my child’s classmates about disabilities?.....	13
4. Health and Activity Issues	14
4.1 Which professionals may become involved in my child’s life?.....	14
4.2 What is a Paediatric Neuromuscular Clinic, and what happens there?.....	15
4.3 Doctors suggest that I should put my child on steroids – is this a good idea?.....	16
4.4 My child has weight issues – whom should I talk to about this?.....	16
4.5 What types of exercise or stretches would be helpful for my child?.....	16
4.6 How can my child get involved in recreation?.....	17
4.7 I need some help with my child’s personal care – what services are available?.....	17
5. Future Planning	20
5.1 What options are available to my child after graduation from high school?.....	20

1. About Neuromuscular Disorders

1.1 Neuromuscular Disorders

The term “neuromuscular disorder” describes over 150 conditions that have in common a loss of muscle strength caused by a defect in either the nerves or muscles. The rate at which a neuromuscular disorder will progress differs from individual to individual. Medication and other treatments can help manage the condition and the ongoing loss of muscle strength.

Many neuromuscular disorders have a genetic basis, whereby a gene is unable 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 harms the body’s own tissues for no apparent reason.

While we have used the pronoun “he” throughout this document for ease of reading, neuromuscular disorders can affect both genders.

To find out more about a particular type of neuromuscular disorder, please visit Muscular Dystrophy Canada’s website: www.muscle.ca

1.2 What research is being done to find better treatments and a cure for my child’s condition?

Research towards a cure for the various neuromuscular disorders is happening all around the world at this very moment. In fact, over 500 research projects are currently underway. To find out more about these groundbreaking projects, please visit one of the following websites:

<http://www.muscle.ca>

<http://www.mda.org/research/>

<http://www.muscular-dystrophy.org/research/>

<http://www.nmdrc.org/>

<http://clinicaltrials.gov>

1.3 How can I get involved with Muscular Dystrophy Canada?

Muscular Dystrophy Canada is a volunteer-driven organization and relies on dedicated, enthusiastic, diverse and dynamic people to help us meet our mission. Volunteers are respected members of Muscular Dystrophy Canada’s human resources team and play a vital role in the delivery of our fundraising campaigns, programs and services.

To learn more about the ways in which you can get involved, please contact the Muscular Dystrophy Canada office nearest you (see Foreword) or visit www.muscle.ca.

2. Coping with a Neuromuscular Disorder

2.1 How do parents feel when their child is diagnosed with a neuromuscular disorder?

The following is adapted from the Muscular Dystrophy Canada publication entitled *Why Me? A guide to living with your child's neuromuscular disorder* (2007).

In the beginning, most parents who learn of their child's condition go through similar emotional experiences. Shock is often the first reaction. The body, the mind and the spirit are suddenly numbed by the news from the doctor and the whole world seems to shrink down and become heavy and unreal.

Individuals often become isolated from everyone around them as powerful emotions like fear, guilt, anger, sadness, hurt, depression, and helplessness begin to bubble to the surface. There is usually a yearning for time to go backwards, and for there to be a different outcome with regards to diagnosis. Eventually, however, most people's initial, scattered feelings begin to give way to a stronger, more focused individual response:

- Some feel that it is their duty to their child to always appear strong, even though they are harbouring deep-rooted unresolved negative emotions like resentment or fear.
- Others go into a period of denial and avoidance, looking for second, third and fourth opinions, as they struggle to deal with the reality of the situation.
- Some get angry – directing their anger at themselves, their doctors, their family, their friends and sometimes their child.
- Some collapse into a frozen depression, feeling helpless and unable to go on any longer out of fear for the future.
- Others go through all of these responses at various times and to varying degrees. Many parents also experience moments of profound hope, support and determination.

Your own reaction to your child's diagnosis is healthy, and is actually appropriate considering what you are going through. Your grief is your own personal method of protecting yourself from the intense mental and emotional strain. For more first-hand accounts and advice from other parents of children with disabilities, check out the following resources:

- Hickman, Lori. *Living in My Skin: The Insider's View of Life With a Special Needs Child*. Communication Skill Builders, 2000.
- Simons, Robin. *After the Tears: Parents Talk About Raising a Child With a Disability*. Mariner Books, 1987.
- York, Rebecca. *Touching the Halo: An Emotional and Spiritual Journey of Parenting a Child with Disabilities*. Universe, 2001.
- <http://www.parentingyourcomplexchild.com>
- <http://childrenwithspecialneeds.com>
- <http://fcsn.org>
- <http://arch-online.org/disabled-child-advice-for-parents-of-disabled-children.htm>

2.2 I am finding it difficult to cope with my child's diagnosis – whom can I talk to?

The following is adapted from the Muscular Dystrophy Canada publication entitled *Why Me? A guide to living with your child's neuromuscular disorder* (2007).

It is difficult to stress sufficiently how important a strong, caring support network will be in the years ahead. There is nothing worse than feeling like you are facing an entire universe of troubles on your own. In order to ease your burden, you need to maintain a group of loved ones to fall back on for mental, emotional and even physical support.

If you are married, or living with a long-term partner, your spousal relationship can often be the hardest hit by the transition into your new life. From the time of the diagnosis on, your partnership will undergo a significant transformation. Many of the routines, commitments and rules (spoken and unspoken) that initially guided your relationship will be in need of important re-evaluation. It is imperative that you open a clear line of communication with each other, right from the onset. If you don't understand your partner's reaction, you may misinterpret it, possibly causing yourself unnecessary grief and pain. You need to clear away these barriers so that you can both grieve and find mutual coping solutions together.

If you don't already know who else to include in your support network, you should compile a list of everyone that you think you can trust to help you when you need them: your parents, family, friends, siblings or maybe even a trusted therapist or doctor. In all likelihood, these people are all worrying about you. You need to tell them how important their love and support is to you, and let them know what you are going through right now.

The ones who are the most important will be there immediately once they know how much you need their help. From then on, you will know without a doubt that you have important pillars of strength in your life that you can fall back upon in times of need. Be direct, tell the people you love what practical things they can do to give you support. Let them know what kinds of actions and words you find helpful right now, and if certain things are unhelpful. Often people do not know how to respond, but want to do the very best they can for you and your family.

In addition to the people in your personal network, be sure to include Muscular Dystrophy Canada and its local chapter on your list of supporters. Not only are Muscular Dystrophy Canada staff and chapter volunteers an important source of knowledge, experience, support and information, but they are also the source of a number of important services and programs like peer support, where you can connect with other parents who can identify with what you are going through and offer you support.

Peer support is a simple but effective way to address isolation, one of the most difficult consequences of being the parent of a child with a neuromuscular disorder. A significant number of parents living in rural areas experience it, but even those living in cities and towns often lack support networks, and struggle to find other parents who can truly understand the challenges they face.

2.3 What should I tell my child regarding their disorder and when should I do it?

Your child will notice early on that his* level of physical ability is less than that of his peers. Your child may believe that this difference is somehow his own fault and that he can actually do something to correct it. At this point, your child may begin to ask you questions on the subject, express frustration or remain silent on the issue.

This would be a good time for you to share some basic information about your child's disability. If his disorder will likely limit his life span and you feel that he is too young to fully comprehend or cope with this fact, it would be perfectly understandable for you to delay that part of the discussion for a later date. However, if your child asks you directly if he will die from his life-limiting disorder, it is important to be truthful with him. Tell him that no one knows how long they will live – human life is an uncertainty for everyone.

Let your child know why his muscles or nerves don't work the same as other people's do. Here are examples of how you could explain some of the more common types of neuromuscular disorders:

Duchenne or Becker Muscular Dystrophy – their muscles didn't come with the right instructions on how to stay strong.

Spinal Muscular Atrophy – the nerve command centre in their spine is missing an ingredient that tells their muscles how to stay strong.

Myotonic Dystrophy – their muscles didn't come with the right instructions on how to work properly.

Charcot-Marie-Tooth Disease – their nerves are not sending some important messages to the rest of their body, including their muscles.

Friedreich's Ataxia – their nerves are not sending some important messages to the rest of their body, including their muscles.

All parents will want to shield their child from the truth, but this could have several repercussions. For one, your child could become depressed, angry or anxious when dealing with the fact that he has unexplained limitations. Secondly, children at school might tease your child if your child cannot explain why he is different than the other kids. Thirdly, your child may sense that you are sad when you are around him and he might come to the conclusion that he has done something to disappoint you. Fourthly, your child may discover what type of disability he has from a different source (potentially with the wrong information), leaving him feeling betrayed by you and losing trust in you.

2.4 What should I tell my child's sibling(s), relatives and others about the disorder?

When it comes to your child's sibling(s), what you tell them will depend on their age(s). For young siblings, it would probably make the most sense to tell them exactly what you told your child with a neuromuscular disorder. Also be sure to answer any questions they may have. If they don't appear to have any questions, perhaps you could ask them what they may have heard or already know about their sibling's disorder, at which time you could correct or clarify any misinformation they may have.

* While we have used the pronoun "he" throughout this document for ease of reading, neuromuscular disorders can affect both genders.

For siblings who are older (in or near their teenage years), it is important to share more detailed information with them, given the fact they could easily find all of the disorder information on the Internet. In fact, you could encourage them to do an Internet search and then debrief with you afterwards.

If you decide to let your child's sibling(s) do their own research on a neuromuscular disorder that could be considered life-limiting, it is important to share this information with them ahead of time. Warn them that the online literature will present vastly differing opinions regarding the life expectancy associated with the various neuromuscular disorders depending on how recent and informed the site's research happens to be. Remind them that no one knows how long their sibling will live – human life is an uncertainty for everyone.

When sharing information with siblings (especially younger-aged ones), it is recommended that you avoid telling them to keep it a “secret.” This would put undue stress on them and would likely disrupt family dynamics (by putting your children on an unequal footing with one another).

When a child is diagnosed with a neuromuscular disorder, it makes sense that (for a time) a lot of emotional energy and attention surrounds that child and their diagnosis. It is important to remember that siblings will also be picking up on this energy and processing it in their own way. Several older siblings who have grown up with a brother or sister with a neuromuscular disorder have suggested the following important tips in order to assist the siblings through their own process:

- Remember that siblings without a neuromuscular disorder have challenges and problems too – their challenges may be somewhat different and may not seem as profound in this moment, but they are real and important. Some older siblings have suggested that when a lot of attention is focused on the needs of the child with a neuromuscular disorder, it is easy for them to feel like they have to be strong and not have any problems in order to support the family. Internalizing their feelings about this can have long-term effects. It is important for parents to keep checking in with each child.
- Find activities that all of the siblings can do together and bond over as abilities change (arts and crafts, attending sporting events or concerts together, etc).
- Talk to all the siblings about positive experiences and role models of people who have neuromuscular disorders. Share stories and books about things people with disabilities have accomplished. Help them to have a positive outlook on the future for their sibling.
- Role model what to say and what not to say when people in the community ask them questions about their sibling.
- Encourage the sibling(s) to focus on their own goals, plans and dreams for their life without feeling guilty. Check in with them about this often, as feeling guilty for not having a neuromuscular disorder is a common experience.
- Make sure that it is the parents who are solving the problems. Although siblings can be encouraged to help with the needs of their brother or sister, they should not be made to feel responsible for solving problems related to their sibling.

In regards to relatives, disclose the diagnosis in the same manner that you would share it with your child's older siblings. It is important to share this information with relatives, as there is a good chance that you will need their support at some point in the future. Keep in mind that your news may stir up a variety of emotions, ranging from sadness to shock and fear, so be prepared for unexpected reactions.

After telling family members about your child's diagnosis, you should (after consulting with your partner, if applicable) consider letting your very close friends know about it too. Their understanding and support will be invaluable as you move ahead. If it is important to you, ask your friends to keep the information you share confidential, since it is not their information to share.

At this point you may want to pause before sharing the diagnosis with anyone else. You will probably need some time to process your own feelings prior to "going public" with the news.

2.5 How much does it cost to buy adaptive equipment, and who might pay for it?

Depending on the progression of your child's neuromuscular disorder, he may require one or more of the following pieces of equipment at some point in the future:

<u>Equipment</u>	<u>Estimated Cost</u>
Custom leg braces (AFOs)	\$1,600
Manual wheelchair	\$2,000 - \$4,000
Overhead lift system	\$3,000 - \$4,000
Portable ramps	\$800 - \$1,000
Specialized shoes	\$150 - \$500
Scooter	\$3,000 - \$5,000
Power wheelchair	\$10,000 - \$25,000
Cough Assist	\$5,000 - \$7,000
BiPAP	\$3,000 - \$7,000

There are a variety of public and private funding sources that you may be able to access for adaptive equipment. Your provincial government and private insurance would be the best place to start. If they are unable to provide enough funding, you may be eligible to access Muscular Dystrophy Canada's equipment program. Please call your regional office (see Foreword for contact information), and our Services Staff will help you determine if Muscular Dystrophy Canada is likely to be in a position to assist. For more information about our equipment program, please visit www.muscle.ca.

For other resources, speak with your child's occupational and/or physical therapist, or contact service organizations like Easter Seals Canada (<http://www.easterseals.ca>) and your local Rotary Club (<http://www.rotary.org>) for help.

2.6 How do I support my child in dealing with their need for mobility equipment?

In some cases, your child may reach a point where he would benefit from using mobility equipment like braces, crutches, a wheelchair or a scooter. Interestingly enough, this fact is often more difficult for parents to cope with than for the children themselves. This is worth noting because a parent's negative opinion of the need for mobility equipment could affect the way the child also views it.

To help your child to better accept the idea of mobility equipment, try to present it as a positive development. Refer to it as something that will make it easier for your child to get around on his own and to do things with friends. If your child still feels uncomfortable with the idea of using this type of equipment, you could introduce it to him in stages. Get him to try out the equipment around the house or while on vacation before using it around school peers.

Another way you can support your child's transition to using mobility equipment is to be proactive. Although the need may not be urgent right now, if your child is likely to need it at some point, you will need to keep this in mind as you choose houses and neighbourhoods to live in, and vehicles to drive.

2.7 My child has low self-esteem – how should I address this issue?

Children with a neuromuscular disorder that affects their appearance in some way (e.g., through physical differences, the use of a wheelchair or the need for assistance in the classroom) are likely to experience low self-esteem at one time or another. As a parent, there are a number of things you can do to help your child to deal with these feelings. First, listen to his concerns and let him vent – give him the opportunity to air his frustrations. Second, acknowledge your child's concerns, no matter what they happen to be, because they are real to him. Do not simply dismiss his concerns and pretend that everything is okay – it is important for your child to learn to work through his feelings, challenges and disappointments.

The third thing you can do is to encourage your child to identify his own strengths and to brainstorm ways of coping with his perceived shortcomings. If he gets stuck, you can offer some of your own suggestions. But, wherever possible, let your child come up with the answers.

2.8 How would I know if my child were experiencing depression and/or anxiety?

All children can experience depression and anxiety. For children with neuromuscular disorders, these feelings are often a normal reaction to their disability. Depression and anxiety may become apparent in a few ways: lethargy, withdrawal, irritability, changes in appetite, changes in sleep patterns, lack of interest and poor academic performance. If these changes continue for a longer period of time, you may consider seeking professional advice.

2.9 How should I respond to my child's questions about sexuality and relationships?

Parents, whether or not you realize it, are the main source of education regarding sexuality for their children. What you say and don't say, as well as what you do and don't do, will form the foundation of their

sexual knowledge. If you appear uncomfortable around this issue, so will your child and he may not feel safe to approach you with their questions.

The fact that he is asking you questions about sexuality and relationships should be seen as good news – it is a sign that you have created an atmosphere where your child feels safe to confide in you. This may be strange territory for you as it may be the first time that you have considered your child to be a sexual being. Young people with a neuromuscular disorder will have the same anxieties and desires as others their age, as well as hormonal swings.

Whatever questions your child asks you, it is important that you provide answers that are factual. And if you don't feel as though you can fully and completely answer a particular question, then it would make sense for you or your child to seek professional advice from the school nurse, the school counsellor or your family doctor. You may want to encourage your child to set up a private appointment with a professional so that he can have some of his more sensitive questions answered, questions that he may not feel comfortable sharing with you.

More information and resources on sexual health:

<http://www.sexualityandu.ca/en>
<http://www.youngandhealthy.ca/caah>
<http://www.comeasyouare.com>

There are some questions, however, that you may be the best person to answer. Below are some of the typical questions you may be asked, followed by possible answers:

Question: Will I ever have a girlfriend / boyfriend?

Answer: Yes, it is possible. Many people with neuromuscular disorders have a girlfriend/boyfriend. Before you can find a partner, you must first believe that you can. If you have confidence in yourself, others will have confidence in you too; but that is not enough. You need to have interests, hobbies, and passions and you need to be engaged in life. Romance takes work. You need to take care of yourself, be active and talk to people. People will want to date you for who you are and for the common interests that you share.

Question: Will anyone find me attractive with my disability?

Answer: As the saying goes, beauty is in the eye of the beholder. Your disability may be too much for some people to handle, but not for others. If you accept your body and embrace your differences, then others can too. And keep in mind that your disability is only part of who you are. People will be attracted to your personality more than anything, so let your light shine through!

Question: Can I get married and have a family?

Answer: Yes, you can. Other people with your disability are married and have families so you might too one day.

2.10 What words of advice can adults with neuromuscular disorders offer my child?

As you expand your circle of support, it is important to reach out to adults with neuromuscular disorders and other adults with disabilities. Many of them have grown up with their disability and will have a lot of advice to offer concerning what was helpful for them over the years. Adults with disabilities can give you important information on what they want the world to know about people with disabilities (such as information on the language used to describe your child's disability, the importance of choice and independence, etc). Some of their messages will be important for you to teach your child as he grows up.

The following messages come from adults with a neuromuscular disorder:

Kareem - "Don't let the small words harm you, make a difference in your life by looking at the things you CAN do."

Vicki - "The biggest disabilities are other people's inability to see *you* before the disability – feel sorry for them not yourself."

Grady - "Accept what you can't do, but fight hard for what you can."

Ken - "Don't be afraid to take chances and to explore opportunities that may on the surface seem impossible. Be realistic about your limitations but do not let your physical inabilities collide with your mental abilities. You will exceed your family's expectations if given the opportunity."

Luke - "Doing something will always lead you somewhere, while doing nothing will only lead you nowhere."

3. School Issues

3.1 My child will be going to a new school – how do I prepare the school for this?

After registering your child for the school, request a meeting with the principal and your child's teacher to discuss your child's needs and accommodations that may be required. Consider providing the school with a copy of the *MuscleFacts School Resource Guide*. 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, school personnel will find tips on how to effectively include a student with a neuromuscular disorder. To obtain the *School Resource Guide* and other resources, please contact Muscular Dystrophy Canada (see Foreword).

Remember, Muscular Dystrophy Canada staff and volunteers are available to help you through this transition. We can provide professional development for school staff, and information on how to foster an inclusive and supportive environment for your child.

3.2 How do I plan for my child's education?

For children with a disability it is important to establish an individual education plan (IEP) with the school. This process brings together all the people who work with your child (including the parents) to create and implement an action plan that meets your child's particular needs. The objectives of an IEP are to establish a mutual understanding of your child's abilities, needs and interests; discuss and determine your child's current performance levels in various settings; identify priorities; decide on how and where to best meet those needs; and how to report on your child's progress. An IEP is reviewed a couple of times a year as needs change. It is important to contact the principal or counsellor at your school to initiate the IEP process as soon as possible.

3.3 Other kids are teasing or bullying my child – how should I deal with this?

Every school likely has policies related to bullying. Contact the school counsellor to access this general information and for basic advice on the subject. As well, given that the teasing or bullying is probably a reaction to your child's neuromuscular disorder, there are two ways in which you could prepare your child to handle this. First, ensure your child knows as much as possible about his neuromuscular disorder. This knowledge can be very empowering for your child and can help prevent him from being surprised or hurt by anything that other students may say about his disability. Second, you and your child could work together to come up with ways to respond to common comments made by other students regarding your child's disability.

For more anti-bullying information and advice, check out the following resources:

<http://www.prevnet.ca/>

<http://bullying.org>

<http://www.stopbullying.gov>

Freedman, Judy S. *Easing the Teasing: Helping Your Child Cope with Name-Calling, Ridicule, and Verbal Bullying*. McGraw-Hill, 2002.

3.4 My child is having behavioural challenges at school – what should I do?

Some children with a neuromuscular disorder may have limited ways of expressing their feelings and could behave in an angry, frustrated, stubborn or withdrawn manner. When this occurs at school, it is important to take action. A teacher may not have the resources necessary to deal with such a behavioural issue on their own and could benefit from a coordinated intervention. As a parent, the best way to make this happen would be to contact the school counsellor or principal and request an individual education plan (IEP) meeting.

3.5 What can be done to help educate my child's classmates about disabilities?

There are a few ways to increase the level of disability awareness among the students in your child's class. The first would be to contact the Muscular Dystrophy Canada to request a MuscleFacts presentation. These age-appropriate presentations are designed to teach children about concepts like human difference, helping others and interacting with people who have a disability. MuscleFacts presentations can be conducted in two different ways: Muscular Dystrophy Canada staff and/or volunteers can come to your child's school or, if this is not possible, Muscular Dystrophy Canada staff can send a MuscleFacts lesson plan kit to your child's teacher instead. Either way, discuss the idea with your child ahead of time to ensure that he is comfortable with it.

In addition to arranging a MuscleFacts presentation, you could also ask your child if they would be interested in explaining their disability and its challenges to their classmates directly. A third idea would be to encourage your child's school to purchase a disability awareness video that can be shown in all the classrooms. This type of video can be purchased from one of the following websites:

Program Development Associates
<http://www.disabilitytraining.com>

Fanlight Productions
<http://www.fanlight.com/catalog/subjects/disability.php>

Video Press – University of Maryland
http://www.videopress.org/disability_awareness.html

4. Health and Activity Issues

4.1 Which professionals may become involved in my child's life?

In order for your child to remain as functional as possible for as long as possible, he will need a supportive, patient-centered health care team who understands neuromuscular disorders, your child's personal situation and the options that will be available to him. As time goes by, you will need to work with your child's health care providers to treat various symptoms of the neuromuscular disorder and adapt to an array of functional changes. The following is a detailed list of the professionals your child may encounter:

Primary Doctor: Tasks performed by your child's doctor may include explaining the diagnosis and possible progression and treatment of the disorder. The primary doctor will also consult with other health care providers and make any necessary referrals in order to best manage your child's care.

Neurologist: A specialist who can confirm a diagnosis of a neuromuscular disorder. The neurologist will also help to outline the types of treatment options available, help your child preserve a positive self-image and maintain morale, work with your child to identify specific needs and concerns and refer him to therapists who may be able to find solutions.

Nurse Clinician/Registered Nurse (RN): They will generally analyze your child's data, and then draw up and implement a care plan. Other nursing functions may include teaching skills and providing demonstrations, limiting the development of complications and providing interventions if problems arise.

Occupational Therapist (OT): An OT helps your child maintain health, and works to increase independent function. An OT also assesses clients for things such as mobility aids (i.e., wheelchairs) and other assistive devices. You can also look to an OT to help your child perform daily activities independently and more efficiently.

Physiotherapist/Physical Therapist (PT): A PT teaches techniques and exercises to maintain strength in muscles and maximize your child's range of motion. PTs achieve this through prevention, treatment and rehabilitation. After various assessments, a PT will put together a treatment plan. PTs can also help to reduce pain and stiffness using manual therapy methods such as massages and manipulation. Like OTs, a PT can also prescribe assistive devices.

Physiatrist: A medical doctor specializing in physical and rehabilitative medicine who can evaluate the extent of disability and functioning, and gauge the level of muscle function your child still has (residual level). On the basis of these findings, treatment plans may be designed.

Dietitian: This professional's role is to help your child maintain safe and adequate nutrition and hydration, in order to prevent life-threatening nutritional deficits from developing. The dietitian may assess or evaluate your child's functional abilities (ability to self-feed or to administer tube feedings), nutritional status and dietary intake.

Clinical Psychologist: Clinical psychologists deal with mental, emotional and behavioural issues by means of therapy. They do not prescribe medications.

Education Consultant: This person is a link between the educational and medical systems who collaborates with other professionals to recommend appropriate educational supports for your child.

Respirologist: A medical doctor who specializes in care for the respiratory system. Depending on how your child's neuromuscular disorder progresses, they may be referred to or seen by a respirologist in the event of a respiratory infection, or to discuss mechanical ventilation.

Respiratory Therapist (RT): An RT devises strategies to optimize remaining muscle function and reduce discomfort, and institutes a program of chest care if necessary. Among other duties, a respiratory therapist also evaluates pulmonary function status, provides suggestions for managing decreasing breathing function and sets up home ventilation where appropriate.

Speech-Language Pathologist (SLP): The SLP provides advice on techniques and strategies to allow people with neuromuscular disorders to continue to communicate throughout life. An SLP evaluates functional abilities, such as oral motor function, cognitive-linguistic function, augmentative communication function and swallowing function.

Social Worker: A social worker provides both practical assistance as well as emotional support to help your family cope with everyday life. The social worker offers emotional support, information about available community resources and assistance in accessing these resources, and helps with setting short-term and long-range goals and making plans that will meet future care needs.

4.2 What is a Paediatric Neuromuscular Clinic, and what happens there?

A Paediatric Neuromuscular Clinic is a specialty service for children with a neuromuscular disorder and their families. Assessments, education, training, recommendations for equipment, treatment options, school adaptations, etc., are available and individualized according to the needs of each child.

The Paediatric team usually includes representatives from many of the professions described in the answer to Question 4.1. Team members may evaluate your child alone or together with other therapists. The clinic visit may last for an hour or two, or it might take the full day. This depends on the therapists that your child needs to see, and upon the specific type of appointment needed.

Children with neuromuscular disorders should be evaluated at least once per year. It could be more frequent depending on your child's condition and which professionals are involved in his care. By having a full clinic review with a selection of team members on a yearly basis, it is hoped that problems may be detected early, and perhaps prevented from worsening by modifying equipment, positioning, nutritional supplementation, etc. Optimum health with a neuromuscular condition is our goal for your child.

To prepare your child for the visit, let him know that several different people will see him. He will be asked to play or to show how he performs normal functions in his daily life. There will be questions for you and your child to answer. Most of the evaluation is by examination and observation, and is not considered to be invasive. The most important point to tell your child is that the staff is there to help him be the best he can be at home, school and in the community.

Depending on the practice at your local clinic, you may receive a report following your visit that describes the evaluation done by each professional as well as the recommendations made and any further action that is needed. If you have given consent, copies of this report may be sent to your child's primary doctor, to the school, to your community therapists, etc. in order to keep them informed of recent developments and recommendations.

4.3 Doctors suggest that I should put my child on steroids – is this a good idea?

If your child has Duchenne or Becker muscular dystrophy (DMD/BMD), your doctor may prescribe steroids (also called corticosteroids). The goal of steroid medication is to help the child walk independently for longer, and to minimize breathing, heart and orthopedic problems. The other potential benefit is reduced risk of scoliosis (curvature of the spine.) While there is a lot of research happening currently in the area of new drugs for DMD/BMD, at the present time, steroids are the only medicine known to help slow down muscle weakness. It is important that the potential side effects of steroid therapy be discussed and monitored on an ongoing basis with your child's health care team.

For more information on the issues related to steroid therapy, please refer to Muscular Dystrophy Canada's *The Diagnosis and Management of Duchenne Muscular Dystrophy: A Guide for Families*, which is based on the best practice guidelines established by international experts in 2010.

4.4 My child has weight issues – whom should I talk to about this?

Some children with a neuromuscular disorder can be prone to putting on excessive weight, while others may be underweight. The major causes of obesity in children with a neuromuscular disorder include inactivity, steroid use and a high-calorie diet. In terms of being underweight, some affected children may not take in enough calories during the day due to self-consciousness about needing to be helped to eat or because of difficulties with chewing and swallowing. The best person to talk to in either case would be a dietitian (see Question 4.1).

Check out the following links for more dietary resources:

Healthy Canadians

<http://www.healthycanadians.gc.ca>

Dietitians of Canada

<http://www.dietitians.ca/>

Academy of Nutrition and Dietetics

<http://www.eatright.org>

4.5 What types of exercise or stretches would be helpful for my child?

Children with neuromuscular disorders are at increased risk of developing contractures as a result of their

mobility-limiting disability. Contractures often occur when muscles deteriorate, causing the tendons in the arms and legs to tighten, feet and hands to curl in, and knee and elbow joints to no longer straighten out. To help reduce this risk you can access the services of a physiotherapist, whose job it is to help children reach their maximum physical potential. They can show you how to perform a number of beneficial range-of-motion stretches with your child.

When it comes to exercise, however, you will need to be cautious. Children with neuromuscular disorders are prone to both muscle fatigue from overuse and muscle contractures from underuse. This is why it is so important to find a fine balance of activity for your child. An excellent form of exercise for children with a neuromuscular disorder is swimming. It provides a supported medium for movement and helps to maintain a range of movement in the joints.

4.6 How can my child get involved in recreation?

There are many websites that promote recreational opportunities for children with disabilities:

The Canadian Abilities Foundation
<http://www.abilities.ca>

Active Living Alliance for Canadians with a Disability
http://www.ala.ca/Content/About_ALA/partners.asp?langid=1

SportAbility
<http://www.sportabilitybc.ca>

Canadian Wheelchair Sports Association
<http://www.cwsa.ca/en/site>

Canadian Electric Wheelchair Hockey Association
<http://www.cewha.ca>

Powerchair Football Canada
<http://powerchairfootballcanada.com>

Special Needs Camps in Canada
http://www.mysummercamps.com/camps/Special_Needs_Camps
<http://ourkids.net>

4.7 I need some help with my child's personal care – what services are available?

When your child reaches the point where he requires assistance with some or all of the activities of daily living, this can be challenging for families who are also trying to meet a number of other household responsibilities. There will be times when you will simply need a break from caregiving in order to maintain a healthy balance in your life. This is when you have to make your needs known – no one else will know until you tell them.

Since health care is the responsibility of each province, you would have to find out what care support your province offers to families of children with physical disabilities. As well, it would be a good idea to contact your local health authority to see if they have any programs or services that may assist you. It may also be helpful to contact any local disability or independent living centres for information about nonprofit programs in the community. The following is a list of the provincial government programs available to children with disabilities:

ALBERTA

Children and Youth Services: Family Support for Children with Disabilities

<http://www.child.alberta.ca/home/591.cfm>

BRITISH COLUMBIA

Children and Family Development: At Home Program

http://www.mcf.gov.bc.ca/at_home/

MANITOBA

Manitoba Family Services and Labour: Children's disABILITY Services

<http://www.gov.mb.ca/fs/pwd/css.html>

NEW BRUNSWICK

Social Development: Community-Based Services for Children with Special Needs (CBSCSN)

<http://app.infoaa.7700.gnb.ca/gnb/Pub/EServices/ListServiceDetails.asp?ServiceID1=10195&ReportType1=All>

NEWFOUNDLAND AND LABRADOR

Health and Community Services: Home Support Program

<http://www.health.gov.nl.ca/health/>

NORTHWEST TERRITORIES

Health and Social Services: Home Care Program

http://www.hlthss.gov.nt.ca/english/services/home_care/

NOVA SCOTIA

Department of Health: Continuing Care Programs: Home Care

<http://www.gov.ns.ca/health/ccs/homecare.asp>

NUNAVUT

Health and Social Services: Home and Community Care Program

Tel: (867) 975-5933

<http://www.hss.gov.nu.ca/en/Your%20Health%20Home%20and%20Community%20Care.aspx>

ONTARIO

Children and Youth Services: Special Services at Home

<http://www.gov.on.ca/children/english/programs/needs/services/>

PRINCE EDWARD ISLAND

Health PEI: Community Programs and Services: Home Care

<http://www.gov.pe.ca/health/index.php3?number=1020609&clang=E>

QUEBEC

Régie des rentes du Québec: Mesure de Soutien aux enfants – Supplément pour enfant handicapé

http://www.formulaire.gouv.qc.ca/cgi/affiche_doc.cgi?dossier=9249&sujet=28

SASKATCHEWAN

Social Services: Community Living (people with intellectual disabilities only)

<http://www.socialservices.gov.sk.ca/community-living/>

YUKON

Health and Social Services: Continuing Care

<http://www.hss.gov.yk.ca/programs/continuing/>

5. Future Planning

5.1 What options are available to my child after graduation from high school?

The transition from the daily predictable schedule of high school, where your child can access a variety of resources, to the unpredictable world of life afterwards can be an intimidating prospect for both the teenager with a neuromuscular disorder and his parent(s). This is a critical time in your lives as you deal with a host of emerging issues such as funding, transportation, care support and access to community resources.

How these issues get resolved will depend largely upon the activities your child chooses to pursue. Does he want to: a) further his education; b) enroll in an employment readiness program; c) get a job; d) start a business; e) volunteer at a nonprofit organization; f) participate in a day program; or g) do something else?

To help answer these questions, Muscular Dystrophy Canada currently offers a program in British Columbia called Bridges to the Future. Bridges assists and empowers youth with physical disabilities between the ages of 15 and 24 with the necessary skills to move forward into adulthood as independently as possible. The success of Bridges is largely due to its focus on motivating, supporting and coaching youth as they work toward their goals. Check out www.bridgestothefuture.ca for more information.

There may also be goal-setting programs offered at a local independent living or disability centre that can help your child plan for his transition into adulthood. It is important to remember that education, employment, independent living and relationships are dreams that we all have, whether or not we have a neuromuscular disorder.

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1-800-884-6322

QUEBEC *infoquebec@muscle.ca*

1425 boul. Rene-Levesque Ouest,
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Montreal, QC H3G 1T7
Tel: 514-393-3522
1-800-567-2236

Centre hospitalier de Jonquière,
C.P. 15
2230 rue de l'Hôpital, 7^e étage
Jonquière, QC G7X 7X2
Tel: (418) 695-7760
1-877-295-7911

WESTERN CANADA *infowest@muscle.ca*

7th Floor - 1401 West Broadway
Vancouver, BC V6H 1H6
Tel: 604-732-8799
1-800-366-8166

1024 - 10th Ave SE
High River, AB T1V 1L3
Tel: 403-649-6247
1-888-649-6247

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

104 - 901 4th St South
Martensville, SK S0K 0A2
306-382-2172

204 - 825 Sherbrooke St
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www.muscle.ca

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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