

Our Mission

Muscular Dystrophy Canada supports the independence and full participation of Canadians with neuromuscular disorders.

We fund research to improve the quality of life for people with neuromuscular disorders and to find a cure.

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

What is Muscular Dystrophy Canada?

Muscular Dystrophy Canada (MDC) is a national voluntary agency, incorporated in 1954 by a group of parents and friends of children with Duchenne muscular dystrophy and supported by Fire Fighters.

Today, MDC is working to combat over 100 neuromuscular disorders. We're committed to funding leading research to find the causes, treatments, prevention, and cures for each of the disorders. But until we do find a cure, we provide information, vital services, and hope to tens of thousands of Canadians living with neuromuscular disorders.

MDC conducts year-round fund-raising campaigns to support our programs. Your gift will help MDC provide the dollars necessary to assist individuals living with neuromuscular disorders and fund much needed medical research, educational information, advocacy, medical equipment funding, a loan equipment program and peer support.

If you would like to make a donation, or become involved as a volunteer, please contact the MDC office nearest you or call our toll-free number.

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Introduction

If you have always considered yourself a strong, collected person who is up for any challenge, then it is likely that your child's recent diagnosis with a neuromuscular disorder (NMD) has drastically changed your perspective. Most parents who have gone through the same ordeal have found that there is almost nothing that can prepare you for the diagnosis. Everything that you thought you knew about parenting and every idea you had about raising a child is proven wrong in one painful instant. Something that was so far removed from you before – something that only happened to other people's children – suddenly becomes the centre of your life.

It is enormously difficult to cope with this initial shock alone. In all likelihood, the skills that you have built up your whole life to cope with your problems have become insufficient to deal with this new burden of grief, stress, and fear. What you need now more than anything is courage, but in times of hardship like this, it is not so easy to come by.

Even so, you need to gather all the strength you can muster so that you can begin to develop new coping mechanisms that will allow you to go on with your life.

Although this pamphlet's purpose is to help you get through this difficult time, it will by no means tell you how to cope with your grief. Every person is different, and will develop different methods of coping that are suited to their own personality. All that this pamphlet can do is point you in the right direction. Once you are able to recognize where your positive sources of strength are, and once you are able to understand and deal with the powerful emotions that mark this initial period, you will have made the first step in taking back your own future so that you can begin to free your child's as well.

Explore your grief

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 the diagnosis to come out differently. 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, looking for second, third, and fourth opinions, never accepting the reality of their situation.
- Some get angry – randomly directing their anger at themselves, their doctors, their family, their friends, and sometimes their child.
- Many others collapse into a frozen depression, feeling helpless and unable to go on any longer out of fear for the future.

What you need to understand about your own reaction is that it 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 that has assaulted you.

You cannot escape this period of grieving, just as you cannot make your child's disorder go away. Grieving is a natural, necessary process that your mind and body need in order to cope with the pain. As long as you come to terms with your pain, and begin to properly deal with it, grieving is always a productive thing.

Grief only becomes a problem when you let it take over and run your life. Permanently denying your child's disorder, or permanently holding a grudge against your child, spouse, or self, can only end up having a negative impact on your life, as well as your child's – building up a wall of resentment and hate where love and understanding are needed more than anything. For now, at least, all that you can do to help yourself is to recognize these feelings and their urgent need to be addressed.

*Take one day
at a time, and remind
yourself that your best is
good enough.*

Reach out for understanding

Truly understanding your feelings on your own can be a daunting task. If you really want to begin to come to terms with your initial pain and stress, you must first express the mental and emotional struggles that you are facing to someone else.

It is imperative that you don't bottle up how you feel for any reason, even if it is how you have always dealt with your problems. Forget any rules that you thought society held for how men or women should act. Now, more than at any time before, you need to let loose these emotions, especially if they seem foreign or out of character. If you need to cry – cry. If you merely need to sit silently with someone you love, tell them that. Don't feel constrained by what people will think of you or how you may have acted before.

Too many people wear themselves out trying to be strong, even though they are agonizing inside. Real strength will be derived from your ability to cope with your life and problems. Men and women alike need to let their partners, their friends, and their support networks know how they are feeling. By expressing any frightening or disturbing thoughts openly to someone you trust, you can begin to pry out irrationalities, inconsistencies, and falsities in your thoughts and feelings. If you bottle these feelings up, they can only end up having an extremely damaging effect on your mental, physical, and spiritual health.

If, for whatever reason, you don't feel comfortable sharing your feelings with someone else, it is important that you find another way of expressing yourself. Writing can often be a powerful medium for addressing and coping with your grief. By writing down what you feel, you can begin to find order in your initial chaotic feelings. Once a thought is written on paper, it can be looked at more critically and you can begin to make sense of your reaction, and how it has affected your life.

Inform yourself

An important part of the coping process involves coming to terms with the facts about NMDs. By remaining ignorant about your child's disorder, you are allowing yourself to harbour some false assumptions about what it implies about you or your child. Some people actually continue to feel guilty their whole lives, believing that somehow they were at fault for their child's condition and that they could have done something to prevent it. If you are informed about the condition, you can clear these false assumptions from your mind, freeing yourself from a considerable load of guilt and stress.

Being informed also gives you the ability to communicate intelligently about your child's disorder. Much of the fear and intimidation that went along with your initial conversations with doctors and specialists will be removed when you are able to translate their conversation from medical jargon to your own terms. You will also be able to inform the public, who generally know nothing about the disorder. Instead of having them remain ignorant about your child's needs, you will be able to illuminate your friends and family members, as well as your child's teachers, doctors, and therapists on the disorder and what it will mean to their re-relationship with you and your child. Once they understand the nature of the disorder itself, most people will stop treating your child like "someone with a disease" and start treating them like they would anyone else.

There's lots of information out there. Some good places to start are the Muscular Dystrophy Canada (MDC), the Internet, and your local library. Once you think you have a good grasp of the basics, go further. Look up more information all the time so that, eventually, you too can feel like an expert.

Find strength in your support network

It is difficult to stress sufficiently how important a strong, caring support network will be in the days 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.

Especially if you are a single parent of a child with a NMD, your support network will become one of your new vital organs. It is impossible to deal with the mental, emotional, and physical demands of being a parent of a child with a NMD alone, and no one is expecting you to give up everything that you once had in order to take care of your child. More than anyone else, you need to call out to your loved ones for help. They will be there for you, but only if you help them understand what you need from them.

*Your child's muscles
may be weak, but her
spirit is strong.*

*Help her nurture that
spirit so she becomes the
best that she can be.*

If you don't already know who 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 go to them, 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.

Permanently add MDC to your list of supporters if you may have forgotten them. Not only are MDC staff an important source of knowledge, experience, support, and information, but they are also the source of a number of important services and programs that will be invaluable to you and your child.

If your child needs a new piece of equipment, MDC may be able to help fund it. If you need some information on anything to do with NMDs, MDC will be the best place that you can go. Most importantly, MDC is also the best source for getting in contact with people who live or deal with NMDs every day. By becoming involved in your local chapter, various MDC fundraising events, or the Peer Support Program, you can learn that you are not alone, and that there are many people out there who have shared your experiences and are willing to help you.

Strengthen your important relationships

Your Support Network

Your relationships with your loved ones are going to become part of your essential life support functions in the days ahead. This does not, however, mean that everyone will immediately be supportive, or even helpful to you.

NMDs are complex. They require a great deal of care and attention and will often be misunderstood by those around you. Many will be upset, seeing how much pain and stress that you are going through, and they will provide you with pity rather than positive support. Others may ignore the seriousness of the condition, denying your child's problem while insisting that it is a misdiagnosis. Some may even place blame on your child for everything that you are going through.

If you let your loved ones perpetuate these kinds of attitudes it will only add to your stress and put an uncomfortable strain on your relationships. You need to begin by educating those around you on the NMD – what it means to your child and what it means to your life. By letting them know how you see the disorder, and how you want them to see it, you may go a long way towards preventing future problems that could drive a wedge in your friendships.

Your Spouse

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.

*I want my son to grow up
confident and able to
cope...*

*my goal is to help him
discover and develop his
own unique talents.*

The months immediately after the diagnosis are always the hardest. Both of you will be grieving in your own way, and may become isolated from one another. 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.

Your child's NMD will also trigger some enormous changes to your day-to-day life that may isolate you and your partner even further. With the time it takes to go to work, take care of your child, go through daily therapies and exercises, do the necessary household chores, and sleep, you may find that your free time has become scarce. If you don't adapt your traditional roles as parents to this new hectic lifestyle, you may find that one partner is being overburdened with an extremely unfair workload.

If the husband, for instance, has always been in charge of the household care-taking duties and childcare, while the wife has traditionally been in the workforce supplying the family with a steady income,

then some important issues need to be addressed. When a child has a NMD, they become a full-time commitment that does not stop at 5 o'clock after work is over. Being expected to keep taking care of your child throughout the whole evening after you have been busy taking care of them all day long, while the other partner rests or watches television after work, is just unfair.

The working partner must take on childcare responsibilities as well, even if they are at work all day. This will not only reduce any unfair strain that one of you may be experiencing, but it can also bring you closer together. Through sharing tasks, you can find out how the other partner is really coping, and in just what areas they need your support the most.

Strain in your relationship does not always have to arise out of conflict. With your new tightly-packed schedule, you may find it hard to find time when you are not just a parent, but a husband or a wife as well.

Besides when you go to sleep at night, there may be very few times a week when you are truly alone with your partner. You need to make time for each other.

If you leave all of the things that made you fall in love with your partner out of your life, then you may begin to feel some dangerous distance developing in your relationship. Schedule time alone once a week when one of your friends, family members, or a babysitter will take care of your child.

Go for dinner. Go see a movie. Go anywhere where you can talk and be alone with each other. You may just find that this is the most important part of your whole week.

Your Children

Children also face grief and loss issues, especially if they are having a hard time doing things that other kids find easy. Once they become aware that there is something different about them, your child may start to ask questions that you don't know how to answer. Their moods might also change and you may notice signs of isolation, depression, guilt, or anger.

Most parents find this to be an especially difficult time. Dealing with your own grief issues might make it much harder to deal with your child's. You need to start preparing yourself for these issues ahead of time so that you will have the strength to properly react to your child's grief. Turn to positive sources like MDC, other parents of affected children, or a family counselor. These sources will help you understand what your child is going through, and what kinds of strategies will be most effective. Make sure, though, that you don't neglect these issues.

It will only make it harder for your child if you hide the problem rather than addressing it positively from the beginning. If you have other children, now may be an extremely difficult time for them as well. Emotionally, most children are not ready to find out that something serious is wrong with their brother or sister. All children deal with this sort of thing differently but, as time goes on, many begin to feel isolated or even unwanted by their parents.

This will be a difficult problem to deal with, especially considering the amount of care that your child with a NMD will require. One of the best first steps that you can take is to educate all of your children on their individual differences. Explain why they need such different things from you and why you can't treat them the same way. If

*If your child has
confidence,
he will be able to cope
with all that life throws
at him.*

you have trouble doing this on your own, MDC is a great source of valuable books and information that can help you bring these serious issues to the attention of your children.

Another good way of gaining your children's understanding is by letting your unaffected children become involved, or at least familiarized, with many of the care taking duties that you provide for their brother or sister. As long as you don't force them to do this against their will, it will help them to feel useful and wanted, while working towards giving them a better understanding of the importance of their brother's or sister's needs.

Most of the time, kids need more than just explanations if they are going to accept their own role within the household. For the majority of children, your actions lie in one of two ballparks: fair or unfair. If your unaffected child is given more responsibility, different rules, or different rewards and punishments than their siblings, then they are likely to develop some serious problems dealing with you, as well as their brother or sister. They will see your rules as unfair and will often rebel or misbehave in order to get the attention that they feel they are lacking.

Even though one child is living with a NMD, it does not mean that you should treat them differently when it comes to things like chores, rewards, or discipline. At some point in their lives they are going to need to feel at least somewhat independent. If you baby your child for too long, giving them no responsibility, they may begin to feel like they can't do things that are actually within their abilities, and it will make it difficult for them to deal with each progression of their condition. Their siblings will also have a harder time relating to them, and will resent their lack of real responsibility.

Children also resent you when you try to force a sibling relationship on them. Let them adapt to each other at their own pace. If you force your unaffected child to take care of their brother or sister at school, or if you constantly make them act as a babysitter, it will only build up resentment and a greater rift between them. Like all children, they will need to develop a relationship on their own time. They will not always get along and there will be struggles, but you must give them the benefit of the doubt and rely on your ability as a parent to raise healthy and well-adapted children.

*There are times when the
worry and financial stress
make me feel like
walking away. I've found
that, if I just keep
focused on my family,
these times usually pass
and things get better.*

(A father)

Come to Terms With Your New Life

The final, most important ingredient to any positive coping solution involves coming to terms with the changes that have been, and will be, taking place in your life. For the sake of your own health and well being, you need to learn to accept that there are many new and very difficult aspects of your life that you have no control over and cannot change. Once you stop struggling against these changes, and allow them to enter into your life, you will find that you have more strength to focus on the parts of your life that can and need to be changed.

It is easy to lose yourself amidst all these rapid and difficult changes. You need to ensure that you don't let the things that you love doing, and that have always made you happy, be pushed off to the side. Just as your child is much more than just CMT or Duchenne muscular dystrophy, you are also much more than just a parent of a child with a NMD. Do not feel that you have to completely give up the career you love, your favourite hobbies, or your own health and well being in order to properly care for your child. Make time for these things, and don't feel that you are being a bad parent for it. If you are resentful and miserable about all the things that you have lost, then you won't be very much help to your child or those around you.

Remember.

This is by no means the end of anything. Don't give up on your dreams of the future, or your child's, for anything. Continue to make plans, continue to dream, and let your child do the same. You have many years ahead with your child that you would not trade for anything. Be sure that you make them the best possible for you and your child.

In Conclusion

Time is one of the most important ingredients to the coping solution. You are going to become a stronger person than you have ever imagined that you would be, and you will find that your experience raising your child will provide you with an infinite number of opportunities for personal growth that were previously unavailable to you – but it is impossible for anyone to learn to deal with all of this right away, so don't feel that anyone is expecting you to. Move at your own pace. There is only so much that you can possibly absorb at one time. If you ever feel lost or alone, make sure that you turn to your loved ones for strength. There will always be someone who is willing to help. And remember, never underestimate the power of your own courage to carry you through these difficult times and to the brighter days ahead.

For more information, contact the Services department in your local Region:

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