

Introducing Dystonia

A GUIDEBOOK FOR TEENS

DYSTONIA
MEDICAL
RESEARCH
FOUNDATION
CANADA



FONDATION DE
RECHERCHE
MÉDICALE SUR LA
DYSTONIE
CANADA

*serving all dystonia-affected persons
déservant toutes personnes atteintes de dystonie*

“I am thrilled that the DMRF Canada gave me the opportunity to participate in reviewing this guidebook. As a grade 12 student living with generalized dystonia, I can relevantly connect many aspects of this information back to my own school experience. The one thing that I wish I had realized sooner in my journey is that when you truly accept your diagnosis on a personal level, every other aspect of living with dystonia becomes easier to handle.”

Sarah Anderson, Teen Ambassador for DMRF Canada.

PART ONE: INTRODUCTION

So You've Been Diagnosed with Dystonia?

Muscle spasms you can't control force parts of your body into awkward positions or movements. Sometimes those spontaneous muscle contractions are painful as well as frustrating. And they always interfere with what you were doing, or what you want to do. Why, you are wonder has this happened to you?

You might be surprised to learn that dystonia is a condition you share with about 300,000 people throughout Canada and the United States. It's a neurological movement disorder that affects individuals from all walks of life, both genders and all ages...including children and teens.

So, you are not alone.

However, dystonia is a complex condition that has many different forms. Your symptoms may be quite unlike those experienced by other people.

If you are reading this booklet, it probably means you have some challenges to face and may be entering new territory. Not only are you faced with the demands and stresses of your teenage years, but you have the added challenge of dystonia. The first thing you should know is that there are young people all over the world who have dystonia – there may even be others in the province you live in. You are not the only person on the planet who is faced with going through high school with dystonia. You are not the only person on the planet who is faced with going through high school and dystonia, and you are not alone.

PART TWO:

Working with your Doctor



Preparing to See a Neurologist

When you see a neurologist, there are two main things he or she will do.

The first thing that he or she will do is ask questions.

If the neurologist is directing most of the questions to your parents as if you're not even in the room, you should feel free to politely say, "Dr. please feel free to direct your questions to me. I am happy to answer them for you."

You can then defer to your parents if necessary or arrange with your parents ahead of time that you will answer and ask most questions.

If you are meeting the neurologist for the first time, he or she will want to know about your health and your life so far. The doctor will want to know all sorts of things such as your health as an infant and child, and how

you're doing in school. The neurologist will also want to know about the health of your family members. If you have been visiting your neurologist for a while, he or she will be more interested in how you are responding to your treatments and if your dystonia symptoms have changed since the last time he or she saw you.

The second big thing the neurologist will want to do is to examine you. He or she will probably ask you to walk around, use a pencil, or pick up objects. At a first visit, the neurologist may do seemingly random things like shine a light in your eyes, look at your fingernails, or examine your spine. These may be little "tests" to rule out other health conditions or help the doctor understand your symptoms. Sometimes the doctor will do things that are uncomfortable such as take a blood sample. Although they may be unpleasant, these things are necessary, so the doctor can understand how dystonia is affecting you and recommend appropriate treatment.

Even though you can probably think of hundreds of other things you'd rather be doing than visiting the doctor, it is a crucial part of taking care of yourself. Hopefully you can find a doctor who you trust and don't mind visiting from time to time.

Finding a Movement Disorder Specialist

In addition to the Pediatrician or General Practitioner you see for more common health matters, you should also have a movement disorder doctor who you visit to treat your dystonia. DMRF Canada can help you locate health care professionals who are knowledgeable about dystonia. Visit: www.dystoniacanada.org/support for a listing of professionals organized by city and province.

You may also visit a physical therapist, occupational therapist, speech therapist, or other health professionals who help in your care.

Getting Prepared – Some Reminders:

Before you visit your neurologist, you may want to consider writing a checklist of how things have been going for you recently. As you experience different challenges, try to remember specific details (like, for example, that you can't grasp your bike handlebars as well as usual or that your foot is dragging more). *Little things like this will help your doctor to decide the next step in your treatment.*

1 Track Your Symptoms

Consider keeping a journal or writing notes in your iPad, phone or tablet. This will help you keep track of how you are doing physically as well as emotionally on a day to day basis as you experience your symptoms. It is important to track both our physical symptoms as well as your emotional symptoms. Even just recording a couple sentences each day about how you are feeling and what your symptoms are doing can be very informative to look back on. Its important that you remember to bring your notes to your medical appointments. If you happen to go to the Doctor on a day that you are feeling good, you may forget to mention other symptoms that have been bothering you since your last appointment.

2 Write Down Your Questions as They Come Up

It's not a bad idea to write down questions you have for the doctor, too. For example, is there a symptom or body part that is giving you a lot of trouble? Is the medication you were prescribed making you feel sick to your stomach or tired or something else? Medical appointments can be hectic, so writing a list (and being sure to bring it with you) will help you remember everything when you need to have that information available.

3 Don't Pretend Everything is Okay if it Isn't.

Its important that you are honest with your healthcare providers (and your parents, and others in your life). Don't try to be a hero, and don't' be worried about complaining, or focusing on the negative. There are times when remaining positive is important – but when you're seeing your Doctor, its important that you tell her or him everything that is relevant to your dystonia experience. The more they know the more they can help you.



Treatments

Although there is presently no cure for dystonia, multiple treatment options are available. Because every person with dystonia is unique, treatment must be highly customized to the need of the individual. No single strategy will be appropriate for every case.

The purpose of treatment for dystonia is to help lessen the symptoms of muscle spasms, pain, and awkward postures. The ultimate goal is to improve the quality of your life and help you function with the fewest side effects possible.

In most cases, the most appropriate kind of doctor to treat dystonia is a movement disorder neurologist. Establishing a satisfactory treatment plan requires open communication and patience on the part of both the affected individual and the physician. Make the effort to locate the most experienced physician you can, and someone with whom you feel comfortable.

The first step in treating dystonia is to determine as much as possible about the underlying cause. Information about the cause of dystonia may direct the course of treatment. For example, a person with dystonia associated with another neurological disorder will require a slightly different approach than a person with a primary focal dystonia.

Visit: www.dystoniacanada.org/about-dystonia/treatments for specific details on therapies.

Connect the Doc's



If you are seeing more than one doctor or health professional, make sure they all know about each other and are communicating with each other. Know that you are the most important part of your health care team, and that you must be an active participant.

Being an active participant means:

- Being concerned about your health and taking care of yourself;
- Learning as much as possible about dystonia and treatments;
- Being aware of the dates and times of medical appointments and what they are supposed to accomplish;
- Bringing questions with you to your appointments. This includes specific symptoms that you would like to address, such as **“Ok, the botulinum toxin injections are helping my neck, but what can we do about the way my foot turns in?”**;
- Making sure that your questions are answered to your satisfaction and in words that you understand. Don’t be shy about asking your doctors to repeat themselves in simpler language. If your doctor gives you a monologue of gibberish, try putting on a smile and asking, **“Ok, if you had to explain that to a 9-year-old, what would you say?”**
- Knowing the names and dosages of all medications you are taking. Be responsible for your medication. If necessary, develop a system to help you remember to take your meds such as setting an alarm on your watch or cell phone
- Speaking up if a medication is making you feel like a newly unearthed zombie or like you’re losing your mind
- Not being afraid to tell your parents and your doctors what is working for you and what is not.

Even though you depend on your parents to support you and your health care team to advise you about how to best take care of yourself, remember that it’s your body that is affected by the dystonia. You are the most important part of your health care team. You can’t do it alone, but don’t be afraid to take charge of your dystonia and make decisions about your health care.

PART THREE:

Living Well with Dystonia



Everyone needs to take good care of themselves, and people with dystonia have added reason to do so. Dystonia can be physically rough on your body, so you need to treat yourself with kindness.

The first step to treating yourself well is to love and accept yourself, both on the inside and on the outside. Dystonia may make you look different on the outside, but it doesn't make you any less loveable or less deserving of a healthy life. Although dystonia may make your body do things you wish it wouldn't, you will be happier and healthier if you can accept your dystonia and focus on the many fabulous parts of yourself. Although dystonia impacts the physical body, and it can also affect emotional and psychological health. Living well with dystonia includes treating the physical symptoms, protecting emotional and psychological well-being and accommodating your unique treatment needs as an individual.

There is no single strategy for living well with dystonia, however, on the following page there are suggestions have been compiled from individuals who have experience with dystonia.

Seek Out Expert Healthcare Providers

It often takes a team of experienced professionals to diagnose and treat dystonia. This may include a movement disorder neurologist, physical therapist, psychiatrist, psychotherapist or counselor and others.

Actively Participate In Your Treatment

Learn about dystonia. Make informed choices about your care with the input of your medical team.

Listen To Your Body

Respect and honor your individual need for sleep, rest, nutrition, exercise, relaxation and time/scheduling.

Cautiously Explore Complementary Therapies

Talk to your Doctor about non-traditional therapies that interest you. Different approaches may work for different people but keep in mind that numerous practitioners and outfits falsely claim to have a unique ability to treat dystonia.

Exercise

Consider working with a physical therapist to develop an exercise plan that works for you. You can contact the Canadian Physiotherapy Association to learn more: <http://physiocanhelp.ca/>. *Be sure to speak with your Doctor before you explore complimentary therapies.*

Seek Help When You Need It

If you need assistance, reach out and be specific about what you're having trouble with. Accept help when offered and without shame or guilt.

Treat Mental Health Issues

Mental health issues, including anxiety and depression, can dramatically impact quality of life and the severity of motor symptoms. If you worry you may be experiencing undue anxiety, depression or other mental health issues, consider consulting a mental health professional.

Be Mindful Of Stress

Being a teenager is stressful. Regular stress reduction and relaxation practices can have a positive impact on symptoms and overall well being. Consider taking a light yoga or meditation class to try to reduce stress in your life.

Remain As Active And Social As Possible

It may be physically and / or mentally demanding to go certain places or complete specific tasks. Plan, pace yourself, and rest when needed.

Visit: www.dystoniacanada.org/livingwellwithdystonia for more links that could be helpful to your specific needs.

PART FOUR:

Being a Teen with Dystonia



Being a teen in general offers challenges and stresses. An adolescent's worst nightmare is to stand out and to be or feel different. This can also be a time when an adolescent can thrive recognizing his or her uniqueness as an individual (usually in cases where the uniqueness/individuality is admired by peers).

Young people with dystonia are just as intelligent as others their age. Dystonia may create extra challenges to managing in school, but you can continue to use your skills and creativity finding ways to adapt and compensate. Though dystonia may make you look or move differently than some, it does not need to affect your ability to make friends, to fit in.

Many kids with dystonia have found that one of the best ways to avoid being stared at or gossiped about at school is to find a way to explain dystonia to the other students. There is no excuse for anyone to be rude to you or make comments about your symptoms, but people may act weird around you simply because they are not educated and don't know how to act. Once people understand why you can't take Phys Ed or why your body moves the way it does, they are less likely to act up around you. It is up to you to decide who at school should know about your dystonia, but it might make sense to at least educate the teachers and students in your classes.

Ideally, prior to your first year at High School, it would be recommended for any adolescent with dystonia to arrange a meeting with the school administration (Principal, Vice Principal, Guidance personnel) - with the adolescent's advocate (parent or other advocate) to both explain your situation and proactively let them know your needs (accessibility, locker height, accommodations, etc.). Scheduling this advance "heads up" meeting would save both time and effort in having to fix, change and amend situations after the event. It would also go a long way to protect the adolescent from undue humiliation or unnecessarily feeling the need to suppress expression of needs.

No matter how much you explain your condition, the reality is there may be people who choose to not care or understand your condition. Do not blame yourself for this. If someone is harassing or bullying you, tell your trusted friends and guardians. If someone is making you absolutely dread the idea of getting on the bus or entering the school building, tell an adult that you need help finding a solution immediately.

Here are some very basic things to consider ensuring a firm foundation to work from:

- Are you able to communicate with your teachers? Are they available for extra help after school if you need it?
- Do you know who your school counselor is? Do you know the kinds of things he/she can help with and how to reach him /her?
- Are the desks and chairs (reasonably) comfortable? If dystonia is making it hard for you to sit in a chair or work at a desk, changes can be made.
- Can you easily reach and open your locker? If not, talk to your homeroom teacher or guidance counselor about switching to a more convenient locker.
- Are your classrooms accessible? Is it difficult for you to use school facilities? Do you need extra time to get around or a key to the elevator?

Tools to Help You Succeed in School

Dystonia can make it difficult to write, sit at a desk, and move around. Some of the medicines used to treat dystonia can make it difficult to pay attention, stay awake, and remember things. All of this can make it hard to succeed in school. The good news is that public schools in Canada (and other countries as well) recognise that students with dystonia often need to do things differently than other students to succeed in school.

Finding ways to do things differently to help you succeed at school is called accommodation. You and your parents need to meet with your teachers and administrators at school and figure out what you need to help you succeed.

Just as every student is different, every student with dystonia is different.

About Individualized Education Programs

In order for your teachers, and school to understand your needs, and the accommodation that is required, you and your parents will need to work to develop an IEP—an Individualized Education Program.

An IEP is developed with input from you (if you are sixteen years of age or older), and your parent(s) and/or guardian(s). To learn about the IEP in your province, please visit: www.dystoniacanada.org/individualized-education-programs

Not all students with dystonia need accommodation, but here are examples of what the school can do for you:

- More time to complete assignments, including tests and quizzes
- One set of textbooks for school and one set for home so you don't have to lug them around
- Alternatives to physical education class.
- Improvements to the physical accessibility of buildings
- Extra time to travel in between classes
- A copy of class notes from the teacher or a classmate
- Specific emergency exit procedures for situations such as a fire drill
- Changes to bathrooms, water fountains, sinks, etc. to make them accessible
- Help developing a plan for life after high school, including postsecondary education or employment training

Understanding your Needs

Make sure you have a very clear understanding of what your accommodation entails. Find an advocate at school. An advocate is an adult such as a teacher, social worker, counsellor, vice principal, or principal who knows that you have accommodation needs and can help you if you have questions.

It is very important that you take advantage of the accommodation that is made for you. For example, if you are allowed extra time for tests and quizzes, that means you get extra time for every test or quiz. You should not feel embarrassed to use the accommodation that you are entitled to, or to remind the teacher if he or she forgets. If you have a substitute teacher, you should feel comfortable telling him or her what you need, such as **“I can’t write at the desk, but I can take the test if I lay on the floor.”** You earned the accommodation, and you deserve to have it.

Explaining Accommodation to Other Students

In previous pages, you read about trying to educate students in your class to help them understand dystonia. The same goes for accommodation. If you decide, for example, to make a presentation to your classes about dystonia and how it affects you, feel free to also explain the accommodation you need and why you need it. For example, you can say, **“My hand gets tight and hard to control when I pick up a pencil. So, it takes me twice as long to write a sentence. I get to use a laptop computer to do schoolwork because my hands do not cramp up when I type. If I type I can do the assignment as fast as everybody else and not fall behind.”**

Here’s another example: say in the middle of the school year you get a new chair to help you sit up at the table in the art room. Maybe you would feel comfortable if your teacher made an announcement to the class such as, **“You may have noticed that Mark has a new chair today. He was having**

trouble sitting up in the old chair, and this one makes it easier for him to work at the table. If any of you have questions about this, feel free to ask him or me about it, but please wait until after class.” If you would like your teacher to make an announcement like this, talk to the teacher beforehand or tell your parents and they can help you find the best way to talk to the teacher about it.

Remember its your right to do things a little differently at school to help you succeed. Your school can help you get the best education possible. Be responsible for your education and for your accommodation.

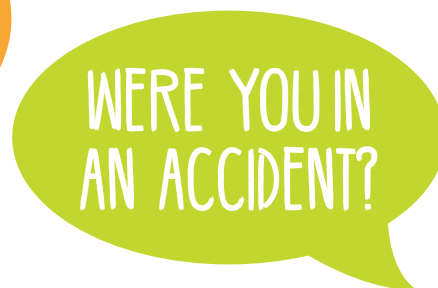
PART FIVE:

How to Talk About Your Dystonia

As you know by now, talking to others about dystonia can be tricky, especially if they do not know very much about it. Similarly, it can be difficult to answer the same questions repeatedly:

**Did you hurt your leg or something? Were you in an accident?
Aren't you a little young to need a cane?**

Circumstances will arise in which it is helpful to have a way to explain dystonia to other people.



People who care about you will want to know what dystonia does to you. Other people may be curious about why you don't take physical education in school or why you sometimes need a wheelchair. Sometimes, it is helpful to let other people know about dystonia. Other times, it is none of their business. **When it comes to explaining dystonia to other people, you have choices about:**

WHO to tell?

No doubt, you know a lot of people, and a lot of people know you. There are your family, friends, neighbors, teachers, kids at school, coaches, teammates, and so on. You choose who you wish to tell about your dystonia. For example, you may want your close friends to know you have dystonia but choose not to tell those in your larger circle. Having dystonia is a personal thing, and it is ok to be picky about who you share that with.

HOW to tell?

Once you decide who you want to educate about your dystonia, you may wish to think about how to tell them. For example, say you wish to educate the students in your classes at school. Do you want to talk to them individually, or would you like to give a presentation to the class that educates everyone at once? What about your teachers? Do you want your parents to help set up a meeting outside of normal school hours to explain dystonia to them? Your parents can help you brainstorm about how to approach people.

WHAT to tell?

You also can decide exactly what each person needs to know. Close friends may like to know that having dystonia means that you can't go hiking for long periods of time or you have trouble holding a fork or pen. School administrators and teachers need to know if there are things they can do to help you succeed in school such as allowing you more time to take tests.

If you know your dystonia is inherited or was caused by an accident or other health condition, you may wish to think about how much of that information to share with other people.

When describing dystonia, be sure to consider the age of the person/people you are speaking to. For instance, if you are talking with a young child, you may want to take a simple, literal approach instead of describing it using medical terminology.

One method of going about this would be to ask the child/children to perform an action such as hold their arms out straight, take a step, etc. You can then explain that they are able to do this action because their brain can send the correct message to that body part. Next, do the action yourself, saying “when I try to do the same action you just did, it takes me more time and I look a bit different because my brain cannot send the correct message to my body part.” The physical action used in this method often keeps the child/children’s attention, helping them better understand dystonia.

Here are more examples of how some young people explain dystonia to others:

- I have a neurological disorder that affects my left hand and neck muscles.
- My muscles contract too much which makes me lose control over what my muscles do.
- My leg does whatever it wants.
- Dystonia means that my brain sends wrong messages to my body.

WHY tell?

An important thing to think about is the reason for telling someone about dystonia. For example, teachers and administrators at school need to know at least a little about dystonia so that they can help you get the best education. You may find that strangers come up to you and ask bizarre questions. Sometimes these people mean well, and sometimes they are just curious. Trust your feelings about whether it seems like a person is trying to be friendly or just being rude. Remember that it is your choice to tell them as much or as little as you want. A common question people with dystonia get is “What’s wrong with you?” There are several ways to handle this:

You might simply hand them documentation from the Dystonia Medical Research Foundation Canada and leave it at that.

Another way to answer nosy questions is by saying **“I’m sorry, but I don’t discuss these things with people I don’t know.”** Or you can give them the facts. Help to educate them about what dystonia is and how it affects you.

As you go along it will become easier to see who needs to know the truth. While we all need to help educate people about dystonia, this does not give anyone the right to ask you about your symptoms in a rude or demeaning way.

PART SIX:

Creating your own Independence

Jobs and Dystonia

Achieving some degree of financial freedom feels very good and may even be a relief to your parents.

So, if you’re looking to make some cash, realize that you have many options. People with disabilities in Canada are protected by a legal “duty to accommodate” under the Canadian Human Rights Act (CHRA). Some people with dystonia require accommodation to work and some do not. Some require accommodation for certain jobs and not others. An employer is required to provide a reasonable accommodation to a qualified person who is applying for a job or an active employee unless the employer can prove that the accommodation would be exceedingly difficult or expensive. An employer cannot expect you, as an employee, to pay for accommodation.

An employer cannot make up the cost of providing a reasonable accommodation by paying you less than other employees in similar positions. The measurement of whether the accommodation you need is too expensive or difficult for the employer to accomplish is based in part on the financial resources of the employer, the cost of the accommodation to the employer, the effects



of accommodation on other employees, and the effect of the accommodation on how the business operates.

If you are applying for a job, it is illegal for an employer to ask if you are disabled or to ask about the nature or severity of your disability. An employer can ask if you can perform the duties of the job with or without reasonable accommodation. An employer can also ask you to describe or to demonstrate how, with or without accommodation, you will perform the duties of the job.

If you think you will need accommodation to apply for a job or to perform the essential job duties, you should inform the employer that an accommodation will be needed. It is also your responsibility to tell the employer what kind of accommodation you need.

Driving

Learning to drive is a skill that, once mastered, provides independence and freedom. It accommodates personal and professional pursuits. Driving is one more skill that allows individuals to call their own shots. Just because you have dystonia doesn't mean you cannot learn how to drive. It just means you may have to go about it differently.

You can access driving rehabilitation services across the country. The driver rehabilitation specialist will assess your ability to operate a motorized vehicle and determines if you have the potential to qualify for driver training. This service can also determine what is required with respect to adaptive driving equipment and altered driving techniques. Visit: www.dystoniacanada.org/teenguide for a complete list of driving rehab service organizations across the country.

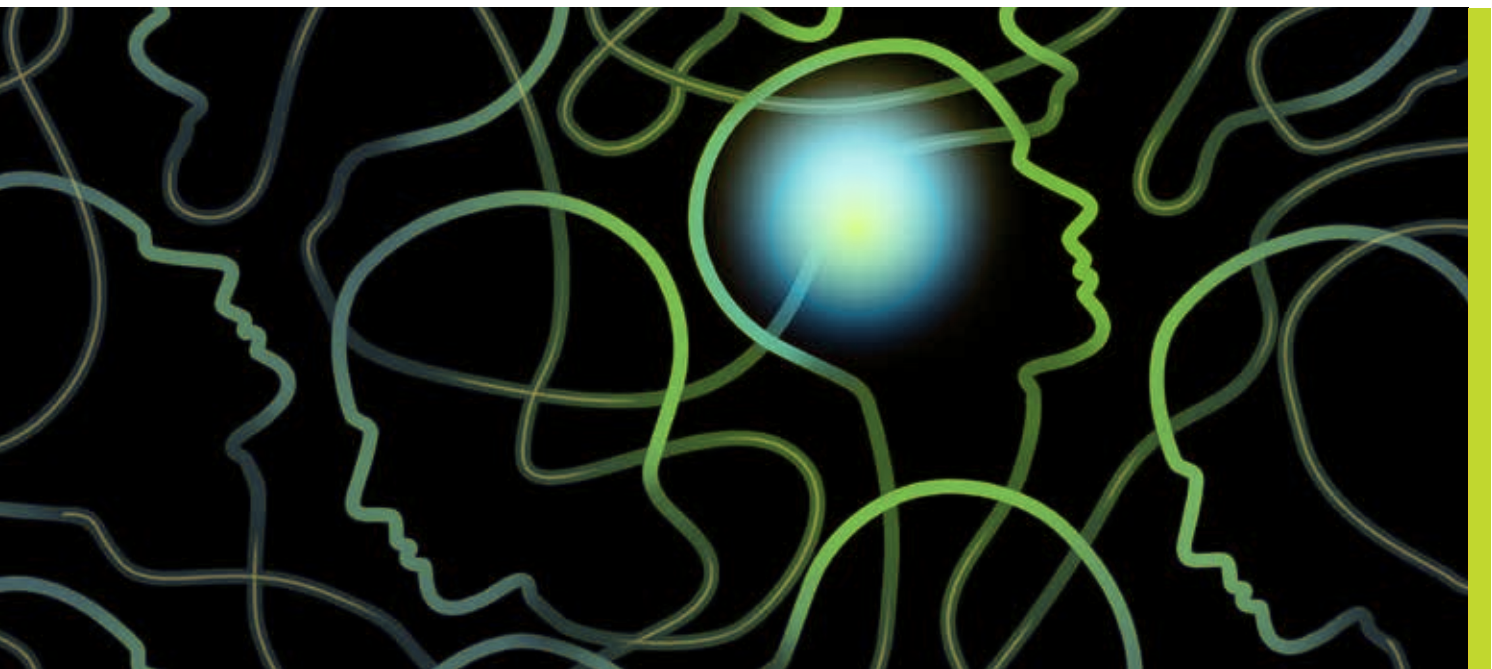
Knowing What the Government, Charities and Support Groups Can Do for You

Part of creating your freedom is knowing your rights and knowing what resources the government and community can provide you. Visit www.dystoniacanada.org/guideforteens for a complete list of links and resources, including charities, government programs, and groups and coalitions that advocate for teens with disabilities.

It may be a little overwhelming at first, but explore the sites and you may be surprised by the benefits and programs for which you are eligible.

PART SEVEN:

Dystonia and Mental Health



Neither being an adolescent nor having dystonia are easy. It is understandable to feel frustrated, exhausted, sad, stressed or anxious from time to time. Adolescents are particularly vulnerable to feeling all of these things and more; moreover, to feeling these things intensely, and of course to fluctuations in mood and feeling states.

Given that adolescents in general often experience difficulties socially, emotionally, behaviorally and/or psychologically, **it makes sense an adolescent with dystonia may similarly experience challenges with:**

- relationships (family & friends)
- school work
- experimentation with sex
- use of substances such as alcohol or drugs
- behavioural challenges such as anger outbursts

Challenges with any of the above or worries about any of the above may be due in part to the “normal” course of adolescent development. For help understanding what might be the average expectable, or when in doubt, seek professional advice.

Many teens experience mental health challenges, including depression, anxiety, attentional or sleep disturbances, disruptions in their interpersonal relationships, school difficulties, eating disorders, to name but a few. These and other mental health issues can affect anybody, including teenagers with dystonia. All teens feel sad or irritable from time to time.

If you have any of the following symptoms and they last more than a couple of weeks or cause a big change in your routine, your perspective, **your outlook, there are people who can help:**

- You feel sad or cry a lot, and it doesn't go away.
- You feel guilty for no reason; you feel like you're no good; you've lost your confidence.
- Life seems meaningless or like nothing good is ever going to happen again.
- You have a negative attitude a lot of the time, or it seems like you have no feelings at all.
- You don't feel like doing a lot of the things you normally enjoy such as music, sports, being with friends, going out. You want to be left alone most of the time.
- It's hard to make up your mind. You forget things, and it's hard to concentrate.

- You get irritated often.
- Little things make you lose your temper; you overreact.
- Your sleep pattern changes; you start sleeping a lot more or you have trouble falling asleep at night. Or you wake up early most mornings and can't get back to sleep.
- Your eating habits change; you've lost your appetite, or you eat a lot more.
- You feel restless and tired most of the time.

You are not alone, nor are you alone in seeking help. Many adolescents benefit from talking to a professional, an adult who is not a parent and not a friend, with whom they can share their stress, anxieties, worries and fears in confidence. You can too.

If you've had several of these symptoms and they've lasted more than two weeks or cause a big change in your routine, you should talk to someone who can help, like an adult you trust.

There are many people you can talk to:

- parents or a trusted family member
- school counselor
- family doctor
- psychologist
- professionals at a mental health center

If you are not comfortable speaking with a family member or other trusted adults in your life, there are professionals who will listen and who can help. Worrying, feeling concerned about having a mental health issue or challenge or simply wanting help from/to talk to a third-party professional does not mean a person isn't really trying. It is a sign of strength not weakness.

Perhaps your family doctor, school social worker or guidance counsellor can recommend a mental health professional such as a registered psychotherapist, psychologist, a social worker who practises psychotherapy or other mental health professionals.



Having depression doesn't mean that a person is weak, a failure, or "isn't really trying." It means they need treatment. So, when your problems seem too big and you're feeling low for too long, remember that there is help available and you can ask for help.

Visit: www.dystoniacanada.org/teensanddepression for details on signs and symptoms, risk factors, and who to speak with about your depression.

Suicide

Although most people who are depressed do not commit suicide, depression can increase the risk for suicide or suicide attempts. Suicidal thoughts, remarks, or attempts are always serious. If you are preoccupied with death or thoughts of suicide, you must tell a responsible adult immediately. Feeling suicidal is no joke. Ever. There are people who can help you to feel better. You do not have to do this alone.

The importance of accepting and sharing your feelings

It can be hard to open up about how you're feeling—especially when you're feeling depressed, hopeless, ashamed, or worthless. It's important to remember that many people struggle with feelings like these at one time or another. They don't mean you're weak, fundamentally flawed, or no good. Accepting your feelings and opening up about them with someone you trust will help you feel less alone.

No matter what it feels like, people love and care about you, and if you can muster the courage to talk about your depression, it can—and will—be resolved. Some people think that talking about sad feelings will make them worse, but the opposite is almost always true. It is very helpful to share your worries with someone who will listen and care. They don't need to be able to "fix" you; they just need to be good listeners.



If you're suffering and don't know where to turn...

In Canada, call the KidsHelpPhone.ca helpline at 1-800-668-6868.

PART EIGHT:

Meeting Others with Dystonia

As dystonia is fairly uncommon, it can be really beneficial to be connected to other teens in Canada who are interested in sharing thoughts, stories and feelings about their diagnosis.

DMRF Canada has created a system for teens in Canada to connect with each other. All you have to do is visit www.dystoniacanada.org/supportteens and have your parents fill out our permission form allowing us to connect you to others in the Country via email. That way you know that you are speaking with other individuals who have dystonia in a safe and secure way.

Remember – Facebook and other social networks are very public. Don't post anything on the Internet that you don't want broadcasted publicly. Also keep in mind that people you meet in cyberspace might not be who they seem to be. If you're in any type of public online network, avoid giving out your full name, mailing address, telephone number, the name of your school, or any other private information-especially if someone is specifically interested in getting that information from you. The same goes for revealing information about your family and friends. Don't reveal any of the above information about other people.

In this way, you are doing your best to ensure the people that you will be connected to will be other teens who have dystonia and whose parents have provided permission for their contact information to be shared with others (this is to ensure a safe connection is made).

Connecting with the “Locals”: Meeting Others with Dystonia

One of the most important ideas for you to remember is that you are not alone in your struggle with dystonia. There are resources for you to use, and people to support you. DMRF Canada is dedicated to helping all people with dystonia. We can do this by connecting you to other teens, or to speak with you about any of your concerns (and connect you with professional agencies or contacts who can help you with your specific needs).

There is no right or wrong way to negotiate the various aspects of being a teen with Dystonia. You have what it takes to face your challenges and thrive. Always remember that although Dystonia is a part of your life, it does not define who you are or what you can achieve. With the right supports and a positive attitude, the possibilities are limitless!

To access additional resources, please visit: <http://www.dystoniacanada.org/guideforteens>



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Dystonia Medical Research Foundation (DMRF) Canada

The Dystonia Medical Research Foundation was founded in 1976 by Samuel and Frances Belzberg of Vancouver, after their daughter was diagnosed with generalized dystonia.

The mission of the Dystonia Medical Research Foundation Canada (DMRFC) is to advance research for more treatments and ultimately a cure; to promote awareness and education; and to support the needs and well being of affected individuals and families. DMRFC is a registered non-profit Canadian charity governed by a volunteer Board of Directors.

DMRF Canada works in partnership with the Dystonia Medical Research Foundation in the United States to ensure funding of the best and most relevant dystonia medical research worldwide and partners with like-minded research organizations to fund excellent dystonia research in Canada.

A Note on Medical Professionals

Throughout the document you will note there are recommendations regarding working with a variety of medical professionals. For good order medical professionals would include doctors, neurologists, psychiatrists (the latter also a mental health professional). Mental health professionals would include psychologists, psychotherapists and psychiatrists. Schools usually have personnel, such as guidance counsellors or rotating social workers who would also fall under the mental health umbrella. Our thanks to Philippa Orsborn, Registered Psychotherapist for her thorough review of this guide.

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