

# Dystonia Guidebook for Kids (Ages 8-12)



Dystonia Medical  
Research Foundation







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### **Dystonia Medical Research Foundation**

Founded in 1976, the Dystonia Medical Research Foundation has a three-fold mission: to advance research for more treatments and ultimately, a cure for dystonia; to promote awareness and education; and to support the needs and well-being of affected individuals and families.







## Dystonia Guidebook for Kids (Ages 8-12)

If you are reading this booklet, it probably means that you are a young person who has dystonia. You may have symptoms that started only a short time ago, or you may not be able to remember a time when you didn't have dystonia. The first thing you should know is that there are kids all over the world who have dystonia—there may even be others in the state or province you live in. You don't have to feel like you are the only person on the planet who has this.

This booklet was created for young people with dystonia between the ages of 8 and 12. We hope this book will help you understand this disorder and give you information that will help you live successfully with dystonia. You may choose to read this book privately or share what you read with your family as a way to start a conversation about how dystonia affects you.

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## Chapter 1: What is Dystonia?

**D**ystonia is a disorder that affects the way a person moves. A small problem in the brain makes your muscles tighten and twist when you don't want them to. These muscle spasms may force your body into strange positions or movements that get in the way of walking, sitting, using a pencil, using a fork, speaking, and other activities. Because dystonia affects these important activities, dystonia is considered a *disability*.

You may have noticed that your symptoms started in one part of your body and spread to other parts. Some people have dystonia just on one side of the body and not the other. Some people have their dystonia all the time, and for some people it comes and goes. No matter what dystonia does to your body, it does not affect your intelligence, memory, or ability to think.

Even famous doctors are not really sure what causes dystonia. Some children get dystonia because they inherit it from their parents, grandparents, or relatives—just like they inherit the color of their eyes or the shape of their feet. For some kids, it is a surprise that happens to them and no one else in the family. Some people get dystonia from having a serious accident or as a side effect of taking certain medicines. People with diseases like cerebral palsy may also have dystonia.

Children with dystonia are just as smart, if not smarter, than others their age. Dystonia may make you look or move differently than other people, but it does not affect your ability to be liked or make friends. Although you may *have* dystonia, *you are not dystonia*. Dystonia does not affect your imagination, creativity, sense of humor, or personality. The fact that you have dystonia does not make you who you are. Young people with dystonia succeed at school, make friends, get dates, graduate from college, get good jobs, get married, have families, and accomplish great things.

Although living with dystonia is confusing sometimes, it is nothing to be ashamed of or embarrassed about. If you need help understanding what is happening to you, talk to your parents. Together you can find the right words to describe what dystonia is to you.







## Chapter 2: Explaining Dystonia to Other People

**I**t 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 have a cane. 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?**

Chances are, you know a lot of people. There are your family, friends, neighbors, teachers, kids at school, people at church, coaches, teammates, and so on. You get to choose who to tell about your dystonia. For example, you may want your close friends to know you have dystonia. You may want the annoying kid on the school bus to know nothing about you at all. 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 tell, you may wish to think about how to tell them. For example, think about the students in your classes at school. Do you want to talk to them one at a time, or would you like to give a presentation to the class that lets everyone know how dystonia affects you? Do you want your parents to help you speak to your teachers?

### **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 run for long periods of time or that you have trouble holding a pencil and can't write notes to them in class. Teachers will need to know if there are things they can do to help you succeed in school such as having more time to take tests. (We'll talk more about this in the "School" chapter.)

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







Here are examples of how some kids with dystonia explain dystonia to other people:

*My leg does whatever it wants.*

*I have a neurological disorder that affects my left hand and neck muscles. My muscles contract too much which makes me lose control over my muscles.*

*Dystonia affects my ability to walk. Also it affects my neck somewhat.*

*The short version is that it's a movement disorder. If they are really interested, I don't mind telling them the whole story of how I got it.*

*Dystonia makes me wiggle.*

*Dystonia means that my brain sends wrong messages to my body.*

*Mother usually explains since speech is not possible.*

*I say it's a disease in my nervous system that makes my legs tight and that is why I have trouble walking.*

*My legs give up and I need a break.*







### WHY tell?

An important thing to think about is the reason for telling someone about dystonia. For example, teachers 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 weird questions. Sometimes these people mean well, and sometimes they are just being nosy. 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 get is, "What's wrong with you?" There are several ways to handle this:

- ★ You can put on a big smile and say "There's nothing *wrong* with me. Why? Is there something wrong with you?"
- ★ You can ignore the question and say something that has nothing to do with anything such as, "Did you know that a clam can live up to 150 years?"
- ★ You might just say, "My muscles don't work right."
- ★ You could make up some exciting injury such as you fell off a cliff while mountain climbing in the Rockies or you were attacked by a wild horde of sting rays while scuba diving in Australia.
- ★ 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."

As you go along it will become easier to see who needs to know the truth and who doesn't. 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.







## Chapter 3: Taking Care of Your Body

**A**ll people need to take good care of their bodies, and people with dystonia have an extra reason to do so. Dystonia can be hard on your body, and 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 wonderful parts of yourself. If you had a friend who looked different or had a disability, you would not treat him or her any differently because of it. You deserve to treat yourself as well as you would treat a friend.



### Rest

People with dystonia often notice that their dystonia symptoms get worse when they are tired or very busy. Getting enough rest will help keep your symptoms under control and give you energy. Make sure you get enough sleep (even if it means going to bed earlier than you would like), including naps or moments of rest when you need them.

### Exercise

Your body also needs exercise. Your heart needs exercise and your muscles do too. Your parents and your doctor may be able to help you find the right activities for you. You may play team sports, swim, find a good fitness videotape to do at home, walk the dog, or just play around outside with your friends. You want to pay special attention to your muscles and joints to keep them as loose and flexible as possible. Dystonia can make your body tight, and stretching exercises, physical therapy, and massage can help you loosen up.

### Drugs & Drinking

Hopefully you have already heard a million times that drugs and drinking are bad news. Drugs have never solved anyone's problems. They only create new ones. Doing drugs does not make you appear more grown up or independent. And there are tons of better activities to experiment with such as sports, music, movies, and so many other things. Doing drugs is harmful to your body and can only make your life worse, not better.

The scariest part about doing drugs is that they change the way your brain works. That's why people feel different when they're doing drugs. Drugs







mess around with your brain, nerves, and muscles so that you feel different than you usually do. Having dystonia already puts your nervous system under stress, so stressing out your nervous system even more by taking drugs or drinking can do terrible damage to your body. Plus, many people with dystonia take medications that treat the nervous system and adding illegal drugs can cause serious side effects, including death.

So the bottom line is drinking before you are legally allowed and abusing drugs are never a good idea, and are especially risky for young people with dystonia. You deserve better than to abuse your body by using drugs and alcohol.

## **Stress**

Your dystonia symptoms may get worse when you feel excited, worried, angry, scared, hyper, or nervous. So, your symptoms may get worse at really inconvenient times like when you are standing up in front of the class during a spelling bee trying to remember how to spell "pisciform," or when all you want to do is skate over to your friend's house to watch your favorite TV show. Luckily, there are things you can do to help control how your body reacts in stressful situations.

Just like you have to go to baseball practice before playing in a game, it helps to practice chilling out to prepare for stressful situations that may come up. Here are some things to try that will reduce your stress:

### **★ *Prepare Ahead of Time***

Sometimes we set ourselves up to be stressed by not preparing ahead of time. For example, if you know you have a week to prepare for a spelling bee, what are the things you need to do to be ready for that day? Setting enough time aside during the week to study your vocabulary words, getting enough sleep (especially the night before), and eating a good breakfast the morning of the spelling bee will all help you be more focused when it is your turn to spell a word. And if you know there are people in the class who whisper constantly or make distractions, say to yourself, "I know what's-her-face and that-guy-over-there may be distracting during my turn at the spelling bee, but I will be concentrating on spelling my word and not on them."

### **★ *Exercise Regularly***

We mentioned exercise before as a way to take care of your body, but exercise will also help slow down your thoughts and reduce stress. It will help you think clearly and sleep better too. Exercise will energize you and help you focus. Even just 20 minutes a day of playing with your pet, dancing around, jumping rope, raking leaves, or playing a sport will make a difference. Know that your talents as an athlete are not in your arms or legs or body. Your







athletic talents are in your determination, sense of competition, and drive to succeed. Find a sport or activity that appeals to you and find a way to get involved.

★ *Meditate*

Some people misunderstand what meditating means. It does not have to involve sitting in a loin cloth and turban with your eyes rolled back into your head and humming like a demented bumble bee. (However, if that sort of thing helps you relax, go for it!). Meditating simply means paying attention to your body and your breathing. There are many ways to meditate. Here is one way to do it:

1. Find a quiet place to sit or lay comfortably.
2. Close your eyes.
3. Focus on breathing. Notice how your breath goes in and out of you.
4. Empty your mind so that all you are thinking of is your breathing. When other thoughts creep in, just ignore them and go back to breathing.
5. As you breathe in, say to yourself "I am..." and as you breathe out, "calm and relaxed." Repeat this with each inhale and exhale and feel the stress melt away from your body.

Try to meditate for 1-2 minutes, and gradually increase the amount of time each time you do it. Meditating for 10 minutes can make you feel as good as taking a two-hour nap. You can also get audiotapes or CDs to listen to that help you relax and meditate.

★ *Have a Hobby*

Is there an activity you can do at home that you especially enjoy? Maybe you collect marbles or cards from your favorite cartoon show. Do you like to do puzzles or build models? Drawing, painting, sculpting, playing a musical instrument, and writing are all creative, artistic ways to express yourself. All of these things can help you be more relaxed every day. Remember that your artistic ability or talent for doing something is not in your body. It is in the way you see the world and there are many ways to do a hobby or express your art.



★ *Warning Signs & Solutions*

Do you know the signals your body gives you when you are getting stressed? Does your face get hot or does your belly feel weird? Do you clench your fists or start to sweat? If you find yourself in a stressful situation, take a break from what you are doing and take the time to relax. You can do any of the things mentioned above (prepare, exercise, meditate, or focus on a hobby) or you can also try these ideas:

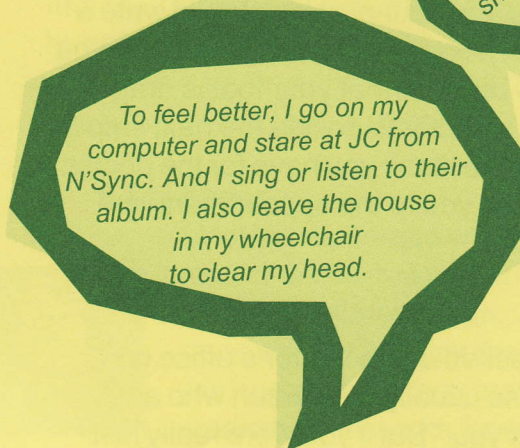
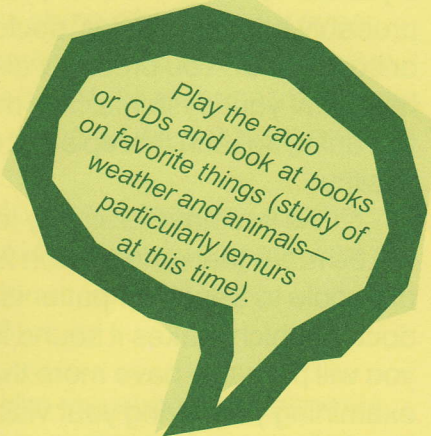
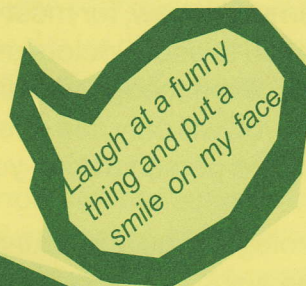
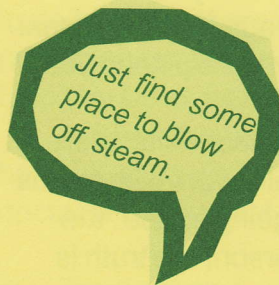




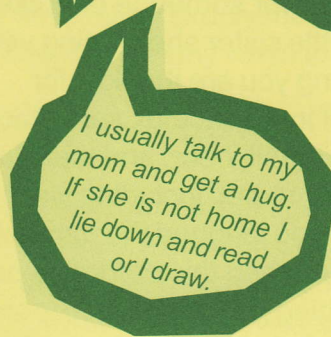
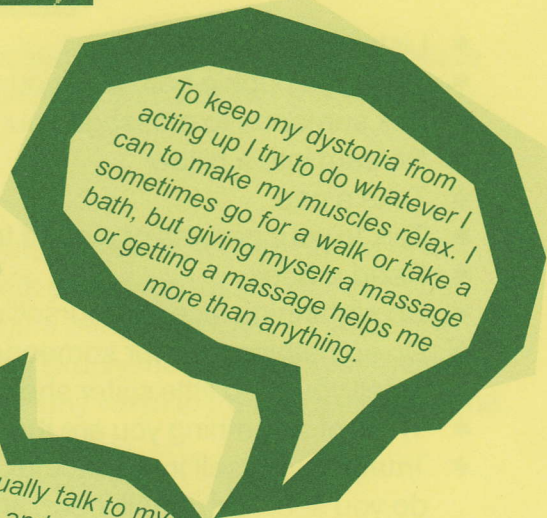
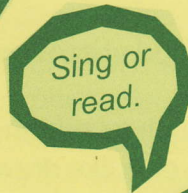


- ★ Listen to a favorite CD
- ★ Soak in a bubble bath until you are wrinkly
- ★ Ask someone to massage your head
- ★ Scream into a pillow
- ★ Take a nap
- ★ Talk to your parents or a good friend about how you are feeling
- ★ Read a book
- ★ Do something nice for yourself such as rubbing your feet
- ★ Do something nice for someone else like draw a picture for your mom or tell your wild little sister she's being very good today
- ★ Think of something you are thankful for
- ★ Imagine yourself in a peaceful, safe place. Use all your senses: what do you see, feel, smell, hear, and taste in this place?
- ★ Spend time with your pet, including watching fish in an aquarium
- ★ Think of the time you laughed the hardest you ever have in your life
- ★ Breathe! We mentioned this before as part of meditating but slowing down your breathing is helpful in every stressful situation. Remember: inhale "I am..." exhale "calm and relaxed."

Here is how some kids with dystonia make themselves feel better when they get stressed or upset:







### Visiting the Doctor

If you are reading this book, you have probably visited many doctors. You probably have a “regular” doctor who you visit when you get an ear infection or sore throat. You probably also have a “dystonia” doctor who you visit to help treat your dystonia. You may also visit a physical therapist, occupational therapist, speech therapist, or other professional adults who help keep you healthy.

As you have probably learned by now, for most medical visits, there will be more than one person for you to see. Doctors usually work with teams of people to treat their patients. So even though you are going to see “the doctor” which makes it sound like you will only see one person, the truth is you will probably have more than one person asking you questions and examining you during your visit.

Before you visit your neurologist, you and your parents should write a checklist of how things have been going lately. Remember things like 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. You should also write down questions you have for the doctor. Writing a list (and remembering to bring it with you to the appointment) will help you remember everything.

### Communicating with Your Doctor

One of the funniest questions you may be asked at the doctor’s office is, “How are you?” It is a funny question because usually the person who answers the question just says, “I’m fine, thank you.” But if you were really just







“fine” then you wouldn’t be in the doctor’s office, would you? Probably not. You’d probably be out doing something you enjoy. So one way to answer your doctor if he or she asks, “How are you?” is to smile and say, “Well, I’m here because I have some things to talk to you about.” The doctor will then probably ask you what you’d like to talk about. At that time, you and your parents can tell him about the things you wrote on your list and what your dystonia is doing to you.

When you see a neurologist, there are two main things he or she will do. The first thing is that he or she will ask you and your parents 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 if you were a healthy baby, when you started talking, when you started walking, if you have spent any time in the hospital, if you learned to ride a bicycle, and how you’re doing in school. The neurologist will also want to know about your brothers, sisters, parents, and other family members. If you have been visiting your neurologist for a while, he or she will be more interested in how your body is doing 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 take a look at you. He or she will probably ask you to walk around, use a pencil, or pick up objects. The neurologist may do weird things like shine a light in your eyes, look at your fingernails, or look at your back. Sometimes the doctor will have to do things that are uncomfortable such as take blood. All of these things are necessary so the doctor can understand what’s going on in your body and help you be as healthy as possible.

Even though you can probably think of 643 other things you’d rather be doing than visiting the doctor, it’s very important. Hopefully you can find a doctor who you trust and don’t mind visiting.

### ★ *Treatments*

Visiting your doctor is important because he or she can suggest treatments that may make your dystonia better. Your doctor cannot cure dystonia, but hopefully he or she can help you be more comfortable. There are three kinds of dystonia treatments. They are: medicines you take by mouth, medicines you get in a shot, and surgery.

#### 1. Medicines



Most young people with dystonia take medicines by mouth. These medicines calm your body down so that your symptoms may get better. It is super, mega, very important that you take your medicines exactly the way the doctor tells you to. Otherwise they may not work properly or they may make you feel worse. There is not one medicine that works for everyone. So, you may try a medicine and



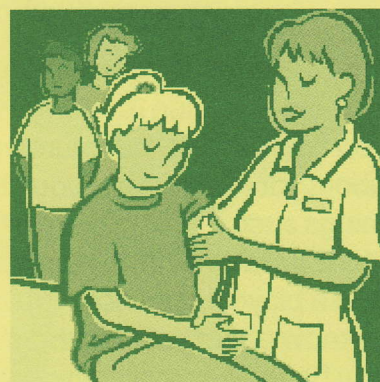




find that it doesn't help or it makes you sleepy or forgetful or cranky. You may have to try more than one medicine before you find one that helps you the best.

## 2. Botulinum Toxin Injections

*Botulinum toxin injections.* Try saying that as fast as you can three times in a row! (Or just say the initials *BTI* instead.) A botulinum toxin injection (BTI) is a shot of medicine that is injected with a needle into your muscles. BTI's are a little like the shots you get in your arm or your backside to prevent you from getting diseases like measles. BTI's are injected into your tightest muscles as a way to relax them. BTI's usually hurt more than a normal shot and you may have to get them several times a year, but the needles are much smaller and the shots are over with faster. Your doctor will let you know if he or she thinks that BTI's will help you.



If the thought of getting a BTI makes you a little anxious, here are some suggestions to help make you feel better:

- ★ Before you visit the doctor, do something relaxing such as listening to music or taking a bath. Picture yourself after the BTI and how much better you will feel after the medicine begins to work.
- ★ Plan a reward for yourself after you get your BTI. When the doctor is giving you the shots, turn your head away and think about what you are going to do to reward yourself after your appointment. Maybe you can go to the mall, see a movie, or have a sleep over with your friends.
- ★ Take your favorite stuffed animal with you to your appointment and squeeze it if you need to.
- ★ Ask the doctor to use a medicine to numb your skin before giving any shots.
- ★ Don't forget to breathe! Ever notice how you hold your breath when you get scared? This is a normal reaction. But it tightens up your muscles and makes the dystonia worse. So remind yourself to take nice, deep, even breaths. Imagine calm feelings entering your body as you breathe in and the icky feelings exiting your body as you breathe out.







It may take the medicine in the BTI about a week to start working, but when it does it will hopefully help your tightest muscles relax.

### 3. Surgery

Some young people need to have surgery to help their dystonia. Here is one way to think about it: imagine you have a car and it is not working quite right. When you bring the car to the mechanic, the mechanic may not be able to figure out what is wrong just by looking at the car or listening to the sounds it makes. Sometimes the mechanic needs to open the hood of a car to look at the engine inside. By looking inside, the mechanic can figure out the best way to help the car run better. And even though your body doesn't look anything like a Toyota, sometimes doctors need to look inside your body to help you move and feel better. The good news is that the doctor will give you medicine to make you sleep through the whole thing, so you won't feel any of it.

The doctor may need to look inside your head at your brain. Or the doctor may need to look inside your back or in your legs.

Not every child with dystonia needs surgery, but if your doctor thinks surgery is the best way to help you, the doctor and your parents will explain exactly what part of your body the surgery will treat. They will also explain what the surgery will try to do for you. Before you have the surgery, you will probably get to see the rooms of the hospital you will go to before and after the surgery, the people who will be there, and some of the equipment they will use. If you have questions, don't be afraid to ask! Surgery is a big deal, and it is natural to have questions about what is going to happen to you. Your parents and doctor won't know what questions you have unless you ask.

When you have your surgery, the doctor will give you medicine to put you in a deep sleep. You probably won't even remember going into the operating room. You definitely won't feel or remember anything from the surgery. When the operation is over, the doctor will stop giving you the sleep medicine and you will wake up. When you wake up, you'll probably have an intravenous (IV). This is a needle in your hand or arm that is attached to a bag of fluid on a pole. The fluids contain medicine to help you heal from the surgery. After a few days of recovering you will be able to get up and move around again. If the surgery treated a leg or arm, you may be in a cast. You may also need crutches or a wheelchair until you heal.

As you recover from your surgery, it may take some time for you to feel like your dystonia is better. Just be patient with yourself and take good care of yourself as you recover. You may need to do physical therapy or continue to take medicines. Do your best to do what your doctor recommends, and soon you will be recovered.







## Chapter 4: Family

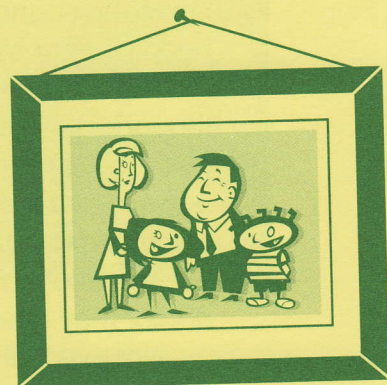
**E**ven though you may be the only person in your family who has dystonia, the fact that you have dystonia will affect the other people in your family—especially your parents, siblings, and family members you live with. Dystonia will affect them mostly because they see how dystonia affects you and want the best for you. Your family cannot “catch” dystonia from you, so there is no need for you to worry about that. And if your siblings or cousins develop dystonia, it has nothing to do with you and is not your fault. Not even a little bit.

### Parents

Your parents are responsible for raising you and protecting you. There may be times where you feel like your parents are too protective, worry too much, and do not give you the freedom to do things on your own. You may feel like there are times when your parents push you too hard or nag you about things that do not seem like a big deal. And then there are times when your parents get it just right—they find a way to make you laugh when you are having a bad day, they help you solve a problem, or they surprise you by doing something nice you did not expect.

Your parents are doing what they feel is best for you. Sometimes you will agree with them, and sometimes you won't. Although they probably know you pretty well, they cannot read your mind. When it comes to making decisions about treating your dystonia, school, chores, bed times, and permission to do things outside the house, you need to let your parents know what you think is right and why you think so. The best way to figure out what is best is for you and your parents is to talk about it. Here are some general tips for keeping open communication with your parents:

- ★ Get things clear. Make sure you and your parents recognize the same expectations and responsibilities for each family member. For example, what are your responsibilities for school? How do your parents expect you and your siblings to treat each other? What chores around the house are you responsible for and when should they be done?
- ★ Are there rules that you would like to change? If you are frustrated because your parents only allow you to walk to your friend's house with an adult, give your parents a chance to explain why they feel that is necessary. If you feel like they are “babying” you, suggest a compromise. Perhaps they could walk with you until they can see the friend's house and you can continue on by yourself while they just watch until







you get in the door. Try to reach agreements that make both you and your parents comfortable.

- ★ Be active. If a problem comes up, such as a particular chore is becoming too difficult or if you disagree with what is expected of you, talk to your parents and explain how you feel.
- ★ Keep a calendar that everyone in the family can read that keeps track of medical appointments, family outings, sports schedules, or other events that affect the family.

### Planning Ahead & What if? Games

In a previous chapter, we talked about thinking ahead as a way to reduce stress. Planning ahead is also a good way to help keep a clear flow of communication with you and your parents. To put it plainly, your parents worry a lot about you. That's their job. So, planning ahead is a way for them to worry less and give you a little more freedom.

For example, your new friend Michelle asks if you want to go to the zoo with her and her family next weekend, so you ask your parents if you can go. Your parents say yes, but... they have a million questions. Your parents don't know Michelle's parents, so the first thing to ask is how much, if anything, do you want to tell Michelle's parents about your dystonia? And then the next question is: Do you have Michelle's phone number so we can talk to her parents? That way your parents can call and introduce themselves and make sure it's ok for you to go.

Your parents might want to play *What if?* games. *What if?* games are a way of planning ahead for activities or events. For example,

- ★ What if you find yourself getting tired as you are moving around the zoo? Are you comfortable telling your friend's parents that you need to stop and rest?
- ★ What if your leg brace gets loose? Can you adjust it yourself?
- ★ What if there is no handicap accessible entrance to the lizard house? Should your parents call ahead and find out?
- ★ What if a big mother orangutan escapes from her cage and decides to scoop you up and adopt you? How long could you live in a tree?

Planning ahead may seem like a pain and some of the questions your parents ask may seem a little ridiculous, but planning ahead will help you avoid unpleasant surprises. *What if?* games will help your parents not worry so







much and create less stress for you. One of the best things you and your parents can do in your conversations about how dystonia affects you is plan ahead. Plan ahead for field trips, sleepovers with friends, family outings, family vacations, and school.

### **The Gift of Gab**

Make sure you talk with your parents about things that have nothing to do with dystonia, too. Your parents will probably love to hear about who sits next to you at lunch, what you are studying in your science class, or how some kid at the bus stop swears that jelly beans grow on plants like green beans but that you think that is just plain crazy.

### **Brothers and Sisters**

Whether your siblings are older or young, whether you have 1 or 11, try to make them your partners. Siblings often make wonderful friends. Here are some tips for getting along with your siblings:

- ★ Treat your siblings the way you would like them to treat you.
- ★ Help each other. If your brother helps you by carrying your books to the bus stop one day, is there a way for you to return the favor? Maybe you can help him study for a math test or let him play with one of your favorite toys?
- ★ Be careful about jealousy. Does it frustrate you that your baby sister can ride a bicycle with no hands and you can't ride at all? Think about ways that your sister might be jealous of you. Do you have a later bedtime than she does, or do you usually beat her when you play checkers? For all the things you feel jealous about, there may be people who are jealous of you. Focus on the positive things you *can* do, not the things you can't.
- ★ If your brother teases you or won't get off your back, talk to him. Maybe he thought he was joking and didn't realize he was hurting your feelings.
- ★ Do things with your siblings that have nothing to do with dystonia. Find activities you can do together without the dystonia getting in the way. Maybe you can swim together at the public pool, play video games, or trade cards.

Remember that your siblings cannot "catch" dystonia from you as if it was a cold. If a sibling or other family member gets dystonia, it has nothing to do with you and is not your fault in any way.

If you have a sibling or family member who has dystonia don't be afraid to talk about it. You may find you have a lot in common and can help each other.



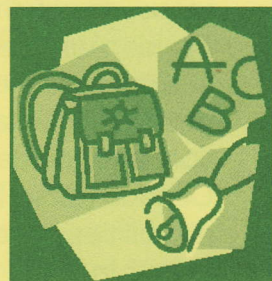




## Chapter 5: School

**C**hildren with dystonia are just as smart, if not smarter, than others their age. Dystonia may make you look or move differently than other people, but it does not affect your ability to be liked or make friends. Remember that no one at school can “catch” dystonia from you.

Many kids with dystonia have found that one of the best ways to avoid being stared at or whispered about at school is to find a way to explain dystonia to the other kids. You may want to go back to the section of this booklet called “Explaining Dystonia to Other People.” 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 do not understand dystonia or do not have the courage to get to know you. 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 like goofballs around you. It is up to you and your parents to decide who at school should know about your dystonia, but it probably makes sense to at least educate the teachers and students in your classes.



### 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 schools recognize that kids with dystonia often need to do things differently than other students. Finding ways to do things differently to help you succeed at school is called *accommodation*. Another big word. (Almost all kids with dystonia have very impressive vocabularies.)

Now, unfortunately, you cannot go to your teacher and say, “Hey guess what? I have dystonia in my arms which means I can’t write well on tests, so just go ahead and give me all A’s because that’s what I would get if I could write.” It doesn’t quite work that way. You and your parents need to meet with your teachers and people at school and figure out what will help you succeed. Every student with dystonia is different. Here are examples of what the school can do for you:

- ★ More time to complete assignments, including tests and quizzes
- ★ Typing assignments on a computer instead of writing long hand
- ★ One set of textbooks for school and one set for home so you don’t have to lug them around
- ★ Excuse from phys ed class
- ★ Making sure you have a buddy in class with you to help you out if you need it







Once your family and the school agree on what accommodation you need, it will be written down on paper. Your parents should make it very clear to you what things you can do differently from the other students. Ask your parents to help you find an advocate at school. An advocate is an adult such as a teacher, social worker, counselor, vice principal, or principal who knows that you have accommodation and can help you if you have questions.

It is very important that you use 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 the school is giving you 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. Plus, laws in both the United States and Canada (as well as other countries) state that public school students with disabilities have the right to accommodation.

In the rare case that you have a teacher who is not giving you the accommodation you need or if you need different accommodation because your symptoms are changing, ask your parents to step in and speak with the people at school.

### **Explaining Accommodation to Other Kids**

In another chapter of this booklet, you read about trying to educate kids in your class to help them understand dystonia. The same goes for accommodation. If you decide, for example, to make a little presentation to your class about dystonia and what it does to 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 use a lap top computer to do school work 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 your desk. 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 his desk. 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, tell your parents and they can help you find the best way to talk to the teacher about it.

Remember, the law states that you are allowed to do things a little differently at school to help you succeed. The school cannot give you the answers to tests or just give you A's and B's because you're a neat kid, but the school can help you get the best education possible.







## Chapter 6: Fun Stuff

**D**ystonia should not get in the way of having fun. Remember that dystonia does not affect your sense of humor, your personality, or your curiosity about the world. Seek out new experiences as much as possible. Don't think that having dystonia prevents you from being an athlete, an artist, a traveler, a comedian, or anything else you'd like to be.

### Sports

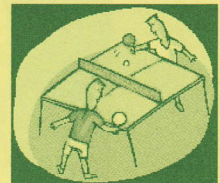
With a little planning ahead, children and families with dystonia can enjoy any activity that children and families without dystonia can enjoy, including sports and outdoor activities.

Have you ever tried:

- ★ Baseball
- ★ Basketball
- ★ Track
- ★ Archery
- ★ Sailing
- ★ Table tennis
- ★ Shooting
- ★ Horseback riding



- ★ Rugby
- ★ Tennis
- ★ Soccer
- ★ Skiing
- ★ Hockey
- ★ Golf
- ★ Volleyball
- ★ Racquetball



All of these sports and more can be played by people with health conditions such as dystonia. In this booklet you will find the names of organizations that will help you find a sports program near you that welcomes young people with disabilities. By looking on the Internet with your parents, you can find organizations in the state or province you live in.

### Overnight Travel & Camp



People who have dystonia have the same opportunities for travel as people who do not. It does not really matter where you go. You might want to see another continent, another country, or simply another part of the state or province you live in. What matters is that you are comfortable venturing out beyond your everyday world. There are travel agencies that specialize in helping people with disabilities see the world. There are hundreds of overnight camps. Many camps make

it easy for young people who are disabled to visit and participate. Disney World has a very good reputation for taking good care of guests who have wheelchairs or need special services. If your family is interested in traveling, there is a list of websites in the back of this booklet for your parents to visit.



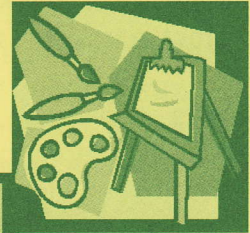




## Hobbies

Having a hobby that you can do at home or in your neighborhood is good for taking your mind off your dystonia and leading a well-rounded life. Have you ever tried:

- ★ Playing a musical instrument
- ★ Photography
- ★ Making home movies
- ★ Cooking
- ★ Sewing
- ★ Singing
- ★ Gardening
- ★ Knitting/Crocheting
- ★ Making a family tree
- ★ Carpentry
- ★ Drawing



- ★ Painting
- ★ Sculpting
- ★ Pottery
- ★ Papier-mâché
- ★ Reading books (or listening to books on tape)
- ★ Making books
- ★ Building models
- ★ Collecting coins
- ★ Collecting cards
- ★ Collecting marbles
- ★ Collecting old dead toe nails (not necessarily your own!)

Remember that your interests and talents are not in your body. It is in the way you see the world. There are many ways to do a hobby or pursue your interests. Just because you hold a paintbrush with the inside of your elbow (or even your feet) does not make you any less of an artist that someone who holds the brush with his or her hands.







### **Helping Others**

One of the best ways to help yourself feel good and have a well-rounded life is to volunteer your time for a charity.

Find out what charities interest you. There are organizations that help children, animals, hospitals, people who are homeless or ill, people who are elderly, people in the military, police and fire rescue workers, and others. The Dystonia Medical Research Foundation (the people who published this booklet) is a charity that helps people of all ages who have dystonia. You might be able to volunteer your time, for example, washing dogs at the local animal shelter or writing letters to people in the military. You might want to volunteer your energy by raising money for research about dystonia. You could do this by having a lemonade stand, holding a car wash, or saving a portion of your allowance.

Volunteering gives you a chance to help make the world a better place. It also gives you a way to feel extra good about yourself because you know you are doing something generous.

### **Meeting Other People with Dystonia**

One of the most helpful things for people with dystonia is to meet other people who have it. This is not always easy, but there are ways to do it. There are dystonia support groups in many parts of the United States and Canada that help people with dystonia meet each other. Also, the Dystonia Medical Research Foundation organizes meetings for people with dystonia to come together and learn about dystonia. The Dystonia Foundation even has special meetings for children and their families.

Dystonia Foundation meetings are helpful and fun because you can be yourself. You are with people who know what dystonia is and understand what the symptoms are like. It is pretty much impossible to go to a Dystonia Foundation meeting for children and not make new friends.

Your parents are welcome to contact the Dystonia Foundation for more information about opportunities to meet or be in contact with other families affected by dystonia.







## Chapter 7: Living with Dystonia

**Y**oung people with dystonia are normal kids. Young people with dystonia have challenges that other children do not, but they succeed in doing everything that children without dystonia can do. Young people with dystonia are very good at finding creative ways to succeed in school, play sports, do fun activities, and lead interesting lives.

Having dystonia is not always easy and there will be times when you feel frustrated. It is not unusual to feel sad, angry, and depressed once in a while, but if these feelings stay with you for more than a few days tell your parents. Dystonia is hard enough to deal with without feeling depressed, so let your parents help you when you feel bad. You don't have to do it all on your own.

Here is some advice kids with dystonia have for others kids like them:

Treat other people nice and take a break when you get tired.

Stay strong and never care about what people who don't care about you think. Stay active.

Remember we are not different from other kids.

Make sure to tell people how you're feeling and what's bothering you. Maybe they can help.

Do not give up!

It's ok to ask for help. Sometimes it makes life much easier and enjoyable.

Learn to do the best you can. Always focus on what you can do, not what you can't do. Don't let dystonia rob you of your childhood and your future goals.







Try to do  
your best.

Try not to get stressed  
out because that makes the  
dystonia worse. Keep a positive  
and up-beat attitude. Never  
stop fighting or else you've let  
dystonia get the best  
of you.

Get involved in  
a competitive physical  
activity and don't let  
the disorder become  
enmeshed with  
your personality

Write down your life goals and  
try as hard as you can to achieve  
you at this time, make a list of new  
ones that you can achieve and go  
back to the other goals when you  
are able to achieve them.

Never give up.  
Always believe in  
yourself. Have a  
positive attitude.

Be like a palm tree.  
When the winds blow,  
learn with it, and when  
it stops, straighten  
back up.

Don't let your dystonia get you down.  
Just because you have dystonia  
doesn't mean you can't do what you  
want. Don't let people tell you that you  
can't do something because you have  
dystonia. Prove them wrong and show  
them you are capable of anything you  
put your heart into.

Think positive  
and don't feel  
sorry for  
yourself.







There is no secret trick to living with dystonia. You will have hard days and wonderful days. Strangers may stare or ask weird questions, but you will also make fantastic friends who make you feel like you are the greatest thing since sliced bread. Your family will drive you crazy and show you great kindness. In short, you will have a life pretty much just like any other kid. Do your best to succeed in school, be kind to others, and take care of yourself. You have what it takes to be successful in your life.

### **Your Future**

Your future is as bright as you make it. Make plans for your future, and take it day by day. Make big plans like what do you want to do when you grow up and what kind of adult do you want to be? Make middle-sized plans like what you want to do during your winter break from school?

Here is what some young people with dystonia would like to do with their lives as adults:







## Chapter 8: Questions & Answers

### ***How does the doctor know I have dystonia?***

The doctor makes a diagnosis of dystonia mostly by looking at the movements of your body. Neurologists go to school for many years to learn how to recognize dystonia and other disorders.

### ***How did I get dystonia?***

Some children get dystonia because they inherit it from their parents, grandparents, or relatives. For some kids, it is a surprise that happens to them and no one else in the family, and no one knows exactly why. Some people get dystonia from having an accident, from operations for other health conditions, other illnesses, or from taking certain medicines.

### ***Can you die from dystonia?***

No, you cannot die from dystonia.

### ***Will the dystonia go away?***

Most children who get dystonia have it for the rest of their lives. So the dystonia will probably not just go away. But there are treatments that can help the dystonia stay as mild as possible. Some kids have dystonia that comes and goes. Children with this form of dystonia may find that the dystonia gets worse for a while when they are teenagers, but then gets better as they become adults.

### ***Do a lot of other kids have dystonia?***

There are kids all over the world who have dystonia. There may even be young people in the state or province you live in who have dystonia. The best way to meet other young people with dystonia is to attend a meeting organized by the Dystonia Foundation.

### ***Can other people catch dystonia from me?***

Absolutely not. It is impossible for other people to catch dystonia from you.

### ***Do all kids with dystonia get a wheelchair?***

Every person with dystonia is different. Some use wheelchairs, some use canes, and some do not need anything to help them move around. Not all kids with dystonia need a wheelchair.

### ***What is going to happen to me in the future?***

There is no way to predict how dystonia will affect you in the future. Your symptoms will probably change over time. They may get better, or they may get worse. The good news is that there are many scientists studying dystonia so that they can make better treatments for dystonia and even a cure. By taking care of yourself and being positive, you will be able to handle whatever dystonia brings.







## Glossary

**Accommodation**—Tools to help you succeed in school. These tools may include items such as a computer or extra textbooks. These tools may also include things like extra time to take tests.

**Advocate**—An adult at school who is familiar with the accommodation you need and is available if you have questions or need help.

**Botulinum toxin injections**—A treatment for dystonia that involves a doctor injecting medicine into your muscles with a needle. The medicine relaxes tight muscles.

**Cerebral palsy**—A disorder that causes a person's muscles to become stiff and hard to control. Cerebral palsy may affect a person's ability to walk and talk. Sometimes people have cerebral palsy and dystonia at the same time.

**Inherit**—This word refers to when a child is given certain traits from his or her birth parents. Traits are personal characteristics that make one person unique from another. Traits include eye color, skin color, and blood type. Certain diseases can also be passed on from parents to children, including some forms of dystonia. However, just because a person has dystonia does not mean that his or her children will have dystonia. They may or may not.

**Intravenous**—"IV" for short. A way to deliver medicine into the body through a needle (usually in the arm). The needle is attached to a thin plastic tube that leads to a bag containing liquid medicine.

**Muscle spasm**—When a muscle tightens up against your will.

**Symptom**—A change in your body caused by a disease or health condition.

**Measles**—A disease that causes a fever and red spots all over the skin. Most children get shots that prevent them from getting this disease.

**Nervous system**—Your brain, spinal cord, and nerves. The nervous system allows different parts of the body to communicate with each other. Your brain sends messages through the spinal cord and along nerves to the rest of your body. Your body also uses nerves and the spinal cord to send messages back to the brain.

**Neurologist**—A doctor that specializes in treating disorders that affect the nervous system.

**Occupational therapist**—A health professional who can help you find easier ways to do everyday things that dystonia may make difficult such as writing, eating, or putting on your shoes.

**Physical therapist**—A health professional who helps you maintain flexibility and strength in your body.

**Pisciform**—Shaped like a fish.

**Sibling**—Someone who has the same parents you do; a brother or sister.

**Side effect**—Symptoms caused by a medication that you may not expect. For example, you may take a medicine to help your dystonia but discover it makes you sleepy. The sleepiness is a side effect.

**Stress**—Feeling uneasy or fearful about a situation.

**Stressful**—Something that causes you to feel stress.

**Treatments**—Medicines and procedures to help reduce symptoms of a disease.

