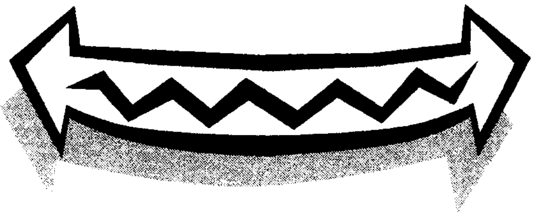
Finding Your Way



The Dystonia Guidebook for Teens

Dystonia Medical Research Foundation

Finding Your Way: The Dystonia Guidebook for Teens

The development of this publication was based on "8-18" A Guidebook for Young People with Dystonia *by Meryl Ohlhausen Kasdan & Emily Blum, published by the Dystonia Medical Research Foundation in 1996.*

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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.

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Introduction: Welcome to Dystonia

There is an old joke among members of the Dystonia Foundation that to someone who has never heard the word, the term *dystonia* sounds more like the name of an obscure little country in Eastern Europe than the name of a disorder. And some people with dystonia compare living with this disorder to being in a foreign country—it's difficult to get around, it seems like no one understands you, and there are times when you feel quite lost. But people with dystonia will also tell you that, like living in a foreign country, there are times when you become very proud of how far you've come, meet amazing people, and learn to feel very at ease with yourself and your surroundings.

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 state or 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 alone.

You have what it takes to face your challenges and thrive. Chances are, you have already been through some very tough and confusing days. You have survived this far, and that is a tremendous achievement. We hope this booklet will help you understand dystonia and give you information to help you live successfully with dystonia—but the real source of knowledge and strength is already inside you. Hopefully this booklet will help you realize the power and competence you already possess.

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.

Although dystonia itself may not make you feel welcome, even in your own body, know that there is a community of people—including other teenagers—who know what you are going through and hope to make you feel as comfortable and at ease with yourself as possible. Believe it or not, you're in good company. So, *welcome.*

Chapter 1
Getting Your Bearings: What You Need to Know About Dystonia

In a nutshell, dystonia is a disorder that affects the way a person moves. Therefore, dystonia is classified as a *movement disorder*. A small problem in the nervous system (which is made up of your brain, spinal cord, and nerves) makes your muscles tighten and twist against your will. 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 any number of other activities. Because dystonia interferes with these important life activities, dystonia is considered a *disability*.

For people who do not have dystonia, the brain sends clear instructions to the muscles of the body about how and when to move. The brain also signals to the muscles how and when to *stop* moving. Scientists believe that, in people with dystonia, the brain is sending chaotic messages to the muscles. These chaotic messages enlist more muscles than are necessary to complete a movement and do not tell the muscles the proper time to stop moving. (An example is when someone with dystonia moves the hand and arm to pick up a pencil, and all of a sudden the shoulders and back want to jump in and get involved.) The muscles respond to these messages and send equally chaotic signals back to the brain that reinforce the unnecessary movements. So both the brain and the muscles get caught in a cycle of "bad information." Because the nervous system is affected, dystonia is also classified as a *neurological disorder*.

Symptoms & Causes

You may have noticed that your symptoms started in one part of your body and spread to other parts. Most young people with dystonia develop *generalized* dystonia, which means that a combination of arms, legs, torso, and neck are affected to some degree. *Focal* dystonia stays in one part of the body such as the arm or neck. Some people have dystonia just on one side of the body and not the other. This is called *hemidystonia* (*hemi-* meaning "half"). Some people have their dystonia all the time, and for some people it comes and goes. When the dystonia comes and goes, it may be referred to as *paroxysmal dystonia* or *paroxysmal dyskinesias* (*paroxysmal* meaning it comes and goes, and dystonia or *dyskinesias* referring to movement).

The dystonia may be severe or mild. No matter what dystonia does to your body, it does not affect your intelligence, memory, or your ability to think.

Even expert dystonia doctors are not entirely sure what causes dystonia. Some people get dystonia because they inherit it genetically from their parents or ancestors—just like they inherit the color of their eyes or the shape of their feet. For some people, it is a surprise that happens to them and no one else in the family. Some people get dystonia from a trauma, such as a serious accident or head injury, or as a side effect of taking certain medications used to treat mental illness and profound nausea. Sometimes people with diseases like cerebral palsy and multiple sclerosis also have dystonia.

Teenagers with Dystonia

Teenagers with dystonia are just as intelligent, if not more intelligent, 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, make friends, or date. Although you may live *with* dystonia, you do not live *in* dystonia. Your life will go on beyond the boundaries that dystonia sometimes seems to impose.

Dystonia does not affect your personality, creativity, imagination, sense of humor, or style. The fact that you have dystonia does not make you who you are. Young people with dystonia succeed at school, make friends, learn to drive, get dates, have sex, graduate from college, develop fulfilling careers, get married, have families, and accomplish great things. Although living with dystonia can be confusing and difficult at times, it is nothing to be ashamed of or embarrassed about.

Chapter 2
The Art of Translation: Explaining Dystonia to Other People

As you may know, talking to others about dystonia can be tricky, especially if they do not know very much about it. Similarly, it can become tiresome to answer the same questions over and over again: *Did you hurt your leg or something? Were you in an accident? Aren't you a little young to need a cane?*

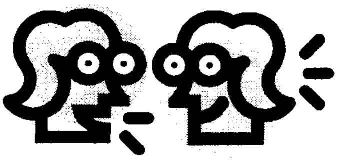
Circumstances will arise in which it is helpful to have a way to explain dystonia to other people. People who care about you will want to know what dystonia does to you. Other people may be curious about why you don't take physical education in school or why you sometimes need a wheelchair. Sometimes, it is helpful to let other people know about dystonia. Other times, it is none of their [insert colorful derogatory adjective] 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, people at church or temple, 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. You may want the kid on the school bus who has blue hair and believes her parents are aliens to know nothing about you at all. (Unless, of course, you *are* the kid on the bus who has blue hair and believes her parents are aliens.) 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? Do you want to create a scrapbook or homemade comic book that illustrates what your life with dystonia is like and make copies for the people you want to tell? 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 pencil and that's why you can't write them notes in class to fill them in on the latest jaw-dropping gossip. 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. (We'll talk more about this in the "School" chapter of the booklet.)

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.

Here are 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.

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.

My leg does whatever it wants.

I have hemidystonia. One side of my body is perfectly normal, while the other side is definitely not. My good side can get very tired, as it is doing the work of both sides.

"I have an ankle problem." Blank stare. "It's genetic." Eyes widen.

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.

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 can put on a big smile and playfully say, "There's nothing *wrong* with me. Why? Is there something wrong with you?"
- You can say, "I have a movement disorder called dystonia."
- You might just say, "My muscles don't work properly."
- You can ignore the question and say something that has nothing to do with anything: "Did you know that ancient Romans dyed their hair with bird droppings?"
- You could make up some exciting injury such as you were trampled by raging bovines at the Running of the Bulls in Pamplona, Spain, or your parachute failed while sky-diving and a conveniently-placed pile of cinderblocks broke your fall.
- You might simply hand them a three-fold card from the Dystonia Medical Research Foundation 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."

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.

Chapter 3
Taking Care of Your Body and Mind

All people need to take good care of themselves, and people with dystonia have added reason to do so. Dystonia can be physically rough 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 fabulous parts of yourself. If you had a friend who looked different or had a disability, you would not treat him or her differently because of it, right? 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 when their lives get hectic. Getting enough rest will help keep your symptoms under control and give you energy. Make sure you get enough sleep (even if it means the sacrifice of going to bed earlier than you would like), including naps or moments of rest when you need them.

Exercise

Your body also needs exercise—both your heart and your muscles must be attended to. Your doctor may be able to help you find activities that appeal to you. You might play team sports, swim, find a good fitness videotape to do at home, walk the dog, wrestle the neighbor's pet alligator (don't forget your helmet and knee pads!), or just mess around outside with your friends.

A form of exercise that others with dystonia have recommended is Pilates. Looks like *pie-lates*, pronounced *pih-lah-tees.* Pilates is a program designed to build strength—especially in your abdomen and back—and flexibility. The best way to begin Pilates is to find an instructor, rather than getting a book or videotape. (There are resources at the end of this booklet.) Before starting any exercise class, you may wish to meet with the instructor and explain how dystonia affects you. This way the instructor may be able to help you modify the activity to your needs.

With all exercise, 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, yoga, physical therapy, and massage can help you loosen up.

Doctors Appointments

If you are reading this book, you have probably visited more doctors than you care to remember. You probably have a pediatrician or GP (general practitioner) who you visit when you get strep throat or need a physical. You should also have a movement disorder doctor who you visit to treat your dystonia. You may also visit a physical therapist, occupational therapist, speech therapist, or other health professionals who help keep you healthy.

Before you visit your neurologist, consider writing 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. Consider keeping a journal—this will help you keep track of how you are doing physically as well as emotionally. 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. Bring your journal to your medical appointments.

It's not a bad idea to write down questions you have for the doctor, too. For example, is there a particular 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? Medical appointments can be hectic, and writing a list (and remembering to bring it with you) will help you remember everything.

➡ Doctors Do the Darnedest Things

One of the most ironic questions you may be asked at the doctor's office is, "And how are you today?" It is a bizarre question because usually the person who answers is expected to say, "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 more amusing. 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 take the bait and ask you what you'd like to talk about. At that time, you can tell him about the things you wrote on your list and what is going on with your dystonia.

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 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. Gandalf, 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 most questions and that you will ask most of the 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, all of 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 482 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. The Dystonia Foundation can help you locate health care professionals who are knowledgeable about dystonia.

➡Treatments

The most important thing your doctor can do is suggest treatments to lessen your symptoms. Your doctor cannot cure dystonia, but hopefully he or she can help you be more comfortable. The treatment of your dystonia may test your patience, because every person with dystonia is different and needs to have their treatment customized just for them. You may have to try several treatments or combinations of treatments before finding what works for you.

There are three kinds of dystonia treatments. They are: oral medications, injected medications, and surgery.

1. *Oral Medication*

Most young people with dystonia are prescribed medications to take by mouth. The purpose of these medications is to relax your body so that your symptoms may be reduced or alleviated. It is very, hugely, vastly, seriously (need we go on?) important that you take your medications precisely the way the doctor recommends. Otherwise they may not work properly or they may make you feel worse. If you don't understand the prescription directions or are unsure of how to take your medications, *call the doctor's office that prescribed the medication and ask them.* Make sure you understand the directions before taking the medicine.

There is not a single medication 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 without side effects.

If you have to take medications during school hours, arrangements can be made for you to do so, usually involving the school nurse. Consider making a little "just in case" card to show to the occasional teacher who doesn't know about your dystonia and grows suspicious upon seeing you hurrying to pop pills at the water fountain in between classes. The card can simply state:

"My name is Frodo Baggins and I have a disorder called dystonia. I take drug X, prescribed by Dr. Aragorn,

Department of Neurology, Middle Earth Medical Center."

Also on the card, include the doctor's phone number and a phone number to reach your parents. If the eagle-eyed teacher wishes, he can confirm this with the school nurse.

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 BTI is a shot of medicine that is injected with a needle into your muscles. BTI's are somewhat similar to the vaccination injections 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 vaccination injection and you may have to get them several times a year, but the needles are much smaller and the shots don't take as long.

Not all people with dystonia get BTI treatment, but it can be helpful.

There are two forms of botulinum toxin that are available: type A[1] and type B. Your physician will initially determine which is best for you. If, for example, you have had several BTI's using type A and are not seeing the relief you were hoping for you might ask your physician if using type B is appropriate for your particular case.

If the thought of getting a BTI makes you a little anxious, here are some suggestions to help you prepare for it:

➡ 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 kick in.

➡ Plan a reward for yourself after the BTI. When the doctor is giving you the

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[1] Cheers to you for bothering to read the footnote! The product name of type A is *Botox®*. Because Botox® was the first and only botulinum toxin product available for a long time, the word "Botox" is sometimes used when taking about botulinum toxin in general. But you should know that Botox® really only refers to the type A that is commercially available in the US and Canada.

injection, 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 hang out with your friends.

- Don't forget to breathe. Holding your breath is a natural reaction to feeling anxious or scared, but it tightens up your muscles and can make the dystonia worse. So remind yourself to take nice, deep, even breaths. Imagine calm feelings entering your body as you inhale and the icky feelings exiting your body as you exhale.

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

3. *Surgery*

Not every person who develops dystonia needs or undergoes surgery. Surgery may be an option for young people with severely disabling dystonia who do not get adequate relief from oral medications or botulinum toxin injections.

The types of surgeries that are used to treat dystonia fall into two broad categories: brain surgery and peripheral surgeries.

a. *Brain Surgery*

If the idea of brain surgery makes you think of Frankenstein's monster, don't worry—medicine has come a *long* way since the late 1700s. You get to keep your own brain and you won't wake up from surgery to discover that you are enormous and green. (Unless of course you were enormous and green before the surgery.) That is, it won't change your personality or ability to think straight.

Earlier in this booklet, we explained that dystonia is a neurological disorder, meaning that it is a disease that affects the nervous system. The brain is the "control center" of the nervous system, and so brain surgery attempts to create beneficial changes in the nervous system by going after this control center.

There are two basic forms of brain surgery:

➡ Ablation Surgeries.
The medical term *ablation* means to *remove* or to *reduce.* Ablation surgeries seek out and carefully "disable" the part of the brain believed to be sending chaotic messages to the muscles. By partially disabling this part of the brain, it cannot send out the chaotic messages and the symptoms of dystonia may be reduced. The targeted part of the brain is disabled permanently, and cannot be returned to its original state.

➡Deep Brain Stimulation
Deep brain stimulation (DBS) is a procedure that recreates the effects of ablation surgery by disabling a part of the brain with electrodes that deliver electrical impulses. This means that an electrode is implanted into the brain. A very thin wire runs from the brain to a battery that is implanted in the upper part of the chest. The electrode, wire, and battery are all inside the body, well under the skin. The battery provides the power necessary to create the electric signals. These signals change the way the brain and muscles communicate. Sound a little like science fiction? It is pretty wild. Doctors have been performing DBS for people with dystonia since about the late 1990s.

The people who are eligible for ablation surgeries are typically the same as those eligible for DBS. There are pros and cons to each approach which must be carefully discussed with your neurologist and neurosurgeon before deciding which (if either) is right for you.

b. *Peripheral Surgery*
Peripheral surgeries are surgeries that treat any part of the body other than the brain. Peripheral surgeries may treat the muscles and nerves that are affected by the dystonia, rather than the nervous system (which is the source of the problem). Peripheral surgeries that treat muscles and nerves are usually reserved for adults who have focal dystonia, meaning a dystonia that is

limited to one part of the body such as the neck or eye muscles.

An example of a peripheral surgery that treats the nervous system is *intrathecal baclofen*, also known as the *baclofen pump*. Baclofen is a type of medication that is often given to people with dystonia. Taken orally, baclofen can cause significant side effects in the doses usually needed to help control generalized dystonia. However, by implanting a little pump inside the abdomen that delivers baclofen directly into the blood stream, many of the side effects that occur by taking baclofen by mouth are reduced or eliminated.

Peripheral surgeries may also include orthopedic surgeries to help your body compensate for the dystonia. An example of such a surgery is to lengthen tendons in the legs to prevent the dystonia from permanently limiting the range of motion of a limb by constantly contracting the muscles.

If Surgery is for You . . .

If your doctor thinks surgery is the best way to help you, the doctor and your parents should explain exactly what part of your body the surgery will treat and 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, at least some of the people who will be involved in the surgery, 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 concerns you have unless you ask.

As you recover from your surgery, it may take some time for you to feel as though 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 medication. Do your best to do what your doctor recommends, and soon you will be recovered.

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 a watch or cell phone with an alarm.
- 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.

Chapter 4

Unnecessary Baggage: Obstacles to Living with Dystonia

Just like there are habits and activities that can help you live with dystonia, there are also some that will get in your way. However, the obstacles discussed here are things that you can avoid or at least control to a degree that they will not be detrimental to your life.

Drugs & Drinking

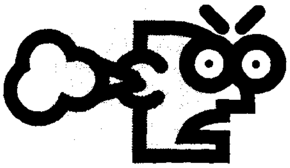
Hopefully you have already heard 64.2 million times that drugs and drinking are a bad idea. Drugs (including alcohol) have never solved anyone's problems—they only create new ones. Doing drugs does not make you appear more grown up or independent. And there are so many more worthwhile activities to experiment with such as sports, music, art, and so many others. 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 nervous system works. 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 is begging for disaster. 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 that drinking before you are of legal age 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.

If you think you have a problem with drugs or alcohol, get help. Seriously. Confide in an adult you trust. There are resources printed at the end of this booklet to point you in the right direction.

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 trying to study for a huge exam late the night before, or when all you want to do is hurry up and skate over to your friend's house to watch a favorite movie. 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 before stressful situations 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 two weeks to prepare for an exam, what are the things you need to do to be ready for that day? Setting enough time aside during those weeks to study, getting enough sleep (especially the night before), and eating a good breakfast the morning of the exam will all help you be more focused when it is your turn to ace the test. And if you know there are people in the class who whisper constantly or make distractions, say to yourself, "I know whats-her-face and that-guy-over-there may be distracting during the exam, but I will be concentrating on completing the test and not on them."

➡Exercise Regularly

We mentioned exercise before as a way to take care of your body, but regular 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 walking, lifting weights, dancing around, swimming, raking leaves, or playing a sport will make a difference. There are video exercise programs designed for people in wheelchairs, such as "Seat-A-Robics" by Daria Alinovi, "Nancy's Special Workouts" by Nancy Sebring, and "Basic Strength Training for Wheelchair Users" by the National Strength and Conditioning Association. Convince a buddy to exercise with you. 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 it means to meditate. It does not require sitting in a loincloth and turban with your eyes rolled back into your head and humming like

The Amazing Human Weedwacker (In A Loin Cloth). However, if that sort of thing helps you relax, go for it!

Meditating simply means paying attention to how your body feels and paying attention to your breathing. Try it:

1. Find a quiet place to sit or lay comfortably.

2. Close your eyes and focus on breathing. Notice how your breath comes in and out.

3. As you inhale, feel your belly expand—gently make yourself have a potbelly. As you exhale, draw your tummy in toward your spine. This may feel awkward at first, but don't pressure yourself and just keep going with it.

4. Try to slow down your breathing and empty your mind so that all you are thinking about is your breathing. When other thoughts creep in, just ignore them and go back to focusing on your 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. Meditating may also reduce pain. You can find audiotapes or CDs that may help you relax and meditate.

It seems simple, but paying attention to your breathing is one of the best and most effective ways to reduce stress.

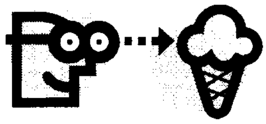
➧Get Crafty

Is there a hobby or activity you can do at home that really floats your boat? Maybe you read crime novels or collect Asian metal band CDs. Do you like to design and sew your own clothes 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 everyday. 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 stomach feel weird? Do you clench your fists or start to sweat? If you find yourself in a stressful situation, take control by stopping what you are doing and give yourself time to relax. You can do any of the things we mentioned above (prepare, exercise, meditate, or focus on a hobby) or you can also try these more short-term 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
- Watch a great and uplifting movie



- Vent into a journal
- Do something nice for yourself like rubbing your feet
- Do something nice for someone else like make a card for your mom (parents love that stuff!) or tell your wild little sister she's acting 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? Stay in this place until you feel like you're in control again.
- 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."

Many of the items listed above may also help with pain.

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

Play baseball.

Dance.

Just find some place to blow off steam.

I try to do whatever I can to make my muscles relax. I sometimes go for a walk or take a bath, but giving myself a massage or getting a massage helps me more than anything.

Sing or read.

Laugh at something funny.

I used to use a punching bag or pillow to let my frustrations out. Now, I have moved away from that and focus on my sports to get through the frustrations of having dystonia.

I usually talk to my mom and get a hug. If she is not home I lie down and read or I draw.

Play the radio or CDs and look at books on favorite things (study of weather and animals—particularly lemurs at this time).

Think about all my accomplishments.

I talk to my friends or I try to think of something different.

To feel better, I go on my computer and stare at JC from N'Sync. And I sing or listen to their album.

I leave the house in my wheelchair to clear my head.

Play PlayStation.

Depression

Having dystonia is not easy and there will be times when you feel frustrated and sad. Everybody feels gloomy now and then, but if you're sad most of the time and it's giving you problems with...

- school work
- relationships with your family and friends
- alcohol, drugs, or sex
- controlling your behavior in other ways

...then the problem may be *depression*. There are ways to treat depression and to get you feeling better soon.

Clinical depression is a serious illness that can affect anybody, including teenagers. It can affect your thoughts, feelings, behavior, and overall health.

When you're depressed:

- 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 really 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 think about death, feel like you're dying, or have thoughts about committing suicide.

If you have 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
- clergy
- professionals at a mental health center

Having depression doesn't mean that a person is weak, a failure, or "isn't really trying." It means they need treatment.

Most people with depression can be helped with counseling, provided by a mental health professional (such as a social worker, counselor, or psychologist), and some are helped with counseling and medicine. With treatment, most depressed people start to feel better in just a few weeks.

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.

➡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 won't feel miserable forever.

➡The Bottom Line about Feeling Low

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 or an adult you trust. Dystonia is hard enough to deal with without feeling depressed. You don't have to do it all on your own.

Chapter 5

Comforts of Home: Your Family

By the time you reach high school, your time and energy are probably being pulled in multiple directions at once: school, friends, boyfriend/girlfriends, after school clubs, going out, and your family. Embrace your family for all the positive things it was meant to provide: a support system of people who care about you, a place where you can just be yourself, an instant party for celebrating your successes, a provider of hugs after a hard day... and the occasional shuttle service and extra $20 for a pizza.

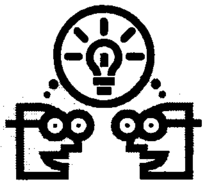
Even though you may be the only person in your family who has dystonia, the fact that you have it will affect the other people in your family—especially your parents, siblings, and family members you live with. Dystonia will affect them mostly because they are "along for the ride" with dystonia and witness how it affects you on a daily basis. They care about you and want the best for you.

Hopefully you know without a doubt that your family cannot "catch" dystonia from you as if it were a cold. It is physically, scientifically, downright impossible for someone to catch dystonia from you. And if your siblings or cousins happen to develop dystonia, it has nothing to do with you and is not your fault in any way. You should never feel guilty for things that are beyond your control.

Parents

Your parents are responsible for raising you and protecting you. Because of this, many parents of young people with health conditions feel an incredible amount of guilt that their child is faced with challenges that other kids don't have. Logically, of course, it's not your parents' fault that you have dystonia. It's not anyone's fault. However, when you become a parent, your supreme responsibility in life becomes protecting your child. If a child develops a disability, sometimes the parents feel as though they have somehow failed to protect that child.

It is *never* your responsibility to help your parents work through their issues, but the guilt thing may help explain some of their behaviors. Sometimes parents feel like they need to compensate for the fact that they couldn't protect you from getting dystonia by working extra hard to protect you from the rest of the world. There may be times when you feel like your parents are too protective, worry too much, and do not give you enough freedom to live your own life. You may feel like there are times when your parents expect too much 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 help you solve a problem or surprise you by doing something nice you did not expect. So, just try to be mindful that your parents are experiencing your dystonia in their own way and it may cause them to act kind of wacky from time to time.



Communicating with Your Parents

Your parents are doing what they feel is best for you. Remember that not every rule your parents make or limit they set has to do with your dystonia—they may reflect their values or their expectations due to your age. It's normal to challenge constraints when you are a teen. It is your parents' job to slow down your headlong rush into adulthood so you don't get caught in a speed trap.

Sometimes you will agree with your parents, and sometimes you won't. Although they probably know you pretty well, they cannot read your mind (thank goodness!). When it comes to making decisions about treating your dystonia, school, chores, privileges, and permission to do things outside the house, you need to let your parents know what you think is appropriate and why you think so. The best way to figure out what is best is for you and your family 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 is expected of you with regard to 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 won't allow you to get dropped off at the mall with your friends, give your parents a chance to explain why they feel the way they do. If you feel like they are treating you like a little kid, suggest a compromise. If you called them from the mall at a specific time to confirm that you have not been robbed, kidnapped, or killed, would that make them feel better? What if you had a cell phone (and promised to keep it on)? Would they feel better if you took a self-defense course? 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 work it out. For guidelines to help negotiate with your family, see the upcoming section on "Negotiating and Family Meetings." (Family meetings are not as dorky or formal as you may think—it's just a way for your family to talk to each other in a productive way.)

- Keep a calendar that everyone in the family can read that records 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 ward off stress. It is also a good way to help keep a clear flow of communication between you and your parents. Planning ahead is an excellent way to help them worry less and give you more freedom.

For example, your new friend Michael asks if you want to go to on a day-trip to the city with him and his family next weekend, so you ask your parents if you can go. Your parents say yes... but they have more questions than your algebra II final exam. One of the first things they may want to talk about, especially if your parents don't know Michael's parents, is how much do you want Michael and his parents to know about dystonia and how to tell them.

Your parents might like to play *What if?* games. If they did this when you were a little kid, it's a hard habit for them to break. Indulge them a little and play along. *What if?* games are simply a way of planning ahead for activities or events, which is never a bad idea if you are going some place new, especially if you have a disability.

- What if you find yourself getting tired as you are wandering around the city? Are you comfortable telling your friend's parents you need to stop and rest?
- What if they are planning to take public transportation? If you know you have trouble maintaining your balance on the subway or a crowded bus, can you call the city's transit department to see about special door-to-door services or reduced taxi cab rates for disabled passengers? What if your parents agreed to float you the cash to rent a stretch limo with a mini-golf course on the roof instead...?
- What if your new meds make you a little queasy during the escapade? Do you need to put some over-the-counter antacid tablets in your pocket to take with you?
- What if there is no handicap accessible entrance to one of the art galleries you are planning to visit? Can you call ahead and find out?
- What if you are "discovered" on the street by a big-time movie director and asked to return with him immediately to Los Angeles to star in his next big film about the secret lives of underwater beekeepers?[2] Will you still make it home in time for supper?

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. It will help your parents not worry so much and create less

[2] You're reading another footnote! You win $10! (just kidding) For future reference, if anyone claiming to be a big movie director invites you anywhere because he says he can make you famous, politely decline. This sort of thing is commonly referred to as *attempted kidnapping.*

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

➡Negotiating & Family Meetings

Consider meeting with the members of your household at least every two or three weeks. If the words "family meeting" eek you out, call it something different: A Conglomeration of Kin, a Fam Jam, a Peeps Meet, (no doubt you can think up something *much* better). Just think of it as a way to get your family in one place to check in and talk.

Set regular dates for your meetings. Appoint someone to lead each meeting and rotate this position among all family members. Consider posting a piece of paper somewhere conspicuous in your home like on the fridge where family members can write issues they would like to discuss at the next meeting. Make the meetings fun: order a pizza, decorate each other with fake tattoos beforehand, or plan to go to a movie afterward. If you have a problem or a household rule that you would like your parents to reconsider, this is a good time to find a solution that the entire family is comfortable with.

In order to come to a solution without getting mired in an argument that solves nothing, conduct your meeting in six steps:

1. State the problem and what you would like to see happen
2. Let the group respond, without saying yes or no
3. Brainstorm solutions to the problem
4. Summarize and clarify the most viable solutions
5. Agree on the best solution
6. Make plans to carry out the solution

Here are some general tips to help make family meetings work:

- Don't meet for too long. If you run out of time, schedule another meeting.
- Listen when others are talking.
- Focus on solving the problem rather than placing blame.
- State how you feel rather than making accusations (For example, "I wish I could be more independent and do things on my own.

Now that I'm 16, I would like to start taking driving lessons" rather than "You won't teach me to drive because you think I'm going to wreck the car!")

- Never criticize people's suggestions as stupid or silly—brainstorming means every idea is up for consideration, even bizarre ones.
- Ask someone to take notes during the meeting to record the ideas, decisions, and plans that are developed.
- Have a positive and upbeat attitude.
- Set a time to review how the solution is working and if additional issues have come up

➡The Gift of Gab

Try to talk with your parents about things that have nothing to do with dystonia, too. It's difficult to appreciate how much your parents will love hearing about your life: the people you sit with at lunch, what you are studying in your science class, or the latest TV commercial that made you laugh so hard that you inadvertently transformed your mouthful of cheesy snacks into an airborne spray of orange confetti. Talking with your parents helps them feel like they know what's happening in your life and they still have a part to play as your parents. You don't have to tell them *everything*, but be compassionate about the fact that they don't want to be shut out just because you are growing up.

Brothers and Sisters

Like your parents, your siblings experience your dystonia in their own way. Try not to be offended if it takes them a while to "get it" and understand what dystonia does to you. Believe it or not, your brothers and sisters may also feel unnecessary guilt—they may feel guilty that you have dystonia and they don't. They may also worry about your health, and wonder if they will get dystonia too. So again helping your siblings work through their feelings is not your responsibility (it's your parents') but just be aware that your siblings are experiencing dystonia in their own way.

Whether your siblings are older or younger, whether you have 1 or 11, try to make them your allies (a.k.a. comrades, co-conspirators, partners-in-crime). Siblings often make pretty decent friends. Here are some tips for getting along with your siblings:

- Help each other. If your sister 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 her with a school project or let her read your most sacred comic book?

- Be careful about jealousy. Does it bother you that your little brother can skateboard like a madman and you can't even ride a bicycle? Think about ways that your brother is probably envious of you. Are you allowed to stay up later than he is, or are you able to beat a level in a video game that he has been stuck on for three weeks? For all the things you feel jealous about, there are probably 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 just 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, make ice cream sundaes, or trade cards.

- The bottom line: treat your siblings the way you would like them to treat you. Consider this honestly: do you enjoy waking up at 6 am on a Saturday to discover that whilst thou slept one of your kin smeared peanut butter on your face and feet and let the three family mutts come bounding in your room to say good morning? Are family members in your household encouraged to fool each other into thinking they are being eaten alive by canines? If so, then stock up on the Jiff®! Set the example of how you would like your sibs to treat you.

- Remember that siblings can be friends and allies. Lay the foundation now for a long-term friendship.

Chapter 6

School: Its Own Universe

The high school experience is more than academics, but doing well in your studies remains the primary reason for attending. Doing well in school will prepare you for vocational training, college, and/or a career. Believe it or not, even if 15 years from now you don't remember the symbol for sodium on the periodic table[3], your schooling will give you skills to help you excel in your adult life.

Young people with dystonia are just as intelligent, if not more intelligent, than others their age. Dystonia will create extra challenges to succeeding in school, but you will find ways to adapt and compensate. Dystonia may make you look or move differently than other people, but it does not affect your ability to be liked or make friends. 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 gossiped about at school is to find a way to explain dystonia to the other students. You may want to go back to the chapter of this booklet about "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 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.

If someone is harassing or bullying you, don't deal with it by yourself: *tell your friends and your parents.* If someone is making you absolutely dread the idea of getting on the bus or entering the school building, tell your parents that you need help finding a solution.

Basics

There is a lot to keep track of in high school. Here are some very basic things to consider to help establish a firm foundation to work from:

- Do you know how to study productively? Studying is

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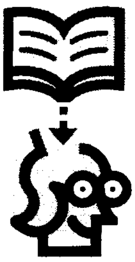
[3] Sodium is a tricky one. The symbol is Na.



not an instinct—we all have to learn how to study. You can find books in your local library for study methods or cruise the Internet for resources as well. You can also ask your parents, guidance counselor, or a favorite teacher to help you.

- Do you need tools to help you study, such as a device to hold your textbook open or tabs to make it easier to turn pages? Investigate assistive devices. An incredible resource is the ABLE DATA website: http://www.abledata.com/
- 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 the US and Canada (and other countries as well) recognize 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.*

Now, unfortunately, you cannot go to your teachers and say, "Hey, 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 administrators at school and figure out what you need to help you succeed. Every student with dystonia is different. 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
- Excuse from or 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

Once your family and the school agree on what accommodation you need, it will be recorded in either a document called a 504 Plan (in the US) or an Individualized Education Plan (IEP) (in the US and Canada). 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, 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 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." (Carry those handy dystonia three-fold cards for disbelieving subs.) You earned the accommodation, and you deserve to have it. Plus, there are laws in both the US and Canada that state that students with disabilities are entitled 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, talk to your guidance counselor or ask your parents to step in and help you contact the appropriate administrator at school.

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 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 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, it is your right 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. Be responsible for your education and your accommodation.

Chapter 7

Creating Your Own Declaration of Independence

One of the best things about your teenage years is that it usually marks a time in which you gain increasing freedom, in the form of both privileges and responsibilities. You begin having a life apart from your family. You deserve to be increasingly independent, knowing that independence comes with responsibility.

Privacy

Do you feel frustrated at times because your parents check up on you a lot, go through your schoolwork, don't like you to be home alone for even short periods of time, or are uncomfortable with you even being in your room with the door closed? In an effort to care for you and know what's going on with you, your parents may act in ways that you consider snooping or being a busybody. However, part of independence is simply having time alone, and you are entitled to privacy.

If you feel as though your parents don't give you enough privacy or are overly curious about your life, try beating them to the punch:

- Talk to your parents enough about your life and school so that they feel like they know you.
- Ask your parents for advice once in a while.
- If they go through your schoolwork, how about offering to show them your assignments and homework once in a while? Or encourage them to speak with your teachers.
- If you think they are overly fearful about leaving you alone in the house for even short periods of time, tell them it makes you feel as though they don't trust you. Talk about a compromise—what if they had a cell phone so you could reach them if you needed? What if you promised to not do things that make them especially nervous like light a fire in the fireplace or juggle knives?
- Ask them to please knock—and wait for a response—before entering your room.

- *Don't be afraid to tell them that you feel like you need more privacy*, and that you wish they would realize that you need time to yourself.

- Show them this section of this booklet as a way to begin a conversation.

Jobs

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. Here are things to keep in mind as you explore your options, especially if you are looking for a job during the summer months when you are out of school:

- Food service. Working in a restaurant is a rite of passage for many teenagers. Restaurants offer a variety of positions that pay differently and appeal to different people.

- Amusement parks typically hire large numbers of people in the summer.

- Summer camps, resorts, and hotels also hire lots of people depending on the season. The range of positions is pretty vast: from counselors and maintenance at camps, to housekeeping and administration in resorts and hotels.

- Consider volunteering. Volunteer positions at hospitals, shelters, clinics, and youth programs may not pay, but the experience can be very beneficial to future jobs and college admissions.

- Entry-level jobs with a small business. It may be helpful to have a skill the business can use such as typing or computer skills, but it's not necessarily a requirement and the company may train you.

- Look for summer intern programs at companies in your area.

- Ask about opportunities in your local or state government offices. Many states and municipalities offer summer job programs.

- Be self-employed. Create a lawn care service, baby sit, paint houses, or do minor maintenance jobs—get creative and think of a service you can offer people in your neighborhood and community.

- Find a job in an area you are interested in studying in college.

- Try to land a job at a store that gives employee discounts on clothes or technology you lust for!

Be ambitious. Think about what you would do if you could do *anything*. See what kinds of opportunities are available. You might be surprised with what you find.

Jobs and Dystonia

If you have dystonia and are qualified to do a job, an American law called the American's with Disabilities Act (ADA) protects you from job discrimination on the basis of the fact that you have dystonia.

In order to be protected by the ADA, you must also be qualified to perform the "essential" functions or duties of a job, with or without accommodation. (In this case *accommodation* simply means tools to help you become employed, much like accommodation for school.) This means two things:

1. You must satisfy the employer's requirements for the job, such as education, employment experience, skills, or licenses.
2. You must be able to perform the essential functions of the job, either with or without reasonable accommodation. For example, if you are applying to be a desk clerk at a hotel, an essential duty may be to answer the telephone. If you need your employer to provide you with a headset to answer the phone, you are still competent; you simply need accommodation. An employer cannot refuse to hire you because your disability prevents you from performing duties that are not essential to the job.

Reasonable accommodation is any change or adjustment to a job or work environment that allows a qualified person with a disability to apply for the job, perform the essential functions of a job, or enjoy the same benefits and perks of the job as employees without disabilities. For example, reasonable accommodation may include:

- Providing or modifying equipment or devices, including telephones and workstations
- Part-time or modified work schedules
- Being assigned to a different position
- Adjusting or modifying training materials or policies
- Making the workplace accessible to and usable by people with disabilities

People with disabilities in Canada are similarly protected by a legal "duty to accommodate" under the Canadian Human Rights Act (CHRA).

Some people with dystonia require accommodation in order 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

Growing up with dystonia often means growing up with some apprehension about what the future will hold. There are expectations of guaranteed happiness, such as finally being old enough to attend any movie without a parent. There are also expectations that may bring worry, such as the degree of independence you will have and if you'll be able to drive. Driving is an activity for which assistive devices and services are available to persons with a wide range of disabilities.

You cannot be denied the opportunity to apply for a driver's license or permit because you have dystonia. You can make arrangements for accommodations for your written exam by contacting the driver's license supervisor at your local Department of Motor Vehicles.

You might consider getting an evaluation from a *driving rehabilitation specialist* to determine if there are assistive devices that will help you drive or if the vehicle you plan to drive can be modified in a way that will help you. The result of such an evaluation will be a detailed report that describes the devices or modifications that are needed for you to drive comfortably and safely.

Such a driving evaluation is offered by vehicle and adapted equipment dealerships, rehabilitation clinics, and driving schools. Keep in mind that this evaluation will not provide any guidance with regard to cosmetic flourishes such as a fuzzy dice, 20 inch rims, or the style of shades to wear while behind the wheel. That is entirely up you. The evaluation will, however, assess:

- Vision
- Physical attributes: range of motion, flexibility, strength
- Judgment and reaction time
- Ability to physically operate and drive the vehicle with assistive devices
- Type of vehicle best suited for your needs

To locate a driving rehabilitation specialist, contact the Association of Driver Rehabilitation Specialists at 800-290-2344 or use the directory on the website at <http://www.aded.net>. Investigate if your parents' insurance company will pay for the evaluation. Find out if you need a letter from a doctor to receive benefits.

If you need to make modifications to a vehicle or purchase a modified vehicle, investigate ways to save money by contacting your state or province's Vocational Rehabilitation services. Again, see if the company that insures the drivers in your family may cover some of the costs. Some car manufacturers offer rebates or reimbursements for modifying new vehicles, including Chrysler, Ford, General Motors, Saturn, Volkswagen, Audi, and others. See information at the end of this booklet.

Driver's Education

By law, if a driver's education program is offered by a public high school, the school district is obligated to get the equipment a disabled student needs for the course. This may include providing adaptations to the regular driver's education course or paying for the student to attend a special needs driver's ed course. The school is obligated to do what is most appropriate for the student, not what is most convenient for the school. The student can only be charged the same fees every other student is charged for driver's education.

Of course, if the school district purchases or rents equipment, it belongs to the district and the student is not entitled to keep it at the end of the course.

Similarly, if the driver's education class takes place at the high school but is run by a private firm that is advertised to the students at the school, the private driving school is obligated by law to make reasonable modifications.

Knowing What the Government Can Do for You

Part of creating your freedom is knowing your rights and knowing what resources the government and community can provide you.

If you live in the United States, check out the US Federal Government's Programs & Services for People with Disabilities web page at <http:/www.disability.gov>.

In Canada, check out the Canadian National Government's Website for Persons with Disabilities at <http://www.pwdonline.ca>.

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.

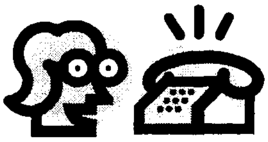
US states and Canadian provinces each have Vocational Rehabilitation services that can assist young people with disabilities with various aspects of employment, career development, education, training, and driving.

Chapter 8

Exploring & Seeing the Sights: Relationships, Activities, & Fun Stuff

Dystonia 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 punk rock virtuoso, or anything else you'd like to be.

Friends



Friendships are a huge part of life. Many situations give you the opportunity to meet and connect with other people: school, after school activities, sports and clubs, volunteer work, religious education and services... the list is pretty much endless. By getting involved with activities or an organization, you will meet people with whom you already have something in common—if you join the school volleyball team, chances are you'll meet people who like to play volleyball. You may even discover that some of these people like the same music you do (or detest the same music you do) or are obsessed with the same video games.

Ask your guidance counselor if there is anyone else in your school with dystonia. If there is, there is no guarantee you'll be friends but maybe you'll discover someone who really understands you.

Don't ever think that people won't like you because you have dystonia. It's simply not true. You may feel shy about approaching people, but dystonia is nothing to be embarrassed about or ashamed of.

If you find it difficult to talk to or connect with people, here are some tips:

- Believe that you are likeable and deserve friends. (Because it's true!)

- Smile at people. It's amazing how often something as simple as a smile can lead to a surprisingly cool conversation. And cool conversations easily lead to friendships. Try smiling at people and see what happens.

- When someone says hi, say hi back.

- Don't be afraid to make meaningless small talk. The beauty of small talk is that it doesn't have to be complicated or intellectually stimulating. It can be as simple as making an observation and inviting someone to voice their opinion. For example, if a girl you've been wanting to talk to is standing behind you in the lunch line, you can turn and say, "I can't tell if those are mashed potatoes or wet cement. What do you think?"

- Offer or ask for help. It's remarkable how borrowing or lending a piece of paper or verifying math problem answers can spark a friendship.

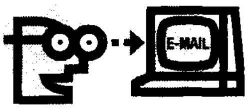
- Be attentive. We've all had experiences when a stranger we like is speaking to us and instead of listening we sort of freak out and think, "Holy baloney, he is talking to me. *He is talking to me*. He is actually *talking* to *me*. I can't believe this is happening..." and before you know it the conversation ends and, for the life of you, you have no idea what was said. When people approach you, show that you are attentive: make eye contact, get close enough so that you can hear them, and even nod once in a while to show you are listening.

- Believe it or not, the vast majority of people in this world want to make friends and want people to be nice to them. Try thinking about approaching people and making friends as giving someone a little gift. By smiling or making small talk or paying attention to someone, you are showing kindness. Kindness is a gift that everyone can use a little more of.

- Express your style. It's amazing how funky shoes or a funny sticker on your wheelchair can break the ice and inspire a conversation. Realize that there are people around you who want to get to know you but are shy. Expressing your style is a way of letting people know a little about who you are and giving them an easy way to start a conversation with you.

Online Friends

The Internet can be a tremendous tool to meet people both in your community and literally around the globe. There are many wonderful people online as well as a fair number of creepy people.



When using any online forum, such as chat rooms, bulletin boards, or online games, think of it as being out in a public place—pretty much anyone can read what you post. So, don't post anything on the Internet that you don't want broadcasted publicly.

Keep in mind also, that people you meet in cyberspace might not be who they seem to be—the 14-year-old girl who tells you she is trying out for cheerleading might really be a 41-year-old man who's out on parole. No kidding. If you're in any type of public online forum, 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 your family and friends. Don't reveal any of the above information about other people.

If a conversation feels weird, it probably is. And if a conversation feels ok, it probably is too but for the sake of your own safety you must be careful. If you feel like you want to meet someone you've met online, you *must, must, must* discuss it with your parents (and be prepared for them to be squeamish about the idea). If you do meet, make sure it's in the daytime in a public place and bring a friend or two (or your parents) for company. Never go alone to meet someone you met online.

Connecting with the "Locals": Meeting Others with Dystonia

One of the most important ideas for you to take from reading this booklet is that you are not alone in your struggle with dystonia. There are resources for you to use, and people to support you. The Dystonia Medical Research Foundation (the folks who developed this booklet) is dedicated to helping all people with dystonia.

The Dystonia Foundation does three main things:

1. Sponsors medical research for better treatments and a cure for dystonia
2. Helps educate people with dystonia and their families about the disorder as well

as educating the general public

3. Provides resources to help people and families with dystonia live successfully with dystonia

Become familiar with the resources that the Dystonia Foundation can provide you:

- Information about dystonia and treatments
- Materials about coping with dystonia
- Opportunities to meet with others with dystonia through support groups and/or patient meetings
- Information about the resources on the Internet

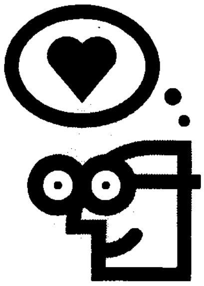
If you have questions about dystonia or the dates of patient meetings, contact the Dystonia Foundation. The staff will answer phone calls, emails, or letters—whatever makes you the most comfortable.

Making the effort to reach out and meet other people with dystonia—especially other teenagers—may be one of the most important gifts to give yourself. 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 Foundation organizes meetings for people with dystonia to come together and learn about dystonia. The Dystonia Foundation even has special meetings for young people and their families. Oftentimes, the Foundation can provide scholarships to help cover the costs of attending.

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 young people and not make new friends.

You and 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.

Dating



Falling in love, crushes, and dating are funny things. Sometimes they happen, and sometimes they don't. Sometimes they spring up when you least expect it, and yet when you want them the most, they are nowhere to be found. In high school, it can seem as though dating is more of a competition than a way to enjoy the company of others. It can be tempting to compare yourself to what other people are doing (or what they want you to believe they're doing).

Your parents probably have pretty strong feelings about what they think is appropriate for you as far as dating and sex. Make sure you know how they feel, and make educated decisions. (And if your school offers sex ed, pay attention in class! It's valuable stuff.) Know that dystonia doesn't affect fertility, so the fact that you have dystonia will not in any way prevent you from getting pregnant or getting someone else pregnant-the normal rules of biology still apply.

Here is what some young people with dystonia have said about dating, love, and sex:

Don't think that someone won't fall in love with you because you have dystonia. Having dystonia—or any disability— does not disqualify you from having major relationships.

Your worth as a person is not linked to whether or not you have a boyfriend or girlfriend. Who cares what other people are doing! Don't obsess about having a relationship.

If you feel like you're in a hurry to have sex, maybe you should slow down. And don't ever let anyone else rush you. You have to love and be comfortable with your own body before even thinking about going there.

You can't force relationships. Sometimes you just have to be patient. It stinks but you'll live.

Don't just settle for the first person who acts interested in you, unless you actually like that person! Find someone who likes you for you and accepts the dystonia.

Try to be up front about your dystonia. If the person you're dating can't handle it, too bad for them! Don't waste your time with them and move on.

Your love life is one part of your existence. Your love life does not make you who you are. It's not always easy to do, but keep it in perspective. And keep in mind that your love life often takes off when you least expect it to. If you relax and remain open to new situations and new experiences, romantic opportunities will present themselves.

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

Have you ever tried:

- Baseball
- Basketball
- Track
- Archery
- Sailing
- Table tennis
- Weight lifting
- Swimming
- 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 a whole range of abilities. By looking on the Internet, you may be able to 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 doesn't 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. Disney World has a very good reputation for taking good care of guests who have wheelchairs or need special services. If you call ahead, airlines can provide transportation to and from the gate and can arrange for you to have a wheelchair if you are an occasional user and don't want to bring your own.

There are hundreds of overnight camps. Many camps make it easy for young people who are disabled to visit and participate.

If you or your family is interested in traveling or attending camp, there is a list of websites to visit in this booklet.

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. Helping others is also an anti-depressant because it allows you to focus on the needs and problems of someone else, and not your own. Volunteering gives you a chance to help make the world a better place. Volunteering also gives you a chance to feel really good about yourself because you know you are doing something generous.

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. As mentioned before, the Dystonia Medical Research Foundation is an organization that helps people with 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 a charity by holding a car wash or saving your allowance.

Dystonia Advocacy
The Dystonia Foundation can provide you with ideas and materials to help you become a dystonia activist, if you so choose. Raising money for dystonia research and educating your community about dystonia give you a way to actively contribute to a national and international movement to improve the lives of people with dystonia. You did not choose to be inducted into the dystonia community but now that you are a part of it, what good can you create from it? You can do your part to help this community of people who, like you, know what it is like to live with dystonia firsthand. By doing so you will also help yourself by knowing that you are contributing something meaningful to the community and to the world.

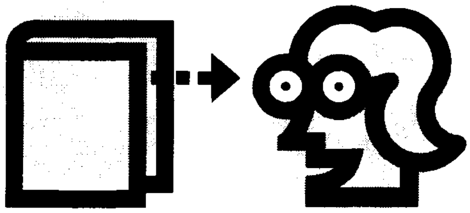
Think of how amazing it would feel for you to educate another person about dystonia only to find out that your efforts helped that person's mother get diagnosed after years of not knowing what was wrong with her.

What if the $50 you raised for dystonia research by organizing a car wash was the last $50 needed to fund the science project that discovered a new treatment—or a cure! Young people with dystonia are capable of great things. Do not underestimate the good you can accomplish by getting involved in dystonia awareness or fundraising.

Ideas for dystonia advocacy:

- Do a report on dystonia for an English or science project.
- Make a presentation about dystonia to your class or school.
- Ask your principal to help you find a way to distribute a brochure about dystonia to every student and teacher in your school.
- Have a garage sale and donate the proceeds to the Dystonia Foundation.
- Organize a car wash and donate the money you raise.
- Ask a local business to put a dystonia donation can on their counter for six months and collect the donations each week or so (the Dystonia Foundation can supply the can).
- Get some family and friends together and shake donation cans outside your local supermarket or another busy location (the Dystonia Foundation can help you plan).
- Contact your local newspaper and invite them to write a story about you (the Dystonia Foundation can help!)

The possibilities are endless. The Dystonia Foundation can provide you with an entire manual for organizing fundraising and awareness projects. Contact the Dystonia Foundation with your ideas and the staff will be more than willing to provide you with the tools, information, and materials you need.



Chapter 9

New Horizons: Life After High School

When you're a little kid, the question of what you want to be when you "grow up" is easy to answer because it's a fantasy: *I want to be a racecar driver, a ballerina, a rodeo clown.* By the time you're in your late teens, however, you have to start thinking about real life. It's not as scary as it may sound.

Career Ambitions

You may have ideas of what you'd like to do with your life as an adult, or you may feel quite clueless. Both are perfectly ok. If you need help figuring out the kind of career you might like to pursue, consider asking adults you know about the careers they have had—you may be surprised to learn that Dad wasn't always a real estate broker and once auditioned for the Ice Capades. During a vacation from school, ask a parent or adult relative if you can come to work with him or her for a day—just to be a fly on the wall and observe. See if your guidance counselor has magazines about career choices.

If you need more ideas, make a list of the most enjoyable activities you've accomplished in the last five years. Think about what you liked about them and what skills you needed to do them. For example, if you were in a play with the drama club, think about the skills you used:

- You may have had to review several plays and vote on which production to do
- Negotiating the roles of people in the club—not only who would play what part in the play, but who would be in charge of developing scenery, costumes, and designing the playbill
- Memorizing lines
- Coaching others to help learn their lines
- Selling tickets
- Speaking in front of a group of people
- Emergency health care (when the leading man got nervous on opening night and you prevented him from hyperventilating)

This is a pretty impressive list of skills. The skills you need to participate in a school play—critical reading, negotiating roles within a team of people, remembering key ideas or facts, tutoring others, sales, public speaking, and nursing—are all skills that can be useful in a wide variety of career fields. Sometimes it's difficult to identify individual skills, but over the years you have probably accumulated more than you think.

Identifying the skills you have—and skills you wish to learn—can help point you in the direction of a career path. If you can't settle on a career field, consider taking a liberal arts or general studies course load at a two- or four-year college. Those studies will expose you to a range of fields and you may discover subjects that interest you.

One surefire way to be happy in your career is to identify what you like to do and figure out a way to make money doing it. If you do have an idea of a career you would like, explore the schooling and training required for that occupation. Depending on the occupation, a community college degree, a four-year college program, a graduate degree, an internship, an apprenticeship, and/or on-the-job training may be appropriate.

Making the Transition

If your accommodations for school are outlined in a document called an *IEP*, by the time you are 16, this document should include measures to help you plan for life after high school, and specifically transition to college or other postsecondary (after high school) education. Options after high school include various community college programs, career certificate programs, a traditional 4-year college or university program, internships, apprenticeships, on-the-job training, or applying for government benefits programs.

Your transition plans may include:

- Knowing the kinds of accommodation you need to study and succeed in school, including assistive devices
- Making sure that you are able to explain dystonia and describe the kinds of accommodation you need
- Identifying postsecondary schools or programs (such as colleges, universities, trade schools, or other career training) that interest you and the requirements to apply to those programs
- Developing a resume
- Being aware of community support resources and programs, such as those

available through your local Vocational Rehabilitation services

- Being aware of the programs and benefits available through the government, both federal and state-wide
- Being able to direct and manage personal assistant services if you need them
- Planning for financial support such as scholarships
- Identifying and arranging for accommodation at the postsecondary school or program you plan to attend

The items listed above may seem like a lot, but much of it is simply a matter of being organized. Your parents and advocates at school will guide you through the process.

Attending a College, University, or Postsecondary Program

Your academic career at the postsecondary level is quite different than your high school experience. For one, the bulk of the responsibility for your education is transferred from your parents and the school district to *you*. This includes not only finding and applying to the school or program you wish to attend, but also actively identifying and getting the accommodation you need. It also includes creating your own schedule and managing your own time (which can be great!).

Colleges and universities receiving federal financial assistance must not discriminate in the recruitment, admission, or treatment of students with disabilities. For example, colleges and universities must not limit the number of students with disabilities admitted, or ask questions about a potential student's disability during the application process.

All postsecondary educational programs and activities must be accessible, to the greatest extent possible, to all students with disabilities. For example, colleges and universities may do this by permitting the use of computer software programs or other assistive devices to assist a student with taking tests and studying. Colleges and universities may also permit extended time for completing exams, changing the test format, or increasing the frequency of tests or exams. Often these services are arranged through the colleges' and universities' Disabled Students Services office.

The Disabled Students Office at the postsecondary school you attend will have a big impact on your college career, particularly with regard to accommodation. When considering applying to a school, communicate with and visit the Disabled Students Office. Talk to them about your needs and explore the support system in place for disabled students. If possible, speak with disabled students who have attended the college.

Your rights as a college student include:

- To not be denied access due to dystonia or another disability
- To receive reasonable and appropriate accommodations to provide you with the same opportunities as other students
- To have access to assistive devices and technology
- To not be counseled toward an academic or career program that you don't want
- To receive assistance from the Disabled Students Office in removing any barriers standing in the way of you receiving an education, whether they are physical, academic, or pertaining to the attitudes of faculty.

Selecting a College, University, or Postsecondary Program

Deciding which postsecondary education or career training program is right for you may seem like an overwhelming task. It is indeed a big decision, but with a little imagination, motivation, and planning, it can all fall into place. Some careers require a very specific training path. However, some people will argue that the benefit you get from a postsecondary program has less to do with where you go and what you study, and more to do with going through the process. The process will cause you to emerge from the experience better educated, more independent, and more capable of making a career for yourself, regardless of the subjects you studied. In order to find out what is available to you, consider:

- Getting brochures and catalogues from your school guidance counselor
- Talking to older siblings or the older siblings of your friends about how they made decisions about what to do with themselves after high school
- Going to a college or career fair

Here are some things to consider when selecting a postsecondary program, especially colleges and universities:

- Educational program—does the school have academic programs that interest you?
- Location—will you live at home or away?
- Size of the campus—how will you get around?
- Accessibility—how accessible are the classrooms, lecture halls, libraries, dorms, cafeterias, student union, school stores, restrooms (both in public buildings and dorms) and athletic facilities?
- Disabled Students Office—what services do they provide?

Visiting the campus of the postsecondary school you wish to attend is crucial. Only by physically going to the campus will you get an accurate idea of what life at that school will be like. In your junior year, start visiting campuses. For example, if your older friends have headed off to college, visit them and have them give you a firsthand look at what life at their college is like. You may even consider finding a summer program for the summer before your senior year as a way to "test drive" a college before attending as a full-time student.

When it comes to choosing a curriculum or classes, challenge yourself but do not burden yourself. If you think you want to take half a course load during your first semester to feel things out, do it—you can always pick up the pace in the next term. Investigate on-line study opportunities as well. Don't be afraid to take your time. Customize your education to your needs.

Life on Your Own

Living on your own, away from your parents, is not an essential part of having personal freedom. And in some cases, it's simply not practical. However, it can be very liberating. Living on your own or with roommates requires quite a bit of responsibility, and most of it is best learned simply as you do it. But before you decide to find an apartment and start packing, ask yourself if you need practice with any of the following skills and activities:

- Getting around your city/town, including public transportation if applicable
- Opening and managing a bank account, and managing your money in general
- Acquiring a picture ID
- Operating kitchen appliances such as the stove top, oven,

microwave, and (if you're lucky enough to have one) dishwasher

- Using common kitchen tools such as knives, can openers, bottle openers
- Cooking basic meals (or at least having your favorite take-out menus and phone numbers handy)
- Using a washer and dryer
- Doing minor maintenance such as changing a light bulb or unclogging a toilet (it is indeed a skill)
- Knowing community emergency telephone numbers
- Understanding a lease and knowing responsibilities of tenants and landlords
- Arranging and paying for utilities such as electricity, phone, and water services
- Getting help from maintenance and service people
- Managing and directing personal assistant services if necessary
- Throwing a party! (Ample quantities of beverages and toilet paper are key...)

The list above covers just the basics, and, as stated previously, many of the skills you need to live on your own are skills you learn best simply by doing them.

Having a Family of Your Own

Having dystonia may raise serious questions in your mind about having children and raising a family. We mentioned earlier that dystonia does not affect fertility, so dystonia will not in any way impede your ability to conceive a child. The question then becomes, *if I conceive a child will he or she have dystonia*? Unfortunately, this is not the easiest question to answer. But here we go:

The question of whether or not your children will have dystonia depends on the type of dystonia you have. The answer is also somewhat limited by what scientists know about dystonia. There are genetic forms of dystonia that can be inherited from family members, there are non-genetic forms that are not inherited, and then there are forms that may or may not be inherited—scientists just don't know yet.

If your dystonia is the result of a serious accident, exposure to medications, or a stroke then it is probably not genetic and your children will in all likelihood be dystonia-free. If you know the form of dystonia you have is inherited—especially if you have other family members who have it—then there is a chance that your children may develop dystonia. Traits (such as eye color and blood type) are passed from parent to child through genes. A small error or mutation in a gene can result in changes to the body, including certain disorders. These errors get passed along with the genes, and this is how disorders may be inherited.

One form of dystonia that often affects young people is called *DYT1 generalized dystonia.* It is called DYT1 dystonia because we know it is caused by a tiny mutation in a specific gene called the DYT1 gene. If you have this gene mutation and you have a child, that child has a 15% chance of developing dystonia. The dystonia may be mild or it may be severe, there is no way to predict it.

There is a procedure called *preimplantation genetic diagnosis* (PGD) that allows parents who have the DYT1 mutation to conceive a child who has about a 99% chance of being dystonia-free. PGD is expensive and can only be done at special clinics, but it is an option for some people.

If a woman is already pregnant and she is concerned that the fetus may have the DYT1 mutation because she has it or the father has it, the fetus can be screened. (For more complete information about how dystonia is inherited and family planning options, you can contact the Dystonia Foundation and request a booklet called *DYT1 Dystonia & Family Planning.*)

If you have what is called *dopa-responsive dystonia, paroxysmal dystonia,* or *non-DYT1 generalized dystonia* there is currently no way to predict if your children will have dystonia—they may or they may not. But genes have been discovered for some of these forms, and scientists are constantly working on finding dystonia genes and then developing tests to help people know more about their dystonia and how it may affect their families. If your dystonia is related to another health condition, it depends upon the nature of the other health condition.

Adoption, egg or sperm donation, and surrogate parenthood are also options for people with all forms of dystonia—genetic, non-genetic, or unknown—who want to become parents.

Parenting a child responsibly is a staggering task that can probably never be fully appreciated until you find yourself in the thick of it, mind-numbingly sleep-deprived at the kitchen sink and wondering if the wiggling little bald dude you are trying to bathe isn't really part octopus. However, anyone who is considering parenthood—able-bodied people included—needs to at least make an attempt to fully appreciate what he or she may be getting into. There are reasons to have kids, and there are reasons not to. We won't get into weighing those reasons here. As you go through your life you will become very aware of what you can handle and what you can't, both physically and emotionally.

As a teenager, you have many things to accomplish in your life before parenthood should even remotely resemble a good idea. When that time comes, educate yourself and know that having dystonia does not automatically disqualify you from being a parent.

Advice on Living Independently

Your independence is something that evolves over time. Being self-sufficient does not happen overnight. Enjoy the process of learning—maybe you can volunteer to cook a meal for your family once in a while, or your school or church or favorite community group may offer overnight fieldtrips. If you want to get a taste of what it is like to care for children, "shadow" a parent you know and observe the many demands of parenthood, volunteer at a YMCA after school program, or offer to baby sit young cousins or neighbors.

Here are some words of advice from young people with dystonia who have made the transition from high school to adult life:

Strive for independence and freedom whenever possible and take advantage of the resources around you.

Don't let dystonia rule your life. Take the bull by the horns and be happy. Take responsibility and never settle for anything less than what you deserve.

Look out for yourself and be your own advocate.

Don't be afraid to admit you don't know how to do something—use it as an opportunity to learn.

Do not trust an unreliable toaster oven. Know how to use a fire extinguisher.

Learn as you go!

Chapter 10
Living Beyond Dystonia's Boundaries

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

Here is some general advice for young people with dystonia from others like them:

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

Remember we are not different from other kids.

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.

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

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

Do not give up!

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 them. If your goals aren't realistic for 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.

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 future goals.

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.

If your family doesn't treat you like the rest of the household, ask them to do so.

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

Closing Thoughts

The fact is that even though dealing with dystonia may sometimes leave you feeling like you're stuck in a foreign country, remember that you live *with* dystonia, not *in* dystonia. You live your life beyond the limitations that dystonia creates for you.

There is no secret trick to living with this disorder. You will have rotten days and wonderful days. Strangers may stare or say ignorant things, but you will also meet fantastic people who make you feel amazingly good about yourself. Your family will drive you crazy and show you great kindness. In short, you will endure situations that many people your age will never experience but, when it comes down to it, you will have a life pretty much like any other teenager. Do your best to succeed in school, be kind to others, and take care of yourself. You have come this far, and you are on your way to becoming a remarkable person. You have what it takes to live beyond the boundaries that dystonia may create and to be successful in your life.