



**Tourette Syndrome
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LIVING WITH TOURETTE SYNDROME

One Teenager's Viewpoint

Written by Adam Seligman

Number III in a series of booklets on
"Coping With Tourette Syndrome"

Dedicated
To My Mother Muriel
With Love

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I've had Tourette Syndrome for over ten years. I recently completed high school. Throughout the years I've developed some ideas on coping with Tourette Syndrome and surviving high school that I'd like to share.

BECOMING A SURVIVOR

There are two types of people with Tourette Syndrome: Victims and Survivors. At first glance there isn't much difference between the two. They both tic. But their attitudes about life are the opposite of one another. The Victim is a person who has given in to his or her disorder. He's been told that he's handicapped so many times that he starts to believe it and eventually ends up acting it. The only thing he knows for sure is that he CAN'T do anything well.

The Survivor, on the other hand, is someone who has more or less accepted his or her symptoms and then gets on with the business of living. He knows that the tics can and often do get in the way — but not to the point that all functioning is disrupted.

Very often the determination of whether you become a victim or a survivor has its roots in high school. Why? Because during adolescence, your body goes through dramatic changes. The chemical changes in your body and brain tend to increase the severity of Tourette symptoms. The combination of puberty and intense Tourette symptoms can be too much for some people. They become victims. Others face it as yet another challenge to tackle and overcome this hellish period.

SCHOOL

If you're a teenager with Tourette Syndrome, you probably are still in high school. Believe it or not, even kids without Tourette Syndrome find their high school years to be stressful ones. But if you have Tourette Syndrome, you'll find even more pressure placed on you and it sometimes gets in the way of getting an education. You'll have to deal with schoolwork, your peers, teachers, conforming to the norm, and just plain surviving. While you may feel singled out at times, remember that everyone has problems: you just stand out in the crowd.

Often it's hard to do your schoolwork when you have tics. You might lose your place in the book; or you can't concentrate; or you might scatter papers with your arm movements. As difficult as it may be at home, it's even harder in the classroom. Tension makes your tics worse; stares from teachers and classmates make you feel even more pressured to control your tics.

If you have trouble with a subject, ask for a tutor. It's not a cop-out, nothing to be self-conscious about. Many people without handicaps use the service of a tutor. That's why schools provide them.

If your handwriting is poor and you're tired of translating it for your instructor, learn to type or ask for permission to do your work on a tape recorder. It might take a little longer at first but a clearly written paper or an oral answer is easier to grade. Teachers will appreciate your thinking of them.

One way of dealing with examinations is to get permission to take your tests in a separate room. That way you can concentrate on the test and not the stares from other students. You also won't be so self-conscious about disturbing others with your vocalizations.

When you begin a new class, be certain that the teacher understands what Tourette Syndrome really is. The Tourette Association has a great deal of material that you may use. Ask your teacher to explain Tourette Syndrome to the class. Better yet, do it yourself. After all, you know better than anyone else what it's like to live with Tourette Syndrome and it's good experience for you to get up in front of a group of people. Your classmates will probably be more understanding once they know why you're doing what you're doing. You might show some of the films about Tourette Syndrome or use other materials available from the Tourette Association.

Remember, explain your condition to your teachers as soon as possible. Don't let them predetermine that you're a troublemaker. Teachers are like other normal people — if they don't know what's wrong, they won't understand. If, after explaining Tourette Syndrome to your instructor, you still feel he or she is giving you a difficult time, talk with your guidance counsellor, principal, or other school administrator.

You have a legal right not to be hassled because of your symptoms. It may be hard for the teacher to understand all the problems inherent in your disorder. Try to work with, not against, your instructor.

If you're in your junior or senior year and are planning to go to college, you'll probably have to take the Scholastic Aptitude Tests (S.A.T.). You are entitled to special test arrangements by law. You can take the test in your own school with a proctor. There's no use taking the most stress-filled test in high school in a strange environment with a room filled with strangers which might make you tic more.

SEX, DRUGS, AND ROCK & ROLL

At some point in your life, you will notice two things. The first is that you have an interest in the opposite sex. The second is that your interest isn't always returned. You can't help but be a little depressed by this. It's true, however, that some teenagers shy away from someone who seems different. They prefer people who "fit in." There's not much you can do about this attitude. You can, however, find activities in school to become active in. When you do, you will meet people who will be able to see beyond your handicap and accept you as the person you are because you will be involved together in a common interest.

Start talking to people. As with anything new, it's hard. Seek out people with the same interests you have — sports, music, theatre, travel — the topic really isn't that important. If you like a person and don't seem to have anything in common, don't give up. Something may turn up or the two of you may develop a mutual interest. Be a volunteer. Most groups need an extra helping hand and when you're working with others on a joint effort, you automatically have that in common. Don't give up!

If you do become close friends with someone, (especially if it's someone of the opposite sex), it probably will be a person who is more sensitive than most. There aren't a great many like that in high school; it's not a place noted for the maturity of its inhabitants. But these people do exist. If you are lucky enough to meet one of this special breed, it will make the years of loneliness and depression

worth it. It will give you the motivation to go beyond your limits and strive for success. It could make you a survivor.

If, however, your special relationship ends, don't automatically blame Tourette Syndrome. The ways of love and lust are weird. It has a life of its own. Teenagers without TS also have romances that fizzle. Try to avoid taking refuge in self-pity. It hides you from others who may otherwise seek you out.

In an attempt to be accepted by teenagers, you may be tempted to try drugs. There's something to keep in mind about recreational drugs: they alter brain chemistry. Because Tourette Syndrome is a brain chemical disorder, there are some drugs which are dangerous for people with Tourette Syndrome. You should avoid "mind expanding" drugs. Acid is a very overrated drug and one that most likely will make your tics worse. You might have heard cocaine feels delightful – but be alert for violent mood shifts. It also could be psychologically addictive. Uppers should never be messed with. Figure it out yourself. Downers are about as much fun as Haldol, if that's your idea of a good time. Grass may not make your tics worse but it will get you stoned, which will interfere with your school performance.

Two drugs you don't hear a lot about are caffeine and alcohol. I've been warned that caffeine will make my Tourette symptoms worse. Alcohol is a brain chemical depressant. You certainly don't need to go out of your way to get depressed! The truth is, if you have Tourette Syndrome, you're better off saying "no" to all such drugs.

Speaking of drugs, always carry some type of identification with you that explains you have TS and describes its symptoms. That way you don't have to worry about a policeman stopping you, thinking you are on drugs or under the influence of alcohol. The TSA identification card is useful as is the Brain Bank card. (If you haven't joined the Brain Bank, do it now. Don't be squeamish. Only by studying the brain tissue of deceased TS patients will doctors be able to determine what changes actually take place and hopefully one day soon, why. Write the TSA for their brochure explaining how the Brain Bank works.)

HOPE

You're afraid to go outside
You spend endless nights alone in bed
No one to hold on to
No one to talk to
No friends and no romances
No hurting no healing
Just endless sleepless nights in bed
Endless sleepless nights in bed
You're hiding from the animals.

Author: INSECT IDOL 1980©

At some time in your life you might feel that there is no point to living with a disorder like Tourette Syndrome. The burden may seem too great. Long past midnight, you may think of suicide. PLEASE DON'T DO IT! It's not a choice you can take back. There are millions of people with handicaps as great or greater than yours who are not killing themselves. They survive and fight to live with the same kind of dignity as so-called "normal" people. You have a great deal to offer the world. Look for the positives in your life. When a cure for Tourette Syndrome is found, you want to be around to benefit by it.

While there is no cure at present, there are some treatments that can control some of the symptoms. Perhaps you take Haldol or similar drugs. You may have side effects. This is the time in your life that you must take responsibility for yourself. It is *your* disorder, not your parents'. You should decide whether or not you should stay on the drug or if you can function on a lower dosage. If you think you can exist without any medication, try it. You can always go back on it. It isn't good to stay on any drug for long periods. Periodically you should probably take a drug vacation. An increasing number of doctors recommend drug-free periods for their patients.

FAMILY

For about five years before I was diagnosed, I had a lot of trouble with my older sister. She felt I was twitching in order to get attention. Her remedy for this was to make my life hell. After I was diagnosed, it was a different situation. She felt very guilty. She kept her anger hidden, except when she was really upset with me. Then she overacted. It took about four years before we settled in to a normal sibling rivalry.

It's important to make sure that your entire family understands the problems of Tourette Syndrome – how tension or fatigue makes the tics worsen, how you can control tics for a short time, what the medicine does to you, how you feel when you tic, etc. There *still* may be some jealousy when you get more than your share of attention. There may be some resentment too. They may suspect that sometimes you use your disorder to get out of something you don't want to do; you know that sometimes they're right.

My best advice to you is to be open and honest with your family. Communication – talking and listening – is vital.

EMPLOYMENT

If you look for a job, be ready to discuss all your attributes with your prospective employer. Bring some of the Tourette Syndrome Association pamphlets so he or she can understand your disorder. By talking about it freely, while you also "sell" yourself as a good prospective employee, you should be able to show your maturity and willingness to work.

If, once you have landed a job, you find your co-workers bothering you because of your tics, show them the brochures as well. You might as well level with people because there's no way you can hide your disorder from them. Most people will be supportive when they learn the truth. Occasionally, however, you may run into discrimination because of your Tourette Syndrome. If you really feel that it is discrimination, then you do have legal recourse.

LIFE AFTER HIGH SCHOOL

Each person must make his or her own decision concerning what to do after graduation. Some may decide to take a year off; others may try to find a job; others may think about going to college. If you do choose the latter action, you might step in slowly by taking a course or two at a local community college. If you decide to go away to school, carefully consider where you would be more comfortable – a small school where the students and faculty know you and understand your disorder or a large campus where there might be hundreds in a lecture hall.

Whatever your decision, don't be limited by Tourette Syndrome. Samuel Johnson was a famous poet and writer, yet suffered from TS. Tiberius Claudius, the fourth Emperor of Rome is believed to have had TS as well; many modern day musicians I know have it. Of course, becoming a neurosurgeon might be out of the question if you have severe arm tics but if you want to go into medicine, there are many other specialties you could consider. Think positively about what you can do. Because of your unusual childhood and teen years you have a great deal to offer others. Make lemonade when life hands you lemons!

Take each day as it comes and make the most of it. Enjoy small successes. It won't make your tics disappear but it sure will make you happier.

I hope this booklet has given you some ideas for coping with Tourette Syndrome. May you be a Survivor! Good Luck.

Editor's note:

The following is excerpted from a letter that was written about Adam by the principal of the school from which he graduated. We are reprinting it for you here because we feel it sheds further light on the kind of survivor Adam is and may serve as a further inspiration to many.

June 1980

TO WHOM IT MAY CONCERN

Adam Seligman has been a student at New Dimensions School for the past five years.

During that time I have had the pleasure of working with Adam as his teacher and more recently his principal.

Adam is a unique individual in many ways. He is bright, articulate, diligent, cooperative, creative and suffers from Tourette Syndrome. I list his characteristics in the above order purposely to indicate that his neurological disorder is only a factor of his composite personality. Tourette Syndrome is a hurdle, an obstacle for Adam to compensate for by hard work and perseverance.

Over the past five years I have watched as Adam has struggled to have a normal adolescence in our school setting. It has not been easy for Adam to conquer hurdle after hurdle and the conquest has been laced with moments of frustration and anger,

but Adam has persevered. He has gained respect and popularity amongst his peers, he has proven his ability to be an excellent student, he has performed beautifully in school dramatic productions and he has done all this battling TS.

From my experience, working with Adam in an educational environment does present certain administrative problems. Namely, what could the school do to make Adam's social, emotional and educational adjustment to our setting a smooth transition? In keeping with the philosophy at New Dimensions, we felt it would be beneficial to educate the other students regarding Tourette Syndrome so that they would not be threatened by Adam's symptomatic behaviours. Actually, Adam became the most important educational tool by presenting a lecture and film on Tourette Syndrome to each classroom and making himself available to discuss and answer questions other students may have had. In conjunction with Adam's lectures, the staff and administration determined that we would work as a team in handling any teasing, taunting or other forms of adolescent mockery by requiring the guilty party to attend a student conference for educational, problem-solving purposes. The vast majority of students were very apologetic when they realized the extent of their insensitivity.

My association with Adam and his family has been an education in the value of warmth, support, encouragement and perseverance.