

Teens and Tourette Syndrome

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you that these are
the best years
of your life —
they're lying!

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Teens and Tourette Syndrome

If anyone tells you that these are the best years of your life — they're lying! Or they've seen too many movies about cheerleaders and captains of the football team, and they've forgotten what it was really all about. Being a teenager is tough. Tourette Syndrome makes it even tougher. But you will get through this. It may not seem that way all the time but you will!



This publication is intended to provide information about Tourette Syndrome. Families should be advised to first consult a physician concerning all treatments and medications.

The TS Challenge

TS — with tics, medications, worried parents and confused teachers — adds an extra challenge to your experience as a teenager. You're not just dealing with the usual variety of teen pressures because TS is always present. It's a factor in all your decisions and makes many of your choices more complicated — just when you'd like life to be simple. It may help to know that many people with TS find that their symptoms wane during adolescence so your tics may lessen with each birthday and, perhaps, all but disappear.

Self Esteem

Teenagers aren't known for their self esteem. Teenagers with TS may feel like they're starting at less than zero. It may help to focus on the positive when life gets difficult.

Ben Herzig, who will soon attend the University of Pennsylvania, acknowledges that TS can have an impact on self-esteem but has found that a constructive personal philosophy has enabled him to project a positive attitude.

I believe that we all receive both blessings and challenges. It's how we deal with them that defines us as people. Especially with TS, self-esteem can run low, but we need to draw strength from our challenges. TS and the associated disorders have forced me to accept who I am and to value what I have.
Ben Herzig

Sue Conners, an educator and TS activist, reminds teenagers she mentors that the "...kids who make fun of you have more self-esteem issues than the kids with TS."

Friends, Dating and Other Teenagers

It helps to remember that TS is only one part of you. It isn't the only thing people see when they meet you but it may be the first thing they notice. It's a cliché, but the people who take the time to get to know you — the you behind the symptoms — are really the people worth knowing anyway. Real friends get past

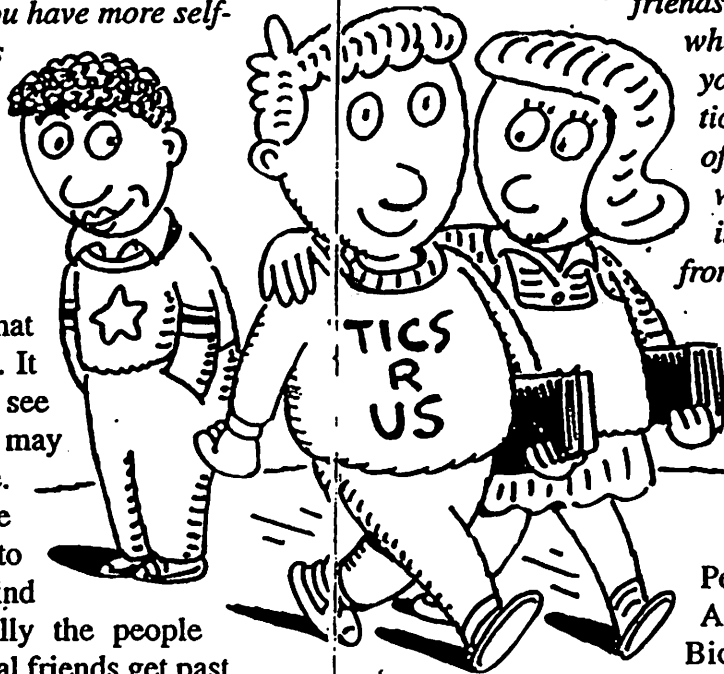
the surface but, since you've managed to make it this far in life, you already know that.

High school can be viewed as one long popularity contest. You can opt out entirely or you can increase your odds of connecting, by getting involved in things you enjoy. Making friends through a shared activity is the best way to find the people who will spend enough time with you to get to know you. So do something — anything that you really enjoy — from the chess club and the school newspaper to the basketball team and the drama club — like minds gather. It's another cliché but clichés are often true.

When you make a new friend, especially during school days, I think you're usually energized by something you have in common or some event you participate in together. And that shared experience can completely overshadow the tics. It is hard to be mocked or avoided because of something you can't help or even don't understand. But your friends tend to stick with you

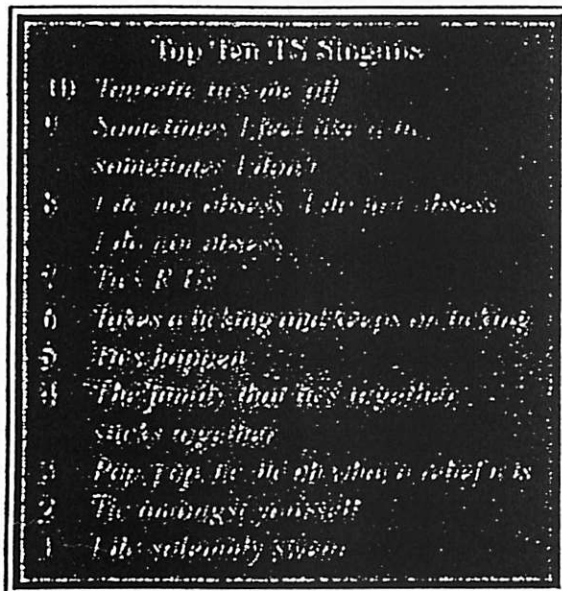
whatever they think of your tics — perhaps particularly during the years of teen tribalism. Kids who project something interesting or special up front — academic success, a sense of humor, caring, charm, athletic ability, etc. — are more than capable of getting other kids to look past their tics and become friends.

Peter Hollenbeck Ph.D.
Associate Professor of
Biological Sciences at
Purdue University



Some teens find that developing a thick skin is the only way they can survive the social pressure cooker that we call school. High school bullies are more sophisticated than the idiots who made fun of you in elementary school but their motivations are the same — they make themselves appear to be clever or funny by teasing and taunting you. You don't have to be a pawn.

Sue Connors is a great proponent of the use of humor for diffusing tense TS-related situations. Her list of the top ten TS slogans reflects the attitude that nothing — including TS tics — will ever get her down. Some of the teens she has counseled proudly wear outrageous T-shirts that effectively take the jokes out of the mouths of bullies.



Rachel Silverwood, high school student and actress, found herself in a group of friends she described as "controlling." It became important for her to find new friends who supported her sense of independence and appreciated her individuality. TS has a way of defying the typical teenagers desire to

"fit in." Rachel reached out to kids who were both more accepting and more fun.

Ben Herzig sums up his ideas about friends in one simple sentence: *A true friend is someone who looks past your image to discover the beauty of your individuality.*

Dating is especially tough. Does it help to know that everybody else is miserable too? The happy teenagers in movies are FICTION. Romantic rejection is part of everyone's life.

If you have TS and your tics are particularly obvious you are probably going to experience an extra helping of rejection. There is no easy way to deal with this reality. Girlfriends/Boyfriends are fickle creatures. If you're lucky you'll find someone who really cares about you. In the meantime do what everyone else does — complain to your friends, write dreadful poetry and daydream about the future.

In many ways Rachel Silverwood is a typical teenage girl. She says that she is very insecure about her appearance but is popular and has been dating for a couple of years.

I started dating the summer before my sophomore year. I had a date for Valentine's Day my freshman year but had no clue it was a date until I got there. I started going out with my best guy friend but that didn't work out very well. I don't really have much advice. I'm very traditional, and I won't ask guys out. I'm not confident in my looks, and I wait for guys to come to me. I hate the idea of rejection. Rachel Silverwood

Peter Hollenbeck graduated from high school a long time ago but his perspective on dating is valid for romantics of all ages.

I often wonder whether having tics provided me with a "people filter," especially in teenage years. No one was going to pretend

to fall in love with me because I was a tic-free perfect specimen of manhood. It is worth understanding - although cold comfort, perhaps - that in the world of romance lots of other things will probably make more trouble for a teenager than tics will. If you are the "wrong" shape and size- - as nearly all of us are — that will be used at some point to make you feel much smaller than your tics could ever make you feel. Life is never fair, and sometimes it stinks - which is exactly why we need romance and friendship AND need to treat those who offer these things like the precious part of our life that they are. Kids with TS need to know that nearly everyone suffers as much as they do, but to different degrees and for different reasons. Peter Hollenbeck

To Tell or Not to Tell

Sometimes there's no choice. If your symptoms are getting in your way — socially and academically — you simply have to explain yourself. But if your symptoms are more subtle (or effectively controlled by medication) you have to weigh the pros and cons of talking about TS. There is no question in Sue Conners' mind. She tells as many people about TS as she's able. But for many individuals with TS the downside of talking about TS — being singled out as different — makes keeping TS quiet preferable.

I suggest that teens start with a few of their close friends. They will usually find that it helps to tell people, and that harboring a secret is very stressful. Talking about it lessens the burden while denying TS makes things worse. Kids may get double messages from home. Parents who hate to see their children hurt may pretend that TS is not an

issue. They do this out of love, but the result is that kids get the idea that they shouldn't talk about TS, and how it makes them feel. The teens who are best adapted and most successful are the ones who keep TS in the open. They don't use it as an excuse but they learn to accept it and understand it. Sue Conners

Peter Hollenbeck advises teens — and adults too — to be prepared to explain TS.

Whether you are young or not, a succinct and confident explanation of what your tics are all about can be both comforting and impressive to many people. It can put at ease not just friends but teachers, relatives, bosses, employees. I think that one very good reason to explain your tics to someone is that without such an explanation, some people dealing with you think that you have a "nervous tic" that reflects discomfort at being around them. Peter Hollenbeck



When honesty is simply the best policy, you may want to use some of the TSA literature to help you prepare your own explanation of TS. National TSA has pamphlets that cover the medical and social aspects of TS symptoms.

Party Time

Whether you have TS or not, this is a no-brainer. When the question is about the recreational use of drugs and alcohol, the answer is NO. TS is a brain chemistry disorder so you may want to discuss the impact of drugs on people with TS with your doctor. Mucking around with chemicals is probably the worst thing you can do. In addition to the TS-related dopamine imbalance in your brain, you're probably taking at least one kind of prescription medication. You don't want to be some kind of guinea pig in an amateur science experiment.

Ben Herzig is adamant on the subject of recreational drug use. *Drugs and alcohol serve to contaminate and corrupt the mind. Our minds are pure and special, and should only be exposed to substances that serve an understood medical purpose. We also need to be careful to not over-prescribe medicines.* Ben Herzig

The right group of friends is an important factor in dealing with the temptations offered by recreational drugs and alcohol.

Rachel Silverwood is happy with her new group of friends because, *"When we have parties I never have to worry about drugs and drinking."*

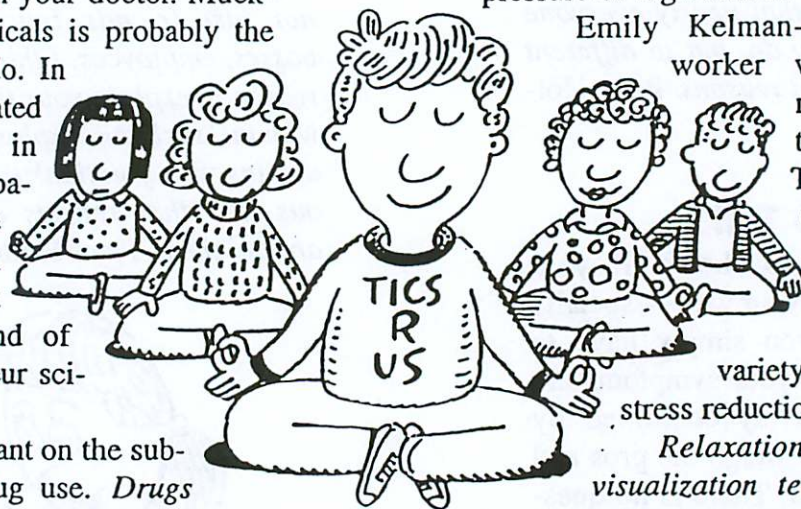
Dealing with Stress, Anxiety and Depression

High school is stressful. The transition from middle school, or junior high, to high school is particularly anxiety-provoking. TS symptoms are exacerbated by stress, and just thinking about embarrassing yourself on a big day at school causes even more stress. You no doubt already know that, and you may already have become "phobic" about the first day of school, exam time, football try-outs, etc. But there are many effective ways to reduce stress and deal with the increased pressure of high school.

Emily Kelman-Bravo, a social worker who has helped many teens and their families at TSA's New York City Counseling Program, recommends that teens with TS explore a variety of strategies for stress reduction.

Relaxation, breathing and visualization techniques, meditation, biofeedback and assertiveness training, are all ways you can learn to reduce your overall stress level. Learning to manage your time more effectively, exercising and good nutrition are additional stress reducers. Thought-stopping techniques can help you control repetitive negative thoughts which can also alleviate anxiety and stress. If you are still experiencing anxiety and stress that significantly interferes with your life, you may need to consider psychotherapy and or medication. Emily Kelman-Bravo

The academic and social pressures of



high school can be overwhelming. Students who plan to go on to college should understand that the pressure is likely to increase dramatically and “real world” on-the-job work pressures can be even greater! Learning to cope now will help you for the rest of your life — so experiment with exercise and meditation, join a support group, open up to your friends, reach out to experts and develop a coping style that will help you now and in the future.

Depression is not unusual and it is not unnatural but when ‘the blues’ take over your life, it’s time to do something constructive. It’s important to recognize the difference between being chronically depressed and being anxious and depressed about finals, social difficulties or family problems. All teens have their moments of anxiety and days when there seems to be a dark cloud hovering over the world. It’s just part of life. But when you feel so bad that you’re not able to function, consult your doctor about the appropriate treatment for you.

Therapy and medications can offer concrete solutions to this very real and debilitating problem. Therapy, support groups and a good network of loving and supportive friends is sometimes just what a depressed teen needs, but medication is sometimes also necessary. Don’t be afraid to talk to a professional about feeling depressed. Learning when to ask for help is an important step toward leading an independent life.

Ms. Bravo addresses the reluctance some people feel about taking medication for clinical depressions. *Most people will take medication to treat medical conditions. Unfortunately some people are reluctant to take medication for depression even though it is highly effective.*

Depression can be debilitating, and it is as real as diabetes, asthma and TS. If you need medication — take it.

Academic and Vocational Planning

Everyone in high school has one eye on the future — whether they are planning the great escape from a boring home town or pushing to get into a top notch college enroute to medical school.



TS often complicates your ambitions for the future. If your grades or test-taking skills are not what they should be — ask for help! Tutoring may give you the edge you need to get going in the direction of your dreams. Don’t be ashamed to ask for the help you need.

Explore the resources available at your school, in your local TS Chapter and in your local community. Seek out adults who can be

your mentor and help you focus on your personal goals.

For Ben Herzig the key is simple — hard work and an unwavering focus on his objectives. *While it helps to be bright, which TS kids tend to be, the most important tool you can use to succeed academically is your work ethic. I have found that having TS has made me a more determined person, which has positively influenced my life in many ways, including the drive to succeed academically. The most important thing is to not allow yourself to feel that you can't set high goals for yourself just because you have TS or the associated disorders; I am my school's student body president and valedictorian and I have TS, obsessive compulsive disorder, attention deficit disorder, oppositional defiant disorder, and a past of clinical depression.*

TS symptoms can sometimes get in the way of academic achievements. The law requires that schools make accommodations for kids with TS, but because TS varies from person to person, there is no simple recipe for you and your school to follow. Negotiating your way through the system — with the help of your parents and other TS-savvy adults — may enable you to do better in your school work. If there's a room at school where you can “release” your pent up tics, the rest of your day may go much smoother.

Test-taking is a major issue for many teens with TS. Arranging to take tests in a separate, and quiet, room is one strategy that works for many kids. You may find that it improves your grades and diffuses the tension your tics may cause during a test in a crowded room.

Ben Herzig shares his thoughts on the SATs and college admissions in general.

Taking the SATs untimed is a good move if your TS or learning disabilities put you at a disadvantage. If you can handle the time constraints, then it is best to take it timed, because no matter what they say, I find it hard to believe that the more competitive colleges completely ignore that asterisk next to your score. If you can put a positive spin on your experience with TS, the college essay is a good place for that. Colleges love to admit students who have been faced with difficulties and who have emerged stronger people because of them.

Sue Connors agrees that asking for accommodations may be helpful with the SATs. She reminds kids with TS that they, “*shouldn't be afraid to accept help.*” And recommends that they find someone who can offer them guidance.

“Find one person, a teacher, a guidance counselor, a social worker — and share what you're going through. There is always at least one person you can trust. Kids have that innate intuition so look around and find that person.”

Students should also be aware that colleges offer accommodations to students with disabilities. Not everyone with TS qualifies, or needs, these accommodations but if you do, you should explore how the school can assist you once you've been accepted.

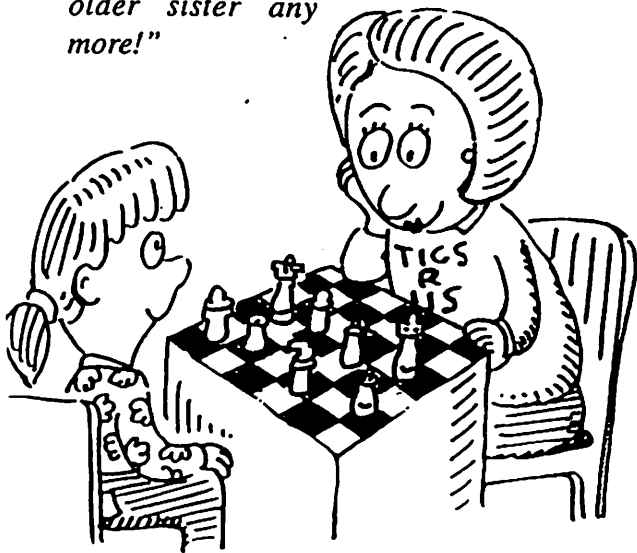
Never underestimate the importance of your extra-curricular activities at school. Your dedication to the year book committee, your contributions to the school newspaper, that set for the drama club's play and your second violin in the orchestra, may help you find a career direction or get into a college despite a less-than-spectacular grade point average.

Sibling Relationships

As you and your siblings mature, your relationships will grow and change. Some kids with TS are “late bloomers” coming into their own a little later than their siblings without TS. Coping with TS may have been a “family project” for many years, and now that you’re feeling more independent and better able to cope on your own, your siblings may feel disoriented, jealous or very, very happy to see you out on your own.

Rachel Silverwood describes an evolution in her relationship with her sister.

“We’re best friends, then we fight and then we’re best friends again. My sister and I have a really interesting relationship. When I was younger I needed an older sister but I’m the older sister. My kid sister took the role of an older sister for me, and I hung out with her friends. I used to hate sleeping alone because I had obsessive thoughts. My sister invited me to share her room. I shared it with her for years. Now that we’ve switched roles again, it is sometimes awkward but usually good. I don’t need my younger sister to be my older sister any more!”



Adult Decisions About Medication

Unlike most teenagers, teens with TS find themselves involved in complex medical decisions. As a child your parents and doctors took the lead, but as you approach becoming an adult, it’s important that you become one of the decision-makers. Discuss your medications with your doctors. If you have questions — ASK. It may help to write them down before your appointment.



As a teenager, you can monitor your reactions to your medications and assist your doctors in ways you never could as a child. By becoming a responsible member of the team, you will become better able to make medical decisions as an adult.

A Few Words of Wisdom — From People Who've Been There

Being a teenager has never been easy. Being a teen with TS can be particularly difficult but things do get better — symptoms wane, self-consciousness lessens, priorities change — and you may find that you not only survived your high school years — you've thrived!



Academics...

Lots of people work their butts off with non-TS brains and don't get A's. Everyone has to work hard and develop ways to learn and concentrate — they may have to work harder but it can most certainly be done. Peter Hollenbeck

Medication...

I talk about how I'm feeling. I make the decisions about how long I go between appointments with my TS doctor, and then my Dad and my doctor work out the medication thing. But I make the ultimate decisions.

Rachel Siverwood

TS...

Get to the point where you understand all the aspects of TS. Self-understanding is key — so learn about it! Sue Connors

ADDITIONAL TSA RESOURCES

VIDEOS

An Inservice Film for Educators, A Regular Kid, That's Me — A new aid for teachers to help understand the complexities of teaching children with TS. Includes explanation of the complexities and suggests interventions that work. 45 min.

I'm a Person, Too — Narrated by Cliff Robertson — Featuring five people with TS — two elementary school students and three adults — from diverse social and economic backgrounds. They talk about a broad variety of symptoms and their personal experiences living with the disorder. With moving impact, this award-winning documentary conveys a message that fosters greater understanding of TS among the viewing public.

Positive in outlook, this video has been well-received worldwide by educators and their students, health care and social service providers as well as general audiences. 22 min.

Talking About TS — A physician leads an in-depth discussion with a brother and sister, both of whom have TS. 45 min.

LITERATURE

Problem Behaviors & Tourette Syndrome — Drs. R. Brunn, K. Rickler and E. Kelman-Bravo, CSW, MS. Describes recent research and what is known about the relationship of a variety of behaviors and TS. Contains helpful advice about the management of problem behaviors for families and individuals with TS. 21pp

An Educator's Guide to Tourette Syndrome — S. Bronheim, Ph.D. Covers symptoms, techniques for classroom management, attentional, writing and language problems. 16pp

The Need to Know — J. E. Smith. Recollections of a young woman with TS who was misdiagnosed for many years. 4pp

Dear Diary, My Sibling has Tourette Syndrome — Written by Elaine F. Shimberg and Illustrated by Abby Denson. A humorous, poignant, clever and informative look at TS from a sibling's point of view. This booklet will foster empathy, and it's a fun way to introduce complex family relationships to school-age children. 16pp

An up-to-date catalog of publications and videos, including prices, can be obtained by writing to:

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