

Adults Have Tourette Syndrome Too

by Elaine Fantle Shimberg

Introduction

Although there are a number of good books describing the problems of children learning to cope with Tourette Syndrome, there are few that focus on issues for adults with TS. This is curious as children with TS do grow up and become adults with TS. This brochure attempts to rectify that oversight by tackling difficulties that arise once we become adults.

Definition

For those who haven't struggled with the disorder throughout their lives, a definition is warranted. "Tourette Syndrome is a chronic, neurobiological tic disorder, characterized by both motor and phonic tics. It is *not* (as previously believed) a psychological illness or psychosis, nor is it an 'acting out' of resentments, frustrations, or anger; it is not a nervous habit, nor a means of getting attention."

TS is biochemically based, and in almost all cases, genetically transmitted. However, there are some case histories of individuals developing the disorder after suffering neonatal damage or other trauma to the brain or seemingly without a known family history.

Question: Can someone with TS control the tics?

Answer: Yes, most people with TS can control their tics for a short period. Then the symptoms break out, much like a sneeze you've tried to suppress. Although the movements are not caused by a psychological problem, they do become worse when the person is tired or stressed. Also, they seem to decrease when the person is completely focused, e.g. playing the piano, working on the computer, or otherwise fully engaged.

People can often sense when a tic is coming on and learn to mask or substitute the movement or sound. For example, someone with a neck tic might rub his or her neck to mask the jerking movement. Someone whose vocal tic is a hoot or yelp can turn the sound into a cough or a word that is accented in a way that is more acceptable, such as "WASN'T that a fine movie?" or "WHO is coming over this afternoon?" An attorney whose tics include "funny finger movements" might

hide his hands under the table or in his coat pocket, while others curl their toes inside their shoes where no one can see the movements.

Knowledge is Power: Getting a Diagnosis

If you're reading this, it may be that you've never been diagnosed with TS, and yet you've had motor and vocal tics for as long as you can remember. Actually, many of us never received a proper diagnosis until we brought our children in to be seen and the doctor mentioned casually, "Oh, by the way, you have Tourette's too!"

Many have seen four or five physicians before finally getting the diagnosis of TS. If you think you may have this disorder, begin with your internist or family physician, but then ask for a consultation with a neurologist. To find such a specialist in your area who is knowledgeable of TS, contact the Tourette Syndrome Association at 1-888-4Touret or e-mail ts@tsa-usa.org and ask for some recommendations. If you live in a community with a major university, you might contact the Department of Neurology or Psychiatry and ask them who specializes in Tourette Syndrome. Remember that many physicians still are not aware of the symptoms of TS or how to make the diagnosis. Many doctors still believe that coprolalia (involuntary inappropriate verbal outbursts) is necessary for the diagnosis. It isn't. Actually, only about 10-15 percent of those with TS develop this type of vocalization. Don't get discouraged; get help.

Social Relationships

For children with TS, the major struggle centers on their experiences with peers (and teachers) at school. When you're an adult, however, the focus is primarily on social relationships and work issues.

While most people enter adulthood armed with social skills acquired and honed during childhood and adolescence including a sense of teamwork learned on the playing field and in the classroom, you may have missed some of that socialization as you struggled with

learning and motor coordination problems, behavioral difficulties, rages, tantrums, and those embarrassing tics. Kids tend to be brutal when someone is different, and you may have coped by pulling away from others, preferring solitary pursuits. Some people may have chosen to become the class clown.

But now, as an adult, you have the opportunity to start over. It's likely that your tics have lessened since childhood or that you've learned to mask them so they aren't so obvious. It's time to let down those lines of defense you built to get you through your younger years and take the chance of stepping into adult relationships.

It's important to realize that often it isn't the actual tics that may worry a relationship. Instead, it's the other aspects that may tag along with TS, such as obsessive-compulsive behavior, anger outbursts, or impulsivity that can damage it.

Question: What can I do about feeling lonely?

Answer: Realize that you're not alone when it comes to loneliness. Whether they have TS or not, most people have felt alone at some or, more likely, many times in their lives. But you can do something to overcome this emotion. Reach out to others. Becoming a volunteer and helping others is a wonderful way to battle a sense of loneliness. You not only shift the focus from yourself to another person, but you may meet other people by volunteering. Working at a food kitchen, building a home for Habitat for Humanity, helping at a children's hospital or a retirement home, or delivering food to shut-ins through Meals on Wheels may quickly dissipate your sense of loneliness. It may seem difficult at first, but once you reach out to others you'll be amazed at how much better you feel and how many wonderful people you can meet. Interacting with others also gives you the opportunity to educate other people about Tourette Syndrome.

Many battle loneliness by getting a pet to keep them company. Although having a pet is an extra responsibility, you do meet a lot of people when you're walking your dog, taking the cat to the veterinarian, or heading back to the fish store to restock your aquarium.

But if you find your sense of loneliness is leading you into depression, contact your physician or a mental health professional. The symptoms of depression include an overwhelming and persistent sadness, an inability to experience pleasure, difficulty in sleeping or sleeping more than usual for you, decreased energy level, decreased or increased appetite, or recurrent thoughts of death. If you experience some or all of these symptoms do get professional help. The TSA maintains lists of counselors who can respond.

Don't wait, assuming the feelings will just go away. There are medications available as well as talk therapy that can help you.

Never turn to drugs or alcohol, believing that their effects can help you cope. Alcohol is a depressive drug and can make your depression worse. Drugs only create additional problems and reduce your control. Never be embarrassed to seek help for depression. It's so common that depression is often referred to as "the common cold of the mind." In addition to counseling sessions and medication, you'll find that exercise can help reduce your stress. Get involved in jogging, karate or kick boxing, tennis, swimming, or dance classes, anything that exercises your body and eases your stress level.

If you've ever thought of suicide as "the way out," don't brush off the feelings. Go to the nearest hospital or mental health clinic, see your pastor, rabbi, priest, or other religious leader, or contact a mental health professional. You are a unique person and the world needs you.

Question: How do I meet people?

Answer: There are many places to make social contacts. Some of them include church, synagogue, or other affiliated or community based groups, through volunteer activities, at classes or lectures, at the health club or dances and dance classes, at museums and art galleries or at sporting events (either as a participant or simply a fan), on single cruises and other vacations for singles.

Be proactive and invite your neighbors over for a barbecue, potluck supper, video with popcorn and hot dogs, or a swim party. Keep it casual and give them a chance to get to know you better. Be comfortable answering any questions they might have about your TS.

For those just beginning social relationships, your local or regional TSA Support Group offers a safe and supportive peer experience. By joining you can hear and share familiar stories, learn coping techniques, and strengthen a wavering self-image. Help with events such as TSA Awareness Day or fundraisers. Become an advocate for others with TS. (Contact the national TSA office to learn the nearest location of such a group. If there isn't one that is convenient for you, start one!)

Don't feel you're "odd man out" just because you're single. Get comfortable with yourself and learn to like and accept yourself as you are. Focus on your good points, rather than your weaknesses. Remember that no one is perfect! Stop looking for the perfect person as well. Sol Gordon, Ph.D. and I stress this point in our book, *Another Chance for Love* (Adams Media, Inc.) "Look for friendship first." Why is that? Because when we look for friendships, we're much more accepting of

human imperfections. While the goal for a potential spouse may be the tall, dark, and handsome male or the thin, blonde, and beautiful female, we may be more apt to make allowances in our friendships and then find to our surprise that the "simple" friendship develops into something more than a mere friendship.

Question: What should I tell someone I meet in a social relationship?

Answer: The truth. If your tics are obvious, you probably should tell the person right away. It may be tempting to pretend that your constant sniffing is from a sinus problem or a head cold, but if that tic changes (as they often do) and becomes an eye blink, hoot, shoulder twitch, or something else more obvious, your new friend or date will wonder why you weren't honest from the outset. If you have the compulsion to touch people or things, count steps or chairs, or echo what the other person is saying, try to find the humor in those situations. Be matter of fact, answer any questions the other person might have, and then enjoy his or her companionship.

Question: What about intimacy?

Answer: Physical intimacy is an important part of an adult's life. Don't let your TS stand in the way of a fulfilling sex life. Unfortunately, for many people it's difficult to discuss sexual problems, even with their physicians. This may be largely because many doctors appear uncomfortable talking about sexual matters. Nevertheless, if there are areas of concern, you should talk about them with your partner, a knowledgeable physician, a therapist, or contact the American Association of Sex Educators, Counselors, and Therapists (AASECT). The latter is an association of certified professionals who have been trained in the field of sex counseling. For the names of qualified sex therapists in your state or province, contact the American Association of Sex Educators, Counselors, and Therapists (AASECT), PO Box 5488, Richmond, Virginia 23220-0488, 319-895-8407. You also can look them up on the Web at <http://aasect@aasect.org>. As this is only a referral agency, do not send a letter describing your particular problem.

Remember that sexual intimacy is only one aspect of a relationship, albeit an important part. If your medication's side effects cause a decreased sex drive or impotency, there are other ways to show love and tenderness without actually having sexual intercourse. Hugging, caressing, hand holding, old-fashioned necking, and other intimacies are all ways to give the gift of touch to someone for whom you care.

What Type of Job Is Right For You?

We know of people with Tourette Syndrome who are active in almost every type of employment, including the sports world, university professors and high school teachers, musicians, the military, real estate developers, disc jockeys, nurses, surgeons and family practitioners, journalists, truck drivers, insurance salesmen, and so on. The list is endless. The important point is to find something you enjoy doing and that has some flexibility, so you're not under a great deal of tension as that can make the tics worse.

Knowing yourself is important. If you don't like to follow instructions, look for positions where you have some autonomy, such as free lance artist, landscaper, sales, and so on. Select jobs that play to your strengths, not your weaknesses.

An excellent book to read is *What Color is Your Parachute?* By Richard Nelson Bolles. Originally published in 1970, it is revised annually and versions printed in 1990 and 1991 had a special section titled, "Job Hunting Tips for the So-Called Handicapped."

Another valuable resource is the TSA brochure entitled *Tourette Syndrome in the Workplace: Issues and Solutions* by Mitzi Waltz.

Thanks to computers, fax machines, scanners, modems, and other electronic magical devices, there are many nontraditional locations for work today. There also are shared jobs, where two people divide up the work for one position, and flextime, where it doesn't matter if you punch a time-clock, as long as you get the work done. That means you could do your job in the evening, on weekends, to suit your personal schedule, rather than have a typical 9-5 job.

Working is important because it marks us as an adult, and contributes greatly to our self-confidence and self-esteem. But if your symptoms are so severe that you cannot hold down a job, don't think that gives you an excuse to become a couch potato. Again, consider volunteering and making a difference in someone else's life. You will not only feel better about yourself, but you'll meet people and may even discover skills you never knew you had. These activities could well lead you into a paying job at some point. But the important thing to remember is that you'll be helping another person and by giving, will receive much pleasure in return.

Know Your Employment Rights

As part of the Rehabilitation Act of 1973, Congress passed Section 504, the first federal civil rights law protecting the rights of individuals with handicaps. It provides that "no otherwise qualified individual with handicaps in the United States...shall, solely by reason of...handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."

Agencies, such as schools, libraries, and other state providers receiving Federal money could lose their funding if they do not abide by this regulation. Another important regulation to know about is the Americans with Disabilities Act of 1990 (ADA) that makes it unlawful to discriminate in employment against an otherwise qualified individual with a disability. The operative word, of course, is "qualified." What this means is that if your ability, training, and education are comparable or superior to that of other applicants, they can't be hired instead of you solely because you have TS and your tics and other symptoms might be bothersome to others. The employer is obligated to make accommodations for you, such as providing a computer if your motor tics make your handwriting illegible, or moving your desk so that you're not distracted. For more information on what these laws mean for you as an employee, read Chapter 20, "Knowing Your Employment Rights" in *Living with Tourette Syndrome* by Elaine Fantle Shimberg, (ISBN 0-684-81160-X) or contact the TSA. Remember that the Americans with Disabilities Act (ADA) offers you the following "Bill of Rights:"

- The right not to be discriminated against on the basis of being regarded as a person with a disability.
- The right to be judged on your own merits.
- The right not to be screened out of employment on the basis of a disability.
- The right to reveal to an employer a disabling condition without being discriminated against.
- The right to be tested fairly as an applicant for a job.
- The right to request and be provided with reasonable accommodations that are not an undue hardship on an employer.
- The right not to be disqualified in employment based on the inability to perform nonessential job functions.

- The right not to be limited, segregated, or classified as a person with a disability.
- The right not to be asked about a disabling condition.

Should You Tell The Boss?

Despite the above ADA Bill of Rights, many people with mild symptoms hesitate to reveal that they have TS. Yet the majority of those interviewed suggested, "You might as well tell as employers are required to provide reasonable accommodation only for the physical and mental limitations of qualified individuals with disabilities of which they *are aware*." If you don't disclose beforehand, how can they make the accommodation?

The best way to inform a prospective employer is to be very matter of fact. Offer an information sheet with pertinent questions and answers or one of the TSA brochures. Say something like, "The tics you see are symptoms of a neurological disorder I have called Tourette Syndrome. They are involuntary, but they don't interfere with my ability to perform this job. I'll be happy to answer any of your questions." Chances are, there won't be many.

Question: How do I handle my coworkers?

Answer: Keep a sense of humor. You may not be able to change how others may feel or react to you, but looking at the funny side of things can make you feel better. Also, try to avoid becoming over-tired. While it may be tempting to work over-time to earn extra money, fatigue can increase your tics and make it more difficult to keep your temper. Let your coworkers get to know you. Chances are they may not have known anyone else with Tourette Syndrome, so take this opportunity for you to educate them and to assure them that TS isn't "catching."

Symptoms Don't Go Away Just Because You're Grown

It would be nice to think you outgrow TS symptoms as you mature, but it doesn't always happen that way. Many do find their tics lessen to some degree as they get older, and some lucky ones see them fade away except when they are fatigued or under stress. Other adults still struggle with the myriad of symptoms associated with having TS. Be sure your physician understands your disorder and is aware of the various medications that are available. If one isn't effective, you can work with your doctor to try something else. Your TSA has a list of physicians who are familiar with TS treatment; so contact them if you need a referral.

Sensory Sensitivities

Tactile

If you're among the numerous men who remember having to wear pajamas under your Bar Mitzvah or Confirmation woolen suit, chances are you still may have tactile sensitivity. What's more, it's likely you still don't wear wool sweaters next to your skin because it feels "itchy." You also may not like to get your hands dirty or to touch goopy substances such as glue or paste.

Sound

Noise may still bother you. If a co-worker plays a radio too loudly, ask nicely if he or she would lower the volume as it's hard for you to concentrate. If that doesn't work, request a change of desk location.

Visual Distraction

You may find it difficult to concentrate if you face a window or other people. If you're easily distracted by people walking by your desk, a bird landing on a nest on the tree outside your window, or clutter, turn your desk so you face a wall or put the stacks of paper and files on the floor or in a cabinet so you can't see them.

Marriage

There's no reason why you shouldn't consider getting married if you so choose. Many people with Tourette Syndrome are happily married and enjoy fulfilling relationships. By the time you're thinking about marrying someone, your significant other should be used to your tics and other TS symptoms. Remember that one of the most important criteria for success in a marriage is open communication. Start sharing your feelings long before you book the wedding reception hall!

What About Kids?

Because TS is inherited, many people are concerned about having children for fear of having a child with TS. While there is a genetic basis for TS, there are some who have it with seemingly no family history of tics of any kind.

As noted in the TSA booklet *The Genetics of Tourette Syndrome*, "the genetic vulnerability to TS is transmitted from one (or both) gene-carrying parent to the male or female offspring. The precise expression and severity differ from one generation to another. That means if one parent has TS or is a TS gene carrier, there is about a 50 percent chance that each child born to that couple

may inherit the genetic vulnerability for a tic spectrum disorder."

However, remember that not every child who inherits the genetic vulnerability for TS will exhibit symptoms. With that knowledge, should you go ahead and have children? It's strictly a personal decision. The TSA brochure *The Genetics of Tourette Syndrome: Who it Affects and How it Occurs in Families* addresses many common questions on TS and Genetics.

Housing

You may wonder why housing is included in this brochure for adults. It's because having your own home (away from that of your family) is important. It means that you are an independent adult and making your way in the world.

In the booklet, "Guide to Housing for Adults with Tourette Syndrome," the TSA suggests finding housing in a neighborhood that is partly commercial. In this way traffic sounds and noises from the street prevent your neighbors from hearing your vocal tics. Choose an apartment with as few common walls as possible, such as an end or corner unit. Carpeting, drapery, wall-covering, and upholstered furniture all help to absorb sound as well.

If your symptoms are noticeable, consider telling your neighbors about TS, either face-to-face or in written form. If they don't understand your behavior, they may be fearful, especially in today's nervous world. Educate the people you do business with—your hair stylist, grocery, health club, bus drivers, etc. Once they understand, they can explain any unusual behavior to others. If it helps, make up a card that you can hand out to others briefly explaining what TS is, your specific tics, and your TS related behavior. Or, ask for "medical ID cards" from TSA.

You're a Big Kid Now . . . And in Control

Yes, now that you're an adult, you really can be more in control of your life. TS may still be with you, but you can explain, educate, and yes, even learn to laugh at yourself and in doing so, defuse those same issues that became problems when you were a child or adolescent. Take pride in your accomplishments, and don't dwell on things that you don't do well. Everyone has strong points and weak ones, so focus on your successes. In 1952 Norman Vincent Peale wrote about the power of positive thinking. His book has been printed in 15 languages, sold 7 million copies, and is still in print,

so there must be something to this positive thinking. Indeed, there is. Talk to yourself and be sure that the messages you give yourself are positive ones. Boost yourself (and your self-esteem) as you would a good friend.

While this brochure can't give you all the answers, hopefully it has empowered you to deal with situations as they arise and to have confidence in yourself as a productive, desirable, and interesting adult.

Good luck!

THE AUTHOR

Elaine Fantle Shimberg has three children with TS. She is a medical writer, author of ten books including *Strokes: What Families Should Know*, *Depression: What Families Should Know*, *Gifts of Time* (written with Fred J. Epstein, M.D., NYU Medical Center) and *Relief of IBS: Irritable Bowel Syndrome*. Mrs. Shimberg has a B.A. in speech, an M.A. in health and human services, and is a past member of TSA's national Board of Directors. She is also the author of the TSA publications, *When Your Grandchild Has TS* and *Divorce, Tourette Syndrome and the Family*.

This paper offers a discussion on living with Tourette Syndrome for general information purposes only. It is not intended as a substitute for medical, psychological, legal or other professional advice. Please consult with a professional provider relevant to your individual matter(s).

TSA has made every effort to consult with leading practitioners in the development of this booklet. It is intended to provide information about medications currently in use for TS treatment. Readers are cautioned against taking and/or changing any medications based on this information without first consulting a physician.

Visit "Living with TS" at <http://tsa-usa.org/aPeople/LivingWithTS/LivingTS.htm>
Free articles cover topics including Exercise and Sports, Avoiding Medical and Alternative Health Scams, Getting Older, Airline Travel, Dating, Ticking in Public, Military Service, Benefits, College, Self Advocacy, Health Insurance Issues, and TS and the ADA.

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Available in our Online Store (<http://store.tsa-usa.org/>) for a nominal charge are publications such as *Getting Into College - TSA's Complete Guide to the Applications & Admissions Process* (Publication #E110 and downloadable Publication #E110DD), and *TS in the Workplace: Issues & Solutions* (Publication #A114, and downloadable Publication #A114DD). An up-to-date Catalog of Publications and Videos may be obtained by going to TSA's Online Store, and clicking on the "Download Catalog" button on the left of the screen, or calling TSA at 718-224-299, Ext.231.

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Free Online Videos

Mike Higgins: Overcoming the Odds (approx. 5 minutes) – an extraordinary individual with Tourette Syndrome; and Paul Devore on Self Esteem – an inspiring practical video, giving guiding principals (with a downloadable transcript). For a listing of these and all TSA Free online videos go to: http://tsa-usa.org/aabout_tsa/videos.html



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Self Advocacy

A Short Guide for Adults with TS

by Mitzi Waltz

When you use the health care system, try to get benefits, or assert your rights at college, work, and other parts of your life, you've got to use all of your persuasive power. It's not easy, is it? Most of these systems are highly resistant to "square pegs"—if you can't advocate for yourself effectively, they'll try to squeeze you into the proverbial round hole regardless of whether you fit.

Self-advocacy, as the term indicates, starts within you: you've got to believe that you deserve equal treatment, that having TS does not make you worth less than anyone else. **Letting go of self-defeating attitudes** goes a long way towards giving you confidence to make a change. **Identify your greatest strengths first**, as these can be used to compensate for areas where you often encounter difficulty.

Good self-advocates have taken the time to think through what their preferences are when it comes to education, career plans, health care choices and the rest. When you know what you want, it's much harder for someone else to push you in an unwelcome direction.

Of course, these preferences have to be based on knowledge, so **one of the first skills for a budding self-advocate to work on is research**. You need to know as much about the system you plan to navigate as possible. For example, if your target is improving your career prospects, you'll need to find out what kinds of jobs might suit your style and interests, how you can gain the needed skills and qualifications, and what barriers you might encounter along the way. You might need to come up with ways to deflect illegal job interview questions, for instance, or learn how to get the support you need to succeed as a college student.

Obviously, **you can't find all of this information on your own**, especially since much of it will relate to either legal issues or the internal procedures of agencies or employers. Your state TSA chapter is likely to have quite a few facts on file, and being a member of a local support group can do wonders for both your self-confidence and your knowledge base.

Your next step is actually **putting it all into action**. Many organizations are accustomed to clients and customers who don't speak up for themselves, so don't be surprised if you encounter some resistance. On the other hand, **your goal is to succeed, not to "win"**, so make sure you don't approach things in a confrontational way. **When you have to work within a system to get what you need or want, success will almost always require cooperation and even, occasionally, compromise.**

Luckily, **many organizations offer self-advocacy training** to help you build your skills. These are usually short courses that start with a bit of "consciousness raising," move on to legal basics, and then help you apply what you've learned to either hypothetical or real-life situations.

If you're interested in taking a self-advocacy course, the best place to start your search is probably your state Protection and Advocacy (P&A) Center or Client Assistant Program (CAP.) These centers have a Federal mandate to protect the legal rights of people with disabilities, including Tourette Syndrome. Helping people become good self-advocates is part of their mandate, along with

providing legal advice and even representation when it's needed. You can find contact details for the closest P&A or CAP center at <http://www.napas.org/>

Another excellent resource, the National Mental Health Consumers' Clearinghouse at <http://www.mhselfhelp.org/training/index.php>, is an umbrella organization that offers its "Freedom Self-Advocacy Curriculum" for use by a variety of disability-related groups. You can have a look at its materials online: they'll give you a good idea of what self-advocacy is all about.

Finally, keep in mind that ***sometimes self-advocacy is not enough***. When your legal rights have been violated in a serious way and your response is not greeted with respect, contact your state's P&A Center or another legal representative for professional advice. If a problem is affecting not just you but people with Tourette syndrome or disabilities in general, an effective campaign is more likely to be a group action. In cases like these, the TSA and more general disability organizations can be good resources for discussing ideas and developing responses.

GETTING OLDER WITH TS

by *Mitzi Waltz*

Tourette Syndrome usually starts in childhood and gradually becomes less noticeable in adulthood. However, a significant group of people with TS go through their 20's and 30's waiting for the promised improvement that never comes. Often, hitting 40 or 50 marks the turning point.

For those still coping with TS in later life, here's an outline of some challenges you may face—and some ways of dealing with them. **ALWAYS CONSULT WITH YOUR PHYSICIAN BEFORE UNDERTAKING LIFESTYLE OR MEDICAL CHANGES.**

- **Medication after-effects.** It's important to review your medications now and then with your doctor. Long-term use of neuroleptics is sometimes associated with side effects, including the movement disorder tardive dyskinesia, hypoglycemia, weight gain and diabetes. These and other medications can also affect heart and liver function. Your doctor can help you learn the "early warning signs" for tardive dyskinesia, and alternating between different meds or taking an occasional "medication holiday" can help to prevent it. **IT IS ADVISABLE TO CHECK WITH YOUR PHYSICIAN REGARDING ANY CHANGES IN MEDICATION REGIMEN.** Make sure tests for hypoglycemia/diabetes, and for heart and liver function, are part of your annual checkup. These simple steps should turn up any signs of trouble while it's still reversible.
- **Health changes.** Almost everyone has some new ailments in later life, such as arthritis, back pain, or Parkinson's disease. These have nothing to do with Tourette Syndrome, but there may be clashes between medications for other health problems and medication for tics. Check package inserts, and make sure your doctor is alert to the situation. It can be harder to cope with pain and soreness from ticcing as you get older, too. Complementary approaches like Tai Chi and Pilates exercises can give you pain relief and increased flexibility. Fitness centers, alternative health providers, and day programs for older adults are good resources for finding out what's available near you. **CHECK WITH YOUR PHYSICIAN BEFORE UNDERTAKING ANY PROGRAMS OR APPROACHES.**
- **New issues.** Workplace and parenting stresses tend to diminish as you get older, but fresh stresses (such as health worries) can have a negative impact on your TS symptoms, or activate problems like depression, anxiety or obsessive-compulsive disorder. OCD is a particular problem for some older people with TS, especially if obsessive-compulsive behaviors have become entrenched over the years. New treatments, including more recent drugs and developments in cognitive behavioral therapy, are definitely worth trying—even if past efforts have been unsuccessful. Discuss possible new treatments with your provider.
- **Getting past the legacy of discrimination.** Don't let the past drag you down. Although even 50 or 60 years later, childhood bullying, school failure, and workplace discrimination can affect your circumstances, it's never too late to try on new, assertive attitudes. One of the best parts about being older is that people actually take you seriously, so use that fact to join in campaigns for changes that will improve your life, and help the next generation as well.
- **Avoiding social isolation.** Thanks to myths about TS and some people's insistence on conformity, it's not uncommon for people with TS to experience periods of social isolation. Others remove themselves from social situations in fear of disapproval, or because it's simply exhausting to have to suppress your tics for hours. Even if you haven't before, do seek out the company and support of other adults with TS via your local TSA branch. You'll find resources there to help you become more comfortable in other social situations, too. Take positive steps to stay in the social swing, from joining community groups to signing up for group travel or adult education classes.

Sadly, some older adults with or without TS face harassment, intimidation or physical assault in their communities. Don't suffer in silence—report these crimes. The perpetrators may be in “double trouble,” as their actions can fall under state or Federal hate crimes legislation.

- **Retirement and financial issues.** If you do not have an unbroken work history, it may affect your financial planning for retirement. Older people with TS can also face high premiums for disability, personal liability, and life insurance. As early as you can, check to see if a nearby Independent Living Center (see <http://www.virtualcil.net/cils/>) or a local disability group offers help with financial planning. If free help isn't available, see an independent financial advisor. The National Association of Personal Financial Advisors (<http://www.napfa.org/>) provides a listing of professionals who work on a fee-only basis; avoid “financial advisors” who have an interest in selling you investments or insurance. Also, check to make sure your Social Security eligibility is maintained—you may need to make voluntary contributions during periods of unemployment to avoid loss of benefits. See a local Social Security Administration office or the SSA Web site (<http://www.ssa.gov>) for complete details.
- **Long-term care.** An advance directive and providing concise, accurate information about TS to long-term care staff are important strategies for ensuring appropriate treatment and avoiding abuse in residential care. A lawyer can help with advance directives. The National Long Term Care Ombudsman Resource Center (<http://www.ltombudsman.org/>) call tell you where to go if you have concerns about your own care or someone else's.

Young people with TS are usually told that their symptoms will lessen once they reach adulthood, and for most that's the case. But even if yours don't, years of persevering will have made you truly older and wiser, more capable of coping with any challenges that come your way. The key to handling the changes is taking charge of your health, your relationships, your leisure time, and your finances.

TICGING IN PUBLIC

8 Smart Ways to Deal with It

by *Mitzi Waltz*

1. Medical ID Card/Bracelet

When you were a kid, your mother might have carried one of those medical identification cards that the Tourette Syndrome Association sells. Remember those? Some stranger would make a rude remark, or you'd be having a visible/audible tic in the grocery store, and mom would flash the card. It might have helped you both in some situations.

If your tics are quite severe, one of these cards in your wallet is probably still a good idea, just in case someone seriously misinterprets your movements or sounds. It's not for flashing at random strangers, though (and you might prefer a Medic-Alert style bracelet or pendant for more difficult situations).

For your public outings, we suggest seven more methods for coping with tics that won't stay in the closet when you're out and about:

2. Don't isolate yourself

It's tempting, especially if you get nasty remarks and curious looks, but you've got as much right to enjoy public spaces and places as anyone else. In totally public venues like the local library, the swimming pool, the shopping mall, or the sidewalk, don't worry about doing anything special. These places belong to everyone, and that includes you. Some "public" places are a bit different, because other people come to them with certain expectations: upscale restaurants, the opera, that sort of thing. For these rare exceptions, see below.

3. Bring something attention-absorbing

When your mind is totally focussed, your tics tend to recede. Waiting around in a public place might cause tics to come to the forefront. Always carry a book of really hard crosswords, number puzzles, a hand-held computer game, needlework, sketchbook, an iPod with the ultimate party mix, or something similarly engrossing, and let yourself really get absorbed by it. Not only are you less likely to tic, but you won't even sense it if you do, and you won't observe any stares from other patrons either.

4. Bring a friend

If you're enjoying their company and they're enjoying yours, it will put strangers around you at ease. They may notice your tics, but they'll also notice that you're obviously a normal guy or gal with friends who like you. It's an automatic icebreaker.

5. Be prepared

Think about your current tics, and how you might minimize both your own discomfort and others' potential reaction. For a spitting tic, bring a handkerchief so you can be discreet about it. If you're sniffing loudly, try a bit of Vick's VapoRub or similar strong-smelling ointment under your nose -- it will change the sensation, quite possibly short circuiting the tic for a while. If you have complex tics

that slow you up, allow extra time to get into and out of events. If you find that you're better relaxed after an hour at the gym or yoga class, schedule your life accordingly. And so on...

6. Prepare others

For events where the noise level might not be high enough to camouflage vocal tics, contact the venue in advance to see if they can suggest a solution. Perhaps a private box can be arranged (and if it's a disability accommodation, there really shouldn't be any extra cost to you...). Many movie theatres now have "VIP Seating" for people who like to talk and canoodle during movies, and "Cry Rooms" for people who want to bring babies. These facilities can be helpful for you too.

7. Frame your response

If someone goes out of his way to be rude, use your judgement, but don't be shy about defending your rights. You can reply directly with an explanation, complain to the management of the venue, or take your business elsewhere. The only thing you shouldn't do is take it personally. You can't control your tics, but you can raise the level of the dialog, and, just maybe, add to someone's knowledge.

8. Seek opportunities

Look for places where you can really let go: if you're a (young?) rocker, head for loud clubs, rock concerts, that sort of thing. Other activities to explore include running, skiing, swing dancing, swimming, bicycling---all provide wonderful energy outlets. (For quieter fun times, there are always TSA Conferences and events).

Moving Out and Moving Up!

by *Mitzi Waltz*

It's that time. You're getting ready to make the big move—out of your parents' house and into your own place. As a person with TS, what do you need to know?

The first thing is that becoming more independent is great, but it isn't easy. Stacey, 24, says that just getting up the courage to do it was her main hurdle: "I was teased a lot at school. It made me really shy. Home was the one place where I could be sure nobody would say anything about my Tourette's so I just didn't want to go, really."

From feeling safe where you are to fearing what future roommates might say about your tics, there are a million reasons for inertia to set in. In fact, research into why it takes some young people longer to launch has pinpointed very close relationships with parents and feeling insecure as top reasons for living in the parental home longer than usual.¹

The keys to success seem to be having one or more strong relationships outside your family, and having a clear plan that takes potential problems into account. So if inertia is keeping you glued to your childhood bedroom, cultivate an independent social life now, while saving money and making a plan:

Step 1: Make a realistic budget.

Step 2: Decide whether you'll be happier living on your own or with roommates.

Step 3: Find your new space and move in.

Budget Blues

You will almost surely need a deposit, and first and last month's rent, to move in. In some areas you may need more (for example, nonrefundable "key money" is a common, though illegal, request in New York City).

Your budget must also cover utilities, food, and all those not-so-optional "extras" like your cellphone bill, internet, going out and health insurance. You may find there's a trade-off between having a nice place and being able to afford a car. Check out the cost of a monthly bus pass and make sure you can get to everywhere essential by bus, bike or walking from the neighborhoods you're considering before making that choice, however.

You'll also want to set aside cash for picking up some essentials, like dishes, silverware, and a few bits of furniture. Don't go nuts though, start with the bare minimum and build up from there. Ask friends and relations what lurks in their garages and attics, hit the Goodwill, and check out resources for absolutely free stuff like your local Freecycle (<http://www.freecycle.org/>) group.

Roommates or Not?

Making a budget invariably makes you consider sharing costs. For Jakob, 28, roommates have been the best and worst part of moving out. "I found my first place from a card posted at college, these two guys looking for a roommate," he says. "I soon found out why, they were total stoners who never cleaned the place and had obnoxious friends who hung out all the time. The place I

have now is the exact opposite. I live with a guy I know from work and his girlfriend. We all get along, get the housework done. It's not 'Friends,' but it's friendly."

If your TS is obvious, you might as well tell prospective roommates right away so you can answer any questions. Better to be rejected before you move in than to find out you're living with a prejudiced or abusive person. If it's not so obvious, it's up to you. Jakob adds: "One of the nice things about my current roommates is that they already knew. It's just never been an issue."

Finding a Place

Often the very best deals are through friends (or friends of friends) so let everyone know you're looking. Also walk or drive around the area you want to live in most, looking for "For Rent" signs or posters up in local shops and coffeehouses.

Not as many landlords use newspapers to advertise vacancies these days, the real action is on Web sites like Craigslist (<http://www.craigslist.org>). But watch out for scammers—never pay money unless you have seen the apartment, met the landlord, and signed a contract. And never, ever send money via Western Union or another wire service; reputable landlords do not use these.

It's not legal to refuse to rent to you because you have TS. However, a landlord can evict you if your tics include disruptive or destructive behavior that affects other tenants or damages the property. So if you know that in the past you have had such a tic (frequent loud whooping noises, for example, or a tendency to hit or kick doors) consider ways to ensure it's never a problem for others.

When you find a place, do a walk-through with your camera or camera-phone and put the pictures somewhere online, like Photobucket (<http://photobucket.com>), where they won't get lost or deleted. Make sure they are "time-stamped" to prevent any confusion if there is a dispute.

Most important of all: get your lease in writing.

Stay Organized

Keep to your budget by having a place for paying and filing bills—a box or folder will do. One mom of a young adult with TS we know, has a smart tip for keeping other crucial info handy. "Save in your cellphone the names and phone numbers of doctors seen in the recent past," she says. "Use the 'notes' function to list current medications taken and dosage instructions, as well as any drug allergies."

Thousands of young adults with TS leave home successfully every year. With a bit of planning and luck, you can do it too!

References

- 1 Seiffge-Krenke, Inge (2006) "Leaving home or still in the nest? Parent-child relationships and psychological health as predictors of different leaving home patterns," *Developmental Psychology*, 42 (5): 864-876.

Exercise, Sports and Tourette Syndrome

by *Mitzi Waltz*

Soccer star Tim Howard, baseball MVP Jim Eisenreich, and NASCAR driver Steve Wallace have something in common. You probably already know that it's Tourette syndrome. There's more than a diagnosis connecting these men, however. TS may very well have been a driver in their sporting success, not an impediment to overcome.

That's because a bit of obsessiveness, repetition and high energy are nothing but helpful for the would-be sports champion. Indeed, neurologist Oliver Sacks has suggested that extraordinarily quick reflexes may be a beneficial core feature of TS¹—and obviously this would be an advantage for anyone participating in sports.

In return for their hard work, sports gave these champs many benefits, including self-discipline, better health, and (important for young people who are often the target of cruel taunts) a way to show up those who teased them for ticcing.

Better Health and Fitness

So what is known about the potential benefits of exercise programs and participation in sports for people with TS? Only one thing is certain: your mileage may vary. There is no study proving that a particular form of exercise will reduce tics or improve TS-related symptoms for everyone, although there are many reports of people finding personal benefit from a wide variety of physical pursuits. For some, tic reduction is among these.

Many people find that sports or forms of exercise that are both mentally and physically involving can be especially helpful. The kind of sports that keep you constantly paying attention and moving—obvious examples include ice hockey, soccer, squash and tennis—are more likely to fill the bill than those that easily allow the mind to wander or include periods where you are standing still until the action starts again.

Another way that exercise can be helpful is its power to reduce anxiety and the mental stress that causes it. As Barbara Moe has written, "one of the best and most helpful ways to relieve stress is exercise."² Librarian Josh Hanagarne took up weightlifting and found that learning to control his muscles really helped. "My symptoms didn't change," he said. "But the discipline I've picked up along the way makes everything seem bearable."³

Another important reason for exercise is the side effect of neuroleptic medications that everyone who takes them dreads most: weight gain. Research has shown that as part of a plan that also includes diet and behavioural therapy, exercise can help prevent and even roll back weight gain from medications like risperidone and olanzapine.⁴

As with anything that some people with TS find helpful, not everyone finds sports or exercise to be all they're cracked up to be. Overdoing it to the point of fatigue can make tics worse, pressure to perform well in competitive sports may increase stress, and a few people report that their tics actually increase when they do vigorous exercise. Finally, those with an additional diagnosis of OCD may find that their chosen activity becomes an obsession, and so may need to set personal limits on practice time.

Handling Difficult Situations

Assuming that you find a positive benefit from the sport or exercise of your choice, the only potential down side is dealing with unhelpful attitudes at the gym, in exercise classes, or on sports teams.

Different people handle situations in different ways. Here are two different approaches , each with its positives and drawbacks. Approaches that work for one person may or may not work for another.

It helps to be up front, says Lainie, 43, who has been attending yoga and aerobics classes at a community center for about eight years:

"I have vocal tics and because I have some health problems in addition to TS I haven't been able to take medication for a long time now. I met with the manager of the community center and explained that I really needed to be able to take these classes, and that I didn't want to anyone to be shocked or to stare if I ticced during a class. She talked to the instructors, who told the other students about my TS before I started. I still felt kind of funny the first couple times I made a noise but everyone has been supportive."

Jake, 21, says an "in your face" attitude has worked better for him. "I was teased mercilessly in high school football until I put on an act like I could care less," he says. "I insulted anybody back who got started. It may not be the 'nice' way but a lot of guys who play ball are just jerks really and being nice is not going to get you anywhere with them. If they find out something bothers you, they'll ride you til you're sick of it. My insults were funnier than theirs so I was able to turn it around."

Sometimes teasing is part of sports. However in all cases, one must take care to use humor appropriately so that indeed the best aspects of your personality are put forward. Only you can know whether, how and when to take this approach. You do not want use of humor to "backfire" or be seen as provocative when what you mean to do is assert yourself in a positive fashion.

Finally, although most of the examples in this article are of traditional sports, any activity that gets your heart pumping and your motor running can be helpful. Dancing, canoeing, rock-climbing, skateboarding, even "extreme sports" like parkour/freerunning, base jumping and skydiving can provide better fitness and a "legal high" that beats anything else on offer.

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¹ Sacks, Oliver (1985) *The Man Who Mistook His Wife for a Hat*. New York: Summit Books.

² Moe, Barbara (2000) *Coping With Tourette Syndrome and Tic Disorders*. New York: Rosen Publishing Group.

³ Hanagarne, Josh (2009) "Moving my body, saving a life," Xtreme Human Performance, 8 October. Online at: <http://extremehumanperformance.com/blog/moving-my-body-saving-a-life/> [Accessed 10 January 2010]

⁴ Vreeland, B., et al (2003) "A program for managing weight gain associated with atypical antipsychotics," *Psychiatric Services*, 54: 1115-1157.

DATING AND TS

by Mitzi Waltz

When it comes to meeting and dating, lots of people have something to hide – or, at least hope to reveal later on in a relationship. Tourette Syndrome may loom large in your mind, but it's "way down there" in the scheme of things – consider being "separated but not divorced", having previous entanglements with the law, having flunked out of college. Think of it this way - Everybody's got SOMETHING.

Get it "Out of the Way" Early

You don't need the added pressure of concealment—plus the more you try to hide tics, the worse they can get. Although you probably shouldn't introduce yourself with, "Hi, my name's Joel, and I have Tourette's," it's a good idea to clear the air early on. Suggestion: Take the opportunity offered the next time you tic. You can be sure he or she noticed, so you might say, "you know that twitchy thing I do? It's because I have Tourette Syndrome." After that you can provide as much or as little information as the person's reaction seems to require. A joke or two can come in handy as well.

Blurting

That very tic-like occurrence that happens when you feel compelled to say something completely inappropriate—is one of the most frequent worries that people with TS have on a date. It's a concern because it does happen sometimes. If this is one of your fears, it's a lot easier to explain before it actually happens than afterwards.

Symptom Substitution

is one strategy you can use if you currently have a tic that you fear might offend your date. Talk to a doctor or therapist who knows TS well about how to do this (basically, it involves finding an alternative behavior that satisfies the same urge). For example: say you have a nose-picking tic—there might be something else you could do with your finger when that urge comes on. With a bit of practice, you can avoid causing offense, even though it might not be possible to stop ticcing altogether.

Talk About It, Role Play

Many people with TS, especially those whose symptoms are more severe, worry about finding a partner to discuss these things with. The issue may be what you think about yourself, not how others see you. Childhood and adolescent experiences of being teased and bullied, can lower self-esteem. In one Canadian study¹, 40 percent of adults with TS reported problems in dating or making friends. For some, seeing a counsellor can help talk through your experiences, and perhaps help you role-play the things you worry about, like introducing yourself to someone new or telling a date about your TS.

Lower the Stress Level

Meeting new people is stressful for everyone, but the same things that work for others can work for you too. Find ways to be in low-stress situations with lots of potential partners. Instead of the high-anxiety bar and club scene, for example, you might try joining a martial arts class or taking a night class in a foreign language. Meeting someone with a shared interest reduces the stress level because you aren't literally "on the prowl," so there's less pressure to perform. Others swear by speed dating events, organised singles parties that include icebreaker games and such. And of

course, going out with a group of friends means you can check out the local venues but still have a great time if your pick up lines fall flat. Online dating is a possibility as well.

Play Your Strengths

Many people with TS have some advantages over others when it comes to dating – good verbal skills, quick minds and quick wit. You can probably charm anyone—just give yourself the chance. Try honing your “charm” skills with relatives, neighbors, barristas, even pets.

1 Champion, L.M., Fulton, W.A. and Shady, G.A. (1988) “Tourette Syndrome and Social Functioning in a Canadian population,” *Neuroscience and Biobehavioral Reviews*, Fall-Winter, 12 (3-4): pp. 255-25

Tourette Syndrome in The Workplace: Issues and Solutions

by Mitzi Waltz

Having a good job is about more than just paying the bills. It can also provide you with a sense of self-worth and identity. So finding and keeping work that you enjoy is important to anyone, including people with Tourette syndrome. Although people with a TS diagnosis may sometimes encounter barriers to employment, there are strategies that can make things easier. There are also laws to protect you from discrimination.

Preparing for Work

If you're about to enter the world of work for the first time, or if you're getting ready for a major career change, you're lucky. You have an opportunity to assess your interests, skills, and abilities, match them to the perfect job, and go after it.

It isn't always easy to be objective about yourself, or to see just how valuable your personal attributes might be to an employer. Talking to a friend, relative, or professional career counsellor can be really helpful. What you want to do is "inventory yourself": take a look at the best aspects of your personality, the subjects you got the highest grades in at school, and the hobbies and everyday activities you enjoy most. Concentrate on the positive—it's far easier to find a job that fits you than to fit yourself to a job.

You might consider trying a few adult education classes to check out various career possibilities in a low-stress atmosphere. Community colleges often offer "taster" classes that can introduce you to everything from working as a chef to high-tech pursuits. Talk to people you know about their jobs and try to imagine yourself in their place. If you can, visit several workplaces to get a first-hand view of what different jobs are like.

As you inventory yourself and try out some ideas about work, you'll find that while you have much to offer an employer. You may also uncover a few important "skill gaps" that can be easily filled. For example, if you notice that most of the jobs that interest you require computer skills or money-handling experience,

a short course or an internship at an appropriate company should be enough to prepare you to move forward.

Looking for Work

Once you've identified the kind of work that suits you best, it's time to find an employer who has that sort of job on offer. Want ads in the newspaper are only one possibility. Online job listings can give you leads, and employment agencies can also get you in touch. Make sure everyone around you knows that you're job-hunting, too—personal connections are always the easiest way to get inside information about openings.

Researching potential employers will give you another edge on the competition. Find out as much as you can about each potential employer you contact. This knowledge will make you stand out from other applicants, and it will also give you a list of topics to turn the conversation towards if things start getting uncomfortable at an interview.

Once you get an interview, use it to sell your abilities, skills, and talents. Practice answers to typical interview questions, and prepare some short "sales pitch" speeches that showcase your most positive attributes. Several popular books are available that list good answers for common interview questions. Personalize these little scripts, and ask a friend to critique your responses.

Consider taking some classes in interview techniques if your first few efforts go badly. Classes are available from private firms and from public agencies, such as state employment offices. If you are a student, your school may also offer help. These classes can help you learn to "read" interviewers better. They'll put you at ease, ensure that you come up with the right responses, and teach you how to handle curveball questions. Interview technique classes usually include lots of practice sessions, sometimes with your performance videotaped so you can judge it later. If you do take a class, ask the instructor to work with you specifically on how you can tackle questions about TS if they come up.

Think hard about the references you provide, too. If a potential employer has questions about how TS might affect your work, a stellar reference from someone who knows you and your symptoms well could make the difference. References can be from a former employer, but you may know a teacher, professor, or volunteer group member who can offer a more rounded and positive picture.

If you tend to get stressed out in interviews, you may have already experienced increased ticcing just when you wanted it least. Preparation should reduce your stress level, but learning and applying anti-stress tactics like breathing exercises or aromatherapy can also help.

You may be able to substitute an "invisible" tic to stave off a more diverting one until after the interview. For example, you might squeeze your knee under the table ten times instead of shrugging your shoulder. Tic substitution doesn't work for everyone, but if you can do it, it's handy in stressful situations.

To Tell or Not To Tell?

This is probably the biggest question most people with TS have going into an interview. It's a complicated issue, and the decision is up to you.

Under the Americans With Disabilities Act (ADA), you don't have to reveal anything about health problems or disabilities unless a prospective employer asks you directly, and the conditions under which you can be legitimately asked are fairly narrow. These conditions are:

- If the employer practices affirmative action for people with disabilities, it can ask (but not require) you to reveal that you have a disability on the application form. This may work in your favor.
- If your disability is obvious during the interview, you may be asked to explain how you would carry out actual job duties despite it. This question has to be specific to the requirements of the job you're applying for. For example, if you have an eye-rolling tic, an interviewer could ask whether it will affect your ability to read text on a computer screen if doing so is part of your job.
- If neither of these conditions is met and the interviewer asks anyway, you can choose to respond in several different ways. If you don't want to tell, here are some truthful responses that may work:

"Oh, I don't have any health problems that will make a difference on the job."

"That's kind of a personal question, and I'm not sure the answer would relate to the job specification."

"Why do you ask?" (This one can put the interviewer on the back foot, although it can also backfire.)

A response that deflects the question will work best if delivered with a smile, a joke, or a diversionary tactic that takes the conversation in another direction. Quickly segue into a pre-chosen question of your own, perhaps something that's tangentially related, such as "does your company have a health promotion program for employees?"

If you have decided that you will tell if asked, keep it short and positive. For example:

"Yes, I have Tourette Syndrome. But it doesn't affect my ability to [type, write, cook, etc.]"

"I've had Tourette Syndrome since I was [insert age here], so long I don't really think much about it anymore. It's just a part of me, like having [insert your color] eyes. Doesn't affect me much at work."

"Yes, I have Tourette Syndrome. Do you have any questions about whether it has affected me on previous jobs or at school?"

"Yes, I have Tourette Syndrome. At work it might affect me [name the way or ways]."

Alternatively, you may decide to bring up TS yourself. Perhaps you have a frequent, obvious tic or two, or something on your application (a stint as a volunteer group leader with a Tourette Syndrome support group, for example) offers a clue. Simply choose an appropriate moment in the interview to present the fact of your diagnosis in a brief, positive way, then try to move the interview on to how great you'll be in the job.

Pre-Employment Physicals and Testing

More and more companies are requiring people who have been offered a job to attend a pre-employment physical, at which questions about your health may be asked. These physicals are supposed to concern themselves solely with things that pertain to the job you have been offered.

Be careful about what you fill out, sign, and say at such physicals—especially if psychometric testing, "stress quizzes," or supposedly casual questions are used. For example, one "stress quiz" used by a major IT firm includes questions about "nervous tics," and the scores obtained are employed to decide whether an employee or prospective employee is overly prone to stress. As you know your tics are due to a neurological condition, checking "no" to such questions might be OK.

It is sometimes possible to get the physical waived with a letter from your doctor stating that you are in good physical health and able to perform the duties listed in the job specification.

Keeping Your Job

To create the best chance for workplace success, try to build in flexibility from the start. Think about what helps you get things done well and quickly when you're in charge. Does it help to slip away for a couple of minutes now and then to release your tics? If smokers get a "ciggie break" now and then, maybe you need a regular "tic break." You may be able to just take one, or you may need to discuss it with a line manager first.

What if you're feeling embarrassed about a tic? Whether they are already attracting notice or not, some tics (coprolalia, copropraxia, certain sounds and movements) can give the unenlightened the wrong impression of you as a person. The best defence is making sure people get to know the real you. Spend time talking with your coworkers when you aren't having obvious tics, if that's possible. Tell some jokes—humor can make light of what could otherwise be an uncomfortable situation. Make sure people know that you're a hard worker, conscientious, and kind. That gives your coworkers (and your boss) some important positives to weigh up against tics that they might see as negative.

If someone's actively rude, try discussing it. Maybe there's something you can do to diminish their discomfort. It might be information they need. It might even be an apology—although it can feel wrong to apologize for something you can't help doing. Maybe you could switch desks, or add a privacy screen. It is very hard for some people to be understanding. Try to think of their problem with understanding as a disability you're really glad you don't have. If despite your best efforts a co-worker or supervisor continues to give you a hard time simply because you have TS, talk to your company's Personnel department. Harassment is not something you have to put up with.

Some employees with TS may feel comfortable doing a sort of "in-service" on Tourette syndrome for their coworkers, especially if the Personnel Department in your company supports this approach. You could show a short film, give a talk about your experiences with TS, and answer questions. This out-front approach is not for everyone, of course, but for those with lots of confidence, it can clear the air fast.

Coping with Difficulties at Work

Many people with TS consider the quick-mindedness and ability to think "out of the box" that often accompany Tourette Syndrome to be a positive factor in their work lives.

That said, occasionally you may have a difficulty at work that derives from your TS. Here are a few that many people have experienced at one time or another:

- Fatigue and repetitive stress injury (RSI) from ticcing
- Hyperfocus: a tendency to focus on one topic or task to the detriment of others
- Medication side effects, particularly as some people with TS who have or want to have employment may feel pressured to take more or different medications to minimise symptoms, which can mean more side effects
- Distracting or embarrassing thoughts or actions
- Stress from having to suppress tics, or from coping with remarks from bosses and coworkers

Fatigue and repetitive stress injury (RSI) are two issues cited quite often. Sometimes fatigue is a medication issue, as many meds for TS and related conditions can have increased tiredness as a side effect. Talk to your doctor about medication changes, adjunct medications, and lifestyle changes that could boost your energy levels back to normal. If you are experiencing fatigue due to tiresome tics, this can also be a medication issue. Perhaps a different medication or different dose will help. Learning new movement patterns, getting regular massages, or trying other types of bodywork can also reduce the impact of painful tics.

As you probably know, medication changes can lead to new problems for awhile, such as gastrointestinal symptoms that keep you near the restroom or extra tiredness. If you aren't coping well, talk to a sympathetic person in Personnel about possibly changing your duties or schedule temporarily during these adjustment periods.

Avoid succumbing to pressure to make your TS completely invisible at work. Not only does suppression create unnecessary stress for you, overuse of medication can lead to further interference in the form of side effects.

Repetitive stress injuries can happen from any movement that is done over and over, whether it's a work task or a tic. Some people with TS may be particularly prone to RSIs on the job because of habitual posture and movement differences, which could make

using certain equipment or performing certain physical tasks harder than it should be.

Experts are available who can analyse movements and equipment to find solutions for RSIs.

Special devices are also available to ease the strain, such as wrist rests, arm guards, special chairs, and more. You can ask for this kind of help whether the problem is related to your TS or not. Often rest is the best remedy.

Many people with TS have eye tics, and this can lead to eye-tracking problems that affect reading or using a computer. Devices and techniques are available that can prevent this problem, too. For example, voice-activated computing and alternative data-entry systems or display systems may be useful.

What about tics that really do give offense to someone? So far, case law indicates that if someone complains about offensive words, racial slurs, or inappropriate gestures, having Tourette syndrome may not be considered an adequate explanation or defence and legal challenges continue. These are symptoms you can't hide, and they can't necessarily be medicated away, either. That can be hard for coworkers, employers, and customers to understand, especially if their knowledge of TS is sketchy.

Tics that are not offensive in of themselves must be accommodated by your employer. Those that could give offence require you to be proactive to prevent problems, with sympathetic assistance from your employer. For example, you may need to request reassignment to a role that doesn't include public contact, or contact with an easily offended coworker, until the symptoms in question subside.

Tourette Syndrome and the ADA

The ADA doesn't mention TS specifically, but it's supposed to cover any health condition that can "substantially limit" a life activity, including employment. So if you are turned down for work or fired because of your TS symptoms, you may be covered by the ADA.

You may also be covered by state disability discrimination laws, some of which are tougher than the ADA. For example, the ADA applies only to employers with at least 15 workers, but many state laws cover smaller companies.

What the ADA and similar state laws do is mandate equal access to work for people with disabilities. That means a potential employer should set aside your tics when considering your application, and an employer needs to accommodate your symptoms on the job. You must be otherwise qualified for the job you are applying for or doing, however.

Very few people with TS have brought employment cases under either the ADA or state disability laws, so there aren't many legal precedents to rely on just yet. People with TS should use proactive planning and other strategies rather than relying solely on the ADA and state disability laws.

Rather than focusing on the down side of having TS in the workplace, do as much as you can to put the spotlight on what's great about you: your quick wit, your sparkling personality, your ability to focus and yet keep several projects juggling at once, whatever it is that makes you a great person to work with. Let your light shine, and challenge the idea that having TS is necessarily a problem.

THE AUTHOR

Mitzi Waltz is a parent, journalist, and health researcher who has long been an active advocate for people with disabilities. She is the author of eight books on living with neurological conditions, including Tourette Syndrome, OCD, and autism. For more information about the author and her work, visit <http://www.mitziwaltz.com>

RESOURCES

Tourette Syndrome Association Inc.
42-40 Bell Blvd.
Bayside, NY 11361
(718) 224-2999
<http://tsa-usa.org>

The TSA offers advice, support, and sometimes legal pointers to people with Tourette Syndrome in employment or seeking work. It also has several publications that may be helpful.

Pre-Employment Screening and the ADA
http://www.tourettesyndrome.net/Files/pre_employment.htm

This Web site discusses what potential employers can ask about your health in an interview or in pre-employment screening to assess fitness for a job—and what they can't ask.

Regional Disability and Business Technical Centers
<http://www.adata.org/dbtac.html>
(800) 949-4232

These 10 centers, sponsored by the National Institute on Disability and Rehabilitation Research, can give you information on the ADA, technical assistance with adapting jobs to meet your needs (for example, help with RSI issues), and can advice for employers as well. Call or see the Web site to get in touch with the nearest center.

US Equal Employment Opportunity Commission
<http://www.eeoc.gov/>
(800) 669-4000

The EEOC provides information and help for all workers on a variety of discrimination issues, including disability. Its Web site includes reports, case descriptions, and the text of Federal laws.

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Interviewing and Tourette Syndrome

by Melinda Dunaway, TSA Birmingham Support Group Steering Committee

Job hunting! Interviews! Starting a new job! It can all be so stressful for anyone that is looking for work. Add a noticeable neurological disorder and you can double that stress. If you are one of the 12 million or so people in the U.S. looking for a job - you know that the job hunting process itself is a full-time job. If you have Tourette Syndrome - you have unique concerns to consider in this process.

There are basic interview tips for all interviewees such as

- 1) Always arrive 5-10 minutes prior to your interview
- 2) Research the company you are interviewing with and know as much as you can about their history, what they do and their culture & values (e.g., web site, articles or Annual Report.)
- 3) Dress for success
- 4) Make good eye contact
- 5) Prepare good questions to ask about the company and the specific job duties
- 6) Follow-up with a thank you card or email.

In addition to the basics, a person with Tourette Syndrome has so much more to prepare for. Anytime there is a situation that may be a distraction to the interviewer, it is best to address this during the interview so there will be no question or doubt in the interviewer's mind. You don't want to leave an interview and have the hiring manager wondering, 'why did this person roll his eyes at me repeatedly?'. If the interviewer is busy trying to figure out your tics, he may be unable to truly evaluate your experience and skills during an interview.

How do I approach this awkward moment in my interview? Honesty is the best policy. If your tics are not noticeable, then you probably have no reason to bring up your TS. If they are, you must address the situation.

If your tics are verbal or make it difficult to communicate over the phone, do most of your communication (prior to your interview) by email. The less time on the phone - the less time for your tics to be noticed. If phone calls are necessary and your tics are obvious on the call, you may have to address it over the phone. Your goal is to get the interview. Once you get in front of the hiring manager, he/she can get to know you and fairly evaluate your skills.

When you get the interview, it is your time to shine! In order to keep the tics from being a question in the interviewers mind, explain it early in the conversation. It may go something like this:

Interviewer: "Mrs. Jones, thank you for coming in today to meet with us about the Accounting Clerk position"

Candidate: "I appreciate your time and am very excited about this opportunity. I would like to let you know that during our meeting, you may notice that I move my head a lot and snap my jaw open. This is caused by a neurological condition I was born with called Tourette Syndrome. Have you heard of it? (Allow them time to respond and ask questions) My TS has never stopped me from accomplishing my goals or being a great employee. My TS will not affect my job performance."

As with any situation, once an individual has been made aware that you have Tourette Syndrome, the ball is in their court. It is up to them to decide whether or not to let that be a barrier. It is completely out of your control at this point. Do not waste your energy trying to persuade someone to accept you. If a potential employer, potential friend, or potential relationship of any nature cannot accept your TS, you do not need that person to be a part of your life. That is not the kind of relationships to strive for and not the kind of employer you would want to work for.

ny people have had successful careers with their TS in tow including teachers, surgeons, motivational speakers, ors, musicians, and athletes just to name a few. Remember to remain confident in your abilities and not let TS i from finding the job you were meant to be in.

linda is a local Technical Staffing Specialist helping people find employment for the past 10 years. As part of her , she coaches candidates on interviewing and making the best impression. Melinda is also the proud mother of 1 with Tourette Syndrome. Specific job hunting/interviewing questions can be emailed to Melinda at parent@yahoo.com.

19 Ways to Succeed on the Job with Adult ADHD

Staying organized at the job can be challenging for many ADHDers, but these workplace tips will help you get more done in less time.

Focus on One Thing Only

When sitting at your desk, keep only what you're working on in front of you. Place paper and future assignments in an inbox, drawer, or the credenza behind you, out of your line of sight. If your eyes keep jumping around when reading long documents, use a folder or a piece of construction paper to block out everything but the line you're reading.

Silence Your Inner Critic

Don't let perfectionism thwart your ability to get things done. Ask yourself how to make things quick and simple. Try bulleting items in memos or calling a coworker instead of e-mailing him.

Download Tasks to Paper

If a swarm of concerns is keeping you from attending to the task at hand, take five minutes to get things out of your head and on paper. Once these tasks are on paper and you no longer have to worry about remembering everything, you'll find it easier to focus on your current assignment.

Stay Focused in Meetings

> Confide in a friend who sits near you in business meetings. Ask him or her to tap you lightly on the shoulder if you appear to be zoning out.

> To fight off boredom in meetings, take a lot of notes. This not only helps you focus, but also provides an outlet for restlessness.

Activate Your Attention

Before tackling a boring task, do some physical exercise or a favorite activity. Walking up and down a few flights of stairs, doing a crossword puzzle, or listening to music for 15 minutes enhances your executive functioning, priming you for the work ahead.

Stick to a Game Plan

> Color-code papers and projects according to their priority. Place projects with impending deadlines in red folders, for example.

> Go through your in-basket several times a day. This keeps you from being sidetracked every time a new piece of information crosses your desk.

Put Time on Your Side

> People with ADD often have a poor sense of time. Instead of giving yourself all day to finish that report, give yourself two hours. Set an alarm or a computer alert to go off when time's up.

> Figure out the time of day when you are most productive and schedule your hardest tasks for that period.

Arrange—and Rearrange—Your Priorities

Each morning list your top 10 "to-do" items. This keeps you on track during the day. Write them on a white erasable board. If your priorities shift, you can re-juggle the list with the swipe of a paper towel.

Keep Your Work Space Tidy

Take 20 minutes every day to straighten up your work space, placing unwanted papers and junk mail in the shredding bin. This is the best way to avoid "buried desk" syndrome. If you wait to get organized later in the week, it will seem too overwhelming to tackle.

Start the Day Strong

If you have trouble getting to work on time or getting organized in the morning, start getting ready the night before. Lay out your clothes, fill the coffee pot, and prepare lunch before you go to bed. Create a "launch pad" by the door to place important items you will need, such as your car keys, cell phone, and purse.

Take Notes

- > People with ADD often have trouble remembering spoken instructions, so keep a written record of all requests. Write down any assignments your boss gives you.
- > Keep a carbonless message pad by your office phone. File one copy of the message with relevant project materials. The remaining pad becomes a "master list" of numbers and contacts.

Don't Let E-mail Control You

Do not check your e-mail first thing; it puts you in a "reactive" mode — allowing others to set your priorities. Instead, set your own priorities by scheduling all your tasks for the day. Schedule regular times for checking your e-mail, rather than allowing it to interrupt and drive the focus of your day.

Block Out Noise and Limit Interruptions

ADHDers are often distracted by the smallest sound. If you are taken off task by office conversations or noise around the office, use a white noise machine, noise-canceling headphones, or listen to music to block it out. Limit interruptions by hanging a small sign on your door or cubicle that says "Busy working on a big project. Will be available at 2."

Get on the Same Page

If you have trouble remembering details from conversations with your boss about projects, ask her to send a detailed follow-up e-mail. After being given instructions, repeat them back to make sure you are both on the same page. Ask for specific deadlines, so you know what is being asked is really doable.

Manage Distractions

Work on major projects early, late, or on weekends when the office is quiet. If you work in an open office, or if your office has too many distractions, see if you can arrange for a quieter workspace—a file or storage room, say—or ask about working from home.

Get Ahead of Things

ADHDers often have trouble keeping track of details and oral instructions. For big events, such as conferences, find out as much as you can ahead of time. Ask for a list of conference participants, a schedule of events, and any resources pages that will be given out during presentations. Review these before the event starts.

Ask – Discreetly – for Help

You can ask for assistance without bringing up your ADHD. If you do ask for help, be prepared to give a business justification for it. "By working from home one day a week, I'll be able to finish those reports two weeks before the deadline" is preferable to "There are too many distractions in the office, so I need to work from home."

Seek Outside Help

Get an ADHD coach to help you develop a weekly to-do list, or to call you at work to make sure you stay on task. Have a professional organizer sort your office papers and files on a weekend when no one else is in the office.

Pump Up Flagging Attention

> Feel the urge to fidget at your desk? Clicking a pen, playing with your hair, or sucking on a hard candy will help you pay attention.

> If you have the need to move, find a place to stand or walk while you work. Take your work to an empty conference room or stand at the counter in the office kitchen.

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The Procrastinator's Guide to Getting Things Done

Do you put off starting important projects until it becomes painful? Whether you're terrified of letting someone down or you just can't get your thoughts in order, here are straightforward strategies to help ADHD adults start — and finish — even the toughest projects.

by Sandy Maynard, Michele Novotni, Ph.D., and the ADDitude editors

Difficulties Getting Started

You have a big project coming up. But it seems overwhelming, and like many ADHDers, you've been putting off getting started for days, or even months. Knowing that others see failure to complete projects on time as a sign of disrespect, incompetence, or even laziness fuels your anxiety, fear of failure, imperfection, and indecisiveness, making it even harder to break through the paralysis. There's hope! Cognitive behavior techniques can help even the chronic procrastinator.

Know That You Can't Do Everything Perfectly!

Stop the negative self-talk! Think of positive, realistic things you can say to yourself to stay motivated. Write down "positive affirmations" and keep them nearby. For example: "I'm going to feel great when I hand this in to my boss on time." Or, simply, "I can do this!" Instead of saying "This will take forever," say "I might not finish this today, but I can do the first two steps within the next 30 minutes." What we silently say to ourselves about doing the task at hand has a strong impact on how (or whether) we do it.

Create the Right Environment

Create the workspace that's right for you. Some ADHDers get more done when listening to loud music. Others need clutter-free, distraction-free zones -- many ADHD college students go straight to the library, not their chaotic dorm room. If noise distracts you, noise-reducing headphones can be a lifesaver. If your racing thoughts are distracting, putting them on paper can banish them from your mind. Lock your door. Put your phone on silent. Do what works for you.

Set Up the Task

Before even starting the project, give yourself the task of collecting everything you'll need in one place - papers, graphs, directions from the boss -- and place it in your inbox, on your desk, or on your chair. For *ADDitude* blogger Stacey Turis, this includes a cup of green tea and a square of dark chocolate. The setup doesn't take long, but it makes it much easier to jump into the task.

Break Big Projects Up

Break projects into smaller projects, and **assign a deadline** for completing each step. Most of the time, we're given a deadline for the date by which the entire project has to be completed. To keep yourself on track, mark the date by which you should complete one-quarter of the project, one-half, and so on. Those dates will alert you to problems while there's still time to play catch-up.

Post Your Deadlines

Post deadlines for each step of your project where you can see them. This will remind you to use your time wisely. When ADHD coach Sandy Maynard was struggling to finish her long-delayed thesis, she created a computer screensaver that read "February 26 or Bust."

Do the Fun Stuff First

To get started, many people with ADHD find that once their brain is both relaxed and active, they can transfer that positive involvement to begin a daunting project. So, light up your brain by going for a walk, listening to music or practicing breathing exercises or short meditations. You can also just start with the project's fun stuff. Set a timer for fifteen minutes if you are worried about getting lost in the fun zone.

Start Somewhere, Start Anywhere

After your project is broken into small pieces, you face the moment when you have to start. Set a timer for fifteen minutes and tell yourself that you can do anything for fifteen minutes. Even if your first completed work is a bit sloppy, hey, at least you're moving! Half the time, you'll get in a groove and be ready to move forward with the next steps.

Make It Public

Knowing that we need to answer to other people can be a tremendous motivator. Ask a friend to call you at a prearranged time to make sure you're sticking to your deadlines. It's okay to ask for help -- that's what friends are for, right? You can return the favor later on when she needs a boost.

Beware of Multitasking

You know what they say, "Out of sight, out of mind." Only have on your desk what you're currently working on and don't try to multitask. If you absolutely must work on two projects at a time, don't bounce back and forth haphazardly. Stop the first project at a point where you can easily pick up, and shift your focus completely to the second task.

On the Job with ADHD...

Want more tips for managing ADHD at work? Check out:

How to Get Stuff Done

Careers for ADHD Adults: Which One is for You?

Managing Up With ADHD

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Avoiding Medical and Alternative Health Scams

by Mitzi Waltz

Dodgy little blue pills and dubious anti-aging creams aren't the only face of medical scams. There are predators aplenty willing to prey on people with health conditions, including Tourette syndrome. How can you avoid being their next victim? Know where to find reliable information about medications or procedures, and know how to recognize a scam.

Some General Rules

When you're making choices, there are a few rules that can help to keep you safe. First, stick to practitioners who have real credentials. It's easy to check whether someone has a medical license using your state medical board Web site (http://www.fsmb.org/directory_smb.html). If a doctor is licensed but has been disciplined for some reason, that information should also show up. Credentialed allied professionals such as licensed psychologists, social workers and other counselors may be researched in similar fashion.

Alternative healthcare providers can be harder to check up on. Check with your state to see whether they license practitioners—naturopaths and osteopaths are usually under the medical board, just like MDs, and acupuncturists and massage therapists are usually licensed as well.

Avoid any practitioner who recommends medications, herbal or homeopathic remedies, or nutritional products that they also sell. This is an obvious conflict of interest, but not unheard of. Would you trust a doctor who made extra money for every prescription she talked you into taking?

Whatever you try, keep good notes about dates, doses, and sessions. And before you start something new, decide what would mean "progress" or "success" for you: a reduction in severity of tics, perhaps—but only if it lasts longer than three months. To make sure you aren't fooling yourself, take the time to count or rate your tic severity all day over a couple of days before starting a treatment. Then you have something to measure against after you've given a new drug or treatment a try. As you know, TS tends to wax and wane on its own, and the placebo effect is very real. If you expect something to work it probably will... for a little while.

Getting Reliable Information

Where profit is involved, some people will lie, and some of them lie convincingly well. They will cite studies that don't actually say what they claim is true, or use meaningless but medical-sounding language. They may also tell you that further research would just take too much time, or that the whole medical establishment is against them!

Even if the treatment or drug is being evaluated by mainstream medicine, that isn't proof that it's actually worth trying, or safe. One or two small (e.g., with groups under 20) studies aren't enough, nor are successful case studies of just a few people. Early evidence may be promising, but what if it goes wrong—and what if it's you, or your child, that pays the price for trying it too soon?

Here's where to find reliable information:

- Medline Plus (<http://www.nlm.nih.gov/medlineplus/>) is a public service of the National Library of Medicine. It includes a decent medical dictionary, drug and supplement information, and general health condition guidelines.

- PubMed (<http://www.ncbi.nlm.nih.gov/pubmed/>) is a massive database of medical journal articles. Remember, not everything will have been peer-reviewed (checked by other doctors) before it was published, some articles will be speculative, and many will be about just one patient. The articles that are "gold standard" evidence are peer-reviewed studies involving many patients, where a comparison is made between new and existing treatments (or a placebo) without the patients knowing which they received.
- [TSA Medical & Treatment pages](#). The TSA keeps up with all the latest advances and provides high-quality basic information as well.
- Particularly questionable practitioners and treatments may be featured on the Quackwatch (<http://www.quackwatch.org/>) Web site!

What to Watch Out For

Just like used car salespeople, peddlers of dubious drugs, supplements and treatments have some favorite tricks. One is saying the treatment comes from some exotic place (Europe or the Far East, perhaps) and putting a huge price tag on it. Exotic, expensive... must be worth trying, right? Wrong.

If anyone tells you what they are selling will "cure" TS, they are lying. Likewise, if you're told the drug or procedure is a secret, beware: in real medicine, claims must be tested by others who don't have a financial interest in the drug or procedure, and the results should be published. If you had a cure for TS, or even just a promising treatment, would *you* keep it a secret? You really have to doubt the motivations of anyone who would...

Another trick is saying something is new and unique, unrelated to anything used before. Think about it—does that make sense in medicine? It's true that breakthroughs do occur, but usually it's because existing treatments are investigated until researchers find out how they work and then improved, or tried for different conditions. One medication was found to help reduce tic severity because a few people with tics took part in testing it for high blood pressure. No one ran out and prescribed it for people with TS right away, though, it had to be tested first. Success builds on success, it almost never comes out of nowhere.

Also beware of anyone who claims to have all the answers. Even famous specialist facilities like the Mayo Clinic, with hundreds of doctors and access to experimental treatments, don't claim to be able to fix everything that ails you. Some supplement-makers claim their wares will fix not only your tics but everything from asthma to warts.

If you're told to not talk to your primary care physician, or to stop using mainstream treatments, that's also a bad sign. It's as if someone has something to hide, isn't it? It's crucial to tell your doctor about anything you are trying. Your doctor may be able to prevent you from coming to harm, and he or she also needs to know in case the treatment is successful!

If there's something new and effective, your doctor, and organizations like the TSA, will want to make people aware of it. So don't get pulled in by hype and sales pitches: investigate carefully, and choose wisely. Always check with your treating physician about any findings or questions you may have.