

NAVIGATING TOURETTE SYNDROME A Young Adult's Guide



This toolkit is intended to be a guide for young adults who are learning to navigate life with Tourette Syndrome (TS). Many people mistakenly think of TS as a childhood disorder, yet it is important to understand that TS affects people of all ages. Being a teenager and entering adulthood presents new challenges and opportunities. There are many life transitions and much to learn and consider when living with TS. This guide serves as a reference to assist you with the life experiences you may encounter.

In this toolkit you will find information on a variety of helpful topics, including: the basics of TS and co-occurring conditions; potential treatment options; transitioning to high school, college, and the workplace; social skills and dating; stress management; and frequently asked questions which young adults might have regarding life with TS.

TOURETTE SYNDROME: THE BASICS

- Tourette Syndrome is a neurodevelopmental disorder which becomes evident in early childhood or adolescence. TS is part of the spectrum of similar conditions known as Tic Disorders. Motor and vocal tics are the main characteristics described in a TS diagnosis.
- Motor tics are uncontrolled movements, such as eye blinking, shoulder shrugging and jumping. Vocal tics are repetitive, involuntary sounds or words, including sniffing, grunting and repeating others' words.
- TS and tics are more common than you might think. TS and Tic Disorders affect at least 1 in 100 people during childhood.
- Over time, tics might change in type, intensity, and/or body location.
- Scientists are not yet sure how common Tourette Syndrome is in adulthood. Most people with TS see improvements by late adolescence or early adulthood, but some people continue to have persistent, severe tics into adulthood. Compared to children, most adults report that their tics are more stable and do not change as much in terms of type, intensity, or body location.
- The cause of TS is unknown. Tourette Syndrome tends to occur in families and studies have confirmed that genetics are involved. Researchers are continuing to search for genes and other potential factors that may cause TS.

If you would like to learn more about Tourette Syndrome or find a doctor near you, please contact the Tourette Association at tourette.org or by calling **888-4TOURET**.

CO-OCCURRING CONDITIONS

Someone with TS may have one or more co-occurring conditions. These co-occurring conditions may be more bothersome than the tics themselves. Among people diagnosed with TS, an estimated 86% have been diagnosed with at least one additional condition. The most common co-occurring conditions can include the following: problems with writing, depression, anxiety, ADHD (attention-deficit/hyperactivity disorder), learning challenges, a hard time with changes, difficulty concentrating and rage. Another common co-occurring condition is obsessive compulsive disorder, or OCD for short, which involves the need to do something a certain way or until it feels just right.

Some individuals with TS also have difficulties with reading, writing, mathematics and/or information processing. These difficulties can create particular challenges in school and the workplace.

Additionally, people with TS may experience other problems such as: trouble falling or staying asleep, difficulty managing anger, impulse control problems, sensitivities to touch, sound, taste, or smells and difficulties establishing and maintaining relationships.



SUBSTANCE ABUSE

Some people misuse substances, such as alcohol and other drugs, to cope with their tics and co-occurring symptoms. Substance abuse can cause lasting effects to all aspects of a person's life including negatively impacting health, job or school performance, and personal relationships. Signs of substance abuse include:

- Taking drugs in larger amounts/for longer than intended.
- Wanting to cut down on drug use but not being able to do it.
- Spending excessive time getting the drug.
- Needing to take more of the drug to get the desired effect.
- Cravings and/or withdrawal symptoms.
- Taking the drug in a dangerous situation (e.g.- before driving).
- Continued drug use despite social, interpersonal, or work-related problems.

If you or someone you know is struggling with substance abuse, you can call the Substance Abuse and Mental Health Services Administration's free, confidential 24/7 hotline at: 1-800-662-HELP (4357) or [click here](#) for more information. This service provides referrals to local treatment facilities, support groups, and community-based organizations, as well as other free resources.



TREATMENT FOR TOURETTE SYNDROME

When tics are mild and manageable, treatment is not required. However, if tics are bothersome, treatment may be needed. The first step in getting treatment is to be evaluated by a medical professional who is familiar with TS. While some doctors are experienced in treating tics, it can be helpful to be evaluated by a specialist, such as a neurologist or psychiatrist. Your doctor can advise you on how to find an appropriate referral or [click here](#) to find a TS specialist. Treatment for TS can involve behavior therapy and/or medication. For many people, a combination of the two is most effective.

You will need to work with a doctor who is familiar with TS to understand the treatment options that are available. **It's important to know that you are not alone in this, and that it may take some time to determine the approach that works best for you.**

COMPREHENSIVE BEHAVIORAL INTERVENTION FOR TICS (CBIT)

Comprehensive Behavioral Intervention for Tics (CBIT, pronounced "see-bit") is a behavioral, non-medication treatment which has been shown in clinical studies to reduce tics in both children and adults. Studies have also indicated CBIT to be as effective as medication in many cases, and is often recommended as the first form of treatment.

There are three main components of CBIT:

- Training the person to be more aware of his or her tics and the urge to tic.
- Training people to do competing behavior(s) when they feel the urge to tic.
- Making changes to day-to-day activities in ways that can be helpful in reducing tics.

CBIT may seem like a simple type of therapy, but be aware that it takes effort and time for CBIT to be effective, like any new skill. CBIT does become easier as time goes on and many people experience a decrease in tic severity. CBIT is most appropriate when tics are very severe and negatively affect daily life. CBIT is not intended to treat co-occurring conditions.

For more information on CBIT, visit tourette.org/research-medical/cbit-for-patients/.

TIC MEDICATIONS

If you have multiple or severe tics, your doctor may recommend medication. Although medication may help, it does not cure tics.

Haloperidol (Haldol), Pimozide (Orap), and Aripiprazole (Abilify) are the only medications currently approved by the U.S. Food and Drug Administration to treat tics. Be sure to ask your doctor about the benefits and risks for any use of medications.

For more information on medication options, visit tourette.org/research-medical/pharmacology/.

TREATMENT FOR CO-OCCURRING CONDITIONS

Co-occurring conditions often cause more problems and distress than tics. Treatment for co-occurring conditions is different from those used to treat tics. In addition, some co-occurring conditions, such as ADHD, can make it harder to learn behavior therapies like CBIT. In such cases, the co-occurring condition must be treated first. Treating co-occurring conditions usually involves medication, psychotherapy, or a combination of the two. Research has shown that for most co-occurring conditions, such as depression, anxiety, and OCD, a combination of medication and psychotherapy is most effective.



PSYCHOTHERAPY FOR CO-OCCURRING CONDITIONS

Psychotherapy involves working with a mental health professional to better understand your challenges and to learn healthy coping skills. Psychotherapy is often used in combination with medication. There are many different types of psychotherapy. The type that is best for you depends upon the nature of your problem(s), your individual situation, and your personal preferences. Psychotherapy teaches people to identify and change unhelpful patterns in the way they think, behave, and regulate their emotions so that they are better equipped to cope with situations and stressors in their everyday lives.

If you feel that you are struggling from symptoms related to a co-occurring condition, know that you are not alone. You should discuss these symptoms with your parents or someone you trust, and your doctor, to determine a plan for treatment that will work best for you.

REHABILITATION AND ANCILLARY SERVICES

There are other services that can help to improve your daily life with TS and co-occurring symptoms. These services include but are not limited to: occupational therapy, physical therapy, and speech-language pathology services.

- Occupational therapy (OT)- Therapy to improve everyday life by modifying the environment and establishing healthy habits and routines in the home, school, workplace, community and other settings.
- Physical therapy (PT)- Therapy to restore, maintain and promote physical function.
- Speech-language pathology (SLP)- Treatment of speech, language, social communication, cognitive-communication and swallowing disorders.
- If your tics or co-occurring symptoms interfere with activities in the home, workplace, school, or community, seeking rehabilitation services may help. Below are a few questions to consider asking a facility when looking for services:
 - *Does your facility offer interdisciplinary care with OT, PT and SLP?*
 - *Do you have specialty training or certification in the above areas?*
 - *Do you have any training specifically tailored to treat patients with TS (or any of the co-occurring conditions that you are addressing)?*

KNOW YOUR RIGHTS

The United States Department of Justice considers TS a qualifying disability. While many people are able to manage Tourette Syndrome with little to no accommodations, it is important to know your legal rights. This is important because people with TS are sometimes discriminated against despite managing their symptoms and not posing any threat to themselves or others.

Individuals with TS have the right to:

- Receive fair housing under the Department of Justice's Fair Housing Act.
- Receive appropriate educational and testing accommodations.
- Receive fair consideration for hiring and promotions.
- Receive reasonable accommodations in the workplace to ensure performance of essential job duties.
- Travel by plane without harassment due to tics.
- Use other forms of public transportation without harassment.
- Maintain employment for which they are qualified, and not be fired solely due to their diagnosis.

For more information on federal rights and accommodations, visit [tourette.org/resource/americans-disabilities-act-ada/](https://www.tourette.org/resource/americans-disabilities-act-ada/).

TRANSITIONING TO HIGH SCHOOL

High school can be an intimidating, yet exciting time. Sometimes, having TS can be an added challenge during high school. Your peers might target and bully you because of your tics. Other students may ask you, "Why do you do that?", and mimic your tics.

One of the reasons that students may target you is because they don't understand what TS or tics are. Educating your classmates and teachers about Tourette Syndrome may make it easier for you. You might be reluctant or nervous about doing this because you do not want to be the center of attention. But, don't worry—being nervous is a natural feeling. Often, the opposite actually happens. Many young adults with TS report feeling more comfortable with their classmates after a peer education presentation. Many even report tic reductions because their stress decreases and they feel less socially anxious.



For resources on educating your classmates about TS, visit tourette.org/resource/educating-classmates-tourette-syndrome/. Additionally, you can request an in-school presentation from a [Tourette Association Youth Ambassador](#). The TAA Youth Ambassador program consists of teens trained to talk about TS.

TRANSITIONING TO COLLEGE

Transitioning from high school to college can be a challenging and rewarding process. You may be away from home for the first time and have to adjust to living on your own. You will likely have more freedom and independence. You are also more responsible for your education and taking care of yourself.

Social relationships developed in college are also very important and meaningful. However, deciding if or when to tell people about your TS may be overwhelming. You may want to be open and honest with your friends about your condition. Your friends will probably be understanding and supportive.

It is okay if you need help. Unlike high school, where your parents probably advocated for your needs and accommodations, you may have to self-advocate in college. If you need accommodations, you may want to meet with your college's disabilities office. Colleges are required to consider Tourette Syndrome as a qualifying disability in the classroom. Many colleges have disability offices or resource centers which can help you to obtain appropriate accommodations to meet your needs. Colleges will require documentation and verification of your diagnosis, as well as specific information on accommodation needs.

If you are seeking further education or employment training resources, vocational rehabilitation may be a program option for you. Additionally, extra financial and support resources for young adults with TS may be available through your state or local vocational rehabilitation programs.

Many community resources exist to help young adults with Tourette Syndrome in finding ways to meet their goals and live meaningfully. For more information on these resources, you can visit your local vocational rehabilitation office or a [TAA Center of Excellence](#).



TRANSITIONING TO THE WORKPLACE

Transitions from school to employment can be challenging for anyone, but can be especially stressful for individuals with TS. *People with TS are represented in every field and occupation.* One key aspect of transitioning from school to the workplace is recognizing, maximizing and utilizing your strengths. Recognize that TS does not have to be the barrier for what you want to do in life. Below are three general tips which can aid in your transition from school to employment.

Remember the three Ps:

Stay **Positive**.

Be positive about TS, your abilities and your future. Maintain a positive attitude throughout the job search, interview process and while transitioning to the workplace. Your positivity will spread to those around you.

Be **Proactive**.

Plan ahead and think realistically about whether TS and co-occurring conditions are likely to have an impact on your job performance on a day-to-day basis. Reflect on your strengths and weaknesses, as well as how you can capitalize on your strengths so you can be successful and happy in the workplace.

Remain **Persistent**.

Understand that there will be roadblocks and setbacks. View setbacks as challenges which you can overcome. Most importantly, don't give up or procrastinate when things get tough. Set goals and work towards them.

BEFORE THE INTERVIEW

Tourette Syndrome does not define you. Reflect on your strengths and weaknesses. Think about the type of jobs that interest you, and how TS might affect those jobs. It might be helpful to write down your thoughts and create a plan to ensure that you are seeking the right job to fit well with your skills. If you are having doubts, contact your local vocational rehabilitation office for help. Vocational rehabilitation programs offer a wide variety of services for individuals joining or rejoining the workforce, including career counseling and job placement services.

INTERVIEW PROCESS

Remember the purpose of the interview is to see if you are capable of doing the job, if you are a good fit for the job and if the employer wants to hire you. It is also an opportunity for you to evaluate whether the job and workplace is a good fit for you. Prepare and practice your job interview with friends, family, or other supportive people in your life. It is important to sell yourself as an individual and talk about your skills and why you are a good fit for the company. If your tics are noticeable—and you do not want it to become “the elephant in the room” or it seems to be awkward because people are not talking about it—you may want to disclose to your prospective employer upfront, as early in the interview process as possible. In addition to practicing your job interview, practice your disclosure. As always, remember to stay positive!

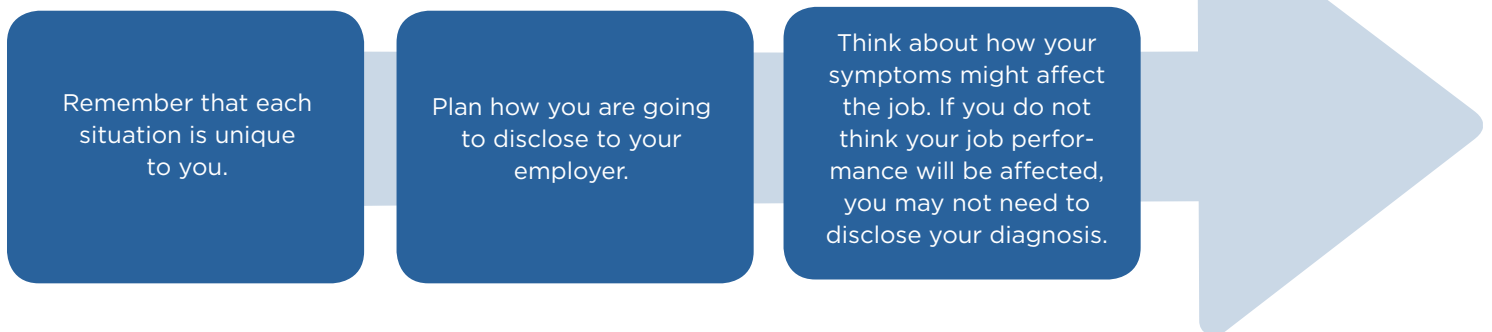
TELLING YOUR EMPLOYER

Knowing when to tell your employer that you have TS is a common question among young adults. There is no simple answer to this question. Research has shown self-disclosure reduces stigma and increases the likelihood that a co-worker will choose to partner with you on a task.

People experience TS differently and Tourette Syndrome is highly individualized. For example, some people’s tics may be more noticeable than others, and in some situations, co-occurring conditions are more bothersome than the tics. During all stages of the employment process, being proactive is key. You should consider how your tics might affect you while on the job. If you don’t believe that Tourette Syndrome will affect your job performance, it might not be necessary to tell others that you have TS. However, it is also important to consider the parts of TS that are not as visible to others, including but not limited to: aches and pains, fatigue, anxiety, and medication timing and side effects. Thinking carefully about how your symptoms affect you is helpful in deciding when or if you would like to disclose to your employer and/or other co-workers.

If you feel that your job performance might be affected by TS and you do decide to tell your employer, you should plan and practice how you are going to disclose your diagnosis. If you are going to disclose, remain professional, maintain a positive attitude and be open and factual. You want to openly and professionally explain that you have TS, and that you can manage your symptoms. Do not expect that your employer understands Tourette Syndrome and how it affects you personally. It might be helpful to provide information on the complexities of Tourette Syndrome. If you would like more general information on TS, visit tourette.org/resource/patient-tool-kit/.

To sum it up, while searching for a job, keep the following in mind:



It is important to remember that people with Tourette Syndrome are protected under the Americans with Disabilities Act. You have rights in this area. If you are a qualified candidate for the job, and TS does not impede with essential job functions, it is discrimination if you are not hired because of Tourette Syndrome.



ACCOMMODATIONS IN THE WORKPLACE

Your employer can help to maximize your success in the workplace. When asking for accommodations, it is important that you and your employer both understand how (or whether) TS will affect your essential job functions. Formalized workplace accommodations may be implemented if Tourette Syndrome or co-occurring conditions are affecting your ability to do your job. For example, if you are someone who struggles with deadlines or comes to work late as a result of a co-occurring condition such as ADHD, it is important to inform your employer as to how this will affect your essential job functions, as well as what accommodations will help to ensure you are successful at your job. The specific accommodations you will need depend on your symptoms. If you are not sure what accommodations you might need, be proactive in talking with your doctors and/or your local vocational rehabilitation office. Start this process early, as it can take some time.

SOCIAL RELATIONSHIPS

Relationships are hard work. Creating and maintaining healthy relationships as a young adult with Tourette Syndrome can come with specific challenges. The most important part of developing better social skills is becoming aware of areas in which you may struggle. If you have trouble in social situations, you can learn coping skills by meeting with a therapist or counselor, speaking with a social worker or occupational therapist, or asking for feedback from people you trust.

BUILDING SOCIAL SKILLS

If you struggle with social situations, it is important to regularly practice social skills building to gain better communication skills. Some examples of social skills building include:

- Mindfulness techniques, such as deep breathing exercises, before entering stressful social situations.
- Practicing open and honest ways of telling others you have TS.
- Using active listening skills.
- Utilizing “I” statements when discussing, clarifying, or discussing emotions with others (e.g.- “I felt confused and sad about what you said.” vs “You were confusing and made me sad.”).

DATING

When looking for a romantic relationship, dating can often be as scary as it is exciting. You may feel extra stress when deciding how or when to tell a potential dating partner that you have TS. Your tics may increase due to dating stress and co-occurring conditions may make dating more difficult. If you avoid public spaces because of your tics, this could also keep you from meeting romantic partners. It’s important to remember that having TS should never be an excuse to avoid dating or socializing.

While Tourette Syndrome can sometimes make dating more difficult, honesty is always the best policy. Being open and up front can help you feel comfortable and ensure that others around you understand that TS does not define you. Having self-confidence is good for your relationship. Remember that you have qualities and interests that are important, so when meeting someone new don’t let having TS interfere with dating. By focusing on talking about hobbies, careers, and goals, you may find that your tics are reduced by concentrating on the conversation. Be with a person who accepts you, supports you, and works with you to manage your tics.



For additional assistance with social skills and techniques, look for local social skills therapeutic groups in your area or attend a local TAA support group. For more information on support groups in your area, visit tourette.org/resources/find-local-chapter/.

STRESS MANAGEMENT

Stress of any kind is the most common trigger for TS symptoms. While tics cannot be completely eliminated, managing your stress and recognizing how your emotions create stress are important parts of tic management. Stress is an inevitable part of life and can be managed in two important ways: **emotion regulation** and **distress tolerance**. While tics may be involuntary, learning to take ownership for and managing emotions is a crucial part of leading a healthy and productive life.

- **Emotion regulation:** the ability to shape your emotions, including when you have them and how you experience and express these emotions.
- **Distress tolerance:** your actual perceived ability to stand up to emotional distress.

Emotion regulation and distress tolerance are important ways to manage stress, build relationships, and maintain jobs. Having a lower distress tolerance might make it harder to control negative reactions to situations, people and places. Additionally, gaining skills in this area can help to balance your mood, keep your mind focused and cope in healthier ways. When emotion regulation and distress tolerance are low, tics can increase!

Some examples of skills on which you can work to regulate emotions are:

- Distracting: Learning how to change your focus away from upsetting thoughts and emotions.
- Self-soothing: Learning to use your senses to calm your mind and body.
- Focusing on the pros and cons: How to navigate what will happen if you tolerate your feelings of distress and notice other ways you can cope with the emotions that are arising.

One of the most fundamental ways to develop stronger emotion regulation and distress tolerance is deep breathing, which helps to activate the part of our brain that manages stress and anxiety.

There are many types of breathing techniques. Speak with a local mental health professional for individual recommendations. You can also use the breathing technique listed below.

DEEP BREATHING EXERCISE

1. Laying down or sitting up straight in a chair, close your eyes.
2. Breathe in deeply through your nose and fill your stomach with air while counting to six. If you place a hand on your belly, you should be able to feel it move outward.
3. Loosely hold the breath to the count of three.
4. To the count of six, breathe out through your mouth while pursing your lips as if blowing into a straw.
5. Repeat for 2-5 minutes.
6. At the end of the time, see if you notice any differences in your posture, muscle tension and/or your mood.

This practice is meant to be regularly used during times of stress to help the mind to respond in a healthier way and to decrease the release of stress hormones in the brain. Other techniques that can also be used include yoga, meditation, tai chi and general mindfulness practices.



ACTIVITY SCHEDULING

Many individuals with TS and co-occurring conditions restrict or avoid activities which they enjoy. Research has shown that restricting activities can:

- Lead to loneliness.
- Decrease self-worth and self-esteem.
- Damage social relationships.
- Worsen co-occurring symptoms, such as anxiety and depression.
- Decrease quality of life.

Scheduling and engaging in enjoyable activities can help to improve symptoms. Examples include: attending a support group, joining a club, starting a hobby, and spending time with loved ones.

FREQUENTLY ASKED QUESTIONS

What type of doctor or professional should I see if I am still struggling with tics and/or co-occurring symptoms as an adult?

The type of medical professional who will be most helpful for you depends upon your specific needs. Fortunately, many medical doctors, including neurologists, psychiatrists and some family practice physicians, are knowledgeable about TS and common co-occurring conditions. A knowledgeable medical doctor can evaluate your healthcare needs, prescribe medication (if needed) and connect you with other non-medical services and resources, such as mental health therapists and occupational and educational assistance programs. The TAA maintains a list of professionals knowledgeable about Tourette Syndrome and is a good place to start when seeking a healthcare provider in your area.



I tried several different treatments for Tourette Syndrome when I was younger and they did not work very well. Should I try again?

Although we do not have all of the answers about the causes and treatments of TS, we know a lot more now than we did even 10 years ago. New treatments are continually being developed and tested; effective treatments are becoming more readily available. In addition, the brain continues to develop well into young adulthood, which can have important implications for both medical and non-medical treatments. If you are still struggling with tics and/or co-occurring symptoms in adulthood, it is worth taking time to consult with a medical professional about new treatment options which might be available.

I have heard that tics decrease or go away in adulthood. Is this true?

For many individuals, tics tend to decrease in severity and/or become more stable after puberty. Unfortunately, this is not the case for all individuals with TS, and whether a person's tics will improve is difficult to predict. Sudden onset and/or worsening of tics in adulthood is relatively rare but has been reported. If your tics persist or worsen into adulthood, we recommend consulting with a medical professional to explore possible explanations and treatment recommendations. Changing roles and responsibilities that come along with adulthood (such as entering the workforce) can create new challenges for individuals with TS, so it is important to be proactive in learning how to effectively manage and cope with tics and co-occurring symptoms.

My tics are not as bad as they were when I was younger but my co-occurring symptoms are not improving (or are worsening). Why?

Many youth with TS are diagnosed with co-occurring conditions. Although these issues typically emerge in childhood, timing is different for everyone. Although tics improve after puberty for many people, conditions such as ADHD and OCD are more likely to persist or worsen into adulthood. In addition, for some individuals, co-occurring conditions may have been overlooked in childhood or might not develop until adulthood. Because these conditions often cause more challenges than tics, it is essential to seek help if you are struggling with co-occurring conditions, regardless of whether your tics have improved.

I have a hard time controlling my anger, mood and/or other emotions. How can I learn to better control my emotions?

It is important to note that changes in a person's mood and emotions are perfectly normal; people express their emotions in many different ways. However, some individuals with TS report that they struggle to control and express their emotions to the point that it is causing stress and affecting their ability to function. In some cases, challenges



with managing emotions may be a sign of an underlying condition, such as depression or anxiety. In other cases, it is related to life stressors. Numerous other factors can impact a person's mood and emotions. If you are struggling to effectively control and/or express your emotions, we encourage you to talk with your doctor.

I want to have children someday, but am worried that because I have tics my child will also have Tourette Syndrome or tics. What are the chances of my child inheriting tics/TS?

Although the exact cause of TS is not clear, we do know that genetics play a role. We know this because children are more likely to develop tics if one or both of their parents has/had tics. We also know that Tourette Syndrome does not involve a single gene, but rather likely involves several genes that increase a child's risk for developing it. As a general rule, if one parent has TS, there is about a 50% chance that the child will inherit the risk for developing it. This means that those children who inherit the genetic risk will be more likely than other children to develop symptoms at some point in their lives. The exact odds of a child developing symptoms of Tourette Syndrome, even if they do have "risky genes", depends upon several other factors, many of which we do not yet fully understand. We do know, however, that boys are more likely than girls to develop tics if they inherit the "risky genes". It is also important to note that the severity of the

parent's TS is not a strong predictor of whether the child will develop tics or the severity of his/her symptoms.

Are there any dietary or natural treatments for tics or co-occurring conditions?

At this point, there is no scientific evidence to support the use of specialized diets or dietary supplements to treat Tourette Syndrome. However, many individuals report that certain foods or food additives, such as caffeinated beverages, worsen their tics. If this is the case, it might be a good idea to limit the intake of those foods. In addition, some preliminary research suggests that a healthy lifestyle involving a nutritious diet, exercise, and sufficient sleep can improve mood and cognition, reduce tics, and improve quality of life. If necessary, seek help from a personal trainer, dietician, or therapist for advice on how to make practical lifestyle changes and stick to a healthy lifestyle routine. Of course, speak with your doctor before making any significant changes to your exercise routine or diet.

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This publication was supported by the Grant or Cooperative Agreement Number, NU58DD005375-02, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.



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