

## RISING INCIDENCE OF FUNCTIONAL TIC-LIKE BEHAVIORS

### What’s happening? Why now?

Throughout the COVID-19 pandemic, doctors and patient associations have noticed a surge in tics in people with Tourette Syndrome (TS) and they have also noticed what appears to be a potentially related type of movement disorder among youth that closely resembles a Tic Disorder. The Tourette Association of America (TAA) convened an international, multidisciplinary working group to help understand this functional neurological disorder and its relationship to Tourette Syndrome.

### Tourette Syndrome and the Tic Disorders

Since the start of the pandemic, medical and therapeutic specialists who treat tics have experienced an increase in evaluation visits among young people presenting sudden onset, tic-like symptoms that differ from those usually seen in Tourette Syndrome or other Tic Disorders (3-9).

These patients are exhibiting symptoms that are distinctly different from those typically seen in Tourette Syndrome and Tic Disorder patients, yet they are similar to one another. The patients are often teenagers who report no history of tics and who are experiencing movement symptoms for the first time. Many experts believe this phenomenon of sudden onset tic-like behaviors could be a complex mix of tic exacerbation in people with Tic Disorders, tic expression in those without an identified history of tics, and functional neurological symptoms. Sudden onset tic-like behaviors are not specific to the COVID-19 pandemic and have been seen before.

Tics	Functional neurological disorder
Childhood onset	Teen onset (or marked teen worsening)
Male preponderance	Female preponderance
Simple to complex, motor to vocal	Elaborate tic symptoms
Premonitory sensation	No premonitory sensation

Some of these young people have tics that look similar to tics shown in popular videos on social media platforms like TikTok (10, 11, 12, 13). Over the past few years, tics and tic-like symptoms have gained visibility, especially on social media. Young people who watch others with tic-like symptoms on social media may develop

symptoms similar to those in the videos. Social distancing during COVID-19 has increased time spent on social media, which has greatly exposed people to this content on a global scale.

This increased media exposure combined with a myriad of other stressors and anxiety could have paved the way for the surge.

## **Understanding Tourette Syndrome and Functional Neurological Disorder**

Tourette Syndrome is a neurodevelopmental disorder that typically begins in early childhood between the ages of five and seven and is characterized by motor and vocal tics. It often continues into adolescence and can become more complex. Tourette Syndrome is part of a spectrum of Tic Disorders that includes Chronic Motor Tic Disorder, Chronic Vocal Tic Disorder, and Provisional Tic Disorder. Tics can occur in bouts, vary across individuals, and usually change within a person over time. We know tics can be simple or complex and often worsen in stressful and high-emotion situations.

The first experience of tics is often a simple motor tic, such as blinking. In some cases, tics may become more complex motor tics and/or vocal tics. They often begin in the head, face, or neck, and may eventually involve the rest of the body. Many people who experience tics describe a feeling or sensation just before the tic, called a “premonitory urge,” that either disappears or decreases in intensity after the tic.

In Tourette Syndrome, there is an incidence gender ratio of 3:1, boys to girls. Under-diagnosis or misdiagnosis in females may exist because of gender differences in symptoms. Some evidence suggests that tics in females may be more complex, begin later in life, and relate more to co-occurring mood and anxiety disorders. (16).

People with tics often have someone in their family or extended family who also has a history of tics, Obsessive-compulsive disorder (OCD), and Attention-deficit/hyperactivity disorder (ADHD), and/or other co-occurring conditions including anxiety and depression.

There are no specific diagnostic tests for the diagnosis of Tourette Syndrome but there is a lot of information about its typical course and symptoms. A health care professional can make a clinical diagnosis after examining and speaking with the patient.

In Functional Neurological Disorder (FND), a patient experiences a known set of neurological symptoms not explained by any recognized illness. It is often thought to be a physical manifestation of psychological distress.

Functional Neurological Disorder and the tics seen in Tourette Syndrome and other Tic Disorders share many features, including appearance, suggestibility, distractibility, and worsening in times of stress. Echophenomena, the repetition of external movements or sounds, is associated with FND as well as TS and Tic

disorders (20).

Functional tic disorder symptoms are not explained by a known illness, and they are not produced intentionally. Historically, stress or trauma have been considered the risk factors for FNDs. FND is not thought to be purposeful or voluntary. In other words, those with FND are not “faking it.”

The diagnosis of FND may occur by itself or co-occur with neurological conditions such as Tic Disorders. Distinguishing tics seen in Tic Disorders from tic-like behaviors in FND is challenging, especially for the general public or for clinicians who do not specialize in Tic Disorders. The changing nature of Tourette Syndrome presents a challenge to doctors, often requiring particular expertise.

Making the correct diagnosis is vital to avoid inappropriate interventions and to find the best treatment for the patient.

### **Typical FND Symptoms**

Several authors have studied the patients’ experiences of functional tic-like behaviors, reporting both expert opinion and data from various cases (17, 18, 19). Many agree that there has been an increase in functional tic-like behaviors, with many potential causes. One factor is a rise in anxiety, mood symptoms, and psychosocial stress throughout the COVID-19 pandemic.

The tic-like behaviors in a growing number of people do not follow the usual tic patterns seen in Tourette Syndrome and other Tic Disorders. Some authors have suggested “TS symptom portrayals on highly-viewed TikTok videos are predominantly not representative or typical of TS (19).”

Clinicians have noted they are primarily seeing this phenomenon in adolescents, and that females are at higher risk. Additional research and evidence are still needed to understand gender differences and symptoms. Until then, no generalizations can be made.

This group of young people does not have an identified or family history of tics (though one needs to be thoughtful about a potential history of tics that went undiagnosed (6)). They often report co-occurring anxiety or depression and significant psychosocial stressors. The sudden onset of complex motor and vocal tic-like symptoms, typical of FND but rare in Tourette Syndrome and other Tic Disorders, should be further evaluated by professionals.

### **How To Differentiate Tics and Tic-Like Behavior**

To better understand the difference between Functional Neurological Disorder and Tourette Syndrome, it is important to be aware of the following features of FND: (4, 7, 21, 22, 23,24).

- FND often has a sudden and abrupt onset
- FND commonly begins in the mid-teens
- Studies suggest a higher risk in females, but all genders can be affected.
- Tic symptoms closely replicate those of someone whom the patient has observed (particularly in the absence of other motor or vocal tics).
- Lack of urge (premonitory sensation) before movement/vocalization and involuntary control (non-suppression). In FND, there is often a report that the movement is done *to* them vs. done *by* them.
- Tics involve the body or limbs without a history of tics involving the eyes, face, and head.
- There is no rise and fall of the severity of symptoms in FND. A rise and fall in symptom severity is well-documented in Tourette Syndrome.
- “Attacks” of tic-like behavior—discrete episodes of complex movements/vocalizations, lasting from minutes to several hours with an abrupt onset and offset, often described as appearing to be “seizure-like” (3; 25).
- Behaviors dramatically disrupt the person’s intended actions or communications.
- Movements/vocalizations are dramatically different in the presence of others versus when alone.
- An increase in other functional neurological symptoms.
- No individual or family history of Tic Disorders, OCD, or ADHD.

## What We Recommend

### Make A Proper Assessment

The diagnosis of Tic Disorders or FND can *only* be made by a doctor. Lab tests and MRI are not needed to assess FND.

When a patient has an appointment with a doctor, they should be ready to share the following information:

- When did your symptoms begin?
- Have your symptoms changed over time?
- How have your symptoms affected daily living?
- Have you had similar symptoms earlier in your life or within your family?
- Do you know anyone else with similar symptoms?
- What has been your recent experience with social media?
- Have you already received treatment, and if yes, what happened?

Consider writing a journal or bringing a video of symptoms with you to your appointment.

## Know The Treatment Options

The best treatment for FND is still evolving. Most experts believe that the prognosis is good, but symptoms may take time to improve.

Anti-tic medications are not recommended in the treatment of FND. The exact treatment will vary from patient to patient. However, for most people, education and appropriate management leads to a full recovery.

The best strategy for people with relapsing or persistent symptoms will most likely be a multidisciplinary approach (involving multiple healthcare professionals, such as a neurologist, psychologist, or psychiatrist).

## Interventions Available

Receiving a correct diagnosis of FND is critical to avoid inappropriate medical interventions. FND treatment is individualized and often requires a multidisciplinary team approach.

Sometimes doctors will prescribe medications, such as selective serotonin reuptake inhibitors (SSRIs) or serotonin-norepinephrine reuptake inhibitors (SNRIs) to help treat other conditions which often co-occur with FND, such as anxiety, depression, or headaches.

Controlled studies of treatments for functional tics do not exist. The best treatment results for other functional symptoms have come from Cognitive Behavioral Therapy (CBT). Several antidepressant medications have been shown to help with non-motor functional symptoms, even for patients without current depression. These medications may be helpful to adjunctive therapy in some cases (26).

Medications for tics, including dopamine-modulating medications (e.g., aripiprazole, risperidone) may not be helpful unless other diagnoses require them.

## How to Reduce Triggers

There are often personal or environmental triggers that increase the chances of developing functional tic-like behaviors. Some are predictable, and some are personal and individual factors. Knowing and reducing the trigger is key. Often identifying the trigger can be accomplished by working with a psychologist or counselor.

For many young people, watching videos on social media of tic-like behavior or watching highly visible personalities displaying tics and tic-like behaviors, may trigger similar symptoms. This is especially true in people who have an underlying susceptibility.

This working group acknowledges that social media can play a significant role in creating a support community for people with Tourette Syndrome, however, doctors would suggest that someone with FND and those experiencing worsening symptoms of tics should consider cutting down on watching tic-related content. Reducing the consumption of tic-related videos will also increase the likelihood of recovery when receiving behavioral therapy and treatment.

Identifying sources of stress, while sometimes difficult for people with FND, is vital in receiving appropriate treatment. Sometimes, people with FND cannot initially identify the cause of stress in their lives. The ongoing COVID-19 pandemic has contributed to a myriad of stressors, including fears of illness, personal loss and grief, changes in social life and daily routines, and financial stressors. Counseling can help explore the impact of everyday life and how to recognize and manage stress.

### **How to Avoid Reinforcement**

Tic-like behaviors can impact one's school, personal, or professional life. Family members and friends can help the person with FND by showing empathy. It's crucial for loved ones to gently encourage the person with FND to approach stressful but necessary aspects of life, knowing that the people around them are supportive.

Occasionally, well-intended responses by parents or teachers may worsen symptoms. For example, excusing someone from chores or homework because of functional tics, or over-focusing on these symptoms, may provide unintentional reinforcement causing the symptoms to continue.

### **How to Retrain the Brain**

One of the key aspects of treating FND is retraining the brain to recognize how to manage movements and sounds. Cognitive-Behavioral Therapy (CBT) has been adapted for FND, and treatment recommendations exist (27, 28, 29). Increasing awareness of functional movements and learning to manage them can successfully happen with counseling, CBT, or a modified version of Comprehensive Behavioral Intervention for Tics (CBIT).

CBIT is an effective treatment for tics in Tourette Syndrome and may be helpful for some functional tic-like movements although research has not been conducted to support this possibility. CBIT includes Habit Reversal Training (HRT), which coaches the use of a competing response or less intrusive behavior instead of the tic-like behavior and uses functional assessment and intervention to understand the factors that trigger or worsen the tics.

Engaging the body and reinforcing voluntary motor and vocal patterns can help steer the brain away from unwanted movements and sounds. For some people, incorporating physical, occupational, or speech therapy can be helpful. These therapies can also be useful in helping the person with FND develop ways to use voluntary movements and sounds to avoid unwanted movements and sounds when

triggers may be present.

## Know the Co-Occurring Conditions

When a person with functional tic-like behaviors also has additional conditions such as anxiety or depression, it is critical to identify and address those in addition to the tic behaviors. CBT and medications targeting these other symptoms should be considered to improve the course of FND.

## Learn about FND

Education is a main priority in the management of FND. This includes explaining the diagnosis, counseling on potential causes or contributing factors, and discovering potential triggers that lead to worsening symptoms.

Patients and their supporting caregivers or partners can benefit from education and resources. This [FND website](#) is an excellent place to start.

## How We Can Help

Perhaps you or a loved one or someone in your community is experiencing some of the challenges we have described here – if so, you should be aware you are not alone. It's not helpful to judge others, either online or face-to-face.

No matter what diagnostic label they might have, everybody needs compassion in the face of misunderstanding, stigma, and discrimination. Do not tell those experiencing these symptoms that they are faking it, or that their symptoms are being done on purpose. Only an experienced doctor can make a diagnosis through a clinical interview and investigation.

The TAA is here to provide support and information. Here are some additional things you can do to help:

- Be kind and nonjudgmental. Let's reduce the stigma that can affect someone's quality of life.
- Whenever someone has these symptoms, they should talk to their doctor to understand their best possible diagnosis and treatment options.
- Work with a provider to best understand how to support someone during and in between episodes.
- Provide empathy to the person.
- Discuss the person's social media use with them. Would a break or reduction in watching tic-related content be helpful for them?
- Educate others to increase awareness and understanding.
- In the broad scope of neurodiversity, accepting differences rather than labeling them is more productive and healthier for everyone.

## More Resources

If you are experiencing functional tic-like symptoms, please seek out the aid of a healthcare professional. To find a provider near you, visit our [Find-A-Provider Tool](#). Here are a few other valuable resources that we recommend:

- [Neurosymptoms.org](https://www.neurosymptoms.org)
- [‘Tics, and Tic Disorders; the sudden onsets and influences of the pandemic’ – In conversation with Dr. Tammy Hedderly](#)
- [University of Calgary Tic Center](#)

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