What is a functional neurological disorder?

Functional neurological disorder (FND) is a brain-based condition that can affect movement, sensory, emotional, and cognitive systems. FND arises from a problem with how networks in the brain are **functioning** – that is, how the brain sends and receives signals to and from the body. It differs from other neurological disorders in that there is no damage to the physical structures of the brain or nervous system, or at least none that would explain the symptoms one is having.

Even without structural damage, FND can cause significant disability and often remains chronic without proper treatment. Symptoms may involve a variety of symptoms and can look similar to other neurological disorders. Some common subtypes of FND include:

- Functional movement disorders include shaking (functional tremor), jerky movements (functional myoclonus), tics. walking difficulties (functional gait disorder), sustained muscle contractions (functional dystonia), weakness/paralysis in a body part (functional weakness), or speech disturbances (functional speech disorder)
- **Functional non-epileptic seizures** <hyperlink to other page> (also called) psychogenic nonepileptic seizures) that look like epilepsy but are not associated with abnormal electrical discharges from the brain on EEG. These can look like episodes of uncontrollable body movements, inability

Seizures_{Depression} to move (or speak) with full awareness, and/or alterations in awareness ("blacking out" during episodes or feeling disconnected somehow).

Drop attacks Tremors

Dustonia Fleeting sensations

Stroke-like symptoms Dissociation

Walking difficulties spasms

Loss of bladder /bowel function

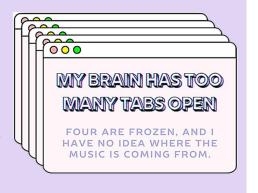
Cog fog Chronic pain

Limb weakness speech impairmen

Dizziness Anxiety Fatigue

- **Functional sensory changes** such as disturbances in vision or hearing, or altered body sensations (over-sensitivity or under-sensitivity)
- Functional cognitive disorder, including difficulty with memory, attention, thinking abilities, or "brain fog"
- Functional dizziness or persistent postural-perceptual dizziness (PPPD), which causes imbalance and dizziness that feels like swaying or rocking. This dizziness usually worsens when you are processing a lot of visual information or standing.
- Chronic pain, migraines, and fatigue are also common co-existing symptoms.

If we think of our brain as a computer, then FND is like a "software glitch" that can occur for various reasons. You may have too many programs open at once, or there might be one program consuming all of the energy that you didn't even know was running in the background, you may have downloaded a virus, or you may have one program that just is not communicating properly with another program. In each of these scenarios, the computer is not functioning properly even though the "hardware" (i.e., the physical structures) would appear normal on an X-ray.

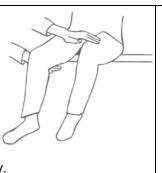


In functional movement disorders, it is like you have downloaded a corrupt "motor (movement) program" and you are unable to active the old, normal one. The old one still works, it's just not active. Physical therapy and psychotherapy can help you "rewire" your brain and activate the old, normal motor program.

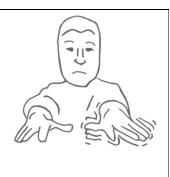
How is it diagnosed?

FND is diagnosed based on the presence of specific findings or "**positive signs**" on neurological exam. The positive signs in FND are distinct from those seen in other neurological disorders, in that they may demonstrate intact "hardware" (the physical structures in a computer) but malfunctioning "software." Sometimes the symptoms of FND seem to defy our understanding of how the nervous system works. Below are some examples of tests that may be completed:

With leg weakness, testing for the Hoover's sign may be performed to test strength under effortful and automatic conditions to determine whether normal movement can be obtained involuntarily.



With tremor, the entrainment test can show that the rhythm of the functional tremor can change or disappear entirely by copying a rhythm with your good hand.



These positive signs show that there is a *problem with voluntary movement* (e.g., you can't move correctly when you are trying to), but they also show that *normal movement is possible under involuntary conditions* (e.g., situations when you are not thinking about or actively trying to move). This aligns with what many people with functional movement symptoms have observed themselves – that symptoms seem to get worse the harder you try or they seem to fluctuate a lot, causing "good days" and "bad days."

Myth: FND is just diagnosed when all the tests are normal.

Fact: FND is now diagnosed based on the presence of specific criteria seen on neurological exam. When these "positive signs" are present, the diagnosis can usually be made with confidence.

It is helpful to ask your doctor to explain any positive signs to you, so that you can understand how the diagnosis was made. Plus, being shown your positive signs allows you to see that normal movement is still possible. You can Positive signs can also even be used as a form of physical therapy to encourage normal

Functional ≠ higher functioning

Myth: FND is not as serious as other neurological conditions.

Fact: People with FND have similar rates of disability to people with epilepsy and multiple sclerosis. FND can become chronic when left untreated.

movement. Unfortunately, some doctors misinterpret positive signs as evidence that a patient is "not trying," though in fact the *more* patients try, the *worse* the symptoms become.

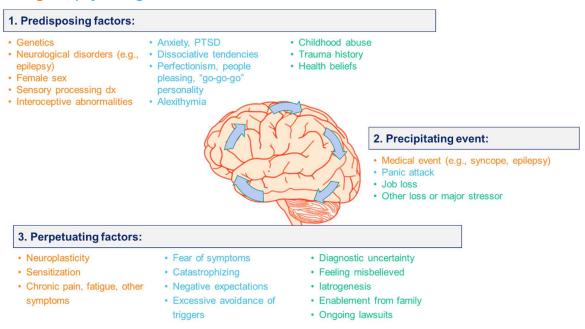
Normal scans, labs, and additional tests (e.g., EEG, EMG) can help to make the diagnosis, but it is really the clinical exam findings and history that are the most critical.

What causes FND?

We often never know *why* an individual develops any kind of condition. For example, we know of several genetic, environmental, lifestyle, and even psychological risk factors for Parkinson's disease and multiple sclerosis that increase one's likelihood of developing these conditions, yet at an individual level, a single "cause" can rarely be identified. Similarly, FND is caused by a complex set

of factors at a biological, psychological, and social/environmental level that differ from person to person. Most people are surprised to learn that the factors that led to the development of FND are often different than the factors that keep the symptoms going once they have started. See the figure below for some examples of factors that are often at play in FND.

Biological, psychological, and social factors that can cause FND



We call the factors that increase someone's risk of developing FND "predisposing factors." These range from having certain neurological diagnoses, to personality traits, to a history of childhood trauma.

Many people – but not everyone – experience a **precipitating event**, like a major life change, a medical illness, or an accident, which seems to trigger the FND symptoms to start.

Finally, different factors keep the symptoms going and make them worse over time. These are known as the "perpetuating factors" and are often what is being targeted in therapy.

In functional movement disorders, patterns of movement that people develop to work around their symptoms in the short-term (e.g., changes in posture, muscle tension, decreased use of a body part, avoidance of triggers, frequently checking for symptoms, increased self-monitoring) can often worsen the problem in the long run.

How is FND treated?

Because FND is not caused by permanent damage in the brain, your brain has the potential to "relearn" normal movements. The goals of treatment are to control symptoms, improve your functioning, and help you return to the things that are important of your life. Your provider may recommend the following treatments for FND:

- **Specialized physical therapy** helps you regain control of movements, improve balance, and reduce abnormal movements.
- Occupational therapy helps you perform your routine tasks, like getting dressed, cooking, and writing.
- Speech therapy can help with speech, swallowing, and sometimes thinking difficulties.
- Psychotherapy can help you understand your "personal equation" of factors that caused your FND, develop healthy ways to cope with and gain control of your symptoms, and manage low mood or anxiety

Not all therapists are familiar with FND, but it is best to see a therapist who has experience treating FND!

Can I recover from FND?

Because there is no damage to the nervous system, it is very possible to treat, and many times, *cure* FND. However, the road to recovery is not easy and usually takes a lot of persistence and motivation. A small percentage of people improve after receiving a clear diagnosis and using self-management techniques, but many require more structured treatments to get better. Some factors that are known to complicate recovery are the presence of disabling pain or fatigue, being involved in a lawsuit, or applying for disability benefits. As a result, sometimes these factors need to be worked out before starting treatment for FND.



Myth: You can just "will" your symptoms away.

Fact: Often, the harder people try and "fight with" or stop their symptoms, the worse the symptoms fight back. This does not mean you can't learn to control them – you just may need to change your approach.

Educational Materials:

For Healthcare Providers:

Functional Neurological Disorder Society www.fndsociety.org/: The Functional Neurological Disorder Society is a professional society of healthcare professionals, scientists, and students who are interested in functional neurological disorders.

Book Resources:

- Overcoming Functional Neurological Symptoms: A Five Areas Approach by
 Christopher Williams, MD and Alan Carson, MD. This is CBT-based self-help workbook with
 many tools and techniques for overcoming FND. It may not all apply to your personal
 situation.
- <u>Taking Control of Your Seizures: Workbook</u> by Joel M. Reiter, MD, DonnaK. Andrews, PhD, and Charlotte E. Reiter, MD. This workbook offers practical guidance for people with functional seizures to help them better understand and manage their seizures. There is also an <u>accompanying therapist guidebook</u>, which can be helpful to give to your therapist if they are unsure about how to help you with your symptoms.
- <u>FND Stories</u>: Personal and Professional Experiences of Functional Neurological Disorder. Eds. Rawlings, G.H. et al. 2024. Jessica Kingsley Publishers. This book interweaves patient experience with medical professional's experience treating FND and can be a great way to feel less alone and learn more about the condition.

Apps:

- myFND: A mobile app specifically designed for tracking and improving FND symptoms.
- Curable: a neuroscientifically-grounded app for treating chronic pain

Online Resources:

- **FND Guide** <u>www.neurosymptoms.org</u>: this website contains several educational videos, patient testimonies, and handouts on topics related to symptoms, diagnosis, and treatments.
- **FND Hope** <u>FNDHope.org</u>: An international patient-run registered charity for patients with functional neurological disorders. Material for patients with functional neurological disorders, like symptoms, providers, research, and stories.
- FND Action <u>www.FNDAction.org.uk:</u> An organization with educational and support resources for people living with FND as well as their families/caregivers.
- **FND Portal** <u>FNDPortal.org</u>: An expert on FND from personal experience who has contributed to many national and international medical associations
- **Self-Managing Your FND** <u>www.uclh.nhs.uk/our-services/</u> This resource from the NHS contains helpful videos related to self-managing FND symptoms.
- <u>Cadenza for Fractured Consciousness</u> an in-depth personal and factual essay on the history, neurobiology, and social impact of FND by FND Portal. A must-read for anyone interested in a deep dive. It's a long read, but there is an audio version on YouTube: https://youtu.be/buSwZMsrEX4.
- FND Recovery a lovely page by Max, a person with FND, who created her own unique approach to healing.
- #Informthedoctor information sheet. Many doctors still know very little about FND and
 may hold outdated beliefs about it. FND Action's #informthedoctor campaign has the
 materials you need to bring your doctor up to speed.

Free Downloadable Fact Sheets from www.neurosymptoms.org/

Symptom Description Link to Fact Sheet

Functional cognitive symptoms	Problems with memory or concentration (e.g. losing	www.neurosymptoms.org/wp- content/uploads/2021/02/Functional-
	track, going "blank", mental	cognitive-disorder-information-sheet-v1-
	fuzziness, memory loss)	<u>final.pdf</u>
Functional seizures	AKA non-epileptic seizures,	www.neurosymptoms.org/wp-
	psychogenic non-epileptic	content/uploads/2020/12/Factsheet.pdf
	seizures (PNES), non-epileptic	
	attack disorder (NEAD), and	
	dissociative seizures	
Drop attacks	Sudden falls without a change	www.neurosymptoms.org/wp-
	in consciousness or "blackout"	content/uploads/2020/11/Drop-Attacks-
		information-sheet-May-2014.pdf
Persistent postural-	Persistent dizziness or	www.neurosymptoms.org/wp-
perceptual dizziness	unsteadiness and/or balance	content/uploads/2020/11/Dizziness-
(PPPD)	problems	PPPD-information-sheet-v2.pdf
Functional tics	Rapid, repetitive, and	www.neurosymptoms.org/wp-
	arrhythmic movements or	content/uploads/2021/05/Functional-Tics-
	sounds	v9.pdf
Chronic headache	Headaches that are present	www.neurosymptoms.org/wp-
	most days for most of the day	content/uploads/2021/03/CDH-2010.pdf
Functional limb	Difficulty walking or one-sided	www.neurosymptoms.org/wp-
weakness	"heaviness"	content/uploads/2020/11/FactSheet.pdf
Functional tremor	Uncontrollable shaking of a	www.neurosymptoms.org/wp-
	part of the body	content/uploads/2020/11/Functional-
		<u>Tremor-information-sheet.pdf</u>
Functional dystonia	Abnormal postures, typically of	
	the hand and wrist or foot and	content/uploads/2020/11/Functional-
	ankle	<u>Dystonia-information-sheet.pdf</u>
Functional myoclonus	Sudden jerky movements as	www.neurosymptoms.org/wp-
	part of a functional movement	content/uploads/2021/03/Functional-
	disorder (FMD)	Myoclonus-Information-sheet.pdf
Functional facial spasm	Spasm of muscles of the face,	www.neurosymptoms.org/wp-
	typically around the eye and	content/uploads/2020/12/Facial-Spasm-
	sometimes neck and lower face	information-sheet.pdf
Chronic urinary	Inability to empty the bladder	www.neurosymptoms.org/wp-
retention and Fowler's	at all or all the way	content/uploads/2021/03/Chronic-
syndrome		<u>Urinary-Retention-Fowlers-Syndrome-</u>
		information-sheet-v8.pdf
Scan negative cauda	Severe low back pain with	www.neurosymptoms.org/wp-
equina syndrome	pain shooting down one or	content/uploads/2021/03/Scan-negative-
	both legs, as well as	cauda-equina-sydnrome-information-
	incontinence, bowel	sheet-v7.pdf
	symptoms, and/or leg	
	weakness	

Functional Neurological Disorder (FND) Program at Inova:

At Inova, we offer the following treatment options for adults.

- FND Neuropsychology Clinic: This involves consultation and individual therapy for people with all types of FND.
- Functional Movement Disorders Interdisciplinary Clinic (FMD IDC): This involves an interdisciplinary evaluation and rehabilitation program for people with functional movement disorders (FMD). Our core team includes a movement disorders neurologist, neuropsychologist, and physical therapists with specialized expertise in FMD care.
 - During your visit, you will meet individually with 3 providers over a 3-hour period. This includes:
 - Movement disorders neurologist Dr. Mick Reedy
 - Neuropsychologist Dr. Emmi Scott
 - Physical therapist Ashlie Williams or Abi Ortmeyer
 - This comprehensive assessment allows our team to confirm your diagnosis, understand the factors contributing to your condition, and collaboratively design a personalized treatment plan tailored to your goals and needs.
 - After your visit, we will create an individualized treatment plan based on your goals, lifestyle, and functional needs. The treatment program may involve working with:
 - Physical therapists (FND-trained therapists at all 5 Inova hospital-based rehabilitation departments)
 - Occupational therapists
 - Speech therapists
 - Neuropsychologists or rehabilitation psychologists

FMD interdisciplinary clinic & therapy program

Interdisciplinary clinic visit: Interdisciplinary rehabilitation A single visit where patients will see: Movement disorders program: neurologist Neuropsychologist Patients may be offered any Physical therapist* combination of FND-informed Outcomes of this visit: psychotherapy, physical therapy, Confirmation of the diagnosis occupational therapy, and Understanding of personal speech therapy. factors contributing to FND Creation of an individualized treatment plan

Program Goals & Values

Patient-centered care

Comprehensive treatment plans are made based on a patient's individual goals, symptoms, predisposing, precipitating, and perpetuating factors.

Shared patient goals

Patient-initiated goals are shared and targeted by all disciplines.

FND-informed treatment

Therapists use evidence-based practices for treating patients with FND that target the mechanism driving the symptoms.

Collaborative, team-based care

Team members communicate regularly through biweekly conferences, secure messaging, and EHR notes to reinforce consistent strategies and messages to patient.

Contact Us: 571-472-4167