FUNCTIONAL NEUROLOGICAL DISORDER

F N D HOPE

Front Cover
This information will help to provide you with a basic understanding of Functional Neurological Disorder (FND). FND is a condition that results from a problem with the functioning of the nervous system and how the brain and body send and receive signals.

For some, the path to diagnosis is a long and frustrating journey leading to isolation and feeling misunderstood. But you are not alone. Your symptoms are real and can be as debilitating as other neurological illnesses. While early treatment is best, even those patients with chronic functional symptoms can see improvement.

Our goal is to simplify this complex illness by providing the basic tools needed to understand the diagnosis so you may feel empowered and confident in taking an active role in your healthcare choices.

Together, we can move forward with determination and hope that recovery is possible.

Content written by:
Bridget Mildon, CEO FND Hope, United States
Tim Nicholson, Neuropsychiatry, England
Jon Stone, Neurologist, Scotland

All content was current at time of print. Information is for educational purpose only. Please, do not attempt to diagnose yourself.
What is FND?

Functional Neurological Disorder (FND) is a problem with the functioning of the nervous system and how the brain and body send and receive signals.

Symptoms

FND is a genuine disorder, in which symptoms are out of the patient’s control. It is a common cause of disability and distress, and may overlap with other conditions.

The symptoms of FND are caused by a problem with the functioning of the nervous system, and not by structural changes. Research studies involving people with FND are beginning to help us understand more about these abnormal changes in brain function, but FND can’t yet be diagnosed on brain scans or blood tests.
Who FND affects

FND is as common as conditions such as Multiple Sclerosis (MS) or Parkinson’s Disease. It is one of the most common reason for a neurological outpatient visit after headache/migraine. FND can affect anyone, but it is uncommon in children under 10 and affects more women than men, at a ratio of 2:1.

Important points:
1. FND is a positive diagnosis: it is not just a case of excluding other conditions.
2. Treatments can help many patients, but not all.
3. Self-management is a vital part of coping with FND.
What causes FND?

It’s generally accepted that FND has multiple causes, not just one, and that these causes may vary from patient to patient.

The most important thing to understand is that the symptoms are caused by disordered nervous system functioning - not by a known disease.

Put simply, the brain doesn't send and receive signals correctly. The nervous system is not damaged - it's just not working properly. Signals between certain parts of the body and the brain are jumbled up or wrongly interpreted by the brain, causing your body to react in unexpected ways.
Other conditions or diseases such as physical injury, infectious illness, panic attack or migraine may trigger your first FND symptoms. However, while these problems may clear up, the FND symptoms become stuck in a pattern in the nervous system - resulting in a genuine, disabling condition that you cannot control.

For some people, FND may be triggered by psychological factors. They may make a connection between their symptoms and recent or past stressful events in their lives. They may also have problems with anxiety and depression. However, for many people with FND, there are no such psychological factors.
What are the symptoms of FND?

Each patient has their own combination of symptoms, and these can vary widely in their nature. The severity of symptoms varies from patient to patient. Some patients may have just one or two mild symptoms; others have many disabling and distressing symptoms which can last anywhere from days to years.

Historically, there has been a misconception that FND patients are in control of these symptoms – which has had a negative impact on their treatment. However, scientific studies show that FND symptoms are not feigned, and cannot be turned on and off at will.
Symptoms

FND symptoms most commonly occur in three areas:

Motor dysfunction: A problem with your movement
- Muscle weakness
- Movement disorders, including tremors, spasms, jerks
- Speech problems, such as stuttering or slurred speech
- Paralysis of one or more limbs - often on one side of the body

Sensory dysfunction: A problem with the way your brain receives or responds to messages from the senses
- Loss of vision or double vision
- Numbness or pins and needles

Episodes of altered awareness: When you are not fully conscious
- Seizures, blackouts or faints

It is important that new symptoms be appropriately investigated and not automatically considered functional.

-Dr Tim Nicholson
How is FND diagnosed?
Diagnosis involves finding positive signs that are unique to FND (see next page) such as Hoover’s sign or a Tremor Entrainment test.

Looking for other neurological conditions
Your doctor will need to carry out tests to ensure that no other disorder - such as stroke or multiple sclerosis - provides a better explanation and reason for your symptoms.

You will be given a physical examination and may also have scans and blood tests.

If you have FND, it is possible that you may also have another medical disorder or illness. Being diagnosed with FND should not stop or impair the treatment you receive for this other condition. If you develop new symptoms after a diagnosis of FND, your doctor should not assume these are linked to FND. These symptoms may relate to the same condition, but should be assessed on their own merits.

To understand your FND diagnosis, ask your doctor to show you your positive functional signs.
Positive FND Tests
The following tests are used to show positive signs which are unique to FND.

The Hoover’s Test
This test assesses functional leg weakness. You may have difficulty pushing your ‘bad’ leg down, but when you are asked to lift up your ‘good’ leg, your ‘bad’ leg moves more normally.

Tremor Entrainment Test
This test is used on patients with shaking in one of more limbs. If you have FND, the shaking becomes momentarily better if you are copying a movement made by your doctor.

Seizure
Rather than looking at just one symptom, a specialist will look for a combination of features such as closed eyes, a long duration attack (>3 mins) or side-to-side head movements.

If you have FND, then tests will generally show that your automatic or reflex function (the part of your nervous system that reacts without you even thinking about it, like blinking when something is near your eyes) works better than when you are trying to move.

The diagnosis of FND is based on positive features and is not a diagnosis of exclusion.

- Professor Jon Stone
How will I be treated for FND?

FND treatment is most effective when it includes a combination of different therapies and treatments tailored to your individual symptoms.

It’s important to remember that not all patients get better, even with a sound understanding of their condition and access to a good treatment programme. FND can be a chronic, disabling condition – and if this is the case, your treatment should focus on maximising your independence and quality of life. However, the sooner you begin treatment after diagnosis, the more likely your recovery will be.

Depending on your symptoms, your neurologist may recommend:

- Physiotherapy/Physical therapy
- Speech therapy
- Occupational therapy
- Psychotherapy
- Medication

The aim of treatment is to ‘retrain your brain’ to unlearn abnormal movement patterns and re-learn normal ones. It also involves learning to balance your daily routine and gradually increasing activity as able.
Physiotherapy/Physical Therapy
FND-specific physiotherapy can help many people improve their movement. You may have treatment from a physiotherapist alone, or as part of a rehabilitation package that can include occupational therapy, speech therapy, exercise therapy and psychotherapy.

Psychological Therapy
Psychological therapy, such as Cognitive Behavioural Therapy (CBT), can be helpful for many patients with FND, especially those who suffer functional seizures. It involves learning more about your symptoms and what factors may contribute to them, and learning specific techniques to control them, such as distraction and relaxation.

Medication
There’s no evidence that any particular medication is effective for FND specifically. However, some clinicians may prescribe medications to help alleviate symptoms such as pain, low mood and anxiety, which commonly co-occur with FND.

Support
A good support network is a valuable aid to recovery - whether it is your family, friends, online support or healthcare professionals.
What are Grounding Techniques?

Grounding Techniques are learned skills used to “ground” you in the present moment by calming or awakening the nervous system. They work by engaging the mind and body, so both can consciously reconnect. The techniques can be useful tools for some to manage symptoms but may require practice.

Grounding Takes Practice:

It’s best to practice the various grounding techniques when you are in a calm and safe environment. The goal is to become familiar with several grounding techniques and discover the level of activity that suits you. The purpose is to awaken your senses without triggering symptoms.
Grounding Sensory List:
- Sound: Turn on some music
- Touch: Grip a cold object
- Smell: Sniff essential oils
- Taste: Bite into something sour
- Sight: Take an inventory of everything around you

More Grounding ideas:
- Touch objects around you and describe them
- Make a fist and squeeze tightly then release - repeat
- Carry a small object to rub such as a smooth rock or cloth
- Run water over your hands or cool rag on your face
- Repeat the alphabet backward
- Count backward from 100 by 3’s, 6’s, etc.
- Repeat the lyrics of your favorite song
- Focused breathing
How can balancing your daily activity help?

Learning to balance activity and rest is an important part of treatment. The word ‘activity’ is used in a broad sense, to include mental and emotional activity, as well as the more obvious physical sort. Learning to maintain balance in your daily life can lead to fewer and/or less intense symptoms for some.

Better Coping

It is difficult to experience a major change in health. Learning to accept your current physical state may help you follow a realistic and achievable approach to symptom management.

Stability

When illness reduces your activity levels it can lead to weakness or reduced stamina. It is also easy to try to make up for lost time on better days. But overdoing things often leads to symptom setback.

Control

Avoid the boom or bust cycle. By keeping your activity levels within sensible limits, you have a realistic chance of achieving the activity planned, without symptom setback.

Focused Recovery

Illness management helps you to rethink your approach to tasks, so that you resist the natural tendency to keep going until you are forced to stop by fatigue or symptoms. Setting small achievable goals builds stamina and avoids you becoming discouraged.
Balancing in Practice
Managing your symptoms is not always easy and requires planning and discipline. It may also seem restrictive, but learning to pick up on the signals that your body gives you and making sense of them is important.

Remember Rest and Relaxation
Short, regular rest periods throughout the day are essential to give you time to recharge your batteries. For your mind and body to get real benefit you need to be fully relaxed and properly resting your brain.

Find Your Baseline
A baseline is a level of activity that you can comfortably manage on a regular basis without making your symptoms significantly worse.

Prioritise Activities
You may need to look at each activity and judge how essential it is, as you won’t be able to do everything that you did before your change in health.

Increasing as Able
You could do this by adding one small extra task or by lengthening an existing activity. Any increase to your baseline should be very gradual and the process should be initiated and controlled by you. Be mindful of the normal effects of increasing activities and the negative effects of having overdone it. This will enable you to reflect on your own particular circumstances and achieve balance.

Marcy, US.
FND Hope International is comprised of charities registered in the United States, England, Wales, Scotland, Canada, and representatives in Australia and the Netherlands. We have joined forces as a global network to create a world where FND patients can expect to be treated with dignity, care and respect.

Our mission is to promote awareness, support affected individuals and advance research for the prevention, treatment and recovery of FND.

JOIN OUR GLOBAL FND MOVEMENT!
Empowering Patients to Better Health

For more information visit

F N D  H O P E
fndhope.org
neurosymptoms.org

Designed by go2north.co.uk

FND Hope International/US Registered 501C3
FND Hope UK Registered Charity England & Wales 1173607 and Scotland SC048333
FND Hope Canada