



Functional Neurological Disorders

Information for Patients



Scan with your
smartphone to see FND
videos from NHS clinicians

What is Functional Neurological Disorder?

Functional Neurological Disorder (FND) is the diagnosis given to symptoms which are due to a problem with the functioning of the nervous system, and not damage or disease of the nervous system.

One way to try and understand this is by thinking about a computer when it malfunctions. Often if a computer breaks down, this is because of the '**software**' (the programming and coding that makes it work) rather than the '**hardware**' (the keyboard, hard drive). FND can be thought of in the same way: the hardware of your body (brain, nerves) is not damaged, but the software is not working as it should.

About one third of all patients who attend a general Neurology clinic will receive a diagnosis of FND.

Common Symptoms

FND symptoms affect patients in many different ways.

Symptoms may include:

- Chronic pain
- Cognitive changes, poor concentration
- Fatigue
- Gait and balance problems
- Headaches and migraines
- Involuntary movements (shakes, tremors, jerks)
- Paralysis and weakness
- Functional seizures
- Sensory changes
- Sleep disturbances
- Speech problems
- Bladder and bowel changes
- Visual impairments

These symptoms are **real** and not imagined: they occur with no conscious control.

It is worthwhile discussing any concerns or symptoms, new or ongoing, with your GP for further support and guidance.

How can my doctor be sure I have FND?

Your neurologist or GP will have taken a detailed history of your symptoms and medical background. They will also conduct a neurological examination that can identify positive signs of FND. Occasionally other investigations may be required, such as MRI, CT scan etc., which can rule out other conditions that may look like FND.

Who is involved?

Your Neurologist or GP (whoever gave the diagnosis) will have discussed how they came to their decision, and give you an opportunity to ask questions.

Your neurologist or GP can refer you to specialist services, if required including:

- Physiotherapy
- Occupational Therapy
- Speech and Language Therapy
- Neuropsychology
- Psychiatry
- Dietitian

Self-Management Tips

Depending on your symptoms, there are many different tools you can use to help manage and live with your symptoms. Getting to know what makes your symptoms worse or what makes them easier to manage can help you develop a self-management plan. A good plan with achievable goals, can help reduce the likelihood of a flare up in symptoms and assist in managing symptoms. Patients with FND have told us they have found the following strategies helpful:

Managing Activity Levels – energy levels change day by day. Managing this means not overdoing it when you feel energetic, only to later ‘crash’ for a day or two to recharge. It focuses on doing a small amount of activity every day, knowing when to stop, and building up the baseline energy levels to improve overall daily activity, if possible.

Improve your Sleep – poor sleep can act as a trigger for symptoms and can also keep symptoms going. Exploring ways to manage this will be helpful.

Build in regular opportunities to move your body – this will vary depending on your fitness levels and interests. For some this might be more gentle exercises such as Yoga or T'ai Chi. For others it might involve going for a walk outside or for some it may involve doing some stretches at home. Patients have also told us they have found swimming a helpful way to manage their FND symptoms.

Build relaxation into your day – this will be different for everyone. Some people find mindfulness or other relaxation exercises helpful. For others relaxation might be about engaging in activities they enjoy. Setting a goal to use Mindfulness techniques was the top goal set by those attending our group programme. Mindfulness is about being aware and focusing on the present moment to help ease anxiety and fear about the future as well as harmful fixation on the past. The most useful Mindfulness techniques reported by patients were grounding, breathing exercises and meditation. These can help regulate the autonomic nervous system and help us to manage our attention.

Meet others with FND – patients attending our FND Group found it beneficial to meet others with the condition and set a goal to continue meeting. Peer support can help people living with FND feel less isolated. Speaking to others with the condition can also identify helpful strategies and management techniques others have found that may work for you too. See the Helpful links section for details about FND Hope who run a Peer Support Network.

Managing stress - research shows us that stress negatively affects symptoms of FND. Stress affects symptoms and this can make them worse or more noticeable. Patients have found that knowing about their condition gave them confidence to ask for support from their social circle and

employers. There are a number of techniques that you could use to manage stress:

Do:

- Use breathing exercises
- Listen to music/podcast
- Distract yourself with activities you enjoy
- Find company: talk to a friend/loved one
- Take a short walk/gentle exercise, preferably outside
- Engage in a hobby, new or ongoing

Don't:

- Do too much: keep realistic expectations of what you **can** do
- Overload yourself: ask for help or space when needed
- Ignore your emotions: it can be overwhelming at times, and sharing this or taking note of your feelings in a diary can help

If you experience symptoms such as tremor, emotional overwhelm, fast breathing, increased heart rate etc. activities that offer the best response will be those that are calming e.g. breathing exercises, mindfulness, visualisation.

If your symptoms are more in line with fatigue, dissociation, numbness and low mood activities then engaging in activities that are stimulating and getting you moving or using your five senses are more helpful.

Being Kind to Yourself - we all have an inner critic, many people attending our FND group have set a goal to manage their critical voice. You can start to do this by noticing if you are using harsh words and what the tone of your voice is like when you talk (or think!) about your symptoms. Ask yourself if you would you talk to a friend the same way. If the answer is no it is important to change your choice of words and tone to offer yourself the same support and compassion you would offer to others as you learn to live with FND. You did not choose to have these symptoms. It will take time to learn to anticipate what your needs are and how best to meet them.

Self-help resources - there are many useful websites, online groups and books that are of support to those with FND. Take a look at the '*Useful Links*' section at the end of this leaflet for more information.

If your symptoms react strongly to these treatments, it may be a sign that they can be helpful – use your best judgment to determine if or how you would like to participate.

Not all of these will work for everyone – find what works for you. Be creative! Try some new activities.

Will I get better?

There is no definite cure for FND. Everyone's journey with FND is different. People can improve by understanding their FND and how it affects them and by using strategies to manage their symptoms.

What works for one person may not be of benefit to another – it's a case of finding what works best for you!

Whilst there is no cure, research is being undertaken to help us understand more about FND, and what may help.

Useful Links

NeuroSymptoms

Website: <https://www.neurosymptoms.org/>

Functional Seizures

Website: <https://nonepilepticattacks.info>

FND Hope

Email: bridgetm@fndhope.org

Website: <https://fndhope.org/>

FND Action

Email: contact@fndaction.org.uk

Website: <https://www.fndaction.org.uk/>

Samaritans

Phone: 116 123 (free to call)

Website: www.samaritans.org

“Overcoming Functional Neurological Symptoms: A Five Areas Approach” Chris Williams. (Book available on Amazon and other retailers)