

What is FND?

Functional Neurological Disorder (FND) is an altered motor or sensory function, incompatible with recognised organic neurological conditions. Also known as Functional Neurological Symptoms Disorder, non-organic, psychogenic, psychosomatic, somatogenic and conversion disorder, these labels refer to the time when it was assumed that FND was purely a mental health disorder. Fortunately, it is now understood that this thinking was very simplistic, and that the symptoms now have a neurological cause, as is the fact that a source of psychological distress is no longer needed for a diagnosis of FND. However, it is essential to remember that the symptoms are **real**, FND is **not** a mental health condition, the symptoms are not made up, and no-one should make you feel that you are imagining things.

What does this mean?

FND is a disorder of the nervous system, where signals to and from the brain are not sent or received properly, or they get scrambled. This causes the body part or system that the signals are feeding, to not function as it should. It is not something that you have any control over. The nervous system malfunction causes symptoms that mimic other conditions such as MS, Epilepsy, Parkinsons and Stroke but when further tests are carried out, none of the abnormalities that are found in these conditions are present. This does not mean that the symptoms are any less real or any less debilitating.

FND is a positive diagnosis in its own right and should include positive tests that can be done for some FND symptoms (such as the **entrainment** test or **Hoover test**). It is **not** a diagnosis of exclusion, although sometimes further tests may be carried out such as **MRI** or **Nerve Conductive Studies**. These tests may be carried out if your symptoms are typical of another condition such as MS. Sometimes further tests may be done purely to reassure the patient that nothing more sinister is going on, or to make sure there is not another condition running alongside the functional symptoms.

Until recently, FND was often thought of as a medically unexplained diagnosis. This is no longer correct, as it is understood what is causing the symptoms. However, there is a lot of work to be done to describe exactly what is going on at the molecular level in the brains of those suffering from FND. Some research carried out in the USA, using 3D Functional MRI, has shown that there are actually some subtle changes in the brain of FND patients.

FND can bring different experiences to different people. If treatment begins early enough, many FND symptoms can be reversed as the brain is '**retrained**' to act normally again. However, it is very difficult to predict how one particular person will react to a specific treatment. For some people, it is possible to maintain a 'normal' life (holding down a job, raising a family, etc.) Others may be significantly disabled by their symptoms, struggling to function normally and potentially requiring the use of mobility aids, carers etc. Another group of individuals may find that their symptoms follow a relapse / remission / relapse pattern. There would still be symptoms during remission but at a lesser level.

Symptoms

The symptoms depend on which body part is being affected but the following are typical of FND:

- Paralysis
- Weakness
- Unsteady gait
- Stroke like symptoms
- Tremors
- Dystonia
- Bladder & bowel problems
- Cognitive difficulties
- Speech & communication problems
- Swallowing issues
- Vision impairment
- Brain fog
- Trembling felt inside
- Dizziness & nausea
- Chronic pain
- Fatigue
- Blackouts
- Dissociation & seizures (often referred to as NEAD - Non-Epileptic Attack Disorder)

Someone may only have one symptom or whilst others may have many. For a complete list of symptoms, please see the www.neurosymptoms.org website written by **Professor Jon Stone**.

Who gets FND?

FND doesn't discriminate. It can be developed without regard for age (children can have it too), gender, nationality, race, social class, sexual orientation or religious belief.

It can present suddenly, at any time, or symptoms can come on slowly. FND does not only affect the patient: it can have a negative impact on the carer, partner, parents, children and friends too as people face the financial burden from having to give up work, and social isolation as many are unable to lead the lives they were used to.

In some families, individuals from multiple generations develop symptoms, suggesting a genetic cause, although this is yet to be confirmed. FND is classified as “chronic” if symptoms have been present for over a year.

Causes

Recent studies (2019) have shown that contrary to previous estimates, the figures show that around **30%** of sufferers have been triggered by emotional trauma. This may have been childhood trauma, bereavement, breakdown of a relationship, abuse, bullying, acute or chronic stress, to name a few. Symptoms can come on many years after the event or may come on during or just after the trigger.

Around **70%** of triggers are now thought to be from other sources. These could be physical trauma such as an accident, an assault, traumatic brain injury which has healed but still symptomatic, even concussion, an operation, general anaesthetic, pre-existing neurological condition (the nervous system can mimic other pre-existing conditions such as epilepsy, POTS), a virus such as flu or glandular fever, an ear infection or a drug reaction. Empathy Fatigue / Vicarious Trauma experienced by first responders or counsellors. For some people, they can develop FND for no obvious reason.

UK Commonality

It is difficult to put a number on but it is thought to be as high as **2.5 million** nationwide suffering with FND. This is because many people don't realise they have it as their doctor may have said that their symptoms are “functional”, “non-organic”, “non-epileptic events” without saying “FND or Functional Neurological Disorder”.

People may have seen a Gastroenterologist to investigate bowel problems and the consultation letter comes through saying “IBS (Irritable Bowel Syndrome) / the symptoms are simply functional digestive symptoms”.

Indeed, most medical specialisms can and will diagnose functional symptoms. Some migraine, neurogenic bladder, dysfunctional breathing, ME/CFS and Fibromyalgia all join IBS and NEAD in their own specifically named group of symptoms but they are also all under the FND umbrella. What we do know is that FND is the second most common new diagnosis going through Neurology only after headache/migraine. It is more common than MS, Parkinsons, Epilepsy and all the other neurological conditions it mimics.

Treatment

Therapies

Once diagnosed, most people will be further referred to see a **neuro-psychologist** or a **neuro-physiotherapist**.

Some people will find the below can help.

- Cognitive Behavioural Therapy (CBT)
- Neuro Linguistic Programming (NLP)
- Meditation
- Mindfulness

Some of those with movement disorders such as dystonia find **mirror therapies** useful.

Occupational Therapists can help with equipment to make life easier both in the home and outdoors.

Other therapeutic treatments that are rarely available on the NHS include:

- Hyperbaric Oxygen Therapy
- Pilates
- Gentle yoga
- Hydrotherapy

Medication

Medication may be offered to help control pain or other symptoms but there is no specific medication available to treat FND. Being prescribed **antidepressants** is very common whether you feel you need them or not. Some **antidepressants** have other benefits such as pain relief, (in particular nerve pain) too.

It may be worth trying them instead of instantly dismissing them. Some anti epileptics may also help with pain management. An increasing number of people are trying CBD oil which you can place under the tongue or vape. This is available widely online and on the high street. People are reporting good results in relief of some of their symptoms.

Inpatient Rehabilitation Programmes

There are a number of **inpatient** programmes across the country which have a multi disciplinary approach. This means you will be seen by **neuro-physiotherapists**, **Occupational Therapists (OTs)**, **neuropsychologists**, plus take part in activities such as:

- Group meditation
- Planning a meal
- Shopping for groceries
- Cooking
- Gardening
- Art therapy/crafting

The different centres offer different lengths in stay ranging from **3 weeks** to **12 weeks**. The closest for people in the South West of England is:

The Rosa Burden Centre

Southmead Hospital
Bristol

The Woolfson Neurorehabilitation Centre

Queen Mary's Hospital (Part of St George's)
London

National Hospital for Neurology & Neurosurgery

Queen Square
London

If your GP or consultant is less than sympathetic about your situation, it is reasonable to ask for either a different consultant or GP. GP's are also able to refer you for treatment anywhere in England (provided you live in England) under NHS England. Consequently, it is perfectly reasonable to request to see a consultant in London, provided you are able to cope with the travelling etc.

Practically, there is a wealth of help available, if you know where to look. People may be referred to the social work team, so that they can be assessed for direct payments to help pay for **carers & Personal Assistants (PAs)**.

Carers can ask for a **carers assessment** at the same time. There is financial assistance available to help with house adaptation (although it is means tested), council tax reductions are available for those who use a wheelchair, and the person affected by FND may apply for welfare which includes:

- Personal Independence Payment / Disability Living Allowance (PIP/DLA)
- Employment & Support Allowance (ESA)
- Other welfare payments

Carers allowance is a benefit that carers are able to claim. There are some rules surrounding this so you would need to check current eligibility.

If you would like any information to give to GPs, other doctors, Occupational Therapists or Physiotherapists please let us know as we have training packs specific to those professions.

If you would like any information regarding social services, carers centres, and referrals, again, please let us know and we can provide you with these if they have not been given out with this information.