

#### Patient Information

# **Functional Neurological Symptoms**

#### Introduction

This leaflet will help you understand more about functional neurological symptoms and how you can get help.

## Why have I been given this leaflet?

In most cases, you will have had a neurological assessment before receiving the diagnosis of a Functional Neurological Disorder (FND).

For some people, this may have taken a long time and come after many investigations and appointments with different health professionals. Receiving this diagnosis can lead to many different feelings. Some people may feel relieved that they finally have an answer. Some people may feel scared, confused or may have doubts about the diagnosis. There is no right or wrong way to feel about a diagnosis of FND

## What are functional neurological symptoms?

Functional neurological symptoms can include a wide range of physical, sensory and/or cognitive symptoms including:

- Movement symptoms such as tremors, spasms, jerks, problems walking
- Limb weakness
- Speech symptoms such as slurred or stuttering speech, difficulty finding words
- Sensory disturbance such as numbness, tingling, pain
- Fatigue (extreme tiredness)
- Pain
- Blackouts/non-epileptic attacks (see also separate leaflet on non-epileptic attacks for more information if relevant to you)
- Poor memory and concentration

You may experience some or all of these symptoms. You are not alone; functional neurological symptoms are very common.

Functional neurological symptoms can appear similar to symptoms of other neurological conditions but they have different mechanisms.

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FNDs are thought to be due to a problem with how the brain and body sends and receives signals rather than a structural disease process.

For most individuals these symptoms are short-lived, but for others they can continue for months or years. The symptoms can also change with time.

# How are functional neurological symptoms diagnosed?

The diagnosis is usually made by a neurologist or medical professional following a description of your difficulties, a medical examination and sometimes investigations such as scans.

Specialists can often tell differences between functional neurological symptoms and other neurological conditions when described in detail and on examination.

Results of investigations are often normal and usually do not show any evidence of disease.

## Am I just imagining my symptoms?

When nothing unusual is identified through testing, some people worry they are not being believed. They may fear people think they are making up their symptoms or that their symptoms are 'in their head'.

**This is not the case.** Functional neurological symptoms are **real** and can have an impact on quality of life similar to other neurological conditions.

# Why do functional neurological symptoms happen?

Functional neurological symptoms are a complex problem. They are caused by different reasons in different people. There is still much that we do not understand about what goes wrong in the nervous system to cause functional neurological symptoms. There is ongoing research looking at this.



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There is rarely a single cause of functional neurological disorders.

Factors thought to trigger or keep symptoms going in some people include:

- Physical injury
- An illness that caused a lot of fatigue (tiredness) and bed rest
- Past or recent emotional event/trauma/complicated grief
- Current stressors
- Family history of illness/a neurological condition
- Concern about bodily symptoms/attention focused on symptoms
- Worry about the cause of symptoms
- High levels of anxiety

For others there may be a build-up of circumstances over time. For many it is not possible to identify a particular reason why these symptoms have developed. This lack of a specific answer can cause feelings of confusion, anger and anxiety and lead to doubts about the diagnosis.

## Other symptoms

When you have a diagnosis of FND you may experience other symptoms alongside your functional problems. These can include:

- Low mood
- Worry
- Anger and frustration
- Lack of enjoyment in life
- Problems with sleep

#### Following diagnosis

After being given a clear diagnosis, some people improve and get better without the need for further help.

For other people the functional neurological symptoms may be having a major impact on their lives and they may need more help in recovery.



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#### Services you may be referred to:

#### **Physiotherapy**

For individuals with motor symptoms (such as difficulties walking or a tremor), physiotherapy can sometimes be helpful.

#### **Health Psychology**

For some individuals it is helpful to look more widely at thoughts, emotions and experiences that could have played a role in the development of symptoms or may be maintaining the symptoms.

Functional neurological symptoms themselves are often experienced as stressful to manage and live with and psychological therapy can be helpful in developing confidence in managing the symptoms and reducing their impact.

#### Local talking therapy services (e.g. Let's Talk service)

There is some overlap between health psychology and other talking therapy services and so it is often unhelpful for people to be seen by both services.

However, for individuals who may be experiencing anxiety and low mood, contact with local talking therapy services may be suggested instead. These services provide individual and group support for a range of difficulties including depression, anxiety and post-traumatic stress.

#### **Medically Unexplained Symptoms Clinic**

This clinic is run by the liaison psychiatrists who are trained in working in the general hospital to help patients with mental health conditions alongside physical conditions. The clinic assessment process helps patients understand how their psychological health might be affecting their symptoms. In addition, it may be possible to create a treatment plan (in agreement with the patient) to address their health needs and to advise others involved in their care.

#### **Psychiatry services**

Some patients might be offered help from mental health recovery teams for treatment of disorders such as depression or anxiety. These teams offer a variety of treatments including key working and outpatient appointments.



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Recovery teams can also offer a wide range of psychological therapies and intensive home treatment via their colleagues in Crisis and home treatment services.

Referral to these services may not be appropriate or necessary for all individuals with functional neurological symptoms.

#### What can I do to help myself?

Find out more about functional neurological symptoms. If you have ongoing doubts about the diagnosis, this may cause continuing worry/frustration and get in the way of managing and improving your symptoms.

You can find more information about functional neurological symptoms at the website www.neurosymptoms.org. This website was developed by Professor Jon Stone, Consultant Neurologist. You may also wish to discuss your diagnosis further with your nurse or neurologist.

Help family and friends to understand your diagnosis by sharing information with them. This will help them to stay calm when your symptoms occur.

Notice triggers and factors that may make your symptoms worse or better.

If your activity levels have reduced or if you have stopped doing things you would usually do, it can be helpful to slowly build up your activity levels, balancing activity with rest.

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