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# Understanding Functional Neurological Disorder (FND)







This leaflet has been designed in collaboration with people who experience **Functional Neurological Disorder (FND)** to help you understand the diagnosis of FND.

It explains what FND is and how it can be managed.

If you have any questions about this leaflet, please ask a member of staff or email the Clinical Neuropsychology Department at:

@ reftoneuropsych@srft. nhs.uk

### What is Functional Neurological Disorder (FND)?

People with FND experience episodes of temporary loss of control that happens when the connection between the mind and body is interrupted.

FND is not dangerous. FND does not cause any damage inside your brain or body and is never fatal.

FND can affect anyone. It often happens to people who are good at "putting up" with difficult situations or stressful events and can "carry on" under pressure for a long time. There may however, be a number of reasons why a person develops FND and these may not be obvious at first.

FND is manageable with the right information and support. In many cases people are able to lead independent lifestyles with little disruption.

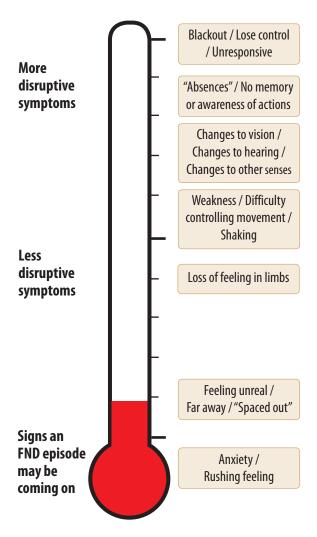
Some people worry that being diagnosed with FND means that doctors think they are "pretending" or that it is "all in their head". This is **NOT** true: Symptoms of FND are real.

### How many people have FND?

In hospital outpatient services, FND symptoms are amongst the most common reasons why someone may see a Neurologist.

#### What does FND look/feel like?

FND episodes are not always the same. You may experience symptoms that affect your movement, senses or awareness. Some examples are below (though you may have some symptoms not in this diagram).



### Why does FND happen? - Mind-Body link

Psychological experiences affect the body all the time.

For example:

- Sudden shock = heart beats faster
- Embarrassment = face goes red
- Upset = eyes produce tears

It is normal for some changes to happen to the body without a medical cause or disease (e.g. tears when we feel sad are not caused by a disease; it is the mind-body link).

These examples are real effects of the Mind-Body link that can happen to any of us, at any time.

They are not always within our control and can happen automatically. FND also happens through the Mind-Body link.

#### What makes the Mind-Body link cause FND?

One way of understanding FND is to imagine a pressure cooker.

When heat is turned up under a pressure cooker, steam builds up inside. A pressure cooker needs a valve to release excess steam, but sometimes this valve can be blocked.

Difficult life events and ongoing stresses affect people in the same way as heat affects a pressure cooker.

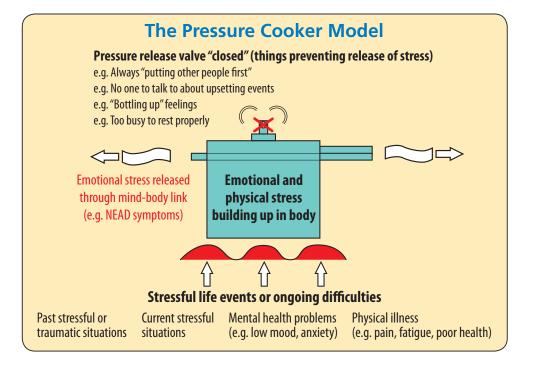
Emotional and physical stress builds up inside people, similar to the way that steam builds up in a pressure cooker.

This can be sudden (e.g. unexpected bereavement, a sudden serious illness) or gradual (e.g. financial difficulties, living with physical health conditions, overworking for long periods).

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Just like a pressure cooker needs a valve to release steam, we all need to have ways of releasing pressure/ stress.

If we are not able to do things that will help us to release stress then stress is released through the mind-body link and FND episodes can happen.



#### Why do only some people develop FND and not others?

FND can affect anyone, but it usually happens in people who are good at "carrying on" through difficult experiences that affect their lives.

There can be a number of reasons why a person's pressure cooker fills up and the stress is not released:

- Some people may not notice the build-up of pressure over time and may not feel stressed when they should do
- Some people can get into the habit of "bottling up" feelings and emotions or "carry on going" in situations that other people might find too difficult
- Some people may believe they shouldn't burden people by talking about difficult life events
- Some people may feel they must always put others first and are unable to take a break when they need to

Often the exact factors affecting a person's pressure cooker are not obvious at first, because everyone's lives are different.

People are sometimes concerned that FND symptoms are their fault, that they have caused them or that they should be able to control symptoms. This is **NOT** true.

You did not bring on the FND symptoms, **BUT** with the right information and support you can learn to manage symptoms and lead an independent lifestyle with little disruption.

#### How is FND diagnosed?

FND symptoms are often thought to be a neurological disease at first, but a Neurologist or Neuropsychiatrist knows the important differences to look for to make the FND diagnosis.

Sometimes a diagnosis can be made quickly, though it may be necessary to carry out several tests that may take time.

People often feel uncomfortable or confused with the diagnosis of FND because they have not heard of it before or it has taken a long time to get the diagnosis.

An FND diagnosis is made from signs and symptoms that a specialist can recognise. It is not made because doctors are "giving up" or "have run out of tests".

#### How do we manage FND?

Research and national guidelines recommend people who experience FND episodes work with a psychological therapist and/or physiotherapist specially trained in FND.

Some people believe that working with a psychological therapist is a sign that they are thought of as "pretending" or that symptoms are "all in their head". This is **NOT** true.

A specialist psychological therapist is trained to help you understand how the Mind-Body link works and to manage the causes of FND.

There is no medical treatment for FND because it is not caused by disease or damage to the body.

Some people may notice their FND symptoms include difficulty controlling their movement. In these cases a physiotherapist specially trained in FND can help.

Physiotherapy can help in a number of ways:

- Develop better control over your movement and relearn normal movement patterns
- Retain your movements by using distraction techniques to allow automatic movement
- Reduce the amount of any unwanted movement patterns being reinforced
- Avoid developing unhelpful reliance on walking aids / wheelchairs
- Increase independence in everyday tasks

Treatment is made up of three stages:

- **1. Information:** Learning about what FND is and how it happens.
- **2. Stabilising:** Strategies to control and reduce episodesusually with a short course of physiotherapy.
- 3. Support making changes:
  Find new ways to manage
  stressful situations and
  patterns of coping that prevent
  FND returning in futureusually with an outpatient
  psychological therapist

## What will happen to my FND symptoms in the long term?

FND symptoms are reversible. Most patients find their symptoms improve naturally with time, but recovery is usually better with access to the right support. Many people find that once they gain an understanding of FND and how to manage the symptoms they stop happening as frequently.

An inpatient hospital environment is not usually the right place for patients with FND. Patients who spend too long in hospital may lose confidence in their independence - this makes their long term recovery poorer.

There is no medical treatment for FND. It is normal for clinical staff to help patients to be discharged home as soon as possible, by making it a priority to provide information about FND and showing patients how to manage their FND symptoms independently in the community.

REMEMBER: FND is not dangerous. It can affect anyone and it is not your fault. With the right information and support you can learn to manage symptoms and lead and independent lifestyle again.

### Useful links, associations & contacts

www.neurosymptoms.org www.nonepilepticattacks. info

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