

vulnerable to these symptoms and something about their mechanisms in the brain but there is still a lot we do not understand. We know that in dealing with these illnesses it is important to think about the whole person and not just their arm or leg for example.

Sometimes everything would feel a lot simpler if you could just tell people you had suffered something like Parkinson's disease, something that everyone understands and sympathises with. Its very important to know that unlike someone with Parkinson's disease you **have the potential to get better** even after having the symptoms for a long time.

A good way of thinking about your symptoms is:

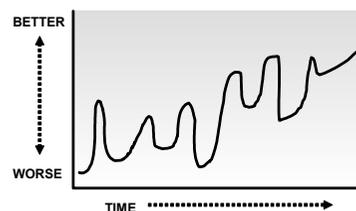
**You didn't bring the symptoms on but you can help to make them better**

### *What can I do to help myself get better?*

If you have had the symptoms for a long time you cannot get better quickly from them. These are some of the things that may help:

- **Feeling comfortable and clear about the diagnosis.** If you have ongoing doubts that the diagnosis is wrong then it is unlikely that you will get better. Getting better requires dealing with symptoms that may change from day to day. There may be days when you feel 'back to square one'. This is very hard to do without a belief in your ability to improve.
- **Gradually increasing your level of activity**– this is hard to describe in a nutshell but it involves setting very small goals for yourself. (maybe going for a 50 or 100 yard walk) which you can gradually build on including other activities that you may have stopped doing. It is often helpful with functional movement disorders not to think too hard about the problem – you may have already found that functional tremor is often best when you're distracted by something else. You are not 'imagining' the tremor, but paying attention to it can make it worse. You should expect 'relapses' of your symptoms as you try to improve, aiming for each relapse to be not quite as bad as the last one with slow gradual improvement in between.

- **Increasing activity (continued)** Symptoms usually vary a lot day to day and may be worse after exercise. If you can start improving your recovery may look like this on a graph.



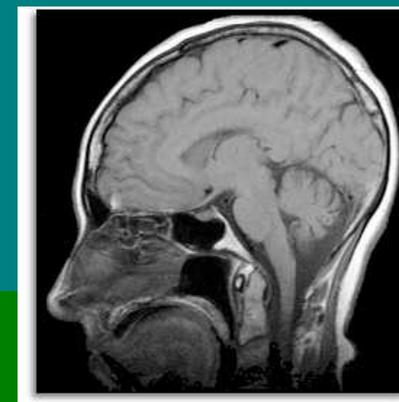
- **Physiotherapy**—this can be very helpful if you can find a physiotherapist who is happy dealing in this area. The physio is there to guide your self-help and rehabilitation not to do the treatment for you
- **Hypnosis and Sedation**– sometimes hypnosis can improve functional movement disorders. For patients with functional dystonia, an examination under a light anaesthetic can also be therapeutic
- **Drug treatment**—so-called antidepressants can be helpful in these illnesses, even for people who are not feeling depressed. They are not addictive, like Valium or painkillers, and will not harm you. They seem to work as a 'nerve tonic' - putting right imbalances in chemicals in the brain and making the nervous system work better again . You can get better without them but they may well increase your chances of success.
- **Dealing with stress** – not everyone with functional movement disorders are under stress, but if you are it then talking to family, friends or a professional such as a psychologist or psychiatrist may help in trying to overcome the problem

### *Where can I go for more information?*

There is very little information for patients with functional movement disorders. However, you may find some practical information on coping with fatigue, pain and other symptoms in this book written for people with any diagnosis:

*'Living with a Long Term illness—the facts by Frankie Campling and Michael Sharpe, Oxford University Press', Oxford 2006. ISBN: 019852882-5*

## **What are Functional Movement Disorders?**



### **Patient Information Leaflet**

## Functional Movement Disorders

This leaflet aims to explain a bit about functional movement disorders and how you can begin to overcome them

Not all of it may apply to you and you should discuss it with the doctor who gave it to you



**Patients with functional movement disorders often end up not feeling believed by doctors**

### What are functional movement disorders?

A functional movement disorder means that there is abnormal movement or positioning of part of the body due to the nervous system not working properly.

Patients with a functional movement disorder may experience a range of distressing and disabling symptoms: Some patients may experience *too much* movement of a body part, for example, tremor (shaking), jerking or twitching of a limb or the head. Other patients may experience *too little* movement of a body part, for example "spasm" or clenching of an arm or leg which is then difficult to move.

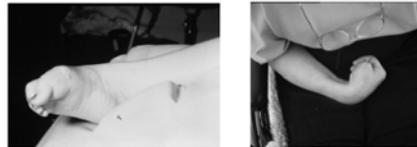
Unlike other movement disorders (e.g., Parkinson's disease), a functional movement disorder is **not caused by damage** or disease of the nervous system. It is however due to a **reversible** problem in the way that the nervous system is working. This means that a functional movement disorder can get better and even go away completely.

### Why are my tests normal?

Patients with a functional movement disorder have normal scans and other investigations. When they are examined, the doctor usually does not find any change in reflexes or other evidence of nervous system disease. This is because in a functional movement disorder all the parts of the nervous system are there, **they are just not working properly together.**

Your doctor may be able to find specific physical signs of a functional movement disorder when you are examined and make the diagnosis in the same way as you would with a condition like migraine (which also does not have a 'test')

If you were a computer, it's a bit like having a software problem rather than a hardware problem.



**Patients with functional dystonia often have a 'clenched hand' or a twisted foot**

### Am I just imagining it then?

One of the big problems patients with a functional movement disorder experience is a feeling that they are not being believed. This is partly because many doctors are not trained well in physical symptoms that are not due to disease and research in these areas is very poor. Some doctors really don't believe patients with these symptoms. Others do believe them but find it hard to know how to help.

*So if it's a real condition but it's not a disease, what is it? Am I just imagining it?*

The answer is you are not imagining or making up your symptoms and you are not 'going crazy'. You have a functional symptom or functional illness.

### What about all my other symptoms?

These are some of the other symptoms that patients

with functional movement disorder can experience as part of their illness. Often these symptoms are also caused by dysfunction of the nervous system as part of the same illness.

- Weakness or Paralysis of a Limb
- Numbness or tingling
- Fatigue
- Arm or Leg pain
- Back or Neck pain
- Headache
- Poor concentration
- Sleep disturbance
- Word finding difficulty
- Slurred speech
- Blurred vision
- Bladder or Bowel symptoms
- A floaty, distant feeling that things around you aren't quite real (derealisation)
- Attacks that look like epilepsy but are not
- Frustration, Anger
- Low mood
- Lack of enjoyment
- Worry

### Why has it happened?

Functional movement disorders are a complex problem. They arise for different reasons in different people. Often the symptoms are accompanied by feelings of frustration, worry and low mood but these are not the *cause* of the problem.

We recognise a number of different situations in which functional weakness can arise. Your symptom may fall in to one of these categories although often none of these appear relevant:

1. **After an injury / with pain**—People seem particularly vulnerable to functional movement disorders after a physical injury or if they have a lot of pain (particularly severe neck or back pain)
2. **An illness with a lot of fatigue or bed rest**—functional 'dystonia' (clenched hand or twisted foot) often develops slowly in people who are suffering from severe immobility or pain in a limb.
3. **Waking up from an anaesthetic after an operation**—this is not due to damage from the anaesthetic but may be something to do with the temporarily altered brain state when coming round. Functional movement disorders may also begin after experiencing a 'spaced out' or dissociative attack

We are beginning to understand why people are ....