

We are beginning to understand why people are 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 a stroke, something that everyone understands and sympathises with. Its very important to know that unlike someone with a bad stroke 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**

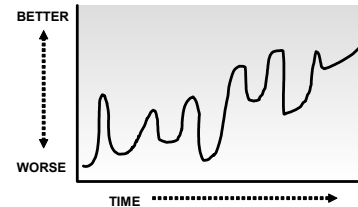
### *What can I do to help myself get better?*

If you have had the symptoms for a long time you cannot get better quickly from them.

These are some of the things that 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 weakness not to think too hard about the limb when you are using it—you may find this only makes it harder for the messages to reach it from your brain.

- **Increasing activity (continued)** 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. 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
- **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 weakness is 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

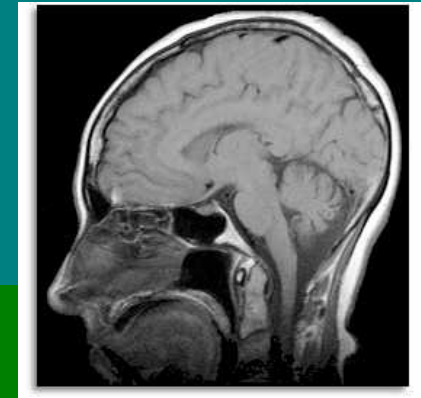
### *Where can I go for more information?*

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*

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## **What is Functional Weakness?**



**Patient Information Leaflet**

## Functional Weakness

This leaflet aims to explain a bit about the symptom of functional weakness and how you can begin to overcome it

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



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

It is likely that in common with other patients with functional weakness, that this is not your only symptom

### What is functional weakness ?

Functional weakness is weakness of an arm or leg due to the nervous system not working properly. It is not caused by damage or disease of the nervous system.

Patients with functional weakness experience symptoms of limb weakness which can be disabling and frightening such as problems walking or a 'heaviness' down one side, dropping things or a feeling that a limb just doesn't feel normal or 'part of them'.

To the patient and the doctor it often looks as if you have had a stroke or have symptoms of multiple sclerosis. However, unlike these conditions, with functional weakness there is **no permanent damage to the nervous system** which means that it can get better or even go away completely.

### Why are my tests normal?

Patients with functional weakness have normal scans and other tests. 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 functional weakness all the parts of the nervous system are there, **they are just not working properly** so that when you try to move your arm or leg it doesn't do it as well as it should.

Your doctor may be able to find specific physical signs of functional weakness 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 weakness sometimes drag their leg behind them like this**

### Am I just imagining it then?

One of the big problems patients with functional weakness 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 its 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 weakness 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.

- 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
- Panic

### Why has it happened?

Functional weakness is a complex problem. It arises 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 weakness 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**— weakness can develop slowly in people who are suffering from a lot of fatigue or exhaustion. In some patients too much rest can bring the symptoms on
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. Similar things sometimes occur when you wake up normally.