

UNDERSTANDING FUNCTIONAL LIMB WEAKNESS

When you first go to your doctor with the alarming symptoms of arm or leg weakness, you may wonder if it is caused by a stroke or multiple sclerosis.

However, there is another cause for these symptoms, known as 'functional limb weakness'.

In functional limb weakness the symptoms are due to a problem in the way the nervous system is working but not due to permanent damage to the nervous system. This means that there is the potential to get better.

Functional limb weakness is not a well known condition, even among health professionals. The aim of this factsheet is to help you understand functional limb weakness and how to cope with it better.

All of this information may not apply to you and you should discuss your own situation with your doctor.

There are other ways functional symptoms can affect people such as movement disorder and numbness.

The website www.neurosymptoms.org has more information.

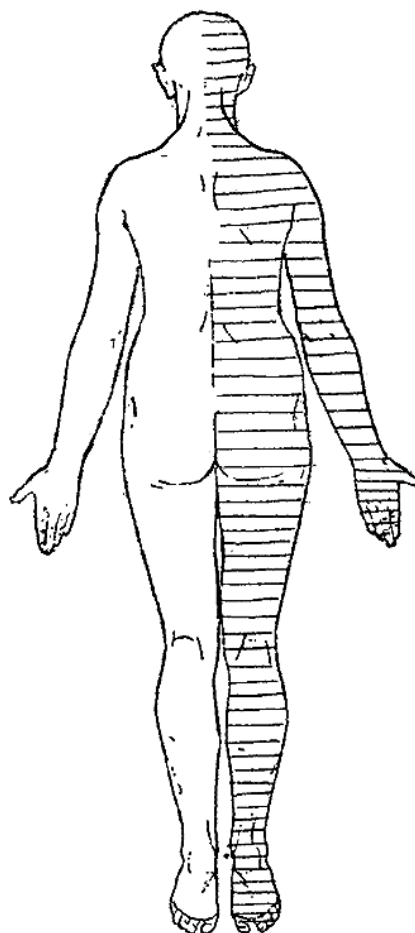
What is Functional Limb Weakness?

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

If you have functional limb weakness you may experience symptoms such as:

- problems walking
- 'heaviness' down one side
- dropping things
- feeling that a limb just doesn't feel normal or 'part of you'

The symptoms can all be disabling and frightening.



FACTSHEET

How is a diagnosis of functional limb weakness made?

The diagnosis of functional limb weakness is usually made by a neurologist or stroke physician.

There are positive features when the doctor examines you which lead to the diagnosis.

Positive features include the following:

- Hoover's sign – in this test, your affected leg, for example, may be weak when you try to push down. However, when the doctor asks you to push up with your other leg the strength in your affected leg returns to normal. Some people with functional limb weakness use this as a form of physiotherapy to encourage normal movement in their affected leg (and to help demonstrate to themselves that the diagnosis is correct).



Doctors use tests like Hoover's sign to positively diagnose functional limb weakness. The picture on the left shows that the patient's leg is weak. The picture on the right shows the leg strength returning when the patient lifts up their good leg.

- A pattern of weakness called 'global weakness' in a limb. This means that all the muscles in a limb are affected equally, whereas in a stroke some muscles are weaker than others. This type of weakness can lead to a 'dragging' type of walk which is typical of functional limb weakness.



- A difference between the amount of power on the bed and when walking. Some people with functional limb weakness have relatively normal leg strength on the bed but weak legs when walking. The reverse can also be true. This is not because they are not trying; the variability of strength is a key feature of the diagnosis.
- Collapsing weakness – this is a tendency for an arm or leg to ‘collapse’ when being tested. This may be interpreted by a doctor as ‘not trying’. In fact, people with functional limb weakness typically find that the limb gets weaker the more they try.

Your doctor will not usually find changes in your reflexes or other evidence of a structural neurological disease (such as stroke or multiple sclerosis).

In functional limb weakness, scans and other tests may be done. The results of these tests will usually be normal unless you have an additional /different neurological condition as well as functional limb weakness.



What about other symptoms?

It is likely that, in common with other people with functional limb weakness, that this is not your only symptom. Other symptoms that you may have include:

numbness or tingling	sleep disturbance	attacks that mimic epilepsy but are not
fatigue	finding the right word	frustration and/ or anger
arm or leg pain	slurred speech	low mood
back or neck pain	blurred vision	lack of enjoyment
headache	bladder or bowel problems	worry
poor concentration	a floaty, distant feeling that things around aren't quite real (dissociation)	panic

So am I imagining it?

You may wonder sometimes if your problems are 'all in your mind' or 'just imagined', because it can't be seen on a scan, because your symptoms are variable, or because nobody you know has heard of it.

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

In functional limb weakness all the parts of your 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.

If you were a computer, you would have a software problem rather than a hardware problem.

People with functional limb weakness often worry that health professionals don't believe them. Feeling that you are not being believed is one of the worst issues to cope with.



Not all doctors and nurses are well trained in dealing with functional symptoms like this and don't always know how to help. This can make you feel like you are being abandoned or ignored.

Why has it happened?

Functional limb weakness is a complex problem. It arises for different reasons and is often accompanied by feelings of frustration, worry and low mood but these are not the cause of the problem.

There are different situations in which functional limb weakness may arise. For example:

- after a physical injury
- with pain (particularly severe neck or back pain)
- with a panic attack or hyperventilation (some people describe a frightening spaced out feeling called dissociation at the moment the symptom starts)
- an illness with a lot of fatigue or bed rest
- waking up from a general anaesthetic
- a migraine attack

You may fall into one of these categories although sometimes none of these appear relevant.

APPROACHES TO RECOVERY

Doctors and other health professionals are beginning to understand more about the day to day problems of living with functional limb weakness. It is helpful for everyone involved in your care to think in terms of all your symptoms and not just your affected arm or leg.

It is frustrating not to be able to explain your symptoms to other people especially when the symptoms can be very debilitating. It is understandable to feel that it would be simpler to tell people you have had a stroke, as this is something that people recognise and sympathise with. However, functional limb weakness is increasingly being recognised as a common problem in neurology and public awareness will improve over time.

It is very important to know, and remind yourself, that you have the potential to get better, even after having the symptoms for a long time.

Feeling confident about your diagnosis

If you have functional limb weakness it is really important that you feel confident about your diagnosis. If you aren't confident in the diagnosis then it makes it hard to do many of the things that are necessary to try to overcome the problem.

If you find that you have been given this diagnosis but you just can't gain any confidence in it, then there are several things to consider:

- Go back to your specialist and ask them to explain again why they have made the diagnosis. There should be positive features of the diagnosis on examination as listed above.
- You might have rejected the diagnosis of functional limb weakness because a doctor said the problem was 'stress-related' (and you weren't feeling stressed). You need to discuss this with your doctor. Both doctor and patient need to understand that the diagnosis is based on the nature of the limb weakness, not whether there was stress present or not.
- You might have developed a constant worry about having another condition like stroke or multiple sclerosis which you can't shake off even though you know it is not logical (in the same way that some people have a phobia of flying even though they know it's not logical). This is called 'health anxiety'. It is only experienced by a small proportion of people with functional limb weakness but it is worth identifying as it can usually be successfully treated.

Taking a rehabilitation approach to recovery

People with functional symptoms often have fatigue, weakness or pain which is made worse by exercise.

To overcome this you will need to think about gradually increasing the amount of activity you do.

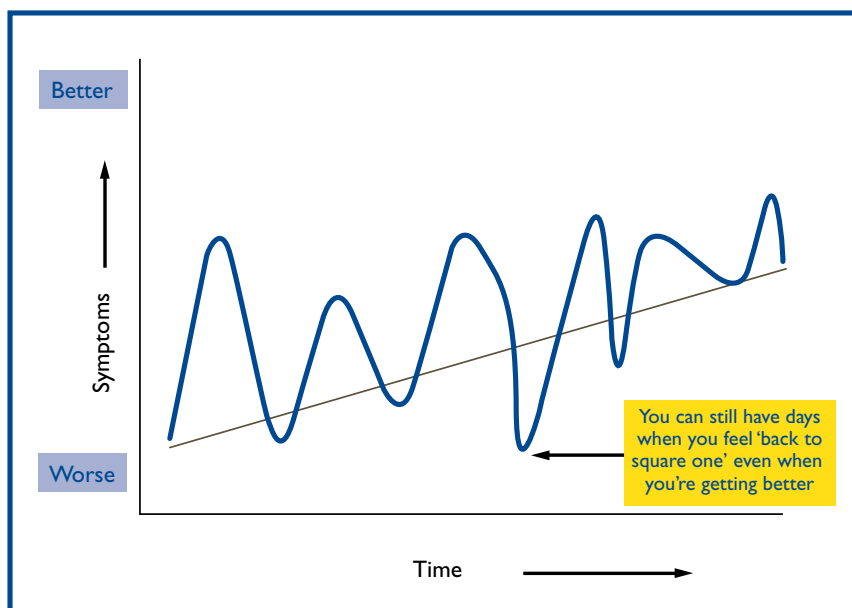
What often goes wrong is that increasing activity leads to increasing symptoms, which can make you think that you must be making your condition worse, or causing damage to your back or muscles.

The important thing to remember is that you're not causing damage if you do it slowly. Yes, activity makes the symptoms worse; but no – **you are not causing more damage.**

A very common problem in rehabilitation is a tendency to do too much on a good day and then feel much worse later that day or the next day.

- Getting better requires dealing with symptoms that may change from day to day.
- You will probably experience good and bad days. There may be days when you feel you have gone 'back to square one'.
- You should expect 'relapses' 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.

When your symptoms get worse again, it is demoralising, but this is to be expected. It is a common event as people try to recover from a debilitating illness. The graph below shows what happens.



It is important not to overdo or underdo it:

- Set yourself a modest task; it might be a walk to the shop; or a small task in the house. Make it something that is a bit less than you would do on your best day but more than you would do on your worst.
- Stick to the same level of activity every day, and hopefully you'll find that after a while, perhaps a few weeks, this same level of activity may make you just a little less weak and tired than it did before, or cause just a little less pain. You can then slightly increase the activity, in length or pace, and do the same again.



You will still have days when you feel as if you're 'back to square one'. But try to concentrate on knowing that you are slowly improving overall.

This is all 'easier said than done' and it needs your motivation to succeed.

The more activity you do, the fewer symptoms you will get – in time. This may be weeks, but if you have had symptoms for months it may be much longer.

Physiotherapy

It can be very helpful if you can find a physiotherapist who is experienced with functional limb weakness.

The physiotherapist is there to guide your self-help and rehabilitation: not to do the treatment for you.

You may find that your weakness is worst when you are trying your hardest to move and improves when you are distracted. Physiotherapists can give you some exercises involving your whole body which helps you avoid thinking so hard about the limb when you are moving it.

Physiotherapists and occupational therapists can often be very helpful in these situations. They are used to working with the day-to-day limitations that people have regardless of



their cause. They may be able to design a graded exercise program that suits your particular symptoms and help you work through it.

Your employer may also be able to provide an occupational health nurse who can liaise with you, your doctor and your employer about arrangements for a phased, planned return to work.

Drug treatment

Treatment with antidepressants can be helpful for some patients with functional limb weakness, even if you are not feeling depressed. They are not addictive, like tranquillisers or painkillers, and will not harm you. They seem to work as a 'nerve tonic' – putting right imbalances in chemicals in your brain and making your nervous system work better again, particularly if you are having trouble sleeping. You can get better without them but they may well increase your chances of success.



Dealing with stress

Doctors used to think that everyone with functional limb weakness had some sort of recent life stress causing their symptoms. We now know this is not the case for a lot of people and it can be frustrating when a health professional insists that there must have been some sort of stress.

However, many people with functional limb weakness can be under stress, either from the uncertainty and worry of the symptom itself, or from other external factors.

Talking to family, friends or a health professional or counsellor may help in trying to overcome this.

Psychologists and psychiatrists may also be able to help if you have developed anxiety, depression or panic attacks along with functional limb weakness.

They can also help you cope with the inevitable 'ups and downs' that go along with attempting this kind of rehabilitation and with understanding the diagnosis.

Where can I go for more information?

There is a lot more information on functional limb weakness, other functional neurological symptoms and common associated symptoms like pain and fatigue at:

www.neurosymptoms.org

The information in this factsheet has been adapted for use by CHSS, by kind permission of Dr Jon Stone, Consultant Neurologist Edinburgh University December 2012

**If you would like to speak to one of our nurses in confidence,
please call the Chest Heart & Stroke Scotland Advice Line**

0845 077 6000

The Advice Line is open from Monday to Friday 9.30am - 4pm.