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Functional disorders
An information leaflet

This document gives information about **functional disorders** - what they are, how they are diagnosed, and how they may be helped. It is designed primarily for patients and their families, but it is also relevant to professionals. Its main messages are that these disorders are common, can be diagnosed specifically, and patients with a functional disorder can get better. The document stresses that the disorders are not imagined (by the patient), and that it is usually difficult to pinpoint any specific cause. The exact nature of the disorders and how symptoms and problems arise is unknown, but it is best considered within a holistic model of health and illness; a separate document discusses holistic medicine. (see: http://www.noc.nhs.uk/oce/research-education/holistic-health-care.aspx).

The document considers:

- making the diagnosis
- why it has this name
- how it arises and risk factors
- what happens over time
- what treatments are possible
- how a patient may help him or herself

The main facts are that:

- functional disorders are very common, being present in at least 20% of most out-patients and possibly 5% of inatients
- the diagnosis is a positive diagnosis, and it is not simply one of desparation
- there is rarely any single cause, and it is likely to be related to a multitude of factors
- there is no specific treatment, although several therapies may help to an extent:
  - anti-depressant drugs
  - cognitive-behavioural therapy
  - graded progressive exercise
  - structuring each day including regular sleep and activities
- other drug treatments are usually unhelpful and may add symptoms

The key to successful recovery is for the patient, with support from his or her friends, family and others, to take control over the illness and to devise and set out their own goals for recovery and rehabilitation. A way of doing this is set out in the document

Introduction
You have recently been seen and assessed, and it has been concluded that your problems arise through functional mechanisms and do not represent any specific disease or diagnosis. The doctor seeing you has concluded that you have a '**functional disorder**'.

This document tries to explain this and to help you get better. This document does not specifically relate to your particular problems, but does relate to the type of problem that you have.

The document has two main parts. The first part discusses the diagnosis; how is it made, what is a 'functional disorder', what causes it, is it a psychiatric illness etc? The second part discusses treatments.

The Diagnosis

This section is primarily about the nature of the disorder.

How was the diagnosis reached?
You are probably concerned that no test has been done to prove the diagnosis, and that you have many symptoms and problems that the doctor has not particularly looked into. Not surprisingly, you are probably doubting that the diagnosis is correct. This section gives a brief explanation about how the diagnosis was reached.

Diagnosis of any illness has at least three inter-connected parts:

- Can disease of or damage to one organ cause the symptoms experienced?
- Is there an alternative explanation for the symptoms?
- What is the most likely diagnosis?

The doctor has probably used the following logic to reach the diagnosis:

- no single disease could account for your symptoms.
- the symptoms are typical for a functional disorder.
- functional disorders are extremely common, accounting for 20%-40% of all consultations.
- therefore you have a functional disorder.

Making medical diagnoses
All medical diagnoses are made in the same way. When making a diagnosis, the doctor (or other person making the diagnosis) will consider all of the symptoms, how they started, what types they are, and any other characteristics of these symptoms. The doctor will also consider other factors, such as how much someone is able to do.

He or she will then consider whether disease of or damage to a particular part of the body could possibly account for the symptoms and other problems. If necessary he or she will organise further tests either to confirm a particular diagnosis, or to rule out a particular diagnosis.

The diagnosis given eventually is the one that, in the doctor's opinion, is most likely to account for the particular pattern and type of symptoms.

All medical diagnoses are subject to some uncertainty. Even with relatively straightforward diagnoses, such as Parkinson's disease, experienced neurologists will make a mistake in about 10% of cases. It is relatively rare for a diagnosis to be absolutely certain, and usually one is only certain after taking a biopsy or doing an operation.

Nonetheless in practice most diagnoses are correct, and in hospital over 80% of diagnoses are made by the doctor on the basis of the general practitioner's letter and the history given by the patient. Examination and investigation may help with the next 10%, and in 10% it is simply a matter of waiting to see if any diagnosis becomes obvious.

Diagnosing a functional disorder
The diagnosis of a functional disorder is a positive diagnosis. In other words the diagnosis is made on the basis of the history and the symptoms. The diagnosis is not made simply because the doctor cannot think of any other diagnosis. In other words the doctor is **not** saying "*I cannot explain your illness and so it must be functional*"; she or he **is** saying "*I can explain your illness; it is a functional illness because … (see next paragraph)*".

The following features make a diagnosis of a functional disorder much more likely:

- the presence of very many symptoms usually over many years,
- symptoms that vary from time to time over weeks, months or years
- symptoms that come from many different parts of the body
- symptoms that would indicate disease of many different organs
- symptoms that are often difficult for someone to describe in detail
- marked variability in symptoms on a day-to-day and hour-to-hour basis
- the presence specifically of fatigue, reduced memory and concentration, and pain
- often worsening of symptoms on or shortly after doing more
- sometimes symptoms that are in association with other events or activities.

In practice by the time the diagnosis is made the person has also usually had a large number of investigations. Usually most if not all of these have been normal but sometimes one or two may be abnormal.

There are three explanations for abnormal test results in this situation:

- 'normal' is defined as what 95% of the population have; 5% will always be abnormal.
- Minor 'abnormalities' are common, but in most cases are irrelevant and unrelated to the symptoms experienced.
- Rarely the abnormality is due to an incidental (unrelated) event or illness (e.g. injections or falls may cause some enzymes to be raised)

It is important to stress that:

- no test can prove the diagnosis of a functional disorder (because there is no abnormality to find)
- abnormal tests do not, in themselves, prove that a disease is causing symptoms (or even, in many cases, that a disease is present).

It is also important to realize that

- it is impossible to prove absolutely that a disease is **not** present (proving a negative is impossible)
- between 20% and 40% of people seeing doctors in any and every clinic have symptoms that do not arise from disease.

Are functional disorders common?
Yes. Somewhere between 20% and 40% of people attending almost any hospital clinic have symptoms, and sometimes disabilities for which there is no specific explanation. In other words the doctors cannot find evidence for any disease, or other damage to account for the symptoms.

In General Practice it is quite likely that the number is even higher. This finding has been confirmed in many research studies, over many years, and in many parts of the world.

Why is it called a 'functional disorder'?
There is no good name for this type of illness. Many different names have been used over the years. At the moment the preferred name is "a functional disorder". This term is used because the person has a disturbance of their functioning that arises in the absence of any disease. The person's function is disordered.

The following names have been used by some people sometimes:

- hysteria, hysterical disorder, conversion disorder
- somatisation, somatoform disorder
- non-organic symptoms, non-organic illness, medically unexplained symptoms
- stress-related symptoms, anxiety, atypical depression.

Many other names have been used.

Are there different types?
Yes and no! Although all of the functional disorders are similar and are best considered as the same type of problem, there are many different names used. In part this is because different people have different types of symptoms. In part this is because different doctors and different specialists have used different names.

Some examples of functional disorders include:

- irritable bowel syndrome, functional bowel symptoms
- headache, migraine, stress headache, benign headache
- chronic pain syndrome, chronic low back pain, fibromyalgia
- chronic fatigue syndrome, neuraesthaenia, myalgic encephalomyelitis (ME)
- non-cardiac chest pain,
- pseudo seizures, non-organic seizures, non-organic epilepsy
- functional dystonia, non-organic movement disorders
- post-traumatic stress disorder

There are many more, but you will see that there are many names. Although all of these different types have been recognised and described at some time or other, it is extremely important to understand that they are all probably part of the same problem or disorder. Indeed many people with one of these labels will also suffer from symptoms characteristic of another syndrome, and the label given depends on which clinic the person attends.

Can the diagnosis be wrong?
It would be foolish to state that the diagnosis can never be wrong. As stated above, no diagnosis is ever certain for ever. However in practice the diagnosis is almost always correct. This is because no disease could:

- Possibly account for the huge range of symptoms experienced.
- Be compatible with the marked variation seen in symptoms and in severity
- Be present for so long without being obvious, even without tests.

Sometimes some investigations will have minor abnormalities. This is to be expected. For medical tests, normal is defined as what is present in 95% of people. One test in 20, according to this definition, is going to be abnormal. Consequently if you have many tests, several are going to be abnormal. This does not disprove the diagnosis.

What is the cause?
This is not known, but it is extremely unlikely that there is any single cause. This is true of many medical diseases.

Obviously for most diseases we know what has to be present for the disease to occur, but we still do not know why a particular person gets a particular disease at the time they do. For example we know that stroke is more

likely if you have diabetes, high blood pressure, and other risk factors, but we still have no idea why someone has a stroke on the day and at the time they do, nor why they had a stroke and their friend, who has the same risk factors did not.

We do know some so-called **risk factors** for functional disorder. These are items that are found more commonly in people with functional disorders. This does not mean that these factors are causes.

The factors that appear to be associated with functional disorders include:

- a stressful childhood, with such things as abuse, being orphaned, and losing a parent
- experience of a severe unusual stress, such as exposure to a very nasty accident
- ongoing high stresses in life, such as an unsatisfactory job, problems at home, financial worries.

However it is vital to emphasise two points. First, these factors are unlikely to be direct causes. Most people with a functional disorder do not notice any obvious relationship between changes in external factors, and changes in their symptoms. In other words changes in stress do not lead to changes in the severity of the problem. Equally many people with these stresses do not develop functional disorders.

Second, the word 'stress' is not particularly good. It refers to anything that causes a stress reaction in the person, and people vary enormously in what causes a stress reaction. It is s useful concept but rarely useful in deciding on clinical treatments.

Why have I got it?

We cannot tell why you have got it. There are probably several things that, taken together, have caused you to have a functional disorder. No one factor is particularly the cause, and removing one factor may not change matters.

Furthermore it is important to distinguish between things that precipitate an illness and things that prolong or maintain an illness. For example an accident might cause pain in an ankle due to mild strain of a ligament lasting a few hours or days, but it cannot explain why someone still has pain (and usually much more) many months or years later.

Therefore it might be true to say that the illness started because of something (if there was an obvious cause), but this cause does not explain why the illness was prolonged and is still present.

Does it get better?

This is not easy to predict for a particular person. In general we know that people who have only had these problems for a few days or weeks tend to get better, and we know that people who develop the symptoms after a sudden and unusual event also tend to get better. On the other hand people who have already had functional illnesses of one sort or another for more than 10 years usually do not get better, certainly on their own.

We do know that if it does get better, it does so slowly and in a fluctuating way. In other words it does not progressively get better on a day by day and week by week basis, but tends to fluctuate. On average it improves, but on a day-to-day basis it may sometimes get worse for a short while.

However there is always the potential for a full recovery because we do know that there is no abnormality in the body that precludes full recovery.

Is this "all in the mind"? Am I imagining it?
No.

First, all the symptoms are experienced by you and are therefore real. For example everyone has pain from time to time, and no one believes that that is "*all in the mind*". People also get "*butterflies in the stomach*" when they are nervous, but no one believes that they actually have butterflies in the stomach nor do they believe that this is "*all in the mind*".

Second it is important to stress that this is not something that you are causing for yourself. As far as we know people cannot give themselves this type of illness. Although some people are more likely to get it to others, it is not something that you can invent, makeup, pretend, or imagine.

Is this a psychiatric or psychological illness?
This question cannot really be answered. Some people believe that any illness that does not have an obvious disease causing it is a psychological or psychiatric illness. The big American book of psychiatric classification of illness includes functional disorder as a psychiatric illness. However most psychiatrists, in the UK at least, do not believe that this is a psychiatric disorder.

The best way to consider it is as follows.

This is certainly not a psychiatric disorder like schizophrenia, or other disorders where thinking is markedly disordered and an individual experiences delusions and hallucinations.

There is some relationship with depression. However it may well be that the depression is secondary to the functional illness. In any event depression is extremely common, and many people would not consider depression or anxiety to be a psychiatric illness.

Psychological factors may be among the factors that precipitate or prolong this disorder. This will depend upon the individual case. This does not make it a psychological illness necessarily.

However psychological treatment methods do help.

In summary, antidepressant medication and psychological treatment techniques certainly help people with this type of illness. Whether or not you choose to define it as a psychiatric or psychological illness is up to you, but it should not really be important.

Treatment

This part considers how to get better.

Is there any drug treatment?
There are some treatments for some of these conditions that have been shown to be beneficial. There are also some treatments that can seem very unlikely to work.

For some particular symptoms, such as headache which come on an occasional basis, it is perfectly reasonable to take tablets or other drugs that are known to help that particular symptom. The major caution is not to take this type of treatment on a daily basis, at least without discussing this, because often the treatment ceases to be effective if taken every day.

We know that painkillers are often not very effective in the long-term for the pain that is associated with functional disorders. In the short-term painkillers are effective, as they are for everyone. In the long-term they are usually ineffective.

We know that antidepressant drugs often help; this applies to all functional disorders. We do not know how this works, but there is

good evidence that it does work. Certainly antidepressant drugs can help with many of the common symptoms including poor sleep, chronic pain, and low mood. As far as we know all antidepressants do this, and your doctor can choose one that he or she is familiar with. They work even if you do not feel depressed.

We should stress that the fact that anti-depressant drugs work does not prove that this is a form of depression. First, research shows that improvement in symptoms is not necessarily related to changes in mood. Second, we know that anti-depressant drugs have other effects beyond reducing depression, such as increasing appetite, controlling bladder irritability and reducing pain.

For some functional disorders a specific drugs seems to help many people. For example mebeverine often alleviates the problems of the irritable bowel syndrome.

Apart from taking antidepressant drugs, the general advice is to avoid taking drugs on a regular basis. This is for two reasons.

First, there is no good evidence that taking any drugs on a regular basis over a long time helps with most functional disorders.

Second, all drugs carry side-effects and quite often the side-effects are very similar to the problems associated with the functional disorder. For example many painkillers lead to fatigue, constipation and other symptoms that are already part of the functional disorder.

What about therapy?
It is possible, for some people with quite severe disability, that a short episode of physiotherapy or occupational therapy on an outpatient basis may help, primarily through teaching someone how to walk or undertake an activity safely. It may also restore confidence to an extent.

However, generally speaking rehabilitation therapy in terms of physiotherapy, occupational therapy or speech and language therapy is usually not particularly helpful, certainly in the long term.

The main health therapy that is known to be helpful comes from a clinical psychologist. They can help you to learn for yourself how to help yourself get better. This usually involves a form of treatment known as "cognitive behavioural therapy". This is a therapy where you learn how to think differently about your symptoms, and also to behave more normally despite your symptoms.

Recently it has been shown that cognitive behavioral therapy can be given primarily through using work-books and/or internet-based programmes.

The second main effective approach involves changing life-style and this depends largely on the patient. The evidence would suggest that the following will help most people, regardless of the specific label:

- establishing a normal, regular sleep pattern
- ensuring that each day has a planned structure, with definite times for events such as getting up, eating, going out, an going to bed
- increasing regular exercise in a progressive, graded manner

This change in life-style may need to be combined with cognitive behavioral therapy because most people will say *"but I have tried that and I feel worse"*.

What else?
Many other treatments have been considered. Counseling is rarely helpful. There is no evidence to support it and

although past trauma may be associated with increased risk, we cannot undo or alter past events.

Sometimes there is a clear relationship with a particular stressful factor that can be changed, such as caring for a heavily dependent child without help, but this is rare. Generally reducing apparent stress rarely helps, certainly in the short-term; it may help in the long term.

What can I do to help myself?
The key to success in this condition is in fact for **the person with the condition to help themselves**. The following steps are important.

First, it is important to **stop looking for or asking for further tests**, or further medical consultations. Tests carry risks. Medical consultations take time. It is important to understand and realise that there is never going to be a specific other diagnosis found. No single cause will be identified and no single treatment that will lead to a 'cure' exists. Your general practitioner will be able to give you all of the specialist medical help and diagnostic expertise that you need.

If you can come to understand and accept that there is not a disease causing these symptoms, you are probably already halfway to getting better.

Second, it is important to **stop looking for a specific treatment**. You must realise that no external treatment such as a drug or course of tablets, or a course of therapy is going to cure you. Most of the work comes from you.

However, as we have said earlier, it is often helpful to take an antidepressant for up to 12 months. Ideally this would be combined with cognitive behavioral therapy. This will allow you to help yourself more efficiently. It is also possible that taking symptomatic treatment on an occasional basis, for example for headache may help you.

The important third step is to reduce and **reduce and stop as many of the medications** you are taking at present as possible, obviously checking with your general practitioner that they are not needed for some other reason. **This must be done slowly.**

Next it is important to understand that **your condition will fluctuate** on a day-to-day and week by week basis. You must not expect to get better on a steady course. This fluctuation has no meaning.

You should certainly not look for a cause for this fluctuation, and you should not attribute any slight decline to something that you have done or failed to do. We do not know why the condition fluctuates, but it is not related to things that people do or fail to do.

Specifically you should not stop doing things simply because you have got a little worse. You must accept that 'bad days' (and even weeks) may occur for no obvious reason.

Finally, and most importantly, you need to **set your own goals**, and to **take control of your own treatment**. In other words, although you may seek advice from doctors and therapists and others, you need to decide for yourself how quickly you are going to get better, and what you are going to concentrate on improving first.

The general principles are reasonably easy.

Your aim should be to develop or return to social activities and roles that are important to you, and you should focus on this; **you should not focus on the symptoms at all**.

Therefore you should concentrate upon activities (i.e. things that you do), and should not worry much about the symptoms.

Generally speaking if you start doing more, the symptoms will get less on their own. Choose activities that are important to you. You should attempt to get better in areas that concern you most.

Set yourself goals about four weeks apart. These goals should be reasonably likely to be achieved, but must challenge you to an extent. They should be functional, and will usually involve timing something or measuring something. For example, if at present you only go to a local shop, and only spend five minutes shopping, and only do so once a week then you might set a goal of spending 10 minutes shopping, and doing so twice a week. Later on you could set goals about going to more distant shops, or spending longer doing it.

You should aim primarily to reduce how bad you are at your worst, rather than aiming to increase what you can do at your best. Your 'average' should improve because your worst slowly gets less bad.

You should to a little more each day or week. You must not reduce your activities simply because symptoms get worse, because as you increase activity the symptoms will initially worsen – this is natural in all long-term illnesses.

You should avoid going "over the top" on a good day. When things are going well, do not try to do an excessive amount. In other words you need to build up your tolerance and capability slowly.

Write down your goals. Keep a record of what you achieve. Because this is a slow process, it is very easy to forget what you had intended to do, or what you have already achieved. However the record should be brief and to the point, and should focus on activities.

Do not write down a record of your symptoms. You should ignore your symptoms as much as possible, and certainly you should not be aiming to reduce your symptoms. While you make your main focus the reduction of symptoms, you will not make so much progress.

If I get better, will it come back again?
This is certainly possible, but if you have learned how to get yourself better then you are less likely to get it back again, and you will certainly be able to treat it for yourself.

Conclusion
You have been diagnosed as having a common disorder, best referred to as a functional disorder. Further medical tests are not needed. The only specific treatments known to have general benefit are antidepressant drugs, and psychological treatment techniques. As far as possible all other drug treatments should be reduced and stopped. Improvement is certainly possible, but largely depends upon you being able to take control, and gradually increasing the amount of activity that you undertake. **A brief guide on helping yourself is on the last page.**

Postscript
I hope that this is helpful. Any comments on how it could be improved would be most welcome. If you have any specific questions than please feel free to contact me.

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Your plan – a brief guide

Take control – set your own goals
You will only get better if you (with your family) take control. You need to get expert at helping yourself. The best way is through setting goals, **writing down** what you will achieve. You should:

- write it down
- specify the activity (what you do) and when you will achieve in (e.g. 2 weeks away)
- usually set goals for two to four weeks
- never set goals that concern symptoms (e.g. pain)
- stick to the goal

You need to decide what things you are not doing are most important to you, and aim to get these back first. Then you need to set some milestones between the current situation and your main goals, putting your main goals about 9-12 months away and dividing up progress equally over that time.

Reducing medication
Generally this should be slow, but continued regardless. A reasonable plan is to stop one tablet (**not** one drug) each week or two. In other words if you take a total of 27 tablets each day now, reduce to 26 tablets next week, 25 the week after and so on. It is important to:

- discuss your plan with your GP, getting advice on best drugs to reduce first
- write down your plan, with dates
- stick to it whatever happens in the short term

Increase activity (what you do)
First you should write down for one week what you actually do (what, how long, how much). Then you need to do two things:

- Choose a minimum level of activity slightly above the lowest. Then never go below that level. And next week move it up a little.
- Choose a slight increase above the top level, and try to achieve that a bit more often or try to do a little more.

The important points are to:

- establish your level of activity now over one or two weeks
- set your own goal as to what level you will try for
  - make it a bit hard but not too hard
- not be over ambitious
- write it down

Establish structure/routine in your life
Many people with this condition lose the regular routine in their life. They no longer go to work, and often most other fixed points such as the time of going to bed and getting up, and the time of meals become less fixed.

There is some evidence that re-establishing a good daily routine helps in recovery. In children with this disorder it has been found that a good pattern of sleep helps.

Therefore you should try to:

- go to bed at the same time each night. You should prepare for and get into bed and try to sleep. If you do not actually go to sleep, stay in bed until you do.
- get up at the same time each morning. This should usually be between 07.00 am and 08.00 am. If you may not wake up, use an alarm and get up.
- Eat meals at a regular fixed time (usually with others if there are other people in your house)
- Avoid having sleeps during the day
- Develop a routine of when you do certain activities such as cooking, cleaning, going out.