

Taking control of your functional symptoms



Information for patients

Neurology - Psychotherapy Service



Diagnosed with functional neurological symptoms?

Some tips which may help

People often feel quite confused and helpless when they are diagnosed with functional symptoms. They are told that they can't be cured by medication and may assume that there is nothing they can do. They may feel as if their symptoms have such an impact that they are no longer the person they used to be. However, there are many things you can do that may help you to take control of your symptoms and your life. Perhaps your friends and family can help as well. This booklet describes some approaches that many people find helpful. It may well take time to learn some of the techniques and feel the benefits from them, so be patient and keep on trying.

Things you can do

1. Understand the diagnosis

It can be difficult really to accept that your symptoms are not caused by a physical illness. Some people feel that the doctors just haven't got to the bottom of things, so they continue to look for a physical cause and ask for more tests and second opinions. Others end up feeling that they are not being believed by the doctors. They may feel embarrassed and isolated because they have never heard of functional illness and don't know how to explain it to other people. It is very helpful to get yourself better informed. Read the leaflet 'Functional symptoms: a short guide for patients and families', produced by this Trust. There is also an excellent website which will answer many of your questions. It gives interesting examples of other people's experiences and the wide range of functional symptoms:

- www.neurosymptoms.org

2. Understand your triggers

- Do your symptoms come and go, and do they vary in how severe they are? If so, see if you can start to understand what causes your symptoms or makes them worse. A good way to do this is to keep a diary of your symptoms and feelings. Write down each time your symptoms are triggered or get worse, when it happened and what had been going on in your life that day. Particularly make note of anything that might have made you feel emotional in any way.
- Also notice whether you were feeling tired, ill, where you were at the time and what you were doing.
- If you were watching TV, what were you watching?
- If you were chatting with friends, what were you talking about?

That way you may start to understand triggers that you were not aware of. For some people the symptoms may start or get worse straight after the trigger, for others it could even be the next day.

3. Sensory grounding

Some people find that their symptoms, particularly those that come and go, can be controlled or improved by something called 'sensory grounding'. In addition, many people with functional symptoms also have anxiety and panic attacks. Sensory grounding can be a good way to control these too, and this may improve your symptoms.

There are a number of ways of doing sensory grounding but the one described below has been found to be helpful by many people.

- It is best to practice this when you are feeling OK so that you will remember it better when you need it.
- Explain it to the people close to you, so that they can encourage you to use it if you forget in the heat of the moment.

- Many people find it helpful to carry something (e.g. a rough pebble, small nail file) around with them in their pocket or bag to rub during the sensory grounding.

This is what you do:

1. Feel something, preferably something rough or textured, with your fingers and thumbs. Really focus on what this feels like and how the sensations may change as you experiment with rubbing it harder or softer or in different directions. As you do this, put your feet flat on the floor and notice how solid the ground feels under your feet. If you are sitting down notice how solid the chair feels underneath you.
2. Look around you and really focus on the things you can see. Describe them to yourself in detail.
3. Listen and notice what sounds you can hear, e.g. people talking, birds singing, traffic noises, etc.
4. Remind yourself where you are, what day of the week it is, what year it is, who you are with, etc.
5. Remind yourself that you are safe.

4. Relaxation

Many people find that their symptoms are worse when they are tense. If you are tense you may find yourself squeezing your hands together or fiddling with things. You may tap your hands or feet, grind your teeth or hunch your shoulders. You may often feel 'wound up' or easily startled. In this case some kind of regular relaxation may be helpful.

- There are many relaxation CDs available, which may describe how to tense and relax your different muscle groups. Other CDs use soothing music, meditation techniques, whale song, etc to help you relax.

- Choose whatever works for you, or maybe just stop everything, listen to your favourite 'flop-out' music and give yourself time to unwind.
- You may find it helpful to put your relaxation CD onto an iPod or MP3 player if you have one so that you can use it wherever you like.

5. Abdominal breathing

Many people with functional symptoms or anxiety attacks find that at times it can feel difficult to breathe, or their breathing becomes quick and shallow. This is called hyperventilation. It can make you feel strange, dizzy and light-headed and can cause many symptoms, including numbness, tingling and stomach symptoms such as bloating or burping. Often people hyperventilate without realising it but your doctor or therapist may recognise what is happening. Abdominal breathing is a way of controlling your breathing, reducing these symptoms and feeling more calm. Practice this at home and then use it whenever you start to hyperventilate or feel anxious or panicky.

This is what you do:

1. Sit comfortably with one hand on your abdomen below the navel.
2. Slowly breathe in through your nose, and as you breathe in feel your stomach expand beneath your hand.
3. Pause for a count of 3.
4. Slowly breathe out through your nose and as you do so think "relax".
5. Rest for a moment.
6. Breathe for 20 breaths or until you feel back in control.

6. Time out on the spot

This is another good technique to use when you feel stressed or anxious. You can use it anywhere or anytime, and no-one else needs to know you are doing it. Just take a few minutes out of the stressful situation to go to the relaxing place in your mind.

This is what you do:

Think about a place you have been where you felt happy and relaxed. It might be somewhere you have been on holiday or a special place in your home. It should be somewhere you have felt calm and at peace. Imagine yourself in that place. Picture it clearly and think about what you can see there, what you can hear, how it smells, how it feels to be there. Get the image fixed in your mind so that you can call it up whenever you like.

Now, when you are feeling stressed, imagine yourself opening a door which takes you to this place. In your mind, picture yourself stepping into this place and soak up the atmosphere, feel the relaxation wash over you. You just need to do this for a few minutes, and then return to where you were or what you were doing before, but imagine taking some of the happy, relaxed feelings back into your life.

7. Don't be over-cautious; look for solutions not problems

Functional symptoms can feel frightening and disabling. Some people react to this by stopping many of their normal activities. So people may stop work and stay in the house most of the time. They may never go anywhere alone, stop using buses and trains and avoid being with people because they are embarrassed or worried about their symptoms. If you do this you are likely to get bored, feel frustrated, lonely and depressed and to focus all your attention on your illness. This can make your stress levels go up, affect your self-confidence and put a strain on

relationships. The longer you go without going out or doing much, the harder it gets to start again, and the more depressing life becomes.

- It is better to try to carry on with your normal activities as much as possible.
- Gradually start to do things and become more independent again. Find ways of tackling problems.
- Don't put life on hold until after your symptoms have gone. The happier and more interesting your life is, the better you will feel. This may well bring about an improvement in your symptoms.
- So plan outings, arrange treats for yourself and do things that are fun and interesting. This way, life becomes meaningful again.

8. Don't let yourself become isolated

Many people feel embarrassed or ashamed about their symptoms. They often don't know how to explain to people what is happening to them. As a result they may stop seeing friends, avoid going to places where there are people around, or even stop going out altogether. This too will make you feel lonely and depressed. It is much better for you to carry on seeing people and this may well help your recovery.

- So try to be bold and don't let embarrassment stop you doing things.
- Explain to your friends and family that you have functional symptoms.
- Talk to them about your symptoms and your worries about them, just as you might with any other medical condition.
- Give them any information you may have about the condition (including this leaflet).
- Tell them about any problems your symptoms may cause, and whether there is anything you would like them to do to help you.

- Use the techniques in this leaflet, such as sensory grounding, abdominal breathing or time out on the spot, to help if you feel a bit anxious.
- Try to think about other things and not to dwell on your worries or embarrassment about your symptoms.
- Go out, see people and enjoy yourself.

9. Learn to delegate and say 'no'

Are you one of those people who is always there looking after everyone else but no-one seems to look after you? Do people always bring you their problems but you feel you shouldn't 'burden' anyone with yours? Are you continually busy with all the demands and responsibilities you have and never seem to get a moment for yourself? Does it feel selfish if you think of saying 'no' when someone asks you for help, as if you would be letting them down?

Many people who have functional symptoms spend all their time looking after others but ignore their own needs for rest, space, enjoyment, support, exercise and a balanced life. As a result they become stressed, tired and even resentful, and have more symptoms. If this applies to you, think about your life:

- Do you really need to do everything you are doing?
- Do you have a partner or teenaged children who should be doing more around the house?
- Are there people who would like to give you support if only you let them know?
- Are there chores you do that aren't really essential?
- Are there things you are doing that people really should and could do for themselves?
- Talk to your friends and family and see what they think and try to make space for you - to rest, relax and do things you enjoy.
- You deserve it as much as anyone else.

10. Talk about your feelings

Many people who have functional symptoms have a tendency to push away or 'bottle up' difficult feelings. They may have been brought up feeling that it was weak or bad to experience emotions, so they never allow themselves to have them. Whatever difficult things life throws at them they 'just get on with it'. They may feel that if they started crying they would never stop. Other people do experience strong emotions but only let them out when they are alone. They don't want to 'burden' other people. Others bottle things up for as long as they can and then explode in an uncontrollable outburst.

However, it is by talking about difficult emotions and experiences and sharing them with others that we deal with our feelings. Talking about what is wrong can help us to realise that we are not alone. It can make emotions feel less frightening and more manageable. When we try to lock things away in boxes and throw away the key, they tend to cause other problems. These may include a variety of physical symptoms or psychological problems such as anxiety or depression.

- So try talking about your worries and feelings to people you can trust.
- If there is no-one available to talk to, writing feelings down can often help. This could be in a diary, by writing poetry or just plain writing.
- Telephone help-lines may also be a good way to unload.
- Your thoughts and symptoms may seem strange and frightening. This is not unusual for people with functional symptoms. Tell your doctor or psychotherapist about them as it may be very helpful for your treatment.

Things others may be able to do for you

Friends and family can often feel confused and anxious themselves when their loved one is diagnosed with functional symptoms. They may feel helpless and not know what to do. However, there are many ways that they can help you to recover. Here are some of the helpful things they can do.

1. Help you become more independent

Understandably your family may feel anxious about your safety and discourage you from doing things that they feel put you at risk. However, as we have seen, stopping doing things can have a bad effect on your life and actually make your symptoms worse. Your loved ones can help by:

- Encouraging you to do more.
- Not doing things for you that you can do for yourself.
- Helping you find ways of starting to do things that you have been avoiding e.g. going shopping, travelling on trains and buses.

Although they may find this worrying to start with, it is a really important role they can take.

2. Accepting your feelings

The people close to you may also try to protect you by stopping you from getting upset. They may think that this will make your symptoms worse, or they may just find it hard to see you upset. In fact functional symptoms are often linked to feelings that are not expressed. So if you need to talk about your feelings or have a good cry the best thing that friends and family can do is to:

- Listen, encourage you to talk and try to understand.
- Let you cry if you need to.
- Give you a cuddle if you want one.

- Not rush to find solutions or make it all better.
- Take your feelings seriously.
- Be patient with you. Some things that seem trivial to them may be very important for you.

3. Take some of the pressures off you

If you are one of those people who are constantly on the go, doing things for other people and never taking time for yourself, your family can help by:

- Sharing the household tasks.
- Encouraging you to take time off for yourself.
- Helping you to plan some enjoyable leisure activities.

So give it a try. Different things seem to work for different people, and you may well find other approaches that help as well. Use the ones that work for you and start to take control.

Some helpful contacts

Our department website is written by our team as a source of information for patients, families and other health professionals.

www.sth.nhs.uk/neurosciences/neurology/neurology-psychotherapy-service

Functional and Dissociative Neurological Symptoms: A patient's guide. This is the very helpful website mentioned earlier in this booklet with a lot of information about the different types of functional symptoms. It includes accounts of the experiences of different patients.

www.neurosymptoms.org

Non-Epileptic Attacks - information about non-epileptic attacks and non-epileptic attack disorder

This website was set up by the Department of Neurology at Sheffield Teaching Hospitals to provide information for patients, their families and other professional about all aspects of non-epileptic attack disorder.

www.nonepilepticattacks.info

FND Hope is a website set up by people with personal experience of functional neurological symptoms to promote awareness, offer support and advance research. They aim to empower those affected to achieve a higher quality of life.

www.fndhope.org/

The Samaritans offer confidential support 24 hours a day to people who are going through a crisis or feeling suicidal. You can ring them on:

08457 90 90 90 or contact them by email:

jo@samaritans.org

CRUSE offers bereavement counselling

Daytime Helpline: **0844 477 9400**

Alcoholics Anonymous offers support for people with problematic drinking and their families. You can ring their free national helpline on:

0800 9177 650 or contact them by email:

help@alcoholics-anonymous.org.uk

National Domestic Violence Freephone Helpline:

0808 2000 247 (staffed 24 hours a day)



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