

Service Leads

Dr Jayne Martlew

Consultant Neuropsychologist

Dr Christine Burness

Consultant Neurologist



The Walton Centre NHS Foundation Trust

Lower Lane

Fazakerley

Liverpool

L9 7LJ

Telephone:

0151 556 3179 / 0151 556 3183

Website: www.thewaltoncentre.nhs.uk



The Brain Charity offers emotional support, practical help, and social activities to anyone with a neurological condition. We also provide support for family, friends and carers.

Tel: 0151 298 2999

For practical advice our Patient Experience Team can be of assistance.

Tel: 0151 556 3090

email:

patientexperienceteam@thewaltoncentre.nhs.uk

©The Walton Centre NHS Foundation Trust. All rights reserved. No reproduction by or for commercial organisations is allowed without the express written permission of The Walton Centre

Produced by: Dr C Burness, Dr J Martlew, and Dr H Bichard Version: 2

Produced : January 2021

Review: January 2023

The Walton Centre 
NHS Foundation Trust

Taking Control of your Functional Neurological Symptoms



Some Self-Help Tips

Excellence in Neuroscience



People often feel confused and helpless when they are diagnosed with functional symptoms. You've been told that there's no structural problem, but you have very real and physical symptoms, which might be extremely disabling. You may feel that there's nothing you can do, and that your life will always be controlled by your symptoms. Thankfully, there are actually many ways to take control of your symptoms - and your life. Some of the techniques that can help are in this leaflet. It may take time to feel the benefits - so be patient, and keep on trying.

Section 1: Taking control of your symptoms

1. Understand and accept the diagnosis

It can be difficult to accept once and for all that your symptoms aren't 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. Some end up feeling that they aren't being believed by the doctors, and become angry as a result. Some may feel embarrassed and isolated, because they've never heard of functional illness, and don't know how to explain it. Sometimes the people around us only add to these feelings of doubt and uncertainty. It's very helpful, therefore, to get yourself better informed, but from reliable sources - not Dr Google! Read our leaflets **Functional Neurological Disorders (FND)** and **Non-Epileptic Seizures**. We also strongly recommend you take time to look at the website neurosymptoms.org, which should answer many of your questions. It gives interesting examples of other people's experiences, and the wide range of functional symptoms.

2. Understand your triggers

If your symptoms come and go, and vary in their severity, keeping a diary can help to identify triggers. Write down what was happening before, including anything that made you feel emotional. Understanding triggers doesn't mean you should then avoid them (for some people relaxation is a trigger, and

Section 4: Useful contacts

- * **neurosymptoms.org** is an excellent UK website written by a neurologist specialising in FND. Outlines wide range of symptoms, and other people's stories.
- * **nonepilepticattacks.info** this is another UK website put together by a clinical team specialising in FND. It has other tips for managing symptoms, including the ones outlined here.
- * **fndhope.org** was set up by people with FND. It has great advice on managing symptoms, and some fascinating webinars. There are Facebook groups so you can connect with other people with FND, and they are in the process of setting up regional peer support groups, both online and face-to-face.
- * **The Samaritans** offer support 24 /7 to people who are going through a crisis or feeling suicidal. You can call them on **08457 90 90 90** or email jo@samaritans.org
- * **Alcoholics Anonymous** offer support for people with problematic drinking and their families. National helpline: **0845 769 7555**
- * **CRUSE** offer bereavement counselling: **0844 477 9400**
- * **National Domestic Violence Helpline: 0808 2000 247**
- * **RASA** support survivors of rape and sexual abuse across Merseyside. Website: rasamerseyside.org; Helpline: **0151 666 1392**; Email: liverpool@rasamerseyside.org

3. Take some of the pressure off you

If you are the kind of person who is constantly on the go, doing things for other people, your family can help by:

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

4. Practice the techniques with you

Show other people some of the techniques recommended in this leaflet. Things like 4-8 breathing and muscle relaxation are helpful for *everyone*, not just people with FND. They're likely to enjoy it, and feel the benefit. And they're nice activities for you to do together.

But it also means they can help out when you're suffering: reminding you about sensory grounding, for example, and talking you through it.

Different things work for different people, and you might find other approaches that help you too. Use whatever works for you, and start to take control!

And if you do find something else that really helps, please let us know, so we can include it in this leaflet, and hopefully help others too.

avoiding ever feeling relaxed would be impossible and unhelpful! But understanding triggers means you can be prepared to jump in with some of the techniques below.

3. Sensory Grounding

The **1-2-3-Safe** method can help stop, or at least delay, dissociation, anxiety, and panic. You need to practice when you're feeling ok, so that it comes automatically when you need it. Just like you wouldn't wait to practice first aid until someone was in trouble!

1. Feel one thing that has an interesting texture (e.g. keys, pine cone) with your fingers and thumbs. Focus your thoughts on how it feels (even talking out aloud) and how the sensations change as you rub harder or softer in different directions. As you do this, put your feet flat on the floor, and feel how solid the ground feels., pushing up against you, supporting you.

2. Look around and find **two** objects. Describe them to yourself in detail. Again, you can do this out loud.

3. Listen hard to the space around you and identify **three** sounds e.g. birds singing, washing machine, traffic.

4. Remind yourself that you are **safe**.

4. Distraction

Many people find simple distraction helps. But it needs to absorb your mind fully to work best. You therefore need something that's hard work! You know best what might engage your attention, but examples would be:

- Count backwards from 100 to 0, subtracting 7: 100, 93, 86, 79...
- Count forwards, alternating letters and numbers: A, 1, B, 2, C, 3

- Try to spell 'supercalifragilisticexpialidocious'
- Name all the players in the football team you support

Again, practice this when you're symptom-free, so you can find the ones that work for you best when you need it.

5. 4-8 Breathing

People with functional symptoms or anxiety attacks may find it difficult to breathe, or their breathing may become quick and shallow. This is called hyperventilation. It can make you feel dizzy, strange, and lightheaded, can cause tingling, numbness, and visual changes, and make it difficult to think. This is due to an imbalance in the amount of oxygen and CO₂ in the body, because we have been breathing in too much, and not breathing out enough. The 4-8 technique restores balance, by getting rid of more CO₂. Here's how you do it, and it really is as simple as it sounds:

1 - breathe in for a count of 4.

2 - then breathe out for a count of 8.

If it's difficult to lengthen your breaths this much, then breathe in for 3 and out for 5, or whatever suits you best, *as long as the out-breath is longer than the in-breath*. Continue in this way for 5 minutes, or longer if you have time. Enjoy the calming effect it will have on your mind and body. A bonus of 4-8 breathing is that the very act of counting is a distraction.

6. Mental 'minibreak'

This is another simple but highly effective technique. Nobody needs to know you're doing it, and you can use it anywhere, at anytime.

Section 3: Helping others to help you

Friends and family often feel confused and anxious when their loved one is diagnosed with FND. They may feel helpless. However, there are many ways that they can help you to recover. Here are some of them.

1. Help you to become more independent

Your loved ones may discourage you from doing things that they feel put you at risk, because they are worried about your safety. As we have seen, this can actually have a negative effect on your symptoms and your life. They can help by:

- Encouraging you to do more
- Not doing things that you can do for yourself
- Helping you to find ways to start gradually doing things that you have been avoiding (e.g. going out, shopping, travelling on the bus or train).

This might make them anxious at first, but it's really important.

2. Accept your feelings

Your friends and family may try to protect you by stopping you from getting upset. Functional symptoms are often linked to feelings that are not expressed. So if you need to have a good cry, or talk about the past, the best things that your loved ones can do are:

- Listen, encourage and try to understand
- Let you cry if you need to
- Not rush to find solutions to make it all better
- Take your feelings seriously
- Be patient with you. Some things that seem trivial to them, might be very important for you.

others (even healthcare workers) who don't understand their symptoms.

Isolation can lead to loneliness and depression. Try to keep seeing people. Be brave. Don't let embarrassment stop you. Explain to your family and friends that you have functional symptoms. Talk about them just as you would about any other medical condition. Show them this leaflet and other information. Tell them about anything you would like them to do to help you.

3. Learn to delegate and say 'No'

Many people with functional symptoms are always busy helping others. You may be shouldering the responsibility for others' problems, but not feeling you can 'burden' anyone with your own problems.

If this sounds like you, think about your day-to-day life. Are there things that you don't need to do, or that your partner or children could help with? Talk to your friends and family and see if they can support and help you so that you have space to rest, relax, and do things that you enjoy.

4. Talk about your feelings

People with FND often 'just get on with it' and push away or bottle up difficult emotions. This may be because of the way they were brought up, or they may just find it hard. Others hide their emotions, or try to keep a lid on them, but sooner or later those feelings explode in an uncontrollable outburst.

Talking about feelings can be difficult, if you're not used to it. But for many people with functional symptoms, this 'bottling up' plays an important part in keeping the condition going.

Try to talk about your worries to people you can trust. Writing feelings down can help, either in a diary, or on a piece of paper that you can keep for yourself, use to help others understand how you feel, or destroy after getting those feelings out. Telephone helplines can be a good way to off-load safely to a stranger.

Your thoughts and feelings may seem strange or frightening. Many people with FND feel this way. Tell your doctor or therapist about them as it will probably really help your treatment!

Think of a place where you felt at peace, that everything was just right. It might be a local beach, a nearby wood, or somewhere perfect you visited on a special holiday. Imagine yourself there. Think about what you can see, hear, smell, and touch. Describe it to yourself. Make it really rich in detail. Think how it feels to be there. Fix the image in your mind - imagine pressing 'copy and paste'.

Whenever you feel stressed, picture yourself opening the door to this place. Step through the door and feel the relaxing atmosphere wash over you as you experience this wonderful place that has been waiting for you to visit again. Drink it all in. When you're ready, return to what you were doing, but bring some of the lovely feelings back as a souvenir from your 'minibreak'.

7. Progressive Muscle Relaxation

Find a quiet place free from distractions. Lie on the floor or recline in a chair. Loosen any tight clothing, and remove glasses or contacts. Rest your hands in your lap, or on the arms of the chair. Slow your breathing. If you haven't already, spend a few minutes practicing **4-8 breathing**.

Now, focus your attention on the following areas, being careful to leave the rest of your body relaxed.

Forehead: Squeeze the muscles in your forehead, as if frowning, holding for 5 seconds. Feel the muscles becoming tighter and tenser. Then, slowly release the tension in your forehead while counting for 5 seconds. Notice the difference in how your muscles feel as you relax. Breathe slowly and evenly.

Jaw: Clench the muscles in your jaw, like you're angry, holding for 5 seconds. Then release the tension slowly while counting for 5. Again, notice the feeling of relaxation, how different it is from when the muscles were tense.

Neck and shoulders: Increase tension in your neck and shoulders by raising your shoulders up toward your ears and hold for 5 seconds. Slowly release the tension as you count for 5. Notice the tension melt.

Hands: Make your hands into fists and hold for 5 seconds, squeezing as tight as you can. Then slowly release while you count for 5. Continue breathing slowly and evenly.

Arms: Curl your biceps, like you're trying to crush an apple between your lower and upper arms. Press as hard as you can for 5, then relax.

Feet: Point your feet like a ballet dancer, as tensed as you can, and hold for 5, feeling that tension in your instep. Then uncurl them, and notice the tension dissolve. You can experiment with other muscle groups. Really pay attention to the difference between tension and relaxation. Some people visualise the feeling of relaxation flowing like water, or white light. Search for 'progressive muscle relaxation' on Youtube or Spotify, and you'll find recordings that talk you through it. As with all the other techniques, practice this when you don't have symptoms, so that it comes easily when you do! Even just tensing and releasing your fist, and focusing on that flood of relaxation, can help in a crisis.

8. Mindfulness

Mindfulness is one of the most helpful techniques of all, but is difficult to do justice in a leaflet! It's more than just relaxation - although some people do find it relaxing, which is a bonus. Nor is it about being *mindless*, and freeing ourselves of thought. Mindfulness is really about training our attention, so we can direct it like a spotlight where we want it, and not where we don't. It teaches us how to step back from all the noisy chatter in our heads, all the thoughts and feelings we have, and simply observe them instead, like leaves floating down a stream.

This is really relevant when it comes to Functional Neurological Disorder, as we know that attention plays an important role in the development and maintenance of functional symptoms. Mindfulness is also recommended by NICE as a treatment for anxiety and low mood.

We would strongly suggest looking into Mindfulness - online, or in books - and making meditation part of your daily routine. There are some fantastic 3 minute meditations, and we can all find 3 minutes in our day! **Headspace** is a good place to start, a popular app with a wide selection of guided meditations. It's available in app stores, online, and also now on Netflix. **Smiling Mind** and **10% Happier** are also good - and free! Have a look too at the NHS web page on mindfulness:

www.nhs.uk/conditions/stress-anxiety-depression/mindfulness/

Section 2: Taking control of your life

1. Don't put your life on hold

People often feel frightened by their functional symptoms, and expect the worst. They might begin to avoid situations, and stop working. This can lead to boredom, frustration, and depression. Your illness may become the focus of your attention. This will cause more stress and affect your self-confidence and relationships, and is actually likely to make the symptoms worse. The longer this goes on, the harder it is to start doing things again.

Try to carry on with your normal activities as much as you can. Gradually start to do things and to get more independent. Plan outings, arrange treats, and do things that are fun and interesting. Having structure, purpose, and routine will make you feel better and happier, and may well lead to an improvement in your symptoms.

2. Don't let yourself become isolated

Many people with functional symptoms start to avoid people because they feel ashamed or embarrassed, or they have had negative reactions from