

associated with a wide range of symptoms including changes to conscious experiences, feeling distant, dizzy, disconnected or numb, feeling detached, mind blanks, disrupted to speech/ language/ memory, out of body feelings, and/or feeling like the world around is “strange” (like Déjà Vu or “not real”). Physically people can have body numbing, coldness, pain sensitivity, loss of sensation, loss of body awareness (e.g. hunger, thirst, feeling of a limb) and so on.

- Fears that the diagnosis is incorrect or that if stress becomes a focus, it will then be used to “write you off” or be “jumped on” as evidence the symptoms are “all-in-the-mind”. This often causes people to feel in danger and frightened to express any distress, so try to avoid it.

Using the Hardware vs Software Explanation

A good way to explain Functional Neurological Symptoms is to make a comparison with computers.

Computers can stop working properly or “crash” because of:

1. “Hardware” problems - damage to the physical computer, like neurological damage to the brain.
2. “Software” problems – errors or overload to the computer's processes and programmes, like Functional Neurological Symptoms and neuropsychological processes

If your computer or phone has ever crashed on you, you will know software problems are real, genuine and disabling, just like Functional Neurological Symptoms. Software (like Functional) problems happen for more than one reasons. These include:

- The type of computer
- The type of programmes on the computer

- The computer being left on too long
- Stressing the computer by having too many programmes open at once
- Overload from processes files or information too large or complex

When we translate this into brain and people terms, this can include problems with:

- The type of brain (genetics, early development, injuries)
- The type of learning experiences people have had (experience of illness, family, life events, memories)
- Sleep problems
- Low energy resources (e.g. diet, overworked, not enough support, worry, depression)
- Active physical and emotional stress (but this may be from the past and “minimised” in the background)
- Physical or emotional pain
- Having difficult experiences such as receiving difficult information, bad memories or challenging dilemmas to deal with (e.g. decisions about work/school, health, family), that put constant pressure on the mind, body and brain

It can help to explain your symptoms in this way, and remember that just as computers can crash, glitch, shutdown or go into “safe mode”, so can the mind and brain.

Bringing it together

By now is it hopefully clearer to you that Functional Neurological Symptoms are complicated to understand, but certainly not “imagined”, “just stress” or “all-in-the-mind”. Hopefully it is also clearer that just like when a computer crashes, your symptoms do not

happen on purpose and you are not to blame; you did not mean for this to happen.

When thinking about your own risk factors you need to consider lots of different ones, which includes things like getting knocked-off through another illnesses, injury, accident and different stresses/demands. Factors from the past like a history of being under prolonged physical and psychological stress, being overworked or things that can put the nervous system under pressure such anxiety, depression and/or exposure to frightening or overwhelming experiences, play a role for some people.

Negative life events tend to disrupt brain function most when they happen during stages of major development (e.g. childhood), and during times your brain is trying to correct errors; your mind is trying to figure out what is wrong (e.g. what happens when the symptoms start, such as serious fears about dying or severe lifelong disability and frightening experiences like emergency hospital admission etc). Once you have symptoms, they can start to create a vicious cycle especially when you do not know what is wrong.

Despite all the negatives and problems faced by people with Functional Neurological Symptoms, the main positive is that with help and information, people can learn to cope with symptoms and have good potential to find ways to reduce or completely regain control over their symptoms. Sometimes this happens quite naturally without the need for other treatment.

Compared to many other neurological diseases, there is much better potential for full recovery. This starts with understanding the diagnosis and learning about it. Doing this allows people to become much more proactive again after having had to wait to get a diagnosis and an explanation or after a diagnosis has been changed.

This means you can start trying new approaches to coping/management, looking for triggers and working on any background problems that might be influencing things, rather than being stuck in limbo feeling powerless until a doctor can find something to explain the symptoms, a medication cures it or being stuck worrying and perhaps having treatments for diseases that are not the cause of the problem.

Focusing on gradually reducing the ways in which symptoms have caused you any disability and pacing yourself back to every life is vitally important.

Once you understand your symptoms this can be done with reduced fears about causing yourself permanent harm, and with the knowledge that you have the potential to get better. This is not to take away from the fact that recovery can be very challenging. Both physical (e.g. falls, symptoms flair-up, fatigue) and psychological (e.g. embarrassment, feeling vulnerable, anxiety) factors can make the process slow and difficult. Together such factors can increase a person's sense of danger (e.g. fear of harm, anxiety when symptoms worsen with activity or fears of being publicly humiliated by a fall or seizure). It is important to recognise ways you might feel in danger from your symptoms in order to find ways to overcome these barriers.

Getting Better

If you have been told you have Functional Neurological Symptoms, it is important to ask yourself:

- “Am I (or other people whose opinions are important to me e.g. family, GP) still worried that something has been missed and that my symptoms are caused by another disease?”

- If the answer is "Yes". It is important to think about what is worrying you, discuss this with your doctor and learn more about Functional Neurological Symptoms, such as on www.neurosymbols.org, or other references below.
- If you make an appointment with your GP, neurologist or other professionals to discuss the diagnosis, it can really help to bring this guide with you.
- If you have very serious concerns that something has been missed, and you do not think your diagnosis is correct, this really needs to be addressed as best as possible with the medical professions involved in your care (e.g. GP, neurologist, other specialists) as improvement is much less likely until this is dealt with.
- Understanding and feeling you have the correct diagnosis is vitally important because it is very hard to manage and get better from any health problem if you are confused about the diagnosis, believe the diagnosis is wrong or are worried about causing yourself damage through activity or aggravating the symptoms.

Considering Service/Treatment Options (if you need them)

- You may be able to recover without any external help, but with more severe and chronic symptoms you may need additional treatment and rehabilitation supports.
- Management of Functional Neurological Symptoms is aimed at trying to improve people's functioning and overall physical and mental health, as well as quality of life. This can also help reduce or stop the symptoms for some people.
- Treatment involves trying to tackle any problems that might perpetuate things (keep the problem going). These can include things like:

- Confidence in the diagnosis
- Removing fears about other serious illness or disease
- Improving any relevant lifestyle factors, particularly sleep, activity and eating patterns (over- or under- sleeping and eating are very common problems)
- Setting and working on realistic rehabilitation goals aimed towards reducing symptoms and improving activity slowly overtime.
- Pacing activity as to not become overloaded or fall into a pattern of high activity when feeling better, and then crashing with increased symptoms and exhaustion (called the “boom and bust” pattern which is a major contributor to relapses and “up & down”).
- Making sure any wider health issues are being treated and managed (be they related to physical or mental health e.g. diabetes or depression)
- Trying to keep use of aids and adaptations to a minimum (e.g. walking aids, holding onto the wall or furniture for support, never going out alone). It is of course important to be safe and supported. But, as with all conditions, these coping strategies can help and feel necessary in the short-term but long-term can start to change the way we move, reduce confidence and independence, and increase disability.
- Managing any problems that might be in the background (for example, stresses or problems from the past or present); similar to the computer analogy of having programmes minimised in the background, that are still having an influence on performance, even if we cannot see them. Psychological therapy can help maximise or bring these problems up again in order to close them down.

- Learning techniques to stop symptoms e.g. breathing, distraction and behaviours that can block symptoms escalating.

Self-Management & Services

Unfortunately there are currently no specific treatment services for Functional Neurological Symptoms in Northern Ireland. Most people will not see a neuropsychologist regarding their symptoms, and there are no neuropsychology treatment services in the community for this type of problem.

Instead, people who need treatment access various different services, often starting with neurology and hospital services and then, depending on their needs, may get help from community physiotherapy, occupational therapy, social work, psychology, counselling and/or community support services.

Your GP can give you information and/or a Directory of Services to help improve mental health and emotional wellbeing in your Health and Social Care Trust area.

Depending on your personal circumstances and symptoms, there are a number of services you could consider discussing with your GP that might help:

- If you are interested in trying treatment within mental health and psychology services, a referral to your local Community Mental Health Team and/or Psychological Therapy Services can be considered. It is natural that you may feel a little uncomfortable or worried about seeking psychological help, particularly when your problems are likely mostly with physical symptoms. Remember, attending these services does not mean

your symptoms are not real or “all-in-the-mind” and there is research evidence to suggest psychological therapy can help with Functional Neurological Symptoms; Functional Neurological Symptoms have a two-way relationship with stress and problems like anxiety or low mood. This means that people who are for example overworked, exhausted and anxious, are more vulnerable to experiencing changes in their brain functioning leading to symptoms. In reverse, people with problems with brain functioning and symptoms are more vulnerable to developing greater problems with stress and reduced mental health (due to things like experience of disability, worries about the condition, lifestyle and relationship changes, being off work/school and so on).

- Psychological approaches to treatment can include:
 - Helping you explore and understand what factors might be important in your case to the development and maintenance of Functional Neurological Symptoms.
 - Treating factors that maintain your symptoms e.g. managing triggers, roles of anxiety or depression, thinking styles and looking at what you do that helps and does not help.
 - Learning tools and strategies to help feel back in control, trying to interrupt or reduce symptoms, coping with symptoms day-to-day, increasing activity, talking about your condition to others, improving sleeping, improving daily routines, setting realistic goals, evaluating your progress, being more assertive, feeling better about your condition and so on.
- Physiotherapy and/or occupational therapy can also be important and effective in the treatment of Functional

Neurological Symptoms, particularly if you have problems with walking and movement. Physiotherapy aims to help you relearn normal movement patterns, reverse movement habits that might have developed because of pain or weakness, reduce use of aids and also helps with psychological factors like rebuilding confidence walking outside or reducing fears of making symptoms worse or causing harm through exercise.

- For those with chronic pain symptoms, referral to Pain Management Services or support groups run by Arthritis Care can be considered (these are funded by an arthritis charity but are open to everyone with chronic pain).
- If you have no significant symptoms of things like anxiety or depression but need space to talk about changes in your life or other problems in your life (e.g. loss; bereavements; negative life experiences; relationship problems) you can typically access general or specialist counselling through GP or self-referral (see the Service Directory mentioned above for some ideas too).
- If you need help in terms of your level of physical disability and/or need practical support or care needs, a referral to your local Physical Health and Disability Team Social Work Team could be considered. This has a focus on providing care and support services into the home.

Further Sources of Information

As mentioned above, the website www.neurosymptoms.org is a really useful source of information about Functional Neurological Symptoms and is run by a neurologist.

Research studies have shown the more people can learn and understand Functional Neurological Symptoms, the better they tend to feel and cope. This improves the chances of getting better.

- Leaflets on Neurosymptoms.org include:
 - Dissociative (Non-epileptic) Attacks
 - Chronic Daily Headache
 - Drop Attacks
 - Functional Movement Disorder
 - Functional Weakness
 - Functional Dystonia
 - Dizziness (Persistent Postural-Perceptual Disorder)
 - Sleep problems
- The website: <https://web.nth.nhs.uk/selfhelp/> also has a large range of useful self-help guides on things like:
 - Low mood & depression
 - Anxiety problems
 - Post-traumatic stress disorder
 - Bereavement
 - Sleep problem
- If your Functional Neurological Symptoms include attacks/fits/seizures, more information can be found at www.nonepilepticattacks.info & www.codestrial.org/
 - The first website is written by a clinical team in Sheffield, UK and has lots of useful information.
 - The second site is from a research team looking at psychological treatments for dissociative (non-epileptic) attacks.

Websites Run by Patient Groups

Patient groups and websites can be very useful sources of information and support. It can be great to know other people have been through what you have, and to find out many people have had similar experiences. However, some people have also told us they have encountered negative and upsetting information, or have been given

information that has caused them further doubt or distress about their diagnosis (e.g. people suggesting other diseases to them or suggesting people were misdiagnosed). **This most often relates more to chatrooms and message boards.** So we must give you a disclaimer to remind you that *these sites are not run by medical professionals. We therefore cannot control or be responsible for their content. It is important to warn you that information may be contradictory to the advice in this booklet or that of your doctor. Information might be misleading or advise things that could even be harmful to you. Therefore you should always consult your doctor about any concerns or ideas you have regarding treatment seen online.*

- **FND Hope** (www.fndhope.org) was the first patient support organisation for patients with Functional Neurological Symptoms. It has a large and growing amount of material for patients with functional neurological disorders, especially symptoms like movement disorder and weakness.
- **FND Action** (www.fndaction.org.uk). Launched in 2016, is a charity that provides information about FND, with a particular focus on the UK.
- **FND Dimensions** (fnddimensions.org) is a UK charity for FND with the aim of setting up patient led support groups.

Self-Management Resources & Books

- If you want to work on managing symptoms directly at home, there is a self-management book available called “Overcoming Functional Neurological Symptoms” which some people find helpful (ISBN-10: 1444138340; Sometimes local libraries can order in books for you for free)

- There are other books in this range which can also be useful sources of information, advice and management/treatment advice including:
 - Overcoming Chronic Fatigue
 - Overcoming Chronic Pain
- For those who experience dissociative or non-epileptic attacks there are self-help guides including:
 - Taking Control of Your Seizures: Workbook by Charlotte Reiter & others (ISBN: 019933501X).
 - "Psychogenic Non-epileptic seizures: A Guide" by Lorna Myers (ISBN: 9781492881414).
- For those of you living with chronic symptoms, there is a useful management book called:
 - Living with the Enemy: Coping with the stress of chronic illness using CBT, mindfulness and acceptance by Ryan Owens (ISBN: 0415521203)

Helpful Contacts in an emergency or if you require urgent help and support:

Emergency services: 999 or 112

Police (PSNI): 101 - this will connect you to your local station.

Lifeline: 0808 808 8000 (Deaf and hard of hearing –Textphone users can call Lifeline on 18001 0808 808 800)

Samaritans helpline: Freephone 116 123; jo@samaritans.org; www.samaritans.org

GP Out of Hours services (Evenings, Weekends, Holidays)

- ***Belfast Area***
South & East Belfast: 028 9079 6220
North & West Belfast: 028 9074 4447
- ***South Eastern Area***
Down and Lisburn: 028 9260 2204
North Down & Ards: 028 9182 2344
- ***Northern Area:*** 028 2566 3500 (*Dalriada*)
- ***Southern Area:*** 028 3839 9201
- ***Western Area:*** 028 7186 5195

Regional Emergency Social Work Service (RESWS) - (Weekdays 5pm – 9pm; 24hrs at weekends) – all areas call 028 9504 9999 if:

- Essential & immediate action for care arrangements needed
- There are concerns about the safety of a vulnerable adult
- Admission to Residential/Nursing Home is required
- Person is missing and there is a necessity to liaise with PSNI regarding further action required

Other Contacts:

Carers NI: 028 9043 9843 (Benefits and carers' rights)

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Tell us what you thought of this booklet

We are continually trying to improve our information and make it clear and understandable. We would love to hear feedback about what you thought about this guide. You can tell us what you liked and what you did not like.

If you would like to send us any feedback (good or bad), please write to:

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