



MDS-ES Allied Health Care in Movement Disorders

How to communicate a diagnosis of FND

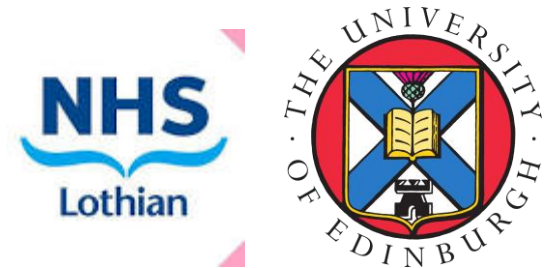
and what to do when it goes wrong

Prof Jon Stone

Consultant Neurologist and
Honorary Professor in Neurology,
University of Edinburgh

Jon.Stone@ed.ac.uk

Twitter: @jonstoneneuro



Outline

- Why is communicating FND such a problem?
- Communication approaches and evidence
- Communication of the diagnosis is really important but not the whole treatment
- Dealing with disagreement
- Triaging for treatment and developing a treatment plan
- When to press pause on treatment

Some resources



How Do I Explain the Diagnosis of Functional Movement Disorder to a Patient?

Jon Stone, FRCP PhD¹ and Ingrid Hoeritzauer, MB BCh MRCP



"Breaking the News" of a Functional Movement Disorder

Jon Stone, Ingrid Hoeritzauer, and Alan Carson

17



Check for updates

Explaining functional disorders in the neurology clinic: a photo story

Alan Carson,¹ Alexander Lehn,^{2,3} Lea Ludwig,¹ Jon Stone¹



You've made the diagnosis of functional neurological disorder: now what?

Caitlin Adams,^{1,2} Jordan Anderson,^{3,4} Elizabeth N Madva,^{1,2} W Curt LaFrance Jr,^{3,4} David L Perez^{1,2}



RESEARCH ARTICLE

Health Care Utilization in Functional Neurologic Disorders

Impact of Explaining the Diagnosis of Functional Seizures on Health Care Costs

Tjerk J. Lagrand, MD*, Maryon Jones, MChD*, Anne Bernard, PhD, and Alexander C. Lehn, MD

Neurology: Clinical Practice 2023;13:e200111. doi:10.1212/CPJ.0000000000200111

Correspondence

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- (4) a referral to a psychologist (or a request to the GP to provide this),
- (5) a letter sent to the GP,
- (6) an appropriate follow-up (<6 months).

3 or more = SATISFACTORY

Results

SATISFACTORY explanations (n=18) = \$5,000 reduced to \$1728 /year

UNSATISFACTORY explanations (n=7)= \$4425 increased to \$20,524/ year

Barriers to communication

Some Barriers to Communication

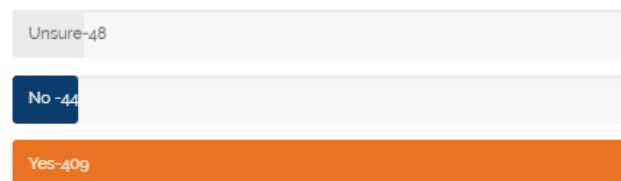
Doctors problem	Societal problem
Stigma / Negative Attitudes	

FND HOPE STIGMA SURVEY

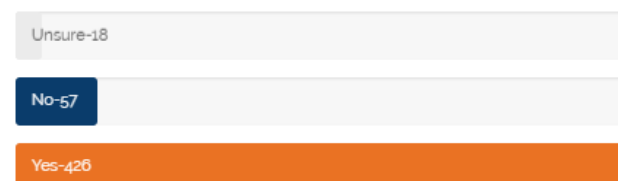
THANK YOU TO ALL THOSE WHO PARTICIPATED.

503 individuals from around the world responded to the FND Hope Stigma Survey.

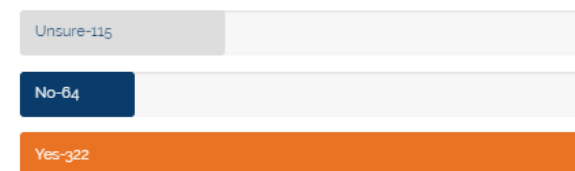
HAVE YOU EVER FELT LIKE YOU HAVE BEEN TREATED POORLY DUE TO STIGMA RELATED TO YOUR CURRENT (FND) DIAGNOSIS?



HAVE YOU EVER FELT DISMISSED/DISRESPECTED/NOT BELIEVED WHEN VISITING A MEDICAL PROFESSIONAL?



DO YOU HAVE A CONCERN THAT YOUR CURRENT (FND) DIAGNOSTIC LABEL MAY HINDER YOUR ABILITY TO ACCESS FUTURE MEDICAL CARE?



“*I am constantly being asked if I understand my condition, many practitioners think once I understand it I will be 'better'. I read and find out all I can but my physical issues remain.*”

“*I was told that going to the ER was wasting taxpayers money.*”

Some Barriers to Communication

Doctors problem	Societal problem
Stigma / Negative Attitudes	
Lack of training / Uncertainty about nature of problem	

Chapter 44

Explanation as treatment for functional neurologic disorders

J. STONE^{1*}, A. CARSON², AND M. HALLETT³

Functional Neurologic Disorders - Handbook of Clinical Neurology – Elsevier -2016.

Available on Pubmed and most University Subscriptions



Survey of the perceptions of health practitioners regarding Functional Neurological Disorders in Australia

Alexander Lehn^{a,b,*}, Joanne Bullock-Saxton^c, Peter Newcombe^d, Alan Carson^e, Jon Stone^e

^a Mater Centre for Neurosciences, Brisbane, Australia

^b School of Medicine, University of Queensland, Brisbane, Australia

^c Active Rehabilitation, Brisbane, Australia

^d School of Psychology, University of Queensland, Brisbane, Australia

^e Department of Clinical Neurosciences, Western General Hospital, Edinburgh, UK

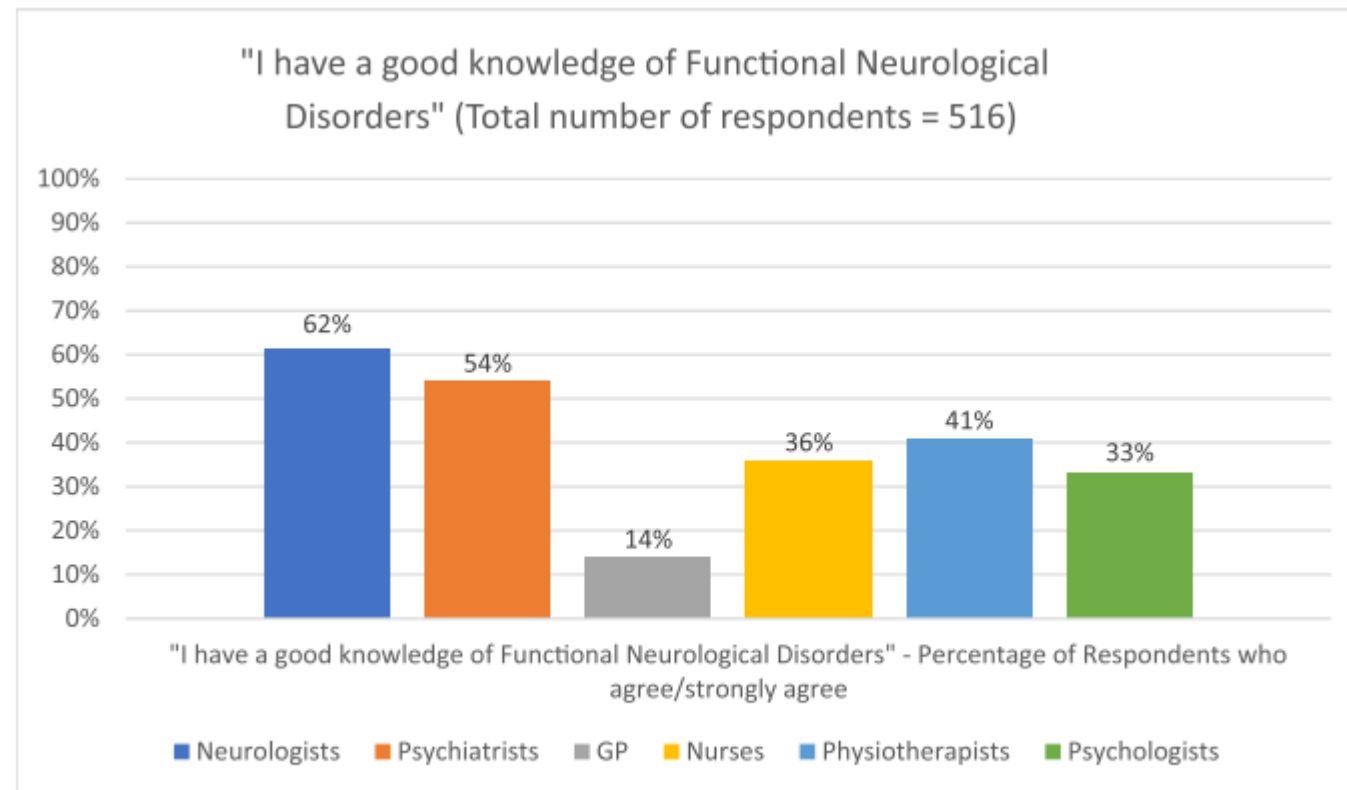


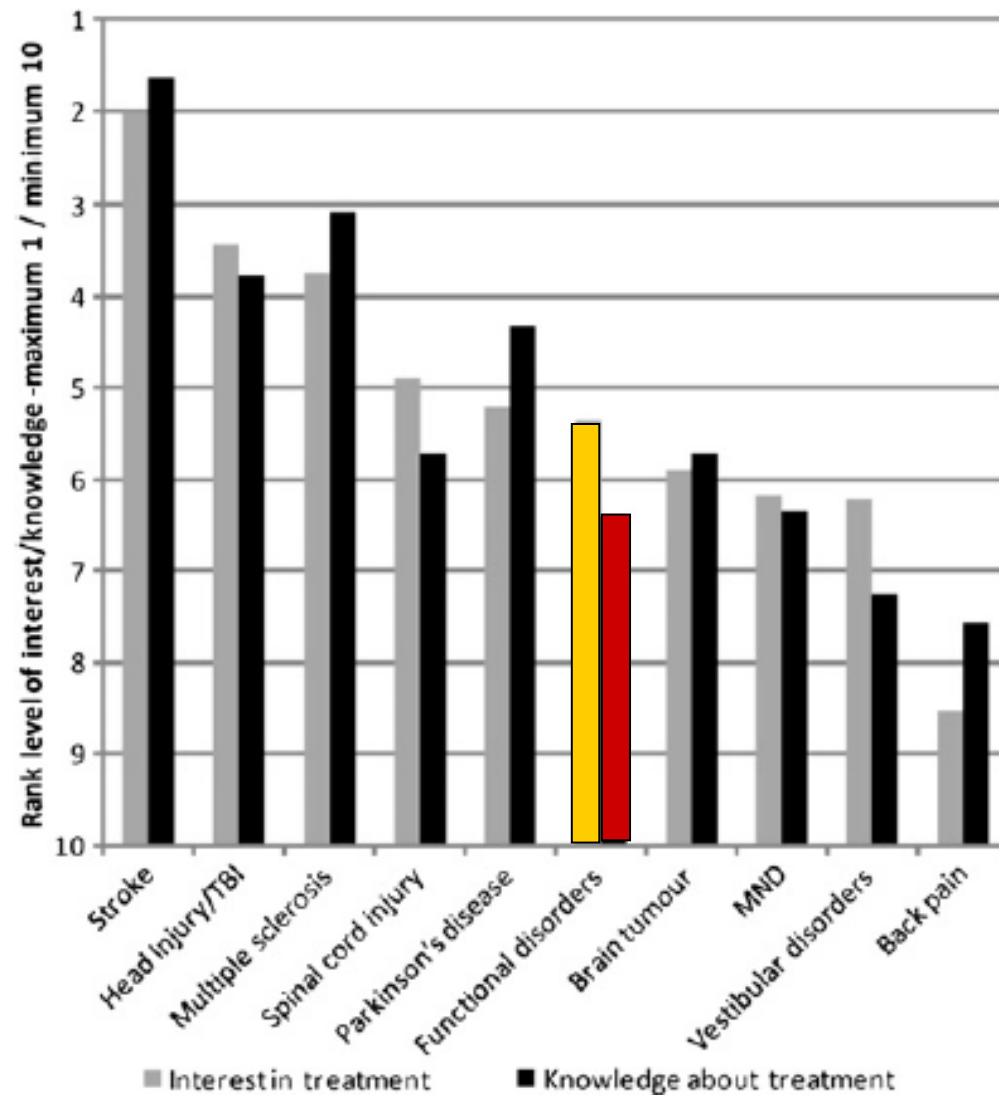
Fig. 2. Knowledge of FND.

SHORT REPORT

Physiotherapists and patients with functional (psychogenic) motor symptoms: a survey of attitudes and interest

Mark J Edwards,¹ Jon Stone,² Glenn Nielsen³

- 702 physios from UK Physio group (ACPIN)
- 75% felt well supported by physiotherapy colleagues
- 25% felt well supported by their referring neurologist.
- 72% thought they had more to offer FMS than is currently the case
- 18% worried they might be making the patient worse.
- 42% described difficulty discharging the patient
- 39% agreed that there were a lack of recognised treatments



Some Barriers to Communication

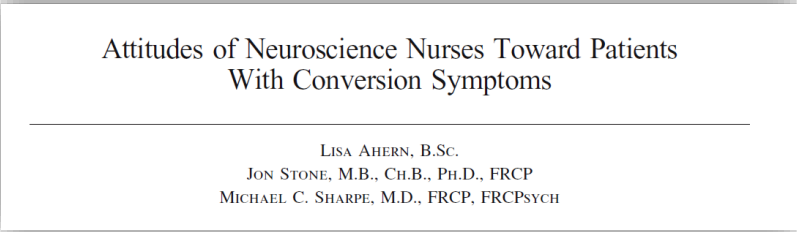
Doctors problem	Societal problem
Stigma / Negative Attitudes	
Lack of training / Uncertainty about nature of problem	
Concerns about Malingering	



Concerns about malingering



Neurologists commonly hold ambivalent views about patients with FND



16% of neuroscience nurses thought FND symptoms were 'not real'

nature reviews neurology

<https://doi.org/10.1038/s41582-022-00765-z>

Perspective

Check for updates

Why functional neurological disorder is not feigning or malingering

Mark J. Edwards¹, Mahinda Yoganarajah^{2,3,4} & Jon Stone⁵

Table 1 | Historical consistency of typical FND presentations

	FND presentation			
	Functional leg weakness	Functional dystonia	Functional facial dystonia	Functional seizures
Clinical features	Dragging gait with hip externally rotated	Clenched fist sometimes with wrist flexion	Orbicularis oculi contraction and contralateral raised eyebrow	'Arc-de-cercle' appearance
19th century				
21st century				

FND, functional neurological disorder. Top row of images, from left to right: reprinted from ref. ⁷⁹, reprinted from ref. ⁸⁰, reprinted from ref. ⁸¹, reprinted from ref. ⁸². Bottom row of images, from left to right: not previously published; reprinted with permission from ref. ⁸³, BMJ Publishing; adapted with permission from ref. ⁸⁴, Jon Stone; reprinted with permission from ref. ⁸⁵, Swiss Medical Forum.

Some Barriers to Communication

Doctors problem	Societal problem
Stigma / Negative Attitudes	
Lack of training / Uncertainty about nature of problem	
Concerns about Malingering	
Concerns about Misdiagnosis	

Some Barriers to Communication

Doctors problem	Societal problem
Stigma / Negative Attitudes	Stigma of functional disorders
Lack of training / Uncertainty about nature of problem	
Concerns about Malingering	
Concerns about Misdiagnosis	

A qualitative study of the experiences and perceptions of patients with functional motor disorder

Glenn Nielsen^{a,b}, Marta Buszewicz^c, Mark J Edwards^b and Fiona Stevenson^c

^aSobell Department of Motor Neuroscience and Movement Disorders, UCL Institute of Neurology, London, UK; ^bMotor Control and Movement Disorders Group, Institute of Molecular and Clinical Sciences, St Georges University of London, London, UK; ^cResearch Department of Primary Care and Population Health, UCL, London, UK



I've lost virtually a year of my life because of my condition. Well you don't have Parkinson's disease, because that's what it feels like, psychological. One of the consultants recommended that I took a glass of wine every evening..... They won't stop. It's all in your head, there's nothing wrong with you at all..... Like, he said like, because I didn't have cancer he didn't want to help me.....

Some Barriers to Communication

Doctors problem	Societal problem
Stigma / Negative Attitudes	Stigma of functional disorders
Lack of training / Uncertainty about nature of problem	Dualism – ‘mind and brain are separate things’
Concerns about Malingering	
Concerns about Misdiagnosis	

New Scientist

WEEKLY April 6–12, 2019

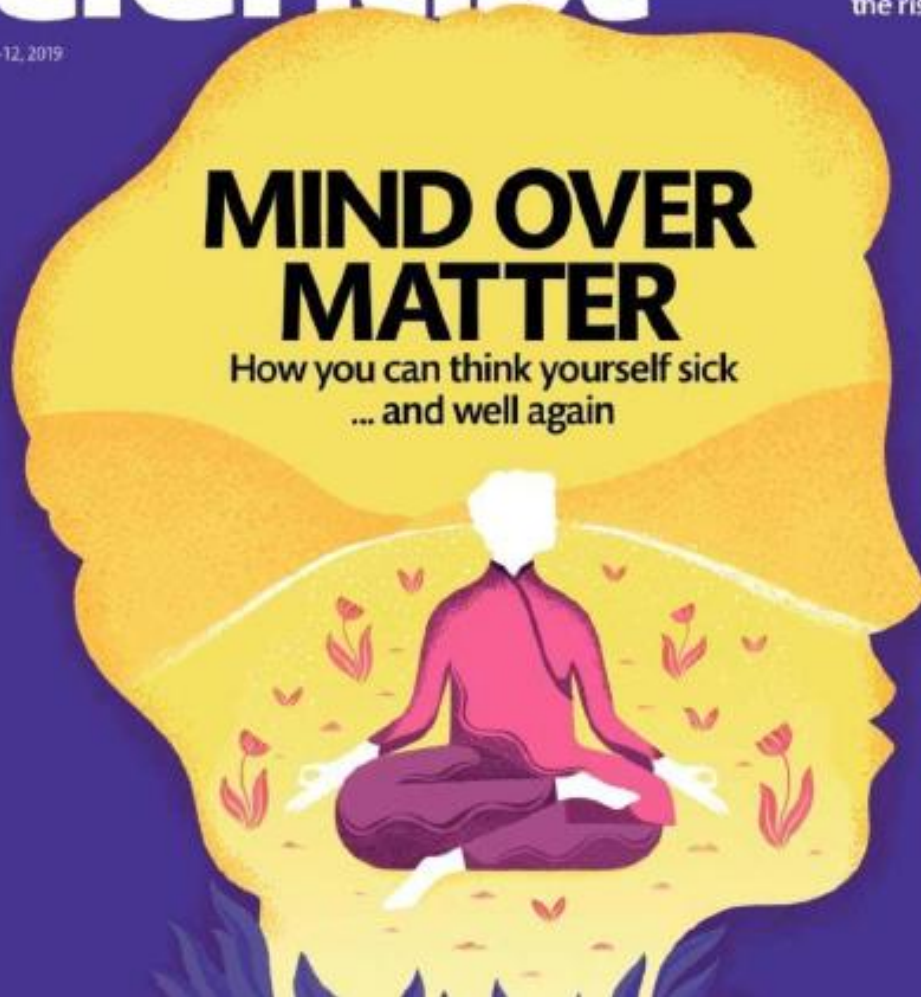
RETURN TO THE MOON
Can NASA really make
it back by 2024?

NORTHERN SOUNDS
The mysterious noise
the aurora makes

THE POWER OF RELIGION
How gods shaped
the rise of humanity

MIND OVER MATTER

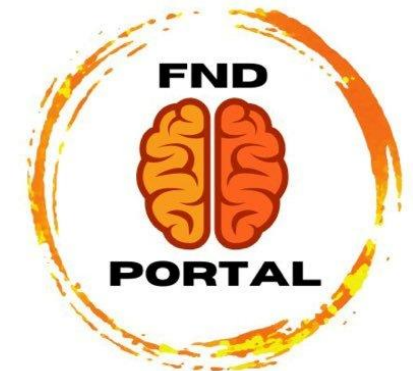
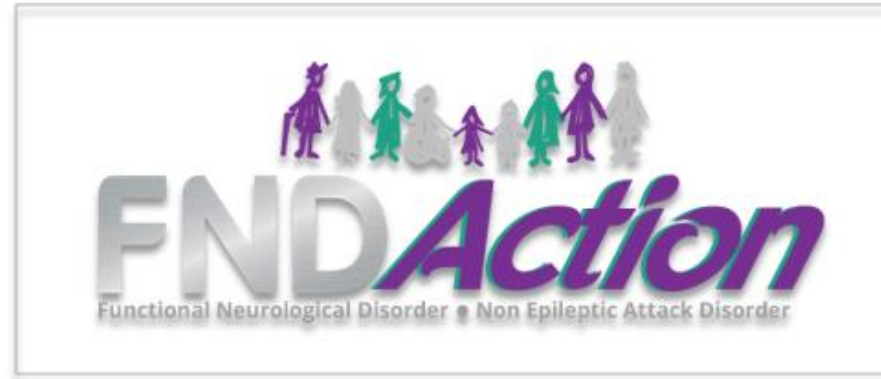
How you can think yourself sick
... and well again



Some Barriers to Communication

Doctors problem	Societal problem
Stigma / Negative Attitudes	Stigma of functional disorders
Lack of training / Uncertainty about nature of problem	Dualism – ‘mind and brain are separate things’
Concerns about Malingering	Lack of public awareness
Concerns about Misdiagnosis	

Patient led organisations and advocates for FND for the first time



Some Barriers to Communication

Doctors problem	Societal / Patient problem
Stigma / Negative Attitudes	Stigma of functional disorders
Lack of training / Uncertainty about nature of problem	Dualism – ‘mind and brain are separate things’
Concerns about Malingering	Lack of public awareness
Concerns about Misdiagnosis	Strong views of alternative diagnosis (in some patients)

What is the evidence for
communication in FND?

What is the evidence for communication?

- Neurologists consider educating the patient the most important treatment for FND (90%) and agreement with diagnosis positive prognostic factor (90%) (LaFaver 2020)
- Relief at diagnosis predicts better outcome (e.g. Carton 2003)
- Training for reattribution to psychological factors or labelling as 'medically unexplained' helps doctors but not patients (Morriss et al 2007, Weiland et al. 2016)

RESEARCH ARTICLE

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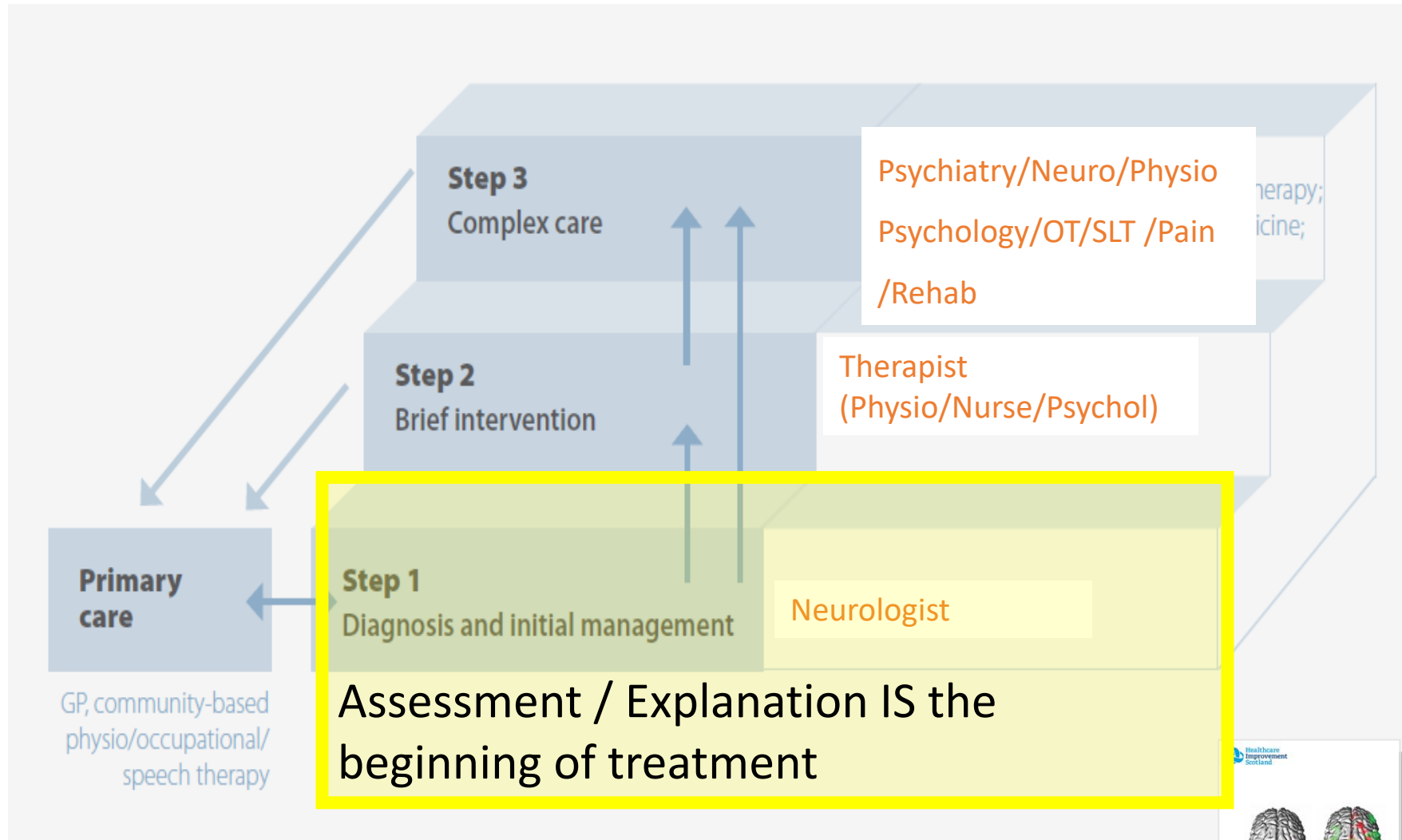
Results

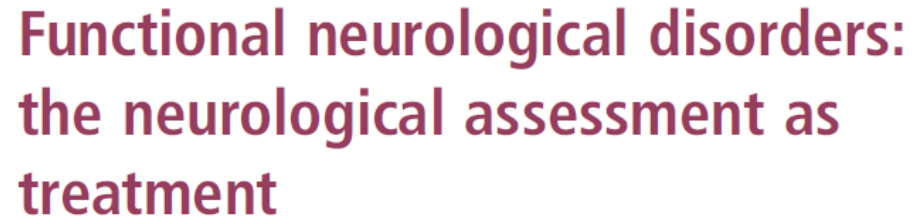
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Communication is greatly aided
by a therapeutic assessment

Stepped treatment for functional movement disorder





- Asking about all symptoms – including fatigue, dizziness, sleep and memory
- Thinking about mechanism and dissociative symptoms
- What thoughts did they have?
- What should doctors should have done by now?
- What were they hoping would happen/would not happen?
- Careful with “psychological” questions
- Using the examination for rapport and for explanation
- Time

Communication –
things that go wrong

What goes wrong: The patient is only told what they don't have....



What goes wrong: The patient is only told what they don't have....



What goes wrong: The doctor introduces possible risk factors before actually explaining what the problem is'



What goes wrong: The doctor introduces possible risk factors before actually explaining what the problem is'



What goes wrong: The doctor introduces possible risk factors before actually explaining what the problem is'



Communication – do what you
normally do for other
conditions

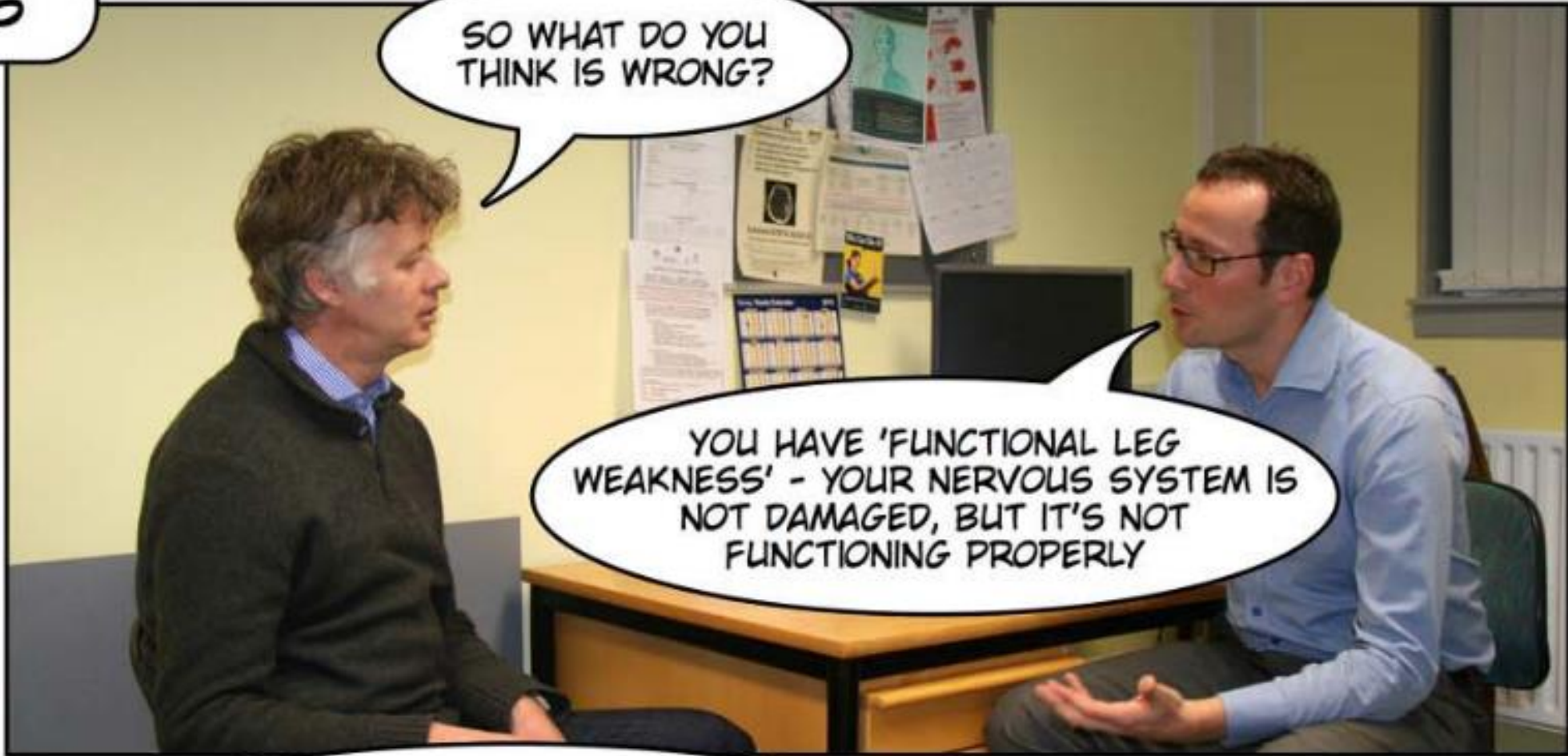
Don't do something weird!

Tell the patient what it is....

5

SO WHAT DO YOU
THINK IS WRONG?

YOU HAVE 'FUNCTIONAL LEG
WEAKNESS' - YOUR NERVOUS SYSTEM IS
NOT DAMAGED, BUT IT'S NOT
FUNCTIONING PROPERLY



Show the patients their positive physical signs

CONTEMPORARY ISSUES IN NEUROLOGIC PRACTICE

Trick or treat?

Showing patients with functional (psychogenic) motor symptoms their physical signs

Jon Stone, MB, ChB,
PhD

Mark Edwards, MBBS,
BSc(Hons), PhD

Correspondence & reprint
requests to Dr. Stone:
Jon.Stone@ed.ac.uk

ABSTRACT

Functional (psychogenic) motor symptoms are diagnosed on the basis of positive signs of inconsistency or incongruity with known neurologic disease. These signs, such as Hoover sign or tremor entrainment, are often regarded by neurologists as 'tricks of the trade,' to 'catch the patient out,' and certainly not to be shared with them. In this reflective article, the authors suggest that showing the patient with functional motor symptoms their physical signs, if done in the right way, is actually one of the most useful things a neurologist can do for these patients in persuading them of the accuracy of their diagnosis and the potential reversibility of their symptoms.

Neurology® 2012;79:282-284

Rachel – Hip Abductor sign of Functional Leg Weakness

Using mental imagery to help explain functional dystonia as a distorted 'brain map'

‘You have something potentially reversible....’

That's positive

Because there is no damage
to the nervous system you
have the *potential* to get better



‘Software not hardware....’

OK...

It's a software problem
in the brain rather than
a hardware problem



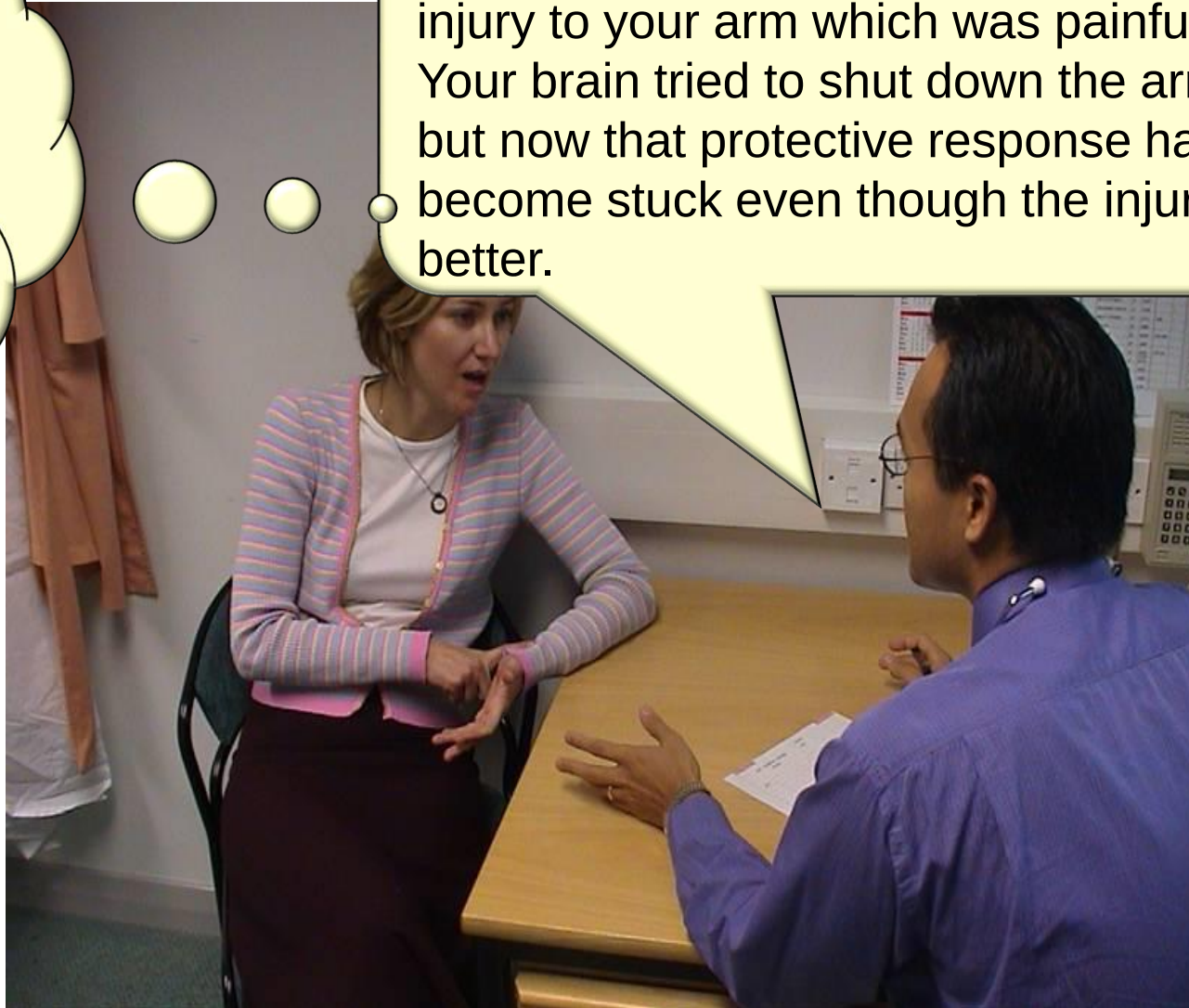
Some other ideas...

- “The automatic movements are OK but the voluntary ones have gone wrong”
- “In FND the brain is working **too hard** on movement, that’s why the more you try to change it the worse it gets”
- “I know you cant just reach inside your brain and fix this – it is really happening to you.”
- “It’s the software not the hardware”
- “Its like a piano that is out of tune rather than broken”
- “Its like the opposite of Phantom Limb - this is a leg that is there but your brain thinks is not’ (*for weakness and sensory loss*)
- FOCUS ON THE ‘WHAT’ BEFORE THE ‘WHY’

Using clues to mechanism to explain functional limb weakness

I can see how that might apply to me...

It looks as if this started out with an injury to your arm which was painful. Your brain tried to shut down the arm but now that protective response has become stuck even though the injury is better.



Introducing dissociation....



‘This is how I’ m making the diagnosis....’

**OK – well I
guess my
attacks do
match up to
what he’s
describing**

These are the five
features of your
attacks that give me
the diagnosis

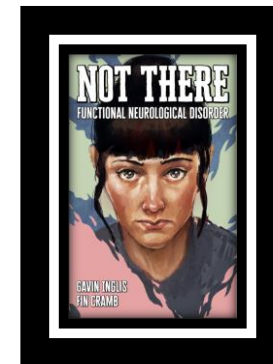


Introduce the concept of distraction techniques

That sounds
difficult

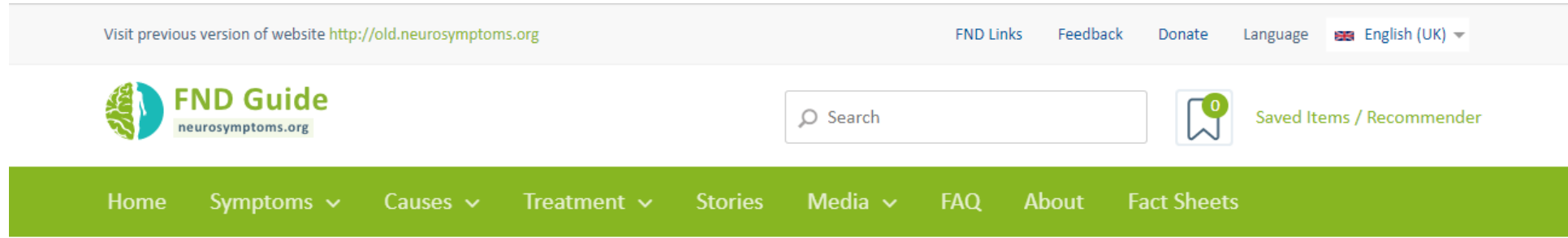
Start trying the distraction
techniques on the website.
You might find you can
lengthen the warning phase





Providing other resources

“Here’s a website which explains more.....neurosymptoms.org”



Functional Neurological Disorder (FND):

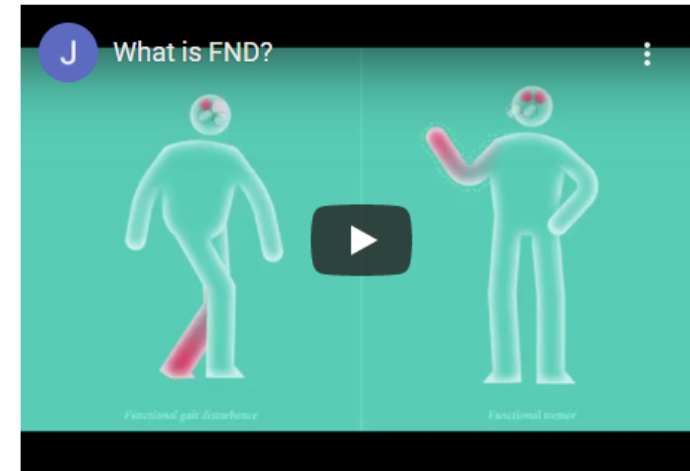
FND describes neurological symptoms like limb weakness, tremor, numbness or blackouts, related to the movement and sensation parts of the nervous system.....

- ✓ Caused by a PROBLEM with the FUNCTIONING of the nervous system
- ✓ A “software” issue of the brain, not the hardware (as in stroke or MS)
- ✓ With positive diagnostic features typical of FND
- ✓ Cause day to day difficulties for the person who experiences them

Functional Neurological Symptoms are:

Troublesome symptoms that someone wishes to understand without necessarily having a ‘disorder’ are called functional neurological symptoms, and this site is for you too.

FND and functional neurological symptoms are surprisingly common but can be difficult for patients and health professionals to understand.



Download FND app



FND videos



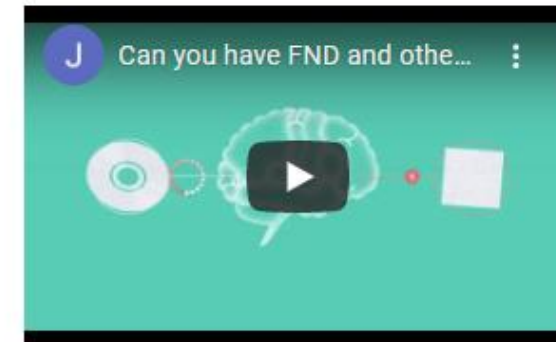
What is FND?

[Read More >>](#)



How is FND Diagnosed

[Read More >>](#)



Can you have FND and another neurological condition?

[Read More >>](#)



How is FND treated?



What causes FND?



Functional Neurological Dis...

[Store](#)[Mac](#)[iPad](#)[iPhone](#)[Watch](#)[TV](#)[Music](#)[Support](#)

App Store Preview

Open the Mac App Store to buy and download apps.



neurosymptoms FND Guide 4+

neurosymptoms FND Guide

[CogniHealth Ltd.](#)

Designed for iPhone

★★★★★ 5.0 • 4 Ratings

Free

iPhone Screenshots



Direct to specific information



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Recommender

Symptoms

- ☒ Functional Limb Weakness
- ☐ Functional (Dissociative) Seizures
- ☐ Functional Movement Disorder
- ☐ Functional Sensory Symptoms
- ☐ Functional Tremor
- ☐ Functional Cognitive Disorder
- ☐ Functional Dystonia
- ☐ Functional Speech Swallowing Symptoms
- ☐ Functional Gait Disorder
- ☐ Functional Dizziness (PPPD)
- ☐ Functional Jerks and Twitches
- ☐ Functional Drop Attacks
- ☒ Functional Facial Symptoms

Causes

- ☐ How has it happened?
- ☐ Why has it happened?
- ☐ Misdiagnosis
- ☐ Not imagined
- ☐ Ten Myths of FND
- ☐ FND and other functional disorders

Treatments

- ☐ Understanding your condition
- ☐ Investigations
- ☒ Physiotherapy / Exercise
- ☐ Occupational Therapy
- ☐ Psychological therapy
- ☐ Speech and Language Therapy
- ☐ Medication
- ☐ Family and Work

Videos

- ☐ What is FND?
- ☐ How is FND Diagnosed
- ☐ Can you have FND and another neurological condition?
- ☐ How is FND treated?
- ☐ What causes FND?
- ☐ Functional Neurological Disorder - an introduction
- ☐ 'dis-sociated'
- ☐ Edinburgh Fringe Event
- ☐ FND - on 'Insight' Australian TV
- ☐ FND - on Australian TV, 2020
- ☐ Georgia's Race Against FND
- ☐ How am I running when I can't walk?
- ☐ Kylee's story

Saved Items

Functional Limb Weakness



Functional Facial Symptoms



Physiotherapy / Exercise



I'm not a robot

Save

Please enter email

Send Email

“Read this factsheet.....”

Dissociative Seizures

This information sheet is written for people with dissociative seizures. It could also be helpful to family members. Friends and others of people with dissociative seizures. It's designed to give information about what dissociative seizures are, what causes them, how they're diagnosed and how they can be treated.

What are Dissociative Seizures?

There are many different names for dissociative seizures. Other names you may hear are non-epileptic seizures, non-convulsive status or pseudo, non-epileptic attack disorder (NEM), psychogenic seizures, functional seizures, pseudotonic or pseudoclonic seizures. Some of these names sound like the seizures are 'just an act' or 'imagined' which they certainly are not.

Status is a word describing any sudden, temporary loss of control over nervous system functioning. You may hear other words used, such as 'blacked out', 'fainted', 'fainted', 'fainted'.

When epileptic seizures are caused by a sudden, abnormal electrical discharge in the brain, dissociative seizures happen through a process in the brain known as dissociation.



Information leaflet taken from www.seizurepages.org
Published by the Royal Society of Medicine, London, UK, in 2014

UNDERSTANDING FUNCTIONAL LIMB WEAKNESS

When you first go to your doctor with the alarming symptoms of arms or legs 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 real motor 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 many other ways functional symptoms can affect people such as treatment disorder and weakness. 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:

- weakness - down one side
- weakness - down one side
- weakness - down one side
- weakness - down one side

The symptoms can be of the following type:

- weakness - down one side
- weakness - down one side
- weakness - down one side
- weakness - down one side

Information leaflet taken from www.seizurepages.org
Published by the Royal Society of Medicine, London, UK, in 2014

Functional Tremor

What is Functional Tremor?

Functional tremor is the commonest type of functional movement disorder.

In functional tremor there is uncontrollable shaking of part of the body usually an arm or a leg. This is due to the nervous system not working properly but not due to an underlying neurological disease.

Functional tremor is sometimes mistaken for Parkinson's disease or other causes of tremor such as 'Essential tremor'.

Unlike Parkinson's disease, functional tremor is due to a reversible problem in the way that the nervous system is working.

This means that a functional tremor can improve and sometimes go away completely although there is a 'long' treatment.



Information leaflet taken from www.seizurepages.org
Published by the Royal Society of Medicine, London, UK, in 2014

Functional Dystonia

What is Functional Dystonia?

Patients with functional dystonia often have 'turned finger' or a 'clenched hand'.



The other common problem in functional dystonia is that the whole hand or arm goes into a 'clenched' position.



These abnormal postures may be hard or even impossible for the patient to change which is why they are sometimes called 'fixed' dystonia.

This may be a temporary movement problem (a spasm) or may be more chronic (like is usually called fixed / functional dystonia).

What has gone wrong in functional dystonia?

Everyone has a 'map' of the body and then there is the brain.

In fixed dystonia what seems to be wrong in functional dystonia is that this 'map' in the brain, for various reasons has 'gone wrong'. The brain thinks that the 'turned' hand or 'clenched' arm position is normal even though you know that it is not.

Information leaflet taken from www.seizurepages.org
Published by the Royal Society of Medicine, London, UK, in 2014

Drop Attacks

A "Drop attack" is the medical term for a sudden fall to the ground without an obvious blackout. A typical drop attack is experienced when walking or standing and without any warning. Drop attacks are frightening and often lead to injuries, especially to knees, forearms and face.

There are many causes of drop attacks, such as simple falls, low blood pressure and reflexes, but quite often, especially in people under the age of 65, it turns out that drop attacks are a type of functional neurological symptom. They are sometimes described as a form of very brief dissociative (non-epileptic) attack.

Before reading this page, please check with your doctor that this information is relevant to you. If you have a diagnosis of 'idiopathic drop attacks' or 'cryptogenic drop attacks' then this information could be relevant. If your drop attacks are due to a known cause such as a heart condition or epilepsy then this information is not relevant.



Patients with Drop Attacks can have injuries to their face.

Information leaflet taken from www.seizurepages.org
Published by the Royal Society of Medicine, London, UK, in 2014

Persistent Posture-Perceptual Dizziness (PPPD) (Functional Dizziness)

Dizziness is a common symptom in neurology and has lots of different causes. There are lots of different causes of dizziness: migraine, middle ear problems (vestibular disorders), low blood pressure, and many other effects are all common ones.

Dizziness occurring as part of a functional disorder is also relatively common according to up to 10% of patients seen in a specialist dizziness clinic. When dizziness occurs as a functional disorder it is called 'Persistent Posture-Perceptual Dizziness' (PPPD) or Chronic Subjective Dizziness.

Other names for it include visual vertigo, motion picture vertigo, Functional dizziness or space and motion discomfort.

PPPD has recently been defined by the World Health Organization as 'Persistent non-vertiginous dizziness, unsteadiness, or both lasting three months or more.

Symptoms are present most days, often increasing throughout the day, but may wax and wane. Momentary flares may occur spontaneously or with sudden movement.

Affected individuals first report when upright, exposed to moving or complex visual stimuli, and during active or passive head motion. These symptoms may not be equally provocative.

Typically, the disorder follows recognition of acute or episodic vestibular or balance-related problems. Symptoms may begin insidiously, and their persistence."



Information leaflet taken from www.seizurepages.org
Published by the Royal Society of Medicine, London, UK, in 2014

Functional Facial Spasm

Patients with functional neurological symptoms can have symptoms affecting the face. These are much more common than was thought even in 1990s when it was first described. They have been recognized for over a century.

Functional Facial Spasm / Dystonia

The commonest type of functional facial symptom is spasm of the muscles around one eye or in the lower half of the face.

Typically functional facial spasm occurs in episodes and affects one half of the face. Attacks around the eye (partial contractions) usually go to the spasm which leads to narrowing of the eye opening with the opposite hand on the affected side (see picture below).



When functional facial spasm affects the lower half of the face then the corner of the mouth may be pulled down and sometimes the jaw is pulled up (see picture of jaw below). The mouth is pulled down because of spasm of a muscle called platysma. This is the muscle in the lower half of the face. The jaw is pulled up because the corner of the mouth is pulled up. The photo on the right shows a person with a functional facial spasm.



I'm grateful to Lucy for consenting to her photos appearing on www.seizurepages.org. You can hear Lucy describing her symptoms on the BBC Radio 4 programme, Inside Health, broadcast in October 2012, available at <http://www.bbc.co.uk/programmes/b0144444>.

These photos show Lucy's jaw tending to be pulled over to the right side of her mouth. In addition she has spasm of the platysma muscle on the right which is pulling her lip down on that side.

Information leaflet taken from www.seizurepages.org
Published by the Royal Society of Medicine, London, UK, in 2014

Post Concussion Syndrome

Post concussion syndrome is a description given to a cluster of physical and cognitive symptoms that sometimes occur after minor head injury or concussion. These include:

- Dizziness
- Poor Memory and Concentration
- Headaches
- Fatigue
- Sleep Disturbance
- Light sensitivity
- Tinnitus
- Ringing in the ears

In this chapter about dizziness when to minor head injury they are not talking about any kind of the head. A minor head injury normally means that there was a brief loss of consciousness (less than 30 minutes) and then in the way of memory loss after the accident (less than one hour).

Concussion doesn't have a universally agreed definition but generally means a blow to the head without loss of consciousness or memory which results in symptoms lasting more than 24 hours.

But we know from large studies that after a mild head injury or concussion, symptoms usually settle within days, weeks, or at most several months.

There are sometimes specific reasons for some symptoms.

For example, a blow to the head of any sort can damage 'grey' in the balance parts of the ear causing dizziness. It is called a mild degree of postural vertigo (PPV). There are other potential complications of head injury that a doctor may need to look for but usually there is no specific reason found for symptoms and tests such as MRI brain scanning and normal.

The brain has a good capacity to recover from bruise to the head like this, so long as they aren't too frequent.

There are situations where people have a blow to the head and experience very little in the way of symptoms. Think of the injuries to the head experienced by American football players, rugby players, or footballers heading the ball. Although you can be dangerous if you are injured again over many years, it's worth thinking how your head injury compares to just one of these sporting head injuries in severity.

Information leaflet taken from www.seizurepages.org
Published by the Royal Society of Medicine, London, UK, in 2014



FND Action @FNDAction · May 4



This is what many doctors see as the only treatment needed for those diagnosed with a Functional Neurological Disorder [#FND](#) [#NEAD](#) [#action4FND](#)

Functional Neurological Disorder



Information – welcomed by patients but doesn't alter outcome

SHARE July 20, 2020 NULL HYPOTHESIS

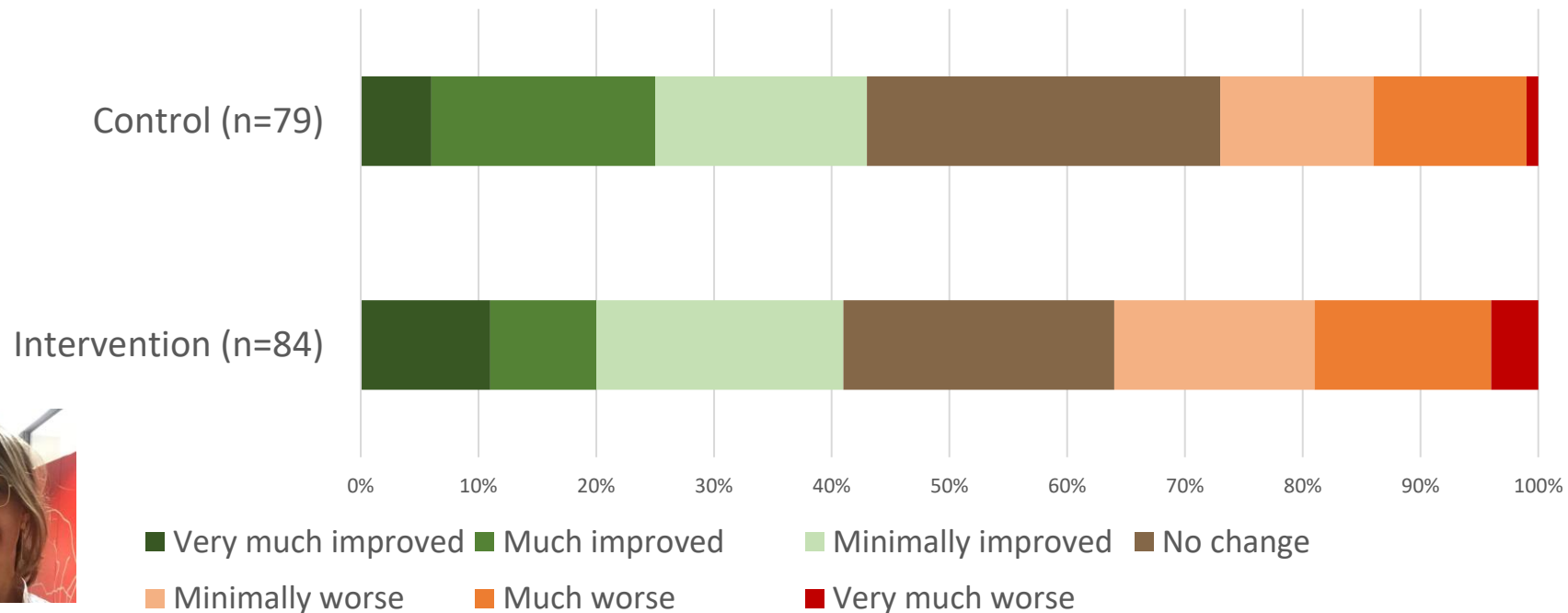
Internet based self-help randomized trial for motor Functional Neurological Disorder (SHIFT).

Jeannette M. Gelauff, Judith G. Rosmalen, Alan Carson,  Joke M. Dijk, Martijn Ekel, Glenn Nielsen, Jon Stone, Marina A.J. Tijssen

First published July 20, 2020, DOI: <https://doi.org/10.1212/WNL.00000000000010381>

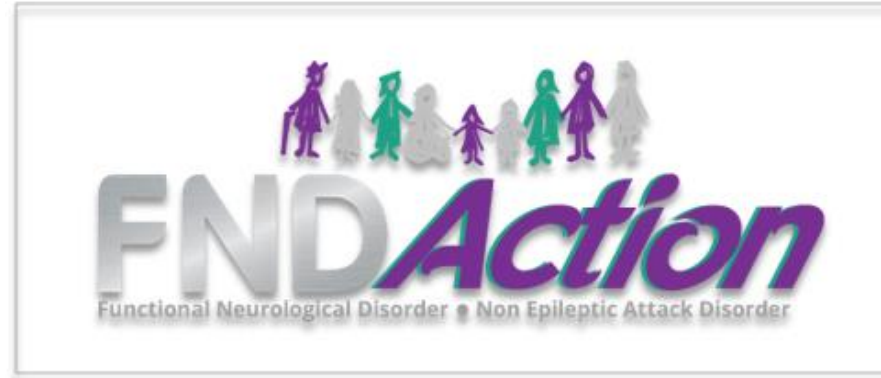
Neurology®

Self-rated general health at 6 months (CGI)



Dr Jeannette Gelauff

Patient led organisations and advocates for FND for the first time



Lorraine Kelly – patron of FND Hope UK



Psychologist (Susannah Pick) and Neuropsychiatrist (Tim Nicholson) raising money for FND hope

FND Hope UK Fundraiser



Susannah Pick

Completing the 50km South Coast Challenge



100KM, 50KM, OR 25KM

#FNDaware | #LetsTalkFND

FND Hope UK, Registered charity England & Wales 1273807 & Scotland SC048133



Dr Tim Nicholson
March 30 2019
5-8pm
JAGS Sports Centre
Dulwich, London
(close to the loP)

Swimathon
#FNDaware
DONATE

5km - (200 lengths)

WORLD FND WEEK
2019 2-13 April
#FNDaware

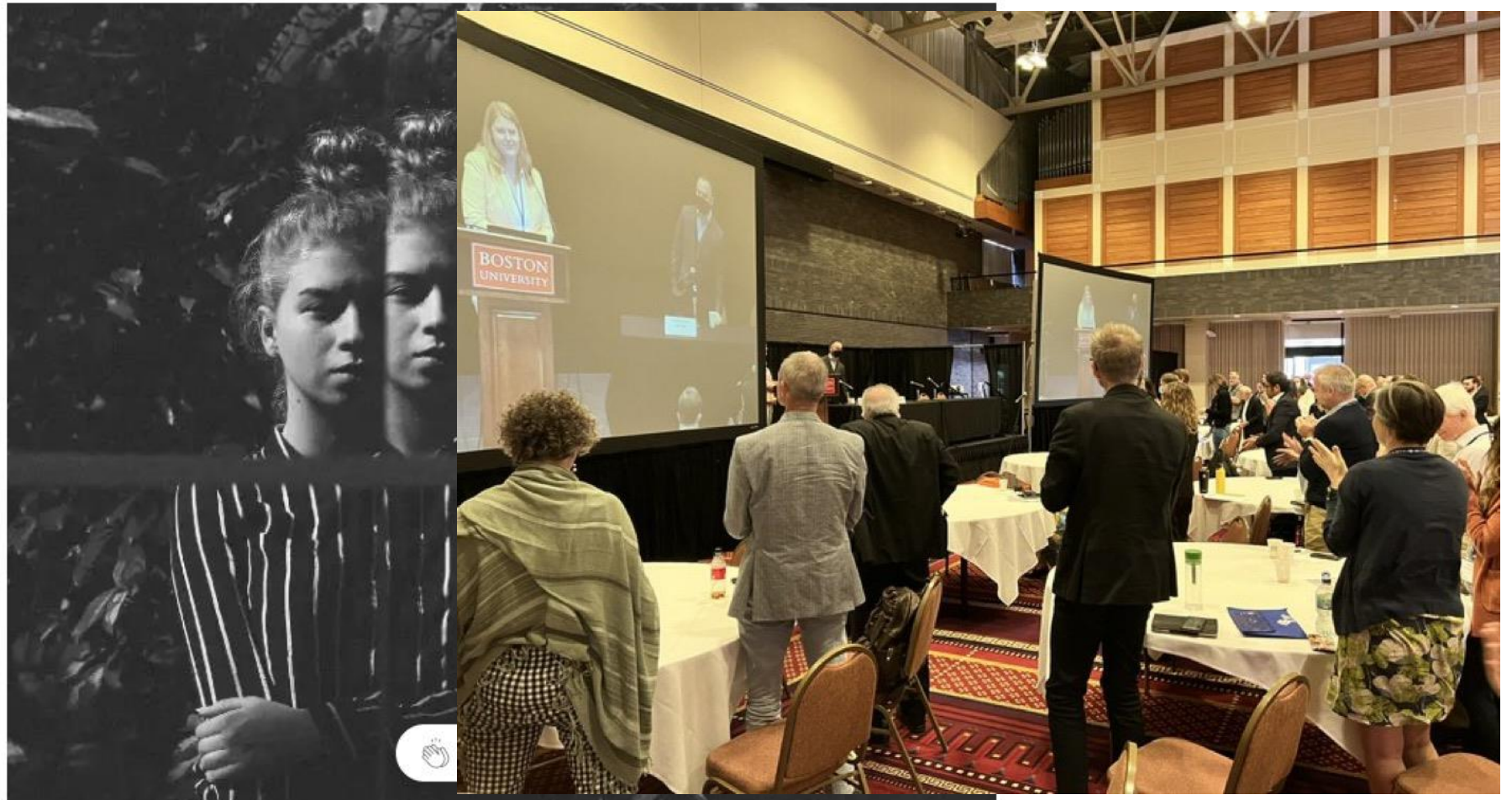


Fnd Portal

Jun 5 · 48 min read · [Listen](#)



Cadenza for Fractured Consciousness: A Personal History of the World's Most Misunderstood Illness



Managing comorbidities

FND – Common comorbidities that anyone can help with

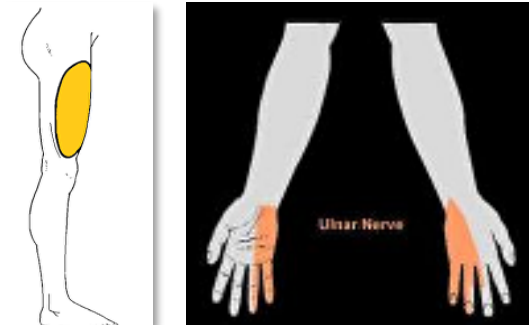
Migraine



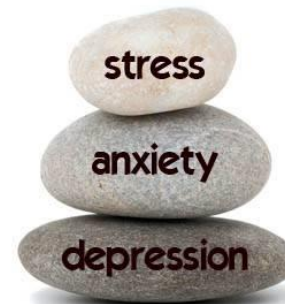
Opiate/ Gabapentinoid consumption



Nerve Entrapment



Anxiety/Depression/PTSD



Why follow up is essential

Why at least one follow up visit is helpful

- **Complex condition – what we normally do**
- **Review investigations/incidental abnormalities**
- **Assess**
 - **Patient agreement**
 - **Motivation for change**
- **Positive feedback/ Learn how to explain better!**
- **Support therapists**



New – FND formulator – to improve communication...



Hello there, I am your FND digital companion. I am here to guide you through the activities below to help you make sense of your health. I recommend that you start with the Symptom Formulator. Go at your own pace and feel free to come back to any of the activities whenever you want. Please remember to save your report before leaving this website. To learn more about FND, please visit neurosymptoms.org.

Welcome to the FND Formulation Tool

Who is this for? If you are living with FND (Functional Neurological Disorder) or are a healthcare professional supporting a person living with FND, you have come to the right place!

- ✓ Help you make sense of your symptoms
- ✓ Understand which of your conditions are functional disorders
- ✓ Think through potential causes and triggers
- ✓ Prepare for your healthcare appointment
- ✓ Communicate better with your healthcare professional

What can you expect? When you go through all four activities, you will be presented with a report of the answers you have selected and thoughts you have shared along the way. You can use this report in many ways:

- ✓ Use it as a way to keep track of how your experience with FND changes over time by revisiting the activities every so often
- ✓ Share it with your healthcare professional to help them understand you better



Symptom
Formulator

Start



Diagnostic
Formulator

Start



Causes
Formulator

Start



Treatment
Formulator

Start

FND Formulation
Report

View sample report



My FND Formulation Report

TIME: 10:53 PM
DATE: 27 Oct, 2022

My Symptoms



● Not at all bothered ● Bothered a little ● Bothered a lot

My quality of life



Mobility

I have severe problems in walking about



Usual Activities

I have moderate problems doing my usual activities



Anxiety/Depression

I am slightly anxious or depressed



Self-Care

I have moderate problems washing or dressing myself



Pain/Discomfort

I have moderate pain or discomfort

Notes

The follow up visit – triaging for treatment



FND Guide

neurosymptoms.org



Home

Symptom Formulator

Diagnostic Formulator

Causes

Treatment Formulator

Report



Use the scale below to share how you feel about the following two questions before we explore treatment options

Do you think your doctor got your FND diagnosis right?



Do you think it's the right time for you to engage with active therapies for FND ?



Triaging for treatment

‘See the patient again.....’

Thanks – that was
really helpful

What did you think of
all that information I
gave you last time?



University Hospitals Division



HAVE A DIAGNOSIS AT LAST.
SOMEONE FINALLY KNOWS WHAT
I HAVE.

“Have a diagnosis at last – some one finally knows
what I have”

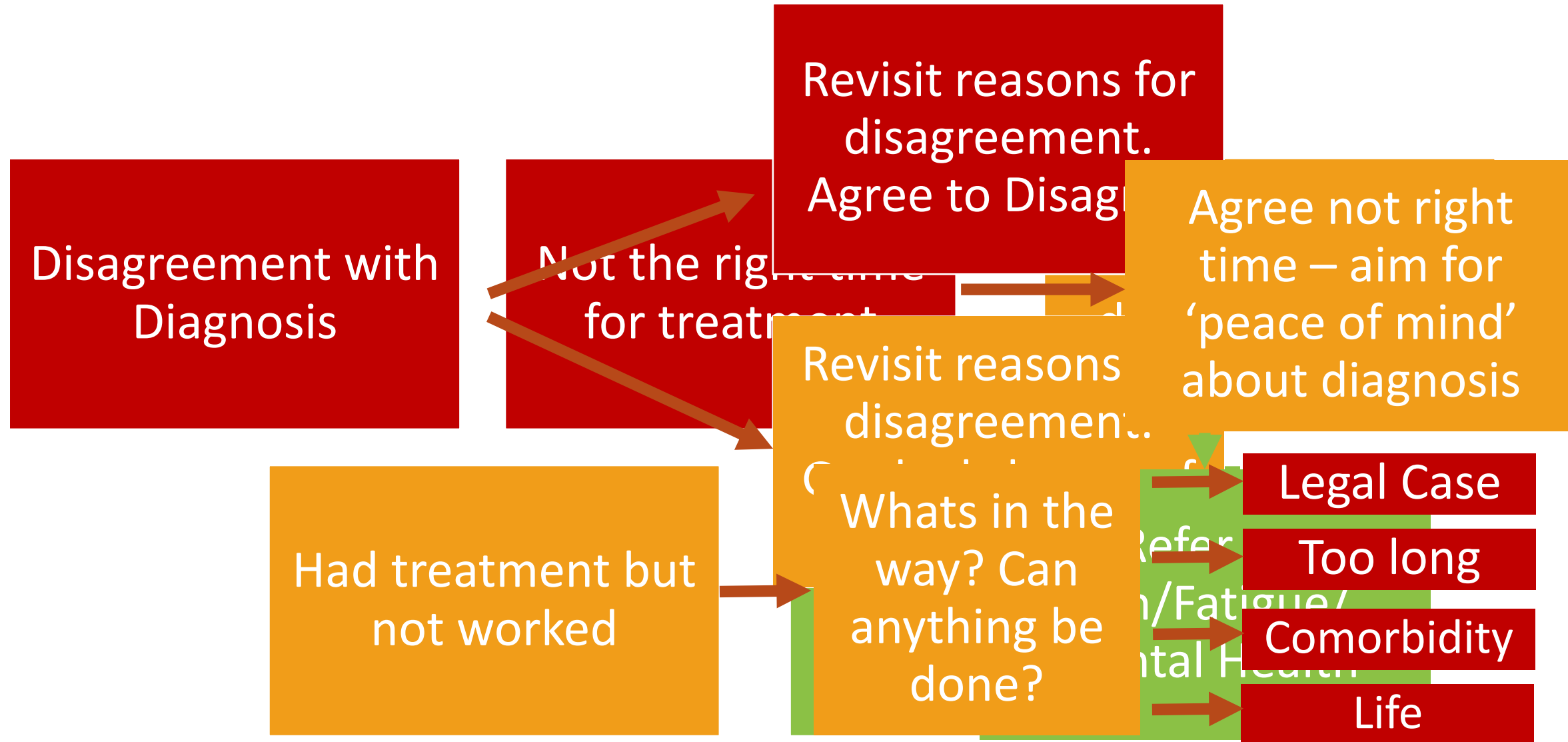
‘See the patient again.,.....’

I can't remember...
can you explain again

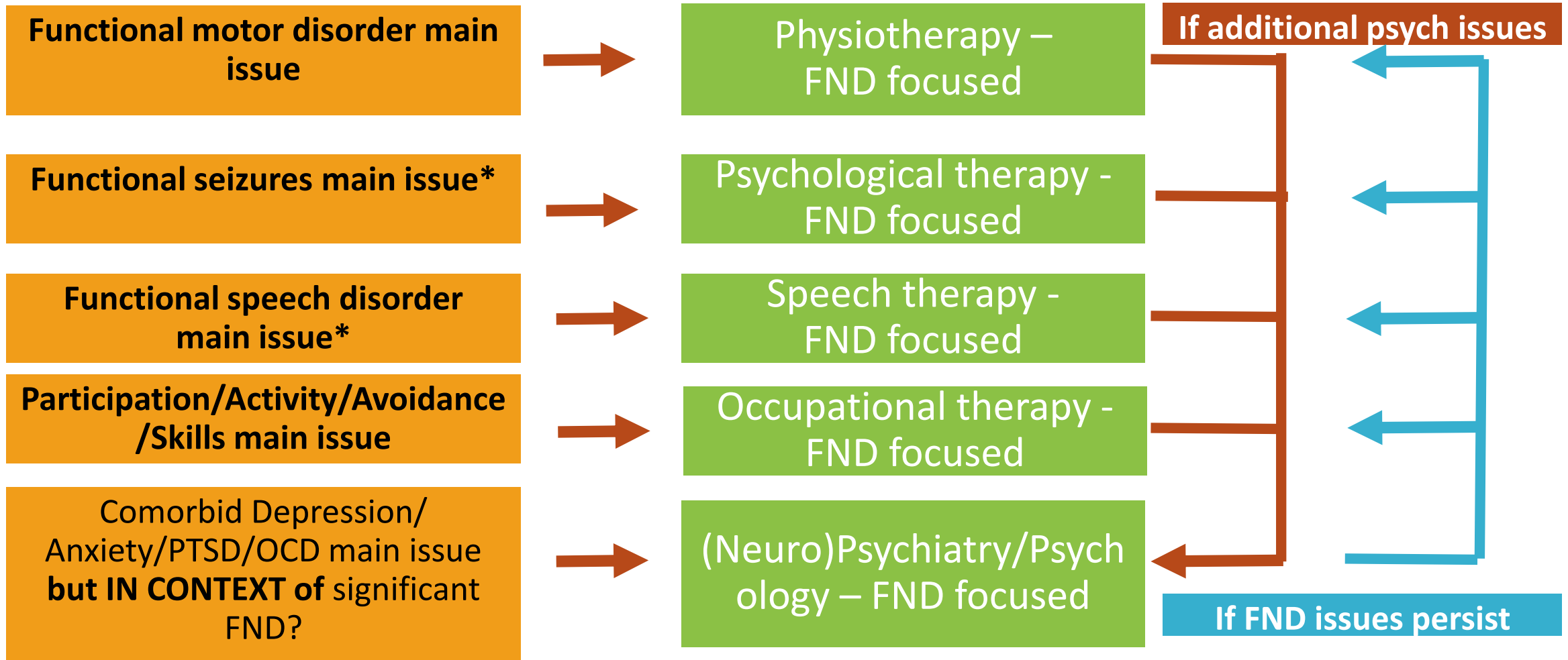
What did you think of
all that information I
gave you last time?



Outcomes of Neurology triage for treatment



Neurology FND triage - who should I refer to first?



*or where it looks like some improvement in FND symptoms will improve mental health

Other communication issues/ questions

- Pain
- Legal case
- Paediatric / Families
- Transcultural
- Learning Disability

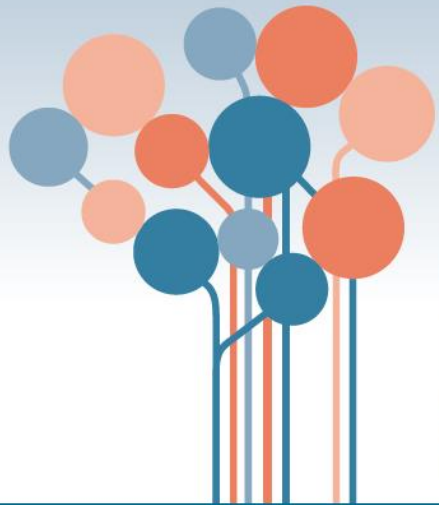
Take Home Points

- Communication barriers relate largely to health professional/societal factors and not the patient
- Communication is an essential platform for subsequent treatment
- But communication is not usually treatment by itself
- Communicate how you normally do for other disorders – don't be weird
- Learn to triage based on agreement and readiness for therapy

Select References

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8-11 June 2024
Verona, Italy



**FUNCTIONAL
NEUROLOGICAL
DISORDER
SOCIETY**
fndsociety.org



5th International Conference on Functional Neurological Disorder



The University of Edinburgh
Edinburgh Neuroscience



FND Research Group

Centre for Clinical Brain Sciences, University of



Jon Stone
Neurology

Laura McWhirter
Neuropsychiatry

Alan Carson
Neuropsychiatry

Ingrid Hoeritzauer
Neurology

FRG – Other current members



Caoimhe
McLoughlin
Psychiatry



Veronica
Cabreira
Neurology



Sarah
McRae
Physio

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**CORE
LIBRARY
for FND**



Alumni and ongoing Collaborators



Alex Lehn²
Neurology
iBook



Lea Ludwig³
Psychology
CODES



Paula
Gardiner
CBT/Physio



Stoyan
Popkirov
Trauma CRPS
PPPD Cognition



Sara
Finkelstein
Neurology



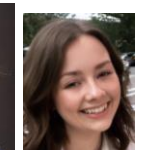
Tommaso
Ercoli
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Hannah
Callaghan
CODES



Jeannette
Gelauff
Neurology



Clare Diamond
Physio4FMD