How to communicate a diagnosis of FND

and what to do when it goes wrong

Prof Jon Stone

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Twitter: @jonstoneneuro

NHS Lothian

THE UNIVERSITY OF EDINBURGH

FUNCTIONAL NEUROLOGICAL DISORDER SOCIETY

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

FUNCTIONAL NEUROLOGICAL DISORDER SOCIETY

Some resources

Movement Disorders
CLINICAL PRACTICE
HOW DO I?

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

Jon Stone, FRCP PhD* and Ingrid Hoeritzauer, MB BCh MRCP

HOW TO DO IT

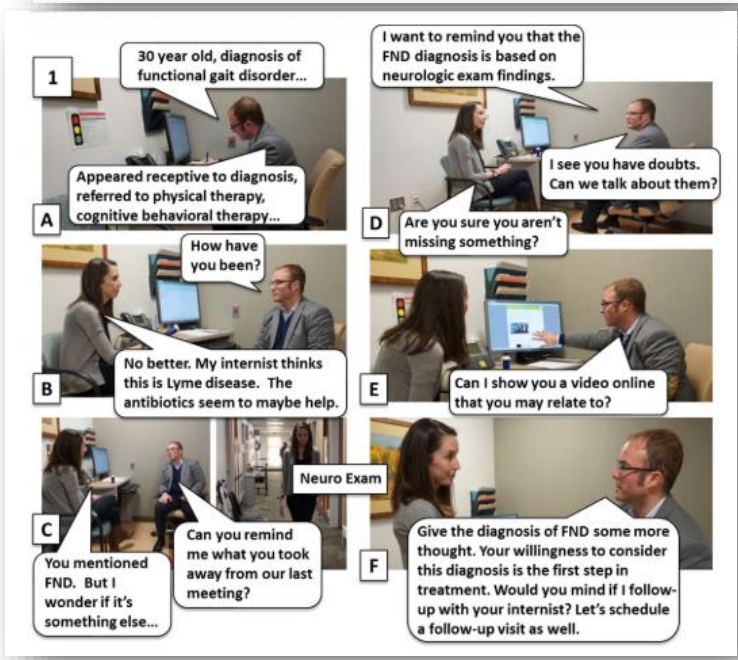
Explaining functional disorders in the neurology clinic: a photo story

Alan Carson,[1] Alexander Lehn,[2,3] Lea Ludwig,[1] Jon Stone[1]

HOW TO DO IT

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]



Check for updates

"Breaking the News" of a Functional Movement Disorder

17

Jon Stone, Ingrid Hoeritzauer, and Alan Carson

FUNCTIONAL NEUROLOGICAL DISORDER SOCIETY

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

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tjerklagrand@gmail.com

(1) mentioning a diagnosis of FS/FND or synonym in the record,
(2) mentioning of an explanation of the diagnosis given to the patient,
(3) provision of self-reading/ online material about FND,
(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

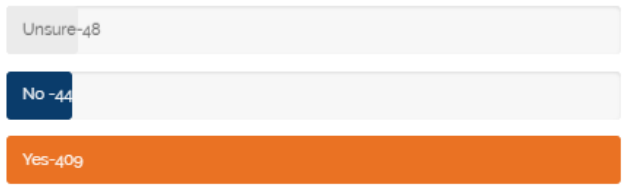
Doctors problem	Societal problem
Stigma / Negative Attitudes	

FND HOPE STIGMA SURVEY

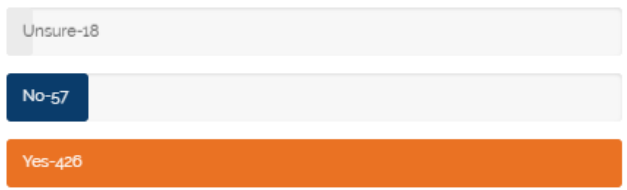
THANK YOU TO ALL THOSE WHO PARTICIPATED.

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

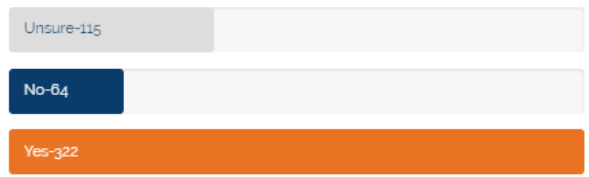
HAVE YOU EVER FELT LIKE YOU HAVE BEEN TREATED POORLY DUE TO STIGMA RELATED TO YOUR CURRENT (FND) DIAGNOSIS?



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."

FND HOPE
FUNCTIONAL NEUROLOGICAL DISORDER

Some Barriers to Communication

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

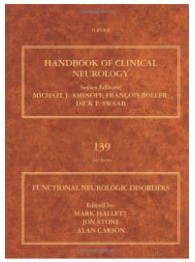
Chapter 44

Explanation as treatment for functional neurologic disorders

J. STONE[1]*, A. CARSON[2], AND M. HALLETT[3]

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

Available on Pubmed and most University Subscriptions



Clinical study

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

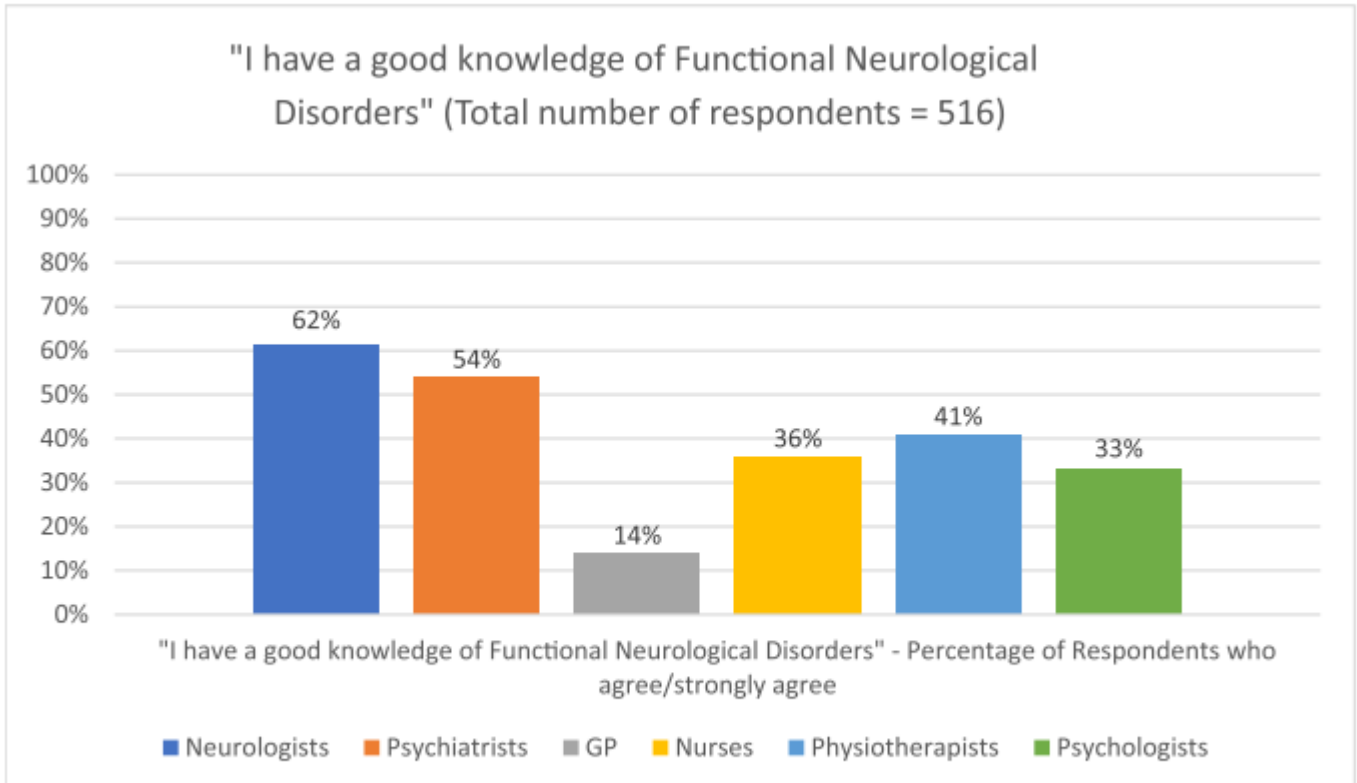


Fig. 2. Knowledge of FND.

Neuropsychiatry

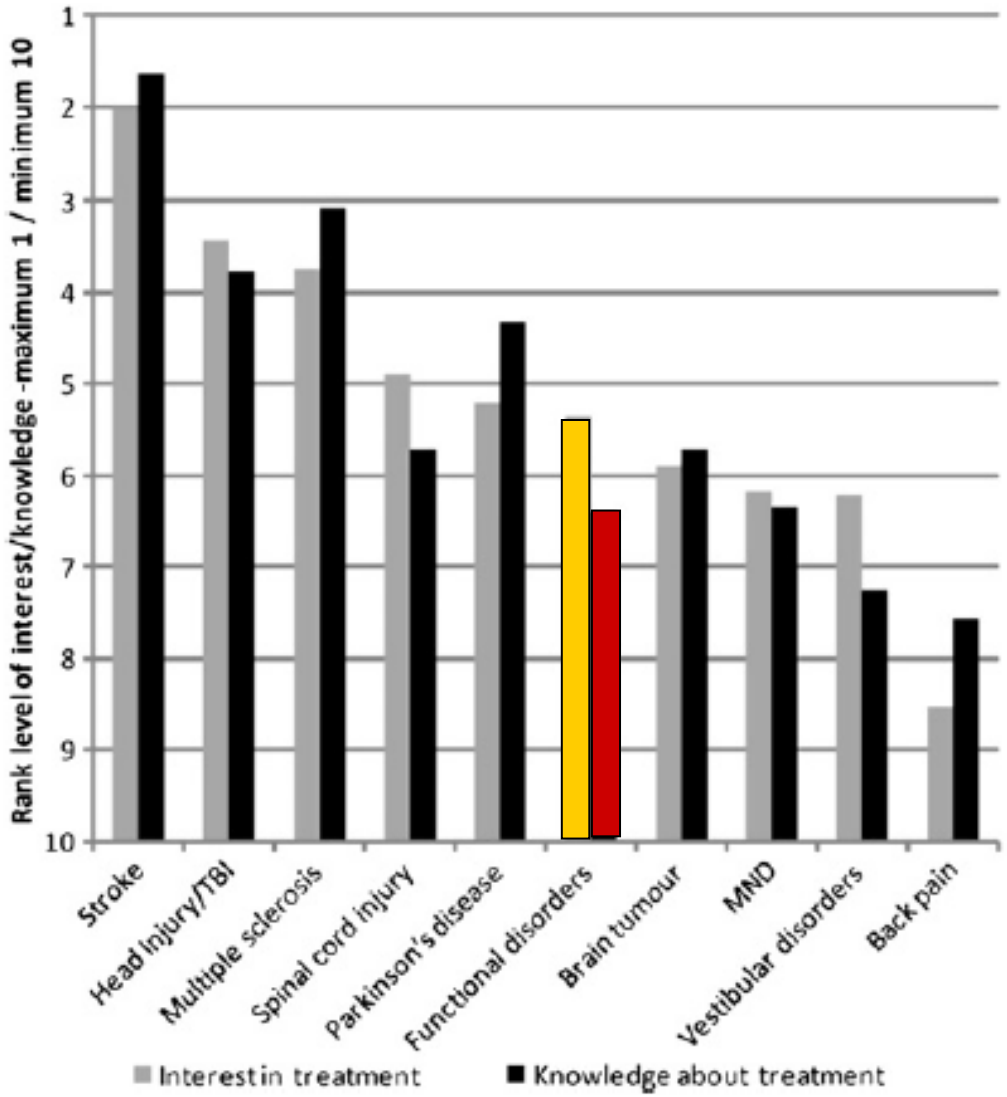
SHORT REPORT

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

Mark J Edwards,[1] Jon Stone,[2] Glenn Nielsen[3]

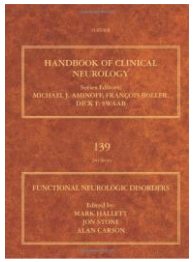
- 702 physios from UK Physio group (ACPIN

- 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

doi:10.1093/brain/awp060 Brain 2009: 132; 2889–2896 | 2889

BRAIN
A JOURNAL OF NEUROLOGY

OCCASIONAL PAPER

In the psychiatrist's chair: how neurologists understand conversion disorder

Richard Kanaan,[1] David Armstrong,[2] Philip Barnes[3] and Simon Wessely[1]

Neurologists commonly hold ambivalent views about patients with FND

Attitudes of Neuroscience Nurses Toward Patients With Conversion Symptoms

Lisa Ahern, B.Sc.
Jon Stone, M.B., Ch.B., Ph.D., FRCP
Michael C. Sharpe, M.D., FRCP, FRCPsych

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

nature reviews neurology https://doi.org/10.1038/s41582-022-00765-z

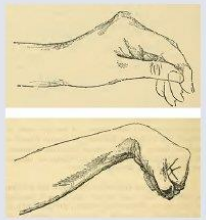
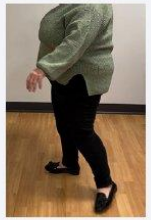
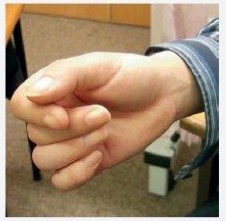
Perspective

Check for updates

Why functional neurological disorder is not feigning or malingering

Mark J. Edwards[1] ✉, Mahinda Yogarajah[2,3,4] & Jon Stone[5]

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 oculis 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 permision 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	

RESEARCH-ARTICLE

Check for updates

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]

[a]Sobell Department of Motor Neuroscience and Movement Disorders, UCL Institute of Neurology, London, UK; [b]Motor Control and Movement Disorders Group, Institute of Molecular and Clinical Sciences, St Georges University of London, London, UK; [c]Research Department of Primary Care and Population Health, UCL, London, UK

I've lost virtually a year of my life because of my condition.

Because that's what it feels like, psychological illness is like it should mean it's literally now you are making it up. It's all in your head, there's nothing wrong with you at all.....

Additionally well you don't have Parkinson's disease, and that's what it feels like, psychological illness is like it should mean it's literally now you are making it up. It's all in your head, there's nothing wrong with you at all.....

One of the consultants recommended that I took a glass of wine every evening..... to stop. They won't stop.....

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)

FUNCTIONAL NEUROLOGICAL DISORDER SOCIETY

RESEARCH ARTICLE

Health Care Utilization in Functional Neurologic Disorders

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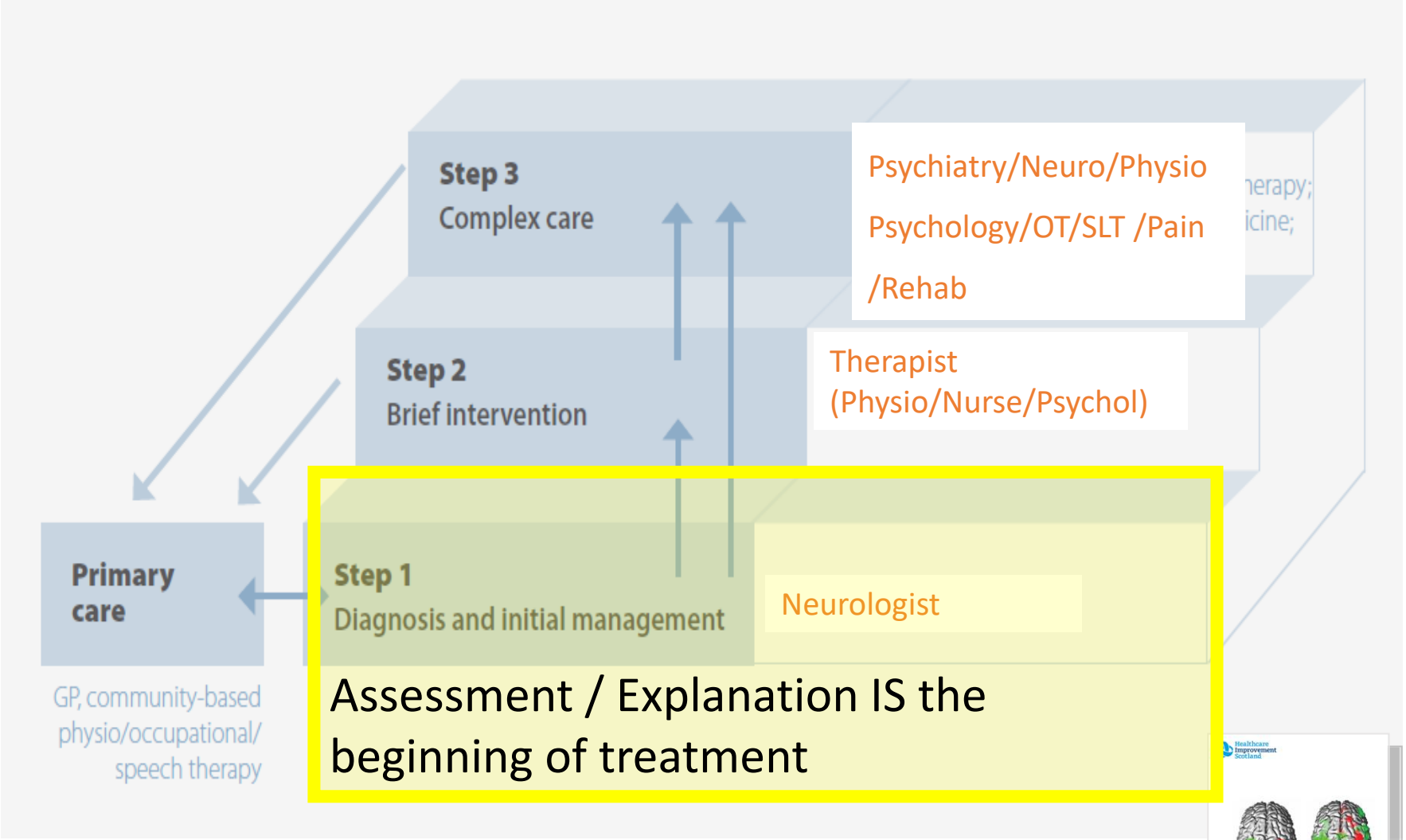
Communication is greatly aided by a therapeutic assessment

Stepped treatment for functional movement disorder



Healthcare Improvement Scotland 2012

www.healthcareimprovementscotland.org

REVIEW

Editor's choice
Scan to access more free content

Functional neurological disorders: the neurological assessment as treatment

Jon Stone

- 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….

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.

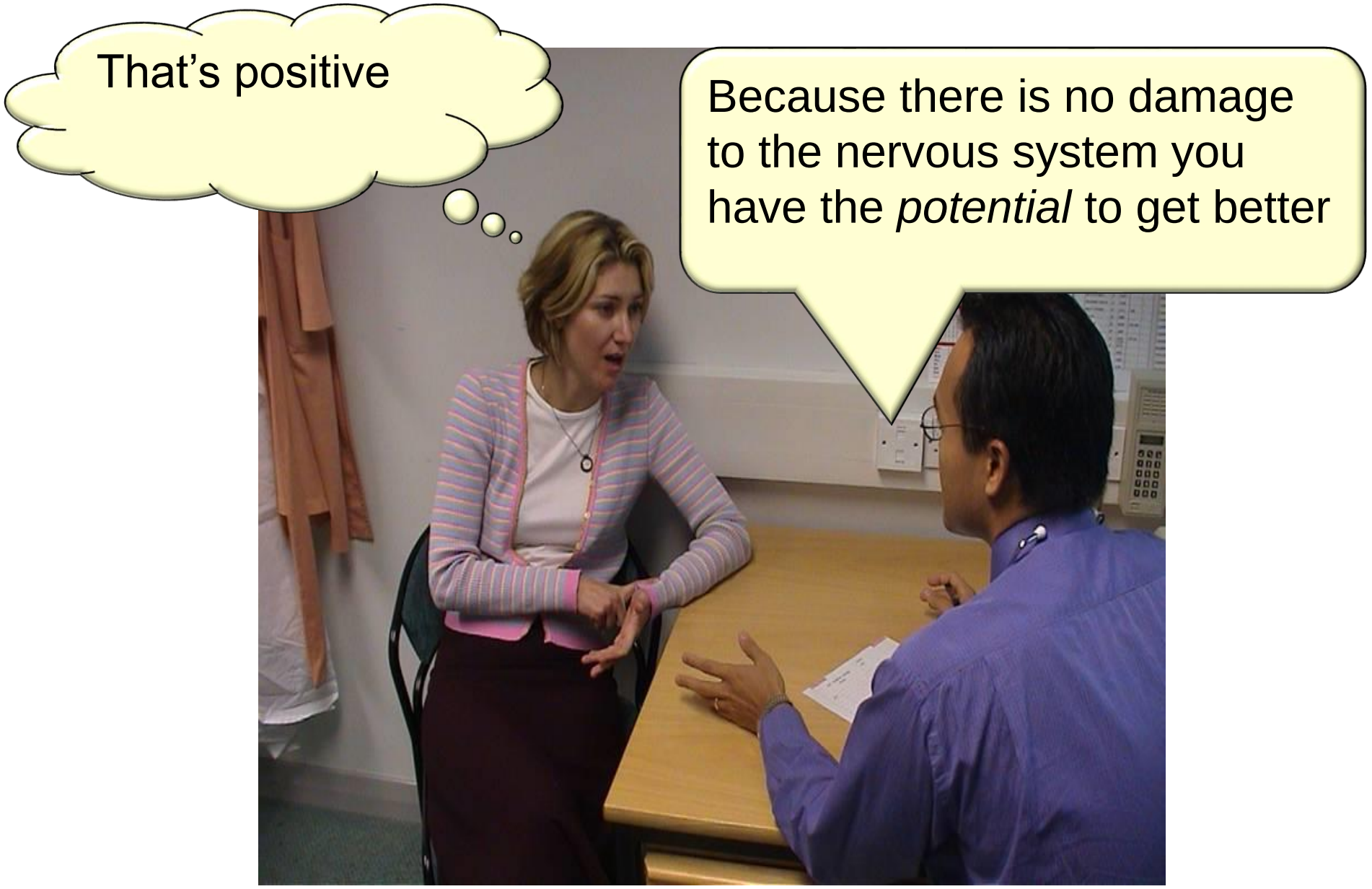
Neurology® 2012;79:282-284

Rachel – Hip Abductor sign of Functional Leg Weakness

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

Stone, Gelauff, Carson. Movement Disorders. 2012

‘You have something potentially reversible….’



‘Software not hardware….’

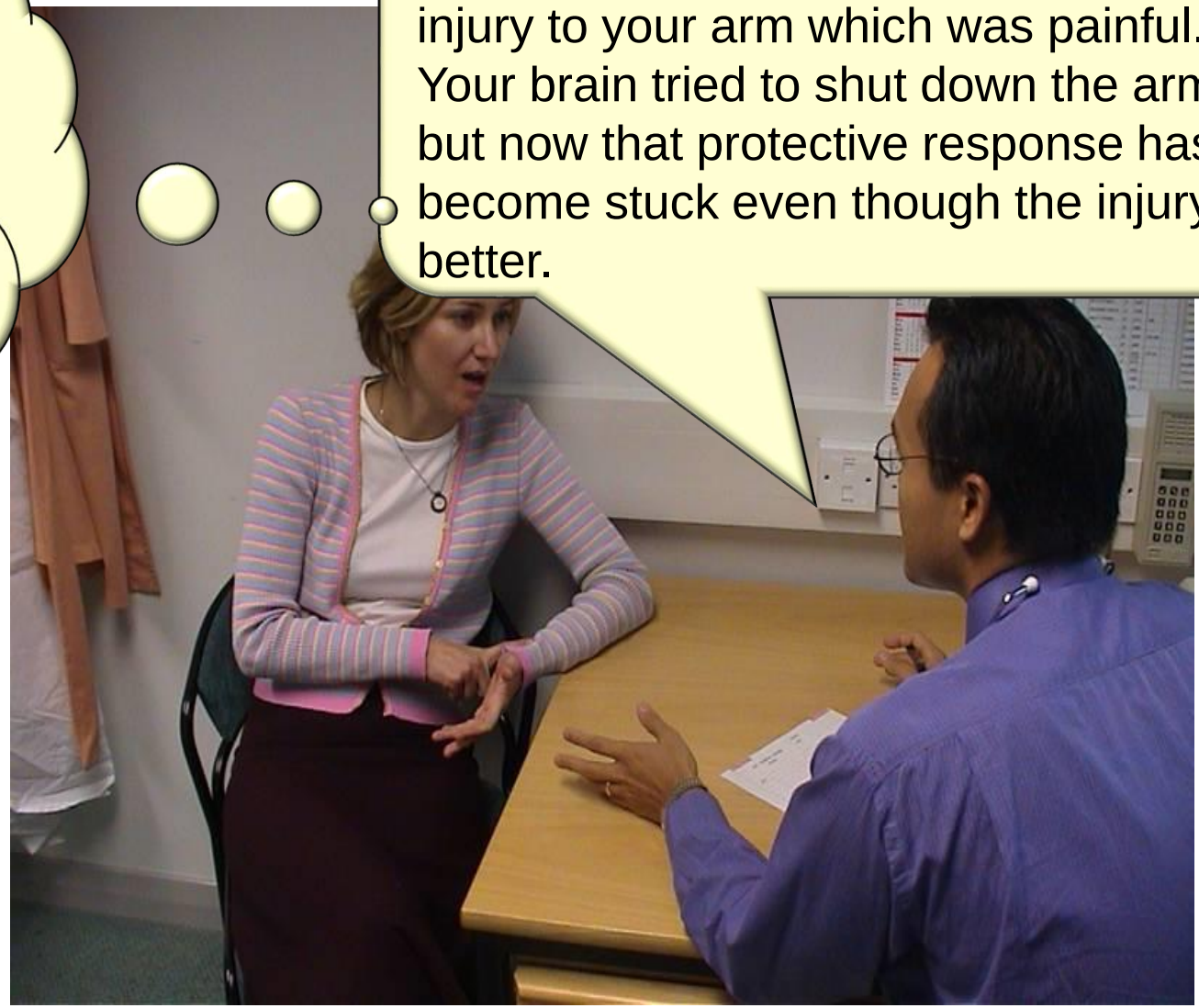
Some other ideas…

- “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’

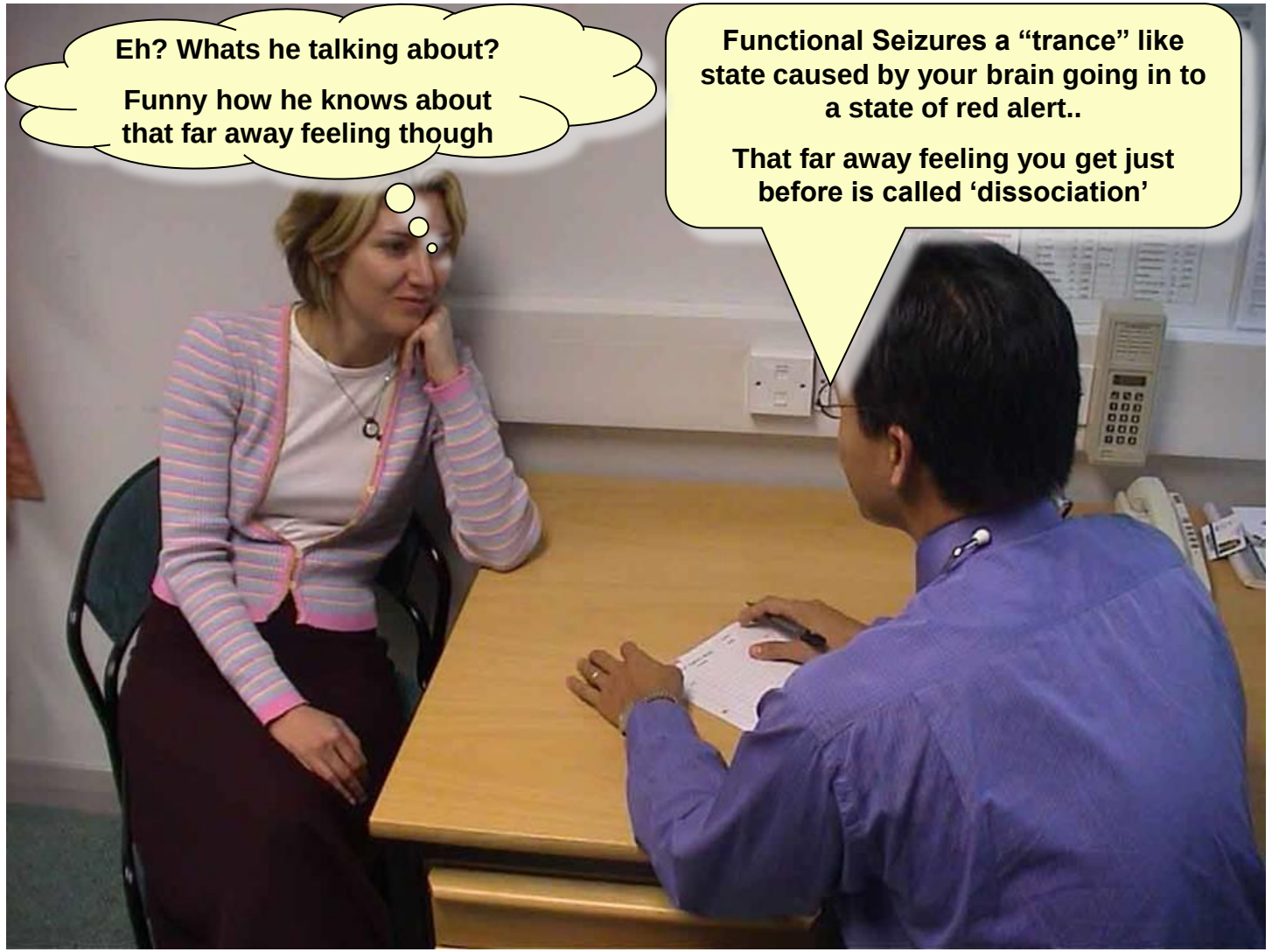
Using clues to mechanism to explain functional limb weakness

I can see how that might apply to me…

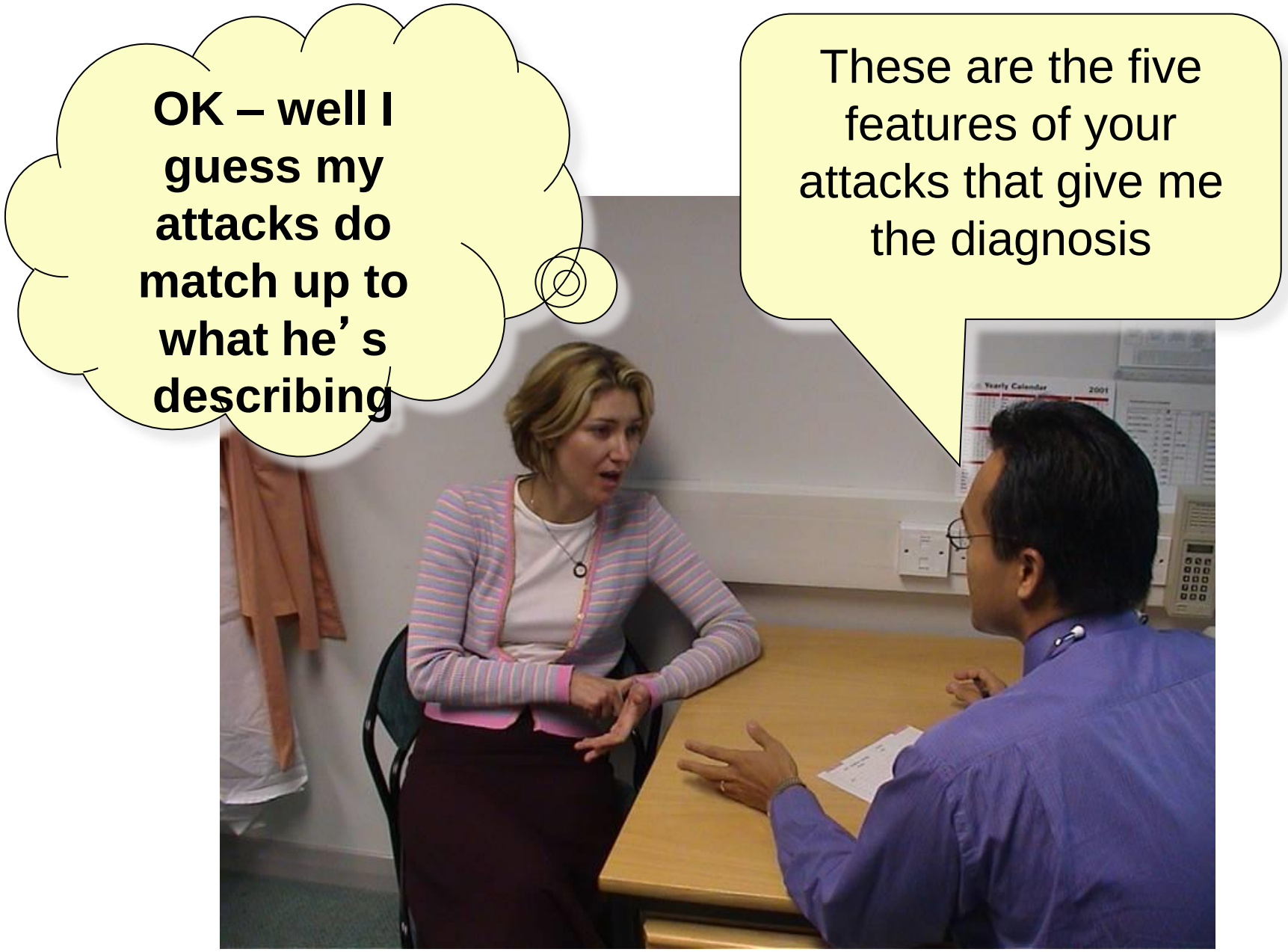


It looks as if this started out with an injury to your arm which was painful. Your brain tried to shut down the arm but now that protective response has become stuck even though the injury is better.

Introducing dissociation….



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



Introduce the concept of distraction techniques

That sounds difficult

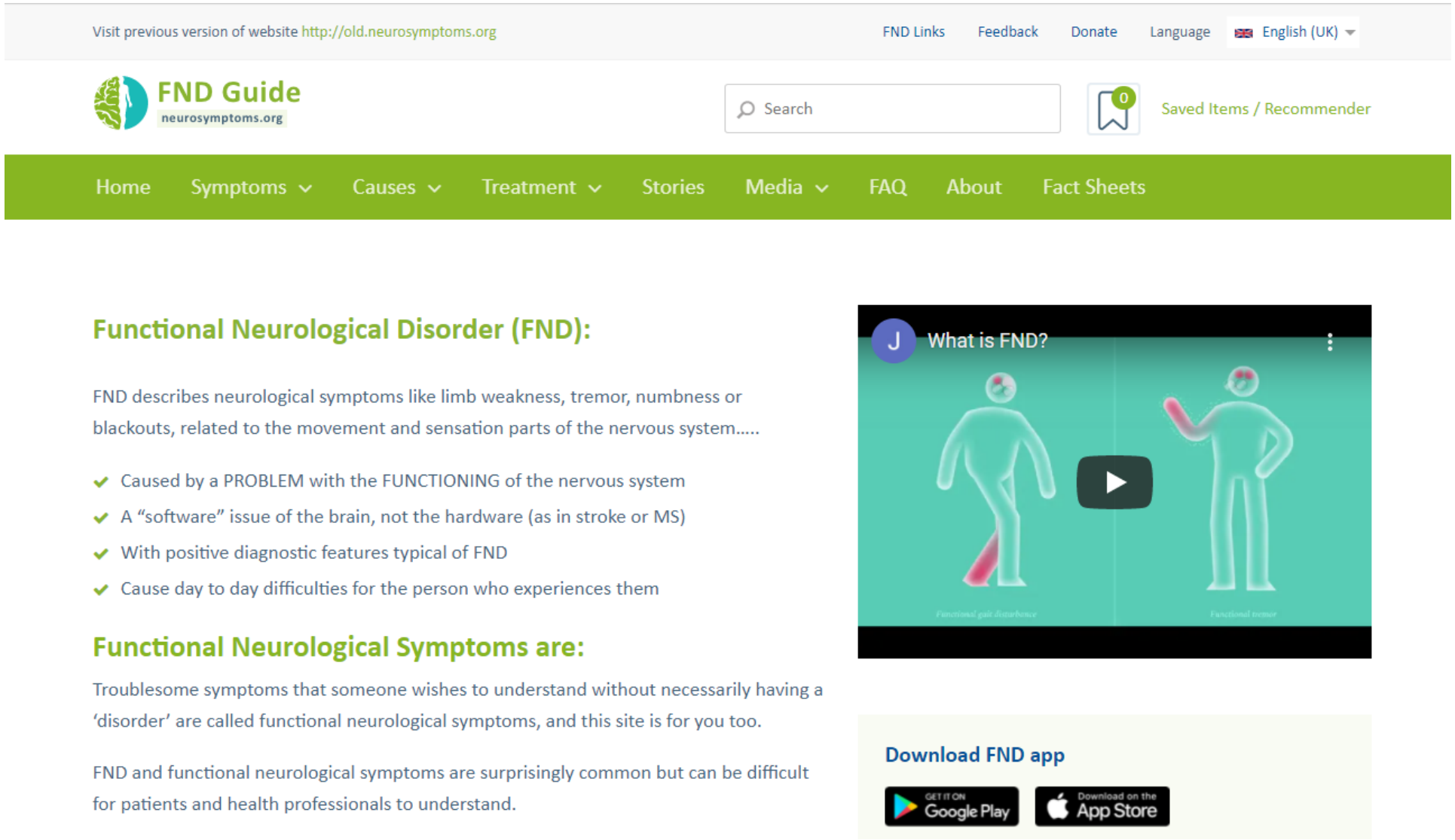
Start trying the distraction techniques on the website. You might find you can lengthen the warning phase


THE ATTACK ITSELF CAN BE A RELIEF FROM THE HORRIBLE, TRAPPED FEELING YOU DESCRIBED.
BUT THIS IS THE CYCLE YOU NEED TO BREAK.
ONCE YOU RECOGNISE THE SYMPTOMS, WE CAN STOP THEM FROM OVERWHELMING YOU.
THE KEY IS TO DISTRACT YOURSELF IN THAT MOMENT.
PERHAPS YOU HAVE A GAME OR PUZZLE ON YOUR PHONE YOU COULD KEEP TO HAND?
IT'S THAT SIMPLE? COUNT BACKWARDS AND IT GOES AWAY?
NO. IT'S HARDER THAN THAT.
BUT YOU CAN DO IT, STEPHANIE.
RECOVERY IS POSSIBLE FOR YOU.

NOT THERE
FUNCTIONAL NEUROLOGICAL DISORDER
GAVIN INGLIS
JIN CRAMB

Providing other resources

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



FND videos

What is FND?

Read More >>

How is FND Diagnosed

Read More >>

Can you have FND and another neurological condition?

Read More >>

App Store Preview

Open the Mac App Store to buy and download apps.

neurosymptoms FND Guide 4+

neurosymptoms FND Guide

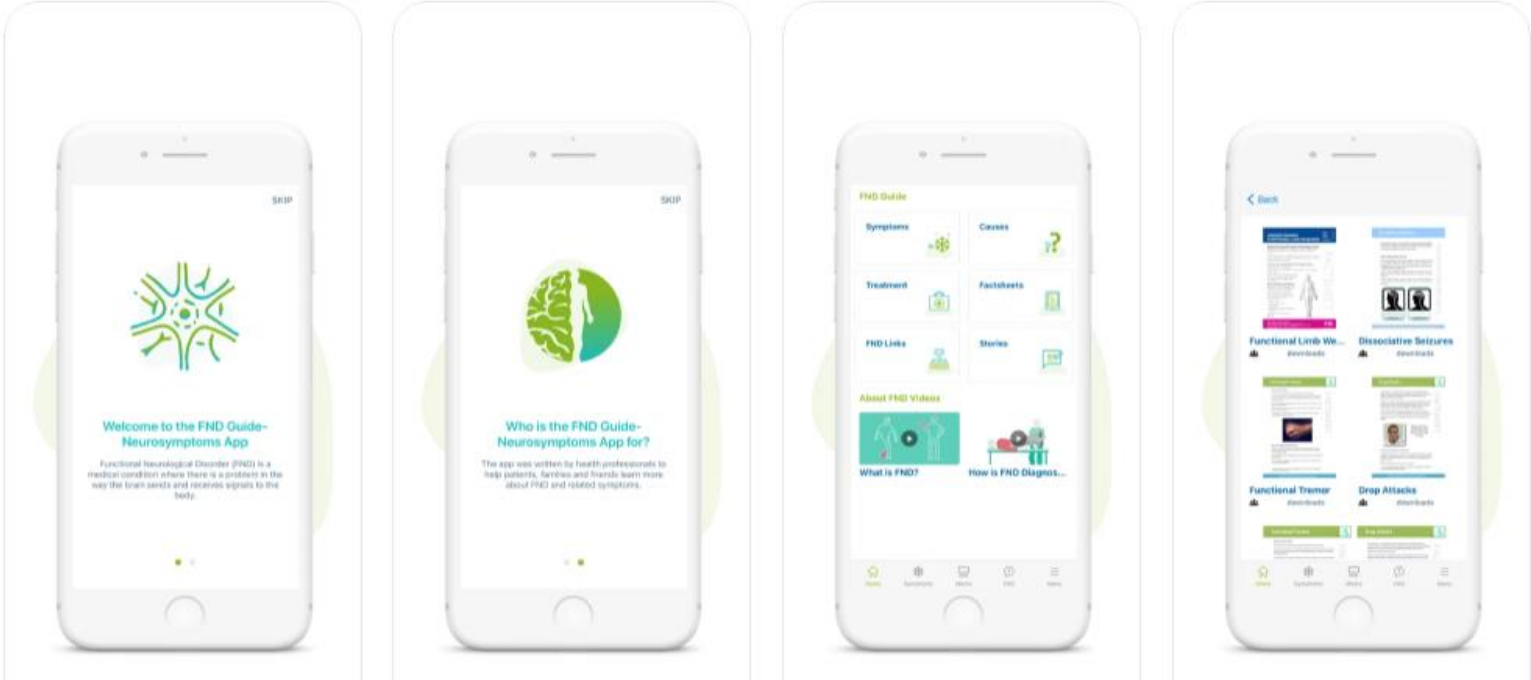
CogniHealth Ltd.

Designed for iPhone

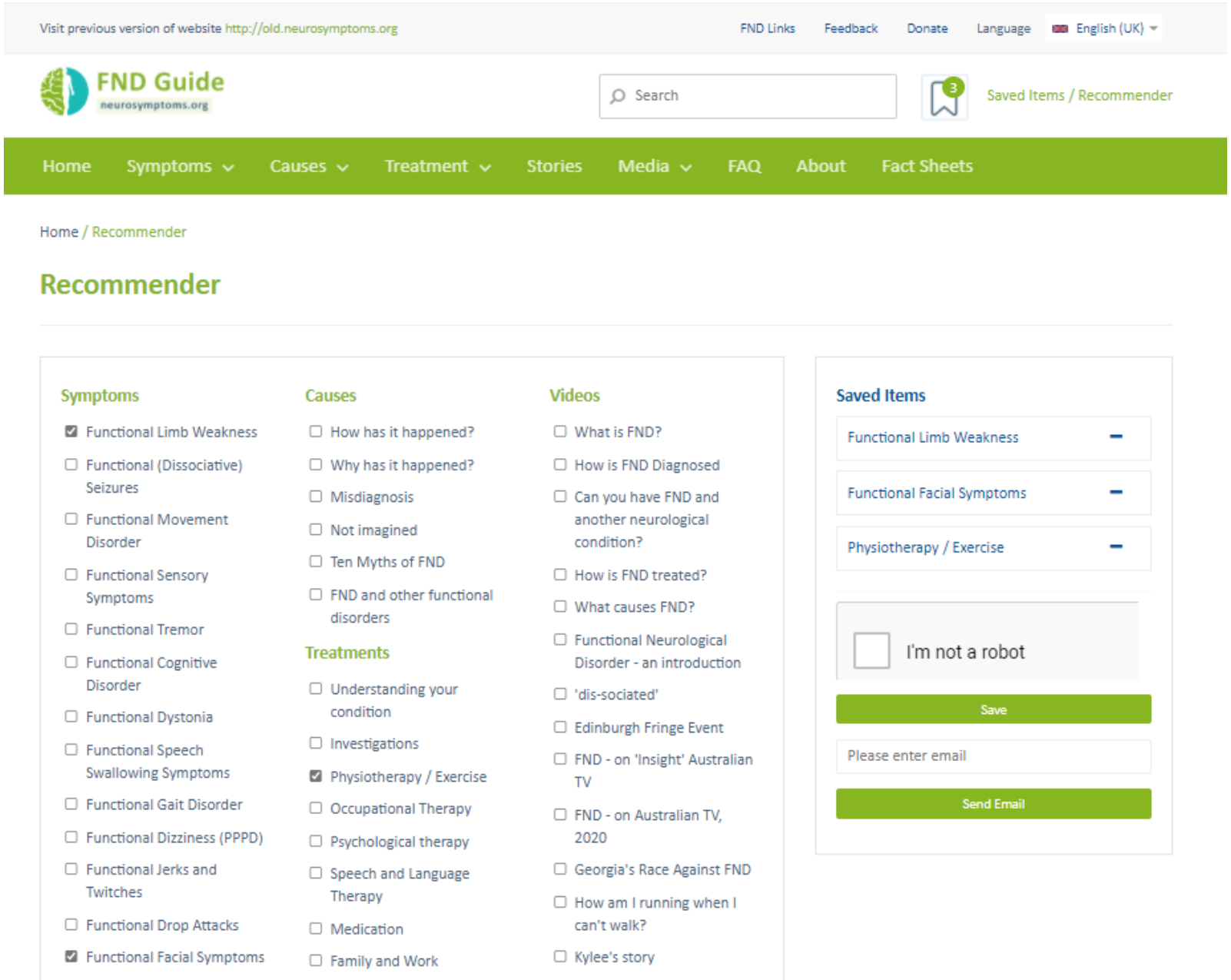
★★★★★ 5.0 • 4 Ratings

Free

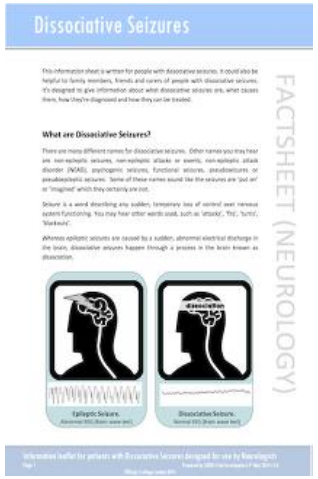
iPhone Screenshots



Direct to specific information

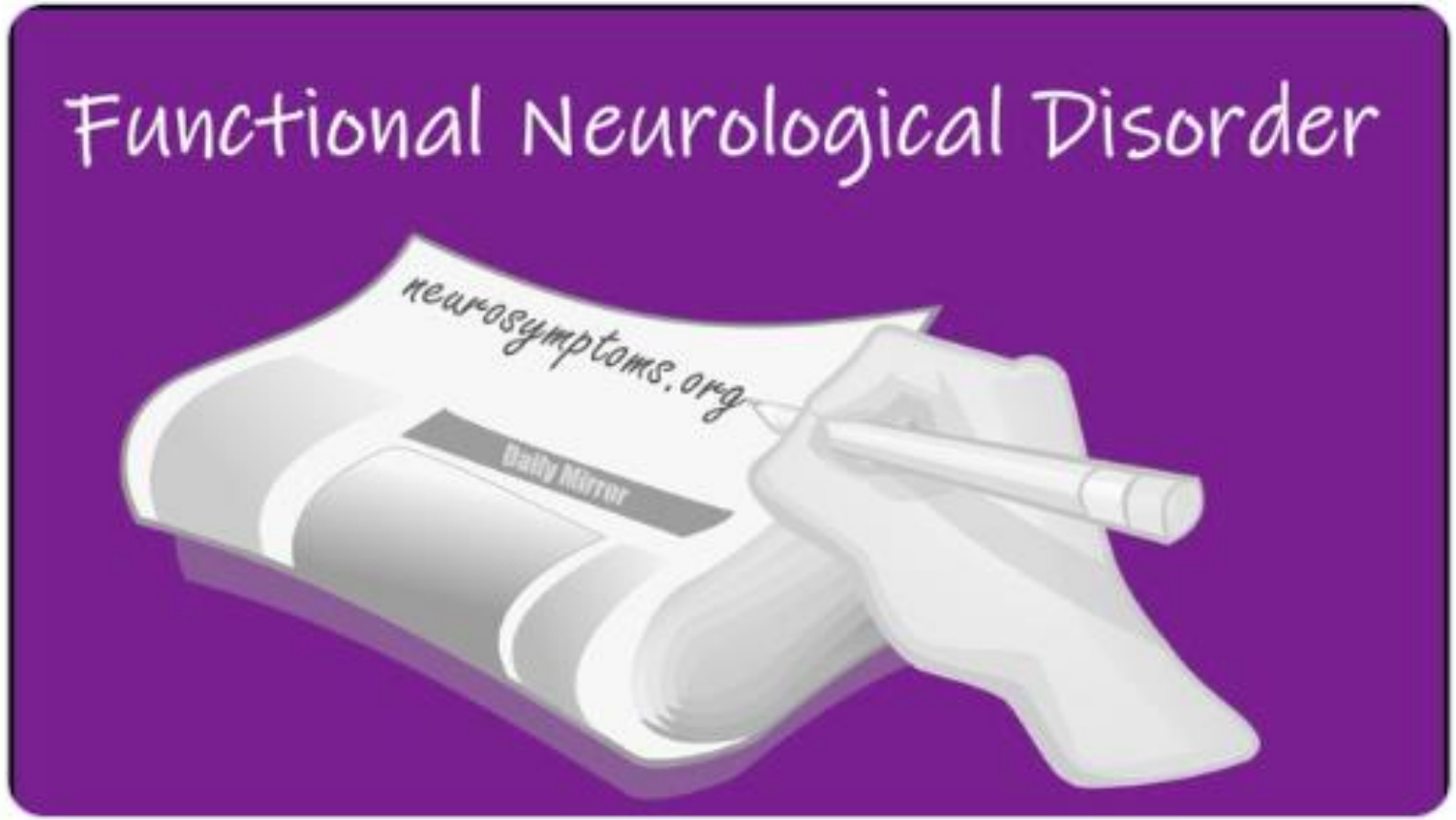


“Read this factsheet……”



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



2 5 14

Information – welcomed by patients but doesn't alter outcome

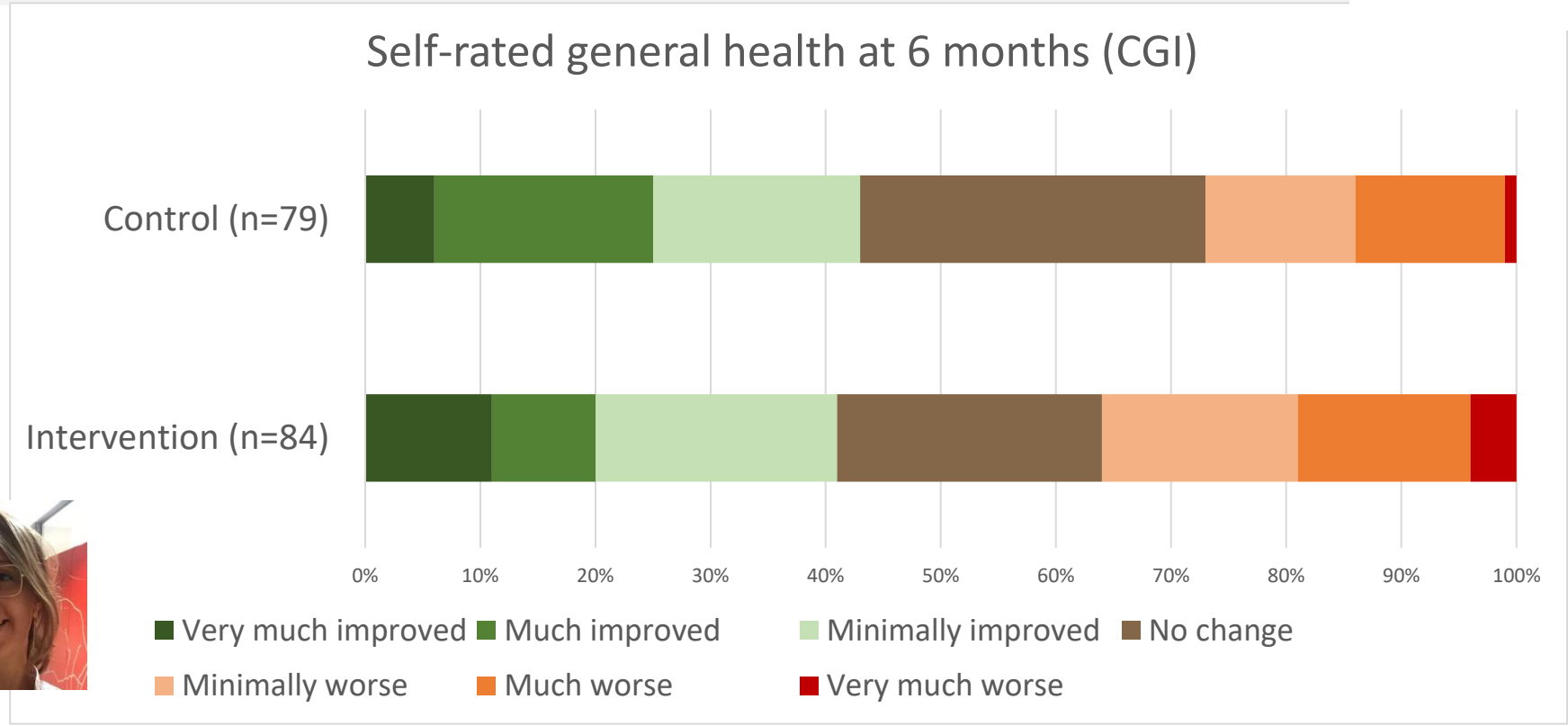
SHARE July 20, 2020 NULL HYPOTHESIS

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

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

First published July 20, 2020, DOI: https://doi.org/10.1212/WNL.0000000000010381

Neurology®



Dr Jeannette Gelauff

Patient led organisations and advocates for FND for the first time

FND HOPE

FND Action
Functional Neurological Disorder • Non Epileptic Attack Disorder

FND PORTAL

FND HOPE
Functional Neurological Disorder

FrieNDs

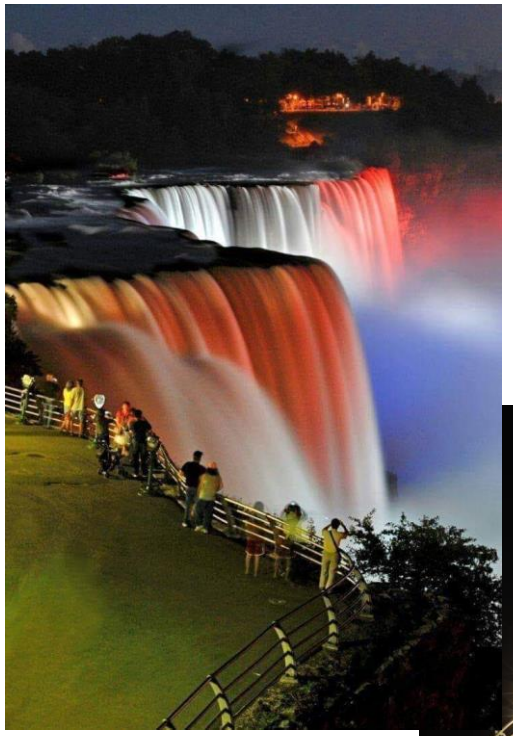
FND Australia
Support Services Inc

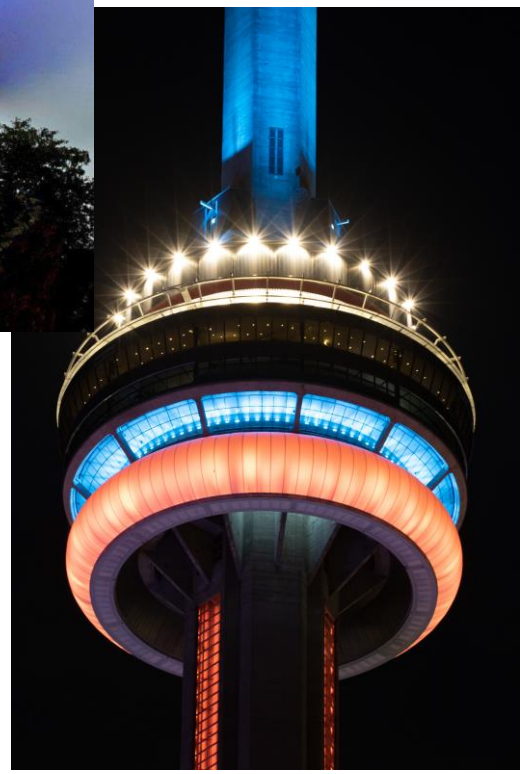
FND Recovery

FND MATTERS NI

FND Dimensions
Support, Knowledge and Awareness

Lorraine Kelly – patron of FND Hope UK



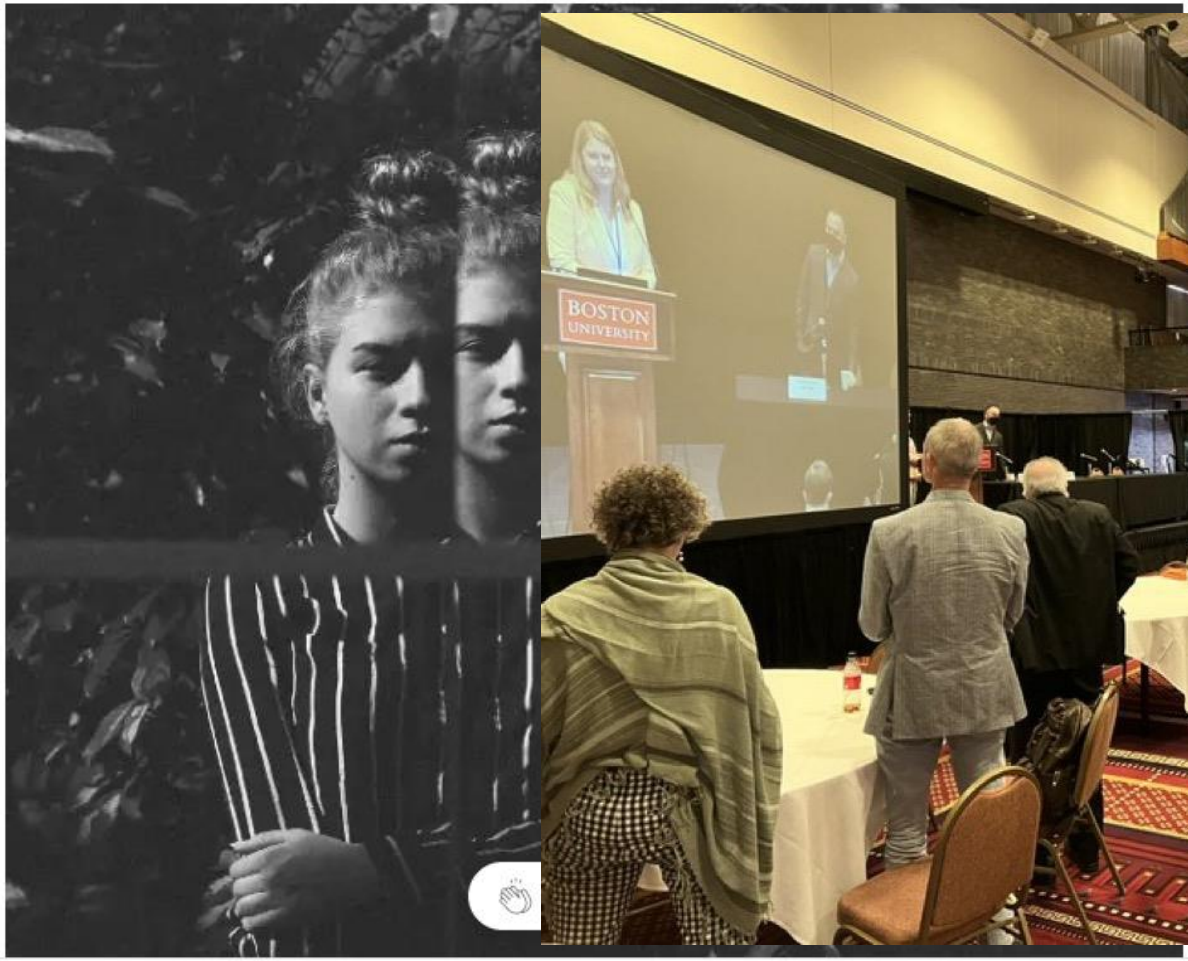


Psychologist (Susannah Pick) and Neuropsychiatrist (Tim Nicholson) raising money for FND hope

Fnd Portal

Jun 5 · 48 min read · Listen

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

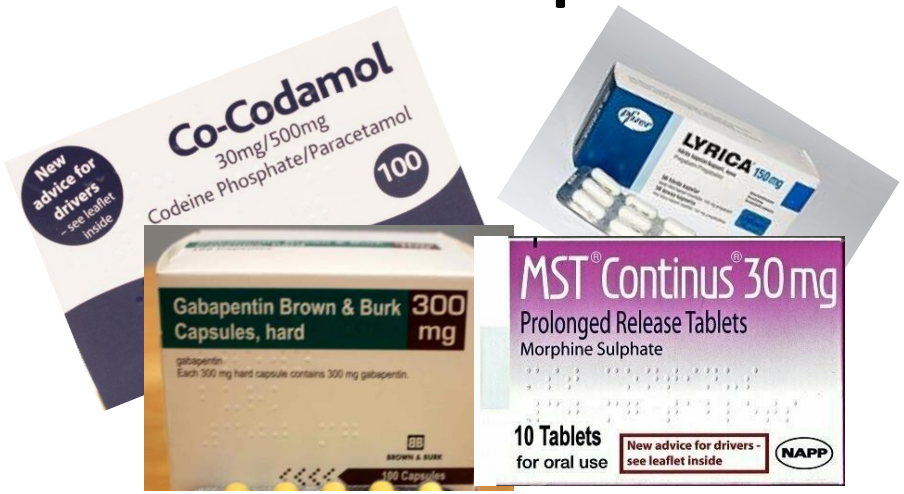


Managing comorbidities

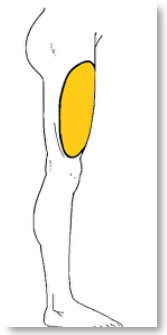
FND – Common comorbidities that anyone can help with

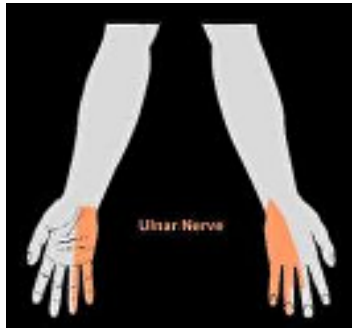
Migraine

Opiate/ Gabapentinoid consumption

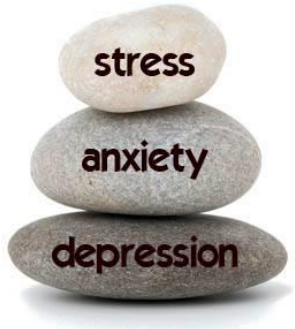


Nerve Entrapment





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…

FND Guide
neurosymptoms.org

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

FND Guide
neurosymptoms.org

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

Self-Care
I have moderate problems washing or dressing myself

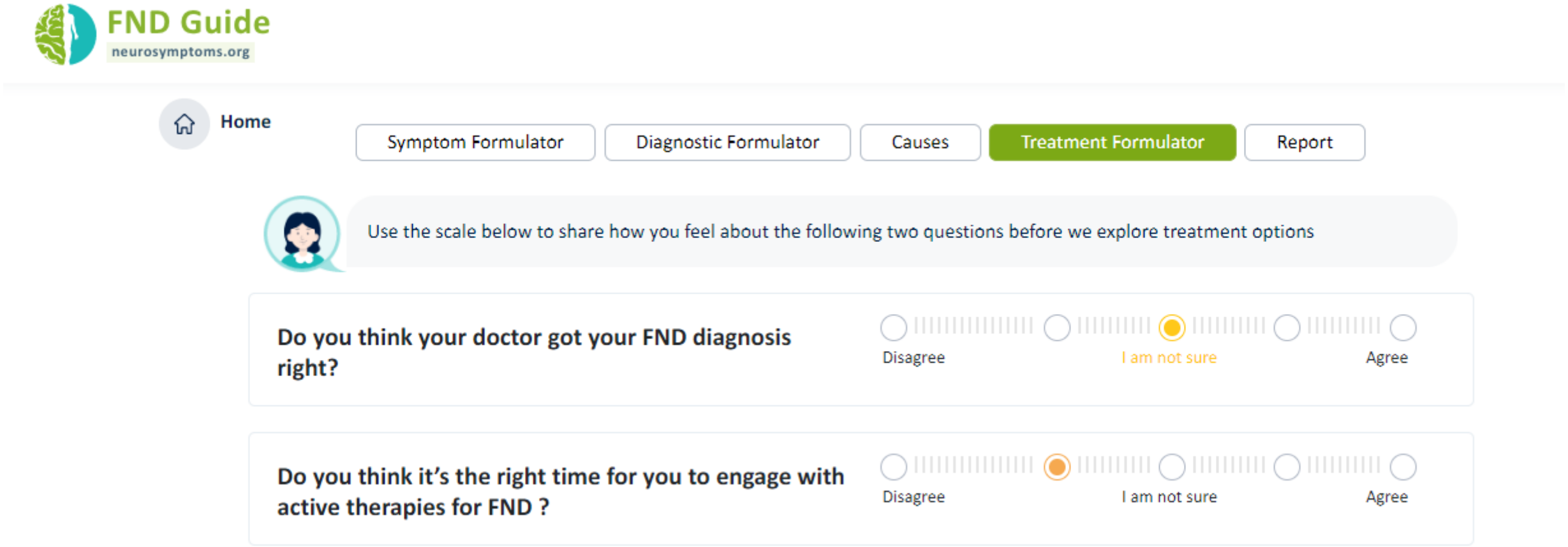
Usual Activities
I have moderate problems doing my usual activities

Pain/Discomfort
I have moderate pain or discomfort

Anxiety/Depression
I am slightly anxious or depressed

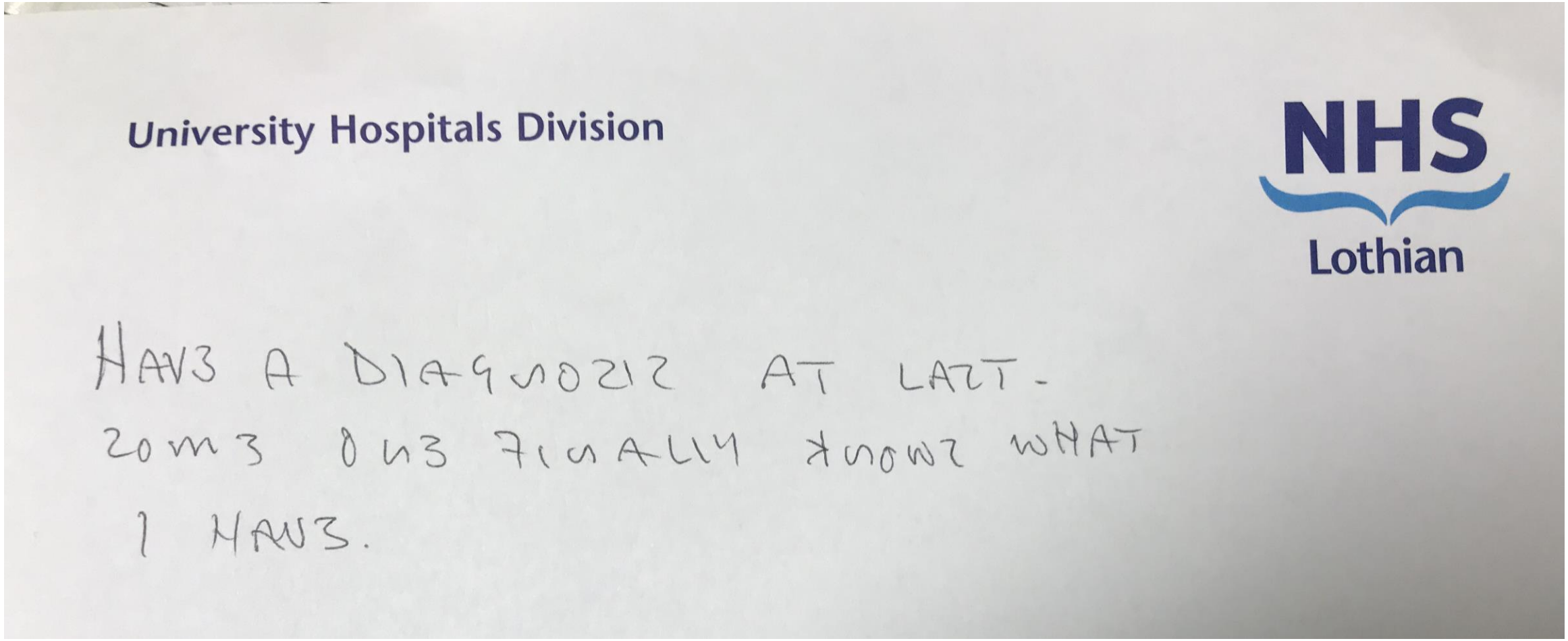
Notes

The follow up visit – triaging for treatment



Triaging for treatment

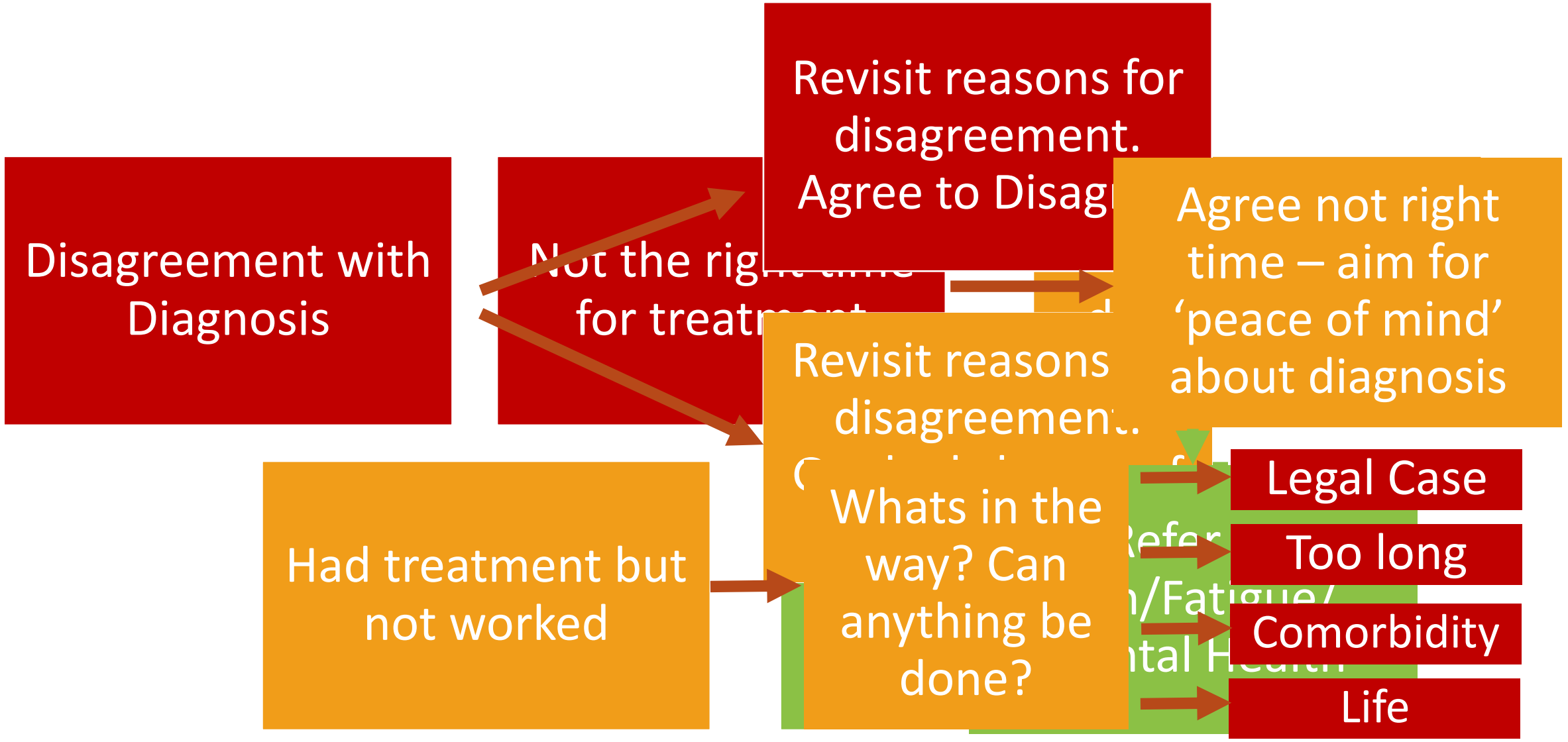
‘See the patient again……’



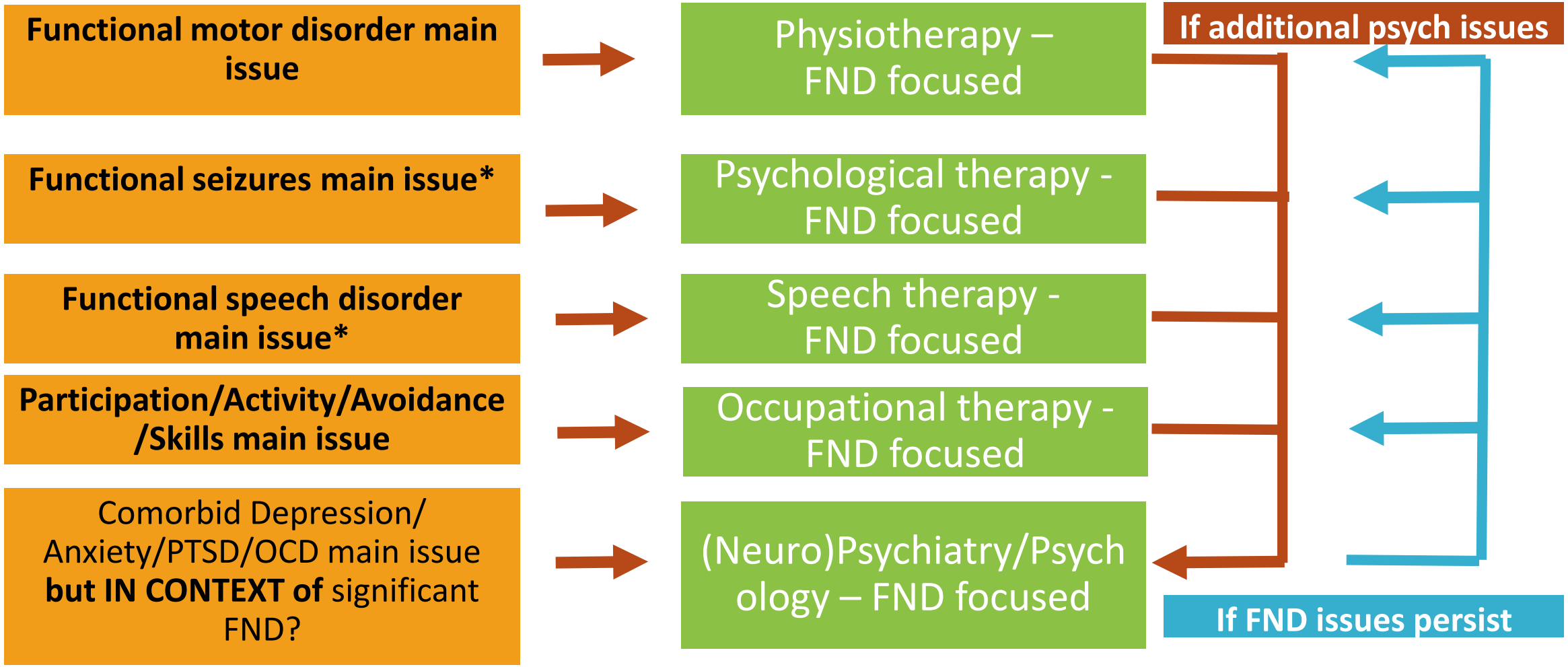
"Have a diagnosis at last – some one finally knows what I have"

‘See the patient again.,…..’

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

FUNCTIONAL NEUROLOGICAL DISORDER SOCIETY

Select References

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- Carson A, Lehn A, Ludwig L, Stone J. Explaining functional disorders in the neurology clinic: a photo story. Pract Neurol 2016; 16: 56–61.

FUNCTIONAL NEUROLOGICAL DISORDER SOCIETY

8-11 June 2024
Verona, Italy

FUNCTIONAL NEUROLOGICAL DISORDER SOCIETY
fndsociety.org

5th International Conference on Functional Neurological Disorder

FUNCTIONAL NEUROLOGICAL DISORDER SOCIETY

The University of Edinburgh
Edinburgh Neuroscience

FND Research Group

Centre for Clinical Brain Sciences, University of

NHS Lothian

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