PMG CONFERENCE 2024 FEEDBACK

Aakriti Shrestha

Chris Ducay

CONTENTS

Functional Neurological Disorder (FND) Dr Elizabeth Mallam, Consultant Neurologist, North Bristol NHS Trust

- FND (previously termed conversion disorder) and somatic symptom disorder are (neuro)psychiatric conditions that fall under the somatic symptom and related disorders category of the (DSM-5-TR).

- **Defined as:** Positive identification of physical symptoms which are incongruent and inconsistent with neurologic disease.

- No need for associated psychopathology.

FND Symptoms

- Functional Limb Weakness
- Functional Movement Disorders
- Functional Tremor
- Functional Dystonia
- Functional Gait Disorder
- Functional Facial Symptoms
- Functional Tics
- Functional Drop Attacks
- Functional (Dissociative) Seizures
- Functional Sensory Symptoms
- Functional Cognitive Symptoms
- Functional Speech Swallowing S...
- Functional Dizziness (PPPD)
- Functional Jerks and Twitches
- Bladder symptoms and FND
- Visual Symptoms

Common Associated Symptoms

- Fatigue
- Pain
- Headache
- Worry / Panic
- Complex Regional Pain Syndrome
- IBS, Chest and other symptoms
- Dissociative Symptoms
- Sleep Problems
- Post-Concussion Syndrome
- Health Anxiety
- Low Mood

SYMPTOMS

Functional seizure

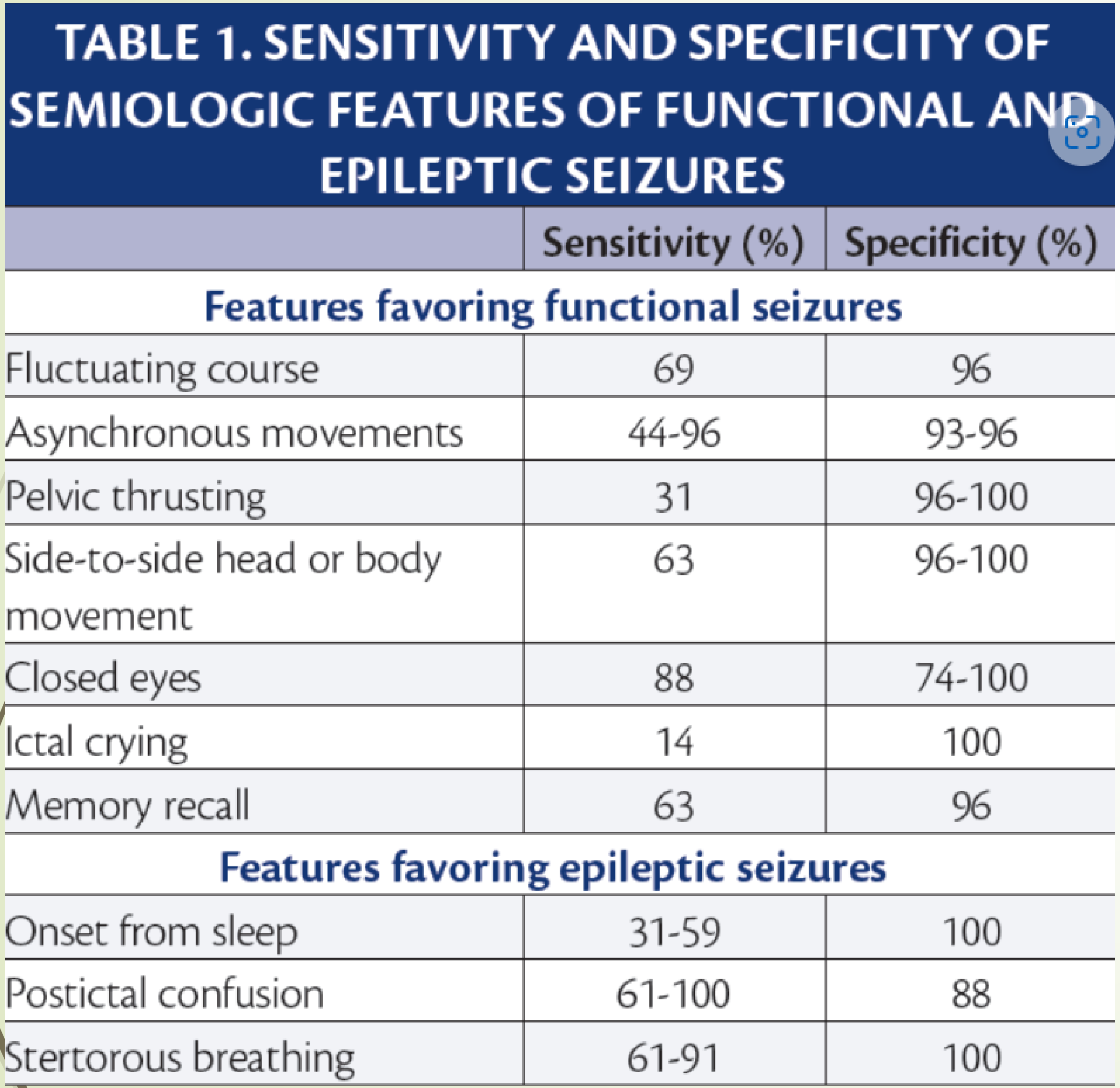
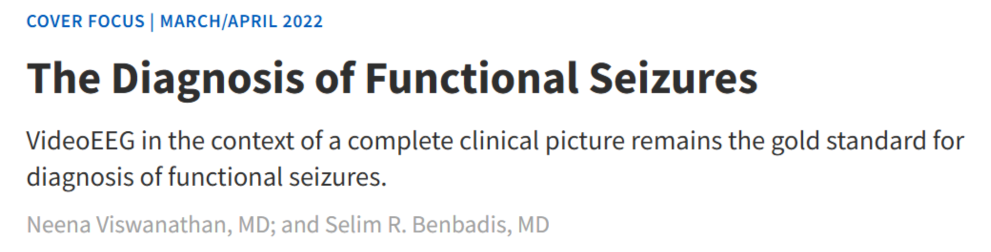


TABLE 1. SENSITIVITY AND SPECIFICITY OF SEMIOLOGIC FEATURES OF FUNCTIONAL AND EPILEPTIC SEIZURES

	Sensitivity (%)	Specificity (%)
Features favoring functional seizures		
Fluctuating course	69	96
Asynchronous movements	44-96	93-96
Pelvic thrusting	31	96-100
Side-to-side head or body movement	63	96-100
Closed eyes	88	74-100
Ictal crying	14	100
Memory recall	63	96
Features favoring epileptic seizures		
Onset from sleep	31-59	100
Postictal confusion	61-100	88
Stertorous breathing	61-91	100

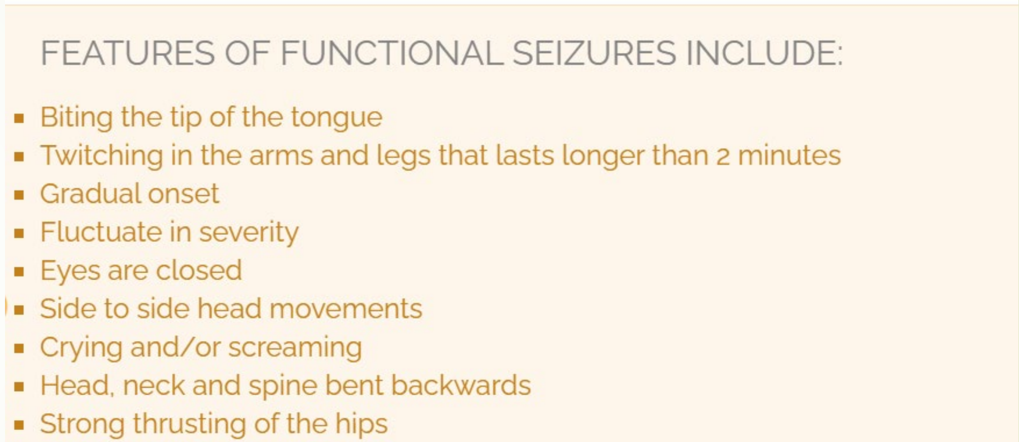


COVER FOCUS | MARCH/APRIL 2022

The Diagnosis of Functional Seizures

VideoEEG in the context of a complete clinical picture remains the gold standard for diagnosis of functional seizures.

Neena Viswanathan, MD; and Selim R. Benbadis, MD

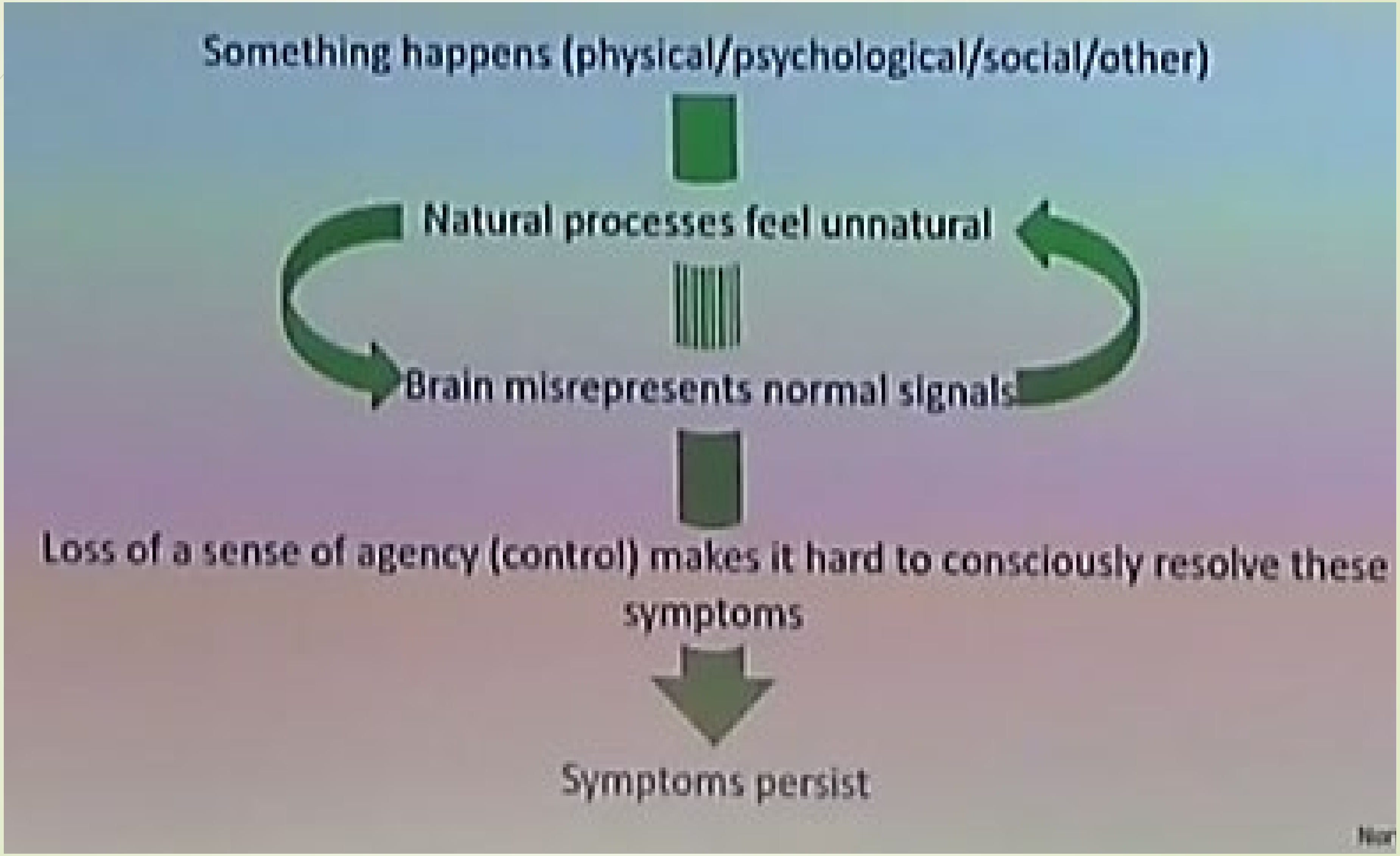


FEATURES OF FUNCTIONAL SEIZURES INCLUDE:

- Biting the tip of the tongue
- Twitching in the arms and legs that lasts longer than 2 minutes
- Gradual onset
- Fluctuate in severity
- Eyes are closed
- Side to side head movements
- Crying and/or screaming
- Head, neck and spine bent backwards
- Strong thrusting of the hips

Right temporoparietal junction under activity in people with FND tremor. Voon et al Neurology 2010; 74: 223–228.

Etiology



Something happens (physical/psychological/social/other)

Natural processes feel unnatural

Brain misrepresents normal signals

Loss of a sense of agency (control) makes it hard to consciously resolve these symptoms

Symptoms persist

Etiology

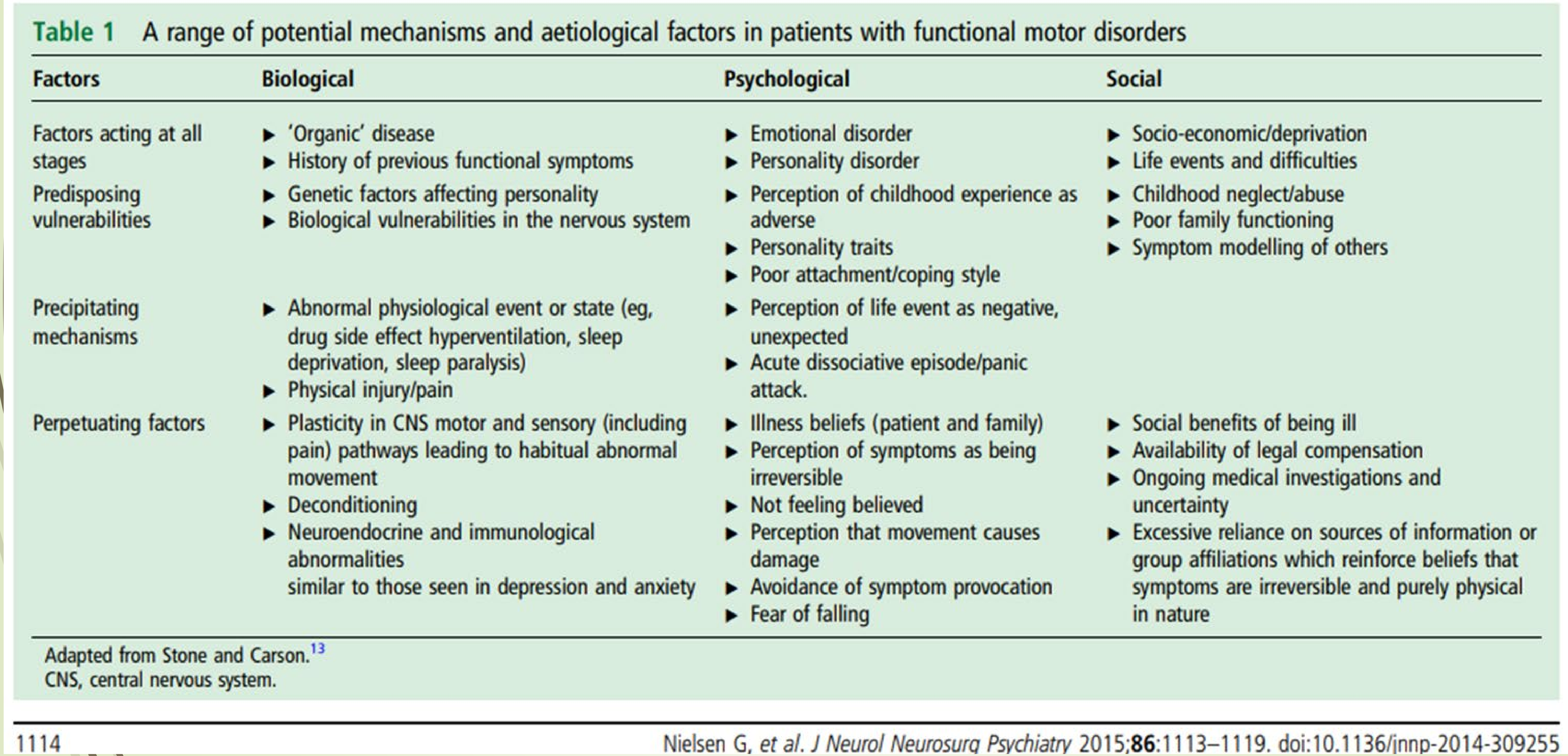


Table 1 A range of potential mechanisms and aetiological factors in patients with functional motor disorders

Factors	Biological	Psychological	Social
Factors acting at all stages	▶ 'Organic' disease ▶ History of previous functional symptoms	▶ Emotional disorder ▶ Personality disorder	▶ Socio-economic/deprivation ▶ Life events and difficulties
Predisposing vulnerabilities	▶ Genetic factors affecting personality ▶ Biological vulnerabilities in the nervous system	▶ Perception of childhood experience as adverse ▶ Personality traits ▶ Poor attachment/coping style	▶ Childhood neglect/abuse ▶ Poor family functioning ▶ Symptom modelling of others
Precipitating mechanisms	▶ Abnormal physiological event or state (eg, drug side effect hyperventilation, sleep deprivation, sleep paralysis) ▶ Physical injury/pain	▶ Perception of life event as negative, unexpected ▶ Acute dissociative episode/panic attack.	
Perpetuating factors	▶ Plasticity in CNS motor and sensory (including pain) pathways leading to habitual abnormal movement ▶ Deconditioning ▶ Neuroendocrine and immunological abnormalities similar to those seen in depression and anxiety	▶ Illness beliefs (patient and family) ▶ Perception of symptoms as being irreversible ▶ Not feeling believed ▶ Perception that movement causes damage ▶ Avoidance of symptom provocation ▶ Fear of falling	▶ Social benefits of being ill ▶ Availability of legal compensation ▶ Ongoing medical investigations and uncertainty ▶ Excessive reliance on sources of information or group affiliations which reinforce beliefs that symptoms are irreversible and purely physical in nature

Adapted from Stone and Carson.[13]
CNS, central nervous system.

1114 Nielsen G, *et al. J Neurol Neurosurg Psychiatry* 2015;**86**:1113–1119. doi:10.1136/jnnp-2014-309255

- **MUST be diagnosed by a neurologist**

...differential includes rare conditions

- **Important to know how to review new symptoms with a neurologist**

...symptoms can evolve

..having FND # immune to developing other conditions

- **Largely clinical**

...history and examination

- **NOT a diagnosis of exclusion**

...when investigations are negative

...its a 'positive' diagnosis

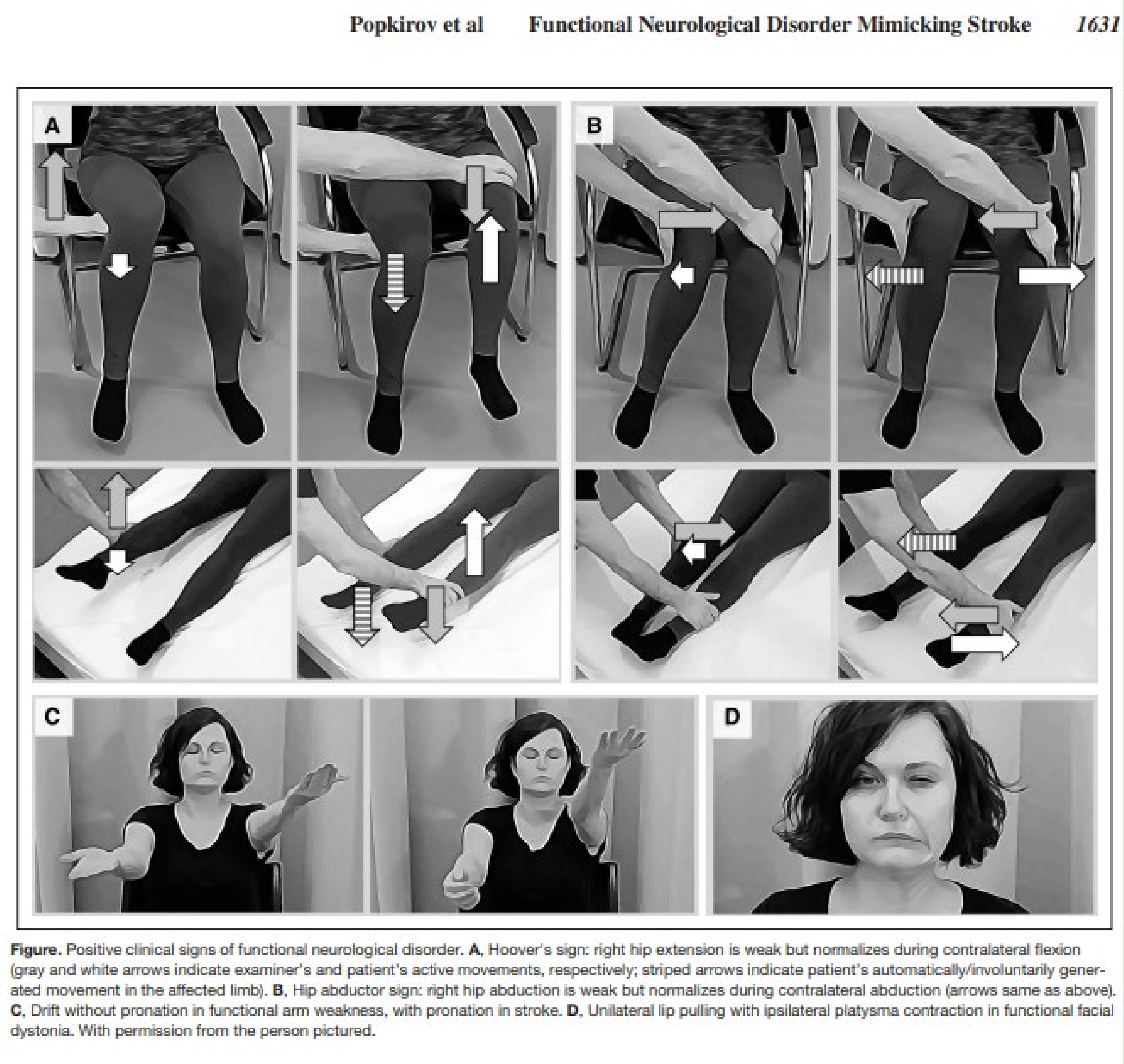
Investigations can and should be used in usual way

..to rule out functional mimics ...

and/or identify physical triggers

Examination

Popkirov et al, 2020



Popkirov et al Functional Neurological Disorder Mimicking Stroke *1631*

Figure. Positive clinical signs of functional neurological disorder. **A**, Hoover's sign: right hip extension is weak but normalizes during contralateral flexion (gray and white arrows indicate examiner's and patient's active movements, respectively; striped arrows indicate patient's automatically/involuntarily generated movement in the affected limb). **B**, Hip abductor sign: right hip abduction is weak but normalizes during contralateral abduction (arrows same as above). **C**, Drift without pronation in functional arm weakness, with pronation in stroke. **D**, Unilateral lip pulling with ipsilateral platysma contraction in functional facial dystonia. With permission from the person pictured.

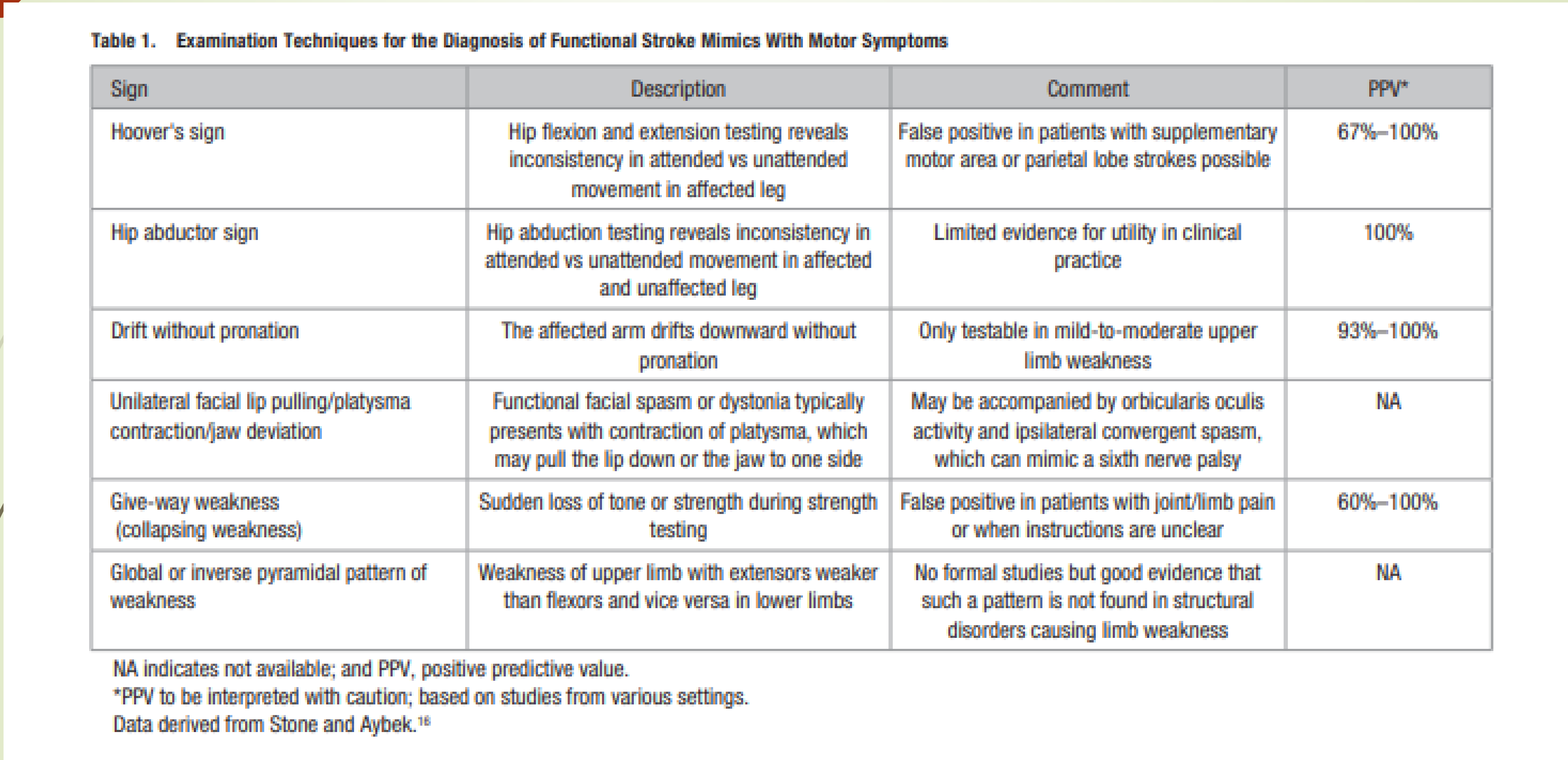


Table 1. Examination Techniques for the Diagnosis of Functional Stroke Mimics With Motor Symptoms

Sign	Description	Comment	PPV*
Hoover's sign	Hip flexion and extension testing reveals inconsistency in attended vs unattended movement in affected leg	False positive in patients with supplementary motor area or parietal lobe strokes possible	67%–100%
Hip abductor sign	Hip abduction testing reveals inconsistency in attended vs unattended movement in affected and unaffected leg	Limited evidence for utility in clinical practice	100%
Drift without pronation	The affected arm drifts downward without pronation	Only testable in mild-to-moderate upper limb weakness	93%–100%
Unilateral facial lip pulling/platysma contraction/jaw deviation	Functional facial spasm or dystonia typically presents with contraction of platysma, which may pull the lip down or the jaw to one side	May be accompanied by orbicularis oculis activity and ipsilateral convergent spasm, which can mimic a sixth nerve palsy	NA
Give-way weakness (collapsing weakness)	Sudden loss of tone or strength during strength testing	False positive in patients with joint/limb pain or when instructions are unclear	60%–100%
Global or inverse pyramidal pattern of weakness	Weakness of upper limb with extensors weaker than flexors and vice versa in lower limbs	No formal studies but good evidence that such a pattern is not found in structural disorders causing limb weakness	NA

NA indicates not available; and PPV, positive predictive value.
*PPV to be interpreted with caution; based on studies from various settings.
Data derived from Stone and Aybek.[16]

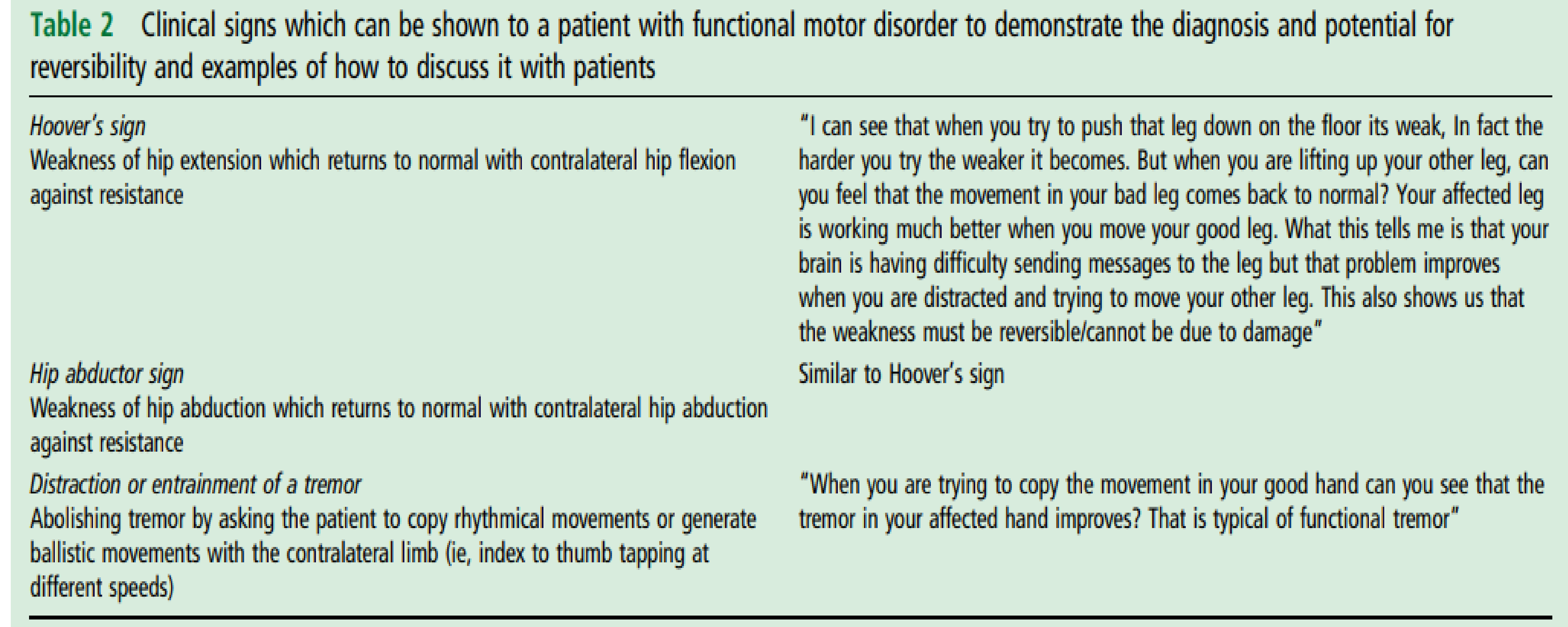
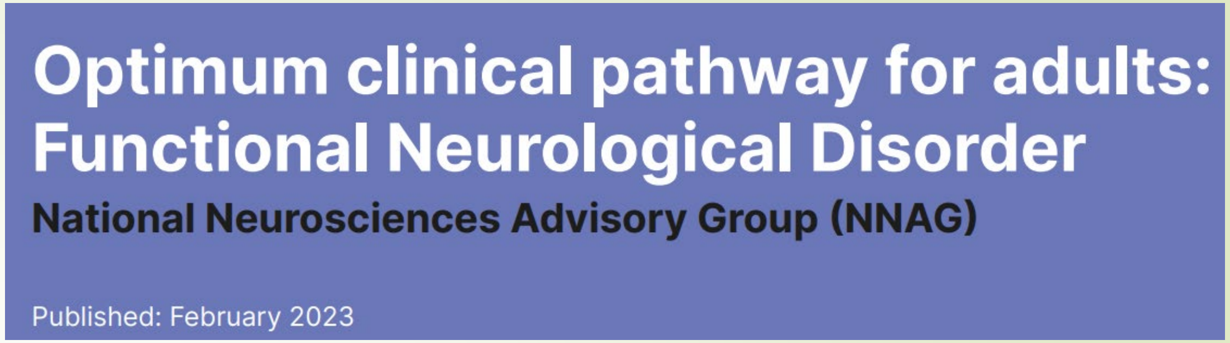


Table 2 Clinical signs which can be shown to a patient with functional motor disorder to demonstrate the diagnosis and potential for reversibility and examples of how to discuss it with patients

Hoover's sign Weakness of hip extension which returns to normal with contralateral hip flexion against resistance	"I can see that when you try to push that leg down on the floor its weak, In fact the harder you try the weaker it becomes. But when you are lifting up your other leg, can you feel that the movement in your bad leg comes back to normal? Your affected leg is working much better when you move your good leg. What this tells me is that your brain is having difficulty sending messages to the leg but that problem improves when you are distracted and trying to move your other leg. This also shows us that the weakness must be reversible/cannot be due to damage"
Hip abductor sign Weakness of hip abduction which returns to normal with contralateral hip abduction against resistance	Similar to Hoover's sign
Distraction or entrainment of a tremor Abolishing tremor by asking the patient to copy rhythmical movements or generate ballistic movements with the contralateral limb (ie, index to thumb tapping at different speeds)	"When you are trying to copy the movement in your good hand can you see that the tremor in your affected hand improves? That is typical of functional tremor"

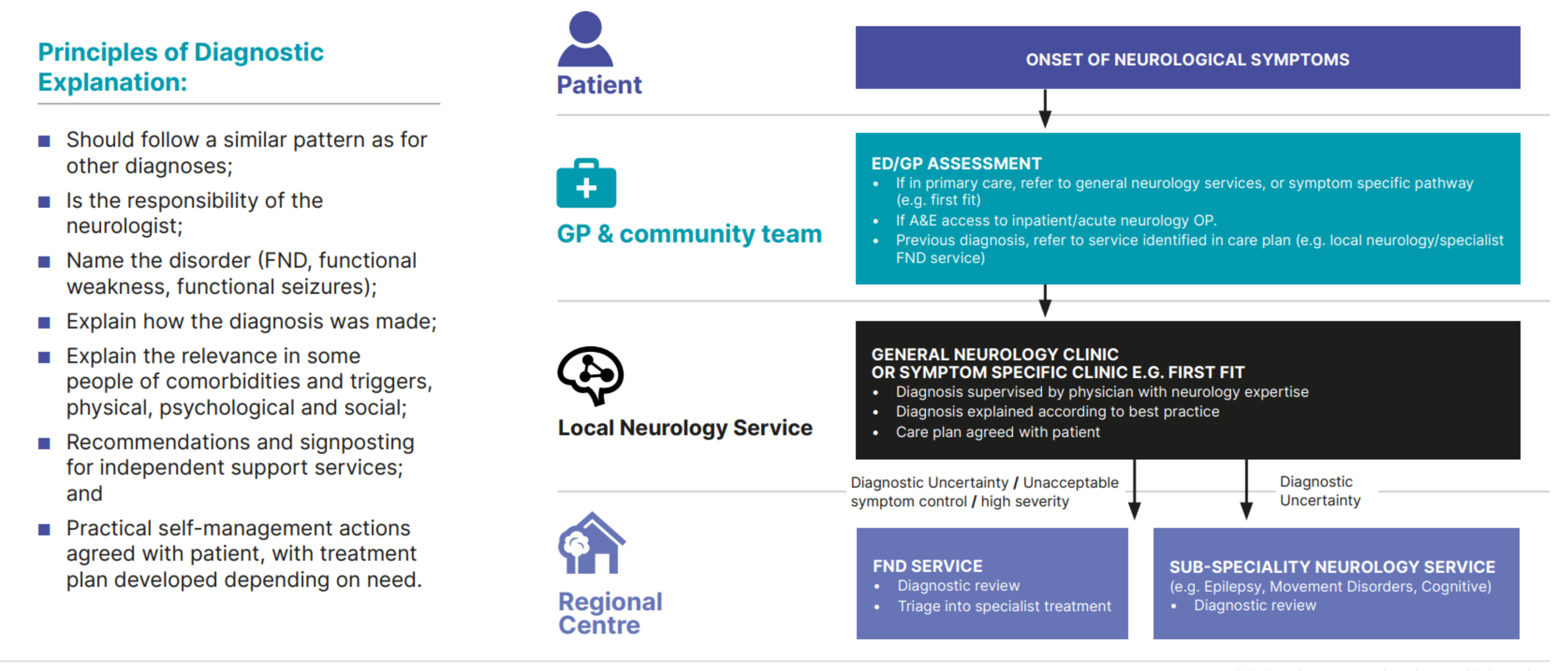
TREATMENT



Optimum clinical pathway for adults: Functional Neurological Disorder

National Neurosciences Advisory Group (NNAG)

Published: February 2023



Principles of Diagnostic Explanation:

- Should follow a similar pattern as for other diagnoses;
- Is the responsibility of the neurologist;
- Name the disorder (FND, functional weakness, functional seizures);
- Explain how the diagnosis was made;
- Explain the relevance in some people of comorbidities and triggers, physical, psychological and social;
- Recommendations and signposting for independent support services; and
- Practical self-management actions agreed with patient, with treatment plan developed depending on need.

Patient

ONSET OF NEUROLOGICAL SYMPTOMS

GP & community team

ED/GP ASSESSMENT
- If in primary care, refer to general neurology services, or symptom specific pathway (e.g. first fit)
- If A&E access to inpatient/acute neurology OP.
- Previous diagnosis, refer to service identified in care plan (e.g. local neurology/specialist FND service)

Local Neurology Service

GENERAL NEUROLOGY CLINIC
OR SYMPTOM SPECIFIC CLINIC E.G. FIRST FIT
- Diagnosis supervised by physician with neurology expertise
- Diagnosis explained according to best practice
- Care plan agreed with patient

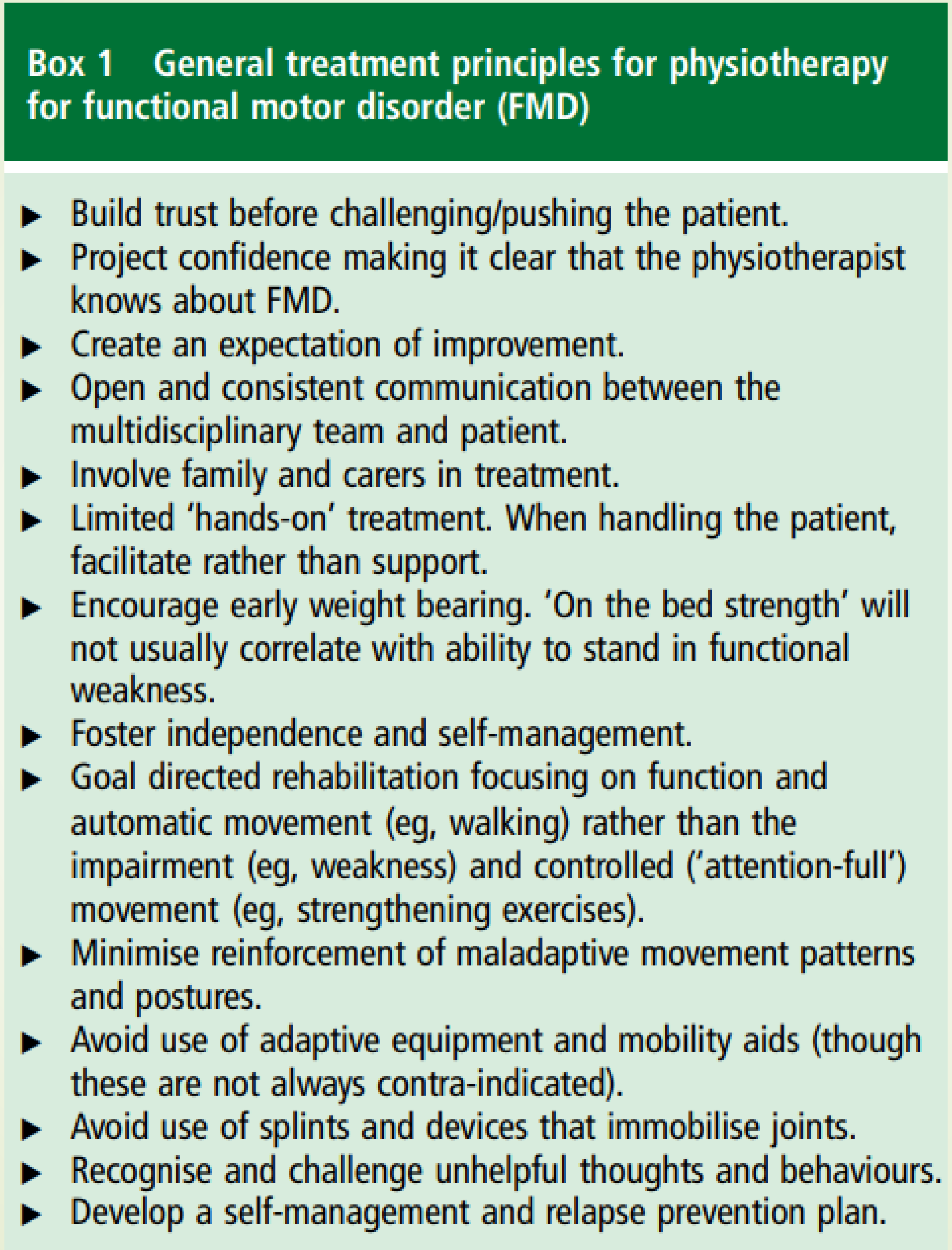
Diagnostic Uncertainty / Unacceptable symptom control / high severity

Diagnostic Uncertainty

Regional Centre

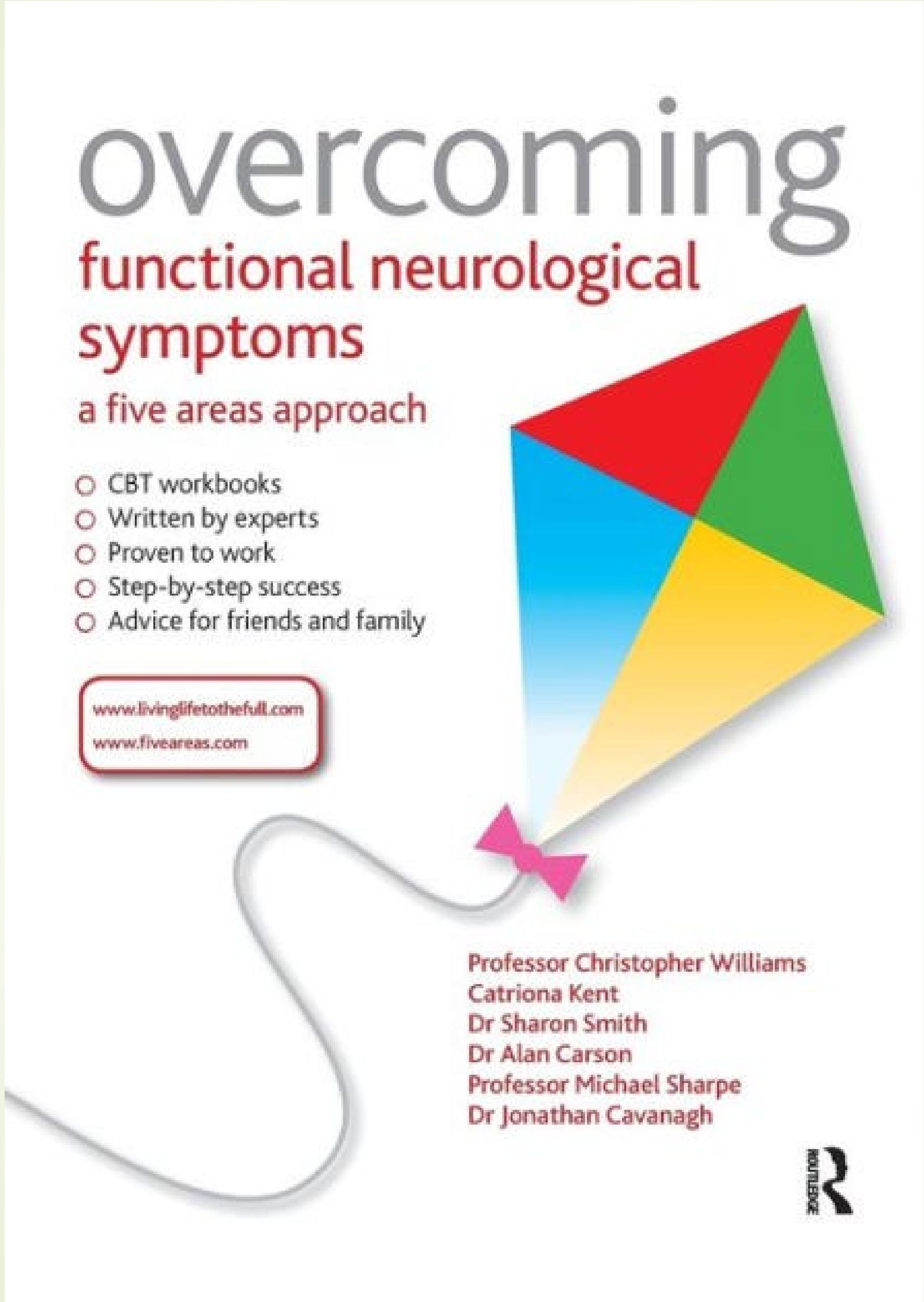
FND SERVICE
- Diagnostic review
- Triage into specialist treatment

SUB-SPECIALITY NEUROLOGY SERVICE
(e.g. Epilepsy, Movement Disorders, Cognitive)
- Diagnostic review



Box 1 General treatment principles for physiotherapy for functional motor disorder (FMD)

- Build trust before challenging/pushing the patient.
- Project confidence making it clear that the physiotherapist knows about FMD.
- Create an expectation of improvement.
- Open and consistent communication between the multidisciplinary team and patient.
- Involve family and carers in treatment.
- Limited ‘hands-on’ treatment. When handling the patient, facilitate rather than support.
- Encourage early weight bearing. ‘On the bed strength’ will not usually correlate with ability to stand in functional weakness.
- Foster independence and self-management.
- Goal directed rehabilitation focusing on function and automatic movement (eg, walking) rather than the impairment (eg, weakness) and controlled (’attention-full’) movement (eg, strengthening exercises).
- Minimise reinforcement of maladaptive movement patterns and postures.
- Avoid use of adaptive equipment and mobility aids (though these are not always contra-indicated).
- Avoid use of splints and devices that immobilise joints.
- Recognise and challenge unhelpful thoughts and behaviours.
- Develop a self-management and relapse prevention plan.



overcoming
functional neurological symptoms
a five areas approach

- ○ CBT workbooks
- ○ Written by experts
- ○ Proven to work
- ○ Step-by-step success
- ○ Advice for friends and family

www.livinglifetothefull.com
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Professor Christopher Williams
Catriona Kent
Dr Sharon Smith
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Professor Michael Sharpe
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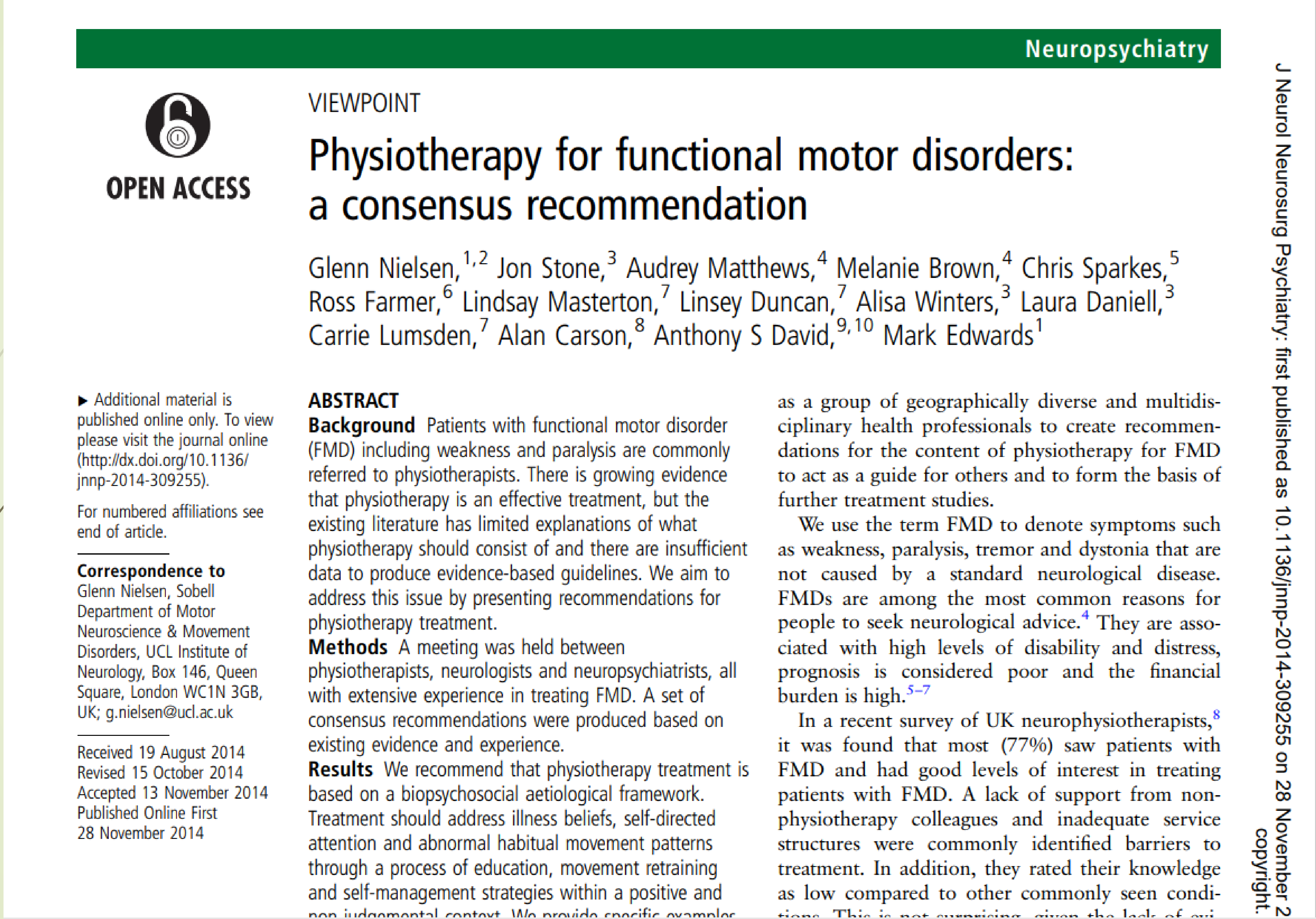

Neuropsychiatry

OPEN ACCESS

VIEWPOINT

Physiotherapy for functional motor disorders: a consensus recommendation

Glenn Nielsen,[1,2] Jon Stone,[3] Audrey Matthews,[4] Melanie Brown,[4] Chris Sparkes,[5] Ross Farmer,[6] Lindsay Masterton,[7] Linsey Duncan,[7] Alisa Winters,[3] Laura Daniell,[3] Carrie Lumsden,[7] Alan Carson,[8] Anthony S David,[9,10] Mark Edwards[1]

▸ Additional material is published online only. To view please visit the journal online (http://dx.doi.org/10.1136/jnnp-2014-309255).

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ABSTRACT

Background Patients with functional motor disorder (FMD) including weakness and paralysis are commonly referred to physiotherapists. There is growing evidence that physiotherapy is an effective treatment, but the existing literature has limited explanations of what physiotherapy should consist of and there are insufficient data to produce evidence-based guidelines. We aim to address this issue by presenting recommendations for physiotherapy treatment.

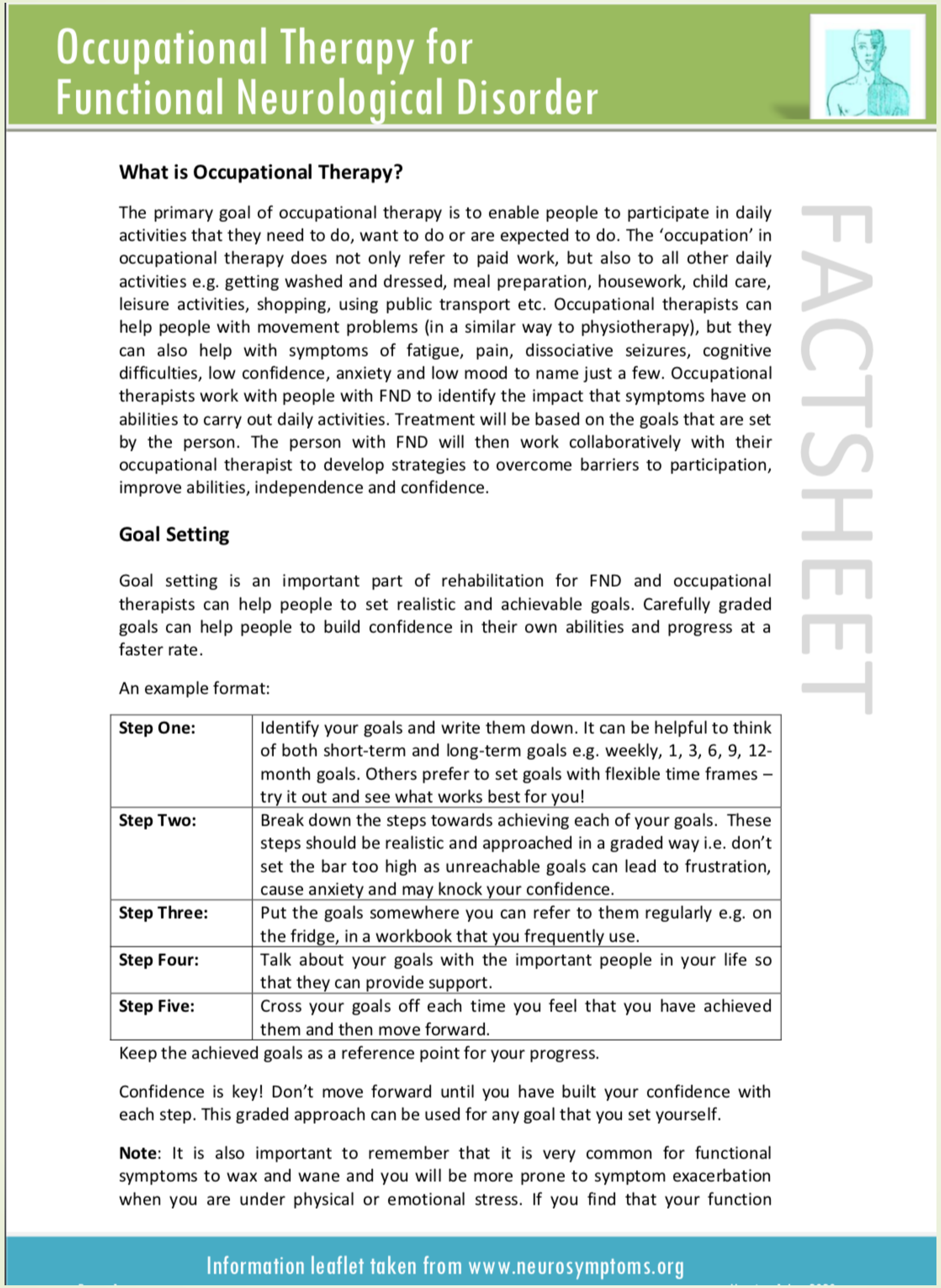
Methods A meeting was held between physiotherapists, neurologists and neuropsychiatrists, all with extensive experience in treating FMD. A set of consensus recommendations were produced based on existing evidence and experience.

Results We recommend that physiotherapy treatment is based on a biopsychosocial aetiological framework. Treatment should address illness beliefs, self-directed attention and abnormal habitual movement patterns through a process of education, movement retraining and self-management strategies within a positive and non-judgemental context. We provide specific examples

as a group of geographically diverse and multidisciplinary health professionals to create recommendations for the content of physiotherapy for FMD to act as a guide for others and to form the basis of further treatment studies.

We use the term FMD to denote symptoms such as weakness, paralysis, tremor and dystonia that are not caused by a standard neurological disease. FMDs are among the most common reasons for people to seek neurological advice.[4] They are associated with high levels of disability and distress, prognosis is considered poor and the financial burden is high.[5–7]

In a recent survey of UK neurophysiotherapists,[8] it was found that most (77%) saw patients with FMD and had good levels of interest in treating patients with FMD. A lack of support from non-physiotherapy colleagues and inadequate service structures were commonly identified barriers to treatment. In addition, they rated their knowledge as low compared to other commonly seen conditions. This is not surprising, given the lack of evi-



Occupational Therapy for Functional Neurological Disorder

FACTSHEET

What is Occupational Therapy?

The primary goal of occupational therapy is to enable people to participate in daily activities that they need to do, want to do or are expected to do. The 'occupation' in occupational therapy does not only refer to paid work, but also to all other daily activities e.g. getting washed and dressed, meal preparation, housework, child care, leisure activities, shopping, using public transport etc. Occupational therapists can help people with movement problems (in a similar way to physiotherapy), but they can also help with symptoms of fatigue, pain, dissociative seizures, cognitive difficulties, low confidence, anxiety and low mood to name just a few. Occupational therapists work with people with FND to identify the impact that symptoms have on abilities to carry out daily activities. Treatment will be based on the goals that are set by the person. The person with FND will then work collaboratively with their occupational therapist to develop strategies to overcome barriers to participation, improve abilities, independence and confidence.

Goal Setting

Goal setting is an important part of rehabilitation for FND and occupational therapists can help people to set realistic and achievable goals. Carefully graded goals can help people to build confidence in their own abilities and progress at a faster rate.

An example format:

Step One:	Identify your goals and write them down. It can be helpful to think of both short-term and long-term goals e.g. weekly, 1, 3, 6, 9, 12-month goals. Others prefer to set goals with flexible time frames – try it out and see what works best for you!
Step Two:	Break down the steps towards achieving each of your goals. These steps should be realistic and approached in a graded way i.e. don't set the bar too high as unreachable goals can lead to frustration, cause anxiety and may knock your confidence.
Step Three:	Put the goals somewhere you can refer to them regularly e.g. on the fridge, in a workbook that you frequently use.
Step Four:	Talk about your goals with the important people in your life so that they can provide support.
Step Five:	Cross your goals off each time you feel that you have achieved them and then move forward.

Keep the achieved goals as a reference point for your progress.

Confidence is key! Don't move forward until you have built your confidence with each step. This graded approach can be used for any goal that you set yourself.

Note: It is also important to remember that it is very common for functional symptoms to wax and wane and you will be more prone to symptom exacerbation when you are under physical or emotional stress. If you find that your function

Information leaflet taken from www.neurosymptoms.org

Cognitive behavioural therapy for adults with dissociative seizures (CODES): a pragmatic, multicentre, randomised controlled trial

Laura H Goldstein, Emily J Robinson, John D C Mellers, Jon Stone, Alan Carson, Markus Reuber, Nick Medford, Paul McCrone, Joanna Murray, Mark P Richardson, Izabela Pilecka, Carole Eastwood, Michele Moore, Iris Mosweu, Iain Perdue, Sabine Landau, Trudie Chalder*, on behalf of the CODES study group†*

Summary

Background Dissociative seizures are paroxysmal events resembling epilepsy or syncope with characteristic features that allow them to be distinguished from other medical conditions. We aimed to compare the effectiveness of cognitive behavioural therapy (CBT) plus standardised medical care with standardised medical care alone for the reduction of dissociative seizure frequency.

Methods In this pragmatic, parallel-arm, multicentre randomised controlled trial, we initially recruited participants at 27 neurology or epilepsy services in England, Scotland, and Wales. Adults (≥18 years) who had dissociative seizures in the previous 8 weeks and no epileptic seizures in the previous 12 months were subsequently randomly assigned (1:1) from 17 liaison or neuropsychiatry services following psychiatric assessment, to receive standardised medical care or CBT plus standardised medical care, using a web-based system. Randomisation was stratified by neuropsychiatry or liaison psychiatry recruitment site. The trial manager, chief investigator, all treating clinicians, and patients were aware of treatment allocation, but outcome data collectors and trial statisticians were unaware of treatment allocation. Patients were followed up 6 months and 12 months after randomisation. The primary outcome was monthly dissociative seizure frequency (ie, frequency in the previous 4 weeks) assessed at 12 months. Secondary outcomes assessed at 12 months were: seizure severity (intensity) and bothersomeness; longest period of seizure freedom in the previous 6 months; complete seizure freedom in the previous 3 months; a greater than 50% reduction in seizure frequency relative to baseline; changes in dissociative seizures (rated by others); health-related quality of life; psychosocial functioning; psychiatric symptoms, psychological distress, and somatic symptom burden; and clinical impression of improvement and satisfaction. p values and statistical significance for outcomes were reported without correction for multiple

Lancet Psychiatry 2020; 7: 491–505

See Comment page 464

*Joint senior authors

†Members of the CODES study group are listed in the appendix

Department of Psychology (Prof L H Goldstein PhD, I Pilecka PhD, C Eastwood MSc, I Perdue MPhil), **Department of Biostatistics and Health Informatics** (E J Robinson MSc, Prof S Landau PhD), **King's Health Economics** (Prof P McCrone PhD, I Mosweu MSc), **Department of Health Services and Population Research** (J Murray BA), **Department of Basic and Clinical Neuroscience** (Prof M P Richardson PhD), **and Department of Psychological**

General neurology

Review

Management of functional communication, swallowing, cough and related disorders: consensus recommendations for speech and language therapy

Janet Baker,[1,2] Caroline Barnett,[3] Lesley Cavalli,[4,5] Maria Dietrich,[6] Lorna Dixon,[7] Joseph R Duffy,[8] Annie Elias,[9] Diane E Fraser,[10] Jennifer L Freeburn,[11] Catherine Gregory,[2] Kirsty McKenzie,[12] Nick Miller,[13] Jo Patterson,[14] Carole Roth,[15] Nelson Roy,[16,17] Jennifer Short,[18] Rene Utianski ,[19,20] Miriam van Mersbergen,[21] Anne Vertigan,[22,23] Alan Carson,[24] Jon Stone ,[24] Laura McWhirter [24]

▸ Additional online supplemental material is published online only. To view, please visit the journal online (http://dx.doi.org/10.1136/jnnp-2021-326767).

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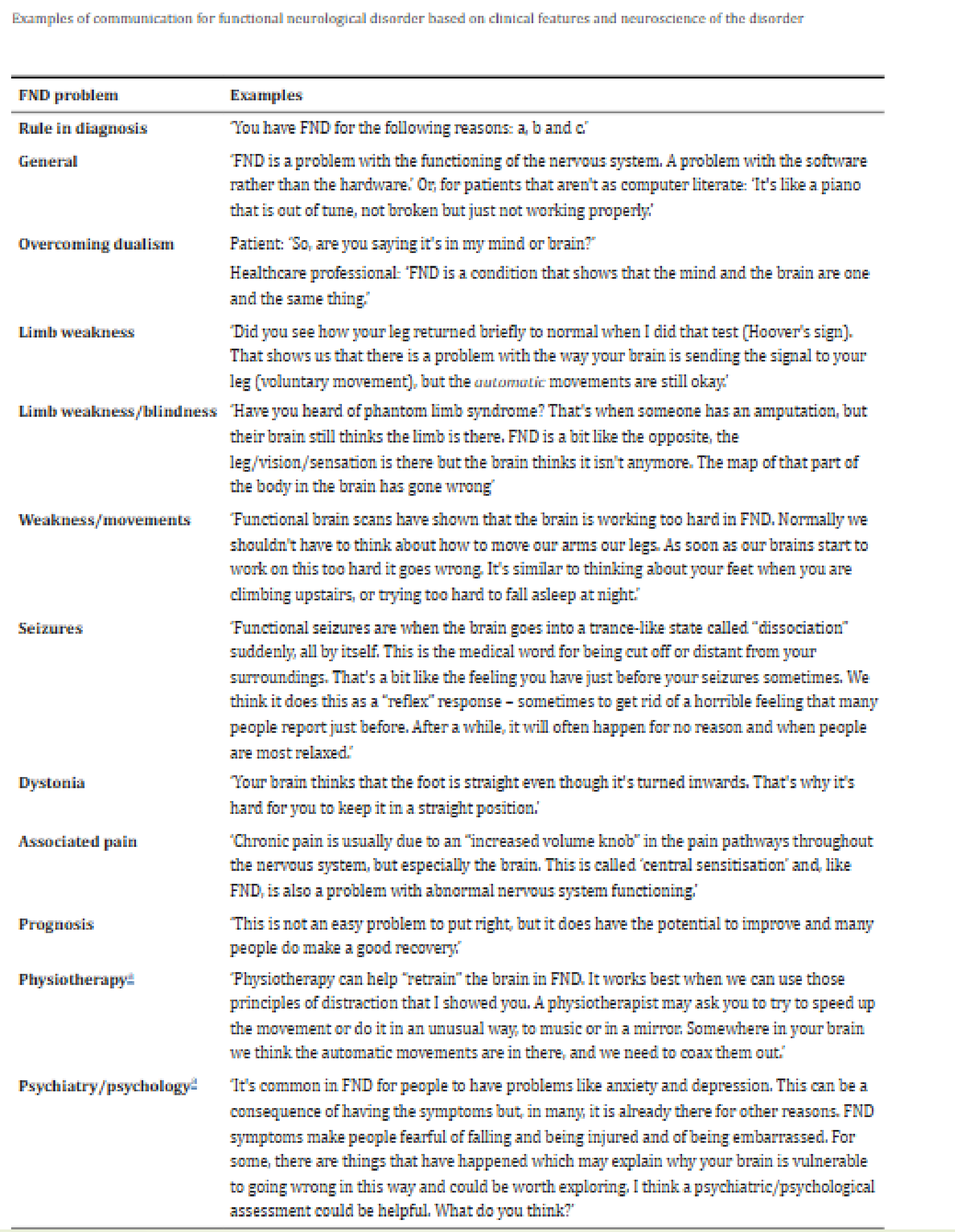
ABSTRACT

Communication problems (eg, dysphonia, dysfluency and language and articulation disorders), swallowing disorders (dysphagia and globus), cough and upper airway symptoms, resulting from functional neurological disorder (FND), are commonly encountered by speech and language professionals. However, there are few descriptions in the literature of the most effective practical management approaches. This consensus document aims to provide recommendations for assessment and intervention that are relevant to both adults and young people. An international panel of speech and language professionals with expertise in FND were approached to take part. Participants responded individually by email to a set of key questions regarding best practice for assessment and interventions. Next, a video conference was held in which participants discussed and debated the answers to these key

been comparatively few intervention and outcome studies for individuals with functional communication, swallowing and cough disorders; while there is some evidence for the assessment and treatment of functional dysphonia and dysphagia, other symptoms have received very little systematic research attention.

In functional neurological disorder (FND), neurological symptoms are experienced which are genuine, and usually associated with distress and disability, as a result of potentially reversible changes in function and not as a result of disease, damage or structural abnormality.[1] FND is a common cause of neurological symptoms, present in around one in six patients presenting to neurology outpatient clinics.[2] Crucially, FND is diagnosed on the basis of positive clinical features of internal inconsistency, and not by exclusion of structural damage or disease.[1] FND



Examples of communication for functional neurological disorder based on clinical features and neuroscience of the disorder

FND problem	Examples
Rule in diagnosis	'You have FND for the following reasons: a, b and c.'
General	'FND is a problem with the functioning of the nervous system. A problem with the software rather than the hardware.' Or, for patients that aren't as computer literate: 'It's like a piano that is out of tune, not broken but just not working properly.'
Overcoming dualism	Patient: 'So, are you saying it's in my mind or brain?' Healthcare professional: 'FND is a condition that shows that the mind and the brain are one and the same thing.'
Limb weakness	'Did you see how your leg returned briefly to normal when I did that test (Hoover's sign). That shows us that there is a problem with the way your brain is sending the signal to your leg (voluntary movement), but the *automatic* movements are still okay.'
Limb weakness/blindness	'Have you heard of phantom limb syndrome? That's when someone has an amputation, but their brain still thinks the limb is there. FND is a bit like the opposite, the leg/vision/sensation is there but the brain thinks it isn't anymore. The map of that part of the body in the brain has gone wrong'
Weakness/movements	'Functional brain scans have shown that the brain is working too hard in FND. Normally we shouldn't have to think about how to move our arms our legs. As soon as our brains start to work on this too hard it goes wrong. It's similar to thinking about your feet when you are climbing upstairs, or trying too hard to fall asleep at night.'
Seizures	'Functional seizures are when the brain goes into a trance-like state called "dissociation" suddenly, all by itself. This is the medical word for being cut off or distant from your surroundings. That's a bit like the feeling you have just before your seizures sometimes. We think it does this as a "reflex" response – sometimes to get rid of a horrible feeling that many people report just before. After a while, it will often happen for no reason and when people are most relaxed.'
Dystonia	'Your brain thinks that the foot is straight even though it's turned inwards. That's why it's hard for you to keep it in a straight position.'
Associated pain	'Chronic pain is usually due to an "increased volume knob" in the pain pathways throughout the nervous system, but especially the brain. This is called 'central sensitisation' and, like FND, is also a problem with abnormal nervous system functioning.'
Prognosis	'This is not an easy problem to put right, but it does have the potential to improve and many people do make a good recovery.'
Physiotherapy[a]	'Physiotherapy can help "retrain" the brain in FND. It works best when we can use those principles of distraction that I showed you. A physiotherapist may ask you to try to speed up the movement or do it in an unusual way, to music or in a mirror. Somewhere in your brain we think the automatic movements are in there, and we need to coax them out.'
Psychiatry/psychology[a]	'It's common in FND for people to have problems like anxiety and depression. This can be a consequence of having the symptoms but, in many, it is already there for other reasons. FND symptoms make people fearful of falling and being injured and of being embarrassed. For some, there are things that have happened which may explain why your brain is vulnerable to going wrong in this way and could be worth exploring. I think a psychiatric/psychological assessment could be helpful. What do you think?'

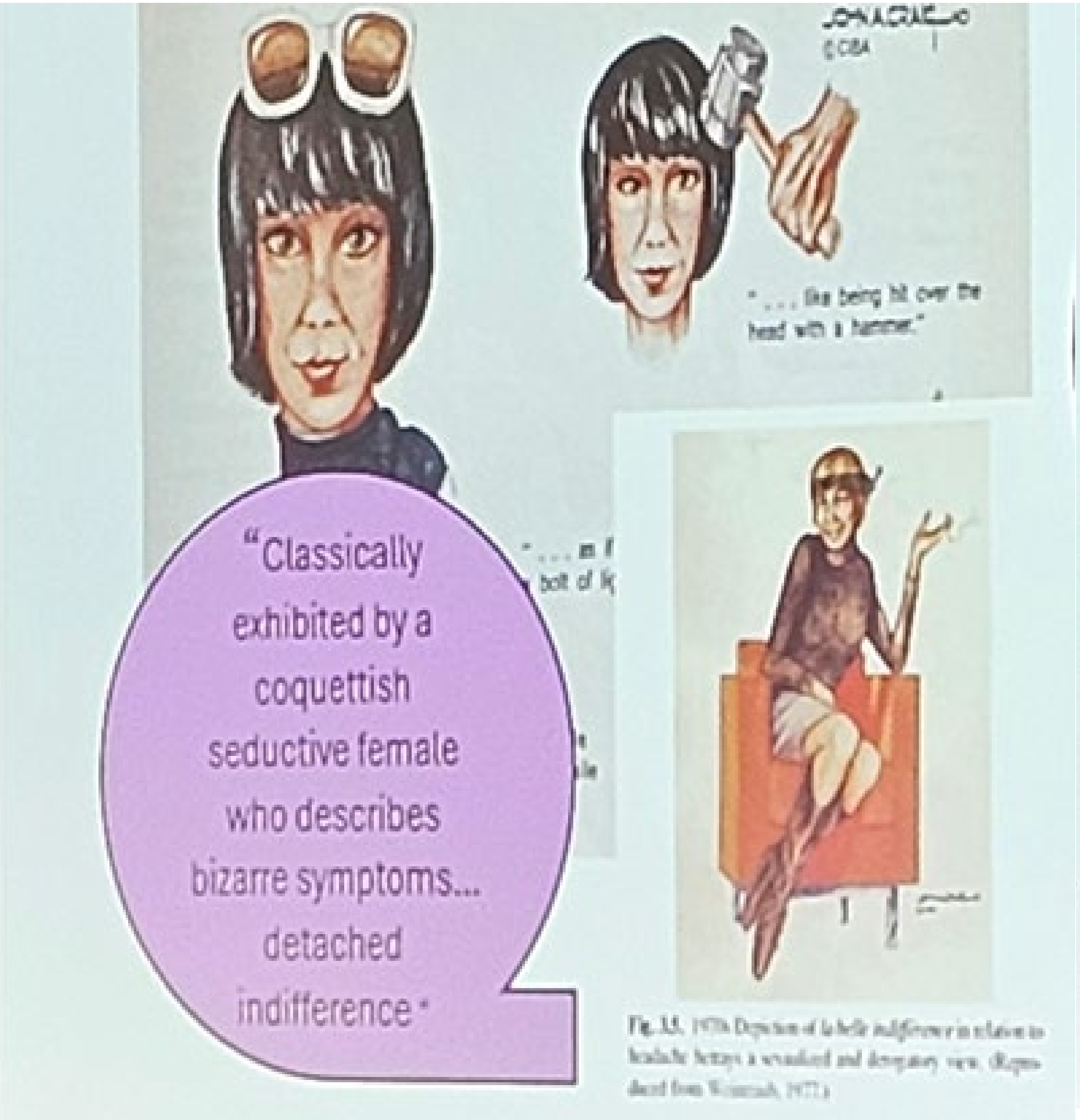
FND is a feminist issue.
Dr Caoimhe McLoughlin, Centre for Clinical Brain Sciences, University of Edinburgh

- According to the current diagnostic criteria (DSM-5, about three-quarters of the adult patients with functional disorders (668/910; 73.4%) would have been classified as suffering from conversion disorder (functional neurological symptom disorder, DSM-5), including all patients with weakness/paralysis/gait disorder, hyperkinetic movements, swallowing problems, speech symptoms, seizures, anaesthesia or sensory loss, and/or special sensory symptoms, including visual and hearing disturbance .

- The majority of the remaining patients with functional disorders would have fulfilled the criteria for somatic symptom disorder. It is noteworthy that 81.7% of soldiers presented with functional neurological symptoms, most of them with a combination of functional neurological symptoms.

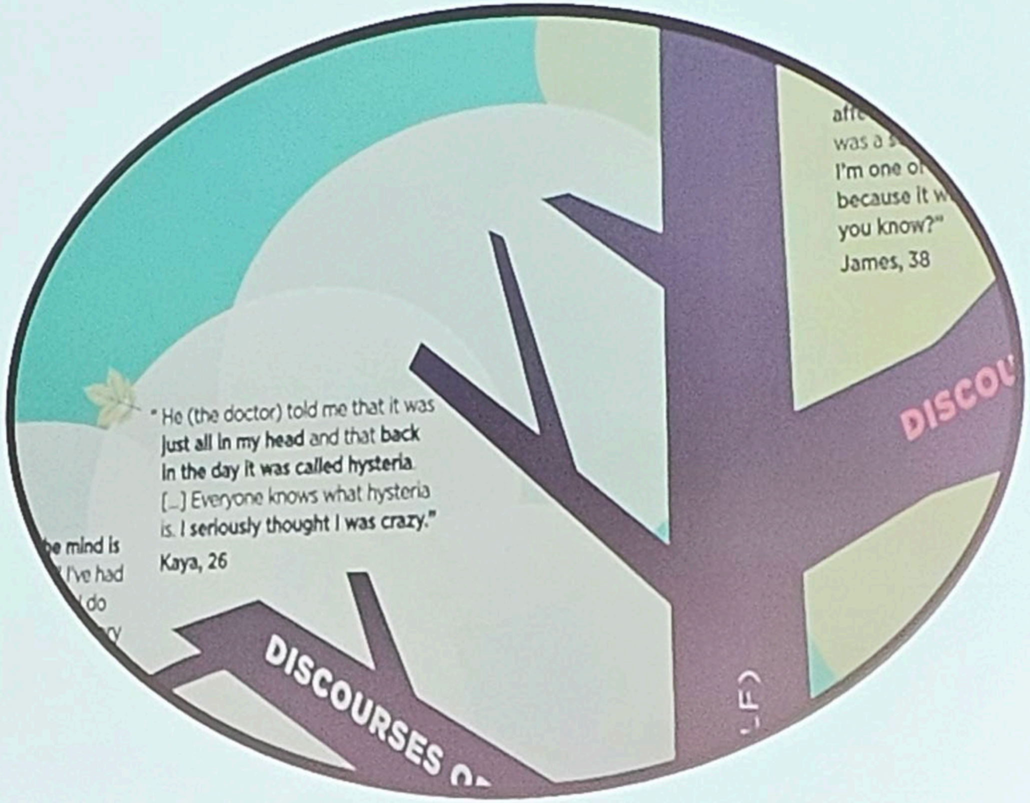
FND is a feminist issue. We say this because:

1. FND predominantly affects women
2. Historical and societal issues
3. Under recognition of FND occurs in men due to potential diagnostic bias
4. Sexual abuse and violence as gender-weighted risk factors
5. Socioeconomic disparity exists between men and women, contributing to inequalities in access to treatment;
6. FND clinical services and research are chronically underfunded, in line with the neglect of disorders disproportionately affecting women



"Classically exhibited by a coquettish seductive female who describes bizarre symptoms… detached indifference"

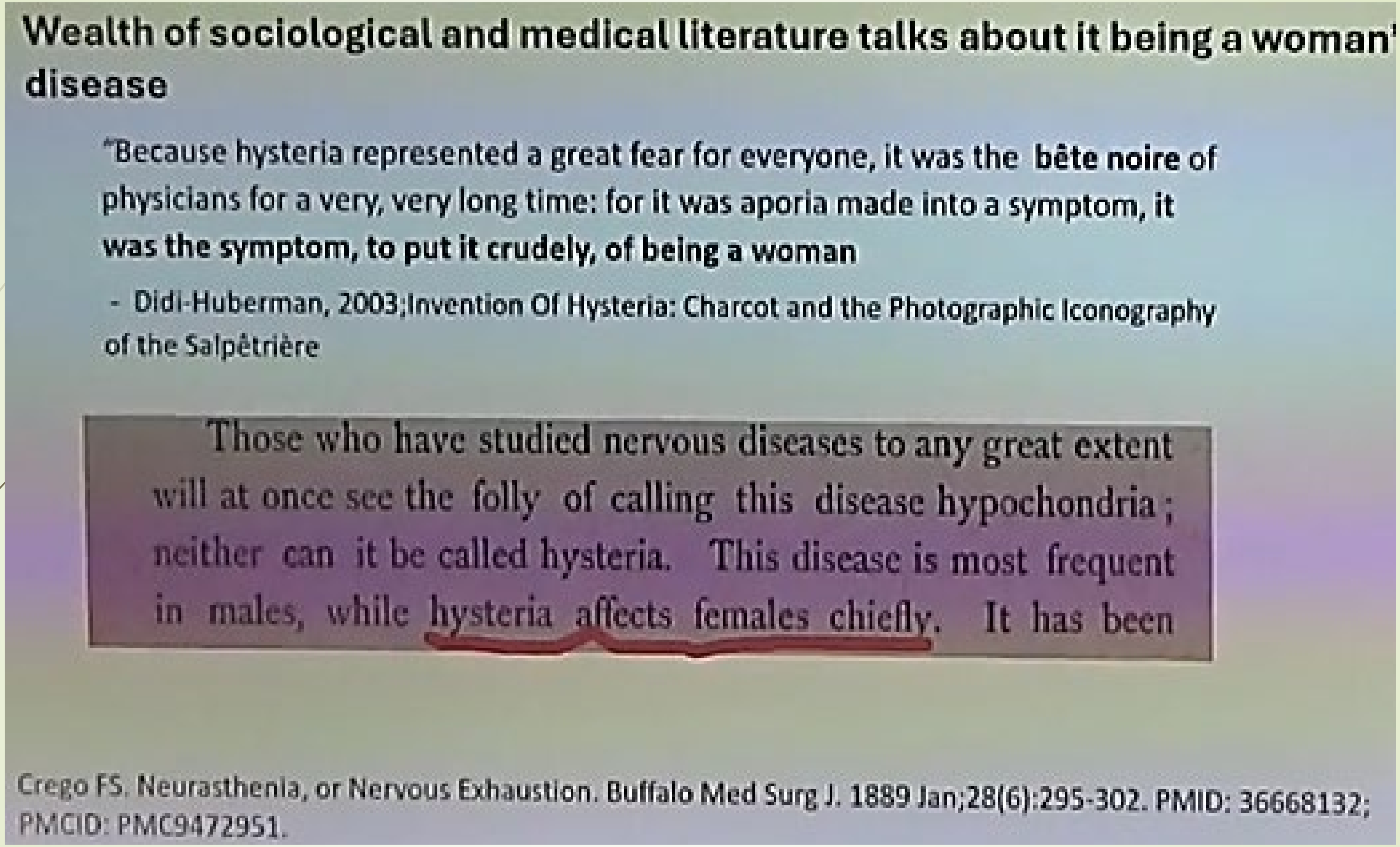
Fig. 3.5. 1970s Depiction of la belle indifférence in relation to headache betrays a sexualized and derogatory view. (Reproduced from Weintraub, 1977.)



"He (the doctor) told me that it was **just all in my head** and that **back in the day it was called hysteria**. [...] Everyone knows what hysteria is. **I seriously thought I was crazy.**"

Kaya, 26

"Navigating Dualism, New Zealanders with FND": Shelley Dawson, Victoria, New Zealand, Poster FND Society Verona, 2024



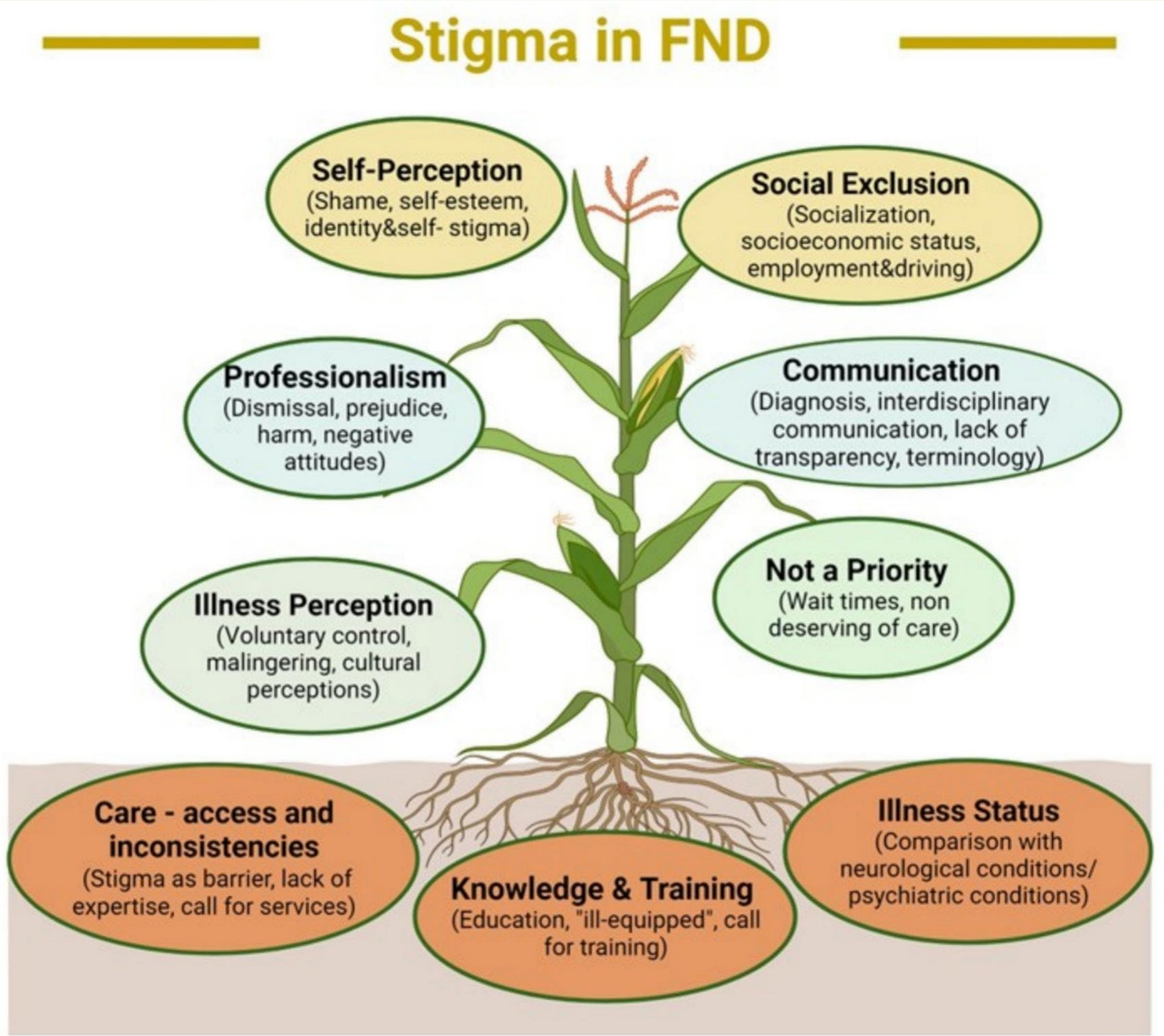
Wealth of sociological and medical literature talks about it being a woman' disease

"Because hysteria represented a great fear for everyone, it was the **bête noire** of physicians for a very, very long time: for it was aporia made into a symptom, it **was the symptom, to put it crudely, of being a woman**

- Didi-Huberman, 2003;Invention Of Hysteria: Charcot and the Photographic Iconography of the Salpêtrière

Those who have studied nervous diseases to any great extent will at once see the folly of calling this disease hypochondria; neither can it be called hysteria. This disease is most frequent in males, while hysteria affects females chiefly. It has been

Crego FS. Neurasthenia, or Nervous Exhaustion. Buffalo Med Surg J. 1889 Jan;28(6):295-302. PMID: 36668132; PMCID: PMC9472951.



Stigma in FND

Self-Perception
(Shame, self-esteem, identity&self- stigma)

Social Exclusion
(Socialization, socioeconomic status, employment&driving)

Professionalism
(Dismissal, prejudice, harm, negative attitudes)

Communication
(Diagnosis, interdisciplinary communication, lack of transparency, terminology)

Illness Perception
(Voluntary control, malingering, cultural perceptions)

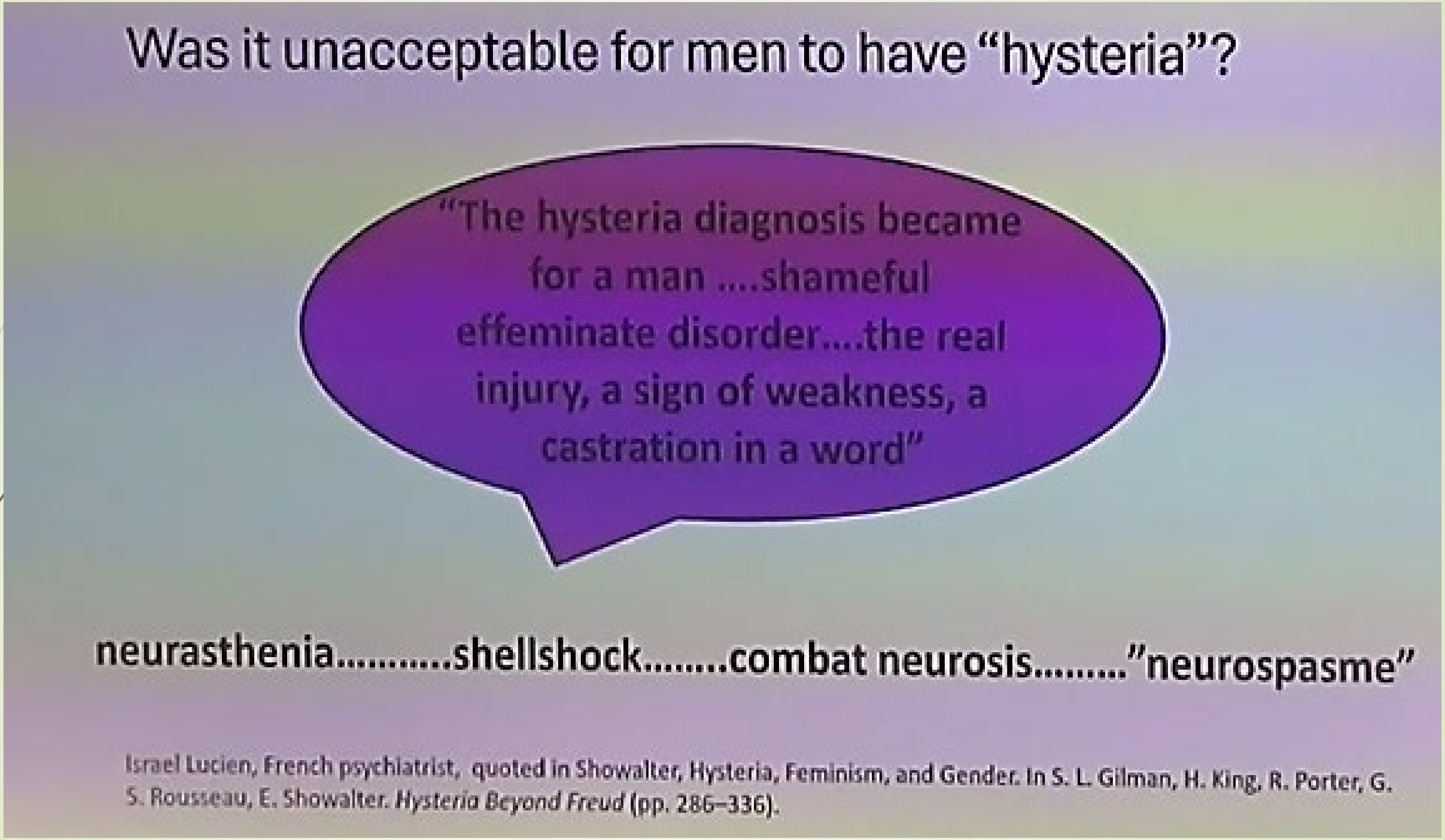
Not a Priority
(Wait times, non deserving of care)

Care - access and inconsistencies
(Stigma as barrier, lack of expertise, call for services)

Knowledge & Training
(Education, "ill-equipped", call for training)

Illness Status
(Comparison with neurological conditions/ psychiatric conditions)

Ref: Stigma in functional neurological disorder (FND) - A systematic review
Caoimhe McLoughlin , Laura McWhirter , Katerina Pisegna , Marina A J Tijssen , Lineke M Tak , Alan Carson , Jon Stone

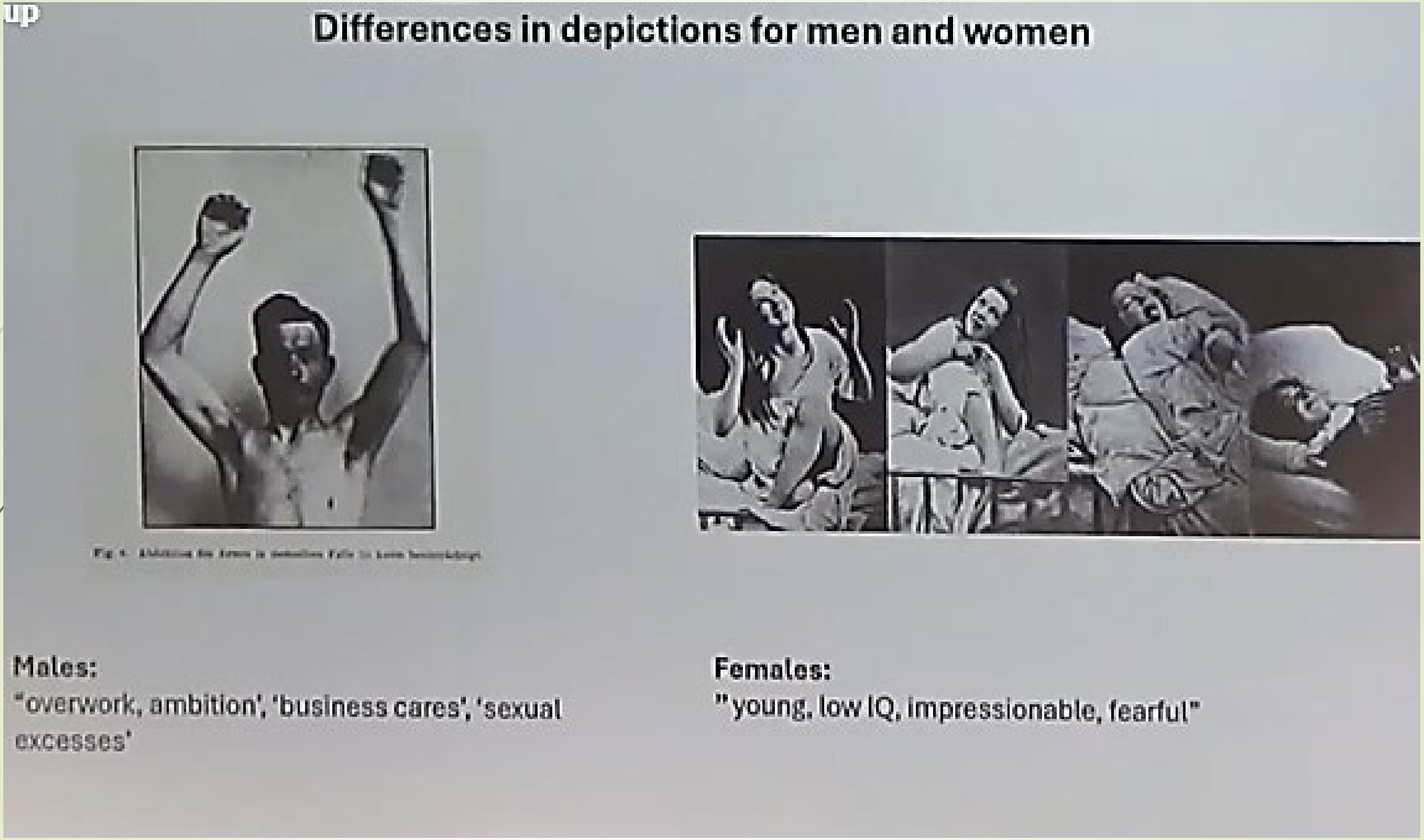


Was it unacceptable for men to have "hysteria"?

"The hysteria diagnosis became for a man ….shameful effeminate disorder….the real injury, a sign of weakness, a castration in a word"

neurasthenia………..shellshock……..combat neurosis………"neurospasme"

Israel Lucien, French psychiatrist, quoted in Showalter, Hysteria, Feminism, and Gender. In S. L. Gilman, H. King, R. Porter, G. S. Rousseau, E. Showalter. *Hysteria Beyond Freud* (pp. 286–336).



Differences in depictions for men and women

Males:
"overwork, ambition', 'business cares', 'sexual excesses'

Females:
"young, low IQ, impressionable, fearful"

The Ethics of Getting Out of Bed
- Jennifer Stanek, AJM Healthcare

- Clinical practice/case study.
- An examination of ethical and practical considerations around practice when a service user with mental capacity wishes us to undertake an intervention that could endanger him.
- Aims to allow clinicians to begin to consider the moral, ethical and practical questions around risky interventions, specifically looking at weighing up our duty of care to protect service users from harm against their right to make what we would consider an unwise decision.

Description

A service user in the catchment requires custom moulded seating following a period of prolonged bed rest.

He has full mental capacity. He has a spinal cord injury and autonomic dysreflexia - known triggers include bladder and bowel issues, including catheter dislodgement and hoisting.

He has a DNR in place, as well as an advanced decision to decline any medication for autonomic dysreflexia.

He wishes the process for custom moulded seating to be followed as per usual and is fully aware of the risks.

This has raised several fairly unique ethical and practical considerations which are worth exploring in a wider forum to raise awareness of the issues more widely.

The COT Professional standards for occupational therapy practice, conduct and ethics (2021) states "Your duty of care is your responsibility to act in a way that ensures that injury, loss or damage will not be carelessly or intentionally inflicted on the individual or group to whom/which the duty is owed as a result of your actions." but also "You uphold the right of individuals and groups to make choices over the plans that they wish to make and the intervention that you provide".

This presentations aimed to get delegates thinking about the issues raised and how they might apply to their own practice.

The importance of giving it a go - Sabrina Robinson and Bicky Ho, Oxford University Hospitals

- Aims to present the importance of recognising the principles of posture management (focussing on the value of not causing damage to the body) and the importance of giving it a go with respect to complex interventions.
- Sheila (63, advanced PD) presented with significant lower limb spastic motor changes and contractures.
- Sheila had received most care in bed for 2 years; she had been told she was unseatable. It was identified that the support surface (bed) was contributing to several secondary complications and therefore causing harm, if not addressed, this harm would likely result in tissue damage, further limitations to function, and pain.
- Trialling for seating was considered essential, as was addressing other aspects of 24-hour posture management.

Clinical Detail

A thorough assessment, focussing on body shape and biomechanical considerations, leading to clinically reason that the significance of LL asymmetries was compounding overall postural presentation; risk factors associated with non-intervention were subsequently increased.

In the clinical judgment, timely intervention was considered to be essential to preserve the already limited joint ranges which were being negatively impacted by the bed.

It was also recognised that Sheila was at a very high risk of developing pressure ulcers, and that if this occurred, there would be no alternative positions for off-loading.

By weighing-up the risks of non-provision and benefits associated with potential intervention, seating (wheelchair and shower) and lying support options were explored despite a successful outcome being considered unlikely.

Thankfully this was not the case – not only was Sheila’s risk of secondary complications related to her posture better managed, but she was able to access her local community and visit local family at home. Transport options were explored, and this is still ongoing.

Discussion

- The service has seen a trend in the increase of complex patients being managed in the community; this is the likely result of many challenges faced by the NHS and social care as well as the aftermath of COVID.
- The study encourages other professionals to recognise the importance of 24-hour posture management and the impact it has on the person holistically; receiving care in bed is not necessarily the least damaging option.
- It recommends tackling complex body asymmetries with all available resources before making absolute recommendations.
- It is recognised that significant time and resources are needed to fully explore such complex cases, this may include seeking second opinions, giving it a go, and cross-agency working.

Assistive technologies including splinting for the management of contractures in Stroke patients - results of a systematic review

Rasheed Meeran, Head of Complex Home Care, CHD Living, and Venu Durairaj, Director, Beacon Neuro Physio

Background

Assistive devices are defined as mechanical, electrical, or electromechanical device used to stretch or lengthen a muscle statically, dynamically, or cyclically. (Farmer 2014)

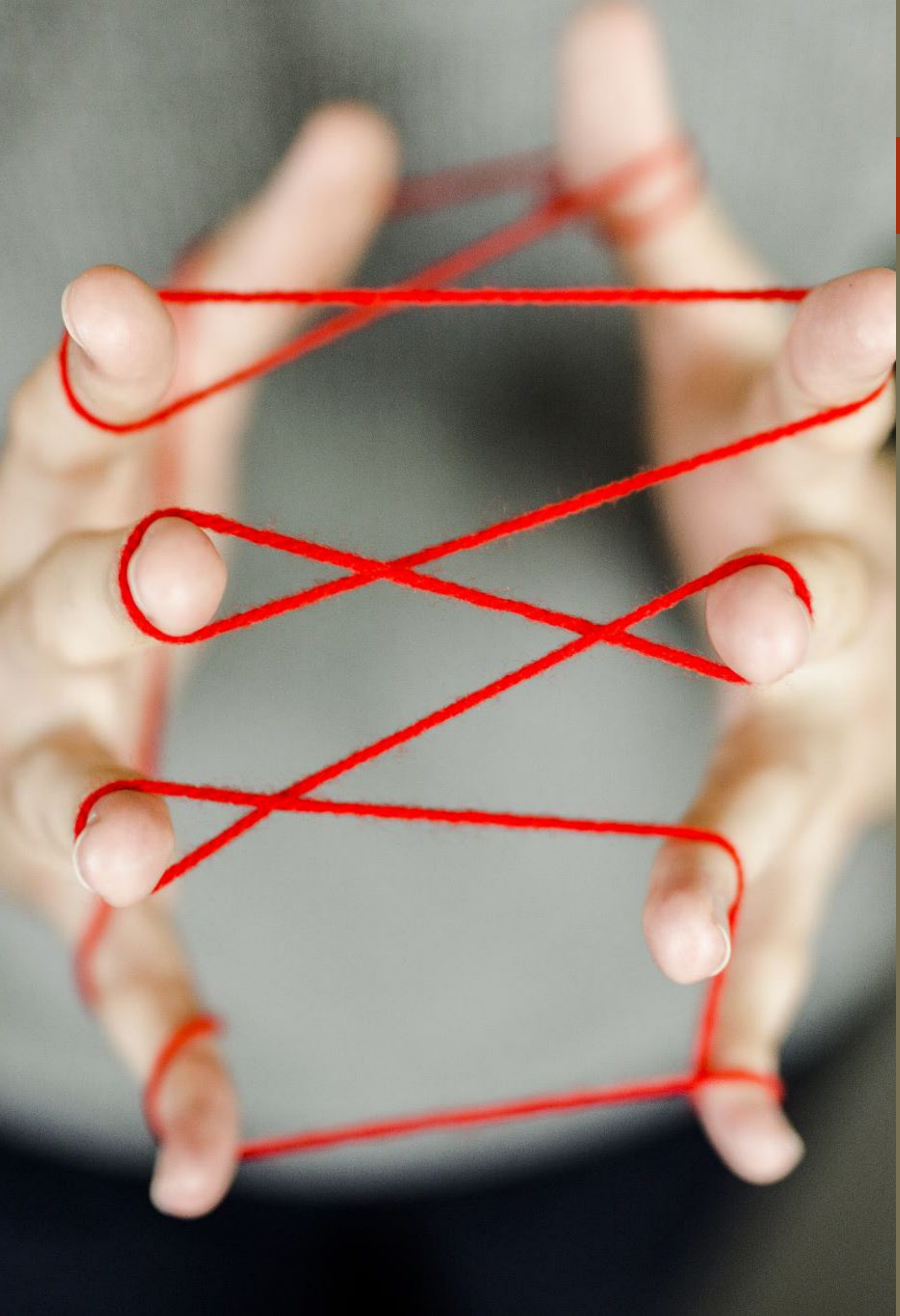
50% - 60% of people with a Stroke develop contracture (O'Dwyer 1996; Sackley 2008).

Consequences of contractures include reduced function, sleep disturbances, deformities, cosmetic problems, falls, and pain (Bhakta 2000).

There is also a cost burden in managing contractures in the form of increased pharmacological and physical treatment (Sackley 2008).

Study selection criteria

- Interventions
  - Electrical, mechanical, and electromechanical devices
  - Studies where assistive technologies were used to provide stretch passively (such as splinting; positioning, or casting) and active assistive technologies (such as dynamic splinting, continuous passive motion, or NMES) were included
  - Assistive technology used to maintain stretched positions (e.g. hinged boards) was also eligible
  - Not AT pillows and sandbags



Stretching

- is a process that leads to placing a muscle and tendon unit under strain (i.e. increased length when compared to its resting length).

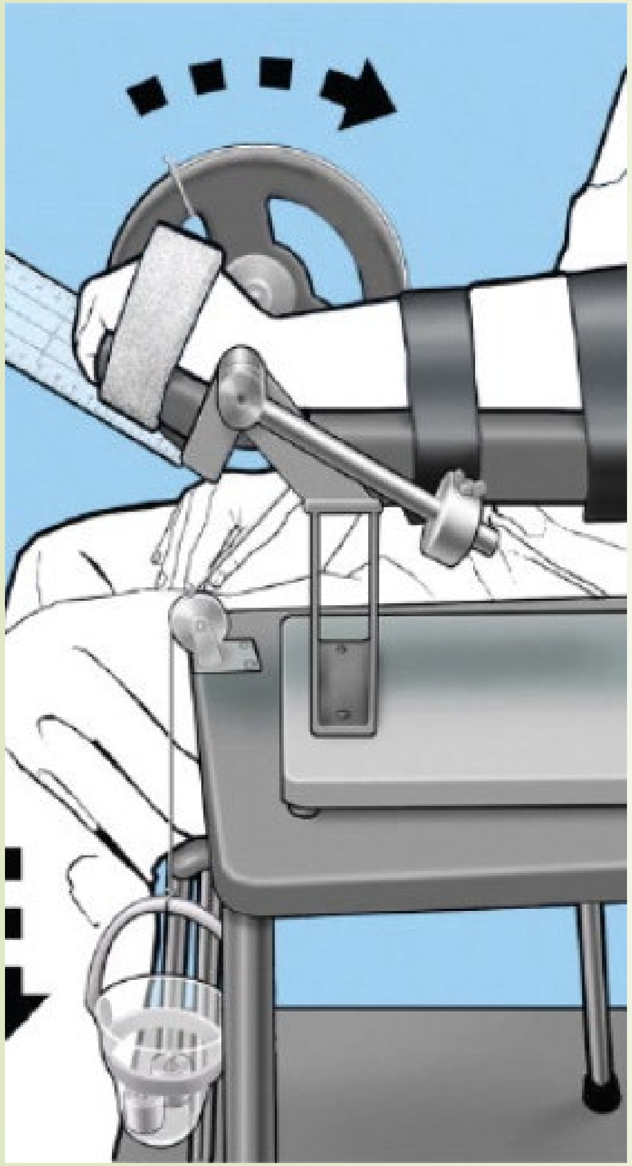
Outcome measures - Secondary

- Stiffness [instrumented/clinical scales]
- Resting posture of limb [with or without pre-stretching]
- Activity measures [ARAT, NHPT, FIM/FAM]
- Pain - visual analogue scale (VAS), numerical rating scale (NRS), or verbal rating scale
- Hygiene (care giver strain index CSI)
- Carer burden
- Function measured on the Motor Assessment Scale (MAS)

Adverse events

- Pain associated with swelling
- Discomfort
- Skin breakdown
- Muscle tear
- Heterotopic ossification
- Dislocation or subluxation
- Dropout from study due to an adverse event
- Any other adverse events occurring as a result of experimental or control group treatment

Study	Intervention	Outcome
Horley 2019	One hour a day active intensive repetitive upper limb training using SMART arm device five days a week for five weeks	Wrist extension Shoulder flexion Elbow extension PROM with standardised force
Lannin 2007	Splinting 9-12 hours overnight for four weeks	Wrist extension PROM with standardised force
Leung 2012	Electrical stimulation to wrist and finger extensors one hour a day for four weeks; both groups had splinting fo 12 hours a day	Wrsit extension PROM with standardised force
Malhotra 2013	Electrical stimulation to wrist and finger extensors 30 minutes a day for 6 weeks	PROM Wrist extension
Turton 2005	Two 30-minutes stretches for wrist and finger flexors using a hinge board	Wrist extension PROM with standardised force
Lannin 2003	Splinting at 10° to 30°, 12 hours a night for 4 weeks	Wrist extension PROM with standardised force



Torque Controlled device (Lisa Harvey et al)

Conclusions - Implications for practice

Poor quality of the studies - Cannot confirm effectiveness, although there is some evidence that splinting may work rather than not work.

When methodology quality was good - Treatment intensity was inadequate -(eg stretch was not provide to end range).

Practice is variable.

Combinations of treatments offered. Skills of professionals involved in the contracture management needs to be carefully considered.

Conclusions- Implications for Research

Only one study provided end range stretch Measurements of stiffness took joints to end range - Poor understanding of contracture

Insufficient evidence on the effectiveness of specific assistive technologies with different frequencies, dosages, and durations of treatment

Future studies should measure stiffness using force that is applied to 'end range' or 'limit of pain'. Further research could establish a common method of measuring stiffness that is scientifically proven

Since contracture is a long-term/lifelong issue, more studies on long-term effects of assistive technology are needed

Is my in-situ sling dangerous whilst travelling in a vehicle? Nicola Holbrook, West Midlands Rehab Centre, Birmingham

Re: Use of slings when transporting patients. In recent months, two individual patients, in separate incidents, have suffered serious injuries as a result of being transported in slings designed for use with a hoist. The NHS Trust recognises that specialist equipment helps us to move patients safely, comfortably and with dignity as well as protects staff from injury. However, slings are not designed to remain in situ during transportation and present a very real risk to the patient slipping from their seat and injuring themselves. Our Patient Transport Service (PTS) provides safe journeys for walking patients, patients with mobility aids, patients seated in their own wheelchairs and patients on stretchers. We can also safely transport patients with complex mobility issues. We are trusted to provide safe transportation and patient-focussed service to those in our care. For the safety of all our patients, we will not commence a journey for someone who still has a sling in place. This decision has been made in relation to all slings as a result of recommendations from incident investigation. Whilst some slings are described as ‘non-slip’ by their manufacturers, these are not designed or risk assessed for use during transportation in a vehicle. If, however, you feel that removal of the sling will compromise a patient’s safety or ongoing clinical care, you may request a risk assessment at the point of making a booking; please note that this can take up to 72 hours to complete.

Introduction

- Importance of safe transportation
- Originating incident 2019
  - No further detail relating to the specific incidents
  - Implemented an approach of individual risk assessments
  - Worked with national back exchange on guidance for identifying in-situ slings from others
- Concerned over heavy breaking, rather than crash scenario
- Occupant slipping out of position due to the presence of a sling
- Compatibility of medical device combination

Current regulations-Overview

ISO 50535:21 Assistive products-hoist for the transfer of persons requirements and test methods

Sling manufacture literature – intended to be remove after transfer unless and in-situ/all day sling with risk assessment

ISO16840-2:2018 Wheelchair seating Part 2 – Determination of physical and mechanical characteristics of seat cushions intended to manage tissue integrity

BPG1 transportation of people seated in wheelchairs v2.2:2019 International best practise guidelines, posture and mobility group

BS 8603:2020 Wheelchair transport passport schemes. Codes of practise- development on from PAS 900:2020

Road traffic Act 1988

MHRA guidance: Occupied wheelchairs in cars and private transport March 2016

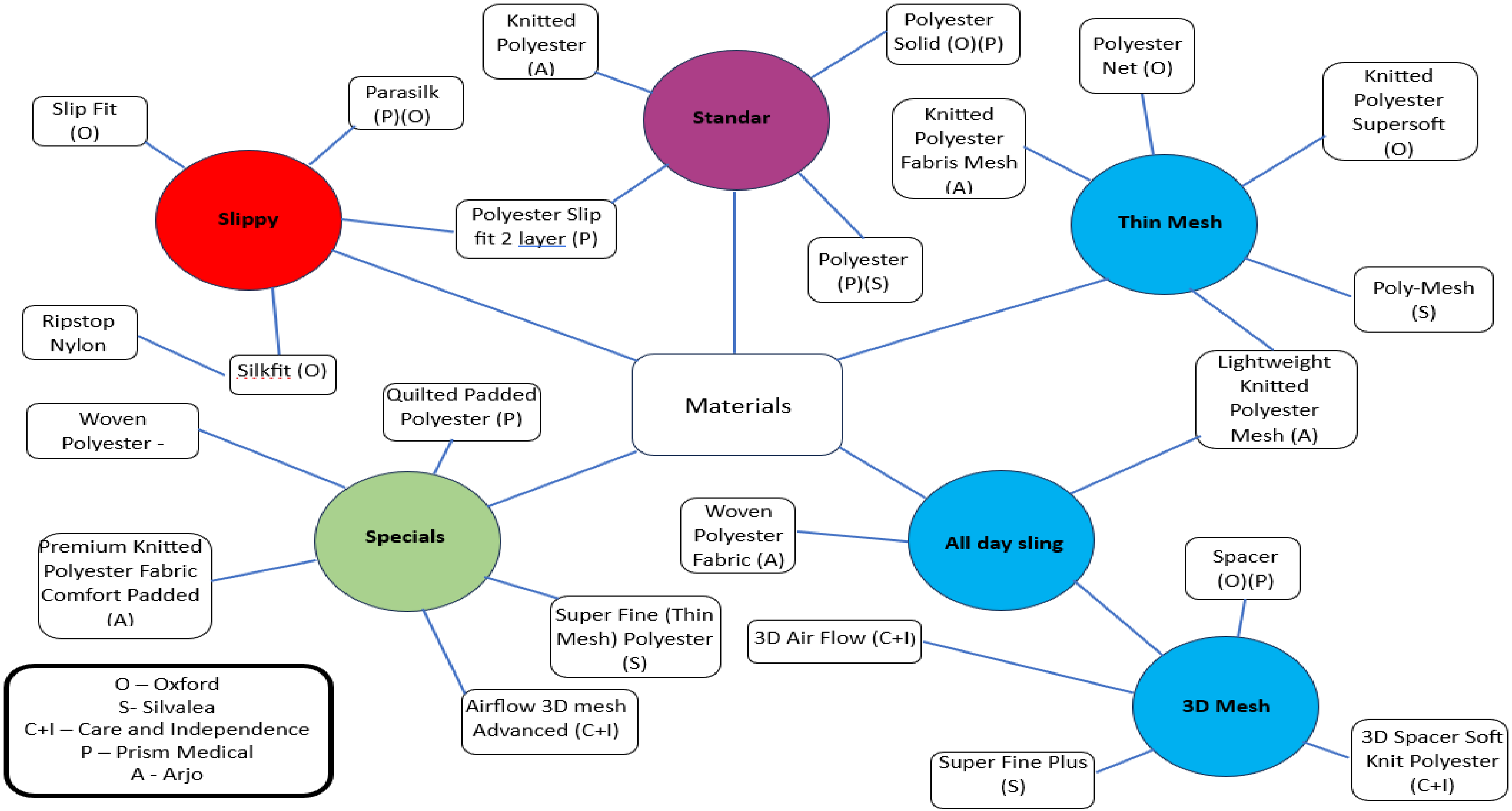
Current Regulations – Sling

- ISO50535:2021 Assistive products –hoist for the transfer of persons-requirements and test methods
  - Non rigid body support unit
    - Durability; fire retardancy, shrinkage; label readability, biocompatibility – nothing about frictional characteristics
- No restriction in clothing, so why would a sling cause a problem?
- Definition of in-situ sling?

– suggestion that a sling called in-situ or in-chair AND fabric is spacer or airflow.

Sling type	Name used
General purpose transfer sling	Quick fit, Fast fit, universal, comfort, full back, full body, divided leg
In situ	In-Situ; in chair; all day
Toileting sling	Access
Bathing sling	Bathing

Current regulation – Slings Materials



Materials

Standar
Knitted Polyester (A)
Polyester Solid (O)(P)
Polyester Slip fit 2 layer (P)
Polyester (P)(S)

Slippy
Slip Fit (O)
Parasilk (P)(O)
Silkfit (O)
Ripstop Nylon

Thin Mesh
Polyester Net (O)
Knitted Polyester Supersoft (O)
Knitted Polyester Fabris Mesh (A)
Poly-Mesh (S)
Lightweight Knitted Polyester Mesh (A)

Specials
Woven Polyester -
Quilted Padded Polyester (P)
Premium Knitted Polyester Fabric Comfort Padded (A)
Super Fine (Thin Mesh) Polyester (S)
Airflow 3D mesh Advanced (C+I)

All day sling
Woven Polyester Fabric (A)

3D Mesh
Spacer (O)(P)
3D Air Flow (C+I)
Super Fine Plus (S)
3D Spacer Soft Knit Polyester (C+I)

O – Oxford
S- Silvalea
C+I – Care and Independence
P – Prism Medical
A - Arjo

Current regulation BPG1

- BPG1 Transportation of people seated in wheelchairs v2.2:2019 International Best Practice Guidelines. Posture and Mobility Group

Current regulation- Wheelchair passports

BS 8603:2020 – Aims to improve the safety of the wheelchair seated passenger

Wheelchair Transport Passport Schemes –
Code of Practice – to ensure the safer transport of wheelchair user

Current Regulation – wheelchair passport

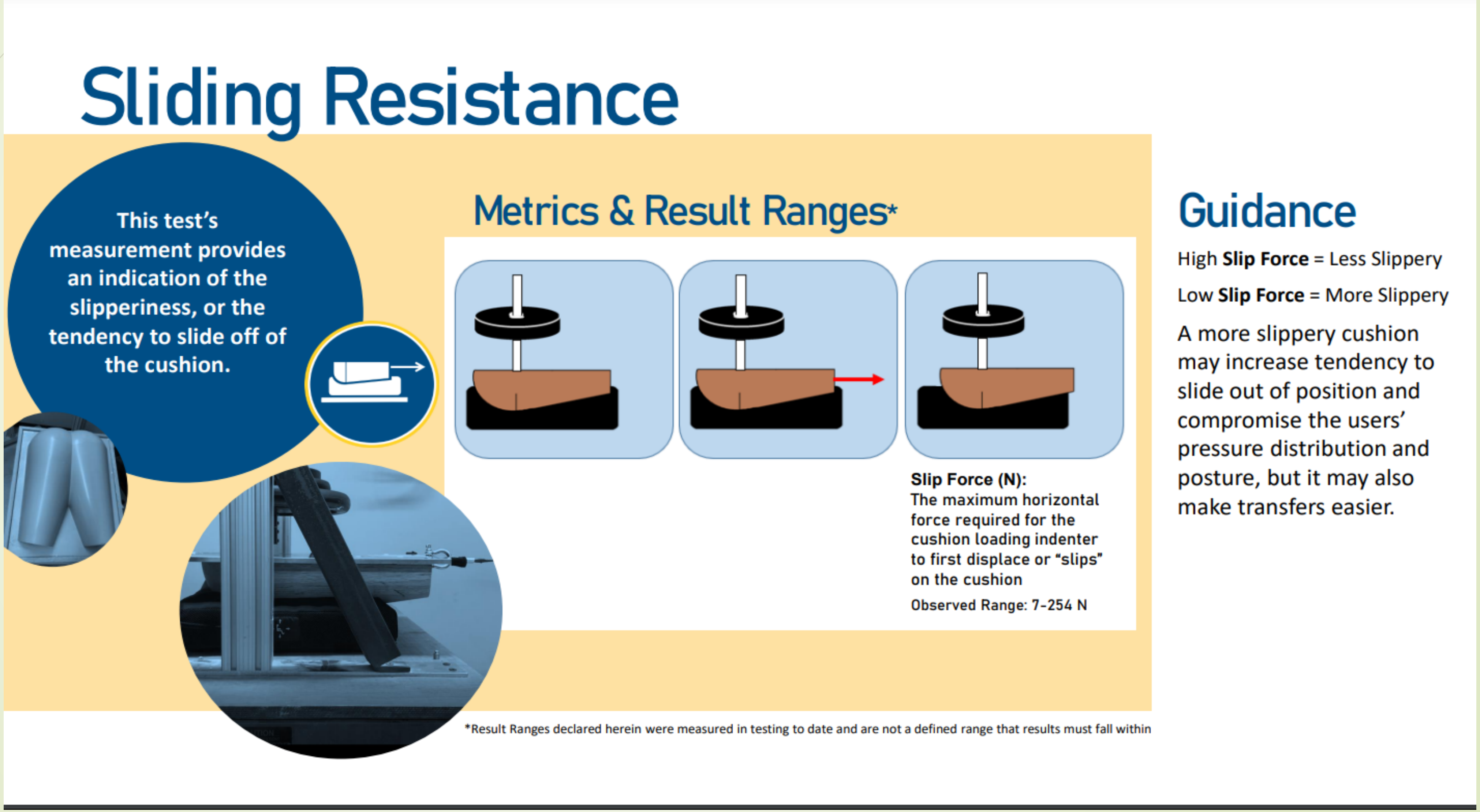
1. Scope
2. Normative references
3. Terms and definitions
4. Operational Framework
   4.1 General
   4.2 Wheelchair Passport Creation
   4.3 Roles, Responsibilities and skills
   4.4 Inter-agency working
5. Information for the wheelchair passport
   5.1 General
   5.2 Wheelchair user informarion
   5.3 Wheelchair and seating information
   5.4 transport requirements

Current Regulation – wheelchair passport

- 6. Passport Design
    - 6.1 Layout
    - 6.2 Durability
    - 6.3 Accessibility
    - 6.4 Use of Images
    - 6.5 mounting
    - 6.6 Replacement
- 7. Marking

Current Regulations – ISO 16840-2:2018

Wheelchair Seating Part 2: Determination of physical and mechanical characteristics of seat cushions intended to manage tissue integrity



Sliding Resistance

This test's measurement provides an indication of the slipperiness, or the tendency to slide off of the cushion.

Metrics & Result Ranges*

Slip Force (N):
The maximum horizontal force required for the cushion loading indenter to first displace or "slips" on the cushion

Observed Range: 7-254 N

Guidance

High **Slip Force** = Less Slippery

Low **Slip Force** = More Slippery

A more slippery cushion may increase tendency to slide out of position and compromise the users' pressure distribution and posture, but it may also make transfers easier.

*Result Ranges declared herein were measured in testing to date and are not a defined range that results must fall within

Current Regulations - Road Traffic Act 1988

- A person is guilty of an offence if he/she uses, or causes or permits another to use a motor vehicle on the road when:
- a) the condition of the motor vehicle or trailer, its accessories or equipment b) the purpose for which it is used,. c) the number of passengers carried or the manner in which they are carried, d) the weight, position or distribution of its load, or the manner in which it is secured
- is such that the use of the motor vehicle or trailer involves the danger of injury to any person.

Concerns from impact of sling ban

Best practice is to remove a patient's hoist sling for transporting on vehicles wherever possible and in cases where the it is not designated as in-situ (or all day) slings,

Removal of sling	Stretcher transport
• pain and discomfort from unnecessary movement . • potential skin shearing/damage • Manual handling injuries • Having to refit a sling whilst seated that is designed to be fited whlst laying or manually lifting the occupant • moving the patient out of position resulting in the lap strap being too loose	• Postural limitations leading to discomfort • many services need to see the patient in their own wheelchair/seating in order to deliver the care intervention they need • Sustained period laying down Is a stretcher safer in transport? Testing at the lower 10g rather than 20g for wheelchairs

Concerns from impact of sling ban

Appointments conducted as home visits

significantly reduces capacity for the service as more patients can be seen in clinic than as home visits

No access to specialist resources the patient may need such as workshop facilities, specialist positioning equipment,

No access to additional clinical expertise which then leads to additional follow-up appointments being required

Delay/cancellation of appointment

Increased waiting times: leading to increased complications, from decreased mobility (e.g. respiratory conditions, pressure ulcers, musculoskeletal injuries) Can place more pressures in both GP practices and Secondary Care Admissions

reduced efficiency of clinical service, increased DNA rates and complaints

Alternative transport

If traveling in patient transport with a sling in place has been said to be too high a risk for the occupant, then what does this imply regarding accessible taxis and private vehicles?

Future and Outlook

National Back Exchange developing guidance
To enable identification of in-situ slings

These are the most common type of sling that you will find in the community

A. Deluxe style sling

B. Universal style sling

C. In-situ Hammock/recline style

D. In Situ pommel style

Sling
Assessed
For
Transport

Sling Indicators

THANK YOU….