https://www.fndaction.org.uk/symptoms/

Hypermobility 115: Functional Neurological Disorder

& Functional Movement Disorders

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Who Am I?

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- Member: Ehlers-Danlos Society Medical and Scientific Board
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- Frequent presenter to professional and patient groups at national and international conferences
- Author of multiple review and research articles on hypermobility
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I do not have any conflicts of interest to report

Hypermobility Lecture Series Schedule

I will refer to these if you want more info

- HSD 101: Basics of HSD/hEDS and self-care
- HSD 102: POTS and POTS self-care, basics of MCAS
- HSD 103: Pain management in HSD/hEDS
- HSD 104: Safe exercise selection and progression with HSD/hEDS
- HSD 104 part 2: Nuts and bolts of modifying exercise with HSD and POTS
- HSD 105: Posture and joint protection
- HSD 106: Gut issues in HSD/hEDS, POTS, MCAS
- HSD 107: Fatigue in HSD/hEDS and POTS
- HSD 108: Headaches, migraines, & TMJ pain associated with HSD, POTS and MCAS
- HSD 109: Breathing disorders in HSD
- HSD 110: Lumbar instability
- HSD 111: Conservative management of cervical instability
- HSD 112: The vagus nerve
- HSD 113: The role of fascia
- HSD 114: Optimizing your hospital experience with HSD, POTS, MCAS
- **HSD 115: Functional Neurological Disorder and HSD/hEDS**
- **HSD 116: *NEW* Excessive Bleeding in HSD**

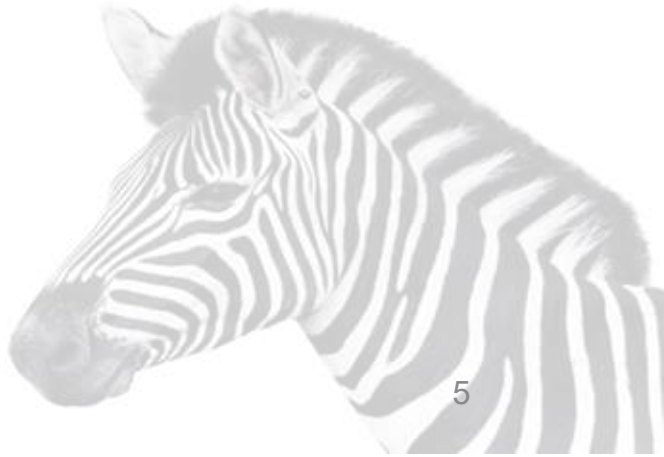
Relevant Handouts Available

- https://webspace.clarkson.edu/~lrussek/research.html

- **FND Hope: Overview of FND booklet**
  - https://fndhope.org/wp-content/uploads/2023/04/Final-Print-FND-Hope-Patient-Booklet.pdf

Disclaimers

The information in this presentation is for general purposes, only, and may or may not apply to your situation.
Check with your health care provider
before starting any new treatment approach
to ensure that it is appropriate and safe for YOU.
I cannot diagnose or make specific treatment recommendations in this lecture.

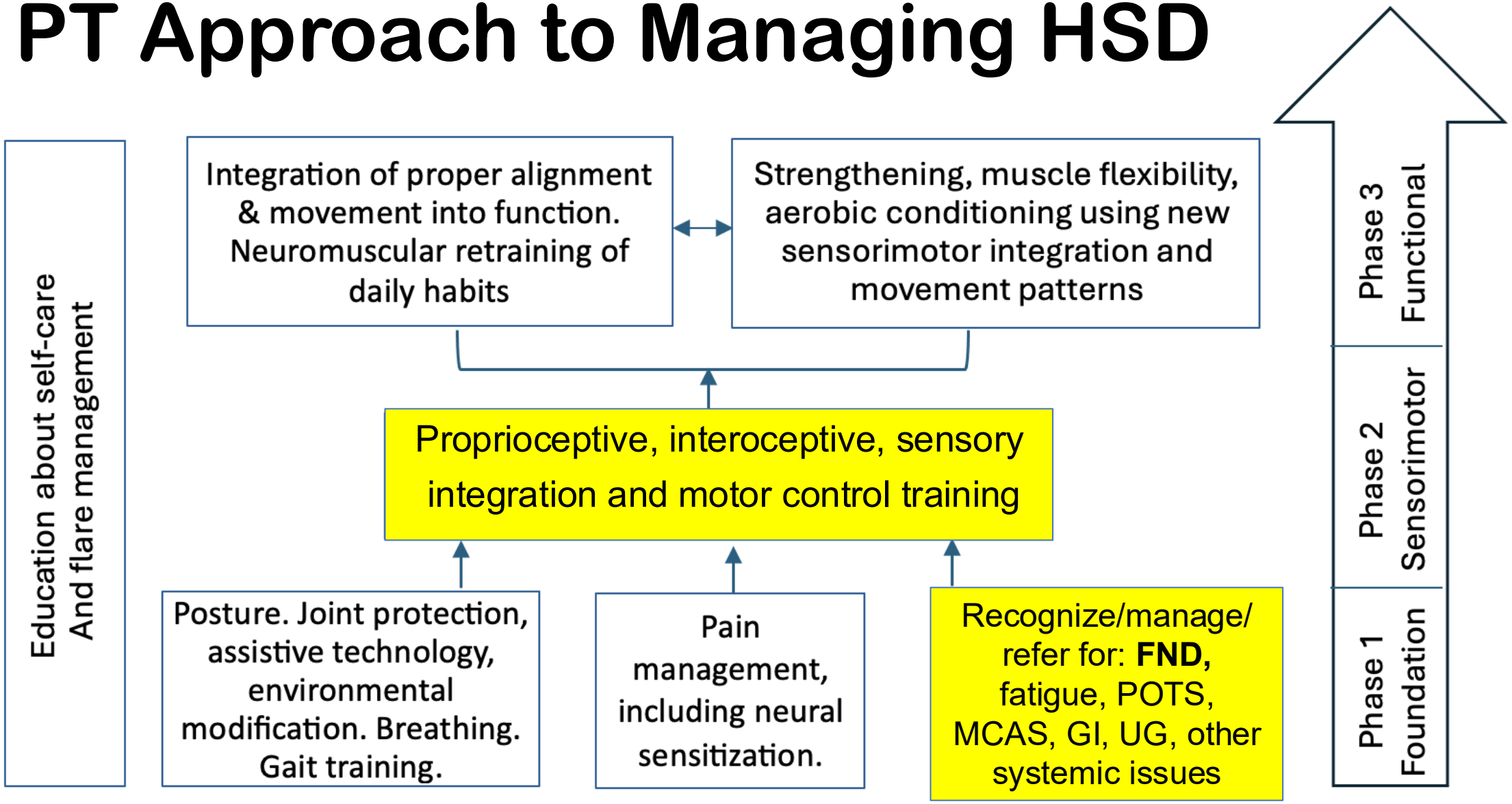


Objectives

By the end of this session, participants should be able to:

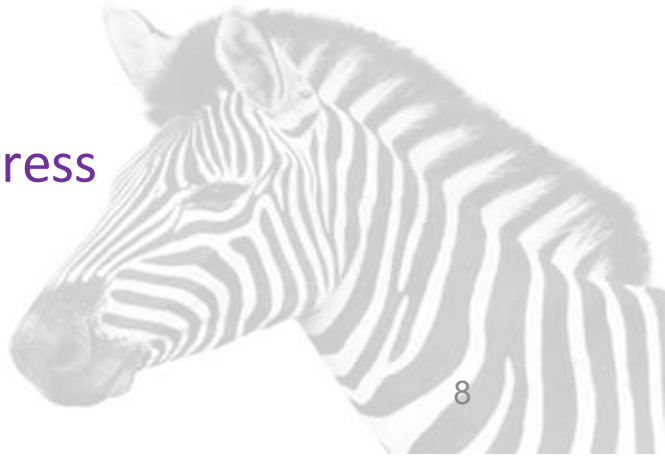
1. Describe what Functional Neurological Disorder (FND) can look like
2. Compare FND to a ‘software problem’ with a disconnect between sensory and motor functions of the brain
3. Explain the basic principle of diagnosis by finding inconsistencies in how the brain and body function
4. Explain how FND is NOT a diagnosis of exclusion (can’t figure out any other explanation), and is NOT a psychosomatic or psychogenic condition.
5. Identify several principles of treating FND

PT Approach to Managing HSD



Before We Start…

- Functional Neurological Disorder (FND) is the current explanation for conditions that have previously gone by many *inappropriate* names:
  - Psychogenic, psychosomatic, or non-organic disorders
  - Conversion disorder
  - Symptom magnification
  - Hysteria
  - Psychogenic, pseudo- or non-organic seizures
  - Munchausen Syndrome
- FND is NOT a psychiatric condition
  - Though it may be aggravated by psychological stress,
  - Just like asthma, psoriasis and heart attacks can be triggered by stress
- FND is a REAL malfunction of the nervous system



How Common is FND?

- FND is the second most common reason people see neurologists (the most common reason is headaches) (Stone, 2010)
- A small study found that 92% of patients with EDS had at least one FND sign, and 12% had 5+ FND signs (Fernandez, 2024)
- A larger study found that 74% of people with FND have hypermobility (Chen, 2024)
- FND can be very disabling and challenging for both the health care system and patient

What Does FND Look Like?

- **Functional Seizures**
  - Long duration, variable limb or head movement, pelvic thrusting, responsiveness and memory afterwards (contrast with epileptic seizures, which have post-ictal confusion)
- **Motor FND (Functional Movement Disorders – FMD)**
  - Variable movement problems: e.g. weakness or paralysis of a limb, shaking, buckling knees
  - Difficulty moving a limb or very slow movement
  - Difficulty walking, poor balance, dramatic walking problems without actually falling
  - Tremor or involuntary movements
- Sensory FND:
  - Bizarre pain patterns, numbness, or sensory changes
  - Headaches or migraines
  - Persistent dizziness
- Cognitive FND:
  - Brain fog, memory loss, dissociative amnesia, depersonalization (feeling outside your body)
  - Difficulty thinking clearly that comes and goes

Hallett, 2022; https://fndhope.org/fnd-guide/symptoms/

Features of FND

- History suggesting FND:
  - Onset at an early age,
  - Abrupt onset,
  - More than one movement dysfunction,
  - Fluctuation during the day,
  - Waxing and waning over time,
  - Presence of pain or fatigue, psychological distress.
- The more you focus on a body part or movement, the worse it gets.

(Hallett, 2022)

Risk Factors for FND

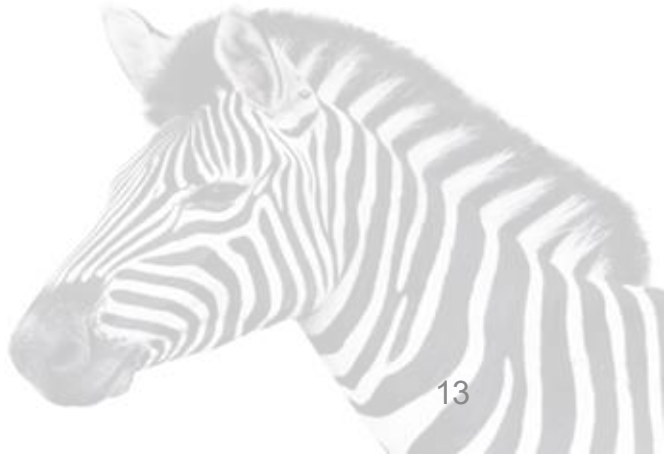
- Physical
  - Being female
  - Genetic and epigenetic risk factors (‘epigenetics’ is where lifestyle factors influence which of your genes become active)
  - Neurological conditions such as epilepsy, Parkinson’s, multiple sclerosis
  - HSD and hEDS! Especially in people with upper cervical instability
  - Virus or infection
  - Trauma, injury or surgery
- Psychosocial
  - Distress from family dysfunction, bullying, abuse, PTSD
  - Acutely stressful events, inadequate stress management

(Hallett, 2022)

What Can Trigger FND?

- Injuries, surgery
- Infections
- Acute pain, such as migraine
- Acute distress, such as PTSD, trauma, panic attack

(Hallett, 2022)



Overview of FND

Hallett, 2022

Technical Information

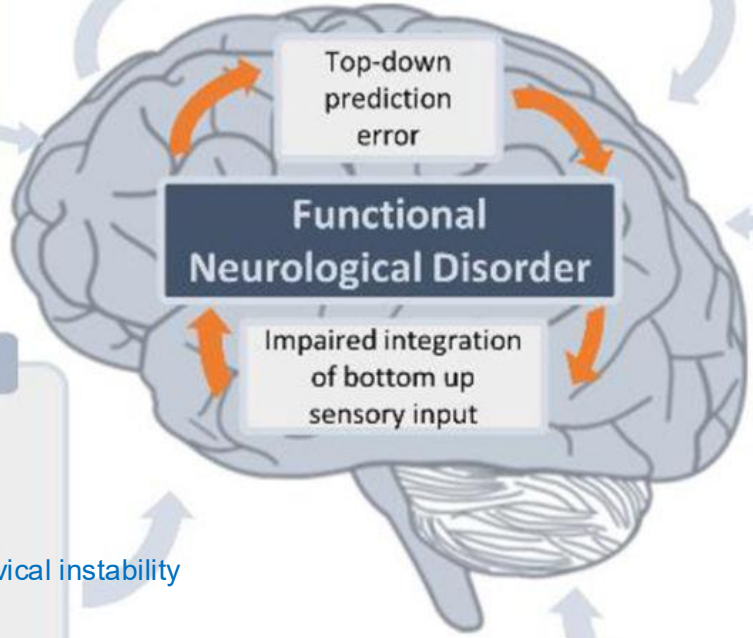
2 Precipitating Factors

FND subtype	*Patho physiological*	*Psycho physiological*
Movement Disorder	Limb injury Drug side effects	Panic attack Dissociation Depression PTSD Anxiety
Seizures	Syncope/ Epilepsy	
Cognitive	Brain injury	
Dizziness	Vestibular pathology	

EDS related injury, Cervical instability

3 Comorbidities

Psychological	*Pathophysiological*	*Other Functional Disorders*
Anxiety/ Panic PTSD Depression Emotional instability	Other neurological and medical conditions	Irritable Bowel Chronic pain Persistent Fatigue Overactive Bladder



4 Perpetuating Factors

Diagnostic uncertainty (from doctor or patient)
Misdiagnosis as another condition.
Poor communication
Lack of treatment
Unnecessary investigations and or treatment/surgery
Sedative/Opiate medication
Obstacles to recovery
Avoidance
Low motivation for change

'Whack-A-Mole' approach to treating EDS

1 Predisposing Factors

Functional Disorders – eg pain syndromes, irritable bowel
Neurological and other medical conditions – eg migraine, epilepsy, Parkinson's prodrome EDS, Cervical instability
Psychological disorders/Stress
Anxiety/Depression
Stressful live events
Childhood Adversity
Genetic risk factors
Sometimes NO vulnerability

Normal Re-Adaptation

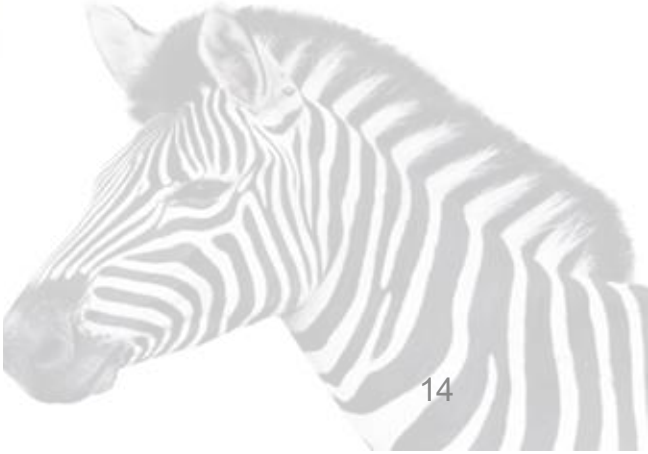
Partial or No Recovery

6 Outcome

Recovery

5 Treatment

Explanation of disorder
Physical / Occupational/ Speech Therapy
Psychological Therapy
Treatment of comorbidities



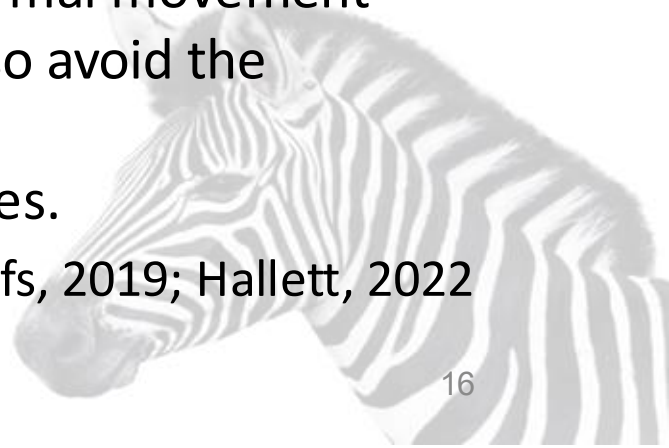
A Brief Story about FND

https://youtu.be/9USepwToLqk?si=V_Qyc3B87D8Z4-Gz

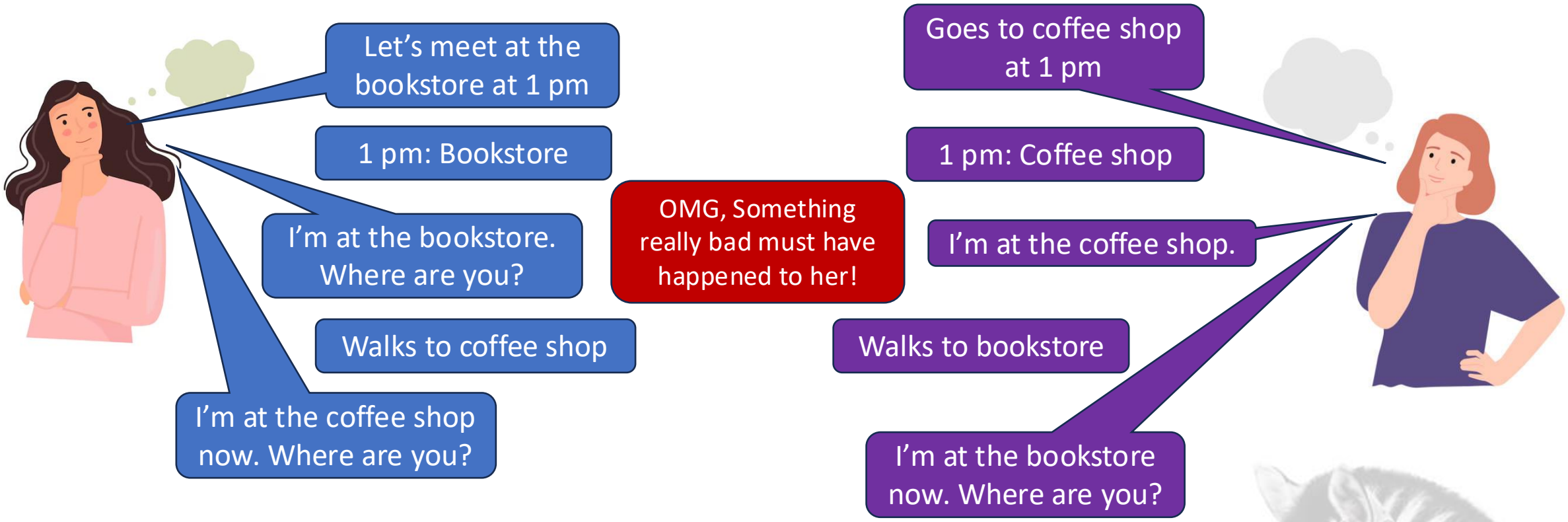
Neurobiology of Functional Movement Disorder (FMD), a type of FND

- The brain normally tells the motor cortex to do a movement ('voluntary movement')
- A predictive image is also sent to the sensory cortex to expect movement
- If the brain's instructions and perceived movement match, the brain feels it has control over the movement, or 'agency'. All good.
- If the brain's instructions and perceived movement do not match, the brain senses inability to control movement and faulty feedback tells the body to move differently
  - Sensory processing problems (poor proprioception & interoception) add to mismatch
- Distracting the brain, so that it isn't able to compare planned to actual movement, sometimes disconnects this faulty feedback loop and allows more normal movement
- Performing automatic movement or reacting to external cues may also avoid the defective neural processing
- It is a 'software' problem rather than 'hardware'. The computer crashes.

Roelofs, 2019; Hallett, 2022



Analogy of Communication Problem



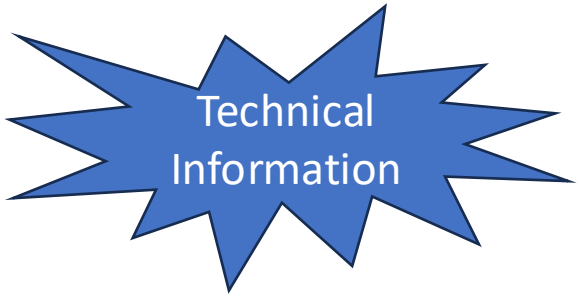
- But, in the brain, this miscommunication occurs in fractions of a second, and can lead to tremor, wobbling movement, or inability to move.
- Or, the mismatch between what the brain perceives and expects can lead to a 'danger' signal that triggers pain rather than movement problems.

Example of Shifting Neural Networks: Talking & Singing

Some types of stuttering are due to disruptions in perception-action integration. Singing can help some people decrease stuttering by using different brain regions.

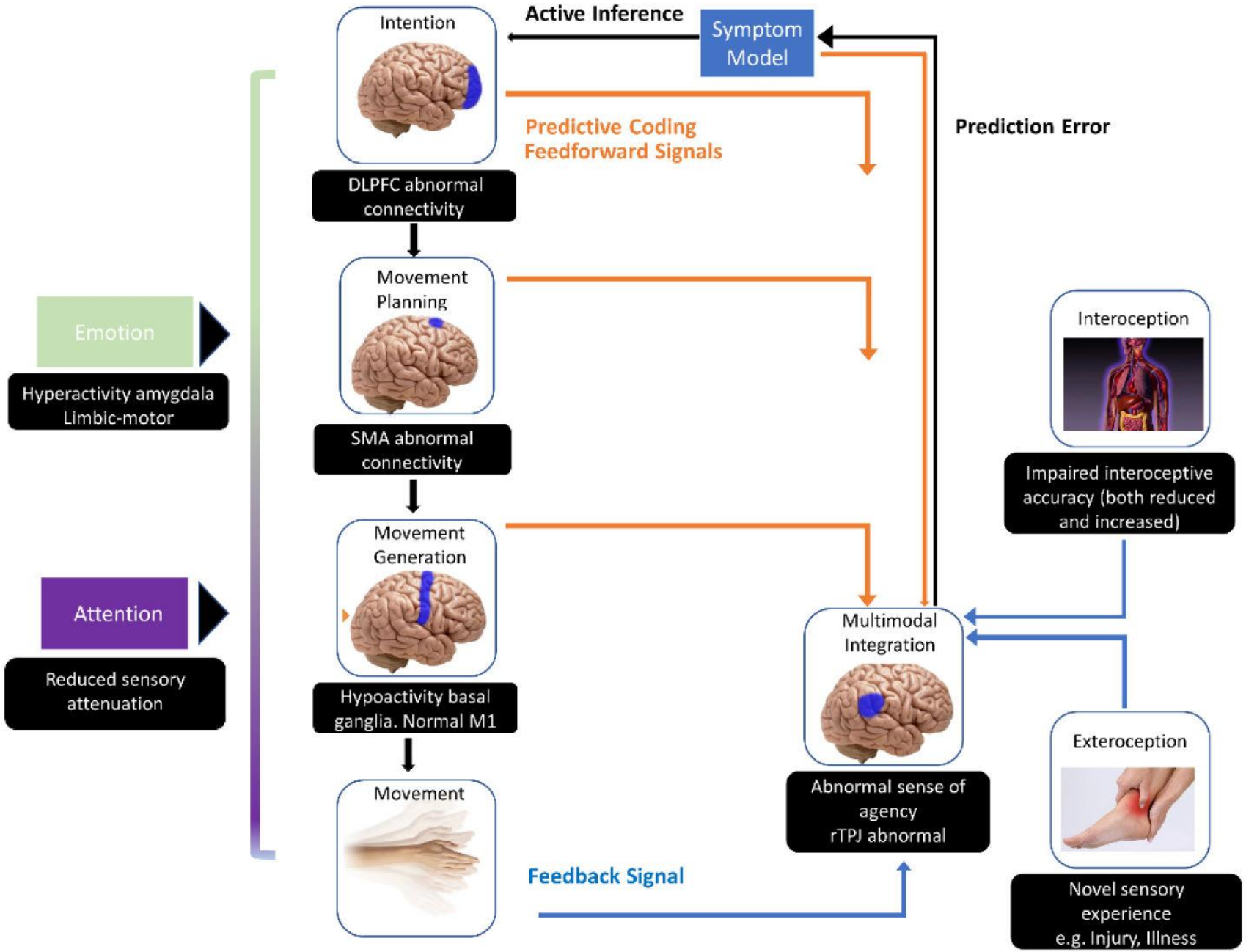
- Some people who have had a stroke lose the ability to talk.
  - This is called “aphasia”
- Sometimes, however, they can still sing!
  - Singing uses a different portion of the brain, that might not have been affected by the stroke
  - Training them to use singing in place of talking helps to bypass the damaged portion of the brain
  - Retraining is still hard work!

Technical Explanation



- The brain has several neural networks that function as groups
- *The Salience Network* assesses the importance of information, detects differences and alerts the brain to potential dangers. It tells the brain what to pay attention to.
  - The “cocktail party effect” where you only hear the person you talk to.
- *The Default Mode Network* is active when you are not paying attention. It becomes inactive during focused thought or goal-directed movement.
- *Central Executive Network* is active during focused, task-related and goal directed activity.
- FND includes problems with sensory processing and integration.

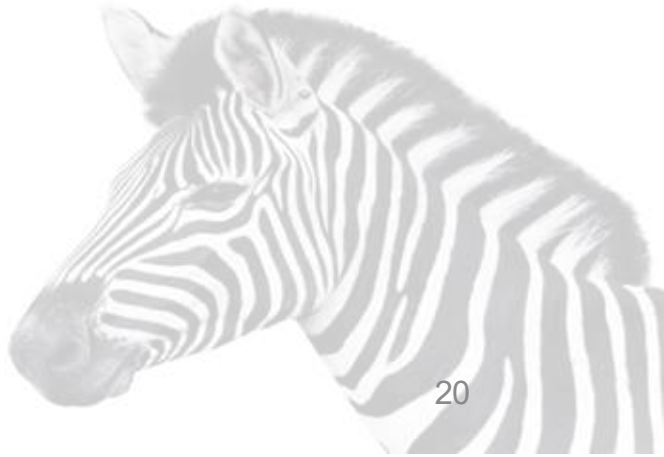
“Sensing FND: The role of the sensory system in the management of FND” presentation, Combined Sections Meeting, 2025



Hallett, 2022

Essentially:

- **What your brain thinks it tells the body to do does not match what the body thinks it's doing, so the brain believes movement is not voluntary.**
- **The brain may overcorrect (tremor, shaking) or stop activating that body part (weakness/paralysis)**



Pathology in FND

- Since standard MRI and CT scans do not show abnormalities, the condition used to be called ‘non-organic’
- More recent imaging of brain activity shows abnormalities in FND
  - Brain ACTIVITY is abnormal, but STRUCTURE is normal
- Excessive nervous system inflammation
  - Decreased brain-derived neurotropic factor (reversible with treatment)
- Increased autonomic nervous system activation (POTS)

(Mark, 2024)

- Brain scans are different for people with FND and people deliberately faking abnormal movement

(Roelofs, 2019)

Diagnostic Testing for FND

- **FND is NOT a ”diagnosis by exclusion”**
  - ”Diagnosis by exclusion means they (think they) have ruled out all other possibilities through diagnostic testing
  - This is problematic in HSD/EDS because it can be very tricky to diagnose things like upper cervical instability (UCI), or aggravating factors such as mast cell activation disorder (MCAD)
- **“Positive” findings must be present.** Examples:
  - Muscles function better when the brain is distracted by something else
  - Tremor can be ‘entrained’ by someone tapping the uninvolved hand
  - “Whack-a-mole sign”: if tremor is immobilized, other body parts begin tremor
  - Able to walk better to music, stepping over objects, walking backwards, or carrying without spilling
- Physical exam tests should be ‘transparent’ – i.e., patients should be informed about what the provider is doing and looking for. Don’t deceive!

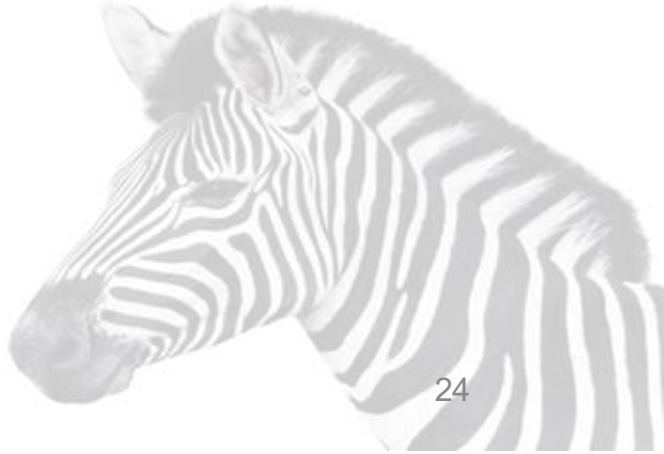
Hallett, 2022; Aybek, 2022

Characteristics of FND/FMD

- The more you pay attention to the problem, the worse it gets. This is true even if you are trying to fix the problem movement.
- Emotional excitement can also increase abnormal movements.
- Distraction can sometimes reduce abnormal movements.
- Abnormalities may follow certain patterns
  - Seizures tend to be long duration (>3 minutes), have closed eyes, or side-to-side head movements
  - Balance problems, usually fall towards support (wall, furniture, etc.) but don't actually fall down

FNDhope.org

Questions?



Treating FND: Basic Principles

The patient should:

1. Learn about about FND
2. Recognize that normal motion or strength can occur
   - Observe the tests that show normal motion or strength
3. Retrain the nervous system, perhaps by circumventing the dysfunctional nervous system networks. This may include distraction or addition of sensory input
4. Change things that trigger the nervous system to malfunction

(Park, 2024)

Treating FND

- A correct diagnosis of FND is essential.
- Patients have to understand and accept that this is a malfunction in the brain, but it is neither structural damage nor psychogenic.
  - Mind and Body are not separate: both are controlled by the brain!
  - It's a software problem.
  - It can be reversed, but requires work.
- Other conditions, such as HSD, also need to be managed.
- Retrain the brain:
  - Try to access automatic movements rather than conscious movement.
  - Try not to think about the abnormal movement or limb. Avoid internal focus. Don't try to force the limb to move or force the tremor to stop.
  - Increase sensory input to the body: compression clothing, braces, weights, taping.
  - Add external sensory input, such as music or visual input.

"Sensing FND: The role of the sensory system in the management of FND" presentation, Combined Sections Meeting, 2025

The Role of Distraction

- Distraction from the task at hand is a common component of treatment for FND
- It is NOT intended to trick the patient into demonstrating that they can move or control the limb
- It works by changing the neural networks involved in producing the movement, or bypassing dysfunctional neural networks
- It may be done by getting you to focus on something else, like not spilling a glass of water while you walk, or by getting you to talk or think about something engaging while moving.

Psychological Treatment

- Because FND can be aggravated by distress or strong emotions, psychological treatment may be a helpful component of management
  - Imaging studies show that strong emotions can influence motor control networks in the brain
  - Not all patients with FND have psychological contributing factors, so psychological treatment is not appropriate for some patients with FND
  - In general, people with Functional Seizures are most likely to benefit from psych treatment, FMD less so
  - However, having FND can be stressful, and sometimes it helps to have support dealing with the FND (and the challenges of the health care system)

Hallett, 2022; https://fndhope.org/fnd-guide/treatment/psychological/

Psychological Treatment

- Psychological treatments may include
  - Cognitive Behavioral Therapy to help provide coping skills to deal with the stress of having FND, as well as stress that may aggravate FND
  - Dialectic Behavior Therapy involves training in distress tolerance, emotional regulation, mindfulness and interpersonal skills
  - Specialized hypnosis treatment can be helpful
  - General relaxation and grounding skills may help calm the nervous system

Hallett, 2022; https://fndhope.org/fnd-guide/treatment/psychological/

Grounding Techniques

KEY POINTS

Grounding Sensory List:

- Sound: Turn on some music
- Touch: Grip a cold object
- Smell: Sniff essential oils
- Taste: Bite into something sour
- Sight: Take an inventory of everything around you

More Grounding ideas:

- Touch objects around you and describe them
- Make a fist and squeeze tightly then release - repeat
- Carry a small object to rub such as a smooth rock or cloth
- Run water over your hands or cool rag on your face
- Repeat the alphabet backward
- Count backward from 100 by 3's, 6's, etc.
- Repeat the lyrics of your favorite song
- Focused breathing

- Helps to ground you to the present moment
- Calms the nervous system
- Activates sensory system and sensory awareness
- May help bypass dysfunctional neural networks
- Relaxation training, such as deep breathing and meditation, can be helpful
- Relaxation and grounding require practice
- https://fndhope.org/wp-content/uploads/2023/04/Final-Print-FND-Hope-Patient-Booklet.pdf

Treatment Based on Clinical Presentation

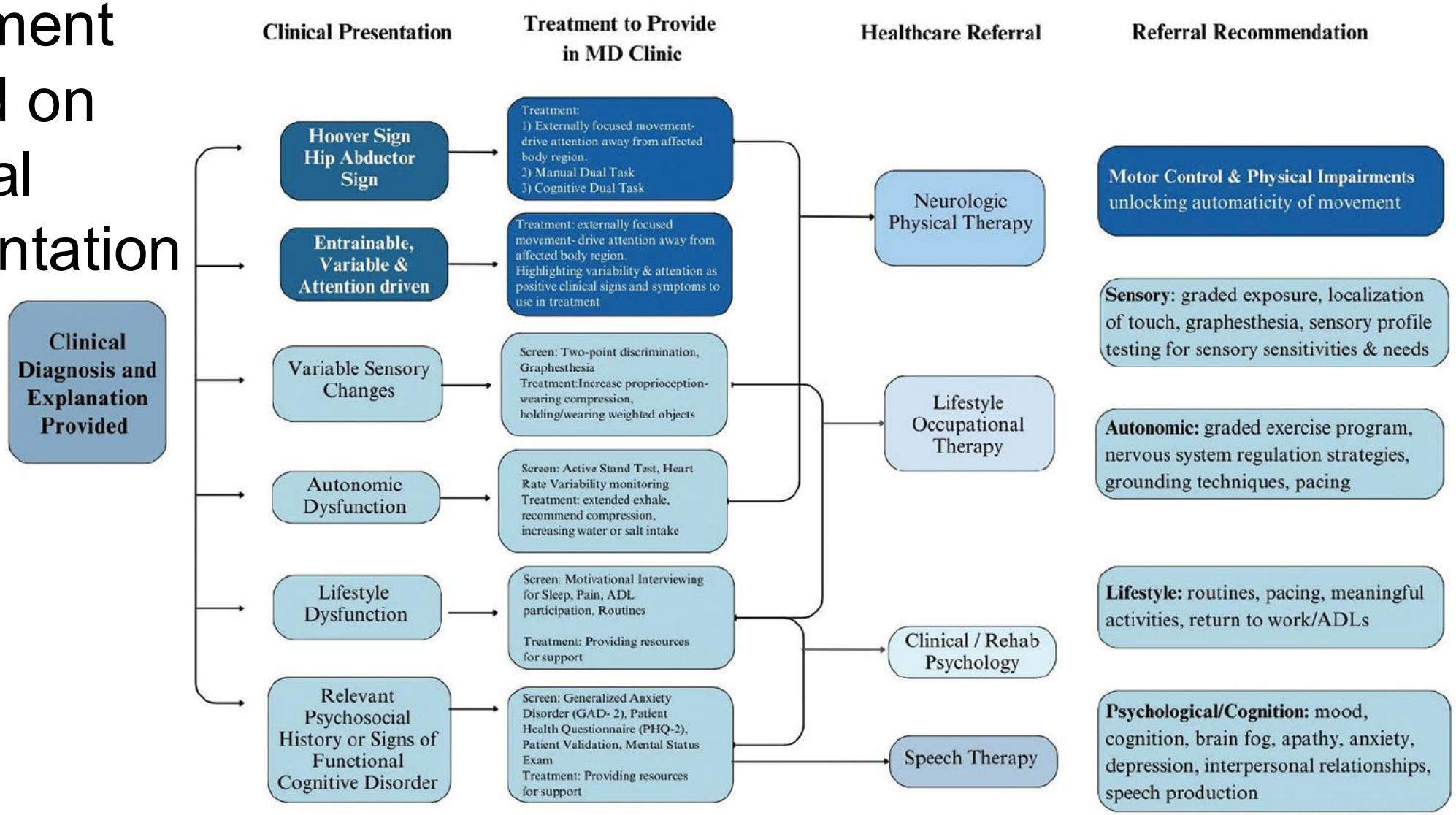


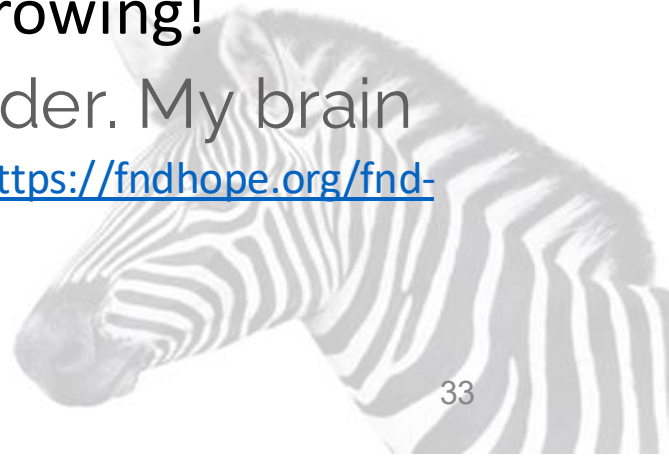
Figure. Decision-making framework to guide testing, screening, treatment, and referral.
Positive clinical tests include the Hoover sign, hip abductor test, and tremor entrainment test. Components of clinical presentation include variable sensory changes, autonomic dysfunction, lifestyle dysfunction, relevant psychosocial history, and signs of functional cognitive disorder.
Abbreviations: ADL, activities of daily living; MD, movement disorders.

How am I running when I can't walk?

- https://youtu.be/Y2kwQrhxttU?si=SawX5aZh0v69kLE3

Summary

- FND is a real condition where the nervous system malfunctions.
- Although stress and trauma can trigger or aggravate FND, it is NOT a purely psychological problem.
- It is NOT voluntary and patients have no control over the abnormal neural processing.
- It can be inconsistent, depending on which neural networks are being activated. This does not mean you are faking or it isn't real.
- There is a lot we still don't understand, but knowledge is growing!
- How to explain it to people "I have a neurological disorder. My brain does not send and receive messages accurately." (https://fndhope.org/fnd-guide/common-questions/)



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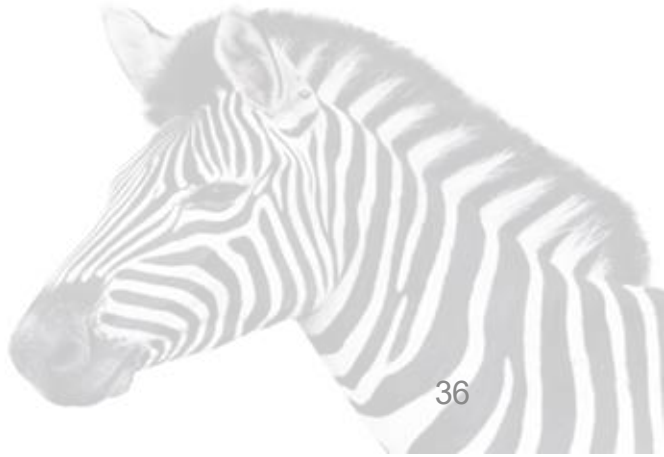
Web Resources

- FND Hope: https://fndhope.org
- FND Action: https://www.fndaction.org.uk
- NeuroSymptoms.org: https://neurosymptoms.org/en/
- FND self-care booklet: https://fndhope.org/wp-content/uploads/2023/04/Final-Print-FND-Hope-Patient-Booklet.pdf
- Video of the professional dancer with FND: https://youtu.be/9USepwToLqk?si=V_Qyc3B87D8Z4-Gz
- Short video explaining Functional Seizures: https://youtu.be/JnZQ_hojxOQ?si=8RLYtTn7Nl-azeZo
- Relationship between FND, EDS and POTS: https://youtu.be/ibVrh5-FGdY?si=zoEQVUc6hmGRts8h

Resources for Health Care Providers

- FND Society, multidisciplinary: https://www.fndsociety.org/membership
- FND Hope resources for Providers: https://fndhope.org/living-fnd/
  - Including handouts about FND to give your patients



Validated Tests for FND

Table 2 | Validated positive motor signs for FND (positive signs evaluated in one or more validation studies with a control group, as well as specificities and sensitivities, and with relevant reference from articles reporting on these signs)

	Positive sign	How to test	Evidence/populations tested	Reference	Note
General signs					
	Distractibility	Engage the patient in another motor or cognitive task and observe changes in the abnormal movement	In 19 functional stereotypies *v* 64 tardive dyskinesia; specificity 100%, sensitivity 58%	Baizabal-Carvallo 2017[45]	Validated in stereotypies but can be seen in all FND subtypes
	Variability	Observe changes during history taking/examination/arriving or leaving the examination room: periods of unexplained improvement/disappearance of symptom	In 19 functional stereotypies *v* 64 tardive dyskinesia; specificity 100%, sensitivity 84%	Baizabal-Carvallo 2017[45]	Validated in stereotypies but can be seen in all FND subtypes
	Convergence spasm	Instruct the patient to focus on your finger, 10 cm away from the face, at either extreme lateral gaze for 5 s. Move toward midline and observe the appearance of disconjugate gaze AND miosis	In 13 functional movement disorder, 11 "organic" controls, and 12 healthy: specificity 87%, sensitivity 15%. Good inter-rater reliability (κ 0.6)	Fekete 2012[46]	
	Eye movement abnormalities during examination	Systematically test for eye movements even in patients with no symptoms: a discordance between no visual complaint and abnormal findings can be seen (excessive blinking, effortful facial expression, increased latency, gaze deviation, limited range, absent frontalis contraction during upgaze)	In 101 FND patients 43% have abnormal examination	Teodoro 2019[47]	No "organic" control group
	Expressive behavior	Look for "expressive" behavior displaying disproportionate effort to the task during examination	In 20 FND *v* 20 "organic" controls, specificity 95%, sensitivity 55%. Good inter-rater reliability (κ 0.5)	Daum 2015[48]	Can be observed throughout the examination
Gait					
	Monoplegic leg dragging	The weak leg is "dragged" like a piece of wood/inanimate object, without spastic circumduction, usually along the floor surface	Validated in 2 studies; pooled specificity 100%, sensitivity 9%. Inter-rater reliability validated in 2 studies: Moderate to good inter-rater reliability (κ 0.4 to 0.7)	Daum 2015,[48] Stone 2010[49]	
	"Huffing and puffing" sign	Look for 6 behaviors; huffing, grunting, grimacing, breath holding, heavy breathing, crying. Rate each on severity 0 to 4 and duration 0 to 4	In 131 FND *v* 37 "organic" controls, when score ≥2: specificity 100%, sensitivity 44%. Moderate inter-rater reliability (κ 0.4)	Laub 2015[50]	
	Falls toward support	The patient tends to fall in the direction of support (wall, furniture)	In 20 FND *v* 20 "organic" controls; specificity 93%, sensitivity 19% Excellent inter-rater reliability (κ 0.8)	Daum 2015[48]	

Aybek, 2022
This table is 3½ pages long – lots more info

Thank You!

Questions?