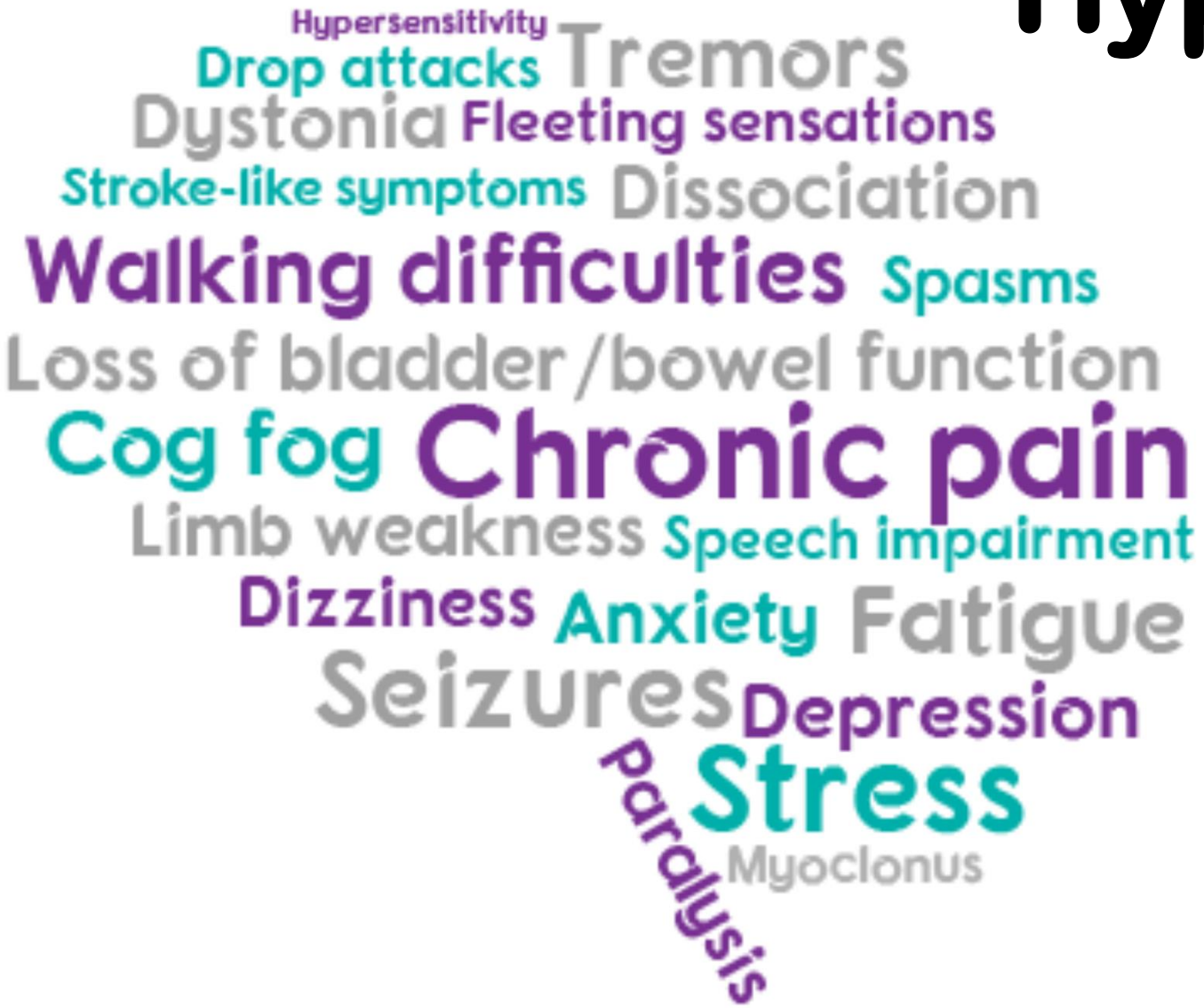


https://www.fndaction.org.uk/symptoms/

Hypermobility 115 Functional Neurological Disorder

& Functional Movement Disorders

Leslie N Russek, PT, DPT, PhD, OCS
Clarkson University

Who Am I?

- Professor Emeritus, Physical Therapy, Clarkson University.
- Staff PT, St. Lawrence Health System, Potsdam NY.
  - Clinical specialties: hypermobility, chronic pain, fibromyalgia, headaches, temporomandibular disorders
- Facilitator of the North America Allied Health Professionals ECHO
- Member of:
  - The Allied Health Working Group of the International Consortium of Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders
  - The National Academy of Sciences, Engineering and Medicine Committee on Selected Heritable Connective Tissue Disorders and Disability.
- Author of ”Chronic Pain” chapter in *Physical Rehabilitation* textbook for PT students
- Lrussek@Clarkson.edu
- https://webspace.clarkson.edu/~lrussek/
- I do free weekly Zoom lectures for people with HSD (see website)

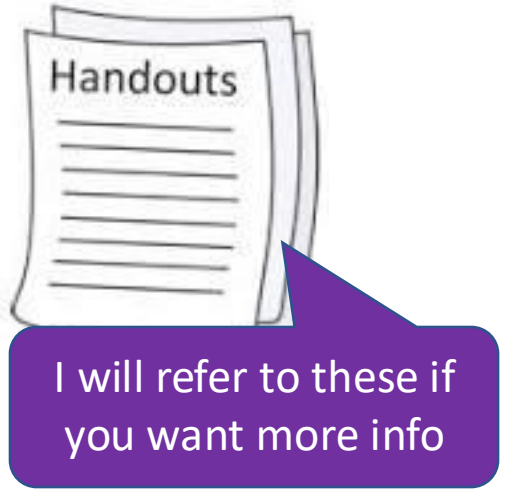
I do not have any conflicts of interest to report

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 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 (NEW)**

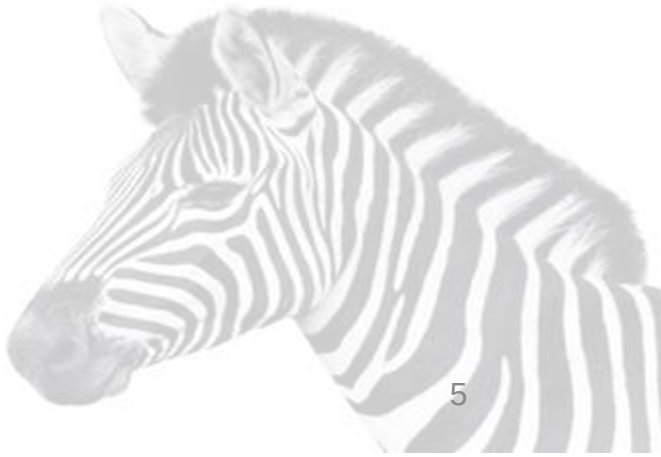
Relevant Handouts Available



- https://webspace.clarkson.edu/~lrussek/research.html
- **Overview of FND booklet**
  - https://fndhope.org/wp-content/uploads/2023/04/Final-Print-FND-Hope-Patient-Booklet.pdf
- **Exercise**
  - Sometimes exercises that tap into automatic movements (rather than deliberate movement) can bypass the faulty neural pathways in FND. Augmented reality games that you can play using your cell phone might be helpful.
  - Augmented Reality Activities for Fitness.

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:

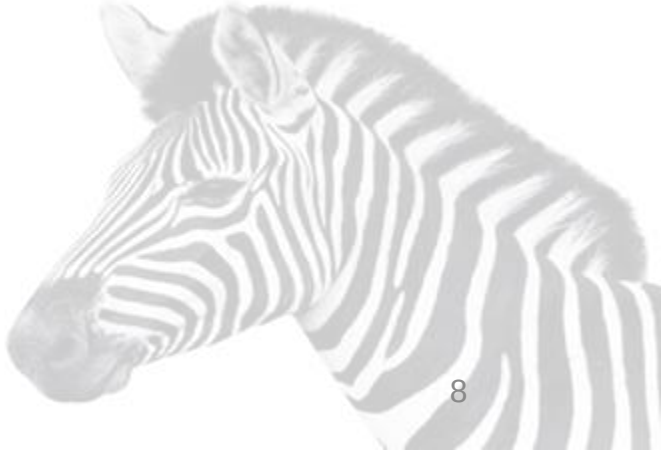
1. Describe what Functional Neurological Disorder (FND) can look like
2. Compare FND to a ‘software problem’ with a disconnect between sensory and motor functions of the brain
3. Explain the basic principle of diagnosis by finding inconsistencies in how the brain and body function
4. Explain how FND 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

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)
- 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)



What Does FND Look Like?

- Motor FND (Functional Movement Disorders – FMD)
  - Non-epileptic seizures or uncontrolled muscle twitching
  - Variable movement problems such as 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

https://fndhope.org/fnd-guide/symptoms/

Features of FND

- Sudden onset of symptoms (70%)
- Anxiety (52%)
- Fatigue (45%)
- Pain (42%)
- 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

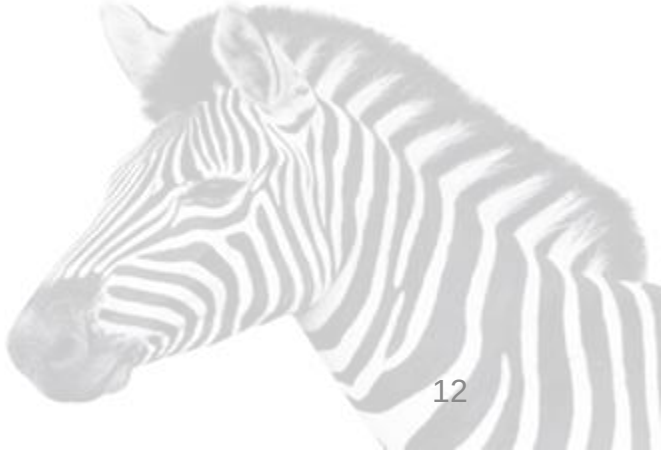
- Physical
  - Being female
  - Genetic and epigenetic risk factors (‘epigenetics’ is where lifestyle factors influence which of your genes become active)
  - Neurological conditions such as epilepsy, Parkinson’s, multiple sclerosis
  - HSD and hEDS! Especially in those with upper cervical instability
  - Virus or infection
  - Trauma 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 or a panic attack

(Hallett, 2022)



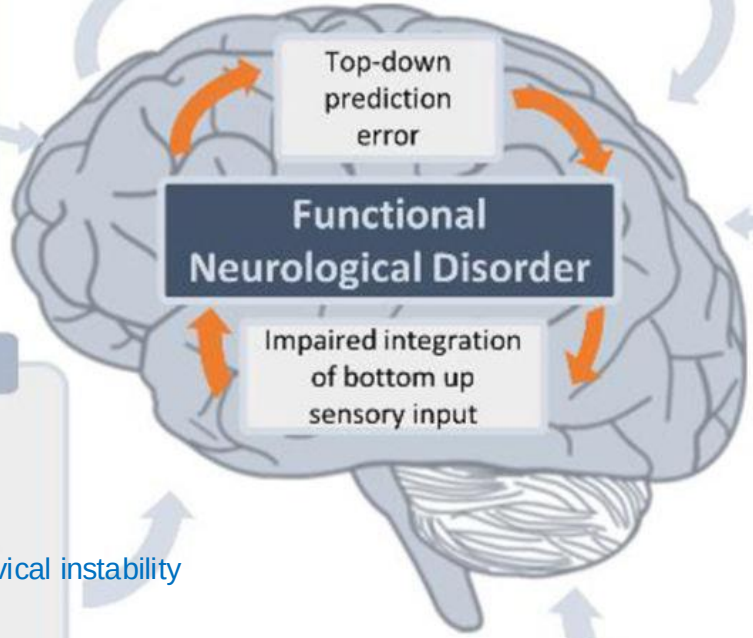
2 Precipitating Factors

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
Psychological disorders/Stress
Anxiety/Depression
Stressful live events
Childhood Adversity
Genetic risk factors
Sometimes NO vulnerability

EDS, Cervical instability

Partial or No Recovery

6 Outcome

Recovery

Normal Re-Adaptation

5 Treatment

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

Hallett, 2022

A Brief Story about FND

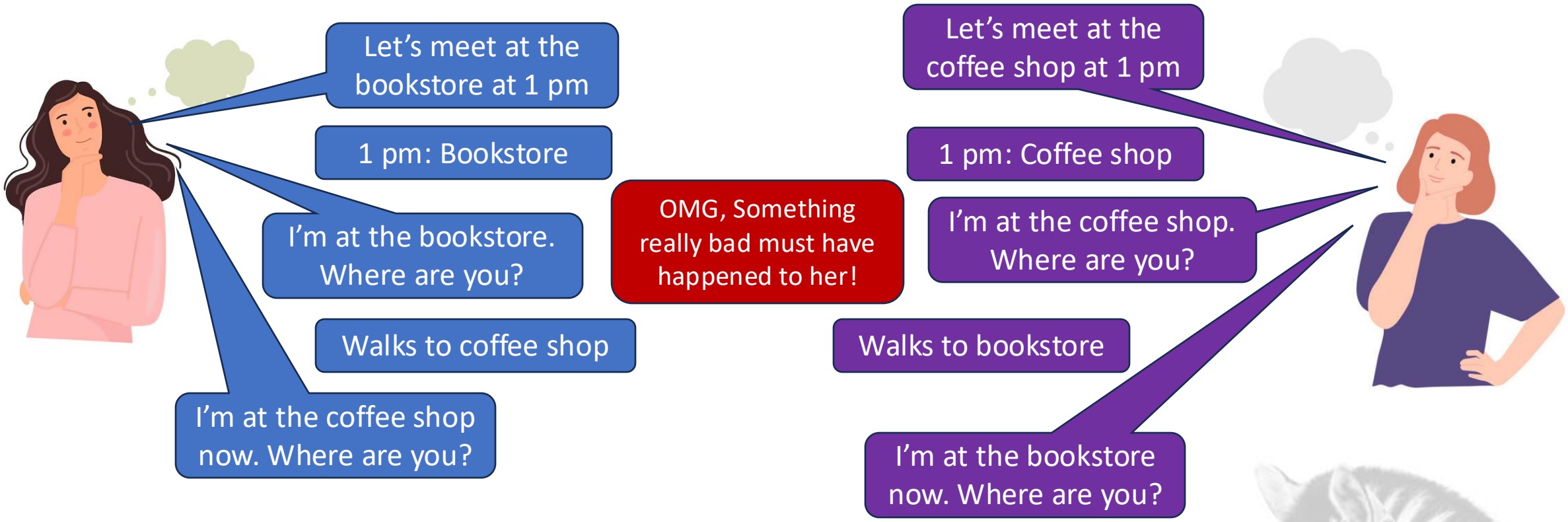
https://youtu.be/9USepwToLqk?si=V_Qyc3B87D8Z4-Gz

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
  - Slowed sensory processing may lead to this mismatch – perhaps poor proprioception & interoception
- 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

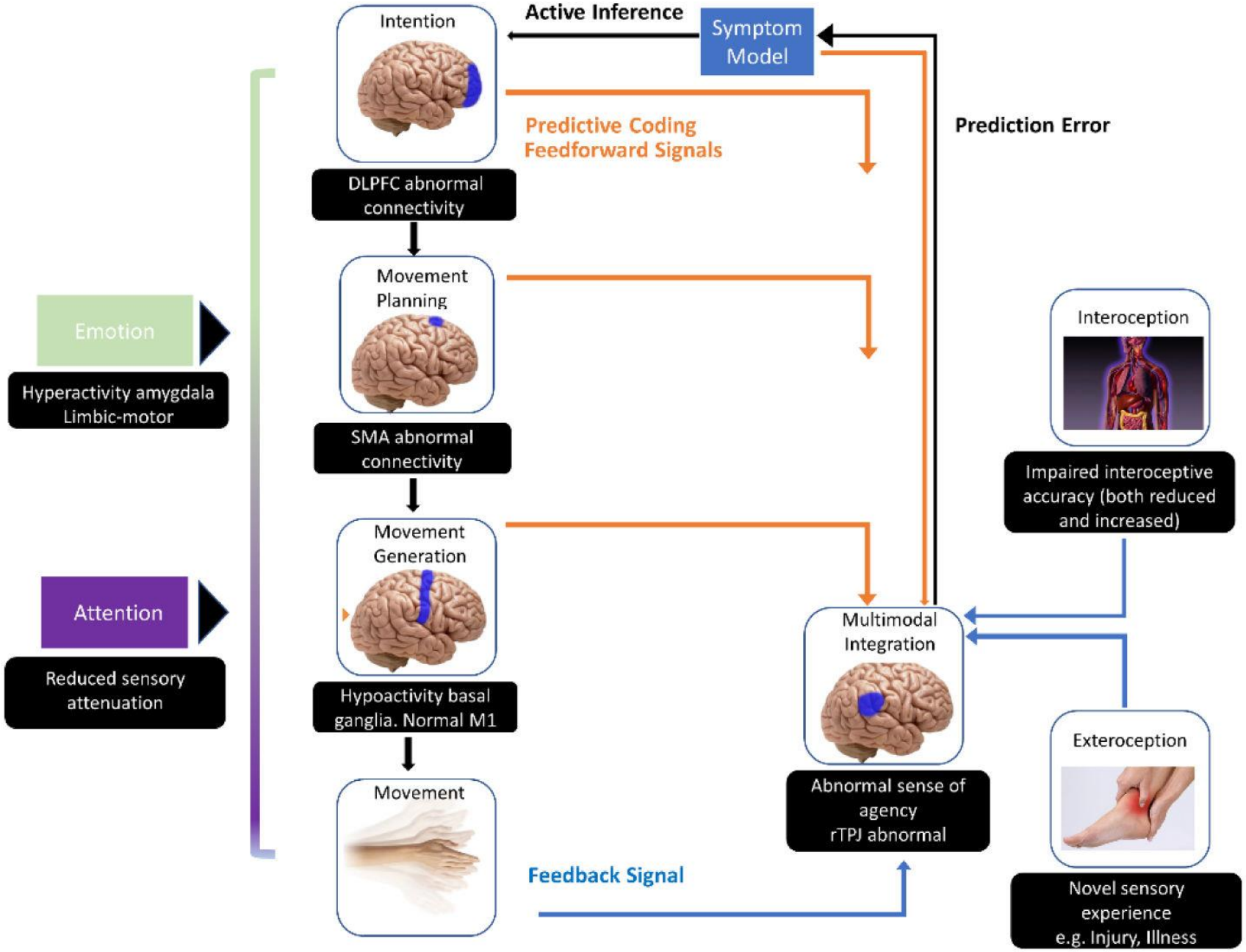


- But, in the brain, this miscommunication occurs in fractions of a second, and can lead to tremor, wobbling movement, or inability to move.
- Or, the mismatch between what the brain perceives and expects can lead to a 'danger' signal that triggers pain.

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



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)

Hallett, 2022

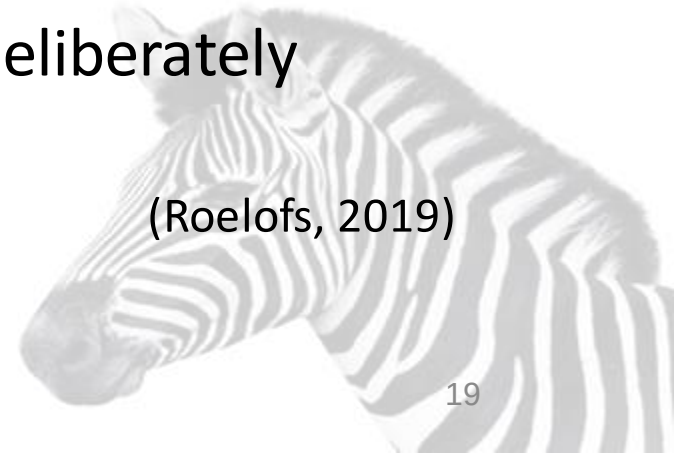
Pathology in FND

- 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
- 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

Aybek, 2022

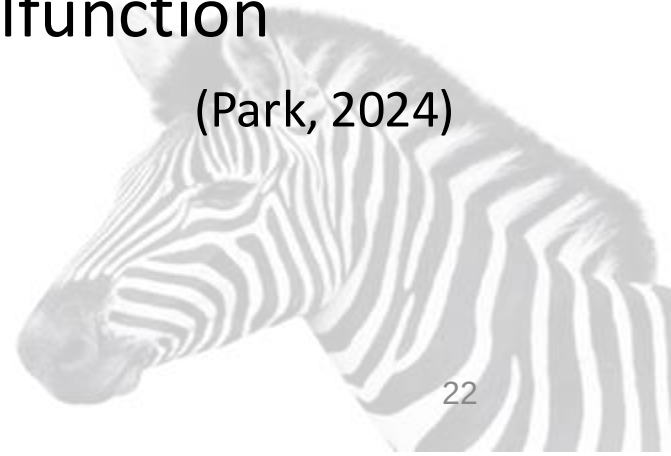
Characteristics of FND/FMD

- 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

Treating FND: Basic Principles

1. Learn about about FND
2. Recognize that normal motion or strength can occur
    1. 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 needed
- 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, need to also 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 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 a treatment program
  - 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
  - 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)
- 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

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

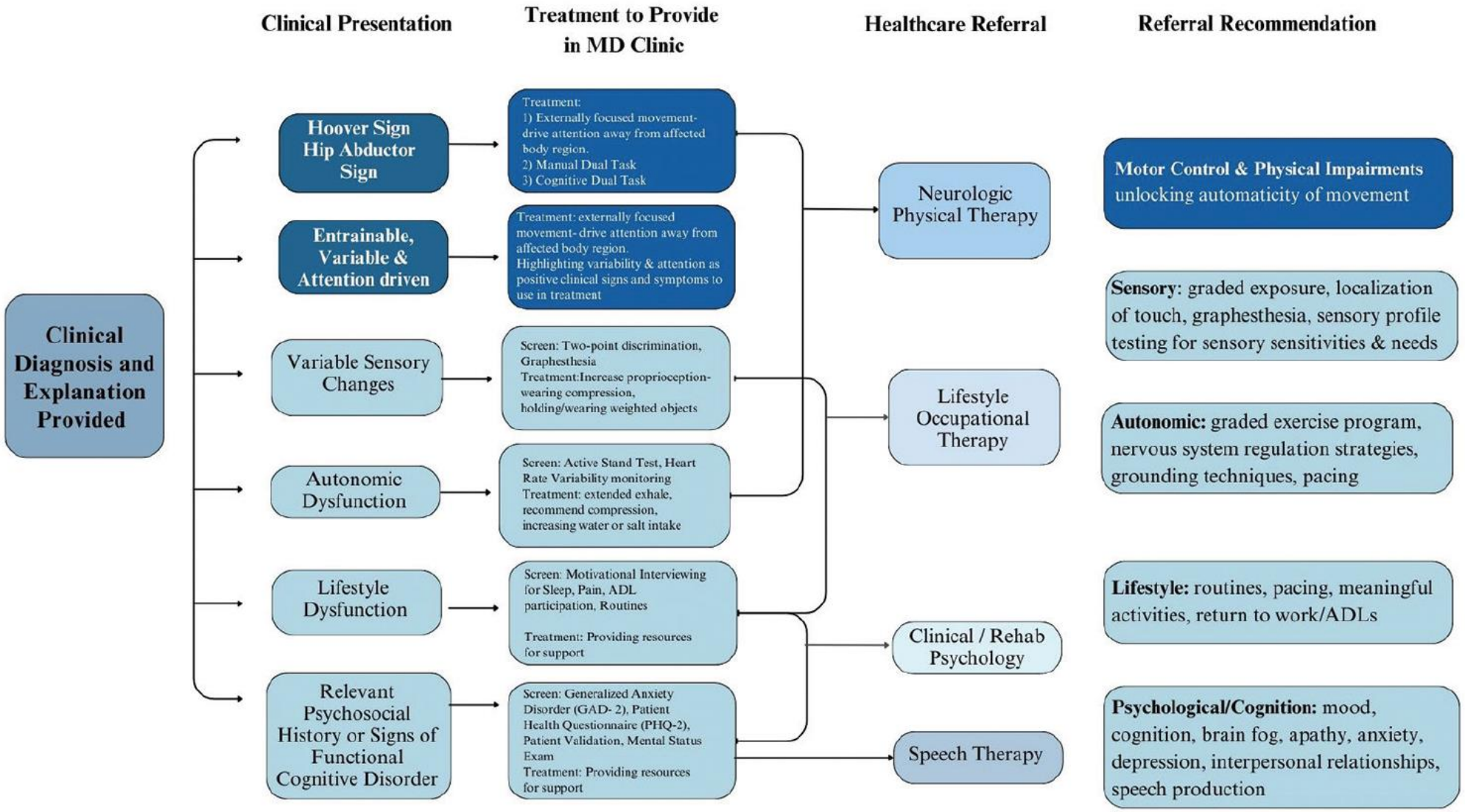


Figure. Decision-making framework to guide testing, screening, treatment, and referral.
Positive clinical tests include the Hoover sign, hip abductor test, and tremor entrainment test. Components of clinical presentation include variable sensory changes, autonomic dysfunction, lifestyle dysfunction, 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://player.vimeo.com/video/149937489?dnt=1&app_id=122963

Summary

- FND is a real condition where the nervous system malfunctions.
- How to explain it to people "I have a neurological disorder. It is when the brain does not send and receive messages accurately." (https://fndhope.org/fnd-guide/common-questions/)
- 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!

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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=z0EQVUc6hmGRts8h

Resources for Health Care Providers

- FND Society, multidisciplinary: https://www.fndsociety.org/membership

Thank You!

Questions?