Functional Neurological Disorders – Empowering Clinicians in Multidisciplinary teams to meet the need

Victorian Paediatric Rehabilitation Service

Monash Children's Hospital

VPRS Victorian Paediatric Rehabilitation Service

Today's facilitators

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Victorian Paediatric Rehabilitation Service VPRS

What is FND? The Neurobiology

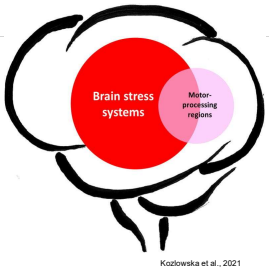
Learning Objectives

- To understand FND as:
  - a disorder of brain network function
  - a positive diagnosis rather than exclusionary

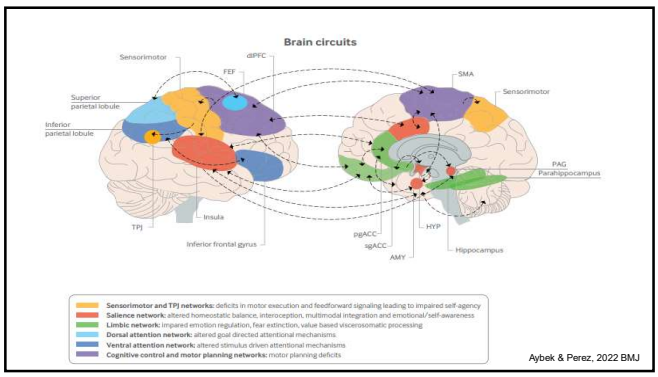
What is FND?

Altered function of brain networks due to biopsychosocial factors

Loss of voluntary motor or sensory control without underlying structural damage



Kozlowska et al., 2021



Shift in Diagnostic Paradigm

Diagnosis of exclusion

Diagnosis of inclusion

Common Positive (rule-in) Neurological Signs Found on Physical Examination in Children with Functional Motor & Sensory Symptoms (Mohammad & Kozlowska, 2022)

Neurological symptom	Neurological sign that the Neurologist may use to support a dx of FND
Across symptoms	• Variability • Improve with distraction • Worsen with attention
Gait difficulty	• Non economical gait • Fall towards support
Weakness (generalised or partial)	• Discordance between strength or functional ability • Limb weakness not conforming to an anatomical distribution
Tremor	• entrainment
Sensory symptoms (pain excluded)	• Sensory sx not conforming to a dermatomal distribution
Visual loss	• Tunnel vision • Preserved response to a "menace reflex" (the rapid approach of an object)

Sensitivity and Specificity of Signs

- High specificity was found for:
  - Variability
  - Distractibility
  - Give way weakness
  - Non economical gait
  - Entrainment with tremor
  - Fall towards support

(Aybek & Perez, 2022)

Demographics

2.3-4.2 per 100,000
Children & adolescents

Mean age
11.8 years

Male : female – pre-puberty
~50/50

Male : female – overall
71% girls

Kozlowska et al., 2007

Review of Acute Admissions for FND Referred to Physiotherapy at Monash Children's Hospital

	2018/19	2020/21
Overall	16	56
Patients on LGBTQI+ spectrum	2	15

Data collected by Fiona Barton - Physiotherapist

Demographics in Adults

Mixed FND
- 4-12/100 000 population per year

Motor FND (abnormal movements and weakness)
- 4-5/100 000 per year

Seizure type FND
- 1.5-4.9/100 000 per year

Prevalence of FND in international neurology outpatient clinics -
- up to one-third of patients.

(Selma Aybek & Perez, 2022)

Demographics in Adults – Aus /NZ

- "74% of 152 general practitioners based in the New South Wales Hunter Region reported seeing patients with "neurological symptoms due to somatisation" at least monthly in a 2021 survey"
- One published Australian neurology clinic series reported FND in 15% of patients.
- About 8% of acute stroke admissions may be due to FND
- FND represents 9% of neurology hospital admissions in New Zealand

(Selma Aybek & Perez, 2022)

Demographics in Adults – Aus /NZ

- In primary care
  - 2021 - "74% of 152 general practitioners based in the New South Wales Hunter Region reported seeing patients with "neurological symptoms due to somatisation" at least monthly
- In specialist clinics
  - published Australian neurology clinic series reported FND in 15% of patients.
- Inpatient setting
  - About 8% of acute stroke admissions may be due to FND
  - FND represents 9% of neurology hospital admissions in New Zealand

(Pepper et al, 2022)

Case Study - 'Jordan'

16 year old male with a diagnosis of FND, presenting with:

- Wheelchair bound due to weakness and legs "collapsing"
- Generalised joint pain
- Fatigue
- Tics and non-epileptic/functional seizures

The Role of the Multidisciplinary Rehabilitation Team

Learning Objectives

- Decide when inpatient vs outpatient intensity is required
- Describe the role of each of the MDT members

Evidence for rehab approach

In Paediatrics

In a recent review:

- Usual Care (n = 214) - 33% full remission
- CBT (n = 72) approaches - 59 – 63% full remission
- MDT rehab - Prospective (n = 242) & retrospective (n = 86) studies - 63 – 95% full remission

(Vassilopoulos, 2022)

In Adults

Recent review in BMJ 2022 highlighting multidisciplinary input of benefit

Eg. Reference to RCT in an MDT rehab setting (n=60)
Significant sustained improvement in gait and qol

(Aybek, Perez 2022)

Rehab Programs for FND

Biopsychosocial Assessment

Focus on Function

"Functional neurological disorders are a neglected but *potentially reversible* source of disability"

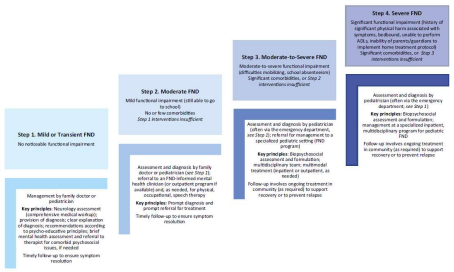
Espay et al., 2018, *JAMA Neurology*

Multidisciplinary Intervention

Post-Discharge Planning

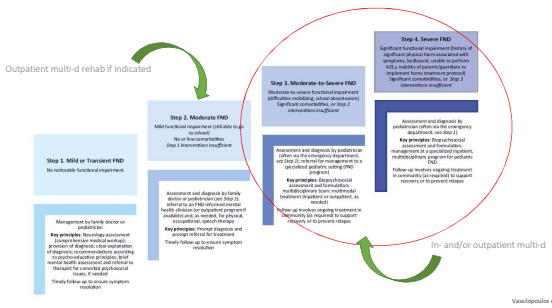
Vassilopoulos et al., 2022

Where does Rehab come in?



Vassilopoulos et al., 2022

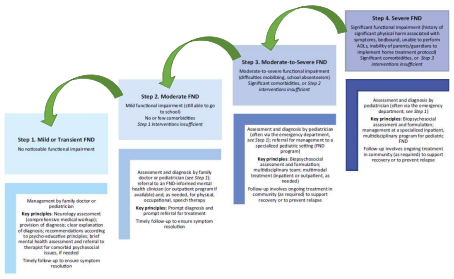
Where does Rehab come in?



Vassilopoulos et al., 2022

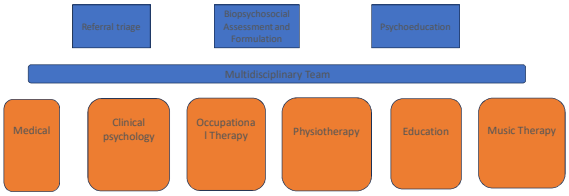
...and beyond?

Step-down to longer-term therapeutic support in community, with likely increased focus on mental health as somatisation decreases



Vasiliopoulos et al., 2022

Overview of where the MDT sits within the rehab process



Explaining the diagnosis – the importance of language

Learning Objectives

- Be able to confidently explain FND in a variety of ways to support your patient's understanding

Talking about FND – *An Example*

Talking about FND – *An Example*

Diagnosis and Language

We may not feel like experts...

... but you're more of an expert than you think!

Using "expert" language from the start can positively impact patient outcomes

Tips and tricks

- Ensure the whole team uses similar language
- Ensure the whole team is comfortable explaining the diagnosis and their role in treatment
- Use language that does not offend
- Use language suitable for the whole family

Diagnosis and Language

Set expectations early

Use positive language that strengthens the therapeutic relationship and enables the patient to understand and accept their diagnosis

Find a balance between validating symptoms and avoiding over-focusing on symptoms

Give a clear and unambiguous diagnosis

Encourage opportunities for questions

(Kozlowska et al., 2021; Pepper et al., 2022; O'Neal et al., 2021)

Tips for Talking About FND

To Convey Confidence and Reassure

- 'What we see with other patients is...'
- 'You've come to the right place'
- 'This is a known diagnosis that we see all the time'
- 'Your symptoms are real'
- Use the term "functional" rather than *psychogenic* or *conversion* or *pseudo-*
- Use metaphors and link to common experiences (like butterflies in your stomach)

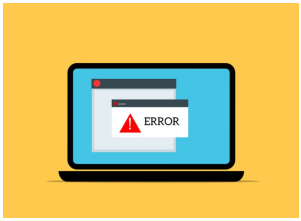
Introducing the Mind-Body Connection

(Krasnik, 2013; Kozlowska et al., 2021)

Case Study - 'Jordan'

The Use of Metaphors

Hardware vs Software



Traffic Light Intersection Metaphor to Explain Motor Disturbance

Visual Metaphor to Explain the Activation of Stress Systems

(Kozlowska et al., 2021)

Case Study - 'Jordan'

Break out session – Practising the language

- Practice explaining what FND is using medical language
- Practicing explaining what FND is using metaphors
- Practice explaining the role of your discipline

MDT assessment

Learning Objectives

- List key components of an initial history taking of a patient with FND
- List key components of an initial objective assessment- medical, physical, occupational and psychological
- Deliver FND psychoeducation

Role of the Doctor – Medical Containment

- Ensuring your comfort with the diagnosis
- Confirming the rule in signs
- Remembering that comorbid conditions can occur - eg. neurological (seizures), mental health, neurocognitve etc
  - Balance between chasing multiple opinions and investigations by the family – and potential medical harm
  - If new symptoms arise – review on their merit – there may be more functional symptoms, or they may not be
  - Joint consults with other clinicians can be helpful if uncertainty

Medical Assessment

- Be thorough with listening to all symptoms
- This itself is therapeutic (as people have often been disbelieved)
- Note possible triggers and relieving factors
- Review
  - Sleep disturbance
  - Fatigue
  - Pain
  - Concentration issue

  As these symptoms are common and can impact function and contribute to disability and may need additional management

Pit Falls

- Failure to consider comorbidity of another medical condition
  - Other functional disorders (such as irritable bowel syndrome and chronic pain syndromes) are common.
  - Comorbid neurological conditions occur in approximately 20% of cases;
- Reliance on unusual clinical features
  - Don't Dx just because there is an unusual sign – look for the positive rule in signs
- Diagnosis based on psychiatric features / recent stress
- Reliance on normal investigations
  - Many neurological conditions may have normal structural imaging.
- Misinterpretation of abnormal investigations
  - Incidental findings

(Bennett et al, 2021)

Collating History

Key strategies of history and examination:

- Rapport, unburden the patient and gain trust
- Explain the examination and the role of attention / distraction
- Co-construct the formulation with the family
  - Ask what has been done so far, what have they been told
  - Aiming for agreement

Physical Objective Assessment

- Gait- different speeds, with cognitive distraction, on heels, toes, with purpose
- Transitions- onto and up the bed, on/off floor
- Games eg balloon tapping sitting over edge of bed

Positive Physical Clinical Features

Functional Limb Weakness

- Hoover's Sign (figure a)
- Hip Abductor Sign (figure b):

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Functional Tremor

Tremor Entrainment (refer to figure above): If, when the patient copies the examiner's rhythmical movement of thumb & forefinger with their better side & the affected side functional tremor ceases during the entrainment test, distractibility is demonstrated

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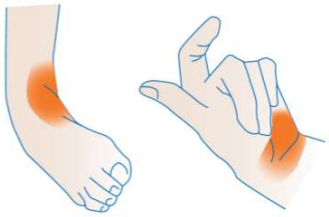
Functional Dystonia

Typically presents with a fixed position, usually a clenched fist or inverted ankle - This is different to other types of dystonia which are usually mobile



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The Initial Psychology Assessment

- Detailed medical and developmental history
- Family genogram (tree)
- Timeline of family life events

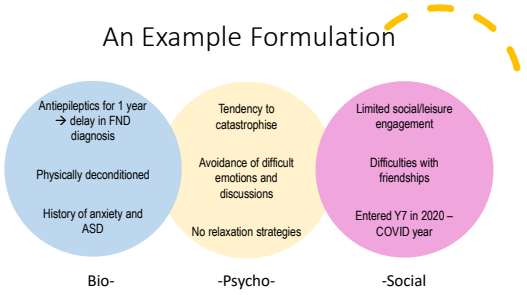
Outcome Measures

- Children's Global Assessment Scale (CGAS)
- Global Assessment of Functioning (GAF) Scale
- Child Health Utility 9D (The University of Sheffield)
- Strength and Difficulties Questionnare (SDQ)
- The WeeFIM
- Canadian Occupational Performance Measure (COPM)

Biopsychosocial Formulation

Factors	Biological	Psychological	Social
Factors acting at all stages	• 'Organic' disease • Hx of previous functional sx	• Emotional disorder • Personality disorder	• Deprivation • Life events & difficulties
Predisposing vulnerabilities	• 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 • Sx modelling of others
Precipitating mechanisms	• Abnormal physiological event/state • Physical injury/ pain	• Perception of events as negative • Acute dissociative episode • Panic attack	• Varied – e.g., relationship rupture, bullying…
Perpetuating factors	• Plasticity in CNS motor & sensory pathways leading to habitual movement • Deconditioning • Neuroendocrine & immunological abnormalities like in depression & anxiety	• Illness beliefs • Perception of sx as being irreversible • Not feeling believed • Perception that movement causes damage • Avoidance of sx provocation • Fear of falling	• Social benefits of being ill • Availability of legal compensation • Ongoing medical investigations • Info reinforcing irreversibility of sx

An Example Formulation



An Individualised Treatment Plan

Adapted from © Kasia Kozlowska 2022

Identified Issues	Treatment Intervention
Sleep disturbance	Sleep intervention to regulate the circadian clock
Attention to symptoms	Focus-of-attention intervention with patient, family, & school
Activated stress systems	Implement regulation strategies to calm the stress system
Disrupted motor function	Psychologically-informed physical therapy
POTS (& associated dizziness)	Good fluid & salt intake, tight leggings, & regulation strategies
Rumination & catastrophising	CBT intervention
Unresolved grief	Grief intervention
Academic stress	School liaison & intervention
Family stress/conflict	Implementation of psychoeducation to parents & referrals to appropriate services (e.g., external psychology referral for parent(s)/sibling(s) &/or referral to a family therapy service
Anxiety/depression	CBT intervention, consideration of Psychiatry consult if an SSRI trial is worth exploring, & referral if required

Break Out Session - Assessment of Jordan

JORDAN HAS COME IN FOR A MULTIDISCIPLINARY ASSESSMENT

WHAT QUESTIONS WOULD YOU LIKE TO ASK HIM?

Case Study - 'Jordan'

Key findings from MDT Assessment:

Social:
- Home with mum and pet bunnies
- Mum has upcoming surgery which will limit her capacity to help
- Maintaining contact with friends but difficult to see them currently

School:
- Difficulty getting to school due to fatigue and lack of support around ASD - keen to change schools
- Continuing TAFE weekly

Function:
- Wheelchair bound, completing independent pivot transfers
- Independent personal care, however requires assistance for shower transfers
- Only in bed for sleeping, otherwise in wheelchair or on couch
- Sleeping 12-13 hours overnight (12am-1pm), plus up to 2-3 hours of napping per day with poor sleep hygiene

Other Symptoms:
- Physical and cognitive fatigue
- Pain
- Motor ticks

Break Time

Preparing for rehabilitation

Learning Objectives

- Understand what strategies to implement to maximise the success of intervention

Preparing for Rehabilitation

- Goal setting
- Determine the best setting for rehabilitation
- Discuss expectations
- Provide FND resources
- Implement strategies to maximise success

Goal Setting

Set *functional* goals

Start with bigger goals, which can be further broken down by different disciplines

Determine the Best Setting for Rehabilitation

Inpatient vs Outpatient

- Severity and length of symptoms
- Supports at home and ability to manage at home
- Competing demands or ability to get to appointments
- Intensity of therapy required
- Number of professions required
- Time away from school/work

Discuss expectations

- LENGTH OF THERAPY
- PARTICIPATION EXPECTATIONS
- SCOPE OF YOUR SERVICE
- HOMEWORK

Provide FND Resources

MANUAL

WEBSITES

Implement strategies to maximise success

(FND Australia, 2019)

Group Session – preparing for rehabilitation

Case Study - 'Jordan'

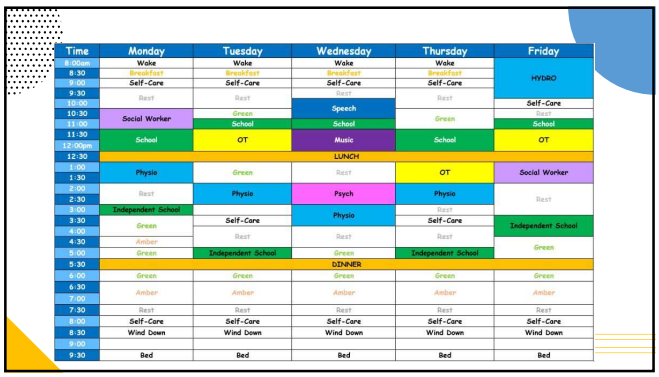
Goals:

- To return to walking
- To manage my fatigue so that I don't need to sleep during the day
- To build routine and a healthy sleep pattern
- To shower independently
- To spend more quality time with my friends
- To be able to sleep in my loft bed in my room

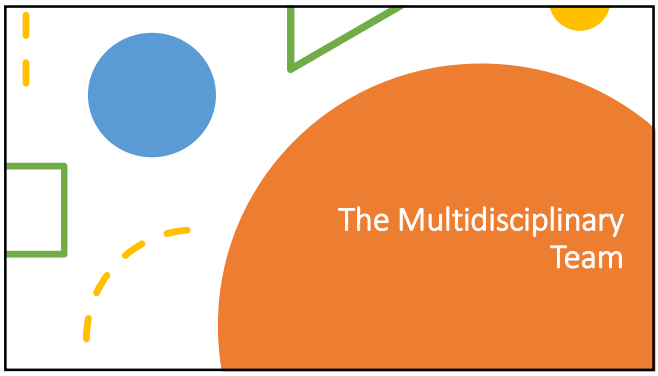
Break out session - Preparing for rehabilitation

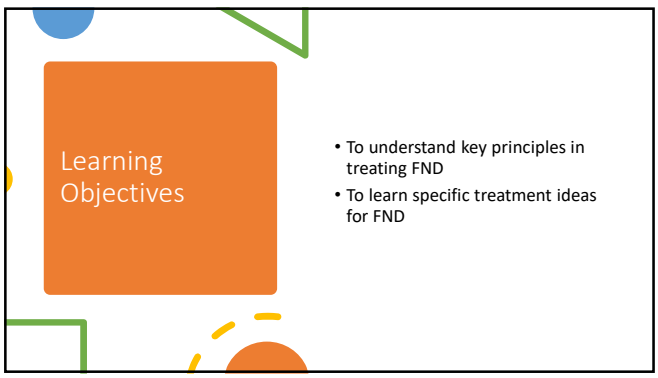
- Would you do an inpatient or outpatient block of therapy with Jordan? Why?
- What expectations would be appropriate to set with Jordan?
- Are there any strategies Jordan would benefit from?

Case Study - 'Jordan'



Time	Monday	Tuesday	Wednesday	Thursday	Friday
8:00am	Wake	Wake	Wake	Wake	HYDRO
8:30	Breakfast	Breakfast	Breakfast	Breakfast	
9:00	Self-Care	Self-Care	Self-Care	Self-Care	
9:30	Rest	Rest	Rest	Rest	Self-Care
10:00			Speech		Rest
10:30	Social Worker	Green		Green	
11:00		School	School		School
11:30	School	OT	Music	School	OT
12:00pm					
12:30	LUNCH				
1:00	Physio	Green	Rest	OT	Social Worker
1:30					
2:00	Rest	Physio	Psych	Physio	Rest
2:30					
3:00	Independent School		Physio	Rest	
3:30	Green	Self-Care		Self-Care	Independent School
4:00		Rest	Rest	Rest	
4:30	Amber				Green
5:00	Green	Independent School	Green	Independent School	
5:30	DINNER				
6:00	Green	Green	Green	Green	Green
6:30	Amber	Amber	Amber	Amber	Amber
7:00					
7:30	Rest	Rest	Rest	Rest	Rest
8:00	Self-Care	Self-Care	Self-Care	Self-Care	Self-Care
8:30	Wind Down	Wind Down	Wind Down	Wind Down	Wind Down
9:00					
9:30	Bed	Bed	Bed	Bed	Bed





Case Study - Jordan

The Role of OT & Physio

- Educate
- Build trust
- Psychologically informed physical therapies
- Demonstrate and retrain normal movement
- Change maladaptive behaviours
- Focus on function and maximising this
- Guide away from dependence and the sick role
- Prevent or treat secondary complications

(Nielsen et al., 2015; Nicholson et al.

Strategies for OT & Physio

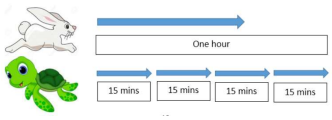
- Distract, but don't *trick* the patient
- Encourage early weight bearing
- Offer choice
- Utilise the patient's existing capabilities
- Normalise pain/discomfort and fatigue
- Reinforce strategies used by the multidisciplinary team
- Graded and progressive exercises
- Attend therapies alone
- Highlight inconsistencies (*if appropriate – pick your patients)*
- Routine
- Make it fun!
- Goal ladder

(Nielsen et al., 2015; Nicholson et al.

Treatment Ideas

- Visualisation
- Early weight bearing
  - Floor exercise, sitting and reaching with feet on the floor, four-point kneeling
- Facilitation "automatic" movement patterns
- Utilise what they have
  - Pull to stand or into high kneeling
  - Standing/stepping with good leg
  - Crawling with fingers
- Hydro
- Fitball
- Obstacle courses
- Trampoline
- Reducing support
  - Finger tips on wall, hoola hoop

Pacing Strategies



Treatment Examples

Treatment Examples

Treatment Examples

Treatment Examples

Strategies to avoid:

- "Hands on"
- "Perfect Practise"
  - (Function doesn't need to look perfect!)
- Over-medicalising condition
- Focus on specific symptoms
- Placing too much pressure on the patient
- Adaptive equipment
- Secondary gain

When you need to use adaptive equipment...

- Be transparent in your reasoning
- Restrict use of adaptive equipment
- Have a clear weaning plan
- Wean as soon as possible
- Avoid excessive assistance

Managing Falls

- Often present as either slumps or controlled descents
- Explain safety boundaries to the patient (e.g., "I can't catch you")
- Set up the environment to allow the patient to fall
- Clinical judgement is required when falls are no longer safe to accept
- Consider floor or pool work when falls are frequent or heavy
- Avoid secondary gain
- Follow the falls protocol at your place of employment

Case Study - Jordan

To be able to kneel from the floor

Able to pull myself to standing

Able to stand with only 1 hand

Able to stand by yourself without holding on

Able to stand in the rails and take 2 steps

RED ACTIVITIES

AMBER ACTIVITES

GREEN ACTIVITIES

Time	Monday	Tuesday	Wednesday	Thursday	Friday
8:00am	Wake	Wake	Wake	Wake	HYDRO
8:30	Breakfast	Breakfast	Breakfast	Breakfast	
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9:30	Rest	Rest	Rest	Rest	Self-Care
10:00		Green	Speech		Rest
10:30	Social Worker	School	School	Green	School
11:00	School	OT	Music	School	OT
11:30	LUNCH				
12:00pm					
12:30					
1:00	Physio	Green	Rest	OT	Social Worker
1:30	Rest	Physio	Psych	Physio	Rest
2:00					
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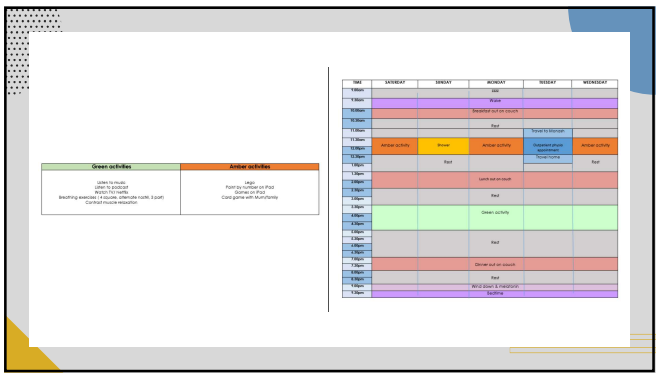
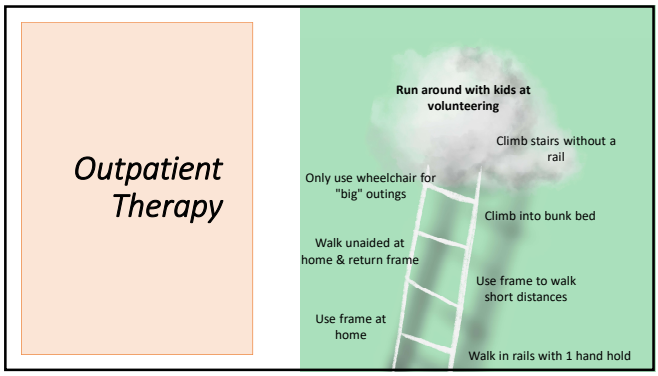
3:00	Green	Self-Care		Self-Care	Independent School
3:30	Amber	Rest	Rest	Rest	Green
4:00	Green	Independent School	Green	Independent School	
4:30	DINNER				
5:00	Green	Green	Green	Green	Green
5:30	Amber	Amber	Amber	Amber	Amber
6:00	Rest	Rest	Rest	Rest	Rest
6:30	Self-Care	Self-Care	Self-Care	Self-Care	Self-Care
7:00	Wind Down	Wind Down	Wind Down	Wind Down	Wind Down
7:30					
8:00					
8:30					
9:00					





Music Therapy

Role of MT:

- Decrease distress/anxiety
- Emotional Expression
- Support identity formation; "Well self"
- As a motivator for functional rehab goals
- Promote healthy uses of music (for sleep, relaxation, creative outlet)
- Skill development
- Support engagement in the creative arts as a therapeutic outlet and form of social engagement

Music Therapy Techniques

- Music listening
  - Lyric analysis
- Play list creation (healthy uses of music)
  - Relaxation Play list
  - Desert Island Playlist
  - Coping Play lists
- Therapeutic music lessons (e.g, guitar, keyboard, singing)
- Song writing
- Instrumental play and improvisation (for emotional expression and regulation)
- Joint MT & PT/OT/SP sessions
- Music and Imagery sessions
- Relaxation Sessions

How can you incorporate the arts?

- Enquire as to what creative pursuits the young person engages in
- Does the young person like; music, art, dancing, nature?
- The arts can be a useful low impact tool for recovery

- **MUSIC BASED QUESTIONS**
- Has the young person ever played an instrument?
- Would the young person like to commence learning one?
- How are they listening to music at the moment?
- What music do they like?
- Is music a useful resource for them?
- Would do they have their own playlists? Consider mood based playlists.

Speech Therapy

- May present with functional communication problems, swallowing disorders, cough, & upper airway symptoms
- The Speech Therapist prioritises rapport building & the creation of a therapeutic space where the patient feels safe to detail the circumstances they recall being associated with the onset of their functional voice disorder

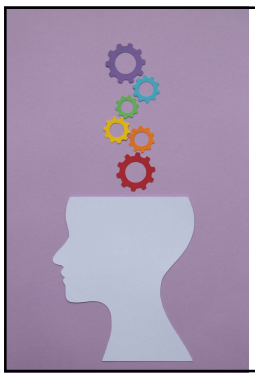
(Baker et al., 2021; Kozlowska et al., 2021)

Positive Clinical Features of Functional Communication & Swallowing Disorders

Positive clinical signs of FND	General examples in functional communication & swallowing disorders
Symptoms are inconsistent with clinical examination & laboratory/imaging findings	• Severity of speech deficit is disproportionate to severity of injury or locus of lesion • Total or partial loss of voice despite normal structure & function of vocal folds during laryngoscopy
Symptoms are internally inconsistent	• Resolution or reduced severity during small talk or other spontaneous discussion, when attention is diverted, or during natural automatic functions, preverbal &/or automatic utterances, playful, emotionally expressive activities, during laryngeal manipulation (voice disorders) • Suggestibility (e.g., the symptom becomes significantly more prominent whilst being discussed)
Symptoms are associated with inefficient & non-ergonomic patterns of movement	• When weakness is major complaint, speech, voice, swallowing fatigues in the direction of muscle hyperfunction • Struggle behaviours – Overmouthing, eye blinking, facial contortions, excessive effort in breathing, neck, shoulders, strap muscles, shifts in body posture – including during non-speech oromotor tasks

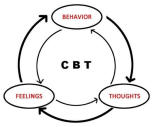
Adapted from Baker et al. (2021)

Clinical Psychology & Mind-Body Intervention



Top-Down Approaches

- 'Talk therapy'
- CBT
- Motivational Interviewing
- Psychoeducation



Bottom-Up Approaches

Mindfulness & Grounding Techniques

- Does not have to be 'formal' mindfulness
- With pets, food, walking…
- Even 'mono-tasking' can help
- Examples include:
  - The 5-4-3-2-1 Technique:
    - What are 5 things you can see?
    - What are 4 things you can feel?
    - What are 3 things you can hear?
    - What are 2 things you can smell?
    - What is 1 thing you can taste?

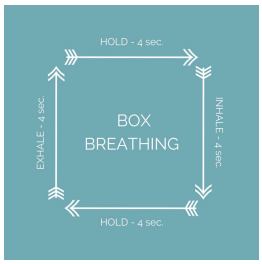
Diaphragmatic Breathing

Be creative! Depending on the age…

- Blow out the candle
- Blow away flower petals
- Different coloured 'paint' as they breathe out
- Box breathing
- Belly breaths

Common issues include:

- Not doing it long enough (5 minutes)
- Shallow breathing
- Parents not supporting if child too young to self-regulate



Break Out Session - Discipline Specific Discussion

Break Time

Managing Functional Seizures

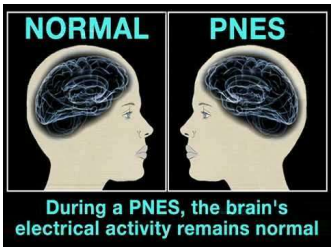
Learning Objectives

- To understand what functional seizures are
- To understand how to approach treatment of functional seizures in young people
- To understand ways to empower young people and parents/carers to manage functional seizures

What are Functional Seizures?

Functional seizures are sudden, time-limited episodes of neural network dysregulation that typically results in a loss of voluntary control of motor function & can also result in a change in consciousness

Savage et al., 2022

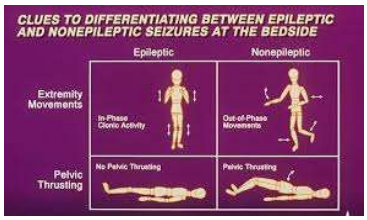


Diagnosis Note

Certainty around FND seizure can be difficult, 20% of those with Functional seizure like events also have comorbid epilepsy - so assistance of a neurologist and interictal and/or video EEG can be important

Aybek and Perez (2022) note – ***"Before good clinical scales with precise cut-off scores are available, subjective reports should be regarded cautiously, and objective assessment through video EEG remains the gold standard."***

Differentiating Functional Seizures from Epileptic Seizures

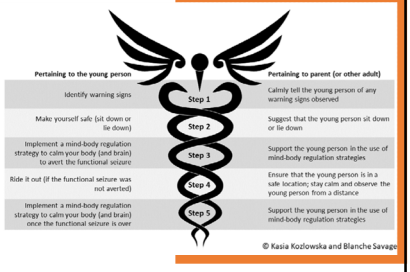


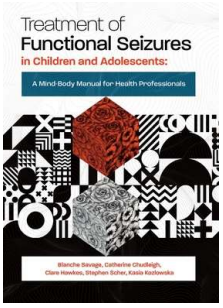
The Foundation of Treatment

- Consistency of approach across home, school, and health professionals
- Attention maintains it – parents, carers, and health professionals may need help to regulate themselves to be able to step back
- Reassure everyone – their brain and body is safe, they are not being damaged

Managing Functional Seizures in the moment...

...this might – probably WILL – happen in your sessions!





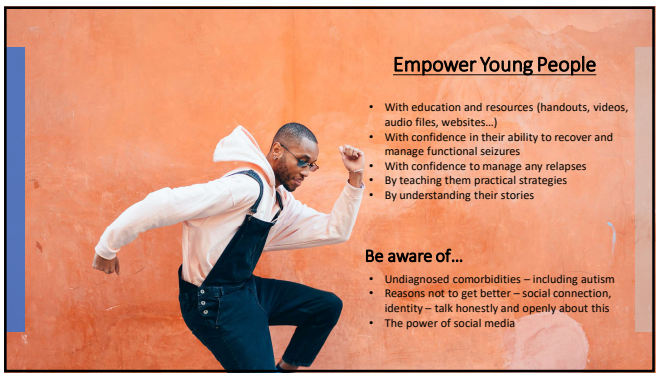
Treatment of Functional Seizures

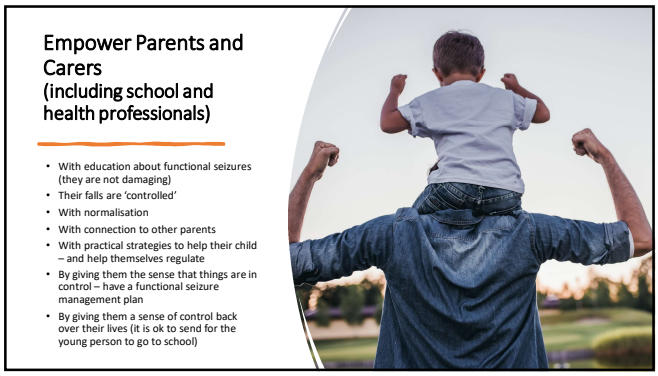
- Mind-body techniques
- Bottom-up + top-down
- Multidisciplinary team (where possible)

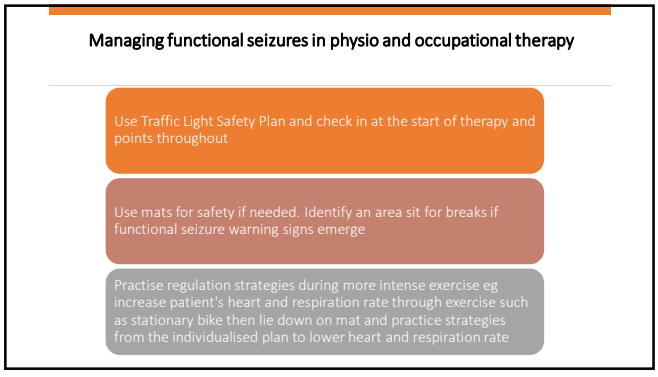
Traffic Light Safety Plan for Managing Functional Seizures

Signs:
Strategies:
Signs:
Strategies:
Signs:
Strategies:

Adapted from Savage et al. (2022) with permission © Danae Laskowski and Kasia Kozlowska 2019


Empower Young People
With education and resources (handouts, videos, audio files, websites…)
With confidence in their ability to recover and manage functional seizures
With confidence to manage any relapses
By teaching them practical strategies
By understanding their stories
Be aware of…
Undiagnosed comorbidities – including autism
Reasons not to get better – social connection, identity – talk honestly and openly about this
The power of social media


Empower Parents and Carers (including school and health professionals)
With education about functional seizures (they are not damaging)
Their falls are 'controlled'
With normalisation
With connection to other parents
With practical strategies to help their child – and help themselves regulate
By giving them the sense that things are in control – have a functional seizure management plan
By giving them a sense of control back over their lives (it is ok to send for the young person to go to school)


Managing functional seizures in physio and occupational therapy
Use Traffic Light Safety Plan and check in at the start of therapy and points throughout
Use mats for safety if needed. Identify an area sit for breaks if functional seizure warning signs emerge
Practise regulation strategies during more intense exercise eg increase patient's heart and respiration rate through exercise such as stationary bike then lie down on mat and practice strategies from the individualised plan to lower heart and respiration rate

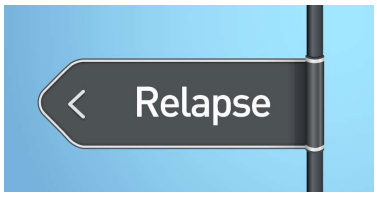
Relapse Prevention and Self-Management Plan

Learning Objectives

- Understand key components to include in a relapse prevention plan

Managing Relapses

- Peaks & troughs are often observed during the recovery course for FND given it can be a relapsing remitting condition
- As rehabilitation is ending the patient and therapy team should create a relapse management plan
- Readmissions to an inpatient setting are generally discouraged
- Manage symptoms through use of strategies in their FND 'toolkit'



(Stone et al., 2020)

Relapse management plans should consider these questions

- What have you learnt about your condition?
- What makes your symptoms worse?/What might trigger setbacks?
- What are the most helpful management strategies that you have learnt?
- What were the unhelpful coping strategies that were making it difficult for you to improve?
- What can you do if you notice that your symptoms and function are getting worse?
- What are your goals for the next 3, 6, 9 and 12 months? (using a graded goal setting approach).

(Nicholson et al., 2020)

Relapse Prevention Plan – *An Example*

Strategies for my Mind

- **Coping strategies** (e.g., talk to friends and family)
- **Triggers to be aware of** (e.g., big life changes)

Building my Strength and Independence

- **Strategies to help stay independent** (e.g., remember it's ok to take things slower)
- **Upper limb exercises** (e.g., use Theraputty or stress ball for hand exercises)

BIG GOAL: To be able to walk 5km without my walker

Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
Practice taking a few steps holding onto a family member for support						Walk 50metres by myself

Working on my Walking

- **Timetable of graded increases in walking** (e.g., 7-day exercise schedule)
- **Strategies to help with walking** (e.g., listening to music while exercising)

Tools to Find my Talking Rhythm

- **Breathing exercises** (e.g., breathe from my belly)
- **Speech exercises** (e.g., focus on my voice, not my mouth)

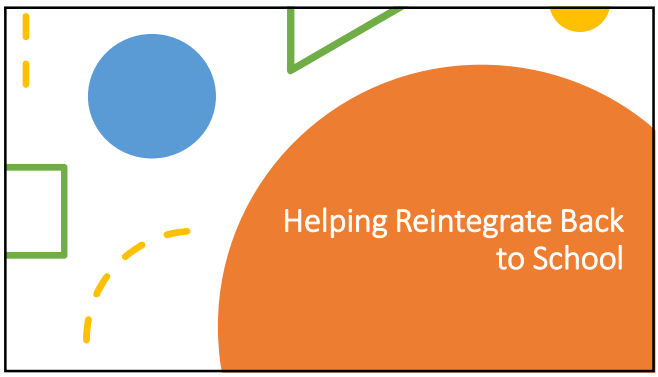
Managing Relapses for Patients with Significant Comorbid Mental Health Difficulties

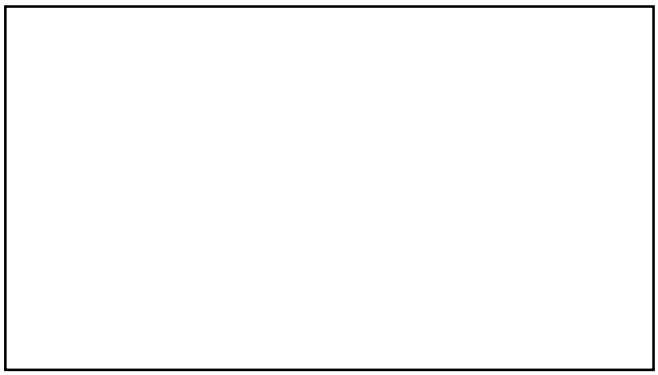
For some patients with significant comorbid mental health difficulties, relapses can be best managed by focusing on mental health intervention &/or family work

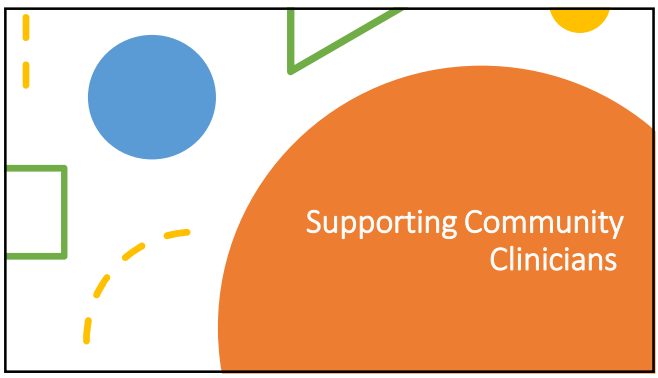
Additional physical rehabilitation may be more appropriate at a later time for a subgroup of this population should functional impairment remain after mental health difficulties have been managed

Psychological difficulties can also become more apparent for some patients with a diagnosis of FND once their functional impairment has significantly improved

Referral to community-based Psychologists &/or tertiary level mental health services (as appropriate) should be considered for all FND patients to provide ongoing support


Helping Reintegrate Back to School



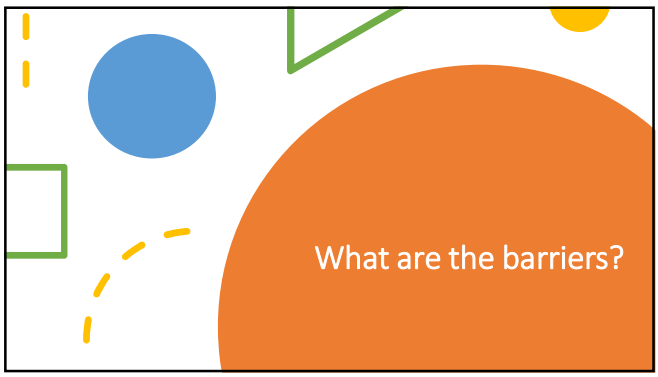

Supporting Community Clinicians

Learning Objectives

- Describe the modes MDT's can use to enhance communication and handover to community clinicians
- Describe key elements of an effective handover

Support options

Key elements to handover



Outcomes in paediatric FND

- Kozlowska 2013 – n100 , specialised interdisciplinary Rx
  - 56% recovered fully, 14% relapsing but well in between, 9% chronic and 21% unknown
- Forsyth 2019
- 21 year FU – 26 of 114 who reached 16yrs old had persisting FND symptoms - 23%
  - Common to have brief self limiting symptoms
- Paediatric outcome is better than adults - Flare up during times of stress

Prognosis often related to parental agreement, acceptance of treatment, length of symptoms, level of functional impairment and psychiatric comorbidities

Barriers to positive outcomes

- Unable to understand the diagnosis
- Refusal to agree with or accept the diagnosis
- Fixated views on an alternative diagnosis
- Longstanding or disabling symptoms
- Cognitive vulnerabilities & the presence of comorbid mental health &/or functional somatic symptoms that do not resolve (Perez et al., 2021)
- Parents as a barrier - **Genuine anxiety:**
  - Unable to be reassured (parents own anxiety leading to over attention of symptoms)
  - Parents who over-medicalise (fuelling the anxiety)
- Parents as a barrier - Inability to accept there may be a psychological component
  - Health belief or even ego driven – non-acceptance of the situation

Barriers to positive outcomes

- Treatment beginning later than 6-12 months from symptom onset
- Unable to build trust
- Chronic pain paradigm in the family
- Anxiety – discharged early form inpatient stay
- Lack of engagement in mental health support

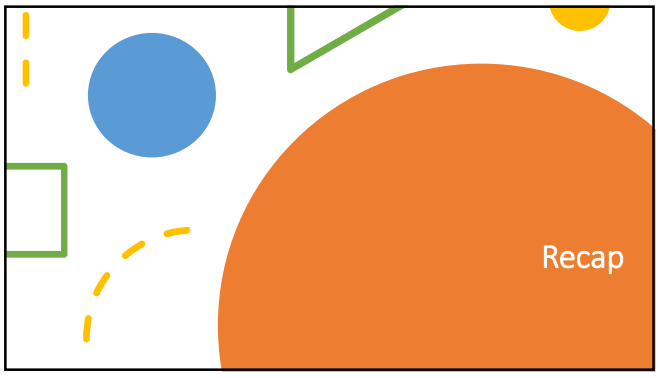
Be confident in your approach!

- 3/4 of children who received specialist interdisciplinary treatment for FND returned to full health & resumed full-time school attendance

Case Study – Not achieving a positive outcome

14yo girl presenting with abdominal pain, inability to walk, vocalisations/unable to speak
Barriers:

- Fixed on the need for investigations
- Not onboard with diagnosis
- Self-discharge from hospital
- Family history of chronic back pain and disability
- Incidental abnormality on MRI (done by external service)
- High reliance on equipment not prescribed by team
- Not engaging in goal setting or therapy sessions
- Anxiety but lack of engagement in mental health services



What we have covered – a recap

- How we diagnose FND
- The importance of language around the diagnosis
- The diagnostic discussion as part of the therapeutic process
- Assessment of a patient with FND
- The role of rehab and the MDT
- Tips for individual therapists
- Functional seizure
- Reintegration into school
- Relapse prevention planning

A 'Good Outcome'?

A good outcome doesn't always mean resolutions of symptoms

Always consider reports from the family and from the team

What patients and families find helpful:

- Being heard
- Being reassured that FND is a known condition with treatments
- Being given tools to manage
- Gaining confidence in their ability to manage – even if symptoms recur or don't completely resolve
- Being supported to reintegrate into usual life

Working as a Team

When we can't see the wood for the trees…

Go back to what you know – the familiar rehab model that focuses on:

- Return to function
- Goal-directed care
- MDT biopsychosocial approach
- Medical containment to assess new symptoms
- Post-discharge planning – Reintegration into normal activities

Case Study - Jordan

Summary

We will see more and more FND

As a diagnosis of inclusion, both standalone diagnoses, and co-occuring with other conditions

We have the skillset to help

The evidence shows that the rehab model can work for FND

We can't 'fix' everyone...

...but there is significant disability we can improve and prevent

Use the power of the multi-d team

Have a shared language and ensure you're on the same page
Be enthusiastic and supportive of one another

Working with FND can be really satisfying

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