



FND Perspective

A SPEECH PATHOLOGY RESOURCE FOR ADULTS WITH
**FUNCTIONAL NEUROLOGICAL
DISORDER**

By Erica Tilley *BSp Path, MClSci*

ericatilley@live.com.au

FND Perspective

22-3-26 v2.2

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WELCOME

Welcome and thankyou for taking the time to understand functional neurological disorder from a lived experience perspective.

This resource begins with a reflection of what shapes clinical-decision making in Speech Pathology. It also touches on multidisciplinary factors such as how medical conditions are defined, and the principles we share with our physiotherapy and occupational therapy siblings.

The second section contains ready-made resources for patient handouts. The final section is for clinicians only and includes self-reflection and case studies.

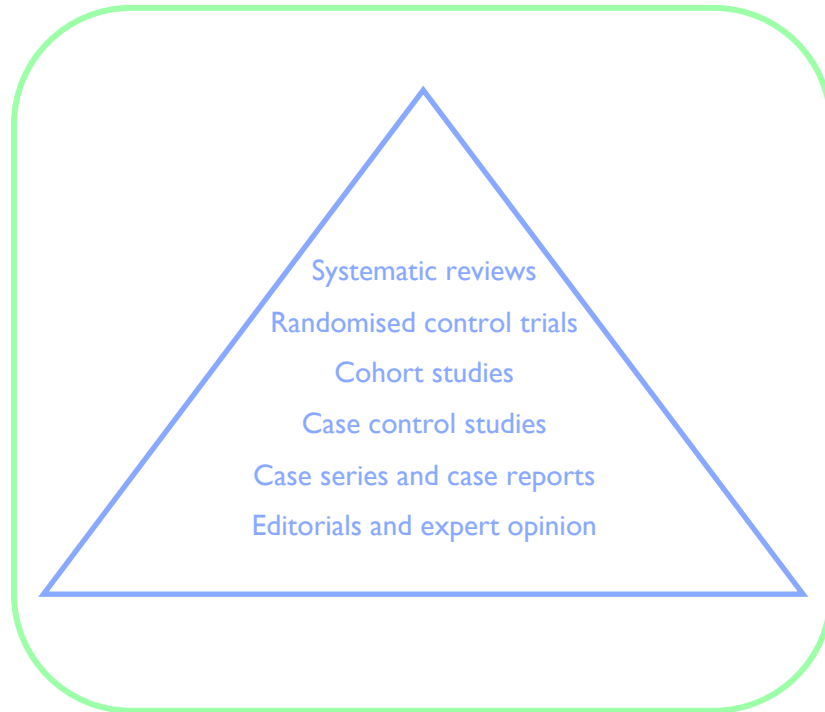
Thankyou to those clinicians who have expressed interest and curiosity. Whether at a brief passing conversation level to an in-depth analysis and providing feedback, it has been so helpful thankyou!

Thankyou to the Mindful Speechies Podcast hosted by Kizzy Searle and Andrew Watt for starting a conversation with me about FND. Without a safe place to talk about FND this resource would not have happened.

Most importantly, I would like to express my appreciation for my family. Thankyou for supporting my all night writing benders every two months. I'll help with the laundry tomorrow I promise.

EVIDENCE HIERARCHY

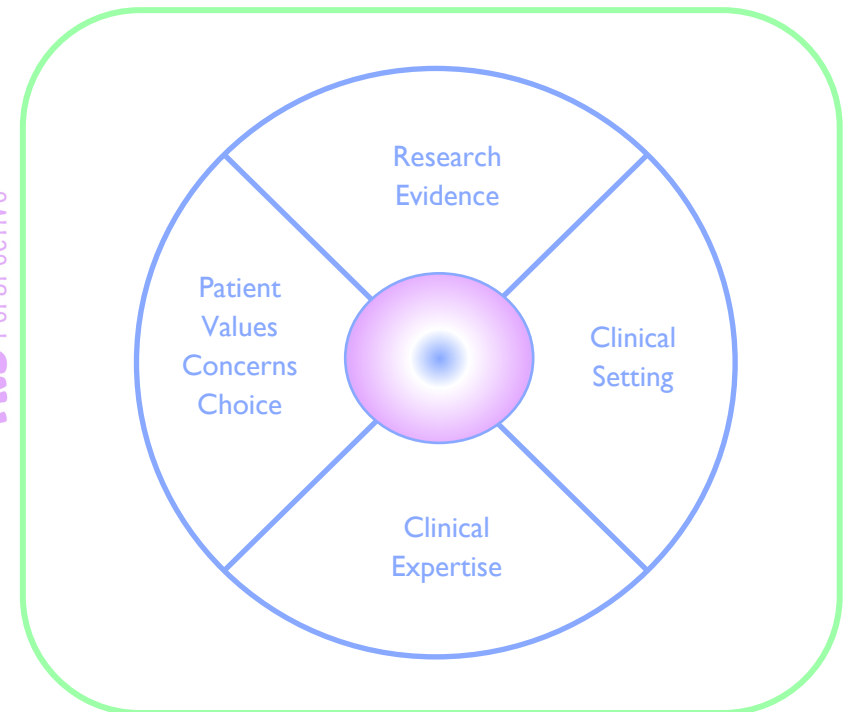
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In the “Evidence Hierarchy” the highest level of evidence or Gold Standard is systematic reviews and randomised control trials. Secondary levels of evidence include cohort studies and case controlled studies. Case reports, expert opinion, editorials and anecdotal evidence are some of the weakest forms of evidence. This is important in considering, “does the therapy work?”

EVIDENCE BASED PRACTICE

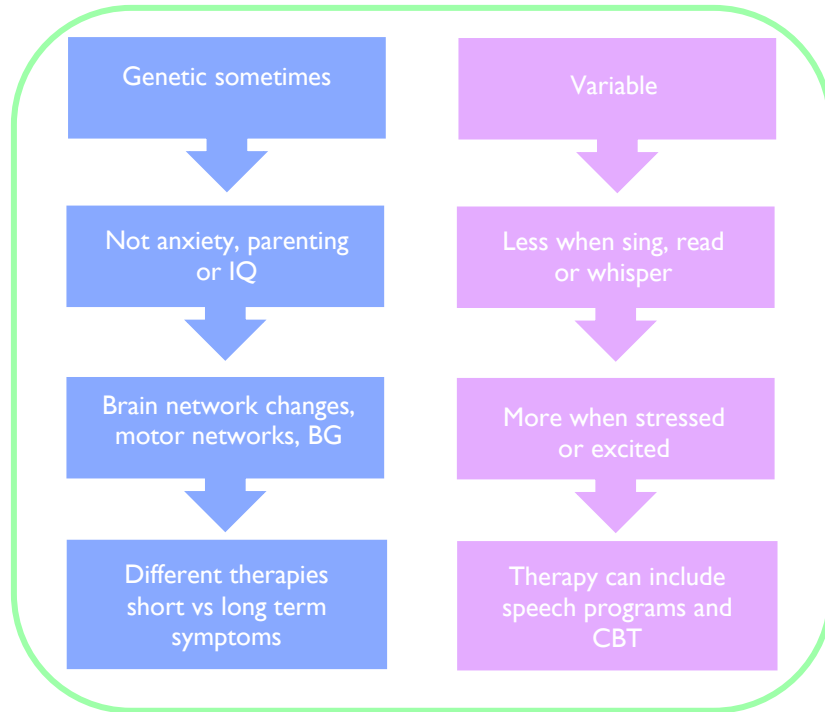
FND perspective



But level of evidence is not the only consideration. Evidence Based Practice is about integrating the best available evidence from research evidence, clinical expertise, patient factors (personal preferences, concerns, expectations and values) and the practice context (hospital vs acute, regional vs metro, resourcing).

DEVELOPMENTAL STUTTERING

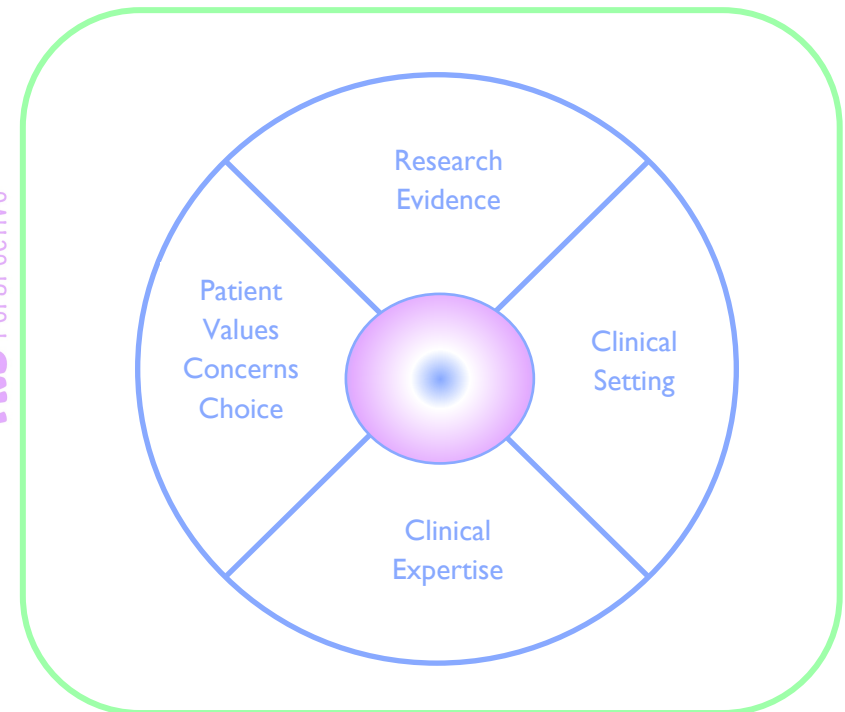
FND PERSPECTIVE



As an example, the levels of evidence for speech pathology interventions for developmental stuttering are high. There is a wealth of research in the form of randomised control trials for a range of intervention types including the Lidcombe Program and the Camperdown Program.

TREATMENT CHOICE

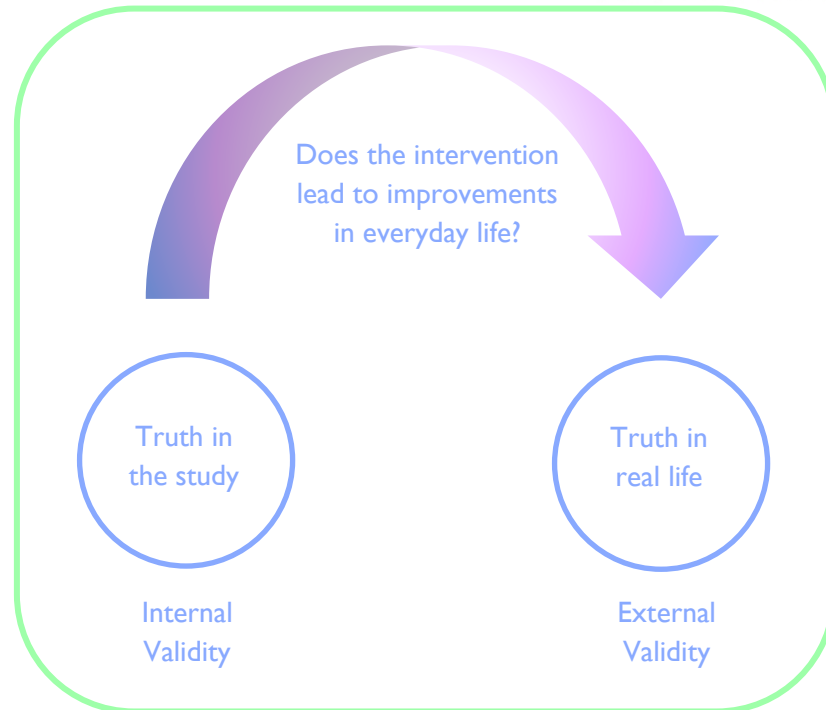
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The treatment program chosen may take into account research evidence, patient factors (funding, age, long-term stuttering, patient choice), clinical expertise and clinical setting preference such as private clinic versus University/Student based programs such as Smooth Speech at La Trobe University.

VALIDITY

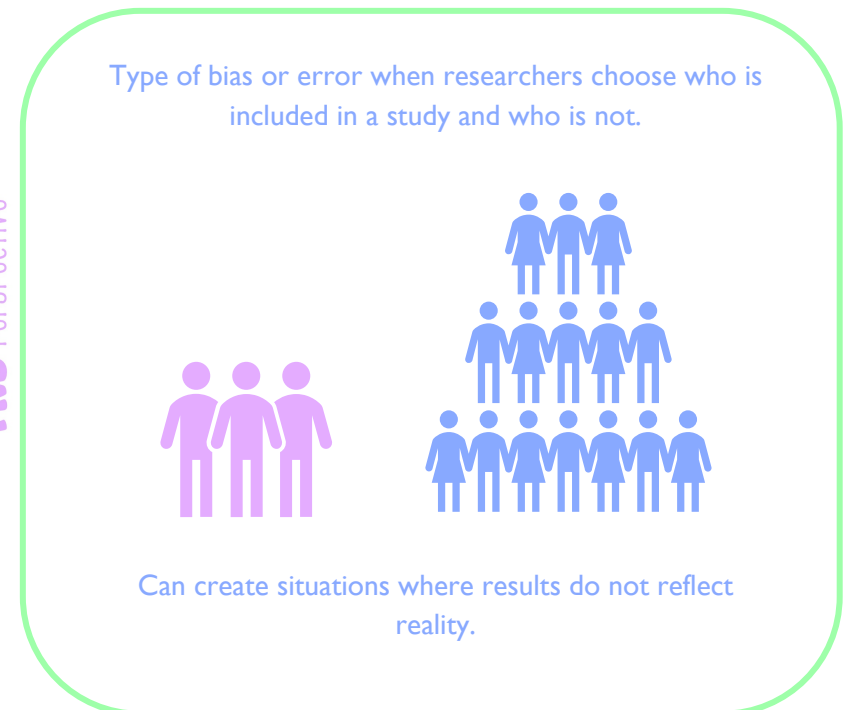
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Internal validity is how well a study establishes a cause-effect relationship that cannot be explained by other factors or variables. External validity relates to whether findings can be generalised and applied to everyday life.

SELECTION BIAS

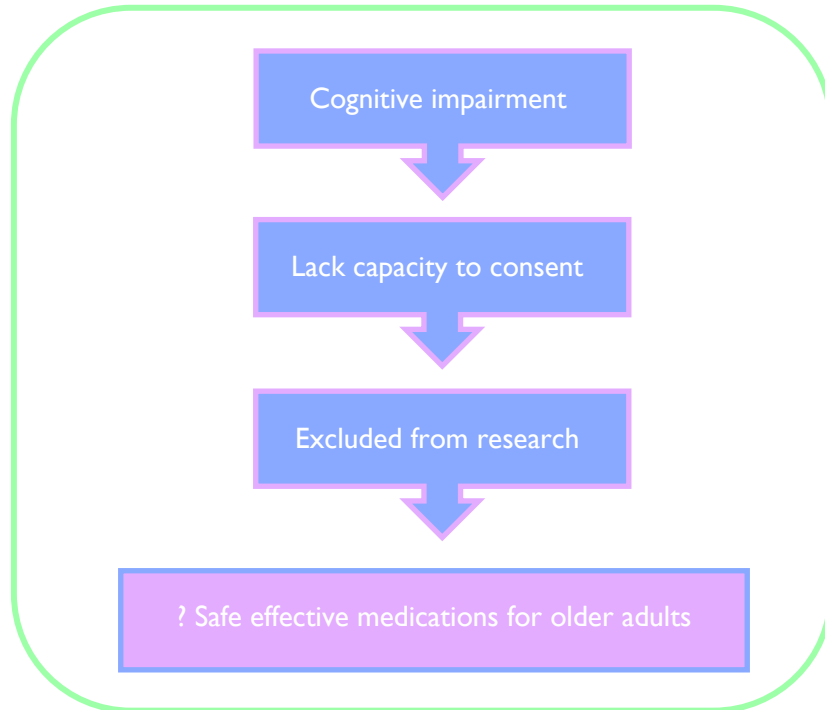
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External validity can be affected by selection bias. There are many types of [selection bias](#). One type of selection bias is when the subjects in the study do not represent the target population. This can create situations where the results cannot be applied to the population, and/or create an inaccurate representation of a causal [relationship](#).

EVIDENCE BIASED MEDICINE

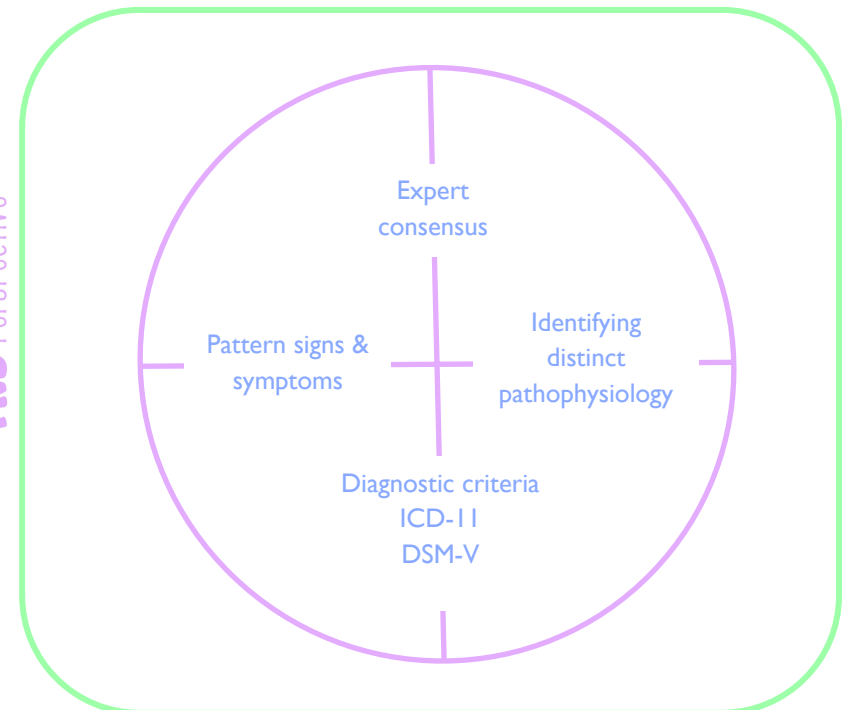
FND PERSPECTIVE



A common example is the exclusion of some older adults from research as they do not have mental capacity to make decisions from themselves. This has led to a lack of clarity whether medications are safe and effective for them, and less innovation in their medical care and treatment as a result. This type of selection bias should be overcome by pursuing alternative arrangements for proxy decision making via a nominee etc.

DEFINING CONDITIONS

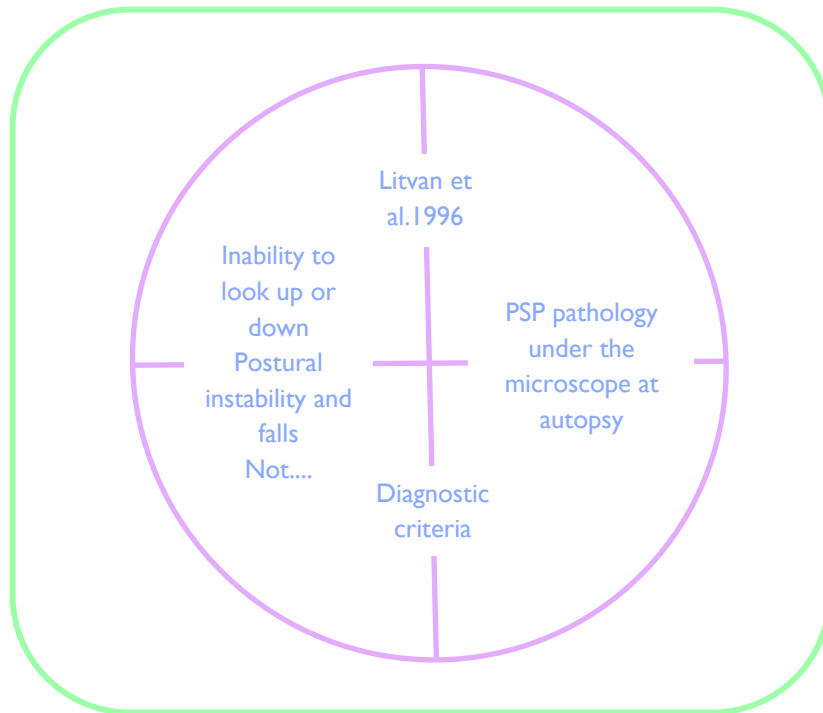
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Medical conditions and disorders are typically defined via the following pathways 1) identifying a consistent pattern of signs and symptoms, 2) understanding the pathophysiology as distinct from other existing defined conditions, 3) obtaining expert consensus and 4) development of diagnostic criteria as contained within the ICD-11 and the DSM-V. Exclusion criteria will typically list similar but 'different' conditions like PSP and CBD.

PROGRESSIVE SUPRANUCLEAR PALSY

FND PERSPECTIVE



Progressive supranuclear palsy (PSP) is more severe than Parkinson's disease, typically levodopa is ineffective, and is not Corticobasal syndrome (CBD) Academic experts can reach 'legend status' like Irene Litvan who published 1996 diagnostic criteria [paper](#). Writing a [systematic review on PSP](#) I saw her name a lot. It was a surreal experience to talk to her about it at a conference, and to realise she is a real person just like you and me.

LIVED EXPERIENCE FEEDBACK

FND PERSPECTIVE

"You said people with PSP fall backwards as compared with MSA [multiple system atrophy]. Well I have MSA, I tell you now... I fall forwards, I fall sideways, I fall backwards, I fall in every direction" Audience member feedback to my presentation to Parkinson's SA.

I didn't know where to look. I didn't know what to say. I felt bamboozled, defensive? Ashamed. I was just repeating what I'd been told and read in the literature. If I had my time again, I would say...

"I DID NOT KNOW THAT. THANKYOU FOR SHARING YOUR EXPERIENCE WITH ME. IT GOES TO SHOW WE CAN UNDERSTAND BETTER WHEN KNOWLEDGE GOES TWO WAYS BETWEEN RESEARCH AND REAL-LIFE EXPERIENCE"

Before this, a local neurologist taught me, anyone can read up on a topic and write a summary using full texts or abstracts available for free on PubMed. Using this information, I presented a slideshow to the Speech Pathology team at lunch, which led to a Ground Rounds presentation where I was called a 'scholarly expert'. It was a shock to get the feedback I did on the same material from lived experience as I have outlined above.

DIAGNOSTIC QUANDRY

FND perspective

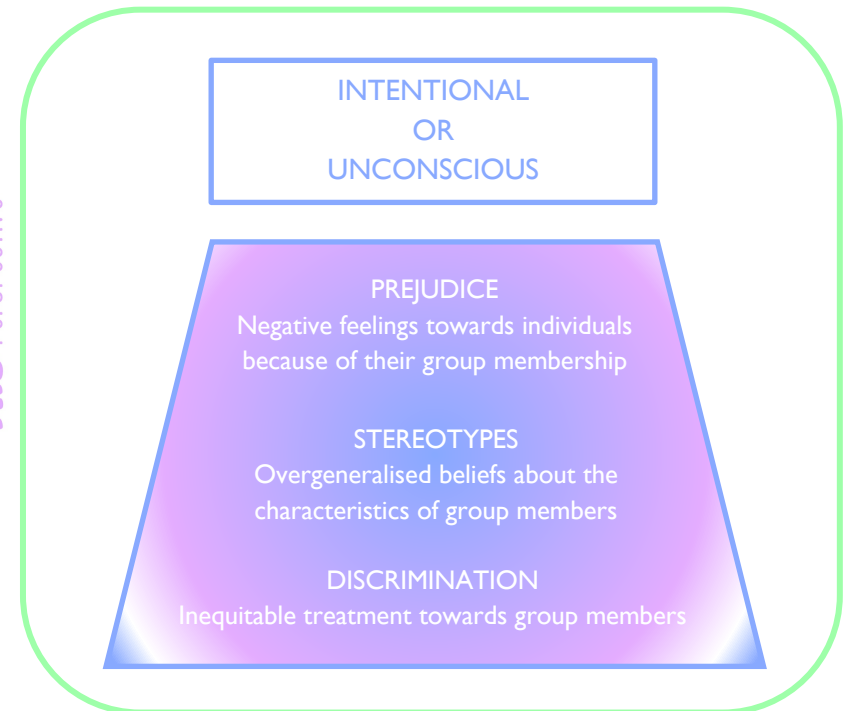
New subtypes of PSP in 2017:

- I. Richardson's Syndrome
- II. PSP-Parkinsonism
- III. PSP-Pure Akinesia with gait freezing
- IV. PSP- Corticobasal syndrome (PSP-CBD)
- V. PSP- Speech/Language
- VI. PSP- Frontal
- VII. PSP-Cerebellar
- VIII. PSP- Postural instability
- IX. PSP- ocular motor dysfunction

Going back to diagnosis, it is not so simple. There is overlap with other conditions (exclusion criteria) in terms of patterns of symptoms and histology. Look at the relationship between PSP and corticobasal syndrome (CBD). Since [2017](#) there are new subtypes of PSP, and there are also subtypes of CBD but how does one tell the PSP subtype PSP-CBD from CBD-PSP? Defining truly 'distinct' or different conditions is messy.

CLINICAL BIAS TYPES

FND perspective



And finally, the impact of clinical bias. Whilst researchers and clinicians do their best to remain objective and impartial, the reality shows that this is not always the case. Clinical bias (listed above) can lead to inequalities in healthcare access and outcomes. An [example](#) in a paper from Minnesota; Blacks vs Whites who receive lower quality of medical care independent of type of disease, clinical setting, insurance levels or other clinical factors.

HOW BIAS SHAPES THERAPY

FND PERSPECTIVE

Autism difficulties with social communication, need for predictability/routine, sensory processing, auditory processing, focussed interests or repetitive behaviours

Often co-occurs with FND, fibromyalgia, intellectual disability, cerebral palsy, Ehlers Danlos syndrome, epilepsy, ADHD, personality disorder, bipolar disorder, schizophrenia and parkinsonian conditions.

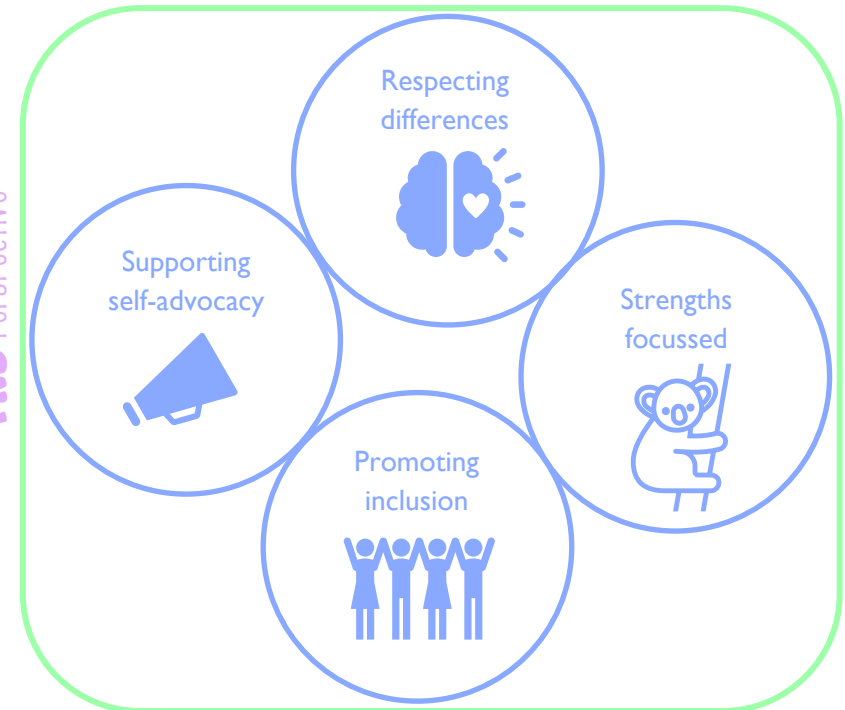
Lifelong challenges associated with stigma/discrimination/access issues across education, employment, health services etc.

Life expectancy usually 15-20 years less than those without autism

Autism is a neurodevelopmental condition associated with symptoms listed above. Previously, dominant voices in the field of autism were autism somethings. That is autism academic experts, autism clinicians, parents/carers of autism, and therapy goals were prioritised that 'hid' visible symptoms of autism. Today, autistic people are better respected in their ability to define what is autism, and what helps, to good effect.

NEURODIVERSITY AFFIRMING CARE

FND PERSPECTIVE



Because autistic people asked, is the goal me hiding my autism or is it more about society accepting who I am? Many clinicians now view autism through a neurodiversity affirming lens and appreciating communication differences such as the “[double empathy gap](#)”. It has opened the door towards therapies that embrace authenticity, inclusion and support to be who we are. But that is not to say new theories do not come with their own [challenges](#).

FND GUIDELINES

FND PERSPECTIVE

MANAGEMENT OF FUNCTIONAL
COMMUNICATION,
SWALLOWING, COUGH AND RELATED
DISORDERS: CONSENSUS
RECOMMENDATIONS FOR SPEECH AND
LANGUAGE THERAPY
JANET BAKER ET AL. 2021

Much of the [evidence-base](#) available for speech pathology interventions for FND is at the lowest levels of the Evidence Hierarchy, including Expert Opinion and Case Reports. Speech pathology does not exist in its own silo. It is common for some principles of care to underpin therapy interventions across multidisciplinary domains with shared approaches across physiotherapy, occupational therapy and speech pathology.

ALLIED HEALTH PRINCIPLES

FND PERSPECTIVE

Examples:

1. Principles of neuroplasticity stroke vs brain injury vs motor neuron disease
2. Parkinson's disease (for example think big LSVT BIG ® for physiotherapy vs think loud for voice LSVT® speech therapy)
3. Functional neurological disorder

An example might be both disciplines approach [motor neuron disease](#) in the same way, where intensity of training may not be appropriate in persons who readily fatigue as it may cause maladaptive responses. It is useful, and more so when evidence is scarce particularly because speech pathology is a much smaller discipline compared with physiotherapy. However, it can be a risk to do this.

ALLIED HEALTH FND PRINCIPLES

FND PERSPECTIVE

1. Tell them that you believe their symptoms are real
2. Establish positive expectations about recovery and affirm hope for improvement of function
3. Focus on function, not symptoms. FND symptoms are exacerbated when attention is drawn to symptoms. 'Retrain' abnormal motor symptoms.
4. Avoid adaptive equipment or any other accommodations as patients may become dependent on these for function.
5. Involve family and caregivers to ensure that they do not reinforce symptoms or contribute to illness beliefs, and request that they promote 'independence'
6. Reach out to other providers and family to ensure that they are on board with the allied health FND principles of care.
7. Psychology and CBT

The types of approaches adopted by the Speech Pathology guidelines are aligned with [cross-discipline](#) principles for treatment of FND as outlined above. The emphasis is on drawing attention to function/not symptoms and correcting illness beliefs. It is thought to be important that people with FND do not meet or discuss their condition with other people with FND, or explore research literature that suggests FND is not usually reversible.

A COMPARISON OF GUIDELINES

FND PERSPECTIVE

FND GUIDELINES ARE

SP
SAME

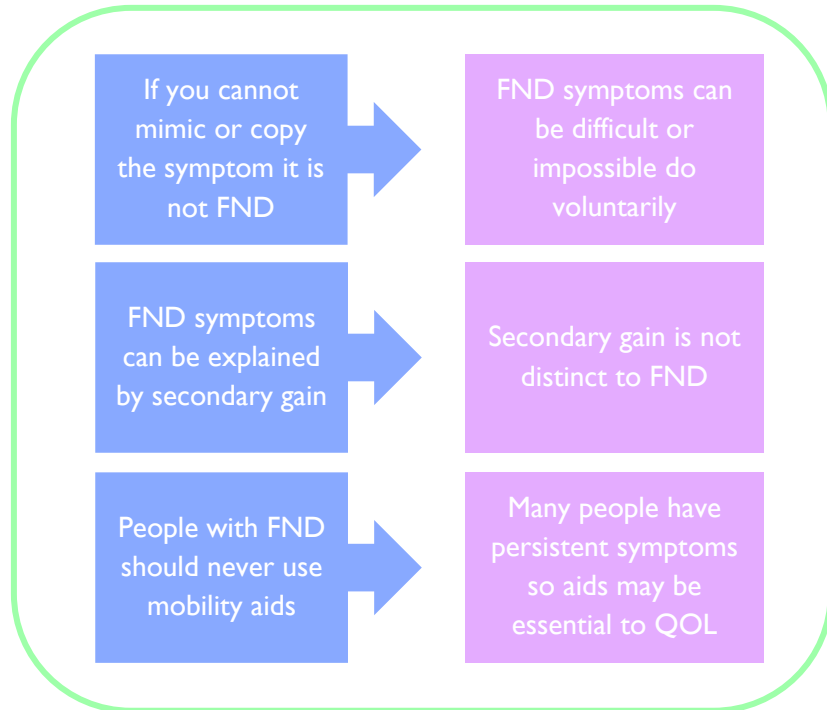
PT
SAME

OT
BUT
DIFFERENT

[Speech Pathology](#) is much more aligned with the FND [Physiotherapy](#) guidelines that highlight illness beliefs and reversibility of the condition. Despite a lot of overlap, 'illness belief' is not used in the [OT Guidelines](#) and there are also some subtle references to the boom-bust nature of FND, and in terms of goal setting that "with FND, it can be helpful to consider that recovery often follows a pattern of symptom remission and exacerbation."

GLENN NIELSEN'S FND MYTHS

FND PERSPECTIVE



Glenn Nielsen is a world-renowned physiotherapist who published RCTs for FND and is primary author in the 2015 Physiotherapy guidelines for FND. He recently shared his [views](#) with the Australian Physiotherapy Association. He advocates for viewing FND through a lens of predictive processing, including the role of impaired interoceptive awareness, neurodiversity and epigenetics. He also feels there are a number of myths about FND.

THERAPY FOR THE 29%

FND PERSPECTIVE

Physiotherapy intervention for FND is based on the work of Glenn Nielsen who keeps one-third of people with FND in his research.

“In a five-day outpatient physiotherapy program, 210 patients were assessed for eligibility with only 60 (29%) deemed suitable. Patients were most commonly excluded due to excessive pain or fatigue, or co-existing psychological symptoms requiring treatment.” [Quote](#) from an article first paragraph, last two sentences.

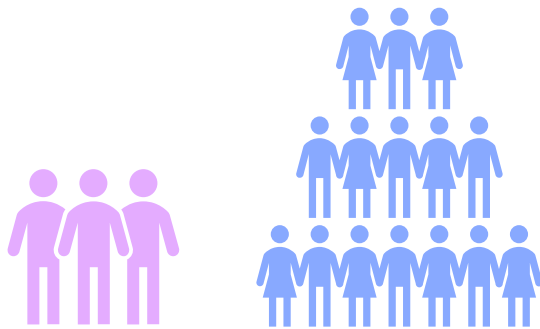
29% INCLUDED
71% EXCLUDED

When reviewing a Glenn Nielsen intervention study, keep a close eye on the inclusion criteria. One example is listed above, another [here](#). It is possible he has developed a mechanism for separating acute vs persistent FND, and successful therapy for a subsection of people with FND. Could FND therapy become more like developmental stuttering (Lidcombe vs Camperdown) with different treatments tailored for acute vs persistent FND?

REFRESHER ON SELECTION BIAS

FND PERSPECTIVE

Type of bias or error when researchers choose who is included in a study and who is not.



Can create situations where results do not reflect reality.

Exclusion criteria are used in quantitative research to reduce confounding variables and to promote consistency, replicability and comparability of findings. The number of patients excluded from research is generally considered 'to high' when it compromises the study's generalisability to real life.

WHEN RESULTS ≠ REALITY

FND PERSPECTIVE

SUBJECTS ≠ TARGET POPULATION

RESULTS ≠ APPLIED TO POPULATION

X INACCURATE CAUSAL RELATIONSHIP

? UNKNOWN IF INTERVENTION IS EFFECTIVE

? UNKNOWN IF INTERVENTION IS SAFE

Some of the consequences of selection bias are listed above. This might mean for the 71% of people likely to have persistent FND excluded from research, we do not know if current FND therapy (designed for the 29%) can be applied to people with persistent FND. We do not know if it is safe and effective, and lived experiences (myself included) hints that acute FND therapy techniques can be harmful for persistent FND.

TELL ME MORE

FND PERSPECTIVE

“The reason why so many patients are excluded in FND research is to remove variables.”

“Sense of agency is big, especially if there are symptoms of disassociation involved... Yes- there has been movement away from the term ‘distraction’ as it can sound quite deceptive but some externalisation strategies work for some people.”

“I’ll look into the affirming approach [there currently is not one], we typically follow a lot of what Glenn Nielsen and his team do over in the UK.”

When undergoing a quality audit against practice standards, a good auditor will not immediately raise a non-conformity. Instead, they will work with you to learn more about the gap, and what you might be able to justify or provide to show evidence in another way. I have reached out to a range of key stakeholders to understand more about the thoughts behind not providing a different type of therapy program for people with persistent FND.

ACCESS

FND PERSPECTIVE

There is understanding that current academic narratives may restrict access to disability support (financial/disability support services/eligibility criteria for permanent disability).

But there is concern that transparency around the long-term nature of FND would reduce the potential for ‘placebo’ that can be quite powerful for all medical conditions.

But how do we balance this with quality of life?

AIHW REPORT 21,500 PEOPLE WITH FND IN AUSTRALIA, 295 ARE ON NDIS WITH FND AS A PRIMARY DIAGNOSIS.

In one of the only case controlled/long term studies on prognosis in FND, it was [found](#) that whilst some improve, most have symptoms 14 years later. Without a doubt, the placebo effect is helpful, but we must also consider the impact of quality of life when people with FND are unable to access health reports that confirm permanency of the condition necessary for accessing financial/disability support and services.

QOL IN PERSISTENT FND

FND PERSPECTIVE

Quote from National Mental Health Commission Report 2019 published by Katherine Gill

“We will only be able to survive for a short period before having to sell our home as I cannot earn enough to pay mortgage, doctors’ bills, prescriptions, and general living expenses. We are using up our savings at the moment.”

“Long term disability is similar to that seen in cohorts of people with multiple sclerosis [MS], but with increased levels of pain, significantly reduced emotional wellbeing and social role functioning, compared to a similar cohort of people with multiple sclerosis [35], with both the FND and MS groups presenting considerably worse than locally acquired population based controls.”

There is a really great [report](#) written by Katherine Gill for Australia’s National Mental Health Commission in 2019 Consumer and carer experiences of FND/CD in Australia “FND is Australia’s silent crisis”. It helps to draw attention to the lived experiences of people with FND, and potentially the types of outcomes because there is not a pathway of care dedicated for people with persistent FND symptoms.

DO NO HARM

FND PERSPECTIVE

**Quote from qualitative research:
OTHERED BY THE HEALTH SYSTEM**

“I kinda got the general feeling that the way to treat FND is to ignore it and so do ignore it means to not talk about it so ... what professional do I get to say this is happening, this is hurting” -Bridget

Response to my question:

That has actually always been my point, they exclude people with seizures, fatigue, significant mental illness etc – and they try and apply the same care to the full population and then blame the person if they don’t recover.

The experiences of Bridget (above) show there is harm having only one FND therapy approach pathway. I asked “Is it Ok that the only physiotherapy for FND is based on the work of Dr Glenn Nielsen where more patients are left out of the study (70%) than included, and when can we expect research and therapy that is neuroaffirming or based on the reality of a group of people with FND?” and received the response above.

CHANGING THE TOPIC

FND PERSPECTIVE



" Let there be a thousand blossoms bloom, as far as I am concerned. But I ain't spending any time on it because in the meantime, every three months, a person is torn to pieces by a crocodile in north Queensland."

Like Australian politician Bob Katter interviewed about the same-sex marriage, I want to change the topic and not talk about this anymore. And yes same-sex marriage in Australia is awesome, and no, people are not torn to pieces by a crocodile in North Queensland often. Having one approach to FND therapy and [Table 1](#) seeped in [clinical bias](#) is traumatising, and re-traumatising, and I'd rather push on about what we can do instead.

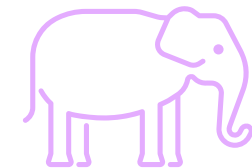
FND IS NOT DISTINCT IN THESE WAYS

FND PERSPECTIVE

Symptoms NOT distinct to FND:

Also present in Parkinson's Disease as one example

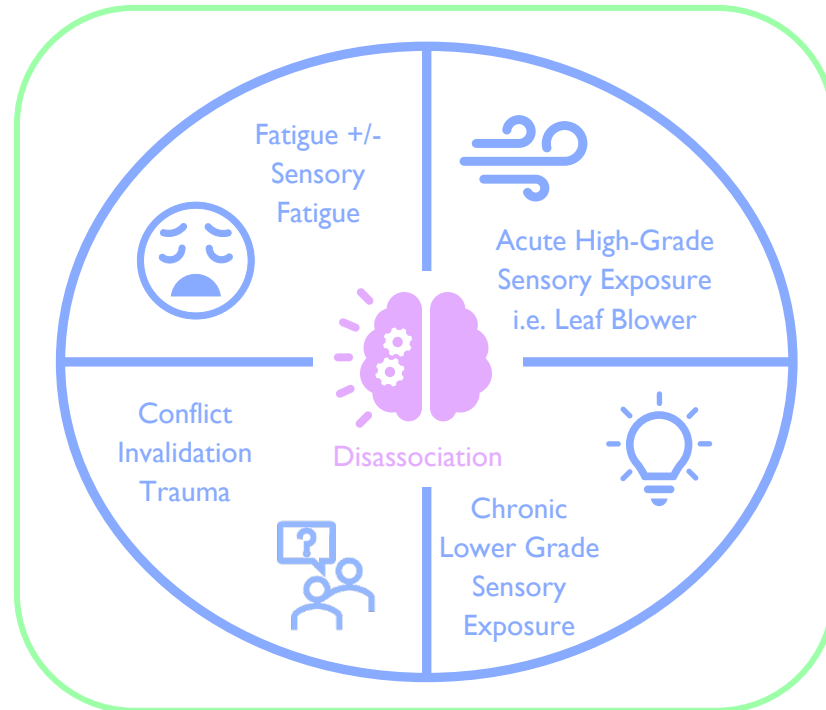
1. Reduced sense of agency
2. Top-down predictive processing
3. Variability of symptoms
4. Jumping to conclusions bias
5. Shift from implicit automatic motor program to an explicit motor program with focussed attention
6. Slow to adapt from walking from a moving platform to a slow one (persistent locomotor after effect)



Neurologists and Glenn Nielsen place emphasis on distinct symptoms in defining what is the underlying mechanism in FND. The elephant in this room is that these symptoms are not unique to FND and are shared across a large number of conditions, I've referenced Parkinson's disease (PD) as just one example. The bigger question, is do we need FND to be distinct to be able to provide effective therapy to manage symptoms in persistent FND?

DISASSOCIATION IN FND

FND PERSPECTIVE



When FND therapy targets the wrong triggers for disassociation (illness beliefs, focussed attention, desensitisation, ↓ avoidance etc.) it worsens illness via invalidation, conflict and sensory overload. When therapy goals target fatigue, sensory overload, naming of emotions and validation, lived experience indicates that range and duration of functioning improves and symptoms become not cured, but more manageable and predictable.

DESENSITISATION IS UNHELPFUL

FND PERSPECTIVE

“Desensitisation is not considered a neurodiversity affirming goal because it asks [the person] to ignore or suppress their response to sensory stimulation, which can involve disassociating from bodily sensations or forcing them to tolerate sensations that hurt or are deeply unpleasant. Changing the focus to self-advocacy helps a [person] to learn to protect themselves and advocate for their sensory needs.”

Desensitisation is wrongly promoted as an appropriate therapy for FND and there is a type of mental whiplash one experiences when being diagnosed with autism and then later, FND, and being directed to do opposite things. In persistent FND, avoiding sensory triggers with associated fatigue is extremely helpful.

TRY NOT TO MINIMISE FND

FND PERSPECTIVE

FND is a severe condition, particularly persistent FND.

1. FND is associated with [increased mortality](#).
2. [Prognosis](#) is often poor in FND.
3. Other neurological conditions are a strong risk factor for FND, so [investigations for possible comorbidities](#) are important.
4. FND is associated with [structural grey matter abnormalities](#) in areas of limbic and sensorimotor circuitry (L) side (amygdala, striatum, cerebellum, fusiform gyrus, sensorimotor cortex)
5. Network/white matter changes prevalent in many severe neurological conditions
6. Using terms like 'a bit of a frequent flyer' is indicative of clinical bias

Please re-frame how you view FND and how you talk about FND to patients, their families and your colleagues. Healthcare professionals develop FND too, and you never know how what you might be saying could be perceived. If you are presenting on FND, and you know someone has it, seek cultural sensitivity feedback on your training materials and take their findings on at face value as part of recognising someone else's experience.

GROUNDING TECHNIQUES

FND PERSPECTIVE

SAY GROUNDING
TECHNIQUES



As discussed offline with the [Mindful Speeches Podcast](#), consider not using the term distraction techniques. Grounding techniques are effective strategies to address flight/fright response and modulating levels of arousal back into the 'green zone'.

MINDFUL SPEECHIES PODCAST

FND PERSPECTIVE

MINDFUL SPEECHIES PODCAST

KIZZY SEARLE & ANDREW WATT

Learn about trauma informed and neurodiversity affirming care in Speech Pathology.

“practical insights, discuss real clinical situations and build a community that supports both SLPs and their clients”

<https://creators.spotify.com/pod/profile/mindful-speechies/>

The Mindful Speechies Podcast is a really great resource for learning about prioritising connection and safety. I also was a guest speaker September 2025.

ABOUT FND PERSPECTIVE

FND PERSPECTIVE

- Lived experience supervision for clinicians, services and researchers only*
- Presentations or workshops
- Speech Pathology Resource (Patient Handouts for Adults with FND) pdf coming soon \$30 for clinicians, \$5 for people with FND
Free for Aboriginal and Torres Strait Islanders and or health professionals who also have FND

If interested please contact me to request services/
quote: ericatilly@live.com.au

*Please note I no longer practice speech pathology and are unable to provide services to patients

I develop FND Perspective resources in my own time, if you could take a moment of your time to make a \$5 donation for these slides and support future projects, I would really appreciate it. You can do this via Send Money (Paypal) to ericatilly@live.com.au. If you do not have PayPal you can set up a new account or email me for alternative payment methods thankyou.

FND perspective



PATIENT HANDOUTS

FUNCTIONAL NEUROLOGICAL DISORDER

By Erica Tilley *BSp Path, MClSci*

ericatilley@live.com.au

FND Perspective

24-3-26 v2.5

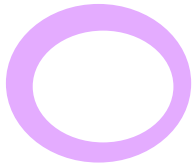
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FND PERSPECTIVE

IF FND WAS A BBQ



Energy (lack of fatigue) is like fuel at a BBQ. No gas, no BBQ. Unless you've considered transitioning to electric, time to order pizza.



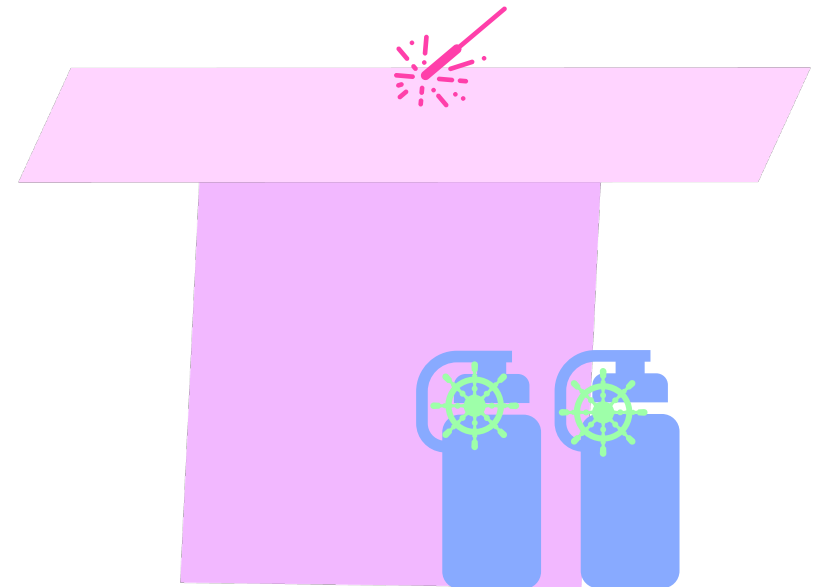
Sensory problems are like having a faulty seal on your gas bottle. Your bottle (energy) just seems empty, even though you went to the servo last week.



A faulty gas knob (hyper/hypoarousal) is like letting a lot of gas out at once, or not enough. It can be a challenge to set the gas knob at the right setting for the right task. Not only do you lose energy, you burn the onions too.


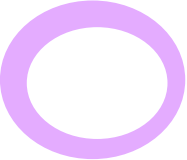




Spark is about initiation and timing. No spark when the gas is running, no BBQ too.



FND PERSPECTIVE

HOW IS FND FOR YOU?

	<p>Do you feel tired a lot of the time? What things can't you do when you are tired?</p>
	<p>Do you get bothered by background noise, bright lights or other sensory issues more than you used to?</p>
	<p>The stress response is what your body does to get ready for doing tasks, for example a difficult work project everyday tasks like having a meal. Do you find your ability to function is affected by stress levels (either too low, drowsy, reduced motivation) or too high (overwhelmed, stressed) Do you find yourself in flight, fright, fight or freeze more than you used to?</p>
	<p>Do you find it hard to get things going sometimes for example, feeling motivated, or also things like getting your movement going such as feeling stuck when talking, swallowing or walking?</p>

FND PERSPECTIVE

- Speech Pathology Resource (Patient Handouts) for Adults with FND) pdf coming soon \$30 for clinicians, \$5 for people with FND
- *Free for Aboriginal and Torres Strait Islanders and or health professionals who also have FND*
- If interested please contact me to request/quote: ericatilley@live.com.au
- I develop FND Perspective resources in my own time, if you could take a moment of your time to make a \$5 donation for these slides and support future projects, I would really appreciate it. You can do this via Send Money (Paypal) to ericatilley@live.com.au. If you do not have PayPal you can set up a new account or email me for alternative payment methods thankyou.
- This resource is not a replacement for clinical advice- seek individualised care from your treating team. It contains a number of strategies which are newly developed and/or have not been researched in people with FND to check effectiveness or safety.

STRENGTH BASED STRATEGIES



Everyone loves doing what they are good at. It feels efficient and less tiring. Getting positive feedback from other people feels good too.



Strength based approaches are about being quite intentional about playing to your strengths, rather than leaving it to good luck. This is important for managing fatigue.







People often do not realise they have strengths because they assume everyone else can do it too. But everyone has strengths, sometimes our weaknesses (and the unique abilities we develop to overcome them) become our strengths.



The first thing about playing to your strengths, is spotting it. The next, is working out how to position yourself so they're inherently part of your everyday life routine. And this can take time, even years, as you further adapt.



STRENGTH BASED STRATEGIES

	What does your daily or weekly routine look like?
	When are you eating, talking (friends vs family vs colleagues) or other forms of communication (listening, messaging, typing), and walking at your best? What are doing, where are you, what is different or good?
	What about your worst? What are doing, where are you, what is different or bad?
	Do you prefer TV/movies, reading, writing, talking, listening (audio books, radio), sending SMS. How do you like to spend time with other people? Do you prefer being alone, being with someone 1:1 or in a large group? Do you prefer face to face work or working from home?

TASK TRADING IN THE HOME



Homes come in all shapes, sizes and species. This can work within homes but also across homes if you live alone, like trading groceries for shared evening meals.



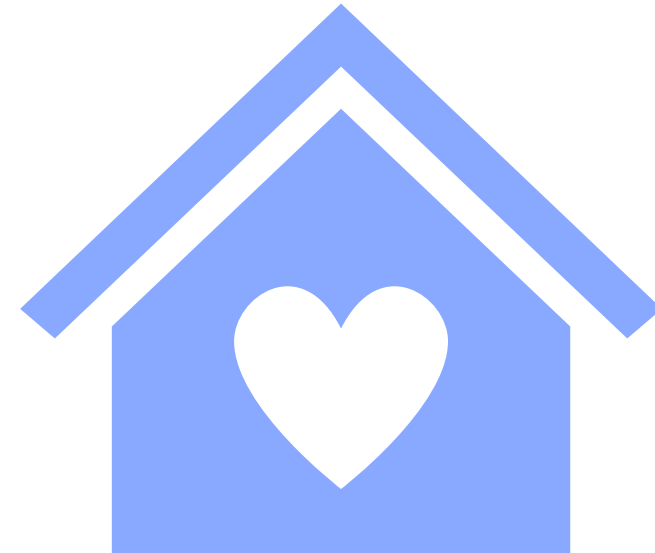
Home tasks can impact on brain fog, speech, swallowing, fluency, and voice due to upstream fatigue, sensory exposure, fluctuating arousal and social factors such as quality of life that comes from being able to contribute.



Optimising division of tasks is untapped potential to increase functioning. Mapping involves identifying who (including kids) are best placed e.g. seated vs standing, spatial vs non-spatial, loud vs quiet, wet vs dry, fast vs slow to do each task.



It is easier to identify and allocate tasks based on what family members 'hate' or 'don't mind doing' then to pinpoint why. If no one wants to do it, break the task into smaller steps and then split.



TASK TRADING MAPPING© E TILLEY 2026

BEST PERSON FOR THE JOB	Instructions: give a copy to each household member. Rate the task from 0 to 3 how much it bothers you, 0= not at all, 2= bothered a little, 3= bothered a lot. If you live alone, find a peer who is possibly interested in task trading with you and can provide transport to each of your homes. If no one likes the task, think about how you can break off the most complex parts and allocate separately.	A	B	C	D
	Clearing the table				
	Rinsing the dishes				
	Stacking dishes in the dishwasher				
	Hard to scrub dishes				
	Putting dishes away				

TASK TRADING MAPPING© E TILLEY 2026

BEST PERSON FOR THE JOB	Rate the task from 0 to 3 how much it bothers you, 0= not at all, 2= bothered a little, 3= bothered a lot.	A	B	C	D
	Wiping the bench/table				
	Vacuuming				
	Mopping				
	Scrubbing the shower				
	Scrubbing the toilet				
	Wiping over rest of the bathroom				

TASK TRADING MAPPING© E TILLEY 2026

BEST PERSON FOR THE JOB	Rate the task from 0 to 3 how much it bothers you, 0= not at all, 2= bothered a little, 3= bothered a lot.	A	B	C	D
	Meal planning				
	Preparing shopping list				
	Doing the main shop				
	Picking up the odd shopping item				
	Packing lunch boxes				
	Making dinner				

FND PERSPECTIVE

TASK TRADING MAPPING © E TILLEY 2026

BEST PERSON FOR THE JOB	Rate the task from 0 to 3 how much it bothers you, 0= not at all, 2= bothered a little, 3= bothered a lot.	A	B	C	D
	Making breakfast				
	Taking the rubbish out to big bins				
	Taking the big bins in/out				
	Changing the doona cover				
	Changing the rest of the sheets				
	Washing the clothes				

TASK TRADING MAPPING© E TILLEY 2026

BEST PERSON FOR THE JOB	Rate the task from 0 to 3 how much it bothers you, 0= not at all, 2= bothered a little, 3= bothered a lot.	A	B	C	D
	Drying the clothes				
	Sorting the clothes				
	Putting clothes away				

FND PERSPECTIVE

TASK TRADING MAPPING© E TILLEY 2026

BEST PERSON FOR THE JOB	Rate the task from 0 to 3 how much it bothers you, 0= not at all, 2= bothered a little, 3= bothered a lot.	A	B	C	D

FND perspective

TASK TRADING MAPPING© E TILLEY 2026

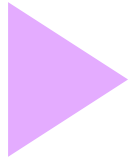
BEST PERSON FOR THE JOB	Rate the task from 0 to 3 how much it bothers you, 0= not at all, 2= bothered a little, 3= bothered a lot.	A	B	C	D

If no one likes the task, think about how you can break off the most complex parts and allocate separately.

USING STRENGTHS IN TASK TRADING



Physical tasks can be particularly demanding for people with FND. But others may need regular movement, or something in the middle. Every person with FND is different. Non-physical ways of contributing are outlined below.



Initiating tasks and body doubling, for example contributing by being there to start or shadow the task not necessarily finish it or do the 'heavy lifting'.



Other ways of helping can be researching, problem solving online or planning the steps. Or helping with repetitive tasks that need to be done at 'some stage' without the high time pressure that can trigger flare-ups.



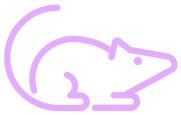
Consider what you can do differently (heat pump dryer gentle on clothes), buying dishes easier to stack/carry and affordable if you drop it (e.g. IKEA OFTAST), investing in epoxy grout (easier to clean) and what you need to outsource with external help/services.



COMMUNICATION STRATEGIES



Sometimes it is not enough to know what you need, it's how to communicate it in a way that produces tangible results. Creating a supportive social environment may be part under your control and partly outside of your control. To reduce overwhelm it is important to label what is and what is not under your control. There are three communication styles; mouse, tiger and owl.



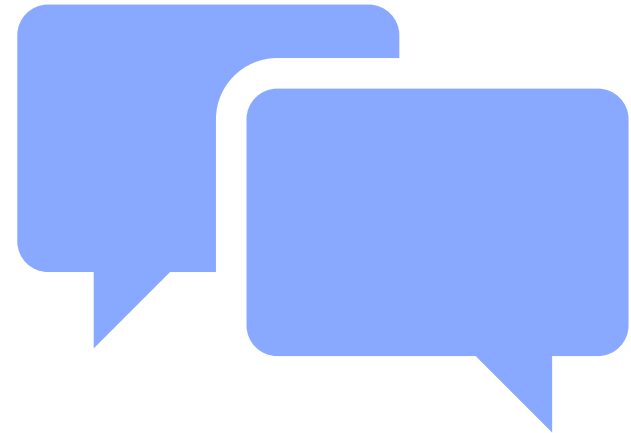
MOUSE: In some situations, people avoid asking to have their needs met because they fear the possibility of conflict. Resentment and fatigue can build internally, and cause symptom flare up.



TIGER: Sometimes one might be very open with their needs. The style might be abrupt, loud volume and time critical, "now!". May use language that is all or nothing, never, always etc.



OWL: Owls are wise, able to problem solve solutions that work for multiple parties and plan ahead. The owl might ask for things by saying "I wonder if we could..." or "it would be great if some stage we could..."



FND PERSPECTIVE

STRENGTH BASED GAME © E TILLEY 2026

Game Scenario 1: Use a dice or random number generator on internet numbers 1-6. You can roll the dice 2 times maximum for free. You can have **extra turns** but you **have to pay 3x coins** for each extra turn. **You have to be blue.** This means you can pass through blue/brown squares but you have to walk around the pink/black ones. You cannot move diagonally. If you walk onto a square with a dollar sign you get 50 extra coins. If you start with 10x coins, how many coins do you end up with at the end?

Game Scenario 2: This time you are pink so you can pass through pink/brown squares but you must walk around blue/black ones. You cannot move diagonally. You can roll the dice 2 times maximum for free or pay extra for more turns (as above). **You can also choose to level up** to a mouse (costs 3x coins) a tiger (costs 3x coins) or an owl (costs 9x coins). If you level up you can ask to choose to change 7x blue squares into pink ones. If you are an **owl**, **all 7x chosen squares will change**. If you are a **mouse**, only **1x square will change**. If you are a **tiger**, only **3x squares will change but 300x coins will be deducted at the end** of the game too. If you start with 10x coins, how many coins do you end up with at the end?

Game Scenario 3: You can **choose what colour** you want to be, you can **choose what level** (owl, mouse, tiger) you want as per extra fee listed above. You can also **choose to lose a turn**- so you will have one turn for free and need to pay for the remaining turns you need to get to the end. **If you choose to rest, you start with 50x coins instead of 10x coins.** How many coins did you end up with at the end?

START			\$							\$					END

FND PERSPECTIVE

FATIGUE SCALE



Fatigue can cause all kinds of problems including emotional dysregulation, symptom flare up and, in a vicious circle, increased sensory issues leading to further fatigue.



It is not always easy to identify you are getting tired until it is too late. When severe fatigue hits without warning, it can impact work and relationships with friends or loved ones.



A starting place can be noticing how your functioning (talking, walking, thinking etc) changes with the first onset of fatigue. You may also have physical symptoms like feeling an itchiness at the back of your head or pounding ears.

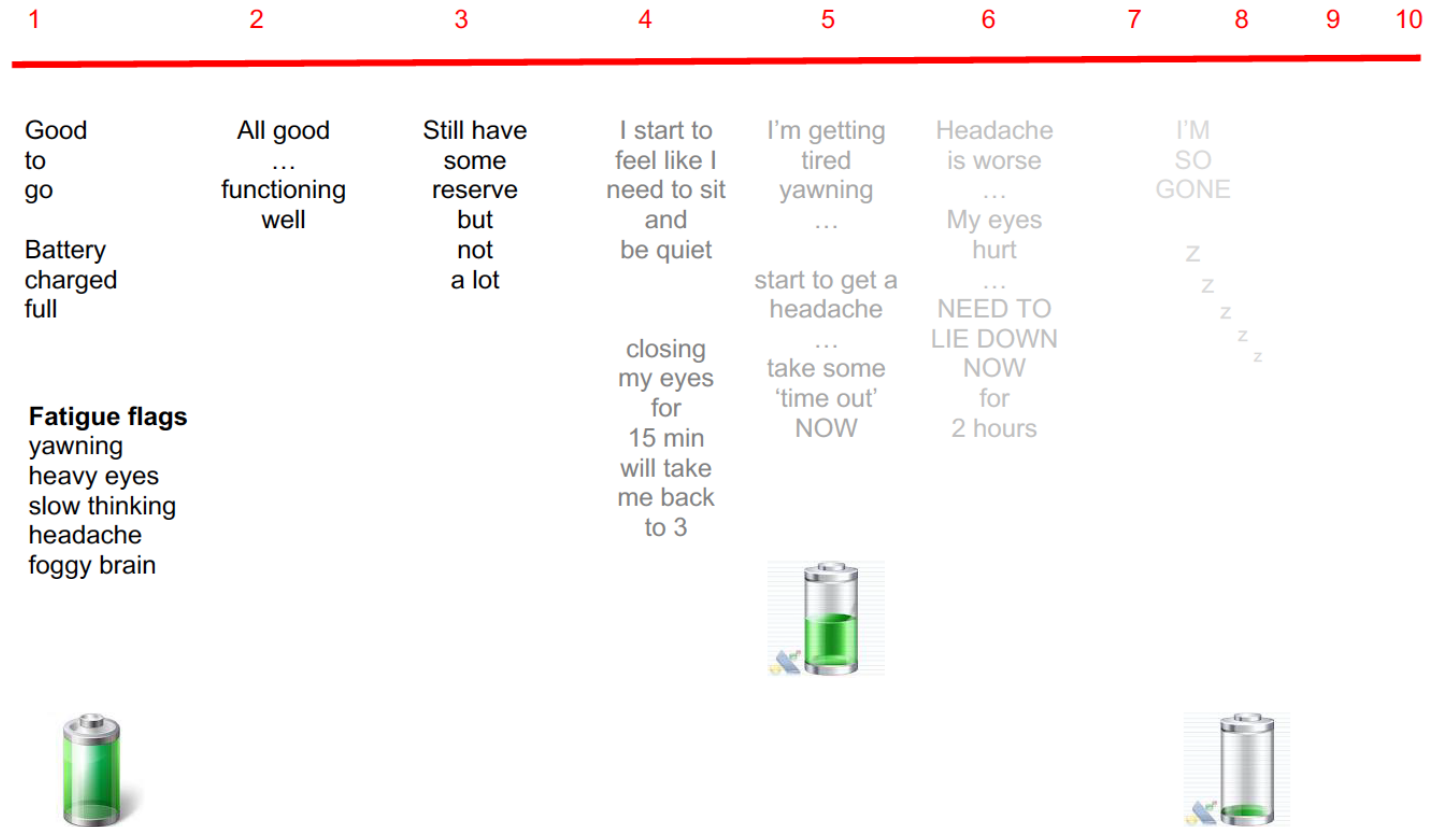


Next you can start to tune into your needs but also share them with the people around you in a way they'll most likely support and understand where you are at. you, and alter your routine way of life to naturally avoid triggers whilst more often.



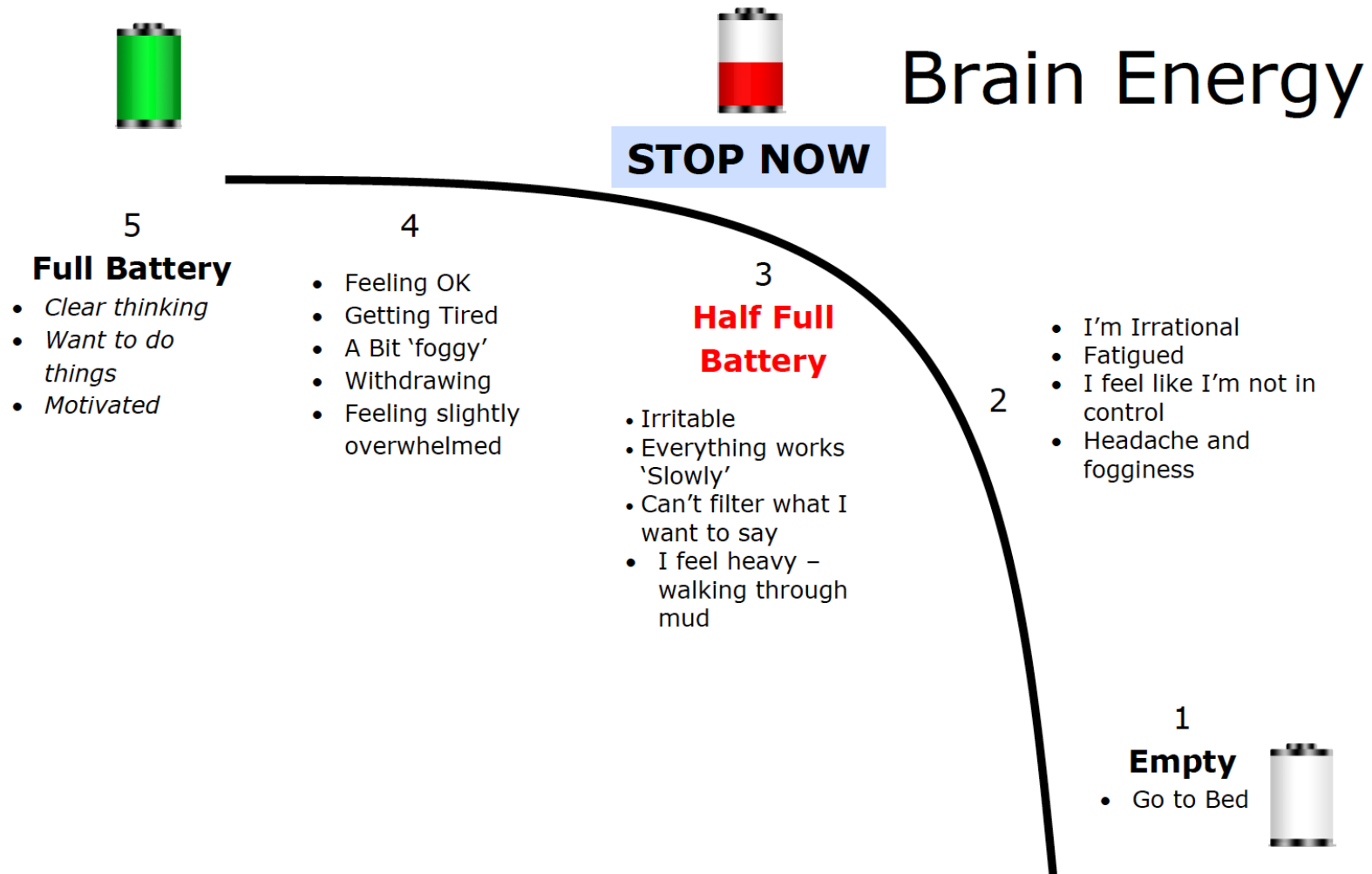
FND PERSPECTIVE

Thinking Energy



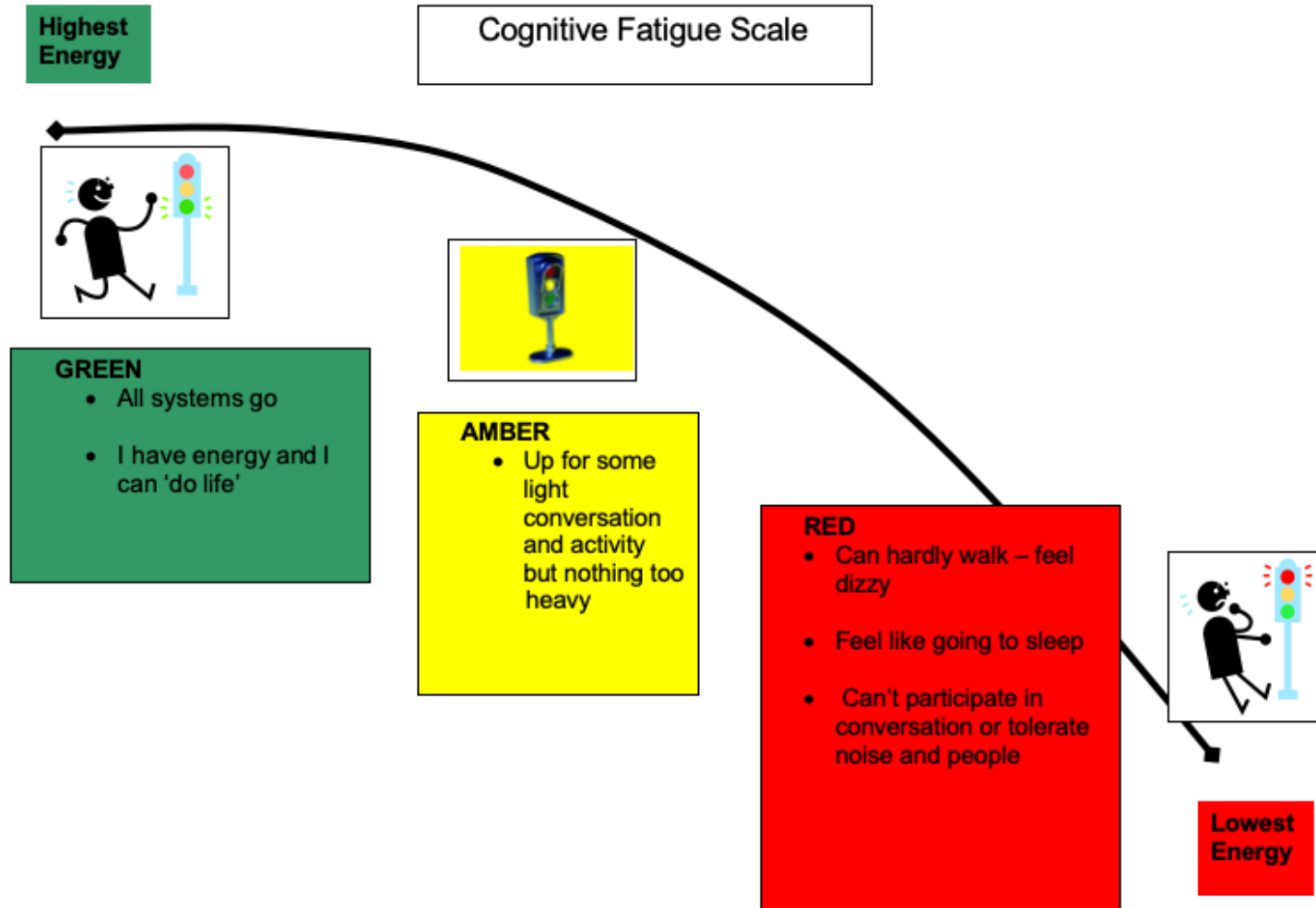
These resource examples only have been kindly shared by a speech pathology clinician- thankyou!

FND PERSPECTIVE



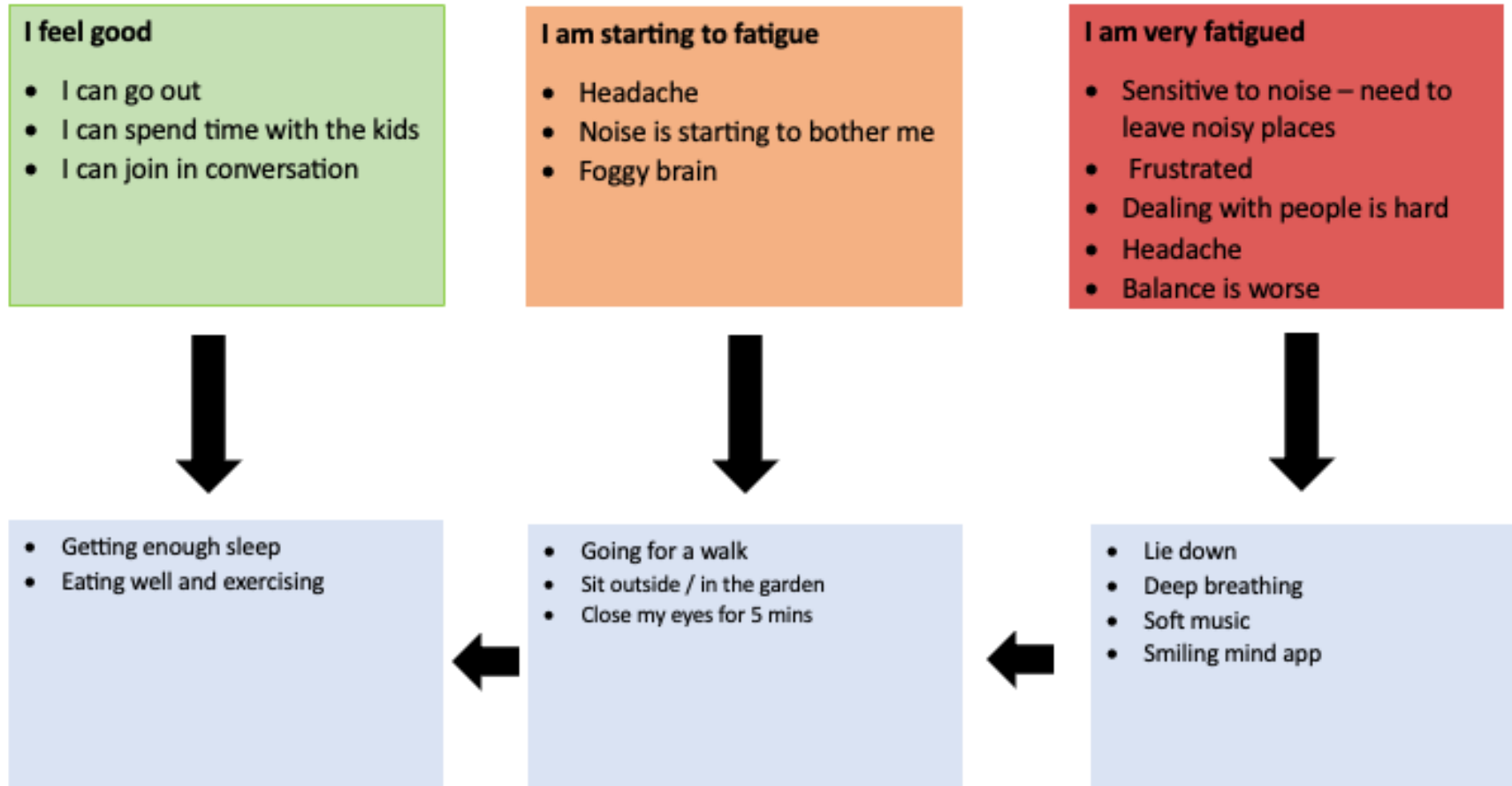
These resource examples only have been kindly shared by a speech pathology clinician- thankyou!

FND PERSPECTIVE



These resource examples only have been kindly shared by a speech pathology clinician- thankyou!





Fatigue Scale



These resource examples only have been kindly shared by a speech pathology clinician- thankyou!

FND PERSPECTIVE

YOUR FATIGUE SCALE

	How does fatigue impact you on a personal, and on a social level (work, relationships with others)?
	What are physical signs (feelings or symptoms in your body)? What might other people see of you? Feeling fresh/not tired: A little bit tired: Severely tired:
	What activities can you or can't you do when you are... Fresh: A little bit tired: Severely tired:
	What helps you? What can other people do to help? If you were to draw your own fatigue scale what would it look like?

FND PERSPECTIVE

EXAMPLE FATIGUE SCALE FOR FND

FEELING HAPPY OR GOOD ENERGY		FEELING TIRED BUT CALM	
LOOKS LIKE	Smiling, animated	LOOKS LIKE	Smiling, bit slow movement
CAN	Short walks, exercise program, gardening, chit-chat/talk outside designated times, onsite work once a fortnight	CAN	Routine TV shows, predictable conversations, slow short walks with rests, ½ exercise program, work with rests.
CAN'T	Can't do things used to do before FND	CAN'T	Can't do loud environment/shops, solve new problems quickly
STRATEGY	Avoid double peak fatigue events where possible, space out onsite work.	STRATEGY	Avoid sensory exposure, finding routines that work for everyone work/or at home, use mobility aids.
FEELING INVALIDATED OR ANGRY		FEELING FEELING LOW OR HELPLESS	
LOOKS LIKE	Frustrated, frowning, upset, tone of voice, not looking at others	LOOKS LIKE	Barely leaving room/bed for a week
CAN	Chat during designated/routine times. Do some sections of exercise routine.	CAN	Work (reading tasks), send SMS, acknowledge help, goodnight routine via messenger kids, playing tapping balloon game from lying in bed. Listen to mindfulness tracks from end of exercise routine.
CAN'T	Can't talk outside of designated times, long conversations. See bigger context as easily. Do balance areas of exercise routine.	CAN'T	Can't do most conversations, chit-chat, solve problems, walk, sit up for long, do most of exercise routine.
STRATEGY	Easy conversations only. Hard ones via SMS. Meals away from fridge sound. Favourite foods. ½ exercise program to regulate. Doing something I know I feel good at or is straight forward work. Psychology/validation. Finding long term solution.	STRATEGY	Modified foods/favourite foods, reading, remember to take vitamins, reducing light in room, wearing sunglasses if leaving room during day. Psychology. Use mobility equipment.

FND PERSPECTIVE

DOUBLE WAVE FATIGUE © E TILLEY 2026



Traditional pacing (or spacing out of activities) is not always simple in FND.



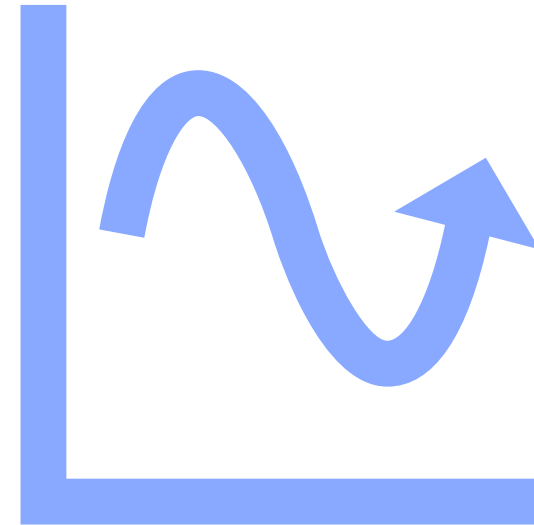
Sometimes some events or activities are so unsuited that they can trigger double wave fatigue.



It can feel like some fatigue after the event, followed by brief recovery and then extreme fatigue approximately 5-7 days afterwards.







It is helpful to identify what these events are, avoid where possible, or if necessary ensure proper rest breaks are scheduled accordingly (do not book back-to-back within the double wave fatigue time span etc.) as fatigue may compound as a result.



FND PERSPECTIVE

DOUBLE WAVE FATIGUE © E TILLEY 2026

	<p>Has there ever been a time where you thought you got through an event relatively unscathed following a short period of fatigue, and then found you were really tired a week later and could not work out what had triggered it?</p>
	<p>If yes, what are the activities? Is it something you really need to do?</p>
	<p>If yes, what about it specifically tires you?</p>
	<p>What are some ways you could do it a different way, or reduce the amount it fatigues you?</p>

FND PERSPECTIVE

WINDOW OF TOLERANCE



Dr Dan Siegel developed the concept of window of tolerance as a picture of hypoarousal or hyperarousal (flight/fright response). The green zone is where life feels easy.



He says its not a problem if you find yourself out of the green zone. It is more about recognising the signs and feelings in your body when that happens, and knowing how you can bring your system from the red/blue zone back into the green zone.



The blue zone is more common when feeling sad, low or shut down.



The red zone is common during times of worry or anger.



FND PERSPECTIVE

RED ZONE (WORRY OR ANGER)

Emotions/thoughts	Overwhelm, panic, anger, rage, feeling unsafe, racing thoughts, flooding of emotion.
Behaviours	Defensiveness, judgemental, impulsivity, rigidity.
Broader impacts	Inability to relax, sleeplessness, and digestive problems.
Maladaptive coping strategies	Overthinking, addictions.

GREEN ZONE

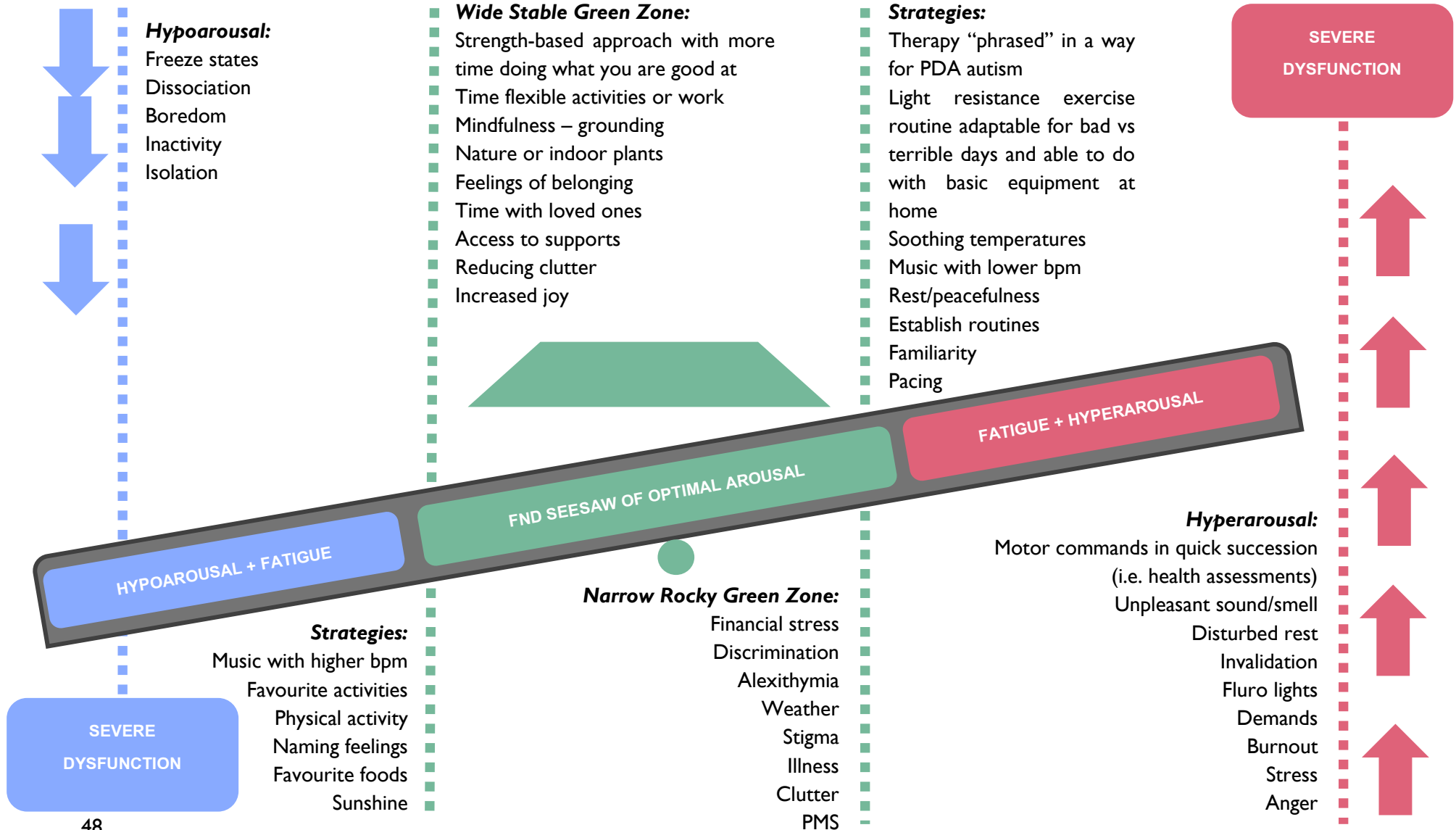
Emotions/thoughts	Feeling open and curious, feeling in the moment, can think and feel simultaneously.
Behaviours	Increased empathy, awareness of boundaries (yours/others), able to adapt to situations.
Broader impacts	Good energy levels, productivity and connection to others.

BLUE ZONE (WITHDRAWAL)

Emotions/thoughts	Numb or no emotions, disconnected, shame, slow cognitive processing, not thinking.
Behaviours	Shut down, flat affect, inability to say no, unable to defend oneself, passiveness, shut down.
Broader impacts	Relative absence of sensation, reduced physical movement, depression, memory loss.
Maladaptive coping strategies	Acting on auto-pilot, excessive napping, chronic avoidance, addictions.

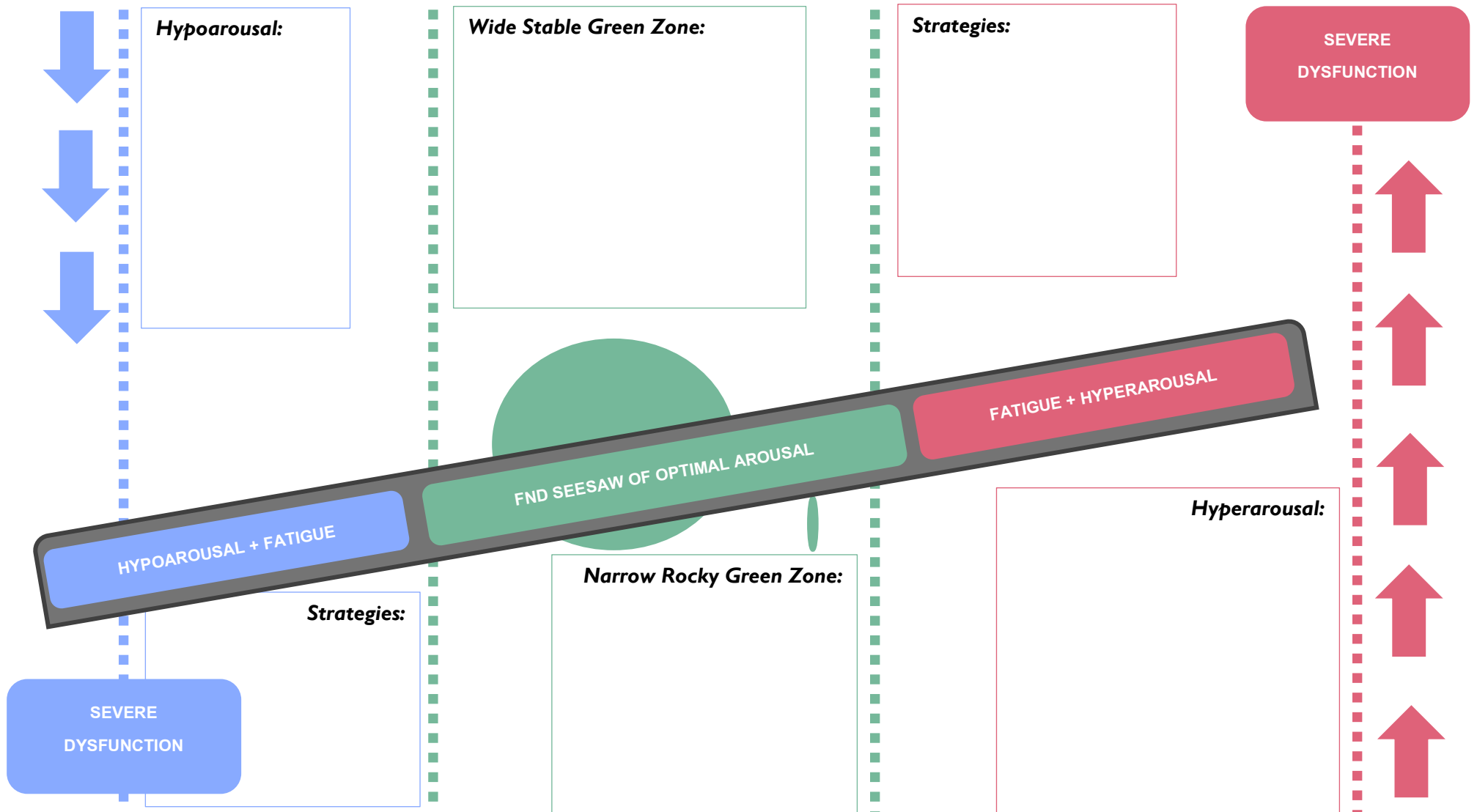
FND PERSPECTIVE

The See Saw model of FND © E TILLEY 2025 outlines suggested strategies to incorporate at time critical points but potentially also aim towards intentional changes to everyday routines to incorporate more of these, more often.



FND PERSPECTIVE

The See Saw model of FND © E TILLEY 2025 Patient Version



SENSORY MANAGEMENT



Hypersensitivity/sensory issues are often a key contributor to FND flare ups including brain fog, speech, swallowing, fluency, and voice problems.



Dysregulation from mismanaged sensory needs can cause flow on effects including disassociation and FND symptoms.



Occupational therapists provide detailed sensory assessments. Speech pathologists are also involved in sensory management in the context of communication and/or swallowing problems for example managing background noise, triggers for laryngeal hypersensitivity, or stimulating taste to support swallowing.



There was a great [study](#) that found that oropharyngeal sensory receptors can be a great “On/off reboot switch” during disassociation by eating something strong like pickle, chili or mints. Medical clearance may be required.







FND PERSPECTIVE

<p>Sensory Triggers</p>	<p>Loud or unexpected noises Unexpectedly touched by something or someone Motion sickness (car, elevators, escalators) Wet clothing (child splashing bath water onto you, wet top after washing dishes).</p>	<p>Very busy environments, crowds. Bright fluorescent lighting Strong perfumes, cleaning products, body odours. Other:</p>	<p>Sensory symptoms</p>	<p>Bothered by background/loud noises Bothered by certain textures (food, certain fabrics/labels on clothes, floor debris,) Sensitivity to bright lights (needing sunglasses, difficulty tolerating fluorescent lighting) Difficulty tolerating physical touch Feeling more clumsy, bumping into things. Using an inappropriate amount of force when handling objects</p>	<p>Intermittent blurry vision/seeing double Difficulty tolerating visual clutter, things lying around the house etc. Difficulty hearing speech over background noise (traffic, multiple people talking) Misinterpret questions and requests, requiring more clarification than usual Feeling of dizziness</p>
<p>General Strategies</p>	<p>Time alone Being around other people Lying down Going for a light walk Exercising Taking a shower Using a cold face cloth Writing in a journal</p>	<p>Drawing Reading a book Colouring Moulding clay Doing chores Humour Listening to music Singing Gardening</p>	<p>General Strategies</p>	<p>Getting a good night's sleep Time outside/nature Deep breathing exercises Meditation Body scanning Engaging in an activity that builds a sense of achievement</p>	<p>Changing thoughts (what's really upset me? What is the worst/or best that could happen? How important will this be tomorrow, next week, next month? What is the bigger picture here?)</p>

FND PERSPECTIVE

<p>Managing sensory difficulties</p>	<p>Sound sensitivities: use ear plugs, headphones, listen to music, close the door (if dryer, washing machine, fridge are loud). Light sensitivities: sunglasses, warm light globes, keep lights off/low.</p>	<p>Car sickness: sit in front seat or drive. Eat something crunchy- mints, dry salty cracker.</p>	<p>Managing sensory difficulties</p>	<p>Double vision: seek optometry assessment for convergence, identify if you require prism glasses when tired (book appointment when your symptoms are worse- end of working week/end of day).</p>	<p>Consider what is your ideal sensory diet:</p>
<p>Do you need calming stimuli?</p>	<p>familiar stimulation activities with positive associations mild stimuli (smells/tastes) quiet environment low lighting repetition consistency low complexity warm temperatures.</p>	<p>decaf herbal tea chewing gum wrapped in heavy quilt shower soft lighting soft or slow music slow and evenly paced rhythms calming sounds of nature soothing or mild scents massage yoga leisure walks soft materials or textures</p>	<p>Do you need alerting stimuli?</p>	<p>novel stimulation or activities fast pace strong stimuli loud environment bright lighting unexpectedness cooler temperatures</p>	<p>cold water or washcloth to face cool room unexpected visual stimuli quick paced or offbeat music alerting sounds of nature (birds) strong or aversive scents (oils/candles) light touch yawning aerobic exercise power walks</p>

SENSORY MANAGEMENT

	What might be some of your sensory triggers?
	Which FND symptoms get triggered by sensory issues in particular?
	What are some helpful strategies?
	Read this study if you have the energy spoons and see if you can find a food that helps you during 'dissociative shutdown'

FND PERSPECTIVE

COST REWARD MAPPING © E TILLEY 2026



Different activities have energy cost to reward benefit ratios. It is important to identify any activity that has High Energy Cost. These can often contribute to FND flare ups, and double wave fatigue (see other patient handout).



What is also important is high reward activities. These are items that are important to maintain in everyday life, in some cases, even though they may come with a high cost if they cannot be done another way or are essential for the current time.



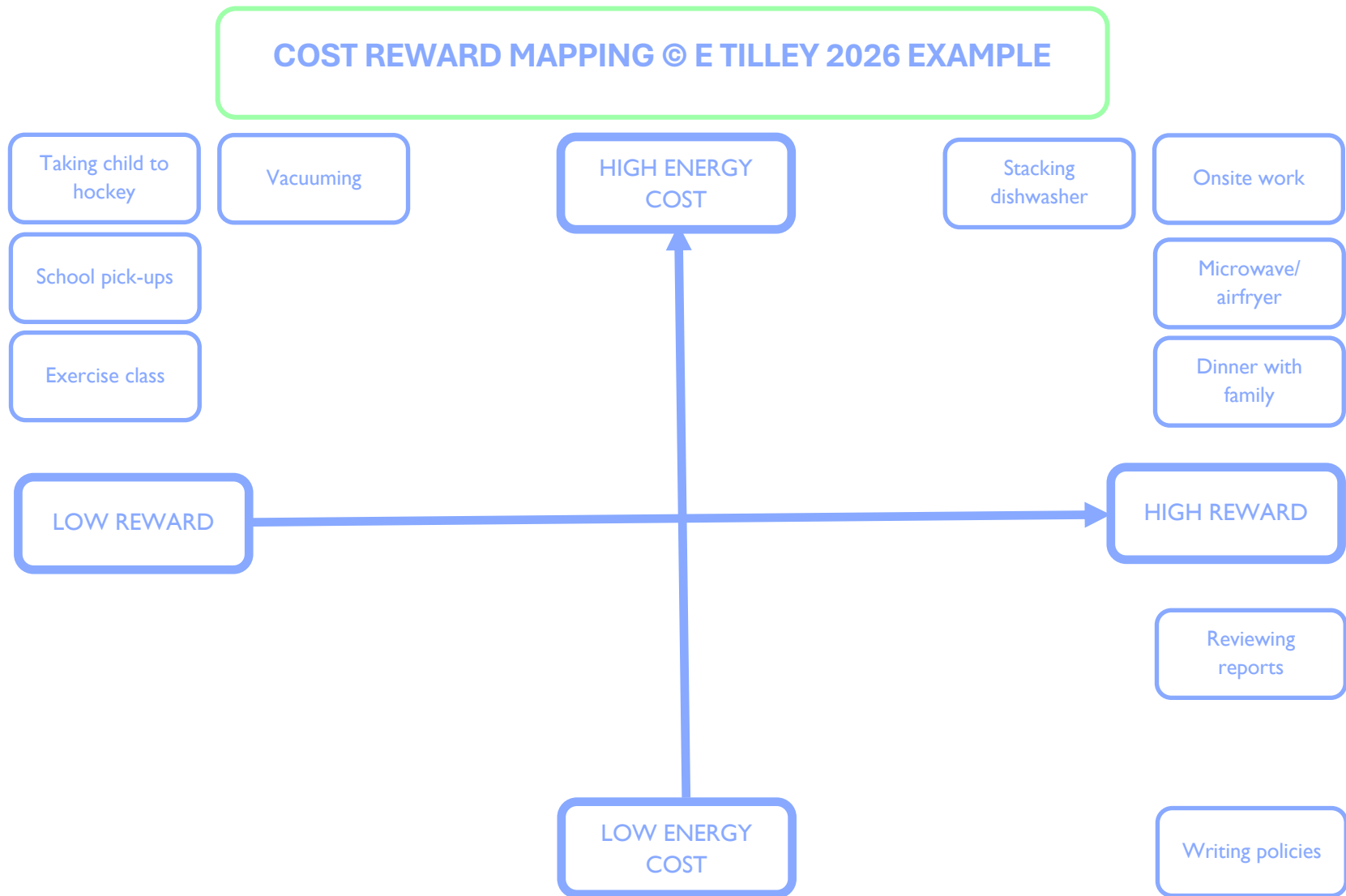
Cost reward mapping involves filling it out from a personal perspective, and then working with others on a group or social level.



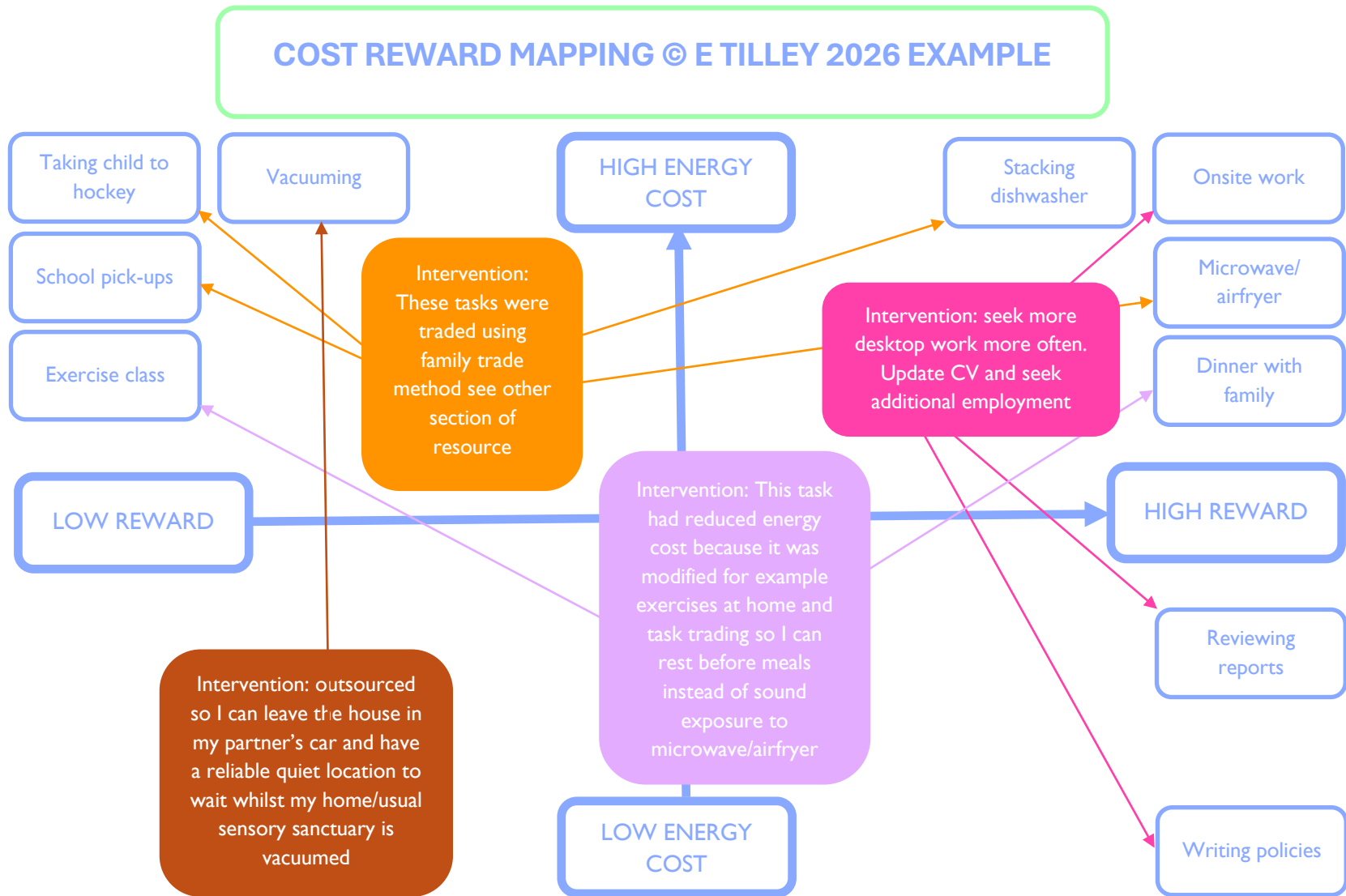
Other people value what they cannot do more. They do not value what you find hard only what they find hard. So, in a group context the same task may be low reward on an individual level if someone else can do it for low effort.



FND PERSPECTIVE

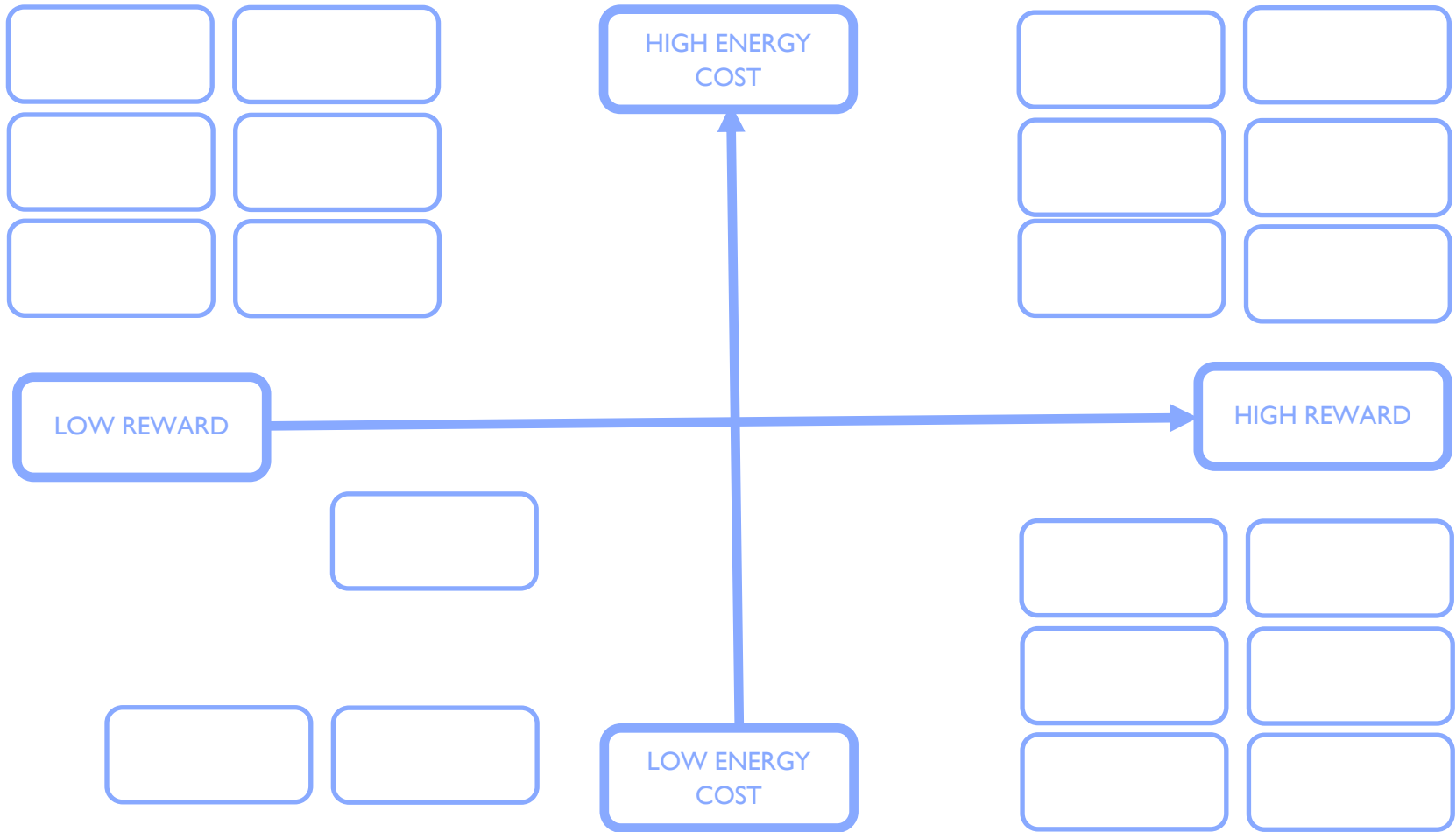


FND PERSPECTIVE



FNO PERSPECTIVE

COST REWARD MAPPING © E TILLEY 2026



ASSISTANCE WITH ADVOCACY SCRIPTS



For big matters if you need a disability advocate, they can speak on your behalf. You can access one from [Ask Izzy Disability Advocacy Finder](#) by entering your postcode to find local options. For everyday situations a health professional who knows you well may be able to assist.



Some people need help scripting their needs calmly and clearly. Sometimes it is hard not to express too much that then gets overlooked. Or to have the function to speak when you need it most to explain what you need to prevent further flare-up.







Letters written for you by your health professional who knows you well are also a great way to help. You might also be able to show it when you experience other similar situations for example using information in a disability parking permit letter of support during a hospital admission when you are unable to communicate your mobility needs during a flare-up.



FND PERSPECTIVE

ASSISTANCE WITH ADVOCACY SCRIPTS

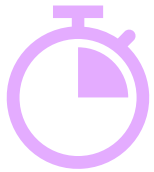
	Are there upcoming interactions in society that you are dreading, for example applications, appointments etc. Because you feel your needs will be misunderstood or misinterpreted?
	If yes, if you had to describe FND in 1-3 sentences how would you describe it? If you had to describe how FND affects you in 1-3 sentences what would you say?
	What are you particularly concerned they will not understand about you? What is the most important thing they need to know.
	If you are comfortable, consider providing the draft to your therapist who knows you to consider as part of their letter they can write to support you.

FND PERSPECTIVE

RATING YOURSELF



It can be helpful to prepare for appointments, keep a track of how your symptoms are going and what strategies are helping by rating yourself. Try to identify what your first priority is so you can make the most of your session.



Be aware that when you give your case history, FND can be more confusing to health professionals as symptoms vary at home compared with clinic. Try not to be too specific so you can paint a clear picture of where you are at on your good vs bad days/moments.



FND also causes a broad range of symptoms that do not map neatly onto speech pathology therapy areas of cognition, speech (articulation, intonation), voice (voice quality), fluency (stuttering), swallowing, inducible laryngeal obstruction (look it up), chronic cough and globus so it may take a few visits to get the help you are seeking.



FND FACTORS SELF-RATED © E TILLEY 2026

SYMPTOM	A	B	C	D	FATIGUE AFFECTED %	DEMAND AFFECTED %	PLANNING AFFECTED %	EMOTION AFFECTED %	SENSORY AFFECTED %	FAVOURITE AFFECTED %	Comments
1. I am unable to swallow when I am hungry and try to eat											
2. It feels like food goes down the wrong way											
3. It feels like drinks go down the wrong way											
4. It feels like there is food stuck in my throat											

A: Symptom not present at all

B: able to manage symptoms with minimal impact to activities of daily living

C: High risk symptom +/- reliably triggered by activities required for everyday living (shops/work, cooking/cleaning, personal care) **and it is essential existing supports are maintained**

D: High risk symptom +/- reliably triggered by activities required for everyday living (shops/work, cooking/cleaning) **and current supports are insufficient or not in place to manage risk to health and safety.**

FATIGUE AFFECTED What % symptom affected by having just woken up +/- end of day or during fatigue flare?

DEMAND AFFECTED What % symptom affected by time pressure, being put on the spot, or following to back-to-back instructions?

PLANNING AFFECTED What % symptom feel like you cannot find the movement you need, getting stuck, like you have forgotten how to do it, or looking back you realise you were unable to break it down into steps?

EMOTION AFFECTED What % symptom affected by your emotion, life stressors or conflict/tone of voice of other person?

SENSORY AFFECTED What % symptom affected by artificial lighting, background sound, weather or other sensory or environment issue for example sound of someone coming into your room.

FAVOURITE AFFECTED What % does your symptom reduce if the activity is related to your favourite (foods, drinks, past-times/hobbies, nice people friends/family/pets). If so, this does not make your symptom less valid, this is possibly due to the collocation of motor and reward/joy brain network pathways.

FND PERSPECTIVE

FND FACTORS SELF-RATED © E TILLEY 2026

SYMPTOM	A	B	C	D	FATIGUE AFFECTED %	DEMAND AFFECTED %	PLANNING AFFECTED %	EMOTION AFFECTED %	SENSORY AFFECTED %	FAVOURITE AFFECTED %	Comments
5. I have trouble with excess saliva or drooling											
6. I have trouble with clear mucous											
7. I have trouble with nausea +/- vomiting											
8. I have unintentional weight loss											

A: Symptom not present at all

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FND PERSPECTIVE

FND FACTORS SELF-RATED © E TILLEY 2026

SYMPTOM	A	B	C	D	FATIGUE AFFECTED %	DEMAND AFFECTED %	PLANNING AFFECTED %	EMOTION AFFECTED %	SENSORY AFFECTED %	FAVOURITE AFFECTED %	Comments
9. I am unable to talk when I need to											
10. I have slurred speech											
11. I stutter when I talk											
12. I have trouble finding the right word											

A: Symptom not present at all

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C: High risk symptom +/- reliably triggered by activities required for everyday living (shops/work, cooking/cleaning, personal care) **and it is essential existing supports are maintained**

D: High risk symptom +/- reliably triggered by activities required for everyday living (shops/work, cooking/cleaning) **and current supports are insufficient or not in place to manage risk to health and safety.**

FATIGUE AFFECTED What % symptom affected by having just woken up +/- end of day or during fatigue flare?

DEMAND AFFECTED What % symptom affected by time pressure, being put on the spot, or following to back-to-back instructions?

PLANNING AFFECTED What % symptom feel like you cannot find the movement you need, getting stuck, like you have forgotten how to do it, or looking back you realise you were unable to break it down into steps?

EMOTION AFFECTED What % symptom affected by your emotion, life stressors or conflict/tone of voice of other person?

SENSORY AFFECTED What % symptom affected by artificial lighting, background sound, weather or other sensory or environment issue for example sound of someone coming into your room.

FAVOURITE AFFECTED What % does your symptom reduce if the activity is related to your favourite (foods, drinks, past-times/hobbies, nice people friends/family/pets). If so, this does not make your symptom less valid, this is possibly due to the collocation of motor and reward/joy brain network pathways.

FND PERSPECTIVE

FND FACTORS SELF-RATED © E TILLEY 2026

SYMPTOM	A	B	C	D	FATIGUE AFFECTED %	DEMAND AFFECTED %	PLANNING AFFECTED %	EMOTION AFFECTED %	SENSORY AFFECTED %	FAVOURITE AFFECTED %	Comments
13. My speech intonation is different											
14. My voice is too quiet or rough											
15. People are unable to understand me when I talk											
16. I do not have a way of communicating when I cannot talk											

A: Symptom not present at all

B: able to manage symptoms with minimal impact to activities of daily living

C: High risk symptom +/- reliably triggered by activities required for everyday living (shops/work, cooking/cleaning, personal care) **and it is essential existing supports are maintained**

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FND PERSPECTIVE

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SYMPTOM	A	B	C	D	FATIGUE AFFECTED %	DEMAND AFFECTED %	PLANNING AFFECTED %	EMOTION AFFECTED %	SENSORY AFFECTED %	FAVOURITE AFFECTED %	Comments
17. People say no to me more than they do to others											
18. People do not believe me when I say I need things a certain way											
19. My personal relationships are affected because of my manner											
20. My work or study are affected because of my manner											

A: Symptom not present at all

B: able to manage symptoms with minimal impact to activities of daily living

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FND PERSPECTIVE

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SYMPTOM	A	B	C	D	FATIGUE AFFECTED %	DEMAND AFFECTED %	PLANNING AFFECTED %	EMOTION AFFECTED %	SENSORY AFFECTED %	FAVOURITE AFFECTED %	Comments
21. I have trouble finding the words to say no, or explain I cannot do something											
22. When tired or stressed I have trouble understanding or mishear. It's like my brain will make up what they have said instead											

A: Symptom not present at all

B: able to manage symptoms with minimal impact to activities of daily living

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FND PERSPECTIVE

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SYMPTOM	A	B	C	D	FATIGUE AFFECTED %	DEMAND AFFECTED %	PLANNING AFFECTED %	EMOTION AFFECTED %	SENSORY AFFECTED %	FAVOURITE AFFECTED %	Comments
23. I have trouble reading due to double vision											
24. I experience brain fog or difficulty thinking when tired											
25. I have trouble staying on topic when talking											

A: Symptom not present at all

B: able to manage symptoms with minimal impact to activities of daily living

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FND PERSPECTIVE

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SYMPTOM	A	B	C	D	FATIGUE AFFECTED %	DEMAND AFFECTED %	PLANNING AFFECTED %	EMOTION AFFECTED %	SENSORY AFFECTED %	FAVOURITE AFFECTED %	Comments
26. I have an irritable cough that has lasted more than 2 months											
27. It feels like my throat is constricting or my airway is being cut off. It comes on suddenly and then stops.											
28. After I heat my food up in the bowl I am too tired to eat.											

A: Symptom not present at all

B: able to manage symptoms with minimal impact to activities of daily living

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SUMMARY SHEET FND FACTORS SELF-RATED © E TILLEY 2026

NAME:

DOB:

DATE:

	A	B	C	D	FATIGUE AFFECTED %	DEMAND AFFECTED %	PLANNING AFFECTED %	EMOTION AFFECTED %	SENSORY AFFECTED %	FAVOURITE AFFECTED %
Number of items with this rating					Average					

A: Symptom not present at all

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FND PERSPECTIVE

U-PERFORMANCE OF AROUSAL

The Yerkes-Dodson Law suggests that there is an optimal level of arousal that facilitates optimal performance at work. There is a useful video to watch [here](#). If your stress levels are too low (boredom, no time pressure, repetitive tasks) your productivity will suffer. If your stress levels are too high (extreme time pressure, high work demands) you will also have low performance.

But, if you find the sweet spot in the middle with optimal levels of stress, your productivity will be working at its best. FND possibly creates a kind of sensitivity where it can be challenging to get the optimum level of arousal for everyday activities including things like going to the toilet, resting, eating, and walking. The slightest background sound, change to someone's tone of voice, or someone entering the room can be like a balanced see-saw one second to a truck thrown on one end the next. Sometimes it can be helpful to use music at a certain number of beats per minute to cue the arousal level indicated by each type of task. Some music beats per minute suggestions below by type of task, but in the words of Zan Rowe, "what's your next choice?" FYI I have found headphones are helpful to maximise effect of music and also impacts other people in the environment less.

Old yoga songs to
new exercises I can
do now instead



Rest/unwinding
100 bpm
*Comptine d'un autre
été, l'après-midi"*



Eating or drinking
143 bpm
João Louisa Sobral



Walking
?85bpm
Edithvale Bec Sykes



Number 2's
143 bpm
João Louisa Sobral

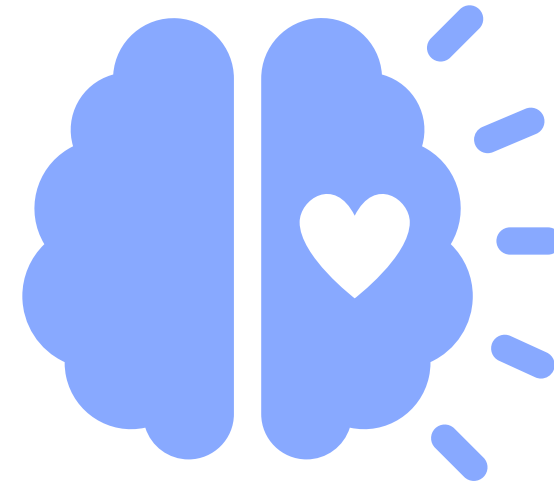


High emotion work
100 bpm
*Comptine d'un autre
été, l'après-midi"*



FND PERSPECTIVE

FND PERSPECTIVE



CLIENT CASE EXAMPLES FOR HEALTH PROFESSIONALS

FUNCTIONAL NEUROLOGICAL DISORDER

By Erica Tilley *BSp Path, MClSci*

ericatilley@live.com.au

FND Perspective

24-3-26 v2.5

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BURDEN OF FND AND THERAPY © E TILLEY

Imagine that everyone had a tapestry that represented their life. The black sections were stitches that represent how much time or space is occupied with 'productive' activities such as work/earning an income, performing home tasks, and carer responsibilities. The white sections were resources for downtime, for example time with loved ones, relaxing with friends, hobbies and sleeping.

Exercise 1

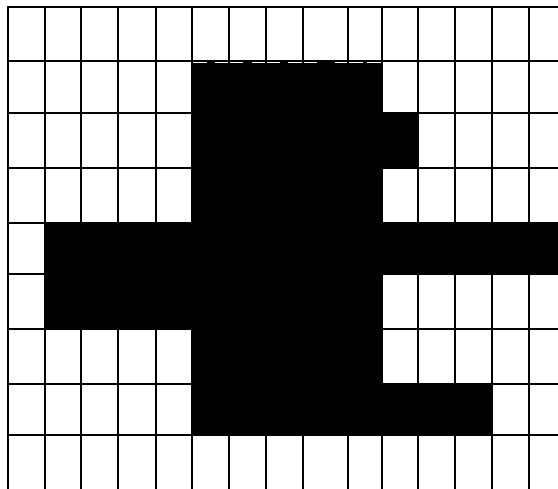


Fig 1. The right kind of balance between work, jobs around the house (black squares), rest and play (white squares). **Instructions: take a pen and colour in 1x extra square in a different colour.** This would be the load of taking on a therapy session once a week as part of 'life'. This can help you to imagine your impact as a clinician. Your hope is that the therapy costs a square but long-term maybe the person can build a spare white square capacity in future because they have accessed effective therapy.

Now imagine you are the person with the tapestry of life, and you had what was as close to as a perfect balance. You did not get it right every time, but mostly everyone was pretty happy with your contributions, you had a way of earning enough to live on, go on holiday, and even make little upgrades to your house. Your kids' needs were met, you had a great relationship with your spouse, you had the odd night out with friends, and finally you were aware that you were soon to be promoted at work due to recognition of your performance. But then one day you got a horrible cold that did not go away for three weeks.

BURDEN OF FND AND THERAPY © E TILLEY

Exercise 2

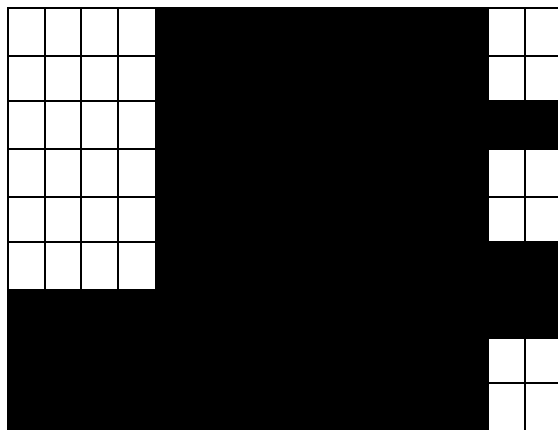


Fig 2. Suddenly, you found that whilst having a cold, work (black squares) took up double what they usually did, leaving limited time for rest and play (white squares). **Instructions: take a pen and colour in 2x extra squares in a different colour.** This would be the load of taking on a therapy session once a week as part of 'life' in addition to everything else.

You found yourself postponing catch-ups with friends, and you took on less projects at work to compensate. Your kids were upset you couldn't make it to their soccer match like you usually do, and date-night with your partner was the last priority at the moment. Even surviving felt like a struggle, everyone was disappointed that you were not more available. Getting better was harder as you had no time for downtime because anytime you weren't working or doing jobs you had to nap you felt so run down. Luckily, its only short term, and you find yourself bouncing back to the way it was before.

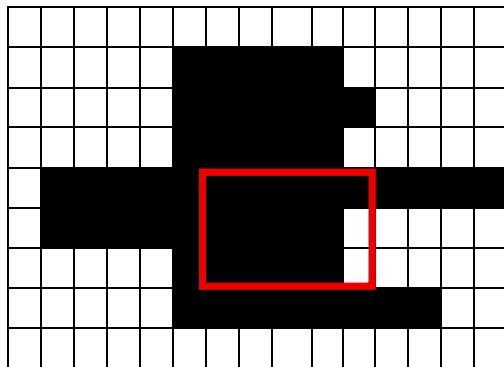


Fig 3. FND capacity in red overlay compared with normal capacity. With FND, it is more like you have reduced capacity by a factor of three. So using Fig 1, you would have the area contained within the red box. Prior to developing FND you may have had other neurodiversity factors which meant you were already on two-thirds of what everyone else has, but FND takes it down that critical notch further.

The worlds of people with FND become extremely small after onset. People find that they can rarely leave the house, they are financially destitute, and when they are not sleeping, they are basically finding ways to survive with what fragments of energy they have left. Stages of burnout extend into new realms never experienced before including incontinence, drop attacks (collapsing whilst remaining conscious),

FND PERSPECTIVE

falls, inability to talk, swallow and functional seizures. Symptoms can come and go seemingly without reason, and the only certainty in life is that you are disappointing everyone in society, including yourself.

As a clinician, it does not take much to probe and find out just how limited people are functioning. It can just take a moment of your internal judgement or opinion towards your patient, fluorescent office lighting, or asking people to perform motor tasks in quick succession to trigger FND symptoms in what might otherwise look like a 'normal' presenting individual.

BURDEN OF FND AND THERAPY © E TILLEY

Exercise 3

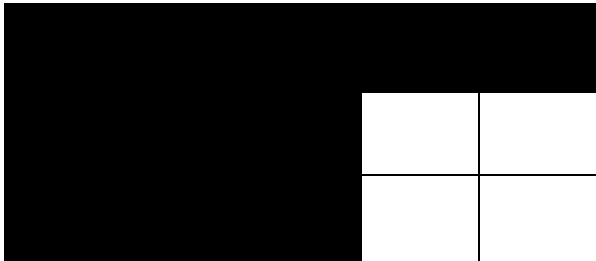


Fig 4. Capacity just after developing FND. Now remember what we talked about with therapy sessions taking up one square. **Instructions: this time colour in three squares to represent burden of a therapy session now that task burden is at factor 3. Compare the black vs white space.**

FND PERSPECTIVE

These are the narrow margins of error that people with FND experience. There is a struggle between surviving in the current day, and investing energy into how to live in the future. Just like people without FND, we just want to be able to live life and go for a walk in the park. Our walk is not that simple, as we have cliffs either side, but does not mean we cannot (or are not worthy of help to) build a paradise up top.



Images from: <https://thelongwaysbetter.blogspot.com/2018/04/cape-raoul-track-tasman-national-park.html>

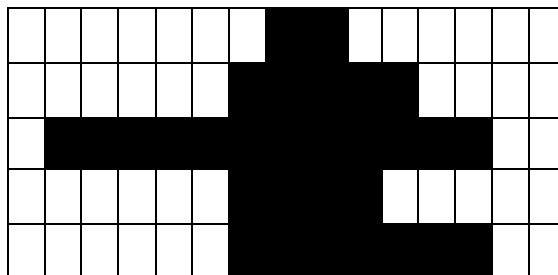


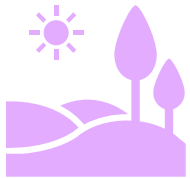
Fig 5. Surviving with FND is about thinking creatively, taking calculated risks, expanding the tapestry as far as it will go, and reclaiming functions of activities (but not the identical activities themselves) but this time in a different more sustainable way.

As a clinician, you have all the tools you need to know to help people with FND with their symptoms. It is more about being mindful of how you frame your approach, how you cultivate rapport and trust, and your awareness of where your intervention fits in as part of that person's journey in reclaiming a semblance of quality of life since developing FND.

REDUCING CLINICAL DEMANDS



Accessing healthcare can be a challenge even before it begins. This includes fatigue from simply spending time in the car to get to the appointment.



It is possible to reduce clinical demands by providing information about parking/directions, and offering the option of waiting in a spare room to reduce background noise/turn off lighting, and a picture of nature or an outside window.



Other strategies that can help include providing questionnaires before the assessment and reading responses so you only need to ask specific questions/reduce energy load.



Asking for motor movements in quick succession can also trigger symptoms. If you need to do this it is better to wait until the end of the session. It is also good practice to ask for consent, and how shall we do this, or this is the type of information I need what would be the best way for you?



FND PERSPECTIVE

Speech Pathology Resource (Patient Handouts) for Adults with FND) pdf \$30 for clinicians, \$5 for people with FND

- *Free for Aboriginal and Torres Strait Islanders and or health professionals who also have FND*
- FND Perspective offers lived experience supervision, including supervision log records, and presentation/workshops.
- If interested please contact me to request/quote: ericatilley@live.com.au
- I develop FND Perspective resources in my own time, if you haven't already if could take a moment of your time to make a \$30 donation for this slides/patient handouts/clinical resources, and support future projects, I would really appreciate it. You can do this via Send Money (Paypal) to ericatilley@live.com.au. If you do not have PayPal you can set up a new account or email me for alternative payment methods thankyou.
- This resource is not a replacement for clinical advice- seek individualised care from your treating team. It contains a number of strategies which are newly developed and/or have not been researched in people with FND to check effectiveness or safety.

EVIDENCE BASED GUIDELINES



There are problems with the 2021 FND Evidence Based Guidelines, in particular for dysphagia in the supplementary material. I outlined these in a presentation for FND Awareness Day 2026 (see start slides) and guest podcast episode on Mindful Speechies Podcast episode September 2025.



Effective strategies that people with FND lived experience expertise use, myself included, are classed in the guidelines as 'maladaptive behaviours'. This creates unnecessary invalidation and prevents optimal functioning.



"Problem behaviours" include avoidance of solids, withdrawing from others and eating in isolation, and having the perception that swallowing is dangerous, harmful or effortful (when steps do need to be taken to manage swallow safety risks, and swallowing can be very effortful in FND)



It also states that functional dysphagia is more often oropharyngeal rather than oesophageal, however people with FND, myself included commonly have oesophageal dysphagia.



DYSPHAGIA

Specific symptoms: functional dysphagia

Functional dysphagia is more often oropharyngeal rather than oesophageal since oropharyngeal musculature is under voluntary rather than autonomic control. For both types of dysphagia exclusion

– Maladaptive behaviours, e.g. Avoidance of solids, withdrawing from others, eating in isolation.

- *Supplementary material Speech Pathology FND Guidelines*
- *jnnp-2021-October-92-10-1112-inline-supplementary-material-1*

▶ Perception that voice use or swallowing are dangerous, harmful, effortful

CASE STUDY VFSS IMAGE CAPTIONS



Figure 1: Note moderate laryngeal penetration during swallowing. Effectively cleared during the swallow.



Figure 2: Trace to a mild amount of vallecular residue.



Figure 3: Spillage of the liquid to the vallecular region prior to swallowing initiation with dual consistencies



Figure 4: Image of the distal oesophagus following swallowing of bread. Possible retrograde bolus transit from the stomach.

REASSURE-WASHING © E TILLEY

- The VFSS study (gold standard assessment of swallowing included these captions and images above. But given the report write up summary below there is mismatch in the findings.
- For example, the summary of the report says there was no penetration into the laryngeal vestibule which differs from the findings from Figure 1.
- There is also no mention of possible retrograde bolus transit from the stomach outlined in Figure 4.
- In practice, swallow function varied a lot between swallow trials with some swallows a lot better than others. However, the report summary brushes over this. In general, I found the clinician to be dismissive of any use of strategies, but I do not hold a grudge as this is in line with the current evidence-based guidelines.
- This is a practice I've termed 'reassure-washing' which is like 'mansplaining' but different. My hope that this example can help to raise awareness that the evidence-based guidelines for FND require urgent review.
- As well, please note that using words like 'functional', 'reassurance' and 'self-reported' (as if it is not a valid thing to say or experience) are not neuro-affirming terms to use, and can cause further FND flare-up via invalidation and hyperarousal pathways.

CASE STUDY VFSS REPORT SUMMARY

Erica presents with a **functional** oropharyngeal swallow. Today's observations are consistent with Erica's reported expectations of the assessment findings which hopefully have provided some **reassurance**. She acknowledges that environmental factors, such as children ***, may aggravate her **self-reported** dysphagia symptoms. Please note that **no penetration into the laryngeal vestibule** or aspiration below the vocal folds was observed. The images were reviewed with Erica. **Some mild residue was observed in the distal oesophagus with solid foods, without reported sensation, and was effectively cleared with a drink.** We discussed the possibility of a review by a Gastroenterologist.

AFFIRMING PRACTICE CASE STUDY

Community Speech Pathology Mealtime Management Plan

Findings: Erica presents with oropharyngeal dysphagia secondary to FND which fluctuates with her FND symptoms and with stress, fatigue and sensory overwhelm.

At times she is able to tolerate a regular diet and fluids well, however at other times experiences difficulty with oral preparation of harder foods, coughing on food and fluid and a sensation of pharyngeal residue. She is suitable to continue on a regular diet and fluids, with diet modifications (soft/easy to chew or puree diet) when required.

Erica has good awareness of her swallowing and can identify the need to modify her diet as required. She will benefit from an environment which considers her sensory needs at mealtimes to reduce challenges. This includes a calm environment including everyone staying seated during shared mealtimes, and turning off background noise/no dishes/dishwasher. She has also experienced some success using a specific upbeat music song on repeat during mealtimes when very fatigued. In the case of acute medical illness and/or hospitalisation she would benefit from swallow review.

AFFIRMING PRACTICE CASE STUDY

Recommendations:

- Erica does not require supervision during mealtimes but may require assistance with set-up to reduce fatigue during mealtimes.
- Reduce sensory overload in the environment in line with sensory assessment.
- Reduce distractions / overwhelming situations during mealtimes.
- Requires a drink with each meal [fluid chasers]
- Extra sauces-gravies

Recommendations for worse days:

- Eating alone
- No dual consistencies
- Fizzy/naturally thick drinks if fatigued
- Calming strategy involves playing song on repeat: Joao Louisa Sobral
- Main meals earlier in day to minimise fatigue

FND PERSPECTIVE

AFFIRMING PRACTICE CASE STUDY



A Mealtime Management Plan was developed by a Speech Pathologist based in the community.



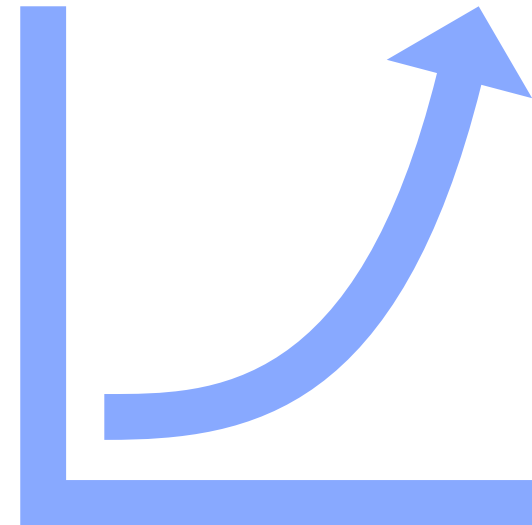
I like that my level of dysphagia is not specified given it fluctuates, and there was consideration of both case history as well as assessment.



I feel relieved knowing that the strategies I use are documented so I can use my plan to self advocate if I am ever unwell and not able to communicate as happened previously. It also has been good for my support network when I have been too tired to speak up. Since the report, I spend less energy getting my needs met now everyone understands.



I hope one day this will become the norm rather than the exception for FND care. There could be a lot to be learned by consulting with people with lived experience of the range of speech pathology FND symptoms.



FND PERSPECTIVE

CLEAR MUCOUS AND NAUSEA



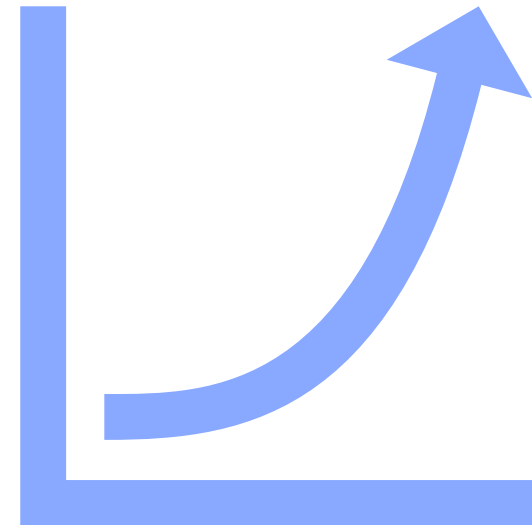
I had heard of symptoms like excess clear mucous, nausea and 'stomach spasms' and did not used to know how patients could manage these. More research and attention are required. Since developing some of these symptoms I have outlined some suggestions below however medical clearance may be required.



Clear mucous: more common when overloaded/pushing body to extremes, eaten more dairy. Very stringy/sticky, triggers vomiting. May have origins in hyperactivity of the nervous system. **Strategy for clearing mucous:** gargling ½ tsp salt/bicarb with hot water whilst also using FESS nasal spray for the nasal cavity to break up stickiness. General fatigue/regulation strategies and lifestyle/reducing stressors also more broadly unless unavoidable.



Nausea/vomiting can usually be held at bay with mints as [my on/off switch](#) for sensory dissociation grounding technique but not effective when mucous there too. The study in the link is worth a read but possibly works by stimulating oropharyngeal receptors (via chilli, pickle, mint etc) to 'reset' the sensory system during sensory crisis or disassociation. They recommend medical clearance by doctor in case of functional/dissociative seizures first or medical contraindications like allergies, fluid or salt restrictions.



FND PERSPECTIVE

SAFE SENSORY FOODS



When taking case history, it can be tricky to navigate spaces where there are symptoms of dysphagia, opting for modified consistencies, but then simultaneously a dependence/frequent intake of a food that is outside of that IDDSI category as it is classed as Level 7- Regular Food. In the case history, these foods are not reported to cause the same swallowing foods as other foods (including more modified consistency foods).



I have tried to highlight to clinicians that symptoms in FND do not easily 'map onto' existing strategies used with other patient cohorts. There is a FND Factors Self-Rated exercise in the patient handout section which seeks to measure from the patients' perspective the impact of fatigue, demand (vs lower demand from flight/fright context), executive functioning (cognitive and motor), emotion hyperconnectivity with the motor pathways (underlying mechanism found in FND), sensory influence and also motivation/reward pathways that are collocated with motor pathways.



In this context it may be possible to understand that if there is a certain food craving, or texture/taste (it is unfortunately not always the healthiest food) it helps to override the sensory dysregulation/hyperactivity. Perhaps working on the same network in the opposite direction of the noxious tastes by the "pickle" researchers above. My experience is that I have been at aspiration risk for a modified food but able to tolerate a hard consistency food that met reward pathways. The best option is likely to support patient autonomy and teach insight rather than a rigid IDDSI approach.



FND PERSPECTIVE

MANUAL SETTINGS



Imagine a dial on a BBQ that you need to twist and double check the setting each time compared with the dial on your cooktop that has numbered settings.



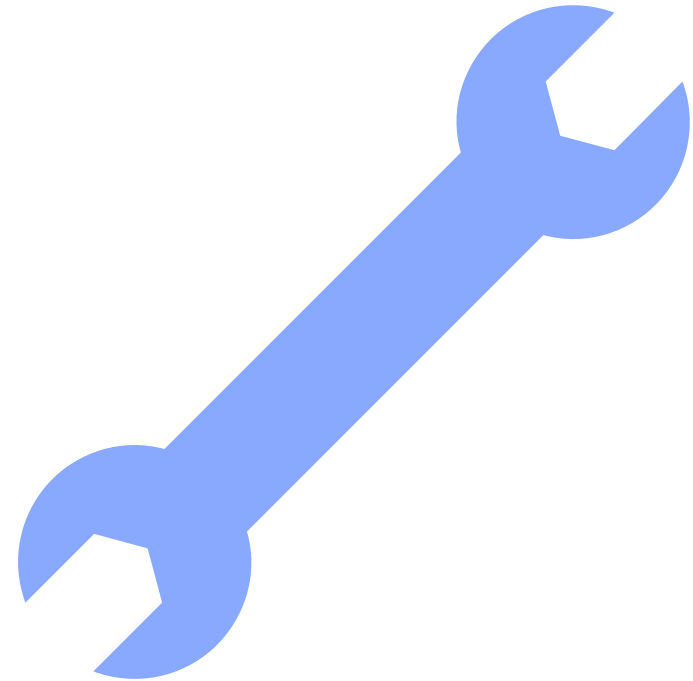
For me, on bad days, I cannot control the loose dial and rely on having numbered settings. I do this using music of different beats per minutes for mundane activities like eating (see U-Performance Arousal in patient handouts) I use the song João Louisa Sobral at 143 bpm.



The only downside is when you are mid-swallow in the short break between repeats, or you've forgotten to press repeat and the wrong song comes on mid-crossing the road (walking is slower than eating song). The wrong song is worse than no music at all. It feels like your body has been caught in a bad traffic jam.



More research is needed. I do not know if it is modulating arousal levels and reducing flight/fright response, or overriding size of movement/supporting coordination via basal ganglia or both. But it may be worth exploring what paced songs suit patients best during eating/drinking much like how physios help patients find their favourite walking-paced song to support functioning.



SPEECH THERAPY TARGETS FND

The self-rating tool in the patient handout section aims to provide clinicians with a broader understanding of patient symptoms in FND, and therapy targets. Ideally, speech pathologists stay involved with patient care as they are best suited to assess and identify improvements in communication and swallowing disorders in the context of “up-stream” interventions targeting fatigue, demand, planning (Executive functioning), emotion, sensory (triggers) and activities that bring joy/safety.

Fatigue management can include things like having main meals earlier in the day, and smaller more frequent meals, to strategies of managing fatigue in everyday life. People with FND often struggle to self-advocate and a big part of this is supporting them with scripts and support to communicate in a way that the information will be more warmly received by the conversation partners they depend on to be mindful of their needs which helps to reduce flare-ups. Social strategies can also extend to how to identify a safe person or best person to talk to at work to get needs met, and identify relationships personal/professional that are equal give and take.



SPEECH THERAPY TARGETS FND

Demand management is about adapting the assessment process to be more consultative/less hierarchical or time pressured with a focus on relationship over compliance. It is more about a partnership and finding a shared way forward. There is also detailed information regarding speech pathology conversation partner training for PDA autism can be helpful in the FND space too.

Executive dysfunction is often impaired/variable in people with FND. Not dissimilar in the way fatigue can impact on coordination and motor planning in elite athletes [under conditions of fatigue](#). When people with FND talk about 'forgetting' how to talk/swallow or getting stuck, they may be referencing executive function issues under conditions of fatigue.

Emotion literacy is often very poor. Speech Pathology to recognise emotions in self and others can be helpful and matching vocabulary with physical sensations. Or might prefer getting better at spotting moments of calm vs 'this conversation is now high stakes' vs clear conflict occurring. Clear steps to navigate conflict situations with rationale of efficiency, for example the importance of repeating back statements another person has said " I can see how x,y,z would have been frustrating, I am sorry. Next time I will.... for me x, y z was hard for me and next time it would be helpful if you could a,b,c".



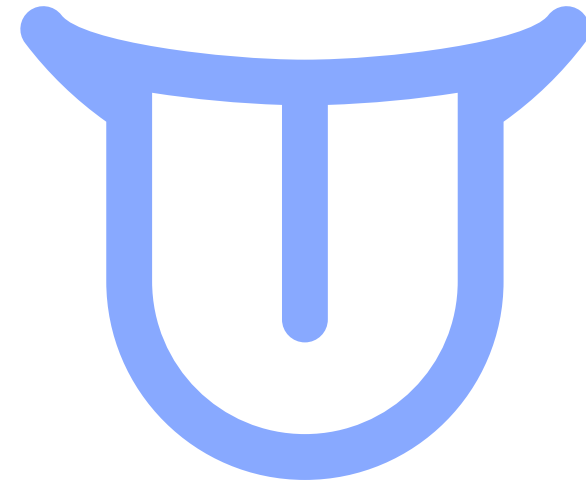
SPEECH THERAPY TARGETS FND

Speech pathologists are very good at helping to identify sensory triggers, for some of the best examples see the works of Anne Vertigan in the identification and avoidance of triggers for laryngeal dysfunction such as cold air, perfume/strong smells, etc. **The most important aspect speech pathologists can assist with is helping patients to find their sensory “on-off reboot switch” by stimulating oropharyngeal receptors with strong foods.**

Some often ‘blanket’ sensory strategies for FND include things like ear plugs, noise cancelling headphones, sunglasses inside, natural lighting, visiting at ‘off-peak times’, and strategies associated with auditory processing.

Auditory processing fatigue can be improved by strategies such as reducing multi-person conversations (setting up intentional 1:1 interactions) to support social connection in a sustainable way and scheduling more predictable activities with more people, and novel activities 1:1 to reduce ‘load’.

It’s helpful to teach conversation partners that the first part of their statement may not be heard unless they have attention first or teaching people with FND to replace ‘what’, with ‘what did you say? Because I heard xyz’.



SPEECH THERAPY TARGETS FND

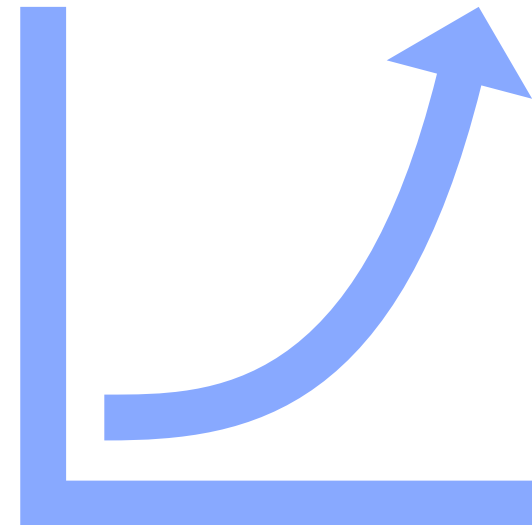
The impact of involving favourite activities should be seen as an effective strategy/not a 'character judgement' towards the patient.

As mentioned above, planning/executive skills are impaired so often instructing someone with rapid verbal instructions to perform a new task can be triggering or ineffective to obtain the best result. It is often helpful to talk about the skill you want to see (e.g. abdominal breathing) and then ask if they have ever done an activity before where they have had to do that before, and ask them to show you.

This will often lead to a better starting point by tapping into previously learnt automated tasks/hobbies that bring joy.

However, it is important that one cannot subsist on favourite activities/foods and whilst improved functioning can be found (it is possible that the threshold for fatigue/inhibition that occurs in elite athletes is lower in mundane tasks like walking vs more complex motor tasks association with passions or hobbies)

There are times where the mundane activities (walking/eating/talking) are impacted and it is as frustrating as it is disabling to not be able to do activities at the timeframe that one needs, a level of functioning that many can take for granted.



REFERRALS TO OTHER DISCIPLINES

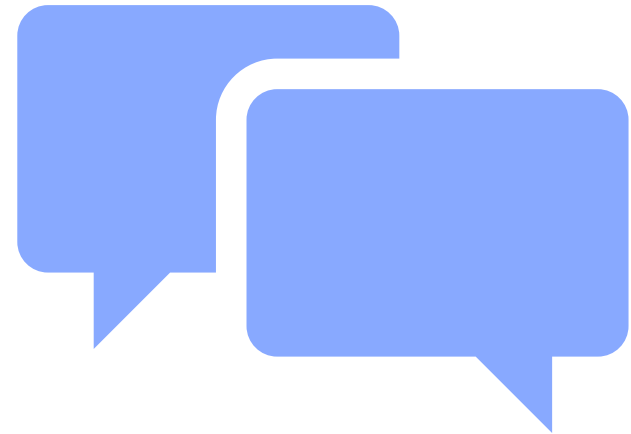
Dietitian: or review of blood tests with high rate of vitamin deficiencies, food intolerances specific to each person.

Optometrist: for prism lenses for double vision (schedule standard test but at end of day when fatigue worse)

Audiology: auditory processing assessment to help build awareness of sources of sensory/fatigue. However, be mindful that desensitisation strategies recommendations not always helpful in FND due to potentially compounding effect on fatigue/deleterious effect on functioning.

Occupational Therapy: sensory profile assessment, sensory diet ideas, functional capacity assessment, mobility aids

Physiotherapy: particularly assistance to find light resistance exercises that can support sensory regulation within individual capability/past hobbies for a pattern of eat-work/task- resistance exercises- nap sequence to help to maximise functioning.



FND Perspective

- Speech Pathology Resource (Patient Handouts) for Adults with FND) pdf \$30 for clinicians, \$5 for people with FND
- *Free for Aboriginal and Torres Strait Islanders and or health professionals who also have FND*
- FND Perspective offers lived experience supervision, including supervision log records, and presentation/workshops.
- If interested please contact me to request/quote: ericatilly@live.com.au
- I develop FND Perspective resources in my own time, if you haven't already if could take a moment of your time to make a \$30 donation for this slides/patient handouts/clinical resources, and support future projects, I would really appreciate it. You can do this via Send Money (Paypal) to ericatilly@live.com.au. If you do not have PayPal you can set up a new account or email me for alternative payment methods thankyou.
- This resource is not a replacement for clinical advice- seek individualised care from your treating team. It contains a number of strategies which are newly developed and/or have not been researched in people with FND to check effectiveness or safety.

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