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FND and FS

EDUEPI

10/10/2024

Pulderbos

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Overview

- What are functional seizures – terminology, definition, diagnosis and epidemiology
- Why would a person get functional seizures and what is the mechanism behind them – etiology and pathogenesis
- What can you do about FS - treatment
- Functional Seizures in RC Pulderbos

What are functional seizures?

Terminology, definition, diagnosis and epidemiology

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Funtional seizures FS

Terminology

- Past: pseudo-seizure, hysteric attack

- Functional Seizure FS
- Psychogenic Non-epileptic Seizure PNES
- Dissociative seizure, stress-attack

- Close but not identical: Hyperventilation attack, pannick attack

- Non-Epileptic Attack Disorder

Functional seizure

Signs and symptoms

- Loss of control over movements: e.g. falling, becoming floppy, trembling, jerking, tightening, complex movements
- Change in awareness/reactivity: e.g. disconnection, alienation
- Sensation:
  - Sensory
  - Emotional e.g. fear, sadness, crying, screaming, moaning
- Paroxysmal occurring

Functional seizure

Signs and symptoms

- Distinction functional – epileptic seizures:
  - Long duration, fluctuating presentation
  - Asynchronous movements, pelvic thrusting, back and forth movements
  - Occurring from apparent sleep, closed eyes, resistance upon eye opening
- Triggers and patterns
- Stereotypical presentation, shifting symptoms over time
- After seizure: tiredness, headache, loss of strength

Functional seizure

Diagnosis: 3 pillars

- Medical history: lived experience of patient
- Semeiology: what seizure looks like, typical characteristics
- Technical investigations: exclusion of other possible causes
  - EEG: electro-encephalography
  - Heart examination, exercise tolerance test
  - Balance test

>> Not a diagnosis of exlusion

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Functional seizures

Degree of certainty of diagnosis (ILAE):

- Documented: typical characteristics ànd confirmation of non-epileptic origin on EEG
- Clinically established: typical characteristics by experienced clinician and normal interictal EEG
- Probable: typical characteristics by clinician
- Possible: typical characteristics by self-report

Functionele aanvallen

Degree of certainty of diagnosis (ILAE):

Table 2. Overview of proposed diagnostic levels of certainty for psychogenic nonepileptic seizures

	History	Witnessed event	EEG
Diagnostic Level			
Possible	+	By witness or self-report/description	No epileptiform activity in routine or sleep-deprived *interictal* EEG
Probable	+	By clinician who reviewed video recording or in person, showing semiology typical of PNES	No epileptiform activity in routine or sleep-deprived *interictal* EEG
Clinically established	+	By clinician experienced in diagnosis of seizure disorders (on video or in person), showing semiology typical of PNES, while not on EEG	No epileptiform activity in routine or ambulatory *ictal* EEG during a typical ictus/event in which the semiology would make ictal epileptiform EEG activity expectable during equivalent epileptic seizures
Documented	+	By clinician experienced in diagnosis of seizure disorders, showing semiology typical of PNES, while on video EEG	No epileptiform activity immediately before, during or after ictus captured on *ictal* video EEG with typical PNES semiology

Key: +, history characteristics consistent with PNES; EEG, electroencephalography (as noted in the text, additional tests may affect the certainty of the diagnosis—for instance, self-protective maneuvers or forced eye closure during unresponsiveness or normal postictal prolactin levels with convulsive seizures).

Epilepsia, 54(11):2005–2018, 2013
doi: 10.1111/epi.12356

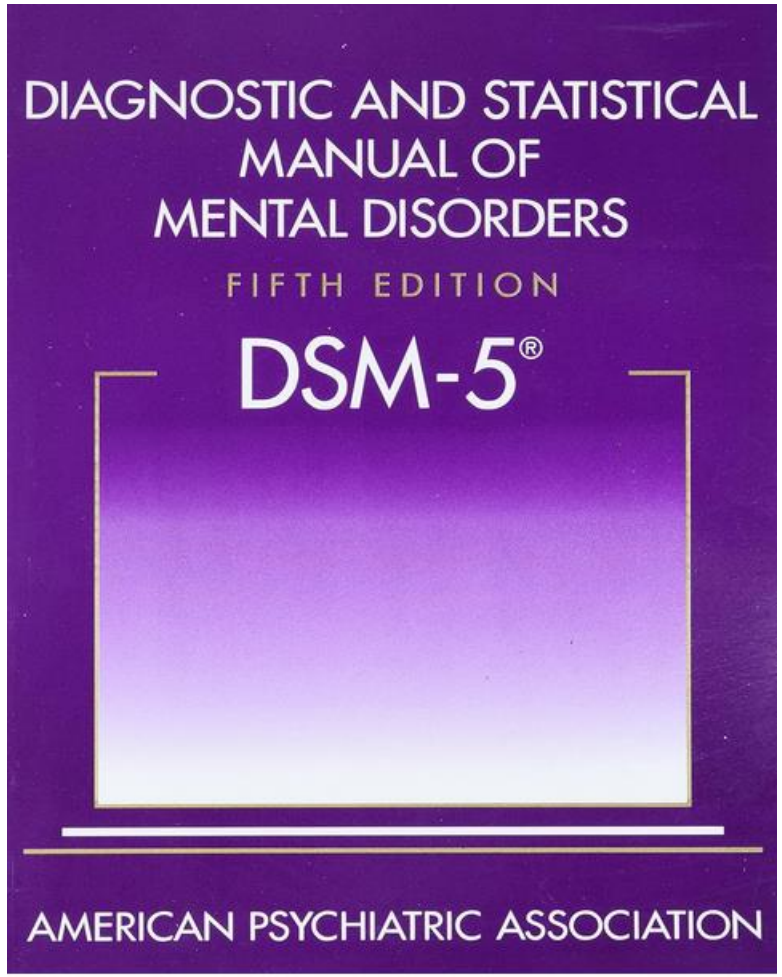
Functional seizures as a symptom…

…of a functional neurological disorder

Functional seizures as a symptom of FND

DSM5:

- 1 or more symptoms of altered motor or sensory function
- Clinical symptoms incompatible with recognized medical neurological conditions
- Not explained by another medical or mental condition
- Causes significant distress or impairment



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Functional seizures as a part of a bigger picture

DSM5:

- Part of FND - SSS
- Part of dissociative disorder
- Part of trauma- and stressor-related disorder
- Comorbidy of anxiety disorder, personality disorder

TABEL 1 **Diagnostische criteria in de DSM-5* voor de conversiestoornis (functioneel-neurologisch-symptoomstoornis)**

A Een of meer symptomen van veranderingen in de willekeurige motorische of sensorische functie.

B Uit klinisch onderzoek blijkt dat het symptoom incompatibel is met bekende neurologische of andere somatische aandoeningen.

C Het symptoom of de deficiëntie kan niet beter worden verklaard door een somatische of psychische stoornis.

D Het symptoom of de deficiëntie veroorzaakt klinisch significante lijdensdruk of beperkingen in het sociale of beroepsmatige functioneren of in het [illegible]elangrijke terreinen, of behoeft somatisch onderzoek.

De conversiestoornis moet gespecificeerd [illegible]ymptoomtypen:

- Met parese of paralyse
- Met abnormale bewegingen (tremor, dystone beweging, myoclonus, loopstoornis)
- sliksymptomen
- Met spraaksymptomen (dysfonie, [illegible]eken)
- Met aanvallen of convulsies
- Met anesthesie of sensibiliteitsv[illegible]
- Met speciale zintuiglijke symptomen (visus, reuk, gehoor)
- Met gemengde symptomen
- Verder wordt aangegeven of de stoornis acuut ontstaan is (minder dan 6 maanden) of persisterend (langer dan 6 maanden) en of er wel of niet een psychische uitlokkende factor is.

Motor conversion

PNES

*Deze beschrijving is overgenomen uit de Nederlandse vertaling van de DSM-5 (APA 2014).

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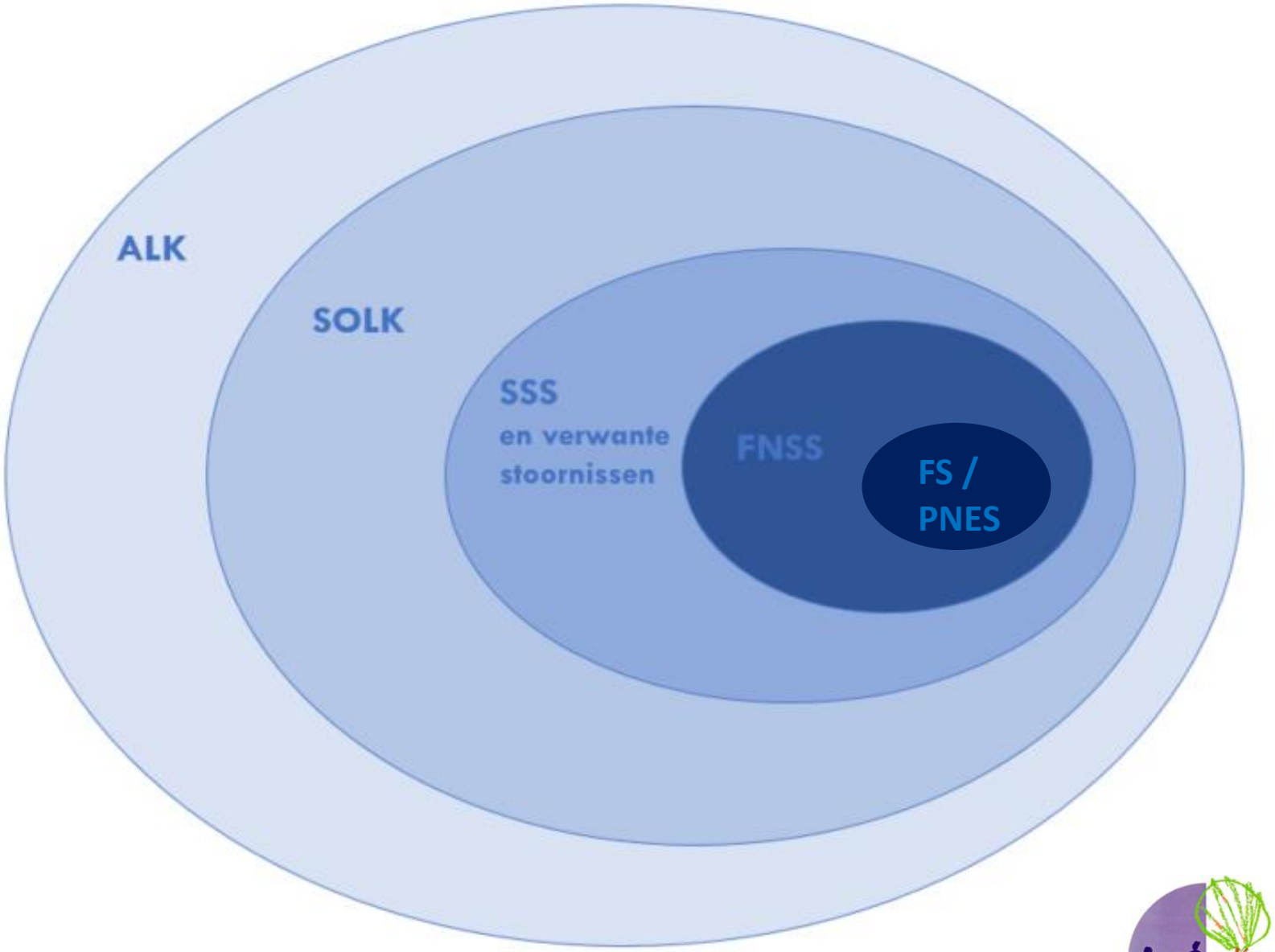
Functional seizures as a part of FND



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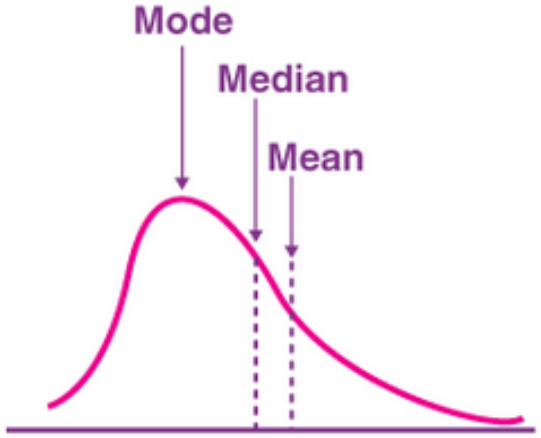
Occurence of FND

Epidemiology of FND

- Broad range incidence numbers ~ group disorders
- Annual incidence 18/100 000 (Young et al 2023)
- FS: Incidence: 1,5-6,17/100 000; Prevalence: 2-50/100 000
- Hospital setting FS:
  - General neurology outpatient clinic: 2%
  - Emergency room: 11% seizures
  - Epilepsy center: 30% of refractory cases

Occurrence of FND



Epidemiology FND

- Age distribution: 70% age 20-40y
- Prevalence highest in 15-19y (60/100000 vs epilepsy 46/100000)
- Rare in < 7-8y
- Women > men
- Comorbidity
- QOL, stigma and caregiver burden similar or greater than other neurological disorders

Children and adolescents

- Mostly motor conversion and functional seizures
- Often more than 1 symptom
- Possibly better outcome

Natural course of FND

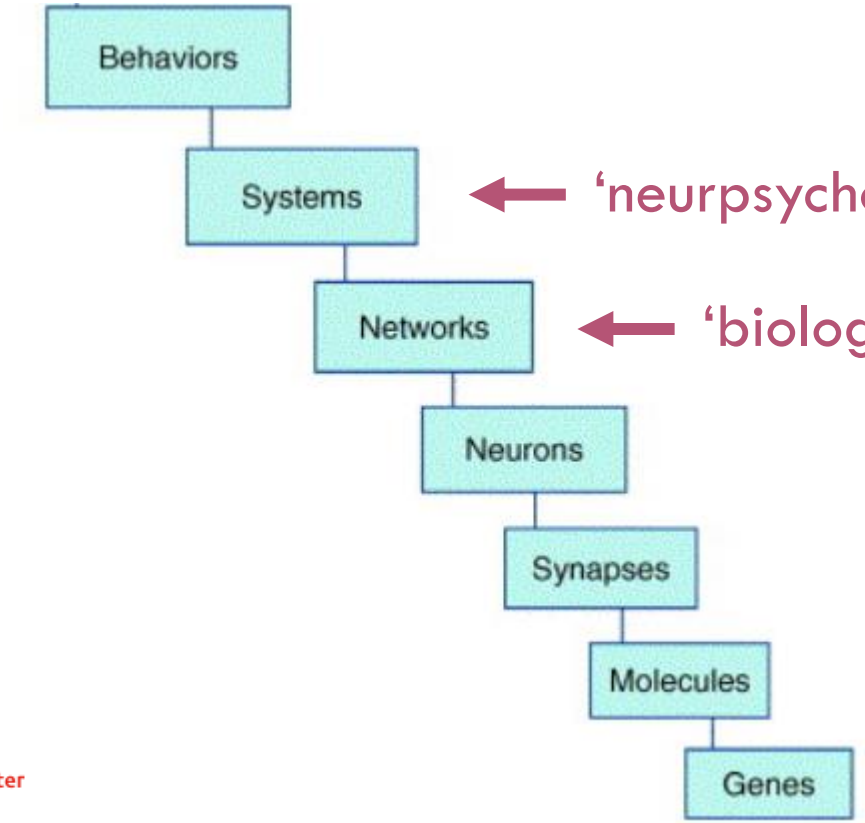
Prognosis

- Wide range of outcomes:
  - 1 episode of symptoms
  - Several episodes of symptoms
  - Multiple episodes of symptoms recurring with stressful episodes of life – shifting symptoms
  - Permanent condition with fluctuating symptom burden – multiple and shifting symptoms
- Prognosis may be better in young people compared with adults
- Prognosis is better for recent onset of symptoms
- Poorer prognosis with comorbidity
  - Developmental disorders e.g. ASD
  - Personality disorders, context mental health problems

Why does someone get functional seizures?
What is the mechanism behind functional seizures?
Etiology and pathogenesis

Functional seizures and FND: why and how?

Etiology and pathogenesis: levels of understanding



‘neurpsychological level’

‘biological level’

Dravet syndrome

Why and how – biological level

Etiology and pathogenesis: scientific research:

- Autonomic nerve system – Vagus Nerve
- Hormonal system: HPA axis (hypothalamus-pituitary-adrenal axis)
- Immune system
- Locomotor system
- Others: pain system, biological clock, …
- Observations partly understood:
  - EEG studies: midline regions increased activity
  - Imaging studies: increase grey matter SMA, ri STG, dorsomed prefrontal cortex

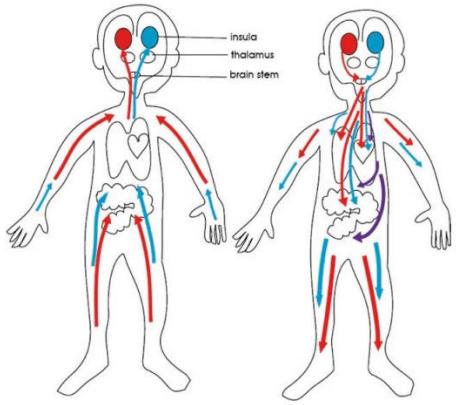
> Differences at group level

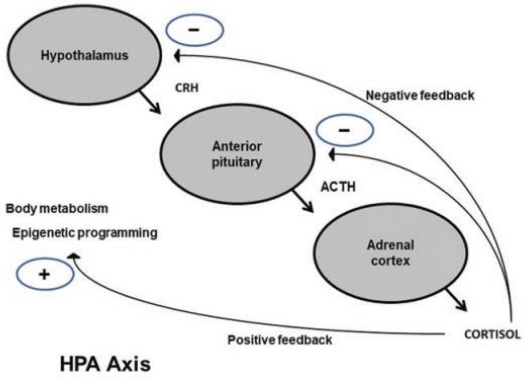
> Not useful as biomarker in clinical practice

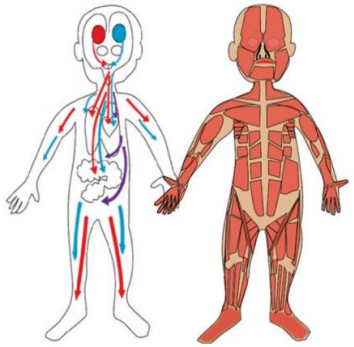
Why and how – biological level

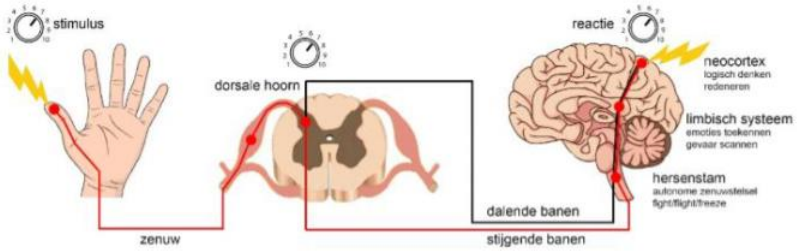
> Differences at group level

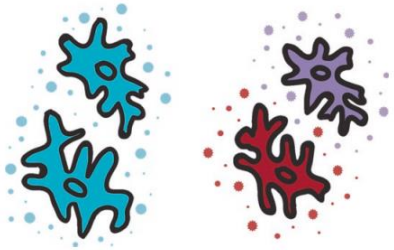
> Not useful in clinical practice

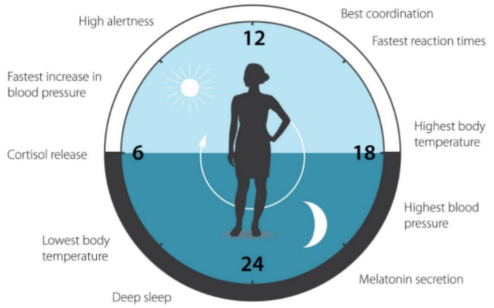




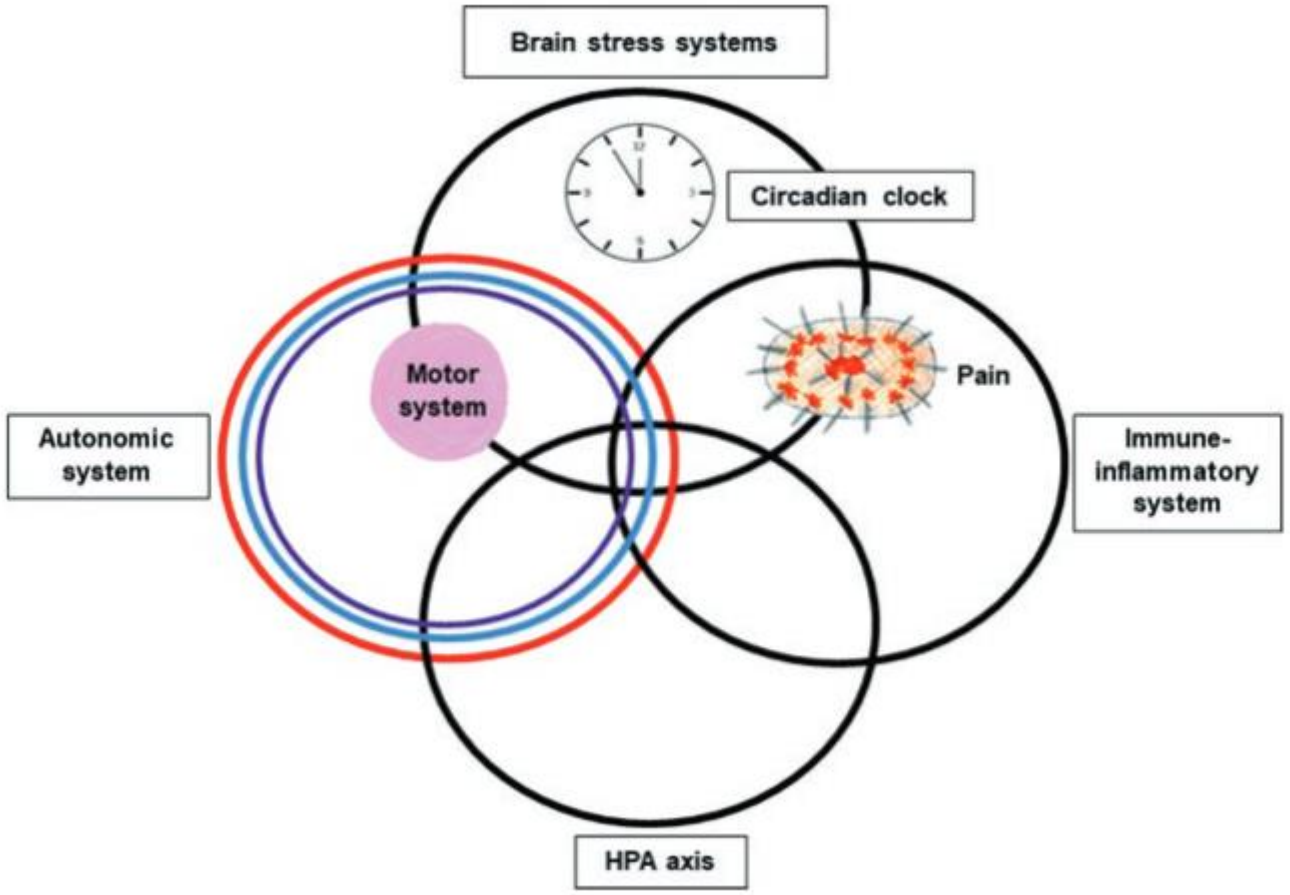




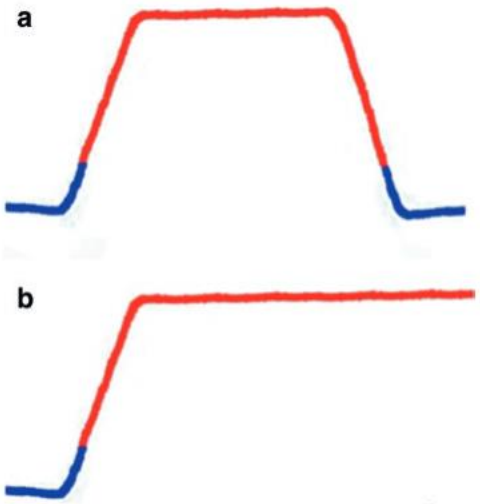


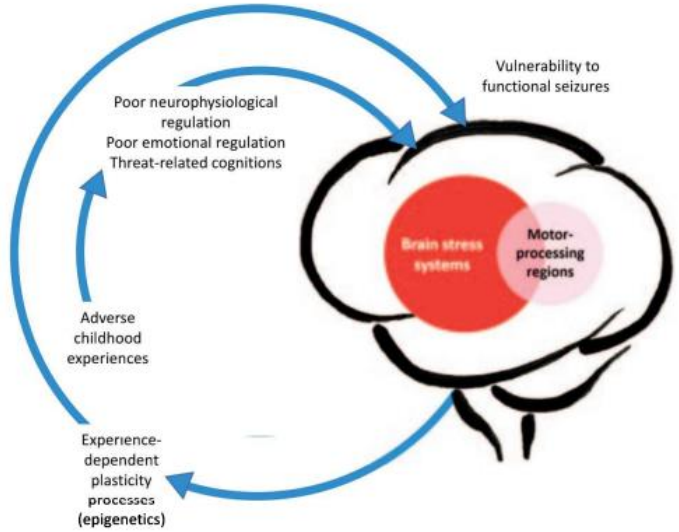


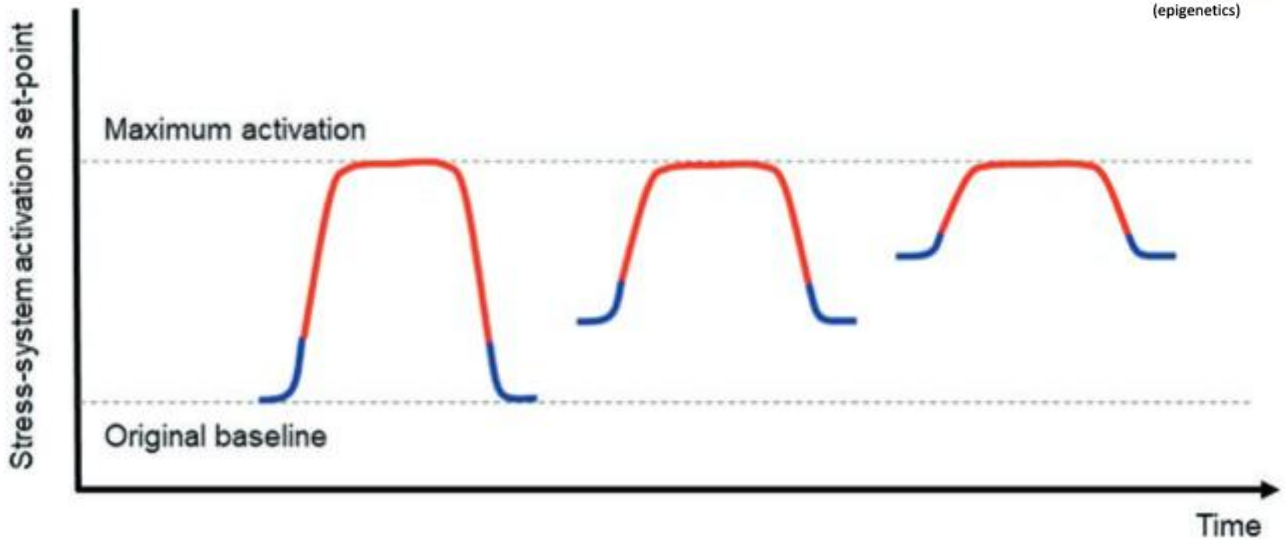
Why and how – biological level



Why and how – biological level







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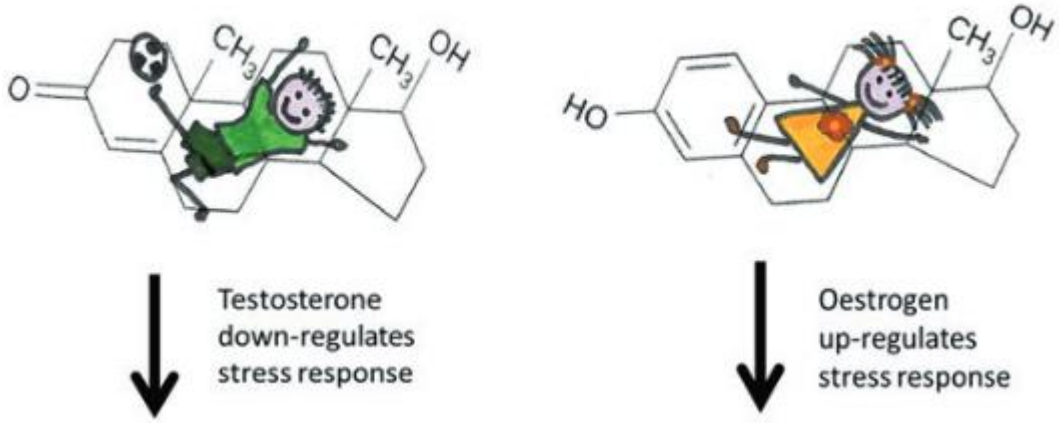
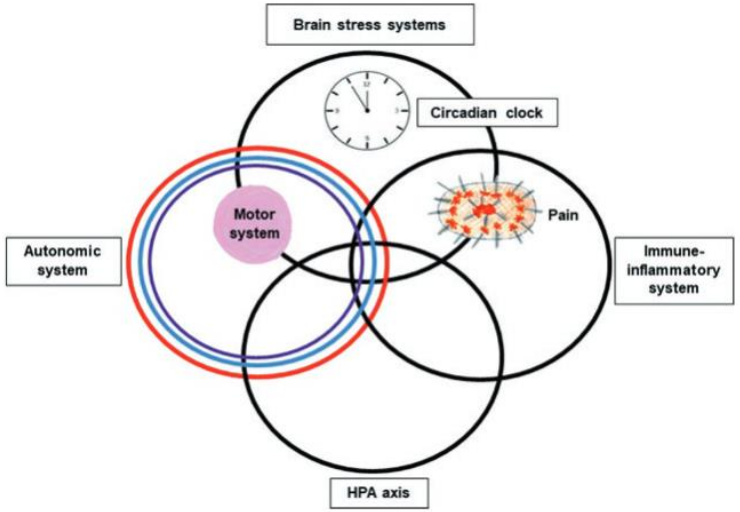
Why and how – biological level

Role of sex hormones





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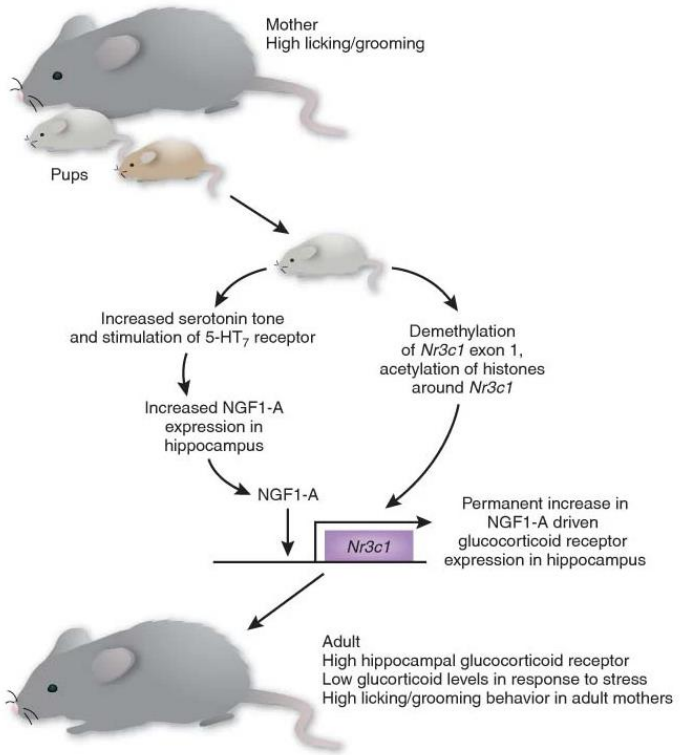
Why and how – biological level

Role of early life events - epigenetics

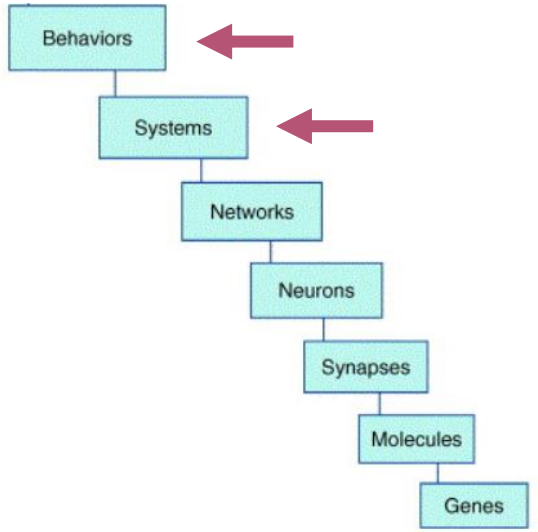
- Epidemio: traumatic life events frequent in FND
- Environmental factors >< genome
- Animal studies > human studies



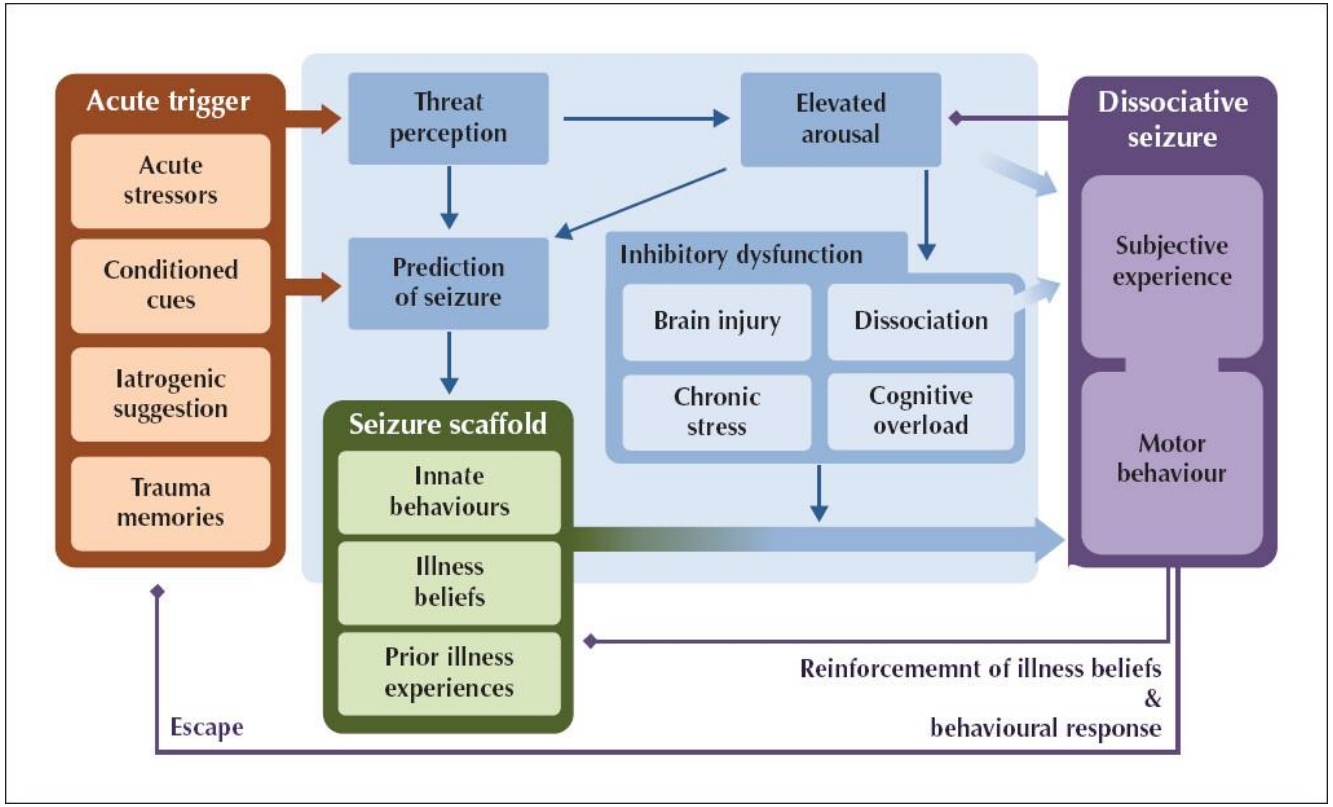
How adversity gets under the skin

Steven E Hyman

Why and how – neuropsychological level



The aetiology of psychogenic non-epileptic seizures: risk factors and comorbidities

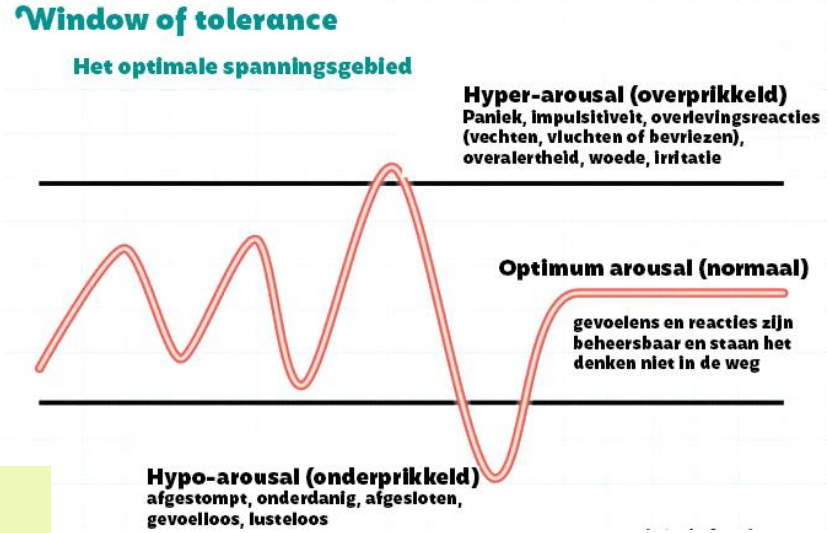


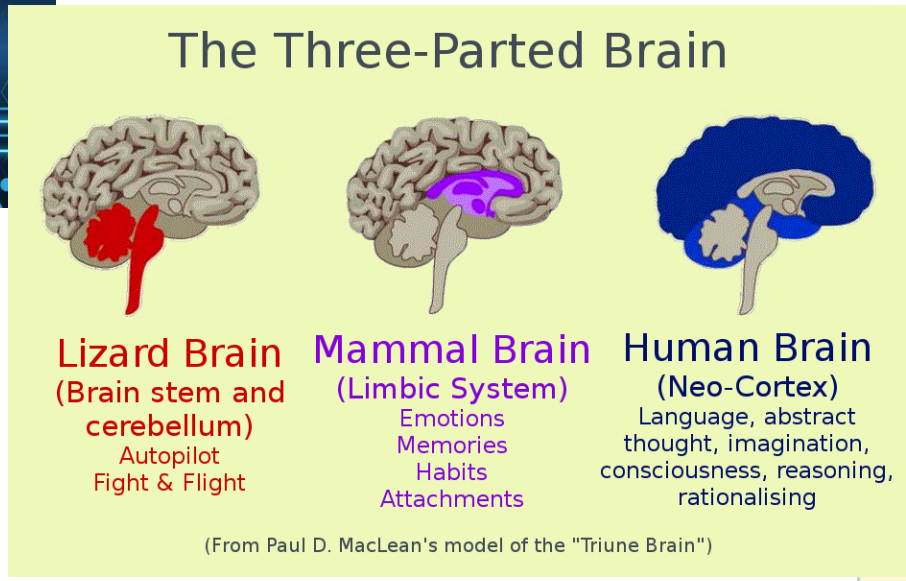
Epileptic Disorders, Volume: 21, Issue: 6, Pages: 529-547, First published: 17 January 2020, DOI: (10.1684/epd.2019.1107)

Why and how

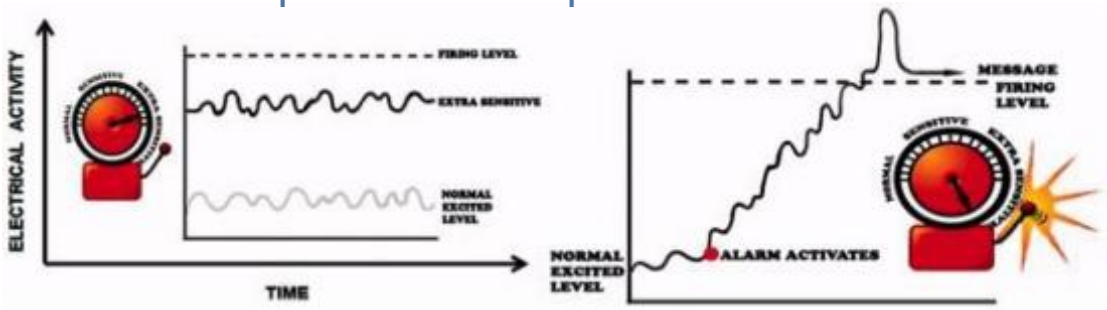
Use of metaphors and models

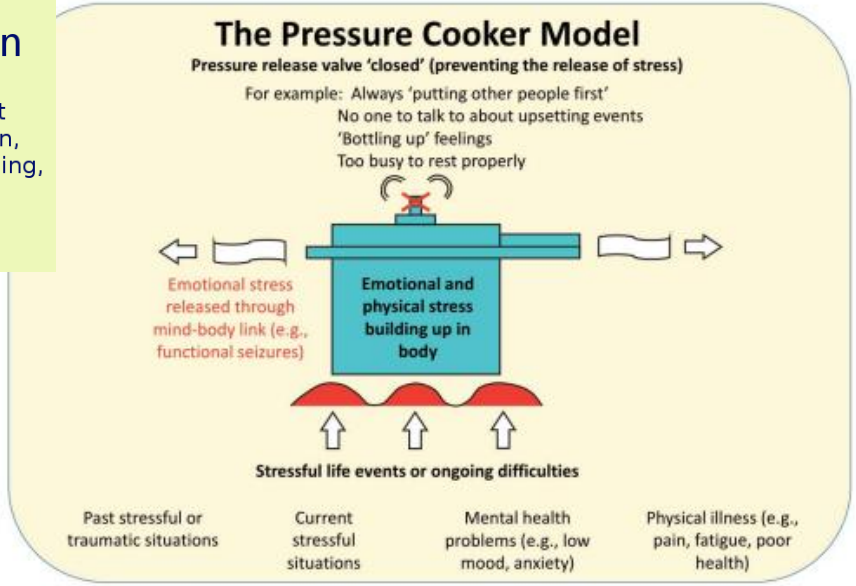
Hardware – software analogy





Alarm-metaphor in chronic pain





Why and how - summary

Etiology and pathogenesis: not 1 cause or mechanism

- Functional neurological disorder = group name
- Functional seizures = group name
- Large heterogeneous group of different kinds of seizures
- Resemblances at behavioral level
- Multiple networks involved
- On clinical level: different accents

> Consequences for treatment

What can you do about functional seizures? Treatment options

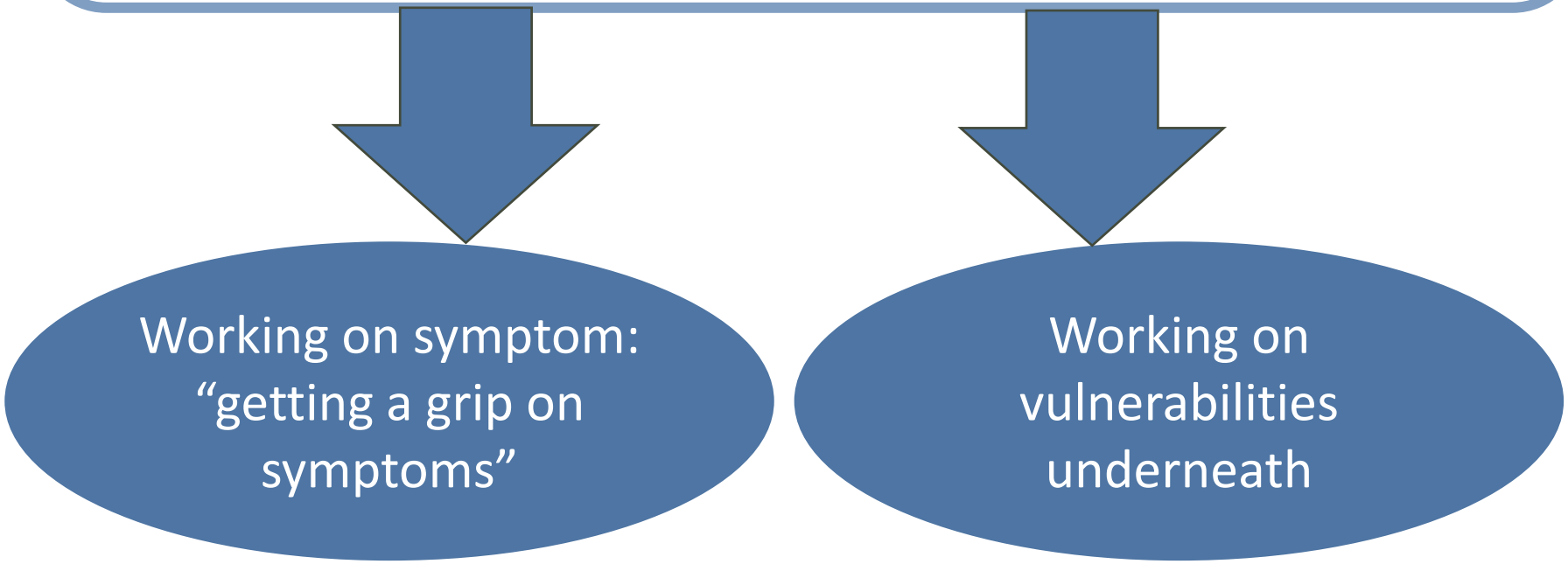
What can you do about it - treatment options

Evidence

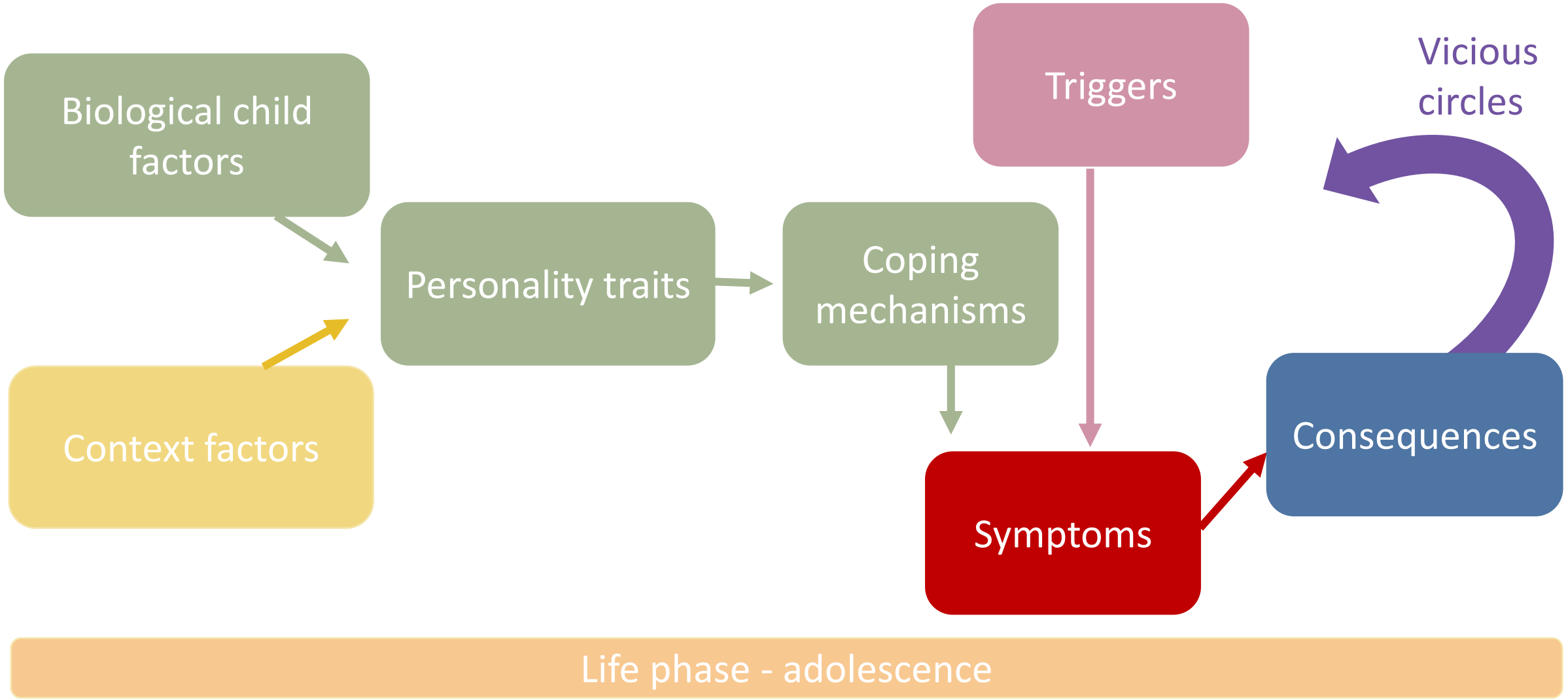
- Little Evidence Base!
- One RCT treatment in young people: ReACT
- Expert consensus/current literature suggests multidisciplinary approach is best
- Psychotherapy trials: psychoeducation, CBT, ACT, MBP, family therapy, …
- Symptom targeting with PT/OT/SLT
- Addressing comorbid conditions

What can you do about it - treatment options

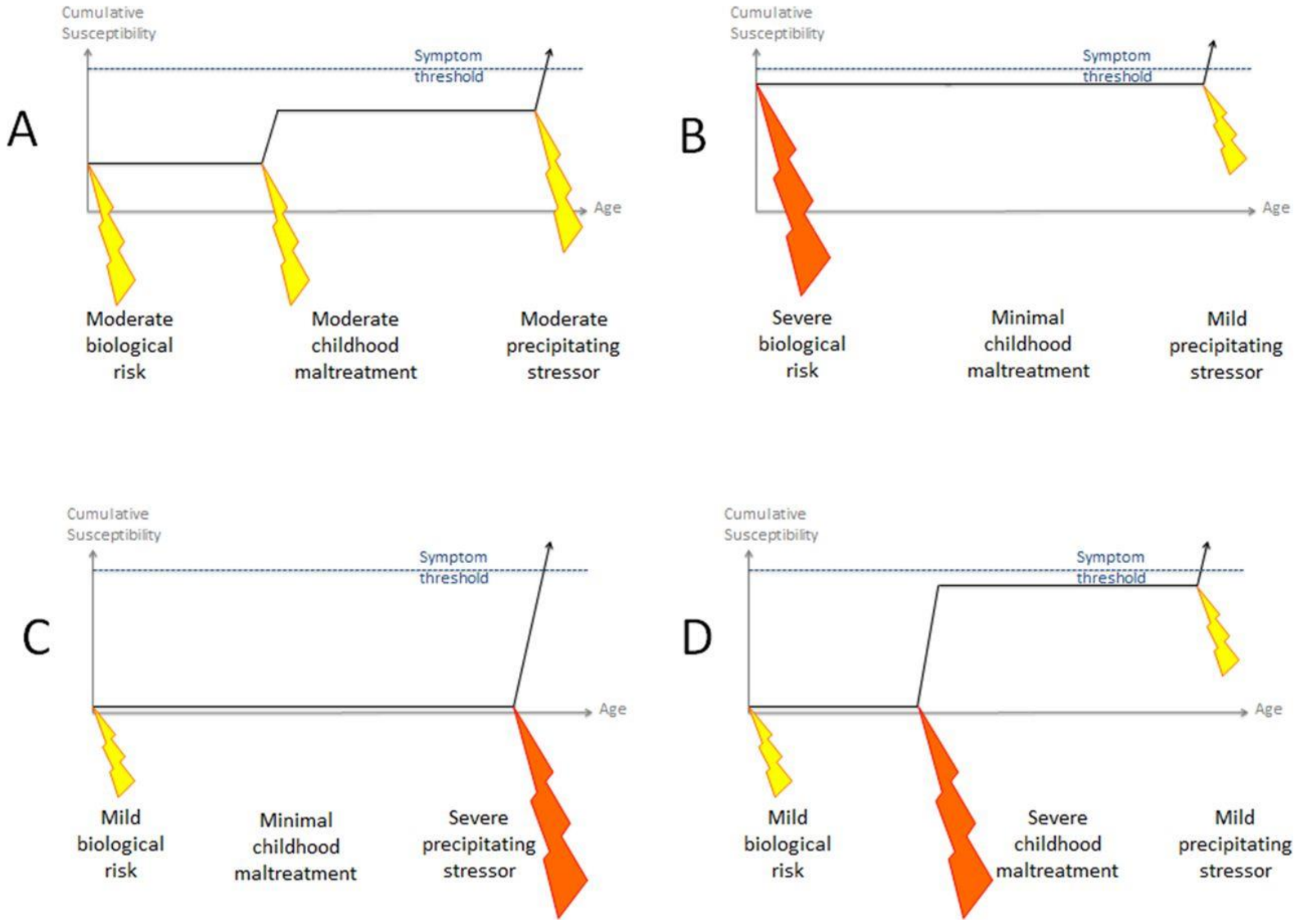
Functional symptom =
Expression of disruption of stress-system
due to longstanding overload



Understanding factors that lead to disruption



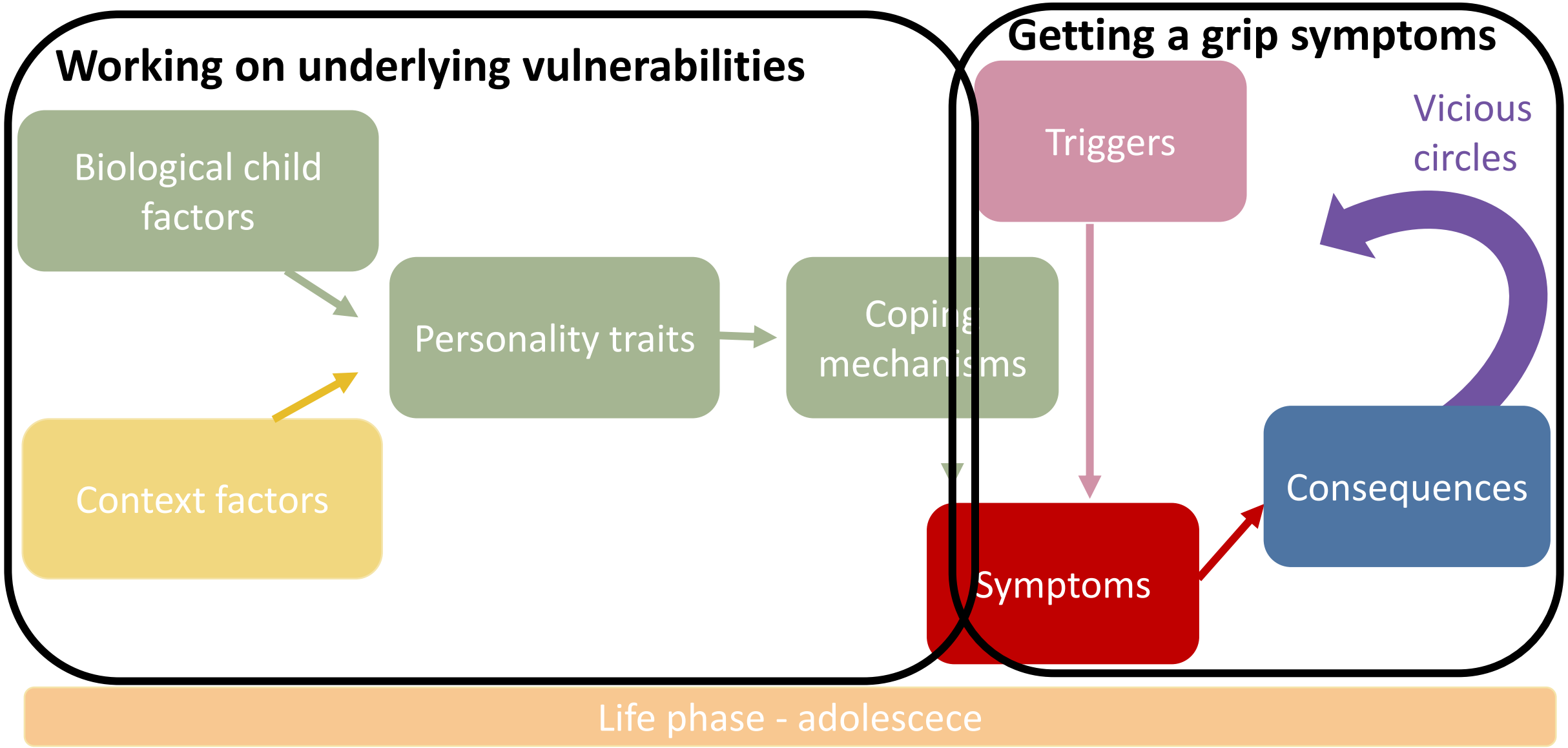
Paths to stress-system overload



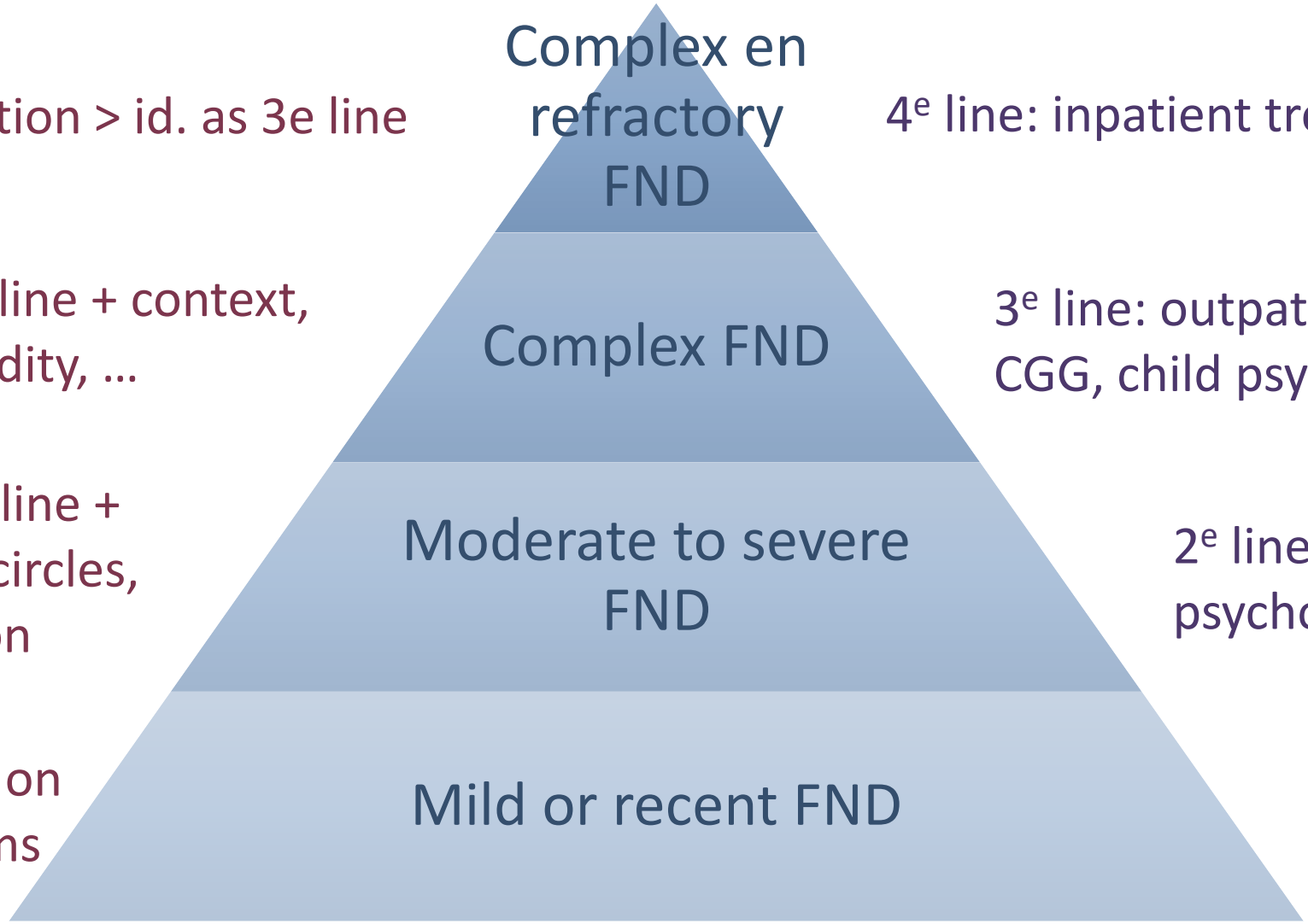
Psychosocial stressors in young people

- N=125, 79% could identify stressors (Fredwall 2021)
  - School performance (24%)
  - Family conflicts/stressors (15%)
  - Peer problems/bullying (10%)
  - Physical trauma (8%)
  - Abuse (6%)
  - Other problems (6%)
  - Grief (5%)
  - Substance abuse (3%)
  - Overscheduled (2%)
  - Perfectionist tendencies (1%)

Which strategies to use when



Treatment: stepped care



Stabilisation > id. as 3e line

4e line: inpatient treatment

Id. as 2e line + context, comorbidity, …

3e line: outpatient multidisciplinary ttm: CGG, child psychiatrist

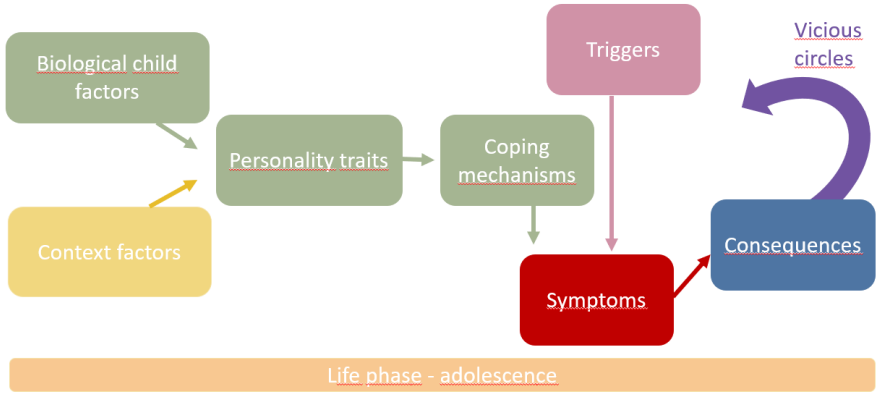
Id. as 1e line + coping, circles, activation

2e line: GP/paediatrician, psychologist, physical therapistT

Ed., grip on symptoms

1e line: GP/paediatrician, SEN coordinator school

Treatment



‘Custom made’ - personalised:

- Based on personalised BPS model
- Multidisciplinary
- Contence:
  - Always: education
  - Always: getting a grip on symptoms
  - More or less: working on underlying vulnerabilities
- Aim:
  - Aim ≠ become symptom free, but reduce impact and consequences of symptoms
  - Aim = get a grip on symptoms → focus will shift from symptoms to functioning
  - Aim = return to acceptable level of activities and participation

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Treatment: short term goals

Short term goals (1e and 2e line):

- Education
- Activation
- Biorhythm
- **Getting a grip on seizures**
- Focus of attention
- Implementation at home and at shool
- Medication?

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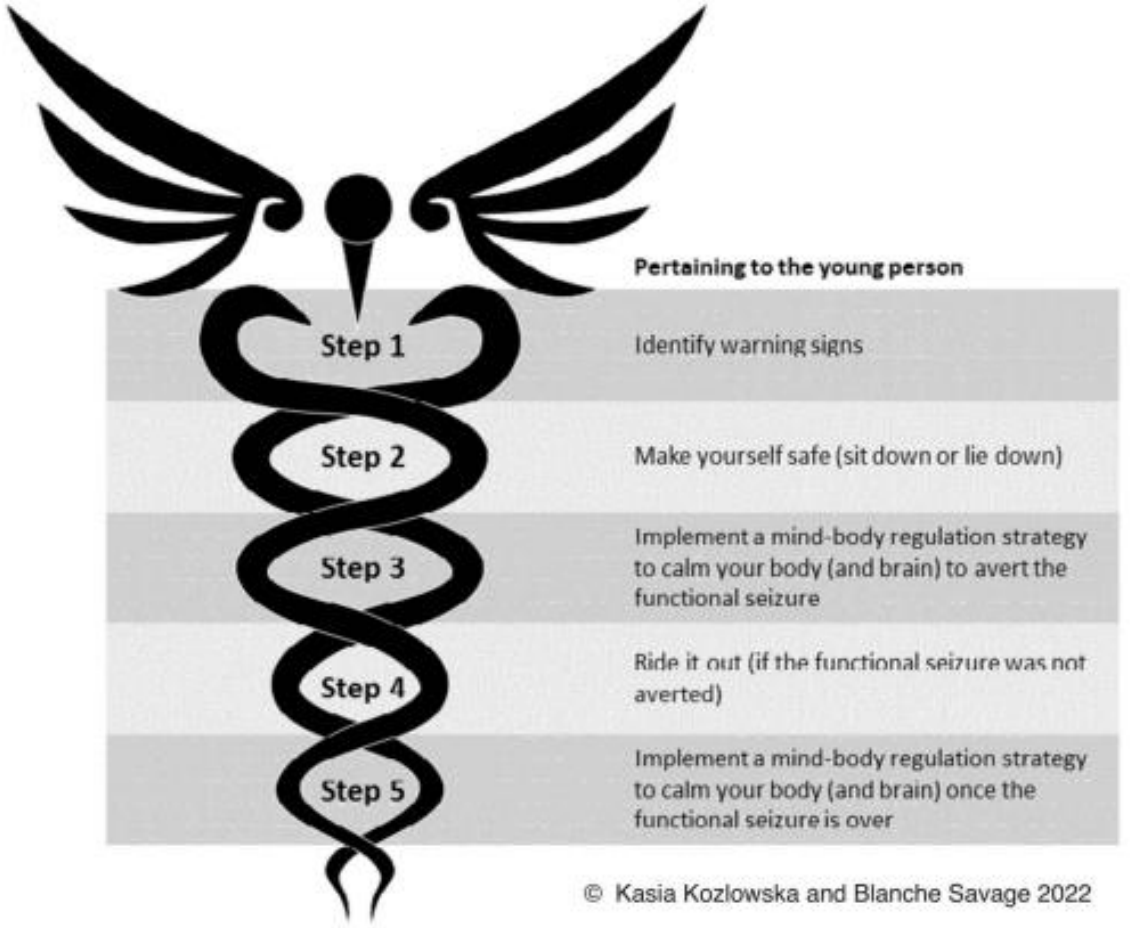
Getting a grip on seizures



5-step plan for managing functional seizures:

1. Recognize your warning signs
2. Make yourself safe
3. Calm your stress-system: use your regulation exercises
4. Let the functional seizure happen: surf the wave
5. Calm your stress-system: use your regulation exercises

Getting a grip on seizures

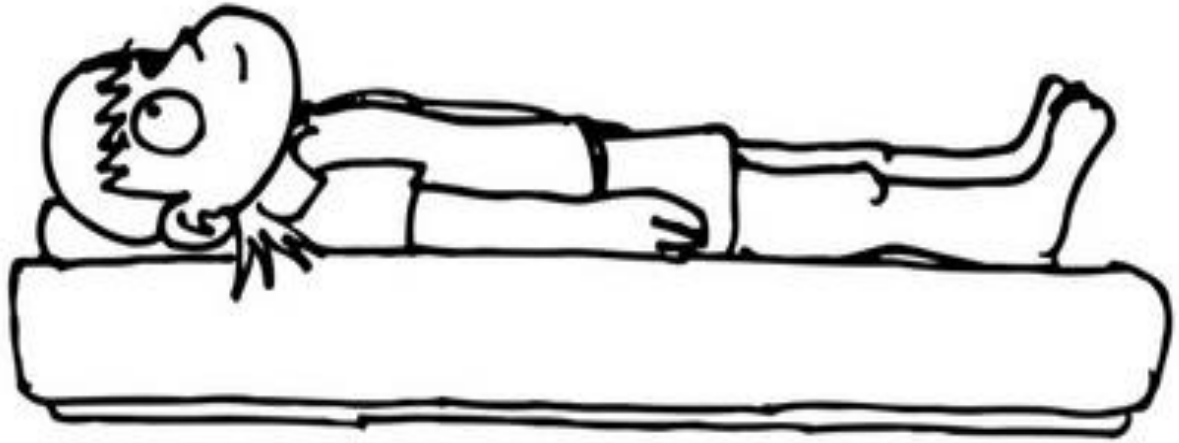
Step 1: recognize your warning signs

- Noticing bodily sensations that precede a functional seizure
- Goal: anticipate
- Often little awareness of bodily sensations
- Takes practice
- External information: mirroring
- PMT: body scan

Getting a grip on seizures

Stap 2: make yourself safe

- Warning signs > sit down or lie down
- Aim:
  - Safety
  - Giving back responsibility
- Start of gaining control



Getting a grip on seizures

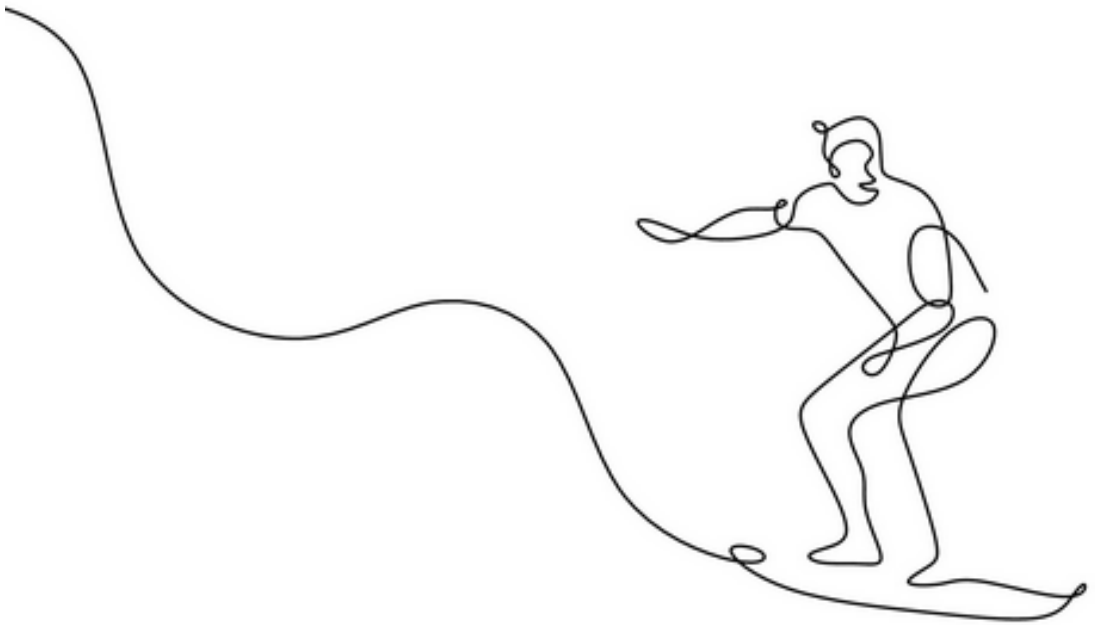
Step 3: Calm your stress-system: use your regulation exercises

- Aim: hold off approaching functional seizure
- Regulation strategies: distract attention, activate parasympathic nerve system
  - Bottom up: breathing exercises, progressive muscle relaxation, sensory stimulation, sensory focus exercise, music, …
  - Top Down: Helping thoughts, visualization-exercise, mindfulness-strategies, …
- Takes practice
- Daily exercise schedule
- Toolbox

Getting a grip on seizures

Step 4: Let the seizure happen

- Aim: If you can't stop the seizure, let it happen without resisting
- Metaphor: 'surfing the wave'
- Central idea: difficult feelings come and go, let them come and go, stop resisting
- Equivalent in therapy: ACT (acceptance and commitment therapy)
- "I am safe", "I can endure this"



Getting a grip on seizures

Step 5: Calm your stress-system: use your regulation exercises

- Aim: help calm body after a functional seizure and resume activities
- 5-10 minutes, then resume activity
- Regulation strategies: see step 3

Getting a grip on seizures

From co-regulation to self-regulation

- Parents/context need practice to react appropriately

- Key message to parents:
  - Not dangerous, not harmful
  - Young persons task to learn to regulate, you can not do this for them
  - Name warning signals
  - Encourage safe position
  - Monitor from a distance
  - Stay calm: brain calms down in calm environment
  - If necessary: perform own regulation exercises or leave room

- Transparency: young person needs to know parents' task
- Parents communicate 'seizure management plan' to world

Treatment: short term goals

Short term goals (1e and 2e line):

- Education
- **Activation**
- **Biorhythm**
- Getting a grip on seizures
- Focus of attention
- Implementation at home and at shool
- Medication?

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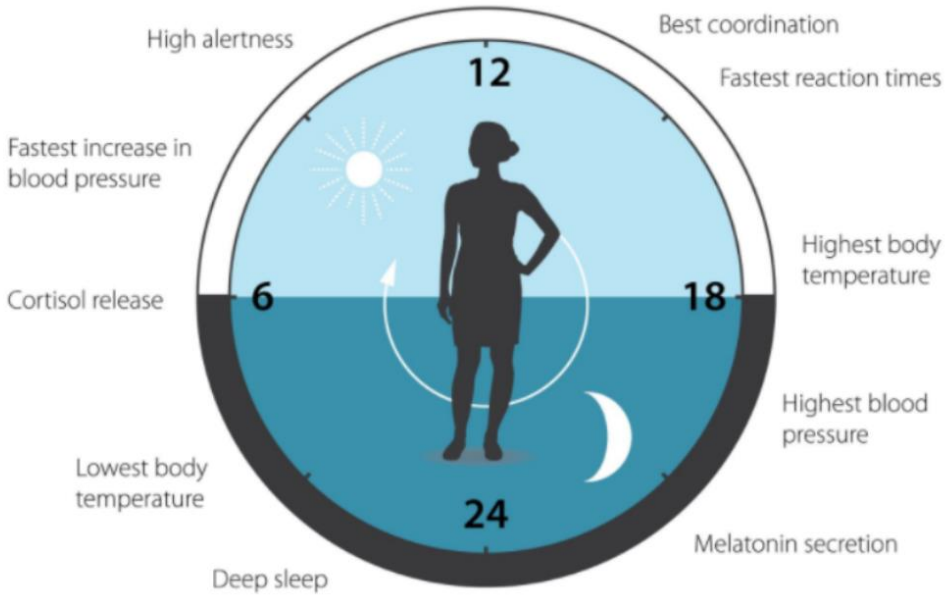
Biorhythm

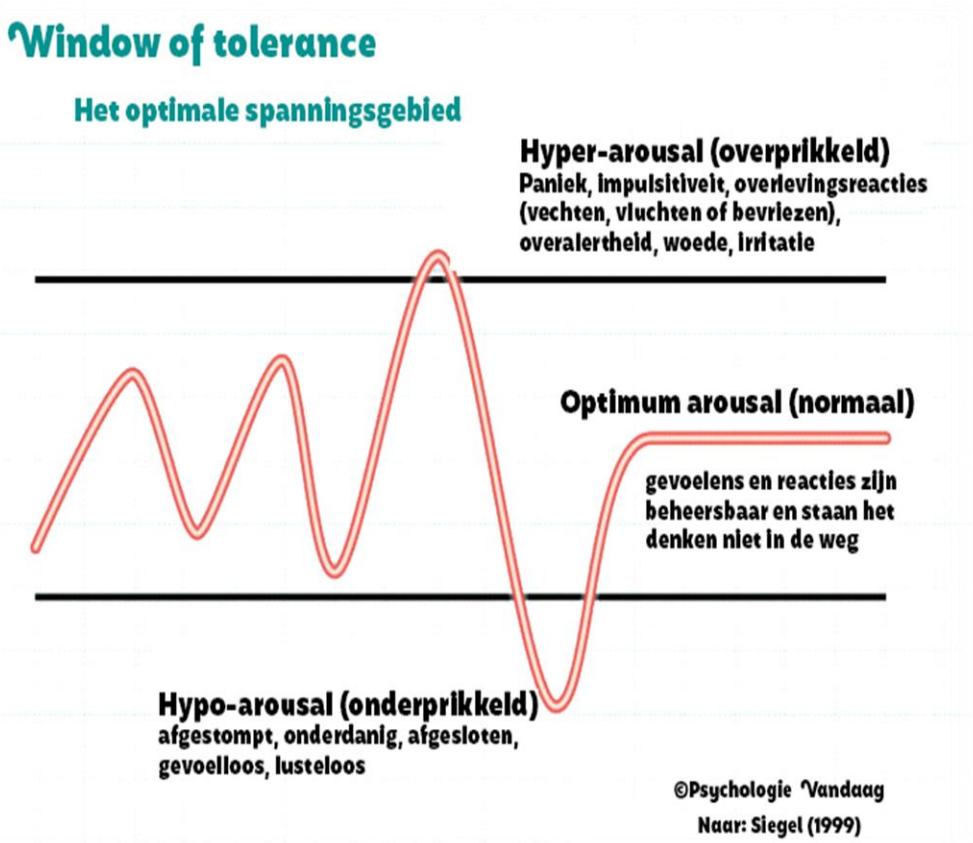
- Regulation of sleep and day-night rhythm
- Nutrition: healthy, sufficient and sufficiently varied meals
- Physical activity
- Screen time

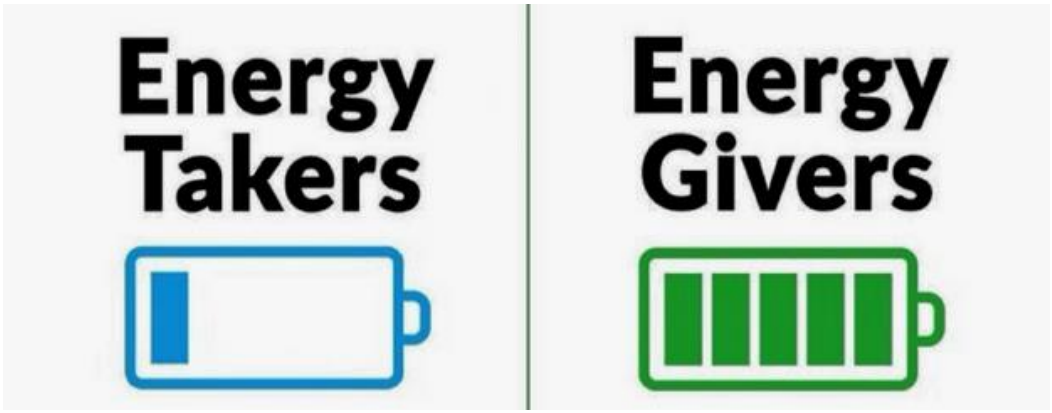


Text Box 5.1
Basic Principles of Sleep Hygiene

- Go to bed and wake up at about the same time each night (including weekends).
- Have a regular ritual before bed to tell your body it is time to go to sleep.
- A warm bath or shower 1–2 hours before bedtime can help with falling asleep.
- Keep your bedroom dark, quiet, and cool.
- Avoid caffeine (in chocolate, tea, coffee, and some soft drinks) for 4–6 hours before bedtime.
- Limit naps to 20 minutes during the day.
- Don't have screen time 30–60 minutes before bed.
- Don't use screens in the bed.
- Don't lie in bed trying to fall asleep. If you aren't asleep in 20 minutes, do something different (e.g., read a book, listen to quiet music) and then try to go to sleep again.
- Go out in the sun first thing in the morning.

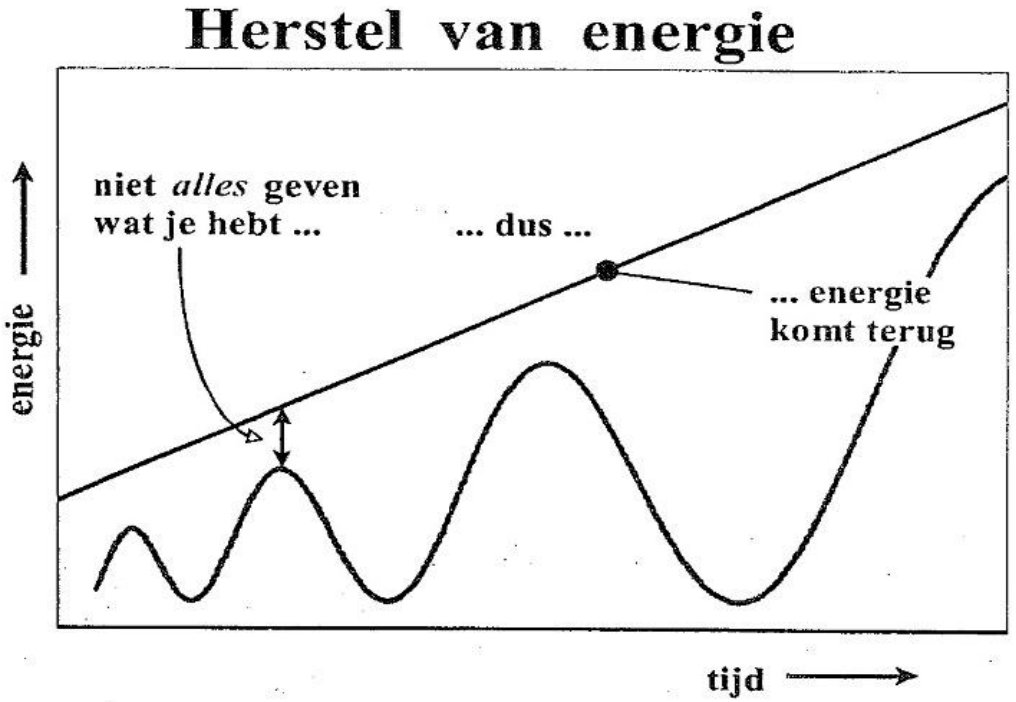
Energy Management





Time-contingent activation program

- Time contingent approach >< symptom-contingent approach
- Therapy : Graded activity
- Therapy: Exposure in vivo
- Avoid yo-yo effect



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Focus of attention

- Aim: shift focus of attention away from symptoms and towards functioning
- Reason: focus on symptoms is powerful perpetuating factor
- How:
  - Stop asking about complaints
  - Focus on activity program – day schedule
  - What did you manage to do? What worked? What gave you energy?
- Large amount of coaching and support of young person and parents
- Balance between recognition for suffering and distraction from symptoms

Coaching the family

- Essential !
- Containing and supporting parental anxiety
- Coaching appropriate reactions in ‘5-step seizure management plan’
- Education about mind-body regulation strategies
- Teaching mind-body regulation strategies for themselves
- Coaching in diverting attention away from symptoms
- Coaching evolving back towards normal family life

- Often underlying family dynamics that require more intensive family therapy

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Coaching the school

- Essential!
- Education about nature of symptoms
- Education about appropriate reactions in '5-step seizure management plan'
- Gradual stepwise increase in school activities is fundamental part of ttm plan
- First goal: reducing fear, keeping in touch with peers
- Ideally : 1- 2hrs to school/day, increase after 2 weeks (+ 1hr/day) …
- Fulltime school program may not be feasible even in long term (comorbidity)
- Take into account what is realistic for school:
  - e.g. 1hr at school is better than being sent home with each seizure

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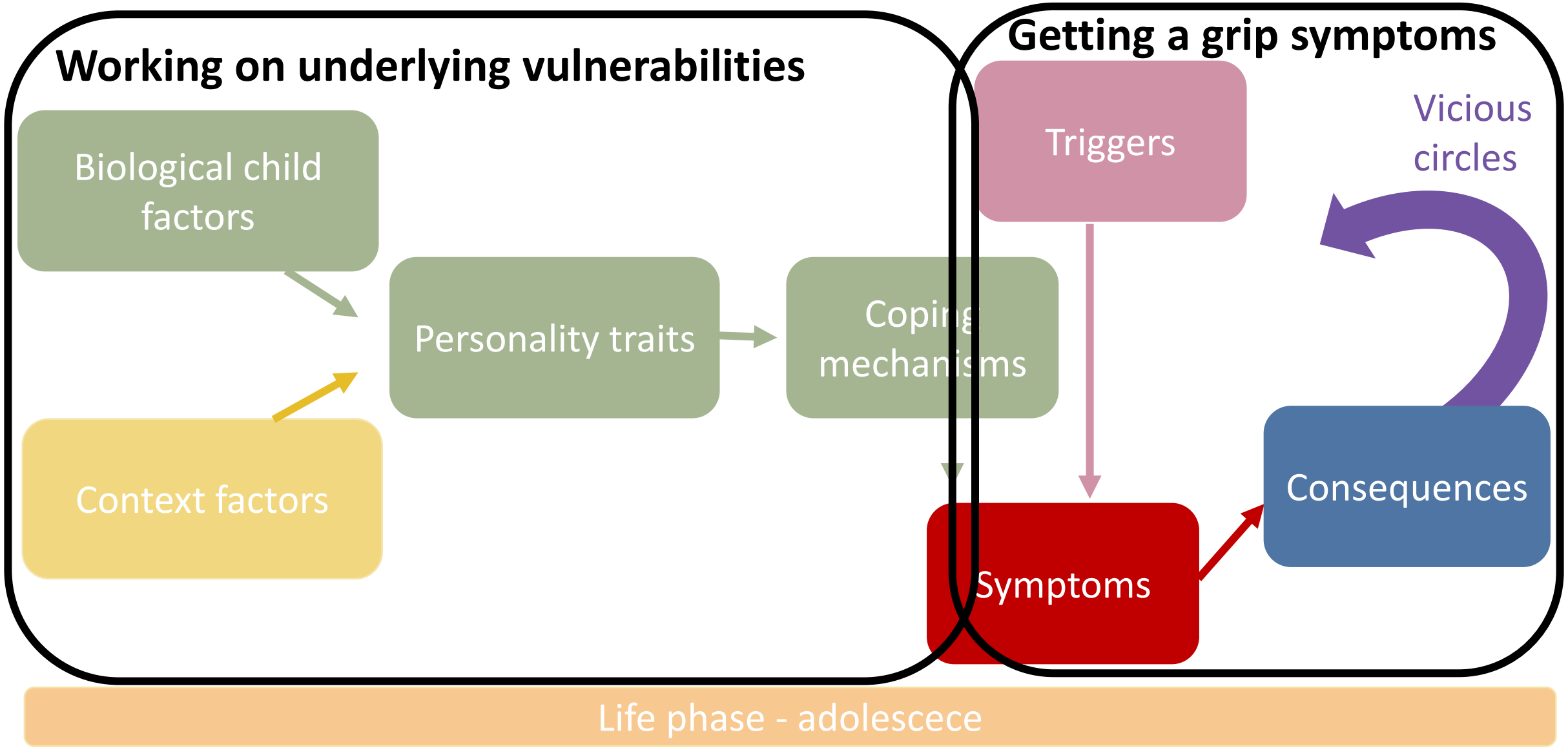
Which strategies to use when



Treatment: long term goals

Long term goals (3e and 4e line): working on underlying vulnerabilities

- Severe-complex FND
- Comorbidities
- Larger team
- Longer trajectory
- Prognosis less fabourable

Psychotherapy

- Top Down regulation strategies (CBT)

- Addressing underlying vulnerabilities

- Identity
- Trauma e.g. EMDR
- Comorbidity : anxiety, depression, autism spectrum disorder, personality disorder, …
- Relationships and family dynamics

Physiotherapy
Psychomotor therapy

- Bottom Up regulation strategies
- Reading bodily sensations
- Reconditioning
- Enjoying physical activity

VIEWPOINT

Physiotherapy for functional motor disorders: a consensus recommendation

Nielsen, G., Stone, et al. (2015). Physiotherapy for functional motor disorders: a consensus recommendation. *Journal of neurology, neurosurgery, and psychiatry*, *86*(10), 1113–1119. https://doi.org/10.1136/jnnp-2014-309255

Consensus aanbevelingen:

- Bouw vertrouwen op alvorens je de patiënt uitdaagt of pusht
- Straal vertrouwen uit, maak duidelijk dat je als therapeut vertrouwd bent met FNSS
- Creëer een verwachting van verbetering
- Open en consistente communicatie tussen MD team en patiënt
- Betrek familie en zorgfiguren in de behandeling
- Beperkt 'hands on' behandeling (faciliteer ipv te ondersteunen)
- Moedig zelfredzaamheid en zelfmanagement aan
- Doelgericht revalidatie met focus op de functie en op automatische bewegingen (bv. wandelen) eerder dan op de beperking (bv. zwakte)
- Vermijd het bekrachtigen van slecht aangepaste compensatoire houdingen of bewegingen
- Vermijd het gebruik van hulpmiddelen, bv gewrichtsimmobiliserende spalken
- Herken niet-helpende gedachten of gedragingen en daag ze uit
- Ontwikkel en hervalpreventie-plan

Occupational therapy

Occupational therapy consensus recommendations for functional neurological disorder

Nicholson, C., et al. (2020). Occupational therapy consensus recommendations for functional neurological disorder. *Journal of neurology, neurosurgery, and psychiatry*, *91*(10), 1037–1045. https://doi.org/10.1136/jnnp-2019-322281

Consensus aanbevelingen:

- Wees empathisch en erken dat FNSS een ernstige aandoening is met grote impact
- Neem de tijd om naar het verhaal van de patiënt te luisteren en een therapeutische vertrouwensrelatie op te bouwen
- Spreek voor de start van de behandeling behandeldoelstellingen af
- Introduceer bij de eerste sessie het concept zelf-management
- Geef uitleg over de diagnose en de symptomen van de patiënt. Betrek hier de context bij.
- Zet de variabiliteit van de symptomen tijdens therapie in op een positieve manier.
- Herken niet-helpende gedachten, overtuigingen en gedragingen en daag ze uit.
- Integreer specifieke functionele strategieën en leer de patiënt aan hoe hij ze zelfstandig kan toepassen.
- Focus op functionele, eerder dan beperking-gerelateerde behandeldoelstellingen.
- Wees open en consistent in verbale en schriftelijke communicatie
- Vermijd waar mogelijk het gebruik van hulpmiddelen of compensatoire strategieën, zeker in de acute fase.
- Vermijd het gebruik van gewrichtsimmobiliserende spalken.
- Maak een hervalpreventieplan en een zelfmanagement plan.

Speech and language therapy

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

Baker, J., et al. (2021). Management of functional communication, swallowing, cough and related disorders: consensus recommendations for speech and language therapy. *Journal of neurology, neurosurgery, and psychiatry*, *92*(10), 1112–1125. https://doi.org/10.1136/jnnp-2021-326767

Consensus aanbevelingen functioneel stotteren:

Educatie

- Geruststelling mbt aard van de klachten en prognose
- Uitleg over redenering achter diagnose FND
- Leg uit dat stotterproblemen een uiting kunnen zijn van verhoogde spierspanning die weer onder controle gebracht kan worden

Symptomatisch

- Verminder overmatige spierspanning door:
  - …
  - …

Psychologisch

- Identificeer niet-helpende overtuigingen, overdreven focus op lichaamssensaties en gevoelens van controle verlies
- Communicatie counseling mbt voorbeschikkende, uitlokkende en onderhoudende factoren
- Leer patiënten meer geschikte manieren van reageren op stottermomenten
- Verwijs naar psychotherapie

Medication

- Decreasing level of arousal
- Treatment of comorbidity
- Sleep

- Reduction of anti-(epileptic)-seizure medication

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Questions?

REVALIDATIECENTRUM
Pulderbos

Functionele aanvallen - FNSS in Pulderbos

PNEA-traject Pulderbos

- Traject FNSS-FA module diagnostiek
- Traject FNSS-FA module revalidatie

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FNSS-FA-traject Pulderbos : Voorwaarden

- Somatisch voortraject extern uitgewerkt
  - Alle somatische onderzoeken moeten afgerond zijn
  - Hulpvraag mbt begrijpen van FNSS
  - Uitzondering: intern voortraject EPI (onderscheid E – functionele aanvallen)
- Matige/ernstige weerslag op functioneren en participeren
  - Stepped Care: geen eerste lijnszorg
- Jongere en ouders gaan akkoord met:
  - Multidisciplinaire aanpak volgens BPS model
  - Kinderpsychiater in consult
  - Schakelfunctie: “ook na Pulderbos zal er begeleiding nodig zijn”

FNSS-FA-traject module diagnostiek

Doel:

- Klachten beter begrijpen: mechanisme, factoren die meespelen
  - Gegevens anamnese / verwijzers
  - Observaties / diagnostiek (oa persoonlijkheid, coping, gezinsdynamieken)
- Zicht krijgen op de ‘puzzel’:
  - Voorbeschikkende factoren
  - Uitlokkende factoren
  - Onderhoudende factoren
- Opstellen van gepersonaliseerd biopsychosociaal kader en vicieuze cirkels rekening houdend met de ontwikkelingstaken
- Therapeutische ingangen zoeken

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