THE ROLE OF EXPLANATION IN FUNCTIONAL NEUROLOGICAL SYMPTOMS – *Why so difficult?*

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”There is a widespread agreement that the way health professionals communicate the diagnosis of functional neurologic disorders has a central role in treatment…”

(Stone, Carson, Hallet (2016): *Explanation as treatment for functional neurologic disorders,* Handbook of clinical neurology Vol 139)

TODAY

- Many doctors find it difficult presenting the diagnosis, though early diagnosis is associated with better outcome.
- Often, we simply fail to present a diagnosis at all – instead explaining ***what it is not.***

(Stone, Carson, Hallet (2016): *Explanation as treatment for functional neurologic disorders,* Handbook of clinical neurology Vol 139)

THE DIFFUCULTIES

Health professionals

”My job is to deal with somatic problems, not psychiatric”

”I don´t know how to help the patient”

”The patient is faking the symptoms (and that makes me mad)”

”I´m afraid I will not recognise a serious disease”

”I´m afraid of the reaction of the patient”

THE DIFFUCULTIES

Patients/family

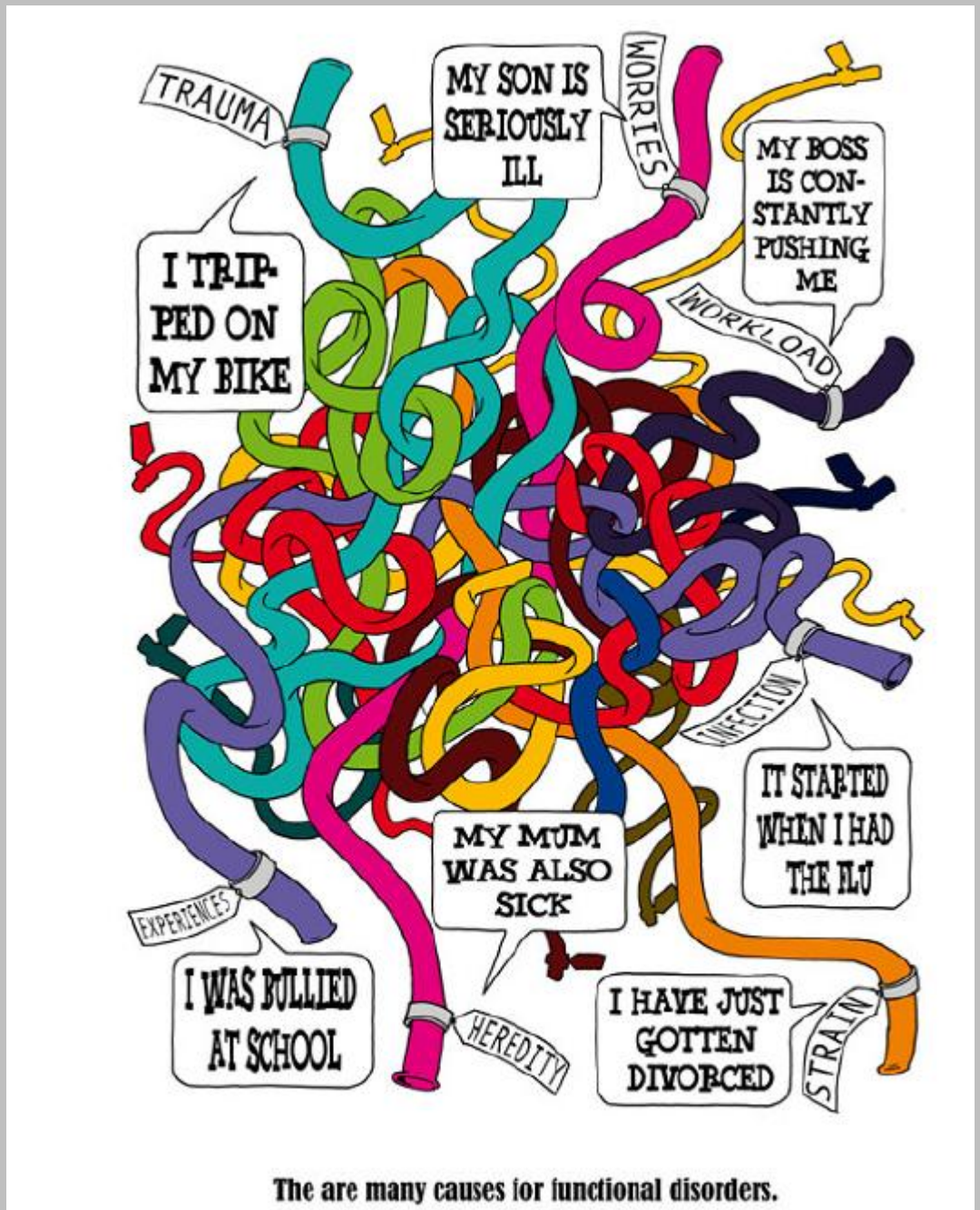
”I think the doctor thinks I´m faking it”

a) There´s some truth in it, but how could I admit that?

b) That´s really not the case

”I am afraid they will fail to recognise a serious disease”

MECHANISMS IN FUNCTIONAL NEUROLOGICAL SYMPTOMS

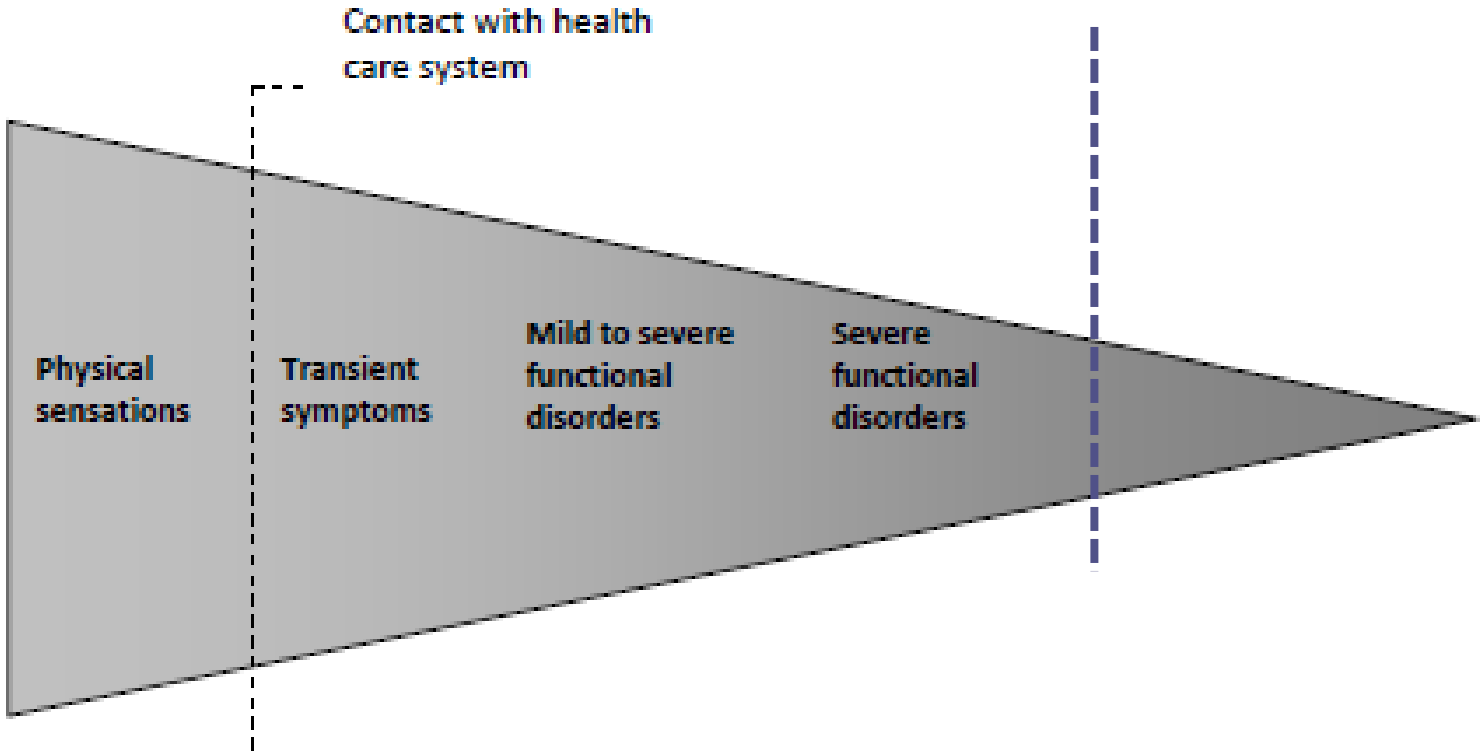


The are many causes for functional disorders.

(From ”When the body says stop”, The research clinic for Functional Disorders and Psychosomatics, Aarhus University, www.functionaldisorders.dk)

It´s a normal mechanism

Figure 1. Functional disorders range from transient symptoms with high incidence to severe disorders with low incidence



Dansk selskab for Almen Medicin: Clinical guideline for general practice: Functional disorders (2013)

	Predisposing	Precipitating	Perpetuating
Biological	*”Organic disease”* *Genetic factors (personality)* *Vulnerabilities in the nervous system*	*Abnormal physiological event/state (drug side effects, sleep deprivation)* *Pain/injury*	*Plasticity → habitual abnormal movement* *Neuroendocrine and immunological abnormalities*
Psychological	*Emotional disorders* *Personality disorder/traits* *Poor attachment style* *Perception of childhood experience as adverse*	*Perception of life events as negative, ”out of my control”* *Acute dissociative episode/Panic attack*	*Illness beliefs (patient and family)* *Perception of symptoms as being irreversible* *Not feeling believed* *Perception that movement causes damage* *Avoidance of symptom provocation*
Social	*Childhood neglect/abuse* *Poor family functioning* *Symptom modelling of others*	*Life events* *Difficulties* *Relation trauma*	*Social benefits of being ill* *Availability of legal compensation*
Iatrogenic	*Uncertainty in diagnosis* *Diagnostic delay*	*Change of doctor*	*Ongoing medical investigation* *Reliance on sources which reinforce beliefs that symptoms are irreversible/purely physical in nature*

Adapted from: Nielsen G, Stone J, Matthews A et al. J Neurol Neurosurg Psychiatry 2014:0 1-16

EXPLANATION MODELS

STRATEGY	COMMENTS
Making no diagnosis: ”no neurological disease”, ”non-organic”	The patient is likely to go elsewhere to seek a diagnosis
Making an ”unexplained” diagnosis: ”these things are common in neurology and we don´t really know how they happen”	The patient is likely to go elsewhere to seek a diagnosis It is possible to make a positive clinical diagnosis
Making an incomplete diagnosis – eg telling someone with a 3-week history of functional hemiparesis triggered by migraine that they just have migraine	May be acceptable to the patient (and be easier for the doctor), but leads to a missed oppurtunity to understand symptoms and their potential for reversibility
A psychogenic model – eg that the symptoms are ”stress-related”	Likely to be rejected by most (80%) patients (Somatic health care) Often equated by patients as ”made up” or ”imagined” Many patients do not have identifiable stress or psychiatric disorder However, consistent with referral for psychological treatment

(Jon Stone Pract Neurology 2016;16:7-17)

A FUNCTIONAL MODEL

For	Against
Emphasis on mechanism rather than etiology – does not jump into conclusion about the cause	Ambigous about absence of neurological disease (vague and wide – ”what is **not** disorder of functioning?” – eg epilepsy)
In keeping with a genuinely biopsychosocial model	Greater difficulty in linking to relevant psychological factors and treatment
Less likely to be equated with ”faking” or ”imagining” symptoms	Any term will acquire stigma over time, terms should be based on mechanism involved
Consistent with referral to physiotherapy (to improve function)	The term should be ”dysfunctional”, not ”functional”.

(Adapted from Jon Stone Pract Neurology 2016;16:7-17,
Stone, Carson, Hallet (2016): *Explanation as treatment for functional neurologic disorders,*
Handbook of clinical neurology Vol 139)

Functional *Non-organic* *Dissociative* *Stress-related*

THE NAME

Hysterical *Psychogenic*

- Whatever name we use, ***how we present it*** will always of extreme importance
- We **need to** address:

- That we **believe the symptoms are real**
- The complexity of causes
- The possibility of complete recovery

- We usually **don´t need to adress:**

- Whether or not the symptoms could be deliberately feigned

COMMUNICATING WITH THE PATIENT AND FAMILY

ILLNESS BELIEF

- Start with the patient´s belief

Have you met someone with symptoms like these before?

Why do you think you got these symptoms? How do you think it works?

Why do you think the symptoms don´t resolve?

How did your family/friends react to your symtoms?

EXPLAIN THE DIAGNOSIS	EXAMPLE
Explain the mechanism rather than the cause	”Your nervous system is not functioning properly, but it is not damaged. There is a problem with the way your brain is sending messages to your arm/leg ”.
Explain how the diagnosis is made (Hoover´s sign)	”I can see that when you try to push that leg down on the floor it´s weak, in fact the harder you try the weaker it gets. But when you are lifting up your other leg, can you feel that the movement comes back to normal? This tells me that the brain is having problems sending the right message to the leg, also that the weakness can´t be due to damage”
Explain what they don´t have	”You do not have stroke, MS, epilepsy…”
Indicate that you believe them	”I believe you. I do not think you are imagining or making up symptoms”
Emphasize that it is common	”I see lots of patients with these symptoms”
Emphasize reversibility	”Because there is no damage you have the potential to get better. Your physical signs show me that”

(Nielsen G, et al J Neurol Neurosurg Psychiatry 2014;0:1-16, 2014)

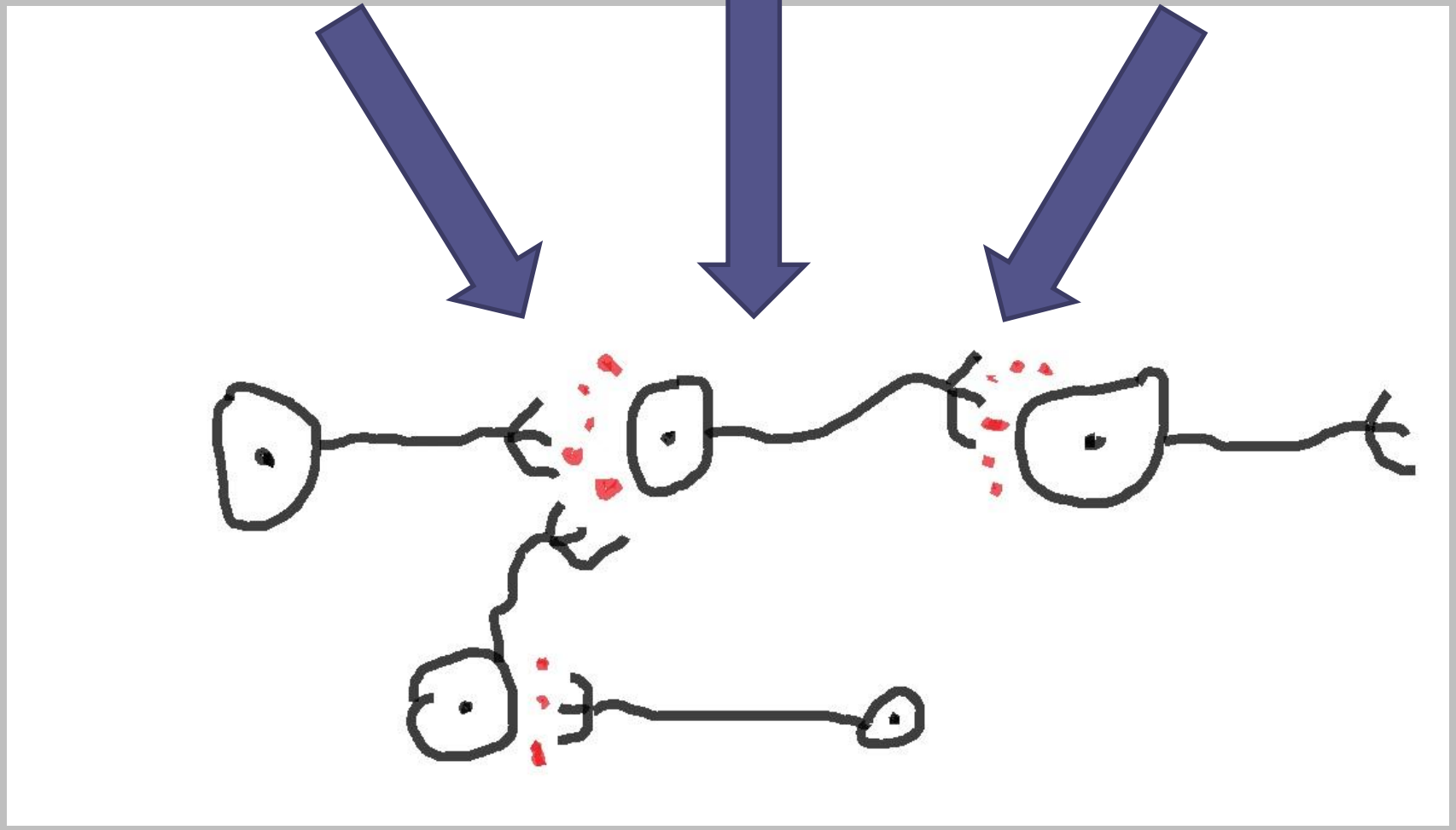
EXPLAIN THE DIAGNOSIS	EXAMPLE
Emphasize that self-help is a key part of getting better	”This is not your fault, but there are things you can do to help it get better”
Metaphors may be useful	”The hardware is alright, but there´s a (reversible) software problem ”
Introducing the role of depression/anxiety	”If you have been feeling low/worried, that will tend to make the symptoms worse”
Involve the family/friends	Explain it to them as well
Provide written information	www.neurosymptoms.org www.funktionellasymptom.se www.nonepilepticattacks.info

(Nielsen G, et al J Neurol Neurosurg Psychiatry 2014;0:1-16, 2014)

DRUGS

PHYSIOTHERAPY

PSYCHOTHERAPY



SUMMARY: components of effective explanation

1. Taking the patient seriously
2. Giving the problem a diagnostic label
3. Explaining the rationale for the diagnosis
4. Some discussion of how the symptoms arise
5. Emphasis on potential for reversibility (rather than damage)
6. Effective referral for treatment, when appropriate

(Stone, Carson, Hallet (2016): *Explanation as treatment for functional neurologic disorders,* Handbook of clinical neurology Vol 139)

“Be a little nicer than you have to”

E. Lockhart, “We were liars” (2014)