

Here are some insights from patient advocates



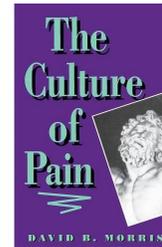
- it's patronising to 'educate' us; we know pain better than you! But we **want your advice!**
- it's important that you **believe us** when we tell you that we're in pain
- we're **isolated, stigmatized and disempowered**
- even after we know that we need to live with pain, we still need to know that you (HCP) **are on our team** because living with pain is a constant struggle

Communications from European Pain Conference 2019 | COMMUNICATING PAIN SCIENCE, WITH PATIENTS AND FOR PATIENTS

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David B. Morris states that



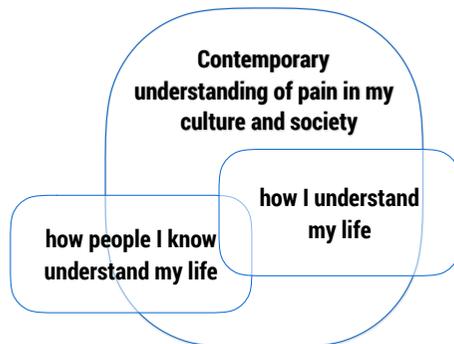
- **Pain is more than a medical issue** and more than a matter of nerves and neurotransmitters
- **Pain has** historical, psychological, and cultural **dimensions**
- **Meaning is often fundamental** to the experience of pain
- **Minds and cultures** (as makers of meaning) **have a powerful influence** on the experience of pain, for better or worse

From: *Pain's dominion*, Wilson Quarterly, Autumn94, Vol. 18 Issue 4

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PAIN-AS-A-SOCIAL-CONSTRUCT METAPHOR



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**MAYBE "PAIN EDUCATION" IS
(ALSO) HELPING THE PERSON
IN PAIN TO COMMUNICATE
HOW THEY FEEL?**

Photo: Morten Hoegh

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A CONTEMPORARY DEFINITION OF 'CHRONIC' PAIN

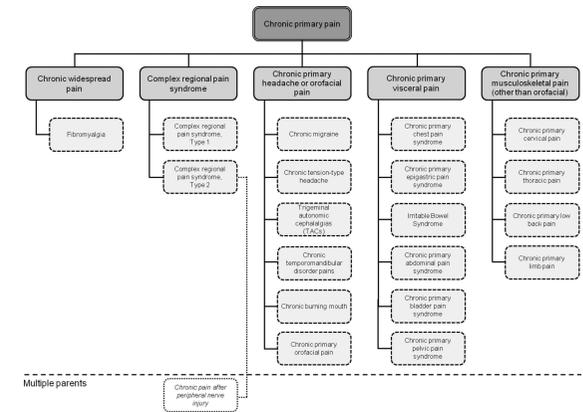
Pain in **one or more anatomical regions** that persists or recurs for **longer than 3 months** and is **associated with significant emotional distress or functional disability** (interference with activities of daily life and participation in social roles) and that **cannot be better accounted for** by another chronic pain condition.

Treede, Rolf Diefel et al. PAIN January 2019 - Volume 160 - Issue 1 - p 19-27

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CHRONIC PRIMARY PAIN (ICD-11)



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M. Nicholas et al. PAIN, 160 (2019) 28-37

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Patient-centred



Focus on **how the patient is affected** by Dx and Rx
 Accepting **patient-as-expert** paradigms
 Allowing patient **autonomy** (e.g. goal setting)
 Embracing a role as **counselor and supporter**

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Expert-centred

Focus on **pathology and evidence**
 Professionals are **knowledgeable experts**
 Healing and **curing is the aim** of the treatment
 Abnormalities (cells, genes, brain function, thoughts) are **causal explanations**

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ICEBERG METAPHOR



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MOVING BEYOND METAPHORS TO HELP PATIENTS TO RE-ENGAGE IN THEIR SOCIAL ROLES



- **Stop using tissue-based explanations** for non-specific pain
- **Accept the complexity** (i.e. search for meaning, not causality)
- Make the **patient expert** and let their perception be in focus
- Acknowledge that **"effect" is a linear response to treatment**
- **Accept and apply "non-specific effects"** (including placebo) in your treatment

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HOW IS PAIN EDUCATION OPTIMISED?

Watson et al

The Journal of Pain 19

Table 7. Principles of Synthesised Findings

SYNTHESISED FINDING	PRINCIPLES
1	S1a) A comprehensive assessment allowing the patient to tell their own story ensuring they felt heard. S1b) Identification of prior understandings and beliefs to facilitate the delivery of PNE in a manner relevant to the patient. S1c) A comprehensive assessment allowing the patient to clarify their story to a HCP to raise their awareness of the biopsychosocial nature of pain.
2	S2a) PNE delivered by a HCP skilled in PNE delivery. S2b) PNE delivered by a HCP skilled in facilitation of group, or one-to-one interactions with, and between patients and other HCPs. S2c) Progress towards reconceptualisation was monitored throughout tailoring concepts that have not been accommodated to ensure relevance of PNE to the individual. S2d) Achieving pain reconceptualisation can enhance patients' ability to cope with their condition.

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Watson JA. et al. in press (2019)

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LISTEN

To really listen is to **focus your attention** on the patients, on what the patients say (and, indeed, on what they do not say) and **how they say it** — not just the words they use, but **the entire behavioral package** (ie, their manner, their posture, their ease of articulation, their expression, **and the attributions they provide for their pain**).

Lotze M, Moseley GL. Theoretical Considerations for Chronic Pain Rehabilitation. *Physical Therapy*. 2015;95(9):1316-1320

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EMPOWERMENT

The most frequently applied behavior-change technique, as identified in our review, was **knowledge** but this isn't sufficient to empower the patient. Knowledge should be combined with **goal setting** and **action planning** to give empowerment.

Werbrouck A, et al. *How to empower patients? A systematic review and meta-analysis.* *Behav Med Pract Policy Res*. 2018;17(1):37-15.

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Health Literacy

"A patients' personal, cognitive and social competences to inquire, understand and utilize knowledge about their health as a mean to promote and maintain a good health"

THINGS TO CONSIDER IN YOUR HEALTH-COMMUNICATION

- ✓ Use short sentences and simple words
- ✓ Use present tenses
- ✓ Use words, which are meaningful to the patient
- ✓ Limit the information (3-5 key points)
- ✓ Be specific and avoid using general terms
- ✓ Support your communication with simple drawings or pictures

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Adapted from: Writing and Oosterveld, Patient Education and Health Literacy, Musculoskeletal Spine (2018)

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GIVE THE PATIENTS **AUTONOMY** AND PROMOTE **SELF-MANAGEMENT**



- 1 ALLOW THE PATIENT TO BE THE EXPERT AND SET THE GOALS
- 2 ALLOW TO MAKE DECISIONS RELATED TO THEIR OWN LIFE
- 3 ALLOW THE PATIENT TO SET THE PACE
- 4 SUPPORT TRUST AND CREATE ROOM FOR TALKING ABOUT DESIRES AND WORRIES

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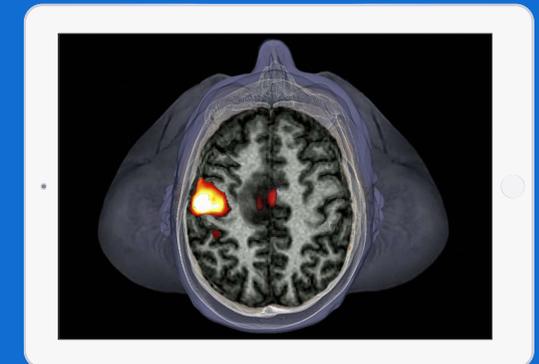
A WORD ABOUT METAPHORS

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METAPHORS ARE COMMONLY USED IN SCIENCE

to explain something complex or abstract to 'outsiders' - but complexity does not disappear when concepts or principles are made clear via communication...



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EXAMPLES OF METAPHORS ABOUT PAIN

01 → Tequila-vaccine

02 ← Alarm system

03 → Staying under the radar

04 ← Sensitised nerves

05 ↑ Pain is like a baby

BUT MAKE SURE THAT THE PATIENT UNDERSTANDS THE POINT YOU ARE TRYING TO MAKE!

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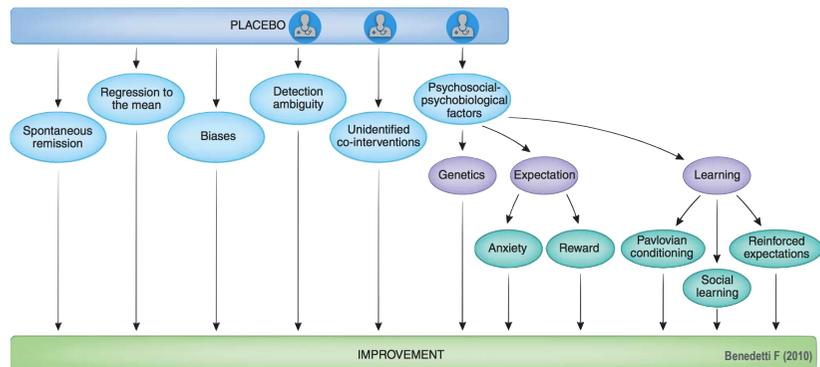
METAPHORS AND THEORIES ARE NOT SCIENCE

- **Metaphors** are explanations
- **Theories** are used to make sense of the pain / information from the patient
- **Science** is a systematic and structured collection of data, which is analysed using a set of rules

PLACEBO AND NOCEBO EFFECTS

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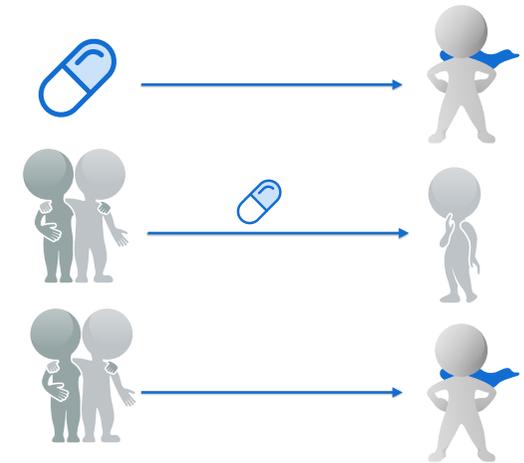
PLACEBO EFFECTS



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MODIFIED PAVLOVIAN (CLASSICAL) CONDITIONING

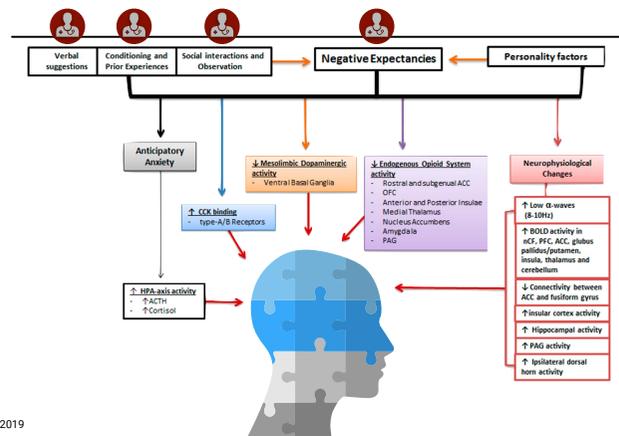


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NOCEBO ALGESIA AND HYPERALGESIA

Blasini M, Corsi N, Klinger R, Colloca L. Nocebo and pain. *PAIN Reports*. 2017;2(2)



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EXPECTATIONS

» Positive treatment expectancy substantially enhanced (doubled) the analgesic benefit of remifentanyl. In contrast, negative treatment expectancy abolished remifentanyl analgesia. «

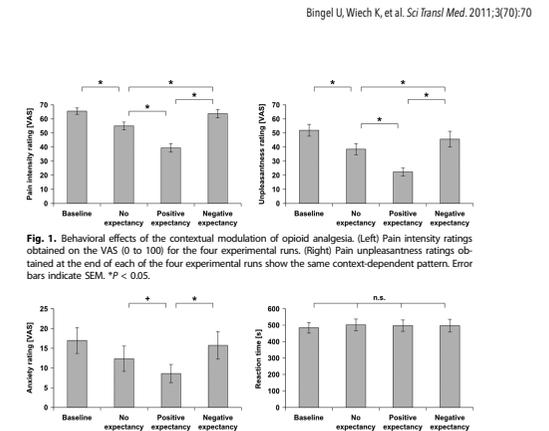


Fig. 1. Behavioral effects of the contextual modulation of opioid analgesia. (Left) Pain intensity ratings obtained on the VAS (0 to 100) for the four experimental runs. (Right) Pain unpleasantness ratings obtained at the end of each of the four experimental runs show the same context-dependent pattern. Error bars indicate SEM. * $P < 0.05$.

Fig. 2. Behavioral effects of the expectancy modulation of opioid analgesia. (Left) Anxiety ratings obtained on the VAS (0 to 100) at the beginning of each of the four experimental conditions. (Right) Mean reaction times (seconds) in the reaction time task performed at the beginning of each trial. Error bars indicate SEM. * $P < 0.05$; n.s., not significant.

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Bingel U, Wiech K, et al. *Sci Transl Med*. 2011;3(70):70

PLACEBO-BASED PRACTICE | STATE-OF-THE-ART?

Table 1

Clinical applications of the placebo effect.

Techniques of negotiations for explaining or applying an acute pain medication, for example, during consult for **acute (postoperative) pain management in the hospital** or when prescribing new medication for chronic pain management

Enhancement of expectations

- Emphasis on **positive drug effects**, avoidance of overemphasis on side effects
- **Explanation of the effects** of the drugs and the mechanism of drug action
- **Personal interaction** rather than only written materials
- Explanation of the course of drug action, **avoidance of unrealistic promises**

Enhancement of learning components

- Applications of analgesics in an **open manner** including many sensory aspects
- **Association of analgesic medication with positive internal states and in positive external conditions**
- **Combination** of the intake of analgesics with **other pain-relieving techniques**
- **Time**: rather than pain contingent analgesic **medication on an intermittent schedule**
- Exploration of analgesic-associated experiences and attitudes and reinforcement of positive and devaluation of negative experiences

Klinger R, Colloca L, Bingel U, Flor H. Placebo analgesia: Clinical applications. 2014;155(6)

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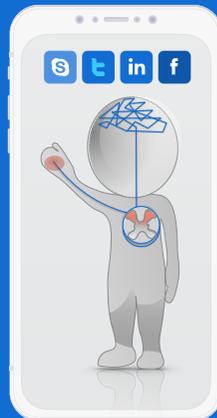
BRINGING IT TOGETHER IN A NARRATIVE

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MAKE PAIN UNDERSTANDBLE AND SOCIALLY ACCEPTABLE

- Create a narrative that provides meaning and a way to communicate about "how I feel"
- Normalise and stabilise functions (rather than boom-bust)
- Contingency plans for flare-up



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CREATE A NARRATIVE FROM THE MUTUAL UNDERSTANDING OF 'MY PAIN'

Should **empower the patient to**

- ✓ explain **how they feel** (pain, discomfort, mood changes, frustration)
- ✓ **why** we think they suffer and what they are doing
- ✓ **control, understanding and predict** their pain
- ✓ **find hope!**



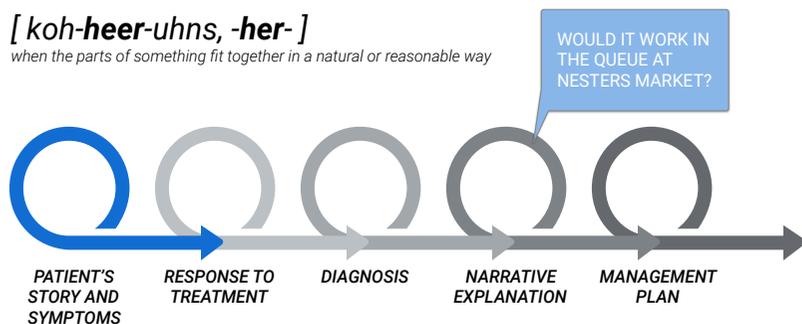
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COHERANCE

[koh-heer-uhns, -her-]

when the parts of something fit together in a natural or reasonable way



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Imagine that Karen was your patient

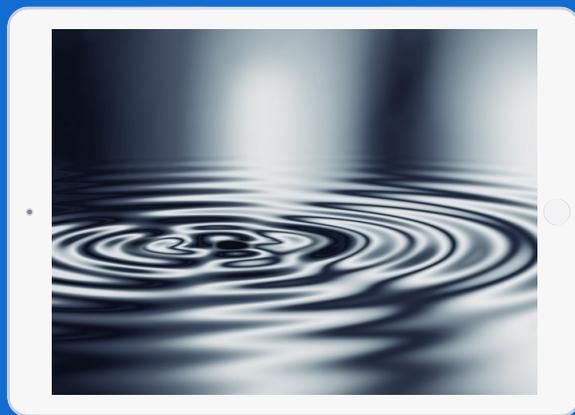
Karen is 47 years old and diagnosed with **Failed Back-Surgery Syndrome**, but here's her explanation:

“ I'm **doing really well**, thank you. Yes, I **did have back problems** and surgery didn't exactly improve my wellbeing. I've **worked out with my GP** that there's **nothing wrong with my back** but my **nervous system has become overactive**; it keeps sending signals as if something was wrong but really I'm fine. I found out that **opioids don't really make my life better and that staying active doesn't make it worse**. So, I've **taken up fitness again**. Feels great to know that I can **safely move**. It's really **given me back a lot of things I had given up on** - including work. I think the **change happened when I learned that my pain was independent of all the things that I had learnt myself to avoid**. I know that pain will be increased if I go out dancing - but, hey - what's life without dancing :) Give me 1-2 days and I'm back to normal. In fact, *I'm going trekking in Yellowstone next week. Didn't you go once...*”

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GRADUAL EXPANSION OF THE NARRATIVE



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Thank you for listening

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