

Empowering Your Well-being: A Comprehensive Pain Management Approach for Ehlers- Danlos Syndrome

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What we will discuss today:

- Why pain is complex
- Some of the tools that are available
- How to take back control

International Association for the Study of Pain: Definition of pain

- An unpleasant sensory **and emotional experience** associated with, **or resembling that associated with**, actual or potential tissue damage
- Pain is always a personal experience that is influenced to varying degrees by biological, psychological, and social factors.
- Pain and nociception are different phenomena. Pain cannot be inferred solely from activity in sensory neurons.
- Through their life experiences, individuals learn the concept of pain.
- A person's report of an experience as pain should be respected.
- Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being.
- Verbal description is only one of several behaviors to express pain; inability to communicate does not negate the possibility that a human or a nonhuman animal experiences pain.



“Pain is whatever the experiencing person says it is,
existing whenever the experiencing person says it
does” - Margo McCaffery RN, MS, FAAN, early
Hospice movement pioneer

Pain is one of the most common reasons why people seek medical care

- Pain **warns us of potential danger to tissue harm or to the presence of injury**
- Or sometimes it's just a signal – like a fire alarm going off with no fire
- And often your providers have not had much training in pain (10h in all of medical school, less for NP and PA's who have a shorter training process)



Barriers to best practices in pain care

Payer administrative and reimbursement issues

Physician workforce and training

Research and utilization of evidence

Stigma

CDC Guidelines and their interpretation

Legal issues and opioid prescribing

Patient expectations

AMA Journal of Ethics®

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POLICY FORUM

Addressing Obstacles to Evidence-Informed Pain Care

AMA Pain Care Task Force


Abstract

Pain is a universal human experience and the most common reason patients seek health care. This article describes barriers to effective, high-quality, evidence-informed pain care. Based on the clinical literature and pain specialists' survey results, the AMA Pain Care Task Force suggests strategies that clinicians can use to offer good pain care to patients. The task force also canvasses key policy-level concerns that situate clinicians in micro- and macro-level complexities related to payers, workforce and training demands, legal and regulatory questions, research, stigma, and patients' beliefs and expectations.

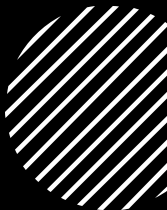
Why Do Some People Hurt More Than Others?

- Comprehensive pain assessment is essential for effective management.
- Treatment plans should incorporate both nonpharmacologic and pharmacologic interventions.
- Multidisciplinary collaboration optimizes outcomes and improves quality of life for patients with pain.
- Intro to spectrum and lived differences





Factors That Influence Pain in EDS



Nervous system sensitivity (central sensitization)



Joint stability and strength



Psychological, social, hormonal, gut, and sleep influences



Access to care and early diagnosis

Biomedical:

Three types of pain

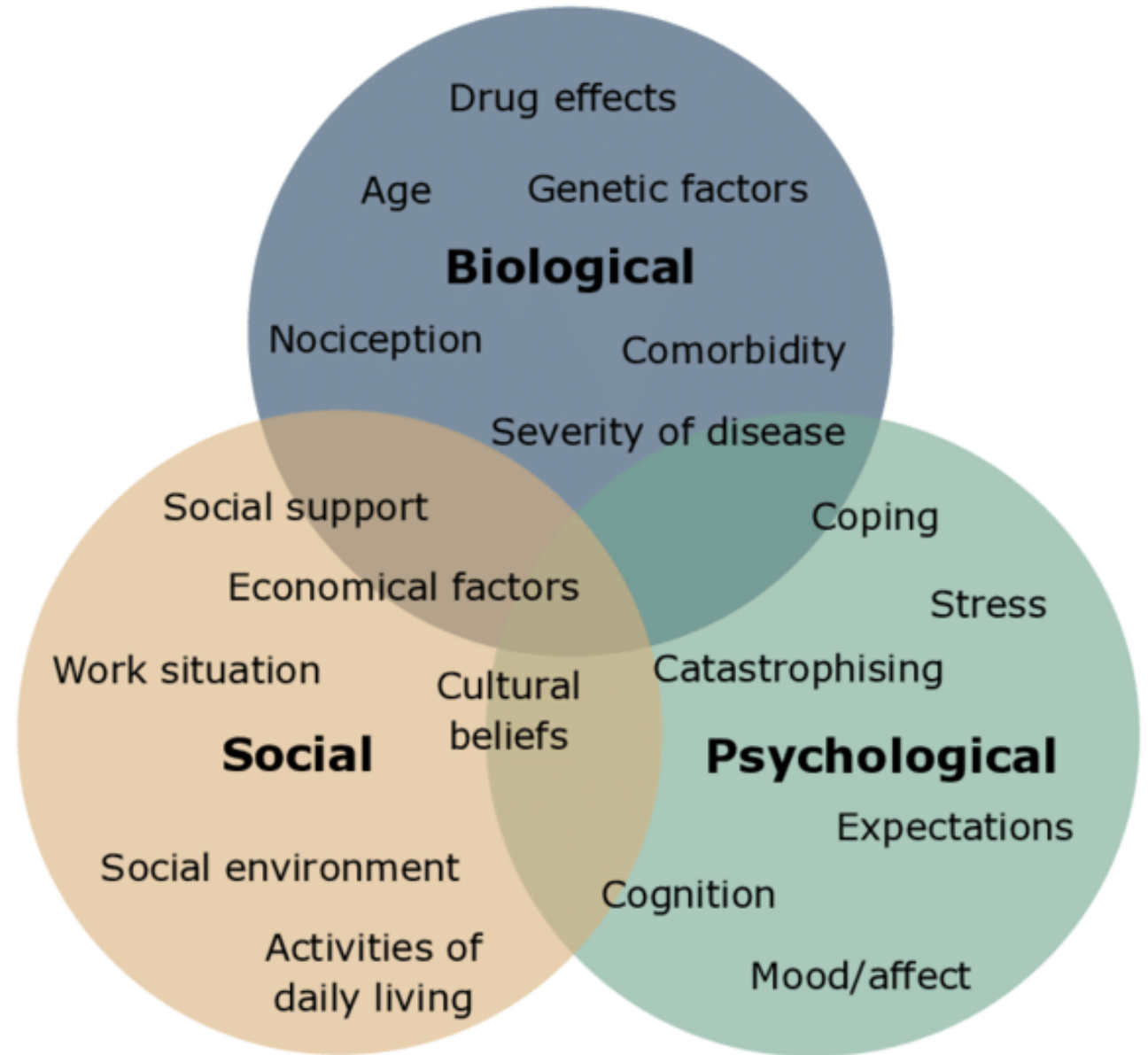
	NOCICEPTIVE/ INFLAMMATORY	NEUROPATHIC	CENTRAL SENSITIZATION/ NOCIPLASTIC
Stimulus	Injury or inflammation	Neural damage, pinching, irritation	Central nervous system dysfunction
Neurons	Nociceptor and non-nociceptor	Nociceptor and non-nociceptor	Non-nociceptor
Site	Peripheral and central nervous system	Peripheral and central nervous system	Central nervous system
Clinical setting	Acute trauma, post-operative, arthritis	Nerve lesions, diabetic neuropathy, shingles, carpal tunnel	Fibromyalgia and a variety of other pain disorders
Function	Protective, healing/repair, pathological	Pathological	Pathological
Pain sensitivity	High or low threshold	Low threshold	Low threshold

SOURCE: A. PATAPOUTIAN *ET AL* / *NATURE REVIEWS DRUG DISCOVERY* 2009
ADDITIONAL REPORTING BY A. DANCE

KNOWABLE MAGAZINE

Biomedical vs. Biopsychosocial Approach

- Why we need a whole-person perspective for chronic pain
- Best outcomes



Patient Empowerment: Advocate for Yourself

Control your controllables





The 5 Empowerment measures - Modifiable factors for patients with pain



Eat



Sleep



Move



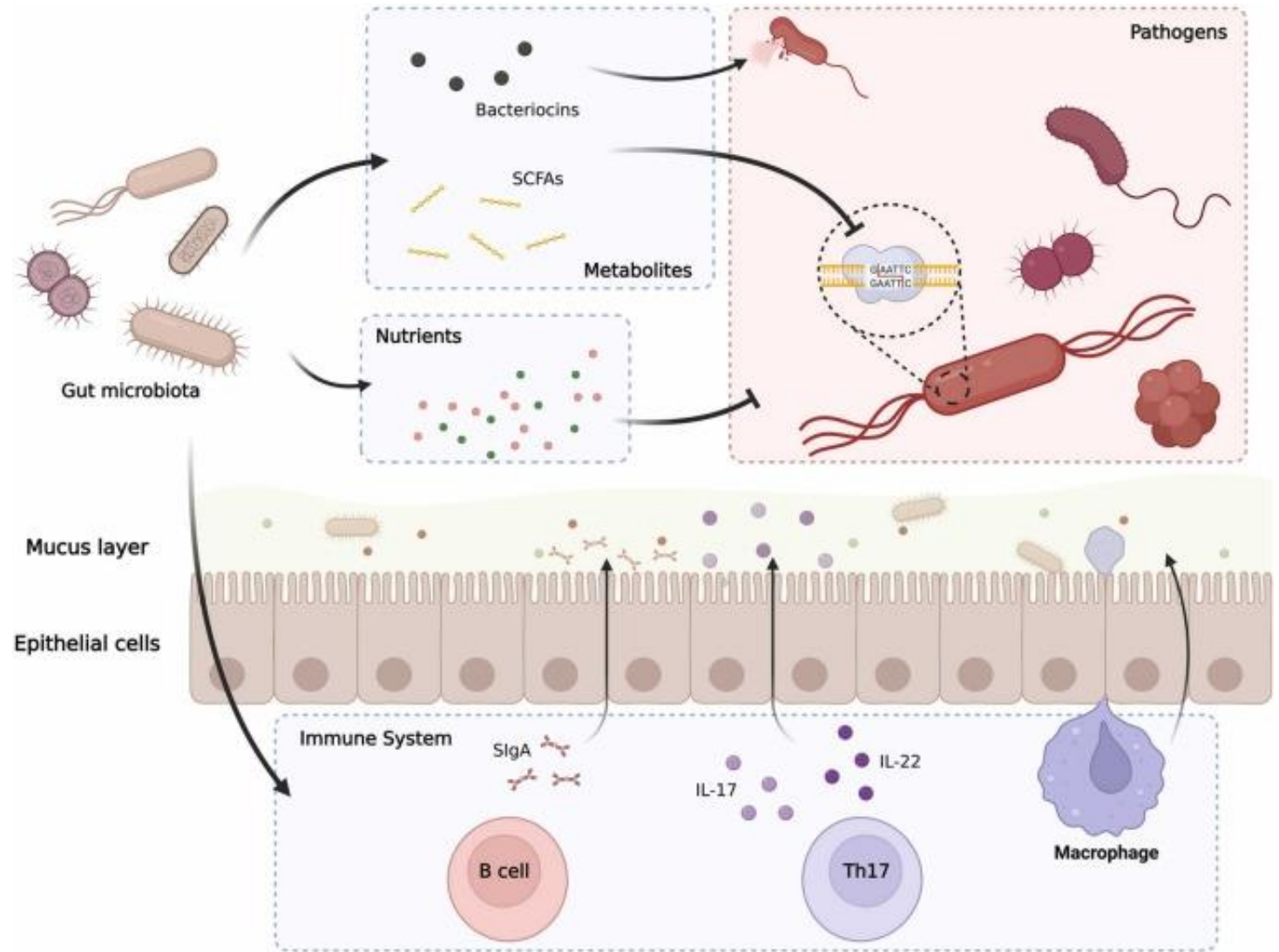
Relax/Unplug



Connect

The Neuroimmune Connection

- Gut dysbiosis and inflammation
- Immune system + nervous system = chronic pain loop
- Why healing the gut can help the brain



Spotlight: Low-Dose Naltrexone (LDN)

How it works (glial inhibition, immune modulation, opioid blockade)

Side effects and access

Use cases: CRPS, fibromyalgia, EDS

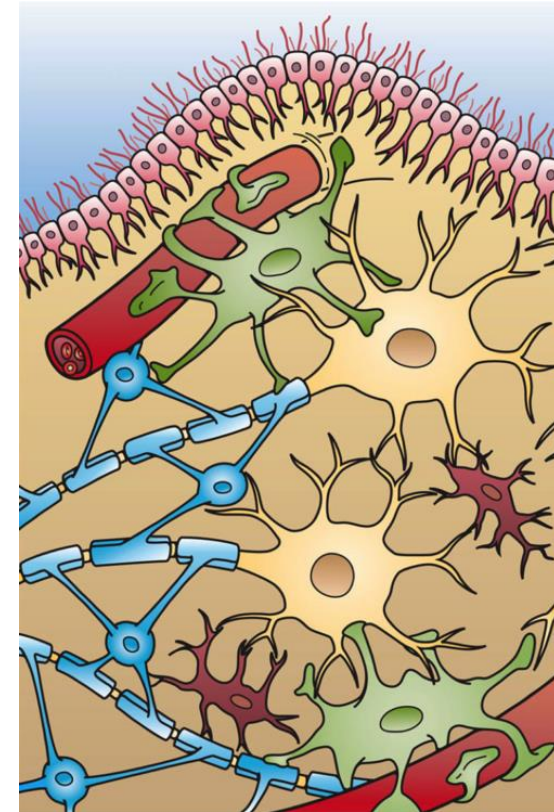


Illustration of the four different types of glial cells found in the central nervous system: ependymal cells (light pink), astrocytes (green), microglial cells (dark red), and oligodendrocytes (light blue). From: <https://en.wikipedia.org/wiki/Glia>

Spotlight: Cannabis

- THC vs CBD
- Role in nerve pain, anxiety, and sleep
- Legal/medical considerations



New Research From AHRQ: Are Cannabis-Based Products Effective in Treating Chronic Pain?

PRODUCTS REVIEWED:



Mostly THC



Mostly CBD



Equal THC and CBD



Synthetic



Whole Plant



Plant Extract

CONCLUSION:

Evidence suggests cannabis can reduce some types of chronic pain.



Adverse effects may include dizziness and nausea.



Each cannabis-based treatment has specific potential benefits and harms.

AHRQ = Agency for Healthcare Research and Quality

Spotlight: Ketamine

Ketamine Infusion for Chronic Pain

@DrMingKao

Ketamine is a potent, non-opioid medication used by Pain doctors to treat chronic pain. It is particularly helpful for patients to reduce opioid use, or to come off opioids entirely

Benefits

Ketamine & its metabolites bind to NMDA & acetylcholine receptors in the brain.

It treats **central sensitization** (heightened sensitivity across the senses) in **CRPS** (Complex Regional Pain Syndrome), **EDS** (Ehlers-Danlos Syndrome), **trigeminal neuralgia**, & **fibromyalgia**.

Ketamine is used by psychiatrists to treat **severe depression**.

Risks

Ketamine can cause hallucinations, anxiety, & nausea, which can be controlled with medication pre-treatments.

Large dose chronic ketamine can cause **chronic cystitis**, a sensation of bladder infection that does not go away.

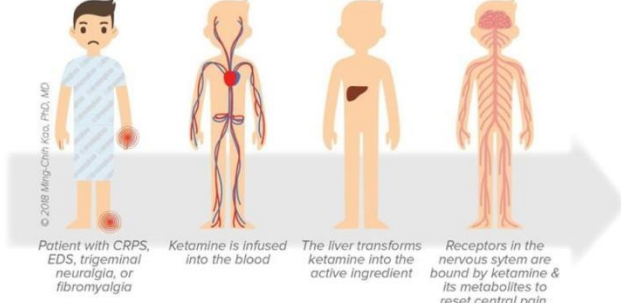
Ketamine has **abuse potential** and can profoundly affect **mood**.

Infusion Logistics

For pain, the treatment effects come from **ketamine's metabolite created by the liver**. The liver requires time to create & build up this active ingredient.

The infusion is typically performed as a **multi-day out-patient infusions** (3 to 5 days of 4-hour infusions each), or **in-hospital infusions** over several days. Patients are **awake but drowsy** during and after the infusion, and will need a responsible adult & dependable transport home.

Ketamine infusion is a part of a **complete pain plan** that includes physical therapy, psychological therapy, and other non-opioid oral pain medications.



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Ketamine can treat chronic pain conditions involving central sensitization – an increased sensitivity across the senses.

This includes:

- CRPS (Complex regional pain syndrome)
- EDS (Ehlers-Danlos syndrome)
- Trigeminal neuralgia
- Fibromyalgia

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October 30, 2024

Add a comment...

- Indications for CRPS and mood
- Mechanism: NMDA blockade, neuroplasticity
- What treatment looks like

Spotlight: Opioids

- Stats on long term use
- Risks vs benefits
- When opioids are appropriate
- Why they should be part of a broader plan

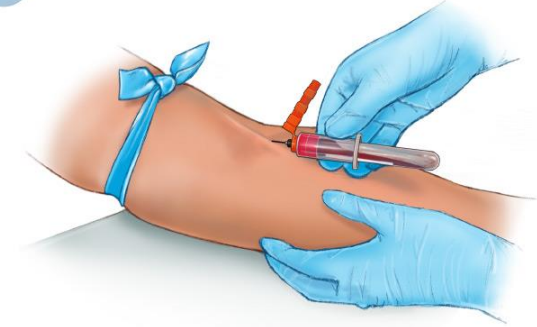


Spotlight: Regenerative Therapies

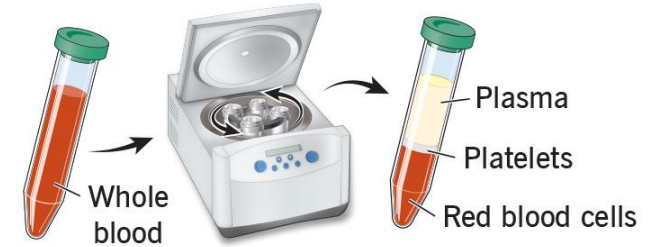
- Prolotherapy and PRP
- How they promote healing
- Best use cases for EDS patients (joints, ligaments, spine)

Platelet-rich plasma (PRP) injection

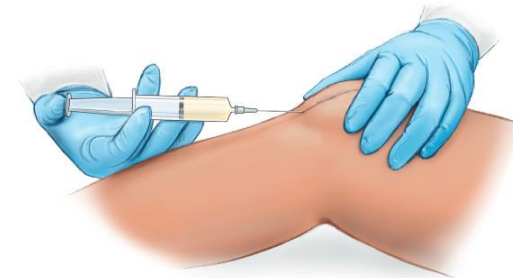
- 1 Your own blood is drawn.



- 2 The blood sample is put into a centrifuge.



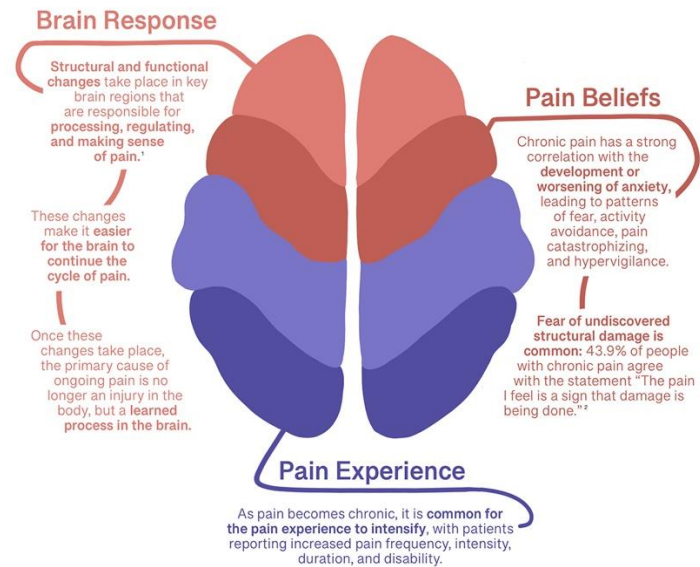
- 3 Platelet-rich plasma is injected into your tissues to promote wound healing.



Pain brain vs healing brain

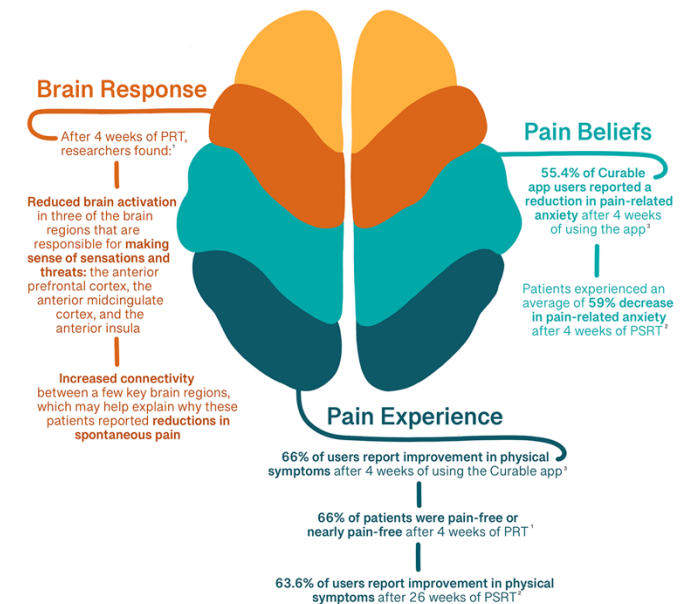
The Pain Brain

What changes when pain becomes chronic?



The Healing Brain

What changes take place when chronic pain is treated with a brain-centric approach?



Building Your Personal Plan

- No one-size-fits-all
- Layering treatments with foundations
- Staying hopeful and tracking your progress



Thank you

Sarah Merritt, MD

Lifestream Health Center

[Lifestreamhealth.com](https://lifestreamhealth.com)

