A truly multidisciplinary approach to managing pain and fatigue

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Disclosures & Warnings

•No financial disclosures or conflicts of interest

•You'll likely not agree with everything I say

•We're probably already behind schedule

•Hoping to leave time for questions

•No time to go into as much depth as I'd like

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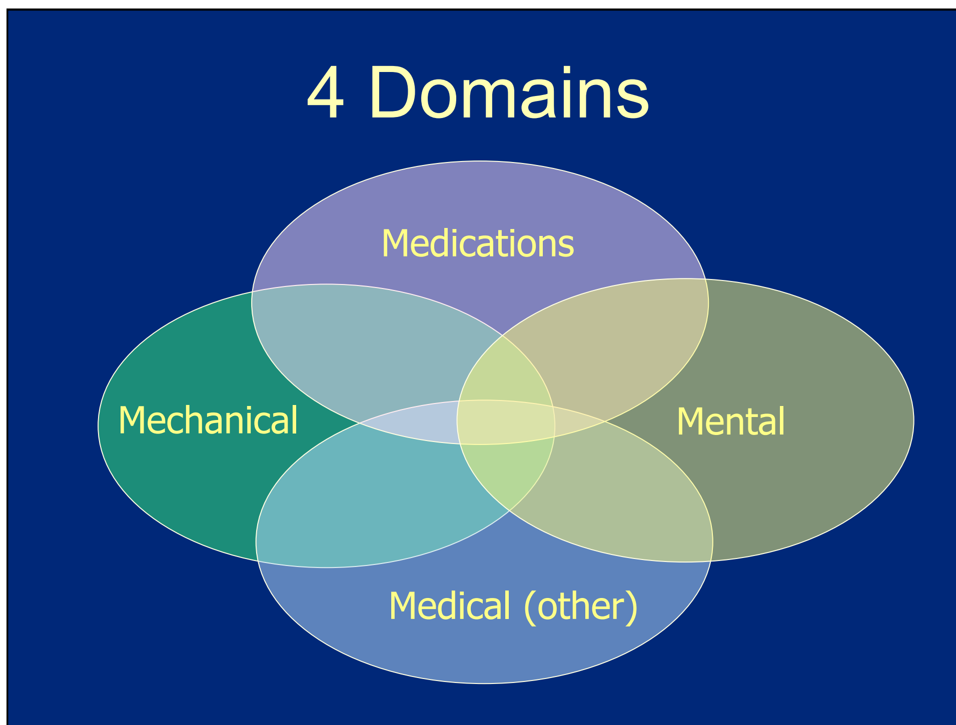

Medications

- Are you sensitive to all or most meds?
- Are you sensitive to opioids/narcotics?
- If yes to (1) but no to (2), does that really make sense?

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Why not just use opioids? (or start with them)

Potential opioid side effects:

- Sedation, clouded thinking (drive/work?)
- Disrupted sleep, sleep apnea
- Urinary retention
- Dry mouth
- Itching, sweating
- Constipation, nausea (worsens IBS)

"But I don't have those side effects, and they help my pain"

Additional problems (regardless of intent):

- Tolerance: need ↑ dose for same effect
- Dependency: withdrawal sx's if stopped
- Addiction:
  - take for reasons other than pain ("I just feel better")
  - modify actions to get more drug

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Opioid problems, continued

- Stigma/suspicion of abuse
- Target of crime
- Written Rx only
- Opioid-induced hyperalgesia (worse pain)
- Narcotic bowel syndrome
- Endocrine suppression (thyroid, adrenal, sex hormones, growth hormone)
- Possibly ↑ fracture & ↓ immune function

Opioid problems, continued

- Exit strategy?

- Government discouragement

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Medications

- Goal is to limit, not eliminate pain
- Prevention works better than relief:
  - Regular schedule to keep pain controlled
- Cocktail of multiple meds
  - Maximize safer, less potent drugs
  - Incremental effects
- Use opioids as last resort & try to limit use to no more than a few years
- Exit strategy?

Medications

- Acetaminophen (Tylenol)
  - Up 4000 mg/day is safe
  - Must account for ALL sources (many OTC meds)
- NSAIDs (ibuprofen, naproxen, etc)
  - Can exacerbate bruising & bleeding, but that is often preferable to pain
- Topical (or injected) anesthetics (lidocaine, etc)

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Medications

- Muscle relaxers
  - Prescription
  - Magnesium
- Neuropathic pain meds
  - Anti-seizure (gapapentin, pregabalin, etc)
  - Tricyclic (& related) antidepressants (amitriptyline, nortriptyline, trazodone)
  - SNRI antidepressants (venlafaxine, duloxetine, etc)
- See Hypermobility EDS GeneReview

Medications: Serotonin Syndrome

May be caused by most of the above (except acetaminophen & NSAIDs)

- Symptoms:
  - agitation, restlessness, tremor, ↑ reflexes
  - poor balance, confusion, irritability
  - ↑ temperature, ↑ heart rate, ↑ or ↓ BP
  - ↑ sweating
  - nausea, diarrhea

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Mechanical

Assumptions:

- Instability → spasm
- Instability → arthritis
- Spasm & arthritis → pain
- Pain & spasm → fatigue

If true, then goals are:

- Reduce spasm
- Reduce instability (increase stability)

Mechanical

Avoid/minimize:

- Resistance & impact
  - Destabilizes joints
- Thin pens/pencils/utensils
- Surgical stabilization
  - Often fails in 0-60 months
- No need to avoid hyperextension!
  - No benefit
  - Can worsen perceived pain

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Mechanical

Reduce spasm:

- Stretch
- Massage, mechanical release, etc
- Heat, ultrasound, electrical stimulation
- Acupuncture/pressure
- Trigger point injections/dry needling
- Rest (but not too much!)
  - Loss of conditioning → more fatigue

Mechanical

Improve stability:

- Braces as needed
- **Tone, NOT strength!**
  - Resting state of muscle contraction
  - Low (or no) resistance
  - Gradually ↑ reps
  - Core & extremity
  - Work within body limits
  - SLOW process (months – years)
  - Insurance problems (“tone” doesn’t exist)

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Mental (Psychiatric)

Pain is a subjective experience, modified by:

- Emotional state
- Thoughts & beliefs
- Fears & expectations
- Memories of past injuries
- Emotional state of close others
- And more

Kozlowska et al (2008) Harv Rev Psychiatry 16:136

Mental (Psychiatric)

Psychological distress exacerbates pain

Common in EDS:

- Anxiety & Depression
- Low self-confidence & self-efficacy
- Negative thinking
- Hopeless/helpless; desperation

Baeza-Velasco et al (2011) Rheumatol Int. 31:1131; Branson et al (2011) Harv Rev Psychiatry 19:259; Castori et al(2010) Am J Med Genet A. 152A:556; Hagberg et al (2004) Orthod Craniofac Res. 7:178; Rombaut et al (2011) Arthritis Rheum. 63:1979

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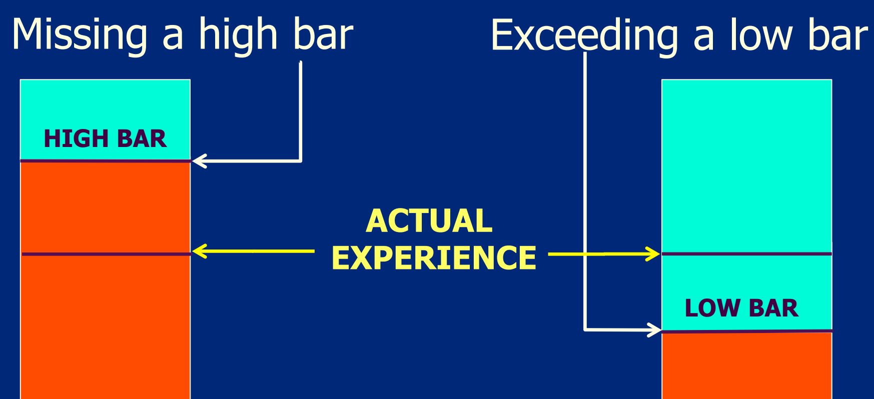
Mental (Psychiatric)

- Avoid psychologic pain escalation
- Learn psychologic pain control
  - Less pain
  - Less medication
  - Fewer side effects

Expectation Management



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Expectation Management

High Bar

- No pain
- No dislocations or subluxations
- "Normal" activity tolerance

Low Bar

- Less pain
- Fewer dislocation or subluxations
- Improved activity tolerance

Effect on mood? On pain experience?

Mental Approaches

- Validation that symptoms are real
- Trust & rapport between patient and medical team
- Reasonable expectations (exceed a low bar)
- Distraction
- Hypnosis, Visualization, Mind/Body
- Meditation
- Counseling (formal and/or informal)

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Counseling

- For depression, anxiety, PTSD…
- For accepting, coping & living with pain, dysfunction & disability
- Cognitive Behavioral Therapy
  - Recognize & emphasize positive thoughts & behaviors
  - Recognize & avoid negative thoughts & behaviors
- Requires acceptance, willingness & active participation

Resistance to Psychological Therapy

- Prior misdiagnoses & accusations
  - Malingering (faking)
  - Depression/anxiety as sole cause
- "It's not in my head—it's real"
- Stigma, perceived weakness, "crazy"
- Belief that help not needed or emotional distress will improve after pain improves

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Resistance to Psychological Therapy

2 Questions & 1 Thought:

- What do you have to lose?
  (other than some of your pain & fatigue?)
- Do you control your mind?
  (or does it control you?)
- “90% of the game is half mental”
  - Yogi Berra

Other Medical Conditions contribute to pain & fatigue

- Most not specifically related to EDS
- Are treated the same, regardless of EDS
- Incremental benefits

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Other Medical Conditions

- Vitamin D deficiency
  - Very common (inadequate sun & diet)
  - Ideal 25-hydroxy D level probably >40
  - Simple oral supplement
- B12 deficiency
  - Dietary, auto-immune
  - Levels between 200-400 borderline—check homocysteine & methylmalonic acid
  - Often requires injection therapy

Other Medical Conditions

- Iron deficiency
  - ↓ transferrin saturation AND ↑ TIBC
  - ↓ saturation alone often misdiagnosed
  - Unnecessary iron → unnecessary constipation
- Hormone deficiencies
  - Thyroid, Cortisol, Testosterone, others
  - Dangerous to supplement if not low
  - May be caused/exacerbated by opioids

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Other Medical Conditions

- Celiac disease
  - Abnormal small bowel biopsy
  - Anti-endoymysial and/or tissue transglutaminase antibody
  - Avoid all gluten
- Gluten sensitivity
  - Poorly understood
  - True sensitivity, or just feel better with less carbohydrate and processed food?
  - If it works for you, avoid gluten!

Other Medical Conditions

- Autonomic dysfunction
  - Fluids (not just water) & salt
  - [almost] no such thing as too much
  - Compression garments
  - Medications (esp beta blocker)
- Insomnia—multiple possible causes
  - Pain
  - Medication side effects
  - Distress
  - Other medical conditions

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Miracle Chocolate Pill

- Brings you back from almost dead
- Take only as needed
- Works fast
- No side effects

Miracle Chocolate Pill

"I don't think they really exist"
("Get used to disappointment")

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