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
4 Domains

Medications

Mechanical

Mental

Medical (other)

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?
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
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
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)
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
Mechanical

Assumptions:
- Instability $\rightarrow$ spasm
- Instability $\rightarrow$ arthritis
- Spasm & arthritis $\rightarrow$ pain
- Pain & spasm $\rightarrow$ fatigue

If true, then goals are:
- Reduce spasm
- Reduce instability (increase stability)

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
Mechnical

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

Mechnical

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)
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


Mental (Psychiatric)

Psychological distress exacerbates pain
Common in EDS:
• Anxiety & Depression
• Low self-confidence & self-efficacy
• Negative thinking
• Hopeless/helpless; desperation

Mental (Psychiatric)

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

Expectation Management

- Missing a high bar
- Exceeding a low bar

ACTUAL EXPERIENCE
## Expectation Management

<table>
<thead>
<tr>
<th>High Bar</th>
<th>Low Bar</th>
</tr>
</thead>
<tbody>
<tr>
<td>• No pain</td>
<td>• Less pain</td>
</tr>
<tr>
<td>• No dislocations or subluxations</td>
<td>• Fewer dislocation or subluxations</td>
</tr>
<tr>
<td>• “Normal” activity tolerance</td>
<td>• Improved activity tolerance</td>
</tr>
</tbody>
</table>

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)
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
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
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
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
Miracle Chocolate Pill

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

“I don’t think they really exist”
(“Get used to disappointment”)