

What we (currently) know about pain...

- Complex and multidimensional
- Not necessarily related to amount of tissue damage
 - Injury without pain
 - Pain without injury
- Pain occurs when your brain perceives a threat
 - Pain = alert that tells you to take action
 - Pain can be protective
 - Your alarm system can become more/less sensitive



The Cup Analogy

Movement habits

Muscle tension

Joint changes

Environment

Posture



Previous experiences

Fear

Fatigue

Beliefs

Interactions with others

(Greg Lehman)

Biomechanics and Pain

- “Structure is not Destiny...but it still might be important” (Lehman, 2017)
- Physical factors (strength/weakness, flexibility, posture):
 - might contribute to pain
 - are not the whole story

The Good News

- Hurt does not necessarily equal harm
- Pain can improve without changes to your body structure
- You don't have to change everything to change your pain

A row of white wooden figures, some standing and some falling, with a single blue figure standing upright in the center. The figures are on a grey surface against a grey background.

Management of Pain

- Pain is individualized. Treatment should be too.
- Set goals that are important to you
- Start small and build slowly
- Be consistent with the basics

Management

- What is in your cup?



Greg Lehman

What's in your cup?

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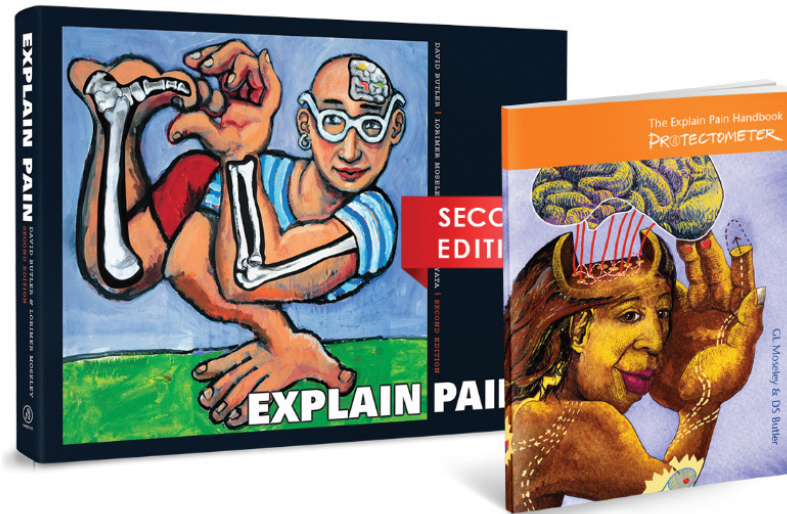
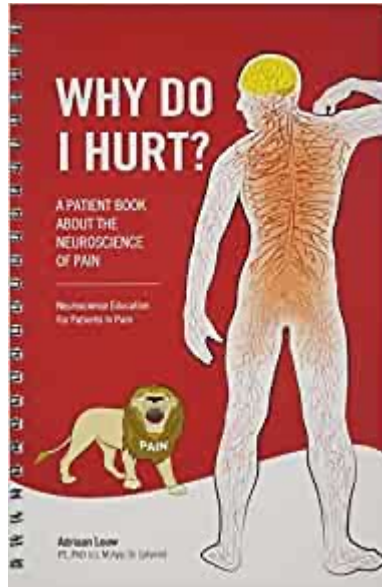
Interactions with others

Management

- What is in your cup?
- What can you do to address the contributors?
- How can you build a bigger cup?



Management: Education



RECOVERYstrategies

- your pain guidebook -

Management: Environment

- Change your physical space
 - Place frequently used items in easy to reach areas
 - Set-up workspace to reduce painful movements
 - Address environmental barriers
- Make your environment more comfortable
 - Music/sound
 - Lighting
 - Temperature

Management: Assistive Devices

- Braces and supports
 - Abdominal binder/ back support
 - Shoulder braces/supports
 - AFOs
- Walking aids
 - Canes, trekking poles, walkers
- Scooters and wheelchairs

Management: Manual Therapy & Modalities

- Hands-on therapy techniques
 - Soft-tissue mobilization
 - Joint mobilization
 - Massage
- Novel inputs to the nervous system (modalities)
 - Foam rolling, yoga balls, self-massage
 - TENS
 - Acupuncture, dry needling
 - Heat, ice

Management: Movement

- Imagined movements
- Targeted exercise
- Structured activities (yoga, Pilates, dance, water aerobics)
- Aerobic exercise (walking, cycling, swimming, dancing)
- Everyday activities (cleaning, cooking, gardening)

Working with a Physical Therapist

- Think of your therapist as a coach
- Look for someone willing to learn about you and FSHD
- Virtual and in-home visits might be options

- Communication is key
- Might take some trial and error to find what works best for you
- Fluctuations in pain might occur

References and Resources

- “Physical Therapy for Facioscapulohumeral Muscular Dystrophy” by Shree Pandya, PT, DPT, MS, and Kate Eichinger, PhD, PT, DPT, NCS,
- www.fshdsociety.org/exercise-and-fitness/
- “Recovery Strategies – Your Pain Guidebook” by Greg Lehman
- “Why Do I Hurt?” by Adriaan Louw
- “Explain Pain” by David Butler & Lorimer Moseley