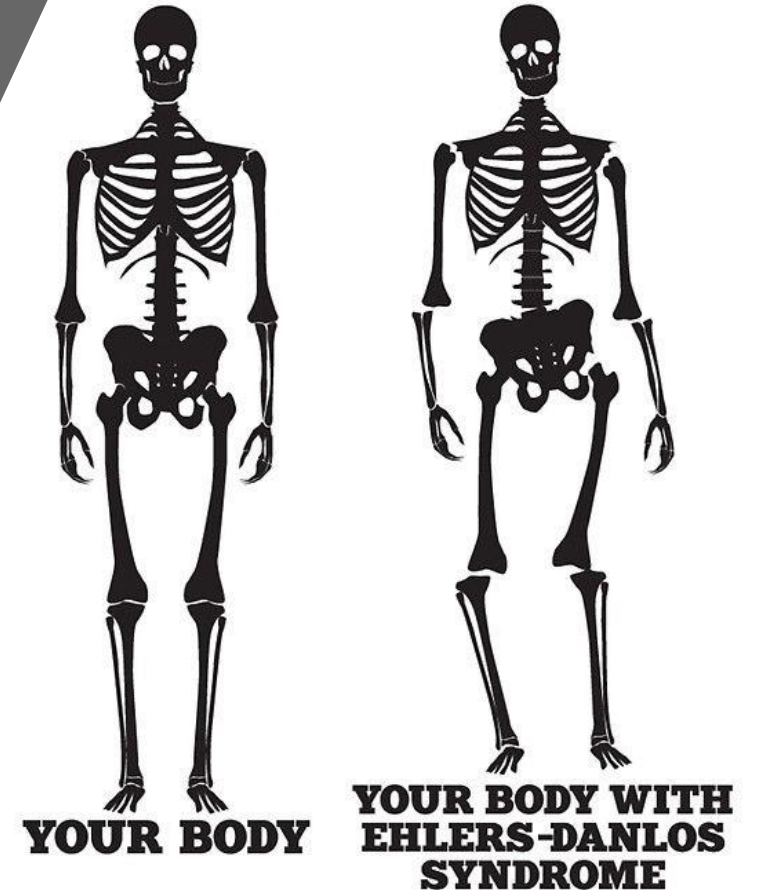


Hypermobility 103: Pain Management for Hypermobile Ehlers-Danlos Syndrome

Leslie N Russek, PT, DPT, PhD, OCS

Clarkson University, Canton-Potsdam Hospital, Potsdam, NY

Slide handouts and recordings are available at:
<https://webspace.clarkson.edu/~lrussek/hsd.html>



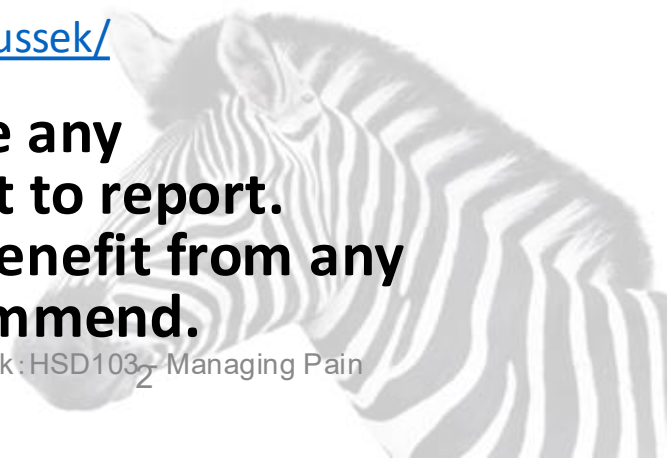
ehlersdanlos



Who Am I?

- Professor Emeritus, Physical Therapy Department, Clarkson University
- Staff PT, St. Lawrence Health System, Potsdam NY
 - Clinical specialties: hypermobility, fibromyalgia, headaches, temporomandibular disorders
- Frequent presenter to professional and patient groups at national conferences
- Author of multiple review and research articles on hypermobility
- Author of "Chronic Pain" chapter in *Physical Rehabilitation* textbook for PT students, and
- "Pain Mechanisms in Hypermobility." In: Di Bon, J. *The Integral Movement Method – An Approach to Hypermobility Management*
- Lrussek@Clarkson.edu
- <https://webpace.clarkson.edu/~lrussek/>

**I do not have any
conflicts of interest to report.
I receive no financial benefit from any
products I recommend.**



Hypermobility Lecture Series Schedule

- HSD 101: Basics of HSD/hEDS and self-care
- HSD 102: POTS and POTS self-care, basics of MCAS
- HSD 103: Pain management in HSD/hEDS
- HSD 104: Safe exercise selection and progression with HSD/hEDS and POTS
- HSD 104 part 2: How to Modify Exercises for HSD & POTS – nuts and bolts.
- HSD 105: Body mechanics, posture and joint protection
- HSD 106: Gut issues in HSD/hEDS, POTS, MCAS
- HSD 107: Fatigue in HSD/hEDS and POTS
- HSD 108: Headaches, migraines, & TMJ pain in HSD, POTS and MCAS
- HSD 109: Breathing dysfunctions in HSD
- HSD 110: Lumbar instability
- HSD 111: Cervical instability
- HSD 112: The vagus nerve
- HSD 113: The importance of fascia
- HSD 114: Hospitalization and surgery with the Trifecta
- HSD 115: Functional Neurological Disorder and EDS



I will refer to these other lectures if you want more info



Relevant Handouts Available

- <https://webpace.clarkson.edu/~lrussek/research.html>

• Self-Care Strategies

- [Self-Care Toolbox](#). A checklist to help you optimize your self-care toolbox.
- [Breathing](#). Breathing incorrectly can increase pain sensitivity, headaches, jaw pain, and more.
- [Posture](#). Good posture decreases strain on muscles and joints, and can prevent many problems.
- [Sleep Hygiene and Positioning](#). Sleep posture and sleep hygiene strategies.
- [Sleep Checklist](#). Sleep is critical to good health. This checklist of sleep promoting strategies
- [Headache Trigger Points](#). Trigger points commonly causing headaches.

• Pain Management

- [Pain self-care plan](#). Create a flare management plan so you can identify what helps you manage pain.
- [Pain flare management plan](#). Create a flare management plan so you know what works when you have a flare. PDF & Doc versions.
- [Topicals for pain management](#).
- [Heart-rate variability biofeedback](#). Biofeedback to increase activation of your parasympathetic nervous system can help quiet sensitive nerves and decrease pain.
- [Free chronic pain management apps for teens](#)
- [Negative \('Unhelpful'\) thinking can amplify pain](#). This worksheet helps you identify 'Unhelpful Thinking' and replace with Positive Thinking.

Scan to access
website



Leslie's Website

Objectives

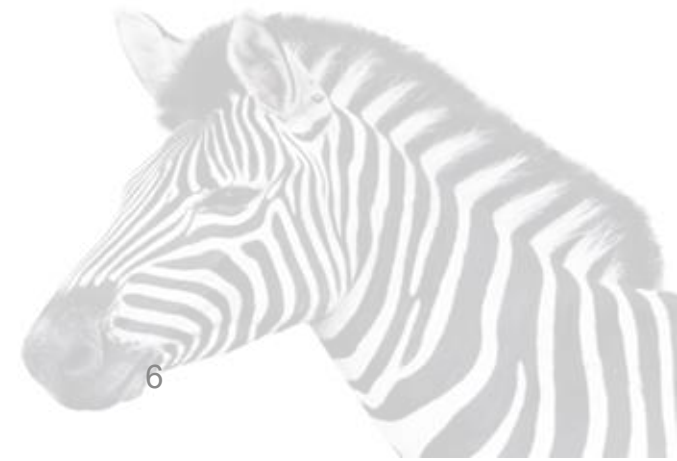
By the end of this session, participants will be able to:

1. Describe the 3 mechanisms of pain: nociceptive, neuropathic, nociplastic (aka sensitization)
2. Identify strategies for managing “issues with your tissues
3. Identify strategies for managing nociplastic/sensitization pain
4. At the end are several optional pain management practices

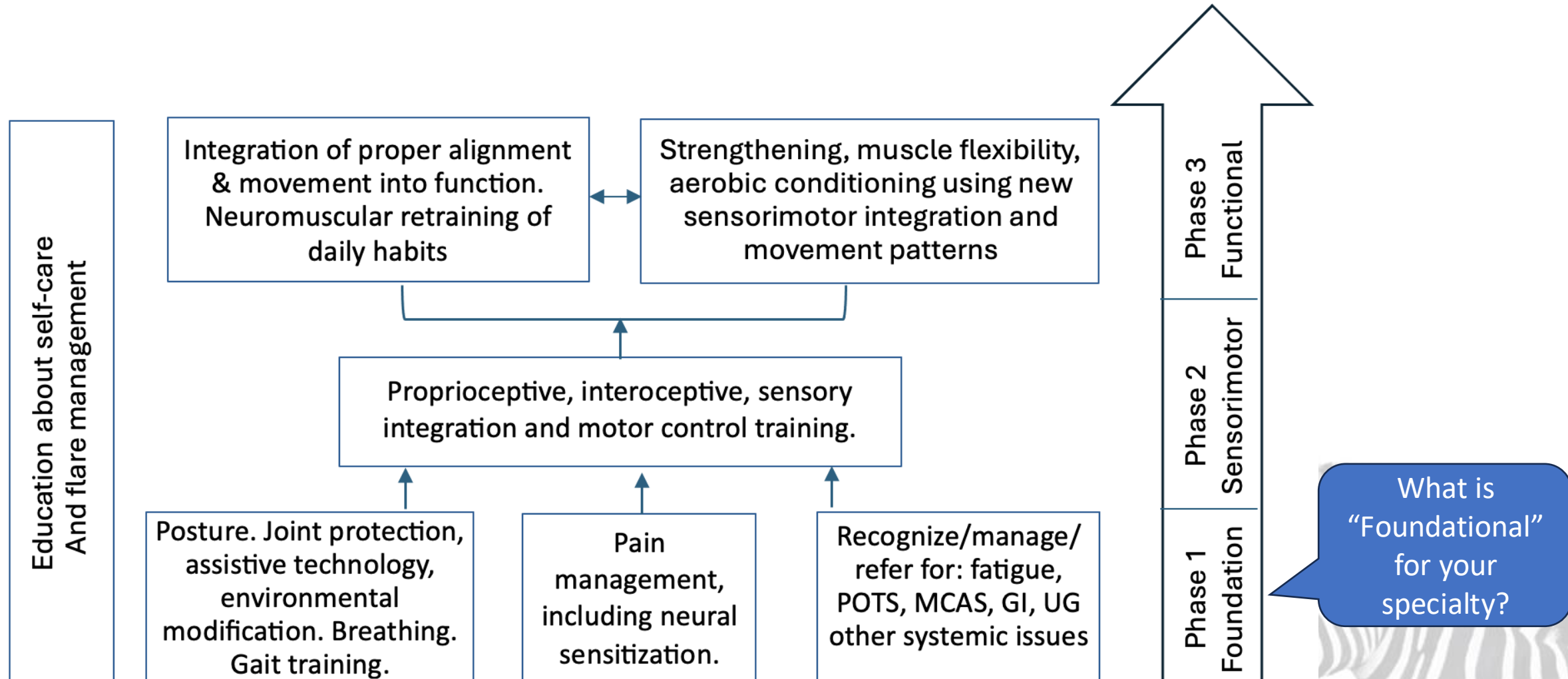


DISCLAIMER

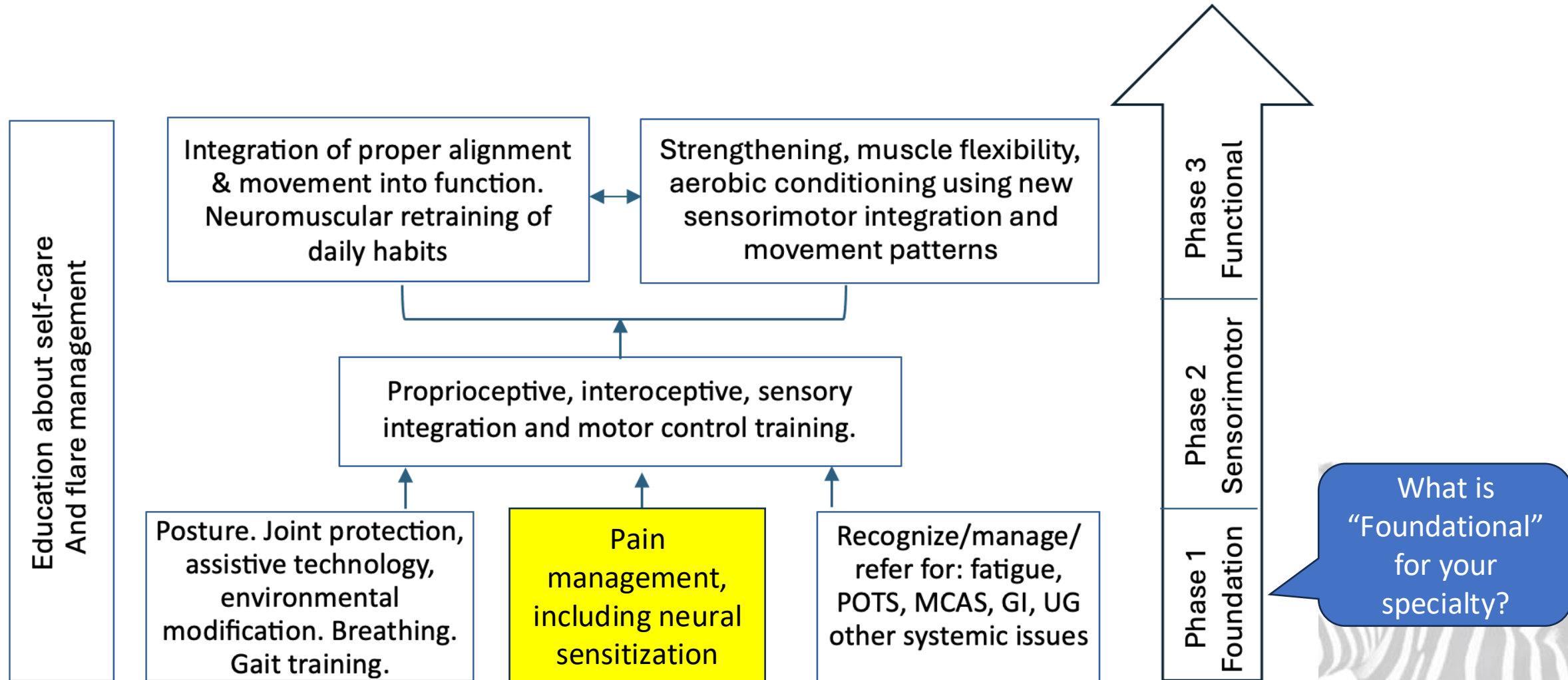
- I cannot diagnose or provide individual medical advice in this presentation.
- The information provided here is generally applicable to HSD/hEDS, but your personal situation may be different.
- You should discuss options with your healthcare provider before starting a new management approach.

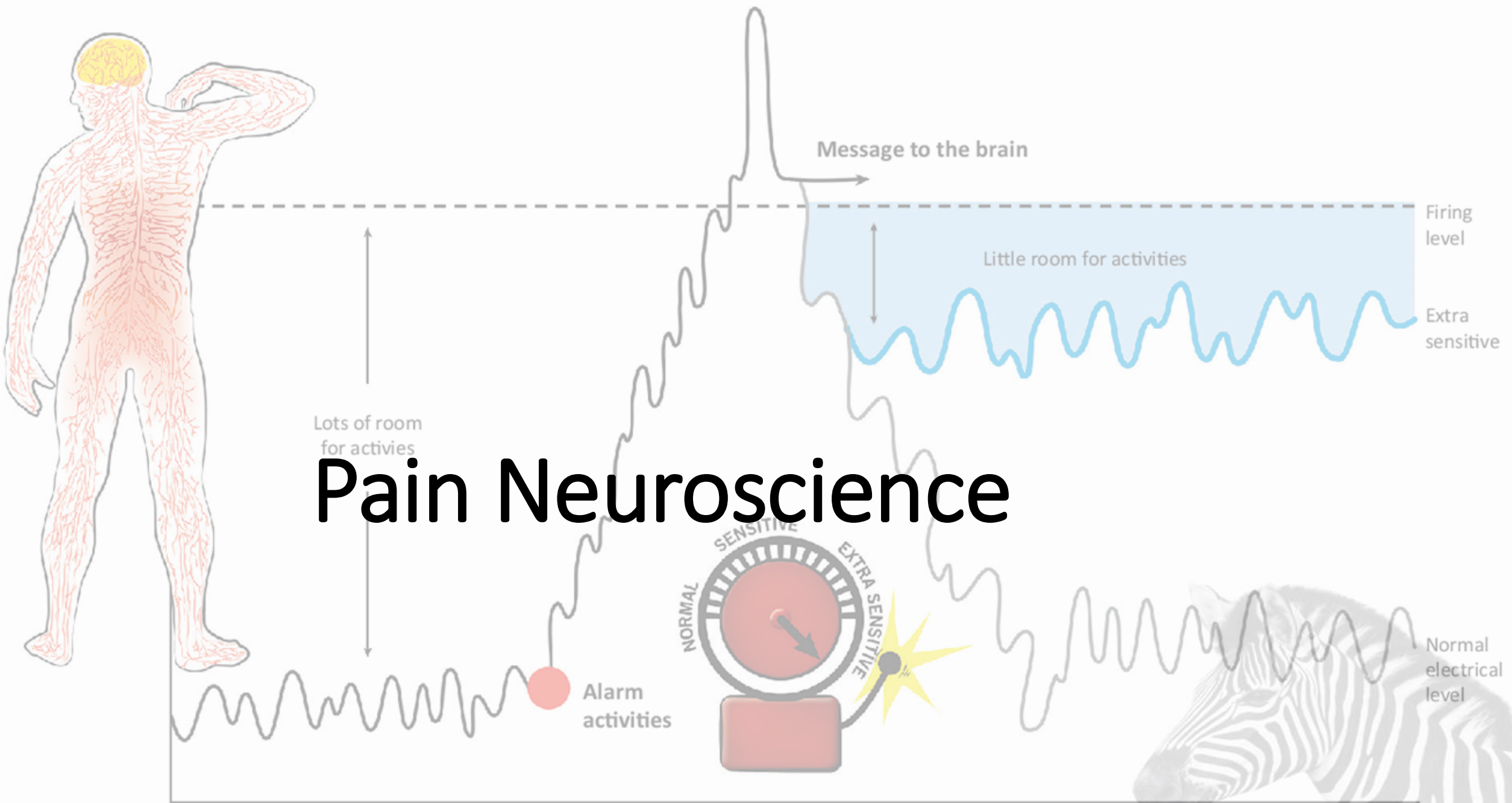


PT Approach to Managing HSD



PT Approach to Managing HSD

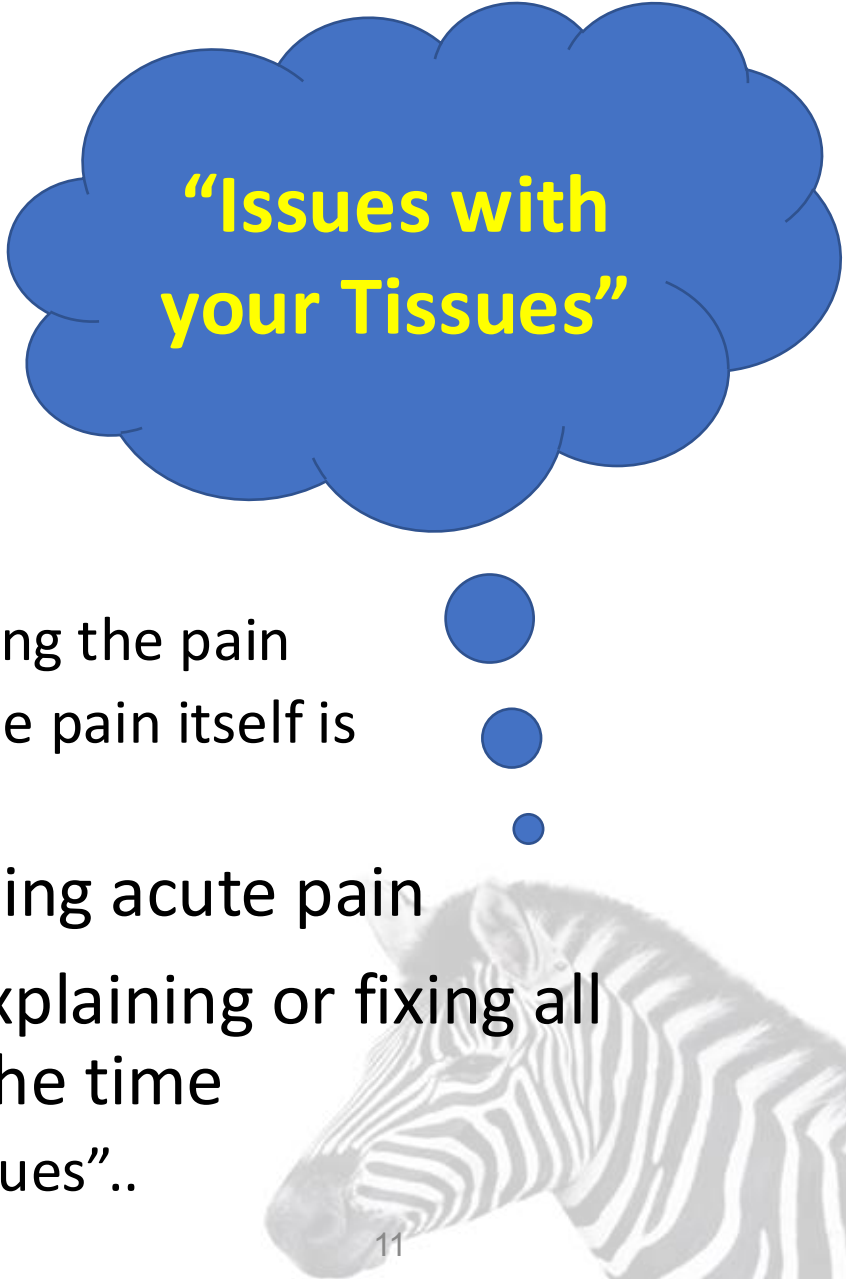




Pain Neuroscience

Biomedical Model of Pain

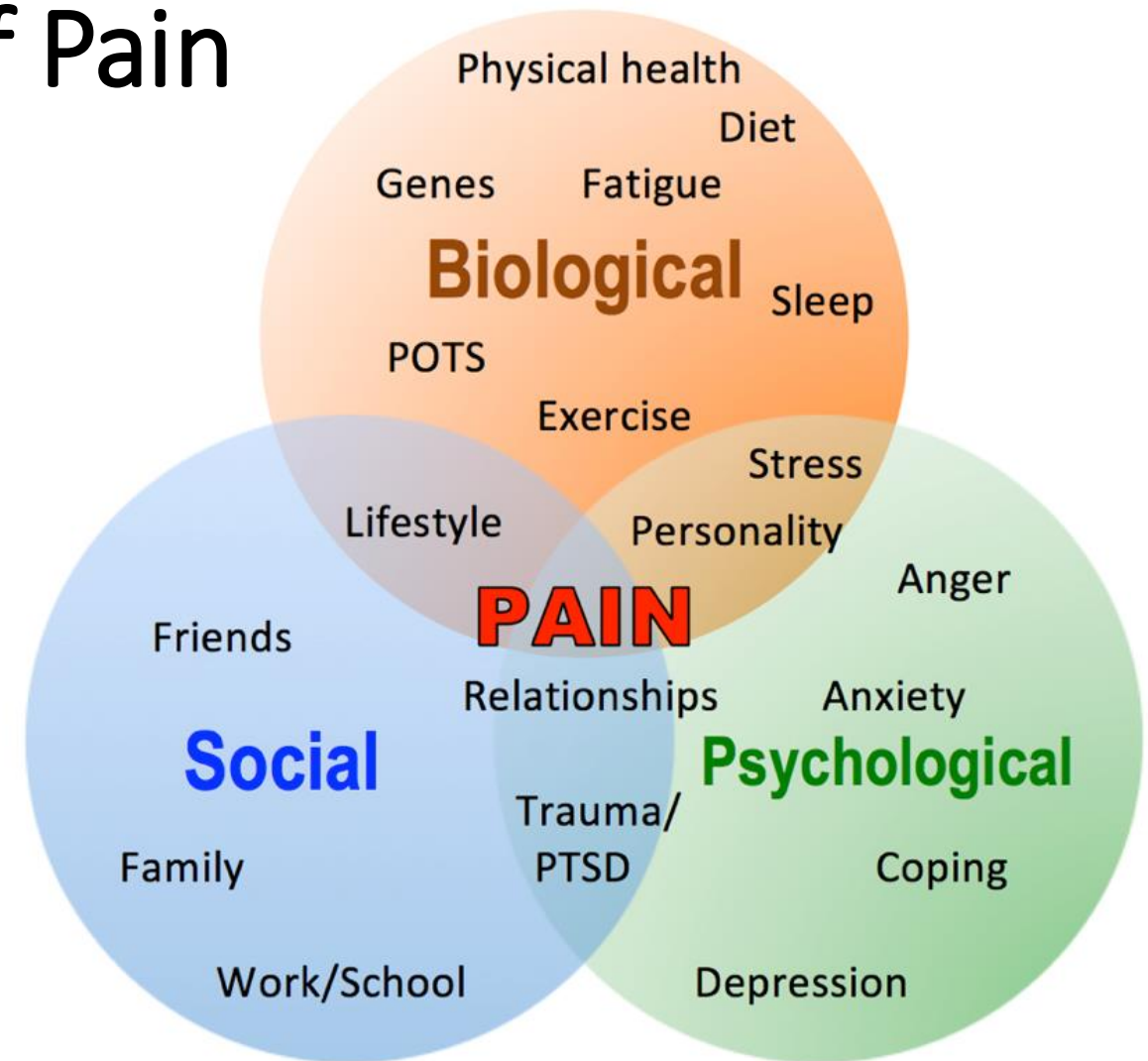
- The belief that:
 - Pain is purely physical
 - Pain reflects tissue damage
 - There is something physical that can be fixed
 - Enough tests will figure out what structure is causing the pain
 - Depression or anxiety may result from pain, but the pain itself is biological/physical
- The biomedical model is fairly good for managing acute pain
- The biomedical model, alone, is not good at explaining or fixing all people with chronic pain, or some people all the time
 - People with HSD often have “Issues with their Tissues”..



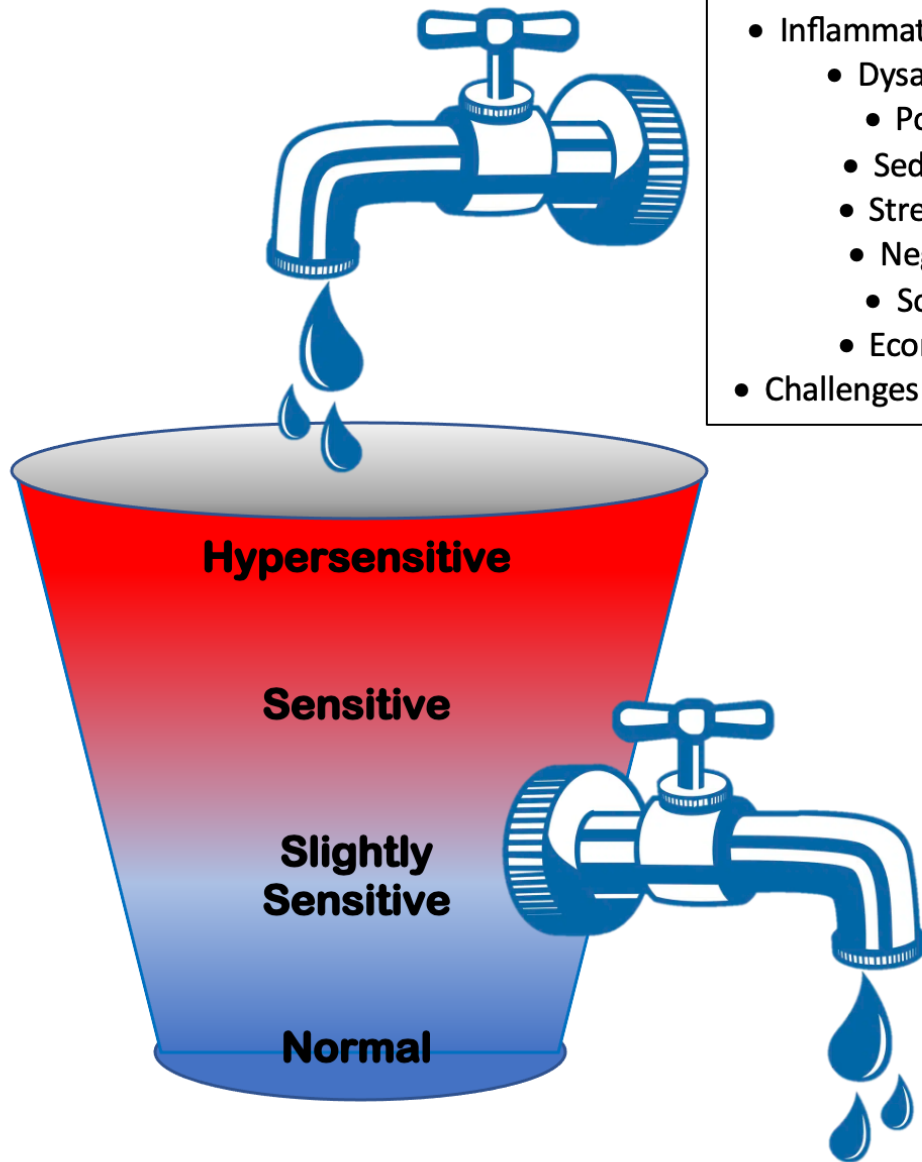
“Issues with
your Tissues”

Biopsychosocial Model of Pain

- The belief that pain is influenced by:
 - Physiologic response to actual or *potential* tissue damage
 - Previous pain experience
 - Beliefs/attitudes about pain
 - Coping style
 - Emotions
 - Family, social, and cultural background
 - Spiritual beliefs
- Pain is an interaction between sensory input and brain processing
- Even if you have “Issues with your Tissues,” psychosocial factors may amplify or perpetuate the pain..



Wallden, 2021; Russek, 2022



Things Filling the Pain Sensitivity Bucket

- Tissue stress/injury
- Inflammation (including MCAD)
 - Dysautonomia/POTS
 - Poor sleep/diet
 - Sedentary lifestyle
 - Stress/anxiety/fear
 - Negative thinking
 - Social stressors
 - Economic stressors
- Challenges of health care system

Things Draining the Pain Sensitivity Bucket

- Good sleep/diet
- Positive coping skills
- Therapeutic alliance
- Relaxation/stress management
- Self-care strategies
- Appropriate exercise
- Social support

The Pain Sensitivity “Bucket”

Pain sensitivity results from the gap between inputs and outputs for the “pain sensitivity bucket”



Pain Mechanisms

Pain Sensitization

- **Nociceptive**: Pain due to damage to non-neural tissue (e.g., musculoskeletal or visceral tissue). Mechanical, inflammatory, hot/cold.
- **Neuropathic**: Pain caused by lesion or disease of the (peripheral or central) somatosensory nervous system.
- **Nociplastic**: Pain that arises from altered nociception despite no clear evidence of actual or threatened tissue damage causing the activation of peripheral nociceptors or evidence for disease or lesion of the somatosensory system causing the pain. Driven by sensitization & neuroplasticity.
 - *Or in the absence of enough tissue damage to explain the experienced pain severity, disability and other symptoms.*
- **Mixed pain**: Any combination of the above.

Malfait, 2021; Nijs, 2021; Russek, 2022; Daylor, 2023

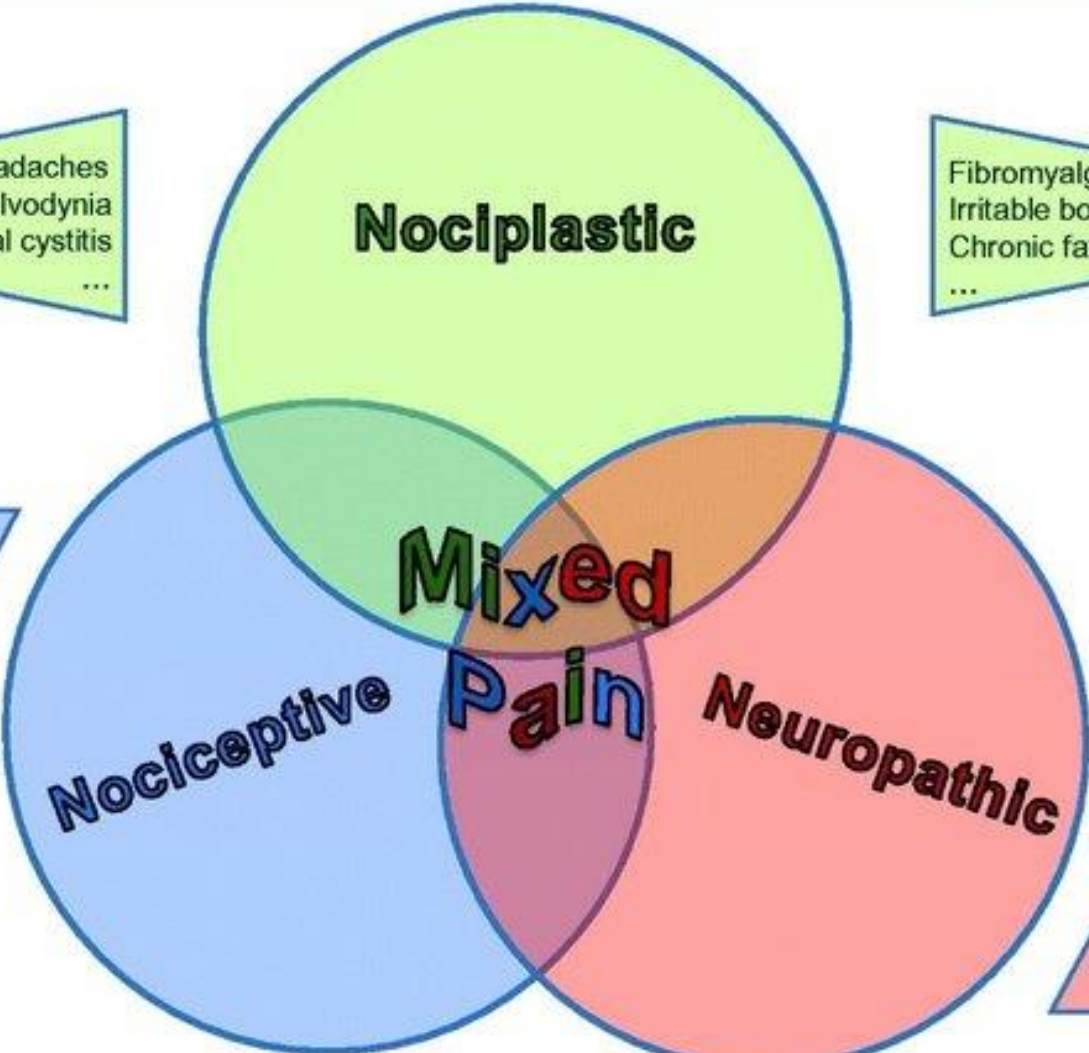


Potential mixed pain states
 Sciatica, Low back pain, Neck pain, Cancer pain, Osteoarthritis pain, Chronic postsurgical pain, Musculoskeletal disorders, Chronic Temporomandibular disorders, Lumbar spinal stenosis, Pain in Fabry Disease, Chronic joint pain, Painful ankylosing spondylitis, Leprosy, Burning mouth syndrome, ...

Nociplastic Pain

Headaches
 Vulvodynia
 Interstitial cystitis
 ...

Fibromyalgia
 Irritable bowel
 Chronic fatigue
 ...



Ankylosing spondylitis
 Unspecific back pain
 Rheumatoid arthritis
 Sickle-cell disease
 Myofascial pain
 Osteoarthritis
 Visceral pain
 Tendonitis
 Bursitis
 Gout
 ...

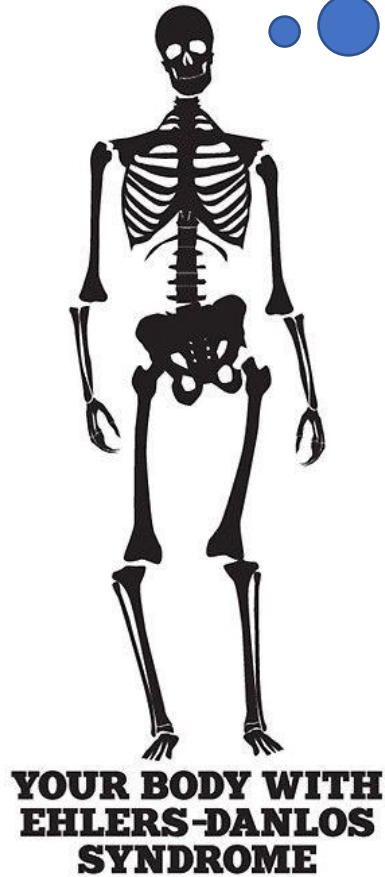
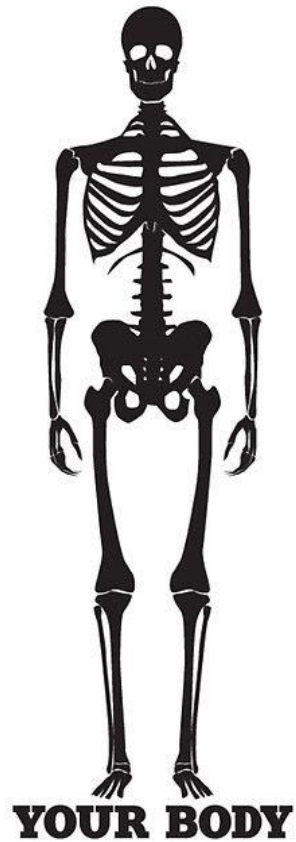
...
 Sciatica
 Post-stroke
 Spinal cord injury
 Multiple sclerosis
 Trigeminal neuralgia
 Postherpetic neuralgia
 Small-fiber neuropathies
 Painful polyneuropathies

Why Care About Pain Mechanism?

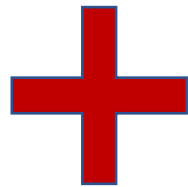
- Fixing a flat tire is okay, but if you are out of gas, you need to address that, too!



Managing Pain



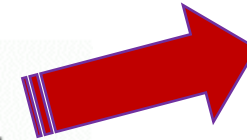
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**“Issues
with my
Tissues”**



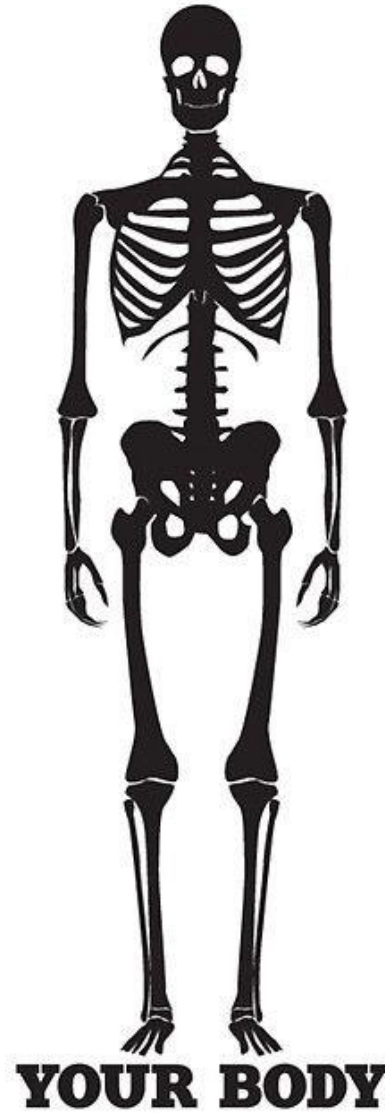
**I THINK
IT'S
STRESS!!**



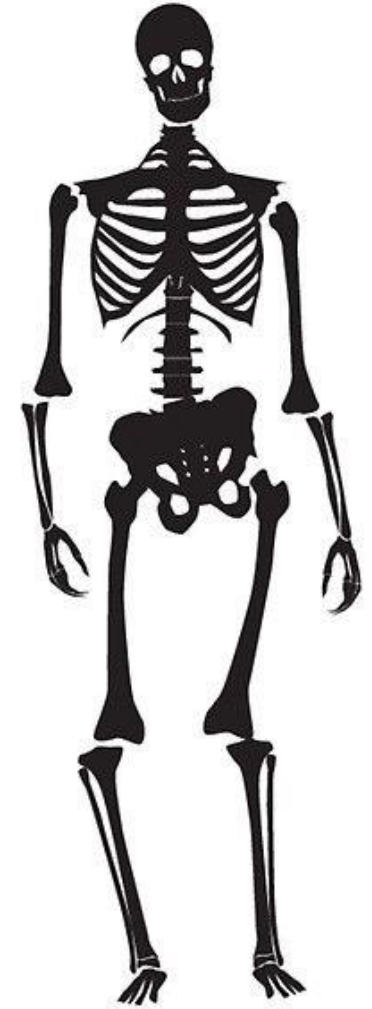
Sensitization



Issues With The Tissues



YOUR BODY



**YOUR BODY WITH
EHLERS-DANLOS
SYNDROME**

Musculoskeletal Problems in EDS

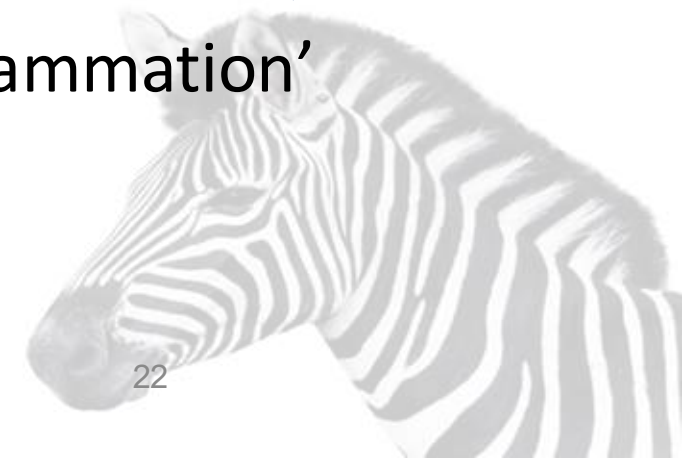
- Being hypermobile, alone, does not necessarily cause pain
 - There are many people who are hypermobile and pain free
 - **Hypermobility is NOT the same as Instability!**
- HOWEVER... being hypermobile makes you more vulnerable to musculoskeletal imbalances and g (visceral) problems that cause pain & instability
- Better understanding can help you become less vulnerable, and have less pain and instability..



“Issues with your Tissues”

- Joint, muscle, and fascia pain from:
 - Joint instability, causing stress to the joint or joint capsule
 - Muscles overworked trying to stabilize joints
 - Causes muscle trigger points and tendon problems
 - Poor body awareness allowing inappropriate/damaging movement
 - Tight muscles, gravity, or poor body mechanics stressing joints
- Nerve pain from compression or stretch
- Systemic inflammation from MCAS or ‘neurogenic inflammation’
- Visceral problems, often gut, urogenital..

HSD 101: Intro
to HSD



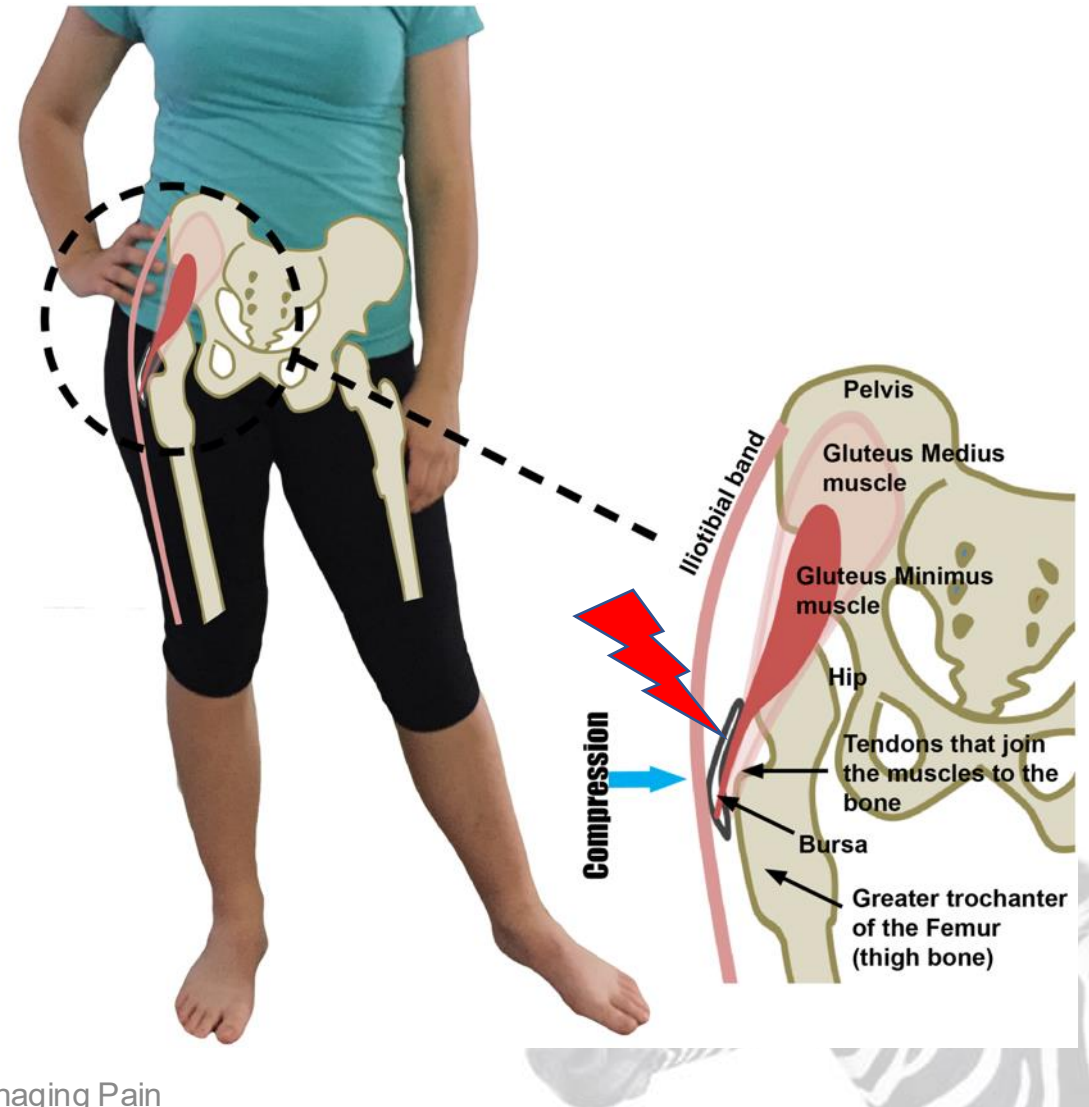
So, What Tissues Cause Issues?

- Figuring this out is the challenge!
 - Many examples are discussed in “Hypermobility 101”
 - You may need a health care provider to help you figure it out
- Some examples...
 1. Localized pain from overuse/misuse
 2. Localized pain from trauma/injury
 3. Referred pain from musculoskeletal tissues, such as trigger points
 4. Referred pain from nerve irritation/injury
 5. Referred pain from visceral problems.



Overuse: e.g. Trochanteric Pain

- Muscles/tendons are overstretched because weak hip muscles don't stabilize hip
- Dropping pelvis while standing/walking aggravates muscle & tendon
 - Due to weakness and/or poor body awareness
- Loose hips may 'slip' out of alignment
- Flat feet allow knees and hips to turn inward, pulling on hip muscles/tendons..



Traumatic: e.g. Ankle Sprain

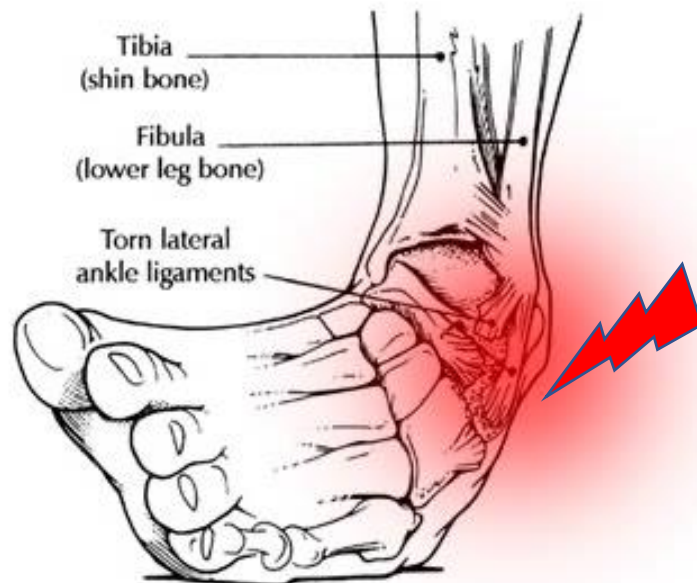
- Stretchy ligaments don't control motion
- Poor body awareness & balance allows excessive motion
- Weak muscles don't control movement well

We cannot change ligaments.
Ankle brace or taping to
control motion if/when
necessary.

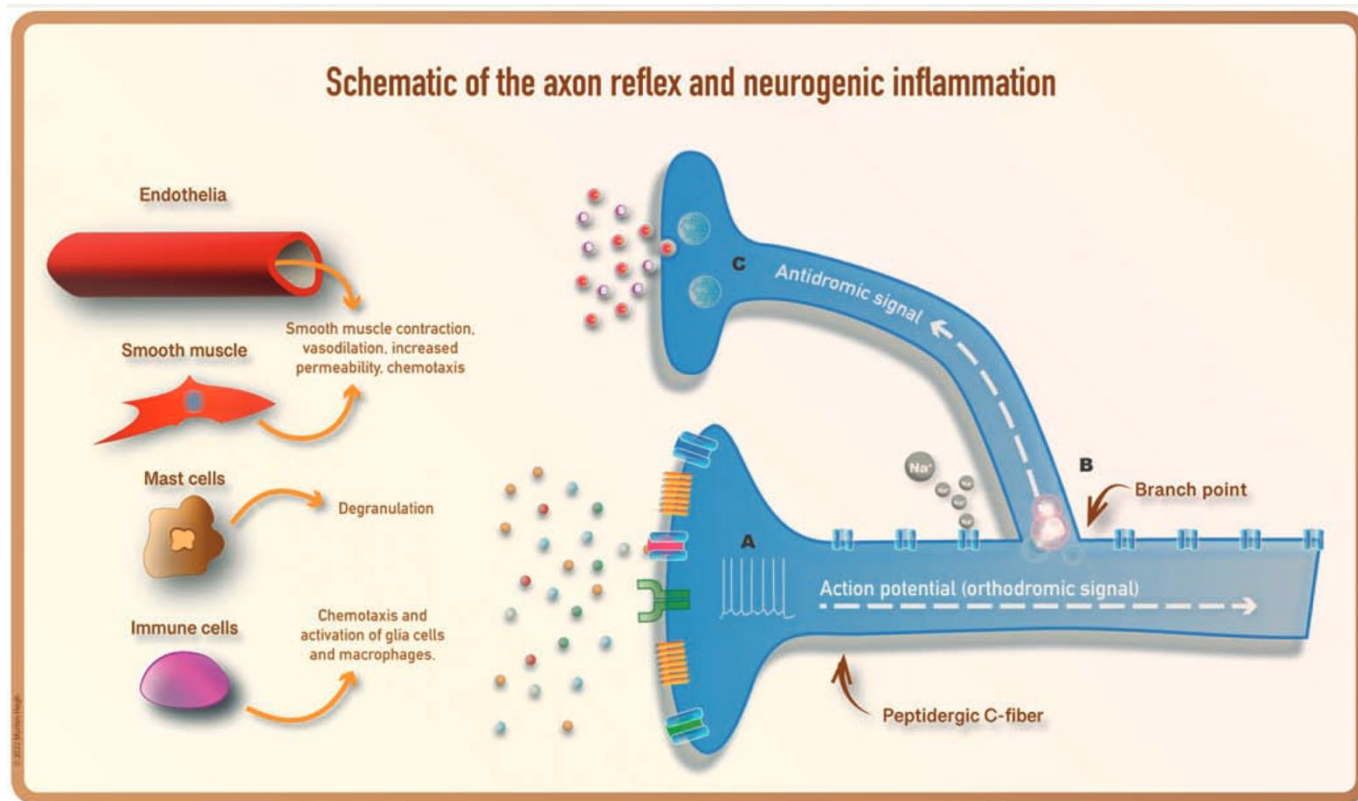
Body awareness
(proprioception);
Balance training.

Compression sleeve and taping
may improve proprioception/
body awareness.

Muscle strengthening.



Pain Due To Inflammation



- Chemicals released from damaged or irritated tissues, MCAS, or decreased vagus nerve activity

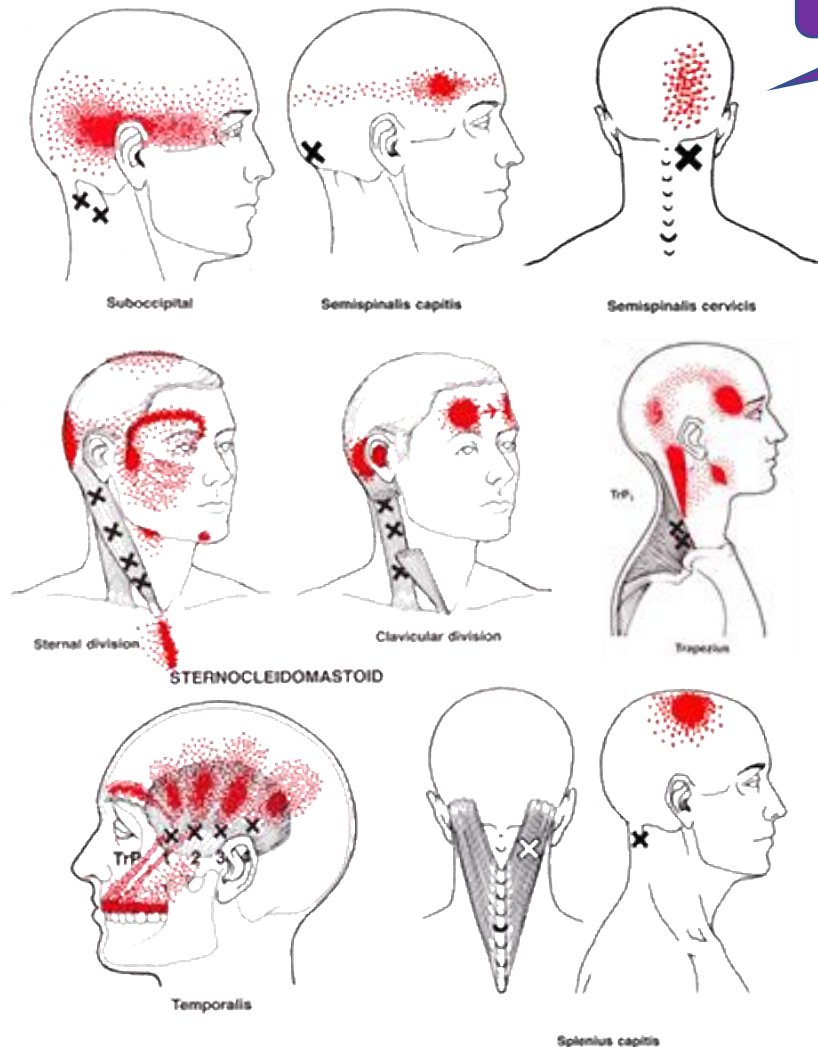
Hoegh, 2022



FIGURE 1. Axon reflex and neurogenic inflammation. Peptidergic C-fibers respond to activation (A) with an antidromic signal from the branching points to peripheral terminals of the branches (B) where it releases calcitonin gene-related peptide and Substance P (peptides) into the surrounding tissue. The peptides cause vasodilation, smooth muscle contraction, and increased capillary permeability, leading to local oedema and erythema. These peptides also facilitate an inflammatory response (and sensitization) by stimulating mast cells to degranulate (releasing, eg, histamine), activating macrophages and glia cells, and they have chemotactic abilities.³

Referred Pain: e.g. Muscle Trigger Points

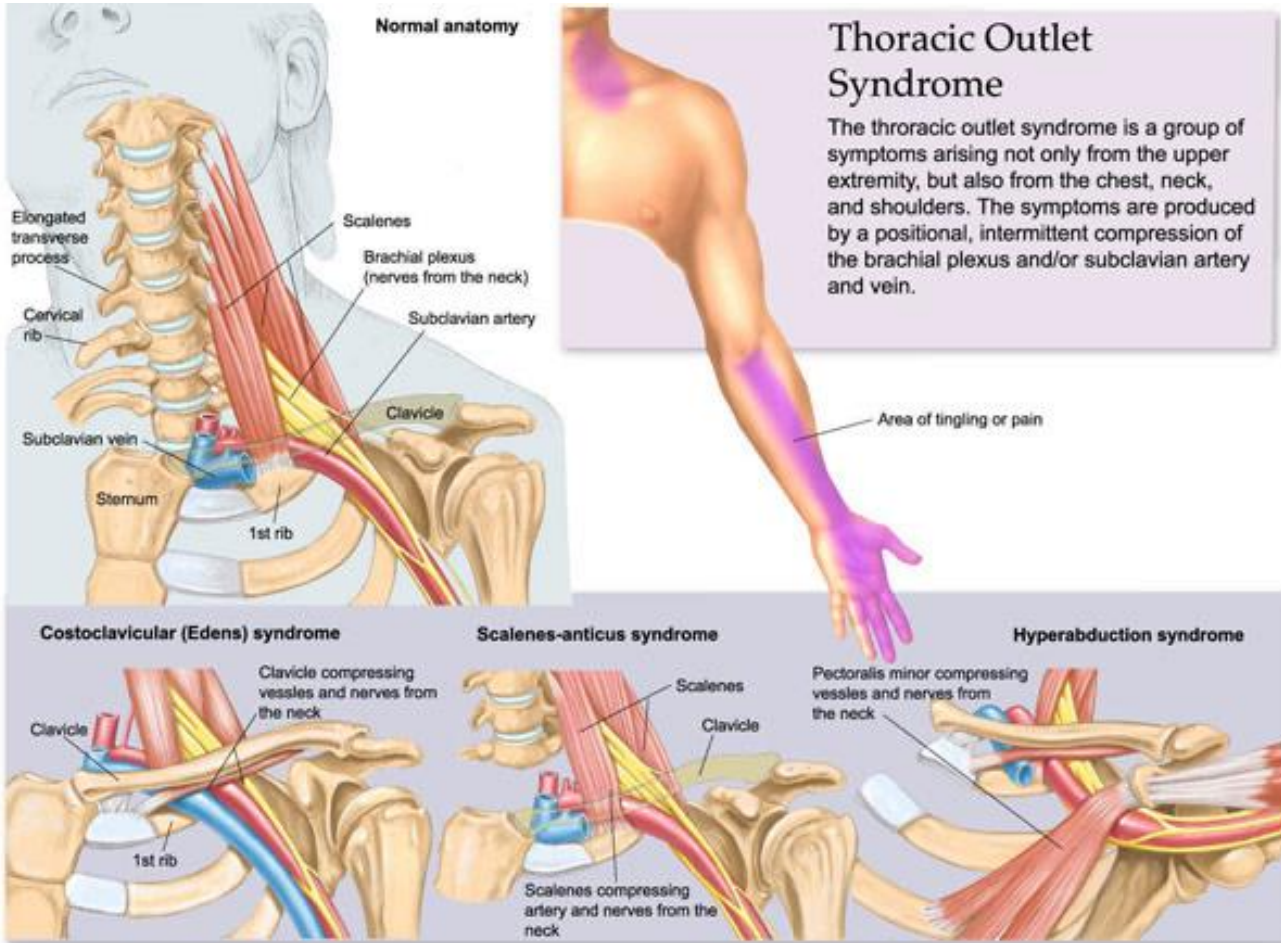
Headache Trigger Points



- Many headaches are caused by musculoskeletal problems in the neck or head
- E.g., Trigger points
- Also referred pain from:
 - Joint problems in the neck
 - Temporomandibular disorders..

• (picture from Travell & Simons)
Valerie DeLaune, Pain Relief with Trigger Point Self-Help is a book with excellent trigger point self-management guidelines

Nerve Compression: e.g., Thoracic Outlet Syndrome

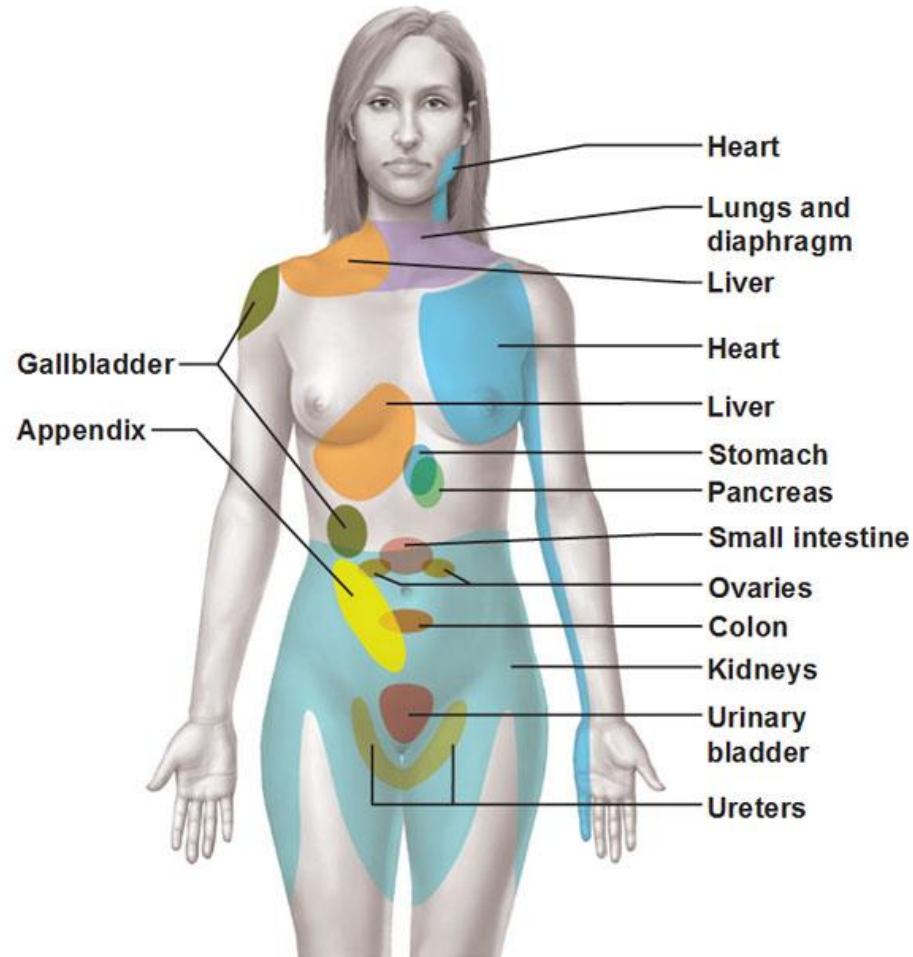


- Irritated nerves or arteries traveling from neck into the arm
- May be compressed by tight neck muscles
- May be stretched by drooping shoulders
- Causes pain, numbness, weakness or poor circulation into the arm..

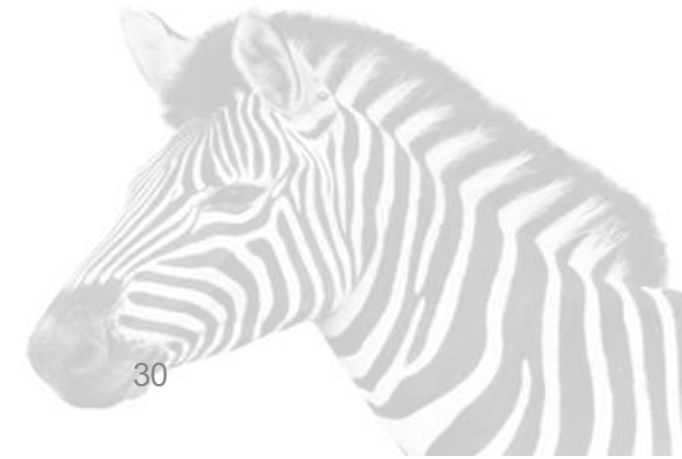


Visceral Referred Pain

A Map of Referred Pain



- Visceral tissues (internal organs) can refer pain
- Pain referral can irritate tissues at the referral site
 - Example: intestinal problems can cause trigger points in abdominal muscles, which then hurt and provoke trigger points..
 - Gebhart, 2016



Managing “Issues with the Tissues”



- **Prevent**

- Educate regarding posture, joint protection, body mechanics, etc.
- Use braces, splints, orthotics, assistive technology, environmental modification, compression garments to decrease stress on joints, muscles and nerves
- Address body imbalances & deficits (including strength, motor control, proprioceptive) to prevent injury and tissue stress
- Avoid triggers (e.g., physical, environmental, dietary, autonomic, etc.)

- **Fix**

- Specific exercise, self-care, or interventions to fix tissue damage or sources of pain (e.g., muscle spasm, nerve compression, motor control deficits, etc.)
- Medications (e.g., to address MCAS, POTS, inflammation, etc.)
- Surgery, recognizing surgery is less likely to be effective in HSD/hEDS

- **Soothe**

- Direct intervention: manual therapy, massage, dry needling, acupuncture, etc.
- Self-care with heat, ice, topicals, TENS, trigger point care, gentle exercise, etc.
- Decrease nerve sensitivity and nociplastic pain amplification
- Analgesic medications
- CBT, coping skills, Acceptance and Commitment Therapy approaches





Questions?



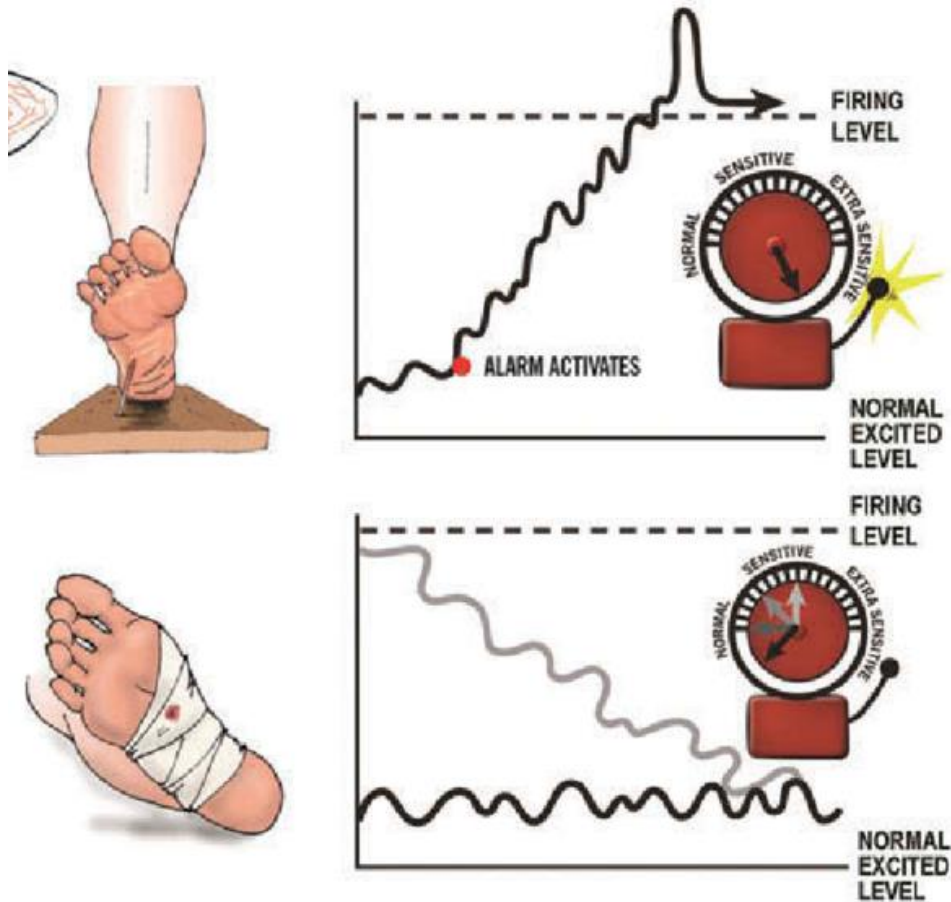
Peripheral & Central Sensitization (Nociplastic Pain)



“Messed up volume control”



Pain as an Alarm



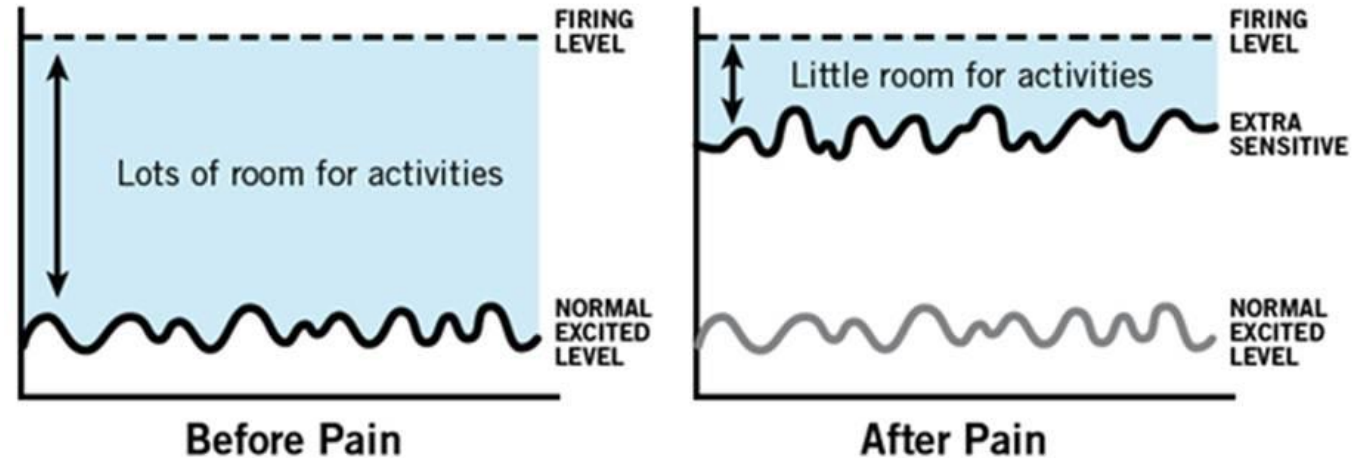
- Pain serves as an alarm, warning us of danger
- It should alert when there is danger
- Most tissue injuries heal if causes have been addressed
- The pain alarm should go quiet when things are safe again..

Pictures and metaphors from A. Louw *Why You Hurt*



Sensitization

- Nociceptive (pain) nerves become more sensitive, react more easily and more strongly
- Caused by inflammatory chemicals, tissue damage, or neuroplasticity
- Enhanced danger detection..
 - *Explain Pain Supercharged*
- Picture:
<https://www.aaronswansonpt.com/11-questions-with-adriaan-louw/>



Why Do I Hurt?; Louw 2013 OPTP



Peripheral Sensitization and Neurogenic Inflammation

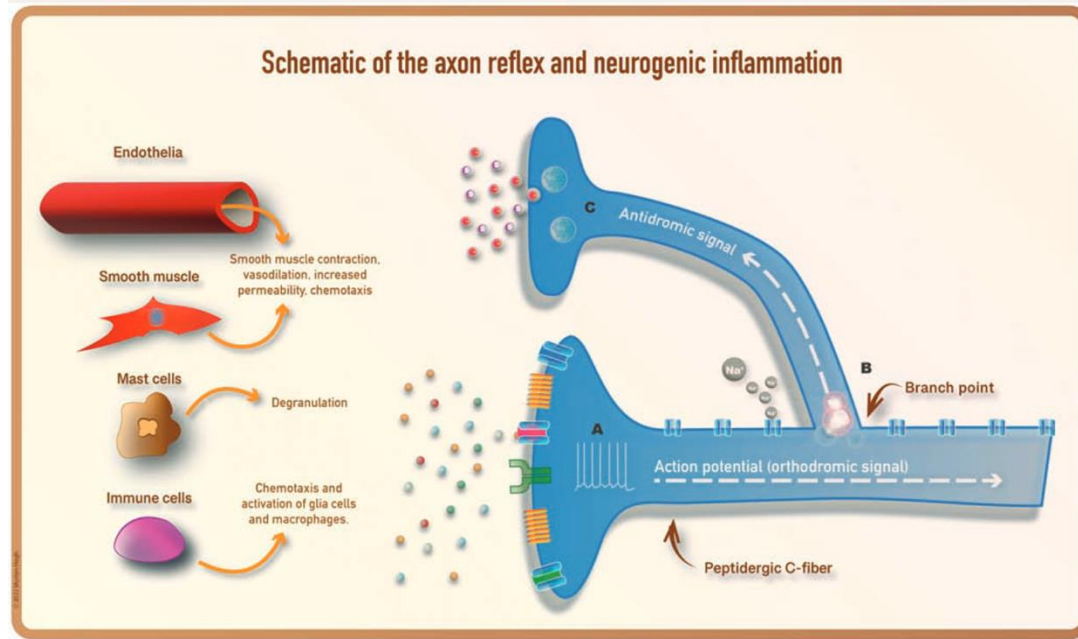


FIGURE 1. Axon reflex and neurogenic inflammation. Peptidergic C-fibers respond to activation (A) with an antidromic signal from the branching points to peripheral terminals of the branches (B) where it releases calcitonin gene-related peptide and Substance P (peptides) into the surrounding tissue. The peptides cause vasodilation, smooth muscle contraction, and increased capillary permeability, leading to local oedema and erythema. These peptides also facilitate an inflammatory response (and sensitization) by stimulating mast cells to degranulate (releasing, eg. histamine), activating macrophages and glia cells, and they have chemotactic abilities.³

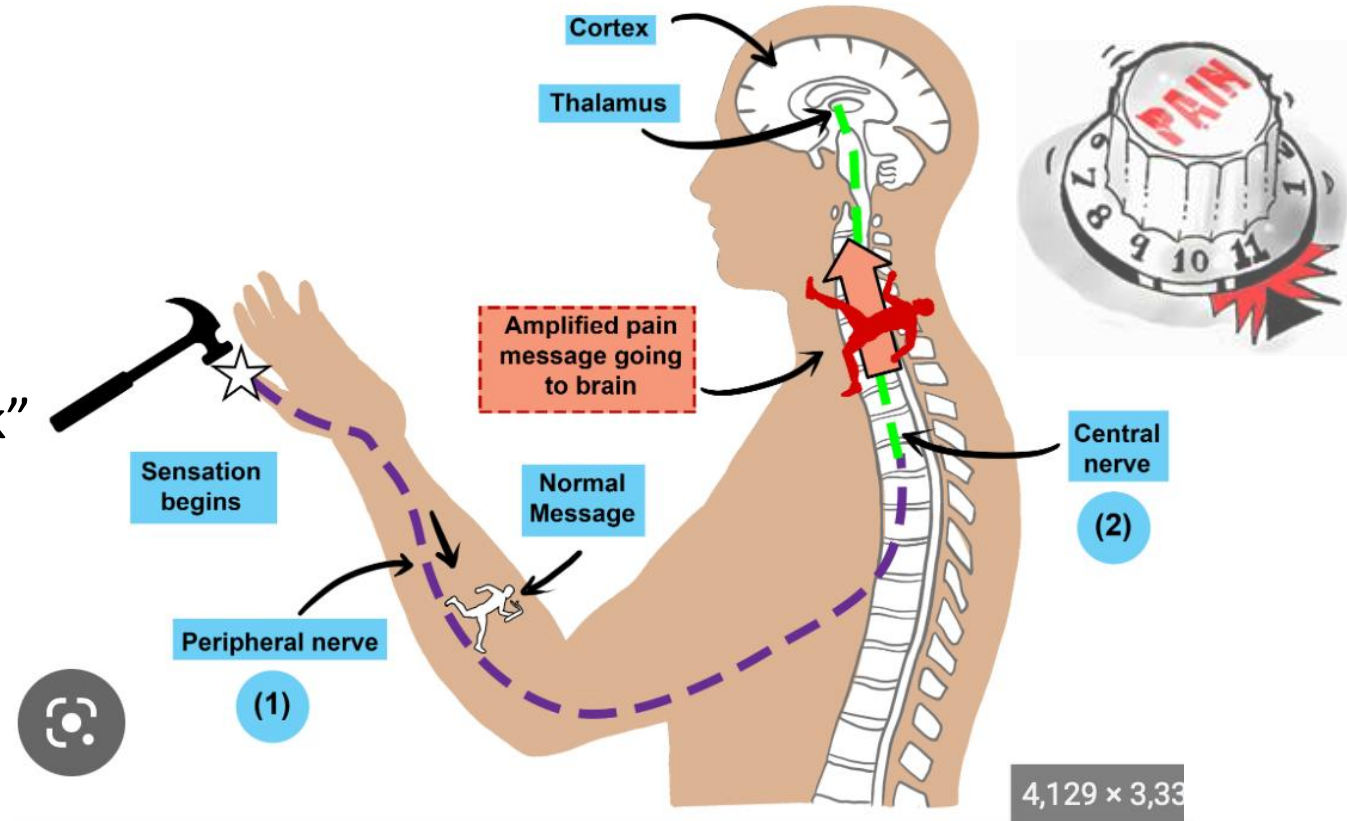
- Peripheral sensitization (PS)
 - Inflammatory chemicals make nerves more sensitive and easier to activate
 - Mast cells contribute to PS
- Neurogenic inflammation (NI)
 - Sensitive central nervous system fires sensory nerves backwards, releasing inflammatory chemicals at the tissue end, causing inflammation
 - Central sensitization and neuroinflammation contribute to NI

Hoegh, 2022



Central Sensitization

- The central nervous system (CNS) becomes oversensitive
 - It “turns the volume up” on pain
 - The nervous system can get “stuck” here through neuroplasticity
- Aggravated by psychological and social factors such as stress, anxiety, etc.
- It is NOT psychosomatic!.
 - Moseley & Butler, Explain Pain Supercharged



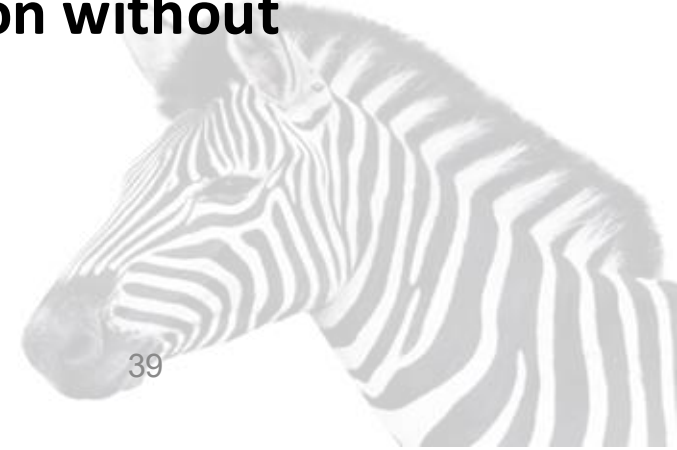
Why do People Have Central Sensitization?

Nociplastic Pain



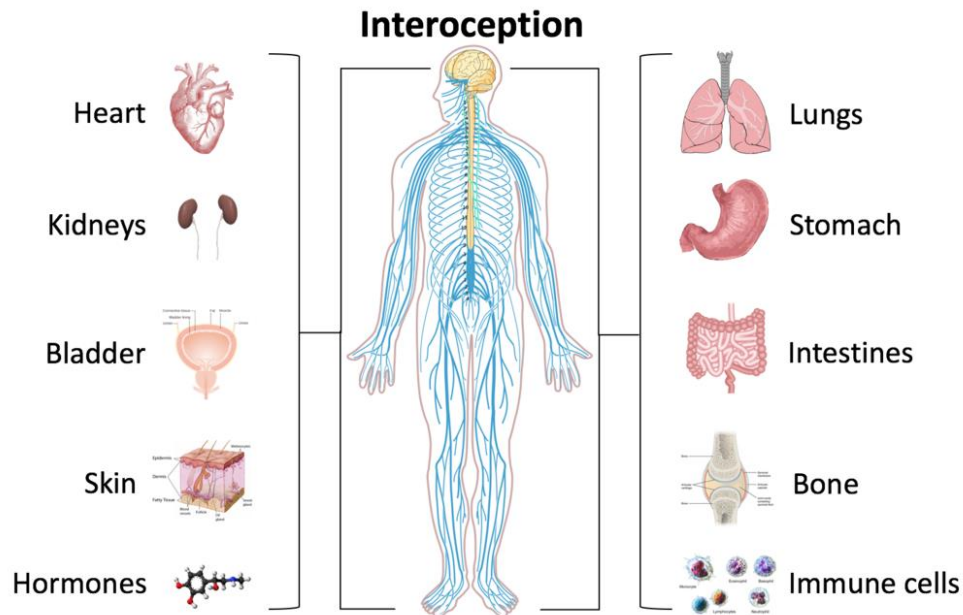
- Some people are vulnerable because of genetics or childhood trauma
- Minor (or major) mechanical stressors (i.e., nociception) may initiate and perpetuate central sensitization
- Inflammation (including MCAS) can amplify sensitization
- Eventually, no tissue damage is required for pain from sensitization
- That means: **you can have pain caused by central sensitization without “issues with your tissues”**

Almansa, 2010



What About Interoception?

- We have 3 sensory systems
 - **Exteroception:** perceiving the outside world. Sight, hearing, taste, etc.
 - **Proprioception:** perceiving body position and forces on muscles & ligaments
 - **Interoception:** perceiving internal body states.



- **Examples of Interoception:**
 - **Pain**
 - Heartbeat, cardiovascular activation, vascular flush
 - Breathing: mechanical (inflation) or chemical (air hunger)
 - Gastric and esophageal distension
 - Bladder and rectal distension
 - Thirst, taste, hunger, satiety
 - Itch
 - Temperature
 - Fatigue
 - Pleasant/affective touch

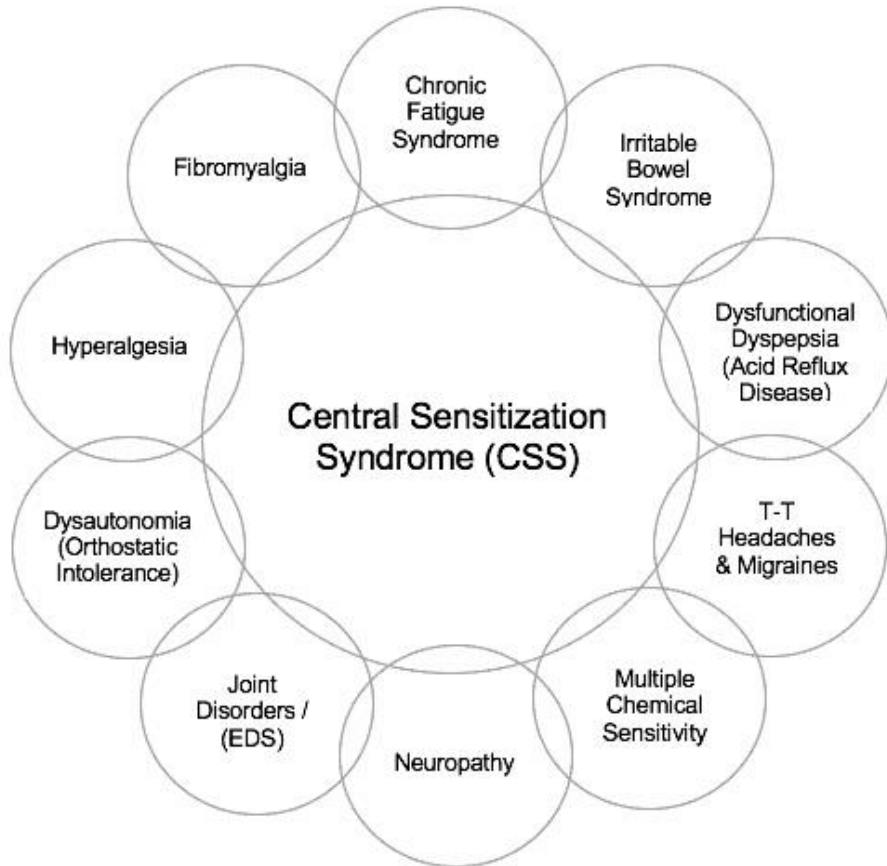


Autonomic Sensitization

- Increased sympathetic nervous system (SNS):
 - Triggers local inflammatory response
 - Inhibits vagus nerve function of suppressing inflammation and leads to increased local or systemic inflammation
 - Causes spasm in superficial/power muscles
 - Makes fascia contract
 - SNS nerves can connect to pain nerves so stress > pain
- Gut sends signals to the brain that interface with pain processing and neural inflammation
- Conditions shown linked to autonomic dysfunction:
 - Headache/migraine, myofascial pain, fibromyalgia, small fiber neuropathy, visceral pain, rheumatoid arthritis, osteoarthritis, phantom limb pain
- Autonomic neuropathy (e.g. in diabetes) can also lead to visceral pain

Elenkov, 2000 (5); Guo, 2019 (5); Johnson, 2018 (5)

How Can You Tell if You Have Sensitization?



Central Sensitization Inventory	Never	Rarely	Some-times	Often	Always
1. Unrefreshed in the morning					
2. Muscles stiff/achy					
3. Pain all over the body					
4. Headaches					
5. Do not sleep well					
6. Difficulty concentrating					
7. Stress makes symptoms worse					
8. Tension in neck and shoulders					
9. Poor memory					
	0	1	2	3	4
Total score					

CSI-9 score

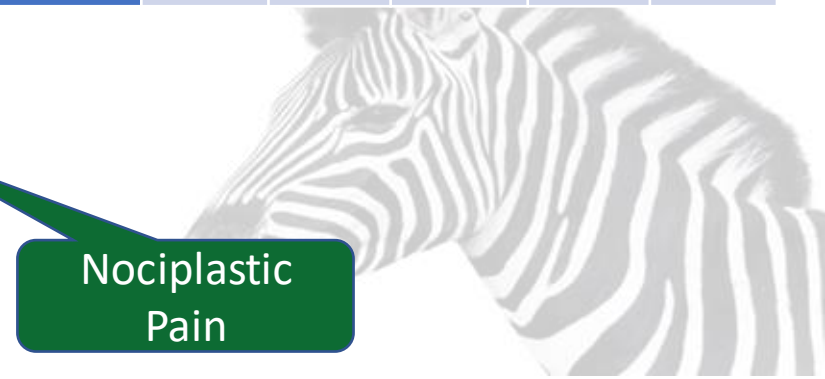
Subclinical 0-9

Mild 10-19

Mod/severe 20-36

(Nishigami, 2018)

- Look for Central Sensitization and nociplastic pain
- Can measure with Central Sensitization Inventory-9



Nociplastic Pain

Nociplastic Pain

HSD102: POTS & MCAS
HSD112: Vagus nerve

- Many regions of the brain are involved in pain processing
- Some pathways can become so well used and strong, they fire:
 - Without input from the body
 - From incorrect/minimal input
 - From negative thinking patterns
- Emotional centers are affected
- The autonomic nervous system gets out of balance:
 - Parasympathetic system (vagus nerve) is underactive
 - Sympathetic system (stress) is overactive



Russek, 2022

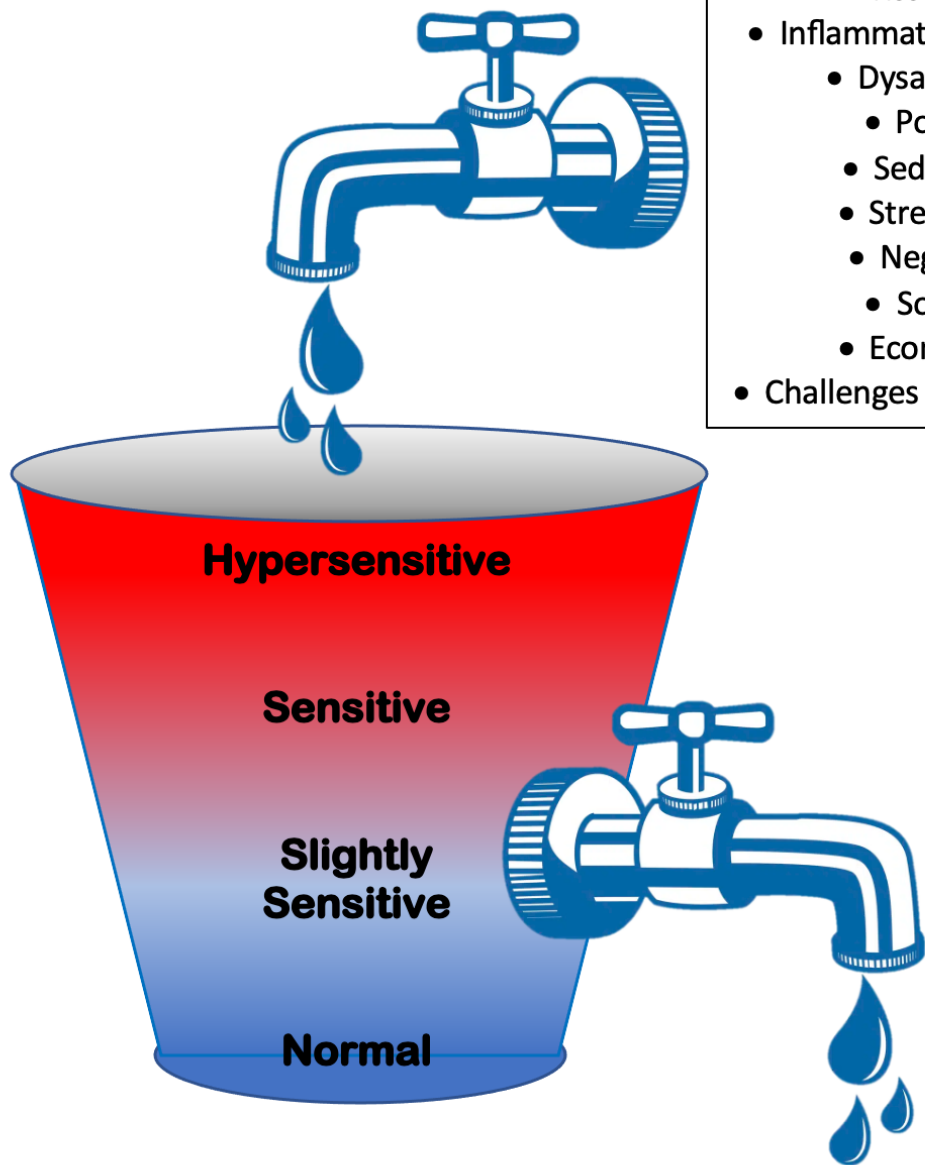
Nociplastic Pain vs. Persistent Pain

- Treatment of nociplastic pain often involves cognitive approaches and ‘pushing through the pain’ so the body can learn that movement is safe

However...

- People with HSD/EDS have more “Issues with their Tissues” than normal people
 - You are not “normal people,” your tissues are more fragile
 - People with HSD/EDS may have persistent tissue damage
- People with HSD/EDS usually have BOTH issues with the tissues AND pain amplification from nociplastic changes
- You need to manage BOTH “issues with the tissues” AND a sensitive nervous system to be successful!





Things Filling the Pain Sensitivity Bucket

- Tissue stress/injury
- Inflammation (including MCAD)
 - Dysautonomia/POTS
 - Poor sleep/diet
 - Sedentary lifestyle
 - Stress/anxiety/fear
 - Negative thinking
 - Social stressors
 - Economic stressors
- Challenges of health care system

Things Draining the Pain Sensitivity Bucket

- Good sleep/diet
- Positive coping skills
- Therapeutic alliance
- Relaxation/stress management
- Self-care strategies
- Appropriate exercise
- Social support

The Pain Sensitivity “Bucket”

Identify things that fill or drain your sensitivity bucket.

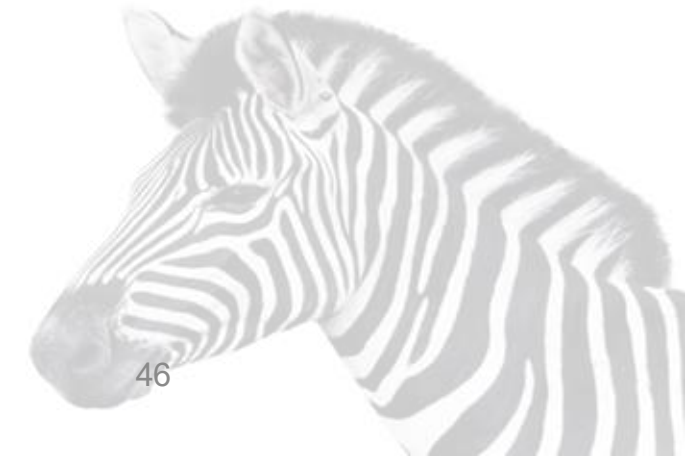
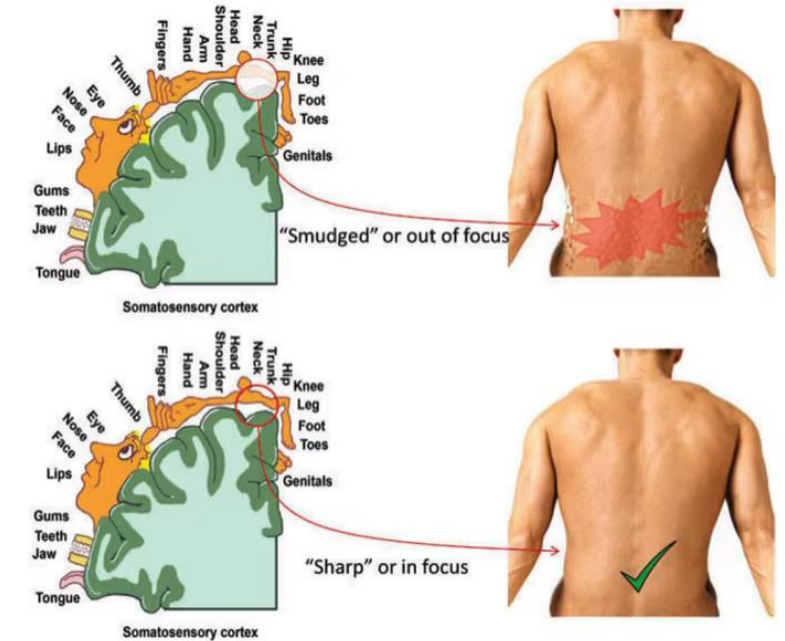
Even things that contribute only 5-10% add up



Effects of Neuroplasticity

- Incorrect nerve connections transmit general sensory information as though it were pain information
 - General sensory & stress nerves connect to pain system
 - “Silent” neurons connect to pain system
- “Smudging” of our body image in the brain
 - Brain cannot accurately map onto the body
 - Incorrect right/left mapping
 - Decreased sensory discrimination: localization, 2-point discrimination, graphesthesia (writing on the skin), stereognosis (ability to identify touched objects without looking)

E. J. PUENTEDURA AND T. FLYNN

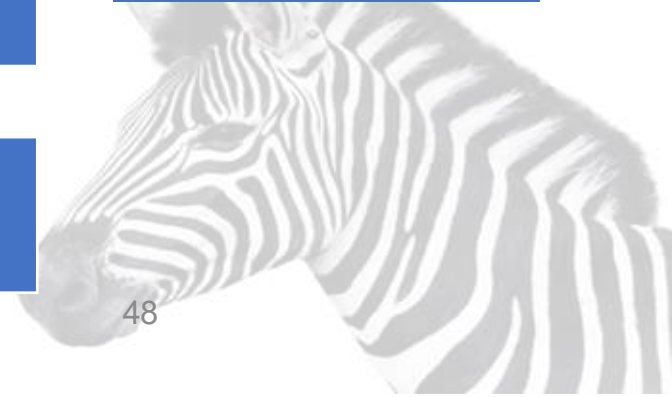
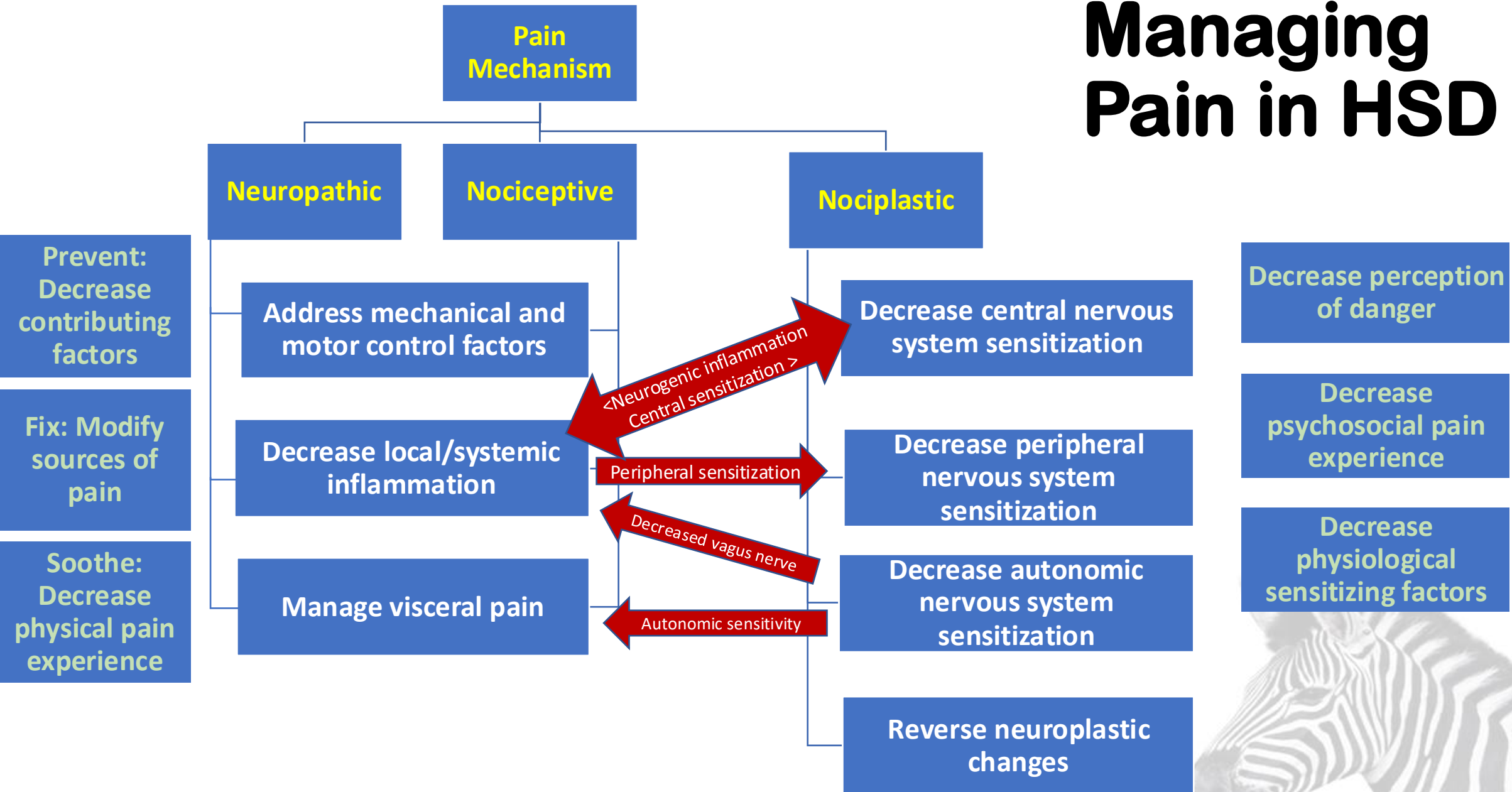




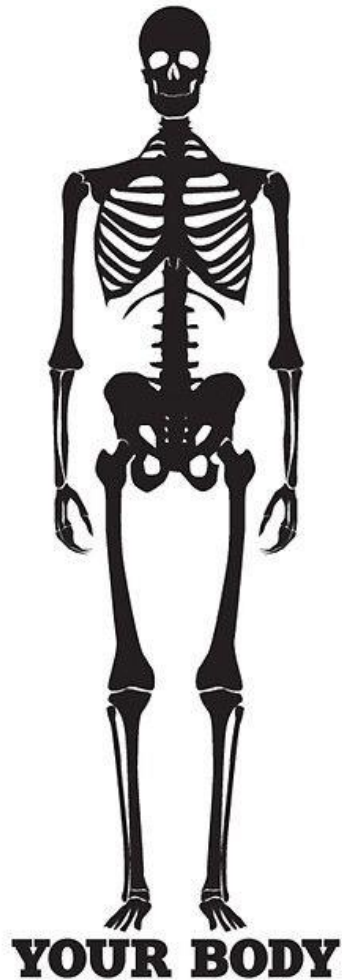
Questions?



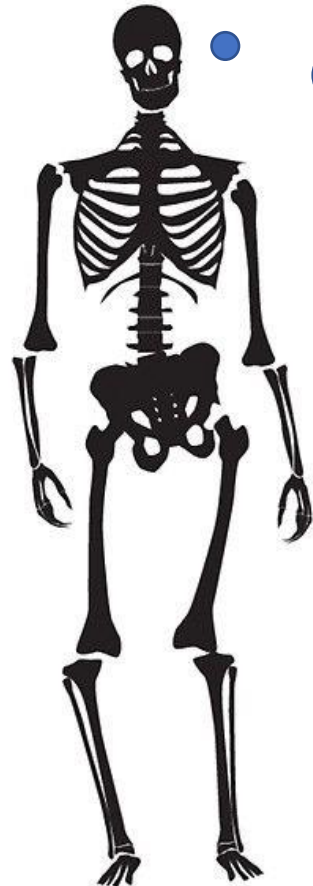
Managing Pain in HSD



Managing Issues with your Tissues



YOUR BODY



**YOUR BODY WITH
EHLERS-DANLOS
SYNDROME**

It is often not simple to figure out and solve each of the issues. More in HSD 101.



Managing “Issues with the Tissues”

HSD 104: Exercise,
HSD 105: Posture & Joint
Protection nerve

- **Prevent**

- Educate regarding posture, joint protection, body mechanics, etc.
- Use braces, splints, orthotics, assistive technology, environmental modification, compression garments to decrease stress on joints, muscles and nerves
- Address body imbalances & deficits (including strength, motor control, proprioceptive) to prevent injury and tissue stress
- Avoid triggers (e.g., physical, environmental, dietary, autonomic, etc.)

- **Fix**

- Specific exercise, self-care, or interventions to fix tissue damage or sources of pain (e.g., muscle spasm, nerve compression, motor control deficits, etc.)
- Medications (e.g., to address MCAS, POTS, inflammation, etc.)
- Surgery, recognizing surgery is less likely to be effective in HSD/hEDS

- **Soothe**

- Direct intervention: manual therapy, acupuncture, etc.
- Self-care with heat, ice, topicals, TENS, trigger point care, gentle exercise, etc.
- Analgesic medications
- Decrease nerve sensitivity and nociplastic pain amplification



Orthotics, Braces, Splints, Assistive Tech, etc.

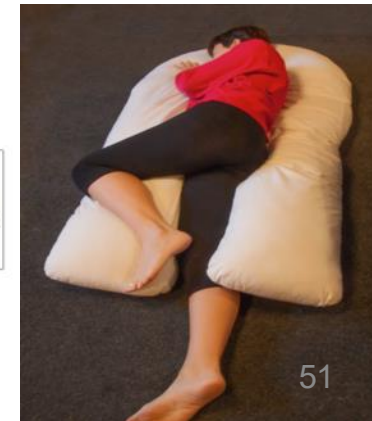
- Address contributing factors: posture, body mechanics, ergonomics, joint protection
- Use of braces, splints, taping, assistive technology, environmental modification.
 - Helpful for acute flares, return to function
 - Some devices appropriate for long-term use..

HSD 105:
Posture & Joint
Protection

(Engelbert, 2017)



03 - Managing Pain



51



Strategies to Decrease Nociceptive & Some Neuropathic Pain

Pain Self-Care Plan

- Appropriate exercise
- Transcutaneous electroneural stimulation (TENS)
- Heat, ice
- Topical rubs
- Massage, manual therapy, trigger point care
- Taping (Kinesiotape, Rock Tape, Thrive Tape)



Exercise to Manage Pain

- Gentle movement and activity are important for giving normal sensory input to the brain
 - Being sedentary increases risk of and perpetuates chronic pain
- Aerobic exercise: walking, water exercise, biking, etc.
- Calming exercise: Tai Chi, qigong, Pilates, yoga (careful not to overstretch joints)
- Stretching tight muscles (stabilize adjacent joints)
- Addressing muscle spasm or trigger points
- Do something you enjoy!

HSD 104:
Exercise in HSD
and POTS



Not All Exercises Are Appropriate

- For exercise to be helpful *and not harmful*, it must be:
 - The correct exercise (for you, now)
 - Done correctly (proper motor control)
 - At the correct dose (intensity, time/reps)
 - Not overstressing other joints or muscles (maybe low impact)
- There is no protocol appropriate for everyone with EDS/HSD

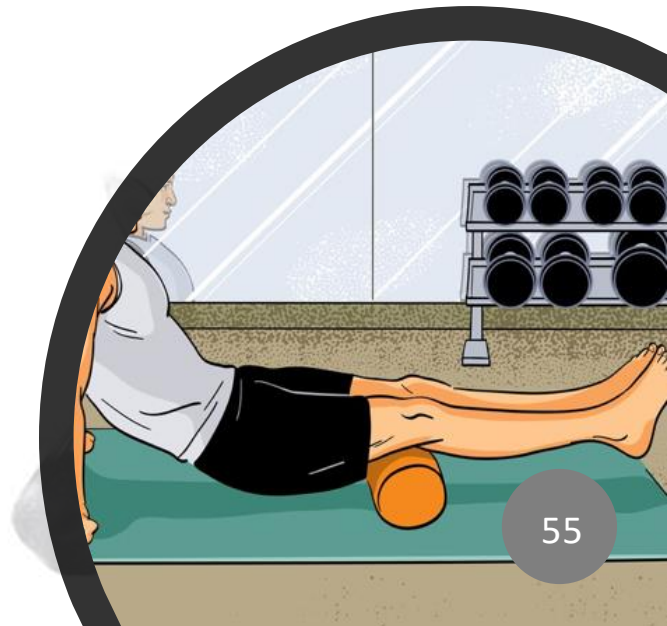


No!





Managing Trigger Points & Spasm



Transcutaneous Electroneural Stimulation (TENS)

- Uses electrical signals to reduce pain sensation & relieve muscle spasm
- Conventional TENS (80-150 Hz) blocks nociceptive signals from getting to the brain
- Acupuncture-like TENS (2-15 Hz) causes release of endorphins, your brain's natural pain-reducing chemicals
- Particularly helpful for pain flares
- No adverse effects, not addictive, you control



Johnson, 2022



Heat and Ice



shutterstock.com • 350490581

HEAT

- Heat is best when there has not been an acute injury or flare
- Heat is comfortable and can decrease pain
- Heat may increase inflammation and muscle spasm
- If you feel worse or more stiff afterwards, stop using heat



ICE

- Ice is better for acute injuries (up to 48 hrs after an injury) or severe injuries
- Ice can be better for muscle spasm, as it decreases muscle activity
- Ice can decrease inflammation and pain

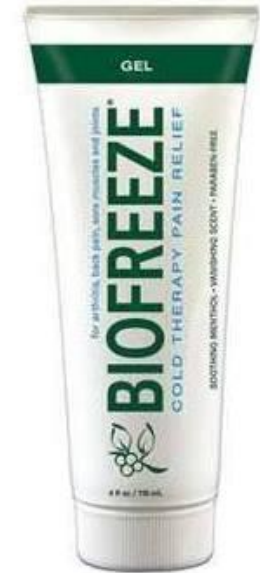


Topical Rubs

Topicals for Pain

There are 4 common topical rubs, containing:

- Menthol: best for muscle spasm and trigger points
- Capsaicin (feel hot): best for joint or muscle pain
- Medication such as trolamine salicylate, voltaren, or arnica can decrease inflammation or pain, depending on the medication
- CBD... we are still figuring out what it is best for.
- Magnesium: improves sleep.



Maloney, 2021

Red Light Therapy

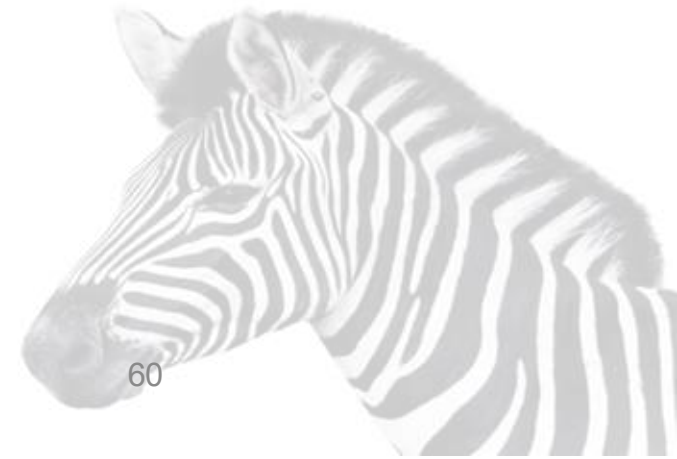


- Red light: wavelength 660 nm
- Near infrared light: 850 nm
- Also called ‘low-level laser light,’ ‘low-power laser,’ ‘non-thermal LED light,’ ‘cold laser,’ ‘biostimulation,’ ‘photobiomodulation’
- Provides the healthful benefits of sunlight without the UV
- Counteracts negative effects of blue LEDs
- Science is still evolving
 - Evidence good for skin, depression, anxiety, TMJ pain, some chronic pain (Farazi, 2024)
- <https://my.clevelandclinic.org/health/articles/22114-red-light-therapy>





Questions?





Managing Nociceptive Pain

AKA: Central Sensitization

L. Russek: HSD103 - Managing Pain



Managing Nociplastic Pain

Nociplastic Pain

- People with nociplastic pain benefit less from physical interventions
(Kohn, 2022)
- Problems with software need to be addressed by reprogramming
 - Pain Neuroscience Education (PNE) and “Explain Pain” to learn that not all pain indicates tissue damage, and it may be safe to move
 - “Physiological quieting” - calming the nervous system
 - Quality sleep
 - Cognitive behavioral strategies
 - Acceptance and Commitment Therapy (live your life anyways)



Pain Sensitivity



- Pain is an alarm system, warning us of danger
- But...it can fire
 - Too easily (sensitivity)
 - Too much (volume)
 - In response to the wrong input (e.g., stress or gentle movement)
 - When there is no tissue damage (“nociplastic pain”).
- Stress, fear, anxiety, anger and lack of sleep can increase pain sensitivity



Sleep Hygiene

Sleep

- **Do:**

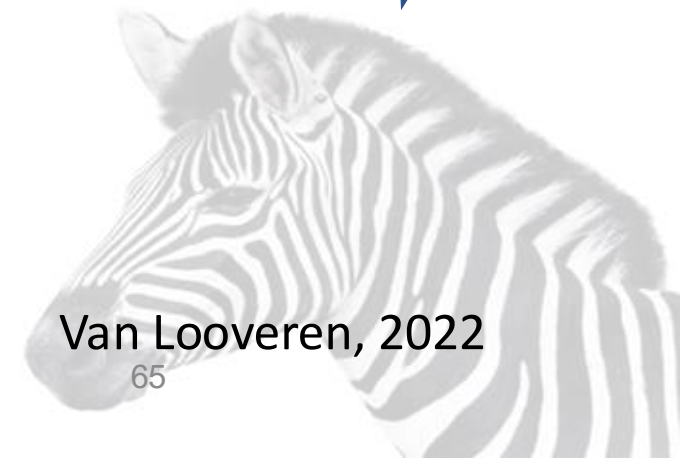
- Use bedroom only for sleep and sex
- Regular sleep schedule and bedtime routine
- Exercise 30 minutes on most days
- Increase exposure to bright light during the day
- Quiet, cool, dark room; bed supportive but soft

- **Avoid:**

- Caffeine, nicotine, alcohol, sweets before bedtime
- Heavy meals 2-3 hrs before bedtime
- Late afternoon naps
- Computers, phones, tablets, blue light before bedtime
- Lying in bed awake (get up, do something boring)..



HSD 107: Sleep and Fatigue

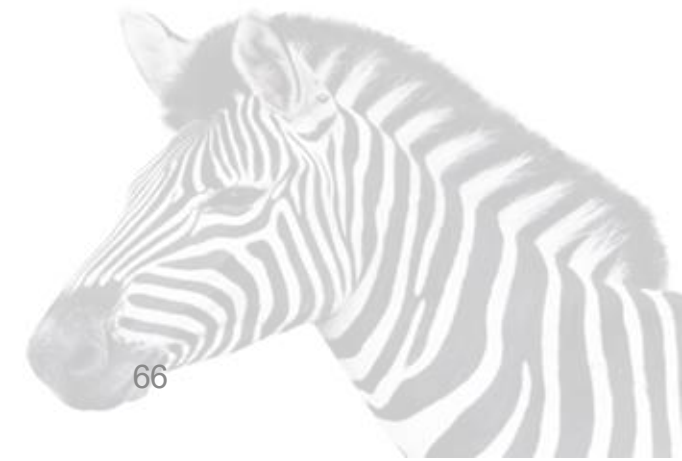


Van Looveren, 2022

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Physiological Quieting

- Mind-body techniques can decrease pain and inflammation
 - Mindfulness meditation, guided meditation
 - Yoga, yoga breathing, Tai Chi, qigong
 - Deep breathing, diaphragmatic breathing, slow breathing
 - Biofeedback (heart-rate variability or slow breathing)
 - Visualization
 - Autogenic training
 - There are many phone apps for relaxation.
 - Vagus nerve activation:
 - Ear massage: <https://youtu.be/LnV3Q2xIb1U>
 - Basic Exercise (https://youtu.be/eFV0FfMc_uo)



Activating the Vagus Nerve

- Electrical stimulation
 - Ear: 25 Hz, pulse width 250 μ s, below uncomfortable
 - Neck: devices such as Pulsetto™, Truvaga™, GammaCore™
- Stress reduction
 - Slow breathing, chanting, laughter
 - Mindfulness meditation
 - Relaxation biofeedback (especially for heart-rate variability)
 - Awe, exposure to nature, positive emotions, forgiveness
- Exercise
 - General (e.g., aerobic exercise, yoga, Pilates, etc.)
 - Vagus nerve specific (no research support, caution about neck motions)
- Manual therapy, including self-massage of ear
- Nutrition fostering healthy microbiome, Omega-3 fatty acids

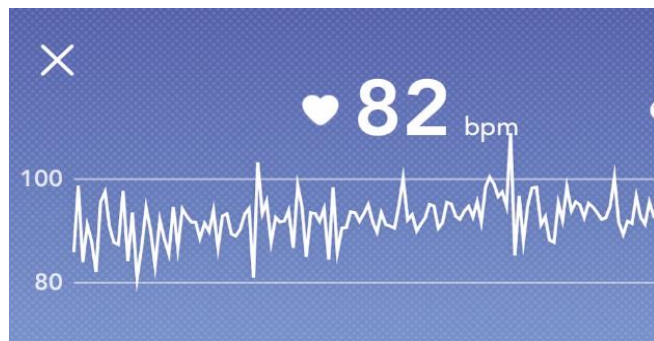
(Wang, 2022; Laborde, 2022; Gitler, 2022; Kalyani, 2011; Inbaraj, 2022; Monroy, 2023; Oriach, 2018)



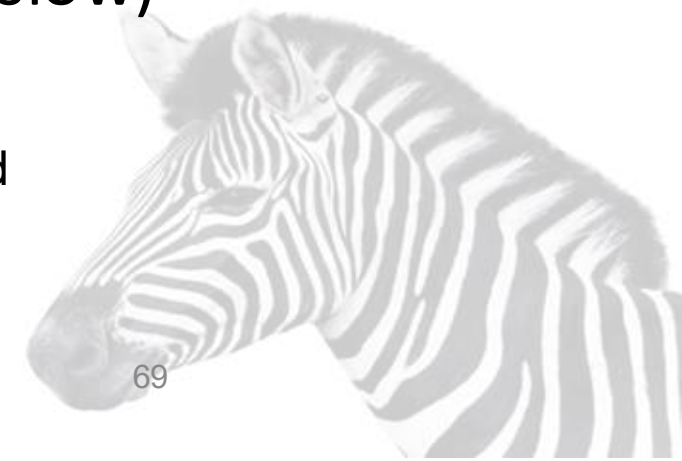
Biofeedback

- More information about biofeedback is available at:
<https://www.mayoclinic.org/tests-procedures/biofeedback/about/pac-20384664>
- Heart Rate Variability biofeedback provides feedback on stress (autonomic nervous system activation)
 - You can use a smartphone with camera/flash to do HRV biofeedback, and there are many apps available
 - StressScan has real-time feedback
 - You can purchase a dedicated biofeedback unit with ear clip: easier to use, more features
 - Inner Balance
- Biofeedback apps also for breathing (diaphragmatic or slow)

Stressed



Relaxed



Cognitive Behavioral Strategies

- Pain education
- Active self-management
- Wellness behaviors
- Pleasant activity scheduling
- Avoid negative thoughts
- Relaxation
- Eliminate fear avoidance or pain persistence
- Pacing (time based rather than task or pain based)
- Progressive activity/exercise
- Pain is not always a good guide to determine safe activity level
 - **Hurt ≠ Harm but don't overstress your body, either..**

Nociplastic Pain.
Free Pain Apps for Teens.

CBT Apps:

- Curable (6 wks free)
- WebMAP for teens (free)
- iBeatPain for teens (free)
- Juva (currently free)



Knoerl, 2016

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How to Develop Positive Thinking Habits

Category	Definition	Negative Example	Positive Alternative
All or Nothing, “Black or White” Thinking	Seeing a situation as all one way or all another way. There is no in between.	“I can’t work anymore, so nothing I do is any good.”	“I can still work part time” “I am able to volunteer at church”
Fortune Telling	Judging your future in a negative way. You do not think about the good things that could happen.	“Oh man, here comes a migraine headache. I know I will have to go get a shot in the ER for sure!”	“I feel a migraine coming on, but I learned some strategies that might help me avoid it. Trying them gives me some control.”
Not Accepting the Positive	Telling yourself that positive situations do not really count. You just got lucky.	“I cooked dinner last night, but that is not really good because before that I had not been able to cook dinner for a month.”	“I was able to cook dinner for the first time in a month. That really made me feel good about myself!”
Emotional Reasoning	Feeling something or believing something in a very strong way means that it must be true.	“I can feel my bones grinding together when I move. I don’t care what the PT says, it is not good for me to exercise.”	“Even though I am scared of exercising, the PT and doctor both say it is safe and good for me. I trust them.”
Labeling	Putting a negative name on everyone in a group.	“All doctors are jerks! They don’t care.”	“This doctor was not very nice to me. But I do have some very good doctors.”
Magnifying or Minimizing	Making the negative seem much worse than it really is. Making the positive seem not as important as it really is.	“My pain is unbearable! I can’t live with it!” “I worked in the garden yesterday and today I feel horrible!”	“The pain is bad, today, but I have dealt with worse. I can handle it.” “I worked in the garden 2 hours yesterday. I am a bit sore, but it felt great to be out.”
Mental Filter	Paying too much attention to one negative detail instead of seeing the whole picture.	“My fibromyalgia/EDS means that I am not a whole person. I am damaged goods.”	“My pain does not define who I am. I still have a lot to offer my family and friends.” “There are a lot of things I can still do.”
Mind Reading	Believing that you know what other people are thinking.	“My husband thinks that I make my pain seem worse than it really is.”	“I am not going to worry about what other people think.”
Overgeneralizing	Because one particular situation is bad, you make it seem like other similar situations will be just as bad.	“I can’t do the work I was trained for anymore, so I won’t be able to go back to work at all.”	“I can’t do my previous job, but I might be able to do an office job that did not require much walking or lifting.”
Should Statements	Ideas about how the world should be, ought to be or must be, and you hang onto these ideas.	“A good doctor should figure out what’s wrong with me and fix it!” “There must be a drug that helps”	“Things are what they are. I will make the best of what I can do.”
Personalizing	When you see yourself as the cause of a negative event, but you really had no control over it.	“This pain is a punishment from God for something I did wrong.”	“Life is sometimes really unfair. But there are other people who have to deal with even worse things, so it isn’t just me.”

Negative Thinking & Pain

This helps avoid having negative thoughts release neurotransmitters that amplify pain

Nociplastic Pain

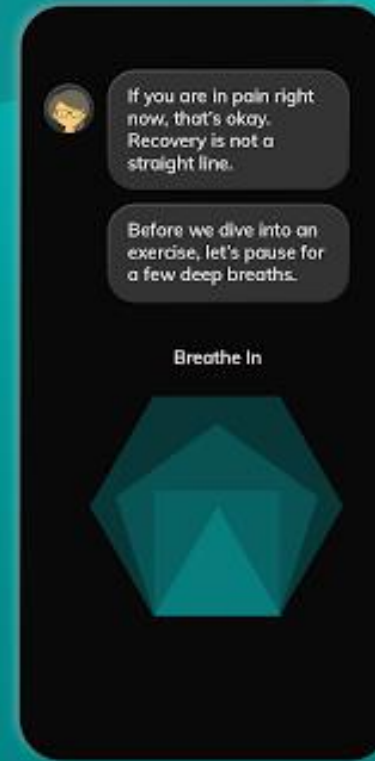
Curable™

- Curable app is a self-directed, cognitive-behavioral therapy (CBT)-based pain self-management program: www.curablehealth.com
- You can get a 6-week free trial of Curable. Scan code at right.



Scan to Activate a
FREE 6 Week Trial to
The Curable App

Use the Panic Button to
Instantly Calm a Flare



Meet Curable:
A step-by-step program
for taking control over pain



Treating Interoceptive Problems

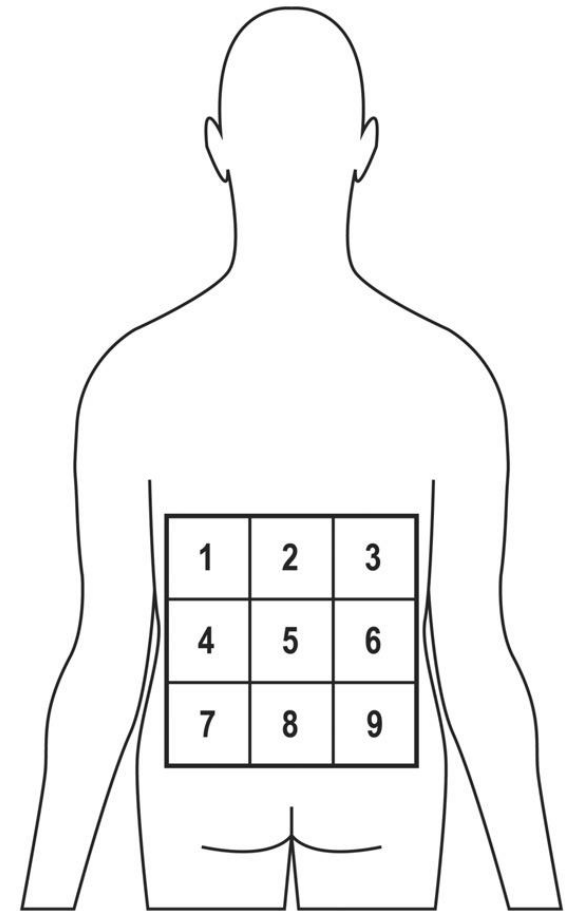
- Mind-body therapies can alter interoception. This might be part of how they can help manage pain.
 - Yoga, Tai Chi, Qigong, Pilates, etc.
- Manual therapy may help through ‘gentle touch’
- Improving interoception may decrease pain by placing it in a context of other body sensations.
- To be continued, as we learn more

• Gnall, 2024



Reprogramming the Nervous System

- Calm a sensitive nervous system, first
- Motor imagery: visualize painful body part without pain
 - Then visualize positions and movements being pain free
 - Use mirrors to 'visualize' moving a painful limb
 - Right/left visual discrimination using **Orientate** app (free)
- Sensory retraining:
 - Localization: identify where, in a grid, you are being touched
 - Graphesthesia: identifying letters or shapes drawn on the skin
 - Stereognosis: identifying objects by touch



Self-Care Toolbox

- Help patients develop a toolbox of pain-management and self-care strategies.
- Different things work for different people. Experiment.
- A physical box with things like hot packs, TENS machine, massagers, etc. can be helpful.

What's In Your Self-Care Toolbox?

Type	Tool	Pain	Instability	Function	Sleep	POTS Sx	Fatigue	MCAS	Inflammation
Physical	<input type="checkbox"/> Heat, hot pack, rice bag (aching pain)	X							
	<input type="checkbox"/> Ice (severe pain, spasm, inflammation, swelling)	X				X		x	X
	<input type="checkbox"/> TENS: conventional or acupuncture-like	X		X					
	<input type="checkbox"/> Topicals: menthol, NSAID, CBD, etc.	X							X
	<input type="checkbox"/> Trigger point release/pressure/rolling	X							
Devices	<input type="checkbox"/> Supports, splints, braces, taping, etc.	X	X	X					
	<input type="checkbox"/> Pacing, modifying the environment	x	x	X			x		
	<input type="checkbox"/> Assistive devices for function or mobility	X	X	X			X		
	<input type="checkbox"/>								
Neural Calming	<input type="checkbox"/> Slow, diaphragmatic breathing	X			X	X	X		
	<input type="checkbox"/> Meditation, mindfulness	X			X			x	x
	<input type="checkbox"/> Prayer, chanting, humming	X			X			x	x
	<input type="checkbox"/> Gratitude, journaling, affirmations	X			X			x	x
	<input type="checkbox"/> Tapping ("EFT"), earthing/grounding, etc.	x			x		?	?	
	<input type="checkbox"/> Vagus nerve activation (manual, e-stim)	X			X	X	X	X	X
	<input type="checkbox"/> Nature, awe, art, beauty	x			x				
	<input type="checkbox"/> Avoid unhelpful/negative thinking	X		x	X		x		
Wellness	<input type="checkbox"/> Diet: things to avoid	X			x	X	x	X	X
	<input type="checkbox"/> Diet: supplements	X			x		x	X	X
	<input type="checkbox"/> Sleep hygiene & positioning				X		X		
	<input type="checkbox"/> Sunshine, red light (avoiding blue light)	x					X		
	<input type="checkbox"/>								
Exercise	<input type="checkbox"/> Exercise: focus on relaxation, breathing	X			X	X	X	X	x
	<input type="checkbox"/> Exercise: correct posture & alignment	X	X	X			x		
	<input type="checkbox"/> Exercise: strengthen and stabilize	X	X	X			X		
	<input type="checkbox"/> Exercise: aerobic (incl: supine, sitting)	X	x	X	X	X	X	x	x
	<input type="checkbox"/>								
POTS	<input type="checkbox"/> Hydration/electrolytes			X		X	X		
	<input type="checkbox"/> Lying down with feet elevated					X	X		
	<input type="checkbox"/> Compression clothing	x	x	x		X	x		
	<input type="checkbox"/>								
Meds	<input type="checkbox"/> Meds: NSAIDs	X							X
	<input type="checkbox"/> Meds: CBD	X			X			x	x
	<input type="checkbox"/> Meds: antihistamines	x				x		X	X
	<input type="checkbox"/> Meds: Other								
other	<input type="checkbox"/>								

Summary: Pain Management Approach

1. Figure out pain mechanism, source, perpetuation
2. Prevent pain from developing, when possible
3. Fix causes of pain, when possible
4. Calm nerves to 'turn down the volume'
5. Use strategies & techniques to decrease pain
6. Optimize your function when you cannot change the pain



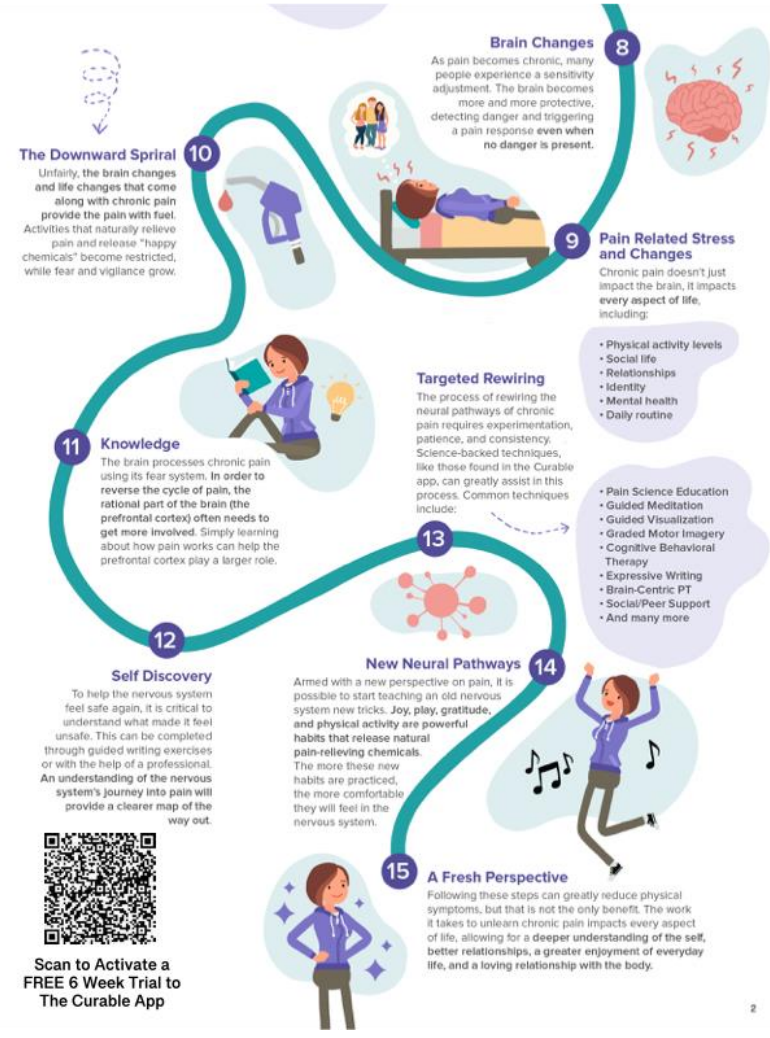
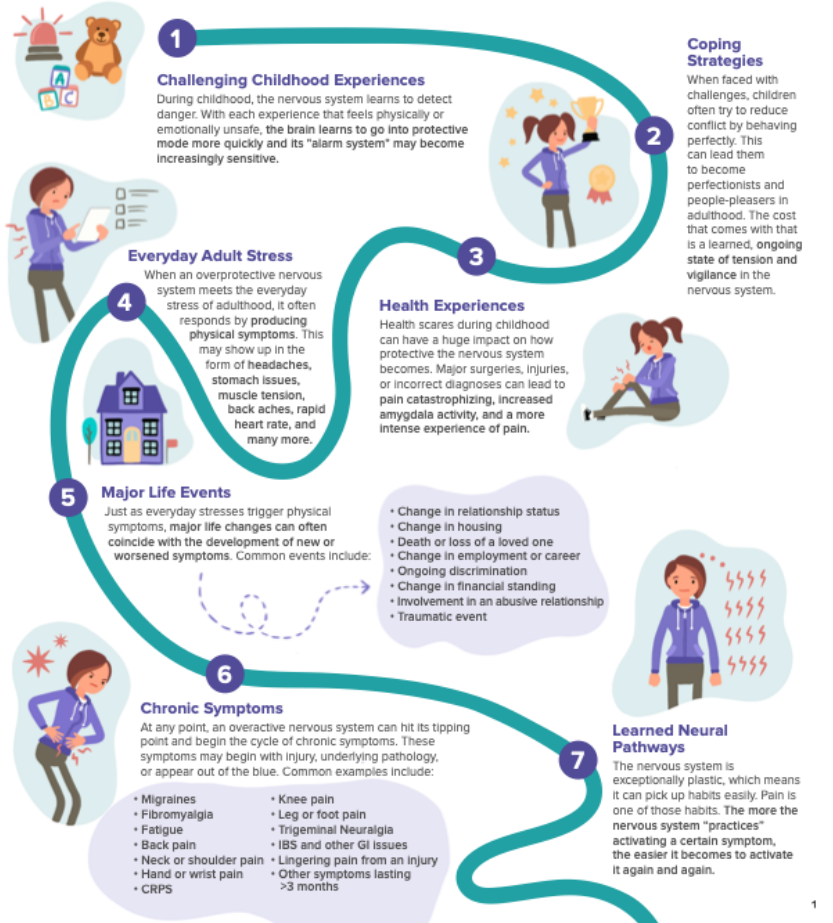
Pain Management Patient Resources

- American Chronic Pain Association: <https://www.theacpa.org>
 - Clinical practice guidelines (appropriate for patients & providers) at: <https://www.theacpa.org/pain-management-tools/resource-guide-to-chronic-pain-treatments/resource-guide-to-chronic-pain-management/>
- On-line pain self-management: <https://www.liveplanbe.ca> has questionnaires to customize information and suggestions for issues that you face
- Pain self-care video series for adults: <https://aci.health.nsw.gov.au/chronic-pain/for-everyone>
- Pain self-care video series for children: <https://aci.health.nsw.gov.au/chronic-pain/painbytes>
- A site with multiple reliable links about chronic pain and pain management: <http://www.instituteforchronicpain.org/resources/educational-links>
- A good description of central sensitization: <https://www.painscience.com/articles/central-sensitization.php>

Example of Curable Resources



The Path In (and Out) of CHRONIC PAIN



Scan to Activate a FREE 6 Week Trial to The Curable App



Pain Education and Self-Care Apps

- **Curable:** www.curablehealth.com (scan code available)
- **WebMAP:** Web-based Management of Adolescent Pain, which is available at <https://webmap2.com/welcome/>. (Free)
- **PainCoach:** Created by the VA, but free to anyone. <https://mobile.va.gov/app/pain-coach>
- **Juva** for Migraine (good for any central sensitization pain, not just migraine): <https://www.juvahealth.com> . Currently free.
- **CBTi** is an app to manage insomnia using Cognitive Behavioral Therapy, but many of the skills are useful for chronic pain. Created by VA, but Free to anyone. <https://mobile.va.gov/app/cbt-i-coach>
- **Orientate** Free is an app to reteach right/left discrimination caused by 'smudging' in the brain

PRACTICE 1: Slow Breathing

- Research shows that optimal breathing rate is ~5.5 breaths/minute, or 10-11 seconds/breath. An easy pattern is 5 seconds in, 5 seconds out. Even better is 3-4 seconds in and 6 seconds out.
 - The longer exhale seems to calm the nervous system better
- “365 Breathing” recommends that you do 3 sessions of breathing 6x/minute for 5 minutes, 365 days a year. Even just a few minutes/day can help.
- It takes about 2 weeks for your nervous system to adapt.



PRACTICE 2: Vagus Nerve Massage

- Sukie Baxter has nice YouTubes
- <https://youtu.be/LnV3Q2xIb1U>



Good books on vagus nerve:

- Porges: The Pocket Guide to Polyvagal Theory
- Rosenberg: Accessing the Healing Power of the Vagus Nerve: Self-Help Exercises for Anxiety, Depression, Trauma, and Autism



PRACTICE 3: Imagery for Relaxation

- Sit in a comfortable position
- Close your eyes
- Listen (2 min)
- <https://youtu.be/TWI639oEzmE>



PRACTICE 4: Visualization

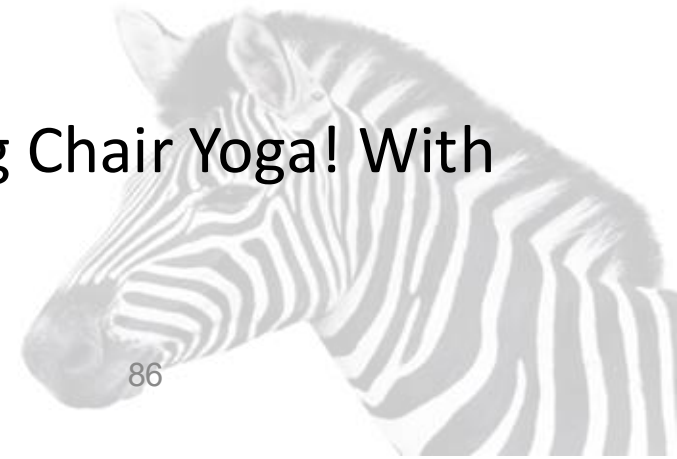
- Rachael Coakley – Abstract pain visualization
- <https://youtu.be/BgOKKjgqqMc>



PRACTICE 5: Chair Exercise With Upbeat Music



- <https://youtu.be/vZJ02gfsp0o>
- Exercise does not need to be aggressive – chair yoga to up-beat music can help.
- You can modify movements so none are painful. Do what works for you.
- Movement can be helpful even if it is small.
- Music can be motivating.
- One fun source: Energizing Chair Yoga! With Sherry Zak Morris



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Questions?

