

Welcome!



Capital Area
Ehlers–Danlos Syndrome
Support Group

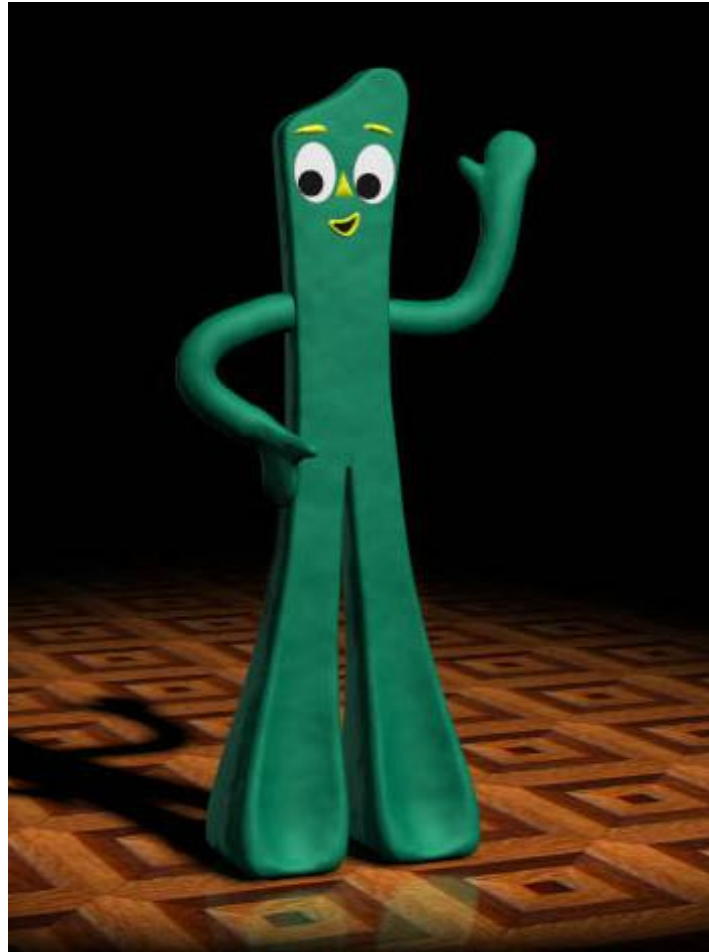
Ehlers–Danlos Syndrome

Pain Management Part One: Overview

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New Mascot for EDS?





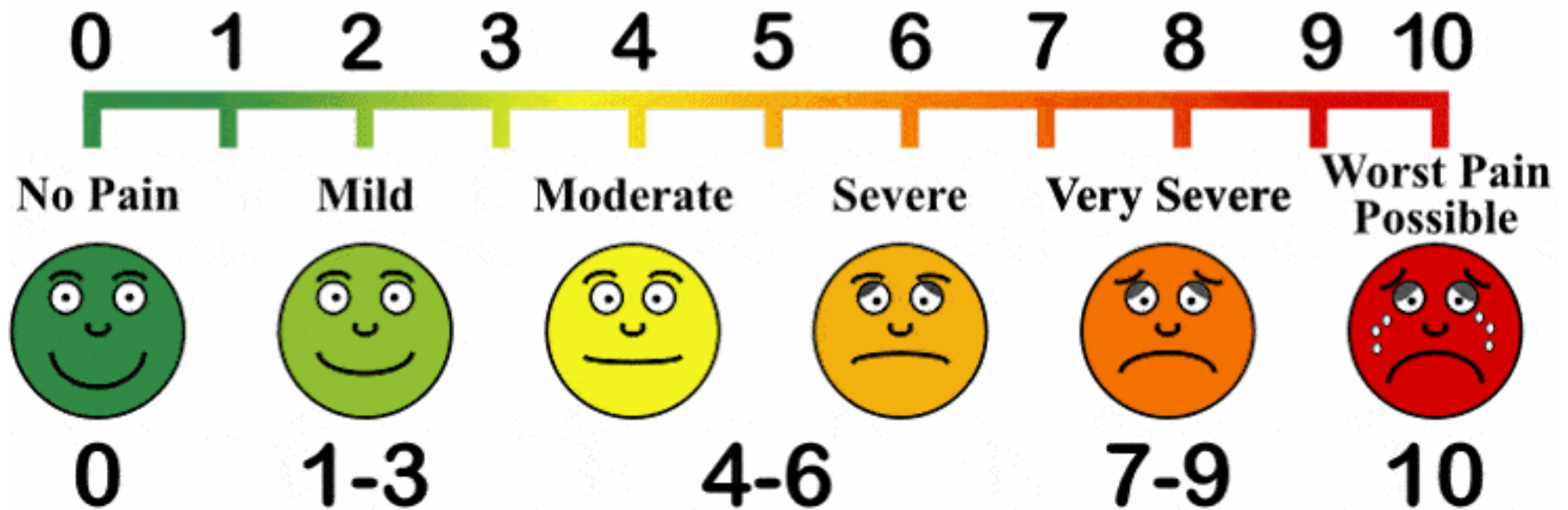
What is pain?

- ▶ Suffering or discomfort caused by illness or injury.
 - Pain may be physical or emotional.
- ▶ The emotional component of pain contributes to suffering.
 - Pain can be present without suffering.
- ▶ Pain of moderate–severe intensity is also accompanied by anxiety and the urge to escape or stop the pain.

Pain is subjective.






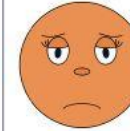
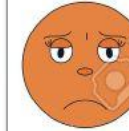

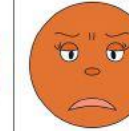


- ▶ Pain is entirely subjective, a personal experience; i.e., there is no test that can measure pain (objective).
- ▶ Medical professionals have no way to quantify pain –they must rely on the individual’s self-report.
 - With acute pain, blood pressure and heart rate may go up (stress response), but with chronic pain the stress response may be blunted or absent.
- ▶ This can lead to misunderstanding and over- or under-treatment of pain.

Pain Scale

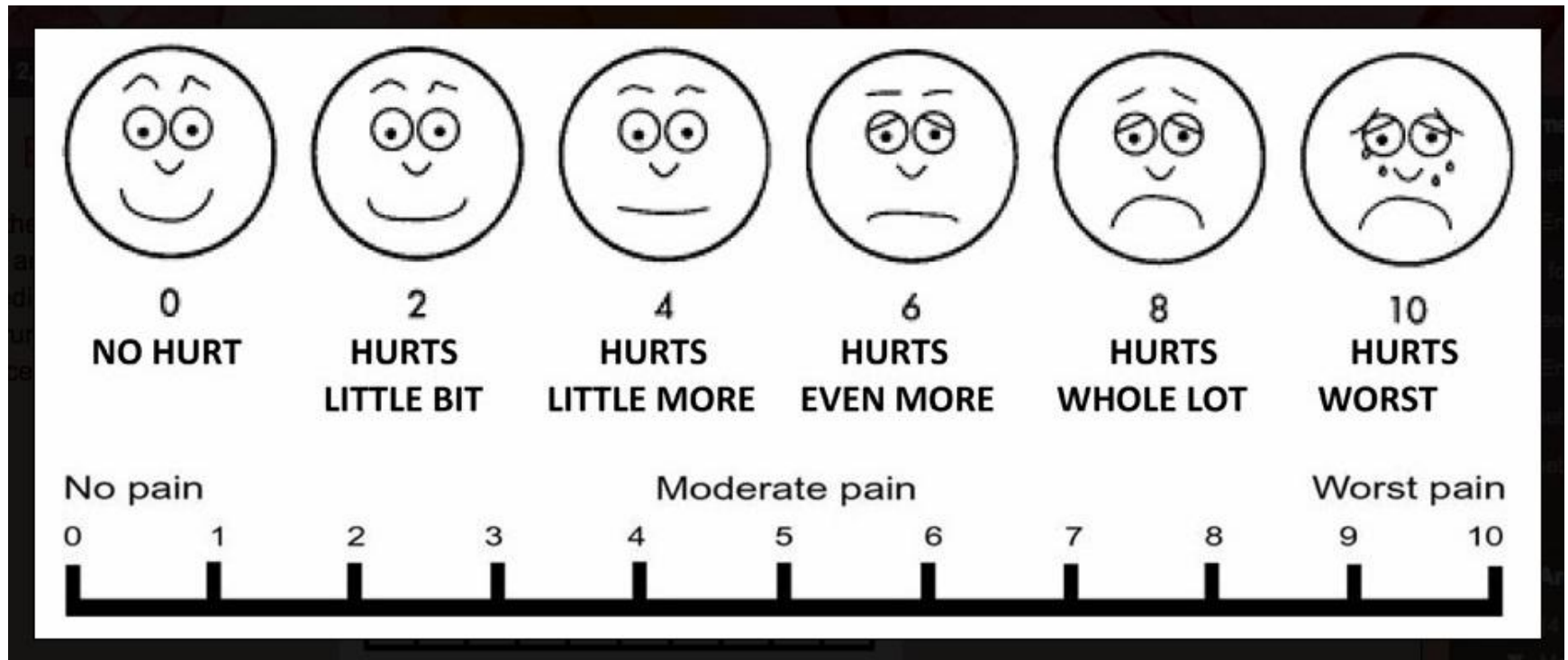


Pain Scale

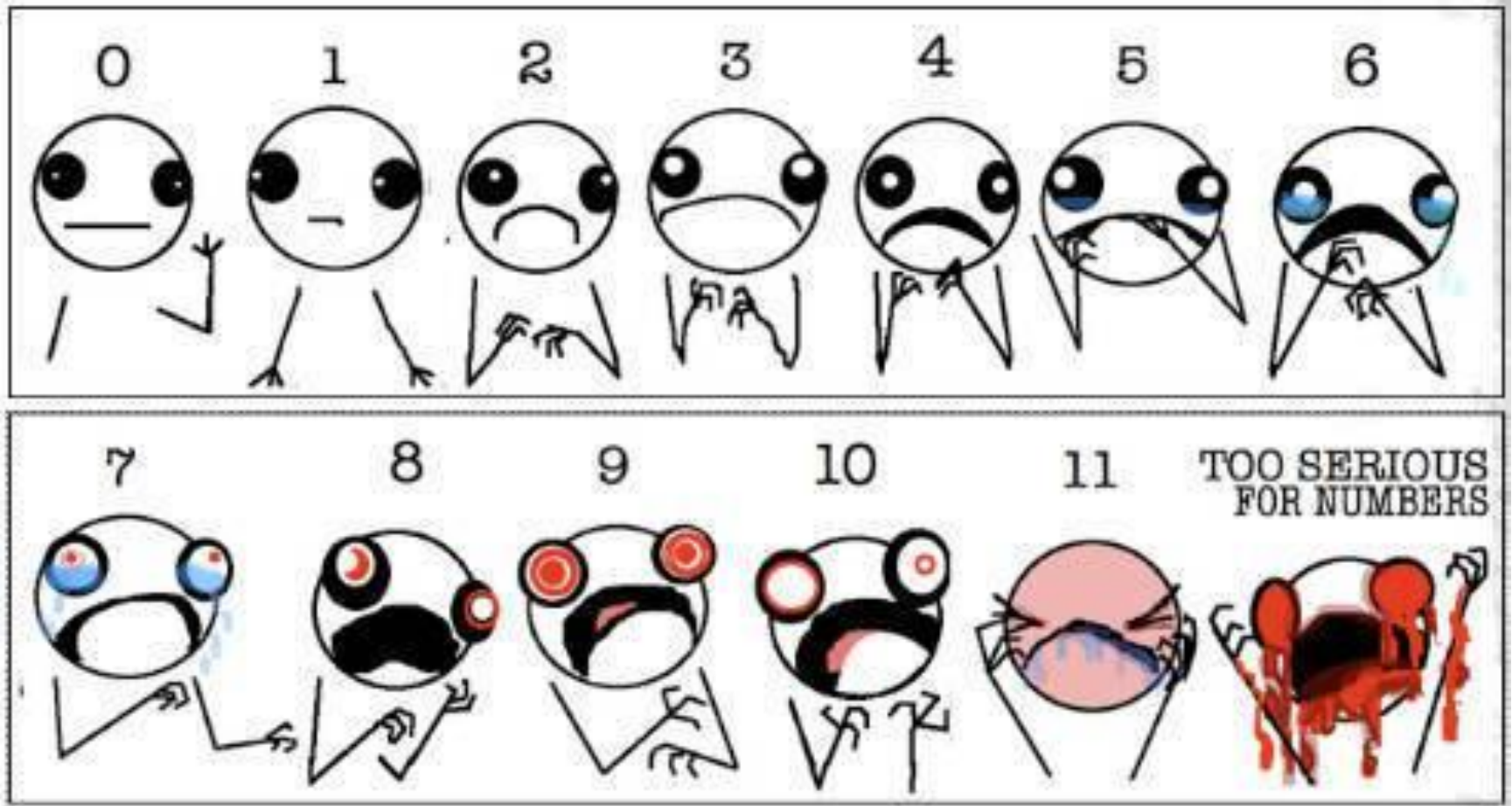
COMPARATIVE PAIN SCALE CHART (Pain Assessment Tool)

										
0 Pain Free	1 Very Mild	2 Discomforting	3 Tolerable	4 Distressing	5 Very Distressing	6 Intense	7 Very Intense	8 Utterly Horrible	9 Excruciating Unbearable	10 Unimaginable Unspeakable
No Pain	Minor Pain			Moderate Pain			Severe Pain			
Feeling perfectly normal	Nagging, annoying, but doesn't interfere with most daily living activities. Patient able to adapt to pain psychologically and with medication or devices such as cushions.			Interferes significantly with daily living activities. Requires lifestyle changes but patient remains independent. Patient unable to adapt pain.			Disabling; unable to perform daily living activities. Unable to engage in normal activities. Patient is disabled and unable to function independently.			

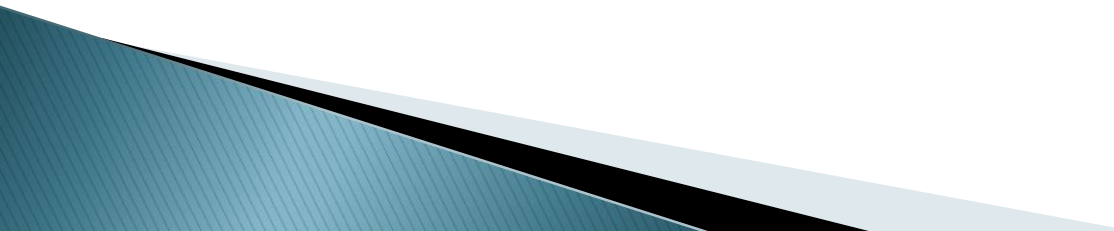
Pain Scale



Real-Life Pain Scale



Why do we have pain?

- ▶ Pain can be protective, helping us to keep our bodies from harm.
 - ▶ Individuals with impaired sensation (e.g., diabetic neuropathy, stroke) often injure themselves or have infections without knowing it.
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Acute vs. Chronic Pain

- ▶ **Acute pain** is a severe or sudden pain that generally resolves within a certain amount of time. Examples of acute pain include illness, injury or surgery.
- ▶ **Chronic pain** is persistent, lasting for months or even longer. Chronic pain can be considered a health condition in itself.

Acute vs. Chronic Pain

- ▶ Acute pain is triggered by tissue damage. Its purpose is to alert you to injury and protect you from further harm.
 - Spinal reflex arc responds before signals reach the brain and cause withdrawal from painful stimulus.
- ▶ With chronic pain, you might not know the reason for the pain. For example, an injury has healed, yet the pain remains —and might even become more intense. Chronic pain can also occur without any indication of an injury or illness.

Chronic Pain

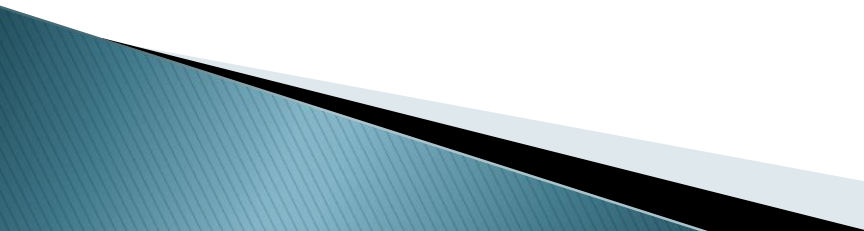
- ▶ The truism is that chronic pain is not helpful, while acute pain is useful, telling us something is damaged and needs to be protected to heal.
- ▶ I think it is time to challenge that truism.

Chronic Pain

- ▶ Perhaps chronic pain *is* telling us something we aren't hearing, and medical professionals, for the most part, aren't trained to look for:
 - Improper posture/alignment
 - Improper movement patterns/ergonomics
 - Lack of exercise/healthful movement
 - Trigger points in muscles from above
 - Emotional/physical stress
 - Unrecognized disease/disorder

Where is your pain?

▶ Muscle

- Spasm from joint laxity and efforts to stabilize joint
 - Compression of blood vessels causing hypoxia (decreased oxygen) or swelling
 - Inflammation
 - Trigger points from overuse, misalignment, posture problems, etc.
 - Muscle fatigue
- 

Where is your pain?

- ▶ Connective tissue (tendon, ligament, cartilage, bursa, fascia)
 - Inflammation
 - Tears or other injury
 - Compression or stretching from dislocation or subluxation
 - Degenerative changes

Where is your pain?

▶ Nerves

- Compression by tight muscles, connective tissues, or joints out of proper position
- Radiculopathy from degenerative changes in spine
- Herpes zoster or other nervous system infection
- Inappropriate sympathetic nervous system activation

Where is your pain?

- ▶ Bone
 - Osteopenia/osteoporosis (?painful)
 - Stress fractures
- ▶ Skin
 - Damage to fragile skin
 - Bruising
 - Painful rashes
- ▶ Viscera (organs)
 - Smooth muscle spasm (cramping)
 - Distention or rupture
 - Inadequate blood flow (ischemia)

Where is your pain?

- ▶ Headaches
 - Chiari Malformation
 - Tension
 - POTS/dysautonomia
 - Migraine/ophthalmic migraine
 - MCAS

Where is your pain?

- ▶ If you find out what is hurting, you can target treatment more specifically.
- ▶ You may be able to eliminate the cause of the pain.
 - This can be a prolonged process.
- ▶ Eliminating the source of the pain is the best treatment for pain, but secondary sites of pain, which were set up by the primary source, may persist.

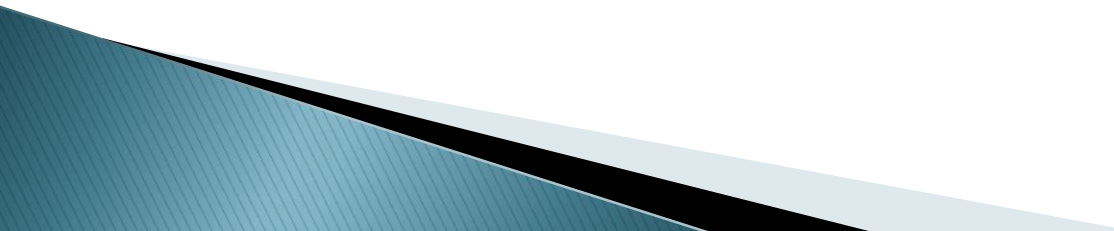
How is pain transmitted?

- ▶ Specialized nerve cells in the peripheral nervous system, nociceptors, are triggered by tissue damage
 - Injury, pressure, heat, inflammation, chemical changes (e.g., pH), decreased oxygen
- ▶ Neuro-electrical signals are sent from the nociceptors to the spinal cord (dorsal horn)
- ▶ In the dorsal horn, reflex arc may occur, and signal is also relayed to the brain

Sensitization

- ▶ With intense, repeated, or prolonged stimulation to damaged tissue, sensitization occurs.
 - Nociceptors then have a decreased threshold for firing and increased frequency of firing.
 - These nociceptors release proinflammatory substances which activate other nociceptors.
- ▶ Normally painless stimuli cause pain, called hyperalgesia or allodynia (e.g., taking a warm shower with a bad sunburn).

Pain Management Goals

- ▶ Decrease pain by about 50%
 - ▶ Become more functional
 - ▶ Have more good days than bad days
 - ▶ Don't expect to be pain-free; this is an unrealistic goal, in most cases.
- 

Pain Management – Medications

▶ Pain Medications

- NSAIDs, acetaminophen (oral, topical, ketorolac IM, IV)
- Opioids (oral, IM, IV, topical, transmucosal, rectal)
- Glucocorticoids (steroids) (oral, parenteral, intraarticular)
- Low dose naltrexone (oral)
- Cannabinoids (oral, topical)
- Capsaicin (topical)
- Local anesthetics (topical)

Pain Management – Medications

- ▶ Adjuvant (helper) Medications
 - Antidepressants
 - Tricyclic
 - SSRI, SNRI
 - Sedatives
 - Muscle relaxers
 - Anticonvulsants
 - Antiarrhythmics

Where do pain medications act?

- ▶ Block at site
 - Local anesthetic, NSAIDs (decrease inflammatory agents at site), capsaicin (depletes substance P)
- ▶ Block at spinal cord
 - Epidural analgesia
- ▶ Decrease nerve firing
 - Anticonvulsants (gabapentin, phenytoin, pregabalin)
 - Antiarrhythmics (low-dose lidocaine, mexilitine)
- ▶ Decrease brain's recognition of pain (centrally-acting –on descending pain control pathway)
 - Opiates, antidepressants

Pain Management

- ▶ Physiotherapy (PT)
 - Manual Therapy (OMM, PT)
 - Massage
 - Electrotherapy, TENS
 - Heat or Cold Therapy
 - Bracing
 - Kinesio taping

Pain Management

- ▶ PT-guided exercise
 - Strength Training
 - Stabilization Training (for core, joints)
 - Aquatic Therapy
 - Stretching

Pain Management

- ▶ Medications / counseling for management of co-morbid psychiatric conditions
 - Insomnia, depression, anxiety, autism spectrum disorders, post-traumatic stress disorder more frequent in EDS
- ▶ Cognitive Behavioral Therapy
 - Helps change perception of pain and affect around pain (e.g., woman in labor)
- ▶ Social Support
 - Those with EDS are often socially isolated because of pain

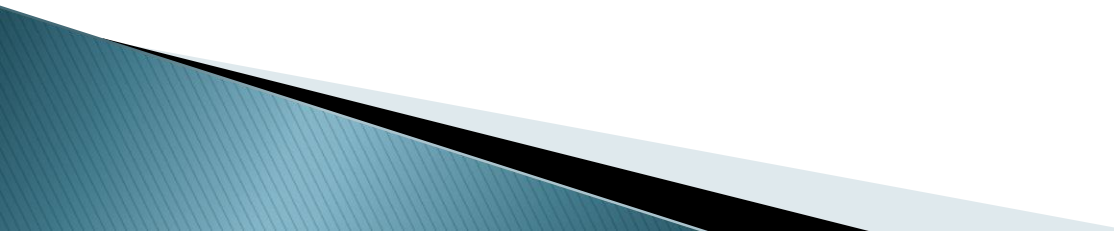
Pain Management

- ▶ Joint/bursa injections
- ▶ Pain Clinic Interventions
 - Epidural steroid injection, facet blocks, rhizotomy
- ▶ Trigger point/muscle injections
- ▶ Spinal column stimulator
- ▶ Surgery
 - Joint replacement
 - Joint fusion
 - Ligament tightening

Pain Management

- ▶ **Alternative / Complementary Medicine**
 - Acupuncture
 - Prolotherapy
 - Herbal remedies
 - Nutritional supplements
 - Others?
- ▶ **Approach with caution.**
 - Look for information on reliable healthcare sites.
 - Check for scams on Quackwatch.org, among others.

Self-management of pain

- ▶ Exercise (“motion is the lotion”), 30 minutes daily
 - ▶ Core strengthening
 - ▶ Posture training
 - ▶ Trigger point release
 - ▶ Self-massage
 - ▶ Self-alignment of joints, reduction of dislocations/subluxations (with proper knowledge of anatomy)
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Self-management of pain

- ▶ EDS “hygiene:”
 - Keep movements of joints within normal anatomic range (70% of what you *can* do)
 - No contortions to entertain others
 - No locking of knees in hyperextension
 - No crossing of legs
 - Stay active; keep muscles strong to stabilize joints
 - Practice exercises to improve balance and proprioception
 - Balance of rest and activity
 - Pace yourself!

Self-management of pain

- ▶ EDS “hygiene:”
 - Be alert for sensitivities to foods and other substances
 - You may try limiting specific foods that may be troublesome –many have found dairy, gluten, GMOs, animal proteins, sugar, etc., to be a problem for them
 - If you do an elimination diet, be sure to keep a diet and symptom diary to track your progress.

Self-management of pain

- ▶ Mindfulness helps decrease pain via descending pathway
 - Meditation
 - Tai Chi or Yoga
 - Spiritual practices
 - Virtual Reality

Self-management of pain

- ▶ Discover your passion!
 - Doing something you love will distract your attention from the pain.
 - Social interaction and helping others does this as well.
 - It is often difficult to do these things if you are in a great deal of pain.

Self-management of pain

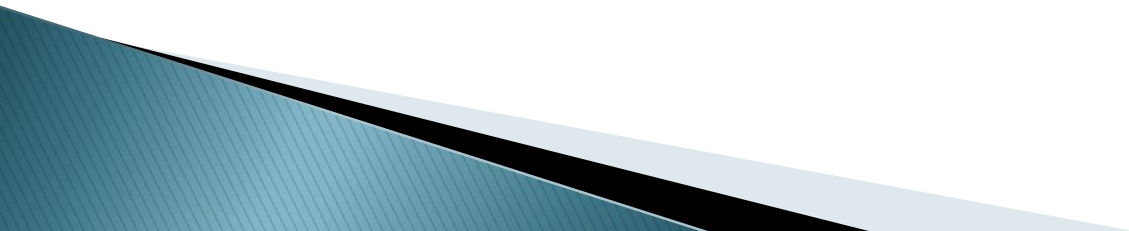
Get to know your body!

Listen to what it tells you!

Take time for yourself!



When you are feeling like this...



When you are feeling like this...

*...you need a support
group!*

Thank You!



-and good night!