

Hypermobility 108:  
Headaches,  
Migraines, and TMJ  
Pain associated with  
HSD, POTS and MCAS

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Slide handouts and recordings are available at:

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

Artist: Richard MacCormack, "Silent Scream"



# Who Am I?

- Professor Emeritus, Physical Therapy Department, Clarkson University
- Retired PT, St. Lawrence Health System, Potsdam NY
  - Clinical specialties: hypermobility, fibromyalgia, headaches, temporomandibular disorders
- Member: Ehlers-Danlos Society Medical and Scientific Board
- Chair: The Allied Health Working Group of the International Consortium of Ehlers-Danlos Syndromes and Hypermobility Spectrum Disorders
- Frequent presenter to professional and patient groups at national and international conferences
- Author of multiple review and research articles on hypermobility
- Author: “Pain Mechanisms in HSD” in Di Bon, *The Integral Movement Method for Hypermobility Management*
- Author: “Chronic Pain” chapter in *Physical Rehabilitation* textbook for PT students
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**I do not have any  
conflicts of interest to report**

Russek: Hypermobility 104p2 Exercise Modifications

# Hypermobility Lecture Series

- 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
- HSD 105: 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 associated with HSD, POTS and MCAS**
- HSD 109: Breathing disorders in HSD
- HSD 110: Lumbar instability
- HSD 111: Management of cervical instability (anatomy & diagnosis portion pre-recorded)
- HSD 112: The vagus nerve
- HSD 113: The importance of fascia
- HSD 114: Surgical and hospital precautions for HSD, POTS, MCAS
- HSD 115: Functional Neurological Disorder

I will refer to these if you want more info

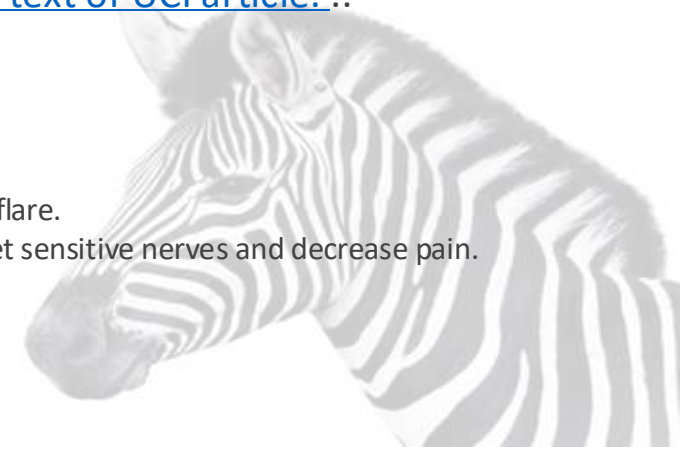


# Relevant Handouts Available



I will refer to these if you want more info

- <https://webspace.clarkson.edu/~lrussek/research.html>
- **Self-Care Strategies**
  - [Headache Trigger Points](#). Trigger points commonly causing headaches.
  - [Headache Diary](#).
  - [Temporomandibular Disorder \(TMD\)](#). TMJ self-care strategies. **Includes Dentist Precautions**
  - [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.
  - [Checklist for POTS self-care management](#).
  - [Suggestions for managing MCAS](#).
- **Cervical instability**
  - [Upper cervical Instability. \(UCI\)](#). People with hypermobility can sometimes have upper cervical instability. This handout is based on the recent article I co-authored. You can access the full article at [Full text of UCI article...](#)
  - A very comprehensive patient guide to [EDS cervical instability by EDSawareness](#).
- **Pain Management**
  - [Pain self-care plan](#). Create a pain self-care plan to improve your pain management.
  - [Pain flare management plan - PDF version](#). Create a flare management plan so you know what works when you have a flare.
  - [Heart-rate variability biofeedback](#). Biofeedback can increase activation of your parasympathetic nervous system to quiet sensitive nerves and decrease pain.
  - [Free chronic pain management apps for teens](#): Cognitive behavioral approaches to pain management.
  - [Chronic pain management app](#). Cognitive behavioral approaches to pain management. 6 weeks free access available.



# DISCLAIMER

- I cannot provide individual medical diagnosis or treatment 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.



# Objectives

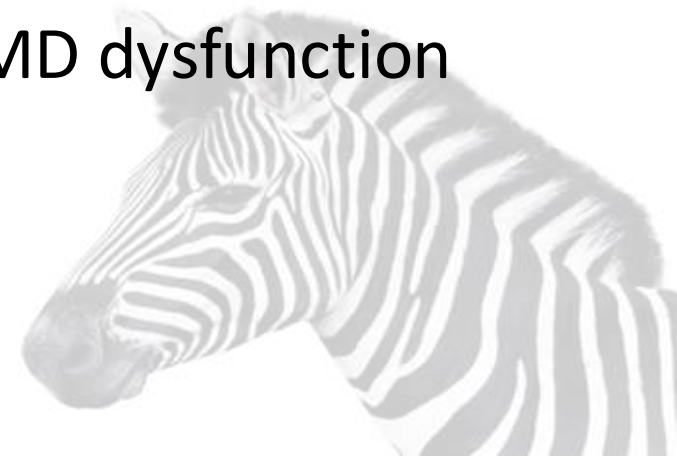
- **At the end of this session, participants will be able to:**
  1. Identify musculoskeletal factors contributing to headaches and TMD in individuals with hypermobility.
  2. Describe the types of HA common in POTS
  3. Describe the links between MCAS, histamine intolerance, and migraines
  4. Identify strategies to prevent HA, migraines, and TMD dysfunction

HA = headaches

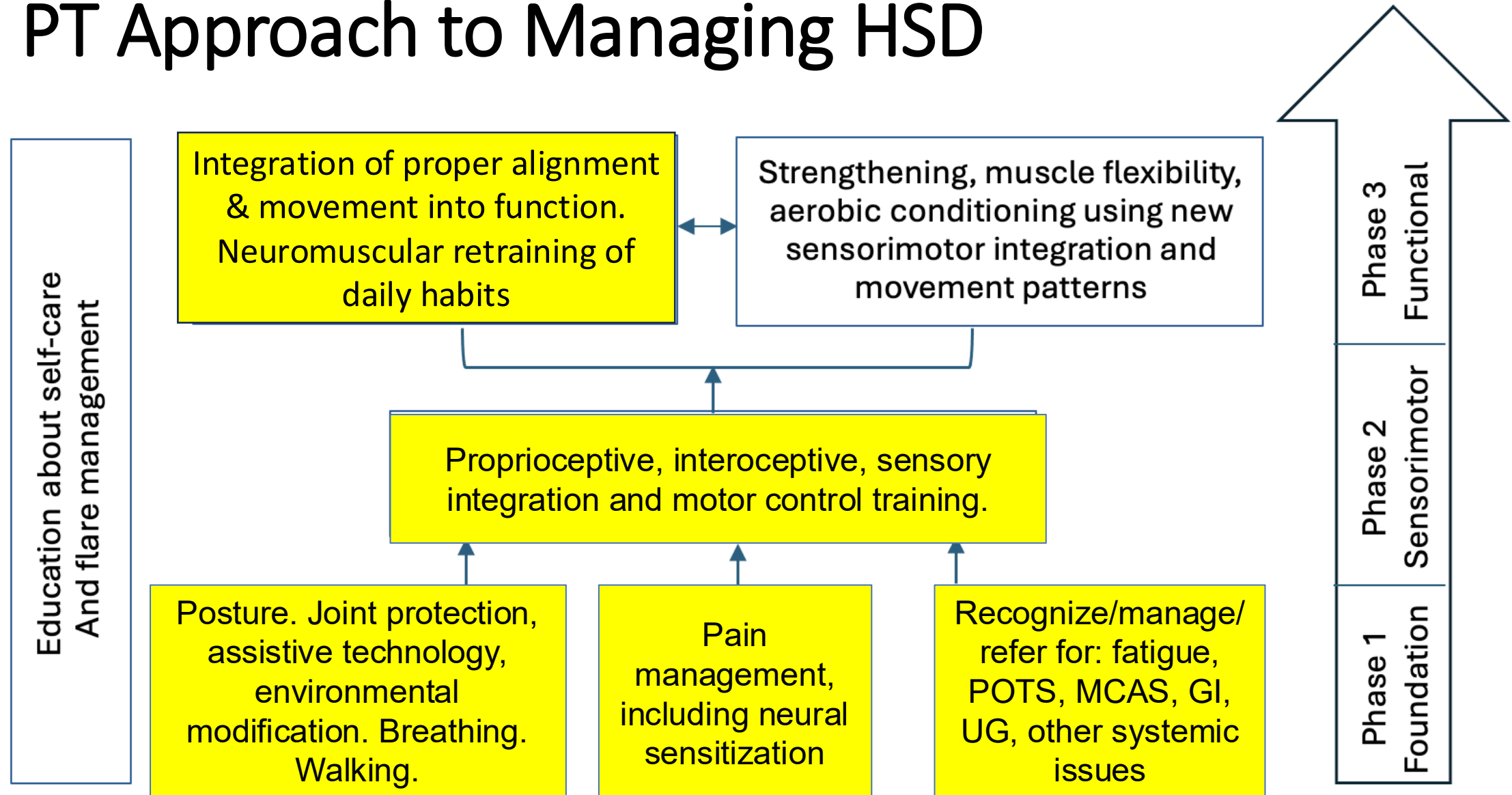
TMD = temporomandibular dysfunction

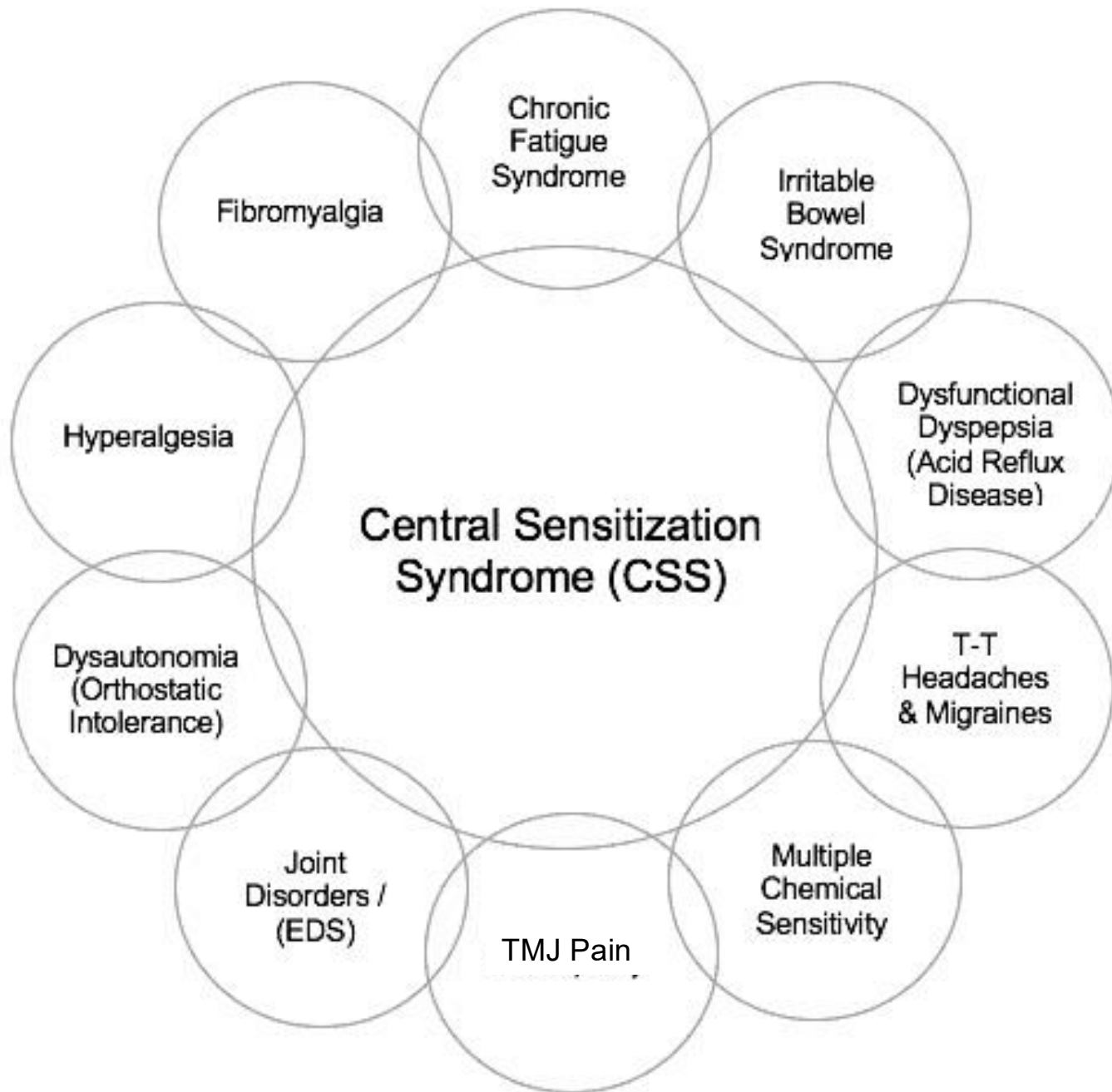
POTS = postural orthostatic tachycardia syndrome

MCAS = mast cell activation syndrome



# PT Approach to Managing HSD



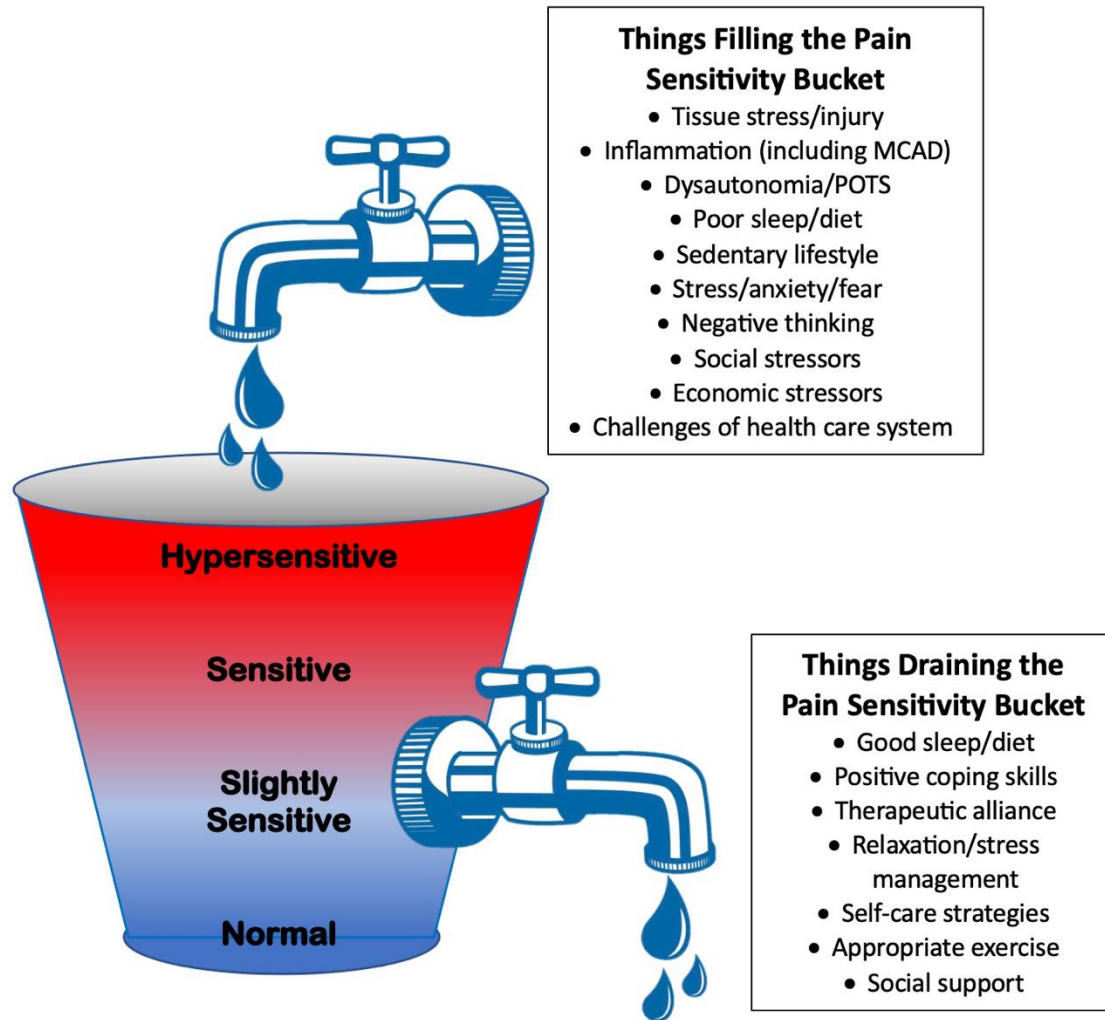


# Headache, Migraine, TMJ pain linked through Central Sensitization Syndrome

Skaper, 2017; Yoo, 2024;  
Diagram Based on Yunus, 2007



# The Pain Sensitivity “Bucket”



- Many factors contribute to Central Sensitization
- Multiple management approaches can decrease pain sensitivity
- The “Bucket” reflects the cumulative effects of all these factors

Russek, 2024

# Prevention Is The Best Treatment!

- The best way to manage HA, migraines, and TMD is to prevent them!
  - Medication and injections just make the symptoms go away
  - The causative factors are often still present, and can still cause damage
- Medications and injections are like using earplugs to 'fix' the bangs and squeaks your car makes



# Common Headaches (HA) in HSD

- HSD-related HA
  - Cervical instability, aggravated by posture
  - Temporomandibular joint disorders (TMD)
  - Compression of spinal cord or brain, CSF leak (Bharat, 2025)
  - Other related conditions: e.g., pelvic congestion syndrome (Smith, 2026)
- POTS-related HA/migraines
- MCAS-related HA/migraines

(Martin, 2014; Castori, 2015)





HA = headaches  
TMD = temporomandibular dysfunction  
POTS = postural orthostatic tachycardia syndrome  
MCAS = mast cell activation syndrome

Russek: HSD 108: Headaches, Migraines, TMD



# Types of Headaches: MD Perspective

## Headaches

<b>Sinus:</b> pain is behind browbone and/or cheekbones	<b>Cluster:</b> pain is in and around one eye	<b>Tension:</b> pain is like a band squeezing the head	<b>Migraine:</b> pain, nausea and visual changes are typical of classic form
			

ADAM.

**Cervicogenic headache (CGH)**  
CGH usually begins as a dull ache in the neck and radiates upward along the back of the head, almost always affecting just one side.



**Occipital neuralgia**  
Occipital neuralgia is characterized by sharp, painful, electric-shock-like sensations on the back of the head, neck, and ears.

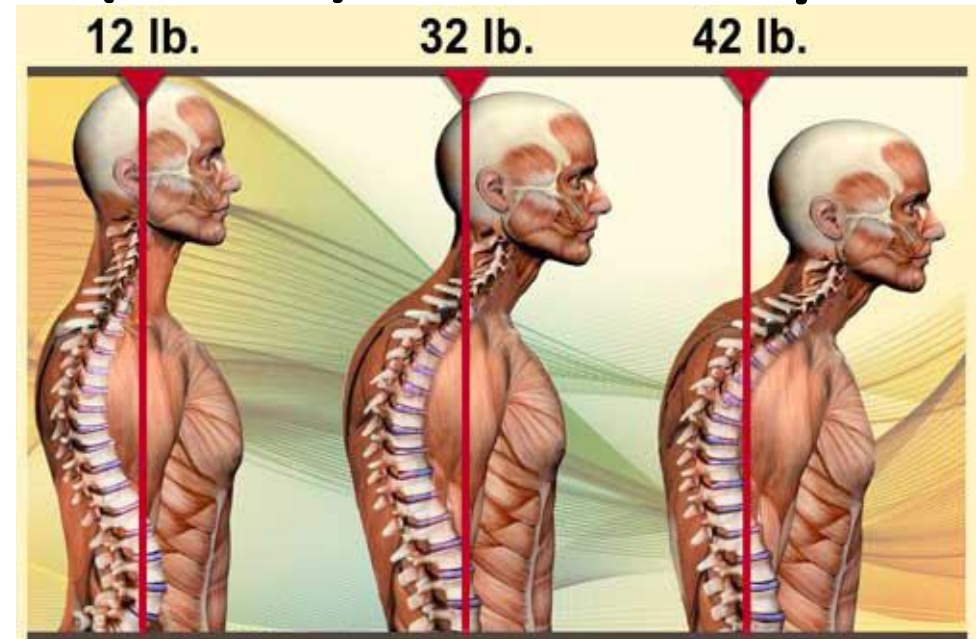
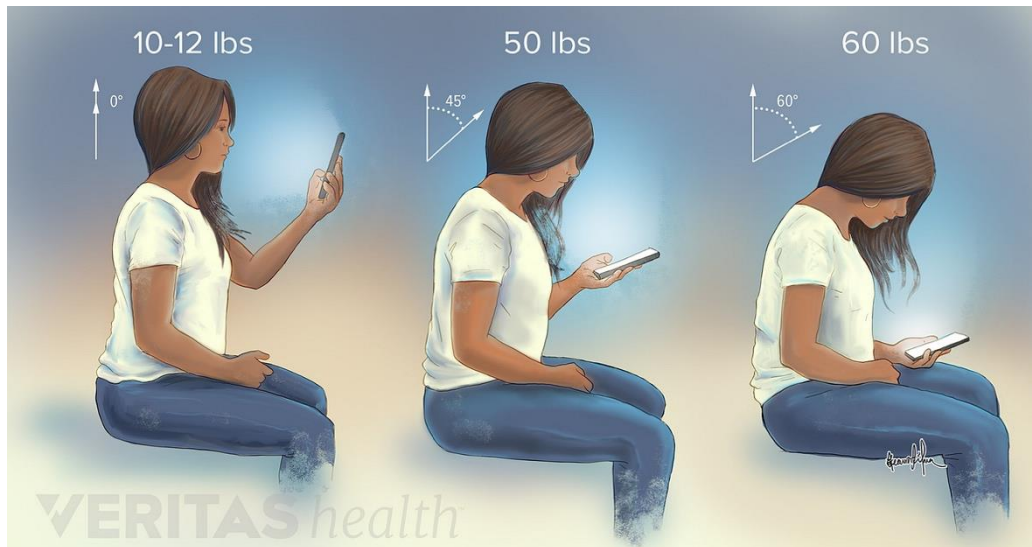


# Types of Headaches: PT Perspective

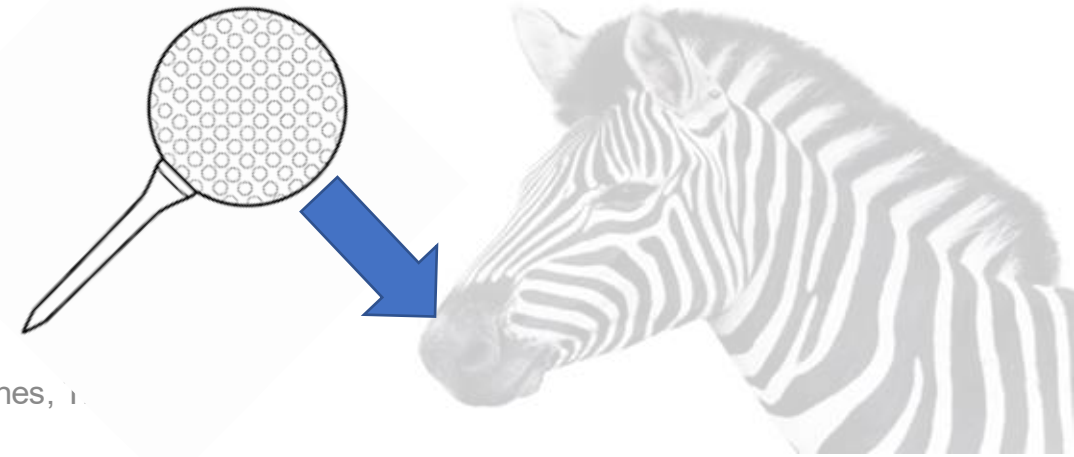
- Musculoskeletal HA from muscle spasm/trigger points, nerve compression, joint irritation
- POTS headaches due to autonomic nerve dysfunction or inadequate blood flow to brain
- Migraines from neuroinflammation (MCAS) or central sensitization (or look-alike from SCM trigger point)
- Facial pain due to TMD
- Central nervous system involvement (Chiari, cord compression, inadequate blood flow to the brain, etc.). These are MUCH less common than the above types of HA

# Effects of Poor Posture and/or (Mild) Instability

- Excessive forces on joints and muscles
- **Muscle guarding & trigger points (TrP)**
- Compression of nerves in the neck
- Compression of spinal cord structures



© 2010 www.erikdalton.com



<https://www.spine-health.com/conditions/neck-pain/text-neck-treatment-and-prevention>

Russek: HSD 108: Headaches, Migraines, ...

# Cervical Instability Headaches

Cervical instability handouts

Cord/brainstem compression

Cranial nerve compression

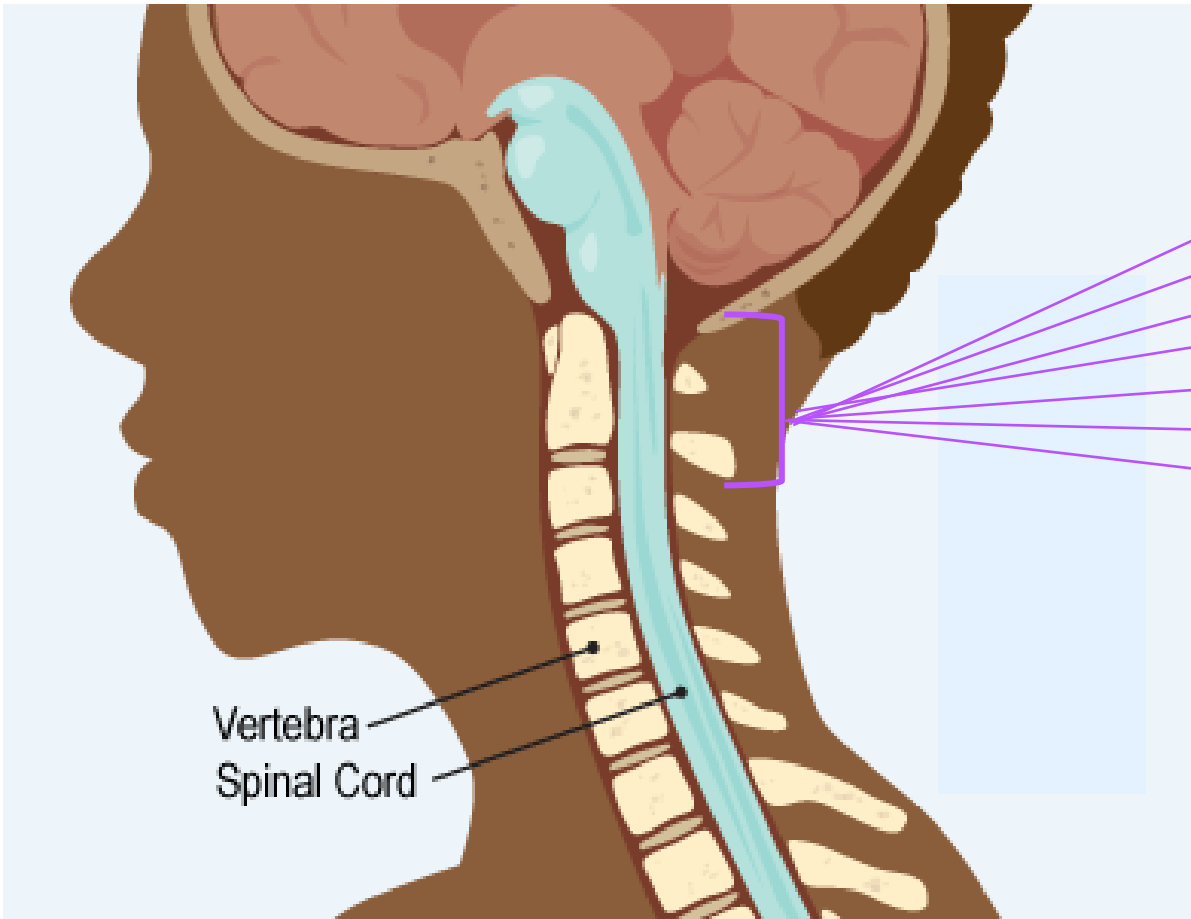
CSF blockage, Chiari

Vertebral or carotid artery occlusion

C1-C2 spinal nerves

Joint capsules

Trigger points and muscle spasm



All of these problems can cause headaches

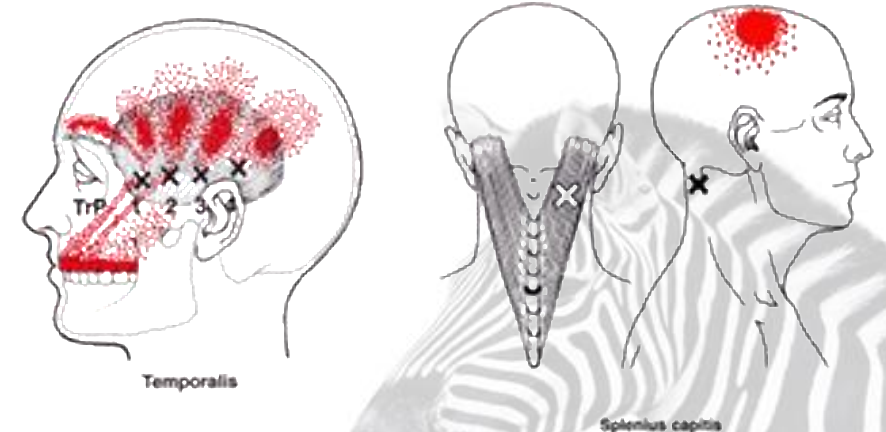
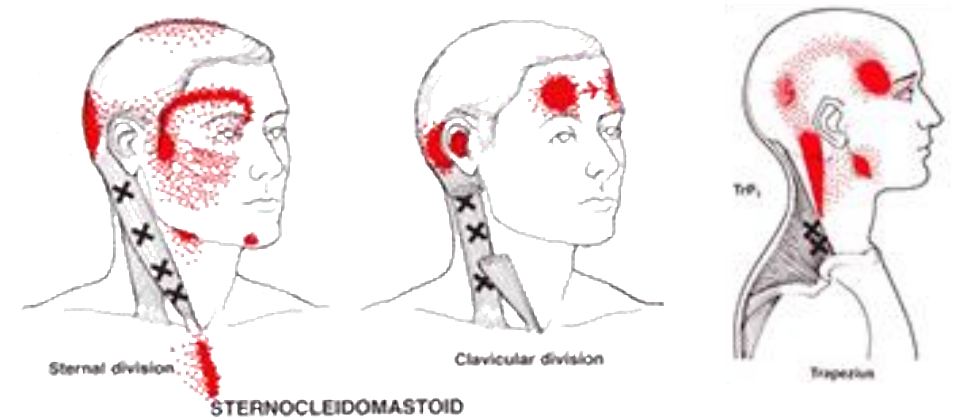
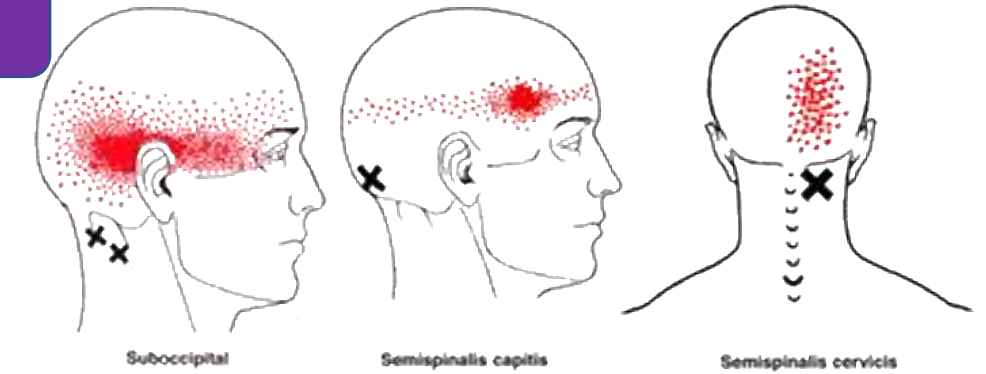


# Trigger Points (TrP)

- Created when superficial muscles are overworked because of:
  - Unstable joints
  - Poor posture
  - Poor body awareness (proprioception)
  - Weak/lazy deep neck stabilizing muscles

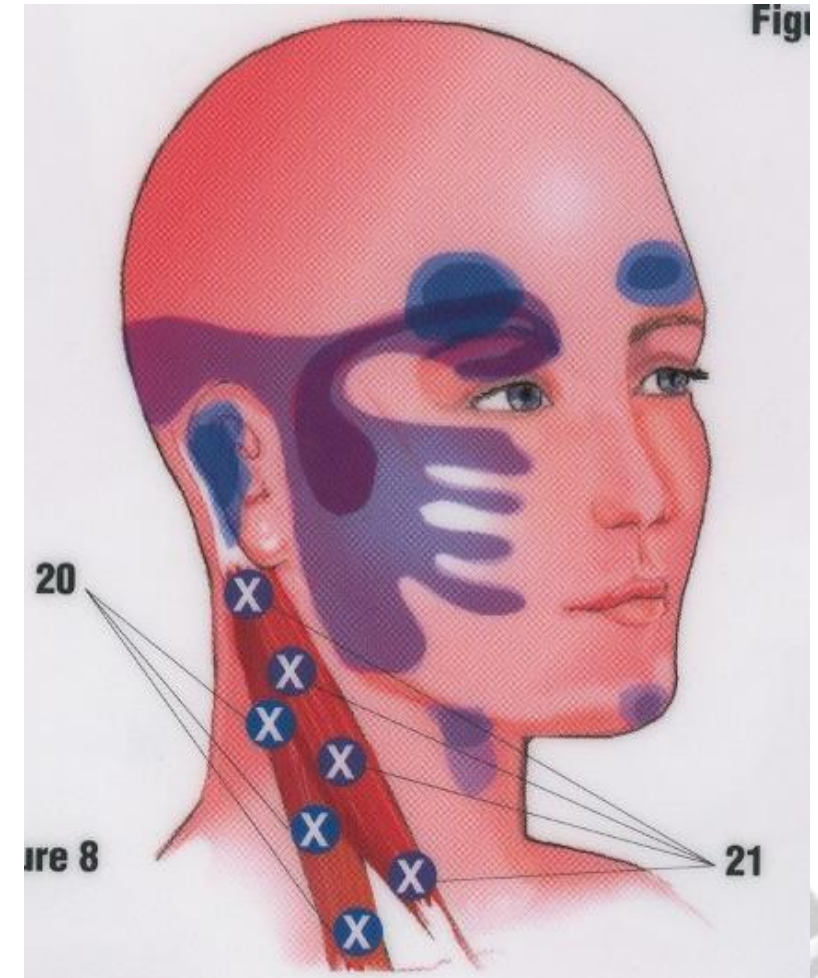
## Excellent resources on TrP:

- Valerie DeLaune, Pain Relief with Trigger Point Self-Help (2011)
- Valerie DeLaune, Trigger Point Therapy for Headache and Migraine: Your Self-Treatment Workbook for Pain Relief (2008)

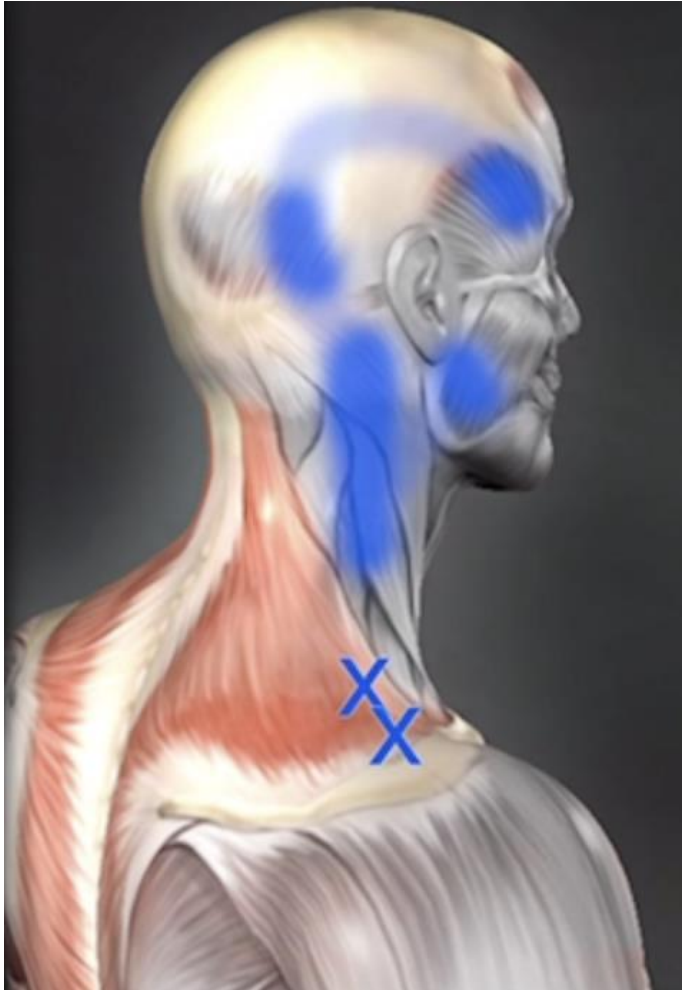


# SCM Trigger Points

- Other symptoms:
    - Ear ache, ear fullness, ringing in the ear
    - Dizziness and balance problems
    - Blurred vision, unilateral tearing/redness, drooping eyelid
    - Sinus pain or congestion on one or both sides.
    - Sore throat or dry cough
    - Nausea
  - Aggravating factors:
    - Whiplash, cervical instability, poor motor control
    - Forward head posture, forward shoulders
    - Chest breathing
    - Prolonged neck rotation, flexion or extension
- (All trigger point information from Travell & Simons)



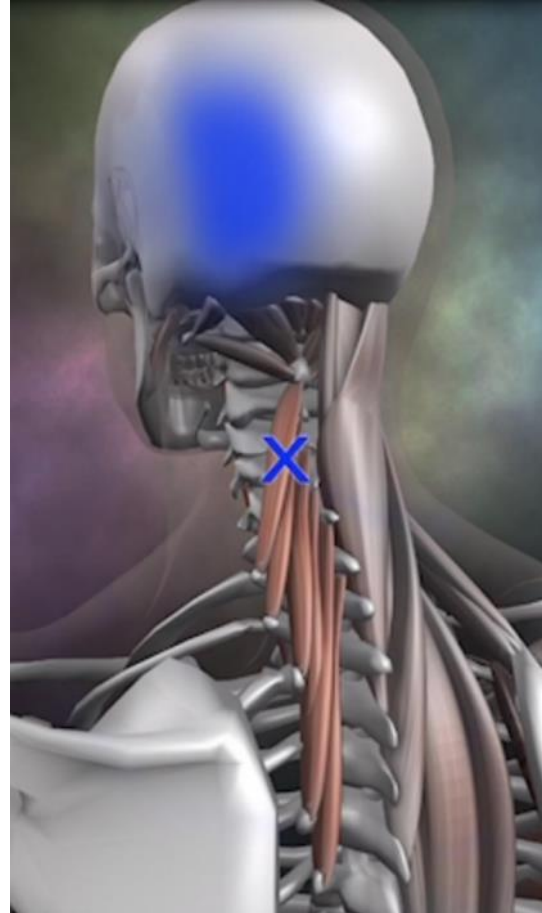
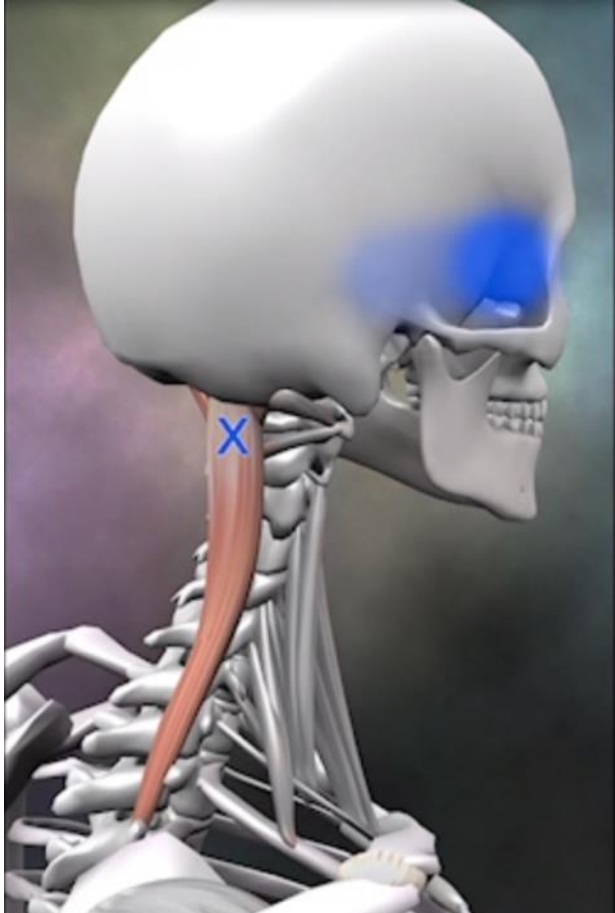
# Upper Trapezius TrP



- Symptoms other than headache:
  - Neck and upper back pain, but no neck stiffness
- Causes/perpetuating factors:
  - Whiplash injury or instability
  - Holding arms up, e.g., typing, working at a counter, assembly work
  - Tight chest muscles pulling shoulders forward
  - Shoulder tension from stress
  - Carrying a heavy purse or backpack or wearing a heavy coat
  - Bra straps pulling on the shoulders



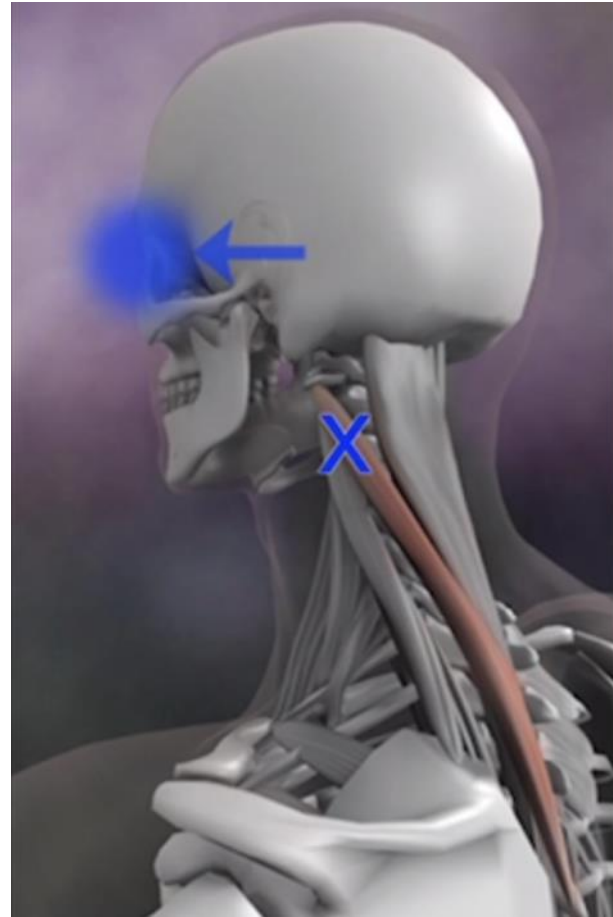
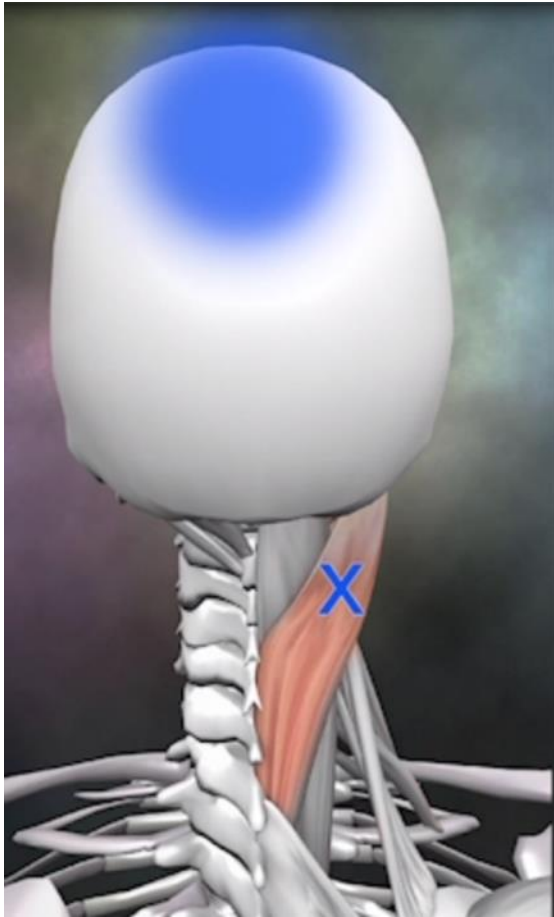
# Semispinalis Capitis & Cervicis



- Symptoms other than headache:
  - Neck pain and stiffness
  - Painful to rest head on pillow
  - Numbness, tingling or burning pain over the base of the scalp
- Causes/perpetuating factors:
  - Cervical instability
  - Injury, especially car accident
  - Forward head posture, rounded shoulders
  - Prolonged neck flexion – e.g., reading



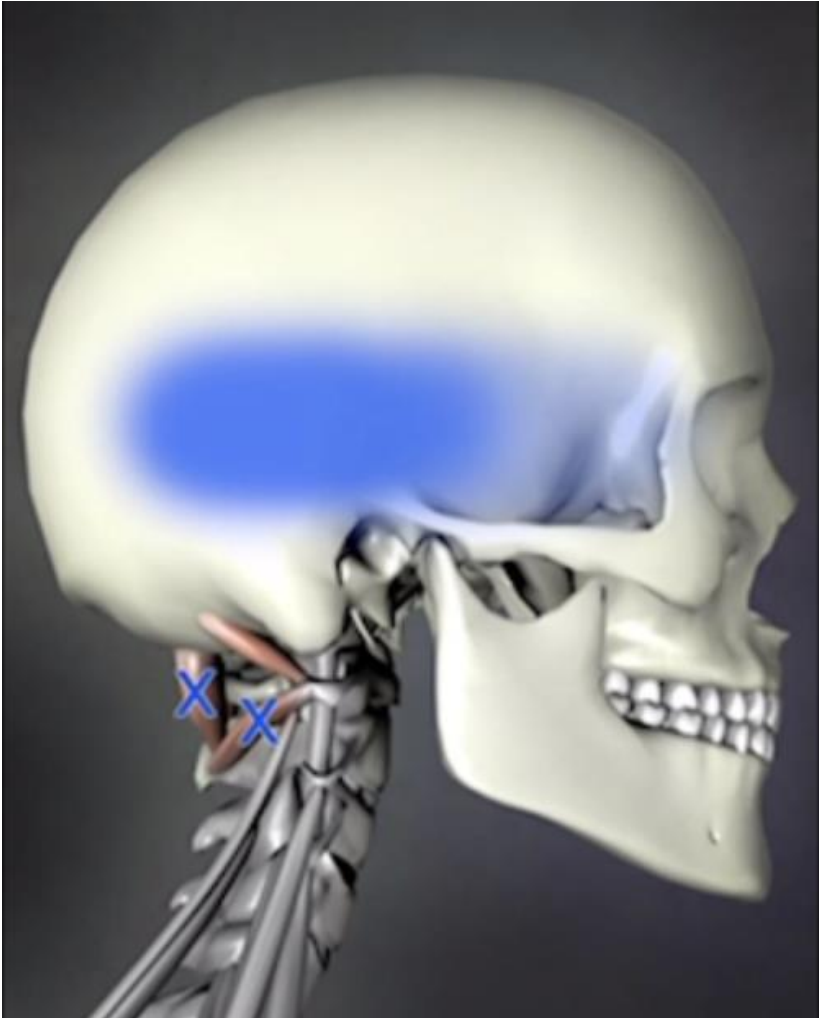
# Splenius Capitis & Cervicis



- Symptoms other than HA:
  - “Ache inside the skull”, retro-orbital pain
  - Unilateral blurred vision
  - Stiff neck
- Causes/perpetuating factors:
  - Cervical instability
  - Forward head or hunched posture
  - Poorly fit or prescription glasses
  - Whiplash-type injury
  - Heavy lifting/pulling



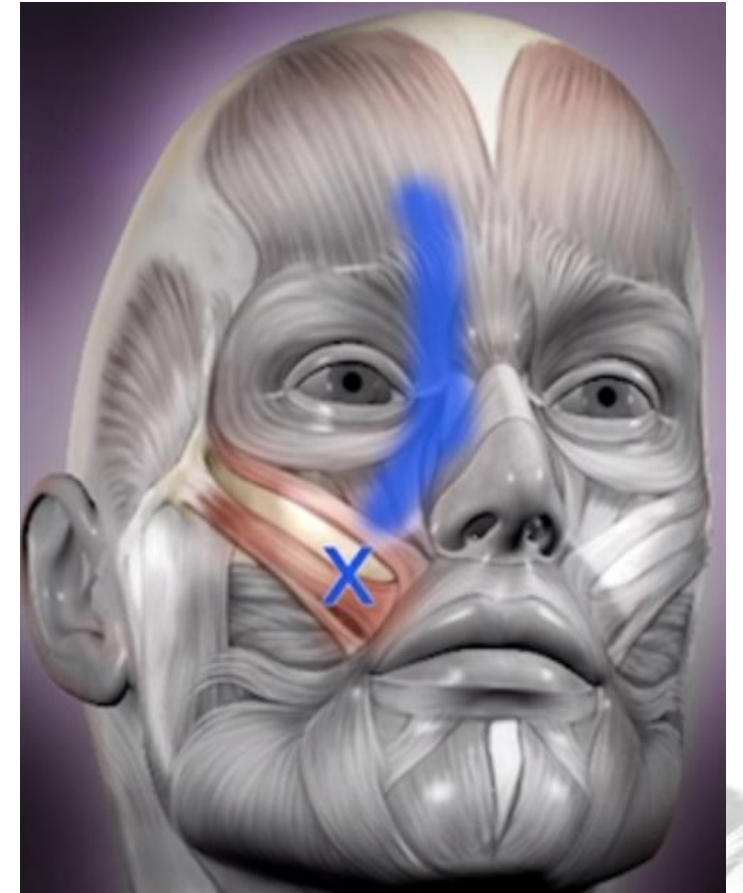
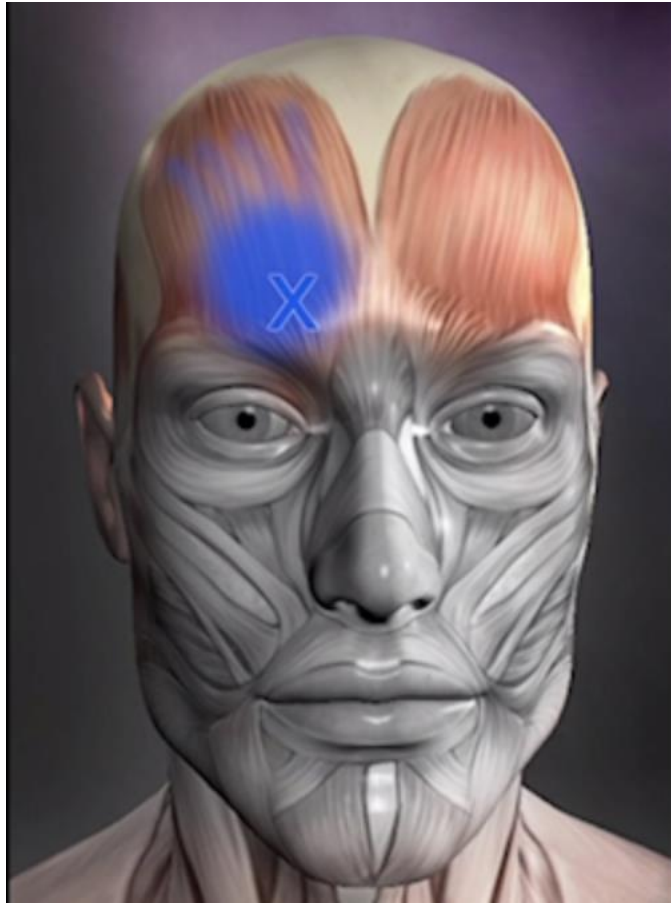
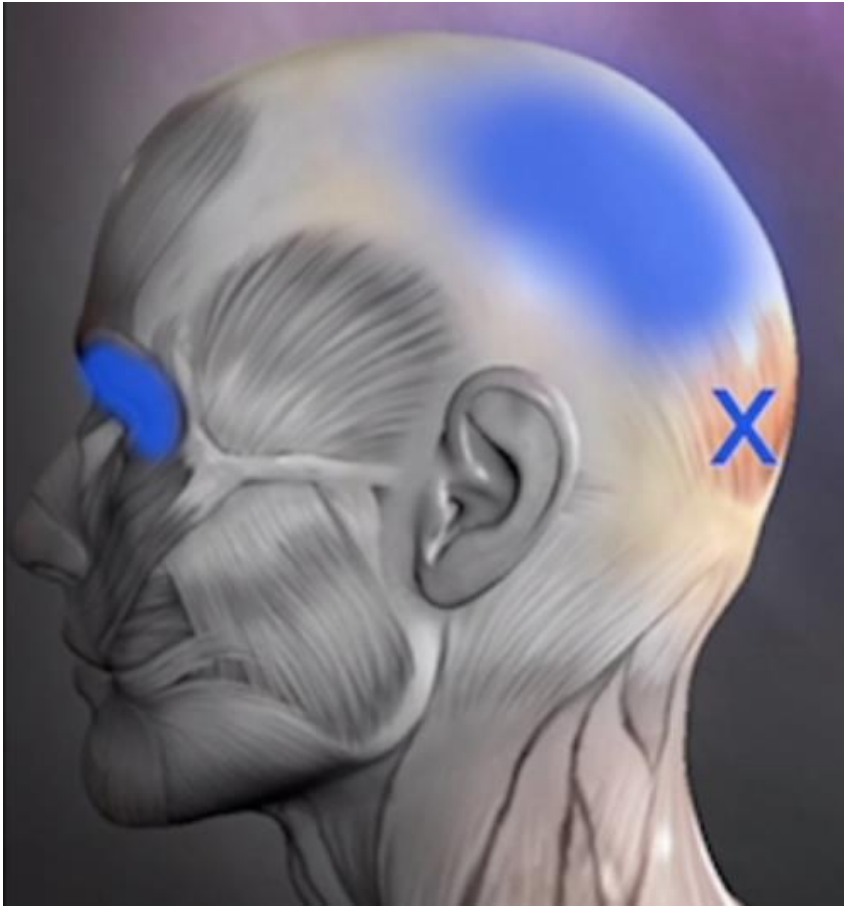
# Suboccipital Muscles



- Symptoms other than headache:
  - Pain laying head on pillow
  - Difficulty turning head to see in 'blind spot' while driving
- Causes and perpetuating factors:
  - Forward head posture
  - Vision problem or poorly fitting glasses
  - Turning of head to one side
  - Trauma to head or neck
  - Upper cervical instability

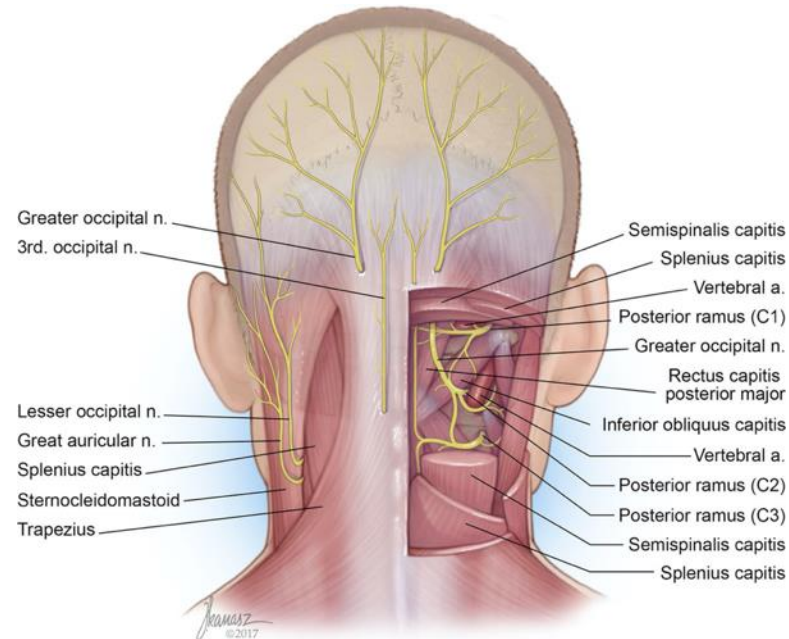
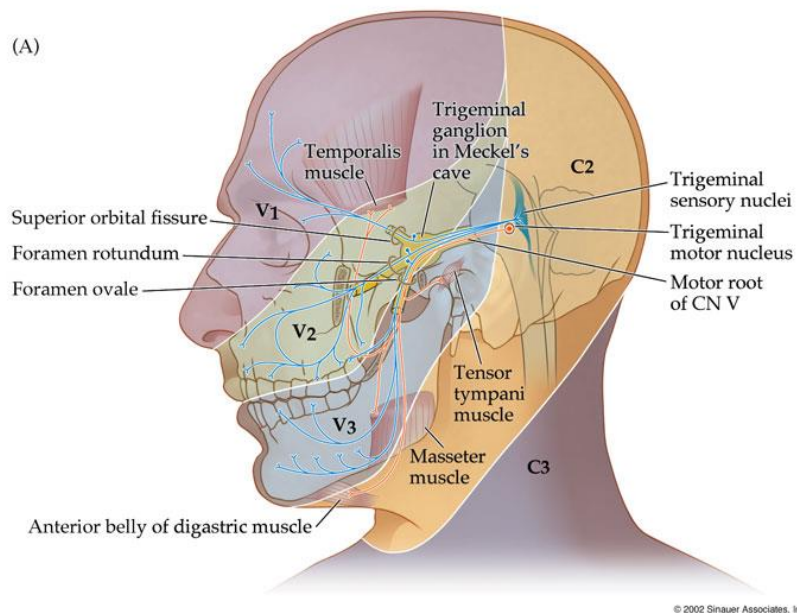


# Occipitofrontalis & Zygomaticus

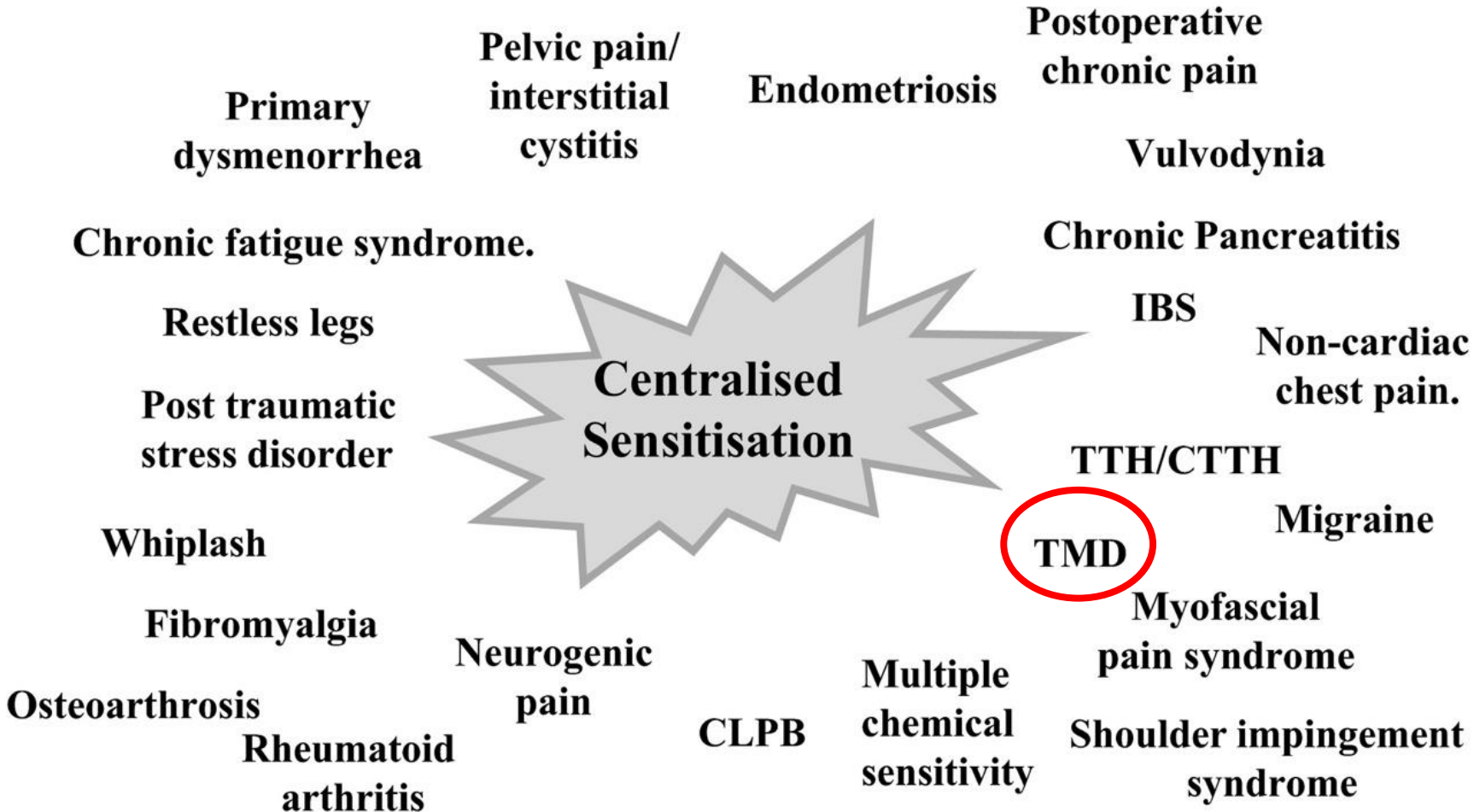


# Peripheral Nerve-Related Headaches

- Often called ‘occipital neuralgia’
- Compression of suboccipital nerve in neck fascia
- Or compression of C1, C2, C3 nerve roots at the upper neck joints
  - Due to instability, poor posture, poor motor control



# Manage Central Sensitization



- If you have several of these issues, you probably have a sensitive central nervous system.
- It is essential to calm the nervous system as part of your management.

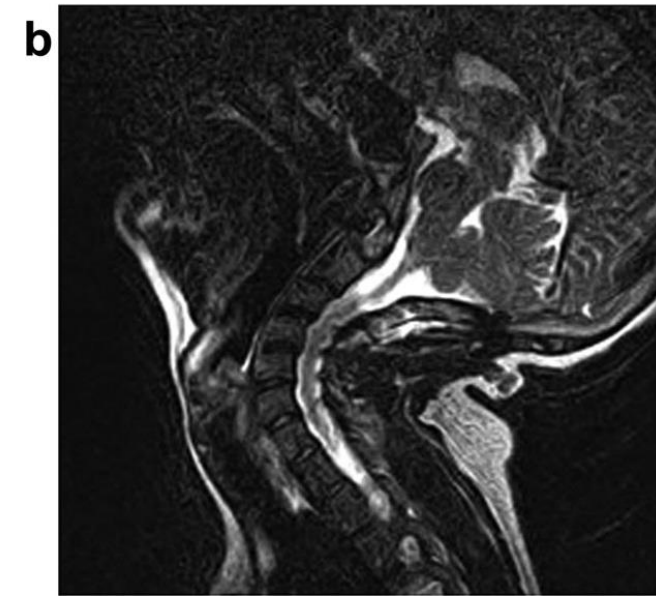
TMD=Temporomandibular Disorder

Arendt-Nielsen, 2017

# Central Nervous System Headaches

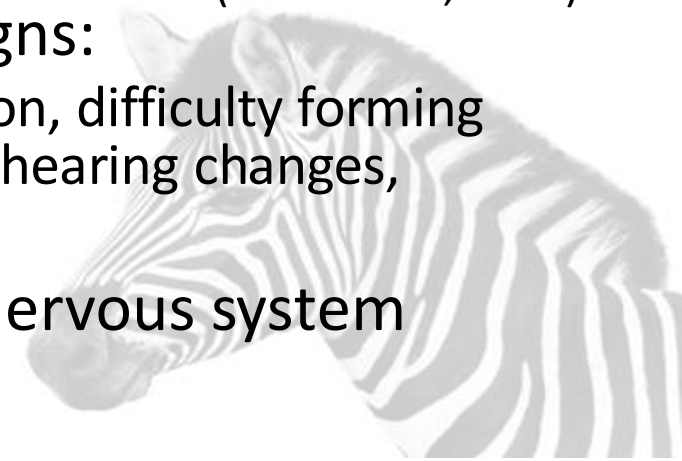
- Much less common than musculoskeletal headaches
- Possibilities:
  - Compression of the spinal cord by severely unstable spine
    - Craniocervical instability (CCI), cervical medullary syndrome
  - Brainstem sinking into the spinal cord
    - Chiari malformation type I
  - Intracranial hypertension or hypotension, cerebrospinal fluid leak
  - Tethered cord
- These problems usually present with more neurological signs:
  - ‘Hard’ neurological findings, unsteady gait, worsening coordination, difficulty forming words, HA worse when coughing or straining (Valsalva), visual or hearing changes, difficulty with quickly reversed movements (e.g., grip-release)
- See a specialist if you suspect HA associated with central nervous system

HSD111: Cervical Instability



<https://onlinelibrary.wiley.com/doi/full/10.1002/ajmg.c.31549>

(Henderson, 2017)



# Sleep Disorder Headaches

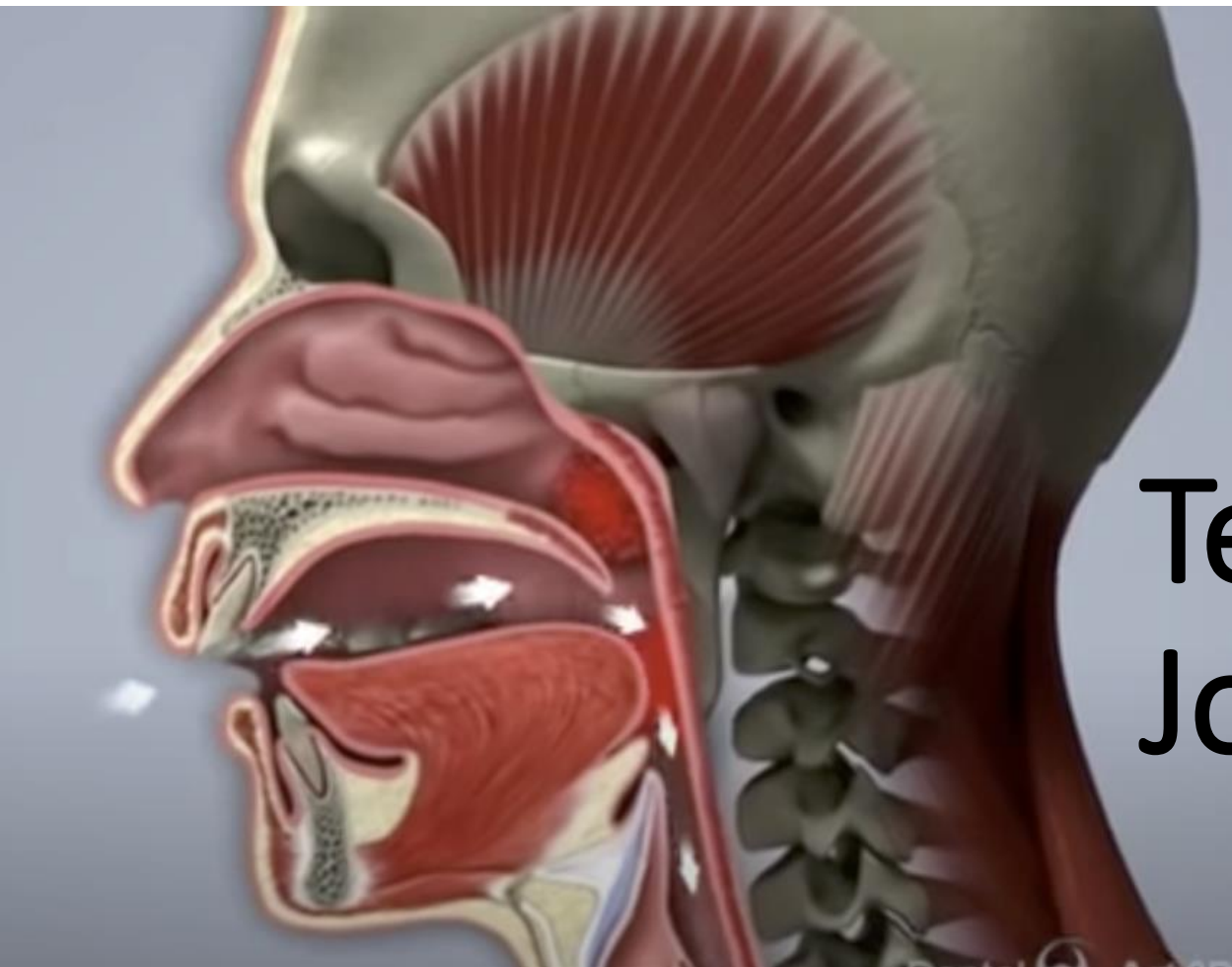
See HSD 107 for more on sleep problems in HSD

- Disrupted sleep can cause or aggravate headaches
- May be due to POTS:
  - POTS 'events' during the night disrupting sleep: tachycardia associated with adrenaline rush
  - Poor temperature control: feeling too hot and/or too cold
  - Anxiety
  - Restless leg syndrome
  - Needing to go to the toilet from drinking lots of fluids during the day
- May be due to HSD:
  - Sleep disordered breathing (e.g., sleep apnea), which is common in HSD
  - Discomfort in bed due to HSD
  - Clenching or grinding teeth while sleeping
- May be due to MCAS
  - Histamine seems to peak at 3-4 am, and may trigger an immune response or POTS flare

Sleep handout

- <https://www.potsuk.org/sleep>
- [https://americanheadachesociety.org/wp-content/uploads/2018/05/Sleep\\_Disorders\\_and\\_Headache\\_Toolbox.pdf](https://americanheadachesociety.org/wp-content/uploads/2018/05/Sleep_Disorders_and_Headache_Toolbox.pdf)



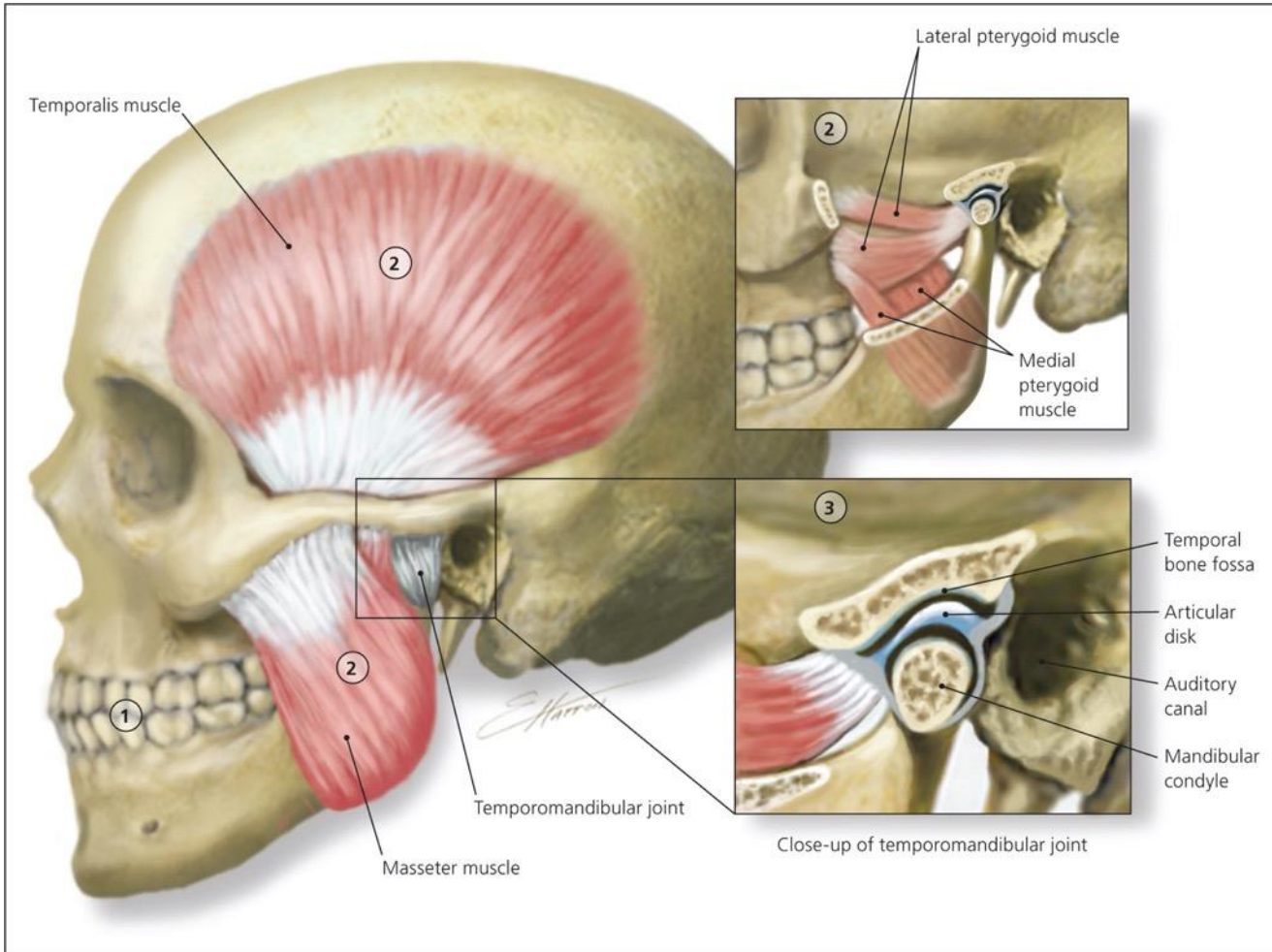


# Temporomandibular Joint Dysfunction



# Temporomandibular Joint

TMD handout



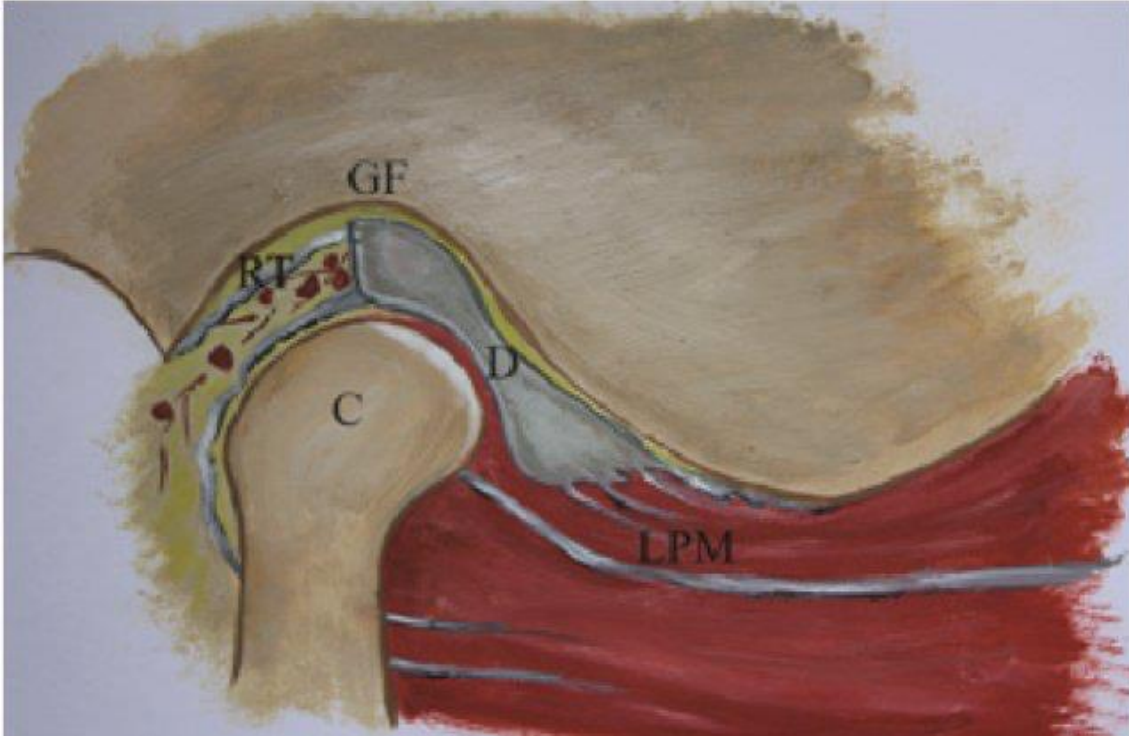
## • Contributing factors

- Hypermobility irritating joint
- Poor proprioception and motor control of TMJ
- Stress causing mm tension and trigger points
- Poor posture
- Habits, such as clenching
- Mouth breathing (<https://youtu.be/CBYwxndys2E>)
- Poor coordination or motor control of jaw muscles

HSD109: Breathing

(Gauer, 2015)

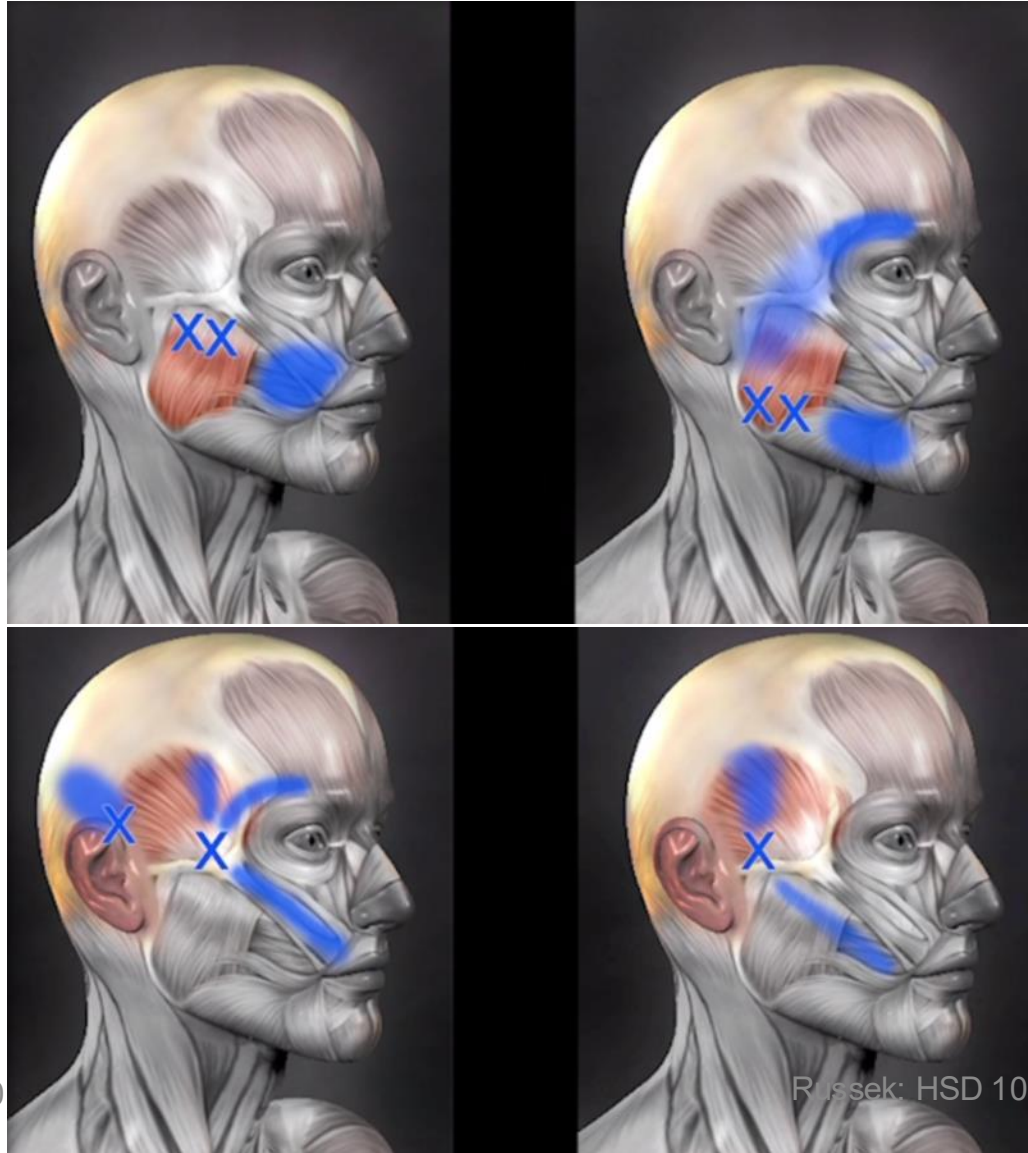
# Temporomandibular Disorders



GF-glenoid fossa; C-mandibular condyle; D-articular disc; RT-retrodiscal tissue; LPM-lateral pterygoid muscle.  
Talmaceanu, 2018

- Connective tissues holding disc are fragile and sensitive
- Disc subluxation/dislocation due to instability, aggravated by muscle spasm
  - Subluxation causes clicking of disc
  - Disc dislocation causes locking or limited opening range
- Lateral pterygoid may be overactive due to tense clenching muscles or mouth breathing; subluxe disc

# Masseter & Temporalis



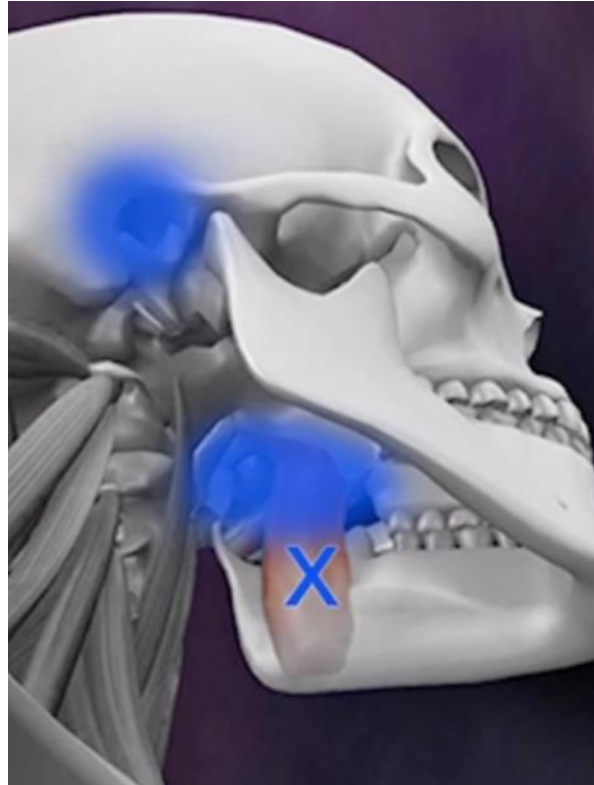
- Symptoms other than pain:
  - Tinnitus
  - Toothache, sensitive to hot/cold
  - Limited mouth opening
    - Inability to fit 2 knuckles in
  - Teeth do not seem to meet correctly
- Causes/perpetuating factors
  - Clenching jaw (bruxism), grinding teeth at night, chewing gum/ice
  - Muscle tension from stress
  - Dental work, opening mouth wide
  - Forward head posture
  - Proprioception deficits

# Lateral & Medial Pterygoids

Lateral Pterygoid



Medial Pterygoid



- Symptoms other than pain:
  - Mouth and pharynx pain
  - Trouble swallowing
  - Earache
  - Teeth do not seem to meet correctly
  - Sinusitis
- Causes/perpetuating factors
  - Clenching jaw (bruxism), grinding teeth at night, chewing gum/ice
  - Mouth breathing
  - Dental work
  - Muscle tension from stress
  - Forward head posture
  - Poor proprioception



# Speech, Swallowing, Chewing in HSD

- Speech and voice may also be affected by HSD
  - Mechanical changes in throat, tongue, vocal cords
  - Neurological issues affecting nerves to throat, tongue, vocal cords
  - Acid reflux affecting vocal cords
- Chewing problems are common
  - TMJ pain or dysfunction
  - Poor coordination in tongue and chewing muscles
- Swallowing problems in ~79% of HSD patients
  - Mechanical changes in throat, tongue, vocal cords
  - Neurological issues affecting nerves to throat, tongue, vocal cords

Williams, 2023





# Managing Musculoskeletal HA

# Managing Musculoskeletal HA

- Identify the sources of pain
  - Psychosocial factors as well as tissue sources
- Address the contributing factors, not just symptomatic tissues
  - E.g., TrP often develop to provide stability, inactivating a TrP without providing alternative stability is ineffective or harmful
- Use caution with muscle relaxers and Botox injections
  - These eliminate the compensation mechanism, but don't fix the cause.
  - Botox may increase instability. (Castori, 2012; Wang, 2018)
- Lidocaine injections into trigger points may be safer (Roy Sebastian, 2026)



# Decrease Perpetuating Factors

- Inappropriate postures

- Forward head posture or 'text neck'
- Poor work ergonomics – both static and motions
- Sleep positions
- Dental work

HSD105: Posture and Joint Protection

Posture handout

TMD handout

Sleep handout

- Stress & anxiety

- Breathing incorrectly:

- Using neck muscles instead of diaphragm
- Mouth breathing instead of nose breathing

Breathing handout



# Treating Musculoskeletal Headaches

- Manual therapy for muscles in spasm and trigger points
  - Neck and jaw muscles
  - You can learn many self-care manual techniques
- Self-care with ice, heat, TENS, topicals
- Exercises to improve posture, proprioception, motor control

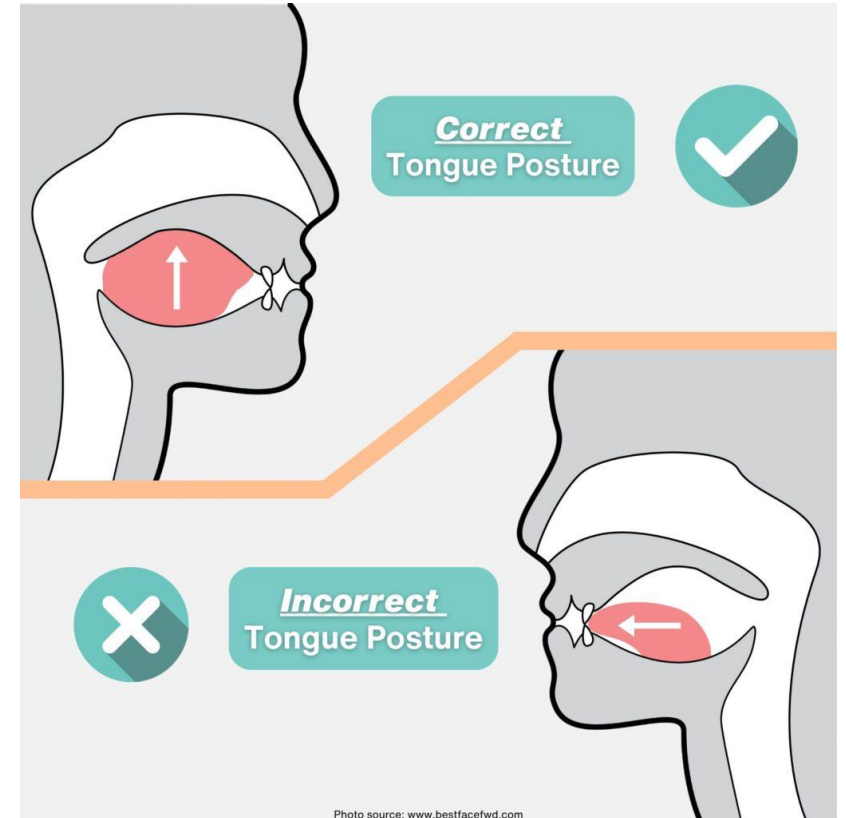
HSD103: Pain Management

HSD101: Cervical Instability



# TMJ and Tongue “Posture”

- The jaw and tongue have an ideal “posture” too!
- Tongue on roof of mouth, teeth apart, nose breathing
- Many muscle connect neck and jaw, so neck posture affects the jaw and tongue



# Avoid Flares at the Dentist

- I often have jaw and/or neck pain for several days even after routine dental procedures.
  - Please allow me to only open my mouth as much as necessary rather than as much as possible.
  - I may open my lower jaw and pull it backward rather than poke it forward, as pulling the jaw back protects my TMJ disc.
  - Please give me “jaw breaks” so I can rest during the procedure. Can we agree on a hand signal?
  - Could we use a “bite block” to help me rest my jaw opening muscles? Holding my jaw open, myself, overworks my jaw opening muscles and may cause my TMJ disc to slip out of place.
  - My gums tend to bleed a lot. This is a common problem in people with HSD/hEDS.
  - I have difficulty healing after dental work.
  - I have had experience with previous dentists who don't understand my condition.
  - I have experienced prior trauma associated with my jaw, and dental work is very stressful to me.
- (TMD handout also addresses POTS and cervical instability at the dentist)



# Managing TMJ Problems

- The mnemonic “RTTPB” for proper resting position for your TMJ:
  - **R** – Relax: Stop what you are doing. Allow the tension in your body to be released.
  - **T** – Teeth apart: Say the word "Emma." Keep jaw in this slightly opened position.
  - **T** – Tongue on the roof of your mouth, just behind your upper two front teeth.
  - **P** – Posture: Imagine two strings. One string pulls straight up from the crown of your head to the ceiling; the second string pulls up and out from your breastbone.
  - **B** – Breathing: Diaphragmatic (from your abdomen). Nose breathing (not mouth breathing)
- To decrease pain and inflammation in the TMJ: ice, heat, topical analgesic rubs
- Appropriate exercise
- Stress management, to decrease muscle tension, self-massage of jaw muscles
- Sometimes, a dental appliance (mouthpiece) for night-time.

(Shaffer, 2014; Gauer, 2015)



# TMD Self-Care

**Self-massage** can be helpful. Here are some video suggestions. Stop doing any technique that is uncomfortable or painful.

- This video is specifically designed for TMJD discomfort to relax the jaw muscles: Racheal Richards Jaw Relaxation (<https://youtu.be/ABDaeO1Z6Ds>)
- Face massage for relaxation mind and jaw: Racheal Richards Jaw Relaxation, Headache Relief and General Anxiety Relief (<https://youtu.be/bNVu4-SpQp8>)
- Rachel Richards 2 minute quick jaw relaxation Technique: (<https://youtu.be/oQsFSqDafOA>)
- This is a guided meditation specifically designed for TMJ relaxation and pain relief. (<https://youtu.be/AeNAcYnDvFY>)



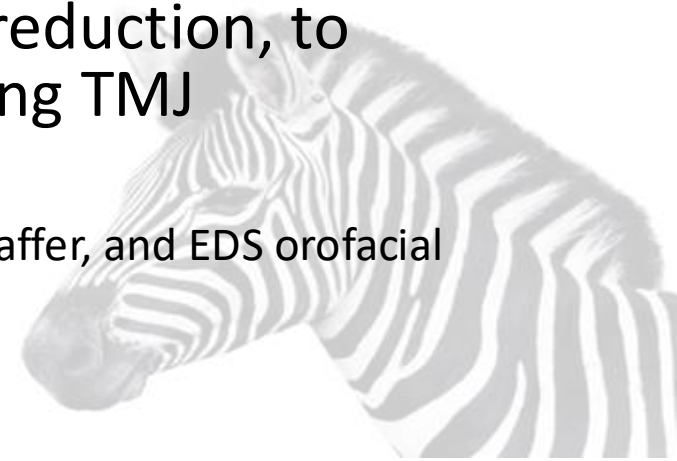
# Disc Relocation Maneuver



- Open until you hear the first click, then slowly close your mouth bringing your front teeth tip-to-tip (your jaw will be jugged forward slightly).
- If you can touch tip-to-tip without hearing the closing (reciprocal) click, you have 'relocated' the disc.
- Gently pull your jaw backwards to draw the disc back, so it is properly positioned when your mouth is closed.
- To keep the disc in place, don't open your mouth further than you can with your relaxed tongue still touching the top of your mouth.
- LR Note: This is something I have found effective; there is no research evidence for it.

# Dental Appliances

- Flat plane splints covering all teeth are used for joint inflammation. Because it will not decrease clenching/grinding, it won't directly help myofascial pain, but decreased joint pain may decrease clenching.
- Splints that don't cover all teeth risk changing the bite. Only use short term for acute joint pain.
- Nociceptive Trigeminal Inhibition (NTI) splints can damage teeth and have a risk of choking. Best to avoid.
- Anterior repositioning splints are for disc dislocation with reduction, to restore disc position, but need to be careful about stretching TMJ ligaments.
- (I don't know much about appliances, but this slide was approved by Dr. Rebecca Shaffer, and EDS orofacial pain specialist)





# Questions?



# Dysautonomia & POTS Headaches



# POTS-Related Headaches

See HSD 102 for  
more on POTS

- Headaches and migraines are common in POTS: 41-96%
- Migraines most common in POTS
- Coat-hanger HA
- Sleep-disturbance HA
  
- POTS is commonly overlooked in patients with migraine
  
- (Cook, 2018; Wig, 2019; Fedorowski, 2019; Iser, 2022)



# Treating Migraine with POTS

Table 2.—Treatment for Migraine and POTS Patients

Wig, 2019

Steps	Overlapping Treatment	Differentiating
1. Lifestyle modifications Avoid triggers	<ul style="list-style-type: none"> <li>• Increase water intake &gt;2-3 L/day<sup>35,38</sup></li> <li>• Increase salt intake &gt;10-12 g/day<sup>39</sup></li> <li>• Sleep hygiene<sup>35,36</sup></li> <li>• Routine meal schedules<sup>36</sup></li> <li>• Graded aerobic exercises<sup>35,36</sup></li> <li>• Postural counter manoeuvres that use the skeletal muscles as a pump to improve venous return (eg, standing with legs crossed, squatting, and sitting in the knee-chest position)<sup>40</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Caffeine and artificial sweeteners are avoided in POTS, whereas in migraineurs caffeine may be used in acute attacks within reason due to its vasoconstriction properties, but it may trigger migraine in excess or caffeine withdrawal. Artificial sweeteners are avoided in migraine<sup>43</sup></li> </ul>
2. Complementary and alternative therapies	<ul style="list-style-type: none"> <li>• Relaxation training, cognitive behavioral therapy, biofeedback, and acupuncture<sup>36,41</sup></li> <li>• Melatonin<sup>35,42</sup></li> </ul>	<ul style="list-style-type: none"> <li>• Nutraceuticals: B2, coenzyme Q10, magnesium, butterbur, feverfew (M)<sup>37</sup> and Vitamin B12, licorice root, and Vitamin C (P)<sup>44-46</sup></li> <li>• Devices: (Neurostimulation, transcranial magnetic stimulation)<sup>38</sup> (M)</li> </ul>
3. Others		<ul style="list-style-type: none"> <li>• Procedures (botulinum toxin and nerve blocks)<sup>36</sup> (M)</li> </ul>

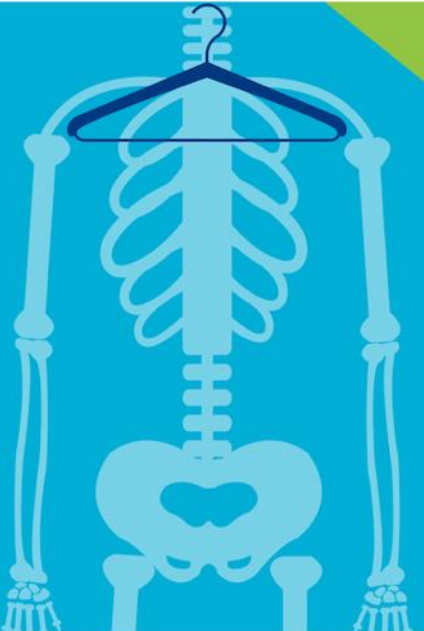


# "Coat-Hanger Headaches"

**DYSAUTONOMIA AWARENESS MONTH**

**SUBOCCIPITAL & PARACERVICAL "COAT HANGER PAIN" THAT WORSENS WHILE UPRIGHT IS COMMON IN DYSAUTONOMIA**

Believed to be caused by poor blood flow to the muscles of the upper back and neck.



[DysautonomiaInternational.org](https://dysautonomiainternational.org)

DYSAUTONOMIA INTERNATIONAL  
AWARENESS ADVOCACY ADVANCEMENT

- Pain in distribution of coat-hanger: occiput, neck, shoulders
- Present in 59-93% of people with POTS
- Aggravated by orthostatic changes: standing or sitting.
- Relief after 5-20 min recumbent.
- May precede syncope (passing out)
- Occurs if hypotension is NOT compensated by increased HR.

(Martin, 2014; Khurana, 2018)

# Managing Coat-Hanger Headaches

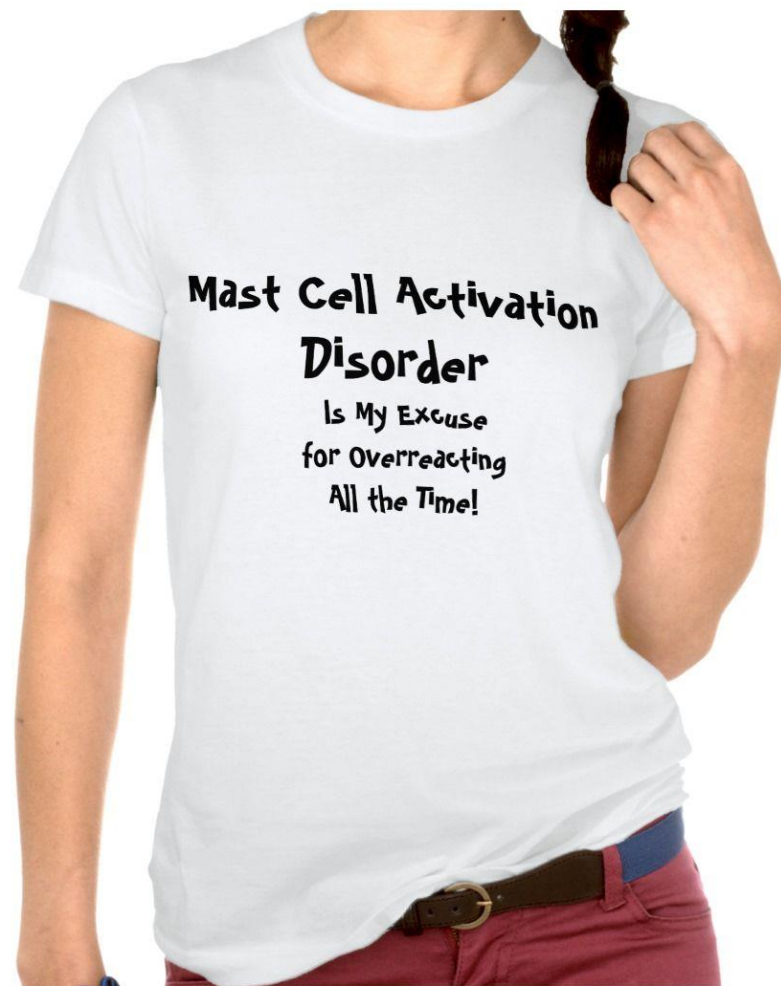
POTS Checklist handout

- Use usual POTS management strategies:
  - Avoid triggers, e.g., large carb meals, heat, hot showers, etc.
  - Hydration
  - Redirecting blood flow: lying supine with feet up, squat, cross legs, etc.
- Avoid medications that increase orthostatic hypotension
  - E.g., beta blockers
- Use medications that increase BP
  - E.g., fludrocortisone, midodrine, droxidopa, pyridostigmine

• (Khurana, 2018)



Mast Cell Activation  
Syndrome/Disorder  
MCAS/MCAD  
Headaches

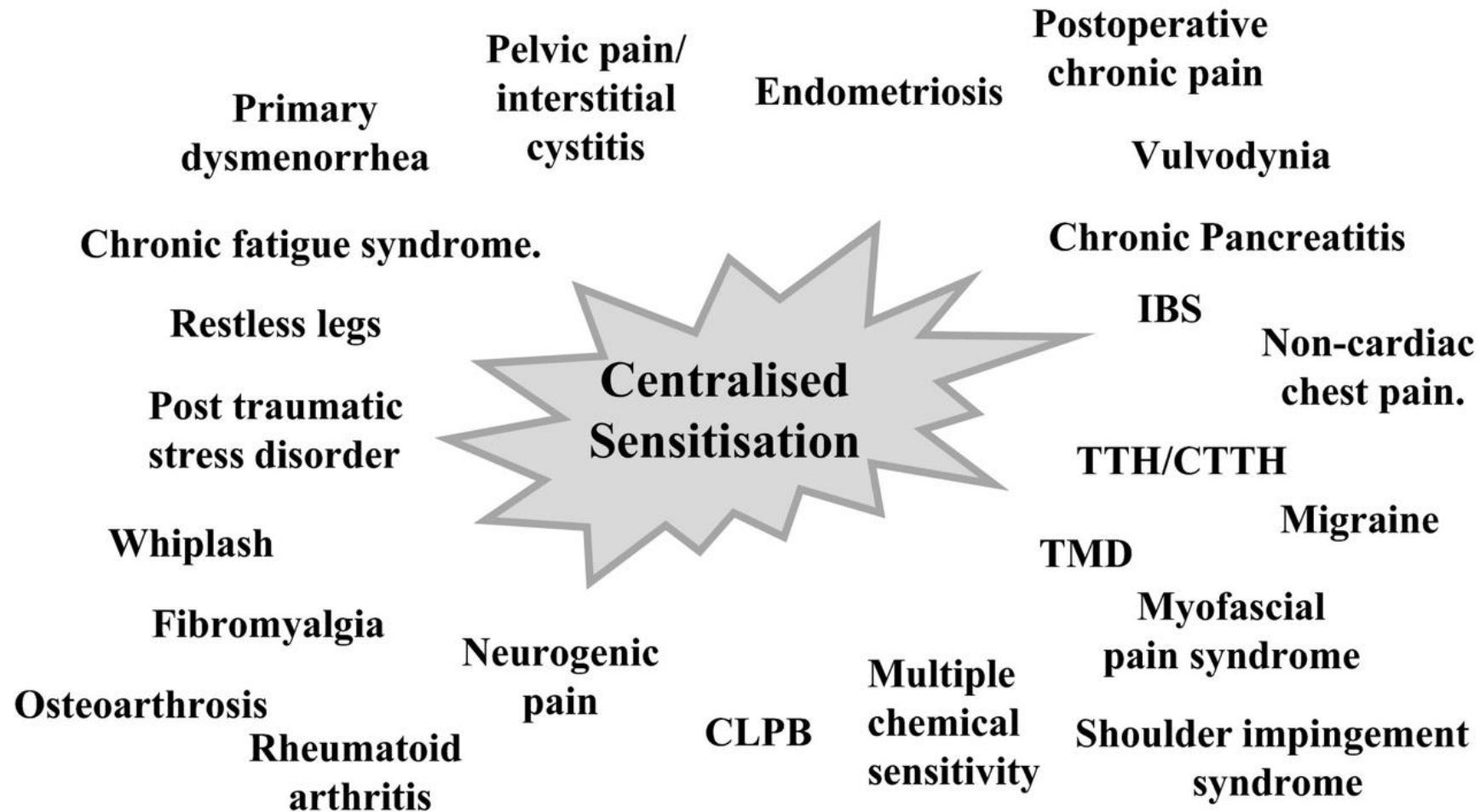


Mast Cell Activation Disorder E... by *TwoRareZebras*

**Zazzle**

# Central Sensitization

MCAS causes central sensitization (Wirz, 2017)



<https://onlinelibrary.wiley.com/doi/full/10.1002/ejp.1140>



# Mast Cell Activation and Migraines

See HSD 102 for more  
on MCAS

- HA/migraine reported in 63% of people with MCAD (Afrin, 2017)
- Migraines are a neuro-inflammatory process associated with mast cell activity and excess histamine in the CNS
  - Migraineurs have decreased serum diamine oxidase (DAO)
  - Migraines respond to DAO supplements that reduce histamine absorption in the gut (Izquierdo-Casas, 2018; Izquierdo-Casas, 2019)
- Triggers for MCAD and migraines are very similar
- Migraines and MCAD are both common in central sensitization (Ramachandran, 2018; Conti, 2018; Arendt-Nielsen, 2017)

See HSD 106 for  
more on histamine



See HSD 102 for  
more on MCAS

# Migraine & MCAS Triggers

## Migraines:

- Stress
- Changes in sleep schedule
- Alcohol (especially red wine)
- Diet: histamine, MSG, chocolate, cheese, dairy, artificial sweeteners, cured meats
- Strong smells
- Sunlight
- Dehydration
- Hormones
- Caffeine
- Weather changes
- (<https://americanmigrainefoundation.org/resource-library/top-10-migraine-triggers/>)

## Mast Cell Activation:

- Stress
- Fatigue
- Alcohol (especially red wine)
- Diet: ripe cheese, dried meat or sausage, tomato, nuts, pickled foods, cured meats fish, food additives
- Strong smells
- Sunlight
- Exercise
- Medications (NSAIDs, antibiotics, opioids)
- Insect and other venoms
- Infections (viral, bacterial, fungal)
- Mechanical irritation, friction
- (<https://tmsforacure.org/symptoms/symptoms-and-triggers-of-mast-cell-activation/>)



# Histamine Intolerance is Part of MCAS

- MCAS involves histamine intolerance – your body over-reacting to histamine
- Headaches & migraines are very common in histamine intolerance
- Histamine may be released by mast cells, or eaten in foods
- Some people lack the enzyme that normally breaks down histamine in the gut (diamine oxidase - DAO)
- Good overview: <https://www.entandallergy.com/blog-posts/details/your-mystery-food-sensitivity-might-actually-be-a-histamine-intolerance#>

See HSD 106 for more on DAO

Reese, 2018; Comas-Baste, 2020



See HSD 106 for more on  
MCAS and diet

# Histamine in Foods

## Foods that have been reported to have higher levels of histamine:

- Alcohol
- Eggplant
- Pickled or canned foods – sauerkrauts
- Matured cheeses
- Smoked meat products – salami, ham, sausages....
- Shellfish
- Beans and pulses – chickpeas, soy flour
- Long-stored nuts – e.g peanuts, cashew nuts, almonds, pistachio
- Chocolates and other cocoa based products
- Seitan
- Rice vinegar
- Ready meals
- Salty snacks, sweets with preservatives and artificial colourings

<https://www.histamineintolerance.org.uk/about/the-food-diary/the-food-list/>

## Foods that have been reported to have released histamine (histamine releasers):

- Most citrus fruits – lemon, lime, oranges...
- Cocoa and chocolate
- Walnuts, peanuts
- Papaya, pineapples, plums, kiwi and bananas
- Legumes
- Tomatoes
- Wheat germ
- Most vinegars
- Additives – benzoate, sulphites, nitrites, glutamate, food dyes

## Foods that have been reported to block the diamine oxidase (DAO) enzyme:

- Alcohol
- Black tea
- Energy drinks
- Mate tea



# Managing Histamine

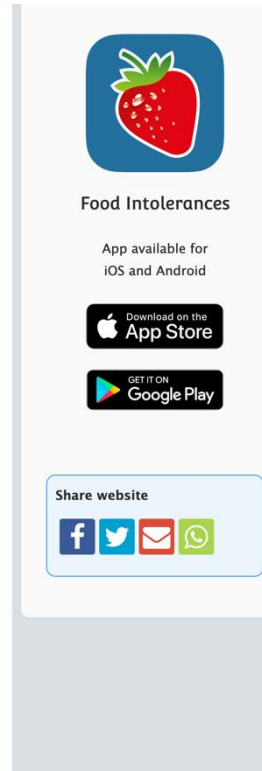
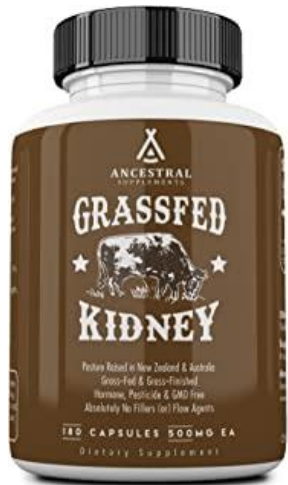
## Food Intolerances App

Low FODMAP Diet, Histamine Intolerance & more

The app Food Intolerances was developed to help everyone who has been diagnosed with a food intolerance and helps you answer the often difficult question: What can I still eat? The food lists range from essential goods to exotic products and enable you to add more variety to your diet. The app also covers food additives, and offers multiple profiles so you can adapt it exactly to your needs.

## Lactose intolerance

Lactose intolerance is a very common condition. Lactose can be found in dairy products and many processed foods. Our app indicates the lactose content accompanied by detailed remarks that help you choose suitable foods.



- Minimize histamine containing foods
  - Avoidance diet for 4 weeks
  - Add back foods one by one
- Take DAO supplements
  - People with migraines are twice as likely to have DAO deficiency
  - Research shows DAO decreases migraines in people with low DAO  
Izquierdo-Casas, 2018,
- Take over-the-counter 2019 antihistamine medications
- Prescription antihistamines

# Caffeine and Headaches

- Primarily works as an “analgesic adjuvant” amplifying benefits of pain medications
  - Caffeine improves absorption of other pain medications by decreasing stomach pH (increasing acidity in the stomach)
- Also works alone to decrease migraines and tension headaches
- However,
  - Caffeine withdrawal can trigger migraines and tension headaches
  - Abstinence from caffeine can decrease frequency of migraines
- Other fun caffeine facts:
  - Caffeine also increases gastric motility (movement of food through the gut), which improves medication absorption
  - Caffeine decreases pain relieving effects of transcutaneous electrical nerve stimulation (TENS)

Lipton, 2017



# Menstrual Migraines

- Menstrual migraines (MM) are reported to be longer, more severe and more resistant to treatment than other types of migraine
  - “Pure MM” occur only on day  $1 \pm 2$  (i.e. days - 2 to + 3) of menstruation
  - “Menstrually related migraine” are worse during menses, but occur at other times
- Are believed to be worse in people with MCAS and POTS
- Management generally the same as for other migraines
- May also consider hormone treatment
  - Often estrogen with progesterone, continuous throughout the month
  - But women with migraines are at increased of blood clots risk using hormones – doctor needs to balance risks and benefits.

Cupini, 2021



# Managing Migraines (in general)

- **Identify and avoid triggers**
  - For migraines, and for other HA that can trigger migraines
- Behavioral Rx: **relaxation, cognitive behavioral therapy, biofeedback**
  - Juva biofeedback device: 1 year free: <https://www.juvahealth.com>
- Neutraceuticals: **vit B2, Mg++, CoQ10, butterbur, feverfew**
- Non-invasive neuromodulation (new approaches, not commonly available)
- Acupuncture studies inconclusive
- Invasive, surgical treatments after all other options tried
- (Botox with caution! It can be safe in EDS-knowledgeable hands, but can cause neck instability if the provider is not careful)

Puleda, 2018;  
Botox: <https://www.neurokc.com/wp-content/uploads/2018/05/Botox-Tx-for-Chronic-Daily-Headache-in-Hypermobility-patients-AAN-2018-Poster.pdf>,  
<https://www.mdsabstracts.org/abstract/increased-risks-of-botulinum-toxin-injection-in-patients-with-hypermobility-ehlers-danlos-syndrome-a-case-series/>



# In Summary....

- People with HSD, POTS, and MCAS are vulnerable to many different kinds of headaches; some are specific to or more common in HSD/POTS/MCAS
- Generally:
  - Hypermobility causes HA and TMD due to muscle trigger points, joints (both neck and TMJ), nerves, and sleep disturbance
    - Pressure on the brain or spinal cord is much less common, but possible
  - POTS causes HA and migraines due to neurological factors, sleep disturbance, inadequate blood flow to head and neck
  - MCAS causes migraines due to immune cell reactivity, histamine sensitivity, and 'central sensitization'
- Figure out what CAUSES your HA, migraines, & TMD and prevent, when possible, rather than just taking medication to treat the symptoms
  - A physical therapist who specializes in HA and TMD can help you figure it out
- Use caution with Botox, muscle relaxer medications, and manipulations

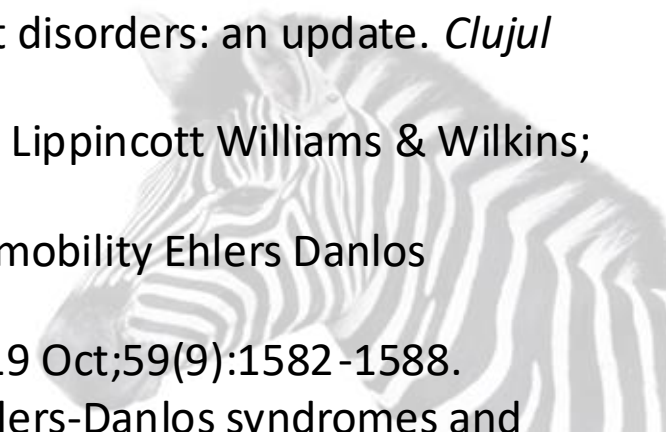


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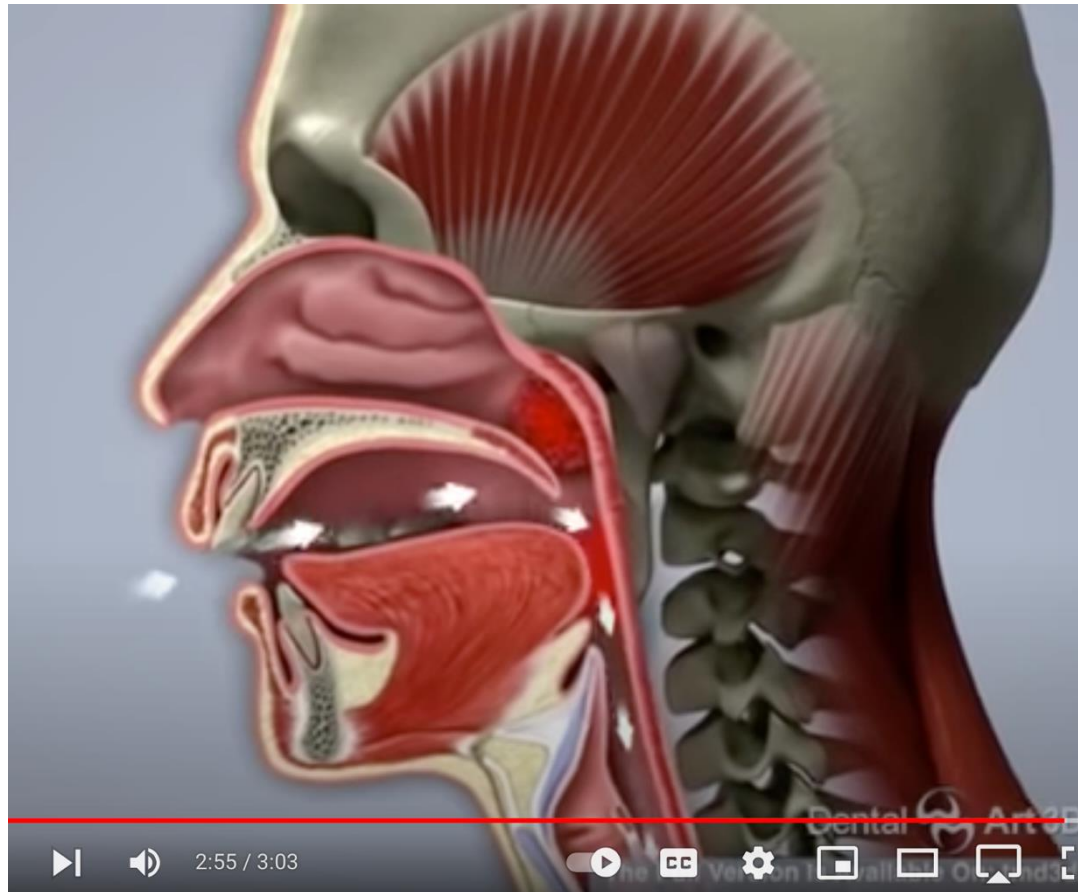


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# The Effects of Mouth Breathing



- <https://youtu.be/CBYwxndys2E>
- Changes tooth alignment
- Changes tongue position and use of muscles in the throat and neck
- Leads to forward head
- Compromises health due to loss of benefits of sinus filtration.





# Questions?

