



Living with EDS & HSD
through a lifetime
The Ehlers-Danlos Society



PRESENTATION

Tips & Tricks for Managing Autonomic Concerns

SPEAKER

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Disclosures

I have nothing to disclose.

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Scottsdale



Tucson

Speed Round



Too Long, Didn't Read (TLDR): these can be helpful if the information is too much and to refer to later

Overview of ANS



Sympathetic (fight/flight)



Pupils open big,
far-vision, dry eyes



Stop salivating



HR increases



Faster breathing



Stops digestion



Holds on to urine/feces



Closes blood vessels

Parasympathetic (rest/digest; feed/breed)

Pupils get smaller,
close-vision

Start salivating

HR decreases

Slower breathing

Starts digestion

Allows urination & defecation

Opens blood vessels

TLDR: the body has a system intended to react quickly and scan for threats and another that helps us to relax and recover

Overview of ANS



Sympathetic (fight/flight)

Potential Symptoms



Pupils open big



light sensitivity, difficulty seeing near, dry eyes



Stop salivating



dry mouth; poor digestion



HR increases



anxious feelings



Faster breathing



shallow breathing



Stops digestion



GI symptoms



Hold urine/feces



differences in bladder/bowel control



Closes blood vessels →

cold hands and feet, color changes

TLDR: some symptoms may indicate the nervous system is in a high-alert state which can help us tune in and react appropriately



The
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**GLOBAL
LEARNING
CONFERENCE**

ARIZONA

**LIVING WITH EDS & HSD
THROUGH A LIFETIME**

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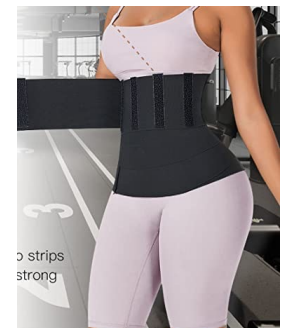
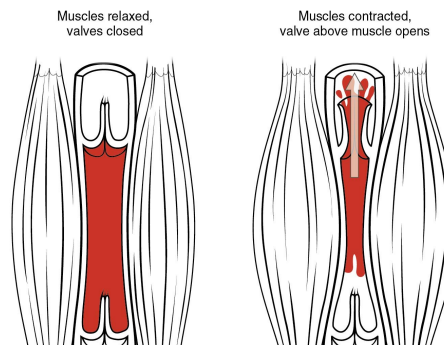
A collection of water bottles and a supplement bottle. On the left is a tall, silver and black Hydrate H2O bottle with a rainbow-colored base. In the center are five smaller, colorful water bottles (pink, blue, orange, pink, blue) with motivational phrases printed on them, such as "DON'T GIVE UP", "KEEP CHUGGING", and "YOU DID IT". On the right is a bottle of Vitassium Electrolyte Capsules, which is white with a blue cap and label. The label includes the brand name "Vitassium", the product name "ELECTROLYTE CAPSULES", and a list of ingredients: POTS, Cystic Fibrosis, EDS, and Vasovagal Syncope. It also mentions "100 Vegetarian Capsules" and "Dietary Free".

Disclaimer: do not make any changes to sodium or fluid levels without first speaking with your medical provider.

Compression

- Goal: blood return to the heart (improve circulation)
 - gravity pulls blood down and it may pool in lower body
- 20-30 mmhg level of compression
- Ideal: waist high + abdominal > abdominal + thighs > socks (knee and below)
- Save energy using donning/ doffing devices or alternate methods (rubber kitchen gloves, plastic bag, powder)

TLDR: full leg plus abdominal binder/waist trainer can improve symptoms; tools can decrease energy demands



Position

- Sitting saves 25% of your energy and helps with OI
 - cooking, showering, brushing teeth, dressing, putting on makeup, grooming hair (blow drying, styling)
- Arms up or overhead → increased demands on body and more symptoms
 - consider how to reposition to have arms at waist level
- Limit time spent laying down (especially in bed)
 - explore options for reclining, sitting with legs elevated
- Take 3-5 good breaths before changing positions and move slow
 - kickstart circulation and give the body time to adjust



TLDR: sit down to save energy when doing a physical task and try to adjust your position to minimize symptoms



Standing

- Calf raise with (optional) rock back onto heels
 - heel lift, toe lift
- Crossing legs at thighs
 - cross legs and gently squeeze thighs together for 2-4 seconds and release; repeat
- Glute squeezes
 - gently squeeze buttocks muscles; hold for 2-4 seconds and release; repeat



TLDR: calf raises, thigh squeezes, and glute/buttocks squeezes can all help improve standing tolerance

Standing

- Standing on one leg
 - more weight on one leg leads to greater muscle activation in that leg and therefore blood return
- Elevating one leg
 - can be helpful for cooking, grooming, bathing, etc.
- Elevating both legs “tall kneel”
 - a good option for a higher height (such as at the stove)



TLDR: shifting all weight to one leg or elevating one or both legs can improve standing endurance

Vagus Nerve Stimulation

- Emerging area of research, limited options
- Research increasingly suggests that stimulating the Vagus nerve can help activate and “tone” the parasympathetic (rest/digest) branch
- Anti-inflammatory
 - Vagus nerve stimulator devices
 - techniques for vagal nerve toning
 - splash cool water on face/body
 - gargling, laughing, singing, humming, “OM”
 - positive emotions + social connection
 - movement (aerobic, stretching, strengthening)
 - slow, deep breathing (6 breaths/min)
 - massage at neck, outer ear, feet
 - relaxation with salivation
 - think of sucking on a lemon
 - listening to Mozart’s music
 - practicing forgiveness
 - sleeping on R side
 - mindfulness
 - gag reflex
 - Omega-3 fatty acids



TLDR: Vagus nerve stimulation/ toning can help activate the rest & digest system in our bodies. There are options for devices & natural means.

References:

Falvey et al., 2022
Johnson & Wilson, 2018
Yuen & Sander, 2017

Temperature Regulation

- Sweat and temperature regulation are controlled by the ANS
- It's often more challenging for people with autonomic dysfunction to regulate temperature
 - both hot and cold
- Devices that can help with regulating:
 - Heat
 - personal fans
 - misters, ice packs
 - cooling towels and vests
 - cooling patches
 - Cold
 - hot hands packs
 - dress in layers
 - mittens
 - personal/space heater



TLDR: there are a variety of tools to regulate temperature, something that is often challenging for people with autonomic dysfunction

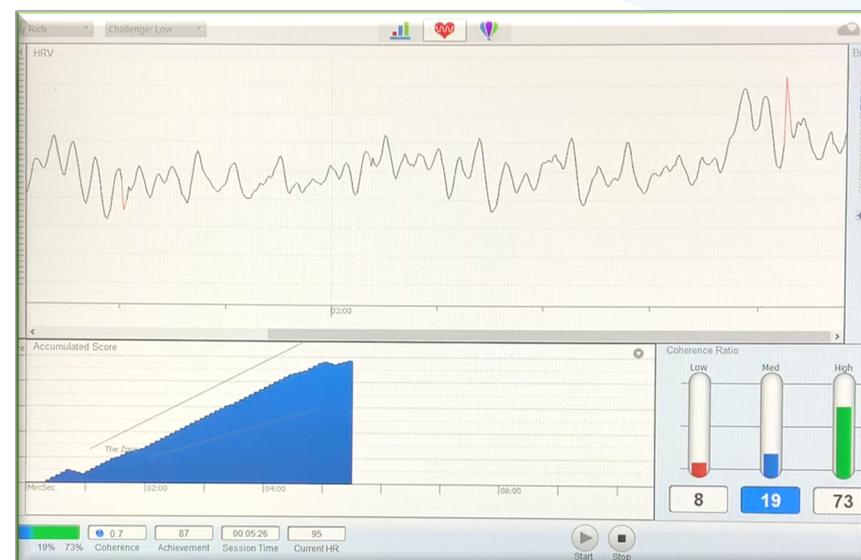


Biofeedback



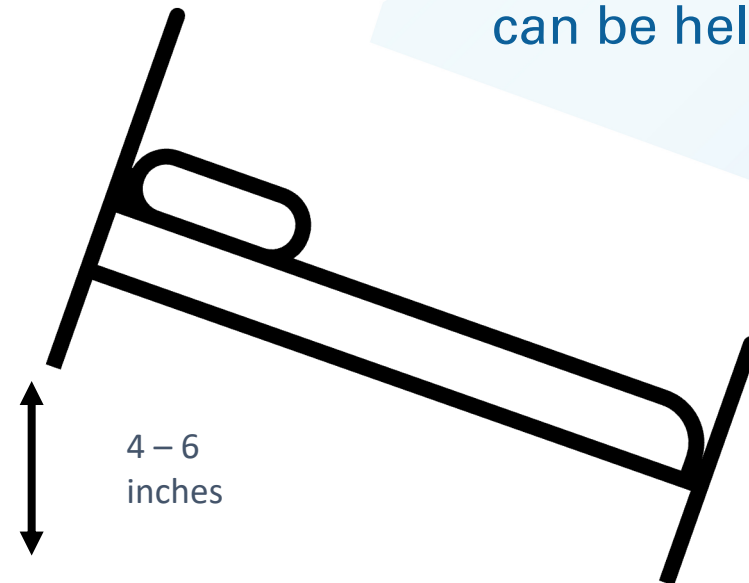
- Increase awareness of internal body states
- Various types:
 - heart rate variability
 - thermoregulatory - temperature
 - EMG – muscle tension
 - galvanic skin response – sweat
 - neurofeedback (EEG) – brain waves
- Seeing a professional is ideal
- At home options and apps:
 - Juva Health app
 - Welltory app
 - Lief therapeutics device

TLDR: biofeedback, or information about your internal body state can help recognize and manage symptoms



Bed Angle

- A helpful strategy for some
 - elevate head of the bed by 4-6 inches
 - use cinderblocks, bricks, bed risers, etc.
 - full-body wedges may be an option, but not half-wedges
- Head higher than kidneys, kidneys higher than hips
- Results in less loss of overall blood volume overnight and easier acclimation to upright upon rising



TLDR: sleep at an incline, with head higher than hips and hips higher than feet can be helpful

Adapt and Modify

- Compensating and finding alternative methods to complete tasks can significantly save energy and minimize exacerbation of symptoms
- In the long run, overtime this can result in increased function, being able to do more, and potentially not requiring the modifications at some point



TLDR: creativity and adaptive strategies can increase overall function over time.

Movement

- A key element of autonomic regulation
- Often more tolerated in laying down, reclined, or seated positions
- Potential options:
 - recumbent bike
 - row machine
 - swimming
 - Pilates
 - horseback riding
- Daily activities that involvement



TLDR: exercises laying down or in a reclined position tend to be better tolerated and can benefit overall symptoms long-term



Sensory Regulation

- Decreasing stimulation, but not completely avoiding
- Strategies to calm nervous system
 - weighted items
 - compression
 - lighting
 - sounds
- All about finding balance



TLDR: use strategies to prevent overstimulation but prevent complete avoidance/ lack of any sensory stimulation

Take Home Message

- Two things from each lecture. No more than two! You can summarize, expand on what you heard, identify how to implement into your own life, etc.



TLDR: only focus on one thing at a time and take away no more than two main points.

Where to Find Emily

- Instagram: @EmilyRichOT
- Twitter: @EmilyRichOT
- YouTube: OT Emily: Oh The pOTsabilities
- Spotify Podcast: Oh The pOTsabilities



TLDR: Find Emily on Instagram for more resources and ideas for managing autonomic dysfunction!



Thank you
for listening