Vision and POTS

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Disclosure

- None

What do they have in common?

- 16yo male first concussion 2013. 3 months bed rest. Feels dizzy and like he is moving even when still
- 12yo female with diplopia and headaches. Multiple falls and injuries over 3 months. Faints during therapy session
- 26yo female who feels heart racing and not well during therapy session
- 36yo female concussion in 2016. Nauseous, dizzy, faints VT
- 17yo female with Brown syndrome (R hypo) increasing dizziness. Cannot get out of bed without falling over
- 7yo with difficulty learning to read, letters keep changing, intermittent blurred vision. Family history of mast cell disorder

Not These POTS

POTS

- **P**ostural
- **O**rthostatic
- **T**achycardia
- **S**yndrome

Knowledge Gaps

- What is POTS?
- What are signs and symptoms?
- What are co-morbid conditions?
- How to manage these patients?
- Appropriate referrals
- How to help patients advocate for themselves?

What is POTS?

- Heart rate increases with change in posture / body position
- HR increment of ≥ 30bpm within 10 minutes of standing or HUT in absence of orthostatic hypotension
- Orthostatic hypotension may be present

Epidemiology

- In US over 500,000 to 3 million
- Worldwide 11 million
- 0.2 to 1% of population
- Young premenopausal Caucasian females (5 to 1)
- Ages 14 to 50 years old
- Initial onset 15 to 25 years old
- Average 5 years 11 months to diagnose

Subtypes

- Autoimmune
- **Neuropathic POTS**: Peripheral denervation results in poor blood vessel muscles (legs and core)
- **Hyper adrenergic POTS**: Overactive sympathetic nervous system
- **Hypovolemic POTS**: Reduced blood volume. Overlap in neuropathic and hyper adrenergic

Tests

- Head-up tilt table test (HUT) – HR and BP with change in posture and position
- Supine for 10 minutes then measure baseline BP and HR
- Stand re-measure at intervals 1, 3, 5 and 10 min
- HR increment of $\geq$ 30bpm within 10 minutes of standing or HUT in absence of orthostatic hypotension
- CBC with differential and urine test
- Echocardiogram
- Blood volume with hemodynamic studies
- QSART (measures autonomic nerves that control sweating)

Mechanism

- Stand 10 to 15% of blood in abdomen, legs and arms
- Less blood reaches your brain
- Leg muscles help pump blood back up to heart
- Autonomic nervous system turns rapid responses releases the epinephrine (adrenaline) and norepinephrine
- Increase heart rate and force
- Vasoconstriction due to norepinephrine
- POTS pool larger amount of blood below heart as stand
- Releasing more norepinephrine or epinephrine
- Blood vessels does not respond but heart does
- Heart rate often increases.
- Imbalance causes symptoms

Symptoms

- Dizziness or lightheaded after standing (up or prolonged)
- Fainting or near fainting
- Forgetfulness or trouble focusing (brain fog)
- Heart palpitations or tachycardia
- Exhaustion/fatigue
- Nervous or anxious
- Shakiness and excessive sweating
- Dyspnea (shortness of breath)
- Chest pain
- Headaches
- Bloating
- Pale, discoloration of hands and feet (below heart level)
- Disrupted sleep – chest pain, tachycardia, night sweats

Co-Morbid Conditions

- Chronic fatigue syndrome
- Autoimmune disorders ex. Sjogren's, Sarcoidosis, Lupus
- Trauma – Concussion, surgery, pregnancy
- Infections – Mononucleosis, Epstein Barr, Lyme disease, COVID
- Ehlers Danlos Syndrome – joint hypermobility and "stretchy" veins
- Multiple Sclerosis
- Diabetes and pre-diabetes
- Deconditioning
- Mitochondrial Diseases
- Mast Cell Activation Disorders
- Paraneoplastic Syndrome - rare tumors of lungs, ovary, breast and pancreas
- Toxicity from alcoholism, chemotherapy and heavy metal poisoning
- Vaccinations
- Vitamin Deficiencies/Anemia

Medications

- May be prescribed
- Correct anemia
- Fludrocortisone (increases salt retention and blood volume)
- Pyridostigmine (decreases tachycardia)
- Midodrine (vasoconstriction)
- Beta-blockers to reduce tachycardia

Patient AM

- 17yo female high school student
- Cannot sit up without dizziness and nausea
- Started 10 days ago has been bedridden
- Is there any role for vision therapy?
- Previous patient
- COVID in June 2022
- Marching band until end of October

What Changed?

- COVID in June 2022
- Marching band until end of October
- Studying for SAT
- Does not like cold weather

Recommendations

- Hydrate
- Breathing exercise 4-4-4-4 2 minutes (4 / day)
- Crawl
- Move three to four times every hour
- Email: Improvement after second set of crawling
- Continue crawling 2 to 3 times per hour

POTS Clinic at Children's

- Medications
  - Florinef bid
  - Midodrine qid
- Hydrate
- Exercise

Patient CS

- 12 year old referred for blurred vision
- CI, decreased VA, AI, OMD
- Multiple injuries (8) over 3 months
- Minor incidents causing major breaks
- Recommend rule out cause
- Genetic testing

Patient CS

- Diagnosed with Ehlers Danlos
- Symptoms of fainting, dizzy
- Worse after Brock string, Quoits
- Dx. POTS
- Medications trial and error
- GI
- Cardiac

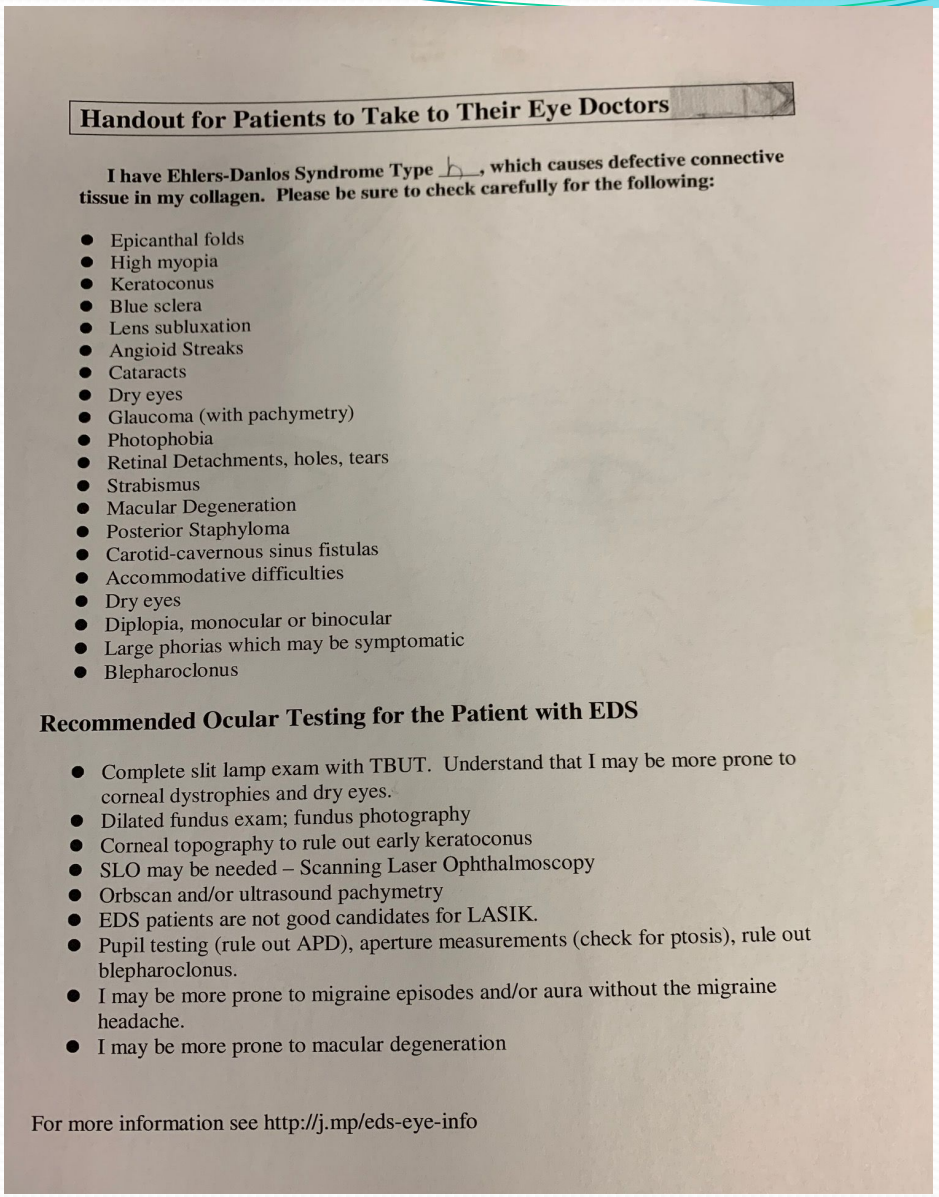
Patient SP

- 7 yo with difficulty learning (2010)
- Headaches, letters keep changing, skipping words, lines
- Difficulty seeing clearly – fluctuates
- Surgery to remove adenoids and tonsils
- Family history of mast cell disorders
- Dx. Decreased bilateral integration, CI, AI, OMD
- Visual processing deficits
- VT initiated

Patient SP

- EDS, POTS
- Reflux and GI issues
- Trial of Midrodine
- Side effects
- Salty foods and hydration
- Exercise
- POTS support group

EDS



Handout for Patients to Take to Their Eye Doctors

I have Ehlers-Danlos Syndrome Type ___, which causes defective connective tissue in my collagen. Please be sure to check carefully for the following:

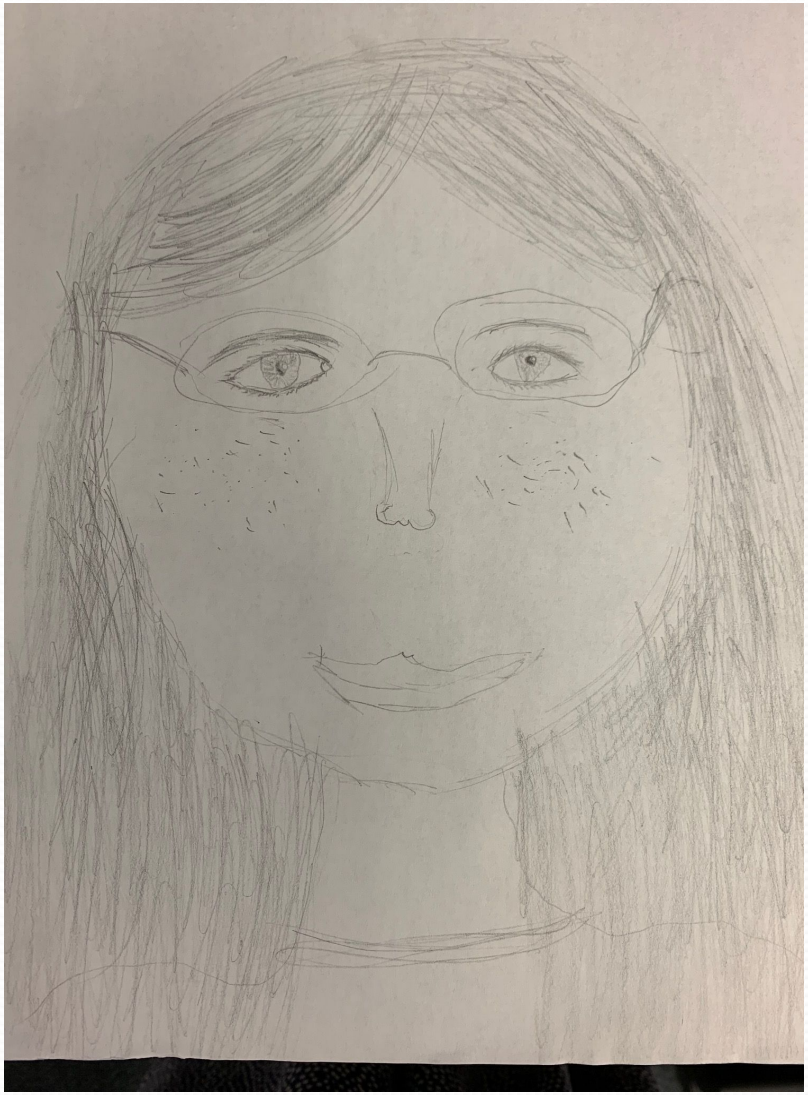
- Epicanthal folds
- High myopia
- Keratoconus
- Blue sclera
- Lens subluxation
- Angioid Streaks
- Cataracts
- Dry eyes
- Glaucoma (with pachymetry)
- Photophobia
- Retinal Detachments, holes, tears
- Strabismus
- Macular Degeneration
- Posterior Staphyloma
- Carotid-cavernous sinus fistulas
- Accommodative difficulties
- Dry eyes
- Diplopia, monocular or binocular
- Large phorias which may be symptomatic
- Blepharoclonus

Recommended Ocular Testing for the Patient with EDS

- Complete slit lamp exam with TBUT. Understand that I may be more prone to corneal dystrophies and dry eyes.
- Dilated fundus exam; fundus photography
- Corneal topography to rule out early keratoconus
- SLO may be needed – Scanning Laser Ophthalmoscopy
- Orbscan and/or ultrasound pachymetry
- EDS patients are not good candidates for LASIK.
- Pupil testing (rule out APD), aperture measurements (check for ptosis), rule out blepharoclonus.
- I may be more prone to migraine episodes and/or aura without the migraine headache.
- I may be more prone to macular degeneration

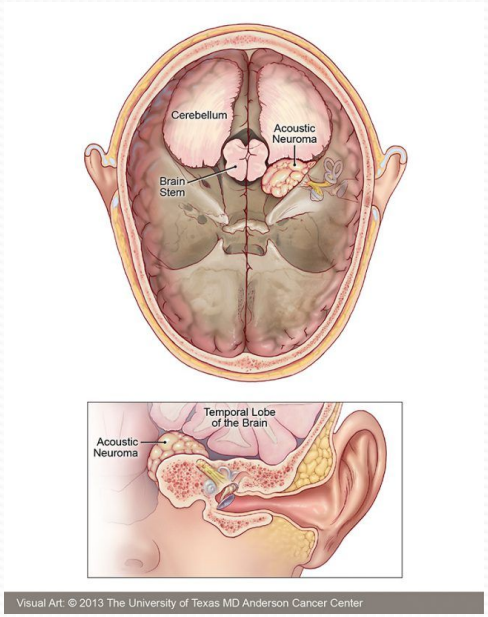
For more information see http://j.mp/eds-eye-info

Artist



Patient MR

- 36 year old female
- Referred as dizzy post surgery
- Three acoustic neuromas
- History of MS
- Breast cancer
- 2 surgeries for breast cancer



Patient MR

- Breathing labored during therapy session
- Feeling faint
- More dizzy than normal
- Increased after vectograms
- EOM, BAR, saccadic sheets

Patient MR – What changed?

- Ate heavy lunch
- Caffeinated drink
- Stairs vs. elevator
- Did not sleep well last night
- Symptoms have increased since last surgery

Management MR

- During therapy session
- Breathe
- Lean forward with hands on lower thighs put pressure
- Cool air
- Hydrate
- Polyvagal stretch (without raised arms)
- Discuss with surgeon & primary care at next follow up

Therapy Sessions with MR

- Monitor symptoms
- Counter maneuvers before transition
- Breathe
- Polyvagal stretches
- Ok with taking time to think ex. keep tossing bean bag
- Prompts to scaffold cognitive load

Patient EL

- 36 year old female
- Concussion in 2016
- First concussion in middle school hit head on locker
- Vision wiggles in middle distance
- Hx of VT, vestibular therapy
- Passed out while nursing infant
- Dx Post-concussion syndrome, CI, AI, OMD, decreased bilateral integration

Patient EL

- Fainted while working on EC
- 5th in office therapy procedure
- Had flu last week
- Therapy session this week – virtual
- Faint after seated vergence procedure
- Sleep deprived, stuffy
- Dehydrated

Patient JB

- 16yo male first concussion 2013
- 3 months bed rest
- Feels dizzy and like he is moving even when still
- Did VT when 8 years old, feels regressed
- Symptoms increased after hit on head with basketball
- 4 concussions
- Fainted during Brock string

Symptoms with Fusion

- Tachycardia with vectograms
- Fainting with Brock string, EC
- Feel sick
- Anxious
- Patients EL, CS, JB, CK, MR

What Helps

- Scheduling activities in the afternoon
- A sock filled with warmed rice - relief from the headaches (dysautonomia).
- Rice socks - Fill a tube sock with uncooked white rice. Close the end. Heat rice filled sock in the microwave for a few min until warm. Be careful (overheat, hot spots)

Sleep

- Elevate bed 4 to 12 inches
- Monitor for sleep disturbances
- Sit for a few minutes before standing
- Consider ankle weights, drinking water
- Stand up slowly
- Walk around for a few minutes

Managing with Diet

- Hydration
- Salty foods
- Identify and avoid food triggers ex. dairy
- Frequent small meals instead of three large meals a day
  - Reduce the amount of blood needed for digestion
  - More blood will be available for the brain and heart
- Refined carbohydrates, white flour and sugar, can exacerbate hypotension (Mathias, 2000)

Hydration

- Water
  - Hypovolemic
  - Blood pooling
  - Idiopathic orthostatic intolerance
  - Drink 8 8oz glasses daily (Low, 2000)
  - Excessive can dilute electrolytes
- Gatorade or electrolyte solutions

Drinking water shown to moderately reduce orthostatic tachycardia in patients with idiopathic orthostatic intolerance (Shannon, Diedrich, Biaggioni, Tank, Robertson, Robertson & Jordan, 2002)

Salt

- Raise blood pressure & blood volume
- Salt tablets and/or electrolyte solutions
- Daily salt 10-15 grams (Low, 2000) to 3-5 grams of salt per day (Grubb et. al., 2006)
- Salt is 39% sodium (15 grams of salt equals 5,850 mg of sodium)
- Not recommended for all patients
  - Low levels of renin and aldosterone
  - Hormones that promote sodium retention and plasma volume (Raj, Biaggioni, Yamhure, Black, Paranjape, Byrne & Robertson, 2005)
  - Renin and aldosterone are regulated by the kidney

Minerals

- Licorice root (alternative to Florinef)
- Magnesium (Ehlers-Danlos syndrome)
  - Decrease in arrhythmias
  - Magnesium deficiency
  - Excessive norepinephrine levels can deplete magnesium levels
  - lower blood pressure.

Exercise

- Tighten and build the leg muscles will help squeeze pooling blood back to the upper part of the body
- Recumbent – first 4 months ex. bike, ergometer
- Swimming (never go into water alone)
- Strength training – leg press, curl, extension, calf raises
- Yoga, Pilates (mat)
- Aerobic exercise - 20 minutes a day, 3x/week (Grubb, Kanjwal & Kosinski, 2006)
- Avoid > 2 day gap

Counter Maneuvers

- Decrease symptoms by lessening the amount of blood that pools in one's legs
- Standing with your legs crossed, sitting in a low chair, sitting in the knee to chest position
- Leaning forward with your hands on your knees when sitting
- Tightening the buttocks, thigh and leg muscles when standing (particularly when standing for any length of time)
- Tensing the leg muscles while standing enhances brain blood flow and reduces sympathetic activity (van Lieshout Pott, Madsen, van Goudoever & Secher, 2001.)
- Squatting - Some patients report an increase in symptoms after squatting

Temperature

- Ambient temperature
- Rub ice pack on neck and feet
- Personal cooling vests
- Plunging feet in cold water
- Avoid hot showers

Compression Devices

- Reduce blood pooling
- Abdominal binders
- Compression stockings
  - 30-40 mm Hg and will work best if they are waist high (Grubb & Karas, 1999)
  - Fitted

Treat Allergies

- Lose their ability to vasoconstrict (Grubb, 2000)
- Antihistamines help constrict blood vessels and increase BP
- Allergies stimulate the sympathetic nervous system
- Find triggers to reduce overactive sympathetic nervous systems

What to Avoid

- Bending up and down ex. bean bag toss
  - Bend at the knee
  - squat down
- Blowing up balloons (Valsalva maneuver)
  - Parent or sibling
- Avoid foods before therapy sessions
  - Dairy
  - Refined carbohydrates
  - Gluten - Gluten sensitivity may play a role in neurological disorders (Hadjivassiliou, Gibson, Davies-Jones, Lobo, Stephenson & Milford-Ward, 1996).
  - Large meal before therapy session
- Dehydration – hydrated before and during therapy session
- Climbing stairs to office

Avoid in Therapy Room

- **Holding the arms up in the air** - the heart to work harder to counteract the effects of gravity. Difficult for the heart if there is already excessive venous pooling in the lower limbs. The heart may not be able to effectively pump blood up into raised arms and tachycardia will result from its effort.
- **Lifting objects** - increased work load on the heart. Straining, bending over, coughing and sneezing raises cerebral spinal fluid pressure. Symptoms while lifting may be due to changes in cerebral spinal fluid pressure.
- **Over-stimulating environments** - overly sensitive to bright lights, loud noises and busy environments
- Singing – can temporarily exacerbate symptoms

What to Avoid

- **Exercise** - Strenuous, exhausting exercise dysautonomia feel worse. Exacerbation of symptoms after exercise that may last for > a day, especially if they suffer from mitochondrial disease.
- Exercise to build and strengthen the leg muscles is beneficial. Avoid being deconditioned.
- **Fatigue** enhances peripheral venous pooling (Grubb & Karas, 1999).
- **Giving blood** can be harmful. Blood pooling in the legs already diminishes the amount of blood flowing to the heart and brain. Especially if hypovolemic (have low blood volume) and need every drop of blood that they have.
- **Heat** dilates blood vessels and will make POTS symptoms worse. Avoid spending a lot of time outdoors on hot days. Not take hot showers/baths , saunas, hot tubs or greenhouses. Heat enhances peripheral venous pooling (Grubb & Karas, 1999).

Stress

- **Stress** (physical, mental or chemical) will often aggravate the symptoms of POTS. Lack the ability to correctly process stress due to malfunctioning or excessive functioning of the autonomic nervous system (ANS). Patients may have high levels of norepinephrine, which is a stress hormone.
- **Stresses** such as surgery, childbirth and trauma (such as a car accident) - preceded or worsened POTS due to excessive blood loss. Give extra fluids.
- **Hind brain compression** during surgery (positioning of the neck), trauma to neck, straining during child birth, hormonal shifts. Damage to the ANS

Travel

- Airplane is challenging for dysautonomia. Pressurized cabin can cause hyperventilation. Increases symptoms of sympathetic activation (Robertson, 2002).
- Dehydration while traveling in a plane
- Well hydrated before boarding, wear compression stockings when flying, request a bulkhead seat
- Elevate legs

Medication to Avoid

- **Energy Drinks,** such as Red Bull. Postural tachycardia syndrome associated with a vasovagal reaction was recorded in a young volleyball player after an excess intake of Red Bull as a refreshing energy drink (Terlizzi, Rocchi, Serra, Solieri & Cortelli, 2008).
- **Epinephrine** - Avoid as it stimulates the heart.
- **Medications will affect autonomic testing results:** Chlorpromazine, thioridazine, tricyclic antidepressants, bupropion, mirtazepine, vanlafaxine, clonidine, alpha blockers, beta blockers, calcium channel blockers, opiates and topical capsaicin (Sandroni, 1998). Discontinue measures at alleviating symptoms before autonomic testing. By doing so, symptoms are more likely to present during testing to discern the true nature of a patient's disorder.
- **Over-the-counter products,** such as melatonin, caffeine. Many products stimulate the heart or lower blood pressure or have diuretic effects, etc. Caffeine can raise blood pressure. Caffeine also increases the length of time that catecholamines remain active; detrimental to hyperadrenergic state.

Pharmacological Agents

- Cause or worsen orthostatic intolerance:
- Angiotensin Converting Enzyme Inhibitors (Grubb & Karas, 1999)
  Alpha Receptor Blockers (Grubb & Karas, 1999)
  Calcium Channel Blockers (Grubb & Karas, 1999)
  Beta Blockers (Grubb & Karas, 1999)
  Phenothiazines (Grubb & Karas, 1999)
  Tricyclic Antidepressants (Grubb & Karas, 1999)
  Bromocriptine (Grubb & Karas, 1999)
  Ethanol (Grubb & Karas, 1999)
  Opiates (Grubb & Karas, 1999)
  Diuretics (Grubb & Karas, 1999)
  Hydralazine (Grubb & Karas, 1999)
  Ganglionic Blocking Agents (Grubb & Karas, 1999)
  Nitrates (Grubb & Karas, 1999)
  Sildenafil Citrate (Grubb & Karas, 1999)
  MAO Inhibitors (Grubb & Karas, 1999)
  Olanzapine

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- Exercise regiment https://www.wbcl.org/data/uploads/Programs/Mid-Morning/CHOP%20modification%20of%20Dallas%20POTS%20Exercise%20Program%20.pdf

POTS and COVID Video

- https://www.msn.com/en-us/health/medical/new-study-finds-link-between-pots-and-long-covid/vi-AA15LVXi?cvid=52e8c5fd44be403681235157bc80598d&category=foryou

Thank You

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