EDS, Autonomic Dysfunction and MCAS – Putting It Together

Miguel Trevino, MD Internal Medicine

Ehlers-Danlos Syndromes

Are a Clinical Subtype of **Connective Tissue Disorders**

They can be *inherited* and are **varied** in:

- *How they affect the body*
- *In their genetic causes*

Characterized *by*:

Joint Hypermobility *(joints that stretch further than normal)*

Skin Hyper Extensibility *(skin that can be stretched further than normal)*

Tissue Fragility, Easy Bruising

Generalized Joint Hypermobility

The ***2017 International Diagnostic Criteria*** for **hEDS** have:

<u>Three Criteria</u> (A,B,C)

ALL of which ***MUST*** be present:

<u>A</u>

- **Five or more *of the following:***
- Soft velvety skin
- Skin hyper extensibility
- Striae (stretch marks)
- Piezogenic heel papules
- Hernias
- Atrophic scarring
- Prolapse of pelvic floor
- Rectum or uterus
- Dental crowding and high palate
- Arachnodactyly (long, slender fingers)
- Arm-span-to-height ratio >1.05
- Mitral valve prolapse or aortic root dilatation

<u>B</u>

- ***Positive family history***
  - In ***first-degree relatives diagnosed*** with these criteria

<u>C</u>

- **Pain** in ***two or more extremities***
  - For three + month
  - Recurrent joint dislocations
  - Atraumatic joint instability

Evaluation of HSD

*There are **NO Diagnostic Laboratory Tests** for HSD*

The *Beighton Score* *is a* **Screening Technique** for *hypermobility*

Used to **Evaluate/Assess** the Range Of Movement in some joints

Joint Hypermobility or Laxity *is the*

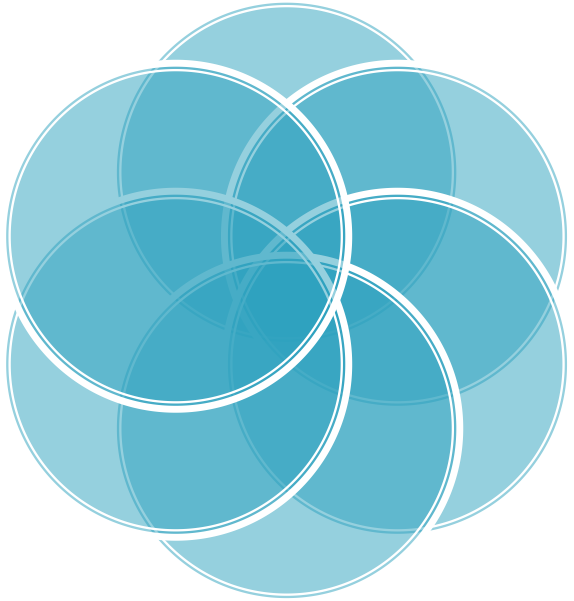
Hallmark of *most* types of **EDS**

Beighton Hypermobility Scale *is widely used*

The following maneuvers are performed:

Flexion of waist with palms on the floor (and with the knees fully extended)

Passive dorsiflexion of the fifth finger >90 degrees with forearm flat



Hyper extensibility of the knee >10 degrees

Passive apposition of the thumb to the flexor aspect of the forearm

Hyperextension of elbow >10 degrees

Beighton Scores

- Assessed in the context of ***Age*** *and* ***Sex Matched Norms***

Scores which identify - Generalized Joint Hypermobility**:**

- ***≥6*** *in* ***children***
- ***≥5*** *in* ***adolescents*** *and* ***younger adults***
- ***≥4*** *in* ***adults aged 50+ years***

According to an ***Analysis Of Population Data*** the **use** of these definitions *may*:

- **Fail to identify Males with unusually high levels of joint hypermobility**
- **Over-diagnose young females as having joint hypermobility**

Not a perfect tool!

The International Consortium on Ehlers-Danlos Syndromes & Related Disorders
In Association with The Ehlers-Danlos Society

Diagnostic Criteria for Hypermobile Ehlers-Danlos Syndrome (hEDS)

This diagnostic checklist is for doctors across all disciplines to be able to diagnose EDS

Distributed by The Ehlers Danlos Society.

Patient name: _____ DOB: _____ DOV: _____ Evaluator: _____

The clinical diagnosis of hypermobile EDS needs the simultaneous presence of all criteria, 1 ***and*** 2 ***and*** 3.

CRITERION 1 – Generalized Joint Hypermobility

One of the following selected:
- ☐ ≥6 pre-pubertal children and adolescents
- ☐ ≥5 pubertal men and woman to age 50
- ☐ ≥4 men and women over the age of 50

Beighton Score: ____/9

If Beighton Score is one point below age- and sex-specific cut off, two or more of the following must also be selected to meet criterion:
- ☐ Can you now (or could you ever) place your hands flat on the floor without bending your knees?
- ☐ Can you now (or could you ever) bend your thumb to touch your forearm?
- ☐ As a child, did you amuse your friends by contorting your body into strange shapes or could you do the splits?
- ☐ As a child or teenager, did your shoulder or kneecap dislocate on more than one occasion?
- ☐ Do you consider yourself "double jointed"?

CRITERION 2 – Two or more of the following features (A, B, or C) must be present

Feature A (five must be present)
- ☐ Unusually soft or velvety skin
- ☐ Mild skin hyperextensibility
- ☐ Unexplained striae distensae or rubae at the back, groins, thighs, breasts and/or abdomen in adolescents, men or pre-pubertal women without a history of significant gain or loss of body fat or weight
- ☐ Bilateral piezogenic papules of the heel
- ☐ Recurrent or multiple abdominal hernia(s)
- ☐ Atrophic scarring involving at least two sites and without the formation of truly papyraceous and/or hemosideric scars as seen in classical EDS
- ☐ Pelvic floor, rectal, and/or uterine prolapse in children, men or nulliparous women without a history of morbid obesity or other known predisposing medical condition
- ☐ Dental crowding and high or narrow palate
- ☐ Arachnodactyly, as defined in one or more of the following:
  (i) positive wrist sign (Walker sign) on both sides, (ii) positive thumb sign (Steinberg sign) on both sides
- ☐ Arm span-to-height ratio ≥1.05
- ☐ Mitral valve prolapse (MVP) mild or greater based on strict echocardiographic criteria
- ☐ Aortic root dilatation with Z-score >+2

Feature A total: ____/12

Feature B
- ☐ Positive family history; one or more first-degree relatives independently meeting the current criteria for hEDS

Feature C (must have at least one)
- ☐ Musculoskeletal pain in two or more limbs, recurring daily for at least 3 months
- ☐ Chronic, widespread pain for ≥3 months
- ☐ Recurrent joint dislocations or frank joint instability, in the absence of trauma

CRITERION 3 – All of the following prerequisites MUST be met

1. Absence of unusual skin fragility, which should prompt consideration of other types of EDS
2. Exclusion of other heritable and acquired connective tissue disorders, including autoimmune rheumatologic conditions. In patients with an acquired CTD (e.g. Lupus, Rheumatoid Arthritis, etc.), additional diagnosis of hEDS requires meeting both Features A and B of Criterion 2. Feature C of Criterion 2 (chronic pain and/or instability) cannot be counted toward a diagnosis of hEDS in this situation.
3. Exclusion of alternative diagnoses that may also include joint hypermobility by means of hypotonia and/or connective tissue laxity. Alternative diagnoses and diagnostic categories include, but are not limited to, neuromuscular disorders (e.g. Bethlem myopathy), other hereditary disorders of the connective tissue (e.g. other types of EDS, Loeys-Dietz syndrome, Marfan syndrome), and skeletal dysplasias (e.g. osteogenesis imperfecta). Exclusion of these considerations may be based upon history, physical examination, and/or molecular genetic testing, as indicated.

Diagnosis: _____

v9

Ehlers-Danlos Syndromes

2017 International Classification

Clinical Subtypes:

- *Classical EDS* **(cEDS)**
- *Classical-like EDS* **(clEDS)**
- *Cardiac-valvular EDS* **(cvEDS)**
- *Vascular EDS* **(vEDS)**
- *Hypermobile EDS* **(hEDS)**
- *Arthrochalasia EDS* **(aEDS)**
- *Dermatosparaxis EDS* **(dEDS)**
- *Kyphoscoliotic EDS* **(kEDS)**
- *Brittle cornea syndrome* **(BCS)**
- *Spondylodysplastic EDS* **(spEDS)**
- *Musculocontractural EDS* **(mcEDS)**
- *Myopathic EDS* **(mEDS)**
- *Periodontal EDS* **(pEDS)**

HSD/old JHD

Hypermobile Spectrum Disorder

- **Most common disorder** among *Hereditary Disorders* of connective tissue
- Affects a *subset* of **10-20%** of the general population with joint hypermobility
- **Genetic testing unavailable**

Note: *Patients with* ***Vascular EDS*** *may not be hypermobile*

Additional

HSD/EDS / hEDS Testing

Imaging

(MRI Brain/spine)

Chiari 1

Labs

Echocardiogram

(Rule out - MVP)

Dexa-Scan

(Rule out - osteopenia/osteoporosis)

Dysautonomia Evaluation

Gastrointestinal

(Caution – Complications during colonoscopy/endoscopy such as perforations & bleeding can occur)

Bladder Dysfunction

Pain Evaluation

(Neuropathic/Musculoskeletal)

Spinal Instability

Median Arcuate Ligament

(Celiac Artery Ultrasound)

Sleep Apnea

Genetic testing

(Family history of Aneurysm Deaths or spontaneous bowel perforation)

Features suggesting an alternative diagnosis

The ***presence*** of ***any*** of the *following features* suggests a need for ***further evaluation*** by a ***Medical Geneticist*** or ***EDS Specialist***

- Extensive widened atrophic scars
- Significant sagging skin
- Premature aged appearance
- Severe periodontal disease
- Severe corneal thinning, retinal detachment
- Significant kyphoscoliosis (
- **History of organ rupture**
- **Young-onset unexplained aortic root dilation, arterial dissection, or aneurysm**
- Hand and foot deformities
- Unexplained significant or extensive varicosities at a young age
- Recurrent large hernias
- Recurrent pneumothorax
- Hypertelorism (wide-set eyes), bifid uvula, or cleft palate
- Intellectual disability

Dysautonomia:

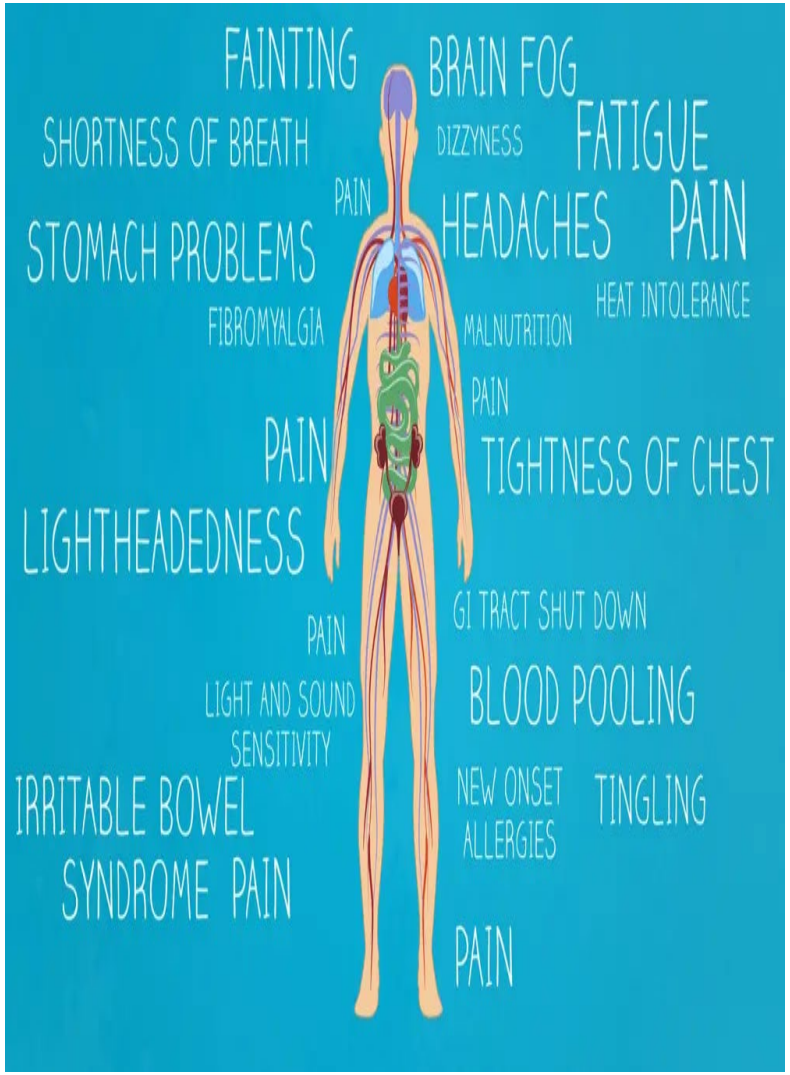
***IS NOT** a specific medical diagnosis, instead, an umbrella term used to describe any malfunction of the autonomic nervous system*

Dysfunction of the **Autonomic Nervous System** (ANS)

Failure of the Sympathetic or Parasympathetic components of ANS
(Affecting multiple organs)

Excessive or **Overactive** ANS actions

Autonomic Dysfunction can affect you from Head to Toe.



Symptoms of Dysautonomia

NOTE: ***Many of these symptoms can be caused by things other than autonomic nervous system dysfunction*** *Ex. Medication*

Blurred vision	Dry eyes/Dry Mouth	Lightheadedness	Fainting	Headaches/Migraines
Sensitivity to light and noise	Difficulty Swallowing	Insomnia	SOB/Palpitations	Chest Pain
Nausea/Bloating	Abdominal Pain	Intolerance to large meals	Constipation/ Diarrhea	Bladder Dysfunction
Heat/Cold Intolerance	Orthostatic Intolerance	Profound Fatigue	Brain Fog	Abnormal Sweating

Primary Causes of Disability

in patients w/ Autonomic Dysfunction

- **Orthostatic Intolerance**
- **Fatigue**
- **Brain Fog**

Patient Evaluation

in patients w/ Autonomic Dysfunction

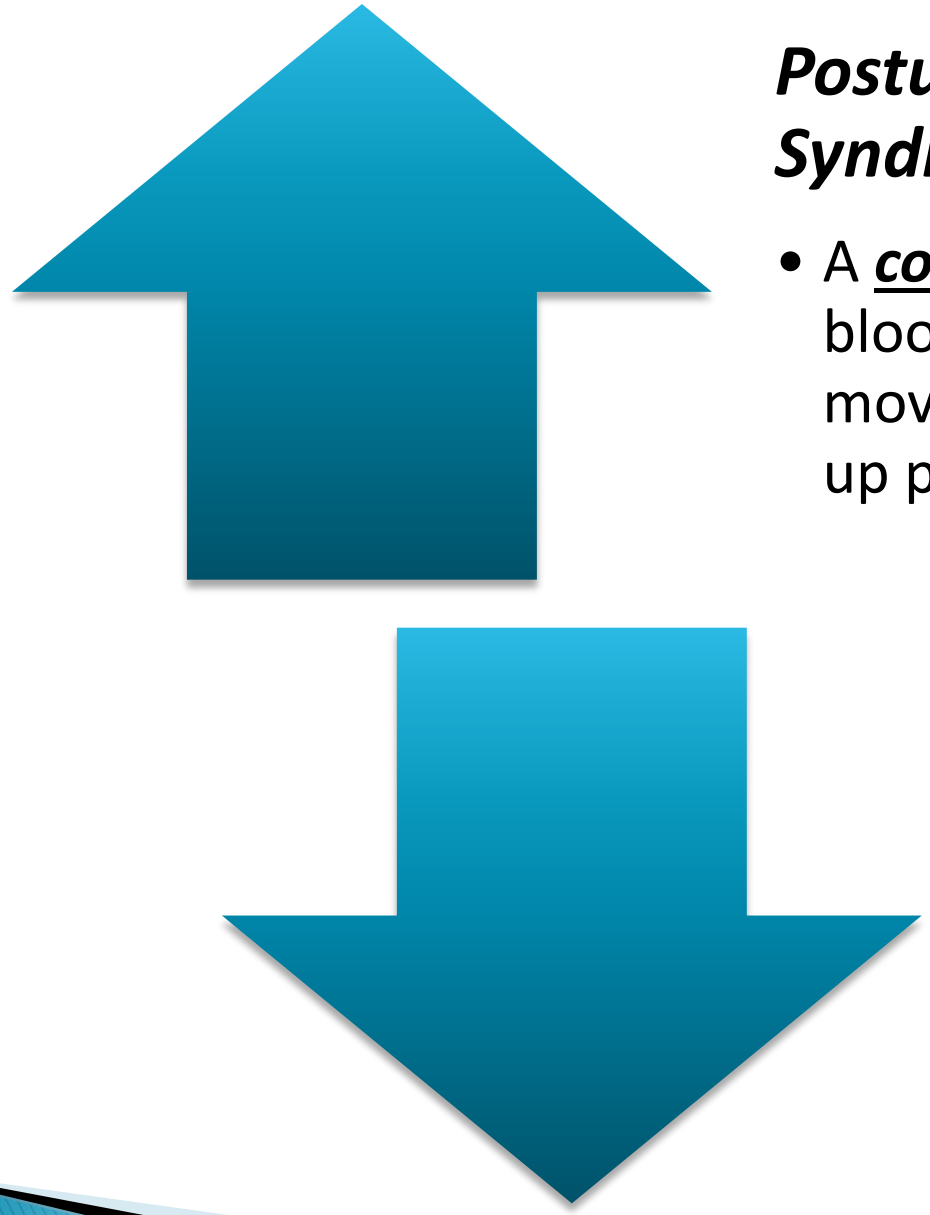
- **Are there other Medical and Neurological conditions?**
- **Determining the need for a referral to a Specialist**
- **Psychiatric/Psychological evaluations**
- **Determination the extent of disability**
- **Medication evaluation**

Diagnosis of Autonomic Disorders

Tilt-table Test	Evaluates the patients blood pressure regulation in response to orthostatic stresses
QSART	Measures the function of the post-ganglionic autonomic nerves that control sweat glands
Cardiac Workup	Electrocardiography, Echocardiogram

Lab Tests

- ❑ CBC
- ❑ B12
- ❑ Folate
- ❑ Vitamin D
- ❑ Celiac panel
- ❑ Ana DS dna
- ❑ SSA SSB
- ❑ Complement Total
- ❑ C3, C4
- ❑ Iga, Igm, Igg,
- ❑ Tryptase
- ❑ Thyroid Function
- ❑ Cortisol
- ❑ Metanephrines
- ❑ Urine
- ❑ Beta Prostaglandin f2 (mast cell)
- ❑ N-methylhistamine
- ❑ Leukotriene E4
- ❑ Lupus Anticoagulant
- ❑ Beta2glycoprotein
- ❑ Antiphospholipid
- ❑ Paraneoplastic Panel (Autoimmune Dysautonomia) also w/u for amyloid immunoglobulin free light chain assay
- ❑ Small Fiber Neuropathy Skin Biopsy



Postural Orthostatic Tachycardia Syndrome (POTS) - *cause of POTS is unknown*

- A ***condition*** characterized by too little blood returning to the heart when moving from a lying down to a standing up position

Orthostatic Intolerance

- ***Causes*** lightheadedness or fainting that can be eased by lying back down

- ***In people with POTS -*** these symptoms are also accompanied by a ***rapid increase in heart rate***

POTS

+

Orthostatic Intolerance

Common and ***can be*** **disabling …….**

Estimated to impact *between* **1,000,000 - 3,000,000** in **United States** and ***millions more*** around the **world**

- ***Affect men and women of all ages***
- ***Most cases are diagnosed in women between the ages of 15 and 50***
- ***Associated with the presence of excessive tachycardia and other symptoms upon standing***

How to do a ***Poor Man's Tilt Table Test*** at home:

- ❑ Lay flat for 2-3 minutes. Take your bp & pulse and write it down.
- ❑ Stand up for 10 minutes without moving from side to side and take BP & Pulse every 2 minutes and write down the results
- ❑ Record any Symptoms while standing every minute during the test
- ❑ Lay back down for another 2 minutes, check BP & Pulse and record if your symptoms go away
- ❑ If it's too difficult to stay standing, then sit or lay back down and stop the test

Take Note:

- ❑ What time of day you took the test
- ❑ When your last meal was
- ❑ What medications or supplements you were taking, *if any*

Examples of…

Drugs that **can <u>cause</u> or <u>exacerbate</u> symptoms** of ***Orthostatic Hypotension:***

Alpha Blockers:	**Terazosin**
Antidepressants:	**Selective Serotonin Receptor reuptake inhibitors, Trazodone, Monoamine, Oxidase Inhibitors, Tricyclic antidepressant**
Anti-hypertensives:	**Sympathetic Blockers**
Anti-Parkinsonism Drugs:	**Levodopa, Pramipexole, Ropirol**
Antipsychotics:	**Olanzapine, Risperidone**
Beta Blockers:	**Propranolol**
Diuretic Drugs:	**Hydrochlorothiazide, Furosemide**
Muscle Relaxant Drugs:	**Tizanidine**
Narcotic Analgesic Drugs:	**Morphine**
Phosphodiesterase Inhibitors:	**Sildenafil, Tadalafil**
Sedatives/Hypnotic Drugs:	**Temazepam**
Vasodilator Drugs:	**Hydralazine, Nitroglycerin, Calcium Channel Blockers**

Mast Cell Activation Syndrome *(MCAS)*

Mast Cells are:

- Part of the **immune system**
- **Mast Cells are white blood** cells found throughout the body
- **1st responder** for your **Immune System**

When **Mast Cells** come in contact with antigens, they **decide** whether to ***create an Immune Response*** to protect you

Symptoms of MCAS

- ❑ **Flushing**
- ❑ **Urticaria** *(Hives)*
- ❑ **Angioedema**
- ❑ **Nasal Congestion**
- ❑ **Rhinorrhea Wheezing**
- ❑ **Bronchospastic Cough**
- ❑ **Multiple Allergies**
- ❑ **Intolerances ex.** *Foods, medicines, smells*
- ❑ **Unexplained rashes**
- ❑ **Allergic Hypotension**
- ❑ **Headache**
- ❑ **Diarrhea**
- ❑ **Gastric Hyperacidity**
- ❑ **Abdominal Cramping**
- ❑ **Nausea +/- Vomiting**
- ❑ **Hypotension**
- ❑ **Tachycardia**
- ❑ **Fatigue, Lethargy**
- ❑ **Memory/Concentration Issues**

Diagnosis of MCAS

Tryptase Levels Before And After A Reaction

Consistent *Tryptase Levels >20 may* indicate other **Mast cell disorder**

Multiple Allergies/Or Inflammation *(not **IgE mediated**)*

Anaphylaxis with Hypotension (*in **response** to a bee/wasp sting)*

Search for **Allergic Diseases** like **Immunocap**

Citation: Up to Date Clinical Software Application: Mast Cell

Symptoms and some Co-Morbidities of

HSD/EDS/hEDS
Dysautonomia
MCAS

HSD/hEDS

Joint and Muscle Pain/Stiffness
- Back/Neck
- Clicking Joints
- Joint Dislocation
- Early onset Arthritis

Pain from Soft Tissue Injuries (Sprains)
Connective Tissue Weakness
Easy Fractures from Osteoporosis/Osteopenia
Varicose Veins
Mitral Valve Prolapse (Palpitations)
Poor Coordination
Bladder Symptoms from Prolapse
Sleep Disturbances
Widespread Pain
Hiatal Hernia w/GERD
- Bloating
- Early Satiety
- Abdominal Pain

Dysautonomia

Dizziness/Fainting
Dry Eyes/Dry Mouth
Difficulty Swallowing
Shortness of Breath
Heat/Cold Intolerance
Bladder Symptoms
Neuropathic Pain
Sleep Disturbances
Widespread Pain
Adrenalin Rushes
Headaches
Flushing (Generalized)
Nausea/Vomiting
Hypotension/Hypertension
- Fast Heart Rate
- Palpitations
- Sweating
- Chest Pains

Cognitive Issues
- Memory/Brain Fog

GERD
Diarrhea
Abdominal Pain
Extreme Fatigue
Urination Urgency/Frequency

MCAS

Hives
Swelling
Nasal Congestion
Nasal Discharge
Wheezing
Bronchospastic Cough
Multiple Allergies
Anaphylaxis (hypotensive)
Intolerance of Foods, Meds, Smells
Rashes (Unexplained)
Irritability
Painful Urination
Gastric Hyperacidity/GERD
Headaches
Flushing (Generalized)
Nausea/Vomiting
Hypotension (Allergic)
- Fast Heart Rate
- Palpitations

Cognitive Issues
- Memory/Brain Fog

Fatigue
Diarrhea
Abdominal Pain
Urination Urgency/Frequency

Citation: Up to Date Clinical Software: EDS

Treatment *for* JHS/EDS/hEDS

Management of Pain

- Musculoskeletal and Neuropathic
  - *(ex. Fibromyalgia)*
- Muscle Relaxants may help with spasms but can make subluxations worse

Joint Subluxation *> Ice*

Muscle Spasm *> Heat*

Physical Therapy

- **Muldowney** or **Divon** Protocols
- 30 Minutes/Day or Every Other Day
- In A Laying Down Position

Avoid Exercises That Over Stretch Your Joints

- ex. Yoga, Competitive Dancing, Cheerleading, Some Martial Arts
- Physical Exercise is an important part of the Treatment of EDS
- Playing certain sports is ok, however, you must take **extra caution** to ensure your joints aren't being over stretched during the exercise/sport

Extra care for Invasive Procedures

Informing Physician:

- That you ***may*** bleed more
- Lidocaine/Novocaine ***May Not Work***
- That all tissues involved should be handled gently because of increased risk of perforation *ex. Colonoscopy/Endoscopy*
- It may take 3X longer to heal, possibly requiring additional pain medicine

Sleep Study *(If needed)*

Treatment for Dysautonomia /Autonomic Dysfunction

- **Improve** *Orthostatic Intolerance*
- **Improve** *Fatigue* and *Brain Fog*
- **Heat/Cold Intolerance**
  - Use an umbrella to block the sun
  - Limit the amount of time outside
  - Use a wheelchair instead of walking

Keep from getting ***Deconditioned***!

It takes a lot of time and effort to get conditioned and **Very Little Time** to get ***Deconditioned***!

Compression garments 30-40 mmhg

- **Compress** from **knees up to belly button**
  - Better than just lower legs *Ex. Brands: Mediven, Jobst, Sigvaris, Sankom*
  - Put on first thing in the **morning**/Take off at **bedtime**
- *Frequent* **small meals** vs. 3 meals/day
  - Helps with **intestinal pooling** and *Gastroparesis*

Extra salt and water

- **Recommendation:**
  - **4 Grams of Sodium =10 grams/2 teaspoons of Salt**
  - **4 liters** of **fluid**
- **Electrolyte drinks:** *Nuun, Liquid IV, Drip Drop, Scratch Labs*

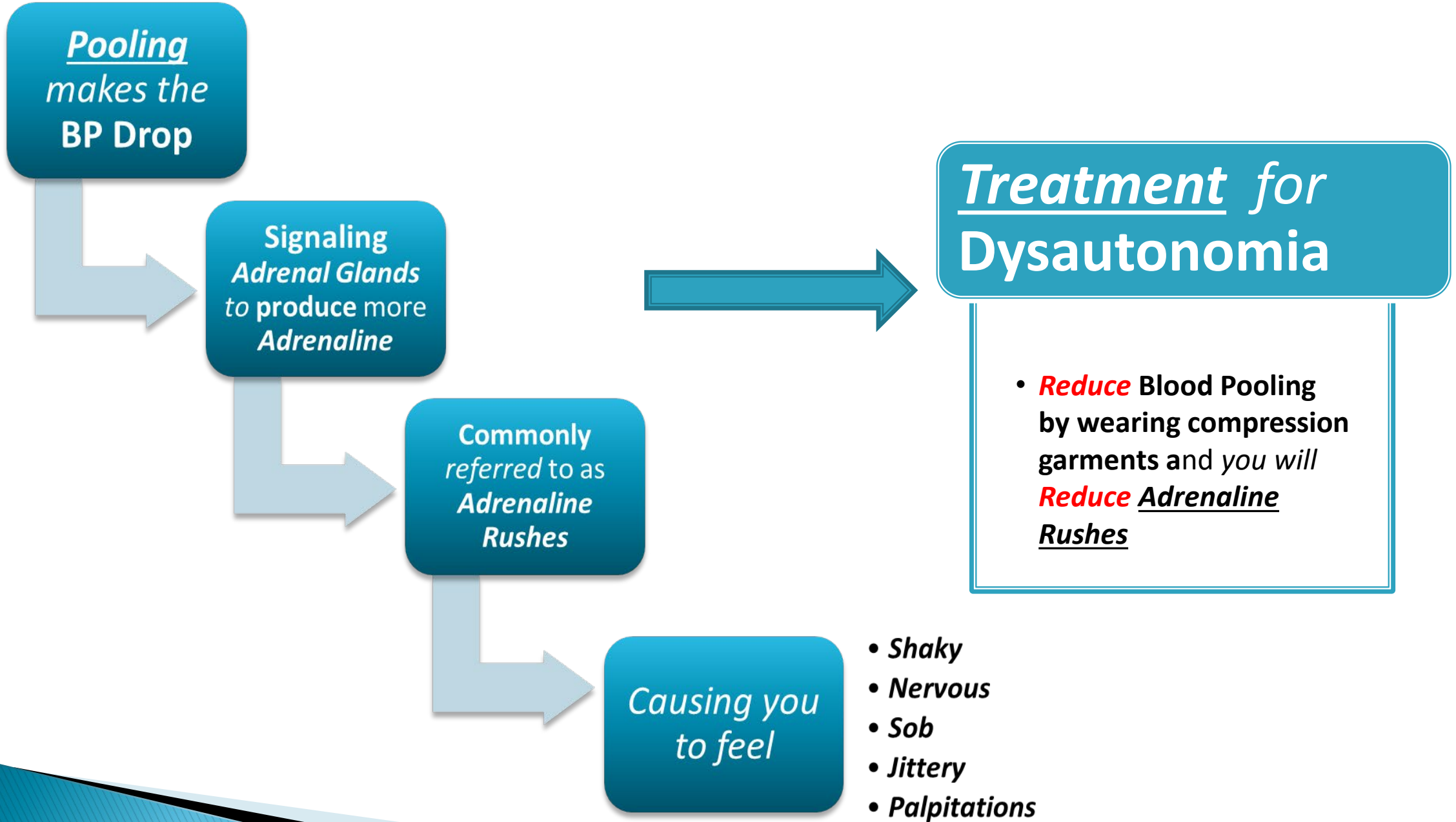
Diet

- Organic/Whole Foods
- **Gluten and Dairy Free** for at least 30 days
  - *See if your intestinal symptoms improve*

Exercise in lateral (flat) position ex. Swimming, Rowing, Recumbent Bike

- Goal – Slowly increase exercise to 30 minutes/day or every other day
- If you're **deconditioned**, start with 1 or 2 minutes
- **Note:** You *may* need to be on ***medications*** like Midodrine **before** you have enough energy to **exercise**!

Avoid Post-exercise Fatigue:
Exercise Laying Down
Stay Hydrated
Go Low And Slow


Pooling makes the BP Drop
Signaling Adrenal Glands to produce more Adrenaline
Commonly referred to as Adrenaline Rushes
Causing you to feel
Shaky
Nervous
Sob
Jittery
Palpitations
Treatment for Dysautonomia
Reduce Blood Pooling by wearing compression garments and you will Reduce Adrenaline Rushes

Treatment *for* Dysautonomia

Medications:

When taking
Multiple Medications –
(“***Polypharmacy***”)

Use Caution

Orthostatic Intolerance

- ***Ex.*** *Midodrine, Northera, Mestinon, Florinef, Beta Blockers, Clonidine, Corlanor*

Migraines

- ***Ex.*** *CGRP (Aimovig), Triptans*

Adrenaline Rushes

- ***Ex.*** *Beta blockers Propranolol, Central Alpha Agonists, Clonidine*

Gastrointestinal

- ***Ex.*** *Zofran, Prochlorperazine, Rabeprazole, Carafate, Reglan*

Bladder Dysfunction

- *Based on underlying causes*

Insomnia

- ***Ex.*** *Belsomra, Ambien, Trazodone, Hydroxyzine HCL*

Fatigue/Brain Fog

- *Mestinon, Possibly amphetamines* ***Ex.*** *Adderall, Provigil*

Treatment for Mast Cell Activation

Important

- With Mast Cell *always* **start with the lowest dose** and **increase slowly**
- *One drug* at a time
- May need to ***compound*** medications

Therapeutic Trial

with

H1 Blockers, H2 Blockers, Leukotriene Inhibitors, and **Cromolyn**

If response is noted

MCAS can be **diagnosed**

and may warrant

other treatments like ***Ketotifen,Xolai***r

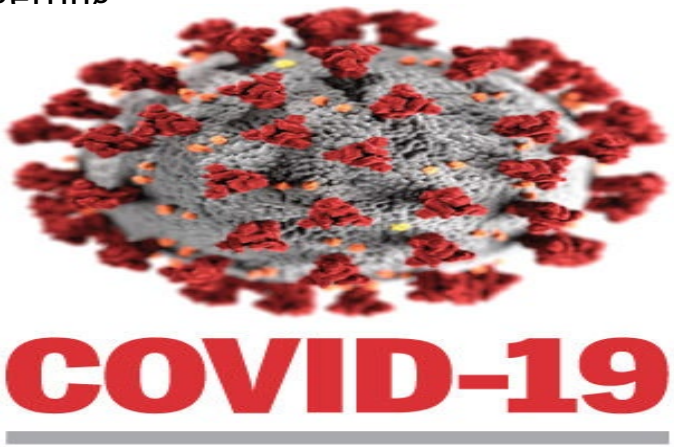
COVID 19 and Autonomic Dysfunction

COVID 19 Vaccine

In general all patients should be vaccinated

- MCAS patients should pre-medicate with H1 Blockers, H2 Blockers, Leukotriene Inhibitors, and Cromolyn
- Ensure you wait 30 minutes after the vaccination before leaving the facility
- Have the vaccine at a medical facility in case there's a reaction
- Expect to have Flu Like symptoms and a Sore Arm for a few days
- Patients who experience Anaphylaxis should consult a Mast Cell Specialist prior to getting vaccinated

COVID 19 is causing Autonomic Dysfunction (Long Haulers)



Helpful Hints….

Migraine Prevention

FeverFew
- 100mg daily

Magnesium

COQ 10
- 150mg daily

Sleep Habits

Have a Set Schedule

Avoid Alcohol, Caffeine, and Exercise Before Bed

Avoid Naps When Possible

Optimize Bedroom Comfort
- *ex. Lighting and temperature*

Keep Head Raised In Your Bed
- *About 6 -10" higher than your body*

Use Natural Products
- *ex. Sleep Well, Valerian Root, Lemon Balm, Passion Flower, Melatonin, THC/CBD*

Sodium Supplements *for* Dysautonomia

Liquid IV

- *500mg Sodium, 370mg Potassium*

Use Code **POTS30** *for 30% off*

Salt Stick Vitassium

- *500mg Sodium, 100mg Potassium*

Nuun

- *"Sport" Formula = 300mg Sodium, 150mg Potassium*
- *"Endurance" Formula = 380mg Sodium, 200mg Potassium*

Others:

- *NormaLyte, Drip Drop, Skratch Labs*

Dysautonomia International FL Facebook Support Group Page

Contains helpful links, handouts, videos for Patients, Employers, Educators, and Physicians

- *Annual Conference Information*

www.DysautonomiaInternational.org

Provides support and education to patients and their families while promoting information sharing and meetups

- ***Note:** On Home page, fill in the Search field with what you're interested in researching*

https://www.facebook.com/groups/DysautonomiaInternationalFLSupport

The Ehlers-Danlos Society

Dedicated to patient support, scientific research, advocacy, and increasing awareness for the Ehlers-Danlos syndromes, hypermobility spectrum disorder, and related medical disorders

https://www.ehlers-danlos.com/

The Mast Cell Disease Society

Dedicated to supporting patients affected by Mastocytosis and Mast Cell Activation Diseases as well as their families, caregivers and physicians through research, education and advocacy

https://tmsforacure.org/

Article in ***ScienceDirect.com***

Applicable to ALL Dysautonomia Patients

Published in December 2018 by President and Co-founder of Dysautonomia International Lauren Stiles with 40+ Leading Dysautonomia Physicians throughout the world

Search: *ScienceDirect.com*
Journal: *Autonomic Neuroscience*
Volume: *215*

Or…

"Postural Orthostatic Tachycardia Syndrome"
https://www.sciencedirect.com/journal/autonomic-neuroscience/vol/215/suppl/C
(***Please note there is a fee of $35.95 to view. Make sure you download or print within 24 hours)***

Additional Articles in *ScienceDirect.com*

- Pharmacotherapy
- Headaches & Chronic Pain
- Cognitive & Psychological Issues
- Managing Fatigue
- Sleep Disorders
- Gastrointestinal Symptoms
- Autoimmunity
- Mast Cell Activation
- Ehlers-Danlos Syndrome
- Adolescents
- Pregnancy
- Surgical & Dental Considerations

How to Prepare for a New Patient Doctors Appointment

- Ensure you submit all of you new patient paperwork
- Preform the Beighton Scale test at home prior to appointment
- If you've never had a Tilt Table Test: Preform a Poor Man's Tilt Table test at home if you're not on any medications. If you're on medications, wait for your appointment
- If the visit is virtual: Ensure you have a blood pressure cuff available for the day of your appointment
- Select the top 3 most disabling issues to discuss at each appointment

Make sure you're Prepared

Things to Remember

- It takes **time** to find the right diagnosis and treatment plan
- Include your family and community
- Try new things and be flexible enough to change your day to day activities so that you can move forward and lead your best life with your diagnosis/disability
- This is a chronic condition with ups and downs
- When you get your period, get a virus, or intestinal flu, it's going to knock you back down and you will have to fight to get yourself back up
- With time and persistent effort, the crashes will be shorter and less severe and recovery will get easier

Goal of Therapy:

Getting patients from a ***9 out of 10 Disability Level*** to a ***2 out of 10 Disability Level***

Note: Patients who achieve optimal results are the ones who follow all recommendations every day