Nerva & Mindset Health

Digestive Health in Dysautonomia

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Overview



- Nervous System Basics
- What is Dysautonomia?
- Symptoms of Dysautonomia
- Diagnosing Dysautonomia
- Gl Manifestations in Dysautonomia
 - Dysmotility
 - DGBI
 - MCAD & Histamine Overload
- Best Practices



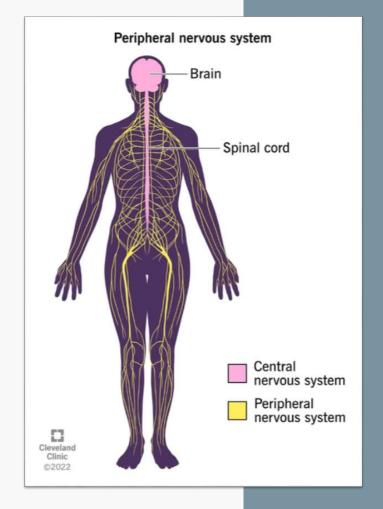
Nervous System Basics

CNS - Central Nervous System

- 1 of 2 main parts to the nervous system
- Consists of the brain and spinal cord
- Collects information from the sensory nerves & processes / responds to them

PNS - Peripheral Nervous System

- The other main part to the nervous system
- Consists of nerves outside the brain and spinal cord
- Some are automatic and some can be controlled





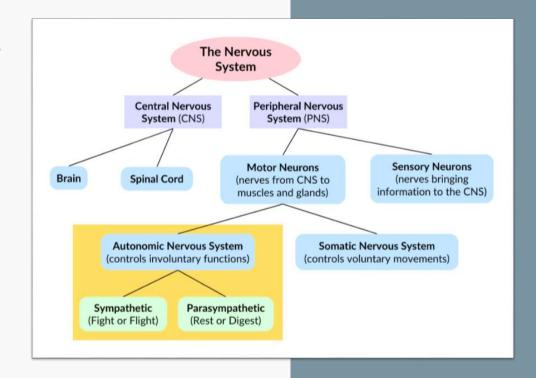
Nervous System Basics

ANS - Autonomic Nervous System

- Network of nerves that control unconscious processes
- Includes the Sympathetic and Parasympathetic
 Nervous Systems
 - Fight / Flight / Freeze vs Rest & Digest

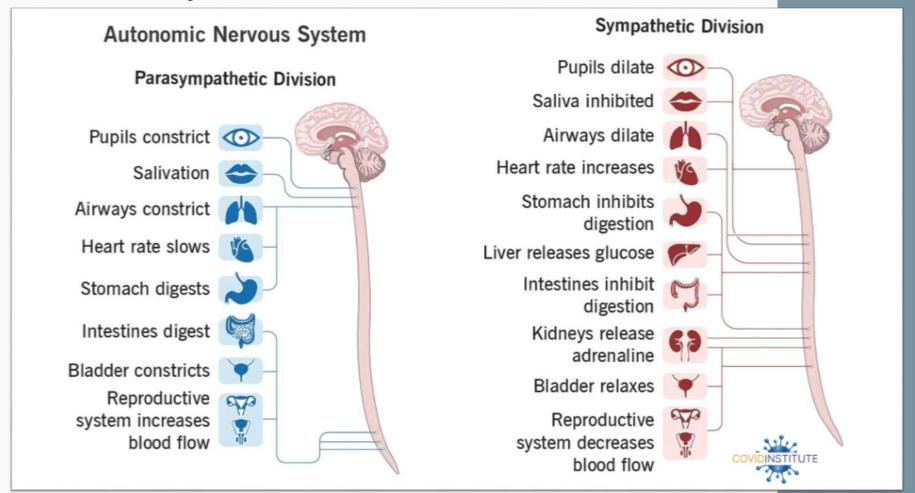
ENS - Enteric Nervous System

- Largest and most complex of all PNS systems
- The nervous system that innervates the GI tract
- Can function with and without input from the CNS





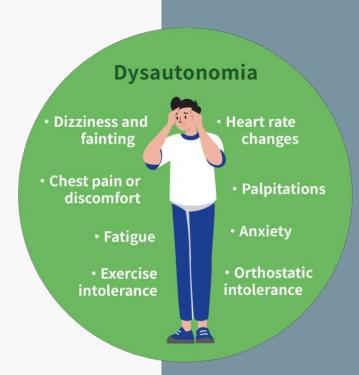
Nervous System Basics



Definition:

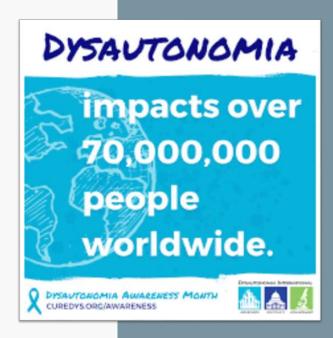
- Dysautonomia is a medical term for a group of different conditions that share a common problem – improper functioning of the autonomic nervous system
- This part of the nervous system controls involuntary body functions:
 - Blood pressure
 - Breathing
 - Digestion
 - Heart rate
 - Kidney function
 - Pupil dilation and constriction in the eyes
 - Sexual function
 - Body and skin temperature control





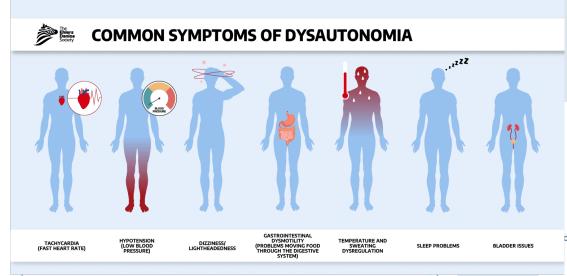
Facts & Figures

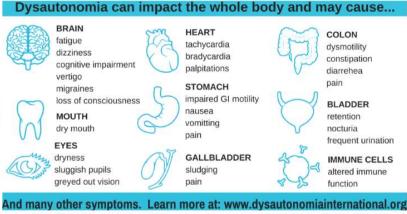
- Worldwide affects more than 70 million people
- Can be present at birth or appear gradually or suddenly at any age
- It affects women and men equally
- 15+ distinct forms of dysautonomia
- Incidence has increased with Long COVID (by up to 79%)
- 1-3 million people in the U.S. estimated to have POTS (most common form of Dysautonomia)
- "Invisible Illness"
 - Individuals may not outwardly appear sick but experience significant symptoms affecting daily life

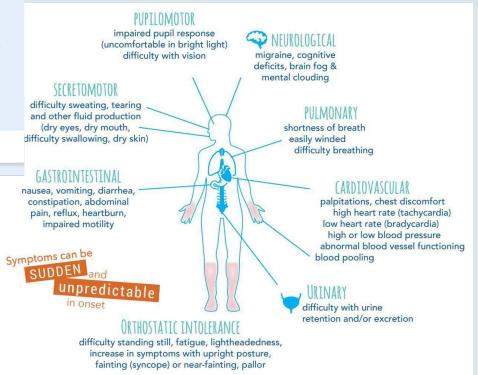




Symptoms of Dysautonomia







Primary Dysautonomia Causes includes:

- Neurocardiogenic syncope (NCS or situational syncope or vasovagal syncope):
 - most common primary form; cause fainting spells
- Familial dysautonomia (FD):
 - more likely to affect Ashkenazi Jews of Eastern European heritage
 - cause decreased pain sensitivity, lack of tears, trouble regulating body temperature
- Multiple system atrophy (MSA):
 - A life-threatening form of dysautonomia, develops in people over 40 years old.
 - Can lead to heart rate issues, low blood pressure, erectile dysfunction and loss of bladder control
- Pure autonomic failure:
 - Fall in blood pressure upon standing and have symptoms including dizziness, fainting, visual problems, chest pain and tiredness. Symptoms are sometimes relieved by lying down or sitting.



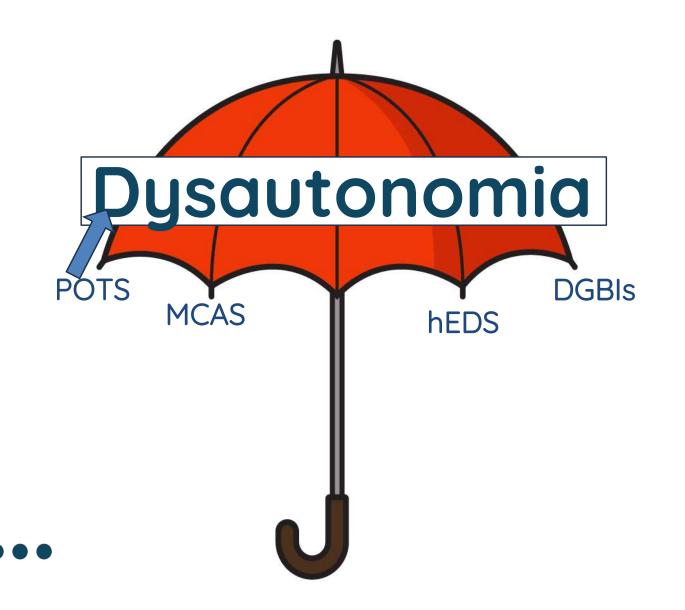
Secondary Dysautonomia includes:

- Diabetes
- Parkinson's disease
- Muscular sclerosis
- Rheumatoid arthritis
- Lupus
- Sjogren's syndrome
- Sarcoidosis
- Crohn's disease, ulcerative colitis
- Celiac disease
- Charcot-Marie-Tooth disease
- Chiari malformation
- Amyloidosis

- Guillain-Barre syndrome
- Lambert-Eaton syndrome
- Vitamin B and E deficiencies
- Human immung ficiency virus (HIV)
- Lyme disease
- Postural ort
 (POTS)
- Disorde Interaction (DGB)
- Hyp

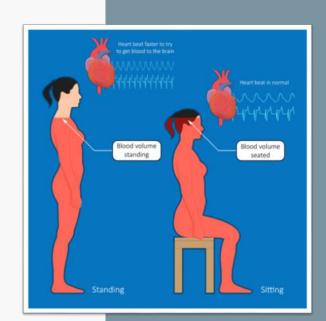
 The Trifecta
 - or The Triad fically

Long Covid



Secondary Dysautonomia Causes includes:

- Postural orthostatic tachycardia syndrome (POTS):
 - Most common form of Dysautonomia
 - When the autonomic nervous system doesn't properly regulate blood pressure and heart rate with changing body position, particularly when standing up
 - A hallmark of POTS = rapid increase in heart rate (tachycardia) upon standing, typically exceeding 30 beats per minute within 10 minutes or reaching a rate of 120 bpm or more
 - Symptoms = significant increase in heart rate upon standing, dizziness, lightheadedness, fainting, heart palpitations, shortness of breath, fatigue, and brain fog

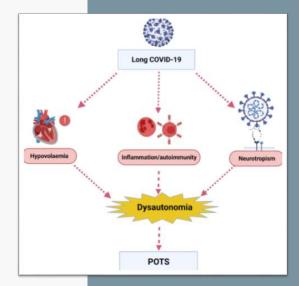




Dysautonomia and Long Covid

Crossover Facts:

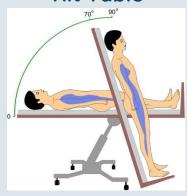
- POTS affects ~ 30% of those with persistent long COVID symptoms
- Estimates vary widely, but as many as 79% of people with long COVID experience dysautonomia
- Some theories for why long covid causes dysautonomia:
 - Antibodies may impair the normal function of the ANS
 - Chronic inflammation and low oxygen levels can trigger the SNS
 - COVID-19 may awaken other viruses that haven't been cleared out of the body
 - Overreaction from the immune system can lead to an attack on the ANS and cause vagus nerve inflammation
 - The virus can enter the brainstem and damage areas that regulate breathing and heart functions





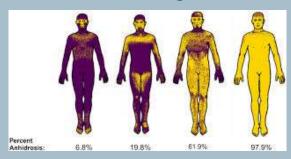
Testing For Dysautonomia

Tilt Table



- Measures blood pressure and heart rate with changes in posture and position
- Positive Test:
 - A decrease in systolic blood pressure of 20 mm Hg or more, or an absolute value below 80 mm Hg
 - An increase in heart rate of at least 30 beats per minute compared to baseline
 - The presence of symptoms like dizziness, lightheadedness, or fainting during the tilt

Thermoregulatory Sweat Test and/or QSART



- Assess autonomic dysfunction by looking at bodies ability to control sweating mechanism
- Place patient in a chamber with controlled temperature and humidity
- Patient is coated with a powder that changes color when wet, indicating sweat patterns
- As the patient's body temperature rises, the sweat patterns are recorded, helping to identify areas of excessive or reduced sweating

Breathing (Valsalva) Test



- The Valsalva maneuver is a breathing technique used to assess autonomic nervous system function, specifically the body's ability to regulate heart rate and blood pressure
- Involves forcefully exhaling against a closed airway, which causes changes in blood pressure and heart rate that can reveal autonomic dysfunction

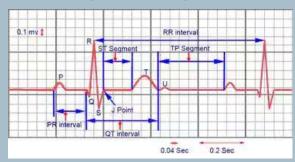
Testing For Dysautonomia

Lab Tests



- Used to rule out other conditions or assess for specific markers
- May include:
 - Comprehensive metabolic panel
 - Complete blood count
 - Vitamin deficiencies
 - Autoimmune testing
 - Cardiovascular G protein-coupled membrane receptors
 - Ganglionic acetylcholine receptors

Electrocardiography (ECG/EKG)



- Records the heart's electrical activity
- ECG use in dx dysautonomia:
 - Detecting Abnormal Heart Rhythms
 - Monitoring Blood Pressure Changes
 - Assessing Heart Function
 - Identifying Arrhythmias
 - Monitoring Treatment Effects

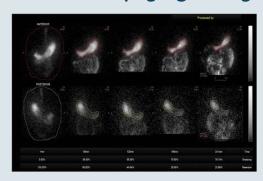
Other



- GI testing (gastric emptying, motility)
- Lyme
- Autoimmune
- Skin biopsies
- Nerve fiber testing
- Bladder emptying tests / ultrasounds
- Hormone testing
- Neurological or small fiber testing
- Etc ...

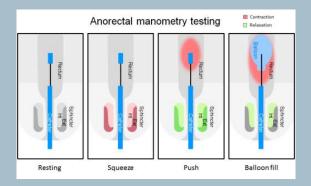
Testing For Dysautonomia

Gastric Emptying Study



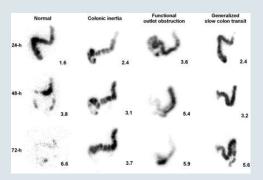
 Measures how quickly food leaves the stomach to assess for gastric motility disorders

Anorectal Manometry

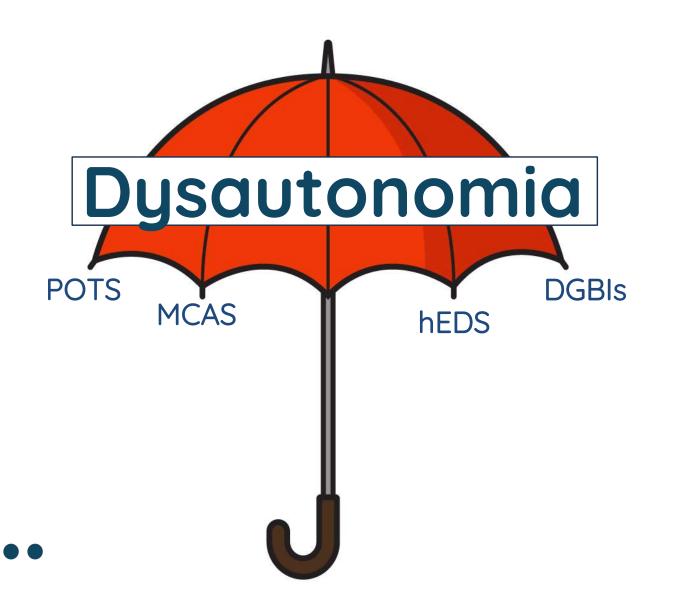


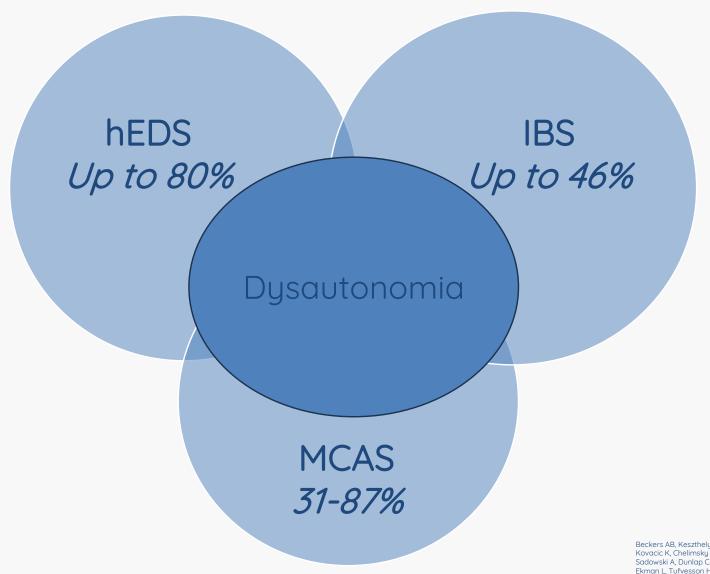
• Evaluates the function of the anal sphincters and can help diagnose lower gut dysfunction including pelvic floor dyssynergia and hypo or hypertensive sphincters

Transit Studies



- imaging or other methods to assess the movement of food through the intestines and could include:
 - Scintigraphy
 - Wireless motility capsule
 - Radiopaque markers
 - Etc...





Beckers AB, Keszthelyi D, Fikree A, et al.. Neurogastroenterol Motil. 2017 Kovacic K, Chelimsky TC, Sood MR, Simpson P, Nugent M, Chelimsky G. . J Pediatr. 2014 Sadowski A, Dunlap C, Lacombe A, Hanes D. . Clin Transl Gastroenterol. 2020 Dec. Ekman L, Tufvesson H, Englund E, Dahlin LB, Ohlsson B. PLoS One. 2025 Jul Quigley EMM, Noble O, Ansari U.. Gastroenterol Hepatol (N Y). 2024 Aug

- 70% of patients experience some combination of heartburn, regurgitation, epigastric pain, nausea, postprandial fullness, and belching
- Most common symptoms bloating, abdominal pain and dyspepsia
- 48% in one study met criteria for IBS and 36% for functional constipation
- Another study showed 50% crossover with functional dyspepsia and 40% crossover with irritable bowel syndrome
- Pelvic Floor dysfunctions may be common in this group
- 59% (10/17) of patients had evidence of esophageal dysmotility
- 12 of 17 patients presenting with upper Gl symptoms had delayed gastric emptying
- 3 out of 7 patients that underwent small bowel manometry showed evidence of small bowel dysmotility

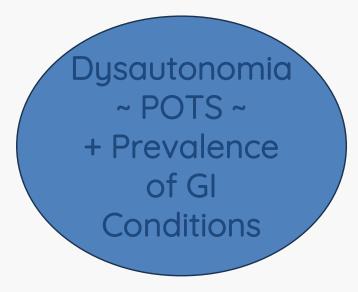
hEDS + Prevalence of GI Conditions

> Beckers AP, Keszthelyi D, Fikree A, et al.. Neurogastroenterol Motil. 2017 Kovar'z K, Chelimsky TC, Sood MR, Simpson P, Nugent M, Chelimsky G. . J Pediatr. 2014 Sudowski A, Dunlap C, Lacombe A, Hanes D.. Clin Transl Gastroenterol. 2020 Dec. Ekman L, Tufvesson H, Englund E, Dahlin LB, Ohlsson B. PLoS One. 2025 Jul Quigley EMM, Noble O, Ansari U.. Gastroenterol Hepatol (N Y). 2024 Aug

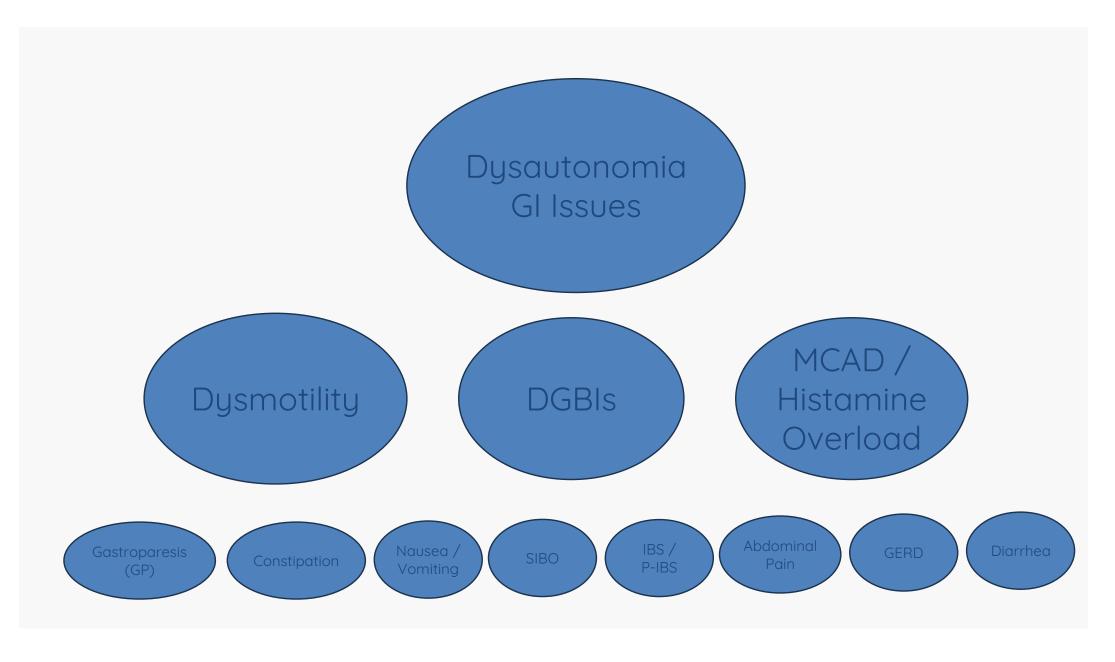


- GI symptomatology related to MCAS is frequently misdiagnosed as a functional GI disorder (DGBIs)
- Most common GI symptoms might be abdominal pain, diarrhea, GERD
- 57% have nausea and vomiting
- 14% have constipation

Beckers AB, Keszthelyi D, Fikree A, et al.. Neurogastroenterol Motil. 2017 Kovacic K, Chelimsky TC, Sood MR, Simpson P, Nugent M, Chelimsky G. J Pediatr. 2014 Sadowski A, Dunlap C, Lacombe A, Hanes D.. Clin Transl Gastroenterol. 2020 Dec. Ekman L, Tufvesson H, Englund E, Dahlin LB, Ohlsson B. PLoS One. 2025 Jul Quigley EMM, Noble O, Ansari U. Gastroenterol Hepatol (N Y). 2024 Aug



- Parasympathetic nervous system activity might be lower in people with IBS
- Symptoms of peripheral and enteric neuropathy are common in POTS
- Prevalence of nausea and abdominal pain = up to 69%
- Rapid gastric emptying in 43% and delayed gastric emptying in 20%
- It has been proposed that dysmotility is a significant driver of GI symptoms in POTS.
- Abnormal manometric findings included neurogenic intestinal dysmotility, gastric or duodenal regurgitation of food, antral hypomotility, and visceral hyperalgesia,
- High prevalence of small bowel dysmotility-and visceral sensitization in POTS



Guidelines



The purpose of this Clinical Practice Update Expert Review is to describe key principles in the evaluation and management of patients with disorders of gut-brain interaction (DGBI) and hypermobile Ehlers-Danlos syndrome (hEDS) or hypermobility spectrum disorders (HSDs) with coexisting postural orthostatic tachycardia syndrome (POTS) and/or mast cell activation syndrome (MCAS).

This expert review was commissioned and approved by the American Gastroenterological Association (AGA) Institute Clinical Practice Updates Committee and the AGA Governing Board to provide timely guidance on a topic of high clinical importance to the AGA membership, and underwent internal peer review by the Clinical Practice Updates Committee and external peer review through standard procedures of Clinical Gastroenterology and Hepatology. These Best Practice Advice statements were drawn from a review of the published literature and from expert opinion. Because systematic reviews were not performed, these Best Practice Advice statements do not carry formal ratings regarding the quality of evidence or strength of the presented considerations.

Clinicians should be aware of the observed associations between hEDS or HSDs and POTS and/ or MCAS and their overlapping gastrointestinal (GI) manifestations; while theoretical explanations exist, experimental evidence of the biological mechanisms that explain relationships is limited and evolving.

BEST PRACTICE ADVICE 2: Testing for POTS/MCAS should be targeted to patients presenting with clinical manifestations of POTS/MCAS, but universal testing for POTS/MCAS in all patients with hEDS/HSDs is not supported by the current evidence.

BEST PRACTICE ADVICE 3: Gastroenterologists seeing patients with DGBI should inquire about joint hypermobility and strongly consider incorporating the Beighton score for assessing joint hypermobility into their practice as a screening tool; if the screen is positive, gastroenterologists may consider applying 2017 diagnostic criteria to diagnose hEDS (https://www.ehlers-danlos.com/wp-content/uploads/2017/05/hEDS-Dx-Criteria-checklist-1.pdf) or offer appropriate referral to a specialist where resources are available.

BEST PRACTICE ADVICE 4: Testing for POTS through postural vital signs (eg, symptomatic increase in heart rate of 30 beats/min or more with 10 minutes of standing during an active stand or head-up tilt table test in the absence of orthostasis) and referral to specialty practices (eg, cardiology or neurology)

Aziz, Qasim et al. AGA Clinical Practice Update on Gl Manifestations and Autonomic or Immune Dysfunction in Hypermobile Ehlers-Danlos Syndrome: Expert Review. Clinical Gastroenterology and Hepatology, Volume 23, Issue 8, 1291 - 1302

Dysmotility

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Dysmotility - Gastroparesis

Symptoms

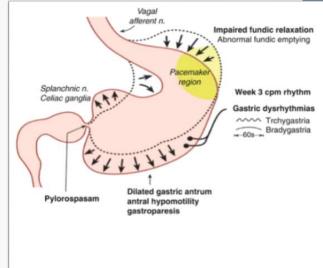
- Early satiety / Postprandial fullness
- Nausea / Vomiting
- Upper abdominal pain
- Bloating / Distension

Nutrition Impact

- Vitamin/mineral deficiencies
- Electrolyte imbalances
- Dehydration
- Weight loss // Weight gain
- Malnutrition

Diet Modifications to Consider:

- Volume:
 - Small, frequent meals (5-6/day)
 - Avoid grazing
- Low Fat / Fiber (soluble vs insoluble)
- Liquid vs solid meals consider particle size, consistency
- Food tolerance individualized patient to patient



Severe fundic accommodation dysfunction maybe be present

Loss of interstitial cells of Cajal (ICC) (Pacemaker cells)

Results in poor milling and emptying

Requires easy to digest foods

Koch K.L. (2017) : Koch K., Hasler W. (eds) Nausea an /omiting. Springer, Cham

Olausson et al, Am. J. Gastroenterol 2014 Mar;109(3) 375-85

Homko et al. Neurogastroenterol Motil (2015) 27,501-508 Wytiaz et al. Dig Dis Sci (2015) 60:1052-1058

Dysmotility - Constipation

Slow Transit Constipation

- Moving agents
 - Osmotic laxatives
 - Stimulant laxatives
 - Stool Softeners
 - Prokinetics
 - Secretagogues
 - Vibrating Capsules
 - Suppositories
- Kiwi
- Prunes
- Whole flax and chia

Dyssynergia or Pelvic Floor Dysfunction

- Pelvic Floor Physical Therapy
- Squatty Potty
- Biofeedback



Dysmotility – H-SIBO & IMO

Symptoms

- Bloating / Distension
- Diarrhea / Constipation
- Flatulence / Gas
- Indigestion / Belching

Nutrition Impact

- Vitamin/mineral deficiencies
- Macronutrient maldigestion
- Malnutrition
- Overly restrictive diets

Diet Modifications to Consider:

- Focus on aiding with symptoms
 - Consider constipation aids for IMO
 - Consider low fodmap diet when abdominal pain, bloating, distention are present



Best Practice Advice 10. Diagnostic testing for functional defecation disorders with anorectal manometry, balloon expulsion test, or defecography should be considered in patients with hEDS/HSDs and lower GI symptoms such as incomplete evacuation, given the high prevalence of pelvic floor dysfunction, especially rectal hyposensitivity, in this population.

Best Practice Advice 11. In patients with hEDS/HSDs and comorbid POTS who report chronic upper GI symptoms, timely diagnostic testing of gastric motor functions (eg, measurement of gastric emptying and/or accommodation) should be considered after appropriate exclusion of anatomical and structural diseases, as abnormal gastric emptying may be more common than in the general population.

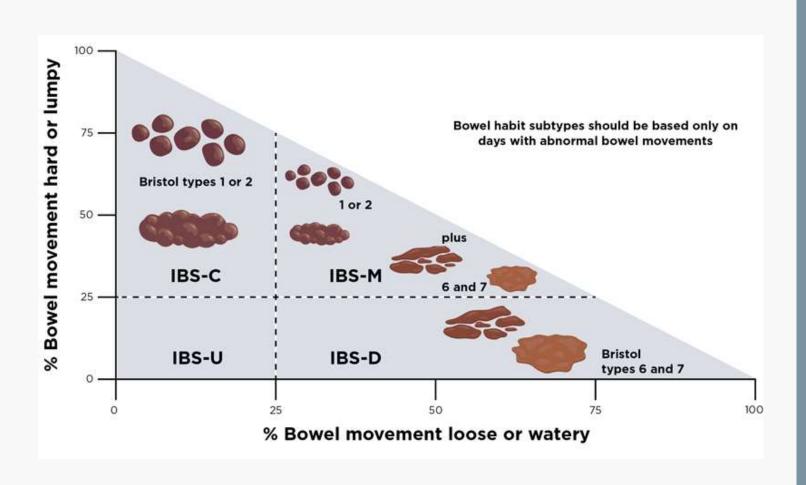
Dysmotility

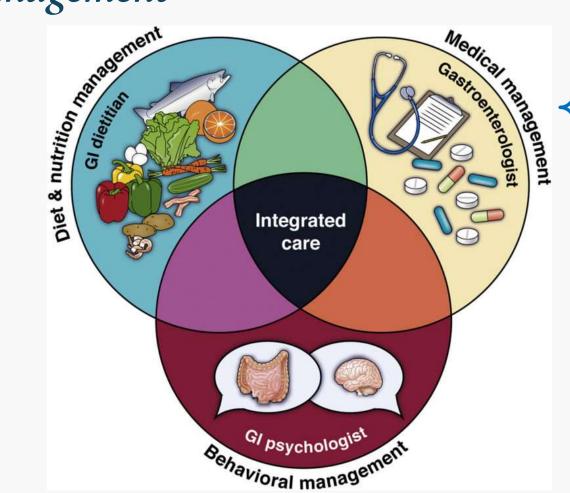
Best Practice Advice 15. Besides general nutritional support, special diets including a gastroparesis diet and various elimination diets (eg, low fermentable carbohydrates, gluten- or dairy-free, low-histamine diets) can be considered for improving GI symptoms. Dietary interventions should be delivered with appropriate nutritional

DGBI's

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IBS Basics





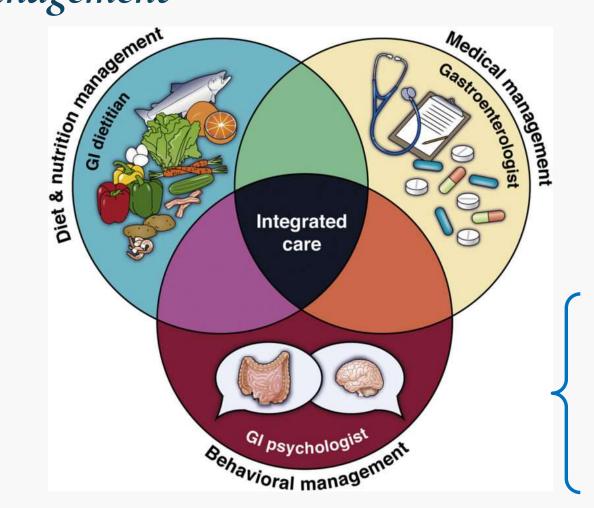
IBS-C

Osmotic Laxatives
Stimulant Laxatives
Stool Softeners
Secretagogues
Vibrating Capsules
SSRI
Suppositories

IBS-D

Anti-spasmodic Anti-diarrheal SSRI / SNRI TCAs

Chey WD, Keefer L, Whelan K, Gibson PR. Behavioral and Diet Therapies in Integrated Care for Patients With Irritable Bowel Syndrome. Gastroenterology. 2021 Jan;160(1):47-62. doi: 10.1053/i.gastro.2020.06.099. Epuib. 2020.



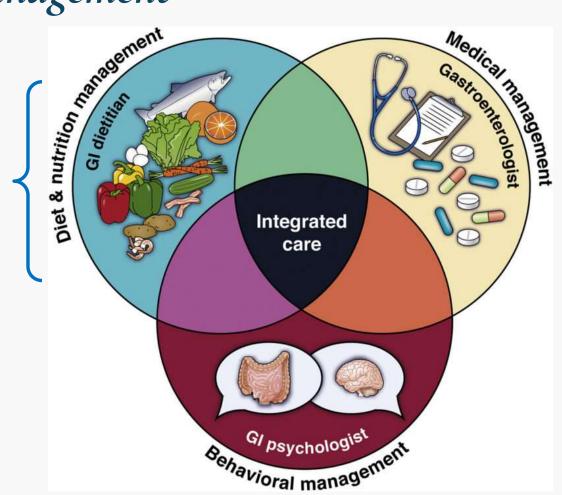
Chey WD, Keefer L, Whelan K, Gibson PR. Behavioral and Diet Therapies in Integrated Care for Patients With Irritable Bowel Syndrome. Gastroenterology. 2021 Jan;160(1):47-62. doi: 10.1053/j.gastro.2020.06.099. Epub 2020 Oct 19. PMID: 3309141

Gut Directed
Therapies:

Hypnosis

Cognitive Behavioral Therapy

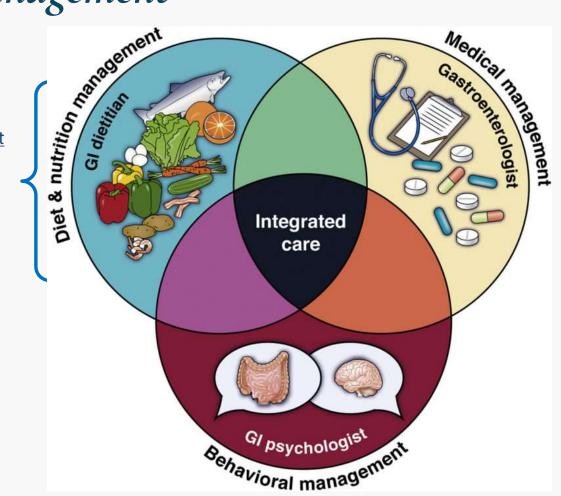
Supplements
Fiber supplements
Peppermint oil
Digestive enzymes



Chey WD, Keefer L, Whelan K, Gibson PR. Behavioral and Diet Therapies in Integrated Care for Patients With Irritable Bowel Syndrome. Gastroenterology, 2021 Jan;160(1):47-62. doi: 10.1053/j.ostro.2020.06.09. Epuib 2020.0ct

Evidence-Based Diet

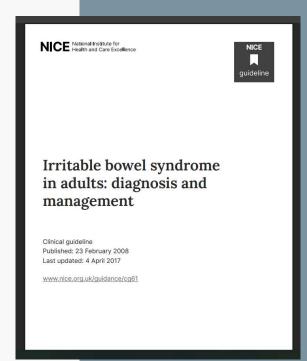
Mediterranean Diet Gluten Free Diet Low Carb Diet NICE Guidelines Low Fodmap Diet



Chey WD, Keefer L, Whelan K, Gibson PR. Behavioral and Diet Therapies in Integrated Care for Patients With Irritable Bowel Syndrome. Gastroenterology, 2021 Jan;160(1):47-62. doi: 10.1053/j.ostro.2020.06.09. Epuib 2020.0ct

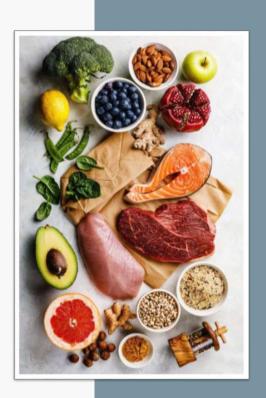
2008 NICE Guidelines:

- Have regular meals and take time to eat
- Avoid missing meals or leaving long gaps between eating
- Drink at least 8 cups of fluid per day
- Restrict tea and coffee to 3 cups per day
- Reduce intake of alcohol and fizzy drinks
- It may be helpful to limit intake of high-fiber food
- Limit fresh fruit to 3 portions per day
- People with diarrhea should avoid sorbitol
- People with wind and bloating may find it helpful to eat oats (such as oat-based breakfast cereal or porridge) and linseeds (up to 1 tablespoon per day)
- Added FODMAP in 2015:
 - If a person's IBS symptoms persist while following general lifestyle and dietary advice, offer advice on further dietary management.
 - Such advice should --- include single food avoidance and exclusion diets (for example, a low FODMAP [fermentable oligosaccharides, disaccharides, monosaccharides and polyols] diet) --- only be given by a healthcare professional with expertise in dietary management



NICE vs. Low FODMAP (2016)

- 92 IBS-D; 4 weeks on either low FODMAP or NICE
- Results.
 - The diets were equally effective at providing 'adequate relief' of overall IBS symptoms
 - 41% of NICE group versus 52% of low FODMAP group
 - More improvement in abdominal pain with low fodmap
 - 23% of NICE group versus 51% of low FODMAP group
 - The low FODMAP diet may be superior for abdominal pain and bloating



IBS Management

LOW FODMAP DIET

FOOD	VEGETABLES	FRUITS	PROTEINS	FATS	STARCHES, CEREALS & GRAINS
EAT	lettuce, carrot, cucumber	strawberries, pineapples, grapes	chicken, eggs, tofu	oils, butter, peanuts	potatoes, tortilla chips, popcorn
AVOID	garlic, beans, onion	blackberries, watermelon, peaches	sausage, battered fish, breaded meats	almonds, avocado, pistachio	beans, gluten-based bread, muffins

IBS Management

Low FODMAP in Dysautonomia

- At this time, there are no studies looking at a low FODMAP diet for dysautonomia, including use in POTS
- Evidence does show a connection between
 - Autonomic dysfunction and IBS
 - · Post infectious IBS and Long Covid
 - HSD with IBS on LFD had greater decreases in abdominal pain and bloating in 1 study
- At this time, clinical discretion is recommended for deciding if a low FODMAP diet is appropriate to use in dysautonomia patients

Best Practice Advice 8. Diagnostic evaluation of GI symptoms consistent with DGBI in patients with hEDS/ HSDs and comorbid POTS and/or MCAS should follow a similar approach to the evaluation of DGBI as in the general population including the use of a positive symptom-based diagnostic strategy and limited noninvasive testing.

outcomes.

Best Practice Advice 16. Management of chronic GI symptoms in patients with hEDS/HSDs who do not exhibit symptoms consistent with POTS or MCAS should align with existing approaches to management of DGBI and GI motility disorders in the general population, including integrated multidisciplinary care involving multiple specialties, where appropriate (eg, cardiology, rheumatology, dietician, psychology).

DGBI's

STRAIGHT AND CHE

Best Practice Advice 12. Medical management of GI symptoms in hEDS/HSDs and POTS/MCAS should focus on treating the most prominent GI symptoms and abnormal GI function test results. In addition to general DGBI and GI motility disorder treatment, management should also include treating any symptoms attributable to POTS and/or MCAS.

Best Practice Advice 15. Besides general nutritional support, special diets including a gastroparesis diet and various elimination diets (eg, low fermentable carbohydrates, gluten- or dairy-free, low-histamine diets) can be considered for improving GI symptoms. Dietary interventions should be delivered with appropriate nutritional

Mast Cell Activation Disorders & Histamine Intolerance

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MCAD Basics

Mast Cell Activation Diseases

Systemic mastocytosis:

• A clonal disorder where there is an abnormal proliferation and accumulation of mast cells in various organs

Mast cell activation syndrome (MCAS):

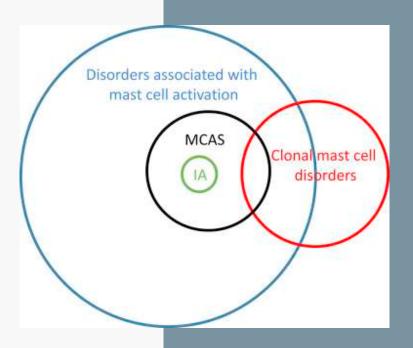
• A non-clonal disorder where mast cells are overactive and release mediators (histamine) without an apparent trigger.

Idiopathic mast cell activation syndrome (IMCAS):

• A form of MCAS where the underlying cause is unknown

Hereditary alpha-tryptasemia:

• A rare genetic disorder characterized by high levels of tryptase, a mast cell mediator



Can J Gastroenterol Hepatol. 2016; Novak J. Am J Clin Nutr. 2007;85(5):1185-11916. April 1000. Nutripote 2024.

MCAD vs Histamine Intolerance

Histamines

- Natural substance produced by the body (skin, GI tract, respiratory system, connective tissue, etc.)
- Present naturally in many foods
- Food spoilage
- Food preservation

Histamine Intolerance

 Where more histamine is taken in than can be eliminated by the body; this could be due to lowered enzymes (DAO), brush border injury, medications, alcohol

MCAD	Histamine Intolerance
Histamine comes from mediators in the body	Possibly comes from outside the body as food and bacterial fermentation
Some high histamine food triggers; lots of other triggers such as exercise, chemical odors, temperature, pollens, stress, etc.	Food triggers from fermented foods
Using a DAO supplement might help reduce symptoms	Using DAO supplements can help reduce symptoms

Can J Gastroenterol Hepatol. 2016; Novak J. Am J Clin Nutr. 2007;85(5):1185-1196.

MCAS Basics

Symptoms

- Headaches
- Low blood pressure
- Arrhythmia
- Wheezing
- Asthma
- Runny nose
- Watery eyes
- Swelling of face/hands/lips
- Itchy skin / flushing skin
- Hives
- Heartburn
- Diarrhea
- Abdominal pain / bloat

Body Systems Affected

- Cardiovascular
- Integumentary (skin)
- Central Nervous System
- Skeletal
- Respiratory
- Reproductive
- Gastrointestinal

What are the symptoms of mast cell activation syndrome?

MCAS causes repeated episodes of severe symptoms in two or more body systems, including:



SKIN

- Flushing
- Itching
- Swelling (often of your face, lips, eyes, tongue or throat)
- Hives



RESPIRATORY

- Nasal congestion
- . Shortness of breath



CARDIOVASCULAR

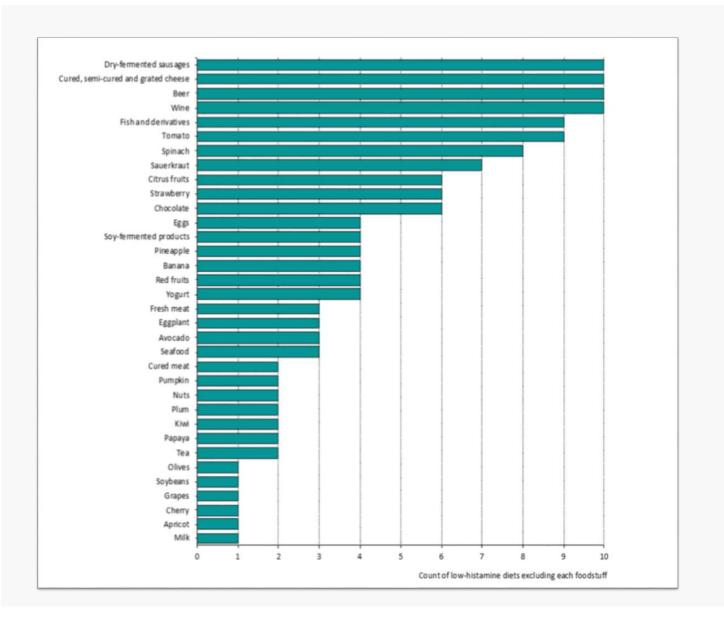
- Drop in blood pressure
- · Fast heart rate
- · Weakness or fainting



DIGESTIVE

- · Abdominal (belly) pain
- Vomiting







Goldberger, J., Arora, R, Buckley, U. et al. Autonomic Nervous System Dysfunction: *JACC* Focus Seminar. *JACC*. 2019 Mar, 73 (10) 1189– 1206. Best Practice Advice 5. In patients presenting to gastroenterology providers, testing for mast cell disorders including MCAS should be considered in patients with hEDS/HSDs and DGBI who also present with episodic symptoms that suggest a more generalized mast cell disorder (eg, visceral and somatic pain, pruritus, flushing, sweating, urticaria angioedema, wheezing, tachycardia, abdominal cramping, vomiting, nausea, diarrhea, urogynecological and neurological complaints) involving 2 or more physiological systems (eg, cutaneous, GI, cardiac, respiratory, and neuropsychiatric), but current data do not support the use of these tests for routine evaluation of GI symptoms in all patients with hEDS/HSDs without clinical or laboratory evidence of a primary or secondary mast cell disorder.

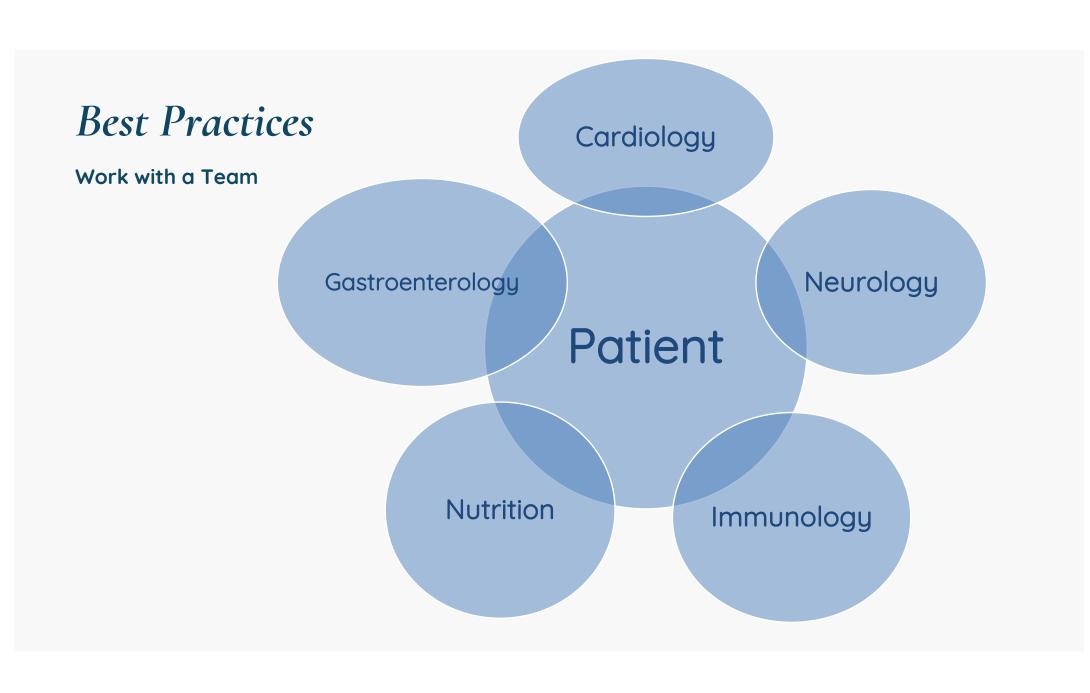


MCAS

Best Practice Advice 14. When MCAS is suspected, patients can benefit from treatment with histamine receptor antagonists and/or mast cell stabilizers, in addition to avoiding triggers such as certain foods, alcohol, strong smells, temperature changes, mechanical stimuli (eg, friction), emotional distress (eg, pollen, mold), or specific medications (eg, opioids, nonsteroidal anti-inflammatory agents, iodinated contrast).



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Comprehensive Assessment

Dysautonomia Conditions Checklist (check for yes)	POTS-Specific Symptoms Checklist (check for yes)	EDS Symptoms Checklist (check for yes)
☐ Mast Cell Activation Syndrome (MCAS)	☐ Cardiovascular Symptoms	Musculoskeletal / Connective Tissue Symptoms
☐ Postural orthostatic tachycardia syndrome (POTS)	Lightheadedness	☐ Chronic musculoskeletal pain
or other orthostatic intolerances	Palpitations	☐ Delayed motor function
☐ Gastroparesis (GP)	☐ Syncope	Joint hypermobility (joint instability, frequent
☐ DGBI (fill out diagnosis here)	☐ Gastrointestinal Symptoms	sprains, dislocations)
☐ Chronic constipation	☐ Abdominal pain	☐ Poor wound healing
☐ Hypermobile Ehlers-Danlos syndrome (hEDS) or	☐ Bloating	☐ Hematologic / Skin-Related Symptoms
other HSD	Constipation	☐ Easy bruising and bleeding
☐ Lyme disease	☐ Irregular bowel movements	☐ Systemic Symptoms
Other:	☐ Nausea	☐ Fatigue
	☐ Vomiting	☐ Gastrointestinal Symptoms
	☐ Acid Reflux	☐ Abdominal pain
	☐ Neurological / Visual Symptoms	☐ Acid reflux
	☐ Blurred vision	☐ Constipation
	☐ Fatigue	☐ Nausea
	•	☐ Diarrhea
	POTS Management Checklist (check for yes)	☐ Vomiting
	☐ Medications	☐ Bloating
	☐ Calcium channel / beta blockers	☐ Constipation
	☐ Sodium intake of 3,000 to 10,000 mg per day	☐ Diarrhea
	☐ Water intake of 2-4 L per day	☐ Postprandial fullness
	4-6 Small, frequent meals	☐ Epigastric pain
	☐ Compression garments	L October 18 Lea
	☐ Exercise (recumbent or semi-recumbent modalities	EDS Management Checklist (check for yes)
	(e.g., rowing, recumbent cycling))	☐ Zebra physical therapy
	☐ Physical therapy	Constipation and motility aids as needed

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Table 2. Treatment Considerations for Patients With Hypermobile Ehlers-Danlos Syndrome or Hypermobility Spectrum Disorder With POTS and/or MCAS

Symptom	Treatment	3,000-10,000	
POTS symptoms	Lifestyle (exercise, dietary fluid/salt, salt tablets, acute/chronic intravenous hydration [rare], Blood volume expanders (fludrocortisone, desmopressin, erythropoietin) Heart rate lowering agents (propranolol, ivabradine) Central nervous system sympatholytics (clonidine, methyldopa) Other (midodrine, pyridostigmine, droxidopa, modafinil)	2-4 liter Compress Ex	
Diarrhea	Dietary modification (low FODMAP, gluten free, soluble fiber) Microbiome modification (rifaximin, Bifidobacterium infantis 35624) Antidiarrheals (loperamide, diphenoxylate) Bile acid sequestrants (cholestyramine, colesevelam, colestipol) μ- and κ-opioid receptor antagonist and δ-receptor antagonist (eluxadoline) ^α 5-HT ₃ receptor antagonist: alosetron (female patients only)		
Constipation	Fiber supplements (psyllium, methyl cellulose) Osmotic laxatives (PEG 3350, lactulose, and milk of magnesia) Stimulant laxatives (bisacodyl and senna) Chloride channel activator (lubiprostone) Guanylate cyclase-C agonist (linaclotide and plecanatide) 5-HT ₄ agonist (prucalopride) Sodium hydrogen exchanger 3 inhibitor (tenapanor)		
Nausea/vomiting	Antiemetics (ondansetron, prochlorperazine, promethazine, aprepitant, off-label use of carbidopa) ^b Prokinetics (metoclopramide, domperidone, pyridostigmine and off-label use of prucalopride) Complementary medicine therapies (aromatherapies, ginger tea, STW5)		
Abdominal pain	Acid Suppression (H ₂ receptor antagonist, proton pump inhibitors) Antispasmodics (dicyclomine, hyoscyamine and peppermint oil) Neuromodulators (TCA, SSRI, SNRI, neuroleptics, anticonvulsants) Psychological therapies (cognitive behavioral therapy, hypnotherapy, relaxation therapies)		
Autoimmunity	Corticosteroids or immunoglobulins ^{20,c}		
MCAS	H₂ receptor antagonist (famotidine, nizatidine, ranitidine) Second-generation H₁ antagonist (cetirizine, levocetirizine, fexofenadine, loratadine) Mast cell stabilizer (cromolyn sodium, ketotifen²) Leukotriene receptor antagonist (montelukast)		

3,000-10,000mg sodium daily 2-4 liters fluid daily Compression Garments Exercise

Give Resources

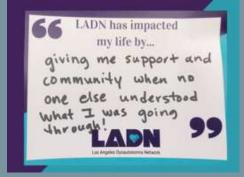
- Los Angeles Dysautonomia Network (support group and events)
 - https://www.la-dn.org/
 - https://www.la-dn.org/events
 - LADN.home@gmail.com
- The Dysautonomia Project
 - https://thedysautonomiaproject.org/resources/
- Facebook Support Groups
- The Ehlers-Danlos Society
 - https://www.ehlers-danlos.com
- The Mast Cell Disease Society
 - https://tmsforacure.org/

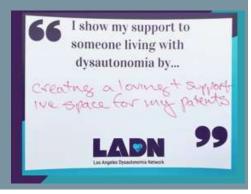
Be Compassionate & Show Empathy & Above all: BELIEVE YOUR PATIENTS!



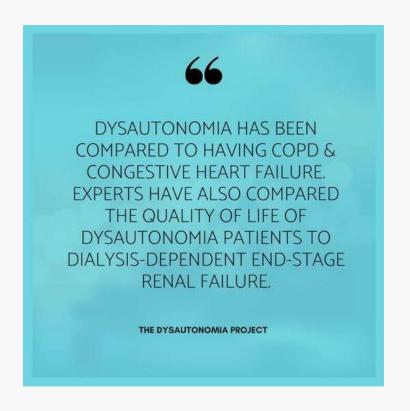


I show my support to someone living with dysautonomia by...





Conclusion





Thank you!

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