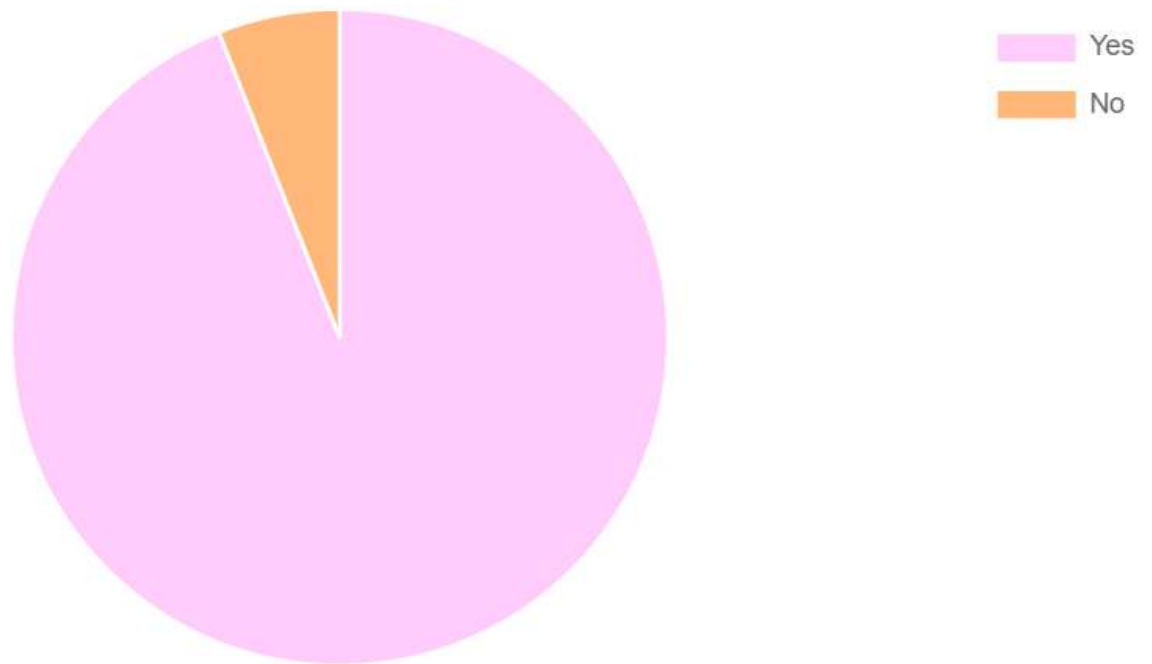


# PoTS and OI

Question 1 ☰ MULTIPLE CHOICE

Do you have symptoms of PoTS?



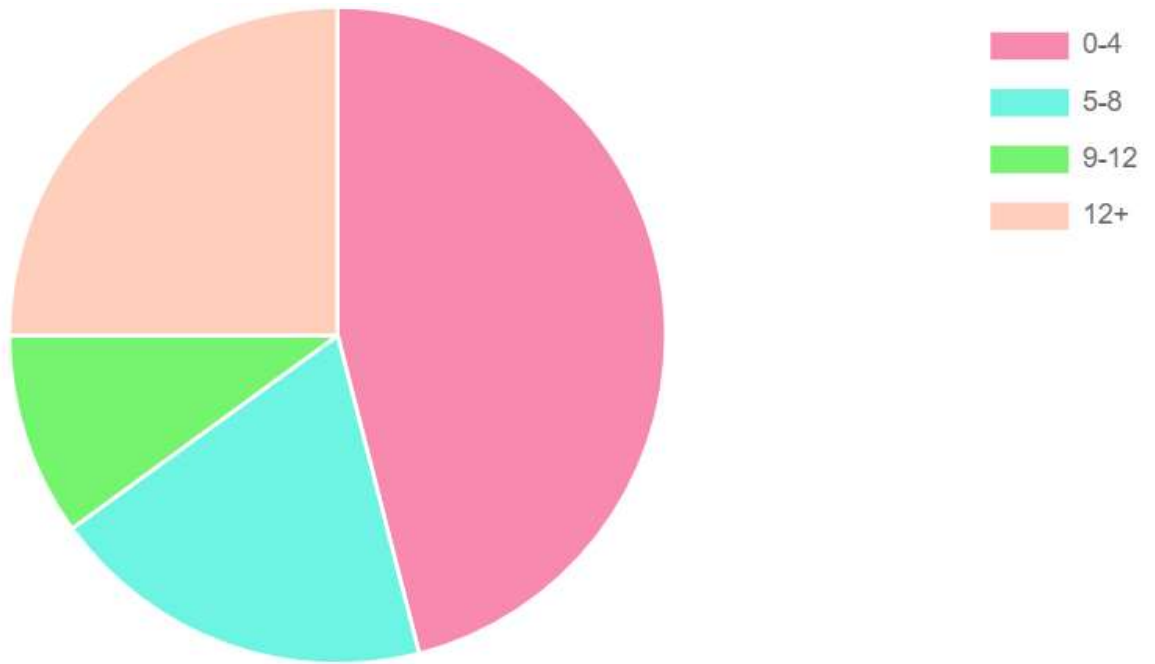
ANSWERS	RESPONSES	
Yes	94%	952
No	6%	63

1015 Answered

0 Skipped

Question 2 ☰ MULTIPLE CHOICE

How many years have you had PoTS symptoms?



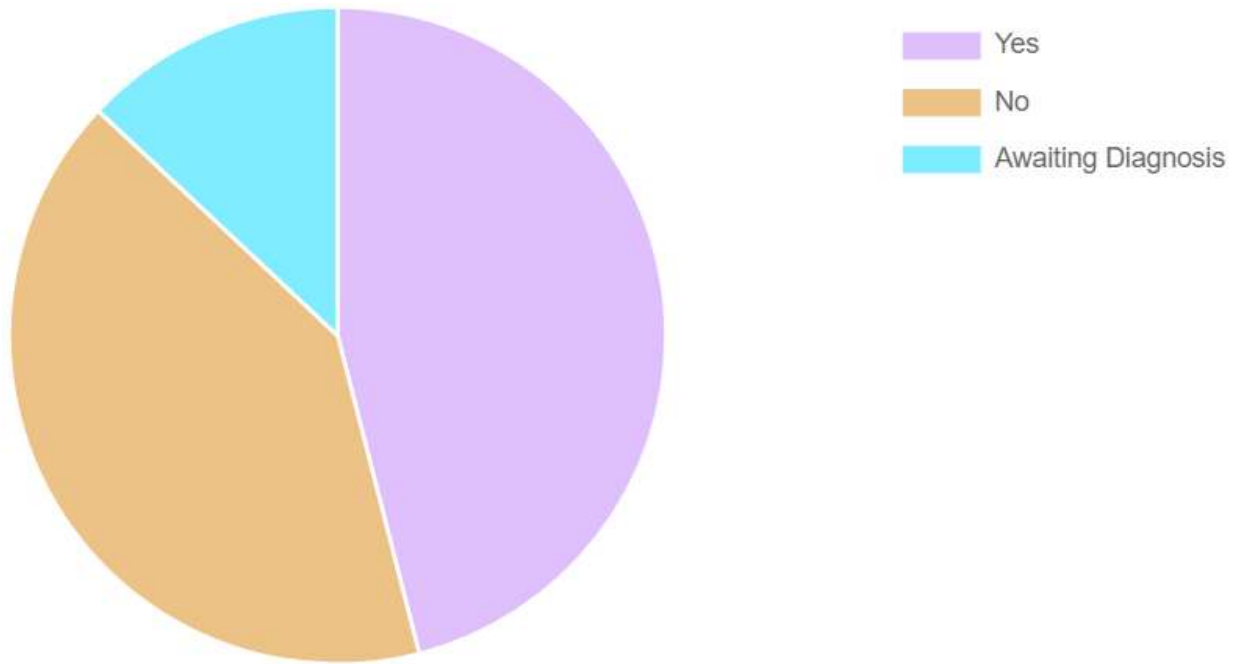
ANSWERS	RESPONSES	
9-12	10%	94
0-4	46%	432
12+	25%	238
5-8	19%	182

946 Answered

69 Skipped

Question 3 ☰ MULTIPLE CHOICE

### Have you been diagnosed with Postural Orthostatic Tachycardia Syndrome (PoTS)



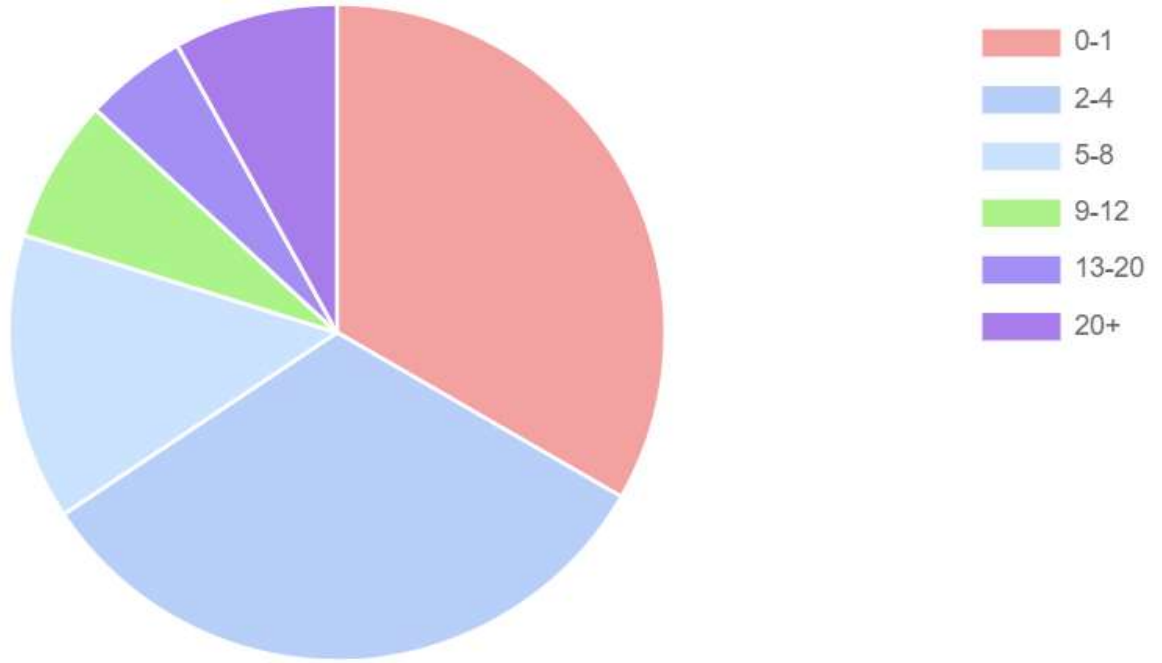
ANSWERS	RESPONSES	
No	41%	387
Yes	46%	440
Awaiting Diagnosis	13%	124

951 Answered

64 Skipped

Question 4 ☰ MULTIPLE CHOICE

How many years did it take to get a diagnosis of PoTS?



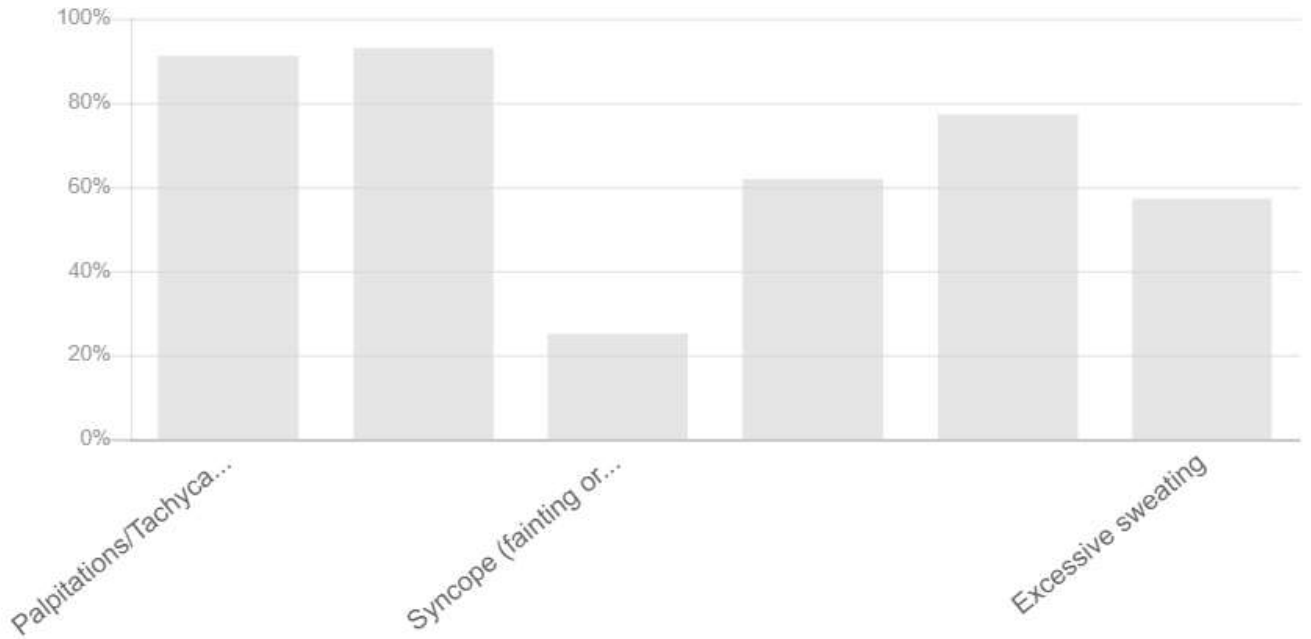
ANSWERS	RESPONSES
2-4	32% 142
5-8	14% 63
0-1	33% 147
13-20	5% 22
20+	8% 33
9-12	7% 32

439 Answered

576 Skipped

Question 5  CHECKBOXES

What PoTS symptoms do you experience?



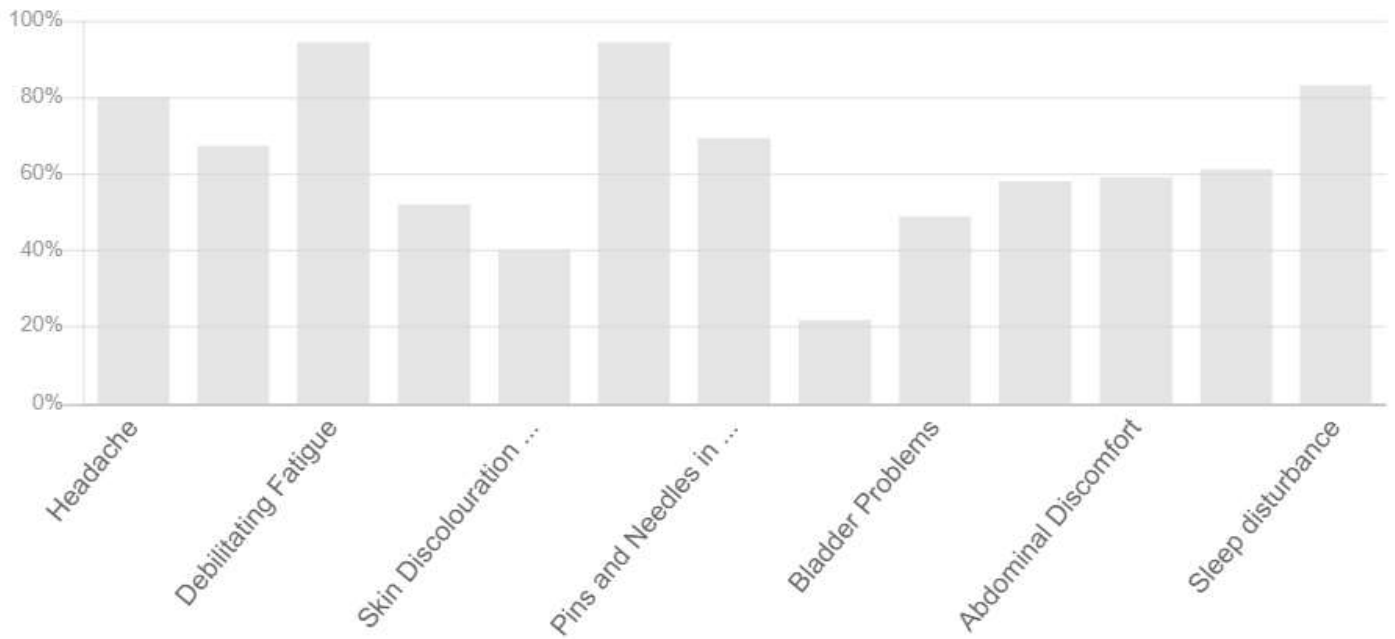
ANSWERS	RESPONSES	
Palpitations/Tachycardia (rapid pulse rate)	91%	864
Dizziness or light-headedness or presyncope (almost fainting)	93%	888
Syncope (fainting or blackouts)	25%	236
Chest discomfort	62%	593
Shortness of breath	77%	728
Excessive sweating	57%	538

950 Answered

65 Skipped

Question 6  CHECKBOXES

Do you experience any of these other symptoms of PoTS - some of which also occur in ME/CFS?



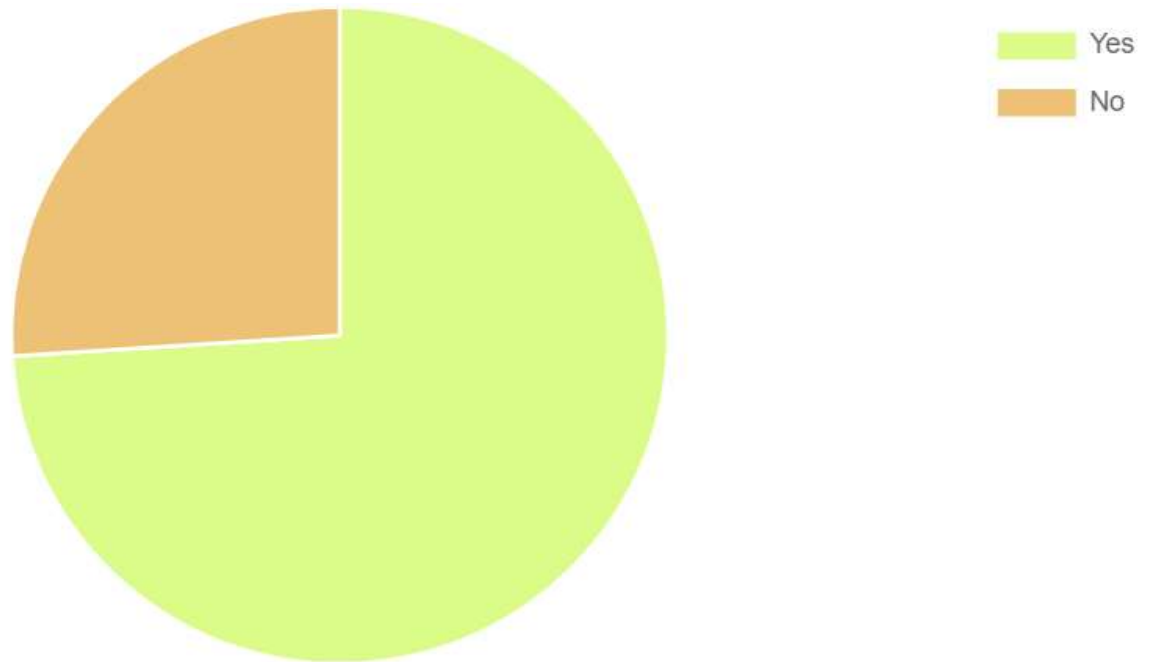
ANSWERS	RESPONSES	
Headache	80%	759
Nausea	67%	636
Debilitating Fatigue	94%	895
Dry mouth	52%	492
Skin Discolouration (blue/dark red feet)	40%	382
Cognitive Dysfunction (brain fog)	94%	891
Pins and Needles in arms and/or legs	69%	651
Swollen extremities	22%	213
Bladder Problems	49%	467
Bowel Problems	58%	547
Abdominal Discomfort	59%	558
Blurred vision	61%	582
Sleep disturbance	83%	784

950 Answered

65 Skipped

Question 7 ☰ MULTIPLE CHOICE

Do you find PoTS symptoms are worse in the summer due to heat intolerance?



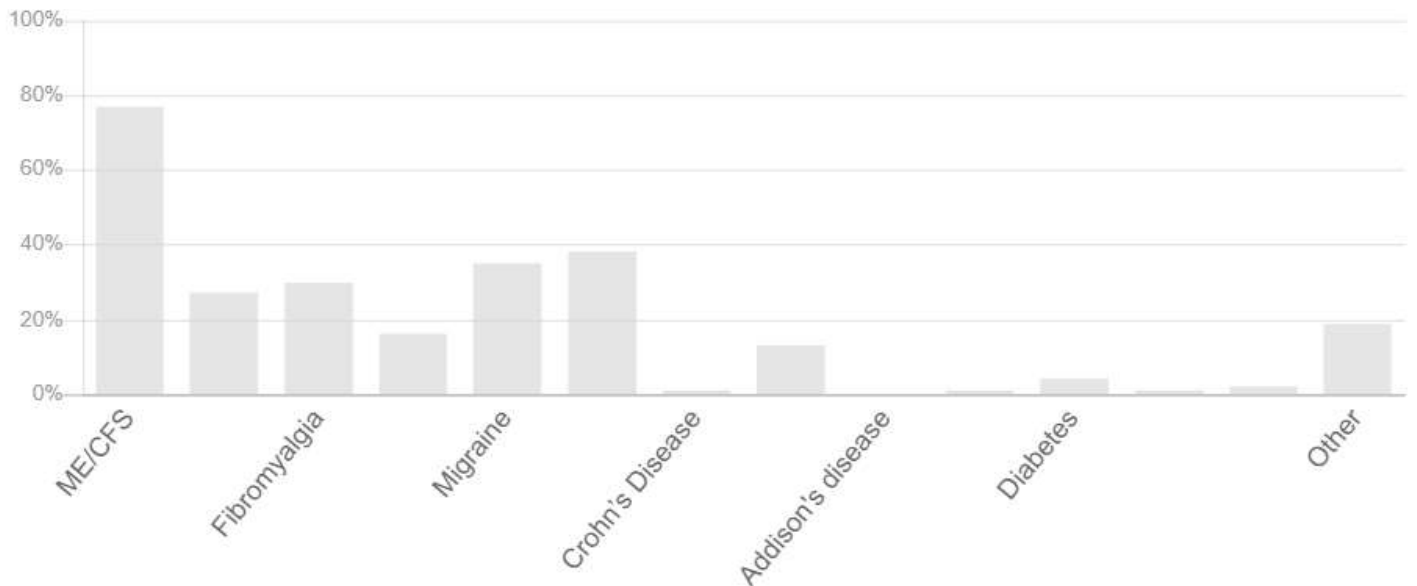
ANSWERS	RESPONSES	
Yes	74%	695
No	26%	238

933 Answered

82 Skipped

Question 8 ☑ CHECKBOXES

Do you have any of the following co-morbidities?



ANSWERS	RESPONSES	
ME/CFS	77%	701
Long Covid	27%	243
Fibromyalgia	30%	275
hEDS (Hypermobility Ehlers-Danlos Syndrome)	16%	147
Migraine	35%	317
Irritable Bowel Syndrome	38%	350
Crohn's Disease	1%	8
MCAS (Mast Cell Activation Syndrome)	13%	118
Addison's disease	0%	2
Crohn's disease or ulcerative colitis	1%	10
Diabetes	4%	37
Lupus	1%	5
Sjogren's syndrome	2%	17
Other	19%	173
















































915 Answered
























100 Skipped



























Question 9  SINGLE LINE TEXT
























## Other co-morbidities not listed above



























ANSWERS	DATE	
Epilepsy	October 24, 2023 at 5:49 am	
Hashimoto's	October 24, 2023 at 8:11 am	
Sinus tarsi syndrome	October 24, 2023 at 8:24 am	
Celiac Disease	October 24, 2023 at 9:05 am	
Allergies including anaphylaxis not diagnosed as MCAS, asthma, low blood pressure, hypothyroidism, multiple aneurysms and pseudoaneurysms	October 24, 2023 at 9:07 am	
Leukemia	October 24, 2023 at 9:11 am	
Myasthenia gravis, stroke, epilepsy	October 24, 2023 at 9:12 am	
Pnes	October 24, 2023 at 9:18 am	
Osteoporosis, arthritis in spine, Dupuytren's Syndrome, asthma	October 24, 2023 at 9:22 am	
Microscopic Colitis	October 24, 2023 at 9:32 am	
Heart failure	October 24, 2023 at 9:52 am	
Gastroparesis	October 24, 2023 at 10:04 am	
Hypothyroidism	October 24, 2023 at 10:23 am	
Spinal cord flattening at C4/5	October 24, 2023 at 10:33 am	
Symptomatic Hypermobility	October 24, 2023 at 10:35 am	
Delayed gastric emptying, hypoglycaemia	October 24, 2023 at 11:20 am	
Rectovaginal endometriosis. Joint hypermobility syndrome.	October 24, 2023 at 12:17 pm	
SPI- SIndrome de piernas inquietas	October 24, 2023 at 1:04 pm	
Graves Disease	October 24, 2023 at 1:05 pm	
epilepsy	October 24, 2023 at 1:26 pm	


























ANSWERS	DATE	
COPD	October 24, 2023 at 1:35 pm	
Coeliac Disease, Hashimoto's disease	October 24, 2023 at 1:48 pm	
Hypermobility spectrum disorder. Autism. ADHD. Lipoedema.	October 24, 2023 at 2:00 pm	
ADHD, Autism, Obstructive Sleep Apnoea, PCOS, Anxiety, Depression	October 24, 2023 at 2:25 pm	
Being investigated for sjrogens my ophthalmologist thinks I have it. I also think I may have MCASa but not sure how to get a diagnosis	October 24, 2023 at 3:06 pm	
Chronic daily headaches, chronic abdominal pain, degeneration disease of lumber spine, PCOS	October 24, 2023 at 3:41 pm	
High cholesterol, gallstones	October 24, 2023 at 3:52 pm	
Chiari Malformation	October 24, 2023 at 4:30 pm	
Hypothyroidism	October 24, 2023 at 6:30 pm	
Bile Acid Malabsorption, SAPHO, Paroxysmal Hemicrania	October 24, 2023 at 7:14 pm	
Raynards, food intolerances	October 24, 2023 at 8:26 pm	
autism, adhd, binocular vision disorder, orthostatic hypotension, vasovagal syncope, awaiting a heds and me/cfs diagnosis	October 24, 2023 at 9:02 pm	
Hypermobility	October 24, 2023 at 9:21 pm	
Vasal vagal syncope	October 24, 2023 at 9:56 pm	
Hypermobility disorder symptomatic	October 24, 2023 at 10:10 pm	
Post covid vaccine syndrome	October 25, 2023 at 12:46 am	
Non-celiac gluten sensitivity, vitamin b12 deficiency	October 25, 2023 at 7:51 am	
Rheumatoid arthritis	October 25, 2023 at 8:25 am	
Hypermobility	October 25, 2023 at 8:46 am	
Multiple allergies & cancers	October 25, 2023 at 9:06 am	
PMDD	October 25, 2023 at 9:45 am	
Lots of issues with 10cm sliding hiatal hernia, Scoliosis	October 25, 2023 at 9:46 am	
Anxiety	October 25, 2023 at 10:07 am	
Pre Diabetes, Asthma	October 25, 2023 at 10:31 am	
High cholesterol	October 25, 2023 at 10:33 am	

ANSWERS	DATE	
Ankelosing Spondylitis and PCOS	October 25, 2023 at 10:51 am	
Diverticulitis	October 25, 2023 at 12:46 pm	
Cardiac syndrome x	October 25, 2023 at 3:14 pm	
Generalised Joint Hypermobilty Syndrome	October 25, 2023 at 5:51 pm	
Tietze's Syndrome, Ectopic Heartbeat, Neurological balance disorder	October 25, 2023 at 6:44 pm	
Endometriosis	October 25, 2023 at 7:47 pm	
Atrial Fibrillation, Ectopic heartbeats, Hypertension increasing further on exertion, Reflux, Asthma	October 25, 2023 at 10:28 pm	
Hypoglacemia, Sensory Overload Syndrome, SIBO,SIFO(cleared), H Pylori, hypochlorhydria,GERD,B12 Deficiency,	October 26, 2023 at 5:22 am	
Hypermobility	October 26, 2023 at 6:56 am	
Menopausal due to cancer treatment (both of which can cause some of these symptoms)	October 26, 2023 at 9:15 am	
Gastroparesis, craniocervical instability	October 26, 2023 at 10:39 am	
Primary biliary cholangitis ( autoimmune liver disease)	October 26, 2023 at 11:41 am	
Joint Hypermobility	October 26, 2023 at 11:47 am	
Gastroparesis	October 26, 2023 at 12:11 pm	
ADHD, sexual dysfunction (erectile), MCAS (raised prostaglandin D2, F2A). Likely ME/CFS, fulfil criteria but no formal diagnosis as being cared for by Long Covid clinic.	October 26, 2023 at 12:14 pm	
Endometriosis	October 26, 2023 at 2:49 pm	
Bipolar	October 26, 2023 at 4:15 pm	
lih, dysmotility, hashimotos, pcos, autonomic neuropathy, suspected sfn but awaiting biopsy via kings pots team	October 26, 2023 at 4:51 pm	
Gastroparesis	October 26, 2023 at 5:36 pm	
Hashimoto's thyroiditis	October 26, 2023 at 6:06 pm	
Osteoarthritis, Myasthenia Gravis, high blood pressure, stroke (TIA), raynards, bulging discs, chronic pain, tinnitus,	October 26, 2023 at 8:06 pm	
Post-vaccine syndrome; chronic coagulopathy; endocrine dysfunction	October 26, 2023 at 10:53 pm	
Long vax	October 27, 2023 at 3:19 am	

ANSWERS	DATE	
Hypothyroidism	October 29, 2023 at 11:39 am	
Functional neurological disorder	November 1, 2023 at 9:21 am	
Rheumatoid arthritis	November 1, 2023 at 9:46 am	
c-ptsd	November 1, 2023 at 9:50 am	
Gilbert's Syndrome	November 1, 2023 at 10:30 am	
Asthma	November 1, 2023 at 11:00 am	
Asthma COPD arthritis	November 1, 2023 at 1:11 pm	
Hypothyroidism, depression	November 1, 2023 at 1:12 pm	
Hypothyroidism	November 1, 2023 at 1:32 pm	
Hashimotos, CVID, anemic, lymphocytopenia, hypogammaglobunemia, etc	November 1, 2023 at 2:04 pm	
R Arthritis osteoarthritis	November 1, 2023 at 2:05 pm	
Hypermobility	November 1, 2023 at 2:35 pm	
Fully controlled epilepsy	November 1, 2023 at 2:45 pm	
Diviticulitiosis	November 1, 2023 at 2:49 pm	
Small fibre perhiferal neuropathy	November 1, 2023 at 2:55 pm	
Hashimoto's thyroiditis	November 1, 2023 at 3:24 pm	
Sarciodosis	November 1, 2023 at 3:44 pm	
Psoriatic arthritis	November 1, 2023 at 3:54 pm	
Classical Ehlers-Danlos Syndrome	November 1, 2023 at 4:32 pm	
Hydrocephalus and IIH	November 1, 2023 at 5:02 pm	
Divaticulitis	November 1, 2023 at 5:19 pm	
Small fibre neuropathy affecting autonomic nerves, hyper mobility	November 1, 2023 at 6:15 pm	
Hypertension	November 1, 2023 at 7:26 pm	
gut dysfunction	November 1, 2023 at 7:44 pm	
Men1	November 1, 2023 at 7:56 pm	
Musculo-skeletal issues	November 1, 2023 at 11:31 pm	

ANSWERS	DATE	
Adenomyosis & Chronic Pelvic Pain, Anxiety & Depression, Asthma, Auto-Immune Chronic Urticaria, B12 Deficiency, Gastroesophageal reflux disease (GERD) & Laryngopharyngeal Reflux (Silent Reflux), Hypermobility, Hypotension(Low Blood Pressure), Reactive Lymph Nodes, Migraines, Osteopenia & Vitamin D Insufficiency, Recurrent Otitis Externa, Recurrent Renal Stones & Calcification, Seborrhic Dermatitis, Inappropriate Sinus Tachycardia & Ectopic Heartbeat, Trigeminal Neuralgia	November 2, 2023 at 1:36 am	
Small fibre neurology	November 2, 2023 at 8:30 am	
Coeliac disease	November 2, 2023 at 8:50 am	
Mastocytosis	November 2, 2023 at 11:08 am	
Scoliosis, kyphosis, sinus tachycardia, idiopathic angiodema	November 2, 2023 at 11:26 am	
Hypothyroidism	November 2, 2023 at 3:43 pm	
Endometriosis, morphea, arthritis low blood sugars,	November 2, 2023 at 11:53 pm	
Coeliac Disease	November 3, 2023 at 8:27 am	
PCOS	November 3, 2023 at 1:05 pm	
TMJ, CRPS	November 3, 2023 at 5:54 pm	
Atrial fibrillation/heart failure	November 3, 2023 at 8:10 pm	
Multiple sclerosis	November 3, 2023 at 8:13 pm	
Severe eczema	November 4, 2023 at 6:05 am	
Benign hypermobility syndrome	November 4, 2023 at 1:21 pm	
Asthma	November 4, 2023 at 4:33 pm	
Dysnergic Defecation / Autism / Other Mental Health	November 4, 2023 at 4:46 pm	
Gastroparesis	November 4, 2023 at 9:49 pm	
Orthostatic Hypotension, Scoliosis	November 4, 2023 at 10:01 pm	
Interstitial Cystitis	November 5, 2023 at 10:12 am	
Dysautonomia	November 6, 2023 at 1:32 pm	
PPPD, Vestibular migraine, non-compensatory labyrinthine failure, functional limb weakness	November 6, 2023 at 2:29 pm	
Coeliac disease and undifferentiated inflammatory arthritis.	November 6, 2023 at 3:06 pm	
Hypothyroidism, asthma	November 6, 2023 at 5:45 pm	

ANSWERS	DATE	
Gastroparesis, FND	November 13, 2023 at 1:49 pm	
digestive problems- gallbladder dyskinesia. bam. bile reflux and gastritis	November 17, 2023 at 4:04 pm	
Rheumatoid Arthritis	November 17, 2023 at 4:37 pm	
B12 deficiency (nerve damage from it can cause pots)	November 17, 2023 at 4:40 pm	
In remission from Graves Disease and Graves Eye Disease (auto immune).	November 17, 2023 at 4:46 pm	
Celiac disease	November 17, 2023 at 4:47 pm	
Myasthenia Gravis	November 17, 2023 at 6:08 pm	
Underactive thyroid	November 17, 2023 at 6:09 pm	
Endometriosis	November 17, 2023 at 6:15 pm	
Sleep apnea, rosacea, Raynaud's	November 17, 2023 at 7:49 pm	
IIH	November 17, 2023 at 7:54 pm	
Functional Neurological Disorder	November 17, 2023 at 7:58 pm	
neurally-mediated hypotension; supine hypertension	November 17, 2023 at 10:29 pm	
Occipital neuralgia	November 17, 2023 at 10:54 pm	
Cluster headaches. Non epileptic seizures.	November 17, 2023 at 11:37 pm	
Microscopic colitis	November 18, 2023 at 12:06 am	
Fragile X Premutation	November 18, 2023 at 12:26 am	
Hashimotos, celiac.	November 18, 2023 at 12:36 am	
Epilepsy	November 18, 2023 at 1:09 am	
Histamine intolerance (not sure if MCAS)	November 18, 2023 at 6:21 am	
Hashimoto's thyroiditis and PA	November 18, 2023 at 7:30 am	
Hashimotos thyroiditis	November 18, 2023 at 7:42 am	
Polymyalgia Rheumatica	November 18, 2023 at 8:35 am	
Psoriatic arthritis	November 18, 2023 at 9:11 am	
Hashimotos hypothyroidism	November 18, 2023 at 9:16 am	
Depression and anxiety	November 18, 2023 at 10:08 am	

ANSWERS	DATE	
Diverticular disease	November 18, 2023 at 10:32 am	
B12 malabsorption issue (thus far unknown cause), been B12 deficient for years before correct treatment with injections was started. Asthma.	November 18, 2023 at 10:35 am	
Hypothyroidism	November 18, 2023 at 11:15 am	
Sarcoidosis	November 18, 2023 at 12:01 pm	
Endometriosis	November 18, 2023 at 12:23 pm	
Vasculitis. Have had cancer.	November 18, 2023 at 12:33 pm	
Small fibre neuropathy (developed more than 10yrs after ME diagnosis)	November 18, 2023 at 12:41 pm	
have ticked hEDS - not officially diagnosed - has been mentioned by drs as likely due to history and symptoms	November 18, 2023 at 2:50 pm	
Meares Irlen Syndrome, MCS	November 18, 2023 at 3:31 pm	
Autistic	November 18, 2023 at 8:09 pm	
Hashimoto disease	November 18, 2023 at 8:29 pm	
Hypercholesterolemia, NAFLD, gallstone, lichen sclerosus, vitiligo, acid reflux	November 18, 2023 at 11:59 pm	
Ménière's disease	November 19, 2023 at 1:58 am	
Hypothyroid.	November 19, 2023 at 2:24 pm	
Gastroparesis	November 20, 2023 at 1:37 pm	
Asthma, PTSD	November 20, 2023 at 6:21 pm	
Hypothyroid	November 21, 2023 at 5:04 am	
NARFLD	November 21, 2023 at 8:47 am	
Hashimoto thyroiditis, rheumatoid arthritis, heart failure (HFpEF), asthma	November 21, 2023 at 10:01 am	
Autism	November 21, 2023 at 11:52 am	
Suspect MCAS but not diagnosed	November 21, 2023 at 1:33 pm	
Cluster headaches	November 21, 2023 at 4:42 pm	
Hypothyroidism	November 21, 2023 at 6:28 pm	
PCOS	November 21, 2023 at 8:20 pm	
PCOS, hypothyroid, asthma, hypermobility	November 22, 2023 at 9:45 pm	

**ANSWERS**

**DATE**

Asthma

November 24, 2023 at 1:04 am

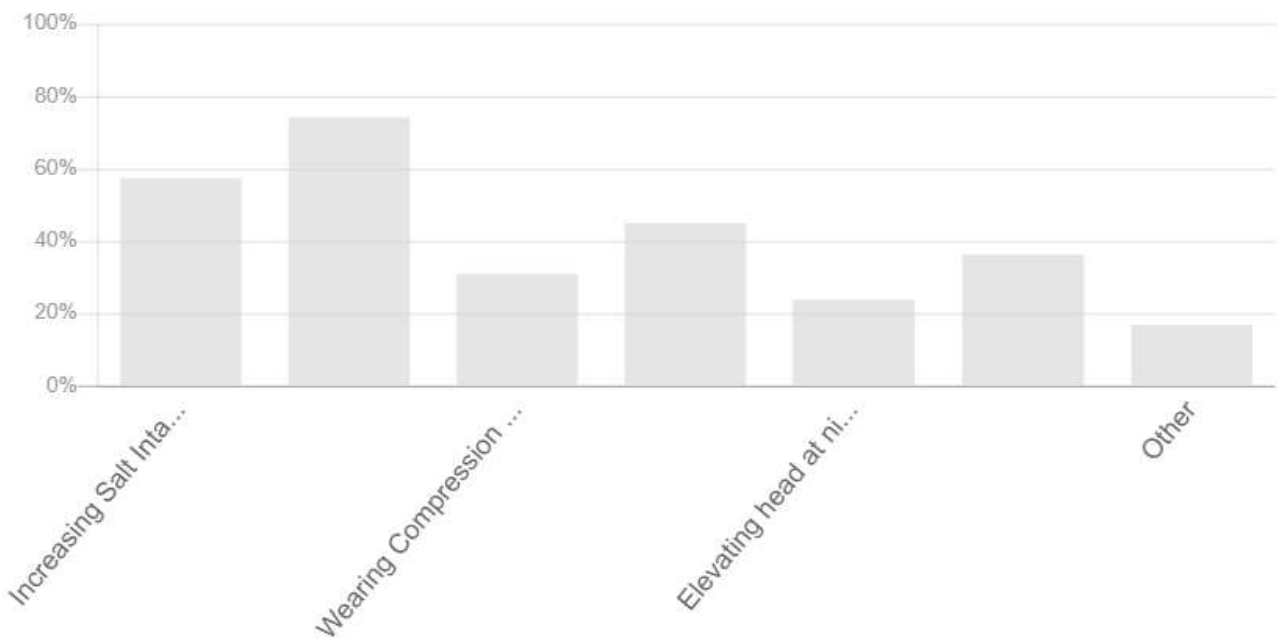


169 Answered

846 Skipped

Question 10  CHECKBOXES

### What lifestyle changes have you found helped the main symptoms of PoTS?



ANSWERS	RESPONSES
Increasing Salt Intake	57% 446
Increasing Fluids	74% 575
Wearing Compression Stockings	31% 244
Maintaining a healthy diet and smaller more frequent meals	45% 350
Elevating head at night	24% 190
Reducing caffeine intake	36% 283
Other	17% 136











































779 Answered























236 Skipped
























Question 11  SINGLE LINE TEXT

























## Other helpful lifestyle changes not listed above















ANSWERS	DATE	
Time	October 24, 2023 at 5:49 am	
just meds	October 24, 2023 at 8:08 am	
Not sitting or standing for too long , raising feet when sitting , no sitting on high stools, not going beyond energy envelope, pacing , avoiding sugar and carbs , standing up slowly , keeping heart rate down by using heart rate monitor, coconut water for electrolytes	October 24, 2023 at 8:23 am	
Avoiding standing still, sit down, jiggle around	October 24, 2023 at 8:24 am	
reduced standing	October 24, 2023 at 8:45 am	
elevating head cricks my neck, we've elevated the bed instead, spending as much time as possible flat if not very supported with pillows etc	October 24, 2023 at 8:53 am	
Having a diagnosis and insight: mine and others, so I can be proactive eg sitting/lying to prevent fainting, carrying a small camping stool, trying to walk and move every day even though ME makes it challenging	October 24, 2023 at 9:07 am	
Using wheelchair	October 24, 2023 at 9:10 am	
Keeping cool with ice hats and caps. Drinking electrolytes	October 24, 2023 at 9:11 am	
Using a shower stool, oral rehydration tablets	October 24, 2023 at 9:25 am	
Medications	October 24, 2023 at 9:32 am	
Pacing	October 24, 2023 at 9:52 am	
Using a stick with a stool	October 24, 2023 at 10:11 am	
Pacing	October 24, 2023 at 10:40 am	
I spend most of my time lying down and when I get up I do it slowly and with a break between sitting and standing to manage the dizziness	October 24, 2023 at 12:06 pm	
Medication	October 24, 2023 at 12:11 pm	
Very small impact - my overall health continued to deteriorate despite these	October 24, 2023 at 12:51 pm	

ANSWERS	DATE	
measures and careful pacing		
Careful pacing and energy management. Low carb diet.	October 24, 2023 at 1:00 pm	
Elevating legs when possible	October 24, 2023 at 1:41 pm	
Still trying to figure it out what works	October 24, 2023 at 3:06 pm	
Lying back down flat when symptoms start until they subside.	October 24, 2023 at 3:41 pm	
Keeping hr under 108 (as advised by Cardiologist) which means frequent lying down during day as hr goes easily to 180. NHS attendant propelled recliner wheelchair so i can I can leave the house as wheelchair allows me to lay completely when episodes occur. Daily aspirin.	October 24, 2023 at 3:55 pm	
Gluten free, low carb meals.	October 24, 2023 at 5:37 pm	
Careful alcohol consumption, regular exercise,	October 24, 2023 at 6:31 pm	
Making myself walk and work, seems to distract my mind and somehow makes me feel better physically.	October 24, 2023 at 7:25 pm	
I so far have not found anything that gives me complete relief	October 24, 2023 at 8:33 pm	
cbd oil, adhd medication	October 24, 2023 at 9:02 pm	
Regular exercise	October 24, 2023 at 9:23 pm	
Meditation	October 24, 2023 at 9:56 pm	
Reducing time spent standing	October 25, 2023 at 7:51 am	
no alcohol, no glutr	October 25, 2023 at 8:27 am	
electrolytes	October 25, 2023 at 8:46 am	
Rest	October 25, 2023 at 9:27 am	
Medication	October 25, 2023 at 10:51 am	
Beta blocker- medication propranolol	October 25, 2023 at 12:50 pm	
Pacing	October 25, 2023 at 1:46 pm	
Staying in a reclining or laying position 23 1/2 out of every 24 hours	October 25, 2023 at 2:42 pm	
Rest	October 25, 2023 at 10:17 pm	
Oxygen machine at home, electrolytes, elevating feet, air con, warm not hot showers, shower chair, mobility aids like stick and wheelchair	October 26, 2023 at 12:49 am	
Noticed significant improvements since taking oral B12 spray	October 26, 2023 at 5:22 am	

ANSWERS	DATE	
Electrolytes, staying in stable temperatures if possible	October 26, 2023 at 6:56 am	
Lying or semi recumbent in bed . Curtains closed. Reduce migraine triggers	October 26, 2023 at 11:41 am	
Laying down/bedridden	October 26, 2023 at 12:11 pm	
It is very variable - hydration/salt sometimes helps, sometimes does not. Intermittent fasting seems to help. Keeping horizontal (unsustainable, but works). Not convinced compression clothing helps, but could be I need greater coverage.	October 26, 2023 at 12:14 pm	
Reclining all day	October 26, 2023 at 12:26 pm	
Abdominal compression	October 26, 2023 at 2:41 pm	
Lying down a lot	October 26, 2023 at 5:50 pm	
Make sure I get plenty of sleep (no alarms) and also take my time in the mornings until my heart rate stabilizes before going to work. Having a late start time (accommodation) for beginning work.	October 26, 2023 at 6:06 pm	
Electrolytes	October 26, 2023 at 6:09 pm	
Hbot- hyperbolic oxygen therapy 4 times a week	October 27, 2023 at 1:20 am	
Heart rate monitoring, use of sensate and cold/ice packs to reduce palpitations. Elevating bed didn't help me so it's normal again now. Compression stockings too hard work to get on and uncomfortable. Neck fan and cool towel for cooling too. Reclining wheelchair and looking to get a reclining sofa, plus rollator with a seat.	October 27, 2023 at 9:18 am	
By upright for short but frequent periods throughout day, raised legs, walking aids etc	October 27, 2023 at 11:17 am	
Heart rate pacing	October 27, 2023 at 8:25 pm	
Light exercise for example swimming	October 27, 2023 at 11:29 pm	
Doing everything more slowly or sitting to complete tasks	October 28, 2023 at 4:23 pm	
Sports compression leggings	October 29, 2023 at 8:50 am	
honestly, little made any difference	October 30, 2023 at 11:47 am	
stop eating bread and pizza.	October 30, 2023 at 12:23 pm	
Magnesium supplements	November 1, 2023 at 9:16 am	
maintaining a healthy diet and managing how long I need to stand up.	November 1, 2023 at 9:24 am	
Meditation, Box breathing	November 1, 2023 at 9:52 am	
Sitting down or walking about, not standing in one place.	November 1, 2023 at 9:53 am	

ANSWERS	DATE	
Daily ORS drinks, avoiding rapid temp changes	November 1, 2023 at 10:11 am	
Using a walking stick to steady myself when dizzy	November 1, 2023 at 10:51 am	
Keep legs up.	November 1, 2023 at 11:08 am	
Feet up whenever possible, get up slowly, turn around slowly, don't stand still - sway when washing up, sit with legs up unless at dinner table	November 1, 2023 at 1:11 pm	
Lying down regularly, and when symptoms worsen	November 1, 2023 at 2:28 pm	
Oral rehydration solution daily, abdominal binder.	November 1, 2023 at 2:40 pm	
Very gradual movements from lying to sitting/standing.	November 1, 2023 at 2:45 pm	
I need to keep feet raised on footstool, lying down for brain to improve, use electric wheelchair with feet raised.	November 1, 2023 at 3:54 pm	
Still trying to find what helps or doesn't help	November 1, 2023 at 4:25 pm	
Vagal nerve stimulation	November 1, 2023 at 4:38 pm	
staying horizontal	November 1, 2023 at 6:16 pm	
I take ceremonial cocoa with mushroom powder (chaga, lion's mane and ashwagandha) in every morning. This with the bisoprolol I take (now reducing dose) has improved the quality of my hugely.	November 1, 2023 at 7:01 pm	
Electrolytes	November 1, 2023 at 7:13 pm	
sitting on a stool in the shower	November 1, 2023 at 7:44 pm	
Gluten free diet	November 1, 2023 at 9:49 pm	
Daily electrolytes intake	November 2, 2023 at 12:12 am	
Exercises given by doctor to prevent passing out like lying down with legs elevated, tapping feet on the ground and pumping hands together, crossing legs and squeezing etc	November 2, 2023 at 1:10 am	
Using a wheelchair, Oral rehydration fluids like Normalyte	November 2, 2023 at 6:24 am	
Lying flat as often as i need	November 2, 2023 at 8:30 am	
Not tried anything	November 2, 2023 at 8:44 am	
Standing up slowly	November 2, 2023 at 12:41 pm	
WHO oral rehydration solution (ie salt with glucose)	November 2, 2023 at 1:43 pm	
None	November 2, 2023 at 1:57 pm	

ANSWERS	DATE	
Taking rests throughout the day	November 3, 2023 at 1:55 pm	
Having a baby!	November 3, 2023 at 7:06 pm	
Pacing, legs up when sitting, control room temperature, low stress, improved sleep	November 3, 2023 at 8:13 pm	
Monitoring VHR	November 3, 2023 at 10:21 pm	
Avoiding activities standing and exercising lying down (Levine protocole+ analeptic exercices)	November 4, 2023 at 6:35 pm	
Not drinking alcohol	November 5, 2023 at 4:41 pm	
Legs up and lying down a lot	November 6, 2023 at 1:32 pm	
lying down minimum 12 hours daily	November 9, 2023 at 9:33 am	
Oral rehydration solution. Abdominal binder.	November 16, 2023 at 12:53 pm	
Avoiding too much upright activity	November 17, 2023 at 4:10 pm	
Elevating feet whenever possible	November 17, 2023 at 4:40 pm	
Lying back all the time. Keeping cool.	November 17, 2023 at 5:26 pm	
Avoiding bending down and reaching up	November 17, 2023 at 6:31 pm	
Avoiding standing for 5+ minutes	November 17, 2023 at 6:43 pm	
none	November 17, 2023 at 7:52 pm	
Reducing carbohydrates	November 17, 2023 at 7:54 pm	
Less intense exercise over a short period of time	November 17, 2023 at 10:10 pm	
pacing, phase change cooling vest, abdominal compression binder,	November 17, 2023 at 10:17 pm	
Not eating fodmaps massively decreased my blood pooling in my stomach. Walking short distances each day. I cannot stand still but can walk a bit which helped my pots. Eating before I go to bed stops adrenaline rushes at night	November 17, 2023 at 10:25 pm	
electrolytes; can't wear socks - take more energy than help provided - but abdominal binder helps; most helpful is being supine in recliner and hospital bed that go itno gravity position	November 17, 2023 at 10:29 pm	
CHOPS POTS exercise programme, taken very slowly, one month at each level.	November 18, 2023 at 6:10 am	
Regular b12 injections every other day stopped the pots symptoms.	November 18, 2023 at 7:30 am	
No alcohol	November 18, 2023 at 9:55 am	
No alcohol and reduced sugar, bread & pasta	November 18, 2023 at 10:32 am	

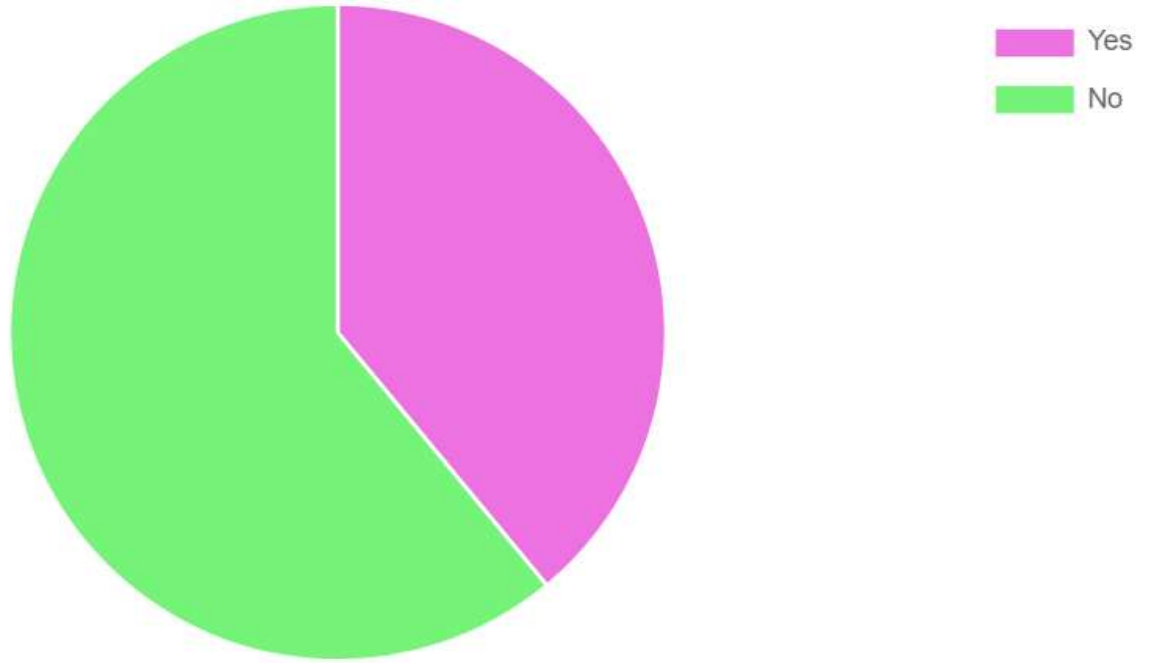
ANSWERS	DATE	
Correcting deficiencies. Such as vitamin D. Zinc. Iron. Folate. Potassium. And vitamin B12. Maintaining a healthy diet but with less frequent meals. Trying to keep a good and healthy sleep schedule. Not push the body or mind, in other words. Not overstepping my body's boundaries.	November 18, 2023 at 10:35 am	
If I can arrange it when out and about I find a place to get my legs up higher than my heart for 10 - 20 minutes. This will vastly prolong the time I can spend away from home.	November 18, 2023 at 12:01 pm	
not moving quickly, going up and down, bending, not standing for too long (didn't tick reduce caffeine as don't drink caffeine anyway)	November 18, 2023 at 2:50 pm	
IV fluids	November 18, 2023 at 2:58 pm	
Building muscle, correcting iron, B12 and vitamin D deficiency	November 18, 2023 at 3:31 pm	
Nothing has helped. Now trying medication.	November 18, 2023 at 3:35 pm	
Abdominal compression	November 18, 2023 at 4:27 pm	
HRT	November 18, 2023 at 6:59 pm	
Electrolytes. Pacing, recumbent exercise,	November 18, 2023 at 8:15 pm	
I'm only just figuring this out via sites like this. My doctor offered absolutely no information whatsoever.	November 20, 2023 at 6:21 pm	
Increased rests	November 21, 2023 at 9:08 am	
Exercise, especially electric bike and swimming; showeing my legs with cold water	November 21, 2023 at 10:01 am	
alcohol and gluten avoidance, pacing, cooler baths, less standing, exercises for muscles	November 22, 2023 at 9:00 pm	
Laying down a lot!	November 23, 2023 at 12:31 am	

123 Answered

892 Skipped

Question 12  MULTIPLE CHOICE

Do you take medication for PoTS?



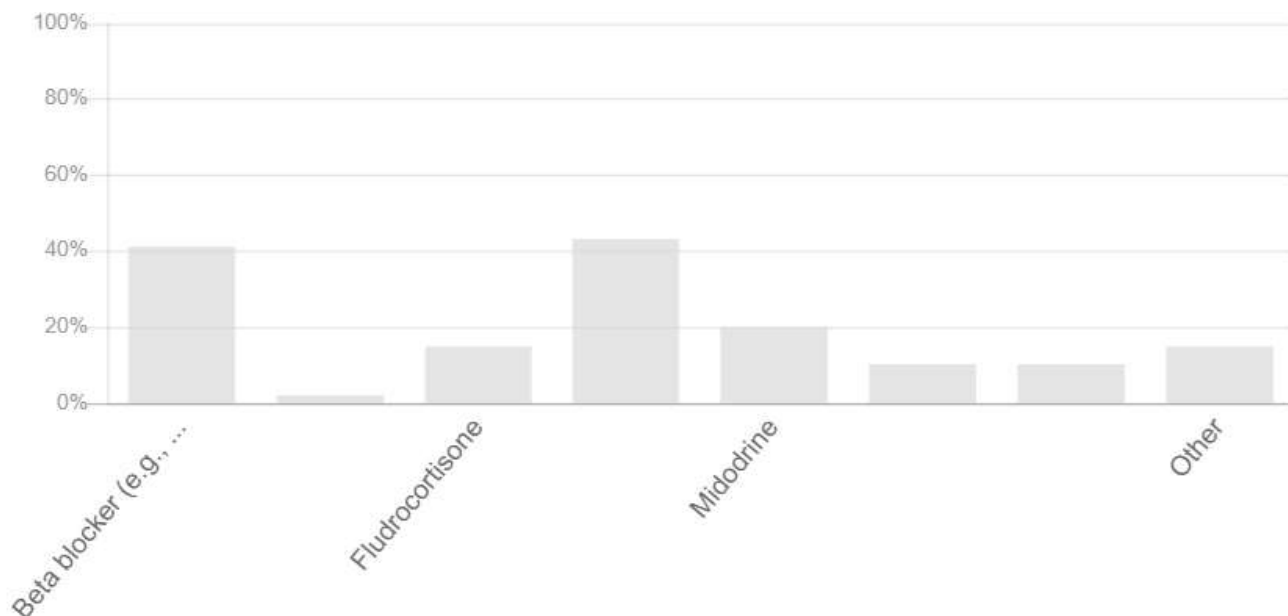
ANSWERS	RESPONSES	
Yes	39%	366
No	61%	579

945 Answered

70 Skipped

Question 13  CHECKBOXES

Do you take any of the following medications?



ANSWERS	RESPONSES	
Beta blocker (e.g., Metoprolol, Propranolol)	41%	149
Desmopressin	2%	8
Fludrocortisone	15%	54
Ivabradine (Procoralan)	43%	156
Midodrine	20%	72
Pyridostigmine (Mestinon)	10%	37
SSRI drug (e.g., citalopram, sertraline/Lustral)	10%	36
Other	15%	56

365 Answered

























650 Skipped























Question 14  SINGLE LINE TEXT










## Other medications not listed above

ANSWERS	DATE	
Betahistine Hydrochloride	October 24, 2023 at 5:49 am	



ANSWERS	DATE	
slow sodium	October 24, 2023 at 8:45 am	
Prescribed sodium chloride tablets	October 24, 2023 at 8:56 am	
Occasional pain meds when it becomes intolerable eg Gabapentin, codeine, until it becomes more manageable	October 24, 2023 at 9:07 am	
Slow sodium	October 24, 2023 at 9:10 am	
Modified release sodium chloride	October 24, 2023 at 10:04 am	
Slow sodium, Famotidine, methylphenidate, ondansetron	October 24, 2023 at 10:23 am	
Slow Sodium	October 24, 2023 at 10:40 am	
Diltiazem	October 24, 2023 at 12:25 pm	
Fludrocortisone for 12 months but caused very high blood pressured and increased severity of fatigue, headaches, cognitive problems and post exertional malaise	October 24, 2023 at 12:51 pm	
Slow release sodium	October 24, 2023 at 2:52 pm	
Salt tablets	October 24, 2023 at 3:08 pm	
Adizem	October 24, 2023 at 10:05 pm	
Verapamil	October 25, 2023 at 12:46 am	
Bisoprolol, Losartan, Diltelazem	October 25, 2023 at 3:01 am	
Amlodipine, Clopidogrel	October 25, 2023 at 6:31 am	
Verapamil	October 25, 2023 at 7:04 am	
Verapamil	October 25, 2023 at 7:51 am	
Verapamil	October 25, 2023 at 11:23 am	
Duloxetine	October 25, 2023 at 12:50 pm	
Sodium	October 25, 2023 at 7:40 pm	
LDN (low dose naltrexone, H1 & H2	October 26, 2023 at 6:56 am	
I take 25mg sertraline and 1mg amitriptyline, I had been on a higher dose of amitriptyline but have been tapering due to possible impact on POTS. I have been offered a beta and ivabradine, but frustrated with the lack of testing available to tailor management... you feel like a guinea pig.	October 26, 2023 at 12:14 pm	
Clonidine	October 26, 2023 at 4:44 pm	
Iv saline	October 26, 2023 at 4:51 pm	

ANSWERS	DATE	
Sodium Chloride Tablets	October 27, 2023 at 2:50 am	
Bisoprol	October 27, 2023 at 10:24 am	
Fexofenadine, famotidine	October 27, 2023 at 1:36 pm	
Slow Sodium tablets	October 28, 2023 at 9:02 pm	
Diazepam, Gabapentin, laxadol	November 1, 2023 at 11:11 am	
Co-codamol, gabbapentin, venoafloxine	November 1, 2023 at 12:17 pm	
Diltiazem (adizem)	November 1, 2023 at 12:58 pm	
Valtrex (improved OI significantly, lowered standing HR). Abilify significantly improved fatigue. LDN helped with flu like body aches. Side note, I was made to feel like meds were bad for years, suffering with severe POTS. Meds have been life savers. I made all recommended lifestyle changes and they only slowed decline/ maintain baseline barely. Meds actually helped. Also, Was on SSRI's for years due to misdiagnosis of Depression, then I became depressed due to situation. But when I realised I should t have been on SSRI's, I stopped and mental health improved significantly and physical a little. In my experience, SSRI's made me much worse.	November 1, 2023 at 3:17 pm	
Slow sodium	November 1, 2023 at 6:15 pm	
Low dose naltrexone	November 1, 2023 at 7:13 pm	
LDN	November 1, 2023 at 7:16 pm	
Verapamil	November 2, 2023 at 1:36 am	
Guanfacine	November 2, 2023 at 1:43 pm	
High dose anti-inflammatory	November 2, 2023 at 5:56 pm	
Ivabradine	November 3, 2023 at 1:55 pm	
Symprove - improves many of my POTS smptoms not just gut. 2-3 sachets of rehydration salts per day	November 3, 2023 at 8:13 pm	
Currently being prescribed - not confirmed which type yet	November 5, 2023 at 10:29 pm	
Slow sodium tablets	November 17, 2023 at 4:16 pm	
Candesartan, duloxetine	November 17, 2023 at 6:03 pm	
Codeine, Buprenorphine Pain Patch, Duloxetine, Omeprazole, Phenergan	November 17, 2023 at 6:08 pm	
IV saline	November 17, 2023 at 10:17 pm	
Sodium cromoglicate tablets	November 17, 2023 at 10:23 pm	

ANSWERS	DATE	
Clonazepam for sleep when POTS symptoms bad.	November 17, 2023 at 10:25 pm	
because I am mostly bedbound, cardiologist stopped midodrine as it can cause hypertension when bedbound. It was my most helpful drug, I can only take midodrine now when I am going to be upright for more that 1/2 hr . Florinef did nothing. Beta blockers caused me to faint. Couldn't tolerate mstinon. SSRI made ME way way worse.or so	November 17, 2023 at 10:29 pm	
Idn and mcas meds (zyrtec and pepcid) which help my pots	November 18, 2023 at 2:21 am	
Triple therapy (aspirin, clopidogrel, apixaban) 2 years - with moderate, without severe	November 18, 2023 at 5:45 am	
Slow release sodium	November 18, 2023 at 11:15 am	
Diltiazem	November 18, 2023 at 2:12 pm	
slow release sodium chloride 600mg up to max x6/day	November 18, 2023 at 2:50 pm	
Iron, vitamin D3 with K2 and B12 injections	November 18, 2023 at 3:31 pm	
Verapamil	November 19, 2023 at 8:25 am	

56 Answered

959 Skipped