# DSN Patient Handbook

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What is Dysautonomia?

Dysautonomia, also called “Autonomic Dysfunction,” is an umbrella term used to describe disorders that affect the autonomic nervous system. The autonomic nervous system is what controls the body’s involuntary functions like heart rate, blood pressure, digestion, temperature regulation, pupil response, and kidney function. A short animated video explaining dysautonomia is available on our website at https://www.dysautonomiasupport.org/dysautonomia.

When you are first diagnosed, you may be given a diagnosis of “Dysautonomia” or “Autonomic Dysfunction” without knowing what type. However, there are actually about 15 types of dysautonomia, and knowing specifically what form you have can be beneficial when it comes to treatment. Regardless of the type, there is no cure for dysautonomia; so, often treatment focuses on symptom management. Some symptoms are similar across all forms of dysautonomia and some are different. It is also important to determine whether you have primary dysautonomia, which is inherited or caused by a degenerative disease; or secondary dysautonomia, which is caused by an injury, illness, or another separate condition.

How is Dysautonomia Diagnosed?

Dysautonomia is not rare, but it is not fully understood or commonly known about in the medical community. It is estimated that it affects around 70 million people worldwide. Autonomic dysfunction can affect people of any age, race, or gender; although it is more common in females than males. However, many people may be misdiagnosed; and it often takes years and multiple doctors before patients get a dysautonomia diagnosis. Diagnosis takes so long because symptoms overlap many other conditions and often these other conditions need to be ruled out first. Also, symptoms can vary widely amongst patients. Some patients may only have few autonomic system problems, while others experience a more systemic or full-body autonomic dysfunction. Symptoms may also come and go for some patients, where they experience “flares” but have little to no symptoms in between.

Because of the range of symptoms, patients may end up seeing a variety of specialists before finding a doctor that recognizes autonomic dysfunction. Most often it is a
cardiologist (particularly an electrophysiologist) or a neurologist, that specializes in autonomic function, who recognizes the issue and diagnoses patients.

Common tests used to diagnose dysautonomia and to determine form or cause include:

- **Tilt Table Test (TTT)** - Blood pressure, heart rate, and EKG are recorded as the patient first lays flat on a table and is then slowly tilted to an almost upright position. These vitals are recorded for anywhere from 10 to 20 minutes. If the patient loses consciousness or a diagnosis is made, the test stops. Otherwise, the patient is often given nitrous (a medication to simulate the effects of aerobic exercise) and the test is continued for another 10 to 20 minutes.
  - A poor man’s tilt may be used in doctors’ offices or for patient home monitoring. This is done by measuring orthostatic vitals without a special table. Blood pressure and heart rate should be recorded lying flat for 10 min, sitting 3 min, and standing at 3, 5, 8, and 10 min; or as the doctor recommends.

- **Autonomic Reflex Tests** - Valsalva maneuver and breathing variability tests measure the autonomic system heart rate and blood pressure response.

- **Holter or Cardiac Event Monitoring** - EKG is recorded over 24 hours or for a longer period. A diary is kept, and a button can be pushed when symptoms occur.

- **Ambulatory Blood Pressure Monitoring** - This is like Holter monitoring, in that it is an at-home test lasting 24 hours. However, unlike the Holter monitor, this test records blood pressure. The cuff is worn for 24 hours and, it automatically takes readings at set intervals. A diary of symptoms and activity level can be kept to observe orthostatic hypotension, exercise intolerance, or if blood pressure changes at certain times of day or after eating.

- **Echocardiogram** - ultrasound of the heart to rule out any anatomical problems.

- **Catecholamine blood work** - at rest and standing blood draws to measure sympathetic response.

- **Autoimmune and Paraneoplastic Panels** - bloodwork done to rule out autoimmune conditions and certain types of cancer that may cause dysautonomia.

- **Electromyography (EMG) and Nerve Conduction Velocity (NCV) Study** - to rule out other neuromuscular and nervous system disorders and to check for myopathy and neuropathy, some of which may also cause dysautonomia.
● **ANSAR** - to determine if the dysautonomia is caused by low sympathetic or parasympathetic tone.

● **Quantitative Sensory Testing (QST), Quantitative Sudomotor Axon Reflex Test (QSART), QSweat, Thermoregulatory Sweat Test, Biopsy** - to diagnose or rule out small fiber neuropathy or other neuropathies as the cause.

● **Acetylcholine Blood Level & Antibodies** - acetylcholine is a chemical messenger in the autonomic nervous system. Unusually low or high levels can affect the function of it. Acetylcholine receptor antibodies and other antibodies are tested to diagnose or rule out Myasthenia Gravis or another Gravis condition as the cause of dysautonomia.

● **Loop recorder**: Sometimes when physicians need to monitor your heart rate for an extended period of time, they will implant a loop recorder under the skin of the chest. This monitors heart rate and rhythm for up to 3 years.

● **Additional Lab work**: immunology, autoimmune, histamine, tryptase, thyroid, blood sugar, and other labs may be done to determine co-existing conditions, causes, or to rule out other conditions that cause similar symptoms.

**Terms to Know:**

**Tachycardia**: fast heart rate, greater than 99 beats per minute.

**Bradycardia**: slow heart rate, lower than 60 beats per minute. (Note: this can be normal in some people, especially athletes).

**Systolic Blood Pressure**: the “top number“ - this is the pressure during contraction of the heart.

**Diastolic Blood Pressure**: the “bottom number” - this is the pressure during relaxation of the heart.

**Pulse Pressure**: this is the difference between the systolic and diastolic pressure. Normal is about 30-40 mmHg.

**Hypotension**: low blood pressure, less than 90/60.

**Hypertension**: high blood pressure, higher than 140/90. It is considered prehypertension if systolic is over 130 mmHg.

**Orthostatic**: changes in position.

**Supine**: lying flat on your back.

**Comorbidities**: conditions that occur together.
Basic Overview of the Autonomic Nervous System (ANS)

Let’s start by talking about homeostasis. Homeostasis refers the ability of the body to maintain normal function and balance. The body has a lot of things going on simultaneously to do so, and the ANS plays an important role. The ANS is made of sympathetic and parasympathetic nerves. Think of the sympathetic system as your “fight or flight” system and the parasympathetic as the “rest and digest” system. Norepinephrine and acetylcholine are the two main chemicals used by the system to regulate autonomic function. Norepinephrine (NE) stimulates the sympathetic nervous system. The parasympathetic system is controlled by acetylcholine (ACh), which works to inhibit the sympathetic system. There are multiple reflexes in the body that sense changes in blood pressure, temperature, digestion, and other autonomic function, and then tell the body how to balance the stimulation or inhibition of the ANS.

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<tr>
<th>Sympathetic - Fight or Flight</th>
<th>Parasympathetic - Rest and Digest</th>
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<tr>
<td>Increase in heart rate and contractility</td>
<td>Decrease in heart rate and contractility</td>
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<tr>
<td>Vasoconstriction → Increase in blood pressure</td>
<td>Vasodilation → Decrease in blood pressure</td>
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<tr>
<td>Increase energy, metabolism, and muscle strength</td>
<td>Stimulates digestion and bowel function and regulates sleep/wake cycle</td>
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The reflexes throughout the body send signals to the hypothalamus in the brain. This is part of the limbic system of the brain, which is buried deep in the center. Directly below it is the brain stem, which includes a section called the medulla. Autonomic nerve cells originate in the medulla. The hypothalamus sends signals to the medulla, which then sends the signal through the autonomic nerves along the spine. The hypothalamus also sends chemical signals to the pituitary gland, which then initiates chemical and hormone changes, which also either have excitatory (stimulating) or inhibitory effects on the autonomic response.
Pathways of autonomic response:

The autonomic nerves are different from other nerves in the body because they have two parts to them - the preganglionic neuron and postganglionic neuron. The neurotransmitter ACh is necessary for the signal to pass through the autonomic ganglion. The signal then transmits either ACh or NE is to the muscles or glands.

Autonomic Nerves:

When a change is noted in the body, the ANS’s response is very fast. For example, blood pressure changes when we stand up, and for most people the time it takes for the body to adjust to that orthostatic change is only a few seconds. Therefore, just about everyone experiences slight dizziness from time-to-time upon standing and you may have heard even people without dysautonomia say, “Oh, I stood up too fast.” This feeling occurs because the body had a slightly delayed reaction. In people with dysautonomia, this reaction may be delayed, or it may be improper in nature or magnitude.
Forms of Dysautonomia

As mentioned earlier, there are many forms of dysautonomia. The overview above is a simplified version of everything that goes on from the time autonomic reflexes notice a change to when there is a response. With dysautonomia, there is a disruption or abnormal response anywhere along this chain of events. Any one thing or combination of things can affect how our body responds to changes in homeostasis or even how the body recognizes change. Some forms of dysautonomia affect how the reflexes tell the brain there’s a problem, some are problems in the brain itself, and others (most) occur because there is an issue with the autonomic nerves. Sometimes, dysautonomia can get quite confusing (for doctors as well); because the definitions for diagnosis change, may have more than one name, or may overlap some.

Here are a few of the forms of dysautonomia along with brief descriptions of each, starting with the more common types. If you click on the name of subtype, it will take you to the quick fact sheet on our website. If you are viewing this document in print, all of the handouts can be found at https://www.dysautonomiasupport.org/copy-of-articles-handouts. In addition you can find peer-reviewed research articles about the various forms of dysautonomia and co-existing conditions at https://www.dysautonomiasupport.org/copy-of-library.

Orthostatic Intolerance (OI): Orthostatic Intolerance is not really a single type of dysautonomia; rather, OI is a broad category of dysautonomias that result in increase symptoms when changing positions. OI is sometimes also referred to as “patchy dysautonomia.” Changes in heart rate or blood pressure usually occur but are generally more gradual or not as severe as in other forms of dysautonomia. Symptoms typically occur only while standing or changing positions. In some patients with OI, blood pooling occurs in the extremities and may result in overreaction of the sympathetic nervous system. Patients may be given this as a stand-alone diagnosis, or they may be given a more specific diagnosis or a diagnosis of another sub-type along with it.

Postural Orthostatic Tachycardia Syndrome (POTS): Postural Orthostatic Tachycardia Syndrome is diagnosed with an increase in heart rate of 30 beats per minute or more OR a heart rate of at least 120 upon standing or within 10 min of standing. For children and adolescents, the increase is greater than 40 beats per min. It is often harder to diagnose in younger patients patients because heart rates are normally more variable
than in adulthood. Generally, blood pressure will not change or may even increase; so, POTS diagnosis should be based on the change in heart rate, not blood pressure. If the heart rate becomes fast enough, blood pressure may then drop because the heart is unable to properly fill when it is beating too rapidly. You can find an additional brochure for POTS patients, as well as handouts for providers including physicians and nursing caregivers on our website at https://www.dysautonomiasupport.org/copy-of-articles-handouts.

Not all POTS patients have a true autonomic dysfunction. Some have POTS because of deconditioning or psychological factors (which are not within the patient’s control). Part of a POTS diagnosis should include investigating underlying causes factors, such as autonomic neuropathy, endocrine issues, deconditioning, and behavioral/cognitive issues. The other part of the diagnosis should include looking for the subtype (which considers the things already mentioned as to the cause). Subtypes of POTS include neuropathic, hyperadrenergic, hypovolemic, joint hypomobility related, autoimmune related, and physical deconditioning. A separate handout about the hyperadrenergic type is also available on our website at https://www.dysautonomiasupport.org/copy-of-articles-handouts. However, there is often overlap between subtypes and patients may have more than one, therefore not all physicians or centers look at subtype or believe there should be a labeling for POTS patients.

**NeuroCardiogenic Syncope (NCS):** NeuroCardiogenic Syncope is also called Vasovagal Syncope (VVS) or Neurally-Mediated Syncope (NMS). Syncope - more commonly known as fainting - is a condition in which a reflex is triggered that causes a sudden drop in heart rate and/or blood pressure, resulting in decreased blood flow to the brain and ultimately a loss of consciousness. Near Syncope or Presyncope is a more mild response to the reflex, in which the person becomes symptomatic but does not have a total loss of consciousness. What distinguishes NCS from OH is the decrease in heart rate and that syncope or near-syncope can occur with reflexes other than orthostatic. Reflexes may be postural, but can also be triggered by things like pain, sudden sounds, or coughing - to name a few. Some people experience disorientation, speech arrest, or seizure-like movements following an episode of presyncope or syncope.

**Autonomic Neuropathy (AN):** Autonomic Neuropathy is term used to describe damage to the autonomic nerves. Typically, this refers to the small nerve fibers; so autonomic
neuropathy may also be called Small Fiber Neuropathy (SFN). However, technically, these are two separate conditions. Nerve damage can be caused by a lot of different conditions, which will be further explained in the coexisting conditions section of this document. There is some debate whether AN can be called a form of dysautonomia vs. a cause of dysautonomia, but patients with AN typically experience OH.

**Autoimmune Autonomic Ganglionopathy (AAG):** Autoimmune Autonomic Ganglionopathy is an autoimmune condition that, in most cases, cause high levels of ganglionic acetylcholine receptor antibodies (g-AChR). The antibodies block the ability for ACh to work properly. In some cases, the antibodies may not be detected. AAG is something that causes either POTS-like conditions (when antibodies aren't present or are too low) or pure autonomic neuropathy, which results in OH.

**Baroreflex Failure (BF):** Baroreflex Failure is a rare form of dysautonomia that is caused by an abnormal response of the baroreceptors. The baroreceptors - sometimes also referred to as the “stretch receptors” in the heart - are responsible for telling the brain that there has been a change in blood pressure. Cranial nerve impairment, damage to the glossopharyngeal nerve, brain stem injury, or damage to the baroreceptors directly, can result in the baroreflex failing to function properly.

**Multiple System Atrophy (MSA):** Multiple System Atrophy a rare, degenerative neurological disease that causes autonomic dysfunction, Parkinsonism and other neurological difficulties. This is a disorder in which the dysautonomia is caused by deterioration in the brain and brainstem. It is one of the few fatal forms of dysautonomia.

**Pure Autonomic Failure (PAF):** Pure Autonomic Failure is also known as Bradbury-Eggleston Syndrome and is a primary dysautonomia. PAF causes deterioration of autonomic nervous system function - both sympathetic and parasympathetic. There is typically severe orthostatic hypotension as well as supine hypertension.

**Familial Dysautonomia (FD):** Familial Dysautonomia is also known as Riley-Day Syndrome. This is a rare genetic disorder that causes the sensory and autonomic nerves to not develop properly; leading to sensory deficits and decreased pain sensitivity, as well as severely abnormal autonomic nervous system functions that are present from birth. This is another form of dysautonomia that tends to have a short
life-expectancy. Since carrier frequency is much higher in Ashkenazi Jews and those of Eastern European descent, FD is referred to as a Jewish Genetic Disease; although it can occur in people of any nationality or race. The chances of inheriting FD are 25% when both parents are carriers.

**Inappropriate Sinus Tachycardia:** Inappropriate sinus tachycardia is somewhat similar to POTS, expect that the heart rate may be increased regardless of position. The average resting heart rate is higher than normal, as is the daily average heart rate. Heart rate increases are greater with exertion or emotional stimuli than is normally seen and it takes longer for heart rate to come back down than normal. There is a decrease in the heart rate when lying flat, but resting heart rates are still higher than average. It is unclear, and still debated, whether IST is a truly a form of dysautonomia or a condition that arises from the sinus node of the heart, which controls heart rate.

Other forms of dysautonomia include autonomic epilepsy, autonomic dysreflexia, and complex regional pain syndrome. Additional information on these disorders can also be found on our website at [https://www.dysautonomiasupport.org/copy-of-articles-handouts](https://www.dysautonomiasupport.org/copy-of-articles-handouts).
Common Coexisting Conditions

Coexisting conditions, also sometimes called comorbidities, are conditions in which there is a higher prevalence of them occurring together than in the general population. Some are causes of dysautonomia, some are caused by dysautonomia, and some share a common underlying cause with dysautonomia. With many of them, it is hard to determine which came first; sort of like the chicken and the egg scenario.

Here are some of the most common - but not all the possible - comorbidities with dysautonomia. As with the sub-types of dysautonomia, if you click on the name of a condition, it will take you to the quick fact sheet on our website. If you are viewing this document in print, all of the handouts can be found at https://www.dysautonomiasupport.org/copy-of-articles-handouts. In addition you can find peer-reviewed research articles about the these co-existing conditions at https://www.dysautonomiasupport.org/copy-of-library.

**Ehlers Danlos Syndromes (EDS) and Hypermobility Spectrum Disorders (HSD):** EDS and HSD are a group of inherited connective tissue disorders. There are several different types, with some associated with dysautonomia and some not. In other words, some patients may experience dysautonomia symptoms, while others experience primarily skin, joint, or blood vessel symptoms, depending on their type. EDS can be a cause of dysautonomia, as it affects connective tissue throughout the body. Our website also contains more information about EDS & HSD at https://www.dysautonomiasupport.org/eds.

**Chiari Malformation:** Chiari is a condition in which the cerebellum - the part of the brain which controls movement, coordination, and sensory perception - is not contained within the base of the skull. Instead, the cerebellum is pushed into the spinal canal. This can affect the flow of cerebrospinal fluid (CSF) between the spinal cord and brain. Buildup of fluid can put pressure on the brain and spinal cord, leading to hydrocephalus (swelling in the brain). Chiari can be acquired or congenital. EDS is one of the causes of acquired Chiari; therefore, it is possible to have all three - EDS, Chiari, and dysautonomia. Our website also contains more information about Chiari, including an animated video at https://www.dysautonomiasupport.org/chiari-malformation.
Mast Cell Activation Syndrome/Disorder (MCAS/MCAD) & Mastocytosis:
MCAS/MCAD and Mastocytosis are disorders in which there is an abnormal response of mast cells in the body. Mast cells are a part of the immune system. If they become overactive, they can respond like an allergic reaction, even when allergens are not present. This means you may experience symptoms like rash/hives, welts, itching, bronchospasm, wheezing, flushing, diarrhea, vomiting, or tachycardia - to name a few. These symptoms may have environmental or food triggers, or they may occur randomly and without known cause. Severe cases of MCAD can result in recurrent anaphylaxis. Some people have what is known as a “trifecta” of POTS, EDS, and MCAD; where all three of these occur together (and often amongst multiple family members). This phenomenon is still being studied. Our website also contains more information about MCAS/MCAD at https://www.dysautonomiasupport.org/mcad.

Marfan Syndrome: Marfan Syndrome is also a genetic connective tissue disorder, like EDS; but it affects the body in a slightly different way than EDS does. Some symptoms are very similar - including hypermobility; but some are different. Marfan syndrome patients typically have certain distinguishable physical characteristics, called marfanoid habitus. Like EDS, Marfan affects connective tissue throughout the body and is a cause of dysautonomia. Our website also contains more information about Marfan Syndrome at https://www.dysautonomiasupport.org/marfan-syndrome.

Gastroparesis (GP) and other GI motility disorders: Gastroparesis is characterized by delayed emptying of the stomach. Other delayed motility conditions include delayed colonic transit and slow transit constipation. All of these conditions occur when the part or all of the digestive system becomes paralyzed or sluggish. This is often a result of dysautonomia and goes along with autonomic neuropathy. There is also a high rate in diabetic patients. Some dysautonomia patients have the opposite problem - rapid emptying of the stomach or colon, resulting in cyclic vomiting syndrome or dumping syndrome. Other patients cycle back and forth between delayed and rapid emptying. Our website also contains more information about GP at https://www.dysautonomiasupport.org/gp.

Neuropathy: This is a tricky one. You’ll notice that it Autonomic Neuropathy was brought up as a form, but neuropathy is also here as a coexisting condition. There are several conditions that cause autonomic neuropathy or other neuropathies, and are therefore coexisting conditions with dysautonomia. Some examples of these conditions are:
• **Autoimmune Disorders**, including: Sjogren’s syndrome, systemic lupus erythematosus, rheumatoid arthritis or other autoimmune arthritis, celiac disease, Guillain-Barre syndrome, Churg Strauss syndrome, and paraneoplastic syndrome (an autoimmune response to cancer).
• **Endocrine Disorders**, including: Diabetes, Addison’s disease, Cushing’s, adrenal insufficiency, and hypothyroidism
• **Other Nervous System Disorders**, including: Parkinson’s disease, Myasthenia gravis, Multiple Sclerosis, migraines, narcolepsy, and certain types of dementia
• **Infectious Diseases**, including: Lyme disease, HIV, Epstein Barr virus, and meningitis
• **Other Conditions**, including: Amyloidosis, porphyria, myalgic encephalomyelitis, and radiation syndrome
• **Surgical Complications** caused by surgery or radiology to the neck
• **Medications**: particularly chemotherapy drugs and Parkinson’s drugs

### Symptom Checklist

Remember that the autonomic nervous system controls many bodily functions including thermoregulation, heart rate and blood pressure, digestion, sleep, and responses to stimuli. Therefore, dysautonomia symptoms can be present in all of these systems as well. Symptoms very much depend on form, cause, and coexisting conditions. Below is a list of many (but not nearly all) of the common dysautonomia symptoms, focusing primarily focus on dysautonomia in general and not coexisting conditions:

- Abnormal heart rates or rhythms, especially with changes in positions, including:
  - Tachycardia (fast heart rate)
  - Bradycardia (slow heart rate)
  - Labile (rapidly fluctuating) heart rates
  - Decreased heart rate variability
  - Palpitations (feeling like the heart must work hard)
- Abnormal blood pressures, especially with orthostatic changes, including:
  - Hypotension or Hypertension
  - Labile (rapidly fluctuating) blood pressure
  - Narrow (decreased) pulse pressure
- Syncope (fainting) or Presyncope (almost fainting)

➢ GI problems, including:
  - Constipation
  - Diarrhea
  - Abdominal pain
  - Nausea and/or vomiting
  - Loss of appetite

➢ Difficulty with thermoregulation, including:
  - Decreased sweating or anhidrosis (absence of sweating)
  - Increased sweating
  - Heat intolerance
  - Cold intolerance
  - Raynaud's Phenomenon

➢ Urogenital issues:
  - Frequent urination, nocturia (increased urination at night)
  - Urinary retention or difficulty urinating
  - Incontinence
  - In men, erectile dysfunction, difficulty ejaculating
  - In women, vaginal dryness or difficulty with orgasm
  - Decreased libido

➢ Sleep disturbances, including:
  - Chronic fatigue
  - Hypersomnolence or excessive daytime sleepiness
  - Insomnia

➢ Mental Health Symptoms, including:
  - Anxiety or panic disorders
  - Depression
  - Mood changes

➢ Sensory symptoms, including:
  - Hypersensitivity to stimuli
  - Deficits in sensory responses
  - Abnormal pupillary response to light

➢ Other symptoms, including:
  - Chest pain
  - Muscle weakness
○ Exercise intolerance
○ Migraines or frequent headaches
○ Vertigo, Dizziness, or Lightheadedness
○ Shortness of breath

A more exhaustive list of symptoms of dysautonomia and coexisting conditions as printable checklist that you can fill out and take to your doctor is available from https://drive.google.com/file/d/1eiyghazoJEL1nyy-J-LkoJhebHAfEDCK/view.

Common Treatments

Dysautonomia treatments tend to revolve around symptom management, unless there is a specific cause that is known and can be treated. Physicians generally start with non-pharmacological methods first. It can take a lot of time and patient and trial and error before the right combination of strategies is found. It’s not a one size fits all sort of thing, so be prepared to try a lot of different things and understand that it may take time to know if the medication or treatment is working or not.

Non-Pharmacological Treatments & Symptom Management Strategies

Below are the main categories of non-pharmacological treatments for dysautonomia. DSN has also compiled a list of our “Favorite Things” - products and services that have helped with symptom management, which can be downloaded from https://docs.wixstatic.com/ugd/cb5ced_ef7e38bab314403aaaa0552abe9e27b5.pdf.

Hydration:

Hydration is important because many dysautonomia patients have low blood volume, so the body has less to work with when trying to respond to changes. Some dysautonomia types also directly result in chronic dehydration. How much water is recommended may be based on your weight, but it is usually 2-3 L/day. Many patients with gastroparesis find drinking plain water to be difficult. Drinking thicker liquids, electrolyte drinks, nutrition shakes, or ginger ale may be more tolerable for these individuals. Many people also need to minimize or avoid dehydrating substances such as caffeinated drinks, alcohol, and diuretics.

1. Electrolytes - It is recommended that at least half of your fluid intake be an electrolyte solution of some kind. Electrolyte solutions can be found in premixed
bottles such as sports drinks, dissolvable powders or tablets that you add to water, or can be made from scratch. Some examples of brands include: Gatorade or Powerade, Pedialyte or Normalyte, Propel, Mio, Liquid IV, Banana Bag, Salt Stick, or Nuun tablets. The goal is to have electrolytes that will help you retain more fluid, not lose necessary minerals, and prevent dehydration.

2. **Fluid Loading** - You may also try “fluid loading” or “bolusing” before exertion. This is done by quickly drinking 500 mL in less than 10 min right before you stand-up or exercise or do anything that would normally require exertion or extended standing, like showering or chores around the house. Some patients report that fluid loading helps prevent drops in blood pressure or blood pooling upon standing. However, the research is mixed about whether this really helps maintain vitals.

3. **Increased Sodium** - Check with your doctor in terms of if and how much you should increase sodium. Some people need daily sodium increase; others only when they are in “flares” or have symptoms. You can increase sodium through eating high sodium foods, drinking electrolyte drinks, adding extra salt to your meals, taking salt tablets, or sucking on sea salt crystals.

**Compression:**

Compression garments come in a variety of strengths (measured in mmHg) and vary in how far up the body the compression goes and how many levels of compression there are. Check with your doctor to determine what’s best for you. Insurance may even pay for compression garments if you get a prescription from your doctor for them. The biggest piece of advice is don’t give up on compression easily; keep trying different brands, strengths, styles etc. until you find what works for you!

1. **Lengths/Styles** - Options are knee highs, thigh highs, chaps, pantyhose, bikers, abdominal binders, and sleeves. Most people need at least thigh high compression to see real benefits. Some people benefit from everyday activewear as compression, so it’s individualized in terms of what is going to work best for you. But, if you want your insurance to cover it, you must get medical grade compression from a durable medical equipment supplier.

2. **Strength** - If you don’t notice a change wearing them, you may need a higher pressure. With significant blood pooling or severe orthostatic symptoms, 30-40 mmHg is often needed.
3. **Size** - Compression must be sized properly! Incorrectly sized compression garments can cut-off circulation and even lead to blood clots. So, we will repeat - compression garments must be sized properly! You can go to a medical supply store or online to get them, but make sure that you measure according to the brand you are buying. If you have never worn compression garments before, it is recommended that you purchase them in a store so that you can be fitted and try them on. Some medical supply stores will also let you return within a certain number of days if they are not right.

4. **Other Options for Compression** - Besides compression garments, some people find benefit to using compression pumps. Others, with chronic edema, find benefit to seeing an OT who specializes in manual decompression therapy.

**Physical Counter Maneuvers:**

These are things that you can do to decrease heart rate and blood pressure, or to increase arterial pressure to keep yourself from fainting or feeling dizzy. These are all very individualized in terms of what is going to feel right to you; and they may not all be appropriate for your form of dysautonomia, so check with your doctor first!

1. **Leg Crossing** - Crossing your legs can raise your blood pressure. Some people say they sit this way all the time naturally, but others feel this causes the feet to go numb quickly. You can also try tightly crossing your legs if you are standing. If this position is difficult or painful for you, some people find the same effect from bending forward and putting a foot up on a chair or bench - like you are tying your shoes.

2. **Tense and Relax** - Alternately contracting/tensing and releasing your muscles can sometimes help your symptoms. You can do a formal version of this called a progressive muscle relaxation, or you can just simply try making a fist and releasing it. Some people report the most benefit from an active contraction, extended hold, and then gradual relaxation of the abdominal or buttock muscles.

3. **Weight Shifting** - Another thing you can try is shifting your weight. This can be accomplished by moving side to side, shifting the weight from one foot to the other. It can also be accomplished by moving forward and back, shifting the weight from the balls of the foot to the toes. You can even try going up on your toes and coming back down, if you are able to balance that way.
4. **Valsalva Maneuver** - Check with your doctor before using this one, and do not try it if you have NCS. But if you're tachycardic trying a valsalva may help bring down your heart rate. To do this, bear down like you are trying to push out a bowel movement or hold your nose and close your mouth while trying to blow air out. Only do for a few seconds at a time!

5. **Hick Maneuver** - This maneuver is a technique used by fighter pilots to keep them from passing out in high g-forces. Some people find it helpful to prevent passing out from dysautonomia as well. Check with your doctor before using this one, especially if you have hyperadrenergic POTS. The hick maneuver is done by contracting as many of your muscles as possible, and simultaneously saying the word “Hick” to increase pressure in the lungs.

6. **Mindful Breathing** - Taking a deep breath in and then slowly breathing out through the mouth has been shown to decrease blood pressure and reduce stress. On the other hand, “Breath of Fire” - where you take a deep breath in and then exhale in short bursts like blowing out birthday candles one at a time - has been shown to be energizing and to activate the sympathetic nervous system. If you would like more specific mindful breathing techniques, you can find them in the DSN Mindfulness Club on Facebook at [https://www.facebook.com/groups/chronicallymindful/](https://www.facebook.com/groups/chronicallymindful/).

**Thermoregulation Tools:**

Many patients suffer from heat or cold intolerance. For many people, dysautonomia symptoms may be exacerbated by heat - especially if you do not sweat sufficiently. For others, poor circulation - caused by blood volume, blood pooling, or inadequate heart-filling - can cause cold intolerance. Some dysautonomia patients also have Raynaud's Syndrome or experience Raynaud's phenomenon (where the extremities rapidly turn colors in response to cold temperatures).

1. **Managing Heat Intolerance** - Those with heat intolerance may find their symptoms can be abated by wearing cooling vests, using cool compresses or ice packs, sleeping on a cooling mattress pad, or carrying a personal air conditioner or portable fan. They generally avoid activity outdoors during the warmest part of the day and, if possible, try to live in regions Temperate climates. Air conditioners in the home are a must for these individuals. Taking lukewarm showers may make showering easier and less likely to be a trigger. Some also find relief by
applying cooling gels or creams which contain menthol or peppermint oils; however, these scents may be symptom triggers for others - especially those with Mast cell issues.

2. **Managing Cold Intolerance** - On the other hand, those with cold intolerance need to take precautions against the cold. Dressing in layers or heat-trapping clothing can help. Heating pads, heated blankets, heated mattress pads, or warm compresses can help and may also provide relief if you suffer from chronic pain.

3. **Managing Raynaud's Symptoms** - Those who suffer from Raynaud's symptoms may be at greater risk of developing frostbite in cold weather, so avoiding outdoor activities when the temperature is below a comfortable level may be necessary. Heated gloves or hand warmers may help if outdoor activity cannot be avoided. Even if you are only outside for a few moments, never go out with bare skin including your hands. It is also common for these individuals to wear gloves - even indoors. Washing your hands and fruits or veggies should be done in warm water only. Oven mitts or silicone tongs can be used to take things out of the freezer or hold cold dishes or glassware.

**Exercise Training:**

This one is extremely important. It can be extremely hard, but it’s also vital. Many patients have a hard time with this one because they have exercise intolerance and become symptomatic very quickly. This then causes you to do less and less exercise, as it gets harder and harder. This is where deconditioning can start or become a lot worse. So, reconditioning your body and increasing your exercise tolerance and stamina are critical.

Remember: Everyone is at a different place when it comes to exercise and what you can tolerate! Underlying conditions can also play a role. Everyone’s level of exercise that is most ideal is going to be different!

1. **Consult a Specialist** - Having a consult with a PT, OT, physiatrist, or exercise physiologist can help you determine where you are currently, what you can do safely, what is most beneficial, how to modify exercises, and how to reach your goals.

2. **Start slow and work your way up!** You may only be able to do lying exercises for short periods of time at first. Gradually build up the number of times per day and how long each exercise session lasts. The next step is usually recumbent
exercise like a recumbent bike or stepper. From there, you can move to seated exercise such as a stationary bike or rowing machine. These machines are great because, in addition to allowing for aerobic exercise in a way that is less stressful on the body; they strengthen leg muscles and abdominal muscles, which are needed to help prevent blood pooling. Eventually, standing exercises may be tried as tolerated.

3. **Aquatic Exercise** - Aquatic exercise can be great, especially for those with joint issues. If you are chest deep in the water, you lose the gravity effect that would cause your blood to pool (a big issue for many trying to exercise). PT can give you exercises to do if you need to work up to swimming or aquatic aerobics. You can also do strength training and endurance-building in a pool. However, chlorine can trigger autonomic issues or mast cell activation in some people; so, this form of exercise is not for everyone.

Your exercise tolerance will change over time. Don’t be surprised if there are ups and downs in terms of what you can do. The important thing is to not stop completely, unless directed by your physician. Remember, even a little activity is still active. If you have a flare or a setback, work on building up again.

Each fall, DSN sponsors a Superhero Virtual 5k. The DSN Superhero 5k is all about empowerment - enabling you to set a goal and adapt to achieve that goal. The virtual nature of the 5k allows you to run, walk, roll, swim, bike, or dance your way to your goal; and it can be completed in as many segments as you need. More information can be found on our website at [https://www.dysautonomiasupport.org/virtual5k](https://www.dysautonomiasupport.org/virtual5k). Also, for year-round motivation, support, and empowerment for your personal fitness goals; consider joining DSN’s Fitness Club on Facebook at [https://www.facebook.com/groups/DSNfitnessclub](https://www.facebook.com/groups/DSNfitnessclub).

**Pharmacological Treatments**

Pharmacological treatments include medications prescribed for blood pressure and blood volume support, heart rate management, and treatment of coexisting or underlying conditions. While there are some over the counter medications and supplements that may help manage your symptoms, please make sure your healthcare team is aware of all medications - including these non-prescription items that you take. Some resources for interaction checking and pill identification can be found on our
Blood Pressure/Blood Volume Support:

1. **Fludrocortisone (Florinef)** - this is a mineralocorticoid used in small doses that helps increase sodium levels and increases fluid retention, which in turn help increase blood pressure. It does also deplete potassium, so blood work should be done to determine if additional supplementation is needed. Side effects are generally mild because of the low dose.

2. **DDVAP (Desmopressin)** - this is an antidiuretic hormone that increases water retention, and thus can improve blood volume. Again, generally small doses are used. Blood work to check sodium and potassium levels are recommended to determine if supplementation is needed. Usually patients should be on an increased salt regimen.

3. **Midodrine (ProAmatine)** - this is a vasopressor (antihypotensive) medication that improves vascular tone and increases blood pressure. It is used primarily for orthostatic hypotension but may also be beneficial in the treatment of POTS that does not have a hyper component. The most common side effect is tingling, particularly in the scalp. This side effect may diminish or disappear over time. Midodrine also decreases cold tolerance and can cause Raynaud's phenomenon. Supine hypertension is also common, so blood pressure should be monitored.

4. **Pyridostigmine Bromide (Mestinon)** - this is a drug used primarily for myasthenia gravis because it prevents the destruction of ACh, which allows for better nerve impulses across the neuromuscular junction. In dysautonomia patients - particularly those with low vagal tone, low ACh levels, or impaired ACh function - this can improve signals that tell the blood vessels to constrict and thus prevent blood pressure drops. POTS patients on this drug have also demonstrated improvement in both heart rate and blood pressure. Side effects are generally mild; with diarrhea, increased sweating and tearing, and muscle twitching being some of the more common ones. For some patients - especially those with gastroparesis - the side effects of Mestinon can also be beneficial.

5. **Northera (Droxidopa)** - the exact mechanism of action is unknown, but this is a drug that works through the norepinephrine channels. It helps increase norepinephrine levels and increases systolic and diastolic blood pressure. It has been studied and approved for neurogenic OH, MSA, Parkinson's, and PAF.
There is some evidence that it may also help POTS patients if there is a decrease in blood pressure and failure to respond to other methods and medication. Patients should be monitored for supine hypertension. Rarely, patients can also develop neuroleptic malignant syndrome, which requires immediate treatment.

6. **IV Saline** - this is known as blood volume expansion therapy. Generally, it is used as needed, when symptoms flare, or when oral fluid intake isn’t feasible - such as with severe GI problems or illness. When GI symptoms are chronic, long-term IV saline infusions may be necessary for consistent hydration. Kidney function should be checked regularly if infusion is of saline rather than lactated ringers.

7. **Epogen/Procrit** - this is an injectable medication that increases red blood cell production. It is typically used for anemia and its use in dysautonomia is an off-label use. In theory, and in some limited studies; it increases blood volume, helps maintain blood pressure, and prevents orthostatic symptoms. There are significant risks that come with this medication, like blood clots, anaphylaxis, and severe hypertension. It can also increase risk for heart attack or stroke, so this should be discussed in detail with your doctor.

**Heart Rate Management:**

Drugs used to decrease heart rate may also decrease blood pressure as well. For some patients, decreasing blood pressure is desired. For others, this can exacerbate symptoms, so balancing heart rate control and blood pressure can be difficult. Often heart medication is combined with one of the blood pressure support medications listed above.

1. **Beta Blockers** - there are several medications that are commonly used in this class including propranolol, metoprolol, nadolol, atenolol, nebivolol, and acebutolol. If it ends in “olol,” it’s probably a beta blocker. These can be trial and error - you may respond differently or have less side effects with one vs. another, so keep trying them. Generally, they work best in small doses. Studies have indicated that using them in higher doses either don’t help or can have detrimental impact on symptoms. Start low and only increase slowly as directed by your doctor. They may also help with chest pain and adrenaline surges. Drowsiness is usually the most common reported side effect. This will often
diminish over time but taking the medication at bedtime can help offset this problem. Dizziness, depression, nausea, vomiting, or diarrhea may also occur.

2. **Calcium-Channel Blockers**: these types of medication slow the heart rate and can be used to control an irregular heart rate or treat tachycardia. Like beta-blockers, these medications can also lower blood pressure and should not be used if you have nOH or NCS.

3. **Clonidine** - this is a medication that is especially helpful in hyper-POTS because it helps decrease both blood pressure and heart rate. It is generally used for severe hypertension, but continuous delivery through a patch or taking orally on a regular basis can help prevent adrenaline surges, which result in large swings in blood pressure and heart rate. Side effects could include bradycardia or hypotension - if it lowers BP or heart rate too much. Drowsiness, constipation, dizziness, and dry mouth are also common.

4. **Corlanor (Ivabradine)** - this is a relatively new medication in the US and currently only FDA approved to treat congestive heart failure. However, its ability to decrease heart rate without affecting blood pressure has made it a popular treatment option for POTS and studies are still ongoing. It is a possible treatment option for people who have failed beta blockers or are unable to tolerate them. Bradycardia is the most commonly reported side effect.

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**Other Medications:**

**Antidepressants:**

Both SSRI and SNRI drugs have been shown to have positive effects on some patients with POTS. This is not because you are depressed, but because of these medications affect serotonin or norepinephrine, depending on what class you use. SNRIs are not recommended for hyper-POTS due to their effect on norepinephrine and the possibility of increasing blood pressure; however, for others that can be a desired effect. They also have the benefit of helping stabilize mood, which can be affected by chronic illness. These drugs are like beta blockers in that finding which one works best is somewhat trial and error. You can do genetic tests to help you determine which you will metabolize best. You may not respond the same to different medications, even within the same class. Side effects may also make tolerating these medications difficult,
particularly regarding fatigue and dizziness, but they may fade or disappear over time. Some, like Cymbalta for example, may also help with pain.

**Mast Cell Activation Disorder/Mastocytosis Medications:**

Treating the underlying cause here may help significantly with dysautonomia symptoms. Some common mast cell medications include:

1. **Histamine Blockers** - these fall into three categories:
   - **H1 blockers** (used for respiratory symptoms, hives, and anaphylactic symptoms). Zyrtec (Cetirizine) or Allegra (Fexofenadine) are commonly taken prophylactically and Benadryl (diphenhydramine) is taken to treat acute symptoms.
   - **H2 blockers** (used for gastrointestinal symptoms). Zantac (Ranitidine) and Pepcid (Famotidine) are commonly taken prophylactically.
   - **H3 blockers** (currently still experimental, but being investigated for the treatment of sleep disorders and certain types of dementia).

2. **Mast Cell Stabilizers** like cromolyn sodium and ketotifen, which may be used topically, as eye drops, as a nose spray, or taken orally.

3. **Leukotriene Inhibitors** like Singulair (Montelukast), Accolate (Zafirlukast), and Zyflo (Zileuton).

4. **Prostaglandin Antagonists** like Aspirin. Though, these are not widely used.

5. **Corticosteroids** like Prednisolone, Methylprednisolone, or Solumedrol. Though these are not often recommended for long-term use.

6. **Immunologic drugs and biologics** like Xolair (Omalizumab).

7. **Epinephrine** - used to treat acute anaphylaxis only. Beta blockers may make this medication less effective, so make sure your physicians know about all the medications you are taking.

**GI medications**

Based on symptoms, patients may take medications that either speed-up or slow-down GI motility, reduce spasms, and/or treat symptoms like nausea, diarrhea, constipation, gas, or heartburn/reflux.

1. **Antispasmodics**: Bentyl, Imodium, Hyoscyamine may help with cramping and slowing down motility. These also have effects on the nervous system, and some patients find they make their POTS or OI symptoms worse.
2. **Anti-Nausea Medications**: Phenergan or Zofran (Ondansetron). Over the counter anti-nausea medications include motion sickness medications like dramamine. Common homeopathic options to treat nausea include ginger, peppermint, and lemon.

3. **Antidiarrhetics**: Most are found over the counter. Common homeopathic options to treat diarrhea include the BRAT diet, which is made up of foods which help bind the stool (Bananas, Rice, Apples, and Toast).

4. **Increase Motility or Treat Constipation**: Reglan is used with gastroparesis, but may also improve overall motility. Another prescription for constipation is Linzess. Over the counter medications for constipation include laxatives, and milk of magnesia, and stool softeners. Common homeopathic options to treat constipation include dried fruits - such as prunes or apricots, or prune juice.

5. **Anti-Gas Medications**: Simethicone is the most common anti-gas medication. Gas pain can be extremely painful, so trying an anti-gas medication may provide relief for abdominal pain - once other more serious causes have been ruled-out.

6. **Reflux Medications**: fall into three categories - acid reducers, antacids, and proton-pump inhibitors. They may be prescription or over the counter. Homeopathic treatments for reflux include licorice - but make sure it is deglycyrrhizinated so it does not affect heart rate or blood pressure.

**Other Medications:**

1. **IVIg**: is gaining popularity and is currently being studied for various forms of autoimmune induced dysautonomia.

2. **Anti-anxiety medications** - may be helpful for anxiety symptoms or adrenaline rush symptoms.

3. **Central Nervous System Stimulants**: including ADHD medications and narcolepsy medications - may help with increased wakefulness and concentration and decreased brain fog in some patients; but may make symptoms worse in others, particularly regarding blood pressure.

**Other Treatments:**

1. **Pacemakers**: these are generally used for severe neurocardiogenic syncope or patients with severe or consistent bradycardia. They help regulate the rhythm of the heart and prevent the heart rate from dropping too low.
2. **Cardiac ablation**: this is most commonly done in patients with severe inappropriate sinus tachycardia that do not improve with other treatments. A catheter is inserted into the heart and used to destroy or scar some of the tissue in the heart that controls the heart rate. The long-term success of this procedure is very modest, with most seeing symptoms return. In addition there is an increased risk of severe complications, including requiring a pacemaker for bradycardia.

**Building a Care Team & Getting The Right Treatment**

**Educate Yourself!** - it is important that you understand your disorder as much as possible. You may have questions that build after you get your diagnosis. Write them down and make sure to ask them at your next appointment. Google can be your worst enemy; so, make sure you are getting information from reliable sources and maintaining a balance between educating yourself vs spending too much on time on the internet. Understand that everyone is an individual and what may work for one person may not work for you and vice versa! The same applies for doctors and facilities. Use trusted sources and look for articles or resources from peer-reviewed journals and medical facilities’ pages. The DSN Library - at [https://www.dysautonomiasupport.org/library](https://www.dysautonomiasupport.org/library) - is a great place to look for information.

**Keep Records** - Start keeping a journal or keep records of symptoms or vital signs to bring with you to appointments but keep it simple. Use it to summarize or to give to your doctor for them to review. Don’t expect that you will be able to go over every number or symptom you have. However, it can help you determine trends, triggering factors, or ways to improve symptoms. DON’T get bogged down in numbers or let them create anxiety. When people are first diagnosed or trying to get diagnosed, it can be common for them to want to record their heart rate and blood pressure all the time, and worry can set in with every change that is seen. That can feed into anxiety and make symptoms worse. So, find a balance of monitoring yourself in a healthy way without becoming obsessed with it. Request office notes from your doctor appointments and copies of all your test results. Keep this information together with your symptom log and vitals. Some apps and computer software that may help with symptom tracking and record keeping are listed on our Assistive Technology page at [https://www.dysautonomiasupport.org/assistive-technology/](https://www.dysautonomiasupport.org/assistive-technology/).
Coordinate Your Care - It often helps for your care team to be in the same medical system, but sometimes it doesn’t work out that way because of insurance or because certain specialties are hard to find locally. For that reason, many patients with find it helpful to get a care manager, case worker, nurse navigator patient advocate to help in the coordination of care between specialists. You can ask your insurance company if they provide any of these services. If not, many mental and behavioral health agencies have them. DSN also can help connect with you patient advocates.

Be Your Own Advocate - Even if you have someone assisting in the coordination of your care, you are still your own advocate too! If you are unsure how to advocate for yourself or how to speak to a doctor about your concerns, you may want to read our “Golden Rules of Physician Communication” document, available at https://drive.google.com/file/d/1RXJiqBcs7rg1zSha-gGgm9A1nbGN9_-G/view. We have also provided this worksheet for you to use to take notes for and at an appointment: https://drive.google.com/file/d/1zCqeijzaehVQj3hUaveT6TnmzdrJDzMW/view.

Get Treatment and Care When You Need It - Many dysautonomia symptoms can be scary, especially if you are newly diagnosed. Many dysautonomia symptoms easily resemble those of more serious medical conditions, such as heart attack or stroke. As such, dysautonomia patients frequently are unsure when they should seek emergency medical care, and when it is not necessary to do so. DSN has compiled an outline with information about when you should consider going to the ER. This document is a general guide and should not be considered medical advice. You can download it from https://drive.google.com/file/d/1rR6-wwxYrZTOAMGz1Y1kG6HR34fElstP/view. If you choose to use this document, please discuss it with your doctor first, as these are general guidelines, and your specific conditions may differ! Also, make sure to ask your doctor when you should call his/her office vs. when you should seek emergency care. Depending on your symptoms, you may want to get specific values for heart rate, blood pressure, and temperature, such as “above X” or “below X.” If you do call, you can use this worksheet to take notes while on with the on-call doctor: https://drive.google.com/file/d/19xFKhykfz47WdaYgCM5Qhu_MJoChSekp/view. If you are in doubt, or you are experiencing new or severe symptoms and/or are unable to reach your doctor, go to the emergency room or call 911 (or your equivalent emergency number if you are outside the US).
**Build a Medical Team** - This is easier said than done, but building a good medical team is important. What doctors/specialists you will want to have will be based on your individual needs. Understand the role of each professional in your team. It is also important to understand that there are subspecialties within specialties. Not all neurologists or cardiologists are going to diagnose or easily recognize dysautonomias, for example. Many times, doctors will specialize within certain patient populations, so some may only see patients that have dysautonomia or syncope.

Finding doctors is often one of the more frustrating and time-consuming parts of being chronically ill and it may take some time to find the right ones. DSN’s healthcare provider map - viewable and searchable at [https://www.dysautonomiasupport.org/providerdirectory](https://www.dysautonomiasupport.org/providerdirectory) is a good place to start. It’s also recommended that you give a doctor more than “one shot.” It’s almost impossible to diagnose, treat, or address all concerns in one appointment. It takes time to establish relationships and understanding. If you have already found a good provider and would like to recommend him/her to others with dysautonomia, you may request an addition using the following form: [https://goo.gl/forms/EMzEWJ5ac3gZHPKi2](https://goo.gl/forms/EMzEWJ5ac3gZHPKi2).

Here are some examples of the providers you may see and what role they can play:

1. **Primary Care (PCP) / General Practitioner (GP)** - these doctors are going first, not because they can typically diagnose dysautonomia, but because they are often your biggest cheerleader and the person who can help you build and coordinate with the rest of your team. Don’t be surprised if they have never heard of your disorder. What you really want in a primary care doctor is a good listener, someone willing to learn and someone who has good connections to specialists and is willing to communicate with them.

2. **Cardiology/Electrophysiologists (EP)** - these are the most common “dysautonomia” doctors, particularly since diagnosing the form is often related to what exactly the heart rate and blood pressure does under certain circumstances. They are also the ones responsible for managing these symptoms. EPs are specialists within cardiology who specifically specialize in disorders that affect the electrical current or rhythm and rate of the heart. They are the ones who most commonly order and interpret tilt table tests; although some general cardiologists that do as well. For those that do specialize in
autonomic disorders, they may also be able to help refer you to physicians in other specialties that can manage other autonomic symptoms when necessary.

3. **Neurologists** - some neurologists specialize in dysautonomias and can diagnose and/or treat the neurological symptoms. There are many common comorbidities that overlap with dysautonomia, so they will often also test for differential diagnoses and treat things like migraines/headaches, neuropathy, movement disorders, seizure disorders, sleep disorders, etc.

4. **Rheumatologists** - these doctors will be important if an autoimmune disorder is the suspected underlying cause of your dysautonomia. They can both test for and treat autoimmune conditions. They may also be able to help diagnose EDS.

5. **Geneticists** - if you have a history of dysautonomia in your family, you may consider seeing a geneticist. Geneticists can test for specific inherited types of dysautonomia including Riley-Day Syndrome, also called familial dysautonomia. Aside from inherited primary dysautonomias, geneticists can also test for EDS (Ehlers Danlos Syndromes). Hypermobile EDS and Hypermobility Spectrum Disorders cannot be tested for with blood work (yet), but geneticists can still make the clinical diagnosis and can determine if additional genetic testing should be done.

6. **Gastroenterologists** - these doctors can help diagnose and treat motility disorders that may go along with your dysautonomia such as gastroparesis or dumping syndrome.

7. **Allergists/Immunologists** - allergy disorders are relatively common with different forms of dysautonomia. Mast cell activation syndrome, mastocytosis, and eosinophilic esophagitis are some of the comorbidities that may be seen which would be treated by an allergist.

8. **Pulmonologists** - if shortness of breath or respiratory distress is one of your dysautonomia symptoms, a pulmonologist may be able to help you with this. However, if breathing difficulties are secondary to cardiac or mast cell issues, they may not be able to do much for you.

9. **Urologists or Urogynecologists** - these doctors can help diagnose and treat pelvic floor disorders that may go along with your dysautonomia or symptoms such as frequent urination or urinary retention.

10. **Therapists** - Occupational, physical, and speech therapists can all play a vital role in treating your symptoms, so don’t underestimate finding a good one!
11. Psychiatrists/Psychologists - mental health is important too! Dysautonomia patients can sometimes be hesitant to add a mental health professional to their team, especially if they were once told it was all in their head or given a mental disorder before their dysautonomia diagnosis. While it may not be the cause, depression and anxiety can go along with chronic illness, and can contribute to symptoms. Being your best self mentally will help you be your best self physically and vice-versa! Find someone who will validate your illness and understand the mental and emotional toll that it can take. They can help you come up with coping tools for those hard days and sometimes just be a great ear and sounding board when you need one.

12. Sleep Specialists - autonomic disorders often come with sleep disturbances, which can in turn exacerbate symptoms. Some people with dysautonomia also suffer from hypersomnia or severe fatigue. A sleep specialist can perform tests to determine how you are sleeping at night, and sometimes during the day, to best treat your individual circumstances.

13. Pain Management - both pharmacological and non-pharmacological support can sometimes prove helpful for those experiencing chronic pain.

14. Nutritionist - working with a knowledgeable nutritionist or registered dietitian is important to be aware of how much sodium you are getting from what you eat. For patients with exercise intolerance, a nutritionist can also work with you to maintain or lose weight, despite limited ability to exercise. If you have Mast Cell issues or food allergies, a nutritionist can help you find and eliminate trigger foods from your diet. Finally, if you have GI motility issues, a nutritionist specializing in these issues can help ensure you are getting adequate nutrition.

There are many other specialties that may be added to your team depending on your own individual needs and comorbidities. Some people also find alternative medicine such as massage, acupuncture, reiki, chiropractic adjustments, osteopathic manipulation, dry needling, or herbs and supplements to be helpful for their symptoms.

The key is to start with finding someone knowledgeable in dysautonomia (maybe you already have) and then let them help refer you to others. Again, the DSN Healthcare Provider Map (https://www.dysautonomiasupport.org/providerdirectory) is a good place to start. As you build your team, make sure all your care team knows about all your diagnoses and all the pharmacological and non-pharmacological treatments you are using!
Support & Resources for Living Well with Dysautonomia

**Build a Support System** - Engage family or friends and involve them in education and possibly doctor appointments. Having one or two people who can consistently go to appointments with you can be very helpful for when you are having difficulty communicating. They can help you remember what is being said as well. It will also help them to understand your disorder better and learn how they can support you through it. Your caregivers and supporters may need support too. They can find it in our Dysautonomia Caregivers Facebook group ([https://www.facebook.com/groups/DSNcaregivers/](https://www.facebook.com/groups/DSNcaregivers/)). If you are both a patient and a caregiver for someone else with dysautonomia, you are welcome to seek support in this group as well.

**Find your Tribe!** - Chronic illness can feel very lonely at times but remember that you are not alone - there are millions of others out there suffering from similar problems! You may find that the healthy people in your life have a hard time understanding or will offer advice that may not always be welcome or helpful. It can also be hard to keep up with social activities or do as much as you would like. Online and local support groups can be a wonderful way to engage with others and share experiences where you will be heard and understood. DSN has a global support community on Inspire ([http://dysautonomia.inspire.com/](http://dysautonomia.inspire.com/)), a global Facebook Support Group - Dysautonomia Divas, Dudes, & Zebras ([https://www.facebook.com/groups/Dysautonomia/](https://www.facebook.com/groups/Dysautonomia/)), and state support groups in all 50 states. We also have Facebook support groups for Caregivers ([https://www.facebook.com/groups/dsncaregivers](https://www.facebook.com/groups/dsncaregivers)) and Military Families ([https://www.facebook.com/groups/dyssupportmilitary/](https://www.facebook.com/groups/dyssupportmilitary/)). A full list of our support groups with links is available on our website at [https://www.dysautonomiasupport.org/dyssupport](https://www.dysautonomiasupport.org/dyssupport).

**Embrace Your New Normal** - Remember that you are more than your diagnosis, and that your worth is not measured by what you can or cannot do. Look for new ways to continue doing what you enjoy doing and to stay connected socially. DSN has Lifestyle Clubs, which help you focus on what you CAN do and not what you can't. They can also help you learn how to modify things to better adapt to your condition or even help you find new interests. Currently, our clubs include Facebook groups, Pinterest Boards, and Inspire Discussions on art, books, crafting, fitness, mindfulness, and writing; with more
coming soon. A full list of our Lifestyle Clubs with information about the specific goals of each and how to join can be found at https://www.dysautonomiasupport.org/clubs.

**Find Emotional and Mental Support** - Understand that being chronically ill is HARD! And it’s a bit of a roller coaster, so you’re going to be up and down both physically and emotionally. Always reach out to someone in your support system or medical team whenever you feel overwhelmed by symptoms or are feeling extremely depressed or anxious! If you find yourself particularly struggling or in a crisis situation, please reach out. Information about national crisis and support hotlines can be found on the resources section of our site at https://www.dysautonomiasupport.org/crisis-resources.

As mentioned above, finding a good mental health professional can be helpful for your symptoms and your mental health. There are also lots of things that you can do with a mental health professional or on your own. These things may include mindfulness, meditation, guided imagery, self-hypnosis, breathing exercises, and yoga nidra to name a few. There are an abundance of great apps and websites with free resources for mindfulness, including the DSN Mindfulness Club (https://www.facebook.com/groups/chronicallymindful/).

Staying involved in church or other religious communities, hobby clubs, and other social groups can also do a lot to help support us emotionally. The important thing is to try and not isolate any more than necessary and to find new life, purpose, and motivation despite your condition. Volunteering can also be a great way to stay involved and connect with others while providing a sense of purpose. For information on volunteering with DSN, visit our volunteer page on the website at https://www.dysautonomiasupport.org/volunteer. Remember that your diagnosis and your symptoms are not the only things that define you!

**How Support Groups Can Help**

Support Groups can help in multiple ways. Perhaps most importantly, in one, you will find that you are not alone. There are others just like you who understand what you’re going through! While they cannot give you medical advice, they can give you insight into what they have experienced and can help point you to resources and information. To read about shared experiences of others with dysautonomia and/or its coexisting conditions, check out the DSN Blog at https://www.dysautonomiasupport.org/blog.
Support groups can also give you a chance to really connect on different levels (besides illness) through shared interests and life circumstances. They can open the door for opportunities for awareness, fundraising, and advocacy. DSN in particular has many of these opportunities - https://www.dysautonomiasupport.org/advocacy-1. Finally, they can provide education and additional resources through social and educational events (https://www.dysautonomiasupport.org/copy-of-meetings-events), grants - like the DSN Service Dog Grant (https://www.dysautonomiasupport.org/servicedogs), and scholarships - like the DSN educational scholarship program (https://www.dysautonomiasupport.org/scholarship).

So whether it’s gaining support and understanding, helping to educate yourself and family members, finding lifestyle clubs that encourage activities outside of dysautonomia, or discovering new possibilities and resources - Dysautonomia Support Network can help you to empower yourself and manage your illness! To read about our mission and find out more about how we do this, visit our website at https://www.dysautonomiasupport.org/copy-of-about-us. We are Stronger Together!