Dysautonomia

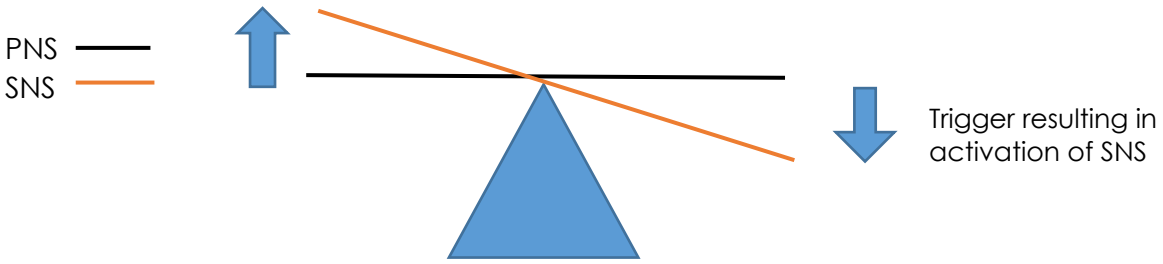
Prepared by Tracey Larsen

October is Dysautonomia Awareness Month

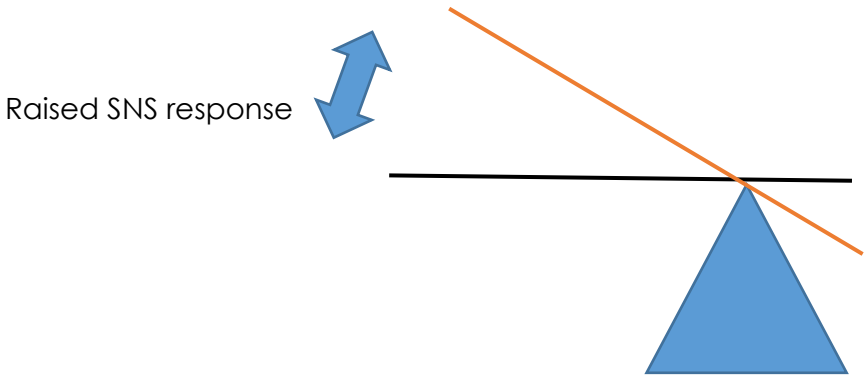
Dysautonomia (Dis-Auto-No-Mia) is an umbrella term for multiple conditions which causes a disturbance in the Autonomic Nervous system (ANS).

The ANS is responsible for regulating and maintaining a constant internal temperature, regulating breathing patterns, and heart rate and keeping blood pressure steady. It is also involved in pupil dilation, sexual arousal, and excretion.

The ANS is made up of the Sympathetic Nervous System (SNS) and the Parasympathetic Nervous System (PNS). The SNS is aroused by stress or a trigger that results in the fight/flight stress response and produces adrenaline, raising the heart rate, breathing rate, blood pressure, dilating the pupils etc.. (like an accelerator of a car). The PNS calms the body back to a balance state after the stressor or trigger has gone or as we get used to the new situation (often known as the rest and digest system and acts much like the brake of a car).



With Dysautonomia, the pivot point for the SNS and PNS is much more sensitive, meaning that a much smaller trigger results in a much higher and prolonged SNS response. Therefore, for example, a change in posture or the simple act of standing can result in much more pronounced and prolonged stress response.



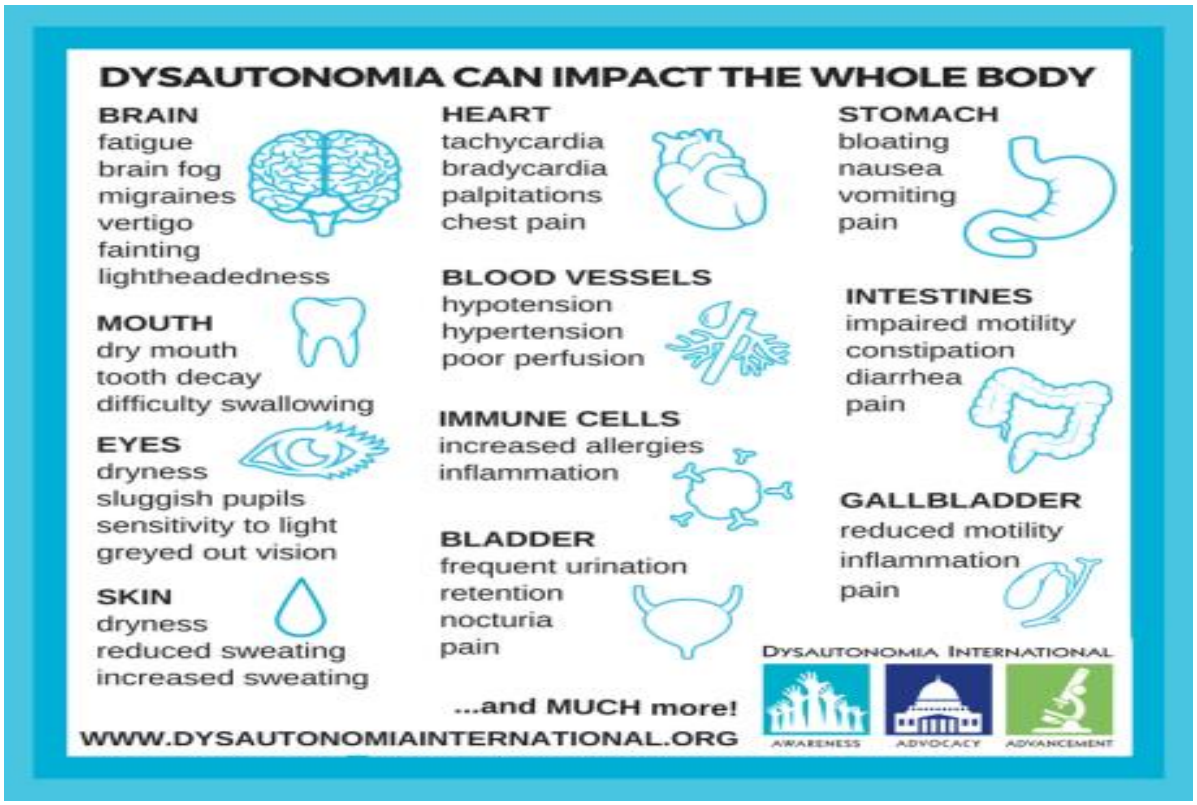


Image sourced from https://www.facebook.com/DysautonomiaInternational/photos/fridayfacts-dysautonomia-can-impact-any-organ-and-system-in-the-body-because-the/3516569141775273/

Common Symptoms Include:

- An inability to stay upright
- Dizziness, vertigo, and fainting
- Fast, slow, or irregular heartbeat
- Chest pain
- Low blood pressure
- Problems with the gastrointestinal system
- Nausea
- Disturbances in the visual field
- Weakness
- Breathing difficulties
- Mood swings
- Anxiety
- Fatigue and intolerance to exercise
- Migraines
- Tremors
- Disrupted sleep pattern
- Frequent urination
- Temperature regulation problems
- Concentration and memory problems (brain fog)
- Poor appetite
- Overactive senses, especially when exposed to noise and light

These symptoms occur in a range of combinations, making dysautonomia a difficult condition to diagnose.

Is Dysautonomia Rare?

No. Dysautonomia is a common condition, with up to 15 different types that can occur on its own through inheritance, or with other conditions and/or injury:

Ehlers–Danlos syndromes	Pre-Diabetes
Sjögren's Syndrome	Lupus
Anti-Phospholipid Syndrome	Multiple Sclerosis
Parkinson's	Lyme Disease
HIV	Guillain-Barre
Mitochondrial diseases	Genetic diseases

Paraneoplastic Syndrome associated with some forms of cancer, certain chemotherapy and other drugs that can cause autonomic nerve damage, as can vitamin deficiencies, heavy metal poisoning and alcoholism,

ME/CFS/FM are two such conditions whereby dysautonomia can often be associated.

The most common dysautonomia conditions for those living with ME/CFS/FM are:

- Orthostatic Intolerance (OI)
- Neurally Mediated Hypotension (NMH)
- Postural Orthostatic Tachycardia Syndrome (PoTS)

Orthostatic Intolerance (OI)

Dr Vallings explains that, for many people living with ME/CFS/FM, they can have low blood pressure, or be on the low end of normal. Many also have decreased blood volume. Both issues can result in sluggish blood circulation. Upon standing one can experience:

- Dizziness and/or fainting
- Light-headedness
- Nausea
- Looking pale
- Heart palpations

When standing for too long, blood may pool in the lower limbs. The dysfunction of the SNS does not compensate properly for gravity in order to maintain effective blood circulation back up to the brain. Heart palpations can then result, as the heart is doing just what it needs to do to, to ensure blood gets back to the brain.

Neurally Mediated Hypotension (NMH)

NMH is very similar to OI, however NMH results from confused communication between the blood vessels, the brain, the heart, the nerves and the endocrine organs. A drop in blood pressure due to standing for long periods therefore occurs. Symptoms are:

- Dizziness
- Nausea
- Fainting
- Fatigue

Dr Vallings refers to this as "3rd Isle of the Supermarket" – after getting from the car to supermarket and around the first few isles, you suddenly feel like the plug has been pulled. You may have a sudden desire to sit down as a heightened risk of fainting and falling can occur.

Postural Orthostatic Tachycardia Syndrome (PoTS)

An abnormal response by the ANS when up right and/or standing is signalled by an abnormally large increase in heartrate (of at least 30 - 40 beats / min) within 10 minutes of standing up. POTS patients usually have a drop in blood pressure on standing too, but some experience no change, or an increase in blood pressure.

Symptoms include:

- Tachycardia (with or without chest pain)
- Fatigue
- Headaches/migraines
- Nausea
- Brain fog
- Visual problems/changes
- Shaking or tremors
- Sweating
- Purplish discolouration of hands and feet (blood pooling)
- Some of the physical symptoms overlap with anxiety, but POTS is **not** caused by anxiety

POTS is normally a secondary dysautonomia. Researchers have found high levels of auto-immune markers in people with the condition, and patients with POTS are also more likely than the general population to have an autoimmune disorder.

There are differing levels of severity for all these conditions. In some cases, they are mild to moderate, a few are unable to sit or stand and some are bedbound.

Triggers

- Holding an upright posture for long periods of time
- Heat and a warm environment can dilate the blood vessels – hot weather, hot, over-crowded rooms, shower/bath too hot, spa pools, over dressing.
- Exercise and physical exertion
- Emotionally stressful events
- Inadequate fluid/salt intake
- REM sleep – can trigger SNS, resulting is disrupted sleep and exacerbating fatigue, pain and other ME/FM symptoms

Diagnosis

- Is by a prolonged standing test or a tilt table test whilst taking blood pressure readings
- As tilt tables are not typically available at your local GP practice, the NASA 10-minute lean test can used by your GP
    - Involves lying down for 5 – 10 minutes, blood pressure and pulse rate are then taken before standing and leaning against the wall. BP and PR are monitored every minute, for 10 minutes, as well as other physical signals and symptoms experienced
    - The NASA test recommends limiting fluid and sodium intake, some medications and wearing compression clothing for 24-48 hours prior to test
- Increased fatigue and malaise often occur for a few days after the test. This can be minimized with intravenous saline solution treatment immediately after the test

Some Simple Self-help Measures

- For sudden onset of symptoms, take 2 glasses of water quickly, with a pinch of salt, lie down on the floor and raise legs up the wall, or on the couch, for 10 minutes or until symptoms (or heart palpations) subside. This helps the blood to get back to the heart and brain
- If unable to lie down, cross your legs whilst standing, or rock up and down on your toes, clench buttocks and abdominal muscles, clench your fists – tightening muscles helps to circulate blood
- Symptoms can be worse in the morning, so have a drink before getting out of bed

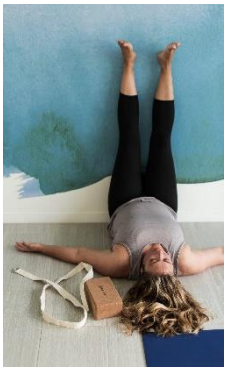


Image Source: https://www.gaiam.com/blogs/discover/legs-up-the-wall-the-most-therapeutic-yoga-pose

- Drink extra fluids (at least 2-3 liters per day); have electrolytes; take extra salt (unless you have high blood pressure)
- Extra salt in the diet can leech potassium so take potassium supplementation, or eat bananas and kiwifruit
- Change posture; move, recline, lie down
- Stand up slowly and avoid prolong sitting and standing
- Pressure garments, support stockings, compression clothing – supports blood circulation
- Rising the head of your bed
- Keeping your feet up when seated
- Good diet – Smaller meals more often – low sugar
- Limit or avoid alcohol and caffeine – these are both dehydrating and can also activate SNS by producing a stress response
- Heat can aggravate by dilating blood vessels – have cooler, shorter showers and baths, dress in layers
- Being cold, on the other hand, can constrict blood vessels, reducing blood flow, so keep yourself at a comfortable temperature
- Massage can help improve blood circulation and help manage stress and activate PNS
- Pacing and task switching regularly to keep heart rate lower
- Physical exertion/exercise can worsen symptoms, but fitness is important. Increasing leg strength and core muscles can be beneficial in pumping blood back to the heart
- For those with more frequent or more severe symptoms, self-help measures may need to be supplemented with medication e.g. fludrocortisone (Florinef) – helps to increase blood volume
- Ensure your sleep hygiene is excellent
- Manage pain well – pain in itself can activate SNS
- BREATHE! – Breathing is the only way we can consciously affect our ANS. Diaphragmatic breathing is excellence in helping circulate blood and bring more oxygen into the blood. An excellent way to help calm an accelerated heart rate and also manage any anxiety that may exist during sudden episodes

Resources

See this link for a 4-minute video to explain PoTS
http://www.dysautonomiainternational.org/page.php?ID=30

Understanding dysautonomia
https://www.youtube.com/watch?v=xVfi2hbg69g

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