

Dysautonomia

Support and Lifestyle Strategies for Symptom Management



My Health – Living Well With Long Term Conditions

Hello everyone, and thank you for joining today.

This presentation is an introduction to dysautonomia. Many people won't know what dysautonomia is so I'm hoping that by the end of this 25 minute session, you will be better informed as to what it is, the symptoms it can cause, and some practical strategies that may help manage those symptoms. Many people find the symptoms confusing or worrying because they affect multiple body systems.

My aim today is to help explain what's happening and provide some simple, evidence-informed approaches that may support recovery and symptom management.

1

What is Dysautonomia?

Autonomic Nervous System (ANS) = Your body's automatic control system

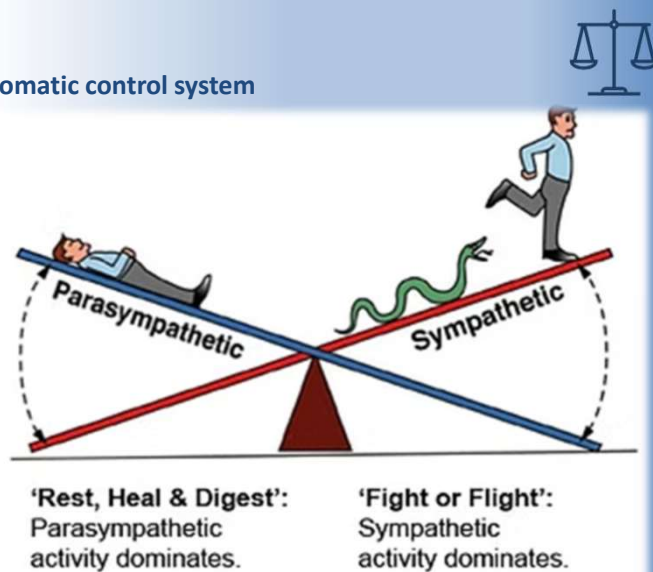
Your ANS controls

- Breathing
- Heart rate
- Blood pressure
- Temperature
- Digestion
- Stress response

Dysautonomia is when the ANS does not respond in the right way for the situation

Common Triggers

- Illness
- Stress
- Major life events



Dysautonomia can feel like you are "stuck" in Fight or Flight

The autonomic nervous system, or ANS, is the part of the nervous system that controls many **automatic** functions in the body. These include heart rate, blood pressure, breathing, digestion, temperature regulation and our stress responses.

Some of these responses are bunched together to make the sympathetic (fight and flight) and parasympathetic (rest and digest). The purpose of this is to be able to react to stressors quickly but conserve energy between times – for example: Your system is calm and relaxed when you are resting, conserving energy, redirects resources to repair and digest (as you will see in the next slide). Ready for when you encounter a danger – this reflex is triggered quickly to be alert, ready to fight or run away.

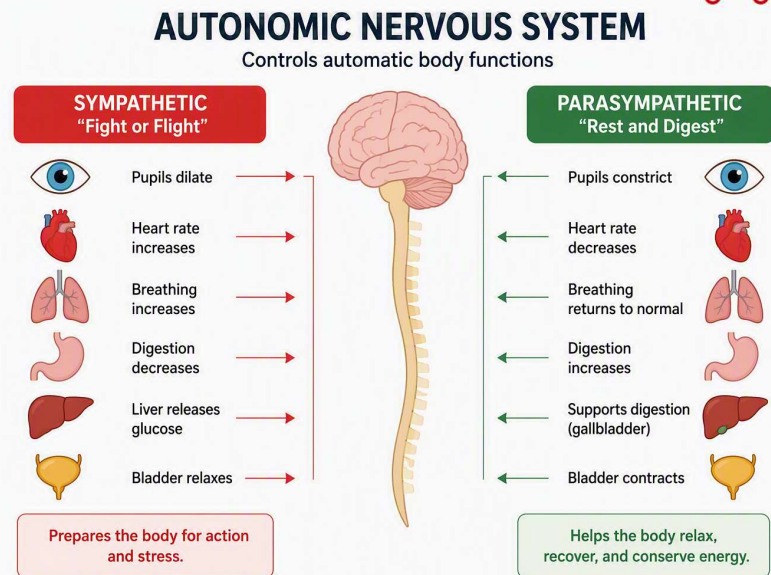
Normally, the nervous system moves smoothly between different states. Sometimes we're resting and recovering, and at other times we're responding to challenge, exercise or stress.

A useful way to think of dysautonomia is that the body's control system becomes less efficient at making these adjustments – takes too long or the response is too sensitive. Many people describe feeling 'stuck in fight or flight', where they feel "wired" or "on edge" for no reason or that the smallest thing can make them feel anxious. Almost like the right side of the seesaw in the picture is stuck in the air and can't come down. This can happen following illness, stress, or other significant life events.

Importantly, the symptoms are real, but they don't necessarily mean damage is occurring.

2 Symptoms of Dysautonomia

-  Heart racing / BP issues
-  Dizziness
-  Breathlessness
-  Brain Fog
-  Temperature dysregulation
-  Headaches
-  Posture dependent symptoms



Within the 2 opposite poles for **Fight + Flight** and **Rest + Digest**, this diagram shows how your body responds:

With the example of the snake from before. Imagine you are lying down relaxing in a park and you see something moving in the tall grass and your imagination tells you that it could be a snake – immediately your body prepares to deal with this potential danger...pupils dilate to let in more light to see and focus more and quickly notice any movement, hearing becomes more sensitive as all senses become alert (including sense of smell). Your heart rate and breathing gets faster to prepare for the higher need for oxygen if you need to run or fight. Blood gets redirected from your digestive organs to your muscles and brain and your liver releases glucose to fuel the potential response. Your bladder relaxes (think about how you may pee more often when stressed about an interview etc) and from an evolutionary stance this is to quickly shed more weight to be lighter for taking off.

Then a rabbit jumps out and runs away – your systems should efficiently switch back to Rest and digest over the next few minutes

So therefore being stuck in F+F for long periods or when not needed can result in some of the symptoms on the slide:

- Heart racing or changes in blood pressure

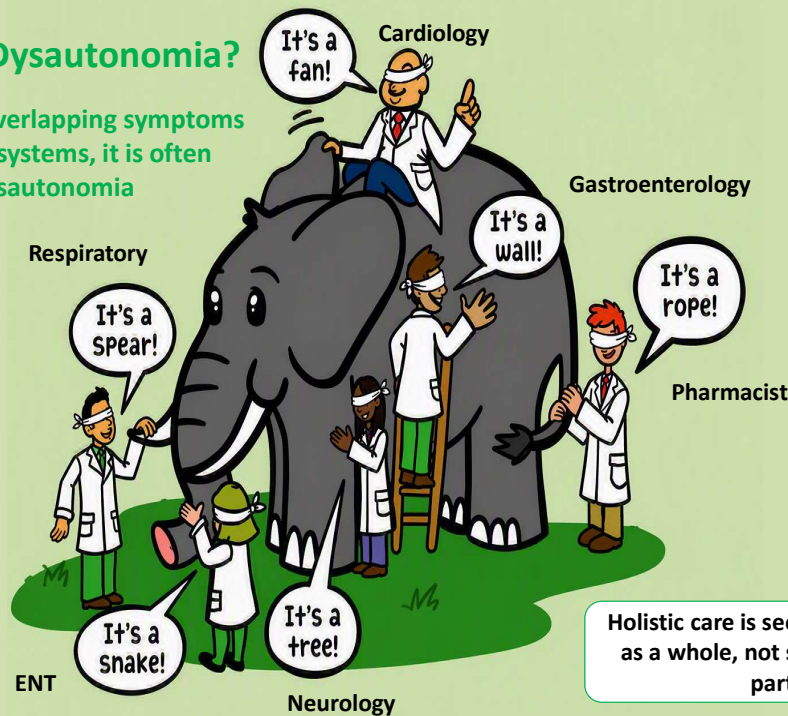
- Dizziness or feeling light-headed
- Breathlessness
- Brain fog or difficulties concentrating
- Temperature regulation problems
- Headaches
- Symptoms that are related to posture, particularly standing upright (which we will talk about in a few slides)

People often experience several of these symptoms together, and symptoms can fluctuate from day to day.

3

Do I have Dysautonomia?

As there are so many overlapping symptoms crossing multiple body systems, it is often difficult to diagnose Dysautonomia



One challenge with diagnosing dysautonomia is that its symptoms overlap with many other conditions.

In most people's cases, they will speak to their GP about the symptoms as the first point of contact. With the vast range in symptoms, they may wish to rule out certain things – these tests will be different for everyone – based on what their symptoms are.

For example, they may test for **diabetes** (which can cause fatigue, dizziness, excessive thirst and frequency passing urine, tingling in hands and feet). They may rule out **deficiencies** (like anaemia which can cause dizziness, tingling in extremities and palpitations) and test your **thyroid, liver and kidneys** and ask that you are not dehydrated (which can cause low BP and fainting) or malnourished.

They may consider **menopause or perimenopause** (fatigue, brain fog, pain, temperature regulatory issues etc) and test your blood or trial HRT.

It may be that all of the diagnostic tests may come back as normal or any trials of medications may be unhelpful, resulting in either no further appointment being made or a referral to a specialist to further investigate their area of specialty if they remain concerned – not everyone will need to see all or any of these specialists and the list is not exhaustive. Your GP decides if a referral is required and in some areas there is a threshold of symptoms before a specialty will accept.

So, looking at the picture of the elephant, the little Doctors are blindfolded and shown 1 part of the elephant and have to make a judgement based on the one body part they can feel:

"It's a fan" - you may be referred to Cardiology - some types of Dysautonomia causes your heart to beat fast, which can be frightening / concerning - there are assessments and investigations your GP can arrange to rule out cardiac cause for this or refer you to cardiology. It may be that they run tests your heart and it no abnormalities are found and discharge you

"It's a wall" - Gastro - A sudden change in bathroom habits should be discussed with your GP before assuming it to be dysautonomia. You may be referred to Gastro. You may have loose stools or stomach pain and are assessed, sent for tests and digestive conditions are ruled out. You are then discharged.

"It's a rope" - you may be referred to the pharmacist within your GP practice to check if any of your other medications cause these symptoms - some meds can reduce your blood pressure, increase your heart rate, can make you pass more urine etc. It may be decided that none of your meds are causing it – no follow up review.

"It's a Tree" – you may have headaches or tingling hands and feet - neurology may see you, send you for tests and struggle to find a cause for it or find pain relief which works – you are then discharged

"It's a snake" - You may be referred to ENT for **Vestibular issues** – this is the communication between your ears and eyes to help you balance – this can get disrupted by an infection / stress / head injury etc. Symptoms may be more "room spinning" or feeling like you are on a boat, you may feel dizzy when turning to a side or lying on your side. You may be assessed and all tests are normal – again you are discharged.

"It's a spear" - You may be breathless and referred to respiratory – they may examine you, send you for a breathing test or an exercise test and everything returns as normal. They discharge you.

And this is often where the diagnosis ends...

Medically, this should all be reassuring....but by the end of these tests people often tell me they feel at a loss, don't know what to do next, feel that something has been missed, feel that they are not believed and some have been told that it is all in their heads. Many are labelled with anxiety.

But taking a step back and looking at the full picture can put these pieces together and explain why this is happening.

This is where holistic assessment is so important. We see the individual as a whole person rather than looking at isolated symptoms.

4

Common Types of Dysautonomia

Dysautonomia is an umbrella term to cover several conditions. Different types of dysautonomia can be impacted by different things

Postural

- Postural Orthostatic Tachycardia Syndrome / PoTS
- Orthostatic Hypotension / OH
- Postural symptoms without abnormal heart rate or blood pressure

Unrelated to Posture

- Inappropriate sinus tachycardia / fast resting heart rate
- Vasovagal Syncope / fainting
- Nervous System Hypersensitivity (not strictly dysautonomia)



Dysautonomia is actually an umbrella term that includes a number of different conditions.

Some are particularly influenced by posture – generally moving from lying or sitting into standing, such as:

- Postural Orthostatic Tachycardia Syndrome, or PoTS
 - Feelings of dizziness and a significant, measurable increase in heart rate on immediate standing or standing for prolonged periods – impacts many body systems so can also cause breathlessness, tingling, stomach upset, fatigue, brain fog and chest pain. There are many lifestyle changes which can help manage this but some people also require medication to manage the symptoms.
- Orthostatic Hypotension – as above but blood pressure drops on standing without any heart rate change, leading to dizziness or fainting – may also be managed with lifestyle changes or with medication
- Postural symptoms without significant changes in heart rate or blood pressure – symptoms without changes to BP or HR – some self-management strategies may help this

Others are not dependent on postural changes, including:

- Inappropriate sinus tachycardia – resting pulse is too fast and gets faster with activity – as your heart is beating faster, it this uses up a lot of energy and can

impact on stamina. Can be frightening.

- Vasovagal syncope or fainting episodes – can be triggered by different things – the sight of blood, warm temperatures, shock – pulse and BP reduce and as not enough blood reaches the brain, you are suddenly made to lie down to restore this. A very clever mechanism to restore blood to the brain but obviously lead to injuries.
- Nervous system hypersensitivity – although technically, this is not a form of dysautonomia, it is the umbrella term above dysautonomia or could be the cause of the dysautonomia – a sensitive nervous system, I find it helpful to think of this condition in a similar way as this is one explanation for the cause of chronic pain and similar conditions (central sensitivity syndrome). At the end of the session, there is a slide with a very interesting video explaining this.

So - different forms of dysautonomia have different triggers and may respond to different management approaches.

One useful tool is keeping a symptom diary – there is an example of this on the webpage or you can note it down in your own diary / journal.

Recording symptoms, activities, food intake, hydration, stress levels and environmental factors can sometimes help identify patterns and triggers that might otherwise be missed

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What can I do?



REDUCE SENSORY OVERLOAD

Support Your Senses. Protect Your Peace.

WAYS TO REDUCE SENSORY OVERLOAD

NOISE REDUCING EARPLUGS Reduce loud or unexpected sounds.	SUNGLASSES Dim bright lights and reduce visual stimulation.	BASEBALL CAPS Shield your eyes and create a sense of personal space.	PARASOL / UMBRELLA Block harsh sunlight and create a cool, calm space.	COLD FLANNEL ON YOUR FACE OR NECK Cool down and soothe your body when overwhelmed.	TURNING DOWN THE TEMPERATURE OF YOUR SHOWERS Cooler showers can help calm your nervous system.	OPT FOR QUIETER PLACES / LESS BUSY TIMES TO VISIT (for example a supermarket or café) Choosing quieter places or less busy times can help reduce overwhelm.
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REINFORCE CALM

MEDITATION Focus your mind. Breathe. Be present.	DEEP BREATHING Slow, deep breaths help your body reset and relax.	MINDFUL MOMENTS Notice the little things. Savor the moment. Bring your attention back to now.	PROGRESSIVE MUSCLE RELAXATION Tense and release your muscles to let go of tension.	CALM ENVIRONMENT Soft lights, quiet sounds, and comforting scents can help soothe.	GROUNDING TECHNIQUES 5 things you see 4 things you feel 3 things you hear 2 things you smell 1 thing you taste Use your senses to come back to the here and now.
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You are not too sensitive. Your nervous system is doing its best to protect you.

Be kind to yourself. You've got this.



Once you have established the triggers, you can work to reduce or eliminate them by:

- Avoiding extreme heat or humidity (hand held fans / umbrellas or parasols to shade in hot sun / cold compress on your face or neck, turning down the temperature of your showers)
- Limiting prolonged standing where this worsens symptoms – considering doing tasks in sitting / lying
- Limit excessive light by wearing sunglasses or a baseball cap
- Reduce loud noises with noise reducing earplugs or opt for quieter places / less busy times to visit (for example a supermarket or café)

Another key principle is reinforcing the body's 'rest and digest' response through relaxation practices such as breathing exercises, meditation and guided relaxation.

Small improvements, repeated consistently, can help reduce the intensity of the nervous system reaction over time

You will get the opportunity to try a breathing technique in a few slides.

6

Lifestyle changes

Depending on the trigger for your dysautonomia, treatment focuses on reducing the severity of the symptom to allow the nervous system to relearn what's "normal"



Lifestyle changes



- Increasing fluid intake
- Optimising nutrition
- Avoiding large meals

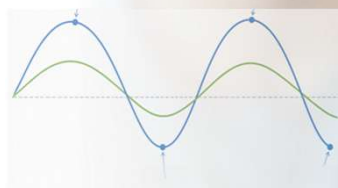


Balance

- Pacing Activity
- Optimise sleep

HRV and Wearables

- Visible
- Smart devices



Flatten the curve,
calm the response



Management depends on the underlying causes of symptoms, but the aim is often to reduce symptoms and help the nervous system relearn what is normal and safe. Lifestyle strategies can make a significant difference.

These include:

- **Increasing fluid intake where appropriate** – this is one of the best strategies to manage PoTS – some people drink plenty but something has gone a bit wrong with the messaging system, causing their body to lose fluid quicker than they can replenish it – either through passing urine, sweating or loose stools. Often the advice is to drink more, sometimes it is to reduce the fluid loss. In PoTS the advice is between 2-3L unless you have kidney damage, high blood pressure or been told to restrict your fluids by a health professional.
- **Optimising nutrition** – reducing caffeine, sugar, and having a balanced diet to avoid deficiencies like anaemia but also trial and error to see what foods might not be working so well with your system. Although fasting may work for some people, others have found that long periods without eating through the day or night can lead to a fight and flight surge.
- **Avoiding very large meals** – this redirects a lot of blood to your tummy and away from your brain (what I call post eating fatigue). Little and often seems to suit a lot of people and reassures the system.
- Pacing your activity levels and avoiding the "boom and bust" cycle is something we'll explore more in the fatigue session. "Boom and bust" happens when you have

periods of doing a lot, followed by a crash that forces you to rest and recover.

- When this pattern repeats, your body can end up constantly switching between "fight or flight" mode and "rest and digest" mode. This can be stressful for the nervous system and may make symptoms harder to manage over time.
 - If you look at the graph, the blue line shows these bigger peaks and dips. This is similar to what can happen when activity levels vary a lot, with periods of overexertion followed by recovery. Your heart rate and symptoms may fluctuate more dramatically as a result.
 - The green line shows a steadier approach, with smaller rises and falls. This is what we aim for with pacing. By taking a more balanced approach to activity, you can help "flatten the curve" and reduce the extremes.
 - Over time, this consistency can reassure your nervous system that you are safe and not in danger. As a result, it may become less reactive, helping to improve your symptom and energy levels.
- **Prioritising sleep** – when you sleep your body should be mostly in rest and digest. Reassuring your system with set bedtimes, good wind downs, minimising stimulants (caffeine or blue screens) can lead to good rest and digest and therefore less spikes during the day.
 - Some people also monitor heart rate variability, or HRV, as one indicator of the balance between stress and recovery, although it should always be interpreted in context.
 - **Wearables** – there is an app called Visible which is designed for chronic illness and helps people pace. It uses HRV to give you a free morning forecast of how resilient your system at that time but also has a paid wearable version with a subscription which can advise you in real time – prompting you to slow down or rest or encouraging good pacing. Some smart watches will give a similar service. Many people have found these to be useful to identify periods where their system is stressed and use techniques like coherence breathing to promote calm.

A phrase I often use is: 'Flatten the curve and calm the response.'

So there are now a few different strategies you could try – but it may be overwhelming to do them all at once. May I suggest that you...

- List the options and pick one change at a time (eg - plan A, B, C, D). That way it is easier to know what is helping – allow a week or 2 with this consistent change and monitor your symptoms.
- If that change didn't help your symptoms then score it off and try a different one.
- Or if it did help, once that change becomes routine, consider adding another or progressing it – for example, your Plan A change may be reducing caffeine by not drinking the evening cuppa. If you found that this small change worked, you may choose to completely cut out caffeine **or** you may add Plan B and choose to consider sticking to a set bedtime and having a good sleep routine. Adding one

layer on at a time as something becomes routine.

7

Coherence Breathing

Coherence or Heart Breathing can help promote a parasympathetic (rest and digest) response and calm ANS

How to practice coherence breathing



Lie down or sit comfortably and supported



Breathe through your nose (in and out)



Breathe deep in your lungs towards your belly



Slow your breath – aim for 5½ secs in



5½ seconds out (no pause)



Repeat often but within comfort

Heart Rate Variability (HRV) can be a measure of stress Vs resilience

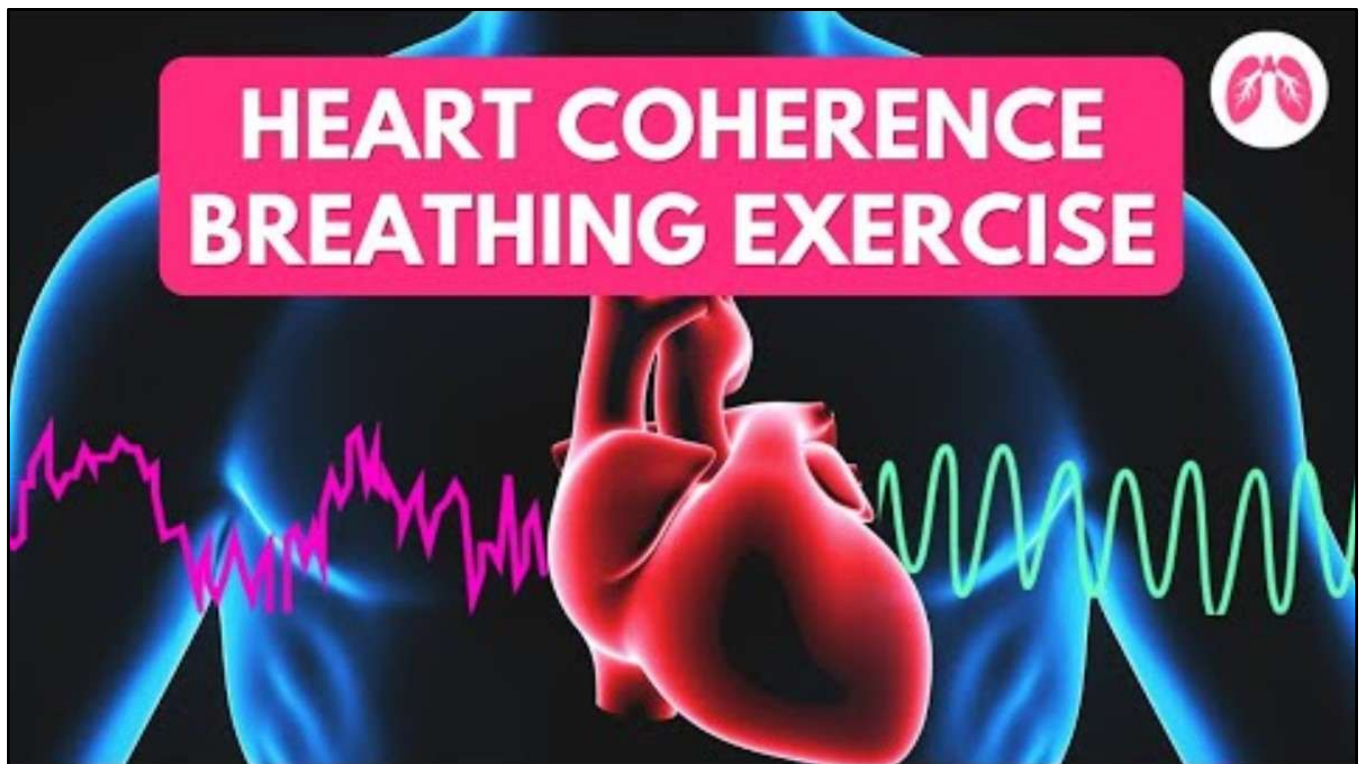
One technique that many people find helpful is coherence breathing, sometimes called heart breathing. This aims to encourage a rest and digest response.

To practise:

- Sit or lie comfortably with good support. If sitting, make sure your back is supported and your feet are planted. You may wish to use a rolled up towel as a lumbar roll so you aren't slumped.
- Breathe in through the nose.
- Breathe out through the nose. Your lips are gently closed for the whole time if you can.
- Allow the breath to move lower into the lungs towards the abdomen. Envisage air going right into the bases of your lungs, your belly will raise and your upper chest will stay mostly still.
- Gradually slow your breathing to approximately five and a half seconds in and five and a half seconds out. If this feels too slow then find where you can do comfortably and build up to 5.5 secs.
- It should be a normal volume breaths (not deep breaths), just aimed deeper in your lungs and slower and quieter
- Avoid holding your breath between the breaths, try to make the breath stretch over the whole 5.5 secs.
- Stay within your comfort zone and stop if symptoms worsen.

This slower breathing pattern may help reduce your body's reaction to stress and

improve nervous system regulation.



I'll play this video for a few minutes for you to try this technique if you like. You can turn down the sound if you don't like the noise and focus on the image, or close your eyes and listen to the sound. Please stop if you are struggling and pick it back up if you can manage. Or just take this next few minutes as a bit of down time to change your focus if needed.

(Play video)

It is a skill to manage, so may take some practice. I would advise little and often – better to practice for 3 breaths, 5 x daily than do once a week for 5 mins. You can use it reactively – to try to calm you down when you feel a lot of dysautonomia symptoms or stress, but also try to practice it when you are already calm. I would suggest you build up to 5-20 mins spread over the day as tolerated. Some people will only manage a few breaths to start so please tailor it to your ability.

8

Conclusion

Dysautonomia is common after illness or stress, but the symptoms can be managed in many ways once other likely causes are ruled out.

Observe your symptoms

Notice triggers

Speak to your GP

Try strategies

One small change at a time



To summarise, dysautonomia is common after illness and stress and it can cause many symptoms across multiple body systems.

The key messages I'd like you to take away today are:

- **Observe your symptoms** – consider what body parts are affected
- **Notice patterns and triggers** – use diaries or journals to link triggers to certain symptoms
- **Discuss ongoing concerns with your GP or healthcare professional** – dysautonomia is more common than people realise, but a diagnosis is a journey, sometimes eliminating other possible causes. If your symptoms are related to standing, once other possible causes are unlikely or excluded, it may be that you are offered a PoTS test and if positive, this may lead to more tailored treatment plan from our team.
- **Experiment with management strategies** – good lifestyle choices like drinking more water, eating healthy, changing what time you are eating / how much in one sitting, flatten the curve of boom and bust
- And probably most importantly, **Introduce changes gradually and one at a time** – don't overwhelm yourself with too many changes at once.

Recovery and improvement are often achieved through a series of small, sustainable changes rather than one single "fix".

9

Read, Watch, Do



Read PoTS UK website

<https://www.potsuk.org/>



Watch Central Sensitivity Syndrome video

<https://youtu.be/BrMb656yJd4?si=YxT4YQ8saBaD9EVx>



Do Coherence breathing

<https://youtu.be/i5apnLrzaT4?si=JkRhX0yo9vXSLdU4>

If you'd like to learn more, I've included some useful resources.

I would encourage you to:

- Read - Visit the PoTS UK website for trusted information on PoTS if you feel that your symptoms are related to standing up
- Watch - the Central Sensitivity Syndrome video for further understanding of nervous system sensitisation
- Do - Try the coherence breathing exercise.



Thank you for listening. I hope this has helped improve your understanding of dysautonomia and provided some practical ideas that you can begin using in daily life.