



British Association of Clinicians in ME/CFS

Dysautonomia

A Guide for ME/CFS

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Introduction

ME/CFS is a complex multisystem condition and research is slowly helping us piece together the abnormal physiology that leads to the symptoms of ME/CFS.

Some people find that understanding what is happening in the body in more detail helps them to make sense of the symptoms they experience and the reasons why their symptoms can keep fluctuating and changing. This understanding provides a good foundation for learning ways to manage the symptoms.

This document is aimed at providing an explanation about one aspect of ME/CFS symptoms that relates to Autonomic Nervous System function. This is a complex physiological system so this document contains medical and scientific language.

ME/CFS can affect people differently and there are different severities of the illness. The information in this document is general advice and someone with severe or very severe ME/CFS may not be able to implement some of the strategies.

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Physiological Dysregulation in ME/CFS

ME/CFS is a condition defined by symptoms which occur due to dysregulated responses in multiple dynamic systems in the body including the immune system, the autonomic nervous system, the endocrine (hormone) systems and the metabolic systems. All these systems interact with each other and when there is dysregulation or 'loss of balance' in these systems it results in a wide array of symptoms reflecting a lack of homeostasis (or 'balance') at both a global and cellular level in the body.

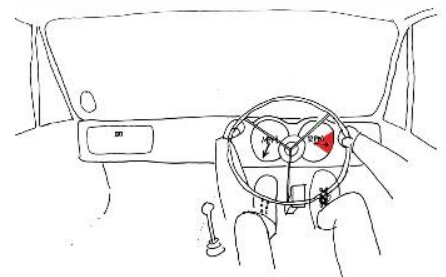
ME/CFS research has shown there can be altered messaging in complex homeostatic systems. This means ME/CFS is a very dynamic illness where symptoms can fluctuate depending on the demands these physiological systems are responding to at any particular time. Different systems can be involved to different degrees in different people, and it is possible that it can change over time so this can help explain why there are lots of different reasons why people develop the symptoms of ME/CFS and why people are affected to different degrees and can experience different patterns of symptoms.

The fatigue pattern that is now considered to be the core symptom of ME/CFS is Post-Exertional Malaise which is where there is a clear relationship between normal everyday activities causing a disproportionate escalation in fatigue and other symptoms, which can occur immediately or can be delayed and has a slow recovery time. This pattern of symptom escalation directly related to activity levels is due to the dysregulated physiological responses meaning there is not sufficient energy production for the requirements of the body and the recovery processes are not functioning correctly.

Most of the medical tests that are done to look for illness are static tests -they just look at a particular thing at a single point in time e.g. a scan would look at the structure of a part of the body or a blood test would look to see if certain things are within the normal range. These tests do not look for changes that occur in response to different demands and this is one of the reasons why the physiological problems that occur in ME/CFS do not show up on standard tests.

One way to think about this is to imagine the body is like a car and it is being driven by these physiological systems. If the car was being driven with the accelerator pedal being pressed at the same time as the brake pedal while changing gear repeatedly and steering erratically the car journey would be very chaotic, jerky and inefficient; 'over-revving the engine but not getting anywhere'.

If the car was taken to the garage and all the individual parts were tested while the car was parked, they would all look to be working OK, but it is only when observing how the car is being driven that you can see there is a problem.



If the body's physiological systems are dysregulated it leads to many body processes not working efficiently including energy production, sleep regulation, digestion etc.

Because there are multiple dynamic systems contributing to the symptoms of ME/CFS there is not a direct treatment that will fix the problems. However, it is possible to identify factors which aggravate dysregulation and strategies which can help improve stability. The aim of ME/CFS management is to try to identify which demands are triggering symptoms and reduce those demands or approach demands more carefully and also put in place strategies which can help facilitate stability and healing.

The pattern of symptoms and the body's response to different demands can vary over time so it will require a degree of flexibility and careful experimentation to find strategies that help support recovery.

This document is focusing on one of the physiological systems that is dysregulated in ME/CFS – The Autonomic Nervous System. Understanding how the Autonomic Nervous System works can help explain some of the symptoms that occur in ME/CFS and it can help to understand why certain activities can cause an escalation in symptoms. There are also some specific strategies that can help stabilise autonomic system function which will help with the management of ME/CFS symptoms.

Further information about the multisystem physiological dysregulation of ME/CFS is available in the BACME document [An Introduction to Dysregulation in ME/CFS](#).

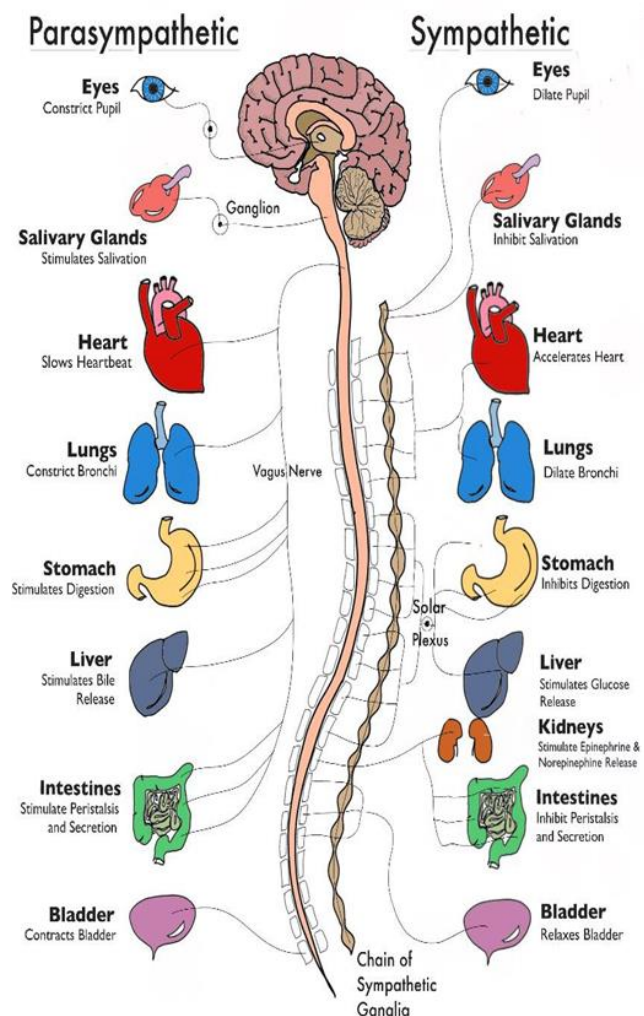
The Autonomic Nervous System

The Autonomic Nervous System is the part of the body which regulates all the physiological functions which can change rapidly. It is involved in all the different systems of the body including the circulatory system, respiratory system and digestive system meaning it is involved in regulating heart rate, circulation, breathing, digestion, bladder function, temperature, fluid balance, pupil size etc. It also has a role in regulating immune system activity and endocrine (hormone) systems. It is a system which responds rapidly and automatically to changes in demand both from inside the body e.g. exercise or digestion along with demands from the external environment e.g. gravity, temperature change. Consequently, if it is not functioning correctly, it can give rise to a wide range of symptoms in different parts of the body which follow a dynamic pattern in response to various activities.

The Autonomic Nervous System is made up of the Sympathetic and Parasympathetic systems. The Sympathetic system responds when the body is more active e.g. during exercise or in response to stress and is therefore referred to as the 'Fight and Flight' mode of physiology. The Parasympathetic system is more active when the body is resting, recovering and digesting and hence is referred to as the 'Rest and Digest' or 'Rest and Recovery' mode of physiology.

The **Autonomic Nervous System (ANS)** is involved in regulating many body processes including:

- Blood pressure
- Circulation
- Heart rate
- Breathing rate
- Body temperature
- Sweating
- Digestion including saliva and digestive enzyme production, and gut movement
- Metabolism including regulation of blood sugar
- Balance of water and electrolytes, including urination
- Sexual response
- Pupil response
- Immune system activity



The sympathetic division is responsible for sending messages to different body systems when there is increased demand e.g. due to physical activity, gravity demand when upright, thinking processes etc. It can be thought of as turning the volume up in the body processes needed for a specific activity.

Sympathetic system bodily changes include:

- Increasing heart rate and force of heart contraction
- Widening blood vessels (vasodilation)
- Widening airways
- Releasing stored energy
- Increasing blood flow to peripheral areas of the body
- Increased sweating
- Increasing conscious processing of sensory information
- Alters focus of thoughts onto more immediate survival needs
- Slowing body processes that are less important for immediate survival such as digestion and reproduction.
- Working with the somatic nervous system to stimulate skeletal muscle and send energy to fuel muscle contraction.

The parasympathetic division sends messages via the Vagus nerve that reverse the processes above to allow recovery. This can be thought of as turning the volume down on body processes.

Parasympathetic system bodily changes include:

- Slowing the heart rate
- Decreasing blood pressure
- Stimulating digestive and reproductive systems
- Using energy from digested food to restore and rebuild tissues
- Filtering out unnecessary sensory input and focusing on what is necessary
- Enabling logical cognitive processing.
- Focus of thoughts onto more long term and strategic needs.
- Supporting sleep.
- Working with the somatic nervous system to relax muscles and conserve energy.

This is a simplified explanation of the ANS as there can be complex changes occurring where both the sympathetic and parasympathetic divisions are active and exerting different effects on different organs at the same time.

Autonomic Nervous System Dysfunction

‘Dysautonomia’

Dysautonomia is the term used to describe the collection of symptoms that occur when Autonomic Nervous System function is altered.

There are many different reasons why ANS functions can become dysregulated, but we don't currently have any reliable way of finding out what the underlying cause of dysautonomia is. It is likely that there are different pathological processes occurring in different people and in some people, there will be multiple factors that have contributed to the ANS function changing.

It is possible there may be genetic factors that make some people more vulnerable to developing ANS problems. Research is starting to explore associations between Dysautonomia symptoms and Neurodiversity and Joint Hypermobility.

Sometimes the timing of when the symptoms started may provide clues such as following an infection episode which may indicate that immune system activity can cause changes in autonomic system nerve function.

Dysautonomia symptoms are also observed to occur during times of hormonal instability such as puberty and the menopause. In some people the symptoms occur during or following times when they have experienced significant emotional demands. There are differences in how the ANS responds to immediate short-term demand or stress on the body and how it responds to long-term excess demand. In repeated exposure to excessive demand there can be lasting adaptations in the body which can impact on energy metabolism and immune response.

Research studies are exploring the many different ways that Autonomic Nervous System responses can be altered in people with ME/CFS and how this links with the symptoms experienced.

One area of autonomic research has looked at cerebral circulation or brain blood flow. It has been shown that the majority of people with ME/CFS have evidence of subtle reductions in the amount of blood flow in the brain, likely due to dysregulated messaging in the autonomic system which means blood flow to the brain doesn't increase as required when there is increased demand.

The Autonomic Nervous System is responsible for making the circulatory adjustments in the body needed when we are in an upright position when gravity is taking effect to pull blood and fluid in our body towards our feet. In some people with ME/CFS there is evidence of abnormal pulse and/or Blood Pressure responses when in an upright position. The brain blood flow research has shown that even in the people who have normal pulse and blood pressure readings, there can still be problems with the brain blood flow and this can link with the severity of fatigue experienced. Studies are now being able to link the demand of being in an upright position with brain fog symptoms, memory problems and it is also potentially linked with some pain symptoms experienced.

Common Dysautonomia Symptoms in ME/CFS

Orthostatic intolerance: This term means symptoms which are worse in an upright position and improve with lying down. This happens because the many physiological changes that are required in response to being upright don't work correctly. Many people experience rapidly escalating fatigue, balance problems, dizziness and increased pain in response to standing upright and often feel an overwhelming need to sit or lie down. Some people will notice a colour change in their feet and hands due to blood pooling or they may look pale. In some people there may be an inappropriate heart rate response meaning the heart rate increases by over 30 beats per minute (called Postural Tachycardia Syndrome or PoTS). Other people experience a drop in Blood Pressure, which may only occur after several minutes of standing. Orthostatic symptoms can occur even when the pulse and blood pressure readings are normal and you can have Dysautonomia and have high Blood Pressure.

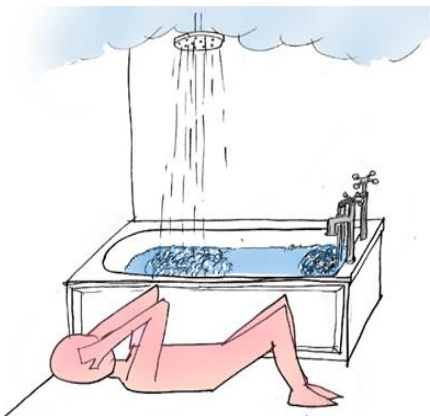


Palpitations: It is common for heart rate responses to be dysregulated. This is not due to any problem with the heart but is due to the autonomic system signalling being dysregulated. This can result in the heart going inappropriately fast for the situation. In some people standing will trigger a fast heart rate, any degree of physical activity like walking or climbing stairs may do it and other people can experience a rapid heartbeat or palpitations when resting or when in bed.

Tasks with arms elevated: It is common for people with dysautonomia to struggle to do things when their arms are raised above their head commonly reporting rapid onset of muscle aching, their general fatigue can escalate and some people feel short of breath. This is because of the additional circulatory demand of raising the arms above the head and the fact the ANS doesn't give the correct signals to the blood vessels and heart to respond to it.



Showering/bathing: Most people with Dysautonomia struggle with showers and baths. Showers are challenging because it requires standing upright and often raising the arms while also dealing with temperature changes. People often report being unstable, feeling exhausted afterwards and some people get palpitations or overheat. Baths can often be OK while the person is in the bath as the pressure of the water can help maintain circulation but commonly people become very fatigued as a result of a bath, may report weakness making it hard to get out or feeling faint when they get out and having to lie down to recover before they can get dressed.

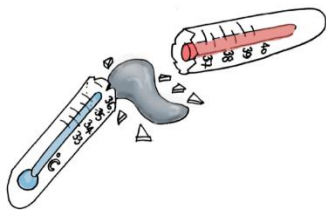


Brain Fog symptoms: Most people with dysautonomia will describe problems with concentration, memory, word finding etc. The research has shown that some of these issues are related to alterations in brain blood flow which probably results in the neurological processes required for thinking tasks to operate at a slower speed. Multitasking and managing emotions are additional cognitive demands which will often put more demand on the brain's circulation needs so can aggravate brain fog



symptoms. Research has shown that being in an upright position does impact on memory function in people with ME/CFS. Some people find they can think better when sitting or lying down. Headaches are also a common feature of Dysautonomia.

Temperature regulation: There are many different patterns that people describe regarding changes in temperature regulation and also sweating. Often people report struggling to regulate body temperature and swinging from too hot to too cold. Changes in environmental temperature will often have an effect on symptoms, some people reporting hot weather making them worse, others find cold weather a problem. Some people experience increased sweating others have reduced sweating or altered sweating in different parts of the body or following demands such as physical activity and eating.



Gastrointestinal symptoms: The ANS has a network of nerves which goes to all parts of the digestive system and has many different roles to play in digestive processes. The ANS regulates the amount of saliva produced and the amount of stomach acid and digestive enzymes produced. It regulates how active the gut is. It also regulates how permeable the gut wall is varying the degree to which different things get absorbed into the body. This means ANS problems can lead to symptoms caused by the gut moving too slowly or too quickly such as acid reflux, feeling full quickly, nausea, diarrhoea and constipation. When food goes into the stomach there should be a small shift of fluid from the circulation into the stomach and bowel. When there is Dysautonomia this fluid shift can be exaggerated which leads to symptoms of bloating and also means the fluid level in the blood stream drops which then causes a sudden escalation in fatigue and typically a need to lie down or sleep. If food passes too quickly from the stomach into the bowel it can result in sweating and palpitations. The ANS also has a role to play in regulating blood sugar levels so long periods without eating can cause symptoms and after eating the blood sugar levels may not stabilise correctly.



Bladder symptoms: The ANS has a role to play in regulating bladder function and fluid balance in the body so Dysautonomia can cause changes in bladder function typically leading to bladder spasms or urgency to pass urine and going to pass urine more frequently including during the night. Some people notice a pattern whereby standing up triggers a sudden urgency to pass urine.

Shortness of breath: The ANS is involved in regulating the speed and depth of breathing so some people with dysautonomia will experience breathing symptoms. This can be getting rapidly out of breath on minimal exertion e.g. climbing stairs or a feeling of being unable to get enough air in or panting type breathing patterns even when resting. It is possible the regulation of breathing during sleep may be affected.



Pain/muscle symptoms: There are many different types of pain that people with ME/CFS experience. Some of the muscle pain, heaviness and weakness may be due to reduced circulation to the muscles caused by Dysautonomia and the altered circulation may mean lactic acid accumulates in muscles after activity. Lots of people with Dysautonomia also describe muscle twitches or spasms some of which are visible and others describe a feeling of an internal vibration. There has been recent research in people with fatigue showing that pain symptoms can change in response to the physiological demand of being in an upright position.

Vision: The size of the pupils is regulated by the autonomic nervous system – this is a part of the survival response where it is important to be able to focus into the distance. If the autonomic system signals are dysregulated it can mean the pupil size varies and can mean the ability to focus on close up things e.g. reading can be difficult and people report blurred vision and problems focusing. This often has a fluctuating pattern so testing eyesight is usually normal. If the pupil size is too big for the light conditions, it can contribute to light sensitivity.



Anxiety/Mood: When someone has an anxious thought it is the autonomic nervous system that causes all the physiological changes known as the ‘fight or flight’ response. If someone with Dysautonomia has an anxious thought they may get a much more exaggerated physical reaction akin to a panic attack. Equally many people with Dysautonomia report ‘feeling’ anxious without having any anxious thoughts and this is because the ANS can be generating the fight and flight responses because of other things such as temperature change, low blood sugar, dehydration etc. When in ‘Fight or Flight’ mode thinking processes tend to become more ‘black and white’ and can result in people being short tempered or angry.

Sleep It is common for people with Dysautonomia to experience sleep problems which can be disturbed or poor-quality sleep or increased sleepiness known as hypersomnolence, or both. It is possible that increased sympathetic activity during dream phases of sleep may result in people experiencing very vivid dreams and they may be woken by dreams and may feel anxious or have palpitations or feel hot. Some people may not fully wake but the sympathetic activity may



prevent transition into the deeper phases of restorative sleep meaning sleep may feel unrefreshing. It is recognised that Dysautonomia can be associated with increased daytime sleepiness and common patterns are to suddenly feel very sleepy after stopping doing physical activity, becoming sleepy with prolonged cognitive demand or feeling sleepy after eating.

Fatigue This is a complex symptom and more than one physiological system can be involved in fatigue and there can be different patterns of fatigue fluctuation. Dysautonomia can contribute to fatigue and as the ANS is a rapidly changing system, dysregulated responses can result in rapid changes in energy levels. Some people will feel OK when they are busy moving or doing an activity but then experience a rapid crash in energy at the point where they stop. Other people become increasingly aware of escalating fatigue while doing an activity, often describing it as a feeling of increasing difficulty putting one foot in front of the other, getting progressively slower or like walking through treacle. It can also be accompanied by an escalation in other symptoms such as brain fog, pain and breathlessness. People often describe the fatigue of dysautonomia as a feeling of heaviness or a feeling of energy draining out.

Potential triggers for Dysautonomia symptoms to escalate

- Upright demand - standing or sitting still for prolonged periods
- Physical activity
- Cognitive activity such as reading, making decisions, talking, thinking
- Emotional reactions including stress, anxiety, excitement, anger
- Dehydration
- Eating
- Low Blood Sugar levels
- Change in environmental temperature
- Sensory stimulus e.g. lights, noise, smells
- Infections

Strategies to help dysautonomia symptoms

Because people with Dysautonomia can experience different patterns of symptoms it usually requires a degree of experimentation to find which strategies are helpful and which don't work or make things worse. Some basic ones to try are:

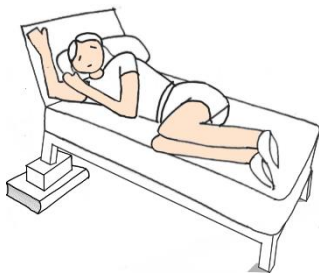
Fluid intake: Research has shown that people with autonomic dysfunction do not keep fluid in their circulation properly so drinks need to be taken regularly throughout the day aiming for at least 2-2.5 litres per day. Having 500ml of fluid on waking and also before doing an activity can help. Drinking 500ml of cold water all at once has been shown to help with brain fog symptoms.



Salt/electrolytes: If there is no evidence of high blood pressure then increasing salt intake can help. Having electrolyte based drinks can also help retain fluid in circulation better.



Bed elevation Some people find that elevating the head of the bed by 4-6 inches is helpful. This is because it alters the circulation to the kidney resulting in a reduction in the amount of urine and salt excreted overnight. This can help sleep by reducing the amount of times needed to get up to empty the bladder. It may also reduce the level of morning dehydration. It may take a few weeks for the benefit to be apparent and the strategy should be abandoned if it appears to be causing more disrupted sleep or any other escalation in symptoms.

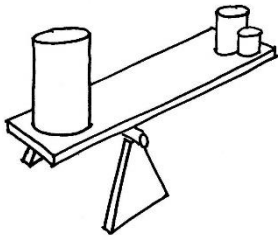


Compression garments: Some people find wearing long compression stockings (i.e. thigh or waist length) or tight clothing and/or underwear, can reduce the severity of their orthostatic symptoms caused by blood pooling in the lower body.

Counter Manoeuvres: If you are standing up or starting to feel faint then sometimes using other muscles to help keep blood circulating can help – try clenching your hands in and out of a fist and squeezing the big leg muscles- calves, thighs and buttocks or generally 'fidgeting'. Sometimes crouching down as if to tie your laces works to squeeze some blood out of the leg muscles back into circulation again.

Gravity demand Because of the problems with being upright, taking rest lying down will be beneficial when symptoms start to escalate. However, spending long periods of time lying flat can lead to the body being less able to tolerate the effects of gravity when upright so it is important to find a careful balance between taking planned, structured rest periods laid down and then having other rest periods sat with your feet on the floor and then short periods of time standing or walking followed by a further rest period.

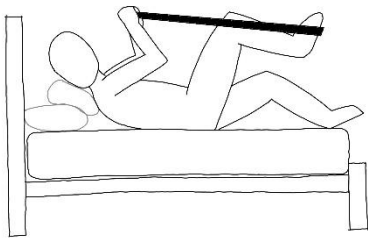
Pacing: This is where all types of activity are broken down into short sections



followed by an effective rest period. All types of activity create a physiological demand and can therefore contribute to fatigue and dysautonomia symptoms. Cognitive activity, emotional activity, social activity and physical activity all need to be paced. Rest will be more effective if taken lying down and doing slow deep breathing exercises helps to activate the parasympathetic system hence enabling the body to rest more effectively.

The phrase '**rest before symptoms increase**' is an important strategy to remember.

Exercise: Deconditioning or loss of fitness is not the cause of dysautonomia symptoms, but unfortunately the loss of muscle bulk and fitness which can happen as a result of the fatigue and exercise intolerance will aggravate the symptoms. Exercise needs to be done very carefully taking into account the principles of pacing. Although exercise can improve dysautonomia symptoms, doing it at the wrong level can cause more dysregulation and escalate fatigue and other symptoms. It can be helpful to separate the demands of gravity, balance and physical activity by considering exercises that can be done sitting or lying down. Trying things like gentle muscle



strength work using resistance bands can be a good starting point. Building strength in thigh and buttock muscles can help maintain circulation better when upright. The Soleus muscle in the calf is important for supporting circulation so exercise that improves tone in that muscle may help. This involves sitting with feet on the floor and then raising the heel

off the floor. This can be useful to do a few times before standing up.

If exercise tolerance improves then low-level recumbent cycling using a pedal device while sat reclining in a chair can be a way to gradually build fitness without the added challenges of gravity and balance. Rowing and swimming are other types of exercise with minimal gravity demand. It is important to start with a very small amount of activity that you can sustain every day without causing any escalation in symptoms before considering trying a very small increase.



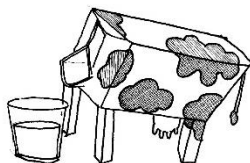
Breathing exercises Doing deep, slow diaphragmatic breathing regularly can help activate the parasympathetic nervous system and hence can help to reduce the symptoms that come about due to exaggerated sympathetic nervous system activity. Doing regular breathing exercises over time can gradually improve sleep quality which in turn may help fatigue issues. Taking a moment to take a few slow breaths repeatedly through the day can help. Another option is to spend 10 minutes twice a day doing slow deep breathing, breathing in through your nose for 4 seconds and breathing out for 6 seconds. There are various apps which can support doing relaxation breathing exercises e.g. Breath Ball.

Emotional demands – The Autonomic Nervous System reacts to emotional triggers such as stress, fear, anxiety, excitement and anger. This means emotional responses can also contribute to the symptom fluctuations that occur in Dysautonomia. Looking at ways to manage these emotions and reducing stresses where possible can be beneficial.



Sleep The amount of time spent asleep doesn't always equate to the quality of sleep. It is possible that some people with fatigue and unrefreshing sleep do not have sufficient periods spent in the deeper phases of sleep often referred to as 'restorative sleep'. When sleep quality is poor it can sometimes help to have daytime naps but this needs to be judged on an individual basis. Taking naps later in the day or for prolonged periods is more likely to result in difficulty waking and feeling groggy and can have a negative impact on night-time sleep quality. Therefore, the best approach to daytime naps is to plan for them and take them at the same time of day, preferably late morning or immediately after lunch. Napping for only 15-20 minutes will avoid the transition into a deeper phase of sleep which can be hard to wake from. Keeping to a regular routine regarding going to bed and getting up will also help as will daylight exposure in the morning and reducing light exposure and screen use on an evening. Keeping meals at regular times also helps to re-regulate the body clock.

Eating Different types of food can provoke different reactions in different people.



Typically sugars and carbohydrates are more likely to cause bigger fluid shifts so people who feel fatigued and need to lie down after eating may find it better to have more protein and low fat food based meals. Planning to lie down and rest for 20 minutes after a meal can also help.

Many people find grazing works i.e. having small amounts to eat gradually throughout the day rather than 3 larger meals. People who have slow stomach emptying may experience low appetite, feeling full quickly, nausea and reflux and in that situation liquid or pureed foods may be easier to digest. Avoiding eating sugary foods on their own such as combining them with complex carbohydrates like oats or protein such as nuts or cheese, can help to stabilise blood sugar levels.

Medication: As you read about Dysautonomia you will find there are many different medications that can be used. None of the medications will fix the underlying problem with the autonomic nerves so none of them will make all of it better. Some people do find a medication that reduces the severity of some aspect of their symptoms but unfortunately for many people medication aggravates other aspects of their symptoms meaning the side effects can be worse than the benefits. This is a very specialised area of prescribing so currently most doctors would not feel confident to recommend medications to manage Dysautonomia symptoms until further research is done.