ORTHOSTATIC INTOLERANCE AND ORTHOSTATIC HYPOTENSION

Symptoms and self-help management

Including:

- About orthostatic intolerance (OI)
- The main symptoms of orthostatic intolerance
- Linked conditions
- What makes OI worse
- What doctors can do
- Causes and management
- Drug treatments

MARCH 2025

Orthostatic intolerance and Orthostatic hypotension was written by **Dr Charles Shepherd**, Trustee and Hon. Medical Adviser to The ME Association.

ORTHOSTATIC INTOLERANCE AND ORTHOSTATIC HYPOTENSION

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DISCLAIMER

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS or Long Covid.

WHAT IS ORTHOSTATIC INTOLERANCE?

Orthostasis means standing upright. So orthostatic intolerance (OI) is the medical term for problems and symptoms that occur when people stand up, or try to remain in a standing position for more than a short period of time. OI is the main reason why most people with ME/CFS try to avoid situations that involve standing still for any period of time. Consequently, sitting in a chair or sitting up whilst lying on a settee or bed is often the most comfortable position to be in.

Orthostatic intolerance is something that affects almost everyone with ME/CFS to some degree and it's a key diagnostic feature of ME/CFS. For some people, orthostatic intolerance becomes a very disabling part of having ME/CFS.

Most of the information and guidance in this leaflet applies to people with ME/CFS who still have some mobility and are able to stand up - even if this is only for a short period of time.

For people with severe and very severe ME/CFS who are bedbound, changing from having the whole body lying flat to a sitting position in bed can also cause OI symptoms. This needs to be taken into consideration, especially when people with severe ME/CFS have to be admitted to hospital.

KEY FACTS:

- Orthostasis refers to standing up. So orthostatic intolerance (OI) is the medical term for problems and symptoms that occur when people stand up, or try to remain in a standing position for more than a short period of time.
- OI can also include orthostatic hypotension (where there is a fall in blood pressure on standing) and PoTS/postural orthostatic tachycardia syndrome (a rise in heart rate on standing).
- OI is nearly always exacerbated by anything that diverts blood flow away from the brain.
- OI is probably caused by a problem with the autonomic nervous system - a part of the nervous system that isn't under conscious control and automatically helps to control heart rate, blood pressure and blood flow to the brain. Problems with balance and muscle weakness in the legs can also play a role.
- There are a number of self-help measures that may be helpful.
- Drugs are sometimes prescribed, especially when OI occurs in association with orthostatic hypotension or PoTS.

WHAT ARE THE MAIN SYMPTOMS OF OI?

In addition to having difficulty in trying to remain in an upright position for any length of time, symptoms which appear to be related to a decrease in blood flow to the brain when standing can also occur. These include:

- Feeling light-headed, dizzy or faint
- Sweating
- Nausea
- Headaches
- Palpitations
- Blurred vision
- Skin pallor

Symptoms are more likely to occur in the morning due to overnight dehydration and blood pressure often being lower in the morning.

WHAT MAKES OI WORSE?

Symptoms of orthostatic intolerance are nearly always influenced or exacerbated by anything that diverts blood flow away from the brain or causes fluid loss from the body. So exacerbating factors include:

- **The time of day:** Symptoms are more likely to occur in the morning due to overnight dehydration and blood pressure often being lower in the morning. This may be one of the reasons why people with ME/CFS find it difficult to 'get started' in the morning.
- **A warm environment** that dilates blood vessels in the skin – as alcohol also does.
- **Eating large meals with a high carbohydrate content** that divert blood flow to the intestines.
- **Physical exertion** that diverts blood to the muscles, which in turn reduces blood supply to the brain. This also helps to explain why cognitive/mental function may decline during physical activity.
- **Fluid loss** from diarrhoea or vomiting.
- **Emotionally stressful events.**

WHAT MAKES OI WORSE?

LINKED CONDITIONS – orthostatic hypotension and PoTS

Orthostatic intolerance forms part of a group of conditions affecting the autonomic nervous system which are grouped under the umbrella term of dysautonomia. Two of these conditions are closely linked to orthostatic intolerance and may also occur in ME/CFS – orthostatic (or postural) hypotension and postural orthostatic tachycardia syndrome – both which are likely to make standing still more difficult. Men who have OI or orthostatic hypotension may also develop micturition syncope.

Orthostatic or postural hypotension and Micturition syncope

Where symptoms such as feeling faint and dizzy appear more acutely and severely after changing position from lying/sitting to standing, this may be due to what is called postural or orthostatic hypotension. This is the medical term for a sudden and significant drop in blood pressure, along with decreased blood flow to the brain, due to a change in position. In some cases, postural hypotension may involve fainting or having a 'blackout'.

Men sometimes report feeling faint, or actually faint, when they are standing up to pass urine – especially when they have to get up suddenly during the night and go to the bathroom. This is called micturition syncope. If this happens, getting out of bed should be done slowly and it's advisable to sit down on the toilet to pass urine.

Postural orthostatic tachycardia syndrome

This is a condition where there is a significant rise in heart rate of 30 or more beats per minute when someone goes from lying or sitting to standing. Symptoms include feeling faint or fainting, palpitations and light-headedness on standing up.

WHAT CAUSES ORTHOSTATIC INTOLERANCE AND ORTHOSTATIC HYPOTENSION?

Research into this aspect of ME/CFS suggests that orthostatic intolerance and/or hypotension is probably caused by a problem with the autonomic nervous system. This is a part of the nervous system that isn't under conscious control and automatically helps to control heart rate, blood pressure and blood flow to the brain in relation to posture.

When we stand up, around 750 mls of blood quickly moves downwards towards the legs. In normal healthy people, any change in posture – especially when standing up, or trying to remain standing – produces an immediate autonomic system response that alters the heart rate and blood pressure to compensate. The aim of this autonomic response is to prevent a sudden fall in blood pressure and maintain a good supply of blood to the brain.

WHAT CAUSES ORTHOSTATIC INTOLERANCE AND ORTHOSTATIC HYPOTENSION?

If the compensation mechanisms are defective and there's a loss of connection between heart and brain, the blood pressure falls. Blood flow to key parts of the brain (known as cerebral perfusion) is then reduced. As blood flow to the brain delivers oxygen and vital nutrients this can affect various types of brain activity. This is also why orthostatic symptoms such as feeling faint, weakness and dizziness can appear quite rapidly following a change in posture.

Two other components of ME/CFS are problems with balance and weakness of the thigh muscles in the legs. Where present, these are likely to contribute to and exacerbate problems with remaining standing.

WHAT CAN DOCTORS DO?

If OI, or the symptoms it causes are getting worse, you should speak to your doctor. A GP can check your heart rate, blood pressure (which should include both lying and standing measurements), carry out a NASA lean test, and arrange an electrocardiogram/ECG if necessary.

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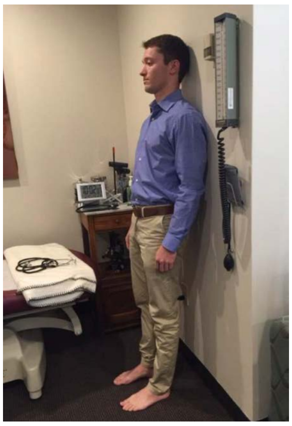


NASA lean test:
https://tinyurl.com/3nattbdh

If symptoms are more severe, you can be referred to hospital for other tests that can measure heart rate and blood pressure in relation to changes in posture. One such investigation is called a 'tilt table test'. This test has been used in a number of research studies that have examined autonomic dysfunction in ME/CFS.

It is also important to consider other medical explanations for orthostatic intolerance and postural hypotension. One condition in particular, that has a degree of overlap with ME/CFS, is Addison's disease. This is caused by a failure of the adrenal glands to produce adequate amounts of the hormone cortisol. Addison's disease causes fatigue, low blood pressure, anorexia, weight loss and patches of brown skin pigmentation.

SELF-HELP MANAGEMENT

There are several self-help measures that may be worth trying. Before doing so, do talk to your GP – because the choice will partly depend on whether you also have orthostatic hypotension or PoTS. So some of these self-help strategies may be appropriate whereas others may not be. Your GP should also be able to demonstrate how to do some of the simple stretching exercises.

Please note that, while there is a lot of patient evidence regarding the use of these self-help approaches, and most of them appear to be sensible and safe, there is very limited research evidence to confirm that they are actually effective - in particular in relation to increasing fluid and salt intake. So it's very much a try and see if it helps approach. This is why the MEA is funding Professor Manoj Sivan in Leeds to develop a new management protocol for these sort of autonomic dysfunction symptoms in both ME/CFS and Long Covid.

https://meassociation.org.uk/npsn

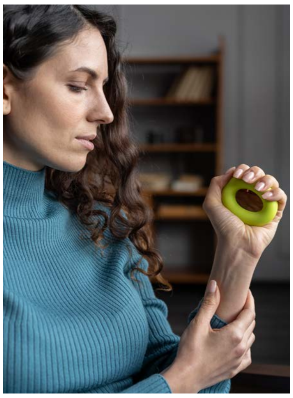
Posture during the day

Keeping your feet up on a stool when sitting down during the day will help to increase blood flow to the heart and brain. Gentle leg exercises aimed at improving the peripheral circulation can be carried out when you are lying down, sitting or standing. Simple exercises include moving your feet up and down at the ankle and crossing/uncrossing your legs. You can also try tightening your abdominal muscles. Avoid sudden changes in posture because bending down or stooping may bring on symptoms.

Keep moving if you can

Try to keep moving around when you have to do a task that is going to involve a lengthy period of standing – such as waiting in a shop queue, working in the kitchen, or doing the ironing.

If you have to stand still for any length of time, try to clench and unclench the calf muscles in the legs. This will help shift blood from the extremities up to the brain. You can also do arm exercises: sustained hand grip or forearm clenching. The same advice also applies if you are sitting still at a desk for long periods.



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SELF-HELP MANAGEMENT

Orthostatic training

Various upright posture exercises may be helpful, particularly if symptoms are more severe or you are fainting.

These should be taught and monitored by a health professional or physiotherapist with expertise in this area. A paper from Professor Julia Newton's research group in Newcastle provides further information on one such approach. An online abstract is available at:

https://tinyurl.com/weqj6mn

Sleep

Raising the head of the bed by about six inches by putting some heavy books or bricks under the bed posts helps the body to retain fluid at night rather than losing it in the urine. Some people find this procedure helpful but others do not.

Get out of bed in stages when blood pressure is likely to be at its lowest. At the same time, use some gentle leg and arm exercises while moving from lying, then sitting and finally to standing. Taking some slow deep breaths can also be helpful.

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Fluids

Drink plenty of decaffeinated fluids during the day – enough to keep the urine looking clear. This is because any type of dehydration is going to make orthostatic symptoms worse.

Having a glass of water before you get up in the morning may also be helpful. But don't drink too much water as this can cause water intoxication. Taking tea and coffee in moderation during the day can be helpful as they will help to keep the blood pressure up.

Alcohol

Most people with ME/CFS avoid alcohol or only drink small amounts because it makes them feel worse. In the case of orthostatic intolerance, alcohol is not a good idea because it dilates the blood vessels and again takes blood away from where it is most needed. Alcohol is also a diuretic.

SELF-HELP MANAGEMENT

Meals

Large meals and foods/snacks that contain a lot of sugary foods or simple carbohydrates are best avoided – especially at night. This is because the process of digesting food requires additional blood to be diverted into the intestines. It is far better to be eating small, regular meals, preferably with complex carbohydrates (e.g. pasta), throughout the day. Also avoid standing after eating. Keep your bowels regular because straining will lower blood pressure and may make you feel faint.

Salt

Salt plays an important role in helping to retain fluid in the body and maintaining blood pressure. So adding a small amount of extra salt to food during the day, or having a bag of crisps, may be advisable. Too much salt can cause high blood pressure and kidney problems. So any change in salt intake should be done with caution and only after you have spoken to your doctor.

If you have to go out in hot weather, make sure you have plenty to drink and know where there is shade and somewhere to sit down. Battery-operated fans and water-mist devices will help to keep you cool.

Heat

Excessive heat – e.g. hot weather, a hot crowded room, a hot shower – will inevitably exacerbate orthostatic intolerance and the symptoms that accompany it.

This is why perfectly healthy people sometimes feel faint when they have to stand up for a prolonged period on a very hot day. If you have to go out in hot weather, make sure you have plenty to drink and know where there is shade and somewhere to sit down. Battery-operated fans and water-mist devices will help to keep you cool.

Support stockings and tights

Support and compression stockings will help to return blood from the legs to the head. These may need to be worn all day if they are going to be effective but take them off at night. In some cases, an abdominal compression garment might be recommended.

SELF-HELP MANAGEMENT

A good place to obtain advice is your local pharmacy, who should have support stockings for both men and women. These products can also be obtained online through companies like:

Duomed: **https://www.duomed.com/en-GB**, and

Essity: **https://medical.essity.co.uk/home.html**

WHAT TO DO IF YOU FEEL DIZZY OR FAINT

Drinking some water can help if you feel dizzy or faint.

- Stop what you are doing and sit down – preferably on the floor.
- If possible, lie down flat and put your legs well above your hips (e.g. against a wall) for five minutes.
- Drink some water
- Loosen any tight clothing
- When you feel OK, get up slowly.

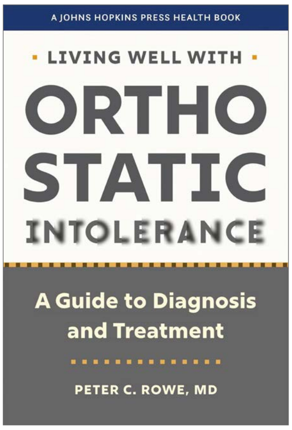
DRUG TREATMENTS

There are a number of drugs that are sometimes prescribed when symptoms of orthostatic intolerance and/or orthostatic hypotension or PoTS are more severe. These include drugs that:

- increase blood volume – e.g. fludrocortisone
- increase blood pressure – e.g. midodrine
- decrease pulse rate – e.g. beta blockers, ivabradine (mainly for use where PoTS is present)

This type of prescription-only medication is normally used only following hospital assessment by a physician with expertise in this area of ME/CFS.

Some types of medication used by people with ME/CFS can affect blood pressure and heart-rate responses. Examples include tricyclic antidepressants (eg amitriptylene), benzodiazepines (eg Valium) and diuretics (water-losing tablets).



A JOHNS HOPKINS PRESS HEALTH BOOK

LIVING WELL WITH

ORTHOSTATIC INTOLERANCE

A Guide to Diagnosis and Treatment

PETER C. ROWE, MD

DRUG TREATMENTS

However, there are other drugs that may actually help improve orthostatic intolerance. So a review of current medication ought to be carried out by either your GP or pharmacist.

FURTHER INFORMATION

MEA information leaflet on Postural Orthostatic Tachycardia Syndrome

https://meassociation.org.uk/snck

Living well with Orthostatic Intolerance is a new self-help guide written by Professor Peter Rowe

https://tinyurl.com/55a3ymtn

RESEARCH PAPERS

Professor Julia Newton and colleagues at the University of Newcastle have carried out a number of important research studies that have investigated autonomic dysfunction, including PoTS, in ME/CFS. This research is described in more detail, along with references for published papers, in Section 5.4.4 of ME/CFS/PVFS – The MEA Clinical and Research Guide. Section 7.4 of the same publication covers drug treatments for autonomic dysfunction that have been tested in clinical trials. These include fludrocortisone, midodrine and and pryidostigmine.

Cerebral blood flow in orthostatic intolerance – a 2025 review in the Journal of the American Heart Association - covers research into how blood flow to the brain may be involved in orthostatic intolerance.

https://tinyurl.com/r2b89be5

HOW WE CAN HELP

■ **COMMUNITY:** We provide a safe and welcoming community for people affected by ME/CFS and Long Covid who come together and benefit from sharing their experiences. We provide membership, an essential support service, excellent website resources and we host engaging discussions on the most popular social media channels. Knowing that you are not alone can be a great comfort and we are happy to answer your questions and share helpful tips.

■ **MEMBERSHIP:** We put the interests of members at the heart of everything we do. Your subscription means that we can support more people, campaign more effectively and fund more medical research. Members receive the exclusive ME Essential magazine which carries the latest news, medical information, personal stories, and feature articles. **Join us today**!

■ **SUPPORT:** ME Connect is the charity's support and information service. We listen and we understand. We provide a personalised service and we're here when you need us most. We have knowledge and understanding of these medical conditions. To view the ME Connect telephone helpline opening hours please visit: **https://www.meassociation.org.uk/me-connect**

■ **INFORMATION:** We produce reliable and timely information written by topic experts and have the **largest range of literature covering all aspects of life with ME/CFS and Long Covid**. We can show you how to recognise and manage symptoms, to get an accurate diagnosis, a referral to specialists, and to obtain the healthcare that you deserve. We also provide an **e-newsletter** and free access on the website to **Medical Matters** and other relevant information.

■ **RESEARCH:** We fund medical research via the **Ramsay Research Fund** and are especially interested in research that can find diagnostic markers, causes, and treatments. We support the UK ME/CFS Biobank and the Manchester Brain Bank, and have invested over £1m in medical research in the last 10 years.

■ **MEDICAL EDUCATION:** We arrange training for healthcare professionals, offer a medical magazine, ME Medical, and are working with the Government, NHS, Royal Colleges of Medicine, and Local Authorities to implement the recommendations from the 2021 NICE Clinical Guideline on ME/CFS – the successful result of 14 years lobbying and hard work.

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ME Essential

FOR PEOPLE AFFECTED BY ME/CFS AND LONG COVID

CHARITY NEWS: The Chairman's Statement for 2024; Severe and Very Severe ME Panel - register your interest.

RESEARCH: Immune T-cells become exhausted in ME/CFS.

MEDICAL: Amitriptyline and ME/CFS; NIH-funded study finds cases of ME/CFS increase following SARS-CoV-2.

CHAMPION BLOGGERS: Choosing and purchasing a new wheelchair.

FUNDRAISING: From ME to You: Your unsung heroes receive festive hampers from the MEA.

LIFESTYLE: Everything you need to know about finding a comfortable bra; Gwenfar's Garden.

REAL ME: Malin talks about her ME and her Sick Artist clothing designs.

> *"Thank you for producing such a helpful magazine. The standard is consistently high and each edition is interesting and varied. I need all the help I can get and this magazine is consistently encouraging, realistic, and helpful."*

SPRING 2025

ME Medical

The magazine for Healthcare Professionals about ME/CFS and Long Covid

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HOW WE CAN HELP

■ **LOBBYING:** We campaign to raise awareness and bring about positive change. We believe in collaboration and work with the NHS and social care services, the Department of Health and Social Care, the British Association of Clinicians in ME/CFS (BACME), Forward-ME, the ME Research Collaborative (MERC), DecodeME, the All-Party Parliamentary Group (APPG) on ME, Physios4ME, the Chronic Illness Inclusion project (CII), Hidden Disabilities Sunflower, and Long Covid initiatives.

■ **HEALTH & SOCIAL CARE:** The charity works with healthcare providers to successfully implement the NICE Guideline recommendations on ME/CFS and Long Covid to ensure that everyone receives the very best healthcare, wherever they live in the UK. We want well-trained healthcare professionals providing excellent services because timely intervention can lead to better health outcomes and improved quality of life.

■ **DONATIONS:** In order to help more people and invest in medical research we depend on your generosity. If you feel able to make a donation or want to raise funds in other ways, please get in touch with the fundraising team: fundraising@meassociation.org.uk or you can **make a direct donation via the website**.

WHAT ARE ME/CFS AND LONG COVID?

We answer key questions about these medical conditions and compare similarities and differences. You'll also find the NICE Guidelines reproduced in full in an easy to use **database**.

MEDICAL MATTERS

Medical Matters is an easy-to-use online supplement to the more detailed literature. The same topic experts provide answers to commonly asked questions.

NHS REFERRAL SERVICES

If you need to locate an ME/CFS specialist service or Long Covid Clinic then we can help. We have listed all secondary care referral services in an easy to use **database**.

> *"The MEA is doing exactly what it said it would by providing support, actively lobbying for recognition, improvements to health and social care, and funding biomedical research."*

THE ME ASSOCIATION

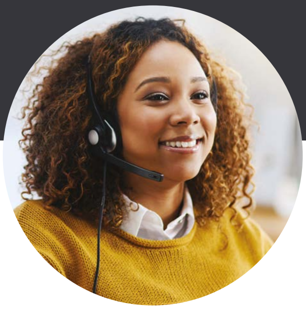
ME CONNECT

The Support and Information Service for people affected by ME/CFS/PVFS and Long Covid

3 WAYS TO GET IN TOUCH:
by phone, email
or social media private message

Freephone
0808 801 0484

For opening hours visit:
meassociation.org.uk/me-connect



HERE TO LISTEN

We are here to listen, validate and empathise with any issues you might be facing.

VITAL SUPPORT

We are here to help you reach an informed decision.

SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where you can be heard and understood.

We're here for you!

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meassociation.org.uk