

it's real!  
it's physical  
it's ME!

# MANAGEMENT FILE

## by DR CHARLES SHEPHERD, our medical adviser

This leaflet is based on an article which first appeared in the ME Association's quarterly *ME Essential* magazine.  
MEA membership costs £18 a year for people living in the UK/BFPO.  
For contact details, see foot of this page.



# ORTHOSTATIC INTOLERANCE

## WHAT IS ORTHOSTATIC INTOLERANCE?

This is the medical term for problems and symptoms that can occur when people stand up, or try to remain in a standing position for more than a short period of time.

Orthostatic intolerance is something that affects most people with ME/CFS to some degree and many doctors would regard it as a key diagnostic feature. For some people, orthostatic intolerance becomes a very disabling part of having this illness.

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

So common 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 does as well.
- Large meals with high carbohydrate content that divert blood to the intestines
- Physical exertion that diverts blood to the muscles. This process, which in turn reduces blood

supply to the brain, also helps to explain why cognitive/mental function often declines during physical activity.

- Fluid loss from diarrhoea or vomiting.
- Emotionally stressful events.

## WHAT ARE THE SYMPTOMS?

In addition to having difficulty in trying to remain in an upright position for any length of time, symptoms directly caused by decreased blood flow to the brain are quite common. These include:

- Feeling light-headed or faint
- Sweating
- Being anxious or breathless
- Headaches
- Palpitations
- Blurred vision
- Skin pallor

## ORTHOSTATIC OR POSTURAL HYPOTENSION AND URINARY/MICTURITION SYNCOPES

Where symptoms such as feeling faint and dizzy appear after changing position from lying/sitting to standing, this may be due to 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 also involve fainting or having a 'blackout'.

Men sometimes report feeling faint, or actually do 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, try sitting down on the toilet to pass urine.

## WHAT IS THE CAUSE OF ORTHOSTATIC SYMPTOMS?

Research into this aspect of ME/CFS suggests that orthostatic intolerance and/or hypotension is almost certainly linked to a problem with the autonomic nervous system – that part of the nervous system that automatically helps to control heart rate and blood pressure in relation to posture.

When we stand up, around 750 mls of blood suddenly 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 the autonomic response is to prevent a sudden fall in blood pressure and maintain a good supply of blood to the brain.

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 is then reduced. This is why orthostatic symptoms such as feeling faint, weakness and dizziness can appear quite rapidly following a change in position.

## WHAT CAN THE DOCTOR DO?

If these sort of symptoms occur regularly, you must speak to your doctor. A GP can check your heart rate, blood pressure (which should include both lying and standing measurements) and arrange an electrocardiogram/ECG if necessary.

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' and this has been used in a number of studies that have examined autonomic dysfunction in ME/CFS,

It is also important for the doctor 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.

## WHAT CAN BE DONE TO HELP?

There are lots of simple self-help measures that may be worth trying. But, before trying them, do talk to your GP – because the choice will partly depend on whether you also have orthostatic hypotension. So some may be appropriate whereas others may not. Your GP should also be able to demonstrate how to do some of the simple stretching exercises.

### Posture during the day

Keep your feet up on a stool when sitting down during the day. This 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

Try to keep moving around when you have to do a task that is going to involve a lengthy period of standing in one place – 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.

### Orthostatic training

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

These need to be taught and monitored by a health professional or physiotherapist with expertise in this area. A fairly recent 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

Try raising the head of the bed by about six inches. You can do this by putting some heavy books or bricks under the bed posts. This will help 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. This will take about five to 10 minutes. 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.

### Fluids

Make sure you regularly 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 these 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. Fluid intake can be a very effective form of management but do discuss how to do this properly with your GP.

### 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.

### Meals

Avoid large meals and foods/snacks that contain a lot of sugary foods or simple carbohydrates – 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 eat small, regular meals, preferably with complex carbohydrates (eg 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 may be advisable. But too much salt can cause high blood pressure and kidney problems so any change in salt intake must be done with caution and only after you have spoken to your doctor.

## **Heat**

Excessive heat – eg 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 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 (such as Duomed) 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. The best 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 BSN Medical: [www.bsnmedical.co.uk](http://www.bsnmedical.co.uk)

## **WHAT DO DO 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 (eg 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 used when symptoms of orthostatic intolerance and postural hypotension are more severe.

Drugs such as fludrocortisone (which increases blood volume) and midrodine (which constricts the blood vessels) have been assessed in people with ME/CFS but their use is normally restricted to people with more severe symptoms.

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

It is also worth noting that some types of medication used by people with ME/CFS can affect blood pressure and heart rate responses. Examples include tricyclic antidepressants (eg amitriptyline), benzodiazepines (eg Valium) and diuretics (water-losing tablets).

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

## **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 – the Postural Orthostatic Tachycardia (fast pulse) Syndrome – in ME/CFS.

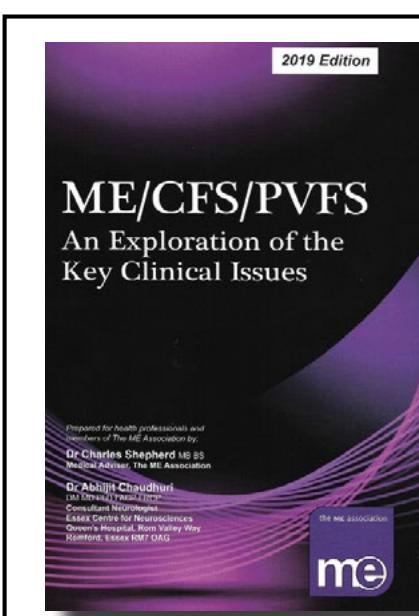
This research is described in more detail, along with references for published papers, in Section 6:4 of *ME/CFS.PVFS: An Exploration of the Key Clinical Issues*.

Section 7:3 of the same publication covers drugs treatments for autonomic dysfunction – including clonazepam, fludrocortisone, midrodine and pyridostigmine – that have been tested in clinical trials.

◆ Please let us know if you have any other tips that have helped with orthostatic intolerance or postural hypotension. You may email Dr Shepherd at [admin@meassociation.org.uk](mailto:admin@meassociation.org.uk) or write to him at:

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*Medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your doctor. The ME Association recommends that you always consult your doctor or dentist about any specific problem. We also recommend that any medical information provided by The MEA is, where appropriate, shown to and discussed with your doctor or dentist.*



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