

# Living with Postural Hypotension in MSA and other autonomic disorders



Sarah Matheson Trust for  
Multiple System Atrophy

[www.msaweb.co.uk](http://www.msaweb.co.uk)  
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## What is Postural Hypotension?

Postural Hypotension is a fall in blood pressure that occurs when changing position from lying to sitting or from sitting to standing.

**Postural** – change in position  
**Hypotension** – fall in blood pressure to a low level

It is also known as orthostatic hypotension. There are several causes of Postural Hypotension, which can require different treatment. Postural Hypotension is a common problem in people with autonomic disorders such as Multiple System Atrophy (MSA) and Pure Autonomic Failure. The information in this leaflet is for people with autonomic disorders.

Blood pressure is regulated by nerves and hormones which direct the flow and amount of blood circulating in the body. A supply of blood to organs like the brain and heart is vital at all times, even when blood is needed for everyday activities such as digesting food and walking. This is a complex system that works automatically under the control of the autonomic nerves.

## What are the symptoms of Postural Hypotension?

A fall in blood pressure leads to a reduced blood supply to organs and muscles; this can cause a variety of symptoms.

- Feeling dizzy and light-headed
- Changes in vision such as blurring, greying or blacking vision
- Feeling vague or muddled
- Losing consciousness with or without warning – this is a 'blackout' or 'faint'
- Pain across the back of shoulders and neck – 'coathanger' pain
- Pain in lower back and buttocks
- Angina-type pain in the chest
- Weakness
- Fatigue

These symptoms can vary from person to person.

## What to do when you get symptoms

Think of the symptoms as a warning that your blood pressure is too low. The only way to improve your blood pressure is to:

**STOP** what you're doing

**SIT** down - use bus stops, walls, benches: **LIE** down if possible

**DRINK** some water

**THINK** about what has triggered your symptoms

If you do faint (blackout) your family or those around you need to:

- **Lay you down flat**
- **Ensure you are safe** - remove any dangers (e.g. hot drinks) and check for breathing and circulation (simple first aid checks)
- **Raise your legs above your hips for 3-5 minutes**

There should be a prompt response to these measures, if not, **URGENT** medical attention is required – call **999**.

## When are the symptoms likely to happen?

At any time when there is an increased demand on the circulating blood, for example:

**Moving** – standing or sitting up suddenly

**In the morning** – when blood pressure is naturally lower

**After meals** – as blood is needed by the digestive system. In particular, big meals or sugary foods increase this demand. Alcohol also has this affect

**During exercise** – exercise (e.g. walking) and activity (e.g. dusting), especially when on your feet, increases the demand for blood in the muscles

**'Straining'** on the toilet when you are constipated or have difficulty passing urine

In addition the following things will make symptoms worse:

- Being dehydrated
- Getting overheated; in a warm room, after a hot bath or on a sunny day
- Illnesses such as colds or infections, especially if you need to rest in bed
- Anxiety and panic, especially if it changes your breathing pattern
- Medication – some medication can worsen Postural Hypotension

## Can exercise help Postural Hypotension?

There are some exercises that help circulation and some manoeuvres which reduce symptoms.

### **Circulation Exercises**

These simple exercises stimulate your circulation. You can do them in bed, or whilst sitting or standing and should do them before you change position or if you have been sitting or lying down for a while.

- move your feet up and down at the ankle
- do gentle 'marching' on the spot

If you get symptoms when you stop moving (e.g. after climbing up a flight of stairs), use these exercises after you have stopped.

### **Manoeuvres**

- avoid standing still, cross and uncross your legs
- crouch or squat down (as if to tie your shoe laces or look in your bag).
- bend forward and press your stomach, this is the position most people use when feeling faint.

These can be used discreetly at the first sign of symptoms.

## Improving control of your Postural Hypotension



**Weigh up the choices you can make** – choose the lifestyle advice in this leaflet that will be easiest for you to follow.

**Make time** - leave enough time to do things safely. This will mean including brief rests during an activity.



**Plan ahead** - plan appointments and visits for your best times of day, usually afternoon and evening. Space out activities that cause postural hypotension. This will give your blood pressure time to recover.

**Support stockings** – need to be worn all day to be useful. If you have difficulty putting them on and taking them off they may not be practical.



### Avoid dehydration

- Drink 3 ½ pints (2 litres) of fluid every day. This can be water, tea, low sugar drinks, ice lollies and sorbets.
- Drink a large glass of water before you get out of bed in the morning.

### Keep your head up in bed

- Sleeping with your head up at night helps to boost your blood pressure when you get out of bed.
- Use a foam wedge under the mattress or blocks under the legs at the head of the bed to do this.

### Take it easy in the morning

- Stay in bed for an extra hour in the morning.
- Prepare your morning medication and a drink the night before and leave it by your bed.
- Take any blood pressure medication before you get out of bed.
- Sit up slowly, an electric backrest that lifts the head of your bed up is useful.
- Get out of bed slowly and sit on the side of the bed before standing up.

### Move safely

- Do the circulation exercises before moving.
- Take your time when changing position (e.g. rising from a chair).
- Talk to an occupational therapist about equipment that can help you change position slowly (e.g. a bed raiser and a reclining chair).
- Sit down to do everyday tasks like getting dressed or preparing vegetables.
- Talk to a physiotherapist about using stairs safely.
- Avoid bending down or stretching up (e.g. hanging out washing).

### Mealtimes

- Eat small meals and snacks at regular intervals during the day.
- Avoid sugary foods (e.g. chocolate, biscuits) and drinks (e.g. Lucozade).
- Eat salty snacks (e.g. crisps, nuts and soup).
- Use drinks containing caffeine (e.g. coffee and diet cola).

### Exercise

- Be active every day.
- Have frequent rests to avoid exhaustion.

### Preventing constipation

- Eat foods with fibre (e.g. cereals and fruit) every day.
- Drink 3 ½ pints (2 litres) of fluid every day.
- Use laxatives to prevent constipation.

### Keeping cool

- Keep the heating turned down and use fans.
- Have a warm shower or bath instead of a hot one.
- Don't sit in the sun.

### New tablets

- Ask if your blood pressure will be affected by any new tablets.
- Read the information leaflets that come with your medication.

### See your GP

- Ask for the Flu jab to help avoid winter epidemics.
- If your Postural Hypotension symptoms suddenly get worse it may be a sign that you have an infection, most commonly bladder or lungs.

## Can medication help?

Medication can be used to raise blood pressure. These include:

- **Fludrocortisone** (Florinef)  
a steroid, taken in very small doses; may cause ankle swelling.
- **Ephedrine**  
works quickly (within 60 minutes). Usually taken three times a day but not after 6pm.
- **Midodrine** (Gutron)  
works quickly (within 30-60 minutes). Only available on a special prescription. Usually taken three times a day but not after 6pm.
- **DDAVP** (Desmopressin)  
used to reduce the production of urine overnight, which will help boost morning blood pressure.
- **Octreotide** (Sandostatin)  
an injection given before meals which reduces hypotension after food.
- **Erythropoietin**  
used when anaemia occurs with Postural Hypotension.
- **Salt tablets**  
help keep water in the blood stream which boosts blood pressure.

These medications can raise blood pressure even when lying down. This can cause problems so it is advisable to:

- Avoid lying flat (head-up tilt)
- Have monthly blood pressure readings (lying & after 3 minutes standing)

## **Other things to think about**

### **Blood pressure monitoring**

Recognising what makes your postural hypotension symptoms better or worse is important but having your lying and standing blood pressure checked regularly is also useful. This should be done by your GP, practice nurse or district nurse rather than using a home blood pressure machine. Ideally you should:

- Lie down
- Rest for three minutes
- Record blood pressure and pulse
- Stand up (or sit up if unable to stand) for three minutes
- Record blood pressure and pulse again
- Keep a copy of the readings to show your specialist.

### **Take your own seat**

Carry a lightweight folding chair (or shooting stick): this will give you a seat whenever you need one, for example in a queue or out shopping.

### **Driving**

You are responsible for informing the Driving and Vehicle Licencing Authority (DVLA) of your condition. You can discuss your ability to drive with your doctor. If your mobility is restricted you may be entitled to a Blue Badge (disabled parking permit), contact your local Social Services Department for advice.

### **Finances**

You may be entitled to benefits such as Disability Living Allowance (DLA) or Incapacity Benefit (IB). Contact the Benefit Enquiry Line (0800 88 22 00).

### **Medical Alert bracelet**

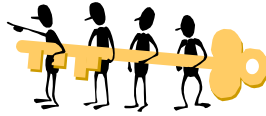
This is a recognised system that tells people about your problem and what to do to help you. Contact Medic Alert (0800 581420, [www.medicalert.org.uk](http://www.medicalert.org.uk)), SOS Talisman ([www.sostalisman.org](http://www.sostalisman.org)), for further information.

### **Holidays**

If you are planning a holiday think about how you will stay cool if you are going somewhere hot. Take enough medication, including some extra for your whole stay. Carry it in your hand luggage. Make sure you have medical cover. If travel companies are aware of your condition they can help with additional arrangements such as use of a wheelchair at the airport.

### **Going into Hospital**

The change of routine, investigations or operations can all affect blood pressure control. Read the *Going into Hospital* information leaflet from SMT.



## Key Points

- Get to know your symptoms and what triggers them
- Have a plan of action for when you feel faint
- Establish a routine, get organised and give yourself plenty of time
- Understand your medication
- Have your lying and standing blood pressure monitored and recorded
- Contact the specialist nurses at the Sarah Matheson Trust for further information or advice

This information was developed by the Autonomic Unit at the National Hospital for Neurology & Neurosurgery (University College London) and the Neurovascular Medicine Unit at St Mary's Hospital (Imperial College London).

Before following any of the treatment and management advice in this leaflet you should discuss the information with your own doctor.

Further information can be found from the following sources:

**Mathias CJ, Bannister R**, eds. *Autonomic Failure: A Textbook of Clinical Disorders of the Autonomic Nervous System* 4<sup>th</sup> ed Oxford: Oxford University Press 2002

**Mathias CJ**. Autonomic Diseases: Clinical features and laboratory evaluation *Journal of Neurology Neurosurgery & Psychiatry* 2003;74(Suppl 3); iii31-iii41

**Mathias CJ**. Autonomic Diseases: Management *Journal of Neurology Neurosurgery & Psychiatry* 2003;74(Suppl 3); iii42-iii47

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