Living with Postural Hypotension

Introduction
This fact sheet has been developed for people affected by MSA who are experiencing drops in blood pressure and postural hypotension. It describes the symptoms of postural hypotension and strategies for managing those symptoms.

What is postural hypotension?
Postural hypotension is a sudden fall in blood pressure that occurs when changing position from lying down 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 extra blood flow 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 or double vision
Living with postural hypotension

- Feeling vague or muddled
- Losing consciousness with or without warning – this is a ‘blackout’ or a ‘faint’
- Pain across the back of shoulders and neck – ‘coathanger’ pain
- 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:

1. **STOP** what you are doing
2. **SIT** down - use bus stops, walls, benches: **LIE** down if possible
3. **DRINK** some water - Two glasses of water will usually bring your blood pressure up within 15 minutes.

**THINK** about what has triggered your symptoms. If you do faint (blackout), your family or those around you need to:

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

If you don’t start to feel better quickly after these steps have been followed **URGENT** medical attention is required – call 999 immediately.

When are the symptoms likely to happen?

Symptoms are likely to occur at any time when there is an increased demand for blood circulation, 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 effect. You should aim to eat six smaller portions of food a day, rather than three large meals.
- 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
- After or during sexual intercourse
Living with postural hypotension

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, in particular some Parkinson’s medications. For further information about these please speak to your MSA Nurse Specialist or Parkinson’s Nurse Specialist.

Can exercise help symptoms?

There are some exercises that help circulation and some manoeuvres which reduce symptoms. These simple exercises stimulate your circulation. You can do them in bed, or whilst sitting or standing and you should do them before you change position or if you have been sitting or lying down for a while. Aim to do these for five to ten minutes:

- Move your feet up and down at the ankle
- Rotate each ankle round and round
- 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.

- Avoid standing still, cross and uncross your legs.
- Clench your buttocks
- Put arms behind back and push shoulder blades together
- 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.

Consider using support stockings – these 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.

Abdominal binders may be helpful for you – please discuss this with your Parkinson’s Nurse Specialist, Physiotherapist, Occupational Therapist or one of the MSA Nurse Specialists.

Avoid dehydration

- Drink 3 ½ pints (2 litres) of fluid every day. This can be water, tea, low sugar drinks, ice lollies and sorbets.
Living with postural hypotension

- 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 (aim for a 30% rise at the head of the bed—discuss this with your Occupational Therapist).
- An Occupational Therapist can supply you with a foam wedge to go under your mattress or blocks to place under the legs of your bed.

**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 riser/recliner 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 too many sugary foods (e.g. chocolate or sweets) and drinks (e.g. lucozade).
- Eat salty snacks (e.g. crisps, nuts and soup, marmite).
- Use drinks containing caffeine (e.g. coffee) but not in the evening.

**Exercise**

- Try to be as active as possible 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 daily to prevent constipation.

**Keeping cool**

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

**New medication**
Living with postural hypotension

- Ask if your blood pressure will be affected by any new tablets.
- Read the information leaflets that come with your medication.
- Speak to your pharmacist to see if there are any interactions with your existing medication.

See your GP

- Ask for the Flu jab to help avoid winter epidemics (your spouse/partner should also have this).
- If your postural hypotension symptoms suddenly get worse it may be a sign that you have an infection, most commonly affecting the bladder or chest.

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.
- Droxidopa
  Is a drug that recently gained approval in the US for the treatment of symptomatic postural hypotension. It is not yet approved for use in the UK.

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

1. Avoid lying flat (head-up tilt)
2. Have monthly blood pressure readings (lying and after three 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. Ideally, you should get this checked at your GP surgery. If you do check it yourself:

- 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.
Living with postural hypotension

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. This is a legal requirement. You should discuss your ability to drive with your doctor. If there is any uncertainty you may be required to take a driving test. 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 Personal Independence Payment (PIP), Attendance Allowance or Employment and Support Allowance (ESA). Check online at [www.gov.uk/benefits-adviser](http://www.gov.uk/benefits-adviser). You may also find this site useful - [www.gov.uk/browse/benefits/disability](http://www.gov.uk/browse/benefits/disability).

Medical Alert bracelet

This is a recognised system that informs the general public about your condition and what to do to help you. For more information contact:

- Medic Alert T: 0800 581 420 | W: [www.medicalert.org.uk](http://www.medicalert.org.uk)
- SOS Talisman T: 0208 554 5579

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 and carry this 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 us and take a copy with you for hospital staff along with a Guide to MSA. We also produce a Hospital Information Folder where you can keep any information you need to show hospital staff. You can request one of these from the MSA trust office.

Key points to remember

- 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 MSA Nurse Specialists at the Multiple System Atrophy Trust for further information or advice
Living with postural hypotension

This information was originally 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.

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References for this information sheet are available by contacting support@msatrust.org.uk.

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