

- What is postural hypotension? Page 1
- What are the symptoms of postural hypotension? Page 1
- What to do when you get the symptoms Page 2
- When are the symptoms likely to happen? Page 2
- Can exercise help postural hypotension? Page 3
- Improving control of postural hypotension Page 3
- Can medication help? Page 5
- Further information Page 6

Living with Postural Hypotension

This factsheet has been developed for people affected by MSA who are experiencing drops in blood pressure, known as 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).

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. Extra blood flow is needed for everyday activities such as digesting food and walking. This is a complex system that works automatically, without conscious thought, 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. The main symptoms are:

- Feeling dizzy and light-headed
- Changes in vision such as blurring or double vision
- Feeling vague or muddled

Living with postural hypotension

- Losing consciousness with or without warning – this is a ‘faint’ or a ‘blackout’ or may be referred to as ‘slumping’.
- Pain across the back of shoulders and neck – ‘coathanger’ pain
- Angina-type pain in the chest
- Weakness
- Fatigue
- Staring or blank episodes, sometimes with repetitive jerky limb movements.

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’re 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 possible.

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

When are the symptoms likely to happen?

Symptoms are more likely to occur 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, large meals or sugary foods increase this demand. Alcohol also has this effect. If your blood pressure does drop significantly after eating, there are benefits to eating smaller portions of food more frequently. Ideally you should aim to eat six smaller portions of food a day, rather than three large meals. Do not reduce your daily calorie intake.
- During exercise – such as walking and activities such as dusting, especially when on your feet because this increases the demand for blood in the muscles

Living with postural hypotension

- 'Straining' on the toilet when you are constipated or have difficulty passing urine
- After or during sexual intercourse.

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 or reduce their likelihood.

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, pumping your calf muscles](#)
- [Rotate each ankle round and round](#)
- [Do gentle 'marching' on the spot movements](#)

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 your arms behind your back \(or as far back as you can\) and push your 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 factsheet 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 the stockings on and taking them off they may not be practical. Make sure you remove them at night before getting into bed.

Living with postural hypotension

[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

- Try to 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.
- Always have a bottle of water with you.

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 longer, up to 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 can be 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 (e.g. to pick up an item from the floor – you could use grippers instead) or stretching up (e.g. hanging out washing).
- Be aware that when your blood pressure drops on standing or changing position it puts you at a higher risk of falls. If you have been in bed or sitting for a while, before getting up, do some calf pump exercises and drink a large glass of water.

Mealtimes

- Eat small meals and snacks at regular intervals during the day, add salt to your food at the table (not during cooking).
- 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.

Living with postural hypotension

Preventing constipation

- Eat foods with fibre (e.g. cereals and fruit) every day
- Drink 3 ½ pints (2 litres) of fluid every day
- Most people with MSA will need to take a daily laxative - discuss with your Health Care specialist if you need advice

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 for long periods.

New medication

- 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 every year to help avoid winter epidemics (your spouse/partner should also have this)
- Ask for the pneumonia vaccination (this is a one-off treatment, not yearly) for you and your spouse/partner
- 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; which may cause ankle swelling. It is usually taken at 8am and/or 12pm, but not any later.
- Ephedrine
works quickly (within 60 minutes). It is usually taken three times a day but not after 6pm.
- Midodrine (Gutron)
works quickly (within 30-60 minutes). Only available on a special prescription. It is 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
This is a drug that has gained approval in the US for the treatment of symptomatic postural hypotension. It is not yet approved for use in the UK. However, in certain cases, it may be available on a named patient basis. Discuss this with your Neurologist if other medications haven't been effective.

Living with postural hypotension

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 regular blood pressure readings - read about this below.

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 or your carer do check it:

- 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.

It might be helpful to record your lying and standing blood pressure twice a week and take the results to show your specialist at your next appointment.

Take your own seat

Carry a lightweight folding chair, shooting stick, rollator or any walking aid with a seat; 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. You may also find this site useful - www.gov.uk/browse/benefits/disability. Please contact our Social Welfare Specialist for further information on benefits and entitlements.

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

SOS Talisman T: 0208 554 5579



Living with postural hypotension

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 for further information.

The MSA Trust's Contact Details:

We have MSA Health Care Specialists that support people affected by MSA in the UK and Ireland. If you would like to find the MSA Health Care Specialist for your area, contact us on the details below or use the interactive map here – <https://www.msatrust.org.uk/support-for-you/hcps/>.

MSA Trust, 51 St Olav's Court, City Business Centre, Lower Road, London SE16 2XB

T: 0333 323 4591

| E: support@msatrust.org.uk

| W: www.msatrust.org.uk

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Patient Information Forum

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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) with additions from the MSA Trust Nurses, Before following any of the treatment and management advice in this factsheet you should discuss the information with your own doctor.