

Understanding Postural Orthostatic Tachycardia Syndrome (POTS)

Postural orthostatic tachycardia syndrome — information for patients

Your clinician has told you that you have, or may have, a condition called postural orthostatic tachycardia syndrome — usually shortened to POTS. This leaflet explains in plain language what POTS is, why standing up makes you feel unwell, what tends to make it worse, and the things that genuinely help. Keep it to refer back to, and bring any questions to your next appointment.

What is POTS?

POTS is a real and common cause of feeling dizzy, lightheaded and exhausted, especially when you stand up. When you stand, gravity pulls blood down into your legs. Normally your body tightens those blood vessels straight away so enough blood returns to your heart and brain. In POTS that response is not strong enough, so your heart races to make up for it.

That racing heart, and slightly less blood reaching your brain for a short time, is why you can feel lightheaded, fluttery, shaky, sweaty or 'foggy'. POTS tends to affect young people, more often women, and it often begins after a viral illness — including after COVID-19.

Most important: *POTS is not dangerous in the way a heart attack is, it is not 'all in your head', and it is not a sign that something serious has been missed. It is a problem with how your circulation adjusts to standing — and it usually improves.*

What might have caused it?

POTS often follows an identifiable trigger, although sometimes no clear cause is found. Common triggers include:

- ▶ **A viral illness.** Including after COVID-19, glandular fever or other infections.
- ▶ **A growth spurt or adolescence.** POTS frequently appears in the teenage years.
- ▶ **A long period of bed rest, surgery or pregnancy.** When the body becomes deconditioned.
- ▶ **Sometimes it runs in families.** Or occurs alongside conditions such as joint hypermobility.

What makes it worse?

Certain situations reliably bring symptoms on or make them stronger. Recognising your own pattern helps you manage it:

- ▶ **Standing still.** Standing and walking feel worse; sitting or lying down brings relief.
- ▶ **Heat.** Hot weather, hot showers and hot baths widen blood vessels and worsen pooling.
- ▶ **Large meals and alcohol.** Especially carbohydrate-heavy meals, which divert blood to the gut.
- ▶ **Being inactive.** The longer you have been resting, the worse symptoms become — which is why gentle exercise is so important.

How is POTS diagnosed?

There is no single scan that proves POTS. Your clinician measures your heart rate and blood pressure while you are lying down and again after standing for up to ten minutes. POTS is confirmed when your heart rate rises by a set amount on standing — without your blood pressure dropping — and your usual symptoms are reproduced. A few blood tests are done to rule out other causes such as anaemia or thyroid problems, and occasionally a tilt-table test or heart monitor is arranged.

How is POTS treated?

Most of the treatment for POTS does not involve tablets, and the steps work best together. Your clinician will tailor the plan to you:

- ▶ **Fluids and salt.** Drinking two to three litres a day and adding extra salt keeps more blood circulating.
- ▶ **Compression garments.** Firm stockings or tights up to the waist stop blood pooling in your legs.
- ▶ **Graded exercise.** A carefully paced return to exercise is the single most powerful treatment — it starts lying down or in water and builds up slowly over months.
- ▶ **Medication.** Some people need a medicine to steady the heart rate or boost blood volume, chosen to fit their pattern.

Please contact your clinic if: *your symptoms suddenly become much worse, you faint repeatedly, you develop chest pain, or you cannot keep fluids down. These need prompt review.*

Looking after yourself

- ▶ **Keep moving.** Returning to gentle activity, step by step, is part of recovery — avoid long spells of bed rest.
- ▶ **Do your exercises regularly.** Little and often is what reconditions your body.
- ▶ **Drink and salt every day.** Make fluids and salt a daily habit, not just for bad days.
- ▶ **Stand up slowly.** Rise in stages, and tense your legs or cross them if you feel lightheaded.
- ▶ **Look after sleep and stress.** Both tiredness and worry turn symptoms up.

What happens over the long term?

The outlook for POTS is generally good. With a coordinated plan most people improve substantially over months to a few years, and many young people recover almost completely, especially when POTS began after a viral illness. Recovery is rarely a straight line — flare-ups happen — but they settle, particularly if you return to your fluids, salt and exercises early.

Reducing the impact of POTS on your life

- ▶ **Build up gradually.** Increase your activity in small, planned steps so your body reconditions safely.
- ▶ **Plan for setbacks.** If a flare comes, restart your exercises and fluids early rather than resting for long.
- ▶ **Keep your appointments.** Staying in touch lets your team fine-tune your treatment.
- ▶ **Be patient and hopeful.** Recovery takes time, but most people with POTS get a great deal better.

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