

How gravity can knock you sideways

For some people, standing up is a hazard that puts them at risk. Barbara Rowlands explains.



Sophie Mortimer suffers with Postural tachycardia syndrome (PoTS) Photo: Martin Pope

By Barbara Rowlands, The Telegraph, 27 June 2011

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A summer's evening in London and 21-year-old Sophie Mortimer was squashed between tourists and commuters on the Piccadilly Line. As she stood, swaying, she felt increasingly lightheaded. Just before the train pulled into the station, she fainted.

“It was a family of American tourists who carried me off the Tube,” she recalls. “I woke up on the platform and the Underground staff gave me water and called an ambulance.” At the hospital, doctors said she might have glandular fever, although they also said she “looked too healthy”.

But Sophie, a student at the London School of Economics, was not at all healthy. She had indeed had a lengthy bout of glandular fever a year before, and the symptoms – sleeping 14 hours a night and difficulty concentrating on her degree – had lingered on.

Her GP dismissed the faint as post-viral, but Sophie knew something else was wrong. Nearly three years after her first fainting fit in 2007, she was diagnosed with a condition that makes it hugely difficult to go from sitting to standing without fainting or feel dizzy. Postural tachycardia syndrome (PoTS) was discovered only 15 years ago, and few doctors have heard of it, let alone know how to diagnose and treat it.

The name may be tricky but the explanation is simple. Normally, when someone stands up, the blood, which gravity dictates should sink below the abdomen and pool around the ankles,

miraculously remains waist high. If you have PoTs, this doesn't happen. Gravity wins and blood drains down into the abdomen and legs. The heart races to try to get blood back to the brain, and the result is fainting and dizziness. Which is what happened to Sophie on the homebound train.

A condition of the autonomic nervous system that controls all our bodily functions, PoTS is surprisingly common, particularly among young women; one estimate puts the number of people with the condition as 1.7 per cent, and studies estimate that one in 100 teenagers are affected. Yet it is so little known by doctors that it is often misdiagnosed as anxiety, depression or chronic fatigue syndrome.

Dr Blair Grubb, professor of medicine and paediatrics at the University of Toledo, Ohio, and a world authority on fainting and autonomic disorders, explains: "When you stand up, the brain tells your heart to beat faster and a little bit more forcefully. It also tells the blood vessels in the lower half of the body to become up to three times tighter, pushing blood up towards your heart. It does it so quickly that you can jump out of a chair and do double back flips and your blood pressure will stay the same. Once you're upright, you have to maintain it and, if gravity wins, you lose."

With PoTS, the blood vessels fail to tighten, or stay tightened, so abnormal amounts of blood drain into the abdomen and legs. With the blood pressure plummeting, the brain tries to make the heart beat harder and faster, to raise it. With less blood being pumped with each beat, the blood reaching the brain has less oxygen, and so someone with PoTS will feel dizzy or faint.

It's not just standing that causes problems; anything that demands more blood – a large meal, heat, the mildest exercise – causes dizziness, weakness, nausea, fatigue, an increased heart rate – and sometimes fainting, or to use its medical term, reflex syncope.

Sophie, now 25, lives at home in Wimbledon, south-west London, with her parents. In the past she was just like any other student – partying and enjoying university life to the full. Now her days are filled with sudoku, reading and the occasional walk. To avoid the symptoms of PoTS, she has to pace herself, managing "big" activities – such as going out to dinner or a supermarket shop – only occasionally.

Although she has only fainted once since that first time on the Tube, she feels permanently drained of energy. "You can also feel quite nauseous. I can't drink alcohol, queue or stand for longer than 35 seconds," she explains. "The feeling gets worse after a big meal. I can't do hot temperatures – about 20 degrees is my limit – so hot rooms and hot places are out."

Sophie fought hard to get a diagnosis (one GP said she was "highly strung"), something that her consultant, Dr Christopher Mathias, professor of neurovascular medicine at Imperial College, London, and a leading authority on PoTS, says is common. Some of Prof Mathias's patients at the two clinics he runs in London have had the condition for up to 10 years without knowing.

This is not surprising, as PoTS is often misdiagnosed as a psychological problem such as panic disorder or depression. Jenni Cozon from STARS, the support group for people with PoTS and other disorders of the autonomic nervous system, says few consultants know about PoTS or are confident dealing with it.

Because PoTS is so easily misdiagnosed, specialists now think more people have it than was previously thought. It affects five times as many women as men and also afflicts teenagers, the trigger being a sudden spurt in growth at around 14. By the time they are in their early twenties, eight out of 10 of them are free of PoTS, but precious years have been damaged.

In addition, a study from Newcastle University suggested that up to 40 per cent of people with suspected chronic fatigue syndrome (also known as ME) may have PoTS.

“There are an awful lot of people out there who have been told they’ve got ME when they’ve got PoTS,” says Jenni Cozon. “And there are people who are suffering with PoTS who we don’t know about because they’ve been told there is something wrong with their mind.”

So what causes PoTS? Prof Grubb believes a tendency to develop it may be inherited but lies dormant. The trigger is often a severe viral infection, usually glandular fever, as in Sophie’s case, but symptoms can also start after pregnancy or a trauma, such as surgery or an accident.

The good news is that once suspected, diagnosis is simple. Take the heart rate and blood pressure while the patient is lying or seated – and then when he or she is standing: if the heart rate increases by 30 beats or more per minute, or exceeds 120 beats a minute, without the blood pressure falling (the racing heart raises it temporarily), then the patient needs to see a specialist, with full diagnosis involving further tests in hospital.

Specialists advise people with PoTS to wear elastic support stockings, take light exercise, drink lots of water and be generous with the salt cellar (since salt raises the blood pressure). Medication can help, the most effective drugs being beta blockers, which tighten the blood vessels, fludrocortisone, which increases the retention of salt and fluid, and midodrine, which raises blood pressure (this last drug is not licensed in the UK but can be prescribed by specialists).

Despite her condition, Sophie managed to get a first-class degree in social anthropology (she had her lectures recorded and listened to them at home), and is hoping to continue her studies. “While having this diagnosis isn’t a quick fix,” she says, “it is so important to know what is wrong with me and, most important, how to go about dealing with it, so that I can get back to being a normal twentysomething.”

For more information, contact STARS (Syncope Trust And Reflex Anoxic Seizures) at www.stars.org.uk