Postural Tachycardia Syndrome PoTS

Version 1.0

Updated

Created in collaboration with PoTS UK

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Overview

What is the condition usually called/ any abbreviations used?

- Postural tachycardia syndrome (PoTS)
- It's also known as postural orthostatic tachycardia syndrome (POTS).

Brief overview of the condition.

Postural tachycardia syndrome (PoTS) is when your heart rate increases very quickly after getting up from sitting or lying down. There is no known cure. It can improve with self management strategies, but some people may need treatment with medicines**.**

PoTS is an abnormality of the functioning of the autonomic (involuntary) nervous system.

In PoTS, this automatic adjustment to upright posture is not working correctly, resulting in an excessive rise in heart rate, increased norepinephrine in the blood and altered blood flow to the heart and brain. In some cases, PoTS can develop after an infection such as a viral illness such as glandular fever or covid 19 infection.

Other possible triggers include bacterial illness, pregnancy or surgery, trauma, and immunisation. However, a link with these potential triggers remains unclear.

Patients often have to adopt many self-management techniques simultaneously such as monitoring and changing their posture and symptoms to avoid fainting, drinking fluids (and toilet visits), eating frequent small meals and daily exercise (where they are able to do this).

There are several conditions associated with PoTS including hypermobile Ehlers-Danlos Syndrome, Chronic Fatigue Syndrome, Mast Cell Activation Syndrome

Presenting Symptoms

Symptoms can include but are not limited to:

Experienced in the upright position (usually standing, but sometimes sitting):

- dizziness or light-headedness
- fainting/black outs or almost fainting- Approximately 30-60% of people with PoTS experience fainting.
- noticeable heartbeats (heart palpitations)
- chest pain
- shortness of breath
- shaking and sweating
- cognitive dysfunction (brain fog)

Other symptoms may include:

- problems with digestion- such as feeling sick, being sick, diarrhoea, constipation, bloating and tummy pain
- Headaches/migraines and problems with sight - such as blurred vision or tunnel vision
- hands and feet looking purple – this impacts around half of all PoTS patients.
- weakness and fatigue - this can be an ongoing symptom of PoTS or last for a considerable time after a PoTS flare.
- problems with thinking, memory and concentration (brain fog)

Conditions associated with PoTS may also case symptoms such as joint problems, allergic reactions and many other symptoms.

Fluctuations

It is a hidden, fluctuating and complex condition, which affects people very differently. It can develop suddenly or gradually over time. Importantly, some people may find symptoms are worse in the morning, and they may change from hour to hour and day to day.

If blackouts/fainting is reported, please explore around:

- How often does this occur?
- Are there any triggers or patterns to when a blackout/faint occurs? Is there a specific time of day they occur?
- How do they feel prior to a blackout/faint? How long before the blackout does this occur? Are they able to recognise this warning themselves? Can these be relieved by sitting/lying down?
- Is there loss of consciousness, and if so how long does it last?
- What symptoms do they have, if any, immediately following a blackout/faint? •How long does the recovery phase last?
- Have they sustained any injuries as a result of a blackout/faint?
- Do they have safety strategies in place to avoid injury?
- When was the last blackout/faint?
- •Do they have any side effects of their medication?

Remember that PoTS can fluctuate and that you may be seeing them on a good day. Enquire about the impact of PoTS on bad days, and how often these occur.

Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY

Do they have any symptoms which could cause a safety consideration?

For some the unpredictable nature of the condition means people are at risk and need supervision and support with various activities. You need to specifically explore extent of any previous incidents completing tasks, why this was and how it was managed in activities 1, 2, 3, 4, 5 and 11

TIMELY

For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

Whilst the individual may be able to complete daily tasks with no restrictions you need to consider how they may be impacted, should they have blackouts and how they manage this with tasks including recovery periods and the side effects of medication. It is important to probe how long a task may take.

ACCEPTABLE STANDARD

How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?

Consider that whilst someone might have a warning/symptoms prior to a blackout/faint you need to consider if it is an acceptable amount of time to make themselves safe, and whether any precautions they take are deemed reasonable or whether this is beyond what is acceptable within PIP.

REPEATEDLY

Are they able to repeat a task as often as required? Is this the same every day?

Recovery period including things like fatigue needs to be considered when thinking about how repeatable an activity is alongside frequency of blackouts/faints.

Sensitivities

What areas might they find difficult to mention or perhaps understate the impact of?

Patients often report this is difficult to describe so ensure this is fully probed.

- Restrictions with memory and confusion
- Associated mental health problems

Some people with PoTS may downplay the impact it has while they try to remain strong and defiant in the face of their condition. They may also not see themselves as disabled.

Due to misinformation patients have often experienced prejudice and assumptions about, not only their condition, but themselves as people for having the condition. As a result they may find it difficult to talk about their condition at all depending on the presentation of the assessor.

You should remember that many claimants diagnosed with this condition have made substantial adaptations to their lives and living environment and consequently feel passionate about this being explored appropriately during the assessment.

Customer Care

In general

- Keep an open mind. Listen to what they say
- Try not to jump to conclusions about how their PoTS affects them
- Don't ask questions in different ways, unless the person clearly doesn't understand the first time
- Allow time for understanding of the questions and don't move on unless you are sure the person has nothing else to say. They might need more time than usual, if the PoTS or medicines cause cognition problems.
- Involve any companions as they can likely elucidate on the reality of what the claimant can actually achieve
- A warm and friendly welcome, and reassurance will hopefully make the experience less intimidating and more relaxed

During face to face interactions

- Explore what they would like you to do, if anything, should they have a blackout/faint whilst with you
- Offer them a short break if they need it – encourage them to eat and drink when necessary

Functional Impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

There can be huge risk factors in the kitchen environment, and many will have support from others. Many may avoid the use of sharp utensils if they have unpredictable faints/blackouts with no warning. Fatigue, dizziness and cognitive dysfunction can impact this; sitting down to complete the task does not always help. Each individual will have a different way to manage this. Some are too exhausted or cognitively compromised to prepare food. Some may need to rest during the day as a result or break up the task, others need assistance.

Remember in PIP…

It is imperative to establish risk in the kitchen. Does their cognitive dysfunction impair their ability to prepare food? Have they had blackouts/faints whilst preparing a meal? Do they avoid this activity altogether due to risk?
When they have blackouts/faints or drop to the floor? Do they have a warning? Is this long enough to get themselves to a place of safety? Have they had any incidents in the kitchen? What is the impact upon their symptoms of preparing a meal? Fatigue management must be explored for completing this task. How long it takes and how repeatable any activity is across the day? Explore the extent of any support provided.

Activity 2: Taking nutrition

People with PoTS may have problems eating; finding eating too exhausting or suffer from nausea, abdominal pain, abdominal distension, and severe constipation or diarrhoea.

Remember in PIP…

You need to have established the individual's ability to be nourished, either by cutting food into pieces, conveying it to the mouth and chewing and swallowing; or through the use of therapeutic sources. You need to explore extent of any weight loss, motivation levels, how diet is managed and what any support does.

Activity 3: Managing therapy and monitoring a health condition

There may be numerous prescribed medications on a daily basis. Some of these medications require close medical monitoring and dose adjustment to achieve optimum benefit. In addition, these medications may have side-effects which are difficult to live with.

Exercise programmes or other therapies may be prescribed by a health professional, please consider whether they may require prompting or assistance to complete these.

Some people may suffer with brain fog. This has an impact on daily life. People may be unable to retain information or concentrate for long periods, they may have poor memory and need support with medication or therapy

Remember in PIP…

Can they manage their own medication? Do they remember when to take it? Do they require prompting or assistance to administer medication? You must consider if there is therapy taking place within the home, do they require assistance with it and how long is this assistance for?

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Activity 4: Washing and Bathing

Where there is unpredictable loss of consciousness and individuals can fall to the floor there is a risk of drowning and/or other injuries in this wet and slippery environment. Many individuals are either supervised or have safety measures in place to support this risk. Some individuals may require aids or help with washing and bathing due to fatigue and dizziness on exertion or standing. Getting in and out of the bath can be very difficult.
Exhaustion after bathing or showering can be profound in PoTS, and patients commonly require to lie flat and recover afterwards, sometimes for hours.

Remember in PIP…

It is imperative to establish risk in the bath or shower. Have they had faints/blackouts whilst washing? When they have blackouts/seizures, do they have a warning? Is this long enough to get themselves to a place of safety? Have they had any incidents in the bathroom? Do they drop to the floor? Do they lose awareness/consciousness?

Where there is reported fatigue and/or dizziness you must explore management strategies. Would aids be reliable? Or assistance more likely?

Activity 5: Managing toileting needs and incontinence

Where there is unpredictable loss of consciousness and individuals can fall to the floor there is a risk of falls.

The movement of going from sitting to standing can also cause dizziness.

Many people with PoTS experience severe diarrhoea requiring frequent, urgent and unpredictable toilet trips. Please ensure incontinence has been probed.

Remember in PIP…

How do they transfer on/off the toilet?

Where there is reported fatigue and/or dizziness you need to explore specifically how they manage this task. It may be a sensitive topic but you need to establish the specifics of how they complete this and what impact their symptoms have on their ability to carry this out.

Activity 6: Dressing and undressing

Some individuals with PoTS may require aids or help with dressing and undressing due to extreme fatigue and dizziness on minimal exertion.

Many people with PoTS find dressing exhausting. They often have to dress on the floor, experience exacerbations during this time and have to factor in recovery times.

Remember in PIP…

Sitting down is considered acceptable within the scope of the activity. Does this reduce their fatigue/dizziness? How long does this activity take? How do they feel after? Can they dress their upper and lower body? Do they have aids or require assistance?

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Safety is not outlined as a direct concern for this activity within PIP.

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Activity 7: Communicating Verbally

When patients are symptomatic with altered blood flow to the brain, they experience cognitive dysfunction. This can last a number of hours after an episode of fainting or near fainting and can impact patient's ability to understand or communicate.

Please consider any co-existing conditions that may impact their ability to communicate.

Remember in PIP…

The scope of the activity is the ability to express and understand verbal information. They must be able to do both. Can they speak on the phone? Can they express what they want to say?

Activity 8: Reading and understanding signs and symbols

When patients are symptomatic with altered blood flow to the brain, they experience cognitive dysfunction. This can significantly impact upon their ability to read or understand signs and symbols and may last a number of hours after an exacerbation.

Please consider any co-existing conditions that may impact their ability to read.

Remember in PIP…

A person needs to be able to read and understand what they have read. Complex written information is considered anything more than one sentence. What do they read? Can they read a text message?

Activity 9: Engaging with others face to face

Due to the restrictions many face with PoTS it can cause social anxiety. Individuals can feel traumatised by having others known and unknown to them witnessing them faint/blackout, or even by the possibility that this may happen. Many individuals experience a level of discrimination day to day which can impact their how they form relationships with others.

Remember in PIP…

If someone reports their PoTS has impacted their mental health, does that impact their ability to engage? Who are they engaging with regularly? How do they engage with unfamiliar people? Do they experience anxiety? If so, how do they overcome this? Do they require specific support?

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Activity 10: Budgeting

Consider any impact of memory, cognition and concentration in those who report brain fog.

Remember in PIP…

Can they manage their own finances? Can they do online banking or shopping? Could they understand change in a shop? If they have associated mental health conditions, does this impact their motivation to budget?

Activity 11: Planning and following a journey

Planning journeys may be difficult due to cognitive dysfunction.

Fainting/blackouts are common. Depending on frequency of faints/blackouts and severity of symptoms, some people may be unable to travel without support and will have difficulty getting about independently on all journeys due to exacerbation of symptoms and risks of being out in public/open spaces and having blackouts/fainting.

Remember in PIP…

*Safety will supersede majority of days. If they are having regular blackouts/faints, have they acquired injuries when out of the home? Do they lose consciousness or awareness which may make them vulnerable when following journeys? **REMEMBER:** Even if someone has a warning prior to a blackout/faint, it would appear clinically unlikely that this would be long enough for them to be able to get home from both a familiar or unfamiliar journey*. .

Activity 12: Moving Around

Some patients are able to walk but as soon as they stop walking the muscle activity that helps to support their blood pressure stops and they can faint or experience severe dizziness and other PoTS symptoms.

Consider any reported physical restrictions such as fatigue, breathlessness or dizziness. Ask about their pace of walk, if they use a walking aid and if their gait has been impacted.

Remember in PIP…

Individuals may struggle to provide specific information. Try to use examples to help or things in their area they might be able to refer to. You must explore whether any journey discussed is repeatable, where possible how long it takes them, how they feel whilst doing it, and any incidents of note such as falls in the past 12 months?

Please remember STAR in each activity and explore HOW they complete the task in depth and if compensation strategies are used. Exploring the extent of symptoms during an activity and how they are impacted after will help you to consider if whether they are completing activities reliably.

Experiences from Individuals with PoTS

“That it's not about being able to do the task, it's the consequences that make life unbearable.”

“Cooking, showering, a gentle walk or eating a meal are exhausting and require bed rest afterwards.”

“Queuing in a supermarket makes me so dizzy and muddled, I can’t work out how much to pay, forget my PIN, and often leave my credit card behind!”

“Everything we do means we will pay for it later. Whilst we could push ourselves, we couldn’t do the same reliably every day.”

“I have trouble with words, can't concentrate on even simple things. I just need to sleep”

“With brain fog I can’t answer questions in meaningful way”

“We may be able to manage a physical task such as prepare food or stand in queues, but it comes at such a huge cost. Whether that's a nap, a syncope episode or feeling horrifically unwell.”

“A single “faint” isn’t over once you regain consciousness. It certainly writes off the rest of the day if not the next few days.”

“My daughter with POTS cannot be trusted in the kitchen - she drops, burns and spills everything. Her brain fog means she will leave hob and oven.”

“PoTS massively affects my stamina, guts, sleep & waking, memory & word recall, concentration and so much sweating”

“I am 25 years old and cannot go out anywhere on my own due to the risk of fainting without warning and having serious injury”

Additional reading or other resources

EXTERNAL

PoTS UK website - the national charity that supports patients with PoTS and provides educational resources for healthcare professionals

What is PoTS Video – YouTube

A profile of patients with postural tachycardia syndrome and their experience of healthcare in the UK- The British Journal of Cardiology

Cognitive and Psychological Issues in Postural Tachycardia Syndrome – National Library of Medicine

PoTS NHS

Version	Date	Signed off by	Comments
1.0	14/02/2024	Jade Mayfield and PoTs UK	New document