

Postural Tachycardia Syndrome



2023
Impact Report

Postural Tachycardia Syndrome (PoTS) can be a life altering and debilitating health condition.

Symptoms include:

- Dizziness or pre-syncope (almost fainting)
- Palpitations
- Fatigue
- Headaches/migraine
- Brain fog
- Sense of anxiety
- Syncope (fainting)
- Shakiness
- Visual problems
- Gut problems (including nausea, diarrhoea, pain)
- Sweating
- Chest pain
- Poor sleep
- Purplish discolouration of skin due to blood pooling in hands and feet
- Bladder problems



It is estimated that **0.2%** of the population were affected by PoTS pre covid.

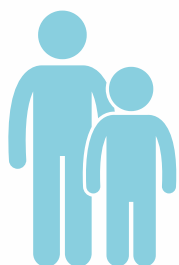


PoTS mainly affects people between the ages of 18-49

92% are female but children and men are affected too.



25% of people with PoTS are wheelchair users.



37% are unable to attend work and **50%** of children with PoTS are unable to attend school regularly.



50% of people with PoTS are told their physical symptoms are all in their head!

Stories about PoTS

“PoTS is something that I have learned to live with, but to be honest I am still learning how to accept it gracefully.”



Lesley

I have recently been diagnosed with PoTS after being misdiagnosed for over 20 years!

I don't think I knew what 'well' or 'normal' felt like. I've lived on a scale of extremely tired, to cripplingly exhausted.

Conor

At the age of 17 my life changed forever after a simple fainting spell!

I think it's extremely important to share my story as a man with PoTS, as it can be overlooked as a 'woman only illness', as I was once told by an incompetent doctor.



Emily

I fell pregnant at the age of 31 and I had severe morning sickness which caused my PoTS symptoms to go completely haywire.

My baby is one now, and though I absolutely adore her, it is tough! Not eating and sleeping properly plays havoc with my symptoms and it's been very different to how we thought things would be.

You can read these stories in full [here](#).

Our year in numbers....



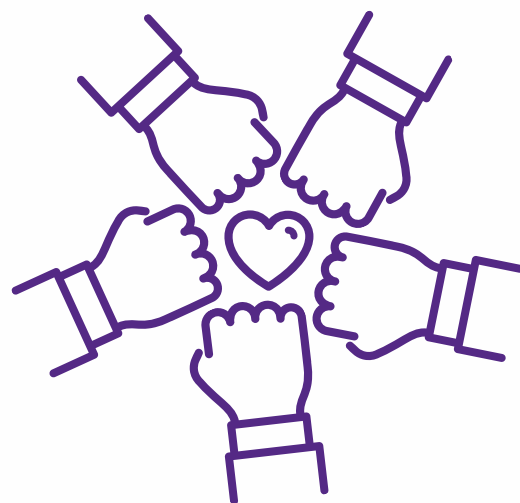
We held

123

Online Peer Support Groups and over

1500

registered to attend.



Our team of

6

specialist nurses responded to hundreds of emails throughout the year, providing you with invaluable support and advice.



We recruited new Peer Support Volunteers bringing our total number of volunteers to

40



We list **39** NHS doctors and nurses with an interest in PoTS and who are supportive of PoTS UK on our website.



Our Chair and Trustees volunteered over

2000

hours of their own time delivering training to GPs, universities, community and hospital staff, attending meetings and events, assisting with research....the list goes on!



Our YouTube channel had
31,558
views last year and
337
new subscribers.



Our
Awareness
Day posts
made
266K
impressions
on X.

80+

buildings 'Lit Up In
Purple" on 25th October for our
PoTS Awareness Day, thanks to our
amazing volunteers and your support
to make this happen.



700

new people
signed up for
our newsletter,
bringing the
total
subscribers to

6384



Our social media

Our social media channels help us raise awareness of PoTS.
You can help by following us, liking and sharing our posts.



Facebook
19,269
followers



Instagram
6,704
followers



X (Twitter)
7113
followers



LinkedIn
741
followers

Your donations and fundraising...



Throughout 2023 your generous support raised an amazing

£65,540.93



You took part in

35

fundraising events
which raised a sensational

£31,434.39



Your overwhelming generosity
meant that we received donations
amounting to

£24,821.11

You bought PoTS merchandise
to the value of

£9,279.43



The funds you raise for PoTS UK enable us to continue the work that we do for PoTS patients.....



Website development and maintenance.

Research projects.



Ongoing training for our Online Peer Support Groups.



Producing our PoTS booklet for hospital clinics and our range of PoTS leaflets.



Expenses for our volunteers (travel, etc).

Developing UK PoTS guidelines.



Lobbying to improve patient services.



Educational events for healthcare professionals.

This year your fundraising and donations have enabled us to.....



Take on an extra part time member of staff, Nikki, who supports Jo and Denise with the ever increasing workload.

Provide online training for staff and trustees to ensure they are update with the latest legislation, policies and procedures.



Provide training and support for our specialist nurses to ensure that they are providing you with updated accurate advice.

Finally, you have supported us (and each other) in many other ways.....



You have commented on, liked and shared our social media posts and supported others in need of advice and support.

You have completed numerous surveys that enable us to adapt and develop the services we are offering to support you.



You have provided invaluable feedback about our Peer Support Groups, ensuring that our volunteers meet your needs.

You actively took part during Awareness Month, contacting buildings to 'Light Up', posting daily during our #31ways campaign, taking part in our yoga challenge and raising awareness whenever you could.





Without your amazing fundraising, donations and ongoing support we would simply not be able to continue the work that we do for PoTS patients.

We look forward to continuing our journey with you throughout 2024 and beyond.

Thank you!