

Trying to survive DofE with PoTS

Postural tachycardia syndrome is an abnormal increase in heart rate that occurs after sitting up or standing due to an abnormality of the functioning of the autonomic (involuntary) nervous system. Some typical symptoms include dizziness and fainting. Many people who have PoTS will experience different symptoms and be affected in different levels of severity (which can cause various levels of disability).

- **Postural** position of the body
- **Tachycardia** increased heart rate
- **Syndrome** a combination of symptoms

I was diagnosed with PoTS in 2012 and have previously completed my Bronze and Silver DofE awards whilst I was at school and had difficulty achieving them. This was due to not being well enough to keep up with a 'normal' group as I didn't have the stamina and energy levels, I didn't have enough rest breaks which meant that I had to drop out due to frequent fainting and carrying a heavy rucksack increased the severity of my symptoms. However, after my experience of these previous expeditions, and also having my PoTS symptoms under more control, I still wanted to continue on with the Gold award as it would be a huge personal achievement for me.

"The Duke of Edinburgh's Award is achievable by any young person who chooses to take up its challenge, regardless of ability, gender, background or location" - DofE

Some handy tips based on my expeditions:

The 20 Conditions for the Expedition section and advice for supporting participants who have additional needs	
DofE qualifying expedition conditions	Guidance on applying the 20 Conditions for participants with additional needs
1 The team must plan and organise the expedition; all members of the team should be able to describe the role they have agreed to plan.	For participants with additional needs they may need prompts or support from staff or buddies to plan and organise the expedition. The aim creates an opportunity for young people to take ownership of the expedition, shaping its purpose to their personal interests and strengths.
2 The expedition must have an aim. This aim can be set by the Leader at Bronze level only.	
3 All participants must be within the qualifying age of the programme level and at the same Award level (i.e. not have completed the same or higher level of expedition).	
4 There must be between two and seven participants in a team (eight for modes of travel which have landed).	
5 The expedition should take place in the recommended environment. Bronze: Expeditions should be in temperate, open countryside near – or border to – a large town or city. Silver: Expeditions should be in temperate, open countryside near – or border to – a large town or city. Gold: Expeditions should be in wild country (where the team is not in a town or city) which is accessible to groups.	Environments at all levels have numerous tracks, bridleways, footpaths and shared railway lines that can be used, many are gradient free. At Gold level, all participants should aim for their expedition to take place in wild country. If this is not possible then open country is acceptable, given that it complies with the Current Organisation and DofE Region/Country Office. It is possible for DofE participants with additional needs who need help with personal care including using toilet-assisted toilets, and support with all daily routines to successfully complete their expedition. Participants going on an expedition who require personal care such as washing, bathing, shaving, dressing or undressing will need to have arrangements in place for their care. DofE centres should consider arrangements with a support staff to assist with daily tasks if needed, including overnight stays. Link sleeping arrangements for certain medical conditions, suitable beds, and suitable vehicles may present particular challenges.
6 Accommodation must be by camping or other simple self-catering accommodation (e.g. camping huts or barnhouses).	
7 The expedition must be of the correct duration and meet the minimum hours of planned activity. Bronze: A minimum of 2 days, 1 night, 8 hours planned activity each day. Silver: A minimum of 3 days, 2 nights, 12 hours planned activity each day. Gold: A minimum of 4 days, 3 nights, 16 hours planned activity each day.	At least half of the planned activity each day should be spent journeying, but this does include rest breaks, and could form an expedition of an expedition that is traditional in type.
8 All expeditions must be supervised by an adult (the Expedition Supervisor) who is able to accept responsibility for the safety of the team.	Teams are not usually accompanied by adults but they must always be supervised by an appropriately experienced individual.
9 Assessment must be by an accredited Assessor. At Bronze level only, the Assessor may also be the Expedition Supervisor.	The Assessor must be notified if the team includes participants who have additional needs and must be aware of any approved variations before the expedition takes place.
10 Expeditions will usually take place between the end of March and the end of October. They may take place outside this period if a non-camping accommodation option should be considered.	Plan the expedition for a time of year which will best suit the team and give them the best chance of success and enjoyment. This can be particularly important for participants with medical conditions which can be exacerbated by the weather.

1. Reduced Mobility Group Expeditions

I would highly recommend looking into completing your expedition with a reduced mobility group if you have a condition like PoTS as it will be more accommodating for your needs. To complete the awards you have to meet the 20 conditions both for a 'normal' group and a reduced mobility group. However, DofE have put in some adaptations of these 20 conditions to support anyone with additional needs such as reducing the weight of your bag and the distance you walk whilst it still being a challenge for you.

2. Consider the time of year and area for your expeditions

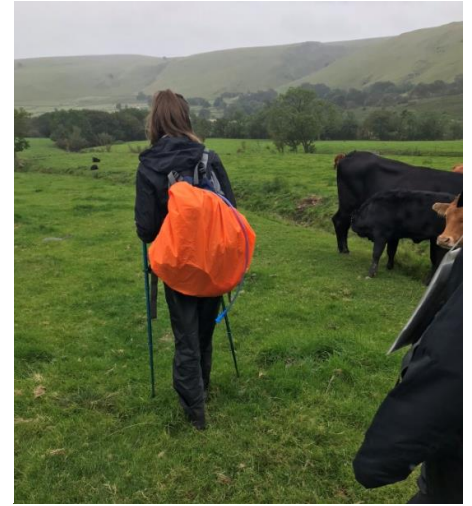
Pick the time of year when it is unlikely to be very hot or very cold as extreme temperatures may affect your PoTS. Spring and Autumn I have found are ideal, but you may not have much choice on this. Pack things that you find helpful for extreme weather conditions if there is uncertainty in the forecast. Location is key to research as well. My expedition location was chosen for me based on my group's abilities. Due to the nature of our conditions our supervisors needed to get access to us quickly if required. Terrain is something to consider as well depending on your ability. My team planned our route so we did a steep incline up the hill at the beginning of the day when we had a little more energy and then walked across the plateaus on the top and then walked down the hill at the end of the day.

3. Stay overnight nearby your expedition location if travelling wears you out

Long journeys can be difficult for PoTSies and you want to be as rested as possible before your expedition. I chose to book a B&B for the night before on both my expeditions as they were a 4 and 6 hour drive away from home. This meant I could recover from the journey and have a goodnight's sleep and wake up refreshed with lots of energy.

4. Rucksacks

On a normal expedition you are expected to carry a 75L rucksack and divide up the group equipment so that you are self-sufficient. However, this can be altered so that you can carry a reduced load in a smaller rucksack – as let's be honest your heart races manically standing upright before putting a loaded rucksack on. I carried a 45L rucksack and only had my food for lunch and snacks, 2L of water and a spare pair of clothes in case I needed them and waterproofs. The rest of my share of the group equipment and personal items were left in my supervisors van and dropped off in the evening at each campsite. This will depend on your level of ability so chat to your supervisor and explain your challenges and how your condition affects you so they can fill in a variants form.



5. Walking boots with ankle cuffs

These boots have seen me through all my expeditions and being hypermobile it meant my ankles were supported better for walking over uneven ground. I also purchased gel insoles that made it more cushioned for me to walk and supporting the arches of my feet. There are so many different types and styles so you just need to find one you find most comfortable to walk in as there's nothing worse than wearing shoes that cause you more pain or are quite heavy and tires you more. They can be pricey but it's worth investing in. You can also lace the boots in different ways to make you feel more comfortable/supported.

6. Clothing – layers, compression and breathable socks

I chose to take a variety of layered clothing for my practice expedition so I could work out what to take for my qualifier. I took a few tops that are sweat wicking tops that are breathable as I can sweat quite a lot. Isocool walking socks came in handy to regulate my temperature as they're also breathable (I took a fresh pair for each day). Check with your doctor if they are suitable for you, but wearing compression leggings/tights/socks or sometimes known as 'skins' have been reported to have some benefit to pots patients (hasn't been proven) and may be some items of clothing to consider, as compression clothes on lower limbs causes an increased blood return to the heart from the legs. I took compression sports leggings as well as walking trousers and various thicknesses of jumpers and fleeces all with zips so I could easily put them on and take them off whilst walking. Overheating became an issue for me so I had to wear thin trousers under my waterproof trousers when it was raining. Your supervisor should give you a kit list so go out for short walks in various different layers to see what works best for you, but your practice expedition will give you a good opportunity to see what works best!

7. Hand warmers

I didn't take these on my expedition but I wish I had! They're perfect as they are lightweight and can be reset in a pan of boiling water. They are helpful if you are struggling to regulate your temperature or you are in pain. Just simply click the metal disk in the pouch and it will instantly heat up. They are very lightweight and can be easily slipped into a pocket.



8. Rest breaks

Rest breaks are crucial for any DofE expedition, even more so if you have medical condition. Again, talk to your supervisor before your expedition so they can gauge how much walking and aim work you are able to do (for a reduced mobility group its roughly 4 hours walking and 4 hours aim work). Be realistic during your planning stages and pace yourself properly. Your practice expedition is there for you to do just that and find what works for you so that when it comes to your qualifier you can remind yourself that it is achievable and everything is in place to help you!

9. Snacks

Snacking and grazing is crucial for any expedition, PoTS or not. Snacks such as peanuts and plantain chips will help increase your sodium levels (if your Doctor recommends it) and other snacks I took included mixed nuts and dried fruits, flapjack and some sweets. Others in my team took Kendal mint cake, malt loaf, sesame snaps and various muesli bars. Eating little and often between meals will help to keep you energy levels up. I separated them into a bag for each day to make sure I had enough. I also had to increase the amount of snacks I had for the final expedition as I didn't know how much I'd needed to consume whilst on the practise.



10. Hydration – Platypus

As you may be aware staying hydrated can help PoTS symptoms. It's recommended by PoTSUK to have between 2-3L a day for an adult. As you are walking and exercising and most likely sweating you may need to increase this. I found it really useful having a Platypus as it meant that I could constantly sip during the day. Members in my team struggled to keep hydrated as their water bottles were in their bags or they forgot about them. I just simply popped mine in the pouch inside my rucksack (make sure the cap is screwed on tight!) and clipped the giant straw to the rucksack strap so I had access to water at all times. (Also makes a great hand wash station/mini shower if you collapse and get plastered in mud!!)



11. Hydration – Isotonic drinks/tablets

Following on from the previous tip, I also took an empty refillable water bottle so that I could use isotonic tablets. As I can sweat a lot and also doing all that walking on top of that, the isotonic tablets made sure my electrolytes were being maintained. They can be purchased from various different shops and come in a variety of flavours. Alternatives are ready made drinks however they will be heavy to carry. However, you can leave Isotonic sports drinks with your supervisor if you wish to take them with you.

12. Handy pockets (aka snack pockets)

I had a rucksack that had handy pockets on the waist straps. In here I kept my snacks and my medication. This was really useful as I had easy access to them which meant I could graze throughout the day and also have my meds without unpacking my bag every time. Make sure you remember to put your medicine in a waterproof bag to keep them protected from the elements. Also handy for alarms and medical devices you use on a daily basis or if you use medical apps on your phone as long as you declare this to your supervisor and assessor before the start of your expedition.





13. Sports tape, splints, braces and walking poles

On a regular basis I see an osteopath to help relieve my aches and pains in my joints. I went to see him the day before I travelled to my expeditions so I was in the least amount of pain before I started walking and we decided to put sports tape on the areas I tend to experience my pain the most. Obviously this isn't for everyone but it's something I found to be helpful to my overall DofE experience. Also Ehlers-Danlos and hypermobility sufferers will benefit from braces and splints to support their joints over unpredictable, steep and rocky terrains. Anything you use on a daily basis to support your joints will be allowed on expedition. You may find walking poles to be useful for stability but be careful they don't increase your energy consumption too much. I used collapsible poles as when I needed a break from using them, I folded them down and they fitted into my rucksack.

14. Once you've completed your expedition...

CELEBRATE!!!! The achievement of completing any of the Duke of Edinburgh awards is amazing, but to complete it with additional needs is incredible. You may be very exhausted and drained (it took me a week to completely recover and rest) but when you look back on it you'll have many memories, possibly new friends, and an award to show how much effort and energy you put in whilst not letting your illness beat you! We arranged to have a pub meal with our families afterwards to celebrate and to re-energize for the journey home. What made my expedition even more special was to complete it with my sister and to see each other overcome our health conditions.



15. The journey home

As you will have just spent many days in an exhausting environment, nothing beats getting changed into clean and comfy clothes. Pack a bag for your family to bring with them when they collect you with things like your favourite snacks and anything else you think you might want at the end of your expedition such as your favourite snacks and a pillow. Remember if you have a long journey home to pace yourself as you will more than likely be at your most fragile state by this point. It's key to stop off at service stations for a 'walk and wee' break. Walking is probably the last thing you'd want to do after an expedition (I got some very strange looks as I seized up quite considerably) but it is vital you stretch and move about every so often to try and minimise being in one position for too long. Do whatever you need to to make yourself comfortable!



Obviously, this is my personal experience of completing the Gold award and these tips are what I have found and improved on from all 3 of my awards. They may not all be useful to everyone but it's all about trial and error on your practice expedition to find out what works for you.

Arrange an appointment to see your doctor or specialist to have a chat about the challenges you may find on DofE and see what ideas they can come up to help you and if it is suitable for you to achieve. Once you have done this, talk to your DofE supervisors about your conditions and what support you will need to achieve your expeditions. Look on the DofE website as well to find out about all the different types of expeditions (e.g. walking/canoeing/horseback), locations and providers. Out of all the tips, I would highly recommend joining a reduced mobility group if you can!

Good luck and congratulations on taking on a massive challenge!