

## **Postural Orthostatic Tachycardia Syndrome and Heat Intolerance**

Heat intolerance and accompanying symptoms such as facial flushing can be often overlooked amongst the severity of other issues that accompany POTs. But for those that suffer with severe heat intolerance, it can prove to be a debilitating and life limiting symptom, affecting the places a POTsy may go, and the things they might do on a daily basis.

Simply looking at other sufferers experiences can highlight the ways in which some people with POTs are affected and also offer suggestions on how to avoid the severity of heat symptoms.

### **Tara and Heat Intolerance**

From the very first moment that any of my POTs symptoms began, my heat intolerance and facial flushing/burning was the most obvious and restricting problem. Although my erratic and consistently high heart rate soon appeared from nowhere-temporarily distracting me from my issues with heat, I realised I was unable to cope without the constant use of fans.

In the middle of winter I am more comfortable outside in the cold than anywhere else. A common problem I have found during winter is trying to cope with the severe temperature change from being outside in the cold to going indoors into a house or shop with heating or open fires. This dramatic change in temperature creates the sensation of walking into a brick wall made of fire, instantly triggering many of my other autonomic symptoms such as dizziness and tachycardia.

It may be below freezing outside, but I guarantee I will be sleeping with the cool air of a fan blowing on me throughout the night. And during the summer months or warmer spells of the year, things go from worse to unbearable. It is difficult to explain the frustration of not only becoming 100% housebound, struggling to get through every minute of the day, but to know and hear about everyone out enjoying the 'good' weather that I once found so appealing.

No matter the time of year or destination, I will always be dressed for summer. I may look odd to some people as I walk along in flip flops in November, but when I walk into a shop or hospital for an appointment, I never regret my clothing decisions. Whilst I can abandon shopping trips or going out for meals in hot restaurants, there are some essential places that I must face. Hospital trips will always remain an ordeal for me, but I resort to sitting outside until my specialist is ready to see me, or insisting on having a fan provided for me in the waiting room. Initially I felt like a drama queen, embarrassed to make demands to hospital staff. But once they see the reality of severe heat intolerance, finding a fan for a patient becomes the much easier and logical option.

Showering has also been a major challenge that many other POTsies face. For me, it is the place I am most likely to faint or suffer from extremely dizzy episodes which has left me more cautious and careful on a daily basis. Sitting down, making sure the water is cooler and taking cool gel packs in with me can ease my symptoms.

The restriction of not being able to go anywhere at all without having to consider temperature issues and problems that may arise has a huge impact on myself and my family and friends. My world became a much smaller place, with typical places and activities such as cooking or going to the local shop becoming an impossibility.

However, there are some tips, tricks and products which can be helpful for those who suffer with severe heat intolerance:

**Icepacks-** I always carry icepacks either in my handbag for short spells out, or in a cooling bag that helps to retain their temperature for longer journeys. I find they are most helpful when pressed on pressure points such as my wrists, but always wrap them before using them directly against the skin to prevent ice burns.

**Cooling eye masks, wrist and neck ties, hats and vests-** These items can usually be found online by companies specialising in cooling clothing. Some work by being immersed in cold water and retaining a cooler temperature. Others such as cooling vests can work by placing icepacks in pockets to keep the clothing colder.

**Chillow pillows-** They work by absorbing water and maintaining a cooling sensation without the need for refrigeration. They are allergy free and great for aches, pains and migraines as well as heat intolerance and flushing. Perfect for travelling too.

**Air conditioning and fans-** This may sound obvious but fitted air conditioning (although expensive) can make life so much more bearable, especially during the summer months.

**Cooling sprays-** Particularly helpful if you don't sweat, sprays such as magicool replace moisture on the skin. Many stay cold in their cans without needing to be placed in the fridge, making them extra helpful when taking them during a warm day out.

**Planning and honesty-** Do not be embarrassed about ringing ahead or telling people that you cannot cope with warmer temperatures and asking for fans. Some places can be very accommodating and helpful. Even those places that aren't, knowing in advance can help you to plan what you may be able to take with you to make things more bearable.

## Liam and Heat Intolerance

Heat is a massive issue for me and really does make symptoms ten times worse. Avoiding it has become one of the most difficult things I face with my POTS.

The obvious one is summer, it's not just the heat of the sun that's an issue, but also the humidity. This makes breathing and fatigue much harder to deal with, and usually during the hottest weeks of the summer, humidity can last for days. The sun itself can generally be avoided provided I'm willing to sit it out indoors. It's not fun, and gets incredibly frustrating, but I am learning to hide away during the day, and then, providing it's not too humid, I will go for a walk at sunset when the heat of the sun is at its weakest. In the summer this is quite late, so during the day I tend to use a recumbent cycle to keep exercising even though I can't go out. I also make the most of cooler overcast days.

The winter has its own issues; in a word - heating. I love the cold, don't get me wrong, I certainly don't like being cold, but at least in the winter I can dress for the conditions. Well, that is until you want to go shopping. Heating is a complete pain. Shops, hospitals, homes, the list goes on. We have a log burning stove at home, so most of the winter I don't even enter our lounge as it quite simply becomes impossible to handle and I get ill very quickly.

If I go to hospital, I dress accordingly, preparing myself for a warm environment. Don't be afraid to mention you have a heat intolerance when you book in for your appointment at reception. I always do, and so far I have generally been shown to a side-room where I have been able to open a window, and in some cases, have also been supplied with a fan.

General shops are a lot more difficult to deal with, so I either shop online, or if I do enter a shop, then I keep mobile. In most cases this results in me looking at an item, getting dizzy, putting the item down, walking to the other side of the shop, and then returning to continue looking at the same item again. Walking, for me, really helps to pump the blood back up. On occasions when it gets too hot, then don't be afraid to lie down, just try to find a suitable place so that you don't get run over by passing trolleys.

Other shops such as opticians and dental appointments can work in the same way as the hospital. In my last optician appointment, I stressed to them about my heat intolerance, and now they always supply me with an air-con blower and turn all the heaters off in store!

You really shouldn't be afraid to ask. I would say that most of the time I have found people go out of their way to accommodate you. It's easy to try and be strong and carry on, but with an illness that is relatively invisible, the only way others are going to know that we are struggling with a situation is if we go out of our way to let them know. There might not be anything they can do to help, but if you don't ask, you'll never know.

Car travel. You'd think sticking the air-con on in the car would make car travel a year round possibility, unfortunately I can't bear the heat of the sun through the window on me. Even with the air-con on in the summer, or if it's -2 degrees in the winter; if the sun is shining through the window then it soon becomes like a greenhouse effect. I avoid car travel on really sunny days, but providing you're not driving, then you can always sit in the shaded side in the back of the car, or use the sun blinds that stick on the window.

Heat isn't just sun related though. It's surprising how many of our daily activities involve heat of some kind. Cooking is a strange one for me. Pre POTS I balanced my studying with a job as a chef in a local country pub - in the summer the thermometer would reach over 40 degrees C, running around, gas stoves, grills - I genuinely feel ill just thinking about it!

Cooking is another of those things that I really miss. I try my best to avoid the kitchen when the Sunday roast is on, or if a big meal is on the go and every ring on the hob is being used. Sadly there is no get around, as heat is ultimately needed to make the food hot! But I love cooking so much that I try to be a part of it as much as I can.

Baking is a great workaround, especially if you can find recipes where all of the mixing and making is done before the oven is switched on. I am fortunate enough to still live at home and have someone around to put the cake in and out of the oven. Decorating of a cake can be done once the kitchen has cooled down again.

Main meals. I find an electric oven and hob is much better than a gas stove, as you don't get the heat off of it in quite the same intensity. If I'm frying an omelette or pancakes or making a pasta dish etc, then I can just about put up with the heat from a couple of rings. I have a chair nearby and sit regularly throughout. Using lids on frying pans and saucepans is also a great way to minimise the heat levels. Veg can be prepared sitting at a table, long before any ovens or rings are turned on, and I also take everything I need to the table to save me keep going back and forth to the fridge. But oven use is certainly something I get someone else to handle, but I have the luxury of having someone available to help out.

Washing is another major factor - no one likes a cold shower! I have mobility aids to help me with these tasks, more for the fact that they offer me a safer environment and the dignity of being able to wash and shower without needing someone to help out or watch over me in case I become ill.

The most important one of these is my bath seat. It's a simple thing that just sits across the bath and I can then shower while sitting down. I hand-hold the shower-head so that it isn't constantly spraying down on my head. Once I've finished, I raise my knees up and down by going up on tip toes while sitting down, this tightens the muscles in the legs and pumps the blood back up; after 30 of those my feet have much less blood pooling. I then stand and dry as normal.

A perching stool is another great aid, allowing me to sit in front of the sink while having a shave, after all, becoming dizzy with a razor in my hand is not the best thing.

I am looking into air conditioning to help out with the heat, as last summer was unbearable. Other than that I use desk fans, which run all year round! Even in the winter I sleep with a summer-weight duvet, window open and fan blowing on me.

Going on holiday is a difficult task already, what with remembering medications etc. but I also have a car packed with desk fan, summer-weight duvet (you never know what weight they'll use in the holiday cottage/hotel) and also a folding plastic stool, which is a good substitute for my bath seat and perching stool as it is small enough to fit in a shower cubical, bath (to use the overhead shower) or in front of the sink to have a shave.