

Who are UK POTSIES ?

UK POTSIES are a team of people with POTs in the UK. It is only in recent years that this rare and debilitating condition is getting the much needed attention it deserves. The people who have dealt with autonomic dysfunction in the past have often suffered in silence, with no means to get the symptoms correctly diagnosed, and it is only now through support groups and ongoing research (which many of the UK POTSIES are a part of) that new knowledge will be gained to educate and help sufferers of POTs.

Our motto is- Life can still blossom
albeit in a different way.



A series of information pamphlets brought to you
by POTs patients for POTs patients-

Some of the information in this pamphlet may
help you and your care team to make your stay in
hospital as comfortable as
possible.

Information Brochures For POTs

POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME

The information in this leaflet cannot in any way
substitute for the care and advice of your
physician.

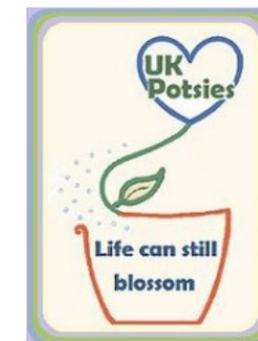
www.ukpotsies.org

HOSPITAL ADMISSION

ADVICE FOR POTs PATIENTS

When Admitted to Hospital

POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME



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HOSPITAL STAYS

Hospital Stays -Hospital stays can be difficult for POTs patients. Whether it is a planned operation, procedure, or an emergency hospital dash to A&E, it can often be difficult to ensure there isn't a worsening of symptoms.

What can be done?

Avoiding dehydration during both planned and emergency visits is extremely important for POTs patients. Retaining fluid in the body can often prevent a drop in blood pressure which is common with the condition. This may lead to less unnecessary dizziness or fainting. Levels of dehydration can be assessed via blood tests or, more simply, the skin, eyes, mouth (tongue) and capillaries refill times can be checked for obvious signs of dehydration. For intravenous (IV) fluid administration, Hartmann's Solution could be more beneficial than saline alone due to its full electrolyte balance.

Avoiding any medications which may cause tachycardia is important. This cannot always be avoided, but it is vital to thoroughly check anything which may not be essential for possible side effects. POTs patients may be more sensitive to the effects of medications and this could sometimes result in more unexpected reactions.

Maintaining a preferable temperature for a POTs patient can often lead to far less symptoms. A common complaint of POTS patients is an intolerance to heat. This can be problematic in a warm hospital as heat dilates blood vessels allowing more blood to pool in the patient's limbs rather than flowing to the heart and brain.

Providing a fan for someone with POTs is often helpful in managing their symptoms and can provide some relief during their stay.

Having heart rate and blood pressure monitored during a hospital stay can prove helpful. Although this is automatically done during an operation, it is important that POTs patients be monitored after any hospital procedure that may involve a general or local anesthetic.

Ehlers Danlos Syndrome is a common condition related with POTs and can sometimes make patients more resistant to sedatives and anesthetics.

It is essential to remember that avoiding fluids as part of fasting before operations or tests can lead to further dehydration, which must be dealt with by providing extra IV fluids and/or adequate oral fluid intake.

Oxygen levels are also routinely monitored before, during and after a procedure to make sure that there are no serious issues which need to be addressed.

Looking through any information on POTs that has been provided by a specialist can help doctors and nurses to understand what the best course of action might be in certain circumstances.

Having contact information for a patient's specialist can help local hospitals to get any relevant details that they may need. Those who suffer with POTs should be very proactive and responsible when it comes to carrying medical cards, lists of medicines and contact numbers.

POTs patients should be inclined to carry or bring any relevant details that are specific to their own condition-such as whether they suffer from seizures or have any other medical issues. This will make it easier for medical staff to work as fast and as efficiently as they can.

Giving blood or having blood taken can be difficult as it can lower blood volume if it is in relatively larger amounts. In line with standard procedures, it is especially important that if blood is taken, it is done so whilst lying down to avoid any repercussions from dizziness or fainting that may occur.

Fatigue and stress should be avoided whenever possible. Emergency hospital trips or inpatient stays for procedures can provoke anxiety. Because of the autonomic nervous system dysfunction that can occur, POTs patients could have a reduced ability to deal with stress. Keeping calm and relaxed as possible can help to prevent additional tachycardia or orthostatic intolerance.

For more help or information, speak to your doctors and specialists for medical support and advice. Please be aware that any advice provided here should not replace the knowledge or help of your medical professional, and should merely act as a possible reminder of some things which may help. For more information on POTS and further publications visit www.ukpotsies.org.