



Tips for Parents of People with PoTS

These tips were devised for parents by parents of children/people with PoTS. They are intended to complement the usual health and lifestyle advice for the management of PoTS

- ♥ **Resist talking about PoTS all the time to your child.** As parents we pretty much spend our whole time thinking about it all, so this is not easy to do. Instead, try setting a regular time in the week to discuss it. Give them time to adjust to and gradually accept their diagnosis.
- ♥ **Maintaining a child's friendships is important.** Think about doing things differently e.g. having friends round instead of going out, dinner party at home, use taxis, craft afternoons, and social media can be a blessing.
- ♥ **Staying in the education system.** Get the school involved as early as possible. Never stop pushing the system, ensure a balance of study and rest. There is advice here www.specialneedsjungle.com
- ♥ **Taking time out of the education system.** Having to take time out of school/college/university is sometimes necessary and both you and your child can feel like failures. You are not; sometimes opting out is the best option and the bravest thing to do.
- ♥ **Believe your child,** you cannot experience their symptoms but you can see how they respond. Sometimes parents worry that children will over rely on the 'I'm so tired/poorly I can't do that now'. You will learn this is not the case as they crave having more energy.
- ♥ **Maintain your child's independence** as much as possible. It is so easy to want to wrap them up in cotton wool to protect them. They will be missing out on so much anyway, don't deprive them of even more.
- ♥ **Relaxation & sleep.** Your child will often want to rest or nap, don't underestimate the power of a nap. Rest time is often so important though can be difficult to build into family life. However, too much daytime napping can affect sleep at night.



- ♥ **Exercise is so important**, even if it is just a short walk. The challenge is often getting your child to do it as they may feel unwell in the short term, but do persevere as it can help symptoms in the long-term .
- ♥ **Encourage** your child to try new things, hobbies and interests they may never have done had they not developed PoTS.
- ♥ **Depression is very common** in people with long term conditions , do not underestimate the impact having PoTS can have on a young person's life. It can take many years for them to come to terms with it all.
- ♥ **Coordinating care** becomes a major role for parents,. You are in the centre of it all, keep records and take copies of letters/results to consultations.
- ♥ **Encourage** your child to take ownership of their illness. They are more likely to feel well if they feel in control of their own health

problems and have a say in what is happening to them.

- ♥ **Look after yourself too.** Along with the usual healthy lifestyle advice do remember take time out to keep yourself well. Speaking to friends or professionals, or finding something positive to do can help you to feel in control.

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Details regarding the sources of evidence used in the production of this leaflet are available on the PoTS website. See www.potsuk.org/sources_of_evidence