



Postural Orthostatic Tachycardia Syndrome and Relationships

Postural Orthostatic Tachycardia Syndrome (P.O.T.S) affects both partners in the relationship and even more so when living together or married where the pressures of daily life, housework and childcare are added into the relationship. As the symptoms of P.O.T.S. are very wide ranging and can alter from day to day and even hour to hour it can make life challenging for both partners. This leaflet hopes to bring more understanding between POTSies and their partners and provide some suggestions for coping mechanisms for a happier relationship. P.O.T.S. doesn't have to mean an end to a good relationship.

ADVICE FOR PARTERS OF POTSIES

Household Chores and Childcare

Looking after the house and children is very difficult when you have P.O.T.S. and POTSies can often feel guilty, sad and extremely frustrated for not being able to do household chores or child care to the extent that they would like to or at all, depending on the severity of symptoms. This can make us snappy or upset but we don't mean to be. POTSies will do as much as we can to help in the house and are not being lazy when we say we can't help out. P.O.T.S. symptoms are worse in the mornings because our blood pressure is lower in the mornings and we dehydrate overnight making our hypovolemia worse. It also takes a while for our medication to help with our symptoms so please try to help with any morning chores. After eating our blood pools in our stomach and abdomen and that makes our symptoms worse so washing up or any household task is much harder after eating. Tell us when you think the household task can be put off or does not need doing as it removes the pressure of feeling we have to do that task and suggest using the energy we have on something nicer instead.

Any household task involving standing still like cooking and washing up is much harder for us because the blood pools more in our legs when we stand still and this makes our symptoms worse. Imagine trying to cook whilst running fast as you can on the spot as that is what our hearts are doing when we stand up. We are more likely to faint (syncope) or get near-syncope when standing still. As we loose blood to our head we get dizzy and lose concentration. Tilting our heads up and lifting our arms above our heads can also exacerbate symptoms and make us more dizzy and affect our vision. Offering to get items out of cupboards for us is really helpful. Taking it in turns to cook or doing all the cooking if we cannot cook at all is very much appreciated. Understanding that for your POTSie having a shower is like you running a half marathon so after we've got ourselves dressed we are already exhausted is something to keep in mind.

Sometimes some of us get very task focused when Patsy and because of the lack of blood flow to our brain we think we can continue with housework or childcare when we clearly aren't well enough to do it but telling us that can be difficult. Walking away or feeling upset with us because we still insist on continuing with the task doesn't help as we are not able to understand why you are getting upset and can result in your Patsie getting snappy. Offering to help and then taking over if need be works better than insisting in an irate tone that we sit down or walking away because you are frustrated.

Communicating Well With Your Patsie

Standing still, walking or just sitting up can affect our hearing- especially if we are concentrating on another task. This is due to the lack of blood flow to the brain so don't assume we are ignoring you. We can hear your voice but it's like hearing a voice underwater. Our brain can't process the sound and we are not being rude or are upset with you if we do not reply. Make sure you talk to us when we are looking directly at you. Talking louder or slower even if we are not facing you doesn't always help and might not be appreciated! We may ask you to look at us when you are talking to us and that's so we can hear you better by reading your lips. Our vision can also be disturbed when we stand up, or for some of us when sitting up. We may not be able to read signs in the train station, supermarket or even the on screen tv guide. Imagine you are drunk and trying to read a sign - the words swim around and no matter how much you stare at the sign it's still impossible to read. That is what it is like for your Patsie.

Patsies often get brain fog. This is an anecdotal term referring to the symptoms of loss of concentration and forgetfulness that can be caused by lack of blood flow to the brain. Filling in the words or the end of the sentence for us or asking us what word we are stumbling for is frustrating and upsetting for us as we know when we have brain fog. We can forget things you tell us even quickly at times and it doesn't mean we do not listen to you or are ignoring you. It just means our blood flow is bad to our brains again!

Please don't wrap your Patsie in cotton wool or treat them like a china doll. We need and want to live as independently as we can and that means making our own decisions on whether we are well enough to go on holiday, go out with friends or family or just a romantic meal for two. We don't want to be treated like a child with you as the parent figure.

No matter how annoyed you might be don't go to bed without making up. It's important that resentment isn't allowed to grow and it's much nicer to kiss and cuddle in bed than sleep as far apart as you can.

Days Out With Your Patsie

As mornings are the worst time for P.O.T.S. symptoms, early morning starts can be impossible. Planning activities for later in the day can help but each Patsie is different. Some are better in the evenings than afternoons or vice versa and this can change day to day.

Don't be afraid of asking how we are and planning going out around our response.

P.O.T.S. symptoms often get worse in loud environments like the cinema, pub or even a busy restaurant. Heat or cold can affect our symptoms too. On some days we will be able to cope with this better than others. We can often be okay in an environment one minute but then get severe symptoms the next. Some Potsies would prefer to leave the environment whilst others prefer to stay and enjoy what they are doing regardless of the symptoms. We don't mind you asking us what we want to do, just don't insist that we leave if we want to stay or we have to stay if we want to leave. For those Posties who are regular fainters but who don't want to let P.O.T.S. stand in their way of living life please don't try to restrict our going out but instead accept that faints will occur and let us be independent. Don't panic when we get symptomatic when we are out and about and insist we cancel the activity if we want to just rest and then carry on.

Intimacy With Your Potsie

Lots of kisses and cuddles really help show you still love us even though we have P.O.T.S. and can make all the difference. Just because we don't feel like making love as often as we used to that does not mean we don't fancy you. Potsies get chronic fatigue which itself is very painful. It's hard to feel sexy when your tummy hurts, you feel sick, your bladder is overactive, your head is pounding and your heart is beating so fast it causes chest pain and breathlessness. We still love you just as much. Pestering us for sex, even if done in a joking way will get you less bedroom fun not more as it hurts our feelings.

Any act of lovemaking, even foreplay can cause our heart to race too fast and cause chest pain, dizziness and even syncope as well as many other symptoms. That can happen even when we are lying flat. We may not be able to swing from the chandeliers often or at all when making love but intimacy and sex can still be very good. Cuddles after making love are always lovely but if we are short of breath and have tachycardia we might want to catch our breath back first or just have gentle hugs.

Some Potsies get all over muscle pain and that can reduce our interest in sex. A good long all over body massage can really reduce our pain and get us in the mood for sex. A percussion massager can be a good investment. Massages mean much more if they don't always lead to sex so don't demand sex after every massage!

If your Potsie is having a bad day but wants to have a shower or bath you can help by running the shower or bath and helping your Potsie wash their hair. This can be very sensual, intimate and caring and can strengthen the bond between you. If you run a bath or shower it must not be too hot as hot water causes blood to pool more easily. Open the window whilst running the bath helps as steamy environments are also bad for making our symptoms worse.

SUGGESTIONS FOR POTSIES

Appreciate that your healthy partner needs support too

Many support sources for sufferers of chronic illnesses offer support and understanding for the sufferer but there is often little support or understanding for the partner. Often healthy partners can feel pushed out, unsupported, undervalued and frustrated. Their life is also directly affected by P.O.T.S. Whilst they do not have to deal with the burden of P.O.T.S. directly P.O.T.S. will adversely affect their lives too. They may have to change jobs to be able to work from home or give up their job to care for their partner. They may have to take on extra housework or childcare whilst still holding down a full time job. Their plans of active or family holidays may now be out of the question. Their social life is curtailed too.

To the healthy partner P.O.T.S. can be the thief that has stolen their partner or the third party in a relationship/marriage. Suddenly it is all about P.O.T.S. P.O.T.S. affects all their partner's activities and it's all that is talked about. Patsies need to limit the times they talk about their illnesses and how they are feeling to their partners to a sensible level. It's very easy to focus so much on it that we don't talk about much else. This is very frustrating for our partners because it is constant negativity. It's also very boring!

For healthy partners there is also the frustration and sadness they that cannot fix their Patsies health which can make them feel helpless. This is especially frustrating to men who just want to fix their Patsie but can't. Try to understand your partner's frustration and sadness that they can't get rid of your P.O.T.S.

Show your partner you care for them. Kisses and cuddles and telling them you love them helps to maintain intimacy even when you feel unwell. Tell them they are sexy or attractive. They can feel unloved and not sexy if you don't tell them you still love them and fancy them.

Let them talk about how they feel P.O.T.S has affected their lives as they too need to vent from time to time. They love you and it is very hard to watch someone you love in so much pain and be so ill. Tell them it is okay to complain about it to you. They will see less of their friends than they did before you got sick so when they see their friends they will probably want happy times not to chat about P.O.T.S!

Treat them to activity or other organised days out on their own if they have a special interest which you can't partake in because of your P.O.T.S. The chance for them to chat to new people is good and they get to have a fun day out free of worries.

Don't begrudge them time out with their friends as they need a break and fun too. Plan a nice activity for yourself so that you too are having fun when they are out- make sure you get some important "you" time or time with your friends and family.

Don't say no to fun activities or days out - say yes too!

Don't let the fear of P.O.T.S stop you doing things with your partner. On days you feel okay do something nice with your partner. Use the energy you have to go out and have fun or to watch a movie on the sofa together - the cleaning can wait! Men are quite happy to leave the cleaning and are often not as fussy as women on how the house looks.

When you can, make an effort to go to events that your partner wants to go to and to seek special assistance in advance for your needs. Many places are only too happy to help you. Try to last as long as you can before you give up and say you need to go home. Your partner needs time doing normal things away from P.O.T.S and they need to see you having a good time. You will feel happier too by saying yes to more fun things.

If your health permits go out for romantic meals. Don't let the effect of a meal put you off. It is worth staggering out of a restaurant in the arms of your partner if you have both had a romantic and intimate evening.

Don't push yourself too hard when having fun

If you aren't concerned about going out, have the tendency to burn the candle at both ends and push yourself past your limits this can also cause major stress for your partner. They don't know when you are really well enough to do something and when you are refusing to give up. Communication here is the key. Tell your partner that you will tell them when you need to go home or need to have a break and tell them before you have a full P.O.T.S crash. Don't get annoyed if they ask you if you need to go home, you might be looking peaky and they might think you are just staying out for them. Your P.O.T.S symptoms can be very horrible for your partner to see. Syncope, tremors and seizures are never nice to watch and even worse when it is someone you care about. Even you just not being able to walk in a straight line can be very upsetting for your partner to watch. If a wheelchair would help you don't be too proud to get one, even if your partner needs to push you. It is much better to have an easy way to get you back to the car than your partner struggling to help carry you. It is better to leave earlier than you would like to so that you end the night in a good way than party on until you collapse.

Relight the flames of passion - you can have fun lying down!

Sex can be a taboo subject when you have a chronic illness but it does not have to be. Orgasms are good for your feeling of well being and bring couples closer so if you are well enough make sure you set some time aside for intimacy with your partner. It can be as frequent or infrequent as you like but remember your partner has needs too and so if you can't make love then foreplay can be a great way to bring intimacy and the "relief" that you both need.

You should never feel pressured into intimacy or sex but if your partner is feeling frisky and you are not feeling up to any intimacy then try to understand your partner's frustration. They still love you and want to express that love. Also their libido has not been affected so they will probably feel frisky more often than you. Bromide in their tea is not the answer!!! Neither is giving into their wishes if you don't feel well enough for intimacy. That will just breed resentment.

Explain to your partner what is and what is not possible in the bedroom. Discuss it honestly and openly but not as a list of negatives. You might have had a much more inventive sex life before P.O.T.S but maybe now most of the Kama Sutra would be impossible. That does not mean all sex is out. Find a position that is comfortable for you and tell your partner what you

CAN do. Wrapping your legs around your partner whilst making love can help contract the muscles in the legs and your bum which can help reduce the symptoms of POTS when making love.

Getting a memory foam mattress topper can help make sex much more comfortable. A comfortable pillow under your head helps too. Battery operated candles can really set the mood and can be good for those times when bright lights hurt your eyes. If your partner can hold their own weight off you when making love then that can really help reduce P.O.T.S symptoms caused when making love. A fan by the side of the bed can help you both cool down afterwards. Your partner will appreciate it too. Don't get up from the bed or wherever until you feel well enough to do so. Take your time in recovering from sex. People get different symptoms from sex and if you are concerned then raise your symptoms with your doctor. Internet support groups can be a good way to discuss what symptoms people get so you can find out if anyone else has a similar symptom when making love. You can take as long or as quick as you both like with sex. Don't grieve for the days when you could do seven hour love making sessions in every position imaginable. Adapt to a new way of lovemaking and enjoy it.

Communicating with your healthy partner

It can be very frustrating talking to someone with brain fog. Your partner does not mean to get upset when they have to repeat things to you but they can often feel as if they are being ignored. If you make sure you pay as much attention as possible when they talk to you, including looking at them as they talk, there is more of a chance you will hear and remember what they say. Remind them that you are not ignoring them but you sometimes just find it very hard to pay attention to what they are saying or recall what they said previously.

Don't snap at them when they try to finish of a sentence or fill in a word. They are only trying to be helpfulannoying as it is! They can get frustrated too and want to get the sentence finished. Laughing about brain fog helps clear the air.

Listen to when they are trying to be helpful and don't brush off their offers of help. If it is not the sort of help you want or need then don't snap at them but ask them to help in another way.

Holding hands as often as possible and cuddles are a great way to bring you closer together. Take your partners hand and smile at them often. Tell them you love them and make them feel special because we can forget to tell our partners what they mean to us and neglect their feelings when we are feeling ill and in pain. Never go to bed on an argument. It doesn't lead to restful sleep and POTSies need good rest.