

Orthostatic Tremor – Information for Family and Friends

Orthostatic Tremor (OT) is a rare and progressive neurological disorder. Tremors occur in the legs when standing still which causes an immediate lack of balance. The cause is unknown and there is no cure.

The tremor is of very high frequency, three times faster than in Parkinson's Disease, and too fast to be seen by the eye. It results in an overwhelming need to find a place to sit or walk away and causes fatigue.

OT is so rare that most Doctors and even Neurologists have never heard of it, diagnosis can take years.

Daily living

Every day, people with OT feel frustrated with the sudden and constant disabling events that happen all the time. Basic tasks such as showering, waiting in queues, browsing shops or markets, and preparing meals are challenging. Even simple things like pegging out washing, filling your car with petrol, chatting to neighbours or queuing for a coffee can be a nightmare, as well as occupations that involve standing.

We go into a panic if we walk into a strange place and can't see any seats. We worry about going to events like parties and BBQs, will we be sat alone in a corner while everyone else is standing chatting and mingling. So we often decline invitations even when we would really like to go.

Variability

OT varies from person to person and can change from time to time – sometimes due to stress or doing too much, but sometimes for no reason at all. The length of time a person can stand varies from just a few seconds to 2 or 5 minutes, this can vary throughout the day or over weeks and months.

Walking

In the early stages of OT, walking may not be affected too much but as the condition progresses our walking distance will reduce. We struggle to walk on uneven surfaces such as soft grass or the beach, and to step off curbs or over things because our balance is terrible. Walking in the dark or squeezing past people in tight spaces can cause us to panic and freeze on the spot.

Stairs are difficult for us, going down them especially, even if there are only a few steps. We always need the handrail and much prefer to use a lift or elevator if there is one.

Exhaustion

People with OT also suffer from extreme fatigue. Basic tasks can take much longer than usual and then we need to rest and recover. We have to set limits for ourselves and stick to them.

The effect of stress and emotion

Stress makes tremors worse. Feelings such as anxiety, anger, annoyance, frustration, apathy and even excitement or anticipation can be a problem and may lead to depression. A lack of confidence often stops us doing the things we normally enjoy.

We know we look fine on the outside, it's an invisible disability, and we try to hide it because we don't want to be disabled. This makes people think it is all in our heads, or we are lazy, but we are fighting a physical battle every day and we worry about being a burden.

Treatments

There is no cure for OT and not any one known treatment. Medications may help relieve some of the symptoms but they have side effects. Deep Brain Stimulation (DBS) surgery is a last resort.

Lifestyle changes, reducing stress and rest are essential. Keeping active and core strength exercises help.

Mobility aids are required such as shower stools, swivel stools on wheels in the kitchen, portable stools for outdoors and walking sticks. People often use walkers (rollators), wheelchairs or motor scooters too.

Handy hints for family and friends

If you are helping someone with OT, such as in the kitchen, try not to get under their feet, we need space.

If we can't sit we need to walk quickly, no dawdling, and others need to try not to get in our way, we can't stop suddenly or avoid bumping into you.

If we are on an outing, we don't want to feel bad about spoiling your day. If we whizz around then go off to find a seat, don't come with us, stay and enjoy the experience at your own pace, we are happy sitting and having a guilt-free rest.

What we need most is for the people who surround us in our lives to understand all these things, and remember them, even when we look okay and say we 'can manage'.