

Supporting Young People with ME/CFS

# Orthostatic Intolerance Explained

This leaflet should be used in conjunction with advice from your ME/CFS Clinician

## **ME/CFS** Patient Information

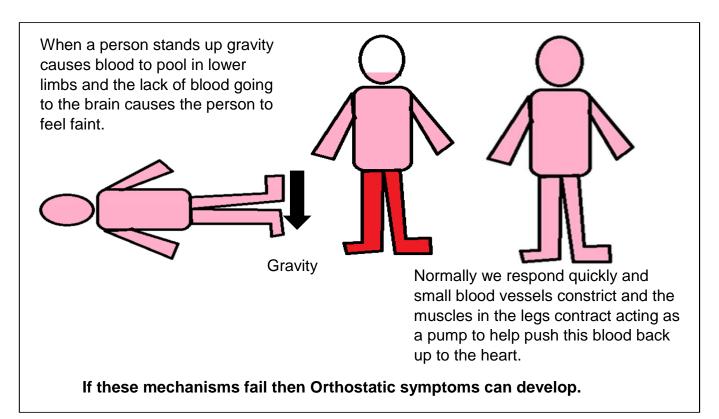
Sometimes people may feel dizzy or experience other symptoms shown in the box below when they stand up, and will feel better again when they lie down. These symptoms are signs of Orthostatic Intolerance and are actually very common.

40% of young people experience symptoms occasionally and in most cases they improve without any treatment. For a minority of people the symptoms are more troublesome because they occur frequently or last for a long time. Children and young people with ME/CFS are more likely to have these symptoms than others. Inactivity can make the symptoms worse.

Dizzy or light-headed Blurred vision Palpitations Headaches Nausea

#### What causes the symptoms of Orthostatic Intolerance?

Dizziness and the other symptoms of Orthostatic Intolerance occur because for a short period there is not enough blood flowing to the brain. The person may get a fast heart rate when they stand up (Postural Orthostatic Tachycardia – POTS), and/or have a drop in blood pressure (Orthostatic Hypotension or Neurally Mediated Hypotension-NMH).



## What can make Orthostatic symptoms worse?

- Dehydration
- Getting up quickly after lying/sitting for a long time
- Standing still for a long time

- Carbohydrate-heavy meals
- Heat exposure or fever
- Straining when going to the toilet
- Can be worse earlier in the day

Alcohol

### What can help Orthostatic symptoms?

Most people will not need any treatment and just understanding what is happening is enough. If your symptoms are more troublesome then there are some simple measures that can help.

You should avoid the things that may make it worse and consider some of the actions suggested below:

Physical actions to help pump the blood back up	Fluid and diet actions to increase the blood volume
<ul> <li>Before getting up clench your toes and contract your leg muscles</li> <li>Get up slowly</li> <li>If symptoms start try: <ul> <li>Bending at the waist</li> <li>Squatting</li> <li>Leg crossing and contraction</li> <li>Toe raising</li> </ul> </li> </ul>	<ul> <li>Drink more water:</li> <li>Increase daily fluid intake - recommended daily intakes: <ul> <li>9-13 years is approx. 1500ml/day</li> <li>13+ years approx. 2litres/day</li> </ul> </li> <li>Drinking 500mls water quickly has been shown to increase blood pressure within a few minutes and this can improve symptoms for up to 2 hours (Only do once per day)</li> </ul>
Mild physical exercise can help	Increase salt intake to at least 8g per day. You can do this by eating 1 bag of crisps or adding a little salt to your food.

For most people following these simple guidelines are enough to control the symptoms. If your symptoms continue to be troublesome let us know since it may be appropriate to do some further investigations and consider some other treatments.

#### Contact

## **Further Information**

01225 821340 Email: <u>ruh-tr.paedscfsme@nhs.net</u>

www.ruh.nhs.uk/cfs

Royal United Hospitals Bath NHS Foundation Trust Combe Park, Bath BA1 3NG 01225 428331 www.ruh.nhs.uk

Please contact the Patient Advice and Liaison Service (PALS) if you require this leaflet in a different format, or would like to feedback your experience of the hospital. Email <u>ruh-tr.pals@nhs.net</u> or telephone 01225 825656/ 826319