

APCP Information – Hypermobility and Hypermobility Spectrum Disorder

Information for parents and carers

What is Hypermobility Spectrum Disorder?

Hypermobility refers to increased movement at a joint. Hyper means 'more' and mobility means 'movement'.

Ligaments offer stability to joints. In hypermobility, ligaments are lax and joints have more flexibility. It is not an illness or a disease, just the way someone is put together. It is considered a normal finding by medical professionals.



If it does become symptomatic, your child may be categorised within Hypermobility Spectrum Disorder. This is the new term instead of 'Hypermobility Syndrome' (<u>https://www.ehlers-danlos.com/what-is-hsd/</u>). This can be further identified as:

- Generalised = multiple joints involved
- Peripheral = limited to hands and feet
- Localised = typically one joint or less than 5 joints
- Historical = self-reported history of symptoms, not necessarily diagnosed by the criteria

How common is it?

Many children are hypermobile, without symptoms. There is not a definitive number for the incidence of hypermobility. One Canadian study suggests the prevalence of joint hypermobility in children is between 7-36%, depending on what criteria and diagnosis has been applied (1).

How is it diagnosed?

Most children will be assessed with the Brighton Criteria, which is a checklist used for all ages of children. This includes the Beighton score. The Brighton Criteria help to identify symptoms that your child may have. Goniometers are used to look for increased ranges of movement at a joint.

What should I look out for?

Hypermobility is a common childhood disorder that affects some children more than others. There can be a variation of symptoms depending on the degree of hypermobility at the joints, as well as how many joints are affected.

Many children who are hypermobile experience no symptoms or difficulties and being hypermobile is beneficial in a lot of sports. Often a lack of strength as well as misunderstanding of the condition can cause more problems.

Common complaints are:

- Clicking joints
- Tiredness after walking long distances
- Flat feet
- More stumbles/ falls, often called clumsiness
- Reluctance to take part in physical activity, especially for long durations
- Pain
- Difficulty with hand writing, using a knife and fork and getting dressed

What might help?

Exercise:

Doing generalised exercise and being active will help to maintain a healthy, strong body. Current literature suggests that strengthening the muscles around a joint can improve control of your child's movement and help to reduce the number of symptoms a child may have, such as pain or tiredness (2,3).

Sport:

Some sports benefit from hypermobile joints such as dance or gymnastics, which will help to strengthen the joints. Some sports activities that may include heavy contact can be seen as potentially a higher risk of injury and the activity may need to be modified, such as rugby. If any of the above activities cause pain or tiredness, pacing may need to be considered and you can seek advice from your physiotherapist.

Pacing:

If muscle pain after exercise is a problem, your child should not stop being active. Instead, pacing activities may help. Pacing means to gradually increase an activity in order to achieve a goal. Don't do too much activity on one day. Spread your exercise throughout the week and focus on building more strength and fitness.

What else can I do?

- Encourage normal daily activities
- Wearing footwear which offers support around the ankle and under the arch with a good shock absorbing sole may help
- If your child is complaining of pain, you could try a warm bath/warm water bottle. ALWAYS check the temperature is not too hot (37°C 38°C)
- Encourage good general and sitting posture
- Pacing activities and modifying more challenging sports

Seeking advice

- Seek advice from your GP if you have any major concerns about your child, or if they are having frequent and severe pain.
- Seek advice from a Physiotherapist if your child is struggling to cope with symptoms. A Physiotherapist will assess your child and may give appropriate exercises and advice, to help alleviate your child's symptoms.
- Occupational Therapy may be appropriate for your child if they are having difficulties with activities of daily living.
- Orthotics or Podiatry may be appropriate if further control of your child's joints is required.

Further information

- 1. Scheper et al., 2013
- 2. Pacey et al., 2014
- 3. Peterson et al., 2018

http://hypermobility.org/

https://www.ehlers-danlos.org/



This leaflet has been produced after a review of literature by the APCP National Committee and where there is a lack of evidence, a consensus of expert opinion is agreed, correct at time of publication. APCP: https://apcp.csp.org.uk V4 Published February 2023 V4 Reviewed June 2024 V4 Review Due June 2029



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