Joint Hypermobility Syndrome

What is Hypermobility?

Hypermobile joints are common in the general population and often present as joints with additional flexibility. Many people with hypermobility do not experience any significant difficulties; in fact in many situations (i.e. sportspeople, dancers etc.) hypermobility can have positive advantages. However some people experience difficulties with symptoms which are understood to be related to being hypermobile; commonly known as Joint Hypermobility Syndrome (JHS) or Ehlers-Danlos Syndrome Type III (hEDS).

It can sometimes be unhelpful for a young person to have the label of EDS III because the significant risks associated with the other forms of EDS can mistakenly be assumed to also apply to this group. For this reason, the preferred term to use is Joint Hypermobility Syndrome (JHS).

How common is it?

Most children are flexible and some more so than others. The majority of children will become less supple as they get older but a small percentage will remain very flexible. Studies have shown that hypermobility is more common in girls than boys. Reports have shown that between 3% to 30% of children have hypermobility without any difficulties.

Common parental concerns

In early development children may initially take longer to achieve crawling, walking and running and may be more likely to bottom shuffle. Other frequent findings are:

- Clumsiness and frequent falls
- Flat feet
- Clicky joints
- Tiredness
- Reluctance to walk longer distances
- Pain
- Difficulty with handwriting, dressing or holding a knife and fork.

Is there cause for concern?

Many children who are hypermobile experience no symptoms or difficulties as being hypermobile is beneficial in a lot of sports. It is not fully understood why some children have more symptoms than others as it is not necessarily related to the degree of hypermobility. However it is believed that these problems are often related to poor muscle strength, poor muscle stamina, muscle tightness and poor control of joint movement and not the hypermobility itself.

What can I do to help?

Some of the symptoms of hypermobility are understood to be related to weaker or tighter muscles and this muscular deconditioning and instability causes the muscles to have to work even harder. It is therefore particularly important to focus on being healthy, strong and fit. The stronger and fitter your child is, the better for their hypermobility and general well-being. Also ensuring that your child does not get overweight as this can stress muscles and joints more.

Encourage normal everyday activities and play, for example:

- Swimming
- Cycling
- Play in parks
- PE
- Dance

Pacing (Spreading activities out throughout the day)

If your child is experiencing muscle pain after exercise they should not stop all activity but break down or separate tasks to help complete them. Pacing makes activities more achievable enabling them to be completed in manageable chunks without increasing pain. Encourage activities over the week consistently to help build up fitness and strength.

For example- if your child struggles with an hour of PE then encourage conversations with teachers to enable rest periods throughout the session or roles such as scoring/umpiring to help break up and implement rest periods.

Practice

Your child needs to build their muscle strength, which takes time and most importantly, practice. We would expect muscle strengthening to take between 3 and 6 months and therefore practice needs to continue over this period of time to see a difference in symptoms.

Pain management

Aches and pains associated with hypermobility are usually a result of muscle fatigue, not damage or injury. A warm bath or a hot water bottle may help. It can be common that pain killers are not very helpful for many children experiencing pain with hypermobility. Try not to focus on pain and encourage activities that focus away from pain.

When to seek advice

Management of JHS can sometimes require professionals, young people and their families to work together if activity is reduced and pain is limiting day to day activities. The overall aim of any intervention is for the child and parents to gain a full understanding of hypermobility and the skills and knowledge to manage the condition themselves.

It is important that pain, fatigue, sleep patterns, diet, exercise tolerance and participation in activity are addressed to prevent any further downward spiral in physical activity and wellbeing of the child.

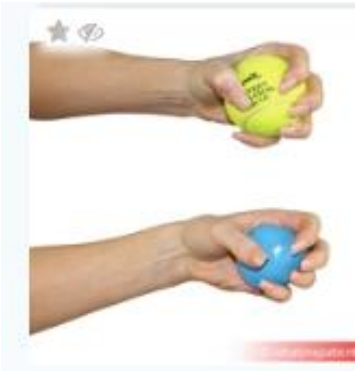
The longer-term outlook for young people with JHS is very positive and with the correct management all young people should be able to participate in all activities they want to without ongoing professional support.

Exercises to trial to support muscle strengthening and reconditioning

We would expect some muscle aching around the exercised areas when completing the exercises and this might take 24 to 48hours to resolve.

When starting the exercises remember to build them up slowly and progress the number of repetitions as you feel you are getting stronger and more confident.

Hands



Resisted finger flexion

Using a tennis ball/rolled up socks, squeeze the ball and hold this position for five seconds, relax and repeat five times. Repeat daily and before long periods of writing.

Resisted thumb extension

Using an elastic band around your thumb and fingers, open your thumb to increase the resistance of the band. Hold this position for five seconds, relax and repeat five times. Repeat daily and before long periods of writing.

Shoulders

Shoulder stabiliser

(**This exercise also helps to increase the stability around your hip and lower back/abdominal muscles**)
Position yourself into a four point kneeling position. Think about keeping your hip and shoulders level.
Start with trying to lift one arm in front of you and then repeat with the opposite leg. Repeat 10 times, x 3 sets.
To make this exercise more challenging repeat with opposite arm and leg extended at the same time.

Shoulder stabiliser

(This exercise also helps to increase the stability around your hip and lower back/abdominal muscles)
Start lying onto your tummy. Bend your elbows and place them directly under your shoulders. Keep your back straight and do not let your tummy drop to the floor (start on your knees if it is too hard). Keeping your back straight and lift your body off from the floor. Hold for 10seconds, x 3 sets – progress to a 30second hold.

Lower limb

Bridge

Lie on your back with your arms by your side. Keep a small gap between your knees. Squeeze your bottom muscles and lift your hips off the floor (try to keep your back straight and not arched). Hold for 5 seconds; repeat 5 times- progress by crossing your arms over your chest.

Balance exercise

Practice standing on one leg. Aim for 30 seconds without losing your balance.

To progress- play throw and catch whilst in this position.

Quadriceps stretch

Lie on your side. Pull your heel towards your bottom (try to keep your knee towards the floor). Feel a stretch into your thigh. Hold for 30seconds and then relax.

Hamstring stretch

Standing, place one heel up onto a chair or stall in front of you. Keep your knee straight in the elevated leg. Feel a stretch behind your leg and knee. To increase this stretch gently bend your trunk forwards. Hold for 30 seconds and then relax.

Calf stretch

Stand facing a wall, place, with the toes of your front foot touching the wall. Keep the heel of your front foot down and bend your knee to touch the wall. Make sure your knee goes over your toes and your feet face forwards. If this starts to get too easy move your front foot aware from the wall slightly and repeat.

You will feel a stretch down your calf. Hold for 30 seconds and then relax.

How soon will I be able to return to normal activities?

If you are experiencing severe pain or you find that the exercises aren't being effective it is advisable to stop all sports for a few weeks to allow time to settle the pain and then after a few weeks slowly reintroduce the exercises and sport to pace your return to previous levels.

Sources of information

- www.sparn.scot.nhs.uk/wp-content/uploads/2017/01/Guidelines-for-Management-of-Joint-Hypermobility-Syndrome-v1.1-June-2013.pdf
- https://apcp.csp.org.uk/documents/parent-leaflet-symptomatic-hypermobility-2012
- Beighton Score: A Valid Measure for Genrelaized Hypermobility in Children
- Bouwein Smits-Englesman, PhG, Mariette Klerks, MS, and Amanda Kirby, MRCGP, PhD 2011.
- Joint hypermobility and its relationship to musculoskeletal pain in schoolchildren: a crosssectional study V Leone, G Tornese, M Zerial, C Locatelli, R Ciambra, M Bensa, M Pocecco, 2009.

Important information

The information in this leaflet is for guidance purposes only and is not provided to replace professional clinical advice from a qualified practitioner.

Disclaimer

Please note this is a generic ESHT information sheet. If you have specific questions about how this relates to your child, please ask your doctor. Please note this information may not necessarily reflect treatment at other hospitals.

Your comments

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Reference

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