Joint Hypermobility

- Hypermobile (increased range of movement, "bendy") joints are common in the general population and many people with hypermobility do not experience any significant difficulties. In fact, in many situations hypermobility can have positive advantages e.g. in sportspeople and dancers.
- Hypermobility should be regarded as a "normal variant": difficulties occur mainly when the body has become weak and deconditioned. Muscles have to work harder to keep the joints in the right position and this can make muscles tired and sore.

Common Problems:

- **Joint and/or muscle aches and pains** often occurring after activity, end of day or during the night. Legs more frequently affected due to weight bearing nature of joints.
- **Muscle and joint stiffness** usually after exercise or increased activity, may occur a few days after (Delayed Onset Muscle Soreness or DOMS). DOMS is a completely normal response to an increased level of exercise and is not an indication of damage. Muscles that move over two joints may become tight despite generalised hypermobility.
- **Fatigue** is commonly linked to muscle weakness due to non-use. Poor sleep will also impact on fatigue levels.
- **Difficulty sitting still** and postural problems.
- **Joints can click** spontaneously or be clicked deliberately and can happen safely many times a day. This only becomes a concern if it becomes habitual and obsessive, impacting on quality of life.
- **Clumsiness and reduced balance** as a result of poor proprioception (body awareness) and core stability.
- **Reduced hand strength and stability** leading to difficulties with holding a pencil, fastening buttons, holding cutlery etc.

For most children, symptoms improve as muscle size and strength increase with growth and age. This muscle growth reduces joint looseness. A small proportion of affected children continue to have problems into adulthood.

Self-Management

- Maintain a healthy lifestyle i.e. eat a well-balanced diet, participate in regular gentle exercise, participate fully in school, activities and social events, and get quality sleep. Current evidence suggests during childhood it may be better to enjoy a variety of sports rather than focus on one. Extra body weight can significantly strain lower limb joints and increase symptoms of pain and fatigue. Becoming underweight is also not ideal as this can make maintaining adequate muscle strength difficult.
- We usually understand pain to be a warning about damage to the body and as a result are often advised to rest. However, it is understood that pain symptoms in hypermobility are an indication that the body is not strong enough and requires strengthening.

- It is important to understand how to pace activities in order to avoid the “boom and bust” cycle where over-exertion leads to pain and fatigue.
- In general, painkillers are not helpful and long-term use can cause problematic side effects like nausea, constipation and indigestion. It is better to manage the pain through non-medication approaches like:
  - Distraction (music, talking, TV).
  - Relaxation treatments like massage and aromatherapy.
  - Gentle assisted stretching exercises.
  - Warm baths and/or use of heated wheat bags/hot water bottles.
- Provision of a wheelchair is not recommended and is counter-productive to developing and maintaining muscle strength and stamina.
- Splints are generally avoided due to risk of allowing the muscles to become weak through non-use, but may occasionally be used alongside a hand strengthening programme.

Activities of daily living

Short-term, small aids may be used as a compensator approach to increase function, however longer term use of these should be discouraged, as their use may contribute to increased muscle weakness.

Pencils	Chunky pencils, large soft pencil grips and easy flow rollerball pens.
Scissors	Easi-Grip scissors and scissors with long loop handles.
Cutlery	Try using moulded cutlery or lightweight cutlery e.g. NRS Kura Care Cutlery/Nanna’s Manners.
Buttons	Try re-sewing buttons onto garments with a looser or elasticated thread. Buttons can be sewn over the top of the button hole and Velcro placed underneath.
Zips	Attach a key ring or small piece of ribbon to the zip to aid grip.
Shoelaces	‘No tie’ shoe laces are available commercially - see separate advice sheet for details.
Wiping after toileting	Wet wipes can be easier to use than toilet paper. Try sitting down to wipe, or holding onto something stable when standing to aid balance.
Personal care/ opening packets	Investigate different containers for products, for example using a pump dispenser for shampoo or flip-tops lids. Jar opening aids are available. Try placing items in sandwich bags or plastic containers for packed lunches.

Where a child is experiencing significant pain and/or difficulty participating in 3 or more areas of functional activity then referral to Occupational Therapy may be warranted. www.wsh.nhs.uk/Services-A-Z/Childrens-services/Childrens-community-services/Information-for-professionals.aspx

This leaflet is based on information from Guidance for Management of Symptomatic Hypermobility in Children and Young People – A Guide for Professionals managing Children and Young People with this condition.. British Society for Rheumatology; 2019.