

Children's Community Therapies and Specialist Inclusion Support Service Information for Patients

Symptomatic Hypermobility

Produced by Specialist Inclusion Support Service
and Children's Therapy Services January 2018



Purpose of this Booklet

This booklet is intended to provide advice on methods to improve children's ability and relieve symptoms associated with joint hypermobility.

The aim of the advice and techniques described in the booklet are to improve children's functional abilities and to manage their pain.

What is Hypermobility?

Hypermobility describes a person with increased movement in their joints. This is caused by loose structures within a joint for example ligaments and connective tissues which allows increased joint movement and reduced stability. It is not a disease or an illness. Increased joint mobility can affect 1 or multiple joints. In order for hypermobility to be determined it needs to affect multiple joints.

Hypermobility is consider a normal finding in children and is often present in younger children. As children's muscles and joints develop joint mobility normally declines thus reducing the effects on the body.

Unless a child has any functional restrictions or pain resulting from hypermobility they do not need any specific intervention.

Symptomatic hypermobility refers to a child who has joint hypermobility which affects their ability to perform daily tasks or causes pain. It is not known why some children have symptoms and others do not.

Hypermobility is very common in children; with up to 71% of children under 8 years of age having joint hypermobility. And 55% of children between 4-14 years of age having hypermobility.

Symptoms Associated with Hypermobility

- Frequent tripping and/or falling
- Clicking of the joints
- Flat feet
- Fatigue and tiredness
- Reluctance to walk long distances
- Pain- commonly in hands/wrists, back, hips, knees and ankles
- Poor muscle strength
- Weak and poor pencil grip
- Poor Handwriting and achy hands when writing
- Poor hand skills.

Reducing a Child's Pain

Managing a child's pain is often a parent's main concern. Often pain will be worse at the end of the day; as well as after activity. Pain experienced in children with hypermobility is normally related to muscle fatigue rather than problems within joint pain. This is because the structures (i.e. ligaments) supporting joints are loose they are not offering the joint sufficient support. As a result the muscles around the joints work harder and thus are 'over worked'. This muscle pain is what a child feels.

Common areas for a child to feel pain is in their hands/wrists with writing and fine motor activities, back pain with prolonged sitting and hip, knee and ankle pain with prolonged walking or after physical activity.

Taking medication for pain is not effective at reliving pain caused by hypermobility and thus not recommended. However please speak to your child's GP regarding this.

The use of heat has been shown to reduce muscle pain and should reduce your child's pain. Using a heat pack and having a warm bath in the evenings will help to reduce pain. It is important not to stop physical activity completely but to work within pain levels.

By avoiding all activities the muscles will weaken further. Therefore pacing of activities is important. This means to break down activities into shorter periods and allowing rest periods. For example if a child experiences hand/wrist pain after an hour of writing then consider having a rest after 30 minutes or consider using alternative methods as well as writing, for example using typing as well as writing. It is also worth looking at the activities done each day and spread out activities throughout the week. For example, on a P.E day don't have a swimming lesson that evening. Instead spread this out throughout the week.

It is important to gradually increase activities as strength improves within pain limitations.

Improving Body Stability and Strength

Children with hypermobility often have weak muscles in particular in their trunk. This means the muscle around their back and hips which provide support for the whole body are often weak. By strengthening these muscles the effects of muscle fatigue will reduce thus reducing pain and symptoms associated with hypermobility. Additionally improved body stability and strength means gross and fine motor skills will become easier.

Activities which improve postural support include:

- BEAM or SMARTMOVES children can be included in these programmes at school– please speak to staff regarding this
- Certain sports are good for children to participate in. These include martial arts, dance, swimming and cycling

There are also many games you can play with your child to develop their body stability and strength:

- Play in a half kneeling position- in this position you can play catch
- Making an obstacle course where a child needs to crawl under things, step or jump over obstacles
- Tightrope walking
- Stepping stones- with either stepping or jumping
- Hopscotch
- Crab football

There are also some specific exercises your child could try at home; these exercises are similar to the BEAM programme. A child can be supported to try doing the following exercises. In order to make a difference the exercises need to be completed 5-7 times per week. All of the exercises need to be completed in a slow and controlled manner and not rushed.

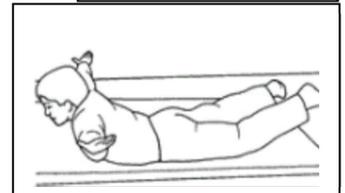
The Cat

Start in a “hands and knees” position, with palms flat on the floor with knees slightly apart. Your child should then arch his/her back like a cat stretching, pushing the head down. Now slowly push the back down and lift the head up. **Repeat 5-10 times.**



The Banana

Start by lying on the tummy with legs straight and arms to the side. Your child then needs lift up their head, shoulders and arms to look forwards. The legs should remain straight and not bent at the knees: they will come off the floor a little. Hold this position for 3 seconds **Repeat this 5-10 times.**



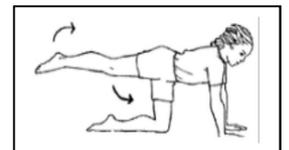
The Bridge

Start with your child lying on his/her back with feet lightly apart and knees bent. Arms should rest on the floor to the child’s sides. Your child should lift up his/her bottom so that the trunk and upper legs are in line. Hold this position for 5 seconds. **Repeat 5-10 times**



The Dog Balance

Start in a “hands and knees” position with palms flat and knees slightly apart. Ask your child to lift up his/her leg, making sure that the trunk does not twist. Try to get the leg in line with the trunk, hold this position for 3 seconds, then lower the leg. **Repeat 5-10 times**



Increase Leg Strength

By improving muscle strength in the legs motor skills such as walking tolerance and balance will be improved. There are many daily activities which can be used to improve leg strength:

- Swimming
- Riding a scooter and/or bike
- Play parks and soft play
- Ball games- for example kicking a ball
- Jumping games

If pain is an issue aim to do these activities in short spells and gradually increase the time your child spends doing them.

There are also specific exercises that a child can do to improve their leg strength:

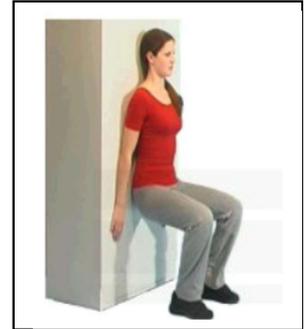
Hip strengthening

Your child needs to lie on his/her side with their legs out straight, make sure they lie in a straight line from the back and hips down to their feet. They then need to lift up the top leg keeping the legs in line, hold this position for 5 seconds and lower slowly. **Repeat 10 times** then do the same on the other leg.



Strengthening the Thigh 1

Stand your child with his/her back against the wall with their feet a little wider than their hips, he/she needs to bend their knees and slowly slide down the wall in a squat position. **Repeat 10 times**



Improving Hand Ability

Fine motor control involves the ability to use hands and fingers precisely during a skilled activity. Good fine motor control stems from solid sensory and motor foundations. The following are activity ideas will fine motor skills and strength of the hand muscles:

Peg and bulldog clips

Encourage your child to use the thumb and index finger to open the peg. Pegs can be sorted into colours around the edge of a box: can be matched with colours drawn onto the edge off a box, or used to clip card letters to the edge of a box to make words.

Using tweezers or sugar tongs

Give your child a plate of objects to hold in the non-dominant hand. Using tweezers held in the dominant hand the child picks up an object and sorts it into piles or pots of similar objects. Objects can include Lego pieces, buttons, seeds etc.

Pipe cleaners

Twist pipe cleaners together to make patterns, shapes, and objects.

Pegboard kits

These come in a variety of sizes to suit all levels of dexterity. Some kits can be melted together to make permanent decorations (a magnet can also be attached to the back).

Textured paper collage

Ask your child to tear up some tissue paper into approx. 2cm square pieces. These can then be scrunched up in the fingers and stuck onto card shapes to make textured pictures.

Other activities include:

- Origami
- Weaving
- Playdough
- Sorting small objects with fingers
- Card games
- Marble games
- Fuzzyfelt
- Sticker books

Other commercial games include:

- Tiddly winks
- Pick-up sticks
- Operation
- Penguin Pile Up
- Pocket Solitaire and Battleships games etc.

Handwriting

“Long writes” (and other lengthy pencil tasks such as colouring) should be avoided with activities being broken down into chunks that are more manageable.

Stationary Suggestions

- Weak hand skills can affect writing. Different writing tools suit each individual, but those with a chunkier handle are often easier to use.
- Provide a pencil with a retractable lead to encourage the child to reduce pressure when writing.
- Use of a writing slope can help to reduce hand pressure
- For homework, consider alternatives to writing such as computer and voice-activated software which can be very helpful.

Choosing the Correct Footwear

All children require supportive shoes and by having the feet correctly supported it gives more support to the joints of the legs.

Children especially girls like to wear shoes that are not supportive- these should be used on special occasions only. For day to day school foot-wear supportive shoes need to be worn. Shoes do not need to be expensive and supermarkets, cheaper shoe shops now offer well supported shoes but the following advice needs to be followed:

- Shoes need to be stiff around the heel
- A sturdy sole is required in order to check this try to bend the shoe. (A supportive sole should only bend at the toe.)
- The shoe should have laces or velcro straps across the top of the shoe. To enclose the foot properly. Straps need to be done up tightly.
- Boots maybe more effective than shoes

Avoid shoes which have

- No support around the heel, for example flip flops and sandals
- Thin soles
- Low sides at the back or sides
- Slip on shoes- these do not have enough support

Good Shoes



Bad Shoes



Advice for Schools

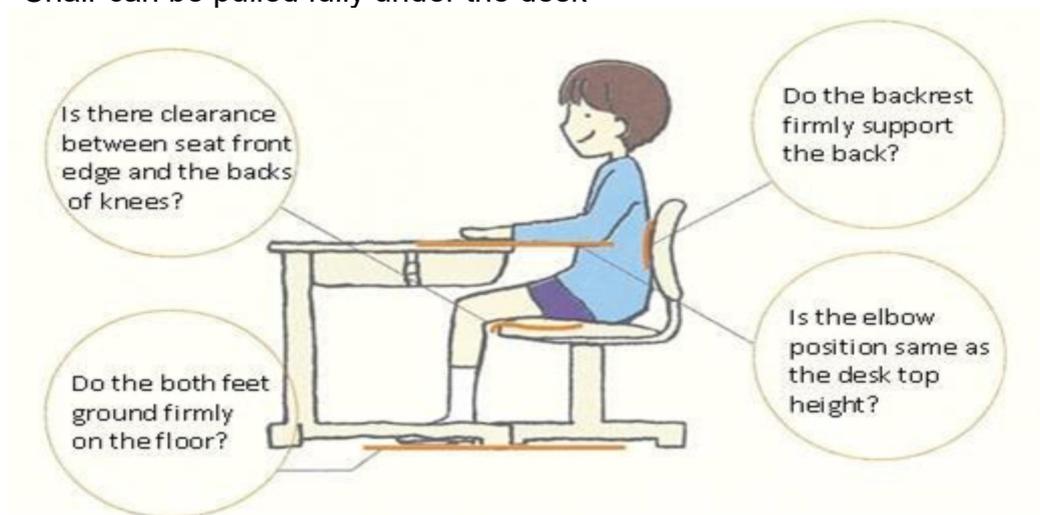
Correct Seating Options

Children with hypermobility are more prone to acquire bad postures. Good seating and positioning is essential to prevent back strain and poor posture, so it is important to get this right as soon as children start school. It is also important for good use of the hands, especially for complex tasks that require a high level of dexterity and concentration such as writing. A child who has poor sitting posture will use more effort to carry out table top activities and the fluency and accuracy of their arms/hand movements will be affected.

Children who have to concentrate on their sitting position will be less able to concentrate on the task that has been set, and may miss instructions or information. They can also appear fidgety and distractible. Improving a child's sitting posture can have a significant impact on their academic attainment and confidence in the classroom.

What does a good posture look like?

- Hips, knees and ankles are at 90 degrees (hips can be a little higher than the knees if this is more comfortable and the feet are supported)
- Appropriate seat depth so that the bottom is at the back of the chair and the thighs are fully supported. Make sure that the front of the seat is not digging into the back of the knees
- Appropriate seat height so that the feet are flat on the floor or are supported in some other way
- Arms rest comfortably on the table, without shoulders "hunched"
- Chair can be pulled fully under the desk



Watch out for:

Children who sit awkwardly on their chair because it isn't the correct height e.g.:

- Sitting on the front edge of the seat
- Kneeling on the chair
- Wrapping their legs around the chair legs
- Tipping the chair forward onto the front chair legs.
- Children who are hunched over the desk with their head too close to their work because the table is too low
- Children who are working with their elbows and shoulders raised because the table is too high



Seating for children with mild motor difficulties

The principles of good seating and posture are especially important for children with mild motor difficulties including those with dyspraxia. Getting seating right is a “reasonable adjustment” that will help schools to ensure all children are able to access learning opportunities in the classroom.

In addition it may also be beneficial to provide the following:

- A chair with sides or arms to provide guidance re trunk position
- A chair with a full back rest
- A chair with a straight, rather than angled seat and back
- A good, heavy footrest (one that can't be kicked away)
- A chair than can easily be moved under and out of a table

Support in the Learning Environment

Environment

- Provide a safe environment – consider any access issues such as steps and slopes. Identify alternative routes around school to minimise walking during the day. A pupil may need more time to get to classes.
- Consider use of a lift pass to reduce distances and use of stairs at busy times.
- Consider accessible toilet and hand rails. Lever or sensor taps and pump soap dispenser will be easier due to poor hand strength.
- Prolonged floor sitting may be uncomfortable, so a reasonable adjustment might be to provide a chair for carpet time or assemblies.
- Ensure seating is appropriate – see separate section on page 11.
- Provide a rest area if required, access to the first aid room and quick access to medication if required.
- Wherever applicable it would be helpful to have the same desk / work-space set-up following appropriate ergonomic assessment.
- Chairs without arm rests and stools (such as those used at lab tables) can be very uncomfortable. Some children have benefited from having bespoke chairs with wheels that can be taken to classes.

Fatigue and Pacing

- A child with hypermobility usually experiences fatigue so it is important to pace physical activities throughout the day and to provide breaks or rest as required.
- Some students may struggle to keep up with peers in the playground or alternatively 'boom and bust' using all their energy at this time, making it harder for them to be able to cope during the rest of the day. Students may not be skilled in their pacing and this will need to be monitored allowing for 'down time' and rest periods during the day.
- Reduce the amount of equipment and weight of school bags. Provide a duplicate set of text books for the student to keep at home so that they don't have to be carried around at school.
- Provide a secure locker or storage space to leave PE kits, equipment, books etc.
- Agree a signal or provide a pass to allow the student to indicate that they need a break without drawing attention to themselves. Examples include putting an object or card on the desk or asking a particular question.
- Allow rest periods. For example, some may use this to stretch painful joints and re-adjust, others to rehydrate etc.
- Identify and allow access to support staff in the school setting which will reduce the need for more time off school. Identification of a 'buddy' to assist the student where and if appropriate can be helpful physically and emotionally.

Classroom Work

- 'Long writes' and other lengthy tasks such as colouring should be broken down into manageable chunks with rest breaks
- Allow for some 'non-writing' time in-between activities such as reading
- Weak hand skills can affect writing. Different writing tools will suit different individuals, pencil grips and chunky pencils, crayons and handles can all be considered. Consider other adapted equipment such as specialist scissors and D&T equipment
- Use of a slope writing board can help to reduce hand pressure
- If practical allow study and completion of course work from home as required.
- Review timetables that make up the various subjects being studied to determine whether high levels of essay work etc. will coincide across the subjects. If it is possible to predict these peaks, is it also possible to then spread the work out and / or extend deadlines for completing work?
- Extra adult support may be needed to help a pupil participate in school-based activities and visits in order to fully include the pupil and not isolate them from their peers
- Consider alternatives to writing such as the use of a laptop in class / lectures and exams for those with poor hand function. The use of voice-activated software or use of a scribe can also be helpful. Consideration will need to be made for the teaching of touch typing skills, training in the use of software, storage and carrying of equipment around school.

For those with poor hand function, to negate the need to type or write things down:

- Ensure course materials presented electronically e.g., power-point presentations and worksheets can be made available in hard copy / electronically.
- Provide adapted copies of worksheets so that student can fill in blanks, underline instead of writing out the whole question.
- Ensure the learning objective date and title are already in the student's book before he/she starts.
- Active use of a home -school book and planners can reduce the possibility of deadlines or homework being missed and also help with home –school communication.

For examinations and controlled assessments up to 25% additional time can be requested, plus an allowance for rest periods as required, and where hand function is poor, allowing work to be typed or to have a scribe if this is the normal way of working.

Recommendations and Suggestions for: Physical Education

Being fit and participating in physical activity and sport is an important part of a child's development. Hypermobile children are encouraged to participate in appropriate physical activity and sport, in order to facilitate their physical development and specifically to improve their co- ordination, muscle strength, stamina and confidence. Unless a doctor or physiotherapist has advised a pupil not to do P.E then participation should be encouraged with the risks minimised and activities differentiated as appropriate. Participation in contact sports needs to be discussed.

Risk Factors: There are a number of injury risk factors for students. These can be sub- divided into two broad categories, internal and external factors:

External risk factors include the nature of the sport, the rules, footwear, playing surface, weather and equipment.

Internal risk factors include: a child's strength, cardiovascular fitness, flexibility co- ordination and level of skill.

Strategies and tips:

- Some students become deconditioned due to avoiding exercise, so build up stamina and strength gradually, allowing time to rest and recover.
- Avoid exercises involving heavy weights and intense muscular exertion/contact sports.
- Focus on activities which promote control of movement, co-ordination, graduated strengthening of muscles, stability of joints and careful cardiovascular fitness.
- Some students may be able to better tolerate sports such as swimming, gymnastics and cycling, usually on a non-competitive basis.
- Provide hands on assistance and/or demonstrations to model the movements required. The use of mirrors to aid proprioception, may help some students better understand body positioning and to master required movements.
- Allow sufficient time for gradual warm-up and cool-down.
- Be receptive to a student who reports certain symptoms, such as pain and fatigue
- Monitor the student's level of exertion more closely in extreme heat or cold. Allow the student rest breaks in order to extend the overall length of participation
- Be aware that symptoms and the severity of those symptoms can change significantly from one day to the next in those with hypermobility. Students may seem able to do an activity with little problem one day and then struggle greatly with it the next

From the pupil's point of view:

- Ask me what I like to do in P.E.
- Don't be afraid to ask me for ideas on how I can be included.
- Always make me feel involved and do not leave me sat on the side-lines, feeling left out or excluded.
- Do a normal P.E lesson, but always adapt it so I can take part. Do it in such a way that it is not obvious and everyone in the class gets something out of it.
- Be adventurous with your adaptations to an activity.
- If I don't want to get involved in the main activity, get me involved in other ways (e.g. scoring, refereeing, and setting up coaching drills) but don't offer this as the only solution, include me as much as possible so I am equal to my peers.
- Make sure the other children are understanding about what I can and can't do.
- Don't be afraid to try, if it doesn't work we will do it differently next time.

Lunchtime and Playground Advice

- Some students may struggle to keep up with peers in the playground or alternatively 'boom and bust' using all their energy at this time, making it harder for them to be able to cope during the rest of the day.
- This unstructured part of the school day can be a vulnerable time for some students, particularly with regard to their self-esteem. This can present with issues such as only choosing finger food items to avoid cutlery, not participating with group play, avoidance of joining lunchtime clubs and behaviour issues.
- The student is at higher risk of trips and falls which can lead to embarrassment.
- Lunch time staff to be aware of the student's needs and to provide and encourage quieter inclusive play activities.
- Students may not be skilled in their pacing and this will need to be monitored by an adult allowing for 'down time' and rest periods during the day.
- Provide opportunities to play with peers in a quieter area or inside if required.
- Consider seating and quiet areas to rest comfortably.
- Adult to monitor and help with undressing and encourage independence when student uses the toilet.
- Outside play equipment needs adult to monitor as the student may be unsteady or lose balance.
- Consider angled cutlery from the 'Good Grips' range to encourage independence. Allow additional time to finish eating.
- Consider supportive lunch time seating



What happens next?

Whilst waiting for an occupational therapy or physiotherapy assessment please try this advice. During this time use the record sheets (sent to you with this booklet) to record what strategies have been tried and the outcomes of these strategies. This will help your therapist direct your child's assessment to the relevant areas and target therapy appropriately.

Once a child reaches the top of the waiting list an appointment will be sent for your child and parents/carers to attend an assessment. Prior to this assessment please can parents/carers and school teacher complete the record sheets. They can then be brought by parents to the assessment. The occupational therapist or physiotherapist will review these records with child and parents and use these to inform the interventions offered.

If you require additional information or clarification on anything in this booklet please contact children's therapies service:

**Children's Community Therapies
Chelmsley wood Primary Care Centre
Crabtree Drive
Chelmsley Wood
B37 5BU**

Tel 0121 722 8010

Our commitment to confidentiality

We keep personal and clinical information about you to ensure you receive appropriate care and treatment. Everyone working in the NHS has a legal duty to keep information about you confidential.

We will share information with other parts of the NHS to support your healthcare needs, and we will inform your GP of your progress unless you ask us not to. If we need to share information that identifies you with other organisations we will ask for your consent. You can help us by pointing out any information in your records which is wrong or needs updating.

Additional Sources of Information:

Go online and view NHS Choices website for more information about a wide range of health topics <http://www.nhs.uk/Pages/HomePage.aspx>

You may want to visit one of our Health Information Centres located in:

- Main Entrance at Birmingham Heartlands Hospital Tel: 0121 424 2280
 - Treatment Centre at Good Hope Hospital Tel: 0121 424 9946
 - Clinic Entrance Solihull Hospital Tel: 0121 424 5616
- or contact us by email: healthinfo.centre@heartofengland.nhs.uk.

Dear Patient

We welcome your views on what you thought of this patient information leaflet, also any suggestions on how you feel we can improve through our feedback link below:

- Patient Information Feedback email: patientinformationleafletfeedback@heartofengland.nhs.uk

If you wish to make any other comments this can be done through the links listed below:

- Patient Opinion: www.patientopinion.org.uk
- I want great care: www.iwantgreatcare.org (Here you can leave feedback about your doctor)

Be helpful and respectful: think about what people might want to know about our patient information and this hospital and how your experiences might benefit others. Remember your words must be polite and respectful, and you cannot name individuals on the sites.

If you have any questions you may want to ask about your condition or your treatment or if there is anything you do not understand and you wish to know more about please write them down and your doctor will be more than happy to try and answer them for you.

