

HYPERMOBILITY SPECTRUM DISORDER



A Guide for Parents about hypermobility and what it means for your child.

WHAT IS HYPERMOBILITY SPECTRUM DISORDER?

“A hypermobile joint is one whose range of movement exceeds the norm for that individual, taking into consideration age, sex and ethnic background”. This is assessed by moving your child’s joints.

Hypermobility Spectrum Disorder has been recognised as a distinct diagnosis since 1967 and has since then been referred to by a variety of names: Hypermobility Syndrome, Joint Hypermobility Syndrome, Hypermobile Joint Syndrome and Benign Joint Hypermobility Syndrome (BJHS).

It is commonly believed that Joint hypermobility result from genetic variations in connective tissue matrix proteins, which results in stretchier tissues. There are other genetic collagen disorders that have hypermobility as a symptom, but hypermobility is also common within the general population and may be a result of normal genetic variation. All other causes of hypermobility will be ruled out before the diagnosis of HSD is given.

Possible features of HSD:

- Joints that are very mobile (hypermobility – **normal**)
- ***Weakness*** of muscles (**this is cause of the problem!**)
- ***Pain*** – this may be very specific (i.e. 1 – 2 joints) or very general (many joints and/or muscles) and is caused by over stretching of the joints and fatiguing of the muscles.
- ***Tiredness*** – caused by ineffective muscles.
- ***Poor balance and co-ordination.***
- Difficulty doing things independently – i.e. walking long distances / writing, cutlery etc – due to weak muscles and pain.
- Easy bruising, abdominal pains, headaches, dizziness, constipation, reflux, clicking joints, fidgetiness, urinary problems, gait problems, flat feet, poor concentration and anxiety occur in some

Your child may experience some or all of these difficulties at various times, but there is a great deal that can be done to help ease or indeed get rid of these problems.

There is little that can or needs to be done about the joint movement as the main cause of the problems are due to the ineffective use of the muscles controlling the joints.

The importance of muscles:

The muscles main job is to either move or to stabilise a joint, therefore allowing a person to move about safely and effectively. Muscles will help to control the range of movement as well as produce the force needed to move. This is therefore very important in hypermobility as the muscles tend to be weak and unfit and are unable to do their job properly.

Therefore the main treatment of hypermobility is to improve muscle strength and fitness to ensure that the joints are protected at all times.

Treatment:

- There is no medication that can be provided to help improve hypermobility; however, pain relief and/ or anti-inflammatory drugs may help at the onset of acute problems. These may help with the management of pain but will not alter the cause of the symptoms.
- The most important treatment is **the exercise programme** that will be given for your child to do at home on a regular basis. This programme will be designed to improve the strength and fitness of each of your child's muscles as well as to improve their general fitness. This will then ensure that the muscles are protecting the joints during all activities and therefore easing the pain. This programme will be gradually progressed to consist of a large number of **repetitions (30)** of the exercises and progressed further by adding resistance by the **use of weights** (max 5-10lbs)
- In some cases the provision of supports such as pen-grips or **insoles** may help. These are to be used in conjunction with an exercise programme to ensure that the muscle strength is improved too. It is important that other types of splint / support are not used as this encourages further muscle weakness and will in fact make the symptoms worse.
- Some need occupational therapy and osteopathy

The Future:

In many cases children grow out of their hypermobility (their joints become less mobile with age) and the symptoms ease spontaneously.

However research has shown that joints that are not protected adequately by strong fit muscles may be more likely to develop osteoarthritis.

Therefore the aim of all of the treatments is to ensure that your child becomes a normal active child who is physically able to do all that they want, ensuring that their joints are protected by strong fit muscles. This however may require a long – term commitment to a home exercise / management programme.

Therapy support:

During the initial diagnosis and establishment of the management programme you may have access to regular therapy input to ensure your child is confident with their exercises and in managing this condition.

However this will not be provided long-term, as home management is the most appropriate method of managing HSD.