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Hypermobility spectrum disorders (Hypermobility syndrome)

Hypermobility spectrum disorders include all people with what used to be called joint hypermobility syndrome, and before that benign joint hypermobility syndrome. Anyone who has symptoms as a result of having hypermobile joints, but who does not have all the features of Ehlers-Danlos syndrome, has a hypermobility spectrum disorder.

These problems mainly affect children and young adolescents with extra-flexible (hypermobile) joints who develop pain on exercise, which persists when they rest. These conditions can have a major impact on school and sporting life. Whilst they do not usually cause long-term harm, they can be associated with injuries and can sometimes persist into adulthood. Treatment is aimed at increasing muscle strength and joint resilience without causing injury.

What are the hypermobility spectrum disorders?

Hypermobility spectrum disorders (HSDs) are a group of conditions that involve joint hypermobility (increased range of motion in the joints, sometimes referred to as "loose joints") and musculoskeletal symptoms, but may not meet the criteria for a specific connective tissue disorder like [Ehlers-Danlos syndrome \(EDS\)](#).

The hypermobility spectrum is considered a spectrum because it encompasses a range of symptoms and severity.

In joint hypermobility, the joints are more than usually flexible (sometimes called being 'double-jointed') and this is linked to joint and muscle pain which typically relates to exercise.

It is most often seen in children and young people, although it can sometimes persist into adulthood. It is not known why some children with 'double-jointedness' have painful muscles whilst others do not.

What causes joint hypermobility?

It's thought that people with hypermobile joints may have stretchier elastic tissues in their bodies, particularly muscles and ligaments, than those without. People vary widely in this 'stretchiness', and hypermobility is probably just the stretchiest group of people in a wide but normal group.

Nobody knows why some children and adults with hypermobile joints develop difficult symptoms, whilst most do not, but it may be that these children and adults are the ones with the most stretchy tissues of all.

Other factors may also contribute, including muscles that tend to be more relaxed at rest than the average. There may also be natural variations in the way bony joints are shaped, so that some people's joints can move to greater extremes than those of other people.

Joint hypermobility can run in families and it cannot be prevented.

How common are hypermobility spectrum disorders and joint hypermobility?

Joint hypermobility and HSDs are very common in children of school age. Everyone will remember children at school who could do 'the splits' easily, for example, and others who never could despite trying.

Up to 4 in 10 of young teenage girls and about 1 in 10 of young teenage boys have hyper-flexible joints. However, for most of these children, there is no associated pain.

About 1 in 10 children with hypermobile joints experience pain related to exercise, and this is then referred to as a hypermobility spectrum disorder. Most will recover with support and graded exercise, but a few will find it more limiting. It is not clear why some children experience pain, whilst most do not.

HSDs are more common in Asian-American children and least common in African-American children. The reasons for that are probably genetic. Many people with Down's syndrome are also hypermobile.

What are the symptoms of hypermobility spectrum disorders?

The main symptoms of HSDs are:

- Joint hypermobility.
- Muscle and joint pains after exercise.
- Tiredness.

There is enormous variation in severity and impact, from children who can 'exercise past it' relatively easily to children who find it has a real impact on their ability to be active, and who experience a lot of discomfort.

Pain

Pain is most common in the legs and knees, feet and ankles, and is usually after activity and at night.

Younger children seem to have more pain. Muscles and joints are often stiff and sore for a few days after increased exercise and children may quickly be put off from exercising.

Back pain and headaches are also common, mainly because posture gets worse as muscles become weaker.

Pain is often a burning or throbbing pain which can make muscles feel restless and fidgety.

Pain may disturb sleep and mood, and can last up to 48 hours. Taking painkillers can add to this if they cause side-effects such as nausea or loss of appetite. Fear of worsening pain may make children stop exercise completely.

Tiredness

As children become less fit they become more tired and their muscles tire more easily with activity. This becomes a vicious cycle as they become less and less active.

Unused muscles become restless and fidgety, so that a distressing sense of leg fidgetiness can be added to the symptoms of soreness and tiredness. Handwriting may be uncomfortable and writing may become harder to form neatly, and harder to read.

Reduced fitness

Reduced fitness affects sleep, energy, concentration and general activity. As muscle tone becomes worse, posture worsens and headaches and back pain become common.

Balance is also affected as the core muscles become less supportive. This means skills at sports like hockey and football will also reduce.

Loss of fitness may lead to weight gain, low mood, a sense of exclusion and difference, and loss of self-esteem. This can be a vicious cycle as frustration sets in when trying to increase exercise and makes things feel worse.

Other symptoms

Other common symptoms of HSDs include:

- Bruising easily.
- Having 'clicky' or 'snappy' joints.
- Tummy (abdominal) pain.
- Constipation.

Rarely, children with HSDs develop hernias and other physical signs of muscle weakness, although this (like dislocation) is more likely to be seen in EDS than in the HSDs.

Fainting or sometimes just feeling faint, is an uncommon symptom. This is thought to be due to rather slow blood pressure 'reflexes' - which means the blood pressure tends to be rather slow to increase when it needs to - for example, when standing up quickly. This may be in part because softer leg muscles don't pump the circulation quite as effectively.

Are hypermobility spectrum disorders different from Ehlers–Danlos syndrome?

The reason we now use the term hypermobility spectrum disorders (HSDs) rather than joint hypermobility syndrome is because everyone is different. Some people are just very flexible – they don't have pain and they never have any other problems.

At the other end of the spectrum is [Ehlers–Danlos syndrome](#), hypermobility type (EDS-HT). This also causes joint hypermobility with chronic pain, although it commonly causes many other more generalised symptoms.

In between these two extremes are the HSDs. These are people who have significant problems such as pain, [joint dislocations](#) or frequent joint injuries. The two conditions are closely related, and their symptoms overlap considerably.

However, EDS is generally the more severe end of the spectrum, and causes a wider range of symptoms.

- Joint hypermobility without pain occurs when children have stretchy or flexible joints, but without exercise-related pain. This is an advantage to some children, and tends to be associated with being good at sport.
- HSDs are the diagnosis where the main or only symptoms are exercise-related pain, together with joint hypermobility.
- EDS is usually thought to be the right diagnosis where there is a family history of similar symptoms, or where conditions like hernia and dislocations occur.

To read more about EDS-HT, see the separate leaflet called [Ehlers–Danlos Syndrome](#).

Is joint hypermobility different from growing pains?

The symptoms of growing pains show some overlap with HSDs, but growing pains are more intermittent, are not generally so clearly related to exercise and tend to affect mainly children aged under 12 years. Growing pains are nevertheless more common in active children and in children with hypermobile joints.

Growing pains are usually felt as aching or throbbing in the front of the thighs or back of the calves. They tend to affect both legs and typically occur at night, but not every night. They are thought most likely to be muscle pain at night from overuse during the day.

Mild cases of HSD may seem like growing pains; however, if your child's pain is clearly related to exercise and is stopping them from joining in, then it's more likely that HSD is the diagnosis.

[For more information, see the separate leaflet called Growing Pains.](#)

What are the complications of hypermobility spectrum disorders?

HSDs can be a problem for young people and for adults. This is not only because of their symptoms, but also because of their possible complications.

Having flexible joints (hypermobility) is commonly an advantage in sport and dance, and is seen in many successful sportspeople. The flexibility of their joints and stretchiness of their muscles make these people extra mobile and extra agile.

However, increased flexibility and ability to stretch can not only lead to pain, loss of fitness, tiredness and poor self-esteem, it can also lead to injury. It can also have a wider-reaching effect on school performance.

Injuries

- HSDs not only lead to pain where there is no injury but, importantly, also make people more prone to injury. Tendon injuries and dislocations occur more easily around joints which are less tightly supported.
- This means that, whilst encouraging children with exercise-related pain to exercise when they have pain is often a part of the solution, this also risks them injuring themselves, because they are being taught they should not stop when it hurts, which is the opposite of what we would normally do. Careful support and management are therefore needed to find a balance between increasing muscle strength, and risking injury.
- Recurrent dislocations can lead to chronic pain in joints, and can make wear-and-tear type arthritis (osteoarthritis) slightly more likely in later life.
- Very occasionally, if your back is hyper-flexible, the bones in the back can slip slightly out of line, causing back pain, This is called spondylolisthesis.

School performance

- The muscle symptoms of HSDs are most commonly felt in the legs. However arms, back and shoulders can also be affected. Handwriting can become a problem, with the hand and wrist hurting with prolonged writing. Some children may benefit from having a scribe in exams.
- Children can also feel generally fidgety and tired and their concentration in class may fade fast, affecting their academic performance.
- It may also affect the ability to join in with team experiences, and the things children learn from sport, such as leadership, teamwork and perseverance. It can therefore have an impact on what a child gains from their education, and important learning opportunities may be lost. It's important for schools to be aware of this and to find other ways that children with a severe HSD, who are not managing team sports successfully, can take part in, and lead, other team activities.

Can you grow out of a hypermobility spectrum disorder?

Most cases will respond to graded exercise and support, and for most children there will be no long-term physical consequences.

For a small percentage of children, symptoms are more severe and need more intensive support. For some, the HSD will continue into adulthood. Some of these children will have other symptoms and may actually have the hypermobility type of EDS.

How is hypermobility spectrum disorder diagnosed?

HSDs are diagnosed from the presence of a set of symptoms, or 'criteria'. These are a combination of the **Beighton hypermobility score** and the child or young person's symptoms.

The Beighton hypermobility score is a 9-point scoring system based on little fingers, thumbs, elbows, knees and trunk. It is used to assess hypermobility, using a standard set of movements of thumb and wrist, fifth finger, elbows, back and knees. For example, one of the tests is positive if the little finger can be bent backwards beyond 90 degrees. For more information, see the 'Further Reading' links below.

Children with a possible HSD are usually seen by a specialist, who will examine the child and talk with them about their activities, including hobbies, physical activity and sleep. They will also talk with them about the effect their symptoms are having at school and at home.

They may want to be sure that your child does not have another condition such as early rheumatoid arthritis, and may arrange a specialist referral or blood tests.

The doctor will use the diagnostic criteria to consider the diagnosis of HSD, and to exclude a diagnosis of EDS. He or she will assess your child's muscle strength by pulling and pushing at various muscles, particularly in the legs and arms. Your child may be asked to walk or run.

There are no other tests; the diagnosis is based on these findings. However, if your doctor still needs to rule out other conditions like arthritis then blood tests or X-rays may be needed.

Where can I get help if I think my child has a hypermobility spectrum disorder?

If your child is hypermobile and seems to have symptoms, read information like this leaflet and visit your GP, explaining what you think and that you would like a referral to physiotherapy or occupational therapy, or to a paediatrician with an interest in muscle and joint disorders.

Also consider talking to your child's school, since many PE teachers will be well informed about this condition and may have information about the most helpful local services.

Patients have often seen a number of health professionals before a diagnosis is reached.

You can also contact the UK-based Hypermobility Syndromes Association (details in Further Reading, below).

What other diagnoses are similar to hypermobility spectrum disorders?

Other conditions which need to be ruled out if your child has joint and muscle pains are:

- [Marfan syndrome.](#)
- [Juvenile idiopathic arthritis.](#)
- [Rheumatoid arthritis.](#)
- [Ankylosing spondylitis.](#)
- [Fibromyalgia.](#)

How are hypermobility spectrum disorders treated?

Strengthening the muscles

The first aim of treatment is aimed at strengthening the muscles that need to support the hypermobile joints. This will improve posture, strength and fitness for most children.

It can be difficult for young patients to persevere with this, since exercise hurts and increasing exercise hurts more. This can be difficult, as it involves exercising through some pain whilst recognising when to stop, since children with the condition are at greater risk of damaging their joints and muscles.

Successfully increasing fitness needs education and moral support, so that children believe in the treatment and will persevere. If injury results then this will be a real setback to the child's faith in exercise as a way of managing their condition.

This needs a graduated supervised exercise programme. This benefits from help from physiotherapy. A visit to a podiatrist to assess the need for shoe inserts to correct foot posture can also be valuable. The goal is full participation in all activities, regaining strength and minimising or overcoming symptoms.

There are also things you and your child should do at home, and when your child exercises.

If a diagnosis of HSD is made, many NHS professionals can help, including physiotherapists, podiatrists and counsellors.

How much treatment is available on the NHS will depend on the severity of the condition and on services in your area. However, your child's school PE department and, for some children, individual sports clubs, can be an extremely valuable source of support and help.

Supported self-management

The aim of treatment, whether from a physiotherapist, doctor, PE teacher or sports coach, is to help children treat this condition themselves. Most children with mild symptoms will recover with parental and school support, without the need for other professional help.

However in severe cases, or where exercise and support are not helping, it is important to go back to your doctor to ask for help again.

The aim of supported self-management is to help young people to understand the need to exercise regularly and work through discomfort over time. It also helps them recognise the difference between the level of discomfort which can be worked through, and the level which may cause injury.

The most important thing is to understand that the muscle pain felt after exercise is not usually a sign of injury and does not mean that exercise is harmful, whilst recognising that this does not mean that over-exercising can't cause injury (this is also true of people without an HSD). The secret is to strengthen muscles as much as possible, but with care.

Managing tiredness

Tiredness is common in young people with an HSD. They need to understand that being tired doesn't necessarily mean they need more rest. In fact, tiredness sometimes shows that the body needs to increase fitness. Gradually increasing activity levels is the most effective treatment for daytime tiredness.

However, it is important for young people to recognise that doing too much may lead to pain and tiredness: they need to learn to listen to their body and pace themselves. They also need to be realistic - although there are going to be times when they have relapses, it is important that they do not stop any activity for long periods of time.

Pain management

Pain can affect concentration, memory, mood and sleeping. Reassurance is needed that the pain is not harmful, as long as there is no injury, but it's also important to find ways to help your child manage the pain.

Before doing so it is important to make sure there is no injury, particularly if your child's pain seems worse. Injury is usually obvious because of increased heat, swelling and sudden worsening of pain.

The pain of HSDs tends to be symmetrical (occurring on both sides of the body) and the 'same as usual'. Much worse pain, pain just in one place, or pain with heat, swelling or bruising, or muscles and joints that your child cannot bear to move, suggest injury.

Painkillers

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).
- Talking and encouragement from parents and friends.
- Relaxation treatments like massage and aromatherapy.
- Gentle assisted stretching exercises.
- Warm baths.
- Encouragement and understanding.

However, occasional use of medicines such as paracetamol or non-steroidal anti-inflammatory drugs may sometimes be needed.

Injury management

- After an injury then the joints and muscles must be treated more gently – but this does not mean no movement at all. It is possible to exercise in a way that provokes very little pain and keeps muscles and joints fit and in working order. Children need to overcome the fear of movement by doing small movements early.
- [See also the separate leaflet called Sprains and Strains.](#)

Physiotherapy

- Physiotherapy uses specific exercises to work on the muscles that most need help. It also helps support your child to help them add regular exercise into their daily life.
- Children with HSDs will at first have a lot of pain and fatigue the day after physiotherapy. It can also be hard for them to repeat the exercises accurately at home alone. It's also important that someone makes sure they are not over-exercising and injuring themselves.
- Parents can play an important role in monitoring and checking the exercises, and your child's school PE teacher may be able to help.

Occupational therapy

This type of therapy aims to help with activities of daily living. An occupational therapist (OT) may look at the type of chair your child uses, at their mattress, or at a pen that makes writing less painful. An OT assessment in school can be helpful.

Podiatry

A podiatrist is a person who is qualified to diagnose and treat foot disorders. A podiatrist may be able to offer corrective insoles to correct the posture of the feet. If these are tilted 'out of line' this tilt can add to leg pain and make recovery more difficult.

Many successful sportspeople, including top tennis players, use these types of insoles. A single appointment may be all that's needed.

Choosing your sport if you have joint hypermobility syndrome

- Some sports are harder on the joints than others, and may need to be avoided for longer than others. This is particularly true of those that strain the joints through repeated impact, such as trampolining and using bouncy castles, and those that stretch the joints further, like gymnastics and ballet.
- Children with HSDs may be very good at these sports, and it is important to find a balance between encouraging them to do what they enjoy, and recognising a cause of pain. As long as your child is not being injured, if they want to continue the sport they have chosen and can live with the level of pain and discomfort it causes then they should do so, although coaches should be made fully aware of the condition.

Weight management

- It is important for your child to maintain a healthy weight. Being underweight will make muscles weaker, whilst being overweight puts more strain on the joints. Both extremes will tend to increase symptoms.
- Fitness and weight are best managed through a healthy diet and regular exercise, even if exercising needs to be light and careful at first.

Mood and joint hypermobility syndrome

If your child has a low mood because of tiredness and pain then they may need help with this from a school nurse or counsellor, or from your doctor.

Special equipment

No special equipment is usually required. Wheelchairs and crutches are very unhelpful in HSDs, and will tend to make the situation worse. Anything that makes your child feel or behave like a physically restricted person is likely to be unhelpful.

Support for joint hypermobility syndrome

The UK-based Hypermobility Syndromes Association (see details in Further Reading, below) is a source for support and information for families, patients and schools.

Surgery

Surgery is not usually recommended for HSDs, but surgery may be needed to repair a tendon if it is torn through injury.

Complementary medicine

There is no evidence to support complementary medicine for the muscle pain in HSDs.

What can schools do to help?

Schools should encourage affected children to take part in sport, whilst making allowances for the child's reduced stamina. Supportive seating will help with backache, fidgeting and tiredness.

Children struggling with handwriting may benefit from keyboard use or from scribes or extra time in tests and examinations. Extra time may be needed to move between lessons and the school should try to avoid expecting children to carry all their books around with them all day.

What is the outlook for hypermobility spectrum disorders?

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. These tend to be the more severely affected children, some of whom may have EDS, hypermobility type (EDS-HT). These tend to be the children whose joint laxity results in easy injury, so that exercise is very difficult and it is hard for them to distinguish between the pain they are asked to exercise with, and the pain that suggests they should stop.

Except at the severe end of the spectrum, an HSD rarely causes long-term problems like arthritis by itself. However, problems can develop with joints that have been repeatedly dislocated.

Young people who continue to have HSD symptoms when fully grown, as adults are at slightly greater risk of developing osteoarthritis of affected joints.

Dr Mary Lowth is an author or the original author of this leaflet.

Further reading

- [Hypermobility Syndromes Association](#)
- [What is Joint Hypermobility?; Versus Arthritis \(pre-2018 Arthritis Care and Arthritis Research UK\), 2019](#)
- [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 \(2019\)](#)
- [Hypermobility EDS and hypermobility spectrum disorders; Ehlers-Danlos Support UK](#)
- [Beighton scoring system for joint hypermobility](#)
- [Yew KS, Kamps-Schmitt KA, Borge R; Hypermobility Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorders. Am Fam Physician. 2021 Apr 15;103\(8\):481-492.](#)
- [Atwell K, Michael W, Dubey J, et al; Diagnosis and Management of Hypermobility Spectrum Disorders in Primary Care. J Am Board Fam Med. 2021 Jul-Aug;34\(4\):838-848. doi: 10.3122/jabfm.2021.04.200374.](#)

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