

Joint hypermobility syndromes

arthritis-uk.org



 **Arthritis**UK

We are Arthritis UK

We're the 10 million adults, young people and children living with arthritis. We're the carers, researchers and healthcare professionals. The families and the friends. All united by one powerful vision: a future free from arthritis. So that one day, no one will have to live with the physical, emotional and practical challenges that arthritis brings.

There are many different types of arthritis. And we understand that every day is different. What's more, what works for one person may not help another. That's why our trusted information blends the latest research and expert advice with a range of lived experiences. In this way, we aim to give you everything you need to know about your condition, the treatments available and the many options you can try, so that you can make better-informed choices to suit your needs.

We're always happy to hear from you whether it's with feedback on our information, to share your story, or just to find out more about the work of Arthritis UK. **Contact us at healthinfo@arthritis-uk.org**

Contents

Heather's story	4
What is hypermobility?	6
What are the symptoms of hypermobility syndromes?	7
How will hypermobility affect me?	8
What causes hypermobility?	10
Diagnosis	11
Treatments	12
Managing your symptoms	15
Living with hypermobility	17
Useful addresses	23
Discover our support services	25
Thank you	26
Support our work	27

Heather's story



Over the years there have been many tears behind closed doors over hypermobility whether it be the pain or just because lots of people don't understand it.

I could always tell there was something not quite right with my joints and growing up I always had a bandage around my knee because it was sore. But most people often thought I just did it for attention.

It was only when I was 13 and my knee had swollen up so bad, I ended up in hospital on bed rest for six weeks that they finally decided something was wrong and diagnosed me with hypermobility.

However, once I left hospital, because I hadn't been using my legs, all the muscle I did have had wasted away. This left me with my knee popping out even more and overall, probably in a worse state than when I had gone in.

I was referred to physio, once my walking had got so bad, I popped my hip out, but I was told to get on with it. So, when I was in my twenties I started looking into complementary therapies, which really helped.

They also helped me work, even though I often found that a week at work would lead me to a weekend in bed.

When I had my daughter Mia, we started to notice that she too was hypermobile.

She would often sit with her legs in a “W” position and all her joints were super bendy. By 18 months we noticed she couldn’t really stand and that was when she was properly diagnosed.

As a mum with hypermobility, I found it difficult, especially at baby groups as I wouldn’t be able to get on the floor and play with her and carrying her car seat to and from the car would cause a lot of pain in my arm.

I would also be met with the question of why my daughter was sitting the way she was, so we stopped going after a while and spent more time with family.

Physio and exercise have been the main things that have helped me over the years. It has helped me keep my muscles strong and my joints more stable.

I still see a physio today and I have a short series of exercises that I do every day.

To anyone who has hypermobility I would say: Be kind to yourself; it is not a weakness to be able to say no to certain situations when you are in pain. Living with hypermobility is challenging and we all have dark days. Try and keep strong by exercise and relaxation. I try and follow the three L’s! Live! Laugh and Love!

What is hypermobility?

Hypermobility means you can move some or all your joints more than most people. It is thought that hypermobility affects one in five people.

Most people who are hypermobile won't experience any difficulties and it can even be seen as an advantage in sports and dance.

Hypermobility syndromes

Hypermobility can, however, cause pain, fatigue, and injuries to joints and ligaments.

When this happens, it might mean you have a hypermobility syndrome.

The term 'hypermobility syndromes' usually refers to two related conditions:

- Hypermobility Spectrum Disorders (HSD)
- Hypermobile Ehlers–Danlos syndrome (hEDS)

These are conditions in which joint hypermobility is the main feature and the cause of symptoms such as pain, fatigue and injuries.

Other connective tissue disorders – such as Marfan syndrome, Osteogenesis Imperfecta and Stickler syndrome – can also include joint hypermobility. However, these are separate and rare conditions with their own diagnostic criteria, and they are not classified as hypermobility syndromes.

In this information we will be focusing on two of the hypermobility syndromes:

- Hypermobility Spectrum Disorder (HSD)
- Hypermobile Ehlers–Danlos syndrome (hEDS)

Some people with HSD or hEDS also have arthritis. Extra movement in the joints can make them less stable and may increase pain or flare-ups. Managing both conditions together can help protect your joints.

The following organisations offer further information and support for people with hypermobility syndromes:

Hypermobility Syndromes Association [hypermobility.org](https://www.hypermobility.org)

Ehlers–Danlos Support UK [ehlers-danlos.org](https://www.ehlers-danlos.org)

SEDSConnective [sedsconnective.org](https://www.sedsconnective.org)

What are the symptoms of hypermobility?

Hypermobility can cause a range of symptoms across many parts of the body. These symptoms can range from mild to severe and can have a big impact on your life:

- pain and stiffness in the joints and muscles – particularly towards the end of the day and after physical activity
- clicking joints
- back and neck pain
- extreme tiredness, known as fatigue
- poor balance and co-ordination

- some people find it difficult to sense the position of a joint without being able to see it, known as proprioception
- joints can pop out, known as joint dislocations or partial dislocations
- regular soft tissue injuries – such as sprains and sports injuries
- easy bruising
- stomach pain
- bladder and bowel problems
- dizziness
- stretchy skin
- abnormal scarring
- Feeling worried or anxious.

How will hypermobility affect me?

HSD or hEDS can both cause the same number of problems and be managed in the same way.

While there is no cure for HSD or hEDS, treatment can protect your joints better and can lessen the impact of your symptoms.

Many people with a hypermobility syndrome can live a full and active life. But it's important to follow healthcare professionals' advice.

If you need support or advice, call our Helpline today on **0800 5200 520**.

Complications

Research suggests that people with hypermobile joints may have weak collagen in other parts of the body as well, which can sometimes cause additional conditions or symptoms.

Some people with hypermobility have a condition called postural orthostatic tachycardia syndrome (POTS). POTS is a condition with many different causes which affects how the body controls blood flow and heart rate when you stand up.

Symptoms include:

- dizziness
- fainting
- chest pain
- shortness of breath
- shakiness.

Hypermobility can also cause digestive issues like irritable bowel syndrome, gastric reflux, and less commonly gastroparesis. This is usually caused by weakness in the muscles that squeeze food through the digestive system, and can lead to symptoms such as stomach pain, bloating, vomiting and constipation.

These rarer conditions may have a big impact on everyday life. If you do have any of these additional symptoms, you should speak to your healthcare professional.

Hypermobility is thought to affect up to one in five people.

What causes hypermobility?

The main cause of hypermobility is genetics. Hypermobility often runs in families and cannot be prevented. If a parent is hypermobile, their children are more likely to be hypermobile too, although the exact pattern of inheritance can vary.

Someone who has hypermobility usually has faulty or weak collagen. Think of collagen as the glue that holds your entire body together.

When this glue is faulty this can cause the strong cords that hold joints together, known as ligaments, to be weak or stretched. This means the ligaments are less able to hold your joints together.

Another reason you may be hypermobile is the shape of your bones. A shallow socket in your hip or shoulder joints means you will have a greater range of movement in the joint. This is likely to only affect a single joint or a small number of joints.

Other things that can influence hypermobility are:

- **your muscle tone** – The weaker or more relaxed your muscles are, the greater range of movement you will have.
- **your sex** – More than 7 out of 10 people diagnosed with EDS and HSD are female, but no specific genetic factors have been identified to fully explain why. Research suggests that female sex hormones, particularly oestrogen and progesterone, may influence symptom severity.
- **your age** – The collagen fibres in your ligaments tend to bind together more as you get older, which is one reason why many of us become stiffer with age. Hypermobile people who are very

flexible and pain-free when younger may find that they're less flexible when they reach their 30s or 40s and that stretching becomes more uncomfortable.

- **your ethnic background** – People of different ethnic backgrounds have differences in the way their body is built. For example, people from the Indian sub-continent often have much more flexible hands than Europeans.
- Research also suggests that if you have **autism, attention deficit hyperactivity disorder (ADHD) or Tourette's syndrome**, you are more likely to have symptoms associated with hypermobility. We don't know exactly what causes this, but it's possible that the development of connective tissues and the central nervous system is related.
- Recent research suggests that hEDS could be related to your immune system, which may have significant effects on how hEDS is treated.

Diagnosis

Your doctor will make a diagnosis of HSD or hEDS by asking you a series of questions, taking a family history, ruling out other conditions and examining your joints.

Your doctor will want to check how mobile your joints are. They will ask you questions such as “while standing can you put your hands flat on the ground with your knees straight?”

This is to work out how flexible you are. It is known as the Beighton scoring system.

Your doctor will ask you how much pain you're in and if you've had

any joint dislocations. They should ask you how you judge where your body is in relation to things around it.

They will also see if you have flat feet, misaligned bones in your elbows or toes or if you have a curvature of the spine.

Depending on the outcome of these tests you may receive a diagnosis of Hypermobility Spectrum Disorder or Ehlers–Danlos syndrome.

Treatments

Treatment for hypermobility should focus on helping you to improve your strength and fitness.

Physical therapies

You may be referred to a physiotherapist, occupational therapist or podiatrist for specialist advice.

Physiotherapy

The best way of treating hypermobility is to protect your joints by improving your muscle strength and general fitness. Physical therapy can reduce pain and improve your strength, fitness, posture and balance. This will help reduce the risk of dislocations.

Your physiotherapist will work with you to create a programme of exercises that works best for you.

Hydrotherapy can also help strengthen your joints. The water takes the weight off your joints, and the heat helps relax your muscles and relieve pain. This makes physiotherapy exercises easier.

Occupational therapy

An occupational therapist can help you maintain your independence. They can offer gadgets and tools to make your life easier.

An occupational therapist can also show you how to use gadgets which can help protect against dislocations. These include splints, support braces, tape and elasticated bandages.

Podiatry

Many people with hypermobility have either a low arch or are flat footed, which can cause pain and problems when walking. Hypermobility in your feet can also increase your chance of strains and sprains in your foot.

Seeing a podiatrist can be helpful. They can assess your feet and walking, and give you insoles to help support your feet. This will reduce the movement of your feet, helping to prevent injury.

Drug treatments

Painkillers such as paracetamol can help ease your joint pain.

If your joint often swells up, especially after a dislocation, a non-steroidal anti-inflammatory drug (NSAID) such as ibuprofen can also be used. But NSAIDs can sometimes cause stomach issues.

Both paracetamol and ibuprofen are available in tablet, gel, and spray form.

If you find your pain isn't being controlled by these options your GP may be able to prescribe stronger painkillers.

Pain clinics

If your pain is not manageable, your doctor may refer you to a pain clinic.

Pain clinics can offer you treatments that your GP is unable to. Alongside helping you to control and relieve your pain, they support you to develop self-help skills.

Treatments may include:

- medicine
- pain relief injections
- physiotherapy
- exercise
- complementary therapy
- psychological therapy.

Surgery

Surgery on your joints is not normally recommended if you have hypermobility. This is because the tissue in and around the joint doesn't usually heal very well.

Some hypermobile people can also bruise easily, and they may need more blood transfusions if they have major surgery.

However, if you tear a tendon, which is more likely if you have hypermobility, then this will usually be repaired with surgery.

Some people with hypermobility are also resistant to local anaesthetics either as topical creams or injections. It's important your dentist or doctor knows your hypermobile, so they know what to do if you have any problems.

Managing your symptoms

Keeping active

Most people with hypermobile joints can exercise safely, and staying active will help strengthen and protect your joints.

But if you find there are sports or exercises that are causing you pain, you should stop these activities until you have a better idea about what is causing your pain.

Gradually increasing how much activity or exercise you do – often called pacing – can help. The key is to start slowly and make small increases, to avoid overdoing it on good days and feeling worse later.

Speak to a physiotherapist about exercises you can do to improve control of your movements. With the right strengthening exercises, it may be possible to return to these activities without increasing pain.

It is a good idea to find a physiotherapist who understands hypermobility.

You don't need any special gear to get started, and a lot of physical activity can be done at home. For more advice, check out these exercises for healthy joints [arthritis-uk.org/exercises-for-healthy-joints](https://www.arthritis-uk.org/exercises-for-healthy-joints)

Swimming can help rest your joints by taking the weight off them. But some people may want to avoid breaststroke, as it can irritate the knee and hip.

Cycling is also recommended.

Arthritis UK runs activities across the country, such as walking groups and seated yoga. To see if we host any physical activity classes in your area, visit [arthritis-uk.org/in-your-area](https://www.arthritis-uk.org/in-your-area).

Pain relief, such as hot or cold packs and a transcutaneous electrical nerve stimulation (TENS) machine, can help you to exercise.

Diet

There's no single diet that will help everyone with hypermobility. However, some people find that making changes to their diet helps their symptoms.

Some people with hypermobility have problems with their digestive system.

Try to include in your diet foods which help to improve your gut health. These include wholegrain foods, such as brown bread and brown rice, fruit and vegetables, beans, and oats.

For more information, see our Eating well with arthritis booklet or visit arthritis-uk.org/information-and-support/living-with-arthritis/health-and-wellbeing/eating-well-with-arthritis

Complementary treatments

Complementary treatments such as acupuncture, massage and relaxation techniques can be useful. Some are available on the NHS, such as acupuncture. But usually there isn't a lot of evidence, so they're not always available on the NHS.

Complementary treatments are relatively safe. But you should always talk to your doctor before you start using them in case they interfere with specific treatments.

They should not replace your prescribed medicines

Before starting any therapy or treatment it's important to make sure the therapist or supplier has a set ethical code, is legally registered and fully insured.



Living with hypermobility

Work

Work can provide financial security, a sense of purpose and a supportive social network.

If hypermobility is affecting your ability to work, speak to your employer's occupational health service if they have one. Your employer has a duty to make reasonable adjustments so that you can do your job.

Reasonable adjustments can be anything from adjusting your working hours or providing you with special equipment that helps you do your job.

Your local Jobcentre Plus can also put you in touch with Disability Employment Advisors, who can arrange workplace assessments.

If your employer can't make all the adjustments you need, you may be able to get help through Access to Work. This can cover grants to pay for equipment or adaptations, support workers to help you, or help to get to and from work.

For more information on work, visit [arthritis-uk.org/information-and-support/living-with-arthritis/work-benefits-and-finances](https://www.arthritis-uk.org/information-and-support/living-with-arthritis/work-benefits-and-finances)

Hypermobility can also affect younger people. If you're facing different challenges at school and university, visit our website for advice [arthritis-uk.org/information-and-support/understanding-arthritis/young-people-and-families](https://www.arthritis-uk.org/information-and-support/understanding-arthritis/young-people-and-families)

Emotional wellbeing

The emotional effects of hypermobility can have just as much impact as the physical symptoms. The pain, fatigue, and changes to your daily life of a long-term health condition can affect your mood.

Studies have also shown that people with hypermobility are more likely to have feelings of anxiety.

If you're struggling, talk to your GP, who can refer you to some helpful services, such as psychological therapies.

There are lots of small ways you can look after your emotional wellbeing. You can:

- Practice deep breathing or mindful meditation to help reduce any anxiety you may have.
- Write your thoughts down in a diary to help you make sense of your emotions.

- Keep active – exercise can give you a boost of feel-good hormones called endorphins.
- Make time for activities that you enjoy, or which help you relax.
- Talk with friends – grab a coffee with a friend, have a phone call with a family member or join an online community.
- You might find it helpful to join an Arthritis UK support group where you can meet people who have been through similar things and talk about what you're going through.
- Or you can join Arthritis Connect, our online community, and connect with real people who share the same everyday experiences as you. For more information visit **community.arthritis-uk.org**
- You can also call the Arthritis UK Helpline for free on **0800 5200 520**, where our trained advisors can lend a listening ear.

Sleep and fatigue

Sleeping can be difficult. Here are some things that you can try around bedtime to improve your sleep:

- Make sure your bedroom is dark, quiet and a comfortable temperature.
- Try a warm bath before bedtime to help ease pain and stiffness.
- Develop a regular routine, where you go to bed and get up at a similar time each day.
- You may like to try listening to some soothing music before going to bed.
- Some gentle exercises may help reduce muscle tension, but it's probably best to avoid energetic exercise too close to bedtime.
- Keep a notepad by your bed – if you think of something you need to do the next day, write it down and then put it out of your mind.

- Avoid caffeine in the eight hours before you go to bed.
- Stop drinking alcohol close to bedtime.
- Avoid eating main meals close to bedtime.
- If you smoke, try to stop smoking, or at least stop smoking close to bedtime.
- Try not to sleep during the day.
- Avoid watching TV and using computers, tablets or smartphones in your bedroom.
- Try to not check the time during the night.



Sex and relationships

Many couples experience challenges in their relationship and sex life, whether they have hypermobility or not. Emotional effects, such as stress, can have as much impact as physical symptoms.

Hypermobility can present a number of challenges in a relationship, including the following:

- Pain and fatigue may mean you enjoy activities you share with your partner less, including sex.
- You might struggle to manage the household jobs you usually do without help.
- If your hypermobility affects your work, you may have some financial worries.
- Having hypermobility may affect your mood and self-esteem.
- Your partner may be concerned about how the condition is affecting you.

For more advice, visit [arthritis-uk.org/information-and-support/living-with-arthritis/emotions-and-relationships/sex-relationships-and-arthritis](https://www.arthritis-uk.org/information-and-support/living-with-arthritis/emotions-and-relationships/sex-relationships-and-arthritis).

Pregnancy, fertility and breastfeeding

Pregnancy and childbirth are often a completely normal experience for those with HSD or hEDS. However, there are a few issues that might cause a problem:

- During pregnancy you may experience an increase in pain, especially in your spine and joints.
- When you are giving birth, you may experience a more rapid labour.

- Some people report that local anaesthetics are less effective. This is something to discuss with your anaesthetist.
- A tear or related wound may heal slower. This should also be considered if you have surgery.

Tell your healthcare team that you have HSD or hEDS, so they are aware of any possible complications. You should also discuss any medication you are taking.

After giving birth, take extra care when doing post-natal exercises.

Having a good support system can also help, as feeding and caring for a baby may be more difficult if you have hypermobility.

Children are often more hypermobile than adults. They may lose this as they grow up and won't necessarily have problems. But if they do, it is important that the doctor knows whether HSD or hEDS is in the family.

For more information on pregnancy, fertility and breastfeeding, check out our Pregnancy and Arthritis booklet or visit [arthritis-uk.org/information-and-support/living-with-arthritis/emotions-and-relationships/pregnancy-fertility-and-arthritis](https://www.arthritis-uk.org/information-and-support/living-with-arthritis/emotions-and-relationships/pregnancy-fertility-and-arthritis).

If you need a bit of extra support, remember you're not alone. We're here to help you, every step of the way.

Useful addresses

Ehlers-danlos support UK

ehlers-danlos.org

Hypermobility syndromes association

hypermobility.org

SEDSConnective

sedsconnective.org

Postural Tachycardia Syndrome UK

potsuk.org

Notes

Discover our support services

You don't need to face arthritis alone. Get the information, advice and support that you need.



Call our free helpline:
0800 5200 520



Connect with our online community, go to:
community.arthritis-uk.org



Chat with AVA, our online assistant, go to:
arthritis-uk.org/ask-AVA-our-virtual-assistant



Track your symptoms with our easy app, go to:
arthritis-uk.org/track-my-arthritis-symptoms-app

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