

Hypermobility syndromes



**VERSUS
ARTHRITIS**

WE ARE VERSUS ARTHRITIS

We're the 10 million people living with arthritis. We're the carers, researchers, health professionals, friends and parents all united in our ambition to ensure that one day, no one will have to live with the pain, fatigue and isolation that arthritis causes.

We understand that every day is different. We know that what works for one person may not help someone else. Our information is a collaboration of experiences, research and facts. We aim to give you everything you need to know about your condition, the treatments available and the many options you can try, so you can make the best and most informed choices for your lifestyle.

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 Versus Arthritis. Contact us at content@versusarthritis.org

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HEATHER'S STORY

Over the years there has 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 can. It is thought that hypermobility affects 1 in 4 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, however, can cause some people pain, fatigue, and injuries to joints and ligaments.

When this happens, it can indicate someone has a hypermobility syndrome.

The term 'hypermobility syndromes' is an umbrella term that includes lots of different conditions including:

- Hypermobility Spectrum Disorder (previously known as joint hypermobility syndrome)
- Ehlers–Danlos syndrome
- Marfan syndrome
- Osteogenesis Imperfecta
- Stickler syndrome

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

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

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



Hypermobility Syndromes Association www.hypermobility.org
Ehlers–Danlos Support UK www.ehlers-danlos.org
SEDSConnective www.sedsconnective.org

What are the symptoms of hypermobility syndromes?

Hypermobility can cause a range of symptoms that often affect many parts of the body. These symptoms can range from mild to severe and can have a great impact on someone's 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 co-ordination
- some people find it difficult to sense the position of a joint without being able to see it, also known as proprioception
- 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.

It is thought that hypermobility affects 1 in 4 people.

How will hypermobility affect me?

Whether your diagnosis is HSD or hEDS they 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 ensure your joints are better protected and can lessen the impact of your symptoms.

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

You don't need to face arthritis alone. If you need support or advice, call our Helpline today on **0800 5200 520**. Our advisors can give you expert information and advice about arthritis and can offer support whenever you need it most.

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 may also have a condition called postural orthostatic tachycardia syndrome (POTS). Some of the symptoms of POTS include dizziness, fainting, chest pain, shortness of breath and shakiness. This is caused by blood vessels not restricting properly when someone with POTS stands up.

Hypermobility can also cause digestive issues like gastroparesis, irritable bowel syndrome or gastric reflux. This can be due to the muscles that squeeze food through the digestive system being weak. This can lead to symptoms such as stomach pain, bloating, vomiting and constipation.

The symptoms of 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.

What causes hypermobility?

The main cause of HSD and hEDS is genetics. Hypermobility often runs in families and therefore cannot be prevented. It is believed that if one parent has hypermobility one in two children will also have it.

Someone who has HSD or hEDS often 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 ligaments to be weak or stretched so they don't hold your joints as well.

Another reason you may be hypermobile is the shape of your bones. If the socket part of your hip or shoulder joint is shallow, the range of movement in the joint will be greater than usual. 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** – Women are more likely to develop HSD or hEDS than men.
- **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 movements become 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 supple 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.

Diagnosis

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

In the examination your doctor will want to check how mobile your joints are and 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.

Your doctor will also assess how much pain you are in, whether you have had joint dislocations and 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.

If you're waiting for a diagnosis, there are plenty of ways you can help to manage your symptoms. For advice, visit versusarthritis.org/about-arthritis/managing-symptoms/



Treatments

Drugs overview

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.

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.

For more information, visit versusarthritis.org/about-arthritis/treatments/drugs/



Physical therapies

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

Physiotherapy

The main treatment for HSD or hEDS is improving muscle strength and fitness, so your joints are better protected.

Physical therapy can reduce pain, improve your strength, fitness and balance which will help reduce the risk of dislocations.

Hydrotherapy can also help strengthen your joints. The water takes the weight off your joints and the therapy pools are heated which help relax your muscles and relieve pain. This makes physiotherapy exercises easier.



Occupational therapy

You may be referred to an occupational therapist who will help you maintain your independence. They can advise on gadgets and tools that can make your life easier.

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

Podiatry

Many people who have 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 the likelihood of strains and sprains in your foot, and for this reason it may be a good idea to see a podiatrist.

A podiatrist can assess your feet and walking and give you a pair of insoles that can help support your feet. These insoles will reduce the movements of your feet, helping to prevent injury.

Pain clinics

If your pain is not getting better your doctor may refer you to a pain clinic.

Pain clinics can offer you treatments that your GP is unable to. They aim to support you to develop your own self-help skills as well as control and relieve your pain.

Treatments may include:

- medicine
- pain relief injections
- manual therapy
- exercise
- TENS machines
- 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 is important for your dentist or your doctor to know your hypermobile so if you have problems with local anaesthetics, they know what to do.

For more information, visit versusarthritis.org/about-arthritis/treatments/surgery/



Managing your symptoms

Keeping active

Regular exercise is important as part of a healthy lifestyle, and there's no reason why people with hypermobile joints shouldn't exercise. However, if you find that certain sports or exercises involve movements that cause pain, you should stop these activities until it's clear why there is pain.

With the right strengthening exercises, it may be possible to return to these activities without increasing pain. A physiotherapist can advise you about exercises to improve control of the movements required in your preferred sport or exercise.

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 **versusarthritis.org/about-arthritis/exercising-with-arthritis/exercises-for-healthy-joints/**

Swimming can help, where the weight of your body is supported by water, although breaststroke can irritate the knee and hip, so it's best to paddle the legs. Cycling is also recommended.

We run activities across the country specially designed for people with arthritis, such as walking groups and Chair Chi. To see if we host any physical activity classes in your area, **[visit versusarthritis.org/in-your-area/](https://versusarthritis.org/in-your-area/)**

Alongside physical exercise other methods of pain relief may help such as hot or cold packs and a transcutaneous electrical nerve stimulation (TENS) machine.

For more advice on getting some more movement in your life, check out our Keep moving booklet or visit **versusarthritis.org/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.

For more information, see our Eating well with arthritis booklet or visit versusarthritis.org/about-arthritis/managing-symptoms/diet/



Complementary treatments

Complementary treatments such as acupuncture can be useful. However, they should not replace your prescribed medicines and you should talk to your rheumatology team before starting a complementary treatment.

Generally complementary treatments aren't considered to be evidence-based and are therefore not usually available on the NHS.

For more information, visit versusarthritis.org/about-arthritis/complementary-and-alternative-treatments



Living with hypermobility

Work

Anyone working with a disability in the UK has a right to equal treatment at work. The Equality Act 2010 protects you from discrimination if you are in England, Scotland and Wales. The 1995 Disability Discrimination Act covers this if you live in Northern Ireland. This also means that your employer should work with you to make the workplace accessible to you by making 'reasonable adjustments'.

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

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 working with arthritis, visit versusarthritis.org/about-arthritis/living-with-arthritis/work



Hypermobility can also affect younger people. If you're facing different challenges at school and university, there's support in place to help you. For tips and advice, visit versusarthritis.org/about-arthritis/young-people



Emotional wellbeing

Studies have shown that you are more likely to suffer from anxiety if you have hypermobility. This along with living with a long-term health condition can cause feelings of depression due to the pain, fatigue, and the disruption to daily life. Therefore, it is important to take care of your mental health.

If you are struggling it is important to reach out to a healthcare professional as they may be able to refer you to a psychologist who can help with coping strategies.

There are also plenty of small ways you can look after your mental wellbeing and build emotional resilience. For instance, you could:

- 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.
- Connect with friends – grab a coffee with a friend, have a phone call with a family member or join an online community.

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

- You might find it helpful to join a Versus Arthritis support group where you can connect with like-minded people and talk about what you're going through. To see if we run a local support group in your area visit [versusarthritis.org/in-your-area/](https://www.versusarthritis.org/in-your-area/)

- Or you could join our Online Community where you could connect with real people who share the same everyday experiences as you. For more information visit **community.versusarthritis.org**

You can also call the Versus Arthritis Helpline for free on **0800 5200 520**, where our trained advisors can lend a listening ear.

Sex and relationships

Most couples – whether they have hypermobility or not – go through phases when their sex life is less exciting or satisfying than it was. There may be physical reasons for this, but emotional factors and stress often play a part.

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

- Pain and fatigue may reduce your enjoyment of sex, and other activities and interests that you share with your partner.
- Hypermobility may mean that you can't always manage the household jobs you usually do, or you may need help with them.
- If your hypermobility affects your work, it may lead to financial worries.
- Having hypermobility may affect your mood and self-esteem.
- Your partner will be concerned about how the condition is affecting you.

For more advice, check out our Sex, relationships and arthritis booklet or visit **versusarthritis.org/about-arthritis/living-with-arthritis/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.
- If you are resistant to local anaesthetics, you may not have any benefit from having an epidural.
- If you experience a tear healing may be slower. This should also be considered if you have surgery.

It is important to tell your midwife or doctor that you have HSD or hEDS so they are aware of any complications you may have. As well as discuss with them about any medication you are on.

After giving birth it is important that all your post-natal exercises are performed with care.

It is also important to have a good support system around you as you may find feeding and caring for the baby harder with your hypermobility.

It is important to note that children are often more hypermobile, and they may lose this as they grow up. Also, if they are hypermobile, it won't necessarily mean they have problems and if they do it is important that the doctor knows there is HSD or hEDS in the family.

For more information on pregnancy, fertility and breastfeeding, check out our Pregnancy and Arthritis Booklet or visit versusarthritis.org/about-arthritis/living-with-arthritis/pregnancy/





Sleep and fatigue

If you are struggling to sleep a change of habits around bedtime to improve it:

- 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.
- Don't drink alcohol close to bedtime.
- Avoid eating main meals close to bedtime.
- If you smoke, try to stop smoking, or at least don't smoke close to bedtime.
- Try not to sleep during the day.
- Avoid watching TV and using computers, tablets or smartphones in your bedroom.
- Don't keep checking the time during the night.

For more information on how to get a good night's sleep, see our Sleep booklet, or visit [versusarthritis.org/about-arthritis/managing-symptoms/sleep/](https://www.versusarthritis.org/about-arthritis/managing-symptoms/sleep/)



For more advice on fatigue, check out our Fatigue and arthritis booklet or visit [versusarthritis.org/about-arthritis/managing-symptoms/managing-fatigue/](https://www.versusarthritis.org/about-arthritis/managing-symptoms/managing-fatigue/)



Research and new developments

Research led by Dr Jessica Eccles at the University of Sussex is testing a new therapy to treat anxiety in people with hypermobility: **versusarthritis.org/research/our-current-research/our-current-research-projects/hypermobility-a-novel-targeted-treatment-for-reducing-anxiety/**

Many people with hypermobility experience greater anxiety compared to the general population, however there are no specific treatments aimed at reducing anxiety for this group of people. The treatment will involve helping people to manage feelings of anxiety linked to changes in their body (such as an increased heart rate).

The study will also involve a pilot trial which will compare this new treatment with a more standard anxiety treatment. Some people on the trial will also undergo brain scans to help understand how the treatment works and how it can be improved. This project will improve understanding of how anxiety effects people with hypermobility and will help people better manage their anxiety and improve their quality of life.



Where can I find out more?

If you've found this information useful, you might be interested in other titles from our range. You can download all of our booklets from our website **www.versusarthritis.org** or order them by contacting our Helpline. If you wish to order by post, please see our address below.

Bulk orders

For bulk orders, please contact our warehouse, APS, directly to place an order:

Phone: 0800 515 209

Email: info@versusarthritis.org

Tell us what you think

All of our information is created with you in mind. And we want to know if we are getting it right. If you have any thoughts or suggestions on how we could improve our information, we would love to hear from you. Please send your views to

bookletfeedback@versusarthritis.org

or write to us at the following address:

**Versus Arthritis, Copeman House, St Mary's Court,
St Mary's Gate, Chesterfield, Derbyshire S41 7TD.**

Thank you!

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Talk to us

Helpline

You don't need to face arthritis alone. Our advisors aim to bring all of the information and advice about arthritis into one place to provide tailored support for you.

Helpline: 0800 5200 520

Email: helpline@versusarthritis.org

Our offices

We have offices in each country of the UK. Please get in touch to find out what services and support we offer in your area:

England

Tel: 0300 790 0400

Email: enquiries@versusarthritis.org

Scotland

Tel: 0141 954 7776

Email: scotland@versusarthritis.org

Northern Ireland

Tel: 028 9078 2940

Email: nireland@versusarthritis.org

Wales

Tel: 0800 756 3970

Email: cymru@versusarthritis.org

Hypermobility syndromes

Hypermobility simply means you can move some or all your joints more than most people can. This may not be a problem in itself, but some people do experience symptoms. This booklet explains what you can do if your hypermobility does cause problems.

For information please visit our website:

versusarthritis.org

0300 790 0400

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