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Hypermobility spectrum disorder (HSD)

***Information for
patients and carers***

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What is joint hypermobility?

Joint hypermobility is the ability to move some or all of your joints beyond the normal range of movement.

Joint hypermobility is common, affecting about 10% of adults (1 in 10 people) and up to 40% of school age children (2 in 5 children).

Some joint hypermobility can be helpful for some people (for example when playing sports, doing gymnastics or dancing).

Who gets it?

Some people are more likely to have joint hypermobility than others:

- Genetics (it's known to be inherited).
- Age (much more common in adolescents)
- Gender (more common in women) and
- Ethnic background (more common in some ethnic groups).

What causes joint hypermobility?

The exact cause is unknown. The increased range of movement at the joints is believed to be due to changes in the soft tissue structures that support the joint (ligaments, joint capsule and tendons).

These supporting structures are made up of several types of protein such as elastin (provides stretchiness) and collagen (provides strength). It's thought that small changes in these proteins cause the tissues to stretch more and so increase the range of movement.

In a few people joint hypermobility can be due to the shape of their bones (such as shallow hip sockets), reduced muscle tone or due to an injury or trauma. It can also be acquired through training and exercise (for example in gymnasts).

What is Hypermobility Spectrum Disorder (HSD)?

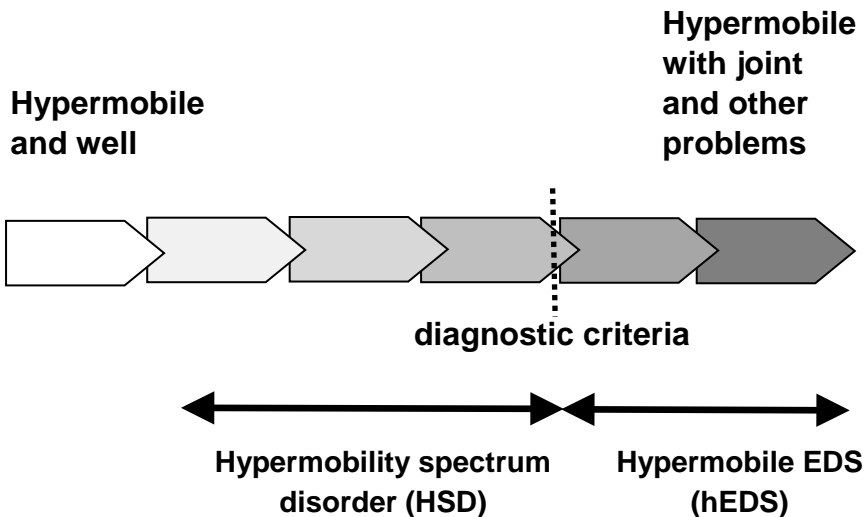
Joint hypermobility itself is not a medical condition and many people who have it are well.

However, some people with hypermobility can develop symptoms because of it such as pain, recurrent injuries, subluxations and dislocations (where joints slip out of place), and fatigue.

Ehlers Danlos Syndromes are a group of rare inherited conditions that affect the connective tissue (such as tendons and ligaments). The most common type of EDS is hypermobile EDS (hEDS) which causes joint hypermobility.

People with problems related to hypermobility who haven't been diagnosed with hEDS are now given the diagnosis of **Hypermobility Spectrum Disorder (HSD)**. HSD was previously known as Joint Hypermobility Syndrome.

It's thought that HSD and hEDS are on the same spectrum which goes from being hypermobile and well to being hypermobile with joint and other complex problems. This is shown in the diagram below. The diagnostic criteria are features used to assess if you have hEDS or HSD. A small number of people are diagnosed with hEDS; both conditions are treated in a similar way.



What are the symptoms of HSD?

Symptoms of HSD may include the following:

Musculoskeletal symptoms

- Pain
- Recurrent injuries or strains
- Subluxations/dislocations (when joints slip out of place)
- Reduced proprioception (your awareness of the position of your limbs)

Other common symptoms

- Fatigue
- Stomach and gut disorders such as Irritable Bowel Syndrome (IBS) and reflux.
- Cardiovascular Autonomic Dysfunction. Your body's autonomic system controls your heart rate and blood pressure. When this doesn't work properly you could have issues such as Postural Tachycardial Syndrome (PoTs) - an abnormal increase in heart rate that occurs after sitting up or standing. It typically causes dizziness, fainting and other symptoms.
- Weakness of the pelvic floor which could lead to a prolapse (a weakness in the support of the pelvic organs) or a hernia.

How is HSD diagnosed?

Your GP, physiotherapist or consultant (hospital doctor) can diagnose HSD by examining you thoroughly and asking you relevant questions.

Hypermobility may be:

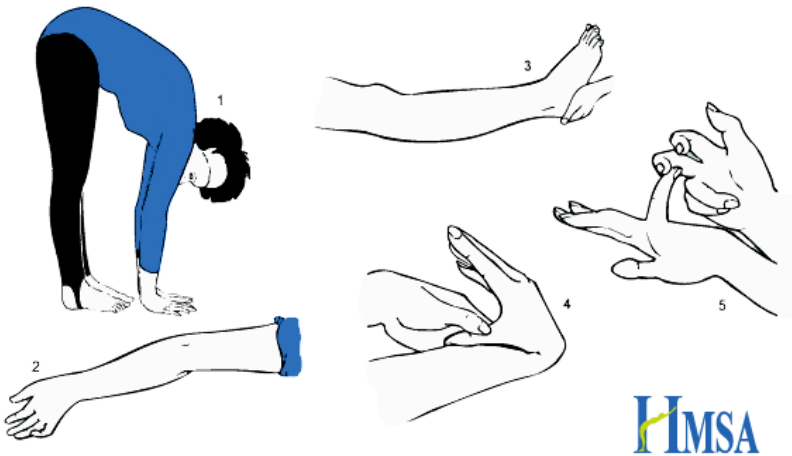
- local (only affecting one or two joints).
- generalised (affecting several joints).
- peripheral (only affects the fingers and/or toes).

There are two main screening tools used for identifying generalised joint hypermobility: the Beighton Score and the 5 Point Questionnaire.

Beighton Score

This measures how flexible you are using a standard set of movements at the thumb and wrist, fifth (little) finger, elbows, lower back and knees.

The pictures below show what hypermobility of these joints looks like.



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*** Picture taken from HMSA website in March 2019**

5 Point Questionnaire

This questionnaire has 5 questions. If you answer “Yes” to 2 or more questions it’s likely you have joint hypermobility.

1. **Can you now (or could you ever) place your hands flat on the floor without bending your knees?**
2. **Can you now (or could you ever) bend your thumb to touch your forearm?**
3. **As a child did you amuse your friends by contorting your body into strange shapes *or* could you do the splits?**
4. **As a child or teenager did your shoulder or kneecap dislocate on more than one occasion?**
5. **Do you consider yourself double-jointed?**

These tools tell us if you’re hypermobile but that doesn’t mean you have HSD. If you’ve any of the symptoms listed previously ***and*** joint hypermobility, speak to your GP.

People with joint hypermobility ***and*** hypermobility-related problems such as pain, recurrent injuries and fatigue may be diagnosed with HSD.

Management of HSD

HSD is not a medical condition that can be “cured” or changed. It’s just how your body is built and as said earlier, sometimes it can be an advantage.

However, if it causes pain, fatigue and recurrent injuries these symptoms need to be managed. This can be done with advice, learning about HSD, physiotherapy, occupational therapy and pain management (if needed).

This will support you in developing the confidence to live as well as you can with your condition.

What can I do to help myself?

Finding out more about your condition will help you cope with your condition in the long term.

We’ve listed some things below that have been helpful for other people with HSD.

Exercise

Everyone with HSD should exercise. Appropriate exercise and rehabilitation helps to restore or maintain muscle strength, range of movement of your joints, restore effective and efficient patterns of movement and improve general fitness levels/maintain physical activity levels

Exercise works best if it’s tailored to your needs. It’s important to start gently and build up gradually.

A physiotherapist can advise you and develop an exercise programme for you.

Pain

We don't know why some people develop pain and others don't. Pain can stop you using your muscles properly and this can lead to you changing your posture and the ways you move. This in turn can result in muscle weakness, reduced control of your muscles and reduced proprioception (the sense that tells you the position of your limbs).

Some people may have acute pain from an injury such as a sprain or subluxation and chronic/persistent pain which is pain that you've had for more than 12 weeks. Your physiotherapist or GP can give you more information on pain.

Posture

Good posture protects supporting structures against injury, enables your muscles to function efficiently and reduces stress and strain on your joints and surrounding structures.

Some people find it difficult to maintain good posture due to pain, injury or reduced muscle control. When you have pain your body adjusts by adopting postures that feel more comfortable. This can cause your soft tissues (muscles etc) to shorten or adapt to your preferred posture. These changes can stop you achieving a good posture and can increase the stress on your other joints.

Whenever you try to achieve a good posture the shortened adapted tissues are stretched which can cause pain and lead you to avoid this position. These changes and

avoiding certain movements and postures lead to general deconditioning (being able to do less and less).

You will need to re-educate your body gradually to change your posture and habits. Your physiotherapist can help you to do this.

Protecting your joints

You can help to protect your joints by reducing the strain placed on them. This in turn helps to reduce your pain and prevents repeated stress on your joints and surrounding tissues and reduces the risk of injury.

Your occupational therapist can give you more information and support on joint protection.

Fatigue

Chronic fatigue is persistent or recurrent fatigue that has been present for more than 6 months. It's not caused by other conditions and is not because of ongoing exertion. It's not improved by resting and can affect your normal levels of activity.

People with HSD often say that fatigue is a major symptom. Common causes in people with HSD include;

- poor sleep pattern
- persistent pain
- physical deconditioning
- anxiety and depression
- autonomic dysfunctions.

If you have fatigue let your physiotherapist or occupational therapist know so they can advise how best to manage it.

Pacing and prioritising

When you have persistent pain/fatigue you lose general fitness, not just because you haven't been able to keep exercising but also because of the time you need to rest and recover if you've had a flare up of your symptoms or if you've had an injury.

People have good and bad days with their symptoms and can develop a "boom and bust cycle".

On a good day (**boom**), you try to do lots of activity to catch up from a bad day or just because you enjoy the activity. The result of increased activity on a good day is often an increase in pain/fatigue. This leads to enforced rest, use of pain relief or other coping strategies (**bust**).

Managing this “boom and bust” by pacing yourself and prioritising what’s most important is very useful when trying to manage your HSD. Your physiotherapist or occupational therapist can help you with this.

Managing a flare up

As mentioned above, people with HSD often have good and bad days. Occasionally, you may have a sudden increase in your pain/symptoms. This could be due to an injury or for no known reason. These episodes are known as **flare ups**. Learning how to cope with your flare ups can be very useful.

You could develop a flare up plan. When a flare up starts, don’t panic, stop and think about what you’ve been doing and then make a plan.

Remember: a flare up is **temporary**. There are several things you can do to help you cope.

An example of a flare up plan

Flare up issue	What can I do?
Increase in pain	Use heat or ice TENS Pain medication Relaxation
Reduced movement	Pacing Gentle exercise Posture Change position, move regularly
Frustration, stress, low mood	Distraction techniques (such as watch TV, listen to music) Relaxation Mindfulness Speaking to friends and family

When the flare settles, think about how you coped and what you can learn from it. What worked well? What you could do better next time? Remember to give yourself credit for coping. Think how you'll gradually get back to your normal activities and how you'll pace your return to exercise.

Self management – a summary

We would like everyone with HSD is to develop skills and knowledge so they can manage their own condition with our support as appropriate.

To help you maintain a healthy everyday life:

- Exercise regularly. Exercise is very important for long-term management. Exercises for core stability, strength, endurance and posture are all essential. We recommend low impact exercises such as swimming, cycling and pilates.
- Have a well balanced diet. There isn't a specific diet for HSD but we recommend a balanced diet to keep your weight under controlled and for your general health.
- Keep doing your normal activities. It's very important to continue with normal activities such as work, socialising and exercise. If you're inactive and don't take part in things this can have a negative effect on your overall fitness as well as your general wellbeing.


Where can I find out more?

Other sources of information and support include:

Versus Arthritis

 **0300 790 0400**

 enquiries@versusarthritis.org

 www.versusarthritis.org

Hypermobility Syndromes Association

 **033 3011 6388**

 www.hypermobility.org

Ehlers Danlos Support UK

 **020 8736 5604**

 www.ehlers-danlos.org

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