

Hypermobility Spectrum Disorder

Patient Information Leaflet

MSK Musculoskeletal Physiotherapy Service



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What is hypermobility spectrum disorder?

Hypermobility means that some or all your joints move more than usual. This can allow you to move your joints into positions that others would find impossible.

Many people can be hypermobile and experience no problems at all. In some cases, this can even help in activities like dance or gymnastics.

However, some people with hypermobility can develop pain, instability in their joints, fatigue or repeated injuries. When this happens, it may be called a hypermobility spectrum disorder.

Symptoms of hypermobility spectrum disorder

Everyone is different, but some of the common symptoms are:

Joint pain and loss of joint function

Pain is often worse when using the joint. The pain can come and go.

Joint instability

Joints may feel loose, unstable or weak. People can experience subluxations, where joints partially slip out and go back in, or people can experience dislocations, where the joint comes fully out of place.

Recurrent injuries

Such as repeated sprains due to the excessive movement in the joint.

Poor balance or coordination

Some people may experience poor balance and coordination due to the excessive movement in the joints. This can lead to falls, being unsteady or tripping over when walking.

Fatigue

Extreme levels of tiredness despite good sleep and rest.

Headaches

Some people experience frequent headaches or migraines.

Autonomic dysfunction

Some people experience dizziness or light-headedness, particularly when changing position. This may be related to changes in blood pressure or heart rate regulation.

Gastrointestinal problems

People can experience symptoms like abdominal bloating, constipation and diarrhoea, or have diagnoses of other conditions like irritable bowel syndrome (IBS).

Anxiety disorders

Alongside a hypermobility spectrum disorder, people may struggle with their mental wellbeing, such as anxiety, low mood or depression.

Heightened sensitivity to pain

People with a hypermobility spectrum disorder can experience a heightened pain sensitivity. This means that things you may not have previously found painful are now very painful and this pain can often last a lot longer.

Causes

Hypermobility spectrum disorder is thought to be influenced by our genetics, meaning it often runs in families. Therefore, if one or more members of your family are hypermobile, you are more likely to be hypermobile too.

Hypermobility is linked to our body's connective tissues, particularly a protein called collagen. Collagen helps provide strength and structure to support our body's muscles, tendons, ligaments, skin and joints. It acts almost like a glue to bind our tissues together. Hypermobility is thought to be related to differences in the body's connective tissues, including collagen. These differences may make tissues more stretchy and can contribute to increased joint

movement. This results in the excessive movement available at the joints.

Diagnosis

There is not a single scan or blood test that can diagnose a hypermobility spectrum disorder.

A diagnosis is based on a combination of:

- your symptoms, medical history and family history
- a physical examination
- exclusion of other conditions that can cause hypermobility

As part of the physical examination, a healthcare professional may complete a test called the Beighton score. This looks at the flexibility in your fingers, thumbs, elbows, knees and spine.

Being hypermobile only becomes a diagnosis of a hypermobility spectrum disorder if it is associated with pain, instability, fatigue or repeated injuries.

Management

Management of hypermobility is recommended if it is causing symptoms and there is a diagnosis of a hypermobility spectrum disorder.

Exercise

Regular exercise and physical activity are one of the most effective treatments. There is no single form of exercise that is better than another. The best exercise for you is one that you enjoy, can afford, fits into your daily routine and you are likely to keep up with.

Guidelines suggest:

- A minimum of 150 minutes of moderate intensity activity per week. This is something that raises your heart rate and gets you breathing more heavily.
- Strength exercises twice a week.

Exercise can help for many different reasons:

Pain relief – exercise stimulates our body to release hormones such as endorphins. These are our body's natural painkillers so can help reduce pain.

Improves mental wellbeing – the release of hormones when we exercise can help reduce feelings of stress, anxiety and low mood.

Helps us feel more alert – release of hormones during exercise helps boost alertness.

Improves sleep – exercise helps improve sleep quality and duration. Exercising can make us feel more tired,

therefore help with sleep, but avoid exercising too late into the evening as this can keep you awake.

Improving muscle strength – if we are inactive, our muscles can become weaker, and our joints become stiffer. Exercise will help your body become stronger and capable of doing more.

When starting a new exercise, don't push yourself too hard too soon as this can cause a significant increase in your pain. However, it is normal when you start a new activity to feel a bit achy. This is because your body is doing something that it isn't used to doing.

Starting small, and gradually building up over time will allow your body to slowly adapt and become stronger, without causing significant increases in pain.

Pacing activities

What is pacing?

Pacing is a way of managing your activity so that you can stay active, without making your pain worse. It means finding an amount of activity that you can do comfortably, and then slowly increasing it over time.

Many people with pain fall into a common pattern of doing too much on one day, which can cause more pain, then needing several days to recover.

This is often called a 'boom and bust cycle'.

Pacing helps you avoid this cycle.

Why does pacing matter?

When you have pain, your tissues and nervous system can become more sensitive. If you suddenly do a lot more activity, your pain may increase. People often call this a flare-up.

Keeping your activity levels steady and consistent gives your body a better chance to adapt and build tolerance.

Common mistakes:

Doing too much on 'good days' – if you wake with less pain, it is easy to try and do everything at once. This often leads to more pain the next day.

Resting completely on 'bad days' – many people stop all activity when pain increases because they worry about causing damage.

However, pain does not always mean harm. Staying gently active is usually helpful.

Increasing activity too quickly – it's tempting to make big jumps in activity when you feel motivated.

However, slow, steady progress works better and is more likely to last.

What do we recommend?

Start with an amount of activity you can manage most days of the week. Then increase it gradually, using small steps rather than big leaps.

Example:

If walking for 10 minutes causes a flare-up, try starting with 5 minutes instead. Do this regularly and then slowly build up as your body adapts.

Look after your mental wellbeing

Our experience of pain is closely linked to our mental wellbeing. Feelings of stress, anxiety, low mood, and other things that affect our mental health can directly influence and heighten the level of pain we experience. Focusing on managing your mental wellbeing can have positive effects on the level of pain.

Strategies may include:

- relaxation techniques and exercises
- engaging in gentle exercise
- spending time doing things you enjoy
- speaking to family, friends or health professionals for support

For more specific guidance and support with managing your mental health, please visit:

<https://selfhelp.cntw.nhs.uk/organisation/leicestershire-partnership-nhs-trust>

Managing sleep

Sleep and pain are very closely linked. When you sleep, your body works hard to:

- repair and restore muscles and tissues
- control the hormones that influence healing and inflammation
- support your immune system
- keep good energy levels, mood and concentration

When you don't sleep well, you may:

- feel more pain
- get tired more quickly
- do less during the day
- take longer to recover
- gain weight over time

Good sleep helps the body and mind, which helps with your quality of life. Most people feel best with about 7 to 9 hours of sleep each night, but everyone is different.

But it's not only about how long you sleep. Good quality sleep is just as important. Deep sleep is important for your body and mind.

Practical ways to improve sleep

You don't need to change everything at once. Small steps can make a big difference.

Exercise regularly

Regular exercise can help you sleep more deeply.

- Exercise guidelines recommend that adults should perform 150 minutes per week of moderate exercise. This means doing something that makes you warm and a little out of breath.

The best form of exercise is something that you enjoy and can perform regularly.

Think about what you eat and drink

Your food and drink choices can affect your sleep, especially in the evening:

- eat a healthy, balanced diet
- try not to drink caffeine later in the day
- try to cut down or stop smoking near bedtime
- avoid alcohol before bed

Make your bedroom a good place to sleep.

Your sleep environment matters:

- keep the room quiet or use earplugs
- keep the room dark or use an eye mask
- keep your room cool and well-ventilated
- use a comfortable pillow and mattress
- keep your bedroom for sleep only – not for eating, drinking, watching TV or scrolling on your phone

Wind down before bed

Help your brain get ready for bed:

- have a calm bedtime routine
- try to address any worries or stress earlier in the evening so that they do not affect your sleep
- do something relaxing before bed, like reading or listening to calm music

Keep a steady routine

Your body likes a regular pattern:

- go to bed and wake up at the same time each day
- try not to sleep in, even at weekends
- avoid napping in the evening

Manage light during the day and night

Light helps control your body's sleep-wake cycle.

This is your body's natural internal 24-hour clock that tells you when to be awake and alert, and when to feel sleepy and rest.

- avoid bright screens for at least an hour before bed
- dim the lights in the evening
- spend more time outdoors during the day
- try to get natural light soon after waking up

If you can't sleep:

- try not to lie in bed worrying about it
- try slow counting in your head
- if you still cannot sleep after about 30 minutes, get out of bed and do something calm, like reading until you feel sleepy again

Final thoughts

Hypermobility means that some or all your joints move more than usual.

Many people with hypermobility experience no pain or symptoms at all.

However, when they do develop symptoms, this is defined as a hypermobility spectrum disorder.

Management of a hypermobility spectrum disorder centres around education and advice on self-management strategies, coupled with physical activity and exercise.

Building strength and confidence is an important part of helping you manage your symptoms and stay active.

If you need help to understand this leaflet or would like it in a different language or format such as large print, Braille or audio, please ask a member of staff.



MSK Physiotherapy Service

Find out more about the MSK Physiotherapy Service and what we offer

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