Prthritis Research UK

Condition
Joint hypermobility

Joint hypermobility

This booklet provides information and answers to your questions about this condition.

> Arthritis Research UK booklets are produced and printed entirely from charitable donations.

What is joint hypermobility?



Hypermobility means that you can move some or all your joints more than most people can. In this booklet we'll explain what joint hypermobility is, what causes it and some possible symptoms.

At the back of this booklet you'll find a brief glossary of medical words – we've <u>underlined</u> these when they're first used.

www.arthritisresearchuk.org

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At a glance Joint hypermobility

Joint hypermobility is very common and most people won't have any symptoms.

What is joint hypermobility?

Hypermobility means that you can move some or all of your joints more than most people can. You may think of it as being double-jointed. If a number of joints are affected, doctors may refer to this as generalised joint hypermobility.

Having a wide range of movement can have its advantages, for example for dancers or athletes. However, some people with hypermobile joints experience pain or other symptoms, and this is known as joint hypermobility syndrome. It may help to think of the difference like this:

Generalised joint hypermobility + symptoms = joint hypermobility syndrome

Hypermobility may also be a feature of other conditions.

What causes hypermobility?

Some people have a single hypermobile joint. This might be caused by:

- injuring the <u>ligaments</u> that keep the joint within its normal range of movement
- unusually shaped bones, such as shallow hip sockets.

Possible causes of generalised joint hypermobility include:

- inheriting the condition from a parent

 about 75% of people affected by
 joint hypermobility have a previous
 family history of it
- having extra-elastic soft tissue though the reasons for this aren't yet fully understood.

What are the symptoms of joint hypermobility syndrome?

When hypermobility does cause symptoms, these may include:

- muscle strain/pain
- joint stiffness
- joint pain
- partly or fully dislocated joints
- <u>hernias</u> or <u>varicose veins</u>, caused by weakened <u>collagen</u> fibres.

What treatments are there for joint hypermobility syndrome?

The aim of treatment is to reduce your symptoms, not to make you less hypermobile. If you have joint hypermobility syndrome then a combination of rest, exercise and <u>physiotherapy</u> will often help, but drug treatments are also available if needed, including:

- painkillers (<u>analgesics</u>), for example paracetamol, codeine
- <u>non-steroidal anti-inflammatory drugs</u> (<u>NSAIDs</u>), for example ibuprofen.

What else might help?

You might find the following useful:

- exercise swimming, cycling and lowresistance strengthening exercises are often recommended
- <u>occupational therapy</u> to help you learn how to avoid straining hypermobile joints
- special insoles in your shoes (orthoses) to support the arch of your foot.

Remember that it's very common to have hypermobile joints and most people won't have any problems. However, some people will find that their symptoms affect their everyday life.



What is joint hypermobility?

Hypermobility simply means that you can move some or all of your joints more than most people can. You may have been aware from an early age that your joints were more supple than other people's – you may think of it as being double-jointed. If a number of joints are affected your doctor may refer to this as generalised joint hypermobility.

Hypermobility isn't a medical condition in itself, and many people don't realise they are hypermobile if it doesn't cause them any problems. Hypermobility might even be an advantage in sports, playing musical instruments, and dance.

However, some people with hypermobile joints may have symptoms such as joint or muscle pain and may find that their joints are prone to injury or even dislocation. If you do have symptoms then you may

have joint hypermobility syndrome.

This may also be referred to as benign joint hypermobility syndrome (BJHS) or sometimes Ehlers–Danlos syndrome type III. It may be useful to think of it like this:

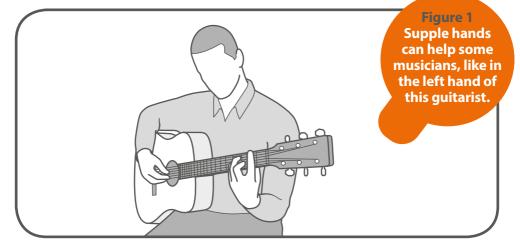
Generalised joint hypermobility + symptoms = joint hypermobility syndrome

What causes joint hypermobility?

Four factors may affect whether or not you have hypermobile joints:

Weak or stretched ligaments -

Ligaments are made up of several types of protein fibre, including elastin (which gives stretchiness) and collagen (which gives strength). Small variations in chemical processes in the body can result in weakened collagen fibres and more elasticity in the ligaments that help to hold your joints together.



This is likely to cause hypermobility in many joints. There's fairly strong evidence that hypermobility caused by abnormal collagen can be inherited. If one parent has this type of hypermobility then half of their children are likely to inherit it, though members of the same family may be affected differently.

The shape of your bones – If the socket part of your hip or shoulder joint is particularly shallow, the range of movement in that joint will be greater than usual and there'll also be a greater chance of dislocation. This is likely to affect a single joint or a small number of joints. It isn't a common cause of hypermobility but is likely to be inherited.

Muscle tone – The tone (or stiffness) of your muscles is controlled by your nervous system. The more relaxed your muscles are, the more movement you'll have in your joints.

Sense of joint movement

(**proprioception**) – Some people find it difficult to sense the position of a joint without being able to see it.

Who has hypermobile joints?

Some people are more likely than others to have hypermobile joints. The main factors that play a part are:

Genetics – Hypermobility resulting from abnormal collagen or from shallow joint sockets is likely to be inherited.

However, we don't yet know whether joint pain linked to hypermobility might be inherited.

Gender – Women are more likely than men to have hypermobile joints.

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.

Ethnic background – People of different ethnic backgrounds have differing degrees of mobility in their joints, which may reflect differences in the structure of the collagen proteins. For example, people from the Indian sub-continent often have much more supple hands than Europeans.

Training/exercises – Joint hypermobility can sometimes be developed, for example by gymnasts and athletes, through the training exercises they do. Yoga can also make the joints more supple by stretching the muscles.

Other conditions – Many people with Down's syndrome are hypermobile. And hypermobility is also a feature of some rarer inherited conditions (see section 'ls hypermobility linked to other conditions?'). Exercise can help to ease the symptoms of joint hypermobility syndrome by strengthening and conditioning the muscles that support the joints.

Strengthening exercises should be done regularly but start gently to avoid straining your joints.

> **See Arthritis Research UK booklets** Occupational therapy and arthritis; Physiotherapy and arthritis.

What are the symptoms of joint hypermobility syndrome?

Although hypermobility itself isn't a medical condition, some people with hypermobile joints may be more likely to have aches and pains when doing everyday tasks. A few may find they're affected to the point where everyday tasks become difficult to manage.

Symptoms of joint hypermobility syndrome may include:

Muscle strain or pain (especially after physical work or exercise): Your muscles have to work harder if your joint is very mobile and this can lead to muscle strain and a general feeling of fatigue. In effect, an 'overuse' injury develops in the muscles around your joint (though the pain may seem to come from the joint itself).

If you do have symptoms associated with hypermobility, these can often be managed with a combination of exercise therapy and painkillers. Joint stiffness: Sometimes your joint may feel tense or stiff, which may be caused by fluid collecting inside your joint. This is probably because your body is trying to repair the small amounts of damage that are caused if a muscle or joint is overstretched. Your pain will often feel worse as the day goes on and improve at night with rest.

Foot and ankle pain: You may easily twist and strain at the ankles, and have a flat arch to your foot that can lead to foot pain, particularly after standing for a long time.

Neck pain and backache: This can be a problem if your spine is particularly supple, and the muscles around your spine aren't working to support it correctly. Very occasionally the bones in your back (vertebrae) can slip on another – this is called a spondylolisthesis.

Injured or dislocated joints:

Hypermobile joints are more likely than normal joints to get injured if they're overstretched. Sometimes the joint may dislocate – this is most common in the shoulder or the kneecap. Sometimes the soft tissues in and around joints (cartilage, tendons, ligaments) can tear.



How is joint hypermobility diagnosed?

Your GP will be able to make a diagnosis of generalised joint hypermobility or joint hypermobility syndrome by examining you and asking you a series of questions.

The Beighton score is a quick measure of your flexibility using a standard set of movements at the thumb/wrist, fifth finger, elbows, lower back, and knees. A high Beighton score means that you're hypermobile but it *doesn't* mean you have joint hypermobility syndrome. If you have problems with joints other than those included in the Beighton score, then you should mention these to your doctor. Other joints which may be affected include the jaw, neck, shoulders, mid-spine, hips, ankles and feet.

The Brighton criteria take into account how many hypermobile joints you have and whether you've had pain in those joints. If you have four or more hypermobile joints and have had pain in those joints for three months or more then it's more likely that you have joint hypermobility syndrome. These criteria also take account of other concerns such as dislocations, injuries to the tissues around the joints, and lax skin.

If you have any of the symptoms listed in this booklet, you should speak to your doctor to find out whether you have joint hypermobility syndrome or whether something else is causing the pain.

What treatments are there for joint hypermobility syndrome?

Joint hypermobility itself isn't something that can be 'cured' or changed. It's just the way your body is built. However, where it causes symptoms, these can often be controlled by a combination of pacing your activity and physiotherapy. However, drug treatments are also available if you need them.

Physical therapies

Research has shown the value of exercise. In most cases you can ease your symptoms by doing gentle exercises to strengthen and condition the muscles around the hypermobile joints. The important thing is to do these strengthening exercises often and regularly but not to overdo them. Use only small weights, if any. A physiotherapist will be able to advise you on suitable exercises. For some people gentle stretching seems to be of additional benefit.

You can use splints, taping or firm elasticated bandages if you need to protect against dislocation. An occupational therapist or physiotherapist can advise on these.

Drugs

Painkillers (analgesics) are the usual treatment if you have symptoms. Paracetamol is normally the first choice. It's often better to take a dose before activity to keep the pain under control rather than waiting until it's very bad. Your doctor can prescribe a stronger painkiller such as co-codamol or codydramol if needed. Note that these painkillers sometimes cause side-effects such as constipation or dizziness.

If your joint often swells up, especially after dislocation, a non-steroidal antiinflammatory drug (NSAID) such as ibuprofen may be better. You can buy this from your local chemist or supermarket without a prescription. See your doctor if the regular dose isn't helping, as they may prescribe a higher dose or a different NSAID if the standard dose of ibuprofen isn't strong enough.

You can also get either painkillers or NSAIDs as a spray or a cream, which you can apply directly onto the site of pain. This may not be quite as effective but may be an option if the tablets aren't suitable for you.

NSAIDs and side-effects

Like all drugs, NSAIDs can sometimes have side-effects, but your doctor will take precautions to reduce the risk of these – for example, by prescribing the lowest effective dose for the shortest possible period of time. NSAIDs can cause digestive problems (stomach upsets, indigestion or damage to the lining of the stomach), so GPs sometimes prescribe them along with a drug called a <u>proton</u> <u>pump inhibitor (PPI)</u>, which will help to protect your stomach.



NSAIDs also carry an increased risk of heart attack or stroke. Although the increased risk is small, your doctor will be cautious about prescribing NSAIDs if there are other factors that may increase your overall risk – for example, smoking, circulation problems, high blood pressure, high cholesterol or diabetes.

Newer NSAIDs known as COX-2 inhibitors (or coxibs) are less likely to cause stomach problems but have been linked with increased risks of heart attack and stroke, so they aren't suitable for people who've had these in the past or for people with uncontrolled high blood pressure.

Doctors have also been advised to be cautious about prescribing coxibs to people who have an increased risk of heart disease, such as people with high blood pressure, high cholesterol levels (hyperlipidaemia) or diabetes, or people who smoke. Some standard NSAIDs have also been shown to be associated with a small increased risk of heart attack and stroke, especially when used in high doses and for long periods. Your doctor should take these risks into account.

Surgery

In general, surgery in and or around the joints isn't recommended for people with joint hypermobility syndrome unless it's absolutely necessary. This is because tissue that's very supple doesn't usually heal as well as less supple tissue. Also, some hypermobile people can bruise easily and may need more blood transfusions if they have major surgery.

However, if you tear a <u>tendon</u> (which is more likely than normal if you have hypermobile joints) then this should usually be repaired with surgery.

Self-help and daily living

Exercise

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

See Arthritis Research UK drug leaflet Non-steroidal antiinflammatory drugs; Painkillers.

Arthritis Research UK Joint hypermobility

exercises to improve control of the movements and loads required in your preferred sport or exercise.

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.

Controlled strengthening and posture exercises such as those undertaken in Pilates, t'ai chi, or the Alexander technique may be helpful. Yoga and stretching may help but you should avoid overstretching your joints.

If any of your joints dislocate regularly it may help to wear a splint, taping, or elastic bandage while exercising. You may need to see a physiotherapist or orthotist for supports if this becomes a significant problem.

See Arthritis Research UK booklet Keep moving.

Diet and nutrition

There's no specific diet to help joint hypermobility, but we'd recommend a balanced diet to keep your weight under control and for your general health.

See Arthritis Research UK booklet Diet and arthritis. If any of your joints are prone to dislocation it may help to wear a splint, taping or elastic bandage while exercising.

Complementary medicine

There's no evidence to support a particular complementary therapy for hypermobility, although <u>acupuncture</u> is recommended in the National Institute for Health and Clinical Excellence (NICE) guidelines for low back pain.

Generally speaking complementary and alternative therapies are relatively safe, although you should always discuss their use with your doctor before starting treatment. It's important to go to a legally registered therapist, or one who has a set ethical code and is fully insured.

If you decide to try therapies or supplements you should be critical of what they're doing for you, and base your decision to continue on whether you notice any improvement.

See Arthritis Research UK booklet and report Complementary and alternative medicine for arthritis.

Footwear

There's a wide variation in the shape of the foot in people who are hypermobile. Most tend to have flat feet but a few have a high-arched foot. Special insoles in your shoes (orthoses) may help to support the arch of your foot. By re-aligning the foot and the way the body's weight passes through the legs it may help balance and reduce pain in the foot, ankle, leg, hip and lower back.

See Arthritis Research UK booklet Foot pain

Is hypermobility linked to other conditions?

Joint hypermobility isn't itself a type of arthritis. However, in some cases it may be associated with <u>osteoarthritis</u> – for example, when there is an abnormal shape to the joint or there has been a tear to the cartilage and this has become worn.

There's no evidence that the symptoms of osteoarthritis are any worse in people who are hypermobile than in people who aren't. If you're hypermobile we'd recommend keeping to a healthy weight as it's known that obesity is often an important factor in the development of osteoarthritis.

See Arthritis Research UK booklet Osteoarthritis

Although joint hypermobility syndrome can cause symptoms in various parts of the body, in most cases it isn't linked to other health problems. However, there are some much rarer inherited conditions that can be associated with hypermobility. These include:

- osteogenesis imperfecta a genetic condition existing at birth (congenital) resulting in fragile bones that fracture more easily than usual. The whites of the eyes often appear blue in people affected by this condition.
- Marfan syndrome a rare inherited disorder that affects the connective tissues of the body (the material that supports and binds other tissue). It's characterised by unusually long, thin fingers and toes, heart defects, extreme tallness, and partial dislocation of the eye lens.
- some types of Ehlers–Danlos syndrome (EDS) – which are rare inherited collagen disorders. Joint hypermobility syndrome is sometimes referred to as Ehlers–Danlos syndrome type III. However, people with other, rarer types of Ehlers–Danlos



syndrome may have unusually stretchy and fragile skin that bruises easily, heals slowly and leaves scars. The joints tend to be looser than normal and more prone to dislocation. Rarely there may also be weakness of the blood vessels and bowel wall such that these may rupture.

Research suggests that people with hypermobile joints may have more supple collagen in other parts of the body as well, which can sometimes cause additional symptoms. For example, weakness in the muscles that squeeze food through the digestive system can lead to constipation, bloating and pain (similar to irritable bowel syndrome, or IBS), or gastric reflux where acid from the stomach flows back into the gullet causing a painful burning sensation. Weakness in the muscles of the pelvic floor may lead to bladder instability and <u>urinary stress incontinence</u>. Sometimes the heart valves may be floppy. This may not cause any symptoms and may only be discovered by chance – for example, during a routine medical examination. However, this may be associated with chest pains and palpitations. Blood pressure may also be lower than normal, so some people may be more prone to feeling faint. If blood pressure drops when you stand up, or sit up from a lying position, then your heart rate may increase noticeably as it pushes blood back up to your head – this is known as postural orthostatic tachycardia syndrome (POTS).

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 doctor, who will be able to arrange tests if needed and to offer appropriate treatments.



Glossary

Acupuncture – a method of pain relief that originated in China. Very fine needles are inserted, virtually painlessly, at a number of sites on your skin (meridians) but not necessarily at the painful area. This interferes with pain signals to your brain and causes the release of natural painkillers (endorphins).

Analgesics – painkillers. As well as dulling pain they lower raised body temperature, and most of them reduce inflammation.

Collagen – the main substance in the white, fibrous connective tissue that's found in tendons, ligaments and cartilage. This very important protein is also found in skin and bone.

Hernia – a condition where an internal part of the body pushes through a weak point in the muscle or surrounding tissue wall. It often involves the intestine.

Irritable bowel syndrome (IBS) – a common condition where the bowel doesn't function as normal, often causing abdominal pain, bloating and episodes of diarrhoea or constipation.

Ligaments – tough, fibrous bands anchoring the bones on either side of a joint and holding the joint together. In the spine they're attached to the vertebrae and restrict spinal movements, therefore giving stability to the back. Non-steroidal anti-inflammatory drugs (NSAIDs) – a large family of drugs prescribed for different kinds of arthritis that reduce inflammation and control pain, swelling and stiffness. Common examples include ibuprofen, naproxen and diclofenac.

Occupational therapy – a therapy which uses a range of strategies and specialist equipment to help people to reach their goals and maintain their independence. It's given by a trained specialist who gives practical advice on equipment, adaptations or changing the way you do things.

Osteoarthritis – the most common form of arthritis (mainly affecting the joints in the fingers, knees, hips), causing cartilage thinning and bony overgrowths (osteophytes) and resulting in pain, swelling and stiffness.

Physiotherapy – a therapy given by a trained specialist that helps to keep your joints and muscles moving, helps ease pain and keeps you mobile.

Proton pump inhibitor (PPI) – a drug that acts on an enzyme in the cells of the stomach to reduce the secretion of gastric acid. They're often prescribed along with non-steroidal anti-inflammatory drugs (NSAIDs) to reduce side-effects from the NSAIDs. **Tendon** – a strong, fibrous band or cord that anchors muscle to bone.

Urinary stress incontinence – an accidental urine leak caused by pressure in the abdomen (such as a laugh, cough or sneeze) opening the muscular valves to the bladder (sphincter muscles).

Varicose vein – swollen and enlarged veins. They're usually blue or dark purple in colour and may also look lumpy, bulging or twisted. They're mostly found in the legs.

Where can I find out more?

If you've found this information useful you might be interested in these other titles from our range:

Conditions

• Osteoarthritis

Therapies

- Occupational therapy and arthritis
- Physiotherapy and arthritis

Self-help and daily living

- Foot pain
- Keep moving
- Looking after your joints when you have arthritis

Drugs

- Non-steroidal anti-inflammatory drugs
- Painkillers

You can download all of our booklets and leaflets from our website or order them by contacting:

Arthritis Research UK

Copeman House St Mary's Court St Mary's Gate, Chesterfield Derbyshire S41 7TD Phone: 0300 790 0400 www.arthritisresearchuk.org

Related organisations

The following organisations may be able to provide additional advice and information:

Arthritis Care

Floor 4, Linen Court 10 East Road London N1 6AD Phone: 020 7380 6500 Helpline: 0808 800 4050 Email: info@arthritiscare.org.uk www.arthritiscare.org.uk

Brittle Bone Society

Grant-Paterson House 30 Guthrie Street Dundee DD1 5BS Phone: 01382 204446 Email: contact@brittlebone.org www.brittlebone.org

Ehlers-Danlos Support Group

P.O. Box 748 Borehamwood WD6 9HU Phone: 020 736 5604 Helpline: 0800 907 8518 www.ehlers-danlos.org

Hypermobility Syndromes Association

Sovereign House 22 Shelley Road Worthing West Sussex BN11 1TU Phone: 033 3011 6388 388 www.hypermobility.org

Marfan Association UK

Rochester House 5 Aldershot Road Fleet Hampshire GU51 3NG Phone: 01252 810472 Email: contactus@marfan-association.org.uk www.marfan-association.org.uk

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We're here to help

Arthritis Research UK is the charity leading the fight against arthritis.

We're working to take the pain away for sufferers with all forms of arthritis and helping people to remain active. We'll do this by funding high-quality research, providing information and campaigning.

Everything we do is underpinned by research.

We publish over 60 information booklets which help people affected by arthritis to understand more about the condition, its treatment, therapies and how to help themselves.

We also produce a range of separate leaflets on many of the drugs used for arthritis and related conditions. We recommend that you read the relevant leaflet for more detailed information about your medication.

Please also let us know if you'd like to receive an email alert about our quarterly online magazine, *Arthritis Today*, which keeps you up to date with current research and education news, highlighting key projects that we're funding and giving insight into the latest treatment and self-help available.

We often feature case studies and have regular columns for questions and answers, as well as readers' hints and tips for managing arthritis.

Tell us what you think

Please send your views to: **bookletfeedback@ arthritisresearchuk.org** or write to us at: Arthritis Research UK, Copeman House, St Mary's Court, St Mary's Gate, Chesterfield, Derbyshire S41 7TD

A team of people contributed to this booklet. The original text was written by Prof. Howard Bird, and updated by Dr Alan Hakim. It was assessed at draft stage by research physiotherapist and clinical specialist Dr Caroline Alexander, and consultant senior lecturer and honorary consultant rheumatologist Dr Emma Clark. An **Arthritis Research UK** editor revised the text to make it easy to read, and a non-medical panel, including interested societies, checked it for understanding. An **Arthritis Research UK** medical advisor, Prof. Anisur Rahman, is responsible for the content overall.

Arthritis Research UK

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You can help to take the pain away from millions of people in the UK by:

- volunteering
- supporting our campaigns
- taking part in a fundraising event
- making a donation
- asking your company to support us
- buying products from our online and high-street shops.

To get more **actively involved**, please call us on **0300 790 0400**, email us at **enquiries@arthritisresearchuk.org** or go to

www.arthritisresearchuk.org

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