

Joint hypermobility

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

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 underlined these when they're first used in the booklet.

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At a glance

Joint hypermobility

What is joint hypermobility?

Hypermobility means that you can move some or all your joints more than most people can. It's often known as being double-jointed and doctors sometimes refer to it as joint hyperlaxity. For some, like dancers and musicians, having a wide range of movement can have its advantages. However, a minority of people with hypermobile joints experience pain or other symptoms, and this is called joint hypermobility syndrome.

What are the symptoms?

Joint hypermobility is very common and most people won't have any symptoms. For those who do, symptoms may include:

- muscle strain/pain
- joint stiffness
- foot pain
- backache
- injured or dislocated joints

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

- weakened collagen fibres, which can cause other symptoms, such as hernias or varicose veins.

If the above symptoms occur, then this is known as joint hypermobility syndrome. It may help to think of the difference like this:

Joint hypermobility + symptoms = Joint hypermobility syndrome

What causes it?

Causes of joint hypermobility include:

- the shape of the bones – e.g. shallow hip or shoulder sockets
- weak or stretched ligaments

- your muscle tone (stiffness) – the more relaxed your muscles are, the greater the range of movement
- a poor sense of joint movement (proprioception) – some people struggle to sense the position of a joint without being able to see it, which may lead to over-stretching
- inheriting the condition from a parent – about 75% of people affected by joint hypermobility have a previous family history of it.

What treatments are there?

If you have symptoms then a combination of rest, exercise and physiotherapy will often help, but drug treatments are also available if needed, including:

- painkillers (analgesics)
e.g. paracetamol, codeine
- non-steroidal anti-inflammatory drugs (NSAIDs) – e.g. ibuprofen
- NSAID sprays or creams.

What else might help?

The following may be useful for people with hypermobile joints:

- exercise (although you may want to be careful what types of sports or exercises you do to avoid overstretching your joints – swimming and cycling are recommended)
- physiotherapy
- occupational therapy
- special insoles in your shoes (orthoses).

It's important to 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 are so severe they have an effect on everyday life.



What is joint hypermobility?

Hypermobility just means that you can move some or all of your joints more than most people can. It's often known as being double-jointed and doctors sometimes refer to it as joint hyperlaxity. Hypermobile joints are very common and most people won't have any problems. But some people will develop symptoms, and this is called joint hypermobility syndrome (see Joint hypermobility syndrome section of this booklet). There are also some more serious conditions associated with joint hypermobility. However, the main focus of this booklet is on general joint hypermobility.

There are some advantages to having hypermobile joints. For example, they can help you in certain sports like gymnastics and diving. Hurdlers must have a wide range of movement at the hip, and swimmers, particularly those

using butterfly stroke, need a wide range of movement at the shoulder. Athletics coaches will often aim to increase flexibility, as well as strength and endurance. Dancers probably need the widest range of movement of all, in most (though not necessarily all) joints.

Hypermobile joints in the fingers can help musicians, particularly keyboard players and string players, although, for string players, only the hand that stops the strings needs to be supple (see Figure 1). For the bowing arm, a flexible shoulder may be more help. Some famous musicians, including the violinist Paganini and the pianist Rachmaninov, were well known for the exceptional flexibility of their fingers.

In extreme cases the joints may be easily dislocated, though most people will have few symptoms or none at all. Very rarely, joint hypermobility is part of a more serious inherited illness.

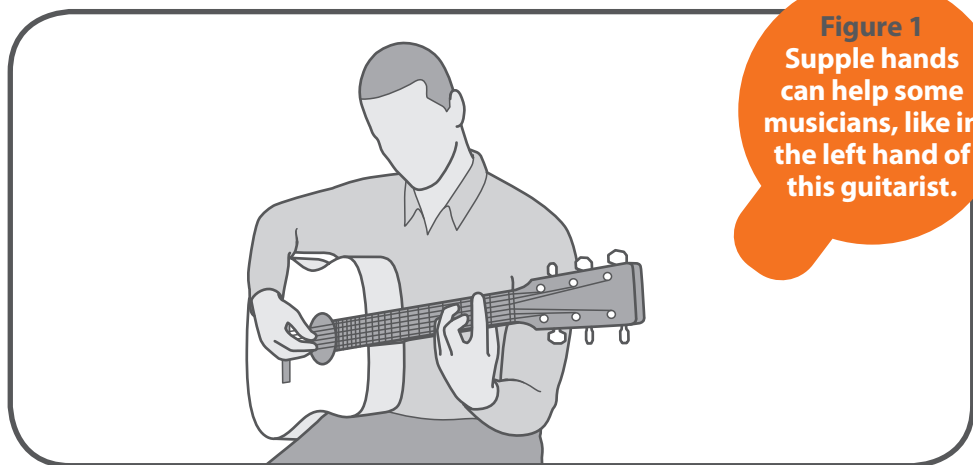


Figure 1
Supple hands can help some musicians, like in the left hand of this guitarist.

What are the symptoms of joint hypermobility?

Most people with joint hypermobility don't have any symptoms, apart from having an unusually large range of movement in their joints. You may have been aware from an early age that your joints were more supple than usual, and this might not have caused any further problems or symptoms. You may even have found that your flexible joints have been an advantage.

But the following symptoms can occur, and this is then known as joint hypermobility syndrome:

Muscle strain: The most common problem with having hypermobile joints is pain, especially after hard physical work or exercise. The muscles have to work harder if the joint is very supple and this can lead to muscle strain. As a result, what doctors call an 'overuse' develops in the muscles around the joint (though the pain may appear to come from the joint itself). Athletes often experience this after hard training or after an event.

Joint stiffness: Sometimes the joint feels tense or stiff, which may be caused by fluid collecting inside the joint. This is probably because your body is trying to repair the small amounts of damage that are caused if a muscle is over-stretched. Your pain will often feel worse as the day goes on and improve at night with rest, although sometimes you may also feel pain at night.

Foot pain: You may have a flat arch to your foot and this can lead to foot pain, particularly after standing for a long time.

Backache: This can be a problem if the base of your spine is particularly supple, sometimes as a result of one of the bones in the back (vertebra) slipping on another. This is called a spondylolisthesis.

Injured or dislocated joints: Hypermobile joints are more likely to get injured than normal if they're over-stretched. Sometimes the joint can dislocate – this is most common in the shoulder.

Weakened collagen fibres: Sometimes hypermobility is caused by weakened collagen fibres (which normally give strength to our ligaments). Weakened collagen can cause other symptoms including hernias or varicose veins.

What are the complications of joint hypermobility?

Recent research suggests that hypermobile people may have more supple collagen in other parts of the body as well as the joints. This may be linked to a number of other symptoms including mild asthma, irritable bowel syndrome (IBS) and urinary stress incontinence. Blood pressure may also be lower than normal, so people who are hypermobile may be more prone to fainting.

Women or girls who are hypermobile may notice that their joints are more painful around the time of their period, and they may be more clumsy than usual. Sometimes progesterone-only contraceptives (either as tablets, injections or coil) may make the symptoms of hypermobility worse, and so it may be best to avoid these.

During pregnancy and breastfeeding, due to the hormonal changes, joints tend to become even more hypermobile. Occasionally the 'waters' may break early.

Sometimes the heart valves can be floppy – though this may not cause any symptoms and may only be discovered by accident when a medical examination of the heart is carried out.

Who gets joint hypermobility?

Joint hypermobility is very common, and whether you're affected or not can be down to such factors as gender, ethnic background, age and whether you inherited it from your parents.

Did I get it from my parents?

There's fairly strong evidence that the condition can be inherited when it's caused by abnormal collagen, and therefore affects many joints. However, members of the same family may be affected differently. Providing your partner isn't affected,

half of your children are likely to inherit the condition, though how much each child is affected varies a lot. Girls are often affected more than boys.

Where joint hypermobility affects one or a small number of joints, particularly the hip and/or shoulder, suggesting shallow sockets in these joints, the condition is also likely to be inherited.

We don't yet know whether joint hypermobility resulting from poor sense of joint movement (proprioception) is inherited (see What causes joint hypermobility? section of this booklet). About a quarter of people affected by joint hypermobility have no previous family history of it.

Gender

Women tend to be more supple than men of the same age because of the effect of a hormone called relaxin (which allows the pelvis to expand during childbirth). Women are therefore 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. This means that joint hypermobility is more common in younger people. Sometimes hypermobile people who are very flexible without pain when younger may find that they're a bit less flexible and find stretching movements more painful when they're in their 30s or 40s.

About a quarter of people affected by joint hypermobility have no previous family history of it.



Ethnic background

People of different ethnic backgrounds have differences in their joint mobility, 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.

Who else gets it?

Joint hypermobility can sometimes be acquired, for example by gymnasts and athletes, through the training exercises they do. Yoga can also make the joints more supple by relaxing the muscles.

Many people with Down's syndrome are hypermobile.

What causes joint hypermobility?

Four factors may affect people in different amounts:

The shape of the bones – If the socket part of the hip or shoulder joint is particularly shallow, the range of movement in the joint will be greater than usual and there'll also be a greater risk of dislocation.

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 changes in the biochemical reactions that take place in the body can result in weakened collagen fibres, and this in turn causes weakness in the ligaments that help

to hold our joints together. This is likely to cause hypermobility in many joints.

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, and may develop joint hypermobility by over-stretching the joints without realising it.

How is joint hypermobility diagnosed?

Your GP will be able to make a diagnosis of joint hypermobility based on an examination and by asking you a series of questions based on two commonly used scoring systems. One is called Beighton's score, which measures your flexibility using a standard set of movements. A high Beighton's score itself means you're hypermobile but *doesn't* mean you have joint hypermobility syndrome. Diagnosis of the syndrome depends on having symptoms as well as hypermobile joints and is made using the Brighton criteria (see Joint hypermobility syndrome section of this booklet).

If you're experiencing any of the symptoms listed previously, you should consult 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?

Symptoms are unusual, but they can often be controlled by a combination of rest and physiotherapy. Drug treatments are available if you need them.

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 co-dydramol if necessary. Note that these sometimes cause side-effects such as constipation or dizziness.

If the joint often swells up, especially after dislocation, a non-steroidal anti-inflammatory drug (NSAID) such as ibuprofen may be better. This can also be purchased from chemists 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 allows them to be applied directly onto the site of pain. This method 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 in most cases they'll be given along with a drug called a proton pump inhibitor (PPI), 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 they've 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.



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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.

i See Arthritis Research UK drug leaflet *Non-steroidal anti-inflammatory drugs.*

Physical therapies

Research funded by Arthritis Research UK has proven the value of exercise. In most cases you can reduce your symptoms by doing gentle exercises to strengthen and condition the muscles around the joints that are particularly flexible. 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 as effective as strengthening.

Splints or firm elasticated bandages can be used if necessary to protect against dislocation. An occupational therapist or physiotherapist can advise on these. It's also quite common for hypermobile

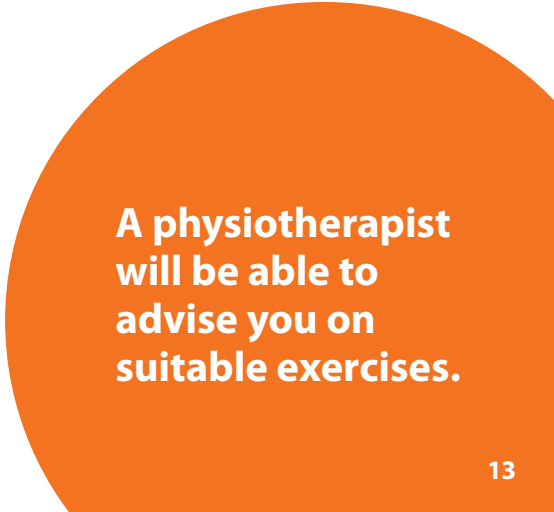
people to manipulate and click their loose joints, which often makes the joints feel better. But sometimes you may need professional medical help to manipulate the joint back into place.

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

Surgery

In general, surgery isn't recommended for hypermobile joints. 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 major surgery is carried out.

However, if you rupture a tendon (which is more likely than usual if you have hypermobile joints) this should usually be repaired with surgery.



A physiotherapist will be able to advise you on suitable exercises.

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 or play sports. However, if you find that certain sports or exercises involve movements that cause pain then you should stop. What's important is to avoid overstretching your joints. Swimming can help, where the weight of your body is supported by water, and so can cycling. We also recommend simple strengthening exercises.

If any of your joints are prone to dislocation it may help to wear a splint or elastic bandage while exercising.

i See Arthritis Research UK booklet
Keep moving.

Diet and nutrition

There's no specific diet to help joint hypermobility, but we would recommend a healthy, balanced diet to keep your weight under control.

i See Arthritis Research UK booklet
Diet and arthritis.

Complementary medicine

People with hypermobile joints often ask about complementary therapies. These are dealt with in more detail in a report recently published by Arthritis Research UK and in the Arthritis Research UK booklet. Although the report and booklet don't deal specifically with hypermobility, the sections on fibromyalgia and osteoarthritis may be of interest.

i See Arthritis Research UK booklet and report *Complementary and alternative medicine for arthritis; Complementary and alternative medicines for the treatment of rheumatoid arthritis, osteoarthritis and fibromyalgia.*

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 the shoes (orthoses) often help to restore the arch of the foot. If your legs are different lengths this could cause a twist in the spine, but an orthosis can correct the difference. This is the subject of ongoing research by Arthritis Research UK.

i See Arthritis Research UK booklet
Feet, footwear and arthritis.

What else should I know about joint hypermobility?

While joint hypermobility isn't itself a type of arthritis, some forms of hypermobility are thought to be associated with an increased risk of developing osteoarthritis.

It's hard to predict whether hypermobility will lead to osteoarthritis in any particular case. If you've inherited hypermobility and osteoarthritis is also common in your family then you'll probably have a greater risk of developing osteoarthritis yourself. Joint injuries, whether they result from hypermobility or not, can also increase the risk of osteoarthritis later on.

However, 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

If any of your joints are prone to dislocation it may help to wear a splint or elastic bandage while exercising.

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.

i See Arthritis Research UK booklet *Osteoarthritis*.



Joint hypermobility syndrome

Most people with joint hypermobility don't have joint pains. The Beighton criteria state that if you have 4 or more hypermobile joints and you've had joint pains in those joints for 3 months or more then it's likely that you have joint hypermobility syndrome, also known as benign joint hypermobility syndrome (BJHS). It may be useful to think of it like this:

Joint hypermobility + symptoms = Joint hypermobility syndrome

People with joint hypermobility syndrome may experience joint pain and be more prone to injury when performing everyday tasks.

Joint hypermobility syndrome can range in severity. The majority of people will only experience a few symptoms but others may have hypermobility as part of a more serious condition. More serious conditions that may be associated with hypermobility include:

- osteogenesis imperfecta, which causes the bones to become fragile
- Marfan's syndrome, which involves the heart, the eyes and the blood vessels
- Ehlers–Danlos syndrome, which is the most difficult to diagnose because there are many different types. The most severe form causes weakness of the major blood vessels, which may swell (this is called an aneurysm).

The symptoms of these conditions may have a large impact on everyday life. Also, some people may find that they are greatly affected by the symptoms of joint hypermobility syndrome, to the point where everyday tasks become difficult to manage.

Research and new developments

Research funded by Arthritis Research UK is currently trying to find out why so many children and young people with joint hypermobility syndrome stop their treatment or drop out of clinical trials. Three hundred young people are currently taking part in a 10-week NHS clinical trial examining an intensive treatment programme. However, it's expected that about 26 families will drop out of the trial, and the research backed by Arthritis Research UK aims to find out why this may be the case. This research is hoping to find out about the strengths and weaknesses of treatment for joint hypermobility syndrome so that improvements can be made.

Glossary

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

Asthma – a condition that affects the airways that carry air in and out of the lungs. The muscles around the walls of the airways tighten and the lining of the airways becomes inflamed and starts to swell, causing breathing difficulties.

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.

Ehlers-Danlos syndrome – an inherited disorder of collagen, the building material of body tissues. People with Ehlers-Danlos syndrome have unusually stretchy and fragile skin that bruises easily, heals slowly and leaves scars. The joints tend to be looser than normal and prone to dislocation.

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.

Marfan's syndrome – a rare inherited disorder that affects the connective tissues of the body (the material that supports

and binds other tissue). It is characterised by unusually long, thin fingers and toes, heart defects, extreme tallness, and partial dislocation of the eye lens.

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 therapist – a therapist who helps you to get on with your daily activities (e.g. dressing, eating, bathing) by giving practical advice on aids, appliances and altering your technique.

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.

Osteogenesis imperfecta – a genetic condition existing at birth (congenital) resulting in fragile bones that fracture easily. The whites of the eyes of affected individuals often appear blue.

Physiotherapist – a therapist who helps to keep your joints and muscles moving, helps ease pain and keeps you mobile.

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).

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*
- *What is arthritis?*

Therapies

- *Occupational therapy and arthritis*
- *Physiotherapy and arthritis*

Self-help and daily living

- *Complementary and alternative medicine for arthritis*
- *Complementary and alternative medicines for the treatment of rheumatoid arthritis, osteoarthritis and fibromyalgia (80-page special report)*
- *Diet and arthritis*
- *Feet, footwear and arthritis*
- *Keep moving*
- *Looking after your joints when you have arthritis*

Drug leaflets

- *Drugs and arthritis*
- *Non-steroidal anti-inflammatory drugs*

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

Arthritis Research UK

PO Box 177
Chesterfield
Derbyshire S41 7TQ
Phone: 0300 790 0400
www.arthritisresearchuk.org

Related organisations

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

Arthritis Care

18 Stephenson Way
London NW1 2HD
Phone: 020 7380 6500
Helpline: 0808 800 4050
www.arthritiscare.org.uk

Brittle Bone Society

Grant-Paterson House
30 Guthrie Street
Dundee DD1 5BS
Phone: 01382 204446
Helpline: 0800 028 2459
www.brittlebone.org

Ehlers-Danlos Support Group

P.O. Box 337
Aldershot
Surrey GU12 6WZ
Phone: 01252 690940
www.ehlers-danlos.org

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Hypermobility Syndrome Association (HMSA)

49 Orchard Crescent

Oreston

Plymouth PL9 7NF

Phone: 0845 345 4465

www.hypermobility.org

Marfan Association UK

Rochester House

5 Aldershot Road

Fleet

Hampshire GU51 3NG

Phone: 01252 810472

www.marfan-association.org.uk

National Osteoporosis Society

Manor Farm, Skinners Hill

Camerton

Bath BA2 0PJ

Phone: 01761 471771

Helpline: 0845 450 0230

www.nos.org.uk



We're here to help

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

We're the UK's fourth largest medical research charity and fund scientific and medical research into all types of arthritis and musculoskeletal conditions.

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 our quarterly 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 of our booklet

Please send your views to:
feedback@arthritisresearchuk.org
or write to us at:
Arthritis Research UK, PO Box 177,
Chesterfield, Derbyshire S41 7TQ.

A team of people contributed to this booklet. The original text was written by Prof. Howard Bird, who has expertise in the subject. It was assessed at draft stage by clinical nurse specialist Sue Brown, consultant senior lecturer and honorary consultant rheumatologist Dr Emma Clark, consultant rheumatology nurse Diana Finney and consultant and reader in rheumatology Dr Gabrielle Kingsley. 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.

Get involved

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 gifts from our catalogue

To get more **actively involved**, please call us **0300 790 0400** or e-mail us at enquiries@arthritisresearchuk.org

Or go to:
www.arthritisresearchuk.org



Providing answers today and tomorrow

Arthritis Research UK

Copeman House,
St Mary's Court,
St Mary's Gate, Chesterfield,
Derbyshire S41 7TD

Tel 0300 790 0400

calls charged at standard rate

www.arthritisresearchuk.org

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