

Living with
osteoarthritis



devised with and for people with arthritis



ARTHRITIS CARE

*Empowering
people with arthritis.*



If you have osteoarthritis there is a lot you can do to make daily living easier. Osteoarthritis is a disease of the joints affecting almost everyone as they get older. Around eight out of 10 people over the age of 50 are affected, but younger people – even teenagers – may develop it. Most people are likely to experience some level of pain and some degree of mobility problems. Osteoarthritis cannot be cured, but an early diagnosis can help slow its progression and a lot can be done to ease the symptoms.

Contents

Introducing OA	I
About the condition	
Getting a diagnosis	6
The process of getting diagnosed	
Communicating with health professionals	7
Who you will see, what you can do to manage your arthritis. Treatment with drugs	
Looking after your joints	11
Ways of living with arthritis. Using exercise, diet and complementary therapies to look after your joints	
Practicalities	20
Managing at home, in work and education. Access to transport and benefits	
Caring for yourself	26
Considering your emotions, relationships and self-management	
Useful organisations	29

Arthritis Care is now a certified member of The Information Standard. This means that you can be confident that Arthritis Care is a reliable and trustworthy source of health and social care information.

All people pictured on the cover and quoted in this booklet have arthritis.

INTRODUCING OA

■ What is OA?

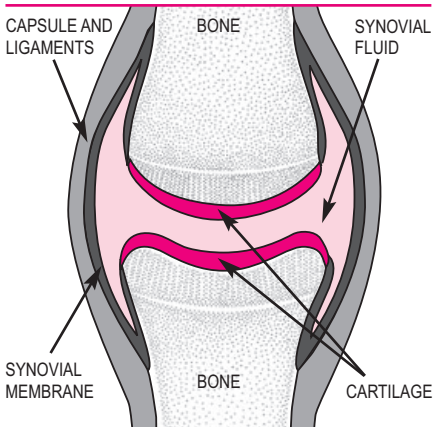
Osteoarthritis is a condition that usually develops gradually, over several years. It affects a number of different joints.

For some people, the changes are so subtle and develop over such a long period of time that they are hardly noticeable. But others may experience gradually worsening problems, including pain and restricted movement, particularly in large joints such as the hip or knee. You may have to see the doctor from time to time to discuss your condition and your treatment.

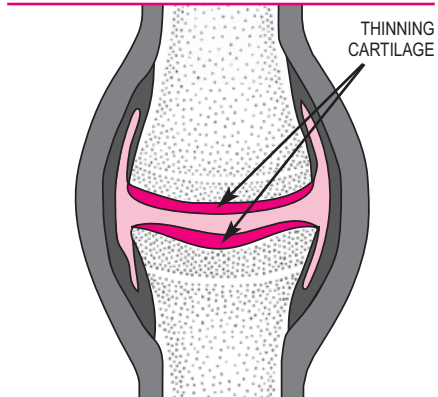
We do not yet know the causes or the cure for osteoarthritis. Although there is a connection with the ageing process, doctors and researchers are trying to identify what factors in this process trigger the disease. They no longer see osteoarthritis as being an inevitable part of ageing or a wear and tear disease, but more an important challenge to fight.

■ What happens?

Healthy cartilage – the protective layer that covers the bone end in the joint – is very smooth, strong and flexible. It absorbs the stresses put on a joint and protects the bones from damage. In osteoarthritis,



A normal joint

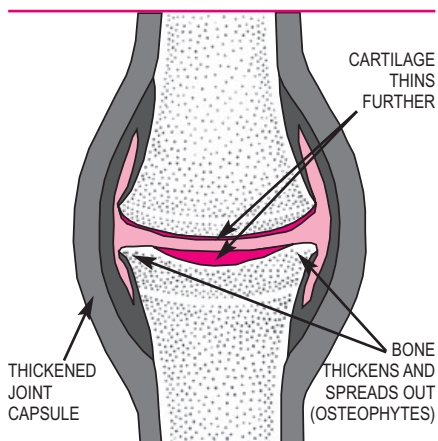


The early stages of osteoarthritis

this becomes pitted, brittle and thin. Over time, it can wear out completely. When the cartilage deteriorates, the bone underneath thickens and broadens out.

As the cartilage becomes thinner, the bones of the joint rub together, causing pain, inflammation and the gradual build-up of bony outgrowths (osteophytes), which make it look knobby.

At the same time, the joint capsule becomes thicker and the amount of synovial (lubricating) fluid can increase, often causing the joint to swell. It may also become stiff and painful to move.



More advanced osteoarthritis

■ Causes

Specific causes of osteoarthritis are hard to pin down. Several factors can increase the risk of developing it.

Age – Osteoarthritis usually develops in people over 50 years of age and it is often undiagnosed. Although it is uncommon before the age of 50, it can develop in young people. It is not known exactly why older people tend to develop it, but it is probably due to bodily changes which come with old age, such as the muscles becoming weaker, putting on weight and the body becoming less able to heal itself.

Gender – Osteoarthritis is more common and often more severe in women, especially in the knees and hands. It often starts after the menopause.

Obesity – The effects of obesity on osteoarthritis are well documented. Carrying extra weight puts pressure on weight-bearing

joints, especially the hips, knees and spine. It also increases the chances of osteoarthritis worsening once it has developed.

I know it's best not to be overweight with OA, but it's difficult

Joint injury – A major injury or operation on a joint may lead to osteoarthritis at that site later in life. Normal activity and exercise are good for the joints and do not cause osteoarthritis. However, very hard, repetitive activity may injure joints.

Exercising too soon after an injury has had time to heal properly may also lead to osteoarthritis in that joint later on. It is always best to check with your doctor, physiotherapist or nurse when it is safe to exercise after you have sustained an injury.

Heredity – One common form of osteoarthritis – nodal osteoarthritis – runs strongly in families. This particularly affects the hands of middle-aged women. In other common forms of osteoarthritis, heredity plays a small part compared with obesity, ageing and joint injury. There are some very rare forms of osteoarthritis that start at a young age and run in families and these are linked with single genes that affect collagen – an essential component of cartilage.

The standard explanation for osteoarthritis is that it is a result of wear and tear. Studies of people who have led very similar lives show some will have almost perfect joints, while others have quite severe osteoarthritis. Therefore, it seems there must be an inbuilt susceptibility to, or protection against, osteoarthritis.

Other types of joint disease – Osteoarthritis is sometimes caused by injury and damage from a different kind of joint disease. For example, people with rheumatoid arthritis can develop osteoarthritis in the joints that were most affected by rheumatoid inflammation.

Myths – Osteoarthritis does have other causes – we just don't know what they are yet. But we do know enough to correct some myths.

Although there is no evidence to support the claim that weather makes arthritis worse, many people find that their joints often tend to feel worse when the atmospheric pressure is falling, for example, just before it rains. Although the weather may temporarily affect symptoms, it does not affect the arthritis itself.

My knee and spine are more painful when the weather turns bad

Warmer regions in the world do not have lower incidences of arthritis than colder regions. Osteoarthritis occurs all over the world, in all types of climate.

While some types of arthritis – gout for example – are directly affected by diet, there is no evidence that a particular diet will eliminate the condition. However, some people claim certain foods make their pain or inflammation worse. It is very important to keep your weight as close as possible to the ideal for your height and age.

Excess weight compounds the problem by putting extra strain on damaged joints. Eating a balanced diet will nourish muscles, cartilage and bone. This will reduce the risk of osteoarthritis.

■ Which joints?

Osteoarthritis affects different joints in different ways, but is most commonly found in the knees, hips, hands and spine.

Pain can be so mild that many people don't even notice it, or so severe that mobility and quality of life is affected.

The spine and weight-bearing joints such as the knees, ankles and hips are most frequently affected by osteoarthritis, making mobility difficult. Osteoarthritis in the fingers, thumbs and wrists reduces grip strength and the ability to perform everyday tasks such as writing, opening jars, picking small things up and doing up buttons.

Shoulder and elbow joints are also susceptible to arthritis although this is much rarer. Some people may experience a grinding feeling in the shoulder and a reduced range of movement. Elbows are very sensitive to injury so very mild arthritis here can lead to quite a significant loss of mobility.

■ Early signs and symptoms

The early signs of osteoarthritis are so mild that they are often easy to miss. The main symptoms are stiff and painful joints, with the pain tending to be worse while exercising the joint and at the end of the day.

Stiffness usually wears off after resting, but the joint may not move as freely or as far as normal and may 'creak' or 'crack' when moved. Muscle-strengthening exercises can prevent the joint giving way.

Symptoms can vary and you may have bad patches of a few weeks or months followed by better periods. You may find that it depends on how much physical activity you do. Joints may appear swollen. In more advanced cases, there may be constant pain and everyday tasks and movement may become difficult.

It is important you visit your GP. Don't ignore your symptoms because early diagnosis will help prevent unnecessary damage.



GETTING A DIAGNOSIS

Your GP will be able to assess whether you have osteoarthritis or whether your symptoms are due to another illness.

■ Your history

Your GP will begin by asking you to describe the symptoms, and when and how they started. Make sure you tell your doctor exactly how you feel, giving a good description of pain, stiffness and joint function, how they have changed over time and how your work and daily life are affected. Finally, you will be asked about any other medical conditions you may have and whether you are taking any medicines.

■ Physical examination

Your doctor will examine your joints and may check muscles, nerves and aspects of your general health, feeling for any bony swellings and creaking joints. They will also look for any restricted movement, joint tenderness and any thinning muscle, excess fluid or instability in the joints.

After a time, you may be referred to a physiotherapist or occupational therapist. They can give you special exercises to do and advice on how to relax, overcome mobility problems, avoid joint strain and cope with pain. If your arthritis is severe, you may be referred to a hospital specialist such as a rheumatologist or an orthopaedic surgeon.

■ Testing for osteoarthritis

There is no blood test for osteoarthritis although you may be given one to rule out other types of arthritis.

X-rays are the most useful test to confirm osteoarthritis and to see how much damage has occurred. These will show such things as cartilage loss, bone damage and osteophytes (bony growths). X-rays do not determine how much your arthritis will trouble you – an X-ray that shows severe changes does not necessarily mean that you will have a lot of pain or disability. Also, they may not show early osteoarthritis damage.

COMMUNICATING WITH HEALTH PROFESSIONALS

Your GP will be your main contact for your treatment. It is important to develop a good relationship to ensure that you are given the treatment that is most effective for you.

Don't be afraid of asking questions if something is not clear. It may help you to write things down or to take a friend or relative with you.

Doctors are often rushed, but it is important that you make the most of your consultations. This will help you understand and feel confident about any treatment you are given.

You and your GP must work together to help you manage your arthritis and help you live as normal a life as possible. Ultimately, only you know how you feel and the difficulties you face.

The National Institute of Health and Clinical Excellence (NICE) has guidelines for the management of osteoarthritis in England & Wales. These guidelines should help your doctor support you to manage your condition. Call Arthritis Care's helplines to find out more or if you have any questions about your condition – 0808 800 4050 (10am-4pm weekdays).



■ Getting the most out of your GP appointment

It is a good idea to have about four questions to ask your GP before your appointment in case your mind goes blank.

If you feel that you need more time with your doctor, you can always ask for another appointment or perhaps book a double appointment. Your local surgery will be able to tell you about its rules.

When you join a practice you can ask at reception if a GP has a particular interest in arthritis.

Don't be afraid to discuss treatment options or to take on more responsibility for your own needs. It is worth reminding your GP of any other conditions you have or medications and supplements you are taking.

I took a friend to the surgery with me, to prompt me in case I forgot to ask anything

Should your condition deteriorate to the point where your mobility is severely affected, you may be advised by your GP to see a rheumatologist for specialist advice on medical management, or an orthopaedic surgeon to discuss the possibility of joint replacement surgery.

■ Treatment versus prevention

While it can be difficult to avoid, injuries to a joint can increase the risk of developing osteoarthritis in the same joint, years later.

However, maintaining a normal weight for your height and body type, keeping physically active and avoiding excessive stress on the joints as you get older, can reduce the severity and impact of osteoarthritis.

Ways to reduce stress on the joints include:

- sticking to your ideal weight
- pacing yourself. Instead of attending to the chores that need doing all at once spread them out
- wearing shoes with thick, soft soles can act as shock absorbers and reduce jarring
- using a walking stick can reduce the weight and stress on a painful hip or knee joint.

■ What you can do to manage your arthritis

- General exercise – keep moving. Don't be afraid to use your joints.
- Swimming in a heated pool can help.
- Massaging the muscles around the joints will help ease pain and help keep you supple.
- Sleeping on a good mattress can ease pain.

■ Treatment with drugs

Mild to moderate disease can usually be managed successfully with painkillers, such as paracetamol or ibuprofen (a non-steroidal anti-inflammatory drug). Make sure you follow the dosage instructions on the packet.

A GP may prescribe a different non-steroidal anti-inflammatory drug (if this is appropriate for you) or a stronger codeine-based painkiller.

The medication each person is prescribed and how often they take them depends on their disease and on how they react to the drugs. Some of the most commonly used drugs for osteoarthritis are listed below. There is more information in Arthritis Care's booklet on drugs.

Analgesics – These are pain-relieving drugs, such as paracetamol, that do not affect the arthritis itself, but help relieve the pain and stiffness. They come in varying strengths and the stronger ones are only available on prescription.

Paracetamol, which is available over the counter, is the simplest and safest painkiller, and the best one to try first. Side effects are unusual, although taking too great a dosage can cause liver damage.

Many pain relieving drugs, including pain relief gels, can be bought over the counter. Never take more than the recommended dose and, if in doubt, talk to your pharmacist or doctor.

Stronger, combined painkillers such as co-codamol and

Painkillers don't remove the pain completely, but they alter the nature of it, making it more bearable

co-dydramol are available on prescription. They contain paracetamol and a second codeine-like drug. These are more likely to cause side effects, such as constipation or dizziness. Some anti-inflammatory drugs such as ibuprofen can be used as painkillers in low doses.



Non-steroidal anti-inflammatory drugs (NSAIDs) – If you have mild inflammation in your joints, your doctor may prescribe a course of non-steroidal anti-inflammatory drugs (NSAIDs). However, if there is no inflammation, as is often the case with osteoarthritis, these drugs may have no advantage over painkillers.

NSAIDs are more likely to cause side effects – especially indigestion and diarrhoea. They can interfere with the effectiveness of other drug treatments used to treat high blood pressure and heart disease. Ibuprofen and diclofenac are commonly used NSAIDs but there are many others. Your doctor will advise you which is the appropriate one to take, and the correct dose. Creams and gels can often help, especially for knee and hand osteoarthritis.

Cox-2s – Cox-2 inhibitors are a newer type of NSAID, designed to be safer for the stomach. However, both the older type (such as ibuprofen and diclofenac) and the newer Cox-2 inhibitors are thought to increase the risk of cardiovascular (heart) disease and high blood pressure, especially in people with a history of heart disease or stroke. This risk may be increased when the drugs are used at higher doses for prolonged periods of time. Longer-term studies are being done to determine the safest NSAID.

Always ask your doctor or pharmacist about side effects and other concerns you may have.

Steroids – If you have moderate to severe pain from osteoarthritis, you may be offered a steroid injection directly into a particular joint to reduce inflammation and pain.

LOOKING AFTER YOUR JOINTS

Most people can lead a full, active life with osteoarthritis by properly managing the condition and making small, common-sense alterations to their life.

There are many things that can be done to help alleviate the symptoms and prevent the disease from progressing. Regular exercise, protecting the joints from further injury and maintaining an ideal weight through a healthy diet will all benefit you.

Inflamed or damaged joints need to be cared for and protected. Keeping healthy is part of this, but you also need to avoid straining joints by overdoing things or doing them awkwardly.

You may have to give more thought to the clothes and shoes you wear, to the way you lift, grip and carry things or to the way you arrange your home or place of work. An occupational therapist can help with all of this.

■ Occupational therapists

Occupational therapists (OTs) can help if you are having difficulty with day-to-day tasks like washing, dressing, cooking and cleaning. They can also advise on ways to improve your work environment.

OTs are experts on what equipment is available to help you and where you can buy these items. They may also be able to supply some of the more expensive items on temporary loan.

Your GP or hospital consultant can put you in touch with an occupational therapist. This may be at your local hospital or they may visit you at home. If you are having trouble getting a referral to an OT, then you can refer yourself by phoning your local social services department and asking for an assessment.

■ Exercise and rest – a fine balance

Exercise can be the furthest thing from people's minds when they live with pain on a daily basis. However, for people with arthritis, the benefits of exercise are enormous. Exercise protects joints by keeping the muscles strong and keeping you mobile. It is also good

for pain and stress and can help you lose any extra weight which puts strain on joints.

Change the way you move

- Spread the load – use both hands to lift and hold, for example.
- Shift rather than lift – slide heavy pans along a kitchen top.
- Use larger, stronger joints – rather than pushing a door open with your hand and wrist, use your shoulder or hip.
- Don't grip things too tightly – choose a fatter pen, for example. Hold it as loosely as possible or expand the grip with padding.
- Change positions often – shift position or stretch every half an hour.
- Watch your posture – slouching can add strain on muscles and joints.

Exercise won't make your arthritis worse – as long as it is the right sort. The wrong sort of exercise could put strain on your joints and damage them further. You can ask your GP to refer you to a physiotherapist, who will help you work out a programme combining flexibility (range of movement), strengthening or aerobic exercises. Arthritis Care's booklet on exercise includes examples of these.

Range of movement – Range of movement (ROM) exercises form the backbone of every exercise programme. Everyone should do these as they help maintain flexibility, and are important for good posture and strength.

The exercises involve taking joints through their comfortable range of movement and then easing them just a little further. ROM exercises are done smoothly and

My condition gets me down but walking can help at least to minimise the pain a bit



gently so they can be done even when in pain.

Strengthening – Strengthening exercises are especially beneficial, because they help to strengthen the muscles which move, protect and support your joints. Many people become less active when they develop arthritis because of the pain and fear of causing damage. This can lead to muscle wastage and weaker joints.

By developing strong muscles, joints become more stable and activities such as walking and climbing stairs are easier.

Start slowly and gradually increase the number of movements. As the muscles get used to doing more, they become stronger. The type of exercises you do will depend on which joints are affected and how severe your condition is. Always check with a doctor or physiotherapist before starting a new form of exercise programme.

Aerobic – Aerobic just means exercise that raises your heart rate. This type of exercise burns off calories, speeds up the body's metabolism, helps maintain a strong heart and helps muscles work more effectively. It also helps control and reduce weight, improves sleep, strengthens bones, reduces depression and builds up stamina.

The best forms of aerobic exercise for people with arthritis are walking, cycling and swimming.

Begin any exercise by stretching to warm up. To get any benefit, aerobic exercise must be done for 30 minutes five times a week. You are at a good level if you start to sweat and can still hold a conversation at the same time.

Check with a doctor before beginning any exercise programme. These exercises done correctly and consistently will provide some relief from the pain of arthritis, help with good posture, and increase your energy and vitality.

Warm water exercise – Gentle exercise can be carried out in hydrotherapy pools that will usually be heated to around 34 degrees centigrade.

The warm water soothes the joints, relieves stiffness, and

promotes better blood circulation. The water enables gentle and low-impact exercise, and also offers the resistance needed to keep muscles and joints in shape.

Your doctor may refer you for hydrotherapy – exercising in a heated pool under the supervision of a physiotherapist. Because the water supports your weight, the range of movement in your joints should increase and pain decrease. Most hydrotherapy pools have a shallow end. If you cannot lower yourself into the water, there will usually be a hoist. Hydrotherapy sessions may be held in your local hospital.

As with any exercise programme, consult your GP before you begin this type of exercise. It is very important not to overdo things. Rest your joints – especially when they are inflamed or particularly painful. Resting painful joints will make them more comfortable, but too much may make them stiff. You need to strike a balance between rest and activity.

■ A healthy diet

Your body needs a range of nutrients, so make sure you eat a healthy, balanced diet. Include lots of fruit, vegetables, pasta, pulses (such as beans and lentils), fish and white meat. Try to cut down on sugary and fatty foods.

There is a lot of debate about whether what you eat affects arthritis and whether certain foods may help. Studies on essential fatty acids (found in oily fish) show that they can ease joint pain and stiffness. Try to include more of these in your diet and consider taking a supplement.

Some people claim that some foods seem to make their inflammation or pain worse. If you can work out which food is the trigger, talk to your doctor for advice. It is important you don't miss out on essential nutrients. Research in this area is complicated and much

I had hydrotherapy sessions which were wonderful, but by the time I drove 15 miles home, I undid all the good work

more needs to be done.

If you are considering a diet, talk it over with your doctor or dietician first. Beware of diets that claim to cure osteoarthritis, and never begin a diet that involves stopping medication without discussing it with your doctor.

Read Arthritis Care's booklet on healthy eating for further information.

■ Supplements

People with arthritis take a huge range of supplements including herbal remedies, homeopathic medicines, vitamins, minerals and dietary supplements.

Many people with osteoarthritis believe they do offer relief. So far there is little evidence they improve arthritis or its symptoms, though recent findings for omega-3 fatty acids are promising.

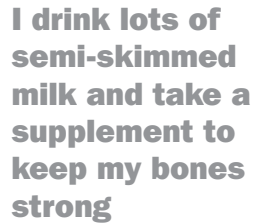
Before you start taking supplements:

- find out as much as you can
- remember that supplements will not cure arthritis
- check with your doctor or pharmacist for interaction with prescription drugs
- tell your doctor if you are taking any supplements and report any side effects immediately
- keep a record of how you feel so you can see if they are having an effect
- buy brands from reputable manufacturers
- consider the cost – taking supplements can be expensive.

Below are a few of the supplements most commonly taken by people with osteoarthritis.

Glucosamine

Glucosamine is popular with people who have osteoarthritis. It is a



I drink lots of semi-skimmed milk and take a supplement to keep my bones strong

natural substance extracted from crab, lobster or prawn shells. While it does not cure arthritis, some people believe that it does help ease pain and stiffness, especially in the knees. The latest research suggests that glucosamine does not reduce joint pain. If you haven't seen an improvement after two months, it probably won't help you.

There are no known major side effects, but lesser ones include nausea and indigestion. Glucosamine, which comes in capsule form, is often taken in combination with chondroitin.

Glucosamine is now available on prescription under the brand name Alateris. Glucosamine is not recommended for use within the NHS.

Chondroitin

Chondroitin sulphate exists naturally in our bodies and is thought to give cartilage elasticity and to slow its breakdown. In supplement form it is derived from the trachea of cattle or sometimes shark cartilage.

Don't expect to see any improvement for at least two months. If you have severe cartilage loss you probably won't get any benefit. The latest research suggests that chondroitin is not effective. There do not seem to be any serious side effects, but minor ones include nausea and indigestion. It could increase the chances of bleeding if you are taking any blood-thinning drugs. The long-term effects are not known.

Fish oils – omega-3 fats

Fish oils, like cod liver oil, can produce a modest improvement in joint pain and stiffness. Some people find them helpful, but there needs to be more scientific research to find out how effective they are for osteoarthritis.

A daily dose, often in capsule form, must be taken for at least three to six months. Any benefit is lost when you stop taking it. Care should be taken not to exceed safe levels of vitamin A when taking cod liver oil. Studies still need to be carried out on the possible long-term effects of taking fish oils.

■ Complementary therapies

Many people with arthritis have tried a range of complementary therapies in addition to the conventional drugs prescribed by their doctor. However, what works for one person may well not work for another.

There are a multitude of different therapies. Some are thoroughly reputable and are regulated by statutory bodies. Other therapies make highly dubious claims with little or no evidence to back them up.

Complementary therapies can generally be used alongside orthodox treatment, although doctors may vary in their attitudes to them. Any practitioner of these therapies who advises you to stop using conventional medications should be regarded with extreme caution.

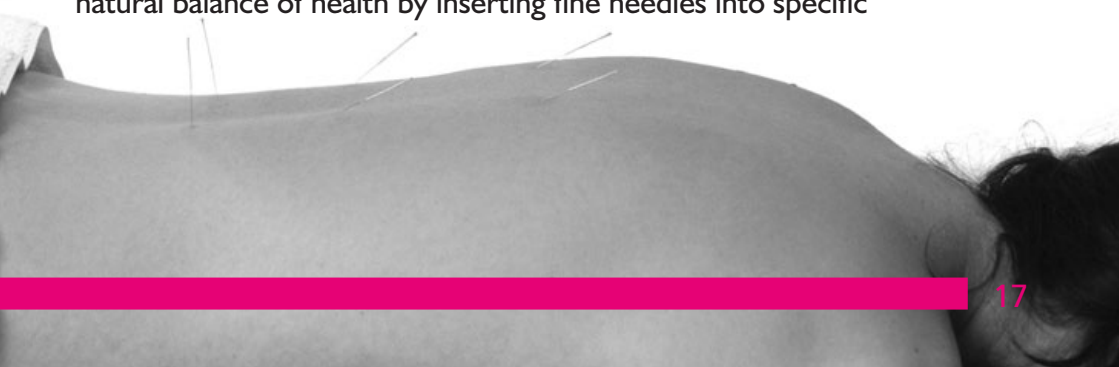
Some complementary therapies are available on the NHS and some private health insurance companies will pay for treatment. However, the majority of people pay for their own treatment which can be costly.

Complementary therapies do not offer a cure for arthritis. They can, however, help alleviate some of the symptoms such as pain and stiffness as well as dealing with some of the unwanted effects of taking drugs.

Complementary therapies can play an important role in encouraging positive changes in lifestyle and outlook, such as increased self-reliance, a positive attitude, learning relaxation techniques and appropriate exercises. Lifestyle changes like these may help to stabilise or improve your arthritis.

Some of the most popular therapies are listed below.

Acupuncture may be useful for osteoarthritis. It claims to restore the natural balance of health by inserting fine needles into specific



acupoints in the body to correct imbalances in the flow of energy, thereby relieving pain.

The Alexander technique concentrates on how you use your body in everyday life. By learning to stand and move correctly, people can alleviate conditions that are exacerbated by poor posture.



The Alexander technique really helps my posture and relieves pain



Aromatherapy uses essential oils obtained from plants to promote health and well-being. The oils can be vaporised, inhaled, used in baths or a burner, or as part of an aromatherapy massage.

Chiropractors use their hands to adjust the joints of your spine, aiming to improve mobility and relieve pain.

Massage can loosen stiff muscles, ease tension, improve muscle tone, and increase the flow of blood and lymph. A good massage leaves you feeling relaxed and cared for.

Osteopaths manually adjust the alignment of the body and apply pressure to the soft tissues of the body to correct structural and mechanical faults and allow the body to heal itself.

Tai chi is a non-combative martial art designed to calm the mind and promote self-healing through sequences of slow, graceful movements.

Finding a good therapist

Some therapies are available on the NHS, so it is worth asking your GP if he or she can recommend a therapist or a particular therapy.

Ask other people with osteoarthritis if they can recommend a therapist, but remember that what works for someone else may not suit you.

The Institute for Complementary and Natural Medicine (see page 29 for contact details) can also help you find a qualified therapist.

Ask how much treatment will cost, and how many sessions you will need to feel a benefit. Ask if the therapist is a member of a professional body, what kind of training they have had and how long they have been practising. Ask if they have insurance in case something goes wrong. They should take a full medical history from you.

Tell your therapist about any drugs you are taking, and your doctor about the therapy. Don't stop taking prescribed drugs without talking to your doctor first.

There is more information in Arthritis Care's booklet *Drugs and Complementary Therapies*.

■ Surgery

While some people with arthritis will never need to have surgery, others find it is very successful in relieving pain caused by arthritis, improving mobility and reducing stiffness. Surgery is usually only considered after all other suitable treatment options have been explored. You should be referred for surgery if your symptoms (pain, joint stiffness and reduced joint function) are having a substantial impact on your quality of life – and before there is further damage to your joints.

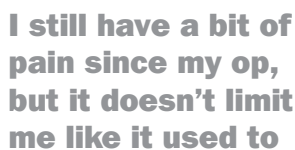
Surgery can be minor or it can be more intrusive – to replace or to fuse a joint.

There is a risk the operation won't work, or will lead to further physical complications. Recovery may take some time and a lot of effort on your part.

However, many people decide that the positive effects on their lifestyle will outweigh any risks. Having surgery could bring about a dramatic improvement in your pain levels and quality of life. Surgery can also prevent joints deteriorating further and prevent disability.

Surgery is improving all the time. Most people who have had a joint replacement have much less pain and more mobility in the new joint. However, some people may still have a degree of difficulty or pain.

You will find more information in Arthritis Care's booklet on surgery.



I still have a bit of pain since my op, but it doesn't limit me like it used to

PRACTICALITIES

Living with osteoarthritis may not be easy, but there are plenty of sources of help and there is plenty you can do to help yourself. See pages 29 and 30 for a list of useful organisations.

■ At home

There are many ways you can set things up at home to make sure that daily living is as streamlined and stress-free as possible.

In the kitchen, for instance, this might include:

- rearranging cupboards and drawers so the things you use the most are nearby
- lightweight pans, mugs or a kettle
- equipment with easy-to-use buttons
- an electric tin opener, a cap gripper, or knives and peelers with padded handles
- a stool to sit on while you are preparing food, or a trolley for moving heavy items
- devices for turning taps more easily
- evening-up your worktops, or raising the oven and fridge, so they are at the right height for you and for sliding things around.

Help with costs – Your local social services department (social work department in Scotland, health and social security agency in Northern Ireland) may be able to help with equipment or adaptations to your home.

You are entitled to have your needs assessed – usually by an occupational therapist – to see whether you are eligible for help. Eligibility varies throughout the

Don't let your pride get in the way of using equipment that may really help you



UK and you may have to contribute towards the cost. You may also have to wait a long time for an assessment or for equipment. If your needs change, contact social services so they can move you up the waiting list.

Some equipment may also be available on the NHS. Local home improvement agencies and voluntary organisations also offer help or funding for equipment and adaptations.

There is more information about home life in Arthritis Care's booklet on independent living.

You have the right to an assessment of your care needs at home – again, contact your local social services department. If you have a specific carer, the assessment must also take their needs into account.

Help varies a lot from area to area, but social services may be able to arrange for care workers to visit you for domestic care, such as cleaning and shopping, or to give you support with personal tasks.

■ Work and education

Your arthritis may not significantly affect your work at all, but struggling on if you have difficulties could make your arthritis worse. The best policy is to be positive, honest and clear about your needs, and help people understand how osteoarthritis affects you.

Smarter ways of working will help protect your joints and conserve energy. They can include:

- organising your work –
rearranging your work area, using computer equipment correctly, taking regular breaks, relaxing, pacing yourself and varying tasks
- flexibility – perhaps working a shorter day or different hours, or being based at home some of the time if that fits in with your job.

After I gave up work I went back to university and got a degree. It really kept me occupied

An occupational therapist can help you figure things out, as can a disability employment adviser (DEA). DEAs are based at your local Jobcentre Plus (Jobs and Benefits Offices in Northern Ireland). They offer support and advice to disabled people and employers, referring

to training schemes where appropriate.

Check www.direct.gov.uk or www.nidirect.gov.uk (in Northern Ireland) for the latest information as changes are planned to the help available.

Access to Work advisers offer in-depth information on the Access to Work programme – a Government scheme that helps disabled people and their employers overcome work-related obstacles. This could be by providing equipment or adaptations to your workplace, and work-related expenses, such as taxi fares. Contact your local Jobcentre Plus for more information.

There is also financial and practical help on offer if you want support finding work, handling application forms and interviews, or making the move from benefits to work. Your DEA can help you access this.

Depending on how your arthritis affects you, the time may come when you need to consider changing jobs. Some people do have to stop working altogether. It's important to get professional advice about your rights and options beforehand.

Giving up work doesn't mean that you are giving up your life: retraining, further education and voluntary work may all open new doors. It is important to discuss options before making your decision.

The Equality Act 2010 says that all employers must take reasonable measures to ensure they don't discriminate against disabled people. These can include changing the working environment, moving your workspace to the ground floor, or retraining you and reallocating your duties. But you will only be protected by the legislation if your employer knows about your arthritis. The Equality Act also covers recruitment, training, promotion and dismissal.

More information for people with arthritis looking for – or already in – work can be found in Arthritis Care's booklet on working with arthritis.

If you are going into higher education (post-18), you may be eligible for a Disabled Students' Allowance. The allowance covers any extra costs or expenses students have because of a disability. For more information, visit the Skill website (see page 30).

■ Transport

There are many ways to adapt your car to enable you to keep driving. A few minor adjustments – such as a padded steering wheel, a steering wheel knob, a headrest, extra side-mirrors or a wide-angled mirror – may help. An automatic gearbox and power steering can reduce strain on joints and muscles.

There are some transport schemes and services run by local authorities, and voluntary and commercial organisations to allow you to maintain your mobility, but service provision throughout the UK can be patchy.

Some local authorities (in the phone book) produce guides to accessible bus, train, minicab services and transport schemes.

Your local disability organisation (in the phone book), library or local newspaper may also be able to tell you what's on offer locally.

The mobility component of the DLA allows me to run a car

The Disabled Persons Railcard is valid throughout the UK and gives a third off many rail tickets – www.disabledpersons-railcard.co.uk. To be eligible to buy one you need to be receiving Attendance Allowance (AA) or Disability Living Allowance (either the mobility component, or the higher or middle rate care component).

You can apply for a Blue Badge, which means that you will be allowed to park in a designated parking space closer to your destination. The badge belongs to the disabled person who qualifies for it (who may or may not be a car driver) and can be used in any vehicle they are travelling in. Apply for one at your local authority.

If you receive the higher rate of the mobility component of the Disability Living Allowance, you may be able to use it to hire or buy a car, wheelchair or scooter through the Motability scheme (see page 30).

If you need a specially adapted car, contact an accredited driving assessment centre. The Forum of Mobility Centres has a list of centres. Don't forget to tell the Driver Vehicle Licensing Agency (DVLA) and your insurance company if your arthritis affects your ability to drive.

■ Benefits

You may be entitled to state benefits to help with the extra costs of having arthritis or if you are unable to work. Claiming benefits can be complicated and time consuming so, before you start, it is worth getting expert help and advice from:

- your local social security office or Jobcentre Plus office (Jobs and Benefits Office in Northern Ireland – see the phone book)
- a social worker or welfare rights officer at your social services department (social work department in Scotland, health and social security agency in Northern Ireland)
- your local Citizens Advice or other advice centre
- Benefit Enquiry Line – an information line run by the Government, which aims to advise disabled people of their benefit entitlements and assist them in making a claim. Call 0800 882 200, or 0800 220 674 if you are based in Northern Ireland.

Changes are being planned to benefits, for the latest information go to your local Jobcentre or equivalent or visit www.direct.gov.uk (www.nidirect.gov.uk in Northern Ireland).

DLA and AA – Whether you are working or not, you can claim Disability Living Allowance (DLA) if you are under 65 and need help getting around or with personal care (such as washing and dressing). If you are 65 or over you may be entitled to Attendance Allowance (AA) for help with personal care.

DLA and AA are not means tested, are tax free and are paid in full on top of other income and all other benefits you get.

They also mean you may qualify for other benefits or help, so it is worth applying for them if you need help getting around or with personal care. If your claim is initially unsuccessful, ask to have the decision reconsidered. Many people go on to qualify on further attempts.

To help complete your application keep a diary for a couple of weeks, listing any things you have trouble

“ If you get turned down, then fight. I had to fight for DLA and got it in the end ”

doing and the time it takes you to do them, so you don't underestimate how much help you need.

This benefit is being reviewed and is planned to be replaced in 2013/14 with the Personal Independence Payment.

Working tax credit and child tax credit – If either you or your partner work 16 hours a week or more and you have a disability, Working Tax Credit (WTC) can top up earnings if you are on a low income. There is no upper limit on the amount of savings you can have, but income from savings will be taken into account.

Child Tax Credit (CTC) is also available if you are responsible for children, whether you are in work or out of work even if your income is quite high.

Employment and Support Allowance – If you can no longer work because of health problems, you may be able to claim Employment and Support Allowance (ESA).

You usually need to have paid a certain amount of national insurance contributions to get it.

Any occupational pension or health insurance you receive may reduce the amount of ESA you are paid. If you currently receive Incapacity Benefit you will continue to receive it for the time being. See the Arthritis Care website for up-to-date details.

Other benefits – If you are on a low income, there are several other benefits you can apply for such as Income Support, Pension Credit (if you are over 60), Housing Benefit and Council Tax Benefit.

Carers can apply for benefits too, but should check first that claiming Carer's Allowance will not affect the benefits of the person they care for.

CARING FOR YOURSELF

■ Your emotions

Everyone's experience of arthritis is different. Not all people experience the same symptoms, feelings, level of pain or fatigue. Don't be surprised if you feel frustrated one day and perhaps angry the next.

It is good to let your emotions out. Bottling them up can make things worse.

Pain can usually be controlled, stiffness and inflammation relieved, and there are ways to overcome the loss of strength, grip and mobility.

Some people find that their lives do not change that much and that they can more or less carry on as normal. Some people become stronger and more determined as a result of having to adapt their lives to fit in with their arthritis – everyone is different.

Your own reactions to arthritis will differ from week to week, but it is perfectly natural to feel out of sorts sometimes. You may find Arthritis Care's booklet on emotions helpful.

■ Your relationships

Sharing information about your condition with family and friends can really help them to understand what you're going through. They may really want to help, but not know how.

You may be worried about letting them down or about depending



The invisibility of pain is most frustrating

on them too much. Talking and listening is the key. Explain how your arthritis affects you and be as clear as you can about how you are feeling.

Relationships may come under a bit of strain. If you have a partner, talk to them about how you feel, both physically and emotionally and encourage them to ask questions.

If you are feeling stiff or having trouble moving around, it is hard to be spontaneous; even a hug can be difficult if you are in pain. There will be times when you are just too tired or in pain to get close to your other half, but there are alternatives.


Try different positions or supporting your body with pillows and cushions to make love-making more comfortable. A warm bath or shower beforehand will help to loosen your joints. You could even try persuading your partner to give you a gentle massage.

Don't be embarrassed to raise the issue with your healthcare team. Some people find Arthritis Care's booklet on relationships useful.


■ Living well

From time to time, your arthritis will get on top of you. Anger, frustration, uncertainty, depression and fear are all very understandable and very common. Several things may help:

- try to build a good relationship with your health professionals
- find out as much as you can about your arthritis. It will make you feel less worried about the future
- accept your limitations. Think about what you can do and enjoy, rather than the things you can't
- try to make space for your social life
- include exercise in your day. It will build your strength, help you to keep flexible and boost your mood
- talk to somebody who understands how you are feeling. This could be someone close to you or someone else with arthritis.



If I go out socialising, I accept I might feel a bit off colour the next day



■ Consider a self-management programme

There are plenty of things you can do to prevent osteoarthritis taking over your life. There is a lot of help available.

Arthritis Care's popular programme, Challenging Arthritis, focuses on what you can do for yourself, how to get the most from your health professionals, handling pain, fatigue and depression, relaxing, and keeping active. It is a great chance to meet with others in the same position.

The new shorter Challenging Pain programme, delivered over two sessions, is specifically designed to provide coping skills and techniques for managing chronic pain.

If you have any questions about living with arthritis, contact Arthritis Care or one of the organisations listed on the following pages.

The more you know about your condition, the more powerful you feel



Our information is regularly reviewed. This booklet will be reviewed in 2013. Please check our website for up-to-date information and reference sources or call 020 7380 6577.

USEFUL ORGANISATIONS

GENERAL

● Arthritis Care

www.arthritiscare.org.uk

UK office:

Tel: 020 7380 6540

South England office:

Tel: 0844 888 2111

Central England office:

Tel: 0115 952 5522

North England office:

Tel: 01924 882150

Northern Ireland office:

Tel: 028 9078 2940

Scotland office:

Tel: 0141 954 7776

Wales office:

Tel: 029 2044 4155

● Arthritis Research UK

Tel: 0300 790 0400

www.arthritisresearchuk.org

Funds medical research into arthritis and produces information.

HEALTH SERVICES

● NHS Choices

For links to NHS services in your area and information. Call NHS Direct on 0845 4647 and NHS 24 in Scotland on 08454 242424.

www.nhs.uk

● British Association/College of Occupational Therapists

Tel: 020 7357 6480

www.cot.org.uk

Details on local practitioners.

DAILY LIFE

● Disabled Living Foundation

Tel: 020 7289 6111

Helpline: 0845 130 9177

www.dlf.org.uk

Advice and information on equipment.

● DIAL UK

Tel: 01302 310123

www.dialuk.info

Details of your nearest disability advice and information service.

● Ricability

Tel: 020 7427 2460

www.ricability.org.uk

Consumer guides on products and services for disabled people.

● RADAR

Tel: 020 7250 3222

www.radar.org.uk

National campaigning organisation which also publishes a wide range of information on disability issues.

COMPLEMENTARY THERAPIES

● Institute for Complementary and Natural Medicine

Tel: 020 7922 7980

www.icnm.org.uk

Umbrella body. Can help you find qualified practitioners locally.

MONEY AND BENEFITS

● Disability Alliance

London E1 7SA

Tel: 020 7247 8776

www.disabilityalliance.org

Provides information on benefits.

USEFUL ORGANISATIONS

- **Benefit Enquiry Line for disabled people**

Tel: 0800 882 200

Mon-Fri, 8.30am-6.30pm.

Sat, 9am-1pm.

In Northern Ireland, the Benefits Enquiry Line is run by the Social Security Agency.

Tel: 0800 220 674

PAIN MANAGEMENT

- **The British Pain Society**

Tel: 020 7269 7840

www.britishpainsociety.org

Information about chronic pain and pain clinics.

- **Pain Concern**

Helpline: 0844 499 4676

www.painconcern.org.uk

Information and helpline.

GETTING AROUND

- **Motability**

Tel: 0845 456 4566

www.motability.co.uk

Provides cars and powered wheelchairs through the Motability scheme.

- **Forum of Mobility Centres**

Tel: 0800 559 3636

www.mobility-centres.org.uk

A network of organisations across the UK offering advice to individuals who have a condition that might affect their ability to drive.

PREGNANCY AND PARENTING

- **Disability Pregnancy and Parenthood International**

Helpline: 0800 018 4730

www.dppi.org.uk

Information and advice for disabled parents.

RIGHTS AND DISCRIMINATION

- **Equality and Human Rights Commission Helpline**

www.equalityhumanrights.com

England: 0845 604 6610

Wales: 0845 604 8810

Scotland: 0845 604 5510

- **Equality Commission Northern Ireland**

Tel: 028 90 890 890

www.equalityni.org

WORK AND EDUCATION

- **Skill: National Bureau for Students with Disabilities**

www.skill.org.uk

Information about further, higher and continuing education, training and employment for disabled young people and adults.

ARTHRITIS CARE

Arthritis Care exists to support people with arthritis. We are the UK's largest charity working with and for all people who have arthritis. We offer support wherever you live in the UK.

It costs us £1.10 to provide you with this booklet. If you are able to access information online, you'll help us save money and the environment.

Get involved with us today if you can.

- Make a donation.
- Leave a legacy in your Will.
- Join as a member.
- Become a volunteer.
- Support us in your local area.
- Take part in events.
- Campaign on our behalf.
- Find out about our self-management training and support.
- Join our online discussion forum.
- Visit our website.
- Ring our confidential helpline.
- Join a local support group.

We exist for everyone with arthritis, but we rely on the support of people like you. If you would like to make a contribution to our work, please phone us on 020 7380 6540. Or you can donate online.

www.arthritiscare.org.uk



ARTHRITIS CARE

*Empowering
people with arthritis.*

**To find out more about
arthritis and Arthritis Care**

Freephone our confidential helpline

0808 800 4050

(weekdays 10am-4pm)

Visit our website

www.arthritiscare.org.uk

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