Living with osteoarthritis

devised with and for people with arthritis

Empowering people with arthritis.
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. As this booklet explains, there is a wide range of treatments to try and there is a lot you can do to make day-to-day living easier.

Contents

Introducing OA 1
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

All people pictured on the cover and quoted in this booklet have arthritis.
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,
this becomes pitted, brittle and thin, and, over time, 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 knobbly.

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.

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

Age
People usually develop osteoarthritis from their late 40s through to old age and it is often undiagnosed. Although it is uncommon before the age of 40, young people can develop it. 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 virtually 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 years before. 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.

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

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. However, although the weather may temporarily affect symptoms, it does not affect the actual arthritis itself.

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. It is also
important to eat a balanced diet to nourish muscles, cartilage and bone. This will reduce the risk of osteoarthritis.

■ Which joints?
Osteoarthritis is very variable and can affect different joints in different ways, but is most commonly found in the knees, hips, hands and spine.

Pain can vary in severity and 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 affects grip strength and the ability to perform everyday tasks such as opening jars, picking small things up, writing 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 and don’t ignore your symptoms, as 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 the condition 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.

You may be referred, after a time, to a physiotherapist or occupational therapist who 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 to do with matters concerning your treatment, and 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.

■ Getting the most out of your GP appointment

It is a good idea to make a list of 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.

“I did a lot of research before I went to my GP, it really helped me”

Don’t be afraid to discuss treatment options or to take on more responsibility for your own needs.

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

It is worth reminding your GP of any other conditions you have or medications and supplements you are taking.

**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 structure, 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.
● 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.

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 with drugs
The medication each person is prescribed and how often they take them differs depending on their disease type and on how they react to the drugs. Some of the most commonly used drugs for osteoarthritis are listed below.

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 recommend dose and, if in doubt, talk to your pharmacist or doctor.

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

Stronger, combined painkillers such as co-codamol and 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, concerns have been raised about their side effects, including increased risk of cardiovascular problems, especially for people with a history of heart disease or stroke. Some drugs within the class have been withdrawn. At the time of printing, the future use of Cox-2s is under review, although most Cox-2s are still available on prescription. If you want to know the latest about Cox-2s, discuss with your doctor what treatment is most suitable for you.
Most people can lead a full, active life with osteoarthritis by properly managing the condition and making small, common-sense alterations to 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 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.

“I’m a Walking for Health leader. The fact that I have a new hip gives participants confidence”

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. Ask your GP whether it is appropriate for you to be referred 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 full range of movement and then easing them a little further. ROM exercises are done smoothly and 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, gradually building up the repetitions. 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 regime.

**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 a prolonged period (20-30 minutes) two to three 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 regime. 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.

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.

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 range in depth and if you cannot lower yourself into the water, there will usually be a hoist.

Hydrotherapy sessions may be held in your local hospital.

■ 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 also cut down on sugary and fatty foods.

There is a lot of debate about whether what you eat affects arthritis – 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 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 diet and supplements 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 and glucosamine 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.

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

**Glucosamine**

Glucosamine is popular with people who have osteoarthritis. It is a 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. There is not much scientific evidence to support this at this stage. 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.

**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. 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**
Fish oils, like cod liver oil, can produce a modest improvement in joint pain and stiffness and have a good record of easing the symptoms of osteoarthritis.

Recent research has found that omega-3 fatty acids are effective because they reduce the activity of the enzymes responsible for cartilage damage, and they switch off another enzyme known to cause much of the pain and inflammation of arthritis.

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 and D when taking cod liver oil. Studies still need to be carried out on the possible long-term toxicity 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.

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

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 and they 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 aims to restore the natural balance of health by inserting fine needles into specific acupoints in the
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, improve muscle tone, increase the flow of blood and lymph, and ease tension. 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 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 must take a full medical history.
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 about 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 and when the joint is badly damaged by arthritis.

Surgery can be minor – to assess damage done or to smooth joints and repair cartilage (known as an arthroscopy), 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.

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

In spite of great progress with artificial joints, many people with osteoarthritis who have had surgery still live with difficulties and pain because of their condition.

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

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

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 you can slide 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 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 what osteoarthritis means for 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) and offer support and advice to disabled people and employers, referring to training schemes where appropriate.

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 Disability Discrimination Act (DDA) 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 DDA if your employer knows about your arthritis. The DDA 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.

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, contact Skill (see page 30).

■ Transport

Getting around is very important. If it becomes difficult for you to use public transport or drive a car, your life can
become very restricted. 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 about what’s on offer locally.

If you receive Attendance Allowance or the higher rate Disability Living Allowance you can purchase a Disabled Persons Railcard. This is valid throughout the UK and entitles you to up to a third off many rail tickets (www.disabledpersons-railcard.co.uk).

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. For further details visit the Department for Transport website at www.dft.gov.uk

If you drive, then a few minor adjustments – such as a padded steering wheel, 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.

“The mobility component of the DLA allows me to run a car – it has opened up my life.”

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 Citizens Advice Bureau 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.

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

For more information, see Arthritis Care’s information sheets on benefits.

**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 think you are eligible. If your claim is initially unsuccessful it is worth reapplying as many people go on to qualify on further attempts.

To help complete your application keep a diary over a couple of weeks, listing any things you have trouble doing and the time it takes you to do them, so you don’t underestimate how much help you need. Reflect the bad days as well as those when you can manage.

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.

Incapacity Benefit
If you can no longer work because of health problems, you may be able to claim Incapacity Benefit.

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 Incapacity Benefit you are paid. 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, level of pain or fatigue or the same feelings. 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.

‘The invisibility of pain is most frustrating’

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 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.

‘Nothing is more annoying than when someone says: “But you look so well”’

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 painful 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:

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

- try to build a good relationship with your health professional
- find out as much as you can about your arthritis. It will make you feel less worried about the future
- accept your limitations. Remind yourself 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.

Consider a self-management programme
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. For more on what Arthritis Care offers, see the back page.

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

Osteoarthritis does not need to take over your life – there are plenty of things you can do to avoid this, and there is a lot of help available. If you have any questions about living with arthritis, contact Arthritis Care or one of the organisations listed on the following pages.
USEFUL ORGANISATIONS

GENERAL
● arc (Arthritis Research Campaign)
Copeman House, St Mary’s Court, St Mary’s Gate, Chesterfield, Derbyshire S41 7TD. Tel: 01246 558033
www.arc.org.uk.
Funds medical research into arthritis and produces information.

HEALTH SERVICES
● NHS Direct
Tel: 0845 4647
www.nhsdirect.nhs.uk
Information on conditions, treatments, support groups and local NHS services.

● British Association/College of Occupational Therapists
106-114 Borough High Street, Southwark, London SE1 1LB
Tel: 020 7357 6480
www.cot.org.uk
Details on local practitioners.

DAILY LIFE
● Disabled Living Foundation
380-384 Harrow Road,
London W9 2HU
Tel: 020 7289 6111
Helpline: 0845 130 9177
www.dlf.org.uk
Advice and information on equipment.

● DIAL UK
St Catherine’s, Tickhill Road,
Doncaster DN4 8QN
Tel: 01302 310123
www.dialuk.org.uk
Details of your nearest disability advice and information service.

● Ricability
30 Angel Gate, City Road,
London EC1V 2PT.
Tel: 020 7427 2460
www.ricability.org.uk
Consumer guides on products and services for disabled people.

● RADAR
12 City Forum, 250 City Road,
London EC1V 8AF
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 Medicine
PO Box 194,
London SE16 7QZ
Tel: 020 7237 5165
www.i-c-m.org.uk
Umbrella body. Can help you find qualified practitioners locally.

MONEY AND BENEFITS
● Disability Alliance
Universal House,
88-94 Wentworth Street,
London E1 7SA
Tel: 020 7247 8776
(voice and minicom).
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**
    21 Portland Place, London W1B 1PY. Tel: 020 7631 8870
    www.britishpainsociety.org
    Information about chronic pain and pain clinics.
  - **Pain Concern**
    PO Box 13256, Haddington EH41 4YD. Tel: 01620 822572
    www.painconcern.org.uk
    Information and helpline.

- **GETTING AROUND**
  - **Motability**
    Motability Operations, City Gate House, 22 Southwark Bridge Road, London SE1 9HB. Tel: 0845 456 4566
    www.motability.co.uk
    Provides cars and powered wheelchairs through the Motability scheme.
  - **Forum of Mobility Centres**
    Kilverstone Mobility Assessment Centre, 2 Napier Place, Thetford, Norfolk IP24 3RL. Tel: 0800 559 3636
    www.mobility-centres.org.uk

A network of 17 organisations across the UK offering information, advice and assessment to individuals who have a condition that might affect their ability to drive or access a motor vehicle.

- **PREGNANCY AND PARENTING**
  - **Disability Pregnancy and Parenthood International**
    Unit F9, 89-93 Fonthill Road, London N4 3JH
    Helpline: 0800 018 4730
    www.dppi.org.uk
    Information and advice for disabled parents.

- **RIGHTS AND DISCRIMINATION**
  - **Disability Rights Commission**
    DRC Helpline, Freepost MID 02164, Stratford-upon-Avon CV37 9BR
    Tel: 08457 622 633
    www.drc.org.uk
    Works to eliminate discrimination against disabled people.

- **WORK AND EDUCATION**
  - **Skill: National Bureau for Students with Disabilities**
    Chapter House, 18-20 Crucifix Lane, London SE1 3JW
    Voice/text: 020 7450 0620
    Information line: 0800 328 5050
    www.skill.org.uk
    Information about further, higher and continuing education, training and employment for disabled young people and adults.
Arthritis Care is the UK’s largest organisation working with and for all people who have arthritis.

Our booklets and magazine, website and professional helpline are tools to enable people to make positive choices. Our network of local groups, self-management programmes and internet forums bring people together to support each other in living life to the full. Our campaigning work promotes civil rights, better access to health and social care provision, and tackles issues important to people in their local area.

Get in touch with us

- Our helpline offers confidential information and support. Call free on 0808 800 4050 (10am-4pm weekdays) or email Helplines@arthritiscare.org.uk
- Our website provides information on all aspects of arthritis and what we are doing in your area. Visit us at www.arthritiscare.org.uk
- Call us to find out more about what we do or how to become a member.

Arthritis Care contact numbers:

UK Head Office: 020 7380 6500
South England: 020 7380 6509/10
Central England: 0115 952 5522
North England: 01924 882150
Northern Ireland: 028 9448 1380
Scotland: 0141 954 7776
Wales: 01239 711883

Published by Arthritis Care, 18 Stephenson Way, London NW1 2HD