

Living with **rheumatoid arthritis**



devised with and for people with arthritis



ARTHRITIS CARE

*Empowering
people with arthritis.*

Rheumatoid arthritis is a challenging, complicated and unpredictable disease. This booklet is for anyone who has rheumatoid arthritis or is interested in finding out more. You will find out about the different approaches to living with the condition – from drugs to keeping active – and get a taste of the skills and strategies that will help you cope.

Contents

Introducing rheumatoid arthritis	1
What happens in RA, what the causes are and what joints are affected.	
How a diagnosis is reached	
How rheumatoid arthritis will affect you	4
How to get the most from your team and what treatment you might be given	
Managing your arthritis	6
How to use and rest your joints; how diet, exercise and complementary therapies might help	
Taking care of joints	14
How to manage at home; what help is available in terms of work, education, transport and benefits	
Practicalities	23
Coping with pain and fatigue; dealing with feelings and relationships; how self-management training can help	
Useful organisations	29

INTRODUCING RHEUMATOID ARTHRITIS

Rheumatoid arthritis is a condition that makes the joints in your body become inflamed. It is the second most common form of arthritis.

Between one and three people in every hundred develop rheumatoid arthritis, and it can start at any age. Most of these people, around three-quarters, are women. Although you are more likely to develop rheumatoid arthritis in your middle years – between 30 and 50 – children, young adults and older people can also get it.

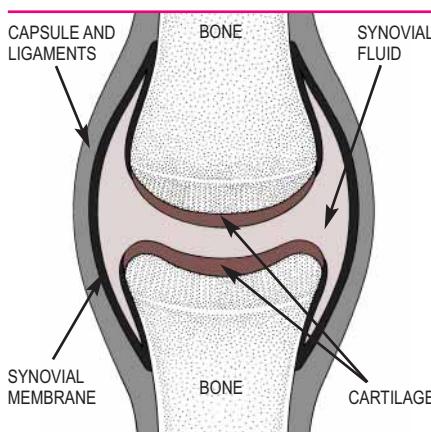
■ What happens?

To explain what happens in rheumatoid arthritis, it helps to understand how a normal joint works.

Joints are the hinges between bones. The two bones are kept in place by ligaments, which are like elastic bands. Muscles move the joint and come in pairs: as one lengthens the other shortens. Tendons attach the muscle to the bone. Small, fluid-filled sacs called bursae allow the muscles and tendons to move

over each other easily. A coating of slippery cartilage covers the bone surface and helps the joint to work smoothly.

The joint is surrounded by a joint capsule that protects and supports it. The joint is lined on the inside by a thin layer of tissue called the synovial membrane (or synovium). This membrane produces a thick lubricant called synovial fluid, which provides nutrients to the joint and cartilage.



A normal joint

■ Inflammation

In rheumatoid arthritis, your immune system attacks your joints – and sometimes other

parts of your body – for no reason. The attack can go on for a long time, or come and go.

Inflammation particularly affects:

- the synovial membrane
- the tendon sheaths (tubes in which the tendons move)
- the bursae.

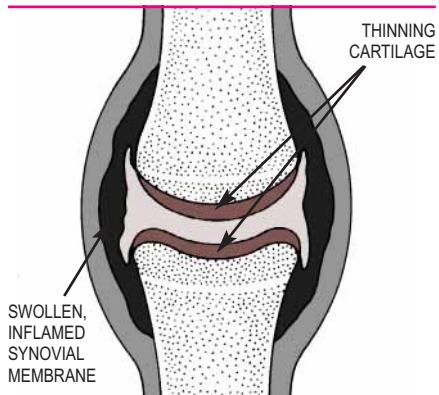
The joint capsule swells and the inflamed tissues in the joint become stiff, painful and swollen.

If the inflammation isn't tackled, it can damage the joints. We now know that much of this damage can happen in the first months and years of rheumatoid arthritis. This is why it is vital to get rheumatoid arthritis diagnosed and treated as early as possible.

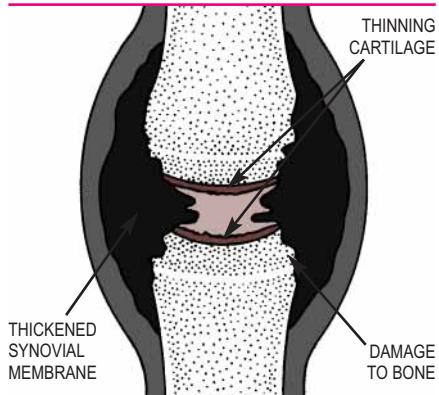
■ Causes

It is probable that certain genes which play a part in the immune system are linked with rheumatoid arthritis. Having these genes doesn't mean you will definitely get rheumatoid arthritis – it simply means you have a tendency to develop it.

However, some people who have the genes will never get rheumatoid arthritis, and some people who have rheumatoid arthritis don't have these genes.



The early stages of rheumatoid arthritis



More advanced rheumatoid arthritis

Researchers now think that something must trigger rheumatoid arthritis in people who have a genetic tendency to develop it.

There is speculation – but no real evidence as yet – that triggers might include stress, an

infection or virus, or hormonal changes.

■ Which joints?

Rheumatoid arthritis varies a lot from person to person. Although it can affect almost any joint, hands and feet are usually involved. Knees and shoulders can also be affected and, less commonly, elbows, hips, the neck and other joints. Most people are affected in more than one joint.

Rheumatoid arthritis usually affects both sides of the body – not always at once, but usually within a very short space of time.

■ Diagnosis

There is no single test for rheumatoid arthritis, and diagnosis can be complicated. Your doctor will ask you about the difficulties you've been having. All of these are useful clues. Your doctor will examine your joints and skin, and test your muscle strength.

I've now learned to accept my diagnosis and am not so hard on myself,

He or she may then refer you to a rheumatologist for tests such as blood tests or X-rays, if some form of inflammatory arthritis is suspected. You may be asked to go to your local hospital for some of these. These tests will help the doctor get a better picture of what is going on.

Since getting RA, I think a lot more and write a lot more,

It may take time to get a definite diagnosis of rheumatoid arthritis. It is important to get the right diagnosis and treatment as early as possible. Because most GPs see only a handful of new cases each year, they are now encouraged to refer people they suspect have rheumatoid arthritis to their nearest rheumatologist.

HOW RHEUMATOID ARTHRITIS WILL AFFECT YOU

When you are diagnosed with rheumatoid arthritis, you are bound to have questions about what the future holds for you.

One of the most unpredictable things about rheumatoid arthritis is that symptoms can come and go. Most people have times – known as flare-ups – when the inflammation suddenly becomes more active, and pain, swelling and stiffness get worse. You may find it very hard to move, especially when you wake up. And you may also feel generally unwell and very fatigued. Flare-ups can be over in a couple of days, or stretch for a month or so.

At other times there is little inflammation. These periods are known as remissions and can last for months or even years.

There are ways of coping

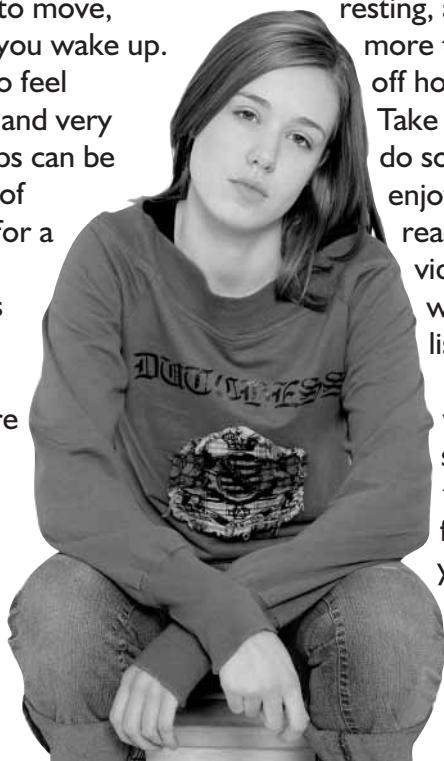
during a flare up. Increasing your painkillers or anti-inflammatory drugs may help. Heat or cold can soothe a painful joint, and resting the joint in a natural position – perhaps with a splint – will help minimise any damage. Gently keeping the rest of your joints moving will stop them getting stiff.

You may feel like curling up in bed, but you are probably better off on the sofa. You will still be

resting, and there will be more to take your mind off how you feel.

Take the time out to do something you enjoy – perhaps reading, watching videos, catching up with friends or listening to music.

Sometimes you will be able to spot what triggered the flare-up. Perhaps you've been pushing yourself too hard, been ill, or had



difficulties in your home life. You might come up with better ways of coping with or avoiding these situations in future. But don't give yourself a hard time: often there won't be an obvious explanation. And remember that while flare-ups can be extremely frustrating and taxing, they do pass.

If you have a remission, grab it with both hands even if it's only for a day or two

As rheumatoid arthritis progresses, it can start to destroy the cartilage and bone within the joint. The surrounding muscles, ligaments and tendons become weak and don't work properly. When this happens, the joint becomes unstable. You can end up using the joint incorrectly and it may become deformed.

Most people have some problems with their joints and flare-ups from time to time, but overall they can carry on as normal, with adjustments.

For some people – around one in five – rheumatoid arthritis seems to last only a few months

or years and there is little or no noticeable damage to their joints.

A few people – around one in 20 – have very active arthritis for many years, and a series of bad flare-ups. Several joints can be involved and rheumatoid arthritis is likely to have a serious impact on their lives.

Whatever happens, rheumatoid arthritis will always be part of your life to a greater or lesser degree, and there are some common difficulties. The first is the pain and loss of strength in inflamed joints. The second is feeling generally unwell and fatigued.

Stiffness can be bad, especially first thing in the morning or after sitting still for a long time. You may also have problems with some everyday activities.

Nobody with rheumatoid arthritis would say that dealing with it is easy. But remember that you are not alone.

Working with your health professionals and getting the right treatment will help you manage your arthritis; and discovering new skills and resources will help you adapt and carry on with your life.

MANAGING YOUR ARTHRITIS

There is plenty that can be done to help control rheumatoid arthritis and make it more manageable. Many different professionals will work together to help you manage your arthritis, but they are all aiming for the same goals:

- to reduce inflammation and slow down, or even stop, any damage to your joints
- to relieve your symptoms – like pain, fatigue and stiffness
- to help you get on with your normal life as far as possible.

You will probably see some members of the team several times a year, either in a rheumatology unit at your local hospital, or at your GP's surgery. They will keep a close eye on you – and use blood, urine and other tests and X-rays – to find out how active your arthritis is and how it is developing. They will work out the best form of treatment, and look out for any side effects of drugs.

The part you play in all of this is vital. Only you know how you feel, the difficulties you face and the sort of help you need most. You have the job of taking charge

of your arthritis, learning how to manage it and adjusting to how it affects your life.

It's worth trying different things out. You don't know how they will affect you, but hopefully they'll improve your prospects ,

■ Getting the most from your team

It is important to make the most of your appointments. Give as much information as you can, and try to be as specific as possible when you describe how things are going. You are the expert on how it affects you. Sharing your experience will help them work out how best to help you.

You have to push for things – those that shout loudest, get ,

You may find it useful to take a friend or family member along to appointments and to write down what you want to say or ask



beforehand. Your appointment may not be when you are feeling at your worst, so this can really help to give the full picture. You can also make notes when you are there.

If you don't understand something, say so – and ask for a more detailed explanation. You need to be sure that you understand and feel confident about any treatment you are given.

If your treatment doesn't seem to be working or you've had problems sticking to it, say so. If something you want is not provided, ask for it. Be firm but tactful.

■ Your team

General practitioners

Your GP may be involved in monitoring your treatment and should be in close touch with the rest of the team. GPs can also put you directly in contact with physiotherapists, occupational therapists and other professionals who can help.

Rheumatologists

Rheumatologists are specialists trained in diagnosing and treating arthritis and rheumatic diseases. They are mostly based in hospital rheumatology units. They will establish your diagnosis and identify a suitable treatment plan for you. You will probably see the rheumatologist regularly to monitor your disease and treatment.

Orthopaedic surgeons

Orthopaedic surgeons specialise in operating on bones and joints, and can replace worn joints, repair torn tendons or fuse joints.

Physiotherapists

Physiotherapists can help you maintain the strength, movement and function of the joints and muscles affected by your arthritis.

Your physiotherapist will offer you treatment and advice about an exercise programme, hydrotherapy, relaxation techniques or splinting. He or she will be closely involved in your rehabilitation after any surgery.

Occupational therapists

Occupational therapists provide advice and help if you are having difficulties with day-to-day tasks like washing, dressing, cooking and cleaning.

They show you how to do things in ways that put as little strain on your joints as possible, and give you advice about equipment.

Rheumatology nurses

Rheumatology nurses specialise in rheumatology and help with practical advice on all aspects of arthritis. Most rheumatology departments have one.

Podiatrists

Podiatrists can help if you have problems with your feet or ankles. They try to prevent joints

altering and improve their position if there are already deformities.

They can provide moulded insoles to hold your foot in a better position, adapt your shoes, or recommend the right kind of shoe.

Dietician

Dieticians can help you eat healthily and show you how to change what you eat if you need to lose weight.

Orthotist

Orthotists make splints to support and position joints.

Phlebotomist

Phlebotomists perform blood tests.

Radiographer

Radiographers take X-rays.

Psychologist

You may be referred to a psychologist if pain affects your emotional well-being, or if you are becoming very depressed or find it difficult to adjust to having rheumatoid arthritis.

Pharmacist

Pharmacists are a good source of information about the drugs you are prescribed. They can tell you which over-the-counter drugs you can take with them, and which may cause problems.

■ Drug treatment

Dozens of drugs are used to treat rheumatoid arthritis – and many people are prescribed a combination of them. Some are used only for pain relief, some tackle inflammation. Others are used to try to slow the course of the disease.

‘Your body needs time to adapt to new treatment or a change in dose’

Your doctors will make a careful decision about which drugs are right for you, and you will need to keep taking them even when you feel better. It is not unusual to try out several approaches before you find something that suits you, and over time your treatment may need to be adjusted.

This is just a brief overview of the different drugs your doctors may suggest. For more information about specific drugs and their potential side effects, see Arthritis Care’s booklet on drugs and therapies, ask your doctor or pharmacist, or look inside packaging for drug information sheets.

Painkillers (analgesics)

Most people with rheumatoid arthritis need some form of pain relief and there is a big range of painkillers in different strengths. Pain is actually a useful way of protecting your joints: it warns you not to overuse them. So when you are taking painkillers, you will still need to use your joints sensibly.

Painkillers will make you feel more comfortable. But they don’t tackle the underlying reasons for the pain. So they are usually prescribed in combination with drugs that do.

Non-steroidal anti-inflammatory drugs

Non-steroidal anti-inflammatory drugs (NSAIDs) tackle inflammation in the joint lining. NSAIDs relieve pain and stiffness and reduce swelling. There are many NSAIDs, but you may be prescribed:

- indometacin (brand names include Indocid and others)
- naproxen (Naprosyn and others)
- ibuprofen (Brufen, Nurofen and others)
- diclofenac (Voltarol, Diclomax)
- nabumetone (Relifex).

It is important to take NSAIDs with food, and not on an empty stomach. They can cause stomach problems and stomach bleeding, so you may need to be prescribed an anti-ulcer medication at the same time. If taking NSAIDs is not relieving your pain and stiffness, you need to ask your doctor whether you should continue with them.

Cox-2 inhibitors

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.

Steroids

Steroids (properly known as corticosteroids and sometimes referred to as cortisones) can be very effective in reducing inflammation. Most people with rheumatoid arthritis who need steroids are prescribed

prednisolone (brand names include Deltacotril, Precortisyl, Predsol).

Taken long-term and in high doses, steroid tablets can cause side effects such as weight gain and osteoporosis, diabetes and high blood pressure. Your doctor will try to give you the lowest effective dose and you will be carefully monitored. You should not alter the dose yourself, or stop taking steroids suddenly.

Steroids can also be injected into an inflamed joint, or they can be used in soft tissue injections such as tennis elbow, when they are injected into the muscle. They can be injected directly into the veins during a

flare-up. Injecting doesn't usually cause the same side effects as oral steroids.

Disease modifying drugs

Disease modifying anti-rheumatic drugs (DMARDs) can slow down the progression of rheumatoid arthritis. There is strong evidence that early treatment with DMARDs reduces long-term damage and disability – so the sooner you are prescribed them the better.

DMARDs tackle the root of the rheumatoid arthritis rather than just its symptoms. They act slowly, taking weeks or even months to have their full effect – so don't stop taking them if you don't see any difference at first. You may need to keep taking painkillers or NSAIDs.

Some DMARDs work specifically to damp down the effects of the immune system's attack on the joints. These are known as immunosuppressives. DMARDs are taken by mouth or injection. Not all are taken every day. You may be prescribed:

- gold by injection or tablets (Myocrisin, Ridaura)
- D-penicillamine (Distamine)
- sulphasalazine (salazopyrin,

Sulazine)

- methotrexate (Maxtrex)
- azathioprine (Imuran, Azamune, Immunoprin)
- cyclophosphamide (Endoxana)
- ciclosporin-A (Neoral, Sandimmun)
- anti-malarial drugs such as hydroxychloroquine (Quineprox, Plaquenil)
- leflunomide (Arava).

Biologic response modifiers

Another recent development in treatment, this group of drugs includes anti-TNFs – which work by blocking the action of a chemical called tumour necrosis factor (TNF). TNF is thought to play an important role in driving the inflammation and tissue damage of rheumatoid arthritis, and anti-TNFs may be able to delay or even prevent this damage.

You may be prescribed:

- etanercept (Enbrel), given by once- or twice-weekly injections (at home, by you or someone else)
- infliximab (Remicade), given by infusion every eight weeks in hospital
- adalimumab (Humira), given by fortnightly injections

(at home, by you or someone else).

Research findings on anti-TNFs are very promising. Though they are not free of side effects and aren't suitable for everyone, they may offer new hope to people with severe rheumatoid arthritis who have not been helped by older disease-modifying drugs. They are often taken in conjunction with methotrexate or another DMARD.

For cost and other reasons, the use of anti-TNFs is governed by strict guidelines which have to be followed in assessing who is eligible. Ask your rheumatologist whether you could be a suitable candidate.

Side effects

Taking drugs can be a worrying business, and you may be concerned about side effects.

You will be carefully monitored for the side effects of certain drugs, with regular blood, urine and other tests.

Discuss possible side

effects with your doctor and find out what to do if you experience them. Side effects are not inevitable. Not everyone will get them and some may disappear over time.

Sometimes the dose can be reduced; some side effects can be treated individually. And there may be another drug that does the same job but suits you better.

Go back for advice before you stop taking any drugs – unless the side effects are severe. And never stop taking steroids suddenly.

You will need to take time to weigh up the risk of side effects against the benefits of treatment.

Questions to ask about drugs

Make sure you understand which drugs you have



been prescribed, how they will help your arthritis and how long they will take to work.

Find out how much to take, how often and when – with meals, for example. What should you do if you miss a dose? If you are only taking the drug once a day, what is the best time?

Check whether the drug is safe to take with any other medication you are on (whether prescription or bought over the counter). Tell your doctor about any nutritional supplements or herbal remedies you are taking.

With some drugs, you need to avoid alcohol, as they can combine to damage your liver.

Some drugs, such as methotrexate, can cause problems during pregnancy and breast-feeding, and you may need to stop taking them. If you are thinking of starting a family, talk to your doctor first.

Some drugs, such as cyclophosphamide, can affect your fertility – again, ask your doctor about this.

Keep a record of the drugs you are prescribed and take it with you to each appointment, whether with your GP or your rheumatologist.

Surgery

Although you won't necessarily need any operations for your rheumatoid arthritis, surgery is another useful way of relieving pain, keeping your joints working and preventing disability.

I have my mobility and life back since my knee replacement

But having surgery can be a big decision to make, and it is usually the last resort after other treatment options have been explored.

Surgery can be minor – to remove the inflamed lining of a joint (synovectomy), or release a trapped nerve or tight tendon, for example. It can also be more intrusive – to replace or resurface a hip joint, say.

There are always risks associated with surgery – it might not work or could lead to further physical complications. Recovery may take a lot of time and effort. A new joint replacement may only last 10 or 15 years. You will find more information in Arthritis Care's booklet on surgery.

TAKING CARE OF JOINTS

It is important to start looking after your joints as soon as you know you have arthritis. You may have to re-learn the way you do things, and become aware of what you are doing all the time, not just when your joints are stiff or hurt.

■ Change the way you move

Try following some of these tips to use your body more effectively.

- Spread the load – use both hands to lift and hold, for example.
- Use less effort and shift rather than lift – slide heavy pans along a kitchen top.
- Use larger, stronger joints – protect the fragile joints in your fingers and wrists by using larger ones. So rather than pushing a door open with your hand and wrist, use your shoulder or hip.
- Don't grip things too tightly –



with pens, for example, choose a fatter one, hold it as loosely as possible or expand the grip with padding.

- Change positions often – shift position or stretch every half an hour to help you avoid joint stiffness, fatigue and pain.
- Watch your posture – if you slouch, the weight of your body falls forward putting added strain on muscles and joints.

■ Balance activity and rest

Rest is important, especially when your joints are inflamed or your arthritis flares up badly.

Resting inflamed joints makes them more comfortable, but too much rest will make them stiff. So it is important to strike a balance between rest and activity.

Exercise protects your joints by keeping the muscles strong and keeping you mobile. But it is also great for reducing pain and stress; and it can help you lose any extra weight to take the strain off your joints.

Exercise won't make your arthritis worse – as long as it is the right sort. Your

physiotherapist will help you work out a programme combining different types of exercise:

- range of movement – these exercises gently take your joints through their range of movement, then ease them a little further
- strengthening – these tighten and relax muscles around a joint to protect it
- aerobic – any exercise that raises your heart rate and gets you slightly out of breath.

I don't want pain to beat me, but you do have to give in to it occasionally

Tips for exercise

- Begin gently and build up gradually. Do a little every day, rather than a lot every now and then.
- Find something you enjoy. Try walking, swimming, dancing or cycling – but avoid high-impact activities like squash or contact sports that will jar.
- Exercise when you are least in pain, stiff or tired and your medication is most effective.
- Do your range of movement

exercises at least once a day. First thing, they'll help ease morning stiffness; last thing at night they'll help stop it developing.

- Listen to your body and don't overdo it. If you feel more pain two hours after exercising than you did before, do less next time. And don't continue with an exercise or activity that causes severe pain, stiffness or fatigue.
- If you have a flare-up, only do range of movement exercises.

‘You can do your exercises even when you’re sitting down or have your feet up’

For more information on exercise, see Arthritis Care's booklet on safe exercise.

■ Healthy eating

Your body needs a range of nutrients, so make sure you eat a healthy, balanced diet. Include lots of fruit, vegetables, pasta, fish and white meat, and cut down on sugary and fatty foods. Eating well will also help you lose any extra pounds which can put extra strain on your joints.

There is a lot of debate about whether what you eat affects rheumatoid arthritis. Certain foods may help. Studies on essential fatty acids (found naturally in oily fish) show that they can ease joint pain and stiffness – though it might take several months. Include more of these foods in what you eat, and consider taking a supplement.

Some people notice that certain foods make their arthritis flare up. If you notice this, and can work out which food is the trigger, it makes sense to avoid it in future, as long as you don't miss out on essential nutrients.

Get advice if you are unsure, and don't assume that what works for someone else will work for you.

‘When I take my supplements I don’t notice much, but once when I forgot to buy them, I felt very stiff’

Beware of diets that claim to cure rheumatoid arthritis, and never begin a diet that involves stopping medication without discussing it with your doctor. Other than essential fatty acids,

there is little evidence that the many supplements marketed to people with rheumatoid arthritis work. They are not cheap, and can be dangerous in high doses. But if you do decide to take a supplement, tell your doctor – some can react with prescribed drugs and cause side effects.

Arthritis Care's booklet on food, healthy eating and supplements has more information.

■ Complementary therapies

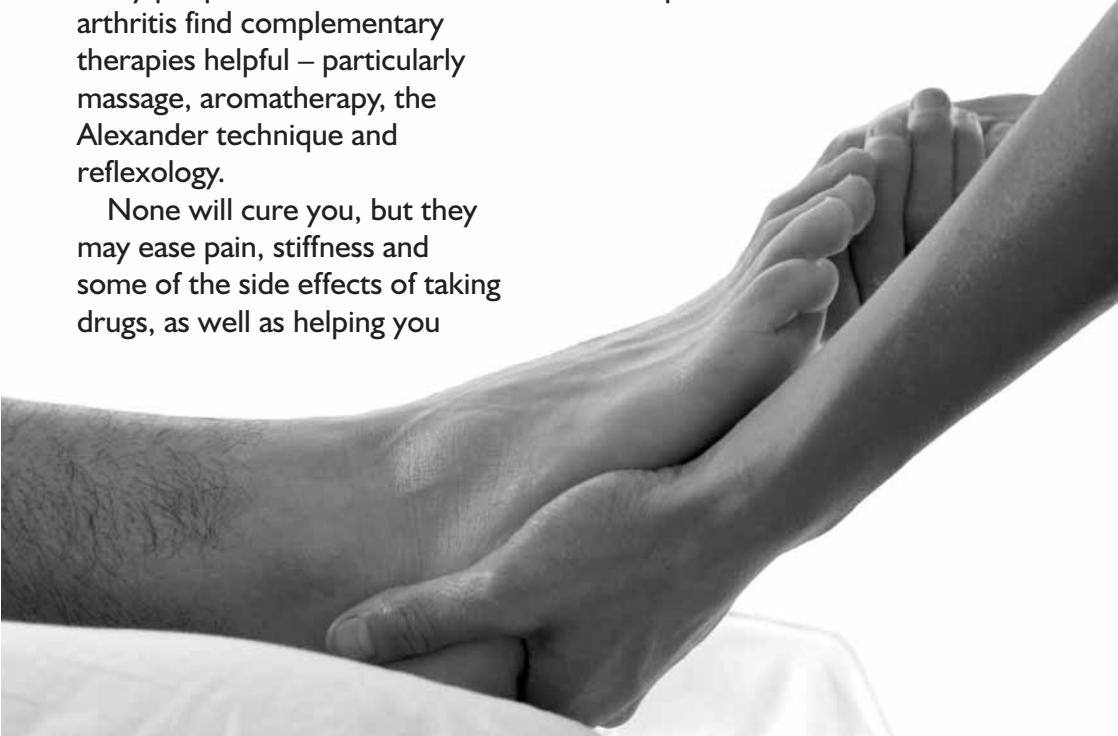
Many people with rheumatoid arthritis find complementary therapies helpful – particularly massage, aromatherapy, the Alexander technique and reflexology.

None will cure you, but they may ease pain, stiffness and some of the side effects of taking drugs, as well as helping you

relax. You can usually use them alongside conventional treatment, though doctors vary in their attitude towards them.

Find out as much as you can about the effectiveness, potential risks and safety of the therapies you are interested in. It is a good idea to get a recommendation and check a therapist's qualifications and always treat therapists who advise you to stop conventional treatment with extreme caution.

You can learn more by reading Arthritis Care's booklet on drugs and therapies.



TAKING CONTROL

Sometimes having rheumatoid arthritis can feel like a never-ending cycle. Pain makes you tense your muscles and puts you under stress.

Changes, uncertainty and everyday difficulties can knock your confidence and leave you frustrated, depressed and angry. Depression wears you out and makes pain feel worse – and so it goes on.

There is a lot you can do to develop the tools, skills and resources that will help you start to break this cycle and help you to learn how to self-manage your arthritis.

■ Coping with pain

Pain is one of the biggest problems you are likely to face, and learning to cope with it can be a real challenge. It can be caused by inflammation, loss of movement, damaged joints or muscle strain.

Pain is very personal – it can range from a dull ache to short stabs; and for some it comes and goes, while others have persistent daily pain. One of the hardest things is that other

people can't see your pain, and you may feel lost for words to describe it.

Getting the right treatment should make a big difference, but there are also plenty of strategies and tips you can try yourself.

Distraction

The more time you spend thinking about your pain, the more pain you will feel. Try to distract yourself by doing or thinking about something you really enjoy or find absorbing, and turn your focus away from the pain. This can work to get you through short activities as well as longer-lasting pain.

I distract myself to make it more bearable. I listen to music or a relaxation tape, breathe in and out, let things go loose, write stories

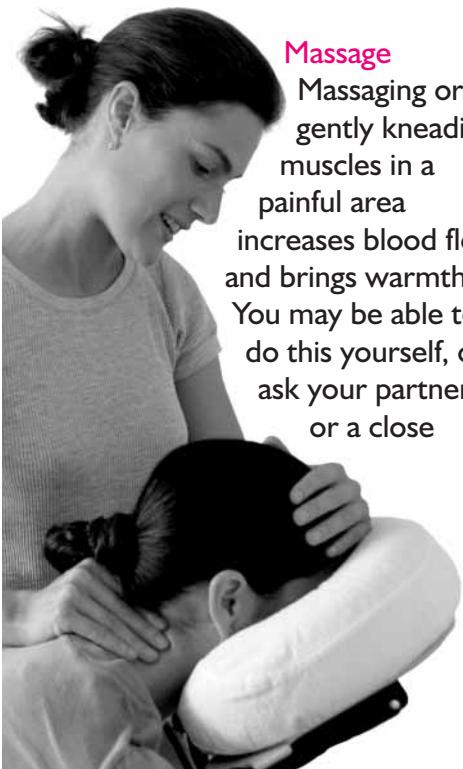
Relaxation

Learning how to relax your muscles may help. There are several ways of doing this – including breathing exercises and

guided imagery. Ask your doctor or local library about relaxation tapes or classes.

Heat and cold

Some people find that heat makes them more comfortable, while others don't like it. The same is true of cold – though it can really help soothe inflammation during a flare-up. But even simple techniques like hot baths or pads, or cold packs made from a well-wrapped bag of frozen vegetables might work for you.



Massage

Massaging or gently kneading muscles in a painful area increases blood flow and brings warmth. You may be able to do this yourself, or ask your partner or a close

friend to help out. Always use a lubricant like baby oil or massage oil to protect your skin, and stop if you feel any pain. A professional therapeutic massage may also bring relief and help you relax, but ask for advice from your doctor or physiotherapist first. Massage isn't suitable for hot or inflamed joints.

Tens machines

Transcutaneous electrical nerve stimulation (Tens) machines use electrical impulses to block pain. Many people find them helpful, but get advice from a physiotherapist before you begin to use one.

There is lots more information about these and other approaches in Arthritis Care's booklet on coping with pain.

■ Working with fatigue

Most people feel tired after a hard day, but the fatigue that comes with rheumatoid arthritis is altogether different. It tends to be worse during a flare-up, but varies from a stubborn, ongoing tiredness to a sudden drop in energy that leaves you completely wiped out. It may mean that you are too tired for

even simple tasks, and can be extremely frustrating.

Like pain, fatigue can vary a lot and may have a number of causes. But several things may be worth trying to help you make the most of your energy.

Sometimes I think if I don't get to bed, I'll have to drop on the floor, clothes and all

- Decide on your priorities and pace yourself – what do you really want or need to do? Can you rearrange your time so that you can do important tasks when you are at your best? Is there anything you can drop or do less frequently?
- Rest when you need to – listen to your body and don't tough it out. Take a short nap or relax once or twice a day.
- Keep active – when you are exhausted it is tempting to cut down on exercise, but muscles in a poor condition will tire sooner than strong ones.
- Try to get enough sleep – only you know how much sleep your body needs.
- Eat a healthy, balanced diet –

food is your body's fuel and you need it to keep going.

I have had to be more organised – I do things like shop on the internet now

■ Dealing with feelings and relationships

From time to time, your arthritis is going to get on top of you. Anger, frustration, uncertainty, depression, fears about whether you can cope or what the future holds – all of these feelings are very understandable and very common. Several things may help.

- Gather information – if you are worried or frightened, perhaps about the future, find out as much as you can. Talk to your team, or to other people who have or know about rheumatoid arthritis. Don't let worries gnaw away at you. You may find that your fears don't match the facts.
- Ask for help and support from others if you need it – don't feel you have to struggle on alone.
- Accept your limitations – try not to get too tangled up in

wishing that things were different. Focus on the here and now, and remind yourself about what you can do and enjoy.

- Keep going – even if it feels as though nothing is working, don't give up on yourself or your arthritis, and don't be too hard on yourself.
- Get out and about – keeping up with friends can be tricky if you are having problems with your rheumatoid arthritis or you are not sure how you will be feeling. But try to make space and time for your social life.
- Let it out – talk to somebody who understands how you are feeling, whether that is someone close to you, one of your team, or someone else with arthritis.
- Feelings most commonly experienced by people with arthritis are looked at in detail in Arthritis Care's booklet about emotions.

I can't do everything so I choose how I can most enjoy my time with friends

Rheumatoid arthritis can put distance – both physical and emotional – between you and your partner, family, friends and colleagues.

You may not look like you have rheumatoid arthritis, are tired or in pain, and people may find it hard to understand why it affects you so differently from day to day. People you are close to may really want to help, but not know how. You may be worried about letting them down, or about depending on them too much.

I used to keep things bottled up. Now I keep my wife in the picture about where I am with the arthritis and what's going on

Keeping quiet can lead to misunderstandings, so communication – talking and listening – is key. Explain how your arthritis affects you and be as clear as you can about how you are feeling.

Sexual relationships can be affected too. If you are feeling stiff or having trouble moving around, it is hard to be spontaneous; and even a hug can

be difficult if you are in pain. Rheumatoid arthritis may also change how you see yourself and your body. Again, communication is at the heart of sorting things out. Don't feel shy of raising the issue with your team if you want advice or support.

You may find Arthritis Care's booklet on relationships helpful.

■ Young people

Having rheumatoid arthritis is a challenge at any age, but it can be particularly difficult for teenagers and young people.

In addition to everything else you've got going on, you may be worried about people seeing you as different or not understanding your arthritis. And it can be frustrating if you can't be as independent as you had hoped.

‘I’m living life as a normal teenager plus I’ve had to deal with this on top’

Arthritis Care can help with information, courses, events and groups. Find out more by contacting our young person's helpline, The Source, on 0808 808 2000, weekdays 10am-4pm.

■ Challenging Arthritis with Arthritis Care

You can learn more of the skills that will help you deal with rheumatoid arthritis on one of Arthritis Care's self-management programmes.

Challenging Arthritis, our most popular course, 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 and share tips with other people who know what you are going through.

Arthritis Care also runs personal development courses, workshops for young people and pain management courses – all delivered by people with arthritis. For more about what Arthritis Care offers, see the back page.

‘My arthritis has made me much more determined to make something of my life. There are no boundaries, just obstacles’

PRACTICALITIES

Adjusting to rheumatoid arthritis may not be easy, but there are plenty of sources of help. The first step is finding out what is on offer and what your rights are.

The organisations listed on page 29 also have a wealth of practical advice and experience to share.

■ At home

There are many ways you can set things up at home to make sure your environment is as stress-free as possible.

Equipment and adaptations

There are lots of handy gadgets and tools and useful changes or adaptations that can help around the home. In the kitchen, for instance, they might include:

- rearranging cupboards and drawers so the things you use the most are nearby
- lightweight pans, mugs or kettle
- equipment with easy-to-use buttons and switches
- 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 across the room

- devices for turning taps more easily.

'You have to be like a dog with a bone and keep chewing until you get the best quality of life possible'

It makes sense to try out a gadget before you buy it – it could save you a lot of money in the long run. Alternatively, make a list of criteria that the gadget must meet to avoid a bad purchase.

If you find you are doing a lot of work around the home, what about getting someone else to help? Friends and family may be able to lend a



hand. You could also think about paying a cleaner, or getting a handyperson in for bigger tasks. Local organisations may be able to put you in touch with volunteers to help you with jobs around the house.

Ask your local council, citizens advice bureau or library if they know of any.

Don't compare yourself with other people, but find out what they're trying

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 to see whether you are eligible for help.

There is no hard and fast rule on what you will get: 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 to get equipment. If your needs change, contact

the social services department 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 lots more information about home life in Arthritis Care's booklet on independent living.

Work and education

Most people diagnosed with rheumatoid arthritis are of working age – so you may well be settled in a career already.

Only you can decide how much you want to tell people at work about your rheumatoid arthritis. It may not affect your work at all – other than time off for hospital appointments or surgery – but hiding it and 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 rheumatoid arthritis means for you.

Smarter ways of working will

help protect your joints and conserve energy. They can include:

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

I've got a good, comfortable chair and my desk is set up correctly. I've had lots of equipment from Access to Work

Disability employment advisers are based at your local Jobcentre and offer support and advice to disabled people and employers. They will also tell you about Access to Work – a government scheme that can help you with a support worker, equipment or adaptations to your workplace, and work-related expenses, such as car adaptations or taxi fares.

Depending on how your rheumatoid arthritis affects you,

the time may come when you need to consider changing jobs. Some people do have to stop working altogether – this is never an easy decision and it is important to get professional advice about your rights and options. Remember that giving up work doesn't mean that you are giving up your life: retraining, further education and voluntary work may all open new doors.

If you are going into higher education (post-18), you may be eligible for a Disabled Students Allowance. The allowance is intended to cover any extra costs or expenses students have because of a disability. You don't have to be a full-time student to get it. The funding situation in further education (post-16) is more complex and varies around the UK. For more information, contact Skill (see page 30).

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. Those in education are also protected by the DDA. Education providers are required to provide suitable access to their facilities – this may include making permanent physical adjustments to the premises.

■ Getting around

People with rheumatoid arthritis often find getting out and about difficult. Many rely on cars – either driving themselves or lifts – or public transport to get around.

There are a few things you can try to make driving easier. An automatic gearbox and power steering will also reduce

strain. Minor adjustments, such as a padded steering wheel, a headrest, extra side-mirrors or a wide-angled mirror may make driving easier.

Some car manufacturers offer disabled people discounts on new vehicles and if you get the higher rate of Disability Living Allowance mobility component, you may be able to use it to hire or buy a car through the Motability scheme (see page 30). Don't forget to tell the Driver and Vehicle Licensing Agency (DVLA) and your insurance company if your arthritis affects your ability to drive in any way.

The Mobility Advice and Vehicle Information Service (Mavis) can help you select the right car and adaptations and will also provide a list of other

assessment centres.

Public transport can be difficult for some people to access – either



physically or because a service does not run in their area.

Some local authorities produce guides to accessible bus, train and minicab services in their area; and some run their own transport schemes.

Your local disability organisation, library or local newspaper may be able to tell you about what is on offer locally (including any concessionary fares), and any other schemes run by the Community Transport Association or other voluntary or commercial organisations.

Transport services were not fully covered by the original DDA requirements, although subsequent regulation and legislation is addressing this. Physical access to transport is improving, but there is a long road ahead.

Bus companies are required to achieve full accessibility by 2017 and the date for trains is 2020. International transport by air and sea remains a problem.

■ Benefits

You may be able to get state benefits to help with the extra costs of having arthritis or if you

are unable to work. Some of the main ones are listed below.

Claiming benefits can be complicated and time-consuming, so it's worth getting expert help and advice from:

- a social worker or welfare rights officer at your social services department (social work department in Scotland, social security agency in Northern Ireland)
- your citizens advice bureau or other advice centre
- your local social security office (under Benefits Agency or Social Security in the phone book)
- the Benefit Enquiry Line (see details on page 29)
- 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 substantial help getting around or with personal care (such as washing and dressing). If you are 65 or over you may be able to get Attendance Allowance (AA) for personal care.

DLA and AA are not means

tested, are tax free and do not affect any other benefits you get. They also mean you may qualify for other benefits, so it is worth applying for them if you think you are eligible.

Having DLA has given me choices. I'm not sure I could afford to get out and about without it

Disabled Person's Tax Credit
Disabled Person's Tax Credit (DPTC) aims to encourage disabled people to return to, or take up, work. It has been split into Working Tax Credit and Child Tax Credit.

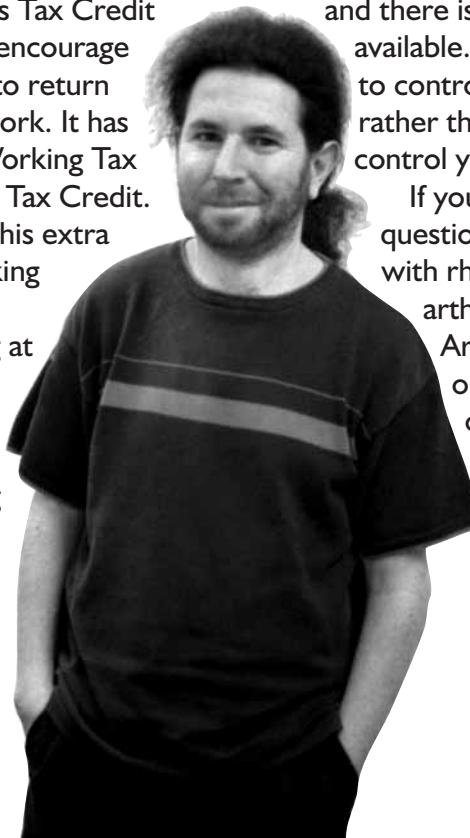
To qualify for this extra element of Working Tax Credit, you must be working at least 16 hours per week and meet one of several qualifying benefit tests. There is no savings limit, but income from savings is taken into account.

Incapacity Benefit

If rheumatoid arthritis means you can't work any longer, you may be able to claim Incapacity Benefit. You usually need to have made a certain amount of national insurance contributions to get it, and any pension or health insurance will be taken into account.

There are many ways in which you can learn to manage your rheumatoid arthritis effectively and there is a lot of help available. You can learn to control your arthritis rather than let it control you.

If you have any questions about living with rheumatoid 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.

● National Rheumatoid Arthritis Society

Unit B4, Westacott Business Centre,
Westacott Way, Maidenhead,
Berks SL6 3RT. Tel: 01628 823524
www.rheumatoid.org.uk
Offers an advisory and information service to people with rheumatoid arthritis.

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.

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.

● Benefit Enquiry Line for disabled people

Tel: 0800 882200 Mon-Fri,
8.30am-6.30pm. Sat, 9am-1pm

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
Offers information and a helpline.

HEALTH SERVICES

● NHS Direct

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

USEFUL ORGANISATIONS

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.

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 all aspects of education, training and employment.

COMPLEMENTARY THERAPIES

- **Institute for Complementary Medicine**
PO Box 194, London SE16 7QZ
Tel: 020 7237 5165
www.i-c-m.org.uk
Can help you find qualified practitioners locally.

GETTING AROUND

- **Mobility Advice and Vehicle Information Service (MAVIS)**
Crowthorne Business Estate,
Old Wokingham Road,
Crowthorne, Berks RG45 6XD
Tel: 01344 661000
www.dft.gov.uk/access/mavis

● 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.

CHILDREN AND YOUNG PEOPLE

- **Children's Chronic Arthritis Association**
Ground Floor Office, Amber Gate, City Walls Road, Worcester WR1 2AH. Tel: 01905 745595
Support for children with arthritis and their families.

● Contact a Family

- 209-211 City Road, London EC1V 1JN. Tel: 0808 808 3555
www.cafamily.org.uk
Offers a helpline, support groups and contacts. The Lady Hoare Trust has now merged with Contact a Family.

● Choices

- PO Box 58, Hove, East Sussex BN3 5WN
www.kidswitharthritis.org
Support group for families of children with arthritis.



Arthritis Care is the UK's largest voluntary organisation working with and for all people with arthritis.

Our publications are just one of the many services Arthritis Care provides. These include a confidential helpline, self-management and awareness training, information for people with arthritis and health professionals, and local activity and support. We also campaign locally and nationally to help change attitudes and laws and to ensure people with arthritis have access to the treatments and services they need and deserve.

Contact us

- For confidential information and support, contact the Arthritis Care helpline:
0808 800 4050 (calls are free)
10am to 4pm, weekdays only
Helplines@arthritis.org.uk
 - For information about Arthritis Care and the services we offer, contact us at:
www.arthritis.org.uk
- Arthritis Care UK office and England regional services:** Tel. **020 7380 6500**
- Arthritis Care in Northern Ireland**
Tel. **028 9448 1380**
- Arthritis Care in Scotland**
Tel. **0141 954 7776**
- Arthritis Care in Wales**
Tel. **01239 711883**