

CARING FOR A PERSON WITH ARTHRITIS

An Information Booklet



Committed to curing arthritis

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About this booklet

This booklet is designed to help you care for someone with arthritis, either as a family member or as a friend. It will help you understand more about arthritis and about the usual problems which affect people with arthritis. As well as discussing in general what caring involves, the booklet suggests how you can offer practical help to someone with arthritis. The most important thing to realise is that there are no rights and wrongs in caring for someone who has arthritis, and there are as many ways of coping with arthritis as there are people with arthritis. The booklet covers the most common questions which carers ask, and gives sources for further support and information.

How can a carer help someone with arthritis?

Looking after and caring for someone with arthritis is a challenge. You need to achieve the right balance between providing support and motivation without overprotecting them. Most people with arthritis will wish to retain as much control over their lives as possible, and you need to help them to retain their independence. This may mean that in certain circumstances help may not be wanted. This may be a difficult judgement for you and you must be sensitive to signs that indicate this, which may not be verbal.

There are four main ways in which you can help:

- 1. Understand what arthritis means** – what causes it, how it develops, and how it affects people. In the same way that understanding helps people with arthritis to cope with their disease, the more you understand of arthritis the more you will be able to provide successful care and support.

- 2. Communicate effectively** Good communication in both directions is essential. The person with arthritis needs to feel well supported and may also need reassurance that the responsibility falling on you is not resented.
- 3. Offer practical help with the treatment** This may mean helping the person to take their medications or assisting with recommended exercises as well as helping with any activities or therapies that they have found helpful in reducing the symptoms of their arthritis.
- 4. Support the person with arthritis in applying for any benefits and advice** they may be entitled to. There are a number of benefits that they may not be aware of (see 'Are they getting the benefits that they are entitled to?').

Understand what arthritis means

There are many different types of arthritis. Doctors often divide them into two groups:

1. where the problems are caused by inflammation (e.g. rheumatoid arthritis or ankylosing spondylitis)
2. where the problems are caused by 'mechanical' problems or wear and tear (e.g. osteoarthritis or mechanical back pain).

The person with arthritis should get a diagnosis from the doctor. The table below lists the main types of arthritis. There is an Arthritis Research Campaign (**arc**) booklet on each of these which explains how the condition develops and the main treatments. Most forms of arthritis run a very uneven course with day-to-day variation, and you need to be aware of this. The outlook is also very variable and difficult to predict. The arthritis can occasionally become very bad, or it can go away completely, but

Group 1 Inflammation	Group 2 Non-Inflammation
<ul style="list-style-type: none"> • Rheumatoid arthritis • Psoriatic arthritis • Gout • Ankylosing spondylitis 	<ul style="list-style-type: none"> • Osteoarthritis • Back pain

most people have something in between. The person with arthritis needs to be able to cope with the different symptoms that arthritis can cause.

How can arthritis be treated?

Treatment is available for all types of arthritis, although cures are a little way off. Many of the symptoms of arthritis can be relieved through the right combination of exercise, drugs, diet and learning to cope.

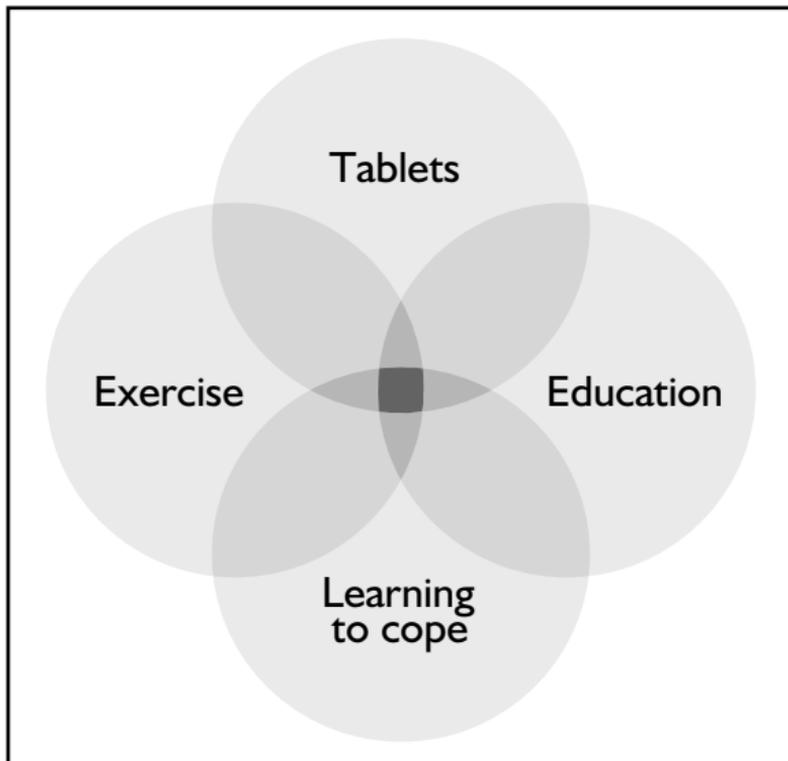


Figure 1. A combination of factors can help relieve the symptoms of arthritis.

How does it feel to have arthritis?

Arthritis affects different people in different ways, and there are no right or wrong ways to feel. It can make someone feel pain, stiffness, tiredness and frustration at different times, or at the same time. The problem with the pain of arthritis is the fact that it goes on day-in, day-out. If asked to put up with it for a few hours, few people would have problems. Facing it on a regular basis is much less easy. Most people will get some relief from their pain once they start treatment. As arthritis usually varies with time in an unpredictable way, most people need to find their own way of coping. Learning about the disease is an important factor in coping, and a specialist nurse will often help with this by teaching patients about the condition. Information can also be gained from booklets like this one.

Communicate effectively with the person who has arthritis

Good communication is essential. It is important that you and the person with arthritis discuss how you are both feeling. You need to agree how to work together so that the person will feel able to ask if they need extra help and to turn it down if they don't. Sometimes it will mean that you have to stand back and watch your partner, child, friend or colleague struggle to achieve a goal that is important to them. Try to respect their wishes, allowing them to maintain their self-esteem. Communication is also necessary so that you can judge how they are feeling and respond sensitively. Carers have suggested the following practical hints:

- Learn to recognise the signs when the arthritis is bad, as extra support may be needed at this time. Remember that pain can make people irritable, angry and depressed at times.



Figure 2. Communication is essential.

- Be patient if the other person has to do things differently and not as quickly as before.
- Do not allow yourself to become isolated. Make sure that you still see family and friends and do the activities that are important to you. Find time for yourself. Roles may have to change within the home and at work. This needs to be discussed and you may need the support of a trained health professional such as a specialist nurse or an occupational therapist. Be sensitive to the feelings of the person with arthritis – it is very difficult, for example, to sit and watch someone else doing what you had regarded as your job.
- Join in the exercises or other activities so that they become shared activities. Encourage the person to find other activities to replace ones which may have been lost. They might, for instance, involve themselves in voluntary work, or start an educational course.
- Remember that you have needs as well. Caring can be hard work. At times you may feel irritable and

depressed. This is normal and understandable. If it appeals to you, join a local support group. You can also get advice from Carers UK (see ‘Useful addresses’).

Offer practical help with the treatment

You have an important part to play in helping and supporting the person coping with their arthritis. The most common practical questions we receive from carers are shown below.

How can a carer help with the pain and stiffness?

- Be aware of how the different drugs work and what is a reasonable expectation of how effective they will be. If the prescribed painkillers are not providing adequate relief, they may work better by being taken regularly or they may need to be reviewed by the doctor.
- Pain may be eased either by warming or by cooling the painful area. Wrap a hot-water bottle or an ice pack (or bag of frozen peas) in a towel and hold it against the painful joint for 10–15 minutes.
- Pain makes muscles tense and more painful. Relaxation, massage and yoga can help. Join in – you may enjoy it too!
- The pain does not damage joints, and regular movement is needed to stop them becoming stiff and painful. (See **arc** leaflet ‘Keep Moving’.) Try not to be over-protective: encourage the person with arthritis to do as much as they can to keep the joints mobile.
- Space out daily activities instead of trying to do everything in one go. This can help reduce pain and stiffness and still enable activities to be carried out successfully.



Figure 3. A hot-water bottle wrapped in a towel can be helpful for pain in the muscles or soft tissues.

- Encourage regular movement. Sitting in the same position for too long can increase stiffness.
- Find non-physical ways of occupying the mind.
- If certain activities are causing problems, encourage the person to find a different way of doing it. There usually is one. For example, carrying shopping is better done in two equal-sized bags than one big one. If that is impractical then a wheeled trolley can be used. Alternatively, is there somebody who could help with shopping trips by sharing transport? Or check whether any local supermarkets offer a delivery service. If there are problems with activities around the home then a visit from an occupational therapist for advice on aids and adaptations can be very helpful. Ask your GP or hospital rheumatology department about this. (See **arc** leaflet ‘Occupational Therapy and Arthritis’).

How does arthritis make a person feel?

It is normal for people with arthritis to experience a wide range of feelings and emotions. They may be tearful, or angry, or upset, or any number of things. Encourage them to focus on positive experiences and think about what they can do and not what they have difficulty in doing.

Should a carer encourage exercises?

Yes – it is very important to keep the joints moving to minimise pain and stiffness. Try to encourage exercise as a daily habit. Swimming and cycling (it can be on a static bike) are good exercises. Physiotherapists are the experts in this area, but the person with arthritis may have their own preferences about exercise and should be encouraged to express them. If you join in the exercises then this can become more of a social activity and less of a chore. It is important to start gradually with any exercise and increase the amount over time as the body adjusts to the extra requirements being made of it. (See **arc** leaflet ‘Keep Moving’).



Figure 4. Joining in with exercises can help.

Is it natural for the person to feel tired?

Having arthritis makes most people tired, particularly if they have rheumatoid arthritis. For some people the tiredness is more difficult to cope with than the pain. Tiredness can be reduced by:

- spreading activities throughout the day
- doing regular exercise
- establishing a regular sleep pattern – for example, avoiding daytime naps and going to bed at the same time each night.

Is it necessary to take the drugs?

Drugs are one of the main treatments for reducing the effects of arthritis. They are usually divided into fast-acting ‘first-line’ drugs, which treat the symptoms of pain and stiffness, and slow-acting ‘second-line’ drugs, which are intended to modify the disease itself (disease-modifying anti-rheumatic drugs, or DMARDs). (See **arc** booklets on specific conditions and **arc** leaflets on drugs for arthritis.)

As far as treatment of symptoms is concerned, the person with arthritis is in the best position to weigh up the benefits and decide whether to take the tablets or not. They should at least try a painkiller (analgesic) or anti-inflammatory (NSAID) if offered by their doctor in order to judge whether they help or not.

Other treatments need to be taken as prescribed, or variations in their use agreed with a doctor. For example, allopurinol for gout has to be taken continuously or it may make the attacks worse. Prednisolone must not be reduced too quickly or stopped suddenly as this can be dangerous. Most ‘second-line’ drugs for rheumatoid arthritis (sulphasalazine, penicillamine and methotrexate are examples) need to be monitored with blood tests. These precautions are essential to the safe use of these drugs.

Are they getting the benefits that they are entitled to?

There are a number of important benefits and places where you can seek advice on these. If the person with arthritis is having difficulty with work, they can arrange an appointment with a Disability Employment Adviser (DEA). These advisers can be contacted through a Jobcentre or Jobcentre Plus office and can provide advice on adaptations, support and retraining. There may also be a doctor or health adviser at the person's place of work who could help.

Common benefits that people with arthritis can claim are:

- Disability Living Allowance (for people under the age of 65 years)
- Attendance Allowance (for people over the age of 65 years).



Figure 6. Disability Employment Advisers can be helpful.

To qualify for these benefits the person must either have difficulty walking or carrying out self-care activities such as dressing or bathing, or need help from another person with these activities. The Citizens Advice Bureau can help complete the forms to apply for these benefits. Or your county/city council may have a welfare rights department which can help. If the person with arthritis gets Attendance Allowance or certain rates of Disability Living Allowance, you, as a carer, may be able to apply for Carers Allowance.

More information can be obtained from the Benefit Enquiry Line (see 'Useful addresses'). If you get a bad response from the agency assessing a claim, try not to take it personally. You may wish to appeal against an adverse decision, but, in any event, try not to let it upset you.

Practical help may also be available from your local Social Services department if the arthritis is causing substantial difficulties in everyday activities (see 'Useful addresses').

Where can a carer obtain more advice and support?

Many hospitals have a specialist nurse who can provide support and information. There may be a support group in your area where you can share information with other carers in a similar situation. Most people feel better for sharing feelings and concerns rather than keeping them bottled up inside. It is natural to feel anger and resentment at times (as your life has changed too) and sharing these feelings can make it easier to move forward.

Useful addresses

The Arthritis Research Campaign (arc)

PO Box 177, Chesterfield
Derbyshire S41 7TQ
Phone: 0870 850 5000
www.arc.org.uk

As well as funding research, we produce a range of free information booklets and leaflets. Please see the list of titles at the back of this booklet.

Arthritis Care

18 Stephenson Way
London NW1 2HD
Tel: 020 7380 6500
Helplines: 020 7380 6555 (10am–4pm Mon–Fri)
or freephone: 0808 800 4050 (12pm–4pm Mon–Fri)
www.arthritiscare.org.uk

Offers self-help support, a helpline service (on both numbers above), and a range of leaflets on arthritis.

Benefit Enquiry Line (for people with disabilities – run by Department for Work & Pensions)

Phone: 0800 882200
(8.30am–6.30pm Mon–Fri, 9am–1pm Sat)
www.dwp.gov.uk

Carers UK

20/25 Glasshouse Yard
London EC1A 4JT
Phone: 020 7490 8818
Carers Line (for advice to carers): 0808 808 7777
(10am–12pm and 2–4pm Mon–Fri)
www.carersonline.org.uk

Provides information and advice to carers, and aims to raise awareness of carers' needs.

Citizens Advice Bureau (CAB)

Can provide advice on benefits and help with filling in application forms. To find your local office see the telephone directory under 'Citizens Advice Bureau'

or the Yellow Pages under 'Counselling and Advice', or contact the National Association of Citizens Advice Bureaux:

Phone: 020 7833 2181

www.nacab.org.uk

Dial UK (Disability Information & Advice Line)

St Catherine's

Tickhill Road

Doncaster DN4 8QN

Phone: 01302 310123

www.dialuk.org.uk

The helpline will put you in touch with a local office for information in your area.

NCH Action for Children

Central Office

85 Highbury Park

London N5 1UD

Phone: 020 7704 7000

www.nch.org.uk

Runs young carers' projects around the country.

Queen Elizabeth's Foundation Mobility Centre

Damson Way

Fountain Drive

Carshalton, Surrey SM5 4NR

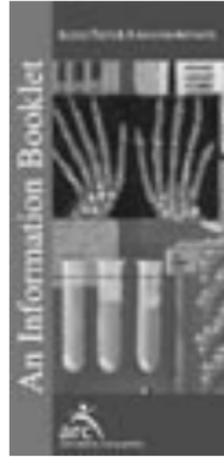
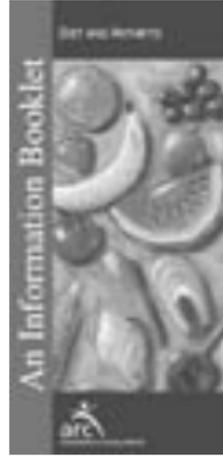
Phone: 020 8770 1151

www.qefd.org.uk/mobilitycentre/index.htm

Supplies a list of assessment centres and driving instructors throughout the UK.

Social Services

Social Services can provide practical support such as Meals on Wheels or Home Help in certain cases. Look in the telephone directory under the name of your county council or city council.



Booklets and leaflets

These free booklets and leaflets are available from **arc**. To get copies, please send for our order form (stock code 6204) or write to: **arc** Trading Ltd, James Nicolson Link, Clifton Moor, York YO30 4XX for up to **THREE** titles.

DISEASES

Ankylosing Spondylitis
Antiphospholipid Syndrome
Behçet's Syndrome
Carpal Tunnel Syndrome
Fibromyalgia
Gout
Introducing Arthritis
Lupus (SLE)
Osteoarthritis
Osteoarthritis of the Knee
Osteomalacia (Soft Bones)
Osteoporosis
Paget's Disease of Bone
Polymyalgia Rheumatica (PMR)
Polymyositis and Dermatomyositis
Pseudogout
Psoriatic Arthritis
Raynaud's Phenomenon
Reactive Arthritis
Reflex Sympathetic Dystrophy
Rheumatoid Arthritis
Scleroderma
Sjögren's Syndrome
Vasculitis

JUVENILE ARTHRITIS

Arthritis in Teenagers
Growing Pains (for children)
Tim Has Arthritis (for children)
When a Young Person Has Arthritis
(for schoolteachers)
When Your Child Has Arthritis

TREATMENT

Blood Tests and X-Rays for Arthritis
Complementary Therapies
Hand and Wrist Surgery
Hydrotherapy and Arthritis
Occupational Therapy and Arthritis
Pain and Arthritis
Physiotherapy and Arthritis

SUMMARY

A summary leaflet listing the main topics covered by all the others shown here

PARTS OF THE BODY

Back Pain
Feet, Footwear and Arthritis
Joint Hypermobility
Knee Pain in Young Adults
A New Hip Joint
A New Knee Joint
Pain in the Neck
The Painful Shoulder
Shoulder and Elbow Joint
Replacement
Tennis Elbow

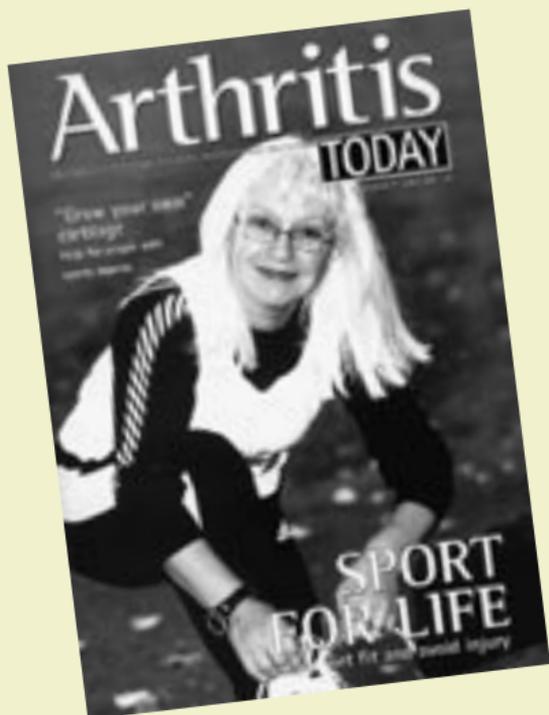
LIFESTYLE

Are You Sitting Comfortably?
Caring for a Person with Arthritis
Diet and Arthritis
Driving and Your Arthritis
Gardening and Arthritis
Keep Moving
Looking After Your Joints (RA)
Pregnancy and Arthritis
Sexuality and Arthritis
Sports Injuries
Stairlifts and Homelifts
Work and Arthritis
Work-Related Rheumatic Complaints
Your Home and Arthritis

DRUG INFORMATION

Drugs and Arthritis (general info.)
Adalimumab
Anakinra
Azathioprine
Cyclophosphamide
Cyclosporin
Etanercept
Gold by Intramuscular Injection
Hydroxychloroquine
Infliximab
Leflunomide
Local Steroid Injections
Methotrexate
Non-Steroidal Anti-Inflammatory
Drugs
Penicillamine
Steroid Tablets
Sulphasalazine

Arthritis Research Campaign



The Arthritis Research Campaign (**arc**) is the only major UK charity funding research in universities, hospitals and medical schools to investigate the cause and cure of arthritis and other rheumatic diseases. We also produce a comprehensive range of over 80 free information booklets and leaflets covering different types of arthritis and offering practical advice to help in everyday life.

arc receives no government or NHS grants and relies entirely on its own fundraising efforts and the generosity of the public to support its research and education programmes.

Arthritis Today is the quarterly magazine of **arc**. This will keep you informed of the latest treatments and self-help techniques, with articles on research, human interest stories and fundraising news. If you would like to find out how you can receive this magazine regularly, please write to: Arthritis Research Campaign, Ref AT, PO Box 177, Chesterfield S41 7TQ.

How we raise our funds

We constantly need to raise money by our own efforts to fund our work.

As well as a head office fundraising team we have an extensive network of regional staff, volunteer fundraising groups and charity shops throughout the UK.



Photo courtesy of the Eastbourne Gazette

Where our money goes

Every year, we raise approximately £24 million to fund around 350 research projects across the whole of the UK.

In addition, **arc** funds the Kennedy Institute of Rheumatology in central London, at a cost of £3.1 million per year. We also set up the Arthritis Research Campaign Epidemiology Unit in Manchester, currently funded at £1.6 million a year, which collates data on arthritis and its cost to the community.



A team of people contributed to this booklet. The original text was written by a nurse with expertise in the subject. It was assessed at draft stage by doctors, allied health professionals, an education specialist and people with arthritis. A non-medical editor rewrote the text to make it easy to understand and an **arc** medical editor is responsible for the content overall.



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