

# Independent living and arthritis



devised with and for people with arthritis



ARTHRITIS CARE

*Empowering  
people with arthritis.*

Achieving the level of independence you want can be a challenge if you have arthritis. Daily activities, such as dressing, cooking and shopping, can take longer as a result of pain, loss of mobility and fatigue. This booklet looks at how to overcome these barriers to independent living by managing your condition, organising your life both inside and outside the home and, if necessary, enlisting help from friends, family and professionals.

Everyone's arthritis affects them in different ways, therefore not all the examples given in this booklet will be appropriate to you. However, there are plenty of ideas that you might be able to adapt and use to make life that bit easier.

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The College of Occupational Therapists welcomes this comprehensive booklet to help people with arthritis live independent and fulfilling lives

## AN INDEPENDENT LIFE

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Everyone has a different definition of what independence means to them. Some people define independence as the freedom to live their life the way they want to. Others might say that independence is living in their own home or being financially self-sufficient. Ultimately, independent living is about having choice and control over how you live your life.

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**“Independence is living in your own home, being able to do what you want while acknowledging that you may need help”**

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Running a home on a day-to-day basis and caring for yourself might be difficult when you have arthritis. It might take you longer than others to carry out daily activities such as dressing or doing the shopping – and enjoying your leisure time might take a little more planning.

### ■ **Barriers to independent living**

Fatigue, pain, and loss of strength and mobility are some

of the effects of arthritis that make it harder for people with arthritis to live independently.

Some people may find that they need to allow extra time to move around the home to do things like answer the door or pick up the telephone. Strength and dexterity can be issues when it comes to opening doors or windows, or doing jobs that involve carrying loads – like the washing or bringing in the shopping. People with arthritis may also find the fluctuating nature of their condition difficult to manage. On good days, managing alone may be easy. On bad days, people may find daily tasks tiring and painful, which can be frustrating.

It can be difficult to accept that you may not be able to do everything – try to focus on what you can do with a little adjustment. Some people find that changing their routine can help manage fatigue and pain. Others might decide that they are going to give themselves permission not to do some daily tasks, and leave the vacuuming or ironing for someone else to do.

External factors can also make life difficult for people with arthritis – such as shops that are inaccessible, and family, friends and strangers who don't understand your situation or your needs.

There is a lot that you can do to make it possible to carry on with daily activities. You may need to rethink how you organise yourself and your home. See the 'How to get what you need' section later in this booklet for more information. In general, consider:

- changing how and when you do things to put the least strain on your joints and to conserve your energy
- buying equipment with a better design (try regular shops, your local Disabled Living Centre, or specialised equipment store – or obtain equipment on loan through an occupational therapist)
- redesigning or reorganising your home
- forward planning trips out
- how you communicate with others
- getting help from others.



## YOUR LIFE

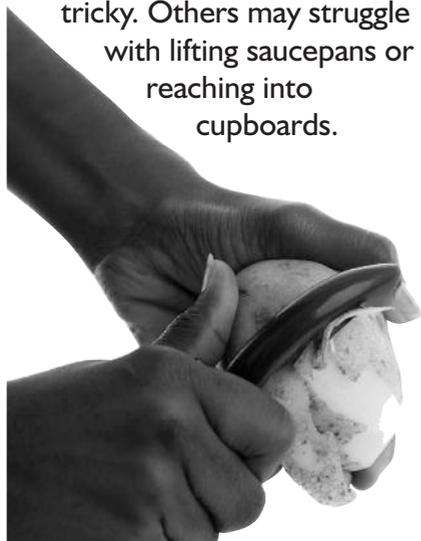
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There is plenty that you can do to make the many different aspects of your everyday life easier. Start by breaking down what you do in the day and think about whether there are easier ways of going about things.

Some ideas on making the daily aspects of life easier are outlined in this section.

### ■ Cooking

People with arthritis may find it difficult to prepare meals for a number of different reasons. For those that have problems with gripping, tasks such as chopping food and opening jars can be tricky. Others may struggle with lifting saucepans or reaching into cupboards.



How you organise yourself in the kitchen can make cooking easier, as can the multitude of handy gadgets available.

### Organising yourself in the kitchen

The first thing to think about is whether the design of your kitchen aids or hinders you in preparing meals. Difficulties might be resolved by simply rearranging the kitchen so that the things you need most frequently are within easy reach – or you may have to rethink the layout of the whole room.

You should also consider how you can avoid straining your joints. For example, if your arthritis affects your hands, arms or shoulders, you could try sliding saucepans across the worktop to the sink or the hob instead of lifting them. Kitchen trolleys can be useful for transporting things around the house as well as for support while walking.

Much of your food preparation and cooking – and even the washing up – can be done sitting down. Many people

use perching stools that can be moved around easily.

Although you may prefer to prepare fresh food, there are some shortcuts that you can take to make life easier. Buying ready chopped fresh fruits and vegetables saves time and energy. Frozen vegetables often contain more vitamins than fresh ones that have been sitting on the supermarket shelf for a while.

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**“I use prepared cuts of meat so they are easy to grill or ovenbake”**

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It is worth keeping your store cupboard well stocked with essentials for when you do not feel up to much cooking or shopping. Consider cooking extra food when you are feeling better and freezing it for the



days when you do not feel so well.

Some people with arthritis prefer to cook food using a microwave rather than a

conventional hob as less heavy lifting is generally involved, and it can be easier to reach if placed on a worktop surface.

Microwaves are also handy for heating up pre-prepared meals.

### **Useful gadgets for the kitchen**

There are a wide range of kitchen implements specifically for people who have reduced strength and dexterity, such as:

- food processors to chop and mix foods
- non-slip, lightweight chopping boards
- an ergonomic, angled knife for chopping
- a lightweight wire basket or slotted spoon to lift vegetables out of a pan
- lightweight pans with two handles for easy lifting
- a kettle tipper
- clamps and holders to keep jars stable so they can be opened with one hand
- lightweight and easy-to-grip cutlery and cups
- electric can opener.

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**“My food processor does all my chopping, grating, slicing and shredding”**

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## ■ Chores around the home

Housework can be very tiring, so it is important not to do it all at once or to feel that you have to do everything yourself. You may be able to enlist help from your family or hire a cleaner (see 'Employing someone to help you'). If you manage a little every so often, it can be good exercise.

### Cleaning

Many people with arthritis use a long-handled dustpan and brush for cleaning to avoid having to bend over. It may also be worth getting a lightweight vacuum cleaner – try before you buy. Some people with arthritis prefer to keep one vacuum cleaner upstairs and one downstairs to avoid having to carry one around at all.

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***“A dustpan and brush with very long stick handles is good as I don't have to bend”***

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### Washing and drying clothes

Carrying around heavy loads of washing can put a lot of strain on your joints. Why not try throwing the laundry down the

stairs in bags instead of carrying it down?

Front-loading washing machines are usually easier to use than top loading ones, and can be raised on a platform to minimise the amount you have to bend down. A grabber stick could help you to get clothes out of the machine.

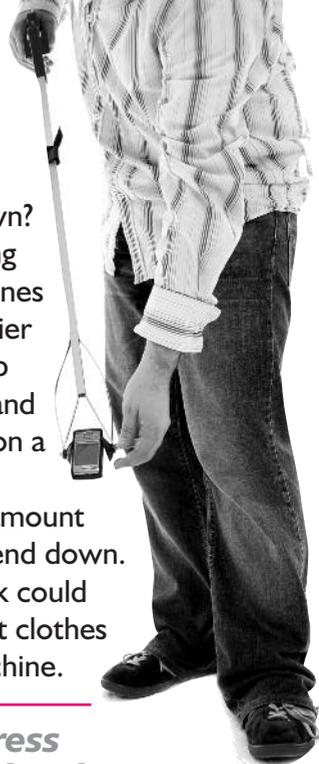
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***“I use a press instead of ironing, which is a godsend”***

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Ironing boards can be difficult to open and close so try this out before buying. You can buy lightweight boards and even ones with attached seats. Alternatively, you could use a wall-mounted ironing board. Make sure you choose a lightweight iron as some models can be very heavy.

Buying clothes that do not require ironing also makes life much easier – as does only ironing the essentials or using a tumble dryer.



## Making the bed

You may dread making the bed. Lack of strength can make lifting the mattress difficult. It may help to use a large spatula, shoehorn or ruler to tuck in the sheets – or to use fitted sheets. Don't be afraid to ask for help.

## ■ Relaxing at home

Life isn't all about chores – being able to relax in your home is an important part of living independently.

Try to find furniture that is at the right height, or you can raise your armchair on blocks. Some people prefer to use recliner chairs that can automatically raise you up in a seated position – there are some swanky designs on the market.

You might find putting your legs up on a stool comfortable. Holding a book for a long period of time can be painful. Try using a cushion or a book-rest to ease the strain on your joints.

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**“For reading, I prop books on a pillow”**

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A remote control for your TV, DVD or radio will save you energy. Make sure your electrical equipment is at the right height so that you don't have to bend down to reach it. Power sockets can be moved up the wall, or you can buy extension leads that can be fixed to go up the wall. Plugs with hand grips can also be helpful.



## ■ Gardening

Gardening need not be a problem when you have arthritis – with the right tools, choice of plants and garden design.

It is important to protect your joints when maintaining your garden. A few ways you can do this include:

- using long-handled, lightweight tools with a good grip
- using grabber sticks to pick things up
- choosing plants that are easy to look after and can be left alone for periods of time
- growing plants in raised pots and beds to minimise the time spent bending down
- ensuring that there are resting



places in the garden and using a stool to sit on whilst you work

- putting in a handrail for extra support when moving around the garden.

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**“I have a large patio to reduce the amount of grass I have to mow”**

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## ■ Sleeping

The pain and stiffness of arthritis can sometimes make it hard to get a good night’s sleep. You may feel not just tired, but thoroughly exhausted.

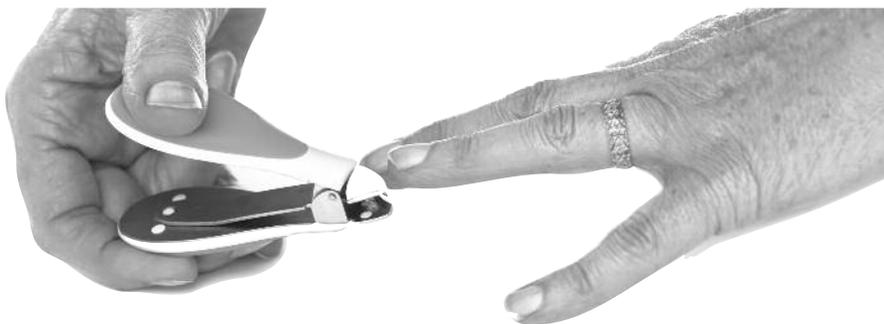
Being comfortable in bed can make a big difference. You might want to consider:

- a heavy duvet or blanket may make it harder to move around in the night
- an electric blanket or hot water bottle could help with pain relief and relaxation
- a comfortable mattress and bed will help ensure you get adequate rest.

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**“I have an electric heat pad which I use at bedtime – it’s so much easier to go to sleep after using it”**

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It is important that your bed is at the right height for you. You can raise it using blocks if that helps. Powered leg lifters are available for those who have problems lifting their legs into bed. They may be pricey, but electrically operated beds are more commonplace these days and can help you to sit up.

## ■ Washing and personal care

There are many ways in which you can make washing and personal care easier. You may need to simply allow extra time for these activities – or you might have to think about purchasing some equipment to assist you, such as a bath seat, a long-handled sponge or a stool to perch on at the washbasin.

Many people find lever taps easier to use in the bathroom. If you cannot get lever taps fitted

you can buy tap turners to fit over existing taps.

A raised toilet seat might make it easier to get on and off the toilet. A grab rail by the toilet is also useful for this purpose. Or you could perhaps install a toilet which is itself slightly raised.

## Showering and bathing

Getting in and out of the bath can be a problem for people with arthritis. Grab rails fitted on the wall or floor next to the bath can help. Putting in a non-slip mat on the floor of the bath is also important in preventing accidents.

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**“I have rails in the bathroom that help me bathe independently”**

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There is a lot of equipment available for those who need extra help with getting in and

out of the bath, including:

- bath seats and/or bath boards
- bath lifts
- walk-in baths that open on the side.

If you are worried about getting out of the bath, try to make sure someone is at hand in case you need assistance – it might be best not to lock the bathroom door. Shower cubicles can be fitted at level access with the rest of the bathroom or with a small step – wet rooms are all the rage on home improvement programmes. You may find it more comfortable to use a shower stool – these can be either free-standing or they fold down from the wall.

### Drying

It may take less energy to put on a towelling dressing robe to absorb water rather than drying yourself. You could then use a small towel or hankie for drying each part of your body in turn, or even a hair dryer for hard to reach parts.

Another (expensive) option is to use a body dryer. This is a bit like a hair dryer for the whole body, and is usually installed in the shower – another ultimate in home design.

## ■ Dressing

Dressing and undressing can seem like a major hassle, particularly first thing in the morning when your joints may feel the most stiff. Some people find that it helps to sit down to get dressed.

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***I usually have a baggy clothes day when I can't put my arms up above my head***

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The right choice of clothing can also help – and it can still be fashionable. You may want to think about buying clothes:

- that are loose fitting and that you can pull on
- that are made of stretchy materials
- with elasticated waists
- with easy-to-use fastenings, such as Velcro or magnets rather than buttons or zips
- with fastenings that are easy to reach – at the front or sides of the clothes rather than up the back.

Zips, buttons and hooks can be difficult if you have stiff or painful fingers. Buttonhooks are available which help you draw buttons through their holes. You could try attaching a piece of

ribbon to your zips to make them easier to pull.

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**“I have a long-handled shoe horn for putting shoes on”**

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Some people choose to buy slip-on shoes to avoid having to fiddle around with buckles and laces. You can also buy shoes with Velcro fastenings or buy elastic laces.

There are gadgets available to help you put on tights and socks, such as long plastic applicators (known as sock gutters) or long tongs.

## ■ Being secure at home

Making your home a safe environment is not only about putting in adequate security measures, but ensuring that the layout means that accidents are less likely to happen. This could include thinking about:

- allowing enough space to move around furniture and keeping clutter to a minimum
- the choice of flooring and lighting – slippery flooring, loose rugs or poor lighting could lead to trips and falls.

## Security measures

If you are concerned about security, alarm systems can be fitted to your home or carried on your person. They may either connect to an external source of help or alert those around you. Some local authorities run alarm services. Alarms may also be provided by charities such as Help the Aged.

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**“I have a door entry system – if I am having a bad day it saves me that struggle to the door”**

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Door entry systems enable you to speak through a microphone to a person at your door (and sometimes view them on a screen). You can then decide whether to let them in by pressing a button on a handset in your home.

It is a good idea to have a cordless or mobile phone in the home as they can be carried around easily. Alternatively, put in a phone handset upstairs and downstairs. If arthritis affects your hands, try a hands-free phone – one with big buttons that are easy to press.

Putting in an answering machine or using an answering service will mean that you do not always have to run to answer the phone. If you cannot use a phone book, British Telecom provides a free online directory enquiries service.

## ■ Getting around – mobility equipment

Going up and down the stairs can be very tiring and puts extra pressure on the joints. You can minimise the journeys you make by keeping a set of the things that you might need during the day downstairs. To make negotiating the stairs easier, consider:

- fitting a second bannister and/or some grab rails
- carpeting the stairs – you will be less likely to slip
- putting in a stairlift.

Some people with arthritis will need equipment to help them get around the home or outside of it. Everyone's mobility needs will vary – a physiotherapist or an occupational therapist can help you decide what you need. Some mobility equipment will be available through social services and some you might

have to buy. You should be able to try out most equipment at your local Disabled Living Centre.

You might feel uncomfortable or embarrassed about using a visible mobility aid. It might feel like a big decision to start using something like a stick or a wheelchair, but give yourself time to adjust. It might help to really focus on the things you can do through using it, compared with the difficulties you would have without it.

### Walking sticks and crutches

Walking sticks are useful for people who require some extra stability when walking, but might not be suitable for someone whose hands, fingers or elbows are affected by arthritis.

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***“I have a folding walking stick that I keep in my handbag. This means if my hips and legs become painful I have support to hand”***

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There are many different types of walking sticks available, so consider what will suit you:

- straight or curved sticks
- lightweight and fold away sticks
- walking sticks with ergonomic handles and seats.

People with arthritis may also use crutches.

Under the arm crutches may cause nerve damage if not used correctly – seek medical advice before using. Alternatively, it may be possible to use crutches under your elbows and/or forearms.

### Walking frames

A few people may wish to use walking frames – with or without wheels. They usually have four legs and the person using them either lifts and moves (or wheels) the frame forwards and steps into it. They can be a very useful means of support, but can be difficult to manoeuvre, particularly through doorways, around corners and on steps and slopes. They may be difficult to use for people with arthritis in their hands and arms.

### Wheelchairs

If you have arthritis, needing to use a wheelchair is by no means inevitable, but for some, it can make a world of difference and be a great tool to independence. Some people may use a wheelchair all the time, just on bad days, after an operation, or to get around large spaces like shopping centres or an airport. Wheelchairs can be self-propelled, pushed by someone else, or electric.




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***‘Using a wheelchair means I can still do everyday things and be independent. I enjoy wheelchair dancing. We do modern ballroom – if I was on my feet I’d probably fall over.’***

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If you need to use a wheelchair within your home, some changes might be necessary. For example, you may need to put in ramps, widen doorways, adjust

the height of units in kitchen, and lower light switches and door handles.

The NHS wheelchair service may be able to provide you with a wheelchair. Health and social care professionals can refer you to the scheme for assessment to see if you are eligible. In some areas, wheelchairs may also be available as short-term loans from community equipment services. Contact your local authority (or local health trust in Northern Ireland) for details.

If you are receiving the higher rate mobility component of the Disabled Living Allowance (DLA), you may also be eligible for a wheelchair through the Motability scheme (see page 31).

The Disabled Living Foundation has more information for people interested in adapting or customising a wheelchair to suit their needs (see page 31).

### **Scooters**

You may find using a scooter or buggy is better for you, if you are able to get on and off the seat easily and do not have painful shoulder joints or weak arms. Many people with arthritis use their scooter for some trips

outdoors rather than using it all the time.

If you are receiving the higher rate component of DLA, you may also be eligible for a powered scooter through the Motability scheme.

### **■ Using public transport**

Using public transport might seem like a daunting prospect, particularly if you are worried about access and facilities. But remember, you have as much right to use public transport as everyone else (see the 'Know your rights' section for more information).

Try to find out as much as you can about your journey before you travel, such as:

- how long will it take to get to the bus stop or train station?
- does the station have access facilities, such as a lift or escalators?
- are there any steps to get onto the bus or train?
- what is the best time to travel – you may wish to avoid busy times if you can?
- will there be any staff there who can help and do you need to pre-book special assistance (wheelchair users will need to

book ramps to board most trains)?

- are there resting places in the station or at the stop?

It can be difficult to pinpoint where to find this information with the many train and bus operators working across the UK. The following organisations can provide detailed information on accessibility, fares and timetables:

- Transport Direct – ([www.transportdirect.info](http://www.transportdirect.info)) this website allows you to plan a journey door-to-door (except Northern Ireland) using air, bus, car, coach, ferry, train, tram, tube and taxi
- Transport for London ([www.tfl.gov.uk](http://www.tfl.gov.uk))

- Translink Northern Ireland ([www.translink.co.uk](http://www.translink.co.uk))
- Traveline – to plan bus, coach or train journeys across the UK ([www.traveline.org.uk](http://www.traveline.org.uk) or phone 0871 200 2223)
- National rail enquiries – phone 0845 484950, or use their site to find the details of the relevant train operating company ([www.nationalrail.co.uk](http://www.nationalrail.co.uk))

There are a lot of concessions available to help you with the costs of travel if you have limited mobility:

- free off-peak fares for older and disabled people on some local bus services. Contact your local authority (or local council in Northern Ireland).
- discounted coach travel on National Express for older and disabled people ([www.nationalexpress.com](http://www.nationalexpress.com) or phone 0121 423 8479)
- a third off rail travel with the Disabled Persons Railcard for the holder and an accompanying adult ([www.disabledpersons-railcard.co.uk](http://www.disabledpersons-railcard.co.uk) or 08457 484950). Those receiving Attendance Allowance, or the higher or lower rate mobility

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component of the Disability Living Allowance for at least a year or the higher or middle rate of the care component are eligible)

- free travel on public transport in London with a Freedom pass – only London residents aged over 60 or those with a substantial and long-term adverse effect on their ability to walk are eligible.

### ■ Private transport

Taxis and private vehicles can be an important means of transport for some people with arthritis. Although there are no agreed accessibility standards for taxis, in many larger cities licensed taxis are required to be accessible. To find out if there are wheelchair accessible taxis in your area, contact your local taxi licensing office at your local council.

People who are unable to use public transport can benefit from subsidised door-to-door taxi services, such as Dial-a-ride, in some areas.

### Driving

Driving your own car may be the only option if you are unable to

use public transport and live in a remote area. If you receive the higher rate component of the Disability Living Allowance, you may be eligible to:

- start driving at 16 (instead of the national age of 17)
- receive grants for driving lessons
- exemptions from paying tolls on some UK bridges and tunnels. See the Disabled Persons Transport Advisory Committee (DPTAC) website for more information:  
[www.dptac.gov.uk/door-to-door](http://www.dptac.gov.uk/door-to-door)
- buy or lease a car, powered wheelchair or scooter through the Motability scheme, which can reduce the costs of vehicle ownership.

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***“I have a car mirror that is longer than average because I can’t turn around very well”***

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It is also worth finding out if you are entitled to a Blue Badge, which allows you to park in allocated spaces. Contact your social services department for information.

There are many considerations to buying a car when you have arthritis. For more information, including the regulations around driving when you have arthritis, consult Ricability's guide, *Motoring with Arthritis*, or Radar's booklet *Get Motoring*.

### ■ Going to the shops

Getting the shopping done can be tricky for people with arthritis. Travelling to and from the shops and carrying heavy grocery bags can pose real difficulties. There are many ways to make buying what you need easier with some forward planning.

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#### “I go shopping early in the day before the shops get busy”

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Some of the ways you can make life easier for yourself include:

- going shopping when you are feeling your best
- taking a friend to help you
- asking for assistance to help find products, pack bags and carry items to the car
- consider whether doing your shopping in one trip or a little and often suits you best

- using a bag with firm handles to carry your shopping, or even a shopping basket on wheels if you are walking home.

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#### “I use a shallow trolley rather than a deep one, to prevent back pain”

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Many people prefer to do their shopping online, particularly for heavy groceries. You can usually arrange for a delivery when convenient, although most companies charge to deliver. Other alternative ways of shopping include buying over the phone, or from mail order catalogues.

#### Getting help with the shopping

Shopmobility is a scheme that allows people with limited mobility to borrow wheelchairs or scooters to enable them to shop. They are based in shopping centres, and staff can also arrange for you to have an escort to help with shopping. Some offer a free service, whereas others charge a fee ([www.justmobility.co.uk/shop](http://www.justmobility.co.uk/shop)). If you do not feel able to go out to the shops, help might be available from social services.

## ■ Leisure outside the house

Having a social life is an important part of independent living. However, the pain, fatigue and loss of mobility associated with arthritis might mean that you do not always feel up to going out. Be open with your family and friends about what you feel able to do and what is beyond you, and make sure you set aside rest days.

Before you go somewhere new – whether to the shops, a restaurant, sports centre or the cinema – phone ahead and ask about access. It is unlawful for service providers to discriminate against a disabled person, but this does not mean access will always be available (see the ‘Know your rights’ section for more information).

Some other things to consider when choosing where to go for your social pursuits include:

- how big is the location – will there will be a lot of walking around?
- are there steps or is the site very hilly?
- are there likely to be long queues?
- how can you travel there and is there accessible parking?

Your local authority (or local council in Northern Ireland) will be a good source of information about facilities in your area. There may be a local leisure centre for example, where you can join a yoga class or use the swimming pool. Some local authorities provide leisure passes, which allow you to use their facilities at a discounted rate. Many cinemas run schemes that include passes or discounts for disabled customers. The local paper is also a good place to find out about social or sports groups.



## HOW TO GET WHAT YOU NEED

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There is a lot you can do for yourself to enable you to live independently. A big part of this is being able to manage your condition so that you are able to do the things that are important to you. It is also about having the information you need to make the choices to enable you to control your life – and about knowing who can help you to facilitate this.

### ■ Taking control

Self-management is about taking control of your condition, rather than letting it control you. This is something that you can learn for yourself, or you can attend Arthritis Care's Challenging Arthritis programme.

### ■ Pain management

Pain is one of the most common symptoms of arthritis. It can be very difficult to continue to do the things you want to do when you are in pain, but there are ways in which you can manage your pain. These include:

- finding time to relax
- controlling your weight – excess weight can put extra

strain on your joints

- a good night's sleep
- taking medication as prescribed
- conserving your energy and pacing yourself.

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***‘I plan to make sure that the washing is done one day in the week and the hoovering another to conserve my energy’***

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For more details, read Arthritis Care's booklet on pain management. Arthritis Care also runs self-management programmes on dealing with pain.

### ■ Adapting your home

If you are considering a redesign, or fairly major changes to your home, a good way to start is by visiting a Disabled Living Centre. This will give you an idea of the different equipment available.

An occupational therapist can also help you obtain equipment or adapt your home (see the 'health and social care professionals' section).

## ■ Knowing your rights

Many people with arthritis and other conditions that have a long-term impact on their daily life have rights under the Disability Discrimination Act (DDA).

Whilst you might not consider yourself disabled, about three-quarters of people with arthritis are covered by this legislation, preventing them from being discriminated against. The DDA states that a disabled person is 'someone with a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.'

### Access to public services

According to the DDA, people who provide services to the public have to change the way they do this if they are difficult for disabled people to use. This includes making 'reasonable adjustments' (adjustments that

are practical according to the size of the business) such as:

- making sure steps, stairways and toilet facilities are accessible
- providing disability awareness training for staff who have contact with the public.

### How to enforce your rights

If you find that your needs are not being met – at your local supermarket, for example – there is a lot you can do:

- explain what your needs are to the service provider
- tell them that they should comply under the DDA
- campaign – write a letter to your local member of parliament (or elected representative) or to the local paper, or perhaps join the Arthritis Care Campaigners Network and find out what others are campaigning about in your area.



## PEOPLE WHO CAN HELP YOU

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For some, asking for help may seem like an admission of failure, but accepting your limitations and asking for help can enable you to achieve what you want. Often, people may be willing to help, but are afraid of offering in case they cause offence.

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**“ I think living independently is a state of mind. I have carers but still consider myself independent. ”**

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There are several groups of people who can help you – from friends and family to health professionals and various organisations. You may need help from different groups at certain times depending on the circumstances.

### ■ Family and friends

Friends and family are often the first point of call for people wanting help to live independently. You may want help with occasional, ad hoc tasks, like putting up shelves and moving furniture. Alternatively, you may want or need more consistent help with things

that need to be done on a more regular basis – like cooking meals and washing.

Explain your condition to family and friends to help them understand what they can do to support you practically. You may need to discuss how household tasks could be shared – this might take some compromise.

### ■ Family, friends and neighbours as carers

A carer is someone who provides help and support, without payment, to a family member or friend on a regular basis. This could include help with tasks such as washing, dressing, cleaning and collecting prescriptions.

Some people find having help from people they know is easier than hiring a personal assistant. A friend or family member is more likely to know how you



like things done and may be more flexible about the times you need them. However, some people do not like to feel they depend on their family and prefer to have a more professional and practical relationship with the person who assists them on a daily basis (see the section ‘Employing someone to help you’). Family members can sometimes be excessively attentive, leaving people feeling as if their independence is being taken away from them. If someone you know well is your carer, make sure you clearly outline where their responsibilities begin and end.

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**“ I did have to tell people to stop helping me as I wanted to get on with things myself ”**

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## ■ Health and social care professionals

Various professionals can be particularly useful in helping you to live independently.

### Occupational therapists (OTs)

OTs provide advice and help if you are having difficulties with day-to-day tasks like washing, dressing, leisure activities and your work.

OTs are usually based in hospitals or social services departments (social work departments in Scotland or health trust social work teams in Northern Ireland). OTs may also work in the voluntary and independent sectors. A directory of private OTs can be accessed via the College of Occupational Therapists Specialist Section – Independent Practice website ([www.otip.co.uk](http://www.otip.co.uk)).

Your doctor, nurse or physiotherapist can refer you to a hospital or social services OT and in some areas you can refer yourself. Social services OTs can arrange for structural adaptations within your home, depending on your income.

An OT will ask you questions about which daily activities you can do and wish to do, such as getting up and down from a chair, holding a pen and so on. They can help you in a number of ways by:

- finding more energy-efficient ways of doing things
- suggesting equipment and adaptations, including splints
- advising you on how and where to buy equipment
- supplying some equipment

- giving you ideas on how to manage pain, improve and maintain strength and movement
- advising on mobility issues, including wheelchairs and scooters
- providing support at work/school – to ensure you are able to carry out your job/study, and that you are supported to do so by your employers/teachers.

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**📖 My OT gave me lots of information on gadgets and on joint protection 📖**

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### **Physiotherapists**

Physiotherapists are health professionals who:

- specialise in helping people with arthritis maintain the strength, movement and function of the joints and muscles
- will do a physical assessment of how your joints are working
- will provide appropriate treatment including hydrotherapy, or splinting
- will assess you on whether you need a mobility aid

- may devise an exercise programme for you to follow at home and have regular sessions with you.

### **Rheumatology nurses**

Rheumatology nurses are based in rheumatology departments at hospitals. They can:

- advise you on treatment options, pain management and lifestyle issues
- assess and refer you to other healthcare professionals.

### **■ Other organisations and services**

There are a number of organisations and services that can help you to live independently. They may be able to provide financial and non-financial assistance in getting housing, equipment, adaptations and care at home. There are many local agencies and charities that may also be able to help – check out your phone book or local library for information.

### **Your local authority (or local council in Northern Ireland)**

You have the right to have your needs assessed by social services (social work department in

Scotland, or your local health trust social work team in Northern Ireland). Usually this will involve a visit at home from an occupational therapist.

They will recommend equipment and adaptations, such as handrails or adjusting the height of light sockets, on the basis of an assessment of your needs. The local authority (or local council in Northern Ireland) may help to provide any equipment or adaptations, or you may have to pay yourself (or use your Direct Payments for the larger items – see page 27).

### Home improvement agencies

Home improvement agencies are not-for-profit, locally based organisations that assist older and disabled owners or tenants to repair, improve, maintain or adapt their homes. They give free advice on what work

needs to be done, can arrange for adaptations and equipment, and find surveyors, architects or builders to complete the work (see page 32 for details of your nearest agency).

### Peer group support

Other people with arthritis can be a useful source of ideas and inspiration to enable independence. People on the discussion forum on the Arthritis Care website often exchange tips on making life easier. Log on at: [www.arthritiscare.org.uk/GetInvolved/Discussionforum](http://www.arthritiscare.org.uk/GetInvolved/Discussionforum)

You could also join your local Arthritis Care group. To find your nearest meeting, search online or call the numbers on the back cover.



## EMPLOYING SOMEONE TO HELP YOU

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Some people with arthritis may find that they need regular help with daily activities that they do not want to (or cannot) ask friends or family to provide.

### ■ Personal assistance

If routine daily activities become too tiring, too painful or take up too much time, you may decide that you need a personal assistant. You may need help with any or just some of the following:

- cooking and cleaning
- personal care
- driving and getting around
- medical tasks like giving injections
- routine tasks like shopping, banking and paying bills
- gardening.

If your local authority (or local council in Northern Ireland) agrees you need extra help at home, social services (social work department in Scotland or the health trust social work team in Northern Ireland) can arrange home care services. They may arrange for someone to visit your home to help you with personal and domestic care.

### Finding a personal assistant

If you would prefer to choose your own personal assistant, your local authority (or local council in Northern Ireland) can give you money to buy your own assistance (see 'direct payments' for more information).

Using a Direct Payment to employ your own personal assistant can have a number of advantages: you can employ who you choose, decide on their hours and decide what you expect them to do yourself.

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**“ The personal assistance is very good and is tailored exactly to what I need ”**

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To find a personal assistant you can go to an agency or hire one yourself. Social services (social work department in Scotland or the health trust social work team in Northern Ireland) or your OT will be able to advise you on this. The National Centre for Independent Living also provides support and information on managing your own personal assistance.

It is important to thoroughly check out the person you hire. You should check they have recognised qualifications and an up-to-date Criminal Record Bureau (CRB) or Protection of Vulnerable Adults (POVA) check. Also ask for references from previous employers. It is a good idea to draw up a person specification detailing the minimum skills and experience your personal assistant needs to have before interviewing them. For example, it may be important to you that they hold a nursing qualification, or a full driver's licence.

If you do hire someone directly yourself, remember that you will need to take on the legal responsibilities of being

an employer. This includes paying tax and national insurance contributions. Your local authority (or local council if you live in Northern Ireland) will be able to advise you on your responsibilities as an employer.

### ■ **A domestic cleaner/gardener or handyman**

There are many other people you can hire to help you out in your home. The best way of finding someone is to ask your neighbours or friends for recommendations. Otherwise, you could use a local agency or put an advert in the local paper. Phone directories usually list professionals as well.

## FINANCIAL ASSISTANCE

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There are many benefits and grants available to help you live independently. Eligibility will depend on how your arthritis affects you. Usually, people are deemed eligible if they are considered 'disabled'. Even though you might not consider yourself disabled, the definition could apply to you in terms of the benefits you are entitled to, so it is always worth checking.

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**↳ Independence to me is about having enough money to buy the things I want, not just the things I need** ↳

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The financial assistance available to people with arthritis changes frequently. To check for the latest information, visit the UK government website, ([www.direct.gov.uk](http://www.direct.gov.uk)), or check with your nearest Citizen's Advice Bureau.

Unless otherwise stated, the benefits and grants detailed below are available throughout the UK at the time of writing. For more information on benefits relating to

working/unemployment see Arthritis Care's booklet on working with arthritis and the benefits factsheets which can be downloaded from the Arthritis Care website:  
[www.arthritiscare.org.uk](http://www.arthritiscare.org.uk).

### ■ General benefits/grants for disabled people

#### Disability Living Allowance

Disability Living Allowance (DLA) is a benefit for those who need help caring for themselves (for example, washing and dressing) and/or getting around. It recognises that being disabled can involve extra costs – for example, needing to pay someone to help with your personal care, or to cover the cost of taxis you need to take because you can't walk as far as other people.

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**↳ You have to describe the bad days when applying for DLA** ↳

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The care component and the mobility component are payable at different rates depending on how much help you require.

You must be aged under 65 years to claim DLA. You can claim DLA whether or not you are working and it is not affected by your savings or earnings.

### Attendance Allowance

If you are aged 65 or over and need help caring for yourself, including meal preparation, you may be entitled to Attendance Allowance.

### Direct Payments

Direct Payments are local council payments to enable people to arrange and pay for their own care and support services, and/or equipment, instead of receiving them directly from the local authority (local council in Northern Ireland).

You may be eligible if you are:

- disabled and aged 16 or over
- a parent or carer aged 16 or over
- an older person.

The amount you get will depend on an assessment of your needs by the local authority. Direct Payments do not affect any other benefits.

You can use them to arrange services that the local authority

has assessed you as needing. You cannot use them to pay for permanent residential accommodation, or for a service from your spouse or civil partner, close relatives or anyone who lives in same house as you. You will be expected to keep a record of how the money is being spent.

### Independent Living Funds

Independent Living Fund payments can be used to employ people to provide care for you, but not for adaptations or equipment. Your savings will be taken into account in determining how much you will get.

You may be eligible if you:

- are over 16 and under 65
- already get social services support to the value of at least £200 a week (including direct payments)
- receive the care component of the DLA at the highest rate.

### VAT relief

Disabled people do not have to pay VAT when buying equipment that has been designed solely for disabled people. They also do not have to pay VAT on the cost

of adapting equipment so that they can use it.

## ■ Benefits and grants related to housing

### Disabled Facilities Grant

The Disabled Facilities Grant might be available to owners and tenants in England, Northern Ireland and Wales (see 'housing grants' for information about Scotland). It can be used for certain adaptations that will make daily living easier, such as suitable kitchen and bathroom facilities, widening doors and installing ramps.

Contact your local housing authority (local Housing Executive Grants Office in Northern Ireland) to find out if you are eligible. The amount payable will depend on your income and savings, unless you are under 19 years.

### Housing grants

In England and Wales, a loan or grant may be available from social services, but this varies between each local authority. In Scotland, there are two types of housing grants – compulsory and discretionary improvement grants. Compulsory grants,

which councils must give you (within the limits of their budget) go towards installing any additional standard amenities which are needed because a disabled occupant cannot use the existing ones – for example, putting in a downstairs toilet. You may also be awarded a discretionary grant to make further adaptations.

### Housing benefit

Housing benefit is available to those on a low income and paying rent. You can continue to receive housing benefit for four weeks after you start work, provided your job is expected to last five weeks or more.

### Council Tax reduction

There is reduction in Council Tax for disabled people who need to live in a larger property because of their disability.

Disabled people are considered eligible if they have a home with:

- an additional bathroom or kitchen, or
- any other room (not a toilet) mainly used by the disabled person, or
- enough space for the use of a wheelchair.

## ■ Benefits/grants for young people, families and carers

There are a number of grants that might be available to children under the age of 16 who are severely affected by arthritis. The Family Fund Trust ([www.familyfundtrust.org.uk](http://www.familyfundtrust.org.uk)) makes grants to families for bedding, clothing, holidays and driving lessons. Whizz-Kidz provide wheelchairs and other mobility equipment for children ([www.whizz-kidz.org.uk](http://www.whizz-kidz.org.uk)).

### Child Tax Credit

Child Tax Credit is a payment for parents and carers of children or young people who are still in full-time education. You may get extra if you care for a disabled child. Call the

Tax Credits helpline on 0845 300 3900.

### Disabled Students' Allowance

The Disabled Students' Allowance can provide help for disabled students in higher education who have extra costs, such as specialist equipment and personal assistance. Contact your local authority (local council in Northern Ireland).

### Carer's allowance

Carer's Allowance is a benefit to help people who look after a disabled person. You do not have to be related to, or live with, the person you care for, but there are eligibility criteria you need to meet. Contact your local Jobcentre, pensions office or equivalent.

## USEFUL ORGANISATIONS

- **arc (Arthritis Research Campaign)**

Copeman House  
St Mary's Court  
St Mary's Gate, Chesterfield,  
Derbyshire S41 7TD  
Tel: 01246 558033 or 0870 850 5000  
[www.arc.org.uk](http://www.arc.org.uk)  
Funds medical research into arthritis  
and produces information.

- **Assist UK (formerly the Disabled Living Centres Council)**

Redbank House  
4 St Chad's Street  
Manchester M8 8QA  
Tel: 0870 770 2866  
[www.assist-uk.org](http://www.assist-uk.org)  
Offers advice about choosing and  
obtaining equipment for disabled  
people. Contact to find your nearest  
Disabled Living Centre

- **Benefit Enquiry Line for disabled people**

Tel: 0800 88 22 00  
[www.dwp.gsi.gov.uk](http://www.dwp.gsi.gov.uk)  
In Northern Ireland, the Benefits  
Enquiry Line is run by the Social  
Security Agency  
Tel: 0800 220 674

- **Carers UK**

Tel: 020 7490 8818  
[www.carersuk.org](http://www.carersuk.org)  
Carers UK is the voice of carers.

- **Carers Scotland**

Tel. 0141 221 9141  
[www.carerscotland.org](http://www.carerscotland.org)

- **Carers Wales**

Tel. 029 2081 1370  
[www.carerswales.org](http://www.carerswales.org)

- **Carers Northern Ireland**

Tel. 028 9043 9843  
[www.carersni.org](http://www.carersni.org)

- **Chartered Society of Physiotherapy**

14 Bedford Row  
London WC1R 4ED  
Tel: 020 7306 6666  
[www.csp.org.uk](http://www.csp.org.uk)  
The professional body for  
physiotherapists.

- **Citizens Advice Bureau**

Myddelton House  
115-123 Pentonville Road  
London N1 9LZ  
Tel: 020 7833 2181  
[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)  
The Citizens Advice Bureau Service  
offers free, confidential, impartial and  
independent advice in local offices.

- **College of Occupational Therapists**

106-114 Borough High Street  
London SE1 1LB  
Tel: 020 7357 6480  
[www.cot.org.uk](http://www.cot.org.uk)  
The professional body for  
occupational therapy staff in the UK.

## USEFUL ORGANISATIONS

### ● DIAL UK

St Catherine's  
Tickhill Road, Doncaster DN4 8QN  
Tel: 01302 310123  
[www.dialuk.org.uk](http://www.dialuk.org.uk)  
DIAL UK can give you details of your nearest disability advice and information service.

### ● Disabled Living Foundation

380-384 Harrow Road  
London W9 2HU  
Tel: 020 7289 6111  
Helpline: 0845 130 9177  
[www.dlf.org.uk](http://www.dlf.org.uk)  
Advice and information on equipment.

### ● Independent Living Funds

PO Box 7525  
Nottingham NG2 4ZT  
Tel: 0845 601 8815  
[www.ilf.org.uk](http://www.ilf.org.uk)  
The funds were set up as a national resource dedicated to the financial support of disabled people, enabling them to choose to live in the community rather than residential care.

### ● Motability

Tel: 0845 456 4566  
[www.motability.co.uk](http://www.motability.co.uk)  
Provides cars and powered wheelchairs through the Mobility Scheme.

### ● National Centre for Independent Living

4th Floor  
Hampton House  
20 Albert Embankment  
London  
SE1 7TJ  
Tel: 020 7587 1663  
[www.ncil.org.uk](http://www.ncil.org.uk)  
NCIL is the national organisation providing information, training, expertise and policy development on all aspects of Direct Payments and independent living.

### ● Queen Elizabeth's Foundation

Woodlands Road  
Leatherhead Court  
Leatherhead  
Surrey  
KT22 0BN  
Tel: 01372 841100  
[www.qefd.org](http://www.qefd.org)  
Queen Elizabeth's Foundation encourages and enables disabled adults to increase independence and improve life skills.

### ● RADAR

12 City Forum  
250 City Road, London  
EC1V 8AF  
Tel: 020 7250 3222  
[www.radar.org.uk](http://www.radar.org.uk)  
A campaigning organisation with a range of information on disability issues.

## USEFUL ORGANISATIONS

- **Remap**

D9 Chaucer Business Park  
Kemsing  
Sevenoaks  
Kent TN15 6YU  
Tel: 0845 130 0456  
[www.remap.org.uk](http://www.remap.org.uk)  
Provides tailored equipment  
for disabled people.

- **Ricability**

30 Angel Gate  
City Road  
London EC1V 2PT  
Tel: 020 7427 2460  
[www.ricability.org.uk](http://www.ricability.org.uk)

Consumer guides on products  
and services for disabled people.

- **Home improvement agencies  
in England** – phone 01457 891909  
([wwwFOUNDATIONS.uk.com](http://wwwFOUNDATIONS.uk.com))

- in Wales** – phone 029 2057 6286  
([www.careandrepair.org.uk](http://www.careandrepair.org.uk))

- in Scotland** –  
phone 0141 221 9879  
([www.careandrepairsotland.co.uk](http://www.careandrepairsotland.co.uk))

- in Northern Ireland** –  
phone 028 9042 8314  
([www.foldgroup.co.uk](http://www.foldgroup.co.uk)).

# INDEPENDENT LIVING AND ARTHRITIS



**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](mailto: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](http://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: 0844 888 2111**

**Central England: 0115 952 5522**

**North England: 01924 882150**

**Northern Ireland: 028 9448 1380**

**Scotland: 0141 954 7776**

**Wales: 01239 711883**



This booklet is endorsed  
by the College of Occupational  
Therapists

