Independent living and arthritis

devised with and for 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.

**Contents**

- **An independent life** 1
  What is independence and the barriers to living independently

- **Your life** 3
  Managing daily activities both inside and outside the home

- **How to get what you need** 18
  Self-management, organising your home and knowing your rights

- **People who can help you** 20
  Friends and family, professionals and organisations

- **Employing someone to help you** 24
  Personal assistants and general domestic help

- **Financial assistance** 26
  Benefits and grants

- **Useful organisations** 30

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

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

*All people pictured on the cover and quoted in this booklet have arthritis.*
AN INDEPENDENT LIFE

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.

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, you 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, so 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.

Independence is living in your own home, being able to do what you want while acknowledging that you may need help.
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 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
● more planning before you go out
● how you communicate with others
● getting help from others.
There is plenty that you can do to make the many different aspects of your everyday life easier. Start looking at 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 who 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.

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 is 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
- lightweight and easy-to-grip cutlery and cups
- electric can or jar opener.

I use prepared cuts of meat so they are easy to grill or ovenbake
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, but 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.

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.

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.

If you put clothes on hangers when they come out of the washing machine, this should reduce the amount of ironing you need to do. 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. With a chair you want to sit up as high as possible whilst being able to place your feet on the floor. Sometimes furniture can be adapted, armchairs or a sofa can be raised on blocks. Some people prefer to use recliner chairs that can automatically raise you up in a seated position – there is a range of designs on the market.

You might find putting your legs up on a stool comfortable. A cushion or a book-rest can ease the strain on your joints whilst reading a book or using a tablet.

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.

For reading, I prop books on a pillow
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 gardening. 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.

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 lighter duvet or blanket to make it easier to move around in the night
- a comfortable mattress and bed at the right height to help ensure you get adequate rest

I have a large patio to reduce the amount of grass I have to mow.
● an electric blanket or hot water bottle to help with pain relief and relaxation
● a good quality memory foam pillow and/or mattress topper – but try before you buy.

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.

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

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

“I have rails in the bathroom that help me bathe independently”
● 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 or redesign as a wet room which is 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 folded 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 for drying each part of your body in turn, or even a hair dryer for hard to reach parts.

A more 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 feature 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.

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.

I usually have a baggy clothes day when I can’t put my arms up above my head.
through their holes. You could try attaching a piece of ribbon to your zips to make them easier to pull.

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 Age UK.

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.
Some people with arthritis find it easier to use mobile phones with a touch screen.

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 – www.bt.com

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 banister 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 either inside the home or outside. 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 may 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 may feel like a big decision to start using something like a stick, wheelchair or a mobility scooter, but give yourself time to adjust. It may 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.

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 for independence. Some people may use a wheelchair all the time, others 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.

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) or the enhanced rate of the Personal Independence Payment (PIP), 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 or PIP enhanced rate, you may also be eligible for a powered scooter through the Motability scheme.

Using a wheelchair means I can still do everyday things and be independent.

■ 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 railway station?
● does the station have access facilities, such as a lift or ramps?
● 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 for London (www.tfl.gov.uk)
- Translink Northern Ireland (www.translink.co.uk)
- Traveline – to plan bus, coach or train journeys across the UK (phone 0871 200 2233)
- National rail enquiries – phone 03457 484950, or use their site to find the details of the relevant train operating company (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 most 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 or phone 0871 781 8181)
- a third off rail travel with the Disabled Persons Railcard for the holder and an accompanying adult (www.disabledpersons-railcard.co.uk or 0345 605 0525). You are eligible if you receive Attendance Allowance, higher or lower rate mobility component of the Disability Living Allowance for at least a year or the higher or middle rate of the care component or any rate of the PIP (mobility or daily living component)
- 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.gov.uk/government/publications/door-to-door-strategy
- buy or lease a car, powered wheelchair or scooter through the Motability scheme, which can reduce the costs of vehicle ownership.

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 Rica’s guide, Motoring with Arthritis, or Disability Rights UK’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.

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. Some supermarket delivery services will bring your groceries into your kitchen. Other alternative ways of shopping include buying over the phone, or from mail order catalogues.

If you decide to visit the shops 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.

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.nfsuk.org). 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 internet and the local paper are also good places to find out about social or sports groups.
HOW TO GET WHAT YOU NEED

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.

For more details, read Arthritis Care’s booklet on pain management, Coping with Pain.

■ Adapting your home
If you are considering a redesign, or fairly major changes to your

I plan to make sure that the washing is done one day in the week and the hoovering another to conserve energy
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 Equality Act 2010.

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 Equality Act 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 Equality Act, 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 Equality Act
- campaign – write a letter to your local member of parliament (or elected representative) or to the local paper, or perhaps join the Arthritis Care Campaigns Network, through our website on the back cover.
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.

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.

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 activities (or occupations) like dressing, preparing meals, socialising and 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.cot.co.uk/find-ot/find-occupational-therapist).

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 the daily activities you wish or need to be able to do, such as using a computer or caring for children. They consider your strengths, skills and needs in carrying out these occupations and how the environment supports or inhibits this. They can help you in a number of ways by:

● finding more energy-efficient ways of doing things
- advising and supplying equipment and adaptations, including splints
- giving you ideas on how to manage pain, improve and maintain strength and movement
- advising on mobility issues, including wheelchairs and scooters
- ensuring you are able to carry out your job/study, and that you have the appropriate support.

**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 to assess your needs. They will recommend equipment and adaptations, such as handrails or adjusting the height of light sockets. 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 31 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.arthritiscareforum.org.uk/
You could also join your local Arthritis Care group. To find your nearest meeting, search online on Arthritis Care’s website or call your nearest Arthritis Care office.
EMPLOYING SOMEONE TO HELP YOU

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 some of the following:
- cooking and cleaning
- personal care
- driving and getting around
- medical tasks like 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.

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 Disclosure and Barring Service (DBS) 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 describing 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 or local shop. Phone directories usually list professionals as well.
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.

The financial assistance available to people with arthritis changes frequently. To check for the latest information, visit the UK government website, (www.gov.uk), or check with your nearest Citizen’s Advice.

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 factsheets on benefits, which can be downloaded from the Arthritis Care website: www.arthritiscare.org.uk

**General benefits/grants for disabled people**

Personal Independence Payment (PIP) has been phased in to replace DLA for eligible working age people aged 16 to 64. PIP is based on an assessment of individual need. The assessment is designed to specifically focus on the individual’s ability to carry out a range of key activities in everyday life. Information is gathered from the individual, healthcare and other professionals who support them. Most people are invited to a face-to-face consultation with a trained independent assessor.

Independence to me is about having enough money to buy the things I want, not just the things I need
You may also qualify for other benefits or help, so it is worth applying for them if you need help getting around or with personal care. If your claim is initially unsuccessful, ask to have the decision reconsidered. Many people go on to qualify on further attempts. To help complete your application keep a diary for a couple of weeks, listing any things you have trouble doing and the time it takes you to do them, so you don’t underestimate how much help you need.

**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 or
- already receiving social services support.

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. Your council will tell you what records you need to keep and what information you need to provide.

**Independent Living Funds** – The Independent Living Fund is permanently closed to new applicants and from July 2015 the funding and responsibility of ILF will sit with local authorities in England and devolved administrations in Scotland, Wales and Northern Ireland. The majority of existing recipients will continue to receive payments if they continue to meet the following criteria:
- are over 16 and under 65
- already get social services support to the value of at least £340 per week
- receive the care component of the DLA at the highest rate.

Recipients will remain eligible for ILF provided they are in receipt of the daily living component of PIP regardless of the rate at which this is awarded.
Universal Credit – Universal credit is a single benefit paid monthly if your income falls below a certain level or you are unemployed. It is being phased in to replace income based Jobseekers Allowance, income related Employment and Support Allowance, Housing Benefit, Income Support, Working Tax Credits and Child Tax Credits. To check if Universal Credit is being rolled out where you live visit https://www.gov.uk/universal-credit. Further changes may be made to benefits. Call the Universal Credit helpline on 0345 600 0723.

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 council (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 home improvement 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. Housing Benefit is being replaced by Universal Credit in a staged process.

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.familyfund.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).

**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 the Carer’s Allowance Unit, your local Jobcentre, pensions office or equivalent.

Our booklets are reviewed every 12-18 months. Please check our website for up to date information and reference sources or call 020 7380 6577.
USEFUL ORGANISATIONS

- **Arthritis Care**
  www.arthritiscare.org.uk

**Arthritis Care in England:**
Tel: 0844 8888 2111 or 020 7380 6509/10/11
Email: englandoffice@arthritiscare.org.uk

**Northern Ireland office:**
Tel: 028 9078 2940

**Scotland office:**
Tel: 0141 954 7776

**Wales office:**
Tel: 029 2044 4155

- **Arthritis Research UK**
  Tel: 0300 790 0400
  www.arthritisresearchuk.org
  Funds medical research into arthritis and produces information.

- **Disability Living Centres**
  Tel: 0151 230 0307
  www.alltogethernow.org.uk
  Offers advice about choosing and obtaining equipment for disabled people. Contact to find your nearest Disabled Living Centre

- **Citizens Advice**
  Tel: 020 7833 2181
  www.citizensadvice.org.uk
  The Citizens Advice Service offers free, confidential, impartial and independent advice in local offices.

- **Disability Benefits Centre Helplines**
  Tel: 0345 850 3322 (for PIP)
  Tel: 0345 605 6055 (for DLA if born before 8/4/48)
  Tel: 0345 712 3456 (for DLA if born after 8/4/48)
  Tel: 0345 605 6055 (for AA)
  Tel: 0800 220 674 (in Northern Ireland)

- **Carers UK**
  Tel: 020 7378 4999
  Helpline: 0808 808 7777
  www.carersuk.org
  Carers UK is the voice of carers.

- **Carers Scotland**
  Tel: 0141 445 3070
  Helpline: 0808 808 7777
  www.carersuk.org/scotland

- **Carers Wales**
  Tel: 029 2081 1370
  Helpline: 0808 808 7777
  www.carersuk.org/wales

- **Carers Northern Ireland**
  Tel: 028 9043 9843
  www.carersuk.org/northernireland

- **Chartered Society of Physiotherapy**
  Tel: 020 7306 6666
  www.csp.org.uk
  The professional body for physiotherapists.
USEFUL ORGANISATIONS

- **College of Occupational Therapists**
  Tel: 020 7357 6480
  www.cot.co.uk
  The professional body for occupational therapy staff in the UK.

- **SCOPE-DIAL UK**
  Tel: 0808 800 3333
  www.scope.org.uk/support/disabled-people/dial/about
  DIAL UK can give you details of your nearest disability advice and information service.

- **Disabled Living Foundation**
  Tel: 020 7289 6111
  Helpline: 0300 999 0004
  www.dlf.org.uk
  Advice and information on equipment.

- **Motability**
  Tel: 0300 456 4566
  www.motability.co.uk
  Provides cars and powered wheelchairs through the Mobility Scheme.

- **Queen Elizabeth’s Foundation**
  Tel: 01372 841100
  www.qef.org
  Queen Elizabeth’s Foundation encourages and enables disabled adults to increase independence and improve life skills.

- **Disability Rights UK**
  Tel: 020 7250 8181
  www.disabilityrightsuk.org
  A campaigning organisation with a range of information on disability issues.

- **Remap**
  Tel: 0845 130 0456
  www.remap.org.uk
  Provides tailored equipment for disabled people.

- **Rica**
  Tel: 020 7427 2460
  www.rica.org.uk
  Consumer guides on products and services for disabled people.

- **Home improvement agencies**
  in **England** – phone 0300 124 0315 (www.foundations.uk.com)
  in **Wales** – phone 029 2067 4830 (www.careandrepar.org.uk)
  in **Scotland** – phone 0141 221 9879 (www.careandreparscotland.co.uk)
  in **Northern Ireland** – phone 028 9042 8314 (www.foldgroup.co.uk).
Arthritis Care exists to support people with arthritis. We are the UK’s largest charity working with and for all people who have arthritis. We offer support wherever you live in the UK.

It costs us £1.60 to provide you with this booklet. If you are able to access information online, you’ll help us save money and the environment.

Get involved with us today if you can.

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

Arthritis Care and Arthritis Research UK have joined together to help more people live well with arthritis. Read how at arthritisresearchuk.org/merger. All donations will now go to Arthritis Research UK and be used to help people with arthritis live full and active lives in communities across England and Wales, Scotland, and Northern Ireland. Registered Charity Number 207711, SC041156.

www.arthritiscare.org.uk
To find out more about arthritis and Arthritis Care

Freephone our confidential helpline

0808 800 4050
(weekdays 09:30-17:00)

Visit our website

www.arthritiscare.org.uk