

Arthritis Ireland
Inform. Enable. Empower.



Caring for a Person with Arthritis





Arthritis Ireland helps people with arthritis take their lives back. We provide real solutions by empowering people with arthritis and those caring for them to take positive action to manage the effects of their disease on their lives.

Our innovative and life changing education and support programmes including *Living Well With Arthritis* and *Breaking the Pain Cycle* give people with arthritis the knowledge and practical skills they need to live their best possible quality of life. Our helpline provides vital emotional and practical support and, because we know that knowledge is power and central to living well with arthritis, we provide an extensive range of free educational information, such as this booklet.

Through our work we campaign for increased levels of funding in rheumatology services to provide a world class service that will positively change the outlook and outcome of patients' lives.

We also actively support and fund research into arthritis to ensure that Ireland is at the forefront of new breakthroughs leading to possible cures and also fund the training of health professionals through medical students in university to create a direct and positive improvement in patient care.

Home Instead Senior Care is Ireland's trusted source of home care for seniors and is committed to helping seniors maintain their independence and live at home for longer than otherwise possible. There are 18 Home Instead Senior Care offices throughout the country that provide a range of home care services including specialist care for people with chronic conditions such as arthritis. For further information on Home Instead Senior log on to www.homeinstead.ie or call 1890 930 013.



Introduction

This booklet has been launched to mark a new pioneering programme, *'Caring Hands'*. This programme has been developed by Arthritis Ireland in partnership with Home Instead Senior Care to help people caring for someone with arthritis learn about the condition, understand more about its symptoms and realise how they can support someone with arthritis to live a full and independent life.

By participating in a free half day workshop, carers will learn about arthritis, what the 'pain cycle' is and how to break it, the importance of exercise, and the benefits of relaxation methods. They will also receive some practical tips on improving communications between the carer and the person being cared for, as well as information on treatments for arthritis, and how to identify medical priorities. Ultimately, and most importantly they will learn about self management and how to provide help and assistance while enabling the person with arthritis maintain as much mobility, independence and control over their life as possible.

The information in this booklet has been kindly supplied by Arthritis Research UK
www.arthritisresearchuk.org



Providing answers today and tomorrow

Contents

Introduction	1
How can a carer help someone with arthritis?	4
Understanding what arthritis means	5
Communicating effectively with the person who has arthritis	8
Offering practical help with the treatment	10
Are they getting the benefits they are entitled to?	16
Where can I get support as a carer?	22

HOW CAN A CARER HELP SOMEONE WITH ARTHRITIS?

Looking after and caring for someone with arthritis is a challenge. You need to achieve the right balance between providing support and motivation without being overprotective. Most people with arthritis will wish to retain as much control over their lives as possible, and you need to help them to retain their independence. This might mean that in certain circumstances help may not be wanted. This can be difficult to judge and you must be sensitive to signs, which may not be verbal, that indicate you should stand back and not insist on helping with a particular task or activity.

There Are Four Main Ways In Which You Can Help:

- Understand what arthritis means – what causes it, how it develops, and how it affects people. In the same way that understanding their condition helps people with arthritis to cope with it, the more you understand about arthritis the more you will be able to provide successful care and support.
- Communicate effectively. Good communication in both directions is essential. The person with arthritis needs to feel well supported and may also need reassurance that you do not resent the responsibility falling on you.
- Offer practical help with the treatment. This may mean helping the person to take their medications or assisting with recommended exercises, activities or therapies that they have found helpful in reducing the symptoms of their arthritis.
- Support the person with arthritis in applying for any benefits and advice they may be entitled to. There are a number of benefits that they may not be aware



of (see 'Are they getting the benefits they are entitled to?' - page 16). We will look at each of these aspects in more detail in the following sections.

UNDERSTAND WHAT ARTHRITIS MEANS

It is important that arthritis is diagnosed by a doctor (often a rheumatologist, but sometimes a general practitioner). This is because there are many different types of arthritis, and treatments differ according to which type of arthritis a person has. Doctors often divide the different types of arthritis into two groups:

'I thought I knew what arthritis was until I visited www.arthritisireland.ie.'

- problems caused by inflammation (e.g. rheumatoid arthritis or ankylosing spondylitis)
- 'mechanical' problems or wear and tear (e.g. osteoarthritis or mechanical back pain).

The table on the next page lists the main types of arthritis in each group. Read Arthritis Ireland's booklets on "*Living with Osteoarthritis*" and "*Living with Rheumatoid Arthritis*" for further information or check out www.arthritisireland.ie for information on psoriatic arthritis, gout, and ankylosing spondylitis.

Most forms of arthritis run a very uneven course with day-to-day variation, and you need to be aware of this. The outlook is also very variable and difficult to predict. The arthritis can occasionally become very bad, or it can go away completely, but most people experience something in between. A person who has arthritis needs to be able to cope with the different symptoms that arthritis can cause.

Group 1 Inflammatory	Group 2 Non-inflammatory
• Rheumatoid arthritis	• Osteoarthritis
• Psoriatic arthritis	• Back pain
• Gout	
• Ankylosing spondylitis	

‘I took the time to read up about arthritis and learn about its effects which has really helped me understand what my Mum is going through. It meant a lot to her too.’

How can arthritis be treated?

Treatment is available for all types of arthritis. Many of the symptoms of arthritis can be managed through the right combination of exercise, drugs, lifestyle changes and learning to cope.



How does it feel to have arthritis?

Arthritis affects different people in different ways, and there are no right or wrong ways to feel. It can make someone feel pain, stiffness, tiredness or frustration. Frequently they may experience several of these symptoms at once. The problem with the pain of arthritis is the fact that it goes on day in, day out. If asked to put up with it for a few hours, most people would cope. Facing it on a regular basis is not so easy. Most people will get some relief from their pain once they start treatment. As arthritis varies in an unpredictable way, people need to find their own way of coping. Learning about the disease is an important factor in coping, and a specialist rheumatology health professional will often help with this by teaching patients about the condition. Information can also be gained from booklets like this one.

A person with arthritis can also learn more of the skills that will help them deal with arthritis on one of Arthritis Ireland's self-management programmes or on www.arthritisireland.ie

'When I find being a carer difficult, talking about it with someone else really helps me see the positive side again'

COMMUNICATING EFFECTIVELY WITH THE PERSON WHO HAS ARTHRITIS

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

- Learn to recognise the signs when the arthritis is bad, as extra support may be needed at this time. Remember that pain can make people irritable, angry and depressed at times.
- Be patient if the other person has to do things differently and not as quickly as before. They may find it difficult to carry out normal everyday activities such as housework, picking up a telephone or using a knife and fork. They may find it embarrassing to talk about the difficulties they face, especially if personal issues like washing or dressing are involved. If you notice changes in the way the person behaves it may be because they need help with these activities, and either you or a health professional may be able to help by raising this issue tactfully.
- Do not allow yourself to become isolated. Make sure that you still see your family and friends and take part in the activities that are important to you. Find time for yourself. Roles may have to change within the home and at work. This needs to be discussed, and you may need the support of a trained health professional such as a specialist nurse, an occupational therapist or a professional caregiver. Be sensitive to the feelings of the person who has arthritis – it is very difficult,



for example, to sit and watch someone else doing something that you saw as your job.

- Join in the exercises or other activities so that they become shared activities. Encourage the person to find other activities to replace ones which they can no longer manage. Doing useful work can make some people feel better – they might, for instance, involve themselves in voluntary work, or start an educational course.
- Remember that you have needs as well. Caring can be hard work. At times you may feel irritable and depressed. This is normal and understandable. If it appeals to you, join a local support group.
- You can also get information, support and advice from The Carers Association (tel: 1800 240 724 or www.carersireland.com or email: info@carersireland.com.) Home Instead Senior Care have also published a guide to help caregivers cope with stress. Entitled, *'Running on Empty: Who cares for the caregiver?'*, the guide offers insights and information on coping with caregiver stress. You can download a free copy from www.homeinstead.ie. Alternatively you can call 1890 930 013 to order a free copy.

OFFERING PRACTICAL HELP WITH THE TREATMENT

You have an important part to play in supporting and helping the person to cope with their arthritis. The most common practical questions we receive from carers are included in the following pages.

- Be aware of how the different drugs work and what is a reasonable expectation of how effective they will be. If the prescribed painkillers are taken only when the pain is very bad and they are not providing adequate relief, then they may work better by being taken regularly, or they may need to be reviewed by the doctor.
- Pain may be eased either by warming or by cooling the painful area. Wrap a hot-water bottle or an ice pack (or bag of frozen peas) in a towel and hold it against the painful joint for 10–15 minutes.
- Pain makes muscles tense and more painful. Relaxation, massage and yoga can help. Join in – you may enjoy it too!
- Regular movement is needed to stop the joints becoming stiff and painful. Try not to be overprotective: encourage the person with arthritis to do as much as they can to keep the joints mobile.
- Space out daily activities instead of trying to do everything in one go. This can help reduce pain and stiffness and still enable activities to be carried out successfully.
- Encourage regular movement. Sitting in the same position for too long can increase stiffness.
- Find non-physical ways of occupying the mind such as reading, doing a crossword or just talking.
- If a particular activity is causing problems, encourage the person to find a different way of doing it. There usually is one. For example, carrying shopping is



better done in two small bags than one big one. If that is impractical then a wheeled trolley can be used. Alternatively, is there somebody who could help with shopping trips by sharing transport? Or check whether any local supermarkets offer a delivery service – some schemes allow you to shop as usual at your local store and have the items you choose delivered to your home later in the day. If there are problems with activities around the home then a visit from an occupational therapist for advice on aids and adaptations can be very helpful. Ask your GP or hospital rheumatology department for more information about this.

‘The worst exercise you can do for your arthritis is none’

How does arthritis affect a person's mood?

It is normal for people with arthritis to experience a wide range of feelings and emotions. They may be tearful, or angry, or upset among other emotions. Encourage them to focus on positive experiences and think about what they can do rather than things they have difficulty with. Arthritis Ireland's booklet '*Coping with Emotions*' provides information on the difficult emotions that people living with arthritis often face.

“When Jack's arthritis flares up and he feels low, sometimes the best support I can give is not the practical tasks. It's just to be there to listen and support.”

Should a carer encourage exercise?

Yes – it is very important to keep the joints moving to minimise pain and stiffness. Try to encourage exercise as a daily habit. Swimming and cycling (it can be on a static bike) are good exercises. Physiotherapists are the experts in this area, but the person with arthritis may have their own preferences about exercise and should be encouraged to express them. If you join in the exercises then this can become more of a social activity and less of a chore. It is important to start gradually with any exercise and increase the amount over time as the body adjusts to the extra requirements being made of it. For more ideas on exercising when you have arthritis, check out Arthritis Ireland's '*Be Active with Arthritis*' exercise DVD and booklet specifically designed for people with arthritis, available to purchase on www.arthritisireland.ie. You could also find out if there's a local walking or exercise group near you such as one of Arthritis Ireland's walking groups.

‘My husband used to find it difficult to get motivated to exercise, so now we walk down to the shops for a newspaper every morning. We enjoy the exercise together, and I can really notice the difference in him.’

Is it natural for the person to feel tired?

Most people with arthritis will find they get tired more easily, particularly if they have rheumatoid arthritis. For some people the tiredness is more difficult to cope with than the pain. Tiredness can be reduced by:

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

Is it necessary to take drugs?

Drugs are one of the main treatments for reducing the effects of arthritis. They are usually divided into:

- Fast-acting ‘first-line’ drugs, which treat the symptoms of pain and stiffness and can be used for most types of arthritis
- Slow-acting ‘second-line’ drugs, which are intended to modify the disease itself (disease-modifying antirheumatic drugs, or DMARDs, and biologics) – these are used only in inflammatory types of arthritis.

See Arthritis Ireland's booklet on "*Drugs and Complementary Therapies*" for information on the treatments available in Ireland.

As far as treatment of symptoms is concerned, the person with arthritis is in the best position to weigh up the benefits of taking tablets such as painkillers (analgesics) or non-steroidal anti-inflammatory drugs (NSAIDs). This should always be discussed with a doctor or nurse specialist, who will be able to give good advice about the benefits and possible side-effects of each of these drugs. If the doctor offers these drugs to relieve symptoms, it is usually worth trying them to see whether they help and then discussing with the doctor whether to continue with them.

The drugs given to modify the disease itself must be taken as prescribed, or variations in their use agreed with a doctor. For example, allopurinol for gout has to be taken continuously or it may make the attacks worse. Prednisolone must not be reduced too quickly or stopped suddenly as this can be dangerous. Most 'second-line' drugs for rheumatoid arthritis (sulfasalazine, leflunomide and methotrexate are examples) need to be monitored with blood and/or urine tests as a precaution against side effects. Everyone is different, so if one drug proves to be unsuitable there is often a satisfactory alternative.

Are there any foods that will help?

It is important for everyone to eat a balanced diet with plenty of fruit and vegetables for general health. People with arthritis should particularly avoid putting on weight – being overweight will increase the stress on the joints. Some people with arthritis do seem to benefit from making changes to their diet, though there is no single diet which helps with all types of arthritis. For more information see Arthritis Ireland's booklet on '*Healthy Eating and Arthritis*'.



‘I love shopping and cooking for my parents - knowing that following a healthy balanced diet will help their arthritis’

Does arthritis affect how people feel about themselves?

Having arthritis can make some people feel less confident in themselves. Your support, if wanted, can increase their confidence and help them to maintain an active social life. This is important for your well-being as well as for the person who has arthritis.

ARE THEY GETTING THE BENEFITS THEY ARE ENTITLED TO?

Here is some information on some of the main benefits and entitlements that might be worth exploring.

Equipment and Adaptations to the Home

The person you are caring for may be able to get help with equipment or adaptations to their home. The Housing Adaptation Grant for People with a Disability, the Mobility Aids Grant Scheme and the Housing Aid for Older People Scheme are administered by local authorities. For further information on these schemes and to see whether the individual might be eligible for help contact the Housing Department of your local authority.

Work and Education

If the person you are caring for has been out of work as a result of their arthritis, it is worth noting that FÁS offers many schemes, job and training opportunities to help them find and retain work. FÁS also has a wide range of supports available for people with disabilities in employment; including adaptation grants, disability awareness training for employers and grants to enable a person stay at work when they have become disabled while in employment. You can access FÁS services by visiting your local FÁS office, by calling the freephone telephone service on 1800 611 116 or by connecting to the FÁS web site www.fas.ie.

If a person is interested in going into higher education, they may be eligible for the Back to Education Allowance, paid by the Department of Social & Family Affairs. Various other education and training schemes exist, AHEAD (Association for Higher Education Access and Disability) www.ahead.ie, have published a relevant booklet *Accessing Third-level Education in Ireland – A Guide for Students with Disabilities*.

Travel

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

There are a few things that can be tried to make driving easier. An automatic gearbox and power steering will reduce strain. Minor adjustments, such as a padded steering wheel, a headrest, extra side-mirrors or a wide-angled mirror may make driving easier.

There are various means tested supports available through the HSE including grants for adapting a vehicle, the Disabled Person's Parking Card and tax relief for necessary adaptations to vehicles. The Irish Wheelchair Association (tel: 045 893 094 or www.iwa.ie) and the Disabled Drivers Association (tel: 094 - 936 4054 or www.ddai.ie) provide advice and information on all aspects of motoring.

If you would like to learn to drive or have lost confidence in your driving skills the Motoring Advice and Tuition Service in the Irish Wheelchair Association can provide assistance to you.

If relying on public transport you can apply for the **Free Travel Pass**, which allows you to travel for free on all public transports and selected private services.

Benefits

The Citizens Information Board offer a comprehensive booklet that outlines all entitlements for people with a disability, including rights relating to work, education and training. You can get this booklet, *Entitlements for People with Disabilities*, by visiting your local office or contacting them on LoCall 1890 777 121 or www.citizensinformation.ie.

A person may be able to apply for state benefits to help with the extra costs of having arthritis or if they are unable to work. Some of the main disability-related payments are:



Social Insurance Payments

- **Illness Benefit:** Illness Benefit was previously called Disability Benefit. This is a short-term payment made to people who are unable to work due to illness. It can be paid in the long-term. To qualify you must be aged under 66 and unable to work because of illness. PRSI contributions or credits must be up to date.
- **Invalidity Pension:** Invalidity Pension is payable for as long as a person is unable to work. At the age of 65, the personal rate of payment increases to the same rate as State Pension (Transition). At age 66 a person transfers to the State Pension (Contributory).
- **Other benefits:** Living Alone Increase is payable regardless of age if a person lives alone. They may also qualify for free travel and the **Household Benefits Package**, which includes allowances towards household bills.
- **Rehabilitative work:** A person may be allowed to do rehabilitative or therapeutic work (maximum 20 hours a week) and retain their Invalidity Pension. They must get prior written approval from the Department of Social and Family Affairs before they start work.
- **The Treatment Benefit Scheme:** A scheme run by the Department of Social Protection that provides dental, optical and aural services to people with the required number of PRSI contributions.

Means-Tested Payments

- **Disability Allowance:** This is a long-term means-tested payment made to people with a disability. The disability must be expected to last at least a year. A person may be entitled to Disability Allowance if they are aged between 16 and 66, satisfy both a means test and a habitual residence test, and have a specified disability which results in them being substantially restricted in undertaking suitable employment. The person's own means and that of their spouse or partner are taken into account. The person's parents' means are not considered. The person may qualify for a Living Alone Increase and the Household Benefits Package, which includes allowances towards household bills.

If a person is awarded Disability Allowance, they get a Free Travel Pass automatically. This allows them to travel for free and their spouse or partner to travel free in their company. If they are medically assessed as being unable to travel alone they may be entitled to a Companion Free Travel Pass.

Health Service

- **Medical Cards:** Most medical cards are granted on the basis of a means test and/or medical need. Each case is decided on its merits but a person may qualify if their income is not much above the guideline figure and their medical costs are exceptionally high. It may be possible for one or more members of a family (who would not otherwise qualify) to get a medical card in their own right if they have high medical expenses or needs.
- **GP Visit Card:** The purpose of this card is to help people who are not eligible for medical cards with the costs of visiting a doctor. The card covers them for GP visits but nothing else. The income guidelines for the GP visit card are 50% higher than the medical card income guidelines.
- **Drugs Payment Scheme:** With a Drugs Payment Scheme (DPS) card, an individual or family in Ireland only has to pay a maximum amount monthly for approved prescribed drugs, medicines and certain

appliances. As of January 2009, the maximum amount a family must pay is €100. Everyone in Ireland who doesn't have a medical card should apply for the DPS card.

- **Hospital Charges:** Everyone resident in Ireland is entitled to be treated free of charge in a public bed in a public hospital. Some people may have to pay maintenance charges. Out-patient services, when you are referred by your GP, are also provided free of charge.
- **Tax relief:** A person may get tax relief on certain health expenses, which they have incurred and for which they have not been reimbursed. The tax relief is at the standard rate of tax of 20%. So, if you spent €1,000 you would get a refund of €200. This claim should be made on a Med 1 form, available from your local tax office or online at www.revenue.ie.
- **Tax relief on home care fees:** Home Instead Senior Care clients or their family can avail of income tax relief of up to 41% on payments to Home Instead Senior Care of up to €50,000 per annum. The tax credit can be adjusted so that the relief will apply on a monthly basis rather than annually, which may otherwise be the case. We also advise families to avail of home care grants, which can be applied for through your local health centre. Please call 1890 930 013 to discuss in detail how you can go about claiming tax relief on home care fees.
- Many hospitals have rheumatology health professionals who can provide support and information to carers as well as to patients. Voluntary organisations such as The Carers Association (tel: 1800 240 724 or www.carersireland.com or email: info@carersireland.com) can provide information on what help is available and how to apply. There may also be a support group in your area where you can share information with other carers in a similar situation. Most people feel better for sharing feelings and concerns rather than keeping them bottled up inside. It is natural for you, as a carer, to feel anger and resentment at times (because your life has changed too) and sharing these feelings can make it easier to move forward.



WHERE CAN I GET SUPPORT AS A CARER?

“I called Arthritis Ireland’s helpline to get some information about caring for someone with arthritis. I felt they really did understand what I was going through.”

There are a variety of benefits that might apply to you, as a carer so it is worth investigating some of the following:

- **Carer’s Allowance:** This is a means-tested payment to people who are looking after someone who is in need of support because of age, physical or learning disability or illness. It is mainly aimed at carers on low incomes who live with and look after certain people who need full-time care and attention. You will also qualify for the Household Benefits Package and a Free Travel Pass.
- **Carer’s Benefit:** This is a payment made to insured persons in Ireland who leave the workforce to care for a person in need of full-time care and attention. You can get Carer’s Benefit for a total period of 104 weeks for each person being cared for.
- **Carer’s Leave:** This allows employees to leave their employment temporarily for a period up to 104 weeks to provide full-time care for people in need of full-time care and attention. The leave will be unpaid but those who propose to avail of Carer’s Leave will have their jobs kept open for them for the duration of the leave.
- **Respite Care Grant:** This is an annual payment made to carers. Carers can use the grant in whatever

way they wish. You can use the grant to pay for respite care if you wish, but it is not necessary to do so. The grant is paid automatically to people receiving Carer's Allowance or Carer's Benefit.

Information on all of the above is available on www.welfare.ie

- **Home Care Package:** If you need a professional home care service you may get help from the HSE under the Home Care Support Scheme. This may include a Home Care Package which you may use to employ caregivers. Home care supports under this scheme operate differently in different parts of the country. In some areas, the HSE directly provides care services at home or arranges for their provision by voluntary organisations or by private home care providers such as Home Instead Senior Care.

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

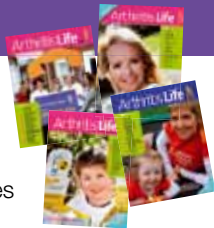
- a social worker from your local Health Office
- a housing welfare officer from your local authority
- your citizens information service:
LoCall 1890 777 121
- your local social welfare office
- the Leaflet Request Line in the Department of Social Protection: LoCall 1890 20 23 25
- online at www.hse.ie.



to become of Arthritis Ireland just €3 a month

1 Receive a year's free subscription to Arthritis Life:

The only magazine in Ireland that addresses the interests of people with arthritis and provides regular updates on our work and events.



2 Stay informed about Arthritis Ireland courses and events:

Be the first to receive notifications of the education courses, seminars and activities running in your area.

3 Have your say:

Have the opportunity to become a member of Arthritis Ireland and be more actively involved if you wish.

4 Receive a free arthritis friendly key turner**:

Receive a FREE key turner to give an easier grip and better leverage when turning keys.



5 Help make a real difference for just €3 per month:

For just **€3 per month** you will help us provide vital education and support services to empower people with arthritis by giving them the knowledge they need to take back control of their disease and their life. Your donation of €36 will enable us to provide information packs to 10 people like you living with this chronic condition.

For more details of how your donation makes a difference to the lives of people living with arthritis, just log on to www.arthritisireland.ie

Become

a friend

of Arthritis Ireland today

In addition to the fantastic range of benefits you receive, you are also helping to make a real difference to the lives of people living with arthritis.

Yes, I would like to become **a friend** today for just €3 per month or €36 per year.

I would like to make a gift of

€ _____

in support of the 1 in 6 people in Ireland with arthritis.

Personal Details: (please fill in all areas)

Name:

Address:

Telephone:

Email:

D.O.B.:

Do you have arthritis?

If so, what type?

Would you like to become a **MEMBER** of Arthritis Ireland at **NO EXTRA COST**? Just tick the box and we will forward you full details.

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Arthritis Ireland
Inform. Enable. Empower.



In partnership with:

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