

Arthritis Ireland
Inform. Enable. Empower.



Living with Fibromyalgia





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*, *Working 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.

Fibromyalgia is a syndrome associated with widespread pain and fatigue. There are no outward signs of the condition and people with fibromyalgia often look well while feeling quite the opposite.

Other people may not appreciate the pain and tiredness that can be experienced by a person with fibromyalgia leading them to increased feelings of frustration and depression. This booklet is for people with fibromyalgia and those who want to better understand the condition, including family and friends.

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WHAT IS FIBROMYALGIA?

Fibromyalgia is a syndrome, which means that it is a collection of signs, symptoms and medical problems that tend to occur together but are not related to a specific, identifiable cause. Fibromyalgia is characterised by widespread muscle pain and fatigue. The word fibromyalgia comes from the Latin term for fibrous tissue (fibro) and the Greek terms for muscle (myo) and pain (algia).

Tender points are particular body locations that are usually somewhat tender for anyone but where people with fibromyalgia feel pain in response to very slight pressure; these tender points are used in the diagnosis of fibromyalgia.

People who have fibromyalgia may also experience aching, stiffness and tiredness, which can be changeable throughout the day, getting worse with activity. Poor sleep quality and waking up without feeling refreshed is very common. Simple chores or activities may prove difficult to undertake because of muscular fatigue or lack of energy. Many people with fibromyalgia can experience emotional distress including anxiety and depression.

In addition, people with fibromyalgia may experience:

- cognitive and memory problems (sometimes referred to as 'fibro fog')
- poor circulation – tingling, numbness or swelling of hands or feet
- headache, irritability or feeling low
- irritable bowel syndrome and an urgency to pass urine.

Women are more likely than men to develop fibromyalgia, as 9 out of 10 people with fibromyalgia are women. Though it is more common to be diagnosed between the ages of 50 and 70 years, people of all ages have been diagnosed.

Fibromyalgia varies from person to person, the type and severity of symptoms you experience may vary greatly.

Fibromyalgia and ME

Myalgic encephalomyelitis (ME), sometimes referred to as Chronic Fatigue Syndrome, and fibromyalgia often display very similar symptoms. People with ME usually have less pain and can link the beginning of their symptoms to a viral infection.



WHAT CAUSES FIBROMYALGIA?

Fibromyalgia is an illness involving both the mind and the body and though we don't understand what causes fibromyalgia there is better understanding of the link between the physical and mental aspects of the condition. Many people associate the development of fibromyalgia with a physical or emotional trauma such as an accident or bereavement. Some associate it with an illness. People with rheumatoid arthritis, lupus or other autoimmune diseases may be more likely to develop fibromyalgia.

The amount of pain felt by a person with fibromyalgia is often affected by the way they are feeling, and the reverse is also true. Feeling depressed, stressed or anxious may make the muscular pain feel worse, which may in turn add to the stress and anxiety.

'Whatever you do during the day ask yourself if it will contribute to a good night's sleep'

Brain wave studies (electroencephalography, or EEG) during sleep have revealed that people with fibromyalgia often lose deep sleep. In an experiment, some healthy people who were woken up in each period of deep sleep experienced the typical symptoms and tender points associated with fibromyalgia.

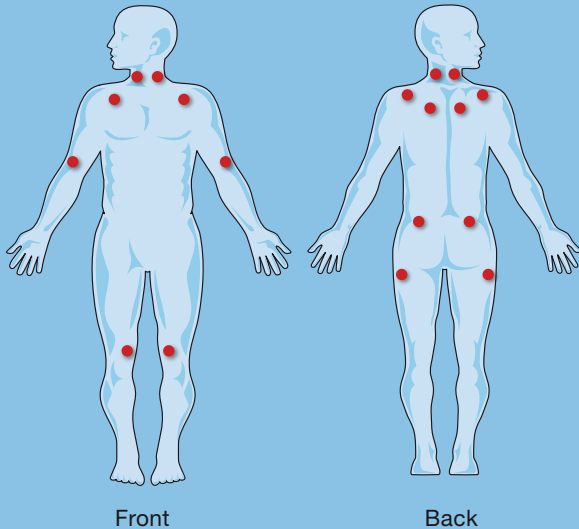
People with fibromyalgia may experience sleep disturbance because of many reasons. The pain or stiffness usually associated with fibromyalgia and other conditions may cause discomfort. Worry or stress brought on by events or relationships at home or at work may also be important factors.



Research has been carried out showing that patients with fibromyalgia experience increased sensitivity (known as sensitisation) to pressure or relatively minor knocks, which would not normally be painful. To some extent this may be related to chemical changes in the nervous system, but this is not fully understood.

If you think that you may have fibromyalgia or if you have been recently diagnosed, you could benefit from calling Arthritis Ireland's Helpline for support and information. The lines are open **Monday to Friday, 10am to 4pm** on **LoCall 1890 252846**.

Fibromyalgia Tender Points



GETTING A DIAGNOSIS

As research continues, fibromyalgia is being diagnosed quicker and more often. There is no test that can be done to detect fibromyalgia as the main symptoms, pain and fatigue, overlap with many other conditions and are not measurable by any test unless they cause damage or inflammation. Therefore, doctors often have to rule out other potential causes of these symptoms before making a diagnosis.

Making a diagnosis is based on a history of widespread pain lasting more than 3 months and the presence of tender points. Pain is considered to be widespread when it affects all four quadrants of the body; that is, you must have pain in both your right and left sides as well as above and below the waist. There are 18 standard tender points that are used to identify fibromyalgia. For a fibromyalgia diagnosis, a person must have 11 or more of these tender points (see illustration above). A tender point is confirmed only if the person feels pain upon the application of 4 kilogrammes of pressure to the site. People who have fibromyalgia certainly may feel pain at other sites too.

TREATMENT AND TAKING CONTROL

How is fibromyalgia treated?

As fibromyalgia is a syndrome it may be difficult to treat. Your GP or rheumatologist will be the primary source of this treatment, referring you to other health professionals including a psychologist, physiotherapist or occupational therapist as needed. You will be required to play an active role in controlling your fibromyalgia, working together with your health professionals. There is no cure, but the symptoms may be managed very successfully.

Pregbalin (trade name Lyrica) was the first drug approved to treat fibromyalgia but your doctor may treat fibromyalgia with a variety of medications developed and approved for other purposes.

Some of the most commonly used categories of drugs for fibromyalgia are:

Painkillers (analgesics)

Painkillers come in varying strengths and are used specifically to relieve pain. Paracetamol is a readily available painkiller which you can buy over the counter at a pharmacist. It is the simplest and safest painkiller – providing you follow the correct dosage instructions – and it is often the best ‘over-the-counter’ medicine to try first. Some anti-inflammatory drugs such as aspirin and ibuprofen can also be used as painkillers in low doses. Stronger painkillers – including morphine, buprenorphine, codeine, diamorphine, dihydrocodeine and pethidine – are generally only available on prescription.



Analgesics are usually taken by mouth or given by injection. However, slow release painkilling patches, known as opioid patches, are also available although not widely prescribed. These are put on the skin and the pain killing effects last between three and seven days. The patches are used on people whose pain is not managed with non-steroidal anti-inflammatory drugs (see below) or analgesics.

What you should know

Nausea, vomiting, drowsiness, constipation and occasionally breathing difficulties are all possible side effects of this stronger type of painkiller and these medicines may become less effective if used long term. If your pain is masked by painkillers it is possible to damage or over-use muscles and joints without noticing, so care is needed.

NSAIDs

Non-steroidal anti-inflammatory drugs – NSAIDs for short – may be prescribed. They are often taken alongside painkillers. They function by relieving pain and stiffness, and reducing inflammation. Inflammation is the body's response to injury and is in fact designed to help with the healing process. The number of different NSAIDs can be confusing, especially as each one often has more than one brand name. The most commonly prescribed NSAIDs are:

Ibuprofen:	Brufen/Nurofen and others
Diclofenac:	Voltarol/Diclomax/Difene
Indometacin:	Indocid and others
Naproxen:	Naprosyn and others
Piroxicam:	Feldene
Nabumetone:	Relifex

NSAIDs are usually taken by mouth, but may also be prescribed in suppository form or supplied as creams and gels which you rub onto the skin over painful areas. Your doctor will advise you on which is the most appropriate anti-inflammatory to take. Some must be taken several times a day, while others have a slow release action and only need to be used once a day. A low dose is usually prescribed at first and increased if necessary.

What you should know

While many have no problems with these drugs, some NSAIDs can cause side effects such as damage to the stomach lining, heartburn, indigestion, rashes and wheeziness.

You can help minimise side effects by making sure you take the tablets with or after meals. You can also help by keeping alcohol to a minimum and not smoking.

Antidepressants

Antidepressants, prescribed at much lower doses than would be used to treat depression, have also proved to reduce pain and fatigue in people who have fibromyalgia. This is done by elevating the levels of particular chemicals in the brain, including serotonin and norepinephrine. It is important to remember that anti-depressants need to build up in your system and therefore take time to reach their maximum benefit so patience is needed. Do not stop taking your medication without consulting your doctor.



Tricyclic antidepressants such as Amitriptyline, in dosages lower than those used to treat depression, can help promote restorative sleep in people with fibromyalgia. They relax painful muscles and heighten the effects of the body's natural pain-killing substances called endorphins.

Selective serotonin reuptake inhibitors (SSRIs) may reduce fatigue and some other symptoms associated with fibromyalgia by promoting the release of serotonin. The group of SSRIs includes citalopram (Cipramil), escitalopram (Lexapro), fluoxetine (Prozac), fluvoxamine (Faverin), paroxetine (Seroxat), sertraline (Lustral) and venlafaxine (Efexor). SSRIs are rarely prescribed alone for fibromyalgia as they can make people feel more energetic which can be counterproductive. They may be prescribed with a tricyclic antidepressant to allow for this.

Other Medications

Doctors may prescribe other medications depending on a person's symptoms or fibromyalgia-related conditions. Gabapentin (Neurontin) is currently being studied as a treatment for fibromyalgia. Other symptom-specific medications include sleep medications, muscle relaxants, and headache remedies.

Self-Management

People with fibromyalgia may also benefit from physiotherapy, from learning pain management and coping techniques, and from properly balancing rest and activity. You can learn more of these skills on one of Arthritis Ireland's self-management programmes. *Living Well with Arthritis*, our most popular course, focuses on what you can do for yourself, how to get the most from your health professionals, handling pain, fatigue and depression, relaxing and keeping active. It is a great chance to meet and share tips with other people who know what you are going through.

'Having participated in the Living well With Arthritis course it dawned on me that I could no longer wait for someone to fix me. If I wanted to improve my situation I would have to make changes in my life and in my approach to it'

Arthritis Ireland also run a *Breaking the Pain Cycle Programme*, a *Working with Arthritis Programme* and workshops for young people – all delivered by people with fibromyalgia and arthritis. For more information about Arthritis Ireland and the services we offer visit www.arthritisireland.ie.

Complementary Therapies

As their name suggests, these types of therapies are designed to complement and work alongside conventional medicine and treatments – not replace them. They concentrate on treating the whole person. Even if your usual drug

treatment is working well, you may be curious to know why many people living with fibromyalgia are choosing to explore therapies like acupuncture, aromatherapy and reflexology, and want to know whether you could benefit too. The wide choice of complementary therapies can be bewildering, but they all have a common goal: to treat the person, not the condition itself.

Like conventional medicine, though, complementary therapies cannot offer a cure. Unlike conventional medicine, there is very little scientific evidence to support these therapies. However, many people claim they help alleviate symptoms such as pain and stiffness, as well as counteract some of the unwanted side effects of drugs.

Arthritis Ireland's booklet '*Drugs and Complementary Therapies*' and www.arthritisireland.ie contain more information on the topic.

'When my fibromyalgia flares, gentle stretching, exercise and rest in patient moderation, taken in combination and response to my own body, helps me heal'

Will fibromyalgia get better with time?

Fibromyalgia is a chronic condition, meaning it may last a lifetime. However, it may settle down by itself, but this can take weeks, months or years. Unlike arthritis it is not a progressive disease, it is never fatal, and it won't cause damage to your joints, muscles, or internal organs.



What can I do to try to feel better?

Taking Control

Learn about fibromyalgia – Find out if there is a local support group in your area, sharing the frustration of having this condition and knowing that other people out there have similar problems can be enormously helpful. Arthritis Ireland can provide you with details of their support groups that meet all around the country.

Involve your family – Your illness will be affecting them too. Ask them to read this booklet and encourage them to discuss your condition with you so that they can understand how and when to help you.

Get enough sleep – Many people with fibromyalgia have problems such as pain, restless legs syndrome, or brainwave irregularities that interfere with restful sleep.

To help get a good quality night's sleep avoid alcohol, tea and coffee late at night and keep regular sleeping patterns – going to bed and getting up at the same time every day – even on holidays and at weekends. Take some time to relax before bed and prepare for rest.

Exercising – Exercising may hurt at first and make you feel tired but it has been shown to greatly improve the symptoms of fibromyalgia. Begin slowly, even ten minutes a day. Don't overdo it, pace yourself and build up gradually to at least 3 hours a week. Experiment with different



exercises to find an activity that suits you. Avoid exercising within 3 hours of your bedtime as it can be stimulating and keep you awake. It may be helpful to work with a physiotherapist to design an exercise programme suited to your needs and lifestyle.

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.

Making changes at work – Most people with fibromyalgia continue to work. Some people cut down the number of hours they work, switch to a less demanding job, or adapt a current job. The best policy is to be positive, honest and clear about your needs, and help people understand what fibromyalgia means for you. If you face obstacles at work, such as an uncomfortable desk chair that leaves your back aching or difficulty lifting heavy boxes or files, your employer may make adaptations that will make things easier. An occupational therapist can help you design a more comfortable workstation or find more efficient and less painful ways to cope with your working environment.

FÁS offer many schemes, job and training opportunities to help you find and retain work. Through FÁS you can access a wide range of supports for people with disabilities in employment; including adaptation grants, disability awareness training for your employer and grants to help you stay at work when you 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 website www.fas.ie.

The *Working with Arthritis* programme, run by Arthritis Ireland is a course for people with arthritis or fibromyalgia who are looking to return to work or who are currently in employment, education or training and seek support in facing the challenges of the workplace.

Eating well – No particular diet has been shown to help fibromyalgia though it is important to have a healthy, balanced diet. Not only will proper nutrition give you more energy and make you generally feel better, it will also help you avoid other health problems. For more information see Arthritis Ireland's booklet '*Healthy Eating and Arthritis*' or visit www.arthritisireland.ie.

'Helping to organise and run a fibromyalgia support group along with two other people with fibromyalgia has given me an opportunity to experiment, discover and get the support I need'

De-stress – Address any sources of stress, worry or anger. Your GP may be able to refer you for counselling. It is important to keep in touch with others, particularly if you are on sick leave.

Relaxation – A relaxed body and mind will feel less pain. Try to ensure you have some relaxing activities. You can also learn to practice relaxation, which is a lot more focused and effective. Techniques such as meditation and deep breathing are examples of this. An occupational therapist can teach you a range of relaxation techniques.

Soft-collars – May be worn while you sleep to help you feel more comfortable, it is important not to get into the habit of wearing them during the day. A physiotherapist may be able to advise you on their best use.



PRACTICALITIES

At Home

Simple changes around the home will make everyday tasks easier. You might consider rearranging your cupboards so that the most used items are easy to reach or using a seat in the kitchen when preparing food. There are many items now available to help with difficult tasks. Arthritis Ireland's *Easy to Use Programme* provides information and advice on practical, easy to use products and services that can make it easier for you to live day to day with your arthritis. Visit www.arthritisireland.ie for further details on these products.

Driving

There are a few things you can try 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's National Mobility Centre (tel: **045 893 094** www.iwa.ie) and the Disabled Drivers Association of Ireland (tel: **094 936 4054** 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.

You may be able to apply for state benefits to help with the extra costs of having arthritis or if you 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. Your PRSI contributions or credits must be up to date.
- **Invalidity Pension:** Invalidity Pension is payable for as long as you are 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 you transfer to the State Pension (Contributory).

Other benefits: Living Alone Increase is payable regardless of age if you live alone. You may also qualify for free travel and the Household Benefits Package which includes allowances towards household bills.

Rehabilitative work: You may be allowed to do rehabilitative or therapeutic work (maximum 20 hours a week) and retain your Invalidity Pension. You must get prior written approval from the Department of Social and Family Affairs before you start work.

- **The Treatment Benefit Scheme:** A scheme run by the Department of Social and Family Affairs 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. You may be entitled to Disability Allowance if you are aged between 16 and 66, satisfy both a means test and a habitual residence test, and have a specified disability which results in your being substantially restricted in undertaking suitable employment. Your means and that of your spouse or partner are taken into account. Your parents' means are not considered. You may qualify for a Living Alone Increase and the Household Benefits Package which includes allowances towards household bills.

If you are awarded Disability Allowance, you get a Free Travel Pass automatically. This allows you to travel for free and your spouse or partner to travel free in your company. If you are medically assessed as being unable to travel alone you 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 you may qualify if your income is not much above the guideline figure and your 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 Cards:** The purpose of the card is to help people who are not eligible for medical cards with the costs of visiting a doctor. The card covers you 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:** You may get tax relief on certain health expenses, which you have incurred and for which you 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.

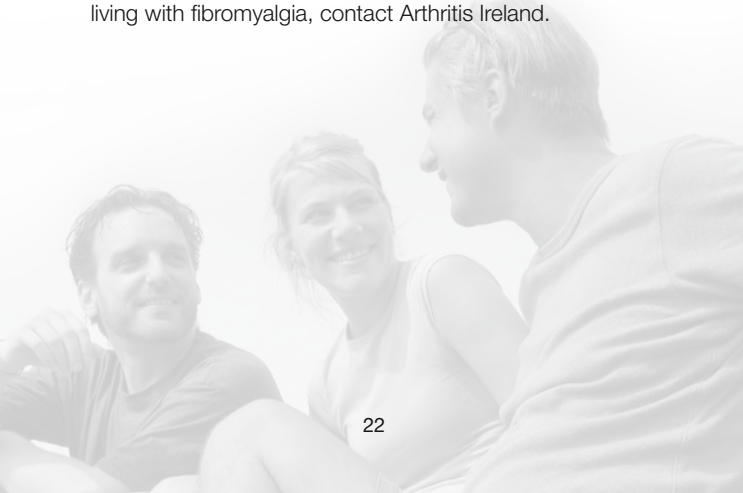
Claiming benefits can be complicated and time-consuming, so it's worth getting expert help and advice from:

- 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 & Family Affairs: **LoCall 1890 20 23 25**
- online at www.hse.ie.

It is possible to control your fibromyalgia rather than letting it control you. If you have any questions about living with fibromyalgia, contact Arthritis Ireland.



For further information on how **Arthritis Ireland** can help you live your best possible quality of life, contact us on **LoCall 1890 252846** or visit our website at www.arthritisireland.ie.



5 Great Reasons a friend

Sign up today for

to become
of Arthritis Ireland
just €3 a month

A person with arthritis who is well informed about their condition is more likely to lead a better quality of life*. Becoming a FRIEND of Arthritis Ireland is an easy way of staying up to date while helping us to make a real difference to the lives of people living with arthritis.



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.

* Research by: People with Arthritis/Rheumatism in Europe (PARE).

** Free gifts are subject to change and supply.

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. ☐

☐ Payment by **Standing Order:**

Standing Order is cost effective, convenient, and confidential, please fill in details below

Bank Name:

Bank Address:

Your current account no:

Sort Code:

 - -

Name of account holder:

Address (if different than above)

Signature:

Date:

Please pay to: AIB, 52 Upper Baggot Street, Dublin 4, Sort: 93-10-63, for the credit of Arthritis Ireland.

Account no: 00373035 **Reference:** Arthritis Ireland Friends

☐ Payment by **Cheque** or **Postal Order:**

Please make payable to Arthritis Ireland

☐ Payment by **Credit Card:**

Please charge my: VISA / MasterCard / Laser
(please circle)

Credit Card Number:

Expiry Date:

CW: (3 digits on reverse)

**Please return to: Arthritis Ireland, Freepost,
1 Clanwilliam Square, Grand Canal Quay, Dublin 2.**
Using a stamp on your return envelope will help us save costs.

Arthritis Ireland
1 Clanwilliam Square
Grand Canal Quay
Dublin 2

Helpline LoCall 1890 252 846
Email info@arthritisireland.ie
Web www.arthritisireland.ie

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