

Arthritis Ireland
Inform. Enable. Empower.



Let's Talk Arthritis

Getting the most from
your appointment





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.

An Introduction by Prof. Geraldine McCarthy, Consultant Rheumatologist

Communicating effectively with your rheumatologist will allow you to share information and work together to make the best decisions about your health. This will result in the best possible care for you. It is important to know the right questions to ask your rheumatologist.

It is also really important that your rheumatologist, for example, knows about the things that are worrying you, such as the level of pain you are experiencing, where the pain is and whether the pain is getting worse. Discuss your medication and treatment with your rheumatologist, for example, are you experiencing side effects or is the medication working?

This booklet, along with Arthritis Ireland's website and helpline, help you to fully prepare for your appointment.

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DURING THE CONSULTATION

The Statistics

What do patients learn from their consultation?

Access to rheumatologists in Ireland is limited compared to other countries in Europe. A patient can wait a long time before their first appointment. A survey was conducted by Arthritis Ireland to learn more about patient's experiences during the consultation and also to see if areas can be improved. Below are some of the results that have been obtained from the survey:

- around 27% of patients surveyed felt that their condition could be explained better
- 33% felt that information on their treatment could be better
- in almost 40% of cases, no printed information was passed on to them or the printed information was poor
- almost half of the patients surveyed occasionally or never prepared for their first visit
- during the visit 33% of patients sometimes or never asked questions and almost 80% occasionally or never took notes
- in more than 81% of cases patients occasionally or never took somebody with them to the consultation, yet in around 38% of cases someone else's presence would have been appreciated or helpful
- two out of three people did not take a leaflet away from the consultation explaining their disease. Yet around 67% would find a leaflet useful.

The survey was conducted amongst a representative sample of people who are members of Arthritis Ireland.

BEFORE THE APPOINTMENT

Get the most from your appointment

Planning before you see your doctor:

1. Be prepared. Before your appointment write down your questions, items to discuss, and any changes in your condition. If you are organised you can make the best use of your time and your rheumatologist's expertise.
2. Be confident. Don't be afraid to ask questions. This will help you understand what is going on. If something is confusing then repeat it back to the doctor and ask him/her to explain more clearly. Seeing your x-rays or using diagrams can often help. If there is something you want to know then ask!
3. Bringing a family member or a friend can be very helpful. It will help you relax and also remember to ask the right questions. Moral support is always nice as is having someone to help you get around.
4. Think of ways to describe your pain and symptoms. You may be asked: Where are your symptoms? How much does it hurt? When did the stiffness start? Have things changed over time?
5. Make sure you have a list of things that have happened since your last visit. You may be asked: How are you feeling? Are you taking your medicine? How are things at home or at work? Make a note of the answers to such questions before you go to the appointment.
6. We have provided a 'pain scale' diagram on page 7 and some pages to make notes at the back of this booklet, which we encourage you to use to help discuss your symptoms, treatments and other matters relating to your arthritis with your doctor.



DURING THE APPOINTMENT

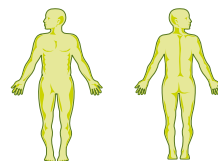
Steps to getting the most from your appointment

1. **Take notes.** Write down any important information or instructions. It is well known that up to half of what is said in the doctor's consulting room is forgotten. Keeping your own records will help you become more informed.
2. **Prioritise.** On many occasions things brought up during the last five minutes of an appointment are very important and can make a real difference. So introduce important topics as soon as possible in your conversation.
3. **It is important your doctor knows the whole story.** Make sure that you tell your doctor of any medication or treatment you are taking on your own, including the full extent of your pain and worries. Don't be embarrassed to share details.
4. **Make sure you tell your doctor of any complementary treatments you are using,** such as herbal medicine, acupuncture or massage therapy.
5. **Share information and decisions.** Let the doctor know if there are any problems with following their recommendations, such as financial concerns, conflicts with sleep, eating habits or daily schedule with work or study.
6. **Repeat key points.** Repeating things will also help your doctor to clarify anything that has been confusing and will help you remember what has been discussed.

PAIN MANAGEMENT

Mark the Figures where Your Pain Occurs

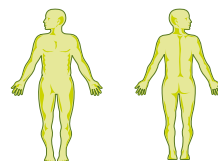
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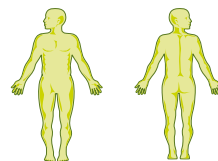
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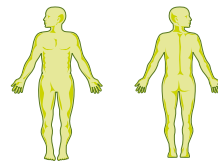
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Meeting Notes

Mark your pain from 1 to 5 below:



1



2



3



4



5

AFTER THE APPOINTMENT

Steps to getting the most from your appointment

1. Follow up if you need to. If you forgot to ask a question during your appointment, call the clinic to get an answer. You may not be able to speak with your doctor immediately however, you can leave a message for someone to call you back.
2. Remember there is no perfect treatment for everyone. It is important to understand that there is no single treatment that is best for everyone with arthritis. Try and keep an open mind on treatment options when working with your doctor.

REMEMBER TO TAKE P.A.R.T.

Take P.A.R.T. in your consultation

- P.** Prepare a list of questions, concerns and symptoms to discuss with your doctor
- A.** Ask questions during your appointment so you understand your treatment plan
- R.** Repeat what your doctor recommends so you can be sure you understand
- T.** Take action to reduce any obstacles you may have in following your treatment plan.



FAMILY, FRIENDS AND COLLEAGUES

Many changes occur in the life of someone who must live with a chronic condition such as arthritis. It not only affects the person who has the disease, but also significantly impacts the people around them.

Marriage

Living with chronic arthritis can have a major impact on a marriage. As the arthritis develops, some activities may need to be curtailed. Social life is one thing that can be affected, the healthy spouse can become frustrated because their social life is impacted too.

Responsibilities may need to be transferred to another family member who can better handle it. This can create a stressful situation for both the person who must undertake more responsibility and the person who must admit to themselves that they have become more dependent.

Financial responsibility is another area which may require modification if the patient has been the main breadwinner in the family. In order to overcome these issues patience is required and the willingness to openly communicate fears, concerns, and anxieties. An understanding between partners must be achieved in order to continue working as a team.

Children

It is very important that parents talk to their children about the disease. When a parent has chronic arthritis and the children are still very young, the child will likely grow up approaching the disease the way they observe their parent approaching it. If the child observes acceptance, they will feel acceptance themselves. If they see you coping they are likely to adopt coping strategies themselves, however if they see or hear constant complaining then the child is likely to imitate this behaviour. It is difficult to accept as a parent you cannot do as much with your child, especially in the physical sense.

Focus on things that can be done together. Quantity of time spent together becomes secondary to quality time. Young children are unlikely to ask many questions about arthritis, be open to addressing their fears. Make it known to them that arthritis is not a fatal disease, and convey to them the feeling that everything is under control. Allow them to feel secure. Adolescents are able to read, learn, and understand more complex information. They are likely to have more questions about the disease and about the resulting family situation. Address all questions which adolescents might pose realising their need to understand the situation.

Work and Colleagues

Arthritis can have a big impact on a person's ability to work. People with arthritis may need to adapt their work situation to their disease. The severity of the arthritis coupled with employer support are key factors. You can compensate for much of the difficulty caused by arthritis if the relationship with your employer is communicative, respectful and honest. A relationship with an employer which is antagonistic or difficult is unlikely to produce cooperative results. Communicating your arthritis to work colleagues can also help create a good working environment. In order to continue working, it is important to continue the course of treatment you are on to keep the arthritis as well-managed as possible.



Younger People with Arthritis

Young people get arthritis too! This can be a shock to extended family and friends. Parents can sometimes feel guilty, confused and fearful. Brothers and sisters of young people with arthritis often feel overshadowed by their sibling's condition, and the amount of their family's time it takes up. This can lead to bickering, arguments and jealousy. Communication is key to overcoming these issues. Young people are particularly interested in long-term outcomes, future relationships and even pregnancy. Internet forums, discussion groups and help lines can sometimes help in understanding these issues.

For more information on relationships and arthritis, read Arthritis Ireland's booklet '*Coping with Emotions*', call the Arthritis Ireland Helpline on **LoCall 1890 252 846** between **10am and 4pm Monday-Friday** or visit **www.arthritisireland.ie**.

'Discussing how my arthritis affects our family has improved my relationship with them, we talk openly and regularly together'



GLOSSARY OF MEDICAL TERMS

Acute

Describing a disease of sudden onset

Arthritis

When there is joint pain, stiffness and swelling

Autoimmune

A situation when the body's own immune response system departs from normal operation and attacks components of the body itself

Bursitis

Inflammation of the protective 'cushions' between joints

Chronic

Describing a long term condition

Connective Tissue

Tissue that supports or binds other body parts and tissue

Contracture

Thickening and shortening of muscle or connective tissue causing a joint to deform

Deformity

Abnormal shape of joint or misalignment of two bones forming a joint

'I ask the doctor a lot of questions about my arthritis and medications. It takes a little time but I find it benefits me'

Fibromyalgia

Fibromyalgia is a syndrome predominately characterised by muscular pains and fatigue

Gout

Gout is an arthritic condition with elevated levels of uric acid in the blood stream leading to recurrent episodes of joint inflammation

Immune system

Protects us against infections and foreign substances. Our immune system seeks and destroys invading microbes

Inflammation

The way in which the body reacts to infection, irritation or injury through redness, warmth, swelling and pain

Psoriatic Arthritis

A form of arthritis associated with the skin disease psoriasis

Rheumatoid Factor

A blood test which may be positive with rheumatoid arthritis, can be present in the absence of any illness

Osteoarthritis

The 'wear and tear' form of arthritis and is uncommon before the age of 40

Rheumatoid Arthritis

A severe inflammatory form of arthritis

Synovitis

Inflammation of the membrane which lubricates joints

Systemic Lupus Erythematosus (SLE)

A chronic inflammatory condition caused by an autoimmune disease

DRUGS USED IN TREATMENT

Drug class

Non-steroidal anti-inflammatory drugs (NSAIDs)

Example:

Acetylsalicylate (Aspirin), naproxen, ibuprofen, and etodolac.

How they work:

Reduce tissue inflammation, pain and swelling.

Side effects:

Stomach upset, abdominal pain, ulcers, diarrhoea and even gastrointestinal bleeding.

Drug class

Corticosteroids

Example:

Prednisolone, methylprednisolone, dexamethasone.

How they work:

Orally or injected directly into tissues and joints. Particularly useful for short periods during severe flares of disease. They suppress the activity of the immune system.

Side effects:

Weight gain, facial puffiness, thinning of the skin and bone, easy bruising, cataracts, risk of infection, muscle wasting, and damage to bones of large joints, such as the hips.

Drug class

Disease-modifying anti-rheumatic drugs or DMARDs

Example:

Hydroxychloroquine/chloroquine, sulfasalazine, methotrexate, gold therapy, d-penicillamine, leflunomide.

How they work:

DMARDs have an effect on altering the progression of inflammatory arthritis and can promote healing.

Side effects:

Upset stomach, skin rashes, muscle weakness, and vision changes. Kidney damage with leakage of protein in the urine, and bone marrow damage with anaemia. Fever, chills, mouth ulcers, liver disease, diarrhoea. Tendency to infection and/or bleeding.

Drug class

Immunosuppressive medicines

Example:

Cyclosporin, azathioprine, methotrexate

How they work:

Immunosuppressive medicines suppress the activity of the body's immune system.

Side effects:

Depress bone marrow function. Can increase the risk of infections, can lead to liver and kidney disorder and allergic reaction.

Drug class

Biological Medications

Example:

Abatacept, adalimumab, etanercept, infliximab, rituximab, tocilizumab.

How they work:

Stop the inflammation process. Symptoms can be significantly, and often rapidly, improved in patients using these drugs.

Side effects:

Mild skin reaction at the site of the injection. Itchiness, redness and minor swelling. Headaches during intravenous infusion, and there may be an increased susceptibility to infection including TB.

Drug class

Dietary supplements

Example:

Gamma-linolenic acid (GLA), fish oil, glucosamine and chondroitin.

How they work:

GLA is an omega-6 fatty acid that is found in the oils of some plant seeds, including evening primrose. GLA can be used by the body to make substances that reduce inflammation. Fish oil contains high amounts of two omega-3 fatty acids. As with GLA, the body can use omega-3s to make substances that reduce inflammation.

Glucosamine and chondroitin are popular dietary supplements for arthritis.

Side effects:

Increased risk of bleeding or affect the time it takes blood to clot. Belching, stomach disturbances, and nausea.



For further information on how **Arthritis Ireland** can help you live your best possible quality of life, contact us on **LoCall 1890 252846** or log onto 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

Arthritis Ireland
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