

**Arthritis Ireland**  
*Inform. Enable. Empower.*



# Coping with Emotions



# About Arthritis Ireland

Arthritis Ireland provides real solutions. We empower people with arthritis and those caring for them to take positive actions to manage the effects of their disease on their lives.

We dramatically improve the quality of life of people affected with arthritis through the provision of innovative and life changing education and support programmes which are specially designed to give people with arthritis the information and skills they need to take back control of their disease and their lives.

We actively support research into arthritis to ensure that Ireland is at the forefront of new breakthroughs leading to possible cures.

We fund training of health professionals through university medical schools to create a direct and positive improvement in patient care.

We lobby key decision makers in Government departments to invest the necessary funding in rheumatology services to provide a world-class service that will positively change the outlook and outcome of patients' lives.



# Introduction

When you have arthritis, it is not just the physical symptoms that affect you. You will also experience a range of different emotions, which may change over time. Having the same disease as someone else does not mean that you will feel the same – either physically or emotionally. Just as everyone is different, so is their experience of arthritis: their symptoms are different and their feelings and emotions are different.

This booklet will outline what type of emotions you might experience and how to deal with these emotions as well as providing details of what supports are available.

It has been developed by Arthritis Ireland in response to the results of a survey on the effect of arthritis on well-being and relationships which revealed the significant impact that it can have on people's quality of life, reducing their ability to participate in social activities, causing sadness and depression and ultimately leading to social isolation. This research was kindly supported by an unrestricted educational grant from Schering-Plough Pharmaceuticals (Ireland).

Many people with arthritis have learnt to manage their condition, and gain back control of their lives with the right support.

Please remember that support is only a phone call away. You can call Arthritis Ireland's helpline on **LoCall** 1890 252 846 Monday to Friday from 10am – 4pm.

# Initial Diagnosis

When you are first diagnosed with arthritis you will probably experience a whole host of different emotions. The most positive and proactive thing you can do now is to get as much information about your condition as possible. Your doctor should be able to explain to you what type of arthritis you have and the likely impact it is going to have on your life going forward. He/she will be able to answer any queries you may have in relation to blood tests and x-rays, medication management and the role of the multi-disciplinary rheumatology team. Arthritis Ireland will be able to provide you with literature on your condition and the details of support services available to you.

**Below are some of the most common emotions that are experienced when you are first diagnosed.**

## **Shock**

On being informed of their condition initially many people just feel numb and do not take in much of what their doctor tells them. It may take a few days/weeks for the reality of the situation to sink in. This is a perfectly normal reaction.

## **Relief**

Strange as it may sometimes seem, many people feel a sense of relief when they are diagnosed with arthritis. A diagnosis of arthritis is often the culmination of a long and difficult journey. You may find that discovering what is causing your pain and fatigue and having a name for it is actually a relief as it enables you to inform yourself about it and therefore deal with the disease. It is also good to know that there are treatments for your condition.

## **Confusion**

Understanding what arthritis is and why you have been diagnosed with it can cause a lot of confusion and anxiety. This is why it is extremely important to get as much information as possible from your doctor and to inform



yourself about your disease. Arthritis Ireland's website [www.arthritisireland.ie](http://www.arthritisireland.ie) and its LoCall helpline can provide you with information about your arthritis.

### **Fear**

When you are first diagnosed with arthritis, it can be a very frightening time. You may be afraid of the pain associated with the condition, the medication you may have to take and the effects it will have on your job and family. It is important not to become overwhelmed at this point and not to panic, but instead to focus on what you can do to overcome these fears. As you learn more about your condition and begin to recognise your fears you will be in a much stronger position to manage them.

### **Disbelief**

When you learn you have arthritis, you may find it difficult to believe. Try to give yourself some time for the idea to settle in and for you to get used to it.

### **Denial**

Many people pretend that they are fine, and find it difficult to accept. However, the longer you put it off, the longer it will take you to adjust. Many people find that talking to others, particularly other people with arthritis is very valuable in helping them to accept their condition and adjust their lives.

### **Anxiety**

As with fear, anxiety may be experienced when you contemplate the impact that arthritis may have on your life. When you experience extreme anxiety, you may become

short of breath and your heart may beat rapidly. You might feel uneasy and unable to relax, and trying to calm yourself down does not help. Some people experience panic attacks which occur when the level of anxiety becomes too much. You can prevent anxiety developing into a panic attack by using relaxation techniques, or perhaps by challenging the negative thinking behind your anxiety. You could talk to a counsellor about relaxation techniques.

### **Frustration**

Feelings of anger and frustration may also be experienced around this time. Gaining an understanding of your condition and speaking to doctors, family and friends may help ease these feelings. Try to focus on what is causing the frustration, and try to accept that some things may change now that you have arthritis. Using relaxation techniques and doing things that you enjoy will help.

### **Sense of Loss**

As realisation of your condition sinks in, you may experience an intense sense of loss. This sense of loss can occur when you are worried about future changes in your personal and domestic circumstances as a result of being diagnosed with arthritis. The realisation that things may never be the same can be extremely daunting and upsetting but these feelings, once acknowledged and addressed, can be channelled in a positive way.

### **Depression**

Learning that you have a chronic condition may cause feelings of anger and depression. Depression may present as feelings of helplessness and being alone, hopelessness, anger, sadness and despair, mood swings, problems sleeping and lack of appetite. It is not unusual for younger people to feel especially angry or depressed at being diagnosed with a disease that is mistakenly thought to affect only older people.



Depression can range from being a mild problem to a very severe one. The physical symptoms of arthritis like pain and fatigue can cause many people with arthritis to feel depressed. Unfortunately, feeling depressed can make it very hard for you to manage your arthritis effectively.

If you think you are depressed, it is very important to consult a health professional. With the right treatment and support, most people learn to manage their depression. Recognising that you may be depressed and need help is a step in the right direction and vital in learning how to manage your arthritis.

### **What You Can Do to Manage Depression**

- Inform yourself about your arthritis as much as possible, it will help you regain a sense of control over your condition.
- Taking care of your emotional wellbeing and accepting that you may have to adapt some areas of your life is important. Accepting this will enable you to move on. Consider the benefits of discovering new hobbies and try not to focus on the loss of some activities which may be more difficult for you now.
- Give yourself time to understand that feelings of depression and loss are a natural process, but don't get stuck there. Be honest about your feelings and if you need help, ask.



- If thinking about the future makes you unhappy, then don't think that far ahead. Sometimes focusing on the here and now will get you through.
- Exercise is not only extremely beneficial for arthritis, it can play an important role in the treatment and management of depression as it releases endorphins, 'feel good chemicals', and can take your mind off your situation.
- Allow yourself to feel tired. You needn't feel guilty about the things you haven't done or can't do. When you need to rest, rest.
- Talk about your situation with someone you trust, whether a family or friend or a health professional.

“I try not to allow my arthritis to interfere with my mental health. I work hard at keeping my outlook positive.” Joe (33)



# As Time Goes On...

As time goes on and the arthritis evolves so too do the emotions you may experience. These can often include:

## Acceptance

This is a very powerful positive emotion. Once you gain understanding and acceptance of your arthritis you have the freedom to concentrate on other aspects of your life.

## Guilt

People living with arthritis can often feel a sense of guilt about their situation and the limitations and effects it can have on them and those closest. It is important to recognise that you could not have predicted or prevented your arthritis. Open communication is very important here so that your family and friends understand how you are feeling emotionally.

## Boredom

Not being able to take part in some aspects of work, hobbies or family life as actively as you used to can leave you with a lot more spare time on your hands. It's important that you come up with other ways of staying active and enjoying your time that will not interfere with or aggravate your arthritis. Choose a hobby that you have always wanted to take up, and one that suits you whether playing a musical instrument, joining a book club, taking up art or going to the cinema.

“I have art class and swimming two days a week. It's often not easy to get up and get out but I always feel better after it.” Lucy (57)

## Anger

Often people living with arthritis experience thoughts and emotions such as 'why me'? These feelings of anger and resentment are common and perfectly natural. They will tend to diminish with time, the more acceptance is gained.

## Stress

While stress is a part of everyday life, sometimes it can get out of hand. Thinking about arthritis might cause you to feel stressed about the future, whether your medications are correct for you and what treatment you may need. Stress is exhausting. When we exercise, we use our energy stores in a healthy way to feed and revive our minds and bodies.

## What Can You Do to Cope with Stress?

- Exercise regularly, whether swimming, walking or stretching exercises. If you're not sure what exercises are suitable for your condition, Arthritis Ireland's exercise book and DVD 'Be Active with Arthritis' provide exercises that are tailor-made for people with arthritis.
- Try using relaxation techniques, such as breathing exercises and meditation to focus on other things.
- Get enough sleep: sleep is essential to give your body time to recuperate and rest.
- Try to identify what is causing the stress, and what your triggers are, so that you can eliminate them from your life or concentrate on reducing their impact.

## Lack of Control

Many people living with arthritis find that they have to live with uncertainty. Because the disease can improve or disimprove at any time, it is often difficult to make plans. Some days it's possible to do everything you would have done before, while other days it's difficult to do even the simplest of tasks. Talk with your family and friends to prevent misunderstanding, and take

control of your condition by learning to manage its effects. Arthritis Ireland runs a range of self-management programmes, which enable people with arthritis to gain control of their condition. These are held in various locations throughout Ireland each year, so contact us to find out if one of these may be suitable for you.

### Loneliness

It's possible you might feel left out or unwell because of your arthritis. Sometimes you might think that people don't understand you or the effect that your arthritis has on you.

1 in 3 people say they feel less confident socially because of their arthritis.

Some people with arthritis can push others away because of a fear of rejection or of developing new relationships, some simply get into a habit of not spending time with others like they used to. One way to end loneliness is to try and get out and about as much as you can. Reach out to those nearest to you to explain how you are feeling and seek support. If you can't get out, use the telephone or internet to stay in contact with people. If you find it difficult to meet others, consider getting involved in activities in your local community, or perhaps enquire if there's a local branch of Arthritis Ireland in your area.

“I now make the most of the things I can do.” Sean (61)

# Relationships

One of the most difficult aspects of dealing with arthritis is often the effect that it can have on your relationships. This can include your relationships with your spouse, partner, children, friends and colleagues. One of the most successful ways of managing all these relationships is to be as open as possible about your condition and the impact that it has on you and your quality of life. Encouraging understanding of arthritis promotes acceptance, especially within a work environment.

Poor communication is the biggest factor in poor relationships, whether between partners, family members, friends, co-workers or doctors and patients. When you have a chronic condition such as arthritis, communication is extremely important. Remember that communication is a two way street, and it's up to you and those you interact with to keep the lines of communication open.

2 out of 3 say they can talk to people close to them about their pain.

## You and Your Doctor

Having an open and honest relationship with any health professional you deal with, whether your GP, rheumatologist, nurse, physiotherapist or occupational therapist is vital to ensure that you get the best care and advice possible. It is important that you provide as much information as possible on how you are being affected by your arthritis, to be honest and open and also to ask as many questions as possible about your condition. Think of ways to describe your pain and your symptoms and prepare well in advance for any appointments you have. This helps create a greater understanding of your condition, which in turn allows you to manage it better.



### Partner/Spouse

It is important that your partner/spouse is fully informed of your condition and how you are physically and emotionally affected by it in order for them to offer you the physical and emotional support that you need. Living with a chronic condition can have a major impact on a relationship, but openness and honesty can bring you closer. If your relationship has lost some of its closeness, you could rediscover it by sitting down and going through things that you would appreciate, however trivial they might seem. Your partner may not understand your pain and might not know how to approach you or when is best for you to discuss things. In this instance, it's very important to explain the impact of your arthritis, and to establish a way of discussing how it is affecting you as time goes by.

Having arthritis can put a huge strain on physical relationships too. If you are in pain, stiff, or exhausted, it is difficult to show affection and be intimate with your partner. Although you may want to, sometimes you may not be able to get as close to your partner as you would like. It may be useful to try different positions when making love that are more comfortable for you both. Hot baths and gentle massage can help you relax and can help loosen your joints before you make love. Always try to make time in your week to concentrate on your relationship with your partner.

Remember that you can discuss these issues with your partner or another person.

3 out of 4 say their spouse has a good understanding of their condition.



## Children

If you are a parent of young children or adolescents they will have to come to terms with the impact of your condition and the limitations it may put on your quality of life. Again the most positive way of helping them deal with this situation is to provide them with as much information on arthritis as possible and answer any questions they may have as best you can. Use language that they will understand and let them see how you are coping with it. Once your child sees you dealing with arthritis in a positive way they are more likely to deal with it in the same way especially if they understand the disease, its symptoms and how it affects you. It is difficult to accept that you might not be able to do things you used to do with them, such as playing or outdoor activities. One way of dealing with this is to focus on the things you can do together.

2 out of 3 people feel their children have a good understanding of their arthritis.

**“My children understand my condition. They help me and I help them with the things I can do.”** Catherine (37)

## Friends

In order to maintain friendships it is very important to be as open as possible with your friends about your arthritis and how it affects you physically and emotionally. If they can appreciate the type of physical pain that you experience they will understand how you may not always be ok to socialise like you used to or play sport. Being able to communicate openly with friends is really vital for people living with arthritis.

## Parents

Your parents might find it difficult to deal with your arthritis, especially if they are healthy themselves. As with other people in your life, it's important to talk to them about your condition and to encourage them not to worry too much, and not to fuss over you in a way that's not helpful to you.

## Colleagues

You might spend more time with your work colleagues than those closest to you, so it's important to consider your relationships with them. If employers are aware of and understand your arthritis, they can prepare for it and respond appropriately. Arthritis Ireland's Working with Arthritis programme is aimed at people with arthritis who are working or seeking a return to work.

4 out of 5 say their employer and their colleagues know about their arthritis and are supportive. It doesn't prevent them from fitting in with their colleagues.

“Because of my arthritis I have adapted how I work. I don't see this as a bad thing as many things change in life, not just our health.”

Maria (25)



# Coping Techniques

There are plenty of actions you can take to at least minimise if not eliminate a lot of the negative aspects of arthritis.

## **Positive Mental Attitude**

The first step in dealing with both the physical and emotional effects of arthritis is having a positive attitude as much as possible. It won't always be easy. However, it is essential in managing your condition effectively that you are optimistic and positive about yourself, your future and your arthritis. It is important to remember that this is your condition and you control a lot of its effects.

## **Laughter**

Laughing is a great way of making yourself feel better. When we laugh, feel good chemicals are released in the brain, and these chemicals block pain and help us feel better. It's not always easy to laugh or to keep a happy demeanour. You could keep a stack of comedy DVDs or books handy – anything that helps you see the funny side of things and lightens your mood.

## **Exercise**

Regular exercise serves to benefit both the body and the mind. It is a good idea to develop an exercise programme with a doctor/friend or family member that is appropriate to your lifestyle. Regular exercise will serve to relieve stiffness, maintain or restore flexibility and improve your overall sense of well being. Exercising is often more



“I realise that I need to exercise more and get out and do things.”

Helen (41)

enjoyable when done with a family member or friend and they can also serve as your motivator when you may not be feeling up to it! Remember that Arthritis Ireland's exercise book and DVD, 'Be Active with Arthritis' contains gentle exercises and stretching movements that are specifically developed for people with arthritis.

### Massage

Massage can help relax the muscles and improve their condition by increasing the blood flow. This can provide temporary relief from localised pain. You could ask a partner/friend for a massage or go for a professional therapeutic message. Remember to get the approval of your health professional before you get any massage, as each person experiences their arthritis in a different way and the effect that massage has on them is different.

### Sleep

Getting a good night's sleep restores your energy and improves your ability to manage your pain both physically and emotionally. It is important that both your bed and pillow are supportive to ensure your body is benefiting fully from the rest. Often a brief nap may be all you need to replenish your energy levels and rest your joints and mind.

### Relaxation

Learning to relax your body and mind properly is essential in managing your pain with arthritis. When we are tense, our muscles compress our joints and as a result they hurt and the joints are painful. Developing the ability to relax can help you reverse these effects. Some of the more effective ways of relaxing may include deep breathing, meditation, walking or swimming. Everyone has different methods of winding down but it is particularly important for anyone affected by arthritis to find an outlet that will allow both their body and mind to rest regularly.

## Treating Yourself

Giving yourself the “feel good” factor is important for all of us but especially so when we may be feeling dragged down emotionally by our arthritis. When feeling low, it is important to remember you owe it to yourself to pick yourself up and do something kind for yourself. This might just mean sleeping for an extra hour or visiting a friend. The list is endless and so are the benefits!!

## Asking for Help

Often people don't know what they can or should do to support someone with arthritis, so it's up to you to let them know and to discuss it openly with them. You could consider giving them some of Arthritis Ireland's information leaflets, which contain information and advice on living with various forms of arthritis.

Sometimes it helps to talk to someone you don't know. Arthritis Ireland's helpline is manned by people who are living with arthritis and is the first of its kind in Ireland, providing vital emotional and practical support and information to people affected by arthritis. The helpline supports people who have just been diagnosed or who are living with arthritis for some time, their family members and friends who want to know how to support a loved one, and health professionals.

Because every member of the helpline team has experience of living with arthritis themselves, callers can be sure they will speak to someone who understands what it's like to have arthritis and the issues that they face in their daily lives. Arthritis Ireland is encouraging people with arthritis, their families and carers to contact the helpline between 10am and 4pm Monday to Friday on **LoCall** 1890 252 846 for the price of a local call. People can call the helpline for all sorts of information including how to manage pain, information about specific conditions, types of medication and treatments available, identifying what exercise or diet may be appropriate and how to manage living with arthritis on an emotional level.



## Supports Available

Living with arthritis means that you will need both emotional and practical support from time to time. The following are just some of the supports available to you:

### **Arthritis Ireland**

Arthritis Ireland is working towards a future where everyone with arthritis and those caring for them are empowered to take positive action to manage the effects of the disease by providing the practical and emotional support needed to help people take back control of their disease and their life. In addition to the helpline, they provide a range of self-management programmes nationwide, a quality quarterly magazine prepared specifically for people with arthritis and regularly hold information talks around the country. They also have a vibrant branch network of volunteers who provide support to people locally living with the condition.

### **Doctor**

On initial diagnosis your GP will be your first port of call with any queries you may have. They should be able to explain your condition in as much detail as you wish and they will also be able to provide you with details of support services available.

## **Rheumatology Clinic**

The doctors, nurses, physiotherapists, occupational therapists and administrative staff are there to provide you with the support you need to manage your arthritis. Some rheumatology clinics have telephone advice lines, which are operated by the rheumatology nurse. Check what resources your rheumatology clinic provides next time you have an appointment.

## **Occupational Therapist**

An OT will be able to give practical advice on everyday tasks such as washing, dressing and cooking. They can recommend special equipment to you that may make life easier and help make simple tasks more enjoyable.

## **Physiotherapist**

A physiotherapist will be able to recommend and help you implement a fitness plan that will improve your joint & muscle movement, posture and how you move around in general. Treatment and advice may include exercise, hydrotherapy, mobilisation techniques, acupuncture and forms of pain relief.

## **Family/Friends**

Most importantly, your family and friends are essential in offering you the emotional support that you require. As mentioned, the more they understand about arthritis, the more support they will be able to offer you. It is important that you keep them informed about what stage your arthritis is at and how it is currently affecting you, both physically and emotionally.

# Looking to the Future

Taking into consideration the pain and stress that arthritis can cause you and your family, the future may at times look very bleak. However this does not need to be the case. There are substantial steps that you can take in order to control your arthritis and craft a future that you desire.

## **Accept Your Situation**

Once you learn to accept the reality and implications of your condition you will start to make decisions that are better for you and will ultimately improve your life.

## **Setting Goals**

By setting both short and long term goals you are giving yourself something to both work towards and look forward to. It is important that you are as conscious about your self esteem and motivation as you are about the physical effects of the arthritis.

## **Be Determined**

It is important to continually focus on what you can do rather than what you cannot. You may need to be prepared to adapt the ways you do things in order to keep doing them and with an open mind you will learn new tips that will enable you to live your life more easily while still getting the most out of it.

## **Stay Informed & Trust Your Doctor**

Knowledge is power and the more you keep informed about your particular condition the more control you will have over it. It is important that you choose a doctor who you feel comfortable communicating with and trust the advice that they give you.



### **Keep Active/Protect Your Joints**

By motivating oneself to continue to be active a person gains emotionally through warding off sadness & depression, ending isolation and avoiding feelings of hopelessness. Joint protection can reduce stress on arthritic joints and decrease pain.

### **Watch Your Weight**

Being overweight, even just moderately, impacts weight-bearing joints and can increase joint pain. As you walk, your hips, knees, and ankles bear three to five times your total body weight. For every pound you're overweight, the equivalent of three to five pounds worth of added pressure is added to each knee as you walk. The flip side of that is good news: losing just 10 pounds causes 30 to 50 pounds of extra stress to be relieved from the joints.

### **Seek Mutual Support**

Arthritis not only affects you, it also affects the people you share your life with, especially family and friends. People living with arthritis and those who have loved ones with the disease can gain insight and draw inspiration from others facing similar challenges.

“Discussing my illness and talking about it openly with my wife helps her to understand my condition better so we can overcome problems as they arise.” Eamon (45)



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