

Coping with **emotions**



devised with and for people with arthritis



ARTHRITIS CARE

*Empowering
people with arthritis.*



When you live with arthritis, it is not just physical symptoms that affect you. The emotional effects of living with a long-term chronic condition are not widely talked about, although it is very important to acknowledge the different feelings that surface.

This booklet aims to cover the commonest emotions that people with a severe, long-term condition experience and offers plenty of ways to cope. It is aimed at people with all types of arthritis but, of course, no two people are the same. Everyone feels differently at different stages. Even though many of the feelings mentioned here will be negative, positive aspects do exist too.

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

All people pictured on the cover and quoted in this booklet have arthritis.

LIVING WITH ARTHRITIS

Everyone's experience of arthritis is different. Not all people with arthritis experience the same symptoms, the same level of pain or the same feelings.

For example, people with osteoarthritis may find that their symptoms become gradually worse, and then settle, becoming easier to manage; whereas people with rheumatoid arthritis tend to feel generally unwell in addition to experiencing pain, and loss of strength and movement. However, having the same disease as someone else does not necessarily mean that you feel the same – either physically or psychologically.

You may not be the type of person who expresses their emotions freely, but it is good to let your emotions out. Bottling them up can make things worse. Even though there is no known cure for most types of arthritis, there is much that can be done to help.

Pain can usually be controlled, stiffness and inflammation can be relieved, and there are ways to overcome the loss of strength, grip and mobility. Some people find that their lives do not change that much and that they can more or less carry on as normal. Some people become stronger and more determined as a result of having to adapt their lives to fit in with their arthritis – everyone is different.

Other factors in your life, such as work, college or university, stress,

I get quite fearful for the future and worry about how my arthritis will progress



getting older, and sleeping less, may also affect your emotions and your arthritis. Even your own reactions to your arthritis will differ from time to time – you may feel positive one week and negative the next. All the more reason to learn to control your emotions. It is perfectly natural to feel out of sorts sometimes, though.

I think I've changed. I'm a much more understanding person now

As you read through, you will notice that the first half of this booklet addresses the more negative emotions and what causes them, while the second half discusses the positive aspects and coping strategies.



WHEN YOU ARE DIAGNOSED

When you are first diagnosed with arthritis, you are bound to feel a little overwhelmed – after all, it is not easy to accept that your life may change.

You may not react at all to the news until the message sinks in, or you could react in many other ways, going through every emotion from shock and disbelief to anxiety, anger and frustration.

You could be worried about the fact that you may not be able to keep up hobbies such as golf or long walks (this might just mean playing shorter rounds or taking shorter walks), or you may be more concerned about how you're going to cope from day to day.

Below are some of the main emotions that you might experience when you are diagnosed with arthritis.

Shock – Many people feel numb to begin with when they receive distressing news. You may not really take in anything that your doctor says – your reaction may come later on.

Disbelief – After the initial shock of being told that you have arthritis, you may experience a sense of disbelief. Give yourself time to get used to the idea – nobody said that accepting this information was going to be easy.

Anxiety – Anxiety and panic are common emotions to feel when you have just been diagnosed, especially if you do not know much about arthritis.

Anxiety can be experienced in varying degrees and you may have all kinds of questions whirling around inside your head, such as 'What is arthritis?'; 'What's going to happen to me?'; 'Who's going to look after me?' and 'Will I ever get better?'. All these questions are very normal, as is feeling vulnerable when you realise that you will have

When you are diagnosed you feel devastated

arthritis for the rest of your life.

Relief – Strange as it may sound, many people feel relief when they are diagnosed with arthritis. It is a relief to be told what the reason is for your various aches and pains; and a comfort to know that you are believed. It is also good to know that there are treatments for your condition which now has a name.

When I was diagnosed I felt relief – there was a reason for my symptoms

Denial – It is not unusual to deny accepting that you have arthritis and to pretend that everything is okay. However, the longer you put off facing reality, the longer it will take for you to adjust. Try to get your head around the fact that you have this condition and that it is going to be with you, perhaps for some time. Then, try to plan your activities and put all your effort into handling what life throws at you as best you can.

It may help to ask for further explanations of your condition or read more about it. Many people find that talking to others with arthritis is very valuable in helping to adjust.

As well as the above emotions, you may experience other feelings too, such as damaged self-esteem. For example, you might worry that having arthritis will threaten your relationships and impose on your family and lifestyle, or that you will become more reliant on others than you'd like. Some people may even blame themselves for having arthritis.

Thinking these things is perfectly natural, but your valuable energy would be better spent focusing on improving the way you deal with your emotions. Concentrate on banishing the negative thoughts and turning them into positive and rational ones.



COMMON EMOTIONS

When you were first diagnosed, you may have been frightened of the future and in need of lots of reassurance. But, after a while, your most pressing questions were perhaps answered and you started to adjust to having arthritis. This doesn't mean to say that you will never feel anxious about having arthritis again. New fears and concerns may arise as your condition changes, but there are plenty of ways of dealing with them. Below are some of the most common emotions you may experience.

Fear and anxiety – The difference between these two emotions is quite subtle. Anxiety can be experienced as a feeling of

uneasiness where you feel restless and out of control. Fear is more specific and is directed at a situation, event, person or thing. We experience fear when we feel threatened.

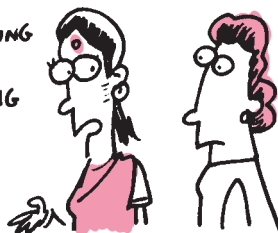
You may be afraid of many aspects of arthritis – the fluctuations in pain, the drugs you will have to take and their potential side effects, going out, the effect on your employment prospects and even dying. As you would expect, many people feel a lot more negative during a flare-up of the disease and more positive when they are feeling better – and this is quite normal.

But even when symptoms subside a little, some still feel anxious – perhaps, about their symptoms returning.

When you are anxious you may become short of breath and your heart may beat rapidly. You will perhaps feel jittery and shaky and unable to relax. When you try to calm yourself down, you find that you can't – increasing your anxiety even further.

I often get anxious about coping when I'm out and about

I'M NOT SURE WHETHER I'M FEELING ANXIETY OR FEAR... AND THAT'S MAKING ME REALLY NERVOUS.



Some people experience panic attacks. These occur when the level of anxiety becomes too much for the body to bear.

There are many ways of preventing anxiety and fear from escalating into panic. Try to pin down a specific reason for your fear and to challenge the negative thinking behind your anxiety. Use relaxation techniques to help overcome your panic. If these don't help, some may find a visit to their doctor or rheumatology nurse helpful. Medication or counselling may also be the way forward.

Everyone feels frightened from time to time – it is perfectly normal. The main thing is to prevent your fears from becoming overwhelming. As you begin to recognise your fears, you will begin to feel more in control and able to handle whatever may come along.

Anger – Anger is the emotion we feel when we are highly annoyed or displeased. As it is a strong emotion, it is important to learn to recognise it, control it and turn it to your advantage.

I am seething, bubbling over with the injustice of it all. Why me?

Anger is triggered by many things, like having to wait to see your doctor, feeling that you are not being understood, or that friends and family are trying to wrap you in cotton wool. Being forced to do something that you don't really want to do or can't do can also cause anger to build. Becoming aware of why it is that you are angry will help you to deal with these negative feelings and help you to analyse whether they are realistic.

If you can admit that you are angry and find out why you are feeling this way, you may be able to prevent it from boiling over, or at least channel it in an acceptable way.

You may even feel stronger and more powerful when you are angry – anger is a form of energy, spurring us on to take action. If these angry feelings aren't released in a controlled manner, they may take the form of something less desirable. Extreme anger that lasts for a long time can be physically damaging, causing ulcers, hypertension and headaches. So there are some very valid reasons why it

makes sense to try to diffuse your anger.

Anger isn't all bad, though. It can give you an indication that

something needs dealing with and it

can motivate you to do something about your problems in an assertive way. The key things to remember are not to become overwhelmed by your anger, and not to be afraid of it.

I've become Mrs Angry and I don't like it

Depression – or periods where you feel very low – affects many people with arthritis. It can make you feel completely helpless, exhausted, anti-social and unable to enjoy anything. Many people are not even aware that they are depressed – often family and friends are the first to notice.

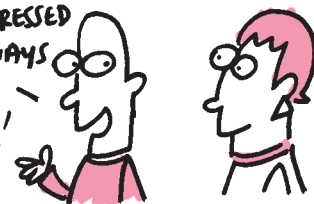
Depression is a very unpleasant feeling of unhappiness and despair and can range from being a mild problem to a very severe one. You may feel as though the whole world is against you and that life is a constant struggle.

People who are depressed report feelings of excessive amounts of hopelessness, anger, sadness and despair. They are either unable to eat or eat too much, sleep too much or too little, burst into tears for no reason and feel withdrawn and lacking in energy. The more of these feelings that you experience, the more likely it is that you are depressed and need to take action.

A bout of depression may start with one specific thing that makes you unhappy, leading on to a chain reaction. It is vital that you try to stop yourself from falling deeper into depression because it can be very hard to climb back out again, but it is possible.

There is a difference between feeling depressed and feeling fed up, even though it may be difficult to identify it at the time. What is certain is that dealing with depression is

ONE DAY I REALISED THE TRICK WAS TO STOP BEATING MYSELF UP FOR BEING DEPRESSED AND LOOK FOR WAYS OF BEATING DEPRESSION!



an essential part of coping – don't wait in the hope that it will just go away on its own because it may not. It

wouldn't hurt to have a chat with your GP if you are feeling persistently low.

Various aspects of your arthritis may be causing your depression, such as the realisation that you may no longer be able to do certain things, or when you meet other people who don't really understand. If you are single, you may feel down because you think that you might not meet anyone or be able to develop a meaningful relationship due to the changes in your life you've had to make. You might feel depressed about the future and the fact that you will probably need to take medication to stop your arthritis getting worse, and you might even feel depressed about the way your body looks or feels as well.

So how can you cope with depression?

- To get better emotionally, you have to take care of yourself physically.
- Look after your emotional wellbeing and accept that you will have limitations in life. Once you have accepted this you can get on with being constructive and positive instead of mourning what you used to be able to do. For example, you may not be able to dance or play sports anymore, but you could find a slower, more gentle activity such as tai chi or take pleasure from watching or supporting others.
- Stay in control. Being able to make your own choices will help you feel the power you still have over your life. Exercise is another way of lifting your mood as it makes the body release endorphins – the 'feel good' chemical – as well as acting as a distraction. There



I was depressed. I became very quiet and washing seemed really unimportant

is more information and details of exercises available in Arthritis Care's booklet on exercise.

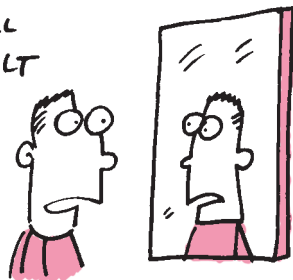
- Try to think positively and keep things in perspective. Anti-depressant medications may be prescribed by your doctor if depression persists. This will probably be a temporary measure. Many of these may have side effects. You should tell your doctor if you experience any side effects so that he or she can determine whether your medication should be continued.
- Talking through how you feel with family and friends may help to alleviate your depression, especially if you trust their opinion. They may be more objective and be better able to come up with constructive solutions. If this is not an option, consider speaking to a professional such as your GP, rheumatology nurse or hospital doctor. Getting rid of depression is not easy, but if you follow the suggestions here and set yourself realistic goals, you will be able to prepare yourself should it arise.

Guilt – Guilt is an unpleasant feeling and there are countless reasons for feeling it. You may feel guilty when you don't stick to your diet or do as much exercise as you believe you should. You might feel guilty for resenting people who don't have arthritis, or if you can't be the parent or partner that you think you ought to be because of your arthritis.

There are two components of guilt. The first is a sense of wrongdoing – a sense that you have either done something wrong or not done something you should have. The second is a feeling of badness caused by self-blame – often when you tell yourself that you 'should' have done something. When you start telling yourself you're a bad person, you start to feel guilty. Some people feel guilty that they have done something that has contributed to their arthritis. This is not rational and can leave you drained.

Pinpointing the source of the

HAVING ALL
THIS GUILT
IS MAKING
ME FEEL
REALLY
GUILTY



guilt – just as with anger – will help you to reduce or even eliminate the guilty feelings. If you feel guilty because of your arthritis, ask yourself if you made it happen. Of course you didn't. Don't give up if you can't find one clear solution. Look for ways of partially solving the problem and reduce the guilt.

I sometimes feel guilty about holding people up – everything takes longer with arthritis

Stress – A certain amount of stress in our lives is normal, but sometimes it can get out of hand and become harmful. There are many things that can act as triggers. Work problems, marital disputes and bereavement are just three examples. Even exciting events can cause us to be stressed.

Where arthritis is concerned, you may be stressed about how the disease will affect you in the future, the long surgery waiting list you may have to face, or whether the medications you are on are right for you. Even the smaller things, such as worrying about planning your holidays or even getting down to the shops can be enough to trigger stress. It is important to keep an eye on your stress levels.

Stress is a response that occurs in our bodies – too much stress is not pleasant. Learning to deal with stress will help take the pressure off you while you experience the changes that arthritis brings.

The physical symptoms of stress include sweaty palms, fatigue, nausea, diarrhoea or headaches, among other things in varying degrees. Emotionally, you could feel depressed, anxious or frustrated. Stress affects your body by speeding up your circulatory system, causing blood to rush to different parts of your body and raising your



blood pressure. If you are very stressed you may experience a rush of adrenaline and feel sweaty and shaky.

You may also experience more rapid breathing, a dry mouth and a sick feeling. Your body is automatically preparing to defend itself against an encounter that may threaten its survival – this is called the fight or flight response. This is when stress can be a good thing.

If we need to physically exert ourselves, the muscles are exercised and the energy released. However, if there is no physical exertion, the energy is not released in the same way. This might explain why we feel exhausted after being stressed, even though we have not done anything physical. Stress becomes a problem when you can't get rid of it.

If you experience stress over a period of time, it can put quite a strain on the body, leaving you even more vulnerable. Emotionally, stress can leave you unable to concentrate and perhaps feeling afraid to do things and lacking in confidence in yourself.

I know that stress makes my joints much, much worse

What are good ways of dealing with stress?

- Regular exercise, whether that includes stretching exercises specifically for your arthritis or more general exercise such as swimming or going to the gym. (Remember to always check with your doctor before starting an exercise programme.)
- Relaxation, getting more sleep or doing an activity you enjoy will help relieve stress. Relaxation will help to give your body the chance to rest and recuperate as well as helping you to sleep better. It can make you feel as though you have real control over your life, despite having arthritis. This booklet will explain the different techniques further on.

To identify what is causing your stress, try keeping a daily list of all the things that make you feel stressed. You will soon recognise that the people or events that crop up more often are the ones causing you problems. If it is still difficult to work out, try rating them on a scale of one to 10, depending on how stressed they make you feel.

Your stress triggers will soon become apparent and you will then be able to eliminate them from your life. If removing the trigger is not an option, concentrate on building a tolerance to it. Do this by using the relaxation technique that suits you best and you will be well on your way to a stress-free life.

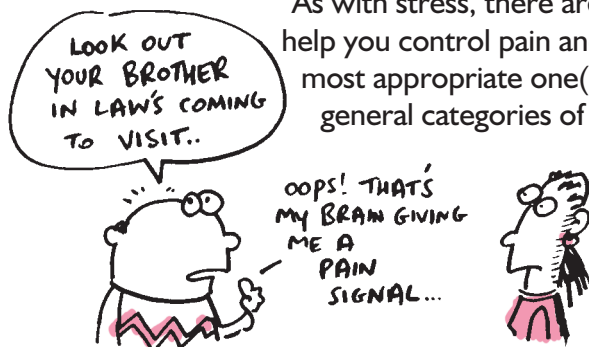
Pain – Even though pain itself is not an emotion, it is responsible for the way we feel to quite a large extent and vice versa – your emotions can quickly worsen any pain you perceive. Anxiety can bring pain to the fore, stress can make you tense thereby increasing the pain, and depression can cause you to focus on your pain. If you are tired, this can also worsen the pain. If you learn to control some or all of these factors, you will learn to better manage your pain.

People who have had arthritis for a while say that, generally, they learn to live with pain and that, odd as it may seem, it can be strangely comforting in that they feel reassured that ‘nothing else is wrong’. However, the results of your pain can have a devastating effect on those closest to you, it can make you snappy, grumpy and, generally, not nice to be around. Pain can cause you to be reluctant to talk about it for fear of boring others. Remember that as pain isn’t visible, it can be hard for others to understand.

I find sleep deprivation a big problem and something that has a great effect on my emotions

As with stress, there are many different techniques to help you control pain and it is up to you to find the most appropriate one(s) for you. There are three general categories of treatment – medical

treatment, physical therapy and psychological strategies – and they all work by interrupting the pain signals the brain receives. Medical treatment includes painkillers,



anti-inflammatories and long acting drugs. Physical therapy includes hot and cold therapy, massage, TENS machines and exercise. Psychological strategies include relaxation techniques, imagery and hypnosis. Don't forget to check with your doctor first before trying anything new.

I find living with pain emotionally exhausting

There are simple ways of coping with pain:

- get plenty of rest
- keep active within your limits
- take control of your medical treatment and learn as much about it as possible
- keep a pain diary so you can see if there is a regular pattern
- use stress reduction techniques
- do things that you enjoy and remain positive.

More information is available in Arthritis Care's booklet on coping with pain.

■ Other emotions

There are some other emotions experienced by people with arthritis aside from those already mentioned. These are boredom, loneliness, frustration and grief.

Boredom – Boredom can be an uncomfortable state to be in. You may feel restless and can have a horrible feeling of life passing you by while everyone else is carrying on with theirs.

When you have arthritis, boredom is mostly brought on by the fact that you are limited in your activities due to a flare of the disease, after an operation or tiredness. You may not even be bothered to try



something new because you think that you will be restricted by your arthritis later on. You feel that your life is going nowhere and that nothing is challenging you.

In order to banish boredom you need to tell yourself not to give up. Accept that there will be things that you can no longer do, but remind yourself that there are plenty of things that you can. Try to find new activities that you can enjoy and will find interesting. Give something a whirl that you have never tried before. Learning something new may spark your interest and make you eager to learn more about it.

Loneliness – Loneliness comes about when you become upset about – and aware of – being alone. You might feel lonely because you feel left out or unwell, or because you think that others don't understand your arthritis and don't want to be with you, though this is often not really the case. Even though there may be plenty of opportunities to be in the company of others, you may turn them down.

So why would you want to be lonely on purpose? There are several possible reasons.

- You may prefer your own company rather than the company of others
- You might not want to meet new people because they never seem to meet your requirements.
- You may have resigned yourself to being lonely and tell yourself that this is part of having arthritis.
- You may avoid seeing family and friends because you think you will make them gloomy.
- You may be lonely because you are frightened of rejection and of developing new relationships.

One way to end loneliness is to stop pushing people away and to make people want to come into contact with you. If you are welcoming and smiley, which can be difficult when you are in pain, it will let people know that you like being with them. Make contact with others as often as you can, maybe through an organisation. You may want to get involved with an arthritis support group where you

will meet others with similar worries, and put an end to the occasions where you feel lonely in others' company. You may even pick up some coping skills and find ways of helping others.

Alternatively, you could always try evening or day classes or a new hobby instead. Try to get out and about as much as you can so that you feel less isolated. Remember that you are never far from others. The telephone and the internet are other ways of connecting with people, so use them.


Frustration – There are many aspects of your arthritis that you will find frustrating. You may get very frustrated with not being able to do the things that you want to, like playing certain sports, even going on impromptu walks or outings. Or you may feel annoyed with yourself for not being able to work full-time, if at all.

You may get fed up with the fact that it takes longer to plan things and that you have to do things more slowly or with the help of others. Some people say that it feels as though you have to do a balancing act of conserving energy in one task so that you can do something else or something extra.


Others find it particularly frustrating that they can no longer have as fulfilling relationships with their families or partners as they had before their arthritis. It can also

be very frustrating if you feel that you are not being involved in decision-making, whether it is regarding your treatment or changes in family life. Claiming benefits can be difficult if you are shy or get confused by paperwork and bureaucracy too; and you may get annoyed if people start answering for you, presuming to know what you want, need or feel.

Try to focus on what aspect is causing the frustration. Try to accept gradually that things won't be the same now that you have arthritis and that certain things will get on your nerves. Using relaxation techniques will help, as will doing the things that you enjoy.



I find it frustrating when people don't understand the unpredictability of my arthritis



Grief – Feelings of grief are common when you are first diagnosed. You may feel as though you have lost something, such as your old lifestyle, and so feel it appropriate to grieve for it. If your arthritis has had quite an impact on your family or working life, you may grieve for the loss of the role that you once had. This is particularly pertinent for the breadwinner of the family, who may feel at a loose end now that a major role has been taken away from them.

The way forward is to look at what is causing this feeling and work your way through it. For example, if your arthritis means that you might have to take on a less demanding job, then put all your effort into finding one that you will enjoy and that will make you feel valued.

Many people feel that having a good cry helps enormously. Crying is the body's way of releasing pent up emotion and you will feel so much better afterwards. Talking about your feelings with people close to you will help too.

I FEEL IN
NEED OF A
GOOD CRY..

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WANT ME TO GET
YOU A ROMANCE
NOVEL, A SOPPY
VIDEO OR OUR
CREDIT CARD BILL?


RELATIONSHIPS

You may be worried about what others are going to think now that you have been diagnosed with arthritis and how they are going to react. Below are some ways of dealing with any problems that may crop up.


■ You and your doctor

Developing a good relationship with your doctor and rheumatologist, and indeed your nurse and therapist, is very helpful. Don't hesitate to ask them about the different treatments for your arthritis. Try to make them aware of how important these concerns are to you.

There is a lot to be gained from having a good relationship with your health professionals. If you are unhappy, then you may have to reconsider this relationship – perhaps by changing doctors.



My doctor really listens to me as he knows I am the expert on me



■ Your family and friends

Getting along well with your family is very important as you probably spend more time with them than anyone else. They can provide you with valuable emotional and practical support.

They may, understandably, find it difficult to accept your condition and go through similar emotional turmoil as yourself. Changes in family responsibilities or roles, financial concerns and general limitations as a result of your arthritis may put added pressure on the family and they will tend to bear the brunt when you are having a flare up.

Your children will have to learn that you can't always go on outings or accompany them to various activities. They will have to adjust to your arthritis just as you do. Encourage them to ask questions about your arthritis. This will help you feel really close to your children and reassure them that you have not lost interest in them.

If you find it difficult to talk to your loved ones about your arthritis,

treatment or feelings, don't give up. It is important that your concerns are out in the open. It may be a good idea if they also have somebody to speak to outside of the family about the situation. There are support groups around, which they could join, or they could seek counselling. Once they see that it is possible to cope with arthritis, it will help your adjustment process.

Your relationship with your partner may come under a bit of strain too. Again, it is a question of accepting your arthritis and adjusting to it. They may become frustrated if your social life has plummeted or may just feel plain helpless. Once you have learnt to manage your arthritis better, you may find that you will be able to resume at least some of the activities you did before. Until then, try to find less strenuous alternatives.

The same goes for your love life. There will be times when you are just too tired or in too much pain to get close to your other half, but there are alternatives. Try different positions: perhaps supporting your body with pillows and cushions to make love-making more comfortable. A warm bath or shower beforehand will help to loosen your joints. You could even try persuading your partner to give you a gentle foot or back massage.

Be open with your friends and family, telling them honestly how arthritis affects you and how that may mean changes to your social life. You could even give them some Arthritis Care booklets so that they are fully informed about how your condition affects you.

Arthritis Care's booklet about relationships explores issues surrounding relationships, sexuality and arthritis.

My mum is sometimes more irritable than she used to be because of her arthritis

NOW THAT I KNOW I'VE GOT ARTHRITIS, THANKS FOR NOT KEEPING MUM ABOUT WAYS TO COPE...



■ When your child has arthritis

It can be a shock to discover that your child has arthritis and it is common for parents to find it hard to cope.

You may worry about dealing with the medical side of the condition or wonder how your family will cope with the lifestyle changes it will bring. But try not to let arthritis take over your lives. Children and young people with arthritis need to lead a normal and full a life as possible.

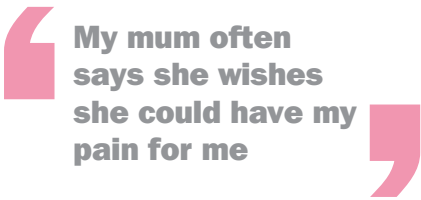
Try to banish any emotions of guilt or fear that you may have – you will need all your energy to keep all your lives ticking along as usual. Also, try not to let your child see how unhappy you are. This may cause them to feel guilty and is not healthy.

Children react to the pain, isolation and fear that arthritis may bring in much the same way as adults. Some may withdraw and become unsociable, keeping their bodies covered at all times. Others are very open about it and may use their arthritis to get extra attention. Many children fall in between these two extremes. Encourage your child to take part in activities such as swimming, which will benefit their health. Encourage them to develop good reading skills and to do well academically. This can provide a great psychological boost.

It will be hard to avoid being overprotective, but try not to be. Guide your child in the right direction and they will learn on their own what they can and can't do.

As your child becomes a teenager, communication may become a little more strained. Adolescence brings with it a desire to be independent and at the same time a desire to 'fit in'. The hardest thing you will have to do is relinquish some of the control you have over your child, but it will be for the best as they will then be able to find things out for themselves rather than be wrapped in cotton wool.

There is more information on Arthritis Care's website:
www.arthritiscare.org.uk/Youngpeople/Breakout



My mum often says she wishes she could have my pain for me

WHERE YOU CAN FIND SUPPORT

When you live with arthritis, there will be times when you do need help and support from a range of different people. This may be emotionally, practically or both. There are many places and people offering help if you are in need of support.

Your GP will treat you as best they can and refer you on to other professionals if you need further help.



**Having arthritis
has made me very
resourceful**



Occupational therapist (OT) – an OT

will give practical advice on how to cope with everyday tasks such as washing, dressing and cooking. They can provide special equipment to help you, or tell you where to get it and can make splints to support and protect joints severely affected by arthritis. Your hospital doctor or GP may refer you to an OT, or one may visit you at home to assess if your house can be altered to make it better suited to you. In this case, you will probably be referred to a community OT based at your local social services department. Ring your local social services department (in the phone book, under the name of your local authority) and ask for an assessment of your needs at home under the NHS and Community Care Act 1990.

Physiotherapist – if your doctor refers you to a physiotherapist, you will be given a full assessment of your joints, muscles, posture and how you walk and move around. Taking into account your general health and arthritis, a treatment plan will be decided upon and agreed between you and your physiotherapist. Treatment and advice may include exercise, hydrotherapy, mobilisation techniques, acupuncture, relaxation techniques and forms of pain relief.

Rheumatology department – based at your local hospital, can give you access to nurse counselling, physiotherapy, podiatry, pain management and pain clinics.

Citizens Advice – can offer you legal advice on your rights as a disabled person or someone with arthritis.

Arthritis Care – can supply general information leaflets and booklets so

you can learn more about your arthritis. There is also the opportunity to contact the helplines team to talk through your feelings, and to meet other people with arthritis at local branches or on the online forum: www.arthritiscare.org.uk/forum Arthritis Care also offers self-management training which can help you learn skills to take control of your arthritis.

Pain clinics – your GP or hospital consultant can refer you to a pain clinic if you continue to have persistent and unmanageable pain.

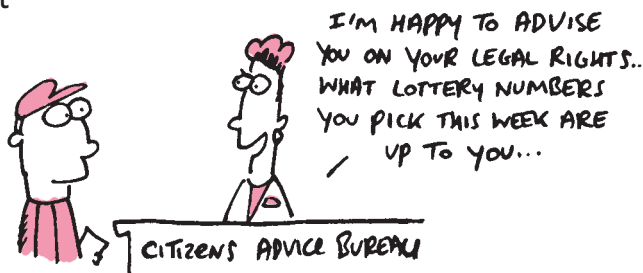
Friends – your friends and peers are a very important source of support. Don't give up on them or your social life. Look around to see what new things are going on – becoming a member of a club could be the start of something good.

I talk to friends a lot and that helps me cope

Family – keep the communication lines with your family open and talk about your arthritis and the things that are bothering you. They may need as much support from you as you need from them from time to time.

Religion – many people find great comfort in their faith. You may find it can be a great source of support in times of need.

Information resources – use the internet and your library to find out information about arthritis. You may find information about various organisations and groups and you can even use the internet to chat via email or on discussion forums to someone else with arthritis. If you do not have internet access at home, ask your local library if they have a computer that you can use. Many will provide it free of charge. Remember to judge the information you find very carefully as it may not have been checked thoroughly.



ON A MORE POSITIVE NOTE...

Having arthritis is not all doom and gloom. Having to battle through the more difficult emotions mentioned in this booklet means that you are emotionally stronger and better equipped to cope with what life may throw at you.

Many people feel more empowered and determined as a result of their arthritis, and feel that they are more able to stand up for themselves. Others report a gain in understanding of other disabled people and medical conditions, while children of people with arthritis often tend to grow up as particularly caring individuals.

Acceptance of your arthritis feels very positive when it finally happens to you. Until that point, you may feel as though you are fighting against your arthritis. Try to learn to accept the following things:

- you are different to someone who doesn't have arthritis and you are also different to the person next to you with the same form of arthritis
- it is not your fault – arthritis is not caused by being a bad person
- don't feel guilty about what you can or can't do – accept your limitations
- you may need to change how you work or give up work and make changes to your lifestyle in general
- you may need help or assistance
- there is no cure at the moment (although this is not to say that a cure isn't just around the corner) and you may need to persist with different medication or treatments to find the right one for you.

With so many negative feelings about arthritis, it's important to find the positive too

COPING STRATEGIES

There are many coping strategies to help you deal with your emotions and it is a good idea to set aside some time each day to strengthen yourself and prepare for the next day. By doing this you will feel more positive because you are exercising some control over your arthritis. This section will deal with ways of coping in more detail.

Positive mental attitude – If you look at things in a more positive light, you will find that you are much more able to take control of your emotions. Thinking negatively will only magnify any emotional problems you may already have.

Thinking positively will improve your attitude and other aspects of your life.

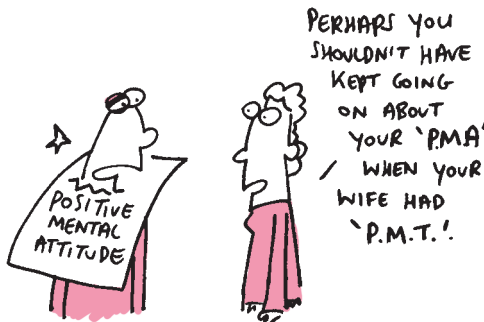
Positive actions you can take – Be determined – life is about living. Focus on what you can do, not what you can't.

- Adapt the ways you do things so you can continue to do them.
- Get help from wherever available, whether this is practical or financial.
- Learn new tips to enable you to live your life more easily.
- Communicate with your family who could be supportive and

understanding.

- Ask questions – get as much information as you can.
- Build good relationships with the health professionals treating you.
- Have some faith – you need to believe you will come through it, even if you can't see how.

Despite my arthritis I've got so many good things in life that I want to concentrate on those



Laughter – Laughing is a brilliant way of making yourself feel better. Research has shown that, when we laugh, endorphins – or ‘feel good’ chemicals – are released by the brain. These chemicals block pain and help us feel good.

Seeing the funny side of life will help you to release tension and can help distract you from the pain of arthritis or anything else that’s bothering you.



Laughter is a great tonic when you are feeling low

If you are having a really bad day, it will obviously be hard to laugh at yourself. In this case, it would be better to keep a stack of comedy videotapes, DVDs or books handy – anything that will make you see the funny side of things and lighten your mood.

Set yourself goals – This is a good way to help you look to the future. You could set a short-term goal such as buying a book by a favourite author, or a long-term goal such as planning to visit some old friends in another town. By making sure that your goals are realistic and positive, you will be giving yourself something to look forward to achieving every day.

Treat yourself – If your arthritis is getting you down, even though you’ve done all your exercises and taken your pills, you may feel as though you are being punished. On days like this, there’s nothing wrong with a little pampering to remind yourself that nice things do happen and that you deserve them. Buy yourself a tub of your favourite ice cream, treat yourself to a gift or spend more time with people whose company you enjoy. The list is endless.

Relaxation – Learning to relax – and it is usually something that has to be learned – is very valuable. It helps to relieve the stress and tension in our lives that will sometimes be magnified by arthritis. By using various relaxation techniques, you will be able to identify the problems affecting you and be able to deal with them better.

● Progressive relaxation – this involves tensing and then relaxing the

different muscle groups in your body, one group at a time to reduce tension. Find out more from the library, the internet, or speak to a professional.

- **Meditation** – allows you to achieve a deep state of relaxation in a short space of time. It involves remaining calm and focusing the mind. By doing this, you can clear out any negative thoughts, making way for a more calming, relaxing state of mind. This technique is best taught by a professional or can be learned from a book, tape or video.

- **Deep breathing** – this technique is used widely, increasing relaxation and reducing pain. Lie in a comfortable position and put one hand on your abdomen and the other on your chest. Inhale slowly and deeply through your nose so that the hand on your abdomen moves higher. Hold your breath for as long as it is comfortable, then exhale slowly through your mouth. Feel the hand on your abdomen sink slowly, allowing a growing feeling of relaxation to deepen inside you. Repeat this for 5 to 10 minutes, then wait a few minutes to become aware of your surroundings before getting up.

Imagery – Imagery involves conjuring up mental pictures or scenes in your head to harness your body's energy. As well as reducing stress, imagery has been known to help control headaches, hypertension, depression and pain.

Get into a relaxed position in a chair or on a bed. Breathe smoothly and rhythmically and relax. Then imagine a scene, making it as vivid and real as possible. For example, if your knees are particularly painful, imagine that they are being hit by a hammer or are full of pins. Then, imagine the hammers disappearing or the pins being removed one by one and then a healing lotion being applied.

You could picture many scenes like this, imagining



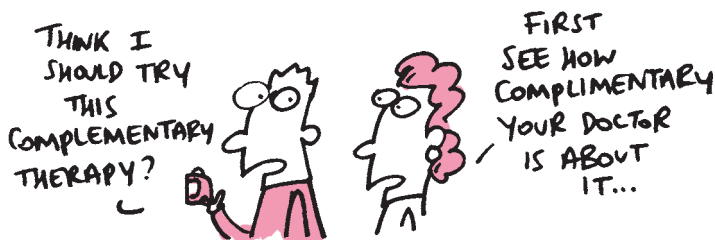
yourself being massaged or having a warm, scented bath. Look out for books on imagery in the library or information on the internet.

Complementary therapies – Complementary therapies can be used with medical treatments, although it is wise to check with your doctor first. A lot of these therapies have not been tested scientifically, so be sure you see someone who knows what they are doing.

- **Massage** – which incorporates acupuncture, reflexology, polarity therapy and therapeutic touch, is an ancient practice, helping to balance energy in the body and induce a feeling of well-being. It helps to reduce tension in the muscles and stimulates circulation. If you don't want to go to a professional, ask your partner if they will massage you.

- **Acupuncture** – this ancient Chinese technique has gained increasing acceptance by professionals in recent years. It is based on the belief that health is determined by qi or chi – the vital energy present in all living organisms. Very fine needles are inserted into parts of the body at various angles and depths aimed at suppressing pain and triggering the release of endorphins. The needles are not painful, rather, they feel like a little 'pinch'. Ask your doctor who will refer you to a qualified professional.

- **Herbal remedies and dietary supplements** – these can be effective in helping reduce pain and other symptoms. If you visit a herbalist, or nutritional adviser, make sure they are qualified. Always inform your doctor what herbs, nutritional supplements, vitamins and minerals you are taking as supplements can interact with conventional medicine. See Arthritis Care's booklets on drugs and complementary therapies and healthy eating for further information.



ADJUSTING TO LIFE WITH ARTHRITIS

Now that you have read about the range of emotions to expect when you have arthritis, the next time you feel angry, frustrated or even happy, it won't come as so much of a surprise. The feelings that you experience won't go away entirely – they can reappear throughout life. For example, just before an operation or when you are changing medication, or when you are less mobile.

If you can adopt some of the coping strategies mentioned here, you will be helping yourself and taking charge of your arthritis. It will be hard to adjust at first, but facing your arthritis is the only way to really accept it. Finding out as much about arthritis as possible will help you to understand what is happening to your body.

Once you have accepted your arthritis, it will become easier to pinpoint the changes you will need to make and the things that you will be able to continue doing as usual. Life will begin to seem more manageable. You will have already done a little of the thinking and planning ahead and you can get on with enjoying life.

SINCE I LEARNED
TO COPE WITH
MY FEELINGS,
I'M FEELING A
LOT MORE
POSITIVE
ABOUT COPING!



If you have had arthritis for a long time, it becomes a part of your personality and character

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

USEFUL ORGANISATIONS

ARTHRITIS

- **Arthritis Care**

UK office:

Tel: 020 7380 6500

South England office:

Tel: 0844 888 2111

Central England office:

Tel: 0115 952 5522

North England office:

Tel: 01924 882150

Northern Ireland office:

Tel: 028 9078 2940

Scotland office:

Tel: 0141 954 7776

Wales office:

Tel: 029 2044 4155

- **Arthritis Research UK**

Tel: 01246 558033

www.arthritisresearchuk.org

Funds medical research into arthritis and produces information.

- **CCAA (Children's Chronic Arthritis Association)**

Tel: 01905 745595

www.ccaa.org.uk

NEED TO TALK?

- **British Association for Behavioural and Cognitive Psychotherapies (BABCP)**

Tel: 0161 705 4304

For details of cognitive behavioural therapy practitioners.

www.babcp.com

- **British Association for Counselling and Psychotherapy (BACP)**

Tel: 01455 883 300

Fax: 01455 550243

Has a comprehensive list of counsellors across the country.

www.bacp.co.uk

- **Samaritans**

Tel: 0845 790 9090 (UK)

email jo@samaritans.org

www.samaritans.org

ORGANISATIONS WHO CAN HELP

- **Depression Alliance**

Tel: 0845 123 23 20

www.depressionalliance.org

- **Depression Alliance Scotland**

Tel: 0131 467 3050

- **Journeys (Wales)**

Tel: 029 2069 2891

www.journeysonline.org.uk

- **MIND**

Mental health charity covering England and Wales.

Tel: 020 8519 2122

Mind infoline: 0845 766 0163

(open Monday to Friday, 9am-5pm)

www.mind.org.uk

- **Scottish Association for Mental Health**

Information service:

2-4.30pm, Monday to Friday

USEFUL ORGANISATIONS

0800 917 3466
www.samh.org.uk

- **Northern Ireland Association for Mental Health**

Tel: 028 9032 8474
www.niamh.co.uk

COMPLEMENTARY THERAPIES

- **Institute for Complementary & Natural Medicine**

Tel: 020 7922 7980
www.icnm.org.uk

For a list of qualified practitioners, send a large SAE stating the therapy.

- **British Complementary Medicine Association**

Tel: 0845 345 5977

Have an online directory of practitioners.
www.bcma.co.uk

EVENING CLASSES

Contact your local education authority or adult education centre for a list of courses on a variety of topics, including tai chi and yoga.

GENERAL HEALTH

- **NHS Choices**

For links to NHS services in your area and information. Call NHS Direct on 0845 4647 and NHS24 in Scotland on 08454 242424
www.nhs.uk

- **The British Pain Society**

Tel: 020 7269 7840
www.britishpainsociety.org
General information on chronic pain.
Details of pain clinics in the UK.

SELF-MANAGEMENT COURSES

Arthritis Care runs self-management courses to enable people with arthritis to manage their condition more effectively and improve their quality of life. For more information, call 020 7380 6500

GENERAL HELP

- **Citizens Advice**

www.citizensadvice.org.uk
The Citizens Advice service offers free, confidential, impartial and independent advice. See your local telephone directory for contact details.

- **Benefit Enquiry Line for disabled people**

Tel: 0800 882200.
Available 8.30am-6.30pm Mon-Fri and 8.30am-1pm Sat.
www.direct.gov.uk/disability-money
In Northern Ireland the Benefits Enquiry Line is run by the Social Security Agency.
Tel: 0800 220 674

ARTHRITIS CARE

Arthritis Care exists to support people with arthritis. We are the UK's largest charity working with and for all people who have arthritis. We offer support wherever you live in the UK.

It costs us £1.10 to provide you with this booklet. If you are able to access information online, you'll help us save money and the environment.

Get involved with us today if you can.

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

We exist for everyone with arthritis, but we rely on the support of people like you. If you would like to make a contribution to our work, please phone us on 020 7380 6540. Or you can donate online.

www.arthritiscare.org.uk



ARTHRITIS CARE

*Empowering
people with arthritis.*

**To find out more about
arthritis and Arthritis Care**

Freephone our confidential helpline

0808 800 4050

(weekdays 10am-4pm)

Visit our website

www.arthritiscare.org.uk

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