



Living with long-term pain: a guide to self-management









# What's inside:

#### 2 About this guide

# 4 Case study: An all too common story of chronic pain

# 9 Section 1: Introduction to long-term pain

- What is long-term pain?
  - Why do I have long-term pain?
  - What's the difference between short-term and long-term pain?
  - What types of long-term pain are there?
- What can I do to help myself?

# 19 Section 2: About you

- It's just pain or is it?
- What are you doing to manage your pain?
- Is it working?
- A change of focus?
- What should I do?
- Wrapping it all together

# 31 Section 3: Where can I get treatment and advice?

- Getting the best out of your general practitioner (GP)
- What can I expect from my GP?
- What types of treatments can GPs prescribe?
- Who can GPs refer to?
  - Pain clinics/ pain management centres
  - Psychologists
  - Neurologists
  - Rheumatologists
  - Physiotherapists

- Occupational therapists
- Hand therapists
- Orthopaedic surgeons
- Podiatrists
- How would complementary therapies help me?
- Charity and voluntary groups

# 47 Section 4: Specific treatments and therapies for long-term pain

- Drugs
- Cognitive behavioural therapy and other psychological therapies
- Physical rehabilitation and selfmanagement approaches
  - Pain and movement
  - How can I increase my physical activity?
  - Hydrotherapy
  - Pain and daily activity
  - Maintaining healthy joints
  - Splints for painful joints
  - Conserving energy
  - Relaxation
  - Getting a good night's sleep
  - Coping better at work

# 63 Section 5: Research and pain

- Arthritis Research UK pain research
  - Our national pain centre
  - Research into the placebo effect
  - Novel research using mirrors
  - Telephone-delivered CBT
  - Other research

# 67 Section 6: Resources and further reading

# **About this guide**

This guide is aimed at people who have long-term musculoskeletal pain that has become worrying, interfering or, in some cases, an all-consuming reality. It's for people who spend their days unable to do what they want to do or were once able to do, and can find no relief from persistent pain despite the best efforts of doctors and other healthcare professionals. It's for those who don't know where to turn next to seek the relief they so desperately need, leaving them feeling isolated, alone, inactive and let down by society.

This guide has been written because we realise that there are many people who find themselves in this situation. A substantial number of the calls that the Arthritis Research UK information line receives are from people with arthritis who are at the end of their tether. Despite the improvements and advances in treatment and care for people with arthritis and other long-term musculoskeletal conditions, we're only too aware that the needs of these people haven't been properly addressed, let alone met.

We produced this guide following the results of our Active Listening campaign in 2010. We asked people with arthritis to contact us to tell us what was really important to them, and the biggest problems they faced. Overwhelmingly, you told us that long-term pain was the worst thing about your arthritis. Forty per cent of people who got in touch stressed the impact of joint pain and stiffness on their mobility and the degree to which they were no longer able to manage their everyday activities. For many, arthritis has had a massive impact on their ability to do activities that ought to be simple and ordinary such as bathing, getting dressed, getting in and out of bed, and housework. Others were frustrated by their increased dependency on people around them, and said that their situation was made worse by the fact that their pain relief and medication offered only limited respite. A number reported feelings of fear, depression and anxiety about their increasing dependence on others, often combined with a sense of isolation and frustration

We hope this guide will help you manage your pain more effectively.

#### Living with long-term pain

It also became clear to us that many sufferers found their pain management ineffective and, as a consequence, they often turned to complementary and alternative therapies such as massage, herbal remedies and magnetic bracelets.

We don't pretend that we've got a miracle cure or that we have all the answers, but we hope that this guide will help you to take a more proactive approach to managing your pain and, at the very least, let you know that you're not alone.

There are sections explaining long-term pain, what you can do to help yourself, what you can expect from your GP and what other NHS services are available to you. We have also included information on what drugs and other treatments are available, as well as the details of other organisations who can provide further support and advice.

Often there isn't one single approach that will immediately cure long-term pain, and finding something that works for you may require a process of testing, adjusting, persisting, learning, and even practicing, to achieve a result. We have therefore made this report as interactive as possible to help you really think about your own experiences and answer the following questions:

- What pain relief approaches have I tried?
- Why haven't they been useful?
- What may help me in future?

During our Active Listening campaign in 2010, you specifically told us that:

Pain relief medication offered only very short-term pain relief, often only for an hour or so.

Other pain relief treatments such as injections and rubs were also ineffective.

Pain clinics offered only minor benefits.

Steroid injections offered some a few months' relief but pain often returned, and doctors were reluctant to offer more injections.



# **Case study**

# An all too common story of chronic pain

People with chronic musculoskeletal pain have different experiences but they often also have some experiences in common. The following is a made-up story by physiotherapist Gail Sowden based on the real-life struggles of many patients.

When her pain began, Pat was hopeful that her GP would be able to get rid of it or would make a quick referral to a more specialist service. Her friends told her their stories of similar problems and how they were sorted out relatively quickly. The healthcare professionals that saw Pat spoke confidently of people they had treated who have had a similar problem to her and who by following one particular treatment or another had achieved great results.

Pat found that different healthcare professionals gave her different diagnoses, explanations and advice, which was confusing. She was aware that, like her, many people's tests come back as relatively normal or don't explain the amount of pain the person is in. Pat saw one clinician who she felt said. or implied, that the pain was imaginary or psychological or 'all in her head'. This was very distressing and Pat felt angry about this for a long time afterwards. She had read on a website forum how people suffering with pain often experience many years where they feel they haven't been heard, believed or taken seriously.

# The pain didn't lessen

As well as conventional treatments, Pat borrowed or bought a variety of heating, vibrating and massaging gadgets and gizmos. She also tried different aids, appliances and adaptations (such as a walking stick) in an effort to try and reduce the pain. Occasionally they seemed to make things easier in the short term but she worried about becoming

#### Living with long-term pain

dependent on them or more disabled by them. As time moved on, despite these attempts to eliminate or reduce pain, Pat felt that the pain didn't lessen or didn't lessen for as long as promised. All these treatments and gadgets came at considerable costs in terms of money. dependence, side-effects, time and effort, as well as the emotional cost of managing the disappointment when yet another thing failed to deliver what it promised or what Pat had been told or had hoped for. The more time Pat spent trying these things, the less time she was able to spend doing rewarding and enjoyable activities.

Pat worried that if she did certain activities and her pain increased that this meant she was causing herself harm or damage. Not surprisingly, she tried to avoid doing these activities. She found that if she did less, sometimes her pain reduced for a short while – but this meant that she was doing less of the things that she enjoyed or that were important to her.

# Being in pain started to affect Pat's relationship

The combination of doing less but still being in pain started to affect Pat's relationship with her husband, and she found she was more irritable and short-tempered and that they were less able to do things together. Pat felt guilty when her husband or others did the tasks that she had previously managed. She didn't want to lose her independence, and found on a good day that she would try and make the most of it, only to pay for it

People with chronic musculoskeletal pain have different experiences but they often also have some experiences in common.

in terms of increased pain later. She found her concentration and problem-solving were not as good as they used to be, and worried that this might be related to all the pain medication she was taking.

Pat found that friends didn't invite her out as much as before and she tended to say 'no' to invitations, as she didn't know how she was going to be one minute to the next. She didn't want to let people down and worried if she said yes and went out that she would be holding the others back or would overdo it. She felt increasingly isolated and started to wonder if she might be getting depressed.

# She hoped the answer was out there

In spite of all this, Pat continued to hope that the answer was out there and thought that if she just tried harder, demanded more, asked to see another professional, or invested in some other gadget she would find the answer. Increasingly, well-meaning relatives and friends suggested things or advised she see a particular complementary or alternative therapist or try some type of new, often radical treatment. Whilst some of these treatments felt nice and relaxing at the time, they failed to provide any long-term reduction in symptoms or increases in activity. Pat felt increasingly desperate as she thought about how things used to be and how her life seemed to be falling apart.

Pat had heard about different injections and operations and her new GP agreed to refer her to try some injections. Unfortunately they didn't work, and although Pat was in severe pain she was told that she was not suitable for surgery. She was told that operations are only appropriate for a minority of people and that even in these people it might not help, particularly in the long term. In a way she was relieved that she wasn't suitable for surgery as she was aware from previous abdominal surgery that she'd had that there were potential risks and complications, no quarantee of success and often a long and difficult recovery period.

#### She started to lose confidence

The more Pat struggled to reduce or control her pain, the more she tended to avoid the things that were important to her, such as spending time with her family and friends, gardening, playing with her grandchildren, doing her hobbies and interests and going on holiday. She started to lose her confidence in going out of the house and in meeting people.

# A pain rehabilitation centre

Pat went back to her GP and asked about other treatments. He suggested another course of physiotherapy but also mentioned a new pain rehabilitation centre that had opened. Pat was keen to find out more about what the new service could offer her and asked her GP to refer her to it. Pat attended the service and was assessed by a team of different clinicians. They spent time finding out about her pain and how it had affected her. They explored Pat's current medication and her experience of treatments aimed at reducing or controlling pain. Pat's experience was that these hadn't led to long-term reductions in pain or increases in function. Rather than repeat treatments aimed at getting rid of pain or at reducing pain that had already been tried and failed, they suggested a different approach that would involve rehabilitation to help her to do the things that were important to her in life, with the pain. Pat was sceptical at first as she felt she'd already tried to do this and

#### Living with long-term pain

understandably didn't want to be in pain. They asked Pat to identify what she would like to be able to do in the future in important areas of her life, and outlined the purpose and structure of a group pain rehabilitation programme aimed at helping her to achieve her goals. Pat and the pain team thought that she would be suitable and might benefit from the group rehabilitation programme.

Pat attended the programme and felt that she had benefited from being with other people who had similar difficulties to her. The programme was hard work and at the end of it her pain was pretty much the same as before. However, she was able to do more of the things that were important to her. She had a better understanding of the choices available to her in a given situation and what to use as her guide in making decisions about what she did and how she went about doing it. She also felt less distressed by her pain and was less disabled. She was playing with her grandchildren again, socialising more and went on holiday for the first time in years. Overall, she felt that she had a much better quality of life and that she, not her pain, was now back in charge of her life.

# Further information







This case study is based, with the authors' permission, on one written by Dr Kevin Vowles and Dr Miles Thompson in a book chapter in 2011 (Acceptance and Commitment Therapy for chronic pain. In L. M. McCracken (Ed.) *Mindfulness and Acceptance in Behavioral Medicine: Current Theory and Practice* (pp. 31–60). Oakland: New Harbinger Press).

Gail Sowden is a consultant physiotherapist with the Interdisciplinary Musculoskeletal Pain Assessment and Community Treatment (IMPACT) Service in Staffordshire and the Arthritis Research UK Primary Care Centre at Keele University.



# Introduction to long-term pain

Pain is something we're all familiar with and will experience at some point in our lives, but it's likely that you're reading this because you've had pain for a number of months or perhaps even years.

# Section 1: Introduction to long-term pain

#### What is long-term pain?

Pain is something we're all familiar with to some extent and is something we'll all experience at some point in our lives. However, it's likely that you're reading this because you've had pain for a number of months, or perhaps even years, and the ways that pain has affected you may have been more significant than for other people. Long-term pain is often referred to by healthcare professionals as 'chronic' pain; likewise, short-term pain is often called 'acute' pain. Don't be surprised if you hear these terms used instead of the ones we're using in this guide.

The British Pain Society defines 'chronic' pain as pain that has lasted for more than 12 weeks or that has continued after the time you'd expect healing to have occurred following trauma or surgery.

Sometimes pain can be present when there are no visible signs of damage to your body or it continues after an injury has healed. About 10 million people in the UK live with long-term pain and this can have a significant impact on their daily lives, those of their families and the people who care for them. Many people with long-term pain struggle to stay in work – they may become unemployed or experience a change in their role in society and within the home.

#### Why do I have long-term pain?

If you have an underlying condition or disease that results in visible changes to your body, this can explain the reasons for your pain. For example, in some types of arthritis the structure or alignment of your joints may become altered so they no longer allow a smooth movement to be performed and bone rubs against bone.

However, sometimes pain can be present when there are no visible signs of damage to your body or it continues after an injury has healed. This type of pain can be particularly difficult to understand. Friends and family may think that your pain is 'just in your mind' and you can 'snap out of it'. This attitude can be distressing and if you experience it you may begin to question whether the pain is 'real' or not.

Many people may experience a mixture of both of these types of pain. For example, some people report persistent knee pain, which suggests they may have osteoarthritis, but their x-ray shows that the changes in their joint don't explain the level or pain experienced, or their pain persists after they've had a knee replacement.

#### Living with long-term pain

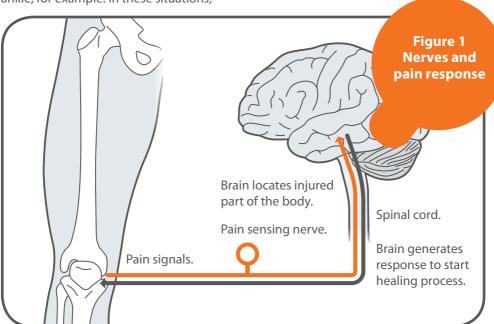
We don't completely understand the reasons for long-term pain where there's no obvious cause, but we know there are important differences between short-term and long-term pain in terms of how we process information between the body and the brain. We'll look at these differences below.

# What's the difference between short-term and long-term pain?

Pain is usually considered to be a warning sign to your body that damage, or the threat of damage, has occurred. It also helps the healing process as we protect areas that are hurting and use them less. This is particularly true of short-term (acute) pain, which you experience if you cut yourself, break a limb or sprain an ankle, for example. In these situations,

messages travel from the damaged part of your body through your spinal cord to your brain. Your brain locates the injured part of your body and generates a response to start the healing process and warn you that damage has occurred (see Figure 1). Your experience of pain is an outcome of those processes, and it's nearly always accompanied by an emotional response. Your emotional response will be unique because everyone has different experiences of pain, and it will also depend how bad the injury is. The pain usually disappears once the area has healed.

In long-term (chronic) pain, your experience of pain is different because the processes aren't the same as those described above.



An increase in pain in response to activity may make you feel more certain that there's something structurally wrong and lead you to move from one specialist to another...

...but what you really need to do is try and identify the root cause of your pain.

Living with long-term pain

Long-term pain occurs without an obvious injury or persists after the part of your body has healed. In this situation, pain no longer works as a helpful warning sign but as something that can incapacitate your life and alter your long-term function.

When you have long-term pain, your nervous system can cause you to feel pain without there being any damage to your body. Your nerves can trigger your body to think it's under threat and so you experience pain. Changes happen in your brain, spinal cord and tissues that result in a disruption of how messages are transferred and interpreted between your body and brain. This can mean that your nerves are more easily 'triggered' to react to external stimulation, so you experience light touch as painful or areas of your body simply hurt when you do activities that wouldn't normally be painful. Our brains and nervous systems are very complex, so it's often very difficult to identify why pain persists and how we can alleviate it.

You're the expert on your pain and the best person to manage it.

Our bodies are designed to protect a painful area, rest it and look for a cure, so our natural response is to reduce our activities and think that there's something structurally wrong that can be fixed. When your joints and muscles are rested for any length of time they start to become weaker and bones can lose some of their density. You become less fit and tire easily, so when you exercise you may feel very stiff. This may increase your pain, so you'll want to avoid any activity that causes this. An increase in pain in response to activity may make you feel more certain that there's something structurally wrong and lead you to move from one specialist to another in the hope of finding a cure. This is a very natural and understandable reaction, but it's unlikely to result in an improvement in your pain and can lead to increasing frustration.

# Types of long-term pain

#### Musculoskeletal Pain

Musculoskeletal pain comes from structures involved with your skeleton or its movement, for example muscles, tendons and ligaments. This type of pain is often experienced by people who have arthritis. You may experience flare-ups, which can cause stiffness and a feeling of warmth in the affected part when the arthritis is active.

#### **Neuropathic Pain**

Neuropathic pain is caused by damage or disease of the nervous system. You may experience burning and other sensations such as a persistent itch, pins and needles or shooting pains. This type of pain is particularly difficult to treat.

A recent research study showed that more than two-thirds of people with neuropathic pain were shown to still have pain when taking painkillers. When a nerve is cut or becomes altered by disease, it tends to 'fire' more easily, and sometimes spontaneously, so a constant sensation is experienced. Sometimes, the reverse happens and the nerve(s) become less sensitive so an area can feel 'dead' or numb. Ouite often, over-sensitivity and reduced sensation can be present together. Neuropathic pain can be accompanied by changes in skin colour and temperature over the affected area and these changes can fluctuate over the course of a day or even within the hour.

In conditions which typically include chronic widespread pain, such as fibromyalgia, or persistent pain in a single limb, such as complex regional pain syndrome, the quality of the pain experienced can be very much like that experienced in neuropathic and/or musculoskeletal pain but there's no evidence of damage to the body.

This type of pain is no less 'real', but it's usually generated by a disruption in the communication systems within the body rather than an obvious physical cause. Some people like to think of this type of pain as similar to a fault on the hard drive of a computer because it causes a wide range of persistent problems, but trying to isolate the cause and fix the problem is very difficult.

The types of long-term pain described above may be present on their own or as a combination. For example, some people with rheumatoid arthritis may also experience fibromyalgia, and they may feel different types of pain across these two conditions, with different areas of their body affected depending on which type of pain is most prominent. Having a combination of these types of long-term pain often means that the symptoms of each need to be treated in different ways because medications designed for musculoskeletal pain sometimes aren't effective in neuropathic pain and vice versa.

#### What can I do to help myself?

Pain is a very distressing experience and it can be difficult to ignore and just get on with life as normal.

Nobody else can experience your pain or fully understand what it's like to live with long-term pain. You're in the best position to understand your own pain experience and are the best person to manage it. However, because long-term pain is often accompanied by lost confidence, depression, anxiety and fatigue, it can be very difficult to feel motivated to seek help or change your lifestyle. In addition to this, your local community and healthcare services may not be the same as others around the country or you may simply not know what type of care or advice you need to help you manage your pain.

You may have already tried a wide range of treatments and therapies, and you'll

have personal preferences or beliefs about what works for you. You'll also be aware that some days seem better than others and will probably have developed a routine that has adapted to life with pain. Getting to know what helps you to lead a full and enjoyable life can be very helpful, but sometimes you can develop less helpful patterns of behaviour and beliefs. Remember that pain almost always comes with emotional consequences so it's important to include both your mental and physical health when considering your health needs.

Appropriate professional advice may help you, as well as support from family and friends. There are treatments and therapies available that can considerably help you to live a full and satisfying life despite still experiencing pain. These treatment strategies often need to be tailored to your personal needs, different aspirations and physical and mental health requirements.



Although everybody understands the word 'pain' means, it's still difficult to define. Put simply, it's a protective mechanism that alerts the brain when damage has occurred...

...but it isn't just a sensation, it has emotional effects on us too.

Living with long-term pain

Notes	

Living with long-term pain

Notes	

Living with long-term pain

Notes	

Sometimes it's difficult to explain the exact causes of long-term pain and this can also make it difficult to treat effectively...

...so it's important to work closely with your doctor to find what works for you.





# **About you**

This section will look at what you currently do to manage your pain and what other things you could try.

# **Section 2: About you**

Most people see pain as an abnormal or unusual sensation, and if you have longterm pain you probably experience it in the same way. This reaction is entirely understandable and is quite normal – after all, pain is supposed to serve as an alarm when something is wrong with your body. Short-lived (acute) pain and long-term (chronic) pain are both very common experiences. More than 60 per cent of people will have a problem with back pain, and between 15-30 per cent have persistent pain that affects their daily activities. More than 20 per cent of visits to GPs are for conditions that include pain. These percentages increase in older age groups. So if you experience recurrent or persistent pain, vou're not alone.

Try to identify things that are difficult so that you can confront your feelings towards them to help understand and deal with them.

This section will look at what you currently do to manage your pain and what other things you could try. You make choices every day, and sometimes pain influences these choices. These include your choices in using medication, seeking additional treatment, resting, asking for help, refusing or accepting invitations, exercising, eating right, keeping yourself active, educating vourself about your condition and so on. Sometimes these choices don't achieve your goals in the best possible way – if they achieve them at all – either because choices are made too quickly, such as through depression, or because all the options available haven't been explored. It's wiser, though far more difficult, to slow down, take a breath and carefully consider new things that could be done before you make a choice.

If you want to learn a little more about your pain and how it leads to and may be influenced by other problems, try completing the phrases found on the chart overleaf.

Once you've filled this in, you'll hopefully know a bit more about your experience of pain and the problems connected with it. After this we'll help look at what you're currently doing to help yourself.

# It's just pain - or is it?



If your pain is a significant problem, you may find that it's connected to other issues. These could include:

- sleeping problems
- reduced physical activity
- low mood
- spending less time with others
- missed work or retirement
- changes in your relationships or sex life
- · difficulty with concentrating and remembering
- additional symptoms like fatigue or weight gain
- side-effects from medications or other treatments.

You may even feel that these are bigger problems than the pain.

When we focus on things we're unable to do, that we've lost or feel uncertain, we tend to feel low, frustrated and anxious. But it's useful to recognise these feelings as legitimate, and even useful. And this depends on our ability to approach or confront them. If we can confront the feelings associated with life's challenges, then we can look more closely at the challenges themselves. By identifying and analysing things that are difficult, we can learn how they happen. With this clear knowledge we can deal with them more effectively.

Living with long-term pain

If you want to learn a little more about your pain and how it may be influenced by additional problems, try completing each of the following phrases.

Since my pain began:	Date:
I spend more time thinking about	
I spend less time thinking about	
I spend more time doing	
I spend less time doing	

Living with long-term pain

If you want to learn a little more about your pain and how it may be influenced by additional problems, try completing each of the following phrases.

Since my pain began:	Date:
I spend more time thinking about	
I spend less time thinking about	
I spend more time doing	
I spend less time doing	

Living with long-term pain

If you want to learn a little more about your pain and how it may be influenced by additional problems, try completing each of the following phrases.

Since my pain began:	Date:
I spend more time thinking about	
I spend less time thinking about	
I spend more time doing	
I spend less time doing	

Living with long-term pain

# What are you doing to manage your pain?

Below are some of the many methods and strategies people use to deal with persistent pain. Which ones have you tried? Shade the boxes to show how effective these methods were out of 5:

■□□□□ 1	box =	only	slightly	effective
---------	-------	------	----------	-----------

	5	boxes =	very	effective
--	---	---------	------	-----------

Method tried	Tried (tick)	Rating	Method tried	Tried (tick)	Rating
Taking medication			Modifying your home		
Resting			Seeking a clear diagnosis		
Seeing your GP			Denying you have pain		
Seeing another doctor			Trying to pace activities		
Seeing a physiotherapist			Acupuncture		
Taking time off work			Chiropractic treatment		
Distracting yourself			Homeopathy		
Trying to relax			Massage		
Stopping painful activities			Other alternative treatment		
Asking for help with tasks			Physical exercise		
Operations			Hydrotherapy		
Looking for information			Looking for the answer		
Using braces or aids			Complaining		

Living with long-term pain

# What are you doing to manage your pain?

Below are some of the many methods and strategies people use to deal with persistent pain. Which ones have you tried? Shade the boxes to show how effective these methods were out of 5:

<b>■</b> □□□□ 1 l	box = only	slightly	effective
-------------------	------------	----------	-----------

					5	boxes	=	very	effe	ctive	2
--	--	--	--	--	---	-------	---	------	------	-------	---

Method tried	Tried (tick)	Rating	Method tried	Tried (tick)	Rating
Taking medication			Modifying your home		
Resting			Seeking a clear diagnosis		
Seeing your GP			Denying you have pain		
Seeing another doctor			Trying to pace activities		
Seeing a physiotherapist			Acupuncture		
Taking time off work			Chiropractic treatment		
Distracting yourself			Homeopathy		
Trying to relax			Massage		
Stopping painful activities			Other alternative treatment		
Asking for help with tasks			Physical exercise		
Operations			Hydrotherapy		
Looking for information			Looking for the answer		
Using braces or aids			Complaining		

Living with long-term pain

# What are you doing to manage your pain?

Below are some of the many methods and strategies people use to deal with persistent pain. Which ones have you tried? Shade the boxes to show how effective these methods were out of 5:

<b>■</b> □□□□ 1 l	box = only	slightly	effective
-------------------	------------	----------	-----------

					5	boxes	=	very	effe	ctive	2
--	--	--	--	--	---	-------	---	------	------	-------	---

Method tried	Tried (tick)	Rating	Method tried	Tried (tick)	Rating
Taking medication			Modifying your home		
Resting			Seeking a clear diagnosis		
Seeing your GP			Denying you have pain		
Seeing another doctor			Trying to pace activities		
Seeing a physiotherapist			Acupuncture		
Taking time off work			Chiropractic treatment		
Distracting yourself			Homeopathy		
Trying to relax			Massage		
Stopping painful activities			Other alternative treatment		
Asking for help with tasks			Physical exercise		
Operations			Hydrotherapy		
Looking for information			Looking for the answer		
Using braces or aids			Complaining		

More than 60% of people will have a problem with back pain, and between 15–30% have persistent pain that affects their daily activities.

More than 20% of visits to GPs are for conditions that include pain.

If you want to achieve your goals it's important to keep in focus what will get you there.

# What are you doing to manage your pain?

The methods listed on the previous chart aren't necessarily good or bad – some of them are effective to a certain degree for some people, while some of them certainly aren't. You don't need to this list as a guide to methods you should try.

If this list doesn't seem to capture the things you've done very well, you might like to create a specific list of your own.

Some of these may come from the list we provided but you may have others. When you have your list, ask yourself the following questions about each method or strategy:

- Has doing it honestly helped your pain in a lasting way?
- Has it helped you to live the kind of life you want to live, especially in the long-term?

These may look like the same thing, but they're not – you may have experienced a treatment that reduced your pain but which didn't help you to participate in activities better. Does your answer for some of your methods differ depending on how you ask the question? For most people it does.

You should also consider whether the method paid off in terms of providing you with the ability to do more of the things you most want to do versus the time and energy you gave to it. If so, you might like to try this method more often. If not, you might like to change your approach. You can make notes that reflect your answers and not simply do it in your head, as it works better to write about these things and to get them out where you can look at them.

# Is it working?

When we have problems, we automatically try to analyse and solve them. But have you ever tried to solve a problem that didn't have a solution? Have you found yourself refusing to give up on a problem even though you weren't succeeding in fixing it? If you're like the rest of us, your answer will be yes. But at the other extreme, we sometimes feel confused or scared when we have problems, and we do nothing or withdraw. Knowing you own reactions to pain and to the other feelings that pain evokes can help you deal with long-term pain more successfully.

Whatever methods you use to manage your pain, you may feel the need to defend it as correct and necessary. As you look at your pain-management methods, see if you notice this tendency and, at the same time, get to the heart of how the methods are working for you.

As you look at your battle with pain, see if there's a pattern.



# Ask yourself the following:

- Do you feel that each of the ways you're trying to solve, manage or fix pain is successful?
- Is each method successful in controlling pain?
- Is it successful in improving your life?
- Do you ever feel like you're struggling and getting nowhere?
- Do you ever notice that sometimes trying to control pain actually stops you from doing what you want to do?

Note that this exercise isn't designed to find the right answer, although it might show you things you didn't realise before. It's mostly an exercise to practise letting your experience be your guide and using the quality of your life as a measure for the success of pain management methods. If there are methods that aren't working, and it's up to you to choose, perhaps you can stop them. This may then give you more time and freedom to experiment with other methods.

# A change of focus?

A way to get out of the habit of stubbornly refusing to give up or passively withdrawing from a problem is to focus on your goals – the positive achievements you want to reach. We say that if you want to achieve your goals it's important to keep in focus the circumstances that will get you there. Pain, fatigue or other symptoms can distract from these circumstances, especially if they're always dominating your attention.

Do the following simple exercise if you'd like to remind yourself that you have the ability to determine your own focus.

Put up an index finger in front of you face and stare at it.

- **1.** As you do this, what looks clear and what looks blurry?
- 2. Now shift your focus beyond your finger and notice what looks clear and what looks blurry?
- **3.** Which view shows you more of what is around you, gives you a more complete picture, and which one is a better way to see where you're going?

Sometimes we can be preoccupied with one issue or another that feels close in our experience, like the finger. Notice that these issues don't affect us the same way if we look at a wider view. A 'finger in front of your face' is one thing you can focus on, and you can always change your focus.

As you do this exercise, don't think about it too much or try too hard to figure it out. It's enough to simply notice what the experience is like of switching focus and seeing what's in front of you in a different way.

Consider this question: who is in charge of what you focus on?

Identifying specific goals that are desirable and realistic, and the steps needed to achieve them, will help you reach your aims.

#### What should I do?

When dealing with long-term pain, we sometimes tie ourselves into struggles that aren't very successful. We spend more time trying to get rid of the experiences that we don't want rather than seeking the ones we do want. These struggles can leave you feeling tired and frustrated.

In some ways, pain is like a bully. It demands that you pay attention and respond to it. One way to deal with bullies is to realise that all of their power is in their ability to intimidate, and when you're intimidated you try to do what they say so they'll leave you alone. The problem, however, is that doing what they say makes them more eager to return, and they often come back.

So another way to deal with bullies is to do what you want instead. And to do this, you'll need to identify precisely what it is you want. Consider a slightly modified version of the questions we asked earlier in the guide and complete the statements on the next table, overleaf. Keep in mind the mind-focussing exercise mentioned in the previous section.



### See table overleaf

See if you can identify activities where you want to focus more of your effort. Identifying specific goals that are desirable and realistic, and the steps needed to achieve them, will help you reach your aims, so consider setting yourself targets related to these activities. Prepare yourself for barriers along the way, but think about how you can reach your goals today or tomorrow, even if your actions are very small at first.

Give yourself an added boost towards your success by making a public commitment and telling someone about your goals and plans.

If you're having difficulty identifying activities that interest you and provide you with a sense of motivation, ask yourself this question:

 'If my pain and other health problems were taken away, what would I do and how would I spend my time?'

This is a good way to identify positive, healthy and interesting activities to pursue.

### Wrapping it all together

Attempts to seek treatment for the control or management of pain are useful when they work. But they can hold you back when they're ineffective. While it's normal to wrestle with pain, it can create a life focused on pain and not on other goals or activities. If you find yourself stuck in this trap, noticing that you're in it is the first step – and once you're aware of this then you're moving in the right direction. After that, letting go of trying to 'win' against pain can be helpful.

Sometimes it's only by letting go of this battle that you can win in another way, in achieving your goals. In a sense, you win as soon as you refuse to do battle.

Hopefully this section has encouraged you to be practical and determine what to do with your pain based on your own experience of what helps. We're not suggesting you should guit all treatments on some impulse to reduce intimidation by pain. Once your health is being managed successfully by you and the health professional caring for you, and you're clear in following your their advice, then you have choices. One way to make these choices is to be guided by your own experience. There will be times when you can wrestle with your pain or pursue your other goals, not both. It's up to you to choose.

If you want to achieve your goals it's important to keep in focus the circumstances that will get you there...

...ask yourself: who's in charge of what I focus on?

Now that I have pain:	Date:
I want to spend more time thinking about	
I want to spend less time thinking about	
I want to spend more time doing	
I want to spend less time doing	

Now that I have pain:	Date:
I want to spend more time thinking about	
I want to spend less time thinking about	
I want to spend more time doing	
I want to spend less time doing	

Now that I have pain:	Date:
I want to spend more time thinking about	
I want to spend less time thinking about	
I want to spend more time doing	
I want to spend less time doing	

Notes	

Notes	

Notes	

Because it's so difficult to explain what causes long-term pain, many people find it hard to show family, friends and colleagues how they're feeling...

...those people, in turn, may then find it difficult to deal with the problem.





# Where can I get treatment and advice?

This section provides an overview of the 'typical' treatment pathway for those living with pain, from your general practitioner to a range of more specialist services and healthcare professionals.

# Section 3: Where can I get treatment and advice?

In the previous section we looked at considering how you can take more control of your life while living with long-term pain, and this may have highlighted which particular areas of your life you'd like some professional help with to support you in your chosen goals. Your goals can be anything you choose, in such areas as family activities, time with friends, work, your health and fitness, or learning new ideas or skills. Perhaps you want to begin some volunteer work or maybe start walking regularly. You can discuss your goals with a healthcare professional, who can help support you in achieving them.

Section 3 provides an overview of the 'typical' treatment pathway for those living with pain, from your general practitioner to a range of more specialist services and healthcare professionals. You'll find a brief definition of the role of the healthcare practitioner or service followed by a description of what they can provide. It should help you to identify which services would be most helpful in the self-management of your pain, but it's important to note that access to services can vary across the country. Many of the services listed below are also available in private practice.

It's important to remember that everyone will have a different experience with their healthcare team, or specific practitioners. The information below is a 'best practice' guide which should help show you how to get the best out of your healthcare team.

# Getting the best out of your general practitioner (GP)

General practitioners (GPs) have many different roles. Perhaps the most obvious is their role as a primary physician and coordinator of care. GPs are highly trained and skilled medically. It's not uncommon to think that seeing a specialist will result in the best care. This may be true in some situations but it can also be counterproductive because it's easy for care to become very disjointed and lose focus without someone to coordinate it. especially for long-term conditions. Your GP is best placed to consider whether a medical problem really does need specialist input, which can be discussed and decided between you.

Living with long-term pain

GPs are often good at listening and offering reassurance. By understanding the problem fully it's easier to put things into context. This may not mean that the problem goes away, but by working in partnership with your GP a plan of action can be drawn up. This is especially important in the management of persistent pain. It can be confusing trying to tell apart 'new' pain and a flare-up of long-term pain, which can have many medical and non-medical reasons, and knowing when and when not to react (for example by ordering further tests) is essential.

It's not surprising that the assessment of persistent pain is very complex. Pain has both sensory and emotional parts to it that we can't easily separate. Long-term pain affects all aspects of day-to-day life and can often cause very significant disability and distress, which in turn can lead to worsening pain. This vicious cycle can sometimes be made worse by a sudden event, which causes additional stress or anxiety and perhaps impacts on your day-to-day function. It's easy to misinterpret worsening pain for a new medical problem, so it's important for an accurate assessment to understand this better.

If any healthcare provider focuses purely upon the physical aspects of your pain (the sensory parts, or what you feel), then they can miss a huge part of what pain really is. Even more importantly, if they try but fail to treat the biomedical parts and ignore any disability or distress, then they miss an

By working in partnership with your GP a plan of action can be drawn up.

important part of pain treatment. GPs are very well trained in exploring all aspects of medical problems and usually know how to treat problems related to pain.

Most of us are guilty at some stage of saving something and realising later it wasn't understood in the way it was meant, and clinicians are no different. This could be related to how it was said. what words were used, and sometimes even our body language. A recent study showed that patients had a better experience when they were spoken to in a positive way compared to when information was given in a negative way, so it's better if your doctor doesn't make a problem worse by saying alarming things. This means you may want to consider gently challenging the information you're given if you find it alarming or confusing and to ask for clarification if you're worried or unsure.

Long-term conditions such as persistent pain need a good long-term strategy to manage things effectively. GPs are often familiar with this. Living well despite pain is a skill which takes time to master. Your GP will be crucial to how you deal with long-term pain, so it's important that you try to build a relationship with them where you can speak openly and be listened to, ask questions and trust the advice you're given.

#### What can I expect from my GP?

Because GPs are often good listeners, they should usually be able to help you with problem solving. Sometimes the problem can't be fixed, but simply talking can be helpful.

Your GP should also know how to interpret symptoms and signs accurately. This can be vital in long-term conditions which can flare up for no obvious reason or co-exist with a new problem which may need further evaluation. Not prejudging a new problem and putting it all down to your existing condition without proper evaluation is essential.

Your GP should be able to use a short time effectively and prioritise the important issues if there are a few things to discuss. They won't know everything, but they'll know where to find answers. This may involve medical research, checking guidelines or referring to specialists for another opinion.

Being able to access a GP appointment at short notice is ideal but isn't always possible. Long-term conditions can become unstable and need closer monitoring, so you may want to discuss with your GP how best to get an appointment at short notice so you don't have to use out-of-hours services or unplanned care centres.

Managing long-term pain can be easier when the focus is placed upon things that help. This sounds obvious, but too often the emphasis can be placed on finding the right medication, a new procedure or an injection and can ignore other methods. This is like using different tools in a toolbox. GPs can help sort out the different tools that work best for you.

GPs can help sort out the different tools that work best for you.

# What types of treatments can GPs prescribe?

Often one of the problems of long-term pain is finding effective treatments. Generally speaking, medications used for this type of pain are less predictable in terms of effectiveness compared to those for short-term pain, and sometimes the side-effects are significant.

In addition to simple painkillers, GPs often prescribe anti-inflammatory medicines (diclofenac, ibuprofen) or opioids (codeine, dihydrocodeine). Occasionally medicines that aren't traditionally used to treat pain can be prescribed, for example anti-seizure medication like gabapentin, which was originally developed to treat epilepsy, can be effective for neuropathic pain. Anti-depressants are also commonly used to treat long-term pain, whether you have depression or not.

#### Who can GPs refer to?

GPs are good at knowing where to refer you to if you need other treatments. However, you may also find it helpful to take this guide with you when you meet with your GP to help steer your discussions.

Your GP isn't just there to pass you on to other services but are an expert and guide regarding further opinions. The disability and distress that often comes with long-term pain can sometimes be helped with the following, and your GP can help you get access to these services if necessary:

- exercise to maintain fitness and general health
- occupational therapy to help with daily living and functionality
- psychology to help optimise coping strategies and living well
- physiotherapy for specific musculoskeletal problems
- other doctors for second opinions.

The initial aim of a pain clinic will be to reduce the intensity of your pain as much as possible.

Your GP may have known you and your family for a long time, so they may be able to give other clinicians important information. This can help avoid situations where other clinicians may 'pre-judge' your situation before seeing you based on inadequate information on referral.

# Your GP will be able to refer you to all of the following:



- Pain clinice
- Pain medicine specialists
- Psychologists
- Rheumatologists
- Physiotherapists
- Occupational therapists
- Hand therapists
- · Orthopaedic surgeons
- Podiatrists
- Rheumatologists
- Neurologists

### Pain clinics/ pain management centres

Pain clinics and pain management centres offer a multidisciplinary assessment, advice and treatment service for patients with long-term pain. They're generally led by consultants in pain medicine and anaesthesia who work alongside clinical psychologists, specialist nurses, neurologists, physiotherapists, occupational therapists and occasionally alternative practitioners. There currently aren't many pain clinics in the UK, which means there may be a long waiting list, but they're still worth pursuing as part of your treatment.

#### What can I expect from the pain clinic?

Most clinics accept referrals from GPs, hospital consultants and sometimes from other allied healthcare professionals. You'll usually be assessed by a consultant pain medicine specialist, who'll take a comprehensive history, perform a clinical examination and order any relevant tests. In most cases a specific diagnosis will be established in order to determine the most effective approach to treatment.

The initial aim of the pain clinic will be to reduce the intensity of your pain as much as possible, and ideally to get rid of it completely. It's often impossible to completely relieve the pain and so the secondary aim of pain clinics is to reduce the impact that the pain has on your life.

Wide ranges of treatments are available in pain clinics, including drugs, physical techniques and psychological support.
Once the pain consultant has reduced the

#### Living with long-term pain

intensity of your pain with medication and/or injection therapy, they may refer you on to other members of the multidisciplinary team for further help.

Most pain services also offer a pain management programme, usually on an outpatient basis but occasionally on a residential basis. Pain management programmes are multidisciplinary, group-based treatment sessions which aim to lessen the impact of long-term pain. These programmes are generally led by psychologists with additional input from nurses, physiotherapists, occupational therapists and pain physicians (see also 'Cognitive behavioural and other psychological therapies').

#### Pain medicine specialists

Pain medicine specialists are doctors who train in general medicine before specialising as anaesthetists and taking further training in pain medicine. They sometimes continue to work both as anaesthetists and as pain specialists. Pain medicine doctors work in multidisciplinary teams alongside other healthcare providers such as psychologists, physiotherapists, clinical nurse specialists and occupational therapists.

Pain medicine doctors are familiar with all of the various techniques used in the treatment of pain which are outlined in this document. They'll be able to advise patients on which treatment package is the most suitable for their particular condition.

#### **Psychologists**

There are many different kinds of psychologists. All psychologists providing treatment are registered as 'practitioner' psychologists within the Health Professions Council (HPC). Clinical psychologists are primarily interested in mental health problems, such as depression and anxiety-related disorders, although they work with people with many different kinds of health problems. Health psychologists or clinical health psychologists are mainly interested in physical health and illness. More particularly, they focus on how a person's behaviour and psychological influences on their behaviour can interact with their health state, their symptoms and their daily functioning. Diet, exercise, smoking, disease management strategies, patterns of daily life, and following doctors' advice are all forms of behaviour that psychologists are trained to understand and to modify when needed.

A psychologist can help you to manage symptoms of pain and fatigue, keep healthy habits, follow methods to reduce disability and deal with other challenges more skilfully. Many psychologists use treatment methods that are referred to as cognitive behavioural therapy or CBT. The role of psychology is to use principles developed from research into human experience and behaviour to help you make changes in your behaviour to live your life more effectively.

#### **Neurologists**

Neurologists are specialists in the diagnosis, treatment and care of disorders of the nervous system. Some neurologists have expertise in the immune system, the use of electrophysiological tests, the peripheral nervous system or muscle problems.

Your neurologists will have trained at medical school and for several years following this in both general medicine, based in hospitals, and at recognised neurology training units. They work in hospital and as part of a team of therapists including specialist nurses, physiotherapists and occupational therapists.

Diagnosing neurological disease can be challenging and is based on an examination and tests.

Most neurological conditions can be managed, but often can't be cured, so patients can see their neurologist over many years.

#### Rheumatologists

Rheumatologists are specialists who are trained in diagnosing and treating arthritis and other rheumatic diseases. Some rheumatologists have expertise in pain from the back and soft tissues, diseases of the bone, including osteoporosis, autoimmune diseases or children's arthritis. They work at community hospitals as well as in larger hospitals.



Living with long-term pain

They work with other professionals, such as specialist nurses, physiotherapists and occupational therapists, as part of a multi-disciplinary team.

The majority of patients who regularly see a rheumatologist have inflammation in their joints, usually from rheumatoid arthritis, but there are many different types of arthritis. Diagnosing inflammatory arthritis is sometimes challenging and can require more than one visit. It's often necessary to have blood tests and x-rays, and sometimes further imaging using MRI, ultrasound and other scanners.

Most rheumatologists will be able to give you painkillers and related medicines. They also prescribe drugs that affect the immune system such as methotrexate and the newer biological therapies. These treatments can also provide some pain relief.

Unfortunately, most types of arthritis can't be cured, but symptoms can be controlled to some extent with medication. Patients may therefore see their rheumatologist over many years.

#### **Physiotherapists**

Physiotherapists help people to get the best quality of life possible by maximising movement and functional abilities. They're registered with the Chartered Society for Physiotherapists. They work within many areas of healthcare to promote health, prevent health problems, treat specific problems after injury or illness and rehabilitate those with long-term disability. This means that physiotherapists

Most pain services also offer a pain management programme, usually on an outpatient basis.

work in many different places, including hospitals, health centres, sports centres, schools, private clinics and workplaces. Community physiotherapists even work with people in their own home.

Your physiotherapist will have completed a specific university degree related to physiotherapy and will have learnt about the biological nature of health and illness as well as understanding how psychological factors influence the course of recovery. Most physiotherapists, especially those working in pain management, use a biopsychosocial approach to their treatment, which means your physical, psychological, emotional and social wellbeing are considered during assessment, diagnosis, treatment and management planning.

Physiotherapists use a variety of skills, including exercise, manual therapy, electrotherapy and education to aid recovery of movement dysfunction and maximise movement potential, which is central to your health. All physiotherapists have some expertise in assisting those in pain but the level of experience may be variable. You may be referred, in the first instance, by your GP.



#### Living with long-term pain

Depending on where you live, you may also be able to refer yourself to your local physiotherapy department. Specialised physiotherapists in pain management may be most helpful for you.

Many physiotherapists work within an multidisciplinary pain team and make their unique contribution through exercise-related strategies, lifestyle advice and other self-management techniques, often within a cognitive behavioural framework (see below), to lessen the impact of pain, restore activity levels and help you achieve your valued goals at home and work.

#### **Occupational therapists**

Occupational therapists (OTs) are registered with the Health Professions Council (HPC). They're health and social care professionals who are experts in helping people of all ages carry out activities that have become difficult or impossible as a result of illness or disability. OTs working within hospital settings provide treatments, advice and education about how to improve function within the context of your specific condition.

Occupational therapists specialising in rheumatology generally work within the hospital setting and provide treatment to both inpatients and outpatients. The rheumatology OT will evaluate your pain as part of their assessment and discuss and advise you about ways you can improve how you function within the limits of your pain.

The role of OTs working in social care is to assess your home needs, which often

involves meeting with you at home. Social care OTs are experts in advising on adapting your home or providing equipment to suit your needs. This work is carried out in close collaboration with local councils and health trusts.

#### **Hand therapists**

Hand therapists are Health Professions Council (HPC) registered occupational therapists or physiotherapists who have done further training to specialise in treating conditions affecting the hands, arms and shoulders. The aim of hand therapy rehabilitation is to get your hand working as well as possible following injury, disease or deformity affecting the upper limb. Hand therapists can identify and evaluate difficulties associated with persistent pain that affect the hand and arm. Rehabilitation involves advice on exercise, preventative care, aids to daily living and work-based activities. Hand therapists often work alongside orthopaedic surgeons to plan and implement treatment after hand or arm surgery in order to aid recovery.

#### **Orthopaedic surgeons**

Orthopaedic surgeons are specialists in operations on bones and joints, as well as tendons and ligaments. They may specialise in a particular region or joint, and some may also specialise in a particular technique such as joint replacement, arthroscopy or resurfacing procedures.

Your orthopaedic surgeon will have studied at medical school before training as a general surgeon and then At least 30% of people in the UK use complementary and alternative medicine each year.

in orthopaedics for several years before becoming a consultant. Orthopaedic surgeons work in hospitals and depend upon access to operating theatres and the support of the theatre team, as well as the anaesthetist. They work in teams of junior and senior surgeons in the orthopaedic department, but they also usually work with physiotherapists, occupational and hand therapists as part of rehabilitation after surgery.

The majority of patients who see an orthopaedic surgeon will have been referred so they can consider an operation. Many patients won't have surgery for a number of different reasons. The surgeon will confirm the diagnosis and explore what treatments have already been tried. Any decision to operate will be a balance of several different factors, including your personal view, and can sometimes be a complicated process.

Operations can be very successful in reducing the amount of pain that a patient experiences, but this potential benefit needs to be balanced against the potential risks of surgery, including

any possible problems from having an anaesthetic. Your surgeon can advise you on the disadvantages and possible side-effects, how likely you are to experience them and the likely time you'll need to get back to normal afterwards.

#### **Podiatrists**

A podiatrist/chiropodist is a Health Professions Council (HPC) registered professional who specialises in the assessment, diagnosis and treatment of basic and complex lower limb conditions, especially in the feet. Podiatrists work in both National Health Service (NHS) and private healthcare settings.

They have a role to play in keeping people moving, providing symptom relief and improving quality of life for people with arthritis. Long-term pain in the feet is surprisingly common, especially in older people or people with conditions such as arthritis or diabetes. Other lifestyle factors such as too much or too little activity, poor diet and smoking can also increase the risk of chronic foot pain.

The foot is very complex and is made up of 26 bones, 33 joints and over 100 muscles and ligaments. This complexity, combined with its role in bearing all of the body's weight, makes the foot susceptible to arthritis which can result in deformity, poor function and soft-tissue problems such as corns and calluses. Long-term foot pain can be caused by several types of problem, the most common being soft-tissue strain and mechanical joint pain with and without arthritis.

# How would complementary therapies help me?

Many people with chronic pain turn to complementary medicines and therapies when they become frustrated with the lack of effectiveness of more conventional approaches to pain relief.

Arthritis Research UK has produced two publications aimed at helping you through the confusing array of available complementary medicines and therapies, with the aim of informing you whether there's scientific evidence to support the clinical effectiveness and safety of a range of products you may encounter. Sometimes claims for effectiveness are made, but these aren't substantiated by hard evidence.

The first report, Complementary and alternative medicines for the treatment of rheumatoid arthritis, osteoarthritis and fibromyalgia, looks at current clinical trial data for a number of products taken orally or rubbed onto the skin, such as glucosamine sulphate, capsaicin gel and rosehip, and scores them between one

and five for effectiveness and either red, amber or green for safety.

Our second report, Complementary therapies for the treatment of rheumatoid arthritis, osteoarthritis, fibromyalgia and back pain, follows a similar format, but considers physical therapies such as yoga, t'ai chi and magnet therapy.

#### **Charity and voluntary groups**

There is a wealth of charities and support groups across the UK who provide reliable health and self-management information on individual conditions and generic topics such as pain management.

Many also provide direct services such as free phone helplines, local support groups and online forums where you can talk to others going through similar experiences. You can find a comprehensive list of national support groups and organisations at the back of this guide.

You can also find out more about local groups by asking at your library.

#### Further information: www.arthritisresearchuk.org





REPORT: Complementary and alternative medicines for the treatment of rheumatoid arthritis, osteoarthritis and fibromyalgia



REPORT: Practitioner-based complementary and alternative therapies for the treatment of rheumatoid arthritis, osteoarthritis, fibromyalgia and low back pain

There are pain management clinics available, specialising in the care of long-term pain. Your GP should be able to refer you for advice and help...

...the main aims are to reduce your pain and lessen its impact.

Notes	

Notes	

Notes	

Be careful of the many unconventional treatments that you may find advertised in magazines or online which have little or no scientific evidence...

...always discuss new treatment options through with your GP first.





# Specific treatments and therapies for long-term pain

This section provides details on the particular therapies and treatments that are commonly used to help people live with long-term pain that would normally be available under the NHS.

# Section 4: Specific treatments and therapies for long-term pain

The previous section provided a description of which healthcare professionals and health services can help you with the management of your pain. This section provides details on the particular therapies and treatments that are commonly used to help people live with long-term pain that would normally be available under the NHS. It also includes self-management strategies and ideas on how you can use these within your daily life. It's by no means an exhaustive list, as people with long-term pain tend to try a very wide range of treatments in the hope of finding some relief from their pain or even a cure. It's very understandable that you might want to try anything and everything. Unfortunately, there are many unconventional treatments that

You should review your medication on a fairly regular basis to make sure you're getting the best balance.

you may find advertised on the internet or in magazines which have little or no scientific evidence to prove they do any good, so you need to be realistic about what's working for you.

The treatments and therapies suggested here are all recommended by registered healthcare professionals and have been shown to provide relief from pain in large groups of people.

#### **Drugs**

There are a many different analgesics (painkillers) available and a lot of other drugs can be used in the treatment of pain. For this reason, we'll only give a brief outline of the possible drugs used for pain. You should discuss your own personal treatment with your GP.

The use of drugs to treat pain is based on the World Health Organisation (WHO) analgesic ladder. This is a three-step approach starting with simple painkillers (such as paracetamol) and non-steroidal anti-inflammatory drugs (NSAIDs). The second rung consists of the weak opioids such as codeine, dihydrocodeine and tramadol. The third rung of the ladder is the strong opioids such as morphine, oxycodone, fentanyl and buprenorphine. The principle is to start at the lower rung of the ladder and progress upwards until you reach a satisfactory level of pain relief.

Table 1 Common examples of analgesics

#### PAIN LEVEL

	Mild	Moderate	Severe
		ТҮРЕ	
	Simple non-opioid analgesics e.g. paracetamol, aspirin, ibuprofen	Compound analgesics e.g. co-codamol, co-codaprin, co-dydramol	<b>Opioid analgesics</b> e.g. codeine, tramadol, morphine
What are they?	The most common form of analgesic, also including non-steroidal anti-inflammatory drugs (NSAIDs)	A combination of drugs in one tablet, usually including paracetamol, aspirin and codeine	The strongest types of painkiller
What are they used for?	Mild to moderate pain, for example headaches, injuries and osteoarthritis, or as an addition to stronger painkillers	Mild to moderate pain, for example injuries and osteoarthritis, or as an addition to NSAIDs	Moderate to severe pain caused by osteoarthritis, or as an addition to NSAIDs for severe pain
Where do I get them?	Over the counter at supermarkets and chemists, although some NSAIDs are only available on prescription	Milder forms are available over the counter, but stronger types are only available on prescription	Only available on prescription
What are the common side-effects?	Paracetamol has few side-effects but high doses can cause liver damage NSAIDs have more side-effects, particularly on the stomach	Compounds made from codeine can cause constipation, nausea and loss of concentration	Nausea and vomiting, constipation, drowsiness and dizziness
What else should I know?	Shouldn't be used at high doses for long-term pain Paracetamol and some NSAIDs are available as suppositories	Can be used instead of NSAIDs if these can't be taken for any reason	Can cause more side- effects compared with non-opioid types

Remember that fear, anxiety, sadness and frustration are entirely normal reactions to long-term pain.

Alongside painkillers, there are many other drugs which can be introduced at any time while progressing up the WHO analgesic ladder. These drugs are commonly referred to as adjuvant drugs, which means they were originally used for something other than pain. The most common adjuvant drugs used in the treatment of pain are antidepressant drugs and anticonvulsants or antiepilepsy drugs. The most widely used of these are the antidepressant drugs amitriptyline and duloxetine and the anticonvulsant drugs gabapentin and pregabalin.

Most drugs for pain are taken by mouth but some are available as patches, ointments or under-the-tongue tablets. Injected medication should be avoided in the treatment of long-term pain conditions due to potential undesirable side-effects.

Drugs used in the treatment of pain will often need to be taken on a long-term basis and will very rarely cure the condition. Most drugs have side-effects, so when using drugs for pain you need to find a balance between the beneficial effects of the drugs and any actual or

potential side-effects. It's advisable to review your medication on a fairly regular basis to make sure that you're getting the best balance.

# Cognitive behavioural therapy and other psychological therapies

Cognitive behavioural therapy (CBT) is a term used for a wide range of psychological approaches designed either to manage symptoms of mental or physical health problems or to change behaviour so that your ability to function on a day-to-day basis is improved. All forms of CBT are based on the idea that our thoughts, beliefs, feelings, behaviour and the situations we're in interact with each other. For instance, thoughts and beliefs can influence our behaviour; our behaviour can influence our feelings: situations affect our behaviour and so on. CBT includes assessing and understanding how these interactions create problems for people and then modifying these interactions in targeted ways so that the problems can be improved.

Within physical health, psychologists in particular often teach coping skills. This can include relaxation methods, methods for working with thoughts and beliefs, activity management methods (such as goal-setting and pacing methods) and methods for working with painful or discouraging moods. These latter methods can include what is technically called 'behavioural activation' for depression and 'exposure' for anxiety or fear. These are highly effective ways to become more active when low mood is

associated with withdrawal from activity, and ways to systematically confront the sources of fear and anxiety when these experiences have led to patterns of avoidance. These descriptions may sound complicated but it's important to know that CBT isn't simply 'having a chat' or seeking advice, but a process of learning new skills and capacities so that you can handle your challenges in life more effectively.

There are studies of CBT for arthritis that were done as early as the 1980s, so it's a well-established approach that is known

Another approach that's becoming more and more popular to treat both mental and physical health problems is called mindfulness or mindfulness meditation. This is a method for regulating your focus of attention so that it's more connected to the present moment – more aware and open – and leads to actions that are less impulsive or less driven by distress. Mindfulness is sometimes called paying attention, moment-to-moment, to experiences as they're actually happening and not just your thoughts about experience.



It's unusual and difficult to understand mindfulness just by its descriptions – it's better to investigate it directly. There are many psychologists and other professionals or trainers who provide training in mindfulness to help people with health problems. It can help people with arthritis and related problems.



# If you'd like to do a very simple mindfulness-type exercise, try the following:

- **1.** Whatever you're doing right now, pause.
- **2.** Now look around and notice five things you can see.
- **3.** Listen carefully and notice five things you can hear.
- **4.** Now focus on sensations on the surface of your body and notice five things you can feel.

If you're like other people who try this simple exercise, you might find that you feel more focused and your mind seems less busy after you do it. By the way, this particular exercise is based on one described by a physician and therapist in Australia – his name is Russ Harris.

Russ and other professionals, including Tobias Lundgren, JoAnne Dahl and Steve Hayes, are researchers who've written quite a lot and produced books and workbooks you might find useful.

# Physical rehabilitation and self-management approaches

#### **Pain and movement**

Long-term pain, for whatever reason, affects the way in which you move your body. You may, for example, stop using specific joints properly in an attempt to minimise the pain, and you may reduce your overall activity. This results in a steady loss of joint mobility, muscle strength, co-ordination, balance and function – and it doesn't stop the pain. In protecting the painful part via non-use or misuse you stress other parts of your body, which can result in secondary pain.

Increasing physical activity and understanding the effect of good posture during activity is vital to your future health. Not only will an increase in physical activity have a positive effect on your ability to carry out daily tasks, such as climbing stairs or opening jars, it'll make you feel better in yourself, give you more energy and enhance your ability to sleep. All of which may help you to cope with your pain more effectively. Importantly, increasing your daily physical activity will help in controlling your weight, which is especially vital if you have leg pain.

### How can I increase my physical activity?

There are many ways in which you can increase your daily physical activity to maintain or improve physical fitness. Simple things like parking your car further away from your destination will allow you to walk a little more. In time this will lead to small but important improvements in your

physical fitness. While strategies like this accumulate to provide benefit, considering more formal ways of increasing physical activity is also important.

Community activity/exercise classes are an excellent way of increasing physical activity and have the added benefit of meeting other people.

Leisure or community centres, libraries and GP surgeries often hold details of local activities, many of which involve different forms of exercise. One activity of particular benefit to your cardiac health is walking, and the 'Walking for Health'

initiative has over 600 local schemes, which means that there's likely to be one close to you. Health walks are designed for all abilities (and disabilities) and are led by trained walk leaders.

While the leader and the walking group may enhance your motivation, paying attention to the way you walk rests with you.

There are many ways in which you can increase your daily physical activity to maintain or improve physical fitness.

Remember to stand tall with stomach pulled in when you're walking as correct posture minimises the strains on your body.

Other community activities which have been shown to offer significant health benefits and have a moderate effect on pain are t'ai chi and qigong. Both are examples of Chinese exercise and consist of gentle, low-impact slow movements which can be practiced either when standing or sitting. It's therefore a suitable form of exercise for anyone, whatever their physical challenges.

Yoga has been shown to be beneficial for people with low back pain, and a clinical trial funded by Arthritis Research UK found that a specially devised 12-week yoga programme led to improvements in back function, and enabled participants to perform everyday activities more confidently than those offered conventional forms of GP care.

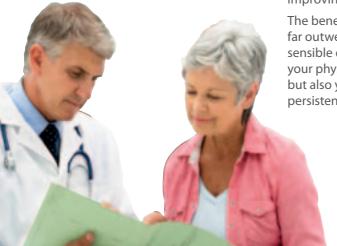
Whatever type of physical activity you prefer, it's important that your instructor is properly qualified. There's little

regulation of exercise professionals in the UK, but taking time to speak to the teacher before starting an activity and communicating your needs will give you some reassurance as to whether the instruction will be beneficial.

Increasing physical activity through community groups and adopting exercise strategies as a lifestyle choice provides the best long-term strategy to persistent pain. But there may be times when you need help from a physiotherapist – for example, if you have particular difficulty with daily activities, such as rising from a chair, or if you experience falls, develop pain or lose function in a new area.

Your physiotherapist will assess your difficulties before teaching you specific exercises to move your joints, strengthen your muscles and enhance your coordination and balance. Remember, you'll only feel the benefit of any exercises if you follow the instructions given to you. Your physiotherapist will also advise on local community initiatives to assist you in maintaining and improving your physical fitness.

The benefits of increasing physical activity far outweigh those of doing nothing, and sensible exercise will not only improve your physical and mental wellbeing but also your ability to cope with persistent pain.



Living with long-term pain

#### **Hydrotherapy**

Many people with long-term pain find exercise in warm water is a comforting and effective way of moving the joints fully and stretching and strengthening the muscles. The warmth of the water soothes pain and the buoyancy reduces the stresses on your joints. Hospital hydrotherapy pools provide an excellent environment, but sadly a lack of such pools means that access can often be limited. However, many facilities offer out-of-hours access on a time-limited and paid basis, and you should contact your local hospital for details.

Local swimming pools tend to be cooler than hydrotherapy pools, but exercise classes such as aqua aerobics provide a safe and fun way of exercising. Alternatively, local hotels with spa or hydrotherapy facilities may provide swimming and/or exercise in water classes.

#### Pain and your daily activities

Long-term pain can greatly affect your ability to carry out daily activities. You may find that certain movements are particularly painful so you avoid doing them altogether. But it's important to remain as active as possible as lack of use can lead to loss of strength and dexterity. An occupational therapist (OT) will be able to give you advice on maintaining and improving your function within the limits of your health condition.

# **Maintaining healthy joints**

It's important to understand the way in which your condition affects your joints and causes pain so that you're aware of It's important to understand the way in which your condition affects your joints and causes pain.

how best to move without unnecessary strain or force. An occupational therapist (OT) specialising in rheumatic conditions can explain how to effectively use and protect the health of your joints as well as minimise pain. This may involve changing the way you normally do things – for example, learning different ways of doing a particular task or using aids like jar openers and key turners to help you.

You may have an opportunity to try out a range of small gadgets to see what works for you, and your OT can advise on where to purchase these items. Suggestions on how to reorganise your home or work environment, such as relocating items that you use most so they're within easy reach, may also help.

# **Splints for painful joints**

A further option that an occupational therapist (OT) may suggest is to wear a splint in order to reduce pain in your joints and help function. 'Splint' is a term that covers a variety of devices that are mainly worn on the hand but can be for other parts of the body such as the neck or foot. They can be made from soft, flexible material

such as neoprene, which can be readymade items or tailor-made by the OT from a type of plastic to specifically fit your joints.

Splints may be suggested for a variety of reasons, such as to rest the joint and reduce pain or to correctly position the joints to prevent deformity and to improve function. The OT will recommend when you should wear the splint and how long you should wear it for. This is because overuse can lead to muscle loss due to lack of joint use. You should also take it off regularly to allow your skin to breathe.

#### **Conserving energy**

Fatigue is common in people with arthritic conditions and is often related to pain. A key aspect in managing pain and fatigue is striking a healthy balance between activity and rest, otherwise known as pacing. Rest helps to recharge the batteries and enables you to keep active for longer. Short breaks of 3–5 minutes every 30–45 minutes to sit and rest the joints are recommended. Alternatively, 'microbreaks' of 30 seconds every 5–10 minutes may be more suited

Occupational therapists may suggest wearing a splint in order to reduce pain in your joints and help function.

to your lifestyle. The trick with rest and pacing is to be sure that they're helping you achieve your goals. Obviously resting too much is a risk, but keeping your goals in mind and scheduling yourself stimulating, productive, and enjoyable activities to do each day may help.

Balancing different levels of activity can also help with energy conservation. There's a temptation to do heavier activities on a 'good day' and physically suffer for a while after. Your occupational therapist, physical therapist or psychologist can advise on how to improve your energy levels by planning to evenly distribute lighter and heavier activities throughout the week. Use the chart at the end of this section to record your daily activities and highlight periods where pain or fatigue caused difficulties. You may be able to spot and avoid patterns of activity which cause you problems.

#### Relaxation

Many people find relaxation an effective way of managing their pain. Relaxation helps to reduce stress and can produce a general sense of wellbeing. Various forms of relaxation are available and techniques can be easily used to complement pain-relieving medication. Listening to relaxation audio tracks, either downloaded from the internet or via a DVD, is popular. Some approaches take you off on a scenic journey describing restful locations such as a beach (known as guided imagery), while others focus on tensing and relaxing various parts of your body (progressive muscle relaxation) or use other visualisation approaches.

#### Living with long-term pain

It's worth trying a few different approaches to decide what works best for you.

Self-directed forms of relaxation include meditation, which involves concentrating on breathing or a sound (called a mantra) that you repeat to yourself. Alternatively, specific breathing techniques can be used which, once mastered, can be performed on the spot to relieve anxiety. You'll probably need to attend a class to practice in order to perfect the technique, but the effectiveness of relaxation improves with practice.

Just as with pacing and rest, it's best to apply relaxation in a way that promotes the activities you want to do and that serve your goals. Believe it or not, it's possible to relax too much. Sometimes brief methods of relaxation or methods that you can incorporate into your activities are best. Long imaginary exercises that function as a form of escape from reality are perhaps less useful, particularly if done too often. Finally, as with anything else, practice is needed to truly master the ability to relax effectively whenever it might be helpful.

# Getting a good night's sleep

Pain often affects getting off to sleep or interrupts it. A lack of sleep frequently results in feeling more pain, which contributes to an unhealthy cycle of sleep deprivation due to pain. Establishing a regular bedtime routine that may include a warm bath, calming music and relaxation can improve your ability to sleep. Other factors such as a supportive

pillow, avoiding caffeine or watching TV may also help. Your occupational therapist can discuss different approaches with you and identify areas that might improve your sleep.

People often automatically consider sleeping medications if they're struggling with sleep. These are probably only partially effective for most people and aren't best for long-term sleep problems. On the other hand, there are highly effective psychological methods for improving sleep. If modifying your night-time routine alone isn't enough, once again methods of CBT can be useful here. Particularly if you find that you're spending long hours in bed and not sleeping during many of those hours, or if you're sleeping more than you want during the day, there are treatments you can consider.

When patterns like this happen we say that you have low 'sleep efficiency'. This literally means that for the time you spend trying to get sleep you aren't getting enough.



Treatment to reverse this pattern includes using methods that combine or 'compress' all of your sleep time into night time hours, helping you to first sleep efficiently and establish a regular pattern of being asleep and awake, and then later to sleep enough. Your GP or a psychologist can help you with this if you ask for more information on CBT for insomnia.

#### **Coping better at work**

Pain is often a challenge to remaining in work. Learning practical things that you can do yourself to help manage the pain, such as joint protection, pacing, exercise and relaxation, will help. If your company has an occupational health advisor whose role is to support the health of employees at work, you may wish to approach them for advice.

Occupational therapists can advise on improving your job by evaluating work tasks in order to modify and reduce the effort required. They may recommend changes to your physical working environment, and they can provide support by liaising with your employer. Some may carry out workplace assessments with you. It's important to reach a good work-life balance that will help you to continue working.

# **Summary**

In summary, there's a lot you can do if you're interested, if you choose, and if you stick with it. You may find that it helps to be more informed about your condition. Here we've provided you with a step along the way in that process of learning. Likewise, you may find that it

helps to know what treatment providers and treatments there are, and what these have to offer you. This isn't to say that you need to see them all, it's just to know that they're there. Should your particular circumstances require it, you can perhaps first speak with your GP and proceed from there. The main point is that the more informed and aware you are, the more you'll be able to take the driver's seat in managing your own health and functioning.

A few times in this guide we've asked you to reflect on your current circumstances and your experience, asked you to consider your goals in life, and whether you're achieving them. We know that just focusing on pain and illness isn't very interesting after a while and it can't be the complete solution. Whatever your health condition, as important as that might be, there's more to you and to your life than just your health condition. Maybe you'll see that taking this wider view more often provides a sense of encouragement and the feeling that there are more possibilities you can achieve.

Finally, there were just a few short exercises presented here. You didn't have to do them. If you did, perhaps something interesting happened or perhaps it didn't, and maybe you'll do them again. Nonetheless, it's our way to communicate that ideas and information alone probably won't help you achieve what you want to do, if you aren't already doing it – this will require that you take action, even if it's a small action to start with.

# Long-term

# **Arthritis Research UK**

# Pain and fatigue chart

Try planning the next few weeks and review your progress as you go.

Date	Midnight to midday (morning)											
	12	1	2	3	4	5	6	7	8	9	10	11
Monday												
Tuesday												
Wednesday												
Thursday												
Friday												
Saturday												
Sunday												



	Midday to midnight (afternoon/evening)										
12	1	2	3	4	5	6	7	8	9	10	11

As a charity, one of our 10 goals is to ensure that more people with arthritis will remain active and free from pain.

Our research into reducing arthritic pain takes many forms and different approaches.

Notes	

Notes	

Notes	



# Research and pain

As a charity, one of our 10 goals is to ensure that more people with arthritis will remain active and free from pain.

# Section 5: Research and pain

# Arthritis Research UK pain research

As a charity, one of our 10 goals is to ensure that more people with arthritis will remain active and free from pain. research into reducing arthritic pain takes many forms and different approaches.

#### **Our national pain centre**

Since 2010 we've been funding a national pain centre in collaboration with the University of Nottingham in a bid to tackle long-term pain, involving clinicians and scientists from different research fields including rheumatology, neuro-imaging and psychology. These experts are working together in a multi-disciplinary, integrated approach to research better treatments for the painful symptoms of arthritis.

Visit the Arthritis
Research UK website
for more information on
all the latest research being
done into long-term pain and
related conditions.

Go to:

The pain centre researchers' aims over the next five years will be to gain a better understanding of how people experience pain, to use that knowledge to fully understand the biological basis of pain in osteoarthritis, to develop new drugs to treat pain more effectively and to target existing drugs more effectively at individual patients. They are:

- looking at pain from a social context; finding out from patients their own understanding of what pain is, and what they expect from treatment
- investigating closely two forms of pain mechanisms: the role of peripheral pain (pain that comes from the nerves in the joints) and central pain (the way that the brain responds to and processes chronic pain) and trying to produce new compounds that target these pain pathways
- running clinical trials aimed at testing existing drug therapies, and any new painkillers that may be produced over the next five years.

Living with long-term pain

### Research into the placebo effect

We're funding some interesting research into the power of the placebo effect. The placebo effect – where patients feel an improvement in their symptoms due to the power of suggestion rather than due to the effects of an actual drug – is a hugely important phenomenon in the treatment of long-term conditions such as arthritis and chronic widespread pain.

Our research team are giving placebos to volunteers with osteoarthritis and fibromyalgia to find out if they release natural painkillers in the body, known as endogenous pain control mechanisms.

The researchers are using laser stimuli to induce experimental placebo responses in the three volunteer groups. It's believed that people with chronic widespread pain have abnormalities of how they anticipate and focus on pain and the researchers suggest that this results in them feeling greater pain than other people.

# **Novel research using mirrors**

Our research has shown that mirrors can trick the brain into recovering from severe, long-term pain.

Researchers have found that patients suffering from severe pain in a limb (such as complex regional pain syndrome) found relief by looking at a reflection of their healthy limb in a mirror. The reflection of the non-painful limb gives the person the impression of now having two healthy, pain-free, functioning limbs. The treatment is based on a new theory about how people experience pain even when doctors can find no obvious direct cause.

The theory suggests that the brain's image of the body can become faulty, resulting in a mismatch between the brain's movement control systems and its sensory systems, causing a person to experience pain when they move a particular limb. Imaging studies have demonstrated that chronic pain reduces activity within the brain's sensory and motor systems that relate to the painful area. Mirror visual feedback therapy has been shown to reactivate these areas, thereby improving function and reducing pain.

#### **Telephone-delivered CBT**

Our research has shown that cognitive behavioural therapy provided over the phone can have a positive impact on people suffering from chronic widespread pain compared to usual care provided by their GP.

Patients who received a short course of CBT over the telephone from trained therapists reported that they felt 'better' or 'very much better' at the end of a sixmonth treatment period, and also three months after it ended.

Our trial was the first-ever trial of telephone-delivered CBT for people with chronic widespread pain.

Exercise was also shown to improve pain and disability and helped people manage their symptoms.

#### Other research

Much of our research looks at pain at specifics sites - the back, neck, knee or hip, for example. We've shown that yoga can help people with back pain manage that pain more effectively, and we're currently investigating acupuncture and Alexander technique as possible treatments for neck pain. We're looking at better ways of managing back pain in primary care by developing a new screening tool for GPs which has been designed to pick up whether a patient's risk of back pain becoming chronic is low, medium or high - and which is enthusiastically being taken up by GPs around the country.

Patients are then offered different treatments, with those at highest risk of their back pain becoming chronic given the most intensive physiotherapy treatment, while those at low risk are encouraged to avoid numerous sessions of treatment that are unlikely to be beneficial.

We're looking at whether a particular intense form of CBT that can help people whose back pain has become chromic and intolerable, and comparing it to physiotherapy delivered by experienced physiotherapy practitioners. This form of CBT primarily aims to help those whose chronic back pain has led them to withdraw from society and normal life, people who are known as 'fear avoidant'. Early results look promising.

Research suggests that mirrors can trick the brain into recovering from severe, long-term pain.

Notes	

Notes	

Notes	



Resources and further reading

# Section 6: Resources and further reading

www.nhs.uk

Disabled Living Foundation: charity that provides independent advice about assistive equipment and services. Telephone helpline 0845 130 9177

Website: www.dlf.org.uk

Free internet arthritis self-management programme from Stanford University USA www.selfmanage.org/BetterHealth/

www.selfmanage.org/BetterHealth/ SignUp

Looking after your joints when you have arthritis. Arthritis Research UK booklet

www.arthritisresearchuk.org/arthritis\_information/arthritis\_and\_daily\_life/looking\_after\_your\_joints

#### Relaxation

http://www.mentalhealth.org.uk/help-information/podcasts/

http://www.innerhealthstudio.com/

http://www.hypnosense.com/

#### Pain

www.paintoolkit.org www.action-on-pain.co.uk

### **British Pain Society**

www.britishpainsociety.org

# International Association for the Study of Pain

IASP.org

# **Physical activity**

www.bhf.org.uk

www.wfh.naturalengland.org.uk

www.nhs/change4life

www.healthqigong.org.uk/what-is-health-qigong

www.exerciseregister.org

# **Professional registering bodies**

Health Professions Council (HPC) http://www.hpc-uk.org

To find a physiotherapist contact the Chartered Society of Physiotherapy on 020 7306 6666 or http://www.csp.org.uk/ your-health/find-physio

Living with long-term pain

### **Further information on podiatry**

# The Society of Chiropodist and Podiatrists

http://www.feetforlife.org

# **Podiatry Rheumatic Care Association**

http://www.prcassoc.org.uk/

The Podiatric Rheumatic Care Association (PRCA) is the association for podiatrists with special interest in the area of rheumatology and musculoskeletal disease. It aims to encourage and support research, promote podiatry in the related fields and improve multidisciplinary understanding and care delivery of podiatry.

# Current guidelines on the management of musculoskeletal foot health conditions:

# National Institute for Clinical Excellence (NICE):

NICE CG 79 - RA - Rheumatoid Arthritis

http://www.nice.org.uk/nicemedia/live/12131/43327/43327.pdf

NICE CG 59 - OA - Osteoarthritis

http://www.nice.org.uk/nicemedia/live/11926/39720/39720.pdf

Redmond, AC (2008) Standards of care for People with Musculoskeletal Foot Health Problems Arthritis and Musculoskeletal Alliance and Podiatric Rheumatic Care Association, London http://www.arma.uk.net/pdfs/ musculoskeletalfoothealthproblems.pdf

### **Useful organisations:**

The following organisations may be able to provide additional support and information

**NHS Direct** provide 24hr health advice and reassurance: 084546 47

# Support groups for the different types of arthritis

#### **Arthritis Care**

18 Stephenson Way London NW1 2HD Phone: 020 7380 6500 Helpline: 0808 800 4050 www.arthritiscare.org.uk

#### **Arthritis Care Northern Ireland**

Unit 4 McCune Building 1 Shore Road Belfast BT15 3PG Phone: 028 9078 2940 www.arthritiscare.org.uk/inyourarea/ northernireland

#### **BackCare**

16 Elmtree Road Teddington TW11 8ST Phone: 0208 977 5474 Helpline: 0845 130 2704 www.backcare.org.uk

# **Behçet's Syndrome Society**

8 Abbey Gardens Evesham Worcester WR11 4SP Phone: 0845 130 7328 Helpline: 0845 130 7329 www.behcets.org.uk

Living with long-term pain

# SSA (British Sjögren's Syndrome Association)

PO Box 15040

Birmingham B31 3DP Phone: 0121 455 6532 Helpline: 0121 455 6549

www.bssa.uk.net

# **Churg-Strauss Syndrome Association (USA)**

PO Box 671 Southampton MA, USA www.cssassociation.org

#### **Ehlers-Danlos Support Group**

P.O. Box 337 Aldershot Surrey GU12 6WZ

Phone: 01252 690940 www.ehlers-danlos.org

#### **Fibroaction**

46 The Nightingales Newbury RG14 7UJ Phone: 0844 443 5422 www.fibroaction.org

# Fibromyalgia Association UK

Training and Enterprise Centre Applewood Grove Cradley Heath, B64 6EW

Phone: 01384 895002 Helpline: 0844 887 2444

www. fibromy algia-association uk. org

### Fibromyalgia in Wales

Phone: 07885 488 288 Email: mail@fibro-wales.com www.fibro-wales.com

#### **Hughes Syndrome Foundation**

Louise Coote Lupus Unit Gassiot House St Thomas' Hospital London SE1 7EH Phone: 0207 188 8217 www.hughes-syndrome.org

# Hypermobility Syndrome Association (HMSA)

Oreston Plymouth PL9 7NF Phone: 0845 345 4465 www.hypermobility.org

49 Orchard Crescent

# **Lupus UK**

St James House Eastern Road Romford Essex RM1 3NH Phone: 01708 731251 www.lupusuk.org.uk

#### **Marfan Association UK**

Rochester House 5 Aldershot Road Fleet

Hampshire GU51 3NG Phone: 01252 810472

www.marfan-association.org.uk

#### Living with long-term pain

# **Myositis Support Group**

146 Newtown Road Woolston

Southampton SO19 9HR Phone: 023 8044 9708 www.myositis.org.uk

# National Ankylosing Spondylitis Society (NASS)

RCN 272258

Unit 0.2, One Victoria Villas

Richmond

Surrey TW9 2GW

Phone: 0208 948 9117 www.nass.co.uk

#### **National Kidney Federation**

The Point, Coach Road Shireoaks, Worksop Notts S81 8BW

Phone: 01909 544999 www.kidney.org.uk

# **National Osteoporosis Society**

Camerton Bath BA2 0PJ

Phone: 01761 471771 Helpline: 0845 450 0230

www.nos.org.uk nurses@nos.org.uk

# nras (National Rheumatoid Arthritis Society)

Unit B4, Westacott Business Centre

Westacott Way Littlewick Green

Maidenhead SI 6 3RT

Phone: 0845 458 3969 or 01628 823524

Helpline: 0800 298 7650

www.nras.org.uk

#### **Paget's Association**

323 Manchester Road Walkden, Worsley Manchester M28 3HH Phone: 0161 799 4646 www.paget.org.uk

#### **PMR-GCA UK**

Centre for Disability Studies

Rocheway Rochford Essex SS4 1DO

Phone: 0300 111 5090 www.pmrgcauk.com

# Psoriasis and Psoriatic Arthritis Alliance (PAPAA)

PO Box 111 St Albans

Hertfordshire AL2 3JQ Phone: 01923 672837 www.papaa.org.uk

# Psoriasis Scotland Arthritis Link Volunteers (PSALV)

54 Bellevue Road Edinburgh EH7 4DE Phone: 0131 556 4117

webplus.psoriasisscotland.org.uk

# Raynaud's & Scleroderma Association (RSA)

112 Crewe Road

Alsager

Cheshire ST7 2JA

Phone: 01270 872776 or 0800 917 2494

www.raynauds.org.uk

Living with long-term pain

### **Scleroderma Society**

PO Box 581

Chichester PO19 9EW Phone: 0207 000 1925 Helpline: 0800 311 2756

www.sclerodermasociety.co.uk

#### **St Thomas' Lupus Trust**

The Louise Coote Lupus Unit Gassiot House St Thomas' Hospital London SE1 7EH Phone: 0207 188 3562

www.lupus.org.uk

#### **Stuart Strange Vasculitis Trust**

West Bank House Winster, Matlock Derbyshire DE4 2DQ Phone: 01629 650549 www.vasculitis-uk.org.uk

# **UK Gout Society**

PO Box 527 London WC1V 7YP www.ukgoutsociety.org

#### **Vasculitis Foundation**

PO Box 28660 Kansas City MO 64188-8660 USA www.vasculitisfoundation.org

#### **Pain relief**

#### **Action on Pain**

PO Box 134 Shipdham Norfolk IP25 7XA Phone: 01362 820750 www.action-on-pain.co.uk

#### **British Pain Society**

Third Floor, Churchill House 35 Red Lion Square London WC1R 4SG Phone: 020 7269 7840 www.britishpainsociety.org

#### **Pain Relief Foundation**

Clinical Sciences Centre
University Hospital Aintree
Lower Lane
Liverpool L9 7AL
Phone: 0151 529 5820
www.painrelieffoundation.org.uk

#### **General**

#### Citizens Advice Bureau

To find your local office, see the telephone directory under 'Citizens Advice Bureau' or the Yellow Pages under 'Counselling and Advice'. www.citizensadvice.org.uk

Living with long-term pain

#### **NHS Choices**

Phone: 0845 4647

www.nhs.uk

### **NHS Expert Patients Programme**

Phone: 0800 988 5550 Scotland: 08454 242424 www.expertpatients.co.uk

#### **The Patients Association**

PO Box 935

Harrow, Middlesex HA1 3YJ

Phone: 020 8423 9111

www.patients-association.com

#### **The Samaritans**

Chris P.O. Box 90 90 Stirling FK8 2SA

Phone: 08457 90 90 90

www.samaritans.org

# Arthritis Research UK public information

If you've found this information useful you might be interested in these other titles from our range:

#### **Conditions**

Complex regional pain syndrome (CRPS) Fibromyalgia
Osteoarthritis
Rheumatoid arthritis
What is arthritis?

#### **Therapies**

Hydrotherapy and arthritis Occupational therapy and arthritis Physiotherapy and arthritis

#### Self-help and daily living

Complementary and alternative medicine for arthritis
Everyday living and arthritis
Feet, footwear and arthritis
Keep moving
Sex and arthritis
Sleep and arthritis
Work and arthritis

# **Drug leaflets**

Non-steroidal anti-inflammatory drugs Painkillers

You can download all of our booklets and leaflets from our website of order them by contacting:

Arthritis Research UK PO Box 177 Derbyshire S41 7TQ 0800 389 6692

www.arthritisresearchuk.org



Notes	

Notes	

Notes	



# **Get involved**

You can help to take the pain away from millions of people in the UK by:

- Volunteering
- Supporting our campaigns
- Taking part in a fundraising event
- Making a donation
- Asking your company to support us
- Buying gifts from our catalogue

To get more **actively involved**, please call us **0300 790 0400** or e-mail us at enquiries@arthritisresearchuk.org

# Or go to:

www.arthritisresearchuk.org

Providing answers today and tomorrow



Providing answers today and tomorrow

# **Contributors**

#### **Professor Candy McCabe**

Professor of nursing and pain sciences Royal National Hospital for Rheumatic Diseases, Bath

#### **Professor Lance McCracken**

Professor of behavioural medicine King's College London, London

#### **Dr Anthony Redmond**

Arthritis Research UK senior lecturer in rheumatological podiatry
University of Leeds, Leeds

#### **Dr Jenny Lewis**

Senior clinical research occupational therapist Royal National Hospital for Rheumatic Diseases, Bath

#### **Arthritis Research UK**

Copeman House, St Mary's Court, St Mary's Gate, Chesterfield, Derbyshire S41 7TD

# Tel **0300 790 0400**

calls charged at standard rate

#### **Dr Chris Barker**

GP with a special interest in pain management Liverpool and Sefton Primary Care Trusts, Liverpool

#### **Dr Nick Shenker**

Rheumatologist/clinical research fellow Addenbrooke's Hospital/ University of Cambridge, Cambridge

#### **Dr Jane Hall**

Senior clinical research physiotherapist Royal National Hospital for Rheumatic Diseases, Bath

#### **Dr Peter Brook**

Consultant anaesthetist and pain physician University Hospitals Bristol NHS Trust and Bath Centre for Pain Services

# www.arthritisresearchuk.org

Registered Charity No 207711 Scottish Charity No SC041156 © Arthritis Research UK 2011 Published October 2012 2799/PAIN-REP/12-1