

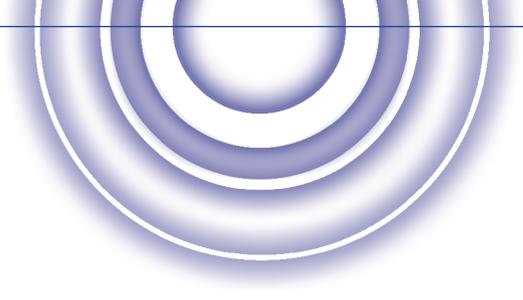
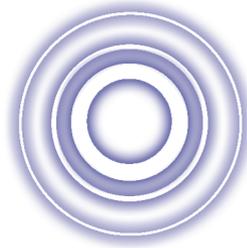


Manage your pain

A guide to becoming more active
and reducing flare-ups



Liz Macleod and Dr Paul Cameron



Preface

In this booklet Liz Macleod brings together a lifetime's experience in helping people understand and manage their pain. Her practical approach gives encouragement to anyone who wants advice and support in living with pain. This new edition of the booklet has been updated by Paul Cameron, ensuring that all the information inside is as relevant now as it was when first published.

James Boyce
Managing Editor, Pain Concern

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*Edited by Tom Green and James Boyce.
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Understanding your pain

One of the most important steps in learning to manage your pain is developing your understanding of it. This can help reduce concern and increase your confidence in movement. Pain has different ways of behaving. Let's look at this a bit more and see if, by recognising your pain, you could find ways of managing your pain that would be helpful for you

Pain from tissues

We can experience pain from our muscles, tendons, joints, etc., if we overdo activities or are not quite fit enough for that activity. If you are gardening, especially at the start of the summer, you may feel pain from the joints and soft tissues letting you know when they need a rest. You may stop from time to time for a stretch or a break, which helps, but if you carry on too long you find yourself creaking into the standing position! Usually a soak in a warm bath can do the trick and the next day you're ready for the garden again.

This kind of pain is normal, and not a sign of a problem. It is simply a reflection of muscles working hard (sometimes harder than normal), and needing some time to recover. However, regular use like this will allow time for the muscles to adjust, and the pain you experience from

this type of activity will lessen as you become fitter, stronger and more tolerant to the activity.

When pain behaves in this way, coming at the time of activity and settling down with soothers, an exercise programme can be planned and built up. The messages from the tissues at the time help you decide a sensible level and should you overdo it, the pain will settle quickly when you stop.

Pain from a 'sensitised' pain system

Some people have a different pain experience. Working in the garden may produce very little discomfort from the tissues at the time but later, whether the same day or the next day, the pain flares up. This increased pain can often last for days and a rest, warm bath, tablets or a combination of these may make things more bearable, but the pain takes its own time to settle down and in many cases does not settle completely.

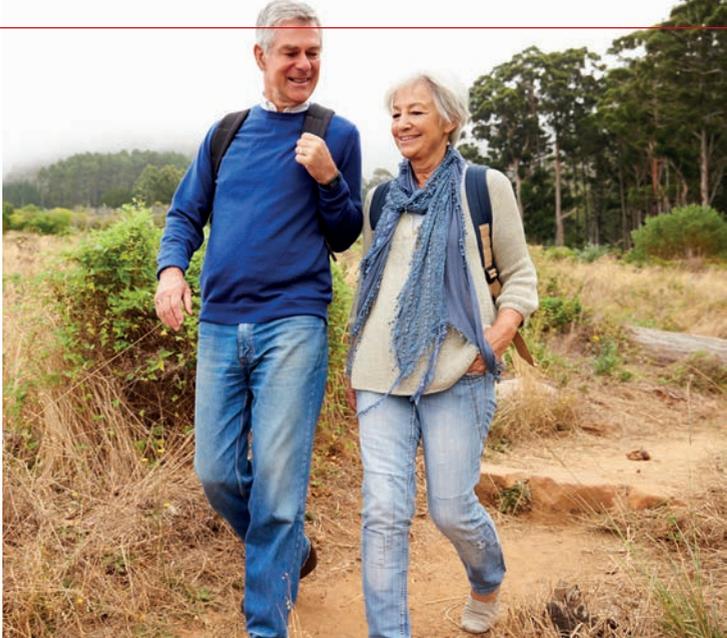
The same thing can happen after exercises given as part of a physiotherapy programme or from the fitness instructor at the gym. Getting no warning signals from the body at the time of exercising means it is difficult to set a level that can be kept going and increased over time.

Why does the system become sensitised?

We know from pain scientists that this kind of pain is happening because of changes at many points along the pathways carrying signals to, and from, the brain. These changes result in the warning signals remaining switched on, even though nothing is happening to the tissues at the time. The trigger was the bending and kneeling in our gardening example but, because the sensitised pain system stays switched on, messages are still being sent to the brain hours or days after stopping the activity, and the brain continues to respond to them with pain. For some people, pain is triggered by problems with the nerves themselves. Please read our *Neuropathic Pain* leaflet to find out more about pain caused by damage to the nerves.

So how do I manage to exercise without producing a flare-up?

The same idea of desensitisation or slowly building up tolerance also applies to increasing your activity levels. If you have a sensitised pain system, you will have good days and bad days as well as flare-ups.



Set a level of exercise that would be comfortable on a bad day and stick with that amount on a good day. You will be able to gradually build up the amount over time if you are patient and are prepared to go slowly. If you are not patient, you will be tempted to do more on your good days and this will lead to flare-up and disappointment. Worse still, you might give up altogether and believe that exercise is unhelpful. The exercise is not the problem; the amount set is too high.

Setting limits within a comfortable range at the time is usually a good guide to reducing the chance of a flare-up later. Some people may find becoming more active very hard with flare-ups leaving them bedbound. If you need some extra help, ask your GP, or a physiotherapist, for more advice.

Good days and bad days

When you have chronic pain, you lose fitness, not just because you may have been unable to keep active, but also because of the time you need to rest and recover from pain flare-ups. Do you have a good understanding of your flare-ups? Do you know why you have good days and bad days with your pain? Flare-up is a topic we will come back to, but first we'll look at the good days and bad days, and see if we can work out how to avoid the bad days

What do you do on a good day?

Do you use it to catch up on all the things you have been unable to manage on your bad day? Many people describe this habit.

They wash windows, do shopping, get out into the garden, all in an attempt to catch up. Sometimes they know they will pay for it the next day but are driven on to do it anyway by feelings of guilt or frustration. Or maybe it's enjoyable to be in the garden and worth paying for. Sometimes they feel the pain is on the mend and carry on with fingers crossed! The result of this increased activity on a good day is almost certainly increased pain. This in turn leads to enforced rest,

probably an increase in painkillers, low mood and, as a consequence, less gets done. We call this cycle the 'overactivity-rest cycle'.

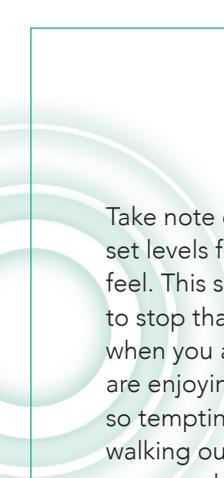
So what is the answer?

If you use a paced approach to activities, gradually pacing or building up the amount you do, you will reduce the number of bad days and may do away with them altogether. This sounds simple and it is in theory, but it needs some thought and, most of all, application. Like any skill, it requires practice, and you are likely to get it wrong to start with. But don't be disheartened. Practice is the key! Eventually, pacing will become second-nature to you.

Of course, there will be some activities that are impossible to pace, and you have little control over. In these instances, try to anticipate them, and plan them appropriately. You will need to be ready for an increase in pain, and use your own personal toolkit to help keep the pain levels under control.

Find your baseline

Find a baseline for the activity that flares you up. The baseline is the amount of that activity you can do **before** you feel the pain increase.



Take note of that time and use it to set levels for that activity, however you feel. This sounds easy! The hard bit is to stop that activity at baseline levels when you are having a good day and are enjoying what you are doing. It is so tempting to carry on, for example, walking outside on a nice, warm summer day, until the pain stops you. The result, of course, of ignoring your baseline is pain flare-up later that day or the next day, and you're back in the overactivity-rest cycle with the pain in control again.

We have baselines for all our activities, including less active activities such as sitting. Sitting beyond baselines can cause flare-up too. You have probably experienced sitting watching an interesting programme on TV and becoming absorbed. You may also then have experienced pain when you moved at the end of the programme. This means you have sat for too long, so, beyond your baseline.

If you learn to use your baselines effectively, you can perhaps manage to do the same amount of activities in your day, but spaced out over the day. Vacuuming the house would be a good example. If your baseline was half a room, you could split the vacuuming up into chunks of this size, spacing them throughout the day, and still complete the task of vacuuming the house, but without ending up in pain.

The rewarding part about sticking to baselines (apart from avoiding the overactivity-rest cycle) is that you can extend these baselines so that you are able to manage more of the activity as you practise. This is because your fitness levels are increasing all the time, rather than being lost while you rest and recover from flare-ups. It is much better to be 'in control' rather than have the pain stop you all the time. You will find your confidence grows as you feel able to manage more activities and have more successful outcomes from your efforts.

When life gets complicated

Some of the activities we do are complex. Golf, for example, has lots of 'bits' to it. You have to walk, carry, bend, stand, swing the club, not to mention getting to the course, which may include a walk, bus or car journey. It may be that in order to play golf, you will need to find the baseline for all the 'bits' and work at these in order to build up your levels.

Shopping is another complex activity that patients with chronic pain find difficult. Again, breaking the activity down into its parts and setting baselines is helpful. You may need help from family and friends to begin with, so that you can stop at baseline level, but if you can pace up each part of the activity you will be able to do more and more yourself.



Keeping active



Physical activity is vitally important in all types of chronic pain. It improves mood, sleep and general well-being by releasing the body's own 'feel good' hormones – endorphins. It helps to condition soft tissue and bone, which results in a strong body structure. It has a part to play in weight control too, so it really does have a lot to offer us. While some of you may have a regular programme that you can rely on to keep you fit without flaring up your pain, others may have had difficulty and become largely inactive

Flare-ups

Do you have pain that you manage quite well until a bad episode comes along? The flare-up may have started for no reason that you can think of, or may have resulted from a movement such as twisting or reaching, or in some people with neuropathic pain even a slight breeze can be enough. What do you do to help you get through the bad patch? Many of you will consult your GP, who may send you to the physiotherapist. You may indeed have seen the physiotherapist last time you had a bad patch. You were very probably taught a range of exercises as part of the treatment plan

and asked to practise these every day. You perhaps carried on until the pain flare-up settled and you were left with your old manageable pain. Exercise practice seemed less important then, and maybe you stopped doing it regularly or stopped altogether. Crisis over! Does this sound familiar?

This is not unusual – it's human nature. Whether it's indigestion after overeating, or sunburn, we all make promises that if only we could be relieved of a self-inflicted misery we would never let it happen again. So it is in the agony of a flare-up. We promise to continue with the exercises forever if only the pain would settle down.

Body maintenance

Some of you may recognise the trap of 'crisis' management. Others may have tried to keep going with exercises the physiotherapist taught you but have found this difficult. Some may have managed to practise one or two exercises regularly and are pleased to be able to move more freely as a result.

If regular practice has not been a habit, stiff and tight tissues will have led to poor posture, lack of confidence and fear of moving. The combination of these outcomes means you have much more difficulty with ordinary activities such as climbing stairs, getting on and off the

bus and pushing the shopping trolley. If there's anything around to trip over, you're the one to find it!

The likelihood of pain flare-up can be reduced if body tissues are kept in good condition. That means a regular commitment to exercise – maybe even a daily commitment to exercise. After all, you wouldn't think about starting your day without some teeth maintenance, so why not some body maintenance!

Build up gradually

It's really important to learn how far to take each exercise to get success. If you push through the pain, flare-ups are a likely consequence and you will then be unable to build up repetitions and benefit from improved exercise tolerance and fitness. This is the main reason for people giving up.

Find the level of activity or exercise you can tolerate. This may be just one repetition. Many people think they should be able to do more than that, but when they try to increase it they flare-up and get set back. So start at one repetition of an exercise and build up tolerance to increase it to two and then three and so on. The increasing tolerance phase between increased repetitions allows the body to build up the muscles, tendons and ligaments. This doesn't happen overnight – it can take two to four weeks.

The golden rule of exercise and chronic pain is that you should not feel significantly worse afterwards. If you do, it is not that you have caused yourself more harm or damage, but that you have flared up a sensitive nervous system. It might be useful to think 'would I be able to do the same thing again tomorrow?' If the answer is 'no' then you are probably overdoing it!

Feeling fitter

Why not make time in your day for some exercise practice and see if you can improve your feel-good factor!

- Pick a 'best' time for yourself during the day. Some people will prefer mornings, others will find later in the day suits better.
- Take your time and don't push through the pain – that's not helpful and can lead to flare-ups.
- Start with a few repetitions and gradually build up. You shouldn't need to spend any more than 10–15 minutes each day to get results.
- Commit to daily practice for three months before judging whether or not this is worthwhile. If

you're very unfit, it may take some time to feel an improvement, so don't give up!

The best exercise programme for you to start work on will be one which you have been taught by your physiotherapist. If you haven't attended physiotherapy for some time, you may want to try gentle, low impact exercise such as swimming, walking, yoga or tai chi, being sure to build up gradually.

Over time you will notice that you feel more confident, stronger and have improved self-esteem as your body adapts and you start to be able to do things that you had thought were written off.



Flare-up planning

Even if you become an expert at planning activities and improving your posture according to baselines, there will still be occasions when you have flare-ups. Situations may arise when you have to respond without being able to plan effectively and you may overdo things. One morning you may wake up after lying in an awkward position and find your pain has flared up

Accepting the problem

People on pain management programmes have said that, prior to attending the course, their only way of dealing with a flare-up was to give up on activities, rest, take more medication and wait until the pain settled down again. As many of you will have experienced, this can leave you frustrated, fed up and feeling that you have little or no control. You may also find that the next time you try the activity the pain returns, but more quickly.

So what else can you do? The first thing to realise is that the flare-up is part of chronic pain and will happen, so trying to accept this can be useful in itself. If you can view the flare-up as a nuisance, but not something to

worry about, you are less likely to become as agitated and annoyed. You will also be more able to work at managing the situation.

Know your triggers

Try to think about what may have triggered the flare-up. If there is a clear pattern, it's easier to avoid the same set of circumstances in the future. If you don't avoid the trigger, then you can expect another flare-up. Sometimes it is difficult to associate an activity with pain when the flare-up occurs the day *after* you have carried out the activity or maybe even the day following that. If you have difficulty identifying the cause of flare-up, try keeping a diary of your activities and at the same time a score of your pain. You can then look back over your week and see if a pattern arises.

A real-life example is of one individual in a pain management programme who noted that an increase in her pain occurred two days after her baby grandchild came to stay for the morning. She then began to notice that she sat in an uncomfortable position when she was feeding the baby. She rearranged the seating position, shared feeding with granddad and the flare-up of pain



after babysitting no longer appeared! If there is no apparent trigger it will be difficult to know what to avoid; you will have no warning, so it is essential to have a clear plan for coping.

How to manage a flare-up

Soothe the pain Note the things you can do that make your pain easier; maybe a heat pad or warm bath. What about a visit to your local Jacuzzi? You may be surprised by how effective a Jacuzzi can be in helping you relax. The whirling water soothes tired, painful muscles which feel in spasm or are guarding the pain. If massage helps you then this is the time to use that option. Sometimes lying down for a little while can help. Lying for

longer periods can result in feelings of stiffness, so short periods, often, are more likely to lead to success.

Relax Have you learned any relaxation techniques? Your muscles hold you tightly and guard more when you have increased pain, so learning how to let go and ease the tension can be really helpful. Relaxation can help you feel calmer and more at ease with the situation. You can listen to the self-help guide, *Living with Chronic Pain*, online (paincd.org.uk), borrow a CD from your local library or there may be relaxation classes nearby.

Distraction Being able to take your focus away from the pain and think about something else can be helpful.

Examples are counting how many doors in your street are painted black, or trying to make a word from car registration letters. Imagine a situation where you felt peaceful, in control and happy. Use the image to help you remember how that felt and how enjoyable it was for you.

Cut back on activities In a flare-up it's a good idea to cut back slightly on your activities, but not to give them up altogether. There is a risk that you will lose fitness for these activities if you stop them. After all, the flare-up may last a week or two, which is plenty of time for your muscles to lose tone and your cardio-vascular system to become a bit sluggish. To cut back you may need to ask for a bit of help from family, friends or work colleagues. As the flare-up begins to settle, you will be able to get back gradually to your usual levels of activity.

Catch negative thoughts Feeling fed up and frustrated with your situation is normal in times of flare-up. It is at this time though that unhelpful thoughts creep in which lead to anxiety or low mood. Try to be aware of these and nip them in the bud! Remember, the flare-up will settle and you will get through it.

Medication Hopefully, if you have had success with the above

strategies, you will not need to take extra pain medications during flare-up. If, however, you feel extra medication could help you at such times, you should talk with your doctor, pharmacist or other qualified prescriber. They may be able to help with planning the dose you could take, and advise how long you are likely to need your medicine before cutting back.

People who tackle a flare-up in this way will have worked out a mini plan for a flare-up lasting a day or two, and a plan for a longer period of flare-up. They know how and when to cut back. A flare-up is no fun, but if you can plan for it and feel more in control, it may be easier to manage and less stressful.



Keeping flare-ups at bay



One of the main challenges faced by people who have pain is learning how to reduce flare-ups. People often say that if their pain stayed as a constant ache, they could manage to deal with day-to-day activities. Flare-up, on the other hand, leads to a feeling that the pain is in control and they are left with a sense of helplessness

Finding a tolerance level

As we have seen, one of the main strategies you can use to help reduce flare-ups is pacing. Decide the amount of an activity, task or posture you can manage before the pain kicks in, and

set that level as a tolerance level. If you don't go beyond this level, you will keep the pain under control and manageable.

Seems simple? In theory, yes, but in practice it can be difficult. Practical problems with mobility, access to shops or leisure facilities, limited public transport can all lead to compromising tolerances. The demands and expectations of others, friends, family or workmates, can put pressure on you to push into flare-up. You may feel unable or reluctant to ask for help, in case others think less of you for not being able to do what you

used to do, or for not 'pulling your weight'. You may feel patronised or treated differently by friends or family if you have to ask for help.

Many people are determined that their pain problems are not going to be a negative influence on their children's lives and they push through pain to, for example, play football with the kids or go on shopping expeditions with teenagers.

Another common reason for ignoring tolerances is that people are angry at their pain and set out to 'beat it'. They report being unwilling to 'give in' to the pain or are determined not to 'lie down to it'. Others feel they cannot let the pain interfere with basic beliefs, for example, 'if a job's worth doing, it's worth doing well'. 'If I start a job, I have to finish it' is another commonly held belief that results in flare-up. There are many more reasons for people having difficulty sticking with tolerances, but even mentioning a few highlights how resourceful people have to be to manage their pain effectively.

Learning to negotiate

During work in pain management, healthcare professionals have watched as some people have made major changes to their lifestyle and reduced their flare-ups, while others have made few or no changes and

endured the pain patterns, which resulted in on-going distress. The main difference is often found to be the person's ability to negotiate with their pain. **The pain always beats those who see the relationship as a constant battle, which they are always trying to win.** Those who negotiate and reach an 'I win, you win' situation with their pain, manage their pain and improve the quality of their lives.

Less of a fight

Some people have found it helpful to think about their pain in the same way as, perhaps, a diabetic would consider their diabetes. Diabetics have to see their diet as an important part of managing their disease. If they eat the right kinds of foods at the right times of day, their diabetes is kept under control. Foods such as chocolate cake might be avoided in favour of a piece of fruit. In time many diabetics would not even consider chocolate cake as an option and would not miss it. Can you imagine trying to eat the cake to 'beat' the diabetes? Much more can be gained by negotiating with the condition we have to live with.

Establishing tolerance levels and putting them into practice is a good negotiating strategy when it comes to dealing with pain. It reduces the chance of flare-ups and, with time and practice, leads to a sense of control

over the pain. This sense of control results in a better quality of life. If you think of this kind of negotiation in the same way as diabetics have to view their diet, it may feel easier to ask for help to do a task. It may seem less of a fight if, for instance, you have to slow down your walking pace or divide gardening activities into fifteen-minute chunks of time.

If you need help to negotiate with your pain and want to know which strategies would be best for you, Pain Concern produces useful leaflets and an innovative and informative

online radio show, **Airing Pain**. You could also ask your doctor to consider referring you to a pain management programme where staff would help you to improve these skills.

Pain Concern hopes this booklet will help you to manage your pain. Keep working at it, and you should see a real difference.

Pain Concern would like to thank the people in pain and healthcare professionals who helped us in revising this publication.

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If you would like to know more about the sources of evidence consulted for this publication, please visit painconcern.org.uk.

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