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Action on Pain is a registered charity run entirely by volunteers most of whom either have chronic pain or are healthcare professionals working in pain management.

Our dedicated telephone helpline "Painline" is open Monday - Friday between 1000-1600 hours with a monitored answerphone at all other times.

This is one of our range of publications dedicated to provide support and advice for those affected by chronic pain. For details of our other titles please visit our website at:

www.action-on-pain.co.uk

PainLine: 0845 6031593 (lo-cal rate)

Registered charity: 1088789

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LIKE SOME HELP UNDERSTANDING AND MANAGING YOUR CHRONIC PAIN?



THEN READ ON!!

www.action-on-pain.co.uk

Action on
pain!

Registered Charity No. 1088789

Do you or someone you know have chronic pain? Have you known for a long time but only recently decided to find out more about it? Perhaps you've heard negative things about it:



“Yes I have chronic pain....it’s terrible you know!”

“This pain has taken over my life!”

“I can’t do anything because of my pain!”

There may be times when chronic pain can overwhelm an individual: they may feel that they want to give up.

This booklet helps to give a better understanding of your pain enabling you or others to help you live with your pain rather than letting it take over!

This booklet looks at:

**Explaining what chronic pain actually is.
Different ways that may help you cope with your pain. What to expect if you are referred to a pain clinic.**

So what actually is chronic pain?

Chronic pain is pain lasting for longer than three months. The actual cause of the pain may be unknown perhaps starting gradually or by some event that has ‘long gone’. Yet the pain may remain, possibly for many months or even years, often with difficulty in obtaining relief from it. Pain becomes persistent because processing systems in the brain alter. The brain may respond to signals that you would not normally expect to cause pain.

This is one of the reasons why even if the cause of the pain is discovered and treated the chronic pain does not easily go away. Some message systems to the brain may also excite the pain or make it feel stronger whilst others inhibit the pain or quieten it down. This is why the pain may vary from day to day without any warning.



Sadly, whilst you are trying to come to terms with your pain, you may receive conflicting advice on how best to deal with it!

What do you do about your pain whilst you possibly undergo various tests or see a number of specialists who are assessing if they can offer any help?

I'D ENCOURAGE YOU TO READ ON!!

TENS (Transcutaneous electrical nerve stimulation)

This is a small battery operated portable unit. Small self adhesive, removable electrodes are applied around the painful area and send a comfortable tingling sensation along the skin that can modify the pain sensations. Action on Pain sells a reasonably priced machine that is both versatile and compact. Call 0845 6031593 for further details.

Other complimentary therapies

Treatments such as hypnosis, reflexology, Reiki and massage may be useful to consider but they are rarely available on the NHS.



Nerve blocks

These may be considered instead of taking oral or intravenous medication. A pain killer or other medication can be injected into the space next to a nerve to prevent pain signals passing to the brain. Alternatively nerves may be cut via surgery in order to stop the pain signals. This tends to be considered in more severe cases of pain when other approaches have been unsuccessful. Surgery may also be used to take the pressure off a nerve that is causing symptoms of nerve pain such as burning sensations or pins and needles.



Attitude

The way you respond to your pain can influence it. People who are able to maintain a more positive attitude often feel less pain. Being angry about your pain can cause more muscle tension as well as tending to increase the pain response; that is how pain signals pass to the brain.

It can be difficult to remain positive if your pain is particularly severe or if you have experienced it for a long time. Here are a few tips:

Share your concerns with your GP or someone close to you.

- ✓ Spend time with someone who can make you laugh! Humour can also modify your pain!
- ✓ Use heat or cold - a hot bath or wheat pack can be a great tonic!
- ✓ Take care of yourself. Find time for rest and relaxation. Find time to meet with other people such as a voluntary organisation or pain support group.
- ✓ Understand how pain can affect the person as a whole.

Support groups

Meeting with other people who are in pain provides a forum to share feelings, and concerns. It is an opportunity to provide support as well as tips on successful management of pain. Your local pain clinic or hospital should know if there is a group nearby. Have a look at the internet or ask at your local library.

And finally.....

Be actively involved in managing your pain, using help and support from other people. Work with your pain rather than your pain taking over you!!

Examples such as these are also helpful to share with family and friends. It is important to give them an opportunity to express their concerns about your pain as well:

- ✓ Are they frustrated because they can't do things that used to be done, for example as a family?
- ✓ Do they get cross because you always seem tired and have lost interest in things?
- ✓ Are they frustrated because they feel helpless in the way they care?

Try to work together with family members or friends to enable activities to still be achieved but with good pacing!

Other approaches can be considered in managing pain. If you are uncertain of their suitability for you discuss the ideas with your GP or another health professional: a physiotherapist or occupational therapist may be able to give advice on aspects such as relaxation or exercise.

Relaxation techniques

Pain can cause stress and muscle tension, both of which may make you feel more tired. Different types of relaxation may assist in reducing this, such as –

- ✓ Contracting and relaxing different muscles in the body
- ✓ The Laura Mitchell approach, which encourages positions of ease rather than of tension.
- ✓ Imagery- where individuals are encouraged to focus upon pleasant events in their life or to picture a pleasant scene.
 - ✓ Distraction techniques, such as listening to music.



Exercise

Provided that it is carried out in a controlled manner, exercise can modify the pain response. Depending upon how you get on, the exercise may be gradually increased. But be realistic about your goals.

A few minutes a day may be all that you can initially achieve. Aim to go out regularly for a walk. You may be able to start a gentle exercise programme. Some areas of the country provide exercise referral schemes, usually based within local leisure centres. Some people benefit from attending a Pilates class. This is a relatively new approach to exercise, focusing upon strengthening the stabilising muscles within the body that can support vulnerable or painful areas. Exercise can also 'lift your mood'. It gives a sense of purpose, some achievement and the opportunity to get out of the house!

How can I work with my chronic pain?

We've got there at last!!



Medication

Your GP or consultant may prescribe medication for you and should outline any possible side effects. You may be unable to take certain medication due to side effects or the way they affect other medication that you are taking. When treating chronic pain, different medication or a combination of medications may be used which give each other a boost in their effectiveness.

Chronic pain sufferers are often concerned that they will become addicted to their medication. With monitoring from your GP or a pain clinic, the opposite may happen: if your pain is better controlled other aspects of your life become more manageable so you may be able to reduce your medication. This doesn't always happen...but it's worth bearing in mind!

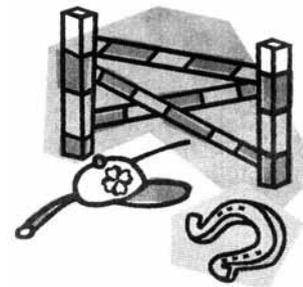
Emotional factors

Shown to significantly affect an individual's response to pain. This is due to 'The pain gate control theory', where pain messages travel to the brain, being controlled by a gate system that may or may not allow messages to enter. Emotion is one factor that may open or close the gate.

With the gate closed, there is less pain. With the gate open, there is more pain.

Factors that open the gate: more pain

- Prolonged pain
- Stress and negative emotions - depression or anxiety.
- Alcohol - although some alcohol can encourage 'the feel good factor!'
- Special centres within the brain.



Factors that close the gate: less pain

- High levels of your body's natural pain killers called endorphins & enkephalins
- Exercise
- Diet
- Sexual activity
- Types of nerve stimulation such as acupuncture and TENS
- Special centres within the brain.

Relaxation and meditation

Tension tends to open the pain gates. If your body is tense the brain registers that it is prepared to fight or flight and instructs these fighting muscles to increase their tension ready for action.

Different types of relaxation techniques may be more effective for an individual than another. So be prepared to try different approaches and see how you get on.

Exercise

“When I move my affected limb too much the pain gets worse. Wouldn't it get better if I allowed it to rest until the pain settled down?”

No - This is a common misunderstanding but appropriate exercise has been shown to:

Loosen tight tissues within your body that can cause pain when you try to move.

Maintain muscle strength to make your movements easier and help to support aching joints.

Improve the circulation and help to keep you generally healthy

Encourage a release of your body's natural painkillers - the endorphins and encephalins.

Take your mind off the pain!

Try to have a regular daily activity or exercise that suits your capabilities. Perhaps taking the dog for a walk or strolling to your local shops.

It doesn't have to be

adventurous but try to increase the amount of exercise as your body gets more used to it.

If you have recently received an exercise regime from a chartered physiotherapist, try to use it.



But remember the following:

- ✿ *Don't do too much in one go*
- ✿ *Don't change your exercises because a different one helped somebody else –seek advice first.*
- ✿ *Don't work through sharp pain*
- ✿ *Don't stop the exercises if you are having a 'bad day'- try and do a little bit.*
- ✿ *Try to enjoy them!*

Cognitive behavioural therapy.

This is often taught by a clinical psychologist within the pain clinic team and is a technique that teaches people how to respond more positively to their pain. It helps people to change their behaviour and attitude towards their pain and the way they handle it.

dreadful the next day. His pain is worse and remains so for the next three days: he can hardly do anything and falls into the familiar pain cycle. Thankfully a week later he is feeling a little better and more refreshed. The sun is shining and he decides to go into the garden. He loves his gardening - it's bound to do him the power of good! And so he works away regardless of the time.....!!!!



HELP!

Activity is good for you. Exercise can modify the pain response and give a sense of well being.

But it is important to pace yourself!

Do a small amount of activity at a time and see how your body responds to it. Don't be too ambitious in what you try to achieve. Don't think back to what you used to do - be pleased with what you can do! Avoid Jim's story with days of inactivity followed by too much activity. Try to achieve a more even balance of activities each day so that you balance activity with rest!



Sharing your thoughts about your pain

People who are in pain are often afraid to express their thoughts, concerned that they are being a nuisance. It is important to express your feelings to enable other people to understand your situation and to be able to offer help whether they are a carer, friend or health professional.

Your GP needs to know:

How you feel about your pain and what concerns you may have. Try to describe your pain - what makes it feel worse or better; what it stops you doing, what it is like; what fears you may have about it.

Consider aspects such as:

- ✓ Rating your pain on a scale from 0-10 (0 is no pain and 10 is the most severe pain).
- ✓ Is your pain consistent or does it come and go? Is it an ache; a throb or a burning sensation or would you describe it in a different way?
- ✓ Does it affect your sleep? Is it worse after a particular activity such as standing for a long period of time?
- ✓ How does it affect your family life? Or if you live alone, discuss your concerns about being on your own - pain can often be harder to cope with when alone.
- ✓ Fears that people may not believe you have pain.



If you are experiencing side effects then discuss this with your GP or pharmacist. Some types of medication have been developed with fewer side effects. Alternatively another type of medication, such as a different pain killer or anti-inflammatory may suit you better. Some side effects wear off as the body gets used to the medication. Other side effects can be treated, possibly with some other medication.

Becoming addicted to tablets is a common fear but this rarely happens amongst people experiencing pain.

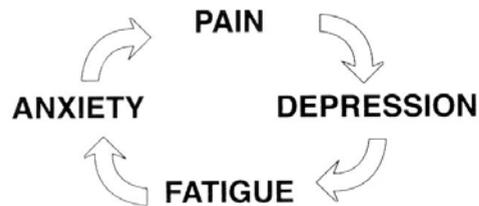
People may become dependent upon their medication but can be weaned off this or offered alternative forms as their pain alters or their needs change. It is important that you discuss any fears that you have about your medication with your GP.

Taking tablets for the rest of your life need not be the case. Managing your pain through a variety of ways may enable you to reduce your medication. Once you feel more in control of your pain, your general outlook on life may alter; you feel less stressed; less tense or anxious. These changes and others may also enable you to reduce your medication.

Pacing activities and the pain cycle.

Are you familiar with this picture?

You wake up with pain and become anxious. Anxiety causes muscle tension which can increase your pain. You go to bed with pain and are unable to sleep which makes you tired. You become more tired during the day which makes you more vulnerable to your pain. And so the pain increases until you find yourself in a never ending spiral which can cause depression and increase the pain even more.



That's why it is important to break through this pain cycle which can become harder to manage if it goes untreated. Appropriate use of medication may be one route but others will be considered in this booklet.

Poor pacing of daily activities can also create a vicious cycle that may spiral out of control. **How does this story sound ?**

Jim has experienced low back pain for over ten years and is no longer able to work. One day he awakes feeling more comfortable - he'd had a good night's sleep for a change. The sun is shining and he decides to do some gardening. He works fairly solidly for nearly three hours taking very few breaks. He is delighted by what he has achieved but by the afternoon he is exhausted. He takes some painkillers and goes to bed. He sleeps fairly well but then finds he is unable to sleep at his normal time. He has a restless night and feels

Pacing activities

Different health professionals may help an individual to understand **the under-activity - over-activity pain cycle.**

As a sufferer of chronic pain or as someone who knows a chronic pain sufferer, does this following picture seem at all familiar ?

Much to her surprise, Ruth wakes feeling 'good' with a bit more energy than usual. Deciding to do a spot of housework she focuses upon the kitchen, quite enjoying herself: there are plenty of 'nooks and crannies' to sort out! She is having a satisfying time and feels 'worthwhile' It must be doing her some good; the physiotherapist said that it was important to remain active. Despite some gradual aches and pains she continues her activities with very few breaks ending up exhausted and aching all over! The next morning Ruth feels too unwell to get out of bed and stays there for the next day. By the end of the week she is feeling better and decides on another activity - it's time to sort out the spare room - that's always cluttered. So off she goes again having very little rest. And this vicious cycle continues with 'over doing activities' and then doing very little.



It is important to get the balance right - gradually introducing activities and monitoring the body's response to them. If you anticipate that a particular day is going to be more demanding, try to prepare by having a slightly easier day either side of the activity rather than stopping events all together.

Understanding the pain cycle

Pain can be very tiring: it places many more demands on a person's body, to enable them to cope with activities of everyday life. This can cause anxiety and tension in turn causing more fatigue. This may lead to depression, aggravating the pain response and so the cycle of pain begins:

Pain → Anxiety/ Tension → Fatigue → Depression → Pain etc.....

Pain management may assist in breaking this cycle. People are taught different techniques to avoid tension and reduce anxiety. They may be given ideas on how to lift their mood in order to avoid becoming depressed or low in mood. Some of these approaches have already been discussed.



Chartered Physiotherapist

The physiotherapist is trained in physical examination. They identify the ways that different muscle groups relate to movement and how they work. The physiotherapist may advise on the best way to stretch and use muscles by providing specific exercises if necessary. Some physiotherapists are now focusing upon different muscles that provide specific stability to the spine or other joints which may be linked with chronic pain. These exercises may help where previous exercises have not.

The physiotherapist may use techniques such as heat, various pain free electrical treatments, certain mobilising techniques, massage, acupuncture and TENS (transcutaneous electrical nerve stimulation). This is a small battery operated machine delivering an electrical frequency into the skin over or around the painful area and reduces the pain signals. TENS is not a cure but may assist you in managing and coping with your pain.

Hydrotherapy may be offered. Gentle exercises are carried out in purpose built pools heated to a higher temperature than public baths, recognising that the actual heat can be beneficial. Do not worry if you are unable to swim as different types of floats fully support you whilst in the water.

Occupational therapy

Occupational therapists can assist people in regaining their independence. They can offer techniques, ideas or equipment that may make activities easier, either at home or at work. This can in turn improve the confidence and self esteem of individuals. If they can achieve a task more easily they are less likely to become tired or agitated: both of which can increase the pain. Some occupational therapists are also trained in relaxation techniques or counselling and may be able to assist with pain management in this way.

Acupuncture

This can assist in relieving various types of pain, acute or chronic. It can also be used to treat trigger points within the body. These are specific areas of muscle tension and are often associated with chronic pain. Acupuncture is thought to cause a local response at the point where a needle is placed, (which can be helpful in treating trigger points), as well as causing the body to release its natural pain killers.

Communication

Sharing your feelings about your pain with either a close friend or a member of your family can also help. It helps other people to understand your pain as well as sharing ideas on how best to manage it.

“MANAGING YOUR PAIN”

Pain is very difficult to understand, especially pain you have had for some considerable time. Most pain is caused by damage to soft tissue within the body and may be associated with joints or nerves. Sometimes there is a reason why someone is experiencing pain: at other times there may appear to be no reason. But whatever situation you are in, the pain is real to you! The only problem is that other people cannot see your pain - they may only see how it is affecting you which does not always tell the whole story.

What is most important is how you can help yourself and others to manage your pain. We know when we are in pain because messages, the pain signals, pass along nerves via the spinal cord to the brain. Pain control focuses upon modifying the response of these pain signals so that the brain is given a different message. Basically, if someone stamped on your foot, the pain message would be sent to your brain in order to get a response from you - “Ouch!” You might then respond by rubbing your foot in an attempt to reduce the pain - to modify the pain response.



Pain may be managed by:

Medication

Here are some reasons why some people may stop taking tablets to help their pain-

The tablets don't seem to be working

I can't cope with the side effects

I may become addicted to them

I find it hard to swallow tablets

I don't want to take tablets for the rest of my life!



If your tablets seem ineffective they may need modifying or altering. Pain can be helped by a variety of drugs. Anti-inflammatory tablets or analgesics, based upon the poppy seed - opium are usually the first type of drugs offered. These can be given at different strengths depending upon the severity of the pain. Other drugs may be considered that are specific to a condition such as rheumatoid arthritis. Different tablets may be used if the pain has become more complicated such as in nerve type pain. These tablets act on the brain in a different way to provide relief.

To achieve the best results from your medication their strength may need increasing or a combination of tablets may be considered so that they compliment each other in the way that they work.

Medication usually works best if it is taken regularly **and before the pain becomes too severe.**

If you are unable to take tablets, medication may be offered as a suppository; as patches; in liquid form or as an injection into a vein, muscle, the skin or the spine. Portable pumps that deliver medication into a vein, the skin or the spine may also be used.



Emotional factors such as depression or anxiety that can make your pain worse may be discussed. Action on Pain often find this last area causes concern for patients who feel they are “going round the twist” if these points are mentioned. Nothing could be further from the truth as they are frequent symptoms of somebody with chronic pain. Chronic pain can and does wear you down leaving opportunities for depression and anxiety to creep in. By discussing these issues there is the opportunity to deal with them “head on.” If they think that emotional factors are having a significant affect on your pain and your ability to cope with it, they may refer you to see a Clinical Psychologist.

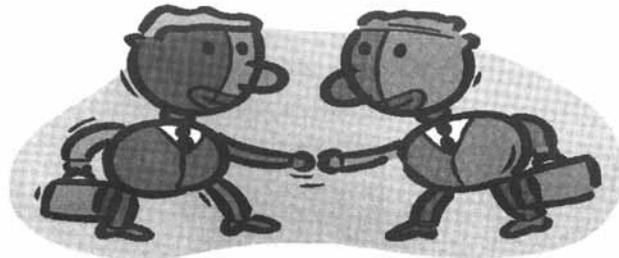
Other treatment options are:

- Review medication for your pain as this may need altering.
- Acupuncture.
- Pain relieving injections into tight muscle, (called trigger points) or into certain joints in the spine.
- Other types of injections that can alter the pain response.
- Referral to a pain management programme.

It is important that you are honest about your pain and how you really feel about it so that they can obtain a clear picture of what may be going on.

Some treatments may be given over a period of time whilst others such as altering your medication may only need monitoring.

It is important that you work with the pain team in trying to achieve the most satisfactory outcome for yourself!



Some key factors to assist your pain management

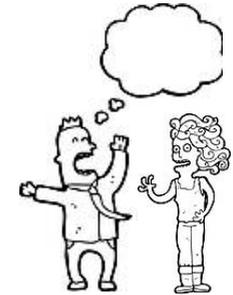
Accept and understand your pain

- Δ Be realistic about your goals - don't think back to what you used to be able to do. Be proud of what you can do!
- Δ Don't give up trying to accomplish new goals.
- Δ Success is far more rewarding than looking for sympathy or making excuses.
- Δ Recognise that pain does not necessarily mean harm.
- Δ Some actions may always hurt but in moderation it doesn't mean that you can never do them.
- Δ Try to understand your pain
- Δ Does it follow a certain pattern?
- Δ Are there actions that increase or decrease your pain?
- Δ Are there people who are more helpful to have around when your pain has increased?



Reduce stress

- Δ Consider using relaxation or meditation as discussed earlier.
- Δ Choose suitable activities or hobbies that interest you.
- Δ Find time to 'switch off' from a busy day.
- Δ Get away from it all - lie down for a short period or go for a walk.



Why not volunteer?

Keep yourself occupied by getting involved with community work or organisations. Even if you only manage a little, other people will appreciate your involvement. It can give you a sense of purpose and satisfaction as well as distract you from your pain. It can help you to become involved with other people, focusing upon their needs rather than your own.



But whatever you choose to do - don't forget to pace yourself!

Stay healthy

This can help you feel better and make you less vulnerable to pain by:

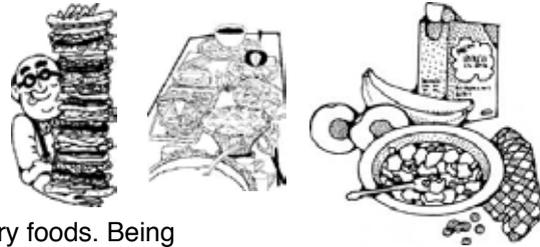
Maintaining a regular pattern of eating and sleeping.

This can assist in routine activities, meeting with friends, or keeping a job. Avoid sleeping during the day although a 20 minute power nap can be helpful.



Have a good diet consisting of a variety of healthy foods from each food group:

- Fruit and vegetables
- Bread, other cereals and potatoes.
- Meat, fish and alternatives.
- Milk and dairy foods.



Try to avoid too many fatty or sugary foods. Being overweight may aggravate your pain and reduce your mobility. Avoid stimulants that may increase your pain such as caffeine from coffee, tea and soft drinks.



Stop smoking and limit your drinking

Smoking is a health risk and nicotine acts as a stimulant that may increase your pain. Alcohol may effect your medication but a moderate amount could give you the occasional needed 'boost'!



Some misunderstandings about chronic pain

"I don't believe that person has chronic pain - they're able to work!"

Everyone's pain is different as well as their ability to cope with it. A person may still be able to work because they have modified their lifestyle in order to cope with it. It may also help their pain as it keeps them occupied. Pain is not obvious so don't make the mistake of comparing your pain with someone else's.

"I must be going mad! They can't find a reason for my pain so it must all be in my head!"

The original cause for your pain could have gone but the brain has a memory and something described as plasticity. These are reasons why the pain can continue and be ever changing. Even if you don't know the actual cause, there is still a lot that can be done for your pain..... with your help.



"Perhaps if I ignore the pain it will go away." Sadly this isn't the case. You may be able to take your mind off the pain for a short period of time. But as this booklet explains, many different approaches could be tried by you to help you effectively manage your pain.

"There must be drugs that can get rid of my pain."

Drugs can help many people but they are not a permanent cure and do not suit everyone. Some people are unable to take certain drugs because of their side effects.

"That person pretends he's in pain just to get noticed and to get out of work."

Most people with chronic pain would be delighted to work and to be rid of their pain. Very few people fake it although some people may seem to over react to their pain because that is the only way that they can cope with it.

"My doctor never seems interested in my pain or how to deal with it ."



Doctors and various health professionals will try to find ways to reduce your pain. Sometimes they may be as frustrated as you are because their efforts may not be effective. Pain is very complicated. If they are unsuccessful, it doesn't mean that they don't care.

What to expect in a Pain Clinic

If you are still having significant problems coping with your pain then your GP or Consultant may refer you. If they don't and you wish to be seen at a pain clinic, then ask to be referred. However you should be prepared for a long wait for a first appointment with a pain specialist .

The Pain Clinic is less interested in the precise cause of the pain as this is often impossible to assess. They focus more on the "pain mechanism" which basically means: "Is the pain coming from muscles; nerves; bones or a combination of all three?"

It is important to understand this so that your pain can be treated properly. Most consultants working in a Pain Clinic are anaesthetists who have other health professionals working with them. This may include psychologists, physiotherapists, occupational therapists and nurses as well as clerical support. Many patients are surprised to see an anaesthetist but when you think about it, they are best equipped in managing and understanding your pain: Anaesthetists are involved with minimising pain before, during, and after surgery!