

Living with Persistent Pain

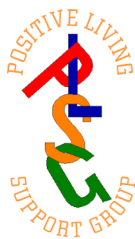
The following booklet has been co-written by patients and staff at the RUH pain clinic to help people understand chronic pain. It explains why chronic pain is different to acute pain, why it is so persistent and cannot be cured and why it is real. It also describes different ways to help manage it and achieve a reasonable quality of life despite the pain. Included to illustrate the points are quotes and opinions from people who live day to day with persistent pain.

*Written by the Pain Clinic (Royal United Hospital, Bath)
and The Positive Living Support Group.*

Acknowledgements

Many thanks to the Positive Living Support Group for their support, input and funding for this project.

Most importantly, thank you to all the chronic pain patients who described their experiences and gave quotes about living with chronic pain for use in this booklet so that others might receive some kind of help, understanding and comfort.



Hello, we are members of the Positive Living Support Group having gone through the Pain Management Programme at the Royal United Hospital in Bath. We have all achieved something positive out of the programme and the group, which we would like to share with you.

We have been there and know what it is like to suffer chronic pain. We have had the tears and the laughter, the hope and the despair, so we have put together feelings and quotes to let you know how we struggled to understand our pain, and manage to cope with it in our daily lives.

*We are not saying we are perfect, that we have all the answers or that it isn't a struggle - **but there is hope.***

We hope this booklet helps you to improve your quality of life and manage your pain within your home and/or your working environment as best you can.

If you do not suffer from chronic pain, but know someone who does, please keep reading.

Positive Living Support Group

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Introduction.

To manage pain well it is important to understand it as much as possible.....

What chronic Pain is ... a working definition.

Chronic Pain is persistent pain. It is pain that has lasted for longer than 3 – 6 months, and has a significant effect on the person and their family. It affects the way you feel, the things you do and the things you think about. It is different to the pain that immediately follows an illness or injury which we call **Acute Pain**.

The word chronic means the pain has lasted longer than 6 months. It means your pain is persistent and is likely to remain for the foreseeable future. Not forever perhaps, but for now. It's likely that if you have chronic pain that your life has changed in many ways because of it – *“it touches almost every part of your life”*.

Chronic pain usually means that all attempts to cure it have been unsuccessful and what you are having to do now is live with it. You did not choose to have pain but despite all attempts to relieve it or lead a normal life and control it, it persists. Coming to terms with the fact that your pain has defied all attempts to cure it and is here to stay for a while is neither simple nor easy.

Chronic pain is ‘an unpleasant sensory and emotional experience’. The mistake people always make when thinking about chronic pain is that it is all about the physical intensity of the sensation (the ouch) and how much it hurts. Pain does not have to be severe all the time to cause problems – the fact that it is there every day and feels unpredictable, confusing and uncontrollable is important. It can interfere with every part of your life down to the smallest things that you do (like sitting in a chair or making a drink). Chronic pain can wear you down and at times you can feel that it is an effort to be positive, hopeful and friendly. How unpleasant chronic pain is varies from hour to hour, day to day and person to person.

Pain does not have to dominate and run your life – but it is unpleasant and, at times, confusing. It is unpredictable and you will have good days and bad days with no real reason as to why one day is good and one day bad.

The aim of this book is to help people to understand and manage their pain as much as possible. Nothing in this book will help you to control the pain or cure

it but could help you towards developing a meaningful quality of life despite the fact that the pain remains.

Many of the things described in this booklet you may do already. All the time when you read this booklet remember that chronic pain affects people in many ways and to varying degrees. Some of the descriptions below will apply to you, some will not, some will apply only very mildly, some very strongly depending on your personal, social and medical circumstances.

“Chronic pain won’t kill you, but it won’t let you live either – it can touch every part of your life if you’re not careful.”

The effect of chronic pain on people

Living with persistent pain affects us in many different and sometimes surprising ways. Much of the time the effect is private and nobody knows about it but you. Some things we would all feel to some degree if we had pain....

For example:

Pain and thinking

Chronic pain disrupts our thinking. You can’t have a good short-term memory, good attention or concentration if you have pain. It makes you forgetful and distractible – *‘a mind like a sieve’*

Pain and thoughts

Chronic pain also brings with it difficult thoughts and questions, some of which have no answers, such as:

“Why me?, When will it end?, Why doesn’t anybody do anything?, or, I am useless, I am a burden to others”

These thoughts can be difficult to live with.

Pain and worry

Chronic pain can make you worry about many things.

- about making things physically worse, *'If I move too much I will do more damage to myself, cause more pain and end up in hospital'*.
- about being disbelieved by others. Chronic pain is difficult to understand and communicate and a lot of people in chronic pain worry a great deal that other people don't believe that their pain is real and think that they are weak or lying about it.
- About money, relationships, the future.

Pain and feeling

Chronic pain can also give you powerful feelings you might never have had before, such as:

- Frustration.
- Anger, irritability and bitterness.
- Pessimism.
- Self-criticism and low self-confidence.

Anger can be a big problem. You can't have pain and a long fuse – ask yourself a question, *"if you gave your pain to a big dog, would it be safe with people?"*. Pain makes us aggressive. It may stay private and you may put a lot of effort into keeping it private, but pain can make us snappy and irritable and this is something you have to learn to manage.

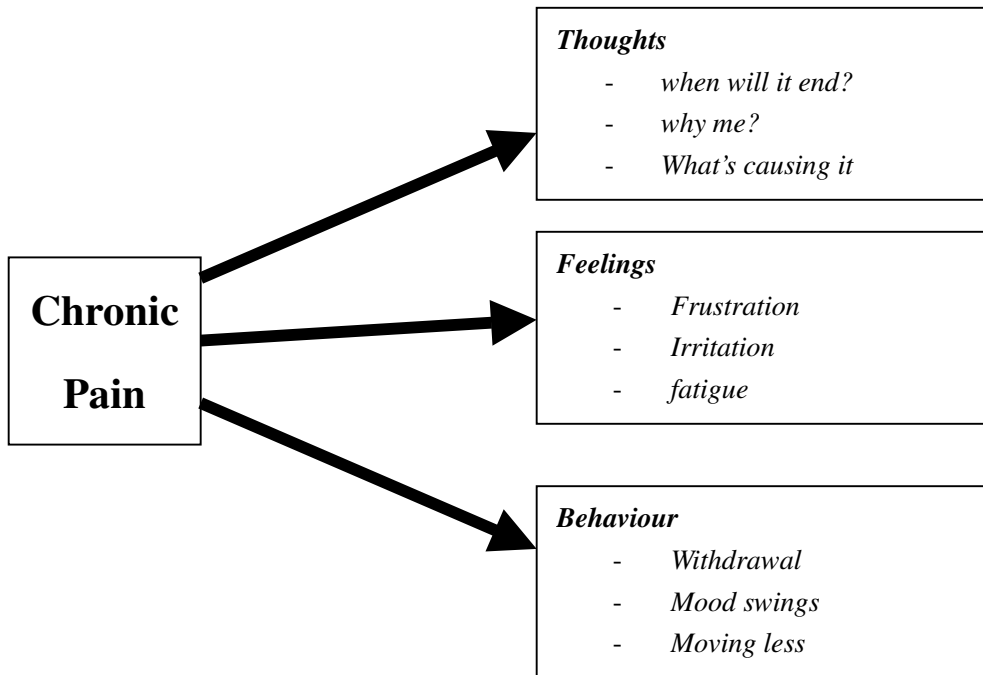
Pain and behaviour

Since the pain arrived you have probably found that you do many things differently such as:

- Social Withdrawal – don't have the energy to socialise, find people tiring, rather be alone.
- Fatigue - feel tired a lot of the time, low in energy and not so happy-go-lucky as you were.
- Loss of activity – hobbies, work, social life, sex life.
- Mood swings – one minute you're ok, next you're not - Jekyll and Hyde – more tearful or aggressive than before.

- Over-doing it – out of hope or frustration you do to much and pay for it with a pain flare-up later.

You could show it in a diagram this way:



Chronic pain can affect you in all of these ways and each of them can make life and the pain more difficult to deal with.

What is also clear is that these feelings, thoughts and behaviours affect each other and at times this interaction can make the pain worse. Doing too much or too little, feeling miserable, anxious, self-critical tired or angry can all make it very difficult to manage the feeling of pain.

When this happens it can set up vicious cycles.

These unhelpful feelings, thoughts, and behaviours do not cause pain as such but they can make the pain much worse and leave the sufferer feeling overwhelmed by their pain. People don't choose to think or feel these things but never the less these thoughts and feelings do visit and appear from time to time when you are in pain. They may be mild and almost un-noticeable, or very powerful and disabling. They may be very private and only the person with the pain knows about it.

Managing the way you think and feel when you are in pain is very important in helping to minimise how much the pain affects both your quality of life and the quality of the relationships you have with the important people in your life.

Chronic Pain Mechanisms.

Pain Mechanisms - Why is pain so unpleasant?

Pain is usually a warning sign that something is wrong with the body. However this mechanism can go wrong and you can get a persistent pain called chronic pain, which is not caused by damage to the body, but to the pain system itself.

What is the Pain Gate?

The nervous system can be thought of as a highly complex electrical network in the spinal cord and brain which can increase or block the transmission of pain.

One particular mechanism in the spinal cord is known as the **Pain Gate**, which lets pain signals through when it is open and blocks pain signals when closed.

In chronic pain, the pain gate is the problem - it won't shut.

It fails to close completely and as a result pain is felt most of the time. It is like an alarm system that is broken in the 'on' position, constantly sending out a signal long after it was triggered and should have shut down.

There are many ways of closing the gate to some degree, that's why you get good days and bad days, although there is a lot of variation between individuals.

Very gentle exercise, relaxation, normal activity, acupuncture and TENS etc., can help to close the gate and reduce the sensation of pain.

"It can be so hard to understand this pain - it comes and goes. It moves and you can never tell why on any one day it can hurt more than others."

“I couldn't explain my pain – so it made it difficult to explain it to other people.”

Overdoing it, low mood, anger, tension and inactivity tend to open the gate and let more pain messages through which increases the sensation of pain.

Can I take tablets to close the gate?

You can, some drugs can close the gate and reduce the pain to a degree, but unfortunately the effect weakens with time and has side effects.

How else is chronic pain different to acute pain?

Both acute and chronic pain varies from mild to severe.

Chronic pain is any pain that has persisted for longer than 3 – 6 months.

Acute pain usually follows injury and is present for less than two months, it fades as the injury heals.

Acute pain is usually easier to treat than chronic pain - it goes away when you heal.

Does continuing pain mean there is continuing damage going on in my back?

No, in chronic pain there seems to be a vicious circle where the pain leads to loss of mobility. After a while, joints and ligaments become stiffened and attempts at exercise can strain the ligament and joints causing yet more pain. Keeping active in a gentle way has major benefits.

Although it may feel as if it does because it can cause an increase in pain, movement does not cause more tissue damage – it opens the pain gate increases the pain signal, but it doesn't mean you have caused more physical damage.

So if I exercise like mad will my pain go away?

No, the pain system has been sensitized and is running very 'hot', there is a great risk of doing too much, making the pain system more sensitive and causing further pain.

Try to keep moving gently, however little.

So how much exercise should I do?

Start very gently and by building up your tolerance to exercise slowly you should be able to increase your level of activity without increasing your pain. The balance is difficult to learn and takes time.

If you grit your teeth and try to ignore the pain for too long, you will pay for it.

Similarly, if you keep still, stay in bed and do very little you will also get more pain.

Do every thing as gently as possible.

Chronic Pain and Tension.

The stress or adrenalin response

The natural stress response of the body is there to help us. It gets us ready to fight or run when we are in danger. It enables us to protect ourselves with a quick, powerful action and to respond quickly to a dangerous situation or event. We need it to save us in life-threatening emergencies.

This natural response is commonly referred to as the fight or flight response.

Stress in your life

We have learnt that stress affects everyone and is a natural bodily response to threatening situations we experience during our lifetime. These situations and experiences are commonly known as stressors and can be divided into four different types:

1. Daily hassles e.g. car breaking down, children etc.
2. Life events e.g. loss, marriage, bereavement etc.
3. Emergencies e.g. accidents.

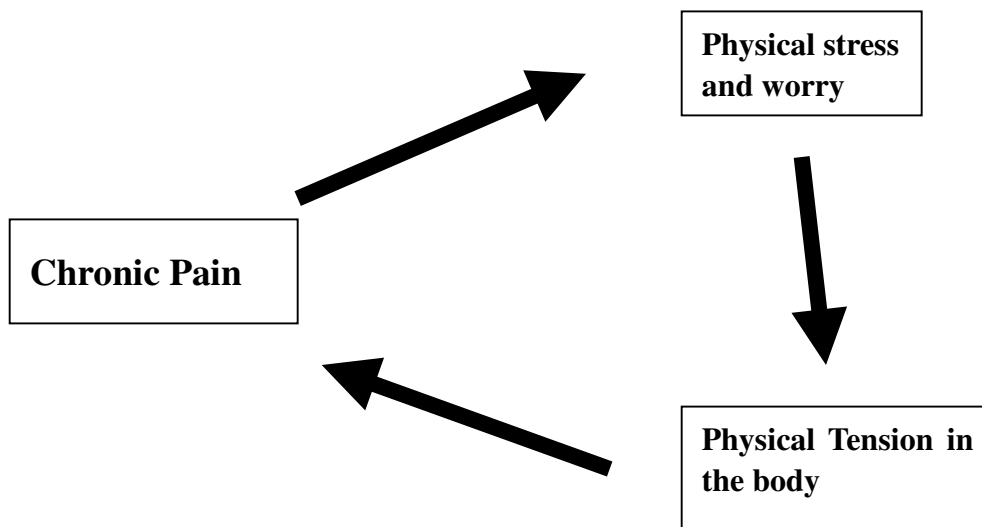
4. Private frustrations e.g. loss of hopes and dreams for the future, and being very self-critical.

Chronic pain could be in any one of these four sections at different times and as such can be a significant cause of distress.

Within these four sections there are many different types of stress with each individual feeling it in a different way. Consequently, events which make one person feel tense or stressed, may not have the same effect on the next person.

Chronic pain and the body

The stress response can be demonstrated as a vicious cycle affecting both the body and mind.



Chronic pain can be a cause of chronic and persistent stress, which can cause unpleasant physical and mental symptoms in the long term.

The hormones produced by the body in preparation for the fight /flight response are often not used up because our response to modern-day stresses rarely involves actually running away, or physical fighting.

The racing heart, cold sweat, dizziness and other stress symptoms that can happen, cause muscle tension. The muscles of the body are kept tense in readiness to respond to danger.

This increases the level of pain experienced and in time will increase the stress and tiredness the person experiences.

Stressful thoughts and feelings about chronic pain and the effect on the life of the chronic pain sufferer can also increase tension and the level of pain, prolonging the stress response further.

The stress response also affects the immune system of the body which protects us from infection. It can deteriorate, and the chronic pain sufferer will become more susceptible to common ailments such as colds, flu and fatigue.

Vicious cycles like the ones in the previous illustration can make it harder to cope with the pain.

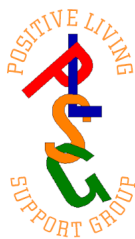
What many people find is that regular relaxation can help reduce mental stress as well as reducing physical muscle tension. The vicious cycle winding you up can then be broken.

“Pain can wind you up and grind you down at the same time.”

“Pain can make you snappy and irritable – you don’t like it but it’s hard to control.”

“Pain saps your confidence – you start not wanting to see people – you have to be careful to watch that doesn’t go too far.”

“Other things can get to you as well, and that doesn’t help the pain.”



Message from PLSG

You have now read enough perhaps to identify with some of what has been written and we are sure you will wish to continue.

Maybe you now have an insight into what chronic pain is, although you can never truly know it unless you live with it, but by continuing to read you can learn more and hopefully it will teach you to understand about pain management, it may sound easy but be assured it isn't.

Partners need a great deal of patience with us to be able to cope and understand our moods and irritability, the need we have to resist their help at every turn and why we ask "why me?". We get depressed and frustrated at not being able to achieve the things we would like to, especially in the beginning, however, it is possible to get past this if you have the help and support you need (although these feelings may return periodically).

It is important to remember that you haven't failed because depression and frustration comes back, you will have good days and bad days, even people who do not suffer chronic pain can feel low sometimes. Keep trying and keep going.

Regards

Positive Living Support Group

Pain Management.

Starting to manage chronic pain

Now that you have read about what pain is we hope that you have recognised some of your experiences. The next section looks at the constructive management of pain – the various things that people have found helpful.

Before we get to that however, this brings up the question of change.

In chronic pain – not changing is not an option. Many things will have changed for you since you're pain began and you will have had many losses as things which you loved doing have been ripped away from you.

A big question is – are you ready to acknowledge that change, accept that you're in pain, that it is persistent and will be with you for the foreseeable future – are you willing to change and think about adapting so that you can have a meaningful life despite your pain?

Not everybody is.

If you react to the statement above and reject it automatically – if it makes you feel bitter, resentful or offended – then it is unlikely that you will find this book helpful because it is all based on making changes. Perhaps at another time in the future you might find it more acceptable.

If you have read the words above and feel ready, (sad and angry perhaps, but ready,) to think about change and managing your pain – please read on.

Acceptance

What is acceptance?

Acceptance is important in pain management but it is not:

- Surrendering to the pain.
- A sign of weakness.
- Giving up.
- Resigning yourself to pain.

- Not fighting on.
- A sign that you are inadequate and a failure.

Acceptance is:

- Acknowledging that the pain is here for the foreseeable future (it's not your fault but it is here).
- Understanding that it is a pain disorder, not a sign of a weak character.
- A willingness to think about change.
- Understanding that pain does not have to dictate your life or define your personality.
- A willingness to think about working towards a life with some meaning in it despite the pain.
- Focusing less on controlling your pain and more on doing things despite it.
- Grieving for your past life.

Acceptance is an emotional task that is a bit like going through bereavement and grief. It involves coming to terms with something that is senseless, confusing, undeserved and imposed upon you (you didn't choose it).

"It feels like a punishment, but where was the crime, what did I do that was so bad?"

It is easier said than done, but it has to be done as not changing somehow is not an option in pain management. Everybody in pain resists acceptance at first and describes an angry, protesting phase when they find it hard to give up on the idea of a magic cure.

You will already have realised that gritting your teeth or sheer stubborn bloody mindedness may get you a day of activity – but that you pay for it in the end, the next day or that evening or the next week.

“You cannot just ignore pain and grit your teeth each and every day – you might as well throw an egg at a rock the good it will do in the long run to use will-power to overcome the reality of chronic pain which will just wait until your finished and then return”

“Accepting pain helps you to live with it better”

Recognise yourself

Before you think about pain management, think a bit about the following questions.....

- Do you understand (to your satisfaction) why your pain persists and why it causes such disruption to your life?
- Do you think that your pain is real and legitimate, or are you ashamed of it, how much pride and dignity do you have right now?
- How much do you accept that your pain is persistent (chronic) and that pain management, not cure, is the best way forward now (be honest)?
- Are you a people pleaser, do you find it hard to say no to people?
- Are you stubborn and bloody minded, refusing to change out of pride?
- Do you try and over-achieve all the time, over-doing it and paying for it with pain later?
- Do you try and get everything done in one go, find it difficult to take breaks?
- Do you conceal and hide your pain and feelings from everyone all the time?
- Does anyone know what its like being you or do they always have to guess?

If you recognise yourself a little bit from some of the questions above – bear this in mind when you read about pain management – addressing the questions described above all make management a little bit easier to achieve.

Pain Management is easier said than done, but it is possible, all the ideas described in this book have helped people in chronic pain to live better lives?

“Losing an income and your independence is very hard to come to terms with and when you are suffering pain as well sometimes you feel like giving up at the beginning, but it does get better. It took me at least three years to get my medication sorted out, realise I was unlikely to work again and to look forward to the future, but now although the pain is still unbearable at times, I have learnt to live with it and make the most of what I have. It is very important to be strong to help you cope – don’t give up.”

Long-term Pain and the Effects of Inactivity.

How pain affects activity

When we suffer an injury the pain we feel usually makes us avoid certain movements e.g. if we sprain our ankle it is difficult to walk because of the pain. Resting the ankle for a short period allows the healing process to begin.

With chronic pain we experience pain even though there is no healing process going on. If we respond by resting and avoiding movement over a long period this will lead to more problems, including more pain.

The effects of inactivity

A vital requirement for the health of our joints and muscles is movement. Our joints need to move through their full range everyday in order to keep healthy and function normally.

Our muscles need to fully contract and fully stretch regularly in order to maintain their strength and endurance and they also need to be able to relax and return to their normal resting position.

If there is a long-term decrease in normal every day activity, which may be common to those suffering from severe chronic pain, this will result in:

- Stiff joints (due to tight ligaments and muscles)
- Weak, tight muscles.
- Less stamina (the ability to keep going with activities) due to decreased muscle power and decreased efficiency of the heart and lungs.
- Tension/tightness in nerve fibres, leading to increased sensitivity/pain.
- Decreased calcium absorption in the bones, leading to osteoporosis.
- Poor posture.
- Problems with weight control – leading to more strain on the joints.
- Poor balance/co-ordination.
- More pain – as joints become stiffer and muscles, tendons, ligaments and nerves become shortened, attempts at movement result in even more pain.
- Bad digestion and irritable bowel problems.

In the chronic pain situation it is very important to break this cycle but to do it very gently with the right advice from a physiotherapist.

Pacing.

Activity cycling

Many people base what and how much they do each day on how they feel at the time. A common thing with long-term pain is to do more when the pain feels better and catch up on lost time. However, this often makes the pain worse and the following days activity is much restricted. This is known as activity cycling.

Pacing

Pacing means trying to keep a regular amount of activity on both good and bad days. We do this by basing what we do on a plan and not on how we feel.

Pacing is a very simple idea, 'do things little and often' – but it can be very difficult to do - particularly if it represents a major change in the way you have always done things.

“Feel the pain and do it anyway - you must learn what you can and cannot do.”

“Pacing is really difficult - to not achieve an objective is stressful.”

“Some days pacing feels impossible – but it does help – holding yourself back on a good day is the key.”

“Your head still thinks you are what you were – so it doesn't think about pacing unless you make it.”

“Having pain does mean you have to pace yourself – but then that means you might not get as much done as you want – this can bring on a deep sense of guilt – guilt takes no prisoners so stamp on it before it stamps on you.”

Chronic pain means that the pain system has a low threshold – that means it doesn't take much to trigger off a sensation of pain. This is different to pain tolerance, which is the point at which the person cannot bear it any longer.

One of the problems for people in chronic pain is that they develop a high tolerance for pain - they can grin and bear it for ages. Unfortunately this means that they continue to do things in high levels of pain and only wind the pain system up further.

“If you wait until you can bear it no longer then that is too late, the damage has been done, be smart, take a break before then and let your pain system cool down for a few minutes”

Time limits

The first part of the plan is to work out what your limits are in some basic activities so that on good and bad days you are able to keep your activities much the same. The time limits will be different for everyone.

Baselines

What are Thresholds?

Thresholds are judged by the length of time an activity can be carried out before the pain increases dramatically and cripples you. In some cases this may be as little as 30 seconds to begin with.

An activity threshold is the individual's unique response. People with prolonged or recurrent pain tend to have an increasingly low activity threshold. This is something you can work on.

The usual pattern for people with chronic pain is to avoid an activity, or to try to force themselves to manage it for as long as possible (like they used to before they had pain). For instance: some people rarely sit at home, but will attempt to sit for over an hour for a necessary journey, usually finding the experience so painful and distressing that they are unwilling to repeat it.

Basic threshold activities include walking, standing, sitting, lying, kneeling or any position that may be personally important to individual patients. Once you have identified your activity thresholds you will need to set a baseline for each of them.

Most activities involve either sitting, standing or walking.

Work out how long you can do each of these activities at the moment - this is your threshold, e.g. sit for 10 minutes.

Baselines - where to start

It is often more realistic to work out how much you can do on two or three occasions, at different times of the day, rather than just once.

Set your own baselines for each of the activities by cutting the time on a good day to half or just below. The baseline is not the maximum length of time for which you can tolerate the pain, but a level which is easily achievable, e.g. if your threshold for sitting is 10 minutes then your baseline is 5 minutes. By establishing your baseline this way you are sure to be within your capabilities and not overdo it. If you stick to your baseline as much as possible your threshold and ability to do these activities will increase gradually over time.

For instance: Threshold baseline

Good day

| | Morning | Afternoon | Evening | Time Limits |
|-----------------|----------------|------------------|----------------|--------------------|
| Sitting | 20 | 25 | 30 | 10 minutes |
| Standing | 15 | 15 | 15 | 7 minutes |
| Walking | 10 | 15 | 5 | 5 minutes |

This means that the person here would sit, stand and walk using these time limits, taking a small rest or changing their position at the end of each time limit.

Pacing means doing this whether you feel good or bad. It means not overdoing it on a good day or doing very little on a bad day, but doing a steady amount of activity every day. If you stick to your baseline as much as possible your threshold and ability to do these activities will increase gradually over time.

Examples of pacing

Look at this example below to see what this means in practice.

Mrs. Jones' baseline for walking is 10 minutes. She would like to be able to walk to the corner shop, which is 20 minutes way.

Mrs. Jones plans to walk to the corner shop and home again using pacing. She could:

- Walk for 10 minutes.
- Sit down and rest on a bench or wall for 2-3 minutes.
- Walk another 10 minutes to the shop.
- Stand outside the shop for 1 minute.
- Walk around the shop for about 5 minutes.
- Rest outside the shop for 2-3 minutes on a wall or bench.
- Walk home 10 minutes at a time with a sit down half way.

Using pacing, Mrs Jones can walk to and from the corner shop without making her pain worse. By doing this on a regular basis she can improve her fitness and stamina so that she may be able to take fewer rest breaks and will be able to walk for longer.

“Always ensure an escape route is available so you can rest.”

“It helps to think ahead and not just hope things will work out.”

“The idea of pacing can feel really stupid, and unrealistic, but it does work if you try it and are willing to change.”

A similar approach can be used with more varied tasks, like gardening, where a number of different activities are involved (e.g. standing, walking and kneeling).

Time limits are used for each of the separate activities, changing regularly before the pain increases.

Goal setting

What are goals?

Goals are the things, which we would like to try and achieve. They can be anything from routine daily activities, e.g. household chores to quality of life activities e.g. hobbies, interests and social activities.

Any goal, which you set out to try and achieve, should be:

Concrete:

What is it I want to achieve? How much do I want to achieve it, and by when do I want to achieve it? By doing this it will help you clarify what you're aiming for and to know when you've achieved it.

Realistic:

Be honest with yourself about what is possible:

- Is what I am trying to achieve realistic?
- Is it appropriate to my age, family situation and general health?
- Can I honestly expect to achieve the goal at this point?
- Can I actually achieve this now, or at a later date when my abilities, fitness, stamina and confidence have improved?

Relevant:

- Is what I am trying to achieve relevant to my lifestyle and, more importantly, to me?
- Are there changes that I really want to work on?

If goals are not relevant, then you will not be motivated to try and achieve them.

“Getting yourself a goal makes life easier – it’s just keeping to it!?”

“Be realistic about the change that is necessary to live within your capabilities – you may need to take advice.”

“Always find some way to reward yourself.”

“The thing with goals is – talk it over with someone.”

“A goal can be anything – small ones are best.”

“I achieved a goal recently – to have a bath – the feeling was great!!”

Goals can either be long or short term

Goals should be chosen by the individual based on what they want to achieve and not on what they or other people think they should do. Having said that, it is very important to include the people close to you in the decision making.

What is goal setting?

Goal setting is working in a planned way towards achieving your goals. It is a process which:

- Enables you to regain control of your life and activities.
- Enables you to plan both what you do and how much you do at any one time.
- Can help you achieve specific changes that you would like to make to your life.
- Can help you develop new skills.
- Provides a focus for your life and can help increase your self-esteem.

Think of the goal setting process as a flight of stairs, with your overall goal at the top. It takes time to reach the top of any flight of stairs you cannot get there in one leap you have to take it one step at a time.

Don’t just think of practical goals, think of emotional ones too, or those to do with relationships – it may be more important to you to set a goal like – ‘I will become closer to my family’ or ‘I will become more intimate with my partner’

What's important is that the goals help you achieve something which you value and believe is important to you - something which improves your quality of life and your relationships.

"I decided to work on getting closer to my wife, fight less, it wasn't all that easy to break down into steps or anything like that, but we did it and it was worth it"

How do I set goals?

The first thing you need to do is to think about and write down those activities that you can't do, but would like to do and those that you don't do as much as you would like.

Having written your list, think about which of these activities are most important to you what are the important changes that you would like to make to your life?

Make a second list.

Look at the example of goal setting on the next page and then attempt to answer the questions below for each activity on the second list:

- How much do I want it or is it just something I think I should do?
- How necessary is it? How would the achievement enhance my life?
- Is it specific and concrete - have I stated exactly what it is that I want to achieve and can I visualise the point of achievement?
- Is it achievable either now or later?
- Is it relevant to my lifestyle and myself?

Answer:-

Having answered these questions you will probably find that there is at least one activity to which you have positive answers to all the questions - this can be your first goal.

At a later stage, when your stamina, threshold, fitness and confidence has improved, you may well find that some of the activities which are not possible to achieve now are more realistic and achievable and you can start working towards them.

It is important to remember that what is not possible now, may well be possible in the future - don't think that what you can't do now you will never be able to do again.

You have now decided on what it is you want to achieve - what do you do next?

Think about the activity in detail: exactly what does it involve - what movements/positions are required in order to be able to carry it out?

Now ask yourself the following questions, writing the answers down:

- What are my current strengths?
- Why can't I do this activity now - what are the obstacles/difficulties that prevent me from achieving them?

Answer:-

An example of Goal setting

What is my overall Goal - What is it that I want to achieve?

I would like to be able to walk more.

How much do I want it?

A great deal - I would be able to get out and about a lot more if only I could walk more than I can at the moment.

How necessary is it?

Very necessary - walking is an essential part of life.

Is it specific and concrete?

No - not as it stands at the moment - it is much too general.

Can I break this down so that it is much more achievable?

I would like to be able to walk for 30 minutes twice a week.

Is it achievable?

Yes - if I take it slowly and pace myself gradually.

Is it relevant?

Yes - if I could walk further, I would be able to walk down to school and meet the children.

Is it realistic?

Yes

What are my current strengths?

I am fit and healthy, apart from my pain, and enjoy walking, I can stand for 15 minutes without pain. I have the support of my family who will encourage me to achieve my goal.

Why can't I do this activity now?

Because I can only walk for 10 minutes before it becomes too painful to continue.

What is my current baseline for walking?

5 minutes

Strategy

What are my mini-goals to help me achieve my overall goal?

Example:

- To walk for 5 minutes, three times a week for 2 weeks, to gain some confidence.
- To walk for 7 minutes, three times a week for 2 weeks.
- To walk for 10 minutes, three times a week for 2 weeks
- To walk to school one way (15 minutes), meet the children and arrange a lift back.
- As above but twice a week.
- I will continue to walk to school until I manage it everyday of the week, and feel confident about doing it.
- To gradually build up my walking time, by going to the shops en route to school, so that eventually I can walk to and from school and meet the children two afternoons a week. I will not increase my walking time until I feel comfortable with the amount I am already doing.

"Goals – sign up to it. Keep on the wall to ensure you follow it. Don't worry about bad days. Start again."

"No shoulds, oughts or musts, don't make yourself do things that don't help."

How long will it take?

"It doesn't really matter as long as I achieve it eventually."

Summary

- Think of the goal setting process as a flight of stairs with your overall goal at the top. You cannot get to the top of the stairs and achieve your goal in one big leap - you have to do it step by step. Each step towards achieving your goal must be easy - work in small, achievable steps.
- Goal setting is systematic. Each time you achieve a mini-goal you will feel confident enough to go on and take the next step.
- If you don't achieve a step exactly as planned, don't be disheartened - you may need to put in an extra step or two to get there.

Reward yourself when you achieve a mini-goal. Achieving these tends to be reinforcing in itself, but actually giving yourself 'reinforcers' (treats) helps you stick to your goals, irrespective of how you feel (good and bad days). Reinforcement from others can be very rewarding - let your family and friends know what you are trying to achieve so that they can help you and give you encouragement and reinforcement.

Make sure you don't move onto the next step until you are sure you have achieved the previous step and can complete that mini-goal without difficulty.

Pain Medication.

A variety of drugs are used to try and reduce chronic pain. All drugs have some side effects.

Types of drugs used in Chronic Pain

Most painkillers, or analgesics, were developed for the treatment of acute pain. As we have already seen chronic pain is different to acute pain. Painkillers can be graduated like a stepladder, from mild analgesics (like Paracetamol) to strong opiates (like Morphine). In acute pain, analgesics (painkillers) are chosen which have suitable strength to match the pain of the patient. In general, the stronger

the analgesic, the greater the number and severity of side effects.

The Analgesic Ladder

Step One. The analgesic ladder starts with simple analgesics like Aspirin, Paracetamol, Ibuprofen, etc.

Step two. This consists of a simple analgesic like Paracetamol combined with a mild opiate, e.g. Tylex (Paracetamol and Codeine). With this type of drug you may get side effects such as constipation, nausea, drowsiness, even hallucinations, stomach pain and bleeding.

Step three. This consists of mild opiates on their own, usually in higher doses than used in step two drugs. Typical drugs in this group include DFI 18, Codeine and Temgesic (Buprenorphine). Typical side effects include constipation, nausea, vomiting and sedation.

Step four. This consists of strong painkillers like Morphine and Fentanyl. These drugs are the most powerful known painkillers.

Unfortunately they are of limited use in chronic pain, firstly, because they have less action on joint, bone and muscle pain than on internal pain, e.g. gall stone pain. Secondly, the patient rapidly becomes used to the pain killing action so he/she has to take more to get the same effect. Side effects include nausea, vomiting, constipation (constipation is a real danger), reduced breathing and withdrawal symptoms on stopping the medication.

Addiction to these drugs is a real possibility and doctors avoid their use for this reason.

“You end up with a love hate thing with your medication – you don’t like taking them, but they do help.”

“Don’t just let your medication go on and on without someone checking it every now and again.”

Unconventional Drugs

Antidepressants

These were first tried as an attempt to treat the depression caused by being in chronic pain. However it was found that even at a low dose such tablets had extra effects. They made other painkillers more effective and also seem to reduce pain messages at a spinal cord level. These effects are variable and unfortunately don't seem to last more than a few months. These drugs also do not start to work until you have been taking them for a week or two. Examples include Amitriptyline, Imipramine, Lofepramine, Nortriptyline. All cause similar side effects: dry mouth, blurred vision, constipation, problems passing water, sweating, tremor and rashes.

Anti-Epileptic Drugs

These drugs are normally used to control the over-excited brain cells in epilepsy. Some chronic pain is due to over-active nerve cells in the rest of the body. These drugs act by calming down the nerve fibres. They tend to cause sedation, dizziness, nausea, double vision and hair loss.

Typical drugs of this type include Sodium Valproate (Epilim), Gabapentin and Carbamazepine (Tegretol)

Summary

- Side effects occur with all drugs.
- Taking the recommended dose at the recommended time may improve efficacy and reduce side effects.
- Taking extra tablets. E.g. Paracetamol may result in overdose.
- Pain tablets are usually of limited help in chronic pain.
- Using stronger painkillers is unlikely to help with pain, but may increase side effects.
- Reducing painkillers may not increase the pain, but will remove side effects.
- If you want to consider reducing your present medication, you can discuss this with your doctor, **don't do anything like this in a hurry or when you are in a mood.**

Exercise.

Exercise helps you to:

- Become more supple.
- Strengthen your muscles.
- Increase your stamina.
- Improve your co-ordination and balance.
- Improve your posture.
- Improve your circulation and strengthen the heart and lungs.
- Keep to your correct weight.
- Gain a sense of well being.
- Helps bowel movement and digestion.

You can become fitter despite having chronic pain. Improved fitness will help you to become more confident in your body and enable you to cope better with your daily activities.

Stretching exercises are good for you because they:

- Help lubricate the joints and keep them healthy.
- Improve circulation to the muscles and joints.
- Increase your suppleness.
- Prepare you for increased activity, i.e. they are 'warm - up' exercises.

"I found the light exercises given to us on the Pain Management Programme, are still one of the best for making the body more supple and easier to get around each day. If you pick the ones most suitable for you to do each morning for 5 to 10 minutes, after a week or so it will make your body muscles stronger, to face each day with less pain."

Relaxation.

The ability to relax can be helpful when you are in pain. It may look simple but it is far from easy to learn in practice.

Relaxation is important for a number of reasons:

- To reduce muscle tension.
- To produce a calming effect.
- To promote sleep.

Once learnt, relaxation techniques can be used to reduce the effects of pain and provide a way of being in control. For many people being able to relax is easier said than done, but it can be achieved with time and practice. Begin by practising in a quiet, comfortable place and as it becomes easier you will be able to use it whenever and wherever required as part of your everyday life.

Tips to help relaxation

- Learning to relax is like learning a new skill. To begin with many people set aside a regular time to practice when they are not stressed and there are no distractions.
- Don't wait until you are feeling really tensed or upset before trying to relax. It is much easier to relax when you first feel tense.
- Notice what happens when you become tensed. A clenched jaw, tight neck, a fist, or tight across the eyes. Use these as a cue for relaxation.
- While you are doing something, practice letting go of tension as you breathe out.
- Loosen tight clothing and try not to eat before relaxation.
- Sit quietly for a few minutes before carrying on.
- As you become more confident about relaxing you will find you are also able to relax in more stressful circumstances. Even taking the edge off tension can be helpful.
- Try different techniques to find one that suits you. (Staff at the pain clinic can help you with the different ways).
- Don't rush off to do something after a relaxation session, you'll lose the benefits.
- The earlier you use relaxation, the more helpful it will be. Don't wait until you are so wound up, that nothing can work.

How to relax

There are many ways of relaxing. The simplest is described below.

These can be used:

- When you feel yourself getting tense and irritable.
- When you feel your pain getting worse.
- When you want to get to sleep.
- Everybody should allow himself or herself the opportunity to use and enjoy relaxation.

Breathing for relaxation

- You will remember that one of the effects of the stress response is to speed up your breathing. When it is stressed your body is working harder and it needs more oxygen. This makes your breathing become fast and shallow. This fast, or 'over-breathing', is something that happens very often in people vulnerable to stress and needs to be controlled.
- Lie down on the floor, or on your bed with a thin pillow under your head and, if this is comfortable for you, another larger pillow under your knees. The last pillow is often particularly helpful if you have a back problem. Make sure your clothing is loose, especially around your rib cage, waist and abdomen.
- Become aware of your breathing and just observe it for a moment as your breath flows in and out. Breathe through your nose as this filters and warms the air. Let your breathing be slow and steady. Notice the in and out movement of your rib cage and abdomen. Don't do anything; just watch what happens as you breathe. You may notice your ribs moving at the side and may also feel the expansion of your back against the floor or bed.
- Place your hands between the lower part of your ribs and abdomen and you will feel the rise and fall of your breath. As you breathe in, close your eyes and imagine a balloon inside your abdomen filling with air, as you breathe out imagine the balloon collapsing. As you breathe out, feel your body relaxing and say to yourself 'relax'. No other part of your body needs to move, so check your upper chest and shoulders are still.

- This is called diaphragmatic breathing - continue for as long as you like - at least five minutes. Be sure not to force your breathing mechanism in any way. This is a process that takes place quietly and naturally. You will gradually become more and more relaxed, allowing body processes to function normally and smoothly.

Practice this as often as you can each day, perhaps four or five times. Once you have practised lying down in this way a few times, practice steps b) c) and d) when you are sitting and standing.

When sitting, be sure to maintain an upright and poised posture - sit in a chair, hands clasped behind your head. If you slump, there is no room in your body for the expansion of your rib cage and diaphragm.

Diaphragmatic breathing will soon become your normal way of breathing for much of the day. Once the pattern of breathing is established you may like to continue with the practice anyway because it is so relaxing and pleasurable.

Hopefully you will find this breathing practice so effective that you will use it as the main form of relaxation.

Positions for relaxation

It is important to find a position in which you feel as little tension as possible for relaxation. The following points may help you find a position that suits you.

Lying down

- Don't lie on anything too squashy, otherwise you may be tensing muscles you don't mean to.
- Support your neck and knees for greater comfort.
- Have your arms by your side, let your palms roll gently outward and your elbows out and fingers apart.

"I find deep breathing exercises help my pain, especially if I am lying down."

Sitting

Any comfortable, supportive armchair can be used when relaxing.

Tips to help form a pattern of breathing for relaxation

- Organise a reminder for yourself to practice the habit of taking diaphragmatic breaths at all times during the day. One or two breaths every half an hour every day is ideal. That is, 20 or 30 breaths scattered throughout the day.
- Match the diaphragmatic breathing with your normal routines so that it becomes easy to remember to do it.
- Use diaphragmatic breathing to prevent the build up of the stress response on a regular basis, even if you feel quite relaxed.
- If you feel stressed, the breathing can help you to calm down.
- For instance, every time you make yourself a drink or go to a certain part of the house, stop and do one or two breaths.

- Remember that you don't have to stop what you are doing to breathe diaphragmatically.
- Do remember to practice relaxation each day.
- There are other forms of relaxation that you can investigate – such as progressive muscle relaxation.

“Relaxation is a real help to me.”

“Definitely helps.”

“Relaxation takes a bit of practice, but when you can do it, it really helps.”

“Pain winds you up – relaxing helps bring you down.”

“I can't take pain killers so relaxing is a must – You have to learn to relax when all around is frantic – it can be hard.”

Feelings and Thoughts.

This section describes the role of thoughts and feelings and the part they play in the experience of chronic pain.

Recognising the effects of situations on our feelings

Certain situations will produce certain emotions or feelings in all of us. Also our responses to situations will depend on things which are individual to us. For example, being let down by someone can make you feel sad or angry or frustrated. Achieving a personal goal can make you feel happy, successful, and positive about tackling the next one.

Long-term health problems, such as chronic pain, produce a whole range of feelings, both positive and negative. As people re-adjust to what they must go through, they can experience confusion, loss, worry, frustrations and disappointments.

Feelings or emotions can produce certain types of thinking, unhelpful emotions such as frustration, anger and helplessness can be linked to unhelpful thoughts, such as:

“I can’t cope”

“There’s nothing that will help me”

“I’m never going to get any better”

“I ought to be able to cope with this”

“I must get myself on top of these problems”

“I’m no good to anyone”

These unhelpful thoughts are very destructive. They can put a lot of extra pressure on you. For instance if you tell yourself *“I should be able to cope”* you can push yourself to do more than is helpful. As we have learnt, this will usually make your pain worse. If you allow these sorts of thoughts to become common ones, then you will stop doing the practical things that may help with the pain - relaxation, pacing activity and exercise, mixing with other people.

“It’s easy to sink back into yourself and cut yourself off when you have pain - try not to all the time.”

“You can become bitter and frustrated and feel hopeless – you have to watch out for that.”

What you can do to manage negative thinking

Recognise and challenge the ideas and thoughts that you have, try and see them as thoughts, not facts, not the truth, just the way you feel.

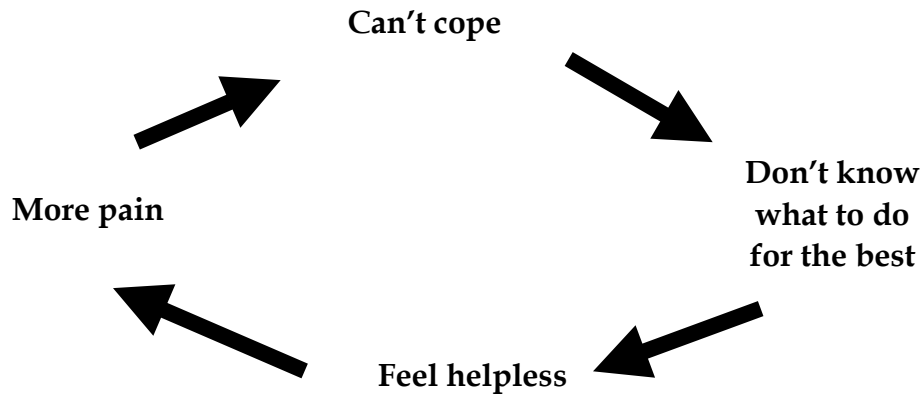
- Recognise – *“I can’t cope with my problems.”*
- Challenge – *“some things I can’t do, but others I can.”*

“If I pace myself, I can do quite a lot, I can cope better if I don’t get too tense.”

Vicious cycles and positive cycles

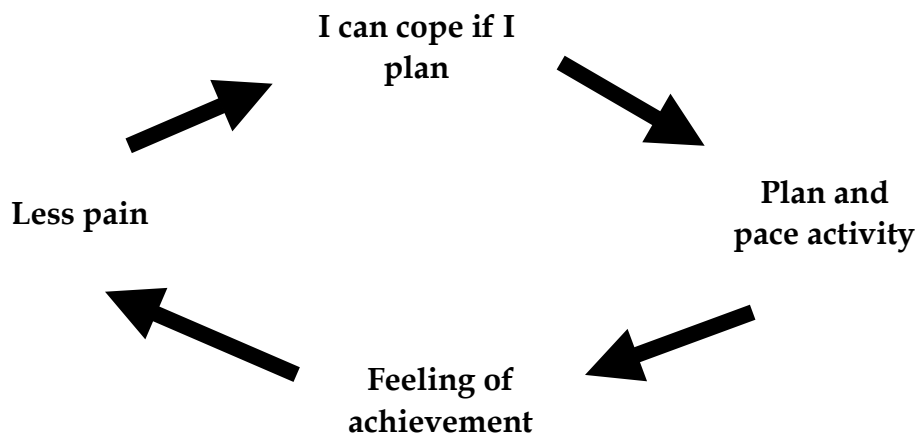
Negative thoughts create a vicious cycle. They stop you from taking positive action, which feeds negative feelings or emotions and proves the negative thoughts to be true.

For example, a common vicious circle is:



Challenging unhelpful thoughts can be useful, although it isn't easy.

An example of a positive circle is:



These diagrams make it look so simple – when emotions run high, or deep, it isn't so simple.

When you have pain for a long period of time you can start to feel very negatively about yourself. And perhaps think poorly of yourself *“I am a burden / useless / hopeless”*.

The difficult thoughts we have about ourselves just add insult to injury and make us feel more miserable and disabled.

Don't keep these to yourself, talk about them and try to challenge them too, try to offer yourself compassion and understanding, not criticism.

Also remember - pain will affect your concentration and memory

- don't expect to do things as efficiently as you did when you weren't in pain.
- You will be forgetful.

Do not underestimate the effort it takes to manage pain. It can be tiring and leave you washed out at the end of the day.

Do not ignore the emotional impact of the daily grind of chronic pain. You have to take it into account to understand chronic pain and manage it well.

The Normal Psychology of Chronic Pain.

Just to recap - if you remember earlier in the book there are many ways that pain can affect you. They vary from person to person but it affects everyone in pain to some degree.

For example, to some degree you will feel:

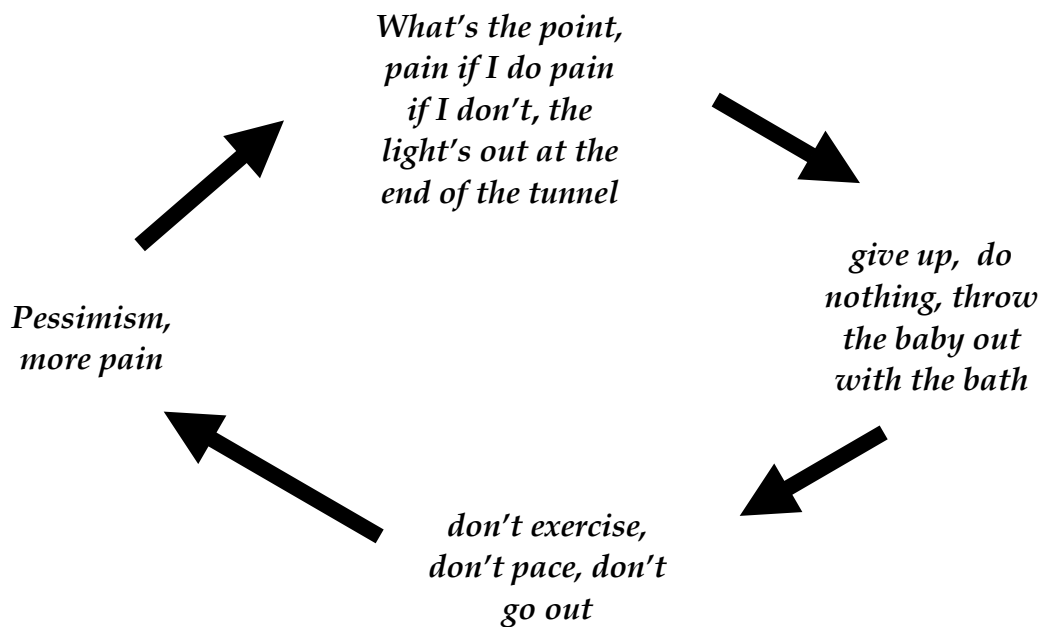
| | |
|-----------------------------|---------------------|
| Fatigue | Low self-confidence |
| Irritability and bitterness | Self-criticism |
| Withdrawal | Frustration |
| Worry | Pessimism |

Managing chronic pain means managing all of its unpleasantness, including the feelings described above. At some point feelings like those described above will visit you to some degree and can make you do things that cause more pain or make things worse in other ways.

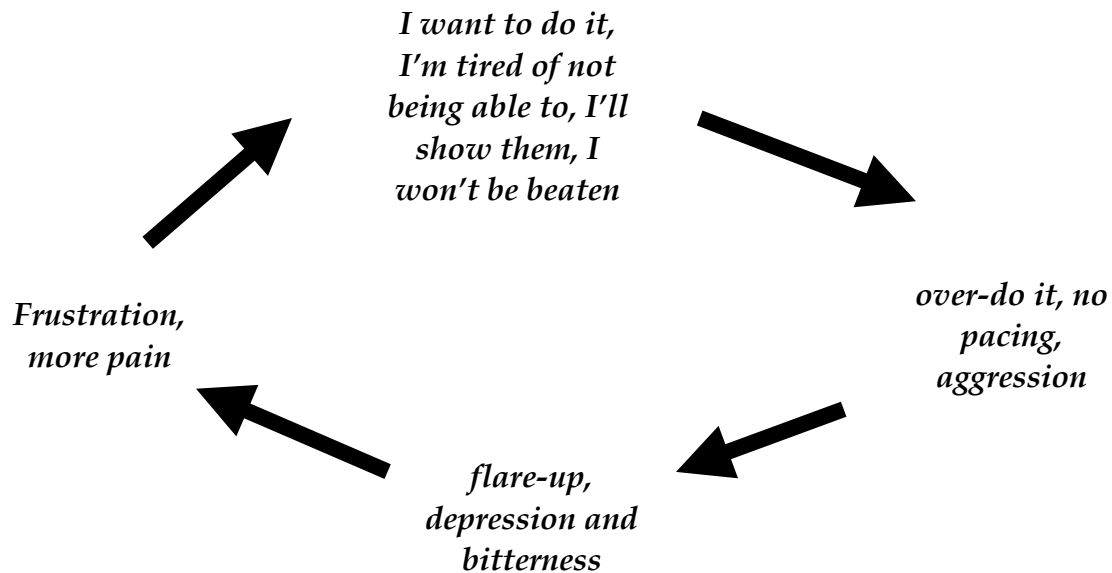
Because people in pain work hard to keep these things private - other people may not know all of the feelings that you have sometimes and you might put considerable effort into making sure that they stay private.

Vicious cycles can occur, in particular there are 2 evil twins that can cause real problems if they take over, such as:

Pessimism



Frustration.



It's important to manage these feelings and not let them make a difficult situation worse. The more awareness and insight you have into these processes the better.

Self-talk

How you talk to yourself and treat yourself is important - ask yourself this question?

When I make a mistake or get pain - am I understanding, helpful and kind to myself ...

...or...

...am I abusive, critical and angry with myself?

If you are usually self-critical and this tends to be an automatic response - it may seem unimportant but ask yourself what it must be like for some-one to be talked to that way and criticised in that way all the time, all day, all week, each month, all year - it doesn't help as the pressure builds up silently and grinds you down.

It adds insult to injury, adds salt to the wound - **do you do this to yourself?**

Another question?

Would you let some-one talk to some-one you love, the way you talk to yourself sometimes?

Self-criticism is mostly invisible but it wears you down and makes you defensive, low in confidence, tired, irritable, and bitter.

It is not easy but try to be more self-compassionate, try not to add insult to injury and try to encourage yourself more towards doing things you value. Its bad enough being in pain without twisting the knife and being mean to yourself.

Shoulds, Oughts and Musts

We all judge ourselves and have values and standards that we use that help us to see ourselves as decent people – put another way we have things that we feel we should, ought or must do to feel that we are moral, good and decent people, safe from social judgement and punishment – when we bend those rules we feel guilt, embarrassment and shame.

Sometimes pain makes it difficult to live up to these shoulds, oughts and musts but we try anyway and pay for it. It can be an obstacle to change and cause a flare up of pain.

We know people in pain would rather feel pain and risk a flare up than be embarrassed in public or feel guilty or ashamed.

“Don’t feel guilty for not doing things around the house. Do it when you feel able”

Think about the things you do because you think you should – do you have too?, or is there another way around it – can you give yourself permission to change what you do so that it doesn’t trigger off loads of pain but still feel ok about it? Talk to people about it, they might be able to help.

What shoulds, oughts and musts cause you to do things that cause more pain?

Some of them might be:

- I should fight to overcome my pain, not give an inch.
- I should ignore my pain.
- I should never complain.
- I should not make any allowances for my pain.

How much do you agree with this statement?

“To do any of the above is weak and wrong”

Its important to be very honest with yourself as this could be one reason why your pain is hard to manage or why you find it hard to make changes.

Communicating Effectively.

“Living with chronic pain for me is very lonely”

Communicating with people when you have pain is difficult. The pain is invisible and it can make you short-tempered and confused. Often the people you live with don't understand why you get angry, or withdrawn and quiet. They don't realise that it's anger directed towards the pain and they take it personally.

Often you end up not talking about it at all. This can cause problems, as pain is one of the most important things in your life.

Pain and other People

Pain invades families, not just bodies. It affects the way you treat people and the way they treat you.

“During the first few years of pain people can see you are unable to do all the things you used to and are eager to help, but as time progresses and they see you are trying to be as independent as possible, they behave like you are not so reliant on them and

eventually stop offering to help unless you ask them to do it. This makes you feel angry and unhappy because to ask makes you feel useless and guilty. Then resentment builds up. You feel they expect you to do more but this may not be the case as they would be pleased to help but through the pain and discomfort you are unable to see it like that. Therefore you end up being aggressive."

One of the most important aspects of living with chronic pain is the effect it has on the people around you and on your relationships with them. Other people can be your best support and your biggest source of hassle and worry.

It is vital that all the important people in your life understand chronic pain and its problems properly. This doesn't mean you have to talk about it all the time – but you can get into real problems if you never talk about it at all. It will be difficult to make even small changes if those around you don't get involved – it will be easier to change if you let them help you.

Remember – chronic pain is hard to understand and other people who don't have it will be as ignorant about chronic pain as you were before you had it. Some people will expect you to look really ill if you say you have pain, they will be confused if you look good and again you might think they disbelieve you. This can cause problems as it can feel like the only way to be believed about your pain is to look terrible, but if you do that you worry people will think you are putting it on. Good communication is crucial.

"If I have to prove I'm ill, how can I get well?"

"If you suffer pain at a workable age and had to give up a career, people look at you as though you should be at work, because pain is not visible. Most don't realise you really want to work and you feel guilty because you can't and this upsets you."

Chronic pain is **invisible** and so other people will have no idea from looking at you what your pain is like. This will cause confusion and misunderstanding and you can spend a lot of time worrying if people believe you or not and they can spend a lot of time worrying what is going on in your mind. Don't leave them to guess what you are thinking.

Chronic pain is a very private experience and most people, for loads of reasons, spend most of their time concealing it from others and trying to look pain-free. If some-one asks you how you are – you say "fine" – this is probably a very wise thing to do but what can happen is that you never talk to anyone about it ever.

When this happens you get into the strange situation where the one thing that has changed your life the most and caused you so many problems - is never talked about.

“People around you cannot see your pain, unless they know you really well, or are able to read your face or body language. Unless you are bed bound, a wheelchair user, or have a disability that people can see, you spend a great deal of time explaining to others, just what is wrong with you.”

“Having had surgery, I get remarks such as “surely you should be better by now”.’

“When I make an effort to be sociable, people see this as you being “well” – should you suffer a flare up, the attitude of some is –“you were alright yesterday”, you then feel guilty and are left with the feeling people think you are putting it on.”

It may be that you are sick and tired of thinking about pain, worried about being misunderstood or judged poorly - whatever the reason – what can happen is that those closest and most important to you feel as if they don't know you – and you don't know them – and they can only guess how you think and feel about things (particularly if you get a bit like Jekyll and Hyde and they never know what mood you are going to be in).

...and...

You will have no idea how they are – when was the last time you asked them how they were and listened to what they said? (when we are in pain or under pressure we can forget other people have feelings too).

Pain can cause family members to drift away from each other and become distant – talking to other people about their worries but not to each other – never using the word ‘we’ in conversation, always ‘me and him/her’.

Try and avoid the situation where the first time you learn that some-one close to you is worried about something is when you over-hear them telling some-one else.

“Being amongst a group of people who can very often tell at a glance or by the sound of your voice, what sort of a day you are having is wonderful- you can laugh on a good day, without feeling guilty and cry on a bad day and be supported – it makes

the awful disability of chronic pain manageable, to know that you are not alone in your suffering, and that you are "believed" when you say how bad the pain is."

Families in chronic pain can also try to protect each other from worries too – and once again, end up not talking.

"Sometimes family members can be over protective and try to prevent you from doing things you wish to do, this can lead to resentment, although you know they really want to help you it makes you feel as though they are interfering."

Pain stops people talking to each other - a lot.

When people aren't communicating they can take things personally that were never meant that way – being angry about the pain or the situation you find yourself in or being withdrawn can be taken as a personal insult or rejection – that you are angry at them or no longer love them – and you could never know about it - if you don't talk to them how will you? This can be particularly difficult if because of the pain your intimate, romantic or sexual relationship has dwindled.

Another thing is that strong feelings only come out in strong relationships and as a result we tend to vent our anger or frustration more on the important people in our life than strangers, *"You always hurt the one you love"* – another reason why pain can damage relationships.

What other people think of us

With rare exception – we all care about what other people think about us, even people who say they don't will change their behaviour according to what they think other people are thinking about them. This is particularly true if we are worried that other people might think badly of us or be critical.

In chronic pain, it can be easy to worry about other people and assume that they disbelieve you or think that you are mad, bad, lazy or weak. This can make you defensive and withdrawn, avoid people, talk less or over-do it when people are around.

Don't assume that you know what other people are feeling or that they know what you are feeling.

Quotes from partners of chronic pain sufferers

"I don't think I have, or ever will accept my wife's pain or disability, however, I do everything I can to help and support her and I feel that is one of the most important things."

"I don't think people realise that chronic pain affects partners' lives much. It has affected every part of my life, as well as my wife's, including our sex life and our social life which is now non-existent because people do not realise how much she is suffering. It makes me angry that she has to suffer so much and I can do nothing to help her, this in turn makes me feel inadequate as I should be able to protect her."

"A carer requires the ability to forward plan, i.e. parking as close to shops etc. as possible, avoidance of stairs if possible and patience in realising that the other person does not have the same physical abilities as oneself."

Finally, remember ...

People in pain wear a mask in public much of the time, concealing their pain behind it – this takes effort and is tiring to keep in place. You feel relief when you can take it off, can be alone and be yourself.

So...

Pace People Too – as much as you would any physical activity – relating to other people is more tiring than anything else

Don't avoid people – isolation is not helpful – but don't feel trapped with people or feel you have to be with them for lengthy periods of time, take breaks from them, pace the time you spend with them and maybe you will start to enjoy their company again and start to look forward to going out – but in smaller doses that you control – go down the pub but come back after an hour, whatever suits you.

Communicating effectively involves:

- Being open, honest and clear in expressing your opinions and feelings.
- Asking for what you want in a simple way, without disregarding other people's needs.

There are several situations in which it can be difficult to communicate

effectively. These situations may well occur more frequently for people with long-term pain.

They include:

- Saying no to requests or suggestions.
- Asking for help.
- Wishing other people knew what you feel or want, without you having to say.
- Explaining the pain problem.

“You can become angry and withdrawn – so very often.”

“Pain is helped when shared.”

“Other people know as little about chronic pain as I did before I had it.”

“It can feel if no one believes you, as if they think you’re making it up – that can get you down.”

“Pain invades families – not just bodies – don’t forget your family will have their own worries about your pain.”

“Make sure you keep talking to your family.”

‘Ask your family to read this book – it makes for better understanding of what you are going through.’

Styles of communicating

It is possible to recognise three different styles of communication.

These styles have been described as:

- Passive - putting other people’s needs first and ignoring your own.
- Aggressive - putting your own needs first and ignoring other people’s.
- Assertive - being very clear about your own needs, but taking account of other people’s needs as well. This is the ideal style of communicating.

The consequences of these different styles of communicating often include:

Passive

- Being frustrated (unless your needs coincide with other people's).
- Being liked by others, but not respected or trusted.
- Having an image of yourself as not important or worthy of respect.

Aggressive

- Poor relationships with others (because of friction and stress).
- Lower chances of satisfying your own needs in the long term because others are less likely to help in the future.

Assertive

- Mutual respect and effective achievement of goals.

How to look at your own style of communicating

One way of looking at how you communicate is to analyse a situation, using three simple steps. Think about a recent situation with a significant other.

- What did you want?
- What did you do?
- What did you get?

If it was not what you wanted - the problem is probably what you did. By being more assertive in the way you communicate, you may find you achieve your goals more effectively.

Have I the right to ask for what I want?

To communicate effectively, it is important to be clear about what you want and also what you believe to be your rights. Here are some suggestions:

Avoid talking about things when you are really angry or having a row – nobody listens when they are angry – talk about things on a good day.

A Bill of Rights

It's important to remember that everyone has the following rights

- I have the right to be treated with respect.
- I have the right to have and express my own feelings and opinions.
- I have the right to be listened to and taken seriously.
- I have the right to say no without feeling guilty.
- I have the right to ask for what I want.
- I have the right to make mistakes and to say when I do not understand.
- I have the right to ask for information from professionals.
- I have the right to change my mind.
- I have the right to decline responsibility for other people's problems.

Remember - Rights also involve obligations. There is a need to grant to others what you ask as a right for yourself.

Use a LADDER to achieve your goals

L Look at your rights and what you want

A Arrange a time and place to discuss the problem situation

D Define the problem situation

D Describe your feelings using 'I' messages

E Express your request in simple terms

R Reinforce co-operation

If you want to communicate more effectively, it needs planning and practice. You may be surprised at what you can achieve.

Managing Setbacks.

The nature of chronic pain means that there will be times when you experience increased pain and associated symptoms for longer than 24 hours. These episodes may be referred to as flare-up's, or attacks, but the term setback is more appropriate.

However the good news is that it can be worked through with the help of pain management skills and it does not mean that the progress you have made previously is lost. Once the increased pain of a setback begins to settle, you can use your knowledge of baselines for activity to set simple goals to help you resume your progress.

Causes of setbacks

Unless you have done something fairly drastic (like falling down the stairs), it is unlikely that the increased pain is due to new damage to the body. Increased pain is more likely to be due to irritation of the pain system, and caused by factors which open the pain gate (allowing through more pain signals) rather than closing it.

These include:

- Over activity. (e.g. finishing a job today rather than keeping to your baseline and continuing tomorrow).
- Under activity. (e.g. stopping regular activity/exercise).
- Illness. (e.g. flu).
- Stress (e.g. family problems).
- Bereavement.
- Perhaps there is no obvious reason.

“It helps not to panic during a setback - don't fight it – give yourself time to get over it.”

“Try not to panic about your pain. The sooner you can calm down in a setback the better.”

Guidelines for management

- Recognise that you are having a setback. The earlier you do this, the sooner you can take steps to manage the setback and minimise its effects.
- Seek G.P's advice if you have had an injury or are concerned that you have a new problem.
- Reduce activities but keep mobile, i.e. return to initial baselines (starting goal) for exercise/activities.
- If lying down helps the pain, rest in this position, but practice gentle mobility exercises (e.g. shoulder stretches) and try to walk a little at intervals. Bed rest for longer than 48-72 hours is not recommended by current national guidelines on back pain.
- Take medication as prescribed - a regular dosage is more effective during a setback than waiting until the pain is too much to bear. Consult a G.P. if resuming medication that you have not taken for some time.
- Try to relax using the breathing techniques taught to you.
- As soon as possible, gradually start to increase activity, working towards simple goals.

When you are feeling better

It can be helpful to review your setback and how you managed it.

- What factors might have contributed to the setback? (Understanding these might help prevent a similar setback).
- What things helped when you had increase?
- Talk to partners/family/friends and let them know how they can help you during a setback. Remember effective communication is essential in achieving your goals and easing frustration.

“This book may get put back on the shelf, but it is always useful to refer back to after a bad spell, as it encourages me not to get too low and depressed and to put a bad week back into perspective.”

Personal Activities of Daily Living.

This section looks at solutions for activities that most commonly cause problems.

Washing/Shaving/Cleaning Teeth

Sit on a stool or edge of the bath, if it is near to the basin. Bending over the basin may lead to increased pain. By sitting you can help reduce the strain.

Dressing

Early morning stiffness is a common problem for people with chronic pain. You may find the following suggestions helpful.

- Try some warm up exercises before you begin dressing.
- Sit down to put socks and tights on, or place a foot on a stool.
- When dressing your lower half, tights, underwear, trousers etc., place painful/stiff leg in first.
- When undressing take painful/stiff leg out last.
- Try a lying or sitting position to dress. It is sometimes easier.
- Wear loose, manageable clothes when possible.

Showering

- Try showering if you have problems getting in and out of the bath. It can be safer.
- Use a stool or chair in the shower if you find it difficult to stand.

Bathing

It may be difficult for you to sit in the bath with your legs straight. The following may help:

- Kneel in the bath or sit with knees slightly bent, or lie back in the bath.
- Avoid lengthy sitting in the bath.
- Let the water out of the bath before getting out.
- Try kneeling first and then get out. It may be easier.
- Non-slip bath mats are a good idea.

Washing Hair

- The easiest approach is to wash your hair in the shower or use a hand held shower unit attached to the bath taps.
- Do not stand and bend over a sink.
- Kneel on a stool or chair to reduce the pulling on the leg muscles and reduces stress on your back.

In the kitchen or workshop

- Reorganise cupboards and shelves so that the things you use are easy to reach and at a manageable height.
- Keep heavy appliances at waist level.
- Check height of worktops. Make sure worktops are a few inches below elbow height, or invest in a table that is the right height and work at that.
- Use a high stool or chair to sit and carry out tasks, e.g. peeling vegetables or washing up, painting or sanding.
- Stand as close as possible to the work surface to save unnecessary bending and reaching.
- Try to stand with one foot slightly higher than the other when at the sink or workbench, e.g. place one foot in the cupboard under the sink or on a block. This will reduce tension in the low back.

Remember: Pace your activities

Domestic activities of daily living

Household activities

Dealing with Washing Clothes

- Kneel or sit on a stool to load or unload washing machine and tumble dryer.
- Wet washing is heavier than dry. Remember to half fill your basket only.
- Keep your washing basket handy on a small box or stool. This saves unnecessary bending and reaching.
- Do more small loads.
- Get other people to do their own clothes.

Be sensible about your clothes line.

- Use a rotary clothesline if possible.
- Stand on a wooden box or small steady stool if the line is too high.
- Put the basket on a stool to avoid bending when hanging washing on the line.
- Use a pulley or prop system if you don't have a rotary line.
- Keep a straight clothesline at an easily reached height. Use a clothes prop if necessary.

Washing up

Sinks are never the correct height for everyone in the household.

- Place a second bowl upside down under the top one if the sink is too deep or too low. Or stand the bowl on the draining board and fill with a short length of hose.
- Stand close to the sink.
- Stack dishes before you wash to reduce time at the sink.

Ironing

The ironing board should be adjusted for sitting or standing.

- Use a high stool to perch on, if you are unable to sit whilst ironing.
- Place laundry basket on a stool to avoid bending to reach items and place ironed clothes on a table.
- Use a steam iron if possible. It may be easier as it needs less pressure.
- Stand as close as possible to the ironing board.
- Pace yourself. Do a little at a time.

Vacuuming

Upright models tend to place less strain on your lower back.

- Hold the handle of the equipment at hip height.
- Walk forwards with the vacuum - avoid leaning.
- Avoid twisting movements.
- Consider a carpet sweeper. They are light and easy to use.
- Only vacuum one room at a time or just the parts that show.
- Ask someone to carry the vacuum cleaner up and down the stairs.

Making beds

Duvets make bed making easier.

- Do not stretch over the bed to tuck in the sheets.
- Sit on the bed or kneel beside it and move around the bed on your knees.
- When changing sheets on a double bed get someone to help you.
- Encourage each member of the family to make their own beds.

Shopping

- Do not carry all the weight in one hand; distribute the weight evenly between two bags.
- Remember the key points about lifting.
- Consider a shopping trolley. They put less pressure on the back although they may be difficult to get up and down kerbs and in and out of cars and buses.
- Try pulling supermarket trolleys instead of pushing them.
- If available, use one of the special trolleys with a shallower basket which supermarkets now have which reduce the need for bending.
- Use the Internet and have your shopping delivered.

Remember:

**Pace all your activities.
Thought and planning can save a lot of effort.**

Driving

The following tips may help you to drive with less pain.

Remember it is important to pace your driving. A long journey that you are unused to may increase your feelings of pain.

When getting into the car

Place your bottom on the edge of the seat, so that you are facing outwards. Turn towards the front of the car and lift your legs into the car, either together or one at a time.

Comfortable driving

- Adjust the driving seat so that all the controls are within comfortable reach.
- Adjust the rear view mirror to remind you to sit up and to stop you slumping.
- Bend your knees slightly when touching the pedals.
- Relax and keep your chin tucked in. If you put your chin forward it puts considerable strain on the muscle at the back of your neck.
- Wriggle in your seat when stationary, or at neutral at traffic lights etc. This will stretch muscles and will help especially when in heavy traffic or on long journeys.
- Adjust headrest to the correct height, to protect your head in the event of an accident.
- Wear flat shoes. Never drive in high heels, otherwise your calf muscles will be stretched.
- Have frequent breaks. It will make the journey more bearable.
- Use a moulded backrest to give support if you have a back problem.
- Check to see if you need to readjust the mirror and seat at the end of the day. We all shrink during the day by up to 1/4 of an inch, due to gravity and water loss. This is regained at night when we rest. It does mean readjustment may be needed during the day.

When getting out of the car

Step both feet out of the car, and turn your body at the same time to face outwards. Move to the edge of the seat before trying to stand up.

Managing luggage

Always apply good practices for lifting to any load.

- Limit the weight of things you lift into the boot. Use a few smaller loads rather than one big load.
- Don't try and lift an object that is too heavy for you. Test the weight before you start, by lifting the corner.
- Avoid twisting round to pick up things from the back seat. Open the door and pull them out.

“I found it difficult driving a geared car and so became virtually housebound – we now have an automatic car and it’s great as I can drive it no problem - I am back out in the big wide world again.”

Buying a new car

Car manufacturers put a lot of thought into the design of cars. The results are aimed at Mr and Mrs Average. Most of us are not Mr and Mrs Average. When buying a car, we need to take into consideration its suitability for our size and build.

- Test-drive a car for at least half an hour to see if it is suitable to your size and shape.
- Check that seats are fully adjustable. Seats should be firm and give good support to your back and thighs. They should not be so long that they cut into the back of your knees. The seat should be leaning back slightly. This makes it easier for your back and neck. Very short or tall people may need a seat with a built in height adjustment. Ensure that the seat will move back far enough to let you have your legs and arms in a comfortable position. In some cars you can adjust the steering wheel to make driving more comfortable on the arms.
- If you are replacing your car, think about buying one with an automatic gearbox.
- Consider cruise control for motorway or long distance driving.
- Rally sport bucket seats are good for back pain.

Working in the garden

The following tips may help you to continue to look after your garden doing the things you enjoy. These tips cover various special tools and alternative suggestions for gardening as a hobby.

Equipment

Specialist equipment for people who have difficulties with gardening is available from any Garden Centre Shop.

- Use lightweight long handled tools.
- Kneeling pads can be useful, as can stools and old carpets to sit on.
- Never buy any equipment without trying it for height, weight and

- suitability for the job.
- Choose a two-wheeled wheelbarrow with a pram handle.
 - Use the correct tool for mowing and shearing. Hover mowers should be used by holding them from behind. Never swing them from side to side. Wherever possible choose an electric start mower or an electric mower. Mow a little at a time and keep as upright as possible. Use long-handled shears to trim edges.
 - Use secateurs that have a cut and hold action when pruning.
 - Consider changing plants to ones that are easier to maintain.

Practical alternatives

- Consider raised beds, tubs or window boxes. These mean less bending and reaching.
- Raise seedlings inside and plant out. A greenhouse with workbenches at the correct height means that you can sit down as you work.
- Get help with any very heavy work.
- Keep your back straight when digging. Dig a little at a time and take a break every 10 minutes.
- Consider paved areas with tubs of flowers, shrubs or herbs. These require less work. Vegetable plots, large trees that shed leaves and fast growing hedges all require constant heavy work.
- Work from a kneeling position. Weeding and planting can put strain on your back if it is bent and stretched for too long.

Lifting and handling – The six rules

The main rules for a good lifting technique are as follows:

- Back straight.
- Hand hold.
- Elbows in.
- Foot position.
- Head up, Chin in.
- Body weight.

Back straight

- Squat down bending your knees not your back.
- Stick your bottom out if you have to lean forward so that you are moving at the hips. Stick one leg out behind to balance yourself if necessary (for

- example, when getting shopping out of the car boot).
- Try not to stand with your feet still and don't twist your back if you have to turn. Either take small steps or pivot. Keep your feet moving.

Hand hold

Use the whole of the hand to grip and keep your hand relaxed. This lessens the tension on your neck, shoulder and arm.

Elbows in

- Keep your elbows tucked in against your body at all times, whether your arms are straight or bent. This allows you to handle a greater load without experiencing strain on your back.
- Hold the weight close to you so that there is no daylight between you and the object. By doing this you are transferring the weight through your body and your arms have less work to do.

Foot position

- Spread your feet so that you have a wide base and good balance.
- Keep the weight you are lifting between or close to your feet, otherwise you are likely to topple over and strain your back.
- Your leading foot should be pointing in the direction in which you intend to move.

Head up, chin in

- Don't look down at your feet when you are ready to lift.
- Keep your head up with your chin tucked in. This straightens the back.

Body weight

Once you have started to lift, lift and move off in one smooth movement, using the momentum of your body weight.

Points to remember for practical lifting

- Use these techniques when picking up any item from a heavy box to a pencil.
- When carrying shopping - divide into smaller loads by half filling the

- shopping bags.
- Breaking down a lift into several stages is often easier and puts less strain on your back Remember - more journeys, less load.
 - Try and avoid reaching above shoulder level. When reaching up to things on high shelves use a step stool or firm chair.
 - When you have to bend down, even to pick up small light objects, always bend from the hips and knees. It is good practice lifting lighter objects.
 - If you are not sure whether you can safely lift an item, do not attempt it - get help.

Posture

Although we tend to think about posture ('good' or 'bad') in relation to static or still body positions, e.g. standing, our posture is in fact constantly changing. Our bodies take many various positions, appropriate to whatever activity we are doing, e.g. lying down, sitting, walking, running, picking up a cup of tea.

In a healthy child, natural 'good' posture is shown beautifully, but as we get older, various factors may intervene to produce postural problems. These factors include:

- Social or work requirements to stay in one position for a very long time, e.g. sitting at a desk doing paperwork or using a computer.
- Over estimation of the body's capacities, e.g. lifting an object that is too heavy or too awkward in shape.
- Poor body awareness and postural habits, e.g. always sitting on a soft, low sofa.
- Chronic pain in a particular area of the body, causing 'muscle guarding' or spasm in that area, or reluctance to move that part.
- Fatigue.
- Anxiety and depression.

All of these factors can result in an alteration in the normal alignment of the body parts, especially the spine.

This altered posture may produce:

- Excessive strain on joints, ligaments and muscles resulting in pain. Regular exercise and efforts to maintain good posture can help prevent this and contribute to the health and functioning of the spinal joints.
- Extra demands on muscle energy, resulting in fatigue.

- Alteration of normal movement patterns.
- Adverse effects on internal organs, e.g. constriction of the lungs.
- Increased susceptibility to injury.
- Pain.

How can posture be improved?

- Increase your awareness of how you are sitting/standing/walking. Think about your posture - it is important!
- Strengthen the postural muscles: - the muscles supporting the head, particularly those at the back of the neck, the shoulder girdle muscles, the spinal muscles, the abdominals, the buttock and thigh muscles and the muscles supporting the ankles.
- Practice stretching exercises to ease stiff joints and tighten muscles and allow better posture.
- Avoid staying in any one position for too long - the muscles will fatigue and you will be less likely to maintain good posture.
- Follow simple guidelines on how to achieve correct sitting posture and correct standing posture.

“If the problem is at the base of the back it is possible to buy a cushion. A wedge shaped cushion with a piece cut out of the back, so when you sit the pressure is not so bad on the spine. Things like this can really help.”

Exercises to strengthen these muscles can be recommended by a physiotherapist.

Efforts to improve your posture need perseverance, because at first the improved posture will feel strange. The body has become adapted to the incorrect posture. However improved posture will have longer-term physical benefits as well as increasing feelings of self-worth and confidence.

Over-reaching often stimulates pain, always avoid over-doing it.

Sitting

This section covers the principles of a good sitting posture, and suggestions on how to make sitting more comfortable.

Sitting is something people take for granted, yet poor posture resulting from how

we sit, and the type of chair we sit in, often contributes to our back problems. Today's lifestyle encourages us to sit for long periods of time. You may be involved in driving to work, sitting at a desk or computer, and then sitting to watch television in the evening. If the chair provides little or no support, this may result in fatigue, stiffness and increased pain.

Correct sitting position

We are all individuals of differing heights, weights and body structure. There are three main measurements that need to be considered when looking at a sitting posture:

The length from:-

- Floor to knee.
- Knee to hip.
- Hip to top of head.

Points to look for in choosing a comfortable sitting position.

- Choose a chair that supports your lower back.
- Sit with the base of your spine supported by the chair.
- Choose a firm seat rather than a soft one.
- Make sure your feet reach the floor.
- Don't cross your legs

Problems you may find with seating.

If your chair is too low, your knees are higher than your hips, making it difficult to maintain a good posture. If your chair is too soft, getting out of the chair is difficult. If you sit too long in the seat, your feet may not reach the floor, or they may reach the floor but the base of your spine is not supported.

Possible solutions for seating.

There is no one type of chair that will be right for everyone.

There are several things you can do to make your chair more comfortable:

- Make sure that you are sitting with your bottom well back into the chair. Place a rolled up soft towel (in a sausage shape) in the small of your back.

A small cushion could also be used, in the same way.

- To improve a soft seat and make it easier to get out of, use a high-density foam wedge. Sometimes a board under the cushion can help - however, this should only be used as a short-term measure.
- A foam wedge will also create a better position for your back. When you sit on the wedge, your hips are higher than your knees, which opens up the angle at the hips and places less strain on your back. (The wedge should be placed with the thicker side towards the back of the chair).
- Think about using a large beanbag to give flexible support.

To find your ideal sitting position:

- Sit on a stool, or sideways on a chair, and slouch completely.
- Sit up as straight as possible for a few seconds.
- Now let yourself relax slightly.

This is your ideal sitting position

Standing

In correct standing posture, the natural curves of the spine are maintained - these curves allow for better shock absorption and flexibility of the spine.

- In the neck there is a small inward curve just above the shoulder girdle (looking at the body from the side).
- In the small of the back, there is a second inward curve, just above the pelvis.

When these curves are reduced or increased, pain can develop, due to over stretching of the muscles and ligaments. Regular exercise and effort to maintain good posture can help prevent this.

Chronic Pain and Sexual Problems.

People with chronic pain can quite often experience problems with their sex life. Sexual activity can make the pain worse, although not always. This frequently leads people with chronic pain to avoid sexual activity. Unfortunately they also often avoid any kind of gentle hugging and touching. This could be brought on by fears, either that it will last for too long and become painful or that it will lead inevitably to intercourse which will in turn increase the pain. This kind of

thinking can lead to the avoidance of any tender physical contact, even holding hands.

This situation can lead to tension between partners, anxiety, loss of confidence and depression as well as feelings of unattractiveness, failure, frustration, shame and sometimes of guilt on both sides.

These feelings are linked to self-expectations such as: -

- Thinking you must satisfy your partner.
- Thinking you must always be willing for your partner.
- Confusing sex with love and intimacy.

It is important to realise that there are no universal rules where our sex lives are concerned just as there are none in relationships in general.

Communication

Everyone has their own needs and desires and it is important to share these with your partner. Otherwise it is very difficult for him/her to understand what is wrong, and how they can help. If your partner does not understand why having sex is impossible at the moment, they may imagine that you do not want it, that you no longer love or desire them.

Negotiation is important when setting limits that will be satisfying for both partners. You can discuss what the manageable and tolerable limits are for both of you.

Being assertive also helps both of you when you respond to your partner or when you raise the subject. Allow yourself to say “no” when too much is demanded and to express your own feelings.

Explain what you would enjoy, instead of rejecting your partner. For example you could say “*making love is too much for me but I would fancy a cuddle*”

Using these communication skills can help to deal with the problems of shame, guilt and anxiety. If it doesn't take away all the frustration of not having complete intercourse, it reduces it because tenderness becomes possible again and love can still be expressed.

Sharing thoughts and feelings, thinking about what is realistic and planning it

are all very helpful.

“We all miss out a great deal in our lives - sex can be a ‘no no’ area (taboo), but it’s important to think about this no matter what age we are.”

Try something new, swap roles - sex is good for you, it releases tension.”

“It’s bad enough having pain – without not having sex as well – any kind of sex is better than none – experiment and find a better way.”

Thoughts and feelings

It is important to try and identify the thoughts and feelings that are associated with the idea of having sex, and which may be making you feel anxious.

Very often people have these sorts of thoughts and feelings:

“I must please my partner”

“I will suffer from this, it will be dreadful”

“How can I stop this, I’m powerless”

“I cannot deal with this demand, it is too much”

When identified, these thoughts should be challenged. This does not have to be done alone. It can be much easier and more helpful to discuss these thoughts with your partner.

Pacing

Pacing helps avoid overdoing it, both physically and emotionally too early. As with the other activities, setting yourself a baseline is the starting point. If you start low, you regain confidence when you see what you can achieve. Remember not to overdo it. Set an upper limit, otherwise an increase in pain may follow. (This will confirm all your fears!)

When partners are more confident and happy with what they are doing, it can be time to build up slowly. Full intercourse does not have to be the final aim for every couple. A lot of people have a happy sex life without having intercourse.

Lying together, caressing each other's bodies and genital areas can provide great physical pleasure.

“Try having sex during the day when you are not so tired – it doesn't have to be at night when the children are asleep – get a lock fitted to the bedroom door.”

“If you find that on a certain day of the week you are taking it easy and feel fresher make an arrangement with your partner to make love on that day each week. If you get to that day but do not feel up to the act of intercourse then just satisfy each other with caressing. By doing things this way the pressure of having to perform on other days is lifted. Remember that you don't have to have sex constantly - just because the media portray such lifestyles, it doesn't mean that, that is the right way - there is no such thing as the right way, only the way which you and your partner are happy with.”

Pain does not mean harm

It is important to bear in mind that no harm can come from having sex. However like when you exercise for the first few times, it is possible to set off temporary increases in your pain.

For example, if your back and hips are very stiff and unused to some of the positions that may be used in sexual intercourse, then to use those positions for some considerable time, for the first time, will cause some soreness. No damage has been done, but you may have overdone things and not paced yourself properly.

Some positions are better for people with back pain than others.

Conclusion

Sharing thoughts and feelings, planning together and communicating will provide a great help to people with chronic pain and their partners. Nevertheless, guidance may be useful, especially when problems are not restricted to the couple's sex life. Services such as Relate, Well Woman Clinics or G.P. practice counsellors offer good advice.

Sleep.

Many people who suffer from chronic pain experience problems with sleep. Sleep loss is a problem in its own right, and will add to the various other difficulties, which already occur as a result of pain.

All living creatures have times when they are active and times when they are inactive, even human beings.

To be awake during the day and to sleep at night is a pattern of sleep we develop as individuals, beginning at birth this is called the biological clock.

Everybody requires some sleep to enable the body to restore energy and allow growth and repair. Each individual's needs are different, ranging from three to ten hours per night and vary according to sex, physical and emotional health, age, lifestyle, work and social demands. Therefore to compare sleep patterns is unhelpful.

Sleep problems may occur in three ways.

- Difficulty in getting off to sleep.
- Waking during the night.
- Waking early in the morning.

Identifying the type of problem individual's may have, can be achieved by keeping a sleep diary for a few days.

It is also useful to think about the reasons for sleep problems and the effect lack of sleep has on the body.

Some reasons for sleep problems are:

- Under/over activity.
- Daytime naps.
- Medication use and withdrawal.
- Coffee, cigarettes and alcohol.
- Worry and stress.

- Irregular hours.
- Clock watching.

There is no instant remedy for sleep problems, but over time you could work to improve your sleep pattern by:

- Identifying the type of sleep problem by using the sleep chart.
- Developing a personal way of tackling the problem of lack of sleep by using some of the suggestions listed on the next page.

“Foam egg-box mattress has been a great success.”

“Sleep is crucial – the more you can get the better you’ll feel.”

“Changing your sleep pattern takes effort – you have to turn it into a project and work at it for a few months.”

“I invested in an electric bed and I haven’t looked back since.”

“Pain stretches time – especially at night when you are supposed to be asleep.”

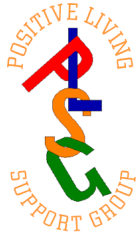
Suggestions to aid sleep.

- Try to avoid stimulants, such as coffee, tea, chocolates and cigarettes 4-6 hours before bed.
- Try to keep the evening alcohol intake low - for many people, more than a glass of wine or beer can affect their sleep pattern (even if they help you to get off to sleep).
- Gradually increase your daytime activity and exercise. Your daily exercise and goal setting programmes will help here.
- Try not to nap for too long during the day, no matter how tired you feel. This will help your mind and body make a clear distinction between day and night.
- Get up at the same time every morning, no matter how you slept the night before. This will help to keep your ‘body clock’ regular.
- A wind down time in the hour or so before bed will help prepare you mentally and physically for sleep. A regular order of locking up for the night, cleaning your teeth, undressing and so on before bed will help to settle you for sleep.

If you are kept awake by worry, it can be worth trying the following.

- Write down the worries or problems that are on your mind.
- Write down the next step that you think you could take towards sorting out the problem. Do this in some detail.
- Try to complete this at least an hour before winding down for bed.
- If you wake, or don't fall asleep for worrying about the problem, remind yourself that you have the matter in hand and that going over it now will not help. If a new worry crops up at night, write it down in a notebook you keep by your bed and deal with it in your 'worry time' the next day.
- Relaxation - breathing, progressive muscle relaxation.

"If you endure sleepless nights and have not yet tried a 'memory mattress' (a cheaper version of the Tempura mattress), I urge you to try one. They mould to your body and then spring back into shape when you move position. Most members of the positive living support group who have tried one experienced a good nights sleep"



Message from PLSG

We have now come to a close and we hope you have found some benefit in the words you have read. If you feel you need more help don't hesitate to talk to your G.P.

Living with chronic pain day in, day out is hard work, at times you can feel like giving up. We hope you will keep trying and if you can accept how you are this is easier to do. You've got to like yourself first and this is hard when you are low, but there can be a light at the end of the tunnel.

All the very best

Regards

PLSG