



Pain Management workbook

Type of pain treatment	Short-term effects on pain	Long-term effects on pain	Long-term effects on quality of life

When you have completed all of the above, what conclusions do you come to?

Many people find that, despite their best efforts and the help they have received from doctors, nurses, physiotherapists, psychologists, their friends and family, that they are still left with a substantial degree of pain. They also often find that seeking help and searching for a cure comes with its own problems. People with chronic pain often feel increasingly desperate as time goes on and their pain continues. Each failed new treatment makes this feeling of desperation worse. Sometimes these treatments can produce significant problems of their own, such as side-effects from medicine and discomfort from procedures and exercises that they have tried.

Thinking over this might well make you feel more fed up about your situation. However, we have not done this exercise to show that nothing works in the longer-term for chronic pain, but mainly to highlight the costs to you of trying to avoid pain. All of the effort involved in seeing different doctors, trying different medicines with different side-effects, cutting back on things in order to avoid pain, has meant that life has become increasingly difficult and restricted.

Metaphor

Tug of war with a monster

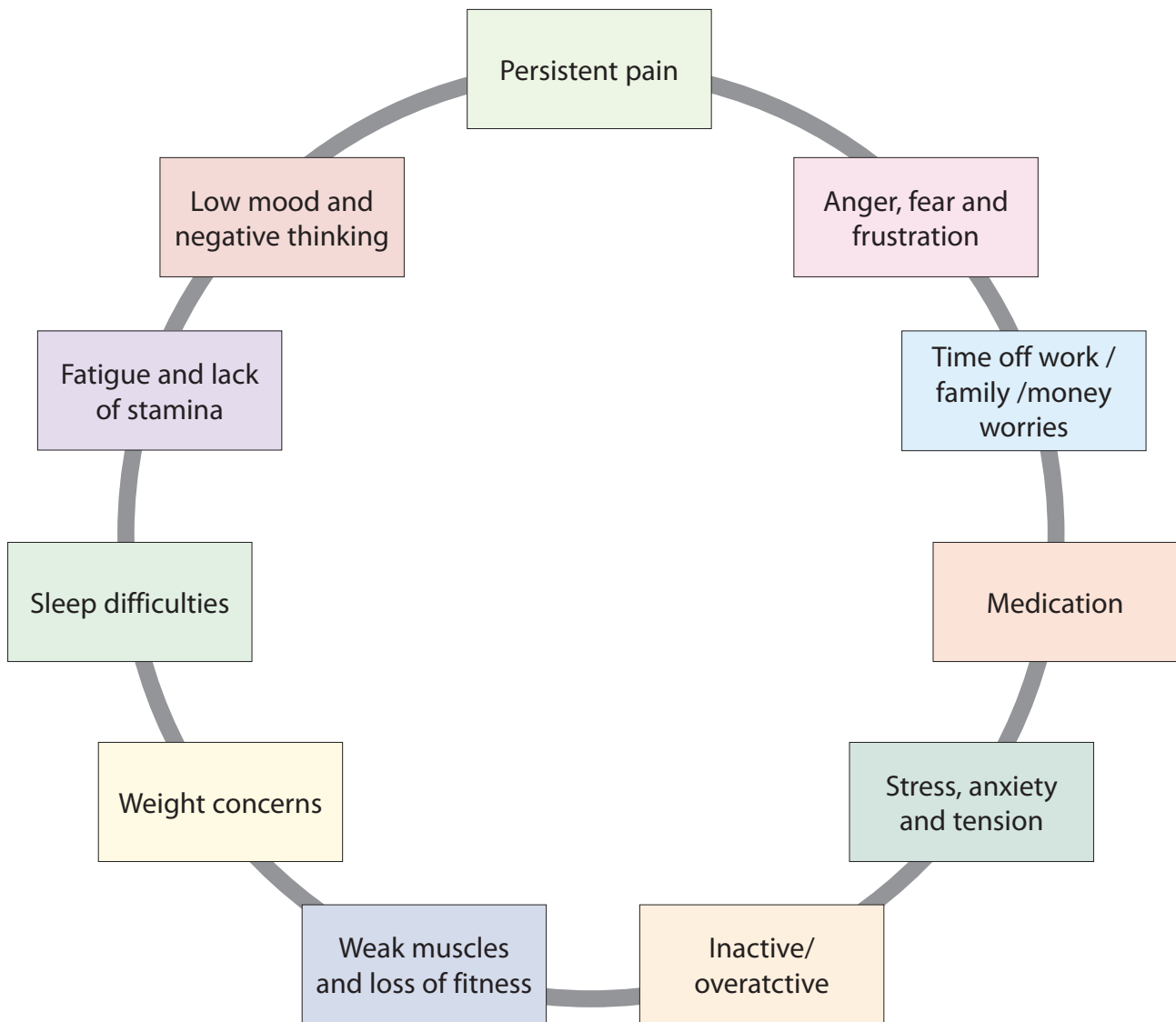
Imagine you are in a tug of war with some huge anxiety/pain monster. You have one end of the rope and the monster has the other end. In between you there is a huge bottomless pit. You are pulling backward as hard as you can, but the monster keeps on pulling you ever closer to the pit. What is the best thing to do in that situation? Pulling harder comes naturally, but the harder you pull, the harder the monster pulls. You are stuck. What do you need to do? Dropping the rope means the monster is still there, but you are no longer tied up in a struggle with it. Now you can do something more useful.

Some experts in chronic pain make the distinction between two kinds of suffering. There is the original suffering, from the pain/injury/accident (we call this primary suffering), but there is also the suffering that has been caused by all of the things that people have done to avoid or control this pain and the impact that this has had on your life (this is called secondary suffering).

When people with pain experience an increase in their pain, they also often experience other reactions. There is the mental reaction, the emotional reaction and the effect this has on the things the person is prepared to do (and not do). For example, a sharp pain from bending might produce a number of upsetting thoughts, such as “now I can’t even bend anymore. How am I going to be able to pick up my grandchildren if I can’t get down to them? What kind of grandparent am I?” These reactions are understandable. These thoughts are likely to be accompanied by a lot of sadness and even tears. This could be so off-putting that the person becomes reluctant to meet with their grandkids anymore because it makes them feel bad.

These reactions **accompany** the pain, but are not the pain. Although these reactions are understandable, they might not be necessary. These reactions are likely to have been immediate and have seemed inevitable, but are they really? Part of learning to accept the situation is learning not to be pushed around by pain, including not reacting to pain so drastically, but having a calmer response.





The sad truth is there are some unpleasant things in life that cannot be controlled and, unfortunately, sometimes it is impossible to control pain. The worst thing about this is that struggling to control the uncontrollable always produces its own set of problems. Later on, you will hear about how efforts to avoid pain can actually lead to more pain.

Can anything be done? The good news is yes, the bad news is that it is hard and means a big change in your attitude to pain. What we hope to do in this workbook is to help you make that difficult change in attitude towards pain. At the same time, we want to help you recover those other parts of your life that have been affected by the struggle with pain.



Metaphor



The bear and the blueberry bush



Imagine you are following a path through a forest. You have been following the path for several hours and you are not exactly sure where you are going. Already on the journey there have been some enjoyable moments, but there have been some unpleasant moments that may have been scary and worrying. Right now you know you are tired and hungry.

Then you come to a fork in the path, which splits off in two directions. When you look down one path you see it is bathed in sunlight with a tall lush blueberry bush. When you look down the other path you see shadows and an enormous grizzly bear.

This is not a trick question. It is normal human behaviour to choose the path with the blueberry bush. Very few people would choose to be in direct contact with a grizzly bear. This is common sense – it is part of human behaviour to be naturally motivated towards things that are pleasant and avoid stuff that is or feels threatening. This approach works in the short term as there is a sense of relief from not having to put up with those horrible thoughts and feelings. The trap is when this is applied and our lives become very limited. Nothing changes, you do not do the stuff that matters most, and you do not grow, develop or push yourself.

What is pain?

We all experience pain, some more than others, and there are many kinds of pain. There can be sudden pain when we fall and cut our knee or twist our ankle. This is sudden. Pain can be unpredictable - for example, you could lift an object hundreds of times without a problem and then, without warning, one lift causes pain. Pain can also start with no obvious injury - for example, someone who has worked in an office for 15 years who starts to get neck pain.

Pain from sprains, cuts and posture are everyday pains. The brain concludes the tissues are under threat, so we change our posture or rest our sprained ankle to allow healing and the pain lessens. We remember the uneven ground we tripped on or the posture that caused the pain, our memory helps to protect us from making the same mistake twice.

Pain can also be a more complex experience. It can be amazing and confusing!

We have all heard stories of people in the Emergency Department with objects like six inch nails through their hand. When you look at the nail passing through the damaged tissues you think there must be pain, but when asked they report little or no pain. Injury sends messages to the brain via the nerves, but this does not necessarily result in pain.



The ratio of the amount of injury to the amount of pain swings the other way too. All of us will have had a paper cut. We know how painful they can be but at the same time we struggle to see where the cut is. It can be hard to believe that such a little cut can cause so much pain. This is one of the confusing bits about pain. The pain you experience does not necessarily relate to the amount of tissue damage. It can be difficult to understand and accept that pain does not always mean harm.

People who live with persistent pain have told us that learning a little more about pain and the nervous system helps them manage their pain better. So here goes...

The nervous system

All over our skin we have receptors. These are nerve endings or 'danger sensors'. Different receptors pick up different information. Some react to temperature, some to pressure. The information that the receptors pick up is sent through the nerves to the spinal cord. The message that is sent is more like a question asking "How dangerous is this really?" Not all messages are sent. We are not aware of every time we are touched; we do not constantly feel our clothes on our skin and sometimes we cannot remember getting the bruise that we discover on our leg. The spinal cord acts a little like a postal sorting office and decides when and which 'danger?' messages are sent to the brain. When enough 'danger?' messages reach the spinal cord, the message is sent to the brain.

The brain processes the 'danger?' messages and decides if the body is at risk of harm or injury. If the brain decides the body is at risk we will feel pain and react to get ourselves out of danger. If our hand touches something hot, like a kettle, the 'danger sensors' will send messages to the brain. Our tissues are not designed to withstand much heat, so to protect the tissues our brain sends a response of pain and we very quickly remove our hand. We will remember that kettle and not touch it, especially if there is steam coming out of the spout!

It is sometimes easier to think of how the danger sensors and the brain combine together to form an alarm system. As we have discussed with the stories about the six inch nail or the paper cut, pain does not always equal harm, so when we talk about the nerves sending messages, instead of thinking of these messages as pain signals, we like to call them 'danger?' messages. It is the brain's use of this information from the alarm system that results in the feeling of pain. The brain is working out "How dangerous is this really?"

So, why does it hurt?

Most of us will have sprained an ankle at sometime in our lives or know someone who has. Remember how quite quickly after the injury the area became swollen, red and tender to touch? This is because of all the chemicals involved in healing

arriving at the injury site to do their job and start the healing process. This is inflammation. These chemicals irritate the nerves, making the area tender to touch. This reaction has a protective role. The first few days after the sprained ankle you may have rested more or even used crutches to ease the pain when walking, this allows the injured tissues time to heal.

Over time, as healing takes place, we can walk more, and then jog, and later run to catch the bus or return to football training. There was a useful reason for this pain. It meant we rested the injury and allowed the tissues time to heal. As the healing takes place, the chemicals stop being produced and so should the pain.

This process takes time but the tissues heal, the body is very good at this. All tissues in our body will eventually heal. A broken bone will heal in six weeks, tendon and ligament injuries within six to twelve weeks. The body will continue to remodel a scar for three to six months after it is healed.

So, why does the pain last after the tissues are healed?

Researchers have learnt more about pain in the last 10 years than in the last 100 years. They can see what changes happen in the nervous system that produce persistent pain, even though the tissues are completely healed. For some people the pain starts without damage to the tissues. Unfortunately, we do not fully understand why this persistent pain starts.

So, what is happening in the tissues to cause the pain?

The brain continues to receive the 'danger?' message; it thinks that the tissues are still under threat of damage. The brain decides the body needs all the protection it can get. It starts to build more defenses; it upgrades the alarm system. It needs more information from the tissues, so it creates more 'danger sensors'. The brain thinks, the more information the better!

More 'danger sensors' create more 'danger?' signals. All these messages are sent to the spinal cord. The spinal cord or postal sorting office becomes overloaded with messages, it starts working overtime to deal with all the extra messages. It becomes quicker at processing the messages and sends out more deliveries, allowing more of the messages to be sent out as soon as they arrive. Before it would have been more selective of which messages needed to be sent. The spinal cord is now starting to amplify the signals it receives from the tissues.

Our brain receives more messages, it becomes better and quicker at recognising the 'danger?' messages. The alarm system stays on high alert. This now means that we receive the pain message more often. Pressures and movements that did not used to hurt now hurt and things that hurt now hurt more. The alarm system is now going off when someone taps the window, instead of only when the window breaks.

As time goes on...

The pain starts, it does not go, and you become worried. In the past when you had pain you rested, so now you do the same and avoid movement to protect the area and avoid more damage.

The pain stays; you keep the reduced level of activity because any time you try to do more it hurts. Your muscles and tissues become weaker and less flexible as they get used to doing less. When you walk further than normal you become out of breath, hot and sweaty. You find that you can no longer do things that you used to find easy.

Also when you become active, it takes less to stress your muscles and tissues, which are now tighter and less fit. When the tissues are stressed they release 'danger?' chemicals - as the brain is now on alert and quicker at recognising these signals, it is more likely to send a pain message.

Tighter tissues, weaker muscles and lots of 'danger?' chemicals irritating the over excited alarm system; it is not surprising that the smallest stretch starts to feel so painful. Even though the tissues are healed, you feel pain. This pain can often feel exactly like the pain you had when you initially had your injury. This familiar pain helps to reinforce the thoughts that there must be something wrong; there must be damage to the tissues. Hopefully, now we know that this is not always true, and pain does not always mean harm.

Pain and your memory

Pain memory can be very powerful. A well known pain researcher, Lorimer Moseley, tells the story about when he got bitten by a snake. He is an Australian and was on a camping trip in the "bush". He got up one morning and was walking to the river to have a swim when he felt something scratch his leg. He thought nothing of it but shortly started to feel unwell. He ended up in hospital for a few days but recovered well apart from pain in the leg where the bite was. This, over time, lessened and eventually disappeared.

A couple of years later he was walking with friends in a forest park. He felt a scratch on his leg, the sensation felt identical to the snake bite. He panicked believing he had been unlucky enough to be bitten again. He got all his friends to search for the snake to identify it. He started to feel pain in his leg, just like the pain from the snake bite, but no one could find the snake. He looked at his leg and realised there were no bite marks, just a scratch from a tree branch. The pain in his leg started to lessen.



Lorimer tells this story at a lot of his lectures. I think he is amazed at how his nervous system reacted to the 'danger?' message from the scratch. That he could feel so much pain from so little damage. This man knows almost all there is to know about pain, but his body still reacted immediately, well before he had time to think about what was happening. This shows how powerful the 'danger' alarm system is in producing pain and making us act in ways that we think will protect us from further harm.

Hopefully you can see that persistent pain is definitely not in your head, but that the brain does play an important role in what we feel as pain and how we react to it. If we had no brain, we would feel no pain!

Thoughts and feelings as added extras...

Thoughts and feelings are often involved too (the brain involved again!). A lot of people living with persistent pain say that it affects their mood. Over time they have started to feel low, anxious, irritable or even forgetful. Some people have realised that when they feel like this their pain feels worse too.

Researchers have shown us by doing very detailed scans of the brain that when we are in pain certain areas of our brain becomes active. These areas are the same areas that become active when we are stressed, anxious, depressed or angry. So, if you add anger or depression to persistent pain those areas in your brain become more active. It is like having a 100 watt bulb in your brain instead of a 40 watt one.

On the flip side, a pain patient once said that his pain felt a little easier when he watched The Three Stooges. So when we feel happy and relaxed it is possible to dim down the 100 watt bulb! When we are happy or relaxed, endorphins (natural pain relieving substances) are released in our bodies. This is one reason why relaxation techniques and doing activities you enjoy and value are an important part of your pain management tool kit.

So the pain we feel is not just to do with tissue damage, in fact as we have mentioned earlier it is possible to feel pain even without injury to the tissues. If we go back to the question the alarm system is asking - "How dangerous is this really?" - we can hopefully see that there are lots of factors that influence this question - for example, if the alarm system is on high alert (sensitisation), memories of previous experiences, tight muscles, thoughts and emotions. All these factors can mean the nervous system assesses more threat and, therefore, we can feel more pain.

As previously discussed we now know that multiple factors influence the onset, duration and severity of an individual's pain. The image below shows a model called the bio-psychosocial approach towards pain. It highlights some common problems that have been recognised as key factors towards decreasing function and quality of life of patients with persistent pain.



Workbook task

Can you identify from the previous image with some of the parts that may be impacting on your condition? There are many factors that contribute towards your pain, however, we often do not realise this. From the previous section, we discussed that curing all pain may be unachievable, however, the majority of the examples from the above model can be improved with structured rehabilitation.

You may find it useful to consider some of these factors within your own circumstances and document them within the model. This can then be discussed with your therapist in order to plan how to address these.



What does this mean for the future?

As discussed before, when the pain stays, there are more messages and the brain becomes better at recognising the messages and quicker at processing the pain signal. The alarm system is on high alert as a way to protect us from what it assesses as potential threat. The alarm system is trying to answer the question "How dangerous is this really?"

There are systems in the body that lessen the level of threat the alarm system perceives., A good example of this is endorphins, which are released when we do things we enjoy, relax and exercise. This pain management workbook will help you look at other strategies to help increase flexibility and function, ways

to manage unhelpful thoughts and emotions and identify the links between our memories, our behaviour and pain. Many of these strategies can alter the level of threat the alarm system perceives.

If you think of the brain as an orchestra, which can play many types of music (classical, jazz, folk, rock), it can play many different tunes in many different keys and tempos. Pain is just one of the tunes the orchestra can play.

If the orchestra plays the same tune over and over, it becomes automatic, it goes by memory, and no one uses the sheet music or even looks at the conductor. It becomes very difficult for the orchestra to play anything else. We have all had that annoying song going round in your head. If you try to think of a different tune you somehow end up humming the first tune.

What we need to do now is remind the nervous system and brain that it can play another tune, it can play lots of different tunes and can play them really well!

Values and valued goal setting

Lots of things will have changed since you have had your pain problem. Some people who have had pain for a while feel that they have changed as a person and that their old self would not recognise the person they have become. Even those who feel that they are essentially the same person today as they used to be would admit that there have been lots of changes in the things that they do.

It is also true that what we do says a lot about the kind of person we are. So if there have been changes in what we are able to do, sometimes there is the feeling that we have changed too. Perhaps other people might see us differently or treat us in different ways to how they would have done in the past.

Below are a number of common changes that happen when people have had pain for a long time:

- Doing less overall.
- Giving up on things they used to like doing.
- Being unable to do things that really matter.

These changes may well have made you feel sad, frustrated or even angry.

Pain can make you realise what things are important and what things are less so. However, sometimes this understanding can get lost in the day-to-day struggle of living with pain.

One of the major aims of this workbook is to help you to be able to do more while having pain. However, it does not make sense to do more of just any old thing.

Rather, it is sensible to do more of the things that you really care about. This next exercise is to help you to be clear in your own mind about what parts of your life matter the most to you.

It is common to compare what we used to do in terms of leisure activities such as hill walking, going to the gym or going out to the pub with friends, and thinking these activities seem out of our reach at the moment. The important thing is to remember why we did these activities in the first place. It might have been that you enjoyed hill walking because you are someone who values the outdoors and nature, or that going to the gym was because you valued being someone who looked after themselves.

The exercise below will help you to understand this further and simply involves using your imagination (and, of course, filling in the table below).

Imagine that you are living in the time of space travel and, for whatever reason, you have to take a journey to another galaxy. The galaxy is a long, long, long, way away (approximately 2.6 million light years away) so communication back home is going to be impossible and it will be years before you return. Naturally, a big party is arranged in order to give you a proper send off. At the party, you see all your family, friends, old work colleagues. Everyone is chatting away, sharing stories and laughs when someone starts tapping a glass and bringing the room to order and the farewell speeches start. One after another, you see your family and friends take the stand and say what they are going to miss about you while you are away. "I'm going to miss {your name here}" and so on. You hear lots of people saying "What I'll remember {your name here} for is..."

Now the big question... what would you like to hear them say about you?

You might want to hear them say that you were always a good friend or a good parent/ son/ daughter and so on. You might also want them to say that you were always interested in other people, or you were someone who always worked hard. Perhaps they will say you were brave, kind, curious, whatever.

- What sorts of things came up during the exercise?
- What did people say?
- What do you want to be remembered for?

The kinds of things that you will have come up with are known as your values. That is, they tell us the parts of your life that are most important to you.

When you are doing this exercise it is important to bear a few things in mind. Firstly, values are things that define you. They are what you find inspiring and describe how you would like you to be. They are not just desires -for example, being rich, or even being pain-free, and they are different from goals. Goals are

things that tell you that you are a step along the way towards living a life that agrees with your values. A good example is, if someone were to say that 'being a good parent' was their value, then they might set the goal for themselves of spending more time with their kids. A goal is a signpost along the way. It is something that you can actually achieve. We will look at setting goals later in the workbook.

A good tip for finding out if something is a value or not is to consider if you would want to see it written on your tombstone.

Speech exercise

What did they say? For example, "She/ he was always so generous with their time."

1. _____	6. _____
2. _____	7. _____
3. _____	8. _____
4. _____	9. _____
5. _____	10. _____

In the meantime, it is worth considering how successfully you are living by your values at this moment in time. We want to know what are the most important areas of your life, as well as which areas are most affected as a result of your pain.

Most people identify values in the following areas:

- Couples/ intimate relationship
- Parenting
- Family (other than marriage and parenting)

- Friends/ social life
- Work
- Learning/ education
- Hobbies/ fun
- Spirituality
- Physical care (diet/ exercise)
- Appreciating art, music, literature
- Getting into nature



The farewell speech exercise may have started you thinking about what is important to you. You may have identified lots of aspects of your life that are important to you, and perhaps some of these have been affected by your pain over the years. By identifying these as part of the workbook we would then talk about how you can move towards these valued areas.

However, you might already have recognised lots of areas which are very important to you but the next step is to identify which of these areas is the most important, and which of the areas you are least satisfied with.

Some areas may be important and going well -for example, learning may be important to you, and if you are enjoying a course at the moment you may be satisfied with this area. Some areas may be fairly unimportant and not going so well - for example, you may have a very limited relationship with extended family members but you may actually be reasonably content with this. The areas we are most interested in are those areas that are important to you but are not going so well - for instance, it may be really important to you that you can go to the countryside once in a while, but you have not done this for many months. This is where we want to start directing your energies so that you can feel like you are moving towards something that really matters to you.

Below are two questionnaires that will help you to identify which areas are important to you and how satisfied you are with those areas.

Valued living questionnaire – 1

Below are areas of life that are valued by some people. We are interested in your quality of life in each of these areas and how important these areas are to you. Rate the importance of each area (by circling a number) on a scale of 1 to 10. 1 means that area is not at all important and 10 means that area is very important. Not everyone will value all of these areas, or value all areas the same. Rate each according to your own personal sense of importance.

Area	Very important					Not important				
Couples/ intimate relationships	1	2	3	4	5	6	7	8	9	10
Parenting	1	2	3	4	5	6	7	8	9	10
Family (other than marriage and parenting)	1	2	3	4	5	6	7	8	9	10
Friends/ social life	1	2	3	4	5	6	7	8	9	10
Work	1	2	3	4	5	6	7	8	9	10
Learning/ education	1	2	3	4	5	6	7	8	9	10
Hobbies/ fun	1	2	3	4	5	6	7	8	9	10
Physical care (diet/ exercise)	1	2	3	4	5	6	7	8	9	10
Appreciating music, art, literature	1	2	3	4	5	6	7	8	9	10
Getting into nature	1	2	3	4	5	6	7	8	9	10

Valued living questionnaire – 2

In this section, we would like you to give a rating of how satisfied you are with each of these areas. We are not asking about your ideal in each area. We are also not asking what others think of you. Everyone does better in some areas than others. People also do better at some times than at others. We want to know how you think you have been doing during the past week. Rate each area on a scale of 1 to 10. 1 means that you are completely satisfied with your value. 10 means that you are not satisfied with your value.

Area	Satisfied					Not satisfied				
Couples/ intimate relationships	1	2	3	4	5	6	7	8	9	10
Parenting	1	2	3	4	5	6	7	8	9	10
Family (other than marriage and parenting)	1	2	3	4	5	6	7	8	9	10
Friends/ social life	1	2	3	4	5	6	7	8	9	10
Work	1	2	3	4	5	6	7	8	9	10
Learning/ education	1	2	3	4	5	6	7	8	9	10
Hobbies/ fun	1	2	3	4	5	6	7	8	9	10
Physical care (diet/ exercise)	1	2	3	4	5	6	7	8	9	10
Appreciating music, art, literature	1	2	3	4	5	6	7	8	9	10
Getting into nature	1	2	3	4	5	6	7	8	9	10

Now, using that information, let us go a step further and start narrowing it down.

Focusing your energy

If you could choose just five of these 11 areas to work on, which would they be?

1. _____
2. _____
3. _____
4. _____
5. _____

If you could choose just three of the eleven areas, which would they be?

1. _____
2. _____
3. _____

If you could pick just one of the eleven areas to work on, which would it be?

1. _____

Now you have identified the area of most value, this may be where you would like to start focusing your energy when setting goals.

Everyone sets goals even if they do not realise they are doing it. Elite athletes, for example, set goals and track what they do. They often do this because goal setting and tracking keeps them accountable and helps them maintain the training needed to reach their goals. Patients can set activity goals and track their progress for the same reason. Tracking your progress helps you to see that you have improved. Often improvement is slow and we do not realise we have improved until we reflect back on how we were feeling and what we were doing in the past.

If we also think about the earlier section on understanding pain, slow steady improvements work best with goals as it is less likely to set off the alarm system of the sensitised nervous system. We will cover this further in the section managing activity.

To go back to setting goals, there are a few steps involved:

Choosing your goals

You have made one of the biggest steps by working out where you want to focus your energies by starting to identify your values. We often suggest setting a few goals such as an activity, relaxation and a fun/ valued goal.

Ask yourself is it:

- **Realistic?** Am I trying to get there too fast? If you have not walked anywhere for months a target to walk half a mile every day is not realistic and may set you back. A more realistic first target might be by walking the 200 yards to the end of the road every day.
- **Enjoyable?** Do I really want to do it? The more enjoyable your target the more likely you are to succeed. If it is a chore, then it is hard to keep the motivation to work at this longer term. The best kind of target is one with a reward at the end.
- **Specific?** Is it described precisely? How do you know you have achieved this? The target must describe exactly what you do, so that someone else could read it and do exactly the same amount. 'Go for a walk' is not specific and you would not know if you were making any progress. 'Walk 100 yards, twice a day, every weekday' is more specific and a good target.
- **Timed?** When am I going to do it? This might include how many times a week, time of day or when you would like to achieve your goal by. Practising a target should become a routine. Choose a time of day when you will not be rushed or distracted by other people or things.

Do your targets and score them

As soon as you have done it, score it! If you leave it, it is hard to get an accurate rating. If it was more than a 5 effort/ challenge, set a lower target, so it will be around 5 next time.

Review your plan regularly

Some people like to increase their target when it scores less than 5 for a few days in a row. We would encourage people to nudge up their target every day or every other day rather than a big increase once a week as it can be too challenging. Remember back to the understanding pain section as well. When the nervous system is sensitised we want to retrain this system so comfortable, confident, routine progress is what we would be expecting.

Are you ready?

Now ask yourself are you ready to start? Has a goal quickly come to mind?

If not, do not panic. Finding goals can be difficult. It might be worth going back and reading what value you identified as the area you would like to work on and think of different ways you might work towards this. If your value was about being a caring partner, there could be lots of ways someone might work towards this with goals - for example, spending some time each night together talking about your day or arranging regular outings together.

Instead of asking yourself "What do I really want to get back to?" instead ask "Why do I want to get back to it"? It is not about what you used to do but what you used to get out of it that is important.

"What would make my life a bit better now? How can I use my energies on things that are important to me?"

If you just feel you cannot face it, again do not panic. It might just feel a bit overwhelming. No energy? Too fed up? Too much pain? Worried that you will cause more pain? Fears of others seeing you do more and what they might think? It might be worth reading the section on emotions and pain and discussing your concerns about setting goals with your health care professional who is working with you with this workbook.

Equally, if this all sounds a bit confusing even after reading it a few times, could someone help you with this? A partner? A friend? Someone in the clinical team?

Before you get started here are some examples of what other people set as goals and their plans to achieve them.



Wendy's goal

Wendy wanted to re-engage with her value of being creative. She used to enjoy painting, making cards and sewing but since her pain problem she had not spent any time on these activities.

Value	To be a creative person.												
Goal	To spend an hour twice a week on a creative task in six weeks' time.												
Week number:	As soon as you have completed a target give it a score out of 10 for effort.	0	1	2	3	4	5	6	7	8	9	10	
		Too easy					Too hard						
		Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7					
Step 1	To ask my partner to bring my box of paints and materials out of the loft.												
Step 2	To set up my workstation in the spare room so I do not have to set up and pack it away each time.												
Step 3	Spend 10 minutes each day sorting out resources.												
Step 4	Spend 10 minutes once a week on a creative task.												
Step 5	Spend 10 minutes twice a week on a creative task.												

Allan's goal

Allan wanted to re-engage with his value of being more active and being someone who looked after himself.

Value	To be an active person who looks after myself.									
Goal	To increase walking distance to 30 minutes in a month's time by walking the dog.									
Week number:	As soon as you have completed a target give it a score out of 10 for effort.	0	1	2	3	4	5	6	7	8
		Too easy					Too hard			
		Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7		
Step 1	To work out my walking baseline (what I can achieve on any given day).									
Step 2	To walk myself every day within my baseline.									
Step 3	To slowly increase this limit each day within a comfortable and confident level.									
Step 4	To walk with my partner with the dog.									
Step 5	To walk the dog independently.									

If you are ready to get started, first write down your goals on the goal sheets included earlier in the workbook. Remember to REST test it. Is it realistic? Enjoyable? Specific? And timed?

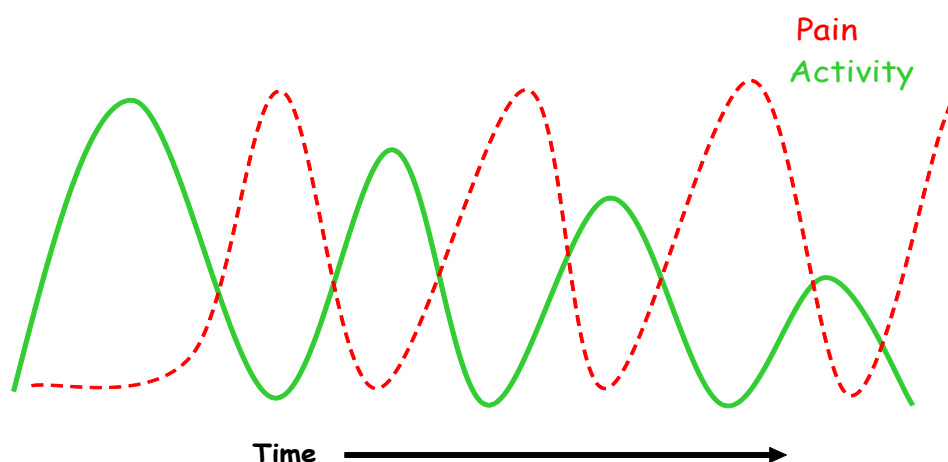
Managing activity

Whenever people are setting goals, especially around activity-related goals, they often worry that increasing their activity will make their pain worse.

Remember the vicious cycle of pain in the understanding pain section? It is very common that when you have had pain for a long time you are likely to be a lot less active than you were before. The less active you become, the less you move your joints and the less you use your muscles. Muscles and joints were built for using – they like to be active and moving.

Most people with persistent pain describe a pattern of good and bad days in their week. When they get a good day, they try to fit in all the jobs they have been putting off or walk that bit further or spend longer out with friends. Unfortunately, the next day they 'pay for it' and the pain can be so bad they may have to do a lot less or stay in bed for a day or two. A couple of days later they will wake up and feel they can tackle the next list of jobs and the cycle continues.

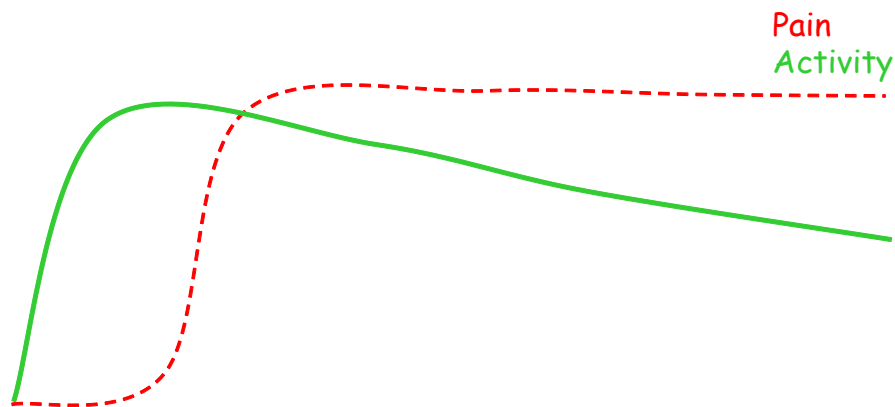
Over- Under Activity Cycle



Over time, due to all the rest days and maybe a little caution because of the memory of the last bad day, what they can manage on a good day seems to become less and less. The pain feels like it is getting worse and taking over their life because they cannot do as much as they used to do. They are nervous about trying to do more because they remember the pay back from the last attempt.

Those people who do not feel they fit into that 'boom: bust' pattern might be more likely to be overactive. They might tell us that they just keep going despite the pain as they are juggling responsibilities of work and family life or they feel that no matter what they do their pain is the same.

Over Activity Cycle



Often when people keep an activity diary they can see that over time their activity reduces but their pain level stays high.

No matter which activity pattern you think fits best, it is important to think about a few things:

- Identify what is important to you. You may like to look back at the values section. Are you using your energies on things which give meaning and value to your life?
- If not, then do more of the things which are important to you. This may mean initially doing less of other things.
- Take care of your own needs. Say no more often if saying yes comes at a cost and is not sustainable.

We often talk about the 3 'P's when it comes to managing activity:

- Plan
- Prioritise
- Pace

You might have heard of some of these things before but we will go through them individually now.

Plan

Often we fall in to the trap of 'doing what we feel', and that has maybe also been reinforced by other health care professionals, but we know that with persistent pain the motto of 'do what you feel' does not work. When you feel good (pain, fatigue, mood) you run the risk of overdoing it and if it is a bad day you run the risk of not doing enough.

That is why the motto of 'do what you plan, not what you feel' works much better.

Prioritise

A good place to start is thinking about what would keep you motivated to do more and if this is linked to your valued goals this means that you are using your energies to carry out important activities and tasks.

It might be that you write a list of all the tasks you have to do over the week and prioritise what tasks you must do that day, the next day or over a longer timeframe.

Pace

Most people have heard about pacing before but it is not as simple as just doing bite-size chunks of activity along with rest, that is stopping and starting. Pacing should help you increase activity without aggravating your pain; remember back to that sensitised nervous system we talked about. Pacing and managing activity helps desensitise the nervous system which means we can do more without more pain.

Earlier, we talked about the vicious cycle that develops when you become less active. Muscles and joints become stiffer and tighter, and when you start to move you are more likely to feel aches and pains. These pains are not a sign that you have harmed yourself, they are commonly called 'training pains' and all of us will have experienced them at some time. Before the long persistent pain started, you can probably recall how your body felt the first day after the start of football training or the day after spring cleaning the house or starting the gardening. Your body let you know that it was not used to being so active.

However, by the second or third training session or after a few weeks of gardening you did not feel sore and achy the next day as your muscles and joints got used to the level of activity. The thought of training did not fill you with dread about how sore you would be the next day and you probably started to look forward to the training.

The good news is that if you start an exercise programme at an 'easy' level (a baseline level you are comfortable and confident at) and build up the amount of exercise gradually, you can get fitter without making yourself too sore. Think about how long it would take someone to train for a marathon. A lot of people know that they will have to start up to a year in advance. They plan their training programme to gradually increase the distance they run to allow the muscles and other tissues time to adapt and gradually increase their strength and endurance. So, we like to think of the training programme you might be starting to plan as one that will take time, that by finding a comfortable starting point or baseline you will be able to lessen the aches and pains by gently increasing the amount of exercise you do. It is good to remember that to achieve a gentle increase the

exercise has to be done regularly and with each increase, it is normal for your muscles and joints to feel tired and even a little achy – but not flare-up your pain. We call the amount you increase your exercise by the ‘quota’. Remember that pain does not always mean harm.

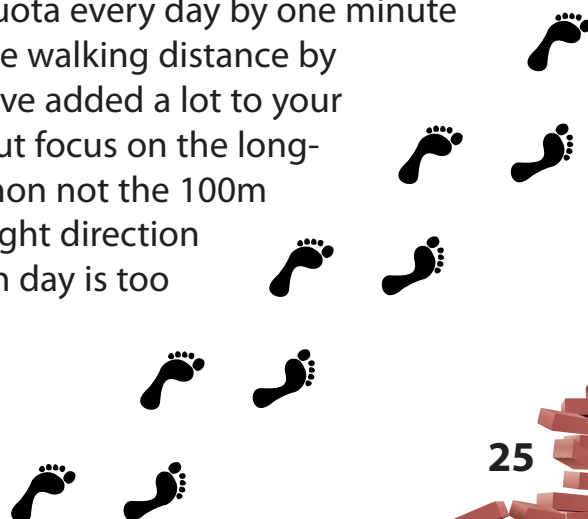
Re-training the nervous system

As discussed before, when the pain stays, there are more messages and the brain becomes better at recognising the messages and quicker at processing the pain signal. The alarm system is on high alert as a way to protect us from what it assesses as potential threat. The alarm system is trying to answer the question “How dangerous is this really?” When working on increasing activity and finding the baseline for an activity it is important to keep this information in mind. It is usually worthwhile to start with a level of activity that you are confident and comfortable to do as this sends ‘good’ messages to the brain. If, when exercising you are repeatedly flaring up the pain, and sending floods of ‘danger messages’, the alarm system stays on high alert and increasing the amount of exercise is difficult. With pacing, it is almost as if you are gradually re-training the nervous system, not just the muscles and joints. Allowing the nervous system to figure out what level of activity is good to do and not perceived as a threat.

How do I set my baseline?

When you are starting to increase your activity levels it is not unusual for this to be a process of trial and error before you find the right baseline. This will take time, and it is the foundation for this training programme. Remember that the baseline should be an amount of an activity you are comfortable and confident that you can do on any day without flaring up your pain. Basically, this is the amount you could do on a bad day and not just what you can do on a good day.

Figuring out your quota (the amount to increase your activity by) is also difficult to do and can take a few attempts to find. However, each attempt is a step closer to finding this amount, which you can do on any day. The quota should be a manageable amount, and in the start, this can seem like a very small amount. Nevertheless, remember if you are increasing your quota every day by one minute you could have added seven minutes to your baseline walking distance by the end of the week. After a few weeks, you could have added a lot to your comfortable walking distance. It can be frustrating but focus on the long-term goal. Remember you are training for the marathon not the 100m sprint! Even the smallest of increase is a step in the right direction – for example, if adding a minute on to your walk each day is too much, add on a lamppost’s distance a day.



What if I do too much?

Do not panic! It is not unusual for people to be a little too enthusiastic and set a quota which is too big and sends them into flare-up pain. The next day it is best to go back to the previous level you were comfortable with and reduce your quota, again remembering to be comfortable and confident with it. Here is an example...

Mark's walking

On Monday Mark has planned to go out for a 10 minute walk. He comes back home and feels happy that he completed the walk without causing flare-up pain. On Tuesday he decides to go out for a 15 minute walk. He struggles home and realises he increased his walk by too much. On Tuesday night he is planning the walk for Wednesday and decides to increase the walking time by just one minute a day. Mark feels confident and comfortable with this quota. He realises this will be a slow process but is confident that by next week he could have added on seven minutes to the walking time he can do on any day. So on Wednesday he goes for a 10 minute walk (his previous comfortable level) and on Thursday he goes for an 11 minute walk.

These principles can be applied to most activities. A lot of people want to increase the time they can sit for so they can, for example, use the computer or play the piano. Just find the baseline you can sit for and decide on how much you will increase this by each day. The same can be done for increasing a weight to be lifted, for example, a kettle. You could start by lifting an empty kettle and then gradually add a bit more water every day.

Sounds too good to be true?

As mentioned before, finding out your baseline can be tricky. Sometimes people with chronic pain do not want to admit to themselves how little they can do, so they fight through the pain and soon give up because living with more pain is too hard to cope with. They have set an unrealistic baseline. Others want to improve too quickly, and increase their activity by too much. They go back into the over-under activity cycle and find they have to rest the day after. They become disheartened because they do not feel they are ever likely to reach their goal. A smaller quota may have avoided this.

As a coach will often say, "you have to make mistakes if you are to improve". So although you may take time to find your baseline and quotas, each attempt means you are a step closer!

Motivation – can values help?

Building up your activity without flaring up your pain can be a slow process. Motivation can lessen over time. It may help to remind yourself of your values to help you keep focused on your goal!

Progress can be slow but steady so keeping an activity diary can help to remind you how much you have improved. Use a diary or calendar, or the activity pacing chart on the next page.

Be kind to yourself

You will have set yourself a goal, so when you achieve it, reward yourself! If you have successfully increased your baseline of activity this is something to congratulate yourself on, as often people say that over they have not increased this baseline for years.. Hopefully this will encourage you to keep going and enjoy the changes to your life this will bring.

Pacing record sheet

Week:	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
1							
2							
3							
4							

Barriers to progress

As you are working towards your goals it is understandable that things may get in the way. These barriers to progressing further can be things which we notice within ourselves such as negative thoughts like “this isn’t going to work” or “what if this makes my pain worse” or it may be things such as others expecting more from you.

Unfortunately, even if you are the most expert self manager, challenges will always arise. In this section we are going to look at a few of the things people tell us often get in the way and strategies for moving forwards.

Flare-up

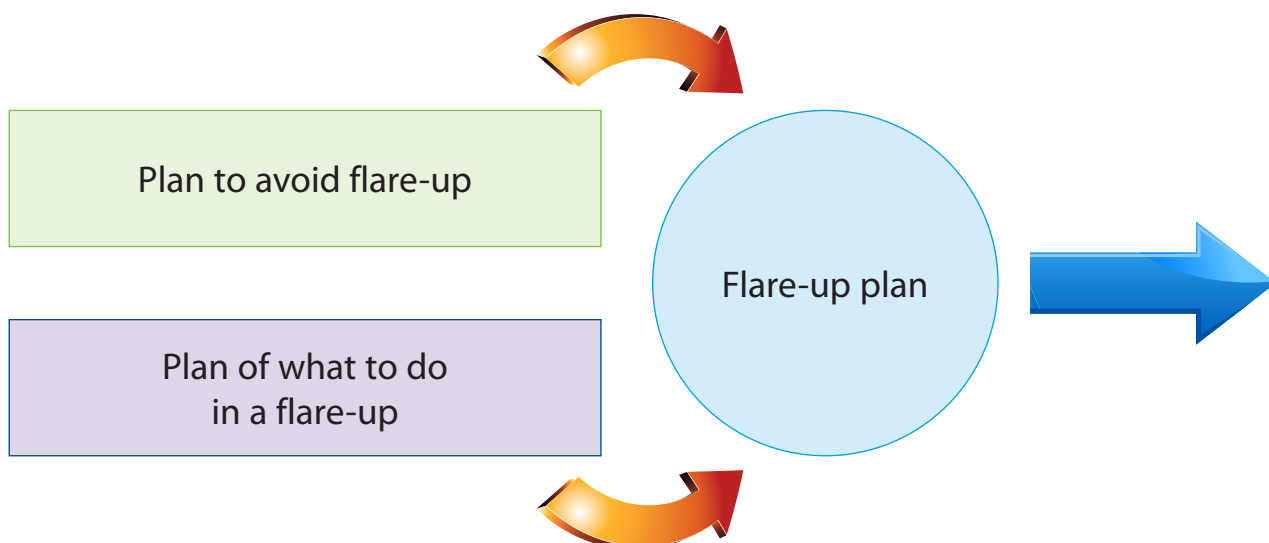
Even with a successful pain management plan in place, flare-ups of your pain beyond the normal fluctuating levels can sometimes occur. It is important that you remember that there are ways you can manage to stay in control of your pain, even during these particularly challenging times.

By preparing a **flare-up plan**, when your pain levels are manageable, you can then rely on the plan to help direct you when your pain is more severe. It allows you to put in place strategies to get you through the hardest of times.

A flare-up plan has two parts:

- A plan to avoid a flare-up.
- A plan of what to do if a flare-up happens.

By using your flare-up plan, you are giving yourself the best chance of maintaining your great gains towards successful pain management.



Plan to avoid flare-up

Flare-ups are unfortunately part of a long-term pain condition. You may have noticed that there are certain situations or triggers which may result in a flare-up of your pain. Examples of these may be overdoing activity, socialising with family, not sticking to your plan or emotional stressors. Some of these things cannot be avoided but if we learn ways of recognising when the flare-up is starting we can often manage this better. This means that it does not escalate as much or it takes a shorter time to recover from your pain flare-up.

Recognising changes in your pain, mood and irritability may allow you to be aware of a flare-up happening as well as situations which may cause this. Often patients tell us that they may notice other signs first before a rise in their pain intensity such as being more tearful or having a shorter fuse.

The table below is to allow you to write down the trigger which you may notice to allow you to plan strategies for when, not if, they arise. Writing down this plan often makes it easier to put it in to place and help support you in a flare up.

Triggers	What can I do? Strategies I could use

Plan to manage a flare-up

When in a flare-up it is often difficult to think about the tools and strategies you have in your 'toolbox' to support you in managing a flare-up. The table below is not exclusive and again writing this down before a flare-up allows you to refer back to this when it is needed and remind you of some of the strategies which have worked for you in the past.

Strategies to minimise flare-up intensity For example, take a stretch break	
Consider the following:	
Medicines	
Physical activity	
Rest	
Meditation/ relaxation	
Healthcare team support	
Family, friends and work	
If I have a pain flare-up, I will do this for the next few hours: (for example, practice my relaxation and breathing)	
If I have a pain flare-up, I will do this for the next few days: (for example, cut back my activity but do not stop)	
Back on track plan: (for example, start back with activity by commencing a walking program for 10 minutes a day – remember to implement my pacing skills)	
I will reward myself once the flare-up settles by: (for example, spending some extra time with my friends)	

Flare-up points to remember:

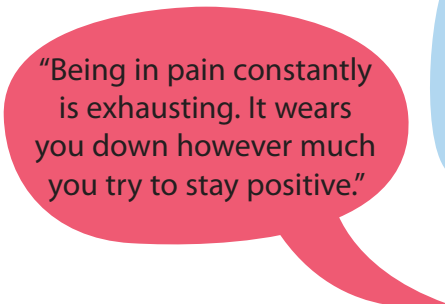
- Flare-ups are common, predictable and manageable.
- Have a flare-up plan before you grade up your activity.
- Do not panic - if managed well flare-ups usually settle fairly quickly.
- Cut back activity but do not stop! Any activity is better than no activity.
- Try and keep rest periods short - less than 30 minutes.
- Use positive self-talk - "This too will pass".
- Monitor your improvement through the flare-up.

Emotions

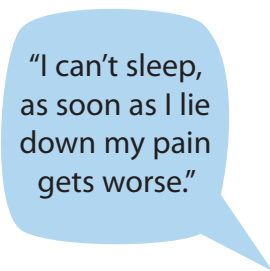
You might remember earlier in the workbook we got you to write down all the different strategies and types of pain management you have tried, not just medicines or physical treatments but ways that you have tried to treat yourself, like staying in bed, cancelling activities, having a drink to 'escape' or 'numb' feelings. We have mentioned the impact these can have, not just on your pain, but on your quality of life. It may have struck you that you have tried many different treatments, often with mixed results, and few, if any, are moving you closer towards the kind of life you want to be living.

Sometimes it seems as if all the messages around us seem to be saying "if you are not controlling the pain, the pain is controlling you". So we work really hard to try to control the pain, make choices that we would not otherwise have made in order to keep the pain at bay. You might take medicines that may or may not keep the pain a little at bay, but even those medicines may create other problems. You try to get control over pain so much that you back yourself in to a corner. At what point do your attempts to control the pain actually give the pain control over you? Remember back to the first section and the story of the pain monster and the chart about primary and secondary suffering. The ripples of our actual pain were far reaching in all different aspects of our life and, therefore, have a knock-on effect to our thoughts, feelings and emotions.

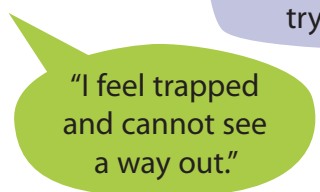
Living with long-term pain can be very stressful. This is what other people have said:



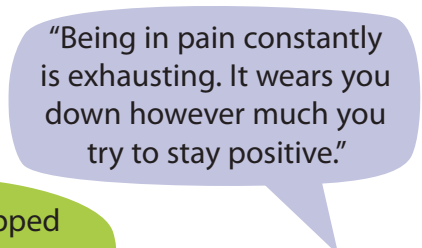
"Being in pain constantly is exhausting. It wears you down however much you try to stay positive."



"I can't sleep, as soon as I lie down my pain gets worse."



"I feel trapped and cannot see a way out."



"Being in pain constantly is exhausting. It wears you down however much you try to stay positive."

Stress leads to bodily tension, which can add to the pain. Go round this circle and try to find out where you are storing tension.

You can remember this quick check and use it during the day to find out if you are getting tense.



Stress can affect our lives in many ways:

Physical effects: aches and pains, dry mouth, feeling tired all the time, muscle spasms, no appetite or always hungry, feeling ill, tight chest, sweaty, funny tummy, cold hands and feet, easily startled, sighing a lot, palpitations, headaches.

Behaviour: avoiding people and places, avoiding things that might make the pain worse, putting off doing important things, smoking or drinking more, being generally restless, sleeping poorly, arguing with people, problem making decisions.

Feelings: jumpy, snappy, frustrated, angry, fearful, hopeless, dependent, lonely.

Thinking: worrying thoughts going round in your head, poor concentration and memory, thoughts becoming mostly negative, only seeing the problems, never the good side of what is happening.

We need to understand how thoughts create stress.

If you have ever been in danger of being attacked, or in a car accident, or had a big fright, you'll know what it does to your body. Racing heart, weak

legs, shaking, dry mouth - all the effects of stress.

Having to give a talk, or taking a test can do it too. Famous actors are sometimes sick before they go on stage because of 'nerves'.

This is because every time we think things like:

- "this could be nasty"
- "I'm going to look stupid"
- "I could get hurt"
- "this is going to be painful"

Our adrenaline level goes up.

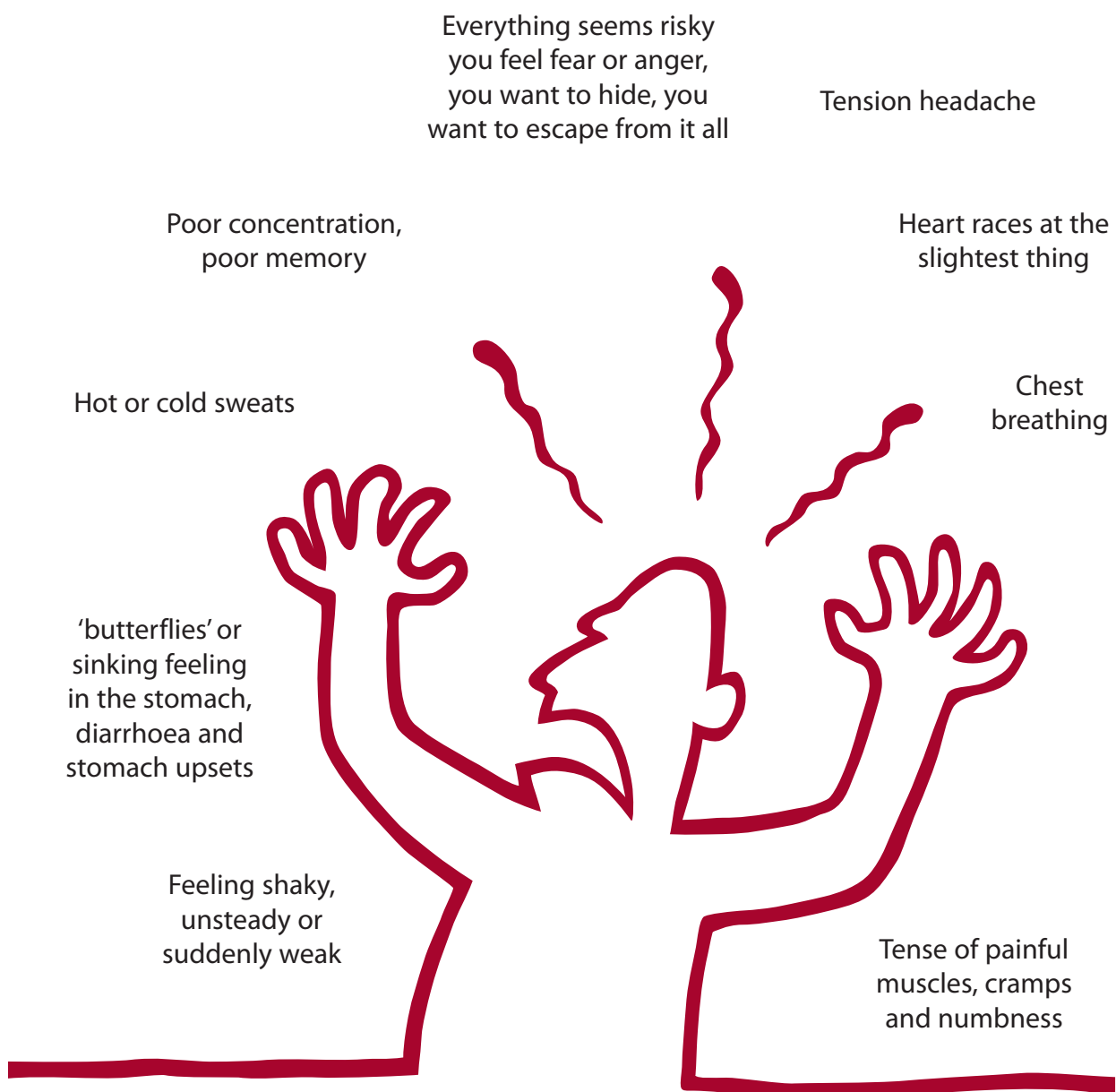
Every time we think things like:

- "I'm safe"
- "This is great"
- "I've survived!"

The adrenaline is turned off and we produce other chemicals that make us feel calm and relaxed.

Adrenaline is a useful chemical that is designed to help us when we are in danger. The picture below shows some of the things it does to our body. All these changes give us extra power to run away or stay and fight! Sportsmen know that they have to get adrenaline going to get the extra strength and aggression they need to win. Adrenaline is very powerful. There have been cases when a wife has been able to lift a car off her husband due to the extra power adrenaline gave her!

It has an equally big effect on all of us. It affects how we think and what we do. Adrenaline is helpful in short bursts but when it is high all the time it causes problems.



Nowadays most of our problems we can't run away from or settle by having a fight!

They are things like:

- pain won't stop;
- worrying about money;
- work and unemployment;
- relationship problems;
- the government;
- noisy neighbours;
- kids; or
- life.



If we are constantly thinking 'oh no!' thoughts our adrenaline is high all the time. The good news is we also have 'happy' chemicals. They make us feel calm and relaxed. We can make these chemicals by practising things such as relaxation. Our natural painkiller chemicals can be increased by physical activity.

Every 'oh no!' thought makes us more stressed. The more stressed we get the more 'oh no!' thoughts we have! These thoughts are usually exaggerated. But, when we are stressed out we believe they could really happen. It is another vicious cycle.

If we spot the 'oh no' thoughts we can manage them before they set off the vicious cycle of adrenaline rising. 'Oh no!' thoughts are almost always over the top. When the adrenaline was high we are more likely to have thoughts such as "I am going to lose my job", "this pain means there is something serious going on".

If you are able to recognise the 'oh no!' thoughts we are often able to develop anti-stress thoughts to work against them, such as "I'm not going to lose my job if I say no to the weekend training course" but this can immediately set off another 'oh no!' thought- "my colleagues will think I'm lazy". Then you need to think of an anti-stress thought for that worry as well.

Research tells us that if we recognise and manage 'oh no!' thoughts this can bring down the suffering of pain.

The problem is that everyone has 'Oh no!' thoughts and they are almost instant and very hard to spot! We often only know they've happened because we feel the adrenaline going up.

Can you write down some of your 'oh no!' thoughts here - for example, "if this goes on I'll be in a wheelchair", "everyone is going to be fed up with me", "this is going to hurt", "this pain could be cancer!"

Can you now write down an anti-stress thought for each of your 'oh no!' thoughts? This can be difficult so it might be easier to think "What would I say to someone else if they told me these thoughts?"

How thoughts affect our behaviour

People with persistent pain have told us that they feel the need to avoid people and things, especially if they are having negative automatic thoughts that it might cause more pain. People might avoid things like walking or going shopping, or going out socially. This may help in the short term but often makes the problem worse over time. The problem is usually the negative automatic thought. It sets off the adrenaline which does its job and makes us 'run away' from the 'danger'.

Every time it wins and we do run away or avoid it, it makes it more likely it will win again the next time. Every time we win and it all turns out fine, it has a little less power over us. It's not always a threat of more pain. It can be anything that sets off a worrying thought. For example, Allan didn't want to go out as he was afraid of being seen out having fun when off sick from work. The 'danger' was other people losing respect for him. Every time friends asked him to go out he felt a bit panicky. The thought made him sick. But later he did set a goal and it got easier and easier each time. If anyone saw him out he would tell them "I'm doing a special pain management plan and need to go out once a week!"

Are there things you avoid doing?

Write down the situations or things you avoid here and see if you can recognise any negative automatic thoughts and work out more accurate thoughts to replace them.

Seven stress busting strategies

Noticing tension

Check in with your body regularly during the day to make sure that you haven't tensed up. Some people find it helpful to practise relaxation exercises.

Correct your breathing

Correcting your breathing can help lower your adrenaline levels and help you stay calm and in control. The problem is we soon start breathing the wrong way again. Check frequently during the day and correct yourself each time you are chest breathing and not belly breathing.

Take regular activity to burn off adrenaline

Use goal setting to make sure you have periods of enjoyable activity each day. In the bad weather walk in a shopping centre or have a routine in your home rather than walking in the park.

Use distraction

Using distraction can help to keep the 'oh no!' thoughts out of your head for a while. It has to be something that needs concentration, playing a musical instrument, sudoku, crafts, crosswords, sewing, cooking a new dish or a computer game.

Have something to look forward to each day

People who are stressed or in pain often avoid pleasure, they feel they don't have the time or it is stupid or that they 'don't deserve it'. To start with you may have to set goals which are fun!

Challenge negative automatic thoughts

Notice and challenge the negative automatic thoughts. If you can spot these thoughts write them down. Then when you are feeling calm, think how likely is that really? Check them against facts or with a friend or partner. Develop your own set of anti-stress thoughts so you're ready for them when they come.

Tackle avoidance

If you have been avoiding people or things it will help to set some goals around these areas. Start with the easiest and work up to the most challenging over time. Using the goal sheets can help.

Pace it up, start with an amount that seems 'just right' and build up as it gets less challenging. Get out of the house and regularly meet people. If you prefer your own company that is fine, but still find somewhere you can visit regularly to get out of the house.

The good news is these stress busters can help with:

- experiencing less pain;
- sleep problems;
- reducing irritability, anger and frustration;
- reducing tension headaches, muscle spasm, numbness;
- improving relationships with other people; and
- making you stress resistant and cool under pressure!



Anxiety

Anxiety is the medical term that means worry and stress are beginning to have a serious affect on a person's life. There are three common ways it can affect people.

An anxiety state is when the symptoms of a high adrenaline level are with you all of the time. Life becomes miserable, and you may feel agitated most or all of the time. You may have a feeling of dread that something bad is about to happen.

A panic attack

Is where all your adrenaline is released in to your blood stream at once. Your heart may pound, you will feel terrified and you may think that you are about to collapse or die.

A phobia

Is where being forced to be in a particular situation or close to a particular object can trigger a panic attack. It can be a situation, like crowded spaces, heights, lifts or an object like a needle.

People with persistent pain sometimes worry that if they admit to any 'psychological' issue their pain will be seen as 'in their mind' or 'imaginary'. Any health professional who says 'it's all in your mind' has not had the appropriate training in treating persistent pain. Stress and anxiety is very common in people with persistent pain. It is almost always because of the pain, not the cause of it. There are simple effective treatments for anxiety. If you are recognising some of the symptoms of anxiety above speak to your healthcare professional or family doctor (GP). Anxiety is a normal human emotion and is nothing to do with being 'mad' or 'mentally ill'.

Coping with persistent pain is enough to get anyone down. When we get low or thinking becomes negative. We all have our own negative thoughts. Ones which automatically come up when things go wrong. For example, "I can't do it", "it's not fair", "everything always goes wrong for me."

Can you write down your automatic negative thoughts?

If we have a lot of negative thoughts it can lead us in to a spiral of stress and avoidance and we certainly get a lot more fed up! This cycle can make living with pain even more difficult.

Each negative thought knocks us down, just a little more – drip, drip, drip. Slowly wearing us down, making pain worse to live with. We are so used to our personal thoughts, they are so automatic, that we don't usually notice them.

Negative automatic thoughts are almost always wrong or at least exaggerated. So if you recognise them, don't put up with them. For example, if you are thinking "I'm useless at everything" stop and think "ok, so where is the evidence for that? I am not useless at everything. I am good at cooking, I have been a good parent, I have dealt with my pain better than most people could. I am not useless." Also remember to give yourself praise for things when you do well at something, we are not very good at giving ourselves a pat on the back or positive self-talk. Try it out the next time you do well at something or something good happens.

Depression

Most of us feel low, fed up or down from time to time. This is normal. Depression is different. A person who is depressed can't cheer up. However hard they try.

They find it impossible to feel pleasure in anything. They may

- stop washing and caring for their appearance;
- become slowed down in thinking and have no energy;
- be tearful a lot of the time;
- feel life is unbearable to the point where they think of ending it.



Depression is an illness not a weakness. It can strike anyone at any time. It is very common in people living with pain. People who are depressed have low levels of a brain chemical called serotonin. They also have very nasty negative automatic thoughts. Each negative automatic thought drives down the serotonin level, leading to more automatic negative thoughts. Medicines can help increase the serotonin levels and help depressed people recover. It is also possible to treat depression by working on the negative automatic thoughts but it might be that you need more support with this.

Speak to your healthcare professional or GP. Often the negative automatic thoughts stop us asking for help when we need it. If you cannot talk to your healthcare professional or GP speak to someone you can and ask for support in talking to a professional about how you are feeling. The good news is that when depression is treated the pain can become much less of a problem too, or less challenging to manage.

Remember we mentioned earlier about 'letting go of the rope' and not getting stuck in a tug-of-war with our pain. Often people talk about acceptance. You might be thinking "Great, they are just telling me to give up and accept my pain." What we are suggesting is completely different to 'giving up'. That would be letting pain win because you think there is nothing else you can do. Acceptance is about starting to think about living a life with your pain alongside you for the ride, but not letting it steer the direction you go in.

Acceptance is about how you live your life day-to-day. It is an active choice to move forward and towards things, which what matters to you in life and how you can get closer to these things, rather than wasting energy in a battle which keeps us exhausted and stuck. You have started to move in this direction while working through this workbook; looking at things differently, identifying your values and making goals to move towards things which are of value and matter to you.

There is not a magic point where you 'accept' and everything fits in to place, it is all part of your journey forwards of living better with persistent pain and all the sections in the book will help towards this step-by-step.

Relationships and communication

Persistent pain can affect relationships. It can strengthen them but also can put a lot of stress on family and friends.

How do you think your pain affects your relationships with others? What would you like to say to them? It might be helpful to write down some of your thoughts.

Other people with persistent pain have told us that they recognise ways in which they deal with things differently within their relationships due to pain and also how others feel they deal with them differently.

A family can be overprotective or wrap you up in cotton wool. It is kind but it doesn't help. Some people feel more frustrated as they feel they are losing more of their independence. Others can feel grateful for having everything done for them by others but this can have a negative effect of making them less able and more disabled.

A lot of friends and family start off very worried and protective but as time goes on they get used to the situation and show less concern. It can feel to the person with pain that they don't care anymore or believe they are still in pain. This is more than often not the case but they often don't want to upset or make the person more angry or frustrated by asking how they are all the time.

Pain can also lead to a role reversal in that the person who once made all the decisions no longer feels confident in doing this. Or the person who was the main breadwinner, homemaker or child carer changes and this can lead to more automatic negative thoughts and feeling guilty and useless.

Pain is invisible so people with pain often feel they need to tell people how bad it is. Often this is because they need to justify why they can do less. Another way of showing pain is through 'non-verbal' communication; groaning, grimacing, rubbing the painful part. Other people get used to this and soon stop responding with concern or help. Unconsciously this can lead to these non-verbal signs getting more dramatic. This may lead to some doctors thinking a patient is exaggerating the pain, when really it is just a way of people being heard about their pain.

Other people, get too embarrassed to let others know that they cannot stand for long or walk as far and pretend that everything is fine. This results in the person grinning and bearing it, which results in a flare up of pain.

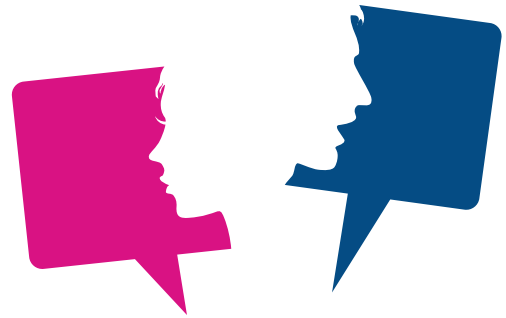
As we mentioned before we often avoid seeing those we love the most or participating in activities that we used to enjoy and this can lead to us feeling isolated and low.

The key to a lot of these problems is good communication. It can be difficult to say how you feel. Especially when there is bad feeling between you and 'talking' can end in an argument that makes things worse.

Communicate clearly. This is often called being assertive.

Assertiveness is the ability to stand up for ourselves and to say how we feel when we feel we need to. It includes:

- expressing your own opinion and feelings;
- saying 'no' without feeling guilty;
- setting your own priorities - for example, choosing how you spend your time;
- asking for what you want;
- being able to take reasonable risks;
- choosing not to assert yourself at times when you feel it would be better not to say anything; and
- if you are missing out on any of these it is possible that you have difficulty asserting yourself.



Lack of assertiveness

Here are a few typical problems caused by lack of assertiveness:

- Saying 'yes' to requests for favours from friends and relatives, no matter how unfair or difficult they will be for you.
- Being afraid to return damaged goods or point out poor service in shops and restaurants.
- Difficulty expressing positive feelings - for example, giving compliments. Worry about being criticised by others.
- A fear of people in authority.

People who do not assert themselves not only fail to get what is due to them, they also tend to feel bad about themselves. They may go over a situation in their mind time and time again thinking, "Why didn't I say that?" or "If only I'd done this". This can lead to feelings of blame, depression and anxiety. Remember from our discussions, the overdoing it because it is hard to say no and then struggling for days afterwards? Or withdrawing from things so you don't cause a fuss?

Common mistaken beliefs about being assertive

The main reason for unassertive behaviour is a fear of what might happen if you are assertive. What do you fear might happen if you stand up for your rights? You may fear that you would feel extremely guilty or anxious after asserting yourself. These fears are usually based on false beliefs about assertiveness.

“I’ll be being selfish if I say what I want”

All we are doing by being assertive is putting our own needs on an equal level with the needs of other people. It is important for our own wellbeing to do this. This is helpful for other people as well. We are not doing anyone a favour by letting them take us for granted or get whatever they want from us.

“If I stand up for myself the other person will become upset and angry”

Finding problem areas

The first task in becoming assertive is to work out the situations where you do not stand up for yourself. Does it happen at work, at home or when you are out with friends? Does it happen more often with certain types of people (for example, those in authority, young people, relatives, the opposite sex)? Is it harder giving compliments or criticism or are both difficult? Think about what you worry might happen in these situations if you were assertive and consider how realistic this is in the light of the discussion above.

Make a list of situations where you would like to be more assertive:

Work out what you want (I want my family to stop fussing. I want to do the shopping with my partner). Ask yourself what you want. It might be helpful to write this down here.

Planning and rehearsal

Having chosen a situation and identified the problems, the next step is to plan what you are going to say and do. Of course, it is not possible to make complete plans as you do not know exactly what will happen. The most important thing is to plan what you want to say (and do) and the best way of saying it.

It often helps to have a 'dry run' or rehearsal before actually going into the situation. You can do this with a friend or by yourself. If you are doing this with a friend, ask them to play the other person. Then you could try swapping round, with you playing the other person.

Think about what you want to say and how you are going to say it. Write it down. Put them away for a day or so and come back and read them over again. Ask yourself "How would I feel if s/he said that to me?" "Are there words here that always start a fight?" Here are some tips on behaving assertively:

- Keep what you want to say clear and to the point.
- Avoid long explanations.
- Look at the other person, stand (or sit) upright and keep a calm tone of voice.
- There's no need to apologise if you feel you are in the right.
- Be polite but firm.
- Try to relax, rather than becoming angry.

Going into the situation

You may feel nervous beforehand but this is quite natural. Try and keep to what you have planned to say even if the conversation doesn't quite go as you expected. Remember, you can only do your best. After it's all over ask yourself how you did. What things did you do well? What could be improved? Give credit to yourself where it is due and learn as much as you can from what happened to apply to the next time.

Some specific techniques

You may find the following suggestions helpful for particular situations:

'I' messages

None of us like to be told what to do, especially by someone else! Don't use words like 'you think'/'you want'/'you always'. Instead change them to 'sometimes I feel that you are thinking'/'it makes me think you want'/'it feels to me as if'

If you are unhappy about someone's behaviour is it best to say how you feel rather than attacking the other person. This means using the word 'I' in what you say. For example, suppose you had cooked a meal several evenings on the run for your partner or flatmate and each time he or she had arrived late and the dinner had been spoiled. A suitable 'I' message might be:

"I get very upset when you arrive late for dinner because I put a lot of energy into making it and I feel it's a waste if the food is cold or overdone."

This tells the other person how you feel and paves the way for a helpful discussion of the situation. This is different from 'you' messages which attack the other person. For example:

"You're always late for dinner. You're selfish and inconsiderate. You can make your own dinner from now on."

The scratched record

This can be useful with strangers when you have a specific task: for example, when taking goods back to the shops. It consists simply of repeating your point several times no matter how the other person tries to divert you. For example:

- Customer: "Hello, I'd like to return these trousers because they've got a mark on them"
- Shopkeeper: "Hmm...well, it's only a small mark. It will probably wash off".
- Customer: "I'd still like them changed please."
- Shopkeeper: "We don't have any more of that size in stock."
- Customer: "I would like a replacement pair."
- Shopkeeper: "OK. We'll re-order them and they should be in by the end of the week."

A final word

Listening to what they have to say is also important, even if it sounds hurtful or you don't agree. You can check that you have understood what they are saying, "I think what you are saying is..." So there is no miscommunication.

If an agreement is to work, you both need to gain something from it. It might be suggesting something that the other person wants in return for what you want.

Keep calm and relaxed, don't choose a time when either of you are tired, in too much pain or rushed. Remember to say how much you love/respect/ need the other person and are worried that you might hurt them. If you find it difficult to say aloud, ask them to read it in a letter.

If you look again at the list of assertive skills at the beginning of this section, you will see that the last one says 'The right to choose not to assert yourself'. There is no rule saying that you have to assert yourself all the time and in some situations you may feel it is better not to say anything. Generally, though, you are likely to find that being more assertive has a significant positive impact on your life. These techniques can feel a little strange and artificial at first but they do become more natural the more we use them.

Sleep

Pain makes sleeping difficult. Our bodies repair at night. However, people with persistent pain often find they have difficulty getting to sleep or wake up frequently throughout the night.

Getting comfortable can be a major problem. Even when it's possible, sleep may not come, or will not last the seven hours that most of us want. Things that prevent good sleep are:

- catching up/napping during the day;
- not doing enough to get tired;
- worry, adrenaline and stress;
- alcohol, caffeine and smoking before bed;
- sitting up most of the night, in bed most of the day; and
- pain.

In the dark, our whole attention is free to focus on our pain. This makes the pain much louder and at the forefront of our minds. Like a ticking clock, we don't notice this until the lights are out and suddenly it's so noticeable we are unable to sleep with it.

Whatever the cause, poor sleep and feeling tired the next day is one of the most common reasons pain can seem worse.

What can be done to improve sleep?

Over your lifetime your sleep cycle will change. Your sleep cycle as a child is usually very different to your sleep cycle as you get older. You may be doing less than you used to, so you are likely to need less sleep than you once did and that can take some getting used to. As many of you are doing less than you did previously, you are likely to need less sleep than you once did and that can take some getting used to. One thing is certain though, worrying about not sleeping doesn't help! There are some practical steps you can take that have been shown

to make a big difference. We also know that the more you follow good sleep practices then the more likely you are to have a better night's sleep.

Increase your daytime activity levels

Over the course of time as a result of pain, your activity levels may have reduced. So your body is not able to use the amount of energy that you may have burned in the past through activity. This means that less sleep is needed in order to repair those tissues making falling asleep more challenging.

Gradually increasing your activity means your body needs to use more energy. This can make you feel more tired and more likely to fall asleep within a normal bedtime routine.

Build a sleep routine

It is possible to train your rhythms by building up associations between sleep and external factors. You will have some of these associations already. Having a night time routine, such as switching the lights off; locking up; brushing your teeth; getting into your pyjamas; all help to signal to your body that it's time to start the release of hormones that make you feel sleepy. If all you do in your bedroom is sleep, then simply entering your bedroom will become a trigger for sleep. However, you can break this link by lying in bed awake, particularly if you are tossing and turning or worrying about getting to sleep. You can build up an association between your bedroom and a sense of frustration. The same also applies if you do other 'non-sleep' activities in your bedroom, such as watching TV; using a computer; or writing letters. If you have a PC or TV in your bedroom – move them out!

Try not to nap or sleep through the day. Try to go to bed at the same time when you are feeling sleepy. If you can't sleep after being in bed for 30 minutes it is unlikely you are ready to sleep and continuing to try may lead to more frustration. At this point you may need to get up and continue the process of winding down until you are ready to try again. Try to get up at the same time each morning regardless of how much time you slept during the night – set an alarm clock.



Use distraction techniques

When you are trying to get to sleep, use distraction techniques to fill your mind with something else. This leaves less room for the pain. It has to be something that takes a lot of concentration but is calming and not exciting. The traditional thing to do is count sheep. However, not all of us are now able to get a clear picture of this. Here are some examples of what patients say have worked for them:

"I imagine walking around the local park from start to finish. I imagine taking a different route each time and try and notice all the different scenery in the park before I fall asleep. Nowadays, I'm asleep after a few minutes and don't make it until the finish."

"I think about an old school photo and try and remember everybody who was in it one by one."

"I use deep breathing exercises that were encouraged by my physiotherapist."

Sleep diary

Building a new sleep routine can be a challenge for lots of different reasons. One of the best ways to develop a sleep plan is to first find out what your sleep pattern is at this moment in time. The best way to do this is by keeping a sleep diary. A sleep diary allows you to track your sleep over the course of a week. Then once you have made a change to your routine, repeat the diary at a later date. This will show the impact the change in sleep routine has had on your sleep and help you to make further changes in the future. Modern day technology may also help, for example: with SMART watches.



Here is a template of a sleep diary.

Complete the diary each morning ('Day 1' will be your first morning). Don't worry too much about giving exact answers, an estimate is enough.

The date of day 1

Enter the Weekday (Monday, Tuesday, Wednesday and so on)	Day 1	Day 2	Day 3	Day 4	Day 5	Day 6	Day 7
At what time did you go to bed last night?							
After settling down, how long did it take you to fall asleep?							
After falling asleep, about how many times did you wake up in the night?							
After falling asleep, for how long were you awake during the night in total?							
At what time did you finally wake up?							
At what time did you get up?							
How long did you spend in bed last night (from first getting in, to finally getting up)							
How would you rate the quality of your sleep last night? 1 2 3 4 5 Very poor = 1 Very good = 5							

Sleep summary

- go to bed and get up at a regular time;
- have a bedtime routine and wind down before bed;
- get up if you are worrying or not asleep after 30 minutes and do something relaxing;
- exercise regularly, but not late in the evening;
- remember that our sleep cycle does change throughout our life
- if you are feeling drowsy for whatever reason, it is best not to drive or to operate dangerous machinery; and
- make your bedroom and bed as comfortable as possible noise, dim the light, temperature and so on.

Conclusion

This workbook has been developed from research from leading professionals working in pain management. We would like to take this opportunity to thank them for ongoing work in this field.

We appreciate that living with persistent pain can be distressing from a physical and a psychological perspective, that can impact on your quality of life. We hope that the topics covered in this workbook help you to put some self-management strategies into practice and move forward with your condition.



Useful links/Resources

Pain Association Scotland

Telephone: 0800 783 6059

www.chronicpaininfo.org

Pain Association Scotland is a unique organisation that has pioneered the development and delivery of self-management training for people with persistent pain.

A local community based self-management group for people with persistent pain is run by Pain Association Scotland at Biggart Hospital, Prestwick and Nethermain Community Centre, Kilwinning.

The group aims to improve quality of life and wellbeing for those with persistent pain by developing and maintaining skills in pain management. It is a rolling 12-month programme covering a number of different topics.

Pain Association Scotland has been endorsed by the Scottish Government and receives support from NHS Ayrshire & Arran. If you would like to attend, you can just go along. You can get a list of group dates and times on their website or by contacting the Freephone number above.

A range of excellent online self-management videos are also available on the website.

Chronic Pain Management

<http://paindata.org/index.php>

This website provides information and advice for people with pain and those caring for them, as well as healthcare professionals.

Pain Concern

Telephone: 0300 123 0789

www.painconcern.org.uk

Email: help@painconcern.org.uk

Pain Concern produces 'Airing Pain', an online radio show which brings together people with pain and specialists, and 'Pain Matters' magazine. It also has a helpline service and forum.

The Pain Toolkit

www.paintoolkit.org

The Pain Toolkit is a simple information booklet that will help support you in managing your pain.

Arthritis Research Campaign

www.arthritisresearchuk.org

Arthritis Research has an extensive range of excellent information booklets, including 'Living with long-term pain: a guide to self-management' and 'Fibromyalgia'.

Neuropathy Trust

www.neurocentre.com

The Neuropathy Trust provides support to people affected by Peripheral Neuropathy and Neuropathic Pain.

Active Scotland

www.activescotland.org.uk

Looking for ways to get active, but not sure where to start? Active Scotland will help get you going. Put your postcode or town in the search box to find activities close to home, from easy to extreme.

Local exercise schemes

East Ayrshire CHIP project: 01563 576717

North Ayrshire K:A Leisure: 01294 605128

South Ayrshire Activity for health: 01292 294716

These provide accessible community-based physical activity programmes to encourage and support individuals in making the transition to an 'Active Healthy Lifestyle'.

Benefit Enquiries

Job Centre Plus: 0845 606 0234

Employability

East Ayrshire:	01563 503000
South Ayrshire:	01292 283935
North Ayrshire:	01294 322707

Living Life Guided Self Help – NHS 24

0800 328 9655

A free confidential service based on a cognitive behavioural therapy approach is available to anyone suffering low mood, mild to moderate depression and/or anxiety. You can be referred by your GP or just contact the number above.

Mood Juice

www.moodjuice.scot.nhs.uk

This site is designed to help you think about emotional problems and work towards solving them. It has a section on chronic pain.

Active Scotland

www.activescotland.org.uk

Looking for ways to get active, but not sure where to start? Active Scotland will help get you going. Put your postcode or town in the search box to find activities close to home, from easy to extreme. These schemes provide an accessible community-based physical activity programme to encourage and support individuals in making the transition to an active healthy lifestyle.



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