

SWBH Pain Management Programme

Companion leaflet

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Feedback from a previous group

"It has been useful to know how other people deal with pain and share some experiences. Have learnt some key skills but the challenge now is to put them into practice - which is not easy. A knowledgeable and approachable team who have been able to get a lot of information across in a small timeframe.

Overall very informative."

(January 2023)

Welcome

Ground rules

- Be kind and respectful
- Only one person talking at a time
- Please keep your phones on silent. If you need to take a phone call, please leave the room
- Try to be on time
- Stand up and move around when you need to
- Confidentiality – ok to share ideas, but not identifying information
- Please try to be non-judgemental

Pain Management Programme

- A training course on how to manage long term pain, based on research.
- 10 sessions, each 2.5 hours long. It's important to attend them all.
- Facilitated by professionals from different disciplines - physiotherapists, nurses and psychologists.
- It's ok to be sceptical – but please try to come with an open mind and try to be respectful of other people's point of view.

There are many years of pain experience within this group. The facilitators bring knowledge of long-term pain and experience of working in a pain service, and you are the experts in knowing what it is like to live with pain. This group takes a collaborative approach - sharing and building our knowledge and expertise.

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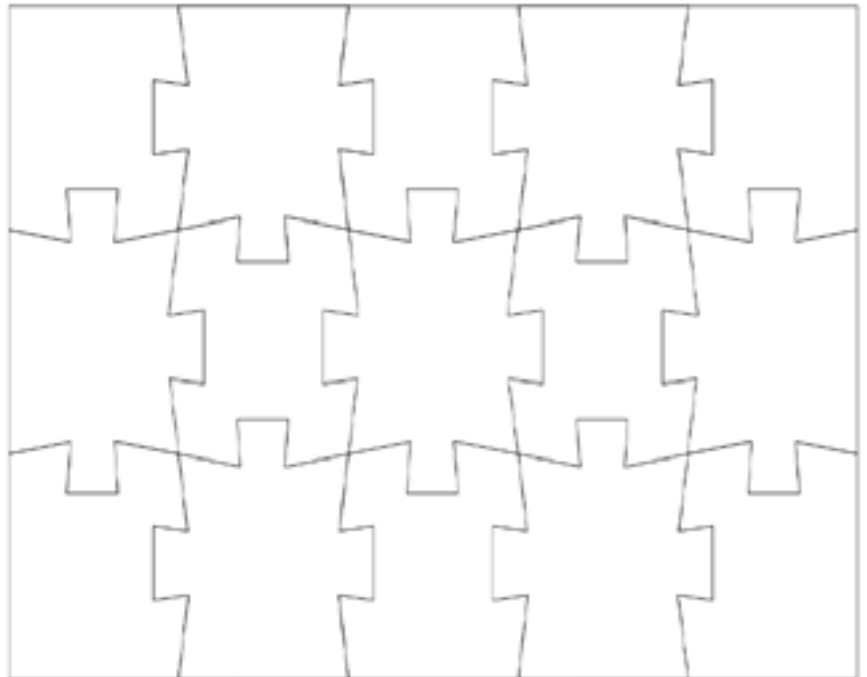
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Pain jigsaw

Within this group we discuss together the impact of pain on your life.

Viewing the experience of pain a bit like a jigsaw can highlight both the complexity of pain and build up understanding of its impact. It can also show how rather than managing all aspects of the pain at once, focusing on one or two areas can have helpful knock on effects on others. Having space to discuss together what already works for you, and developing skills on top of what you already know can help in managing each aspect. We hope it then becomes a bit like expanding your toolbox of things that can be helpful in supporting you with your pain.



Take away messages

Our aim is not to take away the pain, we don't know how. We aim to help people manage it better, function better and improve quality of life. The jigsaw shows how many areas are affected by pain and the impact of pain can often feel like too much to cope with. The group will give space to think about what works for you already, and what you can add... a bit like building up a toolbox.

You can use this space to make your own notes

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Explaining pain

Pain = 'when you hurt yourself, or something hurts you'. We start with looking at what happens in the body when there is acute pain. Acute means it lasts for a short time. Initially, the nerves in a specific body part (e.g. back, shoulder) pick up that something is happening, and send a message to the brain. The brain needs to work out 'how dangerous is this?' Our expectations, stress level, mood and past experience can help the brain work out the danger level. If the brain decides there is potential danger, it needs to get you to stop. To do this, the brain sends out a STOP / Pain signal.

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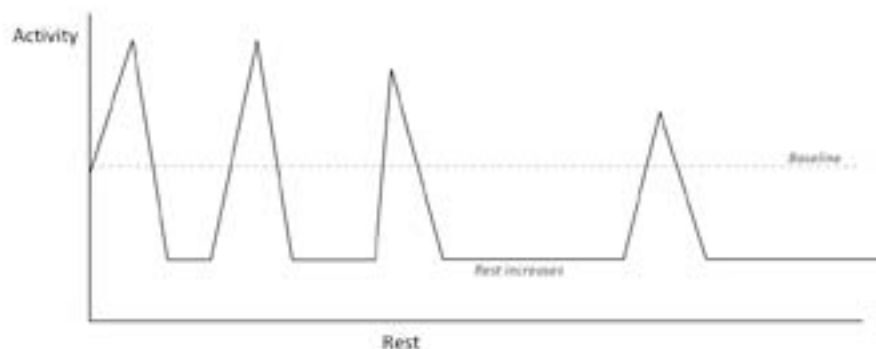
Chronic Pain = Long Term Pain

In long term, also known as chronic or persistent pain (pain for three months or more), the nervous system works very hard for a long time. The nervous system can become more sensitive to pain. Sometimes people are not able to stop when they experience pain for very good reasons. Then the body ‘turns the volume up’ and sends stronger and stronger pain signals.

More sensitive does not mean you are overreacting and does not mean your pain threshold is low. It means the nervous system and brain have been working hard for a long time, and now the pain is more easily triggered. Also, although we are talking about the brain, this does not mean that the pain is in our heads. We talk about the brain because the brain is responsible for and coordinates all functions in our bodies, including the pain. The pain is very much real, there is no doubt about that – because you can feel it!

Pacing

You might find on good days when your pain is not as bad, you might try to “make hay while the sun shines.” Understandably, people tell us that they feel good or “normal” when able to do this. At the same time, it is easy to end up overdoing it on those days. This sudden increase in activity can have an impact on pain and often leads to reduced activity for the next day or two. This leads to the spikes in the picture below.



The boom and bust cycle can be managed by pacing. The aim of pacing is to gradually balance activity and rest levels; it should not make your pain worse. Pacing is about doing an activity without pushing yourself too much. Over time, you may find that pacing helps you to slowly increase activity levels. It can help to keep the pain levels steady. It can improve planning and it can help with flare ups.

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As well as increasing activity, recovery is also very important. If we push ourselves too much, this will make pain worse. Even pro-athletes have to learn to plan active recovery in their training programmes.

What does recovery look for you? This will be different for each person.

You can use this space to make your own notes

Take away messages

Pacing aims to gradually balance activity and rest. It's about stopping before the pain stops you. Active recovery can differ for everyone. Think about what recovery looks like for you. It can take some trial and error to pace activity and to find what helps you to recover.

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Role of Activity

Some examples of barriers to activity are listed below:

- **Pain** = Your pain may get in the way of movement.
- **Cost** = for example, paying for a membership to a gym
- **Motivation** = You may feel so exhausted with your pain and fatigue you may experience low motivation to engage in activity
- **Weather** = Cold or really hot weather is often associated with more pain
- **Time of day** = You may find evenings are more difficult for your pain
- **Support** = Some people find they enjoy activity much more when they are doing it with someone else
- **Equipment** = Some equipment may be needed for some people to engage in activity

Various solutions may help, some of these are listed below:

- More sleep
- Pacing
- Support / partnership
- Groups
- Active recovery
- Visualisation
- YouTube

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Sleep

We need sleep. Disruptions in our sleep can lead to fatigue, brain fog, and impact on our mood. Each person is different and there are no rules about how much sleep you should have. However, it is important to develop a regular pattern that's right for you. Sleep difficulties commonly occur because we are feeling uncomfortable (e.g. due to pain) or things are on our mind. Sometimes sleep is disturbed by noise, partners, children or medication side effects. Once we are awake, we can find ourselves unable to switch off from worries and we can get into a struggle to sleep.

Your sleep plan:

Many things including pain can affect your sleep – what things come to mind that get in your way?

What helps to restore the sleep pattern?

Bedtime routine – we all need wind down time before we feel able to nod off!

Going to bed around the same time each night and getting up around the same time each morning may also help.

Avoid smoking, caffeine and alcohol before sleep.

Try to only go to bed only when you feel sleepy.

Consider using relaxation.

Think about making your bedroom dark, cool and quiet and your bed comfy.

Gentle exercise earlier in the day can help.

If you still can't sleep after about 20 minutes, avoid struggling to – get up and do something different.

Stress

Anything that can overwhelm our capacity to cope can result in stress.

Causes of stress include life events (e.g., moving house/ bereavement), daily pressures (e.g., childcare/money worries/coping with long term health problems like pain) and emergencies (an emergency stop in the car). Even pleasant events can cause stress.

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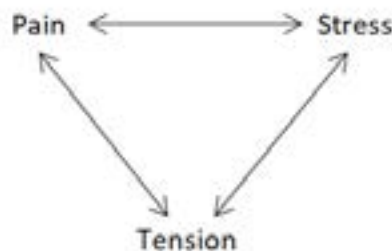
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Physical symptoms of stress include: increased heart rate and blood pressure, faster breathing, shallow breathing, headaches, dizziness, shaking, muscle tension e.g. jaw clenching, digestive problems. The stress response is a normal and protective response; it is as if the body is going into a higher gear to prepare the body to take action.

When the brain picks up on a threat, stress hormones are released, automatically, in milliseconds. The brain's job is to work out 'how serious is the threat?' and 'how should I respond?' Our hardwired responses include fight/flight/freeze. The brain chooses a strategy - depending on what has worked before. We have evolved to react this way - the classic example is how would our ancestors react if faced with a tiger predator? Whether it's a tiger chasing us, or a worry about money, the stress response is similar in our body.

Pain and stress can be linked.



What can we do about stress?

There is no magic wand to take it away, but here are some suggestions about how we can manage it...

- Sometimes we can remove ourselves from the stressful situation.
- Understand our own stress levels. Consider what works when? And what do I have control over?
- Sometimes starting to address the tension in the body is very good starting point. Breathing deeply, relaxation (including slowing the breath down) and/or mindfulness techniques can be very helpful here. These are described in the next section.
- Find something that releases stress for us – hobbies / music / holidays / talking / crying / pleasurable activity / nature / pets / time with children, family or friends
- Can planning help? Might help to write it down – keep a diary.
- Prayer / faith
- Surround self with the right people. Hugs from others. Find someone to offload to.
- Laughter, engaging in activity that brings you joy.

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- Learn to say 'no' and creating space for yourself
- Think about ourselves – Tune in and listen to our body, be kind to ourselves.

You can use this space to make your own notes

Breathing, relaxation and mindfulness

Experiencing pain is stressful for the body. Pain often increases tension, potentially leading to muscle spasms. Breathing, relaxation and mindfulness can all help to reduce tension and lead to improved sleep and mood. When we breathe well, it can help with activity. Breathing poorly can contribute to panic, dizziness, chest tightness and other stress symptoms. During the programme, we try breathing through our diaphragm (diaphragmatic or deep breathing). We also introduce other breathing exercises. These can be relaxing, which in turn can promote sleep. Mindfulness has a different emphasis - rather than trying to relax, mindfulness is about being aware of how we are right now in the moment - focussing attention on this, rather than our minds jumping backwards and forwards. We can be mindful of the breath, our surroundings, and even how we move and approach activity.

Diaphragmatic breathing

1. Sit comfortably. If you're sitting in a chair, your knees should be bent and your head, neck, and shoulders, relaxed.
2. Place one hand on your upper chest
3. Place the other hand below your ribcage on your abdomen. Please breathe normally – what do you notice? Now let's try the technique:
4. Firstly, take your shoulders gently up and back. Your chest should feel open and relaxed, your shoulders should feel relaxed. No need to push here.
5. Breathe in slowly through your nose. The air going into your nose should move downward so that you feel your stomach rise with your other hand. Don't force or push your abdominal

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muscles outward. The movement (and the airflow) should be smooth, and it should ideally mainly involve your stomach area. You shouldn't feel like you're forcing your lower abdomen out by clenching your muscles. The hand on your chest should remain relatively still. This can take a bit of practice.

6. Breathe out through your mouth. Let your abdomen relax. You should feel the hand that's over it fall inward (toward your spine). Don't force your stomach inward by squeezing or clenching your muscles. Exhale slowly through slightly pursed lips. The hand on your chest should continue to remain relatively still.

Repeat this for around 5 breaths at a time: 4 times a day.

Slowing the breath down

1. Find a comfortable seated position. You may also do this exercise standing, for example, if you're waiting in line. If you are lying down, you can place one hand on your chest and the other hand on your abdomen.
2. Gently lower your eyes to the floor in front of you or close your eyes.
3. Begin to notice how your breath feels today.
4. Take a breath in through your nose for two counts and exhale through your nose for two counts twice, counting in your head:
'Breathe in- 1, 2/ Breathe out: 1, 2'.
'Breathe in- 1, 2/ Breathe out: 1, 2'.
5. Take a breath in through your nose for three counts and exhale through your nose for three counts three times, counting in your head:
'Breathe in- 1, 2, 3/ Breathe out: 1, 2, 3'.
'Breathe in- 1, 2, 3/ Breathe out: 1, 2, 3'.
'Breathe in- 1, 2, 3/ Breathe out: 1, 2, 3'.
6. Take a breath in through your nose for four counts and exhale through your nose for four counts four times, counting in your head:
'Breathe in- 1, 2, 3, 4/ Breathe out: 1, 2, 3, 4'.
'Breathe in- 1, 2, 3, 4/ Breathe out: 1, 2, 3, 4'.
'Breathe in- 1, 2, 3, 4/ Breathe out: 1, 2, 3, 4'.
'Breathe in- 1, 2, 3, 4/ Breathe out: 1, 2, 3, 4'.
7. When you're ready, return to your normal breathing without trying to control it.

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- This will take some practice. To begin with, you might only be able to go up to 3 counts. This is OK; you may find that this changes slowly with practice and you can go to 4 or even 5 counts breathing in and breathing out.

What is mindfulness?

- Awareness – of our body, senses, thoughts, sounds, and anything else around us
- Paying attention /concentrating in a particular way
- Drifting away and then gently pulling focus of attention back
- Using the breath - acting as an anchor to the present moment
- Different for everyone, different everytime
- A whole range and mixture of emotions may be present - appreciation, annoyance, anger, panic, calmness...
- Noticing if you are 'striving' for some ideal
- Non-judgmental toward yourself and your experience (If you notice that you are making judgments, trying not to be judgmental about that!)
- Be gentle and kind to yourself
- Being curious about the experience
- Working towards acceptance... whatever it is, it is already here...

Thoughts and feelings

We discuss the experience of a high pain day considering:

Body e.g. pain
/ fatigue

Actions e.g. push
through, cancel,
avoid activity

Thoughts e.g. 'I used
to be able to manage
this', 'I'm useless',
'other people think
I'm exaggerating'

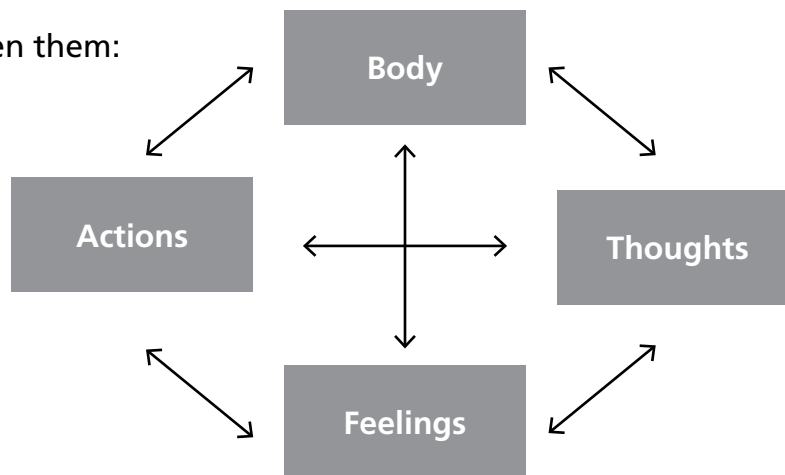
Feelings e.g. sad,
worried about
coping, angry

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And the links between them:



What things do you notice come up when you are in pain?

It is normal for unwanted thoughts and feelings to show up in the presence of pain. Everyone has unwanted thoughts and feelings, regardless of their circumstances.

Where could we begin to make a change if we wanted to improve our experience on a high pain day?

The body symptoms are hard to change, although we could try comfort strategies, breathing or sleep management techniques.

We might decide to act or do things differently - or change the level of activity (remember the section on Pacing).

We might try to change our thoughts and feelings - this can be possible sometimes, but other times, it's like trying to push a beach ball underwater... it only works for a little while. How helpful or unhelpful would it be if we were constantly putting our efforts into trying to change our unwanted thoughts and feelings...?

Changing any of the parts can have knock on effects on the others - they are interlinked.

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More on difficult thoughts and feelings

Everyone has difficult thoughts and feelings. This is normal in life. Such difficult thoughts could include things like I'm unlovable, I'm not good enough and I am a failure. These might show up more in the presence of pain. Most of us do not want to experience these and we tend to try really hard to not think about them. However, these thoughts and feelings are often so distressing and loud that they can pull us away from what matters to us.

We explore ways to respond to these unwanted thoughts and feelings. There are many approaches to this and these discussions can vary in different groups.

Some examples:

Beach ball: Pushing away unwanted thoughts and feelings can be like trying to push a beach ball under water – it takes lots of energy and will only work for a while. Instead of spending so much time and effort on pushing it away, what would happen if we just let it be?

Paper in front of our face experiment: Choose one thought or feeling that you struggle with. Write it down and hold it in front of your face – whilst still holding the paper, try to tell your partner about your journey this morning. Then do the same thing with the paper resting on your lap. What did you notice that was different between these two experiences?– Was it possible to sometimes let thoughts and feelings be there without struggling against them?

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Medication

Most painkillers are designed for short term use for acute pain, and they only play a small part in managing long term pain. When painkillers are continued long term, they usually become less effective and can cause unpleasant side effects.

True or False - All painkillers are the same? This is False

There are four main groups of medication:

Opioids Fentanyl Morphine Oramorph Buprenorphine Tramadol Cocodamol / Zapain Codydramol	Anti-inflammatories Arthrotec (Diclofenac + PPI) Ibuprofen Diclofenac Naproxen Aspirin
Anti-neuropathic Pregabalin Gabapentin (not within 2 hours of indigestion remedies) Amitriptyline (can aid sleep) Duloxetine	Paracetamol Under-rated Centrally acting Anti-inflammatory Least side effects

Opioids

Are a broad group of pain-relieving drugs that work by interacting with opioid receptors in your cells. They work on pain in the brain and spinal cord.

NSAID's (anti-inflammatories)

Work by stopping the production/release of prostaglandin. They are no longer prescribed long term, short course only with lowest effective dose.

Anti-neuropathic

Used for neuropathic nerve pain, they stop the nerves sending pain messages to the brain and also affect serotonin levels which affect mood. When introducing these, increase the dose slowly and when stopping, decrease the dose slowly.

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Paracetamol

Is often under-rated in managing pain. It is a centrally acting, anti-inflammatory medication with the least side effects. Paracetamol does not fit in any of the groups, still not sure how it works but it's been around for a long time. When taken with other drugs, especially opioids, it can enhance their effectiveness.

True or False, All painkillers have side effects? This is True

Side effects can include:

Opioids

- Drowsy – can affect breathing
- Weight gain
- Hallucinations
- Addiction/dependence/tolerance
- Constipation – can slow down the bowel
- Nausea and vomiting
- Dry mouth
- Tremors
- Pruritus (itchy skin)

Long term effects

- Hormones (reduction)
- Endocrine
- Immune (reduction)
- Fertility (reduction)
- Hyperalgesia (increase in pain)

NSAID's

- Kidney damage
- Upset stomach
- Stomach ulcers
- Heartburn
- Indigestion
- Bleeding
- Cause broncho spasm in asthmatics

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Anti-neurpathics

- Weight gain
- Drowsy
- Dry mouth
- Hallucinations
- Suicidal thoughts (Duloxetine)
- Dizziness

Paracetamol

- Liver damage in overdose

All these drugs can have the opposite side effects for some patients. Here are some frequently asked questions regarding medication:

Frequently asked medication questions

Why do we take these medications?

People take medication in the hope that it will reduce pain enough to help them get on with life. Some people take medication in the hope it will cure the pain – but there is no quick fix, even with medication.

How effective are they?

Some medications take a few weeks to have their full effect. It is important to understand that pain medication may not help you and even if it does, it is not usually possible to control pain completely with medication. Sometimes side effects interfere with life and outweigh any benefit.

Should I only take painkillers when the pain is severe?

Long term use can cause problems. We suggest looking at reducing pain relief when having good days. We also advise building your confidence by using other pain management tools before reducing medication.

If I take painkillers regularly, will I become addicted and unable to manage without them?

We know that pain causes the brain to react by releasing natural pain reducing endorphins. Taking medication makes stronger endorphins and stops the production of natural endorphins. So, when you stop taking medication, it can take up to one month for the natural endorphins to kick back in. This is why pain increases when you stop taking the medications.

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Over time, you can get used to some pain medications, so they become less effective - this is called building up tolerance. Sometimes people take more and more to try to get the same effect, but we know that high doses are unlikely to be helpful in the long term. Addiction is when medication is taken to produce a high feeling, rather than pain reduction. Dependency is when the body gets used to taking a medication so when you stop taking it, you get side effects such as nausea, vomiting, shakes and sweating. When stopping analgesia, especially opioids and anti-neuropathics, you need to reduce the medication slowly.

Are there alternatives to medication for managing pain?

There are alternatives including pain self-management, physiotherapy, relaxation, massage, heat, meditation, tens machine and exercise. Painkillers are not the answer on their own - physical and psychological therapies are just as important.

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More on recovery:

Recovery is important, we should all try to build it into our routine. Even top athletes need to build in recovery time and would not exercise at their max every day - this would not be sustainable.

Small group exercise: discuss what active recovery looks like for you.

Examples: try to give brain a rest (TV escapism), colouring, art, crafting, music, chatting with understanding friends, zoning out, relaxing, game on mobile, watch a movie, reading, take a shower or warm bath...

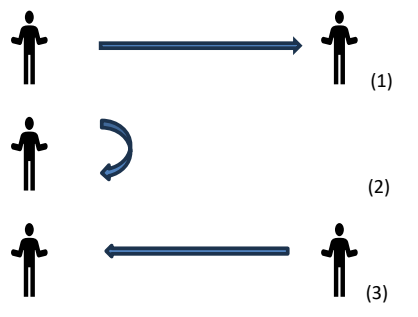
Some of the barriers to recovery include: our own internal thoughts or feelings/pain/family/medication side effects. Examples of steps forward include: taking time out for ourselves, changing the environment, be realistic, don't be afraid to ask for help, try to stick to plan, take small steps...

Compassion:

Compassion is noticing someone's suffering and being committed to want to do something about it. A compassionate person acknowledges the other person's suffering, they want to help, and they are not judgemental.

Flows of Compassion

Compassion flows outwards to others¹ and inwards to ourselves². We can also receive compassion from others³. We call these the three flows of compassion as shown in the diagram.



In your everyday life is there one flow that is more prominent?

Is there one flow that feels more difficult than the other?

A balance between all three flows is very important in order to be able to respond in a helpful way to our needs and those of others. Have you heard the phrase – “you can't pour from an empty cup?”

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What is it like to think about self-compassion? Do you think this could be useful? Please use this space to make your own notes:

Self talk

How do you talk to yourself when you are in pain? What things do you say about yourself on high pain days? How is this self-talk working for you? Do you find it encouraging or unhelpful? Does it impact your mood, pain, or wellbeing?



The way we can talk to ourselves can lead to added suffering. It can increase difficult thoughts and feelings and pain.

Let's imagine you have a pet donkey that you want to help you carry some items to market. What is going to be the best way to motivate the donkey? Whip it with a stick or offer it a carrot?

Both methods will get your donkey to carry the load for you. But what will happen to the donkey that's being hit with a stick? They are going to end up miserable, bruised and battered. Whereas the donkey being motivated by a carrot is going to be more content, healthy and have amazing night vision!

Now let us imagine the donkey is us. The sticks are the harsh words we say to ourselves and the carrots are self-compassion.

What do you tend to do more? Do you use the stick or carrot? Is this helpful or unhelpful for you? Do you want to make any changes? Most people would never dream of hitting a donkey with a stick, yet we are quick to say harsh words to ourselves.

Everything we talk about in this programme falls under the umbrella of looking after ourselves and responding effectively to our own needs – it's about how we treat ourselves. Showing ourselves compassion can be hard at times, and often people find it easier to be compassionate towards others. It may need some practise to show ourselves compassion.

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How do we go about this?

Putting these skills into practice can take time. We have spoken about activity and pacing; exercising; releasing tension from body and mind; responding differently to difficult thoughts and feelings; sleep routines; communicating with other people. This is on top of existing life circumstances, commitments and demands. It may not be possible or realistic to expect that everything will fall into place all at once and that is ok. One step at a time.

Flare ups

Everyone experiences flare ups now and then. Usually (but not always) we can see the early signs of a flare up and why it happened. Knowing the early signs and triggers can help us prevent some future flare ups. Please think about recent / past flare ups and whether there were any early signs or triggers...

You can use this space to make your own notes

We discuss what might help during a flare up. It can be useful to build a tool kit of strategies for coping with a flare up. As with a real tool kit, different tools work on different occasions, a good mix is helpful.

You can use this space to make your own notes

Early warning signs

Triggers

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Take home points – think about the early signs of a flare up for you (it might help to think about what those close to you might notice first). Visualise or write down what is in your tool kit – what helps you manage on the difficult days?

Values

Values are the things that matter to us, values are important in our life and in our heart. It's about what we want to stand for, how we want to behave, the kind of person we want to be. Examples of values are family / friends / companionship / creativity.

Pain affects what we value – it can take important aspects of life away and make lives feel smaller.

On the programme, it's a chance to think about what matters, and whether we are living our values.

What would I add to my coping strategies / tool kit?

Action point: can we identify one value – and plan how can we move towards it in the next week? Between the sessions, we invite people to build in a value-based activity – remembering that even small steps count.

You can use this space to make your own notes

Take home points: Do what matters. Start easy and build up steadily. Small steps add up.

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Communication

How do other people know we are in pain? How does this differ for short term (acute) and long term pain? How can people close to us tell when the pain is flaring up? What is the best way people can respond to us? Do we even know? Is it always the same response that is needed?

Sometimes people do not know what to say when we are in pain. Sometimes we don't know either – and this is something we think about on programme. We think about what it might be like if someone we care for experiences pain – how might we feel? It's hard to tolerate seeing a loved one in pain.

People's responses can vary between under- and over-protective. Under-protective is when people really minimise the pain and/or the impact it might be having. Over-protective is when people make a constant effort to protect us from further pain. Neither extreme is likely to be helpful. We explore how communication is a two-way street. Sometimes we can work out what we need, ask for it and get it. Sometimes, people are not going to hear. It's never purely one person's responsibility.

If you get stuck with pain related communication, there is time on the programme to think about what you want to express and finding the right words, tone, and body language to get it across.

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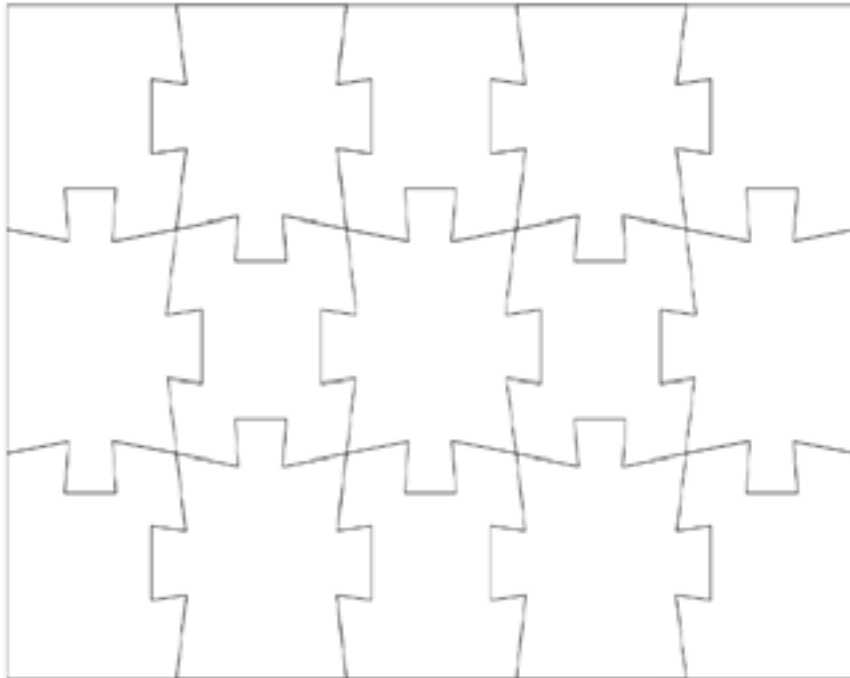
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Pain jigsaw revisited

We revisit the jigsaw, taking time to recap the take home messages of the group. The jigsaw pieces link - and even making change in one area can have positive knock-on effects.



Last thoughts

In the last week, we focus on how people feel about ending the group. There can be mixed feelings of course, but typically people will miss the chance to share their pain related experiences in this unique group where others experience similar issues. The shared understanding and first-hand experience is the power of the group.

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Future options

There is chance to think about establishing goals, or perhaps building on changes already initiated during programme. A key idea is 'do different to get different' – the group will be most powerful if it moves beyond ideas and discussions, into active change.

As creatures of habit, getting going is challenging. Putting change into action takes courage, time, effort and practice though please recognise you're already on your way by joining this group! As you move on from the group, prioritise where to start and take it small step by small step. Be your own judge - if something works for you, build on it. We know that the suggestions in the programme are easier said than done – it's normal to fall off track sometimes, however, we hope that this leaflet has something that can help you when that happens.

We update the group on our Pain Service pathway and further support options within the service.

You can use this space to make your own notes

My future plan is...

Useful contacts

T'ai chi - Fragrant buddha (YouTube)

Relaxation – Patrick Hill (YouTube)

SWBH Pain Management Programme Companion leaflet

Information and advice for patients

Pain Management

Feedback from a previous group

Feedback on what can be taken from the experience:

“Meeting people from all backgrounds with a similar pain background

Informative – putting pieces of the puzzle together, understanding symptoms and the domino effects

Gets you out of the house and interacting

Learning to control the spikes of pain

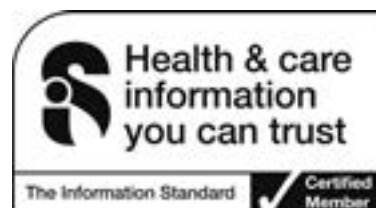
Learning about life beyond pain – and how to make it happen. “Accepting and managing your condition.”

(April 2023)

Sources used for the information in this leaflet

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