



**Health
Innovation**
East Midlands



Let's Live Well With Pain Programme

Facilitator's guide

**A programme based on the 'Ten Footsteps to living well with pain'
developed by Live Well with Pain.**

It aims to support people living with ongoing pain and enable the use of self-management techniques that people have found useful to improve their quality of life, despite the pain they are experiencing.




LiveWell
with pain

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We thank Lister House Surgery, Joined Up Care Derbyshire and Live Well with Pain for working in collaboration with Health Innovation East Midlands to develop, promote and support this pain management programme.

If you are reading a printed copy of this document and wish to view the pdf and follow the links within it, visit



About this guide

This guide is intended for facilitators to use when planning and delivering the Let's Live Well With Pain (LLWWP) Programme. It may also be useful for peer support groups such as Pain Cafes.

This programme is based on the '*Ten Footsteps to living well with pain*' developed by **Live Well with Pain**. It aims to support people living with ongoing pain to use self-management techniques, that others have found useful, to improve their quality of life despite the pain they are experiencing.

This programme was originally developed by the Lister House Surgery in Derby in collaboration with Live Well with Pain and we thank them both for sharing their resources. There is also an [implementation guide](#) available to support the course.

The full suite of resources provided by **Live Well with Pain** are available [here](#). They are updated regularly so please refer to the website for the most up to date information. The ten footsteps from the programme are explored over the six-week course. This guide will state the footstep that the content relates to.

For each week we have provided a range of information and resources to support the facilitator. There are also suggestions for content and topic discussion that are written in **magenta**.

IMPORTANT INFORMATION ABOUT MEDICINES

Medicines is an important topic and whilst it has not been specifically included in this guide it is important to include it in one of the sessions. Experience suggests that waiting until at least halfway through the programme is best. If the facilitator is not a clinician, it is recommended that a clinician supports this topic as attendees will often ask specific clinical questions. It also provides the opportunity for attendees to meet the clinician who will be inviting them to a medication review after completing the course. **Live Well with Pain** provides information on medicines in footstep 9 to support clinicians with this topic and has information attendees can be referred to if there are questions.

FAMILY MEMBERS AND CARERS

Family members and carers are welcome to any or all of the group sessions to provide support and interpretation if needed. This support is particularly useful in week six when next steps and further support needs are discussed.

Live Well with Pain
<https://livewellwithpain.co.uk>





Week 1:

Understanding pain

AT THE START OF THE SESSION:

- Completion of 'Health and Wellbeing check tool' either on paper or digitally, if not already completed (Appendix A)
(**Top tip:** bring paper copies)
- Introductions and an opportunity to share your story, hobbies and skills
- Establishing some ground rules
(**Top tip:** Create these with the group but think about including rules that:
 - Allow people to be as involved as they want to be
 - Avoids people talking over others
 - Allows everyone to have their own views)
- What do you want to gain from the programme?



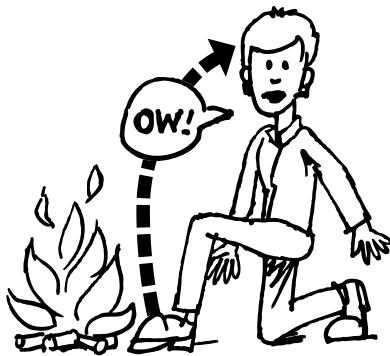
Footstep 1: Pain and the brain

ACTIVITY ONE:

Question: What words come to mind when you think about pain?

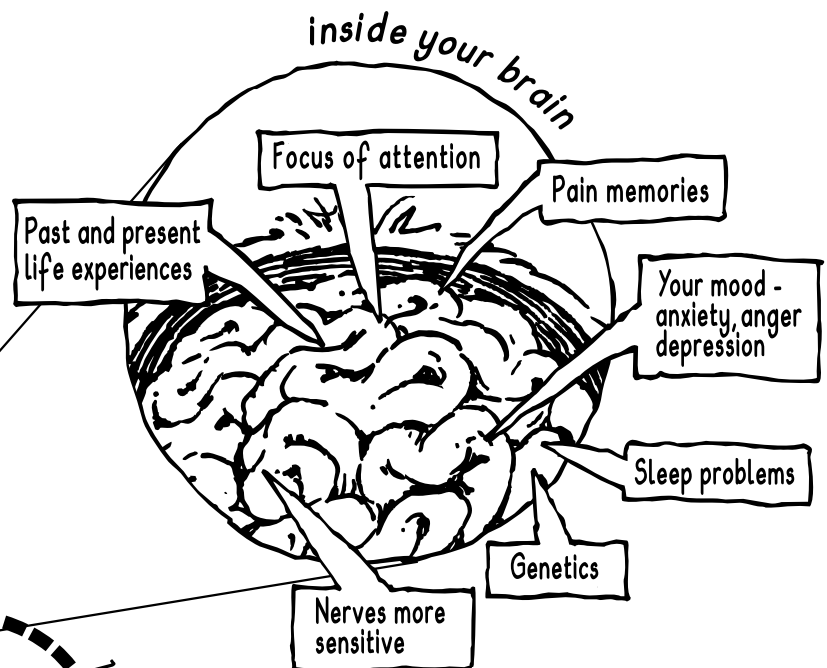
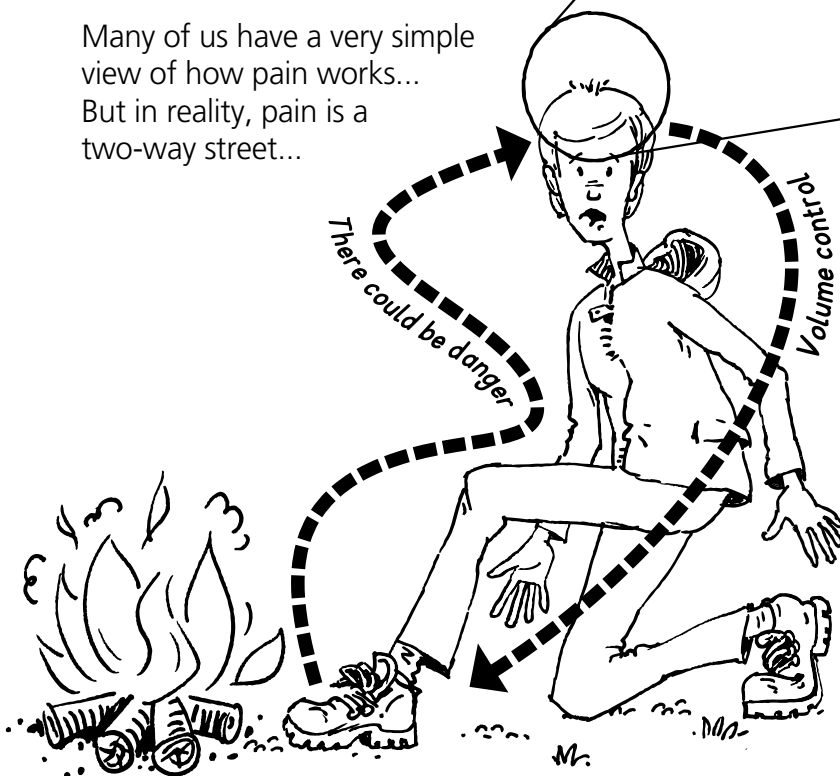
Persistent pain is very different from the kind of pain you experience when you touch something hot or injure yourself. It goes on long after the original cause and affects different parts of the brain and nervous system.

Sensations can resemble the original injury or damage, so it feels as though the damage has not healed when it actually has. It's like a radio switched on permanently and the volume turned up. So what can change? Is it possible to turn the volume down?



Pain and the brain - how it *really* works:

Many of us have a very simple view of how pain works... But in reality, pain is a two-way street...



Pain and the brain - how it *really* works:

- Pain is one of our protective systems. It is designed to keep us safe and well, and it's controlled by the brain.
- Our brain decides when to protect us based on information it receives from:
 - 1) areas of the body, and
 - 2) many other factors it gathers from elsewhere
- It assesses the current situation based on both these types of information.
- If the brain decides it needs to protect, pain will happen.

In persistent pain, even though the original trigger for the pain may have stopped, the other factors are still there, so the brain becomes over-protective and keeps the pain going. It's a bit like the brain struggling to turn down the 'volume control'.

Persistent pain can cause a range of problems, including:

Excitable nerves. Slight pressure can cause unpleasant and painful sensations like pins and needles or electric shocks.

Sensitivity. Skin, muscles or nerves can be more sensitive to pressure, touch or heat.

Faulty brain activity. The systems that turn down pain don't work.

Low mood. Living with persistent pain can cause strong feelings such as anger and frustration.

ACTIVITY TWO:

Question: What can you do to reduce ongoing pain?

It can come as a bit of shock to realise that, to reduce your pain, you need to help your brain to turn the pain down.

You can retrain the brain by getting fitter and stronger, balancing your activities and focusing more on your valued goals and less on the pain.

Over time as you are living a healthier life, being more active and doing things normally and focusing on living life, your brain will become less overprotective and your pain more manageable.

The rest of the Footsteps in this programme will show you more about how to do this.

People who have learned to self-manage have said: "I now run my life rather than the pain running it."

Pain is very isolating and invisible, no-one else can see or feel your pain. This can add to the frustration of living with it.

Emotions like anger, anxiety, or depression can wind-up pain nerve networks making them more sensitive. Try to remember: "This is not your fault."

ACTIVITY THREE:



Watch the video: Understanding pain video

[Tame The Beast — It's time to rethink persistent pain - YouTube](https://www.youtube.com/watch?v=ikUzvSph7Z4)
www.youtube.com/watch?v=ikUzvSph7Z4

Pain is like an Iceberg

(Appendix B)

Questions: What are your thoughts on this?

What would you like to focus on from the Iceberg resource?

ACTIVITY FOUR:

Discuss Footstep 1 - Pain and the brain: Key ideas

(Appendix C)

FOOTSTEP 1 - PAIN AND THE BRAIN: KEY IDEAS



- Persistent pain is different from the kind of pain you experience when you injure yourself
- It goes on long after the original damage has healed – it's as if the brain can no longer 'turn down the volume'
- Reducing persistent pain involves retraining your brain
- Learning self management skills so you can live your life despite the pain are the best way to 'turn down the pain'



End of session

Explain what the next session will cover and ask for feedback.



Week 2:

Acceptance and pacing

AT THE START OF THE SESSION:

- 'Check in' with everyone from the previous week
- Re-share the agreed ground rules



Footstep 2: Acceptance

ACTIVITY ONE:



Watch the video: YouTube video on acceptance

<https://livewellwithpain.co.uk/ten-footsteps-programme/acceptance>

Question: What are your thoughts on accepting pain/this video?

Why is acceptance important in managing persistent pain?

Many people with persistent pain spend years looking for a medical explanation and for someone to fix their pain. It can lead to feeling frustrated and stressed.

It is normal to feel this, because our human brains tend to focus on trying to fix a problem rather than looking for ways to live with it.

Sadly, most persistent pain can't be cured or fixed. This does not mean that things can't change or improve, however.

It can be hard to accept you are not the person you once were and that your life is different now. However, if you can accept that things have changed, then it's easier to switch your focus and energy towards living well.

Your day to day life will then be led by your plans and ideas of what is possible, not by the pain.

You can experiment and learn what works for you. Today we are going to look at [pacing](#) but in other weeks we will look at other skills such as [goal setting](#) and [managing moods](#) that may help.

Donna's story from Live Well with Pain:

Donna found that acceptance didn't happen overnight. It was something she learnt to do over time:

"You don't just suddenly wake up and go: 'I've accepted my pain'. It's a long journey you're on and the road is twisty, and you can come off it now and then. It was a gradual thing – I can't tell you the day I accepted I would always have persistent pain, but I knew I'd got there when I was no longer battling with my body."

Resources

Pacing: <https://livewellwithpain.co.uk/ten-footsteps-programme/pacing>

Goal setting: <https://livewellwithpain.co.uk/ten-footsteps-programme/setting-goals>

Managing moods: <https://livewellwithpain.co.uk/ten-footsteps-programme/managing-moods>

Learning the skills of acceptance

Acceptance is not the same as 'giving up' or 'putting your head in the sand'. It is an ongoing journey of change in which people with ongoing pain recognize that their real-life situation is difficult. It may not be what they would have chosen, but they can begin to look at themselves, their own

thoughts and feelings, and the future in a different, more helpful way.

To help you explore this further, and learn some skills to help you on your journey towards acceptance, here are some activities you can do...

ACTIVITY TWO:

Discuss the following three activities to help your journey to acceptance:

- 1. Focus on what you can change** (Consider the "circle of control")
- 2. Think about opportunities** (Consider the "shift of loss to gain")
- 3. Mindfulness**

1. Focus on what you can change

Changing your outlook on yourself and your future can be hard work and takes both time and being 'willing to let go'.

Many people with pain have been on long journeys to try and answer the 'why pain' question. They have spent a lot of time seeking an explanation and solution for their pain. Sadly, it is impossible for persistent pain to be cured or fixed. We now understand a lot more about [pain, the brain and pain nerve networks](https://livewellwithpain.co.uk/ten-footsteps-programme/pain-and-the-brain) (<https://livewellwithpain.co.uk/ten-footsteps-programme/pain-and-the-brain>). We know that to remove persistent pain permanently is an impossible task. In fact, often people find that when they focus on trying to solve their pain, their pain systems actually become more sensitive and the pain becomes worse.

So instead, try to focus on the things you *can* change. Consider:

- slowly adjusting how you do things
- accepting and adapting to being a different person
- thinking and viewing yourself and life differently
- patiently and steadily shifting the focus towards what you really want to do each day
- shifting your attention from the pain to your breathing
- using some techniques from [mindfulness](https://livewellwithpain.co.uk/ten-footsteps-programme/relaxation-and-mindfulness) (<https://livewellwithpain.co.uk/ten-footsteps-programme/relaxation-and-mindfulness>) like mindful stretching or meditation
- finding the best type of support and help

2. Think about opportunities

Having chronic pain may give you an opportunity to look again at what life means to you.

It can be about finding a new and hopeful meaning in your current life situation. Events that may seem

negative can also be seen as openings for growth, interest, a different path, or new understanding.

Now think about the opportunities that you have had, or could have, since experiencing your pain.

They can be small things, not just major ones. (If it's difficult to do this alone, try talking it through with someone else).

Write down five positive changes or new opportunities that have come about since you had pain. Remember that they don't have to be big things – anything counts.

Writing down these opportunities can help you change your focus from what you have lost, to what is more positive – both now and in the future. Try doing this exercise every few weeks, and you'll gradually start to see more opportunities and look on your situation with more acceptance.

3. Use mindfulness to regain control

Mindfulness is about the kind of awareness that you bring to a situation. It means being in control of what you pay attention to, and for how long. It can be a helpful way of managing distress and many people have learnt to manage their pain more successfully using it.

The aim is to be in a 'state of mind' that is more helpful to managing and living with pain. This state of mind helps the brain to process pain in helpful ways and is soothing and calming.

When you focus on your pain, it can lead to distress and unhelpful negative thinking about yourself and the future. This increases tension within your body and leads to more worrying or anxious thoughts. Finding different ways of directing your awareness – for example by

practicing relaxed breathing, without becoming distressed – can really help manage pain. In turn, this can change the way that you experience the pain.

Mindfulness aims to balance 'reasonable' and 'emotional' thinking. It uses a 'wise mind' thinking approach to being with yourself as you are in your life, in the here and now.

ACTIVITY THREE:

Discuss the self compassion activity
(Hand on heart - Appendix D)

ACTIVITY FOUR:

Discuss Footstep 2 - Acceptance: Key ideas
(Appendix C)

FOOTSTEP 2 - ACCEPTANCE: KEY IDEAS



- Acceptance is an ongoing journey of change, that takes time
- People who accept their persistent pain find that it has less impact on their day to day lives
- Acceptance is not about giving in, but changing your focus towards what you want to do with your life
- Many people use mindfulness to manage their pain more successfully



Footstep 3: Pacing

ACTIVITY ONE:

Question: What do you think of when we say the word pacing?

People living with persistent pain find that pacing is one of the key everyday skills to learn and use. Pacing can help you achieve your goals without increasing your pain or letting tiredness force you to stop. As you'll see, pacing is like the story of the tortoise and hare: slow and steady wins the race...

How can pacing help in managing persistent pain?

Pacing means changing how you exercise and do daily activities so as not to flare-up your pain and to gradually increase what you are able to do. Pacing helps you to become more active and fitter, stronger and healthier.

Pacing is about choosing when to take a break from an activity – before pain, tiredness or other symptoms become too much. In other words, not carrying on until pain forces you to stop.

Here are some of the positive changes that people with pain noticed after they learnt the skills of pacing:

Positive changes reported by people who learnt to pace:

Doing more They could do more over time, either by themselves or with family and friends.

They could tick more things off their 'to-do' list.

Sleeping better They could sleep better at night.

More control They felt they had more control over the pain and their activity levels.

Less medication They depended less on medications and thus experienced fewer unpleasant side effects.

Brighter moods Life became more enjoyable – they had more fun.

More energy They felt stronger and more energetic – they had more 'get up and go'.

A better social life With more confidence that their pain was manageable, they could plan for a better social life and do more things with family and friends.

Less pain They found they had less pain and had fewer setbacks, which didn't last as long.

Less effort They felt less effort was required to achieve daily tasks and activities.

ACTIVITY TWO:

Question: What are your experiences in pacing?

Unhelpful pacing

Whether we know it or not, we all do pacing – it just might not be the best kind for us.

Generally speaking, there are three unhelpful styles that people with persistent pain often use: overactive, underactive and 'boom and bust'. As you read about unhelpful pacing styles, decide which pacing style you currently use:

Overactive pacing

This means doing too much activity or too many tasks over a short space of time.

Typically, this happens if you are having a good day, with less pain, or your mood is better: you try to do too much and end up with more pain and tiredness. This means you miss out on enjoyable things because you have to take time out to recover.

Underactive pacing

Underactive pacing means that you are doing too little activity to help keep up your strength, stamina and flexibility in your muscles, ligaments, joints and bones.

Most of your time is spent resting, sitting or lying down, which is understandable, especially as lack of fitness makes muscles and other tissues tight, weak and painful.

However, this can actually add to your pain, so over time you end up doing less and less because of the pain.

'Boom and bust' pacing

Often people use pain and energy levels as a guide to their activities and pacing them. This means they risk doing too much activity on good days (overactive), which makes their pain worse. They are then forced to rest while the pain settles down (underactive).

This is a mixed style of pacing, which is unhelpful in the long term. It's sometimes known as 'boom and bust'.

Whether you feel that you tend towards being an overactive pacer, an underactive pacer, or a 'boom and bust' type of pacer, then the good news is there's lots you can do to change your pacing style.

ACTIVITY THREE:

Discuss theories such as the "Spoon theory"

Spoon theory was originally developed by Christine Miserandino. A spoon is a unit of energy and a person with a chronic illness, such as chronic pain, has a limited number of spoons that they can use in a day to complete their activities. The person learns to choose how to use their "spoons" carefully. The full story is available [here \(https://butyoudontlookicks.com/articles/written-by-christine/the-spoon-theory\)](https://butyoudontlookicks.com/articles/written-by-christine/the-spoon-theory) (There is an infographic available in Appendix E)

ACTIVITY FOUR:

Discuss resources: Activity diary and Daily pacing plan (Appendix F & G)

ACTIVITY FIVE:

Discuss Footstep 3 - Pacing: Key ideas (Appendix C)

FOOTSTEP 3 - PACING: KEY IDEAS



- Pacing is one of the key self-management skills for people living with persistent pain
- It can help you achieve your goals without increasing your pain
- There are both helpful and unhelpful styles of pacing
- Changing your pacing style could bring many benefits and lessen your pain



End of session

Explain what the next session will cover and ask for feedback.



Week 3:

Setting goals and getting active

AT THE START OF THE SESSION:

- 'Check in' with everyone from the previous week
- Re-share the agreed ground rules



Footstep 4: Setting goals and getting active

Setting goals

Goals are a helpful way of noticing and recording the progress you make over time. Sometimes however, for people with ongoing pain, reaching your goals may be so challenging that it doesn't even seem worth trying.

Achieving your goals may take longer and require more planning. However, this doesn't mean it's impossible. One way of increasing your ability to reach your goals is to develop the skill of goal setting.

As we'll see, goal setting helps you get back control in many different areas of your life and this, in turn, will increase your self-confidence...

ACTIVITY ONE:

Question: How do you measure your goals?

Why goal setting is so important for managing pain

People with pain have found that they are more likely to reach their goals once they have developed the skill of goal setting.

You can set goals for any area of your life. For example, you might want to be more physically active, so you could set yourself a goal to swim two lengths of the local pool twice a week, to be achieved over a three month period.

You may want to be less reliant on medicines to manage your pain, so you could set a goal with your GP or pain specialist to reduce them over a period of time.

Or you may want to socialise more, in which case you might set a goal of having a family meal out, going and listening to a band, or a half-day shopping trip to the shopping centre with friends, once a month.

How to be SMART with your goal settings

Think of your goals as if they are an end destination. If the destination is close, then goals will be short term. Alternatively, if your sights are set far in the distance, then it may be long-term goals that you need.

When you set goals, you need to think about how you will achieve them. What kind of journey are you going to take? For people

who live with ongoing pain, setting goals and working towards them can be a challenge.

Rather like a train taking you on a journey, you may have to change routes, deal with delays, faults on the line or timetable changes; but in the end, you will get there.

So, let's look at what might help...

ACTIVITY TWO:

Discuss smart goals and ways of recording progress and motivation

SMART goal setting

(Facilitator note – this is the version of SMART goals in the LWWP content for people living with pain. This is slightly different to the version in the practitioner’s guide)

SMART goal setting is a way of setting goals so that you have the best chance of achieving them. To understand this, let’s start by imagining some typical goals that a person might have:

SMART is way of focusing your goals to make sure they are:

Specific, Measurable, Achievable, Rewarding, Timed

Specific – means setting out exactly what will be achieved

Measurable – means deciding how often something will happen, or for how long

Achievable – thinking about this ensures your goal will be *realistic*

Rewarding – this is a reminder to make sure your goal will be enjoyable

Timed – means planning how much time is needed to achieve the goal

If you apply these SMART rules to your goals, you’ll have a much better idea of how to go about achieving them. And you’ll be far more likely to get there!

SETTING GOALS – SOME MORE TIPS



- **Avoid an unpleasant chore or a really tricky goal** like losing weight, as these can demotivate you.
- To get started with SMART goal setting, **experiment by trying a fairly easy goal.**
- **Don’t overdo it.** People with pain often aim too high, or try to do things too early or quickly, which often leads to setbacks and a sense of failure.
- Your goal should be **a bit of a challenge but not too difficult** so that your pain becomes more difficult to manage.
- Don’t be afraid to **review and revise** your goals as you go along.
- **It isn’t a test.** So if it seems a struggle, try a more fun or rewarding goal.
- **Try sharing your goals** with other people – it will help them to understand what matters to you and how they can help you make progress.

Rewards

Another useful way to reach your goals is to use rewards. Rewards are tiny treats or pleasures that can provide a boost when you are working towards goals. They could be things like a trip to the movies, spending some time in the garden, or simply having afternoon tea with a friend.

Rewards, when used in conjunction with goals, give a sense of pleasure, satisfaction

or achievement and help build confidence. They give us the drive to keep going, even when it seems difficult. They encourage us to think ‘it’s worth a try’.

Rewards also help us to repeat activities. We tend to do more of something if we feel rewarded for it, either by ourselves or by others.

ACTIVITY THREE:

Discuss goal setting resources: Smart goal ladder (Appendix I)

And other resources on [Live Well with Pain Website](https://livewellwithpain.co.uk/dashboard/10-footsteps/setting-goals)
(<https://livewellwithpain.co.uk/dashboard/10-footsteps/setting-goals>)

ACTIVITY FOUR:

Discuss Footstep 4 - Goal setting: Key ideas (Appendix C)

FOOTSTEP 4 – GOAL SETTING: KEY IDEAS



- Having goals helps you to focus on the things that matter most to you
- Developing goal setting skills will increase your ability to achieve your goals
- Using SMART goals will give you a better idea of how to go about achieving them. And you'll be far more likely to get there!
- Writing down your SMART goals and your weekly steps towards them will help keep you on track.
- Don't forget to build in some rewards!

Getting active

People with pain find it helps to be more active and build fitness even if it was not really part of their life before pain arrived. This is because enjoyable, rewarding, and regular activity builds confidence to do things and lessens the struggles with pain.

ACTIVITY FIVE:

Questions: What are your perceptions on the benefits of physical activity?

What do you currently do to be active?

How can I get fitter and more active?

Like many people with persistent pain, you may be avoiding physical activity because you are worried it will make your pain worse.

These fears are normal and understandable – when you live with pain, the last thing that you want to do is aggravate it further! So, it may be encouraging for you to know that getting fit and staying active is actually good for your sleep and your pain.

The key to getting fitter is to keep it going every day. To help maintain regular activity levels, there are a number of things that you can do:

1. Do physical activities that you enjoy

Quite simply, if you enjoy what you're doing then you'll be more motivated to keep it up. There are some ideas on the next page.

2. Learn the skill of pacing

Pacing is a really useful skill as it guides you to do the level of activity that is right for your body. When you pace your activity, you take a break before pain, tiredness or exhaustion forces you to stop. You can learn more about the skill of pacing.

3. Try doing activities outside during the day

Being outside in the daylight helps your body clock to stay in balance with day and night time patterns. It can help with stressful feelings too.

4. Avoid energetic activities shortly before sleep

Exercising late in the day 'wakes up' your body and so it can lead to problems falling asleep or staying asleep. To help with sleep, the best time to exercise is late in the afternoon or early evening.

Four ideas for getting – and staying – active

OK, so you've decided you're going to become more active. The tricky bit is deciding what to do, how to do it, and how much time and effort to put in. Here are four ideas that can help.

1. Choose something easy and fun

You're far more likely to keep it up if you choose a gentle activity you enjoy. Here are some ideas:

- A gentle walk in a favourite place – pace the time and length
- Stretching and listening to your favourite radio program
- Gentle yoga or pilates, guided by a DVD, website or app
- Volunteering in a museum, public garden or library
- Dancing to enjoyable music at home
- Planting out bedding plants in tubs or in the garden

2. Explore local fitness and activity opportunities

Find out what's available in your local area. It could be a fitness group – but anything that involves moving and stretching, such as a pottery class or a singing group, is also fine.

3. Keeping motivated

This can be a tough one, so here are some tips:

- If the activity you choose is too much effort, simply do something else.
- Give yourself regular rewards for your successes.
- Tell other people what you've achieved so that they can see your progress and support you.
- Find other people to do the activity with – fitness is more fun with friends, and that means you're more likely to keep it up.

4. Dealing with difficulties

Many people use their pain as a guide as to when to start and stop an activity. This is the pain managing you – it's not you managing pain!

The main thing to remember is that when you begin to stretch and exercise, it is normal for pain levels to increase.

The good news is, these pains soon go away if you *grade* your activities. Grading means gently increasing the amount of time you spend doing your stretches, exercises or fitness plan.

For example if you are stretching:

- **Day 1:** hold the stretches for 5 seconds and do three repeats
- **Day 2:** hold a stretch for 6 seconds and do three repeats
- **Day 3:** hold a stretch for 7 seconds.... and so on
- Over the next few days slowly build up the repeats and time on stretching.

What kind of activity should I consider?

They may include:

- **Stretching**
 - Activities that involve stretching help loosen tight muscles, ligaments and joints and increase flexibility.
- **Strengthening exercises**
 - Strengthening exercises are anything that builds stronger muscles and joints so that you can stand, walk and play for longer. This helps you to get out of chairs and use stairs and slopes more easily. Your balance improves and this reduces the chances of falls and pain setbacks.
- **Stamina activities**
 - These will enable you to do things for longer without more pain or tiredness. This helps you enjoy a range of day-to-day activities, join in with family and friends and reduce our fear of more pain.

ACTIVITY SIX:

Complete one or more simple physical activities

ACTIVITY SEVEN:

Discuss the useful resources (Appendix H)
and ideas to increase activity levels? What has worked before?



End of session

Explain what the next session will cover and ask for feedback.



Week 4:

Relaxation, mindfulness and sleep

AT THE START OF THE SESSION:

- Check in with everyone from previous week
- Re-share the agreed ground rules for the group



Footstep 5: Relaxation and mindfulness

There is plenty of evidence showing that relaxation and mindfulness can help people with difficult health problems such as persistent pain. For example, we know it can lessen pain levels, reduce stress and improve concentration.

So let's look at how you can make a positive difference to your life and your pain by learning how to unwind your body and your mind ...

What is relaxation?

Relaxation happens when you or someone else guides your mind to unwind the tension and tightness within your body.

Relaxation often involves using breathing skills and focusing the mind on relaxing images, colours or experiences.

Gentle tightening or stretching and relaxing movements with focus on the

breath can also help to lessen the tension within the muscles and body.

Most people who have struggled with pain say that it is so important to learn relaxation. It helps to do it with support and keep doing it on good and bad days.

Learning relaxation can be easier than you expect and many people say they can feel positive results very quickly.

ACTIVITY ONE:

Question: How do you relax?

Some different types of relaxation to explore:

Breathing and muscle relaxations

- Belly breathing (also called diaphragmatic breathing)
- Progressive muscle relaxation
- On the spot reduction of anxiety or anger reduction (OTSAR)

Distracting the mind's attention

Imagining a pleasurable activity like a walk in the countryside or along a beach can help shift your focus away from pain and other unpleasant feelings.

Doing activities that help you unwind.

Here are some suggestions:

- Gentle exercise programs like yoga, tai chi or pilates
- Sitting in a beautiful garden and smelling the flowers
- Listening to a relaxation CD or app
- Listening to a favourite piece of music
- Taking a photograph of a beautiful scene
- Attending a local relaxation group, gym or self-help group
- Listening to recorded nature sounds
- Knitting or crocheting
- A warm bath and using scented oils.



Experiment and build your own relaxation program. Choose to do one or even two things that are helpful each day.

Practicing relaxation – how to develop your relaxation skills.

Here are two useful approaches that people with pain find helpful:

1. Time-out relaxation

Making time to practice and focus on relaxing will help you learn how to relax fully and deeply. For a 'time-out' relaxation session, set aside about twenty to thirty minutes.

When you first learn a relaxation technique, being in a quiet, comfortable place can help. Lie down on a bed or mat or sit in your most comfortable chair. Try to find a time when you are unlikely to be disturbed.

If you wish, a partner or friend could do the relaxation session with you. Or you may prefer to do it alone.

Listening to a recording or going to a class can be called 'time-out' relaxation. There are lots of relaxation apps or online recordings available to buy.

Try and look at your relaxation sessions as part of your self-care skills, viewing it in the same way as a daily activity program.

NOTE: If you plan to use a relaxation recording, don't use it while driving or operating machinery!

2. Quick relaxation

As well as using a 'time-out' technique, you can start to use relaxation in everyday situations. As soon as you notice any tension or hardness build in your muscles, practice 'letting go' of the tension, 'breathe it gently away' and relax. When you have had a bit more practice, you can use relaxation and breathing in more stressful situations – for instance, when you feel yourself getting angry or frustrated.

You can also practice 'scanning'. This means checking your body for tension by noticing your feet, your legs, your knees, your hips, your abdomen, your chest, your shoulders, your neck, your head, your face,

and your jaw. As you notice any tension let it go, release it from you. As a tip, start from your toes and work upwards, 'letting go' of your tension on the out-breath.

You can also observe your breathing and remember to breathe calmly and comfortably. As you breathe in, your tummy should rise a little; then rest back as you breathe out. Don't force things, as this may make you feel a little 'light-headed'.

TIP: Use 'reminders' – for example, put a sticker on the fridge or on your mirror, and check for tension each time you see the sticker.

What is mindfulness?

Mindfulness is being aware of your body and mind in the “now”. It is about noticing what you think, feel or want at this moment without being critical or judging yourself.

Mindfulness is about exploring with all your senses: taste, touch, sound, sight, and smell.

- It guides you to see your thoughts as events in the mind rather than facts or truths.
- It allows you to choose how to respond to your thoughts rather than react to them.
- It helps you make kinder choices on how to manage your pain, your situation, or your thoughts.

We now know from research that mindfulness helps us to live better with difficult health problems like pain, tiredness and so on. It also helps the brain to work better in many ways, like improving memory or helping with attention so you focus and concentrate better. It is good for learning problem solving and being creative, so helps self-management. Mindfulness practice helps to reduce stress hormones and so lessen moods like anxiety, depression and anger and our thoughts getting tied in with them.

How to learn mindfulness:

There are lots of ways to learn. It just depends on how you learn best. You could:

- Get support from a friend or help from a mindfulness trainer.
- Access an internet course, read a guidebook or work with a CD course.
- Join a local relaxation class or mindfulness meditation course and practice at home.
- There are also mindfulness movement courses that link breathing and movement together and are very helpful for stiff and tight muscles and bodies.

At the end of this footstep there are ideas and resources that you can explore. Give them a try and if you are struggling then find some professional help.

You could get support from a pain specialist physiotherapist, a talking therapist or a mindfulness teacher who can guide your relaxation and mindfulness skills.

ACTIVITY TWO:



Watch the video: Breathworks

www.youtube.com/watch?v=iSGsTWcofhM&feature=emb_imp_woyt



Question: What are your thoughts on this?

Mindfulness exercises

Here are some exercises that you can do to experiment with mindfulness:

1. A mindful breathing exercise

- Give yourself a few minutes to sit quietly.
- Notice your breathing.
- Pay attention to your breath going in and coming out.
- Try to let your attention focus on the bottom of your in-breath.
- Actively 'let go' as you breathe out.
- When you notice that your thoughts have wandered, always bring your attention back to your breathing.
- Spend a few minutes bringing your attention back to the centre in this way. This can lead to a state of feeling calm and secure.

2. A mindful observation exercise

- Be aware of your hand on a cool surface (e.g. a table or a glass of cold water). Be aware of your hand on a warm surface (e.g. your other hand).
- Pay attention to, and try to sense, your stomach and your shoulders.
- Stroke just above your upper lip. Stop stroking.
- Notice how long it takes before you cannot sense your upper lip any longer.
- 'Watch' the first two thoughts that come into your mind – just notice them.
- Imagine that your mind is a conveyor belt and that thoughts and feelings are coming down the belt. Put each thought or feeling in a box near the belt.
- Count the thoughts or feelings as you have them.
- If you find yourself becoming distracted, observe that too. Observe yourself, as you notice that you are being distracted.

Note: It is usual to have to start and re-start several times when you practice 'stepping back' and observing in this way.

3. A 'describing', 'non-judgemental' exercise

- Practice labelling thoughts in groups, such as 'thoughts about others' or 'thoughts about myself'.
- Use the 'conveyor belt' exercise described on the previous page. As the thoughts and feelings come down the conveyor belt, imagine sorting them into boxes, e.g. one box for thoughts, one box for sensations in your body, one for urges to do something, etc.

ACTIVITY THREE:

Discuss useful resources
(Appendix K)

ACTIVITY FOUR:

Discuss Footstep 5 - Relaxation and mindfulness: Key ideas
(Appendix C)

FOOTSTEP 5 - RELAXATION AND MINDFULNESS: KEY IDEAS



- Mindfulness and relaxation can lessen pain levels, reduce stress and improve concentration
- Learning relaxation skills can be easier than you expect
- Mindfulness helps in many ways, such as improving memory or attention so you can focus and concentrate better



Footstep 6: Sleep

If you're living with pain and struggling with sleep then you're not alone. It's very common for people with persistent pain to have difficulties getting to sleep or staying asleep.

Recent research shows that by adjusting what you do during the day, as well as night, it is possible to achieve a healthier sleep pattern.

Why can't I sleep?

It's likely that there are a number of causes of your sleep difficulties. Here are six triggers often found by people living with pain:

ACTIVITY ONE:

Question: Does pain affect your sleep and how?



A vicious cycle

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You have probably discovered that poor sleep can have some unhelpful effects on your day-to-day life. After a broken night's sleep you may find:

- it's harder to concentrate.
- you are short tempered with other people.
- your mood is low.

It's very common for people to find that poor sleep makes their pain seem worse. They can find themselves in a vicious cycle where pain makes sleeping difficult, and poor sleep worsens pain. The really good news is that there are lots of ways to improve your sleep.

ACTIVITY TWO:

Question: Are there any strategies that help you sleep?

ACTIVITY THREE:

Discuss sleep tips

Five changes for better sleep

There are lots of changes you can make to help you to sleep well. Over a period of five to six weeks these can make a huge difference.

Here are the five areas that people living with pain have found to be most helpful:

1. Your daily routines

Get into a regular routine.

Make sure that each day you go to bed, get up, eat meals and do activities around the same times. Try to stick to your routine no matter whether it is a weekday or a weekend and what kind of sleep you had the previous night.

Avoid napping.

If possible, avoid taking naps during the day. This can be difficult – you may feel very drowsy

because of your medication or be tired because you've had a restless night. If you feel like you absolutely 'must' sleep, then keep your nap short – around 15 minutes at most.

Avoid using your bedroom to rest in the daytime.

If you need to take some time out because of your pain, then try to find another place in the house to rest or do a relaxation activity.

2. Your activity levels

Like many people with persistent pain, you may be avoiding physical activity because you are worried it will make your pain worse. These fears are normal and understandable – when you live with pain, the last thing that you want to do is aggravate it further! It may be encouraging for you to know that getting fit and staying active is actually good for your pain *and* for your sleep.

Learn the skill of pacing.

Pacing is a really useful skill as it guides you to do the level of activity that is right for your body.

Do physical activities you enjoy.

Quite simply, if you enjoy what you're doing then you'll be more motivated to keep

it up. This could be anything from taking a morning walk, to swimming, playing badminton or gentle tai chi or yoga.

Try to do some activities outside.

Being in the daylight during the day helps your body clock to be in balance with day and night-time patterns. It can help with stressful feelings too.

Avoid energetic activities shortly before sleep.

Exercising late in the day 'wakes up' your body and so it can lead to problems falling asleep or staying asleep. To help with sleep, the best time to exercise is late in the afternoon or early evening.

3. Your food and drink choices

Avoid caffeine in the evening.

Caffeinated drinks can have a stimulating effect on your body. Usually this lasts for around 4-5 hours, so it's best to stop caffeine from late afternoon onwards to help you sleep well.

Try not to drink too much just before you go to bed.

It may help to limit yourself to sips of water if you are thirsty before bed or in the night. Remember, too much fluid could cause you to wake up and head for the bathroom.

Avoid drinking alcohol late in the evening.

Alcohol can get in the way of a good night's sleep. It has a dehydrating effect which can cause you to wake up feeling thirsty. It can also interrupt the pattern of your sleep.

Eat your main meal earlier in the evening and have a small snack just before you go to bed.

If you have an empty stomach when you go to bed you might wake up hungry in the night. On the other hand, if you eat a big meal late at night then your body may be too busy digesting your food or coping with heartburn to rest easily.

If you are awake in the night, avoid snacking.

This could be training your body to wake up because it expects food. You could have a soothing drink instead – try herbal teas such as chamomile or peppermint, or warm milk.

4. Your night-time routines

Follow a wind-down routine every evening.

Start by setting a wind-down time around 1 to 1 1/2 hours before bed. After this time, do things that help you to relax. This might be taking a bath, watching TV, listening to music or reading a book or magazine.

Only go to your room when it is time to sleep.

Don't go up earlier to watch TV in bed, go on the internet or mobile phone. If you do non-sleep activities in bed then your brain is learning that it is okay to be awake and alert in bed.

Get the temperature right.

Being too hot can cause restlessness and being too cold can make it difficult to sleep. Make changes to your bedding to find the best mix of layers to sleep well. Try a fan or heater on a timer if your bedroom temperature seems to be a problem.

Make sure your room is dark.

When it's dark, our bodies release melatonin which helps us to relax and fall asleep. Block out light from outside by using blackout curtains or blinds. Cover up any light sources such as alarm clocks. Some people find it helps to wear an eye mask.

5. Helping mind and body to rest

Make sure you have a good bed.

To find out more about beds and mattresses visit www.sleepcouncil.org.uk

Find a comfortable position.

To find a comfortable position, you may need more pillows or cushions so your body feels relaxed.

Use relaxation techniques.

It can be very common to lie in bed worrying about how much sleep you are going to get. Using relaxation techniques to help you feel calm and quieten your mind can really help with this.

Avoid checking the time during the night.

Some people keep checking the time if they can't get to sleep or if they wake up in the night. This can increase worrying and make it harder to sleep. Try covering your clock or putting your phone away from your bed so you can't check it.

If you wake up in the night – don't struggle.

It's very common to feel frustrated or worried if you wake up in the night. Different techniques can help with this. Some people use relaxation techniques, other people find it helps to get out of bed after 15–20 minutes and do something calming in a different room. It can also help to simply lie in bed and accept that 'sleep will come when it's ready.'

ACTIVITY FOUR:

Discuss how to sleep well with pain resource (Appendix J)

ACTIVITY FIVE:

Discuss Footstep 6 - Sleep: Key ideas (Appendix C).

FOOTSTEP 6 - SLEEP: KEY IDEAS



- Lots of people with pain have difficulties sleeping, but recent research has shown that sleeping well with pain is possible
- Making some changes to what you do during the day will help you sleep better
- Regular physical activity will help improve your sleep
- Your food and drink choices will have an impact too
- Getting into a regular night-time routine is important
- Making sure that your bedroom is 'fit for sleep' can make a big difference



Week 5:

Communication, managing moods and nutrition

AT THE START OF THE SESSION:

- Check in with everyone from the previous week.
- Re-share the agreed ground rules for the group.



Footstep 7: Communication

*You can't see pain, so how can other people understand what you're dealing with?
People living with pain know that talking to those around them can be a challenge.*

ACTIVITY ONE:

Discuss How easy, or hard, is it to communicate what you need regarding your pain?

People living with pain sometimes tell us that they begin to wonder how to talk to their relative or friend, because so many conversations become dominated by pain, appointments or medicines.

As a consequence, the small things in life that are part of normal chat – such as something you might have seen on social media, or whether there is enough cat food to last the week – begin to be lost.

Some common communication traps

- Not wanting to talk
- Mind reading, or second guessing what the other person is thinking
- Not being honest with each other or trying to protect each other from problems
- Misunderstanding what they are saying or what they want
- Not knowing what to say
- Guilt because you feel you shouldn't burden the other person
- Conflict because neither person's needs are being fully met

ACTIVITY TWO:

Discuss whether any of these resonate with you?

You might overcome communication traps by:

- Having a mid-morning coffee together and chatting about what's in the paper.
- Identifying a time to do the week's menu together.
- Being honest with yourself and your friend or relative about your own needs.

It can help to let people know how the pain limits you. Other people can't see the invisible effects of pain. So talk to them about ways they can support your goals or help you live better with pain.

Some people find it useful to make a list of things they need people to know about what it's like living with persistent pain. It might be useful to have a different list for different people e.g. friends and health care professionals

Most people don't know what it's like to live with persistent pain. So we need to find ways to tell them what we need and why. Otherwise they'll have to guess – and will probably get it wrong!

- Be confident and assertive (being clear)
- Manage your stress (we will be talking about this next)
- Breathe! (Manage your breathing to keep calm, and you'll communicate better.)
- Know what to say
- How do you say it?
 - Think tone and volume
 - Keep good eye contact
 - And remember – be clear!

ACTIVITY THREE:

Discuss Footstep 7 - Communication: Key ideas (Appendix C)

FOOTSTEP 7 - COMMUNICATION: KEY IDEAS



- When life is dominated by pain, the art of everyday conversation can get lost – so it's important to avoid some common communication traps.
- Other people can't see the invisible effects of pain. So talk to them about ways they can support your goals or help you live better with the pain.
- Assertiveness is a key skill for talking to other people about your pain.
- Plan what you want from meeting your health care professionals – and you'll get more out of it.



Footstep 8: Managing moods

ACTIVITY FOUR:

Question: What sort of words come to mind when you think about your pain experience and your moods?

It is normal to struggle with moods when you have persistent pain. Emotions or moods linked to pain can take over day-to-day life.

People with pain find that managing their mood changes in positive ways makes a valuable difference to their pain and their lives.

What do we mean by 'managing moods'?

We all go through periods of 'moodiness' when we feel irritable, sad, frustrated or worried.

People with pain often find they feel:

- Angry and frustrated
- Fearful and worried
- Low and unmotivated

If you have these feelings then you probably find that they get in the way of your day-to-day life and feel quite overwhelming at times. It is common to think that there is nothing you can

do as they just 'take over' and go on for a long time. This is because these mood changes come from the struggle of living with pain.

This is "not your fault". It is more about how our human mind works when it is stressed with pain, we feel unwell or deal with difficult life events. The mind is trying to make sense of everything that is happening and cope with it all.

The good news is that you can do things to manage moods.

ACTIVITY FIVE:

Question: How do you manage your moods?

Ways to manage moods better.

A tape recording in my head

You may have thoughts like, "I'm useless now", "I'll never do that again", "Things are not going to work out" and "No-one seems to understand me now or want to help".

It is like a tape recording in your head, which no one else hears. Realistic positive changes can come from learning to deal with these unhelpful thoughts.

Be kind to yourself

Being kind and compassionate to yourself is one of the best things that you can do. It's very easy to be self-critical and be "hard on yourself" for not being perfect or not getting the job done. But the more you do this, the more likely negative and unkind thoughts emerge. This pushes your pain networks into stress mode, they become more sensitive and so increases pain and distress.

You don't have to be perfect!

So, trying to be '100% perfect' all the time can be unhelpful. Instead, ask yourself, "What is kind and caring for me, my body, or mind right now?" Experiment and do things that lessen the stress or pressure. This will help your body's natural opioids (the pain-reducing chemicals) to work better so they soothe some of the pain and upset in your mind. This in turn can reduce the adrenaline levels that increase stressful pressure and symptoms.

Remember that it is "not your fault" that the pain refuses to go away. So how can you help lessen the stress or pressure?

Below are nine ways to work with moods

The trick is to discover which ones work best for you and then use them often.

Nine ways to help you manage moods.

1. Noticing negative thoughts

Negative, unhelpful thoughts often quickly come into your mind and affect your mood without you even noticing them. This is what makes them so powerful and believable. If you can get into the habit of spotting your negative thoughts as you have them, then you can use different techniques to balance or soothe them.

2. Practice 'balanced thinking'

Write down some of your negative thoughts and then imagine what a best friend would say if they knew you were thinking them. Make a note of what your friend would say and use this when they pop back into your mind. You will start to see that these negative thoughts are not always 100% true or believable.

3. Do things that unwind your mind

Do things that unwind and soothe your mind, like walking the dog, listening to music, doodling, breathing calmly or doing craft activities, knitting... anything that is calming.

4. Build a list of positive things you have done today, or this week

This will show you that you are coping or managing life, despite the pain. Keeping a 'Positive Facts Diary' helps deal with "I can't do this" thinking. You'll find that you are actually doing positive things. It is just that your mind gets too distracted and focused on the negatives to realise it.

TIP: Using your mobile phone to take photos of your positive moments is a quick and easy way to collect the facts and keep a visible record to remind yourself!

5. Practice being kind to yourself

For instance, check you are balancing activities and effort (ie. [pacing https://livewellwithpain.co.uk/ten-footsteps-programme/pacing](https://livewellwithpain.co.uk/ten-footsteps-programme/pacing)); work towards fun goals in paced steps; do something enjoyable, like a meal out with a friend.

6. Learn from others with similar pain issues

Find out what other people do to deal with negative thinking and moods through local support groups or useful websites (see resources, on page 35).

7. Get into helpful habits

Find what made a really useful change for you last week and then use it again this week.

8. Discover other ways to tackle negative thinking

You can find self-help resources to manage moods in most local libraries or explore the websites below.

9. Share your plans with people you trust and get their support

Remember that you are not alone. We all need support and encouragement from other people, so try not to feel bad about asking friends and family to help you.

ACTIVITY SIX:

Discuss resources and tools: Focus on what you have achieved, Self-compassion, consider the hand on heart technique

(<https://self-compassion.org/exercise-4-supportive-touch>),

Relaxation and Mindfulness (covered in week 4 – Footstep 5), Wellbeing apps such as:

www.england.nhs.uk/supporting-our-nhs-people/support-now/wellbeing-apps

www.nhs.uk/every-mind-matters

www.nhs.uk/every-mind-matters/mental-health-issues/low-mood

www.mind.org.uk/information-support/tips-for-everyday-living

ACTIVITY SEVEN:

Discuss Footstep 8 - Managing moods: Key ideas

FOOTSTEP 8 – MANAGING MOODS: KEY IDEAS



- It is normal to struggle with moods when you have persistent pain
- People who have learnt to manage their moods find it makes a big difference to their pain – and their lives
- Be kind and compassionate to yourself. Remember – it is “not your fault” that the pain refuses to go away
- There are many ways to lessen the stress or pressure you’re under. Discover which ones work best for you and then use them often
- Remember, you are not alone. Don’t be afraid to ask friends or family for help



Footstep 9: Nutrition

Eating well and having a normal-range weight will help you to build better health and cope well with pain.

Healthy eating

Being overweight affects at least 50% of people with pain.

Key tips from people with pain are:

Do not do yet another weight reduction diet.

It can make you feel low even thinking about it!

Medications for pain can lead to you putting weight on.

This is unhelpful and makes managing pain trickier. So, explore options including a medication review with your doctor or pharmacist.

Try and go Mediterranean.

Eat more healthy food like pasta, fish, lentils, chicken, vegetables and fruits as these help joints, muscles and nerves work better. Use olive oil as your main cooking oil as it is healthy oil. Explore more about these foods known as the Mediterranean diet, on www.nhs.uk/

Healthy eating doesn't just help you lose weight.

It also reduces your risk of heart disease, stroke, dementia, cancer, diabetes and constipation as well as depression and anxiety.

Low Vitamin D is linked to persistent pain.

It's sensible to take daily supplements as levels can often be low in people with pain. Sunlight helps your body produce Vitamin D but getting enough is difficult in winter or if you're indoors a lot.

(NHS guidance is available www.nhs.uk/conditions/vitamins-and-minerals/vitamin-d and recommends that adults should consider taking 10 micrograms of vitamin d throughout the year.)

Never skip breakfast, as breakfast helps the body be less stressed, tired – and painful!

Start with easy, small portions like two or three tablespoons of cereal or yoghurt or half a banana. People with pain who skip breakfast find eating very small portions is a good start to eating better. Fruit juices and water are healthy too and help reduce drinks with caffeine like coffee and tea.

Eat meals regularly with small portions if you are quite inactive

Snacks can be tempting but unhelpful for managing weight and pain!

ACTIVITY EIGHT:

Discuss 5 a day/eat well guide (on page 37), services for weight management, more support at www.nhs.uk/live-well
What ideas can you share?

Eatwell Guide

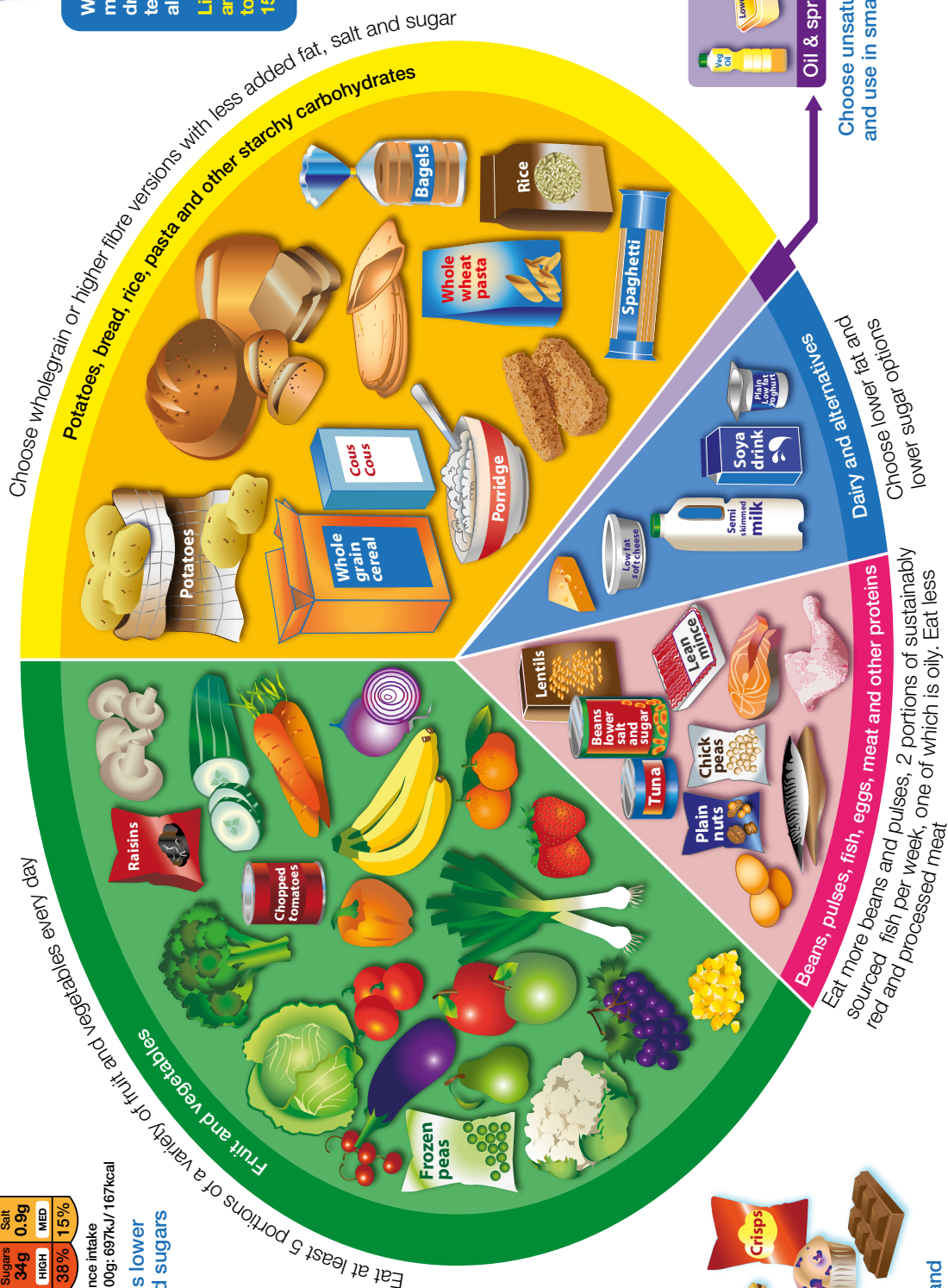
Check the label on packaged foods

Each serving (150g) contains					
Energy	Saturated	Sugars	Salt		
1048kJ	3.0g	1.3g	34g	0.9g	
250kcal	LOW	LOW	HIGH	MED	
13%	4%	7%	38%	15%	

Typical values (as sold) per 100g: 697kJ/167kcal of an adult's reference intake

Choose foods lower in fat, salt and sugars

Use the Eatwell Guide to help you get a balance of healthier and more sustainable food. It shows how much of what you eat overall should come from each food group.



Eat less often and in small amounts

Per day 2000kcal 2500kcal = ALL FOOD + ALL DRINKS



Week 6:

Managing setbacks and next steps

AT THE START OF THE SESSION:

- Check in with everyone from previous week
- Re-share the agreed ground rules for the group.



Footstep 10: Managing setbacks

Setbacks are very common in managing pain. Being confident to deal with them is a 'must have' skill for an easier time.

Setbacks can be due to many reasons – think of them a bit like what can happen to athletes in training. For athletes, a setback can be due to injury, tiredness or mental challenges. A setback with pain is similar and is often linked to tiredness, pacing difficulties or mood issues.

Sometimes a setback could be caused by changes in your medication – and sometimes for no obvious reason at all.

So, let's look at how to deal with setbacks effectively.

Managing setbacks with a setback plan

To cope better with setbacks and reduce the stress, panic or low mood that they sometimes cause, it is helpful to have a setback plan.

Thinking about a setback plan now means you'll be more prepared for when a setback happens.

Here are some ideas for things to include in your setback plan:

1. Ease back, easy does it

Cut back on normal activities for some days. **Take more, small regular breaks** in the day, lie or sit down and unwind the body using relaxation breathing.

Bed rest weakens muscle strength rapidly. You lose about 1% of total muscle strength each day if you totally rest up. So, **keep gently active** and moving to speed recovery and shorten setbacks.

Be kind to yourself. Say 'NO' to any big, stressful or unhelpful demands until you feel stronger and confident.

Don't be too proud or scared to **ask for help from others**, support helps in setbacks!

2. Pace more and keep active

Remember to pace yourself even more. Begin gentle stretching and movement as soon as possible to regain flexibility. Start on the same day as the setback if possible! Your body will work with you if you take it gently, steadily and move often.

Build up the time you spend stretching and moving. Keeping active may seem alien but don't be put off as it really does work!

3. Relaxation

Practice relaxation or mindfulness breathing (from week 5).

Do things to soothe and calm you – it could be listening to music, knitting, doodling, stroking the cat or dog – whatever works for you.

4. Refocus your thinking

Tackle your thoughts. Try not to think of the setback as the 'worst thing that can happen'. This puts your mind and the pain into a negative spiral of thought and moods.

Accept that you have a setback and that now is the time for the setback plan. Share with yourself that "just as it came, it will settle more easily. I now have a plan to help me get back on track". (Refer to the tools discussed under acceptance).

ACTIVITY ONE:

Share the Managing setbacks leaflet and discuss your plans for avoiding setbacks

<https://livewellwithpain.co.uk/ten-footsteps-programme/managing-setbacks>

ACTIVITY TWO:

Discuss Footsteps 10 - Managing setbacks: Key ideas (Appendix C)

FOOTSTEPS 10 - MANAGING SETBACKS: KEY IDEAS



- People with pain experience setbacks for many reasons – and sometimes for no obvious reason at all
- Having a setback plan ready can help you get back on track sooner
- Cutting back on activity – but still being gently active – is the key
- Using your pacing skills is more important than ever during a setback
- Remember to be kind to yourself and that "it will pass"



ACTIVITY THREE:

Question: Would you like to recap on any topics from the course?

NEXT STEPS



Introduce the social prescriber.

Ask the attendees to complete a Health and Well Being Check tool. Ensure that paper copies are available (Appendix A).

Question: Have the responses changed since week one and how?

**Discussion (group or individual):
What support is needed now the course is coming to end?**

Share information about local community groups/leaflets/peer groups.

Explore whether the group wish to keep in touch with each other after the course and how will that happen.

This is also a useful opportunity to identify attendees who may be able to support future cohorts attending the programs by sharing their lived experience.

Remind attendees that they can have a medication review if they would like one and what the process will be if they are going to be invited.

Final reflection and request for feedback on the course. Ensure all attendees have been signposted to support or have follow-up planned as appropriate.

Thank people for attending.

Appendices

Appendix A. Live Well with Pain Health and Well Being Check tool

Live Well with Pain Health and Well Being Check

Exploring how pain affects your health and life

Please help us understand about your health and the main obstacles to improving your quality of life and self managing with confidence.

There are **four steps** to completing this Health and Well Being Check. Please complete all four steps – tick or circle all the answers that apply to you.

STEP 1 How do you feel?

For each statement please circle which is closest to how you have been feeling over the past two weeks

	all of the time	most of the time	more than half the time	less than half the time	some of the time	at no time
I have felt cheerful and in good spirits	5	4	3	2	1	0
I have felt calm and relaxed	5	4	3	2	1	0
I have felt active and vigorous	5	4	3	2	1	0
I woke up feeling fresh and rested	5	4	3	2	1	0
My daily life has been filled with things that interest me	5	4	3	2	1	0

STEP 2**Tell us a bit about your pain****Your current level of pain**

Circle one of the numbers on the scale to rate your pain level at present.

0 = 'No pain' 10 = 'Worst/extreme pain'

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

Your pain over the last seven days

Circle the number on the scale to rate **how distressing** the pain was on average over the last seven days.

0 = 'No distress' 10 = 'Extremely distressing'

0	1	2	3	4	5	6	7	8	9	10
---	---	---	---	---	---	---	---	---	---	----

Managing your pain

Please rate **how confident you are** that you can do the following things at present, despite the pain. Circle one of the numbers on each of the scales.

0 = 'Not at all confident' 6 = 'Completely confident'

"I can live a normal lifestyle, despite the pain"

0	1	2	3	4	5	6
---	---	---	---	---	---	---

"I can do some form of work, despite the pain"

0	1	2	3	4	5	6
---	---	---	---	---	---	---

(work includes housework, paid and unpaid work)

STEP 3**Do you have any problems or difficulties with:**

- | | | |
|----|---|--------------------------|
| 1 | Walking or moving about, lack of fitness and stamina | ☐ |
| 2 | Balance or recurrent falls | ☐ |
| 3 | Side effects or problems with current pain medication e.g. tablets etc. | ☐ |
| 4 | Pain relief | ☐ |
| 5 | Understanding why persistent pain occurs | ☐ |
| 6 | An unhelpful pattern of activity of doing too much, getting more pain, then doing too little | ☐ |
| 7 | Eating the right sort of foods, weight changes | ☐ |
| 8 | Disturbed sleep, tiredness or lack of energy | ☐ |
| 9 | Managing mood changes of depression, anger, anxiety or worry | ☐ |
| 10 | Relationship difficulties: with partner, family etc, or sex life concerns | ☐ |
| 11 | Remaining in work or returning to work and/or training | ☐ |
| 12 | Financial or money difficulties | ☐ |
| 13 | Other difficulties (for example, concerns about housing, leisure or social events, drinking, gambling or drug use). Please describe here: | ☐ |

STEP 4

**If you ticked more than three boxes above,
please circle the three most important ones to change.**

Have you completed all four steps?

Please have the completed form with you at your **pain management and medicines review**.

We will look at it together to help explore your concerns, issues and problems linked to your pain.

Thank you for helping us understand how your pain is affecting your health and life.

Your name

Your date of birth

Date filled in

Appendix B. Iceberg Analogy

- Ask the patient to circle three things that they would like to change now (they can also add any other issues that aren't listed on the poster).
- Explore different ways that they could deal with these issues.
- They can then take the poster away with them to help remind them of what they plan to tackle.

A poster illustrating the Iceberg Analogy for persistent pain. It features a large iceberg floating in the ocean. The tip of the iceberg, which is visible above the water, is labeled 'Persistent pain'. The much larger, submerged part of the iceberg represents the hidden impacts of pain. To the right of the submerged part, a list of impacts is provided. At the bottom left, the 'LiveWell with pain' logo and website are displayed. At the bottom right, there is a small copyright notice.

Persistent pain

Its impact:

- Sleep problems**
- Loss of fitness**
- Money worries**
- Medication side effects**
- Feeling low**
- Stress + fear, anger, shame**
- Grief and loss**
- Relationship worries**

Circle three areas that need to change now
To find out more about how to change these areas, explore options with your clinician

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Appendix C. Key take home ideas

(n.b. the key ideas for footstep 9 relate to medicines, and as this topic will be covered by a clinician they have not been included here)

Footstep 1 - Pain and the Brain: Key Ideas

- Persistent pain is different from the kind of pain you experience when you injure yourself
- It goes on long after the original damage has healed – it's as if the brain can no longer 'turn down the volume'
- Reducing persistent pain involves retraining your brain
- Learning self management skills so you can live your life despite the pain are the best way to 'turn down the pain'

Footstep 2 - Acceptance: Key Ideas

- Acceptance is an ongoing journey of change, that takes time
- People who accept their persistent pain find that it has less impact on their day to day lives
- Acceptance is not about giving in, but changing your focus towards what you want to do with your life
- Many people use mindfulness to manage their pain more successfully

Footstep 3 - Pacing: Key Ideas

- Pacing is one of the key self management skills for people living with persistent pain
- It can help you achieve your goals without increasing your pain
- There are both helpful and unhelpful styles of pacing
- Changing your pacing style could bring many benefits and lessen your pain

Footstep 4 - Goal setting: Key Ideas

- Having goals helps you to focus on the things that matter most to you
- Developing goal setting skills will increase your ability to achieve your goals
- Using SMART goals will give you a better idea of how to go about achieving them. And you'll be far more likely to get there!
- Writing down your SMART goals and your weekly steps towards them will help keep you on track (try using the handy resources above).
- Don't forget to build in some rewards!

Footstep 5 - Relaxation and mindfulness: Key Ideas

- Mindfulness and relaxation can lessen pain levels, reduce stress and improve concentration
- Learning relaxation skills can be easier than you expect
- Mindfulness helps in many ways, such as improving memory or attention so you can focus and concentrate better

Footstep 6 - Sleep: Key Ideas

- Lots of people with pain have difficulties sleeping, but recent research has shown that sleeping well with pain is possible
- Making some changes to what you do during the day will help you sleep better
- Regular physical activity will help improve your sleep
- Your food and drink choices will have an impact too
- Getting into a regular night-time routine is important
- Making sure that your bedroom is 'fit for sleep' can make a big difference

Footstep 7 - Communication: Key Ideas

- When life is dominated by pain, the art of everyday conversation can get lost – so it's important to avoid some common communication traps.
- Other people can't see the invisible effects of pain. So talk to them about ways they can support your goals or help you live better with the pain.
- Assertiveness is a key skill for talking to other people about your pain.
- Plan what you want from meeting your health care professionals – and you'll get more out of it.

Footstep 8 - Managing moods: Key Ideas

- It is normal to struggle with moods when you have persistent pain
- People who have learnt to manage their moods find it makes a big difference to their pain – and their lives
- Be kind and compassionate to yourself. Remember – it is "not your fault" that the pain refuses to go away
- There are many ways to lessen the stress or pressure you're under. Discover which ones work best for you and then use them often
- Remember, you are not alone. Don't be afraid to ask friends or family for help

Footsteps 10 - Managing setbacks: Key Ideas

- People with pain experience setbacks for many reasons – and sometimes for no obvious reason at all
- Having a setback plan ready can help you get back on track sooner
- Cutting back on activity – but still being gently active – is the key
- Using your pacing skills is more important than ever during a setback
- Remember to be kind to yourself and that "it will pass"

Appendix D. Self-Compassion activity

Reference: <https://self-compassion.org/exercise-4-supportive-touch>

Supportive Touch

One easy way to care for and comfort yourself when you're feeling badly is to give yourself supportive touch. Touch activates the care system and the parasympathetic nervous system to help us calm down and feel safe. It may feel awkward or embarrassing at first, but your body doesn't know that. It just responds to the physical gesture of warmth and care, just as a baby responds to being cuddled in its mother's arms. Our skin is an incredibly sensitive organ. Research indicates that physical touch releases oxytocin, provides a sense of security, soothes distressing emotions, and calms cardiovascular stress. So why not try it?

You might like to try putting your hand on your body during difficult periods several times a day for a period of at least a week.

Hand-on-Heart

- When you notice you're under stress, take 2-3 deep, satisfying breaths.
- Gently place your hand over your heart, feeling the gentle pressure and warmth of your hand. If you wish, place both hands on your chest, noticing the difference between one and two hands.
- Feel the touch of your hand on your chest. If you wish, you could make small circles with your hand on your chest.
- Feel the natural rising and falling of your chest as you breathe in and as you breathe out.
- Linger with the feeling for as long as you like.

Appendix E. Spoon theory

www.knowpain.co.uk/wp-content/uploads/2018/11/Using-Spoon-Theory-to-Explain-Chronic-Illness.pdf

Appendix F. Activity diary

My activity diary

Use this in conjunction with *Pacing – a really useful skill for people with pain*, from Live Well with Pain



Time	Activity	How many minutes did you do?
8am	Shower Got dressed Made me and Anne some breakfast	10 5 20
9am	Washed the dishes and tidied the kitchen	25
10am	Sat with Anne, had a coffee and a chat Sat in kitchen and wrote a shopping list	45 15

Appendix G. Daily pacing plan

My daily pacing plan

Use this in conjunction with *Pacing – a really useful skill for people with pain*, from Live Well with Pain



Activity	On a good day	On a bad day	On an average day	Number of times per day	Effort scale level (0-10)
Standing and cooking	10 mins	5 mins	7 mins	5	6
Lying down for a rest	15 mins	60 mins	25 mins	2	1
Walking	5 mins	2 mins	3 mins	3	5-7

Appendix H. Physical Activity resources

- [NHS Live Well - gentle exercises](http://www.nhs.uk/live-well/exercise/sitting-exercises)
www.nhs.uk/live-well/exercise/sitting-exercises
- [NHS Fitness Studio](http://www.nhs.uk/conditions/nhs-fitness-studio)
www.nhs.uk/conditions/nhs-fitness-studio
Needing more ways to being or staying active?
Explore *NHS Choices Fitness Studio* online
for exercise videos and learn yoga, tai chi
and pilates at your own pace at home.
- [15 reasons to exercise](http://www.paintoolkit.org/pain-tools/exercising#main-pain-tools)
www.paintoolkit.org/pain-tools/exercising#main-pain-tools
Pain Toolkit – exercising *Pain Toolkit*
website has 15 reasons why stretching
and exercising is good for you...

My goal ladder

Use this in conjunction with Reaching goals and creating rewards -
a guide to SMART goal setting from *Live Well with Pain*

My goal is:

My SMART goal at the end of 4 weeks is to:

	Steps on the way to reaching my goal	Things that will help my progress	Things that might block my progress
Week 4			
Week 3			
Week 2			
Week 1			
START - Week 1			

Goal setting

Goal(s)

Day/Date	Goal Achieved?	Problems Identified	Plan
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

How to Sleep well with pain



If you're living with pain and struggling with sleep then you're not alone. It's very common for people with persistent pain to have difficulties getting to sleep or staying asleep.

Why can't I sleep?

It's likely that there are a number of causes of your sleep difficulties. Here are six triggers often found by people living with pain:



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A vicious cycle

You have probably discovered that poor sleep can have some unhelpful effects on your day-to-day life.

After a broken night's sleep you may find:

- it's harder to concentrate
- you are short tempered with other people
- your mood is low

It's very common for people to find that poor sleep makes their pain seem worse. They can find themselves in a vicious cycle where pain makes sleeping difficult, and poor sleep worsens pain.

The really good news is that there are lots of ways to improve your sleep.

The good news

Thanks to recent research, we now know that sleeping well with pain is possible, with a different approach and maybe a few new skills.

Over the next few pages we will share with you some ideas and techniques that other people living with pain have found helpful. We're going to look at **five areas** of your life and suggest some simple changes that you can make to your activities and routines.

Some things you can try out straight away; others may need a bit more thought and planning. So we're also going to show you how to set some **sleep well goals** and then create a plan so that you can get going.

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Appendix K. Relaxation and mindfulness resources

- Mindfulness on Soundcloud

Listen to free mindfulness audio meditations on the [Breathworks Soundcloud](https://soundcloud.com/breathworks-mindfulness) (<https://soundcloud.com/breathworks-mindfulness>) page.

Listen to the audio meditations

- Mindfulness self-compassion. For a *mindfulness self-compassion* approach to pain and life struggles try these two trusted and useful sources:
 - self-compassion.org
 - centerformsc.org
- **Meditation for sleep**

The *Headspace* website has hundreds of articles for any mind, any mood, any goal, including lots on sleep. Try this audio 'meditation for sleep' and read more about the benefits of sleep meditation.

Listen to the meditation for sleep (<https://www.headspace.com/meditation/sleep>)



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