



Understanding Persistent Pain & My Pain Management Journey



To accompany this booklet, why not take a look at Flippin' Pain's website - filled with patient stories, resources, mythbusting and FAQs that you may find helpful in your journey: www.flippinpain.co.uk

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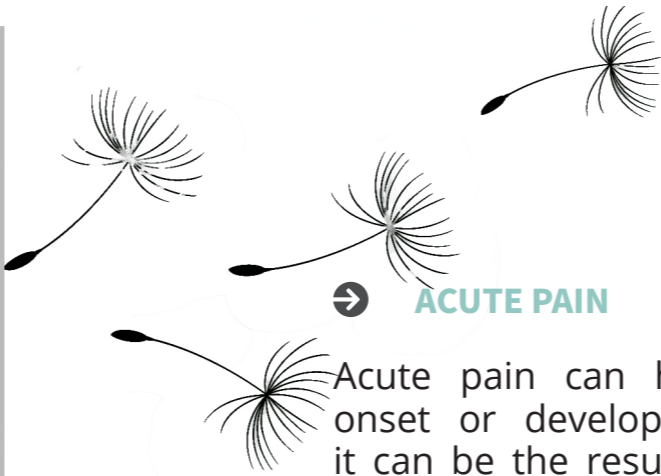
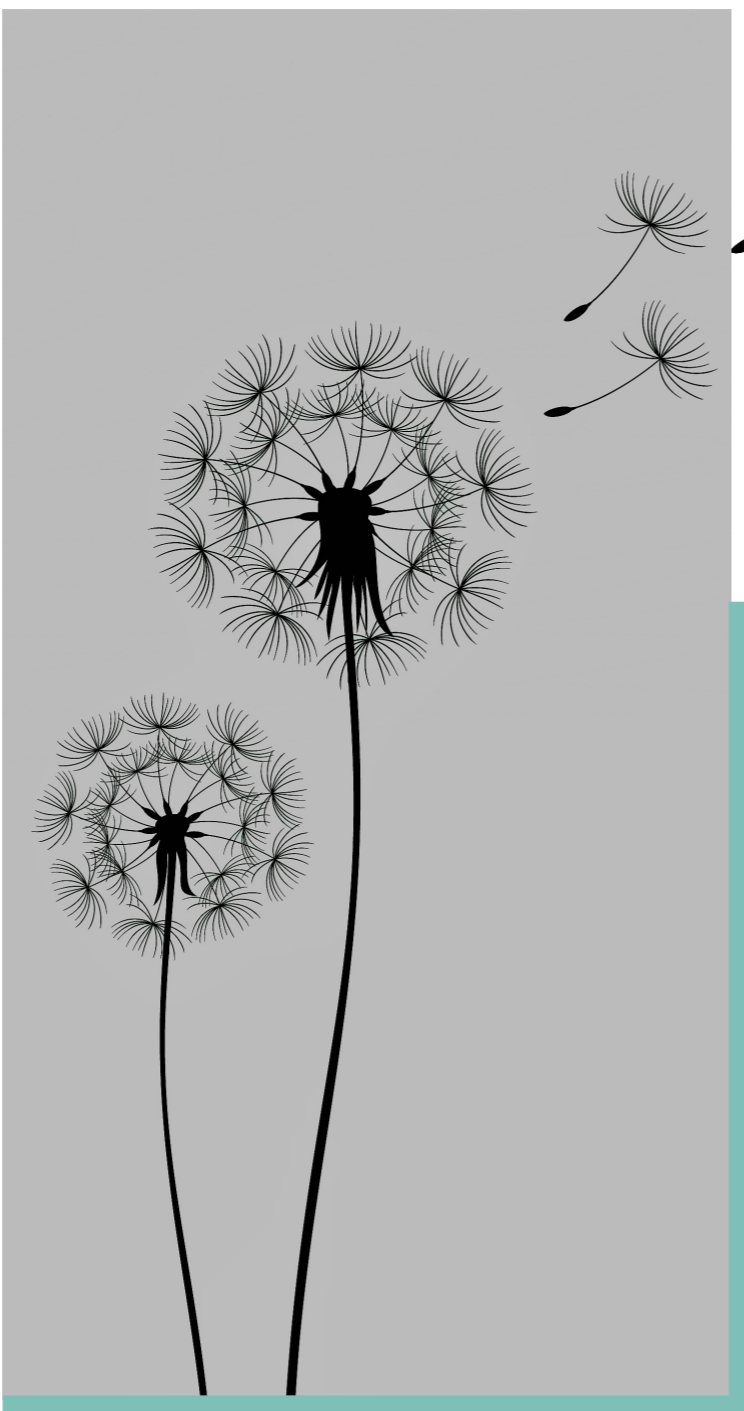
FOREWORD

This handbook is designed to help you understand and manage persistent pain. It is a tool to support anyone being referred to a pain management service.

It may also help you to continue doing the things that you enjoy, or need to do, improve your quality of life and help you with how you feel. It will provide links to other resources and services as well as give you ideas about how to self-manage and live with persistent pain.



01



➔ ACUTE PAIN

Acute pain can have a sudden onset or develop gradually and it can be the result of injury or a medical condition. It is useful as, although unpleasant, it protects us from hurting ourselves. It makes us stop using a hurt part of our body, so we have time to heal. It typically goes away within a few hours, days or weeks. Symptoms can often be treated with pain medication.



People can experience both acute and chronic pain

Dr Wendy Holden, Arthritis Action Medical Advisor



➔ PERSISTENT PAIN

Persistent (or chronic) pain can form independently or be caused by various health problems, for example arthritis. Therefore, there isn't always an obvious cause or 'label' for this pain, which can be intermittent or constant, as there are often multiple contributory factors. Building yourself a strong toolkit can be effective in accepting and living with persistent pain. This guide will focus more on persistent pain, but a lot of the information contained here can be used to help either.

DID YOU KNOW?

You are not alone. Persistent pain effects over 43% of people living in the UK.

UNDERSTANDING PAIN

Pain is categorised as either **Acute pain** - pain that lasts less than twelve weeks, or **Persistent (also known as chronic) pain** - which is pain lasting more than twelve weeks.

Pain can be perceived as a warning of potential damage, but can also be present when no actual harm is being done to the body. Your system could be sounding an alarm, or it could become overprotective if it is perceiving damage for a long period of time.

Living with pain can be stressful and present itself in different ways. By engaging with good habits, and understanding what is going on, you can reduce the likelihood of it having an effect on your career, relationships and hobbies.

02

MANAGING YOUR PAIN



Retrain your pain! Your brain and nervous systems are very clever. They will learn and remember pain and they talk to each other about it, sending alarms and asking you to stop doing some activities and movements that they remember hurting last time. This is because they want to protect you from experiencing further injury and allow for your recovery. But sometimes, they can become too good at their job and their alarms no longer benefit your recovery, instead affecting how you move and how you use your body longer term. **It is important to note, that this is not 'all in your head'.** It is your system responding too well to a perceived threat. However, if that threat is no longer present, it is time to learn again and influence your brain and nerves to become less sensitive about their worry. Through good exercise, healthy eating and having the right support, you can learn to continue doing more of the things you enjoy again and not allow the pain to rule your actions.



To further understand and overcome your chronic pain, take a look at the below website from 'Retrain Pain Foundation'
www.retrainpain.org

A, B, C, D

ACCEPTANCE

Pain could be something you live with for a while. **Acceptance** is important if you want to control your pain and the impact of pain on your life. Be kind to yourself and your body. Worrying about your pain could affect your **mental health** and your **sleep**, both of which are important to help manage pain.

BODY & MIND

The **body and mind** love movement and gradually becoming more active is essential for treating and managing chronic pain. It is important to **pace** yourself when you are increasing physical activity.

CALM

Try to find ways by which you can reduce the negative impact of stressful situations and times of tension on you. Can a frustrating task be broken into smaller chunks? Can you find a space to re-centre or unwind after a moment of stress to do something you enjoy?

DISCIPLINE

You need to continue focusing on the things most important to you. Understandably, pain and how to relieve it can often become the **focus** in your life. Doing things you enjoy can help you to keep things in perspective. Focusing on what you're thankful for and what you are able to do can help you keep a positive attitude even when you are in pain.

Speaking to a healthcare professional

Don't suffer in silence! The understanding of pain and of how to manage pain is better now than it has ever been. It is always a good idea to start by talking with someone (for example your GP) who can arrange all appropriate screenings and investigations, so that once excluded, your focus and efforts can be entirely aimed in the right place. Healthcare professionals can also give you good advice, refer you to appropriate help and services, and discuss skills to manage your pain and recovery.

‘SLEEP HYGIENE’

Sleep is an essential part of feeling well and feeling happy, but almost everyone experiences problems sleeping at some time of their life. People with long-term pain are more likely to have problems with sleep. Lack of sleep robs you of needed rest, making management of your illness more difficult. Bringing sleep patterns under control is important - you need your rest. However it often takes some time (several weeks) to get problematic sleep under control. Sleep problems are often known as ‘insomnia’.

Sleep onset insomnia is trouble falling asleep.

Sleep maintenance insomnia is trouble staying asleep, especially in the second half of the night.

An important factor in sleep onset insomnia is having a lot on your mind, so focusing on relaxation and learning how to manage thoughts and feelings can help.

For both types of insomnia, paying attention to good **sleep hygiene** is a first step you can take towards establishing good sleep.

DID YOU KNOW?

There is good evidence that a more natural sleep pattern (and one our pre-electricity ancestors had) was ‘bi-phasic’ - The night time sleep was not one long period of sleep but was split into two, with an hour or so of night-time wakefulness between them. One theory is that when we try to suppress the normal mid-night waking period, it may lead to fragmented sleep through a longer section of the night. In other words, for some people, sleep maintenance insomnia may not be ‘true’ insomnia, but be their body’s attempt to sleep in a bi-phasic pattern.

DO:

- Go to bed and get up at the same time each day.
- Get regular exercise each day, preferably in the morning (there is good evidence that regular exercise improves restful sleep).
- Get regular exposure to outdoor or bright lights, especially in the late afternoon.
- Keep the temperature in your bedroom comfortable to keep your feet and hands warm. Wear warm socks and / or mittens or gloves to bed.
- Keep the bedroom dark enough to facilitate sleep.
- Keep the bedroom quiet - try thicker curtains, sleeping at the back of the house, or even use ear plugs, to avoid being woken by noise.
- Try to avoid using your bed for daily activities e.g. watching TV or working from a laptop etc.
- Use a relaxation exercise or tape just before going to sleep.
- Try muscle relaxation to help distress and unwind, e.g. a warm bath or a massage.
- If you lie in bed awake for more than 15 minutes, get up, go to a different room (or a different part of the bedroom), participate in a quiet activity (e.g. non-excitable reading or television), then return to bed when you feel sleepy. Do this as many times during the night as needed.

DON'T:

- Exercise just before going to bed.
- Engage in stimulating activity just before bed, such as playing computer games, watching an exciting program on television, or having an important discussion with a loved one.
- Have caffeine in the evening (coffee, teas, chocolate etc.)
- Have alcohol in the evening or use alcohol to sleep (it may make you drowsy but it doesn’t improve sleep and you will wake up to go to the toilet)
- Smoke before going to bed - nicotine is a stimulant and will keep you awake.
- Read or watch television in bed.
- Go to bed too hungry or too full.
- Take another person’s sleeping pills.
- Take daytime naps or doze off in front of the TV in the evening - keep yourself awake with something stimulating or you risk resetting your body clock.
- Command yourself to go to sleep. This only makes your mind more alert.

PLEASE
DO NOT
DISTURB

WHAT CAN A PAIN MANAGEMENT TEAM DO FOR ME?

Part of your journey may involve being referred to a pain management interdisciplinary team. This means seeing a team made up of different professionals who work jointly to make sure that their expertise comes together to meet your needs.

THE ROLE OF A PSYCHOLOGIST

The role of the psychologists is to work with you to reduce psychological distress and promote psychological well-being. Psychologists work with people with emotional and physical health problems.

You probably already know that being in pain does not just affect you physically, but can make you feel stressed, frustrated, anxious and down. Many people find that pain leads to strained family and social relationships.

However, you do not need to be feeling stressed or low to get something out of psychology. A psychological approach might involve looking at the ways you cope with pain and finding ways to improve them.

Whatever the nature or cause of your pain, speaking to a psychologist can help you to find ways of coping with these problems and so can mean you feel less distressed about pain.

THE ROLE OF AN OCCUPATIONAL THERAPIST

Occupational therapists focus on what people 'do'. On the activities that occupy us. That might include your job if you're working, getting washed and dressed, hobbies, doing housework, social activities, and so on.

Occupational therapists help you to deal with the issues that get in the way of you being able to do what is important to you. This might include activities that allow you to care for yourself and your family, and activities that give you satisfaction, enjoyment and a sense of purpose.



Sussex MSK Partnership East work with two providers offering pain management services. Find out more about each by visiting their websites -

Sussex Partnership NHS Foundation Trust:

www.sussexpartnership.nhs.uk

Connect Health:

www.connecthealth.co.uk/connect-health-pain-services

THE ROLE OF A PHYSIOTHERAPIST

Some people tell us they have seen a physiotherapist in the past, which did not help as it was too painful or difficult. Physiotherapy within the persistent pain service is different from general outpatient physiotherapy; The approach is less 'hands on' and more focused on helping you gradually and gently build up your strength, mobility and fitness, without causing flare-ups in pain.

Our physiotherapists use a variety of methods to help you get moving confidently and to exercise effectively and independently in everyday life. Physiotherapists working in the pain team will work with you to make sure you have a clear understanding of how your body works and of how pain and movement relate to each other. Keeping physically active is essential to keep your muscles and joints healthy, which has a positive impact on pain in the long term.

THE ROLE OF A NURSE SPECIALIST OR PAIN CONSULTANT

The medical team (nurse specialists and pain consultants) work with you to identify what is causing your pain, although it is important to bear in mind that this is not always possible.

Their aim is that you feel confident in, and have as clear an understanding as possible of, the factors involved in your pain. They can help you rationalise your pain medication and look at other appropriate interventions. Feel free to go to these appointments armed with questions and any concerns you may have.

03

EXERCISE



If you have ongoing pain, fear of increasing the pain or doing more damage means that you may avoid exercise or moving altogether. This is called 'avoidance'.

But, the body and mind **love** movement and gradually becoming more active is essential for treating and managing chronic pain.

However, don't overdo it either! Find a good balance for you. Doing too much puts you in danger of succumbing to 'Boom or Bust' which is where you go too hard too quickly and then give up.

The exercises in this section may not be suitable for everyone, so always adhere to any medical or physiotherapy advice previously given. **With any exercise it is important not to push through the pain, only go as far as you can with each movement.**

BENEFITS

Exercise gets us fit.

Some of the benefits of exercise include: the joints become lubricated and glide easier; some structures including the nerves and the discs of the spine need movement to get their nutrients and to be healthy; the muscles get stronger and don't fatigue as easily; the nervous system winds down promoting relaxation; reduced flare-ups and improves mood.

Most importantly, your body produces its own pain relieving medication (e.g. endorphins) that work like the pain medication doctors prescribe. After a bout of exercise your pain tolerance increases, things hurt less, and this can last for up to an hour depending on the exercise.

CARDIOVASCULAR

Your ability to take in and for your body to use Oxygen.

Cardiovascular exercises improve how your heart, lungs and circulation work.

MUSCULAR

Your muscular fitness is broken down into four main areas.

Motor: Your co-ordination and reaction time.

Strength: The force or power you can use.

Flexibility: Finding achievable range of motion at a joint or group of joints without causing injury.

Endurance: Usually the more you exercise the longer you will be able to do so. It's important to pace yourself and gradually increase what you do, if it isn't making the pain worse.

MENTAL HEALTH

Wellbeing

If your mental wellbeing is suffering then exercise can help with depression and anxiety.



SIMPLE EXERCISES

Stand tall and stretch upwards several times a day. As you feel stronger, you can increase repetitions of these exercises.

REMINDER



STRETCH AND LEAN

Place both hands above your head, lean to the right and hold for 10 seconds. Then lean to the left and hold for 10 seconds.

Find yourself a comfortable space and get yourself an upright chair. Take three deep breaths.

ARM RAISE

Lift one hand over your head, hold for 10 seconds. Repeat with the opposite hand.



SHOULDER ROLL

Relax your shoulders.

Place your hands on your shoulders and roll them forward 10 times, then backwards 10 times.



ELBOW PRESS

Keeping your shoulders relaxed, with your hands together, move your elbows together 10 times.



STRAIGHT BACK LEAN

Place your hands on your thighs, keep your back straight and lean forward and back 10 times.



KNEE TOUCH

Touch your hand to opposite knee. Hold for 10 seconds, repeat with opposite hand.



TOE RAISE

Place your feet flat on the floor.

Then point your toes up towards the ceiling. Repeat 10 times.



KNEE RAISE

Lift up your knees one at a time. Repeat 10 times. Repeat with opposite foot.

Stamp your feet and wiggle your toes.



Cool down by taking three deep breaths.



WATCH 'Mindful Movements', created by our own Pain Management Team, following the link below to YouTube
<https://youtu.be/c5oOv2lOIHs>



PRACTICAL STRATEGIES TO HELP MANAGE ACTIVITY

PACING

Pacing involves regularly changing your position, breaking activities into smaller more manageable parts, using small frequent periods of rest, changing or stopping activity before pain makes you stop.



For more information about pacing, activity sheets and tips, see the following website:

<https://my.livewellwithpain.co.uk/resources/self-management/pacing>

GRADING

Means changing how you do an activity to reduce its impact on you. E.g. sitting down to iron, using a stool to do the washing up, using a supportive chair when using a computer.

DELEGATING

Involves asking someone else to do a task instead of you. E.g. asking family members to stack the dishwasher, hang out laundry, make telephone calls about bills. It works better if carried out on a regular basis. Try not to expect anyone to be able to do a new task straight away – they may need 'training'.

ORGANISING

Involves thinking ahead before doing a task. Plan out your week to try and balance out demands and your resources (energy levels), planning in structured rest periods, relaxation and pleasurable things. It can be helpful to use a diary / calendar.

PRIORITISING

Look at all your daily tasks. Is there anything you can stop or is non-essential? Consider what is important to you. This is the time to put yourself first.



MIX & MATCH

Try and mix up different tasks – a mental activity followed by a physical / social activity / pleasurable activity followed by a rest / relaxation period.

04



Relaxation and Mindfulness practises help me cope with the stress of living with pain. They are part of my everyday life now, though it took some practice and time to work out what suits me best.

Ruth, Service User

RELAXATION AND MINDFULNESS

RELAXATION

Relaxation practises can help you reduce physical tension and manage stress. As well as carrying out these practises when you're feeling tense, it is a good idea to make them part of your daily routine, to help prevent the build-up of stress and tension.

➔ PREPARATION

Find a quiet space preferably where you will not be disturbed.
Lie down or sit comfortably with your legs uncrossed.
Lightly close your eyes, or focus on a spot in front of you.
Focus on your breath. Thoughts may pop into your mind, and this is normal, just let them pass through and bring your attention back to your breath.

➔ BREATHING EXERCISE

Place one hand on your chest and the other over your stomach. You want your stomach to move more than your chest as you breathe.
Take slow, regular breaths in (through your nose if you can).
Breathe out slowly through pursed lips. Repeat this 10 times.



➔ VISUALISATION EXERCISE

Create in your mind an ideal spot to relax. This can be real or imaginary. Somewhere you find restful, calming, safe and happy. Somewhere you would want to return to when you need to relax.
Imagine it in as much detail as you can, using all your senses.
Close your eyes and take slow, regular breaths in (through your nose if you can). Become aware of your breathing while focusing on your relaxation place. Do this for 10-20 minutes.

➔ MUSCLE RELAXATION EXERCISE

Make sure you are sitting comfortably.
Close your eyes and concentrate on your breathing.
Make a fist, squeezing your hand tightly. Hold for a few seconds, noticing the tension. Slowly open your fingers and notice the difference between your muscles when they are tense and when they are relaxed.

If you have any physical injuries or conditions that may cause muscle pain, don't tense the muscle in that area.

➔ AFTER RELAXATION

Don't rush to get up. Sit with your eyes closed for a few minutes to avoid the possibility of feeling dizzy. Open your eyes and make sure you feel alright before standing.

Try not to judge yourself on how you did as mindfulness is something that takes practice, and the benefits may not be felt immediately.

MINDFULNESS

Mindfulness is a way of paying attention to your mind, in the present moment and with self-compassion, without getting caught up in thoughts. It is not the same as relaxation, though many people do find mindfulness helpful in managing stress and tension.

People can find that mindfulness helps them to feel calmer and kinder towards themselves. Mindfulness consists of a number of techniques that:

1. Get us to experience our sensations in a non-judgemental way.
2. Change how we view and label our difficult experiences so that our relationship with them changes and they are no longer experienced as 'the problem'.
3. Allow us to be in the 'here and now' and not worry about the future or regret the past.



WATCH the below 'Three Minute Breathing Space' exercise in action from Mindful, on YouTube

<https://youtu.be/amX1luYFv8A>

THREE MINUTE BREATHING SPACE EXERCISE

Find a comfortable, upright position, and either close your eyes or focus on a spot in front of you.

Take a deep breath to bring yourself into the present moment (pause), just noticing whatever you are experiencing right now.

Notice any sensations, be they of discomfort or tension.

Notice your feet on the ground, or, if you're sitting, notice whatever you are sitting on; notice your clothes against your body and the air against your skin. (Pause for five seconds).

Notice whatever is in your mind. Whatever thoughts are here, and as best you can, just observe your thoughts as they are in your mind right now (pause for five seconds).

Notice whatever you are feeling emotionally. Don't try to change it, but just notice how you are feeling (pause for five seconds).

And now, bring your attention to your breath, just noticing the rise and fall of your stomach as you breathe in (pause), and as you breathe out (pause for five seconds).

Notice the cool air flowing in through your nose as you inhale and the warm air as you exhale (pause), as you breathe in and out (pause).

If you find your mind wandering away from your breath, simply bring it back to noticing each breath in, and out, as they follow, one after the other (pause for five seconds).

Allow your awareness to expand to encompass your breath moving in your body (pause), bringing your awareness to your thinking (pause), and whatever you are feeling emotionally right now.

Gently broaden this awareness to notice the whole experience, holding everything in awareness (pause for five seconds).

Now bring your attention back to the room; open your eyes slowly if they are closed.

Notice what you can see; notice what you can hear.

Push your feet into the ground and have a stretch; notice yourself stretching. Welcome back!



MANAGING SET BACKS AND FLARE-UPS

When you are living with long term pain, progress is not a smooth line upwards. It is completely normal to have ups and downs.

When we use the term 'flare up', we are talking about an increase in symptoms which are more severe than the ups and downs that are part of 'normal' life with persistent pain. Although sometimes flare-ups are unavoidable, if you know what tends to trigger your flare-ups, and learn to notice the early warning signs of them, you can go some way to preventing them.

BE PREPARED

If you can't prevent a flare up, it helps to have a plan in place to help you cope with it. Although most people think of a flare-up in terms of physical symptoms, flare-ups also often bring with them difficult emotions, such as frustration, worry and sadness. Coping with a flare-up means thinking about your physical, practical, mental and emotional needs.

Your Flare-up Plan may include making preparations in advance so you have what you need to hand when the time comes. **Some people find it helpful to have a flare-up box** which means everything is in one place and is easy to find – no searching in cupboards when your pain is at its worst. As you read the following, think about what you might need in your flare-up box.

MANAGING ACTIVITIES DURING A FLARE-UP

Most people reduce how active they are during a flare-up. Resting can be very helpful but remember that spending more than a few days in bed or lying down is likely to prolong the flare up overall. If you do need some bed rest, start to get (gently!) moving after a couple of days. Remember to pace yourself and gradually build up your activity levels.

MEDICATION

It's best to talk to your GP or pain specialist about how to use medication during a flare-up and whether there are any additional medications that it would be suitable for you to take at these times.

Doing this IN ADVANCE of having a flare-up means you can start taking any additional medication as early as possible, and can avoid having to get to your GP during a flare-up.

DISTRACTION

Having nothing on your mind except the pain can make it feel more overwhelming. While distraction won't reduce your pain levels, it can help give you another focus. Distracting activities can also help with your mood – watching a favourite comedy or listening to music or a podcast that lifts your spirits, for example.

Most people find pain makes it hard to concentrate so bear this in mind when choosing distracting activities.

As it is important to regularly change the position your body is in, and to mix up resting and moving, it is a good idea to have a few things you can do, each for a little while.

SUPPORT

Having help with your practical needs – getting food, running a bath, helping you get dressed and so on – is important. Particularly if you live alone, letting people know (ideally in advance) what you might need during a flare up (and then asking for it!) can feel difficult but can make a big difference.

Emotional support is also important during a flare-up. Take a few moments to think about who you might find most helpful to talk to at that time. Could you let them know you'd welcome their support in a flare-up?

Some people can find it helpful to write themselves messages of support to look at when they need too – what do you think you need to hear when you are in the middle of a flare-up?

DON'T FORGET

Keep calm and breathe.
This flare up will pass.
Just deal with it moment by moment.
Be kind to yourself.
Don't forget to eat.

EATING WELL (AND TREATS)

During a flare-up, cooking can feel too much. Having food in the cupboard or freezer which is quick to prepare can make sure you eat nutritious food with minimum effort – soups and frozen meals, for example.

Many people put food treats in their flare-up boxes – a bar of chocolate or special box of biscuits. It is recommended having a treat or two in your flare-up box – treating yourself with kindness is an important part of managing a flare-up. We've heard of all kinds of treats – magazines, a new book, a scented candle, DVD... only you can decide on what would be right for you!

05

USEFUL RESOURCES

MY FLARE-UP PLAN:

BEING PREPARED - WHERE IS MY FLARE-UP BOX - WHAT DO I NEED IN MY FLARE-UP BOX:

ACTIVITY AND MEDICATION - DO I NEED TO REDUCE ACTIVITY - SETTING MYSELF TARGETS - DO I REQUIRE MEDICATION - MY MEDICATION PLAN:

SUPPORT - THESE PEOPLE WILL HELP ME WITH - I CAN CALL THIS PERSON IN A CRISIS:

MY TREATS - THINGS I WILL ENJOY - GOOD DISTRACTIONS:

OTHER THINGS TO THINK ABOUT - COMMITMENTS I WILL MAKE TO MYSELF DURING A FLARE-UP - EASY MEALS I CAN PREP - WHO ELSE NEEDS TO KNOW:

THINGS TO DISCUSS AT MY NEXT SESSION

WEBSITES & SIGNPOSTING

ADDITIONAL TO SERVICES SIGNPOSTED THROUGHOUT THIS DOCUMENT, LISTED BELOW ARE A SELECTION THAT MAY BE BENEFICIAL THROUGHOUT YOUR PAIN MANAGEMENT JOURNEY.



<https://livewellwithpain.co.uk>



www.flippinpain.co.uk



www.arthritisaction.org.uk



www.cftc.org.uk



<https://1space.eastsussex.gov.uk>



www.headspace.com



<https://healthinmind.org.uk>



<https://oneyoueastsussex.org.uk>



www.paintoolkit.org

Offers hands-on, practical help to combat the pain of arthritis through self-management and lifestyle advice. Offering people with arthritis a holistic self-management approach, looking at both the physical and mental aspects of arthritis. Also offers a membership.

Do you look after someone who couldn't manage without your help? CftC are here for you if you need free practical or emotional advice, information and support. There are also a variety of ways you can volunteer and support others.

An online directory bringing together groups and organisations that offer care, support and wellbeing services to people in East Sussex.

Through science-backed meditation and mindfulness tools, Headspace helps you create life-changing habits to support your mental health and find a healthier, happier you.

Offering free courses and therapy for people in East Sussex, to help with stress, anxiety and low mood, via self-referral.

Support to make simple changes towards a longer, happier life. Providing tools, motivational support and encouragement every step of the way, to help improve your health right away.

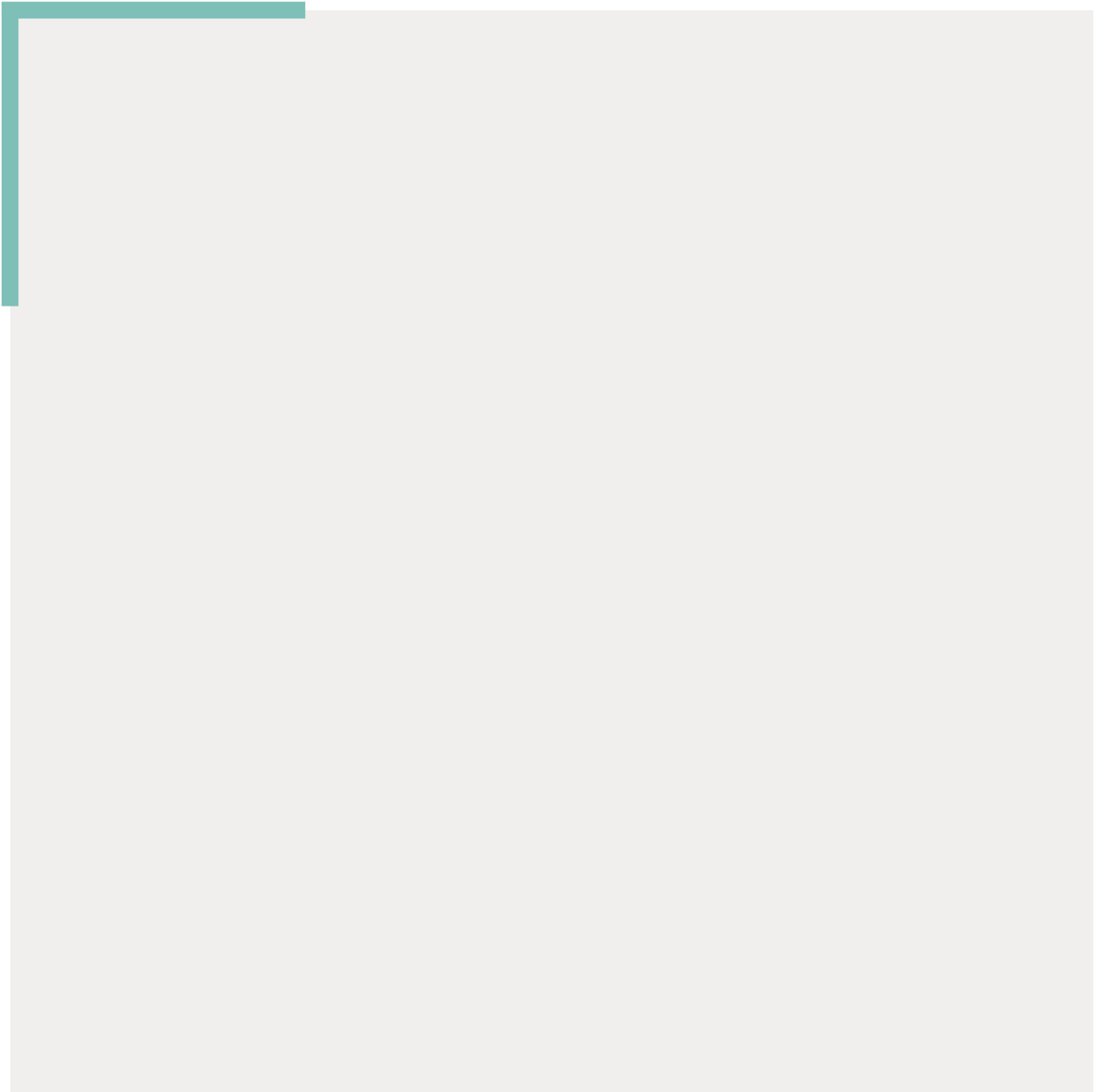
Pain self-management is about learning new (or using old) skills, trying them out to see what works. Pain is like a finger print, each person may need to find individual skills to suit them. This toolkit helps you find your fingerprint.



Sussex MSK Partnership East Resources Pages

www.sussexmskpartnershipeast.co.uk/resources-help-while-you-wait

ROOM FOR NOTES



NEED MORE INFORMATION?

GO TO

sussexmskpartnershipeast.co.uk

OR CALL US ON

0300 300 0003

(Local Rate)

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