



Royal Berkshire
NHS Foundation Trust

Xplore Pain Management Programme

Information for patients, relatives and carers

Compassionate

Aspirational

Resourceful

Excellent

Introduction

This booklet aims to provide you with the information covered in your Pain Management Programme and help you to continue to make positive changes to improve your quality of life.

Some people find it helpful to periodically review this information.

There is a lot of information so please take your time when reading through the booklet.

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What is pain?

Pain is defined as, “an unpleasant sensory and emotional experience associated with actual or potential damage or described in terms of such damage.” (International Association for the Study of Pain).

Pain is both normal and needed – it is a way for our body to try and protect us from what it believes to be a threat. Pain makes us change our behaviour. Pain stops us from doing certain activities to avoid further damage or allow healing and this can be helpful for example if we have injured ourselves and need to heal.

More about the nervous system

Our body is constantly trying to protect us from what it believes to be a threat. One of our body's systems, the nervous system, is designed to collect information from within our body and our external environment. This information helps us to understand our world and how to interact with it.

The nervous system is a complex system of nerves and cells carrying messages from the brain and spinal cord to various parts of the body. Nerves are like sensors – they sense what is happening in the body and in the world.

Nerve endings are found in the skin, muscles, joints, organs, etc. They detect changes in things such as:

- Temperature
- Pressure and touch
- Chemicals

If lots of sensors in the nerves are stimulated, an electrical current is sent to the spinal cord and then up to the brain.

Signals from the brain are also sent down to the rest of the body via nerves – it's a two-way street! The signals are processed in the brain using multiple information stores, such as past experiences, memories and the electrical impulse from the nerves.

There isn't specific 'pain sensors' or 'pain nerves' in the body. The nervous system and the body use all the messages and information it receives to decide whether it is in danger or not. Therefore, whether we experience pain is based on how the brain processes all of this information. It is important to recognise that our alarm system can produce pain in response to actual or perceived threats as well as physical or psychological threats.

Pain can change your behaviours so that you can avoid things that may be harmful and perhaps allow tissues to heal. For example, if you sprain your ankle, it is sensible to allow some time for the tissues to heal. This means that pain is a critical protective device, our body's own alarm system that works to protect us.

What is chronic pain?

Chronic pain, also known as persistent pain, is pain that continues after the expected tissue healing time or when no clear structural cause for the pain can be identified. Chronic pain does not accurately reflect the state of the tissues and does not mean damage, injury or harm is occurring in the body. It occurs due to changes in our nervous system sensitivity. Chronic pain is still our body's attempt to be protective, but it is not always helpful.

Chronic pain is complex...

You may find the following video useful: <https://www.youtube.com/watch?v=1XZIEzvDH6k>

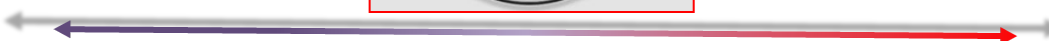
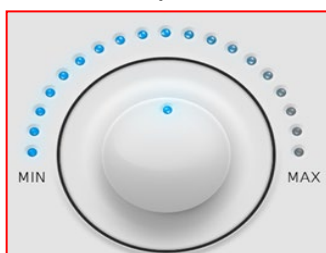
(The video can also be found by searching in Youtube "What is the Biopsychosocial framework? Dynamic movement and recovery")

When we experience persistent pain our "alarm system" can become too sensitive. This increased sensitivity means we can begin to experience pain in response to non-harmful stimulus. As a result, non-harmful daily activities including walking, commuting, household chores, recreational pursuits and even sleep can trigger our pain system.



Spectrum of sensitivity

Pain levels in the body can often go up and down, just like a volume control. Pain is individual to each one of us, and our own 'pain dials' will all be different.



Low sensitivity
Low irritability
Hyposensitive

High sensitivity
High Irritability
Hypersensitive

What can lower my sensitivity?

What can increase my sensitivity?

Sometimes, an area of the body may feel very sensitive, and pain may be easily triggered. Sometimes, an area of the body may have low sensitivity and so it may be hard to feel. Here are some examples of different ends of the spectrum where this may occur. Can you think of any others?

The struggle with pain

When you are in pain it is natural to do things to try to reduce or control it. These things may be helpful in the moment; however, there may be a downside. Sometimes, things that seem like a solution initially can become part of the problem.

Example 1

You might stop going to the pub because the seats are uncomfortable but over time your social life then suffers.

Example 2

You might avoid bending to prevent increasing your pain. However, over time the muscles and joints can become tight, stiff, and/or weak and in turn cause further pain.

There may be a variety of things you've done to manage or reduce your pain.

These could include...

- Things that you have done (resting, pushing through)
- Things that you have stopped doing (work, hobbies)
- Things you have used (medication, diet, alternative remedies)
- People you have been to (different healthcare professionals)

Everything we do can have both short-term and long-term consequences.

For example, acupuncture:

- Short-term: short term pain relief (up to a few days)
- Long-term: expensive

Please use the table overleaf to think about the strategies you have used for managing your pain. Think both about the short-term benefits but also what is likely to happen over the longer term and the impact that this will have on your quality of life

Strategy	Benefits	Long-term consequences	Impact on quality of life
<i>e.g. Avoid exercise</i>	<i>e.g. Not flaring up my pain</i>	<i>e.g. Reduced fitness or reduced function</i>	<i>e.g. Not being able to go out for a walk with the dog</i>

Pain Protectometer – Can it help us to better understand our individual unique experience of pain?

Our pain levels may vary sometimes unpredictably which can leave us feeling frustrated and unable to make plans.

Pain researchers and educators Lorimer Mosely and David Butler developed the Protectometer to be used as a tool to help us understand how our lives interact with our pain. It may enable us to identify ways to better manage our pain and engage in the life we want. The protectometer tool is based on the concept of ‘neurotags’ which are the connections different parts of our brains make as we experience our world.

We notice these neurotags in everyday life for example when a smell reminds us of a pleasant memory eg cut grass and spring, leaving us feeling warm and happy, or a sound such as a dentist drill causes us to notice tension on our bodies. These neurotags are unique and individual to each of us and we may have neurotags that we are not aware of. Pain or unhelpful neurotags can be triggered by any of the above and may lead us to experience more pain or make our brains more ‘threat’ focused so that something that would normally not bother you causes you pain. Better awareness of these connections may help us better manage our pain. Additionally, increased awareness of more helpful neurotags may help us to reduce pain intensity.

As we’ve previously noted we experience pain as a response to a threat. The Protectometer is a tool to help us recognise when pain or unhelpful neurotags, called DIMS (Danger in Me) increase the sensitivity of our nervous system resulting in us experiencing more pain. More helpful or calming neurotags are called SIMS (Safety in Me) and are things that enhance our wellbeing. SIMs may decrease the sensitivity of our nervous system resulting in us experiencing less pain.

	DIMs	SIMs
Things you hear, see, smell, touch, taste	Looking at an X-ray The dentist’s drill Alcohol Traffic jams	Hearing a scan is all clear Hearing your favourite song
Things you do	Take medications Avoid friends	Gentle exercise Learning about pain
Things you say	It’s just old age This will never get better	I am sore but safe Pain doesn’t always mean tissue damage
Things you think and believe	Pain is forever No one believes me	Belief in in health care professionals
Places you go	Hospital Manager’s office	Hospital Dinner with friends Place of worship
People in your life	Out of date health care professionals Friends Family	Up-to-date health care professionals Family Friends
Things happening in your body	Worry Inflammation	Hope Inflammation

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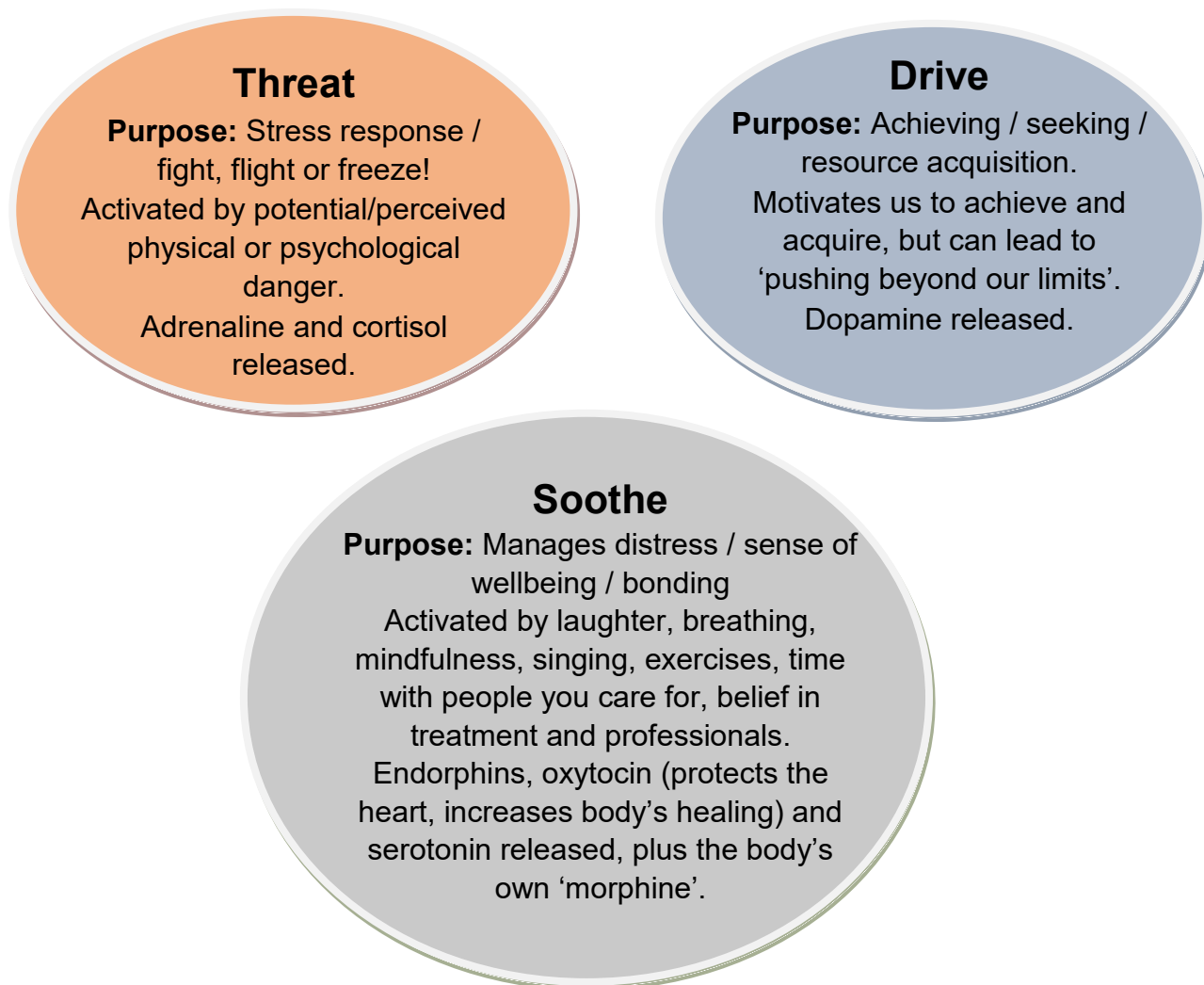
How to use it:

1. Write down DIMs and SIMs that you are aware of in each category, preferably on post it notes.
2. Stack multiple DIMs and SIMs in each category, with the most powerful at the top.
3. Write today's date and your current pain rating, e.g. pain 3/10.
4. This is not a one-off activity. We recommend you regularly review and reflect on your DIMs and SIMs as you start noticing them over days, weeks and months.
5. Review your protectometer:
 - If you are in pain, there is likely to be more DIMs than SIMs or really powerful DIMs.
 - If you are not in pain, there is likely to be more SIMs than DIMs or really powerful SIMs.
 - Does your DIM/SIM balance match your current pain levels? If not, you may need to review your DIMs/SIMs – they can hide in hard to find places.
 - Is there anything you can do to better balance or even increase your SIMs if you are experiencing more pain?

Please see <http://www.protectometer.com/> for more information

Emotion regulation system

Dr Paul Gilbert (a clinical psychologist) describes three emotional systems – the threat, drive and soothe system. He proposed that human beings can switch between the three systems to manage their emotions and that the systems work best when they are in balance. The systems are shaped by a number of factors, including genes, previous experiences and the culture we currently live in.



Pain may trigger a number of perceived threats (including social and emotional threats), which in turn may activate the threat system. Although we may not realise, most of us are likely to spend most of our time in the 'threat' or the 'drive' system and so it's important to notice when the 'soothe' system may need to be utilised and developed. All three systems are needed, but if too much time is spent in the 'threat' or 'drive' system, often we can feel distressed.

Have a think about what helps you to feel soothed and calm?

What helps to increase your soothe system and turn down the threat system?

These might include some of the things covered during the programme, such as:

- Breathing exercises
- Mindfulness
- Self-compassion...

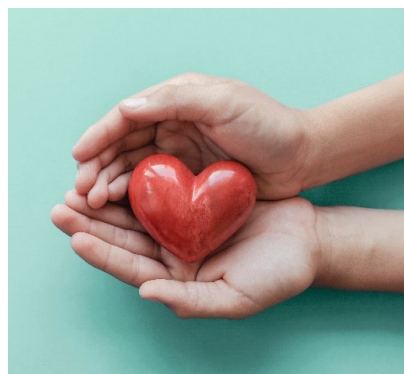
Self-compassion

Is:

- Acknowledging that you are suffering and responding with kindness and care

Is not:

- Self-indulgent and self-pitying
- Pretending that everything is fine and just trying to think positively



Self-compassion does not always come easy and can take time to develop. We can learn to develop a kinder and less-judgemental way of talking with ourselves. By being more compassionate towards ourselves we also improve our ability to be able to self-soothe and “turn down” the threat dial.

Dr Kristin Neff, a researcher in self-compassion, has described three key components of self-compassion:

- 1. Mindfulness** – acknowledging the presence of our pain (both physical and psychological) and doing this without getting caught up in judgements or criticisms about this experience. Not trying to avoid or suppress the emotions.
- 2. Common humanity** – recognising that we are not alone in our suffering. Emotions such as shame, guilt or fear can leave us feeling isolated, but these are emotions experienced by all humans.
- 3. Kindness** – treating both others and ourselves with warmth and kindness.

Ways to be kinder to ourselves:

- Think about how you would treat a friend.
- Speak to ourselves gently, as we would to a loved one.
- Spend quality time with people who treat us well.
- Use kind self-touch such as placing a hand gently on top of a painful area, or applying some hand cream and giving our hands a massage.
- Do kind deeds for ourselves or others.
- Make time for self-care or a self-soothing activity.
- Using pleasant smells which create a sense of wellbeing e.g. candles, essential oils.

Self-compassion exercises

- Video – <https://www.youtube.com/watch?v=AyQdeYjXUhE> (or try searching for ‘Being Kinder to Yourself’ by Greater Good Science Center)
- <https://self-compassion.org/category/exercises/#exercises>
- Guided practices (audio) – <https://www.compassionatemind.co.uk/resource/audio>

Doing what matters

During the programme, we have asked you to think about the things which matter to you and the way you want to be as a person. Sometimes, these things can get buried under other pressures and demands, or we lose sight of them due to situational factors which demand our focus (such as persistent pain!).

These things may **be how we aspire to behave towards ourselves and others**, based on personal qualities that we hold deep within ourselves. They guide and motivate us in terms of **what we want to do and how you want to do it**.

Unlike goals, these qualities are not something that can be ‘ticked off’ – for example if you value being a warm and loving partner, you don’t achieve that and then just stop and become cold and unloving!

Instead, it’s a **direction we want to head towards** which will involve *ongoing* action (i.e. you have to keep working at it...).

These are what are important to you. They influence the way you live your life, and they tend to stay the same throughout life.

Some examples might include:

- Kindness
- Family-orientated
- Healthy
- Hard working

There are many values and they’re all individual to each one of us. They should be about what matters to you, rather than what we think we ‘should’ be doing.



STEP 1: Choose one or two parts of your life that you're less happy about and would like to work on. There may be more than two areas you would like to choose but just take two to start with.

Examples you could choose include:

- Social life and friendships
- Health and wellbeing. This can include emotional and psychological health as well as physical. Remember it is about your behaviour rather than wanting your health to be different
- Family
- Marriage or significant relationships
- Parenting
- Work (either paid or unpaid)
- Education and personal development
- Hobbies, interests and recreations
- Religion and spirituality. Whatever spirituality means to you is fine. It may be as simple as communing with nature, or participation in an organised religious group
- Community and citizenship. How would you like to contribute to your community or environment, e.g. through volunteering, or recycling, or supporting a group/ charity/ political party?

The areas I have chosen to focus on are:

Area 1: _____

Area 2: _____

STEP 2: For the chosen parts of your life, think about what sort of person would you like to be?

Questions to consider:

- **Social life and friendships:** If you could be the best friend possible, how would you behave towards your friends? What sort of person would you like to be in social situations?
- **Health and wellbeing:** How do you want to be acting towards yourself and your health? What is it that makes this important to you?
- **Family relations:** What sort of son/daughter, uncle/auntie do you want to be? How would you behave towards others if you were the being the best family member you could be?
- **Marriage and significant relationships:** What sort of partner would you like to be? How would you interact with your partner if you were the 'ideal you' in this relationship?
- **Parenting:** What sort of parent would you like to be? What sort of qualities would you like to have? What sort of relationships would you like to build with your children? How would you behave if you were the 'ideal parent'?

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- **Work (both paid and unpaid):** What do you value in your work? What would make it more meaningful? What kind of worker would you like to be? If you were living up to your own ideal standards, what personal qualities would you like to bring to your work? What sort of work relations would you like to build?
- **Education and personal growth:** What do you value about learning, education or training? What sort of student would you like to be? What personal qualities would you like to apply?
- **Hobbies, interests and recreation:** What sorts of hobbies, sports, or leisure activities do you enjoy and how would you like to be while doing them? How do you have fun?
- **Religion and spirituality:** What qualities would you like to show more of in connecting with your beliefs?
- **Community and citizenship:** What sort of citizen would you like to be? How do you want to be acting whilst engaging with your community?

Here is an example to demonstrate.

George is feeling isolated and wants to work on developing more of a social life and friendships. He also wants to work on his health and wellbeing.

With regards to My social life and friendships (Area 1) I would like to be:

Fun

Supportive

Kind

With regards to My health and wellbeing (Area 2) I would like to be:

Self-compassionate

Accepting of myself

Active

Write down some words to describe your “best self” in each of your chose areas.

With regards to _____ (Area 1) I would like to be:

_____,
_____ and

With regards to _____ (Area 2) I would like to be:

_____,
_____ and

Here are some ideas to help you think about how to describe your “best self” (don’t feel you have to stick to these, you can come up with your own as well):

- **Social life and friendships:** Lively, Caring, Patient, Genuine, Compassionate, Humorous, Respectful, Sincere, Trustworthy, Loyal
- **Health and wellbeing:** Self-caring, Self-compassion, Healthy, Self-acceptance, Fitness, Independence, Nurturing, Mindful, Self-respect
- **Family:** Assertive, Accepting, Generous, Encouraging, Forgiveness, Honest, Loving
- **Marriage or significant relationships:** Caring, Loving, Committed, Appreciative, Sensuality, Sexuality, Loyal, Patient
- **Parenting:** Fun, Caring, Consistent, Fairness, Loving, Encouraging
- **Work (either paid or unpaid):** Co-operative, Innovative, Reliable, Hard-working, Dedicated, Responsible, Skilful
- **Education and personal development:** Curious, Courageous, Brave, Skilful, Determined, Perseverance
- **Hobbies, interests and recreations:** Adventurous, Creative, Exciting, Engaged, Innovative
- **Religion and spirituality:** Authentic, Connected, Mindful, Committed
- **Community and citizenship:** Reliable, Connected, Engaged, Contributing, Open-minded

How much are you being your best self?

STEP 3: Now we would like you to think about how much you are currently being “your best self” in these areas?

We will use George’s example to demonstrate a way to do this.

George gives himself a score out of 10 for how he is doing in each segment of his chosen areas. Where 10 = doing it completely, all of the time, and 0 = Not doing it at all. He feels he is a supportive and kind friend quite a lot of the time and gives these a score of 7 and 8. However, he thinks he is not that much fun as a friend and only gives this a 3. With his health and wellbeing, he has noticed he is very rarely self-compassionate so this only gets a 1. He has started to do tai chi every other day and is eating more fruit and vegetables but feels that he has some way to go. He therefore gives Accepting of myself and Active both 4s.

With regards to My social life and friendships (Area 1) I would like to be:

Fun 3,

Supportive 7 and

Kind 8.

With regards to My health and wellbeing (Area 2) I would like to be:

Self-compassionate 1,

Accepting of myself 4 and

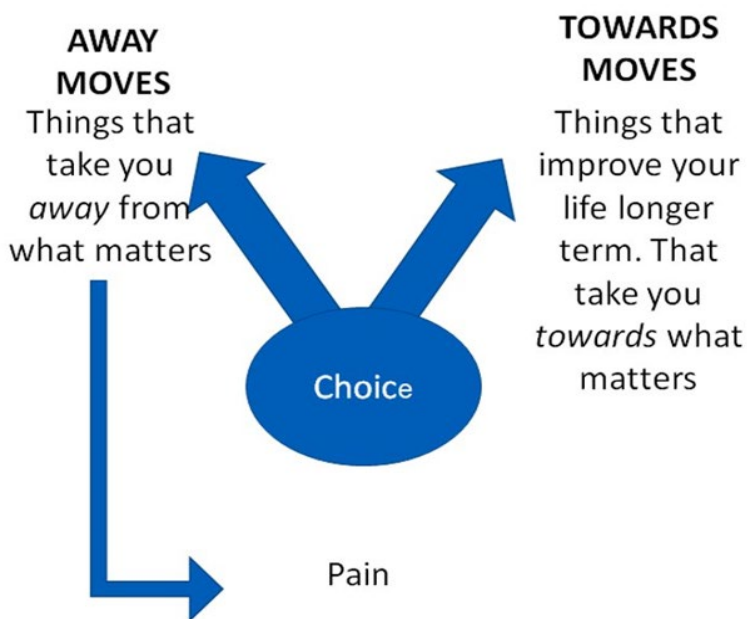
Active 4

Now it's your turn

Give yourself a score out of 10 for how much you are living up to each word or description. Where 10 = doing it completely, all of the time and 0 = Not doing it at all.

Choice point

Throughout all of our day-to-day lives, we all make choices. Sometimes these choices take us away from our values and the person we want to be – known as ‘away’ moves. And sometimes they take us towards our values and the person we want to be – ‘towards’ moves. This is represented in the diagram below, known as a ‘Choice point’.



What are hooks?

Hooks are anything that hook us into making those choices that take us away from the things which matter to us/the person we want to be (the ‘away’ moves) – we all have them. These hooks can be anything from thoughts, feelings, emotions, surrounding environment etc.

What are helpers?

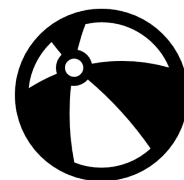
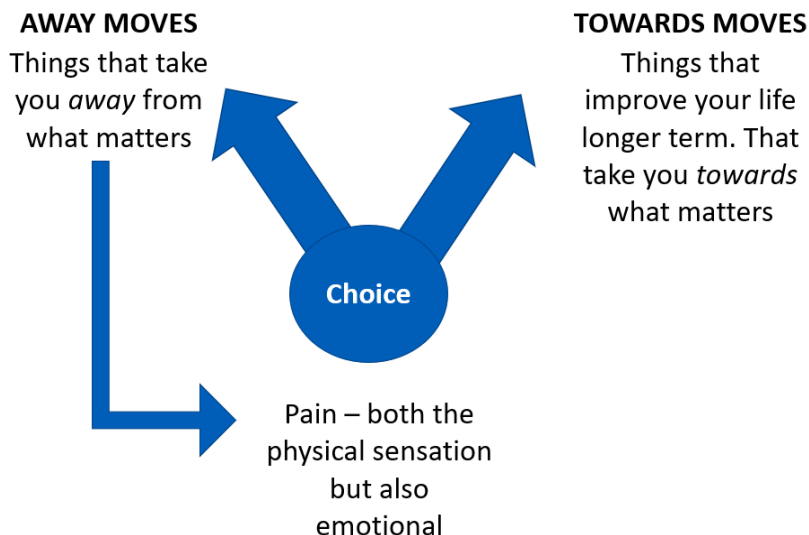
Helpers are things that we know help guide us towards the things which matter to use. They help us make the ‘towards’ moves. Again, this could be anything.

Our hooks and helpers, just like with pain, will be individual to everyone.

It is important to remember that there are no right or wrong choices, especially in difficult situations. But it is also important that we start recognising whether we think the choices are in line with the things which matter to us and the person we want to be.

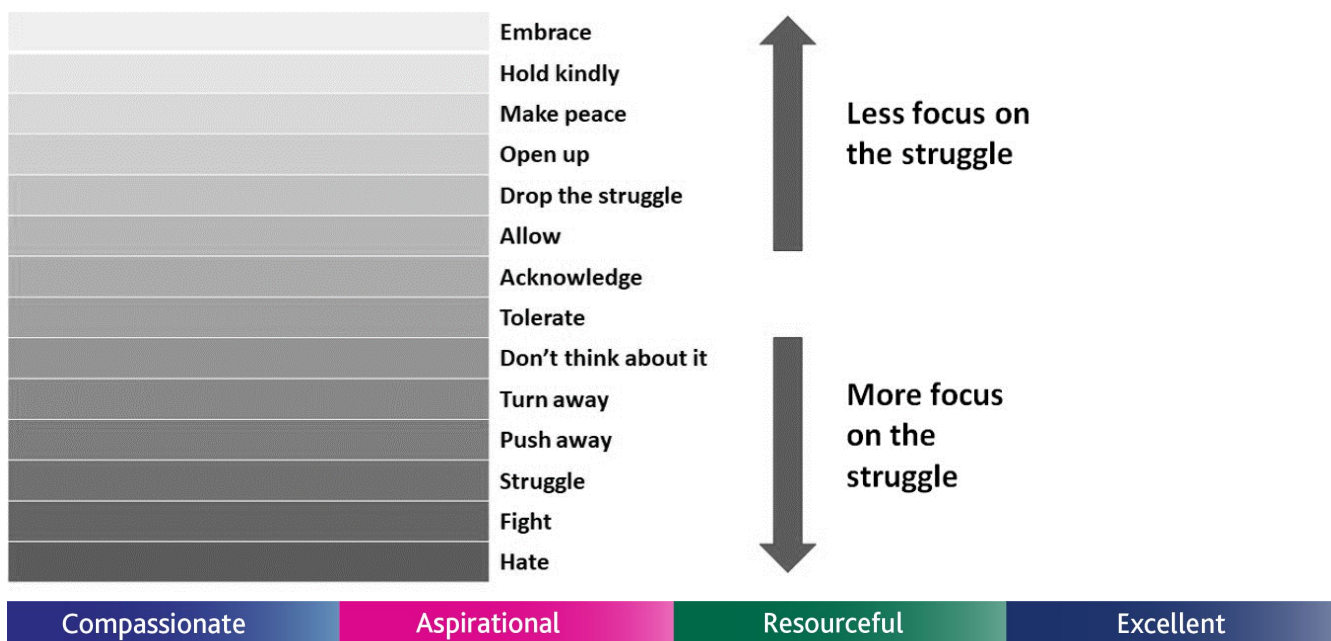
Dropping the struggle

While it is completely understandable to want to try to control pain or make it go away, what we know from experience is that this struggle with pain can create further distress and pull you away from doing the things which matter to you.



This struggle with pain can be imagined like trying to keep a beach ball under the water. You can use a lot of your energy and attention to keep the ball under the water but as soon as you let go it comes back up again. Instead, you can allow the beach ball to just float there. It's not gone away but you're no longer using your time and energy fighting with it.

When thinking about 'dropping the struggle' it might seem like there are only two options – you drop the struggle or you don't. Instead it can be helpful to think of 'dropping the struggle' as having shades of grey in between, rather than being black or white. It might feel more helpful to think about reducing the time and energy spent on the struggle with pain and making more room for the things which matter to you. Where you are on this spectrum may vary over time.



Dropping the struggle with pain does not mean...

- That your pain doesn't matter
- That you're no longer in pain

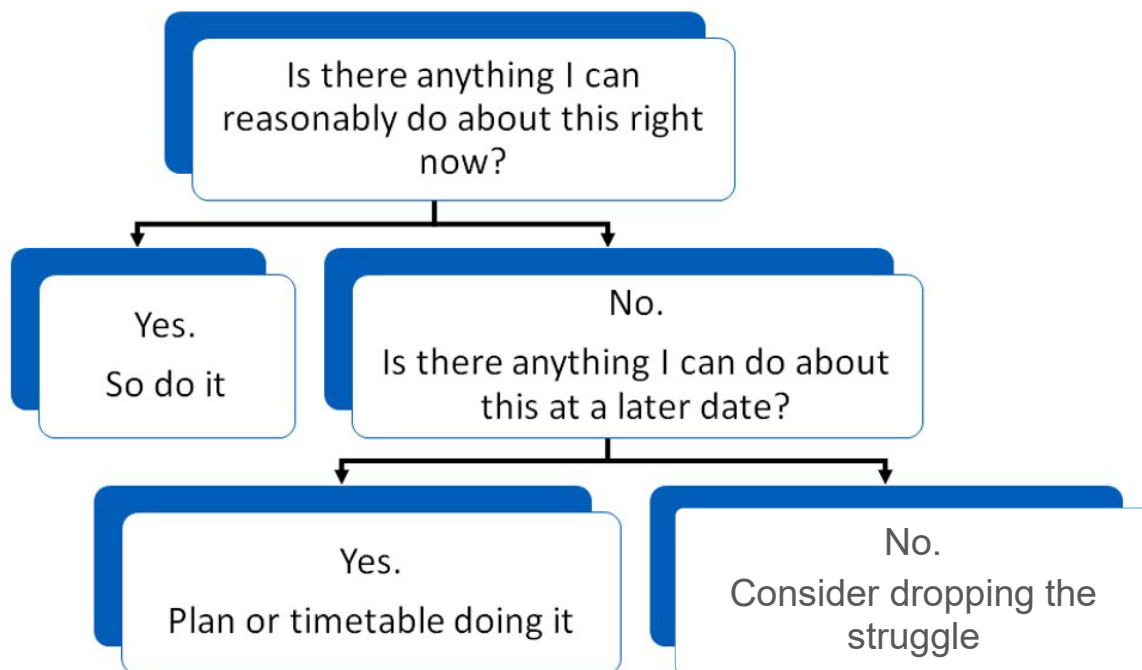
Dropping the struggle is about acknowledging difficulties and focusing attention back on to the things that matter to you,

Dropping the struggle doesn't mean that you have to be passive.

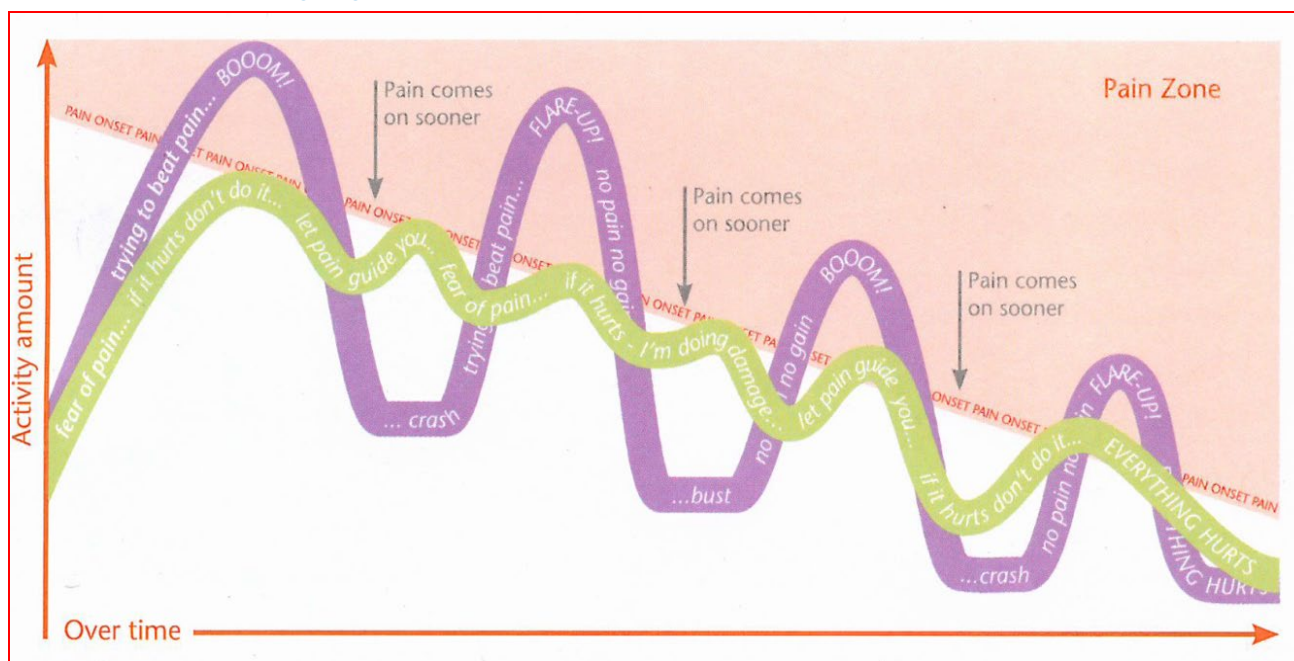
If there are things which you can do to improve your quality of life (which might include doing the things which matter to you as well as helpful strategies for managing your pain), do them!

The decision tree shown below can be a helpful tool in responding to difficulties – this can help you to consider if this is a difficulty you can do something about or whether it is a difficulty outside of your control. If it isn't a difficulty you can do something about, it might be helpful to consider dropping the struggle.

You can still work on things - it's not being passive



Unhelpful activity cycles in chronic pain:

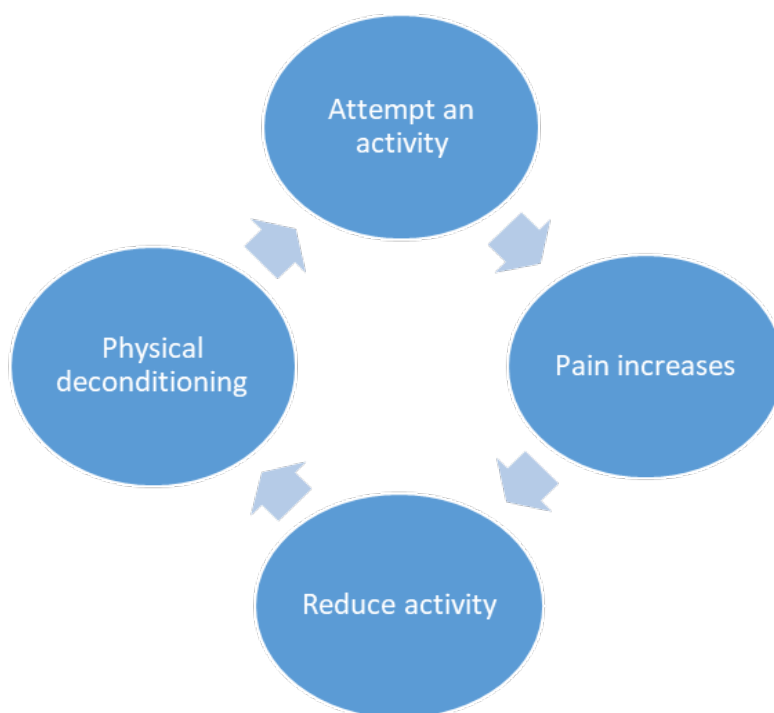


Deconditioning

When you live with persistent pain it is not uncommon to start to avoid activity that can make pain worse. Unfortunately, by avoiding activity to reduce your pain levels, you may notice a reduction in your 'fitness' levels. Your joints can begin to feel stiffer, and become less flexible, your muscles can become tense or weak and your stamina may decline. You may even find yourself red faced and short of breath with small amounts of exertion. This process is known as deconditioning and is associated with a reduced activity tolerance and increased pain when trying to do too much.

Boom/bust cycle

Often pain can vary throughout the day, or from day to day. On 'bad' pain days you may be forced to reduce your activity levels and even rest. On 'good' or better pain days you may try to increase your activity levels to make up for your bad days and get things done. On these days it is easy to over-do your activity. Often with this increase in activity there is an increase in pain which may cause you to have to rest and recover. This rest and recovery time also



leads to deconditioning and over time our tolerance for certain activities is reduced. Unlike with acute pain, with chronic pain, it's not helpful to decide your activity level based on pain levels as it can lead to this unhelpful cycle. Often in persistent pain you find that the more pain there is, the less active you are; and the less pain there is, the more active you are. This can make planning very difficult.

Deconditioning and the boom/bust cycle can make us feel like the pain is in control of our life. The pain can feel very unpredictable, and you may find yourself avoiding making plans or declining commitments because you worry they may make your pain worse, or cancelling at the last minute and then feeling frustrated and worried that you may be disappointing and letting others down. This in turn can cause you to feel low in mood and anxious.

Sometimes, overdoing an activity or 'pushing through' on better pain days can be initiated by some unhelpful thoughts.

What sort of thoughts do you have in relation to activity on your 'good days'?

What does this often result in over the next few days?

Activity and pain

Activity can include walking, jumping, sitting, standing and even lying down.

Over-doing an activity means doing something for too long, even if that means not moving.

For example:

- You may notice an increase in stiffness or pain if you've spent a few hours sitting down watching TV.
- You may notice an increase in fatigue the day after having a day out.

Over-doing activities and the resultant increase in pain doesn't mean you've caused damage to yourself, but it can cause the already sensitive nervous system to send more signals and perhaps increase in the sensation of pain.

It's important to remember that this pain doesn't always mean there's damage, but that the nervous system is sensitive. It is safe to move even on a bad day however 'pacing' can be used to help break unhelpful activity cycles.

Pacing

Pacing is a personalised, flexible, and practical technique that has the following benefits:

- May help you identify current patterns or cycles that may be influencing your pain
- Recognise your current activity tolerance
- Better manage and possibly increase your activity levels
- Get more done
- Reduce pain flare frequency, intensity, and length
- Reduce the distress and frustration associated with recurrent flare ups
- Regain control
- Plan to allow enjoyable activity
- Gradually increase your activity levels
- Improve physical function and condition
- Reduce the need for pain medication
- Improve your self-care
- Increase your quality of life
- Drop the fight with your pain

What is pacing?

Pacing is:

1. Making your activity levels 'even' throughout your day or day to day
2. Dividing activities into manageable 'chunks'
3. Taking appropriate rests or changing your activity.

When you pace it's important you do about the same amount of activity each day, without too much increase in pain. Some increase in pain is expected, however you want to stop before it becomes unmanageable. As pain isn't a useful guide for your activity, consider

using distance, time, frequency or weight as indicators for the amount of activity you can do on both good and bad days.

Sounds simple?

Pacing can be a challenging strategy to master. In addition, pacing can initially be frustrating and feel restrictive, but it allows the nervous system to get used to the activity sensitivity.

Our tendency to push through and overdo activity can be driven by wanting to gain a sense of achievement, we may judge ourselves against our own or other's rules or standards. We may also be enjoying ourselves or feel excited or distracted and inadvertently do more than we planned.

It is important to accurately assess your current activity tolerance as many people overestimate their capabilities especially if they have been active in the past.

Additionally, it can be challenging to press our 'stop' buttons and learn to do less on 'good' days. Notice your emotions and consider how they may be influencing your behaviour.

Pacing is often a matter of trial and error. We encourage you to be flexible and don't be afraid to change your approach if necessary.

Remember a 'break' could involve movement, a change in position, change in activity or rest. Make sure you plan your 'breaks' rather than letting the pain control your activity.

Some people find it helpful to prioritise, plan and keep a track of their progress in a diary or on a chart.

You may find it helpful to reflect especially if you experience an unexpected flare up of pain but remember pain is a complex thing that can be influenced by many things not just activity, so try not to over-analyse or berate yourself. A pain flare is not your fault.

Do ask for help when needed and delegate some tasks if you are able.

Most importantly please remember that an increase in your pain symptoms does not mean you have injured or damaged yourself.

You may find the following links informative and helpful:

[Chronic Pain and the Boom Bust Cycle - YouTube](#)

and

<https://www.youtube.com/watch?v=EPsWYO-kWdU> which can also be found by searching: Geelong Chiropractor - Chronic Pain and Pacing

Activities

Write down in the boxes below some things that you think may help you, and some things that are perhaps not so helpful:

What helps me? <i>e.g. small movements of my back while sitting</i>	What doesn't help me? <i>e.g. standing for more than 10 minutes</i>

The aim here is for you to explore the helpful movements more often and the unhelpful ones less often. We don't want to avoid the unhelpful ones altogether but we want to explore them using the skills that you are learning now.

For example: *standing for 10 minutes is a problem – but how about 5 minutes at a time with some movement?*

Some people find using an activity diary helpful (see next page). It may be helpful to think about the following questions again when thinking about your week:

- What is priority this week?
- What requires the most effort?
- Can you break the task down?
- Have I balanced the “have to” tasks and the “I’d like to tasks?”

‘Live well with pain’ also have a very good example of an activity diary as well as many other resources:

- [Understand pain | My Live Well With Pain](#)
- <http://my.livewellwithpain.co.uk/wp-content/uploads/My-Activity-Diary.pdf>

Activity diary

Day	Activity	How long for?	Comments
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

The advice is to build up activity gradually once you can manage your activity regularly at the same level. This means that once you have become comfortable with your current pacing (and this can take time), then you can begin thinking about slightly increasing your activity. Some people like to increase activity by a percentage or a little at a time. Remember you can consider using distance, time, frequency or weight as indicators for the amount of activity you can do on both good and bad days.

Think about your goals (see next section) and the activities involved in these. How will you start working towards these goals at a manageable pace to you?

Finally, it is very normal to experience a “getting going pain” after starting to increase movement. This means that there may be a slight increase in pain as you increase the activity that you are doing. It is important to remember that the increase in pain can be explained by the increase in movement.

The trouble with too much rest

After a long rest period, returning to normal activity leads to fatigue and muscle pains – these are separate to your underlying pain problems. It may feel as if you will never have the same amount of energy again, and this in itself may cause stress and worry about the future. Stress generates further pain and fatigue symptoms, and the cycle of inactivity continues.

Avoiding doing things over a long period of time can often lead to emotions such as anxiety or worry.

It makes it harder to re-engage in these things that have been avoided, in the future.

Breaking the avoidance cycle is important to be able to lead a life that we would like to.

Goals

Now that you’ve identified the things which matter to you, you might have noticed areas of your life where you are not living your ‘best self’. Goals can be used to help move you towards the things which matter to you and how you want to behave.

Goals are based on the things which matter to you. They can be checked off a list and measured. It’s something that you plan to achieve and commit to in line with what matters to you. They tend to change with time and experience.

It’s important for goals to be SMARTER...

S	M	A	R	T	ER
Specific Who, what, where, when, why, which?	Measurable Can you track the progress and measure the outcome?	Attainable Make sure the goal is not out of reach!	Relevant Is the goal worthwhile and will it meet your needs?	Timely When will you complete this goal?	Evaluate and Revise Do you need to make any changes to your goal?

It's important for goals to be SMARTER, not just SMART. Sometimes, things happen that mean we have to revise some aspect of the goal. It's important to be kind to yourself in these moments.

'If-then' plans

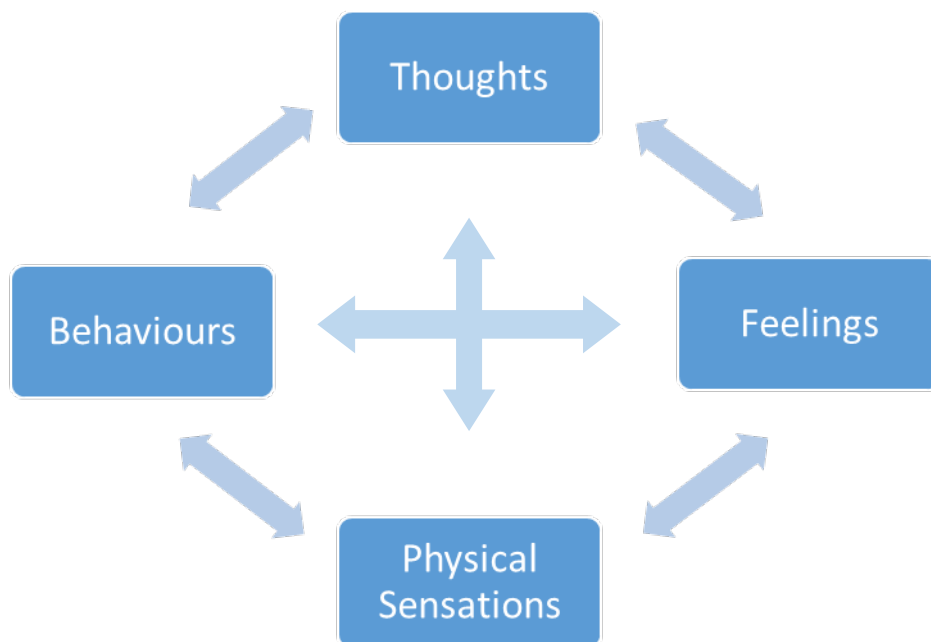
After identifying your goal, it's also important to think about what might get in the way of you achieving your goal.

It may help you to make some 'if-then' plans with your barriers for this goal. For example: *'If I need to go into work on the Wednesday, then I will move the day I go swimming to a Tuesday'*.

Using cues can also help. For example, some people choose to complete their mindfulness practice before they get out of bed, and as they get in to bed. What cues might be helpful to help you to achieve your goals?

Thoughts and emotions

Our thoughts, emotions, body sensations and behaviours are all interlinked, with each affecting the other. This is sometimes summarised in a diagram called a 'hot-cross bun model' (shown below):

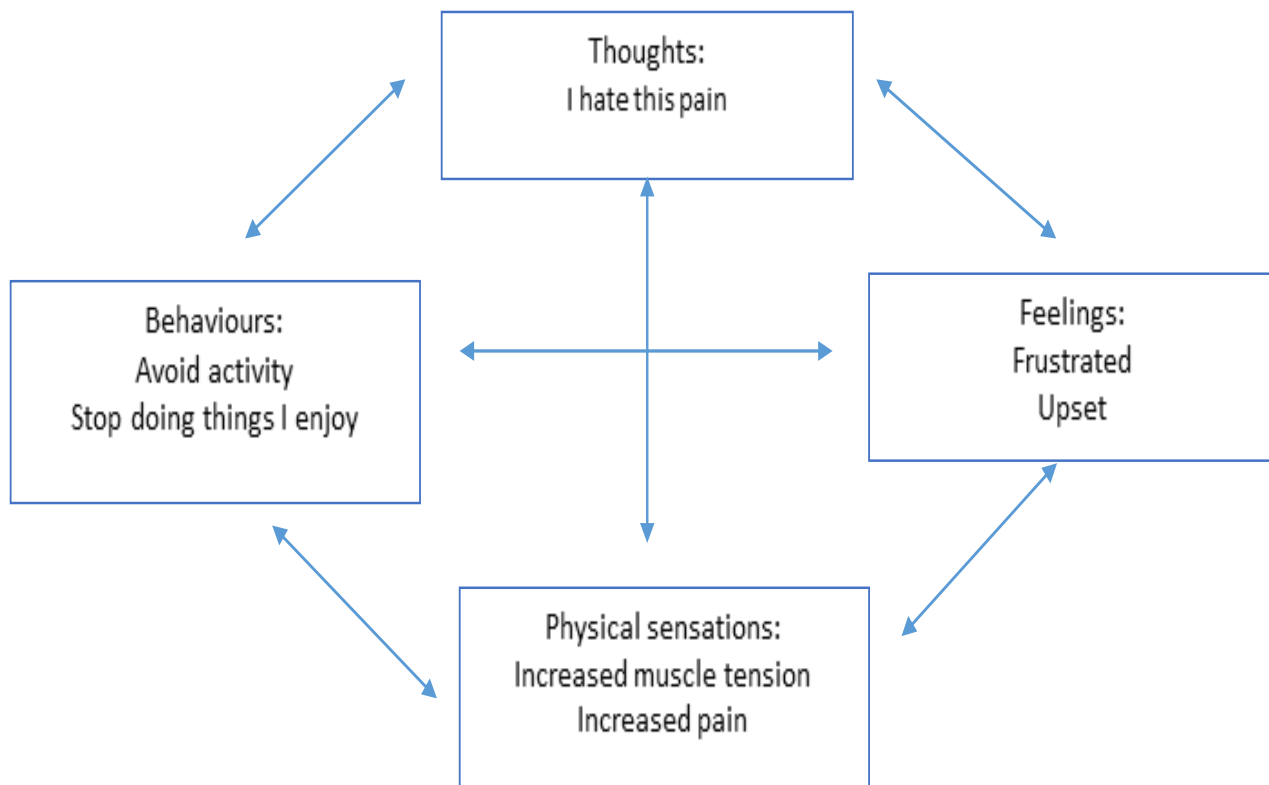


Our thoughts can sometimes feel very powerful and impact on our emotions, behaviour and even our body sensations, as highlighted by the hot-cross bun model – just think about the reaction your body can have to just thinking about your favourite food!

Sometimes though our thoughts might pull us away from doing the things that matter to us or create feelings of distress (think back to the 'choice point' on page 14).



We might notice that we start to put lots of our attention and energy into trying to avoid, ignore or get rid of difficult thoughts. However, this pulls us away from doing things which matter to us.



Creating space from thoughts











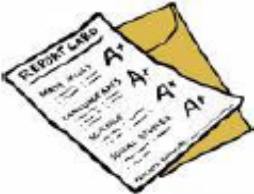

When we notice that we are being hooked by difficult thoughts, it can be helpful to try and create a sense of distance from the thought. This can make these thoughts to feel less powerful.

One way in which we can do this is by noticing whether we might be experiencing one of the thinking patterns shown on the next page. These are common thinking patterns which we can all experience. Some thinking patterns may happen more frequently than others. Recognising these patterns can help us to start notice when they are happening.

When you do notice this happening, taking a moment to acknowledge or name the pattern (either out loud or in your head) can help to create some distance from the thought.

For example, you might say “There goes my mind with catastrophising”, or “I notice I’m mind-reading again”.

Thinking patterns

 <p>Mental Filter - When we notice only what the filter allows or wants us to notice, and we dismiss anything that doesn't 'fit'. Like looking through dark blinkers or 'gloomy specs', or only catching the negative stuff in our 'kitchen strainers' whilst anything more positive or realistic is dismissed. <i>Am I only noticing the bad stuff? Am I filtering out the positives? Am I wearing those 'gloomy specs'? What would be more realistic?</i></p>	 <p>Judgements - Making evaluations or judgements about events, ourselves, others, or the world, rather than describing what we actually see and have evidence for. <i>I'm making an evaluation about the situation or person. It's how I make sense of the world, but that doesn't mean my judgements are always right or helpful. Is there another perspective?</i></p>
<p>Prediction - Believing we know what's going to happen in the future. <i>Am I thinking that I can predict the future? How likely is it that that might really happen?</i></p> 	<p>Emotional Reasoning - I feel bad so it must be bad! I feel anxious, so I must be in danger. <i>Just because it feels bad, doesn't necessary mean it is bad. My feelings are just a reaction to my thoughts - and thoughts are just automatic brain reflexes</i></p> 
<p>Mind-Reading - Assuming we know what others are thinking (usually about us). <i>Am I assuming I know what others are thinking? What's the evidence? Those are my own thoughts, not theirs. Is there another, more balanced way of looking at it?</i></p> 	<p>Mountains and Molehills Exaggerating the risk of danger, or the negatives. Minimising the odds of how things are most likely to turn out, or minimising positives <i>Am I exaggerating the bad stuff? How would someone else see it? What's the bigger picture?</i></p> 
<p>Compare and despair Seeing only the good and positive aspects in others, and getting upset when comparing ourselves negatively against them. <i>Am I doing that 'compare and despair' thing? What would be a more balanced and helpful way of looking at it?</i></p> 	<p>Catastrophising - Imagining and believing that the worst possible thing will happen <i>OK, thinking that the worst possible thing will definitely happen isn't really helpful right now. What's most likely to happen?</i></p> 
<p>Critical self Putting ourselves down, self-criticism, blaming ourselves for events or situations that are not (totally) our responsibility <i>There I go, that internal bully's at it again. Would most people who really know me say that about me? Is this something that I am totally responsible for?</i></p> 	<p>Black and white thinking - Believing that something or someone can be only good or bad, right or wrong, rather than anything in-between or 'shades of grey'. <i>Things aren't either totally white or totally black - there are shades of grey. Where is this on the spectrum?</i></p> 
<p>Shoulds and musts - Thinking or saying 'I should' (or shouldn't) and 'I must' puts pressure on ourselves, and sets up unrealistic expectations. <i>Am I putting more pressure on myself, setting up expectations of myself that are almost impossible? What would be more realistic?</i></p> 	<p>Memories - Current situations and events can trigger upsetting memories, leading us to believe that the danger is here and now, rather than in the past, causing us distress right now. <i>This is just a reminder of the past. That was then, and this is now. Even though this memory makes me <u>feel</u> upset, it's not <u>actually</u> happening again right now.</i></p> 

www.getselfhelp.co.uk/unhelpful.htm © Carol Vivyan 2009, permission to use for therapy purposes www.getselfhelp.co.uk

There are several ways in which we can try and create some distance from our thoughts. You might have to try a couple to see what works best for you...

I notice I'm having the thought that...

When you become aware of an unhelpful, difficult or distressing thought, you can try saying to yourself, 'I notice that I'm having the thought that....' followed by the thought itself. For example, 'I notice that I'm having the thought that there's no point in trying because it won't help'. By doing this you can give yourself some distance or separation from it. This can help you see it more clearly for what it is (i.e. just a thought, not a fact) and that you have a choice about how to respond.

Youtube – <https://www.youtube.com/watch?v=kwIYXupjoal>

Search for 'Defusion – I'm noticing I'm having the thought...' by Social Work & ACT

Radio Doom and Gloom

You could see your thoughts like a radio without an 'off' button! You might not be able to switch it off, but you can decide whether to tune in and listen to it. Or you can choose to let it play in the background while you focus on something else. Check in with your thoughts every so often – ask yourself 'What thoughts do I have?'

Youtube – <https://www.youtube.com/watch?v=Bu2k0EGXAVo>

(Search for 'Radio Doom and Gloom' by Dr Russ Harris)

Thank you mind

When you notice a difficult thought, simply respond with "Thank you mind" and then re-engage with what you are doing in the present moment. This might seem simple, but it can help you to acknowledge the thoughts without engaging with them.

Youtube – <https://www.youtube.com/watch?v=206WtwEyqzq>

(Search for 'Thanking Your Mind: Taking The Power Out of Difficult Thoughts' by Dr Russ Harris)

Mindfulness – increasing awareness

When we become aware of our thoughts and emotions this can help give us a chance to consider how we would like to respond – think back to the choice point (page 14) and doing what matters!

Mindfulness can help us to notice when our attention has become caught up in challenging thoughts. Once we have noticed this we have the chance to use some of the other strategies to create some space from these thoughts and re-engage with what matters.

Mindfulness involves paying attention to the present moment, with **openness, curiosity and flexibility**. This is an active process and can take time and practice to develop fully. It is not about emptying your mind, but just noticing what is happening in the present moment.

Video on 5 myths about mindfulness:

https://www.youtube.com/watch?v=E_gXW9bo3uQ

Or search for 'The Happiness Trap: The Five Mindfulness Myths'

Mind Full, or Mindful?



There are several ways to practice mindfulness...

Part of everyday activities

This involves paying attention whilst doing normal day-to-day activities.

For example, you could practice mindfulness while washing up, brushing your teeth, eating a meal or having a cup of tea.

Think your five senses, noticing what you can see (colours, size), feel (temperature, texture), hear (loud or quiet), taste (flavour, sweetness) and smell (does it have a strong odour).



Mindfulness exercises

There are a variety of different mindfulness exercises available, both online, in books and in apps.

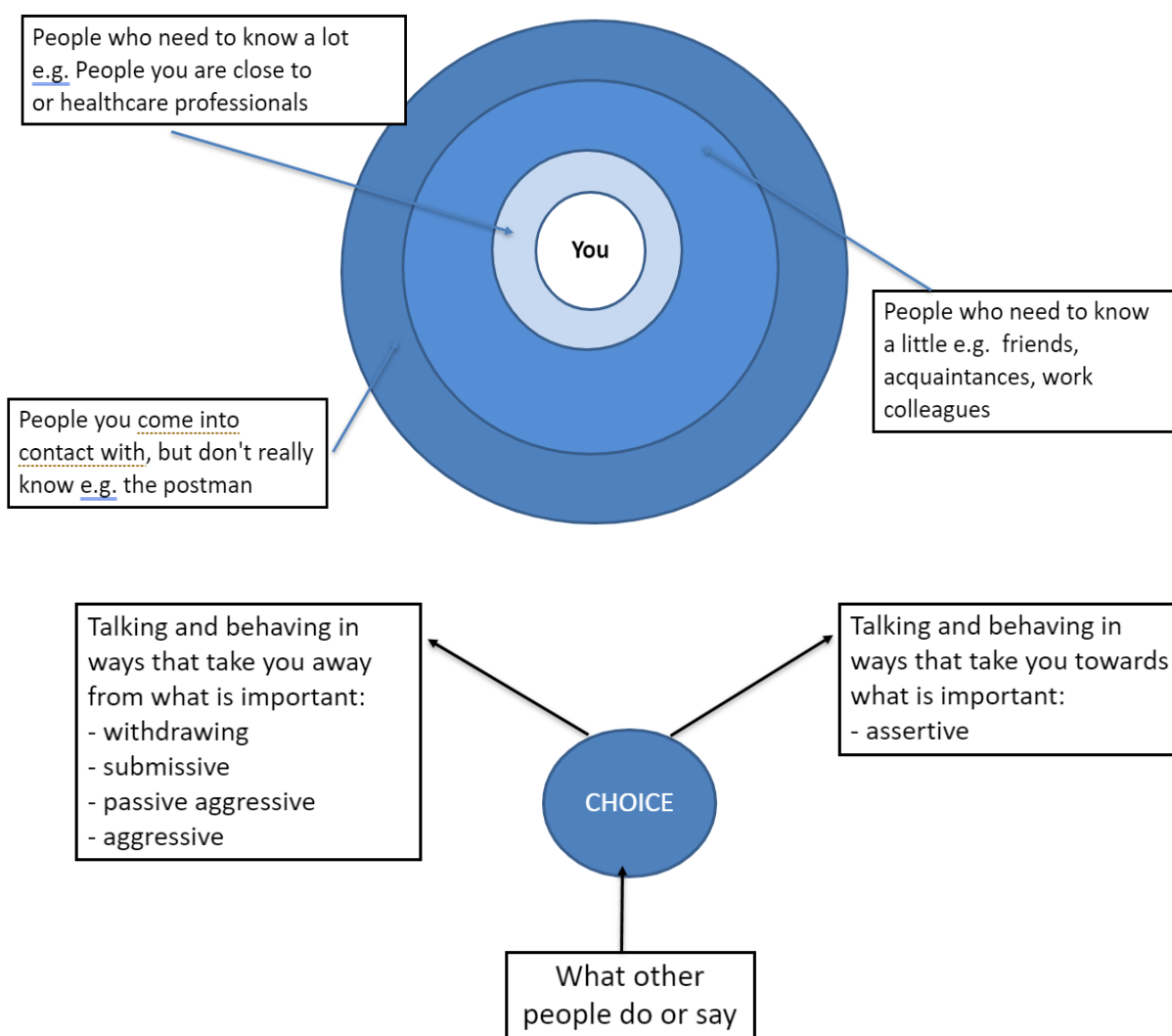
Two minute breathing exercise – www.youtube.com/watch?app=desktop&v=wfDTp2GogaQ (search for ‘Mindful Breathing Exercise’ by Every Mind Matters)

Other resources

Tips on how to be more mindful – <https://www.nhs.uk/mental-health/self-help/tips-and-support/mindfulness/>

Communication

It can be helpful to think about who you would like to know about your persistent pain and how much you tell them. This can help people closest to you to better understand your pain and how you would like them to support you.

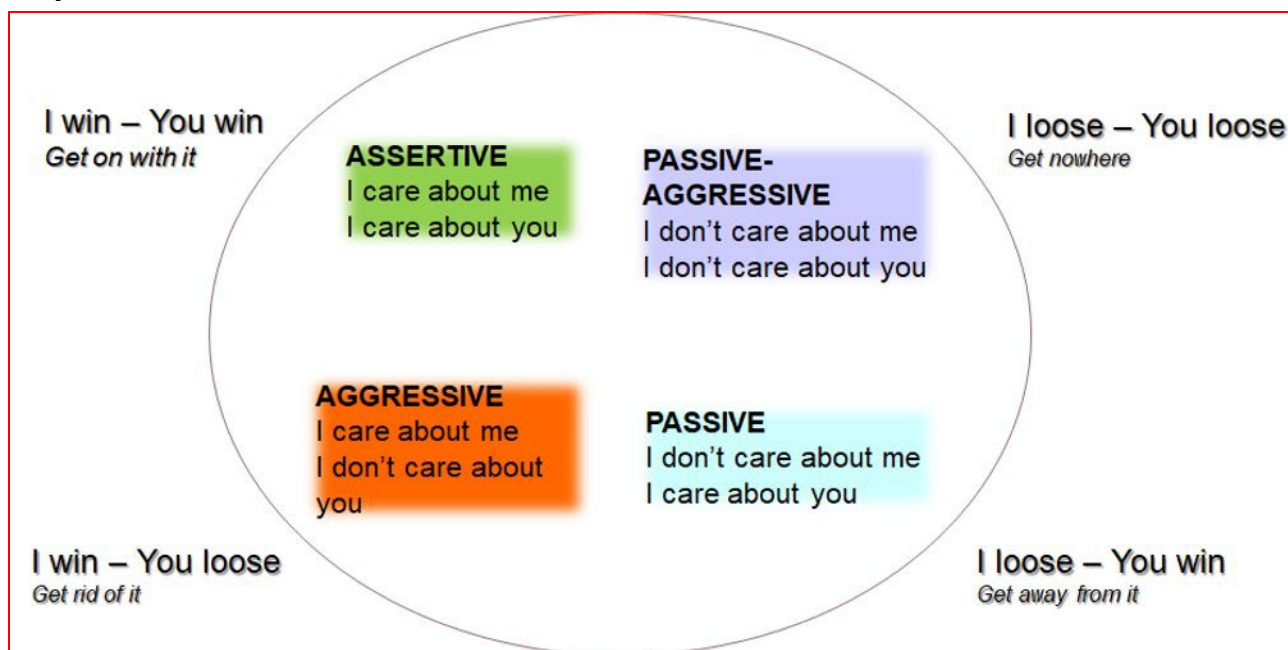


It is also important to consider how you communicate and whether this is in line with the person you want to be. Whilst we can't control what other people do or say, we can control how we respond. It's important to remember that you might not always respond how you would like to, and to be compassionate towards yourself if this happens.

Different styles of communication

Assertive	Passive	Passive-Aggressive	Aggressive
Clear, firm communication. Words and actions align	May be compliant, submissive, non-committal in their responses	Indirectly expresses aggression or displeasure. Words and actions may not align	Critical or disrespectful towards others, such as by interrupting or being sarcastic
Takes both own and other's needs into account	Ignores own needs	Ignores both own and other's needs	Ignores the other person's needs
Open and friendly body language	May appear nervous e.g. fidget, avoid eye contact	Might appear to agree but then not follow through on actions, or may withhold communication	Behaves in an aggressive manner e.g. hands on hips, raised voice, pointing

Assertiveness is communicating our needs, wants and feelings clearly and with respect for ourselves and others – it's a win-win...



Communication – what does and doesn't work

What works?

- Choosing the right time or making time
- Using non-verbal communication too
- I feel/felt...
- Being specific rather than general
- Compromise

What doesn't work?

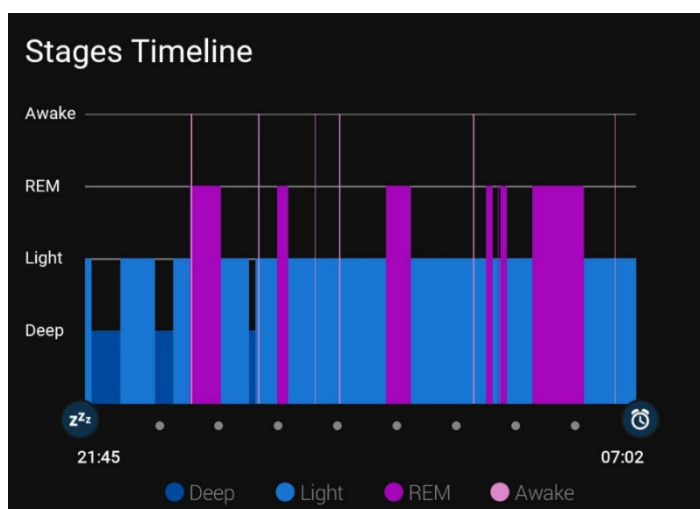
- Not listening – communication goes both ways
- Thinking we can read minds or expecting others to
- Unhelpful body language
- Bottling things up

Sleep

We often think of sleep as one of the last pieces of the puzzle, e.g. If I sort my pain / anxiety / workload etc. then my sleep will improve. Sleep is often not our focus. However, we know sleep to be central to healing, wellbeing and health.

What is 'normal' sleep?

- Everybody's different but most adults with 'normal' sleep get between 5 and 10 hours per night, with some people only needing 5-6 hours, and others needing 10-12. The average, and what we could all try to aim for, would be between 7-8 hours a night.
- Our total sleep time decreases with age, and the quality of our sleep changes too. This is a normal and natural change in sleep as we get older.
- We go through different stages of sleep during our sleep cycle. We naturally wake at the end of each sleep cycle, roughly every 90 minutes. Most people don't even realise this as they just go back to sleep. However, someone with sleep difficulties may believe that their night wakings occur because they have 'abnormal' sleep or because of their pain, and these natural wakings might then trigger anxiety about not being able to get back to sleep (which then makes getting back to sleep even harder – it's a catch 22!)



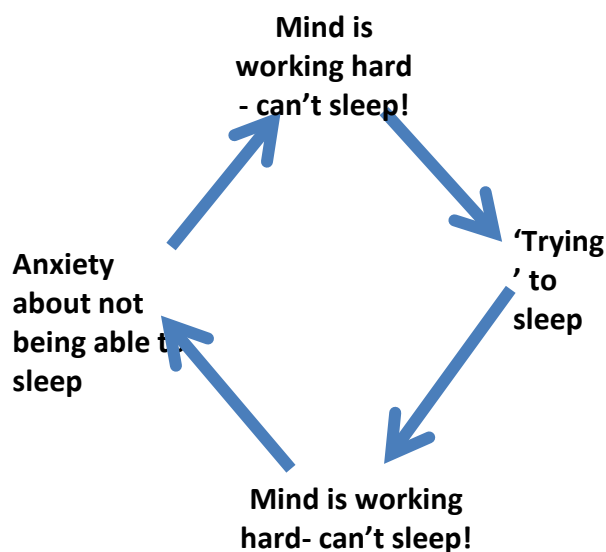
Sleep traps we can get caught in:

Pain and sleep

- Sleep is a stronger and more reliable predictor of pain than pain is of sleep – in other words, if your sleep is poor, you're more likely to experience pain; your pain is not necessarily the cause of poor sleep.
- It can be a vicious cycle, but research shows us that sleep problems predict episodes of pain.
- Trying to chase away the pain in order to sleep may not be helpful – it may raise levels of wakefulness and frustration.

'Trying' to sleep

- If you ask somebody who doesn't have sleep difficulties what they do to get to sleep, they will usually say 'nothing'. Sleep just 'happens' because it is a natural process.
- For someone with sleep difficulties 'trying' to sleep may involve a *conscious effort*, which means that we are keeping *wakefulness levels* high. The electrical currents in the nervous system do not decrease and so it keeps us awake – this may raise discomfort, frustration and anxiety.



Helpful/unhelpful factors that can affect sleep

Caffeine and nicotine

- Both caffeine and nicotine are stimulants and so keep us awake. Caffeine is not only found in coffee but also tea, some herbal teas and some fizzy drinks. Try to avoid caffeine and nicotine 6 hours before going to bed.



Alcohol

- Alcohol is a depressant and may even help us fall asleep BUT it has a huge impact on sleep quality and is associated with increased waking throughout the night. It also affects healing. Try to avoid alcohol 3-6 hours before bed.

Food / drink

- Try not to go to bed hungry or too full. Eating too close to bedtime will cause the body to kick into action and fire up the digestive system, just as we need things to be slowing down.

- If needing the loo in the night is a problem (because it wakes you up and it's then difficult to get back to sleep), you could try and reduce fluids after 7pm to see if it makes a difference. It can be helpful to go to the bathroom before going to sleep.

Exercise

- Regular exercise increases the length of time we sleep for and reduces the amount of time it takes to fall asleep.
- However, it is important not to exercise too close to bedtime as doing so has been found to increase the time it takes to get to sleep (as it gets the adrenaline pumping). The ideal time to exercise would be late afternoon or earlier. Try to finish exercise at least 3 hours before bed.

Medications

- Some medications (including some pain medications) can affect sleep, if they are either stimulatory or depressive in nature – you may need to speak to your GP or consultant to discuss the medication you are on.

Environmental factors

- Noise levels, light, temperature, bed comfort etc. It's about finding what works for you, while not getting too caught up in the finer details (e.g. the room needs to be precisely X degrees!). Sleeping in a dark, quiet, and cool room tends to work for most people but find what works for you.

Relaxation

- It has been found that practicing regular relaxation can lead to improvements in sleep and mood, and reductions in anxiety.

Sleep routine

- Having a routine around bedtime is really important! Doing a set pattern of things before bedtime helps the brain to learn that when these things are happening it's time to get ready for sleep.
- Having a set bedtime is really helpful. The bedtime routine can then be built around this e.g. if bedtime is at 10.30pm, then a potential routine could be bath/shower, brushing teeth, getting into pyjamas etc. from 9.30-10.00pm, reading in bed from 10.00-10.20pm, relaxation from 10.20-10.30pm, with lights out at 10.30pm. Obviously this is just an example!

Bath/shower

- Studies have shown that our body temperature drops as it gets ready for sleep. Getting out of a warm bath/shower causes a drop in our body temperature which mimics this

natural physiological change, so there is some evidence to suggest that including a bath/shower into the bedtime routine may be helpful for some people.

Blue light

- The light that is emitted from screens such as mobiles, tablets, TV's, laptops etc. has been found to affect sleep, by blocking the release of hormones that tell our bodies to get ready for sleep.
- The general rule of thumb is to try and avoid blue light for an hour before bed. However, if TV is something that we know winds us down and gets us ready for bed, it could negatively affect sleep by removing this. So again, it's about finding what works for you!

Naps

- When we've had a terrible night's sleep, it can be really easy to start relying on a nap to get through the day. However, the body's need for sleep builds throughout the day and will then drop after a nap, which will impact on your tiredness at bedtime.
- Nap wisely during the day, if you need one, and not after 3pm, as this may affect your ability to sleep at night.

Associations we have with our bed / bedroom

- Use the bedroom for sleep and sex only.
- Try to avoid working or doing other activities in bed to prevent your brain associating being in bed with wakeful activities.
- Get out of bed if you can't sleep so that you don't associate being in bed with being awake. Use the 20-minute rule – *if you've been awake or have become irritated by not sleeping for 20 minutes, get out of bed to do something soothing e.g. breathing practice, mindfulness, reading. Try to avoid TV or radio as these can be stimulating. Once you start to feel sleepy or relaxed again, try going back to bed to sleep.*

Are there some changes you could make?

- Consider the factors that affect sleep; is there anything that you could change in light of this information?
- Plan a bedtime routine. It should be realistic and flexible (e.g. bedtime = 10.00pm, give or take half an hour) in order to increase the likelihood you'll stick to it.
- Try to go to bed and get up at a similar time each day (even on the weekends). This can help your body into get into a consistent sleep routine.
- Do some relaxation every day (even just 5 minutes a day!), for two weeks to start with, and see if you find it to be helpful.



- Try to be kind to yourself if you can't sleep. Tell yourself that just by being in bed you are resting, which is really beneficial! Taking the pressure off sleep in this way can make a big difference.
- Include 'wind-down' time as part of your routine around 30-45 minutes before going to bed. The idea of this period is to lower your energy, alertness, activity and light levels. The 'wind-down' is not done with the aim of promoting sleep but rather helps remind the brain that sleep is on its way.

Important to consider

If you make any changes in line with these recommendations, one thing to think carefully about is the intention behind the change.

Making changes with the sole aim of falling asleep quickly can put a lot of pressure on these changes to be effective. In turn this pressure may then create anxiety and backfire by keeping us awake. For example, instead of enjoying and truly engaging with relaxation, we may be critically evaluating it – *'I don't feel tired yet, this isn't working, I'm never going to be able to get to sleep, this is rubbish'* etc.

Try instead to focus on creating optimal sleep conditions for yourself, rather than trying to control your sleep, and creating a soothing, enjoyable bedtime routine.

Nutrition

Recent and on-going research is discovering that the different ways in which we eat may impact our pain. It is thought that some foods or drinks can cause low-grade inflammation which can contribute to the sensitivity of the nervous system and affect our pain. Our digestive tract is 'defended' by our immune system, and it seems likely that the health and function of our gut may influence this inflammatory state. Furthermore, links between our brain, nervous system and gut has led researchers to suggest that gut disorders can affect how we feel and our pain levels, and how we feel can affect our gut and digestion. Finally, research exploring the role of the gut microbiota (the bugs that live in our digestive tract) suggests that it may have direct links between our health and wellbeing.

No particular diet has been shown to influence pain levels directly; however, many people notice that improvements in their diet helps their pain and general wellbeing. Conversely, some people notice that if they eat 'junk food' their pain and associated symptoms can worsen. The NHS recommends that people eat 'real' food and attempting to 'eat a rainbow' daily may have anti-inflammatory properties. Furthermore, increasing our physical activity can have positive effects on our general health, wellbeing and possibly even our gut bugs!!

Managing flare ups

What is a flare up?

A flare up is different to the “get going” pain. A flare up is an increase in pain or related symptoms that lasts more than a few hours. It is more than you would expect from “getting going” pain. Sometimes they can just happen without a trigger and sometimes there may be an obvious reason.

It is often helpful to know your own warning signs of a flare and also what you find most helpful when this happens. Flare checklists can be beneficial as sometimes it can be hard to think clearly during a flare. Everyone’s flare plan will be different as pain is individual to each one of us.

It can be useful to keep your flare checklist somewhere visible or easily accessible to help you identify and manage flare ups. Some people can also find it helpful to share their checklists with family or friends so that others know how best to support them during a flare.

Flare checklist

Triggers	Signs of flare	What helps?

Planning for the future

You'll have been given lots of information over the last few weeks and hopefully have some ideas for how you can make some positive changes in your life.

While the programme may have ended, now is the time to think about how you can take forward the changes you have started to make and continue your progress. Below are some questions to help you think about how you can continue to make positive changes and what will help you to do this.

You can revisit these whenever you need to in the future to help you...

1. What changes have you made?
2. What has helped you make these changes?
3. How have these changes helped you to do more of the things that matter?
4. What have the challenges been? What has got in the way of making change?
5. Is there anything you are continuing to struggle with?
6. What changes are you planning to continue with / make in the future?
7. What are you going to do to ensure this happens?

Useful resources

Websites:

- Live well with pain: <https://my.livewellwithpain.co.uk/>
- The Pain Tool kit: <https://www.paintoolkit.org/>
- Flippin' Pains: <https://www.flippinpain.co.uk/>

Videos

- Tame the beast – <https://www.youtube.com/watch?v=ikUzvSph7Z4>
- TEDxAdelaide – Lorimer Moseley – Why things hurt
<https://www.youtube.com/watch?v=gwd-wLdIHjs>

Sleep

- Sleep well with pain leaflet – <https://my.livewellwithpain.co.uk/resources/sleeping-better/sleep-well-with-pain-leaflet/>
- NHS website – <https://www.nhs.uk/live-well/sleep-and-tiredness/how-to-get-to-sleep/>

Books

- The Pain Free Mindset by Dr Deepak Ravindran
- You Are Not Your Pain: Using Mindfulness to Relieve Pain, Reduce Stress, and Restore Well-Being – An Eight-Week Program Vidyaamala Burch
- The Happiness Trap by Dr Russ Harris

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

Pain Management Unit, March 2022

Next review due: March 2024

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