

Coping with Pain

A guide for young people



**Paediatric Psychology and Liaison Service
Royal Hospital for Children and Young People**

With thanks to Great Ormond St Hospital,
Rotherham NHS Foundation Trust,
and Sheffield Children's NHS Foundation Trust.

We hope that you find this booklet useful for helping you to manage your experience of pain. You can work through the booklet at your own pace, by yourself, or with the help of a parent or your clinician.

We suggest that you do this section by section.

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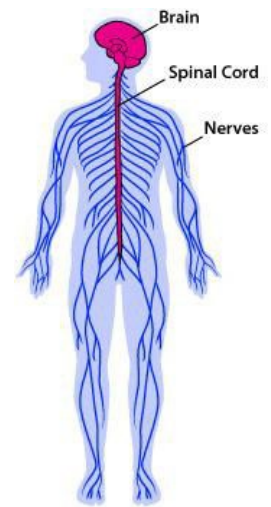
Understanding pain

What is pain?

Pain is the unpleasant physical sensation that we have when a part of our body becomes injured or could be injured. Pain can both affect and be affected by our emotions too. Sometimes pain can last for longer than we expect it to after having an injury or period of illness, even when our body has healed. 'Persistent pain' is when the discomfort has lasted for 3 months or more and does not go away with normal pain treatment. The intensity and frequency of this pain can vary from person to person. It can feel dull or sharp, be continuously there, or come and go in waves.

Different parts of your body are involved in processing the pain you feel including the area or body part in pain (e.g. your leg), your spinal cord (the long bony structure which runs up your back), and your brain, specifically:

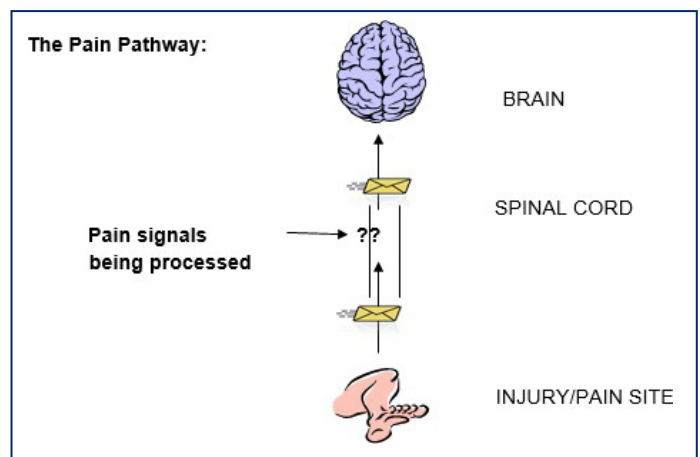
- The pain centre inside the brain
- Messages to and from the brain about the pain
- How we think about and remember pain.



How is pain processed in the body?

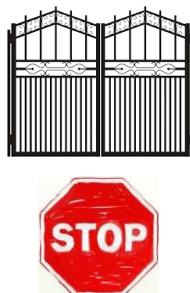
Messages about your pain travel from the sore spot, along your nerves and into your spinal cord. Your spinal cord then carries these messages to your brain. We only feel the pain when the brain receives the pain message.

When the brain receives this, it usually sends a signal to stop or reduce more pain messages coming through and this makes us feel less pain. This doesn't happen as well as it should do in persistent pain, and sometimes the pain continues even if there is no injury or illness in the body anymore.



Pain gates

Imagine that the pain message travels through a series of gates in the spinal cord before it can reach the brain. There are certain things that open these gates to allow pain messages to reach the brain but there are also things that help close the gate to allow fewer pain messages from getting through. For example, if the brain is busy receiving lots of other messages (e.g. about what we can feel, taste, smell, see and hear) the gates will not open to allow as many messages through. This can affect the intensity of pain that we feel.



Pain intensity

Even though you have pain it is very important that you stay active and continue to follow your usual routine when possible. After a while your body should realise that these pain messages are not helpful and that we do not always need to respond to them. The pain messages will gradually reduce over time as the brain learns to adapt. The intensity (or strength) of pain that you experience may still go up and down for lots of reasons. What we think, feel and do can have a big impact on the pain we experience. Below are some examples of things that can make pain better or worse.

Makes pain better (closes gates)	Makes pain worse (opens gates)
Distraction	Focusing on pain
Relaxation	Stress
Good sleep	Poor sleep
Exercise	Inactivity
Medication	Medical flare ups
Pacing activity	Overactivity or underactivity
Positive thinking/coping thoughts	Negative/unhelpful thoughts
Having fun/doing things you enjoy	Low mood, fear, anger, frustration
Support from friends and family	Arguments with friends and family

Managing pain

So many different things can impact our pain. Sometimes medication can be prescribed to help us with this discomfort and sometimes there are other helpful strategies we can try. The pain we experience and how we manage pain can also depend on:

- Our thoughts and the way that we think about pain
- Our emotions and how we feel about pain
- Our symptoms and how our body feels
- Our behaviour - what we do because of the pain or to avoid further pain

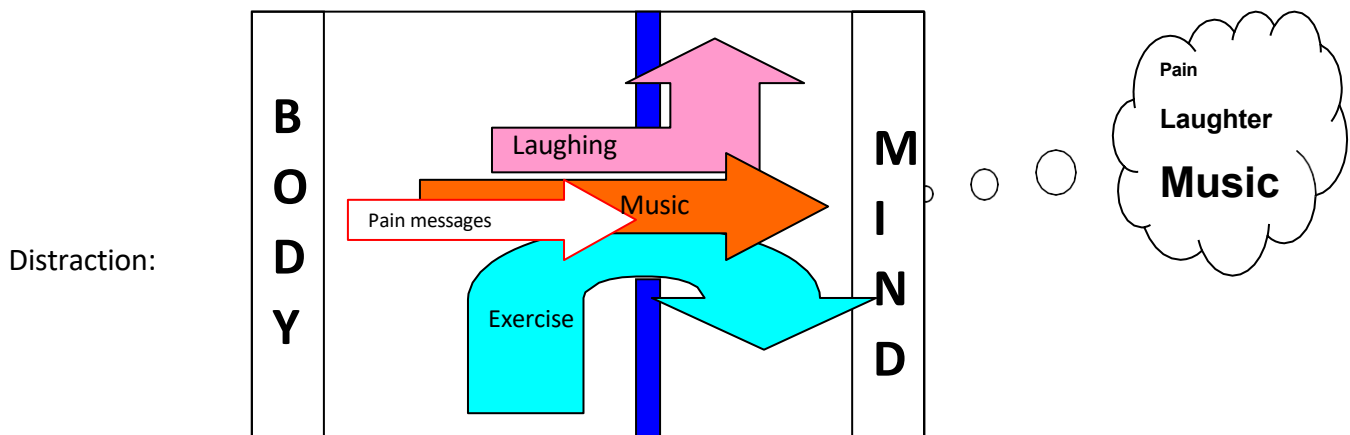
Throughout this booklet we will explore what intensifies and reduces the pain you are experiencing. We can use this information to help us learn useful strategies for managing pain.

Pain management strategies

As mentioned earlier, there are things that can help to lessen our experience of pain. To help you learn how to cope with pain and feel more in control, it can be helpful to think about what makes your pain symptoms worse and explore ways to reduce this by using strategies.

Distraction

We know that focusing on the pain or unhelpful/negative thoughts can increase our experience of the pain. Focusing on something else can keep your mind busy and reduce or prevent pain messages from getting through the pain gates. Distraction and enjoyable activities help by creating lots of other messages for the brain to process which leaves fewer opportunities for pain messages to get through the gate.



Activities

- Watching a good TV show or film
- Listening to music or a podcast
- Read a book or magazine
- Playing a game
- Drawing, painting or crafting
- Baking or cooking
- Doing a fun activity with friends or family.



Number games

- Count backwards from 100, or an even larger number (like 1000)
- Count backwards from 100 subtracting 7 at a time, e.g. 100, 93, 86
- Play 'Fizz-Buzz' – a counting game where you can't say three or seven; instead you have to say 'fizz' for three, and 'buzz' for seven. So 1, 2, fizz, 4, 5, 6, buzz, 8, 9, 10.

To make it harder, do the same for numbers that divide exactly by 3 or by 7. So 1, 2, fizz, 4, 5, fizz, buzz, 8, fizz, 10, 11, fizz, 13, buzz.

Letter or word games

- Think of as many animals, names, foods, or places as you can with different letters of the alphabet. (For example, B for animals - buffalo, bird, bear, baboon ...)
- Play 'stop the bus' with someone. One person says the alphabet quietly and the other person says 'stop'. Choose three different things that each of you has to say beginning with the letter that you stopped on (e.g. a country, a food, and a name). The first person to get all three things with that letter says "stop the bus" and wins (for example, the letter S could be Scotland, sausages, Samantha).
- Play the famous person game. One person says a famous person's name. The next person has to say another famous person beginning with the first letter of the surname, and so on.



Grounding

- Use the 5, 4, 3, 2, 1 method to focus on what is going on around you. Start by sitting in a comfortable place and take a deep breath. Then think of:

5 things you can see

4 things you can feel

3 things you can hear

2 things you can smell

1 thing you can taste.



Why not have a go?

When you notice yourself experiencing pain try to do one of your favourite activities or one of the distraction techniques from above.

Relaxation

Why is relaxation important?

Stress can open the gate and let in more pain messages, so it is important to break the cycle by practicing relaxation. Relaxation can reduce pain levels, improve sleep, and help you to feel calmer and more in control. Learning to relax takes time and practice but you can use it anywhere. Test it yourself by trying these relaxation exercises:

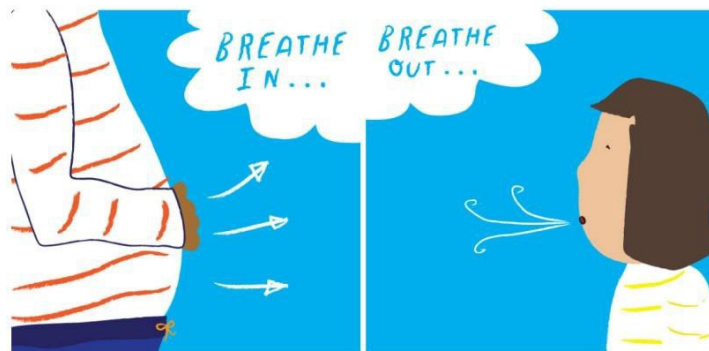
- **Controlled breathing**

Controlled breathing is a simple and quick exercise which can help you to relax and let go of tension. When we are feeling stressed or anxious we can experience lots of unpleasant bodily sensations and often our breathing gets quicker. Deep breaths can help you to calm your body down and gain control of your breathing. You can use this exercise anywhere, at any time.

Why not have a go?

Begin by placing one hand on your stomach and taking a deep breath in. Try to fill all your lungs with air. You can tell when you are taking a deep breath because your stomach will push outwards against your hand.

- Slowly draw in a deep breath while you count to 4
- Hold your breath for the count of 5
- Slowly breathe out while you count to 7
- Repeat this a few times to help take control of your body and feel calmer.



Tips

- You could use a clock, timer, or phone app to help you count
- Why not practice some visualisation while you try this exercise? For example, you could imagine that your stomach is a balloon inflating and deflating as you breathe
- You could count your breaths to help distract you from discomfort or think of an encouraging word with each breath such as 'relax'.

- **Muscle relaxation**

When we feel stressed or in pain, we often tense our bodies without even realising. Muscle relaxation encourages relaxation by reducing and releasing physical tension in the body. To do this, you can focus on a part of your body where you feel tension or you can tense all the major muscle groups in your body, one at a time. Check with your GP or physiotherapist that these exercises are ok for you to do before practicing.

Muscle groups

Face: Scrunch up your face, squeeze your eyes tight, push your lips together, and then relax.

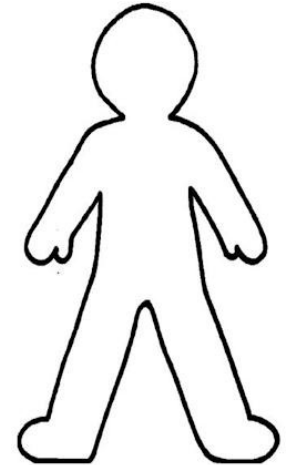
Neck: Push your head backwards against a chair or bed then let it rest while you relax.

Shoulders: Push your shoulders upwards then gently roll them forward and let them fall.

Arms and hands: Stretch your arms out in front of you, clench your hands as if you were squeezing all the juice out of a lemon in the palm of your hand, and then let them rest by your side.

Stomach: Push your tummy out, take a big deep breath, hold it, then relax as you exhale.

Legs and feet: Point your toes downwards, gently raise your legs, stretch them out in front of you, release, and then let them rest.

**Why not have a go?**

Begin by finding somewhere warm, quiet, and comfortable to practice this exercise. You might want to sit in a comfy chair or lie down on a bed.

- Try to find any areas of muscle tension in the body
- Gently tense a group of muscles and hold this tension for 5 seconds before letting go
- Try not to move these muscles for a while after releasing the tension
- Focus on the sensation of tension disappearing from your muscles and take deep breaths to help you relax
- Gently repeat or apply tension to other muscle groups until relaxed.

Tips

- Practice muscle relaxation at a time when no one will interrupt you
- If you experience discomfort or think this exercise is making your pain worse, stop and let someone know
- Exercising is another great way to stretch, tense, and relax your muscles. Why not try going for a fast walk, a run, or even a swim?

• Imagery

Imagery (also known as visualisation) is the process of picturing something in detail in your mind. By drawing attention to these details, we can use our senses (e.g. sight, sound, smell, taste, and touch) to divert attention away from uncomfortable or unpleasant symptoms such as pain. Some people use imagery to think of a relaxing and pleasant thought which encourages relaxation. It can also be used to change the way we view pain and, with practice, imagery can help ease how much discomfort is experienced. Below are some examples of how this can be done.



Colour/sight

How would you describe your pain if it was a colour?

Picture that colour in your mind and visualise it changing to a happy or calmer colour (for example, red to blue).



Sound

What sound would your pain be if it was a noise or musical instrument?

Imagine that noise being made in your mind and change the image to a new sound (for example, noise from a hammer fading into the sound of a calming flute).



How loud would your pain be if it was a volume level?

Imagine that you can turn down the volume and try to relax as it gets quieter and quieter.



Sensation/touch

What does your pain feel like?

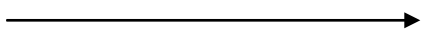
Picture your body gradually filling up with cool blue water from your feet, up through your legs, your stomach and into your arms. Imagine the water easing the pain. Once you are full of cool blue water, imagine the water slowly draining away, taking all the discomfort away with it.

Why not have a go?

You could imagine your pain as a colour or sound or begin by just focusing on its sensation. Once you have a picture of the pain in your head, take a deep breath and imagine the picture gradually changing into something more pleasant as you breathe out. Allow yourself to relax more, focus on your breath and the image changing.

Relaxation diary

Keeping a relaxation diary is a helpful way of monitoring progress and scoring how useful different relaxation strategies are. Using a scale of 0 to 10, mark the diary below to show how relaxed you feel each day, before and after trying relaxation.

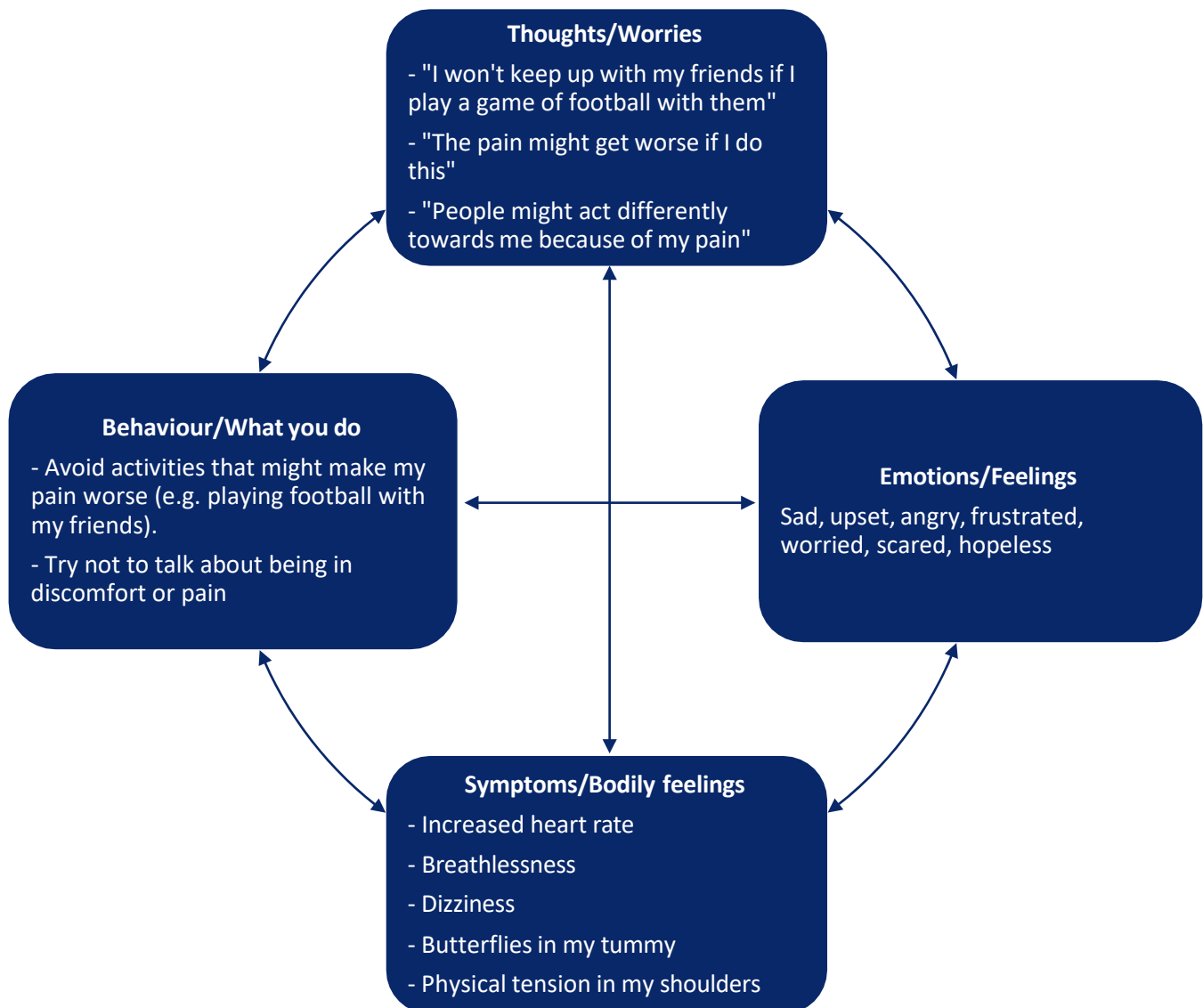
0 1 2 3 4 5 6 7 8 9 10
 Least relaxed  Most relaxed

Day	Relaxation level before	Technique used	Relaxation level after
	0 1 2 3 4 5 6 7 8 9 10		0 1 2 3 4 5 6 7 8 9 10
	0 1 2 3 4 5 6 7 8 9 10		0 1 2 3 4 5 6 7 8 9 10
	0 1 2 3 4 5 6 7 8 9 10		0 1 2 3 4 5 6 7 8 9 10
	0 1 2 3 4 5 6 7 8 9 10		0 1 2 3 4 5 6 7 8 9 10
	0 1 2 3 4 5 6 7 8 9 10		0 1 2 3 4 5 6 7 8 9 10
	0 1 2 3 4 5 6 7 8 9 10		0 1 2 3 4 5 6 7 8 9 10
	0 1 2 3 4 5 6 7 8 9 10		0 1 2 3 4 5 6 7 8 9 10
	0 1 2 3 4 5 6 7 8 9 10		0 1 2 3 4 5 6 7 8 9 10
	0 1 2 3 4 5 6 7 8 9 10		0 1 2 3 4 5 6 7 8 9 10
	0 1 2 3 4 5 6 7 8 9 10		0 1 2 3 4 5 6 7 8 9 10

Monitoring feelings and thoughts

Our thoughts, emotions, bodily feelings, and behaviours are all connected and affect one another. For example, our thoughts about pain can affect how much pain we feel and how we cope with the discomfort. Thinking about and focusing on the discomfort can allow more pain messages through the pain gates to your brain, increasing the intensity of pain that we experience. It is common to feel anxious, stressed, down or frustrated when we experience pain. You may also feel more withdrawn or nervous about doing too much activity in case the pain gets worse. This can often keep us stuck in an unhelpful cycle.

Below is an example of an unhelpful pain cycle using examples that people with pain might give.



While a negative change to one area can have an impact on other areas of our life, it's important to remember that this cycle can work in reverse. A positive change can make a big difference too. For example, instead of avoiding the activity, often engaging in the activity allows you to experience some positive emotions (joy, happiness, enjoyment) which can help you to have more positive thoughts ("that was great fun", "I managed to play with my friends"). This can break the unhelpful pain cycle.

Exploring and challenging unhelpful thoughts

Many people who are struggling with pain have negative or unhelpful thoughts. After any situation we have thoughts which quickly pop into our mind. Much of the time we are not aware that these are happening. These are called 'automatic' thoughts.

When these thoughts are negative or unhelpful it can be difficult to ignore them, especially if they pop up often. The more they pop up the more we may believe them and think they are true. For example, if a person thinks they "will never be able to play football again because of the pain" they may be more likely to feel frustrated and sad, be less likely to join in at football or other activities they enjoy and may experience more pain.



When someone gets stuck in a negative thought cycle, it is useful to explore and challenge these thoughts. We can do this by gathering evidence about our thoughts and worries like a detective and working through an exercise to challenge our unhelpful thoughts and balance our thinking.

Why not have a go?

Let's do some detective work and use the following questions to challenge any worrying or recurring thoughts ...

1. What evidence do I have that tells me this thought is true?
2. What evidence do I have that tells me this thought is not true?
3. What would my friends and/or family tell me if they heard me thinking this way?
4. What would I tell my friends and/or family if they thought this way about themselves?
5. Is there an alternative or more balanced way of thinking about this?

Now re-rate how much you believe the same thought. Has this changed?

Tips

- Keep track of any unhelpful thoughts that you have by writing them down on a notepad or your phone.
- Pick a regular time to practice this exercise each week until you feel ready to challenge thoughts as they pop up.
- Why not try using the thought diary (on the next page) to help monitor and challenge your thoughts?

Coping statements

It can be hard to feel like you are coping when you experience persistent or high levels of pain, especially if the discomfort makes you feel down or worried. It is important to remember that the pain will ease or pass eventually and to remind yourself of all the times you have coped with pain before.

Coping statements are short sentences that you can repeat to yourself to help remind you of this and encourage positive coping. Some people like to keep a copy of their coping statements on their phone, or in their pencil case or wallet to remind themselves of them.

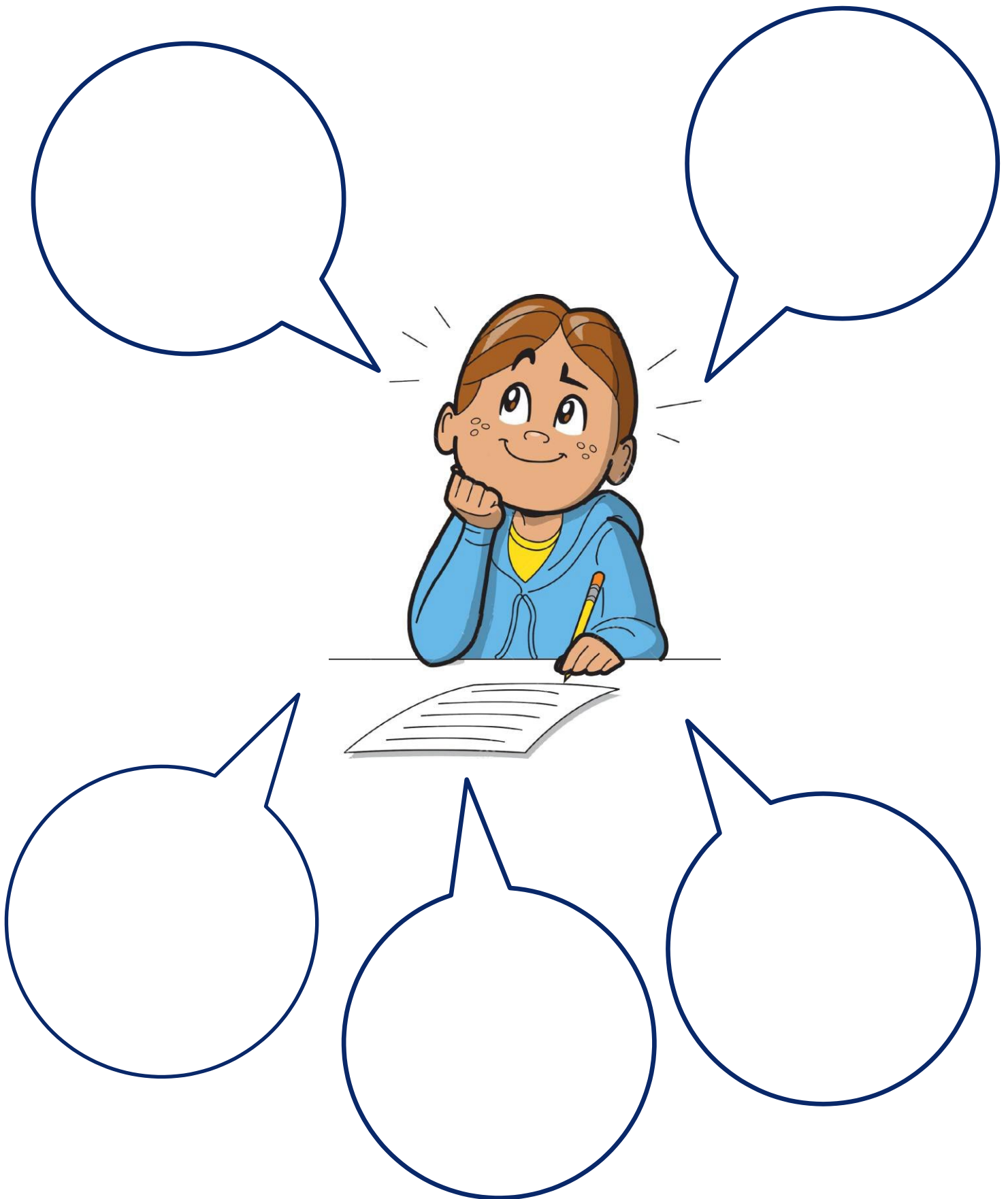
Some examples of coping statements are:

- This pain is uncomfortable, but it will pass eventually
- I can still take part and enjoy myself; I just need to pace myself
- I can get through this one step at a time
- I can use distraction and relaxation strategies to help me cope
- This pain will pass eventually
- I won't always feel like this
- I will be okay.

Why not have a go?

Write down a few of your own coping statements on the next page. Then, when things feel difficult, take a deep breath, and repeat some of your coping statements until you start to feel better.

My coping statements:



Managing energy

It can be difficult to eat healthily, exercise, and get enough sleep when you have pain. However, we know that when we don't get enough sleep, exercise and nutrients, then the pain gate can open and we can experience more pain. You might be tempted to change what you eat or do during the day, but this can have a negative impact on your energy levels and mood.

Diet and exercise

- Eating regular meals is important for maintaining even levels of glucose in the body and avoiding dips in blood sugar. These can sometimes lead to tiredness and tension headaches which make pain worse.
- Dehydration can also cause tiredness and headaches, so it is important that you drink enough water and fluids throughout the day to avoid this.
- Avoid sugary or caffeinated drinks and food after 4pm. This includes tea, coffee, coca-cola and chocolate.
- Regular exercise (without overdoing it) can help improve strength, fitness, mood and energy levels.
- Try not to carry out exercise late in the evening or before you go to bed as this can stimulate your body and keep you awake.



Sleep

- Go to bed and set your alarm to wake up at the same time each day.
- Try not to nap during the day. If you do need to lie down or nap, make sure that you do this on your bed where you would normally sleep.
- Make sure your bedroom is dark enough and a comfortable temperature to sleep in.
- Avoid using technology (e.g. TV, computer games, and phones) in your bedroom in the evening or at night. The bright light from these devices can stimulate your mind and keep you awake. Watching exciting or scary films can also keep you awake so try to avoid this too.
- Create a wind-down routine by making time to relax before bed. You could use this time to practice relaxation exercises or do a calming activity (e.g. having a bath or listen to some relaxing music).
- Having a busy mind or unhelpful thoughts can keep you awake at night. Writing down thoughts or worries that are on your mind each night before bed can help you wind down for bed and is a helpful reminder for any tasks that you need to deal with the next day.
- If you are having trouble falling asleep, try getting up and doing a relaxing activity until you feel sleepy enough to go back to bed. Keep bedroom lights dimmed and avoid doing anything that might make you feel more alert (such as using your phone).



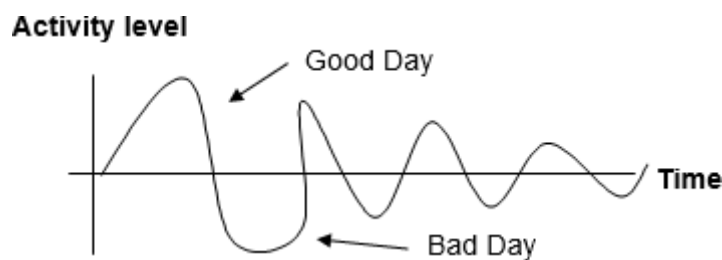
Pacing

Boom and bust cycle

It can be easy to 'overdo it' sometimes, especially if you are in a good mood, have a lot of exciting things planned, or when you feel like you are having a good pain day (e.g. no pain or low levels of pain). Equally, it can be tempting to do nothing or very little on a day when you are having a bad pain day. If you have done too much one day you may notice that you are more tired afterwards because of the additional activities that you have been doing. Too much rest can also increase pain as this makes your muscles weaker and makes it harder to move. This means you'll probably do less and less overall.

What happens when you do this?

These habits can result in an uneven pattern where your energy and activity levels go up (boom) and down (bust) a lot.



We call this '**Boom and Bust**'. Sometimes we get stuck in a boom and bust cycle and this might:

- Cause 'flare-ups' or make your pain feel worse
- Make it seem as though pain controls your life
- Make it harder to plan ahead because the pain could get worse
- Make it harder to follow routines or attend school
- Make you feel frustrated, sad, or like you're not getting anywhere.

What about underactivity?

Sometimes people can feel worried about doing anything in case this makes their pain worse so they might keep their activity to a minimum. This means you can't do anything because you think it might make the pain worse.

Making changes

Some of the activities or tasks we do need more energy than others. We might also have less energy on days when we experience a lot of pain. Pacing your activities can help you to get tasks done while still allowing you to take part in the activities that you enjoy doing and helping you avoid the boom and bust cycle. You can try pacing by making the following simple changes.

Slow and steady wins the race

If you are struggling with discomfort, try not to put too much pressure on yourself to take part in activities for their full duration. Taking breaks or doing things for shorter periods of time will allow you to still take part without overdoing it.



If in doubt, plan it out

Try not to plan too many activities into your day. Begin by doing small amounts of activity every day and gradually build it up when you feel you can manage this. It can help to think about how much you would do on a good pain day and try doing half of that before increasing your activity further. This will help your body to get used to more activity while helping you to avoid underactivity. The main goal is to be able to engage in a steady activity schedule even if you are experiencing pain.

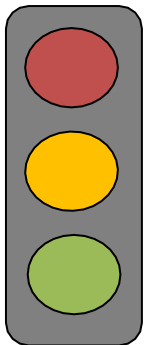
Small steps can make big changes

It can be difficult to make changes or return to activities when you experience persistent pain, so take it one step at a time.

Why not have a go?

Complete the activity diary on the next page to track your activity over the week. You can use a traffic light system to colour each activity based on how much energy it will need and this will help you spot times in the day where you may need to pace your activity or take more breaks.

For example:



Red – Exercise, playing games, schoolwork, worrying

Amber – Talking with friends, reading a magazine, washing

Green – Eating a meal or snack, resting, taking a break

Activity diary

	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
7-8am	e.g. Breakfast						
8-9am	e.g. Get ready						
9-10am	e.g. School						
10-11am	e.g. School						
11-12pm	e.g. School						
12-1pm	e.g. Lunch						
1-2pm	e.g. School						
2-3pm	e.g. School						
3-4pm	e.g. School and snack						
4-5pm	e.g. After school club and bike ride						
5-6pm	e.g. Homework and dinner						
6-7pm	e.g. Relax and talk with friends						
7-8pm	e.g. Watch TV						
8-9pm	e.g. Bath and get ready for bed						
9-10pm	e.g. Read and go to bed						

Goals

Setting small goals can make it easier to manage pain. Why not try making a SMART goal for something that you are willing to try this week?

Each goal will be...

Specific – clear and understandable

Measurable – something that I can track my progress on

Achievable – something that I can manage and work towards

Relevant – based on the topics in this booklet

Timed – something I can achieve this week

My SMART goal:

What other ideas do you have for managing your pain?

Write them down here...

