

The ROYAL MARSDEN
NHS Foundation Trust

Coping with persisting chronic pain



NHS

**Information for children, young
people and their families**

Oak Centre for Children and Young People

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Revised January 2023
Planned review January 2026

This booklet is evidence based wherever the appropriate evidence is available, and represents an accumulation of expert opinion and professional interpretation.

Details of the references used in writing this booklet are available on request from:

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No conflicts of interest were declared in the production of this booklet. The information in this booklet is correct at the time of going to print.

Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

CU-1446-04

Thanks to supporters of The Royal Marsden Cancer Charity, we raised £16 million to build the Oak Centre for Children and Young People. Opened in September 2011 by TRH The Duke and Duchess of Cambridge, it is one of the largest comprehensive children and young people's cancer centres in Europe.

The Royal Marsden is a world leading cancer centre, pioneering new treatments that save lives. To find out more on how you can get involved please visit www.royalmarsden.org

The Royal Marsden Cancer Charity
For a future beyond cancer



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What is pain?

Pain is the unpleasant feeling we have when our body is damaged, or could be damaged. The amount of pain we feel varies from person to person. Pain is both a physical and emotional feeling. We have to cope with the pain in our body as well as the unpleasant emotions that go with it.

Chronic persisting pain is when pain persists past the time when it would be expected for an injury to heal, and does not go away with normal treatment for pain. Chronic persisting pain can be constant, but can also come in waves.

Pain is normally well managed by pain killing medicines. Sometimes the pain can break through and other ways of helping you to cope with the pain are

needed. These added ways can also help you cope with the pain at any other time.

This booklet sets out some things that you can do to help you cope with your pain.

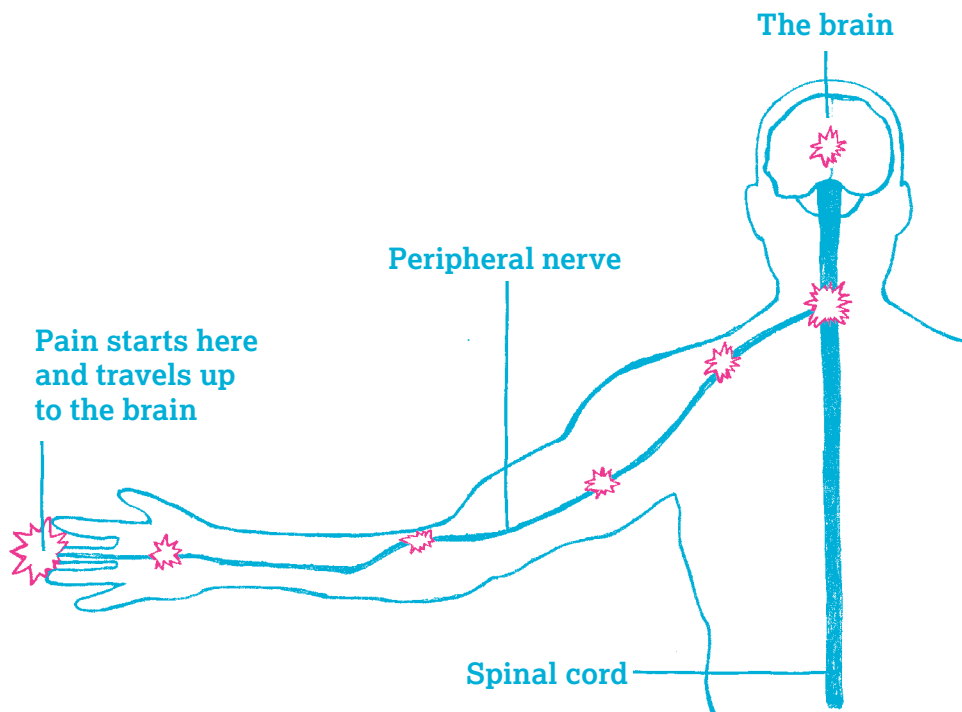
It is your brain that tells you that you are in pain and where the pain is. It is your brain that feels the pain, and tells you how much pain you have.

How does pain work?

When something hurts your body, your pain nerves send signals up the spine to your brain. It is your brain that tells you that you are in pain and where the pain is. It is your brain that feels the pain, and tells you how much pain you have.

Sometimes pain starts with an injury or medical problem, but then carries on even when this has healed. This

is because your brain can get stuck in the habit of feeling pain, even when the cause has gone away. As you only feel pain in your brain, this pain is exactly the same kind of pain you feel when the cause was there at first. Sometimes people do not understand this, and may say that you are “making the pain up”, but this is because they cannot see the part of your body that is causing it.



Things that affect how you cope with pain

Because so many things can affect pain, this means no one thing on its own will help you cope with your pain. Pain is complex. This is why some days you can take pain relief medicines for a headache and they take the pain away, and then other days they do not work at all.



Time off school/college and worries about education

Low mood or thinking negatively about yourself

Pain, anger, fear, frustration

Stress, worry, tension

Weak muscles and loss of fitness

Tiredness and lack of energy

Doing too much or too little

What makes pain feel **better**:

- Distraction (thinking of something nice)
- Having fun and doing things you enjoy
- Not focusing on the pain or paying attention to it
- Thinking positively
- Relaxing
- Having help and support from family and friends
- Medication
- Pacing activities so not doing too much or too little.

What makes pain feel **worse**:

- Stress
- Worrying (particularly about the pain)
- Arguments with family and friends
- Poor sleep
- Feeling down and depressed, angry, frustrated, frightened, wanting to 'give up'
- Overdoing things or not doing enough
- Paying attention to the pain
- Medical 'flare-ups'
- Thinking negatively and 'expecting' to be in pain.

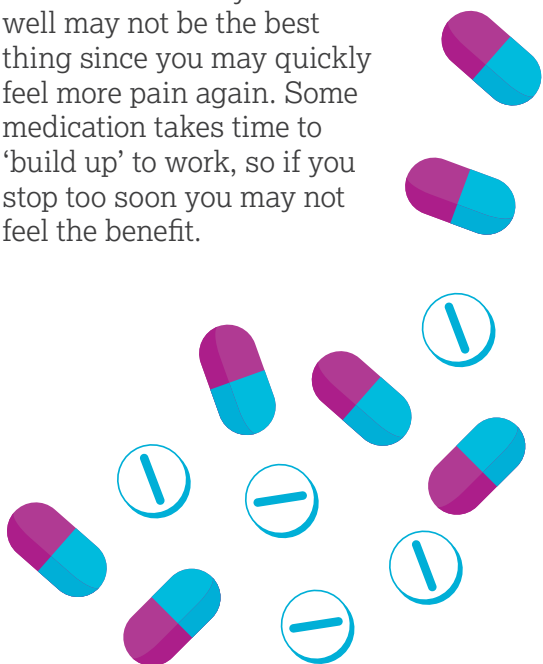
Learning to cope with your pain

Medication

Most people take drugs to help with their pain. If you are reading this booklet, then you are probably taking drugs to help with your pain, but they are not working well for you.

All drugs have side effects, and different people have different side effects to different medications. This is why the doctors and nurses may still be trying to find the best ones for you. It is all about a balance between the amount that takes the pain away with the amount of side effects you can cope with. Make sure you talk to the doctors or nurses if you are not happy with your medication for any reason.

It is important that you take your medication as the doctors and nurses have advised you. Stopping the medication when you feel well may not be the best thing since you may quickly feel more pain again. Some medication takes time to 'build up' to work, so if you stop too soon you may not feel the benefit.





Building a support team

Learning to cope with your pain can take time, and you will often need help from people around you. It can sometimes be difficult to know how to ask for help. You may also have the opposite problem, and have lots of people all trying to give you help and advice, and this may feel unhelpful.

It is important you work together with all the people around you to help you cope with your pain. This may include family, friends, doctors and nurses and other people from the hospital. Find out how people might help you, and make sure you speak to them about the things that you feel they can do to help – as well as what you do not find helpful.

It is important you work together with all the people around you to help you cope with your pain. This may include family, friends, doctors and nurses and other people from the hospital.



Helping you cope with your pain

A lot of these ideas have worked for young people with pain problems.

Different things will work in different amounts on different days. Just because something does not work one day, does not mean it will not work the next day. It may take a lot of patience and practice before you feel confident using these different strategies.

The only thing you need to do to start is to be willing to have a go and see if they help – the results could be better than you think.

These things can be hard to do at first, but the more you practice, the better you will get at coping and managing your pain.

Be kind to yourself if things do not go quite to plan, but do not give up trying.



Doing things you enjoy

It can be hard to distract yourself from your pain. This is because pain is meant to grab your attention, so that you can move yourself away from the thing that is causing your pain. When you have pain that is caused by something inside your body (or the 'habit' your brain is stuck in), you cannot move away from the cause, and it does not help to pay attention to the pain all the time.

Doing things to distract yourself from your pain can help. Things that are more likely to distract you from your pain are things you enjoy doing, and things that involve being with other people. Relaxation is also useful to try to distract you from your pain – particularly in the night, when it is hard to do things you enjoy.

Relaxation

Learning to relax is one of the most useful things you can do to help with your pain. It works by relaxing tense muscles, as well as distracting your mind and slowing down your thoughts.

We all spend time 'chilling out' when we listen to music, watch our favourite TV programmes, or play our favourite games. These are all important things which help to make you feel less stressed, worried or tense, and can help with your pain.

Relaxing is different to 'chilling out'. Relaxing is when you concentrate on slowing your body down and slowing your thinking down. Learning to relax can actually take a bit of effort to do at first, but with practice you will get better.

It can be helpful to practice relaxation when you are not in too much pain or full of worries, as this means you will be better at using it when you are feeling this way.

Dealing with worries

It is normal to have bad days. It is not worth sitting around worrying and waiting for those days to happen, as this will mean you will not do anything else. It also means you are less likely to do any of the things that will help to make it a good day.

Our worries often start with small things, but in thinking about them over and over, they tend to spiral out of control. This means you may often be worrying about much more than you actually need to.

Worrying means you are also always fixed on your pain, and so this is likely to make you notice it more – making it worse.

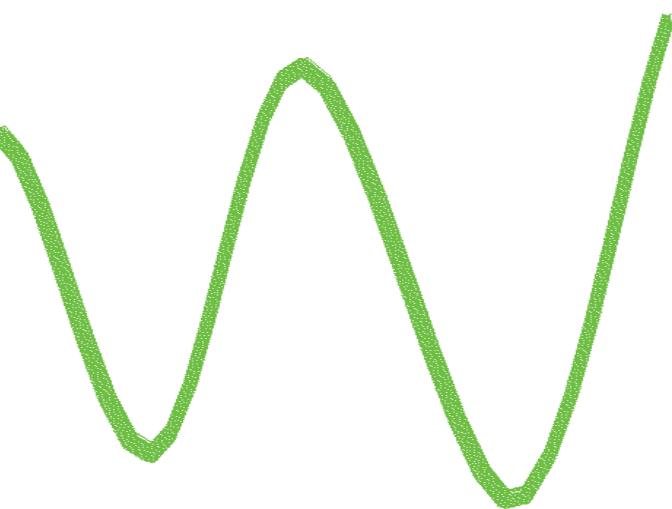


**Real size
of worry**

Reassuring yourself that things are not as worrying as you think they are helps.

This can be done by:

- 1 Talking about your worries with friends, family, doctors and nurses.
- 2 Thinking about what you would tell your friends if they had similar worries – what would you say to help them cope?
- 3 Thinking about ‘gathering facts’ as to whether or not you are right to worry as much. Think about the following questions:
“What are the facts or proof that I am right for thinking this?”
“What are the facts or proof that I am wrong for thinking this?”



Size of worry when thoughts spiral out of control

Looking after yourself

Looking after your whole body is very important.

Try your best to:

Eat a balanced diet

This can help lift your mood as well as help physically by keeping your body fit and healthy. A balanced diet does not mean eating 'perfectly', but it does mean not always eating things that are bad for you.

Regular meal times

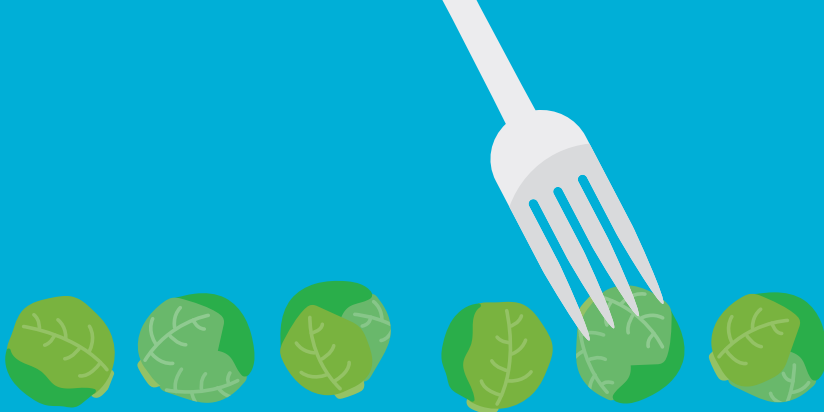
This helps to establish routine to your day and support you getting a balanced diet within waking hours.

Good hygiene

Washing and grooming your body daily will help reduce the risk of infection. It will make you feel better about yourself and more likely to want to go out with your friends.



Another relaxation strategy that you may find useful, is to have stories read to you that help you imagine being somewhere that makes you feel relaxed. Ask your doctor, nurses or psychologist if you would like more information about these.

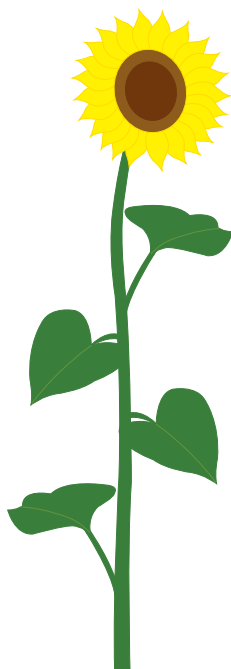


Regular (low intensity) exercise or stretching

This helps keep you busy and also keeps your muscles stretchy and flexible. When your muscles are not used much, they tighten and this can lead to you feeling more pain. Walking is excellent and one of the best exercises that most people can do.

You might have been given exercises to do by your physiotherapist. Physiotherapists are very good at helping you to understand the importance of daily activities to your well-being and so it is best to do what they suggest you try. It can be difficult at times to feel like doing these stretches and exercises, and you might feel worse at first (due to tiredness, or soreness in your muscles), but this will pass with time if you keep going.

If you have not got a physiotherapist, it is important to make sure you get up and have a stretch and move around every once in a while. Never sit in the same position for longer than an hour without stopping to stretch and move a bit.



Pacing activities

On a bad day (when you are in lots of pain) it is tempting to rest and not do anything that may make the pain worse. Then, on a good day (when you do not feel in as much pain) it is tempting to try and make up for it and end up overdoing things, which leads to a bad day... and so on. This is known as a 'boom and bust cycle' (the 'boom' is when you do everything and the 'bust' is when you cannot do anything).

For some people their boom and bust cycles can be weeks long, and for other people they can be hours long – it is not always about good and bad days. They all have the same effect though – over time you make very little improvement.

Pacing daily activities (such as walking, doing school

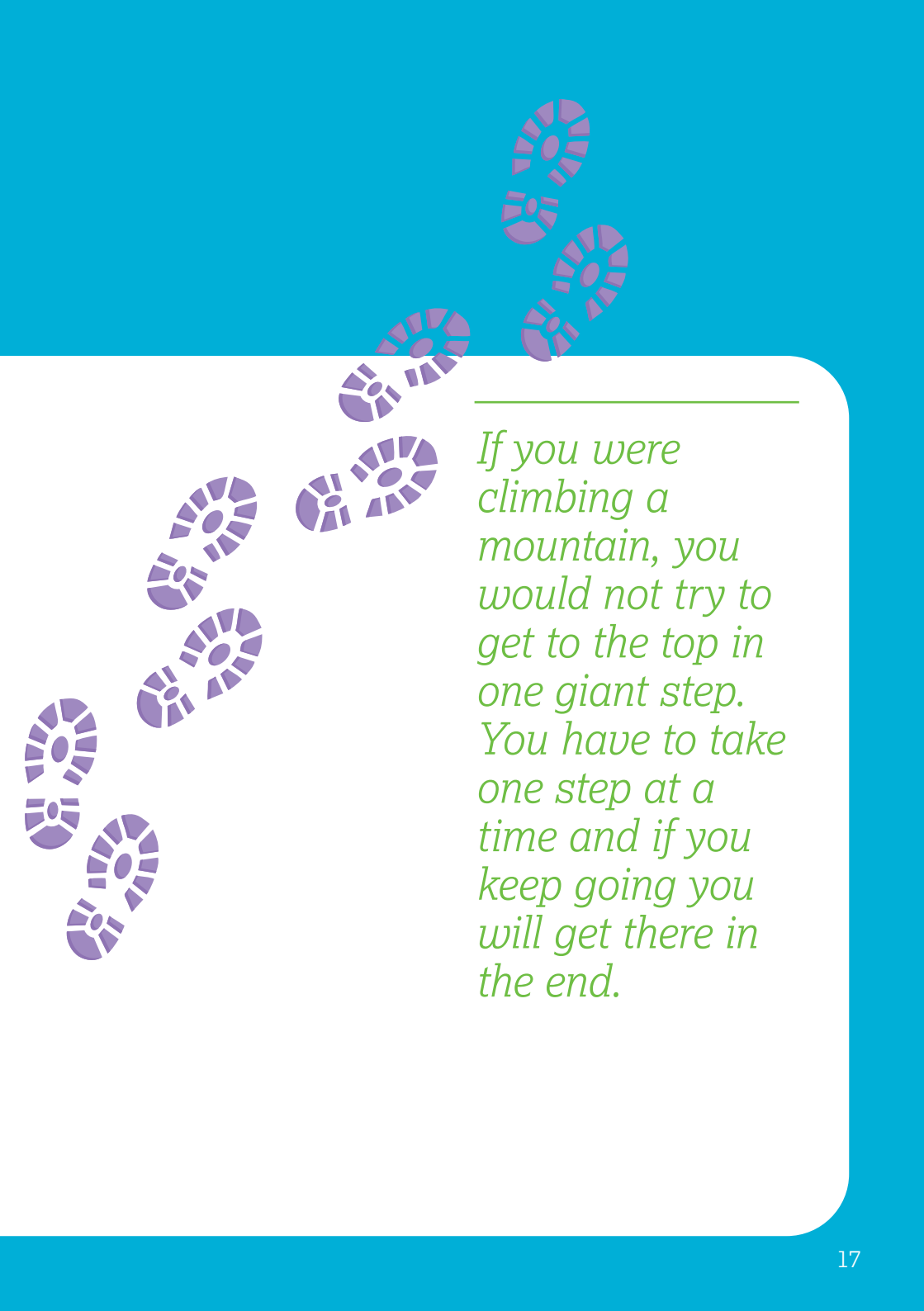
work, playing with friends, and so on) is a key tool for managing your pain.

By not pushing yourself on 'good days', but also doing a little of something (no matter how small) on 'bad days', over time the amount you feel able to do will increase. This is about being kind to yourself and not expecting to do things that you probably will not be able to do.

It involves taking regular breaks from the things you are doing, and making you take breaks before you need them because of your pain.

It is also about breaking things down into small steps and doing them one step at a time.

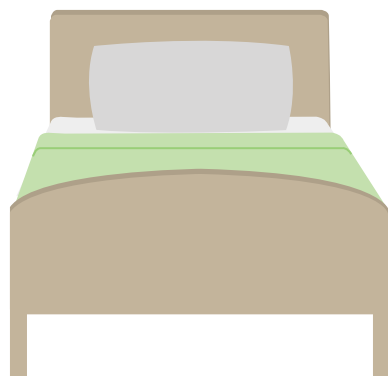




If you were climbing a mountain, you would not try to get to the top in one giant step. You have to take one step at a time and if you keep going you will get there in the end.

Quick and simple ways to relax

- 1 Take deep breaths
- 2 Sit or lie comfortably with your legs uncrossed
- 3 Close your eyes
- 4 Take a deep breath, filling up all of your lungs
- 5 Breathe out slowly (over about five seconds)
- 6 When you breathe out let your body go floppy
- 7 Think of a picture in your head of somewhere that makes you feel calm, safe, happy and relaxed (this can be a holiday you have been on, somewhere you have seen a picture of and always wanted to go to, or it can be a fantasy place). It is helpful to imagine being there with all your senses. What can you see, smell, feel and hear?
- 8 Repeat this for five breaths
- 9 Sit quietly for as long as you want after you have finished.





Sleep

Sleep is hard to do when you are in pain. At night there is less to distract you from your pain – this means pain can be a huge problem at night.

Trying to keep a good sleep pattern is essential. This means going to bed at the same time (not too late) and getting up around the same time. Your body clock works in a routine and is easily messed up by changing when you sleep. If you sleep a lot in the day, you are not likely to feel tired at night. To help cope with your pain, it is better to be awake in the day, and not at night (when there is less distraction).

It can help to:

Set an alarm for getting up at a reasonable time

If you like to press ‘snooze’, include this in the time you plan to get up and allow yourself a fixed number of presses of the ‘snooze’ button.

Keep to a rough bedtime

If there is a film or programme you want to watch on TV – record it or

watch it on catch up another day. The old saying: ‘An hour before midnight is worth two hours after’ is good advice.

Train your brain to think ‘sleep’ when you go to your bedroom

By doing lots of things in your room other than sleeping, your brain can associate ‘being busy’ with being in your room. It can help to only use your room for relaxing and sleeping, and to do active and busy things (such as school work, games consoles, TV) in a different room.

If you do not sleep at night do not try to catch up in the day

When people go on holiday and get ‘jet lagged’ they are not advised to sleep in the daytime, but told to try to get back to their normal sleep pattern. This advice applies to you too – you will sleep better if you only sleep at night.

Setting yourself an action plan

It is time to start planning the things you are going to do to try to help you cope with your pain. It is important you decide on when you are going to do things rather than just thinking/saying 'sometime' – since setting a goal means you are more likely to do it.



Setting targets

Keep things simple and small to start with, but also keep setting something new to try every day.

Be prepared for 'bad days' too, and make a set-back plan

Think about how you will cope if you cannot do the things you want to do, and how you might deal with your pain and disappointment.

Set-backs can actually be helpful too

Make a note of what might have triggered the set-back, and then you can try to avoid it next time.

Learn how to cope when things do not go to plan

This only makes you stronger for the next time you find things are difficult. Knowing you can cope with a set-back can give you confidence to tackle anything.

Contact details



If you have any questions about this booklet please contact a member of the specialist symptom team.

Monday to Friday, 9am – 5pm

020 8661 3625

Useful websites

www.britishpainsociety.org

www.nhs.uk/live-well/healthy-body



My goals

4 You may want to set yourself some goals to improve your pain. Your goals may change over time as your pain changes, so this action plan can be approached in stages.

Small simple steps that gently challenge you can be rewarding.



Example

Main distress or worry that is caused by the pain	Goals to achieve	How can I achieve this goal? (by myself/with help from others)	Date to review goal
Not meeting friends	To go out once a week with friends	<p>Motivate myself to get ready with rest breaks</p> <p>Have a pain plan during the activity with support from the Symptom Team</p>	



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