

My Pain Toolkit

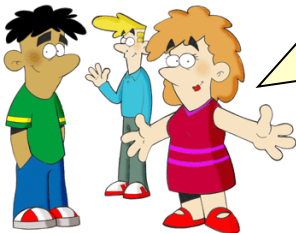
For young people and
teenagers living with pain



- ◆ Does pain stop you from doing the things you enjoy?
- ◆ Do you struggle to understand your pain?
- ◆ Do you want your pain to stop controlling you?

If any of these questions are true then this toolkit is for you!

The Pain Toolkit is a simple guide that gives you some handy tips and skills to help you to understand and manage pain better!



I loved the Pain Toolkit, it wasn't talking at me, but just giving me some tips and ideas that others have used to manage their pain.

By Pete Moore and Jessica Bird

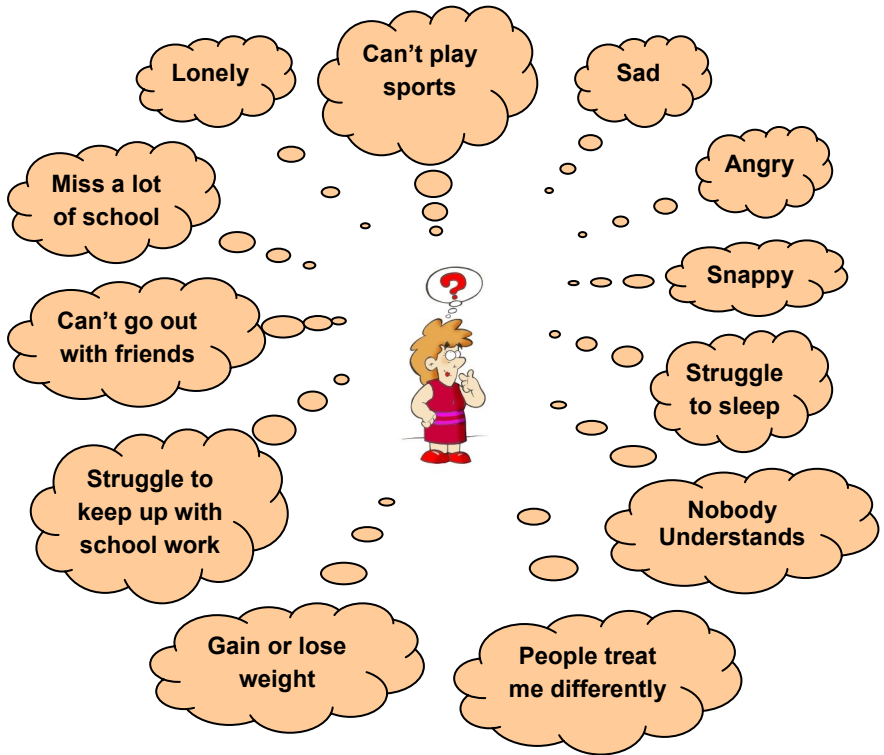
www.paintoolkit.org



How does your pain effect you?

Living with pain can be really difficult. Not only can it effect the things you do, it can also effect the way you feel, the way you think, and your relationships with your friends and family.

Below are some of the most common ways that young people say pain affects them. Does your pain have a similar effect on you?

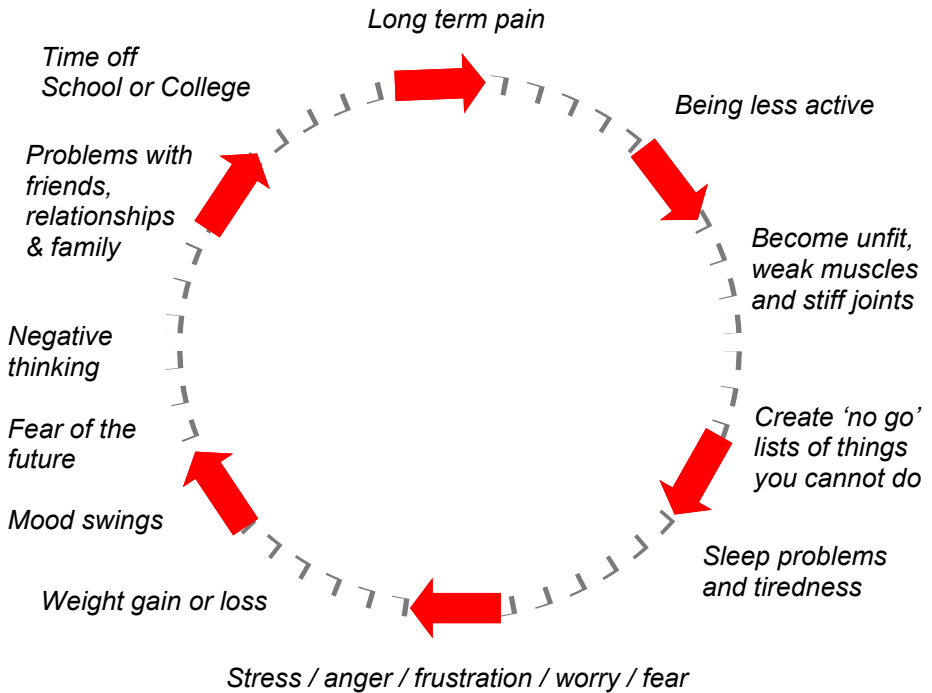


Are there any more that are not listed? List them here:

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The pain cycle

A lot of young people find that having long term pain can create a cycle. Look at the pain cycle below - does it seem familiar?

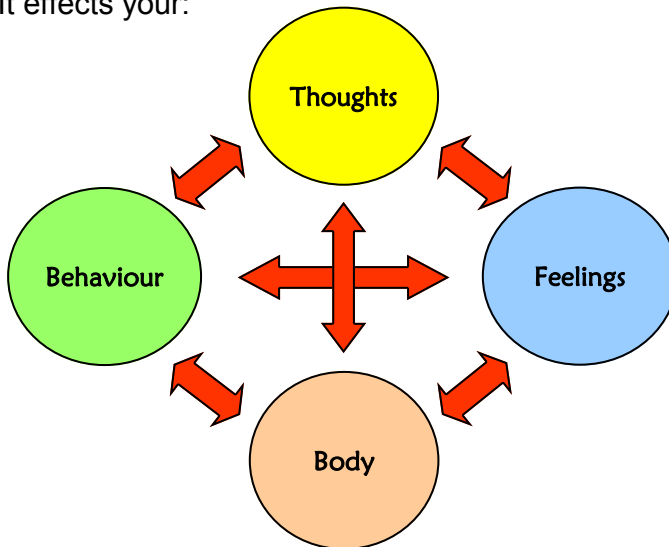


This cycle means that your pain keeps on going and things keep getting worse. **We need to BREAK this cycle**; making changes that will lead to less pain rather than more pain!

The tools in this Pain Toolkit are all designed to help you break your own pain cycle.



So, as you can see, your pain can effect you in many different ways. It effects your:



This is why using only medical treatment doesn't always work for long term pain - it focuses only on the physical symptoms (aches and pains) and ignores your thoughts, feelings and behaviour.

**To successfully manage pain we need to
focus on ALL parts of your pain!**

Managing pain is like learning any other skill such as learning to play the guitar or riding a bike - it just takes time and practice! Sometimes you could get frustrated, but stick with it. It does get easier.

The Pain Toolkit can help you to choose some simple tips and skills that focus on all these aspects of managing your pain. By learning these skills you **CAN** learn to self-manage your pain and live your life normally even though you have pain.

What is pain?

Pain is like a warning, just like the warning light on a car telling us something is wrong and needs attention. Pain is our brain's way of telling us that we are either **harming ourselves** or **about to harm ourselves** so that we can do something to stop it. For example, when you touch something hot, the pain makes you move your hand to stop you burning yourself.

If you do injure yourself, for example breaking an arm, your brain can keep sending pain messages for a while. This isn't because your arm is still being damaged, but as a way to stop you moving it too much so that it can heal quickly. When the bone has healed, the pain goes away as your arm doesn't need protecting any more.

Pain is a message created by your brain telling you to protect yourself

There are two types of pain:

- ◆ **Acute pain** begins suddenly and doesn't last for too long.
- ◆ **Chronic pain**, sometimes called persistent or long term pain, is pain that last longer than three months.

Long term pain

Sometimes pain sticks around longer than it needs to. The usual medical treatment doesn't always work as easily for this long term pain, making it very confusing and difficult to understand.

Like after breaking an arm, this long term pain doesn't mean the painful area is being damaged. In fact in some cases doctors cannot find any damage in the painful area making it hard to understand why it hurts. When this happens, **it's like the brain is confused**, sending pain messages when it doesn't need to!

The pain gate

As we can see, long term pain isn't very simple to understand or manage. However, we have a simple way of thinking about how pain works called the Pain Gate.

The '**Pain Gate Theory**' tells us that there is a 'gate' that controls the flow of messages between your body and your brain.

Remember, it's the **brain that makes you feel pain**, so if the brain's messages can't get through the gate then you won't feel the pain!

- ◇ When you are stressed does your pain hurt more?
- ◇ Is your pain better when your are relaxed and happy?

This is because certain things that we do can either open or close the gate; changing how many pain signals reach your brain. Below is a list of things that can open and close the gate.

Opens Gate	Closes Gate
<ul style="list-style-type: none">• Stress• Tension• Anger• Sadness• Worry• Lack of activity• Focusing on pain	<ul style="list-style-type: none">• Relaxation / calm• Happiness• Stretching / exercise• Distraction• Painkillers / medication• Massage / heat / cold• TENS machine

There are lots of things that YOU can do to close the gate on your pain and make it easier to manage!

Tool 1: Acceptance

Accept that you have chronic pain.. and then move on.

Acceptance is the first and sometimes the most difficult step to make. However it is the most important one in your pain toolkit.

Are any of these thoughts familiar?



Many young people get very sad and angry about their pain, spending lots of time wishing things were different or how they used to be. This type of thinking only makes your pain worse because those negative feelings open your pain gate!

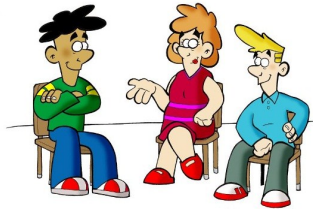
Acceptance is not about giving up but recognising that you need to take more **control** over how you manage your pain and being okay with how things may have changed.

Rather than focusing on what you used to be able to do or what your pain is stopping you from doing, **focus on what you CAN do!**

This acceptance will be a bit like opening a door - a door that will open to a life where you can take control of your pain!

Tool 2: Build your support team

As we know, having long term pain isn't easy and trying to manage it alone may be unrealistic. It is important that you get involved with your healthcare professionals and have people around you who can help you out and support you.



Many young people with pain find their family and friends difficult because they can either be overprotective or not understanding enough of their pain. This means it can be a good idea to choose a couple of people you trust and help them understand. You could even show them your Pain Toolkit! Use these people to talk to when you are struggling, want advice or just need to talk.

Name 5 people who could be in your support team

1.
2.
3.
4.
5.

Ideas

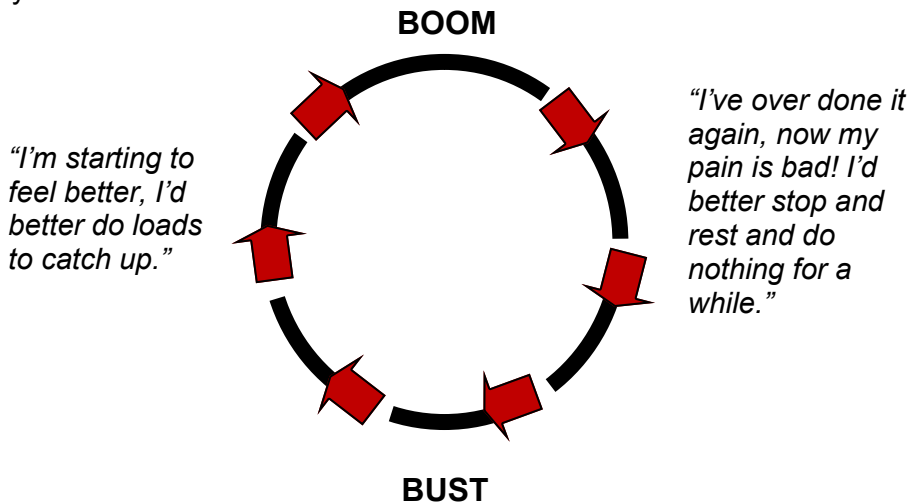
- ★ Doctor
- ★ Family member
- ★ Friends
- ★ Teachers

Tool 3: Pacing

Do you have good days and bad days?

- ◇ On your good days when your pain is better do you try and make the most of it by doing lots?
- ◇ Do you then do nothing and stay in bed on your bad days?

This is the '**Boom and Bust**' cycle - your boom of activity caused you to bust!



However, booming and busting isn't very good for us.

- ◇ Doing too much can strain your muscles and tires you out.
- ◇ Resting too much makes your muscles weak and stiff, making it harder to be active when you want to do.

Over time, we become more tired and weak and we start doing less and less!

IMPORTANT: Show this pacing information to your teachers and explain why you may need to pace your activities and need to take more than usual breaks to avoid your pain increasing.

A different approach...

We can get ourselves out of this cycle by **pacing**. Pacing means taking a break before we think we need to. This can be a tricky skill to learn, but an important one. A tricky one because we want to keep up with others, but this is not always for us. Perhaps in time, it will be.

- ◇ Try and keep your activity level at the **same level every day**, despite the pain.
 - ☆ On a good day try not to over do it - **stop BEFORE you start to feel pain**.
 - ☆ On the bad days, make sure you do something. This way the pain is not controlling your behaviour!
- ◇ Take regular breaks. This will stop you from overdoing it. If you are cleaning your room, stop and have regular breaks.
- ◇ If there is a specific activity you want to do more of, treat it like a marathon. Start slowly and gradually increase how long you do it for over time.



As soon as I saw the boom and bust cycle, I recognised myself straight away and could see why I was so stuck.

Speaking of marathons...

If somebody decided to run a marathon, would they be able to do it without training? Absolutely not! They will need to build up their fitness. They start off going for short runs and gradually, over time, increase the length of their runs until they are fit enough to run the full distance.

Tool 4: Plan your days

And decide what is important!

To be able to pace yourself it can be really helpful to start planning your days and what you are going to do. Think about the things that you want to do. Instead of trying to do it all at once, decide what are the most important things and focus on them. Forget about the less important things for now.

Planning out your days is really helpful for dealing with your pain. Planning when and how long you will do something will help you with your pacing, making it less likely that you will get carried away and do too much! You can plan breaks in between your activities and have dedicated relaxation time.

If there is something big you want to do, break it down into smaller steps and plan out when and how you are going to do each step. Take it one step at a time.

Example plan:

Monday a.m.

Do some stretching as you have a long day at school

Monday p.m.

Do relaxation before homework. Take a 10 minute break after every 30 minutes of homework.

Tuesday a.m.

Have a bath to relax you for the day.

Tuesday p.m.

Clean bedroom, taking a 5 minute break every 10 minutes.

Tool 5: Setting Goals

Setting yourself clear goals is a great way to achieve the things you want and will give you something to work towards. Achieving our goals makes us feel good about ourselves and shows us that change can happen!

Ask yourself what you would like to achieve. This could be anything that is important to you. Make sure your goals are **SMART**:



Specific

You're more likely to achieve your goals if they are specific. For example - "I want to be able to exercise" isn't very clear. "I want to start swimming" is easier to work towards.



Measurable

It is easier to know when you have achieved a goal if it can be measured. Distance, a time limit or the number of times you do it are ways to measure goals; e.g. "I want to swim twice a week".



Achievable

It's important to be honest and realistic. Can your goal be achieved? If not, you will set yourself up to fail.



Rewarding

The more rewarding a goal is, the more likely you will want to do it! Either make sure the goal is something that will make you happy, or give yourself treats for your success.



Timed









Set yourself a timescale. If you don't have a plan then it can be hard to get started and stay focused. You can always change your time limits, but make sure you set them.

Tool 6: Relaxation

Learning to relax is a great way to help reduce your pain. When you're in pain your body tenses up, but being tense actually makes things more painful! Relaxing can stop you from getting tense and also closes your pain gate - meaning you feel less pain!

It is important to make regular time to relax, so schedule it into your day. It may be helpful to plan it in the morning to prepare you for the day or at night to help you sleep.

Good ways to relax:

-  Take a bath
-  Read a book
-  Listen to music
-  Watch a film or favourite TV programme
-  Meet friends
-  Breathing exercises
-  Meditation (you can learn this in Yoga)
-  Or ANY activity that you enjoy and relaxes you!



I'm going to take a bath, then watch a film.



Body Care:

As your body is where your pain is, it's important to look after it!

- ◆ Eat healthy food including lots of fruit and vegetables.
- ◆ Don't drink too much caffeine (e.g. cola, energy drinks, tea, coffee). Caffeine can effect your mood, sleep and pain.
- ◆ Sleep well! Only sleep at night and avoid day time naps.
- ◆ Good hygiene - washing and grooming your body daily.

Balloon Breathing

Breathing exercises can be a great way to relax and deal with your pain. Put on some slow music and do this focused, deep breathing for a set length of time every day, e.g. 15 minutes before bed.



However, try breathing like this for a few minutes if you are feeling stressed or in a lot of pain. It will help to calm you down and make any pain easier to cope with.

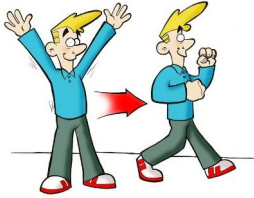
- ◆ Get comfortable, sitting in a nice chair or lying on the bed and close your eyes.
- ◆ Imagine that you have a balloon in your tummy. Every time you breathe in, the balloon inflates: Each time you breathe out, the balloon deflates. Take a deep breath in, and hold it for 2 seconds, then slowly deflate the balloon by breathing out for 2 seconds.
- ◆ In your mind, when you breathe in, say “one”. Then when you breathe out say “two”. Keep repeating this and turn all your attention to the two numbers and the feeling of the balloon breath expanding and releasing.



I always thought relaxation was just doing nothing, but since I have practiced the balloon breathing, my pain has gone down.

Tool 7: Stretching & Exercise

A lot of people are scared of exercise as they think it could cause more problems or increase your pain. However, this is not true.



Regular stretching and exercising actually lowers pain and discomfort. It prepares the body for movement and strengthens weak muscles so you will feel better for it. It also makes your body release special hormones that help to close your pain gate!

Remember to pace! Start slowly and gradually build up your amount of stretching and exercising. It is not as hard as you think.

If you are in pain, remember that unfit and under used muscles feel *more* pain than toned ones. Talk with a physiotherapist or fitness coach about an individually tailored stretching and exercise programme that you can work on steadily and safely. This will help you improve your confidence, muscle and joint strength.

Exercise doesn't have to be anything fancy or intense; just going for a gentle walk is a brilliant way to get you moving and build your fitness. Swimming (or just walking up and down in the pool) is also a great, gentle exercise that is good for joint problems. You can find 15 reasons why exercise is good for you on page 21.



I used to hate exercising as it increased my pain; I was doing too much at once. Now I start off slowly and increase a little each time I do it. I'm starting to feel stronger and not as sore!

Exercise Programmes

Joining an exercise programme can be a fun way to build up your strength, learn relaxation techniques and meet other people. Lots of people with pain find the following ones helpful:

- ◇ Yoga
- ◇ Tai Chi
- ◇ Pilates (pronounced Pil-ar-tes)

Please make sure that the teacher is qualified and experienced in teaching people with persistent pain. Always exercise at a pace that feels right for you.



I noticed that my dog stretches when she wakes up so I asked my doctor why this is. He told me that she is preparing her body for movement. I realised that his was like me and so we stretch together each morning.

Tool 8: Be Patient

It may take you a few weeks or months to see improvements. This can make it hard to stay motivated, but keep at it and take things steadily. If you start telling yourself that it isn't working or you can't do it, you probably won't.

Think positively and believe in yourself - you CAN do it!

When you start to feel good, you may want to catch up with some activities that you may have let go of. But don't be tempted to over do it otherwise it will be harder to stay on track. A good saying is 'take things one step at a time'.

Have you become a 'can't do' person?

A **'can't do'** person has given up the things they used to do such as playing a sport, going out with friends, eating out or taking part in family activities because of their pain. This often makes people lose confidence and so they avoid doing even more, just in case they can't. Is this ringing any bells? Practising the tools in the Pain Toolkit will help you feel more confident and become a **'can do'** person again.



Tool 9: Track your progress

Keeping a diary of your progress will help you to see how far you have come and note the successes you have achieved. This will then help you to build on your success. But it's also handy to note what didn't work so you can learn from those experiences. We sometimes learn more from our errors and not from our successes.

Try to write down one piece of evidence each day to show how **you are positively managing your pain**. Even on bad days you will have done something positive - for example, realising what made things worse is successful pain management! People often find that recognising their progress improves their confidence.

Tool 10: Have a setback plan

Is it realistic to think you will never have a setback where things go bad again?

The simple answer is NO!

Be prepared and have a setback plan so you know what to do if things go wrong. You could ask your healthcare professional if you need help in making one.

If you have a setback, make a note of what it was that made it worse and also what helped. This could be useful information when you experience another.

You can find an example setback plan on page 21.



Using the Internet

Type 'pain' into a search engine and approximately 976,000,000 results will come up! Not everything you read is accurate, and some sites may be trying to sell you something.

Always discuss with your doctor if you are thinking of trying something you have read about.

Tool 11: Teamwork

Teamwork between you and your healthcare professional is vital. Imagine the Arsenal football team playing without a game plan!

Managing your pain is not a 'one way street' and it is not realistic for your health care professional to totally solve it. You have an important part to play and need to get involved.

By working together both you and your health care professional can set an action plan. This action plan can help you both to track your progress and decide what to do next.



Teamwork is also about working with the people around you everyday. This includes your family, friends and teachers. It can be tempting to shut certain people out at times, but accepting peoples support will make your pain management easier. Try to be honest and show them your Pain Toolkit to help them understand.

Tool 12: Keeping it up!

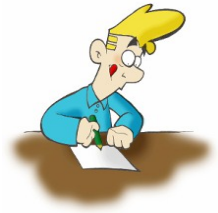
Putting tools 1-11 into practice

You may be asking yourself if you have to put these tools into practice *everyday*? The simple answer is **Yes**.

Just as a person with diabetes has to take their treatment and maintain their diet daily, your treatment is planning, prioritising, pacing, setting weekly or long-term goals/action plans, relaxation, exercise, generally keeping active and being in charge of your pain.

Keeping it up is difficult for many people but it's not as hard as you think once you have set yourself a routine. Just like brushing your teeth, self-managing your pain will become a habit. Get others involved and make pain self-management fun!

What 3 things have I learnt about managing my pain?



1.
2.
3.



What will I try?

.....

.....

.....

Stretching & Exercising

15 reasons why it is good for you

- ✓ Helps to improve and maintain good overall health
- ✓ Increases strong cardiovascular system – heart, lungs and blood vessels
- ✓ Increases muscle strength
- ✓ Improves flexibility
- ✓ Increases endurance and stamina
- ✓ Increases natural pain killers (called endorphins) in the bodies nervous system which help control pain
- ✓ Helps with weight control
- ✓ Helps to improve quality of sleep
- ✓ Helps balance and co-ordination
- ✓ Reduces fatigue and increases energy
- ✓ Reduces muscular tension, stress and depression
- ✓ Helps combat depression and anxiety
- ✓ Helps maintain a positive outlook
- ✓ Helps to prevent constipation
- ✓ Can be sociable



Drinking Water

Water is essential for a healthy life so drinking plenty of water is important for everyone. It's even more important if you are taking part in physical exercise, so make sure you keep properly hydrated before, during and after exercising.

Examples of Pacing

Sophie & Swimming

Sophie used to love swimming. However, since her pain she stopped doing it. After learning the tools she wanted to start again but knew she needed to pace herself. She started by going to the swimming baths on a Saturday and just walking gently in the pool, stopping often. On the third Saturday she took the next step to swimming 5 lengths, but stopping for 5 minutes in-between each one. She did this for another three weeks and then increased it to having a break every 2 lengths. Sophie continued to slowly increase the number of lengths she did and eventually started going twice a week. She found that by pacing herself she built up her strength and could do more and more without getting any pain.

Daniel and Cleaning

Daniel's room was a mess. It was a big job and he knew that if he did it all at once he would be in a lot of pain. He decided to make a pacing plan. He planned to spend 1 hour cleaning each night but to take 5 minute breaks every 15 minutes. However, on the first night he noticed that after the first 15 minutes he was beginning to get pain. He realised that he needed to stop before this so changed his plan to having a break every 10 minutes and stopping after 40 minutes. He did this for 3 nights and got his room tidy without getting lots of pain.

These are just examples. There may be many other everyday activities that you need to think through before you tackle them. If you stop and think about what you intend to do **BEFORE** you do it, there is less of a chance that you will have a set back.

Remember pacing is 'taking a break before you need it' and spreading out your activities.

Your Setback Plan

It is not realistic to think that you will never have a set-back. Having a plan will help you be prepared and recover quicker.

Setbacks are usually caused by doing too much, for example overdoing it, giving into pressure from friends or just forgetting about your pain. It is common to occasionally have setbacks.

Remember, you can always ask your doctor or healthcare professional for help with your setback plan if you are unsure.

First of all, do not panic! Your plan will help you through. Accept that you are having a setback and just as it came, it will go.

Pace yourself and prioritise!

- ◇ Pace yourself by breaking up tasks into smaller portions and resting in between. Reduce your activities until the setback settles.
- ◇ Be kind to yourself. Say 'NO' to any unnecessary demands put upon you until you are feeling healthier. And don't be too proud or scared to ask for help!

Taking your medication

- ◇ Get advice from your GP about your medication.
- ◇ If you have to take it regularly think of ways to remind you. Set a reminder alarm on your phone, use 'post-it' notes, or get someone to remind you.
- ◇ Remember that taking medication may mask the pain and encourage you to do more. Make sure you take things slowly even if the medication has reduced your pain.

For 'musculoskeletal' pain (back, leg, arm, neck etc.)

- ◆ Apply heat and/or ice in a way that makes you most comfortable. You could apply ice packs wrapped in damp towels for 5 minutes every hour for the first one or two days.
- ◆ Always make sure you have a cloth between your skin and the ice to prevent ice burn to the skin. You should avoid lying on an ice pack.
- ◆ People with rheumatic problems may prefer to use heat rather than ice. **If you are not sure, ask a GP.**

Take it easy.

- ◆ Briefly cut back on normal activities. Lie down for a short while and relax (but avoid resting all day - try to do small things).
- ◆ Bed rest weakens muscle strength rapidly; you lose about 1% of total muscle strength a day if you become inactive.
- ◆ After resting make sure you get up and do some gentle activity. Keeping active will actually speed your recovery.

Try to start moving gently

- ◆ Remember to pace yourself. Begin with gentle stretching and movement as soon as possible.
- ◆ Keeping active may seem like the last thing you should do, but with long term pain it is really important. Don't be put off – it does work!

Relaxation

- ◆ Using relaxation is another good way of managing a setback. Have regular relaxation time and use your balloon breathing.

Useful Website Links



- ◇ **Pain Toolkit** www.paintoolkit.org
Download copies of the Pain Toolkit
- ◇ **BBoy Science** www.bboyscience.com
Physical Therapist / B-Boy explains exercise and pain
- ◇ **Fibromyalgia Association UK**
www.fibromyalgia-associationuk.org
- ◇ **ME Association** www.meassociation.org.uk
- ◇ **Youth Health Talk:** www.youthhealthtalk.org
Watch, listen and read about real young people's experiences of health problems.
- ◇ **Mood juice:** www.moodjuice.scot.nhs.uk/
Advice on overcoming a variety of emotional problems
- ◇ **Quiet Mind Café:** www.quietmindcafe.com
Website of free relaxation videos
- ◇ **Pain Relief Foundation:**
www.painrelieffoundation.org.uk
UK charity researching causes and treatment of chronic pain
- ◇ **Your Health Your Way** www.nhs.uk/yourhealth
NHS guide to long-term conditions and self-care.
- ◇ **Young Minds:** www.youngminds.org.uk
Information on emotional health of children and young people

Helplines

- ◆ **ChildLine 0800 1111**
Free, confidential support 24 hours a day, 7 days a week. You can talk through the helpline, through email or through instant messaging online. www.childline.org.uk
- ◆ **Samaritans 08457 90 90 90**
Confidential emotional support 24 hours a day, 7 days a week. You can phone the helpline, write an e-mail jo@samaritans.org
www.samaritans.org
- ◆ **Young Minds Parents Helpline 0808 802 5544**
For anyone concerned about the emotional health of a child or young person.
- ◆ **NHS Direct 0845 4647**
24/7 advice on health related problems. www.nhsdirect.nhs.uk

YouTube Clips

Guided Relaxation

- ◆ <http://tinyurl.com/6gzf4kp>
- ◆ <http://tinyurl.com/clkc2gb>

Progressive Relaxation for Pain

- ◆ <http://tinyurl.com/cgfwks3>

Understanding Pain (What to do about it in less than 5 minutes)

- ◆ <http://tinyurl.com/5ts4xva>

Why things hurt (This may sound technical at first but bear with it as its really cool)

- ◆ <http://tinyurl.com/7g79by3>

More about the authors

Pete Moore & Jessica Bird

Pete lives in Essex and is a keen promoter of pain self-management and other health conditions. Pete lives with pain himself and has written several pain management programmes and books. He is often asked to provide educational seminars for health care professionals and patient groups in the UK and Europe.



Pete Moore

Pete is a member of the:

- ◆ British Pain Society
- ◆ International Association Study of Pain (IASP)
- ◆ Australian Pain Management Association

“Self-managing pain or a health problem is not as hard as you think and the best way to approach it is by taking small steps. Be patient with yourself. We, as that saying goes ‘want to walk before we can run’. Easy does it. You will get there.”

Always ask for help and support from your doctors, family, teachers and friends. In time you will become more confident and in control”.

Jessica lives in Leicester and works as an Assistant Psychologist in child services and has experience in pain management and working therapeutically with children and young people. She has an Honours degree in Psychology and is a member of the British Psychological Society.



Jessica Bird

“Change can be really scary. However, the fact that you are even thinking about changing is a really positive thing. Believe in yourself and take each step when you are ready.”