

My Pain Toolkit

For young people 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!

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



I loved the Pain Toolkit, it wasn't talking at me, but just giving me some tips and ideas others have used to manage their pain. Now I understand my pain better and the Toolkit's ideas worked!

What is Pain?

There are two main 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 then three months.

Why do we get pain?

Pain is like a warning, just like the warning light on a car telling us something is wrong and needs a attention. It is our body's way of telling us that we are either **harming ourselves or about to hurt our self**, 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. This is acute pain.

After you have injured yourself (e.g. breaking an arm) your brain keeps 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

So what is long-term pain?

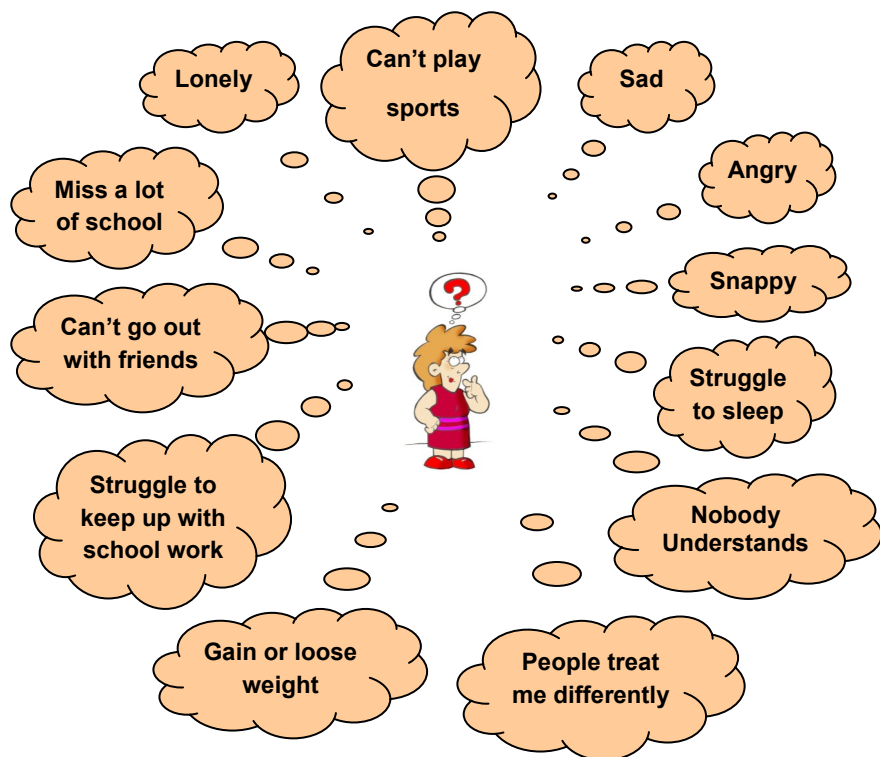
Sometimes, pain sticks around longer than it needs to. The usual medical treatment doesn't work very well for this long-term pain.

Like after breaking an arm, this long-term pain doesn't mean the painful area is still being damaged. In fact, in many cases the area can be completely healed, making it hard to understand why it still hurts. When this happens, **the brain seems to be confused**, sending pain messages when it doesn't need to!

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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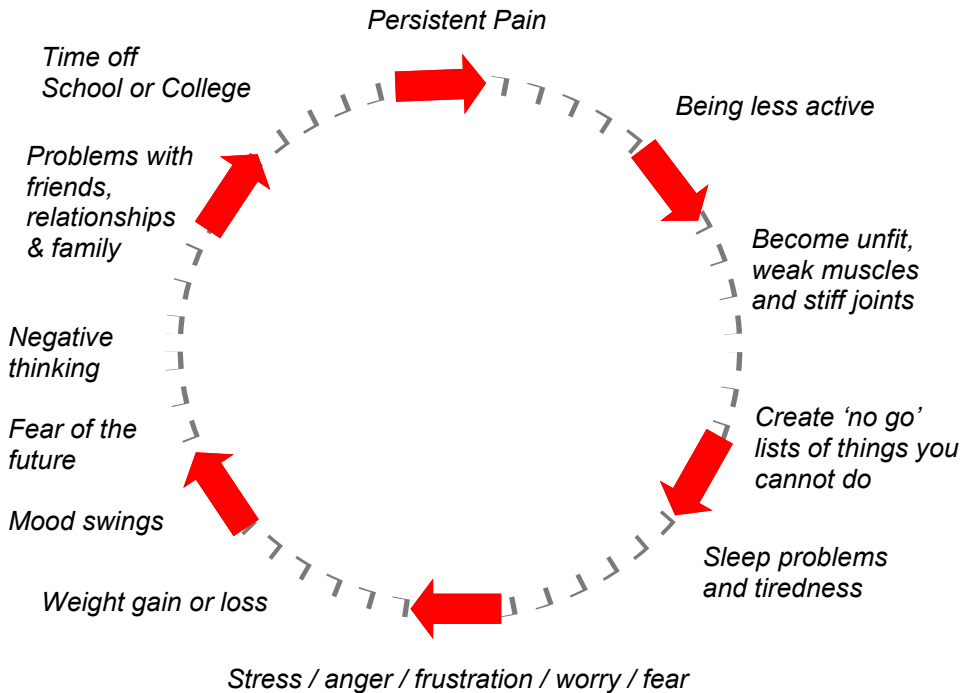
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The Pain Cycle

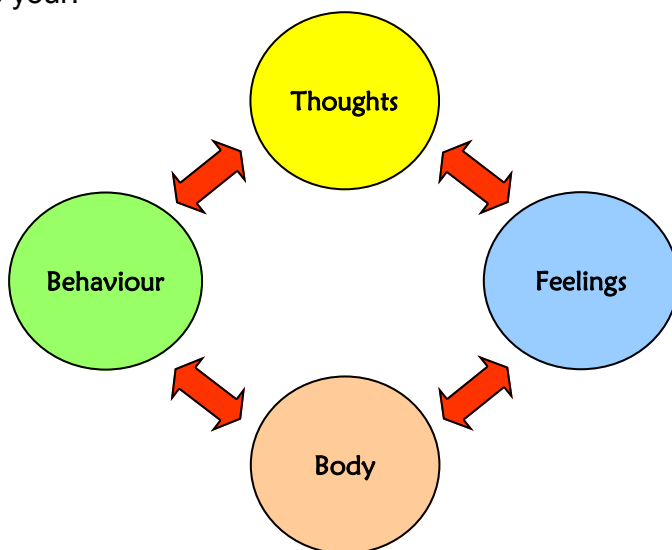
A lot of young people find that having long-term pain can create a cycle. Look at the pain cycle below - does it seem familiar?



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 the Pain Toolkit are all designed to help you break your own pain cycle.

As you can see, your pain can affect you in many different ways. It affects your:



This is why medical treatment doesn't really work for chronic or 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 really like learning any other skill like learning to play the guitar or driving a car, it can take 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.

Okay, lets get started and look a bit more at long-term pain and the Tools in the Pain Toolkit. Its easy!

The Pain Gate

One more bit of information before we go onto the Pain Toolkit!

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

The '**Pain Gate Theory**' tells us that there is a 'gate' in your body that controls which pain messages reach the brain.

Remember, it's the **brain that makes you feel pain**, so if these messages don't make it to the brain then you won't feel it!

- ◆ 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 opens 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• TENS machine

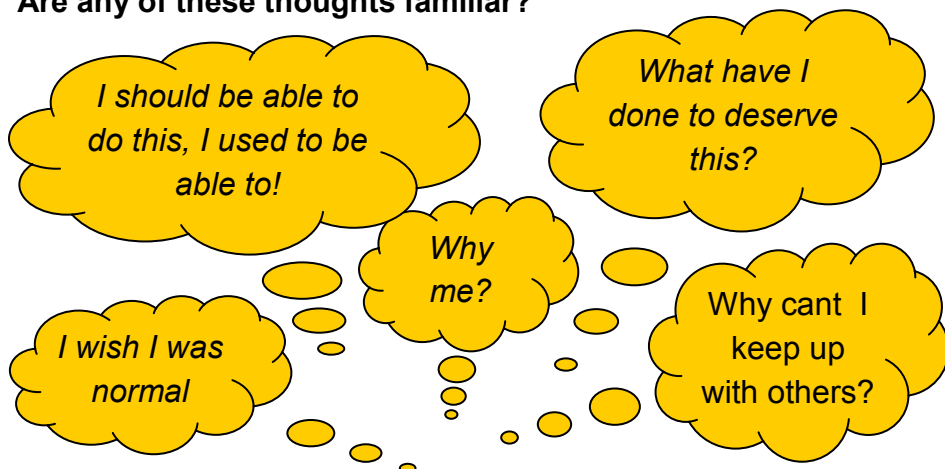
There are lots of things that YOU can do to close the gate on your pain and make it easier to manage!

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 tool in your self-management 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. 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.

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!**

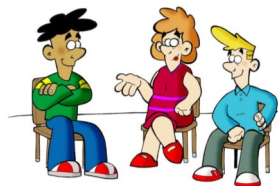
This acceptance will be a bit like opening a door - a door that will open to a life where you can take control of your pain!

Tool 2: Get involved and build a support team

As we now know, long-term pain is a bit tricky. Because of this the doctors probably won't be able to fix or solve your pain on their own. Expecting them to is probably not realistic. With long-term pain it is important for YOU to get involved and take steps to managing your pain. You will also need a support team around you.

Who could be in your support team?

- 👍 Your doctor or health care professional
- 👍 Your family
- 👍 Your friends
- 👍 Your teachers
- 👍



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

A '**can't do**' person is someone who has stopped or given up everyday activities such as playing a sport, going out with friends, taking holidays, going to the cinema, eating out or taking part in family activities because of their pain. When this happens it is usual to lose your confidence and avoid doing even more, just in case you can't. Is this ringing any bells? If so you need to stop and do something about it.

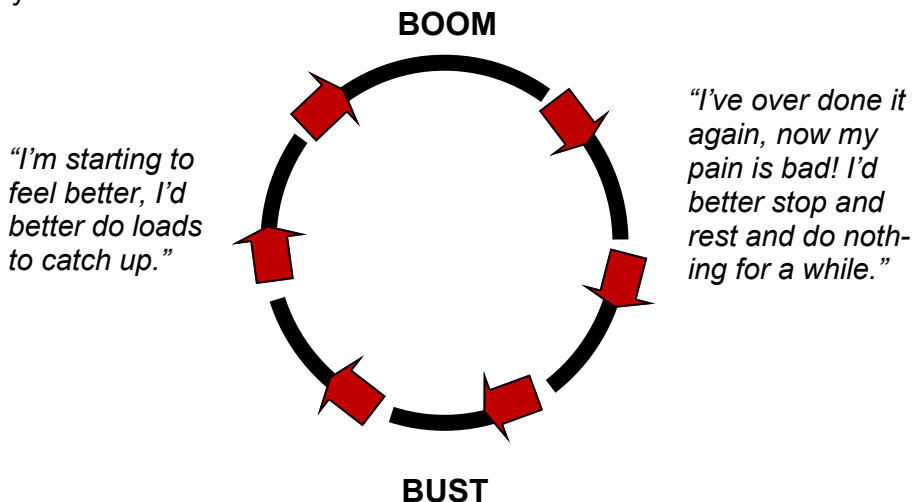
Practising the tools in the Pain Toolkit will help you feel more confident and become a '**can do**' person again; but it could take time so please be patient with yourself!

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!

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 the marathon. Start slowly and gradually increase how long you do it for over time.

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 whole thing.

There are some examples of pacing on page 19.



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

Tool 4: Plan your days

And decide what is important!

To be able to pace yourself it is really helpful to start planning your days and the 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 which ones are the most important 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 week 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.

Using the Internet

Type in pain to a search engine and around 717,000,000 results will come up! Most will try and sell you something. Always discuss with your doctor or health care professional if you are going to try something. Remember, successful pain self-management is team work.

Tool 5: Setting Goals

Setting yourself clear goals is a great way to help you achieve the things you want, giving 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 easily to work towards.



Measurable

It 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 you 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 it makes it hard to get started and stay focused. You can always change your time limits, but make sure you set them.

Tool 6: Be Patient

Take things steadily. It may take you a few weeks or months to see changes or improvements. When you start to feel good, you may want to catch up with some activities that you may have let go of. Don't be tempted to over do it otherwise your chances of yet another set back could increase. A good saying is 'take things one bit at a time'. And also....don't forget to ask for help and support from others - its not a sign of weakness or giving in, it's just common sense!

Tool 7: Relaxing skills

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 that relaxes you!



Balloon Breathing



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, breathing for 2 seconds.

In your mind, when you breathe in, say “one”. Then when you breathe out say “two”. Turn all your attention to these two numbers and the feeling of the breathe expanding and releasing.

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.

I always thought relaxation was just doing nothing, but since I tried and now practice the Balloon breathing, my pain gone down.



Body Care:

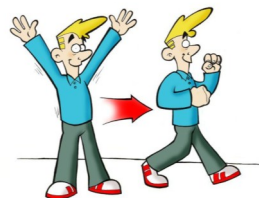
As your body is where your pain is, it's important to look after it! Think about:

- ◆ Eating healthy food including lots of fruit and vegetables.
- ◆ Not drinking too much caffeine (cola, energy drinks, tea, coffee). This can effect your mood, sleep and pain.
- ◆ Sleeping well - sleep only at night and avoiding cat naps during the day!
- ◆ Good hygiene - washing and grooming your body daily.

Tool 8: 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 decreases 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 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 your physiotherapist or fitness coach about an individually tailored stretching and exercise programme that you can work on steadily and safely. This will help you build your confidence, muscle and joint strength.

Remember that swimming (or just walking up and down in the pool) is a good, gentle exercise that is great for you if you have joint problems. You can find 15 good reasons why exercise is good for you on page 22.



I used to hate exercising as it increased my pain. I was doing too much too 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. Here are a few common ones.

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

Please make sure that the teacher is qualified and experienced in teaching people with persistent pain.

You should exercise at a pace that feels right for you.



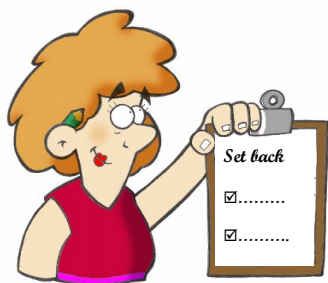
I noticed my dog stretches when she wakes up so I asked my doctor why this is. He told me that she is preparing her body for movement. I thought this is like me so we do some together each morning.

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 is 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 yourself how you are positively self-managing your pain. Young people have often found that this improves their confidence.

Tool 10: Have a set-back plan



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

The simple answer is NO!

Having a set-back plan is really helpful so that you are prepared and know what to do if things go wrong. Ask your

healthcare professional if you need help in making one.

Make a note of what triggered your set-back and what helped. This could be useful information if and when you experience another.

There is an example set-back plan on page 21.

Tool 11: Team Work

Team work between you and your healthcare professional is vital. Imagine the Arsenal football team playing without a team 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.



Tool 12: Keeping it up!

Putting tools 1-11 into daily practice

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

Just as the 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

.....

.....

.....

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 45 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 every day 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 Set-Back 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.

Set backs 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 set-backs.

Remember, you can always ask your GP or health care professional for help with your set-back plan if you are unsure.

First of all, do not panic! Your plan will help you through. Accept that you are having a set-back 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 set-back 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 it 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 your GP.*

Take it easy.

- ◇ Briefly cutback on normal activities. Lie down for a short while and relax but not for too long.
- ◇ 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 a 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.

15 Reasons Why Stretching & Exercising 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.

More about Pete Moore & Jessica Bird

co- authors of the Pain Toolkit and *the motivational bit....*

Pete lives in Essex and is a keen promoter of self-management and other health conditions. Pete has written several pain self-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 is a member of the:

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



Pete Moore

Pete says “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 they 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 and friends. In time you will become more confident and in control”.

Jessica is an Assistant Psychologist living in Leicester who works within Child and Adolescent Mental Health Services and has experience working therapeutically with children and young people. She 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.”

Useful website links for information and support

Arthritis Care www.arthritiscare.org.uk

Arthritis Research Campaign www.arc.org.uk

Depression Alliance www.depressionalliance.org

Healthtalkonline www.healthtalkonline.org

Fibromyalgia Association UK

www.fibromyalgia-associationuk.org

ME Association www.meassociation.org.uk

Migraine Trust www.migrainetrust.org

MIND confidential help and advice on
www.mind.org.uk

Multiple Sclerosis Society www.mssociety.org.uk

NHS Direct www.nhsdirect.nhs.uk (Tel 0845 4647)

NHS Choices www.nhs.uk

Pain Relief Foundation www.painrelieffoundation.org.uk

Pain Toolkit www.paintoolkit.org

Pelvic Pain Support Network www.pelvicpain.org.uk

Rheumatoid Arthritis Society www.nras.org.uk

Samaritans www.samaritans.org.uk

Stroke Association www.stroke.org.uk

Your Health Your Way www.nhs.uk/yourhealth

You Tube clips (type in titles, these are cool)

Understanding Pain: What to do about it in less than five minutes?

Why Things Hurt

