

# My Pain Toolkit

For young people and  
teenagers living with pain

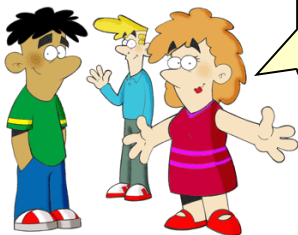
*Canadian Version*



- ◆ 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!**

My 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 My 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](http://www.paintoolkit.org)

*In Canada: [www.pipain.com/youthPainToolkit](http://www.pipain.com/youthPainToolkit)*



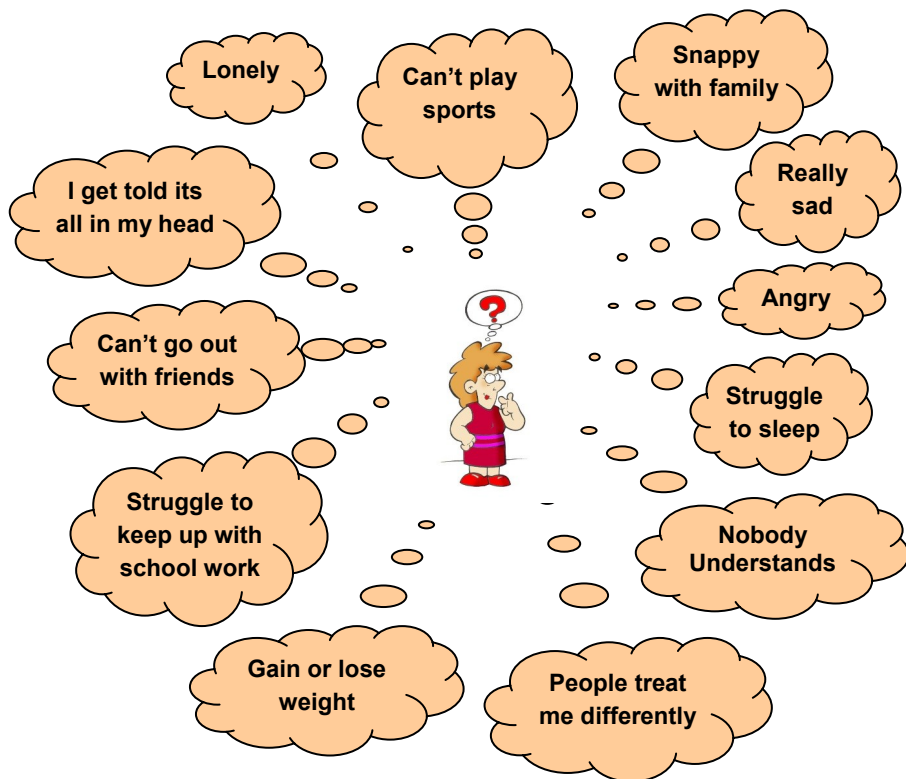
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# How does your pain effect you?

Living with pain can be really difficult. Not only can it affect the things you do, it can also affect 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 affect on you?



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

.....

.....

.....

.....

# Pain in Canada

Pain is a problem that is probably more common than you think. In Canada, about one in five people live with persistent pain and many of them are young people and teenagers.

But pain doesn't only affect the people who actually have pain. It also affects their family, friends and work colleagues. So, if you add these people, more than half of the Canadian population is affected by persistent pain!

**Total population**  
**34,483,000**

**People with pain**  
**6,897,000**

**People effected by pain**  
**19,800,000**



## In British Columbia...

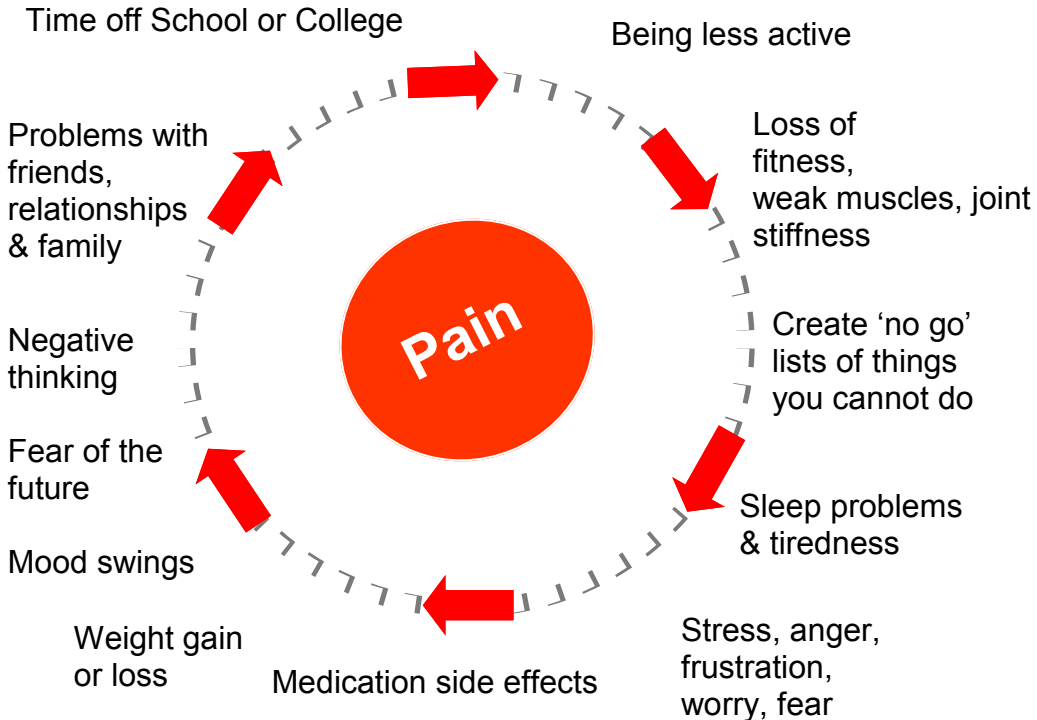


**People with pain**  
**1,000,000**

**People effected by pain**  
**2,200,000**

# The pain cycle

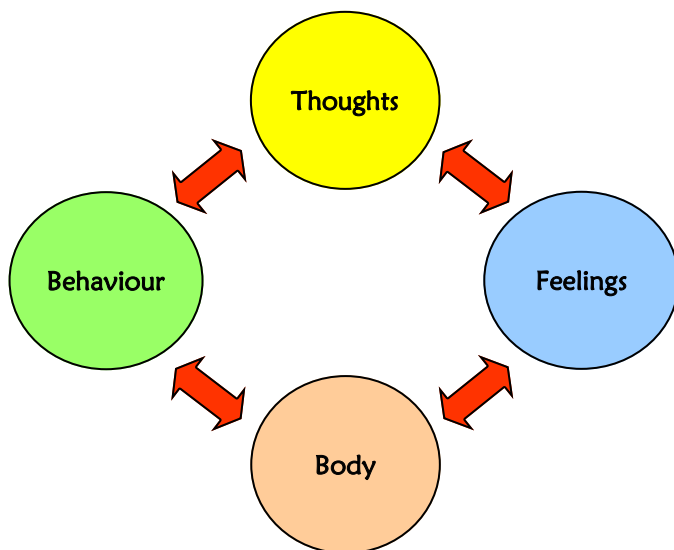
A lot of young people and teenagers find that having persistent pain can create a cycle. Look at the pain cycle below - does it seem familiar?



This cycle means that your pain keeps on going and things keep getting worse.



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



This is why using only medical treatment and medication doesn't always work for persistent 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.

My Pain Toolkit can help you to choose some simple tips and skills that focus on all these aspects of managing your pain.

# The wellness cycle

**You need to BREAK your pain cycle!** By making certain changes to the way you manage your pain you can gradually break away from the cycle of pain and move into a new cycle that can lead your life in a more positive direction that allows you to live a full and happy life despite your pain.



By following the tools in this toolkit you **CAN** learn to self-manage your pain and live within your wellness cycle!

# 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.
- ◆ **Persistent pain**, sometimes called chronic or long term pain, is pain that last longer than three months.

## Persistent pain

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

Like after breaking an arm, this persistent 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, persistent 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.

We can think of our bodies as having 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"><li>• Stress</li><li>• Tension</li><li>• Anger</li><li>• Sadness</li><li>• Worry</li><li>• Lack of activity</li><li>• Focusing on pain</li></ul>	<ul style="list-style-type: none"><li>• Relaxation / calm</li><li>• Happiness</li><li>• Stretching / exercise</li><li>• Distraction</li><li>• Some painkillers / medication</li><li>• Massage / heat / cold</li><li>• TENS machine</li></ul>

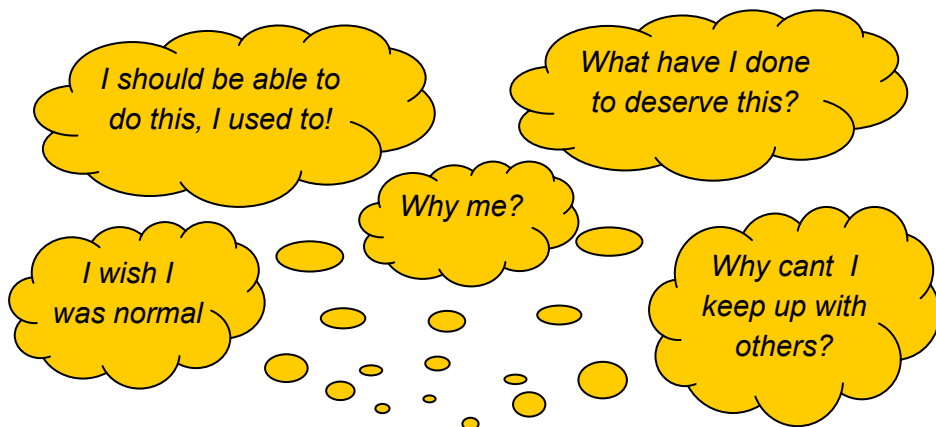
**There are lots of things that YOU can do to close the gate on your pain and make it easier to manage!**

# Tool 1: Acceptance

**Accept that you have persistent 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! Learn what you can about pain and how you can develop more helpful ways of thinking that will help you improve the quality of your life.

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 persistent 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**

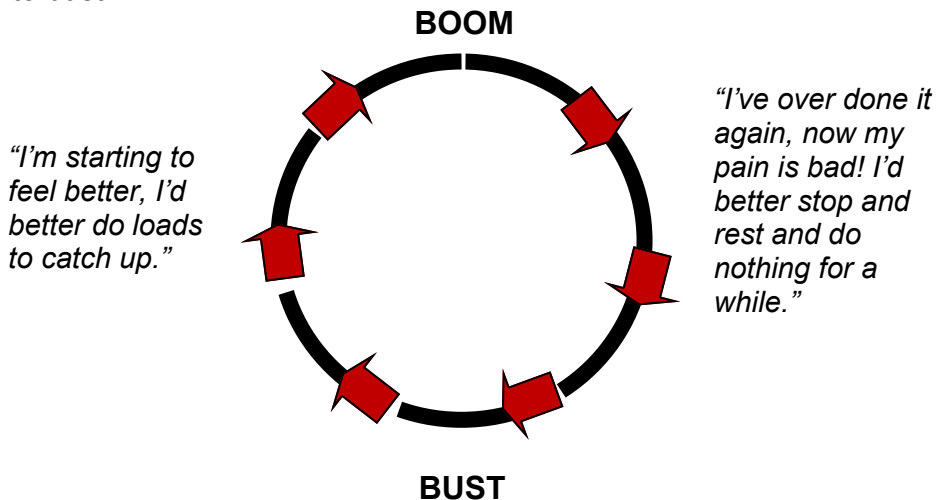
- ★ Family member
- ★ Friends
- ★ Teachers
- ★ Doctor
- ★ Psychologist
- ★ Physiotherapist

## 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. We need to think of pacing in anything active you do including school, seeing friends, shopping, sports or movement.

- ◇ 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. Whatever you are doing, stop and take frequent breaks.
- ◇ If there is a specific activity you want to do more of, treat it like training for 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.

*Make a plan for the next day's activities*

## 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.
- ◇ Keep Moving. Gentle movement and stretching helps to keep flexibility



## 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.

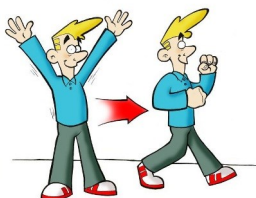
- ❖ Get comfortable, sitting in a nice chair or lying on the bed and close your eyes.
- ❖ Imagine that you have a balloon in your tummy. Every time you breathe in, the balloon inflates: Each time you breathe out, the balloon deflates. Take a deep breath in, and hold it for **3** seconds, then slowly deflate the balloon by breathing out for **5** 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 & Movement

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, exercise and movement 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.



*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.

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 27.



*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 she was like me, stiff, so now 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.

## Sleep

Not getting enough sleep can make us feel tired, unwell and generally make pain more difficult to manage. You should aim to get **8 or 9 hours of sleep** every night to be at your best. Tips for getting a good nights sleep include having a **bedtime routine** where you go to bed at the same time every night and spend the hour or so before winding down with relaxing activities such as having a bath or reading. Avoid watching TV or using computers and phones just before bed as they keep your brain awake! You want your body to want to sleep in your bed, so make your room calming, comfortable and quiet. Also try to **avoid drinks with caffeine** such as coffee, tea or cola for at least 4 hours before bedtime as they will keep you awake. **If you can't get to sleep after about 20 minutes, don't just lie there.** Get up out of bed and do something non-stimulating in another room, such as reading (not TV!) or having a glass of warm milk, and then go back to bed to try again.

## Tool 9: Track your progress

Keeping a diary or a self-discovery journal 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

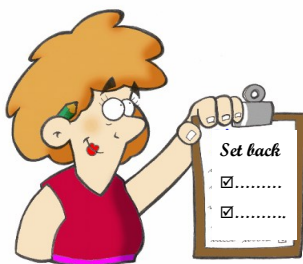
Is it realistic to think you will never have a setback where things go bad again?

**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. Part of a setback plan could be a "Treasure Chest" where you put things you enjoy and can turn to on those bad days. Funny movies, favourite music and good books are good examples of what to have in this chest.

You can find an example setback plan on page 29



### Using the Internet

Type 'pain' into a search engine and approximately 1,140,000,000 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 seen, or read about.**

# Tool 11 Teamwork

Teamwork between you and your healthcare professional is vital. Imagine the Vancouver Canucks hockey 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
- And 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...**



.....

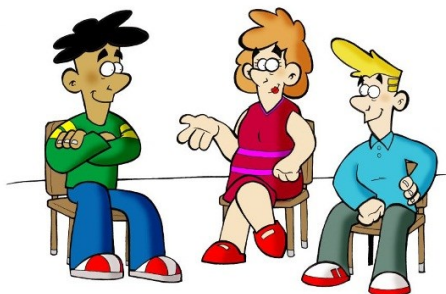
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# Family Support

Pain not only affects the person experiencing pain. Any difficulty that you experience is also going to be felt by the people who care about you.

We have already talked about how important it is for your family to understand your pain to be able to help you. Education is so important as a better understanding can help them to feel better about what is happening and accept the changes that need to be made.



Your family may also be struggling to cope themselves. It is important for everyone to recognise that it is understandable for the family to find things difficult and to feel a whole range of emotions. They may need their own support and advice for how to look after themselves and to help you in your pain self-management.

Encourage your family to get involved and access the support that they need. They may also want to get involved in the pain services, as family members can speak on the behalf of those in pain and are important voices of change!

## Giving back

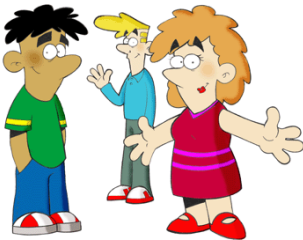
The tools that you may have learned about in this Pain Toolkit will hopefully help you to live life to the full despite your pain.

Once you feel that you have taken control of your pain there is no better feeling than sharing your knowledge with others to help them to improve their life.

Getting advice from someone who truly understands what having pain feels like can be incredibly helpful and inspiring. Imagine giving another young person with pain a real sense of hope that change is possible!

## Ways to give back:

- You could get involved with your local pain services to become an advocate for change and help educate others.
- Work with an existing support group.



*"Helping others really helped me as it made me feel useful"*

*"Hey doc, how can me  
and my buddies help you  
with the*



# Stretching, Exercise & Movement

## 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 Music

Daniel had a big homework project due in. He was worried because he knew that sitting at the desk for too long makes his pain worse. He decided to make a plan. He planned to spend 1 hour on the project each night but to take 5 minute breaks every 30 minutes. However, on the first night he noticed that after the first 30 minutes he was getting pain. He realised that he needed to stop before this so changed his plan to having a 10 minute break every 20 minutes. He did this for 4 nights and got his project done in time without getting too much 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 health 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 it 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 persistent pain it is really important. Don't be put off - it does work!

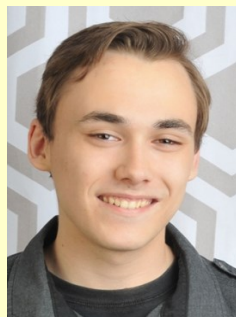
## Relaxation

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

## Your stories...

### **Ryan Gulak, a young person from the BC Children's Hospital Complex Pain Service**

"Some of the most important things you need to take control of your pain are knowledge, support, and the tenacity to succeed. Without the knowledge of pacing, and how to develop an effective exercise regime I would never have been able to reduce my pain to manageable levels. The guidance and support provided to me by the complex pain team at children's hospital was an invaluable asset to me. You have to tackle pain on both the mental and physical fronts, to strengthen and condition the body as well as facing the negative mental effects that accompany chronic pain, and learning how to deal with them. Lastly having the self-motivation required to put your plan in motion and to see it through is absolutely vital. Ultimately no one can do this for you, forcing you to become your own advocate. Learn to tune in to what your body is telling you, and use that to pace yourself effectively. Be proactive and try designing your own exercise programs, and use the support that you have as a sounding board for your ideas. Take charge of your own recovery, and you'll take control of your pain. And when a setback occurs, sudden stresses worsen your pain or anything that begins to slow down your recovery, use your personal support team to get you through it. Whether it's our youth support group, a close friend or family member, don't be afraid to lean on those who care when things get tough."





## **Ella, a young person living with chronic pain in BC**

“For the past 3 1/2 years I have been on a journey that has not been an easy or enjoyable. Along the way I have learned many lessons that have helped me with my chronic pain and all aspects of my life. Despite past struggles with trusting the medical system and the doctors who don't always believe teens or understand pain issues, I have been learning to accept help and to talk about the anger that was hindering my recovery. Having trusted support groups with professionals, family, friends and pets is helpful in providing emotional, mental and physical help. While it is only me that can feel the pain, with the help from others I am not doing this alone. Having a doctor take charge and organize other professionals really turned things around for me. They all started working together as a team, keeping each other informed on my progress and meeting me regularly. As you get better it is normal to have setbacks so planning for this is very helpful, but the recovery process is not easy. It can be like 3 steps forward and 1 step back. I had to learn that lying in bed all day when I had a bad day was not helping, it actually made me worse because I got weaker. I had to start understanding that moving was what I needed to do to get better. Pacing myself when I am having a good day helps to stop me from suffering and when I am having a bad day, although I find it really hard I try and do something to keep active. However, keeping your mental state healthy is just as important as your body. Even when you have a bad day, the pain is a lot easier to deal with if you are emotionally okay. Keeping my life as close to normal as I can always helps me manage better. I am proud to say that I have learned to balance between overdoing it and under doing it.



# Useful Website links

- ◇ **Pain Toolkit** Download copies of the Pain Toolkit  
[www.pain toolkit.org](http://www.pain toolkit.org)
- ◇ **BC Children's Hospital Pain Service** [www.bcchildrens.ca/Services/PainService](http://www.bcchildrens.ca/Services/PainService)
- ◇ **People in Pain Network**  
[www.pipain.com](http://www.pipain.com)
- ◇ **Pain BC**  
[www.painbc.ca](http://www.painbc.ca)
- ◇ **Canadian Pain Coalition**  
[www.canadianpaincoalition.ca](http://www.canadianpaincoalition.ca)
- ◇ **Pain Resource Center**  
<http://prc.canadianpaincoalition.ca/en/>
- ◇ **PIPN Youth Support Group**  
[www.pipain.com/support-group-listing.html](http://www.pipain.com/support-group-listing.html)
- ◇ **Living Well with Pain**  
[www.lifeisnow.ca/pip](http://www.lifeisnow.ca/pip)
- ◇ **BBoy Science** Physical Therapist explains exercise and pain  
[www.bboyscience.com](http://www.bboyscience.com)
- ◇ **Resources, Support and Information for youth in BC**  
[www.mcf.gov.bc.ca/for\\_youth.htm](http://www.mcf.gov.bc.ca/for_youth.htm)

- ◇ **Youth Health Talk:** Watch, listen and read about real young people's experiences of health problems.  
[www.youthhealthtalk.org](http://www.youthhealthtalk.org)
- ◇ **Quiet Mind Café:** Website of free relaxation videos  
[www.quietmindcafe.com](http://www.quietmindcafe.com)
- ◇ **Mindfulness, Meditation and Yoga**  
[www.mindful-living.ca](http://www.mindful-living.ca)
- ◇ **National Sleep Foundation**  
[www.sleepfoundation.org](http://www.sleepfoundation.org)
- ◇ **BC help with depression**  
<http://tinyurl.com/c4psawg>

## 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>

### The mystery of chronic pain

- ◇ <http://tinyurl.com/4xblknn>

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

- ◇ <http://tinyurl.com/7g79by3>

# Complex Pain Service (CPS)

## What is the CPS?

The CPS is an outpatient service working to help children and young people prevent and manage complex pain.

The CPS has a number of different people working together to give young people the best care possible. This includes a pediatrician, an anesthesiologist, a pain nurse, a psychologist and a physiotherapist. We also work with other health professionals including a psychiatrist and a pharmacist to help us out when we need them.

Some of the common types of pain we treat are headaches, abdominal and musculoskeletal pain.



## How does the CPS help?

We aim to help improve children's functioning and wellbeing by lowering the impact of pain on all aspects of their lives. This is achieved by:

- ❖ Promoting and supporting a self-management approach
- ❖ Jointly coming up with a treatment plan with the child and family that includes one or any combination of the following...

- ◇ Medication
- ◇ Physical therapy
- ◇ Cognitive behavioural therapy
- ◇ Complementary therapy (complementary therapies are complementary to your own-going treatment or pain management programme. Discuss first with doctor or parents)
- ◇ Local anesthetic intervention
- ◇ Focusing treatment on physical reconditioning and coping techniques as well as family and educational support
- ◇ Providing treatment on an outpatient basis
- ◇ Referring the child and family back to the community for care once a good treatment plan has been established



More information on the CPS Clinic is available in our Complex Pain Service pamphlet (PDF).

[www.bcchildrens.ca/Services/PainService](http://www.bcchildrens.ca/Services/PainService)

# How to access My Pain Toolkit

These tools have helped many people living with pain and their families in the United Kingdom, Europe, Australia, New Zealand and now for the first time in Canada.

My Pain Toolkit is available through the BC Children's Hospital Pain Service and People in Pain Network website:

[www.pipain.com](http://www.pipain.com)

A special thank you to Pete Moore and Jessica Bird who have worked long and hard to make the My Pain Toolkit available in Canada.



**Heather Divine**



**Gillian Lauder**

An additional thank you to Heather Divine, a person living with chronic pain and CEO of People in Pain Network, and Dr Gillian Lauder from the BC Children's Hospital Complex Pain Service. Heather and Gillian have worked with Pete and Jessica to bring My Pain Toolkit to you.

# More about the authors

## Pete Moore & Jessica Bird

Pete lives in Essex, England and is a keen promoter of pain self-management and other health conditions. Pete 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)

*“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 is currently undertaking her doctoral training in Clinical Psychology at Oxford (UK) and has experience working in pain management and 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.”*

