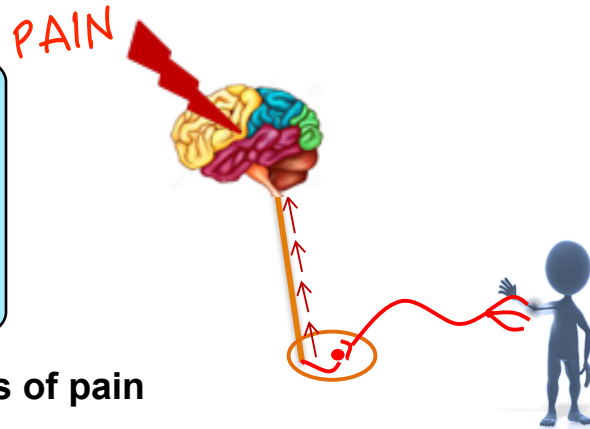


Pain is created by your brain

ALL pain is produced by our brain
No matter how it feels:
Sharp, dull, throbbing, strong or mild
Or how long it has been there:
Minutes, days, weeks or months



There are two different types of pain

ACUTE PAIN

Acute pain starts suddenly and doesn't last for too long. It's **like an alarm bell, which makes our brain send danger (STOP!) messages to protect us**. If you put your hand on a hot stove, pain warns you to take your hand away quickly **to stop you from getting injured**. When you do injure yourself, like breaking your arm, it can keep hurting for a little while. This isn't because your arm keeps getting broken or damaged, it's to remind you to stop moving it too much and to keep resting it **to help it get better**. If it is too sore, there are pain medicines you can take to help while you are getting better and back to doing all your normal things.

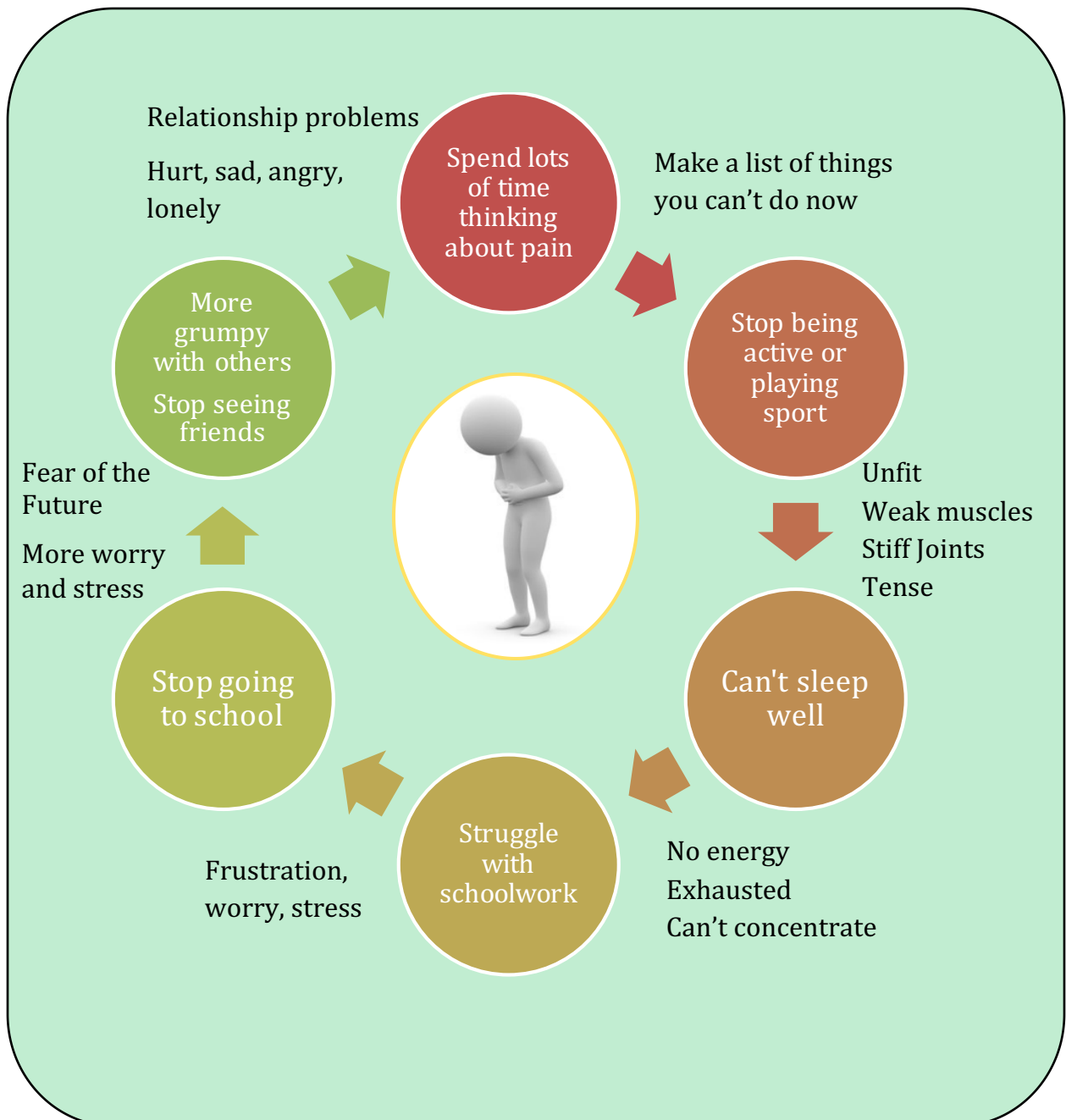
CHRONIC PAIN

As many as 20 to 30% of children and teenagers have pain that keeps going for longer than 3 months. This is called chronic pain. The Starship Complex Pain Team sees about 100 to 120 new patients each year with chronic pain. **When pain keeps going for a long time, it doesn't mean the area is still being damaged**. In fact, doctors often can't find any reason for why the area is still sore. **So why does it keep hurting?** When pain has been there for a while, **our body can get better and better at sending a warning (alarm bells) to the brain. This confuses our brain (like a false alarm) and it keeps telling use we have pain**. This can mean just a touch to the skin, or a change in temperature can cause pain from a "false alarm", **so things that didn't feel sore before, now do and things that only hurt a little bit now HURT A LOT!**

Chronic pain does not respond to the same treatments as acute pain (like rest and the usual pain medicines). But there are lots of things in The Pain Kete that can help you manage your pain better.

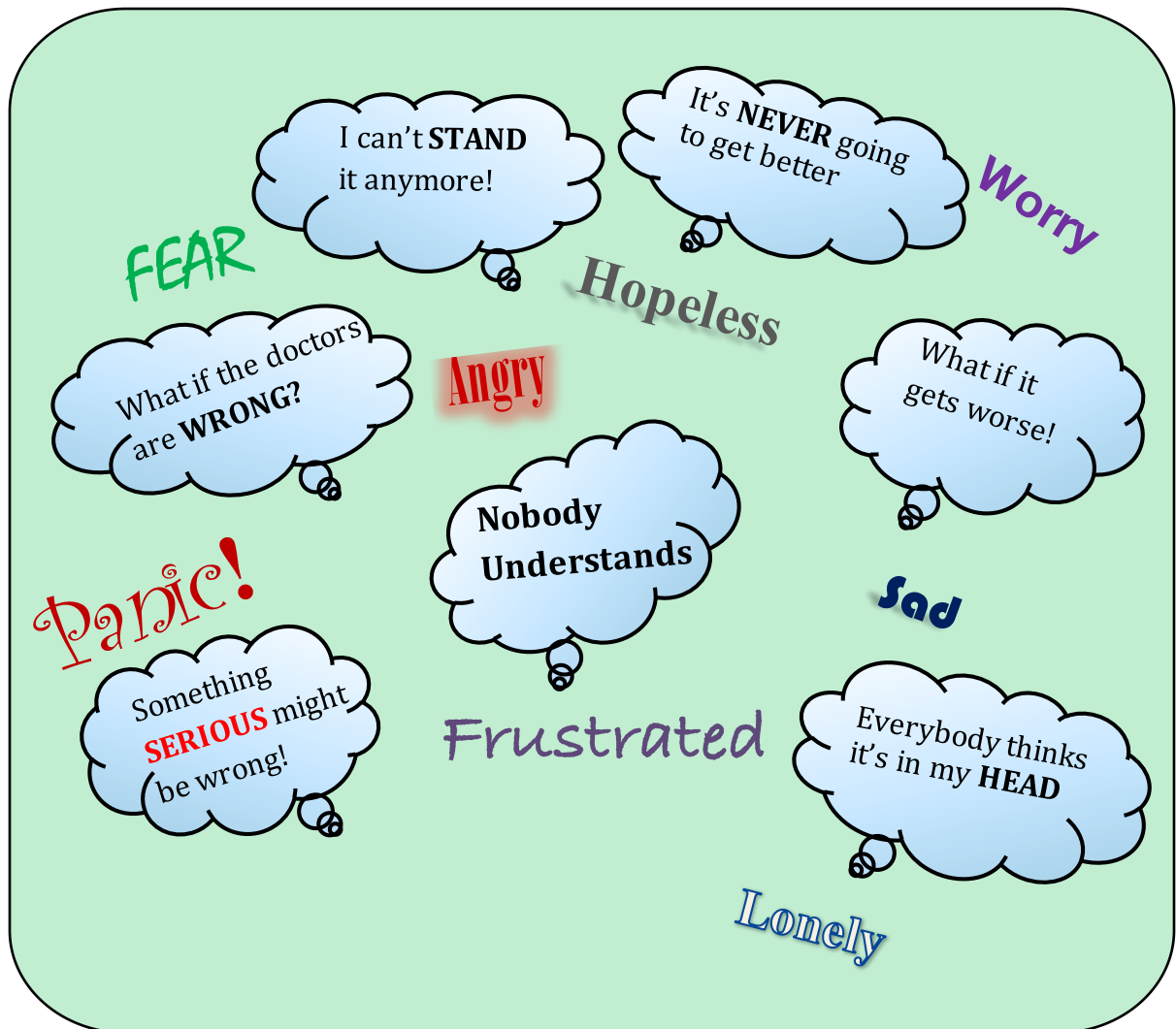
Pain affects what you do

Having pain for a long time can affect what we do and have a big impact on our life. Certain things we do with acute pain, like resting and taking time off school does not help chronic pain. This can mean you get stuck in a **PAIN CYCLE** even when you stop doing everything. The pain keeps on going, making us feel worse and worse!



Pain affects what you think and feel

Chronic pain not only affects what you do, but also what you think and how you feel.

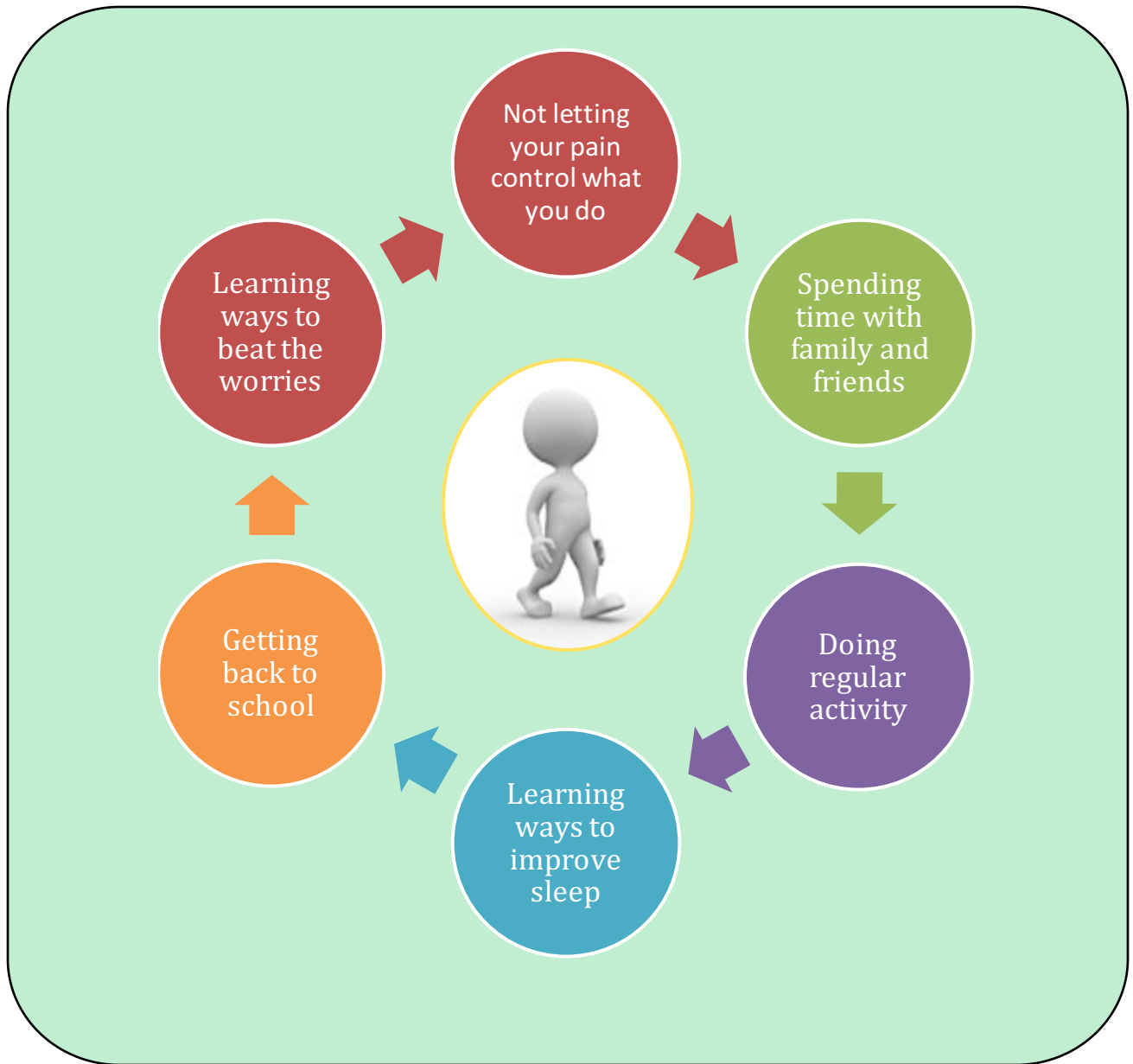


Having pain for a long time can affect us in many different ways. It isn't just something that affects our body it also affects our thoughts, feelings and what we do. This is why only using medicines doesn't always work for chronic pain as it only focuses on our body.

To help you manage pain better, we need to focus not only on your body, but on your thinking, feeling and what you do

Breaking the Pain Cycle

The **PAIN CYCLE** is very unhelpful. Luckily, making some changes in how you respond to pain can help even if it feels really hard to do.



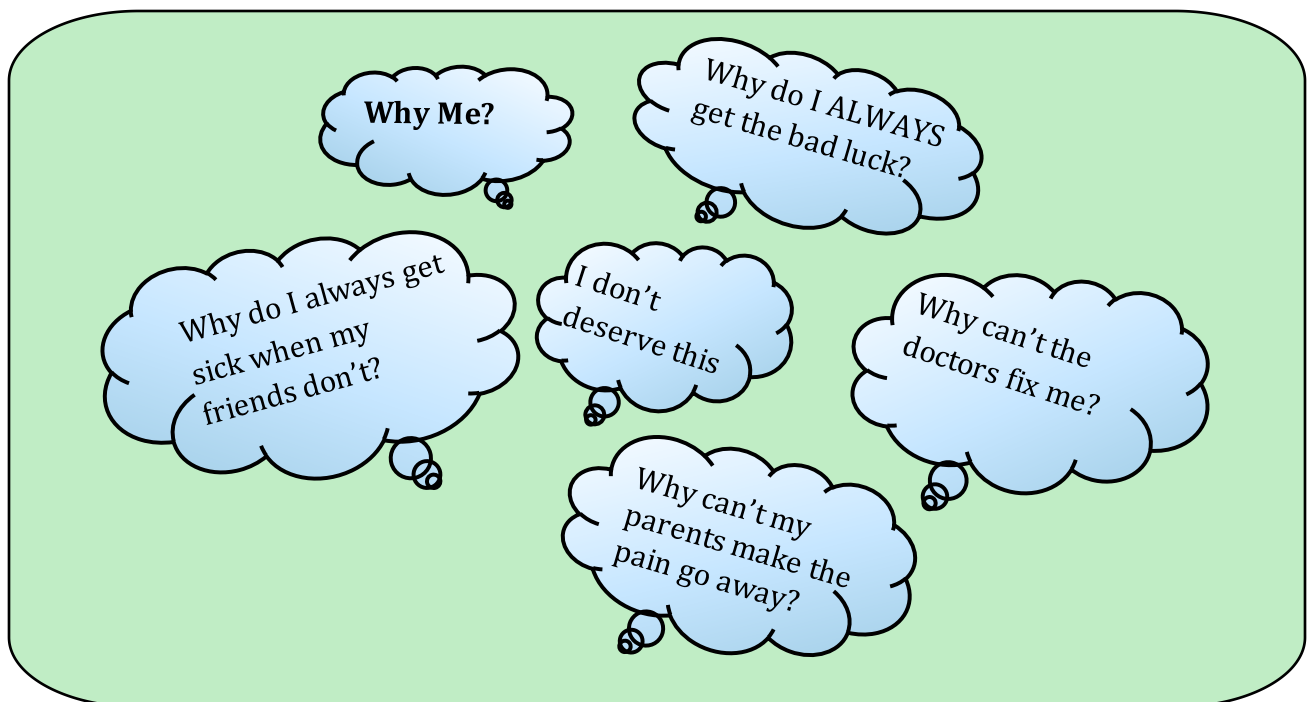
There are lots of tools in **THE PAIN KETE** that can help you make these changes so you can learn to manage your pain and be in charge of your life.

1. Being Brave and Courageous



This is the first step in taking charge of chronic pain. This step is for both young people and their families. Recognise that for a time, pain will be in your lives and something you may think about frequently.

When you have chronic pain, you might find that the following thoughts become familiar:



You may spend a lot of time being angry about having pain and wishing things were different. This can use up energy that can be put into getting back control of your life!

It is helpful to think about being BRAVE AND COURAGEOUS and to start doing things that you are missing. This means doing things with pain, at least for a while. We will talk more about setting tiny goals to get back to doing your favourite activities later. **Think about what you can do, NOT what you can't do.**

If you have chronic pain you may wish for a quick, easy way for it to just disappear from your life. While that would be great (and can sometimes happen) - it can be more helpful to **think about TAKING CONTROL OF THE PAIN!**

2. Have The Right Support

Chronic pain can be hard to cope with. Having the right support is important and needs **everyone to be on board with a treatment plan to help you manage.**

A SUPPORT TEAM

When we are learning something new – whether it is playing a sport or learning how to do a maths problem – **we need others around to help us.** It might be a teacher, a coach, or a friend who knows the skills we are trying to learn. It might be someone who is really good at motivating us to try things or is always good at cheering us up when we get down.

It is the same for learning how to cope with pain!

Who can be on your support team? Try to think of 5 people you would like to be your Support Team – you might want to include your Health Care Therapists, your Doctor, close friends, mum or dad or other family members.



1. _____
2. _____
3. _____
4. _____
5. _____



FOR PARENTS

It is very natural to want your child to be free of pain! However, young people coming to the Pain Clinic usually have complex pain – the kind that needs to be managed and will not be “cured” by anything simple.



Parents can help by accepting their child has chronic pain for now and supporting them through their Rehabilitation Treatment Programme, which focusses on a path of Medical, Physical and Psychological treatment. Young people can do extremely well at learning to cope with chronic pain so that it doesn't affect their lives. Their best chance of doing this is by having parents who support their involvement in the rehabilitation programme. If your mind is still full of questions about why your child has pain and why it cannot be stopped, please discuss this with us again.

Things that can help:

Remove the focus on pain. Avoid asking your child questions about whether he or she has pain or how much it hurts. If they tell you they are in pain, try this: **LISTEN; ACKNOWLEDGE; DISTRACT** (e.g. I'm sorry you're having more pain today-shall we go and sit outside-play cards etc).

Avoid over emphasizing improvements they make. Instead acknowledge improvements quietly, but always remember the pain (e.g. 'I can see you are putting your foot down more despite the pain').

Encourage normal activity during pain episodes. Encourage school attendance and participation in normal activities and expect normal behaviour from your child (e.g. 'Please can you make your bed/ pack the dishwasher etc').

Support your child to engage in positive “well” behaviours. A day of missed school or activities due to pain should be low-key, quiet and not filled with lots of “special attention” or “extra privileges” (such as watching TV, time on a mobile phone or computer or playing games). When your child does attend school or participate in activities, they can earn privileges (such as getting to use the computer or iPad on the days they have been to school).

Support your child with independent management of their pain. Your child may need encouragement to participate in the pain management strategies they are learning, like breathing, relaxation exercises and physiotherapy exercises.



COMMUNICATION

Chronic pain can add to the difficulty in communicating with your child. The two way process of being available to listen as well as being able to clearly let your child know what your concerns are can more easily go wrong.

What can help:

- **Be direct and add in what you feel** – ‘I’m really worried about you not getting to school.’
- **Give your child time to get their point of view across.**
- **Increase the opportunity to communicate** – research shows that parents talk less to teens and it can help to start some regular shared activities so there is more opportunity to talk. (e.g. watching a DVD/TV show together).

Things that DON'T help:

- Lecturing
- Not letting teens speak for themselves at their appointments



3. Pacing, Planning and Setting Goals



PACING

Pacing is the term used when talking about the balance between rest and activity. This is important to understand when managing pain as it can help you get back to being the usual you. You will need to consider all the different parts of your life including, school, hanging out with friends and family and being active. There may be other things to think about, like a part-time job, doing chores at home or walking the dog.

As individuals we have only so much “petrol in the tank”. Think about each activity and how much of your energy it takes. Remember energy is not just how much physical get up and go you have, it’s the energy required of you to learn, walk around school, hang out with your friends and so on. You don’t want to use all your “petrol” on one or two things.

Breaking down tasks may help you to achieve more. Avoid using all of your energy by the end of the day - **save some “petrol” to help you manage your pain in the evening and at night.** We all know that being tired or run down can increase your pain.



The biggest risk of not pacing your time and energy is the BOOM AND BUST CYCLE.

This is a vicious cycle where you do too much when you feel good and it causes a flare in pain. This forces you to stop everything, which can lead to a loss of confidence in keeping active. Pain is in CONTROL!

“My pain isn’t too bad, I’d better do LOTS to catch up on all the things I’ve missed!”

BOOM

BUST

“I’ve done TOO MUCH – now my pain is REALLY BAD! I’d better stop doing everything!”

Building up your activity gently and **keeping a consistent routine each day, at a level you can cope with despite your pain is a much better way to overcome pain.** You may require help from an adult or a member of the Starship Pain Team to do this.

PLANNING



Planning ahead will help to avoid the **BOOM AND BUST CYCLE**.

Over time this may allow you to gradually fit more of the things you used to do back into your life. Trying to do everything can be overwhelming, especially if you have chronic pain. Think about it this way. What do you **HAVE** to do and what do you **WANT** to do? **Instead of doing too much, decide on what are the most important things and focus on them.** Forget about the less important things for now.

A good way is to draw up a chart with days of the week on it and **start filling in what you think you will be able to manage - even on a bad day!** Although it may sound a bit boring, consistency is really important when planning your time. Your body operates best when it knows what is required of it.

Activity, Rest and Sleep Diary

Starship Children's Hospital

Week of		Morning (am)											Afternoon/Evening (pm)												
/	/	12 Midnight	1	2	3	4	5	6	7	8	9	10	11	12 Midday	1	2	3	4	5	6	7	8	9	10	11
Monday																									
Tuesday																									
Wednesday																									
Thursday																									
Friday																									
Saturday																									
Sunday																									

Week of		Morning (am)											Afternoon/Evening (pm)												
/	/	12 Midnight	1	2	3	4	5	6	7	8	9	10	11	12 Midday	1	2	3	4	5	6	7	8	9	10	11
Monday																									
Tuesday																									
Wednesday																									
Thursday																									
Friday																									
Saturday																									
Sunday																									

This key shows you which colour to use for each level of activity:



Exercise or walking



School work or study



Rest or chilling out



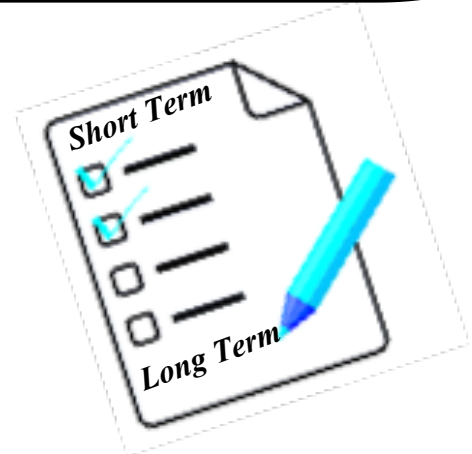
Sleep

SETTING GOALS

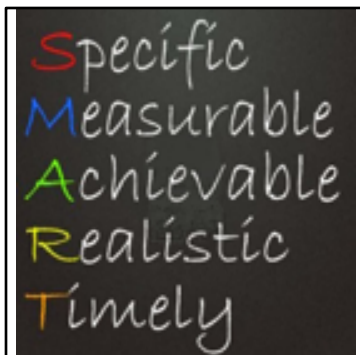


Planning is not only for the day or week, but can be for the weeks ahead. **Making goals is a great way to have something to work towards.**

The best goals are the ones you help make as they are more relevant to you and what you want to achieve. **Sometimes it's good to have both short term and long term goals.** A short term goal can be one of the steps towards the long term one.



It's important to make your goals realistic and achievable!



BE SMART. Health professionals love to **make sure goals are specific and have timeframes.** For example, to walk to the dairy without crutches in two weeks time.

Sometimes **you may need a Plan B** especially **when you are doing big stuff**, like going back to school. Having a plan to help you stay at school, even if the pain gets worse is a great idea. This may mean that your parent or one of the members of the Starship Pain Team can contact school to support you with the plan.



4. Keep Active



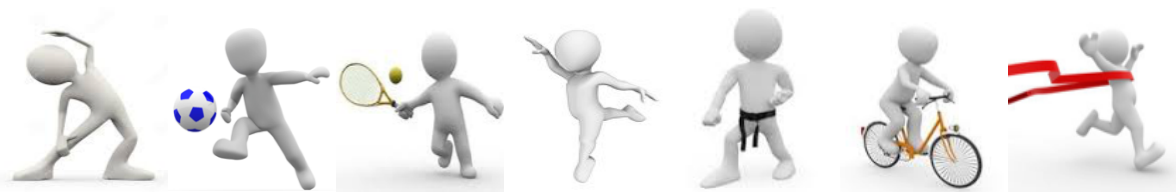
Our natural reaction to having chronic pain is to stop doing things. This, in fact, is exactly what not to do! We know that regular, gentle exercise is important for maintaining a healthy lifestyle no matter who you are. **Healthy body = Healthy mind.**

You cannot wait for the pain to go away before getting active again, you must be courageous and challenge yourself and the pain in what you can do. Remember, pacing and planning will be important tools to help you.

- Like all training, it's good to **start with the basics** – so the normal movements required of the body in everyday life.
- Next **add in practicing the skills of your favourite activity, sport or dance in your own time.** Sometimes doing activities that are familiar and enjoyable, even with pain, can provide some distraction and give you a sense of achievement.
- From there you can **start joining in warm-ups, and when you are ready, slowly get back into game or performance mode.**

Sometimes people can become fearful of movement as they don't want to cause pain. **Remember the pain you are experiencing is not a signal for damage to the muscles or bones.** In fact, by not being active because of pain, the muscles of the body can become weak or tight and joints stiff, which then causes more pain.

Exercise doesn't have to be intense. The best approach is to **start slowly and gradually build up the things you used to enjoy.** Your physiotherapist can help you with exercises to prevent or address deconditioning. They can also give top tips on how to get back in to the physical activities you enjoy.



5. Relaxation

When you are in pain your body tenses up and **being tense can actually makes things more painful!** Relaxing stops your muscles from tensing up and it helps quiet the autonomic nervous system – the system which controls the alarm messages. This can mean you feel less pain. It can also help you feel calmer when you are upset, stressed, frustrated or worried, which can make it easier to cope with the pain – so start now! 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 help prepare you for the day, then again at night to help you sleep.



There are lots of things that can help you relax such as:

- Take a bath
- Listen to music
- Go for a walk
- Read a book

Can you think of anymore?

1. _____
2. _____
3. _____

There are also some exercises you can learn to help with relaxation. Learning to use these exercises is like learning any other new skill (such as playing the guitar or riding a bike), it takes time and practice. It helps if you practice at the same time every day, so you remember.

When you get good at using these relaxation exercises, you will be able to use them to help your body stop tensing up in response to pain.



BREATHING EXERCISE

Get comfortable, sitting in a nice chair or lying on your bed and close your eyes. Imagine that you have a balloon in your tummy. Every time you breathe in, the balloon blows up. Each time you breathe out, all the air flows out of the balloon.

Slowly breathe in through your nose while you count to 5. Your tummy should rise as your balloon is blowing up. Now hold for a moment..... then breathe out slowly through your mouth and your tummy should go down as the air flows out of your balloon. Have a look if you wish. Feel all the muscle tension flow out of your body.

Repeat for 10 - 15 minutes.

MUSCLE RELAXATION EXERCISE

Another exercise that can help you relax your body involves tensing your muscles one by one, then relax them. This exercise takes a little longer than the breathing exercise, and you may need someone (like mum or dad) to help you with it while you are learning how to do it. Or you could record it on your phone and play it back to yourself.

- *First get comfortable, sitting in a nice chair or lying on your bed and close your eyes. Start by doing 5 nice, slow, balloon breaths and notice how your body is starting to feel relaxed and calm as you breathe slowly in and out.*
- *Now think about your toes and feet. Pretend that you're on a beach, and you have your toes in the warm sand. Curl your toes up tightly, gripping the warm sand in your toes. Feel how the muscles of your feet feel all tight or tense - hold that tension - now as you breathe out, let your toes uncurl and relax your feet completely. Breathe slowly in and out - notice how your muscles feel now that they are more relaxed.*
- *Now think about your legs. Pretend they are strong tree trunks as you stretch them out in front of you - try to make them as long as you can. Feel how your muscles feel all hard and tense - hold it - now as you breathe out, let your legs go all floppy and relax completely. Feel how heavy they feel against the chair/bed. Breathe slowly in and out - notice how good it feels to have relaxed muscles.*
- *Now think about your tummy, notice how it feels as you breathe slowly in and out..... now pretend that an elephant is about to step on your tummy. Squeeze the muscles and make your tummy as hard as you can, so that they could even hold an elephant. Feel how the muscles of your tummy feel all tight and hard - hold it - now as you breathe out, let all the air flow out of your tummy and feel how the muscle tension flows out.*
- *Now think about your shoulders and neck, take some time to notice how they feel - now pretend that you're a tortoise. Tuck your head tightly into your shell just like a tortoise... pulling your shoulders up so they almost touch your ears. Notice how your muscles feel now, all tense or tight - hold it - now as you breathe out, let your shoulders drop back down and relax your shoulder and neck muscles. Breathe slowly in and out - notice how your body feels now your muscles are more relaxed.*
- *Now focus on your eyes, nose and jaw muscles. Notice how they feel - now bite down as hard as you can as you tense your jaw muscles, squeeze your eyes shut and scrunch up your nose. Feel how the muscles of your face feel all tense - hold it - now as you breathe out, relax your face.*
- *Breathe slowly in and out and notice how relaxed your whole body feels after all the tightening and relaxing of muscles. See if you can notice any more tense muscles as you keep breathing slowly in and out. Focus on any places where you notice you feel tense or tight - now each time you breathe out, let any muscle tension flow out of your body, helping you feel more and more relaxed.*

6. Top Tips for Sleep



Difficulties with sleep are common with chronic pain. Pain can be more noticeable at night, as there is less distraction, so we can focus more on physical sensations. Dealing with chronic pain can also be very tiring and take a lot of energy during the day. **Getting a good night's sleep is therefore important to ensure you maintain enough energy to use the strategies that can help manage pain.**

Here are some things you can do to help with sleep:

Have a regular sleep and wake time. Keep to it everyday. Avoid catching up on sleep by taking long naps during the day or sleeping in on weekends. This makes it harder to fall asleep at the right time and keep up with your usual sleep and wake time during the week.



Have a good 'ritual'/routine in the hour before you close your eyes. This could include relaxing activities (such as having a bath, listening to quiet, soothing music, reading a book) and practicing your relaxation exercises.

Calm your brain. Put away any homework and switch off all computers and electronic devices at least one hour before

Keep your bedroom for sleeping only (which means no TV, computers, gaming or homework should be done in the bedroom).



Care for yourself during the day. This includes having regular meals, taking part in usual activities, getting some exercise (even a short 5 min walk is good) and spending time outside. Avoid food or drinks that have caffeine in them (such as energy drinks, caffeinated soft drinks, coffee, tea and chocolate) after lunch time.

7. Keep a Record

Everyone living with pain feels stuck sometimes. Pain can make us feel discouraged and even like giving up – that's what pain does!

We know, however, that even people living with really strong pain can have good days and bad days. **Noticing and finding out what makes the difference to your pain is a really important part of managing pain.**

Write down each day how you are doing with managing pain. You can do this on your phone, on paper or you can dictate yourself a memo and save it.

Be sure to include:

- What day it is
- What kind of things you did today (school, sleep, exercise, social)
- What you have been working on
- How hard you tried
- How effective was it in helping your pain
- Anything else you noticed that makes a difference



Write down one good thing (minimum!!) each day. When your pain is bad it might be hard to do, but if your day is a better one – go for it!. Remember lots of things can make us feel better, for some people it may be a hug, others a favourite TV programme or seeing a dog wag its tail. Let your mind go free!!

8. Dealing with Thoughts and Feelings



Learning to cope with stress and “beat worries” will help with your pain. When you have had pain for a long time, it can mean you get stressed or worried about things more easily and avoid doing things you used to, in case they make your pain worse. Having lots of worry thoughts can make it harder to cope with pain. Avoiding doing things can also lead to more worries, make pain worse and lead to feeling frustrated and sad. **It can help to make a regular time for relaxation exercises and put your focus on planning your activities and setting goals to gradually build (step by step) doing the things you used to enjoy.**

Focus on the positive. When you notice yourself thinking about the things you can’t do, shift your focus to what you can do or what you are working towards. For instance, instead of thinking about not being able to play netball, focus on how you are doing some warm up exercises and going for regular walks. This is called **Positive Noticing**. Lots of studies show **what we focus on grows**, whether the thoughts are good (going for walks, playing the guitar) or bad (pain, worries). **When there is a lot of pain**, your focus can narrow so **the good stuff doesn’t get noticed**.

Having someone you feel comfortable to talk to (such as your parents, family member, friend or a member of the Starship Pain Team) if your worries are getting in the way or if you are feeling frustrated or sad can also help.

What are some things you could tell yourself to help you feel calmer when you are feeling anxious or in pain?

1. _____
2. _____
3. _____
4. _____



9. Expect and Plan for Set-Backs

Remember what scouts say? **Be prepared!** Pain is tricky. It usually doesn't just disappear and go forever.

The good news is that **the better you get at managing pain, the easier coping with setbacks can be.** Even how you think about it makes a difference – Be positive, tell yourself “I’m managing this setback” rather than focussing on the negative, “Oh no, pain, again, what will I do?”

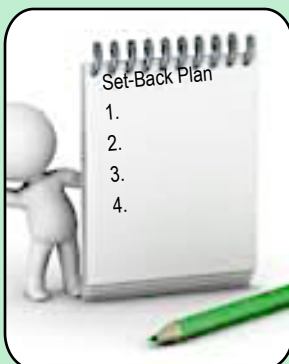
Setbacks can happen as people start increasing their activity and do too much too quickly – this is a good reason to keep a record so you can track this.

MAKING A SETBACK PLAN

Write down what you will do to manage pressures on you when you hit a setback

You may need to reduce the activities in your Activity, Rest and Sleep Diary when you hit a setback. Does resting help you manage your setback or does it make it worse? Some people find going to bed for a little while helps, but staying in bed too long can mean it is hard to get back on track and quickly leads to muscle weakness which can make the pain worse. **Decide on what is essential? What can you get away with not doing for now? What can you get your family to cover or make contact about to postpone or cancel?**

Write down all the things that have helped your pain before. People sometimes give up on these strategies when they have a setback, but this is the time to use them even more!



Here are some examples:

- Ice packs or hotpacks (some people like one, some the other)
- Massage (e.g. “I will ask mum to rub my back for a short time, three times a day”)
- TENS machines
- Vibration pillows
- Biofeedback or relaxation exercises (e.g. I will practice my biofeedback or relaxation four times a day).

10. Patience and Persistence

Sometimes it can seem that pain lingers for a very long time especially when it is having a big impact on what you are able to do. **BE PATIENT!** It may take you a few weeks or months to see improvements. This can make it hard to stay motivated and can make you feel sad, scared and frustrated. By **making goals and keeping a record**, it can **help remind you of how far you have come.**

Finding someone in your family or “team” that you can talk to, especially if you are starting to feel frustrated or sad can also help you keep going with your rehabilitation to manage pain. Don’t be tempted to overdo things to catch up, otherwise you may fall into the BOOM AND BUST CYCLE.



**Take one step at a time and believe in yourself
YOU CAN DO IT!**