#### Kia ora koutou katoa,

As many as 15 to 20% 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 over 100 new children and teenagers each year who have developed chronic pain.

We selected the name Pain Kete as this booklet is designed first and foremost for New Zealanders. A Kete is a traditional Maori basket woven from the leaves of New Zealand flax which is used to hold useful items. This booklet contains a collection of strategies which can be woven together to help each young person and their family manage chronic pain.

We chose a young explorer for our mascot since explorers need to be prepared for anything. Being prepared often means training or practicing for the difficult times such as when the explorer needs to climb a mountain or run or walk a long way. In many ways, you are the explorer who needs to train and practice to reach your goal of doing more and having less and less pain. The best way to do this is by practicing the strategies, using them wherever you go and gradually increasing what you do until you can reach your goal.

#### It also means being brave — the first steps can be the hardest!

"Te tiro atu to kanohi ki tairawhiti ana tera whiti te ra kite ataata ka hinga ki muri kia koe."

"Turn your face to the sun and the shadows fall behind you."

We hope you find our Pain Kete as useful as other children and young people have done in the past,



The Starship Complex Pain Team.

Welcome Haere Mai

Respect Manaaki

Together



## What's in the Kete?



#### 04



Pain is Created by the Brain
Pain Affects What You Do
Pain Affects How You Think and Feel
Stopping the Pain Spiral

#### 10

Have the Right Support

Be Brave and Courageous

Keep Active

Learn to Relax

Get a Good Night's Sleep

Learn to Deal with Thoughts and Feelings

Pacing, Planning and Setting Goals

Getting Back to School

#### 25

Expect and Plan for Setbacks!
Patience and Persistence
For Parents and Caregivers

#### 29

#### More Useful Things for Your Kete:

Relaxation Exercises
Distraction Strategies
Record of What Helps Your Pain
Examples of Activity Scheduling
Planners to Help You Schedule Activities
Tips for Very Sensitive Skin



## Pain is Created by the Brain

No matter what causes pain or how it feels ALL pain is produced by our brain

#### 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

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 us 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.

The Pain Kete

Welcome Haere Mai Respect

Together



# ACUTE PAIN DAMAGE TO THE BODY







Nerves respond to something that could be harmful and send •---- messages to the spinal cord.

## 3 BRAIN

The brain thinks there is a problem and sends an ALARM that gives you pain.

## 2 SPINAL CORD

These messages are sent to the brain from the spinal cord.











STOP BEING ACTIVE OR PLAYING SPORT

CAN'T SLEEP WELL No energy, Exhausted, Can't concentrate

STRUGGLE WITH SCHOOL WORK Frustration, worry, stress

STOP GOING TO SCHOOL

Fear of the Future, More worry and stress

MORE GRUMPY WITH OTHERS STOP SEEING FRIENDS

Issues with friends and family Hurt, sad, angry, lonely

## 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 do not help chronic pain. This can mean you get stuck in a downwards spiral even when you stop doing everything. The pain keeps on going, making us feel worse and worse!

Welcome Haere Mai

The Pain Kete

Respect Manaaki

Together

Aim High



## 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.

Welcome Haere Mai Respect Manaaki Together

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

### Starship Child Health

Paediatric Complex Pain Service

## **Stopping the Pain Spiral**

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

NOT LETTING YOUR PAIN CONTROL WHAT YOU DO LEARNING WAYS SPENDING TIME WITH FAMILY AND FRIENDS TO IMPROVE SLEEP DOING REGULAR ACTIVITY GETTING BACK TO SCHOOL LEARNING WAYS TO BEAT THE WORRIES

There are lots of things 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.

The Pain Kete

Welcome Haere Mai

Respect Manaaki

Together



## **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.



The Pain Kete

#### **A Support Crew**

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 helping us to try things or is always good a cheering us up when we get down.

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

#### THINK OF THE PEOPLE YOU WOULD LIKE ON YOUR SUPPORT TEAM. YOU MIGHT HAVE:

- People who know a lot about chronic pain like a pain doctor, paediatrician, physiotherapist, psychologist or occupational therapist
- People who you want to support you with your plan like whanau (family), a caregiver, school counsellor or nurse
- People who can make you feel good like an aunty or friend. You could include animals too!
- → Who is on your team?

Welcome Haere Mai Respect Manaaki Together Tühono Aim High



## **Be Brave and Courageous**

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

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 even if you have 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!

Welcome Haere Ma

Respec Manaak

Togethe Tühono





## **Keep Active**

**Our natural reaction** to having chronic pain is to stop doing active things. This is exactly what not to do! **Getting back to regular activity is very important to help break the Pain Cycle.** We also know that regular, gentle exercise is important for maintaining a healthy lifestyle no matter who you are.

You cannot wait for the pain to go away before getting active again, you must be brave 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 you know are enjoyable, even with pain, can provide some distraction and give you a sense of achievement.

The Pain Kete

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 of damage to your body. In fact, by not being active, the muscles of the body can become weak or tight and joints get 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. Exercise is good for both your mind and body!

Welcome Haere Ma

Respect Manaaki

Together Tühono



### Learn Relaxation

When you are in pain the muscles in your body tense up which can turn up the volume on pain. Relaxing prevents your muscles from tensing up and helps quiet the system which controls the alarm messages in your body. 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. 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 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 and it becomes part of your daily routine.

With practice, you will be able to use relaxation to help your body stop tensing up in response to pain. Have a look in the useful things section for ideas for relaxation exercises to try.

#### The Pain Kete

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

- Taking a bath
- Listening to music
- · Getting some fresh air
- · Reading a book
- · Riding your bike

Can you	think of	any oth	ers that	you like	e?

Welcome Haere Mai Respect Manaaki Together Tühono

Aim High

If you're stuck, see the 'useful things section'





Difficulties with sleep are common with chronic pain. Pain can increase at night time as there is less going on to distract you and you focus more on what's going on in your body.

**Dealing with Chronic** Pain can also be very tiring and take a lot of energy during the day.



#### Why is sleep important?

- · Can help you feel less cranky, sad or worried
- · Gives you enough energy to enjoy the things you like doing
- Helps you to concentrate at school
- · Reduces pain directly by its effects on the Autonomic Nervous System
- · Makes you feel more able to manage pain









**Make your bedroom a great place to sleep.** Sometimes little changes to your bedroom can make all the difference.

Ask yourself:

*Is it too hot or cold at night?* 

*Is it too noisy?* 

Is it too bright?

Is it tidy and peaceful and a place where I want to rest?

Have a regular sleep and wake time. Keep to it everyday. Avoid catching up on sleep by taking 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.



Welcome

Respect Manaaki

Together



## Learn to Deal 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. Here are some tips to help;

#### Make a regular time for relaxation exercises

**Put your focus on planning activities.** Set goals to gradually work towards, such as taking steps towards doing the activities 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.

**Try talking positively to yourself.** Think of times you've dealt with worries or difficulties in the past or times that you've felt confident. What could you tell yourself that would help? You could try: "I know I can manage this, I know this will pass, I can do this".

**Having someone you feel comfortable to talk to** (such as a parent, 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.

The Pain Kete

Welcome Haere Mai Respect Manaaki

Together Tühono





## Pacing, Planning and Setting Goals

**People only have** 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.

Doing little bits often rather than all at once can 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.

#### **Pacing**

Pacing means doing little bits often or finding the middle road between rest and activity. Over time you will be able to increase how much you can do. 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.

## → The biggest risk of not pacing your time and energy is BOOM AND BUST



Welcome Haere Mai Respect Manaaki Together Tühono

Aim High Angamua This is 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!

The Pain Kete



Building up your activity gently and keeping a similar 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.

Have a look at the example timetables in the 'useful things' section which could help you make a start!



#### **Planning**

Planning ahead will help to avoid BOOM AND BUST. 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.



#### **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 that mean something to you and your family It's good to have big picture goals and then smaller ones as steps along the way

DON'T FORGET YOUR SUPPORT TEAM IS THERE TO HELP YOU!



Welcome Haere Ma Respect

Respect Manaaki Together

Tühono
Aim High

Pain Kete

The



## **Getting Back to School**

**Chronic pain can** get in the way of going to school. Having the energy to get there each day, managing to pay attention in class, dealing with the busy classroom and keeping up with work! Many kids who have not been at school much, worry that friends will forget about them and they are behind with work.

School gives routine to your day, you get to see your classmates and learn new things. It's a big part of being a kid!

#### HERE ARE SOME THINGS THAT CAN HELP YOU GET BACK TO SCHOOL

Make a plan for each week and slowly increase the time you spend at school. The first step must be something you know you can manage like going for three half days a week. The breaks in your plan must be set by you and your family and NOT by the pain. When you have these breaks from school, use these for low key quiet activities.

2

Being active is part of school life and important to consider in your planning. This can include getting to and from school, around the school grounds, doing PE and perhaps sports.

3

If you are not at school, try to keep to the school routine at home. Between 9am-3pm each school day – you should be up and dressed and stay off devices unless for school work.

4

Don't take on too much too soon -gradually build up on school work. Don't' worry about falling behind at school. Use your support team to help plan what work you need to do.

Pain Kete

Welcome Haere Mai Respect

Together

Aim High



#### MAKE A PLAN FOR COPING WITH PAIN AT SCHOOL

- Using reminders in class e.g. little notes saying 'remember to relax', or 'I need to get up and stretch' at the end of each class
- Working out a plan if you have to leave class due to pain:



#### STARTING BACK TO SCHOOL AFTER THE HOLIDAYS

During the school holidays, young people may have less pain because there is less stress and less is required of them over the break. Everyone may feel like 'Yippee! We are over this!' However, we know that going back to school, can be stressful and pain can flare up before school starts or in the first few weeks.

- Review your school goals from the previous year and talk with your support team.
- Start back at the same amount of time at school you finished the previous year at (e.g. if you were attending 3 half days a week at the end of the last school year — start at that same level in February)
- Gradually build up time (remember it is good to have a mid-week break)
- Expect that there may be a 'few steps forward and a few steps back'
- Be cautious about increasing attendance during the Winter Terms

The Pain Kete

Welcome Haere Mai

Respect Manaaki

Together





## **Expect and Plan for Set-Backs**

Setbacks are part of recovery and that's important to know!

You might need a Plan B especially when you are doing big stuff, like going back to school. For example, having a plan to help you stay at school, even if the pain gets worse

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 focusing 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

#### 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 some of your planned activities 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")
- Biofeedback or relaxation exercises (e.g. I will practice my biofeedback or relaxation four times a day).

The Pain Kete

Welcome Haere Ma

Respect Manaaki

Together Tühono



### **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.



### Starship Child Health

Paediatric Complex Pain Service

## **For Parents and Caregivers**

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.

#### Why does my child have Chronic Pain?

We don't really know why some children get chronic pain and others don't. The reason is probably 'multifactorial' meaning there are many factors including the way we are made (biological), the way we think (cognitive) and feel (psychological). Chronic pain can run in families or happens when a child has a physical problem that's been hard to get on top of. Particular personalities can be at risk, such as a young person who puts pressure on themselves perhaps at school or in sports, or a who has an anxious nature or finds it hard to know and express how they are feeling. Sometimes it's hard to find a reason why.

Parents can help by accepting their child has chronic pain for now and supporting them through their rehabilitation which can include medical, physical and psychological treatment. Young people can do extremely well at learning to cope with chronic pain so that it has less effect on their lives. Their best chance of doing this is by having parents who support them in their rehabilitation. If your mind is still full of questions about why your child has pain and why it cannot be stopped, please discuss this with your treating team 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 making too much of 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').

#### Support your child with,

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

The Pain Kete

Welcome Haere Mai

Respect Manaaki

Together



**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 device on the days they have been to school).

**Managing their pain themselves** Your child may need encouragement to use pain management strategies they are learning, like breathing, relaxation exercises and physiotherapy exercises.

Do your best to be confident about the rehabilitation programme and show this to your child. Kids know if their parents don't think something's going to help, even if they don't say so. Studies show that more than 90% of our communication is non-verbal! This means our body language is important. If you are not happy with any part of the rehabilitation programme – let your team know so you can work it out together.

#### The Pain Kete



#### **TALKING ABOUT IT**

Chronic pain can make communicating with your child difficult. It's important to try and be available to listen as well as being able to clearly let your child know what you are worried about.

#### 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 and really listen to what they say
- Make time to talk talking can feel easier when you are both taking part in a shared activity (e.g. watching TV, cooking together). Starting some regular shared activities can give you more opportunity to talk and have fun together.

#### Things that DON'T help:

- Lecturing
- Not letting teens speak for themselves at their appointments
- Focusing too much on pain

Welcome Haere Mai Respect

Together

Aim High



## More Useful Things for The Kete



#### RELAXATION EXERCISES

#### **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.

Welcome Haere Mai

Respect Manaaki

Together Tühono



#### 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 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 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.

The Pain Kete

Respect

Welcome

Together

Aim High



## 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.



#### **IMAGERY EXERCISES**

Using your mind to visualize change can be very powerful. Research has shown that brain activity is the same whether you do an activity in your mind or in real life. Using imagery can turn down the volume on pain and help you cope with pain.

Find a comfortable place and close your eyes. Have a practice of the following ideas and see what works for you.

- Happy place: Think of a favourite place, somewhere you've been on holiday, somewhere peaceful that makes you feel happy. Really picture that place in your mind through your five senses: what can you see, what can you hear, what can you touch, taste and smell. Focus on the happy feelings that come up when you think of this place. If your thoughts wander from this image, gently return your focus to the peaceful, relaxing image in your mind.
- Imagine pain as a colour and visualize it changing to cool and blue or change your pain from hot and burning to cool water that flows away from your body.
- Image you have a remote control for your brain and body, turn down the pain and turn up the comfort level!



- Calm
- Headspace
- Breathe2Relax

Welcome Haere Ma

The

Pain Kete

Respect Manaaki

Together Tühono

## DISTRACTION STRATEGIES

Have a bubble bath Watch a movie Listen to the music you like Go for a walk Look at the clouds in the sky – what shapes can you see? Visit your favourite park or beach Take a long shower Play a Board Game Talk to a friend or family Do some relaxation exercises Arts and crafts Read a book Pet a friendly animal Plant a flower Listen to the birds Make your favourite drink Try some baking Visit your favourite place Write down three things that went well for you yesterday Do something to help someone Play catch Write down ten things that you are better at than you used to be Do some yoga Go through the alphabet and name

animals that start with each letter

Read your favourite magazine

Ride a bike or scooter











## RECORD OF WHAT HELPS YOUR PAIN

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, computer or on paper

#### 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

The Pain Kete

#### **EXAMPLES OF ACTIVITY PLANS**

**Katie is 14 years old.** She has been diagnosed with chronic abdominal pain and hasn't been at school in 4 months. She hasn't been able to do the things that she loves which are riding horses and hanging out with her friends. Since she hasn't been at school Katie has slept in longer and is now waking at 10:30am. She is having more and more difficulty getting to sleep.

Katie really wants to do well in her exams next year. She was also hoping to show her horse at a national event.

She worked alongside her pain therapists to come up with a plan to get back to school and the activities she loves. At times it was really hard to stick to the plan, especially on the days where she was feeling good and wanted to do more and the days where she felt awful and as if she should stay in bed. With courage and support from her team the plan is going in the right direction.

The key was for Katie and her family to think about a plan for the week and feel confident that despite the ups and downs in her pain she would be able to do the planned activity. She also considered the things that she really wants to do and the things she needs to do or is expected to do.

Welcome Haere Ma

Respect Manaaki

Together



#### Weeks 1-2

	Mon	Tue	Wed	Thu	Fri	Sat	Sun
am	School	School		School	School	Meet friend at café	Family outing to the beach for 1 hour
pm	Dishes	Bins out	Visit to horse paddock to groom horses	Walk the dog 20 mins			

#### Weeks 3-4

	Mon	Tue	Wed	Thu	Fri	Sat	Sun
am	School	School		School	School	Horse paddock - walking the horse for 30 minutes	Meet friends at mall for 1 hour
pm	Walk the dog 30 mins Dishes	School Bins out	Visit to horse paddock to groom horses	Walk the dog 30 mins	School		

#### Weeks 5-6

	Mon	Tue	Wed	Thu	Fri	Sat	Sun
am	School	School		School	School	Horse riding – trotting no cantering 45 mins	Meets friends for a movie
pm	School Walk the dog 30 mins Dishes	School Bins out	Visit to horse paddock to groom horses	School Walk the dog 30 mins	School		

The Pain Kete

Welcome Haere Mai Respect Manaaki

Together Tūhono

### PLANNERS FOR YOU TO KEEP

### Starship Child Health

Paediatric Complex Pain Service

#### **DAILY PLANNER**

When using the Daily Planner consider all the elements of your day

For example: time to get up and ready for the day, either planned school attendance or schedule learning sessions, time for quiet activities and time for physical activities, meal times and map out the routine involved with going to bed

Today	Date:
7:00	
7:30	
8:00	
8:30	
9:00	
9:30	
10:00	
10:30	
11:00	
11:30	
12:00	
12:30	
1:00	
1:30	
2:00	
2:30	
3:00	
3:30	
4:00	
4:30	
5:00	
5:30	
6:00	
6:30	
7:00	
7:30	
8:00	
8:30	
9:00	
9:30	
Notes:	

Pain Kete

The

Welcome Haere Mai

Respect

Manaaki

Together Tühono

#### **WEEKLY PLANNER**

The Weekly Planner allows you to plan across the week to get the right balance over a longer time.



Today		Date:	
MONDAY Morning	Morning	Morning	Morning
Afternoon	Afternoon	Afternoon	Afternoon

Notes:



Paediatric Complex Pain Service

**FRIDAY** 

Morning

**SATURDAY** 

Morning

**SUNDAY** 

Morning

The Pain Kete

Afternoon

Afternoon

Afternoon



Welcome Haere Mai

Respect Manaaki

Together Tühono





**Sometimes chronic pain** can change the way the body feels things. For example, warm shower water can feel burning hot or wearing a sock or shoe on a painful foot can be super sore. This is called **sensitisation**. In other words, things that wouldn't normally hurt, really hurt!

The way to help calm the bodies response to a usually not painful situation is called **desensitisation**. This takes time, courage and means doing little bits at a time.

The worst thing that you can do is to continue to avoid doing the things that hurt as it is likely the pain will get worse.

#### Here is an example:

For someone that can't wear a shoe on their foot they could start touching their foot with increasing pressure and time. Next introduce a loose light stocking, then a fluffy baggy sock. Next try a slipper and then into a comfortable lace up shoe. There's not one way of doing this so it is best to get help from a professional experienced in this approach.

When you are doing these challenging things it is good to try to distract yourself or use other pain coping strategies that you have learned or read about in the kete.

Welcome Haere Mai Respect Manaaki Together Tühono Aim High

Pain

The first steps will be the hardest!