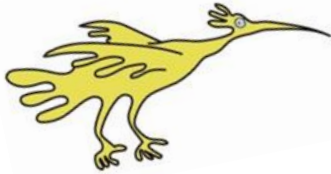
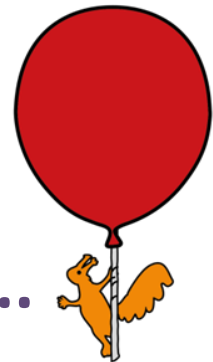


The Chronic Pain Management Team
Alder Hey Children's Hospital



MY CHRONIC PAIN
PASSPORT

NAME:



DATE:



When is pain helpful?

When we injure ourselves, messages are sent by nerves to the brain. The brain processes these messages so that you feel pain. This type of pain is called *acute pain* and is a helpful response which stops you moving that area, allowing the injury to heal. It's like the pain is a warning which needs attention. Once this area has healed and the pain has stopped, we usually get moving again and resume our normal activities. Acute pain tends to come on very suddenly, and there is usually a clear reason for this. Examples of things which might cause acute pain are stubbing your toe and falling off your bike.

When is pain unhelpful?

Pain that has been present for at least 3 months can be called *chronic pain*. For some young people there may be a clear explanation for why the pain started. However, for some young people, pain may start spontaneously, feeling like it has come out of nowhere. You might have seen different specialists or had tests and investigations that have come back as normal, but you still have pain. We believe that your pain is real and can be really tough to live with.

This pain is now no longer helpful or protective and may stop you from doing the things you want to do. Pain staying around does not mean that there is ongoing damage happening in your body. Medicines which you may have had for acute pain don't always work very well for chronic pain.

With chronic pain we may not have a clear explanation for why the pain started or has not gone away. What we do know is that pain nerves continue to send messages to the brain, and this is why you continue to hurt.

When pain has been around for a while, more changes can happen in our nervous system. More pain nerves might join in with sending messages, and this means that you might feel that your pain is getting worse or notice that other parts of your body begin to hurt. Your ability to cope with pain might reduce, and you might start to notice more pain even when you start to do less.

How can chronic pain impact on your life?

We understand that chronic pain may affect you in lots of ways, and may make you feel different to other people. Maybe you can't do the sports you used to do, or socialise with friends as much. Perhaps for you, attending school is the biggest difficulty, or feeling able to do the things which used to make you feel happy. Below are some other ways that chronic pain may cause you difficulties;



*Taken from 'My Pain Toolkit; For young people living with pain'
Pete Moore, Jessica Bird & Dr Frances Cole, April 2012*

We understand that chronic pain can affect a young person in lots of different ways, and this is why it is useful to work as a team, as we are each able to help support you in different ways.

Below is some information on the different people you might have met in your recent chronic pain clinic appointment.

Consultant

The Doctor may start, and advise about medicines which may be helpful to manage chronic pain. Medicines to help with chronic pain are usually not the whole answer but can reduce the level of pain to allow you to begin to participate with other members of the team to manage things better.

The doctor may also make referrals to other specialists and services when appropriate. You may not see the doctor as often as other members of the team, but they lead the team and keep in touch regularly with all the team members to co-ordinate your pain management plan.

Physiotherapy

Physiotherapy is a really important tool to help you to manage chronic pain. You might hear that you are deconditioned. This means that you have lost fitness or muscle strength due to lack of exercise. We appreciate that this may have happened because of your experience of pain. Maybe you have tried to exercise however this has caused pain, and you have lost confidence to try again. Physiotherapy can help with strengthening and stretching muscles which may now be causing pain.

Physiotherapy is not just about learning exercises, we are also able to tailor activities to help you to get back to socialising with friends again, or any of the other things which you would like to do. We can get you started by completing a slow, phased rehabilitation programme. We can educate you on how to pace your activity so that it does not result in a large increase in pain. We believe that you can achieve your desirable goal(s), however we may need to go at a slower pace with regular breaks to get there. As we progress and as you get stronger, your need for breaks will hopefully become less frequent, as your confidence increases to do more.

Pain Nurse Specialist

Clinical Nurse Specialists will help to co-ordinate your care within the pain team, and be your point of contact. We can offer support with pain management strategies and techniques which are not medicine based. We also have experience and knowledge of medicines used in chronic pain and we can provide guidance around potential side effects and managing medication when appropriate.

Clinical Psychology

A Clinical Psychologist aims to understand how a person's thoughts, feelings and behaviours can interact with each other. We are aware that how we feel emotionally can affect how we feel physically, and we know that having a health condition can itself affect our moods and feelings.

As part of helping you to understand and learn ways to manage symptoms, we may offer to meet with you and your family, either separately or together. A Clinical Psychologist will help you think about how you would prefer things to be and will support you to work towards achieving your goals.

We can offer support, which is one to one, and/or we also offer group work. There are many different ways in which support may be provided:

- Listening
- Exploring who you are away from symptoms
- We may ask you about school, family and friends
- We can help you to make decisions about your health care
- Help with managing difficulties such as sleep
- Thinking about things which may make symptoms better or worse
- Setting goals and problem solving
- Working together to explore the impact of symptoms on how you think, feel and behave

Plan from my 1st Chronic Pain Clinic

If I am prescribed any medicine, there is space to write it here;

Medicine Name	Dose	How often do I take this?

Has any other information or advice been given to me today about medicines? If yes, I can write it here:

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Have I been referred to any of the pain team members, and if so why?

Team Member	Have I been referred?	Will the team member talk with any other services?	Is there anything I would like to write down about this, so I don't forget?
Physiotherapist	Yes / No	Yes / No	
Clinical Psychologist	Yes / No	Yes / No	
Pain Nurse Specialist	Yes / No	Yes / No	

If I have any other information I would like to remember, I can write it here:

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YouTube clips I might find helpful

Chronic Pain explained



Understanding Pain in less than 5 minutes, and what to do about it!

https://www.youtube.com/watch?v=C_3phB93rvI

This is a video using cartoon drawings to explain the difference between acute and chronic pain, and the role of the team in helping manage. Although aimed at adults, this should be easily understood for older children as well as teenagers.

A Car with Four Flat Tyres



<https://www.bing.com/videos/search?q=youtu+car+with+four+flat+tyres&view=detail&mid=FE25BACC9B248A0F9EFCFE25BACC9B248A0F9EFC&FORM=VIRE>

This video explains the need for different approaches to help manage chronic pain.

Tame the Beast



Tame The Beast – It's time to rethink persistent pain

<https://www.youtube.com/watch?v=ikUzvSpH7Z4>

This video talks about taming the 'beast' of chronic pain. It may help me to think about the idea of retraining my brain to re-gain some control over pain. The website <https://www.tamethebeast.org/> may be helpful.

What is Pain



What Is Pain Video

<https://www.youtube.com/watch?v=GF2xhUKxzyY> This video introduces the idea of the pain gate, helping us to think about what may make pain harder or easier to cope with.

Online resources I might find helpful

www.paintoolkit.org

Pain toolkit is a website with information, handy tips and skills, to help you understand and manage persistent pain on an everyday basis.

There is also a toolkit for young people, and you can find this at:

<https://www.parksmed.co.uk/wp-content/uploads/2013/09/Pain-Toolkit-for-teenagers.pdf>

This toolkit also contains links to other websites and clips you may find useful.

Sleep and Relaxation.

<http://www.mymind.org.uk/thebox/>

Getting good quality sleep can help with pain control. Cheshire and Wirral CAMHS have a number of tools on their website. Chillax (found under the sleep category) has a factsheet of tips helping young people wind down and prepare for sleep. You can also find many sleep based recordings on free apps like Headspace and Calm. This link also has some useful relaxation tips;

<https://www.getselfhelp.co.uk/relax.htm>

Mindfulness

Mindfulness can be useful for pain management. This is about learning to pay attention to the present moment, when your mind may want to wander away to the past or future. My Mind is website for children and young people aged 5-19years old with links to mindfulness and other tools and activities.

<http://cwpcamhscentre.mymind.org.uk>

Headspace is also a free app to help learn mindfulness techniques. We also like the free app **Insight Timer**, which provides guided meditation to help with difficulties including stress, anxiety and poor sleep.

Calm Zone

This website has a range of activities such as breathing exercises, ideas for managing feelings, coping videos and games to help us with feeling calm.

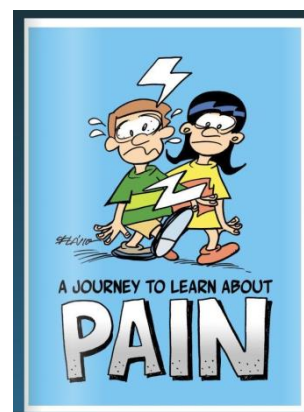
<https://www.childline.org.uk/toolbox/calm-zone/>

Books I might find helpful

A journey to learn about pain

This is a free online book to help children and young people to learn about chronic pain and to learn ways to manage it.

<https://www.yumpu.com/en/document/read/61002254/a-journey-to-learn-about-pain>



'Be the Boss of Your Pain' (Timothy Culbert & Rebecca Kajander)

This is a book aimed at children aged between 7 – 12 years old. It explains links between the body, the mind and pain. It may help younger children to understand how pain can affect their emotions, sleep and appetite. It contains practical skills to help children feel more in control of pain.

The Chronic Pain and Illness Workbook for Teens: CBT and Mindfulness-Based Practices to Turn Down the Volume on Pain (Rachel Zoffness)

This easy-to-use workbook teaches teens about how pain affects both the mind and body, how negative emotions can make pain worse, and strategies to help turn down the volume of pain.

Complex Regional Pain Syndrome (CRPS) Explained: By Teenagers for Teenagers (GR Lauder & R Massey)

This book provides information for teenagers who develop CRPS. It explains the importance of a team approach, and looks at the journey from diagnosis, to management, to recovery. More information about the book can be found on its website – www.crpsexplainedforteenagers.com.

GrrrOUCH! Pain is like a Grouchy Bear (C Morgan & C Beshara)

This is an illustrated book aimed at 6-10 year olds. It presents ideas to help cope with pain using rhythm and rhyme. This book encourages children to communicate their feelings and explore and describe their pain with words and images.

Books my parents might find helpful

Conquering your Childs Chronic Pain: A Paediatricians Guide to Reclaiming a Normal Childhood (LK Zelter & C Blackett-Schlank)

This book is written by a children's doctor, about causes and repercussions of chronic pain in children on both a child and their family. It discusses a multidisciplinary approach to management, with suggestions including yoga, hypnotherapy, acupuncture, relaxation techniques and medications.

Managing Your Child's Chronic Pain (TM Palermo & EF Law)

Written by paediatric psychologists, this book is aimed at supporting parents to learn how to help their child and members of their family, when they have a child experiencing persistent pain. This book discusses deep breathing, relaxation strategies and sleep interventions to help parents support their children develop these skills.

When Your Child Hurts: Effective Strategies to Increase Comfort, Reduce Stress and Break the Cycle of Chronic Pain (Rachel Caokley)

Written by a paediatric psychologist, who works with families of children with chronic pain. It provides research proven and in-the-moment practical strategies for parents to support their child with chronic pain.

Follow-up appointments with the team

To help remind me at my follow-up appointments, I can write any questions I have here so I don't forget.

After I have been to a follow up appointment with any member of the team, the space below is for me to write a summary of any advice I was given, and anything I need to remember. I can keep adding to this section:

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How to manage any future difficulties

It is not uncommon when learning to manage chronic pain, that I may experience times where it feels that things are getting worse. I might see this as a 'set back', or a 'flare' maybe. **The first thing to do is not to panic!**

Below, I can start to make a list of any of the strategies which I have found helpful to manage chronic pain:

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This booklet only gives general information. You must always discuss individual treatment with the appropriate member of staff. Do not rely on this leaflet alone for information about treatment.

This information can be made available in other languages and formats if requested.

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