Chronic pain in children and adolescents
Tips for management and recovery

This information sheet is for parents and/or carers and teachers of children who are experiencing chronic pain. A child or adolescent’s ongoing experience of pain affects emotional, social, physical and academic activities that impact the whole family. Recovery may take some time and it benefits from approaches involving the support from multiple key individuals. This information is designed to assist parents and teachers to recognise chronic pain, provides tips and resources for managing it and illustrates how psychologists can help.

What is pain?
Pain is defined as “an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage” (International Association for the Study of Pain).
Pain is a personal experience that involves not just a physical sensation, but impacts on emotional and mental wellbeing. It is influenced by a child’s attitudes, beliefs, personality and social factors.
Pain is often described as either acute or chronic. Acute pain is pain that occurs within the normal period of healing, for example after an injury like a broken bone or sprained muscle, illness, infection or surgery. Pain is said to be chronic (or persistent) when it continues beyond the usual period of healing. This is often defined as pain that lasts for three months or longer.
As many as one in four children experience chronic pain, and of these, about five per cent experience moderate to severe pain. Girls report pain more frequently than boys. The most common type of chronic pain in children is headache (20%), followed by abdominal pain (10–18%) and nerve pain that usually affects the arms, legs, hands or feet (4–15%).

Consequences of poorly managed chronic pain
Getting the right care and treatment early is important. Many children with chronic pain find going to school difficult and this can result in frequent or extended absences. It can be hard keeping up with schoolwork, maintaining good grades and staying connected to friends. Withdrawal from these important activities can lead to social isolation and inactivity. Sleep and
mental health problems are also very common for children with chronic pain.

While chronic pain is a common occurrence for many children and adolescents, it can take time before it is recognised and diagnosed. This means that teachers may be unaware of how best to manage a child with chronic pain in their classroom and in how to manage the expectations for academic progress.

Managing chronic pain affects all family members. Parents may be required to take regular time off work for appointments and to manage school absence and this can create stress and frustration if treatments do not appear to be working quickly. It is common for families to worry about managing a child with chronic pain. Pain in children has been found to impact family relationships including siblings who can feel neglected.

Tips for parents

Investigate the cause of your child’s pain

• It is important to have a thorough investigation conducted by your doctor. Talking about this first with your GP is a good place to begin. When investigations are properly timed and provide a good picture about your child’s health history you can be confident that should pain persist, you can ask for referral to a pain specialist and/or pain clinic for children and adolescents.

Involve a number of health professionals

• Your child’s GP may coordinate his/her care and collaborate with other health professionals (e.g., psychologist, physiotherapist) or they might refer your child to a specialist pain management clinic. Chronic pain is managed best using an interdisciplinary approach that includes different professionals working together on an agreed pain management plan. It is important to have your treaters communicate and collaborate under a shared understanding of the nature of your child’s pain experience and an agreed approach to treatment.

Work with skilled professionals

• Where possible, work with health professionals skilled in working with children with chronic pain. Your child’s GP may be able to assist with appropriate referrals.

• When making appointments with these providers, ask them about their knowledge of working with a child with chronic pain. When providers are skilled in managing pain well they can help you understand how interventions at first need to involve teaching the body how to move again with pain. Treatment includes learning steps to gradually retrain your child’s whole pain system.

Take a gradual approach to treatment

• Interventions often start with increasing functioning, this can seem illogical at first. By assisting your child to resume routines and activities, it helps to reduce pain, improve their mood and increase their enjoyment from life. So, if activities have not been maintained for some time, a gradual approach to resuming activity is needed and this will require a supportive program of agreed targets.

Supporting your child

• It can be useful to consider if you are being ‘too helpful’. Parents’ intuition when a child is unwell or hurt is to be caring and allow them to rest. This is exactly the right response when your child has a temperature or recent injury. With chronic pain we need to respond differently, and this can sometimes be hard to do. For example, with chronic pain, long periods of rest can lead to a worsening of symptoms; stopping school can lead to getting behind in learning and increasing stress; not doing house chores can mean children do not receive recognition and valuable skills.

Encourage your child to have a go

• Encouraging your child to ‘have a go’ is the best response. To communicate your care for them it can be better not to ask your child about their pain, but rather ask them about a range of things they are doing or are interested in and if they would like any help.

A psychologist can help

• A psychologist is very important in this process of increasing activity. It can be challenging and stressful doing tasks while in pain. If children or adolescents have not participated in activities for some time, they may have lost confidence and be afraid of making mistakes or not being able to finish tasks or activities to the same level as before. Psychologists are very good at helping children develop their problem-solving skills and assisting them to recognise and utilise the talents they already have though may be surprised they have forgotten.

Ensure you have a Pain Management Plan

• The interventions your child receives should be part of the overall plan for their pain management. Your Pain Management Plan should include the goals that your child is working on to better manage their pain and the strategies they can implement for assistance should pain flare up. The professionals supporting your child can help you to establish a plan that is reflective of your child’s needs right now.

Involve other adults such as teachers

• Ensure that all the adults who fulfill a role in your child’s life such as teachers, coaches, other family members or carers are also included in the Pain Management Plan and are clear about the supports they can offer. This will assist everyone to understand their role and know how to respond quickly and easily.
Practise some self-care

- Caring for a child or adolescent with chronic pain can be exhausting, so finding ways to deal with your own stress and frustration is helpful. This might include contact with other parents who are dealing with a similar situation, perhaps through a support group, or a trusted friend or family member. Feeling more on top of the situation and having a positive attitude helps your child to adapt. Time-out for rest, relaxation, and reconnecting with your partner and friends is essential.

Tips for schools/teachers

Teachers may not always be aware that a child in their class has chronic pain. The first sign might be handing work in late, distracted behaviour in class or absences. If you discover that one of your students has chronic pain, then it is important to find out how their academic progress can be supported. In the first instance this may mean discussion with the school’s wellbeing coordinator or the year-level coordinator (depending whether primary or secondary age) and organising a meeting between the school, parent and student. In such a meeting, the focus of discussion is best aimed at supporting the student to stay at school where possible and this may require developing a School Pain Management Plan that includes the following issues:

Physical/environmental adjustments

- Extra time to get around the school
- The student carrying important belongings between their lessons and from one classroom to another
- The temperature of the classroom and how the student works this out with teachers
- The seating of the student in class (aids and position)
- Snacks and water available in the classroom

Academic support

- Modifying/reducing homework requirements
- Working out deadlines and extra time for extensions
- Not being punished for absences or late arrivals
- Access to tutors/teacher supports for topics that are proving difficult

Taking a break

- Students may need to have a break during lesson time to practise strategies from their Pain Management Plan if pain flares. These might include distraction, relaxation, stretching, listening to music, reading, practising a mindfulness or breathing technique, and taking medications.
- This break should be for approximately 20–30 mins (or if in senior school to the next bell for the start of the next lesson).
- Breaks should be supervised usually in a nurse’s office or library or somewhere quiet where the student can practise their pain management skills.
- It is advisable that a student uses no more than two to three breaks in one day and the breaks are preferable to going home.
- Students may often prefer to have a ‘passcard’ system with the teacher to request a break so that they do not have to explain their action. It is important that all teachers involved in a student’s care are aware of how breaks will be requested.

Physical education (PE)

- Adolescents and children with chronic pain may not be able to participate in the full PE curriculum though it is important that they can be included in the way that is identified in their Pain Management Plan or a way that contributes to their progress. They may receive physical therapy as part of their intervention and the suggestions for these sessions may guide what they do in PE.
- The student should not be punished for not participating and they may need to gradually increase their activities over a number of weeks.

Communication plan

- Regular meetings between school, parents and the student are helpful. Adjusting to change can be extra challenging for children and adolescents with chronic pain, and stress can worsen symptoms. Additional support at the beginning and end of every term may be needed and necessary at the start and end of the school year.
- Identifying one school staff member who helps with communication between school and parents is useful, and this person can also communicate to teachers the necessary information. For example, this might include information about medical issues that may interrupt classes.
- When a child has been absent for some time, working out how work gets completed will need to be discussed. This may involve work being sent home or contact with teachers to discuss work requirements. Also, a plan for returning to school may need to be discussed. This might include attendance for regular shorter periods at school while working towards a gradual increase in time spent at school. It is often better for children to attend for smaller periods at school every day than for whole days a few times each week.
How can a psychologist help with chronic pain?

It is likely that a psychologist will be involved in your child’s treatment. Managing tasks with chronic pain is stressful; psychologists work directly with parents, children and adolescents to assist them to better manage stress. They also have many helpful strategies to manage or reduce the pain and associated stress and assist parents and children to work towards their best functioning by setting goals and having a balanced routine.

Psychologists also play a key role in helping children and adolescents manage their learning at school. They can assist children to manage their concentration, motivation and emotions while at school and this can be very important for a student’s continued success at school and confidence.

In addition, psychologists can help children and adolescents with sleep. Pain can be very disruptive for sleep and lack of sleep can reduce the ability to successfully manage pain. Therefore, learning strategies that assist children in sleeping well is particularly helpful for managing school well and recovery from chronic pain.

Accessing help

Help for your child

Accessing support from a psychologist for your child to better manage chronic pain is best discussed firstly with your GP or medical specialist. A Medicare rebate may apply for some psychology services.

As a parent of a child with chronic pain, you are likely to be able to get support through a referral from your child’s health practitioner if none of the existing treatment team can assist. Seek help if you feel that you need additional professional support to manage your child’s chronic pain condition and the stresses associated with it. Psychologists are highly trained and qualified professionals skilled in providing effective interventions for a range of mental health concerns.

To access a psychologist direct:

• Use the Australia-wide Find a Psychologist™ service
• Go to findapsychologist.org.au (within “search by issue” you can go to the “general health” list and select “pain management”) or call 1800 333 497

The APS has a number of resources available to assist Australians manage chronic pain.

Visit psychweek.org.au/2020-resources for more.

Resources

Videos
• The mysterious science of pain
• Why things hurt TED Talk
• The mystery of chronic pain TED Talk

Workshop
The Comfort Ability program
www.thecomfortability.com

Book
Coakley, R (2016). When your Child Hurts: Effective Strategies to Increase Comfort, Reduce Stress, and Break the Cycle of Chronic Pain. Yale University Press

Australian Psychological Society
The APS has a number of resources available to assist Australians manage chronic pain.
Visit psychweek.org.au/2020-resources for more.

The Paediatric Chronic Pain Service at the Women’s and Children’s Hospital Adelaide

• The Paediatric Chronic Pain Service Information for Patients and Families - includes a number of resources, including videos, online learning activities, books and apps.

Pain Australia

• Information and resources for parents, including a current list of paediatric pain clinics and pain programs.
• The TEAc-Pain Project
• PainBytes