

Persistent pain in children and young people

Information for patients, parents and carers

This information is written to provide advice for children and young people who have persistent pain and help their families and carers to assist them in managing these symptoms. Please support a child to read this information.

What is persistent pain?

Persistent pain, also called chronic or long-term pain, is a pain that is present for more than 3 months. Standard pain killing medicines may not make this pain feel better. Even if the examination and investigations are normal, the pain is real.

The pain can:

- Affect any part of the body
- Happen after an injury, surgery, illness or stressful life event
- Come about for no obvious reason.

Why do we get pain?

Pain is our defence mechanism when we injure ourselves, such as making us move our hand quickly if it touches a hot flame. Then usually, once any swelling gets better and our hand heals, the pain stops.

However, for some people this does not happen. The nervous system in our bodies (made up of our brain, spinal cord and nerves) sometimes becomes very excited and continues to send pain messages even when healing is complete. This causes persistent pain or pain which cannot easily be made better. Difficult to manage pain can also happen in conditions such as arthritis, irritable bowel syndrome or inflammatory bowel disease, which means that feeling uncomfortable can be expected.

Who can help manage my pain?

If you have persistent pain, it can make sleeping difficult, affect your mood, affect your ability to attend school, and affect your ability to socialise with friends and family. This may make you tired, stressed, anxious, scared, frustrated or angry. These feelings can also increase the flow of pain messages and make your pain worse. For these reasons, pain is best managed by a group of different professionals, all with different areas of expertise.

These include:

- GP
- Paediatrician
- Physiotherapist
- Occupational Therapist.
- Psychologist
- Specialist Paediatric Pain Management Nurses
- Consultants in Paediatric Anaesthesia and Pain Management.

A team approach to helping your pain has the best chance of success. Depending on the pain you have, you may need help from a few or all of these teams. You and your family have a very important job too. You have to do your part in getting yourself better.

How can I help myself get better?

Sometimes it is important to realise that being in pain is also a medical condition that may not have a cause or a cure and there may be no quick way to make your pain better. Your GP or Paediatrician may suggest options for dealing with your pain. Any improvement is likely to take time. It is extremely important you eat well, sleep well and try to maintain daily routines and activities (physical, mental and social) if possible.

Simple things you can try include:

- Warm baths/showers
- Heat packs/ice packs
- Doing activities bit by bit, taking a break if you need it
- Making goals that you can easily reach, such as walking to a nearby friend's house rather than a mile to the local shop
- Gentle exercise: swimming, walking
- Relaxation: reading, listening to music, seeing friends
- Distraction: doing things you enjoy (hobbies and interests)
- Make up a plan with your family and friends for those 'pain days.' They are likely to happen when you are ill or stressed. Don't panic, stick to your plan.

What can the team managing my pain do to help me get better?

There are a number of ways your pain can be managed such as, a combination of psychological approaches, physical therapies and medicines. These try to improve sleep, school attendance and socialising with friends and family. Treatments may not reduce or get rid of pain, but they should improve your ability to cope and improve day to day life. Some of these include:

Medicines:

- Simple pain medicines paracetamol, ibuprofen
- Specialist pain medicines gabapentin, amitriptyline, lignocaine patches
- Medicines to help you sleep melatonin, amitriptyline.

Alternative treatments:

- TENS Machine (Transcutaneous Electrical Nerve Stimulation)
- Acupuncture
- Massage.

Physical therapies:

Gentle exercise

- Releases the body's natural pain killers (endorphins)
- Can keep your weight healthy
- Improves your mood
- Improves your quality of sleep
- Increases your muscle strength and reduces muscle tension
- Increases your joint flexibility and reduces joint stiffness.

Physiotherapy

Physiotherapists know how your pain affects your physical activity. They will assess your muscle strength, joint movement and balance and provide you with help on a safe exercise programme for your ability and needs.

Occupational therapy

Occupational Therapists know how your pain affects your everyday activities and your independence.

Psychological approaches:

Psychology

- Psychologists look at how your pain affects your daily activities and how you deal with friends and family. They can teach you useful ways to cope with stress and anxiety
- Ways to relax which can help muscle tension and relax your mind (e.g. breathing exercises)
- Ways to help you take your mind off the pain
- Make a plan with you to return you to your daily activities.

Useful Web Links

TED Talk: www.youtube.com/watch?v=I7wfDenj6CQ SpunOut.ie: www.youtube.com/watch?v=sP0twrtoCGk Pain Bytes: www.aci.health.nsw.gov.au/chronic-pain/painbytes

Useful Apps

- Breath2Relax
- Stop, Breath, Think
- One-Moment Meditation
- Mindfulness App: Mindful Gnats (for iPhone or Android), Headspace

For a copy of this leaflet in a larger print, Braille or your community language, please telephone: 0131 242 8181

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