

Parenting a child or young person with chronic pain



This leaflet is for parents of children and young people with chronic pain. We'll look at some of the challenges and how you can face them with top tips from parents, healthcare professionals and young people

What is chronic pain?

Chronic pain is pain that has lasted for more than three months or pain that has lasted beyond the time the body would usually heal or recover. Chronic pain can develop after an illness or injury or for no obvious reason. Chronic pain is caused by changes to the nervous system which mean that the brain produces pain even when there is no harm to the body. Scientists are learning more about why this happens. The medicines available often cannot relieve all of the pain.¹

How will pain affect my child?

Chronic pain can affect your child's emotional wellbeing and cause difficulties for them in school and their other activities. These impacts can be reduced if their pain is well managed. Each child or young person will have a different experience depending on their age, personality and other factors as well as the treatment and support they receive.

What can I do as a parent or guardian?

Parents of a child or young person who has chronic pain often feel stressed, powerless and overwhelmed at times. However, there are things you can do to help your child. Here are some tips from parents and healthcare professionals to help you.

Healthcare appointments and pain treatment?

Visits to the GP and to hospital clinics can be stressful and difficult for you and your child. Parents may feel they have to struggle to have their child's pain be adequately treated, and communication can be a problem.

Tips

1. Tell the healthcare professionals about the pain and its impact on your child's life. Be persistent!
2. Ensure our child understands about their pain and their treatment. You and their healthcare professionals can help explain this,
3. Support and encourage your child to stick to the treatment plan,
4. Support your child to be involved in decisions about their care. This is especially important as they get older,
5. Be realistic about pain relief – 100% pain free is unlikely.

¹ Scottish National Clinical Guideline (Management of Chronic Pain in Children and Young People), <https://www.gov.scot/publications/management-chronic-pain-children-young-people/documents/>

School

Keeping up with schoolwork while in pain can be a challenge. Teachers and classmates may not really understand chronic pain and the impact it can have. Some children and young people can experience bullying because of their chronic pain.

Tips

1. Ask the pain specialist nurse to visit your child's school to inform staff and classmates
2. Arrange for adaptations to help your child get the most out of school. These might include:
 - permission to leave lessons early when necessary,
 - permission to use lifts on the school site,
 - cushions, specially adapted desk furniture,
 - lockers for their books so they have less to carry around,
 - using an iPad/adapted laptop rather than pen and paper,
 - a 'buddy' system with other classmates to help them catch up with their work.

Family

Chronic pain affects everyone in the family, not just the child or young person who has the pain. Chronic pain disrupts family activities and everyday routine and can lead to emotional and financial strain.

Tips

1. DO try to keep the whole family in the loop about what is going on. For example, you could take their brothers and sisters along to a routine hospital appointment,
2. DO speak to other parents in the same situation,
3. DO try to keep a sense of humour and have as much fun as possible,
4. DO NOT overprotect your child with chronic pain. Encourage them to participate in activities,
5. DO NOT focus attention on your child with pain at the expense of their brothers and sisters.

Support for parents and families

Pain Concern's helpline volunteers have been trained to give information and support to parents with children living in pain. Call 0300 123 0789 or email help@painconcern.org.uk.

Many parents we spoke to valued sharing experiences with other families. You could try:

- Attending sessions at pain management programmes for families to meet others in the same situation,
- Finding a local support group for people in pain. Most groups welcome carers,
- Using 'Contact - for families with disabled children to get in touch with local families with a child living with a disability,

- Reaching out to others online through Pain Concern’s HealthUnlocked community or on Facebook.

Family therapists can help you to find ways of teaming up on the pain together. To find therapists specialising in chronic illness visit the AFT (Association for Family Therapy and Systemic

Practice) website.

Tips from parents and children

‘You may feel like you are hitting against a brick wall but keep fighting. Determination!’ – Parent

‘The professionals know a lot about pain but they don’t know your child or what the pain is doing to their life or to family life; so make sure they listen.’ – Mother

‘Mum and I talk things through before the appointment and have a plan. That way we can be sure that the professionals listen and know what’s happening with pain.’ – Young person

‘Even with school... They weren’t understanding what was going on. Then the pain nurse swept in there. Afterwards it was as if we had gone to a different place.’ – Parent

‘I don’t like my siblings seeing me at my worst but at the same time I need them there because I can’t cope by myself.’ – Young person

More information

Visit painconcern.org.uk/families for links to more resources and to listen to podcasts featuring children’s pain and the needs of family and carers.

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