

# PARENTING A CHILD WITH PAIN

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Parenting a child with pain can often be a difficult and challenging role. Many parents at various points may have been faced with a doctor or health professional that doesn't believe them or has said "it's all in their head". Watching your child suffer for months or years can leave you feeling helpless or like a bad parent (Jordan et al., 2007), however there are many things that you can do to support your child to manage their pain and have a good quality of life.

It is important to realise that despite what initially caused the pain, there are a number of factors (physical, psychological and environmental) that can increase a child's experience of pain. In order to help your child function well and improve their pain, these factors will need to be addressed in conjunction with other forms of pain management. These may include:

- Anxiety or low mood
- Beliefs that they are unable to cope with their pain (i.e. a lack of self-efficacy), or catastrophising about the effect of pain on their lives
- Memories and previous pain experiences (previous pain experiences may have lowered the threshold point at which your child experiences pain as too much; memories of pain as traumatising may make chronic pain difficult to manage)
- Poor sleep
- Boredom/lack of distraction and/or focusing on pain
- Learning difficulties or social skills deficits (Kashikar-Zuck et al., 2007; Zeltzer & Schlank, 2005).

Many studies have shown that pain does not exist in a vacuum, removed from the rest of the child's experiences. Mood, in particular, has strong links to a child's ability to cope with pain, as does the environment in which your child is in (Zeltzer & Schlank, 2005). Have you ever watched your child fall over in front of his friends but refuse to cry, yet as soon as they are inside the house they are inconsolable? This effect occurs in chronic pain too. Similarly, what goes on in the family unit can and does influence how a child responds to pain, how long it lasts, how the child copes, and ultimately, how quickly he gets better. It is for this reason that your awareness of all the factors that may influence your child's recovery is so vital!

This information sheet will focus on the other things that a family can do alongside pain management to help a child to cope with pain. This includes emotional support, behavioural management and the management of your own thoughts, feelings and behaviours around pain.

## **Recognising the connection between pain and emotions**

It is important to recognise that although your child may have pain for a medical reason, there is also research that demonstrates that negative emotional states (e.g. sadness or anxiety) can make long term pain worse, and that good moods can actually improve pain. An important start to helping your child is to be able to recognise that an event (e.g. a good friend moving away or the stress of GCSEs) may affect not only the amount of pain your child experiences but also their ability to cope with this pain.

Often children who have experienced pain for a long time can find it difficult to talk (or think) about their feelings in connection to events unrelated to their pain, and can instead express this distress through increased pain. They may have also noticed that a parent will give more time/attention to physical pain than emotional pain, and as such unconsciously describe their distress in this manner (Claarn et al., 2008). Talking about difficult events and teaching your child to look upon them in an objective light may assist them to manage stressful situations, without significantly increasing their pain signals. As parents, then, it is doubly important to teach your children how to cope successfully with emotionally stressful events.

Ways of helping your child with emotions/coping with difficult events can include:

- Identifying people that they feel comfortable talking with

- Having a dedicated 'talking' time each week where they can approach you with difficulties if needed. This may also include talking about pain (which should generally be discouraged on a daily basis)
- Teaching them stress management skills such as relaxation, breathing techniques or looking into other relaxing activities such as yoga/pilates, having a bath, massage etc.
- Helping them to identify when their thinking patterns are overly negative and assisting them to think differently about situations (e.g. Is that the only way of thinking about this?)
- If your child is struggling with coping with their pain, low mood and general life it may be helpful for them to see a Clinical Psychologist, therapist or counsellor.

## **Anxiety**

Anxiety does not cause pain, however it makes all types of pain (even cancer pain) worse (Zeltzer, 2009). There are several types of anxiety that come into play with pain, however anxiety can often cause a child to avoid many everyday situations such as school, playing with their friends or even moving/getting out of bed. Without help from their parents these children may give up readily in dealing with daily challenges, and slowly withdraw from life. Children need to be encouraged to increase their own independence and deal with their fears with an attitude of experimentation and positivity (Walker et al., 2006).

The most common type of anxiety associated with pain is fear avoidance. Often children avoid certain activities due to a fear of pain - they may be so scared that it will hurt (and that they will not be able to deal with this pain) that they may refuse to move, put pressure through the affected body part or utilise it at all. This can also include a fear of getting bumped in crowded streets/hallways or a refusal to complete physiotherapy exercises/PE as they are so afraid that it may cause pain. The problem with anxiety is that it often stops your child from doing all things that will help in the long term to improve their pain. The only way that your child will see improvement is in terms of increased functioning. It is often not until the child is fully participating in life that the pain begins to decrease; for this reason it is important to address your child's anxiety with movement and test out the benefits of activity.

Other children experience anxiety before beginning new (or unfamiliar) situations. This is due to a belief that they will not be able to cope in this situation due to their pain. The longer a child has been off school, the scarier it is going to be, and a child's anxiety may lead them to experience more pain. It is important to keep your child attending school regularly to ensure that this does not become yet another anxiety provoking situation. If your child is avoiding activities, it is necessary for you to encourage them to experiment/test out their fears. Ask them what they predict will happen (e.g. What will happen if you go to school today?) This will allow you to problem solve their fears together and also prove that often the anticipation is often worse than the experience.

Your child's pain may improve when s/he feels more able to control the pain. A sense of control (through knowing what to do when they are in pain) will reduce anxiety and thus reduce pain. Children with chronic pain feel a sense of control and mastery over the pain when they are able to function in spite of it. Try these strategies to help reduce your child's anxiety:

- Encourage your child to try pain management strategies such as relaxation, coping statements, slow breathing etc. (see pain management information sheet)
- Work through their anxious thoughts with them and help them to see when they are catastrophising or over-exaggerating
- Help your child to see that they have control over their pain - write a list of times and ways that they have 'beaten' pain
- Be the parent - for younger children you still have the power to make your child attend school or to try other activities that they fear. By participating in a feared situation your child will learn that it is not as scary as they first thought, and learn ways to cope
- Increase your child's independence in dealing with pain. Ensure they have a list of strategies that they can use at home, at school and at night (these may be very different strategies) so that they feel confident and self-reliant.

## **Behavioural management**

Behavioural management is as important (if not more important) for a child with chronic pain as for any other child. Many parents allow their child to get away with more poor behaviour because they understand that the child is frustrated and upset by the pain, and often feel quite helpless about this. Whilst these feelings and actions are perfectly understandable it is important to place boundaries around your child's behaviour to ensure that they grow into confident and likeable young adults.

Firstly, children respond well to praise, reinforcement and rewards. A child who is encouraged to persist in a difficult task will be more likely to complete the task than a child without this encouragement. Therefore, consider using reward charts and small rewards for completing physiotherapy or when pacing up activities to increase their motivation. Think about what your child enjoys - will they be more likely to walk long distances if they are shopping or walking a dog than walking by themselves? Would a movie night inspire them to complete their exercises? Young children will need more immediate rewards (e.g. stickers) to ensure compliance, whereas teenagers are more likely to be able to work towards larger rewards/incentives.

Many children can become destructive or mean as a result of dealing with long term pain and frustration. If this destructive behaviour happens when your child is having a bad pain episode, then you need to inform them that this is unacceptable behaviour, and help them to find an acceptable alternative for letting out their frustration (e.g. talking to people, arranging a mentor, participating in sport/something active, ripping up thick (unused!) phonebooks/ catalogues). It is also important to provide consequences for their behaviour (e.g. removal of privileges) if they continue to be destructive after being informed that this is not acceptable, and then to provide incentives/rewards for changing their behaviour and coping more effectively with their pain.

Lastly, it is important to change the way that you respond to pain behaviour. If every time your child whines you come rushing to their side, a child will learn to act more disabled/in pain in order to get your attention. Praising/rewarding good coping behaviours (e.g. walking without a crutch, going further than usual, helping to tidy up, not complaining) will teach your child that your attention is more contingent on coping than it is on pain (Claar et al., 2008).

## **Parents' own thinking patterns and behaviours**

As parents your role is extremely important in helping your child to become well. Children learn how to think and act in situations by observing their parents. They are very skilled at picking up your emotions (this is developed from a young baby) and interpreting these to inform their own feelings (e.g. 'Mum is worried when I leave for school - therefore school is a scary place'). Children are particularly sensitive to parental anxiety and use their parents' reactions as a cue for how they should be reacting (Vowles et al., 2010). Examining your own feelings, reactions and behaviours around your child's pain is an important step in helping them to get better.

It is very common for a parent to be anxious and to feel helpless when their child is in pain. This helplessness may lead to increased doctors' visits, constant discussions with school teachers, increased supervision of your child, and constantly monitoring your child's pain through questions/attention. Whilst all their behaviours result from your concern, you may actually be sending your child the message that there is something seriously wrong and that this is worth being worried about! This belief can have many negative consequences on your child's life. Similarly, there is research that the parental belief that the cause of long term pain is 'medical only' (i.e. not affected by other factors) will significantly increase the child's reported level of pain and disability (Guite et al., 2009), thus negatively affecting their lives.

There has been much research into the interplay between adults' behaviours and children's distress. Behaviours such as apologising for their pain, increased reassurance, and criticism have all been typically associated with increased distress in children with pain. Similarly, parents' expectations (whether stated or not) can have a huge impact on how a child expresses (and copes with) his pain, and even on the child's perception of pain as a manageable problem (Kashikar-Zuck et al., 2007). If a parent accepts the current diagnosis and works with the health professionals' expectation of improvement, it is more likely that the child's functioning and quality of life will improve.

The best way to start to give the message to your child that 'I know that you have pain but I believe that you can have a great life despite it', is to start making your own plans for what your life will look like when your child is well. Perhaps you have given up work, or put off studies? Perhaps you haven't gone out with friends in years, or stopped going to the gym? Start living your life as though your child is getting better - this gives the child the message you are no longer hugely worried about their health and that you are confident that they are getting better. Think "what will change in my life when Billy gets better? What will I fill this extra time with?" Now start planning! Acceptance of where your child is at right now has been shown to increase physical and social functioning in adolescents with pain, whereas parental catastrophising (i.e. panic, or making it seem worse than it really is) has been shown to reduce what your child is capable of achieving in these domains (Vowles et al., 2010).

Parental behaviours have also been shown to have an effect on the child's ability to function normally. For example, parental protective responses, such as letting a child stay home from school or spending more time than usual with a child, have been associated with increased physical symptoms, greater functional disability, more frequent school absences and greater child health care utilisation. This is generally because the above examples can actually act as positive reinforcement for the child's pain (Claar et al., 2008).

Lastly, remember your role as a human being! Often parents with children who suffer from chronic pain tend to focus all their attention on the child and forget about their own well-being (Zeltzer & Schlank, 2005). It is important to monitor your own stress levels to ensure that you are fully able to assist your child to manage their pain. Practice relaxation, do something for yourself, talk about your feelings or go out with your friends/partner to ensure that you are not sharing these concerns with your child. Your well-being is just as important as your child's because without you they will struggle to improve.

### **What does not help?**

There are many things that you as a parent can try to help your child to manage pain. To summarise, the last part of this information sheet is a list of what will help, and what won't.

The following behaviours have been found to decrease a child's ability to manage pain, and to increase the amount of disability associated with their pain:

- Asking your child constantly if they are in pain (this increases pain messages in the brain - see information sheets on the physiology of pain)
- Providing an excessive amount of attention for your child's pain or reacting in a very emotional way to their pain
- Allowing your child to miss school and avoid difficult activities
- Allowing 'looser' boundaries around your child's inappropriate behaviour
- Complaining a lot about your own pain and generally coping poorly with stress
- Displaying anxiety about their ability to cope with their pain.

### **What does help?**

- Distraction (engage them in games, telling stories, television shows etc. when they complain about pain)
- School attendance - this acts as distraction, encourages independence and teaches the child to problem-solve and get along with others
- Helping your child to function despite pain - use rewards, reinforcement, positive goal setting and 'experiments' to show that your child can achieve more than they think
- Increase your child's functioning through pacing activities over time
- Set realistic goals for your child in each area of their life (home, school, physical activity)
- Reduce the extent to which family life is structured around the child in pain. Ensure that other children are getting equal time and that equal boundaries are in place for all children
- Before bed telling your child three things that made you proud (e.g. played well with sister; walked up the stairs; cleaned up dinner), particularly things that aren't related to pain
- Quality time - Focussed time spent on positive activities, such as reading together or talking about

things not associated with pain will ensure that your relationship isn't only about pain and doctor's appointments, and allow the child time to be 'normal'.

- Create a 'comfort tool box' - a box/list of things that help your child to manage pain. This can be helpful statements they can say to themselves, massage tools, relaxation techniques, distractions, happy photographs, nice material to touch etc.
- Display confidence in your child's ability to cope
- Exercise!

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