

Assessing your child's pain

A guide for parents of children with complex health care needs who cannot communicate verbally.

Children who have complex health care needs and can't communicate verbally rely on other people to know if they are in pain.

Usually, this will be their parents, who learn to recognise their child's pain by being a constant presence in their life. Because every child is unique and responds differently to pain, there are no rule books and health professionals don't always inform parents about the pain assessments available to them. Parents just 'know'.

Most parents gradually develop this knowledge about their child's pain over time. It is based on what they have learned from every episode of pain their child has experienced, and it continues to grow with their child. Parents say they never stop learning.

What sorts of pain do children who cannot communicate verbally experience?

- ▶ Many children who have very complex health care needs, and who can't communicate verbally, experience regular and significant pain, sometimes on a daily basis. Some of this can be managed well, some is more difficult to control.
- ▶ The main sources of pain are muscles and bones, tummy and gut, infection, and pain from things like uncomfortable chairs or splints.

What are the most important things I can do?

- ▶ **Trust** your instinct. You **know** your child and their pain. If you think your child is in pain and you have considered other reasons why they might be upset, then they probably are in pain. Most of the time parents are right.
- ▶ **Ask** for help. If you are worried that your child's pain is getting worse or they have got a new pain, then seek advice from a health professional.
- ▶ **Explain** why you are worried when you meet the professional. Tell them where you think your child's pain is, what might be causing it, if it is a new or an old pain, and what has worked in terms of pain management in the past.
- ▶ **Remind** them that your main concern, at the moment, is your child's pain.
- ▶ **Tell** the professional to draw on your knowledge and insight but remind them you don't have all the answers and you need their expertise to help find the cause of your child's pain.
- ▶ **Stand your ground.** If you don't feel believed or respected, ask if there is someone else who could give an opinion on your child's pain. It can be tough acting as your child's advocate, but doing it can make a big difference in getting the right help.



Even very skilled clinicians say that assessing pain in children whose responses are atypical can be tricky and complicated. Many will acknowledge that the best people to ask for clarification are the child's parents – but this doesn't always happen. Some parents say they don't always feel like health professionals believe them when they say their child is in pain.

This guide has been developed through research with parents¹ to highlight some of the key issues.

How can a parent assess their child's pain?

- ▶ **Looking, touching, feeling and thinking** are all at the heart of how parents assess their child's pain.
- ▶ **Compare** your child's behaviours when they are in pain to how they are when they are comfortable and happy.
- ▶ **Make notes** of what you have noticed and what other people (such as teachers and carers) have told you about their perceptions of your child's pain.
- ▶ **Use a pain assessment tool** that has been designed specifically for children who can't communicate verbally. This will help you assess your child's pain and the scores you record will help you document whether the pain is getting better, worse or staying the same. This will give you useful information to share with health professionals in the future.
 - The **Paediatric Pain Profile (PPP)**² is a tool designed to help parents to assess and record their child's pain. You can create a detailed profile of how your child

behaves when they are happy as well as their typical behavioural responses to pain. If your child has more than one pain, you can record all of these on the PPP. The scores for each run from 0 (no pain at all) to 60 (the worst possible pain). The PPP document is designed to go with your child to school, hospital and home, in order to provide a complete record. Although it isn't used everywhere, it is still a great tool to use, and can be downloaded for free at www.pppprofile.org.uk

- In hospital, the tool most likely to be used in assessing your child's pain is the **revised-Face, Legs, Activity, Cry, Consolability (r-FLACC)**³. This is a quicker tool to complete. Each element of the tool is scored on 0-2 scale – higher scores reveal higher pain. Some elements are specific for children who cannot communicate verbally and have complex health care needs. <https://media.starship.org.nz/rflacc/rflacc.pdf>

What sort of behavioural responses do children who cannot communicate verbally have?

- ▶ Every child expresses their pain differently and every child's 'normal' baseline is different. However, children in pain will typically show pain behaviours in several of the categories below:
 - **Cry and vocalisations:** such as differences in gurgling noises, pitch of cry, tone of voice
 - **Facial expressions:** such as looking 'startled' or 'frightened' or 'not quite there' or 'looking like a bunny in the headlights'
 - **Activity, posture and tone:** such as 'being very still', becoming 'stiff and rigid' or 'going very floppy'
- **Social interaction:** such as not 'wanting to do anything' or 'withdrawing' and 'not being their usual happy self'
- **Response to being comforted:** such as being 'completely inconsolable' or not wanting 'cuddles'
- **Physiological:** such as 'going all blotchy', 'getting sweaty', and 'going pale'
- ▶ As parents get to know their child's pain behaviours they tend to become more confident about explaining that their child has pain.

What resources are there to support pain assessment in children who cannot communicate verbally?

Apart from the assessment tools there are not many parent-facing resources, however, there are three things you can do:

- ▶ Speak to your nurse and doctor about your child's pain.
- ▶ Check out '**Good Practice in Postoperative and Procedural Pain Management**' [2nd ed]⁴ – this has a small section on pain assessment. onlinelibrary.wiley.com/doi/pdf/10.1111/j.1460-9592.2012.03838.x
- ▶ Check out **Communicating Lily's Pain: parents and professionals working together**. This resource comprises an animation and information sheets (including this one) that focus on pain assessment of children with profound cognitive impairment. www.edgehill.ac.uk/communicatinglilypain/



This information leaflet was funded by WellChild and created by Prof Bernie Carter, Edge Hill University, bernie.carter@edgehill.ac.uk.

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² Hunt A. et al. (2004). *Dev Med Child Neurol* 2004; 46: 9–18. ³ Malviya S. et al. (2006) *Pediatric Anesthesia*; 16: 258–265.
⁴ Howard R, Carter B, Curry J, et al. (2012) *Good Practice in Postoperative and Procedural Pain Management* [2nd ed]. *Pediatric Anesthesia*; 22, s1