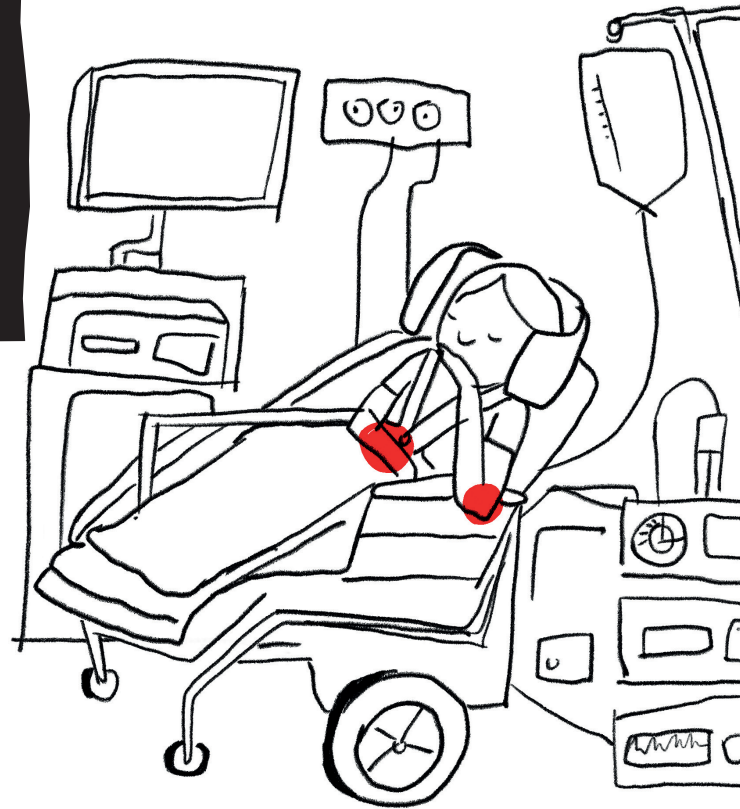


Assessing children's pain

A guide for clinicians caring for children with profound cognitive impairment and complex health care needs.

Children with profound cognitive impairment are often unable to verbally communicate their pain, or purposefully communicate it in other ways. As a result, they rely on other people to interpret a wide range of behavioural indicators, signals which are often atypical and idiosyncratic.

These children are a diverse group who also often have complex health care needs. Even very skilled clinicians say that assessing pain in children whose responses are atypical can be tricky and complex. It can place them 'outside their comfort zone', making them feel less secure about their pain assessment knowledge and skills. This guide has been developed from research^{1,2} with clinicians and parents to highlight some of the key things to consider.



What sorts of pain do children with profound cognitive impairment experience?

- ▶ Typically, children with profound cognitive impairment experience regular, persistent and significant pain, sometimes on a daily basis.
- ▶ The main sources of pain are musculoskeletal, gastrointestinal, infection, and iatrogenic and their pain burden increases with age.
- ▶ If a parent expresses concern about pain, it is likely that they are more worried about pain than any of their child's other usual co-morbidities.

What are the most important things I can do?

- ▶ **Listen** to the child's parents. They **know** their child. Don't dismiss their knowledge.
- ▶ **Give them time** to explain what they think is causing their child's pain, whether they think this is a new pain and what has worked in terms of pain management in the past.
- ▶ **Draw on** their knowledge and insight as a starting point. They will not have all the answers, but they do have a wealth of insights that could inform your approach.
- ▶ **Remember** that parents' knowledge is experiential, and the language they use to describe their child's pain may be figurative.
- ▶ **Be kind.** By the time the parents meet you they will probably have been managing their child's pain on their own for quite a while. They are likely to be tired and distressed.
- ▶ **Reassure them** that you respect their opinion.
- ▶ **Ask a colleague** for advice if you feel uncertain about anything.

¹ Carter B. et al. (2016) Pain Research & Management: <http://dx.doi.org/10.1155/2016/8617182>

² Carter B. et al. (2017) Pain Research & Management; <https://doi.org/10.1155/2017/2514920>

How can I assess a child's pain whose responses are atypical?

- ▶ **Closely examine** the child and focus on what might be causing the child's pain.
- ▶ **Speak to** the child's parents but don't put the responsibility for pain assessment onto them.
- ▶ **Gradually build up** a picture of the child's pain history, including what might have been the trigger for this episode of pain. This may involve 'teasing things out' through ongoing conversations.
- ▶ **Don't assume** your own interpretation of a child's behaviour is enough – this could be swayed by your own assumptions, attitudes and beliefs. Combine it with the interpretation of those who know them well.
- ▶ **Select a pain assessment tool** that has been validated for children with profound cognitive impairment to gain the most accurate assessment. Tools used for assessment of typically developing children can either miss or underassess the severity of pain in this group of children.

What sort of behavioural responses do children with profound cognitive impairment have?

- ▶ Although every child expresses their pain differently and each child's baseline is different, typical responses include changes to their baseline:
 - **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'

What pain assessment tools are validated for children with profound cognitive impairment?

- ▶ Pain assessment tools for this group of children rely on assessment of behavioural cues. All these tools require completion by a proxy.
 - The **revised-Face, Legs, Activity, Cry, Consolability (r-FLACC)**³ is intended for 4–19-year-olds, and the tool most commonly used in practice. Each element is scored on 0–2 scale – higher scores reveal higher pain. media.starship.org.nz/rflacc/rflacc.pdf
 - The **Noncommunicating Children's Pain Checklist-Revised (NCCPC-R)**⁴ is intended for 3–19-year-olds. Scores on a 0–3 scale are given for 27 behaviours within six domains (vocal, social, facial, activity, body and limbs, and physiological) – higher scores reveal higher pain. pediatric-pain.ca/wp-content/uploads/2013/04/NCCPCR_200901.pdf
 - The **Paediatric Pain Profile (PPP)**⁵ is intended for 1–18-year-olds. Each of the 20 items is scored on 0–3 scale – higher scores reveal higher pain. It also includes a detailed profile of a child's usual non-pain behaviours, as well as typical behavioural responses to pain – again higher scores reveal higher pain. www.ppprofile.org.uk

What resources are there to support pain assessment in children with profound cognitive impairment?

Apart from the assessment tools, there aren't a great many resources available. However, you could look at:

- ▶ **Good Practice in Postoperative and Procedural Pain Management** [2nd ed]⁶. onlinelibrary.wiley.com/doi/pdf/10.1111/j.1460-9592.2012.03838.x
- ▶ **Communicating Lily's Pain: parents and professionals working together.** This resource comprises an animation and information sheets (including this one) focusing on pain assessment of children with profound cognitive impairment. www.edgehill.ac.uk/communicatinglilypain/



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³ Malviya S. et al. (2006) *Pediatric Anesthesia*; 16: 258–265.

⁴ Breau LM. et al. (2001) *Journal of Pediatrics*; 138: 721–727.

⁵ Hunt A. et al. (2004) *Developmental Medicine & Child Neurology*; 46: 9–18.

⁶ Howard R, Carter B, Curry J, et al. (2012) *Pediatric Anesthesia*; 22, s1