



“Psychology Works” Fact Sheet: Pain in Children with Cognitive Impairments who are Nonverbal

What is a cognitive impairment?

According to the American Association on Intellectual and Developmental Disabilities, a cognitive impairment, which is also referred to as an intellectual disability:

1. begins before age 18
2. presents itself within different settings (e.g., at school, at home) through observable limitations in both
 - adaptive behaviour (e.g., personal hygiene, social skills), and
 - level of intellectual functioning (i.e., a child’s thinking ability).

These limitations cannot be explained by differences in one’s culture. Children may have these limitations but also have strengths in other areas. Children with cognitive impairments are able to learn and improve in specific areas of functioning when their challenges are well-identified, and personalized supports are put into place.

There are a number of conditions and developmental periods in which a child is at risk for developing a cognitive impairment. First, chromosomal and genetic errors can lead to a number of syndromes associated with intellectual disabilities (e.g., Down Syndrome). Cognitive impairments can also be caused by other factors during the pre, peri, and postnatal period (e.g., extremely low birth weight, infection, physical trauma). The degree of cognitive impairment can be determined, and classified into different categories:

- 1) Mild Cognitive Impairment:
 - these children may experience difficulties in school, and can generally live independently
- 2) Moderate Cognitive Impairment:
 - these children often remain at or below the level of a grade three student, and may be consistently dependent on others in some areas
- 3) Severe/Profound Cognitive Impairment:
 - these children usually require support for the majority of daily activities, and many of these children do not have fully developed language skills.

What does it mean to be nonverbal?

In relation to this information sheet, *nonverbal* refers to children who have been diagnosed with a cognitive impairment and do not communicate using language. In other words, these children do not communicate with others verbally or with a universally recognized form of sign language (e.g., American



Sign Language). A child may occasionally be considered as *nonverbal* if he or she has a few words, but does not use them consistently or meaningfully.

What is pain?

The International Association for the Study of Pain defines pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage". Pain *experience* (how a person perceives what they are feeling) is different from pain *expression* (how a person shows that they are in pain). Pain is subjective: both pain experience and pain expression vary from person to person.

As individuals may experience pain differently, self-report is a very common method of pain measurement. However, many children who have cognitive impairments and are nonverbal may not be capable of providing accurate self-reports about their pain. For this reason, caregivers are often asked to estimate the severity of pain a child is experiencing through observing their behaviour/pain expression.

How does having a cognitive impairment and being nonverbal impact pain experience and expression?

In the past, it was thought that children with cognitive impairments did not experience pain in the same way that those without cognitive impairments do. The belief that children with cognitive impairments do not feel pain, are less sensitive to pain or are indifferent to pain still exists among some individuals. These beliefs are contrary to recent research studies which demonstrate that this is not the case. The reason some individuals with cognitive impairments, particularly those who are nonverbal, may appear to be insensitive to pain could be because they may express pain differently than children who do not have a cognitive impairment. There are many potential explanations for this difference, one being due to difficulty communicating.

In what ways do children with cognitive impairments communicate their pain to others?

As noted above, caregivers are often asked to report on these children's pain. In some instances, caregivers may be able to see the source of pain (e.g., an open wound), however, in other cases, this may not be possible. Lack of a visible source of pain should not be interpreted as an absence of pain. Despite this, assessing pain (either presence and/or severity of) may be difficult for caregivers because children who have cognitive impairments and are nonverbal do not always express pain very clearly. In some cases, even those caregivers who know the children very well still have difficulty assessing pain severity and location. Research suggests that parents are capable of identifying common behaviours expressed by their children who have cognitive impairments and are nonverbal when they are in pain (see section below).

Recent studies seeking to create a list of common ways to express pain in this population have identified some general behaviours that may indicate a child is in pain. For example, the *Non-Communicating*



Children's Pain Checklist^{1 2} is a scale that has been used successfully by professionals, primary caregivers (i.e., parents) of children who have cognitive impairments, as well as adults who work with them, such as teachers. A list of the behaviours on the NCCPC appears below. It is important to note that each individual may express pain differently. Likewise, some of these behaviours may not always communicate pain; they may also express distress or frustration. Further, a child will not necessarily express all of these signals at once while in pain.

- **Vocal Behaviour:** moaning/whining/whimpering (fairly soft), screaming (very loud), crying (moderately loud)
- **Social Behaviour:** not cooperative/cranky/irritable/unhappy; less interaction with others/withdrawn, seeks comfort or physical closeness; difficult to distract/unable to satisfy
- **Facial Expression:** furrowed brow; changes in eyes; not smiling; lips pucker up/tighten/pout/quiver; clenches or grinds teeth/thrusts tongue out
- **Activity:** not moving/less active/quiet; jumping around/agitated/fidgety
- **Body and Limbs:** stiff/spastic/tense/rigid; gesturing or touching part of body that hurts; protects/favours/guards what is hurting; sensitive to touch
- **Physical Signs:** sweating; change in colour; tears; gasping

How can we ensure accurate pain management for children with cognitive impairments who are nonverbal?

Effective pain assessment is critical for effective pain management. Unfortunately, due to differences in pain expression and difficulties with pain assessment for children who have cognitive impairments and are nonverbal, pain management can also be challenging. Researchers are currently investigating how attitudes, beliefs and opinions of caregivers may impact the care and pain management for children who have cognitive impairments and are nonverbal. Thus far, research has focused mainly on primary caregivers and health care providers. More information is still needed regarding other caregivers with whom children may spend time (e.g., respite workers). The creation and implementation of effective pain assessment tools for all of these caregivers could help to improve pain management in this population.

Where can I get more information?

To Access the *Non-Communicating Children's Pain Checklist*^{1,2}:

- <http://pediatric-pain.ca/our-measures/>
- <http://www.aboutkidshealth.ca/En/ResourceCentres/Pain/PainAssessment/MeasurementofPain/Pages/Tools-For-Measuring-Pain.aspx>

¹ Breau, L. M., Finley, G. A., McGrath, P. J., & Camfield, C. S. (2002). Validation of the non-communicating children's pain checklist—postoperative version. *Anesthesiology*, 96(3), 528-535.

² Zabalía, M., Breau, L. M., Wood, C., Lévesque, C., Hennequin, M., Villeneuve, E., ... & Breau, G. (2011). Validation of the French version of the non-communicating children's pain checklist-postoperative version. *Canadian Journal of Anaesthesia*, 58(11), 1016-1023.



Additional Online Resources:

Assessing Children with Disabilities (About Kids Health: Trusted answers from The Hospital for Sick Children):

<http://www.aboutkidshealth.ca/En/ResourceCentres/Pain/PainAssessment/PainAssessmentbyAge/Pages/Assessing-Children-with-Disabilities.aspx>

*Pain Assessment in the Nonverbal Patient: Position Statement with Clinical Practice Recommendations (MedScape) *Not solely directed to children with cognitive impairments*:*

<http://www.medscape.com/viewarticle/533939>

*Understanding Pain in Patients with Intellectual Disabilities (MedScape) *Not solely directed to children*:*

<http://www.medscape.com/viewarticle/752725>

Cited References:

Breau, L.M., Camfield, C.S., McGrath, P.J., & Finley, G.A. (2003). The incidence of pain in children with severe cognitive impairments. *Archives of Pediatric and Adolescent Medicine*, 157, 1219-1226.

Breau, L.M., Camfield, C., McGrath, P.J., Rosmus, C., & Finley, G.A. (2001). Measuring pain accurately in children with cognitive impairments: Refinement of a caregiver scale. *Journal of Pediatrics*, 138(5), 721-727.

Breau, L. M., Finley, G. A., McGrath, P. J., & Camfield, C. S. (2002). Validation of the non-communicating children's pain checklist—postoperative version. *Anesthesiology*, 96(3), 528-535.

Breau, L.M., Lotan, M., & Koh, J.L. (2011). Pain in individuals with intellectual and developmental disabilities. In: Patel, D.R., Greydanus, D.E., Omar, H.A., & Merrick, J. (Eds.), *Neurodevelopmental Disabilities: Clinical Care for Children and Young Adults* (255 – 276). New York: Springer.

Drew, C.J. & Hardman, M.L. (2007). *Intellectual disabilities across the lifespan*. USA: Pearson Education Inc.

Herr, K., Coyne, P.J., McCaffery, M., Manworren, R., & Merkel, S. (2011). Pain assessment in the patient unable to self-report: Position statement with clinical practice recommendations. *Pain Management Nursing*, 12(4), 230-250.

Hunt, K. A., & Franck, L. S. (2011). Special needs require special attention: A pilot project implementing the paediatric pain profile for children with profound neurological impairment in an in-patient setting following surgery. *Journal of Child Health Care*, 15(3), 210-220.

McGrath, P.J., Rosmus, C., Camfield, C., Campbell, M.A., & Hennigar, A. (1998). Behaviours caregivers use to determine pain in non-verbal, cognitively impaired individuals. *Developmental Medicine & Child Neurology*, 40(5), 340-343.

Oberlander, T.F. & Symons, F.J. (Eds.). (2006). *Pain in children and adults with developmental disabilities*. United States of America: Paul H. Brookes Publishing.

Symons, F.J., Shinde, S.K., & Gilles, E. (2008). Perspectives on pain and intellectual disability. *Journal of Intellectual Disability Research*, 52(4), 275 – 286.



Zabalía, M., Breau, L. M., Wood, C., Lévêque, C., Hennequin, M., Villeneuve, E., ... & Breau, G. (2011). Validation of the French version of the non-communicating children's pain checklist-postoperative version. *Canadian Journal of Anaesthesia*, 58(11), 1016-1023.

You can consult with a registered psychologist to find out if psychological interventions might be of help to you. Provincial, territorial and some municipal associations of psychology often maintain referral services.

For the names and coordinates of provincial and territorial associations of psychology go to:
<http://www.cpa.ca/public/whatisapsychologist/PTassociations/>.

This fact sheet has been prepared for the Canadian Psychological Association by Lara M. Genik (University of Guelph), Dr. C. Meghan McMurtry (University of Guelph) and Dr. Lynn Breau (Glenrose Rehabilitation Hospital).

August 2014

Your opinion matters! Please contact us with any questions or comments about any of the *Psychology Works* Fact Sheets: factsheets@cpa.ca

Canadian Psychological Association
141 Laurier Avenue West, Suite 702
Ottawa, Ontario K1P 5J3
Tel: 613-237-2144
Toll free (in Canada): 1-888-472-0657