



Clinical practice points

Chronic pain assessment toolbox
for children with disabilities
Section 2.0, 2014, Version 1





Holland Bloorview

Kids Rehabilitation Hospital Foundation

Section 2.0: Clinical Practice Points

Christine Provvidenza, Knowledge Translation Specialist, Evidence to Care

Ashleigh Townley, Knowledge Broker, Evidence to Care

Tessa Gresley-Jones, Nurse Practitioner, Child Development Program

Andrea Hoffman, Physician, Medicine and Academic Affairs

Deepali Mankad, Clinical Fellow, Medicine and Academic Affairs

Shauna Kingsnorth, Team Lead, Evidence to Care

Conflict of Interest Declaration

The contributing committee members have no conflict of interest to declare.

Acknowledgements

Evidence to Care would like to acknowledge Shawna Wade, Holland Bloorview Senior Director of Inpatient Rehabilitation and Complex Continuing Care, and Dr. Darcy Fehlings, Holland Bloorview Physician Director of Medicine and Academic Affairs, for their contribution to the identification of this evidence to practice gap and development of this project. We thank the Evidence to Care Steering Committee for their oversight throughout the course of this body of work, as well as the Teaching and Learning Institute and the Bloorview Research Institute for the continued support as corporate sponsors. Evidence to Care also acknowledges the following individuals who contributed their expertise and perspectives: Carole-Anne Chiasson, Crystal Chin, Bruno Geremia, Kelly Handler, Michelle Halsey, Dr. Golda Milo-Manson, Aline Nizigama, Laura Thompson and Pui-Ying Wong. Finally, we thank all of the outpatient clinical staff who have supported the implementation and evaluation of the Toolbox.

Funding

Funding for this work was provided by the Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview) Foundation and the Ontario Ministry of Health and Long-Term Care. Evidence to Care would also like to thank the Holland Bloorview Teaching and Learning Institute, Bloorview Research Institute, and the Holland Bloorview Centre for Leadership in Childhood Development for their continuing support of this project.



Copyright

Figure 1 in 1.0 Toolbox Background, has been reproduced, with permission from the publisher, from the *World Health Organization Guidelines on the Pharmacological Treatment of Persisting Pain in Children with Medical Illnesses*. France, World Health Organization, 2012 (Figure 1.1, Page 17, www.who.int/medicines/areas/quality_safety/children_persisting_pain/en/ accessed 07 July 2014).

Figure 2 in 1.0 Toolbox Background, has been reprinted with permission from The Permanente Journal, 9(4), Whitten, C.E., Donovan, M. & Cristobal, K., *Treating Chronic Pain: New Knowledge, More Choices*, page 9-18, copyright (2005). Permission has also been granted by lead author Christine E. Whitten.

Permission has been granted for the use and re-distribution of the recommendations from the *Assessment and Management of Pain Best Practice Guideline (Third Edition)* developed by the Registered Nurses' Association of Ontario (2013).

Disclaimer

This Toolbox contains recommendations from the Registered Nurses' Association of Ontario's ("RNAO") *Assessment and Management of Pain (Third Edition)* and other information from third party organizations referenced herein (together with the RNAO, the "Third Party Organizations"). By using the RNAO's recommendations contained in this Toolbox, you are agreeing to the product's terms of use available on the RNAO's website at RNAO.ca.

Neither the RNAO's nor any other Third Party Organization's information, products and/or website (collectively, the "Third Party Information") are managed by Holland Bloorview, and each Third Party Organization is solely responsible for their respective Third Party Information. Neither Holland Bloorview nor any of its agents, appointees, directors, officers, employees, contractors, members, volunteers or related parties (collectively, the "Holland Bloorview Parties") give or make any representation, warranty or endorsement of the Third Party Organizations or the Third Party Information.

This Toolbox was developed as a guide only for healthcare providers to provide practice points, tools and implementation supports, and does not constitute medical or other professional advice. Healthcare providers are required to exercise their own clinical judgment in using this Toolbox and application of any information contained in this Toolbox should be based on individual/patient needs, the relevant circumstances and the local context. THIS TOOLBOX SHOULD NOT BE USED AS A SUBSTITUTE FOR INFORMATION AND/OR ADVICE PROVIDED BY A HEALTHCARE PROVIDER. IF YOU OR A PERSON YOU ARE CARING FOR HAS A HEALTH-RELATED CONCERN, PLEASE CONSULT A QUALIFIED HEALTHCARE PROVIDER.



Neither Holland Bloorview nor any of the contributors to/authors of this Toolbox are providing medical, diagnostic or treatment services through the information contained in this Toolbox. Moreover, while every effort has been made to ensure the accuracy of the contents of the Toolbox at the time of publication, none of the Holland Bloorview Parties: (i) give any guarantee to as to the completeness or accuracy of the information contained herein; and (ii) **TO THE EXTENT PERMITTED BY APPLICABLE LAW, ACCEPT ANY LIABILITY OR RESPONSIBILITY FOR THE USE OR MISUSE OF THIS TOOLBOX BY ANY INDIVIDUAL OR ENTITY, INCLUDING FOR ANY LOSS, DAMAGE OR INJURY (INCLUDING DEATH) ARISING FROM OR IN CONNECTION WITH THE USE OF THIS TOOLBOX, IN WHOLE OR IN PART.**

How to Cite This Document

Provvidenza, C., Townley, A., Gresley-Jones, T., Hoffman, A. Mankad, D. & Kingsnorth, S. (2014). *Chronic pain assessment toolbox for children with disabilities: Section 2.0: Clinical practice points*. Toronto, Ontario: Holland Bloorview Kids Rehabilitation Hospital. Retrieved from: <http://hollandbloorview.ca/toolbox>

Contact Information

Shauna Kingsnorth, PhD
Evidence to Care Lead
Clinical Study Investigator
Assistant Professor (status), Department of Occupational Science and Occupational Therapy, University of Toronto
Holland Bloorview Kids Rehabilitation Hospital
150 Kilgour Road, Toronto, ON M4G 1R8
1.416.425.6220 x3547
skingsnorth@hollandbloorview.ca
www.hollandbloorview.ca



Chronic Pain Toolbox for Children with Disabilities



Section 1.0 Toolbox background



Section 2.0 Clinical practice points



Section 3.0 Pediatric chronic pain assessment tools



Section 4.0 Implementation supports manual



Section 2.0 Table of Contents

2.0 Clinical Practice Points	7
Section 1a: Conducting a Pain Assessment – The Importance of Assessing Pain	8
Section 1 b: Conducting a Pain Assessment – Assessment Parameters, the Role of Self-Report and Use of Pain Tools	9
Section 2: Pain Reassessment	13
Section 3: Documenting Pain	14
References	15



2.0 Clinical Practice Points

This Chronic Pain Assessment Toolbox for Children with Disabilities is a compendium of resources based upon high quality research evidence intended to support the assessment of chronic pain in pediatric disability clinical practice. [Evidence to Care](#) spearheaded this project using an integrated knowledge translation strategy by engaging an inter-professional group from [Holland Bloorview Kids Rehabilitation Hospital](#).

The current document presents the recommendations sourced from the Registered Nurses' Association of Ontario (RNAO) Best Practice Guideline (BPG) for the Assessment and Management of Pain.¹ This BPG was selected from a structured review and is available for download from the [RNAO website](#). The accompanying evidence-informed practice points were developed through consultation with an inter-professional group of childhood disability experts from Holland Bloorview Kids Rehabilitation Hospital. The practice points are tailored to children with cerebral palsy (CP), but have vast applicability to children with other disabilities with chronic pain concerns.

For additional resources, including implementation supports, please visit the [Evidence to Care website](#) or contact etc@hollandbloorview.ca.



Section 1a: Conducting a Pain Assessment – The Importance of Assessing Pain

Registered Nurses' Association of Ontario Recommendation ¹	Evidence Rating
<p>Recommendation 1.1¹ Screen for the presence, or risk of, any type of pain:</p> <ul style="list-style-type: none"> • On admission or visit with a healthcare professional; • After a change in medical status; and • Prior to, during and after a procedure. 	Ib
Holland Bloorview Cerebral Palsy and Chronic Pain: Practice Points	
<p>1. Chronic pain in children with cerebral palsy (CP) is under-recognized and under-treated, and is one of the most important factors negatively impacting a child's ability to participate in activities of daily living.² The presence of cognitive, communication, and motor impairments can make accurate assessment difficult.³⁻⁶</p> <p>Following the points will facilitate communication between the inter-professional healthcare team who are treating the child, to better the management of the child's pain.</p> <p>2. Be conscientious for any indication of pain by asking the child, family or caregiver about the presence of pain or discomfort.⁷</p> <p>3. Pain assessment should be considered the fifth vital sign in clinical care.⁷⁻⁹ It is essential that children with CP are routinely monitored, assessed, and reassessed for pain and that their experience of pain is well documented.^{10, 11} Screening for pain should be routine and should consider the:</p> <ul style="list-style-type: none"> • Child's level of function (e.g. Gross Motor Function Classification System [GMFCS] level); • CP classification (e.g. type of hypertonia such as spastic or dystonic CP); • Comorbidities (e.g. constipation, gastroesophageal reflux disease, fractures, hip subluxation); • Setting (e.g. home, school, hospital); and • Intervention (e.g. therapy, Botox injections). <p>4. Evaluation of chronic pain in children with CP should involve a comprehensive, child and family-centred health approach, whereby all aspects (e.g. physical, psychological, social) are considered as a whole and not independently in the assessment of the pain (e.g. biopsychosocial circumstances, culture, [family] financial stress, mental health</p>	

Chronic Pain Assessment Toolbox for Children with Disabilities



issues, [family/caregiver] loss of job).¹²

Section 1 b: Conducting a Pain Assessment – Assessment Parameters, the Role of Self-Report and Use of Pain Tools

Registered Nurses’ Association of Ontario Recommendation ¹	Evidence Rating
Recommendation 1.2 ¹ Perform a comprehensive pain assessment on persons screened having the presence, or risk of, any type of pain using a systematic approach and appropriate, validated tools.	Ib
Recommendation 1.3 ¹ Perform a comprehensive pain assessment on persons unable to self-report using a validated tool.	III
Recommendation 1.4 ¹	III



Explore the person’s beliefs, knowledge and level of understanding about pain and pain management.	
<p>Recommendation 3.3¹</p> <p>Teach the person, their family and caregivers about the pain management strategies in their plan of care and address known concerns and misbeliefs.</p>	Ib
Holland Bloorview Cerebral Palsy and Chronic Pain: Practice Points	
<p>Pain Assessment</p> <p>1. When assessing pain in children with CP, it is important to recognize that there is no single objective assessment strategy and that a multidimensional approach (e.g. assessments of behaviour, communication needs, and functional abilities) should be taken.^{10, 13}</p>	
<p>The Role of Self-Report</p> <p>2. Children with CP may communicate in different ways. In addition to verbal self-report, consider self-report through yes/no responses, use of communication devices, facial expressions, gestures, eye contact/eye pointing, and others.</p>	



Involving Family and Caregivers

3. Family and caregivers are integral to the pain assessment process. Their participation in the assessment of their child's pain allows them to:
 - Better understand their child's cause of and response to pain;
 - Provide an opportunity for reflection of ongoing, chronic pain;^{11,14}
 - Draw upon their knowledge regarding the child's communication patterns, mood, and behaviour;¹¹ and
 - Become comfortable and confident with pain assessment and monitoring strategies by learning how to use the pain assessment tools and document pain.
4. In situations where the child with CP is not able to self-report pain, pain assessment may include an observational or proxy tool as well as behavioural and physiological indicators (e.g. behavior appearance, activity level, and vital signs). Whenever possible, standardized measures should be used when assessing pain.

Use of Pain Tools

5. It is important to recognize that no individual tool can be broadly recommended for pain assessment in all children across all contexts. To ensure the most effective assessment tool is chosen for a child with CP and chronic pain, it is important to consider the:
 - Child's individual condition and circumstances (e.g. age, GMFCS level, developmental level, presence of developmental disability, communication ability, setting);
 - Purpose of the pain assessment (e.g. presence of pain, benefit of treatment, coping); and
 - Selection of an alternative tool if the tool that has been chosen is not providing the required information.

The International Classification of Functioning, Disability and Health Model can be used to direct a comprehensive pain assessment.¹⁵

Body Functions and Structure

Pain History

- Conduct a complete medical and pain history, including onset, intensity, quality, location, duration, variability, predictability, exacerbating, and alleviating factors.¹⁶
- Ask about the presence of regular or persistent crying, groaning, facial grimacing, loss of interest in food, difficulty sleeping, changes in appearance, and activity level.^{8, 13}
- Document previous pain experiences (e.g. surgeries, history of unmanaged pain,

Chronic Pain Assessment Toolbox for Children with Disabilities



painful procedures during previous hospitalization) and identify any past or current treatments for pain and associated timelines (e.g. use of medication for >72 hours), level of effectiveness, and any adverse effects.^{1, 8}

Pain Evaluation

- Basic vital signs and growth parameters should be obtained during at least the first evaluation. Additional symptoms such as motor (e.g. increased tone, muscle spasms), sensory (e.g. changes in heart rate, blood pressure, respiratory rate) and autonomic changes (e.g. numbness, hyperesthesia) as measures of pain should be noted.¹⁷
- Include an observation of the child's general appearance, posture, gait, and cognitive state with the focus on, but not limited to the affected area.^{16, 18} Note muscle spasms, trigger points, and areas of somatic sensitivity to touch and functional range of motion.^{18, 19} Serial examinations may be required.¹⁶

General Medical History

Conduct a general medical history by including documentation of primary and secondary diagnosis, past medical history, allergies/sensitivities, risk factors (e.g. airways stability, disease process), medications, review of systems, and impact of interventions (medication, therapy, procedures).^{17, 20}

Activity and Participation

- Assess the impact of pain on daily life activities: sleep, eating, school, social and physical activities, and family and peer interaction.^{8, 16}

Environmental Factors

- Engage parents and caregivers to better understand the cause and response to the child's pain.^{11, 14}
- Review past pain problems and pain experiences, as well as, current treatments (e.g. medications, home remedies, alternative treatments) with parents and caregivers.^{16, 18}
- Assess environmental factors that may impact the child's pain experience (e.g. school environment, home environment, extracurricular activities).

Personal Factors

- Consider the individual's developmental stage (i.e. chronological vs. mental age).
- Consider that language, ethnic, and cultural factors may influence the expression and assessment of pain.⁷
- Assess the child's emotional functioning, coping responses to stress and pain, and the ability to talk about pain.^{7, 16}
- Include information about the presence of psychological symptoms (e.g. anxiety, fears, depression or anger), psychiatric disorders, and personality traits/states.^{17, 21}

Chronic Pain Assessment Toolbox for Children with Disabilities



Section 2: Pain Reassessment

Registered Nurses' Association of Ontario Recommendation ¹	Evidence Rating
Recommendation 4.1 ¹ Reassess the person's response to the pain management interventions consistently using the same re-evaluation tool. The frequency of reassessments will be determined by: <ul style="list-style-type: none"> • presence of pain; • pain intensity; • stability of the person's medical condition; • type of pain e.g. acute versus persistent; and • practice setting. 	IIb
Recommendation 3.3 ¹ Teach the person, their family and caregivers about the pain management strategies in their plan of care and address known concerns and misbeliefs.	Ib

Holland Bloorview Cerebral Palsy and Chronic Pain: Practice Points

Reassess Pain

1. Ongoing pain assessment is an integral component of comprehensive pain management strategy for children with CP.^{8,19}
2. When re-examining the child, be aware of alternative organic causes of pain (e.g. dental pain, pressure ulcers) or psychological (e.g. stress) or psychiatric comorbidities (e.g. depression, anxiety).²² As part of pain reassessment, consider repeating the components of section 1b, practice point 5 (where necessary) and additionally review the:
 - Effects of pain on activities of daily living (ADLs), sleep, and mood;
 - Adverse effects of medications for pain treatment (e.g., nausea, constipation);
 - Level of sedation; and
 - Strategies used to relieve pain, both pharmacological, and non-pharmacological.¹
3. If a child has persistent pain despite the clinician's best efforts to relieve it, involve an inter-professional team to consult on alternative pain reduction strategies.

Involve Family and Caregivers

4. Provide instructions to the child, their family and caregivers on:
 - How to use a pain log or diary (provide a tool); and
 - How to communicate unrelieved pain to their clinician and support them in efforts to advocate for themselves or for their child.¹



Section 3: Documenting Pain

Registered Nurses' Association of Ontario Recommendation ¹	Evidence Rating
Recommendation 4.2 ¹ Communicate and document the person's responses to the pain management plan.	IIb
Recommendation 1.5 ¹ Document the person's pain characteristics.	IIa
Holland Bloorview Cerebral Palsy and Chronic Pain: Practice Points	
1. Document the comprehensive pain assessment including pain history, evaluation, and the impact of the pain on the child and their parent, caregiver and family. Communicate the following information to the members of the inter-professional team: <ul style="list-style-type: none"> • Parameters of pain obtained through the use of a structured assessment tool; • Relief or lack of relief obtained from treatment methods and related adverse effects; and • Child, family or caregiver's goals for pain treatment and the effect of pain on the child.¹ 	
2. Document the pain assessment tool(s) used effectively to capture the child's experience of pain so that there is consistency within the inter-professional team when assessing and reassessing pain.	



Index

Interpretation of Evidence: Levels of Evidence

The following table presents the level of evidence and corresponding rationale, adapted by the Registered Nurses' Association of Ontario and displayed within the Assessment and Manage of Pain, Third Edition¹ (page 11).

Level of Evidence	Rationale
Ia	Evidence obtained from meta-analysis or systematic reviews of randomized controlled trials.
Ib	Evidence obtained from at least one randomized controlled trial.
IIa	Evidence obtained from at least one well-designed controlled study without randomization.
IIb	Evidence obtained from at least one other type of well-designed quasi-experimental study without randomization.
III	Evidence obtained from well-designed non-experimental descriptive studies, such as comparative studies, correlation studies and case studies.
IV	Evidence obtained from expert committee reports or opinions and/or clinical experience of respected authorities.



References

1. Registered Nurses' Association of Ontario. (2013). Assessment and Management of Pain (Third Edition), *Registered Nurses' Association of Ontario*.
2. Parkinson, K.N., Dickinson, H.O., Arnaud, C., Lyons, A., Colver, A., and Group, S. (2013). Pain in young people aged 13 to 17 years with cerebral palsy: Cross-sectional, multicentre European study. *Archives of Disease in Childhood*, 98(6): 434-440.
3. Penner, M., Xie, W.Y., Binopal, N., Switzer, L., and Fehlings, D. (2013). Characteristics of pain in children and youth with cerebral palsy. *Pediatrics*, 132(2): e407-e413.
4. Hadden, K.L. and Von Bayer, C.L. (2002). Pain in children with cerebral palsy: Common triggers and expressive behaviours. *Pain* 99: 281-288.
5. Chen-Lim, M.L., Zarnowsky, C., Green, R., Shaffer, S., Holtzer, B., and Ely, E. (2012). Optimizing the assessment of pain in children who are cognitively impaired through the quality improvement process. *Journal of Pediatric Nursing*, 27(6): 750-9.
6. Oberlander, T.F., O'donnell, M.E., and Montgomery, C.J. (1999). Pain in children with significant neurological impairment. *Developmental and Behavioural Pediatrics*, 20(4): 235-243.
7. Royan College of Nursing. (2009). The recognition and assessment of acute pain in children, in *Improving Practice: Improving Care. Clinical Practice Guidelines*. , Royal College of Nursing: London, UK.
8. Winnipeg Regional Health Authority. (2008). Clinical Practice Guideline: Pain Assessment and Management: Winnipeg, Manitoba.
9. American Pain Society Quality of Care Committee. (1995). Quality Improvement Guidelines for the Treatment of Acute Pain and Cancer Pain, American Pain Society Quality of Care Committee.
10. Herr, K., Bjoro, K., and Decker, S. (2006). Tools for assessment of pain in nonverbal older adults with dementia: a state-of-the-science review. *Journal of Pain and Symptom Management*, 31(2): 170-92.
11. Stallard, P., Williams, L., Lenton, S., and Velleman, R. (2000). Pain in cognitively impaired, non-communicating children. *Archives of Disease in Childhood*, 85: 460-462.
12. Ishizaki, Y., Yasujima, H., Takenaka, Y., Shimada, A., Murakami, K., Fukai, Y., Inouwe, N., Oka, T., Maru, M., Wakako, R., Shirakawa, M., Fujita, M., Fujii, Y., Uchida, Y., Ogimi, Y., Kambara, Y., Nagai, A., Nakao, R., Tanaka, H., and Japanese Society of Psychosomatic, P. (2012). Japanese clinical guidelines for chronic pain in children and adolescents. *Pediatrics International*, 54(1): 1-7.
13. Temple, B., Dube, C., Mcmillan, D., Secco, L., Kepron, E., Dittberner, L., Ediger, J., and Vipond, G. (2012). Pain in people with developmental disabilities: A scoping review. *Journal on Developmental Disabilities*, 18(1): 73-86.
14. Carter, B., Mcarthur, E., and Cunliffe, M. (2002). Dealing with uncertainty: Parental assessment of pain in their children with profound special needs. *Journal of Advanced Nursing*, 38(5): 449-457.



15. World Health Organization. (2001). *Towards a Common Language for Functioning, Disability and Health, ICF*, Editor, World Health Organization: Geneva.
16. Eccleston, C., Goldschneider, K., Larkin, K., Sethna, N., Schechter, N., and Turner, H. (2012). *Assessment and Management of Children with Chronic Pain: A Position Statement from the American Pain Society.* , A.P. Society, Editor.
17. Rosenquist, R., Benzon, H.T., Connis, R.T., De Leon-Casasola, O.A., Glass, D., Korevaar, W.C., Mekhail, N.A., Merrill, D.G., Nickinovich, D.G., Rathmell, J.P., Nai-Mei Sang, C., and Simon, D.L. (2010). Practice guidelines for chronic pain management. *Anesthesiology*, 112(4): 810-833.
18. Daabiss, M. (2008). Management of chronic pain conditions in pediatric populations. *Internet Journal of Health*, 7(1).
19. Wahlstrom, J. (2004). Ask the expert: The child with chronic pain. *Journal for Specialists in Pediatric Nursing*, 9(4): 135-138.
20. Pediatric Pain Committee. (2009). *Pediatric Pain Reference Cards*, University of Rochester.
21. Mcgrath, P.J., Walco, G.A., Turk, D.C., Dworkin, R.H., Brown, M.T., Davidson, K., Eccleston, C., Finley, G.A., Goldschneider, K., Haverkos, L., Hertz, S.H., Ljungman, G., Palermo, T., Rappaport, B.A., Rhodes, T., Schechter, N., Scott, J., Sethna, N., Svensson, O.K., Stinson, J., Von Baeyer, C.L., Walker, L., Weisman, S., White, R.E., Zajicek, A., and Zeltzer, L. (2008). Core outcome domains and measures for pediatric acute and chronic/recurrent pain clinical trials: PedIMMPACT recommendations. *Pain*, 9(9): 771-83.
22. Ramstad, K., Jahnsen, R., Skjeldal, O.H., and Diseth, T.H. (2011). Characteristics and impact of recurrent musculoskeletal pain in cerebral palsy. *Developmental Medicine and Child Neurology*, 53: 63-64.



Holland Bloorview
Kids Rehabilitation Hospital

Teaching
and Learning
Institute