

# Pain in cerebral palsy

Many children and adults with cerebral palsy experience significant pain. It is sometimes difficult to know the origin of the pain as the person may have trouble identifying where the pain is localised. This difficulty can be compounded by communication impairment and/or intellectual disability. Many adults who are able to communicate will report chronic pain that they did not experience as a child.

Pain is a common experience for people with cerebral palsy. In a study of 667 adolescents aged 13–17 years, 75% experienced some pain in a typical week.<sup>1</sup>

- For those able to describe their pain and its location, assessment and management is similar to any other patient of that age and gender and informed by knowledge of conditions more common in people with cerebral palsy.
- For those who have difficulty communicating, pain may be inferred by those who know the person well from changes in facial expression, posture, body language and behaviour.

- Pathological fractures presenting with acute pain or irritability. Fractures can occur during dressing/undressing and change of nappies/continence products.
- Muscle spasm causing pain, particularly in the back, neck or limbs.
- For those with ventriculo-peritoneal shunts, headache due to raised intracranial pressure should be considered.
- Renal stones, especially if on topiramate for management of epilepsy and if hydration is not adequately maintained.
- Abuse. Non-accidental injury is more common in individuals with disability. Consider whether the injury fits with the explanation given by the patient and/or their care providers.

## Chronic causes of pain

Chronic causes of pain common in people with cerebral palsy include:

- Musculoskeletal pain in muscles, bones and joints, particularly due to spasticity and/or dystonia, hip subluxation or dislocation, and bony degeneration and arthritis in adults with cerebral palsy.

## Acute causes of pain

Acute causes of pain are the same as in any other individual of that age and gender and include:

- Acute infections such as pharyngitis, otitis media or urinary tract infection.
- Dental and oral issues including dental abscess, mouth ulcers and dental caries.
- Acute abdominal conditions such as appendicitis.
- Chest pain associated with coronary artery insufficiency, aortic dissection, musculoskeletal pain or reflux oesophagitis.
- Renal stones.
- Women: gynaecological problems including dysmenorrhea or ovarian cyst.
- Men: penile ulceration or testicular torsion.

## Causes of pain in cerebral palsy

Causes of pain seen more commonly in people with cerebral palsy include:

- Acute abdominal conditions including constipation, volvulus or mesenteric infarction.
- Chest pain associated with gastro-oesophageal reflux.



These resources are designed to support healthcare practitioners in the care of their patients with cerebral palsy in Australia. They were developed in partnership by The Royal Children's Hospital; the Centre for Developmental Disability, Monash Health; and Murdoch Children's Research Institute. They have been amended for use by healthcare workers globally in partnership with IAACD. The initial project was funded by an Avant Quality Improvement Grant 2017.

- Arthritic changes in the spine and other joints occur at a much earlier age due to the impaired alignment of bones and joints and the wear and tear associated with abnormal muscle tone and movement across joints. These changes can be seen particularly in the neck, back and shoulders of those using a manual wheelchair; hips in people with hip dysplasia; hips, knees and ankles of those who walk with a diplegic gait.
- Gastrointestinal pain due to gastro-oesophageal reflux and oesophagitis and constipation.
- Dental pain due to poor oral hygiene with gingivitis and dental caries.
- Renal stones, especially if on topiramate for management of epilepsy and if hydration is not adequately maintained.
- Consider pain from ill-fitting orthoses, an uncomfortable wheelchair, or other external causes such as hand splints.

## Assessment

- Take a careful history. Temperature, hormonal fluctuations and disturbed sleep can impact spasticity and pain.
- Examine ENT, abdomen, hips and limbs in particular. A thorough head to toe examination is often required.
- Use pain scales appropriate to the individual (Faces, Numeric, Behavioural, Behavioural / Physiological)  
[https://www.rch.org.au/rchcpg/hospital\\_clinical\\_guideline\\_index/Pain\\_Assessment\\_and\\_Measurement/](https://www.rch.org.au/rchcpg/hospital_clinical_guideline_index/Pain_Assessment_and_Measurement/)
- Investigations that are often helpful include hip x-ray, gastroscopy, abdominal ultrasound or renal CT, bone scan. Investigations play a greater role in people not able to describe their symptoms. An energetic and comprehensive approach to exploring the cause of possible pain using all the tools available is required.
- Consider dental referral.

## Management

- Work with the patient to provide a comprehensive solution.
- Consider use of a pain diary to note time of day, association with activities, and location of pain. Consider non-pharmaceutical ways to help manage pain.
- Does seating or sleeping posture need to be assessed?
- Would review of assistive technology be useful? Consider occupational therapy or physiotherapy referral.
- Treat identifiable causes.
- Provide adequate analgesia and continue to review to ensure resolution. Ensure an appropriate formulation of the analgesia as some people with cerebral palsy have difficulty swallowing tablets.
- If there is no obvious cause after thorough assessment:
  - Consider endoscopy particularly if a history of discomfort after meals or night waking and/or a trial of anti-acid medication.
  - Consider trial of laxatives.
- Social work assessment to evaluate home situation and to organise support services.

## Useful resources

Scope Australia has conducted research into identifying and recognising pain in people with severe/profound disability. The research involved the development of a training session and pain guide titled: Making the invisible visible: A pain awareness guide for support workers, families and carers. Melbourne: Scope (Aust).

For a summary of results, please visit <https://www.scopeaust.org.au/research-projects/identifying-pain/>. Please contact Dr Stella Koritsas at [skoritsas@scopeaus.org.au](mailto:skoritsas@scopeaus.org.au) for further information about this guide.

Tools such as the DisTat (Disability Distress Assessment Tool) and visual Pain Scales (e.g. Wong Baker Faces Pain Scale) can be helpful in assessing and monitoring pain.

CanChild has a useful webinar on pain prevention and treatment in children and young people with cerebral palsy  
<https://www.canchild.ca/en/resources/268-pain-prevention-and-treatment-in-children-and-young-people-with-cerebral-palsy>

The Scottish SIGN guideline may be helpful

<https://www.guidelines.co.uk/summaries/pain>

The Royal College of Nursing (UK) has a virtual forum

<https://www.rcn.org.uk/get-involved/forums/children-and-young-people-professional-issues-forum/communities/pain-in-children-and-young-people>

## REFERENCE

1. Parkinson KN, Dickinson HO, Arnaud C, et al. *Arch Dis Child* 2013 Jun;98(6):434-40. doi: 10.1136/archdischild-2012-303482.



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