



Pain in Adults with Cerebral Palsy

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During the last decade there has been an increased focus on pain in CP. Several scientific studies have identified pain as one of the most common problems experienced by individuals with CP, children and adults alike, and as many as 75% of adults with CP suffer from chronic pain. Pain in CP seems to be overlooked and insufficiently treated by caregivers and health professionals. It has been shown to impact negatively on daily living, quality of life and is associated with worsening walking ability in adults. In CP, many children that have chronic pain have lower school achievements than children without pain. There are only a few studies on treatment of pain in CP and none that systematically evaluate this in adults.

Causes of Pain in CP

- First of all, individuals with CP might, like any other person, have problems with headache, periodic pain and other commonly encountered causes of pain. Pain emerging from muscles, joints and the skeleton are common.
- For some individuals increased muscle tone, spasticity or dystonia can be an important contributing factor for pain. This type of pain, often referred to as musculoskeletal pain can be localized in the back, neck, foot/ankle, shoulder, knee, hip and arm.

- Gastro-intestinal pain often caused by gastro-esophageal reflux secondary to changed muscular function in the esophagus or lower oesophageal sphincter and spinal deformity (scoliosis) is another source to chronic pain. In addition problems with gastrostomy (PEGS) can cause pain.
- Procedural pain, procedures identified as being potentially painful and often encountered by individuals with CP include needle injections.
- Furthermore many activities of daily living such as getting dressed, being lifted and daily assisted stretching can be painful.
- Dental pain, caused by difficulties in maintaining good oral hygiene or gastro-esophageal reflux (causing erosions to the dental enamel and secondary caries) needs special consideration.

Pain Management for Individuals with CP

- Depending on the cause of your pain the treatment will vary.
- First aim to pinpoint the cause and effect of your pain with your Primary Care Provider (PCP).
- Your PCP can then choose to refer to a specialist depending on the source.
- A follow-up appointment is recommended to evaluate the management of pain.



Pain in Adults with Cerebral Palsy (continued)

Pain Management for Individuals with CP (continued)

- There are only a few studies on treatment of pain in CP and none that systematically evaluate this in adults.
- There are several different classes of oral drugs that can be used to alleviate pain. Discuss this with your PCP, family doctor, physiatrist, neurologist or orthopedic surgeon.
- Non-pharmacological treatments can be warmth such as a warm bath or cold as an ice pack. Sometimes massage can help relieve tense muscles.
- For musculoskeletal pain regular exercise is the key to strength and will often reduce pain.
- Optimal *pain management* occurs before, during, and after a *procedure* and should include plans to address anxiety before initiation of any *procedure*.
- It is likely that effective pain management can positively affect the quality of life but also possibility to obtain employment, and to reach a higher level of social integration.
- Thus a pain free life will have important impact for the individual, the socio-economic situation as well as health policy makers.

Special difficulties

- Individuals with cognitive or communicative challenges can present particular difficulties.
- Change in behavior, particularly amongst adults with cognitive difficulty, should be investigated as a symptom of a medical problem before being ascribed to “behavior”. Common causes of changed behavior include pain.
- Pain behavior might include changes in vocal expressions, eating/sleeping, social/personality, facial expression, activity, body and limbs and physiological changes- such as constipation.



Pain in Adults with Cerebral Palsy (continued)

Resources

Assessment tools

1. Brief Pain Inventory (BPI) <http://www3.mdanderson.org/depts/prg/bpif.pdf>
2. FLACC: Faces, Legs, Activity, Cry, Consolability Observational Tool
https://en.wikipedia.org/wiki/FLACC_scale
3. Non-Communicating Childrens Pain Checklist NCCPC – Revised & NCCPC – Postoperative version, (Breau L et al 2000, Dev Med Child Neurol)
http://www.aboutkidshealth.ca/en/documents/akh_breau_post-op.pdf

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