

Pain Assessment

“...An anti-psychotic medication is not going to help an upset stomach.” - Emergency Room Doctor

Pain is a subjective experience—a warning sign to the body of danger. For people with intellectual and developmental disabilities (IDD), there may be challenges to communicating pain, or to identifying the location and intensity of pain. As a caregiver, your ability to help identify and communicate pain is crucial. When pain is unmanaged, it's likely to manifest in behaviours. If we try to manage behaviour without addressing the root cause (pain!), we are doing a big disservice to people with IDD, by prolonging their suffering and invalidating their experiences.

There are many conditions that cause pain and warrant treatment. These include (but are not limited to):

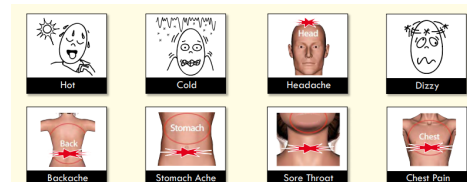
- Degenerative joint disease, arthritis and chronic immobility
- Migraine headaches, sinus headaches/pressure and other chronic headaches
- Gastroesophageal Reflux Disease (GERD)
- Constipation/diarrhea
- Premenstrual syndrome (PMS)
- Cancer
- Anxiety
- Depression
- Abuse and traumatic experiences

Some words associated with pain are: acute (short term), chronic (long term), sharp, full, boring, aching, burning, constant, intermittent, referred (pain in one part of the body but felt in another), ischemic (pain from lack of blood and nutrients to a body part), and phantom (very real pain triggered by a powerful memory often in an amputated body part).

Pain is often missed. This can occur even if we ask about pain—often because people with IDD may be conditioned to be agreeable, or because there are communication challenges. For this reason, it is helpful to ask about pain in a way that the individual understands. This may mean using visual aids to help.



The *Wong-Baker Faces Scale*. Ask the person to tell you how much it hurts. (Generally, avoid asking an abstract question, “How is your pain?” Be concrete and specific. Combine with an observational pain scale)."



The *Hospital Communication Book* contains many examples of visual aids.

Observational pain scales are necessary:

Even if you've asked where it hurts, and how much it hurts, always include observations into your assessment. There are many tools that provide examples of outward signs suggestive of pain. The **Chronic Pain Scale for Non-verbal Adults with IDD** and the **Dis-Dat** are examples of observational tools. They ask you to look for signs suggestive of pain, like grimacing, crying, avoiding, etc.

Unfortunately, similar changes in behaviour in a person with IDD are often misidentified as psychotic symptoms. This leads to the increased use of inappropriate medication to control behaviour. When someone is in pain, help to obtain treatment for the underlying cause. Share your observations and ideas.

- **Chronic Pain Scale for Non-Verbal Adults with IDD:** <http://pediatric-pain.ca/wp-content/uploads/2013/04/CPSNAID.pdf>
- **Dis-Dat:** <https://www.wihb.scot.nhs.uk/LD/toolkit/disdat%20Assess%20tool%2009.pdf>