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Office of Integrated Health Health & Safety Alert/Information

Recognizing Pain in Individuals with Intellectual and Developmental Disabilities Health & Safety Alert

The International Association for the Study of Pain (IASP) describes pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”. The clinical definition by McCathery updated in 1989 and still in use today states “pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does” (Baldrick and Astrasik, 2010). A pain assessment is straightforward for individuals who can communicate, report, describe, and/or identify (in some way), their own pain. However, individuals with intellectual disability who are unable to communicate *effectively* due to varying degrees of speech and language barriers, dementia, and/or those with severe mental health disorders, require others to recognize behavioral symptoms, as well as physiological changes to address their need for pain relief.

Evidence suggests that individuals with IDD and/or those who are non-verbal are at a higher risk for under-treatment of pain. Identifying an individual who is experiencing pain, and subsequently treating their pain, improves daily living, their ability to participate in enjoyable activities, and decreases risk of depression (Lewis, 2011). According to the article, “Pain Assessment in Non-Communicative Adult Palliative Care Patients” pain related outcomes were improved using appropriate pain assessment tools, which helped achieve effective pain management (McGuire, Kaiser, Wolfe, & Iyamu, 2016). During the Individual Support Plan (ISP) planning process, it is essential the known health-related conditions causing pain such as, muscle spasms, arthritis, neuropathy, contractures, pressure injuries, and immobility, be identified and addressed to ensure continuity of care and quality of life for the individual.

Did you know...

The prevalence of chronic pain in the U.S. is estimated to be between 11% and 40% of adults. In 2016 an estimated 50 million U.S. adults reported chronic pain (Dahlhamer, Lucas & Zelaya, 2018).

Signs and Symptoms of Pain

Look for These Behavioral and Physiologic Changes in Non-Verbal Individuals

The presence of any of these behaviors may be indicative of pain and warrants consultation with the individual's Primary Care Physician (PCP) for further investigation, treatment and/or monitoring.

- Vocalizations- either onset of a new sound, or a lack of sound altogether.
- Changes in appetite-refusing to eat.
- Self-injurious behavior- hitting self, biting self, banging head.
- Anxiety-crying, increased breathing/shallow breathing/panting, trembling, sweating, and/or increased pulse.
- Inability to concentrate or stay on task.
- Irritability/agitation.
- Changes in sleep pattern.
- Increased blood pressure.
- Increased pulse rate.
- Nausea and/or vomiting.
- Movement-restlessness.
- Facial expression changes: squinting face or eyes, frowning, mouth turned down, chin quivering as if getting ready to cry, and appears sad, depressed, furrowed brow.
- Muscle tension in shoulders, face, clenched jaw.
- Grinding of teeth.
- Guarding- an individual may shield a certain body part in order to prevent you from touching it, and/or an individual may exhibit a resistance to moving a certain body part.
- Rubbing-an individual might rub or hold an area of their body that is causing them pain.
- Elevated temperature greater than 98.6 degrees.

(Herr, et al, 2006; McGrath, Rosmus, Canfield, Campbell & Hennigar, 1998; McGrath, Rosmus, Canfield, Campbell, Hennigar, 1998).

Did you know...

The inability to escape from pain may create a sense of helplessness and even hopelessness, which may predispose the patient to a more chronic depression (Wells, Pasero & McCaffery, 2008).

Reducing Barriers to Equitable Healthcare and Pain Treatment

Training Staff to Document Observed Pain

Staff and caregivers should be taught how to document observed and/or reported bouts of pain the individual has experienced, and be able to accurately report their observations to the PCP, physician specialist or a nurse (e.g. agency nurse, private duty nurse, home healthcare nurse, PCP's nurse, etc.).

Implementation of a Pain Recognition Protocol

Provide staff training to ensure appropriate use and consistency of pain recognition protocols. Training should encompass all staff, caregivers and family members, before protocols are implemented. Pain will go unrecognized and undertreated if care providers do not understand how to properly implement the pain recognition protocol, how long the process should take when examining someone for pain, or when to notify the individual's PCP, legal guardian, parents, agency nurse, home healthcare professionals, etc. A pain recognition protocol should give specific instructions regarding next steps for direct support staff. A study completed in 2008 revealed most nursing staff based recognition of pain on factors such as crying, moaning, or screaming when many individuals, especially those who are non-verbal, suffer in silence (Kankkunen, Janis & Julkunen, 2010).

Level/Degree of Pain Experienced

A pain recognition protocol identifies when pain may be present, but does not identify the level of pain a non-verbal individual is experiencing such as mild, moderate, or severe pain. An individual exhibiting no behaviors may be experiencing as much pain and/or a greater levels of pain than someone exhibiting several behaviors (Wells, Pasero & McCaffery, 2008). If pain is identified, an individual should be evaluated by a healthcare professional as soon as possible (at the earliest opportunity).

Effective Advocacy on Behalf of Individuals

One of the roles of caregivers and DSP's is to support individuals gain access to healthcare when pain is suspected. Individual's communication difficulties can also prevent them from accurately reporting their symptoms to their PCP. This is further exacerbated by time constraints on the PCP's schedule (Zworth, Selick, Durbin,

Casson & Lunsky, 2019). Caregivers can reduce barriers to healthcare and treatment for pain through effective advocacy and communication with the individual's PCP, nurse and other healthcare professionals. This is especially important for individuals who either cannot speak for themselves and/or those who cannot communicate well enough to accurately report the symptoms they may be experiencing. A confident and empowered advocate can exert a powerfully positive influence on healthcare outcomes and increase the likelihood of equitable healthcare for individuals with IDD. An individual experiencing pain and/or one who may be experiencing pain, (based upon their behavior), should be accompanied to their PCP appointment by a confident, well-versed and familiar caregiver/DSP who can:

1. Accurately relay information to the healthcare professional performing the pain assessment.
2. Ensure the healthcare professional is aware of the individual's normal/regular behavior.

Atypical Symptoms of Pain

Many individuals are unable to report pain themselves, its intensity, its location, or its duration. The only indicators of distress may be nonspecific fluctuations in vital signs and/or increases in behavior from their baseline or normal state of being (Sue, Mazzotta & Grier, 2019). In studies with patients diagnosed with dementia who had cognitive impairment, behavior changes such as aggression, agitation, and restlessness were the **only indicators of pain** (Pautex, Michon, Guedira, Le Lous & Samaras, 2006).

Collaborate with Family, Healthcare Professionals, and Caregivers

The ability of caregivers to determine if an individual might be experiencing pain depends greatly on the level of communication of the individual. Prior to attempting to determine if an individual is experiencing pain, ensure that you are familiar with key words, phrases, facial expressions or non-verbal gestures the individual may have used to indicate pain in the past. Collaborate and seek input from those who are familiar with the individual, such as direct support professional (DSP) staff, family, caregivers, etc. to gain their insight.

Physician-Developed Protocol for PRN Pain Medications

Consult with the individual's PCP, nurse or physician specialist in order to develop a protocol for staff to use before administering PRN pain medications. Pain should be re-evaluated after each intervention within one hour and effectiveness documented in the individual's record to evaluate the action's usefulness (Wells, Pasero & McCaffery, 2008). If the intervention appears to be ineffective in relieving the individual's pain, the individual's PCP, nurse or physician specialist should be notified as soon as possible (at the earliest opportunity).

Example: An individual starts exhibiting behaviors such as increased hand biting. You might consider the following to determine if the individual is experiencing pain or not:

1. Is she/he thirsty or hungry? Offer a snack and/or a drink. Did the behavior resolve?
2. Is she/he bored? Offer a change of environment/activity. Did the behavior resolve?
3. Is she/he uncomfortable? Reposition the individual. Did the behavior resolve?
4. Is she/he wet or soiled? Perform changing or assist individual with toileting protocol. Did the behavior resolve?
5. Is she/he too hot? Look for sweatiness or flushing. Check the individual's temperature with a thermometer. Administer physician ordered medication as prescribed for fever, if fever is present. Did the behavior resolve?
6. Is she/he too cold? Look for blueness or shivering. Put a jacket on the individual or the individual a blanket. Did the behavior resolve?
7. Does she/he have their favorite item within reach? Retrieve it for them. Did the behavior resolve?
8. When was the individual's last bowel movement? Could the individual be constipated? If it has been longer than 3 days since their last bowel movement, follow their bowel management protocol (this might be a PCP order for the individual to receive an enema, laxative, etc.). If there is not a bowel management protocol in place, contact their PCP as soon as possible (at the earliest opportunity).

If any of the interventions above are not successful, make an appointment with the individual's physician for a pain assessment as soon as possible (at the earliest opportunity).

Untreated or Undertreated Pain

There is also sufficient evidence indicating individuals with IDD routinely endure untreated pain or their pain is undertreated, due to their inability to accurately describe their pain to others. One study suggested that some individuals may endure untreated, chronic pain for years (Wells, Paserio & McCaffery, 2008). If you notice an individual having serious limitations in their ability to function and/or carry out their normal daily activities, pain should be assessed (Walsh, Morrison & McGuire, 2011). Pain assessment should also be completed when individuals have experienced surgery, illness, a medical/dental procedure, and/or when they have conditions known to cause pain such as a wound, a medical condition (arthritis), or an injury (a fall, a broken bone, etc.) (Wells, Pasero & McCaffery, 2008).

Interventions/Pain Control Treatment

Interventions relating to pain control should not be withheld based on the individual's disability. All decisions relating to pain control and/or pain management interventions should be made collaboratively with the individual, caregivers, guardians, nurses, physicians, case manager, etc. to help ensure the best interests of the individual and quality of care are being provided (Sullivan, Heng, Cameron, Lunskey, Cheetham & Hennen, 2006).

Did you know...

Some provider/caregivers are now incorporating written policies that include the documentation of an individual's normal/daily activities via photographs that can then be kept in an individual's chart. These photographs can then be used to show healthcare professionals what an individual's baseline "looks like" when the individual is ill. This practice helps healthcare professionals be able to more **effectively assess and gauge the degree of severity of an illness or condition an individual may be experiencing**. It is especially effective for healthcare professionals who have limited or no experience with individuals with IDD (in general) and/or those who lack experience with the individual, such as ER and/or hospital staff.

A picture truly can speak a thousand words.

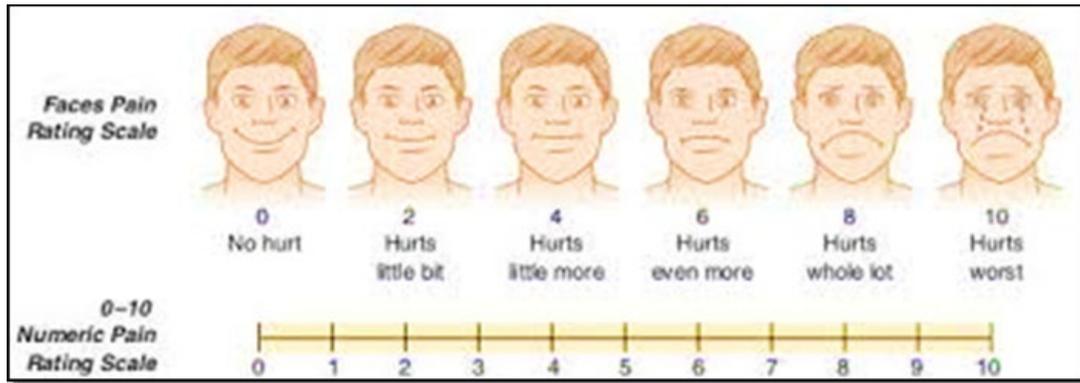


Pain Assessment Tools

There are many pain assessment tools available for use by medical professionals, but there is no standard pain assessment tools specific to people with DD (Baldrige, and Adrasik, 2010). Healthcare professionals should select an assessment tool which is specific to the population and setting. The use of an assessment tool routinely enables providers to recognize pain, evaluate the various treatments of pain for effectiveness, gives evidence for communication with physicians, nurses, other providers, and family, and improves the individual's quality of life (McGuire et al., 2016). Some individuals cannot demonstrate indicators of pain with facial expression due to lack of muscle control or rigid muscles, and are at higher risk for untreated pain (Kankkunen, Janis, Julkunen, 2010).

Listed are examples of non-verbal assessment tools:

- FACES (Wong Baker) (Permission granted to use).



- Non-communicating Children’s Pain Checklist – Revised (NCCPC-R).

Non-communicating Children’s Pain Checklist – Revised (NCCPC-R)

NAME: _____ UNIT/FILE #: _____ DATE: _____ (dd/mm.yy)
OBSERVER: _____ START TIME: _____ AM/PM STOP TIME: _____ AM/PM

How often has this child shown these behaviours in the last 2 hours? Please circle a number for each item. If an item does not apply to this child (for example, this child does not eat solid food or cannot reach with his/her hands), then indicate "not applicable" for that item.

	0 = NOT AT ALL	1 = JUST A LITTLE	2 = FAIRLY OFTEN	3 = VERY OFTEN	NA = NOT APPLICABLE
I. Vocal					
1. Moaning, whining, whimpering (fairly soft).....	0	1	2	3	NA
2. Crying (moderately loud).....	0	1	2	3	NA
3. Screaming/yelling (very loud).....	0	1	2	3	NA
4. A specific sound or word for pain (e.g., a word, cry or type of laugh).....	0	1	2	3	NA
II. Social					
5. Not cooperating, cranky, irritable, unhappy.....	0	1	2	3	NA
6. Less interaction with others, withdrawn.....	0	1	2	3	NA
7. Seeking comfort or physical closeness	0	1	2	3	NA
8. Being difficult to distract, not able to satisfy or pacify.....	0	1	2	3	NA

- Faces, Legs, Activity, Cry, and Consolability scale (FLACC).

FLACC Scale²		0	1	2
1	Face	No particular expression or smile.	Occasional grimace or frown, withdrawn, disinterested.	Frequent to constant frown, clenched jaw, quivering chin.
2	Legs	Normal position or relaxed.	Uneasy, restless, tense.	Kicking, or legs drawn up.
3	Activity	Lying quietly, normal position, moves easily.	Squirming, shifting back and forth, tense.	Arched, rigid or jerking.
4	Cry	No crying (awake or asleep).	Moans or whimpers; occasional complaint.	Crying steadily, screams or sobs, frequent complaints.
5	Consolability	Content, relaxed.	Reassured by occasional touching, hugging or being talked to, distractible.	Difficult to console or comfort.

- Checklist for Non-verbal Pain Indicators (CNPI).

PAIN SCALE FOR COGNITIVELY IMPAIRED, NON-VERBAL ADULTS		
Checklist of Non-Verbal Pain Indicators (CNPI)		
Indicators:	With Movement	At Rest
Vocal Complaints (non-verbal expression of pain demonstrated by moans, groans, grunts, cries, gasps, sighs)		
Facial Grimaces and Winces (furrowed brow, narrowed eyes, tightened lips, dropped jaw, clenched teeth, distorted expression)		
Bracing (clutching or holding onto bed/chair, caregiver, or affected area during movement)		
Restlessness (constant or intermittent shifting of position, rocking, intermittent hand motions, inability to keep still)		
Rubbing (massaging affected area)		
Vocal Complaints (verbal expression of pain using words, e.g., "ouch" or "that hurts," cursing during movement or exclamation of protest, e.g., "stop" or "that's enough")		
Total Score		

Opioid Pain Relievers

Individuals who are prescribed opioids to treat chronic pain, must be monitored closely for side effects (American Society of Anesthesiologists, n.d.). These side effects include sleepiness, respiratory depression, constipation, and nausea. Opioids can cause **serious side effects** and can be **life-threatening** when administered incorrectly. Opioids are a central nervous system depressant. The central nervous system controls autonomic responses: metabolism, body temperature, blood pressure, breathing, etc. When opioids are taken with other CNS depressants (Barbiturates: Valium, Ativan, Xanax), medications used as sleeping aids (Ambien, Sonata, Lunesta, etc.) (Alcohol, other medications, etc.), there can be a compounding effect on the CNS. Although, different classes of CNS depressants work in different ways, all have the ability to reduce activity in the central nervous system and lower levels of awareness in the brain that can cause heart rate and respiratory depression which can be life threatening. When opioid medications are prescribed, monitor the individual every 2 hours after first administration to determine if unwanted side effects such as over-sedation need to be addressed (Wells, Pasero & McCaffery, 2008).

Recognizing an Accidental Opioid Overdose

Even when opioids are physician-prescribed, an individual can have an accidental opioid overdose, due to drug interactions, etc. Studies reveal that unintentional overdose is often due to polypharmacy, alcohol ingestion, and doctor shopping along with medication administration errors (Hall, et al., 2008; Siegler et al., 2014). Symptoms of an accidental overdose may include: respiratory rate depression, respiratory arrest (no breathing), shallow or gurgling breathing, slowed heart rate, or unresponsiveness.

IF AN INDIVIDUAL IS UNRESPONSIVE, BEGIN CPR & CALL 911 IMMEDIATELY.

Basic First Aid/CPR interventions should be initiated immediately if the individual is not breathing and/or is unresponsive and 911 is initiated. Staff caring for individuals on opioids should be trained through the REVIVE! Program to administer Narcan in the event of an opioid overdose. Long term use of opioids significantly increases the risk of addiction and overdose, but can also have a negative effect on the quality of an individual's life (American Society of Anesthesiologist, 2017). However, fear of side effects from opioid treatment and fear of causing harm, such as respiratory depression, sometimes results in undertreated pain (Wells, Pasero & McCaffery, 2008).

Effects of Untreated Pain

Untreated pain can result in depression, increased anxiety and stress, which can negatively affect the individual's ability to participate in meaningful activities. A prolonged stress response can also contribute to gastrointestinal changes due to sympathetic nervous system activation, which can cause gastric emptying and intestinal motility to be affected. Stress can also cause suppression of the immune system, which can put the individual at greater risk for infections (Wells, Pasero & McCaffery 2008).

Resources

Learn more about Revive! (DBHDS, n.d.) a free layperson training on how to recognize and respond to an opioid overdose emergency with the administration of naloxone (Narcan ®) here:

<http://www.dbhds.virginia.gov/behavioral-health/substance-abuse-services/revive>

Learn more about the Wong FACES pain rating scale (Wong & Baker, 2001) here:

<https://wongbakerfaces.org/>.

Learn more about the Non-Communicating Children's Pain Checklist – Revised (NCCPC-R) (Breau, McGrath, Finley & Camfield, 2004) here:

file:///C:/Users/dha92624/Downloads/PainChklist_BreauNCCPC-R2004.pdf

Learn more about the Faces, Legs, Activity, Cry, and Consolability (FLACC) scale (Baldrige & Andrasik, 2010) here:

<https://www1.health.gov.au/internet/publications/publishing.nsf/Content/triageqrg~triageqrg-pain~triageqrg-FLACC>

Learn more about the Checklist for Non-Verbal Pain Indicators (CNPI) (Feldt, 2000) here:

https://geriatricpain.org/sites/geriatricpain.org/files/wysiwyg_uploads/cnpi_tool_with_log_o.pdf

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