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Office of Integrated Health
Health & Safety Alert/Information

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

Introduction

The International Association for the Study of Pain (IASP), 2018, defines pain as "*An unpleasant sensory and emotional experience associated with actual or potential tissue damage*" (22) (16).

The definition of pain, accepted worldwide by Margo McCaffrey in 1968, and still in use today, simply states, "*Pain is whatever the experiencing person says it is, existing whenever the experiencing person says it does*" (9).

Pain is a very personal and individualized experience (9). Self-reporting pain is the most dependable gauge of a person's pain. Measuring pain is straightforward for individuals who can communicate, describe, and/or identify (in some way) their own pain (16). No two persons experience pain in the same way, even if it's from the same source (21).

Pain can range from mild to severe. Numerous words can be used to describe pain such as tingling, burning, stabbing, stinging, shooting, aching, pricking, sharp, or an electrical sensation. There are three types of pain:

- Acute pain starts quickly and ends when the cause is treated or healed. Acute pain acts as a warning sign from the body about injury, disease, overuse, or other external stressors.
- Acute pain can be caused by strained muscles, broken bones, dental work, surgery, infections and/or burns (21).
- Acute pain can turn into chronic pain (21).
- Chronic pain is defined as any pain lasting more than 3 months. Many health conditions are accompanied by chronic pain (21).
- Individuals can experience several chronic pain conditions at the same time (21).
- Episodic pain is irregular and happens from time to time, then disappears (21).

- Examples of episodic pain are sickle cell anemia and migraine headaches. This type of pain can be caused by a trigger or can occur suddenly without warning (21).

Pain and Individuals with Intellectual and Developmental Disabilities (IDD)

Diagnosing pain in an individual with IDD can be a challenging, complex, and complicated process (16) (10).

- Individuals with IDD are twice as likely to suffer from acute, episodic, and chronic pain than their peers in the general population (16) (10).
- Individuals with IDD are less frequently assessed for pain due to diagnostic overshadowing. This is when a healthcare professional attributes an individual’s mannerisms and actions to their intellectual or developmental disability. Their expression of pain is discounted (8).
- Individuals with IDD and/or those who are unable to communicate effectively are at a higher risk for under-treatment or no treatment for their pain (8).
- Individuals with IDD who can use words may not have the cognitive ability to effectively communicate details such as pain intensity or location which impacts their ability to receive treatment (7) (16) (10).
- Healthcare professionals typically ask questions to help assess pain level, type, and location. These questions are not easily answered by individuals with IDD who may not fully understand abstract concepts or human anatomy. Due to this, they may be unable to describe the pain they are feeling, its intensity, when it started, or where it is located (7) (16).
- Many IDD-related syndromes are directly associated with painful health conditions such as arthritis and contractures (18) (7).
- Individuals diagnosed with Down syndrome often experience cervical, spinal, and hip instability, which is often painful (18) (7).
- Fragile-X, Prader-Willi syndrome, and Williams syndrome may be characterized by some forms of pain (18) (7).
- Ill-fitting wheelchairs or leg braces, along with other improperly sized durable medical equipment, can cause acute and chronic pain (8).

- The only indicators of distress in some individuals with IDD may be nonspecific fluctuations in vital signs and/or increases in behavior from their normal state of being (23).

The Individual Support Plan (ISP) should identify health-related conditions that might cause pain such as muscle spasms, arthritis, neuropathy, contractures, pressure injuries, and decreased mobility, to ensure continuity of care and quality of life (25).

Signs and Symptoms of Pain for Individuals with IDD

- Chronic pain negatively affects an individual's ability to function, their emotional state, their desire for social interaction, sleep, appetite, and mobility (8).
- Individuals with IDD who are non-verbal, due to varying degrees of speech and language barriers and/or cognitive issues, require caregivers to recognize behavioral symptoms, physical changes, and facial expressions that might indicate pain (25) (16).
- Individuals with IDD may act out signs and symptoms of pain in different ways than the general population making pain difficult to recognize and diagnose (7).
- Caregivers should be constantly looking for behavioral and physical changes in individuals with IDD which may indicate they are experiencing pain (26) (11).

The presence of any these behaviors may indicate pain and should prompt a consultation with the individual's Primary Care Provider (PCP) for further investigation, treatment, and/or monitoring (7).

Some Behavior Changes Used to Detect Pain in Individuals with IDD, both Verbal and Non-Verbal	
Vocal Expression	• Increased shouting or change in tone. • Whispering • Making loud noises • Forced coughing. • Talks more the usual • Stops talking or making any noise. • Says words in regard to pain
Facial Expression	• Eye narrowing or closure • Red eyes • Frightened expression • Distorted expressions • Brow lowering • Clenched teeth • Nose wrinkling

General Behavior	• Wants to stay in bed. • Wants to sleep more than usual. • Increased weakness • Sits more the usual • Cannot sleep, up at night
Changes in Eating	• Compulsive eating • Compulsive drinking • Stops eating. • Stops drinking. • Vomiting
Emotional Responses	• New or increased crying • New or increased nervousness • Seems afraid. • Unsettled • Increased anger • Sadness • Wants to stay with primary caregiver. • Decreased engagement in activities. • Withdrawal, increased isolation
Body Movements and Posture	• Body rocking • Head banging, throwing head around. • Hand clapping • Constant touching body part that hurts. • Walking slower than usual • Walking more than usual • Limping • Unstable gait • Stands with back bent. • Guarding • Increased fidgeting • Rigidity, unwillingness to move
Physical Changes	• Constipation • Change in facial color: yellowish face, pale face, blushed face. • Fever • Swollen feet and/or hands • Increased dry skin. • Excessive salivation • Increased sweating and perspiration • New incontinence

Aggression	• Increased or new anger toward others • Scratches, bites, or hits self (new or increased self-injurious behavior) • Resisting personal care
Different Behaviors	• New or increased sucking on clothes, or blankets • Hands in/on mouth more often • Falls (26) (5) (7).

Effective Advocacy

Caregivers and family members who are the most familiar with an individual can learn to recognize these subtle changes and can more accurately report concerns regarding suspected pain (8) (11) (10).

Caregivers play a vital part in reducing barriers to healthcare and treatment for pain through effective advocacy and communication with the individual's PCP, nurses, and other healthcare specialists (26) (10).

Caregivers should familiarize themselves with words, phrases, facial expressions, or non-verbal gestures the individual may have used in the past to indicate pain (26).

Caregivers should closely observe an individual's non-verbal communication to understand their personal indicators for pain (19). Is the individual rubbing their head more than usual, grimacing when they swallow, touching their ears, or holding their stomach? Consider if these behaviors are a sign of their pain and discomfort (11).

It is considered a fundamental human right to receive medical treatment to address pain, and the caregiver is the main advocate when accompanying an individual with IDD to a healthcare appointment (26) (8).

An individual experiencing pain and/or someone who might be experiencing pain, (based upon their behavior or facial expressions), should be accompanied to their PCP appointment by a confident, well-versed, and familiar caregiver 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.

Pain Assessment Tools

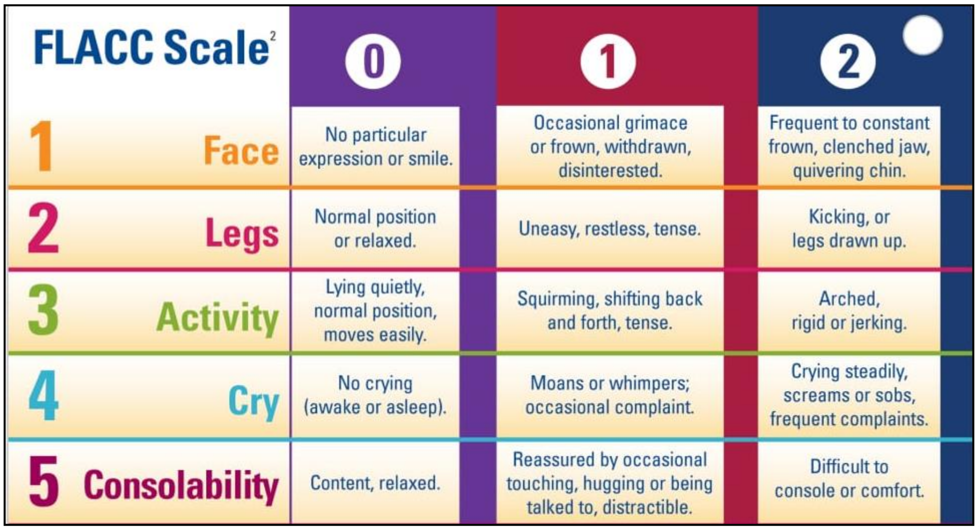
Pain is the body's way of indicating there is a problem (19). Pain assessments are performed by healthcare professionals (7).

Using the right assessment tool improves outcomes and helps to achieve effective pain management, which can greatly enhance the individual's quality of life. Healthcare professionals should select an assessment tool which is specific to the population and environment (8) (16).

Pain assessment for an individual with IDD should be individualized and person-centered, due to the unique response to pain each individual experiences (19).

Examples of Pain Assessment Tools:

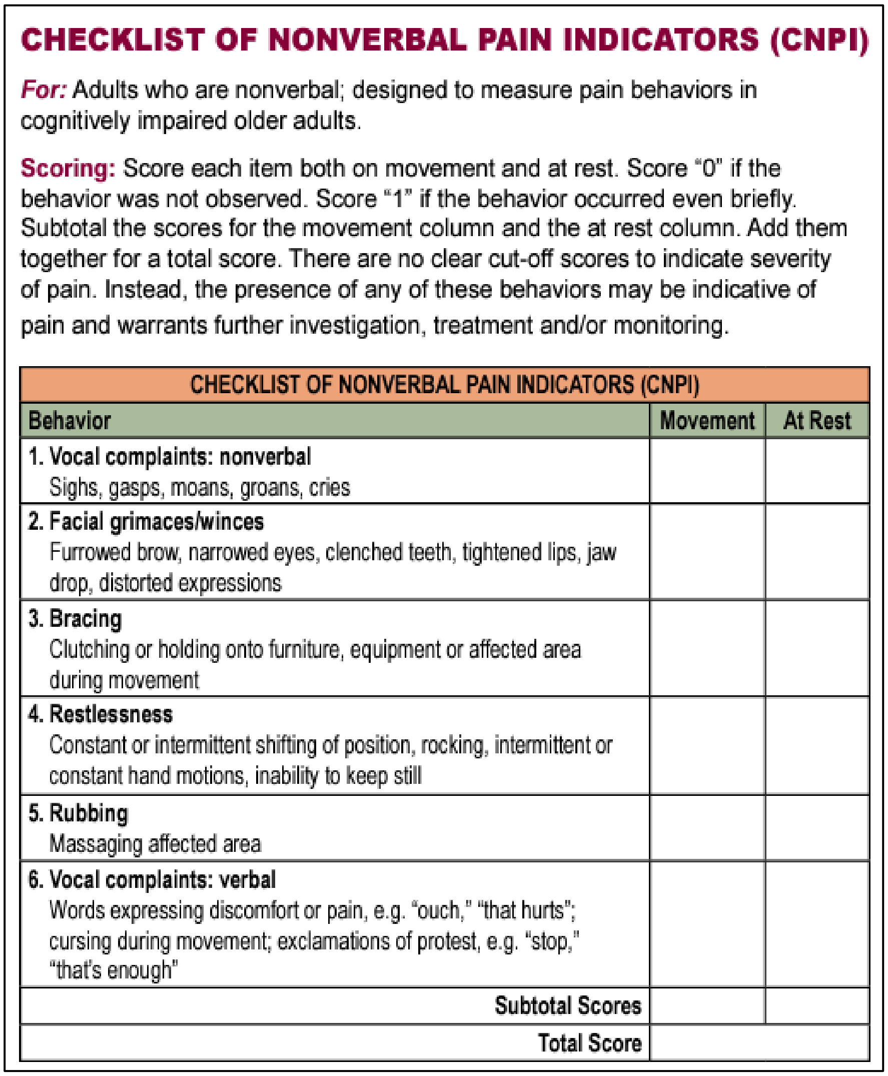
- **Faces, Legs, Activity, Cry, and Consolability (FLACC) scale.**



FLACC Scale[2]	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.

  - Consists of 5 categories of pain behavior, face expressions, leg position/movement, activity, cry/vocal, consolability.
  - This pain assessment was created for use with cognitively impaired individuals (10).

- **Checklist for Non-verbal Pain Indicators** (CNPI) (10).
  - The CNPI was designed to observe and measure pain behaviors in older adults with cognitive impairment ranging from mild to severe.
  - The assessment tool includes six pain behavioral items commonly observed in older adults including nonverbal vocalizations, facial grimacing or wincing, bracing, rubbing, restlessness, vocal complaints (10).



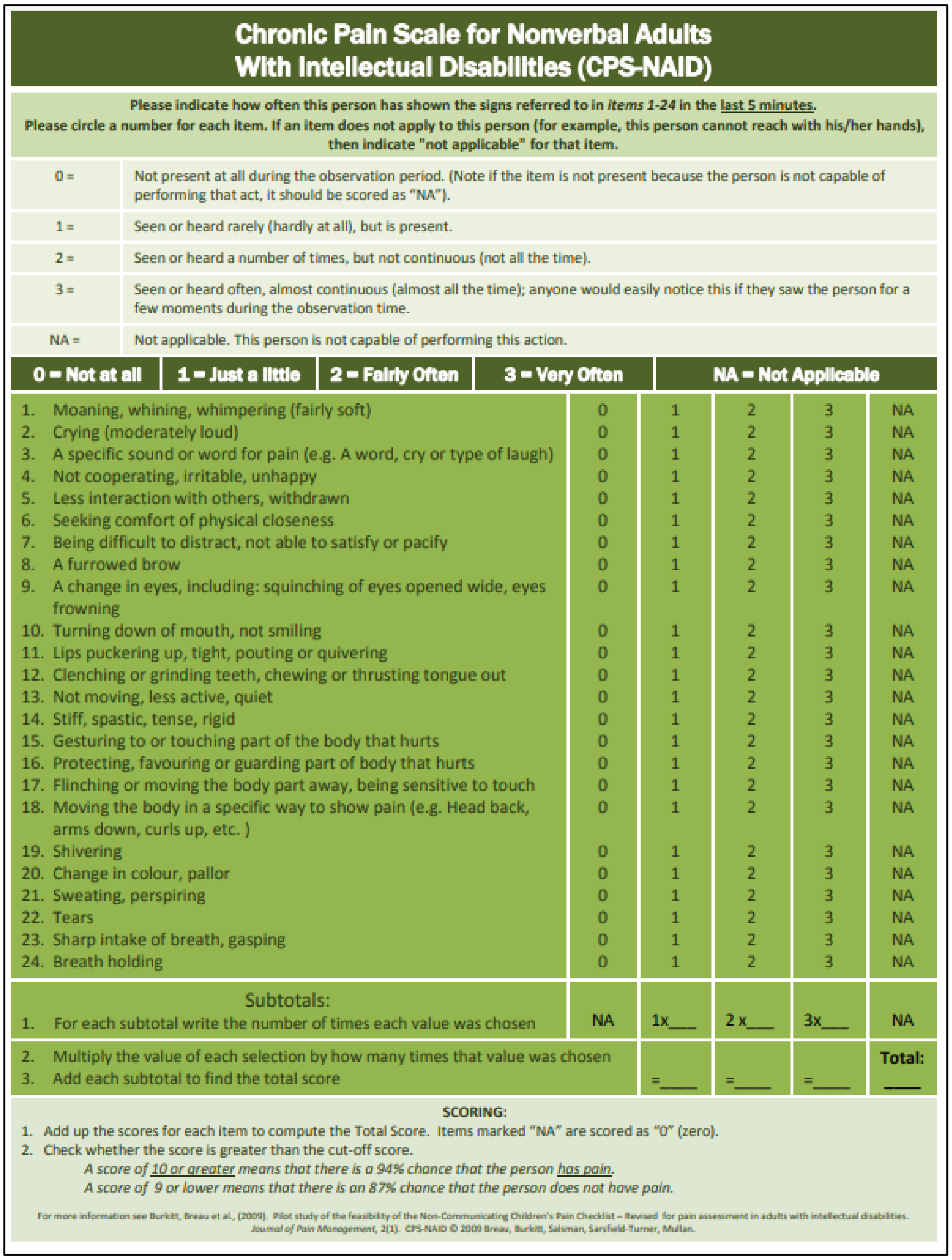
CHECKLIST OF NONVERBAL PAIN INDICATORS (CNPI)

For: Adults who are nonverbal; designed to measure pain behaviors in cognitively impaired older adults.

Scoring: Score each item both on movement and at rest. Score "0" if the behavior was not observed. Score "1" if the behavior occurred even briefly. Subtotal the scores for the movement column and the at rest column. Add them together for a total score. There are no clear cut-off scores to indicate severity of pain. Instead, the presence of any of these behaviors may be indicative of pain and warrants further investigation, treatment and/or monitoring.

CHECKLIST OF NONVERBAL PAIN INDICATORS (CNPI)		
Behavior	**Movement**	**At Rest**
1. Vocal complaints: nonverbal Sighs, gasps, moans, groans, cries		
2. Facial grimaces/winces Furrowed brow, narrowed eyes, clenched teeth, tightened lips, jaw drop, distorted expressions		
3. Bracing Clutching or holding onto furniture, equipment or affected area during movement		
4. Restlessness Constant or intermittent shifting of position, rocking, intermittent or constant hand motions, inability to keep still		
5. Rubbing Massaging affected area		
6. Vocal complaints: verbal Words expressing discomfort or pain, e.g. "ouch," "that hurts"; cursing during movement; exclamations of protest, e.g. "stop," "that's enough"		
Subtotal Scores		
Total Score		

- **Chronic Pain Scale for Nonverbal Adults with Intellectual Disability** (CPS-NAID), (10).
  - Consists of 24 items each rated on an ordinal 4-point scale (0–3).
  - It includes six subcategories: vocal expression, emotional reaction, facial expression, body language, protective reactions, and physiological signs (10).



Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities (CPS-NAID)

Please indicate how often this person has shown the signs referred to in *items 1-24* in the <u>last 5 minutes</u>.
Please circle a number for each item. If an item does not apply to this person (for example, this person cannot reach with his/her hands), then indicate "not applicable" for that item.

0 =	Not present at all during the observation period. (Note if the item is not present because the person is not capable of performing that act, it should be scored as "NA").
1 =	Seen or heard rarely (hardly at all), but is present.
2 =	Seen or heard a number of times, but not continuous (not all the time).
3 =	Seen or heard often, almost continuous (almost all the time); anyone would easily notice this if they saw the person for a few moments during the observation time.
NA =	Not applicable. This person is not capable of performing this action.

0 – Not at all | **1 – Just a little** | **2 – Fairly Often** | **3 – Very Often** | **NA – Not Applicable**

1. Moaning, whining, whimpering (fairly soft)	0	1	2	3	NA
2. Crying (moderately loud)	0	1	2	3	NA
3. A specific sound or word for pain (e.g. A word, cry or type of laugh)	0	1	2	3	NA
4. Not cooperating, irritable, unhappy	0	1	2	3	NA
5. Less interaction with others, withdrawn	0	1	2	3	NA
6. Seeking comfort of physical closeness	0	1	2	3	NA
7. Being difficult to distract, not able to satisfy or pacify	0	1	2	3	NA
8. A furrowed brow	0	1	2	3	NA
9. A change in eyes, including: squinching of eyes opened wide, eyes frowning	0	1	2	3	NA
10. Turning down of mouth, not smiling	0	1	2	3	NA
11. Lips puckering up, tight, pouting or quivering	0	1	2	3	NA
12. Clenching or grinding teeth, chewing or thrusting tongue out	0	1	2	3	NA
13. Not moving, less active, quiet	0	1	2	3	NA
14. Stiff, spastic, tense, rigid	0	1	2	3	NA
15. Gesturing to or touching part of the body that hurts	0	1	2	3	NA
16. Protecting, favouring or guarding part of body that hurts	0	1	2	3	NA
17. Flinching or moving the body part away, being sensitive to touch	0	1	2	3	NA
18. Moving the body in a specific way to show pain (e.g. Head back, arms down, curls up, etc.)	0	1	2	3	NA
19. Shivering	0	1	2	3	NA
20. Change in colour, pallor	0	1	2	3	NA
21. Sweating, perspiring	0	1	2	3	NA
22. Tears	0	1	2	3	NA
23. Sharp intake of breath, gasping	0	1	2	3	NA
24. Breath holding	0	1	2	3	NA
Subtotals: 1. For each subtotal write the number of times each value was chosen	NA	1x___	2 x___	3x___	NA
2. Multiply the value of each selection by how many times that value was chosen 3. Add each subtotal to find the total score		=____	=____	=____	**Total:** ____

SCORING:

1. Add up the scores for each item to compute the Total Score. Items marked "NA" are scored as "0" (zero).
2. Check whether the score is greater than the cut-off score.
   A score of <u>10 or greater</u> means that there is a 94% chance that the person <u>has pain</u>.
   A score of 9 or lower means that there is an 87% chance that the person does not have pain.

For more information see Burkitt, Breau et al., (2009). Pilot study of the feasibility of the Non-Communicating Children's Pain Checklist – Revised for pain assessment in adults with intellectual disabilities. *Journal of Pain Management*, 2(1). CPS-NAID © 2009 Breau, Burkitt, Salsman, Sarsfield-Turner, Mullan.

Pain Protocols

A person-centered protocol is based on the individual's physical and behavioral signs which indicate pain. Creating an individualized pain protocol involves a team effort to include the individual, healthcare professionals, family members, and caregivers. Caregivers and family members, who are most knowledgeable about the individual when they are feeling well and unwell, can help to build an accurate pain protocol for the individual (11) (19).

Based on past episodes of pain or distress the individualized pain protocol should describe how the individual appeared and behaved, and how pain or distress was treated or managed at that time (19).

A pain protocol helps to create a clear picture of the individual’s pain and will assist caregivers to competently address the individual’s pain (19).

A pain protocol should:

1. Identify the presence of pain.
2. Examine the effect of the pain.
3. Consider the underlying causes of the pain.
4. Treat the pain.
5. Verify the helpfulness of the treatment (11).

Identify the presence of pain or distress

Each individual expresses pain or distress differently. A good starting point for a person-centered protocol is with the individual's past history and chronic health conditions (10).

List the probable causes of an individual’s pain or distress to rule out all possibilities. For example, if an individual starts exhibiting increased self-injurious behaviors (hand-biting) for an extended period of time, then caregivers might consider the following to determine if the individual is experiencing pain:

1. Are they thirsty or hungry? Offer a snack and/or a drink. Did the behavior resolve?
2. Are they bored? Offer a change of environment/activity. Did the behavior resolve?
3. Are they uncomfortable? Reposition the individual. Remove leg braces. Adjust tight clothing. Did the behavior resolve?

4. Are they wet or soiled? Change incontinence briefs and do perineal care or assist individual with toileting. Did the behavior resolve?
5. Are they 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. Are they too cold? Look for blueness or shivering. Put a jacket on the individual or the individual a blanket. Did the behavior resolve?
7. Do they have their favorite item within reach? Retrieve it for them. Did the behavior resolve?

If the individual is not hungry, thirsty, soiled, too hot, too cold, or consoled by their favorite item or repositioning, the protocol should give specific direction to caregivers as to what the next steps should be (19).

Examine the effect of the pain or distress

Based on the responses to the interventions, an individual's level of pain or discomfort could be anywhere from mild to severe. Caregivers should observe the individual for a sense of their level of pain (19).

Is the individual displaying minor irritation, or have they become increasingly aggressive? Are they sweating or breathing heavier than normal? Is their heart rate (pulse) elevated from their normal range? Is their blood pressure elevated? Are they refusing to comply with typical activities of daily living? If so, then a higher level of pain can be assumed (19) (10).

If the individual is not able to communicate their level of pain intensity to caregivers, it is helpful to have set time limits on each intervention attempted in the pain protocol. Example: "Do X, Y, Z, wait 5 minutes, then do…," or Do X, Y, Z, wait 30 minutes then do…," and so on.

Consider the underlying causes of the pain or distress

Explore the individual's current acute, episodic, and chronic medical conditions and determine what signs and symptoms might correspond to the individual's expression of pain. What you learn may help identify a connection and a possible cause (10).

A pain protocol should consider all of the individual's physical, behavioral, and mental health conditions and assessment histories. When was the individual's last dental appointment? Could they be having oral pain? When was their last well check with their primary care physician? Should the individual have a follow-up visit, or should they be referred to a medical specialist? (19).

A Board Certificated Behavioral Analyst (BCBA) can also be helpful to rule out behavioral issues which may or may not be related to pain (10).

Documentation and the temporary use of tracking logs for known issues, such as constipation from medications, reflux from diet, monthly menstruation cycles in females, chronic arthritis flare-ups, mobility issues, seasonal allergies, etc. may help identify frequency of pain and specific behaviors an individual expresses during periods of pain or distress (26) (19).

Temporary tracking logs allow for identification of signs and symptoms which can assist with the development of a pain protocol and can help ensure positive outcomes by addressing the individual’s specific pain or discomfort when it is occurring (19).

Treat the pain or distress

For some individuals with IDD, moaning, grunting, and grimacing have no connection to pain and are their typical behavior (baseline). It is necessary to be cautious when administering pain medications and ruling out distress (26).

Commonly identified effective interventions for the individual should be included in a person-centered pain protocol. These might include prescribed over-the-counter medications, or alternative methods, such as favorite music or some form of distraction, a change in lighting levels, repositioning, massage, cold compresses, etc. (19) (10).

Pain protocols should clearly indicate why, when, and how much of all “as needed” (PRN) medications prescribed for an individual (10). Protocols should be as specific as possible and should not require a physical assessment by a direct support professional (DSP). For example, a protocol for the administration of Tylenol for pain should be as specific as possible:

“If hand-biting exceeds 15 minutes, assume pain, give 500 mg. of liquid Tylenol via G-tube. If pain does not resolve within one hour, take the individual to the ER for assessment.”

“If crying exceeds 15 minutes, assume pain, give 400 mg. of Ibuprofen orally. If pain does not resolve within one hour, call PCP office for instructions.”

PRN medications are prescribed by the PCP to reduce an individual's pain and discomfort. It is best practice for caregivers to be familiar with an individual's PRN medications and their administration requirements (19) (10).

Evaluate the helpfulness of the treatment

Best practice is to re-evaluate pain and discomfort after each intervention. After one hour, document the effectiveness in the individual’s record. If the intervention was ineffective, document next steps to get the individual the help they need (10).

Caregivers need to have a clear understanding of when to seek medical attention for an individual if the protocol is not providing pain relief (19) (10).

Clear, concise documentation detailing the caregiver's response to the individual's pain and distress shows exactly how the individual's needs were meet by the provider (10).

All individualized pain protocols should be reviewed and signed by the individual's PCP at least yearly to ensure effectiveness and appropriate outcomes are being achieved (19).

Effects of Untreated Pain

Untreated pain can result in depression and increased anxiety and stress, all of which can negatively affect the individual's ability to participate in meaningful activities (13).

Stress can also cause problems with the immune system, which can put the individual at greater risk for illness due to viruses, infections, etc. (15).

Prolonged stress due to pain can result in gastrointestinal issues such as diarrhea, constipation, etc. (15).

Caregiver Considerations

- Identifying an individual who is experiencing pain, and helping them seek treatment for their pain, can improve their daily living, the individual's ability to participate in enjoyable activities, and decreases the risk of depression (2) (25) (16).
- Family members and caregivers who are the most familiar with the individual are best at determining whether or not the individual may be experiencing pain or discomfort (26) (10).
- A pain recognition protocol can assist with identifying when pain is present for an individual with IDD and allows for early intervention and consistent delivery of care (19) (10).
- It is best practice for all staff, caregivers, and family members to be trained, and have their competency verified, before implementing an individual's pain protocol to ensure appropriate use (26).

Opioid Pain Relievers

Opioids pain medications bind with opioid receptor proteins in the nerve cells of the brain, gut, spinal cord, and other parts of the body. They block the pain messages sent to the brain from the body.

Individuals who are prescribed opioids to treat chronic pain must be monitored closely for side effects (1) (20).

These side effects include:

- Sleepiness
- Very slow breathing
- Constipation
- Nausea

Opioids can cause serious side effects and can be life-threatening when administered incorrectly.

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 (1) (20).

Recognizing an Accidental Opioid Overdose

Even when opioids are physician-prescribed, an individual can have an accidental opioid overdose, due to drug interactions, etc.

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 prescribed 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 (1) (20).

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

Resources

Wong FACES pain rating scale (Wong & Baker, 2001): https://wongbakerfaces.org/.

Faces, Legs, Activity, Cry, and Consolability (FLACC) scale (Baldridge & Andrasik, 2010): https://journals.lww.com/pain/fulltext/2015/11000/systematic_review_of_the_face,_legs,_activity,_cry.7.aspx

The Checklist for Non-Verbal Pain Indicators (CNPI) (Feldt, 2000): https://www.painmanagementnursing.org/article/S1524-9042(00)44237-2/fulltext

American Chronic Pain Association: https://www.acpanow.com/

American Headache Society: https://americanheadachesociety.org/

Arthritis Foundation: https://www.arthritis.org/

National Headache Foundation: https://headaches.org/

National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS): https://www.niams.nih.gov/

National Institute of Dental and Craniofacial Research (NIDCR): https://www.nidcr.nih.gov/

National Institute on Drug Abuse (NIDA): https://nida.nih.gov/

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