

Pain & Dementia







pain and dementia

Pain affects each of us differently. Some people have pain and we would never know. Some people with pain give no signs of it. Others, however, wear facial expressions or hold themselves in ways that let us know they are very uncomfortable, and probably in pain. Healthcare organizations, such as hospitals, nursing homes and hospices commonly ask us to rate the intensity of our pain on a scale of 1 to 10, or by pointing to a chart with faces showing emotions from happy to tearful.

But what about people with dementia? Sometimes they can tell us they are in pain. At other times, the look on their faces or their behavior gives us clues that they

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are in pain. They may not be able to tell us about the pain due to their confusion and lack of insight, particularly in the later stages of Alzheimer's disease and other dementias. They may call out, moan, or become very agitated; sometimes even striking out at caregivers. Too often in the past, we have assumed that dementia-related behaviors were an inevitable consequence of having the disease, and that nothing could be done to make them better, or that only psychotropic medications would alter the behavior. However, we now know that there is a safer, more effective and appropriate way to help.



the pain experience

While pain is not a normal consequence of aging, as older adults age, there is an increased likelihood that they will endure a medical condition that is associated with pain. Musculoskeletal disorders, such as arthritis, and neurologic conditions, such as various neuropathies, are chronic medical diagnoses associated with pain and are very common among older adults.

Similarly, as people age, there is an increasing likelihood that many will develop dementia. As the dementia progresses, they will have more difficulty verbally communicating their needs, pain or any discomfort. As such, they may resort to other ways of communicating pain such as through their behaviors.

People with dementia may resort to other ways of communicating their pain such as through their behaviors.

Ongoing research continues to examine the pain experience for people with dementia. Recent studies indicate that people with dementia sense even low levels of pain similarly to cognitively intact adults, and pain further contributes to cognitive compromise and decline.

Whenever pain is suspected, all people deserve prompt assessment and treatment whether or not they can report their pain. People with dementia are at risk for not having their pain assessed or addressed. This brochure describes ways to identify and treat people with dementia who have pain.

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assessing pain

The first step in assessing pain is learning about all the ways that people with dementia let us know when they have pain. The best approach for assessing pain is self-report.¹ However, caregivers may not ask people with dementia if they have pain, assuming that self-report is unreliable. Research suggests that many cognitively impaired adults can report their pain but as memories fade, confusion prevails and insight is compromised, self-report becomes increasingly difficult.

Pain behavioral assessment tools have been developed specifically to help recognize and assess older persons' chronic, persistent pain if they cannot provide self-report. The Pain Assessment in Advanced Dementia

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(PAINAD) identifies behaviors typical of people with dementia often not associated with pain, such as hyperventilation; noisy or labored breathing; negative vocalization with moans and

crying out; a distressed facial expression; body language which suggests pain; and inconsolability.

The Pain Assessment Checklist for Seniors with Limited Ability to Communicate (PACSLAC) is another good screening tool to monitor an older person's development of behaviors that may be pain-related. The Checklist of Nonverbal Pain Indicators (CNPI) scores behaviors exhibited at rest and during movement. While none of these instruments gives a "total score," they do provide a baseline assessment and with repeated use, they provide information about pain relief after an intervention has been implemented.

Guidelines For Assessing Pain

There are many reasons for dementia-related behaviors. When the behaviors are present, it is imperative that pain or other discomfort is assessed and addressed as an underlying cause. Here are 10 guidelines to proactively assess pain for people with dementia.

1. Do not assume that someone cannot explain or rate his or her pain. Always ask directly if they have pain 'now' as recalling the pain experience may be compromised. If they use the words 'sore', 'ache' or 'hurt' as a way to describe pain, use these words when asking for self-report.

assessing pain

When they can no longer verbally express their pain, but they demonstrate obvious distress, explore further the cause and manifestation of their pain. Always rule out other forms of discomfort, such as a soiled brief or an acute medical condition. Observe when pain occurs, especially during movement, such as ambulation, transfer activities, dressing or bathing.

2. Always take into account the person's medical history. Any new or old diagnoses that suggest pain should be reviewed and re-examined. This could

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include former back injuries, a history of arthritis, post-herpetic neuralgia, or recurrence of cancer, to name

a few. A person's medical history and previous diagnoses that are painful should be reviewed in light of current complaints and caregivers' observations.

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3. Perform a thorough physical examination including palpation, auscultation, percussion, and inspection. Attempt to correlate physical assessment findings with the person's past and current medical history. Note whether the person displays nonverbal cues that suggest pain such as withdrawal, grimacing, moaning, silence, and/or rigidity.
 4. Examine the complete spectrum of factors that suggest or magnify pain. This includes a person who becomes withdrawn, is less interested in his or her food, or when the sleep-wake cycle is disturbed. While these indicators may suggest depression, delirium, or other co-morbid conditions, it is not uncommon to see a functional decline with the onset or continuation of pain.
 5. Complete a comprehensive pain assessment. Attempt to ascertain the cause of pain including the location, intensity, character or quality, pattern, and what makes the pain better or worse. Also review past and current records to determine a person's analgesic history including the medication name(s), doses, efficacy, and side-effects.

assessing pain

6. When using a standardized approach to assessing pain, use the assessment tools under the same conditions each time. For self-report, possible choices include the FACES Pain Scale–Revised (FPS-R), the Iowa Pain Thermometer (IPT), the Verbal Descriptor Scale (VDS), or the 0-10 Numeric Rating Scale (NRS). Once a pain intensity scale is chosen, use the same one each time when assessing pain.
7. When the person can no longer report pain, use a valid and reliable pain behavioral assessment tool, such as the PAINAD, PACSLAC or CNPI. Always ask if they have pain in addition to completing the pain behavior assessment tool.
8. Rely on the person’s professional or family caregivers who know the person best to determine deviation of behaviors from baseline. A knowledgeable informant may know if the dementia-related behaviors are typical of the older person. Look closely for pain if there’s a new behavior or a change in an old one.

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9. When in doubt, assume pain is present or “APP” and move forward with a pain treatment plan.
 10. Document and communicate the findings to all team members and institute a plan to address the behaviors as a manifestation of pain. Based on the assessment and available information, determine the goals of care that will support function, quality of life, and comfort.

If pain is not assessed and addressed, people with dementia may become increasingly frustrated. Their lack of insight, increasing confusion, impaired memory, and inability to communicate can spawn new or escalate existing dementia-related behaviors. Thus, comfort must be at the center of dementia care when pain is continually assessed and addressed.

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addressing pain

After determining that a person with dementia has pain, set short-term and long-term goals and construct a care plan to address it. Continue to assess the pain, evaluate the plan of care, and modify if pain is not relieved. Use these guidelines when treating persons with dementia who have chronic, persistent pain.

Guidelines for Addressing Pain

1. Intervene if pain is suspected. Collaborate with the medical provider to initiate a trial use of a pain medication. This is called a serial trial intervention.
2. When considering a pain medication, review laboratory findings and a person's medical history to determine what medications should be avoided or reduced if a person has hepatic, cardiovascular, or renal disease.

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3. Treat the person with medications that will decrease the pain; noninvasive routes are preferred. For nociceptive mild pain, consider the use of acetaminophen in the dose appropriate for older adults. For persons with moderate pain, consider a pain medication such as an opioid or combination low-dose acetaminophen with an opioid. If acute or severe pain is suspected, urgent medical attention and more aggressive medication management are required. In most cases, NSAIDS are avoided in older adults due to the risk of adverse events.
 4. Start low and go slow when initiating new pain medications or titrating or changing doses using evidence-based practice standards and guidelines. Continuously evaluate side-effects and the overall response to treatment and efficacy.
 5. Consider around-the-clock dosing for a person who has continuous or daily pain. Intermittent pain requires medication before the event triggers a pain episode.

addressing pain

Sustained-release medications are helpful for persons who are cognitively impaired with continuous pain and unable to request pain medications as needed. If sustained-release medications are used, ensure that an immediate release pain medication is available for breakthrough pain.

6. When switching or rotating to other administration routes or pain medications, use equianalgesic dosing, following recommended guidelines and calculations from equianalgesic tables.
7. Consider the use of adjuvant medications or co-analgesics that are helpful for persons with neuropathic pain.
8. Antipsychotics do not treat pain. Often the person with dementia will respond to pain through self-protective behaviors, calling out, or resisting care, to name a few. Look closely for pain first before resorting to other classes of medication.

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9. Always incorporate non-pharmacologic strategies, such as massage, heat, cold, and repositioning, in the plan of care.
 10. Evaluate the results of the serial trial. Receive regular input from all caregiving staff to determine if the treatment plan is providing overall comfort and pain control and if the behaviors or self-report suggest that relief is being obtained. If needed, modify the plan of care or continue if the plan is working. Continue to reassess and document findings and share the treatment plan with all staff and family involved in the person's plan of care.

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adopt a proactive approach to pain

Pain is now considered the 5th vital sign, yet it is often overlooked in the person with dementia. Caregivers or family members may not be certain if the person is in pain, thus delaying appropriate intervention strategies. Often, dementia-related behaviors emerge due to the lack of assessment and treatment of painful conditions. While self-report is always considered first, people in the advanced or terminal stage of dementia may need to be assessed using pain behavioral assessment tools.

Knowing the person is essential in successful pain management. This means that the professional caregiver or family member who knows a person's past routines and medical history should help in determining if the pain or discomfort is new or more severe. Caregivers must execute constant vigilance in monitoring for pain in a person with dementia and provide comfort measures by implementing the most appropriate and effective course of action to relieve pain that includes medication and non-pharmacologic methods.

Each person with dementia deserves a pain evaluation and subsequent treatment and all care needs to be individualized. If there is any indication that a person has pain, it is important to assume pain is present. When working in any healthcare setting, such as hospice, it is incumbent upon each caregiver to adopt the principle that pain is everyone's responsibility and to work collaboratively to meet the person's comfort needs. Interdisciplinary team work is key to maximizing comfort for people with dementia.

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References:

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See the following for more information:

- City of Hope Pain Resource Center. "A State of the Art Review for Assessment of Pain in Nonverbal Older Adults." <http://prc.coh.org/pain-noa.htm>
- GeriatricPain.org at www.geriatricpain.org



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