

Recognizing Pain in People with Dementia

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Objectives:

- By the end of this program the participant will be able to:
- Summarize how dementia impacts pain perception and expression
 - Identify tools that can be used to assess and document pain in people with dementia
 - Utilize professional guidelines for treating pain with nonpharmacological approaches and medication management.

CMS Quality Measures for LTC

Both long term and short stay measures exist for pain

- Percentage who report moderate to severe pain
- The RAI User's Manual instructs the assessor to attempt the patient interviews for pain on all residents who are at least sometimes understood.

Percent of Residents Who Self-Report Moderate to Severe Pain

Residents with a selected target assessment with either/or of these two conditions:

- Report of daily pain with at least 1 episode of moderate/severe pain
- Report of very severe/horrible pain of any frequency

Exclusions

- No pain reported
- One or more items were not completed

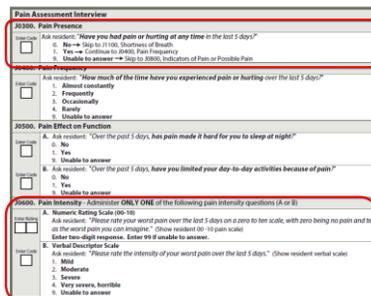
Moderate to Severe Pain

Pain is subjective – it is whatever the person says it is and exists whenever he/she says it does*

Pain can cause suffering associated with:

- Inactivity, social withdrawal, depression
- Functional decline, interference with rehab

Most will need regularly dosed pain meds, and some will require additional PRN pain meds for breakthrough pain.



Pain Assessment Interview

25300. Pain Presence:
 Ask resident: "Have you had pain or hurting at any time in the last 5 days?"
 0. No → Skip to 1130, Assessment of Health
 1. Yes → Continue to 26400, Pain Frequency
 2. Unable to answer → Skip to 26500, Indicators of Pain or Possible Pain

26400. Pain Frequency:
 Ask resident: "How much of the time have you experienced pain or hurting over the last 5 days?"
 1. Almost constantly
 2. Frequently
 3. Occasionally
 4. Rarely
 5. Unable to answer

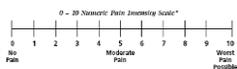
26500. Pain Effect on Function:
 A. Ask resident: "Over the past 5 days, has pain made it hard for you to sleep at night?"
 0. No
 1. Yes
 2. Unable to answer
 B. Ask resident: "Over the past 5 days, have you limited your day-to-day activities because of pain?"
 0. No
 1. Yes
 2. Unable to answer

26600. Pain Intensity - Administrator ONLY ONE of the following pain intensity questions (A or B):
 A. Numeric Rating Scale (00-10):
 Ask resident: "Please rate your worst pain over the last 5 days on a zero to ten scale, with zero being no pain at all and ten the worst pain you can imagine." (Show resident 00-10 pain scale) Enter non-digit responses. Enter 99 if unable to answer.
 B. Verbal Descriptor Scale:
 Ask resident: "Please rate the intensity of your worst pain over the last 5 days." (Show resident verbal scale)
 0. Mild
 1. Moderate
 2. Severe
 3. Very severe, horrible
 4. Unable to answer

MDS Pain Assessment

Assessing Pain

Gold standard for cognitively intact adults
 • Numeric Rating Scale



https://www.atrainceu.com/course-module-short-view/2270158-118_oregon-pain-module-07



https://commons.wikimedia.org/wiki/File:Amantia_House_Care_Home_York.jpg

Assisted Living Facilities

Regulations in 2800.4 Definitions
 Specialist Cognitive Support Services
 • Pain management and person-centered care



What is pain?

Merriam-Webster defined pain as localized physical suffering associated with a noxious stimulus. Also acute mental or emotional distress.

Pain is subjective- exists entirely within that persons lived experience

Cultural- we know that there are cultural factors that impact pain expression and acceptance

Pain- Components

Sensory- Nociceptive	Sensory- Neuropathic	Psychological (Hansen, 2005)
<ul style="list-style-type: none"> Caused by activity in neural pathways in response to potentially tissue-damaging stimuli Post-op pain DJD Cuts/Bruises 	<ul style="list-style-type: none"> Initiated from a primary lesion or dysfunction in the nervous system Stroke Neuropathy from DM CRPS 	<ul style="list-style-type: none"> Limbic system translates sensory signals into "feeling" Attention Anxiety Memory/Learned pain Coping

Pain- Components

Sensory- Nociceptive	Sensory- Neuropathic
<ul style="list-style-type: none"> Localized Aching Annoying Throbbing 	<ul style="list-style-type: none"> Burning Electric Tingling Shooting/Stabbing

Pain in Cognitively Intact Older Adults

Considered to be under-recognized and underreported in older adults (BGS, 2007)

Over 50% of older adults report pain (BGS, 2007)
 As many as 83% of those in SNF report at least one current pain problem

Healthcare professionals consistently tend to underestimate pain compared to patients. (Seers, 2018)



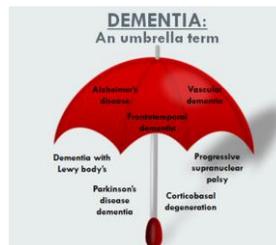
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Pain for People With Dementia

Systematic Review of pain in people with dementia, estimates 46-56% of people with dementia have pain (van Kooten, 2016)

Widely accepted that people with dementia are under-recognized and under-treated for pain.

- Systematic Review of people with hip and pelvic fracture found 50% less use of medication for people with dementia than cognitively intact older adults (Moschinski, 2017)
- Systematic Review found people with dementia had worse oral health but were recognized as having oral pain less than cognitively intact older adults (Dehmel, 2017)
 - Cohen-Mansfield (2005) found 60% of people with dementia were identified as likely having oral pain by dentist assessment
- Systematic Review found nursing home residents with dementia are given less pain medication despite similar number of conditions. (Tan, 2015)



<http://neurowiki2014.wikidot.com/group.dementia>

Dementia Types

Cluster of symptoms that may include...

- Decline in memory
- Loss of thinking skills
- Disorientation to oneself, time, place
- Impaired judgment
- Impaired problem solving
- severe enough to limit their everyday activities

BUT:

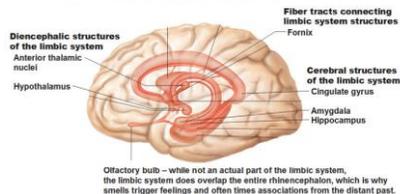
- Different types represent different brain changes
- All people are unique

Pain Experience

Dementia Type	Characteristics Include Impairment of	Pain (van Kooten, 2017)
Alzheimer's Disease	Executive function, memory, judgment and navigation	45.8%
Vascular	Specific to area of brain impacted	56.2%
Mixed	Alzheimer's and Vascular combined	53.9%
Lewy Body	Visual hallucination, disturbed sleep, gait changes	Unable to calculate
Frontotemporal	Personality changes, behavioral and risk taking	Unable to calculate

Limbic System

The Limbic System (the basics)



Limbic system is impacted in Alzheimer's Disease
Beyond storing new memories there is an associated change in mood regulation.

<http://antrank.org/the-limbic-system-and-the-reticular-formation/>

Pain/Alzheimer's Dementia (Achtreberg, 2013)

Believed that behavioral responses to pain are more significant in early/moderate dementia

- Hyperalgesia- response to chronic pain with increased sensitivity to painful stimuli
- Allodynia- painful response to nonpainful stimuli



Pain impact on behavioral expressions

Systematic Review and Meta-analysis (van Dalen-Kok, 2015) found some association between pain and:

- Agitation/aggression
- Anxiety
- Hallucinations and delusions
- Disruptive behavior
- Wandering
- Challenges with personal care



Pain relationship with depression



Norway study found correlation between pain levels and depression in people with dementia. Reducing pain was associated with less depression. (Erdal, 2017)

Systematic Review and Meta-analysis found cumulative odds ratio for pain and depression to be 1.84 (95% CI 1.23-2.80) (van Dalen-Kok, 2015)

Pain relationship with depression

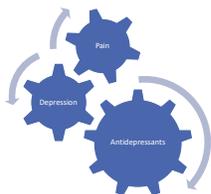


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Question: how many people are being treated for depression when they are really having pain?

Are we treating the right problem?



Is the pain causing depression and thus we see signs like weight loss or disengagement and treating it with antidepressants?

Pain impact on sleep



RCT in Norway of people with dementia use actigraphy to compare pain management vs control group and found that people treated for pain had improved (Blytt, 2017):

- Sleep efficiency
- Sleep onset latency
- Early morning awakening

Pain impact on sleep



RCT in Norway of people with dementia use actigraphy to compare pain management vs control group and found that people treated for pain had improved (Blytt, 2017):

- Sleep efficiency
- Sleep onset latency
- Early morning awakening

Question: How many people would sleep better if we adequately treated their pain?

Signs of Poor Sleep

- Difficulty concentrating*
- Sleep changes*
- Anxiety*
- Suspiciousness*
- Hallucinations*
- Disorganized speech*
- Depression*
- Anxiety*
- Difficulty functioning*



http://news.ndbc.com/news/health/news/poor-sleep-in-old-age-linked-to-hardened-brain-arteries_1445589.html

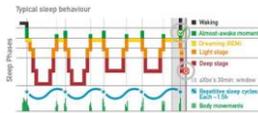
Signs of Poor Sleep

- Difficulty concentrating*
- Sleep changes*
- Anxiety*
- Suspiciousness*
- Hallucinations*
- Disorganized speech*
- Depression*
- Anxiety*
- Difficulty functioning*

*Is also a sign of psychosis

- Are your residents experiencing "dementia with psychosis" or just side effect of sleep fragmentation?
- Are we causing it?

Sleep Cycles



Full sleep cycle takes ~2 hours. 4-5 cycles/night

Stage 3 (Deep)

- physical healing

REM

- psychological healing
- longer phase in later cycles

Interruption = start over

<https://upliftconnect.com/sleep-cycle/>

Are we treating the right problem?



Is pain disrupting their sleep and causing behavioral expressions?

Pain in Dementia

Facial Expressions	Interpersonal Interactions
<ul style="list-style-type: none"> • Grimacing, Frightened, Sad • Rapid Blinking, Tightened eyes 	<ul style="list-style-type: none"> • Resisting care, aggressive, combative • Socially inappropriate, withdrawn
Verbalizations	Activity Patterns
<ul style="list-style-type: none"> • Moaning, groaning, chanting • Calling out, asking for help 	<ul style="list-style-type: none"> • Appetite changes, refusing food • Wandering, rest patterns
Body Movements	Mental Status Changes
<ul style="list-style-type: none"> • Rigid, tense body postures • Pacing, fidgeting, rocking 	<ul style="list-style-type: none"> • Crying, irritability, distress • Increased confusion



My Experience

100s of chart reviews

Consistently see documentation of nursing assessment "are you in pain" to people with dementia

Response- no

Do you believe those are accurate responses?

Pain Assessment in Advanced Dementia (PAINAD) Scale

Items*	0	1	2	Score
Breathing independent of vocalization	Normal	Occasional labored breathing Short period of hyperventilation.	Notably labored breathing. Long period of hyperventilation. Cherry-red skin respirations.	
Negative vocalization	None	Occasional moan or groan Low-level speech with a negative or disapproving quality.	Repetitive troubled calling out. Loud moaning or groaning Crying.	
Facial expression	Smiling or impassive	Sad, Frightened, Frown.	Facial grimaces	
Body language	Relaxed	Tense, Depressed jacking. Fidgeting.	Rigid. Arms clenched. Knees pulled up. Pulling or pushing away. Shaking out.	
Comprehibility	No need to converse	Distacted or measured by voice or touch.	Unable to converse, distract or measure.	
				Total**

* Five item observational tool (see the description of each item below).
** Total scores range from 0 to 10 (based on a scale of 0 to 2 for five items), with a higher score indicating more severe pain (0-10 pain to the "worst imaginable pain").

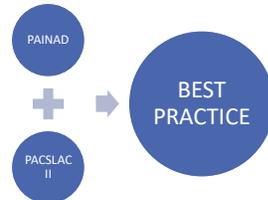
Pain Assessment In Advanced Dementia (PAINAD)
(Horgas, 2008)

Pain Assessment Checklist for Seniors with Limited Ability to Communicate-II (PACSLAC-II)

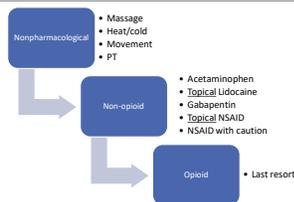
- | | |
|-----------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------|
| Facial Expressions | Body Movements |
| 1. Grimacing | 17. Flinching or pulling away |
| 2. Tighter face | 18. Thrashing |
| 3. Pain expression | 19. Refusing to move |
| 4. Increased eye movement | 20. Moving slow |
| 5. Wincing | 21. Guarding sore area |
| 6. Clenching mouth | 22. Rubbing or holding sore area |
| 7. Clenching forehead | 23. Limping |
| 8. Lowered eyebrows or frowning | 24. Clenched fist |
| 9. Raised cheeks, narrowing of the eyes or squinting | 25. Going into fetal position |
| 10. Wrinkled nose and raised upper lip | 26. Stiff or rigid |
| 11. Eyes closing | 27. Shaking or trembling |
| Verbalizations and Vocalizations | Changes in Interpersonal Interactions |
| 12. Crying | 28. Not wanting to be touched |
| 13. A specific sound for pain (e.g., "ow," "ouch") | 29. Not allowing people near |
| 14. Moaning and groaning | Changes in Activity Patterns or Routines |
| 15. Grunting | 30. Decreased activity |
| 16. Gasp or breathing loudly | |
| Mental Status Changes | |
| 31. Are there mental status changes that are due to pain and are not explained by another condition (e.g., delirium due to medication, etc.)? | |

PACSLAC II
(Hadjistravropoulos, 2010)

Nursing Study for Pain in Dementia (Herr, 2010)



Pain Treatment (AGS, 2009)



Complete pain assessments, medical exam and look for dx that can be contributing to pain (OA, post fall)
Start low, go slow
Assess effectiveness with pain tools looking at pain expressions/changes
Monitor for side-effects

Literature Is Limited But Promising For People With Dementia

Manfredi studies 25 people with agitation with opioid analgesic- 13/25 showed improvement of agitation in 4 weeks. (Manfredi, 2003)

Study of 352 people with dementia in nursing homes (Husebo, 2014)

- Stepwise protocol on pain assessment and behavior
- Reduced pain
- Improved ADL function

Study of 195 residents in 6 Dementia Care Units- Better nonpharmacological management and pain medication use in facilities where nurses received pain education and pain protocol for assessment versus facilities with pain education alone. (Chen, 2016)

Survey Pathways

<https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/GuidanceforLawsAndRegulations/Nursing-Homes.html>

Downloads

- [LTC Survey FAQs - Updated 02/06/2018 \[PDF, 701KB\]](#)
- [Appendix PP State Operations Manual \(Revised 11/22/2017\) \[PDF, 3MB\]](#)
- [List of Revised FTags \[Effective November 28, 2017\] \[PDF, 152KB\]](#)
- [S&C Memo: Revision to State Operations Manual Appendix PP for Phase 2 \(includes Training Information and Related Issues\) \[PDF, 121KB\]](#)
- [F-Tag Crosswalk \[XLSX, 495KB\]](#)
- [Training for Phase 1 Implementation of New Nursing Home Regulations \[PDF, 108KB\]](#)
- [New Long-term Care Survey Process - Slide Deck and Speaker Notes \[PPTX, 8MB\]](#)
- [Entrance Conference Form Beneficiary Notice Worksheet \(Updated 12/06/2017\) \[ZIP, 164KB\]](#)
- [LTC Survey Pathways - Updated 12/13/2017 \[ZIP, 2MB\]](#)
- [LTCSP Procedure Guide \[PDF, 1MB\]](#)

DEPARTMENT OF HEALTH AND HUMAN SERVICES
Centers for Medicare & Medicaid Services

Pain Recognition and Management Critical Element Pathway

Use this pathway for a resident who has pain symptoms or can reasonably be expected to experience pain (i.e., during therapy) to determine whether the facility has provided and the resident has received care and services to address and manage the resident's pain in order to support his or her highest practicable level of physical, mental, and psychosocial well-being, in accordance with the comprehensive assessment and care plan, current professional standards of practice, and the resident's goals and preferences.

Review the Following in Advance to Guide Observations and Interviews:

- Review the most recent comprehensive and most recent quarterly (or the most recent MEDS/CAAs for Sections C – Cognitive Function, C1 – Functional Status, F – Health Conditions, K – Transferring/Nontransferring Status, L – Oral Dental Status, N – Medications, and O – Special Treatment/Pre-Plan) analysis (C1004) or dossier (C1006).
- Physicians' orders (e.g., pain management interventions, PRN or routine pain medications, type of pain medications (opioid, non-steroidal anti-inflammatory), and route (intravenous, oral, topical)).
- Patient diagnoses.
- Care plan (e.g., measurable goals for pain management, current pain management interventions, pharmacological and non-pharmacological interventions, interventions, and approaches for measuring the status of the resident's pain, including the effectiveness of the interventions).

Observations:

- Does the resident exhibit signs or symptoms of pain, verbalize the presence of pain, or request interventions for pain? Does the pain appear to affect the resident's functional ability to participate in routine care or activities? If so, describe.
- For non-verbal or cognitively impaired residents who cannot verbalize their pain, how does staff assess for the presence of pain and effectiveness of interventions for pain?
- If there is evidence of pain, how does staff assess the situation, identify, and implement interventions to try to prevent or address the pain, and evaluate the status of the resident's pain after?
- If care and services are being provided that reasonably could be expected to cause pain, such as therapy, how does staff identify and address these issues, if the extent possible?
- How does staff respond if there is a report from the resident, family, or staff that the resident is experiencing pain?
- If there are pain management interventions for the resident, how does staff ensure they are implemented as ordered or care planning?
- What potential adverse consequences associated with treatment for pain (e.g., medications) does the resident have?
- How does staff respond if the interventions implemented did not reduce the pain consistent with the goals for pain management?
- How long does the resident wait to receive PRN pain medication after requesting it?

Form C-50 (04/16) (3/2017) Page 1

Pain Recognition and Management Critical Element Pathway

Resident, Resident Representative, or Family Interview:

- How does the facility involve you in the development of the care plan and defining the approaches and goals?
- How does the facility ensure the interventions reflect your the resident's choices and preferences?
- How are you involved in developing and revising pain management strategies and revisions to the care plan if the interventions did not work?
- Describe the characteristics of the pain, including the intensity, pain history, location, duration, frequency, timing, and duration of pain.

Nursing Aide Interview:

- Does the resident experience any pain during assistance with activities of daily living? If so, what do you do?
- Does the resident have any complaints, or exhibit any signs or symptoms of pain?
- To whom do you report the resident's complaints and signs or symptoms?
- Do you know what interventions are on the resident's care plan for pain discomfort management (e.g., allowing a period of time for a pain medication to take effect before handling or dressing)? Do you implement any interventions to relieve the resident's pain?

Nurse, DCN, Hospice Nurse, Attending Practitioner, Pharmacist, Medical Director Interview:

- How do you monitor the effectiveness of pain management interventions?
- For residents with significant or difficult to manage pain (How are the interventions developed? What was the basis for selecting them?)
- For residents receiving pain medication (including PRN and scheduled medications) how, when, and by whom are the results of medications evaluated (dose, frequency of PRN use, schedule of intervention)?
- How do you guide and oversee the selection of pain management interventions?

What factors may precipitate or alleviate the pain?

How have you typically expressed pain and responded to various interventions in the past?

Who have you told about the pain/discomfort? How has staff responded? How long does it take for you to receive pain medication when you have asked for it?

What treatment options (pharmacological and non-pharmacological) were discussed and attempted?

Have you refused any interventions (i.e., certain types of medications or non-pharmacological ways to reduce pain without medication)? If so, was there a discussion of the potential impact on you, and what alternative or other approach you've offered?

How do you monitor for the emergence or recurrence of adverse events related to opioid medications or the consequences of analgesia?

For residents with significant or difficult to manage pain (How are the interventions developed? What was the basis for selecting them?)

How do you guide and oversee the selection of pain management interventions?

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Pain Recognition and Management Critical Element Pathway

Resident, Resident Representative, or Family Interview:

- How often is the resident's pain regimen reviewed, and what trigger is a review?
- What is done if pain persists or recurs despite treatment? What is the basis for decisions to maintain or modify approaches?
- How does staff communicate with the provider about the resident's pain status, current measures to manage pain, and the possible need to modify the current pain management interventions?

Nursing Aide Interview:

- Are you aware of any situations where the resident had pain, but interventions were not utilized? If so, when and with whom was this discussed?
- For a resident who is receiving care under a hospice benefit, how does the hospice and the facility coordinate their approaches and communications about the resident's needs and report the outcomes (both effectiveness and adverse consequences)?
- Was there a "significant change" in the resident's condition (i.e., will not involve need without intervention by staff or the implementing standard disease-related clinical parameters, suggest more than one unit of health requires ED review or review of the care plan)? If so, were a significant change comprehensive assessment conducted within 1 day?
- If the resident has elected a hospice benefit, is there evidence that the resident's care is coordinated between the nursing home and the hospice? This includes aspects of pain management, such as:
 - Choice of palliative interventions.
 - Responsibility for assessing pain and providing interventions.
 - Responsibility for monitoring symptoms and adverse consequences of interventions and for modifying interventions as needed.

Review Review:

- Review interventions such as MAOs, controlled medication, research, cost sheets, multidisciplinary progress notes, and any specific non-pharmacological pain that may have been completed. Determine whether the information accurately and comprehensively reflects the resident's condition, and extent to which pain is managed.
- What indicators and characteristics of the resident's pain, including cause and contributing factors related to pain, have been identified, and addressed in the care plan?
- Did the facility identify the resident's history of pain and related interventions? If not, describe.
- What was the resident's response to interventions, including efficacy and adverse consequences and any modification of interventions or findings?
- Do pain management interventions have a documented rationale and is it consistent with current standards of practice?
- What changes to significant medication-related adverse consequences, such as a change in mental status, delirium, falling, constipation, incontinence, or drowsiness, has the resident experienced? What do you think about the appropriateness of these adverse consequences?

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Take Home



Questions? Thank You!

For more information please contact me:
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