Under-treatment of Pain

A particular problem for those with advanced dementia because:

- Cognitively impaired nursing home residents are both prescribed and given less analgesic medication than cognitively intact residents.
- Cognitive impairment interferes with the resident’s ability to perceive, recall, describe, and report pain to providers.
- Caregivers may lack tools necessary to detect pain among residents who are unable to verbally describe pain.
- Caregivers may doubt the validity of pain reports in cognitively impaired residents.
- Caregivers may not realize that residents with dementia are just as likely to have pain as other older adults.

Consequences of Untreated Pain

- Worsening of physical, functional, and mental health conditions.
- Increased depression, fatigue, anxiety, and sleep disturbances.
- Worsening of cognitive function.
- Increased risk of malnutrition.
- Decreased socialization and involvement in activities.
- Increased mobility impairment, gait disturbances, and falling.
- Increased risk of behavioral symptoms among those with dementia.

Common Myths about Pain

- If residents don’t complain of pain, they must not have any.
- ‘Nothing can be done’ to relieve pain.
- Pain is a ‘natural consequence’ of growing older.
- Treatment of pain leads to addiction.
- Older people just need to ‘learn to live’ with their pain.

Assessing Pain in Advanced Dementia

- Pain assessment relies on observing the person’s behavior.
- Research suggests that knowing the person is key to identifying pain.
- Residents who cannot clearly communicate their discomfort are at high risk for under-treatment of pain.
- All ‘traditional’ pain assessment scales rely on both verbal and cognitive skills, which make them ineffective in advanced dementia:
  - Responding to ‘simple’ questions like, “Are you having pain?” may not be possible.
  - Being able to ‘point where it hurts’ requires problem-solving skills no longer available.
  - Rating the ‘intensity’ of pain on a scale using numbers or words is beyond the person’s ability.

The Facts . . .

⇒ 45 to 85 percent of residents in long-term care facilities report chronic pain.

⇒ Pain symptoms in advanced dementia may mimic “agitation.”

⇒ Pain is as common in those with dementia as in those who do not have dementia.

⇒ When one cannot communicate pain verbally, he or she will act it out.
Like other feelings, sensations, and needs, pain emerges in **behavior** such as:

- Facial grimacing
- Agitation
- Pulling away if touched
- Changes in mobility or gait
- Withdrawal
- Sleep disturbance
- Tense muscles
- Disruptive vocalization
- Moaning
- Combativeness
- Restless body movements
- Changes in respiration
- Exiting behavior
- Decreased appetite
- Anger
- Rubbing or holding body parts

### Pain Assessment Tools in Advanced Dementia

The following four assessment tools were tested with cognitively impaired elders:

<table>
<thead>
<tr>
<th>1. <strong>Pain Assessment in Advanced Dementia:</strong> Five domains are rated from 0-2 resulting in a 10 point scale. Shown later in the pamphlet, this tool is used extensively in the Veteran's Administration and is found to be a brief, easy to use, and sensitive measure of pain in persons with advanced dementia. <strong>Source:</strong> Warden, V., Hurley, A. C., &amp; Volicer, L. (2003). Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. <em>Journal of the American Medical Directors Association, 4</em>(1); 9-15.</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. <strong>Proxy Pain Questionnaire:</strong> Three questions are answered by a nursing assistant who knows the resident well; shown to be better than MDS in identifying pain. <strong>Source:</strong> Fisher, S. E., Burgio, L. D., Thorn, B. E., Allen-Burge, R. A., Gerstle, J., Roth, D. L., et al. (2002). Pain assessment and management in cognitively impaired nursing home residents: Association of certified nursing assistant pain report, minimum data set pain report, and analgesic medication use. <em>Journal of the American Geriatrics Society, 50</em>(1); 152-156.</td>
</tr>
<tr>
<td>4. <strong>Checklist of Nonverbal Pain Indicators:</strong> Six pain behaviors are rated as present or absent; cannot easily determine if pain increases or decreases due to limited score (0-6). <strong>Source:</strong> Felt, K. S. (2000). The checklist of nonverbal pain indicators (CNPI). <em>Pain Management Nursing, 1</em>(1); 13-21.</td>
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Pain Assessment in Advanced Dementia (PAINAD)

PAINAD has been tested with older adults who have advanced dementia and is able to detect changes in pain,

<table>
<thead>
<tr>
<th>Breathing</th>
<th>0</th>
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<tr>
<td>Normal</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Occasional labored breathing</td>
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<tr>
<td>• Short period of hyperventilation</td>
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<td>Occasional moan/groan</td>
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<td>Low level speech</td>
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<tr>
<td>• With a negative or disapproving quality</td>
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<td>Repeated, troubled calling out</td>
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<tr>
<td>• Loud moaning or groaning</td>
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<tr>
<td>• Crying</td>
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<table>
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<tr>
<th>Negative Vocalization</th>
<th>0</th>
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<tbody>
<tr>
<td>None</td>
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<tr>
<td>• Occasional moan/groan</td>
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<td>Smiling or Inexpressive</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Sad</td>
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<tr>
<td>• Frightened</td>
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<tr>
<td>• Frown</td>
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<tr>
<td>Facial Grimacing</td>
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<table>
<thead>
<tr>
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<tbody>
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<td>Relaxed</td>
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<td></td>
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<tr>
<td>• Tense</td>
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<tr>
<td>• Distressed</td>
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<td></td>
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</tr>
<tr>
<td>• Pacing</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>• Fidgeting</td>
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<td></td>
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<tr>
<td>Rigid</td>
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<td></td>
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<tr>
<td>• Fists clenched</td>
<td></td>
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<tr>
<td>• Knees pulled up</td>
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<tr>
<td>• Pulling/pushing away</td>
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<td></td>
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<tr>
<td>• Striking out</td>
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<table>
<thead>
<tr>
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<th>Score</th>
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<tbody>
<tr>
<td>No need to console</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>• Distracted or reassured by voice or touch</td>
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<tr>
<td>• Unable to console, distract, or reassure</td>
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PAINAD Scoring: 1 - 3 = Mild; 4 - 6 = Moderate; 7 - 10 = Severe

* Some institutions have developed policies in which a PAINAD score of four or greater must be addressed in the nursing care plan.

Breathing
- **Normal**: Effortless, quiet, or rhythmic respirations.
- **Occasional Labored**: Episodic bursts of harsh, difficult, or wearing respirations.
- **Short Period of Hyperventilation**: Intervals of rapid, deep breaths lasting a short period of time.
- **Noisy Labored Breathing**: Negative sounding respirations on inspiration or expiration. May be loud, gurgling, wheezing, and appear strenuous or wearing.
- **Long Period of Hyperventilation**: An excessive rate and depth of respirations lasting a considerable time.
- **Cheyne-Stokes Respirations**: Rhythmic waxing and waning of breathing from very deep to shallow respirations with periods of apnea (cessation of breathing).

Negative Vocalization
- **None**: Speech/vocalization with neutral/pleasant quality.
- **Occasional Moan or Groan**: Moaning is characterized by mournful sounds, wails, laments, or groaning, by louder than usual inarticulate involuntary sounds, often abruptly beginning and ending.
- **Low Level Speech**: Muttering, mumbling, whining, grumbling, or swearing in a low volume with a complaining, sarcastic, or caustic tone.
- **Repeated Troubled Calling Out**: Phrases or words used over and over in a tone that suggests anxiety, uneasiness, or distress.

Facial Expression
- **Smiling or Inexpressive**: Upturned corners of the mouth, brightening of the eyes, a look of pleasure or contentment. Inexpressive refers to neutral, at ease, relaxed, or blank.
- **Sad**: Unhappy, lonesome, sorrowful, or dejected.
- **Frightened**: Look of fear, alarm, or heightened anxiety. Eyes wide open.
- **Frown**: Downward turn of the corners of the mouth; increased facial wrinkling on forehead and around mouth.
- **Facial Grimacing**: Distorted, distressed look. Brow and mouth are more wrinkled. Eyes may be squeezed shut.

Body Language
- **Relaxed**: Calm, restful, mellow appearance.
- **Tense**: Strained, apprehensive, or worried appearance. Jaw may be clenched (exclude any contractures).
- **Distressed Pacing**: Unsettled activity; fearful, worried, or disturbed element present. Rate may be faster/slower.
- **Fidgeting**: Restless movement. Squirming, wriggling, repetitive touching, tugging, or rubbing body parts.
- **Rigid**: Stiffening of the body. Arms and/or legs are tight and inflexible. Trunk may appear straight and unyielding (exclude any contractures).
- **Fists Clenched**: Tightly closed hands that may be opened and closed repeatedly or held tightly shut.
- **Knees Pulled Up**: Flexing legs and drawing knees up toward chest. Overall troubled appearance (exclude contractures).
- **Pulling/Pushing Away**: Resistiveness upon approach or care. Trying to escape by yanking, wrenching, or shoving away.
- **Striking Out**: Hitting, kicking, grabbing, punching, biting, or other form of personal assault.

Consolability
- **No Need to Console**: A sense of well-being. Person appears content.
- **Distracted or Reassured by Voice or Touch**: Disruption of behavior when the person is spoken to or touched. Behavior stops during the period of interaction with no indication that the person is at all distressed.
- **Unable to Console, Distract, or Reassure**: Inability to soothe the person or stop a behavior with words or actions.

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## Pain in Advanced Dementia

<table>
<thead>
<tr>
<th>KEY PRINCIPLES</th>
<th>COMMENTS / RECOMMENDATIONS</th>
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</table>
| Symptoms of pain in dementia may easily emerge as agitation or other behavioral symptoms. | 1. Ask the caregiver who knows the resident best: “Could this behavior be a symptom of pain?”  
2. Assess pain using one or more pain scales that DO NOT rely on the person’s verbal report.  
   - The Proxy Pain Questionnaire (PPQ) asks 3 questions of nurse assistants who know the resident well.  
   - Pain Assessment in Advanced Dementia (PAINAD) rates five factors from 0 to 2 resulting a 10 point scale. |
| Document the behavior carefully, ruling out common causes of pain before resorting to psychotropic medication. | 1. Use the Antecedent-Behavior-Consequence model to document the behavior.  
   - **Antecedents**: What triggers the behavior? Does it occur in relationship to personal cares? Does movement seem to set it off?  
   - **Behavior**: What? When? Where? How long? How intense is the behavior?  
   - **Consequences**: What reactions occur after the behavior occurs? What comfort measures are offered?  
2. Conduct a thorough pain assessment as you consider possible “antecedents.”  
3. What medical diagnoses does the person have that might cause pain?  
   - Degenerative joint disease?  
   - Chronic back pain syndrome?  
   - Osteoporosis?  
   - History of fractures?  
   - Immobility?  
   - Neuropathic conditions?  
   - Restless leg syndrome?  
   - Post-stroke syndrome?  
   - Peripheral vascular disease?  
   - Pressure ulcers?  
4. Does the person have any new injuries or acute illnesses that might contribute to discomfort or pain?  
5. Any signs of injury on physical exam? Any infections (e.g., respiratory, bladder, oral, other)? |
| Treat pain like you would in a person who is able to report pain verbally. | 1. A three-step ladder is recommended: Start with nonopioids ➔ Proceed to opioid therapies ➔ Use adjunctive nonopioid medications to augment opioid medication.  
2. Reassessment of pain using a standardized method is highly recommended.  
   - Documentation is key to using different and more potent medications.  
   - Do not rely on informal verbal reports alone (e.g., “Is the pain better?”).  
   - Use of different/more potent medication relies on nursing documentation of the person’s behavioral symptoms.  
3. The minimum data set (MDS) pain assessment tends to rely on verbal report and is NOT as effective as other measures, such as the Proxy Pain Questionnaire, in advanced dementia. |