

# LONG TERM CARE COMMUNITY COALITION

*Advancing Quality, Dignity & Justice*

## PAIN MANAGEMENT FOR INDIVIDUALS LIVING WITH DEMENTIA FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

Pain is a serious concern for older adults—especially those living with dementia. Dementia can affect a person’s ability to explain or describe their pain. For example, a person living with dementia may not be able to say *where* it hurts or *why* they’re uncomfortable. Instead, they may communicate their pain in ways that are hard for caregivers and family members to understand. This often results in underdiagnosed and undertreated pain, with avoidable health and quality-of-life consequences.

This fact sheet offers insights and practical tips for identifying, assessing, and addressing pain for individuals living with dementia. For more information and resources, please visit our website, <https://nursinghome411.org/dementia-care-in-the-community>.

### Why Pain Often Goes Unrecognized in Dementia

- **Communication Barriers:** Advanced dementia affects memory, language, and judgment, making self-reporting of pain difficult or impossible.
- **Pain Shows Up in Other Ways:** People living with dementia may express pain through non-verbal signs, such as restlessness, aggression, resistance to care, refusing to eat, or becoming withdrawn, rather than saying they’re in pain.
- **Limited Staff or Caregiver Training:** Care staff or family caregivers may not know how to recognize these signs or may mistake them for “acting out” rather than a medical or environmental issue.

### What Can Happen When Pain Goes Untreated

Comfort is a basic human need and pain, when left unaddressed, robs individuals of comfort, dignity, and quality of life. For people living with dementia, untreated pain can have especially serious consequences. Its impacts can include:

- **Emotional Distress:** Persistent pain can lead to sadness, anxiety, irritability, and disrupted sleep, all of which may be misinterpreted as “behavioral problems.”
- **Physical Decline:** Pain often limits mobility, leading to muscle weakness, reduced activity, and a loss of independence.
- **Social Withdrawal:** Individuals in pain may stop participating in activities they once enjoyed and withdraw from social interaction.

Recognizing and treating pain—especially in those who may struggle to express it verbally—is essential to compassionate, person-centered dementia care.

### Best Practices for Managing Pain in Dementia

The best approach to pain management starts with **careful observation** and **non-drug strategies**, followed by medications only when necessary.

#### Remember:

1. All “behaviors” are a form of communication.
2. People with dementia have **not** lost their ability to feel pain and suffer if it is not treated.

Following is an overview of current standards of practice for assessing and addressing pain in individuals with dementia.

### **1. Use a Specialized Pain Assessment Tool**

Utilize validated pain scales designed for people with dementia, like the PAINAD scale, which considers behavioral cues like facial expressions, vocalizations, and body movements alongside verbal reports (if possible) to accurately assess pain level. Visit <https://nursinghome411.org/dementia-care-in-the-community> for the PAINAD scale and other useful resources.

### **2. Try Non-Pharmacological Approaches First**

- **Identify and address underlying clinical issues:** A thorough examination by a healthcare professional can help determine if a medical condition is causing the pain. Common sources include back pain, arthritis, joint stiffness, constipation, or more serious conditions such as cancer or heart disease.
- **Identify and address environmental causes:**
  - Identify if there are certain places, times of day, noises, or activities that trigger upset.
  - Adjust lighting, noise levels, and room temperature to create a calming environment.
- **Physical therapy or massage:** Gentle exercises, stretching, and massage can address musculoskeletal pain.
- **Cognitive stimulation activities:** Engaging in familiar activities to distract from pain.
- **Music therapy:** Soothing music can be calming and music that the individual has enjoyed in the past can be pleasing and distracting from discomfort.
- **Behavioral management techniques:** Positive reinforcement, redirection, and reassurance to address pain-related behaviors.

### **3. Medication Options (When pain is severe and not alleviated by non-pharmacological interventions.)**

- **Acetaminophen:** Often the first and safest option.
- **Nonsteroidal anti-inflammatory drugs (NSAIDs):** Use with caution due to potential side effects like stomach irritation, especially in older adults
- **Opioids:** Should be used only if pain is severe and other treatments aren't working. Monitor closely for side effects like confusion or drowsiness.
- **✗ Note:** Antipsychotic drugs are NOT appropriate treatments for pain or for typical "behavioral symptoms" of dementia (like restlessness, agitation, or shouting).

### **4. Important Medication Safety Tips**

- **Start low, go slow:** Begin with the lowest effective dose and increase only if needed.
- **Regular monitoring:** Watch for side effects and monitor if the medication is helping.
- **Team-based planning:** Involve different care professionals – doctors, nurses, therapists, and family – to develop and adjust the care plan.

The goal, whenever possible, should be to reduce (and, if possible, eliminate) the use of medications, especially opioids, antipsychotics, and other potentially dangerous drugs.

**Pain doesn't have to be a part of aging or dementia. With the right tools, training, and attention, caregivers can help improve comfort, reduce suffering, and support a better quality of life for the individual.**