

## Organizing to Treat Pain

**W**hat we know: At least half of the people living in nursing homes have some level of cognitive impairment, and for people with cognitive impairment, pain tends to be underrecognized, undertreated, and poorly managed.

**Pain is not normal, but it is common:** There are many potential sources of pain for aging bodies, and people with dementia are as subject to these as anyone else: arthritis, past injuries, previous surgeries, spinal stenosis, osteoporosis, heart disease, irritable bowel, constipation, gout, diabetic neuropathy, hemorrhoids, bunions, boney pressure points, poor circulation, ill-fitting dentures, acid reflux, fragile skin, depression.

### What do we know about Pain and Dementia?

- Pain negatively affects cognitive function.
- There is no evidence that dementia results in the loss of the ability to feel pain.
- For people with advanced dementia (which can last years), pain most often presents as behavioral disturbance, such as withdrawal, apathy, sleep disturbance, screaming, moaning, resistance to care, or agitation. **Pain is the most**

**common cause of behavioral symptoms in dementia.**

**What to do:** Recognizing the need to better address the pain management needs of people with dementia, the Beatitudes Campus in Phoenix, Arizona organized a Campaign to Address Pain. Under the auspices of a Quality Improvement grant from the Arizona Department of Health Services, and using quality improvement principles and processes, they reviewed and upgraded their organizational pain management practices. Their goal was to effectively address individual pain using a systemic approach, and to fully adopt changes consistent with a person-directed philosophy and comfort care approach. They were able to very effectively integrate this effort with their QAPI program.

### Getting Started with Pain Management for People with Dementia

First, decide whether to start with a pilot floor or neighborhood, or with the organization as a whole. After that, put together a team which is representative of different disciplines and different shifts, as well as residents and family members. Engagement of all staff is an essential element for



implementing and sustaining effective pain management, including also housekeeping, dining services, therapies, pharmacy consultants, and hospice staff.

The next step is education, which should address (1) how to recognize and assess pain, (2) methods of documenting pain, (3) use of both pharmacological and non-pharmacological strategies, (4) how to problem-solve an individual's discomfort, (5) how to provide comfort care that is person-directed, (6) effective processes for monitoring improvements. Education then sets the stage for a review of policies, procedures, practices and tools currently in use.

A reviewing of current pain policies and practices should also include an

# RESOURCES

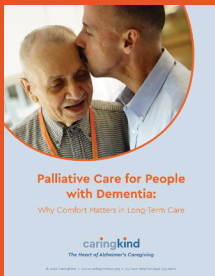
During the fall of 2020 CaringKind presented a four-part webinar series on *Pain and Dementia: Approaches that Work*.

This issue of *ADvancing Care* shares highlights from *Session 2: Organizing to Treat Pain*, focussing on the presentation by Karen Mitchell, RN,BSN, Nurse Educator, Comfort Matters®, Beatitudes Campus, Phoenix, Arizona.

Recordings of all four sessions can be found on the CaringKind website.

Comfort Matters® is a dementia care education and research program dedicated to improving the quality of care and life for people with dementia  
[www.comfortmatters.org](http://www.comfortmatters.org)

*Palliative Care for People With Dementia* is a publication Of CaringKind, and can be found on our website:  
[caringkindnyc.org/publications/#pcguide](http://caringkindnyc.org/publications/#pcguide)



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assessment of the tools used to identify and monitor pain for people with dementia. Areas that should be addressed include:

- In addition to self-report tools (pain intensity scales, ratings), there needs to be a behavior-based assessment tool (such as the PAINAD).
- Frequency of assessments for pain should occur at admission, quarterly, annually, every time a new intervention is tried, when there are new signs of pain or increased pain, when there is rejection of care, or other “behavioral expressions”.
- There needs to be a tool to help staff identify possible causes when someone is exhibiting signs of distress. A simple example of this is the “Roadmap,” which asks the following questions: (1) What are the actions that demonstrate the person is uncomfortable? (2) What is the person trying to tell us through these actions? (3) Possible Remedies? This tool should be revisited as often as needed until the distress has been successfully addressed.
- Gathering information about the comforts, preferences and past history of residents can help enormously. In addition to the MDS, there are tools such as “What Caregivers Need to Know About Me,” which asks questions such as past occupation, places lived, favorite music, favorite food and drink, and preferred forms of comforting touch.
- Typical questions that need to be part of assessing possible reasons for discomfort include: diagnoses, old injuries, new infection, medications, constipation. Other possible reasons for physical pain are hunger, thirst, room temperature, fatigue, soiled brief, tight fitting clothes, uncomfortable position, or loud TV.
- Non-pharmacological alternatives should be explored, such as hand massage, listening to favorite music, exercise, and aroma therapy, alone or in conjunction with medication.
- If pain medication is indicated, round-the-clock medication works best (for people with dementia, PRN usually means Patient Receives None). If there are interactions known to cause distress, such as a dressing change or am care, providing an analgesic a half hour ahead of time can also be helpful. **Anti-psychotics do not treat pain.**

Plan to have the team meet weekly to plan, implement and evaluate changes. Tasks for this group include (1) developing and testing tools; (2) drafting policy; (3) educating staff and families, (4) setting timetables and assessing progress, and (5) celebrating successes. Team meetings should also be used to focus on specific residents who are experiencing distress, using the Roadmap approach. Participation in the project work should be added to daily staff assignments, and all shifts, all departments should be kept informed, using a shared notebook (electronic or paper). As they are developed, dementia-capable pain management approaches should be embedded in policies, procedures, orientation material, job descriptions, and competency/skills testing.

Each person owns the experience of their pain and communicates it in their unique way, and all staff must be involved in recognizing and relieving pain. **Above all, pain is not acceptable: comfort is the mission.**