ADvancing Care™

caringkind
The Heart of Alzheimer's Caregiving

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Understanding the Impact of Pain on People with Dementia

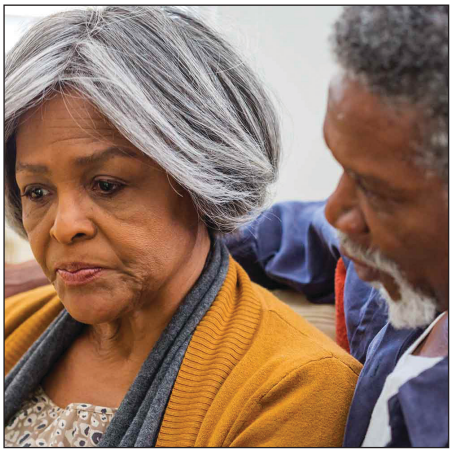
"People with dementia feel pain, just like everyone else. As the dementia progresses, the person's language skills may change, making it very difficult for them to communicate to others when pain is present. This can cause their pain to go undetected and untreated." —National Institute on Health, 2017.

Dictionary definitions of pain describe it as physical suffering or discomfort related to injury or illness, as well as mental or emotional suffering or torment. When someone is in the advanced stages of 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.** The following examples illustrate the strong link between pain and behavior:

• Edna, admitted to her third nursing home after having been asked to leave two others, had moderate dementia, weighed about 80 pounds, and constantly hit and cursed any staff who came near her. When she arrived in her new home, staff had a good idea this behavior was caused by physical pain, and in their assessment discovered she had a frozen shoulder. She had been in a car accident about 10 years before the onset of her dementia, and her shoulder had not healed that well. She had enough recall that anytime someone in scrubs came near her, she knew she would be in pain, and tried to push them away through her actions and words. Staff found clothing that was easier to put on and worked to teach her how to pull her own arm through the sleeve. Her rejecting behavior ceased once the problem was identified and addressed, and she went on to live comfortably in this home for another four and a half years. Once the problem was addressed, her son's response was, "You have given us our mother back."

• Mrs. R, 87 years old and a nursing home resident, was hospitalized with fever, urosepsis, spent 6 weeks in the ICU, was on a ventilator and with a PEG, and had multiple deep pressure ulcers. She cried in pain with dressing changes, was withdrawn, and had been given no opioids because of the belief that opioids were a 'danger' for someone with dementia. Her son requested relief for her pain. She was given low doses of opioids which proved effective and she was finally able to smile and recognize her family again. She went back to her nursing home on hospice care and lived another 3 months. Her son subsequently wrote the hospital a letter of gratitude.

While people with mild to moderate dementia can often report the presence of pain accurately, as someone's dementia



progresses they have increasing difficulty accurately reporting the location, level, type, or frequency of their pain. Fortunately, when pain is addressed appropriately and someone's pain is prevented or minimized, results include significantly decreased agitation and rejection of care, decreased injuries, and decreased use of antipsychotic and antianxiety medications.

Research confirms that pain is undertreated in people with dementia. A now-famous study of older people hospitalized with hip fractures concluded that while 68% to 76% of those who were cognitively intact rated their average pre-operative and post-operative pain as moderate to severe, individuals with advanced dementia received only a third the amount of opioid analgesics as did the cognitively intact adults. In nursing homes, only one-fourth of residents with dementia who are actually identified as having pain receive any analgesic therapy.

RESOURCES

Center to Advance Palliative Care
www.capc.org

For more comprehensive CEU courses, complete CAPC's Pain Management Curriculum and CAPC's Dementia Management Curriculum

"Although the world is full of suffering, it is full also of the overcoming of it."
— Helen Keller

***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

"Learn from yesterday, hope for tomorrow. The important thing is not to stop questioning."
— Albert Einstein

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The first, crucial step is to look for pain. While pain may not always be obvious, whenever someone is expressing themselves through behavioral changes or disturbances, it should be assumed that pain or discomfort is present:
• Assess whether basic comfort needs are being met (toileting, hunger, sleep/rest).
• Use a hierarchy of pain assessment tools, including a behavior-based assessment tool, such as the PAINAD (www.geriatricpain.org).
• Assess for prior pain history/relevant diagnoses (old injury, arthritis).
• Assess for new pain conditions (fractures, cancer, skin breakdown, fecal impaction, urinary retention, cellulitus).
• Assess for emotional pain, such as when someone is looking for something they can't find, or trying to get home to their parents, or to see their husband.

Further steps include making both pharmacologic and non-pharmacologic approaches available. Organizations caring for people with dementia need to develop and implement pain programs that promote consistency, including a routine daily pain assessment policy. All staff, regardless of their position, should be used to identify and combat pain (including physical and occupational therapists). Finally, health disparities and cultural competence need to be taken into account: each of us experiences and responds to pain differently.

Non-Pharmacological Approaches. In order to support people who are uncomfortable, determine what people enjoy and what brings them pleasure and offer it frequently. Examples include:
• Positioning. Long hours of sitting, especially in wheelchairs, can be very distressing.
• Personalized music can bring pleasure as well as provide distraction.
• Hot and cold packs may provide relief.
• Exercise.
• Aroma therapy.

Pharmacological Approaches. Avoid the use of psychotropic medications whenever possible: they do not treat pain.
•If non-pharmacological approaches insufficient, consider a trial of scheduled (around the clock, not PRN) analgesics for pain behaviors.
• Consider pre-emptive analgesia for procedures (turning, repositioning, dressing changes); for example, 30 minutes before morning care.
• Use a stepped-care approach to analgesics, starting with acetaminophen.
• An opioid is appropriate for someone with moderate or severe pain, if their pain is not responsive to non-opioid therapies. It is not opioids, but untreated pain that causes agitation and delirium.
• Start with low doses and titrate up slowly, as needed.
• Monitor for improvement.

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 1: "Why Pain Matters," with presentations by Diane Meier, MD, Director, Center to Advance Palliative Care, and Tena Alonzo, MA, Director of Education and Research, *Comfort Matters®*, Beatitudes Campus, Phoenix, Arizona. A recording of the full session can be found on the CaringKind website.

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