There's Always Something We Can Do: Non-Pharmacological Approaches

Non-pharmacological management strategies are the first line of choice and are often also used in combination with medications. Reactions play a powerful role in how anyone experiences pain, and this is true for people with dementia as well. Pain can lessen when we feel safe, relaxed, cared for, and connected with pleasurable or soothing experiences. Pain can intensify when we feel overstimulated, fearful, anxious, angry, or lonely.

When we experience more positive feelings, we help to loosen pain's grip. Our brains pursue pleasure and avoid unpleasant experiences. To help residents who are experiencing pain, we need to make the brain a better offer towards pleasurable moments, by modifying their environment, their connection with caregivers, and through multisensory experiences and activities that are engaging. We also need to maximize comfort by anticipating the body's needs for comfort, by ensuring they are not too hot or too cold, not hungry or thirsty, whether they have had enough rest, need to move, reposition or stretch, or have a soiled brief or other bowel or bladder needs.

Sensory pleasures. Emotions are generated in the limbic system in the brain in response to sensory information, and what we see, hear, touch, smell and taste can all be sources of pleasure. A back rub, hand massage, holding hands, hugs can all be very pleasant. A warmed blanket, a cool drink or some lavender aroma therapy can bring special comfort. So can listening to favorite music, or walking in a garden, smelling flowers and listening to birds. The smell of cookies baking, or a piece of chocolate melting in the mouth, or looking at pictures of family, or of favorite animals, all hold the potential for pleasure.

Pleasurable Engagement. Active participation in art projects, visiting pets, dance, yoga and gentle stretching, deep breathing, and guided imagery can all help someone be more relaxed and comfortable.

Cues for Spiritual Connection. Spiritual music, hymns, prayers, Bible verses or holding the Bible, a prayer shawl, sights and sounds of nature, or rosary beads, prayer cards, and religious statues can offer familiar experiences that spark a sense of divine presence, strength and abiding comfort.

Katherine had advanced dementia, severe aphasia and very limited mobility. She had a fall resulting in bilateral hip fractures and became completely bedbound. She was enrolled in hospice and prescribed round the clock analgesics. Her caregivers asked, “Is there more we can do to maximize her comfort and quality of life?” After brainstorming they came up with the following creative ideas based on what they knew about Ms. K’s preferences:

• Sound—favorite music
• Touch—hand massages w/lavender scented lotion
• Taste—chocolate kisses
• Spiritual—Lord’s prayer, bible verses & hymn
• Smell—diffuser with florals
• Sight—butterfly mobile above her bed, flowers projected on ceiling.

Non-pharmacological approaches need to be customized to the person, then used on a trial basis and evaluated for effectiveness, with modifications as needed until the person is comfortable. It can be helpful when 2 or more non-pharmacological approaches are used together. Each of us is the EXPERT on our own pain and what brings comfort, including people with dementia.

Principles of Pharmacological Management of Pain in Persons with Dementia

Pain is under-recognized and undertreated in people with dementia who are hospitalized or living in nursing homes. In the absence of proper management, pain behaviors may be inappropriately addressed by psychotropic medications. Relief is not always the complete absence of pain but rather a level of comfort which enables restful sleep, permits comfortable functioning and the ability to participate socially in ways that are personally meaningful.

Key principles:
• Recognize when pain is present (when pain behaviors are observed, changes in condition, and through regular screening with behavior-based screening tool).
• People with mild-moderate dementia
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 3: Treatment Approaches: Pharm & Non-Pharm, and focuses on presentations by Maribeth Gallagher, DNP, PMHNP-BC, FAAN, Director of Dementia Programs for Hospice of the Valley, and Ravindra Amin, MD, Chief of Psychiatry, Coler Rehabilitation and Nursing Care Facility, New York, NY, and Associate Adjunct Professor of Psychiatry, NYU School of Medicine New York, NY.

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

We wish to acknowledge the generosity of the Mayday Fund for underwriting this issue of ADvancing Care and for support of our work in palliative care and pain management for people with dementia.

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RESOURCES

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Pain in people with dementia may not be reported whether or not they have pain; however, for people with advanced dementia pain may be expressed behaviorally.

- Identify and address all causes of pain; often, there is more than one.
- Knowledge of prior treatment(s) and effectiveness can help in developing an individualized pain management regimen.
- An interdisciplinary approach is essential; often used in combination with non-pharm.

Common causes of pain include arthritis, dental problems, UTIs, constipation, diabetic neuropathy, pressure ulcers, and depression. The value of extensive (sometimes painful) medical work needs to be weighed against potential benefits and the person's advance directives.

Pain classifications include (1) **Nociceptive pain**, which includes both **somatic pain** (aching, throbbing, squeezing), e.g., sprains, fractures, burns, inflammation, and **visceral pain** (cramping, squeezing), e.g. appendicitis, gall stones, pelvic pain, and (2) **Neuropathic pain** (burning, tingling, numbness, shooting): e.g. nerve pressure, nerve damage, viral infections, diabetes, alcohol use. The rational use of medications is an essential tool. The ability to measure the pain with some objectivity and an understanding of pain behaviors allows for individualized pharmacological considerations (right medication, right dose and right frequency). Behaviors may be the main way that pain presents: grimacing, agitation/anger, sleeplessness/somnolence, restlessness, withdrawal/apathy, resistance to movements/care, moaning/crying out. For people with dementia, a behavior-based pain assessment tool, such as the PAINAD, is an essential tool.

The World Health Organization 3-Step Analgesic Ladder

**Step 1: Mild pain (1—3)**
- Acetaminophen or aspirin or NSAIDS +/- adjuvants (pain patches, steroids, anti-depressants, anticonvulsants)

**Step 2: Moderate pain (4—6)**
- Acetaminophen or aspirin or ibuprofen+ opioid combination +/- adjuvants (pain patches, steroids, anti-depressants, anticonvulsants)

**Step 3: Severe pain (7—10)**
- Opioids +/- adjuvants (pain patches, steroids, anti-depressants, anticonvulsants)

These are not ‘water tight compartments’; if relief is not reported with one group of meds or cannot be given due to contra-indications, the practitioner should go to the next level.

Common approaches for different types of pain include (1) **Musculoskeletal pain**: step ladder approach + or – muscle relaxants; (2) **Neuropathic pain**: antidepressants, anticonvulsants before considering opioids. Steroids and NSAIDS are useful adjuvants or as primary treatment, and (3) **Bone pain**: NSAIDS + or – opioids.

Additional Considerations

- Acetaminophen: hepatotoxicity can occur with doses over 4 gram/day.
- NSAIDS: caution in elderly with CHF orrenal insufficiency, need GI prophylaxis with most agents.
- Opioids can cause constipation, nausea, sedation, respiratory depression. Fentanyl patch not to be used in opioid-naïve patients. Addiction is NOT a concern in the management of pain in people with dementia.
- Tricyclic antidepressants may have anticholinergic side effects: dry mouth, constipation, urinary retention, blurry vision.
- Muscle relaxants may cause drowsiness, dizziness.

Most important: for people with dementia, analgesics are best administered at a fixed daily schedule as opposed to PRN schedules, which should be avoided.