Pain affects each of us differently. Some people can walk around all day with pain and we would never know. For others, facial expressions or the way they hold themselves may clearly let us know they are very uncomfortable, and probably in pain. Hospitals and nursing homes commonly ask us to indicate how much pain we have by asking us to rate our pain on a scale of 1 to 10, or by pointing to a chart with faces showing emotions from happy to tearful.

But what about the person with dementia? Sometimes they can tell us they are in pain. Other times the look on their faces or their behavior makes it obvious that they are in pain. What we are learning, however, is that pain is much more common among people with dementia than we realized, but they may not be able to tell us about it due to their confusion and lack of insight. They may call out, moan, or become very agitated; sometimes even striking out at caregivers. Too often in the past, we have assumed this behavior was an inevitable consequence of having dementia, and that nothing could be done to make it better, or that only psychotropic medications would alter the behavior. However, now we know there is a safer and more effective way to help.

The first step is learning about all the ways that people with dementia let us know when they have pain. Pain observation tools have been developed specifically to help us do this, and one example is the Pain Assessment in Advanced Dementia, or PAINAD. What makes the PAINAD different is that it identifies behaviors typical of many people with dementia that are often not associated with pain, such as:

- **Breathing**: periods of hyperventilation, noisy, labored breathing
- **Negative vocalization**: crying, loud moaning or groaning, wails or laments
- **Facial expression**: very distressed look on face, may squeeze eyes shut
- **Body language**: the person holds themselves rigidly, or pulls or pushes, hits, kicks or grabs others
- **Consolability**: the person is visibly upset, and cannot be soothed or comforted

Dr. Carol Long, PhD, RN, FPCN, a researcher in Phoenix, Arizona, has been studying pain in people with dementia for many years, and she offers the following typical example:

“Help me! Help me!” calls out Mrs. Green. For more than six months, these are the cries of an 85-year-old woman with advanced dementia who is a typical nursing home resident. On any given day, her screams can be heard at regular intervals, echoing down the long hallways of the facility. She often strikes out at caregiving staff when attempting to put on her clothes. She is placed in her geri-chair in the morning and rhythmically slams her hands on the tray in apparent distress, often for hours at a time. Diagnosed with degenerative arthritis 40 years ago, Mrs. Green had been receiving pain medications and other non-pharmacologic treatments in the past, but not recently because Mrs. Green has not been asked nor does she say she has pain. While caregivers attribute these actions to her usual self and the normal progression of dementia, one has to ask: What is Mrs. Green telling us through her behaviors? Would this scenario be expected for someone who did not have dementia?
In this example, Mrs. Green is telling the caregivers that she is in distress and uncomfortable. The medical team was called to take a look, once again, at her behaviors and consider an antipsychotic to calm her. *Could they too be missing something? And more importantly, what can be done about it?*

After a thorough medical record chart review, a complete physical, and careful analysis of her behaviors, the team decided to start Mrs. Green on a low dose of acetaminophen (for pain) every 6 hours around-the-clock for a three-day trial period. While Mrs. Green sometimes tells others about her pain, the staff has started to use the PAINAD to alert them to when her behavior suggests she is having pain.

Now caregivers regularly reposition Mrs. Green in a more comfortable chair and she lies down each morning after breakfast. Daily grooming activities are staged and her clothes have been modified to assure that she is comfortable when dressing. She no longer calls out or strikes at staff and appears to be more attentive and engaged. With gentle massage to her hands and feet, she often smiles and is less restless. They document her self-report and any behaviors and the response to the interventions in the medical record on each shift. After five days of treatment and continuous evaluation by the caregiving and medical provider team, she is resting more comfortably and the pain medication is administered as prescribed. *No antipsychotics were ordered or ever required.* Mission accomplished? Probably for now, but caregivers will need to be vigilant in ongoing monitoring to determine if Mrs. Green’s comfort needs are still being met, now that staff recognize her behaviors were related to pain and nothing else.

Situations as described above demonstrate it is possible to meet the needs of persons with advanced dementia in a comfort-focused way. There are many reasons persons with dementia may demonstrate behaviors but often pain has not been assessed or addressed. Here are some recommendations to assess and address pain in a proactive way:

1. **Don’t assume that someone cannot explain or rate their pain.** Always ask them directly if they have pain or if they are sore, ache, or hurt. However, when the person can no longer verbally express their pain but they demonstrate obvious distress, explore further the cause and manifestation of their pain. Always rule out other forms of discomfort, such as a soiled brief or an acute medical condition.
2. **When the person can no longer report their pain, use a valid and reliable pain behavioral assessment tool, such as the PAINAD.** Document and communicate the findings to all team members and institute a plan to address the behaviors as a manifestation of pain. When in doubt, assume pain is present!
3. **Intervene if pain is suspected.** Collaborate with the medical provider to institute a trial use of a pain medication while incorporating non-pharmacologic strategies in the plan of care, such as massage and repositioning.
4. **Evaluate the results of the trial.** Receive regular input from all caregiving staff to determine if the treatment plan is providing overall comfort and pain control and if the behaviors suggest that relief is being obtained.