Why Pain in Dementia is Often Missed

Even when we ask about it

Why pain in dementia is often missed

Pain doesn't disappear when dementia develops. The ability to recognize, interpret, and report it often does. This distinction matters more than people realize.

What pain reporting requires from the brain

To report pain clearly, the brain must be able to:

- Notice internal sensation
- Interpret what it means
- Remember it long enough to describe
- Communicate it in a way others understand

Dementia interferes with each of these steps. A person may still experience pain but be unable to label it, describe it, or connect it to a specific cause. Answers to pain questions may be inconsistent, not because the person is confused, but because the question itself requires abilities the brain can no longer reliably manage.

Why standard pain questions often fall short

Pain scales, like asking for a rating with 0-10, rely on abstract thinking, comparison and memory. These skills often decline early in dementia. When someone doesn't respond, or responds with "no pain" or "0", that answer may reflect difficulty using the scale rather than the absence of pain. This doesn't mean pain assessment tools are useless, it means they are incomplete when used alone.

When pain shows up as behavior

When pain cannot be described, it often appears indirectly.
Care partners and clinicians may notice:

- Increased agitation or irritability
- Resistance during care or movements
- Guarding or flinching
- Pacing, restlessness, or withdrawal
- Change in sleep or participation

These changes are sometimes mis-labeled as behavior. They are communicating something else.

A reframe worth holding onto

In dementia care, the absence of reported pain does not mean the absence of pain. It means the brain may no longer be able to tell us in the usual way. Understanding this helps prevent pain from being dismissed or overlooked.

Where pain is missed most often

Pain is not missed in dementia because people don't care.

It is missed because many systems depend on verbal reports, and dementia changes how reliably the brain can provide it.

The limits of "as-needed" (PRN) pain medication

PRN pain medications assume the person can:

- Recognize pain
- Decide it needs treatment
- Request help
- Repeat that request if needed

Dementia often disrupts this entire sequence. As a result, pain medication may be ordered appropriately but rarely given, not because pain is absent, but because the brain cannot initiate the request.

This creates a quiet gap between intent and reality.

Why asking for a short, scheduled pain medication trial is reasonable

When pain cannot be reliably reported, relying only on request-based medication can leave pain untreated.

In these situations, clinicians may consider a short, scheduled pain medication trial to help determine whether pain is contributing to distress. This is not a diagnosis and not a commitment to long-term treatment. It is a way to test whether pain should remain part of the clinical picture when other assessment methods are limited.

This is appropriate when:

- Behavior changes without a clear cause
- Distress appears during care or movements
- Other medical causes have been addressed

Family care partners often notice pain-related patterns first. They may notice resistance occurring at certain times of the day or changes in sleep, appetite or participation in activities.

These observations reflect long-term familiarity and context. When pain assessment relies only on brief encounters or verbal reporting, this information may be underused.

A final reframe

In dementia care, pain is not something a person can consistently report.

It is often something that must be interpreted, using behavior, context, and care partner insight.

Recognizing this does not lower standards of care. It raises them.

Understanding how dementia changes the brain series, adapted from ***Becoming a Brain Interpreter***

This resource supports understanding and communication and does not replace clinical judgment