Pain Matters

A Family Guide to Pain Management in Dementia

Pain and dementia—the 3 R's

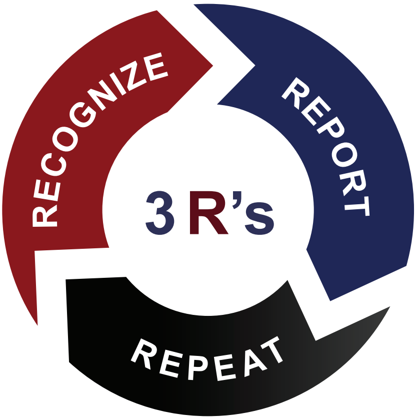
Pain is the body's warning sign that something is wrong. Many chronic illnesses and painful conditions cause pain—such as diabetes, arthritis and toothaches. But because people living with dementia struggle to express pain in typical ways, they often have untreated pain. This is especially an issue for people in the later stages of dementia who may struggle to communicate.

This resource helps us understand the relationship between **responsive behaviour** and **pain**. Behaviour has meaning and it may be an expression of pain.

Untreated pain can lead to depression, loss of appetite, social withdrawal, restlessness, aggression and agitation, which may be mistaken as side effects of dementia. When pain is not treated, its symptoms and responsive behaviours like these worsen.

Pain can be relieved, but first we need to recognize its presence. This pamphlet helps family members of people with dementia by introducing the 3 R's of pain recognition:

- **Recognize** the signs of pain in people living with dementia.
- **Report** signs of pain to a health-care provider.
- Ask for **repeat** pain assessment.



What is dementia?

Dementia is an umbrella term for many brain disorders and can be a symptom of other conditions, e.g. stroke. Changes in a person's behaviour can signal damage to the brain caused by a dementia. Dementia affects everyone differently, but it commonly diminishes abilities related to:

- Language
- Recognition
- Memory (including knowledge of the disease)
- Purposeful movement
- Sensory perception
- Reasoning

What is responsive behaviour?

Responsive behaviour is a term that is used to describe the challenging behaviour of people living with dementia, such as agitation, wandering or aggression. The term shows how the words and gestures of people with dementia are a **response** to something, such as **untreated pain**, environmental factors, etc.

> **"He is not the problem. He has a problem."** ~ Sharron Cooke

Why can pain go untreated?

People mistakenly think pain is:

- Something to get used to
- Mental, not a physical problem
- A natural part of growing old
- Something people use for attention
- Something people with cognitive problems cannot reliably report
- Best untreated because pain medications lead to addiction
- Best untreated early on because using pain medications will limit later options

Reporting no pain is not the same as having no pain. Someone with dementia may not report pain because they:

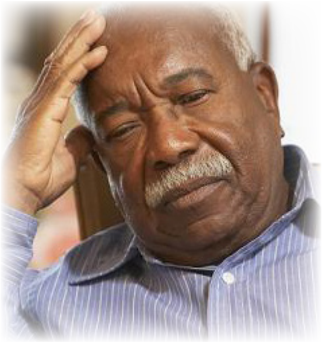
- Believe in the myths mentioned above
- Think that "complaining" about pain may make them fall out of favour
- Mention discomfort, hurting, aching or sore, but not the specific word "pain"
- Misinterpret the feeling of pain because of dementia
- Fail to remember that pain occurred
- Are unable to communicate due to being in the later stages of dementia

What is delirium and how does it relate to pain?

Delirium (or acute confusion) is a change in a person's ability to think and be aware of their surroundings. It can be caused by pain.

A delirious person may:

- Be confused about where they are or what time of day or year it is
- See or hear things that are not there
- Experience frightening mood swings



Delirium's onset can be quick, occur over a short period of time and be temporary. Persons with dementia are especially susceptible to delirium but any older person is at risk. But unlike many dementias, delirium can be treated.

Delirium may be caused by:

- Severe infections
- High fever
- Lack of fluids
- Diseases of the kidney or liver
- The effects of surgery or a fall
- Lack of certain vitamins
- Seizures
- Head injury
- Reactions to certain medications or alcohol
- Lack of oxygen

Delirium in a person with dementia can be the **sign of a serious underlying condition**. It is important not to mistake delirium for dementia.

Recognize and report the signs of pain

Family and care partners can help observe and identify when pain might be present. **Keeping a pain journal** outlining the time of day pain occurred and its severity can be useful when talking with a health-care provider (see page 9). Pain is frequently associated with changes, such as:

- A person has a change in environment, such as moving to a new place, acquiring a new bed, chair or a new assistive device like a walking aid.
- There is a change in medication, especially pain medication.
- A fall occurs, no matter how minor.

You can help identify signs of pain by looking for changes in:

- Facial expressions
- Vocalization
- Body language
- Normal behaviour
- Daily habits
- Activity around sore areas
- Willingness to accept care
- Body movements
- Social behaviour
- Sleep patterns
- Bowel movements

Pain assessment

Regular pain assessment by a health-care professional is best. Expect a health-care professional to:

- Have the knowledge and skills to effectively manage pain
- Understand proper use of strong pain medications
- Recognize how pain relates to illness
- Assess the extent of the pain and its interference with day to day activities and overall quality of life
- Follow institutional policies for documentation of pain assessment
- Coordinate with the health team
- Involve the substitute decision-maker in care planning and discussing levels of pain medication, i.e. sedation, that they are comfortable with
- Involve the family (especially substitute decision makers) in care planning and discussion of pain medications, treatments and impact (e.g. potential side effects)

> **“Dementia is an illness that you can’t manage on your own. You need to work together with people who can help you.”**
>
> ~ Early-stage program participant,
> Alzheimer Society of Niagara Region palliative care

When assessing, ask the health-care provider to:

- Accept the individual's report of pain first and not assume that a person living with dementia is unable to self-report
- Assess at different times of day and during different activities
- Check the person's "pain history"
- Perform ongoing pain assessment, daily at a minimum
- Consider a test treatment to see if the person's behaviour changes as a result
- Consider exploring other factors such as anxiety, fears, spiritual and psychosocial distress
- Use scores collected over time to make decisions
- Use more than one scale

People with advanced dementia symptoms may not be able to report pain and may show pain is present by their behaviours. If your friend or family member:

- Is living with chronic illness
- Is unable to report pain because of more advanced dementia
- And you suspect they are having pain

ask your health-care provider to use a pain assessment tool (such as the Abbey Pain Scale, Doloplus 2, PAINAD) as part of the pain assessment they provide. These are designed for non-verbal/cognitively impaired individuals experiencing pain.

Living with pain and dementia is unique and complex. This guide emphasizes the importance of **recognizing** and **reporting** observations of pain in people living with dementia and working with health-care professionals to do **repeated** pain assessments.

Because only the person experiencing pain knows how it feels, the best approach is to always ask "*do you have:*

- Pain
- Hurt, ache or sore anywhere
- Discomfort
- Pins and needles or numbness anywhere in your body"

Remember behaviour has meaning and it may be an expression of pain.

Daily Pain Journal

Here's an example of a daily pain journal that can be used to record pain.

0	1	2	3	4	5	6	7	8	9	10
No pain		Mild pain		Moderate pain		Intense pain		Severe pain		Worst you've ever had

Date:_____________

Rating your pain

Using a pain scale helps to describe how much pain you have. For instance, try to put a number from 0 to 10 to your pain level. If you have no pain, use a 0. As the numbers get higher, they stand for worse pain. A 10 means it is the worst pain you've ever had. You might say "My pain is a 7 on a 0 to 10 scale" or "a 2 on a 0 to 10 scale."

Time	Pain rating (0 to 10)	Where is the pain and how does it feel? (ache, sharp, throbbing, shooting, tingling, etc.)	What were you doing when the pain started or got worse?	Did you take pain medicine? What did you take? How much? When?	What else did you do to ease your pain (e.g., rest, ice, heat)?	How long did the pain last?	An hour after the medicine, what is your pain rating? (0 to 10)	Include notes about benefits (for example, better able to sleep, eat, be active) and/or side effects causing problems (such as constipation, drowsiness) here

Notes or Comments:

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