

# How does pain affect 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 they are in pain. This can cause their pain to go undetected and untreated. If pain goes unnoticed, the person with dementia may feel significant distress for a prolonged period of time. If the person with dementia is not able to use words to communicate their pain, they may start using behaviours as a way of communication. Some of the behaviours may include becoming agitated or withdrawing from others. Others may find these behaviours disruptive, resulting in inappropriate use of treatments such as antipsychotic medication. Pain should be assessed routinely, and should be considered as a possible cause of any change in the person's behaviour. Often times, treating the underlying pain lowers or diminishes behaviours.

People with dementia are at a higher risk of falling or injuring themselves, both of which can be painful. If the person sits or lies in the same spot for long hours without moving, the risk for constipation, joint stiffness, pressures sores and muscle contraction increases- all of which can cause severe pain and discomfort. In addition, a person with dementia may not remember how they hurt themselves or why they are in pain, adding to the difficulty of trying to communicate their pain to others.

## Assessing pain in people with dementia

Everyone experiences pain differently. A person's self-report is the most accurate measure of pain. You may be able to find out if the person is in pain by asking direct simple questions such as "Are you in pain?", "Is it sore?" or "Does it hurt?". It is important to remember that a person with advanced dementia may not be able to answer your questions verbally. If the person is having a hard time using words to tell you how they feel, it is important to be aware of non-verbal signs of pain and distress. Since we all express pain differently, it is important to pay attention to any changes in the person's behaviour.

## Non-verbal signs of pain

To help you figure out if the person with dementia is experiencing pain it is important to look for non-verbal signs of pain. They can include:

Facial expressions:	Verbalizations, vocalizations:
<ul style="list-style-type: none"><li>• Slight frown; sad, frightened face</li><li>• Grimacing, wrinkled forehead, closed or tightened eyes</li><li>• Any distorted expression</li><li>• Rapid blinking</li><li>• Clenching their teeth</li></ul>	<ul style="list-style-type: none"><li>• Sighing, moaning, groaning</li><li>• Grunting, chanting, calling out</li><li>• Noisy breathing</li><li>• Asking for help</li><li>• Verbally abusive</li></ul>

<b>Body movements:</b> <ul style="list-style-type: none"> <li>• Rigid, tense body posture, guarding a part of the body</li> <li>• Fidgeting</li> <li>• Increased pacing, rocking</li> <li>• Restricted movement</li> <li>• Gait or mobility changes</li> </ul>	<b>Changes in daily activities:</b> <ul style="list-style-type: none"> <li>• Refusing food, appetite change</li> <li>• Increase in rest periods</li> <li>• Sleep, rest pattern changes</li> <li>• Sudden change in usual routine</li> <li>• Increased wandering or pacing</li> </ul>
<b>Changes in thinking or emotions:</b> <ul style="list-style-type: none"> <li>• Aggressive, combative, resisting care</li> <li>• Decreased social interactions</li> <li>• Socially inappropriate, disruptive behaviour</li> <li>• Withdrawn</li> <li>• Increased confusion</li> <li>• Irritability or distress</li> <li>• Crying</li> </ul>	<b>Physical changes:</b> <ul style="list-style-type: none"> <li>• Increased heart rate, blood pressure or sweating</li> <li>• Limited range of motion or slow movement</li> <li>• Guarding a particular body part or reluctant to move</li> </ul>

### Tools for healthcare professionals to assess pain levels:

**The PACSLAC II** – The PACSLAC (Pain Assessment Checklist for Seniors with Limited Ability to Communicate) and the PACSLAC II can be used by healthcare professionals to assess pain in people with advance dementia who cannot express themselves verbally. These checklists include behaviours that are commonly found in people experiencing pain. PACSLAC II is shorter than PACSLAC and it contains more specific descriptors of pain. Both scales take a few minutes to complete.

To obtain a copy of and permission to use the English version of the PACSLAC or PACSLAC II please contact Dr. Thomas Hadjistavropoulos at [Thomas.Hadjistavropoulos@uregina.ca](mailto:Thomas.Hadjistavropoulos@uregina.ca).

A French version of the PACSLAC is can be accessed here: <http://www.pacslac.org/index.php?id=992>

**Abbey Pain Scale** - The Abbey Pain Scale can be used to help measure pain for persons with dementia who cannot express themselves verbally. This scale suggests six possible signs of pain:

- Vocalizations (e.g., yelling, moaning, groaning)
- Facial expressions (e.g., grimacing, tightened eyes, rapid blinking)
- Changes in body language (e.g., increased pacing)
- Behavioural changes (e.g., increase in rest periods)
- Physiological changes (e.g., increased heart rate or blood pressure)
- Physical changes (e.g., as skin tears and arthritis)

You can access the scale here: [http://prc.coh.org/PainNOA/Abbey\\_Tool.pdf](http://prc.coh.org/PainNOA/Abbey_Tool.pdf)

## Strategies for avoiding common causes of pain:

- Check regularly that dentures still fit
- Make sure that clothing fits comfortably
- Check that footwear is appropriate and comfortable
- Check that assistive devices such as hearing aids and eye glasses are fitted and working properly
- Encourage frequent gentle movement of all limbs by bending and stretching regularly

Since pain is easier to prevent than it is to relieve, it should be treated on a regular basis.

## Managing Pain

Analgesics are drugs that relieve pain. There are many available medications that can be used to treat pain. The type of medication chosen depends on different factors such as type and severity of pain, how long the person will need to take the medication for, and if the person has other medical conditions and or is taking any other medications. Medications include aspirin, non-steroidal anti-inflammatory drugs (such as ibuprofen) and opioids (such as morphine). Opioids are often the most effective medications to relieve moderate to severe pain.

Older adults may be more sensitive to some medications and may require a lower dose. It is important to carefully monitor how much pain medication the person is taking and to discontinue their use once the pain has been resolved.

## Useful Resources:

- The Alzheimer Society of Ontario has created some useful resources to help caregivers of people with dementia assess pain. These resources can be found here: [www.painanddementia.ca](http://www.painanddementia.ca)
- People with moderate to severe dementia tend to be undertreated for their pain due to cognitive and language impairments. This webinar discusses practical evidence-based approaches to pain assessment: <https://vimeo.com/192469020>
- To learn more about pain management in end-of-life visit <http://www.alzheimer.ca/en/Living-with-dementia/Caring-for-someone/End-of-life-care/Managing-pain>
- Educational resources related to pain and dementia have been created by experts at the University of Alberta. They include written resources and a tutorial presentation on observing and reporting pain behaviours. These resources are available at [www.painanddementia.ualberta.ca](http://www.painanddementia.ualberta.ca)

## References:

Observing and reporting pain behaviours: A workshop for family members of people with Alzheimer disease and other dementia (2009). University of Alberta. Retrieved from [www.painanddementia.ualberta.ca](http://www.painanddementia.ualberta.ca)

# Alzheimer *Society*



**Alzheimer Society of Canada**  
**20 Eglinton Avenue West, 16<sup>th</sup> Floor, Toronto, Ontario M4R 1K8**  
**Tel: 416-488-8772 1-800-616-8816 Fax: 416-322-6656**  
**E-mail: [info@alzheimer.ca](mailto:info@alzheimer.ca) Website: [www.alzheimer.ca](http://www.alzheimer.ca)**