



FACT SHEET No. 4

Pain Management in Dementia

Several diseases may lead to cognitive impairment, which will lead to progressive problems in daily living and communication and behavior, such as agitation, apathy or sleep disorders. It is this syndrome that we call Dementia. Most common are Alzheimer's disease, Vascular Dementia, and a combination of both. Parkinson's disease, Huntington's disease, AIDS and several other more or less rare diseases may lead to dementia. Although all of these diseases may end in the same 'dementia' state, the neuropathology for all of these diseases is different, and so is the impact on the pain processing system. It has been found that people with dementia (PwD) are prone to poor pain assessment and many studies have found that they use fewer analgesics [1].

Pain processing in dementia may be altered

- In Alzheimer's disease, individuals do feel pain, but the interpretation and cognitive and emotional evaluation of the pain may be different. •
- In Vascular Dementia, individuals most likely have more pain, because of white matter lesions that may stimulate Central Pain. •
- As the causes of dementia are progressive neuropathological diseases, the impact on pain processing is dependent on the stage of the disease. •
- In almost all types of dementia, communication is seriously impaired eventually in the process. •
- Experimental studies show that the pain threshold is somewhat higher in Alzheimer's disease, and that autonomic responses are hampered [2]. •
- Experimental studies also show that facial expressions after a pain stimulus increase in PwD [6].

The challenges of pain assessment in dementia

- Self-report of pain (and the effects and side effects of medication) is not always possible, especially in more advanced stages.
- Regular pain assessment tools are not always feasible, especially in more advanced stages.
- Healthcare professionals are often inadequately trained for communication with PwD, leading to deficits in attitude and knowledge concerning both dementia and pain [8].



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- When regular pain assessment (self-report) tools are no longer valid, observational instruments are available.
- There are more than 35 observational tools, but both validation and implementation is generally poor [4].
- Pain is often expressed as behavior (for instance agitation).
- Formal and informal caregivers focus on treating the behavior, often with antipsychotic medication instead of pain treatment.
- Differentiation between causes of neuropsychiatric symptoms is challenging.

Interdisciplinary and non-pharmacological management

- PwD have a broad array of medical, social and psychological needs. Pain management is always multicomponent and therefore should be interdisciplinary.
- As most persons with dementia are older, they have a higher risk for adverse reactions of drugs. Non-pharmacological interventions (such as social, mental, physical activities, such as music therapy) should always be the first line of thought.
- Because of the altered evaluation and presentation of pain, there is a large behavioral and psychological component in the experience of pain. Therefore, behavioral and soothing interventions that reassure and relax PwD should be also first line of choice. However, there is little evidence base or expert agreement about the content and effect of nonpharmacological intervention for pain in dementia [7].

Pharmacological management

- Paracetamol is an effective analgesic in most PwD, but ‘as needed’ should not be encouraged as they often have trouble communicating effectively about pain.
- When using NSAID’s, one should realize that most of the PwD are older persons, and the risk of serious adverse events (gastroenterological, renal and cardiovascular) is very real. Individuals also find it difficult to communicate possible first signs of serious side effects, so it is advised to be very careful, start low, and try to stop within two weeks.
- The use of weak-opioids is not encouraged because of little proof for effectiveness and the potential side effects, of which delirium is often described.
- When needed, strong opioids should be administered, but ‘start low and go slow’. One should realize that persons with dementia also have more side effects with opioids, so monitor and evaluate at least once a week. Try to stop (‘go slow’) within 6 weeks [5].
- In many countries, patches with Buprenorphine or Fentanyl are very prevalent in persons with dementia, and often used for many months/years.
- Physicians should be critical of the long-term use of any analgesics, including patches.
- Monitoring and evaluation of effectiveness and side effects of the treatment is very important and should be performed regularly.
- Experimental studies have shown that people with Alzheimer’s disease with impairment of frontal functions have no placebo effect. It was also shown that these patients needed a higher dosage of analgesics to reach the same level of pain relief [3].



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- Use an assessment instrument also for evaluation. If self-report is hampered, then a behavioral assessment instrument such as the MOBID-2, PAINAD or PAIC should be used.

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