



PAIN IN DEMENTIA – FACTSHEET

Is pain a common problem in people with dementia?

People with dementia (particularly those who reside in residential or nursing homes or are admitted to acute hospitals for medical or surgical treatment) are at high risk of under-recognition and under-treatment of pain. There are a number of reasons why this may occur:

1. There is a tendency to normalise pain as we become older so that aching and soreness is seen as an “every day” discomfort that should be expected with age.
2. Pain is an individual experience that different people feel in different ways.
3. People with dementia are less likely to report pain. As dementia progresses, speech ability may decline so that the person can no longer communicate their thoughts, feelings and needs. They may not understand questions, may not recall that they have been in pain or may not be able to interpret and understand the feelings they are having.
4. People with dementia may need prompting to remember to take painkillers and may not understand why they are being prescribed.
5. There is some evidence that medical staff believe that painkillers will increase confusion in people with dementia or that they do not feel pain as much as other people.
6. Some people mistakenly believe that all painkillers are “addictive” and that they should only be given when pain is severe.

Common causes of pain in people with dementia

It is important to rule out problems that can be easily treated. Constipation or urinary tract infections occur frequently and can cause great distress. Sitting or lying in one position and uncomfortable or tight clothes or shoes can lead to pressure sores. The weight loss associated with dementia may lead to ill-fitting dentures and sore gums. Those who have teeth may lose the ability to clean them properly causing tooth decay or abscesses. Some studies have found that people with dementia, particularly those residing in care homes, may have undiagnosed fractures leading to great pain and distress.

The consequences of not treating pain

As well as causing unnecessary suffering and distress to the person with dementia, inadequately treated pain leads to problematic behaviours and inappropriate prescription of sedatives and tranquilisers. Pain may decrease functional ability, worsen memory problems or delay recovery after surgery. It may disrupt the person’s sleep (and that of their carers), causing depression and social withdrawal.

Detecting whether someone is in pain

It is important to realise that dementia *does not* alter the fundamental experience of pain. Often the person with dementia who is not able to express pain normally may communicate this in other ways. Social and cultural factors should be also be considered. For example medical staff should use interpreters if the person does not speak English as their first language. The person’s relatives or close carers are vital in making an assessment as they may observe subtle changes in behaviour or mood. It can be helpful to make a note of these changes, the circumstances they occur in and what helps them or makes them worse. For example, while the person is sitting at rest or only when someone is trying to wash or dress them. Pain can be observed in a number of ways:

- **Behavioural changes:** Fidgeting, restlessness, repetitive behaviours, pacing or wandering. A person may become tense or “on edge” when they know physical care is about to be given and may be unusually resistive to care, pushing away carers. Sometimes they may become aggressive or angry if they cannot verbally express the pain they are experiencing.
- **Mood changes:** Depression and withdrawal.
- **Facial expression:** Frowning, sad, grimacing, tense, frightened.
- **Body language:** Guarding, bracing, rubbing or holding the painful part of the body.
- **Speech:** Shouting out repeatedly, screaming, crying or groaning.
- **Signs on physical examination:** Pressure sores, tears in the skin, arthritis or deformities in the joints, changes in

blood pressure or pulse rate, sweating, pallor, noisy or laboured breathing. Food refusal or loss of appetite. Changes in mobility or walking gait. Constipation and retention of urine may cause a distended abdomen.

Use simple “yes/no” questions when asking the person about their pain, or try other words such as “ache” and “hurt”. Sometimes non-verbal communication such as asking them to point at the affected part or using pictures can help the person communicate.

If the source of pain is not obvious, the person will need a thorough physical examination by a doctor or nurse taking cues from the patient’s facial expression or posture. Sometimes it can be helpful to refer the person to other members of the care team. Assessment by physiotherapist or occupational therapist may be helpful for musculoskeletal problems. A tissue viability or district nurse can offer specialist advice regarding the care of ulcers and pressure areas.

Treating pain in people with dementia

There are a number of stages that need to be considered before painkilling medication is prescribed. That is not to say that medication does not have a vital role, often simple interventions may be effective:

1. **Assessment:** A thorough assessment is vital as is information gained from carers. If pain is to be minimised in people with dementia, assessment should be done on a regular and systematic basis.
2. **Acknowledging the person is in pain:** Reassure the person and act on what they are telling you. Explain what you are doing to help them, even if you think they do not understand you.
3. **Treat the cause:** For example, use special pressure cushions and mattresses, reposition someone, relieve constipation, loosen clothing and take the person for regular dental check ups.
4. **Comfort:** Heat or ice packs can be useful for joint problems. Massage may relieve the tension and muscle spasm that is both caused and exacerbated by pain. Alternatively, immobilising or splinting limbs may reduce discomfort associated with chronic fractures or arthritis.
5. **Simple painkillers:** Paracetamol can be very effective for mild to moderately severe pain. Anti-inflammatory drugs such as aspirin and ibuprofen can be effective but have a higher risk of side effects such as gastric irritation and bleeding. It is important to check with the person’s doctor that it is safe for them to take these painkillers. Medication is more effective if

taken at an adequate dose on a *regular basis* to *prevent* pain from occurring.

6. **Stronger painkillers:** Opioid-type drugs such as codeine and morphine are useful for more serious pain that does not respond to simple treatment. Side effects include constipation and increased confusion but this should not stop them from being prescribed, especially if some one is in severe pain or has had surgery.
7. **Consider stopping some medical treatments or investigations:** It may be that some treatments, for example, painful blood tests or invasive physical investigations make little contribution to a person’s health but cause pain and decrease quality of life. At this stage medical staff may discuss with the person (if possible) and their carer stopping such procedures.
8. **Pain at the end of life:** If the person with dementia is nearing the end of their life the treatment will focus on keeping the person comfortable and free of distress. It can be very helpful for the community or hospital palliative care team to be involved.

Conclusions

In the past, the recognition and treatment of pain in people with dementia has been poor. Carers have a vital role in observing and reporting pain to medical staff. Often they can anticipate a person’s needs and ensure their comfort. Basic measures such as thorough assessment and prescribing simple painkillers can give great relief and dramatically improve quality of life.

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The views expressed in this factsheet are those of the author, not necessarily those of the NWDC

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