Pain and dementia

People with dementia may be less able to communicate to their carers that they are in pain, resulting in reduced quality of life. This can be avoided by looking out for non-verbal signs of pain and providing adequate treatment. This sheet provides information about appropriate assessment and management of pain in people with dementia.

How does pain affect people with dementia?

People with dementia may experience physical pain for the same reasons as everyone else. However, because of their declining brain function and abilities, they may be less able to communicate to their carers that they are in pain. This can result in under-treatment of their pain, and reduced quality of life. Such a situation is avoidable, however, by looking out for non-verbal signs of pain and providing adequate treatment.

Pain

How we experience physical pain is very individual; pain due to the same cause feels different to each person. We might use a range of different words to describe our pain – uncomfortable, hurting, a twinge, stabbing, burning, throbbing, etc. We might also unconsciously show signs of pain such as facial grimacing or withdrawing the painful body part from touch.

We feel pain because signals are sent from the affected body part to specific areas of the brain. This is a vital function because pain motivates us to withdraw from potentially damaging situations, protect a damaged body part while it heals, and avoid the same situation in the future.

Pain can be acute or chronic. Acute pain comes on suddenly and may be due to an injury or infection. The pain generally eases as the affected body part heals. Chronic pain is persistent over time and may be due to an underlying long-term medical condition such as arthritis. The pain may be present all the time, or may come and go.

Is pain experienced differently in dementia?

As far as we know, the changes in the brain that occur in Alzheimer's disease and other forms of dementia do not cause pain. However, people with dementia are at increased risk of experiencing pain because they are at increased risk of other things that can cause pain, such as falls, accidents and injuries. Also, older people in general, including those with dementia, are more likely to suffer from a range of medical conditions that can cause pain.

Previously it was thought that people with dementia don't feel pain because the damage occurring to their brain stopped them feeling pain. Research has shown this to be incorrect. A study conducted in Melbourne, using functional magnetic resonance imaging (MRI), revealed that people with Alzheimer's disease showed pain related brain activity in the same brain regions as those without Alzheimer's disease[1]. The researchers concluded that people with dementia feel pain in exactly the same way as those without dementia, they just have trouble explaining it to others.

Dementia typically involves a gradual deterioration of the person's abilities to understand and communicate with those around them. In the early stages of the illness, the person's ability to recognise and report pain may be unimpaired, but in later stages it is likely to be diminished. This potentially leads to the unacceptable situation of a person with dementia suffering in pain without adequate pain relief.

Research has found that people with dementia, especially those living in residential care, report less pain and receive fewer pain relieving medications. We now know that this is not because they feel less pain, but because they are less able to communicate their level of pain and their need for pain relief. It is therefore up to those caring for a person with dementia to take extra steps to assess whether the person is experiencing pain and to employ treatments to effectively manage pain.

Can people with dementia verbally report pain?

In the early stages of dementia, people may still be able to tell someone when they are in pain. But their declining thinking skills may make them less able to understand why they are feeling pain and to know what to do about it. Their declining brain function and communication skills may impair their ability to accurately report the location, level and type of pain or to remember to regularly take pain relieving medication, meaning they are left suffering.

Reasons other than dementia can also make older people less inclined to report that they are in pain. Depression; fear of requiring surgery, hospitalisation or moving to residential care; a misperception that all painkillers are addictive; and not wanting to appear weak or to complain, can all influence a person to under-report their pain. Cultural, religious and gender differences can affect reporting of pain. Some people do not want to lose respect in society by admitting they are in pain and need help, or believe that pain should be borne in silence, while others feel they should report pain right away and get immediate relief. As a result of social and cultural expectations, some men may believe they need to be strong and keep pain to themselves.

A person's background and circumstances, as well as their stage of dementia, need to be considered to determine whether they are at risk of under-reporting pain. Strategies to assess pain may need to go beyond simply asking the person with dementia if they are in pain, even if they appear able to communicate normally.

What are the non-verbal signs of pain?

In the later stages of dementia, many people will lose the ability to verbally report to others that they are in pain. We can still assess whether someone in this situation is in pain, by observing non-verbal signs. In fact, non-verbal signs can be helpful in assessing pain in all stages of dementia. These signs can be obviously pain-related, but sometimes might just represent a change from normal behaviour. They can include:

- facial grimacing
- gestures that indicate distress
- guarding a particular body part or reluctance to move
- moaning with movement
- limited range of motion or slow movement
- increased heart rate, blood pressure or sweating
- restlessness
- crying or distress
- increased or decreased vocalisations
- withdrawn social behaviour
- lethargy or increased sleep
- disrupted or restless sleep
- decreased appetite (and decreased nutritional intake)
- increased confusion
- anger, aggression, irritability or agitation

Of course, some of these symptoms or changes can be a result of other problems, but pain should always be considered as a potential and treatable cause. It is also important to remember that some people will demonstrate little or no specific behaviour associated with their pain.

What are the consequences of untreated pain?

If pain in a person with dementia goes unrecognised and untreated, there is a danger not only of the person suffering needlessly, but also of them being prescribed inappropriate treatments for their changed behaviour. If a person becomes withdrawn or distressed because of pain, they may be assumed to be depressed and prescribed antidepressants. Indeed, chronic pain can make a person depressed, but effectively treating the underlying pain should relieve both the pain and the depression. If a person becomes aggressive or agitated because of pain, they may be prescribed antipsychotics, which potentially have serious side-effects. Again, treating the underlying pain should alleviate the resulting problem behaviours.

Persistent pain can lead to decreased mobility. This may not only interfere with daily activities, but also increases the risk of falls and further injury. Persistent pain can affect brain function and thinking, worsening the symptoms of dementia and hastening deterioration. Failure to recognise and treat pain in people with dementia has profound implications for their quality of life and can lead to poor medical outcomes.

What are the causes of pain?

Potential causes of pain are the same for people with dementia as they are for everyone else. Common causes of pain for older people include:

- constipation and urinary tract infections
- sitting or lying in one position for too long
- pressure sores
- arthritis
- osteoporosis
- old injuries such as hip fracture
- undetected or untreated injuries
- headache or migraine
- back problems
- foot problems
- dental problems
- diabetes
- infections

A thorough assessment may be needed to determine the cause of pain, especially in a person with dementia whose communication skills are impaired.

How should pain be assessed?

There is no simple measure of a person's pain, as there is for something like blood pressure or eyesight. Instead, a person's self-report is the most reliable measure of pain. Patients may be asked to rate their pain on a scale of zero to ten, with zero being no pain at all and ten the worst pain they have ever felt. Patients may also be asked to describe the nature of their pain; whether it is sharp or blunt for example. But, as we have learned, people with dementia may have difficulty understanding these questions and/or providing an answer that accurately reflects their pain.

Health professionals may use formal pain assessment scales to investigate potential pain in people with dementia. The Australian Pain Society recommends the Brief Pain Inventory as a proven useful tool for assessing pain in older people who can communicate verbally[2].Versions for people living in the community and in residential care are available.

Observational assessment tools are available for recording and scoring signs of pain in a person with dementia who cannot communicate verbally. The Australian Pain Society recommends the Abbey Pain Scale for these people[2]. This scale asks the observer to rate the severity of the person's expressions and changes in behaviour, as well as physical signs, and provides a total score indicating the severity of pain.

Health professionals sometimes lack the training and often lack the time needed to recognise, assess and monitor pain in people with dementia. Family members and friends can make a valuable contribution by learning to recognise signs of pain in their loved-one and reporting their concerns to health professionals and care workers.

Proper assessment of the cause, severity and impact of a person's pain is essential for planning the most appropriate treatment.

How should pain be managed?

Once it has been identified that a person with dementia is experiencing pain, they should generally be seen by a doctor who can determine the best treatment approach. Of course, for minor ailments such as headache, paracetamol can usually be safely used without needing to see a doctor. For more significant or ongoing pain, stronger remedies may be required.

A drug that relieves pain is called an analgesic. Many different drugs can be used to treat pain. They include paracetamol, aspirin, non-steroidal anti-inflammatory drugs (such as ibuprofen) and opioids (such as codeine and morphine). The type of drug chosen depends on many different factors including the type and severity of pain, how long the medication is likely to be needed for, and the patient's other

medical conditions and medications. Special care needs to be taken with older people who may be more sensitive to some medications and require a lower dose, and may be more prone to side-effects and to interactions with other medications they are taking. Talk to the doctor and/or pharmacist to make sure everything necessary has been considered, and that the response to medication is carefully monitored.

Non-drug therapies can also be used to help alleviate pain, either alone or in combination with a medication. These may include:

- massage
- application of heat or cold packs
- gentle exercise and stretching
- physiotherapy
- acupuncture
- relaxation

For chronic pain in particular, it is very important that ongoing pain management becomes part of the care plan for the person with dementia. Their pain should be assessed regularly, treatment should be tailored to what works best for them, and therapies should be adjusted when necessary. The most effective way to manage chronic pain is for analgesics to be taken at regular intervals, rather than on an as needed basis. The addition of non-drug therapies such as massage can be very helpful.

What about pain at the end of life?

Many people fear spending their final days in pain, but with good palliative care this should rarely happen. Palliative care is specialised care for someone living with a terminal illness, and pain management is an important part of this service. Dementia is a terminal illness, and people may have other conditions as well that cause pain, so this service is available to them.

Many health professionals lack specific training in pain management, but a palliative care team can ensure effective pain control strategies are put in place if needed[3]. This specialist help can be provided at any stage of the illness, not just in the final few days of life. Of course, not everyone with dementia will require palliative pain management.

Can pain be prevented?

Taking sensible precautions to avoid conditions that cause pain such as infections, fractures and pressure sores should be employed when caring for someone with dementia. Regular use of medication may be needed to control persistent pain in someone with a chronic condition.

References

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Further reading

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Further Information

Dementia Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at **dementia.org.au**

For language assistance phone the Translating and Interpreting Service on **131 450**

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