

Understanding the impact of pain and dementia



Background

Knowing how to identify and manage the symptoms of pain in people living with dementia is an important part of a carer's role. This guide provides an overview of dementia and the pain experience, helping to identify and manage pain in dementia patients.

What is pain?

The most common definition of pain is "Whatever the experiencing person says it is, existing whenever he or she says it does". (McCaffery, 1968)

Another widely used definition is "Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage". (IASP 1994)

It's important to remember that pain is a very individual experience. How we experience pain is a product of many complex interactions in our body and brain.

The intensity and experience of pain can vary not only based on the changes to the nerves and tissues but also other factors such as the person's genetics, their mood, prior pain experiences, thoughts, the attention paid to it, the meanings given, cultural factors, and the influences pain has on their life.

How common is pain?

One in five Australians lives with chronic pain. This prevalence rises to one in three people over the age of 65. Up to 80% of people with dementia in residential aged care services experience some type of pain (Pain Australia), and some reports suggest even higher prevalence.

Dementia and the pain experience

Contrary to myth, people living with dementia definitely experience pain, although their expressions and experiences may vary.

The response to an injurious stimuli is unchanged in most people with dementia. The pain threshold and tolerance can vary based on the changes in the nervous system, as can the ability to comprehend or communicate pain. People with dementia may have difficulty identifying that what they're feeling is indeed pain, or understanding why they have it. This can cause added distress for people living with dementia.

Identifying pain

Knowing how to identify pain is the first step in providing a best practice approach to pain management.

If you are a carer it is especially important for you to have excellent skills in pain identification, as you are with the person every day. For people living with dementia, you are the link between their pain and their management, particularly when they are unable to communicate.

How to identify pain

Ask the person simple questions like “Are you in pain?”, “Are you sore?”, or “Do you have any discomfort?”. Note that the lack of a typical verbal response does not mean the absence of pain. If a person living with dementia states that they are experiencing pain, they should be believed and their issue acted upon.

The **“Listen, Look and Observe”** approach is very important. Listen for any vocalisations such as moaning, groaning or crying. Look for changes in facial expression, like grimacing, frowning or clenching. Observe changes in their regular behaviours, interactions and interests, and daily routines.

The most important part of pain assessment starts with knowing the individual, which includes their physical and mental health, their level of activity and their personal and cultural background.

Common barriers to identifying pain include:

- Lack of recognition, e.g. misinterpreting pain as “dementia behaviour”.
- Lack of sufficient pain education.
- Missed or delayed diagnosis.
- Assessment tools not being used appropriately.
- Not knowing the person.

Tools to identify pain

There are many tools for health professionals to assess pain in people with dementia. The most common are Abbey, Pain-AD, MOBID II, and DoloPlus-2. Pain-Chek is a mobile app-based for pain identification in people who are unable or variably verbalise pain.

It’s important to remember that these tools still have a subjective factor. They are largely used following a movement-based assessment. Using a tool that you’re familiar with is helpful to monitor treatment and communicate with health professionals.

Pain management

Why is pain management important?

Unidentified pain can cause significant physical and emotional distress in people living with dementia.

It can also cause adverse effects, such as muscle weakness, increased risk of falls, reduction in functional ability like walking and self-care activities, and delirium – which could present as sudden onset of increased confusion and fluctuating cognitive abilities, and contribute to responsive behaviours such as the patient being agitated, calling out, yelling, pushing people away or being withdrawn or isolated.

Pain is a common contributor to responsive behaviours in people with dementia in up to 80% of the cases.

Unidentified pain can also result in refusing and resisting personal care. This can add to increased care needs and the need for additional staff resources. Witnessing the effects of pain can often be stressful for family.

Optimal pain management

Pain management isn't solely based on the intensity of pain or a pain score, such as that generated when an Abbey pain assessment is done.

A good pain management plan is based on the type, duration and intensity of the pain. It takes into account the individual factors based on their physical abilities, mood, beliefs, lifestyle, culture and the environment they live in.

Pain interventions do not always have to be medications or a procedure. Often simple comfort measures are the most effective and have fewer adverse side effects.

When pain is persistent, the focus of pain management often shifts from fixing or curing the pain to managing the pain, with the aim to enhance quality of life, optimise physical function and reduce distress

Non-medicine based strategies

The most well-known non-medicine based strategies are reassurance, massage, heat packs, cold packs, and physical support, such as repositioning and supporting a limb.

Another highly recommended strategy is exercise. This can take the form of simple movements, dancing, stretches, chair yoga, walking, aerobic exercises and hydrotherapy. Activity that involves body movement has been found to not only improve function but also alleviate pain and improve quality of life. This can also be preventative and help with improving mood.

Other techniques are diversion, distraction and relaxation. These could be through music, art, mindfulness or group activity. All of these activities need to be adapted and tailored at regular intervals to each individual's interests, capability and unique pain needs.

How do these work?

A major transformation in our understanding of pain happened with the "Gate" theory. Imagine tiny gates in the brain and spinal cord that control the flow of the pain

messages from the body to the brain. When the gates are more open, the pain signals increase. Fear, anxiety, depression, and negative thoughts can all open the gates. When the gates are more closed, the pain intensity reduces. Simple processes like rubbing, and many of the psychological strategies like diversion, distraction, mindfulness and tai-chi can help to close the gates.

Complementary therapies

Complementary therapies such as aromatherapy, naturopathic remedies, Chinese medicine, chiropractic therapy, and remedial massage can also be used to treat pain.

From a medical or scientific perspective there is varying evidence to support the effectiveness of these strategies, however they still may have a role in pain management.

It is also important to be aware that these practices can have negative effects including further damage, cost and delay in effective treatment.

Medications and pain?

A commonly used first line medication for pain is Paracetamol. Paracetamol is the medication of choice for musculoskeletal pain, such as pain caused by arthritis.

Anti-inflammatory medications are commonly used for musculoskeletal pain but are to be used cautiously in the elderly. Even anti-inflammatory creams can cause side effects, as they are absorbed into the blood stream.

There are special drugs for nerve pain, such as anti-epilepsy drugs and anti-depressants that dampen the messages coming from damaged nerves. Strong painkillers like morphine tablets and pain patches are sometimes used for managing pain. These are powerful drugs and useful for new onset pain but their effect wears out over time. They can have serious side effects.

Consult your doctor before making changes to your medications.

Case study

Margaret is an 82-year-old retired teacher, a mother of four children and grandmother to seven, who enjoys knitting and gardening. She was diagnosed with dementia about seven years ago and has seen a significant decline in her general physical health in the last few years, particularly after sustaining a few falls. She has experienced lower back pain and knee pain due to living with osteoarthritis for many years. Following the death of her husband about a year ago, she moved into residential aged care. Her cognition has gradually declined over that period, with variable ability to communicate.

It took her a while to settle and occasionally she has been agitated, resistive and aggressive to carers. She needs assistance with her mobility but frequently attempts to walk. She has entered others' rooms and is verbally aggressive when asked to return to her own room. She denies pain when asked, but is frequently seen rubbing her back and knees.

She has been given Paracetamol as needed, but it is rarely used as she never requests it or says she is in pain. She was started on antipsychotics and sedatives to reduce her behaviours, which only made her more sedated.

The declining quality of life for Margaret, the increasing burden of care for the staff and a lack of a medication to fix the issues and its side effects are becoming more evident.

Possible solutions

It's important to take a personal approach to understanding Margaret, alongside a thorough assessment of the physical, psychological, social, cultural and spiritual factors contributing to her pain.

In acknowledging both the finer details and wider context of the situation, it's essential to involve Margaret, her family, carers, and health professionals.

In addition to identifying the problems, risks and barriers, look at the strengths, supports and positive aspects that can be valuable to Margaret.

Every solution needs to be adapted and individualised. Keep in mind Margaret's dignity and wishes at all times.

For example, a personal care plan for Margaret would include:

- Seeking her permission.
- Providing clear instructions.
- Encouraging her participation.
- Allowing her to direct the care.
- Modifying the care based on her physical comfort and choice.

Consider prescribed pain medications prior to personal care.

Environmental solutions such as a raised garden bed or indoor gardens, good seating arrangements, and frequent position changes to allow for movement and access to music and the outdoors can be useful engagement strategies.

Dementia Support Australia can provide a comprehensive pain review on request with the support of your local general practitioner.

This resource material is informed by literature and associate practice evidence. This guidance should be applied within your organisations policies and procedures.