Dementia Support Australia

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A service led by HammondCare

Identifying and **responding to pain**

Many people living with dementia will experience some form of pain. Understanding this pain can help you respond with the right care.

What do we mean when we talk about pain?

Pain is defined as an unpleasant sensory and emotional experience that may or may not also include physical tissue damage. Most importantly, pain can be a major factor contributing to changes in behaviour for someone living with dementia. This is often because the person may struggle to express their discomfort or needs clearly.

What types of pain are there?

Pain is common, up to 85% of people living in care homes and more than 50% of those living in the community or hospitalised with dementia have pain.

Pain can be categorised by duration:

- **Acute pain –** lasts for as long as the trigger exists, e.g. infection, contractures.
- **Recurrent pain –** when acute pain flares up or worsens due to an underlying disease.
- **Chronic (or persistent) pain –** pain that typically lasts for 3 or more months.

Pain can also be categorised by location:

- **Nociceptive (or inflammatory) pain –** caused by tissue damage, e.g. sprains or gout.
- **Neuropathic pain –** caused by damage to the nervous system, e.g. post-shingles pain.
- **Mixed-type pain –** a combination of both tissue and nervous system pain.

Common sources of pain include osteoporosis, osteoarthritis, headaches, gout, diabetes, fractures, contractures, dental pain, constipation, chronic leg cramps and shingles.

Recognising signs of pain

The same cognitive factors that cause dementia may also impair a person's ability to recognise and effectively communicate that they are in pain. Alternatively, a person may have lived with a particular pain for most of their lives so that it seems normal, or perhaps are no longer sure how to manage this pain as they previously did. In these situations, pain may go unrecognised or undetected. This is why it is important to frequently note any changes in behaviour and their general mood and wellbeing. Pain should always be considered as a possible cause.

Assessing pain in people living with dementia

What to look for	What do to
Increased moving around or has different facial expressions	Use a checklist to know how bad the pain is. When asking whether the person is in pain, be mindful that just because someone may not answer the question, this does not mean they are not in pain. Ask the person "Are you hurting?", or "Are you sore?". You could try pointing at the spot where the person would usually have pain like their lower back and say "Is your back giving you trouble?"
Having difficulty moving or is scared to move, or is holding a part of their body	Observe the changes in mobility and normal functioning, and consider if this could be pain related. If movement is not causing too much pain, encourage them to move as this may help. Not moving can make the pain worse. Refer to a GP to detect the underlying issue.
Not sleeping well	Support the person to keep active during the day, listen to music they like or ask the doctor if they should take pain medication before bed.
Not eating as much	Prepare small meals they like throughout the day. Review their pain at different times. Refer to a GP to make sure there isn't another underlying issue.
Withdrawn or more quiet than usual	Have someone they trust sit with them to encourage talking. Look at their body language to find out when is a good time to start speaking and give them time to reply.
Distressed during personal care	Be gentle and patient during personal care routines and consider adjusting techniques or coming back at a later time.
Increased calling out	Assess whether the calling out may be a sign of pain or a different unmet need. Then take time to redirect their focus e.g. music or providing them comfort.
Physical aggression	Approach gently and attempt to note any source of the pain. Consider a further referral to DSA or the GP.

- **Regular pain assessments** should consider past and present medical and psychosocial history, as well as the day-to-day environment.
- **Pain is subjective** – ask simple and specific questions - "are you in pain", or "does your knee hurt".
- **Just because someone says 'no'** or is unable to respond, does not mean pain is not present. Watch for other signs of pain such as slower movement or facial grimacing.
- **Assess for pain during activities** that involve both rest and movement.
- **If there are changes** to the care plan, to normal routine or a significant clinical event (e.g. falls and infections), re-assess for signs of pain.
- **The Abbey Pain Scale or the PAINAD Tool** provide a way to measure pain, particularly if someone is unable to communicate verbally.

More information on pain and pain assessment in dementia, including the Abbey Pain Scale can be found at dementia.com.au/resource-hub. To download the PainChek app visit painchek.com

Is the pain sudden and severe?

Is it a life threatening or emergency situation? Call 000