

Tips for Nurses: Advanced Dementia



What it is: Dementia is a group of progressive neurological illnesses with a long, slow pattern of decline over many years. Alzheimer's disease is the most common form of dementia, but there are others and it is not limited to older people. Definitions of advanced dementia vary. Dementia Australia defines it as the third stage where the person is severely disabled and needs total care. Dementia is a life-limiting illness.

Why it matters: Need for palliative care depends on the stage of illness and co-existing conditions. It is indicated in advanced stages. Care provided and planned by nurses is important to support a person's often complex needs. People with dementia often have other diseases including cardiovascular and pulmonary disease. Pain is common. These can add to the frailty and decline of a person and may indicate need for palliative care.

What I need to know: Palliative care with dementia supports a focus on care and quality of life to enhance comfort and functioning of the person. It can be difficult to know when a person with dementia is approaching the end of their life.

Many people with dementia receive palliative support in the community. Often by the time a person enters an aged care facility they have advanced dementia. Even if a person with dementia is unable to speak, they may still sense the presence of loved ones, and experience fear and loss. A person with advanced dementia may experience loss of:

- memory
- rationality and judgement
- communication
- social skills
- inhibition
- physical functioning.

This can be frightening for the person and their family.

As dementia advances people may lack capacity to:

- attend to daily tasks and hygiene
- make decisions
- speak
- respond
- swallow
- move purposefully.

Actions

Be patient and remain calm. When talking allow plenty of time for a response.

Remember changes in behaviour and personality are common, including aggression, apathy, agitation and anxiety. But these often reflect a need such as pain relief or fear, but not the person's personality.

Use language and a time frame in a context that the person understands.

Suggest what they can do, instead of focusing on what they can't do.

Conducting case conferences with the person and their family can help to manage and plan care. A person can nominate a substitute decision-maker to make decisions on their behalf when they are unable to make decisions themselves.

Check for signs of deterioration such as changes in:

- level of pain
- alertness
- care needs
- behaviour e.g., agitation or distress
- oral intake
- sense of comfort or discomfort.

Note who is the person's appointed substitute decision-maker and the extent of their decision-making power.

Tools

Tools that may be useful include:

Abbey Pain Scale – useful if a client is unable to communicate their pain

Pain Assessment in Advanced Dementia Scale (PAINAD)

Name:

My reflections:

How many of the people I care for have dementia and how do careworkers/personal attendants report any changes in their behaviour to nursing/supervisory staff?

What do I do for people with dementia to help with communication or to assess for pain?

Are there people who show varied response depending on which staff attend them?
What might this mean?

My notes:

See related palliAGED Practice
Tip Sheets:
Case Conferences
Palliative Care
Recognising Deterioration

For references and the latest version of all the Tip Sheets visit
www.palliaged.com.au/PracticeTipSheets