



Symptom management in palliative dementia care

Physical symptoms commonly experienced by people with advanced dementia include pain, difficulties with hydration and nutrition, dyspnoea and infection. Non-pharmacological approaches are generally first-line, with medicines used as needed to meet the goals of care. For patients who are in the terminal phase of dementia, parenteral administration of medicines is often, but not always, necessary due to problems with swallowing.

This is the final topic in a series on cognitive impairment and dementia in older people. This article should be read in conjunction with "Understanding the role of palliative care in people with advanced dementia" see: www.bpac.org.nz/2020/palliative1.aspx

Pain



Pain is prevalent among people with advanced dementia, e.g. from co-morbidities, current or previous injuries, poor oral health, pressure sores.¹ Problems expressing or communicating the level of pain can lead to behavioural or psychological symptoms of dementia (BPSD) and consequently inappropriate prescribing of antipsychotics rather than adequate pain relief.²

Use a dementia specific pain tool alongside clinical assessment to identify pain in people with dementia, e.g. the Abbey Pain Scale: www.apsoc.org.au/PDF/Publications/APS_Pain-in-RACF-2_Abbey_Pain_Scale.pdf

Consider reversible/treatable causes, e.g. constipation, improperly fitting hearing or mobility aids or supports, immobility, infection, previous history of chronic pain. Once these have been addressed, reassess the patient for pain.

Key recommendations about pain management in dementia:¹

- Non-pharmacological interventions may include:
 - Body positioning
 - Ensuring comfortable and supportive seating or bed
 - Massage
 - Environmental modifications, e.g. adjusting temperature or lighting, music
 - Improving sleep
 - Practicing spiritual or faith activities
 - Social and cultural engagement
- If analgesia is indicated, a stepwise approach following the general principles of the WHO analgesic ladder is recommended, starting with regular paracetamol.³ There is limited evidence to guide NSAID use in people with dementia, however, they may be considered with caution in combination with paracetamol, before stepping up to an opioid.⁴

- When stepping up treatment, expert opinion is that the analgesic benefits of the weak opioids recommended at step 2 of the WHO analgesic ladder (e.g. codeine or tramadol) do not outweigh the increased risk of adverse effects, particularly constipation. Starting with a low dose strong opioid (morphine) is preferable in terms of effectiveness and tolerability.
- There is limited data on use of opioids in people with dementia, and there is uncertainty about the effectiveness and sensitivity to adverse effects in this group.⁴ Follow a “start low, go slow” approach to prescribing, taking into consideration potential medicine interactions, and monitor for adverse effects.
- Consider alternative formulations (e.g. liquid) and routes of administration (e.g. subcutaneous or transdermal) for patients who have difficulties swallowing; discuss with a pharmacist if necessary

👁 For further information on pain management in palliative care, refer to the Palliative Care Handbook: www.hospice.org.nz/wp-content/uploads/2019/07/2.-PCH-18-Pain.pdf

👁 For further information on using strong opioids for pain management in palliative care, see: www.bpac.org.nz/BPJ/2012/December/opioids.aspx



Nutrition and hydration

Advanced dementia is associated with a reduced desire to eat, forgetting how to eat or what food is, and a loss of chewing and swallowing abilities, resulting in reduced calorie intake and weight loss.

Strategies that may help to improve oral intake include:^{2,3}

- Ensuring that the patient has no underlying oral health issues and has good oral hygiene, e.g. denture care
- Offering food choices that are good quality, attractively presented and appeal on multiple sensory levels to maximise eating cues
- Providing food that is appropriate to the patient’s cognitive level and swallowing abilities, e.g. pre-cut, softer or pureed foods, smaller portion sizes more frequently, finger foods where the ability to use cutlery has been lost

- Allowing more time for the person to eat meals in an environment that minimises distractions
- Feeding the person by hand – a swallowing assessment is often needed to check safety; refer to a speech/language therapist if necessary⁵
- Oral nutritional supplements (e.g. Ensure or Fortisip) may be considered for patients who are malnourished and unable to maintain body weight by food intake alone. These should be given between meals, not as a meal replacement.
- Consider referral to a dietitian for nutritional assessment and a care plan, which may include recommendations for strategies such as food fortification (e.g. with iron if deficient), meal timing/frequency and oral nutrition support

N.B. If the patient is unable to swallow tablets needed for symptomatic treatment, consider alternative formulations (e.g. liquid) and routes of administration (e.g. subcutaneous or transdermal); discuss with a pharmacist if necessary. Preventative treatments, e.g. statins, anti-hypertensives, aspirin, bisphosphonates are likely to have been discontinued by this stage.

The role of artificial hydration and nutrition is limited for people with advanced dementia

Persistent loss of appetite, weight loss, difficulties swallowing or recurrent aspiration in a person with advanced dementia should trigger discussions with the person’s EPOA and family/whānau about maintaining nutrition and hydration. Ideally, the person’s preferences will have been discussed and documented in their care plan.

Artificial nutrition (enteral feeding tubes or parenteral feeding) is generally **not recommended** for people with advanced dementia and is usually only considered if requested by the family and is clinically appropriate.^{6,7} Artificial nutrition **does not increase survival** and is associated with potential harms, e.g. complications from tube placement such as pain, infection or bleeding, diarrhoea, constipation and reflux, aspiration, pneumonia and fluid overload.⁸ Subcutaneous or intravenous fluids may be used with caution during an acute illness, avoiding fluid overload.³ Parenteral fluids are not generally appropriate at the very end of life; swabs soaked with water or a saliva substitute may be used to relieve dry mouth symptoms.^{1,3}





Dyspnoea

The incidence of dyspnoea (shortness of breath) increases as people near the end of life.

Potential causes include aspiration, pneumonia, heart disease, chronic obstructive pulmonary disease, tumours, asthma, pain (e.g. rib or vertebral fracture), neuromuscular failure, ascites, pleural effusion,

anaemia, sepsis and anxiety.¹ It may not always be possible to identify a treatable cause.²

Assessing dyspnoea in people with advanced dementia can be difficult as these patients are often unable to self-report symptoms. Indicative symptoms and signs include increased heart and respiratory rates, accessory muscle use, paradoxical breathing pattern (abdomen moves in on inspiration), restlessness, grunting at end-expiration, nasal flaring and looking fearful.⁹ The Respiratory Distress Observation Scale (RDOS) scores each of these parameters from zero to two points, with a total score from zero (no distress) to 16 (severe distress).⁹ The scale can be accessed here: www.homecareinformation.net/handouts/hen/Respiratory_Distress_Observation_Scale.pdf

Key recommendations for managing dyspnoea:²

- Identify and relieve the underlying cause, if possible
- Use non-pharmacological interventions to provide symptom relief, for example:
 - Using a fan or fresh air on the face
 - Breathing techniques and positioning
 - Oxygen is not recommended routinely as it may cause irritation and distress, however, if the patient is agitated and hypoxic, e.g. oxygen saturation < 90%, a trial of oxygen may be appropriate
- Pharmacological interventions include:
 - Low-dose oral morphine; treatment should be initiated at a low dose (i.e. 2.5 mg) and carefully titrated upwards to effect
 - Benzodiazepines may be used to reduce anxiety where other methods (i.e. opioids) have been unsuccessful, e.g. oral lorazepam 500 micrograms (half a 1 mg tablet), every four to six hours, as required; oral diazepam, 2–5 mg given at night if there is continuous anxiety; midazolam 2 mg to 5 mg subcutaneously, every four to six hours, as required, or intranasal midazolam (not funded), if oral route not available.¹⁰ Consider the increased risk of respiratory depression when prescribing these medicines.

- Anticholinergic medicines to reduce secretions (e.g. hyoscine butylbromide (20 mg, subcutaneously [unapproved indication])^{2,11} – there is limited evidence of their overall effectiveness, however, these are prescribed by some clinicians to reduce the secretions associated with end of life. Consider these if the patient is distressed by the amount of secretions. N.B. these medicines can worsen delirium at the end of life.

 For further information on the pharmaceutical options for the palliative management of respiratory symptoms, see: www.nzf.org.nz/nzf_70691

 For further information on managing breathlessness in palliative care, see: www.bpac.org.nz/bpj/2012/october/breathless.aspx

Infection

Infections, particularly pneumonia and urinary tract infections (UTIs), are common in people with advanced dementia and can often be the cause of death.³



Key recommendations for managing infection:³

- Consider infection in patients with unexplained changes in behaviour, e.g. agitation, increased confusion
- The decision to treat an infection with antibiotics should be guided by the patient's care plan and discussions with their EPOA and family/whānau
- Symptomatic treatments for pneumonia include:
 - A trial of oxygen to relieve dyspnoea – only if the patient is hypoxic and symptomatic
 - Opioids to control pain and dyspnoea
 - Anticholinergic medicines to reduce secretions – see “Key recommendations for managing dyspnoea”
 - A benzodiazepine or antipsychotic to reduce anxiety and agitation, after trialling low dose morphine
- Symptomatic treatments for UTI include:
 - Increasing oral fluid intake (if possible)
 - Using a urine alkalinising agent (e.g. Ural sachets)
 - Pain management
 - Benzodiazepine or antipsychotic to reduce confusion or agitation related to the UTI



Role of sedation

Sedatives may be required intermittently or continuously in people with advanced dementia. Intermittent sedation is typically used to relieve psychomotor agitation.

Continuous sedation (also called palliative sedation) is only used at the end of life to relieve suffering when other causes have been addressed or symptomatic treatments are ineffective.² Continuous sedation often uses much higher doses than intermittent sedation, and is typically managed by specialist palliative care clinicians.

Medicines for sedation include:²

- Benzodiazepines, e.g. midazolam, lorazepam
- Sedating antipsychotics, e.g. levomepromazine (see note below)
- Strong opioids, e.g. morphine, oxycodone (only consider if the patient is allergic to or cannot tolerate morphine)

 A new formulation of Nozinan® (Swiss Stock) has been supplied in New Zealand to cover a shortage of the original formulation of levomepromazine maleate (oral). There is a difference in the levomepromazine maleate quantity between the original and Swiss formulation, therefore there are different dosing recommendations for the Swiss formulation of Nozinan. See the NZF for information on dose adjustments: www.nzf.org.nz/nzf_2136

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This article is available online at:
www.bpac.org.nz/2020/palliative2.aspx

