



An Australian Government Initiative

# Key Elements of a Palliative Approach for People with Severe and End Stage Dementia



A booklet developed for health care professionals



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## References for Key Guidelines/Recommendations

Key guidelines and recommendations are shown in green boxes throughout the document and those provided before page 21 are all quotes from the sources noted in brackets, although, for ease of reading, quotation marks have been omitted.





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## Introduction

Although most people who have progressive dementia live with dementia for many years, its expected outcome is death; therefore, dementia is best classified as a terminal illness (Sachs, Shega, & Cox-Hayley, 2004). A palliative approach is a holistic approach that aims to enhance quality of life - and quality of death - for people with such illnesses. This approach also includes support for the family, both during the illness and in bereavement, and is provided by a (generalist) multidisciplinary team with input from specialist palliative care services when needed (Australian Government, 2006a).

Although a palliative approach is not restricted to the end of life, this booklet considers the approach in severe and end stage dementia, in particular, when death within the next 6 months would not be surprising to clinicians. Despite the likely inaccuracy of this clinical estimate, such a focus, recognising impending death, is timely during late stages of the insidious, dementia related, health decline (Lynn, 2005).

The booklet has been developed as a 'dementia specific' addition to the Western Australian Palliative Care Resource Kit (Western Australian Palliative Care Network, 2010). Other resources in this kit are also useful for people who have dementia. However, the booklet concentrates on the needs of people who have dementia so severe that they cannot respond to questions about their symptoms; it also recognises the need to re-examine goals of care towards the end of life when there may not be the obvious and sudden change in health status that more commonly occurs in cancer patients.

Symptoms and conditions addressed in this booklet are frequently encountered in severe dementia and are included under the headings of:

- pain,
- conditions and issues relevant to nutrition and hydration,
- delirium, and
- agitation.

The complexity of care needs for people who have severe dementia requires more than a clear understanding of these topics. It is also essential to recognise:

- potential inter-relationships among the symptoms and conditions (for example, when pain both limits appetite and triggers delirium or when agitation occurs in delirium) and
- the impact of additional, co morbid conditions that may cause further symptoms (eg, lung disease causing shortness of breath).

From the most basic perspective, symptoms need to be assessed and managed, with the goal of care being the best possible quality of life of the person. Symptom assessment recognises the necessity of careful monitoring of the person's condition during this subtle, yet unremitting, health deterioration. Symptom assessment encompasses:

- an understanding of symptoms, that, from the client's history, are likely to be experienced;
- a meticulously conducted physical examination;
- observations of behaviours; and
- using appropriate symptom assessment tools that provide clear and consistent protocols for assessment plus an opportunity to rate and compare symptom levels.

Symptom management involves addressing the causes of symptoms or, when this is not feasible or appropriate, minimising symptom distress; it may involve pharmacological and non-pharmacological 'traditional' approaches and Complementary and Alternative Medicine (CAM) therapies (eg, aromatherapy, massage and touch, music therapy, and multi sensory therapy). However, there are numerous considerations when the person has severe dementia. For example, most people with severe dementia are elderly, requiring medication usage to be tailored appropriately; dysphagia is common in severe dementia, affecting the use of oral medications; and self reporting of adverse effects from treatments is unachievable.

The booklet provides key recommendations and links to resources<sup>1</sup>; it does not provide a comprehensive guide to practice but a starting point from which practitioners may seek additional information. Most resources listed are available via CareSearch, the Australian Government funded Palliative Care Knowledge Network, and almost all are freely available via the internet. Because of the high proportion of aged care residents experiencing dementia, some recommendations and resources are drawn from documents developed for residential aged care. Updates of resources cannot be guaranteed but we have generally chosen those provided by peak bodies or government, for which updates are likely. Some resources are not specific to individual symptoms (see Table 1).

All web links listed in this booklet were correct at the time of printing but may be subject to change.

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<sup>1</sup> Links to resources are provided in tables that also show the references to the resources in full. These references are not duplicated in the reference list at the end of the booklet.

**Table 1: Key relevant palliative care resources that are not symptom specific<sup>2</sup>**

Brief Description	Reference and/or Web Access
Evidence based guidelines for a palliative approach in residential aged care with many transferable recommendations that are relevant in severe dementia in other settings.	Australian Government (2006). <i>Guidelines for a palliative approach in residential aged care, enhanced version</i> . Canberra, ACT: Author. Available from CareSearch <a href="http://www.caresearch.com.au">www.caresearch.com.au</a> click on Clinical Practice/Specific Populations/Aged Care Facilities.
A suite of resources to support the Australian Government's (2006) Guidelines for a Palliative Approach in Residential Aged Care). Includes 'Online Education for GPs in Aged Care Homes' and palliative care training modules for residential care staff.	Available from Palliative Care Australia <a href="http://www.palliativecare.org.au">www.palliativecare.org.au</a> click on Professional Resources.
Resource for the quality use of medicine for older patients <sup>3</sup> .	Australian Medicines Handbook Pty Ltd. (2003). <i>Australian medicines handbook drug choice companion: Aged care</i> . Melrose Park, SA: Author. Available from the Australian Medicines Handbook website <a href="http://www.amh.net.au/">http://www.amh.net.au/</a>
Therapeutic guidelines specific to palliative care.	Palliative Care Expert Group. (2010). <i>Therapeutic guidelines: Palliative care</i> (3rd ed.). Melbourne, Vic: Therapeutic Guidelines Limited. Link to purchase option available from CareSearch <a href="http://www.caresearch.com.au">www.caresearch.com.au</a> click on Clinical Practice/ Physical/ Pain/Health Service Issues.
Australian standards for palliative care provision.	Palliative Care Australia. (2005). <i>Standards for providing quality palliative care for all Australians</i> . Deakin West, ACT: Author. Available from Palliative Care Australia <a href="http://www.palliativecare.org.au">www.palliativecare.org.au</a> click on Standards/ National Standards.

<sup>2</sup> Another potentially useful resource, although not focussed on palliative care or severe dementia, is as follows: National Ageing Research Institute. (2009). *Dementia resource guide*. Canberra, ACT: Australian Government Department of Health and Ageing. See <http://www.health.gov.au> click on For Consumers/Conditions and Diseases/Other Health Issues/Dementia.

<sup>3</sup> Other useful resources relevant to medication use can be accessed via the Australian Government's Health *Insite* Medicines page at <http://www.healthinsite.gov.au> click on Topics/Medicines.

# Pain

People with severe dementia are at a high risk of experiencing pain (Australian Pain Society, 2005). In part, this is because dementia is most common in older age groups, and some causes of chronic pain, in particular (eg, osteoarthritis), become more likely in older people. However, additional painful conditions, such as contractures, are also likely as dementia progresses.

## Pain vigilance and assessment

### *Key guidelines or recommendations relevant to pain vigilance*

1. Advanced dementia should be recognised and managed supportively as a terminal illness. It needs to be recognised that these patients are at high risk of uncontrolled symptoms, in particular pain (Australian and New Zealand Society for Geriatric Medicine, 2009, p. 1).
2. Healthcare professionals should be trained in the management of pain, be experienced in the use of relevant pain assessment tools and be extra vigilant for signs of pain in people with dementia (Gove et al., 2010, p. 139).

Given the limited ability of people who have severe dementia to communicate, pain vigilance requires the practitioner to:

- observe for signs of pain, including incident pain (eg, pain on movement);
- consider informant reports, such as those from family members; and
- consider potential causes (informed by the history and a physical examination) (Australian Pain Society, 2005).

Pain assessment tools for people with severe dementia also involve behavioural observation. A recent systematic review (Zwakhalen, Hamers, Abu-Saad, & Berger, 2006) identified 12 such behavioural pain scales. The Australian Pain Society (2005) recommends the Abbey Pain Scale<sup>4</sup> for use in residential aged care.

<sup>4</sup> Abbey, J., Piller, N., De Bellis, A., Esterman, A., Parker, D., Giles, L., et al. (2004). The Abbey pain scale: A 1-minute numerical indicator for people with end-stage dementia. *International Journal of Palliative Nursing*, 10(1), 6-13.

## *Key guidelines or recommendations relevant to pain assessment<sup>5</sup>*

1. If a person with dementia has unexplained changes in behaviour and/or shows signs of distress, health [and social care] professionals should assess whether the person is in pain, using an observational pain assessment tool if helpful. However, the possibility of other causes should be considered (National Institute for Clinical Excellence, 2006, p. 33).
2. Structured procedures must be used to identify the cause(s) of pain, pain intensity and the impact of pain on [a resident's] activities of daily living, mood, sleep and quality of life (Australian Pain Society, 2005, p. xii).
3. Assessment [of aged care residents with advanced dementia] using dementia-specific pain assessment tools results in more attentive symptom relief for pain and discomfort (Australian Government, 2006a, p. 8).

## **Pain management**

Despite the moral imperative that exists to minimise pain in dying patients, evidence indicates that pain is often poorly managed in people with severe dementia (Australian Pain Society, 2005; Mitchell, Kiely, & Hamel, 2004; Mitchell, Morris, Park, & Fries, 2004; Mitchell, Teno, Kiely, Shaffer, Jones, Prigerson, et al., 2009). Recommendations address the need for well trained staff, the use of both pharmacological and non-pharmacological approaches, and the adaptation of the World Health Organisation's (1996) cancer focussed analgesic ladder for use in severe dementia. The potential for adverse effects from medications (eg, opioid related constipation) also needs to be considered and addressed.

The Australian Pain Society (2005) has recommended strategies for pain management in residential aged care, recognising benefits of combining pharmacological and non-pharmacological approaches. However, some forms of massage (eg, deep tissue massage, see p. 48) are noted to be harmful when used for frail older people and the application of superficial heat is regarded as inappropriate in severe dementia (p. 40). The Australian Pain Society draws particular attention to the avoidance of precipitating pain during manual handling, especially when contractures are present (p. 42).

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<sup>5</sup> Square brackets have been used to indicate words that may be omitted to enhance applicability in the context of this booklet.



## Key guidelines or recommendations relevant to pain management

1. New acute pain or remediable persistent pain should be diagnosed promptly and treated appropriately (Australian Pain Society, 2005, p. xii).
2. Successful pain management is enhanced by the correct diagnosis of the cause(s) of pain because the underlying cause may be remediable and because different types of pain respond to different treatments (Australian Pain Society, 2005, p. xii).
3. The treatment of pain in people with severe dementia should involve both pharmacological and non-pharmacological measures. Non-pharmacological therapies should be used with the person's history and preferences in mind (National Institute for Clinical Excellence, 2006, p. 33).
4. The WHO [World Health Organisation] three-step ladder for treating pain in cancer patients should be adapted for the treatment of pain in end-stage dementia (Gove et al., 2010, p. 139).
5. Medications should, generally, be commenced at a low dose, monitored and titrated slowly as required. More frequent monitoring, dose adjustment and higher doses should be implemented for severe pain as recommended in the Australian Pharmaceutical Advisory Council's Guidelines for Medication Management in Residential Aged Care Facilities 2002<sup>6</sup> (Australian Pain Society, 2005, p. 21).
6. A short-acting analgesic should be used for infrequent or incident pain while controlled release analgesics are best given regularly (around the clock) for persistent or frequently recurring pain. Short-acting analgesics may be necessary when controlled release analgesics do not control the pain adequately (breakthrough pain) (Australian Pain Society, 2005, p. 21).
7. For predictable or incident pain, analgesics are often more effective when given prior to an activity that is known to induce or aggravate pain, for example, changing a wound dressing or changing position (Australian Pain Society, 2005, p. 21).

<sup>6</sup> Australian Pharmaceutical Advisory Council. (2002). *Guidelines for medication management in residential aged care facilities* (3rd ed.). Canberra, ACT: Australian Government. Available from [www.health.gov.au](http://www.health.gov.au) click on For Health Professionals/Aged Care/ Publications.

## Opioids and pain management

Low level evidence and expert opinion indicates that pain management for those with severe dementia is sometimes compromised by misconceptions about opioid use (Arcand et al., 2009; Australian Government, 2006b; Waldrop & Kirkendall, 2009). A discussion around care related goals that anticipates families' questions about the dying process and focuses on the minimisation of suffering may provide a forum in which to address this problem (Lo & Rubenfeld, 2005). Concerns may include that opioids cause addiction; are inappropriate for older people, cause respiratory depression, and hasten death; and should not be commenced too early, or they will be of little benefit when pain worsens (Australian Government). To address these concerns, the following information is provided:

- Although physical dependence and tolerance may occur, it is extremely unlikely that psychological dependence (addiction) will result from the use of an opioid for severe pain in people with severe dementia (Australian Government, 2006b). Opioids are usually administered when all other non-pharmacological and pharmacological treatments have failed and, therefore, opioids are the only way to relieve suffering (Lo & Rubenfeld, 2005). Families may feel that their relative has died a 'good death' when suffering has been minimal (Economist Intelligence Unit, 2010; Jerant, Azari, Nesbitt, & Meyers, 2004; Lo & Reubenfeld).
- Older people are known to be more sensitive to opioid use so "a good principle when using opioid therapy in older individuals is 'start low and go slow'" (Australian Pain Society, 2005, p.24). Some opioid preparations also need to be used with additional caution (Australian Pain Society). Practitioners with appropriate understanding of such issues can tailor opioid usage for the individual to ensure the reduction of suffering with minimal adverse effects.
- Experts determine that there is no ceiling to the analgesic benefits of opioids. Instead, addressing pain earlier may make pain more manageable and failing to address chronic pain can have serious effects, even hastening death (Australian Government, 2006b).

**Table 2: Key resources for pain assessment and management**

Brief Description	Reference and/or Web Access
<p>Expert report that includes pain assessment when the person with dementia cannot respond to questions and appropriate pain management.</p>	<p>Australian Pain Society. (2005). <i>Pain in residential aged care facilities: Management strategies</i>. Sydney, NSW: Author.</p> <p>Available from the Australian Pain Society <a href="http://www.apsoc.org.au">www.apsoc.org.au</a> or CareSearch <a href="http://www.caresearch.com.au">www.caresearch.com.au</a> click on Clinical Practice/Specific Populations/Aged Care Facilities.</p>
<p>Toolkit to support the practical implementation of recommendations from the Australian Pain Society's (2005) Report.</p>	<p>Australian Government (2007). <i>The PMG kit for aged care: An implementation kit to accompany the Australian Pain Society's 'Pain in residential aged care: Management strategies'</i>. (P3 - 1609). Canberra, ACT: Author.</p> <p>Available from the Australian Pain Society <a href="http://www.apsoc.org.au">www.apsoc.org.au</a> or CareSearch <a href="http://www.caresearch.com.au">www.caresearch.com.au</a> click on Clinical Practice/Specific Populations/Aged Care Facilities.</p>
<p>A suite of resources that cover pharmacological and non pharmacological approaches and medication issues specific to older people; they also address 'opioid myths'.</p>	<p>Blue Mountains Division of General Practice, University of Western Sydney, Sydney West Area Health Service, Palliative Care Dementia Interface: Enhancing Community Capacity Project (Australian Government). (2009). <i>Decision-making framework for pain management: Guidelines, supporting information, and train the trainer</i> [Booklets]. Penrith South, N.S.W: Author.</p> <p>Available from CareSearch <a href="http://www.caresearch.com.au">www.caresearch.com.au</a> click on ClinicalPractice/ Specific Populations/People with Dementia/ Decision Making Frameworks.</p>

## Conditions and issues relevant to nutrition and hydration

Over the course of the dementia trajectory, maintaining oral intake of food and fluids can be challenging. Oral health and dysphagia are two issues that can impact upon both adequate oral intake and comfort in severe dementia. Weight loss may cause concern and can become inevitable as death draws near. Artificial nutrition and hydration are not generally considered a helpful option in severe dementia.

### Oral health

Concerns around oral health in dementia include salivary dysfunction, oral hygiene and dental care, and the existence of tooth decay and gum disease (Chalmers & Pearson, 2005). Frequent, regular, oral health assessments provide an opportunity to detect and manage oral problems. An oral health assessment tool that is suitable for use with people with dementia is the Brief Oral Health State Examination (BOHSE), developed by Kayser-Jones and colleagues in 1995 (cited in Chalmers & Pearson). A modified version, trialled in Australian residential care facilities, requires no equipment other than clean gloves (Chalmers, King, Spencer, Wright, & Carter, 2005) and has been further tested and modified in a more recent Australian project (Fricker & Lewis, 2009). In that project, specially trained registered nurses were able to undertake oral health assessments using the BOHSE (Fricker & Lewis, p. 27).

Attention to oral care in severe dementia is a priority. However, it can be difficult to obtain adequate oral access. When feasible, cleaning teeth with water, a soft toothbrush and toothpaste, and/or regular soaking of dentures in a weak non-toxic solution is effective (Australian Government, 2006b). There are strategies for improving oral access, and fluoride and antimicrobial mouth sprays and gels have been recommended for when brushing is not feasible (Fricker & Lewis, 2009; Joanna Briggs Institute, 2004). However, towards the end of life, appropriate oral care needs to prioritise comfort. Conditions that are common at that time, including xerostomia (dry mouth) and stomatitis/mucositis (inflammation of the mouth or lips), which can be particularly painful (Palliative Care Expert Group, 2010, p. 231), need to be detected and treated.

## Key guidelines or recommendations for oral care<sup>7, 8</sup>

1. Rinsing the mouth with water and cleansing teeth with a soft toothbrush and toothpaste is an effective oral cleansing routine that is cost-efficient and reduces the [resident's] risk of oral mucositis (mouth ulcers) (Australian Government, 2006a, p. 10).
2. Access to the mouth may be improved by stimulating the root reflex<sup>9</sup> – that is, stroking the cheek in the direction of the mouth (Fricker & Lewis, 2009, p. 27).
3. Modified dental equipment, such as a backward bent toothbrush may also be helpful in improving mouth access (Fricker & Lewis, 2009, p. 27).
4. Dry mouth products are more therapeutic than moistened swabs to hydrate the mouth (Fricker & Lewis, 2009, p. 27). However, substances with a PH lower than 5.5 (acid condition; for instance, lemon and glycerine) or alcohol as an ingredient are not recommended and should be avoided (Fricker & Lewis, 2009, p. 27).

## Dysphagia

Severe dementia is often associated with swallowing problems (dysphagia) (Robinson et al., 2005); careful monitoring of swallowing is therefore important. Safe swallowing strategies are essential in dysphagia and may be tailored to the individual by a speech pathologist (Australian Government, 2006a). Paying careful attention to issues such as when the person is more alert and which foods and fluids they enjoy is also important to encourage adequate nutrition. Supplements may be helpful, and appropriate supplements for individuals may require recommendations from a dietician (Blue Mountains Division of General Practice, University of Western Sydney, & Sydney West Area Health Service, 2009).

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<sup>7</sup> Square brackets have been used to indicate words that may be omitted to enhance applicability in the context of this booklet.

<sup>8</sup> Many recommendations from the Evidence Based Practice Information Sheet for Health Professionals titled 'Oral hygiene care for adults with dementia in residential aged care facilities' (Joanna Briggs Institute, 2004), also merit consideration in severe dementia (see Table 3).

<sup>9</sup> Otherwise known as the rooting reflex, also observed in infants.

## Weight loss and cachexia

Weight loss is common in severe dementia and, when appropriate, treatable reasons for weight loss should be addressed (Abbey, 2006). However, when weight loss is considerable, it can be due to cachexia. Cachexia is a condition in which an individual is unable to absorb adequate nutrients from food, even when intake is sufficient; it may be viewed as a way of the body preparing itself for death, with the person no longer wanting food and becoming very tired and weak (Abbey). When cachexia has been diagnosed, the best approach is to carefully feed the individual foods that he/she prefers and is able to swallow (Australian Government, 2006a). However, oral intake may not be an option as death approaches. Impeccable communication with the family about the ability of the person with dementia to swallow and/or absorb diet and fluids helps minimise misunderstanding around this issue (Australian Government). If communication about the expected trajectory has occurred earlier, cessation of oral intake may not present as a crisis but as part of an inevitable process in which quality of life is the prime consideration.

### *Key guidelines or recommendations related to dysphagia, weight loss, and cachexia<sup>10</sup>*

1. A formalised multidisciplinary management program that includes input from a speech pathologist is beneficial in promoting early recognition, appropriate management and prevention of complications associated with dysphagia (Australian Government, 2006a, p. 10).
2. For frail residents with substantial weight loss who are unable to have sufficient oral calories, a trial of single nutrients or liquid meal replacements is an appropriate alternative (Australian Government, 2006a, p. 10).
3. A review of a resident's clinical history, the presence of substantial weight loss, laboratory tests and physical examination are required to make an accurate diagnosis of cachexia (Australian Government, 2006a, p. 10).

<sup>10</sup> Although these guidelines were developed for residential aged care, they have strong relevance to the care of people with severe dementia in any setting.

## Artificial nutrition and hydration

Artificial Nutrition and Hydration (ANH) involves medical treatment to allow a person to receive nourishment by tube (Casarett, Kapo, & Caplan, 2005). ANH can be provided enterally, via a nasogastric tube or a Percutaneous Endoscopic Gastrostomy (PEG) tube; it can also be administered parenterally (Casarett et al.; Sampson, Candy, & Jones, 2009). In severe dementia, any consideration of ANH is potentially emotive, confronting, and ethically complex (Gillick, 2000; Sampson et al.).

Common reasons for the use of ANH are to prolong life by correcting malnutrition; reduce the risk of aspiration and pressure ulcers, pneumonia and other infections; optimise quality of life by promoting physical comfort; and respond appropriately to religious or cultural beliefs (Casarett et al., 2005; Gillick, 2000; Sampson et al., 2009). With the exception of adherence to religious or cultural requirements, the evidence does not establish that ANH achieves any of these outcomes in severe dementia (Sampson et al.).

There is also evidence that the use of ANH in severe dementia increases discomfort, mortality, and morbidity; and that it reduces quality of life (Alvarez-Fernandez, Garcia-Ordonez, Martinez-Manzanares, & Gomez-Huelgas, 2005; Mitchell et al., 2004; Sampson et al., 2009). Some of the issues associated with ANH for those with severe dementia include worsening incontinence, associated with an increased risk of pressure ulcers; increased agitation levels that may require restraint to avoid self-extubation; and an increased risk of developing pneumonia (Sampson et al.). In Australia there is no medical, ethical, or legal requirement for dying people to receive ANH (Ashby & Mendleson, 2004). The individual's expressed desire is the key consideration (Casarett et al., 2005; Gillick, 2000). When there is no clear direction as to the person's wishes (eg, when the individual has severe dementia but no advance health directive), the family need to consider this emotionally difficult decision.

In Western Australia, the extent to which decisions are made to introduce ANH in severe dementia is unclear. One study (Calver, McCaul, Burmas, Horner, & Flicker, 2009) examined relevant data from 1994 to 2004 for hospital patients aged 65 years and older. All admissions in the state's public and private hospitals for a first gastrostomy tube insertion were included (N=2,023). Based upon the primary diagnosis, the most common indication for tube insertion was circulatory disease, predominantly cerebrovascular disease. Although the severity of dementia was not considered, 11.2% of all patients were known to have had dementia (47.6% of these also having cerebrovascular disease and 14.1% Parkinson's disease). The study found that 25% of the patients who had the procedure were readmitted within one year for replacement or complications and 54% died within a year. Numbers of tube placements had increased from 83 in 1994 to 252 in 1999, declining to 173 in 2002.

The traditional practice associated with a palliative approach is that, when interest in food is negligible, the individual should not be forced to receive nutrition (Liao & Ackermann, 2008). This practice can present considerable difficulties for families, who may believe that their family member is being starved (Casarett et al., 2005; Gillick, 2000). Expert opinion suggests that families of people with severe dementia should be fully informed that ANH is likely to exacerbate their relative's condition and increase discomfort (Gillick). The high rate of mortality and morbidity following ANH should be explained and quality of life issues explored. For example, family members may be informed that most dying people do not experience hunger even if they have insufficient caloric intake (Chan & Webster, 2010; Gillick).

Eating is a social event with inherent social, religious, and cultural aspects. Therefore, some families may see ANH as appropriate, even when the evidence is explained to them (Gillick, 2000) and enteral feeding may be initiated to alleviate the anxiety of caregivers and families (McCann, Hall, & Groth-Juncker, 2004). However, one study found that family satisfaction with end of life care among residents with severe dementia was greater when the resident was not tube fed (Engel, Kiely, & Mitchell, 2006); in another, most proxies of tube fed residents with severe dementia regretted their decision to initiate ANH (Mitchell, Berkowitz, Lawson, & Lipsitz, 2000).

### *Key guidelines or recommendations for artificial nutrition/hydration*

1. Physicians should explain<sup>11</sup> that unlike the provision of food or other forms of comfort (such as warmth or shelter), the procedures required for ANH and the subsequent administration of ANH are associated with uncertain benefits and considerable risks and discomfort (Casarett et al., 2005, p. 2608).
2. Artificial feeding should not generally be used in people with severe dementia for whom dysphagia or disinclination to eat is a manifestation of disease severity (National Institute for Clinical Excellence, 2006, p. 42).

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<sup>11</sup> to patients (when applicable) and to families



**Table 3: Key resources relevant to nutrition and hydration<sup>12</sup>**

Brief Description	Reference and/or Web Access
<p>A resource that summarises evidence-based recommendations for oral care, many of which are relevant in severe dementia.</p>	<p>Joanna Briggs Institute. (2004). Oral hygiene care for adults with dementia in residential aged care facilities. <i>Best Practice</i>, 8(4), 1-4. Available from <a href="http://www.joannabriggs.edu.au">www.joannabriggs.edu.au</a> click on EBP resources and services/best practice series database.</p>
<p>A resource that covers weight loss assessment and management specific to older people with severe dementia, including end of life (terminal) care.</p>	<p>Blue Mountains Division of General Practice, University of Western Sydney, Sydney West Area Health Service, Palliative Care Dementia Interface: Enhancing Community Capacity Project (Australian Government). (2009). <i>Decision-making framework for weight loss management: Guidelines, supporting information, train the trainer, pamphlets</i> [Booklets]. Penrith South, N.S.W: Author.</p> <p>Available from CareSearch <a href="http://www.caresearch.com.au">www.caresearch.com.au</a> click on ClinicalPractice/Specific Populations/People with Dementia/Decision Making Frameworks.</p>
<p>A brief resource for families that includes key issues related to nutrition and hydration in severe dementia</p>	<p>Blue Mountains Division of General Practice, University of Western Sydney., Sydney West Area Health Service, Palliative Care Dementia Interface, &amp; Enhancing Community Capacity Project (Australian Government). (2009). <i>Dementia: Information for carers, families and friends of people with severe and end stage dementia</i> (2nd ed.). [Booklet]. Penrith South, N.S.W: Author.</p> <p>Available from CareSearch <a href="http://www.caresearch.com.au">www.caresearch.com.au</a> click on ClinicalPractice/Specific Populations/People with Dementia/Decision Making Frameworks.</p>

<sup>12</sup> Constipation is also common in severe dementia and may impact upon oral intake. A relevant resource is: Blue Mountains Division of General Practice, University of Western Sydney, Sydney West Area Health Service, Palliative Care Dementia Interface: Enhancing Community Capacity Project (Australian Government). (2009). *Decision-making framework for bowel management: Guidelines, supporting information, train the trainer* [Booklets]. Penrith South, N.S.W: Author. Available from CareSearch [www.caresearch.com.au](http://www.caresearch.com.au) click on Clinical Practice/ Specific Populations/People with Dementia/ Decision Making Frameworks.

## Delirium

Delirium is sometimes called an acute confusional state; it affects both attention and cognition (Harding, 2006) and is a syndrome manifested in multiple ways, including in hypoactivity, or, contrastingly, hyperactivity (Clinical Epidemiology & Health Services Evaluation Unit, Melbourne Health, & Delirium Clinical Guidelines Expert Working Group, 2006). The development of delirium may be considered in the context of the vulnerability of the individual and the precipitating factors experienced (Tropea, Slee, Brand, Gray, & Snell, 2008).

Those who are vulnerable to delirium have risk factors that may include “older age; cognitive impairment; visual impairment; depression; abnormal serum sodium; use of indwelling catheter; use of physical restraint; and the addition of three or more medications” (Tropea et al., p. 150). Older people with severe dementia therefore form a high risk group. Precipitating factors include severe illnesses and infections (Tropea et al.). Infections (eg, of the urinary and respiratory tract) are considered inevitable in severe dementia, with antibiotic treatment failing to prolong survival (Olson, 2003). Pain, dehydration, and constipation are additional precipitants (Harding, 2006); these, too, are common in people who have severe dementia.

Clearly, maintaining a high ‘index of suspicion’ for delirium in severe dementia is appropriate. Also, the features of dementia, delirium, and depression overlap (Registered Nurses Association of Ontario, 2010, p.12) so assessment needs to be thorough, with findings interpreted carefully by appropriately educated practitioners. The Confusion Assessment Method (CAM) (Inouye, 1990) is a well recognised delirium assessment tool.

Once delirium has been detected, its cause needs to be ascertained and the treatment of this cause considered in the light of the individual’s health status. Non-pharmacological management of the delirium, implemented by appropriately trained caregivers, is recommended before pharmacological interventions are initiated (Clinical Epidemiology & Health Services Evaluation Unit et al., 2006). Delirium is common as death approaches (see guidelines for ‘terminal restlessness/agitation’ in this kit).

## Key guidelines or recommendations relevant to delirium

1. Nurses should screen clients for changes in cognition, function, behaviour and/or mood, based on their ongoing observations of the client and/or concerns expressed by the client, family and/or interdisciplinary team, including other specialty physicians (Registered Nurses Association of Ontario, 2010, p.12).
2. If staff working in residential care and community care settings notice an abrupt change in the cognition or behaviour of a resident/client, a formal diagnostic process for delirium should be undertaken. This may involve administering a diagnostic tool such as the CAM or contacting a medical practitioner for a consultation (Clinical Epidemiology & Health Services Evaluation Unit et al., 2006).
3. Nurses must recognize that delirium, dementia and depression present with overlapping clinical features and may co-exist in the older adult (Registered Nurses Association of Ontario, 2010, p.12)

**Table 4: Key resources relevant to delirium**

Brief Description	Reference and/or Web Access
National clinical practice guidelines for the management of delirium in older people.	<p>Clinical Epidemiology &amp; Health Services Evaluation Unit, Melbourne Health, &amp; Delirium Clinical Guidelines Expert Working Group. (2006). <i>Clinical practice guidelines for the management of delirium in older people</i>. Melbourne, Vic: AHMAC Health Care of Older Australians Standing Committee.</p> <p>Available from CareSearch  <a href="http://www.caresearch.com.au">www.caresearch.com.au</a> click on Clinical Practice/Physical/Delirium/Pharmacological Management.</p>
Nursing guidelines for delirium assessment and management and a related downloadable e-learning package.	<p>Registered Nurses Association of Ontario. (2010a). <i>Screening for delirium, dementia and depression in older adults</i> (Revised ed.). Toronto, Ontario, Canada: Author.</p> <p>Registered Nurses Association of Ontario. (2010b). <i>Caregiving strategies for older adults with delirium, dementia, and depression</i>. (Revised ed.). Toronto, Ontario, Canada: Author.</p> <p>Available from Registered Nurses Association of Ontario <a href="http://www.rnao.org">www.rnao.org</a> click on Nursing Best Practice Guidelines/ Clinical Practice Guidelines Program/ Guidelines and Fact Sheets/Cognitive Impairment.</p>

Brief Description	Reference and/or Web Access
A booklet that summarises issues relevant to delirium and older people.	Harding, S. (2006). <i>Delirium in older people</i> . Canberra, ACT: Australian Government Department of Health and Ageing,  Available from the Australian Government Department of Health and Ageing <a href="http://www.health.gov.au">www.health.gov.au</a> click on For Consumers/ Ageing/ Publications.
An online self directed learning package relevant to people who have delirium and dementia in acute care settings.	Western Australian Dementia Training Study Centre. (2008). <i>Assessment and management of confusion in the acute care setting with a focus on delirium</i> . Perth, WA: Author.  Available from the Centre for Health and Ageing at Curtin University <a href="http://www.cra.curtin.edu.au">www.cra.curtin.edu.au</a> click on WA Dementia Training Study Centre/ Training Resources.

## Agitation

Agitated behaviours are described as “verbalisations or physical activity that interfere with caregiving or are viewed as disruptive by the caregiver” (McGonigal-Kenney & Schutte, 2004, p. 5). Such behaviours are “associated with cognitive impairment and increase in frequency with the severity of the dementia” (p. 7); they are also associated with risk factors, including the use of physical restraint, depression, noisy environments, sensory deprivation, discomfort or pain, and the invasion of personal space (McGonigal-Kenney & Schutte). Constipation is a consideration, given its potential to cause discomfort; agitation might also be precipitated by, for example, dyspnoea resulting from co morbid disease.

The Cohen Mansfield Agitation Inventory (Cohen-Mansfield, Marx, & Rosenthal, 1989) is a tool used to assess the type and frequency of agitated behaviours (McGonigal-Kenney & Schutte, 2004). The NeuroPsychiatric Inventory (Cummings et al., 1994), or its brief clinical form (Kaufer et al., 2000), may also be used. Patterns of agitated behaviours require assessment to establish likely triggers (McGonigal-Kenney & Schutte). Algorithms have been recommended to determine potential causes of agitated behaviours, which can then be addressed (see Table 5); if necessary, other strategies can then be used to calm the individual.

## Key guidelines or recommendations relevant to agitation<sup>13</sup>

1. Once a non-cognitive NPS [Neuro Psychiatric Symptom] has been detected... activities include:
  - Differentiating which disturbance is present....
  - Considering the possible contributing causes<sup>14</sup>....
  - Making sure contributing causes are all addressed and that basic needs are met, and then deciding if an additional treatment is needed

(Lyketsos et al., 2006, p. 567).
2. The principles of care require that non pharmacological interventions be tried first (Lyketsos et al., 2006, p. 567).
3. The selection of specific non-pharmacological therapies should be based on the unique characteristics of the patient, the caregiver, the availability of the therapy, the severity of the NPS, and the likelihood that the specific symptoms will respond to the specific therapy (Lyketsos et al., 2006, p. 567).
4. Principles of care require the use of medications when other approaches have failed and there continues to be a need to treat or when the clinical situation presents sufficient urgency to require pharmacologic intervention before other approaches can be properly instituted (Lyketsos et al., 2006, p. 567).

**Table 5: Key resources relevant to agitation**

Brief Description	Reference and/or Web Access
Includes an algorithm that involves considering multiple potential causes of vocal behaviours including physical and emotional suffering, and how these causes may be remedied.	McMinn, B., & Draper, B. (2005). Vocally disruptive behaviour in dementia: Development of an evidence based practice guideline. <i>Aging &amp; Mental Health</i> , 9(1), 16 - 24.
Guidelines for which development was overseen by an expert reference group of international repute well recognised for knowledge of the evidence in this area. This document provides clear guidance for assessing and addressing multiple potential causes of behaviours using a systematic approach.	NSW Health. (2006). <i>Guidelines for working with people with challenging behaviours in residential aged care facilities: Using appropriate interventions and minimising restraint</i> . Sydney, NSW: Author. Available from the New South Wales' Health Department website <a href="http://www.health.nsw.gov.au/">www.health.nsw.gov.au/</a> at Publications & Resources/Policy Directives & Guidelines, under 'Aged Care'.

<sup>13</sup> The recommendations of the American Psychiatric Association (2007) titled 'Practice guideline for the treatment of patients with Alzheimer's disease and other dementias' are also relevant (see Table 5).

<sup>14</sup> For possible contributing causes please see the risk factors listed on the previous page.

Brief Description	Reference and/or Web Access
<p>Useful guide related to pharmacological interventions.</p> <p>Guidelines that include specific reference to severe dementia and to addressing agitation<sup>15</sup>.</p>	<p>National Prescribing Service Limited. (2008). <i>NPS Prescribing Practice Review 43: Treating the symptoms of dementia</i>. [Brochure]. Surry Hills, NSW: Author. Available from <a href="http://www.nps.org.au">www.nps.org.au</a> click on Health Professionals/ Drug &amp; therapeutic topics /Dementia.</p> <p>American Psychiatric Association. (2007). <i>Practice guidelines for the treatment of patients with Alzheimer's disease and other dementias</i> (2nd ed.). Arlington, VA: Author. Available from the web page of the association at <a href="http://www.psych.org">www.psych.org</a> click on Psychiatric Practice/ Practice Guidelines.</p>
<p>A suite of resources that covers agitation assessment and management specific to older people with severe dementia (algorithm included).</p>	<p>Blue Mountains Division of General Practice, University of Western Sydney., Sydney West Area Health Service, Palliative Care Dementia Interface: Enhancing Community Capacity Project (Australian Government). (2009). <i>Decision-making framework for agitation management: Guidelines, supporting information, and train the trainer</i> [Booklets]. Penrith South, N.S.W: Author.</p> <p>Available from CareSearch <a href="http://www.caresearch.com.au">www.caresearch.com.au</a> click on ClinicalPractice/Specific Populations/People with Dementia.</p>

Addressing agitation in severe and end stage dementia is an area in which there may be benefits from CAM. Potential benefits from aromatherapy, massage and touch, music therapy, and multi sensory therapy are explored here.

<sup>15</sup> These guidelines also refer to other important issues, such as addressing depression in severe dementia.

## Aromatherapy and agitation

Aromatherapy involves the use of essential oils, which are introduced by inhalation, olfaction (smell), or applying to the skin (Janca & van der Watt, 2008). Some methods of administering essential oils for inhalation include the use of heat; clearly, the safety of the person who has dementia needs to be assured when the mode of heating is chosen.

A systematic review of all relevant Randomised Controlled Trials (RCTs) investigating aromatherapy for moderate to severe dementia (Holt et al., 2003, updated in 2008) found four such trials, with only one suitable for inclusion. This small trial (N=71) (Ballard, O'Brien, Reichelt, & Perry, 2002) found that applying a small amount of lemon balm oil to the face and both arms twice a day benefitted people with severe dementia. The application was undertaken by care assistants and involved gently applying the cream to the skin, over 1 to 2 minutes. Benefits were a 30% reduction in measures of agitation for 60% of participants, reductions in social withdrawal behaviours, and an increase in the amount of time participants were involved in constructive activities. There were significant improvements in those receiving the placebo treatment too, but effects were stronger for those receiving lemon balm and no side effects were observed. However, the patients were also taking psychotropic medications and Holt and associates concluded that no recommendations for the use of aromatherapy to address agitation in severe dementia could be made.

## Massage and touch and agitation

Massage and touch are non-pharmacological treatments that have been considered appropriate for use with people with dementia. A systematic review of all relevant RCTs investigating massage and touch for dementia found seven such trials (Hansen, Jorgensen, & Ortenblad, 2006). The reviewers considered that only two of these studies were published in a form that allowed further evaluation, one of which examined agitation as an outcome. In this study, involving 68 people with dementia, 53% at the severe stage, hand massage for 10 minutes was found to lead to both immediate and short term reduction of agitation (Remington, 2002). Hand massage is a low risk intervention; furthermore, it incurs no cost when undertaken by appropriately trained families or volunteers. Therefore, although more research is needed to provide a body of evidence in this area, this booklet recommends hand massage as a CAM strategy that may reduce agitation in some people who have severe dementia.

### *Key guidelines or recommendations relevant to massage for agitation*

Gentle hand massage for 10 minutes daily may reduce agitation levels for people with dementia<sup>16</sup>.

<sup>16</sup> Developed for this document from the literature. However, as noted in the text, this recommendation is based upon the findings of a single study, that conducted by Remington (2002).

## Music therapy and agitation

Music therapy aims to improve quality of life, particularly when there has been functional decline (Vink, Birks, Bruinsma, & Scholten, 2004). Generally, listening to music is considered a recreational activity, whereas music therapy has more specific goals. When working with people with dementia, goals may include reducing agitation. Music therapy is 'receptive' when the therapist plays music, sings, or plays recorded music; it is called 'active' music therapy when participants make music (Vink et al.). Receptive music therapy may be useful in severe dementia.

Vink and associates' (2004) systematic review of all relevant RCTs testing music therapy for dementia discounted the studies' findings because of the quality of the work. However, consistent expert opinion, supported by findings of small studies, suggests that music therapy is appropriate for people with severe dementia, with benefits including reductions in agitation and resistive behaviour (Gerdner, 2005, 2010; Volicer, 2001; Yassuda & Nunes, 2009). A small study also found that using music was effective when it was provided by trained staff and families, meaning that a music therapist was not required (Gerdner, 2005).

Best practice has been said to be achieved when individualised music is played at an appropriate level of loudness for a minimum of 30 minutes before the person with severe dementia's peak periods of agitation (Gerdner, 2005, 2010). Preferences of the person with dementia may be determined by knowledgeable family members (Gerdner, 2005, 2010). A recent small study of people with dementia (74% at the severe stage) examined the effect on agitation of individualised music in the home setting (Park & Pringle Specht, 2009). The results were a significant reduction in agitation levels during and after listening to music. An additional finding was that any music played prior to the study was the preference of the family member, rather than of the person with dementia.

Given the consistent findings of small studies and expert opinion, plus the low risk and possible low cost of the intervention, this booklet recommends individualised music therapy as a CAM therapy that may reduce agitation in some people with severe dementia. However, the limited evidence underpinning the recommendation needs to be considered (eg, before any substantial cost is incurred).



## *Key guidelines or recommendations relevant to music therapy for agitation<sup>17</sup>*

1. Individual music preferences should be assessed prior to commencing music therapy, Such assessments can be completed by knowledgeable family members.
2. Playing the individualised music preferences of a person with severe dementia, for a minimum period of 30 minutes daily before known peak periods of agitation, may result in reduced levels of agitation and resistive behaviours.

## **Multi-sensory therapy and agitation**

The aim of Multi-Sensory Therapy (MST) is to provide sensory stimuli targeted at the primary senses of sight, hearing, touch, taste and smell. MST involves the use of lighting effects, tactile surfaces, meditative music, and the odour of relaxing essential oils (Chung & Lai, 2002). The goal of this approach is to provide a heightened sensory environment for people with dementia. Originally MST was only delivered in a specific room but current approaches consider it to be more integrated. The intention is to provide individualised, gentle, sensory stimulation in a non-threatening environment (van Weert et al., 2004).

A systematic review of all relevant RCTs regarding one type of MST, Snoezelen, found four such trials (Chung & Lai, 2002). The reviewers were unable to systematically evaluate these trials because of the different study methods. However, overall, Snoezelen failed to show any significant effects on behaviour, mood or interaction. Nonetheless, expert opinion suggests that MST may sometimes be an effective, inexpensive, and low risk intervention (van Weert et al., 2004).

The benefits of MST have been cited as promoting relaxation and positive behavioural changes, facilitating interaction and communication, promoting caregiving relationships, and reducing caregiving stress (van Weert et al., 2004). One multi-method study (van Weert et al.) reported changes in residential care staff and residents when MST was implemented. Staff members were interviewed about their experience and reported that they ignored time constraints and worked with residents' preferences during the study, also that these changes led to benefits for residents, including reduced agitation (van Weert et al.).

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<sup>17</sup> Recommendations are from consistent expert opinion and small study findings of variable quality. In particular, they are drawn from the work of Gerdner (2010, p. 10-11) and this work provides further useful information.

Because MST incorporates diverse CAM approaches, some individuals may respond positively and some negatively to particular aspects of the therapy (Chung & Lai, 2002). Therefore, an individualised plan that takes into account known preferences and aversions needs to be developed and the person's reactions need to be monitored to ensure that any negative reactions (such as being upset by a particular component of the therapy) are minimised and taken into account in the future. In this booklet, we make a cautious recommendation for the use of MST as a CAM approach to reduce agitation in dementia. However, any effect from MST may be mediated by the way care is provided when the therapy is introduced.

### *Key guidelines or recommendations relevant to multi sensory therapy for agitation*

The use of multi-sensory therapy may reduce agitation levels, promote relaxation and a more positive mood, and facilitate improved interaction/communication/caregiving relationships in some people who have dementia. Therefore, the use of multi-sensory therapy is recommended when an individualised plan is developed, the therapy is carefully monitored, and positive results are observed<sup>17</sup>.

## Conclusion

In summary, this document addresses recommendations and resources relevant to pain, nutrition and hydration, delirium, and agitation in people with severe and end stage dementia; it provides basic information for practitioners, alongside links to resources for additional material. The importance of practitioners being active seekers of knowledge so that they address the challenges they meet with reference to the most up to date research evidence and expert opinion cannot be over stated. This booklet is designed to support practitioners in their search.

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<sup>18</sup> Developed for this document from expert opinion and with particular reference to the small study described by Van Weert and associates (2004), the findings of which suggest that consideration of the person with dementia's preferences is critical to obtaining any positive benefits from this therapy.

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A booklet developed for health care professionals



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