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# A tool to aid talking about dementia and dying – Development and evaluation



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## KEYWORDS

Dementia;  
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## Summary

**Background:** Health professionals often avoid talking about death and dying with patients and relatives, and this avoidance is compounded in cases of dementia by lack of knowledge of trajectory and prognosis. Unfortunately, this impacts on care, with many terminally ill dementia clients receiving inadequate palliation and excessive intervention at end-of-life. This study developed and evaluated a tool to facilitate conversations about death and dying in aged care facilities.

**Methods:** This study utilised available best-practice evidence, feedback from aged care facility nursing and care staff and specialist input to develop the 'discussion tool', which was subsequently trialled and qualitatively evaluated, via thematic analysis of data from family interviews and staff diaries. The study was part of a larger mixed method study, not yet reported. The tool provided knowledge and also skills-based 'how to' information and specific examples of 'what to say'.

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*Results:* The tool facilitated a more open dialogue between dementia palliation resource nurses (a role specifically developed during this project) and family members. Both resource nurses and family members gained confidence in discussing the death of their relative with dementia, and in relevant cases discussed specific decisions around future care. Family members and nurses reported satisfaction with these discussions.

*Conclusion:* Providing specific skills-based support, such as the 'discussion tool' can help staff to gain confidence and change practice in situations where unfamiliar and uncomfortable practices might normally be avoided. As our populations age, health professionals will increasingly need to be able to openly discuss care options towards end-of-life.

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## Introduction

Health care workers do not always feel comfortable discussing death and by avoiding the topic can create impediments to care (Albinsson & Strang, 2003). This situation is exacerbated for residents of nursing homes, here called aged care facilities (ACFs), who have dementia, because many staff lack knowledge of the progressive and terminal nature of dementia. Mitchell and colleagues' (2004, 2009) seminal works clarified the high likelihood of death, distressing symptoms and burdensome interventions for ACF residents with advanced dementia, as well as systemic failures to appropriately apply palliative care to this group. As health services begin to grapple with the increasing numbers of people with dementia (Access Economics, 2010; Australian Institute of Health and Welfare, 2007), and a cure remains elusive, it is clear that end of life care needs to improve for people with advanced dementia. This paper details the development and pilot evaluation of a tool aimed at facilitating communication between ACF staff and family members of a resident with dementia. The tool was developed and trialled as part of a larger project around dementia and the use of a palliative approach, which is yet to be reported.

## Dementia care in aged care facilities

Dementia is a cluster of terminal neurodegenerative disorders, with Alzheimer's disease being the most prevalent, involving a gradual loss of cognitive and physical functioning over a number of years (Australian Institute of Health and Welfare, 2007). The illness trajectory is unpredictable and characteristically punctuated by intervals of acute decline associated with infections followed by partial recovery to a lower level of functioning (Sachs, Shoga, & Cox-Hayley, 2004). There is no cure, and estimates of median life span from diagnosis vary between 4 and 8 years, depending on the age and severity at diagnosis and the presence of comorbidities (Alzheimer's Association, 2009). The six month mortality rate for those with advanced dementia is around 25% (Mitchell et al., 2009).

People with advanced dementia experience distressing symptoms similar to those experienced by people with cancer such as pain, constipation, pressure ulcers, difficulty swallowing and aspiration, and shortness of breath (Johnson et al., 2009; Kim, Yeaman, & Keene, 2005; Mitchell et al., 2009). Yet a retrospective U.S. study comparing care of ACF residents with advanced dementia and terminal cancer found that despite 72% of the entire dementia cohort

dying within 6 months of admission only 1% were perceived to be terminally ill at the time of admission (Mitchell, Kiely, & Hamel, 2004; Mitchell, Kiely, Hamel, & Park, 2004). This 'blindness' was reflected in the higher use of aggressive interventions, poor management of symptoms and generally suboptimal palliative care given to dementia residents when compared to the residents with cancer (Mitchell, Kiely, & Hamel, 2004). Hospitalisations are a frequent response to end of life illnesses across the developed world and yet are particularly inappropriate for people with advanced dementia because of the increased risk of distress (Aminoff & Adunsky, 2004; Givens, Jones, Shaffer, Kiely, & Mitchell, 2010) and delirium (Inouye et al., 2007; Korevaar, van Munster, & de Rooij, 2005) and lack of evidence supporting therapeutic benefit (Thune-Boyle et al., 2010).

Prognosis for people with dementia is difficult even when the terminal nature is recognised. Entry into the end of life stage is not as easily identified as with other terminal illnesses such as cancer, which often has a more predictable downhill trajectory over a period of weeks or months (Sachs et al., 2004). Compounding this dilemma, while potential prognostic markers such as pneumonia, fever, and difficulty eating are associated with high six month mortality rates (Mitchell et al., 2009), they do not accurately predict entry into the terminal phase of dementia and are therefore unreliable indicators of either impending mortality or the need to initiate terminal care. Further complicating the situation, staff may experience a 'prognostic paralysis' in the face of such uncertainties, impeding discussion around end-of-life matters (Birch & Draper, 2005). It is the absence of clear prognostic markers that leads many to suggest that those with advanced dementia should receive a broader palliative approach to care (Gove et al., 2010; Hughes, Robinson, & Volicer, 2005; Sampson, 2010; Torke et al., 2011). This call has been reflected in a number of recent reports and position statements, both in Australia (ACH, 2009; Alzheimer's Australia, 2011) and internationally (Alzheimer Europe, 2008; UK Department of Health, 2009; World Health Organisation, 2012).

## Communicating about dying

Family members of terminally ill patients often have unmet needs for communication of information by healthcare professionals (Caron, Griffith, & Arcand, 2005) and like staff have a poor understanding of the dementia trajectory (Engel, Kiely, & Mitchell, 2006; Hertzberg, Ekman, & Axelsson, 2001; Johnson et al., 2009; Pillemer et al., 2003; Robison et al., 2007; Russell & Middleton, 2008;

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