

Submission to the Senate Community Affairs Committees Inquiry into Palliative Care in Australia

A New Approach to End of Life Dementia Care

Executive Summary

Dementia is a progressive and terminal syndrome for which we do not yet have a cure. There are an estimated 280,000 Australians living with dementia now, and there will be almost 1 million by mid-century¹. Dementia is currently the third leading cause of death², and well over 1 million Australian's will die of dementia over the next 40 years.

Dying with dementia is different from dying with other chronic diseases. Whereas the terminal stage of cancer or ischemic heart disease is usually limited in time to a month or two, the terminal phase of dementia can range from months to years. Furthermore, the drawn-out 'death of the mind'³ that is loss of cognitive function starts from the very beginning of dementia and often precedes death of the body by years. This results in many families and loved ones dealing with complex and often unspoken grief over the 'loss' of a still-living mother, brother or spouse who can no longer recognise or talk to them, but still requires high-level physical care.

The philosophy of palliative care promotes quality of life and relief of avoidable physical and emotional pain and suffering for people with incurable diseases and their close families. It should play this vital role in supporting people with dementia and their carers as well. However, relatively few people with dementia receive timely and appropriate palliative care services or end of life care. Instead, a significant proportion of people dying with dementia experience suboptimal care that is sometimes inappropriate, and at times negligent.⁴ Most people with advanced dementia also experience high levels of unassessed and untreated pain.

There are two major barriers to achieving quality end of life care for people with dementia.⁴

¹ Deloitte Access Economics (2011). *Dementia across Australia: 2011-2050*. Report prepared for Alzheimer's Australia. Available www.fightdementia.org.au/research-publications/access-economics-reports.aspx

² Australian Bureau of Statistics (2011). *Causes of Death, Australia, 2009*. ABS Publication Number: 3303.0. Available: www.abs.gov.au/AUSSTATS/abs@.nsf/mf/3303.0/

³ Terry, P. (2010). Dementia: 'a death of the mind'. *Therapy Today*, 21(8), 20-4.

⁴ Sachs, G., Shega, J., Cox-Hayley, D. (2004). Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*, 19(10), 1057-1063.

First is the fact that the current approach to palliative care is predominantly based on cancer. Unlike people dying with cancer, people with advanced dementia often 'die' over a much longer time period and more often die in residential aged care facilities than in hospitals or at home⁵. During this extended end-of-life period, they are: a) generally unable to actively participate in decisions about their care; and b) cannot clearly express or describe their symptoms. These are two critical components of palliative care that can only be achieved for people with dementia through advance care planning and proactive assessment and treatment of adverse symptoms.

Second, there is a pervasive lack of understanding of dementia as a terminal illness in the general public and amongst the medical, health, aged care and community care professions. This lack of awareness and stigma associated with dementia results in delayed diagnosis, missed opportunities for advance care planning and conversations about death and dying before the end-of-life phase of the syndrome, and a lack of proactive assessment and treatment of symptoms.

While many elements of palliative care are appropriate for people with dementia⁶, the sequencing and emphasis with which these are applied and funded as part of the current palliative care and aged care systems are not.

Alzheimer's Australia's submission calls for a review of current arrangements for dementia care and palliative care with a view to developing a new framework of supportive dementia care that incorporates, and funds, elements of the palliative approach throughout.

In developing this concept it addresses the following issues and questions:

1. The consequence of dementia being progressive and terminal
2. Whether palliative care is beneficial for people with dementia
3. The challenges of applying the concept of palliative care in the context of dementia
4. Special issues in preparing for the end of life for people with dementia
5. Palliative care as part of a framework of supportive care for people with dementia

⁵ Mitchell, S. L., Teno, J. M., Miller, S. C. and Mor, V. (2005), A national study of the location of death for older persons with dementia. *Journal of the American Geriatrics Society*, 53(2), 299–305.

⁶ Volicer, L. (2007) Goals of care in advanced dementia: Quality of life, dignity and comfort. *Journal of Nutrition, Health and Ageing*, 11(6), 481.

1. The consequence of dementia being progressive and terminal

The only certainty with a diagnosis of dementia is death. How long the journey will take, and how it will impact the individual and their family will vary greatly with the cause of dementia and the social and personal characteristics of the individual and their support networks.

This inherent uncertainty and variability make high quality dementia care, including quality end-of-life care of people with dementia, difficult at the best of times. Dementia has both social and medical implications, and unlike some other conditions, there is no 'one size fits all' approach that can be followed to increase the likelihood of good outcomes. Instead, considerable skill and sophistication is required to provide personalised, appropriate and continuous support and care to the individual and their family across the full course of a journey with dementia symptoms that may be as short as three months, or as long as 10-15 years⁷.

Unfortunately, the skills and resources to provide such sophisticated and flexible care are not widely available. Together with a poor community and professional understanding of dementia and a lack of communication around death and dying, a significant proportion of consumers consequently experience sub-optimal care throughout the dementia journey, particularly during the final stages⁸.

2. Is palliative care necessary and appropriate for people with dementia?

People with dementia and their families often experience sub-optimal care, particularly at the end-stages when hospitalisation and aggressive treatment of medical complications such as aspiration pneumonia and fracture tend to dominate the management of symptoms such as constipation or pain. The result is that people with dementia are often removed from familiar surrounds and sometimes from their families, subject to potent medications or invasive interventions with significant side-effects, and receive inadequate treatment for distressing symptoms.⁹

Hospitals are particularly dangerous and disorienting places for people with dementia. People with dementia are usually admitted to hospital for other

⁷ Mitchell, S. L., et al. (2009). The clinical course of advanced dementia. *The New England Journal of Medicine*. 361, 1529-38.

⁸ Sachs, G., Shega, J., Cox-Hayley, D. (2004). Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*, 19(10), 1057-1063.

⁹ Scherder, E., & Bouma, A. (1997) Is decreased use of analgesics in Alzheimer's Disease due to a change in the affective component of pain? *Alzheimer's Disease and Associated Disorders*, 11(3)

reasons, and are not routinely identified as having particular care needs associated with cognitive impairment. They stay longer than those without dementia¹⁰, are shifted from ward to ward more often, and experience more adverse outcomes due to the confounding nature of the condition (inability to report symptoms, difficulty comprehending medical instructions, forgetting medications, for example)¹¹. While specialist palliative care services are provided by some hospitals, only 5% of patients receiving these services have a primary or additional diagnosis of dementia,¹² meaning that the majority of people with dementia who die in hospital do so without receiving specialist end-of-life care.

Clearly, better end-of-life care is needed, and the principles of palliative care if applied appropriately, would appear to lead to better outcomes for many people with dementia and their families. Evidence has shown that good end of life care, based on the person's wishes and values reduce the bereavement burden for loved ones. Bad care at the end of life has reduces the quality of life of the dying person, and has long term negative effects on those left behind.¹³

However, while there are anecdotal reports about the benefits of a palliative approach to dementia care, there have only been a few rigorous studies that have evaluated this approach, and these have failed to demonstrate clear benefits of palliative as opposed to 'usual' end-of-life care.¹⁴ There are a number of methodological issues that might partly explain the lack of results: ethical complications surrounding randomised research trials on dying, and lack of clear outcome measures for example.

It is also likely that achieving consistent beneficial outcomes for people with dementia through palliative care is complicated by the challenge of applying the concept of palliative care itself to dementia.

3. The challenges of applying a concept of palliative care in the context of dementia

Modern palliative care was developed as part of the hospice movement as an approach to improving the quality of life, and the physical and emotional well-

¹⁰ King, B., Jones, C., & Brand, C. (2006). Relationship between dementia and length of stay of general medical patients admitted to acute care. *Australasian Journal on Ageing* 25(1):20-23

¹¹ Peut, A., Chan, N., Pham Lobb, L. A., Karmel, R., Gibson, D. & Draper, B. The nature of hospital stays for patients with dementia. International Association of Gerontology and Geriatrics 9th Asia/Oceania Regional Congress, Melbourne, 23-27 October 2011.

¹² AIHW (2011). Trends in palliative care in Australian hospitals. Cat. no. HWI 112. Canberra: AIHW.

¹³ Redinbaugh, E. M., Baum, A., Tarbell, S. & Arnold, R. (2003). End-of-Life caregiving: What helps family caregivers cope? *Journal of Palliative Medicine* 6(6): 901-9

¹⁴ Hughes, J. Jolley, D., Jordan, A., & Sampson, E. (2007). Palliative care in dementia: Issues and evidence. *Advances in Psychiatric Treatment*, 13, 251-260.

being of people with incurable cancer and their families. The approach promotes generalist and specialist treatment of distressing symptoms over a curative approach, and is reliant on good communication and continuity of care from multidisciplinary or interdisciplinary teams. Because of this foundation, most of the palliative care guidelines and training that exist today are based on the model of terminal cancer.

Dementia is a terminal syndrome for which there is not yet a cure. Accordingly, the best approach to end of life care for dementia, like incurable cancers, is to avoid invasive life-prolonging treatments that carry detrimental side-effects in favour of tailored and appropriate treatment and management of symptoms, and supportive nursing and spiritual care of individuals and their families.

However, unlike many cancers, the prognosis of dementia varies dramatically from one person to the next. People with advanced dementia may face a number of different clinical crisis points for which they will have lost competence to make decisions regarding their end-of-life care options. This means they must either set out their wishes and preferences in advance, or be dependent on others to make those decisions on their behalf when the time comes. Furthermore, people with all but the earliest stages of dementia will often have some difficulty clearly expressing or describing discomfort or symptoms of pain.

Dementia continues to be incorrectly considered by the general public and many medical and healthcare professionals as just a normal part of ageing rather than a chronic, terminal syndrome. Even when dementia is acknowledged as being incurable, it is often overlooked as fatal. This is evidenced both from surveys of carers of people who have died of dementia,¹⁵ and studies that have demonstrated high levels of under-reporting of dementia as a cause of death on official death certificates.¹⁶ Given the orientation of palliative care towards people who are dying, the fact that dementia is often not recognised as terminal means that much attention is given to the treatment of acute dementia-related medical problems such as infection or fever, and that palliative care becomes an afterthought, if it is thought of at all.

Consequently, although many of the individual elements of palliative cancer care are relevant to those with dementia, the application and sequencing of these elements cannot easily be mapped from cancer directly onto the care of people with dementia.

¹⁵ Sachs, G., Shega, J., Cox-Hayley, D. (2004). Barriers to excellent end-of-life care for patients with dementia. *Journal of General Internal Medicine*, 19(10), 1057-1063.

¹⁶ Ganguli, M., Rodriguez, E. (1999). Reporting of dementia on death certificates: A community study. *Journal of the American Geriatric Society*. 47, 842–9.

4. Special issues in preparing for end of life for people with dementia

Some of the particular end-of-life issues that will be faced by people with dementia and their families include:

- **Timely diagnosis of dementia.** This is one of the biggest issues faced by individuals and their families at the beginning of the dementia journey that significantly impacts their end-of-life care options. A lack of recognition of symptoms or reluctance to seek help on the part of consumers can be one part of the problem in achieving a timely diagnosis. The other part is a lack of understanding, confidence, or training in the assessment, diagnosis and management of dementia on the part of health professionals. Even with a concerned patient and an informed doctor, dementia can be very difficult to diagnose in the early stages. The resultant delay in diagnosis and the regularity of misdiagnosis compounds the traumatic nature of the journey with dementia. From the time of first identifying the symptoms of dementia it takes on average 3.1 years to obtain a diagnosis in Australia.¹⁷ These are 3 lost years in terms of uncertainty and trauma and loss of the opportunity to plan and continue life as normally as possible. As a result, people with dementia often miss vital opportunities for advance planning (for health, medical personal and financial matters) and discussion of end of life and palliative care while they still have the cognitive capacity to do so¹⁸.
- **Reluctance to discuss death and dying.** There is a need to confront death from or shortly after the time of first diagnosis of dementia, as difficult as it is to grapple with our own or loved ones' mortality. Family members of people who have been living with dementia for years are often shocked, upset and confused when medical conversations begin to converge on end-of-life care and dying. For many, the appropriate choice will be to grasp the nettle early and plan accordingly, as difficult as this will always be. National conversation about death and dying are important – with a focus on values and what constitutes a good death for an individual – as is workforce training on end of life care and how to approach the necessary conversations. Evidence suggests that consumers expect their health professionals to initiate such conversations¹⁹, but that health professionals are reluctant to have them or just don't know how²⁰. More emphasis on dementia and end-

¹⁷ Speechly, C. M., Bridges-Webb, C. & Passmore, E. (2008). The pathway to dementia diagnosis. *Medical Journal of Australia*, 189(9), 487-9

¹⁸ Phillips, J., Pond, D., & Shell, A. (2010). No time like the present: The importance of a timely dementia diagnosis. *Alzheimer's Australia Quality Dementia Care Series, Volume 7*. Available: www.fightdementia.org.au/research-publications/quality-dementia-care-papers.aspx

¹⁹ Hoffmann, J. C., et. al. (1997). Patient preferences for communication with physicians about End-of-life decisions. *Annals of Internal Medicine*, 127(1), 1-12

²⁰ Weiner, J. S. & Cole, S. A. Three principles to improve clinician communication for advance care planning: Overcoming emotional, cognitive, and skill barriers. *Journal of Palliative Medicine*, 7(6), 817-29

of-life care is needed in all training courses for people will be caring for those who are dying, with specific modules for people dying with dementia. There is also a need to recognise the complexity of approaching the issue in CALD or ATSI communities, where discussion of death is often different and sometimes taboo.

- **Stigma and social isolation.** The stigma and fear attached to dementia complicates open discussion at many levels including within families, between individuals and professionals and between individuals and their social networks. The isolation experienced by people with dementia and their carers further reduces their quality of life.
- **Advance care planning.** Engaging early in the course of dementia in an advance care planning process with family members and doctors to consider the range of health and care situations (as well as personal and financial matters) that may come up at end of life, and putting in place formal arrangements such as advance care directives and substitute decision-makers to deal with these is the best way to ensure optimal end-of-life outcomes for people with dementia^{21,22}. Yet very few people with dementia engage in formal advance planning at an early stage when they still meet the legal definition of competence to do so. The lack of understanding about dementia means that few people think to engage in this process, and there is also a lack of readily available support and information to assist them to do so.
- **Difficult decisions.** Even with an Advance Care Plan and substitute decision makers in place, the likelihood is that complex and unanticipated personal, family, medical and care circumstances will arise at the advanced stages of dementia that will require very difficult decisions on the part of families, aged care staff and medical professionals. The only way to resolve these issues in a way that satisfies the requirements of all parties is good communication and understanding that is facilitated, if needed, by skilled support and counselling. Some elements of advance directives, such as do-not-hospitalise orders, have been shown to be quite successful in some studies²³. However, the stressful and time-limited nature of acute and aged care means that good communication often falls by the wayside, and the limited available evidence suggests that the values and preferences for palliative care (and non-treatment in particular) of people with dementia

²¹ Caplan, G. et al. (2006). Advance care planning and hospital in the nursing home. *Age and Ageing*, 35(6), 581-5.

²² Teno, J. et al. (2007). Association between advance directives and quality of end-of-life care: A national study. *JAGS*, 55(2), 189-194.

²³ Lamberg, J. L. Person, C. J. Kiely, D. K. & Mitchell, S. L. (2005). Decisions to Hospitalize Nursing Home Residents Dying with Advanced Dementia. *Journal of the American Geriatrics Society*, 53(8), 1396-1401.

and/or their carers – whether clearly stated or not – are often over-ridden, overlooked or ignored²⁴.

- **Progressive decline in capacity.** The fact that people with dementia are unable to be active participants in health and care decision making at the time decisions need to be made is one of the major barriers to effective provision of palliative services in end-of-life dementia care. This progressive decline in capacity also impacts the experience of end-of-life dementia in a myriad of other ways that vary in relation to different issues (whether financial, care, or personal matters). Decisions about capacity and competence, and their implications for managing finances and end of life care issues also present significant challenges to the person with dementia, their families and the professional staff they work with. It is important to consider capacity in the context of medical and legal decision making, but also to understand that regardless of their legal competence, many people with dementia are still able to express their wishes, values or preferences in some way (through emotional reactions to ideas or treatments for example).
- **Symptoms.** People with mid- to advance-stage dementia very commonly experience under-assessed and under-treated pain: often chronic; sometimes excruciating²⁵. The difficulty for people with mid- to late-stage dementia of providing clear verbal communication of symptoms is one critical barrier to better symptom management. So is the fact that the specific skills required to appropriately assess and manage distressing symptoms in patients who may be non-verbal are relatively rare in aged care facilities. There is evidence that pain in non-verbal patients is routinely under-assessed and under-medicated. People with dementia often express the discomfort of chronic pain in the only ways they are able – moaning, lashing out, or agitation and depression – and treatment too often focuses on restricting or treating these signs (for example, through physical restraints or sedatives) rather than recognising and treating the underlying symptoms and causes of pain.

5. Palliative care as part of a framework of supportive care for people with dementia

Current approaches to palliative care are based on cancer and are focused on the last days, weeks or months of life. It is clear from the psycho-social and medical nature of dementia and the specific issues faced by those living with

²⁴ de Boer M.E., et al. (2010). Advance directives in dementia: issues of validity and effectiveness. *International Psychogeriatrics*, 22(2), 201-8

²⁵ Herr, K., Bjoro, K., Decker, S. (2006). Tools for assessment of pain in nonverbal older adults with dementia: A state of the science review. *Journal of Pain and Symptom Management*. 31(2), 170-192.

the syndrome that if a palliative approach is to succeed in improving quality of life and end-of-life care, then the defining elements of the approach must be applied:

1. in a way that can more flexibly cater to the needs of the individuals and their families;
2. in a way that can cover a broader range of issues (for example, legal and financial planning, pain management and dying with dignity);
3. in the context of a much more flexible time frame that can cater for the many years of the dementia journey.

Such conditions would allow end-of-life care for people with dementia that would:

- Assess and manage distressing symptoms such as pain and constipation, including appropriate management of behavioural and psychological symptoms of dementia;
- Affirm life and see dying as a normal process to be neither hastened nor postponed;
- Integrate ongoing and iterative advance care planning throughout the journey, but most importantly from the point of diagnosis, with an emphasis on communication, ascertaining values and preferences, and promoting quality of life;
- Integrate the psychological and the spiritual elements of dementia care;
- Offer a support system to help people with dementia live as actively as possible and to help the family cope with loss over the dementia trajectory and after death;
- Enhance quality of life in a way which might positively influence the course of the illness and relationships;
- Become involved early in the course of the illness and to work in conjunction with other therapeutic approaches, such as mental health services.

There is little doubt that if met, these conditions would result in high-quality dementia appropriate care throughout the journey, including at the end of life. However, they would necessitate such an extension of the palliative approach as it is currently understood that there would need to be questions as to whether the palliative care terminology should still apply. It could be argued, for instance, that a truly flexible palliative approach that caters for the needs of a person with dementia and their family throughout the journey is little different than Kitwood's model of Person Centred Care²⁶

²⁶ Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Open University Press, Buckingham, England.

A framework of supportive care for people with dementia

To deal with these dilemmas, it has been proposed that rather than an expanded, dementia-appropriate approach to palliative care, what is required is a more flexible framework of *supportive dementia care* that incorporates relevant elements of the palliative approach at every stage of the dementia journey.²⁷

A framework of supportive care would guide every element of the care of a person with dementia and their families from the point of first contact with the health and aged care systems (e.g., on first presentation to a GP with troubling symptoms) through to the death of the individual, and to post-bereavement support of the family. The framework would cater to the particular characteristics of dementia that make planning for end of life especially difficult, as well as to the individual circumstances of the person and their family, and the health and care systems within which they are placed.

Importantly, a framework of supportive care would have as its core principles:

- Person-centredness – responding to the needs of the individual and their family;
- Multidisciplinarity or interdisciplinarity – drawing upon appropriately skilled general and specialist medical professionals, nursing, aged and community care workers, allied health, and pastoral care providers as and when needed;
- Communication between professions and with the individual and their family, throughout the journey;
- Continuity of care, from the point of diagnosis;
- Access to and availability of necessary services across the continuum of care, including primary, community, hospital and residential care settings.

Within this framework the elements of palliative care that would be utilised would include:

- Advance care planning (i.e. ascertaining a person's wishes, values, quality of life early on in the course of the journey);
- Honest, empathic and culturally appropriate discussions about death and dying and the general course of the dementia journey;
- Promotion of physical health;

²⁷ Hughes, J.C., Lloyd-Williams, M., & Sachs, G. A. (2010). *Supportive care for the person with dementia*. Oxford University Press.

- Impeccable assessment and ongoing management of pain and other distressing symptoms;
- Appropriate treatment of infections and fevers;
- A considered approach to artificial nutrition and hydration and to resuscitation, that takes into account the wishes and values of the individual and their families;
- A focus on meeting the psychological, social and spiritual needs of the person and their families;
- Mindfulness at all stages and by all parties of ethical issues.

Conclusion

Palliative care is a philosophy focussing on the prevention and relief of pain and suffering associated with terminal conditions, and on the physical, emotional and spiritual well-being of patients and their families. Palliative care is well established as the best-practice approach to end-of-life cancer care. However, the approach is under-researched, not well articulated, and not widely practiced for people living and dying with dementia.

This submission outlines the rationale for a framework of supportive dementia care that incorporates, and appropriately funds the various elements of palliative care throughout all stages of the dementia journey: from the time of diagnosis to death, including bereavement support for family carers and friends.

This is a new concept of palliative care as it applies to dementia. But given the near inevitability of a million people dying with dementia over the coming decades and the fact that only a small percentage of these people are likely to receive much needed palliative care as it is applied at present, we strongly believe that a new concept is needed.

We believe that the framework outlined in broad terms in this submission is an important starting point, and that the Senate Committee's Inquiry can be an important vehicle for elevating the issue of palliative care for people with dementia to receive the policy and political attention that it deserves.

Recommended Resources:

1. Timely Diagnosis of Dementia: Can we do better? A report for Alzheimer's Australia Paper 24 Dr Jill Phillips, Professor Dimity Pond, Ms Susan M Goode September 2011
http://www.fightdementia.org.au/common/files/NAT/Timely_Diagnosis_Can_we_do_better.pdf
2. Planning for the End of Life for People with Dementia: A report for Alzheimer's Australia. Paper 23 Part Two by Professor Colleen Cartwright, May 2011
http://www.fightdementia.org.au/common/files/NAT/20110503_Nat_Paper_EoLP2.pdf
3. Planning for the End of Life for People with Dementia: A Report for Alzheimer's Australia Part One Paper 23 March 2011 by Professor Colleen Cartwright
http://www.fightdementia.org.au/common/files/NAT/20110404_Nat_Paper_23EoLP1.pdf
4. Ethical issues and decision-making in dementia care. Alzheimer's Australia, Paper 20, June 2010, Presentation by Dr Julian Hughes, National Press Club, Canberra
[http://www.fightdementia.org.au/common/files/NAT/20100600_Nat_NP_20HughesEthlssDecMakDemCare\(1\).pdf](http://www.fightdementia.org.au/common/files/NAT/20100600_Nat_NP_20HughesEthlssDecMakDemCare(1).pdf)
5. Early Diagnosis of Dementia Alzheimer's Australia Paper 10, March 2007
http://www.fightdementia.org.au/common/files/NAT/20070300_Nat_NP_10EarlyDiagnDem.pdf
6. Palliative Care and Dementia Alzheimer's Australia Discussion Paper 7, February 2006, Professor Jenny Abbey
http://www.fightdementia.org.au/common/files/NAT/20060200_Nat_NP_DP7DocPallCareDem.pdf
7. ACH Group 2009 - Planning Ahead - An Information Guide for People with Dementia and their families. <http://www.ach.org.au/good-health/dealing-with-dementia/early-intervention>
8. ACH Group 2009 - Planning for Palliative Dementia Care Resource Guide