PALLIATIVE CARE

NATIONAL CROSS CULTURAL DEMENTIA NETWORK

BRIEFING PAPER 1

Prepared by Jaklina Michael, Marianne Potma and Ron Sinclair

SEPTEMBER 2012
BACKGROUND

1. Australia is one of the world’s most culturally diverse societies.

2. Death and dying are among the most significant and sacred events of all societies.

3. Spiritual and religious needs are highly personal and salient to many people at the end of life. It is imperative that palliative care services respect and support the customs, beliefs, rituals and practices of the Culturally and Linguistically Diverse (CALD) person with dementia that can provide meaning and comfort to the person, their families and carers.

4. The National Palliative Care Program aims to help families, carers and local communities with practical support in the provision of palliative care but the program does not take into account the special needs of individuals with dementia.

5. Alzheimer’s Australia Vic (2008) suggests that there is much diversity in perceptions of dementia across different CALD population groups. In some communities dementia is perceived as a mental illness while in others dementia may not be recognised or understood or it may be regarded as a normal part of ageing.

ISSUES

1. Mainstream palliative care services are generally not appropriately funded, designed or structured for people with dementia. Dementia presents different challenges than other diseases in the context of end of life planning due to differences in timescales, issues around capacity, and communication.

2. The current arrangements of the National Palliative Care Program are not meeting the needs of many individuals with dementia and this situation is even worse for those from a CALD background.

3. Differing perceptions of dementia by CALD population groups results in delayed or no diagnosis and management and missed opportunities for advanced care planning for CALD people.1,2

4. Anecdotal evidence suggests that dementia care and palliative care for CALD people is provided as ‘crisis care’ instead of being provided as a normal part of care.

5. There is no Australian research that examines culturally appropriate palliative care services for people with dementia.

6. Individuals from CALD communities often have a poor understanding of the terminal nature of dementia.1,3

7. Language, religious practices, stigma, and cultural communication norms may work against people from CALD backgrounds participating in advanced care planning.4 The delay in dementia diagnosis also contributes to a lack of advanced care planning.5 In addition, CALD communities do not have knowledge of the legal ramifications of advanced care directives6, and CALD individuals may require professional interpreters to fully engage and participate in decision making.7

8. A lack of advanced care planning often results in; a failure to implement personal wishes for end of life, invasive medical procedures, and hospitalisation, and often leads to the unnecessary prolonging of life.

9. Hospital stays are generally longer and lead to poorer outcomes for people with dementia compared to individuals of the same age without cognitive impairment.8 This is greatly exacerbated when the person with dementia has limited or no proficiency in English. Different cultural, spiritual, social and religious norms of people with dementia from a CALD background contribute to even longer hospital stays.

10. It is well documented that there is a need for ongoing and holistic cultural competent staff training for the provision of culturally appropriate palliative care to people with dementia, in all care settings.9

11. A report prepared for the Victorian Palliative Care Cultural Diversity Leadership Group10 proposes a Palliative Care Cultural Responsiveness Strategy to help meet the needs of CALD communities but this proposal does not address the special palliative care needs of people with dementia.
RECOMMENDATIONS

Alzheimer’s Australia’s National Cross Cultural Dementia Network recommends that:

1. The need for culturally appropriate palliative care services for people with dementia be documented.

2. All new and existing palliative care guidelines include the special needs of CALD people with dementia.

3. Community consultations, research and evidence-based practice models relating to the interface of dementia and palliative care routinely include and embed cultural diversity within its format.

4. The recommendations made by Ultra Feedback¹⁰ and Australian Government Department of Health and Ageing¹¹ be implemented by all palliative care services and extended to address the special needs of CALD people with dementia living across Australia.
CASE STUDIES

Stories compiled by Norminda Forteza, CALD Project Officer Alzheimer’s Australia Victoria, for the National Cross Cultural Dementia Network.

CASE STUDY 1: Overseas palliative care preparations - ‘The Journey Back’

“My mother is 94 years old and migrated from the Philippines nearly 25 years ago. She was diagnosed with dementia six years ago, and in just two years her dementia had progressed to a point that she was in need of 24/7 care. One day she fell ill and was hospitalised, unfortunately whilst in hospital she had a fall and broke her hip. The doctors said that she needed to be placed in a nursing home, so as to receive the appropriate care. The family agreed to placement; however she was not able to fully settle into life in the facility. I would go and visit her every other day to make sure she ate, but she would always complain of being hungry. The staff at the facility would comment on mum not wanting to eat the food available like mashed potato or boiled potato, not even toast. We informed staff of mum’s preference to eat rice three times a day with either egg or sausage, but they were not able to accommodate this as it was not on their menu plan. My mother was frustrated with the staff’s response to her needs and she lost so much weight as a result of not eating.

After six months the family decided to provide care for her as she had become weak and frail. On one occasion when the family visited we saw her on the floor, she had been incontinent and was very angry and embarrassed by her state. Because of her condition, we thought it would be better to take her back to Philippines where she could be cared for by family. We would take turns going overseas to assist in her care and sought support from other family members to provide care for mum 24/7. At least in the Philippines she would have the appropriate language and food to comfort her. This environmental change made a big difference to her; she was open to discussing her illness and for the family to plan appropriate care. The cost of ensuring culturally and linguistically appropriate palliative care for mum is now becoming financially manageable however our frustration is now with the Australian government in not allowing her to access her pension overseas to support her care. It is cheaper to provide culturally and linguistically appropriate palliative care in Philippines rather than Australia. We, her family, have worked hard to support our mother and give her a decent life whilst living with dementia but the system cannot work with us.”

Mrs P (carer)

CASE STUDY 2: An Assyrian senior’s silent battle in a nursing home

“My mother passed away years ago and I recall the anguish, anger, and torment we felt when we had to put her into a nursing home. As a male carer and only son, I felt the pressure of caring for an old lady—my mum—who had dementia. When she got to a stage where swallowing was a real challenge, my wife and I thought it was time to move her to a facility. In Australia, I thought places of care for dementia were well supported, but it wasn’t like that. After nearly five years of staying home and living with dementia, my mum was not happy to move to a nursing home in the first place. But for us, there was no where to go. Mum only stayed in that facility for less than a year and she died. We felt that her death was more due to loneliness in the nursing home. It was a silent killer. Unfamiliar faces, unfamiliar food, everyone looks sick, sad and dying. I felt we let her down; no amount of counselling could bring her back to us. The experience has taught us that dementia and loneliness in a nursing home is a silent killer.”

Mr A (carer)

3 Alzheimer’s Australia National Cross Cultural Dementia Network
CASE STUDY 3: Mrs K, a Greek family carer

Mrs K was the recipient of community care services until she died recently. She suffered from dementia as well as diabetes and spoke little English. Mrs K had worked very hard in the family cafe over many decades and her family appreciated the strain this took on her health. Through community care services she received bilingual support workers to take her to and from hospital for dialysis twice a week as well as other support services.

Mrs K’s condition deteriorated so that dialysis no longer contributed to her quality of life. Palliative care services were bought into her home above the family business at this stage. Her dementia had, in the meantime, advanced to the point where she did not recognise her family members and had stopped wanting to eat. Her family was very caring and supportive; however, they had no understanding of the role of palliative care and also did not know about advance care planning. The palliative care team was unable to verbally communicate at all with Mrs K, including during intimate personal care services.

Towards the end of life the family expressed wishes that she be able to die at home surrounded by her extended family that had flown in from interstate and overseas. However, the palliative care nurse recommended that Mrs K be taken to hospital to die as it would be more convenient, and the family acquiesced. It was assumed across the board that Mrs K would be unable to communicate her own wishes due to her dementia.

Reflecting afterwards on this case with the bilingual case manager showed that the local Greek community on the whole had not received information about advance care planning or palliative care, and had not considered dementia in the context of palliative care. Community and aged care staff also had not considered dementia within a palliative care framework, showing a further need for support and training.


Visit the Alzheimer's Australia website at
WWW.FIGHTDEMENTIA.ORG.AU

For comprehensive information about
dementia and care
information, education and training,
and other services offered by
member organisations

Or for information and advice contact the
National Dementia Helpline on

1800 100 500

(National Dementia Helpline is an
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