



# **END OF LIFE CARE FOR PEOPLE WITH DEMENTIA**

**SURVEY REPORT  
FEBRUARY 2014**

**EXECUTIVE SUMMARY**



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# TAKE HOME MESSAGES

The Alzheimer's Australia survey of care professionals and family carers<sup>1</sup> highlights sharp differences in perceptions about the adequacy of access to high quality care at end of life for people with dementia.

**3/4**

of care professionals indicate that people with dementia have access to palliative care services.



**69%**

of care professionals state that their organisation encourages people with dementia to complete an advance care plan.

It is equally clear that a significant number of consumers struggle to get access to appropriate end of life care.

**58%**

lack access to palliative care specialists

**68%**

lack access to hospice care

**1/2**

lack support in the community



<sup>1</sup> Family carers in this survey referred to individuals who are or were close to someone with dementia, for example relatives, friends or neighbours.



# 22%

of family carers experienced difficulties in ensuring the person they were caring for received adequate pain relief.

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# 20%

of family carers experienced difficulties in securing care in line with the wishes of the person with dementia.

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The barriers to accessing appropriate end of life care identified in this survey highlights the need for greater information and awareness to empower consumers, the importance of advance care planning, and the need for more training on palliative care and legal end of life care options for care staff.

Family carers and care professionals both identified education and training, better documentation of wishes and better communication between families and care staff as being critical to improving end of life care for people with dementia.

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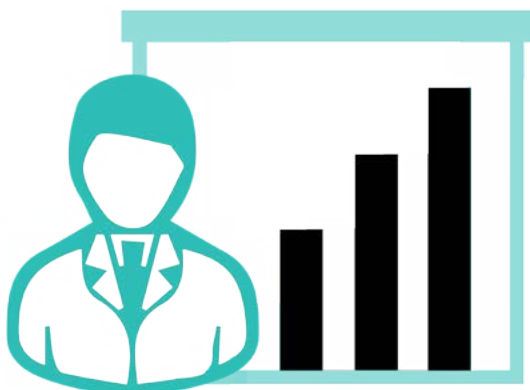
# 41%

of care professionals said they had received no training on assessment of pain in people with dementia.

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# 90%

of care professionals indicated that additional training on palliative care and dementia would be beneficial.



## BACKGROUND

Access to appropriate end of life care for older people in Australia has been identified as a priority for consumers and policy makers. This was emphasised in the Productivity Commission report, *Caring for Older Australians*, and the investment in the *Living Longer. Living Better* aged care reform package of \$21.7 million over five years to improve palliative care services for older people both in the community and residential aged care.

Alzheimer's Australia has released a number of publications as well as conducted seminar series across Australia to raise awareness to both consumers and health professionals about the unique end of life care issues which people with dementia face. Furthermore, we have launched a new online resource called Start 2 Talk ([www.start2talk.org.au](http://www.start2talk.org.au)) which helps people begin the conversations that are needed to plan ahead for future lifestyle, financial and care decisions.

Dementia has characteristics that make it different from other terminal conditions. It has an unpredictable trajectory and there can be difficult issues around capacity, decision making and communication. As a result, people with dementia may struggle to get access to palliative care services or hospices that meet their needs.

To better document the experience of consumers and care professionals, Alzheimer's Australia, with support from Bupa Health Foundation, commissioned Piazza Research to conduct a national survey of care professionals and family carers. We are grateful to a number of organisations who assisted in promoting the survey including the Australian Nursing Federation, United Voice, Palliative Care Australia, Aged and Community Services Australia, Leading Age Services Australia, Consumer Health Forum of Australia, and Anglicare, as well as the hundreds of care professionals and family carers who devoted their time to respond to the survey.

Two online surveys were used to collect data from care professionals and family carers. A total of 783 complete responses were received from care professionals (including registered nurses, General Practitioners, specialists, enrolled nurses, and direct care workers) and 236 complete responses were received from family carers.

## **DO PEOPLE WITH DEMENTIA HAVE ACCESS TO PALLIATIVE CARE SERVICES?**

Most care professionals (75%) indicate that people with dementia can access palliative care services within their care setting.

Many family carers had a different experience and indicated the difficulty people with dementia have in getting access to appropriate services:

- 58% stated that the person with dementia did not have access to palliative care specialists
- 68% indicated that the person with dementia did not have access to hospice care
- 49% indicated that there was no support available in the community at end of life
- 26% reported they were dissatisfied with the care the person with dementia received at the end of life.



The question remains as to whether people are not aware of services that are available, or whether the services are not adequately resourced to provide support to all people who need it.

## ARE THE WISHES OF PEOPLE WITH DEMENTIA LISTENED TO?

In the majority of cases, both family carers and care professionals indicated that the wishes of people with dementia were adhered to.

Unfortunately there is a minority of cases where this is not happening.

- A fifth (20%) of family carers were dissatisfied with adherence to the wishes of the person with dementia, and
- Nearly a third (31%) of care professionals experienced a situation where they were unable to follow the end of life care wishes of a person with dementia.

A number of barriers to providing quality end of life care were noted by family carers and care professionals, including a lack of documented wishes, legal issues, difficulties with communication, and the culture of the organisation. Nearly a third (32%) of family carers indicated they had some conflict with staff over end of life care wishes.

Even when care wishes are documented, such as in an advance care plan, there were still difficulties with adhering to the wishes of the person with dementia. Just over a quarter (26%) of care professionals were very confident in their ability to provide end of life care consistent with documented wishes of the person with dementia, and family carers indicated that in many cases plans were not adhered to completely (34%).

Part of the difficulty may be due to a lack of awareness about the rights of a person to refuse or discontinue medical treatment at the end of life.



- 8% of care professionals indicated that they did not think patients had a legal right to refuse medical treatment or have existing interventions withdrawn.
- 12% did not think that people have the right to refuse food or fluids, with an additional 17% being unsure.
- 11% indicated that they thought refusal of antibiotics was not a legal option for people at end of life.

There is a clear need for greater information and training on legal options at the end of life. 38% of care professionals had not received any training on the legal rights of a person with dementia at end of life.

## ARE PEOPLE PLANNING AHEAD?

There is a consensus among care professionals of the importance of documenting end of life care wishes with 96% indicating that end of life wishes should be documented either before diagnosis or soon after diagnosis. The majority (69%) of care professionals indicated that their organisation either encourages or strongly encourages people with dementia to complete an advance care plan. Surprisingly, 13% of care professionals indicated that they believe advance care plans are not a legal choice for people in Australia or were unsure.

The majority of family carers (60%) report that the person with dementia they cared for did not have an advance care plan or they are unsure if they did. For those who did have an advance care plan, only 34% had prepared a plan before or shortly after diagnosis with most



plans being completed in the mid to advanced stages of the disease. Of those who are currently caring for someone with dementia, only 34% of the people they are caring for have an advance care plan.

## MANAGING PAIN

Pain can be difficult to assess and manage for people with dementia as they are often not able to verbally communicate their distress. The Nuffield Council on Bioethics notes that: “There is evidence that people with dementia experience poor care at the end of their lives, with badly controlled pain”. This is consistent with the survey findings in which:

- 22% of former family carers felt that pain was not managed well at end of life for the person with dementia
- 41% of care professionals had received no training on assessment of pain in people with dementia
- 7% of care professionals indicated they were uncomfortable with their ability to assess and manage pain for people with dementia.



Anecdotal reports indicate that care professionals are at times reluctant to use medications, such as morphine, over fear that they may hasten the death of the person they are caring for. Legally, people have the right to adequate pain control, even if it has a secondary effect of hastening death. Consistent with previous reports, 27% of care professionals did not think adequate pain control (if it might also hasten death) was a legal choice for people in Australia or were unsure.

## DIVERSE BACKGROUNDS

Access to appropriate end of life care can be even more difficult for those from culturally and linguistically diverse (CALD) backgrounds<sup>2</sup>. The survey found that:



- 43% of CALD family carers were dissatisfied with the care at end of life (compared to 26% of all carers)
  - 30% of CALD family carers were dissatisfied with adherence to end of life care wishes of the person with dementia (compared to 20% of all carers)
  - 60% of care professionals believed that their organisation could provide appropriate end of life care for those from CALD backgrounds
- hospitals were least able to provide appropriate end of life support for people from CALD backgrounds with 14% of care professionals in this setting indicating they could rarely or not at all provide for the needs of this group
  - only 46% of care professionals had specific training in providing end of life care for people from CALD backgrounds.

<sup>2</sup> A person was identified as culturally and linguistically diverse if they indicated in the survey that they spoke a language other than English at home or was born in a country other than Australia.



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