

Concluding comments

8.1 Dementia is a significant and growing problem in Australia. In 2012, the Australian Institute of Health and Welfare (AIHW) reported there were 321,000 Australians diagnosed with the illness. Of this number, more than 90% were aged over 65 and more than 60% were women.¹ The incidence of the illness is also pronounced in government-funded residential aged care facilities (RACFs) where more than half the residents live with dementia. With projections that the number of Australians living with dementia will increase to 400,000 by 2020 and almost 900,000 by 2050, it will be necessary to provide care to people with dementia in the community and in RACFs.

8.2 This report has been concerned with the care and management of Australians living with dementia and the behavioural and psychological symptoms of dementia (BPSD). Its focus has been on assessing Commonwealth, State and Territory government services and supports for persons living with dementia in both community care and residential care. The committee's recommendations are based on an understanding that people living with dementia need personalised care from well trained staff and, while there are certainly leaders in service provision, there is no single correct model of care for those with dementia.

8.3 There are pressing challenges for governments, health advocates and the aged care sector to ensure effective care and management of dementia sufferers, for example:

- improving early and accurate diagnosis of the condition, including enabling specialists and family members to become involved in the diagnosis process;
- ensuring there are proper support systems in place for people living with dementia to remain at home;
- ensuring that carers have adequate support, including respite, training, and guidance in accessing dementia services; and
- ensuring a high standard of care for dementia sufferers through adequate funding, innovation and design. While the model of delivery may differ from one provider to the next, the standard of care should be based on:
 - a person-centred approach that takes into account the individual's qualities, abilities, interests, preferences and needs;
 - recognition that dementia alters perceptions and appropriate environments can minimise BPSD;
 - respect for their rights as patients, offering activities that are engaging and stimulating rather than chemicals and restraints to suppress the outward signs of the illness;

1 *Dementia in Australia*, 2012. AIHW noted that 24,400 sufferers were aged under 65.

- training and retaining high-quality residential and community care workers; and
- facilitating greater community awareness and understanding of the illness.

8.4 These challenges, and the response to date, have been themes of this inquiry and report. While the challenges are significant and complex, this inquiry has identified a number of areas where access to, and coordination of, information would greatly assist patients, their families and carers. In this context, the committee has found notable examples of RACFs delivering leadership, innovation and success in response to each of the challenges listed above. The committee believes it is important that government recognise these achievements, and act to promote and publicise this work.

8.5 The committee emphasises the key role that carers play to facilitate the community care system must be supported. Community care is valuable not only in itself but in taking pressure off the more expensive option of RACFs. The committee emphasises that those reliant on community care need to be able to access information on all their options for support as simply and efficiently as possible. The Commonwealth-funded Home Care Packages Program and Home and Community Care Services are both important funding measures. The continuing shortage of BPSD appropriate respite facilities is of real concern to the committee. The lack of respite options for people with younger onset dementia (YOD) and people in regional and remote areas are also areas of particular concern.

8.6 This report has identified residential aged care providers such as Wintringham, Rural Northwest Health, HammondCare and the BrightWater Group as providing a high standard of living for people with dementia. Their models differ but a common theme is their commitment to person-centred care (PCC), high levels of staff training and investment in new ideas and appropriate facilities. These providers have benefitted greatly from managers who take the initiative to explore new ideas in PCC and adapt these new practices to their organisation. They explain the changes to staff and encourage staff involvement as they are implemented. They also demonstrate that existing RACFs can be retrofitted in a way to provide PCC.

8.7 The committee believes that the examples of these leading RACF providers must be more widely acknowledged. The providers deserve a good reputation and should attract strong community interest. The Commonwealth should play a role to publicise the work of these providers and explain to the community what it is about their service for people with dementia that is exemplary. It is to be hoped that these messages will encourage other providers to compete by lifting their standards.

8.8 Skilled and committed staff is crucial to care effectively for people with dementia in RACFs and the community. This inquiry has noted a number of leaders in training and retaining staff with innovative and highly effective training tools. The committee believes that the Commonwealth has a role to facilitate more effective ways to publicise training courses that are available, and to ensure that staff working

with people with dementia have the skills necessary to provide person centred, dementia appropriate care.

8.9 There is important work being done to educate the Australian community about the experience of living with dementia and care for those with the condition. Alzheimer's Australia's newly established Perc Walkley Dementia Learning Centre in Melbourne is a world-class facility. The committee gained considerable insights from its visit to the centre in December 2013 and was most impressed with the staff and the use of technology. As a tool to showcase the sensory experience of those living with dementia, and to highlight how workspaces, homes and public spaces can become more dementia friendly, the centre is an outstanding public resource and deserves wide public attention.

Senator Rachel Siewert

Chair

