

Chapter 1

The care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)

Terms of Reference

1.1 On 28 February 2013, the Senate referred the following matter to the Senate Community Affairs References Committee (committee) for inquiry and report:

(a) the scope and adequacy of the different models of community, residential and acute care for Australians living with dementia and BPSD, with particular reference to:

- (i) Commonwealth-provided support and services,
- (ii) state- and territory-provided services, and
- (iii) services provided by the non-government sector;

(b) resourcing of those models of care; and

(c) the scope for improving the provision of care and management of Australians living with dementia and BPSD, such as:

- (i) access to appropriate respite care, and
- (ii) reduction in the use of both physical and chemical restraints.

1.2 The reporting date for the inquiry was set by the Senate for 26 June 2013. On 18 June 2013, the Senate granted an extension of time to report until 12 August 2013. On 12 August 2013, the committee tabled an interim report expressing the committee's intention to seek re-referral from the Senate to continue work on this inquiry in the 44th Parliament.

1.3 The new Parliament re-referred the inquiry to the committee with the same terms of reference, for reporting on 28 February 2013.

Conduct of the inquiry

1.4 The committee invited submissions from Commonwealth, State and Territory governments and interested organisations. The committee received public submissions from 62 organisations and individuals (listed at Appendix 1).

1.5 Five public hearings were held over the course of the inquiry:

- Hobart – 10 July 2013;
- Canberra – 17 July 2013;
- Melbourne – 16 December 2013;
- Warracknabeal, Victoria – 17 December 2013; and
- Canberra – 14 February 2014.

1.6 A list of witnesses who appeared before the committee is set out in Appendix 2.

1.7 Submissions, additional information, the *Hansard* transcript of evidence and responses to questions on notice can be accessed through the committee's website at: http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Dementia.

1.8 References in this report are to individual submissions as received by the committee, not to a bound volume.

1.9 The committee would like to especially thank the staff and residents at the Yarriambiack Lodge in Warracknabeal in Victoria. The committee had the opportunity to visit the lodge, meeting with the residents, staff and families there. Seeing the options that are available for persons living with dementia in residential aged care facilities shaped much of the thinking in this report.

1.10 The committee also received the hospitality of the Alzheimer's Australia Vic.'s Perc Walkley Dementia Learning Centre in Melbourne and were provided with a glimpse of what it is like to live with dementia through the centre's virtual reality facilities.

1.11 Due to the prorogation of the 43rd Parliament, this inquiry was more protracted than most committee inquiries, and the committee thanks those who participated in the inquiry for their patience.

House of Representatives Inquiry

1.12 On 24 June 2013, the House of Representatives' Standing Committee on Health and Ageing presented a report, *Inquiry into Dementia: Early diagnosis and Intervention* (House report).¹ The House report focused on ways to improve early diagnosis and to improve the quality of life for people with dementia by remaining independent as long as possible. While there is some cross-over between the House report and this report, the committee has endeavoured to complement the House report rather than reproduce or counter it.

Structure of the committee's report

1.13 The committee's report is comprised of six chapters:

- chapter 2 provides an overview of dementia in Australia;
- chapter 3 discusses community care;
- chapters 4 and 5 consider residential care;
- chapter 6 reviews the use of restraints in aged care;
- chapter 7 summarises issues particular to younger onset dementia; and
- chapter 8 presents the committee's concluding comments.

1 House Standing Committee on Health and Ageing, *Inquiry into Dementia: Early diagnosis and Intervention*, June 2013.