

SUPPLEMENTARY SUBMISSION FROM ALZHEIMER'S AUSTRALIA

INQUIRY INTO THE CARE AND MANAGEMENT OF YOUNGER AND OLDER AUSTRALIANS LIVING WITH DEMENTIA AND BEHAVIOURAL AND PSYCHIATRIC SYMPTOMS OF DEMENTIA (BPSD)

Background

The purpose of this submission is to provide additional material which builds on our original submission to the Inquiry.

Alzheimer's Australia welcomes the bipartisan support for the 2012 Aged Care Reforms.

The timing of the Committee's work provides the opportunity to look at the priorities for improving the quality of life of people with dementia over the next three years. In the context of the Committee's Inquiry we thought it important to brief you on:

1. The vision Alzheimer's Australia has for the next three years in building on the 2012 Aged Care Reforms.
2. Important issues in respect of the quality of residential aged care from a consumer perspective.
3. The importance of the work of the Ministerial Advisory Dementia Group
4. The interface of disability and aged care system

The Vision for the next three years

Attached is a draft copy of Alzheimer's Australia's Fight Dementia Campaign document (in confidence). This document sets out the vision from a consumer perspective of what needs to be achieved over the next three years to provide better care, support and social inclusion for all people with dementia.

In the context of the Committee's Inquiry particularly relevant are the actions proposed in respect of:

- The funding of dementia advisors to support people with dementia and their family carers throughout their journey with dementia.
- The funding of dementia specific respite and a trial of individualised funding to demonstrate that flexible respite would enable people with dementia to stay at home longer.
- The implementation of strategies to improve the quality of residential care.
- The agreement of a new National Framework for Action on Dementia.

I ask that this document be kept under embargo until further notice as it is a draft which we will be releasing in February next year.

Quality of Residential Care

Attached is an Alzheimer's Australia report *Quality of Aged Care: A Consumer Perspective* which was released on 12 November 2014. The paper discusses, from a consumer perspective, concerns about quality of care within residential aged care facilities including concerns around the care of people with behavioural and psychological symptoms of dementia (BPSD).

The paper proposes two lines of action. Firstly to take the short term action necessary to give consumers greater confidence in the complaints scheme and accreditation and to ensure minimum standards are in place and upheld for all residents.

Secondly, to develop a more consumer oriented system by supporting greater involvement of consumers in the monitoring, assessment and complaints processes and by ensuring greater transparency in the care outcomes being delivered.

Ministerial Dementia Advisory Group

This group has played an important role since 2005 in providing expert advice to the Minister of the day on dementia policy. The Group is made up of individuals who have considerable professional expertise in dementia including distinguished researchers and clinicians as well as consumer advocates. Family carers and service providers also have played an important role in the group.

Over recent years MDAG has provided expert advice to the Minister on issues that relate to dementia across health, disability and aged care sectors. For example, the group has provided strategic advice such as the development of the National Framework For Action on Dementia and prioritising the funding available to tackle dementia in the aged care reform package.

The group has succeeded where others have failed in bringing together the various elements of dementia care across the health and aged care spectrum, in part due to its interdisciplinary approach. This type of approach will be critical for the issues under consideration in this Inquiry as care and management of people with BPSD cut across both the Health and Social Services portfolios. Part of the success of the group has been to bring together experts across a range of fields to work together on specific issues with the goal of producing strategies and recommendations for consideration by the Minister and the Department. There have been three of these meetings to date in primary care, acute care and most recently driving.

These meetings have been remarkable in how they have led to transformative approaches to long standing concerns at a low cost. For example, at the meeting on acute care, participants identified the National Safety and Quality Health Service Standards as a critical lever in improving the quality of hospital care for people with dementia. As a result, the then Department of Health and Ageing funded a project for the Commission to develop a resource to guide acute care services and improving the quality of care within the mandated framework of the Standards.

At this early stage of the new administration there is uncertainty about how the change in Government will impact on the future of the Group, The hope of Alzheimer's Australia is that the Group, or similar body, will play a vital role in identifying action to improve care for people with BPSD and one component of that work may be to convene a stakeholder meeting on that issue next year.

Interface of Disability and Aged Care

The new administrative arrangements provide an opportunity for tackling some of the difficult issues that people with younger onset dementia face in regards to the interface between the disability and aged care system and cutting unnecessary red tape.

There is growing evidence that in some States younger people requiring assessment and services through the aged care system are experiencing considerable delay and bureaucracy before gaining access to assessment through the aged care assessment teams (ACAT). From the reports we have received, there is particular difficulty in access for people with younger onset dementia in Queensland, Victoria and South Australia. Before an ACAT can assess a person under 65 in these states they require a letter from the state disability services stating that there is no suitable disability supports for this person. Obtaining this letter can be a complicated, lengthy process.

This means considerable delay in assessment and places considerable pressure on individuals and their families at a most difficult time as they struggle to get the appropriate clearances from Disability Services to gain assessment. It is probable that many individuals seeking assessment do so at a late stage when they are already starting to experience BPSD and carers are in need of urgent assistance. It is important that now NDIS and Aged Care are administered in the same portfolio that an effort is made to ensure that regardless of age people with dementia have prompt access to assessment and appropriate services, whether it is through the disabilities or aged care sectors.

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