

1 May 2012

Submission No. 031

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(Dementia)

Date: 01/05/2012

Dr Alison Clegg
Committee Secretary
House of Representatives Standing Committee on Health and Ageing
PO Box 6100
Parliament House
CANBERRA ACT 2600

Dear Dr Clegg

Inquiry into Dementia: Early Diagnosis and Intervention

The Consumers Health Forum of Australia (CHF) welcomes the opportunity to provide a submission to the House of Representatives Standing Committee on Health and Ageing's *Inquiry into Dementia: Early Diagnosis and Intervention* (the Inquiry).

CHF is the national peak body representing the interests of Australian healthcare consumers. CHF works to achieve safe, quality, timely healthcare for all Australians, supported by accessible health information and systems.

CHF's submission addresses the Inquiry's terms of reference relating to improving quality of life and assisting people with dementia to remain independent and helping people with dementia and their carers to plan for their futures. Our work in this area has drawn on consultation with our membership, which includes organisations advocating for older consumers, disease specific groups and networks, state and territory peak consumer organisations and individual consumers.

Improving quality of life and assisting people with dementia to remain independent

The prevalence of dementia is increasing in Australia, with major impacts on both health and social support systems. While high quality care needs to be a priority for all age groups affected by dementia, a key concern for CHF is the matter of obtaining and maintaining access to appropriate services for those affected by dementia before 65. Currently, there are approximately 16,000 consumers with younger onset dementia, including those with Alzheimer's disease or frontotemporal dementia or dementia resulting from cardiovascular conditions, such as stroke or neurological conditions like Parkinson's disease and multiple sclerosis.¹

¹ Deloitte Access Economics (2011) *Dementia Across Australia: 2011-2050*. Alzheimer's Australia: Canberra.

In the current system, there is a significant risk of younger people with dementia being shifted between disability and aged care services without their needs being addressed. Younger consumers with cognitive change and no history of other disability may experience difficulty in gaining access to assessment services, either because disability services are not equipped to assess cognitive impairment or because aged care services refuse assessment because they are not 'frail aged.' This exacerbates the existing disadvantage from any delays in obtaining a timely and accurate diagnosis of the cause of their functional change.

When disability services are no longer able to meet their needs due to the progression of dementia, the consumer and their carers may be required to navigate a second unfamiliar system. This can lead to problems in accessing services that are age appropriate, significantly affecting the independence of the consumer and their quality of life. Although the aged care sector has more experience in supporting people with dementia, there remains a serious lack of age appropriate services available for those who may be otherwise well. Many of these issues are not limited to younger onset dementia.

On this basis, CHF supports recommendation 3.8 of the Productivity Commission's *Inquiry into Disability Care and Support*, which would provide consumers with a person-centred assessment that is portable across all care systems.² This recommendation is also supported by recent research conducted by Alzheimer's Australia and Access Economics.³ CHF agrees that assessment should be planned and ongoing rather than being viewed as a phase of care. Regardless of their circumstances, all consumers with dementia, particularly younger onset dementia, will directly benefit from routine access to regular and ongoing assessment, referral and case management. It is essential that the assessments:

- Are universally available regardless of location, age and co-morbidities
- Are planned and proactive, minimising current crises, such as inappropriate hospital admissions, that may occur when needed support is unavailable
- Are responsive to consumer needs as circumstances change and their condition progresses
- Recognise the ability of many consumers to self-manage for a time, while also recognising that they will experience a progressive loss of capacity and function and that family carers will play an increasing role
- Provide consumers with a smoother pathway to the most appropriate care by harnessing the range of quality support available across all sectors
- Work with existing assessment arrangements, such as the Aged Care Assessment Program, to provide improved and harmonised pathways
- Minimise inappropriate referral to services which do not meet the needs of consumers and their families
- Support the role and wellbeing of carers, providing both early referral to information and advice and more targeted assistance as the care burden increases
- Use the existing expertise of both consumer organisations and condition specific organisations to the advantage of people with dementia and family carers.

² Productivity Commission (2011) *Disability Care and Support: Productivity Commission Inquiry Report*. Commonwealth of Australia: Canberra.

³ Deloitte Access Economics (2011) *Caring Places: Planning for Aged Care and Dementia 2010-2050*. Alzheimer's Australia: Canberra.

Helping people with dementia and their carers to plan for their futures

Many consumers who have provided feedback to CHF consultations on end-of-life care issues have referred to advance care planning. There has been a general consensus that both primary and specialist health care providers must be trained in strategies to conduct end-of-life discussions around advance care planning. This is particularly important to consumers with neurological conditions such as dementia.

Consumers have told CHF that awareness of the option of an advance care plan is dependent on their care location and care provider. In other words, it is dependent on 'luck'. The National Health and Hospitals Reform Commission (NHHRC) recognised this issue, and recommended that consumers, particularly those in residential aged care, should be given opportunities to explore the type of care they would like to receive at the end of their lives, with particular emphasis on consumers in aged care settings.⁴ CHF agrees with this finding, and believes that consumers in aged care settings should be supported to seek access to resources and services in line with their care needs.

CHF therefore recommends that the Committee supports implementation of the NHHRC recommendations to improve palliative care services in residential and community aged care settings. This includes funded programs to support advanced care planning and the provision of end-of-life care as a basic competency for aged care workers.

The importance of advance care planning has also been highlighted by the Productivity Commission, which advised:

...that funding should be made available for community awareness education (which could be linked to better informing Australians about the probability of needing care)... about the importance of talking about dying and advance care directives. Health professionals and aged care providers also need to be appropriately trained to talk to care recipients about end-of-life issues and assist them to put in place advance care directives.⁵

The Commission concluded:

The effective communication of advance care plans between health care sectors (for example from hospital to residential aged care facilities and vice versa) is vital if patient's treatment preferences and end-of-life care wishes are to be known and respected.⁶

In practice, advance care plans can be disregarded in acute care and other hospital settings, particularly if they are not in a legally binding format and the consumer is transitioning from another care setting, or if advance care plans are not communicated, but also if the care plan does not accord with the service provider's care protocols. For the consumer, this can mean unwanted 'heroic' care interventions to extend life with little consideration of its quality. In some instances, it also results in unnecessary and unwanted hospitalisations.

⁴ NHHRC (2009) *A Healthier Future For All Australians: Final Report of the National Health and Hospitals Reform Commission*. Commonwealth of Australia: Canberra.

⁵ Productivity Commission (2011) *Caring for Older Australians: Final Inquiry Report. Report Number 53*. Productivity Commission: Melbourne.

⁶ Ibid.

On this basis, CHF recommends that funding be made available for an education campaign to promote advance care planning and advance care directives, in line with the findings of the Productivity Commission. CHF also recommends that the Committee explore training options for aged care providers around the discussion of end-of-life issues and assistance in advance care planning.

CHF looks forward to reviewing the report from the Inquiry. Please do not hesitate to contact me should you wish to discuss any aspect of this submission further.

Yours sincerely,

Carol Bennett
CHIEF EXECUTIVE OFFICER