Private Mental Health
Consumer Carer Network (Australia)
engage, empower, enable choice in private mental health

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SUBMISSION
Inquiry into the care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)

To: Parliament of Australia, Senate Standing Committee on Community Affairs, References Committee

Sent via email: community.affairs.sen@aph.gov.au

1 Introduction

We thank the Parliament of Australia, Senate Standing Committee on Community Affairs and References Committee for the opportunity to provide input into this Inquiry.

The *Private Mental Health Consumer Carer Network (Australia)* (hereafter Network) represents Australians who have private health insurance and/or who receive their treatment and care from private sector settings for their mental illnesses or disorders and their carers**.** As our title implies, the Network is the authoritative voice for consumers and carers in private mental health settings.

The Network is committed to working with the Parliament of Australia and relevant others in addressing the needs of people with a mental illness and their family or carers. We bring to this Submission, a mental health consumer and carer perspective.

2 Comments

Dementia has profound consequences for the quality of life of the person with the illness and their families and carers. People with dementia become increasingly dependent on support for daily living. Dementia is often associated with ageing but it can affect young people also.

Dementia is not a single specific disease rather a term used to describe a syndrome associated with many other different diseases that are characterised in the same manner in relation to impairment of brain functions, memory, perception, personality and cognitive skills. As it is a progressive disease, the impact increases as the severity of the condition progresses. It is usually gradual from onset, progressing in nature and severity and at this time is irreversible. Many conditions cause dementia including Alzheimer disease.

Dementia and depression can occur separately or together. Sometimes it may be difficult to distinguish between them because the signs and symptoms are similar. However, dementia

and depression are different conditions, requiring different responses and treatment.[1] Many families and carers report that there is often a misdiagnosis or misunderstanding of depression and dementia - and perhaps other mental illnesses - which would require different management.

Dementia is an area which is not well recognised by our Network given the large number of effective and influential community managed organisations within Australia which specialise in advocacy, research, awareness raising and Government lobbying. The *Australian of the Year for 2013* Ms Ita Buttrose has been the President of Alzheimer's Australia since 2011. She has fervently advocated for Alzheimer's disease.

Dementia is a classification in the *International Statistical Classification of Diseases and Related Health Problems* (ICD), which approaches the classification of dementia from a disease perspective and is the data collection protocol most commonly used within the Australian public and private mental health systems; and the *Diagnostic and Statistical Manual of Mental Disorders (DSM)*, which approaches the classification of dementia from a perspective of functioning and which is also used extensively in the public and private mental health system.

- *The International Classification of Diseases*[2] (ICD) is a standard diagnostic tool for epidemiology, health management and clinical purposes. It is used to classify diseases and other health problems recorded on many types of health and vital records including death certificates and health records. This includes a section on mental and behavioural disorders.

- The Diagnostic and Statistical Manual of Mental Disorders[3] (DSM) is published by the American Psychiatric Association and covers all categories of mental health disorders for both adults and children. The manual is non-theoretical and focused mostly on describing symptoms; as well as statistics concerning which gender is most affected by the illness, the typical age of onset, the effects of treatment, and common treatment approaches.

The two systems were developed alongside each other and the two seek to use the same data collection codes. Whilst the DSM provides criteria and descriptions for each mental disorder, the ICD10 provides only code numbers.

While dementia is noted within these two systems, our Network should at the very least have an awareness of current issues, prevalence, national policy and any federal Government initiatives. It is noted however, that dementia is a disease most commonly affecting older people with many receiving care from the aged care sector.

3. Prevalence of Dementia: Australian Institute of Health and Welfare Publication

[1] beyondblue Fact Sheet 25 - Depression and Dementia
[2] The latest version of the International Classification of Diseases is the ICD-10. Version 11 is due to be published in 2015
[3] The latest version of the Diagnostic and Statistical Manual of Mental Disorders is the DSM-IV. DSMV will be published in May 2013

We have extracted the following data from the referenced publication below.[4]

Number of people with dementia is expected to increase markedly
An estimated 298,000 Australians had dementia in 2011, of whom 62% were women, 74% were aged 75 or over, and 70% lived in the community.

Dementia poses a substantial challenge to health, aged care and social policy. Based on projections of population ageing and growth, the number of people with dementia will reach almost 400,000 by 2020. Although projection methods vary, the number of people with dementia is projected to triple between 2011 and 2050, to reach around 900,000 by 2050.

People with dementia rely heavily on health and aged care services
An estimated 552,000 GP attendances (0.5%) in 2010–11 involved the management of dementia. In 2009–10, dementia was a diagnosis for 83,226 (1 in every 100) hospitalisations, and was the principal diagnosis for 12,286 (1 in every 1,000). In that year, 392,796 (0.2%) government-subsidised prescriptions were dementia-specific.

Total direct health and aged care system expenditure on people with dementia was at least $4.9 billion in 2009–10, of which about $2.0 billion was directly attributable to dementia. Of this, $1.1 billion was for permanent residents in residential aged care facilities, and $408 million was for community aged care services.

Many people with dementia have other health conditions, and many need high care
In 2009, people with dementia aged 65 and over had a substantially higher average number of health conditions (5.4) than all people in that age group (2.9). In 2009–10, 53% of permanent residents in residential aged care facilities had dementia. Residents with dementia were more likely than those without dementia to require high care (87% vs. 63%).

Substantial demand placed on informal carers
Estimates suggest that, in 2011, there were around 200,000 informal carers of people with dementia living in the community. Co-resident primary carers of people with dementia were almost twice as likely as all co-resident primary carers to provide 40 or more hours of care per week (81% versus 42%).

4. Recent developments
April, 2012 Funding packages - Australian Government[5]

The Australian Government, Department of Health and Ageing released a funding package in April 2012 as part of the aged care reform titled: *Living Longer, Living Better*. That package included $268.4 million over 5 years to provide dementia-related programs and services. The major part of the package is increased support to enable people to receive

[4] Australian Institute of Health and Welfare 2012. Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW.

[5] Australian Institute of Health and Welfare 2012. Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW.

care in their own homes. Additional funding is being targeted at improving the quality of care for people in community and residential care settings.

Further, in August 2012, Australian Health Ministers recognised dementia as the ninth National Health Priority Area which will assist in focussing attention on dementia and drive collaborative efforts aimed at the national, state and local government levels, the community managed sector, clinicians and policy officers. The federal Minister for Health and Ageing, Hon Mark Butler MP, established a Dementia Working Group to provide him with advice as to the implementation and monitoring of programs and dementia-related issues.

5. Psychiatric care

Mental health services provide a number of services ranging from inpatient care to community care for mental health issues related to dementia.

One of the saddest places is the Psychiatric Inpatient dementia units where the elderly are cared for mostly in a secure setting. Aggression is evident in many, requiring acute care in mental health inpatient settings to meet their needs. Younger people, some in their early 40s, are also admitted to these units and cared for alongside the elderly. Area mental health services and some private psychiatric hospitals have aged care psychiatry services, and there are a limited number of psychiatrists who specialise in treating the elderly and providing treatment to those more seriously affected.

Our concerns are that people with dementia retain the same rights as any other person with a mental illness. We know that the word dementia for many becomes a 'label' that tends to describe all behaviours, especially in the ageing. The risk to people with dementia is that treatment them becomes directed to the diagnosis rather than to the person.

Dementia is a very difficult area made more challenging in that if often occurs 'behind closed doors' for example where the person is a permanent resident of aged care facilities or aged care psychiatric units. As a mental health advocacy organisation, our task is to ensure that those experiencing dementia and their carers are as informed as any other person with mental health issues and that their rights are acknowledged and understood.

Aged care psychiatry is an area requiring dedicated and caring staff. Their efforts and dedication often go unrecognised in the overall scheme of the mental health system.

Given the predicted rise in dementia associated with the ageing population in Australia, the mental health workforce will be further compromised.

6. Conclusion

For simplicity, we have set out hereunder the major issues we are aware of in relation to dementia.

1) As our population ages, the rate of dementia will increase.

2) People with dementia rely heavily on the health and aged care system. The AIHW predicted that the expenditure in regards to dementia for 2009-2010 for example, was $2 billion - of that $1.1 billion was attributed to permanent residents in aged care facilities, and $408 million to community aged care services.

3) People with dementia have many other health problems. This is often as a result of their age, although the health conditions of people with dementia are more prevalent and their overall physical wellbeing is much poorer than that of people of equivalent age without dementia within the general population.

4) Carers of people with dementia carry the burden of community care, usually supporting people in their own homes or in the person with dementia's home.

5) The Australian Government has committed substantial funding toward dementia and named it as a national health priority area.

6) There are a number of influential people and community managed organisations providing effective advocacy, research, awareness raising and government lobbying.

7) Dementia is mostly managed within the aged care sector.

8) There must be no misdiagnosis or misunderstanding between depression and dementia or any other mental illness.

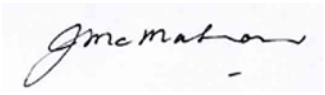
9) People with dementia must retain the same rights as any other person with a mental illness.

10) We must ensure that dementia does not become a 'label' - with treatment directed to the diagnosis rather than the person.

11) Dementia is often a 'hidden' diagnosis.

12) People with dementia and their families and carers must be as informed as any other person with mental illness and their families and/or carers.

We thank the Senate Standing Committee on Community Affairs, References Committee for the opportunity of providing this Submission. If you have any queries, please do not hesitate to contact the undersigned on jmcmahon@senet.com.au or 1300 620 042.



Ms Janne McMahon OAM
Chair
29th April, 2013