Mercy Health

Submission to Senate Committees on Community Affairs Inquiry into Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)

May 2013

Mercy Health welcomes this Senate Committee Inquiry into the care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD).

Mercy Health is a Catholic community provider of care founded and wholly owned by the Sisters of Mercy. We offer acute and sub acute hospital care, aged care, mental health programs, specialist women's health, early parenting, palliative, home and community care, and health worker training and development.

Mercy Health's experience in caring for those with dementia includes the provision of;

- residential dementia specific care to over 200 residents across Victoria and NSW
- EACH-D packages
- home and personal care for clients in early stages or pre diagnosis
- National Respite for Carers Program (NRCP) in the Barwon region of Victoria.

Mercy Health is a partner in the Cooperative Research Centre (CRC) for Mental Health, which researches early detection and treatment of neurodegenerative diseases and psychoses.

A strategic key direction for the organisation over the next five years is to provide services focused on supporting families faced with younger onset dementia. A Younger Onset Dementia Project Management Group was formed in August 2012, which includes representatives from Mercy Health, Alzheimer's Australia Vic, and the Lovell Foundation, a consumer voice to raise the plight of families living with younger onset dementia. This consortium has been formed with the intent of developing a leading edge service for those living with younger onset dementia.

Our submission details the following recommendations:

- Expand support for an integrated, multi-disciplinary health team response to the complex needs of those with dementia and their families
- Increased support for medical practitioners in the diagnosis of dementia
- Increased funding for specialist mental health services
- Providing education for those working in residential aged care facility of the etiology of dementia
- Improved consistency in the approach of Aged Care Assessment Service (ACAS) teams
- Greater investment in the Dementia Behaviour Management Advisory Services.
- Greater investment in community support
- Expanding support for care of those with younger onset dementia.

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Scope and adequacy of the different model of care for Australians living with dementia

It is recognised that most chronic illnesses benefit from a multi-disciplinary approach to care. This is particularly relevant for the complex and disabling diseases that bring about dementia, and likely to become more so if we are able to diagnose and intervene earlier in the course of the condition. The current over-reliance on those arguably least skilled in health care to provide the broad array of services required by people with dementia (PWD) and their families requires redress. Mercy Health would urge that attention be given to supporting an increased involvement of other health providers in the care of PWD, including gerontologists, neurologists, speech pathologists, and occupational and physio therapists, in order that a comprehensive, integrated and quality program of care can be provided to this group who are experiencing one of the most disabling conditions and who are most in need of support.

Recommendation 1: Expand support for an integrated, multi-disciplinary health team response to the complex needs of those with dementia and their families.

General Practitioners are a key resource in the health system. People with dementia and their families overwhelmingly seek assistance from their local doctor early in the dementia trajectory. Yet research indicates that medical practitioners both struggle to make the dementia diagnosis and to impart this diagnosis to the afflicted person and their families. This contributes to what can be years of delay in the person with dementia and their carers receiving adequate social and health supports. We would urge that GP training needs to include substansive content on dementia diagnosis, communication and care, and that practising GPs receive ongoing support and education around the value and processes of making and imparting a dementia diagnosis.

Recommendation 2: Increased supports for undergraduate and practising medical practitioners in the diagnosis of dementia.

The Royal Melbourne Hospital Neuropsychiatry Unit is a state-wide specialist mental health service that offers neuropsychiatric assessment and advice to psychiatric, neurological and other medical and mental health services. This includes vital work in the diagnosis and management of younger onset dementia. But this service has limited resources and a long waiting list for receiving care.

Recommendation 3: Increase the funding allocation to specialist mental health services such at the RMH Neuropsychiatry Unit.

Within residential aged care, those providing care often do not possess the skills required to manage the behaviours of those with dementia.

Education in this area is essential for good care. Providing an appropriate protected environment with low sensory impact features only goes some way to improving the care of dementia residents. Without staff having a greater understanding of the etiology of the condition they have little ability to understand and manage behaviour disturbances. In developing facilities for peoples with dementia there is a challenge in obtaining the correct balance between security and freedom.

Recommendation 4: Increased support to provide education for those working in residential aged care facilities, of the etiology of dementia and how best to care for those with the disease.

Those with younger onset dementia (YOD) should be considered differently from other forms of dementia. These people are still physically fit and sexually active. They may have young families, and potentially they were the major bread winner, leaving their family financially insecure.

For those with YOD, care provided in the community setting is most appropriate (ideally consumer directed care). This allows them to remain with their family, and eliminates the additional stress to themselves and their family involved in moving into a residential aged care facility.

Mercy Health has encountered those with YOD who have struggled to obtain an Aged Care Assessment to receive care. While they have been eligible to receive care as dementia is an age related condition, some ACAS teams will not see the person, or place low priority on those under 65 years of age.

The new Home Care Packages Program while targeted at fail older people does not have a minimum age requirement for eligibility purposes. This, along with the new dementia supplement that all package levels will provide increased support to PWD and their families.

Recommendation 5: improved consistency in the approach of ACAS teams, ensuring that people care access the same level of care regardless of their age and geographical location.

Resourcing of those models of care

With dementia impacting so many Australians and their families, Mercy Health welcomes the support of the Australian Government's $268.4 million over five years to tackle dementia as part of the Aged Care Reform Package *Living Longer, Living Better*.

The Dementia Behaviour Management Advisory Services (DBMAS) funded by the Commonwealth provides valuable clinical support to those caring for PWD, however our anecdotal evidence suggest that this important program struggles to meet demand. Mercy Health calls on the Government to make greater investment in this program.

The $123.3M supporting a new Dementia Supplement for eligible Home Care package recipients representing an increase in funding of 10 percent, while again welcome, will arguably not be sufficient to address the higher cost of caring for a person with dementia living at home, not to mention the high administrative costs frequently associated with such packages. The 'silent workforce' of family and friends who currently support such individuals assumes significant social and economical burden that this increased supplement is unlikely to redress.

Recommendation 6: Greater investment in the Dementia Behaviour Management Advisory Services.

Recommendation 7: Greater investment in community supports.

The scope for improving the provision of care and management of Australians living with dementia and BPSD

Younger onset dementia is poorly understood. The service system is not responsive due to their age range (30's to 60's). Nor are the existing models of aged residential care appropriate to younger people with progressive neurological diseases such as Alzheimer's. It is still commonly assumed that all younger people with dementia will have memory problems and that the course of the disease is similar but as more is understood about conditions such as fronto temporal dementia and PCA (posterior cortical atrophy), there is an increasing appreciation of the need for person-centred services that respond both the characteristics of the pathology and to personal needs and preferences.

People living with YOD are isolated. They commonly know few others with the same condition and often cope primarily within their own resources. Families wish to support their loved one at home for as long as possible, but when the time comes when a higher level of support is needed they want to remain engaged and connected. They want that time to still be a quality life – to have a care facility where their loved ones can still walk and engage with nature, where they can participate in the activities of the home so far is possible.

A major problem to date has been that conventional respite and residential funding and staffing models have been unviable. Demand has also been difficult to secure with certainty.

Consumer Directed Care will provide significant benefits for those with YOD and their family. Support received in the home may not be direct care for the consumer, but be the provision of home support or respite which allows the spouse to leave the house to shop, or attend children's sports events. For the children of those with YOD, counselling could be provided.

Australia could learn from the model used in the Netherlands, the *Dutch National Younger Onset Dementia Care*, in developing an approach to care that responds to consumer and family preferences.

An approach that responds to consumers' and families' preference.

Recommendation 8: expand support for care of those with younger onset dementia and their families. Develop an approach that responds to consumer and family preferences.