

**SUBMISSION
TO
ONE STATE,
ONE HEALTH SYSTEM,
BETTER OUTCOMES**

20 February 2015

Executive Summary

Alzheimer's Australia Tasmania is part of the national peak body Alzheimer's Australia, representing people with dementia and their families and carers. Our vision is for a society committed to the prevention of dementia, while valuing and supporting people living with dementia. Alzheimer's Australia Tasmania welcomes the opportunity to provide a submission to the Minister for Health, Michael Ferguson to inform the reform package "One State, One Health System, Better Outcomes", particularly at a time when we are in the midst of major reform of the aged care and disability sectors in Australia and when we are facing an ageing population with increasing numbers of people experiencing chronic diseases such as dementia.

The care and support of people with dementia is one of the largest health care challenges facing Australia. It is estimated that there are now more than 340,000 Australians living with dementia¹ and over a million people involved in their care². Estimates for dementia prevalence in Tasmania is 7818 people living with dementia in 2015, with a projection of 13,544 people living with dementia in 2040 in the state. By 2050 there will be nearly 900,000 people with dementia³ across Australia and each week there are 1,800 new cases of dementia and this is expected to increase to 7,400 new cases each week by 2050⁴.

Dementia has a large impact on the health and aged care system with the cost of dementia to the health and aged care sectors estimated to be at least \$4.9 billion per annum⁵. Dementia also has a profound social impact, with people with dementia experiencing stigma and social isolation⁶, and family carers often finding it difficult to balance work, life and caring responsibilities⁷.

The increasing prevalence of dementia means that there is both an economic and welfare imperative for Government at state and national levels to develop initiatives to address dementia and ensure that people with dementia have access to appropriate care and support from the moment of diagnosis.

There is overwhelming evidence to suggest that the complex needs of people with dementia cannot be supported through mainstream health and care services. Instead there is a need to fund dementia-specific services which can provide the care, support and social engagement that people with dementia and their families so desperately need.

Alzheimer's Australia Tasmania is mainly federally funded through HACC and Alzheimer's Australia and our work focuses on supporting people living with dementia and their family carers. The state government kindly funds 10% of our operating costs, including the out of hours service of the national helpline in the Tasmania and this has proved to be a highly regarded safety net for people in crisis at all hours of the night and at weekends.

¹ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

² Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

³ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁴ Access Economics (2009) *Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050*. Report for Alzheimer's Australia.

⁵ Australian Institute of Health and Welfare (2012) *Dementia in Australia*.

⁶ Alzheimer's Australia (2014) *Living with Dementia in the Community: Challenges and Opportunities*

⁷ Brodaty & Green (2002) *Who cares for the carer? The forgotten patient*

The recommendations set out in this submission focus on the impetus to improve health outcomes for Tasmanians and Alzheimer's Australia Tasmania seeks to accomplish this through improving social inclusion, and access to specialist early interventions and supports. Investment in these priorities has the potential for savings in the overall health budget as it can reduce or delay the need for costly health services or hospitalisation – a focus you were keen to address in the recent forums held throughout Tasmania.

The priorities for Alzheimer's Australia Tasmania in respect of service delivery and advocacy for people living with dementia and their carers include:

DEMENTIA RISK REDUCTION

- 1 The Your Brain Matters Power of Prevention program is currently funded by the federal government. Two key population surveys of Australians aged 20-75 years, conducted in 2012 and 2014, reveal that since the launch of Your Brain Matters, changes are beginning to take place in public perceptions of dementia risk reduction. However, there is still much work to be done.

Recommendation

Alzheimer's Australia Tasmania seeks support from the State Government to ensure Tasmanians are educated and aware of the risks of dementia and how to reduce the modifiable risk factors associated with dementia.

SPECIALISED DEMENTIA SERVICES

- 2.1 The Younger Onset Dementia Key Worker program, federally funded, ensures that people with younger onset dementia have access to an essential support service tailored to their needs. This program provides one-to-one support from the point of diagnosis throughout the dementia journey. Key workers link clients to early intervention supports and services and build capacity in families and clients to remain independent for as long as possible. The benefits of early intervention are well known and integral in ensuring the person living with dementia remains engaged, independent and maintains a good quality of life for as long as possible following a diagnosis. The Key workers also work within the service sector to develop dementia-specific services and supports.
- 2.2 Alzheimer's Australia Tasmania is a Registered Training Organisation and delivers dementia education and training statewide. Tasmanian Ambulance Service has shown interest in including specific dementia training for its staff, which would build understanding and awareness of frontline staff in the appropriate care required for people with dementia in our community. Alzheimer's Australia Tasmania can deliver this training.

- 2.3 Alzheimer's Australia Tasmania provides overnight respite services for people with dementia and their carers in Hobart (Day Club and overnight) and Launceston (Day Club). These services are highly valued by clients, with regular very positive feedback for the "home from home" and about the high quality of dementia care provided. Emergency referrals are frequent from RHH, but vacancies are rare and a waiting list is in place.
- 2.1 **Recommendations**
- Alzheimer's Australia Tasmania seeks support from State Government to continue building capacity in the community, engaging with more health service providers in Tasmania to afford increased accessibility to this unique program by people with Younger Onset Dementia and their family carers.
- 2.2 Alzheimer's Australia Tasmania can roll out a training program for the Tasmanian Ambulance Service and seeks support and opportunity to carry this out.
- 2.3 Alzheimer's Australia Tasmania respite service is working at capacity and has the intention of expanding in Launceston and Hobart, and seeks further consultation with the State Government and other potential stakeholders to secure funding for purpose-built dementia specific respite services in Hobart and Launceston.

DEMENTIA FRIENDLY COMMUNITIES

- 3 Work has started on a national program to tackle the stigma and social isolation associated with dementia. Building on Australian and overseas experience Alzheimer's Australia has applied for federal funding to be used to support the development of dementia-friendly communities in each state and territory. Alzheimer's Australia Tasmania has already started to be involved in enabling Snug, in the south of the state, to begin this journey. The program will achieve 20 dementia-friendly communities nationwide by 2016. These communities would support projects to both raise awareness about dementia and also engage people with dementia in the community through volunteer opportunities, social activities and improved access to every day services such as banking and retail.

This program will additionally provide an avenue to support the rising number of people with dementia living alone. The majority of this cohort of people in need, who represent an increasing issue of concern in our communities, are not accessing Alzheimer's Australia Tasmania's specialist outreach and support services.

Recommendation

Any support from the State Government to build this program in Tasmania would add value to our community, resulting in stigma reduction and possible dementia prevention or delay. Building awareness and understanding of dementia will increase accessibility by people in the community living with dementia, including those living alone, to Alzheimer's Australia Tasmania's specialist services.

TASMANIA DEMENTIA INITIATIVE

- 4 The Tasmania Dementia Initiative was set up a few years ago by the DHHS to build a strategic plan to address dementia across Tasmania. Currently in abeyance, there was high level input to the steering committee, not least by medical academic Professor James Vickers of the University of Tasmania Wicking Dementia Research and Education Centre, Dr Jane Tolman DHHS Geriatrician, DHHS policy experts and a representative of Alzheimer's Australia Tasmania.

Recommendation

Given the National Dementia Framework is currently with State and Territory Ministers of Health for review, it would be timely to reinstitute the Tasmania Dementia Initiative to drive local strategies towards better outcomes for Tasmanians.

CONCLUSION

Dementia is one of the major chronic diseases of this century. There are more than 340,000 Australians living with dementia and this is expected to increase to nearly 900,000 by 2050. It is estimated that over a million Australians are involved in the care and support of people with dementia. The significance of the economic and social impact of dementia has been recognised with the 2012 decision to make dementia a National Health Priority Area. Unfortunately, people with dementia and their families are still struggling to get access to the care and support they require.

In rebuilding Tasmania's health system, the State Government needs to implement a holistic plan to tackle dementia with a focus on enabling expert dementia service providers to most effectively support people with dementia and their carers in our communities. By tackling social isolation and improving understanding and awareness of dementia a comprehensive approach to improve quality of care in the community will be possible and highly effective.

Building our capacity in Tasmania to address dementia now will save millions in high cost hospital interventions and in lost productivity for years to come as well as improving the welfare of thousands of Tasmanians who are in some way impacted by dementia.