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SAVE AUSTRALIA
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2015-2016
STATE BUDGET SUBMISSION

JANUARY 2015

ALZHEIMER'S AUSTRALIA VIC

About Alzheimer's Australia Vic

Alzheimer's Australia Vic is a society committed to the prevention of dementia, while valuing and supporting people of all ages living with dementia.

As Victoria's peak, non-profit body for people with dementia, their families and carers, we engage in a wide range of activities, which includes:

- face to face and telephonic information, support and professional counselling;
- early intervention programs;
- peer support programs;
- education and training aimed at families and carers;
- education and training aimed at health workers, including GPs and the acute sector;
- targeted awareness raising and support services; and
- broad advocacy and policy positioning.

Through these services and activities we engage directly with some 12,000 people with dementia, their families and carers every year and we deliver education and advice to more than 15,000 primary health, acute care and aged care professionals.

With an estimated 81,000 Victorians currently living with dementia and with that figure projected to increase to 141,000 by 2030, we need to do more to meet the needs of people of all ages living with dementia as well as their families and carers.

For more than 30 years Alzheimer's Australia Vic has worked with members, consumers, stakeholders and all levels of government to ensure that people with dementia, their families and carers are appropriately supported – whether that be within their workplace, home (including residential aged care) or their local community.

Our close engagement with consumers means that Alzheimer's Australia Vic is an effective advocate for those affected by dementia and we advise on related policy matters, identify service gaps and draw on our expertise to collaborate with a wide range of stakeholders.

We maintain two metropolitan and 10 regional offices, and each service centre is aligned with their regional health authority; local hospital/s; primary, allied health and mental health specialists; community support groups, and service providers.

INTRODUCTION

Alzheimer's Australia Vic offers this submission to inform the 2015-16 State Budget process and help the Government deliver support to the estimated 81,000 Victorians of all ages living with dementia. We value the ongoing support of the Victorian Government that has enabled our state to become a leader in the provision of dementia services.

We are committed to continuing to work in partnership with the Government, our members, consumers and other stakeholders to progress the priorities outlined below and to explore service innovations that will more effectively support people of all ages with dementia, their families and carers.

Why focus on dementia?

Dementia is the term used to describe the symptoms of a large group of illnesses that cause a progressive decline in a person's brain function. It is a broad term used to describe impairments in memory, thinking and behaviour. Dementia can affect any adult but it is much more common after the age of 65 (though it is not a natural part of ageing).

Dementia is the major chronic disease of the twenty-first century and has been recognised by the Australian State and Territory Health ministers as a National Health Priority Area. There are currently around 81,000 people living with dementia in Victoria¹ and the number is projected to increase to almost a quarter of a million by 2050 unless there is a medical breakthrough.² Around 2,500 people in the state have younger onset dementia; that is, they have developed the disease before the age of 65. Almost two thirds of people with dementia are women and a third are men.³ Across Australia, dementia will become the third greatest source of health and residential aged care spending within two decades. These costs alone will be around 1% of GDP.⁴

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

Alzheimer's Australia Vic acknowledges the collaboration and support of successive state governments for dementia services here in Victoria, most recently articulated in the Department of Health's *Victoria Dementia Action Plan 2014-18*.⁵ In addition we recognise and commend the strategic importance placed on health and wellbeing as well as liveable, inclusive and sustainable communities within the Victorian Labor Platform 2014.⁶

We are in turn committed to ensuring that every dollar spent in relation to dementia is used effectively and that it leads to better outcomes for consumers – and communities more

¹ Deloitte Access Economics (2012) data commissioned by Alzheimer's Australia Vic.

² Ibid.

³ Australian Institute of Health and Welfare (2012) *Dementia in Australia*. Cat. no. AGE 70.

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

⁵ Department of Health (2014) *Supporting people with dementia and their families and carers: Victoria Dementia Action Plan 2014-18*.

⁶ Victorian Labor Party (2014) *Platform 2014*.

broadly. It is clear that investment in health promotion, early intervention and community services within both the health and aged care sector can lead to a significant reduction in health care costs and improved quality of life for Victorians impacted by dementia.

Victoria has an opportunity to expand our leadership and expertise in supporting people of all ages living with dementia, and in turn save our health system money over the medium to long term. This is a great economic outcome, but more importantly a better health outcome for some of our most vulnerable Victorians.

What should be prioritised?

Alzheimer's Australia Vic is calling for the State Government to take steps towards creating a dementia-friendly Victoria. There are a number of interlinked strategies for achieving this aim and this budget submission outlines the priorities for inclusion in the 2015-16 Budget. In summary, these include:

- **Dementia-Friendly Communities** – A commitment by the Government to take the lead in creating a state-wide Dementia-Friendly Communities initiative, consumer driven and partnered with Alzheimer's Australia Vic. This initiative has significant potential to provide more welcoming environments for all Victorians with spin-off benefits to the retail, small business and tourism sectors;
- **Awareness** – Support for a ground-breaking community awareness campaign about dementia, available help, and the link between healthy lifestyles and reduced dementia risk. While improving health outcomes, the aim is also to save the health budget money over time through both preventative health programs and reduced duplication of services as people are more efficiently directed toward the right level and age-appropriate support;
- **Younger Onset Dementia** – Funding to maintain and increase the number of key workers in addition to service innovations for people who develop dementia before the age of 65, for whom age-specific services are currently limited in both the aged care and disability sectors. The creation of specialist jobs in this area is vital to not only meet the needs of these unique younger people, but to ensure the most efficient use of health budgets;
- **Critical Dementia Service Gaps** – Funding for increased education and networks for health and community service sectors as well as increased capacity in supporting advance care planning and palliative care decisions for people who have dementia, their families and carers. A best-practice trained and informed sector will lead to greater staff retention, efficiencies with earlier diagnosis and service access; and more tailored, person-centred care that will lead to a world-class quality dementia care system in Victoria.

These recommendations are based on extensive consultation with consumers throughout Victoria, as well as with other key stakeholders and available evidence. We would welcome the opportunity to discuss them with you.



Maree McCabe
CEO

RECOMMENDATIONS

1. DEMENTIA-FRIENDLY COMMUNITIES

\$3 million over 3 years

- 1.1 A commitment by the Government to take the lead in creating a state-wide Dementia-Friendly Communities initiative, consumer-driven and partnered with Alzheimer's Australia Vic. This program will engage with local communities and organisations through the creation of Local Dementia Alliances as well as providing education and support for engagement with people who have dementia. The program will aim to achieve at least six dementia-friendly communities by 2018. The initiative will require job creation within Alzheimer's Australia Vic and indirectly through the positive impact on the six communities through increased retail, small business, hospitality and tourism.
- 1.2 The establishment of a Dementia Friends program will place Victoria on the world stage, alongside already successful and proven programs in Japan, Canada and the United Kingdom.

2. AWARENESS

\$2.25 million over 3 years

- 2.1 Deliver a ground-breaking community awareness campaign that combats misunderstanding and stigma relating to dementia, explains the support services available for people with dementia, their families and carers, and highlights the importance of risk reduction strategies. This streamlined information will better support people, reduce duplication of services and decrease health budget expenditure.

3. YOUNGER ONSET DEMENTIA

\$2.4 million over 2 years

- 3.1 Maintenance and expansion of the Younger Onset Dementia Key Worker program across Victoria, resulting in specialised job creation and efficient use of health budgets.
- 3.2 Increased support mechanisms for younger people with dementia to access the care and support services most appropriate for their needs, including counselling, social support programs, peer support programs and early intervention programs, as well as information, education and assistance to navigate the service system.

4. CRITICAL DEMENTIA SERVICE GAPS

\$3.31 million over 3 years

- 4.1 An expanded suite of non-accredited training and education programs for professionals that will encourage sector retention and increase workforce skills.
- 4.2 Expanded community education services, including online access, which will contribute to an enhanced quality of life for people with dementia, their families and carers.
- 4.3 Expansion of the Victorian Dementia Network in order to promote a more integrated, cost-effective service response to the needs of people living with dementia.
- 4.4 Introduction of an education program for community aged care workers on Advance Care Planning that will enhance sector capacity and lead to better continuity of care.
- 4.5 Implementation of a dementia and palliative care program to enhance the skills of professional staff across 13 culturally and linguistically diverse (CALD) communities and result in more integrated and streamlined services for all Victorians.

ALZHEIMER'S AUSTRALIA VIC BUDGET PROPOSAL

Alzheimer's Australia Vic is calling on the Victorian Government to commit an additional \$10.96 million to dementia services and support between 2015 and 2018. The breakdown of this funding is shown below:

Additional Funding (\$ millions)	2015-16	2016-17	2017-18	Total
Dementia Friendly Communities	1.0	1.0	1.0	3.0
Awareness	0.75	0.75	0.75	2.25
Younger Onset Dementia	-	1.2	1.2	2.4
Critical Dementia Service Gaps	1.18	1.18	0.95	3.31
Total	\$2.93M	\$4.13M	\$3.9M	\$10.96M

1. DEMENTIA-FRIENDLY COMMUNITIES

Recommendation

- 1.1 A commitment by the Government to take the lead in creating a state-wide Dementia-Friendly Communities initiative, consumer-driven and partnered with Alzheimer's Australia Vic. This program will engage with local communities and organisations through the creation of Local Dementia Alliances as well as providing education and support for engagement with people who have dementia. The program will aim to achieve at least six dementia-friendly communities by 2018. The initiative will require job creation within Alzheimer's Australia Vic and indirectly through the positive impact on the six communities through increased retail, small business, hospitality and tourism.
- 1.2 The establishment of a Dementia Friends program will place Victoria on the world stage, alongside already successful and proven programs in Japan, Canada and the United Kingdom.

Investment sought **\$1 million per annum for three years.**

Policy context

Like the State Government, Alzheimer's Australia Vic believes that a truly liveable Victoria is one in which everyone – including those affected by dementia – has access to the services and infrastructure that is essential for a good life.⁷ The creation of Dementia-Friendly Communities across the state will not only result in more inclusive societies but work across all levels of government. Indeed, the exploration of Dementia-Friendly Communities at a local level will give local governments a sense of ownership and contribute to the sustainability of their own communities, whether activities are related to health and wellbeing, physical activity, social interaction or the physical environment.⁸

In supporting local councils to adopt consistent dementia-friendly planning models, the Victorian Government will facilitate social and economic frameworks in which broader stakeholder partnerships (including collaboration with Alzheimer's Australia Vic) can be maximised to address gaps and enhance service delivery as well as pilot projects in the health, welfare, community service and hospitality arenas.⁹ The nature of these collaborations will be such that local retailers, hospitality owners, art galleries, public spaces, major and community events, sports clubs, neighbourhood houses, men's sheds, senior citizens facilities and libraries will become mechanisms through which people – including those affected by dementia – can achieve their potential to fully participate in their society.¹⁰

Dementia-Friendly Community initiatives will then become fundamental elements included in all Victorian and Local Government strategies focused on tourism, planning, major events, profile raising, CALD communities, small business support and community engagement.

⁷ Victorian Labor Party (2014), p. 73.

⁸ Ibid., p. 73.

⁹ Ibid., p. 75.

¹⁰ Victorian Labor Party (2014), p. 79; Department of Health (2014), pp. 44-51.

Dementia-Friendly Community initiatives are also in-keeping with a number of strategies outlined by the Department of Health in their *Victoria Dementia Action Plan 2014-18*, including partnering with local governments to promote age-friendly (and dementia-friendly) communities, working with the Municipal Association of Victoria on dementia-friendly projects, developing and supporting resources to support age-friendly and dementia-friendly shopping precincts and businesses, exploring collaborations with large banking, transport and pharmaceutical chains, and exploring private sector engagement.¹¹

Rationale

The onset and progression of dementia has considerable implications for the person's daily life and engagement with society. As well as a decline in cognitive capabilities, people with dementia also experience changes in their personality and emotional state that can negatively affect their social interaction. In addition to changes which are directly related to dementia, some people also experience a profound sense of social isolation and lack of purpose due to social stigma.

A 2012 study about stigma and dementia found:

- 22% of those surveyed said they would feel uncomfortable spending time with someone who had dementia;
- 34% of respondents found people with dementia to be irritating;
- 11% said they would avoid spending time with people who had dementia; and
- If diagnosed with dementia, 60% anticipated that they would feel shame.¹²

People with dementia have identified social isolation as a key concern and members of our national and Victorian consumer advisory committees have provided the following comments:

- "We want to have a real part in the decision making that affects us"
- "Stop looking past us (to our carer) and talk to me, I am here"
- "It is my right to speak for myself, no matter how much time it takes me, or how much of a struggle it is"

Alzheimer's Australia has published reports on dementia-friendly communities and organisations which outline international approaches as well as describing how initiatives could be implemented in Australia.¹³ A number of pilot projects are also underway around the country, including in the community of Beechworth in far northern Victoria.

The goal of developing this approach in Victoria is to create a world-leading, dementia-friendly state that provides services, support and a culture that encourages, empowers, engages and embraces all people living with dementia, their families and carers. Not only will this foster more integrated support for people with dementia but the broader benefits to communities will include business, service sector and tourism opportunities.

¹¹ Department of Health (2014), pp. 50-51.

¹² Alzheimer's Australia (2012) *Exploring Dementia and Stigma Beliefs*.

¹³ Alzheimer's Australia (2013) *Dementia-Friendly Communities: A Way Forward*; Alzheimer's Australia (2014) *Creating Dementia-Friendly Communities: Business Toolkit*; Alzheimer's Australia (2014) *Creating Dementia-Friendly Communities: Community Toolkit*.

The strategy is designed to engage individuals through a Dementia Friends program (akin to those in the United Kingdom, Japan and Canada), which focuses on broad community awareness and understanding of dementia – and the emotional impact that a diagnosis can have on an individual and those around them.

The strategy also promotes engagement with/by whole organisations and local communities through the introduction of local dementia alliances – that is, groups who, together, determine the priorities of their own community and make a commitment to integrate dementia-friendly (and thus inclusive) principles into their way of life.

The scope and content of these action plans are likely to vary in accordance with the priorities and preferences of the local community, but may include a range of short-term and long-term goals that focus on public awareness, the physical environment, social support or even employment/engagement opportunities for people with dementia.

However, sustained financial and educational support for individuals and communities to implement a dementia-friendly approach is imperative. Successful dementia-friendly schemes in the United Kingdom, for example, highlight the importance of free awareness training for local businesses and members of the community as well as support for local dementia alliances and/or councils to engage with and involve those affected by dementia in their community.

As such, Alzheimer's Australia Vic proposes to invest \$1 million per annum for three years into:

- State-wide and local consumer consultations;
- comprehensive community education programs that includes the Dementia Friends scheme and education tailored to local businesses;
- resources for communities, local government, public buildings and spaces to create dementia-friendly way-finding, signage guidelines and practices; introduce dementia-friendly design principles into places such as public toilets, parks and gardens, galleries, hotels, public buildings and spaces;
- dementia-friendly toolkits for local government, community organisations, sporting and social clubs;
- a state-wide road show demonstrating to community members how they can implement the concept in their locality, including a mobile dementia-friendly pop up pod to tour the state;
- Support for the establishment of at least six local dementia alliance action groups with key community leaders, retail, events and hospitality organisations who will be challenged to build their own dementia-friendly community; and
- A multi-media awareness raising promotional campaign.

2. AWARENESS

Recommendation

2.1 Deliver a ground-breaking community awareness campaign that combats misunderstanding and stigma relating to dementia, explains the support services available for people with dementia, their families and carers, and highlights the importance of risk reduction strategies. This streamlined information will better support people, reduce duplication of services and decrease health budget expenditure.

Investment sought **\$750,000 per annum for three years.**

Policy context

The importance of, and support for, health promotion activities features in the Victorian Labor Party's Platform 2014, and the focus on prevention programs relating to dementia are as important as those relating to diabetes or heart disease.¹⁴

The *Victorian Public Health and Wellbeing Plan 2011-15* has also aimed to improve the health and wellbeing of Victorians by engaging communities in prevention and strengthening systems for health protection, health promotion and preventative healthcare across all sectors and levels of government.¹⁵ Alzheimer's Australia Vic seeks to continue and expand these commitments by significantly increasing awareness and understanding of dementia by complementing the mechanisms already outlined in the *Victoria Dementia Action Plan 2014-18*.¹⁶

Rationale

Currently it is estimated there are 81,000 people in Victoria living with dementia. Without a significant medical breakthrough the number of people in Victoria with dementia is projected to increase significantly over the next 35 years. In just 15 years this figure will reach 141,000. This data, combined with our ageing population, means that every Victorian will be impacted by either a diagnosis themselves or of a close family member or friend.

There is no cure but consistently research indicates that individual outcomes are significantly improved the earlier a person accesses the services available. Yet awareness levels within Victoria of what dementia is; knowledge about the differences between Alzheimer's disease and other forms of dementia; the services that are available and where to go to seek support and information is alarmingly low.

Many Australians are unaware that if they make changes to their lifestyle they may reduce the risk of developing dementia. An Australian study showed that if 5% of inactive people became active over a 5 year period, this would reduce Australian dementia prevalence by 11% in 2051. That equates to around 100,000 fewer Australians living with dementia, simply by getting more of us to do regular physical activity.¹⁷

¹⁴ Victorian Labor Party (2014), p. 38.

¹⁵ Department of Health (2011) *Victorian Public Health and Wellbeing Plan 2011-15*.

¹⁶ Department of Health (2014), pp. 34-37.

¹⁷ Nepal B, Brown L, Ranmuthugala G. (2010) 'Modelling the impact of modifying lifestyle risk factors on dementia prevalence in Australian population aged 45 years and over, 2006-2051', *Australasian Journal of Ageing*, 29(3), 111-16.

It is vital that the scope and breadth of awareness campaigns are significantly increased to ensure that all Victorians learn more about prevention and that all people impacted by dementia know to contact Alzheimer's Australia Vic, the gateway to services across Victoria.

Over many years, successful awareness raising campaigns have broken down the stigma associated with cancer and mental health. This has made a measurable, life-changing difference to the lives of many Victorians. To ensure all people living with dementia are treated with dignity and receive the quality of care they deserve it is essential that a major, sustained, and ground-breaking awareness campaign is delivered to inspire Victorians to talk about dementia, to seek information and to ask for assistance early.

The importance of this strategy has already been recognised by the Victorian Department of Health, who, in their *Victoria Dementia Action Plan 2014-18*, have highlighted health literacy and dementia risk reduction as key focus areas.¹⁸

Alzheimer's Australia Vic proposes to invest \$750,000 per annum to develop a comprehensive three-year marketing strategy with key partners on the Victorian Government Marketing Services Panel. The Marketing Strategy will aim to reach all Victorians to communicate these important public health messages.

¹⁸ Department of Health (2014), p. 35.

3. YOUNGER ONSET DEMENTIA

Recommendation

- 3.1 Maintenance and expansion of the Younger Onset Dementia Key Worker program across Victoria, resulting in specialised job creation and efficient use of health budgets.
- 3.2 Increased support mechanisms for younger people with dementia to access the care and support services most appropriate for their needs, including counselling, social support programs, peer support programs and early intervention programs, as well as information, education and assistance to navigate the service system.

Investment sought **\$1.2 million per annum for two years from 2016-17**

Policy context

As the Department of Health's *Victoria Dementia Action Plan 2014-18* recognises, all Victorians have a right to access a person-centred approach to their care and services.¹⁹ This includes people living with younger onset dementia, that is, those who develop dementia before the age of 65. The Labor Government and Alzheimer's Australia Vic share a commitment to promoting access and choice in the delivery of services, with our Key Worker program operating as a unique and tailored service that appropriately supports people with younger onset dementia.

The Victorian Labor Platform 2014 highlights the importance of ensuring that people can remain living independently in their own homes for as long as possible, and with access to high quality services that are delivered by a stable and skilled workforce.²⁰ Alzheimer's Australia Vic's Younger Onset Dementia Key Worker program is a vital component in this strategy because it not only supports a client base who have specialised and unique service needs but also increases access to broader disability participation models, streamlines access to client-centred supports and establishes Victoria as a leader in the provision of care and support for people with younger onset dementia.²¹

Rationale

There are approximately 24,400 people in Australia (and 2,500 in Victoria) with younger onset dementia (that is, a diagnosis of dementia under the age of 65) with most 'falling through the cracks' because they do not fit neatly into the aged care system or the disability sector.

The National Disability Insurance Scheme (NDIS) holds promise for people with younger onset dementia through its broad tenets of supporting independence and participation, the provision of reasonable and necessary supports, consumer choice and control, and access to high quality, innovative supports.²²

¹⁹ Department of Health (2014), pp. 24-25.

²⁰ Victorian Labor Party (2014), pp. 46-47.

²¹ Ibid.

²² National Disability Insurance Scheme Bill 2012 (2012), Chapter 1, Part 2, sub-section 3.

These principles are crucial in supporting people with younger onset dementia because their dementia appears at an earlier stage in their life when they are likely to be more physically and socially active and may be the primary wage earner in a family.

However, the current NDIS trials in Victoria have been useful in highlighting some important issues and barriers for people with younger onset dementia in accessing appropriate support and care under the NDIS. These include:

- Ineligibility for clients with few functional or practical needs, despite having high degree cognitive deficits and burden on carers;²³
- The lack of support for carers under the scheme;
- Difficulty for people with cognitive impairment to complete the application process, explain their condition and needs, manage their plan, and contact and consult with NDIS staff and service providers;
- A lack of appropriate registered services, given that NDIS registered services are largely traditional mainstream disability providers who do not specialise in younger onset dementia.

Given these challenges, the involvement of informal – but especially formal – advocates throughout the application process and beyond is vital.

The Younger Onset Dementia Key Worker Program has been a crucial element in the sustained provision of care and support for people affected by younger onset dementia in Victoria. The program aims to improve the quality of life for people with younger onset dementia, their families and carers, by providing them with a highly skilled key point of contact with which they can develop comprehensive strategies that optimise their engagement with support and care options.

The specialised key worker model of service delivery is underpinned by the principles of a person-centred approach, aiming to provide tailored and flexible services and to build capacity in the service sector.

The two concepts – key workers and the NDIS – must continue to work together in order to appropriately support the unique needs of the younger onset dementia cohort and stop them from ‘falling through the cracks’. The Victorian Government, in collaboration with Alzheimer’s Australia Vic, is best placed to ensure that the funding available for key workers is not in any way diminished and continues to be available for both pre- and post-NDIS assessment.

For this reason, Alzheimer’s Australia Vic requires \$1.2 million funding per annum from 2016-17 to continue operating a Victorian Younger Onset Dementia Key Worker program that maintains a specialised workforce to support the needs of younger people with dementia and their carers across the state before, during and after they receive NDIS assistance. The program will focus on the job creation and continuation of metropolitan and regional key workers who are based across the state and support clients in metropolitan Melbourne and regional Victoria (including the Grampians, Hume, Loddon Mallee, Barwon South West and Gippsland).

²³ In the pilot trial at Barwon South-West, Alzheimer’s Australia Vic data reveals that of the 11 applicants for NDIS funding with younger onset dementia, 5 were deemed ineligible or faced lengthy delays in a determination.

The need for this program is demonstrated by the fact that almost 80 percent of our current client base requires intense, regular support to maintain independence and negotiate the NDIS system. Not only do they require facilitated access to information and education but people with younger onset dementia need access to appropriate activities, support with future care planning and social engagement/peer support appropriate to their age.

Importantly, the Key Worker program also provides support to carers who would otherwise be ineligible for services under the current structure of the NDIS.²⁴

Key features of the program will include:

- Provision of individualised services and support for individuals with younger onset dementia and their families and carers in a way that meets their needs across the dementia journey;
- Linking of individuals with younger onset dementia to appropriate services and supports in their community to encourage care assessment, service planning and delivery process integration across agencies. This includes empowering individuals to manage and access services themselves and remain socially engaged within their community; and
- Building capacity in existing services to better meet the needs of people with younger onset dementia. This will be achieved through consultation, education and training, networking and collaboration. The Younger Onset Dementia Key Worker role will be flexible enough to allow change to meet local and evolving needs.

²⁴ Carer support is highlighted as a priority area in the Department of Health (2014), pp. 52-53; see also Victorian Labor Party (2014), p. 44.

4. CRITICAL DEMENTIA SERVICE GAPS

Recommendation

- 4.1 An expanded suite of non-accredited training and education programs for professionals that will encourage sector retention and increase workforce skills.
- 4.2 Expanded community education services, including online access, which will contribute to an enhanced quality of life for people with dementia, their families and carers.
- 4.3. Expansion of the Victorian Dementia Network in order to promote a more integrated, cost effective service response to the needs of people living with dementia.
- 4.4 Introduction of an education program for community aged care workers on Advance Care Planning that will enhance sector capacity and lead to better continuity of care.
- 4.5 Implementation of a dementia and palliative care program to enhance the skills of professional staff across 13 culturally and linguistically diverse (CALD) communities and result in more integrated and streamlined services for all Victorians.

Investment sought **\$950,000 per annum for three years,**
plus an additional \$233,500 per annum for two years.

Policy Context

As outlined in the Department of Health's *Victoria Dementia Action Plan 2014-18*, improving the services that support people with dementia, their families and carers rely on will not only improve their quality of life but ensure that local primary health, hospital and specialised support networks are strengthened.²⁵ And, in turn, these seamless networks will ensure that the future preferences of people with dementia (including end of life care) are discussed and supported more effectively.²⁶

One element of this sector development lies in professional education and training in dementia and appropriate care pathways. The Victorian Labor Party has recognised that there is an appropriate role for local governments in the provision and funding of home and community care (HACC), and it is important that staff in this sector, along with nurse practitioners and general practitioners, have access to a range of educational supports in different formats and that retention rates and specialist skills are improved.²⁷

Similarly, although government policies recognise the importance of evidence based pathways relating to advanced care planning and palliative care services, it is clear that further capacity building is required for those people affected by dementia.²⁸

²⁵ Department of Health (2014), pp. 34, 38; Victorian Labor Party (2014), p. 35.

²⁶ Victorian Labor Party (2014), pp. 38-39; Department of Health (2014), pp. 54-55.

²⁷ Victorian Labor Party (2014), p. 76.

²⁸ Department of Health (2014), pp. 54-55; Department of Health (2014) *Advance care planning: have the conversation – a strategy for Victorian Health Services 2014-18*; Department of Health (2011) *Strengthening Palliative Care: Policy and strategic directions 2011-2015*.

Rationale

Professional education - \$200,000 per annum for 3 years

The growing demand for dementia education tailored to professionals providing support to people living with dementia in the community consistently exceeds what current funding levels can support. This unmet need can ultimately result in decreased quality of life for the person with dementia (and that of their carer/s) and result in ineffective care pathways, including premature admissions to hospital or residential aged care. Equally, staff who are not equipped to appropriately support people with dementia in the community may feel disengaged or ineffective in their roles, leading to higher than average staff turnover and disrupting individualised service delivery to clients.

It is therefore important that existing funding for professional education in the community is increased so that Alzheimer's Australia Vic can expand the number and geographic distribution of these education sessions, particularly in rural areas. Not only will this lead to a more highly skilled Victorian workforce but it will ensure that the sector is better able to retain highly skilled staff and entice new graduates through professional development pathways.

Community education - \$150,000 per annum for 3 years

A concerted media focus on dementia will not only increase awareness of the disease but raise a wide range of questions for the broader community around specific issues associated with diagnosis, care and appropriate supports for people with dementia. Alzheimer's Australia Vic's existing community seminar series helps to raise awareness around these issues from a highly reputable group of professional presenters.

These seminars are well attended at venues across the state: over 900 people have attended sessions in the past two years. However, demand for this more detailed level of education is always extraordinarily high and an expansion of the program is warranted. In order to make these sessions more accessible, Alzheimer's Australia Vic proposes to double the amount of sessions currently scheduled from eight to sixteen sessions per annum and make them available online to a broader audience.

Victorian Dementia Network - \$250,000 per annum for 3 years

The Victorian Dementia Network is facilitated by Alzheimer's Australia Vic and the Dementia Behaviour Management Advisory Service to support better outcomes in dementia care. This is achieved by providing an inclusive forum for those working across the dementia care continuum to share information, enhance communication and promote better practice care. The objectives for this group span:

- Encouraging opportunities for interface between different sectors along the dementia care continuum;
- Facilitating the dissemination of information about Australian Commonwealth Government and Victorian State Government initiatives including funding, education, research, clinical care and service developments;
- Increasing knowledge and awareness of the supports and resources available to people with dementia, their carers and supporters; and
- Providing a forum for service providers to share ideas to help inform the development and promotion of better practice dementia care.

The scope and ambition of this group is strongly curtailed by the fact that it is an unfunded activity. The addition of funded secretariat support and an interactive website will improve the capacity of the Group to facilitate improved service responsiveness for people living with dementia. The formal support of more integrated partnerships will also result in a more cohesive and specialist workforce and efficient, cost-effective health system.

Advance Care Planning education - \$350,000 per annum for 3 years

Dementia is the single greatest cause of disability in older Australians and the third leading cause of disability burden overall. Unfortunately studies suggest that people with dementia experience suboptimal end-of-life care due to a loss of capacity over medical decision making. People with a diagnosis of dementia have been shown to receive fewer treatment options, lower palliative care referrals and increased lengths of stay in hospitals on admission.

Research in this area has shown that professionals are often more uncomfortable having a conversation about advance care planning with a patient affected by dementia, despite them – and their families and carers – being open to the discussion. It is also striking that, despite these challenges, there is not currently a specific education program which targets professionals working in the community and focuses on advance care planning and dementia.

It is therefore vital that support is given to a project that will aim to educate and train community health care workers who support people living with dementia in the tenets of advance care planning. It is particularly important that this education is accessible to care professionals who are engaging with people in the early stages of dementia, when capacity is maximised. Not only will this promote better health and quality of life outcomes for individuals with dementia but it will also potentially reduce longer-term costs to the health care sector.²⁹

This project would deliver both face to face workshops and also develop an interactive online education module on advance care planning to community care workers across the state.

Palliative care – \$233,500 per annum for 2 years

Alzheimer's Australia Vic and Palliative Care Victoria will collaborate to deliver a dementia and palliative care program over two years to professional staff across 13 culturally and linguistically diverse (CALD) communities.

Knowledge of palliative care principles and the benefits for a quality end of life experience are not widely understood by the wider community. The need for an informed understanding of palliative care is particularly magnified in culturally and linguistically diverse communities. This is further complicated when the dementia dimension is added; there is variable CALD community awareness about the nature of palliative care and of strategies that are available to support people living with dementia, their families and carers. The Department of Health's *Strengthening Diversity Planning and Practice* is committed to respecting the diversity of the Victorian population and is implementing a range of strategies to support this objective.³⁰

²⁹ Department of Health (2014), pp. 54-55.

³⁰ Department of Health (2011) *Strengthening Diversity Planning and Practice: A Guide for Victorian Home and Community Care Services*.

Alzheimer's Australia Vic has undertaken significant complementary work within this framework, particularly over the last three years through our implementation of a highly successful Peer Support Project for 10 CALD communities as part of a capacity building program on ageing and dementia. We have also produced three resources on ethical issues (2010), planning for end of life care (2011) and 'wrestling with dementia and death' (2013). Palliative Care Victoria is also heavily invested and experienced in this sector having delivered a peer support palliative care program to 10 communities, funded by the Lord Major's Charitable Foundation, the Department of Health, Palliative Care Victoria and the Trust Company.

This 'dementia and palliative care in CALD communities' project proposal aims to strengthen work of both organisations and deliver training to staff of 13 CALD communities, specifically on dementia and palliative care. The communities would include Chinese, Vietnamese, Italian, Turkish, Maltese Macedonian, Greek, Polish, Arabic speaking, Croatian, Spanish speaking, and Serbian.

It is proposed to:

- Produce a generic training resource on dementia and palliative care;
- Adapt that resource individually for each of the 13 communities (including bi-lingual productions);
- Hold two combined one day training sessions for staff across the 13 communities (this combined cross fertilisation of experience has been demonstrated to strengthen learning);
- Implement a communications strategy to promote the program, including radio and press;
- Roll out the program over two years (6 communities in year one and other 6 communities in year two); and
- Independently evaluate the project.