Introduction

On 15 and 16 March 2016, Alzheimer’s Australia held a National Consumer Summit at Parliament House to articulate a vision for dementia in Australia and to identify key issues and priority areas for a National Dementia Strategy.

The priorities and recommendations included in this Communique have been developed by people with dementia and carers.

This Summit comes at a critical time after the announcement in November 2015 that the Government plans to make significant changes to dementia programs and services to better support people with dementia and their families.

People with dementia and carers want to ensure that their voices are heard and that the redesign of services involves consumers and leads to greater inclusion, support, and high-quality services that meet the medical, physical, social and spiritual care needs of consumers from all backgrounds.

Dementia is the chronic disease of the 21st century. Currently there are more than 353,800 Australians with dementia and this figure is expected to increase to almost 900,000 by 2050.¹

More than 1.2 million Australians are involved in their care and the cost of dementia on the health and aged care systems is calculated to be at least $4.9 billion per annum.

¹Australian Institute of Health and Welfare (2012), Dementia in Australia.
Consumers, at the summit, unanimously called for a funded National Dementia Strategy with measurable outcomes which builds on the National Framework for Action on Dementia 2015-2019 and addresses the following priorities to:

1. Develop culturally appropriate dementia support that responds to the needs of people from diverse backgrounds including culturally and linguistically diverse, Aboriginal and Torres Strait Islander people, the homeless, people living alone, people with younger onset dementia and the LGBTI community
2. Promote risk reduction
3. Tackle the stigma and discrimination associated with dementia and support social inclusion and participation
4. Improve access to timely diagnosis and high-quality health care
5. Provide care and support in the community that facilitates independence, social engagement and effective support for informal carers
6. Ensure access to high-quality residential care and publicly available information about consumer experience and quality of care
7. Improve end of life care and support for people with dementia
8. Sustained investment in dementia research
9. Implement consumer directed care that leads to real choices and better outcomes for people with dementia and their families
10. Develop a strategy to better support carers of people with dementia

The implementation of a National Dementia Strategy would build on existing areas of success and develop a strategic, collaborative and cost effective response to dementia across Australia.

Summit participants have identified specific programs, services and supports which should be core components of any nationally funded Dementia Strategy.

Culturally Appropriate Dementia Support

For people from diverse backgrounds (culturally and linguistically diverse, people from Aboriginal and Torres Strait Islander backgrounds, LGBTI communities, the homeless, and those living alone) access to quality care and appropriate dementia services can be difficult.

Consumers recommend the following action:

1. Establish a dementia service response for Aboriginal and Torres Strait Islander communities that builds on the learnings and success of Aboriginal Community Controlled Health Organisations.
2. Flexible funding should be available to support diverse communities to identify and address dementia in culturally appropriate ways.
3. Fund a National Dementia and Diversity Program which builds capacity in the sector to improve access to dementia support and services for people from diverse backgrounds including culturally and linguistically diverse, Aboriginal and Torres Strait Islander people, the homeless, people living alone, children of people with younger onset dementia, and the LGBTI community.
Risk Reduction

Research over the last decade has shown that addressing behavioural and related clinical risk factors (e.g. diet and exercise) can help to reduce a person’s risk of dementia.

Up to a third of cases of Alzheimer’s disease are potentially attributable to preventable risk factors, yet there is little community awareness of what can be done to reduce the risk of dementia. Consumers recommend the following action:

1. Building on Your Brain Matters, the world’s first government-funded dementia risk reduction program, implement a campaign to inform and educate Australians of all ages about brain health, and alert people to the links between lifestyle and health factors, their risk of cognitive impairment and dementia, and their risk of developing other chronic conditions. This should include the development of targeted culturally appropriate resources.

Awareness and Social Inclusion

Dementia has profound social implications for both people with dementia and their family and carers. Often after a diagnosis of dementia, people experience social isolation and discrimination.

Consumers speak about being told to give up their hobbies and enjoyable activities following a diagnosis. Consumers recommend the following action:

1. Establish a national Dementia Friends program in Australia to raise awareness of dementia, building on local and international experience. It will offer dementia education sessions to the community.

2. Develop a National Dementia-Friendly Community Resource Clearinghouse to provide information, resources, best-practice guides as well as opportunities for networking and support for creating local dementia-friendly communities.

3. Develop an ongoing campaign to raise awareness about the symptoms of dementia, address stigma and support the rights and cultural needs of people with dementia.

Timely Diagnosis and High-Quality Health Care

There are clear benefits to timely diagnosis and management of dementia. Unfortunately, as many as two thirds of people with dementia live and die with the condition without ever receiving a diagnosis. Access to appropriate hospital care can also be problematic with people with dementia often not being appropriately supported.

Consumers recommend the following action to achieve a health and hospital system that provides timely diagnosis and appropriate care:

1. Reduce the current three year time to diagnosis to six months by 2021 and implement the appropriate awareness, service, training and education response to make this happen.

2. Establish specialist dementia clinics across Australia to support the timely diagnosis of dementia and appropriate referral pathways.

3. Develop a post-diagnostic pathway that provides support for rehabilitation, maximising independence and community engagement in a similar approach to those living with a physical disability or brain injury.

4. Support consumer co-designed programs to put evidence on dementia care and support into practice such as the Dementia Care in Hospital Program.
Community Care that supports Social Engagement

For the 70% of people living in the community, access to high-quality, flexible home care services that support independence and social engagement is essential.

With the increasing reliance on home care, it is essential to ensure that there is adequate support for family carers. Consumers recommend the following action:

1. Fund a dementia-respite supplement to support the development of dementia-specific respite services in the community. This should include a network of cottage and day respite services that prioritise meaningful activity, social connections and peer support, including YOD specific services.

2. Establish a consumer co-designed ‘one-stop-shop’ for dementia. This service would provide coordinated information about all dementia services, information, local initiatives, policy and supports across Australia.

3. Implement transparent measures of quality in aged care including measures of consumer experience, recognising that younger people also receive aged care services.

4. Establish a national key worker program for people with dementia of all ages and their carers from diagnosis to death at whatever level of service required.

Quality Residential Care

For the 30% of people with dementia in residential care, it is critical that all aged care services are well-equipped and motivated to provide high-quality care for people with dementia, as part of their core business.

There is evidence that the needs of people with dementia are often not supported through current mainstream services with reports from consumers about physical, psychological, and sexual abuse, inappropriate use of restraints, unreported assaults, and people in extreme pain at end of life not having access to palliative care.⁵

Consumers have indicated the need to develop a model of support which focuses on promoting wellbeing, community engagement and independence. This would be achieved by:

1. Independent transparent measures of quality of life and consumer experience.

2. Awareness and promotion of advocacy services.

3. Consumer audits of aged care that are part of the Accreditation process.

4. Residential care funding model that rewards independence, engagement and quality of life.

5. New residential care standards that support a social model of care developed with consumer input that include Dignity in Care Principles.

6. Funding and support for an appropriate level and skills mix of staff that have training on a social model of care, with adequate pay and cultural sensitivity.

7. Implement mandatory building standards for aged care that include principles of dementia-friendly environments.

Care at end of Life

People with dementia struggle to get access to appropriate palliative care and support at end of life due to a range of factors including workforce issues, lack of understanding of legal rights, low rates of advance care planning, and inadequate assessment and management of pain.

Consumers recommend the following action:

1. Community education about importance of planning ahead, which includes advance care directives and financial planning, before a diagnosis of dementia.

2. Implement a nationally consistent approach to advance care directives.

3. Incentives to service providers for better access to palliative care including in-reach programs to support people to receive care in the community.

Research

Investment in dementia research has lagged behind other national health priority areas for decades.

The commitment to increase funding for dementia research by $200 million over five years from 2014, and the establishment of the National Institute for Dementia Research is a welcome investment.

However, even with an increase of approximately $40 million p.a., NHMRC funding on dementia research will still be a small fraction of the funding provided to other major health conditions.

Consumers recommend the following action:

1. A commitment by Government to provide increased investment in dementia research over a 10-year period to achieve a level of $80 million p.a. by 2025. This would be equivalent to 50% of the current NHMRC funding for cancer research.

2. Funding and support for meaningful consumer involvement in all aspects of dementia research in Australia.

Consumer Directed Care

All Commonwealth Funded Home Care Packages are now delivered on a Consumer Directed Care basis and there is currently work being done to consider how Consumer Directed Care could be implemented in residential aged care.

Consumers are supportive of greater choice but want to ensure that the implementation of Consumer Directed Care works for people with dementia.

Consumers recommend the following action:

1. Ensure people with dementia and their carers are able to make informed decisions about their care by providing support for decision making, information about the range of services included, transparent information on costs and quality. This includes access to independent advocacy services.

2. Identify areas of market-failure in home care such as remote and diverse communities and develop strategies to address issues around lack of services, limited choice and excessive costs.
Carers

It is estimated that there are more than one million people involved in the care and support of people with dementia in Australia.⁶

Family carers find it difficult to balance work, life and caring responsibilities, often resulting in reduced workforce participation and adverse physical and mental health outcomes.

Consumers recommend the following action:

1. Government develop and implement a program of integrated support to meet the needs of carers of people with dementia.

⁶ Alzheimer’s Australia, (2011), Pfizer Health Report Issue #45 - Dementia, Pfizer Australia
Alzheimer’s Australia is the peak body representing people with dementia, their families and carers. It provides advocacy, support services, education and information. More than 353,800 people have dementia in Australia. This number is projected to reach more than half a million by 2030.

For information and advice contact the National Dementia Helpline on:

1800 100 500

The National Dementia Helpline is an Australian Government funded initiative