



Alzheimer's
Australia Vic
Living with dementia

STRATEGIC DIRECTIONS 2011-2014



Foreword



Dementia: the challenge of our time

Dementia is a major national health issue in Australia today. Rapidly emerging economic, health and social consequences of an ageing society will drive Government health priorities and impact on the lives of our community. It will require an unprecedented response.

This period of history also ushers in the likelihood of new medical breakthroughs. Whilst a cure is not yet on the horizon, the massive international research effort provides a hope that we are on the cusp of interventions that will delay or stop the progression of dementia at an early stage.

The time has arrived to revise the traditional depiction of dementia as an ‘aged care’ issue and bring it into mainstream health with all other chronic health conditions. The evidence is already indicating the need to broaden our thinking beyond ‘dementia’ to include a spectrum of cognitive issues affecting all ages.

Alzheimer’s Australia is promoting the development of a world class dementia care system. We need a new vision and increased Australian Government commitment to build the quality care system.

Our vision is to:

- provide quality dementia care for Australians from all cultures and of all ages, regardless of where they live; and,
- reduce the prevalence of dementia into the future.

In Victoria, Alzheimer’s Australia Vic proposes to introduce initiatives that are matched to the scale of the dementia challenge, and we will be seeking support from Government, corporations and the community to help us realise this goal. This will require a shift in the way we think about, plan and deliver services from traditional approaches to a larger scale response. Alzheimer’s Australia Vic’s Strategic Directions is part of that reform agenda.

Twenty eight years ago a committed group of carers built the foundation from which Alzheimer’s Australia Vic has grown. It is now time to build the next foundation.

David Galbally QC
President



Vision

A society committed to the prevention of dementia, while valuing and supporting people living with dementia

Mission

Providing leadership in dementia policy, risk reduction and services

Values

We value:

- The worth of every individual
- Strength through unity with respect for diversity
- Co-operative relationships
- Organisational integrity
- Responsiveness, innovation, creativity and flexibility
- The contribution of all people involved with our work

The epidemic

Dementia – what is it?

- Dementia is a term that describes the symptoms of a large group of conditions that cause a progressive decline in a person's functioning. It includes loss of mental processing ability - including memory, communication, abstract thinking, judgement and self control. There are over 100 conditions that cause dementia, with Alzheimer's disease, Lewy body disease and fronto-temporal lobar degeneration being the most common neurocognitive disorders.
- Dementia is mostly a condition of old age, but not entirely so, with an estimated 10,000 people under 65 years in Australia with dementia.
- Dementia is the third highest cause of death after heart disease and stroke, and by 2030 will be the highest cause of death in Australia.
- Medications may slow down the progression of symptoms of the disease for some people. There is currently no cure for any form of dementia.

The dementia epidemic

The rate of dementia increases exponentially with age. By age 85 there is a one in five chance of developing dementia for both females and males. The large baby boomer generation, combined with increasing longevity, will dramatically increase the number of people with dementia.

The world

There is an estimated 35.6 million people with dementia in the world (2010¹) and this number is estimated to double every 20 years. There is a projected increase of 40% in Europe, 63% in North America, 77% in the southern Latin America zone and 89% in developed Asia Pacific countries over this time period. The total estimated worldwide cost of dementia is US\$604 billion (2010).²

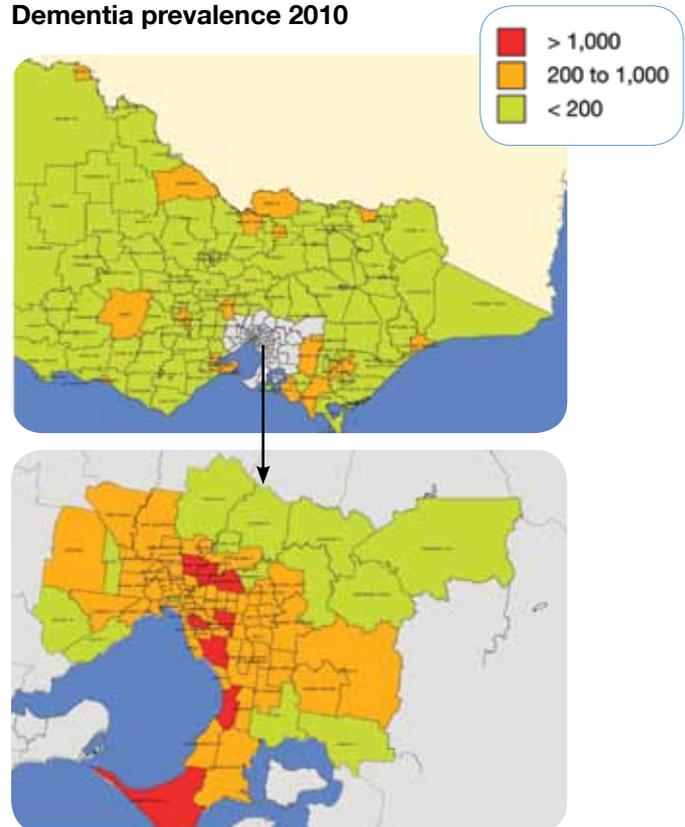
Australia

There are over 250,000 Australians with dementia. This number is projected to double to 565,000 by 2030. Dementia will become the third largest health and aged care expenditure item within two decades, at which time the costs will be around 1% of GDP. By the 2060s spending on dementia will outstrip any other health condition. Dementia is already the largest single cause of disability in older Australians over 65 years.

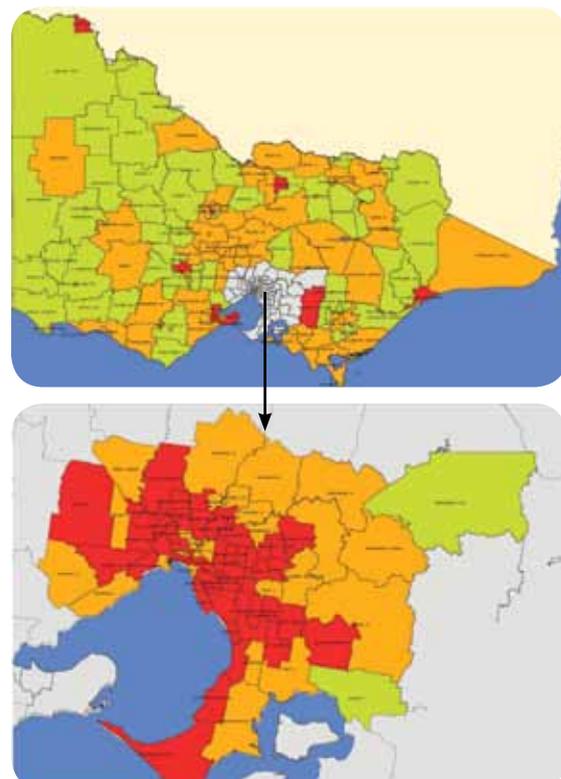
Victoria

There is an estimated 70,000 people with dementia in Victoria in 2011. By 2015 that number will grow to around 80,000 and by 2020 to 100,000 and then to over 140,000 by 2030.³ One in four Australians with dementia is Victorian.

Dementia prevalence 2010



Dementia prevalence 2030



¹ Alzheimer's Disease International World Alzheimer Report 2009

² Alzheimer's Disease International World Alzheimer Report 2010: The Global Economic Impact of Dementia

³ Access Economics, Projections of dementia prevalence and incidence in Victoria 2010-2050: Dept of Health Regions and Statistical Local Areas Table 3.8 p48

A strategy for our time



Alzheimer's Australia is working towards a world without dementia and a better quality of life for those people living with any form of dementia.

Major challenges lie ahead:

- Government funding for services and research is not matching the rapid escalation of dementia and requires a higher profile in government health and aged care planning and structural reform
- Counselling, early intervention and education are effective for individuals and families, but only a small proportion have access to these services
- Dementia risk reduction is not well understood by the general public or the health sector
- The majority of people with advanced dementia are in residential aged care, yet there is not a universal dementia staff training requirement
- There are a range of dementia training and research organisations but no single institution to coordinate

the research effort, promote risk reduction, foster innovation or establish evidence based standards

Alzheimer's Australia aims to become the organisation of choice for consumers and health professionals. Quality dementia care requires further development of services to promote dignity, respect and insightful understanding, and recognition of the contribution that people with dementia have made to society.

The Alzheimer's Australia National Strategic Intent has two overarching objectives:

- To provide quality dementia care for Australians from all cultures and of all ages, regardless of where they live; and,
- To reduce the prevalence of dementia in the future.

Alzheimer's Australia Vic Strategic Directions 2011-2014 will advance these objectives.

Flagship project:

Quality Dementia Care Initiative

Alzheimer's Australia Vic will raise the focus of dementia by seeking to develop a significant flagship project.

Over the next three years Alzheimer's Australia Vic will introduce a major new initiative to raise the awareness of dementia in the Victorian community and promote quality dementia care practice.

Nationally, Alzheimer's Australia has launched the National Quality Dementia Care Initiative to facilitate the rapid adoption of research into practice. In Victoria, Alzheimer's Australia Vic has a vision of building on that initiative through the introduction of a multidimensional working model of dementia care quality practice.

There is a need for a development where innovation can be fostered in areas such as:

- dementia facility design
- assistive technologies to support people with dementia at home
- accommodation suited to younger people with dementia
- the practice of person-centred care
- quality care practices for people living with less common forms of dementia
- development of different approaches to respite care that best suit people's needs
- a place for innovation and the development of best practice in a wide range of areas
- the education of the healthcare workforce

- raising the profile of all forms of dementia
- the development of evidence based approaches to challenging dementia issues such as behaviour and end of life care
- a focus for dementia practice research.

The translation of this vision into practice will be developed with people living with dementia and their families as the central focus.

The vision is likely to involve a building(s) in some form. The current premises in Riversdale Road Hawthorn, and the short term secondary office in Auburn Road Hawthorn that operates as an overflow facility, have served the organisation well. Twenty eight years after the organisation grew out of its consumer lead base, Alzheimer's Australia Vic stands at 80 staff (10 of whom are located in regional Victoria). A larger service base will be needed to accommodate the scale of operations required to meet the dementia challenge, and this will form part of the investigations.

This significant flagship project will require the commitment, skills, funds and drive of government, corporates and the community.

A Flagship Project Planning Committee, consisting of a wide range of public and commercial expertise, will be formed to drive the project.

Alzheimer's Australia Vic Strategic Directions 2011 - 2014

Snapshot

Flagship project

- In line with service development objectives and the current limitation of existing Alzheimer's Australia Vic buildings, this flagship project will seek to provide a facility that provides a focus for dementia programs in Victoria and can accommodate our continued growth. The objective is to link consumers, research and services into a prominent collaboration with the capacity to deliver quality dementia care leadership.

FOCUS AREA 1: Improving advocacy and empowering consumers

1

- **Expand** the participation of consumers and volunteers
- **Advocate** to make the voice of people with all forms of dementia and their carers heard and translated into services that address their needs for improved diagnosis, clearer pathways into care services and the provision of quality dementia care services
- **Develop** a Dementia Ambassadors program
- **Establish** Parliamentary Friends of Dementia in Victoria to complement the program that exists at a Federal level

FOCUS AREA 2: Promoting better quality dementia care

2

- **Develop** evidence based criteria for the aged and community care sectors to guide quality dementia care
- **Increase** service responsiveness to encompass diversity, including cultural and linguistic diversity, Aboriginal people, GLBTI people (gay, lesbian, bisexual, transgender, intersex), homelessness and regional Victoria
- **Establish** a knowledge translation service in dementia practice and environmental design to support aged and community care providers
- **Extend** the scope of early intervention services to reflect the growing number of people with mild cognitive impairment
- **Further develop** specialisation in family and therapeutic services, including counselling interventions, children's services, family re-engagement services, mediation services, secondary consultation, clinical leadership and supervision
- **Identify** assistive devices that support people living with dementia
- **Strengthen** access to dementia services through greater application of telephone and web-based technologies
- **Extend** programs to build the capacity of the health and aged care sector
- **Increase** access to education for families, carers and the wider community

FOCUS AREA 3: Increasing the awareness and understanding of dementia

3

- **Further expand** dementia community awareness
- **Raise** the profile of all forms of dementia
- **Support** General Practitioners in the diagnosis and ongoing care of people living with dementia

FOCUS AREA 4: Identifying effective strategies for preventing and delaying the onset of dementia

4

- **Facilitate** recruitment for dementia research projects
- **Introduce** an Alzheimer's Australia Vic research program
- **Promote** dementia risk reduction research
- **Link** dementia risk reduction into State preventative health planning

1 Improving Advocacy and Empowering Consumers

Objective: To speak out on issues affecting the quality of life of people with dementia, their families and carers. To give consumers a direct voice.

Alzheimer's Australia Vic will expand engagement with consumers to promote community understanding of dementia and advocacy of significant issues affecting the lives of people living with dementia. Service development will include expanded participation of consumers, advocacy, and direct engagement with Members of Parliament and community leaders. Alzheimer's Australia Vic will expand the role and profile of its Consumer Advisory Committee and Younger Onset Dementia Reference Group, introduce a Dementia Ambassadors Program and establish Parliamentary Friends of Dementia.

Issues needing greater community understanding and policy recognition will be advanced. Examples include,

the benefits of early diagnosis, the need for more flexible respite options, pain management for people with late stage dementia, advance care planning and other issues for people with dementia and their families.

Specific initiatives will include:

- the appointment of an Advocacy Officer
- the establishment of a Dementia Champions website
- increased engagement of consumers as media spokespersons
- development of a significant public relations campaign

2 Promoting better quality dementia care

Objective: To make Alzheimer's Australia Vic an acknowledged industry leader in quality dementia care services.

Leadership in the development of quality care for people living with dementia will be a core focus. Proposed activities are extensive and will include a range of new and expanded services.

Alzheimer's Australia Vic will seek to expand its reach. Government funding support will be sought to promote dementia information, counselling and education services for people from diverse cultural backgrounds, people who are gay, lesbian, bisexual, transsexual and intersex, Aboriginal people and people with dementia marginalised due to homelessness or disadvantaged by their geographic isolation.

Resources will be developed to build the capacity of the aged and community care sectors to provide quality dementia care. Amongst a range of proposed initiatives will be a project to develop care guidelines based on evidence based research. These criteria will be a significant contribution to the delivery of a more consistent, higher quality, dementia-specific practice.

Other proposed service development initiatives include a consultancy service to provide advice to residential and community aged care providers on a wide range of issues relating to the provision of quality dementia care and support.

This consultancy with care organisations will complement our existing and growing work in the education of the

aged and health care workforce. Part of this will be to explore e-learning and other ways of making education accessible to this workforce. The objective being to improve the quality of care experienced by people with dementia whether they are living in their own home or in a residential aged care facility.

Assistive technologies will also be promoted. The introduction of GPS technologies to support the walking independence of people with early stage dementia will be further advanced. Information on the range of other technologies will also be made available.

Further specialisation of counselling expertise will be a particular focus. Over the next three years Alzheimer's Australia Vic will build capacity to provide family and therapeutic services through counselling interventions, services to support children where a parent has dementia, family re-engagement services and mediation services. Secondary consultation services will also be offered to professionals supporting people with dementia and their families.

Early Intervention services will be further developed. Support in the period soon after diagnosis is critical and Alzheimer's Australia Vic will extend its current focus to support the increasing number of people identified with mild cognitive impairment and a wide range of neurocognitive disorders.

3

Increasing awareness and understanding of dementia

Objective: To increase community awareness of dementia and reduce the stigma, social isolation and personal discrimination of living with dementia.

Community awareness and understanding of dementia is relatively low, and stigma remains. There is a growing familiarisation of 'Alzheimer's disease', but limited appreciation of other dementias and the support needed to maintain people with dementia in the community and provide them with an adequate quality of life.

For Government, there is growing policy acknowledgement of the effects of the increasing prevalence of dementia as the baby boomer generation ages, but insufficient resource allocation to address a health issue of this magnitude.

Alzheimer's Australia Vic will seek funding to introduce a multi media community awareness program to raise community awareness of dementias and lifestyles that reduce the risk of developing dementia.

Support to General Practitioners will be a particular focus in the awareness raising program. When memory or other cognitive problems start GPs are consumers' first point of contact. For GPs the main issues are rapid access to accurate information, access to screening instruments for dementia and depression, knowledge of key service providers and linkages to organisations that will provide on-going support to their patients and provide GPs with support. Alzheimer's Australia Vic will seek funding to develop structures that will create a support pathway between their doctor and on-going assistance as they need it.

| Current state | Desired state |
|--|-------------------------------------|
| Low awareness | Awareness, understanding & action |
| Stigma | Support / Part of our social fabric |
| Fear | Courage, empathy and care |
| Confusion | Clarity |
| Resignation | Optimism and respect |
| A death sentence | A better quality of life |
| Just an old people's disease | Disease that affects everyone |
| Hidden in a nursing home | All around us |
| An ageing disease | The disease of our time |
| Late or misdiagnosis | Prevention and early diagnosis |
| Overshadowed by cancer, heart disease and depression | Dementia a national health priority |

(Source: Interbrand)

4

Identifying effective strategies for preventing and delaying the onset of dementia

Objective: To support dementia research and promote the introduction of dementia risk reduction programs within a public health framework.

Market research shows that fifty percent of Australians are unaware that they may be able to reduce their risk of dementia by adopting a healthy lifestyle. Alzheimer's Australia Vic will promote a range of research and risk reduction program initiatives.



Alzheimer's Australia Vic will further develop research collaborations and promote preventative health strategies.

In addition, Alzheimer's Australia Vic will continue as an active participant in the Early Diagnosis and Prevention Dementia Collaborative Research Centre and translate research evidence into practice. Web-based information delivery, the development of new iphone/ipad applications, and use of social networking sites to promote dementia risk reduction programs will feature prominently in the work of the organisation.

An Alzheimer's Australia Vic Research (AAVR) program will be established to commission small research grants for projects that will benefit Victorians with dementia and other cognitive impairment.

Alzheimer's Australia introduced the Mind your Mind® dementia risk reduction program in 2006. This internationally leading edge program will be progressively expanded in line with resource availability and will increase its impact by developing linkages to other preventative health initiatives.

Alzheimer's Australia Vic



Board of Directors

David Galbally, QC (President)

Partner of Madgwicks Lawyers, Solicitors. Director Alzheimer's Australia Vic since 2006.

Stephen Hawke (Vice President)

Chartered Accountant, Director of McGrathNicol (Chartered Accountants). Director Alzheimer's Australia Vic since 2002.

Neil Samuel (Secretary)

Director of Dryen Australia Pty. Ltd. Vice President Alzheimer's Australia (national). Director Alzheimer's Australia Vic since 2003.

Ian Knight (Treasurer)

Partner at KPMG (Chartered Accountants). Director Alzheimer's Australia Vic since 2010.

Lyn Allison

Formerly a teacher and Parliamentary Leader of the Australian Democrats 2004-2008. Director Alzheimer's Australia Vic since 2008.

Mary Lyttle

Chief Executive Officer Elder Rights Advocacy. Director Alzheimer's Australia Vic since 1994.

Fiona Mason

Strategic Planning Director for Hayes Berry Tehan advertising agency. Director Alzheimer's Australia Vic since 2009.

Geoff Slade

Chairman of Slade & Partners - Executive search company. Director since 2007.

Keith Wehl

Former Vice President – Insurance & Risk Management for Foster's Brewing Group Limited. Director Alzheimer's Australia Vic since 2007.

Associate Professor Michael Woodward

Head of Aged & Residential Care Services (Heidelberg Repatriation Hospital, Austin Health), Director, Memory Clinic (Austin Health). Major research commitment with many publications in Alzheimer's disease. Director Alzheimer's Australia Vic since 2009.

Contributors

Many people have contributed to the development of this plan including:

- Strategic Planning Think Tank - a forum of stakeholder groups, large corporations, emergency services and media representatives
- Life members, consumer representatives and volunteers focus group
- Alzheimer's Australia Vic staff
- Alzheimer's Australia Vic board members



Chief Executive Officer: Maree McCabe

Alzheimer's Australia Vic

98-104 Riversdale Road
Hawthorn Victoria 3122

National Dementia Helpline 1800 100 500
www.alzheimers.org.au/vic

Alzheimer's Australia Vic Strategic Directions 2011-14 is available at **www.alzheimers.org.au/vic**
Printed copies are also available