

South Australia's Dementia Action Plan 2009-2012

Facing the
Challenges
Together



Government
of South Australia



The fact that most of us are living longer and stronger is an indicator of our progress and a cause for celebration.

**Office for the Ageing
Department for Families
and Communities
in partnership with SA Health**

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foreword

The health and wellbeing of older people is vitally important to the South Australian Government. The fact that most of us are living longer is an indicator of our progress and a cause for celebration.



The Hon Jennifer Rankine MP
Minister for Ageing



The Hon John Hill MP
Minister for Health

However while our ageing population means we have a wealth of knowledge, experience and wisdom which contributes to the success of our community, it also poses challenges in that there are more elderly people requiring services and support to maintain active and healthy lifestyles. Although dementia is not a normal part of ageing, it does mainly affect older people and therefore given that we have an ageing population, we can expect the number of people with dementia to increase. As most people with dementia will continue living in their community, it is essential that health and community care service providers have the capacity to respond to the needs of people with dementia, their families and carers.

Through South Australia's Dementia Action Plan: *Facing the Challenges Together*, we recognise our responsibility in planning for an increased need for dementia services to

ensure that timely and accessible services are available to provide a range of information, support and care for people with dementia, their carers and families.

South Australia's Dementia Action Plan: *Facing the Challenges Together* is a significant document which will benefit those South Australians affected by dementia as well as raise the awareness of other South Australians to the importance of adopting a healthy lifestyle.

Thank you to all those who participated in the consultation and development of South Australia's Dementia Action Plan: *Facing the Challenges Together*.



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1. introduction

Our Vision

A better quality of life for people living with dementia, their carers and families.

South Australia's Commitment

By 2051, in proportion to other States, South Australia's older population will be greater than elsewhere in the nation. Almost 31% of the State's population will be over 65 and the over 85 population will have increased by a factor of four.¹

Living longer is a marker of progress and of the good fortune we share in this State. The ageing of our population however poses challenges in that there will be a significant number of older people requiring services and support to maintain an active and healthy lifestyle.

The proportion of older people from culturally and linguistically diverse backgrounds is increasing; people with disabilities are living longer and this too will impact on both the individual and their carers. Aboriginal people are living longer, although their life span is still up to 17 years shorter than for other Australians. We need to ensure that services are respectful and relevant to everyone's needs.

South Australia's Dementia Action Plan: *Facing the Challenges Together* builds on the fundamental messages expressed in the State Government's ageing policy, *Improving with Age – Our Ageing Plan for South Australia*.

*We must stop thinking old in the way we sometimes perceive the ageing population and start thinking new in implementing innovative responses that tackle head on the frequent misconceptions about older people.*²

In thinking about innovative responses to an ageing population, we cannot escape the fact that as the number of

older South Australians increases so will the prevalence of dementia. Whilst this condition among older people is often associated with a fear of losing independence and control over their lives, it is a condition that affects people in different ways. With adequate support, dementia can be managed effectively.

With this in mind, we must be bold in addressing the prospect of an increase in the number of South Australians with dementia. We must be prepared with services which improve the quality of life for people with dementia, their families and carers. This is South Australia's commitment.

Our Guiding Principles

- People with dementia are valued and respected. Their right to dignity and quality of life is supported.
- Carers and families are valued and supported and their efforts are recognised and encouraged.
- People with dementia, their carers and families are central to making choices about care.
- Service responses recognise peoples' individual journeys.
- All people with dementia, their carers and families receive appropriate services that respond to their social, cultural or economic background, location and needs.
- A well-trained supported workforce delivers quality care.
- Communities play an important role in the quality of life of people with dementia, their carers and families.

Living longer is a marker of progress and of the good fortune we share in this State.

1. Australian Bureau of Statistics (2005) *Population Projections, Australia 2002-2101*

2. South Australian Government (2006) *Improving with Age – Our Ageing Plan for South Australia*

It is recognised that there is a need to support carers of people with dementia.

Facing the Challenges Together

We recognise our responsibility over the coming decades in planning for an increased need for dementia services to ensure that timely and accessible services are available to provide a range of information, support and care for people with dementia, their carers and families.

Facing the Challenges Together emphasises the need for service providers to work closely with Government to face the challenges of dementia and provide individuals with the greatest degree of independence for as long as possible. The aim is to increase the capacity of communities, carers, families and service providers as well as to create new services where required. This Action Plan provides direction for service planning over the next four years and will serve as the blue print for responding to an increased demand for these services.

A key component of this Action Plan will be the development of Regional Dementia Action Plans that include regional dementia statistics on projected service demand, identify service gaps and address the need for dementia care services at the local level. We will work collaboratively with regional agencies and consumers to develop plans that consider the needs of people with dementia.

Service providers will need a point of reference as they plan a continuum of care for people with dementia for each progressive stage. There is an expectation that all community services will be *‘dementia friendly’* and where required, *‘dementia specific’* services will be available and flexible enough to meet the individualised needs of any person with dementia.

In preparing this Action Plan, we acknowledge that older people are at the centre of what we do. They are valued

and respected. The Action Plan also acknowledges the need to ensure all actions are shaped meeting the needs of Aboriginal people, people of culturally and linguistically diverse backgrounds and people living in rural and remote areas.

It is recognised that there is a need to support carers of people with dementia.

A Carer’s Story

“My husband Tom was diagnosed with what was called Vascular Dementia. When we got home from the specialist, Tom went from room to room calling for his brother Roger. Roger lives in England. He then set off muttering something about visiting Mrs Someone-or-other. I caught up with him just as he was about to ring our neighbour’s front doorbell. His mind doesn’t just wander – it positively leaps. One moment he is in the present and quite ok, the next he’s in England forty years ago. He’s not sleeping well either, which means I’m not sleeping well”.

There is growing evidence of an increase in single person households amongst older South Australians and as a result specific strategies also need to be developed to meet the needs of people with dementia who do not have a carer.

An Individual’s Story – The point of diagnosis

“I was getting increasingly frustrated at my forgetfulness. Eventually I decided to see my local Doctor who referred me to a specialist at a large hospital for a bank of tests. When I visited the specialist again, he told me the “bad” news. I had Alzheimer’s disease. To his amazement, I expressed relief that I now knew. Waiting for the results had been terrible – not knowing what was wrong - but at least now I knew what was wrong and I could get on and plan for the rest of my life”.

1. introduction

Joined Up Services

South Australia is a signatory to the *National Framework for Action on Dementia 2006-2010* following recognition of dementia as a national health priority in 2004. This Action Plan reflects our State's commitment to further the objectives of this framework. South Australia will continue to work with the Commonwealth Government to achieve complementary and coordinated seamless services in South Australia while supporting the development of regional dementia plans. We will continue to influence areas where the Commonwealth Government has lead responsibility.

Facing the Challenges Together highlights the areas for joined up action at all levels within the community service sector. We need services to provide an integrated and collaborative response for the person with dementia, and their carer, as their capacity for independence changes over time.

In South Australia, we are already working towards this in a number of ways.

South Australia's State Strategic Plan (updated 2007) outlines clear objectives with measurable targets against which State Government departments will demonstrate outcomes. Under Objective 2 'Improving wellbeing', the Strategic Plan targets T2.4 and T2.6 are relevant to South Australia's Dementia Action Plan and relate directly to quality of life and the well-being of South Australians.

Improving with Age – Our Ageing Plan for South Australia articulates clear strategies for better collaboration between the Department for Families and Communities, SA Health, the community and aged care sectors. Specific kick-start initiatives contained within *Improving with Age* have focused on the development of dementia care services in partnership with Health

agencies. This Action Plan will also seek to line up with the objectives of the *South Australian Health Strategic Plan 2007-2009*.

The *South Australian Carers Recognition Act 2005* and the *Carers Policy* enshrines into legislation the Carers Charter which seeks to recognise and support un-paid carers for their community and economic contributions. Carers of people with dementia including their families need support in their role, and must also have input into the design of dementia care services.

South Australian Health Plan for Older People: Improving Health and Wellbeing Together 2008 – 2016 guides the implementation of the SA Health Care Plan strategic directions for the health care of older people in the public health system. The Plan acknowledges that dementia is and will be a continuing health care issue for South Australia. Accordingly, the Plan places great importance on enhancing the capacity of our health and aged care system in meeting the health and wellbeing needs of people with cognitive impairment and dementia.

We will continue to work collaboratively with the Commonwealth in the design and delivery of dementia care services via a number of policy initiatives including:

The Way Forward: A New Strategy for Community Care (2004) aims to address duplication and gaps in services, improve client access, assessment and service pathways, enhance national reporting and merge Commonwealth care link and respite services. South Australia's Dementia Action Plan will actively pursue these goals.

The National Strategy for an Ageing Australia (2001) aims to enhance and improve the continuum of care, facilitate better coordination between GPs, health and community care sectors and



enhance support for older people to avoid unnecessary hospital or residential care and to get back home after necessary hospital care.

Governance of South Australia's Dementia Action Plan

SA Health and the Office for the Ageing in Department for Families and Communities will be responsible for monitoring state and regional progress towards the actions outlined in *Facing the Challenges Together* and reviewing the resource implications associated with implementing systems and processes, as well as infrastructure. A process for evaluating its success will be developed in collaboration with key stakeholders and regional community care agencies.

The Plan acknowledges that dementia is and will be a continuing health care issue for South Australia.



2. understanding dementia

Dementia is described in the World Health Organisation's International Classification of Diseases³ as:

A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. Consciousness is not clouded. The impairments of cognitive functioning are commonly accompanied, and occasionally preceded, by deterioration in emotional control, social behaviour or motivation. This syndrome occurs in Alzheimer's disease, in cerebrovascular disease and in other conditions primarily or secondarily affecting the brain.

Alzheimer's disease is the most common of these, accounting for around 70% of all dementia with other forms of dementia being Vascular Dementia, Lewy Body Disease, fronto-temporal Dementia, Creutzfeld-Jakob Disease (CJD) and Subcortical Dementia (including Parkinson's disease and Huntington's disease).

Dementia affects the functioning of the brain, often leading to personality changes. The effects are severe enough to interfere with the social and occupational functioning of the person. These changes affect the physical, social and emotional life of the person with dementia, their carers, family and friends. Although dementia mainly affects older people, it is not a normal part of ageing.

Dementia can be described in terms of stages from initial and mild symptoms to a terminal decline of the central nervous

system. These stages are commonly described as **early, mild, middle and late** stages of the dementia pathway. These dementia stages are familiar to general practitioners, specialists and service providers as a conceptual framework for following the progress of dementia.

Dementia is evident in all communities, whether they are rural, culturally and linguistically diverse or Aboriginal. Older Aboriginal people have a different pattern of dementia due to shorter life expectancy and increased risk of vascular disease. Dementia onset can also be present in people younger than sixty years of age and people with disabilities.

Dementia is a progressive disease; however there is the potential to delay this progression through early diagnosis and access to appropriate medication which must be prescribed by specialist geriatricians. Access to early diagnosis is crucial to stem the progression of dementia.

It is important to acknowledge the ongoing impact on the quality of life of people with dementia and their carers. As most people with dementia will continue living in their community, it is essential that health and community care service providers have the capacity to respond to the needs of these people. It is also important to strengthen support to carers to enable them to continue to care. Acknowledging the support that carers give to people with dementia is fundamentally important.

Facing the Challenges Together recognises that when it comes to

3. World Health Organisation (1992a) *International Statistical Classifications of Diseases and Related Health Problems (ICD)*, 10th revision volume 1, Geneva: WHO.

People with younger onset dementia also need to be considered as they require uniquely tailored responses.

providing quality care to people with dementia, no one size fits all. The needs of people with dementia living alone, as well as couples who both have varying stages of dementia have been identified as requiring additional monitoring and support.

People with younger onset dementia also need to be considered as they require uniquely tailored responses. The term 'younger onset dementia' is usually used to describe any form of dementia diagnosed in people under the age of 65 years. Younger onset dementia may be caused by Alzheimer's disease, frontotemporal lobe degeneration, stroke, Parkinson's disease, Lewy bodies and other neurological conditions. Since dementia is rare in younger people, symptoms of these diseases may be difficult to diagnose accurately and are often misdiagnosed initially resulting in delays to appropriate treatment and care. Brain injury, HIV-AIDs and alcohol may also cause dementia in younger people however dementia in these cases usually occurs within the context of an obvious cause and is thus more readily diagnosed and treated. Available evidence estimates that 5% of all people with dementia are less than 65 years of age.

We must respond to individual requirements and be respectful of choices that individuals and families make in regard to the services they receive. *Facing the Challenges Together* means providing flexible, person-centred service options to deliver the best possible services to people with dementia, in close consultation with both them and their families.

Coordinating services

Jane, who lived alone, had always enjoyed leading an active life. When she was diagnosed with dementia, Jane began receiving support visits from the Royal District Nursing Service (RDNS) as well as Home and Community Care (HACC) services through the local Council's Home Assist Program. Later Jane was referred to Domiciliary Care SA where a Community Nurse became involved as her key care coordinator. She arranged for a regular care worker to provide support with shopping, housework, appointments and social activities.

Jane's family attended the Carer Education Program at Alzheimer's Australia and joined a support group so they could meet with other carers, relatives and friends of people with memory loss to share their experiences. Alzheimer's Australia also had a Memory Loss Program developed for people diagnosed in the early stages of dementia, their families and friends. Jane's family arranged Enduring Power of Attorney and Guardianship. Jane lived at home with the help of three regular care staff and volunteers for another two years.

As Jane's dementia progressed, she moved into an extension of her son's home. Jane maintained her independence with help from local dementia services providing personal care with her family providing meals, cleaning, laundry and finance management.

Respite is provided for the family by volunteers taking Jane out three times a week, shopping and attending appointments such as hairdressers and a monthly massage. Jane is still able to enjoy music and painting. Planned, regular care for Jane and flexible support for the family enable Jane to remain living in the community.

2. understanding dementia

Many people with dementia are able to maintain their lifestyle within the community with the support of families, carers, friends and health and community care services. Table 1

explains the impact of dementia on daily living from the onset of dementia, and the percentage of people diagnosed with dementia estimated to fall into the various categories.

STAGES OF DEMENTIA				
IMPACT	Early Onset	Mild	Moderate	Advanced
	Estimated % of people with dementia			
	55%		30%	15%
MEMORY	Slight forgetfulness that happens regularly eg gets lost on a familiar route.	Noticeable short term memory loss that affects everyday life eg has false memories, forgets layout of home.	Substantial memory loss when only old information can be recalled and new information is rapidly lost.	Severe memory loss when only parts of old memories remain.
ORIENTATION – TIME, PLACE AND PERSONS	Generally clear, correct and aware. Reduced attention span, repetitive talk, anxious or suspicion about partner's behaviour.	Confusion about dates and times; sometimes mistaking places and becoming lost; difficulty in recognising familiar people.	Substantial difficulty in recognising time, places and people eg difficulty finding right words, mood swings, wandering.	May recognise people but not recall why; may no longer recognise close family; may no longer talk; may lose mobility.
JUDGEMENT/ PROBLEM SOLVING	Slightly less capacity to problem solve.	Difficulty problem solving eg handling money, driving a motor vehicle.	Increased difficulty problem solving; occasional sexual disinhibition; may become upset when faced with change.	Unable to make judgments or problem solve; severe depression often accompanied by agitation or psychosis.
COMMUNITY PARTICIPATION	Slight communication difficulties that affects participation in social activities.	Difficulty finding 'words' or following conversation; needs support in social activities.	Lack of interest or willingness to attend social activities, difficulty communicating more apparent, requires constant supervision.	Very limited ability to engage and interact with others socially even with supports.
HOME AND PERSONAL INTERESTS	Slight change in ability to do home based activities, hobbies and intellectual interests.	Difficulty functioning at home, undertaking or completing tasks.	Only effective in simple tasks lacks interest in usual home based activities and interests, often suffering from depression	Unable to function at home.
PERSONAL CARE	Manages own self care.	May need prompting.	Requires assistance.	Full assistance required.

Table 1⁴

4. Adaptation from ABS 2004; Barendregt,J.J.,Bonneaux,L. (1998). Degenerative disease in an Ageing Population. Rotterdam: Erasmus University. Berg,L., Miller,J., Storandt,M., et al (1988). Mild senile dementia of the Alzheimer type: Longitudinal assessment. Annual of Neurology 23: 97-84. Alzheimer's Australia (2003) ReBOC: Reducing behaviours of concern: A hands on guide. Canberra: Australian Government Dept of Health and Ageing.



3. dementia and the changing population dynamic

Currently around 200,000 Australians or 1 percent of the population have dementia.

It is predicted that by 2016, dementia will be the major cause of disability for Australians, overtaking cardiovascular disease, cancer and depression.

Graph 1 indicates the prevalence of dementia (%) by age groups and gender in Australia in 2005⁵.

It is predicted that by 2016, dementia will be the major cause of disability for Australians, overtaking cardiovascular disease, cancer and depression. Some estimates suggest that by 2050, nearly 730,000 (2.8%) of the projected population will have dementia⁶.

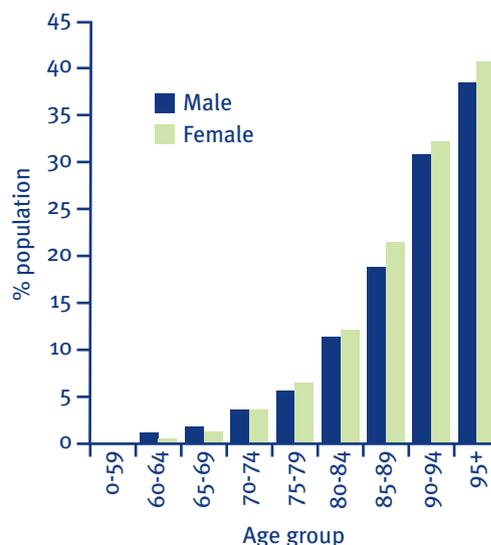
Graph 2 shows the projected percentage increase in the number of people in Australia with dementia from 2002 to 2051, in comparison with the projected total population growth of Australia⁷.

South Australia is the second fastest ageing State in Australia after Tasmania. The prevalence of dementia is expected to rise in South Australia alongside the progressive increase of people over the age of 65.

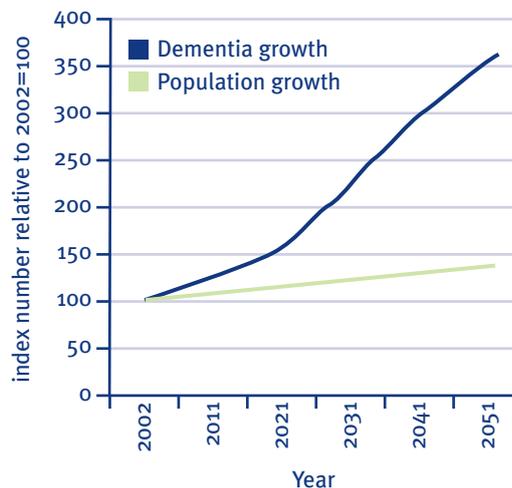
Projected numbers of people with dementia living in South Australia are:

2010	21,760
2020	28,000
2030	36,770
2040	46,240
2050	50,740 ⁸

These projected figures highlight the critical importance of prevention activities, particularly research in order to make the advances necessary to delay the onset of dementia. This will lead to a better quality of life for Australians and make significant savings in the future cost burden of dementia.



Graph 1



Graph 2

5. Access Economics (Feb 2005) *Dementia Estimates and Projections: Australian States and Territories*

6. Ibid

7. Ibid

8. Ibid

4. south australia's plan for action

South Australia's Dementia Action Plan is a supplementary document of *Improving with Age: Our Ageing Plan for South Australia and the South Australian Health Plan for Older People: Improving Health and Wellbeing Together 2008 – 2016*.

It shares the same policy imperatives and it recognises the importance of putting people at the centre of service planning. It enshrines the principle of choice and independence in the delivery of programs and services, and places emphasis on the need for a continuum of care as people's capacities change over time.

South Australia's Dementia Action Plan: *Facing the Challenges Together* is also closely aligned to the objectives of the *National Framework for Action on Dementia, 2006*; however it is mindful of the specific and unique needs of South Australians and reflects this in the strategies.

Timely access to services for people with dementia underpins this Action Plan, and these services need to be available to all South Australians regardless of their location, cultural background or socio-economic situation.

It is recognised that people with dementia need services that value and respect their dignity, as well as the role of their families and carers. Families and carers are best supported when services for people with dementia are designed in consultation with them and the people they care for. The Department for Families and Communities and SA Health will continue to work in partnership across a range of existing and new initiatives to support carers.

In order to provide timely and responsive services, this Action Plan recognises that having a highly trained dementia care workforce (including multicultural and Aboriginal workers) in South Australia guided by a rigorous research base, will be an integral part in shaping an effective response to people in our State who have dementia both now and into the future. Up to date information about dementia, treatment/care options as well as community education is critical for the community and service providers.

Key Action Areas for *Facing the Challenges Together* have been designed to build on those areas outlined in the *National Framework for Action on Dementia, 2006*. The Key Action Areas are:

- Care and Support
- Access and Equity
- Information and Education
- Research
- Workforce and Training

A checklist for the range of community dementia services required for each stage of dementia is outlined below and can be considered by agencies when developing responses to the Action areas (Table 2).



CHECKLIST FOR THE RANGE OF COMMUNITY DEMENTIA SERVICES REQUIRED AT DIFFERENT STAGES OF DEMENTIA ⁹				
SERVICE RESPONSES	Early Onset	Mild	Moderate	Advanced
	Estimated % of people with dementia			
	55%		30%	15%
DIAGNOSIS & ASSESSMENT	<ul style="list-style-type: none"> • Diagnosis • Behaviour assessment • Referral • GP management • Medication 	<ul style="list-style-type: none"> • Diagnosis • Behaviour assessment • Referral • GP management • Medication 	<ul style="list-style-type: none"> • Diagnosis • Behaviour assessment • Referral • GP assessment (depression) • Episodes of acute care 	<ul style="list-style-type: none"> • Medical assessment (nutrition, hydration, medication, pain management) • Behaviour assessment
EDUCATION & SUPPORT SERVICES	<ul style="list-style-type: none"> • Counselling and support for client and if required, carer • Education programs for client, carers and community 	<ul style="list-style-type: none"> • Counselling and support for client and if required, carer • Education programs for client, carers and community • Advance directive planning • Residential care options discussed as part of future planning 	<ul style="list-style-type: none"> • Carer education re behaviour management & care transitions • Counselling and support for client and if required, carer • Case planning/care management 	<ul style="list-style-type: none"> • Carer education re relinquishing home care and transitions • Residential care options • Counselling and support for carer
CLINICAL INTERVENTIONS		<ul style="list-style-type: none"> • Skills Rehabilitation • Psychological treatment 	<ul style="list-style-type: none"> • Behaviour interventions • Therapeutic counselling for carers (depression) 	<ul style="list-style-type: none"> • Consultancy behaviour services
CARE PROVISIONS	<ul style="list-style-type: none"> • Support for community access and wellness programs e.g. exercise, diet, creative activities, music, art etc 	<ul style="list-style-type: none"> • In-home support • Support for community access and wellness programs • Future palliative care decisions made • Monitoring 	<ul style="list-style-type: none"> • Increasing access to community care, respite and home support services • Counselling and crisis support 	<ul style="list-style-type: none"> • Nursing, Community or Residential care • Palliative Care Services

Table 2⁹

9. See Table 1 for characteristics associated with each stage of dementia

5. key priority areas

1 Care and Support

Objective

Effective, appropriate, quality and accessible care is provided:

- Across all settings and geographical locations;
- Focusing on person centred planning;
- Through involving the person with dementia, their carers and families;
- Allowing seamless transition for people with dementia between the different types of care.

ACTIONS	OUTCOMES	LEAD AGENCY
<p>Establish dementia as a national health priority in all State Government policies and forums.</p>	<p>Evidence of dementia specific strategies in Government Portfolio Plans.</p> <p>Key initiatives implemented with appropriate policy and funding support.</p>	SA Health
<p>Regional agencies (health and community care) and consumers will work in collaboration to develop Regional Dementia Action Plans that:</p> <ul style="list-style-type: none"> • Include regional dementia statistics on projected service demand and service gaps; • Develop regional dementia maps showing all essential service referral pathways and points of access; • Identify service gaps and plan to ensure services can meet future need; • Develop proactive waiting list management to ensure prompt service; • Identify and support people with dementia as early as possible through dementia awareness programs; • Regional priorities provided to Office for the Ageing and SA Health annually; • Monitor local and regional trends and collect statistical information to inform service planning. 	<p>Each region within South Australia has developed a Regional Dementia Action Plan by 30 June 2010 which responds to identified regional priorities.</p>	<p>Office for the Ageing in partnership with SA Health, Collaborative Linkages Networks and Alzheimer's Australia (SA)</p>
Assessment systems and tools		
<p>Evaluate and validate a suite of standardised screening and diagnostic/assessment systems and tools.</p>	<p>A suite of standardised tools in use state-wide in health and community care sectors.</p>	SA Health



ACTIONS	OUTCOMES	LEAD AGENCY
Translating principles into practice		
<p>Work with appropriate accreditation bodies to incorporate dementia care standards into acute care and community care.</p> <p>Identify and implement <i>acute care</i> standards that will:</p> <ul style="list-style-type: none"> • Improve diagnosis and management in public hospitals; • Make hospital settings safer for people with dementia; • Utilise hospital avoidance programs or re-admission diversion programs where appropriate; • Ensure that people with dementia, their carers and service providers are all involved in discharge planning. 	<p>Policies and plans of all State Government health and community care services recognise the needs of people with dementia and their carers.</p> <p>Project “Translating Dementia Care Principles into State-wide Practice” managed by Central Northern Adelaide Health Service (CNAHS) and funded by Office for the Ageing, completed.</p> <p>Acute care standards for dementia care included in Australian Council on Healthcare Standards (ACHS) audits.</p>	<p>SA Health in partnership with Office for the Ageing and Alzheimer’s Australia (SA)</p>
Primary Health		
<p>Promote the benefit of early diagnosis in delaying the progression of dementia through appropriate medication.</p> <p>Develop single referral and assessment pathways to maximise sharing of assessment information between GPs, GP Plus Centres, ACAT’s, hospitals, aged care services and HACC service providers.</p> <p>Promote best practice guidelines in referral for specialist diagnosis.</p> <p>Expand awareness, detection and referral for depression of people with dementia.</p>	<p>People aware of early diagnosis services across South Australia.</p> <p>People with dementia and their carers report satisfaction with the referral and assessment processes.</p> <p>Needs of people with dementia and their carers included in depression initiatives.</p>	<p>SA Health</p>
Community Care		
<p>Promote access points, referral and assessment pathways and options for information to be available in other languages.</p> <p>Identify and promote the best ways to assist people with dementia, their families and carers to navigate the community care system.</p> <p>Continue supporting people with dementia to maintain and develop skills that enable them to remain connected to their communities for as long as possible.</p> <p>Identify and promote the best ways to assist people with dementia that are culturally appropriate.</p> <p>Identify and promote range of responses to people with dementia needs that include not only medical and functional diagnosis, treatment, care and support but also innovative opportunities for people with dementia to remain connected to their communities.</p> <p>Promote <i>Dementia Resource Guide</i> to stakeholders.</p>	<p>Community care and health access points incorporate dementia needs.</p> <p>Evidence of user friendly promotional material.</p> <p>Stakeholders aware of CD-ROM available from dementia@health.gov.au or by accessing website for on-line version www.health.gov.au/dementia</p>	<p>Office for the Ageing in partnership with Alzheimer’s Australia (SA)</p>

5. key priority areas

ACTIONS	OUTCOMES	LEAD AGENCY
Dementia Service Initiatives		
Document and address service gaps and develop initiatives that improve responses to people with dementia and their carers.	Expansion of Dementia-specific service models including: <ul style="list-style-type: none"> • Living Alone with Dementia key worker model • Dementia Link-Worker model • Connexus Younger Onset • Translating Dementia Care Principles into Practice. 	Office for the Ageing in partnership with SA Health
Dual disability		
Increase dementia awareness in the disability sector.	Adequate service responses available to support people with dual disabilities.	SA Health in partnership with Office for Disability and Client Services
Younger people (less than 65 years) with dementia		
Identify needs of younger people with dementia. Identify appropriate strategies to address the unmet needs of younger people with dementia.	Adequate service responses available to support younger people with dementia.	SA Health
Carer support		
Identify the needs of carers of people with dementia. Develop strategies to address the unmet needs of carers of people with dementia. Promote counselling services and education and awareness programs to carers of people with dementia at all stages of care continuum. Explore availability of advocacy services for carers and people with dementia, including Office for the Public Advocate and the Guardianship Board.	Regular Carers Forums held to discuss issues and needs of carers, and appropriate support information disseminated to them. Carers are supported in the transition of the person for whom they are caring throughout the care continuum including to residential care or death. Advocacy services for carers and people with dementia identified and promoted within community.	Alzheimer's Australia (SA) in partnership with Office for Carers
Respite Care		
Develop flexible models of respite care (including culturally appropriate) in collaboration with local communities, community care agencies and Office for Disability and Client Services. Identify and address the needs of older couples where one or both partners have dementia.	Evidence of 'best practice' respite care. Evidence that the needs of older couples where one or both partners have dementia have been identified and met.	Office for the Ageing

ACTIONS	OUTCOMES	LEAD AGENCY
Palliative Care		
<p>Work with acute, community and residential care providers of palliative care to ensure people with dementia, their families and carers are included in decision making about how their services will be delivered.</p> <p>Promote awareness of the need for ‘forward planning’ including Advanced Directives, to people with dementia, carers and families, community care and health service providers.</p> <p>Promote palliative care for people with dementia that is sensitive to the needs of different cultures.</p>	<p>Families and carers report satisfaction with services received.</p> <p>Information on ‘forward planning’ including advanced directives available through service networks and in community.</p> <p>Families and carers report satisfaction with services received.</p>	SA Health
Behaviour Support		
<p>Clarify roles and responsibilities between Older Person’s Mental Health Service (OPMHS) in SA and Dementia Behaviour Management Advocacy Service (DBMAS).</p> <p>Identify ‘best practice’ models for dementia services across care continuum in collaboration with health and community care agencies and consumers.</p> <p>Encourage reduction in the use of physical or chemical patient restraints in hospitals, sub-acute care, respite care, and residential aged care facilities and promotion of psycho-social treatments.</p>	<p>Roles clarified in order to maximise available resources and avoid overlap or duplication of services.</p> <p>Best practice service models identified and promoted across care continuum.</p> <p>Best practice models are promoted and considered in Regional Dementia Action Plans.</p> <p>Increased use of psycho-social treatments in hospitals, sub-acute care, respite care, and residential aged care facilities.</p>	SA Health

5. key priority areas

2 Access and Equity

Objective

All people with dementia, their carers and families should be able to obtain quality services that suit their needs,

when they need them, regardless of where they live, their health status, their age, their cultural background, or financial and social circumstances.

ACTIONS	OUTCOMES	LEAD AGENCY
Equity of Access		
Assess existing dementia services in order to identify barriers to equity of access and consider recommendations for resolving these issues.	People with dementia and their carers report improved access to dementia care services regardless of where they live, their health status, their age, their cultural background, or financial and social circumstances.	SA Health
Barriers to access – transport		
Collaborate with the Department for Transport, Energy and Infrastructure to ensure transport options and customer service approaches meet the needs of people with dementia.	Current public transport strategies which support people with dementia and carers such as <i>Plus One Companion Card</i> and South Australian Transport Subsidy Scheme (SATSS) are promoted.	Department for Transport, Energy and Infrastructure
	Work continued in regional communities to develop extended community transport networks which assist people with dementia and their carers to access services and maintain social connections.	Department for Transport, Energy and Infrastructure
	Feedback provided to the State Advisory Committee on Accessible Transport on pertinent issues.	Office for the Ageing
Contribute to the National review of the <i>Austroads Assessing Fitness to drive: Commercial and Private Vehicles Drivers – Medical Standards for licensing and Clinical Management Guidelines</i> (being undertaken by National Transport Commission).	Obligations reinforced of health professionals under section 148 of the Motor Vehicles Act 1959 to notify the Registrar of Motor Vehicles where they suspect a person who holds a driver's licence is suffering from any form of physical or mental illness, disability or deficiency such that their driving capacity may be impaired.	SA Health, Department for Transport, Energy and Infrastructure



ACTIONS	OUTCOMES	LEAD AGENCY
Barriers to access – people with special needs		
<p>Identify barriers to access of care and support for people with special needs and implement strategies to alleviate the barriers.</p> <p>Share information across jurisdictions about strategies that have been effective in improving access to care and support for people with special needs across jurisdictions.</p>	<p>Evidence of greater support for people with special needs to access and be referred to services via an established pathway.</p> <p>Evidence of an increased number of people with special needs accessing services.</p> <p>Evidence of information sharing in journals, newsletters, media releases and via networks and forums including the Dementia Collaborative Research Centres and Dementia Training Study Centres.</p>	<p>SA Health in partnership with Office for the Ageing and Alzheimer’s Australia (SA)</p>
Service models to meet the needs of diverse groups		
<p>Develop dementia specific service models that are responsive to the needs of diverse groups and culturally appropriate.</p> <p>Promote among aged care staff working in all sectors of the aged care continuum, an understanding and awareness of cultural differences.</p>	<p>Evidence of dementia specific service models that are responsive to the needs of diverse groups and culturally appropriate.</p> <p>Greater representation of people with special needs accessing services.</p>	<p>SA Health in partnership with Office for the Ageing and Alzheimer’s Australia (SA)</p>
<p>Linkages to the Australian Health Ministers Advisory Council (AHMAC), Australian Health Ministers’ Conference (AHMC) and National Framework for Action on Dementia Working Group.</p> <p>SA Health and the Department for Families and Communities collaborate in the development of state-wide policies, plans and reports for South Australia in relation to dementia.</p>	<p>National linkages maintained.</p> <p>Evidence of input and joint sign off on policies, plans and reports for South Australia in relation to dementia.</p>	<p>SA Health, Department for Families and Communities</p>

5. key priority areas

3 Information and Education

Objectives

- People with dementia, their carers and families can easily access appropriate information, education and support services.
- The community is aware and understands dementia and how to assist people with dementia, their carers and families.
- Information sharing between jurisdictions is effective.

ACTIONS	OUTCOMES	LEAD AGENCY
Forward Planning		
<p>Promote awareness of the need for 'forward planning' to people with dementia, carers and families, community care and health service providers.</p> <p>Encourage service provider networks and access/referral pathways to promote 'forward planning' services to people with dementia, their carers and families.</p>	<p>Information on 'forward planning' including advanced directives available through service networks and in community.</p>	<p>Office for the Ageing, SA Health, Alzheimer's Australia (SA), Office of the Public Advocate, Legal Services Commission</p>
Guardianship		
<p>Support the work of the Office of the Public Advocate to increase awareness about legislative changes that may affect Power of Attorney and Guardianship; the benefits of forward planning; and organising advanced directives.</p>	<p>Improved awareness of Power of Attorney and Advanced Directives procedures amongst people with dementia, their families and carers.</p>	<p>Office for the Ageing</p>
Community Awareness		
<p>Participate in national processes to determine agreed key messages on dementia.</p> <p>Undertake community awareness programs targeting specific community groups based on nationally agreed key messages.</p> <p>Implement culturally appropriate dementia awareness and risk reduction awareness programs.</p> <p>Promote strategies and lifestyle changes which encourage the early identification of risk factors and signs of dementia.</p> <p>Promote strategies and lifestyle changes that reduce or delay the onset of dementia.</p>	<p>Key community awareness messages developed.</p> <p>Evidence of community awareness raising programs that reflect nationally agreed key messages.</p> <p>Evidence of culturally appropriate dementia awareness and risk reduction awareness programs.</p> <p>Evidence of strategies and promotional campaigns aimed at early identification and risk minimalisation.</p>	<p>SA Health in partnership with Alzheimer's Australia (SA) and Office for the Ageing</p>



ACTIONS	OUTCOMES	LEAD AGENCY
Service provider networks		
<p>Increase the awareness of broader service provider networks that interact with people with dementia and their carers.</p> <p>Establish links between specialist dementia information services and other information services.</p>	<p>Awareness resources developed.</p> <p>Linkages established between specialist dementia information services and other key information services. Up-to-date information on dementia services disseminated.</p>	<p>Office for the Ageing, Alzheimer's Australia (SA)</p>
Prevention of abuse		
<p>Implement "Our Actions for the prevention of Abuse Against Older South Australians" in relation to the needs of people with dementia.</p> <p>Support the provision of care and support for people with dementia and their carers where 'risk' of abuse is escalating or where there is evidence of abuse occurring.</p>	<p>Evidence that the initiatives outlined in "Our Actions" have been implemented.</p> <p>Evidence that management of high 'risk' circumstances has improved the safety and wellbeing of people with dementia and their carers.</p>	<p>Office for the Ageing, Aged Rights Advocacy Service, Health and Community Service Complaints Commission, Office of the Public Advocate</p>



5. key priority areas

4 Research

The National Framework for Action on Dementia 2006 – 2010 states¹⁰ that “mental functioning and age related disabilities, including neuro-degenerative diseases, which cause dementia, have been identified as key research themes. Multi-disciplinary research has been encouraged on these subjects”.

Objectives

- Research is directed to the cause, cure and care of dementia.
- Research is translated into practice and is promoted and available to those who need it.
- Research findings are promoted more broadly in the community.

ACTIONS	OUTCOMES	LEAD AGENCY
Promotion and dissemination		
Promote and disseminate agreed key areas for research to key stakeholders and workforce. Promote and disseminate dementia research findings to community care and health agencies to inform future planning, service management and delivery.	Evidence of promotion and dissemination of agreed key areas for research. Evidence of promotion and dissemination of dementia research findings to community care and health agencies.	SA Health, Office for the Ageing, Dementia Collaborative Research Centres
Data standards and systems		
Implement the national dementia data standards and systems.	Evidence of dementia data collection as per national standards.	Office for the Ageing
Translation of research into practice		
Identify and implement the most appropriate ways to enhance existing practice. Enhance existing practices based on research findings.	Extent to which practice guidelines and service models are based on research findings are identified.	SA Health, Office for the Ageing, Dementia Collaborative Research Centres
Health literacy and dementia		
Identify health literacy needs for people with dementia and carers and develop strategies to promote health literacy based on best practice and available evidence.	Report completed by Healthy Ageing Research Cluster, Adelaide University.	Healthy Ageing Research Cluster, Adelaide University.

10. National Framework for Action on Dementia 2006 – 2010, page 3



5 Workforce and Training

Objective

A skilled and informed workforce is available to care and support people with dementia, their carers and families.

ACTIONS	OUTCOMES	LEAD AGENCY
Training and skill development		
<p>Assess level of competencies against prescribed training i.e. standards, accredited training and recommend strategies to maximise spread of competency across the community, acute and residential care sectors.</p> <p>Identify existing Dementia training and development programs.</p> <p>Develop and implement a sector-wide training and development strategy for working with people with dementia, incorporating:</p> <ul style="list-style-type: none"> • Baseline competencies • On line information and service guides • Access to support or mentoring (immediate crisis management or ongoing development) • Information sharing forums on best practice • Performance criteria for ongoing staff development planning. <p>Seek cooperation from registered training providers including Universities to influence the design and delivery of training for relevant health, community care and aged care professionals with a special focus on curricula related to dementia awareness and care.</p> <p>Support the development of a suite of national dementia specific qualifications ranging from Certificate IV to Masters Degree level.</p>	<p>Base workforce competencies in the care of dementia identified.</p> <p>SA Community Care and Health Workforce Development Strategy developed and recommendations considered.</p> <p>Directory of training providers' in-place and on-line for Government and non-Government agencies.</p> <p>Training and Development Strategy implemented.</p> <p>Specialist competencies and training pathway identified.</p> <p>Evidence of inclusion of dementia awareness and care in relevant curricula.</p> <p>A suite of national dementia specific qualifications exists to meet the differing requirements of workforce.</p>	<p>SA Health in partnership with Office for the Ageing, Alzheimer's Australia (SA)</p>

5. key priority areas

ACTIONS	OUTCOMES	LEAD AGENCY
Incentives for workforce participation in dementia care		
<p>Identify incentives and barriers to recruitment and retention of workers in dementia care.</p> <p>Develop incentives for recruitment and retention of workers in dementia care.</p>	<p>Evidence that more community, acute and residential care staff are choosing to work in dementia care.</p>	<p>Office for the Ageing in partnership with SA Health</p>
Professional development		
<p>Explore practical strategies for flexible delivery of professional development, and work with relevant agencies to implement them wherever possible.</p> <p>Collaborate to provide joint training and development opportunities that foster linkages across community care and acute care services.</p> <p>Provide HACC workforce with regular dementia awareness and skill development training.</p>	<p>Evidence that a range of professional development strategies implemented.</p> <p>Education, training and information on dementia readily available.</p> <p>Evidence of joint professional development initiatives between the SA Health and Department for Families and Communities and the Non-Government sector.</p> <p>Dementia awareness and skill level enhanced within HACC workforce.</p>	<p>SA Health, Office for the Ageing, Alzheimer's Australia (SA)</p>



6. implementation, evaluation and reporting

South Australia's Dementia Action Plan is the first in South Australia – it is just the beginning.

The journey requires true collaboration between Government and non-Government agencies and consultation with people with dementia, their carers, families and service providers to provide effective supports for people with dementia, their carers and families.

The journey requires true collaboration between Government and non-Government agencies and consultation with people with dementia, their carers, families and service providers to provide effective supports for people with dementia, their carers and families. By *Facing the Challenges Together* accessible, seamless pathways for people with dementia, their carers and families can be created.

In undertaking the activities stated in the Dementia Action Plan, outcomes have been identified. However more specific key performance indicators for each action and an evaluation framework will be developed in order to monitor the progress of South Australia's Dementia Action Plan. SA Health and the Department for Families and Communities, specifically Office for the Ageing, will be responsible for monitoring state and regional progress towards the actions outlined in South Australia's Dementia Action Plan. A South Australian Dementia Reference Group will also be established to oversee the implementation of South Australia's Dementia Action Plan, advise on policy planning and resourcing issues and liaise with the Ministerial Advisory Board on Ageing.

A key component of *Facing the Challenges Together* will be the development of Regional Dementia Action Plans that include regional dementia statistics on projected service demand, identify service gaps and address the need for dementia care services at the local level. We will work collaboratively with regional agencies and consumers to develop plans that consider the needs of people with dementia in receipt of agency services.

By working in partnership with all government, non-government, residential and community based agencies, support to people with dementia and their carers and families can be provided in order to ensure that people with dementia have a better quality of life.



7. glossary

South Australia's Dementia Action Plan is the first in South Australia – it is just the beginning.

Acute care – Care provided usually as a result of a medical crisis. Includes care provided in emergency departments and inpatient hospital care.

Advanced Care Directives – Also termed “living will” or “refusal of treatment certificate”. The document states instructions for the care to be implemented in the event of future decisional incapacity. In some cases, it is formal and legally endorsed.

Community care - Care that is provided to a person in their community as opposed to care that is provided in a residential facility.

Carer – Usually a family member or friend. Their work is based on a pre-existing relationship and is unpaid. The primary carer is the person who has provided the most assistance to the person in relation to self-care, mobility and communication and other needs.

Dementia – A syndrome due to disease of the brain, usually of a chronic or progressive nature, which causes a decline in memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement.

Dementia friendly service – People with dementia, their carers and families are central to making choices about care. Service responses recognise peoples' individual journeys. People with dementia are valued and respected. Carers and families are valued and supported and their efforts are recognised and encouraged.

All people with dementia, their carers and families receive appropriate services that respond to their social, cultural or economic background, location and needs.

Depression – A common mental disorder that presents with depressed mood, loss of interest or pleasure, feelings of guilt or low self-worth, disturbed sleep or appetite, low energy, and poor concentration. These problems can become chronic or recurrent and lead to substantial impairments in an individual's ability to take care of his or her everyday responsibilities. At its worst, depression can lead to suicide

Dual disability – The co-existence of two or more conditions such as Down Syndrome and Dementia.

Evidence based – Practices that are informed and supported by reputable research and knowledge bases.

HACC – Home and Community Care services

Primary care – Services provided by GPs, nurses, community nurses and aged care assessments teams. Includes assessment, diagnosis and treatment services.

Regional Dementia Action Plans – Regional dementia action plans are prepared by local health and aged community care service providers in consultation with consumers. The regional plans include regional dementia statistics on projected service demand, identify service gaps and address the need for dementia care services at the local level.

Residential care – Care provided in an aged care facility, such as a nursing home or hostel.

Respite – Temporary care arrangements provided by someone other than the usual carer: also includes short-term residential care.



Dementia – A syndrome due to disease of the brain, usually of a chronic or progressive nature, which causes a decline in memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement.

Quality of Life – An individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns. It incorporates the person's physical health, psychological state, level of independence, social relationships, personal beliefs and relationships to salient features in the environment.

Workforce – Refers to all people employed who provide assistance, care, information or support to people with dementia, their carers and families.

Younger onset dementia – The term 'younger onset dementia' is usually used to describe any form of dementia diagnosed in people under the age of 65 years.



8. references

Access Economics, (Feb 2005), *Dementia Estimates and Projections: Australia States and Territories*, Report for Alzheimer's Australia, Canberra.

Australian Institute of Health and Welfare (Jan 2007), *Dementia in Australia: National data analysis and development*, AIHW cat. No. AGE 53, Canberra: AIHW
<http://www.aihw.gov.au/publications/index.cfm/title/10368>

Australian Government, (April 2005), *A New Strategy for Community Care: The Way Forward* <http://www.dcita.gov.au/cca>

Australian Health Ministers' Conference, (May 2006), *National Framework for Action on Dementia 2006-2010* <http://www.health.gov.au/internet/wcms/publishing.nsf/content/ageing-dementia-nfad.htm>

Government of Australia, (June 2008), *Dementia Resource Guide*, www.health.gov.au/dementia or CD-ROM available by contacting dementia@health.gov.au

Government of South Australia (Updated Jan 2007), *South Australia's Strategic Plan* www.stateplan.sa.gov.au

Government of South Australia, (April 2005), *Connecting to the future 2005-2008* www.familiesandcommunities.sa.gov.au

Government of South Australia, (Feb 2006), *Improving with Age – Our ageing plan for South Australia* www.familiesandcommunities.sa.gov.au



9. appendix

List of Key Stakeholders

By working in partnership with all government, non-government, residential and community based agencies, support to people with dementia and their carers and families can be provided in order to ensure that people with dementia have a better quality of life.

SA Health

Country Health SA

Department for Families and Communities

- Office for the Ageing
- Office for Carers
- Disability SA
- Office for Disability and Client Services
- Domiciliary Care SA
- Families SA

People with dementia, their carers and families

Alzheimer's Australia (SA)

Council of Aboriginal Elders

Multicultural Aged Care

Carers SA

Aged and Community Services SA & NT

HACC funded agencies

Grant funded agencies

Commonwealth funded Dementia service organisations

Health professionals

Residential and Community Aged Care workers

Department for Transport, Energy and Infrastructure

Local Government Authorities

Guardianship Board

Attorney General's Department

Legal Services Commission

Office of the Public Advocate

Health and Community Service Complaints Commission

Council on the Ageing (COTA)

Aged Rights Advocacy Service (ARAS)

Older Person's Mental Health Service (OPMHS)

Universities and TAFEs

Registered training organisations





Government
of South Australia

Office for the Ageing

Department for Families and Communities

in partnership with SA Health

The information in this publication can be provided in an alternative format or another language on request.

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