

**SUBMISSION TO THE HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON HEALTH AND AGEING INQUIRY INTO DEMENTIA: EARLY DIAGNOSIS AND INTERVENTION**

South Australia acknowledges the importance of developing proactive approaches for supporting people with dementia, as our population continues to age. The South Australian Government welcomes the opportunity to provide input into the House of Representatives Standing Committee on Health and Ageing (the Committee) Inquiry into Dementia: Early Diagnosis and Intervention, to progress improvements in this area.

South Australia has the oldest population in Australia; 15.4 percent of the population is aged over 65 years compared with 13.3 percent nationally<sup>1</sup>. Although South Australia's ageing population is expected to continue growing, it is now doing so at the same rate as the national average. As the number of older South Australians increases, so will the prevalence of dementia.

In South Australia 23,710 people in 2011 were reported with dementia and by 2017, dementia is projected to increase to over 29,200 people – an increase of 19 percent<sup>2</sup>. This has significant policy, planning and financial implications requiring the South Australian Government to have in place sustainability strategies that support fiscal and service demands.

To meet the health challenges of an ageing population, the South Australian Health Care Plan 2007-2016 sets a clear reform agenda. Under this, four key service plans influence the quality of dementia care across the care continuum:

- SA Health Services Framework for Older People 2009-2016
- SA Health Statewide Rehabilitation Service Plan 2008-2017
- Chronic Disease Action Plan 2009-2018
- Older Persons Mental Health Service SA Model of Service.

These plans address the specific needs of people with dementia within their broader responsibility.

To develop a more targeted focus on the needs of people with dementia and their families and carers, *South Australia's Dementia Action Plan (SADAP) 2009–2012, "Facing the Challenges Together"*, commenced in 2009. Implementation of this plan has now been completed and the Post-implementation Review Report has made recommendations for planning, coordinating and monitoring dementia initiatives across the state.

---

<sup>1</sup> *State of Ageing in South Australia*. Department for Families and Communities, Government of South Australia (2008).

<sup>2</sup> Access Economics (2011). *Dementia Across Australia: 2011-2050*, Report for Alzheimer's Australia, September.

The SADAP also initiated development of Best Practice Dementia Care Principles, to inform the development of dementia services. These include:

- 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.

These principles and overarching plans form the broad framework for the initiatives highlighted in South Australia's response to the terms of reference. Our submission also considers areas for continued improvement in our responses to the needs of people with dementia, as well as their families and carers.

South Australia also acknowledges that the recent Commonwealth Government commitment of \$3.7 billion over five years for aged care reform, through their *Living Longer Living Better* report will go some of the way to improving diagnosis, intervention and care for people with dementia.

## ADDRESSING THE TERMS OF REFERENCE

### 1. Improving quality of life and assisting people with dementia to remain independent for as long as possible

Quality of life is subjective to each individual, although maintaining independence is likely to be a significant indicator for most individuals. As diagnosis is the first step in determining eligibility for services, South Australia is continuing to focus on initiatives that support capacity for early diagnosis and intervention.

#### Community based initiatives

##### Area Geriatric Services

Area Geriatric Services (AGS) now include Mobile Assessment Service Teams (MAST). MAST provide rapid response assessment and referrals to avoid preventable unplanned hospital admissions and emergency department presentations for older people. MAST also facilitates coordinated planned admissions to the acute and subacute sector where this is clinically indicated and beneficial to clients.

MAST take an interdisciplinary approach and have strong links with General Practitioners (GPs) and hospital based geriatricians for referring undiagnosed clients for Comprehensive Geriatric Assessment. The needs of carers of people with dementia are also targeted by this service, optimising their health and independence.

##### Primary Health Care Networks

Primary Health Care Networks have been established in metropolitan Adelaide to promote awareness and interagency collaboration and improve capacity across dementia care. A particular outcome of the Networks is the establishment of Systems of Integrated care between GPs.

##### Community Practice Nurse Model

The current health system allows GPs to screen for dementia through their *70 Plus Health Checks*. To expand dementia screening capacity, the Community Practice Nurse model has been established. Community Practice Nurses are well placed to provide timely dementia information, screening and referrals for older people, as well as providing dementia education to GPs and allied health professionals.

##### Chronic Disease Management

Dementia has one of the longest chronic courses of almost any other chronic disease. Enhancing capacity for diagnosing and managing dementia and complex conditions is being addressed by the Chronic Disease Action Plan 2009-2018. This work is clarifying chronic care pathways in dementia and identifying appropriate points of service intervention and broader supports. Collaborative and person-centred care approaches, including rehabilitation access, are foundational to this process.

### Transition Care Program (TCP)

South Australia now includes older people with dementia in the TCP target groups. The TCP supports people transitioning from hospital to in-patient short term rehabilitation, and back home. Nearly 30% of people admitted to the TCP have a formal dementia diagnosis. Often the TCP works closely with the local GP and the geriatrician to have formal assessments and diagnosis completed.

### Older Persons Mental Health Service SA Model of Service

The Older Persons Mental Health Service SA Model of Service has developed a comprehensive range of strategies to address the needs of older people with severe Behavioural and Psychological Symptoms of Dementia (BPSD) and mental health conditions. The Model facilitates the smooth transition of diagnosis, assessment and intervention information through the range of services an individual may use as their behaviours change and symptoms progress.

The Model is rolling out Older Person's Mental Health Service (OPMHS) Community Teams in the metropolitan area over the next three years. This will increase in-reach support in nursing homes, improving early intervention and quality of life.

For people with BPSD who can not be supported in generic nursing homes, Intensive Care Behavioural Unit beds are being established to accommodate their more specialised needs.

### Memory Clinics

Memory clinics have been established in both metropolitan and country regions of South Australia. The clinics are intended to be highly accessible and visible in the community and offer memory checks to identify any possible signs of dementia early.

At the moment, there is no dedicated funding for memory clinics in South Australia. This means money for these clinics comes from a variety of innovative sources and gives rise to a variety of memory assessment clinic models and quality and clinical approaches. As a result, there is no identified memory assessment clinic model of care or standards.

## **Acute and Sub-acute care initiatives**

### Every Patient Every Service – Hospital Services Policy

Initiatives supporting early dementia diagnosis capacity across the sub-acute and acute sector include work under the Every Patient Every Service – Hospital Services Policy. This policy aims to develop effective and suitable models of care for patients across emergency departments, including patients with dementia.

Notable developments include the emergence of specific screening tools, assessment strategies and locales for patients attending Emergency Departments with dementia.

#### State Government hospital initiatives

A number of initiatives are operating in State Government hospitals which focus on earlier identification and intervention for people with dementia. Those most relevant to maintaining a person's independence and improving quality of life include:

- Expansion of a sub-acute rehabilitation service, including Geriatric Evaluation Management (GEM) and ambulatory services.
- Development of evidence base improvements to models and approaches used in assessment of individuals with dementia.
- Preliminary implementation of the Blue Dot monitoring system to monitor the progress and transitions of individuals with complex needs (including dementia) across public hospitals.
- Establishment of a Geriatric Liaison Services model in hospitals responsible for undertaking comprehensive assessment and restorative focussed interventions for different geriatric syndromes. These services aim to facilitate efficient and effective patient pathways for older people within the hospital and at discharge.

#### **Institutional care initiatives**

##### Strengthening Communication Pathways

Stronger linkages are being cultivated between Residential Aged Care Facilities (RACF) and acute/sub-acute care services. Strengthened communication between hospital and RACF clinical staff enables seamless transfer of best practice clinical care patient information and care plans, thereby improving knowledge of patient dementia care needs.

##### Community rapid response teams

Community rapid response teams have been established to provide consultation and support services to RACF in the ongoing care management of residents. Of particular focus are initiatives aimed at enhancing communication and consultation with primary care/ general practice, to overcome delays in treatment and reduce acute sector admissions.

#### **Statewide initiatives across the care continuum**

##### Translating Dementia Care Principles into Statewide Practice

This project, undertaken in 2010, mapped dementia services for a significant component of the metropolitan region and identified strategies for reform of clinical care and practices. This work provided important information for future planning in this state. Further exploration of the findings is planned to make sure clinical care for dementia is accessible locally and supported by adequate technology.

### Statewide Older Persons Clinical Network

South Australia has a Statewide Older Persons Clinical Network that is responsible for providing leadership on clinical matters related to aged care. Several working groups under this network have developed models of care that drive quality of dementia care across the care continuum. This includes work to improve timely access to medical specialists skilled in the diagnosis of dementia such as geriatricians, psycho-geriatricians and neurologists.

In 2012 the Clinical Network will establish a working party to develop a dementia care pathway. A plan for dementia health services in South Australia will also be considered in this work.

### **Supports for younger people with dementia**

The issue around early diagnosis and early intervention for dementia needs to be addressed in different ways for people with younger onset dementia compared to the older majority. South Australia is currently undertaking work to make sure that younger people with disability, including people with younger onset dementia, are receiving the support that best responds to their age, circumstances and needs.

#### In home dementia support

For younger people with dementia, there may be more natural supports available to help the person stay at home for longer. For example, parents and spouses are also likely to be younger and more physically capable of providing support. This places an emphasis on home supports and respite to maintain these arrangements, promote wellbeing, independence and community connection.

The South Australian Government provides a range of dementia support services in the home. These include personal care, domestic assistance, carer respite and allied health such as occupational therapy, physiotherapy, podiatry, nutritional support and social work. The social work role can support the individual and their family in dealing with the emotional aspects of living with dementia, as well as facilitating links with other providers, such as general practitioners, geriatricians or health providers.

## **2. Increasing opportunities for continued social engagement and community participation for people with dementia**

Early diagnosis and intervention increases the capacity of the individual to access peer support and community programs and overall enhances their sense of social connectedness. It is however imperative that appropriate and accessible community and social programs are available to capitalise on the benefits of intervening early. South Australia has developed initiatives aimed at enhancing opportunities for community participation for people with dementia.

### Country Community Passenger Networks

The provision of adequate transport support in the country is essential to ensuring access and equity for individuals with dementia and their families/carers. A notable example is the development of a Community Passenger Networks (CPN) across country South Australia. The CPN service providers enable the provision of quality transport services to Home and Community Care eligible clients living in regional areas of South Australia to enable their access to and participation in community activities.

### Dementia Day Program

The Dementia Day Program is a centre based day program for clients who have dementia or memory loss and confusion. This program provides clients with the opportunity to socialise with others, maintain current skills and participate in meaningful activities. Transport is facilitated to and from the Program and staff provide support to meet the physical and behavioural care needs of individuals.

A person's social and communication needs are a major focus of the Program, which provides people with activities to stimulate cognitive and physical abilities according to individual interests and capacity. A wide range of activities and outings are available.

The Day Program also offers specific multicultural dementia and respite services to provide support and options for clients from different cultural groups.

As a spin off from the Dementia Day Program, a men's carers group has been operating to support older men with spouses who attend the Day Program.

### Service Coordination

Dementia service coordinators employed by the State Government, work with a specialised focus to ensure individuals with dementia are receiving support that takes into account the challenges of living with dementia. The role involves learning the needs and wants of the individual with dementia, their family and carers, and then providing the necessary information and linking to the most appropriate services when needed.

### *Innovative Respite*

In home respite services are being developed by State Government agencies which build on an appreciative enquiry and personal story/interest based approach. Using the skills of Occupational Therapists and personal care workers, meaningful activities are provided in the home, based around technology such as ipads and Wii. The activities aim to promote cognitive interest and social connection with others using the technology.



### **3. Helping people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements**

#### Law reform

Currently in South Australia there are several laws governing the legal instruments whereby competent adults can appoint and/or instruct one or more trusted substitute decision maker or write down their wishes for end of life care (without appointing a substitute decision maker). In 2011, the South Australian Government agreed to reform and simplify the laws governing Advance Care Directives (ACDs) for health and personal decision making and the financial powers of attorney.

It is intended that law reform will ensure a simple, accessible and applicable scheme which meets the needs of those wishing to complete an ACD and can be easily understood and applied in all health and community care settings. The simplified scheme will accommodate the needs of people with dementia, provided that ACDs are completed before competence to do so is lost.

Along with this reform, the establishment of electronic health records in South Australia will improve access to ACDs when they are needed.

A greater uptake of ACDs among people with dementia will ensure that care wishes are known in advance and respected, which is particularly important at transition points in level of care.

#### Respecting Patient Choices Program

Improving health literacy in ACDs is recognised as necessary to increase uptake of these tools. The Respecting Patient Choices program is being used as the main approach within the public health sector to achieve this. Coordinators have been appointed in two of the Local Health Networks (Country Health SA and Central Adelaide Local Hospital Network) to raise awareness of ADCs and progress the uptake of this program.

#### Advance Care Directives staff training

Evidence suggests that a lack of competence is often presumed once a dementia diagnosis is made, thereby limiting the rights of people with dementia to complete ACDs. However a dementia diagnosis itself should not be justification for assuming a person cannot complete an ACD, make their own decisions or participate in decisions affecting their lives, to the extent they are able.

ACDs are important tools to empower people and protect their rights in advance of impaired decision making capacity. Frontline aged care staff in state government services are provided with training in ACDs. This provides workers with the knowledge to promote the value of ACDs to clients as appropriate and the ability to talk through issues associated with future care.

### *Futures Planning*

A *Futures Planning* booklet has been developed by the South Australian Government to assist individuals with dementia, their families and carers, to plan for the future. This booklet has been produced in a range of languages and distributed to service providers.

### *Dementia Respite Initiative*

The Dementia Respite Initiative has been established in northern Adelaide. The respite facility can accommodate overnight and weekend clients and is complemented by education, counseling and information services for carers. A similar service has also been implemented in the eastern metropolitan region of Adelaide.

### *Gateways project*

To facilitate early identification and linkage of carers to state government carer support services, the Gateways project has been established. This project raises awareness of the role of carers and promotes the importance of monitoring carer health and wellbeing.

#### **4. Delivering awareness and communication on dementia and dementia-related services into the community**

Early diagnosis of dementia and intervention is only possible when the community is aware of the risks, signs and steps they can take. All of the overarching age care and dementia plans and initiatives have an awareness raising component. Below are two areas where specific work is underway in South Australia to improve community awareness of dementia and communication.

##### *Regional Dementia Plans*

The *National Framework for Action on Dementia (2006-2010)* included information and education as a key priority area. This was translated into *South Australia's Dementia Action Plan 2009-2012* action areas. As a result, six Regional Dementia Plans in South Australia include building community awareness of dementia as a priority area. One way this is occurring is through the establishment of regional networks to facilitate collaborative practices between health and dementia services and a range of community and lifestyle support services.

##### *The Active Cognitive Enhancement Program*

This initiative aims to promote community awareness of the prevention and management of dementia. Designed for those aged 55 and over who wish to improve their mental fitness, this program incorporates a psycho-educational component, brief gentle exercises, individual and group cognitive training activities and mindfulness meditation.

## Proposed areas for future focus

Areas where South Australia has observed possible opportunities for future focus to improve dementia diagnosis and intervention are provided below.

### **Continued effort for education and awareness regarding dementia, with a focus on GPs and primary health care services.**

Consistently, Alzheimer's Australia report that GPs have difficulty in identifying and/or addressing dementia or referring on to specialists and support services. Significant numbers of people in the early stages of dementia are not being diagnosed in general practice and delays of up to three years for those who are diagnosed have been noted. Often, investigative procedures are precipitated by a crisis event that prompts GPs to make necessary referrals. This is changing as awareness increases, but further improvement can be made.

### **Improved understanding of the specific issues and needs for people with younger onset dementia.**

The majority of people with dementia are aged 65 years or over. However the number of people aged under 65 years diagnosed with dementia is increasing, and it is apparent different service responses may need to be available to this emerging group. Research to more clearly understand the specific issues and needs for people with younger onset dementia can highlight gaps in current service provision and inform the development of innovative and age-appropriate service design.

### **Improved service responses for people with severe behavioural and psychosocial symptoms of dementia (BPSD).**

People with BPSD often have co-morbid psychiatric disorders that add an additional layer of complexity with service requirements, making it even more challenging to provide appropriate care. Estimates show that approximately 10% of people with dementia also have severe BPSD, equating to around 26,000 people nationwide in 2011.

### **Establish a nationally consistent memory assessment model and expand availability of memory clinics.**

Memory clinics aid community awareness and offer an opportunity for individuals to be tested for early signs of dementia, even before obvious symptoms emerge. Expansion of this service nationally is proposed along with the development of a consistent model of memory assessment.

### **Focus on collaborative service delivery.**

---

Complexity in funding arrangements and departmental responsibilities can lead to gaps in the provision of services. For example, availability of funding and departmental responsibility for people with younger onset dementia can be unclear. Therefore it is important to consider how jurisdictions and sectors can work together so there is consistency in level of support and best practice advantage for people with dementia, regardless of age of onset.

### **Improving choice and flexibility in service delivery to meet the needs of individuals.**

---

Quality of life is subjective to each individual. Assessments, service options and supports available need to be developed with this in mind, with a renewed focus on choice and flexibility.

### **Development of culturally specific responses in dementia care.**

---

Continuing the theme of improving choice and flexibility of services, the specific needs of people from Aboriginal backgrounds or from Culturally and Linguistically Diverse backgrounds need to be further understood and considered.

Community and residential aged care are the responsibility of the Commonwealth Government. As our population continues to age, and illnesses such as dementia increase, service capacity and resources will need to be carefully considered. This is a challenge that will affect all of Australia, and South Australia acknowledges the importance of this inquiry in looking at this issue and delivering useful findings and constructive ways forward.