SA Health Services Plan *for People with* Dementia (and Delirium) 2015-2018

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Government of South Australia

SA Health

Foreword

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The Older People Clinical Network has described the health system architecture and the models of care required to provide health services designed to meet the needs of older people. This is described in the SA Health endorsed document *Description of an Area Geriatric Service* [1] and the four Model of Care documents that describe the main component parts of an Area Geriatric Service – the *Acute Care of the Elderly Unit* [2], *Geriatric Evaluation and Management Unit* [3], *Geriatric Consultation Liaison Team* [4] and *Community Geriatric Service* [5]. Implementing these services, under the governance of an Area Geriatric Service, is the underlying requirement for providing care designed to meet the needs of people with dementia (and delirium).

This plan describes, in further detail, the reform required to ensure health services are competent in the care of people with dementia (and delirium).

On 10 August 2012, the Australian Health Ministers recognised dementia as a National Health Priority. In 2015, the Commonwealth government will release the second National Framework for Action on Dementia. The priorities of the National Framework are in alignment with the *SA Health Services Plan for People with Dementia (and Delirium).*

All of the recommendations in the plan require clinical leadership to implement, and a number require funding. There is no reason to delay implementation; we can all implement parts of this plan today. We each need to be accountable for changing our own practice so it better reflects what consumers and carers want.

We ask all SA Health staff to reflect on what it's like to be a person with dementia (and/or delirium) in their health service. We ask you to view your service through the consumer and carer's eyes. Examine and reflect upon what you experience and what you see. If you are not comfortable with the level of competence in the care of people with dementia (and delirium), accept accountability for your role in implementing the recommendations put forward in this plan.

Be guided by the values of the SA Department of Health – integrity, respect and accountability. Clinicians, administrative staff, security staff, catering staff, hotel staff, volunteers, managers, executives, planners and policy makers – we ask you to champion these values every day in your work place, as they are fundamental to the development of dementia (and delirium) care competent health services.

"A good plan implemented today is better than a perfect plan implemented tomorrow."

– George Patton

Disclaimer

This plan has been developed by the State-wide Older Persons Clinical Network. There has been investment in geriatric medicine and services for older people across South Australia – this plan is intended to be used to support service change and best practice within the funds that have been allocated. The plan is expected to challenge how any current funds for geriatric medicine and services for older people are spent ensuring that the allocated funds are reviewed and used to deliver this plan. The plan is not a tool to seek funds over and above what is allocated now or into the future for these services.

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Summary

The SA Health Services Plan for People with Dementia (and Delirium) describes what consumers and carers want, how the health system will change to better align service provision with what consumers and carers want, and how to maximise the use of existing levers to drive change.

To do nothing is not an option, dementia is a National Health Priority, the population is ageing, the prevalence of dementia is increasing, people with dementia are more likely to have comorbidities [6], nearly one in three people over 70 years of age admitted to hospital will have some form of cognitive impairment [7] (mostly dementia). As inpatients, people with dementia are at a significantly increased risk of preventable complications and adverse outcomes [7], they are three times more likely to die in hospital [7], they have longer lengths of stay [6] and higher costs (an additional $2,000 per episode of care [6]) compared to people without dementia.

Care should be provided according to the needs and preferences of consumers and their carers, for this reason the goals of the plan are written from the perspective of the consumer and carer, and the recommendations are written from the perspective of the health system, so as to describe what must be done to ensure consumer and carer goals can be achieved.

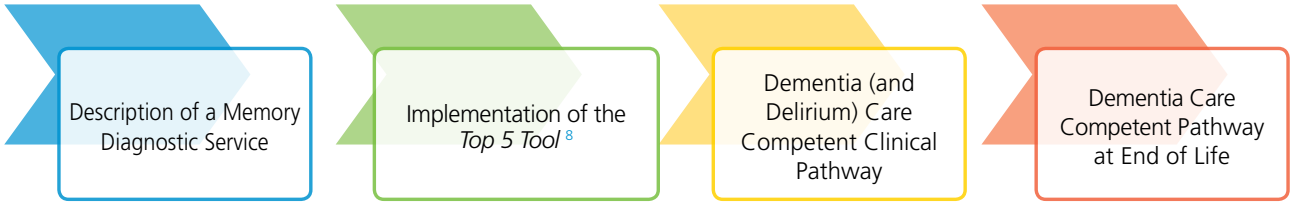
The plan makes clear the fundamentals of reform; that consumers' and carers' expectations are understood and that the workforce needs to be developed, through clinical leadership, education and training, to meet these expectations. There is no doubt that nothing will change without first changing the level of awareness, skill and knowledge of the health workforce. This is reflected in the PRIORITY RECOMMENDATIONS of the plan.

- Each Local Health Network to hold an annual dementia awareness event, such as the Central Adelaide Local Health Network's Mindful of Dementia Day (Recommendation 2.1, p. 16).
- SA Health to support the formation of a collaboration to examine the current and future state of education and training. The future state will describe the reform required to ensure graduates of clinical degrees and practicing clinicians have the skills, knowledge and experience to undertake the clinical, communication and team based competencies in the care of people with dementia (and delirium). Recommendation 2.2, p. 16).
- SA Health with representation from the Local Health Networks, to develop a state-wide model of care for the Local Health Network based Memory Diagnostic Service (Recommendation 3, p. 19).
- Each Local Health Network will identify an Executive Sponsor who will be accountable for the implementation of the *TOP5 Tool* [8] within the geographical catchment of their Local Health Network (Recommendation 4.2, p. 22).
- SA Health, with representation from the Local Health Networks to develop, endorse and implement a Dementia Care Competent Clinical Pathway for use across SA Health's services (Recommendation 6.2, p. 27).

- SA Health, with representation from the Local Health Networks, to develop, endorse and implement a Dementia Care Competent Pathway at End of Life for use across SA Health's services (Recommendation 9, p. 35).

The model of care for the Memory Diagnostic Service, the proposal to use the *TOP5 Tool*[8] to improve communication with consumers and carers within and between different services, the Dementia (and Delirium) Care Competent Clinical Pathway and the Dementia Care Competent Pathway at End of Life will be written as a suite of interconnected documents, which can be read as one, or read separately.

The SA Health Services Plan for People with Dementia is the overarching document to:



The recommendations reflect a requirement to improve performance within existing resources. There is a need for service standards to ensure all consumers and carers can access a similar basic standard of care from all of SA Health's services. When it is possible for services to demonstrate compliance with the basic standard of care, they should be encouraged to innovate, evolve and grow into exemplary dementia care competent organisations.

Recommendations

Chapter 1. Consumer and Carer Expectations

1. The Local Health Networks (LHNs) provide care that is consistent with the Principles of Care, as documented by consumers and carers of people with dementia.

Chapter 2. Dementia (and Delirium) Care Competent Workforce

PRIORITY RECOMMENDATION

2.1 Each LHN to hold an annual dementia awareness event, such as the Central Adelaide LHN's Mindful of Dementia Day.

PRIORITY RECOMMENDATION

2.2 SA Health to support the formation of a collaboration, to examine the current and future state of education and training. The future state will describe the reform required to ensure graduates of clinical degrees and practicing clinicians have the skills, knowledge and experience to undertake the clinical, communication and team based competencies in the care of people with dementia (and delirium).

Chapter 3. Memory Diagnostic Service

PRIORITY RECOMMENDATION

3. SA Health, with representation from the LHNs, to develop a state-wide model of care for the LHN based Memory Diagnostic Service.

Chapter 4. Communication Within and Between Services

4.1 The LHNs review their clinical handover policies to ensure they address the needs of people with dementia (and delirium).

PRIORITY RECOMMENDATION

4.2 Each Local Health Network will identify an Executive Sponsor who will be accountable for the implementation of the *TOP5 Tool* [8] within the geographical catchment of their LHN.

Chapter 5. Hospital Avoidance and Hospital Substitution

5. The LHNs review current hospital avoidance and hospital substitution services to ensure they meet the acute care and palliative care needs of people with dementia.

Chapter 6. Dementia (and Delirium) Care Competent Hospitals

6.1 The LHNs undertake an annual audit of the hospital environment [9] (including plans for redevelopments and new patient accommodation) to understand how it meets the needs of people with dementia (and delirium).

PRIORITY RECOMMENDATION

6.2 SA Health, with representation from the LHNs, to develop, endorse and implement a Dementia Care Competent Clinical Pathway for use across SA Health's services.

Chapter 7. Recording Hospital Activity

7.1 SA Health to develop consistent practices for the coding of dementia as an Additional Diagnosis.

7.2 SA Health to make the submission to the Australian Consortium for Classification Development[10] for a review of the coding standard for dementia.

Chapter 8. Understanding Behaviour

8.1 The Area Geriatric Services and Older People Mental Health Services collaborate in the care and management of people with dementia.

8.2 Clinical leaders maximise the use of, and work collaboratively with, the Dementia Behaviour Management Advisory Service to improve care, and report on use of this service.

8.3 A standardised tool and process to monitor and respond to people with increasing anxiety, agitation and aggression in health services is developed, agreed, documented and implemented in conjunction with a state-wide education and training program.

8.4 The LHN Safety and Quality units support the implementation of mandatory recording and reporting of all forms of restraint for all consumers of health services.

Chapter 9. Respectful End of Life

PRIORITY RECOMMENDATION

9. SA Health with representation from the LHNs, to develop, endorse and implement a Dementia Care Competent Pathway at End of Life for use across SA Health's services.

Introduction

Vision

People with dementia (and/or delirium) and their carers experience a high level of satisfaction with the standard of care provided by SA's health services.

Rights

Equitable access to appropriate services and the highest attainable standard of care is the right of every individual regardless of age, culture, race, language, gender, sexual orientation, geographical location, socio-economic status or housing insecurity [11].

Scope

The scope of the plan has been intentionally limited to State-funded health services; this is in recognition of the urgent need to reform health services to ensure they are 'dementia (and delirium) care competent'. This plan focuses on five areas requiring reform – education and training, diagnosis, communication within and between services, hospitals and end of life care. SA Health expects to demonstrate some evidence of reform in these areas before widening the scope of planning.

Audience

Endorsement of the final version of the plan will be sought from the Executives of the South Australian Department of Health, and the Chief Executives of the Central Adelaide, Northern Adelaide, Southern Adelaide and Country Health Local Health Networks (referred to as the 'LHNs' throughout the document). The plan is for use by the LHNs to guide the implementation of dementia (and delirium) care competent health services. The plan should be read by all who have a professional or personal interest in dementia (and delirium) care competent health services, including consumers (and their carers) of SA Health's services, and all of SA Health's clinicians, managers, executives, educators, planners and policy makers who are accountable for services provided to people who have (or may have) dementia (and delirium).

Purpose

The purpose of this plan is to describe the health service reforms required to ensure SA's health services can reliably deliver care to people with dementia (and delirium) that is in alignment with consumer and carer expectations.

Policy

In 2015, the Australian government will release the second *National Framework for Action on Dementia.* This plan serves as a a guide to jurisdictions as to how to improve care and support for people with dementia and their carers.

The priorities of the *SA Health Services Plan for People with Dementia 2015-2018* are in alignment with the health service priorities of the the second *National Framework for Action on Dementia*. Monitoring implementation of the South Australian plan will enable the State to report progress implementing the National Framework.

The recommendations of the *SA Health Services Plan for People with Dementia (and Delirium) 2015-2018* are consistent with the policy direction set out in key South Australian health policy documents.

South Australia's Health Care Plan 2007-2016 [12] states there will be "better co-ordination of aged care services", achieved through implementation of "specialist programmes to help our staff understand the special needs of elderly people who become ill" and by establishing a "system to improve collaboration between health professionals to ensure elderly people get the best care in the most appropriate place at the right time" (p. 14).

The *Health Services Framework for Older People 2009-2016* [13] states that "one of the key aims (of the Framework) is to strengthen the capacity of the whole health system to meet the health needs and support the wellbeing of people with cognitive impairment and dementia" (p.23)

The *SA Health Services Plan for People with Dementia (and Delirium) 2015-2018* is intentionally limited in scope compared with *South Australia's Dementia Action Plan 2009-2012* [14]. This was considered necessary to ensure the current plan translates into tangible changes that demonstrate health services are becoming dementia (and delirium) care competent.

Definitions – 'The 3 Ds'

This plan is focussed on the care of people with dementia; competence in the care of people with dementia must include competence in the identification of, care of, and management of people with two specific comorbidities, more likely to be seen in people with dementia. These are delirium and depression (often referred to as "The 3 Ds").

Delirium may go undiagnosed and untreated if clinicians mistake the signs and symptoms with those seen in a person with dementia. A person with delirium requires urgent medical attention and that is why reference to this condition is made (in brackets) throughout the plan. Readers should refer to the *Clinical Practice Guidelines for the Management of Delirium in Older People* [15] for further information specific to this medical condition.

The definitions in Table 1 provide a brief summary of "The 3 Ds". For further detail, the reader is referred to the *3Ds Delirium, Depression, Dementia* produced by the Ontario Ministry of Health [16]. The full technical definitions can be accessed in the *International Classification of Diseases version 10* [17] or the *Diagnostic and Statistical Manual of Mental Disorders version IV* [18].

Table 1 Recognising Dementia, Delirium and Depression[16]

	Dementia	Delirium	Depression
Definition	> Dementia is a gradual and progressive decline in mental processing ability that affects short-term memory, communication, language, judgment, reasoning, and abstract thinking. > Dementia eventually affects long term memory and the ability to perform familiar tasks. > Sometimes there are changes in mood and behaviour.	> Delirium is a medical emergency which is characterised by an acute and fluctuating onset of confusion, disturbances in attention, disorganised thinking and/or decline in level of consciousness. > Delirium cannot be accounted for by a pre-existing dementia; however, can co-exist with dementia.	> Depression is a term used when a cluster of depressive symptoms is present on most days, for most of the time, for at least 2 weeks and when the symptoms are of such intensity that they are out of the ordinary for that individual. > Depression is a biologically based illness that affects a person's thoughts, feelings, behaviour, and even physical health.

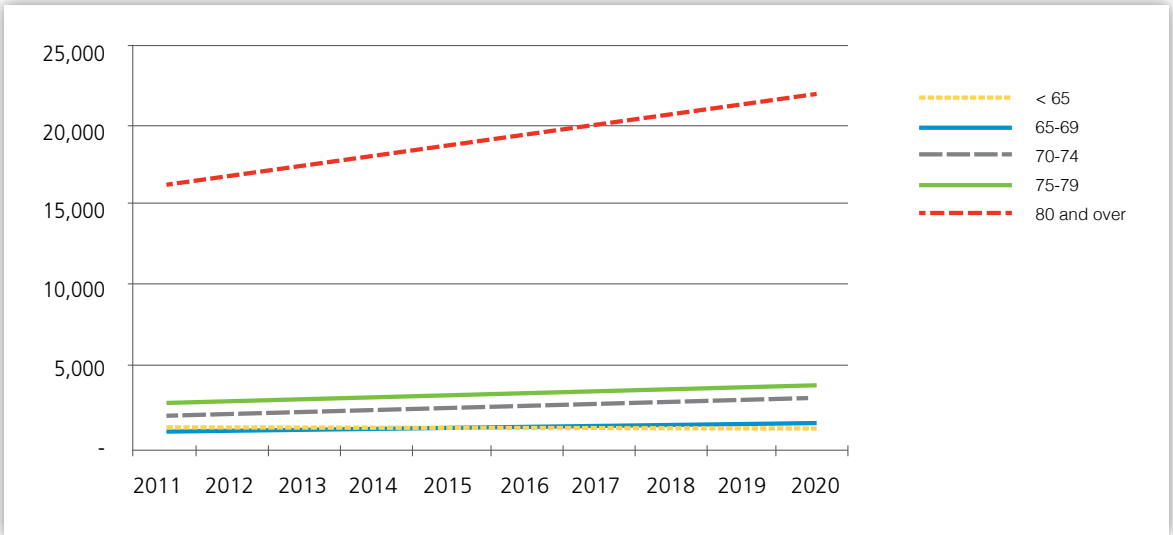
Cognitive impairment, a term often used in reference to dementia (and delirium), is an overarching term referring to deficits in one or more of the areas of memory, problems with communication, attention, thinking and judgement. Dementia (and Delirium) are common forms of cognitive impairment[7].

Dementia – the growing prevalence

In 2011, SA had the Top 3 of the Top 10 Federal Electoral Divisions with the greatest prevalence of dementia – No.1. Hindmarsh (2,940 people), No.2. Sturt (2,584 people) and No.3. Boothby (2,534 people) [19].

In 2013, SA was projected to have 25,533 people with dementia, by 2020 SA is projected to have 32,061 people with dementia. Adults of all ages can develop dementia, but dementia remains a low prevalence disease in people in their 40s, 50s and 60s. The substantial increases in prevalence are projected for people aged 80 years and over (Graph 1) [19].

GRAPH 1. SA dementia prevalence projections, by age category



Source: Deloitte Access Economics [19]

These projections have significant implications for demand for health services, given that people with dementia are known to have multiple morbidities [6] and people aged 80 years and over constitute only 5% of the population, but more than 25% of the overnight occupied bed days in South Australia [1]. As a consequence, demand for hospital inpatient services is highly sensitive to increases in the number of people aged 80 years and older.

Estimates indicate Aboriginal Australians have rates of dementia three to five times higher [20], with onset at a much younger age, than for non-Aboriginal Australians.

There is no national data, based on population surveys, available to measure the prevalence of dementia in Australia. Prevalence rates used in Australia are derived through meta-analyses (based on surveys conducted in other countries) and applied to Australian population data [21]. There is a need for a broad population study to measure prevalence and incidence of dementia, based on clinical diagnosis, in Aboriginal and non-Aboriginal Australians [21].

Implementation

SA Health and the LHNs are accountable for implementation of the plan. Success relies on the unrelenting enthusiasm of clinical leaders, and the support of organisational leaders, to implement changes that will improve health services for people with dementia.

SA Health will work with representatives of the LHNs to develop clinical guidelines and clinical pathways to support an efficient process of implementation.

Implementation relies on an understanding of the relationship between research, policy, planning and practice. There are substantial resources available, and under development, across Australia, which can be tapped into to support implementation [22-25].

Chapter 1. Consumer and Carer Expectations

GOAL – consumers with dementia (and delirium) and their carer(s) expectations will be met whenever they access SA Health's services.

> *"I think the reality of the (healthcare) system is that you get paid well if you stick something in, through or up someone but not if you think deeply about them"* [26].
>
> A/Prof Mark Yates, Geriatrician

It is evident, in the *Principles of Care*, that consumers and carers expect clinicians to think much more deeply about them, as individuals, with different needs and preferences.

The *Principles of Care*, that describe consumer and carer expectations, were developed under the guidance of the consumer and carer representatives on the Older People Clinical Network, in collaboration with the members of Alzheimer's Australia SA's Consumer's Alliance and Access and Equity groups.

The expectations of consumers and carers reflect the Principles of Dignity in Care [27] and the Principles of Care in the National Institute Clinical Effectiveness – Social Care Institute for Excellence Dementia Guideline [28]. Clinicians, administrative staff, security staff, catering staff, hotel staff, volunteers, managers, executives, planners and policy makers, your practice should reflect these Principles of Care, [27,28] each of which are of equal importance:

- Use language that is consistent with the *Dementia Language Guidelines* [29].
- Talk to a person with dementia and listen to a person with dementia, don't prejudge a person's level of understanding or capabilities. Use the *"Talk to me" Good communication tips for talking to people with Dementia* [30] pamphlet as a guide.
- A carer will contribute to the discussion about care, and you must include them, but talk to the person with dementia, don't assume they can't understand.
- Treat people with dementia and their carers with respect at all times.
- People with dementia will not be excluded from any services because of their diagnosis, age (whether designated too young or too old) or co-existing learning disabilities.
- Consumers and carers know that health services employ clinical and non-clinical staff with the required set of skills and knowledge to care for people with cognitive impairment/dementia.
- Zero tolerance of all forms of abuse.
- Provide the kind of support to people you would want for yourself or a member of your family.

- Treat each person as an individual by offering a personalised service.
  - Identify the specific needs of people with dementia and their carers arising from diversity, including gender, sexual orientation, Aboriginality, ethnicity and cultural and linguistic background, age (younger or older), religion, spirituality and personal care. Care plans should record these needs and services should respond to these needs.
  - Identify the specific needs of people with dementia and their carers arising from ill health, physical disability, sensory impairment, communication difficulties, and problems with nutrition, poor oral health, learning disabilities, level of health literacy and social and environmental vulnerabilities including poverty, homelessness and imprisonment. Care plans should record these needs and services should respond to these needs.
  - Identify and accommodate the person's language and if language or acquired language impairment is a barrier to accessing or understanding services, treatment and care, staff should provide the person with dementia and/or their carer with:
    - Information in the preferred language and/or in an accessible format
    - Independent interpreters
    - Clinical assessment and psychological interventions in the preferred language.
- Enable people to maintain the maximum possible level of independence, choice and control.
- Read, recognise, respond to and respect a person's wishes as they have documented in their Advance Care Plan.
- Listen and support people to express their needs and wants.
- Respect people's privacy.
- Ensure people feel able to complain without fear of retribution.
- Engage with family members and carers as care partners.
- Assist people to maintain confidence and a positive self-esteem.
- Act to alleviate people's loneliness and isolation.
- Communicate respectfully and honestly about end of life
  - Talk openly to the person about the fact that dementia is a terminal illness.
  - Support the person to plan for their end of life, to ensure their wishes are documented and understood by their family, friends and carers, including their wishes for palliative care.
  - Talk openly to the person, their family, friends and carers if you believe the person is dying and ensure they have access to palliative care services.
  - Provide dignified support to the dying person and their family, friends and carers at the time of death and following death, which reflects their wishes and cultural and spiritual needs.

The National Safety and Quality in Health Service Standard 2 – Partnering with Consumers[31] should be used as the lever for implementation of the changes required to meet the expectations of consumers and carers.

Recommendation	Implementation
1. The LHNs provide care that is consistent with the Principles of Care, as documented by consumers and carers of people with dementia.	Consistent with the National Safety & Quality Standard 2 – Partnering with Consumers [31], there is evidence that dementia specific / appropriate patient and carer surveys are undertaken, changes made as a result of the findings and reported on annually to the LHN's executive.

Chapter 2. Dementia (and Delirium) Care Competent Workforce

GOAL – Consumers and carers know that health services employ clinical and non-clinical staff with the required set of skills and knowledge to care for people with dementia (and delirium).

The Problems

1. A workforce (professional, clinical, and administrative) that is inadequately skilled and knowledgeable in the care of people with dementia (and delirium) in hospital and health services.

   "I have just had someone in hospital and the staff were not trained on how to deal and work with a person with dementia" [32] *(p.58).*

2. Failure to provide a widespread culture of care according to the Principles of Care (Refer to Section A).

   "Humanness, friendly smile and 'are you ok'? This is driven by the culture of the organisation, not accreditation. Get back to basics" [32] *(p.11)*.

3. Gaps in the multi-disciplinary specialist workforce, including Nurse Practitioners.

4. The lack of a systematic program of education, training and expected level of competency of the workforce in the care of people with dementia (and delirium).

   "There is a pressing need to introduce life-course perspectives and age-friendly principles into all health-related curricula to ensure that both present and future health professionals have the skills to respond to the challenges, requirements and opportunities of the ageing population. Most training for health and allied professions is still based on 20th century healthcare needs. There remains an overwhelmingly strong focus on child and maternal health within that training, yet in reality it is issues relating to older people that most health care professionals are increasingly encountering in their day-to-day working lives. Not only does this situation mean that an opportunity to deliver best practice is being missed, but the skill and knowledge deficit can lead to significant professional dissatisfaction. This leads not only to frustration and rejection but also to potential misdiagnosis and malpractice. One of the important causes of morbidity and mortality in older age continues to be iatrogenesis."

   Alexandre Kalache SA Government Thinker in Residence 2013 [32]

Alexandre Kalache's observation, made in 2013, is consistent with the July 2004 'Statement of Intent' that the "Australian Government and state/territory governments commit to ensure that the generalist and specialist health and aged care workforce have the key competencies necessary to meet the specific needs of older people" [34]. This Statement of Intent was matched with the 'Action and milestone' that "By 30 June 2007, jurisdictions will agree on the workforce roles, tasks and competencies required to successfully deliver effective care to older people" [34]. Now that it is 2014, there is an urgent requirement to act.

The Response

As the largest employer of health graduates in the state, SA Health needs to have confidence that South Australia's universities deliver curricula in undergraduate clinical degrees that produces graduates who can demonstrate the required level of competency in the care of a person with dementia (and delirium).

Given many of SA Health's staff receive their under-graduate education at universities outside of South Australia, and the requirement for ongoing professional development, employers need to provide access to ongoing training to ensure their employees can demonstrate clinical, communication and team based competencies in the care of people with dementia (and delirium).

Excellent resources exist, and could be utilised, in developing and implementing an efficient state-wide approach to education and training. These include, but are not limited to, the Commonwealth government funded Dementia Training Study Centres (SA & NT) [35], delivered through Alzheimer's Australia SA and the University of Tasmania/Wicking Institute's Massive Open Online Course 'Understanding Dementia' [36], a free, nine week, fully online course.

For the past five years, The Queen Elizabeth Hospital, and more recently as Central Adelaide – Local Health Network, in collaboration with Alzheimer's Australia SA, has held a *Mindful of Dementia Day* to raise awareness and champion a culture of care that is respectful and dignified. People with Dementia would benefit from such events being held in all LHNs.

Recommendations	Implementation
PRIORITY RECOMMENDATION 2.1 Each LHN to hold an annual dementia awareness event, such as the Central Adelaide LHN's Mindful of Dementia Day.	An education/awareness event is held each year in each LHN.
PRIORITY RECOMMENDATION 2.2 SA Health, to support the formation of a collaboration, to examine the current and future state of education and training. The future state will describe the reform required to ensure graduates of clinical degrees and practicing clinicians have the skills, knowledge and experience to undertake the clinical, communication and team based competencies in the care of people with dementia (and delirium).	The collaboration is formed, the current state of education and training is examined and implementation of a plan for the future state of education and training is commenced. The collaboration to include consumer and carer representatives, LHN leaders in education, leadership teams of the LHN Area Geriatric Services, Alzheimer's Australia SA, the Dementia Training Study Centre (SA & NT), Prison Health and other key stakeholders.

Chapter 3. Memory Diagnostic Service

GOAL – Consumers and carers have timely access to an adequately resourced face-to-face or telehealth specialist Memory Diagnostic Service, through referral from their General Practitioner.

The Problems

1. The Commonwealth Government's Parliamentary inquiry into dementia: early diagnosis and intervention [26] reported that there is a low level of knowledge, understanding, awareness and acceptance, and an enormous amount of stigma and fear associated with the disease of dementia in the community.

   "Without awareness of people in the community, awareness of families, awareness of people with dementia themselves, awareness amongst health practitioners, then we will not get timely diagnosis, we will not get referral we will not get good management, we will not get services that are required and we are not going to get people attending to… enduring power of attorney and enduring guardianship, advanced care directives, speaking to palliative care. That is number one, awareness" [26].

   Thinking Ahead Report – Prof Henry Brodarty (p.35).

2. Knowledge, awareness and confidence of General Practitioners (GPs) to identify, assess, diagnose and/or refer the person to a specialist.

   "The Royal Australian College of General Practitioners recognises the need for ongoing professional training for General Practitioners to improve knowledge and confidence in early diagnosis and management as well as awareness of available support services" [26] *(p.53).*

3. The health system does not meet the needs of Aboriginal people and culturally and linguistically diverse people with dementia.

   "Country heals people, it is their medicine" [32].

4. Often it will be a carer/family member who seeks assessment for the person who is suspected of having dementia. There is no Medicare Benefits Scheme (MBS) item for carers or family members to consult with a GP or other practitioners about an individual they are concerned with regarding cognitive issues [26].

5. There is inadequate service coverage across Country Health SA.

The Response

The *Thinking Ahead Report*[26] on the inquiry into dementia: early diagnosis and intervention makes 17 recommendations for consideration by the Australian government, many of which refer to the need to improve the education of and access to GPs.

The General Practitioner is likely to be the first point of contact for someone with memory loss. If the GP is not competent to make a diagnosis and provide ongoing care and management of the person, they need to be able to refer the person to a Memory Diagnostic Service.

It is proposed that each metropolitan LHN has a Memory Diagnostic Service:

- Whose workforce and work processes demonstrate a commitment to the Principles of Care (covered in Chapter 1. Consumer and Carer expectations);
- Which reflects consumer directed care by providing information and education about Advance Care Directives;
- A workforce which is part of the LHN's Area Geriatric Service, including specialist medical, nursing and allied health (must include Neuropsychologists) staff;
- A process of triage to ensure timely access to the service according to need and a system of capturing and reporting waiting time according to assigned priority;
- That meets the needs of younger and older people with memory loss, and is accessible by people who live in residential aged care, people serving long term custodial sentences, people who are homeless and people who are unable to leave their house;
- An effective working relationship with Cognitive Neurologists, Psychogeriatricians, Dementia Behaviour Management Advisory Service staff and Alzheimer's Australia-SA Dementia Link Workers; and
- An effective working relationship with the research based Memory Trials Service.

The development of comprehensive LHN Memory Diagnostic Clinics creates an opportunity to collaborate with local General Practitioners to improve identification, care and management of people with dementia. Such collaborations should promote practice that is consistent with the Principles of Care.

The metropolitan Memory Diagnostic Services will need to provide an outreach service to (larger) country health services, making use of telehealth for assessment, diagnosis and ongoing care, to ensure there is state-wide access to a specialist service. This will require consideration of workforce and funding models.

Recommendations	Implementation
PRIORITY RECOMMENDATION 3. SA Health, with representation from the LHNs, to develop a state-wide model of care for the LHN based Memory Diagnostic Service.	LHNs can provide evidence that their Memory Diagnostic Service is provided according to the SA Health endorsed state-wide model of care.

Chapter 4. Communication Within and Between Services

GOAL – consumers and carers observe and participate in communication, between staff of different health services and between staff of the same health service, which reflects what is important to them.

The Problem

Communicating important information about a consumer from one health service to another has been a longstanding problem. It is a problem that information is not provided and it is a problem when information is provided, but it is not read or listened to by the receiver. People with dementia, by nature of their illness, cannot compensate for failed communication by service providers. As a result, when communication between services is ineffective, people with dementia are at greater risk of poor health outcomes.

> *"The right hand does not know what the left hand is doing"* [32] *(p.23)*.

> *"As a carer I had a lot of information that I shared with the (organisation) but they were not interested; never took it on board"* [32] *(p.27)*.

The Response

Health services are required to communicate within and between services according to National Standard number 6: Clinical Handover [31]. The Standard requires each health service to have documented policy, procedures and/or protocols with agreed tools and guides. The Standard also requires that these are reviewed and evaluated. Given the significant proportion of people in SA Health's services with dementia (and delirium), and the increased risk, if clinical handover within and between services fails for these vulnerable people, each service should review their handover policies to ensure they address the needs of people with dementia (and delirium).

In 2014, SA Health released the Policy Guideline *Transfer of Individuals between Public Health Services and Residential Aged Care Services* [37] for use by LHNs to guide practice.

Local Health Network policies must apply to all service providers within and between services, including:

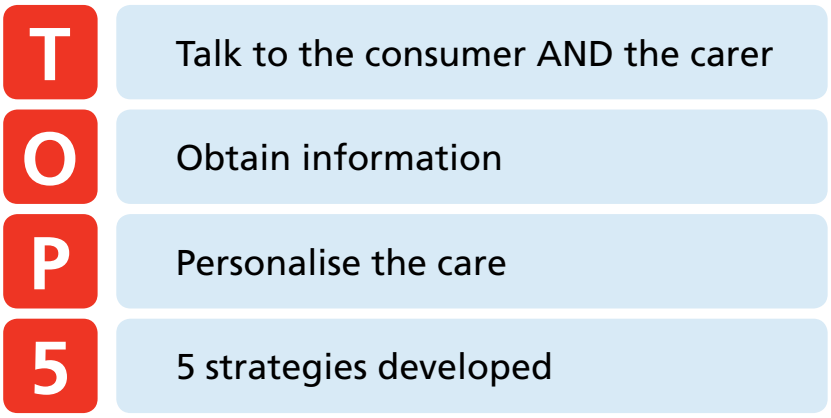
- General Practitioner;
- Pharmacists;
- Aged care providers – community and residential;
- Community service providers;
- Dementia Link Workers;

- Dementia Behaviour Management Advisory Service;
- South Australian Prison Health Services;
- South Australian Ambulance Service; and
- Hospitals (internal and external communication).

The most important message to communicate within and between services, and so at every clinical handover, is that which is important to the consumer and carer. The Standard for clinical handover [31] requires organisations to establish mechanisms to include patients and carers in the clinical handover process. The *TOP5 Tool* [8] was developed by the Central Coast Local Health District in NSW, as a tool for use in the transfer of care and as a tool to promote service providers to talk to the consumer and carer about what is important to them.

It is valuable for use by all consumers of health services and particularly so for people with cognitive impairment, who may not be able to communicate the things that matter most to them, but may have a spouse/carer who knows many things about the person that will guide care.

The *TOP5 Tool* [8] reminds service providers to:



The *TOP5 Tool* [8] is of value because:

- It is in alignment with the Principles of Care (Chapter 1), particularly these three Principles.
  - Use language that is consistent with the *Dementia Language Guidelines* [29].
  - Talk to a person with dementia and listen to a person with dementia, don't prejudge a person's level of understanding or capabilities. Use the *"Talk to me" Good communication tips for talking to people with Dementia* [30] pamphlet as a guide.
  - Engage with family members and carers as care partners.
- It can be implemented by any organisation, within or external to SA Health, including aged care providers, community service providers and general practice, and may be promoted through Primary Health Networks.

- It's use is supported by Alzheimer's Australia and the NSW Confused Hospitalised Older People program [24].
- The tool is very simple to use and can be read in minutes.
- The tool is not designed to capture all information, but that which is important to the consumer/carer, importantly it starts and hopefully continues communication between consumer/carer and service providers.
- The tool is unlikely to duplicate existing processes of documentation.
- The tool could be used to raise awareness of other important pieces of information (ie I have an Advance Care Directive; please ensure my care is in alignment with my documented expectations).
- The tool could be used to increase awareness about language and cultural beliefs – these matters are of great importance to the consumer/carer – but often not provided much attention by health services.
- The tool could be used to highlight services the consumer is receiving ie Domiciliary Care, RDNS, Home Care Package, council home help etc.

Being accountable for communication, within and between services, that is consistent with the National Standard 6: Clinical Handover, and implementation of the *TOP5 Tool* [8] will contribute to the significant cultural and practice change required to achieve "person-centred" care.

Recommendations	Implementation
4.1 The LHNs review their clinical handover policies to ensure they address the needs of people with dementia (and delirium).	Consistent with the National Safety & Quality Standard 6 Clinical Handover [31], LHNs are able to provide evidence of implementation of a clinical handover policy that addresses the needs of people with dementia (and delirium).
PRIORITY RECOMMENDATION 4.2 Each Local Health Network will identify an Executive Sponsor who will be accountable for the implementation of the *TOP5 Tool* [8] within the geographical catchment of their Local Health Network.	The Executive sponsors within each geographical area work with existing Networks, and the Office for the Ageing, to support implementation of the *TOP5 Tool* [8].

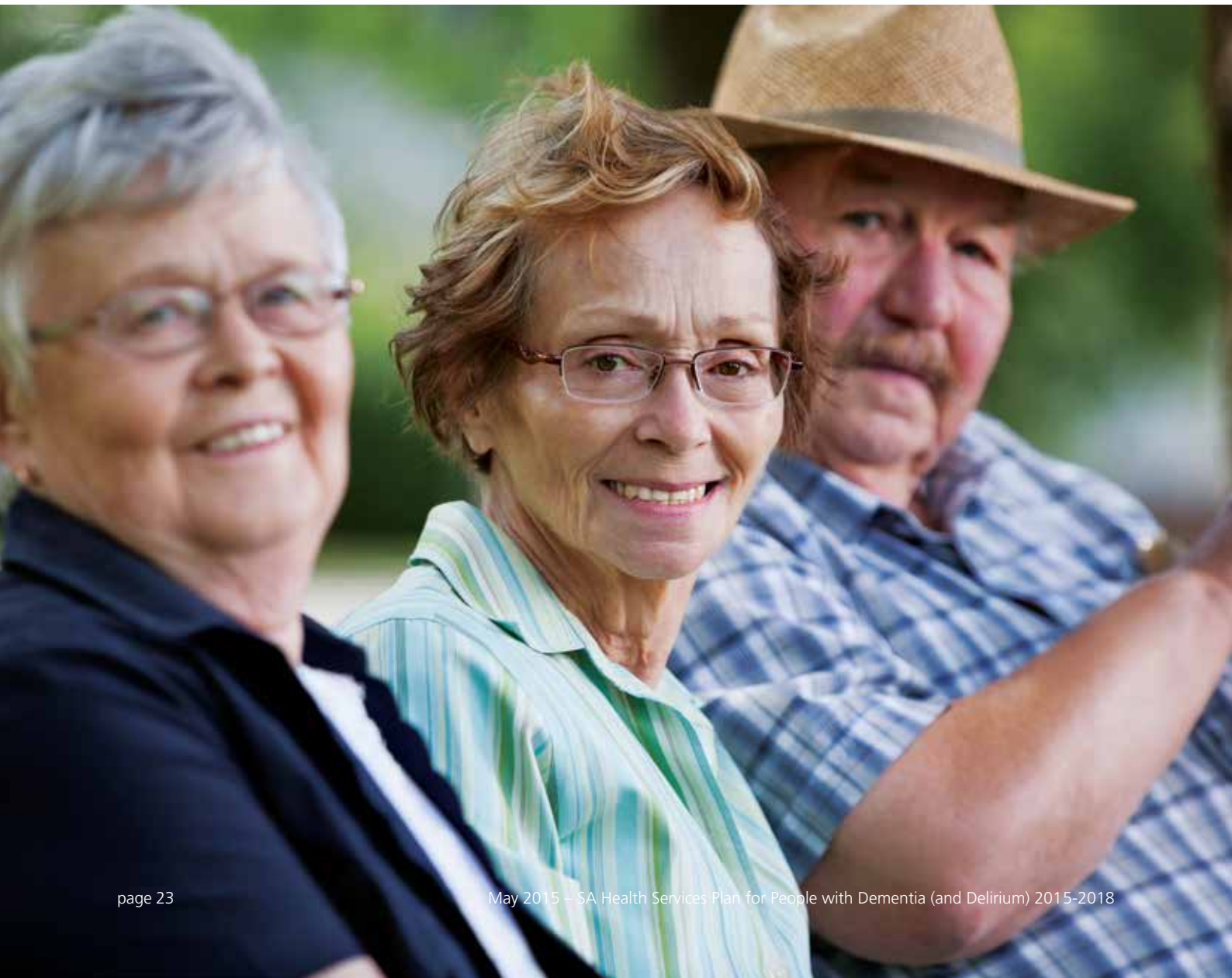
Chapter 5. Hospital Avoidance and Hospital Substitution

GOAL – Consumers and carers have appropriate access to hospital avoidance and hospital substitution services regardless of where they reside in South Australia.

The Problems

> *"Patients with cognitive impairment admitted to hospital are at a significantly increased risk of preventable complications and adverse outcomes"* [7].

Hospitals are not well-designed or staffed to care for people with dementia. As a consequence, people with dementia are more likely to have poor outcomes, associated with increased length of stay and increased costs, when hospitalised [6]. For these reasons, people with dementia would benefit from access to hospital avoidance and hospital substitution services.



In South Australia, existing hospital avoidance and hospital substitution services do not necessarily target, nor are they generally designed to meet the needs of people with dementia. As a result, there are many occupied beds days in South Australia's major and general hospitals accounted for by people whose needs would likely be better met by health services provided in their own home (including those living in Residential Aged Care Facilities and those living in SA Prisons).

Dementia is a terminal illness, and in the advanced stages of the disease, transfer to an acute hospital is likely to result in the person with dementia receiving medical interventions that may cause distress and discomfort, when palliative care services provided at home (including Residential Aged Care Facilities and SA Prisons) would be appropriate, respectful and dignified.

The Response

Local Health Networks currently provide hospital avoidance and hospital substitution programs; these programs require review and redesign to ensure they meet the needs of people with dementia.

Recommendation	Implementation
5. The LHNs review current hospital avoidance and hospital substitution services to ensure they meet the acute care and palliative care needs of people with dementia.	Activity data, which demonstrates the provision of hospital avoidance and hospital substitution services for the acute and palliative care needs of people with dementia, is recorded and reported to the LHN's executive.

Chapter 6. Dementia (and Delirium) Care Competent Hospitals

GOAL – Consumers and Carers know they can access care in a hospital that meets the National Safety and Quality Health Service Standards for the care of people with cognitive impairment.

The Problems

A large proportion of people in South Australian hospitals, distributed throughout all wards and departments of the hospitals, have dementia (and delirium).

According to the Australian Commission on Safety and Quality in Health Care, nearly one in three people over 70 years of age admitted to hospitals will have some form of cognitive impairment, approximately 20% of these will have dementia, 10% are admitted with delirium and a further 8% will develop delirium during their hospital admission [7].

> *"Patients with cognitive impairment admitted to hospital are at a significantly increased risk of preventable complications and adverse outcomes. This increased risk is often associated with deficits in one or more of the areas of memory, problems with communication, attention, thinking and judgement. For these patients, adverse outcomes include being twice as likely to fall and experience pressure injuries, being readmitted to hospital and having longer length of stays. The preventable complications for these patients include urinary tract infections, sepsis and significant functional decline. They are also three times more likely to die in hospital than patients without cognitive impairment"* [38] *(p.4).*

The Standard

The Australian Commission on Safety and Quality in Health Care explains …[7] (p. 11).

What implementing the safety and quality pathway for people with cognitive impairment (dementia and delirium) in hospital means to the:	
Person with cognitive impairment	> When I go to hospital, my cognitive impairment is recognised and responded to. > My management plan is tailored to my needs and is delivered in a way that protects my dignity. > My care is provided in a safe, supportive and culturally appropriate environment.
Carer	> I am supported and recognised as an active participant when decisions are made about possible causes of cognitive impairment and the management plan for the person I care for. > I am encouraged to be an active partner in care.
Whole of hospital workforce	> I am aware of cognitive impairment and can respond to patients' additional communication, orientation and support needs. > I understand the safety and quality risks for patients with cognitive impairment and I know I can act to make a positive difference to patient outcomes. > The system supports me to provide the right care to patients with cognitive impairment.
Health Service Manager	> I ensure that systems and resources are in place to recognise, communicate and respond to the needs of patients with cognitive impairment, their carers and clinicians, to improve patient outcomes and their experience of care. > I ensure that the facility is designed to support the needs of patients with cognitive impairment.
Health System	Mechanisms are in place to: > Include cognitive impairment in safety and quality programs. > Convey to clinicians and healthcare staff the importance of recognising and responding to cognitive impairment, treating patients with dignity and partnering with carers and families. > Support the delivery of high-quality care to patients with cognitive impairment. > Promote the use of hospital substitution and community-based services for patients with cognitive impairment, and their carers and families, where appropriate. > Improve the safety and quality of care for patients with cognitive impairment by ongoing monitoring, evaluation and change processes. > Use nationally consistent coding systems for patients with cognitive impairment. > Record and monitor the incidence and prevalence of patients with cognitive impairment.

The Response

The LHNs undertake an annual audit of the hospital environment to understand, document, measure and monitor how the environment is suitable for people with dementia (and delirium) and where the environment needs to change [9]. Ensuring these changes are prioritised and documented on the hospital's capital works list. Planning for new facilities and the auditing of existing facilities should include strategies to maximise the efficient and therapeutic use of technological innovation.

SA Health, with the LHNs, develops a *Dementia Care Competent Clinical Pathway,* which supports implementation of the Australian Commission on Safety and Quality in Healthcare's *"A better way to care – Safe and high-quality care for patients with cognitive impairment (dementia and delirium) in hospital"* [7,39,40].

The pathway to include:

- The culture of care required to deliver health services according to the expectations of consumers and carers.
- Entry and access to Hospital Avoidance and Hospital Substitution services that meet the needs of people with Dementia.
- How confusion is identified, investigated, treated and appropriately managed in the Emergency Department and on the wards.
- Reference to the Clinical Practice Guidelines for the Management of Delirium in Older People [15].
- The minimum standard of practice in the discussion and documentation of care of confused people – at admission, in interdisciplinary meetings, at handover and at discharge.

Recommendations	Implementation
6.1 The LHNs undertake an annual audit of the hospital environment [9] (including plans for redevelopments and new patient accommodation) to understand how it meets the needs of people with dementia (and delirium).	There is evidence of an annual audit and evidence that changes are made or requested in response to the findings of the annual audit.
PRIORITY RECOMMENDATION 6.2 SA Health, with representation from the LHNs develops, endorses and implements a Dementia Care Competent Clinical Pathway for use across SA Health's services.	Consistent with the Australian Commission on Safety and Quality in Healthcare's *"A better way to care – Safe and high-quality care for patients with cognitive impairment (dementia and delirium) in hospital* [7,39,40]. LHNs can provide evidence of implementation of an SA Health endorsed Dementia Care Competent Clinical Pathway.

Chapter 7. Recording Hospital Activity

Goal – every patient with diagnosed dementia will have that diagnosis documented as a principle or additional diagnosis on their discharge summary to ensure it is captured accurately by the clinical coder.

> *"The complexities of accurately coding dementias will impact upon planning for future treatments and service provision and will have a flow on effect for patients, hospitals and patient care in Australia"* [41].

The Problems

Australian Coding Standards [10] apply to every hospital in Australia and provide the clinical coder with guidelines and standards to aid in assigning ICD-10-AM [17] codes to all hospital separations. A patient can receive a Principal Diagnosis or an Additional Diagnosis of dementia. Identification and documentation of the Principal Diagnosis is the role of the medical practitioner and is usually written on the discharge summary or front page of the patient's admission notes. An Additional Diagnosis should be allocated when a patient's condition requires any of the following:

- Commencement, alteration or adjustment of therapeutic treatment
- Diagnosis procedures
- Increased clinical care or monitoring

Coders require evidence written in the case notes in order to apply an Additional Diagnosis of dementia. Just writing the person is "confused" or "cognitively impaired" is not adequate evidence, particularly for criterion three of the standard "increased clinical care and monitoring". The case notes must clearly state that the person required "increased clinical care and monitoring ***as a result of their dementia".***

As there is no standard practice for writing such comments, coders rely on more extreme evidence of additional care or monitoring, including the requirement for 1:1 close observation, use of restraint and evidence of Behavioural and Psychological Symptoms of Dementia. Clearly such evidence only captures a small proportion of people who have dementia and such evidence does not support the provision of competent care. Evidence of competent care would be documentation that additional time was spent with the person with dementia to support them to maximise their independence with eating, toileting, bathing and mobilisation and the provision of psychosocial support to reduce loneliness.

The application of coding practice would appear to be variable across South Australia's metropolitan hospitals (Graph 2 and 3). It would seem that variable coding practice may be due, at least in part, to the different interpretation of "increased clinical care or monitoring", including how that is measured and recorded.

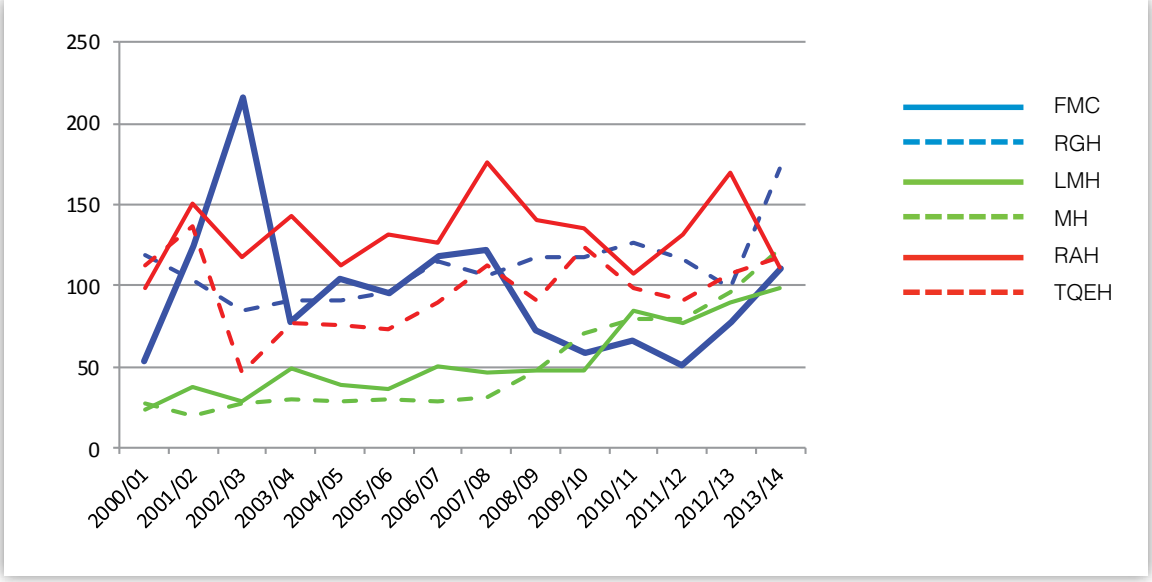
Additional Diagnoses are significant for the allocation of Australian Refined Diagnosis Related Groups. The allocation of a patient to a major problem or complication and co-morbidity Diagnosis Related Group is made on the basis of the presence of certain specified additional diagnoses.

The Response

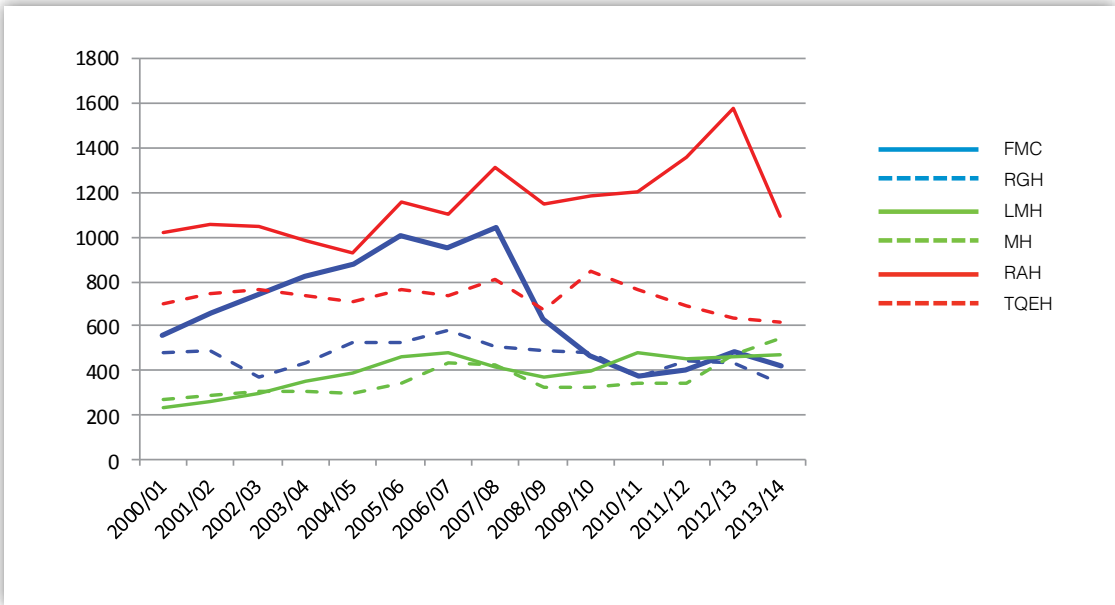
In the medium to longer term this can only be resolved through a revision of the coding standard, and SA Health will take the lead on making a submission to the Australian Consortium for Classification Development to review of the coding standard for dementia to ensure there is consistent practice in the coding of dementia as a Principal and Additional diagnosis.

In the short term, the LHNs need to ensure clinicians document clearly the additional clinical care and monitoring a person with dementia requires when they are in hospital and ***write that the additional care and monitoring is a direct result of the person having dementia.*** Local Health Networks should ensure this is discussed in interdisciplinary meetings, and the discussion should ensure the diagnosis of dementia is clearly recorded in the notes and the discharge summary, when it is appropriate to do so. All health care units should examine activity data reports (for people discharged with a Principle or Additional Diagnosis of Dementia) to ensure the coding of dementia reflects actual activity.

GRAPH 2. Separations with Dementia as a Principle Diagnosis (Metro)



GRAPH 3. Separations with Dementia as an Additional Diagnosis (Metro)



Source: ISAAC [42]

Recommendations	Implementation
7.1 SA Health to develop consistent practices for the coding of dementia as an Additional Diagnosis.	SA Health, to draft a protocol for endorsement by the LHN Chief Executive Officers and implementation by the LHN Health Information Managers.
7.2 SA Health to make the submission to the Australian Consortium for Classification Development [10] for a review of the coding standard for dementia.	SA Health, to make a submission to the Australian Consortium for Classification Development [10].

Chapter 8. Understanding Behaviour

GOAL – consumers and carers observe and experience care that demonstrates competence in the prevention and safe management of all symptoms of the disease of dementia

"All behaviour is communication" Tina Alonzo, Beatitudes Campus [43].

"The staff seemed to think his behaviour was his fault, that he was being difficult on purpose" Carer [44].

The Problems

Because a hospital can be a hostile environment for a person with dementia (and delirium), and people with dementia (and delirium) may have problems with communication, this may lead to a person expressing their escalating anxiety, agitation and aggression in the form of behaviour that is not well understood by those providing care. Behaviour is poorly understood because:

- There is a lack of understanding that dementia is caused by the degeneration of neurons and their connections within the brain which results in symptoms, which may include difficulty communicating or changes in behaviour, which are part of the disease of dementia.
- It is easy to label a person as having "challenging behaviours", without understanding, or being able to reflect on, how the level of communication and care provided may have caused or contributed to the behavioural response.
- It is easy to label someone as 'refusing care' or 'non-compliant', when the person with dementia (and/or delirium) may not understand what is being asked of them.
- It is easy to label a person as having "challenging behaviours" without having made it part of clinical practice to find out about the person and documenting in the case notes, reporting at clinical handover and through use of the *Top 5 Tool* [8], what is important to know about the person, including triggers for behaviour, obtained from both the person with dementia and/or their carer".
- It is easy to label a person as having "challenging behaviours", without understanding, or being able to know how to assess that the person with dementia has pain [45].
- It is easy to label a person as having "challenging behaviours" without understanding the person may be developing a delirium. Delirium is a medical emergency and occurs far more often in people with dementia.
- There is no standard approach to monitoring, documenting and intervening in the care of a person with increasing agitation. As a result the service response is sought when the situation has become extreme and is managed by "code black" (with an emergency team response).

- While the use of all forms of restraint has required mandatory reporting for people cared for under mental health services, the routine collection of these data for older people under the care of other specialities is not undertaken, nor is it mandatory.
- There are discipline approaches to care, when there needs to be collaborative 'person-centred' approaches to care, particularly between Area Geriatric Services and Older Persons Mental Health Services, as described in the Joint Position Statement between the Faculty of Psychiatry of Old Age of the Royal Australian and New Zealand College of Psychiatrists and the Australian and New Zealand Society of Geriatric Medicine [46].
- There is inadequate collaboration between health services and the Alzheimer's Australia-SA Dementia Behaviour Management Advisory Service.

The Response

Understanding dementia (and delirium) requires implementation of all of the recommendations of the plan; it requires building the Principles of Care (Chapter 1) into the culture of an organisation, effective communication and collaboration, awareness raising, education and training, a safe and appropriate environment, and the implementation of a Dementia Care Competent Clinical Pathway.

Four components of the Dementia Care Competent Clinical Pathway (recommendation 6.2) to include in the 'effective management' of a person with behaviour, which may be a symptom of their dementia (and/or delirium), include:

- Collaborative care between Area Geriatric Services and Older Persons Mental Health Services;
- Collaborative care with the Alzheimer's Australia-SA Dementia Behaviour Management Advisory Service;
- The use of a standardised tool to monitor, understand and respond to increasing anxiety, agitation and aggression; and
- Mandatory reporting of all forms of restraint.

These four components are linked. A person with increasing anxiety, agitation and aggression should be monitored with a standardised tool, if their behaviour escalates, despite interventions and advice from carers/family/friends, consideration should be given to seeking advice from the Older Persons Mental Health Service and from the Dementia Behaviour Management Advisory Service, and if escalating behaviour has resulted in the use of any forms of restraint, that must be documented.

Recommendations		Implementation
8.1	The Area Geriatric Services and Older People Mental Health Services collaborate in the care and management of people with dementia.	The LHNs can provide evidence that they have implemented the changes required to ensure their practice is consistent with the principles of the Joint Position Statement [43].
8.2	Clinical leaders maximise the use of, and work collaboratively with, the Dementia Behaviour Management Advisory Service to improve care, and report on use of this service.	Alzheimer's Australia-SA's Dementia Behaviour Management Advisory Service ***and*** the LHNs can provide evidence of use of the Dementia Behaviour Management Advisory Service.
8.3	A standardised tool and process to monitor and respond to people with increasing anxiety, agitation and aggression in health services is developed, agreed, documented and implemented in conjunction with a state-wide education and training program.	The LHNs have evidence of use of a standard tool and process to monitor and respond to people with increasing anxiety, agitation and aggression.
8.4	The LHN Safety and Quality units support the implementation of mandatory recording and reporting of chemical and physical forms of restraint for all consumers of health services.	The LHNs can provide evidence of mandatory reporting of restraint. The LHNs can provide evidence that their executive responds to the findings of the restraint reports.

Chapter 9. Respectful End of Life Care

GOAL – service providers will communicate respectfully and honestly about end of life and consumers can access care according to their wishes, cultural and spiritual needs.

"We are forgotten at the end of life" [32] *(p.30).*

The problems

Clinicians are taught to provide interventions; this results in many people with advanced dementia receiving treatments, which do not improve their quality of life, including use of feeding tubes, use of antibiotics and transfer to hospital.

This is due to:

- Poor health literacy, in the community and in health services, that dementia is a progressive, terminal illness [44] (p.60).

  "People with advanced dementia often do not receive adequate or appropriate end-of-life care. Pain is significantly under-diagnosed and under-treated" [44] *(p.60).*

- Fear of participating in difficult conversations means clinicians and policy makers perpetuate the mainstream use of euphemisms such as "life limiting illness".

  "It is very confronting at times. You need to confront it, not avoid it" [32] *(p.51).*

- Barriers to diagnosis mean people with dementia are afforded less time to plan for their end of life and relatives/carers/guardians may err toward intervention when this is not what the person would have chosen for themselves when they had capacity.

The Response

A respectful end of life refers to an experience, as sought by the consumer and carer, which reflects what the consumer and carer have planned for and represents what is important to them.

A respectful end of life should be delivered according to the wishes the person may have documented in their Advance Care Directive [47].

The pathway for end of life should connect to the model for Memory Diagnostic Service (recommendation 3), Guidelines for Clinical Handover and use of the *Top 5 Tool* [8] (recommendations 4.1 and 4.2) and the Dementia Care Competent Clinical Pathway (recommendation 6.2).

SA Health with LHN representation, to develop a Dementia Care Competent Pathway at End of Life.

The Dementia Care Competent Pathway at End of Life, to include:

- The culture of care required to deliver health services according to the expectations of consumers and carers.
- Identification of the stage of dementia and acknowledgement if the person is at the end of their life, and how that influences care the person wants (Advance Care Directive) and care offered.
- Access to palliative care for people with dementia living at home (including Residential Aged Care Facilities) at End of Life.
- Reference to the Dementia Care Competent Clinical Pathway.
- Use of a standard tool for monitoring and managing a person's pain.
- Identification of a person's Advance Care Directive as part of the admission process.
- Providing support to a person with dementia (and their responsible person) who would like to document an Advance Care Directive.
- Documentation of a Clinical Care Plan for End of Life for all people admitted to hospital who have dementia.
- Uploading the Clinical Care Plan for End of Life on to the person's My HealthRecord is part of the discharge process.

Recommendations	Implementation
PRIORITY RECOMMENDATION 9. SA Health, with representation from the LHNs, develops, endorses and implements a Dementia Care Competent Pathway at End of Life for use across SA Health's services.	The LHNs can provide evidence that health services are provided according to an SA Health endorsed Dementia Care Competent Pathway at End of Life.

Abbreviations

ACD	Advance Care Directive
AGS	Area Geriatric Service
DTSC	Dementia Training Study Centre
FMC	Flinders Medical Centre
GP	General Practitioner
LHN	Local Health Network
LMHS	Lyell McEwin Health Service
MH	Modbury Hospital
NSQHS	National Safety and Quality Health Service (Standards)
OBD	Occupied Bed Days
RAH	Royal Adelaide Hospital
RGH	Repatriation General Hospital
TQEH	The Queen Elizabeth Hospital

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Alzheimer's Australia SA Consumers Alliance & Access & Equity Groups

Interface Workgroup, Chaired by Dr Chris Bollen, with representation from all SA Medicare Locals

Area Geriatric Service – Older People Mental Health Service Interface Group, Chaired by Julie Harrison, with representation from each LHN

The 80 enthusiastic agents of change who attended the Dementia Forum consultation on 5 December 2013

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