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1 Forward

Dementia is a syndrome that most commonly affects older people with varying impact on their families and carers. Although dementia is not a natural part of ageing, after the age of 60 years the likelihood of living with dementia doubles every five years and it affects 24% of those aged 85 and over (Henderson & Jorm 1998).

Because Australia’s population is ageing, there has been growing recognition that dementia represents a significant challenge to health, aged care and social policy. The “Dementia in Australia” report (AIHW 2007) estimated that the number of people with dementia will grow from over 175,000 in 2003 to almost 465,000 in 2031, assuming that the age-specific prevalence rates for dementia remain stable.

Although there is a worldwide intensive search for interventions that will ameliorate the progression of dementia, the current challenge is to maximise the opportunities for care and treatment in an environment most suitable for the person with dementia and their carer. The importance of care provided in the community is undeniable in this context.

Most people with dementia are best managed in the community. A close partnership with the General Practitioner is important so that the person with dementia and their carer can feel safe and confident to live as independently as possible in the community.

Dementia impacts disproportionately on carers and family members associated with all aspects of care. The caring role is also a role that most carers in the community find very difficult to manage. Without adequate support of the carer and family, a person with dementia is at risk of premature admission to residential aged care.

Attendance at a hospital for a person with dementia and their carer can be a negative event and is best avoided if at all possible. The person most often presents at the emergency department of a hospital due to a medical emergency or exacerbation of a chronic illness or following the onset of an acute illness, and rarely for dementia itself. Often, dementia may go unrecognised in hospital especially if carers, General Practitioners and community service providers are not consulted. This often affects the care and discharge planning of the person with dementia whilst they are in the hospital system.

People who provide care to older people with dementia in the hospital environment need to be aware of their special care needs in what can be a bewildering and often hostile environment. If the person with dementia requires care in a hospital, they and the carer need to be assured that all care will be delivered in an age-friendly manner.

The “shared care” model is appropriate in the hospital setting for a person who has dementia. The person with dementia and their carer, treating medical practitioner, consulting geriatrician and other specialists, health professionals and significant others should all be involved in the co-ordinated and planned delivery of day to day care.

At the heart of the model is improved assessment of care needs and clear communication at every point along the continuum of care with a focus on “Person-Centred Care.” A determined effort is required by all care givers across all sectors to understand the particular care needs of the person with dementia and their carer as they confront the challenges posed by living with dementia on a daily basis.

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2 Recommendations

2.1 Recommendation One: Best Practice Frameworks

Adoption of:

- “Age – Friendly principles and practices” endorsed by Australian Health Ministers in July 2004 to ensure that health service environments are age-friendly and therefore dementia friendly (see Key References).
- “A guide for assessing older people in hospitals” endorsed by Australian Health Ministers in September 2004 (see Key References).
- “Best practice approaches to minimise functional decline in the older person across the acute, sub-acute and residential aged care settings” endorsed by Australian Health Ministers in November 2004 (see Key References).
- Royal Australian College of General Practitioners – Care of Patients with Dementia in General Practice – Guidelines (see www.racgp.org.au).
- The Royal Australian and New Zealand College of Psychiatrists - Relationships between Old Age Psychiatry and Geriatric Medicine (www.anzsgm.org/posstate.asp).

2.2 Recommendation Two: Community Care

Simplified access to information, eligibility, assessment, referral options and coordination of community care services.

2.3 Recommendation Three: Risk Screening, Assessment and Diagnosis

Facilitate early risk screening, assessment, diagnosis and management of dementia across the continuum of care.

Enhanced communication of the needs of the person with dementia and their carer across the continuum of care.

2.4 Recommendation Four: Geriatric and Aged Care Consultation and Liaison Services

Formalised access and partnership between General Practitioners, Geriatricians, Psycho-geriatric services and other specialist areas in relation to assessment and management of patients with dementia within the hospital system and in the community.

Strengthening of Geriatric and Psycho-geriatric services across the WA health system specifically for older people in rural and remote areas.

2.5 Recommendation Five: Discharge Planning

Hospital discharge care plans to address the needs of the person with dementia and their carer and be clearly communicated to the recipients of care, General Practitioners and community service providers for ongoing management.
2.6 **Recommendation Six: Older Person and Carers as Partners in Care**
- Carers and the older person with dementia to be provided with simplified access to information and education to assist them understand dementia and the support needs of the person with dementia.
- Continuing support of the Carers’ Recognition Act 2004 Western Australia

2.7 **Recommendation Seven: Workforce Education and Training**
- Staff providing services to people with dementia and their carers have access to workplace education and training.
- Dementia education to be included in appropriate curricula for undergraduate, postgraduate and technical & further education qualifications.

2.8 **Recommendation Eight: Legal Issues**
- Access to information on supported decision making and end of life issues including Enduring Power of Guardianship, Enduring Power of Attorney, Advance Health Directives and making of wills.
3 Overview

3.1 Scope and Purpose

The Aged Care Network with the support of the Aged and Continuing Care Directorate of WA Health, produced this document in collaboration with key stakeholders through the Clinical Advisory Committee, WA Aged Care Advisory Council and the WA Community Care Reform Advisory Group.

The primary purpose of this document is to provide health service environments and related services with a guide, to work towards best practice for improving and implementing dementia care services. This model of care aligns and builds on the National Framework for Action on Dementia 2006-2010 which has been formally adopted by WA.

3.2 Age Friendly Principles

In line with the overarching policy document Aged Care Network - Model of Care for the Older Person in WA ¹, the service delivery model of care for dementia is founded on the underlying “Age-friendly principles and practices – Managing older people in the health service environment” endorsed by the all Australian Health Ministers Council in 2004.²

These principles and practices in themselves require a consistent and sustained promotion across the continuum of care in order to achieve good care outcomes for people with dementia and their carers.

The model focuses on age friendly principles, best practice guidelines and the older person’s journey across the continuum of care. The model of care recognises:

- the emerging evidence for strengthening primary and preventative care in the community;
- the benefits of early detection and intervention;
- a more sensitive approach to the care of the person with dementia in the acute care setting;
- equitable access to flexible and appropriate care options for the person with dementia and their carer;
- the different cultural needs of the ATSI and CALD population groups; and
- the need for Geriatric, Psycho-geriatric and other specialist services for the person with dementia who has a pre-existing mental health condition and/or behavioural problems secondary to dementia.

Much of the evidence base for the Dementia Model of Care is based on the work commissioned by the Australian Health Ministers’ Advisory Council (AHMAC) and endorsed by all Australian Health Ministers at the Ministers’ Council Meeting in November, 2004.

¹ Model of Care for the Older Person in WA. Aged Care Network. Department of Health, WA, 2007
² Australian Health Ministers’ Advisory Council - Care of Older Australians Working Group, Victorian Government Department of Human Services, Victoria Australia, 2005

3.3 Definitions of Dementia

The International Statistical Classification of Diseases and Related Health Problems (ICD), 10th Revision (WHO 1991:312) defines dementia as:

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

Alzheimer’s Australia (2005b) defines dementia as:

“Dementia describes a syndrome associated with a range of diseases which are characterised by the impairment of brain functions, including memory, language, perception, personality and cognitive skills. The functional decline associated with dementia may manifest through different symptoms at various times and often relates to the cause of dementia. In the early stages of dementia, difficulty may be experienced with familiar tasks such as shopping, driving or handling money. As dementia progresses, more basic or core activities of daily living such as self-care (e.g. eating, bathing and dressing) are affected.”

There are over 100 illnesses and conditions that can result in dementia – a comprehensive list of these is included in the International Statistical Classification of Diseases and Related Health Problems (ICD), 10th Revision (WHO 1992a:312) and the Australian modification (ICD-10-AM) (NCCH 2002b). The most common types of dementia in Australia are:

- Dementia in Alzheimer’s disease, estimated to be responsible for around 50-70% of dementia cases;
- Vascular dementia resulting from significant brain injury caused by cerebrovascular disease;
- Dementia with Lewy bodies;
- Frontotemporal dementia;
- Mixed dementia in which features of more than one type of dementia are present.

There are also a number of less common types of dementia including:

- Dementia in Parkinson’s disease;
- Alcohol-induced dementia;
- Drug-related dementia;
- Head injury dementia;
- Other forms of dementia such as that developing in the course of human immunodeficiency virus (HIV) or Creutzfeldt-Jakob disease;
- Reversible forms of dementia such as dementia from B12 deficiency or hypothyroidism.

A definitive diagnosis of many of the diseases associated with the syndrome of dementia is often only possible after death, based on post-mortem examination of the brain, although serial magnetic resonance imaging (MRI) scans can assist with diagnosing some types of dementia. However, the syndrome of dementia is more amenable to diagnosis via a range of screening tests, assessment and diagnostic tools (AIHW 2007).
4 Drivers for Change

The following factors indicate the need for change and continued improvement in the delivery of dementia care.

4.1 Statistical Trends


Specifically the report:

- Predicts the number of Australians affected by dementia is expected to increase from 245,000 in 2009 to 591,000 in 2030 and again to 1.1 million by 2050.
- Highlights the importance of planning service delivery to ensure equitable access to dementia care for those outside capital cities, people from Culturally and Linguistically Diverse communities and those with younger onset dementia.
- Concludes dementia is on track to become the largest source of health and aged care spending.

- Dementia in Australia: National data analysis and development (January 2007) published by the Australian Institute of Health and Welfare is available at www.aihw.gov.au

The data demonstrates the ubiquitous nature of dementia by its prevalence across all types of primary diagnoses or as co-morbidity. This has implications for the management of people with dementia when they are in hospital, affecting their length of stay and recovery rates.

Whilst the ageing population will contribute to the large majority of new cases, the issues of those younger people with dementia should not be neglected.

4.2 National Initiatives

- In January 2005, Australian Health Ministers jointly agreed to the development of a National Framework for Action on Dementia 2006-2010 (the Framework). Developing the Framework has provided an opportunity to create a strategic, collaborative and cost-effective response to dementia across Australia.

- The Australian Health Ministers have identified five key priority areas for inclusion in the Framework: care and support; access and equity; information and education; research; and workforce and training.

The Framework was developed in consultation with people with dementia, their carers and families, the peak bodies that represent them, key stakeholders, and service providers, and represent a shared national vision for action on dementia.
Under the 2005 budget initiative, Helping Australians with Dementia, and their carers – Making dementia a National Health Priority (Dementia Initiative), the Australian Government funded several national projects including:

- Dementia Training Study Centres (DTSCs) in five locations;
- Dementia Collaborative Research Centres in three locations;
- Dementia Behaviour Management Advisory Services (DBMAS);
- Dementia Community Grants program;
- Dementia Research Mapping project;
- Dementia Services Pathways Project; and
- Dementia in Australia – national data analysis and development

Alzheimer’s Australia as a peak body launched the National Quality Dementia Care Network in 2009. The Network aims to promote collaboration between dementia care researchers, service providers and consumers with the objective of improving the quality of dementia care through the rapid dissemination and uptake of research evidence.

4.3 Western Australian Department of Health Programs

- WA Implementation Plan for Council of Australian Governments Long Stay Older Patients Initiative
- Friend In Need Emergency (FINE) scheme
- WA Subacute Care Plan 2009 -2013
- Home and Community Care (HACC)
- Aged Care Assessment Teams (ACATs)

4.4 Key Position Statements

- Australian and New Zealand Society for Geriatric Medicine
  Summary Sheet – Dementia as a Priority (last updated March 2010)
- A joint statement of the Faculty of Old Age of the Royal Australian and New Zealand College of Psychiatrists, the Australian and New Zealand Society for Geriatric Medicine: Relationships between Old Age Psychiatry and Geriatric Medicine (last updated March 2010)
  www.anzsgm.org/posstate.asp
- Care of Patients with Dementia in General Practice – Guidelines
  Royal Australian College of General Practitioners, NSW Department of Health 2003.
  www.racgp.org.au

4.5 Clinical and Workforce Trends

- Hospital based care can be a deleterious event for people with dementia and their carers. Age friendly hospitals and health service environments must be promoted.
- There is a need for risk screening and early diagnosis of dementia which may be super-imposed over depression, delirium, age-related cognitive decline and/or a
combination of these conditions. Early diagnosis of the type of dementia is an important factor in obtaining timely and appropriate care.

- Existing clinical data collection processes in relation to dementia impede the planning for services across the continuum of care.
- There is an increased need for Geriatricians, Psycho-geriatricians, Physicians and General Practitioners, especially in rural and remote areas, to diagnose and treat people with dementia and co-existing conditions.
- Greater capacity for nursing and allied health services to meet the multi-disciplinary care needs (in-patient and out-patient) of people and their carers who require specialist care related to dementia. This is particularly relevant where rehabilitation is an essential component of care.
- Residential Aged Care Facilities and community service providers have workforce issues in recruiting and retaining staff and volunteers with knowledge and skills required for dementia care.

4.6 Best practice standards

The following set of foundation documents are a benchmark to all health services, clinicians and general practitioners for the assessment of dementia and other related conditions that impact on activities of daily living and the ability to function independently.


4.7 Consumer Position Statement - Western Australian Communiqué

The Dementia Model of Care recognises the Consumer Position Statement developed by Alzheimer’s Australia WA Ltd on behalf of people with dementia and their carers in WA. The Model of Care has sought to incorporate the Seven-Point Action Plan for Change. These are:

- Promote and ensure greater public and professional awareness and understanding about dementia and risk education
- Improve the hospital experience for people with dementia
- Improve community support services
- Improve and increase services in rural and remote areas of WA
- Improve the well-being of carers
- Reduce the financial burden on carers and people with dementia
- Research better ways of providing services to people with dementia and their carers

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3 Alzheimer’s Australia WA Ltd. Western Australia Communique - Consumer Position Statement.
4.8 Identified Gaps in Service Delivery in WA – where are the improvements to be made?

The Aged Care Network Dementia Model of Care sub-group provided the following qualitative analysis of gaps in current service delivery and clinical practice across the health care sectors.

The following qualitative statements can be made:

- There has been no prior attempt in WA to develop a state-wide model of care to specifically address dementia care across the continuum of care.
- There is little systematic screening of cognition using culturally specific tools for ATSI or people from CALD backgrounds with dementia.
- Medical and nursing staff often have limited time, skills and training in managing patients with dementia and related challenging behaviours. The staff are often not aware of appropriate mental state assessments, differential diagnosis for dementia and appropriate behaviour management strategies.
- There is limited and inconsistent access to consultation, liaison and advice from Geriatricians and Psycho-geriatricians in the emergency department.
- Carers are frequently not included as partners in care.
- There is a need for culture change, continuing education, involving families and carers, particularly in the hospital setting.
- There is inadequate support in the community for people with dementia, particularly with respect to respite care and transport services.
- There is inadequate access to funded flexible care options for people with dementia to remain in the community when they need increase in complexity.
- There is inadequate access to intensive support services and residential care options for the person with dementia when the condition has reached a stage where they can no longer live safely and independently in the community.
- There is a high degree of difficulty for carers to access information and availability of services.
- There is inadequate data collection processes for inpatient and community based services.
- There is a lack of articulated policy for the treatment and management of older patients who have dementia and related mental health conditions of depression, delirium and behavioural or psychological symptoms both in the in-patient setting and management in the community.
5 Service Delivery Model of Care for Dementia

Objectives
In line with the Model of Care for the Older Person in WA\(^4\), the main objective of the Dementia Model of Care is to improve and strengthen service delivery to older people with dementia and their carers according to best practice approaches across the continuum of care.

5.1 Entering Old Age – staying well
- A focus on dementia as part of health promotion and prevention strategies designed to encourage older people to stay well longer and adopt health enhancement behaviours to minimise functional decline.
- Specific campaigns to increase community awareness and understanding of dementia.

5.2 Transitional Stage – staying at home
- Improving early diagnosis and management of dementia via GP training, best practice clinical guidelines and increased access to specialist services including those provided by Departments of Geriatric Medicine.
- A strong focus on enabling the person with mild to moderate dementia to remain at home for as long as possible by providing access to an array of flexible supports, programs and packages of care which also address the needs of the carer.
- Equitable access to existing Geriatric, Psycho-geriatric and other specialist consultation services to promote hospital diversion, rapid admission and assessment and early discharge for the person with dementia.
- Improve the quality of life for the older person, their family and carer.

5.3 Frail Aged Stage – staying out of hospital
- Increased provision and better co-ordination of ambulatory care with a focus on community case management of the person with dementia by multi-disciplinary teams linked to Departments of Geriatric Medicine and Psycho-geriatric services.
- Increased consultation and liaison with specialist services including Geriatricians and Psycho-geriatricians across all acute inpatient settings.
- Prevention of premature admission to residential aged care.
- Provision of accessible options for care at the end stage of dementia through enhanced discharge options by building partnerships, particularly with the Australian Government and the residential aged care sector.

\(^4\) Model of Care for the Older Person in WA, Aged Care Health Network, Department of Health 2007.
6 Care and Management of an Older Person with Dementia and their Carer Across the Continuum of Care

As the person with dementia and their carer traverse through the continuum of “entering old age” to “transitional stage” to “frail age” to “death”, they experience a pathway of functional decline associated with diagnosed or undiagnosed disease. This necessitates a concerted effort in the areas of prevention, health promotion and provision of increasing basic support needs to maintain optimum quality of life for the person with dementia and their carer.

Diagram below: Reflects the “Trajectory of total support required” in relation to the “Trajectory of normal functional decline in ageing”

Figure 1 “Trajectory of normal functional decline in ageing” and “Trajectory of total support required”.

On a continuum of “Well Aged” to “Transition” to “Frail Aged”, the older person is at increasing risk of adverse outcomes related to functional decline. Healthy lifestyle, a wellness approach, early identification of risk and illness, and early intervention with treatment and rehabilitative effort are needed as means to prevent functional decline and to maintain quality of life.

In the current community service profile it is Home and Community Care (HACC) that provides care and support at the earliest points along a trajectory of functional decline. Establishing a simplified access system into community care is a current imperative for HACC and other community based care.

This necessarily includes GP support and a focus on “informal” carer needs. The intent is to extend the time a person is “well-aged” and to slow functional decline.

Refocusing on the older person’s journey on a continuum of ageing informs us that exacerbation of chronic illness or onset of acute illness results in acceleration of functional decline, pulling the older person down from a normal ageing trajectory. This requires greater attention to the health needs of the older person and their carer that will draw from the following framework of service provision.
The challenge is to ensure that there is an integrated system of complex care services, layered over basic support services, that facilitates early detection, early treatment and care planning, that aims to maximise the older person’s return to their optimal functional status.

This requires access to an integrated suite of acute and rehabilitative care that includes aged care expertise and advice, and access to an array of ambulatory care services with supported primary care.

An older person who has suffered an exacerbation of chronic illness or onset of acute illness or an event (such as a fall), with a significantly increased risk of functional decline, and who is tracking a pathway through a hospital emergency department, admission and return to community, will benefit from the integration and linkage of services along this pathway.

When an older person is returning to the community after an episode or contact with acute care, both the Aged Care Assessment Teams (ACAT) (working in concert with Departments of Geriatric Medicine and allied health) and HACC play key roles enabling access to services and support based on assessed need.

ACAT and HACC services are significant components in achieving the aim of integration across the older person’s ageing trajectory and through any journey across acute services, rehabilitation and community that require assessment for and provision of support services in the community.

6.1 Primary Care in the Community

- Health promotion and prevention strategies

The overarching Model of Care for the Older Person in Western Australia advocates or a strengthening of services at the primary care level for older people that target health promotion, prevention and self-management strategies”. 5

The model recognises that as a person enters older age, a window of opportunity exists to capitalise on the high levels of independence, optimism and mobility that are characteristic of this population and introduce a range of health promotion and prevention strategies that maintain and extend the healthy ageing process well into later years.

The role of physical activity is important in arresting cognitive decline. Recent research indicates that population-wide health promotion strategies aimed at encouraging physical activity will need to “target specific strategies targeting baby boomers”. 6

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General Practitioner management

Since more than half of known cases of dementia are living in the community with mild to moderate dementia and mostly with the support of a carer, appropriate management and referral by the GP is very important. 7

There is currently no evidence of benefit to screening all older people who present without symptoms or a history relating to dementia.

However, since the GP is usually the “first port of call” for an older person when a medical issue requires attention, it is imperative that GP’s adopt the Royal Australian College of General Practitioners guidelines for “Care of Patients with Dementia in General Practice” available at: www.racgp.org.au

The GP also has the option of completing a comprehensive assessment and management plan for patients with early dementia, using the relevant Enhanced Primary Care Medicare Item.

In addition, the GP can perform the vital role of being a gateway to community-based services and providing information and education to the person with dementia and their carer.

GP referral to Specialists - Geriatrician/ Psycho-geriatrician / Neurologist/General Physician

The GP has the option of referring the person with dementia and their carer to a range of specialists such as a Geriatrician, Psycho-geriatrician, Neurologist, and/or General Medical Physician to assist in confirming the diagnosis, treatment, and ongoing management.

GP referral to Department of Geriatric Medicine and Aged Care Assessment Services

The GP has the option of referring the person with dementia and their carer to Department of Geriatric Medicine and Aged Care Assessment Service for further specialist assessment and allied health interventions that address the impact of dementia and related conditions.

The Aged Care Assessment Service is also able to assess for eligibility for more intensive support services funded by the Australian Government that are provided in the community or in a residential aged care facility.

GP referral to out-patient Memory Clinic Service

The GP and specialists have the option of referring the person with dementia and their carer to out-patient Day Therapy Units / Memory Clinics aligned with Departments of Geriatric Medicine. These clinics provide regular monitoring of cognitive decline and allied health interventions, access and referral to community care support services.

GP referral to community based Older Adult Mental Health Teams

The GP has the option of referring patients to the Older Adult Mental Health Teams (located throughout the metropolitan area and some WACHS areas) who provide a number of integrated, multidisciplinary, community and inpatient services to people with dementia and carers living in their own homes or residential care facilities who have mental health problems associated with or complicated by their dementia.

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7 57% of people with dementia live in the community. page 56, Dementia in Australia - National data analysis and development, Australian Institute of Health and Welfare, Canberra 2007.
GP referral to community based support services

The GP has the option of referring the person with dementia and their carer to services that provide information, psychological support, complex care coordination and services in the home to allow them to live as independently as possible in the community. Most people with mild to moderate dementia are able to live in the community, and most often with the support of a carer.

Referrals can be made to services provided by HACC, ACAT, Subacute programs, National Respite for Carers Program and services provided by organisations such as Alzheimer’s WA and Carers’ WA.

GP referrals from rural and remote regions

It will often be necessary for the GP in rural and remote regions of WA to seek specialist Geriatrician or Psycho-geriatric assistance in screening, assessment, treatment and management of patients with functional decline.

The GP’s in rural and remote regions can refer patients to regional Aged Care Assessment Team (ACATs) to assess eligibility to Australian Government funded services. ACATs also have access to visiting geriatrician and psycho-geriatrician services from metropolitan hospitals to facilitate further medical assessments.

In order to enable greater access to specialist geriatric services by GP’s in the rural and remote areas of WA, it is also possible to consider the use of telemedicine technology.

GP referrals to emergency departments

If a person with dementia and their carer has needs which cannot be met in the community, it may be necessary for the GP to refer them to the nearest emergency department as a last resort.

The GP should liaise with the emergency department and provide relevant health information to facilitate rapid assessment, treatment and management of the patient and their carer in the acute setting.

6.2 Entering the Acute Care Hospital System

The optimal environment for an older person with dementia (diagnosed or undiagnosed) who needs acute care is an age friendly hospital. For an older person and their carer, an “age-friendly” hospital is also a “dementia friendly” hospital.

6.2.1 Admission to the Emergency Department

Older person – Triage categories 3,4,5

The Eldercare Pathway\(^8\) risk screening is undertaken by Care Coordination Teams \(^9\) in metropolitan Emergency Departments (EDs). In WA Country Health Service (WACHS) regional hospitals, risk screening is undertaken by National Action Plan (NAP) Coordinators and/or nursing staff in EDs or following a direct admission to wards. Risk screening facilitates early identification of risk factors for further assessment as recommended by “A guide for assessing older people in hospitals.”

\(^8\) WA COAG Long Stay Older Patients Initiative Implementation Plan 2006 -2010
If there is a positive response to risk screening, further assessment may be undertaken to assist in the medical decision to either admit or safely and effectively discharge the patient from ED with relevant community supports. In WACHS, a referral for further assessment is made subject to the availability of resources.

If medically appropriate, the use of age-friendly Short Stay Units located in close proximity to EDs is encouraged during the screening and further assessment process.

- Older person – Triage categories 1,2

Where older people presenting to EDs have health conditions demanding prompt medical and/or surgical attention, risk screening and further assessment will usually occur after the acute intervention and the patient has been admitted to the appropriate inpatient medical/surgical ward. The relevant inpatient team with allied health input will then screen and comprehensively assess older patients for early identification and management of risk factors including dementia and related conditions which will contribute to the quality of care and minimise length of stay.

### 6.2.2 Admission to the Inpatient Setting

The management of a patient with dementia and their carer involves many key partners in the inpatient setting in a “shared care” model.

Depending on the primary diagnosis, patients who have been assessed as having possible cognitive decline will be admitted and may transition across different wards. As such, the care of the person with dementia occurs right across the hospital setting.

In this respect, many health professionals in different inpatient teams are charged with the responsibility of caring for the person with dementia and their carer.

#### The key partners in acute care include:

- The person with dementia and their carer as partners

The person with dementia and their carer should be included as partners in care with provision of information and education and clear communication. Carers’ observations of changing cognitive state and their familiarity with the older person with dementia will often be invaluable to the clinical team. Carers are also a significant resource in any strategy to manage the person with dementia.

The “Prepare to Care” program developed through Carers WA provides information and support for the carer aimed at assisting carers in the smooth transition from hospital to home[^10].

Assessment of the carer’s needs and the use of the tool to assess carer strain – Carer Strain Index - are important in allowing the person with dementia to remain living in the community as independently as possible.

- Treating consultant medical practitioner

The treating consultant/medical practitioner is ultimately responsible for the care of all inpatients and referrals for assessment and interventions. The medical plan is informed by numerous sources including the patient/carer, nursing, allied health and input from the GP and community service providers. The treating doctor also guides the consultation of other aged care specialists in assessing and managing dementia and related conditions in older patients.

Geriatric Consultation and Liaison Services

Geriatricians are best trained to manage and treat the majority of patients with dementia and their carers, but care will be shared with other specialists in the surgical and medical wards and general practitioners as the person with dementia transitions between different care sectors.

Within the hospital setting, consultation and liaison services are vital to extend the expertise of geriatricians where needed across all wards in a hospital setting. This particularly applies to patients who:

- have multiple co-morbidities including dementia;
- are frail;
- who may need rehabilitation;
- where the diagnosis of dementia is not clear; or
- where behavioural problems are significant.

At an organisational level and state-wide (with particular reference to W.A.C.H.S), it is essential to have a formalised, well developed system of access to geriatric expertise and assessment to provide timely consultations.

In tertiary hospitals, geriatric expertise may commence in Short Stay Units for older people and/or Geriatric Evaluation and Management (GEM) units. The main focus of these types of units is a comprehensive assessment and multi-disciplinary care plan that integrates the co-morbidity of dementia with the range of care needs required for the older person. The older person with dementia can also be identified and monitored at an early stage for access to rehabilitation in the hospital journey in such a facility. This approach will also assist in facilitating early discharge.  

The geriatrician not only provides specialist medical care for a range of geriatric conditions but also offers, by virtue of the approach taken by them, a comprehensive multi-disciplinary care approach that includes referral to inpatient sub-acute rehabilitation and care planning across the continuum.

This approach facilitates linkages and access to community care support services, residential care, out-patient based interventions (such as access to Day Therapy Units and Memory Clinics) and follow up with the general practitioner.

Psycho-geriatric Consultation and Liaison Services

Where behavioural problems are significant a Geriatrician may access the services of a Psycho-geriatrician on a consultation and liaison basis.

This is appropriate for patients who present with behavioural problems secondary to dementia and/or where there is difficulty in distinguishing between dementia, delirium and/or depression.

In tertiary and secondary hospitals, it may be appropriate to transfer patients to psycho-geriatric units with dedicated beds for ongoing inpatient care.

Rural and remote areas will have increased access to visiting geriatricians and psycho-geriatricians as well as consultation via tele-health.

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Nursing across the patient journey

Nursing is most often the first and most frequently present in patient care whether in EDs, in the inpatient settings, in restorative and rehabilitative care and in residential care.

Nurses are well placed to facilitate best practice “at the coalface” in the clinical processes of early identification of risk factors, baseline cognitive screening, promoting the foundations of essential care and adhering to clinical standards required for dementia care.

Allied Health across the patient journey

The value of allied health therapy for patients with dementia is well demonstrated through a number of randomised control trials.12 13

Allied health professionals working within inpatient multi-disciplinary care teams are able to act on referrals from emergency departments, treating doctors, general practitioners and nursing staff or adopt a case finding approach to identify older patients with cognitive decline for early assessment and management of dementia.

Allied health professionals in outpatient teams also provide a functional link to assist in continuity of care from the acute setting to the community as part of the discharge planning process.

The Pharmacist

The pharmacist should also be an integral part of care planning. Medication reconciliation and management across the patient journey is a central element of dementia care.

Personal Care Assistants

Personal Care Assistants are important partners in care across the hospital environment. They are often best placed to notice cognitive deficits as they provide patients with food and beverages, assist with showering and toileting, assist in manual handling into wheelchairs and bed trolleys and movement to and from wards, x-ray units and other trips for diagnostic and investigative procedures.

6.3 Returning to Primary Care in the Community

A coordinated transition to the community from a hospital environment is crucial. It is at this point where the person with dementia and their carer is most at risk as it can be a confusing and distressing time.

Optimal integration and communication of health and community care services is essential to achieve a seamless route to care in the community.

Discharge planning, assessment and referral to appropriate services become more complex when the co-morbidity of dementia is layered upon other conditions.

- The person’s medical needs;
- Functional capacity;
- Cognitive and social deficit care needs;
- Carer support needs; and
- Capacity of the service stream to deliver the assessed care needs.

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On the basis of an extensive international literature survey, the NICE – SCIE Guideline reports that patients and carers are not concerned as much with the type and/or range of services but more the quality of the relationship with service providers at every level of service delivery.\(^\text{14}\)

It is at the crucial interface between the hospital and the community that the quality of the relationship with the person with dementia and the carer will be tested.

### 6.3.1 Discharge Planning for People with Dementia and their Carers

Discharge planning should begin at the earliest possible time and preferably prior to admission. Ideally discharge planning will:

- be multi-disciplinary in focus in terms of assessment of the impact of dementia on functional independence and planning for appropriate services upon discharge that promote functional independence.
- be managed by a health professional with the responsibility to provide complex care coordination and trained/skilled in dementia care.
- require the person in charge of the discharge process to act as a liaison between the person with dementia and their carer, key hospital staff, Department of Geriatric Medicine, General Practitioner and community service providers.
- include a care plan developed and agreed to by the person with dementia and/or their carer which should be communicated to the GP and community service providers in a timely manner. The care plan will need to be reviewed on a regular basis especially with changing needs of the patient and their carer.
- incorporate a case management approach with designated responsibility for follow up after discharge is advocated, particularly for complex care clients. The NICE-SCIE Guidelines advocate for this approach as the evidence-based research suggests reduced carer strain, delayed entry into residential care and fewer admissions to hospital.\(^\text{15}\)
- have an emphasis on ambulatory care programs such as Hospital in the Home (HITH), Rehabilitation in the Home (RITH), Residential Care Line (RCL), and Day Hospital/Therapy Centres that provide care for the person with dementia in a secure and familiar environment.
- ensure capacity and readiness of community based services such as Home Settling Services, Short Acute Care, Community Nursing Care, Community Physiotherapy, Home Care Packages (HCP) and Home and Community Care (HACC).
- ensure ACAT approval, capacity and readiness for the provision of care via Australian Government funded community care options including Community Aged Care Packages, Extended Aged Care at Home - Dementia (EACH-D) packages, Transition Care Services and respite/permanent care in a Residential Aged Care Facility (RACF).
- ensure capacity and readiness of carer support and respite services based on assessed needs of the carer.


- ensure where appropriate, communication with the Older Adult Mental Health Team in the community occurs before discharge and in a timely manner.
- ensure that discharge occurs at an age-friendly time. Transfer of a person with dementia after hours including evenings and at weekends is not appropriate without adequate support services in place both for the person with dementia and their carer.
- ensure clear pathways of referral and communication processes between referral source and service providers.
- ensure follow up by the GP and/or relevant outpatient services within a prioritised timeframe based on identified risk factors and assessed care needs.
- ensure ongoing medical governance and complex care coordination by the appropriate service provider.
7 Specific Care Issues Relevant to the Person with Dementia and their Carer

7.1 Age-friendly Short Stay Units

Short Stay Units attached to EDs for rapid assessment of older people are variously termed in the literature and in practice. Some examples are Older Persons Evaluation Review and Assessment (OPERA), Emergency Medical Units and Short Stay Observation Units. The three main functions are:

- observation;
- specialist assessment and diagnosis; and
- short term high level management.

Such units have shown to be appropriate for the management and treatment of older people, particularly where the busy and confusing environment of an Emergency Department can be detrimental to an older person and their carer.

Short Stay Units integrates comprehensive geriatric assessment into the optimal medical and nursing care of patients in a multidisciplinary environment.

Tertiary hospitals in WA have a variety of Short Stay Units. These provide an age friendly environment for the patient/carer, multidisciplinary assessment, medical care review, pharmacological review and early discharge planning.

7.2 People Diagnosed with Early Onset Dementia

The Neurosciences Unit is part of the North Metropolitan Area Health Service and is located in Mt Claremont. It is a state-wide service, which provides specialised diagnostic support to hospitals and community based facilities (both private and public), as well as extensive services for families affected by neurodegenerative disorders such as Huntington's Disease and people with dementia and related disorders.

Services are provided by a multi-disciplinary team consisting of Neuropsychologists, Psychologists, Social Workers and Speech Pathologists. A Consultant Neurologist and Psychiatrist also provide sessional services to the Huntington's disease and early dementia program.

Children (over the age of 6) and adults (all ages) with a known neurological history such as brain impairment resulting from trauma, disease or genetic conditions can be referred.

A wide range of services are offered for families affected by Huntington’s Disease and other neurodegenerative disorders including predictive testing and ongoing welfare management. Referrals can also be made to the Neurosciences Assessment and Care Clinic for younger people (under 65 years) with possible dementia and related disorders.

7.3 Distinguishing Between the Four “Ds”

Optimal cognitive function is important for continued independence and yet changes in cognition are frequently unrecognised among older adults. It is often difficult to distinguish between the conditions of dementia, depression, delirium and age-related cognitive decline particularly in older people where they may be unable to communicate or express their experiences clearly.
In many health care settings, health professionals may have difficulty distinguishing between the four “Ds” particularly if they are not aware of or not sensitised to those conditions.

An incorrect diagnosis can impact on treatment (particularly with respect to pharmacological management) recovery, length of stay and the older person's quality of life.

A “ready reckoner” is useful for health care workers and professionals to assist in distinguishing between the four “Ds”.

7.4 Use of Culturally Appropriate Assessment Tools for Dementia

Development of clinical and care processes relevant to the needs of ATSI and CALD populations is vital. It is essential that culturally and linguistically accessible information be given priority when dealing with older people with dementia and their carers. The appropriate use of interpreters, translation of medical information, communication aids, liaison officers and close involvement with the family/carer is essential.

There are culturally relevant dementia assessment tools for both ATSI and CALD groups. The Kimberly Indigenous Cognitive Assessment tool (KICA) is a validated tool for use with ATSI patients and the Rowland Universal Dementia Assessment Scale (RUDAS) is a validated tool for use with CALD patients.

Indigenous Australians in the Kimberley region of WA have been shown to have a much higher rate of dementia than in the general Australian population. Such results demonstrate the need to focus on a targeted program for the early detection, care and management of dementia amongst the ATSI population, particularly in public health aged care programs and services.

7.5 Rural and Remote Services

WA Country Health Service is faced with the challenges of distance, isolation, staff recruitment and retention, education and training, variable workloads and the inability to benefit from economies of scale.

Issues relating to equity of access, coverage and variable quality are common characteristics of services that are available for the care and management of people with dementia and their carers in rural and remote regions of WA.

The key issues are:

- Variability in General Practitioner coverage, particularly where people in rural and remote areas are reliant on the GP as the only visible presence of health care;
- Variability in GP services and varying levels of awareness and knowledge relating to assessment and screening techniques for cognitive decline;
- Access to specialist services, particularly the coverage and frequency of publicly funded Geriatrician and Psycho-geriatric services;
- Access to specialist investigations and access to specialist follow-up and referral;
- Variable coverage of dementia respite care services in the community;

16 Commonwealth Department of Health and Human Services 1996, Dementia Kit, Canberra: AGPS.
In use by the Cairns Integrated Mental Health Program – Consultation Liaison Team, Queensland Health.
Access to appropriate sub-acute care and allied health services that provide for multi-disciplinary care for the person with dementia and their carer;
Ability and resources to deliver dementia specific training on a regular basis; and
Access to dementia specific residential care services.

The implementation of the WA Subacute Plan 2009-2013, will address some gaps in services in WACHS. These include:

Day Therapy Units (DTU) in Geraldton, Albany, Bunbury and Kalgoorlie offering outpatient and outreach rehabilitation services;
Expansion of Northam DTU to include a Community Physiotherapy program;
Expansion of the Visiting Geriatrician and Psycho-geriatrician services.

WACHS has developed a multi-modal comprehensive training/education package based on age friendly principles targeting health professionals in the acute care and community sectors. The Trainers’ Guide and Materials includes templates for all the administration and promotion of the training sessions which were branded under the title: “SPECIAL care for Older People”, using SPECIAL as a mnemonic to represent each of the seven Age Friendly Principles (Community West, SPECIAL Care for Older People, 2009).

The WA Aged Care Advisory Council which reports to the Minister for Health has recommended the use of the training package as a state-wide resource.

7.6 Palliative Care

For the person with advanced dementia and their carer, it is of significant benefit to implement a palliative approach that incorporates ongoing assessment, attention to distressing symptoms and avoidance of hospitalisation whilst maintaining optimal quality of life and dignity.

Care provided in familiar surroundings is beneficial to the older person with advanced dementia as it helps to maintain their care plan and promote feelings of orientation and security.

Irrespective of the care setting, developing a policy of restraint-free care that includes an education program to avoid restraint use can significantly reduce distress and the risk of falls-related injuries.

Grief and bereavement support to carers of people with dementia is also an essential element of palliative care.

The evidence based “Guidelines for a Palliative Approach in Residential Aged Care” and “Guidelines for a Palliative Approach for Aged Care in the Community Setting” (draft for public comment, May 2008, funded by the Department of Health and Ageing) provide excellent guides to palliative care for people with dementia.

7.7 Advance Health Directives in WA

On 15 February 2010, part 2 of the Acts Amendment (Consent to Medical Treatment) Act 2008 which supports Advance Health Directives (AHDs) and Enduring Powers of Guardianship (EPGs) came into effect in Western Australia.

These legislative changes will have significant implications for patients, families and healthcare professionals in Western Australia:

- An adult with full-legal capacity may now create an Advance Health Directive to direct treatment decisions in the event they are unable to do so in the future.
- An adult with full-legal capacity can now appoint an Enduring Guardian to make personal, lifestyle and treatment decisions for them when they are unable to do so. If a valid AHD has been made in relation to a specific situation, it takes precedence in decision-making.
- Healthcare providers now work within the law in following the directives and working with the appointed decision-maker even if the withdrawal or withholding of treatment may result in death.
- There is a new hierarchy for health professionals to follow when seeking a decision in relation to a person who cannot consent to, or refuse treatment.
- The definition of treatment has been amended to include any medical, surgical or dental treatment, or other health care, including a life-sustaining measure or palliative care.

An Advance Health Directive is a legal document that contains one’s decisions about future treatment. One may either provide or refuse consent for future treatment in specific circumstances. Copies of Advance Health Directives and further information may be obtained from www.health.wa.gov.au/advancehealthdirective. Information on Enduring Guardians may be obtained from the Office of Public Advocate at: www.publicadvocate.wa.gov.au

7.8 The Carers Recognition Act 2004

The intent of Carers Recognition Act 2004 (CRA) is to recognise the role of carers in the Western Australian community and to provide a mechanism for the involvement of carers in the provision of services that impact on carers and the role of carers. It sets out compliance requirements and clear directions as to how carers are to be engaged with and included in decision making where those decisions impact on the caring role.

The CRA requires that all State government funded or administered health and disability service providers have to take all practicable measures to ensure that they comply with the Western Australian Carers Charter.

In addition, those non-care public sector bodies must involve carers, or persons or bodies that represent carers, in any policy or program development, or strategic or operational planning that might affect carers and the role of carers.

These organisations are known as Applicable Organisations and include the agencies in the non-government sector and contracted bodies which are funded to provide public health and disability services.

In addition, the legislation deems that WA Health, Public Hospitals and the Disability Services Commission, are ‘Reporting Organisations’ and must provide an annual report to the Carers Advisory Council on their compliance or non compliance with the provisions of the Act. The ‘Reporting Organisations’ must also report to Carers Advisory Council on how their contracted agencies/service providers comply with the Western Australian Carers Charter.

The Carers Advisory Council is required to assess the Reporting Organisations’ annual reports and in turn provide a report to the Minister for Seniors for tabling in both houses of the Western Australian Parliament.
8 Conclusion

This document is high level in intent and articulates a service delivery model of care for older people with dementia and their carers across the continuum of care.

Given the evolving research on dementia, proliferation of assistive technologies, diversity of views and available resources, the model of care is not intended to be prescriptive in the way in which services are delivered to people with dementia and their carers.

This model of care enables WA to continue to align and build on the key priority areas identified by National Framework for Action on Dementia 2006-2010 and to promote the vision of a better quality of life for people living with dementia and their carers and families.
## 9 Glossary

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
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<tr>
<td>ABS – SDAC</td>
<td>Australian Bureau of Statistics – Survey of Disability and Carers</td>
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<tr>
<td>ACHS</td>
<td>Australian Council on Healthcare Standards</td>
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<tr>
<td>ACAT</td>
<td>Aged Care Assessment Team</td>
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<tr>
<td>ATSI</td>
<td>Aboriginal or Torres Strait Islander</td>
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<tr>
<td>BPSD</td>
<td>Behavioural Problems Secondary to Dementia</td>
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<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
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<tr>
<td>CCT</td>
<td>Care Coordination Team</td>
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<tr>
<td>CIBIC</td>
<td>Clinician Interview Based Impression of Change <a href="http://www.google.com/search?hl=en&amp;q=cibic">http://www.google.com/search?hl=en&amp;q=cibic</a></td>
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<tr>
<td>DGM</td>
<td>Department of Geriatric Medicine</td>
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<td>ED</td>
<td>Emergency Department</td>
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<td>GEM</td>
<td>Geriatric Evaluation and Management</td>
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<td>GP</td>
<td>General Practitioner</td>
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<td>Abbreviation</td>
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<tr>
<td>HITH</td>
<td>Hospital in The Home</td>
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<tr>
<td>IQ Code</td>
<td>Intelligence Quotient Code – Cognitive Assessment Tool</td>
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<tr>
<td>LOS</td>
<td>Length of Stay – ALOS/Average Length of stay</td>
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<td>MMSE</td>
<td>Mini Mental State Examination</td>
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<td>NPS</td>
<td>National Prescribing Service</td>
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<td>NRCP</td>
<td>National Respite for Carers Program</td>
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<td>OPAL</td>
<td>Older Persons’ Psychiatric Assessment and Liaison team</td>
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<td>OPERA</td>
<td>Older Persons Evaluation Review and Assessment</td>
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<td>RACF</td>
<td>Residential Aged Care Facility</td>
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<td>RCL</td>
<td>Residential Care Line</td>
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<td>RITH</td>
<td>Rehabilitation in the Home</td>
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<td>RUDAS</td>
<td>Cognition Assessment Tool for people with poor language skills</td>
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10 References

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