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Dementia services pathways – an essential guide to effective service planning

This guide contains 75 pages
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Introduction

The aim of Dementia Services Pathways – an essential guide to effective service planning (‘the Guide’) is to inform and assist jurisdictions with service planning, by developing dementia services pathways, to improve dementia services along the continuum of care for people living with dementia and their carers, from first symptoms or ‘first inkling’ to end of life.

The guide was developed as an action item of the Dementia Initiative, under the priority area of care and support, with the Australian Government as the lead agency. The Dementia Initiative is the Australian Government’s response to addressing the needs of people living with dementia.

About this project

KPMG were engaged to undertake the development of the Dementia Services Pathways Project for the Department of Health and Ageing. The aim of the Project is to inform and assist jurisdictions with service planning so that they can improve dementia services along the continuum of care for people living with dementia and their carers. The target group for the Dementia Services Pathways Project is as follows:

- Australian, State and Territory Governments
- health and aged care service providers across the continuum of care for people with dementia and their carers
- people living with dementia at different stages of the disease and of all ages
- people living with dementia from metropolitan, regional, rural and remote areas
- carers and families
- people living with dementia, their carers and families from special needs backgrounds, including people from culturally and linguistically diverse and Aboriginal and Torres Strait Islander backgrounds.

The development of the service pathways considered the following key elements:

- Needs (for both the person living with dementia and their carers/s): consideration of the broad needs of people living with dementia and the needs of their carers, at both the individual and community level.
- Service requirements: encompasses the service requirements that best meet the diverse needs of people living with dementia and their carers.
- Populations with specific requirements: consideration of the distinct client needs for specific populations or communities, such as Aboriginal and Torres Strait Islander

communities, people from culturally and linguistically diverse communities, younger onset dementia or living alone.

- Care setting: consideration of the type of care setting that a person living with dementia and their carer/s experiences in the course of their dementia journey. For example, at home and/or within the community, acute facilities and residential aged care facilities etc.
- Geography/location: consideration of the location where a person living with dementia and their carer/s may reside and the access to and range of services available to them in that location. Locations could be classified as urban, outer urban, regional, rural and remote.
- Progression of dementia: consideration of how the personal and care service requirements for a person living with dementia and their carer/s varies as the disease progresses (i.e. early difficulties, impact on activities of daily living (ADL), reduced independence, high care needs, and incapacity).

Key activities completed in developing the Dementia Services Pathways Project include:

- Initial consultations and preliminary research: this involved a high-level literature scan, and consultations with Commonwealth and state/territory government representatives, and the Minister's Dementia Advisory Group to confirm the approach and key issues for consideration.
- National stakeholder consultation and service mapping: twenty-three local and state/territory-wide service provider dementia pathways workshops, and thirty interviews with people living with dementia and their carers in every jurisdiction. Consultations and associated analysis explored needs and service requirements of people living with dementia and their carers, examples of good practice, service gaps and areas for improvement.
- Developing best practice dementia services pathways: in consultation with key stakeholders and the Project Reference Group, Dementia Services Pathways - an essential guide to effective service planning was developed. The guide provides a framework to guide development of dementia services pathways at a jurisdictional and local service system level including to identify the needs of people living with dementia and their carers; highlight key elements to be addressed by stage of dementia; and determine sound approaches to support adoption of better dementia practice within general services and dementia specific services.
- Analysis for final reporting: further analysis was undertaken to identify gaps in service delivery and opportunities to improve existing service pathways to meet the needs and requirements of consumers and carers. The key findings and areas for consideration are presented in this document.

Dementia

Dementia is not a disease, but rather an umbrella term for a variety of symptoms that may accompany or indicate certain diseases or conditions¹. Dementia is a term used to describe a group of diseases that affect the brain and cause a progressive decline in the ability to think, remember and learn². Symptoms may include impaired memory and confusion, difficulty in performing day-to-day or familiar tasks, such as getting dressed or eating, and changes in personality, mood and behaviour. Dementia symptoms are characterised as chronic progressive and degenerative (comparable with common chronic diseases). Dementia is however unique, with decline in cognition resulting in reduced self-advocacy and need for surrogate decision-making.

Dementia is generally characterised by four stages:

- early difficulties (the pre-diagnostic phase)
- the emergence of significant difficulties in daily living
- a reduced capacity for independence
- incapacity and a high dependence on care.

Symptoms commonly linked with the progression of dementia reflect impact on memory, orientation, judgement and problem solving, community participation, home and personal interests, and the level of personal care required (see Appendix D).

- The incidence and prevalence of dementia is anticipated to rise significantly in the next 40 years. The prevalence of dementia is anticipated to increase four-fold from 245,400 people in 2009 to over 981,000 people by 2050³. Over the same period, the prevalence of people with dementia speaking a Culturally and Linguistically Diverse (CALD) language at home is anticipated to triple⁴. Of all Australians with dementia, one in eight do not speak English at home⁵. The faster ageing of regional Australia is also important to consider for dementia service delivery planning, with a more rapid increase in prevalence rates anticipated for regional areas compared to capital cities⁶. CALD and people living in rural and remote communities commonly enter the care system later with an initial assessment of high to very high support needs.
- Dementia is the leading single cause of disability in older Australians (aged 65 years or older). Within two decades, dementia is anticipated to become the third greatest source of health and residential aged care spending⁷.

Most people with dementia are over the age of 65, but only a small proportion of older people have dementia. Dementia affects not only the person with the condition but also family and carers, presenting challenges in providing care and support. Dementia is one of the major reasons why people enter residential aged care or seek community care services. At present, there is no cure for dementia, and it is important for there to be services that assist families and carers to manage challenges throughout the dementia journey. The ageing of the population and changing family structures will lead to higher demand for community and residential care services.

In summary, the projected burden on services across the continuum of care for dementia from 'first inkling' or symptoms of a problem to the end of life is large. These circumstances

highlight the importance of effective service planning, including services that inform and support carers.

Population groups with specific needs

The service requirements for people with dementia and their carers are not homogenous. Different population groups may have differing needs and service requirements that warrant particular attention. This may include, for example, requiring the development of appropriate service models and pathways to meet specific needs, including specific strategies within dementia plans and/or policies. The following population groups are identified as warranting particular attention and consideration when planning dementia services:

- Carers
- Aboriginal and Torres Strait Islander communities
- Culturally and linguistically diverse (CALD) communities
- Younger people with dementia (under 65 years old)
- People living in rural and remote areas
- People living alone
- HIV-related dementia
- Intellectual disability and dementia.

Information describing why these population groups warrant particular consideration is presented in Appendix E.

Dementia services pathways

A services pathway describes the services required (including timing and sequencing) to meet the needs of people living with dementia and their carers (across the dementia continuum). Development of services pathways by exploring the journey of an individual/s with dementia and their carer encourages consideration of efficient and effective service delivery and coordination, keeping front of mind the experience of the person living with dementia and their carer. Service pathways are useful as a planning tool to encourage key service providers to participate in planning activity and to coordinate service responses.

A services pathway represents a series of service steps or 'sign-posts', including provision of information, coordination and delivery of clinical, educational and social support services. The service requirements should broadly reflect good practice in terms of services matching needs and requirements and should reflect requirements that all service recipients should expect.

Service pathways provide steps, activities and roles of health professionals, general practitioners and care workers to guide best practice in care for the person living with dementia, their family and carers. Development of services pathways can support improved quality standards; improved multidisciplinary communication and care planning; improved consumer/carer and provider communication and consumer/carer satisfaction; and decrease unwanted practice variation⁸.

Distinct requirements for dementia care and implications for service planning

One of the key reasons for developing dementia services pathways is to explore how dementia pathways may overlap and intersect with other service pathways – for example older person pathways, or pathways for people with a disability. While it is recognised that service requirements for people with dementia and their carers are commonly coincidental (that is, overlap) with service requirements for physical limitations associated with ageing (frailty) and common chronic diseases, this does not mean the service requirements are the same.

The following service requirements and characteristics are highlighted because of their relative importance and/or unique role for effective dementia care. Considerations of diversity (ethnicity, religion, gender, family, sexuality, location, cultural) are inherent in all of the following service requirements and characteristics which are highlighted because of their relative importance and/or unique role for effective dementia care.

- Focus on overcoming stigma and perceptions of dementia that discourage investigation/ diagnosis and access to information and support, treatment and care services.
- Relative complexity of diagnosis and initial management and care planning (including legal, driving, information and support) highlights the importance of a widely communicated, locally defined assessment and diagnosis pathway to improve levels of diagnosis (both in community and acute settings) to align with underlying rates of incidence and prevalence.

- Role of personal care services and community ‘activity-based’ services to engage the person living with dementia and simultaneously provide short respite for carers, promoting social participation.
- The need to understand the unique impact that dementia has on decision-making – with progress from independent choice and participation in health care decision making, to assisted engagement, to the need for surrogate decision makers.
- The unique role of the carer for a person with dementia. As dementia progresses, the role of the carer becomes greater, with increased levels of supervision, support and surrogate decision making required of the carer for the person living with dementia.
- Day and residential respite – to engage the person living with dementia and simultaneously provide short respite for carers, providing opportunity for social participation.
- Key worker to provide a care coordination role and subsequently a case management role (act as link from assessment to confirmation of diagnosis to post diagnosis and beyond, initiates a care plan, coordinates).
- Minimise transition points in care. Transition points that are recognised as particularly challenging given the importance of service stability for the person living with dementia and their carers include, from:
 - Home and Community Care (HACC) funded community/home services to Commonwealth ‘packages’
 - home to residential care
 - hospital to place (home or residential care).

The framework presents these factors and a range of additional elements for exploration and to be addressed when planning dementia services.

Developing dementia services pathways – a framework

The dementia services pathways framework presented below is designed to guide development of dementia services pathways at an Australian Government, jurisdictional and local service system level – across the continuum of care, to meet the needs of people living with dementia and their carers from ‘first inkling’ or symptoms of dementia to end of life. The process of developing services pathways is intended to inform and assist jurisdictions with service planning activity.

The framework presents for consideration and exploration:

- a vision of the service system to meet the needs of people living with dementia and carers
- principles of service delivery to guide better practice service provision
- four management stages of dementia to address the principles and key elements of service delivery and the distinct service features required for people living with dementia and their carers across the service spectrum.

The framework seeks to guide service planning by providing a structure for developing services pathways which:

- identify the needs of people living with dementia and their carers
- highlights key elements to be addressed by stage of dementia
- determines sound approaches to support adoption of better dementia practice within general services and dementia specific services.

A high-level summary of the dementia services pathways framework is presented on the following page. The remainder of the guide provides information to guide in the process of developing dementia services pathways.

Workshop for pathways development

It is recommended the development of service pathways be conducted as a workshop including a broad spectrum of key service providers across the continuum of care and consumer representatives. This format and range of participants encourages discussion and exploration of current service pathways (or lack there of), better practice options, and consideration of key challenges and opportunities for improvement. Appendix F presents a list of potential participants.

Case scenarios

A single case scenario is presented across the four stages to highlight particular circumstances and encourage exploration and definition of how a local service system can respond to individual needs and service requirements. While this case scenario may have widespread applicability, it does not intend to, nor can it be expected to, capture the range of individual circumstance, geography or service environments that exist across Australia (or within a local community). To prompt consideration of the diversity of needs and service requirements with specific implications for dementia service planning and service delivery, a range of essential case studies are presented at the end of the guide. It is recommended all case studies be reviewed as part of service planning to encourage equitable structures of access.

Self-assessment tool

In addition, a self-assessment tool is provided to support a high level assessment of current dementia service pathways (at a jurisdiction, region or local community level).

It is recommended that:

- the process of completing the self-assessment be used to prompt discussion of current practice and current outcomes for people living with dementia and their carers
- the results of the self-assessment be used to prioritise and prompt particular areas for attention, service planning and action.

The self-assessment tool is provided in Appendix A.

Dementia services pathways framework – summary – page 1 of 2

VISION

A responsive and dynamic service system that supports a better quality of life for people living with dementia and their carers and families.

PRINCIPLES OF SERVICE DELIVERY FOR DEMENTIA CARE

- When concerns about dementia arise, people with dementia have access to competent, multidisciplinary assessment, diagnosis and case management.
- People with dementia are valued and respected. Their right to dignity and quality of life is supported.
- Carers and families are valued and supported.
- People with dementia, their carers and families are central to making choices about care.
- Service responses recognise people's individual journeys.
- All people with dementia, their carers and families receive appropriate services that respond to their social, cultural or economic background, location and needs.
- A well-trained supported workforce delivers quality care.
- Communities play an important role in quality of life for people with dementia, their carers and families.

MANAGEMENT STAGES OF DEMENTIA – Key stages required for developing dementia service pathways

1. Awareness, Recognition and Referral

This stage incorporates general public and service provider recognition and perception of dementia symptoms, and related supporting behaviour including referral for further investigation, assessment and diagnosis; and also includes education, training and awareness raising.

2. Initial Assessment and Diagnosis, and Post-Diagnosis Support

This stage incorporates the spectrum of service providers that may assist with, and/or undertake assessment and diagnosis, and provide post-diagnosis information and support services.

3. Management, Care, Support and Review

This stage incorporates the role of ongoing management (both clinical and non-clinical), review and support across the spectrum of services, across care settings (low and high care) - from first diagnosis, addressing fluctuations in needs, to more intensive case management.

4. End of Life

This stage incorporates the spectrum of service providers, medical and allied health professionals and other support services involved in the planning and provision of quality palliative care (hospitals and hospices, residential care facilities etc).

Carer Support

Catering for the range of carer needs that exists depending on individual circumstances and reflecting that, as symptoms of the people living with dementia progress and change, the carer requirements for support will also vary (e.g. initial information and support at first diagnosis, coping with and managing change, the key role of day respite and residential respite care to maintain social participation, and involvement in end of life decision making [consider advance care planning, the terminal nature of dementia and bereavement]).

APPLIED PRINCIPLES FOR EACH MANAGEMENT STAGE OF DEMENTIA – To be addressed when developing service pathways

Awareness, recognition and referral

- Recognition of dementia as a chronic progressive (and terminal) disease.
- Community awareness, understanding and acceptance of dementia and related behaviours (for all Australians from diverse backgrounds with diverse needs).
- People request and expect timely recognition and referral to other services and/or medical/health professionals for symptoms that relate to a possible diagnosis of dementia.
- Appropriate information and support are available and accessible for carers and family
- Responses are flexible, promote choice and autonomy to best meet the diverse needs and backgrounds of all Australians.

Initial assessment and diagnosis, and post-diagnosis support

- People have access to good quality assessment, information and support from the time they, and/ or their families and carers, become concerned about symptoms that relate to a possible diagnosis of dementia.
- People have a timely (early) diagnosis – one which is at the right time for the person concerned, and for their family.
- Medical/health professionals providing diagnosis of dementia actively encourage inclusion of family and/or carer in discussing diagnosis; and for the person with dementia, family and/or carers to access relevant support services.
- Responses are flexible, promote choice and autonomy to best meet the diverse needs and backgrounds of all Australians.

Management, care, support and review

- All people with dementia, their carers and families receive appropriate services that respond to the variation and fluctuation of needs (with consideration of social, cultural or economic background, and location).
- Service transition points are minimised. Where required, all people living with dementia experience smooth transitions between services and settings with appropriate support (e.g. community care, aged care, acute care, palliative care etc).
- Responses are flexible, promote choice and autonomy to best meet the diverse needs and backgrounds of all Australians.
- Appropriate information and support are available and accessible for carers and family.

End of life

- People living with dementia are provided with opportunity to have advance care planning/directives in place that begins early in the journey, are regularly reviewed and acted upon.
- All people living with dementia have greater service choice and flexibility at the end of life stages that promote their dignity and well-being.
- Responses are flexible, promote choice and autonomy to best meet the diverse needs and backgrounds of all Australians.
- Appropriate information and support are available and accessible for carers and family.

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Dementia services pathways framework – summary – page 2 of 2

KEY ELEMENTS TO BE ADDRESSED

For each management stage, address each of the eight elements

Eight key elements are identified to prompt consideration of what makes good dementia care by management stage of dementia. These elements are important from a planning perspective as they highlight key factors that contribute to health and social outcomes for people living with dementia and their carers. A brief description of each of the elements is presented, to allow review of each during planning discussions (in the context of local settings and circumstances).

| Key Element | Description of element |
|---|---|
| Needs <i>(For people living with dementia and their carers)</i> | This element prompts consideration of the broad needs of people living with dementia and the needs of their carers at both the individual and community level. |
| Service requirements | This element prompts consideration of the service requirements/ functionality that best meet the diverse needs of people living with dementia and their carers. |
| Populations with specific requirements | This element prompts consideration of the distinct client needs for specific populations or communities such as Aboriginal and Torres Strait Islander communities, culturally and linguistically diverse communities, younger onset, people living alone, that are part of the service population. |
| Care setting | This element prompts consideration of the type of care settings that a person living with dementia and their carer experiences in the course of their dementia journey. Care settings could include at home and/or within the community, acute facilities, residential care facilities. |
| Geography / Location | This element prompts consideration of the location where a person living with dementia and their carer may reside and the services available to them in that location. Locations could be classified urban, outer urban, regional, rural and remote |
| Progression of dementia | This element prompts consideration of how the personal and service needs for a person living with dementia and their carer(s) vary as the disease progresses (for example, early difficulties, impact on activities of daily living (ADL), reduced independence, high care needs (including BPSD), incapacity etc). |
| Examples of good practice | This element describes examples of good practice for each management stage along the dementia services pathway for consideration. |
| Supporting documents | This element provides examples of useful documents that illustrate good practice and supporting information for each management stage of the dementia services pathway to prompt further investigation for planning. |
| Outcome indicators (KPIs) | This element prompts consideration of how to measure performance and to assist with evaluating success (outcomes). A range of indicators are provided for consideration in the guide for each management stage along the dementia services pathway. |

Note: The Vision, Principles and Approach are based on Nuffield Council on Bioethics' Dementia: ethical issues (2009); NSW Department of Health's Draft NSW Dementia Services Framework 2010 – 2015; and National Framework for Action on Dementia 2005 – 2010. The management stages of dementia are based on Queensland University of Technology, Dementia Collaborative Research Centres, Queensland Health and The Wicking Trust (2008)

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Elements to be addressed when developing dementia services pathways

The elements to be addressed to aid development of dementia services pathways are represented in each of the four management stages of dementia:

- Awareness, recognition and referral.
- Initial assessment and diagnosis, and post-diagnosis support.
- Management, care, support and review.
- End of life.

The information provided is not intended to be exhaustive but a prompt for considering key elements during development of dementia services pathways. It is also recognised that people living with dementia and their carers may enter the services pathways at various points.

1. Awareness, recognition and referral

AWARENESS, RECOGNITION AND REFERRAL

This stage addresses individual, community and service provider awareness and recognition of symptoms of dementia (change in skills, behaviour and memory loss), and related supporting behaviour of acknowledging concerns and referral for investigation. The stage includes awareness raising, training and education, and behaviour change.

Individual and Carer support

- Access to appropriate information and advice including to recognise the signs and symptoms of dementia, the importance of diagnosis (prompt to seek aid/investigate), and carer support information and services.
- Importance of acknowledging and recognising partner/family/carer perspective for informing appropriate referral.

Needs

- Increase public and professional awareness to address perceptions of and reduce stigma associated with dementia (locally within the service systems and the community at large). Focus on the merits of early diagnosis, maintaining social connection and accessing care/support.
- Public and professional encouragement to respond to symptoms and seek medical advice (merits of early diagnosis as described above).
- Acknowledgement and respect for the concerns of the person with suspected dementia and their carer.
- Appropriate, timely referral for further specialist investigation.
- Appropriate information, support and advice.

Service requirements

- Local community, health and ageing service system awareness/ knowledge of dementia symptoms and merits of early diagnosis.
- Clearly locally defined roles for spectrum of relevant community service providers to gather and share information that can assist to inform diagnosis (especially person's functioning in own home) – and for diagnostic investigation to seek this information (e.g. GENERAL PRACTITIONER or memory clinic).
- Development of guidelines for streamlining pathways between Aged Care Assessment Services (ACAS) and HACC assessment services.
- Clear locally defined pathway for contact and referral points to allow further investigation, assessment and diagnosis (central point of access, e.g. one-stop shop).
- Access to appropriate education and training and awareness raising activities (for key service providers and the wider community) targeting most at risk and populations with specific requirements.
- Role of key worker to assist with community engagement and addressing needs of specific groups.

Populations with specific requirements

- Recognise the variety of stigma and perceptions related to behaviour change and memory loss and ageing by CALD communities and Aboriginal and Torres Strait Islander communities requiring a targeted response.

Common gaps and shortfalls

- Stigma of dementia not addressed. Dementia viewed as a natural part of ageing, the absence of a 'cure' and the debilitating nature of the condition lead to stigma and social isolation.
- Low community-wide awareness and understanding of what suspected memory and thinking difficulties may indicate and what steps could be taken to assist.
- Limited access to health professionals and services relevant to this initial stage, including General Practitioners, key workers, and other health professionals. Response of service providers limited due to unclear pathway/next steps.

Examples of good practice

- Wicking Trust (UTAS) information sharing platform.
- Role of programs including the National Dementia Support Program, Dementia Advisory Service, peak bodies - Alzheimer's Australia and Carer's Australia.
- Awareness raising initiatives and resources, e.g. Dementia Learning Resource for Aboriginal and Torres Strait Islander Communities (Department of Health and Ageing, 2007).
- Aboriginal Liaison Officer, Alzheimer's Australia SA and National Alzheimer's Australia.
- Use of Access and Equity Workers in Alzheimer's Australia (Vic and SA).
- Aboriginal and CALD dementia information and services – Hume Region project for Family Care agencies to provide information and services to these groups.

| | |
|--|---|
| <ul style="list-style-type: none"> Hume Regions Aged Care Plan 2010 – 2015. | |
| Supporting documents | |
| <ul style="list-style-type: none"> See Appendix G. | |
| Potential outcome indicators (KPIs) | |
| PLWD | Carers |
| <ul style="list-style-type: none"> Community awareness and recognition of first symptoms. First symptoms recognised and action taken (medical/health contact and referral). Time from first contact with the service system to appropriate referral to assessment and diagnostic services. Satisfaction with the referral process (including provider acknowledgment of concerns). Outcome of referral process (reported actions). Access to, and use of, dementia and chronic illness resources (information, support and care services). | <ul style="list-style-type: none"> Access to appropriate information and advice including carer support information and related services. Acknowledgement and recognition of the partner/family/ carer perspective for informing appropriate referral (frequently it is the person living with or very closely involved with the person that is first aware of changed behaviour and symptoms). Clear single point of referral for diagnosis and information support (i.e. to General Practitioner and diagnostic pathway, and to access information and support). |

Case scenario – Awareness, recognition and referral

MARY is 80 years old. She lives with her husband, Bill, in the western suburbs of Brisbane. Mary and Bill have lived in the suburb for over 20 years and manage all the household activities between them. Their daughter, Jenny, lives nearby and visits once a week. Mary has a history of falls and, for that past year, has been attending a fortnightly Tai Chi class at the community health centre to assist her with her physical health. The class is run by an Allied Health Assistant.

Mary “Recently we have been very busy and I am worried about Bill. He looks very tired. This morning I couldn’t even find the car keys and Bill found them in my bedside drawer...! They must have slipped off the bench top. And the other day I prepared some vegies for dinner but left them in the kitchen and only remembered to serve them after we had finished our meal. My daughter thinks I am a bit forgetful but I am no different from everyone else my age.”

The next day Mary is due to attend her Tai Chi class and her daughter drops her off at the usual location on the corner of an adjacent street from the community centre with plenty of time to get there. Mary arrives at the class 10 minutes late looking flustered. The Tai Chi instructor has noticed over the last three months that Mary has been having trouble following the exercises and appears to lose concentration during the class. This is unusual as she knows all the exercises and would normally help others if they are having difficulty.

After the class, the instructor chats to Mary. Mary explains to the instructor that she was late because her daughter dropped her off at a different spot and the streets all look the same. Mary laughs about it, suggesting that they have changed the appearance of the building.

The instructor has recently attended a workshop on dementia and is aware that the changes in Mary could be for reasons other than just normal ageing. When Mary’s daughter comes to pick her up from class, the instructor asks if she has noticed any changes in Mary’s behaviour. The daughter tells her about the recent forgetfulness. The instructor encourages Mary and the family to see the General Practitioner regarding her symptoms.

In addition, she provides them with details of the Alzheimer’s Australia Helpline for information about memory loss and behaviour change that may be as a result of dementia. She also provides a telephone number for the local Alzheimer’s Australia service so they can find out what is locally available.

Key message

- Awareness, recognition and understanding of the symptoms and behaviours associated with the ‘first inkling’ of dementia are the first steps to achieving a timely assessment and diagnosis.

2. Initial assessment and diagnosis, and post-diagnosis support

INITIAL AWARENESS AND DIAGNOSIS AND POST DIAGNOSIS SUPPORT

This stage addresses the spectrum of service providers that may assist with and/or undertake initial assessment and diagnosis, and that provide post-diagnosis support.

Carer support

- Recognition and acknowledgment of partner/family/carer perspective for informing assessment and diagnosis.
- Informed of process and timeline for further assessment and diagnosis.
- Access to clear information and support services to assist with understanding, trajectory of dementia, range of information and support/home care services available to support informed decision making and appropriate planning. For example: Alzheimer's Australia – Living with Memory Loss Program; and carer support groups, legal services (e.g. Enduring Power of Attorney, Advance Care Planning/Directive).

Needs

- Concerns of individual and carer acknowledged and respected (not dismissed).
- Appropriate referral for further investigation (pathway to achieve diagnosis).
- Informed of process, pathway and timeline for further assessment and diagnosis.
- Appropriate information/advice (to inform individual and carer planning, including access to support services).

Service requirements

- Role of General Practitioner or key worker to support individual and carer through investigation process and link to post-diagnosis information and supports.
- Focus on diagnosis and access to appropriate treatment and support services to encourage appropriate care and support and inform better decision-making (by individuals and service providers).
- Visible, simplified points of access to assessment/diagnosis services, information/support and to post-diagnosis support/service links.
- Defined diagnosis pathway requires access to multidisciplinary memory clinic functionality. The structures and service role are likely to vary by population density and existing service structures. Coordination of multidisciplinary and specialist resources is essential, e.g. memory clinic, aged care clinic, older person mental health services, centralised booking for specialists, practice based clinics). See Box 1 for further description.
- Commence planning for end of life including education and support regarding advance care planning, Enduring Power of Attorney and wills.

Populations with specific requirements

- Culturally and linguistically diverse communities – use of appropriate assessment tools, and supporting approaches (E.g. recognising particular concerns and/or beliefs and responding appropriately).
- Use professional interpreting services familiar with aged care for dementia assessments, and when care plans are developed and reviewed for CALD and ATSI people.
- Aboriginal and Torres Strait Islander communities – use of appropriate assessment tools, and supporting approaches.
- Workforce capacity and capability to use the appropriate tools and to respond to the needs of populations with specific requirements.
- Younger Onset Dementia population (occurs less frequently and so potential to be unrecognised/overlooked as dementia).

Geography / location

- Challenge of access to assessment and diagnostic services in more remote and lower populated areas (see Box 1). Implications for roles in diagnostic investigation and investigation coordination/management and to likelihood of accessing support service and planning for individuals.

Common gaps / shortfalls

- Low rates of formal diagnosis.
- Time delay between first symptoms and diagnosis.
- No defined pathway to progress assessment and diagnosis.
- Insufficient/inconsistent links to support information and support organisations.

Examples of good practice

- Cognitive, Dementia and Memory Service (CDAMS), Victoria.
<http://www.health.vic.gov.au/subacute/cdams.htm>
- Nurse-led assessment clinics (Hunter NSW).
- General practitioner-led assessment and management of process of achieving diagnosis (NW Tasmania).
- Central point of access to specialist memory services (i.e. multiple specialists in one location).
- Use of professional interpreters and bilingual professional clinicians to undertake assessments – Screening and Diagnostic Assessment of NESB people with Dementia, guidelines and system recommendations for practitioners, service managers and policy makers, Alzheimer's Australia.
- Service-wide use of the RUDAS – South Sydney area Health Service Aged care Assessment Teams and RDNS Victoria.
- KICA assessment for Aboriginal and Torres Strait Islander communities.
- Living with Memory Loss Program, Alzheimer's Australia – as a means of support to the individual and their carer.

| Supporting documents | |
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| <ul style="list-style-type: none"> • See Appendix G. | |
| Potential outcome indicators (KPIs) | |
| PLWD | Carers |
| <ul style="list-style-type: none"> • First symptoms noticed and actions taken ('recognise signs and acts on it'). • Time to first health professional consultation and diagnosis from first symptoms. • Defined local pathway for service providers to follow (including activities and referral). • Access to specialist (via specialist appointment or memory clinic). • Number of diagnoses (by progression of dementia, and by care setting). • Reported actions of first health professional in contact with person (i.e. assessment, referral). • Satisfaction with first consultation. • Referral to and access of dementia and chronic illness resources (information, support and care services). | <ul style="list-style-type: none"> • Satisfaction of partner/family/carer in terms of their perspective/input being sought and used to inform assessment and diagnosis. • Carer satisfaction – clarity of information/direction available on the processes and avenues for further information to assist with understanding, trajectory of dementia, range of information and support services implications. • Access to person centered services for carers. |

Box 1: Initial diagnosis and assessment pathways and service structures

Locally defined pathways for initial diagnosis and assessment are likely to vary depending on density of population, availability of and access to services required for diagnosis, and existing service system structures. The roles of individual service providers may vary according to the approach adopted, particularly for the primary care workforce (general practice). All services should be culturally and linguistically competent and aware of the appropriate tools to assist with initial assessment (e.g. KICA and RUDAS assessment tools).

Regardless of the setting, the pathway should support the coordination of multidisciplinary and specialist resources. Ideally, the pathway will incorporate a central point of access to assessment/diagnosis service and to post-diagnosis support/service links.

For example:

- **High density metropolitan** – Role for general practice (General Practitioner and/or Practice Nurse) to be part of locally defined pathway (in terms of assessment and support). Refer to centralised cognition, memory and dementia service with multidisciplinary and specialist medical resources. Individuals (including carers) self refer and General Practitioners refer.
- **Medium density outer suburban/ regional** – General Practice leads investigation and/or Practice Nurse-led clinics that conduct initial assessment, provide information and refer to medical specialist and/or cognition, memory clinic. Greater role in general practice for coordination and support of investigation and linking to information and support services (e.g. National Dementia Helpline). Potential for centralised point of access to specialist medical resources and services to inform diagnosis.
- **Lower density rural and remote** – General Practice leads investigation and/or Practice Nurse-led clinics, ordering relevant tests and referring to specialist as indicated with supporting information from investigation to aid diagnostic process. This approach may support better coordinated and timely diagnosis when there is limited access to medical specialists (i.e. defined pathway supports General Practitioner to investigate and work up relevant support tests to aid timely diagnosis by medical specialist as required). Incorporation and use of online resources and telehealth consultations may be incorporated into pathway.

Case scenario continued – Initial assessment and diagnosis, and post-diagnosis support

Mary and Jenny (daughter) discuss with Bill what happened at Mary's Tai Chi class. Jenny decides to contact Alzheimer's Australia on behalf of her parents for further information. She is provided with general information about memory loss, details on support services and groups available in her area. On reading the information from Alzheimer's Australia, Bill and Jenny realise that Mary's symptoms could be signs of dementia so they decide to see her local General Practitioner.

Jenny takes Mary and Bill to visit the General Practitioner together. The General Practitioner listens to their concerns and experiences of late and conducts an initial assessment which indicates that Mary is experiencing memory and thinking difficulties. The General Practitioner is concerned that Mary's symptoms are more than just normal aging or related to another cause. She decides to refer Mary to the local multidisciplinary memory service (or specialist) for more detailed investigations and diagnosis.

Further investigations and tests are conducted over a four-month period and Jenny continues to talk with Alzheimer's Australia about her fears and concerns. After a third visit to the specialist, it is confirmed that Mary has dementia. The specialist discusses the cause and likely course of dementia and states that the dementia is at an early stage and, in Mary's case, is likely to be Alzheimer's disease. The specialist also discusses the safety implications of the diagnosis and course of the disease on Mary's ability to continue driving. Mary has held a driving licence for well-over 40 years and does not want to give it up. The specialist advises both Mary and Bill that, if Mary wishes to continue driving, she would need to have an on-road test. The specialist suggests that they return for a review in three months to monitor the progress of the condition and refers her back to her General Practitioner for ongoing care.

Mary and her family feel shaken with the diagnosis and are uncertain what it means, the impact it will have on Mary and how she will manage in the future. Mary's General Practitioner provides further explanation to Bill and Mary what they can expect regarding the progression of dementia. He suggests that they seek more information about accessing community services such as Home and Community Care (HACC) services to assist them with their day-to-day living and care needs. An assigned Dementia key worker provides a single point of contact for Bill and Jenny and assists to explore important considerations including support groups, planning and access to home services.

While shaken, Mary feels that she will be able to continue with her life as before. "I'm more concerned about Bill, he needs to get out more instead of staying at home all the time looking after me – I'm fine. I can also do my own housework – I don't need anyone coming into my own home to help me with that."

On the advice of their Dementia key worker, Mary and Bill attend Alzheimer's Australia's 'Living With Memory Loss' program for people living with dementia and their carers. They learn about dementia pathways, access to personal and home services, community services, activities for people living with dementia, and the legal issues to be organised. As a result, Mary and Bill complete their Enduring Powers of Attorney, their wills and their end of life care documents. Bill also joined a Carers' Support Group and he arranged for Mary to attend Day Centres twice a week.

Key messages

- Concerns are acknowledged and respected and a timely and appropriate referral for further investigation is carried out.
- The person with memory and thinking difficulties, their family and carer(s) are informed of the process, pathway and timeline for further assessment and diagnosis. Explore role of advocate to aid/support in the diagnosis process.
- Appropriate information/advice (to inform individual and carer planning, including access to support services is provided).

3. Management, care, support and review

MANAGEMENT, CARE, SUPPORT AND REVIEW

This stage addresses the role of ongoing management, care support and review across the spectrum of services and across care settings (such as at home, in the community, and in residential care [low and high care]). Services range from post-diagnosis, addressing fluctuations in needs for care and support services, to more intensive case management and care as the disease progresses. This stage primarily focuses on the community setting. Acute care and residential care settings warrant particular consideration (see Box 2 and Box 3).

Carer support

- Carer informed, involved and supported (at time of diagnosis and ongoing).
- Carer needs supported via support groups, respite options, information services.
- Carers needs supported via appropriate cultural and language centres with dementia expertise.
- Managing transition of primary-decision making responsibilities for person living with dementia from individual to carer.

Needs

- Need to maintain cognitive and functional abilities and for services to support quality outcomes for people in the setting of their choice.
- Awareness and understanding of the range of management, care and support services available by care setting (focus on maintaining cognitive and functional abilities to support better quality of life outcomes).
- Service providers facilitate and support autonomous decision making and person centred system of care for person living with dementia (involving support from family/carer as required).
- Ongoing trusted relationship with care provider/s (supporting person centred care).
- Timely access to care, support and information services to meet changing and fluctuating needs (with minimal transitioning between services).
- Access to respite services to support carer to maintain social participation.
- Access to activity-based services – to support social inclusion of person living with dementia (and provide short respite for carer).
- Access to education, advice and treatment for behavioural and psychological symptoms of dementia across all settings.
- Targeted approach to supporting and promoting restorative care approaches (in line with Active Service Model).
- 'Key worker' to act as service coordinator/case manager appropriate to level of need.
- Role for care coordinator/manager prior to receipt of Commonwealth care packages (especially for those who live alone).
- Role of general practice to manage health (especially where chronic condition co-

morbidities exist).

- Consideration of planning and later life issues.
- Finalise planning for end of life including advice and support regarding advance care planning, Enduring Power of Attorney and wills.

Service requirements

- Clear entry points to care (centralised access to range of services).
- 'Key worker' to act as service coordinator/case manager appropriate to level of need/changing service requirements.
- Provision of care, support and information services to meet changing and fluctuating needs (with minimal transitioning between services (with greater use of consumer directed care approaches).
- Quality care and care coordination across care types and care settings.
- Minimise transition points/multiplicity of service providers to the individual.
- Manage transition points/service interface between services (e.g. community care, aged care, acute care, end of life care).
- Support post-acute stay to manage transition and fluctuation in need.
- Transport included with 'activity-based services'.
- See Box 2 and Box 3 for further description of service requirements for acute setting and residential care settings. See also supporting case studies in next section.

Populations with specific requirements

- Importance of culturally appropriate care coordination and case management (consider brokerage to meet CALD communities and Aboriginal and Torres Strait Islander needs).
- Importance of culturally appropriate social activities and access to culturally specific carer support services.
- Community and residential care options suitable for younger onset dementia.
- For those who live alone, the importance of regular monitoring by a care manager and the arrangement of appropriate care/care package to avoid crisis associated with cognitive decline and loss of skills for activities of daily living.

Common gaps / shortfalls

- Decreased social participation by person living with dementia and carer (social isolation).
- Availability and flexibility of day and residential respite catering for people with dementia.
- Cost and time of community service restricted by transport cost.
- Multiple providers in the home with multiple transitions and a lack of communication/coordination between providers (e.g. Home and Community Care to Community Aged Care Packages).
- Regional price differentials and cost of travel are insufficiently weighted.

- Co-morbid conditions are not well managed (importance of maintaining optimum health).
- In some areas, there is underutilisation of Dementia Behaviour Management Advisory Services to assist with managing dementia behaviour across care settings.
- Insufficient appropriate acute care places for patients with Behavioural and Psychological Symptoms of Dementia/Delirium (e.g. inpatient psychogeriatric unit).
- Design of built environment inadequate/inappropriate to optimise the function of people with cognitive impairment (especially hospital and aged care facilities).
- Limited focus on transition from homeless to residential care.

Examples of good practice

- Dementia monitors – volunteers in a community that regularly visit PLWD to check status.
- ‘Bowling for life’.
- Photography classes and excursions.
- Tai chi, music, dance, bocce.
- Day/short term residential respite – Hobart – cottage respite.
- Nell Williams Aged Care Unit, Royal Hobart Hospital.
- Partners in Culturally Appropriate Care (PICAC) and Community Partners Program (CPP) - aims to equip aged care providers to deliver culturally appropriate care to older people from CALD communities.
- Dementia friendly environments project.
- Dementia cafes.
- Improving access to ACAS for Aboriginal people project (Hume, Wangaratta ACAS, Rumbalara and Mungabareena).
- Well for Life - Improving nutrition and physical activity for residents of aged care facilities.
- Count Us In - support initiatives that promote social inclusion for people living in residential aged care.

| Supporting documents | |
|---|--|
| <ul style="list-style-type: none"> See Appendix G. | |
| Potential outcome indicators (KPIs) | |
| PLWD | Carers |
| <ul style="list-style-type: none"> Reduction in avoidable dementia-related hospital admissions. Improved outcomes for people with cognitive impairment in acute care settings. Time to access community care packages and other services/facilities from point of recognised need. Satisfaction with services provided (including transitioning process between services). Number of respite places (and time to access these places). | <ul style="list-style-type: none"> Level of social participation (increased). Carer informed, involved and supported through management and review process. Carer satisfaction with respite options. Carer satisfaction with transition points (e.g. HACC to Commonwealth packages; acute to place; place to residential care). Awareness of and completion of Powers of Attorney and Advanced Care Planning. |

Box 2: Service considerations for the acute setting

Up to 50 per cent of all patients in Australian hospitals have some degree of cognitive impairment, and impaired mental status is the most commonly identified factor in patients who fall while in hospital⁹. Acute care settings have poorer outcomes for people with cognitive impairment – both for people diagnosed with dementia and those not formally diagnosed. People with dementia on average have an increased length of stay in hospital, increased morbidity and poor prognosis.

Generally, people with dementia attend and are admitted to hospital for treatment for other chronic conditions and/or associated with an acute event (e.g. fall). This suggests the need for hospital-wide practice of improved recognition of cognitive impairment, improved access to specialist dementia support and improved care of people with dementia while in an acute setting.

Considerations for service improvement include:

- Minimise unnecessary hospital attendance/admission for people with dementia by defining alternative pathways in the community and in residential care, up-skilling residential care staff, service available outside of the emergency department, supporting greater advance care planning.
- Focus on recognising the importance of providing support and sense of security in an acute environment for person with cognitive impairment.
- Strengthen dementia education/training for clinical and support staff in acute settings (including the involvement of carers).
- Revisit and strengthen pathway for recognition of memory and thinking difficulties and progressing investigation for suspected dementia – as appropriate either during inpatient stay or in place (community or residential care) after acute stay.
- Consider adoption of a symbol for cognitive impairment during inpatient stay (as part of a wider education program).
- Quality dementia care should be a part of routine practice for all hospital staff and incorporated into models of care.
- New hospitals and redevelopments be designed for patients with cognitive impairment.

Box 3: Service considerations for residential care

Greater than 50 per cent of people in residential care have a diagnosis of dementia and many more have cognitive impairment. Considerations for service improvement include:

- Approaches to improve links between primary health care and residential care (linked to likelihood of accessing acute care).
- Access to dementia specific care places that provide accommodation and care for those with severe behavioural and psychological symptoms of dementia.
- Quality dementia care to be part of routine practice for all staff of residential care and incorporated into daily practice.
- In developing local pathways, particular focus is recommended to consider approaches to support alternative care options to transfer to acute setting, and end of life care for people with dementia (see next stage – End of life).

Case scenario continued – Management, care, support and review

Over the past two and a half years, Mary's condition has gradually deteriorated and is complicated by underlying medical conditions. With the assistance of the Dementia key worker, home and community care services have provided home help services, and a community nurse visits. More recently, Mary has had a couple of accidents around the home, one where she spilt a pot of boiling water and burnt her hand and another where she fell in the shower and bumped her head. Her family are worried about her safety.

Her husband, Bill is finding it increasingly difficult to care for Mary. She is always asking the same questions, and her needs have increased, requiring more constant supervision and assistance with daily activities. She will not settle at a task any more and often needs to be assisted in the kitchen (over the last 12 months she has left all the meal preparation to Bill who has not cooked for years!). Bill's health has also been declining and he finds the carer role exhausting. "I can't leave her for a minute without fearing that there will be some trouble – I worry about her all the time." Jenny (daughter) is juggling a full time job and a growing family and tries to support her parents where she can.

Mary's General Practitioner refers Mary and Bill to an Aged Care Assessment Team (ACAT). The ACAT member conducts an assessment with Bill and Mary in the home. It is recommended that Mary receives a care package that includes regular in-home respite, personal care and home help (assisting with shopping, cleaning and preparation of meals). In addition, Mary accepts Bill's recommendation to attend a community club two days per week to provide Bill with some respite (allowing him to see friends and have some time to 'catch up with things'). "Oh, I go to the Club so Bill can see his friends – he needs to get out more."

The Aged Care Assessment Team also arrange for Mary and Bill's house to be assessed to ensure Mary's safety and as a result, loose rugs were removed and shower rails were installed in the bathroom. Bill feels that he is able to cope better with the assistance he receives and continues in his carer role. Mary is able to be supported to continue to live at home, maintain a level of independence and delaying consideration of moving to residential care.

However, over the next two years, Mary's needs increase. On recommendation by her key worker and after reassessment by ACAT, Mary's care arrangements are escalated to include an Extended Aged Care at Home – Dementia Package (EACH-D). The key worker also introduces Bill, Mary and Jenny to home based palliative care services.

Over time, Mary lost mobility and continence and was no longer able to sleep through the night, it was felt that she needed more intensive care and support. Following a reassessment by ACAT, Mary was assisted to move to a nearby residential aged care facility. As part of moving to residential care, the General Practitioner placed copies of Mary's situation and her Advanced Care Planning wishes with the aged care facility.

The residential aged care facility assigned an aged care worker to Mary and also offered support in engaging counsellors to assist Mary's family with the transition. Bill and Jenny, along with Jenny's family and children, were able to visit Mary regularly and felt supported throughout the process. Mary's General Practitioner continued to be her treating doctor and visited the facility as required.

For Bill, “it was the hardest decision I have ever had to make – but I feel she will be better looked after here than at home and it’s easier for the grandkids to visit”.

Key messages

- Awareness and understanding of the range of management, care and support services available by the carer(s) and family.
- Timely access to care, support and information services to meet changing and fluctuating needs and to maintain stability and independence as long as possible.
- Access to activity-based services to support social inclusion of person living with dementia (and provide respite for the carer).
- Role and value of primary care (for example, General Practitioner and practise nurse) to manage health (especially where chronic condition co-morbidities exist).
- Importance of continuity in transitioning between place of residence, types and levels of services.

4. End of life

END OF LIFE

This stage addresses the spectrum of service providers, medical and allied health professionals and other supports involved in the planning and provision of quality end of life care in a variety of settings (such as at home, residential care, hospice and hospitals).

Carer support

- Carer informed, involved and supported through end of life stage - planning, decision-making and involved in end of life care).

Needs

- Support enacting of Advance Care Planning and Enduring Power of Attorney (as required) as per planning commenced in Stage 2 and Stage 3.
- Awareness of, and support to participate in, end of life decision making.
- Relationship with care providers (especially existing relationships, for example with residential care staff and community care package services).
- Person centred care to support dying with dignity.
- Carer involvement in care and bereavement support.
- Awareness of, and support to participate in, cultural, religious and spiritual beliefs, practices and activities.

Service requirements (esp. residential care and in-home community end of life care)

- Clearly defined model of care for end of life care for people with dementia.
- Identify and address needs (person living with dementia, carers and family).
- Supporting documentation (to inform and engage carer/family).
- Development of informal and formal networks (to deliver care and support).
- Encourage and support role of the General Practitioner.
- Coordinated person centred care (focus on minimising transitions to 'new' services/service providers).
- Service providers up-skilled and supported to provide quality end of life care (including discussion with family/carer).

Populations with specific requirements

- Cultural, religious and spiritual beliefs and practices need to be considered when providing care.
- Attitudes and expectations of end of life care and planning processes can vary considerably between different population groups, especially Aboriginal and Torres Strait Islander and CALD populations.
- There is a need for culturally appropriate services that incorporate and/or are sensitive to the cultural and spiritual beliefs and/or rituals of various groups.
- The process of conducting advance care planning and planning for end of life care

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| <p>may not be a cultural norm in some communities, particularly the legal paperwork that is associated with this.</p> | |
| <p>Common gaps / shortfalls</p> | |
| <ul style="list-style-type: none"> • Absence of clearly defined end of life model of care for people with dementia. • Key service providers feel unsupported or disempowered to implement good practice end of life care (in community and residential care setting). • Service transition leads to different service providers unfamiliar with person living with dementia and/or carers. • Insufficient planning for end of life care in the early stages of dementia. • Dissatisfaction by carers/family in response/support to diversity of bereavement. | |
| <p>Examples of good practice</p> | |
| <ul style="list-style-type: none"> • Palliative consulting service. • Palliative care coordinated by community aged care provider. • End of life care pathway (dementia specific with associated education resources). | |
| <p>Supporting documents</p> | |
| <ul style="list-style-type: none"> • See Appendix G. | |
| <p>Potential outcome indicators (KPIs)</p> | |
| <p>PLWD</p> | <p>Carers</p> |
| <ul style="list-style-type: none"> • Awareness and understanding of Power of Attorney and Advanced Care Directive procedures. • Advanced Care Directives developed and deployed. | <ul style="list-style-type: none"> • Awareness and understanding of Power of Attorney and Advanced Care Directive procedures. • Carer informed, involved and supported through end of life stage. • Bereavement support available and provided. • Carer satisfaction with support services provided. |

Case scenario continued – End of life

When Mary was first diagnosed with dementia, Mary and Bill attended a ‘Living with Memory Loss’ program which included discussion of the progression of dementia and what they could expect in the future. As a result, Mary’s family had arranged an Enduring Power of Attorney and, in discussion with Mary, had signed and completed an Advanced Care Plan stating Mary’s wishes, in preparation for when Mary’s condition deteriorated. In addition, Mary’s key worker also introduced Mary, Bill and Jenny to home based palliative care services.

When Mary became seriously unwell, the doctor advised that, without transfer to hospital for invasive treatment, she would probably not survive. Bill and Jenny are informed of the situation and are asked to be involved in deciding what ongoing care will be provided. They are informed of the risks and potential outcomes. According to the Advance Care Plan, Mary’s wishes were to not undergo invasive treatment in such circumstances, instead she wanted to die in her home (place) in comfort and dignity. Bill and Jenny respect this wish and inform the doctors not to carry out the invasive treatment. The residential care staff agree to provide palliative care to Mary in the aged care facility. They are supported by a consulting palliative care team and Mary’s General Practitioner to provide Mary with a dignified death.

After Mary’s death, Jenny and Bill continue to have bereavement support through their dementia support group with Alzheimer’s Australia. Bill is identified as requiring extra help and receives in-home assistance from a subset of the same service providers appropriate to his needs.

Key messages

- Advance care planning including legal and care planning is taken into consideration early in the journey of a person living with dementia in conjunction with their carer(s) and family, and appropriate and timely support and advice is provided to facilitate such planning and decision-making.
- Advance Care Plan signed by the person living with dementia who still has cognitive ability is respected and implemented by the family and the medical practitioners.
- Care providers continue to respect and support person centred care at the end of life.
- Relationship with care providers (especially existing relationships) are respected and continued where appropriate in line with a person centred approach to support quality end of life care.
- Carer involvement in care and bereavement support is fostered and supported.

Case scenarios for review and to be addressed

A single case scenario is presented across the four stages to highlight particular circumstances and encourage exploration and definition of how a local service system can respond to individual needs and service requirements. While this case scenario may have widespread applicability, it does not intend to, nor can it be expected to, capture the range of individual circumstance, geography or service environments that exist across Australia (or within a local community). To prompt exploration of and address the diversity of needs and service requirements with specific implications for dementia service planning and service delivery, a range of essential case studies are presented. It is recommended all case studies be reviewed as part of service planning to encourage equitable structures of access.

While the key elements are reflected throughout the guide and in the framework, the case studies are designed to prompt practical consideration and discussion of service provision requirements to address the spectrum of needs. Key messages are provided at the end of each case scenario.

The case studies presented are:

- Person with dementia from an Aboriginal or Torres Strait Islander community (particularly in rural/remote areas).
- Person with dementia from a CALD background.
- Person with younger onset dementia (YOD) under the age of 65 years.
- Person (with undiagnosed dementia) presenting to an emergency department of a hospital or other acute setting with other co-morbidities.

In addition, consideration of other scenarios that are relevant to your location and population are encouraged as part of planning and pathway development. For example, it may be useful to consider the following scenarios:

- Person with dementia living in a rural/remote location (challenge of access to range of services, consider approaches and define local pathway).
- Person with dementia living at home alone with no formal or informal care arrangements in place (consider assigning the role of 'monitor' to regularly check on the wellbeing of the person).
- Person residing in a residential aged care facility who develops initial dementia symptoms (adoption of good practice to investigate appropriately, and provide care and support to resident living with dementia, and their visiting friends/family).
- Person with severe and complex behavioural and psychological symptoms of dementia (BPSD) and the specialist support required to manage these persons in mainstream services (consider the care coordination required to ensure that they do not fall through the gaps) and specialist inpatient acute facilities.

Case scenario – Aboriginal and Torres Strait Islander

LES is a 46 year old Aboriginal man who lives with his extended family in a small community, 450 kilometres from Darwin. Les is not in good health and has a number of underlying medical conditions which have contributed to a recent stroke. Les' family are having trouble looking after him and understanding what Les is experiencing as his needs have increased since the stroke, and he does not seem to be himself. They are reluctant to send him away for help as he has very rarely travelled outside his community. English is not his first language, and he is a valued and respected Elder in the community.

Les *“Since I had a stroke I don't seem to remember things the way I used to – though I can still tell some stories! I guess I'm getting on and these things happen as you get older but I'm afraid that soon I won't remember the stories to pass on to my children...”*

- Les has an initial assessment using the KICA (Kimberley Indigenous Cognitive Assessment) tool with a key worker from the local Aged Care and Disability team who visits the community regularly. The assessment identified some memory loss which prompted further investigation. An appointment was arranged with a visiting specialist who visits the community every two months. The specialist conducts further investigations and consults with a Geriatrician in Darwin regarding the results. Les is diagnosed with vascular dementia. The Geriatrician recommends he commence some memory medication with the aim of improving the symptoms of dementia.
- Les' family are concerned about Les' fragile health and are worried about the diagnosis of dementia and what it means for Les. The local Aboriginal Health Service's Health Worker visit Les and his family and provide them with some information about dementia and discuss some of the symptoms and difficulties Les is experiencing. They also discuss what limited options are available to Les within the community and what to expect as his dementia progresses. The health worker also makes a referral to NT DBMAS.
- The Northern Territory Dementia Behaviour Advisory Service (NT DBMAS) visit Les' community and they arrange to meet with the family and the local health clinic. The DBMAS representative provides additional education and support to the family and advice to the health worker regarding ongoing management.
- The key worker from the local Aged Care and Disability team and Les' extended family decide to put services in place so that Les can remain at home as long as possible with the support of their local Aboriginal Health Service. Services are put in place from Home and Community Care and an application is made for a Community Aged Care Package (CACP). The family make sure Les is still able to participate in local community events and activities.
- Les' needs continue to increase. Les' family have the option to access respite in the community or in a facility in Darwin. Options for travel to Darwin are for Les to fly to Darwin or for the family to drive Les to Darwin – a 10 hour return trip. The family decides to fly Les to Darwin, but Les will not settle on the plane and becomes very agitated and distressed. The family decide to drive him to Darwin in future, placing a large strain on Les and his family. While in respite care in Darwin, Les is able to see a specialist about his increasing needs.

- As Les' dementia progresses he has reverted to speaking almost exclusively in his own language. He cannot easily be understood by people outside of the community. His treating doctor identifies that his condition is palliative and discusses plans for end of life care with the family.
- Aided by an EACH care package, the local health service and with the consultative support of palliative care services in Darwin, Les is returned to his community to pass away. The family share the care responsibilities throughout the community recognising that it is culturally vital that Les die on his home soil in the company of his extended family. Les seems more at peace until the time of his passing.

Key messages

- Aboriginal and Torres Strait Islander people with dementia rarely access mainstream government funded community care programs. Key role of Aboriginal Liaison Officer (e.g. South Australia and Queensland).
- Crucial role for dementia care provided by Aboriginal Medical Services, Aboriginal Home Care Services, Aboriginal hospital liaison roles and locally skilled services.
- Importance of exploring stigma and perceptions of dementia to encourage investigation of symptoms and seeking treatment, assistance and support (as appropriate).
- Kimberley Indigenous Cognitive Assessment (KICA) – early assessment diagnostic tool recommended for rural and remote Aboriginal and Torres Strait Islander aged 45 years and above for whom other dementia assessments are not suitable.
- Challenge of limited range of diagnostic and support service available in remote locations.

Case scenario - Person with dementia from a culturally and linguistically diverse background

MARIO is 79 years old. He lives with his wife, Sophia in an inner northern suburb of Melbourne. Mario and Sophia migrated from Italy in their early twenties, immediately after World War II. Their daughters live nearby, and family visits occur once a week. Over the past year, Mario has become increasingly disinterested in family activities, gardening and going to his local pensioner club. He has frequent recent memory loss, particularly of recent conversations and events. He is more short tempered than normal and becomes frustrated when he cannot do things. Mario is an insulin dependant diabetic and is not managing his medication well. Sophia is worried about him but puts it down to old age. She does not raise her concerns as she knows how this will upset him.

Mario *“I am not interested in going to the pensioner club. I have nothing to talk about. I am happy at home.”*

Sophia *“Mario has been feeling a bit flat and not really interested in the things he normally likes doing. When the grandchildren are around he gets quite agitated and frustrated with the noise and he has started having difficulty following what they are saying in English. This was not a problem before. Mario thinks that there is nothing wrong with him and I can't get him to the doctor as he hates going to doctor. I just don't know what to do.”*

Sophia attends lunch with her friends at the Italian Club. There is a talk given by the CALD Service Access Liaison Officer from Alzheimer's Australia Victoria (AAV) that has been organised by an aged care worker from COASIT, the local Italian welfare agency. The Officer from AAV is assisted by a professional Italian interpreter. She talks about the difference between normal forgetfulness and memory loss that people are concerned with. She also talks about behaviour change, why seeking medical assistance is important, and how there is a range of information, social and care supports available to help. She distributes information in Italian, including a brochure that contains a checklist of common concerns (Alzheimer's Australia publication - Worried about your memory).

Sophia shows her daughters the brochure obtained at the AAV information session. She discusses her concerns with their oldest daughter, but the daughter dismisses her mother's concerns of memory loss and suggests that her father may be depressed by the recent death of his brother in Italy. Sophia does not want to speak to her friends and extended family about her concerns. Many of them have stopped coming around because of Mario's behaviour. Visitors to the house are offered continuous explanation by Sophia of Mario's behaviour.

With nobody to speak to, Sophia consults with her local church priest for advice on Mario's health situation and the difficult family time. She then approaches the aged care worker from COASIT. She asks the worker to visit them at home to talk about Mario's memory loss and behaviour. The aged care worker visits Sophia at home to talk about recent events with the couple. She has brought with her clear and simple translations in Italian on dementia and behavioural issues (sourced from Alzheimer's Australia Victoria). The worker clearly explains things to Sophia.

Sophia discusses her concerns with Mario. Initially, he is reluctant to admit there is a problem, but he acknowledges that he has not been acting himself lately and knows his wife is worried about him. He agrees to see his doctor for a check up. The doctor refers Mario to the Royal District Nursing Service (RDNS) for daily visits to support Mario with administering insulin injections.

During the assessment process, the District Nurse learns about Sophia and Mario's life experiences, personal and cultural beliefs around health and illness. The District Nurse screens for depression and finds that Mario is not depressed. The District Nurse suspects that Mario may be experiencing early changes to his cognitive functioning. He conducts a cognition assessment using the Rowland Universal Dementia Assessment Scale (RUDAS) to screen for cognitive impairment, with help from an interpreter. The District Nurse discusses the outcome with Mario's doctor, and the doctor refers Mario to the Cognitive Dementia and Memory Service (CDAMS) at The Royal Melbourne Hospital for assessment and diagnosis. The daughters ask that Mario is not told about his diagnosis as they believe that he will give up hope and lose the will to live. CDAMS refers Sophia to the AAV counselling service (Italian speaking counsellor) to assist her in coping with the new diagnosis. In consultation with the AAV counsellor and the local doctor, the District Nurse refers both Mario and Sophia to culturally and linguistically appropriate supports offered through the Home and Community Care Program.

Over the coming years, Mario's symptoms of dementia progress, and Sophia is finding it difficult to manage all the time with Mario. He speaks very little English and he has some problems expressing and understanding in Italian. Mario repeats questions and continually asks Sophia for the day and time. The District Nurse discusses increasing the existing home supports and exploring options including services with Italian speaking staff. Sophia and her daughters agree. The District Nurse makes a referral to the local Aged Care Assessment Service (ACAS), and an aged care assessment is undertaken with the help of a professional Italian interpreter.

A Community Aged Care Package (CACP) package is offered by COASIT and accepted by Sophia. Sophia is encouraged to use activity based services, day respite and home respite to support social participation for her and Mario – and provide respite for Sophia to maintain her carer role. Sophia accepts for Mario to attend an Italian planned activity group one day a week. She does not accept anything else.

In the months following, Sophia's health deteriorates. She is diagnosed with diabetes and is displaying symptoms of depression. She has hip replacement surgery and, during this time, Mario was cared for by his daughters, spending some time each week at the planned activity group and the local Council HACC (Home and Community Care) Italian specific day care centre. He also spent a week at the cottage respite service offered by the local Migrant Resource Centre. Mario has become very dependant on Sophia and now needs assistance with most activities of daily living.

Sophia and her daughters meet with their Case Manager from COASIT to discuss the change in situation. Sophia describes Mario's deteriorating condition as more apparent and disabling. She cries and explains to the Italian speaking Case Manager that Mario is forgetting the names of their daughters and grandchildren. Mario needs help with washing and bathing and is incontinent. Sophia is not coping with the situation. The Case Manager contacts the District Nurse who is supporting Sophia and Mario with diabetes to discuss Mario's additional nursing needs. A continence assessment is undertaken, and the necessary equipment and supports are organised. Mario has been re-assessed by ACAS and is now on an Extended Aged Care at Home-Dementia Package (EACH-D) with

COASIT and the same Italian speaking Case Manager. An Italian speaking personal care worker is offered through the package to assist Mario with washing and bathing and to provide Sophia with some in-home respite. The worker would also drive them to regular medical appointments as both Sophia and Mario are no longer able to drive. Sophia insists that Mario be cared for at home and reluctantly accepts the services offered by the Case Manager.

In consultation with the COASIT Case Manager and the local doctor, the visiting District Nurse instigates a palliative care approach. A referral is made to the local community palliative care service, and the District Nurse works in collaboration with the community palliative care service to assess and plan ongoing care to ensure that Mario, Sophia and their daughters' physical, emotional, social, spiritual and cultural needs and values are met.

The Italian speaking counsellor from the community palliative care service visits them at home to support Sophia and her daughters to better understand the changes that are occurring and understand the benefits that Palliative Care can offer. They are provided with written information about palliative care in both English and Italian. Sophia and her daughters have requested that Mario is not told about his prognosis.

The priest is requested by the family to visit the home to administer the last rights to Mario. He dies at home from pneumonia. Many of the care and service workers visit the house to give their condolences and attend the Rosary and the funeral. The Italian speaking counsellor from the community palliative care service continues to provide bereavement support to Sophia and her daughters for some time after Mario's death.

Key messages

- People with dementia and their carers and family come from diverse cultural backgrounds with diverse needs.
- Perceptions, views and opinions about dementia vary across and within population groups. This greatly influences health seeking behaviour and disclosure about illness.
- High importance of Key Worker(s) across the dementia pathway (e.g. Ethno-specific organisation, CACP/EACH Case Manager, Local Doctor, Alzheimer's Australia, District Nurse, Community Palliative Care Service).
- Older adults from CALD backgrounds are more likely to encounter a range of obstacles along their journey with dementia. These obstacles include a lack of access to culturally appropriate information and support services, culturally sensitive assessment and poor cultural competency of health professionals¹⁰.
- Explicit focus on targeting the range of CALD groups to promote awareness, recognition and understanding of the symptoms and behaviours associated with dementia and the merits of medical investigation (timely diagnosis, forward planning, access to information and support services).
- Linguistically and culturally appropriate service provision is required across the spectrum of service types including general practice, community care, respite, acute and residential care.
- Use professional interpreting services familiar with the aged care sector for dementia assessments, and when care plans are developed and reviewed.

- Most cognitive functioning tests have not been validated for non English speakers, which can lead to over diagnosis of dementia. It is important to use culturally and linguistically appropriate tools such as the RUDAS.
- Linguistically and culturally appropriate ‘activity-based’ services are particularly highly valued.
- Review use of service types by CALD status and work toward addressing any variation by cultural or language status.
- Generally there is under-use of Home and Community Care and Residential Care services by CALD population groups. There is good take-up of packaged care by CALD.
- Consider ethno-specific (targeting a single language group) or multicultural dementia services (catering for numerous language groups).
- When providing care, it is important never to make assumptions about the impact of culture and/or religion on an individual’s (and their family’s) end of life care needs.
- Every individual is unique and requires assessment and ongoing care to ensure their physical, emotional, social, spiritual and cultural needs are met.
- Bereavement and care of a deceased person must be responsive to the diversity of grief and mourning traditions and practices, and the varying views around death and accompanying rituals.

Alzheimer’s Australia National Cross Cultural Dementia Network are acknowledged for input to this case scenario.

Case scenario - Person with younger onset dementia (YOD) under the age of 65 years

PAUL trained as an Engineer and has worked for the past 20 years in a variety of engineering companies, both in Australia and overseas. He has a wide variety of interests and particularly enjoys cycling, reading and practicing his guitar playing in his spare time. He is married with two children – one in primary school and the other in early high school. His wife, Claire works part-time, and they are both actively involved in their children's school activities. Recently, Paul has been struggling at work – he has been finding it difficult to remember things and to communicate what he thinks and feels – he initially puts this down to stress and tiredness.

Paul *“I have always been good at my job and could deal with the day-to-day stresses with ease. I have always been good with figures and had no trouble with the scientific aspects of my work. However, I noticed that I was beginning to have trouble with the things that I have been doing for my entire career, forgetting things and making simple mistakes. I tried to cover this up but felt embarrassed and awkward about it – worried that my colleagues might find out. I had no idea what was going on....”*

- Paul confides to his wife that he is struggling at work and finds it stressful that he is 'not on top of his game' as he used to be. His behaviour has become increasingly difficult and erratic at home and he seems irritable toward his children. His wife, Claire has noticed the change in her husband for some time. She encourages him to see his General Practitioner.
- The General Practitioner conducts an initial assessment and, based on the results, refers Paul to a specialist for further investigation. This upsets Paul as he thought he was just tired and stressed and becomes anxious as he waits for his specialist appointment. The specialist conducts a variety of tests and, after a period of time, diagnoses Paul with fronto-temporal dementia (FTD). The specialist discusses with Paul what this means for him and his family. Paul is in disbelief and Claire feels anxious for the future. They are recommended to get in contact with Alzheimer's Australia for information and support. They do not tell anyone of the diagnosis.
- As Paul's condition progresses, the impact on the family becomes greater. Paul is no longer able to work, and Claire finds herself taking over running the household, looking after the children and working full-time to keep the family going. They are having difficulty meeting their mortgage repayments, and the children are feeling unsettled and the youngest is misbehaving in school. Claire becomes overwhelmed and depressed. Paul is not as engaged with life as he used to be and no longer cycles or plays guitar.

At this point, their General Practitioner refers them again to attend Alzheimer's Australia to access information and support. As a result, Claire and the children attend a 'younger onset dementia' support group. Paul attends a younger onset social/activity group which also provides Claire with some respite. Alzheimer's Australia encourages accessing age-specific day respite care and to consider accessing residential respite when needed. Alzheimer's Australia also help Paul's two children to access a support group for people of the same age to discuss their thoughts and feelings that surface about the changes in their father.

With support from their General Practitioner, Paul and Claire explore and agree to Enduring Power of Attorney and Advance Care Planning. Claire also investigates receiving some in-

home assistance to help with the pressures of running the household. Claire feels a greater sense of control and ability to plan ahead. The whole family benefits from the greater social engagement that these support services allow and provide. Both Paul and Claire also see a financial counsellor/adviser regarding future planning around issues of superannuation, insurance and access to funds to ensure the family is taken care of. The financial planner recommends that Paul and Claire seek financial advice/assistance from Centrelink (such as accessing disability pension and/or carer's allowance).

Over time, Paul displays increasing Behavioural and Psychological Symptoms of Dementia (BPSD) and Claire seeks assistance to manage chronic and acute episodes, including brokered support for respite and residential care/acute inpatient facility.

Key messages

- Consider challenges of younger onset for person living with dementia, their carer/s and family (importance of age-appropriate services, information and support groups).
- Importance of age-appropriate services especially 'activity-based' services, support groups for families and carers, respite and residential care services. Importance of access to support for Behavioural and Psychological Symptoms of Dementia (BPSD) including acute inpatient care, respite care and information and in-home support.
- Consider day-to-day issues such as driving, financial stability and forward planning.
- Commonly no co-morbidities.
- Consider the impact of diagnosis and associated changes in the adult on the children in the family. This might include the change in role from child to carer and the associated emotional and social impacts this will have on the children.

Case scenario - Person (with undiagnosed dementia) presenting to an emergency department of a hospital or other acute setting with other co-morbidities

JOAN is 82 years old and lives in a retirement village. She has type 2 diabetes and rheumatoid arthritis that impact on her ability to perform activities of daily living. Joan has personal carers from Blue Care that come to the home once a day to help her wash and dress and she has a regular delivery of meals on wheels. In addition, a nurse visits her home a number of times a week to dress a chronic leg ulcer on her ankle. Recently, the nurses have noticed that Joan's ulcer is not improving and that she appears to be tired, confused and unsteady on her feet.

Joan *"I have not been feeling myself for a couple of days and my sore leg is bothering me more than normal. It just doesn't seem to be getting better. When the carers came to help me wash this morning I didn't want to get out of bed. I felt really tired and feverish and I was having trouble understanding what they were saying. I'm not really sure what happened next, it was very confusing and a bit frightening, I think an ambulance came to get me, now I'm in the hospital."*

Joan was taken to the emergency department where she was diagnosed with an infection, and it was decided that she would be treated in hospital with intravenous antibiotics. In the emergency department, a member of the Aged Care in Emergency Team (ASET) met Joan and identified that she was confused and agitated. They took her to a quiet area to assess her. A cognitive assessment was conducted, and it identified that she was disorientated, had short-term memory loss suggesting a delirium. The team prompt her to eat and drink during her stay in emergency and provide other cues to orientate her to time and place.

The ASET team contact Joan's General Practitioner and the community services that have been visiting her in the home. They both report a gradual deterioration in Joan's condition over the previous six months. The ASET team liaise with the medical staff, and Joan is fast tracked through the Emergency Department and admitted to an acute geriatric ward.

Joan is admitted to the geriatric ward and her infection responds well to treatment. The ward is less hectic than the normal medical wards and has large clocks and easy to read signs to orientate the patients. While on the ward, Joan has a comprehensive assessment of her underlying medical conditions, current medication and cognition. Her underlying medical problems are identified and rectified by the team. Her cognitive impairment is recognised as warranting further investigation once her delirium has settled. A referral to a multidisciplinary memory clinic (or specialist) is made, and follow up arranged to support/encourage investigation.

To prepare Joan for discharge from the hospital, the multidisciplinary team liaise with Blue Care to find out what services she has been receiving at home. They arrange for an Occupational Therapy assessment of her home. Blue Care agrees to assist in transporting Joan to attend clinic appointments and associated investigations as well as activities conducted by the local Alzheimer's Australia group. Joan's General Practitioner is provided with information regarding her hospital stay and ongoing care arrangements, including a request to encourage Joan and her family to attend the memory clinic (specialist).

Key messages

- Within the hospital setting, there is early recognition and assessment of cognitive symptoms and action taken to minimise the environmental factors that will exacerbate symptoms.
- Presenting illness is treated rapidly and a comprehensive assessment is conducted to diagnoses and treat underlying medical conditions/medications that may impact on cognition.
- Coordinated discharge planning occurs to ensure that there is a seamless transition from hospital to the community – home or residential care (including memory clinic (specialist) engagement) and adequate supports services are in place to prevent readmission.
- People living with dementia are linked into dementia care and supports.

Appendices



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A Self-assessment tool – Dementia services pathways

The following self-assessment tool is designed to support a high level assessment of current dementia service pathways (at a jurisdiction, region or local community level). The tool is designed to be used to support service planning and in conjunction with the Dementia Services Pathways Framework (p.7) and the Elements to be addressed (p.13). The tool may be completed by service planners prior to a workshop, or by workshop participants to prompt discussion. Review of the tool may prompt consideration of how the tool can best be used to assist with local service planning activity.

It is recommended that the:

- self-assessment tool be printed for completion
- process of completing the self-assessment be used to prompt discussion of current practice and current outcomes for people living with dementia and their carers
- results of the self-assessment be used to prioritise and prompt particular areas for attention, service planning and action.

Please rate and complete all sections. The self-assessment calls for a tick (✓) response to each item and a brief comment on areas for attention/further exploration of how to respond.



| (1) AWARENESS, RECOGNITION AND REFERRAL | Not present | In part/ planned | Established | Not Applicable |
|--|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. Is there a program/s to improve the knowledge, skills and behaviours across settings to be aware of, recognise and appropriately respond to symptoms of dementia? | | | | |
| • General Practice | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Community care | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Community health | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Residential aged care facilities | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Acute care services/ hospital setting | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Engage with populations with specific needs (e.g. CALD, Aboriginal and Torres Strait Islanders) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Are there visible, simplified points of access for diagnosis, information and support services? | | | | |
| • For service providers | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • For general public | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments – areas for attention/further exploration</i> | | | | |



| (2) INITIAL ASSESSMENT, DIAGNOSIS AND POST-DIAGNOSIS SUPPORT | Not present | In part/ planned | Established | Not Applicable |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| 3. Is there a locally defined dementia pathway for initial assessment and diagnosis, developed with and including roles for general practice, medical specialists, hospitals, community and aged care services? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Are staff trained and supported to routinely use culturally appropriate assessment tools (e.g. RUDAS, KICA (remote settings), GPCOG)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Are there links and access to post-diagnostic information, counselling and support services for all who receive a diagnosis of dementia, their family and carers? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Is assistance available to access support services for 'vulnerable' people living with dementia or their carers? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. Are comprehensive care plans developed at time of diagnosis? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Do all people living with dementia and their carers have a Dementia key worker to inform and aid timely access and coordination of services? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 9. Is there a system in place for sharing of information related to assessment and subsequent service coordination across the various health and service providers involved in care? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments – areas for attention/further exploration</i> | | | | |

| (3) MANAGEMENT, CARE, SUPPORT AND REVIEW | Not present | In part/ planned | Established | Not Applicable |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| 10. Are there plans/activity to minimise 'transition' points of care provision for people living with dementia and their carers (e.g. from one community service provider to another due to increasing need)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 11. Are people living with dementia and their carers supported to maintain social participation? | | | | |
| • Range of 'social and activity-based' community services for people with dementia | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • In-home and centre-based day care (consider access and utilisation) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Cottage style home and residential respite (consider access and utilisation) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 12. Are the diverse needs of all people living with dementia equally served? | | | | |
| • Aboriginal and Torres Strait Islander populations | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Culturally and linguistically diverse | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Rural and remote | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| • Younger onset dementia | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 13. Are people supported to explore and develop Advance Care Plans and/or appoint enduring guardianship at the appropriate time/s? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |



| (3) MANAGEMENT, CARE, SUPPORT AND REVIEW | Not present | In part/ planned | Established | Not Applicable |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| 14. Are there effective links between general practice, acute/hospital services and residential care to support quality dementia care for people living with dementia in residential care? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Acute/hospital setting | | | | |
| 15. Is there targeted screening and assessment of cognition for presentations/admissions of patients 65 years and over? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 16. Is there a system in place to prevent or minimise exacerbation of behaviours/cognitive symptoms through the provision of adequate nursing support and suitable environments? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 17. Is there a program to reduce adverse outcomes for people with cognitive impairment and improve transition to home or residential care? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 18. Is there a falls reduction program, with cognitive impairment a priority group? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 19. Is there a routine referral for diagnostic investigation of people identified with cognitive impairment undiagnosed prior to presentation/admission (i.e. referral and follow up for diagnostic investigation in the community via General Practitioner or community memory assessment clinic)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments – areas for attention/further exploration</i> | | | | |



| (4) END OF LIFE | Not present | In part/ planned | Established | Not Applicable |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| 20. Are there palliative care teams supporting general practice and residential care facilities with end of life dementia care (for in home and residential care settings)? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 21. Are there dementia end of life service models defined and employed for end of life care? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 22. Are residential care staff, with support from general practice and consulting palliative care teams, providing quality end of life dementia care? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| <i>Comments – areas for attention/ further exploration</i> | | | | |

B Summary – additional areas for state and territory consideration for planning and pathway development

In addition, a short summary of additional areas for consideration for states and territories is provided below.

As part of local, regional and state dementia planning, consider the following:

- Opportunity to **improve community dementia awareness, knowledge and behaviour** (aim to encourage people with concerns associated with dementia symptoms to seek medical advice and contact Dementia Help line/Alzheimer's Australia).
- The **establishment of consistent jurisdiction-wide dementia clinical network/s**¹ for diagnosis, assessment and support to maximise outcomes from resources available, including determining appropriate model/s for diagnosis, assessment and support pathway for local refinement at the regional/local level (especially maximise results based on availability and distribution of current and planned multidisciplinary workforce—including medical specialists).
- A greater emphasis on inclusive dementia service planning – inclusive of spectrum of service providers including local health networks, community, aged and acute care. Ensure inclusion of Dementia Behaviour Management Advisory Service (DBMAS) and Alzheimer's Australia Dementia helpline to access information and support via telephone or consultation.
- **Engaging with primary health care organisations (Divisions of General Practice/Medicare Locals)** – to participate in defining local/regional pathway and encourage uptake of dementia training opportunities by general practice.
- **Include hospital presentation/admission as part of dementia pathways – key interface to dementia service system** including referral for diagnosis and to access to spectrum of services – recognising that for many people attendance or admission to hospital provides an opportunity for entry to dementia pathway (including assessment/diagnostic investigation, and accessing information and support services as appropriate).
- **Increasing access to multidisciplinary memory clinics or comparable functionality** (i.e. multidisciplinary assessment including medical specialists). For lower density populations, where such clinic is not viable, it is critical to define roles and responsibilities of service providers to support a clear pathway for assessment and diagnosis – consider inclusion of spectrum of service providers including community and allied health, general practice (General Practitioner and Practice Nurse), visiting medical specialists, and the use of telemedicine.
- **Use of standardised training and interpretation of dementia assessment tools** as part of pathway – for example, the General Practitioner Assessment of Cognition

¹ Adopted from Queensland Health. Dementia Framework 2010 – 2014. Available from: http://www.health.qld.gov.au/cpic/documents/Dem_Net_Frame14.pdf, accessed May 2010.

(GPCOG), Kimberley Indigenous Cognition Assessment (KICA) and the Rowland Universal Dementia Assessment Scale (RUDAS).

- **Improve links with service system to specialist dementia services and peak bodies** for education, information and support (e.g. Alzheimer's Australia) and dementia behaviour management advisory services (DBMAS).
- The use of telemedicine, online inpatient assessment, data transfer and e-health initiatives to take specialist dementia services into rural and remote areas of each state/territory.
- Developing and implementing widespread training and assessment of all health and community carer professionals' skills and knowledge concerning dementia. Further, these skills should be assessed on a regular basis to ensure a standard quality of care and level of information sharing to improve timely diagnosis and support quality dementia care.
- **Increasing the employment, and use of Practice Nurses** along with supporting their ongoing training and development to aid with the assessment and case management of dementia within primary care.

C Glossary

| Terms | Definitions |
|---|--|
| Acute care | Care provided usually as a result of a medical crisis – planned or unplanned. Includes care provided in emergency departments and inpatient hospital care. |
| Advance care directives | Also termed “living will” or “refusal of treatment certificate”. The document states instructions for the care to be implemented in the event of future decisional incapacity. In some cases, it is formal and legally endorsed. |
| Advance care planning | A process that allows a competent individual to express their views in relation to future health care decisions when the capacity to express those views is lost. The outcome of an ACP process is an Advance Care Plan that may include: <ul style="list-style-type: none"> a) an Advance (Health or Care) Directive (AD) (or other similar instruments); b) a Medical Enduring Power of Attorney (EPA) (or other similar instruments); c) a letter to the person who will be responsible for this decision-making; d) an entry in the patient medical record; e) a verbal instruction or other communication which clearly enunciates a patient’s view; or f) any combination of the above¹¹. |
| Advocate | An advocate is someone who speaks on behalf of another person, especially in a legal context. Implicit in the concept is the notion that the represented person lacks the knowledge, skill, ability, or standing to speak for themselves. |
| ACAS | Aged Care Assessment Service |
| Behavioural and Psychological Symptoms of Dementia (BPSD) | This is an umbrella term for a heterogeneous group of non-cognitive symptoms used to describe a range of symptoms that are associated with disturbed perception, thought content, behaviour or mood related to the presence of dementia, such as anxiety, depression, hallucinations, delusions, misidentifications, mania and personality changes. ¹² |

| Terms | Definitions |
|---|---|
| Community Aged Care Package (CACP) | These packages provide planned and managed packages of community care to individuals who have complex care needs and who live at home. |
| Community care | Care that is provided to a person in their community as opposed to care that is provided in a residential facility. |
| Carer | Usually a family member or friend. Their work is based on a pre-existing relationship and is unpaid. The primary carer is the person who has provided the most assistance to the person in relation to self-care, mobility and communication and other needs. |
| Dementia | A syndrome due to disease of the brain, usually of a chronic or progressive nature, which causes a decline in memory, thinking, orientation, comprehension, calculation, learning capacity, language and judgement. |
| Dementia friendly service | <p>People with dementia, their carers and families are central to making choices about care. Service responses recognise people's individual journeys and are alert to the signs and symptoms of dementia. Cognitive impairment is recognised and steps are taken to minimise the symptoms of anxiety, fear or confusion that may emerge as a result of interaction with the service.</p> <p>People with dementia are valued and respected. Carers and families are valued and supported and their efforts are recognised and encouraged. All people with dementia, their carers and families receive appropriate services that respond to their social, cultural or economic background, location and needs. Also known as 'dementia appropriate'.</p> |
| Dual disability | The co-existence of two or more conditions such as Down syndrome and Dementia. |
| Extended Aged Care at Home Package (EACH) | This is a coordinated package of care designed for care recipients who are eligible for high level residential aged care. Services provided by an EACH package include those available to CACP care recipients plus nursing care and allied health care. |

| Terms | Definitions |
|--|---|
| Extended Aged Care at Home – Dementia Package (EACH-D) | This is an extension on the EACH program described above and has been in operation since 2006. It essentially provides a community care option specifically aimed at high care clients with dementia and behavioural and psychological symptoms. While recipients on an EACH-D package can access the same types of assistance as an EACH package, the difference lies in the degree of flexibility with the approach and strategies that are appropriate for people with dementia, and in providing access to dementia specific specialist services and support. |
| GPCOG | General Practitioner assessment of Cognition |
| Home and Community Care (HACC) | A host of different service agencies may provide particular types of assistance including personal care, domestic assistance, nursing care, social support, allied health care, respite care, centre-based day care, meals and other food services, home maintenance, home modification, transport, formal linen services, counselling/support, information and advocacy, assessment, case planning/review and coordination. |
| Hospice | Hospices provide accommodation and cares services for people with life-limiting illnesses who require permanent accommodation at the end stage of life or shorter-term respite care. |
| Incidence | The number of new cases of a disease or condition in a certain population during a given time period. Incidence provides an indicator of the risk of developing a particular disease or condition during a certain time period. |
| Key worker | This is a health or community professional who is appointed as a single point of contact for the person diagnosed with dementia, their family and carer(s). The role involves case coordination or management. The key worker is often identified in consultation with the person diagnosed and their carer and is a major support for the person diagnosed and their carer along the dementia pathway. Commonly, a key worker for ethnic communities will be workers in ethnic or multicultural agencies. |
| KICA | Kimberley Indigenous Cognitive Assessment Tool |
| MMSE | Mini-Mental State Examination or Folstein test is a brief, 30-point questionnaire/test that is used to assess for cognitive impairment. |

| Terms | Definitions |
|--|--|
| <p>Multidisciplinary Memory Service/Clinic</p> | <p>A specialist multidisciplinary diagnostic service for people experiencing memory loss or changes to their thinking and for those who care about them. It provides expert clinical diagnosis, information on appropriate treatments, education, support, information and direction in future planning.</p> |
| <p>Palliative Care</p> | <p>This is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:</p> <ul style="list-style-type: none"> • provides relief from pain and other distressing symptoms • affirms life and regards dying as a normal process • intends neither to hasten nor postpone death • integrates the psychological and spiritual aspects of patient care • offers a support system to help patients live as actively as possible until death • offers a support system to help the family cope during the patient's illness and in their own bereavement • uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated • will enhance quality of life, and may also positively influence the course of illness • is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.¹³ |
| <p>Prevalence</p> | <p>The total number of cases of a particular disease in a population at a given time. Often used to estimate how common a disease or condition is within a population over a certain time period.</p> |

| Terms | Definitions |
|------------------------|---|
| Primary care | Services provided by General Practitioners, nurses, community nurses and aged care assessment teams. Includes assessment, diagnosis and treatment services. |
| Residential care | Care provided in an aged care facility, such as a nursing home or hostel. |
| Respite | Temporary care arrangements provided by someone other than the usual carer; also includes short-term residential care. |
| RUDAS | Rowland Universal Dementia Assessment Scale – a multicultural cognitive assessment scale. |
| Transition point | A transition point or ‘care transition’ for a person with dementia is any move between or within formal support interventions, whether a move is due to a change in the type or level of care required or due to other factors. |
| Quality of Life | An individual’s perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns. It incorporates the person’s physical health, psychological state, level of independence, social relationships, personal beliefs and relationships to salient features in the environment. |
| Workforce | Refers to all people employed who provide assistance, care, information or support to people with dementia, their carers and families. |
| Younger Onset Dementia | The term ‘younger onset dementia’ is usually used to describe any form of dementia diagnosed in people under the age of 65 years. |

D Progression of dementia

D.1 How does dementia progress?

The natural history or progression of dementia differs according to its cause and between individuals and across population groups. However, there are commonalities that people living with dementia experience as the disease progresses over time. These commonalities or 'signposts' have important implications for the provision of appropriate, responsive and flexible services for people living with dementia and their carers.

Typical phases of the illnesses

Each person with dementia experiences their illness in their own individual way. The condition usually has a gradual onset, with progressive reduction in cerebral function. People with dementia differ in the patterns of problems they experience and in the speed with which their abilities deteriorate. Therefore, it is difficult to describe a 'typical' journey for someone with dementia. In all cases, it is almost certain that the person's abilities will deteriorate - sometimes rapidly over a few months; in other cases, more slowly, over a number of years.

Features of dementia are commonly classified into stages or phases, and not all of the features of each stage will be present in every person. Early dementia is typically only apparent in hindsight. At the time, it may be missed or put down to old age. Some of the signs of the early phase of dementia include: the person may display mild forgetfulness, lose interest in hobbies or activities, show poor judgement and make poor decisions, be slower to grasp complex ideas and take longer with routine jobs and become more self-centred and less concerned with others and their feelings.

During the moderate phase, the person's problems are more apparent and disabling. They may be very forgetful of recent events, be confused regarding time and place, become lost if away from familiar surroundings, forget names of family or friends, or confuse one family member with another, leave appliances on in the home or things on the stove, behave inappropriately - for example, going outdoors in their nightwear - see or hear things that are not there and/or be neglectful of hygiene or eating. The role of a carer and support services becomes increasingly important.

During the later stage of dementia - severe dementia - the person is severely disabled and may need assistance with all activities of daily living necessitating a carer and support services. At this stage, the person may be unable to remember - for even a few minutes (that they have had, for example, a meal), lose their ability to understand or use speech, be incontinent, show no recognition of friends and family, need help with eating, washing, bathing, using the toilet or dressing, fail to recognise everyday objects, be restless, and/or be aggressive, especially when feeling threatened or closed in¹⁴.

End of life

In the later stages of dementia, the ability to cope by the person living with dementia with infections and other physical problems will be impaired due to the progress of the disease, and the person may die because of an infection, a clot on the lung or a heart attack.

However, in some people, no specific cause of death is found, other than dementia. If the person is over 70, ageing may also be given as a contributory factor. Alternatively, the death of a person with dementia could be caused by a condition that is completely unrelated to their diagnosis of dementia.

At the end of life, a person living with dementia may be cared for in a variety of settings. The type of care required will be determined by the features of dementia that they have, combined with features of any other co-morbidities, the symptoms that they are experiencing, the formal and informal care available to them and the wishes of the person living with dementia, their family and carers. These options include: home, Residential Aged Care Facilities, hospitals and hospices.

D.2 Summary table of progression of dementia

This summary table is provided to prompt discussion of the nature of progression of dementia, and the implications to service delivery. Please note this summary table is adapted from South Australia's Dementia Action Plan 2009-2012: Facing the Challenges Together, Government of South Australia. It should be noted that people with dementia may have very different experiences progressing through the following stages and that the timing and severity of symptoms can vary greatly depending on the different types of dementia.

| | PROGRESSION OF DEMENTIA ¹⁵ | | | |
|---------------------------------------|---|--|---|--|
| IMPACT | Early stages | Mild | Moderate | Advanced |
| Memory | Slight forgetfulness that happens regularly | Noticeable short term memory loss that affects everyday living | Substantial memory loss when only old information can be recalled and new information is rapidly lost | Severe memory loss when only parts of old memories remain |
| Orientation (time, place and persons) | Generally clear, correct and aware | Confusion about dates and times; sometimes mistaking places and becoming lost; difficulty in recognising familiar people | Substantial difficulty in recognising time, places and people. Wandering and become lost may occur. | May recognise people but not recall why; may no longer recognise close family; may no longer talk; may lose mobility |

| | PROGRESSION OF DEMENTIA ¹⁵ | | | |
|-------------------------------|--|--|--|---|
| IMPACT | Early stages | Mild | Moderate | Advanced |
| Judgement and problem solving | Slightly less capacity to problem solve | Difficulty in problem solving | Increased difficulty in problem solving; occasional sexual dis-inhibition; may become upset when faced with change | Unable to make judgements or problem solve; severe depression often accompanied by agitation or psychosis |
| Community participation | Slight communication difficulties that affects participation in social activities | Difficulty finding 'words' or following conversation; needs support in social activities | Lack of interest or willingness to attend social activities; difficulty communicating more apparent; requires constant supervision | Very limited ability to engage and interact with others socially even with supports |
| Home and personal interests | Slight change in ability to do home based activities, hobbies and intellectual interests | Difficulty functioning at home, undertaking or completing tasks | Only effective in simple tasks, lacks interest in usual home based activities and interests, often experiencing from depression | Unable to function at home |
| Personal care | Manages own self-care | May need prompting | Requires assistance | Full assistance required |

E Population groups with specific needs

The following population groups are highlighted as warranting particular consideration when planning services as the nature of service provision and/or their service requirements vary substantially from mainstream service delivery.

E.1 Carers

Many people with dementia currently live in the community, supported by families and friends. Family members and carers may face real challenges in providing care and support, with people often feeling isolated. Understanding the needs of carers is crucial to ensure that the sustainability of the caring relationship is supported throughout the dementia continuum – particularly supporting and sustaining social participation by access to ‘activity-based services’, day and residential respite.

As symptoms of dementia progress and change over time for a person living with dementia, the carer requirements for support will also vary. For example, initial information and support at first diagnosis, coping with and managing change – with an emphasis on respite care and end of life decision making, consideration of advance care planning, understanding the terminal nature of dementia and bereavement). As such, the decision-making process between the person with dementia and their carer also changes over time – with the carer likely to have a more substantial role over time.

Unpaid carers face certain challenges in caring for someone with dementia and often face significant life changes over a long period of time. Carers may face deteriorating physical and mental health, social exclusion and isolation, and financial difficulties as a result of caring. Where carers come from a low socio-economic background, or are from an Aboriginal and Torres Strait Islander or CALD background or live in rural and remote areas, they can be further disadvantaged in their experience of caring and access to support¹⁶. The focus of carers’ supports includes access to information and support groups, and a range of respite options (including ‘activity-based’ services, day and residential respite) that facilitates ongoing support social/community engagement (and avoidance of social isolation). It is important to note that not all people living with dementia have carers.

E.2 Aboriginal and Torres Strait Islander communities

There is growing evidence of the nature and impact of dementia in Aboriginal and Torres Strait Islander communities. Prevalence studies in remote communities show high prevalence rates of dementia in relatively young populations^{17,18}. There may be an increased risk of developing dementia at a younger age (from 45 years) reflecting the continuing poor health status and the burden of chronic disease many Indigenous communities face.

Very few Aboriginal and Torres Strait Islander people with dementia access mainstream government funded community care programs in comparison to the rest of the Australian population.¹⁹ According to Australian Institute of Health and Welfare research,²⁰ an overwhelming majority of Aged Care Assessment Program clients were non-Indigenous,

with only around one per cent of clients identifying as Aboriginal and/or Torres Strait Islander.

The percentage of all care recipients registered with a Commonwealth Carer Respite Centre who were Indigenous was just 3.6 per cent.²¹ This is in contrast to the results of a study conducted in Western Australia, where there was a reported prevalence of dementia of 12.4 per cent – much higher than the average of 2.4 per cent for the overall Australian population aged over 45 years.²² As a result, particular attention is warranted with dementia service planning to engage with and provide services for Aboriginal and Torres Strait Islander populations appropriately to address this imbalance. Current research is exploring the prevalence rates of dementia for Aboriginal and Torres Strait Islander populations in urban settings²³.

E.3 Culturally and linguistically diverse communities

There is a general under-utilisation of all types of universal government funded services as well as non-government services by people from a CALD background, influenced by the level of information available, language barriers, cultural factors, cultural appropriateness of services, and often a strong preference for care to occur in the home. These factors impact on the likelihood of and services required as an outcome of initial medical diagnosis.

There can be a tension between culturally and linguistically specific services and universal services – CALD specific services may be better placed to serve the community in terms of their cultural and linguistic needs through their expertise and relevance to CALD communities, while mainstream dementia services are often more likely to have a greater capacity and expertise with dementia focused services.²⁴

Universal agencies may also work in partnership with CALD community and aged care services to provide culturally and linguistically appropriate services and build a greater diversity competence within their service framework. Engagement with all groups (including CALD community groups) is of particular importance, and consideration of culturally and linguistically appropriate ‘activity-based’ activities and support is encouraged to address the diversity of service requirements.

E.4 Younger onset dementia

Dementia in young people, while not common, presents certain challenges not only for the person with dementia, their family and carers, but to the provision of dementia services which is geared toward older people with dementia. Dementia in young people is usually described as younger onset dementia for those aged 65 years and under. There is a very limited range of age-appropriate services for people with younger onset dementia – including community activity based services, day care and residential respite options.

Support services for people with dementia under 65 years of age may be administered as disability support (rather than aged care), and this needs to be considered when planning services. However when residential services are required for people with younger onset dementia, there are limited options and these individuals may be cared for in residential

aged care facilities. This is often not appropriate for the person living with dementia, their family or the other residents in the facility.

E.5 Rural and remote communities

There is a growing body of research arising from the Dementia Initiative of the needs of people with dementia in rural and remote locations in Australia. People with dementia in rural and remote locations face unique challenges with some overlap in issues facing Aboriginal and Torres Strait Islanders with dementia, and reflecting an increasingly diverse population. This is compounded by poorer health status generally than that of metropolitan-dwelling Australians. Common challenges or issues include:

- limited access to medical and community services (many communities are too small to support a range of viable services – especially diagnostic services);
- disruption caused to the person with dementia and their family/carer in moving that person away from home to access services;
- reluctance to use services due to perceptions of greater stigma attached to dementia or behavioural and psychological symptoms of dementia in small communities;
- lack of staff with dementia specific training and skills and low level of awareness of dementia issues; and
- limited respite and residential care options, and isolation (both physical and social).

E.6 Living alone with dementia

It is anticipated that this group will grow in size over time due to the ageing of the population and changing family/relationship structures (divorce, separation, delays in marriage, childlessness, etc). It is important that service planning considers the needs of people living alone with dementia, and how to support the person to live at home as appropriate. Dementia ‘monitors’ who check up on people living alone may be one approach to assist with matching services to the level of need.

E.7 HIV-related dementia

People who have HIV are at risk of developing HIV-related dementia known as AIDS Dementia Complex. AIDS Dementia Complex is a complicated syndrome made up of different nervous system and mental symptoms that can develop in some people with HIV. The incidence of AIDS Dementia Complex is uncommon in people with the early stages of the disease, but may increase as the disease advances. Not everyone who has HIV/AIDS will develop AIDS Dementia Complex.²⁵

Because HIV/AIDS affects so many young people, there are particular issues, such as employment, identity and sexuality, which need to be addressed in concert. HIV/AIDS is still a disease that is stigmatised, and the effect of dementia on top of the diagnosis of HIV/AIDS can pose particular challenges.²⁶

E.8 Intellectual disability and dementia

In Australia, adults with intellectual disabilities have access to general services including medical care. However, availability of services designed to specifically meet the needs of adults with intellectual disability is often limited, and services relating to both ageing and intellectual disability are almost nonexistent.²⁷

Studies suggest that, in comparison to the general population, dementia may be more common among people with an intellectual disability, and they may develop dementia at an earlier age.

F Potential participants for dementia services pathways workshop

- General Practitioners/division of general practice
- Aged Care Assessment Team/Service (ACAT/ACAS)
- Alzheimer's Australia representative
- HACC service provider representative
- Residential Care Facility representative
- Aged care and geriatric service
- Identified dementia specific services including representatives from the private and not-for-profit sectors
- Memory clinics/services e.g. Cognitive, Dementia and Memory Service (CDAMS)
- Dementia advisory service
- Local government representative
- Indigenous representative/Aboriginal Medical Service
- CALD representative
- Palliative care representative.
- Dementia Behaviour Management Advisory Services
- Carers association representative
- State/Territory departmental representatives:
 - Health, including mental health and aged care policy
 - Disability and homecare
 - Community services
- Royal Australian College of Psychiatrists (State representative)
- Australian and New Zealand Society for Geriatric Medicine (State representative)
- Australian Association of Gerontology (State representative)
- Veterans' home care
- Relevant research organisations in ageing and dementia
- Australian Nursing Federation
- Aged/Older Person Mental Health Services, e.g. Aged Psychiatry Team
- Representative of neurology services
- Academic, education and research representatives e.g. Dementia Collaborative Research Centre [DCRC] and Dementia Training and Study Centre (DTSC)
- National Carers Association

G Supporting documents by management stage of dementia

The following references provide examples of useful documents that illustrate best practice for each management stage of the dementia services pathway.

- Dementia Resource Guide, Department of Health and Ageing 2007
<http://www.health.gov.au/internet/main/publishing.nsf/Content/35DF1D4D4EBD8747CA257693001DEFFC>
- Dementia Learning Resource for Aboriginal and Torres Strait Islander Communities
<http://www.alzheimers.org.au/understanding-dementia/dementia-learning-resource-for-aboriginal-and-torres-strait-islander-communities.aspx>
- Centre for Cultural Diversity in Ageing, Dementia Care.
<http://www.culturaldiversity.com.au/resources/direct-care-services/dementia-care>

G.1 Awareness, recognition and referral

- One-Stop Shops for Access to Aged Care Information, Assessment and Services. Department of Health and Ageing. Available from:
<<http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/factsheet-agedcare-03>>, accessed October 2010.
- Alzheimer's Australia. (2008). Perceptions of dementia in ethnic communities.

G.2 Initial assessment and diagnosis, and post diagnosis support

- Cognitive, Dementia and Memory Service (CDAMS), Victoria
<http://www.health.vic.gov.au/subacute/cdams.htm>
- Clinical practice guidelines and care pathways for people with dementia living in the community <http://eprints.qut.edu.au/17393/1/17393.pdf>
- Dementia Resource Guide, Assessment and diagnosis, Department of Health and Ageing 2007 -
[http://www.health.gov.au/internet/main/publishing.nsf/Content/35DF1D4D4EBD8747CA257693001DEFFC/\\$File/3.%20Assessment%20&%20diagnosis.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/35DF1D4D4EBD8747CA257693001DEFFC/$File/3.%20Assessment%20&%20diagnosis.pdf)
- Diagnosis and management of dementia in general practice. Australian Family Physician. Vol. 33, No. 10, October 2004. Available from:
<[http://www.med.unsw.edu.au/psychweb.nsf/resources/adfoap_GPs/\\$file/Diagnosis+and+management+of+dementia+in+general+practice.pdf](http://www.med.unsw.edu.au/psychweb.nsf/resources/adfoap_GPs/$file/Diagnosis+and+management+of+dementia+in+general+practice.pdf)>, accessed October 2010/
- Information and services for people living with dementia, Department of Health and Ageing, <http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-dementia-living.htm>

- Kimberley Indigenous Cognitive Assessment (KICA), <http://www.wacha.org.au/kica.html>

G.3 Management, care, support and review

- Dementia: Carers and Families Learning Guide. Rural Health Education Foundation. (2007). Available from: <http://www.rhef.com.au/wp-content/uploads/616e_facil_lr.pdf>, accessed October 2010.
- Nunn,R. While,C. & Sims,N. (2009). Out of the shadows. Development of a best practice model of care for people living with dementia. Royal District Nursing Service. http://www.alzheimers.org.au/upload/Nunn_and_While.pdf
- Aged Care and Rehabilitation Newsletter 10, July/August 2010. Clinical Networks Tasmania. Available from: <http://www.dhhs.tas.gov.au/__data/assets/pdf_file/0003/61752/Newsletter_No_10_July_August_2010.pdf>, accessed October 2010 .
- Australian Indigenous Health Infonet - dementia information, available at <http://www.healthinfonet.ecu.edu.au/chronic-conditions/dementia>

G.4 End of life

- Guidelines for a palliative approach in residential aged care. National Health and Medical Research Council (2006). Available from: <<http://www.nhmrc.gov.au/publications/synopses/ac12to14syn.htm>>, accessed October 2010.
- Palliative Dementia Care (COP-D1 Project). Available from: <<http://www.caresearch.com.au/caresearch/WhatisPalliativeCare/NationalPalliativeCareProgram/COPD1PalliativeDementiaCare/tabid/1442/Default.aspx>>, accessed October 2010.
- Community Palliative Care (ComPAC Project). Department of Health and Ageing. Available from: <<http://www.caresearch.com.au/caresearch/WhatisPalliativeCare/NationalPalliativeCareProgram/ComPAC/tabid/93/Default.aspx>>, accessed October 2010.
- Dementia and palliative care: further reading. Available from: <http://www.caresearch.com.au/caresearch/ClinicalPractice/SpecificPopulations/PeoplewithDementia/FurtherReading/tabid/795/Default.aspx>, accessed October 2010.
- Taylor, A & Box, M. (1999). Multicultural Palliative Care Guidelines. Palliative Care Australia <http://www.palliativecare.org.au/Portals/46/Multicultural%20palliative%20care%20guidelines.pdf>
- Providing culturally appropriate palliative care: Aboriginal and Torres Strait Islander Resource Kit Project. Available from: <<http://www.caresearch.com.au/caresearch/WhatisPalliativeCare/NationalPalliativeCareProgram/IndigenousPalliativeCareProject/tabid/86/Default.aspx>>, accessed October 2010.

- Successful pain assessment in older adults with dementia: barriers and strategies. Available from: <<http://www.latrobe.edu.au/acebac/publications/?p=24>>, accessed October 2010.

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- ² Australian Health Ministers Conference, *National Framework for Action on Dementia 2006-2010*. Available from: <<http://health.gov.au/internet/main/publishing.nsf/content/ageing-dementia-nfad>>, accessed February 2009.
- ³ Access Economics 2010 Caring places: planning for aged care and dementia 2010-2050 (Report by Access Economics for Alzheimer's Australia)
- ⁴ Access Economics (2009). Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050. A report prepared for Alzheimer's Australia. (p.4)
- ⁵ Access Economics (2009). Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050. A report prepared for Alzheimer's Australia.
- ⁶ Access Economics (2009). Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050. A report prepared for Alzheimer's Australia.
- ⁷ Access Economics (2009). Keeping Dementia Front of Mind: Incidence and Prevalence 2009-2050. A report prepared for Alzheimer's Australia.
- ⁸ Campbell, H. Hotchkiss, R. Bradshaw, N. and Porteous, M. 1998 Integrated care pathways. *BMJ* 1998; 316:133-137 (10 January).
- ⁹ Jennifer Marriott, The Use of Psycho-tropic Medicines in the Elderly -presentation to Nursing the Confused Elderly Person, Melbourne 3rd 4th Feb 2003AUSMED Publications
- ¹⁰ Alzheimer's Australia. (2008). Perceptions of dementia in ethnic communities.
- ¹¹ AMA Position statement 2007 - Position Statement on the Role of the Medical Practitioner in End of Life Care. <http://ama.com.au/taxonomy/term/866> - viewed August 2010.
- ¹² North West Melbourne Division of General Practice. General Practice in Residential Aged Care Clinical Information Sheets – Dementia: Behavioural and Psychological Symptoms. Available from: <http://www.nwmdgp.org.au/pages/after_hours/GPRAC-CIS-DEM.html>, accessed May 2010.
- ¹³ World Health Organisation. WHO Definition of Palliative Care. Available from: <<http://www.who.int/cancer/palliative/definition/en/>>, accessed November 2010.
- ¹⁴ Better Health Channel. Dementia - through all its stages. Better Health Channel. Available from: <http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Dementia_through_all_its_stages>, accessed August 2010.
- ¹⁵ Adapted from South Australia's Dementia Action Plan 2009-2012: Facing the Challenges Together. Government of South Australia.
- ¹⁶ Carers Australia. Submission to the House of Representatives Inquiry into better Support for Carers (July 2008).
- ¹⁷ Alzheimer's Australia 2007 Dementia: A major health problem for Indigenous people. (Paper No.12, August 2007). <http://www.alzheimers.org.au/upload/Indigenous.pdf>

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https://www.neura.edu.au/sites/neura.edu.au/files/LiteratureReviewSummary_DCRC_0.pdf

¹⁹ Broe, T. Jackson-Pulver, L. Arkles, R. Robertson, H, Kelso, W. Chalkley, S. and Draper, B. (2009) Cognition, Ageing and Dementia in Australian Aboriginal and Torres Strait islander peoples: A Review of the Literature (Summary). Dementia Collaborative Research Centre – Assessment and Better Care Outcomes.
https://www.neura.edu.au/sites/neura.edu.au/files/LiteratureReviewSummary_DCRC_0.pdf

²⁰ Australian Institute of Health and Welfare (2006). Dementia in Australia: National Data Analysis and Development. AIHW Cat. No. AGE 53. Canberra: AIHW.

²¹ Ibid.

²² Smith, K. et al. High prevalence of dementia and cognitive impairment in Indigenous Australians. *Neurology*, 2008, 71(19); p,1470-3.

²³ Jackson-Pulver, L. and Broe, T. (2009). What is the burden of dementia in urban dwelling Indigenous Australians? Research in progress.

²⁴ Cultural and Indigenous Research Centre Australia (April 2008). CALD Dementia Strategic Model: Literature Review, Report and Model. Report prepared by the New South Wales Department of Ageing, Disability and Home Care.

²⁵ Alzheimer's Australia. Living with Dementia Factsheet (2005) AIDS related dementia.

²⁶ Ibid.

²⁷ Trollor, J. Dementia Collaborative Research Centres Newsletter. Issue 6, 2008.