



The Royal Australasian
College of Physicians

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Submission No. 022

(Dementia)

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30 April 2012

House of Representatives
House Standing Committee on Health and Ageing
Parliament House
Canberra ACT 2600

Via email: haa.reps@aph.gov.au

Dear Committee Secretary

Inquiry into Dementia: Early diagnosis and Intervention

The Royal Australasian College of Physicians (RACP) and the Australian and New Zealand Society for Geriatric Medicine (ANZSGM) welcome the opportunity to provide a submission to the House Standing Committee on Health and Ageing inquiry into *Dementia: Early diagnosis and Intervention*.

The RACP and the ANZSGM has prepared a joint submission to the inquiry that specifically addresses the following Terms of Reference on how early diagnosis and intervention can:

- a) Improve quality of life and assist people with dementia to remain independent for as long as possible;
- b) Increase opportunities for continued social engagement and community participation for people with dementia; and
- c) Help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements.

The RACP and the ANZSGM make the following comments and recommendations to the inquiry, specifically that the Australian Government work with the State and Territory governments and local networks to:

1. Make dementia a National Health Priority Area and reinstate and expand funding for research and services through a national dementia-specific plan such as The Dementia Initiative and the National Framework for Action on Dementia.
2. Establish and resource systematic specialist, multidisciplinary clinics and services across Australia lead by a medical specialist skilled in the diagnosis, treatment and management of dementia. This will usually be a geriatrician.

3. Appoint local care coordinators to work with service providers to assist people with dementia and their carers to navigate through the health, aged and social care sectors and to access the services they need, when they need them and in their preferred setting. This will usually be a nurse practitioner, specialist dementia nurse or social worker skilled in the biopsychosocial approach.
4. Formalise links between primary, specialist, mental health, aged care and social services through the National Health Reform process and by utilising eHealth technologies to ensure continuity and coordination of care and seamless transition across care settings for people with dementia and their carers over the dementia journey.
5. Invest in the dementia workforce with adequate training, education, remuneration and support for health professionals, support staff and carers across care settings including in hospitals, the community, clinics and residential aged care facilities.
6. Prioritise research and evaluation particularly into the causes of dementia and preventative measures, diagnostic and scanning tools, outcomes of pharmacological and non-pharmacological interventions, and dementia-specific service design and delivery.
7. Improve the delivery of specialist medical care, and particularly palliative care, to people with dementia living in residential aged care facilities such through comprehensive outreach and telehealth.
8. Make acute hospitals “dementia-friendly” and improve the quality of care provided to people with dementia in acute hospital settings including through improved identification, diagnosis and treatment.

The RACP and the ANZSGM would be pleased to provide further information to the House Standing Committee on Health and Ageing inquiry into Dementia: Early diagnosis and Intervention and participate in any public hearings.

Should you require further information, please contact Sarah Barter, Policy Officer

Yours sincerely

John Kolbe

Robert Prowse
President, ANZSGM

Attachments: Submission to the House Standing Committee on Health and Ageing inquiry into *Dementia: Early diagnosis and Intervention*.

Appendix 1: Individual submissions from Fellows of the RACP.



The Royal Australasian
College of Physicians

House Standing Committee on Health and Ageing Inquiry into *Dementia: Early diagnosis and Intervention*

Joint Submission by The Royal Australasian College of Physicians and the Australian and New Zealand Society for Geriatric Medicine

April 2012

The Royal Australasian College of Physicians (RACP) and the Australian and New Zealand Society for Geriatric Medicine (ANZSGM) welcome the opportunity to make a joint submission to the House Standing Committee on Health and Ageing Inquiry into *Dementia: Early diagnosis and Intervention*. The Inquiry is highly topical given the growing prevalence of dementia as a result of the ageing of the population, the severity of the disease, and the demand that dementia is placing on the Australian health, aged and social care system.

Executive Summary

People with dementia and their carers have the right to live independent, fulfilling and healthy lives. Although the progression of dementia results in cognitive decline, functional impairment and disability; there are increasingly services, interventions and treatments available to lessen symptom severity and support people with dementia and their carers to remain engaged, independent and living in the community with high quality of life.

Central to improving quality of life for people with dementia and their carers is improving quality of care across the disease trajectory, from diagnosis to the end of their life. Quality of care is maximised where there is early diagnosis and early referral of the person with dementia and their carer into connected and coordinated systems of care that encompass the necessary health (including mental health), aged, and social care services. Services should be easily accessible, flexible and responsive to the changing symptoms, needs and preferences of the person with dementia and their carer over time and care settings.

Dementia is a particularly complex disease with variable symptom presentations, comorbidities and intervention outcomes. Access to timely, primary and specialist multidisciplinary care services is critical to help people with dementia to manage and maintain health and remain living in the community. Difficulties accessing adequate health care risk premature entry into residential aged care facilities and avoidable hospitalisation.

The RACP and the ANZSGM support a shared care diagnosis, assessment and ongoing case management model for the care of people with dementia involving the general practitioner, medical specialist/s, nurse, pharmacist and allied health professional/s (as needed). In many cases, a geriatrician or psychogeriatrician will be best placed to make the diagnosis, initiate treatment and lead arrangements for multidisciplinary care and complex disease management over the duration of the disease, although other medical specialists may also be involved in providing care depending on the stage of the disease and the symptom presentation. Where possible, the shared care model should focus on providing community-based care in a clinic, in the homes of people with dementia, or in residential aged care facilities (RACFs) to accord with the preferences of people with dementia and their carers, to avoid hospitalisation and to contain rising health care costs.

There exist a number of effective shared care models in operation but access to these services is variable and the long-term sustainability may be questionable. The Australian Government must reprioritise dementia and work with local networks, including Medicare Locals, Local Hospital Networks and Lead Clinicians Groups, within the National Health and aged care reform process to learn from current good practice to develop shared care models

that ensure more comprehensive and systematic access to specialist multidisciplinary services for people with dementia across Australia. Emerging eHealth technologies will ensure vulnerable groups including people with dementia living in rural and remote areas or RACFs can access sufficient levels of care where direct care provision is not possible.

The severity, complexity and variability of dementia means that a one size fits all approach is not appropriate. Clinic or community-based specialist multidisciplinary care must always work in partnership with primary and acute care for the timely diagnosis of dementia and to provide high quality, coordinated care across the disease trajectory. Clinicians and support staff in hospitals and GPs must be trained, educated and supported to diagnose and manage people with dementia. If achieved, this will lead to more seamless referral of the person with dementia and their carer to the relevant health, aged and social services that can provide interventions and support to improve quality of life, independence and community engagement across time and care settings.

Investment in research must be a key plank of a comprehensive and effective long-term dementia strategy. Research will build knowledge about the causes of dementia and possible preventative measures. It will provide evidence about the efficacy and suitability of diagnostic and screening tools, pharmacological and non-pharmacological interventions, and dementia specific service design and delivery. It is through research that major improvements in the health and wellbeing of people with dementia and their carers can be realised.

Recommendations

That the Australian Government work with the State and Territory governments and local networks to:

1. Make dementia a National Health Priority Area and reinstate and expand funding for research and services through a national dementia-specific plan such as *The Dementia Initiative* and the *National Framework for Action on Dementia*.
2. Establish and resource systematic specialist, multidisciplinary clinics and services across Australia lead by a medical specialist skilled in the diagnosis, treatment and management of dementia. This will usually be a geriatrician.
3. Appoint local care coordinators to work with service providers to assist people with dementia and their carers to navigate through the health, aged and social care sectors

and to access the services they need, when they need them and in their preferred setting. This will usually be a nurse practitioner, specialist dementia nurse or social worker skilled in the biopsychosocial approach.

4. Formalise links between primary, specialist, mental health, aged care and social services through the National Health Reform process and by utilising eHealth technologies to ensure continuity and coordination of care and seamless transition across care settings for people with dementia and their carers over the dementia journey.
5. Invest in the dementia workforce with adequate training, education, remuneration and support for health professionals, support staff and carers across care settings including in hospitals, the community, clinics and residential aged care facilities.
6. Prioritise research and evaluation particularly into the causes of dementia and preventative measures, diagnostic and scanning tools, outcomes of pharmacological and non-pharmacological interventions, and dementia-specific service design and delivery.
7. Improve the delivery of specialist medical care, and particularly palliative care, to people with dementia living in residential aged care facilities such through comprehensive outreach and telehealth.
8. Make acute hospitals “dementia-friendly” and improve the quality of care provided to people with dementia in acute hospital settings including through improved identification, diagnosis and treatment.

Introduction

What is dementia

Dementia is the umbrella term for a number of chronic diseases characterised by progressive cognitive decline with symptom presentations that may include memory loss, functional decline, loss of language and communication skills, difficulties completing activities of daily living and changes in personality. The most common dementias are Alzheimer’s disease, vascular dementia, dementia with Lewy bodies and frontotemporal dementias, although other dementias are also recognised.

Dementia is most commonly associated with older age, with 81% of people with dementia aged over 75 years.¹ With the ageing of the Australian population, the number of people with dementia is expected to increase exponentially. Current estimates are that in 2011 there are

266,574 people with dementia however this number is expected to more than triple to 942,624 by 2050.² As a result, dementia is now the third leading cause of death in Australia,³ and this is expected to rise.

Dementia is currently incurable and eventually terminal. The duration of the disease has been estimated at 4.5 years on average,⁴ but it is not uncommon for the disease to last for over 10 years. As the disease progresses, symptom presentation and severity changes, with severe disability likely in the end stages of dementia.

Caring for people with dementia

The progressive nature of the disease means that the care needs and support requirements of a person with dementia will change over time. The stage of the illness, the person's general health and their life circumstances and living arrangements will affect the type and level of care that is needed and where and when it is needed. The impact of the disease on cognition, function and behaviour means that almost all people with dementia and their carers will require access to various support services including residential, community and respite care and social services including day centres and carer support. Strong, ongoing demand for residential care is expected due to the reduced pool of informal carers and the challenging nature of care provision.

Carers are often older and frailer themselves, and may find it especially demanding to care for the person with dementia over the duration of the illness. As a result, family and/or community members are also often involved in providing care and support to the person with dementia, which impacts on the wider community and economy. It is essential that carers can access appropriate support services but also sufficient income and/or welfare payments to support them in their role, which will reduce demand on hospitals and permanent residential care.

Dementia is associated with age, multiple comorbidities and an increased risk of delirium. As such, people with dementia often have complex health care needs and commonly experience age-related conditions including falls, incontinence, polypharmacy and frailty. Over the course of the disease, people with dementia may need access to acute, sub-acute, transitional, community, primary and palliative care. Early intervention by a multidisciplinary team, including specialist physicians, is necessary to respond effectively to and manage the health and medical needs of people with dementia. Medical specialists are regularly involved in providing health care to people with dementia in conjunction with the general practitioner (GP), allied health professionals, nurse and pharmacist.

Specialist medical care is especially required at the time of diagnosis; when medical acuity and/or behavioural and psychological symptoms of dementia (BPSD) increase (frequently at the midpoint of the disease); and at end of life. Geriatricians, general physicians, psychogeriatricians and neurologists are skilled at making a complete and accurate diagnosis of dementia. Geriatricians can optimise medical comorbidities, reduce polypharmacy and assist in the management of acute intercurrent illnesses that are often accompanied by delirium. Geriatricians and psychogeriatricians help people with dementia, their carers and service providers to manage BPSD. Rehabilitation physicians and geriatricians can assist people with dementia to regain and maintain function over the course of the disease whilst palliative medicine specialists can provide much needed support at the end of life. It is important that access to specialist medical services is available, accessible and maintained across these critical time points.

Responding to the looming dementia crisis

With the prevalence of people with dementia growing rapidly and effective treatment and cure not forthcoming, there should be a comprehensive, coordinated and focused discussion at a national level and that involves governments at all levels and local networks on how best to respond to and address the current and future challenges posed by dementia.

Australia has traditionally been a leader in best practice dementia care, beginning in 2005 with the development and funding of a national five year plan, *The Dementia Initiative – Making Dementia a National Health Priority* and the *National Framework for Action on Dementia*. *The Dementia Initiative* has been demonstrated to be cost-effective and useful for supporting people with dementia and their families, and encouraged other countries to develop similar plans.⁵ Most States and Territories also have a specific plan or strategy for dementia.

In 2011, *The Dementia Initiative* and *National Framework for Action* officially ceased. It remains to be seen in the 2012-13 Commonwealth Budget whether and what funding for research, services and programs established under this initiative will be continued. In addition, both the National Health Reform process and the Productivity Commission report into *Caring for Older Australians* did not adequately consider the specific issues posed by dementia and the reform needed to ensure that people with dementia and their carers can access appropriate care and services in the place they need it over the duration of the disease. The current appetite for health and aged care reform presents exciting opportunities to improve the quality of care and quality of life for people with dementia and their carers and families, particularly in the community and at a local level.

Given the disabling effect of the symptoms of dementia on both the person with dementia, their carer, their family, the broader community and the health, aged care and social systems, along with the fact that dementia is a chronic disease requiring awareness, early diagnosis, good management, care, prevention and research; it is essential that dementia is made a National Health Priority Area. Dementia should be considered within a Health in All Policies model, rather than solely within an aged or mental health framework.

Funding for a national dementia-specific plan, such as *The Dementia Initiative* and the *National Framework for Action on Dementia*, should be maintained and expanded. There must be fair and equitable funding and service arrangements that promote choice and can respond to changing needs and preferences of people with dementia and their carers over time and care settings.

The RACP and the ANZSGM commends the Australian Government for their recent announcement committing \$268.4 million to community and residential care and early diagnosis of dementia over five years. This is an important first step but it remains to be seen in the detail and implementation of this announcement how it will improve outcomes for people with dementia and their carers.

Recommendations

1. Make dementia a National Health Priority Area and reinstate and expand funding for research and services through a national dementia-specific plan such as *The Dementia Initiative* and the *National Framework for Action on Dementia*.

Early diagnosis to improve quality of life and independence for people with dementia

Early vs timely diagnosis

Dementia is a severely disabling, terminal condition that is not yet curable nor is there good evidence that it is preventable. Much about dementia remains unknown, including its causes and effects on the individual, which can result in stigma being attached to a diagnosis of dementia. People with suspected dementia and their carers may be hesitant to seek out a diagnosis and some health professionals may be unwilling or unable to provide a diagnosis of dementia.

There is, however, good evidence that people with dementia can continue to live independent and fulfilling lives after diagnosis. More and more, the benefits of early

diagnosis are being realised including access to pharmacological and non-pharmacological interventions that can alleviate and delay symptoms; early referral to support services for the person with dementia and their carers; access to information, education and advice about the progression and management of the disease over time and increased ability to plan for the future while cognitively competent and to be involved in research.

Health professionals involved in diagnosing dementia must be careful to balance, and be sensitive to, the perceived and potential positive and negative effects of a dementia diagnosis. The RACP and the ANZSGM support a person-centred approach to diagnosis that responds to the person with dementia and their carers' needs and preferences. Often timely diagnosis will be more appropriate than early diagnosis.

How a diagnosis of dementia is made

An accurate diagnosis of dementia involves comprehensive assessment including history taking, physical examination and laboratory tests, cognitive testing, and brain imaging. There is also increasing research into the role of biomarkers for identifying early stages of dementia, although the clinical utility of these biomarkers has not yet been established. In practice, dementia is diagnosed by history taking and cognitive testing aided by using time efficient diagnostic tools such as the Mini-Mental State Examination (MMSE), and requires evidence of functional decline, usually provided by a family member. There are concerns that the MMSE has major limitations including poor ability to detect mild cognitive impairment. Other screening tools exist, such as the Addenbrooke's Cognitive Examination – Revised (ACE-R), the Rowland Universal Dementia Assessment Scale (RUDAS),⁶ the Montreal Cognitive Assessment (MoCA) and computerised cognitive testing, such as the CogState, is emerging.

Clinicians involved in diagnosing dementia must have sufficient confidence in cognitive assessment including the tools and investigations to make an accurate diagnosis. They must be expert and trained in interpreting information provided by families and carers to make a diagnosis. The increasing prevalence of dementia also means that testing must be sensitive, cost-effective and time-efficient. To facilitate this, there should be more research into and evaluation of the reliability and utility of diagnostic tools. In addition, clinicians need to be trained to correctly administer, score and interpret results.

In Australia, a diagnosis of dementia may be made by the person with dementia's GP; by the local aged care assessment team or service; or by a medical specialist such as a geriatrician, neurologist, general physician or psychogeriatrician. The assessments for

diagnosis may be administered in hospital, in a GP clinic, in the home or residential aged care facility (RACF), or specialist memory clinic.

Who makes a diagnosis of dementia

Most commonly, the GP is the first point of contact for people seeking a dementia diagnosis. However, GPs can experience difficulties diagnosing dementia, which can prolong and delay diagnosis. Reasons may include insufficient time to administer assessments, lack of knowledge about dementia and available support services and treatment options, and irregular presentations of dementia in the clinic. Often GPs will refer their patient to a medical specialist or a memory clinic for confirmation of the diagnosis and must seek out confirmation of the diagnosis from a specialist before initiation of medication subsidised by the Pharmaceutical Benefits Schedule (PBS) can be approved.

Medical specialists play a key role supporting GPs, administering comprehensive assessments and making and/or confirming a diagnosis of dementia. However, there is no set pathway or process across Australia for assessing and diagnosing dementia or for specialist referral. Even hospitals fail to diagnose, misdiagnose and under-code dementia,⁷ despite up to 50% of patients having some degree of cognitive impairment.⁸ Service arrangements, the involvement of specialists and waiting lists for assessment and diagnosis vary considerably across the states and territories and, as a result, people are at risk of falling through the gaps. This is particularly true for people living in rural and remote areas, people from culturally and linguistically diverse (CALD) backgrounds and Indigenous Australians.

Improving assessment and diagnosis for people with dementia

There is scope to improve referral pathways and the timeliness, accuracy of and satisfaction with the diagnostic process. In one study, a third of carers reported that the diagnostic process could be improved through earlier firm diagnosis, earlier referral to a dementia specialist or a more supportive doctor.⁹

The RACP and the ANZSGM believe that medical specialists should be systematically involved in making a diagnosis of dementia. Given that dementia is overwhelmingly an older persons' disease, geriatricians are the most obvious specialty that has the skill and capacity to take on a more central and consistent role in early diagnosis. Although psychogeriatricians/ psychiatrists, neurologists and some general physicians are equipped and entitled to make a diagnosis, there are often insufficient numbers to ensure widespread and timely access for people with dementia across Australia.

Geriatric services should be integrated into a national service model for the early diagnosis, treatment and ongoing case management of dementia. A network of specialist, multidisciplinary clinics and services should be systematically resourced and comprehensively established across Australia to undertake assessment and diagnosis of cognitive impairment and dementia. It is preferable that the clinic be led by a medical specialist who will usually be a geriatrician (or geriatric trainee) and include, at a minimum, a specialist dementia nurse, social worker and/or occupational therapist and neuropsychologist/ psychologist. Currently, different memory clinic models are in operation across Australian jurisdictions. The Victorian Government's Cognitive, Dementia and Memory Service (CDAMS) clinics represent the best model to inform a national, systematic approach to the diagnosis of dementia.

Even with specialist clinics and services, people with dementia will regularly present to primary and acute care. As such, GPs and hospitals should be upskilled in the diagnosis of dementia. GPs should be educated to identify early those patients who would benefit from specialist, multidisciplinary care and ensure that they are referred to appropriate services. Medical specialists and specialist clinics and services can form linkages with GPs to provide support and advice for the timely and accurate diagnosis of dementia. Telehealth technologies can improve interaction between specialists and GPs, particularly in rural and remote settings.

Hospitals need to be able to distinguish when cognitive impairment is caused by dementia as opposed to when it is the result of an acute, possibly reversible condition such as stroke, delirium or head injury. Further complicating the matter is that dementia and delirium can occur together. It is important that hospitals can identify, assess and diagnose dementia to tailor care and interventions effectively. Clinicians and support staff should be trained in diagnostic tools, and on interpretation of patient history, for accurate and timely diagnosis of dementia in hospital.¹⁰

Recommendations

2. Establish and resource systematic specialist, multidisciplinary clinics and services across Australia lead by a medical specialist skilled in the diagnosis, treatment and management of dementia. This will usually be a geriatrician.

Interventions to improve quality of life and independence for people with dementia

Pharmacological interventions

Currently, there is no medical or pharmacological treatment for dementia that can reverse or stop the progression of the disease. There are medications that can reduce the severity of symptoms although not all people with dementia respond to treatment and their efficacy is only modest. Cholinesterase inhibitors for people with mild to moderate Alzheimer's disease and memantine for people with moderately severe Alzheimer's disease can help improve cognitive function. The initiation of medication for people with dementia should always be overseen by a medical specialist and should be subject to regular and opportunistic review to ensure the quality use of medicines.¹¹ There is scope to improve timely access to these medications by removing the requirement for sending written applications to Medicare and replacing these with a simple specialist initiated telephone authority.

Medication may be more effective when there is early and accurate diagnosis of dementia confirmed by a geriatrician or other medical specialist. Medication may help stabilise the person with dementia and allow them to remain living in the community for longer. However, medication should always be initiated in conjunction with a person-centred care plan that includes non-pharmacological interventions implemented by the multidisciplinary team to manage symptoms and improve quality of life over the duration of the disease.

It should be noted that while antipsychotics are often prescribed to people with BPSD, this is not best practice owing to the adverse effects associated with antipsychotic use including increased risk of falls, hospitalisation and death. The RACP and the ANZSGM strongly support non-pharmacological and functional analysis approaches for the management of BPSD wherever possible. Comprehensive assessment and management of a person with BPSD by an appropriately skilled and resourced care team, that includes geriatricians and psychogeriatricians, can identify whether there are triggers for BPSD such as pain, discomfort, environmental stressors and/or over-stimulation. The team can then develop individually tailored strategies to prevent, overcome or manage the distress.

Non-pharmacological interventions and access to services

In the absence of a cure, interventions for people with dementia and their carers following diagnosis should focus on managing the symptoms and biopsychosocial aspects of the disease to maximise independence, wellbeing and quality of life. Fundamentally, this relies on access to available and affordable care, support and information services that meet the needs and preferences of the person with dementia and their carer.

Once a diagnosis has been made, people with dementia and their carers should be immediately linked (or referred) to a coordinated network of health, aged and social care services. As the symptoms and needs of people with dementia and their carers change over time, the health, aged and social care system should be sufficiently responsive, coordinated and flexible to provide adequate levels of service and support, offer continuity of care and facilitate seamless transitions across care settings and services.

However, people with dementia and their carers often experience difficulty accessing the services they need, when they need them. Waiting lists for community, residential and respite services are frequently long, due to high rates of occupancy, and there is evidence that current planning ratios are insufficient to meet growing demand.¹² People with dementia who live rural and remote areas, who are from CALD backgrounds or who identify as Indigenous as well as people with Younger Onset Dementia (YOD) and/or severe BPSD often experience particular difficulty accessing appropriate, high quality services.¹³

Access to multidisciplinary health care services, including medical specialists, is often limited, especially for people with dementia living in RACFs who are conversely most likely to be in need of multidisciplinary care to manage their complex and comorbid health conditions. Currently, the community and residential care workforce is centred around personal care and social support, with limited skill and capacity to respond to and manage dementia as a terminal, chronic disease that often presents with comorbidities. Reliance is placed on the GP to act as a case manager and referring agent for medical specialists and allied health professionals. There are barriers to the provision of sufficient levels of service by GP to RACFs, including poor remuneration and time constraints, despite recent initiatives to encourage visitation.¹⁴ This impacts on the ability of the person with dementia to access more comprehensive and specialist health care services and increases the likelihood of avoidable hospitalisation. In addition, the limited levels of multidisciplinary and skilled health care available in most RACFs put residents at greater risk of inappropriate prescribing of antipsychotics to manage BPSD.

Improving access to services

Ideally, older people with dementia and their carers should have easy and timely access to coordinated multidisciplinary care over the course of the disease. The standard to aim for should be a shared care model involving (as required) the GP, specialist dementia nurse, medical specialist, pharmacist and allied health professional/s who provide continuity of care and smooth transitions across acute, sub-acute, transitional, community, primary and palliative care settings.

The capacity of GPs, nurses, carers and allied health professionals to care for people with dementia should be supported by medical specialists, both in and out of hospital. Early involvement of medical specialists can result in more responsive, person-centred and restorative care that can increase wellbeing, quality of life and independence, and reduce symptom acuity, particularly where management is more complex, such as with YOD and severe BPSD.

The multidisciplinary team should be involved in making a dementia diagnosis and then engaged to undertake holistic assessment of the person with dementia to develop a person-centred care plan that can maintain and restore function, manage symptoms, and improve independence and quality of life. This should be undertaken in conjunction with the person with dementia and their carer wherever possible. This process should also involve identification of, referral to and integration with the breadth of interventions to support people with dementia and their carers including home modifications, assistive technologies, day therapy centres, life engagement activities, carer support services and other social, financial and legal support and advocacy services.

A case management program should be resourced and implemented to provide long term follow-up care and care coordination. The multidisciplinary team should be facilitated to implement and regularly review the care plan, and any medications, as needed or requested by the person with dementia and their carer. Currently, models such as CDAMS are limited to diagnosis.

For a model like this to be systematically and comprehensively available and accessible across Australia, there must be consideration of the education and training of the multidisciplinary team, workforce requirements, adequate financial arrangements and incentives, examples of good practice, and opportunities presented through emerging technologies and the health and aged care reform process.

- Education and training

Barriers to high quality care for people with dementia can result from gaps in health care provider and carers' knowledge about dementia and dementia services. One study stated that all health care providers indicated that they needed to have greater knowledge about dementia, particularly about diagnosis, medication management, legal issues and management of BPSD.¹⁵

Members of the multidisciplinary team, including medical specialists, involved in the care of people with dementia should be well-trained and educated about dementia including the

symptoms, disease trajectory, the terminal nature of the disease and care planning. They should also be knowledgeable about the range of dementia services available and how to access them in order to assist the person with dementia and their carer to navigate through the health, aged and social care sectors.

One means of upskilling GPs, medical specialists, allied health professionals and nurses about dementia and providing quality of care for people with dementia is through providing training rotations across primary, community and acute care settings. It is important that health and medical practitioners are provided with the opportunity to provide care in RACFs. In this respect, the teaching nursing homes concept is an innovative and exciting opportunity to train and educate health and medical professionals in dementia and aged care, and provides the added benefit of improving access to care for residents' onsite and enhancing opportunities for the professional development of residential care staff.

Dementia care training and courses are also available and targeted to nurses and care workers in residential, community and respite care settings, such as the Australian Government's Dementia Care Essentials and the NSW Dementia Care training. Such training opportunities should continue to be funded, particularly those at risk following the cessation of *The Dementia Initiative*, and expanded to all people who may be involved in providing care to people with dementia including health professionals, carers, families and those in the community who wish to know more about how best to support people with dementia.

- Workforce requirements

A key worker, such as a care coordinator or case manager, is needed to organise and coordinate multidisciplinary team members who may be working across multiple services and settings.¹⁶ The key worker could be attached to the community or residential aged care service provider, the local aged care assessment team or service, the specialist memory clinic or the local hospital network. The main role for this position would be to assist the person with dementia and their carer to navigate their way through the health, aged and social care sectors and provide advice and information. This position could organise case conferences or group consultations with appropriate members of the multidisciplinary team in the person with dementia and their carers preferred setting. This position could also be responsible for maintaining joint records and facilitating communication between members of the multidisciplinary team. A nurse practitioner or a person with a background and/or qualifications in social work may be most suited to this role.

There must also be adequate numbers and spread of medical specialists across Australia trained in high quality dementia care, and who have the capacity to provide care outside of hospital in community settings, including in rural and remote areas. Geriatricians currently do this but there are insufficient numbers to provide timely access to specialist care across Australia. The RACP has developed a model for dual-trained specialist physicians with core training in general medicine and further training in an additional specialty to provide expertise in long term illnesses or population groups, including geriatrics, that require complex management beyond the scope of general practice. The model is currently focused on the coordination of dual-trained physicians in rural hospital settings but there is potential for it to be expanded in the future.

- Financial arrangements and incentives

Financial arrangements should incentivise optimal models of care to increase access to specialist multidisciplinary services outside of hospital and particularly in RACFs. Members of the multidisciplinary team must be adequately remunerated and encouraged to operate within a team- and community-based model for the assessment, treatment and ongoing management of people with dementia. Financial and funding arrangements for the multidisciplinary team must strike the right balance between affordability, sustainability and efficacy. There may be opportunities to introduce private or fee-for-service arrangements, where people with dementia and their carers can afford to pay.

- Examples of good practice

Already there are a number of examples of good practice occurring in pockets throughout Australia. However, many of these examples rely on ad hoc partnerships between services, hospitals and practitioners; result from specific local or jurisdictional initiatives or innovation; and may be dependent on non-recurrent funding. Many initiatives are thus of questionable sustainability over the long term, particularly as governments change, partnerships may end and funding can run out.

There are opportunities to identify and promote good practice so that the key elements can be translated into a national framework for coordinated, multidisciplinary service design and delivery encompassing a shared care model involving the GP, medical specialist, nurse and allied health professional. The CDAMS model is acknowledged to be effective and could be adapted to establish and resource a systematic network of specialist, multidisciplinary memory clinics across Australia, led by a medical specialist who would usually be a geriatrician or geriatric trainee. The clinics would provide support and advice to GPs and would not just be responsible for diagnosis, but also for the initiation of treatment, ongoing

case management and care coordination of people with dementia and their carers over the duration of the disease (which goes beyond the existing CDAMS model).

The aged care assessment model could be further developed and expanded to include long-term management of people with dementia and their carers and an essential feature could be integration with local or regional geriatric, rehabilitation and palliative medicine services that can be provided in primary and ambulatory settings. A shared care model may be embedded in the Aged Care Assessment Team or Service and involve the patient's GP, full-time specialist dementia nurse, and support from a geriatrician to undertake assessment, treatment and case management in a centre-based clinic, in the home and in RACFs.

Guidelines and pathways could be developed to facilitate the referral and transition of people with dementia and their carers to appropriate services and across care settings over the duration of the disease.

- New opportunities

The implementation of National Health Reforms and the Australian Government's aged care reform agenda presents opportunities to consider how best to deliver timely, high quality, coordinated, multidisciplinary services encompassing the health, aged care and social sectors to people with dementia and their carers. Medicare Locals, Local Hospital Networks and Lead Clinicians Groups have been or are in the process of being established across Australia. The mandate for Medicare Locals and Local Hospital Networks is to work together to better coordinate primary health, hospital and aged care; identify service gaps; and link local GPs, nursing and other health professionals to make it easier for patients to access the services they need.¹⁷

We see that a key role for Medicare Locals, Local Hospital Networks and Lead Clinicians Groups is to identify and/or develop innovative shared care models and multidisciplinary services for people with dementia and their carers. Information about these models should be provided to National Lead Clinicians Groups and to the Australian Government to build the evidence base, promote good practice and improve the quality of care and quality of life for people with dementia and their carers across Australia.

Technological developments and initiatives in the area of eHealth, telehealth and telemedicine also present opportunities to develop new service models and capabilities to provide more coordinated specialist multidisciplinary care to people with dementia outside of hospital and in primary and community settings. Telehealth and eHealth technologies have the potential to improve access to medical specialist support and assessment for GPs and

local multidisciplinary team members providing care to people with dementia living in rural and remote areas. Education and training for local workers can also be provided by medical specialists more easily and efficiently using these technologies.

Telehealth and eHealth can also facilitate the provision of specialist medical care to people living in RACFs through virtual consultations. Incentives through the *Connecting Health Services with the Future* initiative,¹⁸ which includes MBS items for video consultations with aged care residents and payments to encourage RACFs to provide appropriate facilities and resources to host telehealth consultations, are important to improve awareness and uptake of new technologies.

Recommendations

3. Appoint local care coordinators to work with service providers to assist people with dementia and their carers to navigate through the health, aged and social care sectors and to access the services they need, when they need them and in their preferred setting. This will usually be a nurse practitioner, specialist dementia nurse or social worker skilled in the biopsychosocial approach.
4. Formalise links between primary, specialist, mental health, aged care and social services through the National Health Reform process and by utilising eHealth technologies to ensure continuity and coordination of care and seamless transition across care settings for people with dementia and their carers over the dementia journey.
5. Invest in the dementia workforce with adequate training, education, remuneration and support for health professionals, support staff and carers across care settings including in hospitals, the community, clinics and residential aged care facilities.

Research

Research is a critical component of effective chronic disease management and a comprehensive public health approach that can improve quality of life, independence and wellbeing for people with dementia and their carers. Particularly for a disease like dementia, where much remains unknown, research will be key to preventing dementia, timely and efficient diagnosis, effective intervention and, eventually, a cure.

There is need for further research to build the evidence on causes of dementia and possible preventative measures such as management of vascular risk factors, cognitive activity, physical activity, social engagement and diet. There should be focus on identifying valid, reliable, time efficient and cost effective screening and diagnostic tools for dementia, with continuing research into the utility and reliability of brain imaging such as PET scans, and

other emerging diagnostic approaches which have the potential to be highly effective in the future. The efficacy and outcomes of pharmacological and non-pharmacological interventions, including assistive technologies, life engagement activities and cognitive or sensory stimulation, designed to treat or reduce distressing symptoms of dementia should be continue to be systematically measured and evaluated.

Research must continue to go beyond formal clinical trials into causes, treatment and interventions to include monitoring, evaluation and economic analysis of dementia service models. Research can develop and identify models of care that can provide high quality, safe and effective care, and do so in a sustainable and cost-effective manner. Funding for esteemed and effective research and evaluation centres, such as the Dementia Collaborative Research Centres, should be maintained and expanded.

The important role of people with dementia and their carers in research cannot be understated. Frequently there are ethical and legal concerns about the capacity of the person with dementia to consent to participate in research. As such, as far as possible, people with dementia who are diagnosed early and who have capacity could be encouraged, or facilitated, to be involved in research. For people with dementia, involvement in research and in the possibility of finding a cure or effective treatment can be life-affirming. There is, however, need for clear guidelines on involving people with dementia in research in a respectful and dignified manner, and for seeking and obtaining informed consent to participate in research.

Recommendation

6. Prioritise research and evaluation particularly into the causes of dementia and preventative measures, diagnostic and scanning tools, outcomes of pharmacological and non-pharmacological interventions, and dementia-specific service design and delivery.

Increased opportunities for continued social engagement and community participation for people with dementia

Community-based care

Opportunities for continued social engagement and community participation for people with dementia is more likely to occur when the person with dementia and their carer are experiencing optimal health and wellbeing and are supported to continue to live in community-based settings. As such, a multidisciplinary team based approach to early

diagnosis, intervention and management that can be provided outside of hospital is necessary to facilitate the social and community engagement of a person with dementia. Delivery of health care at home or as locally as possible is now an imperative to accord with the preferences of people with dementia and their carers, to improve health outcomes, and to contain rising health care costs.

The RACP and the ANZSGM support sufficient funding and availability of social and community services to support people with dementia and their carers to continue to remain at home and engaged in their community. It is important that an adequate number and spread of community health and aged care services are available across Australia including packaged care, especially Extended Aged Care at Home Dementia (EACHD) packages, day centres and day therapy centres, life engagement and social programs, and flexible respite services, particularly in localities where dementia prevalence is high.

Residential Aged Care Facilities

Placement in a RACF is often a necessity for many people with dementia and particularly those with more complex health care needs and limited informal support, such as those living alone. Currently, over 50% of people living in RACFs have a diagnosis of dementia.¹⁹ With the rising prevalence of dementia, and the increasing availability of more comprehensive community services for older people with lower care needs, it is likely that the percentage of people with dementia in RACFs will increase.

There is no reason, however, why people with dementia living in RACFs cannot continue to be socially engaged and participate in their community. Indeed, the RACF itself can hold many opportunities for people with dementia to engage with fellow residents and assist themselves and others. For these opportunities to be maximised, the residential care workforce must be appropriately trained, educated, resourced and remunerated to provide care and life engagement activities for residents with dementia. High quality dementia care and management should be a core competency for all residential care staff and for the overall operation of RACFs. In larger RACFs, a specialist dementia nurse should be employed to oversee the implementation and review of the care plan. In addition, the physical environment of the RACF should be developed to maximise opportunities for social engagement and cater to the strengths of people with dementia.²⁰ There are examples of local services providers who are employing effective and innovative strategies in this area, which could inform wider availability.

Improved social engagement and community participation is again largely dependent on residents with dementia being healthy enough, with sufficient functional and cognitive ability,

to take advantage of opportunities and get involved in activities. Medical specialists, including geriatricians, rehabilitation medicine specialists and psychogeriatricians, can support people with dementia to maximise functioning. However, access to specialist medical care is often limited in RACFs and mostly reliant on the personal interest of specialists engaged in outreach. There is need for more systematic and regular provision of specialist medical care into RACFs. Formal relationships between Local Hospital Networks, private practitioners and RACFs may be required to improve outreach or initiate Visiting Medical Officer style arrangements. Telehealth and eHealth technologies can be utilised to undertake virtual consultations where onsite consultation is not possible or appropriate, such as to rural and remote RACFs, and to communicate and educate carers and care workers.

A growing concern is the lack of specialist and generalist palliative care services for people with dementia living in RACFs. Dementia is a terminal illness, and in most cases, a palliative approach is most appropriate for end of life symptom management. In Australia, there have been concerted efforts to implement a palliative approach for people with dementia in RACFs but many facilities and care staff remain uncertain and apprehensive about providing this type of care. As a result, there is a risk of inappropriate or avoidable admission to Emergency Departments (EDs). In view of this, efforts to better link RACFs into specialist palliative care services should be prioritised.

Acute hospitals

Regardless of the care provided in the community or in RACFs, there will still be people with dementia with acute care needs that require treatment in hospital. Currently, hospitals are daunting places for people with dementia in terms of both quality of care and quality of the environment with higher likelihood of poor outcomes including disability and death. People with dementia tend to have longer hospital stays and an increased number of complications including polypharmacy, undernutrition, skin tears, pressure areas and fall-related injuries.²¹ People with dementia can find hospitals unfamiliar, confusing and disorienting and there is risk of sensory overload from a busy, time-pressured ward.

Improving the hospital environment and quality of care of people with both diagnosed and undiagnosed dementia in hospitals is essential. This will require investment in research, education and training for clinicians and support staff, and the built environment. The diagnosis and management of dementia and dementia associated syndromes such as falls should be a core competency and skill set for all hospital staff and management.

The RACP and ANZSGM are supportive of the considerations listed by KPMG (2011) for service improvement for people with dementia in acute settings. These include providing

support and a sense of security for people with cognitive impairment, strengthening dementia education and training, making quality dementia care part of routine practice for all hospital staff, and ensuring that new hospitals and redevelopments are designed for people with cognitive impairment.²²

In addition, the outcomes from the Hospital Dementia Services Project should provide further direction and guidance with regard to improving quality of care and outcomes for people with dementia admitted to hospital.²³

Younger Onset Dementia and other rarer forms of dementia

A major gap in service provision is for those people with dementia that do not fit neatly into current aged care, disability or mental health service models. People most at risk include those with rarer forms of dementia including YOD, which often has specific and complex symptom presentations. Neurologists and psychiatrists are often the main medical specialists involved in assessing and caring for these people although geriatricians and psychogeriatricians can also provide support, being skilled at managing cognitive impairment. Services, residential facilities, life engagement activities and community participation for these people should be tailored to their age and condition.

There is a case for special purpose accommodation that can meet the needs and preferences of these people with dementia. Again, a number of service models exist in pockets around Australia that are specifically designed to serve these vulnerable groups but access to care is highly variable. Further research and funding should be committed to develop a cost-effective yet high quality network of flexible and targeted services that can cater to the needs of this diverse group of people.

Recommendations

7. Improve the delivery of specialist medical care, and particularly palliative care, to people with dementia living in residential aged care facilities such through comprehensive outreach and telehealth.
8. Make acute hospitals “dementia-friendly” and improve the quality of care provided to people with dementia in acute hospital settings including through improved identification, diagnosis and treatment.

Helping people with dementia and their carers to plan for their futures

There has been much attention on the need for early diagnosis of dementia to assist people with dementia and their carers to plan for the future, including for financial and legal matters and decision-making, and for health care and medical treatment. Given the progressive cognitive decline of dementia, future care planning needs to be promoted and facilitated early while the person with dementia is still competent. However, there is evidence that even when diagnosis occurs early, many people with dementia fail to adequately plan for their future. Some of the reasons given for this include a lack of knowledge about where to access information and a lack of support from health professionals.²⁴

Planning for the future will only be improved if the health, aged and social sectors are better integrated – people with dementia and their carers need easy access to the information and support they need for informed care planning. It is clear that multidisciplinary team members, including medical specialists, can reinforce and promote messaging about planning and refer and support persons with dementia and their carers to appropriate services.

To facilitate this, specific education and training must be provided to health professionals, the person with dementia, and their carer. There is also a need for robust referrals pathways and feedback loops between social, health and aged care providers. As discussed above, more evolved community and clinic-based shared care models for the coordinated, specialist, multidisciplinary diagnosis and management of people with dementia could also aid and encourage future planning. In-house social workers, who may also be the key worker or care coordinator, can support the person with dementia and their carer to navigate the future planning process and link them into relevant services.

Advance care plans allow people with dementia to make specific decisions about future medical care and treatment. Advance care planning directs decision-making when the person with dementia is no longer considered able to make the decision, which can reduce the burden and stress on carers, care workers and health professionals, and families. In particular, advanced care plans can specify a palliative approach at the end of life, which can reduce the use of treatments and interventions to prolong life that may also be expensive, futile and painful or distressing; and reduce transfers to hospitals and EDs. There should be further exploration of the specific opportunities and risks associated with the development of advanced care plans for people with dementia, particularly where the time period between diagnosis and death can be lengthy and, over that time, people's preferences may change.

Conclusion

The best outcomes for a person with dementia and their carer and families are assured when early diagnosis is followed by early referrals and linkages into a connected and coordinated system of care, including health, aged and social care and services that are appropriate to the persons' symptoms, needs and preferences, over time and care settings.

Across the disease trajectory from diagnosis through to end-of-life, medical specialists can work with multidisciplinary teams, which may comprise of a GP, nurse, pharmacist, allied health professionals and aged care providers, to improve quality of life and independence for the person with dementia. The multidisciplinary team should be engaged early to diagnose dementia, undertake assessment, initiate treatment, manage symptoms and develop and review a tailored, person-centred care plan over the duration of the disease.

A shared care model with specialist support for the GP and the multidisciplinary team is likely to be most effective at managing the changing care needs of people with dementia and improving quality of life. Where possible, care and services for people with dementia should be provided in primary and community settings. Where hospital care is necessary, high quality dementia care should be provided in a dementia-friendly environment. Specialist medical care integrated within the multidisciplinary team should be more accessible outside of hospital and in the home, clinic or in RACFs. There are particularly strong arguments for providing specialist multidisciplinary care in RACFs given the high numbers of people with dementia living in RACFs and the higher likelihood of other barriers to access including frailty, reduced mobility and limited informal support.

There are a number of good initiatives occurring in various parts of Australia as a result of local service innovation or state and territory programs. However, there should be more systematic and timely access to community- and clinic-based specialist multidisciplinary care for people with dementia and their carers across Australia. The Australian Government in conjunction with state and territory governments and local networks must prioritise funding and systematic service planning and provision for people with dementia and their carers. There is need to research and evaluate current services across jurisdictions and within localities to identify and translate good practice and ensure access to high quality, coordinated care for people with dementia and their carers.

National Health Reforms and the Productivity Commission's report into *Caring for Older Australians* have set the foundations for what a functional, coordinated and efficient health and aged care system might look like in Australia - a system that is appropriate and adapted to the needs and demands of an ageing population. Now is the time to test these reforms

and opportunities in the context of rising rates of dementia. An integrated health, aged and social system that can adequately support people with dementia, and their families and carers, is one that is fit for purpose both now and into the future.

About the RACP

The Royal Australasian College of Physicians (the RACP) trains educates and advocates on behalf of more than 13,500 physicians – often referred to as medical specialists – and 5,000 trainees, across Australia and New Zealand. The RACP represents more than 25 medical specialties including paediatrics & child health, cardiology, respiratory medicine, geriatric medicine, neurology, oncology and public health medicine, occupational and environmental medicine, palliative medicine, sexual health medicine, rehabilitation and addiction medicine. Beyond the drive for medical excellence, the RACP is committed to developing health and social policies which bring vital improvements to the wellbeing of patients.

About the ANZSGM

The Australian and New Zealand Society for Geriatric Medicine (the ANZSGM) is the professional society for geriatricians and other medical practitioners with an interest in medical care of older people. The ANZSGM acts to represent the needs of its members and the wider community in a bid to constantly review and improve the care of the older people in Australia and New Zealand. ANZSGM's major functions are around education, policy development and review, and political advocacy.

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References

- ¹ Australian Institute of Health and Welfare. (2007). Dementia in Australia: National data analysis and development.
- ² Deloitte Access Economics. (2011). Dementia across Australia: 2011-2050.
- ³ Australian Bureau of Statistics. (2012). 3303.0 - Causes of Death, Australia, 2010.
- ⁴ Xie, J., Brayne, C. & Matthews, F. (2008). Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up. *BMJ* 336(7638): 258–262.
- ⁵ Alzheimer's Australia. (2011). National strategies to address dementia.
- ⁶ Terpening, Z., Hodges, J., & Cordato, N. (2011). Towards evidence-based dementia screening in Australia. *MJA* 194(2): 60-61.
- ⁷ Cummings, E., Maher, R., Showell, C.M., Croft, T., Tolman, J., Vickers, J., Stirling, C., Robinson, A. & Turner, P. (2011). Hospital coding of Dementia: is it accurate? *Health Information Management Journal* 40(3): 5-11.
- ⁸ KPMG. (2011). Elements to be addressed when developing dementia services pathways.
- ⁹ Speechly, C., Bridges-Webb, C., & Passmore, E. (2008). The pathway to dementia diagnosis. *MJA* 189 (9): 487-489.
- ¹⁰ Cummings, E., Maher, R., Showell, C.M., Croft, T., Tolman, J., Vickers, J., Stirling, C., Robinson, A. & Turner, P. (2011). Hospital coding of Dementia: is it accurate? *Health Information Management Journal* 40(3): 5-11.
- ¹¹ NPS Prescribing Practice Review 43: Treating the symptoms of dementia. Available at: http://www.nps.org.au/health_professionals/publications/prescribing_practice_review/current/nps_prescribing_practice_review_43H.
- ¹² Access Economics. (2010). Caring Places: Planning for aged care & dementia 2010-2050.
- ¹³ Alzheimer's Australia. (2011). Report for the Department of Health and Ageing in relation to services for Consumer Engagement in the Aged Care Reform Process.
- ¹⁴ Gadzhanova, S. & Reed, R. (2007). Medical services provided by general practitioners in residential aged-care facilities in Australia. *MJA* 187: 92–94.
- ¹⁵ Hansen, E., Robinson, A., Mudge, P. & Crack, G. (2005). Barriers to the provision of care for people with dementia and their carers in a rural community. *Australian Journal of Primary Health* 11(1): 72-79.
- ¹⁶ KPMG. (2011). Elements to be addressed when developing dementia services pathways; Alzheimer's Australia. (2011). Report for the Department of Health and Ageing in relation to services for Consumer Engagement in the Aged Care Reform Process.
- ¹⁷ Australian Government Department of Health and Ageing. National Health Reform. Retrieved from: <http://www.yourhealth.gov.au/internet/yourhealth/publishing.nsf/Content/medilocals-lp-1H>.
- ¹⁸ Australian Government Department of Health and Ageing. Connecting Health Services With the Future: Overview for Residential Aged Care Facilities. Retrieved from: <http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/connectinghealthservices-RACFH>.
- ¹⁹ Australian Institute of Health and Welfare. (2011). Residential aged care in Australia 2009–10: a statistical overview.
- ²⁰ Report for the Department of Health and Ageing in relation to services for Consumer Engagement in the Aged Care Reform Process.
- ²¹ Kurrle, S. (2006). Improving acute care services for older people. *MJA* 2006; 184 (9): 427-428
- ²² KPMG. (2011). Elements to be addressed when developing dementia services pathways; Alzheimer's Australia.

²³ Australian Institute of Health and Welfare. Hospital Dementia Services Project. Retrieved from: [Hhttp://www.aihw.gov.au/hospital-dementia-services-project/H](http://www.aihw.gov.au/hospital-dementia-services-project/H).

²⁴ Alzheimer's Australia. (2012). What prevents people with dementia making plans for their future?

Dementia: Early Diagnosis and intervention

Although early diagnosis and intervention has shown to improve the quality of life for people with dementia as well as for family members and carers, the diagnosis of dementia is usually made in only 33% of the patients with dementia (unpublished data 2009 – CHAMP study). Therefore raising awareness of carers and primary health care workers with proper diagnosis and management by the Geriatric Specialist teams with dementia as their main interest is suggested. Once diagnosis is made supporting the patient and carer with ongoing education, easy and robust access to services as required, advance care planning and financial support for carers who wish to care for their family members is recommended. The patient hospital journey must also be supported, so that patients with dementia are made known and are taken care of by the appropriate specialist teams who are able to manage and support these patients in the hospital environment efficiently and effectively and at the same time decrease their LOS.

The main problems or challenges that the patients and carers are faced with are the devastating challenging behaviours that ultimately force the carer to place their loved ones in the residential care. Therefore more focus and emphasis i.e. early detection and ongoing management by the specialist teams together with the primary carer in the community, hospital and residential care needs to be given in the management of these neuropsychiatric symptoms.

Re: Terms of reference:

1. Improve quality of life and assist people to remain independent as long as possible

Early proper diagnosis by specialist teams (includes Geriatrician with the multidisciplinary team (MDT). The MDT consists of Occupational therapist (OT), Social worker (SW), Neuropsychologist, dietician, nurse and a diversional therapist (DT). Ongoing patient and carer education and support are key factors.

To improve quality of life for patients and the carers who are willing to look after their loved ones at home they should be supported. The process to meet and sustain these needs should be made easier i.e. patients access to in house or residential respite care. In particular in patients with challenging behaviours (assistance with personal care) should be available and the patient and carer should not wait for months to access this services. These lead to carer stress and result in unnecessary hospital presentations with view to placement or as means to access service.

To meet these above demands, the following resources need to be put in place – services, diversional therapist and availability of specialist service in the patients. At Nepean Hospital the Virtual Age Care Service (VACS) is a specialist service with a multidisciplinary team (MDT) supporting patient and carers at home (either in the community or Age Care Facilities). If patients with dementia require hospital admission they are admitted via Emergency Department Medical Assessment Unit (EDMAU) bypassing ED. In EDMAU dementia patients are assessed, managed and then sent back to their home as soon as possible.

Carer Support

Confirming diagnosis, education and carer support are variable and dysfunctional in the way they are delivered. It is imperative that these are more coordinated and planned strategically

E.g. The dementia clinic set up at Nepean Hospital – there are two models of clinic: one is consultant driven. The other model is consultant with the MDT where the diagnosis and severity of dementia is confirmed with concurrent assessment by the OT/SW followed by a family conference with regular follow up and ongoing MDT support with VAC. The advance care planning

driving and resuscitation status are all discussed after the diagnosis is made with MDT There is an option for the people with dementia to utilise the drop in clinic for advice and management if pt becomes unwell. The dietician service is put in place as required.

People with dementia are seen as soon as possible in the clinics by the consultant. If the patient requires admission then it is organised via ED MAU (bypassing ED) enabling the people with dementia and carer journey to be seamless and efficient.

Over the past 6 months, dementia patients from the consultant driven clinic present to ED more compared to the MDT based clinic (approx 10:1). The main presenting problems of these dementia patients are delirium, challenging behaviours or carer stress due to lack of awareness, education and **support.**

The second point – Financial carer support

This is an ongoing dilemma where the carer resigns from their job to look after their loved ones and they do not qualify for the carer pension. People with dementia and the carer then use their savings which negatively affects the carer quality of life and indirectly the dementia patients.

I would recommend that if the carer is willing to care for their parents with dementia then the carer's pension should be made available to all the potential carers and monitored. It should not be based on the carer's financial status.

This is very important as majority of the carers then go into part time employment and the quality of care for the dementia patients is affected and indirectly affects the economy

2. Increase opportunities for continued social engagement and community participation for people with dementia

It is very important to increase opportunities for continued social engagement and community participation for people with dementia. In considering factors above, the severity of the dementia, the cultural background needs to be taken into account. For these to happen according to the article Enhancing quality of life for people living with dementia by Alzheimer's Society in Canada stated that for effective inclusion it requires action at multiple levels – by people with dementia, carers, friends, service providers and funding organizations.

People with dementia who are active and involved in community dementia support organisations such as support group members and facilitators, committee advisors, guest speakers, panel representatives, book authors and newsletter contributors should be supported.

People with dementia should be treated with respect and dignity and raising dementia awareness in the society with dementia friendly environment.

3. Help people with dementia and carers to plan for their futures, including organising financial and legal affairs and preparing for longer term or more intensive care requirements and how best to deliver awareness and communication on dementia and dementia-related services

I believe that this is very important and should start at the time of diagnosis and therefore these decisions would be informed and patient centred.

Person with early dementia should be so educated so they have a good understanding of dementia, disease progression and prognosis. Therefore people with dementia (mild to moderate dementia as well as Mild Cognitive Impairment (MCI) will be making their own informed decisions so their voices are heard loud and clear in relation to finances, wills , nutrition and advance care directives. These decisions should be made with the person with dementia with the carers present e.g. family conferences.

To enable a more informed society dementia awareness and education is needed to promote the well-being of individuals and families affected by dementia. There is a need for the creation of more enabling and supportive environments for stronger linkages among individuals, families, and community resources. I would also like to promote dementia awareness earlier in schools probably high school, universities and in the community

The Age Care facility (ACF) work force should be well resourced and educated in advance dementia management. People with dementia need group or individualised forms of diversional therapy to improve quality of life. The work force should be given incentives to work in ACF so we can attract educated and well informed carers/workers in this area.

Dr Anita Sharma FRACP, PhD
15th April 2012

Submission to House of Representatives Standing Committee on Health and Ageing

Inquiry into Dementia Early Diagnosis and Intervention

Dr John Ward, Geriatrician and Clinical Director, Greater Newcastle Cluster, Hunter New England Local Health District.
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Summary

In this submission, I wish to make the following points:

- . dementia is highly prevalent in our community and the prevalence will increase dramatically over the next 20 years
- . dementia causes great stress for patients, carers and families over a long period (up to 10 years or more)
- . it is unacceptable for a health system not to have a service for the early diagnosis of dementia and for case management of people with BPSD and carer stress
- . there is evidence that case management by an experienced nurse reduces carer stress and delays residential aged care placement
- . the Newcastle model, which has allowed 60% of all people in the community with dementia to receive a diagnosis and case management, will be described
- . the Newcastle model is based on a shared care approach involving General Practitioner, Geriatrician and a Community Dementia Nurse
- . the Newcastle model is efficient and effective and could easily be extended throughout Australia at an acceptable cost.

Introduction

As mentioned in the Media Alert, there are an estimated 300,000 people with dementia in Australia (15% of people over age 70) and the number is growing rapidly. Access Economics estimate that the prevalence will rise by 300% over the next 40 years.

Dementia is, on average, a 10 year illness which places great strain on the sufferers, carers and family. This is especially so for the 50% of people with dementia who have behavioural and psychological problems.

It is my view, therefore, that the failure of health systems to provide an effective service for the assessment, diagnosis and case management of dementia is unacceptable. This is particularly so now that we have shown in Newcastle that such a service can be established for a reasonable cost. It is this service that I will describe in this submission, giving results for the last four years.

Description of Newcastle model for the assessment, diagnosis and case management of dementia

In the Hunter, we have an efficient and effective shared-care system of assessment and management of cognitive impairment that meets the needs of General practitioners and families. It is a shared-care program with general practitioners, designed around locally based Community Dementia Nurses (CDNs) who work within ACATs, together with a Geriatrician who has responsibility for that community as part of the workload. The community units are 50,000 to 80,000 total

population, giving a population over 70 years of about 5,000 to 8,000. This includes a prevalence of dementia of about 750 to 1,200 (1.5%).

The CDN works full-time while the Geriatrician commits about 2 days per week to the community which includes a centre-based clinic and home and ACF visits. The Geriatrician sees people referred by GPs while the CDN sees people with cognitive impairment referred to ACAT or directly to her from any source. The CDN assists the Geriatrician with the clinic which allows patients and families to be interviewed separately and also provides more complex cognitive assessments e.g. RUDAS, Adas-Cog, ACE-R, etc. The CDN is available to follow-up clinic clients via home visits to complete the assessment and to provide education, information and carer support in a more family-friendly environment.

The CDN case manages people, in conjunction with the GP and Geriatrician, where there is:

- . psychological or behavioural problems
- . carer stress
- . lone livers.

Both CDN and Geriatrician work closely with general practitioners, providing feed-back on assessments, management plans and case management. Case conferences, with or without the family, are held in the general practitioner's surgery if indicated. The service seems to be appreciated by general practitioners, carers and other health care and social support service providers.

Results in the Westlakes Area over four years, Sept, 2007 to Sept, 2011.

The Westlakes Area is the Western side of Lake Macquarie LGA and includes the suburbs from Cardiff in the north to Wyee in the south. The total population is about 80,000 and includes about 8,000 people over age 70 (10%). Using the prevalence rates for dementia as determined by Alzheimer Australia of 1.5%, there are approximately 1200 people with dementia in the Westlakes Area. This is the target population for the Dementia Service.

About 20-25% of the population of the Westlakes Area live in the southern suburbs of Wyee, Morisset, Bonnells Bay, Brightwaters and Cooranbong. Many of these people are referred for assessment of dementia to Neurologists on the Central Coast. In addition, a small number of general practitioners refer to a Geriatrician in private practice in Newcastle who specialises in cognitive impairment.

I have assumed that about 20% of the target dementia population would be referred to Central Coast or private specialists and, therefore, estimated the target population for the Geriatrician to be 1000 people with dementia i.e. 80% of the total population. The target population for the CDN would be all people with dementia living in the Westlakes Area i.e. 100% or 1200.

Over the four years from September, 2007, to September, 2011, the Geriatrician saw 1329 consultations, which included 981 clinic consultations and 348 home or RACF visits. There were 574 individual patients with cognitive impairment of whom 77

(13%) were diagnosed with Mild Cognitive Impairment and 497 (87%) with dementia.

Almost all of the patients with dementia seen by the Geriatrician would have been seen by the CDN but, in addition, the CDN saw 242 people with dementia, not seen by the Geriatrician. Many of these people would have been referred to her by private geriatricians or neurologists in Newcastle or Central Coast.

This means that the Geriatrician saw 497 people with dementia out of a target population of 1000 i.e. 50%. In addition, the CDN saw another 242 people not seen by the Geriatrician.

The Dementia Service of the Westlakes Area i.e. Geriatrician and CDN saw a total of 739 people with dementia out of a target population of 1200 i.e. 62% of all people with dementia living in the Westlakes Area.

Advantages of the Newcastle Model

The advantages of this model include:

- . no more than 90 minutes for initial assessment
- . can see 4-6 patients per day clinic
 - 2-3 new plus 1-3 follow-up
- . can see patients urgently if required
 - routine waiting time 4-6 weeks
- . not coming to a “Memory Clinic”
- . both Geriatrician and CDN can see patients at home or in ACFs
- . allows case management of BPSD and stressed carers
- . embedded in ACAT
 - minimizes duplicated assessments
 - meeting attended by ACAT, MHSOP; Dementia Monitoring Agency; CACP/EACH providers
- . cost-effective
 - Geriatrician covered by Medicare
 - CDN (CNS level RN) - \$100,000pa

Conclusions

The Newcastle model for dementia assessment, diagnosis and case management may be the most cost-effective model available. It is clearly acceptable to general practitioners, patients and carers. The cost to NSW to provide an adequate number of CDNs, i.e. one CDN for every 5000 people over age 70, would be \$14 million annually.

Submission to the House of Representatives Inquiry into Dementia

At present, there is no effective treatment for different forms of dementia. While cholinesterase and NMDA inhibitor therapies are used in patients with Alzheimer's disease (AD), their effectiveness is modest at best. Current research targeting various aspects of the amyloid plaques and neurofibrillary tangles in AD have not yielded better results than status quo. Therefore, early recognition of dementia in this context is less about selecting patients for medical therapies and more to do with managing the biopsychosocial aspects of the illness and their impact on a personal and community level.

From a medical perspective, while there is no effective treatment that can reverse the decline of cognitive dysfunction, early recognition of cognitive and behavioural syndromes associated with dementia will provide an opportunity for education of patients and carers about the illness, symptomatic management, and counselling.

Beside cognitive dysfunction, dementia sufferers are also at risk of a variety of geriatric syndromes such as falls, incontinence and frailty and these are amenable to early multidisciplinary interventions.

For some forms of dementia such as vascular dementia, early recognition of the illness and treatment of vascular risk factors may slow the progression of the disease.

From a social perspective, advanced care planning is necessary for patients with dementia. On a personal level, this will mean support for day-to-day tasks that can be impaired in patients with dementia inclusive of driving and financial matters. On a community level, programs need to be developed to assess and support the capacity of dementia sufferers with respect to these tasks particularly that of driving which can have significant community impact. As dementia progresses, the sufferer usually loses the ability to manage basic ADL and is dependent on other person(s) for routine care. The issue of long term accommodation for the sufferer therefore becomes more inevitable. Early recognition of dementia allows accommodation planning to evolve over time and to reduce patient's and carer's distress associated with this process.

Current dementia care model is quite medicalised and does not adequately address the biopsychosocial impact of dementia on an individual basis and in the general population. While there is vast spending on research chasing the illusive cure for dementia and on modestly effective anti-dementia drugs, investment in holistic dementia care and long-term accommodation for dementia sufferers is inadequate. Dementia care plan for Australia should be developed with the proviso that a "cure" for dementia will remain illusive for the next several decades. The population of dementia sufferers needs support now and structural health changes have to be adaptable to the growing need of this ever expanding population in the future.

The following are a few suggestions in relation to improving the care for dementia sufferers

On a practical level, early detection of dementia can start with the family practitioners. By introducing a new general practice MBS item number for "assessment for dementia" which incorporates an MMSE/ RUDAS, relevant

investigations and community social work/ geriatrician referral, this will raise awareness of dementia and encourage more family GPs to manage patients with dementia. GPs should have easy access to dementia resources in the community.

Secondary and tertiary dementia referral centres should be encouraged in public hospitals. Incentives should be provided to private dementia specialists to encourage early detection and management of dementia in their patients.

The management of dementia and dementia associated geriatric syndromes e.g., falls etc should be made KPIs for various health institutions. In terms of falls, strength and balance training for mildly demented patients may prevent future falls and fractures.

For dementia care co-ordination in the community, a dementia care co-ordinator with strong social work background would be able to assist with community care and accommodation options for patients beyond education alone.

The current number of Dementia Day Centres should be increased to provide “day respite” for community carers. This may allow more dementia sufferers to remain at home. Mobility maintenance programs should be carried out at these centres.

CACP and EACH packages should be prioritized based on the severity of the patient’s dementia and ADL dependence score rather than on a chronological/ waitlist basis. More CACP and EACH packages are required.

Residential respite centres (rather than permanent hostels and nursing homes) should be developed to allow for better ease of access for dementia sufferers due to higher turnover. Emergency accommodation for dementia sufferers may reduce the need for patients to present to tertiary hospitals for accommodation issues.

More dementia specific nursing homes and hostels are required. General nursing homes and hostels should be encouraged to employ activity coordinators for residents.

Public advertisements and dementia awareness campaigns including the links to NSW Guardianship Tribunals for assistance with EPOA etc may be worthwhile. Financial institutions should encourage older account holders to undertake EPOA.

Advertisements to raise awareness about driving and dementia may also be helpful. The RTA should have a separate driving assessment unit for people with cognitive dysfunction. At present OT based driving assessments can only be carried out in some private centres/ hospitals.

Advanced care directives should be aggressively advertised to the general public and new GP MBS item number should be introduced to encourage more GPs to discuss these issues with their elderly patients. ACDs should reduce the need for unnecessary health expenditure in the long run.

Dr Van Nguyen