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Department of Health and Ageing

House of Representatives Standing Committee on Health and Ageing

Inquiry into dementia early diagnosis and intervention

May 2012

Submission on behalf of the Department of Health and Ageing

TERMS OF REFERENCE

On Tuesday 20 March 2012 the Minister for Mental Health, the Hon Mark Butler MP, asked the Committee to inquire into and report on Dementia: Early Diagnosis and Intervention.[1]

The Committee will inquire into and report on the dementia early diagnosis and intervention practices in Australia, with a particular focus on how early diagnosis and intervention of dementia can:

- Improve quality of life and assist people with dementia to remain independent for as long as possible;

- Increase opportunities for continued social engagement and community participation for people with dementia;

- Help people with dementia and their carers plan for their futures, including organising their 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 into the community.

[1] Inquiry website, accessed 9 April 2012 at http://www.aph.gov.au/Parliamentary_Business/Committees/House_of_Representatives_Committees?url=haa/dementia/index.htm

INTRODUCTION

The Department welcomes the Inquiry into Dementia Early Diagnosis and Intervention. The Inquiry provides an opportunity for considering one of the major challenges to be addressed to manage the increasing burden associated with the projected increase in prevalence of people with dementia in line with population ageing. Addressing this challenge must also take into account the growing number of people with younger onset dementia.

There is growing recognition of the many challenges that early diagnosis of dementia poses. The issues and complexities around early diagnosis are evident in the recent research literature and through other work undertaken by the department to improve the dementia care pathway.

The Government is aware of these issues and the need to implement strategies to assist in addressing some of the perceived barriers that impede early diagnosis.

This submission briefly describes dementia and presents some key facts and figures. Then, the major part of the submission looks at the current context of early diagnosis and intervention: the barriers and perceptions hindering early diagnosis; the roles of primary care practitioners, Medicare Locals and Aged Care Assessment Teams; the awareness raising initiatives and support available in the community for people throughout the dementia journey including planning for the later stages of dementia; and the importance of research.

The Submission concludes with an overview of the increased funding and support for *Tackling Dementia* that the Government has committed to through the *Living Longer Living Better* aged care reforms. Announced on 20 April 2012 by the Prime Minister, the Hon Julia Gillard MP, and the Minister for Mental Health and Ageing, the Hon Mark Butler MP, the *Tackling Dementia* commitments closely target the barriers currently hindering early diagnosis and intervention.

What is dementia?

Dementia is not a natural part of ageing nor is it a disease or mental illness. Dementia is a degenerative condition – an umbrella term used to describe the symptoms of a large group of illnesses which cause a progressive decline in the ability to remember, to think, and to learn. The effects of dementia on the functioning of the brain result in impaired decision making and can lead to personality changes.

A person with dementia may find it harder to do previously familiar tasks, such as writing, reading, showering and using numbers. Symptoms may include impaired memory and confusion, difficulty in performing day-to-day or familiar tasks, such as dressing or eating, and changes in personality, mood and behaviour.

Dementia is usually irreversible. It may be aggravated by treatable conditions, such as dehydration, constipation, infection, vitamin deficiencies and imbalances, pain, medication poisoning, brain tumours or depression. It is diagnosed on the basis of a constellation of clinical symptoms and signs, such as short term memory loss and confusion. Neuroimaging can assist the diagnosis in some cases.

Alzheimer's disease is the most common of the dementias, accounting for around 70 per cent of all dementias. At the same time, there are many other causes.

Vascular dementia (the second most common cause of dementia) is a result of the blood supply to the brain being cut off due to clotting or blood vessels bursting in the brain, (aneurism) destroying surrounding tissue and triggering strokes. Vascular dementia accounts for 20 to 30 per cent of all cases in Australia.[1]

Lewy bodies dementia (the third most common cause of dementia) results from a build-up of Lewy bodies inside the areas of the brain that control particular aspects of memory and motor control. Symptoms of Lewy bodies dementia are characterised by pronounced fluctuations in mood with periods of confusion, followed by greater lucidity, and disturbed visual experiences.

Dementia can also be associated with excessive alcohol intake or Korsakov Syndrome, Frontotemporal Lobar Degeneration, and Huntington's and Parkinson's diseases.

Younger onset dementia describes any form of dementia diagnosed in people under the age of 65. Younger onset dementia is often misdiagnosed as depression or anxiety. In a recent paper, Alzheimer's Australia stated that 'frontotemporal dementia is the second most common degenerative disease causing dementia in young adults.[2] This condition when coupled with the younger person's generally high level of mobility and physical capacity can result in behaviours' that cause carer concerns, for example possible increased aggressiveness and resistance.

Dementia facts and figures

Dementia and Alzheimer's disease was the third leading cause of death in 2010. The number of deaths due to this cause has increased 140.7% from 3,740 in 2001 to 9,003 in 2010. This is largely due to an increase in deaths due to dementia, which increased from 2,133 in 2001 to 6,297 in 2010.[3]

In Australia, it is estimated that around 280,000 people have dementia and this figure is projected to rise to almost one million in 2050 in line with population ageing.[4] After the age of 65 the likelihood of living with dementia doubles every five years. Around 1,600 new cases are diagnosed each week in Australia.[3]

An estimated 16,000 Australians under the age of 65 have younger onset dementia.[1] It is recognised that younger people with dementia may have physical, social and/or emotional needs that differ from older people with dementia.

Dementia affects the lives of not just the person with the condition but also their families and carers. It is estimated that nearly 1.5 million Australians are affected by dementia[5] including the families and carers of people living with dementia.

Dementia is the leading single cause of disability in Australians over the age of 65 years. It is one of the major reasons why older people enter residential aged care or seek assistance to continue to live in their own homes. In 2008–09, over half (53 per cent) of the permanent residents (more than 104,400 people) living in aged care homes who were appraised with the Aged Care Funding Instrument had a diagnosis of dementia.[6]

EARLY DIAGNOSIS AND INTERVENTION

There is evidence that in most health systems across the world dementia is under-diagnosed, and that when diagnosis occurs this is typically at a relatively late stage in the disease process. Even in high income countries, only around one-fifth to one-half of the cases of dementia are routinely recognised and documented in primary care records.[7]

Australian and international research indicates that of those who are diagnosed, on average, diagnosis is made around three years after the first health professional consultation.[8]

In Australia, it is thought that between 50 and 80 per cent of people with early stage dementia are not being diagnosed in primary care.

Why is early diagnosis important?

Dementia affects not only the lives of people living with the condition but also their families and carers. Early diagnosis has potential benefits for all of these people.

Early diagnosis of dementia has the potential to improve cognitive function, delay institutionalisation, reduce carer burden and improve quality of life through access to appropriate psychological, psychosocial and pharmacological therapies.

Early diagnosis enables a person affected with dementia to make choices about their future while they are still able: to remain in part time or full time employment in a supportive workplace; to participate in meaningful and appropriate social activities; to arrange powers of attorney and care in advance; to access medicines that may delay cognitive decline; and to receive support from community services which can enable them to continue living in their community for as long as is possible.

Early diagnosis also allows carers and families living with dementia to engage with appropriate support services and networks to help reduce carer burden.

For the person with younger onset dementia, an early diagnosis provides opportunities to address issues and other challenges that older people may not encounter, such as continuing employment, managing family responsibilities, and roles and relationships in relation to dependents and partners. Lack of information, awareness and understanding in the broader community, and amongst professionals and service providers, increases the stress for younger people with dementia. Friends and family struggle when others do not recognise or underestimate the difficulties that people with younger onset dementia and their family and carers experience.

A number of studies report that early assessment of cognitive decline also allows for the investigation and detection of potentially reversible or treatable causes of cognitive impairment. These conditions include thyroid disorders, subdural haematoma, neoplasm, alcohol induced cognitive impairment, intra-cerebral lesions, vitamin B12 deficiency, folate deficiency, metabolic disturbances, fluid and electrolyte disturbances, infections, renal failure, hypoxia and malnutrition.[9]

It is clear that missed or delayed diagnosis leads to lost opportunities for the person with dementia and increased carer burden. Closing the treatment gap – the time from first

symptoms to diagnosis – is one way of improving the quality of life for people living with dementia.

Primary care and early diagnosis – where are we at?

Factors limiting early diagnosis

Research on barriers to early diagnosis by primary care practitioners shows that there are similar issues across countries and health systems: the diagnostic issues faced by people with dementia are complex; the early signs and symptoms of dementia can be ambiguous; and many general practitioners find dementia difficult to diagnose – while others may be indifferent regarding the benefits for diagnosis. [10] [11]

There is no fixed starting point to dementia diagnosis. The initial presenting symptoms can be diverse, and symptoms may mimic other conditions such as normal ageing, depression, anxiety, thyroid disease, or less commonly, a brain tumour. Consequently there is often an absence of a clear indication that formal testing is required.[12]

A major challenge is differentiating the pathological symptoms of early dementia and the normal changes associated with ageing – a challenge made more difficult by the lack of a simple test. Further, a lack of specialist and community resources for referral has also been identified as a barrier to early diagnosis.

Not surprisingly, diagnosing dementia can be a time consuming process.

There is also evidence that those least likely to be assessed early are people who live alone, especially if they have no family member or carer to help initiate discussion with a health practitioner.

In addition, as noted above, often there is a delay between the time the first symptoms are recognised and when the person presents to the first health professional seeking diagnosis. This delay may be as long as three years.

Many General Practitioners find diagnosing dementia a challenge and their perceptions of the factors limiting early diagnosis are consistent with these findings. Several studies have found that:

- The person with dementia often presents with multiple symptoms and health conditions.[13]

- In cases where people present with mild to moderate impairment, they are usually able to perform well on mini mental health assessment tools and practitioners may not complete a full assessment as suggested in the Royal Australian College of General Practice Guideline, so that diagnostic accuracy is reduced.

- There is low awareness, even among General Practitioners and other health professionals, that adults as young as 30 years of age may have dementia. This contributes to delayed diagnosis and leads to poor access to services that provide care and social support.

- General Practitioners' perceptions of perceived benefits (such as access to medication and ability to address future needs and planning) or disadvantages (such as risk of psychological harm or distress through misdiagnosis) also play a part in diagnosis.

- General Practitioners' consultations tend to be brief which is considered to be an impediment to early diagnosis.

- General Practitioners report uncertainty as well as reluctance about their role in relation to legal matters arising in dementia care, e.g. enduring power of attorney, advance care plans. This uncertainty is also a cause of frustration and confusion for the person with dementia and their carer.[3]

A recent study found that in 84 per cent of cases, the General Practitioner is the first health professional a person with dementia consults about their symptoms.[1] As the population ages and the prevalence of dementia increases, dementia will be encountered more frequently in general practice. Consequently, there is a need to improve diagnosis by General Practitioners and other primary care practitioners.

Guidelines to assist primary care practitioners

The *Dementia Services Pathways – an essential guide to effective service planning* (2007), has been developed to assist practitioners in the diagnosis of dementia and the planning of support services once dementia has been diagnosed. The Guide covers four stages of dementia: awareness, recognition and referral; initial assessment, diagnosis and post-diagnosis support; management, care, support and review; and end of life. It emphasises the benefits of early diagnosis but also acknowledges that early dementia is often only apparent in hindsight.

The New South Wales Health guidelines, *Care of patients with dementia in general practice,* provide a framework for General Practitioners in diagnosing dementia. These guidelines have been endorsed for national use by the Royal Australian College of General Practitioners (RACGP). However, research suggests that General Practitioners and their teams do not always adhere strictly to these guidelines.

Medicare items enabling dementia diagnosis, treatment and care

Under Medicare Benefits Schedule (MBS) arrangements, there are no specific items for dementia diagnosis and intervention. However there are a number of items that can be used for these purposes.

These items include, for example:

- health assessments provided for people aged 75 and older that can be undertaken annually – MBS items 701-707;

- comprehensive medical assessments in residential aged care facilities that can be provided annually;

- people of any age, with suspected or diagnosed dementia, are eligible for longer consultations using the standard General Practitioner attendance items – Level C attendance item - lasting at least 20 minutes, and the Level D attendance item - lasting at least 40 minutes;

- support for people living with chronic disease, including conditions such as dementia, is available through chronic disease management (CDM) items such as MBS item 721-732;

- GPs are able to choose Medicare rebateable items for GP-managed care planning and/or team assisted care planning, depending on the health needs of their patients. There are further CDM items for GPs to review care plans and contribute to care plans prepared by other providers, including Residential Aged Care Facilities; and

- the CDM items provide a mechanism for GPs to refer patients for Medicare rebateable allied health services (items 10950-10970).

Whether a person living with dementia is eligible for the CDM and/or allied health items is a clinical judgement for the General Practitioner, taking into account the patient's medical condition and care needs, as well as the general guidance set out in the MBS.

There are also MBS attendance items available to geriatricians to diagnose and treat elderly patients with a range of conditions including dementia – MBS items 141–147 (See further Attachment A).

Integrated care through Medicare Locals

Medicare Locals are improving the coordination and integration of primary health care in local communities, addressing service gaps and making it easier for people to navigate their local health care system. They:

- make it easier for patients to access the services they need, by better linking local General Practitioners, nursing, allied health and other health professionals, hospitals and aged care, and maintaining up to date local service directories;

- work closely with Local Hospital Networks to make sure that primary health care services and hospitals work well together for the benefit of their patients;

- plan and support local after hours face-to-face General Practitioner services;

- identify and target gaps in primary health care for older people, whether they live independently or in an aged care facility;

- identify where local communities are missing out on services they might need and coordinate services to address those gaps;

- support local primary health care providers, such as General Practitioners, Practice Nurses and allied health providers, to adopt and meet quality standards; and

- be accountable to local communities to make sure that services are effective, affordable and of high quality.

This has potential to achieve improvements in the diagnosis of dementia and in ongoing care and support for people living with dementia, and their carers and families.

Aged Care Assessment Teams and diagnosis of dementia

Aged Care Assessment Teams (ACATs) are also involved in the diagnosis of dementia. The role of ACATs is to determine the overall care needs of frail older people and to assist them to gain access to the most appropriate types of care services. In doing this, ACATs comprehensively assess older people taking account of the restorative, physical, medical, psychological, cultural and social dimensions of their care needs.

This includes determining whether a person has dementia or other cognitive conditions, or behavioural problems related to these or other conditions and/or the presence of depression or delirium. An older person may present to an ACAT exhibiting the signs and symptoms of dementia, but may not have a formal diagnosis of dementia. ACATs are expected to ensure that the symptoms are medically assessed to ensure that any reversible causes of the symptoms, such as infections (delirium), contra medication combinations and/or depression are identified and treated. The ACAT would then determine if these signs and symptoms of dementia continue and are consistent with a dementing illness sufficient to approve an individual for dementia specific care and related funding.

ACATs involve clients, their carers, and service providers in the assessment and care planning process. ACATs are also encouraged to involve the person's General Practitioner.

Summary

Both national and international research identify the early diagnosis of dementia as a critical issue, not least because the delay from first noticing symptoms to when a diagnosis is made can be more than three years.

In Australia, the prevalence of dementia is predicted to increase to almost one million people by 2050. This coupled with the fact that dementia is the leading single cause of disability in Australians aged 65 years and over supports the need to improve early diagnosis to assist in ameliorating the increasing burden.

Early diagnosis has significant potential benefits for both the person with dementia and their families and carers. It enables the person with dementia to access appropriate psychological, psychosocial and pharmacological therapies which has the potential to improve cognitive function, delay institutionalisation, reduce carer burden and improve quality of life. It also enables a person affected with dementia to make choices about their future while they are still able.

Research demonstrates that primary care practitioners have a major role in improving early diagnosis and with most people traditionally consulting their General Practitioner first about their symptoms. Consequently, there is a need to improve diagnosis by General Practitioners and other primary care practitioners.

SUPPORT IN THE COMMUNITY AND PLANNING FOR THE LATER STAGES OF DEMENTIA

The Australian Government funds a number of programs and activities to support people with dementia, their families and carers, once dementia has been diagnosed.

National Dementia Support Program

Alzheimer's Australia and its state and territory member organisations are funded to deliver the National Dementia Support Program (NDSP). The Program provides support services to people living with dementia, their families, carers and health professionals. It aims to improve the quality of life for people with dementia and their carers and, where appropriate, to support those with dementia to remain in their homes.

Through the NDSP, Alzheimer's Australia:

- provides information resources, education and training for both carers and care workers, and awareness raising activities, such as displays at rural shows;
- encourages early diagnosis and awareness of the need to plan finances and future care needs, including through counselling and support (both one-on-one and group counselling), information and education services;
- provides referral to and guidance about local services and support through the National Dementia Helpline;
- provides early intervention programs and activities for people who have been diagnosed with dementia, including the *Living with Memory Loss* program;
- conducts a major annual awareness raising activity, Dementia Awareness Week, which includes activities such as dinner dances, morning teas, memory walks and culturally diverse food activities for people from Culturally and Linguistically Diverse Backgrounds; and
- encourages social participation, such as the conduct of support groups following participation in the *Living with Memory Loss Program* and other activities, such as the Memory Lane Cafes and art therapy groups.

Planning for living with the later stages of dementia

One of the benefits of early diagnosis is the facilitation of planning for future care and making or organising legal and financial affairs. It allows a person with dementia the opportunity to actively participate in decision making whilst they have the cognitive ability.

In April 2006, the Australian Health Ministers' Conference endorsed the *National Framework for Action on Dementia 2006-2010* (the Framework). The Framework provides an overarching vision for Australia's dementia care and support services between the Commonwealth and state and territory governments. One of the priorities for action identified in the Framework is to refer the issues of legislative barriers regarding

guardianship, advance care planning and advance care directives, wills and powers of attorney to Australian Government, State and Territory Attorneys General Departments.

Advance care directives are one possible outcome of advance care planning. State and territory governments are responsible for the legislation governing advance care directives. To assist policy makers and planners the *National Framework for Advance Care Directives* was published in September 2011. The Framework consists of a national terminology, a code for ethical practice and best practice standards for advance care directives.

The promotion of greater use of advance care planning to General Practitioners, other care providers and the public, and trialling approaches to advance care planning for people with dementia and other special needs groups are being progressed through the *Respecting Patient Choices* project.

Under the *Local Palliative Care Grants Program*, funding has also been provided for the development of advance care planning resources for people with dementia. Round 5 of the Program, in particular, funded projects that concentrated on innovative approaches to palliative care for people with dementia or mental illness.[2]

[2] Details of these projects are available from http://www.caresearch.com.au/Caresearch/Default.aspx, a one-stop online shop for information about palliative care and is operated by Flinders University.

RESEARCH AND OTHER INITIATIVES UNDERPINNING THE FUTURE

While there is a growing evidence base to help enable a better understanding of the underlying factors that cause dementia and to identify new or improved treatments and services for affected individuals, there is a continuing need for research.

Through the National Health and Medical Research Council (NHMRC), more than $1.1 billion has been provided to fund health and medical research into ageing and age-related diseases and health issues since 2001. The NHMRC identified dementia and Alzheimer's Disease as a strategic priority and in 2011 committed more than $23 million for research in these areas.

The NHMRC funds three Dementia Collaborative Research Centres (DCRC) to undertake dementia research and to translate the outcomes of that research into practice. Each Centre has a specific focus: Early Detection and Prevention; Assessment and Better Care Outcomes; and Carers and Consumers. The work and research of the DCRCs will help improve early diagnosis.

The DCRC for Early Detection and Prevention is collaborating on the Australian Imaging, Biomarker and Lifestyle Flagship Study which aims to improve the understanding of the causes and diagnosis of Alzheimer's disease, examine lifestyle and diet factors that may influence its onset, and help develop preventive strategies. It is a prospective longitudinal study involving a cohort of 1,000 volunteers with Alzheimer's disease (AD), Mild Cognitive Impairment (MCI) and healthy volunteers. A number of the Centres' projects are being undertaken in connection with risk identification, risk reduction strategies and development of risk reduction guidelines for General Practitioners and lifestyle health workers.

The DCRC for Assessment and Better Care Outcomes has recently published *Dementia Management in Community-Based Primary Care: A review of the international literature 1995-2008.* This report provides a summary and analysis of the evidence concerning the role that the General Practitioner, Practice Nurses and other allied health professionals play in diagnosing dementia.

Minister for Mental Health and Ageing's Dementia Advisory Group (MDAG).

The importance of primary care for people with dementia in achieving timely diagnosis and effective management of dementia has also been identified as a priority area by the Minister for Mental Health and Ageing's Dementia Advisory Group (MDAG). MDAG is currently exploring the barriers and opportunities for improving care, including avenues available through Medicare Locals.

As part of their consideration, MDAG plans to host a Dementia in Primary Care Roundtable in mid-2012. The outcomes of the Roundtable will be made available for consideration by the Government.

AGED CARE AND HEALTH REFORMS

Aged Care: *Living Longer. Living Better*

The Australian Government recognises the need for fundamental reform of the aged care system in order to ensure that it continues to provide high quality care and responds to the needs of Australia's ageing population in a way that is sustainable for the future. That is why it commissioned the Productivity Commission's inquiry into aged care.

The Productivity Commission's report, *Caring for Older Australians*, highlights the increasing prevalence of dementia and the need to address the diagnosis and care of people living with dementia.

As part of the extensive conversations on ageing held by the Minister for Mental Health and Ageing across Australia, additional support for people with dementia was one of the most consistent issues raised by older Australians, their families and with industry stakeholders: support for early diagnosis; support when in hospital; and funding to recognise the costs of aged care for people living with dementia.

These views have been critical to informing the development of the Government's aged care reform package.

The Australian Government announced a comprehensive package of reforms on 20 April 2012, to build a better, fairer, sustainable and nationally consistent aged care system. The *Living Longer. Living Better* aged care reform package provides $3.7 billion over five years. It encompasses a 10 year reform program to create a flexible and seamless system that provides older Australians with more choice, control and easier access to a full range of services, where they want it and when they need it. It also positions the aged care system to meet the social and economic challenges of the nation's ageing population.

The reforms will ensure Australia's aged care system is underpinned by fairer and more sustainable financing arrangements. These arrangements reflect a shared commitment to meeting the costs of aged care, protect the most vulnerable in the community and do not involve any changes to the current treatment of the family home.

Key components of the reforms include:

- additional support and care to help older people remain living at home;
- additional help for carers to access respite and other support;
- delivering better residential aged care;
- strengthening the aged care workforce;
- supporting consumers and research;

- better health connections;
- tackling dementia;
- supporting older Australians from diverse backgrounds; and
- building a system for the future.

These reforms are essential if the Australian Government is to provide our nation's seniors with the care, security and – above all, dignity – they deserve in their later years. They take into account the fact that the aged care sector and the wider health system need to work more closely together to tackle dementia and support for end-of-life care.

The reforms will be progressively implemented from 1 July 2012. This will enable consumers and providers to gain early benefits from key changes, while ensuring there is a smooth transition for consumers and providers and sufficient time to adapt and plan ahead of further reform.

The aged care reform package includes $268.4 million over five years to better support people with dementia from when people first approach their General Practitioner with the early signs of dementia through to when they need a very high level of aged care.

This funding is on top of current initiatives, which include:

- A projected $150 million over five years for service improvement, including information provision, counselling, service referral, and training.
- A projected $180 million over five years for dementia research through the National Health and Medical Research Council.

Tackling dementia – the ninth National Health Priority

As a means of focusing attention and effort on dementia, the Australian Government will recommend to state and territory Health Ministers that dementia be recognised as the ninth National Health Priority Area. This will help drive collaborative efforts aimed at tackling dementia at national, local and state and territory levels.

Supporting people with dementia across the health system: more support for timely diagnosis, and expanding the scope of Dementia Behaviour Management Advisory Services

The Government will provide $41.3 million over five years from 2012-13 to:

- Expand the Dementia Behaviour Management Advisory Services into acute and primary care settings with a particular focus on support for older people from culturally and linguistically diverse backgrounds and Aboriginal and Torres Strait Islanders. This will help workers and health professionals to better care for people with behavioural and psychological symptoms associated with dementia and enable people with dementia to be cared for at home for longer.

- Support primary health care providers to undertake more timely diagnosis. General Practitioners and Practice Nurses will receive much needed training and education programs and improved support to help them better diagnose dementia. Funding will be provided to support general practice staff, assist with take up of training, assist in developing appropriate referral pathways and support General Practitioners, practice nurses and all ancillary staff employed in the primary care setting. The program also aims to improve understanding of the medical and social support available to improve the lives of people with dementia and the importance of an accurate diagnosis.

Improving acute care services for people with dementia

Up to 50 per cent of all patients in hospital have cognitive impairment. Many of these people may not be recognised as having dementia and do not receive appropriate care which leads to longer stays than should be the case. The Government is providing $39.2 million to develop and roll out systems to improve hospital services for people with dementia. Staff will be trained to identify early signs of dementia, particularly on admission, and to implement appropriate protocols.

Improved support for people with younger onset dementia

Today there are approximately 16,000 people who have younger onset dementia. The Government will provide $23.6 million to enable younger people with dementia to access better coordinated care and support, assisted by dementia key workers.

There is low awareness, even among health professionals, that younger people may have dementia, resulting in poor access to care and social support. A lack of appropriate care facilities and services means that younger people are often moved between disability and aged care services.

The Government will improve care and support for people with younger onset dementia, their families and carers. It will expand the National Dementia Support Program to improve access to better coordinated services. A national network of specialist key workers will provide a single point of contact to assist younger people with dementia and their carers at every stage of the journey following diagnosis. Funding will assist the younger person with dementia and their carer to navigate the care system and support the achievement of short and long-term goals identified by the person with younger onset dementia and their family.

Better care for people in residential care who have behavioural problems associated with severe dementia

Individuals with severe behavioural and psychological symptoms of dementia often find difficulty in getting access to appropriate services and can experience a lack of understanding of their care needs by staff in residential care. This can lead to hospitalisations, excessive use of medication and additional strain on staff, residents and their families.

The Government is providing $41.0 million to improve the quality of care in aged care homes for residents who have severe behavioural and psychological symptoms of dementia. This funding will be delivered by adding a new Very High Level of funding to the Behaviour Domain of the Aged Care Funding Instrument. Staff will receive improved training, and

guidelines and procedures will be developed to ensure best practice by residential aged care providers.

Better care for people with dementia through home care packages

Funding of $123.3 million will enable additional financial assistance to people with dementia who are receiving Home Care packages through a new Dementia Supplement of 10% on top of the base funding for the package. This will significantly increase the number of people living in the community who will be eligible for this assistance.

Health Reforms

National health reforms

Under the National Health Reform Agreement the Commonwealth has the lead responsibility for the system management, funding and policy development of General Practitioner and primary health care. The Commonwealth will work with the States to implement new arrangements for the health system, with the objective of delivering a General Practitioner and primary health care system that meets the health care needs of Australians, keeps people healthy, prevents disease and reduces demand for hospital services. This work will help define the shape of the primary health care system in coming years, including how the mainstream primary health care system will respond to the needs of specific population groups.

Given the rising incidence of chronic diseases in Australia, the Government is committed to refocusing the health system towards the prevention of chronic diseases, including in light of the evidence that the risk factors for dementia are similar to those for other chronic diseases, such as heart disease and stroke.

Strategies for reform include the Australian Government's promotion of healthy ageing for Australians of all ages across the lifecourse, which is critical to increasing social and workforce participation, preventing the burden of chronic conditions, reducing the risk of disability and suicide in older populations and empowering individuals to monitor their own health and health care needs.

The National Health Reform Agenda aims to reduce the incidence of preventable mortality and morbidity in Australia, through regulation and national initiatives to support healthy lifestyles and chronic disease conditions prevention.

Support is also provided by the Australian National Preventive Health Agency, established by the Australian Government in 1 January 2011. The Agency gives evidence-based advice on appropriate programs, manages a research fund to build further supportive evidence in preventive health, and focuses on a range of other initiatives targeting chronic diseases and their lifestyle related risk factors.

Personally Controlled Electronic Health Records system

The Australian Government is also building the Personally Controlled Electronic Health Records (PCEHR) system. The eHealth records system will have the capacity to contain summary health information created by health care providers such as medical conditions, medications, allergies and the location of advanced care directives medical events. Over time

the system will also include discharge summaries from hospitals and information from Medicare systems should the patient choose to include it in their record.

Older Australians, people with chronic disease are a key focus of the early roll out of the PCEHR. The PCEHR will be of particular benefit to older people who have a range of co-morbidities and/or are on multiple medications. Making comprehensive information available will be of particular benefit in alerting practitioners to early signs of dementia and facilitating early diagnosis. It will also benefit the ongoing care of people with a dementia as it will allow a clear record of care interventions, support and treatment across care settings. Currently information sharing between home care, hospital care and residential care is fragmented, potentially diminishing outcomes for the person with a dementia.

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