



National Primary Health Care Strategy Secretariat
MDP 94, GPO Box 9848
CANBERRA
ACT 2601

Alzheimer's Australia welcomes the opportunity to make a submission to the Primary Health Care Review. The release of the NHRC Interim Report has set the context through the reform agenda that it proposes, giving a higher priority to primary care and health prevention that is long overdue.

The particular concerns of people with dementia and their family carers have been clearly articulated over many years in publications such as:

- *The 2005 National Consumer Summit on Dementia: Communiqué* was delivered by 50 people with dementia and family carers and recommended a seven point action plan for change, of which the first action was to improve the assessment and diagnosis of dementia.
- *The National Dementia Manifesto 2007-2010*, endorsed by our National Consumer Committee in 2007, again highlighted - as their first priority – the need to 'Improve the diagnosis of dementia by GPs'.
- *In our own words: A collection of very personal stories*, provided insights into some of the lives of the 10,000 people with younger onset dementia – infrequently in their teens and 20s and increasingly in their 30s and beyond - and in particular, the often very difficult path to accurate diagnosis.

I have attached copies of these publications for your information. Also attached is our submission. There are no sections in this Submission which are confidential and we are happy for the submission to be published in its entirety.

As requested, we have addressed the questions in the discussion document.

Please contact Glenn Rees - telephone 02 6254 4233 or email glenn@alzheimers.org.au - if you require further information.

Glenn Rees
Chief Executive Officer
27 February 2009

Alzheimer's Australia Submission to the Development of the National Primary Health Care Strategy

Executive summary

Problems with the diagnosis and management of dementia by GPs have been among the most serious concerns of consumers for many years. Successive Governments have continued to regard dementia as solely an aged care rather than as a health issue with the consequence that no particular attention or priority has been given to dementia within primary care. This is notwithstanding the fact that there are over 1000 new cases of dementia every week.

An effective primary care system is critical to the well being of people with dementia and their family carers. The current system is failing many of the 230,000 Australians with dementia and the approximately 1 million Australians who care for them. The current arrangements are characterised by excessive delays in accurate diagnosis, poor communication and poor referral to support services.

The system is also failing younger Australians because there is no recognition in National health policy that lifestyle changes may reduce the risk of dementia. There is no recognition of the links between dementia and other chronic conditions such as diabetes, obesity, vascular disease, HIV AIDS and alcohol abuse. As a consequence, dementia is not included in National health prevention programs or more recently mentioned in that context in *A Healthier Future for all Australians*.

It is of concern that the one recommendation to dementia in *A Healthier Future for all Australians* is in the context of mental health. Dementia care has been largely funded by the aged care system and mental health systems have largely ignored the issue. In the primary health context, a person with dementia is explicitly excluded from GP Mental Health Care Medicare items suggesting that only those with a primary diagnosis of an acceptable mental health condition such as schizophrenia are covered.

Community services are the Cinderella of the health care system and rate barely a mention in *A Healthier Future of all Australians*. Yet services such as transport, respite for the carer and community nursing services are a key part of the support infrastructure of primary care in providing access to services, the maintenance of the carer wellbeing and care in the home. A significant increase in funding of community care services should be part of the reform process.

94 per cent of Australians would go to their GP if concerned about their memory. It is therefore critical that GPs and other health professionals are supported to recognise the benefits of timely and accurate diagnosis through access to education and training opportunities to up skill in dementia care.

Delays in diagnosis not only generate unnecessary trauma for individuals and their families and carers but deny them access to treatment and the opportunity to more effectively plan their lives, their care and their finances.

Management after a diagnosis of dementia is multi-faceted and fits well within the complex and chronic care model. Most people with dementia are older and have co-morbidities such as hypertension, diabetes, depression and arthritis. Primary health care professionals need to proactively address the range of health issues experienced by people with dementia, as well as taking into account the impact of dementia on management and treatment.

The recommendations that capture the responses in this submission to the questions in the discussion paper are set out below under three main headings.

**Recommendation 1:
Improve the diagnosis and management of dementia within primary care**

The failure of the primary care system to diagnose dementia in a timely and accurate way and to provide support is a major concern of people with dementia and their families and carers. The principal actions needed are to:

- Provide Medicare incentives to improve timely and accurate diagnosis and support for people with dementia and family carers in ongoing management.
- Link these incentives to opportunities for dementia training to all GPs, nurse practitioners and other primary health professionals as appropriate, for example in regional areas.
- Foster a multi-disciplinary approach supported by access to specialist services for people with dementia of any age.

This action should be supported by

- Identifying best practice dementia referral pathways and developing these in regions where they do not already exist.
- Identifying opportunities for consumers and consumer organisations to be involved in planning, accreditation and service development.
- Improving the provision of targeted information to support health professionals in providing best practice dementia care and to encourage those with changes in memory and thinking to seek a diagnosis.
- Improving access to specialist advice including through communication mechanisms such as teleHealth and eHealth.
- Introducing dementia specific accreditation for primary care professionals to complement specialist access.
- Improving information available about Government support mechanisms^a that are already available that might be accessible to better support people with dementia and their family carers.

^a For example, the Medicare items available to support complex and chronic care.

- Extending current Government initiatives to improve primary health care access for people in residential care.
- Encouraging consumers to make advanced care directives, and for health professionals recognise them.
- Developing and accepting national guidelines for best practice dementia care for use by the various professions.
- Establishing of a network of primary care professionals and specialists who are willing and able to assist younger people who have concerns about dementia.
- Investigating how software such as Medical Director might be used to prompt primary care professionals to consider the possibility of dementia as people age or where relevant co-morbidities exist, as well as link people with dementia and their family carers with the information and support that they need as dementia progresses.

**Recommendation 2:
Implement a National preventive health strategy on dementia.**

This would include:

- Providing funding for the National roll out of Alzheimer's Australia's **Mind your Mind** program.
- Including dementia as a component of existing preventative health strategies including cardio-vascular and diabetes.
- Promoting preventative approaches to primary care professionals, such as improved information and monitoring for blood pressure and cholesterol; and routine nutritional testing under Medicare within the 75 year old check.

**Recommendation 3:
Undertake initiatives to strengthen primary care for disadvantaged groups.**

- Encouraging use of validated assessment tools for diagnosis dementia in special populations such as people from Aboriginal and Torres Strait Islander communities or culturally and linguistically diverse (CALD) backgrounds.
- Promote awareness to reduce stigma and lack of understanding including through building on partnerships between Alzheimer's Australia and Aboriginal and Torres Strait Islander communities and people from CALD backgrounds.

Alzheimer's Australia wishes to acknowledge the contribution of Dr Nerida Paterson, University of Newcastle and Dr. Fiona Millard, Adjunct Senior Lecturer of Aged Care, James Cook University, to the preparation of this submission.

Living Well With Dementia: A National Strategy

The UK National Health Service has recently developed a National Dementia Strategy aimed at improving services for people with dementia and their family carers. The recognition within this Strategy of the importance of quality and appropriate primary health care for people with dementia mirrors the findings of many studies and reports across the world.

The aim of the Strategy is to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care. The Strategy identifies 17 key objectives which, when implemented, largely at a local level, should result in significant improvements in the quality of services provided to people with dementia and should promote a greater understanding of the causes and consequences of dementia. This Strategy should be a catalyst for a change in the way that people with dementia are viewed and cared for in England.¹

Specific objectives of the Strategy that supports the provision of quality primary health care for people with dementia and their family carers include:

Objective 1: Improving public and professional awareness and understanding of dementia. Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour change in terms of appropriate help-seeking and help provision.

Objective 2: Good-quality early diagnosis and intervention for all. All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis, sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area.

Objective 13: An informed and effective workforce for people with dementia. Health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.

Background

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning. It is a broad term used to describe a loss of memory, intellect, rationality, social skills and what would be considered normal emotional reactions. The most common cause is Alzheimer's disease. The effects of the different types of dementia are similar, but not identical, as each one tends to affect different parts of the brain.

While dementia is not a natural part of ageing, it is more common as you age. Dementia does affect people under 65, including those under 40.

Like other Australians, people with dementia and their family carers stand to benefit from a stronger primary health care sector. In 2009, there is projected to be 234,640 people with dementia. By 2030 this figure will have doubled to 465,460 and by 2050 this figure will reach 731,030.² There are more than 1000 new cases of dementia each week.

Currently almost half of the Australian population knows a family member or friend who has dementia. At the same time, there is a large body of evidence to suggest that current practice in relation to identification, assessment and management of dementia could be improved.³

While projects that aim to improve diagnosis and management have been a particular focus of Government dementia strategies in some jurisdictions in recent years, much remains to be done.

Why are obtaining a diagnosis and ongoing information important?

Accurate and timely diagnosis is the first step on the journey of the person with dementia and their family carers. Ongoing management, assessment and support from primary care providers have an opportunity to provide optimum health, quality of life and care outcomes for those with this complex and chronic condition.

Market research commissioned by Alzheimer's Australia indicates that over 94% of Australian would seek help from their general practitioners if they were concerned about their loss of memory or changed behaviour.

Some consumers are unfamiliar with the symptoms of dementia and may fail to seek help until symptoms are advanced, or may find that when they do seek help, usually from their GP, that little is done in the way of advice or investigation.

Currently many health professionals lack appropriate training in dementia,⁴ and GPs are less likely to diagnose and manage people affected by dementia when supportive multidisciplinary dementia services are absent.⁵

The right to an accurate and timely diagnosis

Obtaining a diagnosis of dementia can be a difficult, lengthy and intensive process. While circumstances differ from person to person, Alzheimer's Australia believes that everyone has the right to:

- A thorough and prompt assessment by medical professionals,
- Sensitive communication of a diagnosis with appropriate explanation of symptoms and prognosis,
- Sufficient information to make choices about the future,
- Maximal involvement in the decision making process,
- Ongoing maintenance and management, and
- Access to support and services.

For some people, there may be barriers to diagnosis, especially to an early diagnosis. These include the belief that memory problems are a normal part of ageing, the perceived stigma attached to dementia, the lack of a cure and fear about the future. However, there are many reasons why early diagnosis is important, some of which are detailed within this paper. Early diagnosis and awareness about dementia are the first steps in designing management strategies. As more effective treatments become available in the future, early diagnosis will become even more important.⁶

Research both in Australia and overseas shows that the pathway to dementia diagnosis is often delayed by many years,^{7,8,9} creating a barrier to access to appropriate support and care management that can improve quality of life and delay admission to residential care.^{9,10}

There is concern that the current primary health care system is unprepared to meet the increasing needs of an ageing population and with it the growing numbers of people with dementia. Cognitive impairment generally has an adverse impact on the management of other co-morbidities, as individuals may be less able to manage their own health.

The “dementia epidemic” will place further demands on GPs who remain the gatekeepers to service provision for older people. In particular, they refer individuals to the specialists who confirm the differential diagnosis of dementia and provide access as appropriate to available medications.

The benefits of timely and accurate diagnosis cannot be achieved without GPs being knowledgeable about dementia and able to provide timely access to specialists and information about services. Timely diagnosis allows GPs to put the measures in place to minimise medication non compliance and to look more critically at other ways to achieve better health outcomes.

For younger people with dementia the problems of diagnosis and ongoing management can be even more problematic as health professionals do not always understand that dementia may occur among younger people – infrequently in their teens and 20s and increasingly in their 30s and beyond.

On diagnosis, people need immediate referral to those who can provide information. Relevant information at the right time supports people affected by dementia and minimizes depression, stress and excess carer burden. Knowing what to expect helps people to stay as well as they can stay.

Consumers’ views on the importance of primary care

Alzheimer’s Australia is committed to a strong consumer focus in which people with dementia, their families and carers actively contribute to the work of the organisation according to their interests, needs and abilities.

At the first National Consumer Summit on Dementia in October 2005, the 50 people with dementia and family carers who participated identified a key priority as the need to improve the assessment and diagnosis of dementia. The participants felt that:

GP’s must know, and be able to recognise, the early signs of dementia so that people can be assessed and diagnosed in a timely manner and effectively provided with appropriate advice, support and interventions. ¹¹

In identifying their priorities, the Alzheimer’s Australia National Consumer Committee again included the improvement of assessment and diagnosis as a high priority in their *National Dementia Manifesto 2007-2010*.

Primary care professionals, including practice nurses, are ideally placed to support people in obtaining the information that they need through the journey from diagnosis to death. This includes referral to relevant community services and support organisations such as Alzheimer’s Australia.

The rest of the submission follows the headings in the discussion paper.

1. Accessible, clinically and culturally appropriate timely and affordable services.

While diagnosis and management of dementia in primary care remains problematic for people with dementia and their family carers, it may be even more difficult for particular groups with special needs. Among those who may be particularly disadvantaged are people from:

- Culturally and Linguistically Diverse (CALD) communities;
- Aboriginal and Torres Strait Islander communities;
- Rural and remote areas;
- Living in residential care facilities; and
- Younger people with dementia.

Further information including approaches to assessment and management is included in the Appendix.

How can we ensure appropriate services for all geographical areas and population groups?

- Professionals with dementia specific skills should be present in every primary health care service, including Aboriginal health services, CALD specific services and practices in rural and remote areas.

The UK National Dementia Strategy proposes to support the commissioning of a dementia service in every region for early diagnosis and intervention.

- Addressing disparities in the costs of and access to primary care in rural and remote areas, for example by improving bulk billing rates and reducing the distance - and travel costs – to reach services.
- In main cities, the GP is the usual point of contact for primary care. Bulk billed consultations are more common for older people and those on a pension. However, rural areas provide less bulk billed consultations, possibly due to higher costs or less competition.

Providing additional funding for older people with identified health needs could assist them to better utilize primary care services as older people are likely to consult less often when visits are not bulk billed.¹²

- Encourage health professionals including GPs making a diagnosis of dementia to refer the individual or carer to support agencies such as Alzheimer's Australia. This could be done through appropriate prompts in medical software such as Medical Director.

- Software like Medical Director could also be used to prompt GPs to consider the possibility of dementia as people age or where relevant co-morbidities exist.
- The Aged Care GP Panels Initiative and the Aged Care Access Initiative have been the first steps in improving access within residential care, however further steps should be taken to ensure that older people in residential care have access to the full range of primary health care services.

A 2007 study indicated that while “dementia was the most common problem managed in residential care at 33 times the usual management rate in everyday practice, significantly fewer medications, non-pharmacological treatments, referral, pathology and imaging test were recorded at RACF consultations”¹³

How could primary health care services/workforce be expanded to improve access to necessary services?

- Australia should follow the lead of the UK National Health Service that has developed a five year strategy to train all GPs in dementia diagnosis.²
- Statistically, people living in rural or remote areas have less opportunities to access GPs.¹⁴ Other health workers, such as nurse practitioners, should be provided with the necessary training to ensure quality and adequate primary health care is received by people in remote locations.
- To expand services, look at alternative ways of delivery that enable wider use of resources, encouraging skills training for allied health and nurses and introducing electronic media.^{15,16}
- GPs and other health professionals should be up-skilled and accredited in dementia knowledge and skills to ensure there is an expert in every practice in every rural location.
- Access to specialist advice should be improved through utilisation of new technologies such as eHealth and teleHealth

What more needs to be done for disadvantaged groups to support more equitable access?

- Disadvantaged groups should be encouraged to contribute throughout the planning, delivery and evaluation of health services, so that the services address their needs and allow them ownership.

- Off-setting the costs of quality primary health services to enable equitable access for lower socio-economic groups and communities outside the metropolitan areas.
- Further development of validated assessment tools to support diagnosis in CALD and Aboriginal and Torres Strait Islander communities. These include the Kimberley Indigenous Cognitive Assessment Tool (KICA) developed for Aboriginal and Torres Strait Islander communities, and the Rowland Universal Dementia Assessment Scale (RUDAS) developed for people from CALD backgrounds.
- Targeted information through accepted community groups and community leaders.
- Development of pathways that take account of cultural diversity and available health infrastructure.
- Resource partnerships between Alzheimer's Australia and CALD and Aboriginal and Torres Strait Islander organisations to disseminate information and promote awareness of dementia.
- Use existing government incentive programs in residential care to:
 - Target information about behavioral and psychiatric symptoms of dementia;
 - Mandate up-skilling through dementia education and training; and
 - Provide individual accreditation as part of Continuing Medical Education.
- Evaluate existing initiatives aimed at improving access to quality primary care within residential care, and improve information about the lessons learnt and the approaches that provide good outcomes.

With limited public health dollars, how could priorities for accessing primary health care services be determined and targeting of public resources improved?

- Quality of life for people with dementia and their carers can be improved through timely and accurate diagnosis and appropriate support, reducing the burden on tertiary and residential services leading to savings in the health budget.
- The GP is the health professional most consulted by people as they get older,¹⁷ and therefore most likely to make a diagnosis of dementia, but they need support in order to make this diagnosis and manage the condition.

- Ideally GPs need to have a 'check list' to prompt them to identify the impact of dementia on the individual's general health, including specific co-morbidities. This will minimise the adverse impacts on the individual and their family and carers.
- Public resources should target prevention in addressing predicted future health challenges. With an ageing population, dementia will present an increasing challenge. If the average onset of Alzheimer's disease could be delayed by 5 years there would be approximately a 50% reduction in new cases each year, resulting in significant savings in the health budget.

2. Patient-centred and supportive of health literacy, self-management and individual preference.

Alzheimer's Australia supports the principles set out in the "Community and Consumer Participation" section of the *AGPN Primary Health Care Position Statement 2008 Update*.¹⁸

Community and Consumer Participation

Consumers and their communities are the principal stakeholders in health care. All stakeholders in the health system have a shared responsibility to seek the best health outcomes that are achievable with the limited resource available. Primary health care has particular responsibilities to support consumers and communities to maximise their health outcomes. It is important that individual consumers and communities are empowered participants in their health. Consumers will have the right to choose their primary health care providers and will have access to their shared electronic health record. During consultations, consumers will be:

- recognised as experts in their own health;
- treated as a partner and involved in decision making; and
- supported to self manage.

Consumers and community will have (to) be involved in decision making and governance at all levels, including:

- health service operations;
- health service accreditation; and
- health system planning.

What is needed to improve the patient and family centred focus of primary health care in Australia for

- Individual patient encounters*
- Health professionals*
- Health service integration*
- Broader primary health system*

Are there specific strategies that are needed to better support consumer engagement and input?

- Consumers will benefit from Government initiatives which promote the role of the consumer as an equal partner in health care. This will help to encourage primary health care professionals to provide the information and support that consumers need to take on this role.
- People should be encouraged to understand the implications of their health issues and be involved in management in line with their interests and cognitive capacity.
- People with dementia should continue to be consulted about their care and involved as a partner in their health management for as long as possible.
- The support role of family carers should be recognised in terms of ensuring optimum care and health management for a person with dementia.
- The degree of cognitive impairment should be factored into care in terms of consumer rights and responsibilities.
- Encourage and promote advanced care planning so that people's health wishes and preferences are taken into account as dementia progresses.
- Access to their health records should be part of the partnership between consumers and primary health care professionals.

3. More focused on preventive care, including support of healthy lifestyles

A number of risk factors have been identified for Alzheimer's disease and vascular dementia including old age, hypertension, stroke, diabetes type 2, elevated cholesterol, smoking, obesity, fatty diet, genetic risk factors and head injury.¹⁹

Mind your Mind® is Alzheimer's Australia's dementia risk reduction program. It is designed to help to reduce the risk of developing dementia and promotes a 'brain healthy' lifestyle. Based on scientific evidence, seven healthy lifestyle factors, referred to as **Mind your Mind** signposts, for dementia risk reduction have been identified:²⁰

- Mind your Brain
- Mind your Diet
- Mind your Body
- Mind your Health Checks
- Mind your Social Life
- Mind your Habits
- Mind your Head

While National Preventative Health strategies have addressed areas such as heart disease, diabetes, cancer and mental health, to date there has been little focus on reducing the risks for dementia. This topic is particularly relevant as our population ages and the numbers with dementia are projected to grow.

The existing strategies have not identified the increased risk of dementia as a potential outcome of poor cardio-vascular health. Similarly exercise has been shown to decrease the risk of dementia by a half, yet dementia is not mentioned when promoting exercise in the community.²¹

There are opportunities when people use primary health care services to provide information about prevention. For example, when testing people who may be at risk of certain health problems, such as cholesterol, raise their awareness of the potential risks, and encourage them to deal with the problem before major health issues arise.

Another risk factor for dementia is poor nutrition, however nutritional tests in older people, such as those measuring neuro-protective vitamins - B6, B12, C, D and E - are not commonly requested. Promotion of these kinds of tests to primary health care providers, and Medicare coverage of the tests could help to alert people to nutritional deficiencies, potentially reducing this preventable risk factor for dementia.

How could primary health care be enhanced to better support prevention activities?

How could health professionals be better supported to provide lifestyle modification advice and support consumers in behavioural change?

How can consumers be linked with local primary health care services to support a stronger focus on population-based preventative health care with national reporting?

- Reach consumers through existing community organisations and workplaces, strengthen the information base and encourage initiatives such as annual health checks after age 35.
- Enhance preventative activities in primary care by targeted funding available under Medicare.
- Incorporate dementia risk reduction approaches into broader existing health prevention strategies. Coordinate messages for primary health care workers into concise messages suitable for passing on to individuals.
- Involve consumers and consumer groups in developing the messages and the activities to promote these messages.
- Promote Alzheimer's Australia **Mind your Mind** dementia risk reduction information to change lifestyle choices.

What measures have been, or could be, effective in addressing prevention for specific population groups (e.g. Indigenous, rural and remote, low socio-economic status, CALD)?

- Provide specific population groups with ongoing opportunities to provide input and advice at all levels of planning to raise awareness within their communities and achieve suitable outcomes which meet their needs.
- Involve local government authorities in health prevention activities through targeted funding.

With limited public health dollars, how could preventative care priorities be determined and public resources subsequently targeted?

- Provide priority for targeted prevention activities as this will result to reduced incidence, freeing up funding for treatment.

- Recognise the links between chronic diseases such as such as diabetes, heart disease, obesity and dementia in National campaigns. If rates of diabetes and vascular disease can be reduced, so too may the prevalence of dementia.

4. Well-integrated, coordinated and providing continuity of care, particularly for those with multiple, ongoing and complex conditions.

Most people with dementia are over 65 and use more health services as they age. As dementia progresses, individuals may experience difficulty in managing their co-morbidities and in securing optimum care. Coordinated care has the potential to reduce health expenditure, particularly in acute care through the reduction of unnecessary admissions and average length of stay.

What target groups would most benefit from active care and/or service coordination?

- While dementia is not necessarily part of ageing, it is more common as a person ages. People with dementia merit active clinical care and service coordination to manage their complex, chronic and progressive condition. The inevitable presence of co-morbidities in older people adds to this complexity in care.
- Older people and those with dementia benefit from a case manager and multi-disciplinary approaches in both primary and tertiary settings.²²
- Timely diagnosis of dementia will save dollars within the overall health budget as long as strategies are put in place to optimise care for co-morbidities, for example reducing health complications, avoidable hospital admissions and medication non-compliance.

Who is best placed to coordinate the clinical and/or service aspects of care?

- Dementia-accredited professionals, including GPs and nurse practitioners, are best placed to play a role in the coordination of services.

How could information and accountability for patient handover between care settings (eg. hospital and general practice) be improved?

- Timely and accurate information supports an integrated continuity of care; the introduction of eHealth may assist.

What changes are needed to improve integration between different primary health care organizations?

- Improve integration by the development, implementation and promotion of appropriate referral pathways in all regions.
- Referral pathways should be transparent and accessible.²³
- The coverage of relevant specialists and dementia-specific services are patchy across certain areas of Australia, thus GPs need to know where they can refer people to within their local area.

Would there be advantages in patients having the opportunity to 'enrol' with a key provider?

- When people with dementia have an identified care coordinator, this type of 'enrolment' reduces the potential for visiting different primary care providers for different problems. This may reduce duplication and promote better sharing of information, producing better outcomes for people.
- Such key providers need to have dementia-specific training and accreditation.

5. Safe high quality care which is continually improving through relevant research and innovation.

The ultimate measure of quality care is improved health outcomes for people such as reduced hospital admissions, less dependence on medication, such as anti-psychotics, and better quality of life. Improved outcomes for people with dementia - including timely and accurate diagnosis – require access to a coordinated and supportive health care team trained in dementia care.²⁴ High quality care also results in best outcomes for people with dementia who have other co-morbidities.

Safe high quality care is supported by the involvement of consumers as full partners in their care. For people with dementia, this also means recognising the pivotal role that family carers may play in ongoing management after diagnosis. As dementia progresses, people with a diagnosis will lose the ability to participate in their own care, making planning via advance care directives an important element of quality dementia care.

Who should be responsible for developing and maintaining a performance framework?

- Medicare data could be better used to ensure appropriate pathways of care are being provided, including referral to and uptake of allied health services.
- PBS data should be used to monitor the appropriate use of anti-psychotics in people with dementia.
- Use existing organisations such as the Divisions of General Practice and other professional groups.
- There may be potentially enormous advantages to the individual in linking their health outcomes to incentives.
- For people with dementia, appropriate referral to information and support agencies should be rewarded as this may improve health and care outcomes, decrease use of tertiary services and improve quality of life.

How can we improve the current research culture and evidence-base in primary health care?

How can we translate evidence or innovation into practice more systematically?

What options could be used to support health care professionals' involvement in research and innovation?

- Link financial incentives to steps taken by primary care professionals, such as GPs and nurse practitioners, to upgrade their skills through dementia education and training.
- Encourage practices, including “super clinics”, to identify a person who has experience in dementia, and support the translation of evidence into practice.
- Encourage health professionals to audit their current practice against accepted guidelines.²⁵ Financial incentives to collect audit data and provide education on evidence based guidelines would assist in changing practice.
- Currently health providers in independent practice generate their income by patient contact, discouraging other activities. Research culture could be improved by providing direct financial benefits to health care providers involved in collecting data and to those organising research.

- Some research is conducted by salaried health professionals who do not always have experience in grass roots primary care. Partnering with community practices should be encouraged.
- Supporting health care professionals in research requires support and funding for appropriate research training and dedicated research time.
- Quality dementia care is supported by the translation of research evidence into best practice policies and practices. Better mechanisms for this translation need to be developed.
- Promote consumer involvement in research, including by supporting concepts like the Consumer Dementia Research Network being developed by Alzheimer's Australia, which will enable the consumer to be a partner in research from setting priorities through to assessing applications, monitoring research and disseminating research outcomes.

6. Better management of health information, underpinned by efficient and effective use of eHealth.

Health information is a tool to support best practice for consumers and should not be an end in itself.

Scientific and technological breakthroughs are providing innovative and effective ways of providing health care across Australia. The use of eHealth records in the primary health care sector is just one development that could provide many benefits for people with dementia and their family carers. As well as providing the necessary information to support quality dementia care, eHealth will also provide better access to advance directives, which set out an individual's wishes relating to their health care and treatment.

It is necessary however, that all sectors of health care use systems that complement each other. For example, most general practices have embraced Information and Communications Technology (ICT), however public hospital systems may still require written records, transcription and hand written summaries. This makes transferring information between service providers difficult and could increase the potential for losing or forgetting health information.

Many health professionals are trained in hospital systems so they are poorly prepared for use of electronic systems when entering independent primary care practice. Money spent on ICT in hospitals appears to target the needs of the hospital, rather than those of the patient or other health care providers.

As pharmacies have electronic records, they can be the most reliable source of medication information for the GP working with other health providers, although complete information may require contact with several pharmacies.

What is the role for eHealth in supporting the provision of quality primary health care?

- eHealth is the key to more accurate information sharing and the provision of quality coordinated health care.
- Mechanisms which ensure that accurate and detailed health information is transferred between services providing care for people with dementia are vital because some people with dementia and their family carers may not be able to relay all the necessary information. This includes the existence and location of advanced care directives.
- The use of electronic records reduces the risk of errors in information sharing. This is particularly the case in medications with many hand written and transcribed hospital discharge medication summaries having significant errors, some potentially fatal.²⁶
- Pharmacy data might be used to encourage people to visit GPs where concerns exist around non-compliance or slowness in filling regular prescriptions, eg for diabetes and hypertension prescriptions.

Where should the Government prioritise its actions in relation to implementing eHealth reform?

- A priority for the Government should be to encourage hospitals to link with other health care providers electronically and discourage electronic systems that do not assist information exchange.

How can the various information systems be integrated (e.g. state health services and general practices)?

- Incentives to link information systems would encourage IT innovations that were interlinked and discourage installation of stand alone systems.
- Although an eHealth system will have substantial benefits for both individuals and providers, due consideration is required to ensuring the system is appropriate for people with dementia. Specific areas of concern that must be addressed are:
 - Privacy and security of information – some people with dementia may be susceptible to abuse in the event of a privacy breach.

- Transparency of the system – people should be given access to their health records upon request. This is particularly important for people with dementia and their family carers.
- Informed consent – it is vital that people with dementia are given detailed and accurate information about the purpose and use of their electronic health records. They should be given the same choices that are afforded to everyone.
- The role of family carers in supporting people with dementia should be considered in terms of access to information.

7. Flexibility to best respond to local community needs and circumstances through sustainable and efficient operational models.

The distribution of dementia services across Australia is uneven. People with dementia and their family carers benefit when funding supports models that provide multidisciplinary services to meet individual needs.

- The GP is the most visited health professional as people get older and transparent accurate referral pathways would enhance their role as gate keeper.
- Local planning for primary care services would benefit from coordinated funding agreements that require agencies to network and discourage duplication of services.
- Local services would be improved by involving consumers as partners in their own care.

The Alzheimer's Disease International Charter supports people with dementia making meaningful contributions to their care management and planning.²⁷

- Consumer and health professional awareness of accurate local referral pathways facilitates effective service utilisation.
- Efficient use of funding should increase accessible responsive services rather than build on management structures.
- Funding should be directed to organisations which have demonstrated efficient and effective use of resources to achieve improved consumer outcomes. Many divisions of general practice have shown themselves to be locally responsive to health needs.²⁸
- Newer models of care should reflect need, as in rural areas where health resources may be scarce.

- Fund holding sees the organisation responsible to the fund provider rather than the individual consumer. Individual needs of health consumers can lose priority.²⁹

There is a need to focus on up-skilling dementia care across all primary care disciplines in rural and regional areas as trained allied health and nursing services are able to provide support for GPs in dementia care.²⁵

8. Working environments and conditions which attract, support and retain workforce.

Ensuring that trained and qualified people are attracted and supported to work in primary care provides significant benefits for people with dementia and their family carers. They will benefit from accessing services where there is minimum staff turn over and supportive teams. Professionals can be supported by practices which support quality care.

- Support for primary health professionals would be improved by financial incentives for quality rather than just the quantity of throughput that Medicare and bulk billing encourage.
- Increasing the variety of Medicare-funded practice nurse activities would encourage skill development and service provision. This could include a Medicare payment for cognitive testing (e.g. Mini-Mental Status Examination (MMSE)) and for coordinating care for those who would benefit from such support, including people with dementia.
- Health professionals may benefit from community and professional support in less attractive geographical areas. Providing funding for communities to engage health service staff through ancillary benefits may encourage recruitment.
- Financial incentives tied into a term of service in less attractive areas could entice new graduates with student debt or doctors approaching retirement.
- Legal issues surrounding the roles and responsibilities of medical professionals need to be clarified. This would provide substantial benefits to people with dementia and their family carers in accessing best practice care.
- Team-based approaches provide opportunities for collaboration in delivering best practice quality dementia care.

9. High quality education and training arrangements for both new and existing workforce.

Education and training are important mechanisms for improving outcomes for both the providers and users of primary health care. Robust research and evidence regarding best practice dementia care must be translated into quality education and training programs aimed at all elements within primary health care. Other approaches to improving education opportunities may include:

- All health professionals should be trained to consider a diagnosis of dementia in at risk people.
- Provide increased funding support for independent practitioners to access education and training opportunities.
- Learning experiences should be enriched by the use of consumers and consumer organisations that may have a different view point, and by providing placement within different settings such as residential aged care.
- Improve vertical and horizontal education through the use of multidisciplinary forums and the utilization of teachers and mentors from all branches of the professional tree.
- Using evidence based teaching methods to improve learning and patient care. Research in Australia²⁶ and at Bradford Dementia Centre, UK³⁰ indicates that to change common practice, mechanisms other than workshops and lectures are needed.

Specific strategies should also be developed to increase education and training opportunities for people working within CALD and Aboriginal and Torres Strait Islander communities. These may include:

- Funding the provision of the Dementia Unit of Competency bilingually or in target languages to assist training of workers from a CALD background.
- Providing workers in Aboriginal and Torres Strait Islander people focused services with better access to education and training in dementia.
- Supporting non-indigenous health professionals to access cultural awareness workshops.

10. Fiscally sustainable, efficient and cost effective.

Alzheimer's Australia believes that investment in high quality and accessible primary health care is essential to addressing and minimising the potential health challenges of the future. The funding of primary health care should support best practice quality dementia care and better outcomes for people with dementia and their family carers.

- Funding should be directed at priorities that produce real outcomes, for instance, recent developments in information technology in general practice has helped to improve the efficiency of GP practice and facilitated the sharing of vital health information.
- The recently released UK Dementia Health Strategy includes funding to train all GPs in dementia diagnosis and care, in preparation for the 'dementia epidemic'. This strategy confirms that access to primary health care is essential for improved community health outcomes.

Are there aspects of a future Australian primary health care system that are not included in these key elements?

Person centred care and continuity of care are crucial for both the person with dementia and their carer. They form a care dyad as the wellbeing of the individual is intimately related to the wellbeing of the carer and vice versa.

While Alzheimer's Australia welcomes the release of the NHHRC Interim Report, *A Healthier Future for All Australians*, and much of the reform agenda that it proposes, it is extremely disappointing that dementia is still regarded only in light of the burden that the increasing numbers will impose and more particularly in the context of mental health.

The report, for example, does not canvas the opportunities for primary care providers to encourage dementia risk reduction strategies within the Australian population nor address the impact that lack of recognition of dementia might have on achieving best management of co-morbidities. This has the potential to increase adverse events such as unnecessary admissions to acute care, and health expenditures.

Community services are the Cinderella of the health care system and rate barely a mention in *A Healthier Future of all Australians*. A significant increase in the funding of services of community care should be part of the reform process. Services such as transport, respite and community nursing services are a key part of the support infrastructure necessary to maintain wellbeing and support health and care in the community.

RECOMMENDATIONS

The recommendations that capture the responses in this submission to the questions in the discussion paper are set out below under three main headings.

Recommendation 1:

Improve the diagnosis and management of dementia within primary care

The failure of the primary care system to diagnose dementia in a timely and accurate way and to provide support is a major concern of people with dementia and their families and carers. The principal actions needed are to:

- Provide Medicare incentives to improve timely and accurate diagnosis and support for people with dementia and family carers in ongoing management.
- Link these incentives to opportunities for dementia training to all GPs, nurse practitioners and other primary health professionals as appropriate, for example in regional areas.
- Foster a multi-disciplinary approach supported by access to specialist services for people with dementia of any age.

This action should be supported by

- Identifying best practice dementia referral pathways and developing these in regions where they do not already exist.
- Identifying opportunities for consumers and consumer organisations to be involved in planning, accreditation and service development.
- Improving the provision of targeted information to support health professionals in providing best practice dementia care and to encourage those with changes in memory and thinking to seek a diagnosis.
- Improving access to specialist advice including through communication mechanisms such as teleHealth and eHealth.
- Introducing dementia specific accreditation for primary care professionals to complement specialist access.
- Improving information available about Government support mechanisms^b that are already available that might be accessible to better support people with dementia and their family carers.

^b For example, the Medicare items available to support complex and chronic care.

- Extending current Government initiatives to improve primary health care access for people in residential care.
- Encouraging consumers to make advanced care directives, and for health professionals recognise them.
- Developing and accepting national guidelines for best practice dementia care for use by the various professions.
- Establishing of a network of primary care professionals and specialists who are willing and able to assist younger people who have concerns about dementia.
- Investigating how software such as Medical Director might be used to prompt primary care professionals to consider the possibility of dementia as people age or where relevant co-morbidities exist, as well as link people with dementia and their family carers with the information and support that they need as dementia progresses.

**Recommendation 2:
Implement a National preventive health strategy on dementia.**

This would include:

- Providing funding for the National roll out of Alzheimer's Australia's **Mind your Mind** program.
- Including dementia as a component of existing preventative health strategies including cardio-vascular and diabetes.
- Promoting preventative approaches to primary care professionals, such as improved information and monitoring for blood pressure and cholesterol; and routine nutritional testing under Medicare within the 75 year old check.

**Recommendation 3:
Undertake initiatives to strengthen primary care for disadvantaged groups.**

- Encouraging use of validated assessment tools for diagnosis dementia in special populations such as people from Aboriginal and Torres Strait Islander communities or culturally and linguistically diverse (CALD) backgrounds.
- Promote awareness to reduce stigma and lack of understanding including through building on partnerships between Alzheimer's Australia and Aboriginal and Torres Strait Islander communities and people from CALD backgrounds.

Alzheimer's Australia wishes to acknowledge the contribution of Dr Nerida Paterson, University of Newcastle and Dr. Fiona Millard, Adjunct Senior Lecturer of Aged Care, James Cook University, to the preparation of this submission.

Considerations for special populations with dementia accessing primary health care.

There are a number of particular considerations for populations with special needs. These populations include:

- Culturally and Linguistically Diverse (CALD) communities;
- Aboriginal and Torres Strait Islander communities;
- Rural and remote areas;
- Living in residential care facilities; and
- Younger people with dementia.

Culturally and Linguistically Diverse (CALD) communities

In today's multicultural Australia, health care practitioners are increasingly providing care for people from different cultural and ethnic backgrounds. Consultations may be complicated by different beliefs about health, illness and communication, as well as linguistic barriers.

A substantial proportion of Australia's population aged over 60 years of age are migrants from non-English speaking backgrounds, with a variety of cultural customs, traditions and values. By 2026 one in every four people aged 80 and over will be from a CALD background (Australian Institute of Health and Welfare, 2001).³¹ Therefore, the number of people with dementia from a CALD background will also increase. This presents a number of specific needs for primary health care professionals to address in order to provide quality dementia care.

Results of a number of survey studies indicate that there is more misunderstanding, less compliance and less satisfaction in intercultural medical consultations compared to intra-cultural medical consultations, even after adjusting for socio-economic variables such as education and income.³²

Furthermore, numerous studies have shown that there are considerable disparities in access to care as well as in health outcomes as a consequence of ethnic background. Although these disparities in healthcare are probably partly related to socio-economic variables such as income, gaps in intercultural medical communication do seem to be responsible for placing ethnic minority patients at an increased risk of receiving inferior care. This combined with cultural belief about and understandings of dementia may provide disincentives to accessing quality dementia care.

Although CALD Australians may have been fluent in English, studies show that the language most recently acquired is lost first for people with dementia. There is also some evidence that people from some non-English speaking backgrounds may present later to services such as memory clinics, even if there is a bilingual specialist available. These Australians have an equal right to access affordable, quality dementia assessment and care services, which can only be available for them if specialist resources are better developed and more widely known.³³

Alzheimer's Australia Vic has recently produced a resource kit which outlines dementia perceptions in a number of CALD communities, including Arabic, Chinese, Croatian, Greek, Italian, Macedonian, Polish, Russian, Serbian, Spanish, Turkish and Vietnamese communities. This resource points to the importance of understanding the backgrounds of individuals when providing a diagnosis and in the provision of services.³⁴

Diagnosis

The general approach to diagnosis should be used, taking into account communication and language barriers and ensuring the use of appropriate validated screening tools.

The literature also stresses the need for increased time spent on diagnosis and management of dementia in people from CALD backgrounds. Apart from other considerations, an assessment involving an interpreter takes nearly double the time of an assessment without an interpreter.^{35,36}

Throughout the screening and diagnosis process, accurate and meaningful communication and cultural understanding are required. This includes understanding of both verbal and non-verbal communication and is usually best achieved through the use of appropriately trained interpreters or clinicians fluent in the person's preferred language.

Particular attention and sensitivity may need to be given to issues of trauma, war experiences, migration, family separation, and disappearance of relatives.³⁴

Validated Tools

Validated and culturally appropriate screening and assessment tools should be used where available. Where appropriate tools are not available, the assessor needs to appreciate the potential bias of the tools used related to cultural, language and other influences.³⁴

The most commonly used screening tool for dementia in general populations is the Folstein Mini-Mental Status Examination (MMSE). This tool was developed and validated in an English speaking population. However its accuracy in other populations and cultures is being questioned. In the MMSE, many words cannot easily be translated and some concepts are less relevant to individuals from other cultures. MMSE scores are influenced by age, education, ethnicity and the language of the interview.³⁷

In recent years, there have been some developments to address the identified short-comings of existing screening and assessment tools for people with dementia from non-English speaking backgrounds in Australia.

Between 1997 and 1999, Rowland et al³⁸ randomly selected 129 community-dwelling individuals from a database of referrals to an aged-care team in South Western Sydney. The Rowland Universal Dementia Assessment Scale (RUDAS) and the MMSE were administered to each subject in random order and the results compared with the clinical judgement of a geriatrician utilising DSMIV criteria and the Clinical Dementia Rating Scale. The RUDAS score was comparable, but no more sensitive than, the MMSE score. The generalisability of this study is limited by methodological problems with sample selection and because the prevalence (48.8%) and severity (median MMSE of 10) of dementia in the study sample were significantly higher than in the average aged-matched population.

Although these recently developed tools appear to have positive results from initial studies, they do need to be subjected to broader research and clinical application before being widely endorsed.

Aboriginal and Torres Strait Islander communities

Alzheimer's Australia held a two day National Indigenous Dementia Workshop in November 2006 with over thirty participants to discuss whether the issue of dementia is a sufficient priority for Aboriginal and Torres Strait Islander people to take action and to determine what that action might be. Workshop participants agreed that dementia needed to be addressed to enhance community Elder's capacity to 'successfully age' into the future. A wellness approach was seen to be necessary to address the issue of dementia with other health conditions that compromise Aboriginal and Torres Strait Islander people's reaching the age of seventy five.³⁹

To date, most research on dementia has been conducted in large metropolitan areas in developed countries. However, there is increasing interest in cross-cultural differences as it becomes apparent that the contributions of age, race and socioeconomic factors can augment the burden of dementia in different cultures.⁴⁰

The concept of dementia in old age in indigenous communities is intrinsically paradoxical. Firstly, few indigenous people reach old age. Secondly, from some indigenous points of view, dementia is either not recognised as a medical condition and is more often thought of as a natural part of the cycle of life and death. In the case of the more disruptive manifestations of cognitive impairment, it may be perceived as ‘madness’. Moreover in the wider context of profound political, social and economic inequality experienced by most indigenous people, the western medical category of dementia may appear to be of relatively minor importance.⁴¹ However, dementia is also perceived as a condition that would make people vulnerable to removal, abuse or exploitation if they were not living in strong, caring families. This process of removal has major implications for people’s relationship with country, their dreaming, their totems and their capacity to care for country and fulfil cultural rights, responsibilities and obligations.

In Aboriginal and Torres Strait Islander communities “the word dementia has no meaning”⁴² or is seen as a “whitefella sickness”.⁴³ Decline in old age, which might be labelled mild or moderate dementia by western medicine, may be interpreted as “tiredness” or “childlike behaviour” in some indigenous cultures. Aggressive or disruptive behaviours of severe dementia may be seen as “madness”.⁴⁴ A similar distinction is drawn in the Torres Strait islands: “It’s either “baby sense” if the person is nice, or “gone off his head” if they are aggressive”.⁴² Thus, patients and caregivers are unlikely to present for medical intervention, as they don’t recognise the behaviours as a medical illness.

Dementia is seen more as a community, rather than an individual problem, in the literature, where the community has a certain ability to accommodate disruptive behaviour. However, as in western culture, if cultural norms are flouted (such as being unable to recall ceremony business, identify kinships and skin groups or no longer recognising taboos), then the communities will seek help.⁴²

Recent research in the Kimberley region suggests that the prevalence rates of dementia among remote and rural Indigenous people could be 4-5 times higher than those in the Australian community more generally. The prevalence of dementia in people aged 45 or older was 12.4 per cent, compared to a rate of 2.6 per cent in the Australian population.⁴⁵

Validated tools

In 2004, the Kimberley Indigenous Cognitive Assessment (KICA) was developed. It assesses orientation, free and cued recall, language, verbal fluency, copying sequence pattern and ideational praxis and includes an informant interview.⁴⁶ It was tested on 70 indigenous subjects over 45 years of age (mean age 72.0). Using DSM-IV criteria, 27/70 (38.6%) had dementia and 11/70 (15.7%) had cognitive impairment not dementia (CIND). The results of the KICA-Cog were compared to an independent assessment by two expert clinical raters using DSM-IV and ICD-10 criteria.

The KICA-Cog performed well, with a sensitivity of 90.6% and a specificity of 92.6%.³⁹ Three items of the KICA-Cog (pension week, recall and free recall) were able to successfully classify 85.7% of participants.

Subsequent to validation, 363 older Kimberly Indigenous Australians aged 45 years and above have been assessed to discover the prevalence and types of dementia affecting Indigenous Australians. Initial results suggest a prevalence rate of 13% (this represents a prevalence rate that is nearly five times higher than in the general Australian population).⁴⁷ This research also indicated that prevalence was higher among males (the reverse of the general Australian population). Among the important risk factors were age, male gender, previous stroke, head injury, smoking and low education.^{40,45}

Management

Currently, there is little in the literature specifically concerning the management of dementia in individuals from ATSI backgrounds. Commentaries in the grey literature observe that indigenous people are confronted with the same lack of health services that non-indigenous people in remote Australia experience. However, this inequality of health service provision due to location is compounded by a distrust of white medicine and government. Additionally, indigenous people's connection to their land and their critical need to die on their land makes residential care placement culturally inappropriate. Studies are currently being conducted by several groups of Australian researchers and it is to be hoped that data will soon be available to help clarify these important issues.

People living in rural and remote areas

People with dementia and their family carers living in rural and remote areas of Australia often face additional barriers to accurate and timely diagnosis and the provision of care and support services.

In 2007, the Australian Government funded Alzheimer's Australia WA to undertake a project to gain an understanding of the support needs of people with dementia and their carers in regional Australia, and their suggestions and recommendations for addressing these needs.

Six major themes were identified from the needs highlighted by consultation participants:

- Emotional and Social Support
- Education and Awareness Raising
- Diagnosis, Assessment and Medical Management
- Community Service Access
- Respite and Residential Care
- Distance and Travel Issues

Among the recommendations were:

- Develop strategies to increase the numbers and retention rate of health professionals with expertise in dementia in regional and remote areas.
- Investigate the provision of memory clinic services in regional centres to facilitate greater access by people with dementia living in remote and regional areas. This could include exploring the use of communication technology and visiting specialist teams to facilitate timely diagnosis, assessment and medical management.
- Investigate the specific transport needs of people with dementia living in regional areas with a view to overcoming hardships created by remoteness from service providers.
- Investigate the apparent higher financial burden experienced by people with dementia and their carers living in remote and regional areas, and recommend strategies to alleviate financial hardship.

People living in residential care facilities

Successive governments have recognised the need to encourage primary health care providers through incentives to improve access to care for residents in residential care facilities.

People with dementia are over represented in residential care. The 2007 report *'Dementia in Australia: national data analysis and development'* released by the Australian Institute of Health and Welfare⁴⁸ indicated that:

- Dementia is the most common primary diagnosis made by Aged Care Assessment Teams in Australia and is associated with high rates of admission to permanent residential care.
- In 2003, the Survey of Disability, Ageing and Care identified 67,650 people in permanent residential aged care with dementia and Alzheimer's disease, comprising 48% of the permanent resident population (as at June 2003).
- A person with dementia is also more likely to be in high level care: 83% of people with dementia require high care compared with 64% of all permanent residents.

These figures are likely to be an under estimate as many frail older residents are likely to exhibit significant cognitive impairment without attracting a formal diagnosis of dementia. People with dementia in residential care merit access to well-informed health professionals and the full range of primary care including allied health supports.

People with younger onset dementia

Younger onset dementia is the term used to describe any form of dementia with onset of symptoms in people under the age of 65. It is estimated that younger onset dementia affects approximately 10,000 people in Australia today.

Timely and accurate diagnosis is particularly problematic for younger people because there is low awareness, including among health professionals, that younger people may have dementia. In many instances, accurate diagnosis can take several years, causing individuals, their families and carers a great deal of anxiety.

In younger people, where dementia is less common, symptoms such as social withdrawal, memory loss, personality changes and mood swings are often initially attributed to stress, marital breakdown, depression or another mental health disorder. Such delays in diagnosis may delay treatment, affect disease progression and reduce the time available for legal, financial and care planning.

The delays in diagnosis for younger people also lead to delays in access to services that provide care and social support for younger people and their carers. People with younger onset dementia are often at a different stage of life than older people with dementia, and as such, require different or tailored services to support them and their families. For example, many are still engaged in paid work, have young children to provide for, and are often more physically capable. Services that are tailored to these specific needs are crucial to providing quality of life for the individual and their family.

The medical classification of dementia as a condition associated with ageing also makes diagnosis and support services problematic for people with younger onset dementia. Dementia support is usually funded through the Aged Care Program. There is a need for certainty about whether this program will continue to provide support for younger people with dementia or whether in future it will be the responsibility of disability and/or mental health programs.

In February 2009, Alzheimer's Australia held the *Younger Onset Dementia Summit* in Canberra, funded by the Australian Government. This summit brought together over 100 participants from across the country to discuss the issues faced by younger people with dementia, and provide a set of action points to the Government. Included amongst these was action point 2 – *Timely and accurate assessment and diagnosis*.

Specific recommendations for this action point relating to primary health care include:

- A nationwide network of accessible specialist diagnostic clinics to assist people experiencing memory loss or cognitive changes be developed.
- All health and community service professionals encompassing neurologists, nurse practitioners and allied health professionals participate in dementia awareness initiatives.
- Dementia Training Study Centres, in consultation with the Division of General Practitioners, develop continuing education programs targeting General Practitioners, nurse practitioners and allied health professionals in dementia related issues.
- A range of appropriate and current clinical diagnostic tools be developed to streamline the assessment on younger onset dementia. Financial incentives and education strategies are needed to encourage the uptake of such tools into practice.
- Review guidelines for accessing pharmaceuticals and diagnostic procedures for people with younger onset dementia to ensure they have access.

¹ UK Department of Health (2009) *Living well with Dementia: A National Dementia Strategy*, available from <http://www.dh.gov.uk/en/socialcare/deliveringadultsocialcare/olderpeople/nationaldementiastrategy/index.htm>

² Access Economics (2005) *Dementia estimates and Projections: All Australia States and Territories*, available from <http://www.alzheimers.org.au/content.cfm?infopageid=1926>

³ Iliffe, S., Eden, A., Downs, M. and C. Rae (1999) 'The diagnosis and management of dementia in primary care: development, implementation and evaluation of a national training programme', in *Aging & Mental Health*, vol 3 (2): p129 - 135

⁴ Cahill, S., Clark, M., Walsh, C., O'Connell, H. and B Lawlor (2006) 'Dementia in primary care: the first survey of Irish general practitioners', in *International Journal of Geriatric Psychiatry*, vol 21(4): p319-24

⁵ Renshaw, J., Scurfield, P., Cloke, L. and M Orrell (2001) 'General practitioners views on the early diagnosis of dementia' in the *British Journal of General Practice* vol 51(462): p37-8

⁶ Alzheimer's Australia (2007) *Early Diagnosis of Dementia: Paper 10, March 2007*

⁷ Speechly, C. and C. Bridges-Webb (2008) 'The pathway to dementia diagnosis' in *Medical Journal of Australia* vol 189(9): p487-489

⁸ Millard, F (2008) 'GP management of dementia-a consumer perspective' in *Australian Family Physician* vol 37(1-2): 89-92

⁹ Waldorff, F., Haugbølle, N., Møller H., Rishøj S. and G Waldemar (2006) 'Memory problems among elderly patients in general practice: the importance of caregiver information' *Ugeskr Laeger* vol 168(40): p3420-4

¹⁰ Fillit, H., Doody R., Binaso K., Crooks G., Ferris S., Farlow M., Leifer B., Mills C., Minkoff N., Orland B., Reichman W. and S Salloway (2006) 'Recommendations for best practices in the treatment of Alzheimer's disease in managed care' in *American Journal of Geriatric Pharmacotherapy* vol 4 Suppl A: pS9-S24

¹¹ Alzheimer's Australia (2005) *National Consumer Summit on Dementia: Communiqué*

¹² Hopkins, S. and N. Speed (2005) 'The decline in 'free' general practitioner care in Australia: reasons and repercussions' in *Health Policy* vol 73(3): p316-29

¹³ O'Halloran, J., Britt, H. and L Valenti (2007) 'General practitioner consultations at residential aged-care facilities' in *the Medical Journal of Australia* vol 187 (2): p88-91

¹⁴ Turrell, G., Oldenburg B., Harris, E. and D Jolley (2004) 'Utilisation of general practitioner services by socio-economic disadvantage and geographic remoteness' in *Australian and New Zealand Journal of Public Health* vol 28(2): p152-8

¹⁵ Loh, P., Maher, S., Goldswain, P., Flicker, L., Ramesh, P. and J Saligari (2005) 'Diagnostic accuracy of telehealth community dementia assessments' in *Journal of the American Geriatrics Society* vol 53(11): p2043-4

¹⁶ Speedie, S., Ferguson, A., Sanders, J. and C Doarn (2008) 'Telehealth: the promise of new care delivery models' in *Telemedicine Journal and e-Health* vol 14(9): p964-7

¹⁷ Nabalamba, A. and W.J. Millar (2007) 'Going to the doctor' in *Health Reports*, vol 18(1): p23-35

¹⁸ *The Australian General Practice Network Primary Health Care Position Statement*, 2008 Update, pg 36 available from http://www.agpn.com.au/client_images/243025.pdf

¹⁹ Alzheimer's Australia (2007) *Dementia Risk Reduction: The Evidence Paper 13* available from <http://www.alzheimers.org.au/upload/RiskReductionSept07.pdf>

²⁰ Alzheimer's Australia (2008) *7 Mind you Mind Signposts* available from <http://www.alzheimers.org.au/content.cfm?infopageid=2178>

²¹ Yevchak, A., Loeb S., and D Fick (2008) 'Promoting cognitive health and vitality: a review of clinical implications' in *Geriatric Nursing* vol 29(5): p302-10

²² Smith, G (2002) 'Case management guideline: Alzheimer disease and other dementias' in *Lippincotts Case Management* vol 7(2): p77-84

²³ De Lepeleire, J., Wind A., Iliffe, S., Moniz-Cook, E., Wilcock, J., Gonzalez, V., Derksen, E., Gianelli, M., and M Vernooij-Dassen (2008) 'The primary care

diagnosis of dementia in Europe: an analysis using multidisciplinary, multinational expert groups' in *Aging Mental Health* vol 12(5): p568-76

²⁴ Milne, A., Hamilton-West, K. and E. Hatzidimitriadou (2005) 'GP attitudes to early diagnosis of dementia: evidence of improvement' in *Aging Mental Health* vol 9(5): p449-55

²⁵ Millard, F., Thistlethwaite, J., Spagnolo, C., Kennedy, R. and B Baune (2008) 'Dementia diagnosis: a pilot randomized controlled trial of education and IT audit to assess change in GP dementia documentation' in *Australian Journal of Primary Health* vol 14(3): p141-9

²⁶ McMillan, T., Allan, W., and P Black (2006) 'Accuracy of information on medicines in hospital discharge summaries' in *International Medical Journal* vol 36(4): p221-5

²⁷ Alzheimer's Disease International, *Charter of principles for the care of people with dementia and their carers* is available at:

<http://www.alz.co.uk/adi/charter.html>

²⁸ Smith, J. and B. Sibthorpe (2007) 'Divisions of general practice in Australia: how do they measure up in the international context?' in *Australian and New Zealand Health Policy* vol 4: p15

²⁹ Dusheiko, M., Gravelle, H., Yu, N and S Campbell (2007) 'The impact of budgets for gatekeeping physicians on patient satisfaction: evidence from fundholding' *Journal of Health Economics* vol 26(4): p742-62

³⁰ Downs, M., Turner, S., Bryans, M., Wilcock, J., Keady, J., Levin, E., O'Carroll, R., Howie, K. and S Iliffe, (2006) 'Effectiveness of educational interventions in improving detection and management of dementia in primary care: cluster randomised controlled study' in *British Medical Journal* vol 332(7543): p692-6

³¹ LoGiudice, D., Hassett, A., Cook, R., Flicker, L. and D Ames (2001) 'Equity of access to a memory clinic in Melbourne? Non-English speaking background attenders are more severely demented and have increased rates of psychiatric disorders' in *International Journal of Geriatric Psychiatry* vol 16(3): p327-34

³² Schouten, B. and L Meeuwesen (2006) 'Cultural differences in medical communication: a review of the literature' in *Patient Education & Counseling* vol 64(1-3): p21-34

³³ Access Economics (2006) *Dementia Prevalence and Incidence among Australians who don't speak English at home*, available from

<http://www.alzheimers.org.au/content.cfm?infopageid=3512>

³⁴ Alzheimer' Australia Victoria (2008) *Perceptions of Dementia in Ethnic Communities*, available from

<http://www.alzheimers.org.au/content.cfm?infopageid=5338>

³⁵ Alzheimer's Australia (2007) *Screening and Diagnostic Assessment of Non-English Speaking People with Dementia*, available from

<http://www.alzheimers.org.au/upload/CALDScreeningGuidelines07May.pdf>

³⁶ Manly, J. and D Espino (2004) 'Cultural influences on dementia recognition and management' *Clinics in Geriatric Medicine* vol 20(1): p93-119

³⁷ Escobar, J., Burnam, A., Karno, M., Forsythe, A., Landsverk, J. and J Golding (1986) 'Use of the Mini-Mental State Examination (MMSE) in a community

population of mixed ethnicity: Cultural and linguistic artifacts' in *Journal of Nervous & Mental Disease* vol 174(10): p607-14

³⁸ Rowland, J., Basic, D., Storey, J. and D Conforti (2006) 'The Rowland Universal Dementia Assessment Scale (RUDAS) and the Folstein MMSE in a multicultural cohort of elderly persons' in *International Psychogeriatrics* vol 18(1): p111-20

³⁹ Alzheimer's Australia (2006) *Beginning the conversation: addressing dementia in Aboriginal and Torres Strait Islander communities: workshop report*, 8-9 November 2006

⁴⁰ LoGiudice, D., Smith, K. and J Thomas (2006) 'Kimberley Indigenous Cognitive Assessment tool (KICA): development of a cognitive assessment tool for older indigenous Australians' in *International Psychogeriatrics* vol 18(2): p269-80

⁴¹ Alzheimer's Australia (2006) *Beginning the conversation: addressing dementia in Aboriginal and Torres Strait Islander communities: workshop report*, 8-9 November 2006

⁴² Zann S (1994) 'Identification of Support, Education and Training Needs of Rural/Remote Health Care Service Providers Involved in Dementia Care' in *Australasian Journal of Aging* vol 26(3): p115

⁴³ Pollitt, P (1997) 'The problem of dementia in Australian aboriginal and Torres Strait Islander communities: an overview' in *International Journal of Geriatric Psychiatry* vol 12(2): p155-63

⁴⁴ Dunlop, S (1988) *All That Rama Rama Mob: Aboriginal Disturbed Behaviour in Central Australia: Volume I & II, Central Australian Aboriginal Congress*

⁴⁵ Alzheimer's Australia (2007) *Dementia: a major health problem for Indigenous people: briefing prepared for Parliamentary Friends of Dementia*

⁴⁶ Smith, K., Logiudice, D., and A Dwyer (2007) 'Ngana minyarti? What is this?: development of cognitive questions for the Kimberley Indigenous Cognitive Assessment' in *Australasian Journal on Ageing* vol 26(3): p115-9

⁴⁷ Alzheimer's Australia (2007) *Dementia: a major health problem for Indigenous people: briefing prepared for Parliamentary Friends of Dementia*

⁴⁸ Australian Institute of Health and Welfare (2007) *Dementia in Australia: national data analysis and development*, available from <http://www.aihw.gov.au/publications/index.cfm/title/10368>