Collaborating for a better future for Australians living with Alzheimer’s disease

Outcomes from a multidisciplinary roundtable discussion

Held in Hobart, Tasmania on Tuesday 14th May 2013

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FOREWORD

Earlier this year, I spent a day with colleagues, before the start of the 15th Alzheimer’s Australia National Conference in Hobart. We were a disparate group of different ages and backgrounds and from wide ranging locations but all connected by our experience with and commitment to Alzheimer’s disease and other dementias, the condition that is redefining the health landscape in Australia. Already dementia costs Australia more than $6 billion a year or 0.8% of Gross Domestic Product (GDP), and this is set to reach almost 2% of GDP by 2050.

Seven of us were professionals in fields ranging from dementia research to nursing, aged care and psychology, while the eighth participant was the daughter and carer of someone living with Alzheimer’s, crucial to keeping the daily experience of dementia at the forefront of our discussions.

Our combined knowledge and experience in the room comprising clinical expertise, academic research, policy development and hands-on practical know-how, were invaluable in helping us come up with a roadmap for change to improve the experience of the more than 300,000 Australians living with Alzheimer’s, or one of the other dementias, and their families. Importantly, we discussed what the future holds and how to develop a more sensitive, informed, efficient and effective approach to tackle the projected 900,000 plus Australians living with dementia by 2050.

Needless to say, we didn’t agree on everything, but there were considerable areas of consensus. Those areas of agreement are the subject of this report, and we believe they should be the subject of discussion and action, by everyone.

And everyone means just that – governments, researchers, health professionals, carers, patients and the general public – because dementia is everyone’s disease and everyone’s burden. Aged care is central to healthcare and dementia is central to aged care.

Professor Henry Brodaty,
Director, Dementia Collaborative Research Centre – Assessment and Better Care
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1. EXECUTIVE SUMMARY

DEMENTIA POSES A HUGE CHALLENGE TO SOCIETY NOW AND INTO THE FUTURE AS THE AUSTRALIAN POPULATION AGES AND THE NUMBER OF PEOPLE LIVING WITH DEMENTIA INCREASES. THIS REPORT PROVIDES A MULTIDISCIPLINARY PERSPECTIVE ON BARRIERS AND POTENTIAL SOLUTIONS IN THE DIAGNOSIS, TREATMENT AND CARE OF DEMENTIA, THEREBY SUPPORTING THE MOMENTUM TO CREATE A BETTER FUTURE FOR AUSTRALIANS LIVING WITH DEMENTIA.

The report is based on a multidisciplinary roundtable discussion held on 14th May 2013 during Alzheimer’s Australia’s 15th National Conference in Hobart, Tasmania. The discussions provided a unique opportunity for a wide range of healthcare professionals involved in dementia care (general practitioner, nurse, neurologist, geriatrician, and neuropsychologist) as well as a carer and a representative of Alzheimer’s Australia, to share their views and perspectives on the diagnosis and care of people living with dementia and Alzheimer’s disease in Australia.

Despite wide ranging views and limited time, there was consensus reached on a number of areas which need to be addressed to improve the quality of care for people living with dementia and Alzheimer’s disease. The recommendations in this report reflect consensus around the following issues:

PERSON-CENTRED APPROACH
There was agreement that as the experience of dementia is unique to each individual, rather than having a single approach to treatment, care must focus on the needs of individuals and their support network. All aspects of care from diagnosis through to end-of-life, should adopt this approach and empower individuals and their carers to be involved in all aspects of decision making. De-stigmatisation of dementia among the general population is essential to improve the patient/carer journey.

There was recognition of the importance of awareness and access to information and services for both patient and carer. These difficulties could be addressed through the funding of a national program of key workers for people with dementia that provide one-on-one support from the point of diagnosis onwards.

A COLLABORATIVE, MULTIDISCIPLINARY APPROACH
There is a need for a connected, multidisciplinary approach to care. Consideration must be given to the complex interfaces between primary care, acute care, aged care and the disability system.

General practitioners (GPs) and practice or community nurses are ideally placed to act as the cornerstone for co-ordinating care from diagnosis to end-of-life care, ensuring patients and their carers/family receive the right management and timely information.

The pre-diagnosis phase is challenging for all. A clear, best practice diagnostic pathway should emphasise greater collaboration between primary care, secondary care, tertiary care and support centres.

BUILDING THE DEMENTIA WORKFORCE
Further work to develop the dementia and aged care workforce is critical.

The current number of people working in dementia and aged care is insufficient to meet the numbers required to provide the specialised care to this increasing segment of the population.

A 2010 report from the Australian Government noted that three quarters of residents in aged care facilities suffered from dementia, a mental health problem, or both. With the expected number of people living with dementia set to increase threefold by 2050, a corresponding increase in the number of people working in dementia, mental health and aged care will be required.

Aged care can be an unattractive career option as there are currently fewer opportunities for specialist training, support courses and career development to leadership or management roles, and in some cases it is associated with lower level wages than equivalent jobs in the hospital sector. A defined career pathway is recommended for nurses, with continuing professional development and accreditation in the area of dementia care.

We need to prioritise training for people working in aged care, so that they are comfortable and happy to look after those with needs specific to cognitive impairment.

A NATIONAL APPROACH TO DEMENTIA
A nationwide, best practice approach for the diagnosis and ongoing care of dementia could improve efficiency and effectiveness. The various models of care can be evaluated to identify the most appropriate model to roll-out nationally. An evidence base for the effectiveness and health economic benefit for dementia models of care is required for sustainable implementation.

The benefits of a National Dementia Registry should be evaluated as a means of ensuring that recommended therapies and services are logged, ensuring timely delivery of information and services, as well as follow-up. A national registry would also provide dementia patients and their families with access to information about participation in research and/or clinical trials.
2. INTRODUCTION

WHY AND HOW THIS REPORT WAS DEVELOPED

The diagnosis, treatment and management of dementia and Alzheimer’s disease in Australia pose a significant challenge to the healthcare system, healthcare practitioners and providers, the government, as well as society. Despite the recent focus on dementia as a National Health Priority Area (NHPA), people living with dementia (patients and their carer/family) can face a difficult and highly variable journey when seeking the broad range of healthcare and support they require.

This report is based on the outcomes from a roundtable discussion that brought together a range of participants, including a GP, nurse, geriatrcian, neurologist, neuropsychologist, psychogeriatrician, public policy manager and a carer. The discussions provided a unique opportunity to identify gaps in diagnosis, treatment and care of people living with dementia from each perspective, and to develop a consensus of recommendations that may help address these gaps – to create a better future for Australians living with dementia.

The roundtable was convened by Alzheimer’s Australia and sponsored by Eli Lilly Australia (Lilly).

WHAT IS DEMENTIA?

The term dementia encompasses a range of degenerative conditions characterised by progressive decline in cognition and impairment in function. Symptoms include impairment of language, memory, perception, personality and cognitive skills. Dementia leads to a decline in intellect, judgement, social skills, ability to manage daily functions and normal emotional reactions. Patients* are also likely to develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering.4,5

The most common type of dementia is Alzheimer’s disease (approximately 50–70% of dementia cases). The next most common types are vascular dementia and Lewy body dementia. With age, the cause of dementia is more likely to be mixed with both Alzheimer’s and vascular pathology evident.

Dementia is typically progressive and irreversible; there is currently no approved treatment available to prevent progression or cure the disease.2

DEMENTIA: A NATIONAL HEALTH PRIORITY AREA

Dementia is the single leading cause of disability in Australians aged >65 years, and is the fourth most common cause of death after heart disease, stroke and lung cancer. Within the next two decades, it will become the third greatest source of health and residential aged care spending.4

The number of people in Australia with dementia is estimated at more than 300,000, and with an ageing population, this is expected to increase to almost 900,000 people living with dementia by 2050.2,6

The Australian Government acknowledged the current and future impact of dementia by making it a NHPA in 2012.

AGED CARE REFORMS

The Living Longer, Living Better. aged care reforms were launched in April 2012. The package involves a 10 year plan to reshape aged care to provide high quality, patient focused care through a nationally consistent and sustainable aged care system.

The aged care reforms have the potential to lead to improved care and services for people living with dementia through expansion of community care, greater choice and control over services, and improved quality within the aged care system.

Aged care initiatives include:

- ‘My Aged Care’ gateway website: Aims to help patients and carers navigate the aged care system, enabling them to access timely and reliable information
- Workforce supplement: Aims to address attraction, retention, remuneration, education, training and career development for aged care workers
- Planned development of national aged care quality indicators and rating systems
- Home care packages.

*Refers to people living with dementia
As part of the reforms, there will be a significant expansion in the numbers of community care packages over the next 10 years from around 60,000 packages (in 2012) to around 100,000 packages (by 2016-17). As of August 2013, the old Community Aged Care Packages (CACPs), Extended Aged Care at Home (EACH), and Extended Aged Care at Home Dementia (EACHD) packages were replaced by four levels of Home Care Packages designed to allow a more seamless continuum of care at home.

A new Cognition and Dementia Supplement is available to all people who meet the eligibility criteria, based on behaviour across any of the four levels of Home Care Packages. It is crucial that access to these four levels of access is facilitated.

All new aged care packages must be provided within the model of ‘Consumer Directed Care’ (CDC). This should mean consumers have greater choice and control over the services they receive.

As part of the reforms, $268.4 million has been committed over five years to tackle the nation’s dementia epidemic. ‘Tackling Dementia’ includes initiatives to address:

- Timely diagnosis
- Hospital care for people living with dementia
- Improved support for people with behavioural symptoms through expansion of Dementia Behaviour Management Advisory Service (DBMAS) services and a new dementia and behaviour supplement in residential aged care
- Initiatives to improve support for people living with younger onset dementia including a National Younger Onset Dementia Key Worker Program.

These initiatives provide important funding and policy direction to begin to address dementia across both the health and aged care system. Additional recommendations on planning for the future ongoing needs of people living with dementia have been covered by reports such as ‘Thinking Ahead – report on the inquiry into dementia: early diagnosis and intervention’ (June 2013); Living Longer. Living Better. from the Aged Care Financing Authority; and the KPMG report on ‘Dementia services pathways – an essential guide to effective service planning’ (February 2011).

While these reforms are welcomed as an excellent foundation for improved dementia care, many issues still need to be addressed. The current report focuses on providing a 360˚ perspective from healthcare professionals and consumers, with a consensus on the need for change in dementia care.

### 3. THE PATIENT EXPERIENCE
#### THE PATIENT JOURNEY

There is no standard or typical journey for people living with dementia; the diagnosis and referral pathway differs greatly between individuals.

Patients may be passed between many different healthcare professionals, depending on their individual presentation stage of dementia, the availability of particular specialists in their area, and the structure of the care system on a state level. Care may include primary care (GP and community nurses), private specialist or hospital outpatient care (e.g. Memory Clinics), and Aged Care Assessment Teams (ACAT) as well as dementia specific services such as the Cognitive Dementia and Memory Service (CDAMS; Victoria only), DBMAS and Alzheimer’s Australia.

Many patients and their carers are only linked to the services they require after they have experienced the stress and anxiety leading up to a diagnosis of dementia or Alzheimer’s disease, or a crisis in dementia care. A wealth of information is available to patients and carers but they are often unaware of it, or they do not receive information in a co-ordinated, or timely fashion.

The nature of the patient journey has a major impact on quality of life for both patient and carer (see Box 1: Case Study).

Alzheimer’s Australia has been active in trying to improve all stages of living with dementia. For example, with funding from the Living Longer. Living Better. aged care reform package, Alzheimer’s Australia provides a National Younger Onset Dementia Key Worker Program for people with dementia aged <65 years. The program has the potential to smooth the journey for eligible people, as the key worker provides information, support, counselling and advice and helps patients (and their families) effectively engage with the services appropriate to their individual needs.
Stigma exists despite Alzheimer’s Australia’s endeavours to decrease stigma and improve awareness of dementia and Alzheimer’s disease in the general population. The experience of patients and their carers is made worse by the stigma attached to dementia. Attitudes towards dementia are similar to those seen with conditions such as cancer or sexual problems many years ago. In an Australian survey, 60% of people said that they would feel a sense of shame if they received a diagnosis of dementia.11

BARRIERS TO DIAGNOSIS

The pre-diagnosis period is a difficult time for both people with dementia and their families.

Family members are often the first to notice early changes in an individual but may not feel comfortable talking to a GP about their concerns in front of their loved one, and may not be able to speak to the patient’s GP alone due to ethical concerns or a lack of opportunity. This can lead to a long delay between the onset of symptoms and medical help being sought.

Many patients have subtle changes in behaviour and function before they meet formal diagnostic criteria for dementia. Resources and services for such individuals are limited, and it is frustrating for patients, carers and healthcare professionals to have nowhere to turn at this early stage.

Cognitive changes must be assessed relative to the individual’s normal background cognitive ability. This is especially important for groups outside the usual ‘norms’, including high functioning individuals (who may not fit usual diagnostic criteria for dementia), as well as those with special needs such as CALD and ATSI populations, and those with younger onset dementia or intellectual disability.

BOX I: CASE STUDY – MRS B

2007: Mrs B was diagnosed with dementia at the age of 83, following a GP health assessment for a driver’s license. Mrs B was referred to a geriatrician who prescribed an appropriate medication but she experienced severe side effects and after two weeks her family stopped the treatment. They tried to contact the geriatrician for advice—without success; he was on a three month holiday.

2008: Mrs B’s GP suggested trying a new drug. The new therapy was helpful, although symptoms continued to progress gradually.

2009: Mrs B was assessed by an Aged Care Assessment Team, which confirmed a diagnosis of Alzheimer’s disease to her family. Disease progression continued and Mrs B showed symptoms of anger, anxiety and distress.

2011: Mrs B continued to be cared for at home by her husband. She was referred to another geriatrician due to increasing symptoms of aggression and anxiety. Two months later, a night time incident occurred in which Mrs B became aggressive and violent towards her husband. Mr B contacted a Commonwealth Respite 24-hour telephone line and medical after-hours telephone number but did not find the advice provided helpful. He struggled to cope and did not know where else to seek help. Mr B was unaware of the 24-hour Alzheimer’s Australia or the Dementia Behaviour Management Advisory Service (DBMAS) helplines.

Late 2012: Mr B called Alzheimer’s Australia, who put him in touch with a local respite centre. This centre now provides care for Mrs B for two days and nights per week. This has been of great benefit to Mr and Mrs B, offering social interaction and engagement in activities for Mrs B and much needed rest and respite for her family. Mr B currently prefers to utilise respite care over in-home services or residential care.

COMMENTS FROM MRS B’S DAUGHTER AND CO-CARER:

“Her GP is a wonderful lady who has been very supportive. There is a lot of support and information out there. We know that now, but we didn’t then. We thought, ‘where was this when we needed it?’

The Respite Centre has been a turning point in our life…If we had known about [the centre] four or five years ago, my mother’s path would have been very different, as would my father’s path as her carer for that period of time.”

PREVALENCE OF COMORBIDITIES

Elderly patients frequently experience unrelated medical comorbidities that must be managed alongside dementia. Appropriate specialist services are not always available as there are few general physicians in Australia and many geriatricians do not have a clinical focus on management of people with dementia (see section 4).

RESIDENTIAL AGED CARE FACILITIES (RACFs)

The quality of care in RACFs is frequently raised as a concern among consumers. As there is no ‘standard’ for consumers to determine the quality of aged care facilities, carers often find it difficult to make informed decisions regarding their choice of a RACF.

The term ‘person-centred care’ is often used to describe the ideal approach in RACFs and community care settings but it is a philosophy that is not always understood and can be difficult to implement in many environments. A lack of appropriately trained staff with knowledge of, or experience in, dementia management may also contribute to poor quality of care in RACFs.

Increasing the number of adequately trained and qualified nursing staff, so that they provide leadership, mentoring, supervision and feedback to other staff members in RACFs, as well as hands-on patient care, has been shown to improve quality of care in RACFs in other countries and may lead to better person-centred care in Australia.
CONSENSUS FOR CHANGE

- A multidisciplinary, person-centred approach involving patients, carers, healthcare professionals and other stakeholders is required from initial diagnosis through to end-of-life (see section 5)

- The patient experience could be improved by extending the National Younger Onset Dementia Key Worker Program to all Australians living with dementia

- Dementia care must focus on the following:
  - Recognising individual needs through engagement with the patient and carer
  - Augmenting functional capacity of the patient
  - Managing symptoms
  - Providing support and counselling (for both patients and carers)
  - Maximising quality of life, giving value and meaning to the patient’s life

- Diagnostic avenues should be clarified for patients and carers

- More referral options and services are required at the early diagnosis stage, together with greater awareness of services available among GPs, carers and families

- Australia-specific data for normal cognitive function is needed. Diagnosis and care of comorbid conditions must be co-ordinated. This could be achieved through making primary care the cornerstone of care (see section 5) and/or through co-ordinating care through the general physician/geriatrician

- Developing the workforce within RACFs is essential (see section 6). The number of adequately trained and qualified nursing staff needs to be increased in order to provide leadership and mentoring to other staff members

- RACFs should have the opportunity to work towards certification for ‘excellence in dementia care’, to assist with consumer choice by indicating to potential consumers that the RACF is qualified to provide good quality, person-centred care for people living with dementia

4. THE CARER EXPERIENCE

CARING FOR THE CARER

The current pathway for patients and carers is ad hoc and differs greatly between individuals. Moreover, a significant number of people with dementia rely on members of the community (friends, neighbours, support services) for care, as they do not have a close family member to provide continuity of care.

Support for carers of people living with dementia has improved over the past decade and there are services available to them. However, care for the carer is still not ideal.

The provision of timely and readily understandable information for carers about the availability of services was identified as a major unmet need. The journey faced by both patients and their carers depends on how and when such information is provided (see section 3). Information about specific services is frequently provided in a format that is difficult to understand for carers, who are often time poor and elderly. Ideally, information should be summarised in a single document with a simple, easy to understand format.

Grief is a common reaction to a diagnosis of dementia or Alzheimer’s disease in a loved one, but there are few support services available for grief counselling in dementia care, and many carers are unaware of how to find emotional support for the grieving process which are available through organisations such as Alzheimer’s Australia and Carers Australia.

Carers play a vital role in the diagnosis and management of dementia – identifying early symptoms, providing support and care for the patient, reporting any changes (e.g. benefits or side effects of treatment approaches) to the healthcare team, and ensuring compliance with follow-up.

The burden on carers of people living with dementia, has been demonstrated to be greater than the burden on carers of people with physical illnesses. Carers and patients are more empowered to be involved in management decisions if they know what to expect.

CONSENSUS FOR CHANGE

- A partnership approach between patients, carers, healthcare professionals and other stakeholders is essential to help facilitate the care pathway and provide a smoother journey for patients and carers

- Carers, and patients, if they are able, should form an integral part of the dementia management team

- Carers should be provided with an easy to understand summary of available services and information at the point of diagnosis

- Information should be provided as appropriate, throughout the course of the disease, to avert crises

- Linking patients and carers to Alzheimer’s Australia at the point of diagnosis should take place routinely
5. MULTIDISCIPLINARY CARE AND COLLABORATION

THE ROLE OF PRIMARY CARE

In Australia and worldwide, GPs correctly identify approximately 50% of patients with early stage dementia. There are many barriers to early diagnosis of dementia in Australian general practice (see Box 2). Notably, the limited availability of referral options (e.g. memory clinics, private specialists), which may deter early diagnosis in Australia. Literature suggests that the wider availability of memory clinics in Europe supports diagnosis of dementia by enhancing the confidence and attitudes of GPs towards managing dementia.

Dementia is often first encountered in general practice or in acute care/rehabilitation in hospital.

BOX 2: BARRIERS TO EARLY DIAGNOSIS OF DEMENTIA IN GENERAL PRACTICE

On average, GPs diagnose two new cases of dementia per year, so it is not ‘top of mind’ during patient consultations.

Four out of five people with memory problems do not have dementia; GPs are therefore likely to consider other diagnoses before dementia.

Patients may not present with symptoms; carers are more likely to seek a diagnosis for a loved one. There is evidence to suggest that 30% of people in a GP’s waiting room would not want to carry out a paper based screening test for dementia due to the perceived stigma attached to the disease. Many felt that if they were diagnosed with dementia they would feel a sense of shame, humiliation or a negative affective response, as well as being placed at risk of discrimination in the health system.

Tools for screening and diagnosis are not sufficiently reliable (e.g. Mini-mental State Examination [MMSE]), too time consuming (e.g. Cambridge Cognition [CAMCOG] assessment) or are not readily available to GPs.

Dementia diagnosis and management are time consuming for busy GPs, so it is often seen as the role of a specialist. Knowledge of the antecedents of Alzheimer’s disease has improved dramatically with identification of biomarkers and use of MRIs and specialised neuroimaging such as positron emission tomography (PET) scans. For these to be more available, access to specialist services and memory clinics would need to be facilitated.

Criteria for diagnosing dementia have recently been amended in the fifth edition of the Diagnostic and Statistical Manual (DSM-5), published by the American Psychiatric Association. Dementia is reclassified as ‘major neurocognitive disorder’ and includes a wider patient population (memory impairment is no longer required for diagnosis). This change may make diagnosis more difficult/confusing for GPs and may also reduce diagnostic accuracy.

There is a perceived lack of referral options and support for patients with early stage dementia. Memory clinics often have long waiting lists and private specialists may not have a clinical focus on dementia.

“In our study, we managed to produce a 20% improvement in dementia identification through academic detailing which raised awareness.” Professor Constance Dimity Pond, Professor of General Practice and Head of Discipline of General Practice, University of Newcastle

Acute care is not an ideal setting to identify dementia, as the diagnosis can be confounded by other illness (e.g. delirium). Furthermore, a transient confusion or memory problem like delirium, while often reversible, is a high risk for the later development of dementia and underscores the importance of having a system of medical follow-up. A hospital discharge recommendation to further investigate a cognitive problem upon discharge, needs to have a uniform process for follow-up by the GP, patient and carers.

Providing a clear diagnostic pathway with improved collaboration between patients, carers, healthcare professionals and other stakeholders would be beneficial.
THE ROLE OF SPECIALISTS AND ALLIED HEALTH PROFESSIONALS

A range of stakeholders, with different roles and perspectives, become involved in the care of a person with dementia or Alzheimer’s disease and their carer/family, at different times (see Box 3).

BOX 3: LONG-TERM MANAGEMENT OF DEMENTIA REQUIRES INPUT FROM MANY DIFFERENT DISCIPLINES

MANAGEMENT INCLUDES:
- Activities of daily living (day-to-day function)
- Brain function
- Vascular risk factors
- Psychological symptoms
- Behaviour
- Comorbidity
- Nutrition
- Safety
- Support
- Services
- Planning for the future.

THE TEAM MAY INCLUDE:
- Patient
- Carer/family
- Medical
  - GP
  - Nurses (e.g. practice nurse, community nurse, RACF nurse)
  - Pharmacist
  - Specialist(s) – geriatrician, psychogeriatrician, neurologist, psychiatrist
- Allied health professionals
  - Neuropsychologist
  - Clinical psychologist
  - Social worker
  - Speech therapist
  - Occupational therapist
  - Physiotherapist
  - Dietician
- Community/social
- Medico-legal
- Government.

It can be difficult for patients, families and carers to understand and navigate their way through the many and varied services and healthcare providers to find the information and services they need. Many patients/carers feel that they are not given enough information about what to expect during the course of the disease and the dementia services available. Conversely, carers can be overwhelmed with suggested services and may simply forget to access a service, or feel that it is not right for them at that particular time.

There are also barriers to effective communication between multiple treating practitioners due to the high administrative burden of meeting/setting up conferencing, which is not currently reimbursed. Televideo conferencing is an important tool to promote multidisciplinary interaction, especially in rural and remote areas as well as other settings.
Collaborating for a better future for Australians living with Alzheimer’s disease
Outcomes from a multidisciplinary roundtable discussion

• Ideally, collaboration among healthcare professionals
• A clear, best practice diagnostic pathway is needed, with
• Currently very few nurses specialise in aged care, with a
path for many healthcare disciplines:
• Almost 900,000 people in 2050.
• Living with dementia in Australia to
• Of more than 320,000 people
• From the current estimated number
dementia prevalence in the future –
estimated threefold increase in
disease needs to increase to
• Of dementia and Alzheimer’s
professionals working in the field
• Developing the workforce is critical

6. Developing the workforce is critical

The number of healthcare professionals working in the field of dementia and Alzheimer’s disease needs to increase to ensure capacity to care for the estimated threefold increase in dementia prevalence in the future – from the current estimated number of more than 320,000 people living with dementia in Australia to almost 900,000 people in 2050.

However, dementia care is not seen as an attractive career path for many healthcare disciplines:

• Currently very few nurses specialise in aged care, with a small (and ageing) cadre of nurses leaving the workforce
• Access to neuropsychologist services is variable and limited, and very few neuropsychologists specialise in dementia in Australia
• Even among geriatricians, which is a rapidly expanding specialty, many doctors do not have a clinical focus on dementia management.

Nurses should be key members of the multidisciplinary team in dementia, as their skills in holistic patient care are central to dementia management. However, registered nurses often see aged care as unattractive compared to acute care or paediatrics. There is an urgent need to de-stigmatise aged care and provide quality, mandatory education in this area during undergraduate training for nurses.

A defined career pathway, with continuing professional development and accreditation to demonstrate excellence in dementia nursing, may increase the number of nurses entering this field (similar to the current accreditation program for mental health nursing). Uniform quality in dementia training for nursing assistants in RACFs is also important, as current standards are highly variable. A sustainable cadre of nursing leadership will be required to develop a workforce of nurses skilled in aged care.

There is also a need to promote de-stigmatisation, recognition of skills and parity of remuneration for doctors specialising in dementia care. Despite managing the complex care of frail patients with multiple comorbidities, doctors specialising in geriatrics will not earn as much as colleagues who undertake procedures. The lack of effective treatments to prevent disease progression may also deter doctors from considering dementia as an attractive career pathway.

Gerontology in general is undervalued, thus dementia care (as primarily a late life disease) is also undervalued. Limited access to healthcare professionals specialising in dementia is a barrier to patient care. Waiting lists for public services are often long, and private consultations are limited by availability (few geriatric or psychogeriatric specialists work in private practice) and cost. Geographical limitations are also common.

For example, in the field of neuropsychology:

• Neuropsychologists focus on areas such as diagnosis and assessment
• Neuropsychologist services are concentrated in Victoria, with few services available in regional or remote areas – and some areas having no service at all (see Box 4)
• Access to neuropsychology services, either in private practice or through outpatient public health services is scarce, partly because there is no Medicare coverage for neuropsychology in dementia. Neuropsychological assessment (to determine competency to make decisions) is required by the Victorian Guardianship and Administration Board, and increasingly required by other state Guardianship and Administration boards. Other dementia specialists, such as geriatricians and psychogeriatricians, currently provide these assessments.
Consensus for Change

- The number of healthcare professionals working in the field of dementia needs to increase

- De-stigmatisation, parity of remuneration and recognition of the skills involved in dementia care are important to encourage greater participation in this field of healthcare

- Quality training and continuing professional development opportunities for career progression in dementia care are needed for enrolled and registered nurses and nurse assistants

BOX 4: ACCESS TO NEUROPSYCHOLOGISTS ACROSS AUSTRALIA

|                               | Full members of the CCN | Dementia prevalence 2012* | Ratio  
|-------------------------------|-------------------------|---------------------------|--------
| New South Wales              | 93                      | 95,028                    | 1 : 1021 |
| Victoria                     | 169                     | 71,544                    | 1 : 423 |
| Queensland                   | 63                      | 51,005                    | 1 : 809 |
| South Australia              | 18                      | 24,627                    | 1 : 1368 |
| Western Australia            | 16                      | 25,177                    | 1 : 1573 |
| Tasmania                     | 9                       | 7,003                     | 1 : 778 |
| Northern Territory           | 0                       | 878                       | NA     |
| Australian Capital Territory | 3                       | 3,445                     | 1 : 1148 |
| **TOTAL**                    | **371**                 | **278,707**               | **1 : 741** |


CCN: College of Clinical Neuropsychologists. Not all members of the College specialise in dementia care.
7. A NATIONAL APPROACH

MODELS OF CARE AND CARE FOCUSED RESEARCH

At present, there is no national agreement on what constitutes the best model of care for the diagnosis, treatment and continuing care of people living with dementia or Alzheimer’s disease and their carers; systems and organisation of services vary between states and individuals.

Further investigation is needed to identify best practice models of care for dementia. This should involve short to medium-term small trials of different models to assess the effectiveness and health economic benefits of different systems, in order to provide an evidence base for sustainable implementation by the Department of Health. It may be necessary to identify a small number of ‘preferred’ models of care, as one single model may not be appropriate nationally for all patients.

Currently used/proposed Australian models should be tested, along with models from other countries that have been shown to be effective. Models discussed included:

- In Victoria, patients are referred to CDAMS, which is often regarded as providing the best standard of diagnosis and care, although there is no evidence that this system works best for all people with dementia. A dual public (CDAMS)/private system (with sufficient specialists having expertise and skills in dementia diagnosis and management), may be a more pragmatic model.

- In New South Wales, a nurse-led model of care has been proposed, in which practice nurses are up-skilled to undertake dementia testing, supported by a specialist community nurse (clinical nurse consultant or clinical nurse specialist) who in turn could consult with a specialist. This model of care has not yet been implemented. However, a similar model has recently been introduced in Newcastle, and is proving popular. In this model, patients are referred to a Nurse Practitioner (NP) who is skilled in dementia diagnosis and management. The NP then holds a case conference with the patient’s GP and practice nurse.

- The Living Longer, Living Better aged care reform package offers a key worker program for people with younger onset dementia. This could be expanded to people of all ages.

- In Canada, a ‘First Link’ program has been introduced by Alzheimer’s Canada (the Canadian equivalent of Alzheimer’s Australia). This is an early intervention service designed to connect individuals and families with services and support as soon as possible after a diagnosis of dementia. The Government has mandated that the healthcare professional who first diagnoses dementia must put the patient/family in touch with ‘First Link’.

Penetration of the mandatory ‘First Link’ system is up to about 50% in some areas of Canada, whereas awareness of some Alzheimer’s Australia services among people with dementia and their carers is much lower (less than 10%).20

As well as best practice models of care, investigations into best practice could encompass:

- Care focussed research on interventions that might have an impact on quality of life, such as diet, exercise, social engagement and mental stimulation.

- Best practice for RACFs – including systems for providing GP care at RACFs (currently residents consult their own GP, which means each individual may have a different GP; it may be more effective to have a single resident GP at the facility) and nursing roles and responsibilities. This would assist in accrediting ‘excellence in dementia care’ in RACFs.

NATIONAL DEMENTIA REGISTRY

Newly diagnosed patients could opt-in (on a voluntary basis) to a National Dementia Registry that would link patients and their carers to appropriate services available in their area and to potential participation in research. This system could help to ensure a clear pathway for diagnosis and follow-up (see section 5).

A National Dementia Registry would enable approved healthcare professionals to review whether patients had accessed a particular service and remind patients about its benefits. Information on currently available treatments, clinical trials as well as discontinued drugs could also be included. The Registry could be linked to electronically-controlled personal health records (e-health records; see section 9). A National Dementia Registry currently operates successfully in Canada.

CONSSENSUS FOR CHANGE

- Different models of care must be tested to identify the ‘best’ model of care or ‘preferred’ models of care.

- The identified best practice model of care should be rolled-out nationally.

- A nationwide, best practice approach for the diagnosis and ongoing care of Australians living with dementia is needed.

- The benefits of a National Dementia Registry should be evaluated, and the role of e-health records in such a registry explored.

- An evidence base for the effectiveness and health economic benefit for dementia models of care is needed for sustainable implementation.

- Care focussed research is needed to identify effective interventions that can improve quality of life for people living with dementia.
The current lack of effective, disease-modifying therapies is a disincentive for some healthcare professionals to diagnose and manage Alzheimer’s disease.

In addition to care focused research (see section 7), more research into pharmacological and non-pharmacological interventions (alone and in combination) in early Alzheimer’s disease and in non-Alzheimer’s dementias is needed. Currently pharmacological studies are mainly funded commercially; public funding for non-commercial trials needs to be increased. Translation of clinical studies into clinical practice must also be a focus of dementia management, to ensure research improves the care of patients in practice.

Currently, diagnosis and treatment of dementia or Alzheimer’s disease occur at a stage when significant brain capacity is irrevocably lost. However, changes occur in the brain well before onset of symptoms of mild cognitive impairment (MCI) or dementia (see Figure 1). Changes in biomarkers may be useful to identify individuals at high risk of developing Alzheimer’s disease and so provide the opportunity to intervene well before the onset of symptoms. Further research is needed on the feasibility and potential benefits of early identification of patients at risk of dementia or Alzheimer’s disease.

Research can also determine which interventions – including lifestyle changes and medications – can prevent or delay the onset of dementia or Alzheimer’s disease in a healthy at risk population. Safe and effective lifestyle interventions identified through research should be advised for all Australians, not just those at high risk.

**CONSENSUS FOR CHANGE**

- Early studies suggest that healthy people at risk of Alzheimer’s disease can be identified before the onset of symptoms. Further research is needed on the feasibility and potential benefits of early identification of patients at risk of dementia and Alzheimer’s disease, and on interventions that may prevent or delay onset of dementia in this population.
- Publicly funded research into pharmacological and non-pharmacological interventions in early Alzheimer’s and non-Alzheimer’s dementia is needed.
- Further research is required to develop accurate clinical diagnostic criteria for MCI. Existing criteria leads to high rates of false positive diagnosis. Accurate early diagnosis of MCI as a precursor to dementia is essential in enabling access to early interventions designed to slow or potentially halt dementia progression.
- A priority should be given to funding knowledge translation. The evidence base for quality dementia care which has been established over the last 20 years and which includes case conferencing, improved communication between care staff, supported decision making and care pathways, has not translated into improved practice.
9. TECHNOLOGY, AN OPPORTUNITY

The development of the Aged Care Gateway website ‘My Aged Care’ is an example of how technology is being harnessed to advance the management of aged care. Many other opportunities already exist.

E-health records allow clinicians to access information on what treatments their patient is currently taking and what they have been prescribed in the past, including when and why it was prescribed and why it was discontinued.

As outlined in section 5, technology already exists for case conferencing via telehealth. Utilisation of this technology could be promoted in the management of dementia, with increased telehealth consultations and communications between healthcare professionals.

There is currently no single source of news and information for healthcare professionals about local research projects in dementia. A website detailing current research and clinical trials would be useful. Clinicians could go online to determine whether their patient met enrolment criteria for any ongoing local research into new interventions or treatment approaches. The Dementia Collaborative Research Centres (DCRC) are currently finalising such a website.

**CONSENSUS FOR CHANGE**

- The greater use of existing technology (e.g. e-health records, telehealth) could optimise communication/collaboration, thereby providing a multidisciplinary approach and ultimately improving patient care.
- Readily accessible news and information on local research and clinical trials in dementia would be useful for healthcare providers.

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**FIGURE 1: CHANGES IN BRAIN BIOMARKERS, BRAIN STRUCTURE AND FUNCTION DURING DEVELOPMENT OF ALZHEIMER’S DISEASE**

![Graph showing changes in brain biomarkers, brain structure, and function during development of Alzheimer’s disease](image-url)
10. Conclusion and Call to Action

The roundtable meeting provided a valuable opportunity for key stakeholders working in dementia care and Alzheimer’s disease to share knowledge, experience and insights from their own perspective, as well as hearing from practitioners from other disciplines involved in dementia care. A number of consistent themes were highlighted by all participants. Current gaps in care were identified, together with suggested recommendations that may help address these gaps.

Summary: Consensus for Change

The Patient Experience

- A multidisciplinary, person-centred approach involving patients, carers, healthcare professionals and other stakeholders is required from initial diagnosis through to end-of-life (see section 5)

- The patient experience could be improved by extending the National Younger Onset Dementia Key Worker Program to all Australians living with dementia or Alzheimer’s disease

- Dementia care must focus on the following:
  - Recognising individual needs through engagement with the patient and carer
  - Augmenting functional capacity of the patient
  - Managing symptoms
  - Providing support and counselling (for both patient and carers)
  - Maximising quality of life, giving value and meaning to the patient’s life.

- Diagnostic avenues should be clarified for patients and carers

- More referral options and services are required at the early diagnosis stage, together with greater awareness of services available among GPs, carers and families

- Australian guidelines for normal cognitive function need to be established from the Australian specific data available

- Diagnosis and care of comorbid conditions must be co-ordinated in the elderly. This could be achieved through making primary care the cornerstone of care (see section 5) and/or through co-ordinating care through the general physician/geriatrician

- Developing the workforce within RACFs is essential (see section 6). The number of adequately trained and qualified nursing staff needs to be increased in order to provide leadership and mentoring to other staff members

- RACFs should have the opportunity to work towards certification for ‘excellence in dementia care’, to assist with consumer choice by indicating to potential consumers that the RACF is qualified to provide good quality, person-centred care for people with dementia or Alzheimer’s disease

The Carer Experience

- A partnership approach between patients, carers, healthcare professionals and other stakeholders is essential to help facilitate the care pathway and provide a smoother journey for patients and carers

- Carers should form an integral part of the dementia management team

- Carers should be provided with an easy-to-understand summary of available services and information at the point of diagnosis

- Information should be provided as appropriate throughout the course of the disease, to avert crises

- Patients and carers should always be offered links to Alzheimer’s Australia and Carers Australia at the point of diagnosis

Multidisciplinary Care and Collaboration

- Primary care healthcare professionals – including GPs and practice or community nurses – are ideally placed to act as the cornerstone for co-ordinating care from diagnosis to end-of-life care, ensuring patients and their carers/family receive the right management and information at the right time

- An opt-in National Dementia Registry was suggested as a means of ensuring that recommended therapies and services are logged and followed up from the point of diagnosis and to enhance research (see section 7)

- Improved availability of referral options for dementia and Alzheimer’s disease could enhance diagnosis in primary care

- A clear, best practice diagnostic pathway is needed, with greater collaboration between primary and tertiary care

- Ideally, collaboration among healthcare professionals should involve verbal communication, such as case conferencing, e.g. via telephone, videoconferencing or face-to-face, as this is quicker and more effective than written reports or care plans. Case conferencing is beneficial and could be facilitated through reimbursement of administrative costs as well as the currently available rebate for the case conference itself

Continued over
• Screening tests (e.g. MMSE) alone, lack sufficient accuracy for the diagnosis of individuals seen in the clinical setting. A comprehensive history from an informant, a physical examination and relevant investigations are required. Specialist referral and comprehensive neuropsychological assessment provides more accurate diagnosis of dementia in its early stages, especially in high functioning individuals.

DEVELOPING THE WORKFORCE IS CRITICAL
• The number of healthcare professionals working in the field of dementia needs to increase.
• De-stigmatisation, parity of remuneration and recognition of the skills involved in dementia care are important to encourage greater participation in this field of healthcare.
• Quality training and continuing professional development opportunities for career progression in dementia care are needed for enrolled and registered nurses and nurse assistants.

A NATIONAL APPROACH
• Different models of care must be tested to identify the ‘best’ model of care or ‘preferred’ models of care.
• The identified best practice model of care should be rolled-out nationally.
• A nationwide, best practice approach for the diagnosis and ongoing care of Australians with dementia or Alzheimer’s disease is needed.
• The benefits of a National Dementia Registry should be evaluated, and the role of e-health records in such a registry explored.
• An evidence base for the effectiveness and health economic benefit for dementia models of care is needed for sustainable implementation.
• Care focussed research is needed to identify effective interventions that can improve quality of life for Australians living with dementia or Alzheimer’s disease and their families.

RESEARCH INTO THE TREATMENT AND PREVENTION OF ALZHEIMER’S DISEASE
• Early studies suggest that people at risk of Alzheimer’s disease can be identified before the onset of symptoms. Further research is needed on the feasibility and potential benefits of early identification of patients at risk of dementia or Alzheimer’s disease, and on interventions that may prevent or delay onset of dementia in this population.
• Longitudinal effective studies on the healthy ageing of Australians need to be examined to better understand the factors that influence healthy ageing in Australia.
• Examination of mid-life factors and later-life disease is crucial to permit targeting risk factors prior to any brain cell death having occurred, which we now know happens well before amyloid accrues in the brain, which occurs well before a dementia diagnosis.
• Publicly funded research into pharmacological and non-pharmacological interventions in early Alzheimer’s and non-Alzheimer’s dementia is needed.
• Further research is required to develop accurate clinical diagnostic criteria for MCI. Existing criteria can lead to high rates of false positive diagnosis. Accurate early diagnosis of MCI as a precursor to dementia will enable better targeting of access to early interventions designed to slow and potentially halt dementia progression.
• Priority should be given to funding for knowledge translation. The evidence base for quality dementia care which has been established over the last 20 years and which includes case conferencing, improved communication between care staff and supported decision making, has not translated into improved practice.
• As our understanding of dementia and Alzheimer’s disease increases, we need to create collaborations with industry to develop biomarker detection, early diagnostics and therapeutics for young people prior to brain cell loss and atrophy.

TECHNOLOGY, AN OPPORTUNITY
• The greater use of existing technology (e.g. e-health records, telehealth) could optimise communication/collaboration, thereby providing a multidisciplinary approach and ultimately improving patient care.
• Readily accessible news and information on local research and clinical trials in dementia and Alzheimer’s disease would be useful for healthcare providers and the general public.

These recommendations need to be incorporated into a National Action Plan for Dementia and Alzheimer’s disease, with funding for sustainable implementation across Australia (including regional/rural/remote areas), and among all Australians (including patients with special needs such as CALD and ATSI populations as well as those Australians living with disabilities).

Many of the suggested actions are relatively simple to implement and could make a real difference to the lives of Australians living with dementia or Alzheimer’s disease, and their families – now and in the future.
REFERENCES


