
The Parliament of the Commonwealth of Australia

Thinking Ahead

Report on the inquiry into dementia: early diagnosis and intervention

House of Representatives
Standing Committee on Health and Ageing

June 2013
Canberra

© Commonwealth of Australia 2013

ISBN 978-1-74366-098-0 (Printed version)

ISBN 978-1-74366-099-7 (HTML version)

This work is licensed under the Creative Commons Attribution-NonCommercial-NoDerivs 3.0 Australia License.



The details of this licence are available on the Creative Commons website:

<http://creativecommons.org/licenses/by-nc-nd/3.0/au/>.

Printed by CanPrint Communications Pty Ltd, Canberra ACT.

Cover design by Lucas Kuncewicz, Department of the House of Representatives
Printing and Publishing Office, Canberra ACT.

Cover images courtesy of Thinkstock.



Contents

Foreword	vii
Membership of the Committee	ix
Terms of reference	xi
List of recommendations	xii

THE REPORT

1 Conduct and context of the inquiry	1
Referral and conduct of the inquiry	2
Context of the inquiry	3
Relevant policy inquiries and reports	3
Australian Government policy frameworks	7
Dementia as a health priority.....	7
National Framework for Action on Dementia (NFAD).....	9
Living Longer. Living Better. – aged care reform package	11
Scope of the inquiry	12
Structure of the report	12
2 Dementia in Australia – demographics and services	15
Impact of dementia.....	15
What is dementia?	17
Signs and symptoms of dementia	19
Prevalence of dementia	20
Data limitations.....	22

Ageing Australia and demand for services	22
Dementia services and supports	23
Medicare and the Pharmaceutical Benefits Scheme	24
Primary care and acute care services	24
Community aged care services	25
Home and Community Care	27
Community Aged Care Packages	28
Respite services	30
Residential aged care services	30
Dementia Behaviour Management Advisory Services	31
National Dementia Support Program	32
State/territory governments and the non-government sector	32
3 Awareness	35
Lack of community awareness	37
Stigma	40
Committee comment	42
Raising greater awareness of dementia	43
Committee comment	49
Awareness for General Practitioners (and other health professionals)	50
Committee comment	55
4 Diagnosis	57
What is 'early' or 'timely' diagnosis?	58
Committee comment	60
Benefits of timely diagnosis	61
How is a diagnosis of dementia obtained?	63
Screening tests	64
Screening challenges	66
Committee comment	69
Targeted screening for dementia?	71
Committee comment	74
Future planning	75
Legal barriers	77

Capacity	78
Committee comment	80
Complexity of legal processes.....	81
Moves towards uniformity	82
Committee comment	85
Awareness about future planning.....	86
Committee comment	88
5 Barriers to diagnosis	91
Who can make a diagnosis of dementia?	92
Barriers to diagnosis in primary care.....	92
Barriers for General Practitioners.....	95
Committee comment	98
Barriers to specialist diagnosis.....	99
Specialist diagnosis in rural, regional and remote communities	101
Committee comment	103
Diagnosis in a multi-disciplinary practice.....	105
Committee comment	108
Specialist nurses.....	108
Committee comment	110
Barriers to diagnosis in acute care	111
Committee comment	113
6 Post-diagnosis	115
Committee comment	116
Referral pathways	117
Navigating the pathway.....	117
Committee comment	120
Referral process.....	120
Committee comment	122
Coordinating pathways.....	122
A multi-disciplinary approach	125
Committee comment	126

Dementia link worker.....	128
Committee comment.....	131
How dementia care services can improve quality of life.....	132
Dementia management in acute care	132
Committee comment.....	135
Accessible and flexible services.....	137
Committee comment.....	142
7 A dementia friendly future	145
Preventing dementia	146
Lifestyle factors	147
Mental activity and social engagement	149
Committee comment.....	152
Dementia research.....	154
Committee comment.....	160
Dementia friendly communities	163
Committee comment.....	166
APPENDICES	
Appendix A – List of submissions	169
Appendix B – List of exhibits	173
Appendix C – List of public hearings.....	177



Foreword

In less than 40 years the number of people living with dementia in Australia is projected to triple. This equates to around 900,000 people with dementia by 2050. It is clear that Australia must plan now to develop a strong system of services and supports to meet the ongoing needs of people living with dementia, and their families and carers.

The potential benefits of early diagnosis and early intervention are far-reaching. An early diagnosis of dementia allows those who receive it to access appropriate treatments at the earliest opportunity, and to make informed choices about their current and future care needs. They can also make important decisions about their legal and financial affairs, while they have capacity to do so. Early diagnosis has the potential to improve quality of life for a person with dementia, and for their family and carers.

The basis of the Committee's report is the diverse and wide-ranging evidence acquired during the 17 public hearings held across Australia, and featured in the 112 written submissions. Evidence was received from professionals working within the health, aged, disability and dementia care sectors, including medical researchers, medical practitioners, community workers and advocates from a range of consumer groups. Importantly, the Committee also heard directly from people affected by dementia – that is from people living with a diagnosis of dementia, their family members and their carers. This latter group a real insight into the challenges they experience and priorities for the future.

Unfortunately, evidence indicates that there is a lack of dementia awareness within the wider community. Misinformation about dementia has contributed to a widespread belief that dementia is an inevitable consequence of ageing, and that nothing can be done to delay onset or slow progression. Furthermore, stigma remains a significant barrier. It seems that many people are reluctant to seek an assessment when they notice signs of cognitive decline, and that doctors can be reluctant to give a diagnosis of dementia. The need for greater dementia

awareness and for destigmatisation to increase opportunities for early diagnosis and intervention was a consistent message.

Aside from the need for greater awareness, several other key themes emerged. Within the health system, the Committee heard there was a lack of linkages and clear pathways of services and supports from diagnosis, to ongoing treatment and management. People felt they needed a 'real person', a case manager, to help connect them and their families and carers to appropriate services and supports.

The Committee heard that GPs, often the first point of contact for a person concerned about signs of cognitive decline, sometimes have difficulty in making a diagnosis of dementia and do not always sufficiently understand the referral pathway to ongoing treatment and support.


The Committee was impressed by the world class and innovative dementia research being conducted in Australia. The Committee believes that further development in research on early diagnosis and intervention is needed. The Committee encourages ongoing government and non-government support for the many facets of dementia research, and has called for an increased effort to determine the influence of psychosocial interventions on brain health.

One of the most important messages which came from the dementia experts in this inquiry was simple: there are choices that people can make right now to improve brain health, and possibly delay the onset of dementia. A healthy lifestyle and continued social engagement appear to be crucial. The Committee has recommended that national awareness campaigns promoting healthy lifestyle choices should feature prominently messages about brain health.

Finally, the Committee heard there is a call to create dementia friendly communities in Australia. These communities engage not only our health sector, but also our banks, transport services, public spaces and all other facets of society, to ensure that people with dementia and their families are valued and able to continue to contribute to society.

In concluding, I offer my thanks to those individuals and organisations that have contributed to the inquiry through submission or by attending one of the public hearings. In particular, I acknowledge the people with dementia and their carers who openly and generously shared their stories with us. I would also like to thank my Committee colleagues for their participation and commitment.

Ms Jill Hall MP
Chair



Membership of the Committee

Chair	Ms Jill Hall MP (<i>from 27/11/12</i>)
Deputy Chair	Mr Steve Irons MP
Members	Mr Mark Coulton MP
	Mr Steve Georganas MP (<i>Chair to 27/11/12</i>)
	Mr Geoff Lyons MP
	Ms Deborah O'Neill MP
	Mr Ken Wyatt MP

Committee Secretariat

Secretary	Dr Alison Clegg
Inquiry Secretary	Mr Muzammil Ali (<i>to 11/11/12</i>) Mrs Renee Toy (<i>from 12/11/12</i>)
Research Officers	Dr Phillip Hilton (<i>from 19/11/12</i>) Mr Sean Kelly (<i>to 11/05/12</i>) Ms Belynda Zolotto
Administrative Officers	Ms Fiona McCann Ms Kathy Blunden



Terms of reference

Australia's population is ageing and over the next 20 years the number of people with dementia is predicted to more than double. Early diagnosis and intervention has been shown to improve the quality of life for people with dementia, as well as for family members and carers.

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

- improve quality of life and assist people with dementia to remain independent for as long as possible;
- increase opportunities for continued social engagement and community participation for people with dementia;
- help people with dementia and their carers to plan for their futures, including organising financial and legal affairs and preparing for longer-term or more intensive care requirements; and
- how best to deliver awareness and communication on dementia and dementia-related services into the community.



List of recommendations

Recommendation 1

The Australian Government, in collaboration with Alzheimer's Australia and relevant consumer groups, develop and implement a national communication strategy and public awareness campaign to promote greater awareness of dementia, using (but not limited to) the following themes:

- Better public awareness and understanding of dementia;
- Reducing the stigma of dementia and challenging discriminatory behaviour;
- Recognising the early signs of dementia to aid early diagnosis;
- Living well with dementia; and
- The importance of a healthy lifestyle and reducing risk.

Recommendation 2

The Australian Government Department of Health and Ageing, in collaboration with the Minister's Dementia Advisory Group and the Royal Australian College of General Practitioners, develop a national evidence-based dementia training program for General Practitioners, with an emphasis on diagnosis.

Elements of the training program should include:

- Challenging stigma and misconceptions;
- Managing sensitive and difficult conversations in the context of the doctor-patient/carer relationships;
- Current best-practice and implications of latest research; and

- Diagnosis, care and support pathways for people with dementia, their families and/carers.

Recommendation 3

The Australian Government, through the Dementia Outcomes Measurement Suite, develop best practice guidelines for diagnosis of people with intellectual disability.

Recommendation 4

The Australian Government collaborate with the state and territory governments, through the Standing Council on Law and Justice, to develop uniform definitions and guidelines relating to capacity.

Recommendation 5

The Australian Government collaborate with the state and territory governments, through the Standing Council on Law and Justice, to develop uniform definitions and guidelines relating to powers of attorney.

Recommendation 6

The Australian Government collaborate with the state and territory governments to develop a toolkit or guidelines to assist medical/legal professionals, or a person diagnosed with dementia and their carer understand future planning options.

Recommendation 7

The Australian Government Department of Health and Ageing undertake a comprehensive review of the use of existing MBS items to determine whether it is necessary to expand existing items or create new items to support identification, assessment and management of dementia in primary care.

Recommendation 8

The Australian Government Department of Health and Ageing implement early and timely diagnosis in regional, rural and remote communities where access to specialist diagnosis is limited by coordinating multi-disciplinary teams comprising primary health care practitioners and visiting medical specialists, supplemented by primary or specialist assessment provided via telehealth facilities.

The need for multi-disciplinary teams should be assessed at a local level, via Medicare Locals, or other such local health networks.

Recommendation 9

The Australian Government, in consultation with Health Workforce Australia, develop an accredited training and support program to increase capacity for specialist nurses to provide dementia assessment and diagnosis in primary care settings, as part of multi-disciplinary teams.

Recommendation 10

The Australian Government Department of Health and Ageing complete and promote practice guidelines for the care of dementia in general practice (or primary care). In consultation with Medicare Locals or other such local health networks, these guidelines should be contextualised and provide information on local dementia care pathways, including information on future planning services, such as legal services.

Recommendation 11

The Australian Government establish clear and streamlined local referral pathways for dementia diagnosis, treatment and support, through Medicare Locals, localised primary health care networks, or other specialist dementia networks such as Memory Clinics.

Recommendation 12

The Australian Government Department of Health and Ageing, in collaboration with the Minister's Dementia Advisory Group, Alzheimer's Australia and Health Workforce Australia, evaluate the creation of a nation-wide multi-disciplinary approach to dementia diagnosis, treatment and support.

Such an approach should build upon the existing workforce and localised infrastructure, such as Medicare Locals and/or Memory Clinics.

Recommendation 13

The Australian Government Department of Health and Ageing examine the case for establishing a Dementia Link Worker program to assist in the ongoing case management of people with dementia and their carers.

A proactive case management approach, utilising a Dementia Link Worker, should include regular scheduled follow up from the time of diagnosis through the progression of the condition.

Recommendation 14

The Australian Government Department of Health and Ageing, as part of the *Living Longer. Living Better.* reforms and through the Council of Australian Governments, trial the following initiatives to investigate their

capacity to assist in improving dementia care in acute hospital settings, with a view to these initiatives being implemented nationally:

- The introduction of Clinical Nurse Specialists in dementia in hospitals;
- The introduction of a Cognitive Impairment Identifier in hospitals; and
- The introduction of a protocol for the identification of cognitive issues at the point of triage.

Recommendation 15

The Australian Government should ensure that messages on brain health and dementia prevention are included in all relevant national initiatives and public health awareness campaigns which promote healthy lifestyle choices through diet, exercise, smoking cessation and responsible consumption of alcohol.

Key messages to be included in any future campaigns with relevance to brain health should also promote the importance of mental activity and social engagement.

Recommendation 16

The Australian Government Department of Health and Ageing and/or the National Health and Medical Research Council initiate targeted research into the influence of psychosocial interventions on brain health and the implications for the risk of developing dementia.

Recommendation 17

The Australian Government collaborate with Alzheimer's Australia to develop a set of flexible values and standards which would inform the creation of dementia friendly communities around Australia.

