

**The impact of dementia
on the health and aged care
systems**

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The impact of dementia on the health and aged care systems

June 2004

Australian Institute of Health and Welfare
Canberra

AIHW Cat. No. AGE 37

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ISBN 1 74024 385 4

Suggested citation

Australian Institute of Health and Welfare 2004. The impact of dementia on the health and aged care systems. AIHW Cat. No. AGE 37. Canberra: AIHW.

Australian Institute of Health and Welfare

Board Chair
Dr Sandra Hacker

Director
Dr Richard Madden

Any enquiries about or comments on this publication should be directed to:

Ageing and Aged Care Unit
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601
Phone: (02) 6244 1000

Published by the Australian Institute of Health and Welfare

Printed by Elect Printing

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Acknowledgements

This report was prepared by Anne Jenkins, John Goss, Cathy Hales and Rosemary Karmel. However, the contributions of people from a number of units within the Australian Institute of Health and Welfare were essential to the completion of this project. In particular, Peter Braun of the Ageing and Aged Care Unit provided data relating to residential aged care use, and Ben Nelson and Evon Bowler analysed data from the aged care censuses. Data on hospital use were derived by Ian Titulaer, Stephen Halpin and Ruth Penm of the Hospitals and Mental Health Services Unit, and staff of the General Practice Statistics and Classification Unit provided data and comment on the use of general practice services. Robert Van der Hoek of the Population Health Unit compiled the relevant mortality data, and, lastly, Nick Mann of the Summary Measures Unit derived the information on health system costs.

In addition, valuable comments on drafts of this report were provided by a number of people, including David Cullen of the Department of Health and Ageing and Glenn Rees of Alzheimer's Australia.

Abbreviations

ABS	Australian Bureau of Statistics
ACAP	Aged Care Assessment Program
ACAT	Aged Care Assessment Team
ACCMIS	Aged and Community Care Management Information System
AIHW	Australian Institute of Health and Welfare
AMTS	Australian Morbidity and Treatment Survey
BEACH	Bettering the Evaluation of Care of Health survey
CACP	Community Aged Care Package
CI	Confidence interval
DALY	Disability-adjusted life year
DoHA	Australian Government Department of Health and Ageing
EACH	Extended Aged Care at Home
GP	General practitioner
ICD-10-AM	The international statistical classification of diseases and related health problems, 10th revision, Australian modification
ICD-9-CM	The international classification of diseases, 9th revision, clinical modification
LCL	Lower confidence limit
MMHA	Mini Mental Health Assessment
OECD	Organisation for Economic Co-operation and Development
RACS	Residential aged care service
RCS	Resident Classification Scale
RFE	Patient Reasons for Encounter
SAND	Supplementary Analysis of Nominated Data (part of the BEACH program)
UCL	Upper confidence limit
YLD	Years of life lost due to disability
YLL	Years of life lost due to premature death

Summary

Background

In the 2002–03 budget, the Australian Government announced funding for a review of pricing arrangements in residential aged care. The review, conducted by Professor Warren Hogan, examined long-term financing options for the aged care sector with consideration of the level and quality of care required by older Australians into the future and taking into account issues of equity of access. It considered the improved care outcomes required from providers under accreditation and the underlying cost pressures faced by the industry, including movements in nurses' and other wages, and increases in workers' compensation and other insurance premiums. The approach taken by Hogan in addressing the aims of the review was to discuss aged care service provision in terms of demand for aged care, the cost of aged care and the supply of aged care services, recognising that these overlap and interact.

The prevalence of disability provides an indicator of the potential demand for residential aged care; and dementia has been found to be the greatest single contributor to burden of disease due to disability at older ages, as well as the greatest single contributor to the cost of care in residential aged care. Therefore, to inform the review by Professor Hogan, the Department of Health and Ageing commissioned the Australian Institute of Health and Welfare in mid-2003 to investigate the extent to which health and aged care service use can be associated with dementia. This report presents the findings of these investigations, examining the prevalence of dementia in the Australian population, the current patterns of service use by people with dementia and the costs associated with this use.

Prevalence of dementia

Dementia describes a syndrome associated with a range of diseases which are characterised by the progressive impairment of brain functions, including language, memory, perception, personality and cognitive skills. These declines in mental function may manifest themselves through different symptoms at various times. Alzheimer's disease is the most common form of dementia, estimated to be responsible for 70% of dementia cases.

The prevalence of dementia has been estimated to double every 5.1 years of age after the age of 65, affecting 24% of those aged 85 and over. To date there has been little progress in preventing or delaying the onset of dementia. Alzheimer's disease shortens total life expectancy and men and women with the disease spend a greater proportion of their remaining life with more impairments than their unaffected age peers.

Because of difficulties in identifying people with mild or moderate dementia no definitive estimates of the number of people with dementia in Australia are available. Using results from a meta-analysis of international studies, it is estimated that in 2002 around 167,000 Australians were affected by dementia, with almost two-thirds of these aged 80 years and over. Among people aged 65 and over, 6.5% are estimated to have dementia.

The care needs experienced by someone with dementia vary greatly as the severity of the cognitive impairment progresses. Using 1998 survey-based age-sex prevalence rates, for

2002 it is estimated that the number of people with dementia always or sometimes needing assistance with either self-care, mobility or communication – that is, with a severe or profound core activity restriction – was 113,000, constituting 1.1% of the population aged 35 years and over; the majority were in cared accommodation, such as residential aged care. Also in 2002, 70% of older people with dementia and a severe or profound core activity restriction are estimated to have been 80 years and over, with around half aged 85 years or more. The number of women with dementia and a severe or profound core activity restriction was about double the number of men in that position. It is estimated that 34,000 people acquired dementia in 2002.

Unless there are significant breakthroughs in the treatment and/or prevention of dementia, the prevalence of dementia is expected to continue to increase in line with Australia's ageing population. The number of people with a severe or profound core activity restriction with dementia is projected to rise from 113,000 in 2002 to 179,000 in 2020 – an increase of 60%. Over half of this increase will be among those aged 85 and over, mostly due to the ageing of the older population: the number aged 85 and over with dementia and a severe or profound core activity restriction is estimated to increase from 59,000 in the year 2002 to 98,000 in 2020.

Service impact

The impact of dementia varies from service to service. In this report a number of national services are considered: general practice, hospital services, home-based community care and residential aged care. There is a variety of other national and state-specific services – both mainstream and targeted at people with dementia and their carers – which it has not been possible to include.

For 2001–02 it is estimated that around 5% of general practitioner adult patients (aged 18 and over) had either diagnosed or suspected dementia. However, dementia was managed in relatively few general practitioner (GP) encounters: in 2001–02, dementia was managed at a rate of 6 per 1,000 GP encounters with adults. Overall, dementia was managed in approximately 505,000 adult encounters, with about one quarter of these involving Alzheimer's disease. In addition, medication was prescribed in the management of dementia at a rate of 29.4 per 100 dementia contacts. Given that only a small proportion of people with dementia are aged under 65, this can be compared with a general prescription rate of between 110 and 120 per 100 encounters for people aged 65 and over. As would be expected from the prevalence of dementia in the population, an overwhelming majority (86%) of encounters in which dementia was managed were for people aged 75 and over.

The impact of dementia on hospital services appears to be relatively greater than that on general practice. In 2001–02, 1.2% of all hospital separations (or 79,000 separations) involved people with either a principal or additional diagnosis of dementia (where additional diagnoses are recorded if they contribute to the consumption of hospital resources). For around one in eight of these separations, dementia was the principal diagnosis. If same-day separations are excluded, people with any diagnosis of dementia accounted for 2.3% of hospital separations. However, people with dementia tend to stay longer than others in hospital. Consequently, nearly 7% of bed days for separations lasting at least one night were for people with any diagnosis of dementia. If the prevalence rate of dementia increases with the ageing of the population as expected, a greater proportion of hospital bed days can be expected to involve people with a diagnosis of dementia.

The care needs of people with dementia grow as the disease progresses. As a consequence, the prevalence of dementia among people using aged care services increases with the level of care being provided by the program. For 2002 it is estimated that 6% to 7% of people aged 65 and over had dementia and 4% had both dementia and a severe or profound disability. However, among people screened for aged care programs by Aged Care Assessment Teams (ACATs), around 20% have a primary diagnosis of dementia. Reflecting the level of care available through the various programs, 18% of Community Aged Care Packages (CACP) recipients have diagnosed dementia compared with 32% of Extended Aged Care at Home (EACH) place recipients. Not surprisingly, dementia has the greatest prevalence in residential aged care services. Precision is not possible, but applying an indicator based on a measure of cognitive impairment developed by consultants for the 1998 review of the Resident Classification Scale (RCS) results in an estimate of 52% of people admitted into permanent residential aged care in 2002 who possibly had dementia and a further 26% who probably had dementia. At the end of 2002, using the same indicator gives estimates of 50% and 31%, respectively, of permanent residents either possibly or probably with dementia.

In general, people with care needs similar to those met by residential aged care have difficulty staying in the community without a carer. However, EACH and CACP recipients with dementia are more likely than other recipients to have a carer, suggesting that people with dementia have even greater difficulty staying at home without a carer. This is particularly true as the disease progresses and care needs become greater: in 2002 nearly all EACH recipients with dementia had a carer (97% compared with 88% of recipients without dementia). A change in the availability of carers would therefore impact on the ability of people with dementia to remain in their homes.

Within a service program, people with dementia generally have greater care needs than those without. This particularly affects residential aged care: at 31 December 2002, around 86% of permanent residents with probable dementia were in the highest two RCS care need categories, compared with 34% of residents with possible dementia and 8% of those without dementia. In addition, in 2002 two-thirds of occupied bed days for people in the two highest RCS care need categories were used by people who probably had dementia. This rises to 97% if people with possible dementia are also included.

Although people with diagnosed dementia have a shorter remainder of life expectancy than others, the length of stay in residential aged care by people with dementia is, on average, longer than stays by other residents. As a consequence, in 2001–02 people with either possible or probable dementia accounted for 80% of occupied bed days by permanent residents. Over the last 4 years this relative use has been increasing – up from 73% of occupied bed days in 1998–99. The rise in use by people with dementia has been driven by growth in bed days for people with possible dementia, with the proportion of bed days for people with probable dementia falling over the period – from 37% of bed days in 1998–99 to 33% in 2001–02.

Burden of disease

Death rates from dementia (age-standardised) have been stable, or declining, over the period 1997 to 2001. However, diseases and disorders can have a range of effects on both quality and length of life. Because of its disabling rather than fatal nature, dementia has a much greater effect on years of healthy life lost than it has on years of life lost due to mortality.

The combined effect of premature mortality and burden of disease due to disability is gauged using disability-adjusted life years (DALYs). One DALY is a lost year of 'healthy' life, and is the sum of years of life lost due to premature mortality and years of healthy life lost due to disability. In 1996, the only year for which data are available, disability accounted for around three-quarters of the total burden due to dementia for people aged 55 and over. Death, however, accounted for a greater proportion of the burden for older than younger people; premature death caused about one-third of the burden for people aged 75 and over, but less than 15% for people aged 55 to 74. For all other causes combined, premature death was the greater source of disease burden, contributing 70% of the burden among people aged 55 and over.

Overall, in 1996, dementia-related disability and death resulted in a loss of 19 DALYs (out of a total of 417 DALYs) per 1,000 men aged 55 and over; for women the corresponding figure was 27 DALYs per 1,000 population (out of a total of 342 DALYs for all causes). Reflecting the increasing burden with age observed for both death and disability, the total burden of dementia increases with age. Among people aged 75 and over dementia accounted for 54 DALYs per 1,000 men (or 7%) and 65 DALYs per 1,000 women (or 11%).

Expenditures by the health and aged care systems

For 2000–01 it is estimated that expenditures for dementia by the health and aged care systems combined were just over \$2.5 billion. An overwhelming proportion of this expenditure was for residential aged care (\$2.1 billion), with this accounting for 84% of total expenditure.

It is estimated – somewhat roughly – that in 2000–01, the cost to government of dementia to the main community care programs totalled around \$100 million. In contrast, for the same year the cost of dementia to residential aged care is estimated to have been nearly \$1.8 billion in government funding. An overwhelming majority of this expenditure was for residents requiring high-level care, with 99% (\$1.5 billion) of Australian Government subsidies for residents with dementia as their main disabling condition being for those with high care needs. The cost of aged care services to users is generally not available; however, a crude estimate attributes to dementia around \$360 million of user payments for residential aged care in 2000–01.

Expenditure for dementia by the health system (excluding health expenditure in residential aged care) was \$307 million in 2000–01. Over half of this expenditure was by hospitals (\$160 million), and nearly 9% was for pharmaceuticals (\$27 million).

As well as the programs considered above, there are a number of others which deliver services to people with dementia. For example, due to lack of relevant data, it has not been possible to consider the cost of dementia with respect to carers – either in terms of costs to individuals or in government expenditure on programs that support carers (such as the Carers Allowance and the National Respite for Carers Program). In 2000–01, the programs included in the above costing together accounted for 93% of government funding on national aged care programs. In addition, there are several state-specific aged care services – both mainstream and targeted at people with dementia and their carers – which it has not been possible to include. Consequently, the above estimates of financial cost to the aged care system understate the total cost.

