Alzheimers
New Zealand Incorporated

Dementia Economic Impact Report 2008

Making life better for all people affected by dementia
Kia piki te ora mo ngā tāngata mate pōrewarewa

Alzheimers New Zealand provides

INFORMATION

Alzheimers News

AWARENESS

"He used to forget our wedding anniversary.

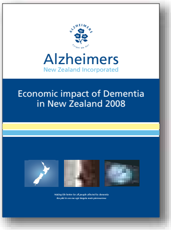
Cuppa for a Cause

ADVOCACY

New Zealand 2008 Dementia Manifesto

Action

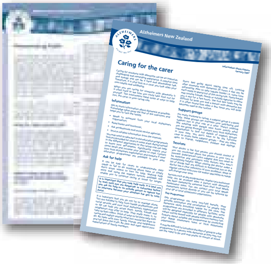
STRATEGIC RESPONSES



Alzheimers
New Zealand Incorporated

Economic impact of Dementia in New Zealand 2008

RESOURCE DEVELOPMENT



Alzheimers New Zealand

Caring for the carer

COORDINATED VOICE & CENTRAL BODY

How are we funded?

Alzheimers New Zealand is a non government organisation (NGO) primarily funded through donations from trusts and individuals. It supports twenty three member organisations throughout New Zealand.

What can your donation pay for?

• development of information packs • development of educational resources in a range of media • conferences, symposiums, lectures • general awareness campaigns • targeted awareness campaigns • health promotion campaigns • partnership activities designed for your organisation • purchase of books, magazines and resources • artwork and printing of national newsletters • advertising • office expenses • salaries

to donate phone: 0900 41234

Foreword

Dementia has a dramatic effect on the lives of people and is fast becoming a reality for an increasing number of New Zealanders. The effects of an ageing population combined with people living longer and the increase in the number of people under the age of 65 years being diagnosed with dementia, means that the impact is already becoming alarmingly evident and is felt in social, economic and health terms.

To date there has been no definitive and reliable New Zealand data available to determine the number of people with dementia. Estimates used to attempt to determine the impact of dementia have been based on overseas data. Whilst this has concerned Alzheimers New Zealand for several years, we have not been a position to do anything about it. Now, thanks to generous funding from the Alzheimers New Zealand Charitable Trust and the Ministry of Health, and a bequest, Alzheimers New Zealand has been able to fulfil a long held hope of commissioning an ***Economic Impact of Dementia in New Zealand*** study. This report provides an up to date profile of dementia, its prevalence now and in the future, and its economic and social impact on New Zealand society.

The stark reality now faced is that there are 40,746 people with dementia in New Zealand today. With an estimated 12,333 new cases of dementia being diagnosed each year, there will be 74,821 people with dementia by 2026.

As yet there is no cure, however much can be done to improve the quality of life for people with dementia, their carers and families. This report identifies the huge challenges New Zealand is faced with in terms of prevalence, costs and burden of disease. It also provides a starting point for future policy, planning and resourcing.

Alzheimers New Zealand's Mission is ***Making life better for all people affected by dementia*** and we urge all those in a position to do so - Government, the Ministry of Health, the Ministry of Social Development, health professionals, researchers and the community - to work with us and act now to ensure a fair go for all people affected by dementia.

JSimpson

Joy Simpson
Immediate Past Chair
Alzheimers New Zealand Board

Alzheimers New Zealand

gratefully acknowledges that funding towards
the cost of this report was provided by
Alzheimers New Zealand Charitable Trust
and the Ministry of Health
William Barlow Estate

ALZHEIMERS
NEW ZEALAND CHARITABLE TRUST

MANATŪ
HAUORA
MINISTRY OF HEALTH

CONTENTS

FIGURES

TABLES

ACKNOWLEDGEMENTS

This report was prepared by Access Economics for Alzheimers New Zealand. The content of the report is independent and not influenced by external sources of funding. Access Economics would like to acknowledge with appreciation the comments, prior research and expert input from the following selected advisors for the project.

Dr Tom Bracken
Clinical Director of a small PHO in Mangere AK
Clinical Adviser to the PATHS project for Work & Income and the DHB.

Dr Vernon Choy
Manager Investment Processes, Health Research Council of New Zealand

Dr Matthew Croucher
Consultant Psychiatrist, Psychiatry Service for the Elderly, Canterbury Health Board
Clinical Senior Lecturer, Christchurch School of Medicine and Health Sciences, University of Otago
Director of Training, Christchurch Psychiatry Registrar Training

Dr Terri Green
Department of Management, University of Canterbury, Christchurch

Professor Peggy Koopman-Boyden
Population Studies Centre, The University of Waikato, Hamilton

Chris Lewis
Information Analyst, New Zealand Health Information Service

Lucille Ogston
National Director, Alzheimers New Zealand, Wellington

Kevin Phillips
Business Analyst, Health & Disability National Services Directorate

Michaela Press
Policy Analyst, Health of Older People Policy, Health & Disability Services Policy Group, Population Health Directorate, Ministry of Health

Professor Ann Richardson
Professor of Public Health, University of Otago

Joy Simpson
Chair, Alzheimers New Zealand

Martin Taylor
Chief Executive Officer, Health Care Providers New Zealand, Wellington

Craig Wright
Senior Advisor (Statistics/Epidemiology), Public Health Intelligence, Health & Disability Systems Strategy Directorate, Ministry of Health

ACRONYMS/GLOSSARY

ABS	Australian Bureau of Statistics
AD	Alzheimer's Disease
ADL	activities of daily living
AIHW	Australian Institute of Health and Welfare
ALOS	Average length of stay
AWE	Average Weekly Earnings
Burden of disease	The loss of healthy life (quality and length) as measured in DALYs
CCPS	Client Claims Processing System, a HealthPAC system that processes payments for providers of health and disability services on behalf of the funders of those services
CDR	Clinical Dementia Rating (scale)
CPI	Consumer Price Inflation
DALY	Disability Adjusted Life Year
DHB	District Health Boards
DWL	Deadweight Loss – real inefficiency losses due to the need to raise taxation revenue
GDP	Gross Domestic Product
GP	General Practitioner
HealthPAC	Health Payments, Agreements and Compliance, a business unit of the Ministry of Health
HRC	Health Research Council of New Zealand
ICD-10	International Classification of Disease Tenth Revision
Incidence	The number of new cases of a condition in a population relative to that population
MoH	Ministry of Health, New Zealand
NSAIDs	non-steroidal anti-inflammatory drugs
NZ	New Zealand
NZHIS	New Zealand Health and Information Service
OECD	Organization for Economic Cooperation and Development
OR	Odds Ratio
PHI	Public Health Intelligence unit of the Ministry of Health
PHO	Primary Health Organisation
Prevalence	The number of total cases of a condition in a population relative to that population
pwd	person/people with dementia
R&D	Research and Development
US	United States
VSLY	Value of a Statistical Life Year
VSL	Value of Statistical Life
WHO	World Health Organization
WTA	Willingness to Accept
WTP	Willingness to Pay
YLD	Years of Healthy Life Lost Due to Disability
YLL	Years of Life Lost Due to Premature Mortality

Note: All $ in this report are New Zealand dollars unless otherwise specified.

EXECUTIVE SUMMARY

This analysis and report estimates the prevalence, financial cost and disease burden of dementia in New Zealand, currently and in the future. It identifies constraints to improving dementia services and conducts a cost benefit analysis of delaying institutional care.

Dementia is a neurological disorder where brain function is impaired, affecting language, memory, perception, personality and cognitive skills. The most common cause of dementia is Alzheimer's disease.

Prevalence

In **2008** there are an estimated **40,746** New Zealanders with dementia of whom 1,483 (3.6%) are Maori, 1,227 (3.0%) are Asian; 683 (1.7%) are Pacific and 37,790 (92.7%) are European/other.

- Of the total, 39.8% are male and 60.2% are female.
- There are an estimated 12,333 new cases of dementia in New Zealand this year, in approximately the same ethnic and gender proportions.

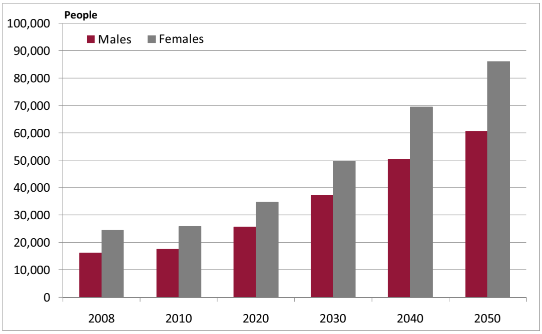
By **2026**, the last year for which ethnic splits are available, the number of New Zealanders with dementia is projected to increase to **74,821** people, of whom 4,338 (5.8%) are Maori, a much higher 6,206 (8.3%) are Asian, 2,153 (2.9%) are Pacific and 63,558 (84.9%) are European/other.

- Of the total, 42.9% will be male and 57.1% will be female and incidence shares will continue to closely mirror prevalence shares, with 22,576 new cases in 2026.

Dementia prevalence increases from **1.0% of the population in 2008 to 1.5% by 2026**, with higher prevalence in females (due primarily to longer life).

- For the European/other group, prevalence increases from 1.2% to 1.9% of the total, while for the minority ethnicities prevalence rates are much lower (around 0.2% currently), due to shorter life expectancy.
- **By 2050, 2.7% of the New Zealand population will have dementia** or **146,699** people, and new cases will comprise 0.8% of the population (44,375 people) each year.

PREVALENCE PROJECTIONS BY GENDER, 2008 TO 2050



Some 55% of cases are estimated to be 'mild' dementia, with a further 30% 'moderate' and 15% classed as 'severe', based on the Clinical Dementia Rating scale.

- ❑ Dementia increases in prevalence from 0.01% of people aged less than 60 years to nearly 34% of New Zealanders aged 90 years and over.

Risk factors for dementia, which have varying degrees of importance depending on the type of dementia, include older age, family history and cardiovascular risk factors such as high blood pressure and smoking. As well as Alzheimer's disease, other common forms of dementia are vascular dementia, dementia with Lewy bodies and fronto-temporal dementia. Dementia progresses over time and is characterised by cognitive decline, psychiatric and behavioural symptoms and increasing dysfunction in activities of daily living. Symptoms vary in different people at different times.

Age-standardised mortality for people with dementia is twice the rate of people without dementia – today around 32 per 100,000 people die each year as a result of dementia in New Zealand.

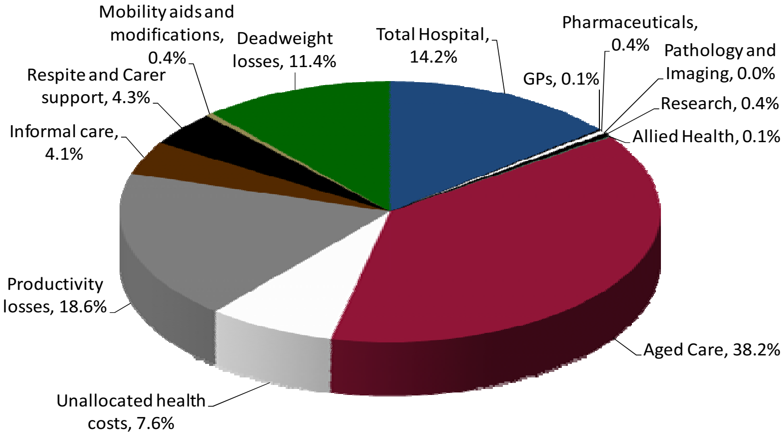
- ❑ **In 2008, this represented 1,378 deaths due to dementia**. As well as the mortality burden, dementia causes substantial reductions in quality of life, for the person with dementia and also potentially for their family carer.
- ❑ The symptoms and behaviours of dementia, as well as the decreased functionality, can be physically and emotionally difficult to manage, and care needs change as the disease progresses.

Financial costs

The total financial cost of dementia in 2008 was estimated as $712.9 million.

- ❑ Of the total, $435.7 million (61.1%) was for health system expenditures and $277.2 million (38.9%) was for other financial costs.

DISTRIBUTION OF FINANCIAL COSTS OF DEMENTIA, 2008



Total health system expenditure ($435.7 million), which is paid for by government, individuals and others, is dominated by the cost of residential aged care at $272.5 million in 2008 (62.5% of health expenditure. Hospital costs were also substantial, totalling $100.9 million (23.2%), comprising $92 million of inpatient costs and around $8.8 million in private inpatient and outpatient costs. Pharmaceuticals and health research were each around $2.9 million. Overhead costs of administering health systems, capital expenditures, public health programs were an estimated $54.5 million, with GPs, allied health, pathology and imaging each under $1 million per annum. These costs only include the additional expenditure on people with dementia over and above that of people of the same age and gender.

- Health cost data were collected from a variety of sources, including special data requests from the New Zealand Health Information Service, the Public Health Intelligence (PHI) unit of the Ministry of Health, residential care data also from that Ministry, and the Health Research Council of New Zealand.

Productivity losses due to dementia comprise the lower employment participation of people with dementia ($124.7 million), higher rates of absenteeism ($2.3 million) and the loss of human capital as a result of premature mortality ($5.5 million). In addition, carers also participate less in the workforce, and the opportunity cost of their informal care is thus valued at $29.3 million. Other real costs are the cost of respite and support services ($30.9 million), the cost of mobility aids and home modifications ($3.1 million) and the deadweight efficiency losses from welfare transfers, government expenditures and taxation revenues forgone ($81.3 million).

- Data for these other financial costs were sourced from Statistics New Zealand (for employment and earnings data), domestic and international literature (for example for average carer hours by severity of dementia, average taxation rates and efficiency losses), the Ministry of Social Development (for Invalids Benefit and Superannuation pensions), and the Ministry of Health (for transport assistance, respite and carer support as well as the Ministry's Disability Services Directorate for funded services for equipment and home modifications).

Of the financial costs, Governments bore 62.6%, individuals bore 30.6%, and others in society bore 6.8%.

Burden of disease

In addition to the financial cost of dementia, there is also the cost of the loss of wellbeing and quality of life. This is measured using Disability Adjusted Life Years (DALYs), an international system for measuring the mortality and morbidity impact of disease and injury.

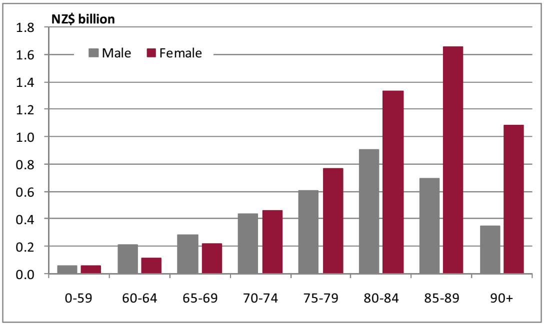
- The burden of disease is calculated from the prevalence of the condition by age and gender, and from global disability weights – 0.27 for mild dementia, 0.63 for moderate dementia, 0.94 for severe dementia, and 1.00 for death.

In 2008, **27,449 years of healthy life were lost due to dementia across New Zealand**. The majority of the burden was due to morbidity (lost wellbeing and quality of life), with 19,464 DALYs making up 71% of total DALYs. The remaining 29% of the burden was due to the estimated 7,985 DALYs caused by premature death from dementia.

- The burden of disease from dementia is **disproportionately carried by women**. While the burden for males was 10,546 DALYs (38% of total), the female burden was 16,903 DALYs (62% of total).

The burden of disease from dementia is converted into a dollar value, by multiplying the total DALYs from dementia by the Value of a Statistical Life Year, which was estimated from meta-analysis of the literature as $335,939 in 2008.

VALUE OF GROSS BURDEN OF DISEASE FROM DEMENTIA, 2008



Source: Access Economics.

The **net value of the burden of disease was estimated as $9.04 billion in 2008**, more than 12 times the financial costs.

Challenges

Preventing and treating dementia presents challenges that require a solution-focused approach.

Medical and hospital services: Prevention to the extent possible (eg, addressing cardiovascular risk factors), **early diagnosis and early intervention** require GP-based strategies (eg, training in differential diagnosis, provision of screening tools for the primary care setting and so on).

- ☐ In addition, new imaging tools (such as PiB PET) and multidisciplinary community memory clinics that incorporate specialist neurologist and psycho-geriatrician skills are useful for coordinating dementia assessments and supporting the person with dementia, their carer and GP.
- ☐ Acute care providers need training, resources (including geriatricians) and strategies to manage people with dementia (secure environments, appropriate assessment tools, care and discharge planning).

Pharmaceuticals: Early access to medications at an affordable price is a major constraint in New Zealand for people with dementia and their families and carers, yet there are approved drugs as yet unlisted by Pharmac which are effective in slowing progression in early stages, enabling people with dementia to stay productive longer, plan their affairs and have higher quality of life.

- ☐ Cholinesterase inhibitors and memantine are publicly funded in other OECD countries, but price prohibits their access in New Zealand.
- ☐ Pharmac's position on access to these effective medications for dementia should be reviewed.

Research: Dementia research expenditure in New Zealand is generously estimated at around $2.9 million. This equates to around $70 per person with dementia per annum, or $1 on research for each $243 of the financial costs of dementia (0.41%). On a per capita basis, this R&D spend on dementia is lower than in Australia and other OECD nations.

- Adopting the US level as a benchmark ($400 per person), expenditure on dementia research should be increased to around $16.3 million annually.
- As middle ground, aiming to make research 1% of the total costs of dementia each year, would suggest spending of $7.1 million per annum.
- Research that prevents onset of dementia would substantially reduce the cost of care, and there is a particular need for research into care services tailored to the New Zealand environment, and epidemiological research for Maori and Pacific people.

Community care: The home and community care services sector is not particularly well developed in New Zealand, with few comprehensive services provided under government programs. Financial barriers thus preclude access for many people. Successful overseas models of service provision could be adapted to the New Zealand setting.

- Respite care services must be appropriate (eg, for younger people, or people with challenging dementia behaviours), regular, flexible and responsive to key changes in the situation of the person with dementia and their carer.
- Family and carer support and education is imperative to prevent burnout and physical injuries, and are cost effective by preventing premature institutionalisation. Alzheimers New Zealand support groups, counselling and training programs could be extended, and a national phoneline help service could also be effective in providing support and information to families and carers. Person-centred principles and key techniques such as dementia care mapping are important for all carers (informal as well as formal community and residential carers).
- To increase employment participation and retention of families and carers, initiatives should include flexible work practices such as part-time home-based work, work-based adult day programs, workplace dementia awareness and destigmatisation.

Residential care: Residential care challenges are:

- increased ongoing training for all care staff in dementia-specific and quality person-centred care principles;
- review of funding and remuneration for nursing and personal care staff;
- planning ratios that make provision for dementia care and challenging behaviours;
- assessment that includes the need for behaviour management and environment, not just the need for nursing care;
- reviewing overall numbers of places and sustainable funding mechanisms in future;
- greater access to care for people with severely aggressive behaviours; and
- newer models of care, such as cluster housing, reflected in facility and care design.

Cross-cutting issues: Issues that cut across all aspects of dementia care, reflecting the different needs of different groups of people, and that require intervention include:

- appropriate savings or insurance schemes to provide for future health, ageing and dementia needs, including consideration of health savings accounts;
- improved access to community, residential and medical services for people with younger onset dementia, including separate strategic planning to meet their specific needs outside the aged care sector;
- improved access for people with dementia and their families and carers who are from different cultural backgrounds (particularly Maori and Pacific peoples), including improved assessment tools;

- greater public efforts to destigmatise dementia; and
- smarter use of new information technologies in delivering services, particularly to people in more remote areas.

Costs and benefits of delaying institutionalisation

A simple cost benefit analysis was undertaken of a delay in the entry of people with dementia into residential aged care by three months. Based on residential care data, the estimated number of days of care that would switch from residential care to home based care under this scenario is 1,126,191. In 2008, this represents a 23% reduction in the number of days of residential care provided to people with dementia and a **saving of $62.3 million**.

If people are not cared for in residential facilities, they consume more resources in the community sector, including informal care services and community services, as estimated in this report. The opportunity cost of informal care associated with delaying institutionalisation by three months is thus $12.1 million (which allows for a higher complexity of care than the average currently in the community). In addition, there would be higher costs associated with aids and home modifications, respite and support services, as well as transfer payments for welfare support and for other services such as transport and travel. These other community costs amount to $18.4 million per annum in 2008, so the **total costs are $30.5 million**.

Overall the **net benefit from institutional delay is thus estimated as $31.8 million** in 2008.

- This equates to a **benefit:cost ratio of 2.04**, which means that each marginal dollar currently invested in community care services to delay institutionalisation returns around $2.04 in reduced residential care costs.

Conclusions and recommendations

A national New Zealand Dementia Care strategy is required, going forward. Five key elements of the future strategy are:

- investment in research for cause, prevention and care in the New Zealand setting;
- early intervention through improvement in diagnosis, and access to cost effective pharmacotherapies through Pharmac;
- comprehensive provision of support, education and respite services – in place in the community as far as is optimal and that considers differences in severity;
- quality residential care, appropriately financed, that is centred on the person with dementia and their family/carer; and
- provision for special needs, including people with younger onset dementia, people with challenging behaviours, people from culturally diverse backgrounds including Maori and Pacific peoples, and people living in more remote areas of New Zealand.

Access Economics
7 July 2008

1. PREVALENCE AND INCIDENCE ESTIMATES AND PROJECTIONS

1.1 EPIDEMIOLOGY OF DEMENTIA

1.1.1 CLINICAL SYMPTOMS AND DISEASES UNDERLYING DEMENTIA

Dementia is a neurological disorder where brain function is impaired, affecting language, memory, perception, personality and cognitive skills. Dementia is characterised by different symptoms in different people at different times, including (Burns, 2001):

1. **cognitive impairment**: problems with memory, speech/language, inability to recognise objects or people, confusion;
2. **psychiatric and behavioural features**: such as depression, delusions/hallucinations, incessant walking/wandering, agitation, repetition, following, crying, and so on; and
3. **dysfunction in activities of daily living (ADL)**: difficulties with household chores and personal functions such as dressing, eating and bathing.

Dementia is not a single specific disease but is associated with over 100 illnesses and conditions. Some of the most common are described below.

Alzheimer's disease is the most common cause of dementia (50-70% of people with dementia have Alzheimer's). The disease is characterised by abnormal brain tissue – 'plaques and tangles' – first identified in 1906 by Alois Alzheimer. Onset of Alzheimer's disease is insidious and lasts for 3-20 years from diagnosis, depending on age at onset.

Vascular dementia is the second most common form (20-30% of cases, sometimes co-occurring with Alzheimer's). It is due to cerebrovascular disease, where narrow arteries cause lack of blood and damage to the brain, either through reduced oxygen supply, strokes or mini-strokes, demyelination or mixed effects. Onset and life expectancy is similar to that of Alzheimer's disease, although the disease course can be highly variable.

Lewy body dementia comprises about 10% of dementia cases and is distinguished by abnormal brain cells ('Lewy' bodies) which can be seen under a microscope. Progress is more rapid than for Alzheimer's, often with parkinsonian and other distinctive symptoms.

Fronto-temporal dementia has rounded proteins ('Pick' bodies, after Arnold Pick) found initially in the front part of the brain, as well as tangles. Family history is an important risk factor for 'Pick's disease' and onset tends to be earlier (as young as 30-40 years), with personality and behavioural symptoms typical.

Where data sets analysed in this report used the International Classification of Disease Tenth Revision (ICD-10) as the basis for coding of diseases, a diagnosis of dementia or Alzheimer's disease was defined as including any of the codes from Table 1-1. This list is based on the list used by Begg et al (2007) in *The Burden of Disease and Injury in Australia 2003* report (Annex Table 1, p204).

TABLE 1-1: ICD-10 CODES FOR DEMENTIA

Code	Description
F00	Dementia in Alzheimer's disease
F01	Vascular dementia
F02.0	Dementia in Pick's disease
F02.1	Dementia in Creutzfeldt-Jakob disease
F02.3	Dementia in Parkinson's disease
F03	Unspecified dementia
G30	Alzheimer's disease
G31.0	Circumscribed brain atrophy
G31.1	Senile degeneration of brain, not elsewhere classified
G31.8	Other specified degenerative diseases of nervous system
G31.9	Degenerative disease of nervous system, unspecified

Source: New Zealand Health and Information Service (NZHIS).

1.1.2 RISK FACTORS AND PROGRESSION

Dementia is not a natural part of ageing, although most people with dementia are older. **Younger onset dementia** refers to onset of dementia in people aged under 65. Younger people with dementia are more likely to be working; have children at home; have heavier financial commitments; have a heritable form of dementia; have high levels of psychological and behavioural symptoms; have difficulty receiving care; have family care givers with higher levels of distress; and have higher associated costs and burden overall.

While the causes (aetiology) of dementia are not always completely understood, certain risk factors are known. This section is drawn from Access Economics (2006).

Age is the most well-accepted risk factor, with the likelihood of dementia increasing from around 1 in 1,000 for people under 65, to 1% for people in their sixties, to nearly 25% for people 85 years and over.

Family history: Genetic factors contribute to dementia risk. Younger onset familial Alzheimer's disease is a relatively rare autosomal dominant condition ie, inherited by 50% of each generation. Abnormal genes have been identified on chromosomes 14, 21 and 1. Other genes have also been associated with a greater risk of Alzheimer's disease but do not necessarily cause the disease. The most important of these genes is Apolipoprotein E (ApoE). The ApoE e4 variant increases the risk of developing Alzheimer's disease but does not cause it. There are strong familial indicators for fronto-temporal dementia: in some cases there is a mutation of a gene on chromosome 17 that makes tau, inhibiting the protein's function and causing it to form tangles. Further research is required to understand the interaction of genes and environment in the causes of the dementias. There is growing concern that genetic testing may lead to misunderstanding, such as insurance companies or employers misusing positive test results.

Gender: Over the age of 80, women are at slightly higher risk of Alzheimer's disease, while men may be at higher risk of vascular dementia. The Boston University School of Medicine Multi-Institutional Research in Alzheimer's Genetic Epidemiology study showed that by age 93, female risk is 13% higher than male risk.

Cardiovascular risk factors, stroke-related and atherogenic causes contribute to vascular dementia and there is increasing evidence that they also contribute to Alzheimer's disease. These include high blood pressure (severe systolic hypertension), narrowing of the arteries (atherosclerosis), irregular heartbeat (atrial fibrillation), ischaemic (coronary) heart disease and attacks (myocardial infarction), diabetes, smoking, high saturated fat and low-density lipoprotein cholesterol intake. Coronary artery bypass graft surgery may contribute to vascular dementia.

Education and employment: One hypothesis is that higher levels of education or a lifetime of mental activity may increase the brain reserve (Stern et al, 1994). Other studies suggest that specific occupational exposures may increase Alzheimer's Disease risk, such as manual work (Fratiglioni et al, 1993) and exposure to organic solvents (Kukull et al, 1995) or electromagnetic fields (Sobel et al, 1995 and 1996), for example in occupations such as carpenter, electrician, machinist, sheet metal worker, typist or welder. If further research strengthens this evidence, and the link is not just socio-economic, there would be further rationale for preventive workplace measures.

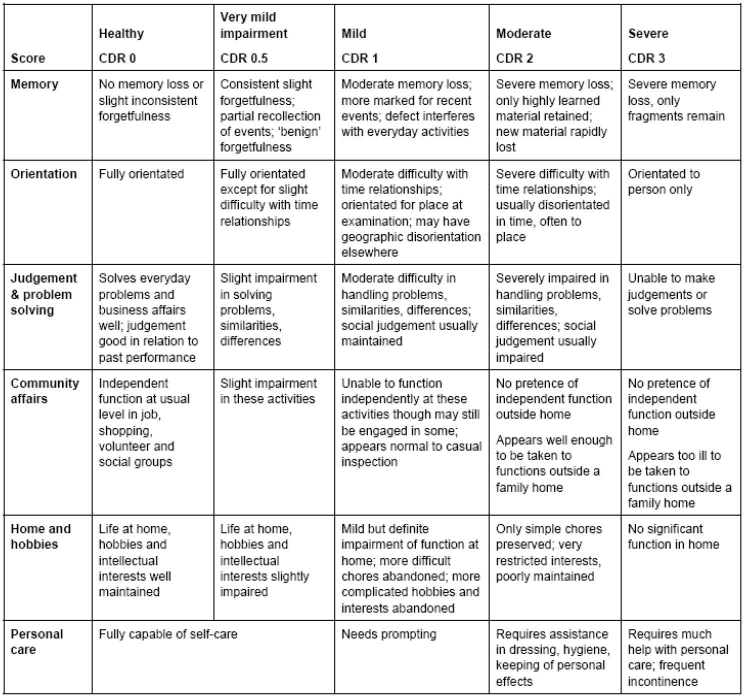
Other possible risk factors include depression, diabetes, high levels of homocysteine (an amino acid) in blood, previous thyroid diseases, head trauma (eg, from motor vehicle accidents or boxing) and excessive alcohol intake. There has been some evidence of lower prevalence rates for Alzheimer's disease in some developing countries and in rural areas, although the evidence regarding ethnic and cultural influences is unclear.

Possible protective factors that may reduce the risk of developing Alzheimer's disease include:

- **Use of pharmacotherapies**: Epidemiological, though not treatment study, research has demonstrated that the use of *anti-inflammatory drugs* (eg, in treating arthritis) – including *non-steroidal anti-inflammatory drugs* (NSAIDs) – and *statins*, the most widely used cholesterol-lowering drugs, may reduce Alzheimer's disease risk or delay its onset. *Oestrogen* was thought to have a protective effect until the Women's Health Initiative Memory Study, a large US trial, demonstrated an increased risk of Alzheimer's disease in women aged 65 or more taking hormone replacement therapy compared to those on placebo.
- **Diet**: High intakes of antioxidants from food – vitamin E and vitamin C for example — may guard against Alzheimer's disease. Other studies have identified fish, wine and Ginkgo biloba consumption as having a potentially protective effect. Theoretically, consumption of more folic acid and vitamins B6 and B12, which can reduce homocysteine levels, may also guard against Alzheimer's disease.

The **progression** of dementia over many years is often categorised as mild (early stage), moderate (middle stage) and severe or advanced (late stage), before the person dies. The clinical dementia rating (CDR) scale is typically used to ascertain progression of dementia. Scores under the scale are shown in Table 1-2.

TABLE 1-2: CLINICAL DEMENTIA RATING SCALE



	Healthy	Very mild impairment	Mild	Moderate	Severe
Score	CDR 0	CDR 0.5	CDR 1	CDR 2	CDR 3
Memory	No memory loss or slight inconsistent forgetfulness	Consistent slight forgetfulness; partial recollection of events; 'benign' forgetfulness	Moderate memory loss; more marked for recent events; defect interferes with everyday activities	Severe memory loss; only highly learned material retained; new material rapidly lost	Severe memory loss, only fragments remain
Orientation	Fully orientated	Fully orientated except for slight difficulty with time relationships	Moderate difficulty with time relationships; orientated for place at examination; may have geographic disorientation elsewhere	Severe difficulty with time relationships; usually disorientated in time, often to place	Orientated to person only
Judgement & problem solving	Solves everyday problems and business affairs well; judgement good in relation to past performance	Slight impairment in solving problems, similarities, differences	Moderate difficulty in handling problems, similarities, differences; social judgement usually maintained	Severely impaired in handling problems, similarities, differences; social judgement usually impaired	Unable to make judgements or solve problems
Community affairs	Independent function at usual level in job, shopping, volunteer and social groups	Slight impairment in these activities	Unable to function independently at these activities though may still be engaged in some; appears normal to casual inspection	No pretence of independent function outside home Appears well enough to be taken to functions outside a family home	No pretence of independent function outside home Appears too ill to be taken to functions outside a family home
Home and hobbies	Life at home, hobbies and intellectual interests well maintained	Life at home, hobbies and intellectual interests slightly impaired	Mild but definite impairment of function at home; more difficult chores abandoned; more complicated hobbies and interests abandoned	Only simple chores preserved; very restricted interests, poorly maintained	No significant function in home
Personal care	Fully capable of self-care		Needs prompting	Requires assistance in dressing, hygiene, keeping of personal effects	Requires much help with personal care; frequent incontinence

Note: Score only as decline from previous usual level due to cognitive loss, not impairment due to other factors.
Source: Reproduced from Morris (1993).

1.1.3 MORTALITY

The dementia specific mortality rate of people with dementia is twice the rate of people without dementia, controlling for co-morbidities and socio-demographic factors. Of people over 75 years with dementia, 70% die within five years (Wimo et al, 1998:24). On average, people with dementia have a life expectancy of 7-10 years after diagnosis (Warner and Butler, 2000).

Death certificates grossly under-report dementia as the cause of death, often citing instead respiratory infection.

Cause of death data for New Zealand are available for 2004 (most recent year) from New Zealand Health Information Service (NZHIS)[1]. Table 1-3 reports the number of deaths with an underlying cause of dementia in 2004.

---

[1] http://nzhis.govt.nz/moh.nsf/pagesns/32?Open#09

There were a total of 1,198 deaths in 2004 where dementia was the underlying cause (396 males, 802 females), with 59% of these deaths occurring for people aged 85 years and over (99% of dementia deaths were in people aged 65 and older, 93% were in people aged 75 and older).[2]

TABLE 1-3: DEATHS WITH AN UNDERLYING CAUSE OF DEMENTIA, 2004

Age	Males	Females	People
0-59	3	3	6
60-64	2	2	4
65-69	13	7	20
70-74	27	28	55
75-79	57	61	118
80-84	117	172	289
85+	177	529	706
Total	**396**	**802**	**1,198**

Source: NZHIS (2007), *Mortality and Demographic Data 2004: statistical tables*.

Table 1-4 shows the death rates from dementia used in this report, calculated using cause of death, and population data for 2004.

TABLE 1-4: DEATH RATES PER 100,000, NEW ZEALAND, UNDERLYING CAUSE OF DEMENTIA, 2004

Age	Males	Females	People
0-59	0	0	0
60-64	2	2	2
65-69	19	10	14
70-74	47	44	46
75-79	125	110	117
80-84	426	400	410
85+	1,098	1,431	1,330
Total	20	38	29

Source: NZHIS (2007), *Mortality and Demographic Data 2004: statistical tables*, and Statistics New Zealand 2004 population data, Series 5.

Mortality rate data for the general population were available for 2007 (most recent year) from Statistics New Zealand. Underlying population mortality rates used in the modelling for this report were based on these data.

New Zealand death rates from dementia are relatively higher than those in Australia as reported by the Australian Institute of Health and Welfare (AIHW, 2007), shown in Table 1-5. The reason for this is not entirely clear, although it may be that the methods for cause of death reporting differ such that dementia is more commonly reported in New Zealand.

---

[2] Counts all deaths for the ICD-10 codes: F01, F03, G30 and G31. Dementia ICD-10 codes in totality comprise F00-01, 020-1, 023, 03; G30, 310-1, 318-9.

TABLE 1-5: DEATH RATES PER 100,000, AUSTRALIA, UNDERLYING CAUSE OF DEMENTIA, 2003

Age	Males	Females	People
0-59	0.2	0.3	0.3
60-64	6.6	5.1	5.9
65-69	9.3	10.9	10.1
70-74	29.1	26.1	27.5
75-79	93.9	77.4	84.8
80-84	228.4	250.8	241.9
85+	770.2	1,035.7	952.3
Crude rate	**14.4**	**29.9**	**22.2**
Age standardised rate	**18.7**	**22.2**	**21.1**

Age standardised using June 2001 Australian population.
Source: AIHW (2007).

1.1.4 MORBIDITY AND SOCIAL IMPACTS

Morbid effects of dementia can include, depending on type: gradual memory loss; decline in ability to perform routine tasks; disorientation to time and place; impaired judgement, abstract thinking and physical coordination; difficulty in learning and concentration; loss of language and communication skills; changes in personality, behaviour and mood; loss of initiative; altered sleep patterns, eating disturbances and screaming.

Cummings (2001) lists the prevalence of neuropsychiatric symptoms that commonly accompany Alzheimer's disease as agitation (60% to 70% of people), apathy (60% to 70%), depression (50%), anxiety (50%), irritability (50%), delusional disorders and psychosis (40% to 50%), disinhibition (30%) and hallucinations (10%).

The symptoms and behaviours of dementia, as well as the decreased functionality in ADL, can be physically and emotionally difficult for families and caregivers to manage, creating additional loss of wellbeing. Caring for a person with dementia, particularly informal caregivers over longer periods – can have impacts in terms of caregiver depression, anxiety, stress, physical health impacts and sleep disruption – more so than for other conditions. Caregiver burden is caused by primary stressors (care recipient characteristics eg, particular behaviours) and secondary stressors (eg, family and work issues). Access to flexible support, information and respite services remain key needs for informal carers, together with workplace and community understanding. All caregivers need to be valued, and evidence suggests that comprehensive, multidimensional dementia-specific training is of benefit.

As people with dementia move through the different stages, their requirements for care change. While informal care (though family and friends) dominates during early stages of the disease, the informal caregiver may require assistance from formal care services (respite care or adult day-care) when the disease worsens. If no informal care is available, community care may need to be provided from an early stage onwards. While formal non-institutional care is usually sufficient at the beginning, people may require institutional care at a later stage of dementia (Moise et al, 2004).

1.1.5 PREVENTION AND TREATMENT STRATEGIES

Although there is no cure, there are ways to reduce risk factors, treat and manage the behavioural and psychological signs and symptoms of dementia, and improve quality of life for the person and their family carer.

- **Prevention** includes elimination or postponement of onset till later in life by addressing contributing medical or psychological factors, such as head trauma or cardiovascular disease and its risk factors (smoking, diet, physical activity, overweight and obesity, hypertension, high cholesterol). Recent developments in neuroscience, genetic and medical technology suggest that prevention in terms of slowing the progression of dementia is possible, although there is a need for further research and, in particular, large randomised prevention trials. If any of these or other future prevention strategies could delay the onset of dementia even modestly, the total years of disabled life may be significantly reduced, with associated substantial public health resource allocation implications (Access Economics, 2004).
- **Early diagnosis/intervention:** Improved diagnosis is now possible through new neuroimaging technologies[3]. Early diagnosis means the person and the family benefit from drug treatments, support and planning strategies. This helps those involved have more control over the disease and their lives and can slow progression due to early access to pharmacotherapies. Financial and legal plans can be made, with the full agreement of the person with dementia. The individual and family can adjust better to the diagnosis, understand the illness and learn how to cope better through adequate counselling and education, remaining productive longer and improving quality of life.
- **Psychosocial approaches** including support, counselling, education and memory loss programs through all stages of dementia progression can be very helpful for the individual and the family. Psycho-education can help the person and their family learn to manage certain symptoms – such as cognitive behaviour therapy – and can help prevent secondary morbidity such as depression or anxiety in the person with dementia and/or their family members. Organisations such as Alzheimers New Zealand are important networks for the provision of such support and information services.
- **Medications** (pharmaceutical and natural) are used to treat cognitive decline and memory loss. The cholinesterase inhibitors work best in the mild to moderate stages of Alzheimer's disease and there is growing evidence they may be effective in other forms of dementia. They improve clarity of thought, ADL functionality, mood and behaviour. They may have (mild) side effects, however, and they cannot so far reverse progression. Other drugs are used to prevent and slow dementia – eg, aspirin and blood-thinning agents to reduce risk of (further) stroke, memantine, secretases, anti-oxidants (prescription and over-the-counter, such as gingko biloba and fish oils).
- **Medical and surgical interventions** – people with dementia may receive care from their primary care provider (general practitioner or GP) as well as from specialist neurologists, psycho-geriatricians, psychiatrists, physicians in geriatric medicine and other consultant physicians. The GP plays a key, long term role from diagnosis to death, while specialists are important for periodic neuropsychological assessments and pharmaceutical management. Two controversial potential surgeries are in the experimental stage, a shunt for cerebrospinal fluid and more radical omentum transplantation.
- **Allied health, community and residential care services** encompass a broad range of services for people with dementia and their family carers. In allied health, there are physical (eg, swimming, hydrotherapy, massage), occupational and speech-language therapies that can assist with specific problems (such as appropriate home modifications), as well as diversional, reminiscence, validation, music, movement/dance and craft therapies. Community care services include a range of nursing, personal care

---

[3] For example, the Australian Imaging, Biomarkers and Lifestyle (AIBL) Flagship Study of Ageing has demonstrated that a neuro-imaging scan called PiB PET can be used to identify people who will develop Alzheimer's disease up to 18 months earlier than currently available diagnostics.

and domestic home help services (eg, meals, shopping, cleaning and home maintenance), as well as respite care. Residential care ideally provides a full spectrum of such services including dementia specific services.

- ❑ **Promoting an understanding of what is quality dementia care**; features of quality person-centred care (Rosewarne et al, 1997) include the need to:
  - *redefine problems and understand behaviours* of people with dementia – ie, focus on the person and not just target the behaviours;
  - plan and implement specialised *activity programs* – to stimulate interest and encourage activities designed to address specific psychosocial needs and preferences;
  - *personalise the care* – emphasising intimate knowledge of who the person is – their history, family connections, values and current circumstances;
  - *give carers ownership and care responsibility* – build relationships by subdividing large numbers of care recipients into small working groups, for whom designated carers are responsible;
  - *create domestically scaled social environments* – clustered residential designs, with kitchen-dining focus areas, have been successful in creating a homelike environment and building social interactions in residential care services;
  - *provide flexibility of care routines and practices* – a relaxed organisational environment using strategies that focus on timing, routines and needs, preventing resistive responses;
  - *cultivate professionalism of care and support of caregivers* – create a culture of doing something innovative, progressive and worthwhile, rather than a task-oriented ‘completion of jobs’ approach;
  - *include relatives in the life and care of the resident* – expend effort to maintain continuity in the person’s life through encouraging ongoing contact with family and others who can provide undivided personal attention.

1.2 PREVALENCE AND INCIDENCE ESTIMATES FROM 2008 TO 2050

The first Section 1.2.1 below estimates rates of prevalence and incidence of dementia by age, gender and ethnicity, while the following Section 1.2.2 applies these rates to New Zealand population data to calculate current estimates and future projections of the number of people with dementia.

1.2.1 DEMENTIA PREVALENCE AND INCIDENCE RATES FOR NZ

Prevalence studies give slightly different results depending on the methods used in the study (Alzheimer’s Disease International, 1999), although all studies show a sharp rise in prevalence rates with age. While dementia can occur at any age, it is rare below the age of 60 years. Because of population ageing, in the future there will be relatively more people in the age groups at most risk for dementia. In the absence of effective prevention or treatment, the increase in the numbers of people with dementia will come about as a simple consequence of an increase in the size of the population most at risk ie, of those aged 60 years and over.

No epidemiological studies of dementia incidence or prevalence in the New Zealand population or in specific ethnic groups within the population were identified in researching this report. It would be worthwhile collecting such information, particularly in ethnic groups such as Maori and Pacific Island people, since it is possible that dementia prevalence rates differ by ethnicity. While there is anecdotal evidence that incidence of dementia may be higher in these (non-white) groups in New Zealand, due to a higher prevalence of cardiovascular risk factors for example, no data were available to enable modelling of the extent of this difference.

As such, and because these ethnic groups are relatively small as a proportion of the total New Zealand elderly population, these estimates are conservatively based on the best available rates from a meta-analysis of international studies (Wancata et al, 2003). Studies included in Wancata et al's meta-analysis were Jorm et al (1987), Hofman et al (1991), Ritchie and Kildea (1995) and Lobo et al (2000), with the average rates derived shown in Table 1-6. These rates triangulate well with (ie, fall within the ranges estimated by) Ferri et al (2005) for the Western Pacific and Southeast Asian regions.

TABLE 1-6: DEMENTIA PREVALENCE AND INCIDENCE RATES, BY AGE AND GENDER, %

	Prevalence		Incidence	
Age	**Male**	**Female**	**Male**	**Female**
0-59	0.01	0.01	0.01	0.01
60-64	1.2	0.6	0.1	0.1
65-69	1.7	1.3	0.4	0.4
70-74	3.5	3.3	0.9	0.9
75-79	5.8	6.3	2.0	2.1
80-84	11.8	12.6	3.8	3.9
85-89	18.6	21.5	6.2	6.6
90+	32.6	35.0	9.4	10.1

Source: Access Economics (2006) based on Wancata et al (2003).

Prevalence by stage of dementia

The distinction between stages is not precise and people move through stages at different rates. Because there are no New Zealand epidemiological data on dementia prevalence by stage, the proportions of people at each severity stage are based on Australian splits (AIHW, 2007:60-61) of:

- 55% mild (CDR 0.5-1) – significant impact on daily activities but still able to undertake daily activities;
- 30% moderate (CDR 2) – independent living is not possible without assistance; and
- 15% severe (CDR 3) – permanent supervision required.

1.2.2 POPULATION DATA AND PREVALENCE PROJECTIONS

The prevalence and incidence projections presented in this report are based solely on demographic ageing trends ie, on 'status quo' assumptions in relation to other factors that may influence the incidence and prevalence rates of dementia over the forecast horizon.

Population projections for the New Zealand population, as well as for the four ethnic groups (European, Maori, Asian and Pacific) were sourced from Statistics New Zealand. Projections for the total population were available by age and gender out to 2061. Population projections for ethnic sub-groups were available out to 2026. As ethnicity is not a mutually exclusive concept, the sum of the four ethnic sub-populations is greater than the whole New Zealand population. For the reasons noted in the previous section, the incidence and prevalence rates from Table 1-6 were used for all ethnic groups.

In 2008, there are an estimated 40,746 New Zealanders with dementia of whom 1,483 (3.6%) are Maori, 1,227 (3.0%) are Asian; 683 (1.7%) are Pacific and 37,790 (92.7%) are European/other. Of the total, 39.8% are male and 60.2% are female (Table 1-7). There are an estimated 12,333 new cases of dementia in New Zealand this year, in approximately the same ethnic and gender proportions.

TABLE 1-7: PREVALENCE AND INCIDENCE, BY ETHNICITY AND GENDER, 2008-2026 (PEOPLE)

Number of people	2008	2014	2020	2026
Prevalence				
Pacific Total	**683**	**1,045**	**1,476**	**2,153**
Male	282	452	652	931
Female	402	593	824	1,223
Asian Total	**1,227**	**2,290**	**3,880**	**6,206**
Male	569	1,067	1,808	2,817
Female	658	1,223	2,072	3,388
Maori Total	**1,483**	**2,095**	**3,049**	**4,338**
Male	658	907	1,322	1,867
Female	825	1,188	1,727	2,472
European/Other Total	**37,790**	**44,687**	**52,897**	**63,558**
Male	14,891	18,382	22,368	27,133
Female	22,899	26,305	30,529	36,425
All Groups Total	**40,746**	**49,315**	**60,333**	**74,821**
Male	16,208	20,435	25,671	32,074
Female	24,538	28,880	34,662	42,747
Incidence				
Pacific Total	**215**	**325**	**454**	**658**
Male	85	135	194	278
Female	130	189	260	381
Asian Total	**378**	**697**	**1,172**	**1,867**
Male	168	315	532	830
Female	210	382	639	1,037
Maori Total	**462**	**644**	**925**	**1,313**
Male	195	267	386	549
Female	266	377	538	764
European/Other Total	**11,429**	**13,447**	**15,880**	**19,190**
Male	4,436	5,458	6,635	8,134
Female	6,993	7,989	9,245	11,056
All Groups Total	**12,333**	**14,853**	**18,122**	**22,576**
Male	4,821	6,059	7,601	9,584
Female	7,512	8,794	10,520	12,992

Source: Access Economics based on New Zealand population data and Table 1-6.

Table 1-7 also shows that, by 2026, the last year for which ethnic splits are available, the number of New Zealanders with dementia is projected to increase to 74,821 people, of whom 4,338 (5.8%) are Maori, a much higher 6,206 (8.3%) are Asian, 2,153 (2.9%) are Pacific and 63,558 (84.9%) are European/other. Of the total, 42.9% are male and 57.1% are female. Again, incidence shares closely mirror prevalence shares.

Dementia prevalence increases from 1.0% of the population in 2008 to 1.5% by 2026, with higher prevalence in females (due primarily to longer life). For the European/other group, prevalence increases from 1.2% to 1.9% of the total, while for the minority ethnicities prevalence rates are much lower (around 0.2% currently), due to shorter life expectancy (Table 1-8). Table 1-9 shows that by 2050, 2.7% of the New Zealand population will have dementia, and new cases will comprise 0.8% of the population.

TABLE 1-8: PREVALENCE AND INCIDENCE, BY ETHNICITY AND GENDER, 2008-2026 (% TOTAL)

% Group Total	2008	2014	2020	2026
Prevalence				
Pacific Total	**0.2%**	**0.3%**	**0.3%**	**0.4%**
Male	0.2%	0.3%	0.4%	0.5%
Female	0.3%	0.3%	0.4%	0.5%
Asian Total	**0.3%**	**0.4%**	**0.6%**	**0.8%**
Male	0.3%	0.5%	0.8%	1.2%
Female	0.3%	0.4%	0.6%	0.8%
Maori Total	**0.2%**	**0.3%**	**0.4%**	**0.5%**
Male	0.2%	0.3%	0.4%	0.6%
Female	0.3%	0.3%	0.4%	0.6%
European/Other Total	**1.2%**	**1.3%**	**1.6%**	**1.9%**
Male	0.9%	1.2%	1.4%	1.7%
Female	1.4%	1.5%	1.8%	2.1%
All Groups Total	**1.0%**	**1.1%**	**1.3%**	**1.5%**
Male	0.8%	1.0%	1.2%	1.5%
Female	1.1%	1.3%	1.4%	1.7%
Incidence				
Pacific Total	**0.1%**	**0.1%**	**0.1%**	**0.1%**
Male	0.1%	0.1%	0.1%	0.1%
Female	0.1%	0.1%	0.1%	0.2%
Asian Total	**0.1%**	**0.1%**	**0.2%**	**0.2%**
Male	0.1%	0.1%	0.2%	0.2%
Female	0.1%	0.1%	0.2%	0.3%
Maori Total	**0.1%**	**0.1%**	**0.1%**	**0.2%**
Male	0.1%	0.1%	0.1%	0.1%
Female	0.1%	0.1%	0.1%	0.2%
European/Other Total	**0.4%**	**0.4%**	**0.5%**	**0.6%**
Male	0.3%	0.3%	0.4%	0.5%
Female	0.4%	0.5%	0.5%	0.6%
All Groups Total	**0.3%**	**0.3%**	**0.4%**	**0.5%**
Male	0.2%	0.3%	0.3%	0.4%
Female	0.3%	0.4%	0.4%	0.5%

Source: Access Economics based on New Zealand population data and Table 1-7.

Table 1-9: Prevalence and incidence, by gender and age, 2008-2050 (people)

Number of people	2008	2010	2020	2030	2040	2050
Prevalence						
Males						
0-59	174	176	183	186	191	194
60-64	1,248	1,354	1,628	1,697	1,549	1,835
65-69	1,370	1,455	1,947	2,406	2,275	2,353
70-74	2,107	2,286	3,486	4,267	4,501	4,148
75-79	2,790	2,825	3,996	5,510	6,931	6,647
80-84	3,882	4,130	5,275	8,484	10,762	11,588
85-89	2,846	3,255	4,631	7,217	10,621	13,857
90+	1,791	2,051	4,526	7,424	13,577	19,926
Total males	16,208	17,531	25,671	37,189	50,406	60,547
Females						
0-59	177	179	184	184	186	187
60-64	644	703	864	938	855	949
65-69	1,108	1,170	1,591	2,029	1,979	1,954
70-74	2,165	2,356	3,574	4,442	4,861	4,462
75-79	3,547	3,541	4,920	6,823	8,807	8,663
80-84	5,657	5,771	6,980	10,975	13,973	15,498
85-89	6,063	6,515	7,525	11,223	16,297	21,565
90+	5,176	5,631	9,023	13,080	22,628	32,875
Total females	24,538	25,865	34,662	49,693	69,586	86,152
Total pwd	40,746	43,396	60,333	86,882	119,993	146,699
% Total people	1.0%	1.0%	1.3%	1.7%	2.3%	2.7%
Incidence						
Males	174	176	183	186	191	194
0-59	104	113	136	141	129	153
60-64	322	342	458	566	535	554
65-69	542	588	896	1,097	1,157	1,067
70-74	962	974	1,378	1,900	2,390	2,292
75-79	1,250	1,330	1,699	2,732	3,466	3,732
80-84	949	1,085	1,544	2,406	3,540	4,619
85-89	518	593	1,308	2,146	3,925	5,760
90+	4,821	5,201	7,601	11,174	15,333	18,370
Total males	104	113	136	141	129	153
Females						
0-59	177	179	184	184	186	187
60-64	107	117	144	156	143	158
65-69	341	360	490	624	609	601
70-74	590	643	975	1,211	1,326	1,217
75-79	1,182	1,180	1,640	2,274	2,936	2,888
80-84	1,751	1,786	2,161	3,397	4,325	4,797
85-89	1,861	2,000	2,310	3,445	5,003	6,620
90+	1,502	1,633	2,618	3,795	6,564	9,537
Total females	7,512	7,898	10,520	15,087	21,091	26,005
Total pwd	12,333	13,100	18,122	26,261	36,425	44,375
% Total people	0.3%	0.3%	0.4%	0.5%	0.7%	0.8%

Figure 1-1 highlights the greater number of women with dementia in the older cohorts (in the younger cohorts dementia is more prevalent in men).

FIGURE 1-1: PREVALENCE BY AGE AND GENDER, 2008 (NUMBER OF PEOPLE)

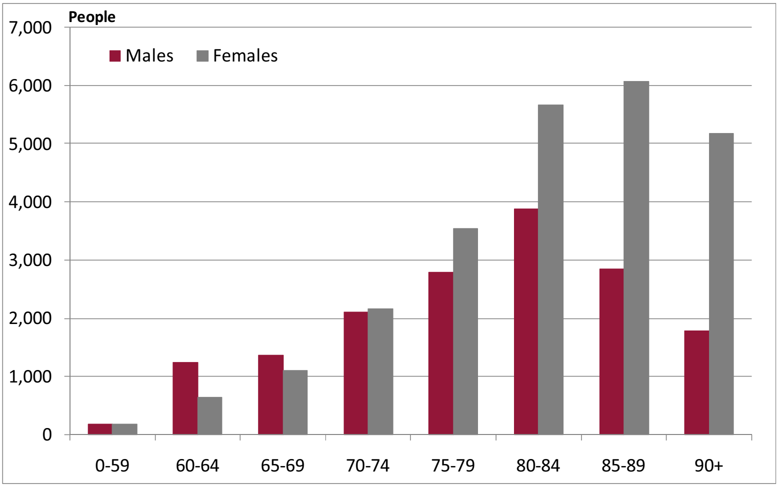


Figure 1-2 highlights the growth rates in dementia for males and females. These rates do not flatten by 2050.

FIGURE 1-2: PREVALENCE PROJECTIONS BY GENDER, 2008 TO 2050

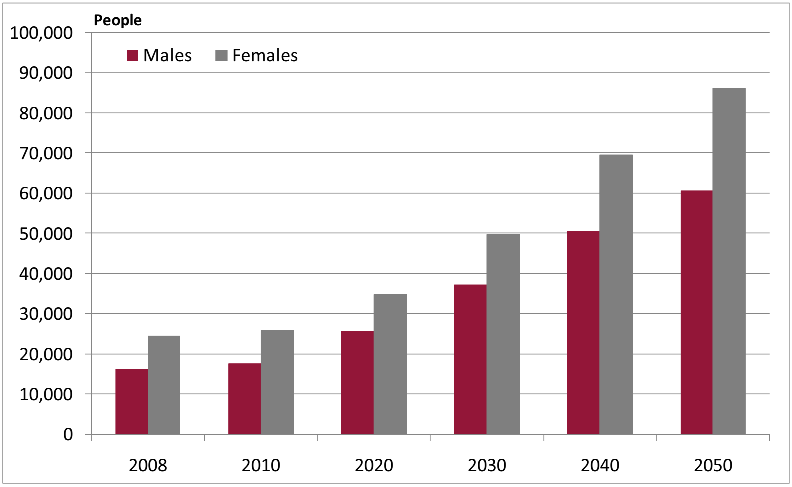
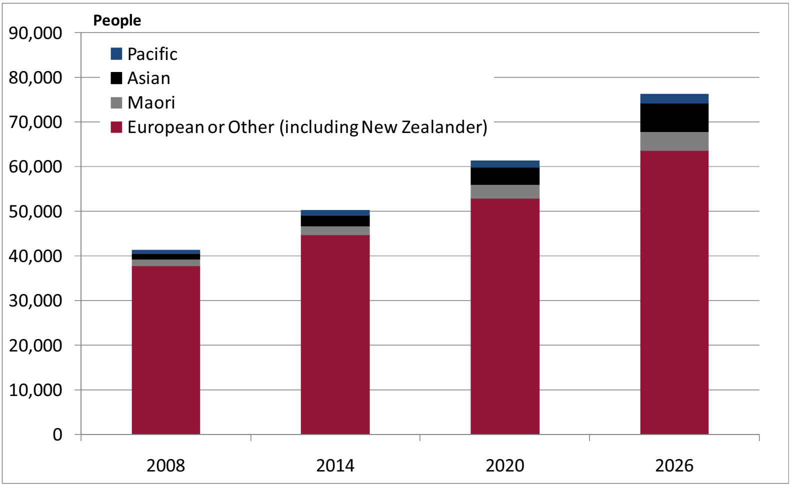


Figure 1-3 underscores the growth in Asian New Zealanders with dementia.

FIGURE 1-3: PREVALENCE PROJECTIONS BY ETHNICITY, 2008 TO 2026



2. HEALTH SYSTEM COSTS

There are two main methods for estimating direct health system costs.

- ‘Top-down’ disease cost data can be derived from central data collection agencies, where these agencies exist.
- ‘Bottom-up’ cost estimates use surveys, diaries and other cross-sectional or data-gathering tools to accumulate information from either a single study or multiple sources.

The advantage of the top-down methodology is that cost estimates for various diseases will be consistent, enhancing comparisons and ensuring that the sum of the parts (health system costs of each disease) does not exceed the whole (total expenditures on health care in New Zealand). The advantage of the bottom-up methodology is that it can provide greater detail in relation to specific cost elements and the same study can be extended to capture information about indirect cost elements as well as direct cost elements.

2.1 DATA SOURCES

In this study, Access Economics has been limited by the lack of comprehensive data of either type in New Zealand.

- In New Zealand there is not the extensive collection of top-down disease cost data that is compiled, for example, in Australia by the AIHW from services utilisation and public and private expenditure such as hospital morbidity data, case mix data, Bettering the Evaluation and Care of Health data, the Australian National Health Survey and other sources (AIHW, 2005).
- It was not possible to source an existing comprehensive bottom-up study of cost elements of dementia in New Zealand, although a variety of different sources exist in relation to certain elements.

Access Economics has therefore utilised a process of data gathering for specific cost items. In the following sections, the sources and methodology in relation to measurement of each cost element are described in detail.

2.1.1 MINISTRY OF HEALTH LINKED DATA SETS

The Ministry of Health (MoH) is the custodian of a number of datasets able to be linked via National Health Index (NHI) numbers, unique patient identifiers used in the New Zealand health system. For this report, data were sought from the Public Health Intelligence (PHI) unit of the MoH on health system utilisation for people with diagnosed dementia compared with people with no diagnosed dementia.

Diagnosis of dementia or Alzheimer's (ICD-10 Ed.3, F00-F03, G30) was identified through Public Hospital or outpatient Mental Health Care data. Data were provided on the following items:

- public hospital visits (discharges, length of stay, cost);
- GP consults (number of consults);
- pharmaceuticals (number of subsidised items dispensed, cost); and
- laboratory tests (number of subsidised tests, cost).

People included in these data were New Zealand residents aged 50 years and older who received subsidised health care in the 2006 calendar year.

There are some important differences between the PHI data set and other estimates in this report. In particular, the measures of dementia prevalence and dementia specific mortality rates in the PHI data differ from those used in this report.

TABLE 2-1: POPULATION IN PHI DATASET, AND COMPARISON OF DEMENTIA PREVALENCE RATES

Age	People with dementia	People with no dementia	PHI dementia prevalence rates	Access Economics dementia prevalence rates
50-54	188	248,694	0.08%	0.01%
55-59	298	231,588	0.13%	0.01%
60-64	432	176,950	0.24%	0.90%
65-69	622	147,751	0.42%	1.49%
70-74	1,339	113,832	1.16%	3.40%
75-79	2,734	98,117	2.71%	6.07%
80-84	4,285	68,730	5.87%	12.27%
85+	7,152	53,422	11.81%	25.04%
Total (50+)	**17,050**	**1,139,084**	**1.47%**	**3.16%**

The prevalence of dementia in New Zealand is known to be underestimated by the PHI data as it is determined by contact with specific data systems (ie, people with dementia who did not have contact with those data systems in 2006 are not identified in this report). Based on the prevalence rates for dementia presented in Chapter 1, only 45% of people with dementia are identified in the PHI data.

As a conservative approach, Access Economics has not revised the cost estimates for the low dementia prevalence identified in the datasets. This is because it is considered likely that people with dementia who are not identified in this data set are likely to be different from those that are identified; particularly it is probable that those not identified have fewer health system contacts. That said, the resulting estimates are likely to underestimate the total costs of dementia related health costs.

TABLE 2-2: DEMENTIA SPECIFIC MORTALITY, PHI DATASET AND ACCESS ECONOMICS' ESTIMATES

Age	PHI mortality rates	Access Economics mortality rates
50-54	6.4%	2.1%
55-59	6.4%	2.3%
60-64	9.0%	1.1%
65-69	8.8%	2.3%
70-74	12.2%	3.5%
75-79	13.5%	5.4%
80-84	16.7%	9.2%
85+	25.4%	19.9%
Total (50+)	**18.7%**	**11.4%**

Mortality rates presented in this table are the number of people who die with dementia (from all causes) over the number of people with dementia. They are different from the population dementia mortality rates presented in Table 1-4.

Dementia specific mortality rates in the PHI data set are considerably higher than the estimate presented in Section 1.1.3 that were based on mortality data. This is despite the lower estimates of dementia prevalence in the PHI data. This could indicate a higher relative risk of mortality for people with dementia beyond the deaths that are directly caused by dementia.

To estimate costs for 2008 based on the 2006 PHI data, figures were adjusted for growth in the number of people with dementia and for health cost inflation between 2006 and 2008.

- Health Cost Inflation from March 2006 to March 2008 was 1%.[4]
- Growth in the number of people with dementia aged 50 years and older was 6.2%.

2.1.2 DISTRICT HEALTH BOARDS

Since 2001, the responsibility for the provision of health and disability services in New Zealand has been devolved to 21 District Health Boards (DHBs). This decentralised approach presents a challenge for conducting bottom-up data collection, as health services vary across districts. The approach taken to the costing of health services for dementia in this report has thus relied heavily on the national data collections held by the MoH.

2.2 HOSPITAL COSTS

In New Zealand, only public inpatient data are collected by the New Zealand Health Information Service (NZHIS). Access Economics has thus used a three-step process to estimate total hospital costs.

1. Public inpatient data were requested for patients with a dementia diagnosis for the most recent year available (2004), with costs estimated and then extrapolated to 2008 based on population growth and health inflation.
2. Private inpatient costs were (conservatively) estimated to be zero. This is based on advice that there are no private inpatient hospital beds in New Zealand that treat people with dementia.
3. Outpatient costs were estimated based on relativities from the Australian ratio of outpatient to inpatient costs as no New Zealand data were available.

2.2.1 PUBLIC HOSPITAL INPATIENT COSTS

Public hospital inpatient data were requested from NZHIS for the most recent year available (2004 calendar year) for people with dementia or Alzheimer's disease as identified by the ICD-10 codes: F00-01, 020-1, 023, 03; G30, 310-1, 318-9 (see Table 1-1).

The NZHIS public inpatient data provided details of 11,405 discharges where the agreed dementia codes were one of 20 diagnoses for admission, and where the discharge date was from 1 January 2004 to 31 December 2004. To avoid overstating or double counting of dementia conditions, only the primary diagnosis was used in the costing (2,145 discharges). Access Economics notes that these data are rich in the ability to identify co-morbid conditions.

Other information in the data included patient age, gender, ethnicity, cost-weight, length of stay and facility type, among other variables.

---

[4] Consumer Price Index, March 2008 quarter, and March 2007 quarter, Statistics New Zealand. http://www.stats.govt.nz/products-and-services/hot-off-the-press/consumers-price-index/consumers-price-index-marc08qtr-hotp.htm?page=para004Master (Surprisingly, there was in fact deflation in health costs between 2007 and 2008.)

Of the discharges where there was a primary diagnosis of dementia 471 (22%) were for stays of over a year in length. The maximum length of stay was 14.7 years, with the minimum stay being 0 days, reflecting same day discharge (to the community, facility transfer or death). The average length of stay was 296.2 days.

The majority (52% or 1,114 patients) of public inpatients with a primary diagnosis of dementia were treated in private hospitals. Of total patients, 897 (42%) were treated in public hospitals, with the remaining patients treated in psychiatric hospitals and a small number in facilities classified as health centres.

The average length of stay for patients treated in private hospitals is longer than for patients treated in public hospitals and other facilities, as shown in Table 2-3.

TABLE 2-3: AVERAGE LENGTH OF STAY (ALOS) OF PUBLIC INPATIENTS, BY FACILITY TYPE, 2004

Facility type	ALOS (days)
Public Hospital	63.3
Private Hospital	510.8
Other	71.4
Total	**296.2**

The average 1.4 years that public inpatients with dementia stay in private hospitals suggests that some patients may be receiving ongoing support services rather than purely medical treatment.

Total costs for public hospital inpatients are calculated using cost-weights and cost-weight multipliers for each discharge. The total costs (including costs for patients who stayed longer than a year) are counted for all patients in the data set. This is because the data are discharge data and do not include the many patients who remain in hospital over the entire length of the calendar year. The overall count of people may thus be understated although the there will be people discharged during the year whose long ALOS is included. However, overall the estimated may be an underestimate of costs.

The cost-weight for each stay is calculated via a complex algorithm that takes account of length of stay as well as other issues related to cost complexity of admissions (District Health Boards of New Zealand, 2003).

- ☐ The cost-weight multiplier converts the cost-weight to a dollar amount;
  - the multiplier for 1 January to 30 June 2004 was $2,728.55 for medical/surgical inpatients.
  - the multiplier for 1 July to 31 December 2004 was $2,854.88 for medical/surgical inpatients.[5]

---

[5] Hospital inflation (from MoH) is high relative to the CPI health index which comprises hospital services, outpatient services and medical products, appliances and equipment. Overall health CPI appears to have been low due to a large fall in the cost of the latter component (medical products, appliances and equipment).

TABLE 2-4: DEMENTIA PUBLIC INPATIENT COSTS BY ICD-10 CODE, 2004

ICD-10 Code	Description	Total $'000	% of Total
F00	Dementia in Alzheimer's disease	71	0%
F01	Vascular dementia	11,409	16%
F02.0	Dementia in Pick's disease	-	-
F02.1	Dementia in Creutzfeldt-Jakob disease	-	-
F02.3	Dementia in Parkinson's disease	-	-
F03	Unspecified dementia	38,094	54%
G30	Alzheimer's disease	18,853	27%
G31.0	Circumscribed brain atrophy	195	0%
G31.1	Senile degeneration of brain, not elsewhere classified	-	-
G31.8	Other specified degenerative diseases of nervous system	1,115	2%
G31.9	Degenerative disease of nervous system, unspecified	442	1%
Total		**70,180**	**100%**

Source: NZHIS data, Access Economics.

Total public inpatient costs for dementia in 2004 were $70.18 million.

To extrapolate the $70.18 million estimate to 2008, it is multiplied by two factors, totalling 31.2% over the four years.

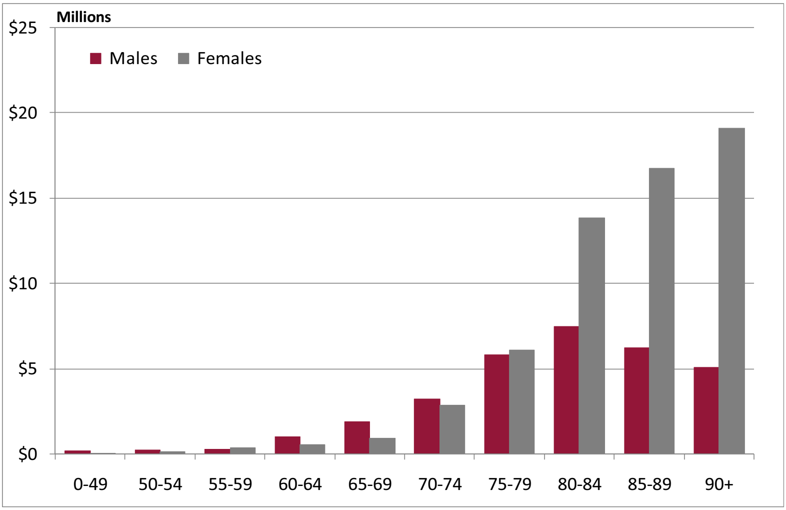
- Inflation in the price of hospital services of 5.9% per annum between 2006 and 2008 based on Consumer Price Inflation (CPI) data from Statistics New Zealand, and estimated at 2.9% per annum between 2004 and 2006[6]; and
- Growth in prevalence of dementia of **12.5%** between 2004 and 2008 (based on prevalence rates by age, gender multiplied by the 2004 official estimated resident population).
- The implicit assumption over the reasonably short period is that services expanded in line with prevalence rather than waiting lists lengthening.

Public inpatient costs are thus estimated to be $92.1 million in 2008.

---

[6] Statistics New Zealand did not include health cost inflation data in CPI prior to March 2006. Average health cost inflation for 2004 to 2006 was estimated as 2.9% per annum based on OECD (2004).

FIGURE 2-1: PUBLIC INPATIENT COSTS BY AGE AND GENDER, 2008 ($ MILLION)



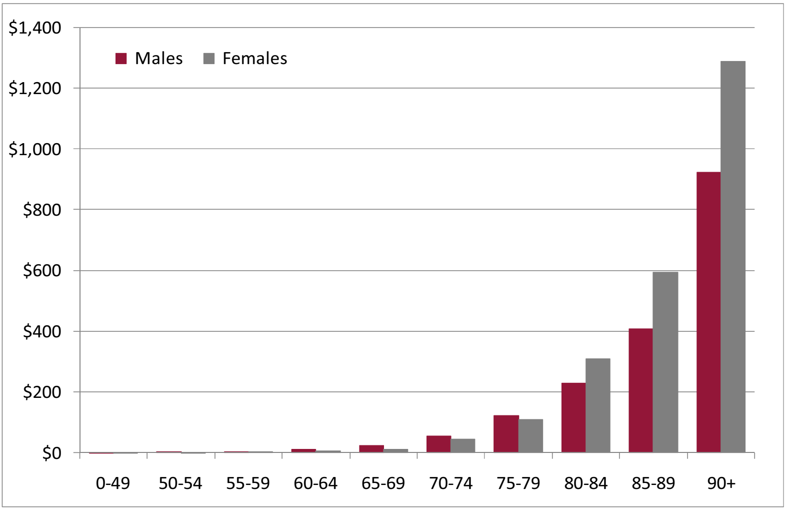
Source: NZHIS data, Access Economics.

Figure 2-1 presents public inpatient data by age and gender for 2008.

- ❑ 65.8% of inpatient costs are for women and 34.2% for men.
- ❑ Over half of inpatient costs (51.2%) are for people aged over 85 years and nearly another quarter (23.1%) are for those aged 80-84 years.

Figure 2-2 shows that some, but not all of the disproportionate spread of hospital costs between men and women can be explained by the relatively longer life-span of women. Per head of population, public inpatient costs for dementia are higher for women than men in the eldest age cohorts.

FIGURE 2-2: PER CAPITA PUBLIC INPATIENT COSTS, BY AGE AND GENDER ($)



Source: NZHIS data, Access Economics.

2.2.1.1 PHI PUBLIC HOSPITAL INPATIENT DATA

Data on public hospital visits were also provided in the PHI dataset. Table 2-5 presents the estimates of the total number of public hospital discharges, bed days, and costs for people with dementia in 2008 based on the PHI data.[7]

TABLE 2-5: PUBLIC HOSPITAL VISITS, PEOPLE WITH DEMENTIA, 2008

Age	Discharges	Bed days	Cost
50-54	168	1,080	$889,694
55-59	222	1,248	$930,782
60-64	430	2,303	$1,876,078
65-69	458	2,759	$2,029,267
70-74	1,135	8,451	$6,034,964
75-79	2,066	13,829	$9,999,538
80-84	3,097	21,588	$15,812,014
85+	4,917	35,980	$25,161,124
Total	**12,493**	**87,239**	**$62,733,462**

Source: PHI, MoH, special data request, and Access Economics.

---

[7] As noted in Section 2.1.1, people with dementia were identified in the PHI data set by the ICD-10 codes F00-F03, and G30. This list is slightly different to the codes used to identify dementia in the NZHIS hospital data (Table 1-1), however the numbers of patients picked up by one set of codes and not the other is expected to be very small. As PHI data included non-hospital data, a dementia diagnosis could also be established from mental health outpatient data even if no dementia diagnosis was recorded in hospital.

The 12,493 discharges for people with dementia in the PHI data is comparable with the NZHIS data where dementia is one of up to 20 diagnoses (but not necessarily the primary diagnosis). Based on the estimated growth in dementia prevalence between 2004 and 2008, the 11,405 discharges for people with dementia in 2004 that was reported from the NZHIS data, equates to 12,828 discharges in 2008.

The 87,239 bed days in the PHI data is substantially lower than the NZHIS data. According to the NZHIS data, the total bed days for all patients with dementia (not just primary diagnosis) was 1.1 million, with an ALOS of 88 days. This compares to ALOS in the PHI data of 7.0 days.

As with the treatment of the NZHIS data above, some of the people with dementia who use inpatient hospital services will do so for reasons other than their dementia. Unlike the NZHIS data, where the primary diagnosis was used to identify the cause of the hospital visit, the number of hospital visits attributable to dementia is identified in the PHI data based on a comparison of hospital utilisation by people with and without dementia. Table 2-6 shows the share of the public hospital inpatient costs that are attributable to dementia based on the relative use of hospital services between people with and without dementia.

TABLE 2-6: PUBLIC HOSPITAL VISITS, PEOPLE WITH DEMENTIA, ATTRIBUTABLE TO DEMENTIA, 2008

Age	Discharges	Bed days	Cost
50-54	144	1,015	$810,042
55-59	180	1,114	$771,821
60-64	342	1,981	$1,510,581
65-69	298	2,149	$1,353,112
70-74	687	6,615	$4,098,592
75-79	992	9,036	$5,411,448
80-84	1,032	11,669	$7,550,642
85+	1,093	14,751	$9,950,690
Total	**4,768**	**48,329**	**$31,456,929**

Source: PHI, MoH, special data request, and Access Economics.

Access Economics believes the NZHIS data provides a more accurate estimate of the hospital costs attributable to dementia, as the ALOS from the PHI data appears too low. Hence **public inpatient costs are estimated to be $92.1 million in 2008**

2.2.2 PRIVATE HOSPITAL INPATIENT

There are no private inpatient hospital beds in New Zealand that treat people with dementia. Such private beds as there are might occasionally see people with probably mild dementia having unrelated surgical procedures but once dementia-related costs start to accrue they are referred to the public system.[8]

2.2.3 PUBLIC OUTPATIENT

Outpatient services include specialists such as neurologists, psycho-geriatricians and geriatricians and allied health professionals such as physiotherapists, occupational therapists,

---

[8] Matthew Croucher, personal communication.

speech therapists, dieticians, needs assessors and social workers. Like other health services in New Zealand these services are provided by DHBs.

There is currently no dataset that will allow for the identification of outpatient costs attributable to dementia in New Zealand. The National Non-admitted Patient Collection (NNPAC), which began in July 2006, collects monthly data on non-admitted patient services, although this does not allow for allocation of costs across diseases. NNPAC does include NHI data so has the potential to be linked with other datasets in future, in the manner of the PHI data analysed throughout this chapter.

Access Economics (2003) estimated the costs of dementia in Australia for 2002. Outpatient and other ambulatory services were estimated to be 9.5% of the cost of public hospitals and psychiatric hospitals from official data. In New Zealand, there are similarities in clinical practice at the tertiary care level, so public outpatient costs for dementia are calculated as 9.5% of $92.1 million, which is **$8.8 million**.

2.3 MEDICAL COSTS

2.3.1 GP VISITS

Data on GP visits were provided by PHI in the MoH. Table 2-7 and Figure 2-3 show the average number of visits to a GP for people with and without a dementia diagnosis in 2006, by age cohort.

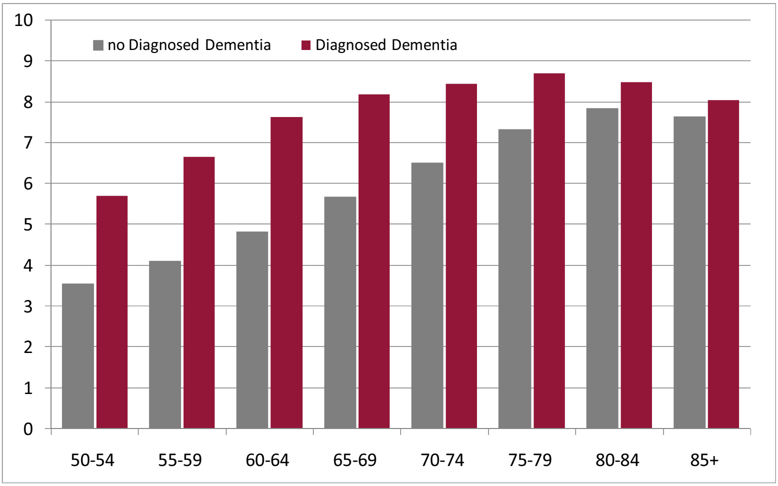
TABLE 2-7: MEAN GP CONSULTS FOR PEOPLE WITH AND WITHOUT DEMENTIA, 2006

Age	With dementia	No dementia	Difference
50-54	5.69	3.54	2.15
55-59	6.65	4.10	2.55
60-64	7.61	4.82	2.79
65-69	8.17	5.67	2.50
70-74	8.44	6.50	1.94
75-79	8.69	7.32	1.37
80-84	8.47	7.84	0.63
85+	8.04	7.63	0.41

Source: PHI, MoH.

People diagnosed with dementia would also visit GPs for unrelated conditions. The ‘Difference’ column above (Table 2-7) shows the number of GP visits per year that are attributable to dementia. Accounting for the relatively older age distribution of people with dementia, the average number of GP visits per year is 0.9 visits greater for people with dementia than for people with no dementia diagnosis.

FIGURE 2-3: MEAN GP CONSULTS FOR PEOPLE WITH AND WITHOUT DEMENTIA, 2006



Source: PHI, special data request.

Table 2-8 shows the total number of GP visits made by people with dementia and the number of those visits that are due to dementia.

TABLE 2-8: GP VISITS, PEOPLE WITH DEMENTIA, TOTAL AND THOSE DUE TO DEMENTIA, 2008

Age	Total GP consults	GP consults for dementia
50-54	1,124	425
55-59	1,991	763
60-64	3,722	1,364
65-69	5,418	1,658
70-74	11,828	2,719
75-79	23,939	3,774
80-84	38,015	2,828
85+	62,750	3,200
Total	**148,788**	**16,731**

Source: PHI, MoH, special data request, and Access Economics.

2.3.1.1 GENERAL PRACTICE COSTS

Most GP visits in New Zealand occur through Primary Health Organisations (PHOs). PHOs receive (First Contact) funding to provide subsidised GP consults for their enrolled members. The subsidy is paid based on a rate of $28.36 per visit for people over six years of age.[9] The remainder of the cost of the consult is charged as an out-of-pocket fee to the patient. According to CPI data, in March 2008 the weighted average retail price for a 'General

---

[9] MoH, http://www.moh.govt.nz/moh.nsf/indexmh/phcs-funding-firstcontact, accessed 20/6/2008.

Practitioner – consultation, adult without community services card' was $28.94.[10,11] Hence the total average cost of a GP visit in 2008 is $57.30.

People with dementia may receive a greater level of subsidy if they are assessed as being eligible for Care Plus, a health care initiative that provides additional funding to PHOs for people who have to visit a GP or nurse more frequently because of a chronic condition or a terminal illness.[12] This affects the distribution of who bares the costs of GP visits but does not affect the average cost per GP visit of $57.30. As no data were available on the numbers of people with dementia that receive Care Plus, or the average subsidy per GP visit under Care Plus, no additional degree of subsidy has been modelled. The distribution of costs, shown in Table 2-9, is hence likely to overstate the costs to people with dementia and understate the cost to government.

TABLE 2-9: COSTS OF GP VISITS ATTRIBUTABLE TO DEMENTIA, 2008

Age	Cost to people with dementia	Cost to government	Total cost
50-54	$12,288	$12,041	**$24,329**
55-59	$22,091	$21,648	**$43,739**
60-64	$39,488	$38,697	**$78,185**
65-69	$47,982	$47,020	**$95,002**
70-74	$78,683	$77,106	**$155,790**
75-79	$109,223	$107,034	**$216,256**
80-84	$81,831	$80,191	**$162,021**
85+	$92,606	$90,750	**$183,356**
Total	**$484,192**	**$474,488**	**$958,679**

Source: PHI, MoH, special data request, and Access Economics.

The total cost of GP visits due to dementia in 2008 is estimated to be $958,679. This amount is borne fairly evenly between government (49.5%) and people with dementia (50.5%).

Figure 2-4 shows costs of dementia related GP visits by age and bearer of costs.

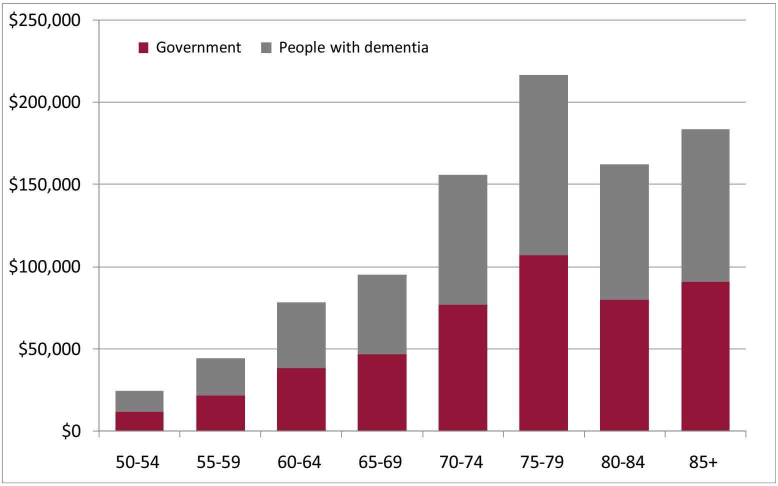
---

[10] http://www.stats.govt.nz/products-and-services/hot-off-the-press/consumers-price-index/consumers-price-index-marc08qtr-hotp.htm?page=para004Master

[11] A Community Services Card, available to people on low incomes, can reduce the upfront fees for visiting a doctor in some circumstances. As PHOs receive an increased level of subsidy for clients that are Community Service Card holders, it is assumed that the average total cost of a GP visit is a constant $57.30.

[12] http://www.moh.govt.nz/moh.nsf/indexmh/phcs-funding-careplus

FIGURE 2-4: COSTS OF GP VISITS, BY AGE AND BEARER OF COSTS, 2008



2.3.2 OUT-OF-HOSPITAL SPECIALISTS

No data were identified for out-of-hospital specialist services provided to people with dementia in New Zealand. Discussion with experts in the field confirmed that there are almost no private psychiatrists, physicians, geriatricians or neurologists seeing people with dementia outside the hospital setting for assessment or treatment. For the few that do provide services in this manner, the cost was considered to be likely to be too small to justify the resource allocation required to collect data on their numbers and annual billings, for example through a survey (eg, the cost of the survey may exceed the annual billing). Consequently, this cost element is conservatively excluded from this analysis.

2.4 PHARMACEUTICAL COSTS

PHI pharmaceutical data for people with dementia are set out in Table 2-10.

TABLE 2-10: PHARMACEUTICALS DISPENSED, PEOPLE WITH DEMENTIA, 2008

Age	Pharmaceutical Dispensed Items	Pharmaceutical Drug Cost*
50-54	13,322	$294,188
55-59	20,059	$403,692
60-64	32,953	$513,614
65-69	45,309	$739,660
70-74	110,463	$1,345,591
75-79	213,940	$2,292,821
80-84	351,475	$3,245,957
85+	545,471	$4,178,121
Total	**1,332,993**	**$13,013,643**

Source: PHI, MoH, special data request, and Access Economics. * Ex-supplier, including GST.

People diagnosed with dementia would also access pharmaceuticals for unrelated conditions. Table 2-11 adjusts the cost down according to mean cost for people with no dementia diagnosis. In the oldest age group, having dementia results in having more pharmaceuticals but these are cheaper overall than otherwise, although the exact reason for this is unclear. **The total pharmaceutical cost due to dementia is $2.95 million in 2008.**

TABLE 2-11: ADDITIONAL PHARMACEUTICALS DISPENSED, PEOPLE WITH DEMENTIA, 2008

Age	Pharmaceutical Dispensed Items	Pharmaceutical Drug Cost*
50-54	11,330	$245,672
55-59	16,312	$310,198
60-64	24,659	$324,520
65-69	29,413	$421,455
70-74	65,757	$568,245
75-79	99,670	$625,401
80-84	118,535	$478,293
85+	57,052	-$22,074
Total	**422,726**	**$2,951,710**

Source: PHI, MoH, special data request, and Access Economics. * Ex-supplier, including GST.

2.5 PATHOLOGY AND DIAGNOSTIC IMAGING

PHI pathology and imaging data for people with dementia are set out in Table 2-12.

TABLE 2-12: LABORATORY TESTS, PEOPLE WITH DEMENTIA, 2008

Age	Tests	Cost
50-54	2,309	$18,596
55-59	3,850	$32,569
60-64	7,326	$60,229
65-69	11,453	$92,231
70-74	22,662	$185,772
75-79	45,455	$368,506
80-84	65,573	$536,913
85+	104,895	$858,991
Total	**263,523**	**$2,153,806**

Source: PHI, MoH, special data request, and Access Economics.

People diagnosed with dementia would also access laboratory tests for unrelated conditions. Table 2-13 adjusts the cost down according to the mean cost for people with no dementia diagnosis. People with dementia in the oldest aged groups have a fewer number of pathology and imaging tests than people without dementia. Hence, **the total pathology and imaging cost due to dementia is small at only $88,572 in 2008.**

TABLE 2-13: ADDITIONAL LABORATORY TESTS, PEOPLE WITH DEMENTIA, 2008

Age	Tests	Cost
50-54	952	$6,491
55-59	1,455	$11,490
60-64	2,656	$19,730
65-69	3,939	$28,176
70-74	4,485	$33,989
75-79	5,758	$39,235
80-84	-2,020	-$22,396
85+	-2,888	-$28,144
Total	**14,337**	**$88,572**

Source: PHI, MoH, special data request, and Access Economics.

2.6 RESEARCH COSTS

There are no data available on overall expenditure (private and public sector) on health and medical research by disease/condition in New Zealand. The approach adopted was thus to:

1. estimate public sector expenditure from data supplied by the Health Research Council of New Zealand (HRC); and
2. estimate private sector expenditure from OECD estimates of NZ relativities.

HRC undertook a search for research projects that it had sponsored based on search terms that included *brain*, *neuron*, *cell*, *Alzheimer*, and *dementia*. Duplicate projects and projects not related to dementia were removed. Projects identified for the years 2000-2008 are summarised in Table 2-14. As the HRC contracts database only allows searches on the title field (ie, it does not allow searches on the lay summaries) some projects related to dementia may be missing from the data. However, HRC has advised that the data provided are likely to cover at least 90% of relevant projects.

Projects include applied research as well as 'basic' or 'developmental' level research that would also provide primary benefits to people with dementia – for example, studies of the effects of physical activity on blood flow to the brain, or studies of the biological mechanisms underlying the major human neurodegenerative disorders including Alzheimer’s disease.

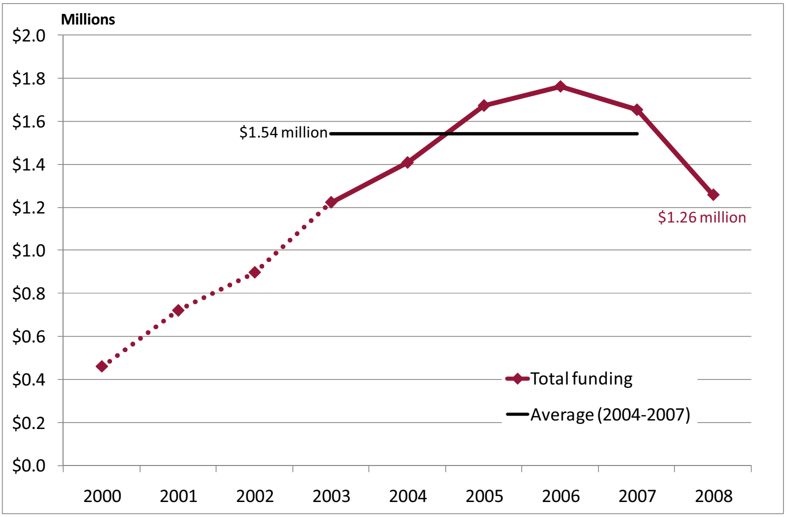
TABLE 2-14: HRC RESEARCH PROJECTS RELATING TO DEMENTIA, 2000-2008

Year approved	Title	Approved budget	Project length (years)
2008	Synaptic targets for neurodegenerative disease and brain repair	$399,000	2.0
2007	Driving neurogenesis as a therapeutic strategy for age-related cognitive decline	$991,955	3.7
2006	Effects of physical activity on blood flow to the brain in young and old humans	$150,000	3.9
2006	Making an IMPACT on brain function	$148,900	3.7
2006	Identification of therapeutic targets for theta-burst magnetic brain stimulation	$66,133	2.1
2006	Long-term functional and neuropsychological outcomes after stroke in New Zealand	$1,015,022	3.7
2006	Molecular studies of human neurodegenerative disease	$100,234	3.2
2005	Older Maori and Dementia: Community research by a supported Maori health organisation	$4,485	1.1
2005	Functional incorporation of new brain cells into existing neuronal networks	$112,532	2.9
2005	Neurogenesis and neurodegenerative disorders of the human brain	$2,844,133	3.5
2004	Mechanisms of synaptic plasticity failure in Alzheimer's disease	$887,621	3.5
2003	Environmental stimulation: Driving novel therapies for Alzheimer's disease	$1,222,842	3.7
2002	Mechanisms of nervous system dysfunction early in Alzheimer's disease	$597,441	2.6
2001	Axon regeneration through regulation of extracellular proteolysis	$490,383	4.3
2001	The adult neuron in neurodegenerative disorders	$582,675	4.0
2000	Neurodegenerative diseases of the brain	$2,286,048	5.5
2000	Nitric oxide in perirhinal cortex and Alzheimer's disease	$98,576	2.0
Average		**$705,764**	**3.3**

Source: HRC special data request.

By allocating project funding across the years in which the research took place, annual estimates for HRC funding for dementia research were determined. Figure 2-5 shows estimated HRC funding each year from 2000 to 2008. Data for the years 2000-2002 are likely to underestimate the true level of research funding in that period. This is because there may have been projects approved in years prior to 2000 that were still receiving funding.

FIGURE 2-5: ANNUAL HRC FUNDING RELATING TO DEMENTIA, 2000-2008



Source: HRC, special data request.

In 2008 the level of HRC research funding for projects relating to dementia was $1,259,208. This is considered to be the full amount for the 2008 year as HRC projects have historically commenced in January. However, this estimate is considered to be conservative given the average level of funding for four years to 2007 was $1,544,827.

The private sector research spend estimate is based on proportionality from a 12-country comparison by the OECD of health R&D in New Zealand and other member countries (OECD, 2004). This study showed the ratio of private health R&D in NZ as 1.33 times public health R&D for the most recent year provided. **The estimate of private dementia R&D is thus $1.67 million and of total dementia R&D $2.93 million in 2008.**

While all the research projects have a potential application to dementia, some may also have benefits in other areas (eg, more general neurological research). Hence the estimate based on these projects is potentially generous.

2.7 ALLIED HEALTH COSTS

People with dementia and their families and carers may also access a variety of allied health services such as psychological counselling, physiotherapy, occupational therapy, hydrotherapy, music therapy, aromatherapy and so on. Where these services are provided in residential care facilities, they are counted in the cost estimates in the next Section (2.8).

Outside of residential aged care facilities, no data were available in New Zealand on the number or cost of allied health services accessed, so estimates for these costs have been based on proportionalities from Australian data. Access Economics (2003) found that pharmaceutical and allied health costs together were 3.5% of total health system costs excluding residential care. Hence an estimate of allied health costs in New Zealand provided outside of residential facilities was calculated to set pharmaceutical costs and allied health costs to 3.5% of total allocated health costs less residential care. In total then, the **allied health costs outside of facilities for people with dementia are estimated as $907,087 in 2008**. It is assumed that costs are borne between individuals and government in the same shares as for GP services, hence the cost to individuals is $458,135 (50.5% of total) and the cost to government is $448,953 (49.5% of total).

2.8 AGED CARE COSTS

Residential care is a common feature of care for frail older people. Mainstream residential services may care for people with a range of complex nursing needs and reduced cognitive capacity and require well-trained staff. Others may provide special services for those with severe behavioural and psychological symptoms of dementia and employ specially trained staff.

Residential aged care in New Zealand is the responsibility of District Health Boards (DHBs). Funding for aged care was devolved to DHBs in October 2003. There are generally four levels of aged residential care:

1. rest homes;
2. continuing care (hospital);
3. dementia units; and
4. psychogeriatric services (also known as specialist long-term care hospitals).

Residential care is provided on a subsidised basis to those deemed eligible to receive the Residential Care Subsidy. Residents can also be required to pay an additional amount, up to a maximum contribution of an average of $719 per week.[13][14]

2.8.1 DATA

Data on residential care in New Zealand were provided by the Ministry of Health. The data were extracted from the Client Claims Processing System (CCPS), which is the client level based payment system that typically makes fortnightly payments to all residential providers.

Financial year data were provided, including data for the incomplete financial year 2007-08 (data up to April 2008). Estimates of residential care costs for 2008 were based on data for the 2007-08 financial year, with adjustment for the fact that two months of data were not yet available (ie, figures were grossed up by a factor of 12/10).

---

[13] The maximum contribution varies slightly by territorial local authority with a range of $703-$773. MoH, http://www.moh.govt.nz/moh.nsf/indexmh/hop-longtermresidentialcare-maximumcontribution**,** accessed 20/6/2008.

[14] The maximum contribution rates increased from 1 July 2008, ranging from $723-$795. Figures in this report have not been adjusted for these increase and the estimates in this report are thus conservative.

TABLE 2-15: RESIDENTIAL CARE, CLIENTS, BED-DAYS AND COSTS, BY LEVEL OF CARE, 2008

Level of care	Clients[1,2]	Bed days	Government contribution[3] ($ million)	Client contribution ($ million)	Total cost ($ million)
Dementia	3,737	831,000	55.2	47.2	102.4
Hospital	15,672	3,139,000	344.3	175.7	520.0
Psychogeriatric	807	177,000	23.3	8.7	32.0
Rest home	16,534	4,101,000	258.4	141.5	399.9
Total	**n/a**	**8,247,000**	**681.2**	**373.1**	**1,054.3**

Source: MoH, special data request.

[1] Clients may be counted in more than one level of care if they move between different levels of care within a year.

[2] Clients for 2008 were based on the historical average number of bed days per client rather than the 12/10 ratio.

[3] Excludes GST.

2.8.2 RESIDENTIAL CARE COSTS ATTRIBUTABLE TO DEMENTIA

People with dementia may be cared for in facilities at any of the four levels of residential care according to their assessed level of need. Eligibility for long-term residential care and determination of the most appropriate level of care is determined in a Needs Assessment conducted by a Needs Assessment Service Co-ordination (NASC) Agency. Apart from specific Dementia care, for which 100% of the costs are attributable to dementia, costs for other levels of residential care are only partially attributable to dementia.

There are two aspects to determining the proportion of residential care costs that are due to dementia:

1 the share of residential care clients (or bed days) with dementia; and

2 the share of the residential care costs for people with dementia that are due to dementia (rather than due to comorbid diseases among people with dementia).

It was not possible from the Client Claims Processing System (CCPS) data to identify people with dementia, or any other diagnosis for that matter. A 2002 report on dementia in New Zealand (MoH, 2002) reported that 60-70% of people living in residential care in New Zealand have some form of dementia. This estimate is relatively high by international standards, for example a survey in Singapore revealed that 26.4-35.0% of nursing home residents have dementia (Access Economics, 2006:18), while in Australia the share of residential care clients with dementia is 49% (AIHW, 2007). While the relatively high rate of dementia among New Zealanders living in residential care may be the result of national differences such as different models of aged care, to be conservative this report has chosen the lower bound parameter of 60% as the share of residential care clients in New Zealand with dementia.

In the absence of data, it is assumed that people with dementia comprise 100% of residents in Dementia specific units and thus 55% of people in all other residential care levels. This assumption will be accurate if people with dementia have the same spread of needs as other residential care clients. In reality, there may be a higher proportion of residents with dementia in psychogeriatric facilities, but since the fewest overall number of people are in this level of care, the results will not be substantially affected.

TABLE 2-16: RESIDENTIAL CARE, PEOPLE WITH DEMENTIA, BY LEVEL OF CARE, 2008

Level of care	Clients	Bed days	Government contribution ($ million)	Client contribution ($ million)	Total cost ($ million)
Dementia	3,737	831,000	55.2	47.2	102.4
Hospital	8,662	1,735,000	190.3	97.1	287.4
Psychogeriatric	446	98,000	12.9	4.8	17.7
Rest home	9,139	2,267,000	142.9	78.2	221.0
Total	**n/a**	**4,930,000**	**401.2**	**227.3**	**628.5**

Source: MoH, special data request, Access Economics.

Numbers presented in this table are estimates based on 60% of people in residential care in New Zealand having some form of dementia.

As dementia is a disease largely of old age, it is usual for people with dementia to experience comorbid diseases. Thus the costs of residential care for people with dementia in Table 2-16 represent an overestimate of the residential care costs attributable to dementia. Even if an overnight cure were to be found for dementia, some people would continue to require residential care due to comorbid diseases.

Determining the share of residential care costs for people with dementia that are attributable to dementia is difficult due to the extensive data requirements to determine patterns of comorbidities and because dementia symptoms can act as tipping conditions, causing faster entry into aged care than would occur in the absence of dementia.

The AIHW analysed residential care data for Australia that included detail on multiple conditions of residential care clients. For Australia the AIHW estimated that 45% of costs for people with main condition of dementia and 40% of costs for people with an additional condition of dementia were attributed to dementia. The proportion of permanent residents of residential care for whom the *main condition* is dementia was 32.7%, with an additional 16.0% of people in residential care in Australia having dementia as an *additional* condition. Access Economics considers that these AIHW rates are too low, based on our evaluation of dementia programs for the Australian Government.

There are important differences between New Zealand and Australia in relation to residential care for people with dementia. As noted above, the prevalence of dementia in residential aged care in Australia is lower than New Zealand (49% compared with 60%). Given similar prevalence rates for dementia among the two countries' populations, there are several possible explanations for the difference in dementia prevalence rates in residential care. For example, New Zealand may have lower rates of institutionalisation for other diseases than Australia (perhaps due to cultural or demographic factors); or there may be a higher rate of institutionalisation of people with dementia in New Zealand than in Australia (perhaps due to fewer community dementia support services), or both. Differences between the two countries limit the applicability of Australian findings to New Zealand, however the concept that not all residential care costs for people with dementia are applicable to their dementia is still relevant. If the Australian rates were to hold for New Zealand then the costs of residential care attributable to dementia in New Zealand would be $272.5 million ($173.9 million government contribution and $98.6 million client contribution), which is around 2.7 times the hospital costs. In Access Economics (2003), where all of the residential aged costs for people with a primary diagnosis of dementia were included, the ratio of residential care costs to hospital costs was around 10.8. As such, **the estimate of $272.5 million should be treated as a minimum estimate of residential care costs in New Zealand**.

2.9 SUMMARY OF HEALTH SYSTEM COSTS

A summary of the health system costs derived from the discussion so far in Chapter 2 is provided in Table 2-17 and Figure 2-6.

- ☐ Total costs estimated in the previous sections are $381.2 million in 2008.
- ☐ However, this excludes health system costs that are not captured in the sections above, including items such as expenditure on community health, public health programs, health administration, health aids and appliances. Allowance is made for these components by factoring up for these costs in the manner adopted by the AIHW (AIHW, 2005) where the 'unallocated' component is estimated as 12.5/87.5 or 14.3%.
- ☐ The unallocated component, comprising the administrative and other items detailed above, is thus estimated as 14.3% of $381.2 million or $54.5 million in 2008 for dementia.

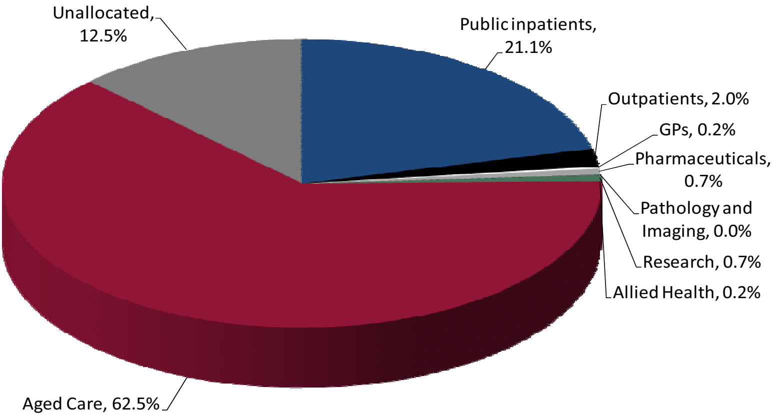
Total health costs of dementia for 2008 are thus estimated to be $435.7 million.

- ☐ Aged care costs represent 62.5% of total costs.
- ☐ Hospital costs are estimated to be 23.2% of the total.

TABLE 2-17: SUMMARY OF HEALTH COSTS OF DEMENTIA, NEW ZEALAND, 2008

Health cost element	2008 $'000	% total
Total Hospital	100,877	23.2%
Public inpatients	*92,091*	*21.1%*
Private inpatients	*negligible*	*negligible*
Outpatients	*8,787*	*2.0%*
GPs	959	0.2%
Out of hospital specialists	negligible	negligible
Pharmaceuticals	2,952	0.7%
Pathology and Imaging	89	0.0%
Research	2,934	0.7%
Allied Health	907	0.2%
Aged Care	272,510	62.5%
Sub-total allocated	381,227	87.5%
Unallocated (administrative, capital, public health etc.)	54,461	12.5%
Total	**435,687**	**100%**

FIGURE 2-6: SUMMARY OF HEALTH COSTS OF DEMENTIA, NEW ZEALAND, %, 2008



3. OTHER FINANCIAL COSTS

Other financial costs are all those that are not ‘direct’ health system costs (Chapter 2) nor intangible costs – the loss of health and wellbeing (Chapter 4). It is also important to make the economic distinction between real and transfer costs to avoid double counting.

- **Real costs** use up real resources, such as capital or labor, or reduce the economy’s overall capacity to produce goods and services.
- **Transfer payments** involve payments from one economic agent to another that do not use up real resources, for example, a disability support pension, or taxation revenue.
  - Transfer costs are important when adopting a whole-of-economy analysis of the impact of a particular disease.

3.1 PRODUCTIVITY LOSSES

Although dementia tends to affect older people, for younger people with dementia or those who choose to stay in the workforce at older ages, dementia can affect their capacity to work. They may work less than they otherwise would, retire early, or die prematurely. If employment rates are lower for people with dementia, this loss in productivity represents a real cost to the economy. In addition, informal carers may also work less, in order to care for their loved one with dementia, and this represents an additional productivity loss.

Access Economics measures the lost earnings and production due to health conditions using a ‘human capital’ approach. The lower end of such estimates includes only the ‘friction’ period until the worker can be replaced, which would be highly dependent on labor market conditions and unemployment/underemployment levels. In an economy operating at near full capacity, as New Zealand is at present,[15] a better estimate includes costs of temporary work absences plus the discounted stream of lifetime earnings lost due to early retirement from the workforce, reduced working hours (part-time rather than full-time) and premature mortality, if any.

In this case, it is likely that, in the absence of disease, people with dementia in each age-gender group would participate in the labor force and obtain employment at the same rate as the general population in New Zealand, and earn the same average weekly earnings. The implicit and probable economic assumption is that the numbers of such people would not be of sufficient magnitude to substantially influence the overall clearing of the labor market in New Zealand.

3.1.1 LOWER EMPLOYMENT

Given the age distribution of dementia, it is probable that most people have left the workforce prior to disease onset. However, for a significant number of younger onset cases, as well as those choosing to work till later in life, there is a productivity loss.[16] It is measured by estimating the age standardised difference in employment rates between people with dementia and those without.

---

[15] New Zealand has experienced a decade-long economic expansion with rising capacity utilization and, in recent years, unemployment falling to historical lows. In 2007, the unemployment rate in New Zealand was 3.6% (International Monetary Fund, 2008).

[16] Younger people with dementia (of working age) need to retire early from work while carers may also have to give up employment in order to care for them, leading to a double loss of income at a critical stage in family life (MoH, 2002:22).

A combination of domestic and international data sources were used to estimate the productivity cost in New Zealand for 2008.

Employment data on the general population in New Zealand were available from Statistics New Zealand by age and gender (Statistics New Zealand, 2008b).

While New Zealand data would also have been preferred to estimate the difference in employment rates for people with dementia compared to those without, these were not available, so the difference was based on the employment impact estimated in Australia (Access Economics, 2003). Given the similarity of the two countries' employment patterns and culture, and the fact that the functional impact of dementia is likely to be similar in any country, this was considered acceptable.

- The 2006 Disability Survey of New Zealand (Statistics New Zealand, 2007) collected information on the characteristics of people with disabilities, including employment status. However, the report did not publish these data and mainly focused on the prevalence and nature of disability in New Zealand, so cross-tabulations between employment rates and dementia status were not able to be derived.
- Access Economics (2003) found that, for people aged 65 years and over, those with dementia were employed at 27.1% of the employment rate of the general population.[17] In the absence of comparable data for younger cohorts, the same relativity was applied to those under 65 years of age.

Table 3–1 is a summary of the combined employment data. It presents the estimated proportion of people employed with and without dementia in New Zealand in 2008, based on the application of the difference in rates to New Zealand employment data.

TABLE 3–1: EMPLOYMENT RATES WITH AND WITHOUT DEMENTIA, NEW ZEALAND, 2008

	General population			Those with Dementia		
	Male	Female	Total	Male	Female	Total
15-65 years						
Employed	81.0%	67.7%	74.3%	21.9%	18.3%	20.1%
Not employed	19.0%	32.3%	25.7%	78.1%	81.7%	79.9%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%
65+ years						
Employed	19.5%	9.9%	15.4%	5.3%	2.7%	4.2%
Not employed	80.5%	90.1%	84.6%	94.7%	97.3%	95.8%
Total	100.0%	100.0%	100.0%	100.0%	100.0%	100.0%

Source: Statistics New Zealand (2008b), Access Economics (2003) and Access Economics estimates.

For modeling purposes, the employment rates for those with dementia were standardised by five year age cohorts and by gender, based on employment data for the general population. The data were not able to be controlled for other factors that might also contribute to lower overall age and gender standardised employment rates (for example, potentially, socioeconomic status).

Compared to the employment rates of the general population, it is estimated that 2,339 people with dementia are not employed in 2008 because of their condition. This is calculated as (1-27.1%) * 3,207 people with dementia who would have worked had it not been for their

---

[17] Access Economics (2003) showed that only 2.3% of those aged over 65 who have dementia are employed, compared to 8.5% of the population as a whole.

condition. The 3,207 figure is estimated by multiplying the people with dementia in each age and gender group by the employment rates in the general population for each of those groups.

The number of people that are not employed due to dementia is multiplied by the average weekly wage to estimate the productivity cost associated with lower employment for those with dementia. Estimates of average weekly earnings (AWE) are based on New Zealand wages data for those employed in the general population (Statistics New Zealand, 2008d). AWE data were only available up to 2007 and estimates for 2008 were thus based on historical growth trends.

At AWE of $1,025 per worker[18] lost due to dementia, **the productivity cost associated with lower employment was estimated as $124.7 million in 2008** (2,339 people * average weekly earnings of $847 * 52 weeks).

3.1.2 ABSENTEEISM

Some people will remain in the workforce in the early stages of dementia, either because they are not yet diagnosed or because they need or want to continue to work for a while. Remaining in employment for a time is more likely if the illness is in the early stages, if the work environment is supportive, if tasks are familiar or repetitive and if supervision and occupational health and safety arrangements are adequate. These people may, however, be absent from work more often than those without dementia as a result of the condition – because they need to take time off for medical appointments, to organise their affairs, or because of their symptoms. This absenteeism represents a further productivity loss.

As with employment participation, due to the lack of New Zealand data on the number of days absent from work due to dementia, these New Zealand calculations were based on Access Economics (2003) estimates from Australian data that dementia results in 5% of work time (or 12 work days) lost per annum, over and above the absenteeism of people without dementia.[19]

For all those with dementia and employed - using the employment data by age and gender from the previous section (3,207 * 27.1%) - the absenteeism loss was thus estimated as the total number of people employed in 2008 with dementia (868) * 12 days = 10,414 days absent in total.

Using an estimate of 240 work days per year (based on 5 days per week for 48 weeks of the year ie, excluding weekends and leave) the number of person workyears lost in 2008 was estimated as = 7,701 / 240 = 43 workyears lost.

At AWE of $1,025 per employed worker, **the absenteeism cost due to visual impairment was estimated as $2.3 million in 2008** (43 workyears * AWE of $1,025 * 52 weeks).

3.1.3 PREMATURE MORTALITY

There are also production losses arising from premature mortality associated with dementia. The income forgone of those who die prematurely has been estimated based on the assumption that if those who died had lived and not had dementia, they would have been

---

[18] The AWE estimate is based on wages data for those that are 'employed', a lower AWE based on wages data for all working age people, which includes those 'unemployed' would underestimate the likely productivity costs, which already accounts for unemployment based on the probability of employment.

[19] The estimate of 5% of work time lost was conservatively based on 8% lost for people with psychotic illnesses with similar cognitive and functional impairments.

employed at the same rate as the general population. This represents a further productivity loss, measured as the net present value (NPV) of future lost income streams for those people who die from dementia prior to when they would otherwise have retired.

The calculation is made separately for the age cohorts, with numbers of deaths attributable to dementia based on the discussion in Section 1.1.3. The NPV of premature mortality is then estimated using retirement age, average life expectancy, average age of death and a discount rate of 3.65% (see below). **The productivity loss from premature mortality was estimated at $5.5 million in 2008**.

Choosing an appropriate discount rate for present valuations in cost analysis is a subject of some debate, and can vary depending on which future income or cost stream is being considered. There is a substantial body of literature, which often provides conflicting advice, on the appropriate mechanism by which costs should be discounted over time, properly taking into account risks, inflation, positive time preference and expected productivity gains.

The absolute minimum option that one can adopt in discounting future income and costs is to set future values in current day dollar terms on the basis of a risk free assessment about the future (that is, assume the future flows are similar to the certain flows attaching to a long term Government bond).

Wages should be assumed to grow in dollar terms according to best estimates for inflation and productivity growth. The estimated discount rate used in the report for New Zealand is based on the following approach, for the reasons discussed in Access Economics (2008).

- ☐ **Positive time preference**: We use the long term nominal bond rate of 6.75% per annum from recent history (New Zealand Debt Management Office, 2008) as the parameter for this aspect of the discount rate. If there were no positive time preference, people would be indifferent between having something now or a long way off in the future, so this applies to all flows of goods and services.
- ☐ **Inflation**: The Reserve Bank of New Zealand (2007) has stated that its policy target shall be to keep future CPI inflation outcomes between 1% and 3% on average over the medium term. This is a realistic longer run goal and we therefore endorse the assumption of 2% pa for this variable. It is important to allow for inflation in order to derive a real (rather than nominal) rate.
- ☐ **Productivity growth**: Statistics New Zealand (2008e) reported that the average annual growth in labour productivity was 2.0% from 1978–2007 and averaged 1.1% from 2000 2007. We suggest 1.1% for the purposes of this analysis as a conservative estimate.

As such, to discount income streams of future earnings, the discount rate is: 6.75% – 2.0% – 1.1% = 3.65%.

3.1.4 INFORMAL CARE

Most people with dementia receive care at home initially, with day-to-day personal needs and support left very much to family and friends. Placing a value on the cost of the informal care provided can be estimated by using either:

- ☐ the **replacement cost method**, which measures the cost of ‘buying’ an equivalent amount of care from the paid formal sector in place of the informal carer; or
- ☐ the **opportunity cost method**, which measures the value in alternative paid employment of the time spent caring by family and friends.

In estimating these costs, it is recognised that there is a wide range of services for people with dementia and their carers in New Zealand, ranging from primary medical care, social work, counselling, day care and other domiciliary support services, to residential and long term specialised hospital services. These services are provided by a diverse range of providers with varied funding arrangements, including public sector organisations, for-profit private companies, not-for-profit religious and welfare organisations and advocacy groups such as the Alzheimer's Society.

The availability of information, however, for consumers and their families about dementia and dementia care services, and support services for carers and families (including respite care) is inconsistent around New Zealand, and access to these services often varies from region to region (MoH, 2002). Thus, the value of informal care provides a minimum estimate of the cost of care provided outside of residential facilities, for people with dementia living at home. It is still necessary to correctly attribute the appropriate portion of informal care costs that are borne by individuals, family, government and other society, where possible.

3.1.4.1 REPLACEMENT COST METHOD

Replacement valuation represents the most generous method of costing and implicitly assumes that, in a counterfactual priced market, the same number of services would be demanded as are currently provided by family and other unpaid carers.[20]

In calculating replacement cost, the value of the hours of care is estimated as the cost of outsourcing the equivalent care hours at standard remuneration rates for care workers. Three tiers of care are modelled, based on a study from the University of Michigan (Langa et al, 2001) of the average hours of care required for people with mild, moderate and severe dementia.[21] The imputed carer rate is $24.85 per hour, based on average total hourly earnings for the industry division 'Health and Community Services' in 2007 and estimated for 2008 based on historical growth rates (Statistics New Zealand, 2008c).

The number of people requiring care in 2008 is based on the prevalence estimates presented in Section 1.2 and data on care arrangements presented in MoH (2002). The number of people with dementia is estimated at 40,746 in 2008. There are 35,000 residential care beds available in New Zealand and 60%-70% of people in residential care have dementia (MoH, 2002). This implies that, at the lower bound of 60%, there are 21,000 people (35,000 people * 60%) with dementia in residential care and there are 19,746 people with dementia (or 48%) living at home (40,746 – 21,000). The data have been further disaggregated by severity based on the shares in Section 1.2.1 and additional data in MoH (2002), which reports that 'in New Zealand, the majority of people (at least 50%) with mild dementia are cared for in the community'. Using 50%, the results are shown in Table 3–2.

---

[20] An interesting variation on replacement valuation is provided in one Dutch study (Van der Wijk et al, 1999). The cost of informal care was valued according to costs that would have been incurred had a professional caregiver provided the service. However, the time spent by informal caregivers was assessed to be much higher than that of professionals, so activities were not valued according to total time spent by informal caregivers, but according to the time professionals *would have* spent on that same activity, asking professionals in institutional care explicitly how much time they spent on performing a certain care task. Thereafter, an hourly rate was assigned to each activity taking account of the specific expertise needed to perform a service. For example, cooking was valued lower than nursing.

[21] These care hours may be quite conservative – a 1985 US study showed the average care hours for mild and moderate dementia to be 22 and for severe dementia to be 56. An Italian study showed 45 hours of personal care required and 18 hours of other non-medical services (Lowin et al, 2000).

TABLE 3–2: PEOPLE WITH DEMENTIA BY CARE SETTING AND SEVERITY, 2008

	Community	Residential	Total
Mild	11,240	11,240	22,480
Moderate	5,699	6,478	12,177
Severe	2,807	3,282	6,088
Total	**19,746**	**21,000**	**40,746**

Using the replacement cost method, **it is estimated that the value of informal care provided by family and friends of people with dementia was $402.1 million in 2008** (19,746 people in home care * a weighted average of 15.8 hours per week of informal care * 52 weeks * $24.85 per hour of care). The results by severity are presented in Table 3–3.

TABLE 3–3: VALUE OF INFORMAL CARE – REPLACEMENT COST METHOD, NEW ZEALAND, 2008

Severity	No of people with dementia in home care	Hours of informal care per week required per person	Hours of informal care per week provided in total	Annual value of informal care provided, $m
Mild	11,240	8.5	95,542	123.4
Moderate	5,699	17.4	99,159	128.1
Severe	2,807	41.5	116,485	150.5
Total	19,746	15.8	311,185	402.1

Source: Langa et al (2001), MoH (2002), Statistics New Zealand (2008c) and Access Economics estimates.

3.1.4.2 OPPORTUNITY COST METHOD

The opportunity cost method is considered to be a conservative estimate of the value of care provided. This approach measures the formal sector productivity losses associated with caring, since the time devoted to caring responsibilities is time that cannot be spent in the paid workforce.

It is calculated as the number of people with dementia who require some level of care, multiplied by the average number of hours of care required, multiplied by an average hourly rate for the wage forgone by the carer, which is weighted by age, gender and the probability of alternative employment.

Using the opportunity cost method, **it is estimated that the value of informal care provided by family and friends for people with dementia was $29.3 million in 2008** (19,746 people in home care * a weighted average of 15.8 hours per week of informal care * 52 weeks * $24.29 weighted average hourly wage * 7.5% weighted chance of employment). The results are presented in Table 3–4.

TABLE 3–4: VALUE OF INFORMAL CARE – OPPORTUNITY COST METHOD, NEW ZEALAND, 2008

Severity	No of people with dementia in home care	Average care hours per week per person	Weighted average hourly wage, $	Weighted average chance of employment	Annual value of informal care provided, $m
Mild	11,240	8.5	24.29	7.5%	9.0
Moderate	5,699	17.4	24.29	7.5%	9.4
Severe	2,807	41.5	24.29	7.5%	11.0
Total	19,746	15.8	24.29	7.5%	29.3

The opportunity cost approach is a more accurate measure of productivity loss, while the replacement valuation method is more appropriate to determine costs if, for example, there were no longer any informal carers able or willing to provide care (perhaps in the very long term as a consequence of demographic ageing). As such, the opportunity cost outcome of $29.3 million is used in this report to estimate productivity losses due to dementia.

3.1.5 TAXATION REVENUE FORGONE

Lower earnings due to reduced workforce participation (for both people with dementia and carers), absenteeism and premature death will also have an effect on taxation revenue collected by the New Zealand Government. As well as forgone income (personal) taxation, there will also be a fall in indirect (consumption) tax, as those with lower incomes spend less on the consumption of goods and services.

Personal income tax forgone is a product of the average personal income tax rate and the forgone income. With dementia and lower income, there will be less consumption of goods and services. Without dementia, it is assumed that consumption would comprise total household income minus any household savings. As such, the indirect tax forgone is estimated as a product of the forgone consumption and the average indirect tax rate.

While the taxation rate for individual income in New Zealand is between 19% - 45% depending on income levels (Inland Revenue, 2008b), the average tax rate for New Zealand is calculated as the ratio between total household primary income receivable and taxes on income for households – around 23.0%.[22] Additionally, the indirect tax forgone is estimated as a product of the forgone consumption and the average indirect tax rate, proxied as the current rate of GST in New Zealand, 12.5% (Inland Revenue, 2008a).

Household savings have been trending downward and, since the early 1990s, become negative, indicating that the household sector has been dissaving: that is, consuming in excess of its disposable income (Bollard et al, 2006). In 2007, the household saving rate was -14.16% of household disposable income (Statistics New Zealand, 2008e). As such, a modelling assumption of no savings nor dissavings has been taken – that is, given the negative savings rate currently in New Zealand (which is unsustainable in the long run), a conservative estimate has been taken that 100% of household income is consumed.

Using the savings rate, the overall tax rate of 35.5% is applied to all the productivity losses, noting that some of the absenteeism loss may be paid by the employers using sick leave, rather than as lost wages which would result in lost taxation. The estimate of taxation forgone on absenteeism assumption may thus be a high estimate, but is small relative to total productivity losses (Table 3–5).

It is estimated that $57.5 million in taxation revenue was forgone due to dementia in New Zealand in 2008. Of this total, $47.1 million is from reduced workforce participation, absenteeism and premature death of those with dementia and $10.4 million is from reduced workforce participation (using the opportunity costs method of valuation) of those caring for people with dementia in their own homes.

---

[22] Calculated as Income Tax ($25,664 million) / Total Primary Income Receivable ($111,397 million) (Statistics New Zealand, 2008e).

TABLE 3–5: PRODUCTIVITY LOSSES, CARER COSTS AND TAXATION FORGONE, NEW ZEALAND, 2008

		Productivity loss	Taxation forgone
People with dementia		132.5	47.1
Lower employment	124.7		
Absenteeism	2.3		
Premature death	5.5		
Carers – lower employment		29.3	10.4
Total		**161.9**	**57.5**

3.2 TRANSFERS AND PROGRAM PAYMENTS

There is additional expenditure associated with people with dementia that falls under the categories of welfare transfers, respite and carer support, travel costs, aids and home modifications.

3.2.1 WELFARE TRANSFERS

Many people living with dementia are reliant on welfare benefits as their main source of income. There are two main in-cash benefits that people with dementia can receive – the Invalids Benefit for those under 65 years of age and the aged pension (known as New Zealand Superannuation) for those 65 years of age and over.

The **Invalids Benefit** provides (means tested)[23] weekly payments for those who are unable to regularly work 15 hours or more a week because of a sickness, injury or disability which is expected to last at least two years (Table 3–6).

TABLE 3–6: INVALIDS BENEFIT, NEW ZEALAND, 2008

Status	Weekly payments after tax, $
Single 16-17	186.28
Single 18 or over	230.19
Married, de-facto or civil union couple each	191.83
Sole parent	302.40

Source: Ministry of Social Development (2008), rates at 1 April 2008.

People under retirement age with dementia may be eligible for the Invalids Benefit and in some cases, the Sickness Benefit. The Invalids Benefit is the main means of income support in New Zealand for people aged 16 years and over whose sickness, injury, or disability prevents them from working. The Sickness Benefit provides assistance for people who are employed and who are temporarily unable to work due to a medical condition. It is not significant in the case of dementia so is not modelled here.

It is estimated that in 2008 there are 40,746 people in New Zealand with dementia and that 2,244 are under 65 years of age. Subtracting the number of people estimated as employed and under 65 years of age (393 people) based on the data in Section 4.1.2, it is calculated that in 2008 there are a maximum[24] of 1,851 people eligible to receive an Invalids Benefit for dementia. **This implies social security payments totalling $21.4 million in 2008** (89 people * $54.05 – disability allowance + 28 people * $226.62 (before tax) for singles 16-17 + 24

---

[23] A person may not qualify for the Invalids Benefit if they have other money to live on, such as a partner's income.

[24] The maximum implies that all people with dementia under 65 and not working would be eligible for the Invalids Benefit; it does not account for any reductions due to means testing (partners' incomes) and as such should be treated as a high estimate.

people * 279.24 (before tax) for Single 18 or over + 1,710 people * 230.62 (before tax) for Married, defacto or civil union).

New Zealand Superannuation provides means tested[25] fortnightly payments for those not working and over 65 years of age (Table 3–7).

TABLE 3–7: NEW ZEALAND SUPERANNUATION, NEW ZEALAND, 2008

Status	Fortnighly payments before tax, $
Single living alone	695.54
Single (sharing)	640.22
Married, de-facto or civil union couple (partner not included)	528.74
Married, de-facto or civil union couple (both partners qualify) - each	528.74
Married, de-facto or civil union couple* (only 1 partner qualifies) - each	502.84

Source: Ministry of Social Development (2008), rates at 1 April 2008.

Since Superannuation is paid to eligible elderly regardless of dementia, only those that would have otherwise have continued working beyond 65 years of age, but instead become reliant on the aged pension are counted in the welfare transfer calculation.

Of the 40,746 people in New Zealand with dementia, it estimated that 38,502 are over 65 years of age. Based on lower employment data from Section 3.1.1, it is estimated that 1,270 people over 65 years of age are not otherwise working because of dementia. Using the lowest New Zealand Superannuation payment ($502.84) as a conservative approach, **implies a transfer payment totalling $16.7 million in 2008 for people over 65 years of age**.

In total, it is estimated that people with dementia receive transfer payments of $38.2 million ($21.4 million for the Invalids Benefit and $16.7 million in New Zealand Superannuation payments) in 2008.

3.2.1.1 RESPITE AND CARER SUPPORT

Respite services are available to disabled people and to carers, family and whanau[26] whose primary role involves the care and support of a disabled family member. Some respite care is provided in the community and in residential care facilities. Short-term care for a person with dementia is known as respite care and, if a person with dementia cannot be left alone, a 'sitter' may be able to come and be with the person while the primary carer goes out. Some Alzheimers' organisations provide sitter services (Alzheimers New Zealand, 2007). Other carer support is a subsidy funded by the MoH to assist the unpaid, full-time care of a disabled person to take a break from caring for that person.

While some centres are funded by the Government, often a small subsidy is asked to be paid for the day care services. Others may use a sliding fee scale based on income. Private medical insurance policies sometimes cover a portion of day care costs when registered, licensed medical personnel are involved in the care. Long-term care insurance may also pay for adult day services, depending upon the policy. Dependent care tax credits may be available to the caregiver as well (New Zealand Care Coach, 2003b).

There are two subsidy rates paid by MoH per day – formal and informal.

---

[25] 'Receiving other income does not affect your Superannuation unless your partner is 'included' in your payments when they do not qualify for Super themselves. If your partner is 'included', you can have other income of up to $80 per week (before tax) between you before your Super is affected. If you earn more than this, we will take 70c off your payment for each dollar of income over this limit' (Ministry of Social Development, 2008).

[26] Whanau means extended family in the Maori language.

- Formal Rate = $75.56 (GST inclusive) per day: applies to relief services provided in a formal or commercial setting (eg, if the person cared for goes to a rest home, or if a home care agency provides care at home); and
- Informal Rate = $64.50 (GST inclusive) per day: applies to relief services provided by friends, neighbours and family members. A ‘family member’ is defined as a daughter, son, sister, brother or cousin who does not live with the client.

Usually the MoH pays direct to the person or service that provided the care, after the care has been given.

Most rest homes that provide short term residential care accept the Carer Support rate. However, with some there may be a shortfall of $150 per week or more and there is usually a requirement to provide your own medications, incontinence products and pay for your own GP (New Zealand Care Coach, 2003a).

Providing adequate supports for family/whanau and other caregivers is also seen as central to enabling people with disabilities to live independently in the community. Caregiver support is relief support provided inside or outside the home. MoH expenditure on caregiver support has increased by about 50% from $41.5 million in 1999-00 to $62.2 million[27] in 2003-04 (MoH, 2004). This increase in expenditure is offset to some extent by the fact that it enables people with disabilities to remain in their homes, and may keep them out of more restrictive and expensive service options, such as residential care (MoH, 2004). The final chapter of this report provides more detail in relation to this benefit.

In New Zealand, carers have available to them four weeks respite care per annum[28]. If it is assumed that all carers have access to this service and use it to its capacity, then the community respite and carer support cost is related to dementia is calculated as: 19,746 people with dementia who live at home * 15.8 hours per week * 4 weeks a year * $24.84 per hour[29]. Given the diversity of providers of these services, it is assumed that the burden of costs for the four weeks respite and carer support falls half on ‘other society’ and half on the government. **This equates to $15.5 million each for government and other society ($30.9 million in total) to provide respite care in 2008**.

3.2.2 TRAVEL COSTS, AIDS AND HOME MODIFICATIONS

Measures provided for people with a disability, including people with dementia, in New Zealand also include travel to services, mobility aids and housing modifications.

People who have a physical, intellectual, sensory (vision or hearing) and/or age-related disability may be eligible for equipment and/or funding for modifications to assist with safety and independence (Disability Services Directorate, 2008).

---

[27] This figure is made up of $43.9 million MoH expenditure (total expenditure from 1 July 2003 to 30 September 2003 (before devolution of disability services for older people to District Health Boards (DHBs) from 1 October 2003) and non-devolved expenditure from 1 October 2003 to 31 June 2004) and $18.3 million DHB expenditure (devolved DHB expenditure for 1 October 2003 to 31 June 2004).

[28] If a carer provides informal care for 48 weeks per year (availing themselves of respite care), it is assumed unlikely that the carer would offset the productivity costs by increasing their paid employment for four weeks of each year.

[29] In calculating the value of respite and carer support, the replacement cost method is a more accurate reflection of the cost of providing that service, rather than the opportunity cost method for the informal care, which takes account of other considerations such as the chance of employment (not relevant to this calculation).

3.2.2.1 TRAVEL AND TRANSPORT

Transport assistance is provided by the MoH to access specialist health and disability services; other agencies also provide transport assistance for people with disabilities through programs such as Total Mobility.

Total Mobility is a nation-wide scheme aimed at assisting people with impairments to become more mobile and active in the community. The scheme offers eligible clients 50% discount on taxi fares for transport. A book of yellow vouchers is issued to each client, and one voucher is redeemed at the completion of each trip. The client must pay the remaining 50% at the time of travel. The scheme is funded jointly by Land Transport New Zealand and local or regional councils. Using details of the scheme based on operations in Northland, the average subsidised fare is $5.90, and the average number of trips was around two per month (Ministry of Transport, 2004).[30] **This implies a cost of around $2.8 million in 2008 across the population of people living at home with dementia (19,746 people).**

Other public and private transport services are available for disabled people, as well as vehicle modifications. The organisation WEKA (What Everybody Keeps Asking – about disability information) provides a central point of information on these topics for the community.

3.2.2.2 MODIFICATIONS AND AIDS

People with dementia and their families and carers may require a variety of additional equipment, aids and home modifications in order to continue living at home safely. There are a number of public programs for older people, people with a disability and their families and carers to assist them to make home modifications and provide aids and equipment that will help them to remain living in their own home and avoid having to go into a residential care facility.

The Housing Modification program is a MoH funded service to help people remain in or return to their home. The program provides housing modifications such as: handrails into the home; access ramps; level access showers/accessible bathrooms to improve safety and independence; and fencing to safely support a person who is at risk of injury because of their disability.

The Equipment and Modification program is another MoH funded service to help people with a physical, intellectual, sensory and/or age-related disability get some equipment and/or funding for modifications to improve safety and independence. Some of the costs are part paid by the resident for the modifications to a house or vehicle. In a few cases, some funding support is available to help with buying a vehicle.

Detailed expenditure on Ministry-funded services for equipment and modifications is presented annually in the MoH’s annual report on health and independence in New Zealand. The latest data is presented in Table 3–8.

---

[30] Data provided by local authorities indicate that the monthly average number of trips taken by Scheme members is low, and in many regions, it may be as low as two trips a month. Data obtained from local authorities indicates the average number of trips taken per person per month on the Total Mobility Scheme ranges from a high of 5.9 trips to a low of 1.17 trips. **http://www.transport.govt.nz/assets/NewPDFs/total-mobility2.pdf**.

TABLE 3–8: EXPENDITURE BY SUPPORT SERVICES CATEGORY, 2000/01-2006/07 ($'000)

Category	2000/01	2001/02	2002/03	2003/04	2004/05	2005/06	2006/07	% of total
Wheelchairs and mobility	8854	9708	12562	13719	13246	11824	14166	28.9%
Housing modifications	8875	8301	11876	15592	12681	11305	10507	21.4%
Equipment for daily living	8253	7994	6903	8549	11510	11862	13702	27.9%
Hearing	1647	3457	3294	3571	5513	3855	9388	19.1%
Vehicles	341	448	469	509	260	291	279	0.6%
Vision	116	396	132	95	174	174	218	0.4%
Comm & information technology	460	352	557	426	486	511	783	1.6%
Total	28546	30656	35793	42461	43869	39821	49042	100.0%

Source: MoH (2007). Note: The 2006/07 information is unaudited and estimates are exclusive of GST.

The 2001 post-census disability surveys (conducted by the MoH and Interagency Advisory Group 2004) reported that 15% of the 716,500 adults with disabilities living in households had received a needs assessment at some time (MoH, 2006). This implies average expenditure on aids and modifications in 2001 of around $285 per person ($30.7 million/ (716,500 * 15%)).

The same method is used to calculate the average expenditure on each of the support services categories, with a breakdown presented in Table 3–9 of per person costs of aids and modifications most likely to be needed by people with dementia. The 2006/07 expenditure data has been inflated to 2008 using the latest CPI data from Statistics New Zealand (2008f). The total cost is $365.46, comprising $134.91 on wheelchairs and mobility, $100.06 on housing modifications and $130.49 on equipment for daily living.

TABLE 3–9: EXPENDITURE PER PERSON BY SUPPORT SERVICES CATEGORY, 2001/02 AND 2008 ($)

Category	2001/02	2008
Wheelchairs and mobility	90.33	134.91
Housing modifications	77.24	100.06
Equipment for daily living	74.38	130.49
Total	241.94	365.46

Note: Estimates are exclusive of GST.

The 2008 per person cost of $365.46 for aids and modifications was then applied to those people living at home who had moderate and severe dementia (8,506 people). It was assumed that those with mild dementia would be less likely to require these services, consistent with the definition used in the 2001 Household Disability Survey (as described in MoH 2004), where people with a moderate or severe disability are identified as having a disability requiring assistance. **This implies a total cost of $3.1 million in 2008.**

3.3 DEADWEIGHT LOSSES

Any extra costs that are borne by government carry with them efficiency costs to the economy, known as **deadweight losses (DWLs)**. In relation to dementia, these DWLs arise from the need to raise additional taxes to cover the impact from:

- reduced earnings (and, hence, lower taxation) due to falls in workforce participation (by people with dementia and their carers) and from absenteeism and premature death as a result of the disease; and
- increased expenditures associated with the disease that are borne by the government, such as the government proportion of health care costs and welfare payments.

The need to raise additional taxation to cover revenue losses and increased expenditures, results in a distortionary impact of taxes on workers' labour and consumption choices.

Internationally, it has been reported that these distortionary impacts are estimated to be in the range between 9%-16% and 50%.[31]

In New Zealand, studies by Diewert and Lawrence (1994, 1995, 1996) found that in 1991 the efficiency loss associated with personal income tax was 18% and for consumption taxes around 14%. They also noted that the efficiency losses associated with labour taxation increased from 5% to over 18% in the 20 years up to 1991. In another study (McKeown and Woodfield, 1995) based on 1988 data, estimates were generated ranging from 24.6% to 146.2% of taxes raised.

Neither estimate includes possible efficiency losses from the taxation of income earned on capital, or administration and compliance costs. In this report, the approach has been taken to adopt the parameter estimate of 18% to calculate the DWL of raising additional taxation revenue to finance government costs associated with dementia in New Zealand. The use of 18% balances the upside risk that the efficiency losses have continued to increase since 1991 against the downside risk that tax raised from non-labour sources has lower associated efficiency losses.

In aggregate, Access Economics has estimated the **DWL incurred in 2005 as $81.3 million**. This total comprises the DWLs from:

- the portion of health care costs borne by government estimated at $60.2 million ($435.7 million * 77% * 18%);
- lost taxes estimated at $10.4 million – using the opportunity cost method to value informal carer costs - ($57.5 million * 18%);
- welfare payments estimated at $6.9 million ($38.2 million * 18%); and
- all other costs borne by government estimated at $3.8 million (($15.5 million for respite and carer support + $2.8 million for travel and transport + $3.1 million for aids and modifications) * 18%).

3.4 SUMMARY OF OTHER FINANCIAL COSTS

In addition to the health care costs identified in Chapter 3, there are substantial other financial costs associated with dementia. In total, other financial costs are estimated as $277.2 million in 2008. The main components are presented in Table 3–10.

---

[31] See Browning (1987); Ballard et al (1985); or Stuart (1984).

TABLE 3–10: OTHER FINANCIAL COSTS FOR DEMENTIA IN NEW ZEALAND, 2008

	2008, NZ$m	% of Total
Productivity losses	**132.5**	**47.8%**
Lower employment rates	124.7	
Absenteeism	2.3	
Premature mortality	5.5	
Informal care	**29.3**	**10.6%**
Respite and Carer support	**30.9**	**11.1%**
Mobility aids and modifications	**3.1**	**1.1%**
Deadweight losses	**81.3**	**29.3%**
Health system costs	60.2	
Taxation foregone	10.4	
Social security payments	6.9	
Other costs	3.8	
Total other finacial costs	**277.2**	**100.0%**

4. BURDEN OF DISEASE

To those experiencing dementia, the loss of quality of life, loss of leisure and disability together present a burden that can go well beyond the health system costs or other financial losses from the disease. Dementia is a disabling condition that can bring turmoil and anguish to those involved. In 2008, it is estimated that 1,378 people in New Zealand will die due to their dementia. This chapter estimates the value of the burden of suffering and premature death from dementia in New Zealand in 2008.

Section 4.1 details the methods that have been developed that allow us to quantify and price this burden. Section 4.2 describes the methodology used to estimate the burden from dementia that is specifically applied in this report, including details of other key parameters used in the calculations. Finally, Section 4.3 presents the results of the estimation of the burden of disease from dementia in New Zealand, including a sensitivity analysis around a key parameter.

4.1 METHODS FOR VALUING LIFE AND HEALTH

4.1.1 MEASURING BURDEN: DALYS, YLLS AND YLDS

In the last decade a non-financial approach to valuing human life has been derived, where loss of wellbeing and premature mortality – called the ‘burden of disease and injury’ – are measured in terms of Disability Adjusted Life Years, or DALYs. This approach was developed by the World Health Organization (WHO), the World Bank and Harvard University for a study that provided a comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990, projected to 2020 (Murray and Lopez, 1996). Methods and data sources are detailed further in Murray et al (2001) and the WHO continues to revisit the estimates for later years.

A DALY of 0 represents a year of perfect health, while a DALY of 1 represents death. Other health states are attributed values between 0 and 1 as assessed by experts on the basis of literature and other evidence of the quality of life in relative health states. For example, the *disability weight* of 0.18 for a broken wrist can be interpreted as losing 18% of a person’s quality of life relative to perfect health, because of the inflicted injury. Total DALYs lost from a condition are the sum of the mortality and morbidity components – the Year(s) of Life Lost due to premature death (YLLs) and the Year(s) of healthy life Lost due to Disability (YLDs).

The DALY approach has been successful in avoiding the subjectivity of individual valuation and is capable of overcoming the problem of comparability between individuals and between nations, although some nations have subsequently adopted variations in weighting systems, for example age-weighting for older people. This report treats the value of a life year as equal throughout the lifespan.

As these approaches are not financial, they are not directly comparable with most other cost and benefit measures. In public policy making, it is often desirable to apply a monetary conversion to ascertain the cost of an injury, disease or fatality or the value of a preventive health intervention, for example, in cost benefit analysis. Such financial conversions tend to utilise ‘willingness to pay’ or risk-based labour market studies as described in the next section.

4.1.2 WILLINGNESS TO PAY AND THE VALUE OF A STATISTICAL LIFE YEAR

The burden of disease as measured in DALYs can be converted into a dollar figure using an estimate of the **Value of a 'Statistical' Life** (VSL). As the name suggests, the VSL is an estimate of the value society places on an anonymous life. Since Schelling's (1968) discussion of the economics of life saving, the economic literature has focused on **willingness to pay** (WTP) – or, conversely, willingness to accept (WTA) – measures of mortality and morbidity, in order to develop estimates of the VSL.

Estimates may be derived from observing people's choices in situations where they rank or trade off various states of wellbeing (loss or gain) either against each other or for dollar amounts eg, stated choice models of people's WTP for interventions that enhance health or WTA poorer health outcomes or the risk of such states. Alternatively, risk studies use evidence of market trade-offs between risk and money, including numerous labour market and other studies (such as installing smoke detectors, wearing seatbelts or bike helmets and so on).

The extensive literature in this field mostly uses econometric analysis to value mortality risk and the 'hedonic wage' by estimating compensating differentials for on-the-job risk exposure in labour markets; in other words, determining what dollar amount would be accepted by an individual to induce him/her to increase the probability of death or morbidity by a particular percentage. Viscusi and Aldy (2002), in a summary of mortality studies, find the VSL ranges between US$4 million and US$9 million with a median of US$7 million (in year 2000 US dollars), similar but marginally higher than the VSL derived from studies of US product and housing markets. They also review a parallel literature on the implicit value of the risk of non-fatal injuries.

Weaknesses in the WTP approach, as with human capital approaches to valuing life and wellbeing, are that there can be substantial variation between individuals. Extraneous influences in labour markets such as imperfect information, income/wealth or power asymmetries can cause difficulty in correctly perceiving the risk or in negotiating an acceptably higher wage in wage-risk trade off studies, for example.

In our own review of international VSL studies (Access Economics, 2008), the average VSL from New Zealand studies was A$7 million, with a range of A$1.1-21.4 million (all in 2006 prices)[32]. This report uses the mean figure of A$7 million to estimate the value of the loss of wellbeing from dementia in New Zealand. This figure is converted to 2008 NZ$ using purchasing power parity between New Zealand and Australia for 2006 (NZ$1.08 = A$1)[33] and then inflated to 2008$NZ using New Zealand inflation data (2008 change from 2006 = 6.0%)[34]. Based on this calculation (A2006$7 million × 1.08 × 1.06), **the estimated VSL for New Zealand for 2008 is NZ$7,998,102**.

As DALYs are enumerated in years of life rather than in whole lives it is necessary to calculate the **Value of a 'Statistical' Life Year (VSLY)** based on the VSL. This is done using the formula:[35]

---

[32] The New Zealand studies are reported in Guria et al (1999); Hansen and Scuffham (1995); Leung and Guria (2006); Miller (2000); and Miller and Guria (1991).

[33] OECD**,** http://www.oecd.org/dataoecd/61/56/39653523.xls (accessed: 10 June 2008)

[34] Statistics New Zealand (2008f), Consumer Price Index, March Quarter 2008, http://www.stats.govt.nz/products-and-services/hot-off-the-press/consumers-price-index/consumers-price-index-marc08qtr-hotp.htm?page=para004Master**, Calculation** compared March 2008 to March 2006.

[35] The formula is derived from the definition:

$VSL = \Sigma VSLYi/(1+r)^{\wedge i}$ *where* $i=0,1,2....n$

where VSLY is assumed to be constant (i.e. no variation with age).

$$VSLY = VSL / \Sigma_{i=0,\dots,n-1}(1+r)^i$$

Where: n = years of remaining life, and
r = discount rate.

Clearly there is a need to know *n* (the years of remaining life), and to determine an appropriate value for *r* (the discount rate). There is a substantial body of literature, which often provides conflicting advice, on the appropriate mechanism by which costs should be discounted over time, properly taking into account risks, inflation, positive time preference and expected productivity gains. In reviewing the literature, Access Economics (2008) found the most common rate used to discount healthy life was 3% – both in Australia (eg, Mathers et al, 1999; Begg et al, 2007) and overseas (eg, perhaps the most eminent being Nordhaus, 2002 (Yale); Murphy and Topel, 2005 (University of Chicago); Cutler and Richardson, 1998 (Harvard); WHO, 2002; Aldy and Viscusi, 2006). This report assumes a discount rate for future streams of health in New Zealand of 3%. Further it is assumed that on average people have 40 years of life remaining.[36]

On this basis, **the estimated VSLY for New Zealand used in this report is $335,939.** Because of the uncertainty surrounding the VSL estimate and the importance of this parameter to the overall estimate of the burden of dementia in New Zealand, this report presents some sensitivity analysis (±$3 million) using a low value of $4,998,102 and high value of $10,998,102. The low estimate of the VSLY is $209,932 and the high estimate of the VSLY is $461,946.

4.2 BURDEN OF DISEASE FROM DEMENTIA

Access Economics adopts 'burden of disease' methodology outlined in Section 4.1.1 to quantify the substantial costs of the loss of wellbeing and quality of life resulting from dementia. Disability weights for mild, moderate and severe dementia are based on the Dutch weights from the global burden of disease study (Murray and Lopez, 1996). These are:

- ☐ 0.27 for mild dementia;
- ☐ 0.63 for moderate dementia; and
- ☐ 0.94 for severe dementia.

The burden of disease is thus calculated on a prevalence basis from the prevalence estimates from Section 1.2 together with disability weights, for the year 2008. This measure includes two components: **Years of healthy life Lost due to Disability (YLDs)** and **Years of Life Lost due to premature death (YLLs).**

4.2.1 YLD

YLDs from dementia are calculated by multiplying the number of people with dementia in New Zealand by the disability weight that applies to them. It is assumed that all people with dementia in 2008 experienced their condition for the entire year. Because disability weights for dementia are defined for mild, moderate and severe dementia, the estimation of YLDs required the average disability weight to be calculated.

---

[36] This assumption relates to the average years of life remaining for people included in VSL studies, not the years of life remaining for people with dementia.

The mild, moderate and severe split of dementia prevalence is 55%, 30% and 15%. Therefore, combined with the disability weights listed above, the average disability weight for dementia is calculated as:

$$(0.55\times0.27) + (0.3\times0.63) + (0.15\times0.94) = 0.48$$

4.2.2 YLL

YLLs are calculated based on the age at which the person dies and the life expectancy for people of that age.

Mortality rates for dementia were discussed in Section 1.1.3.

Table 4-1 shows the estimated number of deaths due to dementia in New Zealand in 2008 by age and gender. In total, 1,378 people are estimated to have died due to their dementia in 2008 in New Zealand.

TABLE 4-1: DEATHS DUE TO DEMENTIA, 2008

	Males	Females	People
0-59	3	3	6
60-64	2	2	5
65-69	15	8	24
70-74	28	29	58
75-79	60	62	122
80-84	140	180	320
85-89	168	404	572
90+	60	212	272
Total	**478**	**900**	**1,378**

Source: Access Economics. Note: rows and columns may not sum exactly due to rounding.

YLLs are calculated based on life expectancy according to the age and gender of people who died from dementia. For estimation purposes, people are assumed to be aged at the mid-point of their age group when they die. No age weighting was applied in the calculation, meaning that years of life in youth are valued equivalently to years of life in old age.

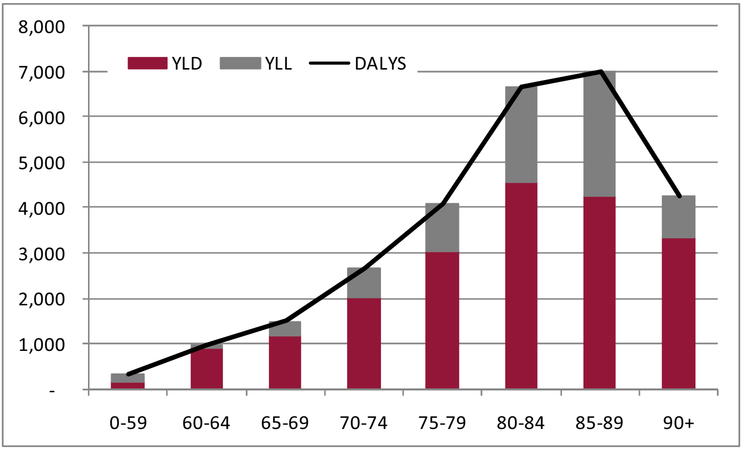
4.3 RESULTS

The total burden of disease from dementia, measured in DALYs is the sum of the burden of morbidity (YLDs) and the burden from premature death (YLLs):

DALYs = YLLs + YLDs

Figure 4-1 shows the burden of disease due to dementia in New Zealand in 2008 by age, broken into its YLD and YLL components. In total 27,449 years of life were lost due to dementia across the New Zealand population. The majority of the burden was due to morbidity (lost wellbeing and quality of life), with 19,464 YLDs making up 71% of DALYs. The remaining 29% of the burden was due to the estimated 7,985 YLLs from dementia.

FIGURE 4-1: BURDEN OF DISEASE FROM DEMENTIA IN NEW ZEALAND, 2008



Source: Access Economics.

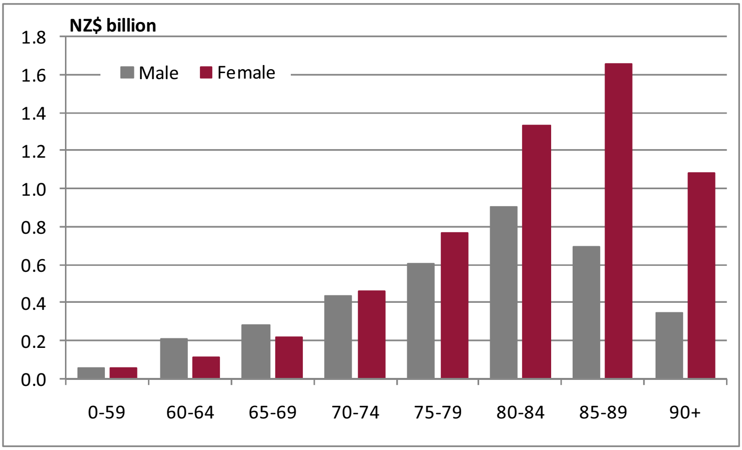
The burden of disease from dementia is disproportionately carried by women. While the burden for males was 10,546 DALYs (38% of total), the female burden was 16,903 DALYs (62% of total). Males experienced 7,743 YLDs and 2,804 YLLs, while females experienced 11,722 YLDs and 5,181 YLLs.

The burden of disease from dementia is converted into a dollar value, by multiplying the total DALYs from dementia by the VSLY.

DALYs × VSLY = gross value of the burden of disease

Figure 4-2 shows the gross value of the burden of disease from dementia in 2008 in New Zealand by age and gender cohorts. The total estimated gross value of the morbidity and mortality from dementia is $9.2 billion ($3.5 billion for males and $5.7 billion for females).

FIGURE 4-2: VALUE OF BURDEN OF DISEASE FROM DEMENTIA, 2008



Source: Access Economics

People aged 80 years and older suffer 65% of the total value of the burden of disease from dementia in New Zealand, or $6.0 billion. On a per capita basis, the burden of disease from dementia increases with age. As is expected for an age related condition such as dementia, the distribution of the disease burden (shown in Figure 4-2) largely reflects the underlying age structure of the New Zealand population.

4.3.1 SENSITIVITY ANALYSIS

The estimates of the value of the burden of disease presented in the previous section are based on a VSLY for New Zealand of $335,939. This estimate was the mean of a range of VSLY estimates reported in Section 4.1.2.

Table 4-2 provides a sensitivity analysis on the estimate of the VSLY, using the low value (VSL = $4.0 million, VSLY = $209,932) and the high value (VSL = $11.0 million, VSLY = $461,946). These values represent a ±$3 million range on the mean estimate. In Section 4.1.2, we reported the range for the VSL in New Zealand from a literature review as being A$1.1-21.4 million, hence the true value of the burden of disease of dementia in New Zealand could fall in an even larger range, however Access Economics considers that the value is most likely to fall in the range reported in this section, based on meta-analysis of the mean and range of VSL found in Access Economics (2008).

TABLE 4-2: VSLY SENSITIVITY ANALYSIS: VALUE OF DEMENTIA BURDEN, 2008 ($ MILLION)

Age	Low (VSLY = $209,932)	Mean (VSLY = $335,939)	High (VSLY = $461,946)
0-59	68	110	151
60-64	206	329	452
65-69	314	503	692
70-74	562	899	1,236
75-79	857	1,371	1,886
80-84	1,395	2,232	3,069
85-89	1,468	2,350	3,231
90+	892	1,427	1,962
Total	**5,762**	**9,221**	**12,680**

The sensitivity analysis provides a range of $5.76-12.68 billion for the estimate of the value of the burden of disease from dementia in New Zealand. The uncertainty regarding the VSL should be kept in mind when considering the burden of disease from dementia.

Bearing in mind that the wage-risk studies underlying the calculation of the VSL take into account all known personal impacts – suffering and premature death, lost wages/income, out-of-pocket personal health costs and so on – the estimate of $9.2 billion should be treated as a 'gross' figure. However, costs specific to dementia that are unlikely to have entered into the thinking of people in the source wage/risk studies should *not* be netted out (eg, publicly financed health spending, care provided voluntarily). The results after netting out are presented in Table 4-3.

TABLE 4-3: NET BURDEN OF DISEASE FROM DEMENTIA, $ MILLION, 2008

	Individual
Gross cost of lost wellbeing	**9,221.2**
Minus production losses net of tax	83.9
Minus GP costs borne out-of-pocket	0.5
Minus aged care costs borne out-of-pocket	98.6
Net cost of lost wellbeing	**9,038.7**

The net burden of disease from dementia in New Zealand in 2008 is estimated to be $9.0 billion.

4.4 ECONOMIC IMPACT OF DEMENTIA

Table 4-4 presents a summary of all the costs of dementia in New Zealand for 2008. The cost summary presents the financial and burden of disease costs separately, since the latter (health/wellbeing) is not considered part of living standards as measured by Gross Domestic Product (GDP), and since greater uncertainty surrounds the dollar estimate of the disease burden.

The total financial cost of dementia in 2008 was estimated as $712.9 million.

- Of the total, $435.7 million (61.1%) was for health system expenditures and $277.2 million (38.9%) was for other financial costs.

The value of the healthy life lost was estimated as a further $9.04 billion, bringing the total to an estimated $9.75 billion.

TABLE 4-4: SUMMARY OF ECONOMIC COSTS OF DEMENTIA, NEW ZEALAND, 2008

Cost Item	$ million	% Financial costs	% Total costs	Individual $ million	Government $ million	Other society $ million
Health system costs						
Total Hospital	100.88	14.15%	1.03%	-	100.88	-
Public inpatients	*92.09*	*12.92%*	*0.94%*	-	*92.09*	-
Private inpatients	*negligible*					
Outpatients	*8.79*	*1.23%*	*0.09%*	-	*8.79*	-
GPs	0.96	0.13%	0.01%	0.48	0.47	-
Specialists	negligible					
Pharmaceuticals	2.95	0.41%	0.03%	-	2.95	-
Pathology and Imaging	0.09	0.01%	0.00%	-	0.09	-
Research	2.93	0.41%	0.03%	-	1.26	1.68
Allied Health	0.91	0.13%	0.01%	0.46	0.45	-
Aged Care	272.51	38.23%	2.79%	98.57	173.94	-
Sub-total allocated	**381.23**	**53.48%**	**3.91%**	**99.51**	**280.04**	**1.68**
Unallocated	54.46	7.64%	0.56%	-	54.46	-
Total health costs	**435.69**	**61.12%**	**4.47%**	**99.51**	**334.50**	**1.68**
Other financial costs						
Productivity losses	132.52	18.59%	1.36%	83.93	1.49	47.09
Lower employment rates	*124.74*	*17.50%*	*1.28%*	-	-	-
Absenteeism	*2.31*	*0.32%*	*0.02%*	-	-	-
Premature mortality	*5.46*	*0.77%*	*0.06%*	-	-	-
Informal care	29.35	4.12%	0.30%	18.92	10.43	-
Respite and Carer support	30.93	4.34%	0.32%	15.46	15.46	-
Mobility aids and modifications	3.11	0.44%	0.03%	-	3.11	-
Deadweight losses	81.28	11.40%	0.83%	-	81.28	-
Health system costs	*60.21*	*8.45%*	*0.62%*	-	-	-
Taxation foregone	*10.35*	*1.45%*	*0.11%*	-	-	-
Social security payments	*6.87*	*0.96%*	*0.07%*	-	-	-
Other costs	*3.85*	*0.54%*	*0.04%*	-	-	-
Total other financial costs	**277.18**	**38.88%**	**2.84%**	**118.31**	**111.77**	**47.09**
Total financial	**712.87**	**100.00%**	**7.31%**	**217.83**	**446.27**	**48.77**
Net burden of disease	9,038.73		92.69%	9,038.73	-	-
Total including net BoD	**9,751.60**		**100.00%**	**9,256.56**	**446.27**	**48.77**
% financial total	**100.0%**			**30.6%**	**62.6%**	**6.8%**
% total including BoD	**100.0%**			**94.9%**	**4.6%**	**0.5%**

Note: Figures may not add due to rounding.

FIGURE 4-3: DISTRIBUTION OF FINANCIAL COSTS OF DEMENTIA, 2008

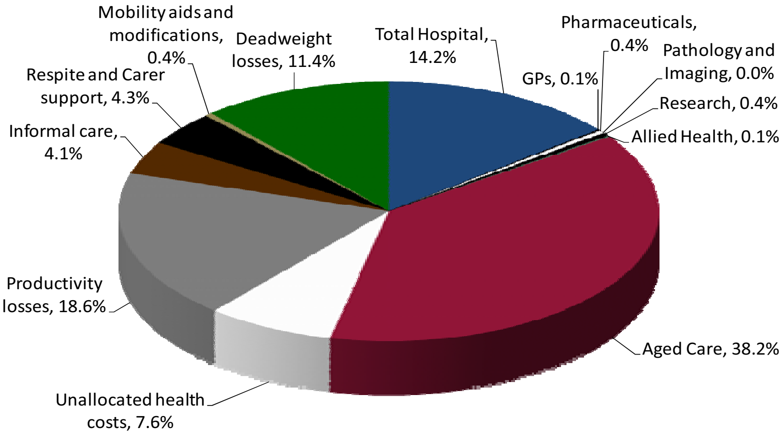
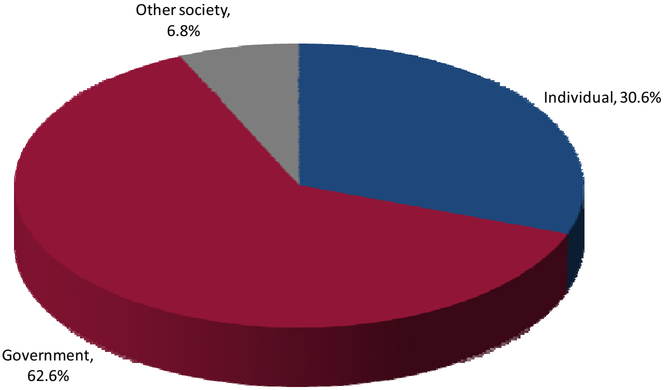


FIGURE 4-4: FINANCIAL COSTS OF DEMENTIA BY BEARER OF COSTS, 2008



5. CONSTRAINTS TO IMPROVING DEMENTIA SERVICES

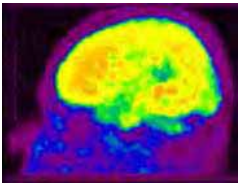
This section identifies constraints to current service delivery and to extending service provision to meet projected need, including medical and hospital services, pharmaceuticals, research, residential care, home and community programs, and demand/distributional issues in the health financing system. A solution-focused approach is adopted.

5.1 MEDICAL AND HOSPITAL SERVICES

Early detection: GPs play a key role in medical treatment – recognising, assessing, planning, managing, referring and supporting the person and their carer. However, studies show that only half of GPs are able to recognise mild dementia and about 70% are able to identify moderate dementia (Creasey and Brodaty, 1998). This is because differential diagnosis can be complex – especially in differentiating depression[37] – and more information and resourcing is required to support GPs in early diagnosis. With better treatments, questionnaires for differential diagnosis and tests now available, GPs may now be more interested and able to diagnose dementia. Interventions are required to assist GPs and others in detecting dementia.

The General Practitioner Assessment of Cognition (GPCOG) is a screening tool that is valid, reliable, quick to administer (less than four minutes for most), easy to use and acceptable to GPs and their patients, representing an advance over former screening tests – performing as well as the Abbreviated Mental Test and at least as well as the Mini Mental Score Examination (MMSE). Many GPs require more information about how to administer the GPCOG and differential diagnosis of cognitive impairment, although MMSE should also continue to be encouraged.

Using PET (positron emission tomography) scans in the early stage diagnostic process for AD has been found to reduce the false-positive rate by half and the false-negative rate by 60%. This analysis, presented by University of California (Los Angeles) researcher Dr Silverman at the American Academy of Molecular Imaging in October 2002, suggested that patients could be kept out of nursing homes for 9 to 18 months longer through such early diagnosis and the use of early treatment of AD with cholinesterase inhibitors. He also found that early diagnosis and treatment could substantially reduce medical and hospital costs. A PiB-PET test currently being trialled in the Australian Imaging and Biomarkers Lifestyle (AIBL) and elsewhere in the world is showing potential to bring forward the diagnosis of Alzheimer's disease by 18 months.[38]



PiB-PET scan, person with Alzheimer's
Photo courtesy of: Associate Professor
Christopher Rowe, Austin Health

---

[37] One key difference is that people suffering from depression are more aware of the problem and more likely to complain about symptoms (Blackmun, 1998).

[38] http://www.csiro.au/news/AIBLStudy.html

Supporting the GP role: After diagnosis, the GP is a key contact in relationship and life planning, learning strategies, prescribing medications, co-ordinating referral to specialists and to community care, arranging admission to hospital and attendance at nursing homes. As the illness progresses, the family or carer will seek the GP's advice more on behalf of the individual. GPs may not be as effective as desired in acquiring up-to-date information on dementia and dementia care, understanding the family's and carer's role and accessing a range of local support services available at different times. 'Shared-care' initiatives, aimed at spreading information between GPs and other aged care professionals, can be useful to help inform and resource GPs for ongoing care. Comorbid conditions require the GP to be up-to-date on the most recent pharmacotherapies, their subsidisation arrangements and their interaction with other drugs for concurrent ailments of ageing. If GPs are to play a central and continuing role in the care and management of their patients who have dementia, they need to be trained in the role and remunerated accordingly.

Supplementary education of GPs and primary care workers is required to assist them in caring for patients subsequent to screening. This should include dementia management principles with the goal of recognising highly trained GPs as 'dementia-accredited GPs'. This is in keeping with the de-institutionalisation of mental health care, the burden of which has fallen largely to GPs. There are also constraints to GPs attending patients in residential facilities (eg, time factors). Information technology initiatives such as teleconferencing may provide support for GPs who are more isolated and may also be of use in GP education and referencing programs.

Specialists and memory clinics: Neurologists, psycho-geriatricians and other specialists also have a key role in assessing, treating and prescribing, undertaking more comprehensive psychometric screening and equipped with skills to diagnose and monitor complex or unusual dementias. Extension of specialist services for early detection of dementia, for example through memory clinics, is important. Multidisciplinary memory clinics with specialist input are a useful, important and accepted community solution to coordinating dementia assessments and supporting the person with dementia, the family carer and the GP.

Acute care hospitals: Acute hospital costs could be reduced by decreasing the time that dementia patients are hospitalised awaiting transfer to a residential facility. Ongoing monitoring is required to assess potential mechanisms for reducing these wait times, and the cost-effectiveness, appropriateness and equity considerations of such interventions. Access to dementia-trained nursing staff should be available also in acute care hospitals for the period of the 'wait'. Acute care providers need training, resources (including geriatricians) and strategies to manage people with dementia (secure environments, appropriate assessment tools, care and discharge planning).

5.2 PHARMACEUTICALS

Early access to medications at an affordable price is a major constraint in New Zealand for people with dementia and their families and carers.

The drugs donepezil (Aricept®), rivastigmine (Exelon®) and galantamine (Reminyl®) work by boosting existing supplies of acetylcholine. These drugs are indicated for people with mild to moderate Alzheimer's disease, and although they are available, they are not currently subsidised in New Zealand. Therefore a month's supply of these drugs may cost between $200-$260 per month depending on where they are purchased.

Memantime (Ebixa®) is another drug that is available in New Zealand and is indicated for the treatment of people with more advanced disease. It works in a different way to the three acetylcholinesterase inhibitors mentioned above. This is also not subsidised in New Zealand.

Pharmac does not list these drugs as they are considered too expensive relative to their benefits. However, they are publicly subsidised in many other Western countries. Moreover, cost-cutting measures that target pharmaceutical expenditures have been found in numerous studies to be ineffective in reducing health costs overall and can increase health costs. Horn (2002) showed that:

- limiting doctors' prescribing choices was found to be associated with increased overall utilisation of pharmaceuticals;
- there are significant associations between formulary restrictions in a drug class and higher health care utilisation (GP or emergency department visits, additional prescriptions, hospitalisations);
- best practice drug use can result in lower carer absenteeism, lower employee turnover and greater labour productivity;
- the negative effects of formulary restrictions lead to particularly suboptimal therapy and outcomes for older people;
- patients with pharmaceutical capitation had 14% higher total health costs than non-capitated patients and 29% higher pharmaceutical costs; and
- newer drugs are often those targeted for cost-control because they can be most expensive; yet these can offer the best outcomes as they are likely to have fewer side effects, improved safety and efficacy, greater ease in use, increased compliance and be better tailored to individual needs.

Kleinke (2000) concluded that the best strategy for preventing over-use and inappropriate use of pharmaceuticals is to tie utilisation of drugs to best practice research and established clinical guidelines.

Pharmac's position on access to effective medications for dementia should be reviewed.

5.3 RESEARCH

Section 2.6 showed that research on dementia in New Zealand is around $2.9 million (and this is a potentially generous estimate). This equates to around $70 per person with dementia per annum, or $1 on research for each $243 of the financial costs of dementia (0.41%). On a per capita basis, this R&D spend on dementia is lower than in Australia and other OECD nations (Access Economics, 2003:57).

- Adopting the US level as a benchmark ($400 per person)[39], expenditure on dementia research should be increased to around $16.3 million annually.
- As middle ground, aiming to make research 1% of the total costs of dementia each year would suggest spending of $7.1 million per annum.

Only a small proportion of New Zealand research on dementia involves the investigation of services, and this knowledge is less importable because there is so much that is unique to the New Zealand situation. In the area of dementia services, research should focus on:

- key factors that can delay institutionalisation – including better understanding of psychosocial approaches to enabling people with dementia to stay at home;
- the importance of new technology in the design and modification of homes and residential facilities, with a focus on being 'home-like' in the latter;

---

[39] Based on 2003 data converted to NZ dollars and inflated at 3% per annum to 2008 dollars.

- the importance of autonomy and user satisfaction with long term care and the role of the consumer as budget holder;
- the evidence available for achieving better coordination of services – in the community and at discharge from hospital in particular;
- advantages and disadvantages of early diagnosis for a consumer, including the role of memory clinics and of early treatment with pharmaceuticals;
- the profile of the minority who will need dementia specific care and/or culturally appropriate services, in particular Maori and Pacific peoples; and
- epidemiological data for dementia in Maori and Pacific peoples.

New Zealand has fallen behind substantially in dementia research. Greater investment in research is imperative in meeting the challenges presented by the projected increases in dementia prevalence in coming decades, with priority accorded to research on care practices and the delivery of services as well as bio-medical and medical research.

Delaying the onset of Alzheimer's disease by five months reduces prevalence and costs by nearly 5% within 35 years, while delaying onset for five years can nearly halve prevalence and costs in that period (Access Economics, 2004).

5.4 HOME AND COMMUNITY CARE

Home and community care services comprise in-home support services (tasks that the person with dementia used to do such as preparing meals, undertaking cleaning and home maintenance and shopping) and support for families and carers (eg, respite care, education and training, information and referral).

The home and community care services sector is not particularly well developed in New Zealand, with few comprehensive services provided under government programs. Financial barriers thus preclude access for many people. Models of provision are available in other countries, from which New Zealand could adapt services relevant to local needs. For example, in Australia there are three national programs that are relevant[40]:

- the Home and Community Care (HACC) program;
- Community Aged Care Packages; and
- The Extended Aged Care in the Home (EACH) Program, recently spinning off the Extended Aged Care in the Home Dementia (EACHD) Program.

Currently, community care in New Zealand is subject only to a voluntary code of practice so the quality of care is heterogeneous across the sector. A mandatory certification regime, similar to that for other health services such as residential care, may help to address this issue.

Services must be capable of supporting people living in the community with dementia. This will require training for respite and case workers, to ensure that all staff in services that have contact with older people are in a position to understand the needs of people with dementia and how those needs impact on service delivery. It will be particularly important to be able to tailor services for people with dementia in different stages of progression and severity.

---

[40] See http://www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/Content/where+to+start for further detail regarding these programs.

Innovative models of family and carer support are required. Particular needs are for flexible community and residential respite services, assistance with out-of-pocket costs, and emotional and psychological support for families and carers, coordinated with specialist psychogeriatric advice and support. Education and training is needed for volunteer carers, including the development and distribution of carer resource materials.

5.4.1 RESPITE

Respite care must be appropriate, regular and responsive to key changes in the situation of the person with dementia and their carer. Respite services must also have the capacity to support people in emergencies (eg, if a carer is hospitalised). Respite care for younger people with dementia can be particularly inappropriate. Moreover, more flexible models of respite care are needed, including overnight and weekend support, cottage style accommodation, extended hours at day centres and extension to many areas where there are access problems and service gaps.

5.4.2 CARER EDUCATION AND SUPPORT

Funding for carer support for people with early to moderate stage dementia has been shown to be cost effective in reducing carer burden and delaying institutionalisation (Access Economics, 2003:Section 3.3.2). Most carers do not have access to appropriate education programs to assist them in their caring role, which means that physical injuries can result as well as psychological burnout.

There remains a lack of access for family carers to informal, practical, age-appropriate and culturally sensitive instruction and advice tailored to their immediate and continuing needs. This need is best met with the assistance of people with first hand experience of dementia care, such as Alzheimers New Zealand. Additional funding could be directed to:

- ☐ subsidise respite care and other participation costs for family carers who need financial assistance to take advantage of the education program;
- ☐ expand Alzheimers New Zealand programs to enhance support groups, counselling, training and other targeted programs;
- ☐ expand dementia specific and quality care programs to respite service providers and residential care staff, based on person-centred principles and key techniques such as Dementia Care Mapping (Kitwood, 1997).[41]

In addition, national phoneline help services can be very effective in providing support and information to families and carers.

5.4.3 WORKFORCE OPPORTUNITIES FOR FAMILIES AND CARERS

Currently there are few initiatives that target employers of family carers to enable them to optimise their workplace participation. More flexible work practices are important in retaining

---

[41] Dementia Care Mapping is a method of evaluating and improving the care given to people with dementia in home-based, respite and institutional settings. 'Mappers' make detailed observations of people with dementia in a particular setting, recording what they see on a grid. Observations are carried out over a prolonged period of six to eight hours covering the full waking day of residents. The resulting data offers a 'map' which shows in summary how each resident fared - what they did throughout the day, what they enjoyed and what caused them distress. It shows how care is distributed among the group, notable characteristics of the style of care as well as an overall index of the general quality of the service. It can highlight individual needs of residents that have perhaps gone unrecognised as well as 'high spots' in a person's day that indicate particularly good practice. Ongoing training with staff on site by the Dementia Team can enhance the good practice and help make necessary improvements.

workers who are also carers. As demographic ageing continues, participation rates – particularly of women – will become increasingly important in maintaining economic growth as well as sustainable public sector revenues from taxation.

Possibilities include part-time home-based work, work-based adult day-centres, or access to work-based services for family carers such as counselling or exercise programs. In addition, dementia awareness and destigmatisation courses could be introduced in workplaces, potentially on a trial basis initially.

5.5 RESIDENTIAL CARE

The capacity for residential care to support people with dementia (both facilities and workforce training) is a serious constraint. In 2008, this report estimates that there were 21,000 people in residential care with dementia, accounting for 60% of all people in residential care. The number of people with dementia is projected to rise quickly with demographic changes. This will necessarily place pressure on residential care and currently the number of dementia beds is not growing. By 2020, if there were to be no change in the distribution of different models of care to people with dementia, the demand for residential care for people with dementia is projected to be 31,000 (and by 2050 to be almost 76,000). Additionally, challenging behaviour and special needs of people with dementia present additional resourcing issues.

The care requirements for dementia can be difficult and complex (e.g. people with dementia may be highly mobile but with otherwise high care needs) and represent a challenge for ensuring the delivery of appropriate care to people with dementia. This will require places that are specifically designed to support people with dementia with challenging behaviours or other special needs, and dementia training for staff caring for these people. To this end, a 2002 Ministry of Health report set out a series of recommendations specifically aimed at improving dementia care in residential care (MoH, 2002).

Waiting lists for residential care will come under increasing pressure as demographic ageing progresses. Even when a place becomes available, it may not suit the individual and there may be bias against individuals with more challenging dementia behaviours. Often decisions are made under pressure, and the family carer may end up taking whatever becomes available, which can result in deep dissatisfaction, particularly if promised services (such as specific therapies) are not forthcoming or if the quality of care is not up to expectations.

Staffing also represents a likely constraint as demand for residential care grows as a result of growing dementia prevalence. Remuneration for nursing and care staff, both historically relatively lowly paid professions, may need to be reviewed to attract the staff required for future demand. Moreover, as the demand for beds grows, care facilities may become more selective in who they accept, potentially favouring people with lower level (and less costly) care needs, including people with no dementia over those with dementia. Such ‘cherry picking’ has been a problem in other countries, and represents a potential challenge in New Zealand in the future also.

When a facility has a ‘no restraint’ policy, staff may become more effective at developing solutions to difficult behaviours of residents with dementia and avoiding inappropriate levels of medication or restraint. Information, education and training materials for aged care staff regarding the appropriate use of restraints can be useful here.

The corollary of the goal of caring more for people with dementia in the community is that those who are in residential care can have more severe impairment and a consequent increase in nursing requirements. Moreover, since a large and growing proportion of residents have dementia, the design, staffing and management of residential aged care services needs to be geared to the particular behavioural needs of dementia residents, rather than just those with only physical disabilities.

There is also a growing demand for dementia-specific care facilities, as residents may be very mobile together with having high care needs. Assessment for admission to residential care needs to reflect the optimal type of environment for the person, and therefore the type of accommodation payment that is most appropriate. Dementia-specific facilities require a higher level of security and need to offer appropriate therapies and spaces, such as safe walking areas for residents. Ideally they are smaller, with only 10 to 15 residents, to minimise confusion of residents. There is a need for capital investment, design and planning that better reflects dementia care needs going forward.

A final issue is care for people with severe (physically aggressive or violent) behaviours. This small proportion of people with dementia who need mental health and aged care services may be unable to adequately access publicly funded services. This can be a significant gap in the care system.

Cluster housing models promote ageing-in-place, as they are integrated facilities that cater for a range of different needs as a person ages, rather than having to move them to a new location. These models cater for the specific needs of the large proportion of residents who already have dementia or cognitive impairment, or who develop these over time while in the facility. Ideally, staff are trained in dementia-specific and quality aged care principles, and the facility design reflects the various stages of ageing as well as the mild, moderate and severe stages of dementia – including secure walking areas, a few segregated areas for people with highly challenging behaviours, low care areas for mobile people and high care nursing areas for those less mobile. Rosewarne et al (2000) proposed separate buildings (‘houses’) each with around 15 beds within a single complex (‘campus’) of around 90 beds. The houses would operate largely as independent care units with a caregiver supported by an on-staff visiting registered nurse. The care follows the resident, so the necessity for developing specialised stand-alone dementia facilities becomes less critical as this mixed campus approach becomes more widely adopted.

In **summary**, residential care challenges are:

☐ increased ongoing training for all care staff in dementia-specific and quality person-centred care principles;

☐ review funding and remuneration for nursing and personal care staff;

☐ planning ratios that make provision for dementia care and challenging behaviours;

☐ assessment that includes the need for behaviour management and environment, not just the need for nursing care;

☐ modelling of the demand for beds required in the coming years and sustainable funding mechanisms in future;

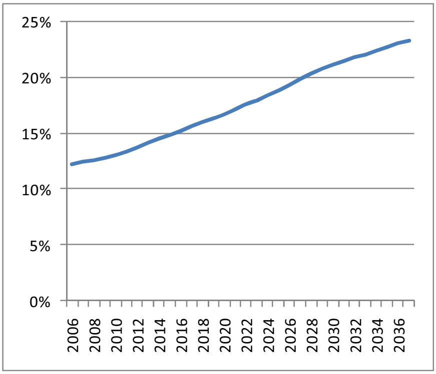
☐ greater access to care for people with severely aggressive behaviours; and

☐ newer models of care, such as cluster housing, reflected in facility and care design.

5.6 CROSS-CUTTING ACCESS ISSUES

New Zealand’s population is ageing, with the share of people aged 65 years and over increasing from 12.6% in 2008 to around 25.9% by 2061. Most of this ageing will occur in the next three decades (Figure 5-1), bringing with it challenging demands on health and aged care services. Medical, hospital and pharmaceutical expenditures are all substantially higher per capita for older people than for younger people. Welfare (disability and carer) payments and aged care services will also burgeon. Moreover, in addition to demographic factors, changing technologies and baby boomer expectations will put sustained pressure on demand for dementia and other health and aged care services – both quantity and quality.

FIGURE 5-1: NEW ZEALANDERS AGED 65+ AS A SHARE OF TOTAL POPULATION (%), 2006-2037



Source: Statistics New Zealand, demographic data.

In addition to demand push factors, there will also be constraints to supply. The relative shortage of younger New Zealanders will mean a scarcity of tax dollars as well as workforce constraints, for formal sector (paid) and informal sector (unpaid). Generation X and Y are less willing to provide home-based care than the baby boomers and their parents. When families and carers are no longer prepared to provide voluntary services, good residential and community care models become increasingly important.

The impact on national budget balances, from both spending growth and a relative contraction of the workforce tax base, will be substantial. Careful planning will be required to meet the future challenges. In particular, investments in prevention and cost effective early interventions will be paramount to prevent expenditures downstream in costly tertiary services. Attention might also be directed at devising savings vehicles for health and ageing. These could include superannuation-type contributions acting as savings vehicles for future residential or even home-based care costs, together with public safety nets to ensure equity of access. These could be voluntary, incentivised accounts, such as are being introduced overseas. Other options could include review of copayments to ensure that marginal prices are sending appropriate demand signals. Appropriate pricing of aged care services will be particularly important in the longer term. Adequate funding is also important for services provided by Alzheimers New Zealand, who would be well placed to develop a National Strategic Framework and Action Plan for Dementia Care.

Financing of dementia care will not be just an ageing issue. Being a younger person with dementia can be even more difficult and costly. Dementia care should not be linked exclusively to aged care. Rather, younger people with dementia should be able to access age-appropriate accommodation (eg, cluster cottage style).

Another access issue relates to the fact that dementia is increasingly multicultural. Dementia policy and services should be increasingly multicultural too, and this requires specialist resources, especially for Maori and Pacific peoples. In particular, there is a need for assessment tools that can be used for people from different backgrounds. Moreover, a lot more still needs to be done to destigmatise dementia.

There is scope for increased use of information technology (IT) in improved models of care. Communication between clinical professionals, caregivers and patients can include videoconferencing and web-based messaging, moderated chats and forums. Caregivers can have their questions answered remotely by medical professionals, or communicate with their peers without leaving home. General practice is another target area for IT-based solutions, which can be particularly helpful for communities that are more remotely based.

Summary: Intergenerational planning needs to acknowledge the need for health and aged care spending to grow in real and relative terms, with strategies for successfully managing the change. These strategies will include minimising inter-generational transfers (fewer young people financing the growing number of elderly), maximising intra-personal transfers (savings schemes), coming to consensus on the private-public mix of care provision, improving models of care to promote both cost effectiveness and quality and providing safety nets for disadvantaged groups. Access for such groups, including people with younger onset dementia and people from culturally and linguistically diverse backgrounds, should also begin to be addressed now. More needs to be done to destigmatise dementia. Better use should be made of Alzheimers New Zealand and of new information technologies in delivering services. Future generations are unlikely to provide the levels of voluntary care that previous generations have provided.

5.7 SUMMARY

A national New Zealand Dementia Care strategy is required, going forward. Five key elements of the future strategy are:

☐ investment in research for cause, prevention and care in the New Zealand setting;

☐ early intervention through improvement in diagnosis, and access to cost effective pharmacotherapies through Pharmac;

☐ comprehensive provision of support, education and respite services – in place in the community as far as is optimal and that considers differences in severity;

☐ quality residential care, appropriately financed, that is centred on the person with dementia and their family/carer; and

☐ provision for special needs, including people with younger onset dementia, people with challenging behaviours, people from culturally diverse backgrounds including Maori and Pacific peoples, and people living in more remote areas of New Zealand.

6. COST BENEFIT ANALYSIS OF DELAYING INSTITUTIONAL CARE

As seen in Chapters 2 and 3, the most significant financial costs of dementia are the costs of residential care and hospital care (the latter appears to be filling an overflow role based on the ALOS data). Productivity losses and the cost of informal care for people with dementia are also relatively substantial costs outside the health system.

6.1 COST BENEFIT ANALYSIS

The scenario being considered in this chapter is a policy intervention that results in a delay in the entry of people with dementia into residential aged care by three months.

It is assumed that every day of delayed entry into residential care is a day less of residential care that needs to be provided to a person with dementia. That is, it is assumed that different models of care have no impact on the life expectancy of people with dementia.

Before considering the details of the two alternative care models (residential care vs home based care), it is necessary to determine the number of days of care per year that would change from residential care to home based care as a result of a three month delay to entry into residential care. This is necessary as the approach taken throughout this report has been to determine an annual cost of dementia, and a delay of three months to residential care entry for all people with dementia does not equal a three month reduction in residential care per year for all people in residential care with dementia.

Section 2.8.1 presented residential care data for New Zealand for 2008. The CCPS data provided by the Ministry of Health did not include any information on the length of stay for clients in residential aged care, hence it was necessary to calculate the average length of stay based on the total number of days of care provided to people with dementia, prevalence of dementia and the average duration of dementia.

People with dementia can either be cared for at home (in the community) or in residential care. Based on the ratio of the prevalence of dementia (40,746) to the incidence of dementia (12,333), the average duration for dementia in 2008 is 3.3 years. Table 2-16 (p33) reported the estimated total days of residential care to be provided to people with dementia in 2008 as 4.9 million. This is an average of 121 days in residential care per year for people with dementia, and a total of 400 days in residential care for people with dementia over their life.[42] Hence if the entry of people with dementia to residential care could be delayed by an average of three months (91 days), the ALOS in residential care for people with dementia would be reduced to 308 days (93 days per year) over their lifetime. This is equivalent to 28 fewer days per year per person with dementia on average.

The estimated number of days of care that would switch from residential care to home based care under this scenario is 1,126,191. In 2008, this represents a 23% reduction in the number of days of residential care provided to people with dementia.

---

[42] Although the discussion here is in averages, it is expected that people with dementia would be cared for at home before they enter residential care to spend on average 400 days. While people with dementia tend to take their residential care in the final stages of their dementia rather than in a cluster of days each year, given that dementia is modelled annually in this prevalence based costing, the difference does not matter across the population.

6.1.1 BENEFITS

There are two main sources of benefits from a policy to delay entry into residential care for people with dementia. Firstly, there are the financial benefits for both individuals and government from savings in residential care costs. Secondly there are the emotional, or quality of life benefits of allowing people to choose the model of care that is best suited to the person with dementia and their family and carers.

6.1.1.1 SAVINGS IN RESIDENTIAL CARE COSTS

The financial benefits from delaying entry into residential care for people with dementia are the savings from the reduction in residential care services that need to be provided.

The costs of residential care in New Zealand were discussed in Section 2.8.2 of this report. In 2008 it is estimated that a total of $272.5 million will be spent on providing residential aged care to people with dementia that can be attributed to their dementia. Of this $173.9 million will be spent by government and $98.6 million will be spent by individuals.

The total cost saving from delaying entry into residential aged care in 2008 is estimated to be $62.3 million. This is based on a reduction of 23% of the costs for each level of care (Table 6-1).

TABLE 6-1: COST SAVING FROM DELAYED INSTITUTIONALISATION, BY LEVEL OF CARE AND COST BEARER, 2008 ($ MILLION)

Level of care	Government	Client	Total
Dementia	5.5	4.7	10.1
Hospital	18.8	9.6	28.5
Psychogeriatric	1.3	0.5	1.8
Rest home	14.1	7.7	21.9
All	**39.7**	**22.5**	**62.3**

6.1.1.2 CHOICE IN MODEL OF CARE

In addition to the financial benefits from reduced residential care costs, an important driver for ‘ageing-in-place’ policies that provide support for at-home care is the choice provided to people with dementia and their families and loved ones.

The transition to residential care can be a difficult and distressing experience for people with dementia and their families and loved ones. For some, the ability to extend the period of home-based care may be preferred to residential care due to cultural norms or the emotional needs of family.

There are limited quantitative data on the size of the benefit of providing the choice of home-based care for people with dementia, however a number of international studies have shown there to be benefits. For example, Graff et al (2007) found that community services improve the quality of life of the person living with dementia and their family carer. Similarly Belle et al (2006) found that case management and emotional support is associated with improved quality of life for caregivers.

The Australian Government has been piloting a community care program, Extended Aged Care at Home Dementia (EACHD), that provides support services to people with dementia whose care needs have been determined as requiring the equivalent of the highest level of residential care. Part of this pilot project has been to measure quality of life for people with dementia and for their carers for those receiving EACHD packages. This study is yet to be completed.

No quality of life difference associated with the model of care received was modelled in our costing of the burden of disease in Chapter 4. Likewise, the burden of disease calculation presented in this report did not included a quality of life affect of dementia on carers and family. Only people with dementia were included in the burden of disease estimate.

Due to the lack of quantitative data on the non-financial benefits associated with home-based care, this benefit has not been costed in this analysis. This is consistent with the approach taken in Chapter 4, however it should not be taken as a reflection of the importance, or lack thereof, of the non-financial benefits of home-based care. The value of providing choice in care models and delaying entry into residential care have real non-financial benefits and these represent an important consideration for policy makers.

6.1.2 COSTS

If people are not cared for in residential facilities, they consume more resources in the community sector, including informal care services and community services. These were estimated in Chapter 3.

Informal care services

From the previous Section (6.1.1) calculating benefits, there are an estimated 1,126,191 bed-days saved in residential facilities, which equates to 160,884 weeks of care required in the community. In Section 3.1.4, there were an estimated 15.8 hours per week of informal care required on average for people with dementia in the community, in order to calculate the opportunity cost of this care. However, people with dementia who would otherwise be institutionalised are likely to require more care than the average of 15.8 hours since they are likely to be more progressed and/or have more complex needs. Consequently, the estimate of care required for people with severe stage dementia is used in this cost benefit analysis – an estimated 41.5 hours per week of informal care required on average.

Multiplying 41.5 by 160,884 gives a total of 6,676,704 hours of informal care required. The opportunity cost of each hour of care on average can be calculated as the replacement hourly rate of $24.85 per hour multiplied by the ratio between the opportunity and replacement cost of care from Section 3.1.4 (ie, $29.3 million/ $402.1 million = 7.3%) ie, 24.85 * 7.3% * 6,676,704. **The estimate of the opportunity cost of informal care associated with delaying institutionalisation by three months is thus $12.1 million**.

Compared to the total annual cost of informal care for people with dementia in New Zealand in 2008, this represents 12.1/29.3 = 41% additional cost. This is higher than the 23% of residential care costs saved because the care that is being substituted back into the community is a higher level of complexity than the average of community care, but the same level of complexity of the residential care that would otherwise occur.

Other community services

As well as the cost of informal care, people with dementia being cared for in the community require real expenditures on (1) aids and home modifications and (2) respite and support services, as well as transfer payments for welfare support and for other services such as transport and travel. These costs were all calculated in Chapter 3, and the extra costs associated with delaying institutionalisation are based on those calculations. Since the extra burden on informal care was estimated above as 41%, this fraction is also used to estimate the extra burden on these other community care services. The results are shown in Table 6-2, with the **other community costs amounting to $18.4 million per annum** in 2008.

TABLE 6-2: ADDITIONAL COMMUNITY COSTS OF INSTITUTIONAL DELAY OF 3 MONTHS ($ MILLION)

	Cost per annum (Chapter 3)	Extra cost per annum, institutional delay
Aids and home modifications	3.1	1.3
Respite and support services	30.9	12.8
DWL for welfare payments	6.9	2.8
DWL for other services	3.8	1.6
	44.7	18.4

Note that there is no assumed increase in non-residential health care services, since people are expected to access the same pharmaceutical, medical and hospital services in either care setting on average, for the same level of need. Similarly, there is no extra productivity or other costs incurred due to care in the community rather than in a residential facility.

Total cost of institutional delay

The total cost of institutional delay is thus estimated as $12.1 million in additional informal care costs plus $18.4 million in other community costs (mainly respite and support services) – a total of **$30.5 million** in extra costs.

6.1.3 COST BENEFIT ANALYSIS

Table 6-3 summarises the costs and benefits calculated in the previous section. Overall there is a net benefit of delaying institutionalisation for three months of $31.8 million in 2008. This equates to a benefit:cost ratio of 2.04, which means that each marginal dollar currently invested in community care services to delay institutionalisation returns around $2.04 in reduced residential care costs.

TABLE 6-3: SUMMARY OUTCOME MEASURES IN THE COST BENEFIT ANALYSIS

Outcome	$m
Benefits	62.3
Costs	30.5
Net benefit	**31.8**
Benefit:cost ratio	2.04

The net benefit of $31.8 million is equivalent to a benefit of $348,000 ($31.8 million/91.3 days) for every day that average entry is delayed into residential aged care for people with dementia. If the average entry into residential aged care for people with dementia can be delayed by three months, there is a net benefit of $780 per person with dementia ($31.8 million/40,746 people).

6.2 DISCUSSION

The analysis of the benefits from delaying entry to residential care for people with dementia presented in this chapter is limited by the lack of diagnosis specific data on residential care for New Zealand. In particular, it is not known whether residential care clients with dementia have a different age distribution or other key characteristics compared to residential care clients without dementia. The estimate of the ALOS in residential care for people with dementia (and hence the estimate of a 23% reduction in annual residential care costs resulting from an average three month delay to residential care) relies on the assumption that there is no difference between residential care clients with and without dementia when it comes to ALOS. The results of the cost benefit analysis should be interpreted in light of the uncertainty around these important parameters.

Another important point for consideration in interpreting the findings of the cost benefit analysis is that no estimate has been included for the cost of the hypothetical intervention that leads to a delay in entry to residential aged care. In reality we would expect some cost to be associated with getting people to delay entry into residential aged care. Examples might be the provision of additional support services (such as respite or home nursing visits) for people receiving at-home care and for their carers, that make remaining in the home an easier option. The results of the cost benefit analysis show that government spending on programs of up to $31.8 million that can delay residential care by three months would produce a net benefit for New Zealand. There may also be quality of life gains.

As benefits from delaying entry to residential aged care are on a per person with dementia basis the net benefits will grow as dementia prevalence grows (as is forecast due to demographic ageing). This means that the incentive to delay entry to residential care will increase over time.

Although there is a net benefit of $31.8 million in total, this is not the net benefit to government. The distribution of costs between government and individuals is different for residential and home-based models of care. Table 6-4 shows the net benefit of a three month delay to residential care for people with dementia to individuals and to government.

TABLE 6-4: SUMMARY OF COST BENEFIT ANALYSIS, BY BEARER OF COSTS

Outcome	Individuals $m	Government $m	Total $m
Benefits	22.5	39.7	62.3
Costs	14.2	16.4	30.5
Net benefit	**8.3**	**23.3**	**31.8**
Benefit:cost ratio	1.58	2.42	2.04

Section 2.8.2 reported the distribution of aged care costs as being borne 64% by government and 36% by individuals. Individuals bear a larger share of the costs of home-based care at 46% compared to the government share of 54%. The benefit:cost ratio is greater than one for both individuals and government, meaning both groups should be willing to invest to delay entry into residential care.

The net benefit includes no estimate for the provision of choice; hence, depending on the government's assessment of the size of this benefit, government may be prepared to spend more than the $31.8 million to delay aged care entry by three months.

REFERENCES

Access Economics (2008) *The health of nations: the value of a statistical life* Report for the Office of the Australian Safety and Compensation Council, Canberra, January.

Access Economics (2006) *Dementia in the Asia Pacific region: the epidemic is here*, Report for Asia Pacific members of Alzheimer's Disease International, September.

Access Economics (2004) *Delaying the Onset of Alzheimer's Disease: Projections and Issues* Report for Alzheimer's Australia, Canberra, September.

Access Economics (2003) *The dementia epidemic: economic impact and positive solutions for Australia*, Access Economics, Canberra, Australia.

Aldy JE, Viscusi WK (2006) *Age variations in workers' value of statistical life*, NBER Working Paper 10199, NBER, Cambridge, MA.

Alzheimer's Disease International (1999) *The prevalence of dementia*, Factsheet 3, April.

Alzheimers New Zealand (2007) 'Caring for the Carer', *Information Sheet Fifteen*, Alzheimers New Zealand.

Australian Institute of Health and Welfare (2007) *Dementia in Australia: National data analysis and development,* AIHW Cat No AGE 53, January.

Australian Institute of Health and Welfare (2005) *Health system expenditure on disease and injury in Australia, 2000–01* Second edition, AIHW Cat No HWE 28, Health and Welfare Expenditure Series No 21, Canberra.

Ballard CJ, Shoven J, Walley DJ (1985) 'General Equilibrium Computations of the Marginal Welfare Costs of Taxation in the United States' *American Economic Review,* March.

Begg S, Vos T, Barker B, Stevenson C, Stanley L, Lopez AD (2007) *The burden of disease and injury in Australia 2003,* AIHW PHE 82, Canberra,.

Belle SH, Burgio L, Burns R, Coon D, Czaja SJ, Gallagher-Thompson D et al (2006) 'Enhancing the quality of life of dementia caregivers from different ethnic or racial groups. A randomized, controlled trial.' *Annals of Internal Medicine,*145:727-738.

Bollard A, Hodgetts B, Briggs P, Smith M (2006) *Household Savings and Wealth in New Zealand*, Reserve Bank of New Zealand; http://www.rbnz.govt.nz/speeches/2823190.pdf**,** last accessed 19 June 2008.

Blackmun S (1998) 'Is It Depression or Is It Dementia?' *Psychiatric Times*, 15(2), February.

Browning EK (1987) 'On the Marginal Welfare Cost of Taxation' *American Economic Review,* March.

Burns A (2001) 'Dementia' *Factsheet for Personal Social Services Research Unit*, North West Dementia Centre, University of Manchester, NHS Executive North West, UK.

Creasey H, Brodaty H (1998) 'New Hope for Early Diagnosis: Research Briefs' *Intouch*, Alzheimer's Association of New South Wales, Issue 27, Summer.

Cummings J (2001) 'Treatment of Alzheimer's disease' *Clin. Cornerstone* 3(4):27-39.

Cutler DM, Richardson E (1998) *The Value of Health: 1970-1990*, JCPR Working Paper 28, prepared for the AEA session on 'What we get for health care spending'. www.jcpr.org/wpfiles/value.pdf

Diewert WE, Lawrence DA (1994) *The Marginal Costs of Taxation in New Zealand,* Report prepared by Swan Consultants (Canberra) Pty Ltd for the New Zealand Business Round Table.

Diewert WE, Lawrence DA (1995) 'The Excess Burden of Taxation in New Zealand', *Agenda* 2(1):27-34.

Diewert WE, Lawrence DA (1996) 'The Deadweight Costs of Taxation' *Canadian Journal of Economics* 29:S658-S673.

Disability Services Directorate of the Ministry of Health (2008) *Ministry Funded services, equipment and modifications* http://www.moh.govt.nz/moh.nsf/indexmh/disability-fundedservices-equipmentmodifications**,** last accessed 19 June 2008.

District Health Boards of New Zealand (2003) *WIES8C Methodology and Casemix Purchase Unit Allocation recommended for the 2003/2004 Financial Year: Frozen Specification for implementation on NMDS*, SFG Cost Weights Project Group, District Health Boards of New Zealand and New Zealand Health Information Service, 12 March 2003, downloaded from **http://www.nzhis.govt.nz/moh.nsf/pagesns/300**

Ferri CP, Prince M, Brayne C, Brodaty H, Fratiglioni L, Ganguli M, Hall K, Hasegawa K, Hendrie H, Huang Y, Jorm A, Mathers C, Menezes PR, Rimmer E, Scazufca M, for Alzheimer's Disease International (2005) 'Global prevalence of dementia: a Delphi consensus study' *The Lancet,* 366:2112-7.

Fratiglioni L, Ahlbom A, Viitanen M, Winblad B (1993) 'Risk factors for late onset Alzheimer's disease: a population-based case-control study' *Ann Neurol,* 33:258-266.

Graff MJL, Vernooij-Dassen MJM, Thijssen MD, Joost H, Willibrord HL, Olderikkert MGM (2007) 'Effects of community occupational therapy on quality of life, mood, and health status in dementia patients and their caregivers: a randomized controlled trial' *Journals of Gerontology Series A-Biological Sciences & Medical Sciences. 62*(9):1002-9.

Guria J, Jones–Lee M, Loomes G (1999) *The Value of Statistical Life and Injuries: Willingness to Pay/ Accept*, Land Transport Safety Authority, Wellington.

Hansen P, Scuffham PA (1995) 'The cost-effectiveness of compulsory bicycle helmets in New Zealand' *Australian Journal of Public Health*, 19: 450–454.

Hofman A, Rocca WA, Brayne C et al for the Eurodem Prevalence Research Group (1991) 'The prevalence of dementia in Europe: a collaborative study of 1980-1990 findings' *Int J Epidemiol,* 20:736-748.

Horn S (2002) 'Implications of restrictive drug practices' *Presentation paper*, 20 February.

Inland Revenue (2008a) *GST (Goods and Services Tax) – About GST*, http://www.ird.govt.nz/gst/gst-registering/gst-about/**,** last accessed 19 June 2008.

Inland Revenue (2008b) *Income tax rates for individuals*, http://www.ird.govt.nz/how-to/taxrates-codes/itaxsalaryandwage-incometaxrates.html**,** last accessed 19 June 2008.

International Monetary Fund (2008), 2008 Article IV Consultation with New Zealand — Staff Report of the IMF Mission, http://www.imf.org/external/pubs/ft/scr/2008/cr08163.pdf, last accessed 21 May 2008**,** last accessed 19 June 2008.

Jorm AF, Korten AE, Henderson AS (1987) 'The prevalence of dementia: a quantitative integration of the literature' *Acta Psychiatrica Scandinavica,* 76:465-479.

Kitwood T (1997) *Dementia Reconsidered: The Person Comes First,* Open University Press: Milton Keynes, UK.

Kleinke J (2000) 'Just what the HMO ordered: the paradox of increasing drug costs' *Health Affairs,* 19(2):78-91.

Kukull W, Larson E, Bowen J, McCormick W, Teri L, Pfanschmidt M, Thompson J, OMeara E, Brenner D, van Belle G (1995) 'Solvent exposure as a risk factor for Alzheimer's disease: a case control study' *Am J Epidemiol*, 141:1059-1071.

Langa KM, Chernew ME, Kabeto MU, Herzog AR, Ofstedal MB, Willis RJ, Wallace RB, Mucha LM, Straus WL, Fendrick AM (2001) 'National Estimates of the Quantity and Cost of Informal Caregiving for the Elderly with Dementia' *Journal of General Internal Medicine*, 16(11), http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=1495283**,** last accessed 19 June 2008.

Leung J, Guria J (2006) 'Value of statistical life: Adults versus children' *Accident Analysis and Prevention*, 38: 1208-1217.

Lobo A, Launer L, Fratiglioni L, Andersen K, Di Carlo A, Breteler M et al (2000) 'Prevalence of dementia and major subtypes in Europe: A collaborative study of population-based cohorts' *Neurology* 54(Suppl 5):S4-9.

Lowin A, McCrone P, Knapp M (2000) *Cost of Alzheimer's Disease and Level of Research Funding* Centre for the Economics of Mental Health, Institute of Psychiatry, Kings College, London.

Mathers C, Vos T, Stevenson C (1999) *The burden of disease and injury in Australia* AIHW Cat No PHE17, AIHW Canberra.

McKeown PC, Woodfield AE (1995) 'The welfare cost of taxation in New Zealand following major welfare reforms' *New Zealand Economic Papers* 29(1):41-62.

Miller TR (2000) 'Variations between Countries in Values of Statistical Life' *Journal of Transport Economics and Policy*, 34:169-188.

Miller TR, Guria J (1991) *The Value of Statistical Life in New Zealand*, Market Research on Road Safety. Land Transport Division, Ministry of Transport, Wellington.

Ministry of Health (2004) *The Health and Independence Report 2004, Director-General of Health's annual report on the state of public health*, Ministry of Health, Wellington, http://www.moh.govt.nz/moh.nsf/0/65461551FA649C5CCC256F6B00782B1B/$File/healthandindependence2004.pdf**,** last accessed 19 June 2008.

Ministry of Health (2006) 'The Annual Report 2005/06 including The Health and Independence Report Annual Report for the year ended 30 June 2006', *Director-General of Health's annual report on the state of public health*, Ministry of Health, Wellington, http://www.moh.govt.nz/moh.nsf/pagesmh/5315/$File/annual-report0506-section4.pdf

Ministry of Health (2007) *The Health and Independence Report 2007, Director-General of Health's annual report on the state of public health*, Ministry of Health, Wellington, http://www.moh.govt.nz/moh.nsf/pagesmh/6850/$File/health-independence-report-2007.pdf**,** last accessed 19 June 2008.

Ministry of Health (2002) *Dementia in New Zealand: improving quality in residential aged care, A report to the Disability Issues Directorate*, Ministry of Health, Wellington.

Ministry of Social Development (2008) *Main benefit information*, http://www.workandincome.govt.nz/get-assistance/main-benefit/index.html**,** last accessed 19 June 2008.

Ministry of Transport (2004) *The Total Mobility Scheme – Review*. http://www.transport.govt.nz/assets/NewPDFs/total-mobility2.pdf**,** last accessed 19 June 2008.

Ministry of Transport (2004) *The Total Mobility Scheme, Appendix 1 – Table A Characteristics of schemes by region and entitlement* http://www.transport.govt.nz/total-mobility-appendix-1/**,** last accessed 19 June 2008.

Moise P, Schwarzinger M, Um M-Y and the Dementia Experts' Group (2004) *Dementia Care in 9 OECD Countries: A Comparative Analysis*, OECD Health Working Papers No 13, Paris. http://www.oecd.org/dataoecd/10/52/33661491.pdf

Morris JC (1993) 'The clinical dementia rating (CDR): current version and scoring rules'. *Neurology,* 43(11):2412–14.

Murphy KM, Topel R (1999) *The Economic Value of Medical Research*, University of Chicago Business School.

Murray C, Lopez A (1996) *The Global Burden of Disease: a comprehensive assessment of mortality & disability from diseases, injuries & risk factors in 1990 & projected to 2020*, Volume 1, Global Burden of Disease & Injury Series, Harvard: Harvard School of Public Health.

Murray C, Lopez A, Mathers C, Stein C (2001) *The Global Burden of Disease 2000 Project: aims, methods & data sources*, Discussion Policy Paper No 36, WHO, November.

New Zealand Care Coach (2003) *Accessing carer support,* CarersnetNZ, http://www.carers.net.nz/modules.php?op=modload&name=News&file=article&sid=205&catid=370**,** last accessed 19 June 2008.

New Zealand Care Coach (2003a) *Adult day care gives everyone a break*, CarersnetNZ, source: http://www.carers.net.nz/modules.php?op=modload&name=News&file=article&sid=210&catid=370**,** last accessed 19 June 2008.

New Zealand Care Coach (2003b) *Accessing carer support*, CarersnetNZ, source http://www.carers.net.nz/modules.php?op=modload&name=News&file=article&sid=205&catid=370**,** last accessed 19 June 2008.

New Zealand Debt Management Office (2008) *Changes to Kiwi Bond Interest Rates – Media Statement*, http://www.nzdmo.govt.nz/publications/mediastatements/2008-02-01**,** last accessed 19 June 2008.

New Zealand Health Information Service (2007) *Mortality and Demographic Data 2004*, Wellington: Ministry of Health.

Nordhaus WD (2002) *The Health of Nations: The Contribution of Improved Health to Living Standards*, NBER Working Paper No.8818.

Organization for Economic Cooperation and Development (2004) *OECD Health Data 2004* 3rd edition, September, *Online* version is downloadable from **http://www.oecd.org/document/16/0,2340,en_2649_34629_2085200_1_1_1_1,00.html**

Reserve Bank of New Zealand (2007) *Policy Targets Agreement 2007*, Agreement between the Minister of Finance and the Governor of the Reserve Bank of New Zealand http://www.rbnz.govt.nz/monpol/pta/3027051.html**,** last accessed 19 June 2008.

Ritchie K, Kildea D (1995) 'Is senile dementia 'age-related' or 'ageing-related'? Evidence from meta-analysis of dementia prevalence in the oldest old' *Lancet* 346:931-4.

Rosewarne R, Opie J, Bruce A, Ward S, Doyle C, Sach J (1997) 'Care Needs of People with Dementia and Challenging Behaviour Living in Residential Facilities' *Aged and Community Care Service Development and Evaluation Reports Nos 24, 26-31*, Commonwealth Department of Health and Family Services, Australian Government Publishing Service, Canberra.

Rosewarne R, Opie J, Ward S (2000) 'Dementia-specific care in Australia: an overview and future directions' *RPAD* Vol 4: Special Care Units.

Schelling (1968) 'The life you save may be your own' in SB Chase (ed) *Problems in public expenditure and analysis*, Brookings Institution, Washington DC, p127-162.

Sobel E, Dunn M, Davanipour Z, Qian Z, Chui H (1996) 'Elevated risk of Alzheimer's disease among workers with likely electromagnetic field exposure' *Neurology*, 47:1477-1481.

Sobel E, Davanipour Z, Sulkava R, Erkinjuntti T, Wikstrom J, Henderson V, Buckwalter G, Bowman J, Lee P-J (1995) 'Occupations with exposure to electromagnetic fields: a possible risk factor for Alzheimer's disease' *Am J Epidemiol*, 12:515-524.

Statistics New Zealand (2008a) *National Accounts (Revised): Year Ended March 2007,* http://www.stats.govt.nz/NR/rdonlyres/61D5633A-FC9C-4794-BFA9-23578BE9EC5A/23054/nayemar07revhhio1.xls**,** last accessed 19 June 2008.

Statistics New Zealand (2008b) *Labour market statistics – March Quarter 2008*, Statistics New Zealand, Auckland.

Statistics New Zealand (2008c) *Labour Market Statistics, 'Average Total Hourly Earnings'* http://www.stats.govt.nz/analytical-reports/Labour+Market+Statistics+2007.htm, accessed 19 June 2008.

Statistics New Zealand (2008d*) Table builder: Income by age, sex and labour force status,* Statistics New Zealand, Auckland, http://wdmzpub01.stats.govt.nz/wds/TableViewer/tableView.aspx?ReportName=Incom es/Income%20by%20age,%20sex%20and%20labour%20force%20status, last accessed 19 June 2008.

Statistics New Zealand (2008e) *Productivity Statistics: 1978-2007*, Statistics New Zealand, Auckland http://www.stats.govt.nz/products-and-services/hot-off-the-press/productivity-statistics/productivity-statistics-1978-2007-hotp.htm**,** last accessed 19 June 2008.

Statistics New Zealand (2008f), *Consumer Price Index, March 2008 quarter*, http://www.stats.govt.nz/products-and-services/hot-off-the-press/consumers-price-index/consumers-price-index-marc08qtr-hotp.htm**,** last accessed 19 June 2008.

Statistics New Zealand (2007) *2006 Disability Survey*, Statistics New Zealand, Auckland, http://www.stats.govt.nz/datasets/health/disability-statistics.htm, last accessed 19 June 2008.

Statistics New Zealand (2008) *Labour market statistics report 2007*, Statistics New Zealand, Auckland.

Statistics New Zealand (2008) *Consumer Price Index, March 2008 quarter*, http://www.stats.govt.nz/products-and-services/hot-off-the-press/consumers-price-index/consumers-price-index-marc08qtr-hotp.htm**,** last accessed 19 June 2008.

Stern Y, Gurland B, Tatemichi T, Tang M, Wilder D, Mayeux R (1994) ‘Influence of education and occupation in the incidence of Alzheimer’s disease’ *JAMA*, 271:1004-1010.

Stuart C (1984) ‘Welfare Costs per Dollar of Additional Tax Revenue in the United States’ *American Economic Review,* June, cited in Vedder RK, Gallaway LE (1999) *Tax Reduction and Economic Welfare,* Joint Economic Committee of Congress Study, April.

Van der Wijk P, Wolffensperger EW, Heuvel WJA, Huijsman R (1999) *Economic evaluation of alternatives for care in residential homes*, Unpublished paper referred to in Chapter 5 of a dissertation available at http://dissertations.ub.rug.nl/FILES/faculties/medicine/1999/p.v.d.wijk/c5.pdf last accessed 14 June 2008.

Viscusi WK, Aldy JE (2002) ‘The value of a statistical life: a critical review of market estimates throughout the world’ Discussion Paper No. 392, Harvard Law School, Cambridge MA. November www.law.harvard.edu/programs /olin_center/

Wancata J, Musalek M, Alexandrowicz R, Krautgartner M (2003) ‘Number of dementia sufferers in Europe between the years 2000 and 2050’ *Eur Psychiatry,* 18:306-313.

Warner J, Butler R (2000) ‘Alzheimer’s Disease’ *Clinical Evidence,* 3:419-425.

Wimo A, Jonsson B, Karlsson G and Winblad B (1998) *Health Economics of Dementia*, Wiley, UK.

World Health Organization (2002) *World Health Report 2002: Reducing Risks, Promoting Healthy Life*, WHO, Switzerland.

Alzheimers
New Zealand National Office

Address: Level 3, 15 Courtenay Place, PO Box 3643, Wellington **Phone:** (04) 381 2362
Fax: (04) 381 2365 **Email:** nationaloffice@alzheimers.org.nz **Website:** www.alzheimers.org.nz
Freephone: 0800 004 001 **Donation Phone:** 0900 41234

Published - July 2008
Cover designed by MSO Design and Art Production