

3 Dementia data in Australian collections

In Australia, information about people with dementia, their carers and their use of health and care services, is collected through a number of administrative data collections and surveys. These collections have different aims, applications and collection methodologies which influence their content, and use different definitions and classifications of dementia.

This chapter briefly describes each of the data sources used in this report, including collection methods, data collection context and scope of each collection. Each description outlines the availability of data elements relevant to dementia, including diagnosis status, type of dementia, cognitive impairment, behaviour, medications/treatments, functioning and carer items. These are summarised in Table 3.1 at the end of this chapter.

In addition to the data sources used for analysis in Section 2 of this report, the chapter also includes information about a selection of Australian longitudinal studies which include data about dementia. Longitudinal studies are particularly valuable when examining progressive conditions such as dementia. A description of the main national health population survey, the NHS, is also included.

A more detailed review and comparison of dementia-relevant data elements is included in Chapter 11.

3.1 Administrative collections

Administrative (or service by-product) data collections are based on information collected as part of the delivery of health or community services. The primary data collected at the point of service delivery can be used to derive data to support secondary (or downstream) information purposes such as reporting, policy, governance and decision support as well as to provide information necessary for patient or client care. The population covered by these collections is generally restricted to the clients of a particular program. Some collections are based on individual client records, while others consist only of aggregated data – this limits the type of analysis that is possible.

Some administrative collections such as hospital-based care collections are mandated for national collection by the National Health Information Group as NMDSs and some of the data elements are used to derive performance indicators required under the Australian Health Care Agreements. Minimum data sets (MDS) contain agreed data elements for collection and reporting relevant to a particular service. The data collected is relevant to the service or care being provided although organisations are not precluded from collecting additional information to meet their own specific needs.

The collections covered in this chapter come from the main national health and care programs that people with dementia and/or people caring for them will access.

Alzheimer's Australia data

Alzheimer's Australia is the national peak body for people with dementia, their families and carers. State and territory organisations provide information, support, advocacy and education services. Alzheimer's Australia delivers the Australian Government's National Dementia Support Program.

The Dementia Education and Support Program (DESP) Database Data Dictionary Version 2.2 (Alzheimer's Australia 2003) contains the data elements that are currently collected by Alzheimer's Australia. These data elements collect information (such as sociodemographic characteristics) about **contacts** with Alzheimer's Australia, whether they are people with dementia, carers of people with dementia or health professionals. Client type categories are used to characterise the individual or group of people involved in the contact.

Identification of people with dementia is based on a range of dementia diagnosis data items recorded across the collections including: dementia diagnosis status, date of diagnosis, diagnosis by whom and type of dementia. A memory and assistance profile collects information about memory impairment and personal care assistance. Data items relevant to carers include carer status and relationship to the person of concern. Additional information about functioning (orientation, judgement, community affairs, home and hobbies and mobility), overall need, carer assistance and carer overall need is collected, but these data items do not appear in the data dictionary.

Medicare Benefits Schedule data

The Medicare Benefits Schedule (MBS) provides access to free treatment to public (Medicare) patients in public hospitals, and to free or subsidised treatment by practitioners such as GPs, specialists, participating optometrists and dentists. These subsidies mostly cover out-of-hospital medical services but also apply to medical services delivered in hospitals to private patients. Medicare Australia is responsible for administering payments and information for the Medicare program.

MBS data collected by Medicare Australia (formerly the Health Insurance Commission) cover only those services eligible for Medicare benefits, as listed in the Medicare Benefits Schedule (DoHA 2004b). The MBS data include Medicare item number, Medicare benefit paid, date of service and processing, provider number, recipient of the service and an indication of whether or not the item was provided in a hospital. The unit of measurement in this collection is the **service**.

There are no dementia-specific services in the Medicare Benefits Schedule, but people with dementia may access a range of services that are eligible for Medicare benefits such as: health assessments (e.g. assessment of psychological functions such as cognition); Medication Management Reviews (e.g. Domiciliary Medication Management Reviews where a person with dementia has difficulty managing their own medications); pathology and diagnostic radiology (e.g. thyroid function tests or MRI to investigate possible dementia); and consultations and case conferencing (e.g. for care planning).

Pharmaceutical Benefits Scheme data

The Pharmaceutical Benefits Scheme (PBS) is administered by Medicare Australia and was established to reimburse pharmacists who have dispensed eligible prescription pharmaceuticals at a cost greater than the patient's contribution.

The PBS data collection includes information on prescriptions dispensed to general patients where a pharmacist is eligible for a reimbursement, prescriptions dispensed to persons who have been issued with a health care card, or those who have reached the safety net threshold. The Medicare Australia website contains aggregate statistics, based on PBS items and medication group categories, for each state and territory (Medicare Australia 2005). Data comprises drug codes as classified in the Pharmaceutical Benefits Schedule (DoHA 2006). The unit of measurement in this collection is **prescriptions**.

Three anticholinesterases are funded under the PBS for the treatment of mild to moderately severe Alzheimer's disease: donepezil hydrochloride (Aricept), galantamine hydrobromide (Reminyl) and rivastigmine hydrogen tartrate (Exelon). An authority is required for PBS funding of these medications. The authority application must include the result of the baseline MMSE. This baseline MMSE must be a score of 10 points or more and, if this score is at least 25 points, the result of a baseline ADAS-Cog must also be specified.

In order to qualify for continuing treatment, following initial therapy, of mild to moderately severe Alzheimer's disease there must be a demonstrated improvement in cognitive function as measured by an increase of at least two points from baseline on the MMSE, or for patients with an MMSE baseline score of at least 25 points, a decrease of at least four points from baseline on the ADAS-Cog. The information about cognitive state is recorded with the details of the prescription.

Information about people who self-fund their anticholinesterase medication is not collected. Information about the use of medications for dementia, other than anticholinesterases, cannot be identified in the collection.

National Hospital Morbidity Database

The National Hospital Morbidity Database is a compilation of electronic summary records collected in admitted patient morbidity data collection systems in Australian hospitals:

1. Admitted Patient Care NMDS: reports data on episodes of care for admitted patients in all public and private acute and psychiatric hospitals, free-standing day hospital facilities and alcohol and drug treatment centres in Australia.
2. Admitted Patient Mental Health Care NMDS: restricted to episodes of care of admitted patients receiving admitted patient care in psychiatric hospitals or in designated psychiatric units in acute hospitals (the scope does not include patients receiving treatment for psychiatric conditions in other units in acute hospitals).
3. Admitted Patient Palliative Care NMDS: records information about episodes of care for admitted patients receiving palliative care in all public and private acute hospitals, and free standing day hospital facilities.

The database records information on hospital **separations** (not patients), where a separation refers to the episode of care, which can be a total hospital stay, from admission to discharge, transfer or death, or a portion of a hospital stay beginning or ending in a change in type of care (AIHW 2005a).

Principal and additional diagnoses responsible for a patient's episode of care in hospital or contributing to the cost of care, surgical and non-surgical procedures and external causes are recorded using ICD-10-AM codes. A list of procedure codes are given in AIHW (2002b). A principal diagnosis is the diagnosis established after study to be chiefly responsible for occasioning the patient's episode of care in hospital (or attendance at the health care facility). An additional diagnosis is a condition or complaint either coexisting with the principal

diagnosis or arising during the episode of care or attendance at a health care facility (National Health Data Committee 2004b). Dementia (as well as cognitive disorder and age-related cognitive decline) may be recorded as a principal or additional diagnosis.

Aged Care Assessment Program MDS

The ACAP is an Australian, state and territory government funded program to assess the needs of frail, older people and recommend and facilitate access to available care services appropriate to a person's needs. The program uses multi-disciplinary Aged Care Assessment Teams (ACATs) which comprise medical, nursing and allied health professionals, as well as social workers, interpreters and other professionals.

ACAT carry out comprehensive assessments to determine eligibility for admission into residential aged care or residential respite care, and for Community Aged Care Packages (CACAP) and EACH places (AIHW 2002b). They may also provide information and refer clients to other suitable services such as services funded by Home and Community Care (HACC), the National Respite for Carers Program (NRCP) and Veterans' Home Care, although they do not determine eligibility for these services. Assessments involve the evaluation of the care needs of a person, incorporating the restorative, physical, medical, psychological, cultural and social dimensions of care (AIHW 2002a; DoHA 2002a).

The ACAP MDS specifies a collection of information on individual assessments (the unit of measurement may be **clients** or **assessments**). Between 1991 and 2001, the MDS underwent a review and then redevelopment, resulting in Version 2.0 of the data collection, designed to report on the core work of ACATs (AIHW 2004c). The ACAP MDS Version 2 was implemented from April 2003. The information collected by ACATs predominantly relates to client characteristics and circumstances, health status, functional abilities, current assistance from services, documentation of the assessment process, and ACAT recommendations for care. Data items relating to carers include carer availability, carer co-residency status and relationship of the carer to the care recipient.

Information about the type of dementia may be recorded as a primary health condition that has the greatest impact on the client's need for assistance, or as one of nine other health conditions that impact on the client's need for assistance – codes are based on the ICD-10-AM. Dementia was the most common primary diagnosis among all ACAP clients in 2002–03 – 19% of all ACAP clients (or 30,800 clients) had a primary diagnosis of dementia (Lincoln Centre for Ageing and Community Care Research 2004). Body function impairments are based on the ICF, and those particularly relevant to dementia fall under the heading of *Mental functions*. Additional questions focusing on cognitive behaviour/ psychological aspects appear on the Aged Care Client Record completed by ACAT, but are not reported in the ACAP MDS.

Home and Community Care program MDS

The HACC program is one of three national programs that provide community-based care services to older people in Australia. HACC is jointly funded by the Australian, state and territory governments, and is the main provider of home-based care services in Australia. The program aims to enhance the independence of frail older people (around 80% of clients) as well as younger people with a disability, and their carers. Some examples of types of assistance provided through the HACC program include assessment, management and

planning of requirements, transport, nursing, home maintenance, counselling and personal care.

The HACC MDS is client-based and reported nationally by HACC agencies every three months. Data collected per collection period are only on those clients who have received HACC-funded services from an agency within the three-month reporting period. Therefore, not all clients are necessarily included in each collection period nor are all type(s) of assistance received from HACC-funded agencies necessarily captured for this reason (AIHW 2002b).

Version 2 of the MDS is currently being implemented. No information about dementia is collected in Version 1 of the MDS. Information about dementia diagnosis will not be collected in Version 2 of the MDS, although information about memory problems or confusion and behavioural problems will be collected, as well as 12 other items about functional status. HACC also collects information about carers, including demographic items, existence of a carer, carer residency status, relationship of the carer to the care recipient, and carer for more than one person.

Community care packages data

Community Aged Care Packages data

The CACP program was established in 1992 by the Australian Government to provide assistance to enable frail older people with complex care needs to continue living in the community (AIHW 2004c). Younger people with disabilities may also access a care package in special circumstances as determined by ACAT assessment (DoHA 2002a).

CACPs provide a range of in-home support services, such as personal care, domestic assistance and social support, to people who would otherwise be eligible to receive at least low-level residential aged care. Recipients of CACPs must be assessed for eligibility by an ACAT. A CACP data dictionary has been developed, but the collection has not been implemented as a NMDS.

Ongoing program data are available from payment system data which are stored in the Aged and Community Care Management Information System (ACCMIS). This data source contains no information about health conditions (including dementia), need for assistance or type of assistance received. Nor are there data about carer arrangements.

Extended Aged Care at Home data

The EACH program provides home- and community-based services such as nursing and personal care to frail older people who would otherwise be eligible to receive high level residential aged care. The program provides an extensive range of support to people living in the community including general services, specialised clinical services, care and support services. Recipients of EACH packages must be assessed for eligibility by an ACAT. As for CACP, an EACH data dictionary has been developed, but the collection has not been implemented as a NMDS.

Current ongoing program data are also available from ACCMIS, and contain no information about health conditions (including dementia), need for assistance or type of assistance received. Nor are there data about carer arrangements.

More comprehensive data will be collected following the implementation of EACH Dementia.

Community care packages census data

In 2002, the AIHW, in conjunction with the Department of Health and Ageing, conducted census collections of the CACP and EACH programs. CACP and EACH service providers completed two types of forms – the first form collected information about the provider’s characteristics and the second collected data about individual clients⁷ and the services delivered to them. Each of the questionnaires for these programs contained a question on whether the client had been formally diagnosed with dementia.

The census also collected demographic information about the client, information about core activity limitations (including communication), as well as items about carer availability, carer co-residency status and relationship of the carer to the care recipient.

Residential Aged Care data

Residential aged care services provide accommodation and support for older people who can no longer live at home. To enter residential care, people must have the appropriate recommendation from an ACAT. In addition to permanent care, short-term respite care services are also provided. Data about residential aged care service providers and residents are also available from ACCMIS.

Available data includes information about resident characteristics including the level of care and supervision provided in respect of 20 specific activities. There are no data about any health conditions (including dementia). However, information about care provided is used in this report and in previous work to estimate the prevalence of dementia among permanent residents and/or their dependency profile.

Data on the care provided to residents are currently collected through 20 questions which form the Resident Classification Scale (RCS). There are eight RCS categories which denote the level of care provided to a resident, with RCS 1 representing the highest level. High level care is generally denoted by RCS categories 1–4, while low level care residents are in categories 5–8. The RCS category for a resident determines the level of subsidy an agency will receive in respect of that person (AIHW 2002b). The appraisal used for the RCS does not consider all of a resident’s care needs, just those that have been identified as contributing the most to differences in the total cost of residential care. New clients are assessed within 30 days of entering a residential aged care facility, and are reassessed every 12 months unless a significant change in care needs occurs.

RCS questions about the characteristics, needs or behaviour of the resident that are particularly relevant to dementia include: verbally disruptive or noisy; problem wandering or intrusive behaviour; emotional dependence; understanding and undertaking living activities; physically aggressive; social and human needs; other behaviour; danger to self or others; social and human needs; and communication. Information about the level of care provided with other activities such as personal hygiene and mobility is also collected.

⁷ Although the CACP and EACH programs refer to those individuals receiving CACP or EACH packages as ‘recipients’ or ‘care recipients’, the term ‘client’ will be used in this report, in order to avoid confusion with those individuals that are recipients of care from an informal carer.

Two RCS questions have been previously used to construct an index designed to estimate the prevalence of dementia in residential aged care: question 1, the *'degree of assistance the care recipient needs in communicating with staff, relatives and friends, and other care recipients for whatever reasons'*, and question 8, the *'care recipient's ability to remember, understand, plan for, initiate and perform general living activities and to react appropriately to information provided'* (Cuthbertson et al. 1998, cited in AIHW 2004f). Combinations of these scores were used to allocate residents to one of three categories: no dementia, possible dementia and probable dementia.

This current report uses a different methodology to estimate the number of people with dementia in residential aged care, based on a mapping of questions from the RCS to questions on the cared accommodation component of the SDAC. This method is described in Chapters 7 and 8.

A new funding appraisal tool called the Aged Care Funding Instrument (ACFI) is currently being developed and trialled to replace the RCS. The ACFI collects information on the care needs of residents rather than on the care provided to residents and will be used to determine government subsidy levels for each resident, including people who have been diagnosed with dementia and other mental or behavioural disorders (DoHA 2005b). The ACFI is currently being tested in a national trial by a consultancy team led by Dr Richard Rosewarne (Applied Aged Care Solutions) and Associate Professor Peter Foreman (The Lincoln Centre for Ageing at La Trobe University).

The trial version of the ACFI consists of 13 domains, of which domains 6, 7, 8 and 12 relate to cognitive skills, problem wandering, physical and verbal behaviour and mental and behavioural diagnosis (based on ACAP health condition codes), respectively. The trial version also includes questions designed to identify shorter-term needs in complex health, nursing and behavioural areas (ACFI Complex Care Indicator). One of these questions is concerned with identifying dementia and/or behavioural needs in terms of: the complexity of care needs; predictability of the person's response to their condition; and the stability of the condition. Information about the level of care required with other activities, such as eating and drinking and personal hygiene, is also collected. The introduction of the ACFI will obviously improve the data about dementia in residential aged care in the future.

National Respite for Carers Program data

The NRCP funds respite services, Commonwealth Carer Respite Centres, Commonwealth Carer Resources Centres and the National Care Counselling Program. Commonwealth Carer Resource Centres provide carers with up-to-date, relevant information and advice about available services and support, government programs, publications, training and education. Commonwealth Carer Respite Centres are run by a wide variety of community organisations, and may organise, purchase or manage respite care assistance packages for carers, if required. Respite care assistance may include in-home, residential, short-term or emergency respite. Many of the respite services are dementia-specific. Commonwealth Carer Respite Centres also work closely with the Commonwealth Carer Resource Centres to ensure comprehensive support for carers and access to carer information and training materials.

The NRCP MDS consists of two separate data collections, which include information about services provided by Commonwealth Carer Resource Centres and Commonwealth Carer Respite Centres. Where data requirements are the same across these collections, the collections have defined the data elements in the same way. Detailed information is collected about the carer, with additional information collected about the care recipient (e.g. dementia

status) and service event. The data are transmitted quarterly to the Department of Health and Ageing collection agency. The MDS is unique in that it is a carer-centred data set which also collects information about care recipients and service events.

As well as demographic information, dementia diagnosis status, primary disability, care needs, level of need and challenging behaviour are collected about the care recipient. Information about the carer and the caring role includes demographics, co-residency status, relationship of the carer to the care recipient, number of care recipients, time spent caring, carer need and use of services.

3.2 Surveys

In contrast to administrative data collections which result from the collection of information necessary to the delivery of a service or program, surveys are primarily designed to collect data for a possible range of purposes. Client surveys focus on the clients of a particular service and on topics that are relevant to service delivery. Like administrative data collections, they allow the estimation of prevalence for client groups. Population surveys, such as the ABS SDAC, may be used to provide prevalence estimates in the population as a whole. The population being surveyed is typically selected through sampling procedures based on household and individual characteristics.

Population and client surveys may be cross-sectional or longitudinal in nature. Cross-sectional surveys collect data at a single point in time. Repeat cross-sectional surveys permit some analysis of the change in populations of interest over time, but do not allow any change in individuals to be examined. However, a longitudinal design that can be used to examine patterns of change at the individual level and investigate causal relationships between variables of interest is particularly useful when considering progressive health conditions such as dementia.

As the prevalence of dementia in the general population is quite low and is concentrated in the older age groups, it is difficult to ensure that there are sufficient cases in a general population survey to permit reasonable analysis. Over-sampling of the older age groups or of people in cared accommodation (a strategy used by the SDAC), or a very large overall sample size, can not only increase the amount of data available and improve the quality of analysis, but also increase the resources required for the study. Alternatively, purpose-designed surveys may use client populations of interest as a sampling frame.

Data may be collected via:

- survey questionnaires (either self-completed or interview administered) – variations on this may include diary completion by respondents
- clinical measurements (e.g. height and weight, or analysis of blood samples)
- researcher observations (e.g. of mobility in the home).

The heavy reliance on self-reporting from questionnaire-based methodologies poses particular challenges for the collection of reliable data about cognitive disorders such as dementia. However, most surveys permit the use of proxy-reporting where the relevant respondent is unable to self-report.

National population surveys

National Health Survey

The NHS is a population survey conducted by the ABS. The NHS is designed to obtain national benchmark information on a range of health-related issues, and to enable changes in health to be monitored over time. Surveys were conducted in 1977–78, 1983, 1989–90, 1995, 2001 and 2004; the 2001 and 2004 surveys are the first two surveys in a new series of triennial ABS health surveys, and covered topics similar to those in the 1995 survey. The NHS is a self-report survey, and is conducted in private dwellings throughout urban and rural areas across all states and territories of Australia (generally excluding sparsely settled areas). No data are collected on people in non-private dwellings, such as cared accommodation.

The content differs between surveys, around a common (or core) data set. For example, the 2001 NHS collected information about:

- the health status of the population, including long-term medical conditions experienced (particularly asthma, cancer, heart and circulatory conditions, diabetes and mental wellbeing) and recent injuries
- use of health services such as consultations with health practitioners and visits to hospital and other actions people have recently taken for their health
- health-related aspects of people's lifestyles, such as smoking, diet, exercise and alcohol consumption
- demographic and socioeconomic characteristics (ABS 2002).

In the 2001 NHS, information about dementia (and cognitive impairment and behaviour) as a long-term health condition is collapsed into the category of *Organic mental health problems* or *Symptoms and signs involving cognition, perceptions, emotional state and behaviour* under *Mental and behavioural problems* (see ABS 2002), and is not separately identifiable in the Mental Health Supplement. The survey does not include any information about functioning or carers.

Survey of Disability Ageing and Carers

The ABS SDAC collects information about people with a disability, older people (i.e. those aged 60 years and over), and people who provide assistance to older people and people with disabilities (ABS 2004). Surveys were conducted in 1981, 1988, 1993, 1998 and 2003. The SDAC collects data about long-term health conditions, and enables national estimates of the prevalence of disability and the conditions, such as dementia, that give rise to it. Other survey data sources that identify long-term conditions (e.g. the NHS) do not collect information in respect of disability and caring. Importantly, the SDAC is the only national survey to collect data about people living in cared accommodation. This is a particularly important consideration when conducting research about dementia.

Information in the 2003 survey was collected from approximately 36,200 respondents from about 14,300 private dwellings (e.g. houses and flats) and non-private dwellings (e.g. hotels and motels), and approximately 5,100 respondents from about 600 cared accommodation establishments such as hospitals and residential aged care establishments. The survey gathers data from people living in both rural and urban areas across Australia.

The survey was conducted using two collection instruments: an interviewer-based computer-assisted collection for all usual members of selected households; and mail-back forms completed by a staff member for residents of cared accommodation facilities. Families

with a member (such as parent or child) with a disability were identified, together with families in which a member was a primary carer. The cared accommodation component covered residents of hospitals, residential aged care and other homes, who had been, or were expected to be, living there for at least three months.

Data from the household component of the survey are based on self-report, or reported by a proxy such as a carer where the person of interest was unable to respond for themselves. Long-term health condition(s) were not identified by clinical assessment or other more rigorous methods of diagnosis. This affects estimates of the prevalence of dementia, particularly in terms of identifying people in the early stages of dementia, before any cognitive or functional impairments or changes in behaviour have become apparent. Where dementia was reported by people or their carers, it was overwhelmingly associated with the experience of profound or severe disability. In 2003, it is estimated that of the 101,900 people with dementia, the number sometimes or always needing assistance with self-care, mobility and/or communication – that is, with a severe or profound core activity limitation – was 98,800. Therefore, the survey is likely to underestimate the prevalence of dementia, particularly for people living in households.

In cared accommodation, the survey is not self-reported but is completed by a staff member who is required to record any long-term health conditions. The data collected were limited to the information a staff member could be expected to know from medical, nursing and administrative records (ABS 2004:15-16). The prevalence of dementia in these settings is likely to be more accurate than in the household component, although people who have undiagnosed or early-stage dementia, or whose dementia symptoms are masked by the symptoms of other health conditions and disabilities, may not be identified.

In the 2003 SDAC, long-term health conditions were coded to a classification based on the ICD-10. A person was considered to have a long-term health condition, such as dementia, if he/she had a disease or disorder which had lasted or was likely to last for at least six months; or a disease, disorder or event (e.g. stroke) which produced an impairment or restriction which had lasted or was likely to last for at least six months. A person was considered to have a disability if he or she had a limitation, restriction or impairment which had lasted, or was likely to last, for at least six months and restricted everyday activities.

Dementia, Alzheimer's disease and Parkinson's disease are coded separately in the list of long-term health conditions. Other types of dementia, such as that arising from Huntington's disease or Pick's disease, fall within other categories such as *Other diseases of the nervous system*, along with other long-term health conditions. Similarly, alcoholic dementia falls within the category *Mental disorders due to alcohol and other psychoactive substance use*.

However, people with Parkinson's disease do not always develop dementia. Therefore, for analytic purposes, only those who report *Alzheimer's disease* and/or *Dementia* as a long-term health condition can be considered to have dementia. People with other forms of dementia, such as dementia in Parkinson's disease or alcoholic dementia, may report having both *Parkinson's disease* or *Mental disorders due to alcohol and other psychoactive substance use* as well as *Dementia*, but it cannot be assumed that this is necessarily the case.

In addition to data about long-term health conditions, a large amount of information about functioning is also collected, including questions on need for assistance with cognitive and emotional tasks, managing own behaviour and making decisions or thinking through problems. Additionally, the SDAC provides some information about carer availability, carer co-residency status, relationship of the carer to the care recipient, impact of the caring role, assistance provided and support access, as well as demographic information. However, the

2003 SDAC CURF only allows co-resident carers of people with dementia to be identified and only collects more detailed information from primary carers.

Further background information about the 1998 and 2003 SDAC can be found in the *Disability, Ageing and Carers* publications (ABS 2000, 2004).

Long-term health conditions in national population surveys

A comparison of the prevalence estimates for long-term health conditions from the National Health Survey and the Survey of Disability, Ageing and Carers highlights the sensitivity of these measures to survey design and methodology.

Overall, the number and proportion of people reporting at least one long-term condition in the 2001 National Health Survey were more than two times those of the 1998 Survey of Disability, Ageing and Carers: 78% of the total population in the NHS compared to about 36% in the SDAC (AIHW 2004d). The difference in these estimates occurs because the NHS recorded long-term health conditions that were not necessarily related to disability, whereas the SDAC recorded conditions that were more likely to be associated with impairments and activity limitations.

However, differences in prevalence estimates between the two national surveys varied with the type of condition. Some conditions had higher prevalence rates for the 2001 NHS than for the 1998 SDAC (e.g. vision problems, back problems, hearing disorders), while higher rates were reported by the SDAC than the NHS for other conditions (e.g. heart disease and stroke). The relatively lower rates of heart diseases and stroke in the NHS is partly because of the exclusion of persons living in institutions, as a substantial proportion of people with those conditions were living in institutions, and partly because of particular questions included in each survey.

The absence of dementia from the data file of the 2001 NHS means that the prevalence estimates from the two national surveys cannot be compared. However, two features of the SDAC design would suggest that it may be more successful in identifying respondents with dementia than the NHS – the inclusion of people in cared accommodation and the inclusion of all people in selected households who were over the age of 60 years. However, its bias towards recording conditions more likely to be associated with impairments and activity limitations suggests another possible reason for the underestimate of mild and moderate dementia prevalence.

Client surveys

Bettering the Evaluation and Care of Health

BEACH is a survey conducted by the Australian General Practice Statistics and Classification Centre within the Family Medicine Research Centre at the University of Sydney (an AIHW Collaborating Centre). BEACH is an ongoing survey that collects information about patients seen, reasons people seek medical care, problems managed and treatments provided in general practice in Australia. The survey began in April 1998 and involves about 1,000 GPs randomly sampled from Medicare records, each year. One hundred consecutive consultations (including indirect consultations by telephone) which result in a management action are recorded from each GP. The GPs are recruited on a rolling basis; approximately 20 GPs participate each week, 50 weeks a year (AIHW: GPSCU 2005).

BEACH uses a cross-sectional, paper-based data collection system and involves three interrelated data collections: encounter characteristics, GP characteristics and patient characteristics. The **encounter** is the primary unit of analysis; information recorded by the GP at each encounter includes demographic characteristics of the patient, patient reasons for encounter, diagnosis/problems managed and how each of these problems is managed. Data collected about management of each diagnosis/problem managed includes information about medications, procedures, other treatments and counselling, new referrals and admissions, and imaging and pathology ordered.

Additional questions about risk factors or special interest topics may be asked of patients in subsamples of encounters, as part of the Supplementary Analysis of Nominated Data (see AIHW: GPSCU 2005). Specific investigations have been conducted under this program to investigate the prevalence of Alzheimer's disease and other dementias or cognitive impairment in adult general practice patients, and to measure the proportion of general practice patients not diagnosed with dementia who, in the GP's opinion, were likely to have dementia or the early signs of Alzheimer's disease (AIHW: GPSCU 2002). The study also examined difficulties with daily living or behaviour changes in patients not diagnosed with Alzheimer's disease or dementia. This study used a sample of 2,194 encounters (with adults) from 88 GPs in August 2001.

Dementia may be recorded as one of three reasons for encounter or as one of four diagnoses/problems managed, coded using ICPC-2 PLUS. Information about commonly prescribed medications including antidementia drugs is collected and classified according to the Anatomical Therapeutic Chemical group (Britt et al. 2004).

Longitudinal surveys

Longitudinal studies typically follow cohort(s) of people over time thus allowing investigation of causation of the outcome of interest. They are of particular value when the outcome of interest concerns a progressive condition such as dementia. There are a number of Australian longitudinal studies which collect data about dementia. Of these studies, the Australian Longitudinal Study on Women's Health is a national survey, while there are five smaller local area longitudinal studies. Information about these studies is drawn from the stocktake of such studies undertaken by the AIHW in 2004 (AIHW: Logie et al. 2004), also available on the Ageing Research Online website (www.aro.gov.au).

National longitudinal studies

Australian Longitudinal Study on Women's Health

The Australian Longitudinal Study on Women's Health (Women's Health Australia) is a national study providing information on women's health issues. The study began in June 1995 in response to initiatives arising from the National Women's Health Policy. The study is designed to explore factors that influence health among women who are broadly representative of the entire Australian population.

In April 1996, the Health Insurance Commission randomly selected 14,739 women aged 18–23, 12,762 women aged 45–50 and 14,011 women aged 70–75 from the Medicare database. Each age cohort is surveyed once every three years (over a 20-year period), via surveys sent in the mail, to see how each participant's health has changed.

Women's Health Australia collects information about the needs, views, lifestyles, health and factors affecting the health of individual women in Australia. It takes a comprehensive view of all aspects of health throughout women's life spans. In particular, the study assesses:

- physical and emotional health (including wellbeing, major diagnoses, symptoms)
- use of health services (GP, specialists and other visits, access, satisfaction)
- health behaviours and risk factors (diet, exercise, smoking, alcohol, other drugs)
- time use (including paid and unpaid work, family roles and leisure)
- sociodemographic factors (location, education, employment, family composition)
- life stages and key events (such as childbirth, divorce, widowhood).

The study also links social, environmental and personal factors in women's lives to health care use data, by record linkage with the Medicare database.

Alzheimer's disease or dementia was added to the list of diagnosed or treated medical conditions from the second survey of the oldest cohort, although an *Other – please specify* category exists for the younger cohorts. In the second survey, 0.5% of the oldest cohort (aged 73–78 years) reported that they had been diagnosed with (or treated for) Alzheimer's disease or dementia. This increased to 1.1% in the third survey, when the oldest cohort was aged 76–81 years. The oldest cohort is also asked about the presence of poor memory and difficulty concentrating. All cohorts are asked questions about functioning.

The survey also identifies those respondents in the two older cohorts that are carers, but no details of the person they care for (such as dementia status) are collected. Demographic information is collected, and questions are asked about physical and emotional health (including information on a range of signs and symptoms such as pain and stress), difficulties with sleep, service use, sources of income, social support and leisure activities, allowing the impact of the caring role to also be examined.

The longitudinal nature of the survey means that patterns of change at the individual level can be described and analysed, and that casual relationships can be investigated. However, the use of self-reporting (or reporting by proxy), particularly via a mail-out survey, means that dementia and carers of people with dementia are likely to be under-reported.

Local area longitudinal studies

A number of local area longitudinal studies also collect information about dementia. Although these studies are small (compared with the national Australian Longitudinal Study on Women's Health), they frequently include clinical measures and assessments.

Australian Longitudinal Study of Ageing

The Australian Longitudinal Study of Ageing began in 1992, collecting data from 2,087 participants in South Australia. The Centre for Ageing Studies at Flinders University is the unit responsible for the study and for data collection. The study allows assessment of the effects of social, biomedical, psychological, behavioural, economic and environmental factors on changes in health, development of disability, general wellbeing, economic security, use of acute and long-term care services, morbidity, mortality and 'successful' ageing in people aged 70 and over. Data about cognitive functioning along with other information about health and functional status have been collected over the period 1992–2003.

Sydney Older Persons Study

This study began in 1991 with 327 war veterans and widows and 320 non-veterans aged 75 and over. The five stages of the study consist of medical and neurological assessments of the participants, and data collection on health and lifestyle and medication history.

Stage 4 of the study had a particular focus on the cognitive and structural correlates of 'normal' brain ageing, and on the impact of age, environmental factors and illnesses on executive functions in older people. As part of this study stage, 102 community-dwelling individuals aged over 80 years underwent MRI scanning of the brain as well as neurological and neuropsychological assessment. Stage 5 of the study concentrated on subjects who had an MRI scan in stage 4. These people were re-invited to participate in a further MRI scan and neuropsychological assessment.

In a substudy of participants from wave 3, Bennett et al. (2003) found that 78 (26%) had a Clinical Dementia Rating (CDR) score of 1 or above (representing mild, moderate and severe dementia), 95 had a score of 0.5 (questionable dementia or mild cognitive impairment), and 126 had a score of 0 (normal cognition).

Canberra Longitudinal Study of Ageing

The Canberra Longitudinal Study of Ageing is a 12-year study into the health and memory of older people. It aims to identify predictors of memory decline and dementia and provide epidemiological data on mental disorders in older Australians. The sample consists of a single cohort of approximately 1,000 people aged 70 years and over with initial collection in 1990–91, and subsequent waves in 1994, 1998 and 2002.

Interviews incorporated the Canberra Interview for the Elderly which provides diagnoses of dementia and the following cognitive tests: Mini-Mental State Examination (screening test), National Adult Reading Test (a test of crystallised intelligence that relies on the reading of words that are not pronounced phonetically), Symbol-Letter Modalities Test (measure of cognitive speed), Episodic Memory Test (four short memory tasks) and the Informant Questionnaire on Cognitive Decline.

Korten et al. (1999) found that the main predictors of mortality between waves 1 and 2 were physical ill health and poor cognitive functioning, and that mortality among men was more than twice that of women even after adjusting for a wide range of other variables. The relation with cognitive performance remained when respondents diagnosed with dementia were excluded from the analysis. Age was not a significant covariate once adjustment was made for health and cognitive performance, but was significant if only physical health was controlled – Korten et al. (1999) suggest that cognitive impairment may be a stronger predictor of mortality than age over short periods of time.

For men the physical health predictor was self-rated health, while for women it was disability in activities of daily living. For cognitive functioning, the predictors for men and women were the Symbol-Letter Modalities Test and the MMSE, respectively. This confirms results from other studies that suggest self-rated health is a better predictor of mortality for men than for women, and that a test of mental speed is a good predictor for men (Idler & Benyamini 1997, cited in Korten et al. 1999).

PATH Through Life Project

The Personality and Total Health (PATH) Through Life Project is a 20-year longitudinal study of 7,485 adult community residents randomly selected from the Canberra and Queanbeyan electoral rolls. It aims to investigate the causes of three classes of common mental health problems: anxiety and depression; alcohol and substance abuse; and cognitive

ageing and dementia. Neurocognitive assessments by a doctor and MRI scans were used in a substudy of the 60–64-year-old cohort that examined relationships between health and memory and looked at memory change over time. In a substudy of 2,551 subjects aged 60–64 years, Kumar et al. (2005) found that 224 (8.8%) screened positive for mild cognitive impairment. Of these, 112 underwent a detailed assessment and 74% met the criteria for at least one recognised diagnosis of mild cognitive deficit. By predictive regression modelling, the prevalence of any mild cognitive deficit in the population of those aged 60–64 years was 13.7%. The estimated prevalence rates for specific diagnoses were mild cognitive impairment 3.7%, ageing-associated cognitive decline 3.1%, CDR 0.5 2.8%, age-associated memory impairment 1%, other cognitive disorders 0.9% and mild neurocognitive disorder 0.6%.

Most tests in the neuropsychological battery were chosen for their sensitivity to the effects of cognitive ageing: MMSE (cognitive screening instrument), List A of the California Verbal Learning Test (immediate recall and recall after a one minute delay), Digits Backwards from the Weschler Memory Scale (working memory), Symbol Digits Modalities Test (speed of information processing) and simple and choice reaction time tasks. The Spot-the-Word Test was administered as a measure of verbal intelligence, as it does not usually show age-related cognitive deficits.

It has been suggested that greater lifetime oestrogen exposure results in better cognition in later life, particularly in the area of verbal memory. However, in a substudy of 760 naturally postmenopausal women in the 60–64-year-old cohort, Low et al. (2005) found no significant associations between reproductive period and performance on any of the cognitive tests, either before or after controlling for potential confounding variables (such as the small but positive correlation between reproductive period and performance on the Spot-the-Word Test).

Dubbo Study of the Health of the Elderly

The Dubbo Study of the Health of the Elderly is a 15-year biomedical and social science investigation of healthy ageing, service use, delay of disability and age-related diseases such as cardiovascular disease, osteoporosis and dementia. A group of 2,805 non-institutionalised citizens aged 60 and over living in the town of Dubbo were first interviewed in 1988.

The study aims to identify patterns and predictors of mortality, hospitalisation and need for residential care. The Dubbo study also includes questionnaires examining life satisfaction, self-esteem, social involvement and support and family and community contributions. A new phase to the study began in 2000 to investigate how income and assets, government entitlements and informal care services modify expected changes in health or family circumstances in later life.

A unique feature of the Dubbo study was gaining participants' consent to undertake record linkage to service provider databases including the PBS and Medicare databases.

Recently, McCallum et al. (2005) reported that 44% of nursing home placements were primarily related to dementia, while dementia was a secondary diagnosis in a further 20% of people admitted. At a 16-year follow-up, Simons et al. (2006) reported that of the 1,233 men and 1,572 women initially free of cognitive impairment (measured using the Short Portable Mental Status Questionnaire), 115 men (9.3%) and 170 women (10.8%) had developed dementia. On average, the men developing dementia were 3.5 years older at baseline than their peers without dementia, and the women with dementia were 5.7 older than their peers. Moderate intake of alcohol and daily gardening were found to predict a lower risk of dementia, and daily walking predicted a lower risk of dementia in men. Impaired peak expiratory flow and higher depression score at baseline predicted an increased future risk of

dementia. Univariate analysis also suggested that lower educational attainment, prior coronary heart disease, poor self-rated health and physical disability were significant predictors of an increased risk of dementia.

Table 3.1: Summary of data items included across national collections

Collection	Dementia diagnosis status	Type of dementia	Cognitive impairment	Behaviour	Treatments for dementia	Functional impairment	Carer items
Alzheimer's Australia DESP	✓	✓	✓	✓		✓	✓
Medical Benefits Schedule							
Pharmaceutical Benefits Scheme			✓		✓		
National Hospital Morbidity Database		✓	✓				
Aged Care Assessment Program		✓	✓			✓	✓
Home and Community Care Program MDS v2			✓	✓		✓	✓
Community Aged Care Packages Program (census)	✓					✓	✓
Extended Aged Care at Home Program (census)	✓					✓	✓
Resident Classification Scale			✓	✓		✓	
Aged Care Funding Instrument (trial)		✓	✓	✓		✓	
National Respite for Carers Program	✓	✓ [†]		✓		✓	✓
Bettering the Evaluation and Care of Health		✓	✓	✓	✓		
Survey of Disability, Ageing and Carers		✓	✓	✓		✓	✓
National Health Survey		✓ [†]	✓	✓			
Australian Longitudinal Study on Women's Health	✓		✓			✓	✓

✓ The program includes a data item that allows for the collection of this information (though this does not necessarily mean that it is always collected).

✓[†] Limited information is collected in this area.

Section 2: Dementia data analysis

4 Prevalence, incidence and burden of disease

4.1 Summary

- Almost 175,000 people had dementia in Australia in 2003, and 190,000 in 2006, of whom 64% were female and 81% were aged 75 or older.
- Since dementia prevalence is strongly age-related, the number of cases of dementia is expected to increase to almost 465,000 by 2031, as the population grows and ages.
- Dementia may be classified as 'mild' in about 96,000 people (55%); 'moderate' in 52,000 people (30%); and 'severe' in 26,000 (15%).
- Most people with mild dementia are living in households and most people with moderate or severe dementia are in cared accommodation.
- There were about 37,000 new cases of dementia in 2003 of which 23,000 are female and 14,000 male.
- Most of the 'burden of disease' caused by dementia is due to disability rather than premature death, with disability accounting for about three-quarters of the total disease burden in 2003.

4.2 Prevalence of dementia

The prevalence of dementia is the number of people in the population affected by dementia at a given time. Prevalence estimates for dementia have commonly been based on data from meta-analyses, which combine data from a number of studies that use similar methods to produce better estimates. In Australia, estimates have also been derived from the 1998 and 2003 Surveys of Disability, Ageing and Carers (SDAC). However, there is evidence that these surveys underestimate cases of mild and moderate dementia in both households and, possibly to a lesser extent, in cared accommodation (see Chapter 3 for a discussion of this). For this reason estimates of prevalence of dementia for Australia based on meta-analyses have been preferred to those based on the 2003 SDAC.

Overview of prevalence estimates from meta-analyses

A number of individual epidemiological studies have investigated the prevalence (and incidence) of dementia, and its major subtypes, Alzheimer's disease and vascular dementia. Although these studies generally show similar results such as increasing rates with age, actual prevalence (and incidence) rates vary markedly from one study to another. Methodological effects such as definition of dementia or sample characteristics have substantial effects on the levels reported (Jorm et al. 1987, cited in Wancata et al. 2003). Meta-analyses pool data from a group of individual studies which have used similar methods, with the aim of producing aggregate estimates with better accuracy than any

individual study. These meta-analyses of the prevalence of dementia differ markedly in the number of individual studies included, the level of detail reported and the findings:

- Jorm et al. (1987) analysed data from 22 studies of moderate to severe dementia carried out between 1945 and 1985 across the world. Studies were excluded if they were based on limited psychiatric case registers; did not involve a broad community sample; or did not present rates for all the elderly aged 65 or more. The authors found that whereas the actual prevalence rates differed greatly between studies (due to methodological differences such as case definitions), there was a consistent underlying trend for prevalence rates to increase exponentially with age, with a doubling of the rate every 5.1 years of age up to about 95 years. No difference was found between males and females in the prevalence rate of dementia. Rates for Alzheimer's disease tended to be higher in females and rates for vascular dementia higher in males.
- Hofman et al. (1991) pooled data from 12 methodologically-similar European studies carried out between 1980 and 1990. The selection of studies was based on sufficient sample size; case-finding through direct individual examination; inclusion of both institutionalised and non-institutionalised individuals; and clinical diagnosis of dementia based on Diagnostic and Statistical Manual of Mental Disorders (DSM), Third Edition or equivalent criteria. The dementia prevalence rate nearly doubled with every 5 years of age over 60 years up to 95 years. Sex differences were the same as reported by Jorm et al. (1987).
- Ritchie et al. (1992) analysed data from 13 European, North American and Asian studies of moderate to severe dementia conducted since 1980. By restricting the studies to more recent data using standard diagnostic criteria the authors found much less variability in prevalence rates than Jorm et al. (1987) and Hofman et al. (1991). Their recommended model implied a doubling of the dementia prevalence rate every 6 years of age. No sex comparisons were reported.
- More recently, Ritchie & Kildea (1995) analysed data from nine recent European, North American and Asian studies conducted since the 1980s. The studies all used DSM-III diagnostic criteria, included samples of elderly people over 80 years of age, and used adequate sampling procedures from both community-dwelling and institutionalised populations. The authors modelled a flattened S-shaped curve which implied that prevalence rates levelled out at higher ages, to about 40% at around 95 years. No sex comparisons were reported.
- Fratiglioni et al. (1999) pooled data from 36 population-based prevalence studies of dementia carried out in Europe, North America, Asia and multi-ethnic communities, published between 1990 and 1998. Selection of studies was based on diagnosis of dementia using comparable diagnostic criteria. The dementia prevalence rate increased exponentially with age even at higher ages. No sex comparisons were reported.
- Lobo et al. (2000) pooled data from 11 European population-based studies of mild to severe dementia conducted in the 1990s, as an update to the meta-analyses by Hofman et al. (1991), and Rocca et al. (1991a, 1991b). The selection of studies was based on detection of cases in face-to-face interviews with the subjects and response rates above 80%. In each study, diagnosis of dementia was made according to DSM-III-R criteria, or equivalent criteria such as the Cambridge Examination for Mental Disorders of the Elderly (CAMDEX) or Automated Geriatric Examination for Computer Assisted Taxonomy (AGECAT). Prevalence rates differed greatly between studies, which Lobo et al. (2000:S7) suggested 'may reflect differences in sample size, or there may be weak risk factors related to dementia and survival that explain the variation in prevalence at older ages'.

Prevalence rates for dementia nearly doubled with every 5 years of age. In most studies examined by Lobo et al. (2000), the prevalence rate of dementia was found to be higher in females than males, particularly in the older age groups. The prevalence rate of Alzheimer's disease was higher in females than in males in all studies. Under 85 years of age, rates for vascular dementia were higher in males than females but the reverse was true after this age.

- Recently, Access Economics (2005) adopted methodology used by Wancata et al. (2003) and Jorm et al. (2005) and published estimates of the number of people with dementia in Australia based on rates from four meta-analyses. Prevalence rates for those over 60 were estimated by averaging the rates from Jorm et al. (1987), Hofman et al. (1991), Ritchie & Kildea (1995) and Lobo et al. (2000) for each age-sex group.

The age-specific rates for dementia from each of these sources are shown in Table 4.1 together with estimates of the number of Australians aged 65 years or over with dementia in 2003, based on these rates.

Table 4.1: Prevalence rates for dementia estimated from various sources, 2003

Study	Age group								Total 65+	
	60-64	65-69	70-74	75-79	80-84	85-89	90-94	95-99	Per cent	Number
Jorm et al. (1987)	0.7	1.4	2.8	5.6	10.5	20.8	38.6	..	6.6	167,200
Hofman et al. (1991)										
Males	1.6	2.2	4.6	5.0	12.1	18.5	32.1	31.6	6.3	71,200
Females	0.5	1.1	3.9	6.7	13.5	22.8	32.2	36.0	8.4	117,900
Persons	1.0	1.4	4.1	5.7	13.0	21.6	32.2	34.7	7.3	185,800
Ritchie et al. (1992)	..	1.3	2.4	4.4	8.1	14.9	27.3	50.2	5.3	135,700
Ritchie & Kildea (1995)	..	1.5	3.5	6.8	13.6	22.3	31.5	44.5	7.6	193,400
Fratiglioni et al. (1999)	0.5	1.5	3.0	6.0	12.0	n.p.	n.p.	n.p.		
Lobo et al. (2000)										
Males	..	1.6	2.9	5.6	11.0	12.8	—22.1—		5.1	57,900
Females	..	1.0	3.1	6.0	12.6	20.2	—30.8—		7.6	106,800
Persons	..	0.8	n.p.	n.p.	n.p.	n.p.	—28.5—	
Ferri et al. (2005)										
EURO A	0.9	1.5	3.6	6.0	12.2	—24.8—		7.1	181,800	
WPRO A	0.6	1.4	2.6	4.7	10.4	—22.1—		6.0	153,400	
Access Economics (2005)										
Males	1.2	1.7	3.5	5.8	11.8	18.6	31.1	38.1	6.0	67,700
Females	0.6	1.3	3.3	6.3	12.6	21.5	33.3	40.3	8.0	113,000
									7.1	180,700

Notes

1. Age-standardised to the 30 June 2003 population (ABS 2003).
2. Final column includes estimates based on age-sex-specific rates.

Henderson & Jorm (1998) concluded that it is not possible to derive a 'true' prevalence rate from meta-analyses. Further, a 2004 report by the Organisation for Economic Co-operation and Development (OECD) concluded that there is currently no means of disentangling differences in dementia prevalence across countries from methodological differences since methodology is still not reproducible from one study to another (OECD 2004).

The prevalence estimates for Australia derived from the studies presented in Table 4.1 are influenced by the different selection criteria and methods adopted by the meta-analyses. Also, the meta-analyses are not mutually exclusive in terms of the individual studies selected

for inclusion. The evidence from the more recent meta-analyses suggests that the prevalence of dementia in Australia in 2003 among Australians aged 65 years or older was between 136,000 and 193,000 (5.3% to 7.6%). Although a prevalence estimate for those aged 65 years or older has not been provided for the study by Fratiglioni et al. (1999), a comparison of the available rates with other studies suggests that it is likely to be within this range.

Estimation of dementia prevalence in this report

In this report, estimates of dementia prevalence in Australia have been derived from the age- and sex-specific rates from one specific meta-analysis, Lobo et al. (2000). The prevalence of the major types of dementia (Alzheimer's disease and vascular dementia) has also been estimated from this meta-analysis. The prevalence of Alzheimer's disease is estimated at 60% of total dementias for men and 75% for women. The corresponding estimate for prevalence of vascular dementia is 40% for men and 25% for women of total dementias.

The decision to use data from the Lobo et al. (2000) meta-analysis as a basis for estimating the prevalence of dementia in Australia was based on the following reasons:

- The meta-analysis is based on population-based studies conducted in the 1990s.
- It provides age- and sex-specific breakdowns for the major subtypes of dementia.
- It is based on studies using DSM-III-R or equivalent criteria (e.g. CAMDEX or AGE-CAT).
- Nearly all of the studies included in the meta-analysis adopted a two-phase screening design to ascertain dementia (i.e. a cognitive screen of the whole sample followed by clinical examination of all people who screened positive).
- It is a follow-up of the Hofman et al. (1991) meta-analysis of studies conducted in the 1980s by the European Community Concerted Action on the Epidemiology and Prevention of Dementia (EURODEM) group of researchers, which gave very similar results to the meta-analysis by Jorm et al. (1987).

The meta-analysis reported clear differences in the age-specific prevalence of Alzheimer's disease and vascular dementia, which supports the modelling of the major types of dementia separately. It is not clear whether the sex differences in the rates reported by Lobo et al. (2000) are real or an artefact of differential survival between the sexes and/or methodological differences (Launer et al. 1999).

The prevalence rates for Alzheimer's disease and vascular dementia were adjusted upwards by an age-sex-specific adjustment factor in order to account for 'other' dementia.

The prevalence of dementia in those aged less than 60 years is very low and is more appropriately estimated from cases that come to medical attention rather than from population surveys (Harvey et al. 2003). This UK study identified cases using multiple methods including hospital records and notification by health professionals. This study has been used to estimate prevalence rates of dementia for age groups less than 60.

Based on Lobo et al. (2000) and Harvey et al. (2003), there were an estimated 174,700 people with dementia in Australia in 2003 (Table 4.2). Almost two-thirds of people with dementia (64% or 112,200 people) were female. There were more females than males with dementia from 75 years of age. However, males with dementia outnumbered females with dementia in the younger age groups.

According to these estimates, 44% of people with dementia are aged 75–84 and 37% are aged 85 years and over. The age profile of males with dementia is different from that of females. For example, a higher proportion of males with dementia are aged less than 75 years (30%) than females (13%).

Table 4.2: Prevalence of dementia, by age and sex, 2003

Age	Rate (%)			Number		
	Males	Females	Persons	Males	Females	Persons
0–64	0.1	—	0.1	5,500	2,600	8,100
65–74	2.0	1.8	1.9	13,200	12,200	25,400
75–84	7.3	9.3	8.4	28,200	48,100	76,300
85+	17.1	24.9	22.4	15,600	49,300	64,900
65+	5.0	7.8	6.5	57,000	109,600	166,600
Total	0.6	1.1	0.9	62,500	112,200	174,700

— Nil or rounded to zero.

Sources: Based on data from Lobo et al. 2000 and Harvey et al. 2003.

Estimates from Access Economics (2005), which are widely reported in Australia, suggest that there were around 192,000 people with dementia in Australia in 2003. This estimate is higher than the 175,000 people with dementia reported in Table 4.2. However, it should be noted that estimates for those aged 65 years or over from both of these sources fall within the range of estimates reported in Table 4.1.

Prevalence estimates by place of residency

Because of the disabling impact of dementia, a high proportion of people with severe and advanced dementia require full-time care and live in cared accommodation. The Australian Bureau of Statistics (ABS) SDAC is the only national population survey to collect data about people in cared accommodation. As Chapter 3 noted, identification of people with dementia is likely to be more accurate in this component of the survey than in the household component, although people with undiagnosed or early-stage dementia or those whose dementia symptoms are masked by those of other health conditions may not be identified by staff completing the survey. Nevertheless, the SDAC is currently the best source of data about dementia in cared accommodation, and has been used in this report to estimate prevalence in this sector.

The prevalence of dementia by place of residency (cared accommodation or household) is shown in Table 4.3. Of the 175,000 people with dementia, 43% (75,000) live in cared-accommodation (based on the SDAC), and consequently the remaining 57% (99,000 people) live in households. The proportion of people with dementia who live in households decreases with age, with 79% of people with dementia aged between 65 and 74 still living in the community. This proportion decreases to 36% of people with dementia aged 85 and over.

The age profile of people with dementia in cared accommodation is older than for people in households. Almost one-quarter of people with dementia living in households are aged 85 and over, compared with 55% of those in cared accommodation.

Nearly half of males aged 85 and over with dementia still lived in households compared to 32% of females in the same age group. This pattern is reflected across all age groups where a greater proportion of men than women with dementia are still living in households.

Table 4.3: Prevalence of dementia in households and cared accommodation, 2003

Sex/age	Total prevalence	Cared accommodation^(a)	Household	Per cent living in households
Males				
0–64	5,500	600	4,900	89.7
65–74	13,200	2,300	11,000	83.0
75–84	28,200	7,300	20,900	74.1
85+	15,600	7,900	7,700	49.3
<i>Total</i>	<i>62,500</i>	<i>18,000</i>	<i>44,500</i>	<i>71.1</i>
Females				
0–64	2,600	600	2,000	76.1
65–74	12,200	3,000	9,200	75.3
75–84	48,100	20,000	28,100	58.4
85+	49,300	33,600	15,700	31.9
<i>Total</i>	<i>112,200</i>	<i>57,200</i>	<i>55,000</i>	<i>49.0</i>
Persons				
0–64	8,100	1,200	6,900	85.3
65–74	25,400	5,300	20,100	79.3
75–84	76,300	27,300	49,000	64.2
85+	64,900	41,500	23,400	36.1
Total	174,700	75,300	99,400	56.9

(a) Cared accommodation includes *Accommodation for the retired or aged, Home for the aged, Home—other, Hospital—general and Hospital—other*. It is broader in scope than 'Residential aged care' reported in Table 7.27 in Chapter 7.

Source: AIHW analysis of the ABS 2003 Survey of Disability, Ageing and Carers confidentialised unit record file; Table 4.2.

Stability of age prevalence rates over time

Lobo et al. (2000) reported that the age pattern of the prevalence estimates seemed stable over time, as there was a general similarity between findings in his study and the results based on studies conducted in the previous decade by Hofman et al. (1991), Rocca et al. (1991b) and Rocca et al. (1991a).

Comparison of the 1998 SDAC and 2003 SDAC shows that the overall age-specific dementia prevalence rates changed little over the five years. However, for the age group 85 and over there was a significant decrease from 21.9% to 17.5% (Box 4.1).

For dementia subtypes, Rocca et al. (1991b) reported stable age-specific rates for the prevalence of Alzheimer's disease over 15 years (between 1957 and 1972) for both sexes with the exception of a decrease for women and an increase for men aged 80–89 which resulted in little overall change. The age-specific prevalence rates of vascular dementia also remained relatively stable over 15 years for both sexes, with the exception of declines for both men and women in the 80–89 age group.

Box 4.1: Comparison of 1998 and 2003 SDAC

The overall rate of dementia in the population aged over 65, as estimated from the SDAC, was 4.0% in 2003 compared with 4.3% in 1998 (Table 4.4). For each age group, estimates are a little lower in 2003 with the difference most marked for the 85+ age group (17.5% in 2003 compared with 21.9% in 1998). The rate of dementia in cared accommodation for those aged over 65 was lower in 2003 (3.0%) than in 1998 (3.2%).

The reduction in the cared accommodation rate from 3.2% of the 65+ population in 1998 to 3.0% in 2003 is statistically significant and represents a reduction of 3,000 people with dementia from what it would have been if the rate had remained unchanged. In the cared accommodation segment of the survey the identification of dementia is made by facility staff not by the resident, and survey methods in both years were consistent.

In the future, data from the Aged Care Assessment Program (ACAP) Minimum Data Set (MDS) and the new Aged Care Funding Instrument (ACFI) will be available to more accurately measure changes in dementia in residential aged care.

Table 4.4: Dementia rates from 1998 SDAC and 2003 SDAC, by age and residency

Age	1998			2003		
	Household	Cared accommodation ^(a)	Total	Household	Cared accommodation ^(a)	Total
35–64	—	—	*0.1	—	—	—
65–69	**0.3	0.3	*0.5	**0.2	0.2	*0.4
70–74	*0.9	0.8	1.7	*0.5	0.6	*1.1
75–79	*1.2	2.0	3.2	*1.3	1.7	3.0
80–84	**0.8	6.0	6.8	*1.5	5.0	6.5
85+	4.8	17.1	21.9	*2.8	14.6	17.5
Total 35+	0.3	0.8	1.1	0.3	0.7	1.0
Total 65+	1.1	3.2	4.3	1.0	3.0	4.0

— Nil or rounded to zero.

* Estimate has a relative standard error of 25% to 50% and should be used with caution.

** Estimate has a relative standard error greater than 50% and is considered too unreliable for general use.

(a) Cared accommodation includes *Accommodation for the retired or aged, Home for the aged, Home—other, Hospital—general and Hospital—other*.

Source: AIHW analysis of the ABS 1998 and 2003 Survey of Disability, Ageing and Carers confidentialised unit record file.

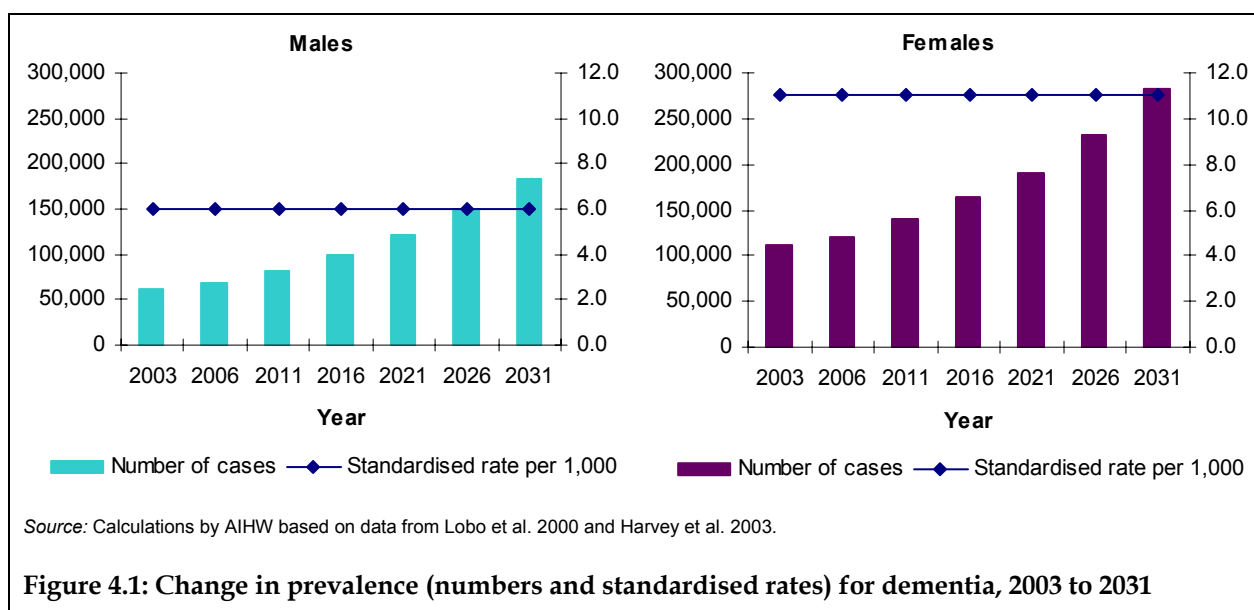
Projections of future prevalence

Between 2003 and 2031, the number of people with dementia is projected to increase from 175,000 to 465,000, an increase of 290,000 persons (Table 4.5 and Figure 4.1). In the eight years to 2011 the number of people with dementia is projected to increase by 27%, in the following decade by 40%, and in the decade to 2031 by 50%. The overall increase is 166%. This expected increase is entirely due to demographic factors, not an increase in the rate of the disease, that is, this increase results from the projected increase in the number of older people over this period and is based on the assumption that prevalence rates for dementia remain stable (Figure 4.1). However, prevalence rates may change as a result of changes in the prevention, detection, management and treatment of the disease.

Table 4.5: Projected number of people with dementia, 2003 to 2031

Sex/age	2003	2006	2011	2016	2021	2026	2031
Males							
0–64	5,500	5,900	6,700	7,100	7,600	7,800	8,000
65–74	13,200	13,900	16,700	20,900	24,100	26,200	28,400
75–84	28,200	30,500	33,000	37,800	47,100	61,000	71,800
85+	15,600	18,300	25,700	34,100	41,800	54,600	74,200
Total	62,500	68,500	82,000	99,900	120,600	149,500	182,500
Females							
0–64	2,600	2,900	3,300	3,600	3,800	3,900	4,000
65–74	12,200	12,600	14,900	18,800	22,100	24,200	26,000
75–84	48,100	50,300	51,500	56,400	67,900	87,400	104,100
85+	49,300	55,300	70,300	84,500	96,300	116,100	148,100
Total	112,200	121,000	140,000	163,300	190,100	231,600	282,200
Persons							
0–64	8,100	8,800	10,000	10,700	11,400	11,700	12,000
65–74	25,400	26,500	31,600	39,700	46,200	50,300	54,500
75–84	76,300	80,700	84,500	94,200	114,900	148,400	175,900
85+	64,900	73,500	96,000	118,500	138,100	170,700	222,200
Total	174,700	189,600	222,000	263,200	310,600	381,100	464,700

For comparative purposes, projections of the number of people with dementia in Australia in 2006, 2010 and 2020 as reported by Access Economics (2005) are 212,500, 242,500 and 332,900, respectively. The projected number of people with dementia in 2030 reported by Access Economics (2005) (465,500 people) is similar to the projected number of people with dementia in 2031 reported in Table 4.5 (464,700 people). Differences between the projections in Table 4.5 and the projections reported by Access Economics (2005) are due to differences in the meta-analyses used to derive prevalence estimates.



4.3 Prevalence by severity of dementia

The severity distribution of dementia in Australia has been estimated from the community-based, prospective study of degenerative diseases described by Barendregt & Bonneux (1998). The study included people in cared accommodation. In this study, severity is defined according to the Clinical Dementia Rating (CDR) scale (see Table 4.6) or a Mini-Mental State Exam (MMSE) score. The CDR score is derived by rating impairment in six domains: memory, orientation, judgement and problem solving, community affairs, home and hobbies and personal care (see Morris 1993). Impairment is defined as decline from the person's usual level of functioning due to cognitive loss alone for each category, not impairment due to other factors, such as injury or depression. Memory is the primary category and the score given for memory is used for the global score unless three or more of the secondary categories score higher or lower than the memory score.

Table 4.6: Clinical Dementia Rating

Score	Healthy CDR 0	Very mild impairment CDR 0.5	Mild CDR 1	Moderate CDR 2	Severe 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.

On the basis of severity definitions used in the CDR, Barendregt & Bonneux (1998) reported that 55% of dementia was classified as mild, 30% as moderate and 15% as severe. This overall distribution was applied to the total prevalence of dementia in Australia (Table 4.8), resulting in about 96,000 people with mild dementia, 52,000 with moderate dementia and just over 26,000 people with severe dementia. This is a critical assumption in the calculation of the burden of disease later in this chapter.

Table 4.7: Comparison of severity of dementia impact in the CDR and SDAC

Clinical Dementia Rating			Survey of Disability, Ageing and Carers	
Disease severity	Definition	Estimate	Need for assistance ^(a)	Definition
Mild (CDR 0.5–1)	Significant impact on daily activities but still able to undertake daily activities	55%	Mild	The person needs no help & has no difficulty with any of the core activity tasks but may use aids & equipment
			Moderate	The person needs no help but has difficulty with a core activity task
			Severe	The person sometimes needs help with a core activity task
Moderate (CDR 2)	Independent living is not possible without assistance	30%	Profound	The person is unable to do, or always needs help with, a core activity task
Severe (CDR 3)	Permanent supervision required	15%		

(a) Need for assistance is based on limitations with communication, self-care or mobility, which may also be caused by a coexisting condition other than dementia.

Sources: ABS 2004; Barendregt & Bonneux 1998.

In order to estimate the severity distribution of dementia separately for households and cared accommodation, the severity categories of the CDR have been mapped to disability severity measures in the SDAC, the source of data about people with dementia in cared accommodation. Although the SDAC has no disease severity measures, the survey does contain measures of **disability** severity based on need for assistance with core activity limitations. Core activities in the SDAC are personal care, mobility and communication activities (see Box 4.2). Such mapping is possible because the CDR domains include a description of the functional outcomes of dementia of different severity, including personal care. Table 4.7 maps the CDR domain descriptions to the SDAC descriptions of need for assistance with core activities.

Mapping between the CDR and SDAC is not perfect since a person's need for assistance as measured by the SDAC may arise partly because of the presence of another health condition. The two scales also use quite different nomenclature. For example, the 'mild', 'moderate' and 'severe' disability categories in SDAC correspond to the 'mild' domain using CDR. Those who are profoundly disabled according to the SDAC criteria mostly belong in the 'moderate' CDR domain and some belong in the 'severe' CDR domain. 'Moderate' is a serious misnomer for the CDR 2 category. As is shown by Table 4.6, people in the CDR 2 category have such severe memory loss that only highly learned material is retained, they are severely impaired in making judgements or solving problems, they often have no pretence of independent function outside home, and require help with personal care. Most people would describe this situation as 'severe' but the CDR labels it as merely 'moderate'. By contrast, the SDAC category of moderate disability indicates that the person needs no help but has difficulty with a core activity task. It is important to note that the language used in the two scales is therefore not equivalent.

Box 4.2: ABS 2003 Survey of Disability, Ageing and Carers: core activity limitation

Four levels of core activity limitation are determined based on whether a person needs help, has difficulty, or uses aids or equipment with any of the core activities (communication, mobility or self-care). A person's overall level of core activity limitation is determined by their highest level of limitation in these activities.

The four levels of limitation are:

Profound: *the person is unable to do, or always needs help with, a core activity task.*

Severe: *the person:*

- *sometimes needs help with a core activity task*
- *has difficulty understanding or being understood by family or friends*
- *can communicate more easily using sign language or other non-spoken forms of communication.*

Moderate: *the person needs no help but has difficulty with a core activity task.*

Mild: *the person needs no help and has no difficulty with any of the core activity tasks, but:*

- *uses aids or equipment;*
- *cannot easily walk 200 metres;*
- *cannot walk up and down stairs without a handrail;*
- *cannot easily bend to pick up an object from the floor;*
- *cannot use public transport;*
- *can use public transport but needs help or supervision;*
- *needs no help or supervision but has difficulty using public transport.*

Source: ABS 2004:72.

Table 4.8 shows estimates of prevalence of dementia by severity and place of residency based on the results of this mapping and on the severity distribution estimated by Barendregt & Bonneux (1998). The number estimated to have mild dementia (CDR 0.5-1) in cared accommodation is considered roughly equivalent to the number with severe, moderate or mild core activity limitation. Those with profound core activity limitation are allocated to the moderate (CDR 2) or severe (CDR 3) category. The split between moderate (CDR 2) and severe (CDR 3) dementia for the 71,907 people with CDR 2/CDR 3 dementia living in cared accommodation is made according to the proportions from Barendregt & Bonneux (1998) (2/3 moderate and 1/3 severe), resulting in 47,900 people with moderate dementia and 24,000 with severe dementia.

The distribution of severity for people with dementia in households is then allocated to fit with both the cared accommodation severity distribution and the overall severity distribution. For example, 52,400 (30%) of people with dementia have moderate dementia; and 48,900 people in cared accommodation have moderate dementia; therefore 4,400 people with moderate dementia must be living in households.

Table 4.8: Severity of dementia, by sex and residency, 2003

Residency/severity	Males	Females	Persons	Proportion by place of residency	Proportion of total dementia
Cared accommodation^(a)					
Mild (CDR 0.5–1.0)					
<i>Mild, moderate, severe core activity limitations</i>	900	2,400	3,400	4.5%	1.9%
Moderate (CDR 2)					
<i>Profound core activity limitations (2/3)</i>	11,400	36,500	47,900	63.7%	27.4%
Severe (CDR 3)					
<i>Profound core activity limitations (1/3)</i>	5,700	18,300	24,000	31.8%	13.7%
<i>Total cared accommodation</i>	<i>18,000</i>	<i>57,200</i>	<i>75,300</i>	<i>100.0%</i>	<i>43.1%</i>
Household					
Mild (CDR 0.5–1.0)					
<i>Mild, moderate, severe core activity limitations</i>	39,000	53,700	92,700	93.2%	53.1%
Moderate (CDR 2)					
<i>Profound core activity limitations (2/3)</i>	4,000	500	4,500	4.5%	2.6%
Severe (CDR 3)					
<i>Profound core activity limitations (1/3)</i>	1,400	800	2,200	2.3%	1.3%
<i>Total household</i>	<i>44,500</i>	<i>55,000</i>	<i>99,400</i>	<i>100.0%</i>	<i>56.9%</i>
All dementia					
Mild (CDR 0.5–1.0)					
<i>Mild, moderate, severe core activity limitations</i>	40,000	56,100	96,100	55.0%	55.0%
Moderate (CDR 2)					
<i>Profound core activity limitations (2/3)</i>	15,400	37,000	52,400	30.0%	30.0%
Severe (CDR 3)					
<i>Profound core activity limitations (1/3)</i>	7,100	19,100	26,200	15.0%	15.0%
Total dementia	62,500	112,200	174,700	100.0%	100.0%

(a) Cared accommodation includes *Accommodation for the retired or aged, Home for the aged, Home—other, Hospital—general and Hospital—other*.

Based on the method described above, people with mild dementia (CDR 0.5 to 1) comprise 93% of people with dementia living in households. Ninety-six per cent of people with dementia living in cared accommodation have moderate or severe dementia (CDR 2 or 3). Moderate dementia (CDR 2) accounts for 64% of people with dementia in cared accommodation and 3% of people with dementia in households.

4.4 Incidence of dementia

The methodological issues associated with determining estimates of dementia incidence — that is, the number of new cases in a specified period — mean that there are few data sources available in this area. As indicated in earlier discussion in this report, the 2003 SDAC underestimates the prevalence of dementia when symptoms are mild. Clinical assessment is also more difficult for mild cases, and this factor has been surmised to be the reason for discrepancies in estimates obtained across studies (Jorm & Jolley 1998). The number of new

dementia cases per year is low and the costs associated with undertaking longitudinal studies in susceptible groups are therefore prohibitively high.

No incidence studies have been undertaken in Australia, but estimates of incidence for Australia have been made using information from overseas epidemiological studies. For example, Access Economics (2005) adopted methodology used by Wancata et al. (2003) and Jorm et al. (2005) and published estimates of the number of incident cases of dementia in Australia based on rates from four meta-analyses. Incidence rates for those over 60 were estimated by averaging the rates from Jorm & Jolley (1998), Gao et al. (1998), Launer et al. (1999) and Fratiglioni et al. (2000) for each age-sex group. Access Economics (2005) estimates that in 2003 there were around 48,900 incident cases of dementia in Australia.

However, this report calculated incidence estimates based on available information about prevalence, duration of illness and mortality over and above background mortality (see AIHW: Mathers et al. 1999:208 for a discussion of this approach). Using this method, it is estimated that in 2003 there were around 37,000 incident cases of dementia in Australia (Table 4.9). (The methods used to derive this estimate are presented in Box 4.3). Incidence rates reported by Access Economics (2005) are higher than those estimated in this report. However, there must be an implausibly high death rate in order for the incidence rates reported by Access Economics (2005) to be consistent with the reported prevalence rates.

Not all of the 37,000 incident cases estimated by the AIHW will be initially visible as people with dementia, as onset usually occurs with mild symptoms. However, as dementia is not reversible, they will over time become part of the visible prevalent population or they will die of other causes. The majority (63% or 23,200) of these were female and 13,800 were male. Incidence increased with age in both males and females, but decreased in those aged 85 years or older.

Table 4.9: Estimated incidence of dementia, by age and sex, 2003

Age	Males	Females	Persons
0–64	1,100	600	1,600
65–74	2,800	2,700	5,400
75–84	6,300	10,100	16,400
85+	3,700	9,900	13,500
Total	13,800	23,200	37,100

Source: AIHW and University of Queensland estimates based on meta-analysis of overseas studies (see Box 4.3).

Box 4.3: Methods used in calculating the incidence of dementia

The incidence estimate for 2003 reported here was derived using a computer software program, DISMOD II (an incidence/prevalence/mortality model). DISMOD was designed primarily to supplement observational data and help disease experts arrive at internally consistent estimates of incidence, prevalence, remission, duration and mortality for the Burden of Disease study. The model assumes no remission and an overall relative risk of mortality of 2.0 for Alzheimer's disease and 3.3 for vascular dementia, which gives an average duration across all ages for both sexes of 4.4 years. For chronic conditions (such as dementia), prevalence information is preferred as an input into DISMOD II as:

- incidence is more difficult to observe because the date of onset is insidious and progressive; and
- comparisons of incidence and prevalence estimates of dementia from meta-analyses are inconsistent (unless an implausibly short duration of two years is assumed with extreme estimates of mortality).

There have been two recent meta-analyses (Dewey & Saz 2001; Jagger et al. 2000) on prevalent cases of dementia and survival. Prevalent cohort survival data typically arise when prevalent cases are followed either until failure or censoring. Such data are collected as part of what are known as prevalent cohort studies (i.e. some people with dementia at the beginning of the follow-up), commonly through cross-sectional sampling, with follow-up, which is often carried out when time and logistics preclude the possibility of incident cohort studies (Asgharian et al. 2005). Both Jagger et al. (2000) and Dewey & Saz (2001) found an increased risk (relative risk of 2.4–2.6) of mortality in people with dementia. The evidence for differential in mortality risk by age and sex is not clear (Jagger et al. 2000; Dewey & Saz 2001), and although Dewey & Saz (2001) found that vascular dementia tends to have a higher mortality risk than Alzheimer's disease, this finding was based on four studies and did not necessarily reach statistical significance. These results are not immediately useful due to the limitations inherent in survival studies of prevalent cases, including:

- the course of the disorder can not be recorded in its entirety because date of onset of disease is not known; and
- prevalent cases include a mixture of new and long existing cases which may bias results in either direction).

As a result the two studies of incident cases and survival (Aguero-Torres et al. 1999 and Helmer et al. 2001), highlighted by the Guehne et al. (2005) review, were considered. Incident studies (i.e. people who were not demented at the beginning of the follow-up and who are prospectively monitored for the incidence or onset of dementia, with follow-up continuing until death) allow more precise statements to be made about the course of the disorder and mortality (Guehne et al. 2005).

The relative risk of death in all dementia of 2.7 (95% CI = 2.1–3.4), in Alzheimer's disease of 2.0 and in vascular dementia of 3.3, was based on the Aguero-Torres et al. (1999) study which controlled for comorbidities. That study was preferred to the results from the Helmer et al. (2001) study as the results were more in keeping with those from prevalent cases; however, it is not clear which study is the most plausible based on the available evidence. An age pattern (based on the Dewey & Saz 2001) finding that the relative risk of death in dementia at age 65 is around 6, whereas by age 85 it has fallen to 2) was built in so that the overall relative risk was in keeping with the Aguero-Torres et al. (1999) result.

Duration is heavily dependent on background mortality and the age distribution of the population. As a result, more emphasis should be placed on relative risks from studies of other contexts rather than durations which are context-specific and hence absolute. The literature on the median survival of all dementia after onset of symptoms appears to converge around 5 years for prevalent cases, with estimates ranging from 3–7 years for Alzheimer's disease and 2–4 years for vascular dementia for several recent studies. Aguero-Torres et al. (1999) calculated a mean survival time of 3.0 years (95% CI = 2.7–3.4) among a sample of 75-year-old demented subjects. Helmer et al. (2001) reported a mean survival time in incident cases of 4.5 years among 65-year-olds. The mean survival time for patients suffering from Alzheimer's disease and vascular dementia from the Aguero-Torres et al. (1999) study was 3.1 (95% CI = 2.8–3.5) and 2.8 (95% CI = 2.2–3.4) years, respectively.

4.5 Burden of disease

Burden of disease analysis is a method for analysing the impact of health conditions and impairments in terms of their mortality and morbidity. The burden of disease approach combines the impact of premature mortality and morbidity in one measure called the disability-adjusted life year (DALY). The premature mortality component is measured in terms of years of life lost (YLL) and the morbidity component in terms of years of life spent living in states of less than full health (years lost due to disability, YLD) (Salmon et al. 2002). The YLD is a measure of the impact of a health condition or impairment in restricting activity and participation.

The burden of disease in Australia for all health conditions has been estimated for 1996 (AIHW: Mathers et al. 1999). The estimates are currently being updated to 2003 and will be published in 2006 by the AIHW and the University of Queensland. While the underlying methodology of burden of disease is standard, the models used for each disease go through considerable development based on literature reviews and expert consultation in order to estimate a model based on a number of parameters – incidence and prevalence, relative risk, mortality and remission. The parameters of the disease model are used in computer modelling software (DISMOD) to produce estimates of the incidence of dementia. More detail on the burden of disease methods is available in AIHW: Mathers et al. (1999).

In this section, the burden of dementia is estimated based on the prevalence of dementia, which is derived from the disease model, and then estimating the severity of the condition or the degree to which quality of life is reduced.

Burden due to premature mortality

In Australia, conditions can be listed on the death certificate as either the underlying or main cause of death, or as an additional or contributing cause of death. The number of deaths with dementia recorded as the underlying cause of death has increased steadily in the period 1997 to 2003 from 3,384 in 1997 to 4,413 in 2003 (Table 4.10). This increase is largely due to population ageing since the age-standardised rate has remained stable over this period for both males and females (Table 4.11).

Table 4.10: Deaths with an underlying cause of dementia, 1997–2003

Sex/age	1997	1998	1999	2000	2001	2002	2003
Males							
0–59	19	23	19	25	26	28	17
60–64	15	21	12	24	23	19	29
65–69	46	45	47	30	36	53	33
70–74	119	86	126	102	104	115	88
75–79	189	205	184	224	204	246	226
80–84	251	287	249	271	283	328	333
85+	457	490	531	502	555	673	693
Total	1,096	1,157	1,168	1,178	1,231	1,462	1,419
Females							
0–59	18	20	19	25	17	10	25
60–64	30	19	20	20	11	29	22
65–69	33	44	38	46	32	28	40
70–74	99	100	103	88	109	118	86
75–79	202	241	220	241	236	278	231
80–84	468	434	452	472	455	571	555
85+	1,438	1,360	1,509	1,698	1,757	1,988	2,035
Total	2,288	2,218	2,361	2,590	2,617	3,022	2,994
Persons							
0–59	37	43	38	50	43	38	42
60–64	45	40	32	44	34	48	51
65–69	79	89	85	76	68	81	73
70–74	218	186	229	190	213	233	174
75–79	391	446	404	465	440	524	457
80–84	719	721	701	743	738	899	888
85+	1,895	1,850	2,040	2,200	2,312	2,661	2,728
Total	3,384	3,375	3,529	3,768	3,848	4,484	4,413

Source: AIHW analysis of the National Mortality Database.

In 2003, age-specific death rates for dementia were low among people aged less than 65 years and more than doubled for each progressive five-year age category, increasing from 10.1 deaths per 100,000 population at 65–69 to 952.3 at 85 years and over (Table 4.11). The age-standardised death rate was greater for women (22.2 per 100,000 population) than for men (18.7 per 100,000 population).

Table 4.11: Death rates per 100,000 people with an underlying cause of dementia, 1997–2003

Sex/age	1997	1998	1999	2000	2001	2002	2003
Males							
0–59	0.2	0.3	0.2	0.3	0.3	0.3	0.2
60–64	4.1	5.6	3.1	6.0	5.6	4.4	6.6
65–69	13.6	13.4	14.1	9.0	10.7	15.4	9.3
70–74	42.2	29.8	42.8	34.0	34.3	37.8	29.1
75–79	99.5	102.1	86.7	102.0	89.7	105.3	93.9
80–84	230.8	259.1	221.1	227.8	220.7	239.2	228.4
85+	715.1	718.3	729.4	647.6	677.5	780.2	770.2
<i>Crude rate</i>	<i>11.9</i>	<i>12.4</i>	<i>12.4</i>	<i>12.4</i>	<i>12.8</i>	<i>15.0</i>	<i>14.4</i>
<i>Age-standardised rate^(a)</i>	<i>18.6</i>	<i>18.9</i>	<i>18.3</i>	<i>17.4</i>	<i>17.4</i>	<i>19.8</i>	<i>18.7</i>
Females							
0–59	0.2	0.3	0.2	0.3	0.2	0.1	0.3
60–64	8.2	5.1	5.2	5.0	2.7	6.9	5.1
65–69	9.4	12.6	11.0	13.3	9.2	7.9	10.9
70–74	30.1	30.2	30.9	26.4	32.6	35.4	26.1
75–79	78.8	89.7	78.3	83.8	80.8	94.3	77.4
80–84	260.2	238.4	246.9	248.4	225.5	270.0	250.8
85+	962.8	867.6	908.5	969.4	958.5	1,043.1	1,035.7
<i>Crude rate</i>	<i>24.6</i>	<i>23.6</i>	<i>24.8</i>	<i>26.8</i>	<i>26.8</i>	<i>30.6</i>	<i>29.9</i>
<i>Age-standardised rate^(a)</i>	<i>21.5</i>	<i>20.2</i>	<i>20.5</i>	<i>21.5</i>	<i>20.8</i>	<i>23.2</i>	<i>22.2</i>
Persons							
0–59	0.2	0.3	0.2	0.3	0.3	0.2	0.3
60–64	6.2	5.4	4.2	5.5	4.1	5.7	5.9
65–69	11.5	13.0	12.5	11.2	10.0	11.6	10.1
70–74	35.7	30.0	36.5	30.0	33.4	36.6	27.5
75–79	87.6	95.0	81.9	91.7	84.7	99.2	84.8
80–84	249.1	246.2	237.1	240.5	223.6	257.9	241.9
85+	888.6	822.4	853.9	870.7	871.7	961.1	952.3
Crude rate	18.3	18.0	18.6	19.7	19.8	22.8	22.2
Age-standardised rate^(a)	20.8	19.9	19.9	20.3	19.8	22.2	21.1

(a) Age-standardised to the 30 June 2001 Australian population.

Source: AIHW analysis of the National Mortality Database.

In 2003, dementia was listed as an additional cause of death on a further 9,820 death certificates. Thus in 2003, dementia was listed as the contributing cause of death (either the underlying cause of death or additional cause of death) on 14,233 death certificates. Only deaths where dementia is the underlying cause of death contribute to the premature mortality component (YLL) of burden of disease.

The YLL is calculated by determining the difference between the age at death and life expectancy for a person of that age as determined by a model life table. The difference is then

discounted at a rate of 3% per year to give the YLL. For example, if a person dies at the age of 72 in 2003 and the life expectancy for someone aged 72 in 2003 in the model life table is 84, then the undiscounted years of life lost will be 12 years. The years of life lost discounted at 3% is 10 years.⁸

The 4,413 deaths where dementia was the underlying cause of death resulted in 24,000 years of life lost (Table 4.12). Almost two-thirds of these YLLs (16,000) were for females and 82% were for people over the age of 75.

Table 4.12: Deaths and years of life lost due to dementia as underlying cause of death, 2003

Age	Deaths			Years of life lost (YLL)		
	Males	Females	Persons	Males	Females	Persons
0–64	46	47	93	714	907	1,621
65–74	121	126	247	1,273	1,553	2,826
75–84	559	786	1,345	3,675	5,835	9,510
85+	693	2,035	2,728	2,433	7,714	10,147
Total	1,419	2,994	4,413	8,094	16,009	24,103

Sources: Deaths data from Table 4.10; YLL data from Begg et al. 2007 (in press).

Burden due to morbidity

The proposed model for dementia is shown in Table 4.13. The model is for dementia as a progressive illness where the disease progresses from a mild impact where there is significant impact on daily activities, to severe impact where permanent supervision is required. The model is based on 55% of the duration of the disease being in the mild severity phase, 30% in the moderate severity phase and 15% in the severe phase of the disease progression (Table 4.7 and Table 4.13).

Table 4.13: The model used in the burden of disease analysis of dementia, definition and severity weight for different stages of dementia

Disease stages	Severity weight	Definition	% time spent in each stage
Mild	0.27	Significant impact on daily activities but still able to undertake daily activities	0.55
Moderate	0.63	Independent living is not possible without assistance	0.30
Severe	0.94	Permanent supervision required	0.15

Source: Begg et al. 2007 (in press).

The overall YLD lost due to dementia is calculated by multiplying the number of people with dementia (Table 4.8) by the appropriate severity weights according to the severity of dementia (Table 4.13). This shows that, overall, there were 84,000 YLD lost due to dementia in 2003 (Table 4.14). Two-thirds of these healthy years lost were for females and two-thirds were for residents of cared accommodation.

⁸ The YLL is calculated using the formula $YLL = \frac{1 - e^{-0.03 \text{ life expectancy}}}{0.03}$.

Table 4.14: Prevalent years of life lost to disability, by sex, residency and severity, 2003

Residency/severity	Males	Females	Persons
Cared accommodation			
Mild	256	657	914
Moderate	7,179	23,022	30,201
Severe	5,356	17,175	22,531
<i>Total cared accommodation</i>	<i>12,791</i>	<i>40,854</i>	<i>53,645</i>
Household			
Mild	10,539	14,491	25,030
Moderate	2,512	307	2,819
Severe	1,346	756	2,103
<i>Total household</i>	<i>14,397</i>	<i>15,554</i>	<i>29,952</i>
All dementia			
Mild	10,795	15,148	25,944
Moderate	9,691	23,329	33,019
Severe	6,702	17,931	24,634
Total dementia	27,188	56,408	83,597

Source: AIHW analysis based on YLD data from Begg et al. 2007 (in press).

Because of its disabling rather than fatal nature, dementia has a much greater effect on years of healthy life lost than it has on years of life lost due to premature mortality. The combined effect of premature mortality and burden of disease due to disability can be gauged using DALYs. One DALY is a lost year of 'healthy' life, and is the sum of years of life lost due to premature mortality and years of healthy life lost due to disability. The majority of the burden of disease caused by dementia is due to disability rather than premature death, with disability accounting for around three-quarters of the total burden in 2003 (Table 4.15). Death, however, accounts for a greater proportion of the burden of disease due to dementia for older than younger people; premature death caused about 40% of the burden for people aged 85 and over, but 16% for people aged 65 to 74.

Dementia accounted for 94,000 DALYs in 2003 which is 4% of total DALYs lost due to all diseases (AIHW analysis based on YLL data from Begg et al. 2007). The 25,000 DALYs lost due to dementia by those aged 85 years or more is 12% of total DALYs lost by this age group and is the leading cause of burden for this age group.

Dementia accounted for 70,000 incident years of life lost to disability (incident YLD) which is 5% of total incident YLDs lost due to all diseases (AIHW analysis based on YLD data from Begg et al. 2007). The 15,000 YLDs lost due to dementia by those aged 85 years or more is 28% of total incident YLDs lost by this age group (22% for males and 31% for females), and is the leading cause of burden for this age group. There were 33,000 YLDs lost due to dementia for persons aged between 75 and 84 years of age, representing 21% of total YLDs for all diseases.

Table 4.15: Years of life lost, incident years of life lost to disability and disability-adjusted life years for dementia, by age and sex, 2003

Age	YLL			Incident YLD			DALY		
	Males	Females	Persons	Males	Females	Persons	Males	Females	Persons
0–64	714	907	1,621	3,971	2,619	6,590	4,685	3,526	8,211
65–74	1,273	1,553	2,826	6,597	8,681	15,279	7,871	10,235	18,105
75–84	3,675	5,835	9,510	11,020	22,063	33,084	14,695	27,898	42,593
85+	2,433	7,714	10,147	3,962	11,361	15,324	6,395	19,075	25,470
Total	8,094	16,009	24,103	25,551	44,725	70,276	33,645	60,734	94,379

Note: A DALY is a disability-adjusted life year and is calculated by adding the YLL and the incident YLD. Incident YLD is based on incidence estimates for dementia and is lower in magnitude than prevalence YLD shown in Table 4.14.

Source: AIHW analysis based on YLL data from Begg et al. 2007 (in press).

The 94,000 DALYs in 2003 is projected to increase to 236,000 in 2031, a 151% increase (Table 4.16). Most of the increase is for those aged 85 years or more where a 242% increase occurs for the number of DALYs. There is projected to be a 49% increase in dementia DALYS for those aged less than 65 in the period 2003 to 2031.

Table 4.16: Burden of dementia, disability-adjusted life years, projected to 2031

Age	2003	2006	2011	2016	2021	2026	2031	Per cent change 2003–2031
0–64	8,211	8,947	10,153	10,841	11,556	11,902	12,242	49
65–74	18,105	18,919	22,500	28,322	32,968	35,878	38,829	114
75–84	42,593	45,052	47,155	52,597	64,160	82,812	98,197	131
85+	25,470	28,845	37,660	46,501	54,167	66,967	87,184	242
Total	94,379	101,762	117,469	138,260	162,852	197,559	236,452	151

Source: AIHW analysis based on YLL data from Begg et al. 2007 (in press).