

# **How we manage stroke in Australia**

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# **How we manage stroke in Australia**

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# Contents

- List of tables ..... vi
- List of figures ..... vii
- Acknowledgments .....viii
- Highlights..... ix
- Introduction ..... 1
- Background ..... 2
  - What is stroke? ..... 2
  - Who is affected by stroke? ..... 2
  - How big a problem is stroke in Australia? ..... 3
  - How can we prevent stroke?..... 3
  - What does the future hold for those who have had a stroke?..... 4
  - What is best practice in the care of stroke? ..... 5
- How do we manage stroke? ..... 6
  - Community awareness of stroke signs and symptoms..... 6
  - Hospital care..... 6
    - About the hospitalisation data ..... 6
    - Initial care for stroke ..... 7
    - Specialised stroke care in hospitals..... 7
    - Other care for sequelae of stroke..... 9
    - Rehabilitation ..... 10
    - Procedures in hospital ..... 12
  - Prevention of further strokes ..... 13
  - General practice care ..... 15
  - Disability and functioning..... 17
  - Formal care services in the community ..... 25
  - Informal care ..... 30
- Cost of stroke care..... 38
- Future trends ..... 40
- Discussion: how well do we manage stroke?..... 41
- Appendix..... 44
  - Codes used in this report..... 44
  - Data sources..... 45
  - Appendix figures ..... 46
- References ..... 49

## List of tables

Table 1: Hospital separations in which procedures were done, 2002–03.....	13
Table 2: Risk factors for stroke among people with previous stroke.....	14
Table 3: Medications taken by people with previous stroke.....	15
Table 4: Multiple medications taken by people with previous stroke.....	15
Table 5: Persons with stroke and persons with stroke and disability.....	19
Table 6: Selected other health conditions reported by people with stroke .....	20
Table 7: Disability types resulting from stroke .....	21
Table 8: Disability status of people with stroke and disability compared with all people with disability .....	21
Table 9: Assistance needed and received by people with stroke and disability living in households .....	22
Table 10: Activity limitations among ACAT clients.....	23
Table 11: Participation in community activities by people with stroke and disability living in households.....	24
Table 12: Living arrangements of people with stroke.....	25
Table 13: Type of assistance received by people with stroke and disability .....	26
Table 14: Assistance providers to people with stroke and disability .....	26
Table 15: Setting for first face-to-face contact for assessment of ACAT clients.....	27
Table 16: ACAT client living arrangements at assessment .....	27
Table 17: ACAT client accommodation setting at assessment and recommended after assessment .....	28
Table 18: Assistance with activities among ACAT clients .....	29
Table 19: Government program support among ACAT clients .....	30
Table 20: Carer availability among ACAT clients .....	31
Table 21: Assistance provided by co-resident primary carers to people with stroke and disability.....	32
Table 22: Weekly hours of care provided by co-resident primary carers to people with stroke and disability .....	33
Table 23: Effect of caring role on co-resident primary carer’s income, living costs and work.....	33
Table 24: Effects of caring role on co-resident primary carer’s health and wellbeing.....	34
Table 25: Effects of caring role on co-resident primary carer’s relationships.....	35
Table 26: Need for and use of respite care by co-resident primary carers of people with stroke and disability .....	36
Table 27: Respite care among ACAT clients.....	37
Table 28: Costs during first year after a first-ever stroke, Australia, 1997 .....	39

# List of figures

- Figure 1: Stroke attack rates in Melbourne, 1996-97 ..... 3
- Figure 2: Hospital separations for initial care for stroke, 2002-03 ..... 7
- Figure 3: Hospital separations for sequelae of stroke, 2002-03 ..... 10
- Figure 4: Hospital separations for rehabilitation for stroke and its sequelae,  
2002-03 ..... 11
- Figure 5: Projected number of strokes with varying rates of stroke attack..... 40
- Figure A1: People with stroke, and people with stroke and disability, by sex ..... 46
- Figure A2: People with stroke, by age and sex ..... 46
- Figure A3: People with stroke and disability, by age and sex ..... 47
- Figure A4: Age distribution of ACAT clients ..... 47
- Figure A5: Sex distribution of ACAT clients ..... 48
- Figure A6: Primary carers of people with stroke and disability ..... 48

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## Highlights

### **Stroke poses a significant burden on patients and their families as well as on the health system and aged care services...**

- Stroke caused 9,006 deaths in Australia in 2003, almost 7% of all deaths.
- In 2003 there were an estimated 346,700 survivors of stroke.
- About 282,600 Australians with stroke had a disability and in around 146,400 of these people the disability resulted from their stroke.
- Most stroke survivors live at home, with only 12% in cared accommodation. This also applies to disabled people with stroke, 15% of whom live in cared accommodation.
- About half of stroke survivors with disability living at home needed assistance with health care, household chores, home maintenance, mobility and transport; and around one in four needed help with self care, cognitive or emotional tasks, meal preparation and paperwork.
- The vast majority of people with stroke had a carer and, excluding people in institutions, informal carers provided most of the assistance with activities. More than half of primary carers spent 40 hours or more each week in their caring role and for about one in four their caring responsibilities adversely affected their income.
- In 2002–03 there were 68,866 hospital separations with a principal diagnosis of stroke, its sequelae, and rehabilitation for stroke or its sequelae, taking up 1,073,645 patient days.
- There were an estimated 269,000 general practice encounters for stroke problems per year over the period April 1998–March 2004.
- The ageing of the Australian population will drive an increase in the number of strokes in the future unless incidence rates fall by 2–3% or more per year.

### **There are signs of improvements in the care of patients with stroke...**

- The number of stroke care units in public hospitals increased from 35 to 50 between 1999 and 2004.
- Hospitals with stroke care units were more likely to have rapid triage and rapid assessment of patients with acute stroke, on-site access to diagnostic equipment, care protocols in place and rehabilitation services.
- A large proportion of people who had had a stroke reported taking medications to help prevent recurrent strokes.
- At least 90% of stroke survivors who needed assistance with activities while living at home were receiving it. About 169,700 people with stroke and disability received informal assistance and an estimated 128,000 received formal assistance in 2003.

### **But work still needs to be done...**

- In Australia 23% of eligible public hospitals provided organised stroke services in 2004. This is quite low compared with some other countries.
- Although most people in the community recognise stroke is an emergency, and many know what a stroke is, very few are aware of stroke signs and symptoms.

- The prevalence of other conditions and modifiable risk factors for stroke remains high among people who have had a stroke, putting them at even higher risk of further events.
- Stroke survivors rely heavily on informal carers for assistance with activities, but only a minority of primary carers access respite care services.

**And data gaps limit our knowledge in several areas...**

- There is no national information on the time elapsed between onset of stroke symptoms, presentation to hospital and start of emergency care; timing of recommended investigations and treatments; medications used in hospital; formal care services delivered to survivors of stroke; or incidence of stroke.

# Introduction

This report aims to present a comprehensive picture of the impact of stroke on patients, their carers, the health system and aged care services. It brings together the latest Australian data on the various phases of the management of people with stroke across the continuum of care. Where possible, it compares current practices to clinical guidelines for best practice in the care of stroke patients. It identifies improvements in care, areas where more needs to be done and gaps in our knowledge.

The *Background* section outlines briefly what we already know about the disease, its risk factors, the people most likely to be affected and the recommended care for patients.

The section *How do we manage stroke?* presents new data covering public awareness of stroke signs and symptoms, hospital care in the acute period through to rehabilitation, prevention of further strokes, care in general practice, disability and functioning after stroke, and formal and informal care provided to survivors of stroke in the community.

The section *Cost of stroke care* gives a detailed breakdown of costs associated with treating episodes of the disease. Estimates for stroke attack projections into the next decades are shown in the section *Future trends*.

The *Discussion* summarises the main findings of the report, draws conclusions from the available data and highlights gaps and limitations of the existing data. The report draws on a range of data sources, described in the *Appendix*.

# Background

## What is stroke?

Cerebrovascular disease comprises disorders in which there is a disturbance of blood supply to the brain. Stroke is the most important manifestation of cerebrovascular disease. A stroke occurs when an artery supplying blood to a part of the brain suddenly becomes blocked (ischaemic stroke) or bleeds (haemorrhagic stroke), accounting for about 85% and 15% of cases respectively. This causes loss of function of part of the brain and may affect functions including movement of body parts, vision, swallowing, communication, and may lead to death.

Symptoms and signs of stroke include one or more of the following:

- motor impairments (weakness or paralysis of parts of the body, including the face, on one or both sides)
- sensory impairments (touch, pain, warm/cold), most often on one side
- speech difficulties or slurred speech
- vision difficulties (sudden loss of vision, blurred vision), most often on one side
- dizziness, loss of balance or unexplained fall
- sudden severe headache
- difficulty swallowing.

Transient ischaemic attack (TIA), sometimes called 'mini-stroke', is a temporary manifestation of cerebrovascular disease that leaves no residual signs or symptoms. It usually results from a temporary blockage of blood vessels that reduces blood supply to the brain and may last only a few minutes, with symptoms disappearing completely within 24 hours.

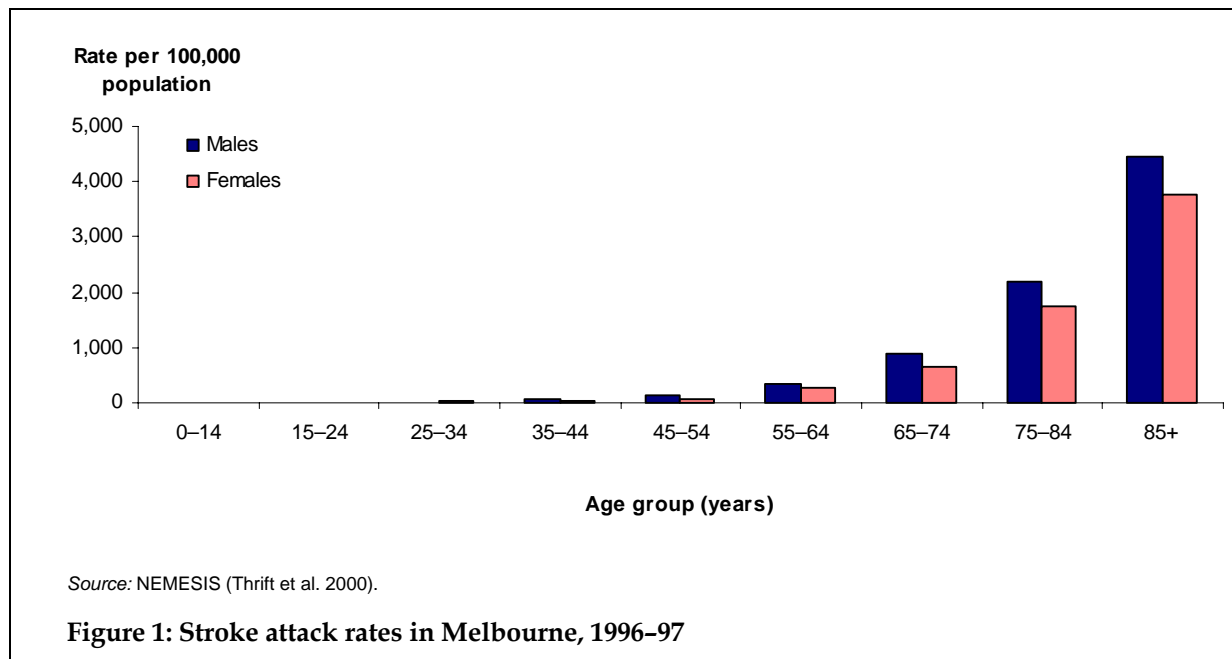
Strokes and TIAs are sometimes referred to as cerebrovascular events.

Note:

The analyses of data presented in this report focus on the subset of cerebrovascular disease (ICD-10 I60-I69) that is stroke (ICD-10 I60-I64), and on sequelae of stroke (ICD-10 I69.0-I69.4).

## Who is affected by stroke?

Stroke mainly affects older people. The rates of stroke increase markedly with age from about 65 years (Figure 1). According to Australian studies, the median age of patients having a stroke is about 79 years (Jamrozik et al. 1999, North East Melbourne Stroke Incidence Study – NEMESIS, unpublished data). The median age of patients having a first in their lifetime stroke is 77 years (NEMESIS, unpublished data).



## How big a problem is stroke in Australia?

Stroke is a significant health problem:

- In 2003 around 346,700 Australians had had a stroke at some time in their lives.
- Each year there are about 40,000–48,000 stroke events among Australians.
- Stroke claimed 9,006 lives in 2003, nearly 7% of all deaths.
- In 2003 about 282,600 Australians with stroke had a disability and in around 146,400 of these people the disability resulted from their stroke.

Allocated expenditure for cerebrovascular disease amounted to \$896 million in 2000–01, which is 1.8% of total health system expenditure (AIHW 2004b). Aged care homes accounted for half of the funds allocated to cerebrovascular disease and hospitals accounted for 40%.

## How can we prevent stroke?

The risk of stroke increases with age, previous transient ischaemic attack or stroke, high blood pressure, tobacco smoking, diabetes, high blood cholesterol, insufficient physical activity, poor diet, excessive alcohol consumption, atrial fibrillation (irregular rapid heart beat), and narrowing of the carotid arteries (carotid stenosis) that feed the brain. People with a number of these risk factors are at even higher risk of stroke (AIHW: O'Brien 2005).

People who have had a TIA are at high risk of further events – one in three will have an ischaemic stroke and another one in three will have repeated TIAs. About 30% of people with a major stroke have had an earlier TIA and 9% of people with TIAs have a stroke within one week (Lovett et al. 2003). Thus, TIAs provide a warning and an opportunity for preventing stroke, and must be treated as an emergency.

Some of the risk factors for stroke are very common:

- 21% of Australians aged 25 years and over (about 2.5 million) were obese in 1999–00 (AIHW 2004a). In addition, 39% of Australians (about 4.9 million) were overweight but not obese.
- 54% of Australians aged 18–75 years (around 7.3 million) did not undertake sufficient physical activity to achieve health benefits in 2000, according to physical activity guidelines (AIHW 2004a; DHAC 1999).
- 51% of Australians aged 25 years and over (6.4 million) had high blood cholesterol levels in 1999–00 (AIHW 2004a).
- 30% of Australians aged 25 years and over (about 3.7 million) had high blood pressure or were on blood-pressure-lowering medication in 1999–00 (AIHW 2004a).
- 17% of Australians aged 14 years and over (almost 2.9 million) smoked daily in 2004 (AIHW 2005a). A further 4% smoked occasionally.
- 7.6% of Australians aged 25 years and over (about 946,000) had diabetes in 1999–00 (AIHW 2004a).

Stroke is highly preventable (Hankey 2005; National Stroke Foundation 2003; Wolf 1998). Reducing the high prevalence of the modifiable risk factors could prevent many strokes. In people who have had TIAs, rapid access to investigations and starting preventive measures immediately are essential.

Community awareness of risk factors for stroke is low (20–40%) and many Australians (almost 50%) do not understand that stroke can be prevented (National Stroke Foundation, unpublished).

## **What does the future hold for those who have had a stroke?**

One in five people having a first-ever stroke die as a result within 1 month of its occurrence and one in three die within 12 months of their stroke (Thrift et al. 2000). Among 30-day survivors of first-ever stroke, about half survive 5 years (Hankey et al. 2002).

About one in six survivors of a first-ever stroke have another stroke over the next 5 years (Hankey et al. 1998).

Nearly all patients are disabled immediately following a stroke event. There may be permanent paralysis of one side of the body, speech or swallowing difficulties, problems with memory, personality changes or a range of other difficulties. Depression, anxiety and cognitive impairment are also common after stroke (Srikanth et al. 2004). By the end of the first year, about half of all survivors of stroke remain dependent on others for activities of daily living (Hankey et al. 2002).

Two years after a stroke most survivors have reduced health-related quality of life, with many survivors rating their quality of life as very poor (Sturm et al. 2004). Physical wellbeing and ability to live independently are most affected by stroke. Stroke survivors rely heavily on medications, technical aids and health professionals even years after the event.

Much of post-stroke disability can be improved (National Stroke Foundation 2005a). Rehabilitation services can improve mobility, physical independence and social relationships by providing mobility and communication aids and modifying the environment. Occupational therapy can reduce limitations to participation in work, social and recreational activities.

## **What is best practice in the care of stroke?**

The Australian Government Department of Health and Ageing funded the development of clinical guidelines for acute stroke management and stroke rehabilitation and recovery, as part of the National Stroke Unit Program (National Stroke Foundation 2003, 2005a). These documents state best practice in the care of people with stroke based on available evidence, and have been used as the benchmark for practice throughout this report.

There is overwhelming evidence that the best care for stroke patients is given on a geographically defined ward area where care is provided by a specialist, multidisciplinary stroke team (Stroke Unit Trialists' Collaboration 2003). This is known as stroke unit care (see 'Specialised stroke care in hospitals', later in this report).

## How do we manage stroke?

This section presents new data covering the stroke patient journey from the first signs and symptoms, through their care in the acute period in hospital, later hospital care for lasting associated problems, rehabilitation, prevention of further strokes, care in general practice, extent of disability and functioning after stroke, and formal and informal care given in the community to stroke survivors.

### Community awareness of stroke signs and symptoms

Despite the high mortality and morbidity of stroke, many people do not recognise the symptoms of stroke or realise that seeking treatment is urgent. Lack of public awareness of symptoms and signs of stroke has an important impact on delays to presentation to hospital. This in turn affects the choice and timing of treatment, and eventual outcomes for patients. For example, patients with no contraindications for thrombolytic drugs can only receive this treatment within 3 hours of the onset of ischaemic stroke.

A national survey of 1,000 Australians aged over 40 years conducted in 2003 showed that two out of three respondents knew what a stroke was but awareness of stroke signs and symptoms was low, with 33% naming paralysis (National Stroke Foundation, unpublished). Community awareness of the less obvious symptoms of stroke was particularly low – numbness (11%), headache (10%), weakness (8%), loss of balance (5%) and blurred vision (6%). However, nine out of ten people recognised stroke as an emergency.

## Hospital care

### About the hospitalisation data

The sections that follow use data from the National Hospital Morbidity Database, described in the Appendix and AIHW 2005b. It is important to keep in mind the limitations of using hospital administrative data. The information refers to hospital separations, not patients. A separation is an episode of care, which can be a whole hospital stay, or part of a hospital stay beginning or ending in a change of type of care. The same patient can have multiple separations within the same year and indeed within the same hospitalisation period. A new separation record is generated when there is a change in care type, for example when a patient is transferred from a medical ward to a rehabilitation unit. Similarly, when a patient is transferred from one hospital to another a new record is created. Therefore, there may be some degree of double counting of patients and stroke events. The actual number of patients admitted to hospital is less than the number of separations.

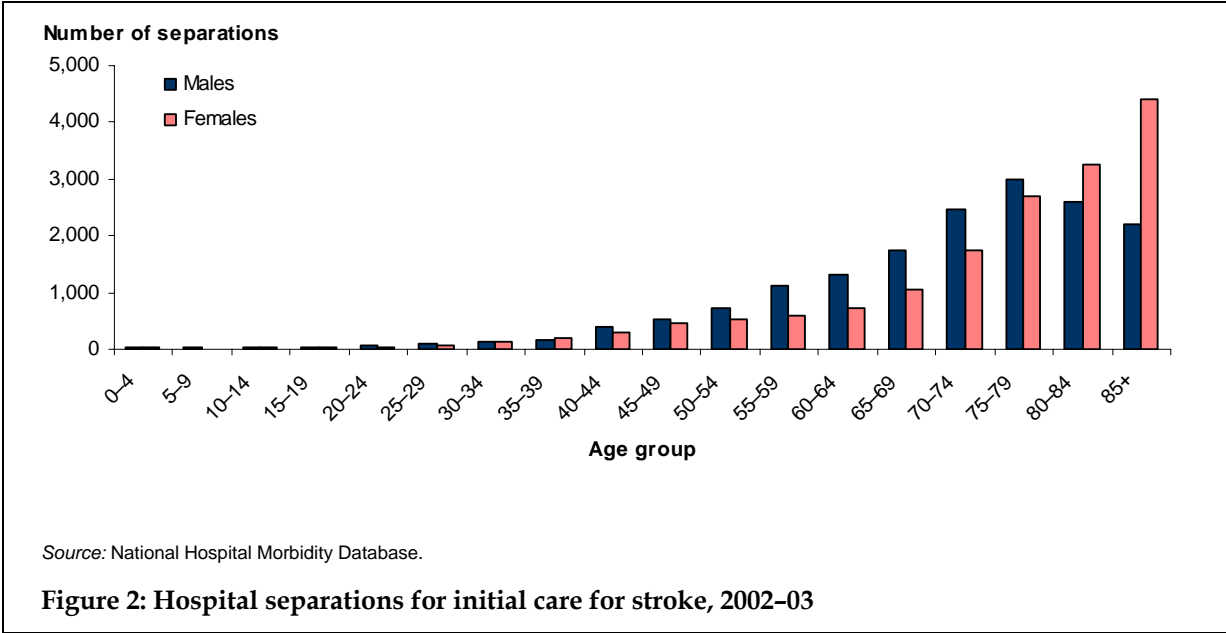
For the reasons given above, the length of stay in hospital (including transfers between hospitals and care types) after a stroke event is probably underestimated in the data presented below.

Note that there are no national data on diagnosis for hospital care provided in emergency departments, outpatient clinics, or services by specialists and allied health professionals.



**Initial care for stroke**

In 2002–03 there were 32,919 hospital separations with a principal diagnosis of stroke (0.5% of all separations), amounting to 379,601 patient days. Males and females accounted for the same proportion of separations overall. However, males were hospitalised more often than females at ages 40–79 and the reverse was true in the older age groups, as there are more separations for older women than men as a whole (Figure 2).



Most (84%) separations with a principal diagnosis of stroke were in public hospitals. Emergency admissions accounted for 84% of all stroke separations, while 11% were recorded as elective which means ‘admission could be delayed for 24 hours or more’.

About 12% of separations were for patients transferred from another hospital. This could reflect transfers to hospitals better equipped to treat patients with stroke in the acute phase. The majority (96%) of separations with a principal diagnosis of stroke were for acute care. Geriatric evaluation and management accounted for 1% and palliative care for 1%.

Same day separations accounted for about 9% of the total. Excluding same day separations, the average length of stay for initial care for stroke was 12.6 days and the median was 8 days.

Patients were discharged to their usual residence in 38% of stroke separations, to an acute hospital in 25%, to residential aged care in 5%, and had a statistical discharge/type change (indicating care continued in that hospital and the patient was, for instance, transferred within the hospital to a rehabilitation unit) in 14%. In 16% of stroke separations the patient died.

**Specialised stroke care in hospitals**

In hospital, people with stroke may be cared for in general medical wards, either by general medical staff or by roving teams specialised in stroke working throughout the hospital, or they may be admitted to a stroke care unit, if there is one. It is well established that the most effective care for stroke patients is provided in stroke units (Stroke Unit Trialists’

Collaboration 2003). Stroke unit care is described in Box 1. The structure for delivering specialised stroke care varies between facilities, for instance stroke teams or mobile stroke services which do not have localised, designated beds.

### **Box 1: Stroke unit care**

*A stroke unit is defined by*

- *patients located in a geographically defined ward area*
- *a coordinated multidisciplinary team comprising a stroke physician, nursing staff, occupational therapist, physiotherapist, speech pathologist, dietitian, social worker and, where possible, a psychologist*
- *staff specialising in the management of stroke and having access to ongoing professional education*
- *team meeting regularly to discuss management and discharge planning*
- *care provided according to agreed protocols*
- *early provision of rehabilitation.*

*Randomised controlled trials have shown consistently that patients have better outcomes when cared for in stroke units compared with conventional care (Kalra et al. 2000; Langhorne et al. 1993; Stroke Unit Trialists' Collaboration 2003). Stroke units are associated with a reduction in deaths, institutionalisation and dependency at 1 year after stroke.*

*It is not clear which aspects of care delivery are responsible for the difference in outcomes. Important practices include early patient mobilisation, physiological homeostasis, early administration of aspirin, thrombolysis when appropriate, anticoagulation in patients with atrial fibrillation, measures to avoid aspiration, early nutrition, frequent monitoring, and management of comorbidities to avoid complications (Cadilhac et al. 2004).*

A national survey of stroke services in acute public hospitals held in 2004 is described in the Appendix. According to this survey, overall, 61 hospitals (23% of hospitals surveyed) provided organised stroke services (stroke unit care, stroke teams or mobile stroke services) in 2004 (Cadilhac et al. 2005). There were 50 localised stroke care units (19% of 261 respondent hospitals) – an increase from 35 units present in public hospitals in 1999. (These figures probably underestimate the absolute increase in the number of stroke units in acute public hospitals due to differences in the definitions used between the 2004 and 1999 surveys). There were 55 hospitals with stroke teams and/or mobile stroke services that usually managed stroke patients throughout the hospital. Most stroke teams worked in a stroke care unit.

In hospitals without a stroke care unit, stroke patients tended to be admitted to acute general medical wards and cared for by general medical staff. In hospitals with stroke care units, most patients were treated in stroke care units or in acute medical wards.

Emergency Department protocols for rapid triage of patients with acute stroke were used in 115 hospitals (44%), being significantly more common in hospitals with stroke care units. Emergency Department protocols for transferring patients to another hospital for management were available in 127 hospitals (49%), most of these were hospitals without

stroke care units. Forty hospitals (15%) had rapid assessment outpatient clinics for TIAs or mild stroke and this was significantly more common where there were stroke care units.

The survey also covered access to diagnostic equipment. CT scanners were available on-site in 133 hospitals (51%), with a further 98 hospitals (38%) having access to CT scanners at another hospital. On-site access to MRI scanners was available in 39 hospitals (15%) and 147 hospitals (56%) had access to MRI at another hospital. Most hospitals with stroke care units had on-site access to CT scanners and some access to MRI scanners.

Overall, 182 hospitals (70%) had access to admitted patient rehabilitation, 89 (34%) had home-based rehabilitation, 166 (64%) had outpatient rehabilitation, and 77 (30%) had early discharge programs. Rehabilitation services were available significantly more commonly if the hospital had a stroke care unit.

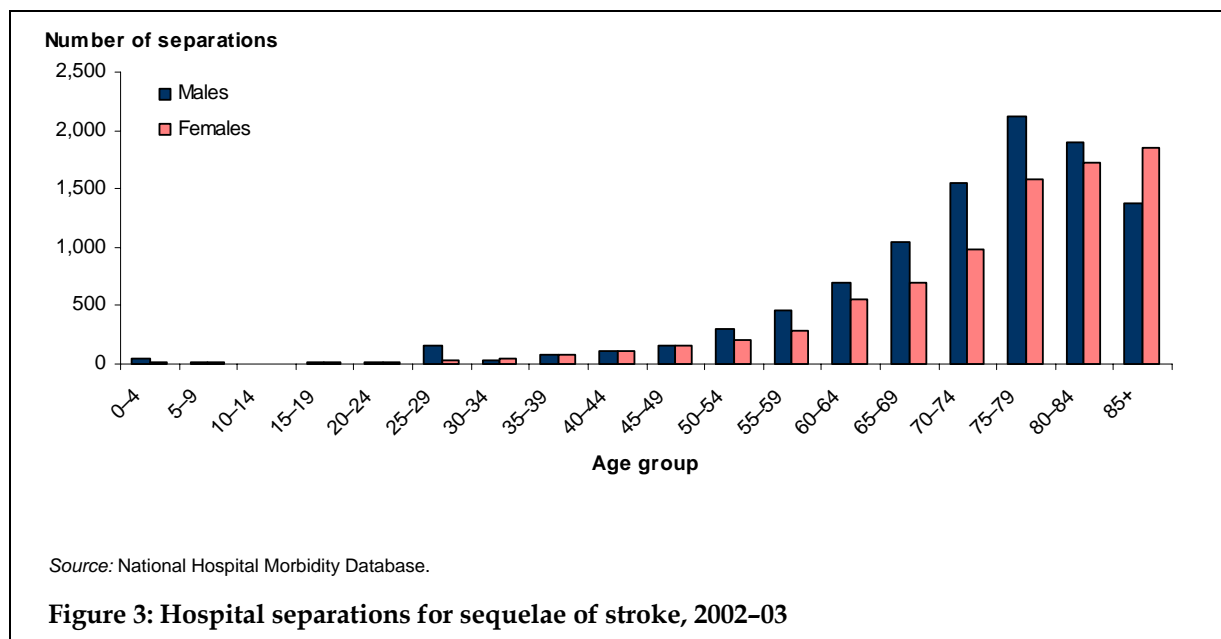
Care protocols for areas such as swallowing difficulties, mobility, neurological monitoring and referral to allied health professionals were much more common in hospitals with stroke units.

A survey of public and private hospital services conducted in 1999 showed inequity in access to hospitals providing optimal stroke services – small, often rural hospitals were less likely to offer coordinated stroke services than metropolitan hospitals and large rural centres (Smarrelli et al. 2001).

In another Australian study comparing care given in stroke units with that in conventional hospital wards, patients treated in stroke units were found to be more likely to have diagnostic tests (carotid ultrasound, brain or carotid angiogram, transcranial Doppler ultrasound, magnetic resonance imaging) (Cadilhac et al. 2004). Stroke unit staff also adhered to protocols and processes of care more often and this was associated with reduced deaths and dependency.

### **Other care for sequelae of stroke**

In addition to those separations discussed previously, there were 18,455 separations with a principal or additional diagnosis of sequelae of stroke in 2002–03, amounting to 332,024 patient days. Separations for males made 55% of the total. In the age group 50–84 years separations for males exceeded those for females, with separations for females more common in those aged 85 years and over, reflecting the structure of the population (Figure 3).



Most (82%) separations with a diagnosis of sequelae of stroke were in public hospitals. Almost two-thirds (64%) of separations were emergency admissions and 24% were elective admissions. About 10% of separations were for patients transferred from another hospital. The majority (89%) of these separations were for acute care. Maintenance care to prevent deterioration of patients with disability accounted for 6%, geriatric evaluation and management for 2% and palliative care for 1%.

Same day separations accounted for about 10% of the total. Excluding same day separations, the average length of stay for sequelae of stroke was 16.9 days and the median was 8 days.

Patients were discharged to their usual residence in 63% of sequelae of stroke separations, to an acute hospital in 11%, to residential aged care in 10%, and had a statistical discharge/type change (indicating care continued in that hospital) in 8%. In 6% of sequelae of stroke separations the patient died.

## Rehabilitation

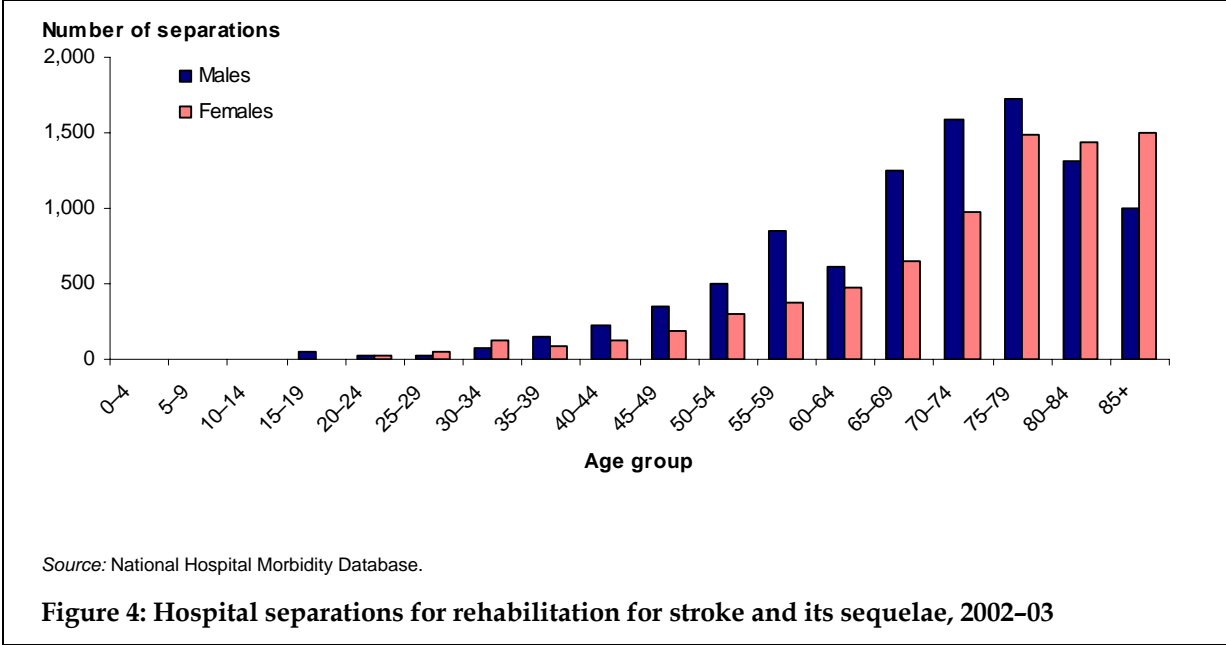
Many stroke survivors need rehabilitation. Rehabilitation aims to improve function, prevent deterioration of function and bring about the highest possible level of independence physically, psychologically, socially and financially (National Stroke Foundation 2005a). Rehabilitation involves the combined, coordinated use of medical, nursing and allied health skills, along with social, educational and vocational services to provide individual assessment, treatment, regular review, discharge planning and follow-up.

Early rehabilitation is a key factor in improving outcomes for stroke patients (National Stroke Foundation 2002, 2003, 2005a). It should begin in the acute hospital, and may continue after the patient has been discharged. Sometimes patients are readmitted to hospital for more intensive admitted patient rehabilitation. In NEMESIS, an Australian stroke study, 45% of 3-month survivors of first-ever stroke and 50% of 3-month survivors of recurrent stroke were admitted to hospital for a period of rehabilitation (Dewey et al. 2003).

In addition to the hospital separations for initial care of stroke and its sequelae described earlier, in 2002-03 there were 17,492 separations with a principal diagnosis of rehabilitation

and an additional diagnosis of stroke or its sequelae. In 44 separations with a principal diagnosis of stroke, rehabilitation was recorded as an additional diagnosis. This makes a total of 17,536 separations where rehabilitation for stroke or its sequelae took place. These separations amounted to 362,020 patient days.

In 55% of these separations the patients were male. Reflecting the same pattern as for initial care for stroke, separations for males exceeded those for females between ages 40 and 79 years, with separations for females being more common for groups over 80 years (Figure 4).



Two-thirds of separations for rehabilitation for stroke or its sequelae were in public hospitals and one-third in private hospitals.

Almost two-thirds (61%) of all rehabilitation separations were elective admissions, while 6% were recorded as emergency. In the remaining 33% there was no urgency status assigned, possibly indicating that they were statistical admissions for a change in care type during the hospital stay, or they were planned readmissions for patients to receive treatment for a current condition.

About 36% of separations were for patients transferred from another hospital and 24% were statistical admissions/care type changes for patients already in that hospital. This may indicate transfers to hospitals or within the same hospital for the specific purpose of rehabilitation.

The majority (96%) of these separations were for rehabilitation care. Geriatric evaluation and management accounted for 2% and acute care for 1%.

Same day separations accounted for about 31% of the total. Excluding same day separations, the average length of stay for rehabilitation for stroke or its sequelae was 28.4 days and the median was 21 days. As would be expected, this is considerably more than the length of stay for initial care for stroke.

Patients were discharged to their usual residence in 76% of rehabilitation for stroke or its sequelae separations, to an acute hospital in 8%, to residential aged care in 5%, and had a

statistical discharge/care type change in 9% indicating care continued in that hospital. In 1% of rehabilitation for stroke separations the patient died.

There are no national data indicating when rehabilitation begins for stroke patients (National Stroke Foundation 2002). However, there is some evidence that little rehabilitation occurs early after a stroke. In one study involving patients treated in stroke units in Melbourne who were observed within 2 weeks of their stroke, it was found that, between 8am and 5pm, stroke patients spent more than 50% of their time resting in bed, 28% of their time sitting out of bed, and 13% engaged in activities with the potential to prevent complications and improve recovery of mobility (Bernhardt et al. 2004).

## **Procedures in hospital**

There is a range of procedures used to diagnose and prevent stroke. Computerised tomographic (CT) scan of the brain should be performed within 24 hours of onset of symptoms to distinguish haemorrhagic stroke from ischaemic stroke and to exclude other pathologies, and repeated if the patient's condition worsens (National Stroke Foundation 2003). Most patients with ischaemic stroke require carotid duplex ultrasound of the carotid arteries. Some patients may need additional investigations, such as magnetic resonance imaging (MRI) of the brain, magnetic resonance angiography (MRA) of the brain arteries, and echocardiography.

In selected patients, carotid endarterectomy may be performed to reduce the risk of stroke. This procedure entails surgically removing atherosclerotic plaque from the carotid arteries in the neck, which supply blood to the brain.

This section presents national information on diagnostic and preventive procedures undertaken in hospital; however, some of these procedures can also be performed out of hospital or may have been performed before the patient was admitted to hospital and therefore not counted in that separation. Table 1 shows the number of hospital separations in which a procedure was conducted. Note that a procedure may have been performed more than once in the course of the same separation, therefore the figures underestimate the total number of procedures.

For diagnostic procedures, the data shown refer to separations with a principal diagnosis of stroke. CT scans of the brain were used in the initial care of acute stroke in two-thirds of separations. Other investigations occurred much less frequently in the initial care of stroke – in one in ten separations or less.

Carotid endarterectomy was performed in 3,422 separations. In the majority of these (71%) the principal diagnosis was occlusion or stenosis of carotid artery, while stroke was recorded as the principal diagnosis in 3% (data not shown).

**Table 1: Hospital separations in which procedures were done, 2002–03**

Procedure	Number of separations	% of separations with principal diagnosis of stroke (initial care) that had procedure
Diagnostic		
CT scan of the brain	21,291 <sup>(a)</sup>	65
Magnetic resonance imaging (MRI) of the brain	3,505 <sup>(a)</sup>	11
Magnetic resonance angiography (MRA) of the brain	1,159 <sup>(a)</sup>	3
Echocardiography	1,159 <sup>(a)</sup>	3
Duplex ultrasound of the carotid vessels	757 <sup>(a)</sup>	2
Preventive		
Carotid endarterectomy	3,422 <sup>(b)</sup>	..

(a) Refers to the number of hospital separations with a principal diagnosis of stroke having this procedure.

(b) Refers to the number of hospital separations with any principal diagnosis having this procedure.

.. not applicable

Source: National Hospital Morbidity Database.

## Prevention of further strokes

Those who have had a stroke are at higher risk of further strokes than people without a history of stroke. The risk of first recurrent stroke is six times higher than the risk of first-ever stroke in the general population (Hardie et al. 2004). People with three or four risk factors are 1.4 times as likely to have had a stroke than those with no risk factors (AIHW: O'Brien 2005). For people with five or more risk factors, the likelihood of having had a stroke is three times. Prevention of further strokes begins very early after stroke and should continue indefinitely (National Stroke Foundation 2005a). In people with transient ischaemic attack or stroke, effective measures for preventing recurrent stroke include:

- lowering of blood pressure
- smoking cessation
- regular exercise
- antiplatelet drugs (aspirin, aspirin + dipyridamole, or clopidogrel) long-term for patients with normal heart rhythm
- anticoagulation (warfarin) long-term for patients with atrial fibrillation
- lowering of blood cholesterol with drugs (statins) in patients with established coronary heart disease
- carotid endarterectomy for patients with severe narrowing of the internal carotid artery on the symptomatic side and who are fit for surgery
- tight control of diabetes
- weight control, if appropriate
- a healthy diet.

The National Health Survey 2001 revealed that among people who reported having had a stroke (311 respondents corresponding to about 217,530 persons), risk factors for stroke remained very common—62% reported having four or more risk factors, 34% reported two or three, and only 4% reported less than two. The risk factors studied are listed in Table 2.

Half of all people who reported a history of stroke had high blood pressure, half were overweight or obese, one in three had high blood cholesterol, one in five smoked and three in four did insufficient physical activity (Table 2).

**Table 2: Risk factors for stroke among people with previous stroke**

<b>Risk factor</b>	<b>% of people with previous stroke and risk factor</b>
High blood pressure <sup>(a)</sup>	49.6
Smoking <sup>(b)</sup>	18.3
Insufficient physical activity <sup>(c)</sup>	77.1
High blood cholesterol <sup>(d)</sup>	30.9
Diabetes <sup>(e)</sup>	15.0
Overweight or obese <sup>(f)</sup>	52.9
Risky alcohol consumption <sup>(g)</sup>	5.1
Low vegetable consumption <sup>(h)</sup>	63.6
Low fruit consumption <sup>(i)</sup>	86.8

(a) Currently having high blood pressure.

(b) Current daily smokers of tobacco.

(c) Sedentary or participating in low amounts of physical activity.

(d) Currently having high blood cholesterol.

(e) Currently having Type 1, Type 2, other type of diabetes or diabetes of unknown type.

(f) BMI  $\geq 25$ .

(g) Average daily consumption of more than 50 ml of alcohol (four standard drinks) for men and more than 25 ml of alcohol (two standard drinks) for women.

(h) Three serves or less per day, where one serve is about 75 g.

(i) One serve or less per day, where one serve is about 150 g of fresh fruit.

*Note:* These data are based on self-reported information from 311 respondents corresponding to about 217,530 persons.

*Source:* AIHW analysis of 2001 National Health Survey.

The National Health Survey 2001 also collected information on medications being taken. It found that two-thirds of people who reported having had a stroke were using blood pressure lowering drugs, one in five were taking blood cholesterol lowering drugs, one in ten were on warfarin, and one in eight on drugs for diabetes (Table 3). Due to the way the data were recorded, it was not possible to establish the proportion of people who may have been taking aspirin or other antiplatelet drugs.



**Table 3: Medications taken by people with previous stroke<sup>(1)</sup>**

Medication	% of people with previous stroke taking medication
Blood pressure lowering drugs	68.9
Blood cholesterol lowering drugs (statins)	21.1
Other lipid lowering drugs	1.1
Antithrombotic drugs (warfarin)	10.3
Other antithrombotic drugs	0
Antidiabetic drugs	12.3 <sup>(a)</sup>

(a) Equivalent to 77.9% of people who reported a stroke and current diabetes.

Note: These data are based on self-reported information from 311 respondents corresponding to about 217,530 persons.

Source: AIHW analysis of 2001 National Health Survey.

Some people who reported having had a stroke took multiple medications simultaneously to manage their condition. About one in five were taking both blood pressure lowering drugs and lipid lowering drugs, while one in twelve were using both blood pressure lowering drugs and warfarin and the same proportion were on both blood pressure lowering drugs and antidiabetic drugs (Table 4).

**Table 4: Multiple medications taken by people with previous stroke**

Medications	% of people with previous stroke taking multiple medications
Blood pressure lowering drugs and statin	19.6
Blood pressure lowering and other lipid lowering drugs	1.1
Blood pressure lowering drugs and warfarin	8.1
Blood pressure lowering and antidiabetic drugs	8.0
Statin and antidiabetic drugs	1.2
Statin and warfarin	1.8
Antidiabetic drugs and warfarin	0.9

Note: These data are based on self-reported information from 311 respondents corresponding to about 217,530 persons.

Source: AIHW analysis of 2001 National Health Survey.

## General practice care

The role of the general practitioner (GP) in the prevention of further strokes is to follow up patients regularly, ensure optimal control of the disease that caused the stroke, encourage patient adherence to medication, and assess and manage any new symptoms, reserving referral to a neurologist if difficulties arise (Hankey 2000). The GP also has a key role in supporting the stroke survivor and family in managing any long-term disabilities and depression associated with stroke, as well as being involved in delivering coordinated multidisciplinary care in the community that improves quality of life after stroke.

The source used here for information on general practice care is the BEACH study, which provides a cross-sectional view of the management of problems in general practice. No conclusions can be drawn in terms of disease episodes, nor in terms of long-term treatment of patients with chronic conditions because the survey is not patient-based and individual records are not linked. The morbidity patterns reflect only the problems managed during the recorded encounters. There may be other comorbidity managed at other encounters outside the recording period that would therefore not be included in the database. Data on medications include only those medications that were prescribed, given or advised for over-the-counter purchase during the course of the recorded encounter. If a prescription was not provided for a given problem it does not necessarily mean that the patient was not already taking medication for the problem. Similarly, the absence of a procedure or a referral does not preclude the possibility that these events occurred at a prior encounter or might happen at a subsequent encounter.

As the frequency of management of stroke problems in general practice is relatively low, to build a more robust picture of current practice, this section presents aggregated data for the period April 1998 – March 2004. Over this period, the survey estimated that each GP managed stroke on an average of 257 occasions per year, at a rate of 0.3 per 100 encounters, representing 0.2% of all problems. This equates to about 269,000 encounters for stroke in general practice each year nationally.

About half of these consultations took place in doctors' surgeries, 15% in nursing homes, 9% were home visits and 6% occurred in hospital.

In 52% of encounters with stroke problems, patients were male. Encounters with female patients outnumbered those with males only in the age group 75 years and over. About half of patients (52%) were aged 75 years and above, and 26% were aged 65–74.

GPs often managed more than stroke at the same encounter, with two problems being managed in 33% of cases, three problems in 22% and four problems in 12%. The most common comorbidities cared for with stroke were hypertension (20% of stroke encounters), diabetes (8%), lipid disorders (4%), depression (4%), atrial fibrillation or flutter (3%), and ischaemic heart disease (3%).

Medications were given in 60% of stroke encounters. These included a vast range of drugs reflecting the variety of problems coexisting with stroke. The most widely prescribed were:

- antiplatelet agents – aspirin (23% of stroke encounters), clopidogrel (8%), dipyridamole (3%)
- anticoagulation drugs – warfarin (19%)
- lipid-lowering drugs – statins (4%)
- blood pressure-lowering drugs (12%) – ACE inhibitors (4%), calcium channel blockers (3%), beta-blockers (2%), diuretics (2%), angiotensin receptor antagonists (1%).

GPs used other forms of treatment in 23% of stroke encounters. These were mainly counselling (4%), physical rehabilitation (2%) and advice or education on the use of medications (2%).

Pathology tests were ordered at 12% of stroke encounters. Coagulation tests to monitor the effect of anticoagulation drugs and guide dose adjustment were the most common (4%). Other tests included full blood count (2%) and lipids (1%).

Imaging was requested in 7% of stroke problems. The most frequent investigations were CT scan of the brain (2% of stroke problems), CT scan of the head (1%), chest X-ray (1%) and doppler ultrasound of the carotid arteries (1%).

GPs referred patients to other health professionals and services in 14% of stroke encounters. These covered the wide-ranging needs of people who have had stroke:

- hospital (4%)
- rehabilitation (4%) – physiotherapy, speech therapy, occupational therapy
- specialists (4%) – neurologists, geriatricians, cardiologists, surgeons
- other (1%) – aged care assessment, home support services, nursing homes.

## **Disability and functioning**

Disability is the umbrella term for any or all of: an impairment of body structure or function, a limitation in activities, or a restriction in participation. Functioning and disability result from the combined interaction of body functions, body structures, the activities people do, the life areas in which they participate, and the factors in the environment which affect these experiences (AIHW 2003). Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. They can facilitate or present a barrier to a person's functioning. People with disability may experience activity limitations (difficulties in executing activities) and participation restrictions (problems in involvement in life situations).

This section presents information on the number of people with stroke and their characteristics, as well as their levels of disability and functioning, as described in the Survey of Disability, Ageing and Carers 2003 conducted by the Australian Bureau of Statistics. The main concepts relating to disability as defined in the survey are shown in Box 2.

According to this survey, in 2003 there were an estimated 346,700 people with stroke in Australia. Of these, about 282,600 (81%) had a disability. This represents 7% of all people with disability (Table 5).

Overall, there were slightly more males than females with stroke (178,300 vs 168,400) but the proportion of people with disability was the same for both sexes (81%) (Figure A1).

The prevalence of stroke in males increased markedly with age from 50–54 years, peaking at 75–79 years. For females, stroke prevalence rose from age 65–69 reaching its maximum at age 85 years and over (Figure A2).

The prevalence of disability among people with stroke followed roughly the same patterns as the prevalence of stroke but the sharp rises occurred from age 60–64 years in males and 70–74 years in females (Figure A3).

Comparison of sex-specific rates showed a very small difference between males and females in the overall prevalence of stroke. The prevalence rate of stroke in males was twice that in females in the age group 60–69 years but this difference became smaller with increasing age (data not shown). The same pattern was observed among people with stroke and disability.

## **Box 2: Definitions used in the Survey of Disability, Ageing and Carers 2003**

**Long-term health condition** is a disease or disorder which has lasted or is likely to last for at least 6 months; or a disease, disorder or event which produces an impairment or restriction which has lasted or is likely to last for at least 6 months.

**Disability:** A person has a disability if they report that they have a limitation, restriction or impairment, which has lasted, or is likely to last, for at least 6 months and restricts everyday activities. This includes for example:

- loss of sight (not corrected by glasses or contact lenses)
- loss of hearing where communication is restricted, or an aid is used
- speech difficulties
- difficulty learning or understanding
- incomplete use of arms or fingers
- difficulty gripping or holding things
- incomplete use of feet or legs
- nervous or emotional condition causing restriction
- restriction in physical activities or in doing physical work
- long-term effects of head injury, stroke or other brain damage causing restriction
- receiving treatment or medication for any other long-term conditions and still restricted
- any other long-term conditions resulting in a restriction.

**Core activities** include communication, mobility and self care.

**Specific limitation or restriction:** a limitation in core activities, or a restriction in schooling and/or employment.

**Levels of core activity limitation:** core activity limitation levels are based on whether a person needs help, has difficulty, or uses aids or equipment with any of the core activities. 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 and 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: Australian Bureau of Statistics 2004.

**Table 5: Persons with stroke and persons with stroke and disability**

Age group (years)	Persons with stroke	Persons with stroke and disability		All persons with disability
	Number	Number	% of persons with stroke	% of all persons with disability
0–29	*4,800	*3,900	81.7	0.5
30–34	*3,700	*2,600	70.1	1.6
35–39	*6,200	*4,300	68.3	2.2
40–44	*7,900	*4,500	57.4	2.0
45–49	*7,200	*4,800	66.3	1.7
50–54	13,300	*9,800	73.9	3.3
55–59	24,000	16,900	70.4	4.9
60–64	26,800	22,700	84.7	6.9
65–69	39,000	28,800	74.0	10.1
70–74	51,000	43,300	84.9	14.0
75–79	61,000	46,800	77.0	15.2
80–84	55,000	50,700	92.2	19.7
85+	47,200	43,600	92.4	18.7
<b>Total</b>	<b>346,700</b>	<b>282,600</b>	<b>81.5</b>	<b>7.2</b>

Note: Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted with caution.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

As would be expected in a mainly elderly group, about 95% of people with stroke had other health conditions present, with 12% reporting one additional condition, 18% two, 18% three, 13% four and 14% five (data not shown). The most prevalent conditions were hypertension (46%), arthritis (38%), deafness or hearing loss (34%) and heart diseases (27%) (Table 6).

**Table 6: Selected other health conditions reported by people with stroke**

Health condition	People with stroke	
	Number	Per cent
Hypertension (high blood pressure)	160,500	46.3
Arthritis and related disorders	130,200	37.6
Deafness/hearing loss	116,400	33.6
Heart diseases	95,200	27.5
Back problems (dorsopathies)	74,800	21.6
Diabetes	56,200	16.2
Sight loss	48,800	14.1
Speech difficulties	47,800	13.8
High cholesterol	46,700	13.5
Depression	26,600	7.7
Dementia including Alzheimer's disease	22,600	6.5
<b>Total people with stroke</b>	<b>346,700</b>	<b>100.0</b>

*Note:* More than one health condition may be present concurrently with stroke.

*Source:* AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

It is likely that the other health conditions reported by stroke survivors may contribute to, or in some cases may be responsible for, the person's disability. In about 50% (146,400) of the estimated 282,600 people with stroke and with a disability, the disability was caused by stroke. This amounts to 42% of all stroke survivors.

The most common types of disability resulting from stroke were restriction in physical activities, incomplete use of limbs, difficulty gripping or holding things and speech difficulties (Table 7).

Generally, people with stroke and a disability were more severely limited or restricted in their activities compared with all people with disability (Table 8). Disabled stroke survivors had a profound limitation of activity much more commonly than the average person with a disability. Persons with profound limitations of activity are unable to do, or always needs help with communication, mobility or self care.

**Table 7: Disability types resulting from stroke**

Disability type <sup>(1)</sup>	People with disability resulting from stroke	
	Number	Per cent
Restriction in physical activities or work	75,300	51.4
Incomplete use of feet or legs	64,300	43.9
Incomplete use of arms or fingers	55,000	37.5
Difficulty gripping or holding things	47,800	32.6
Speech difficulties	42,300	28.9
Slow at learning or understanding	41,300	28.2
Other disability type(s)	27,700	18.9
Chronic or recurring pain or discomfort	25,600	17.5
Nervous or emotional condition	21,500	14.7
Loss of sight	20,400	13.9
Blackouts, fits or loss of consciousness	11,300	7.7
Loss of hearing	11,000	7.5
Breathing difficulties	10,500	7.2
Disfigurement or deformity	9,200*	6.3
Mental illness	7,300*	5.0
<b>Total persons with a disability caused by stroke</b>	<b>146,400</b>	<b>..</b>

*Notes*

1. More than one type of disability may be present concurrently.
2. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted with caution.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

**Table 8: Disability status of people with stroke and disability compared with all people with disability**

Level of activity limitation or restriction	People with stroke and disability	% of people with stroke and disability	All people with disability	% of all people with disability
Profoundly limited in core activities	104,300	36.9	592,200	15.0
Severely limited in core activities	53,200	18.8	646,400	16.4
Moderately limited in core activities	48,800	17.3	698,700	17.7
Mildly limited in core activities	60,900	21.6	1,057,100	26.8
Not limited in core activities but restricted in schooling or employment	*6,000	2.1	384,100	9.7
Not limited in core activities, or restricted in schooling or employment	*9,300	3.3	567,800	14.4
<b>Total</b>	<b>282,600</b>	<b>100.0</b>	<b>3,946,400</b>	<b>100.0</b>

*Notes*

1. For an explanation of levels of activity limitation, refer to Box 2.
2. Core activities include communication, mobility and self care.
3. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted with caution.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

About half of stroke survivors with disability living in households needed assistance with health care, household chores, home maintenance, mobility and transport; and around one in four needed help with self care, cognitive or emotional tasks, meal preparation and paperwork (Table 9). In every area of activity limitation considered, at least 90% of those who needed assistance received it. The sources of assistance are discussed in later sections of this report.

**Table 9: Assistance needed and received by people with stroke and disability living in households**

Area of activity limitation	Whether needs assistance or has difficulty						Whether receives assistance <sup>(a)</sup>			
	Does not need assistance or have difficulty		Does not need assistance but has difficulty		Needs assistance		Receives assistance		Receives no assistance	
	Number	Per cent	Number	Per cent	Number	Per cent	Number	Per cent <sup>(b)</sup>	Number	Per cent <sup>(b)</sup>
Mobility (excludes walking 200m, stairs and picking up objects)	98,300	41.1	37,700	15.8	103,300	43.2	94,600	91.5	*8,800	8.5
Self care	124,000	51.8	50,800	21.2	64,600	27.0	58,300	90.2	*6,300	9.8
Oral communication	221,300	92.5	**1,400	0.6	16,600	7.0	16,100	96.4	**600	3.6
Health care	87,200	36.4	34,800	14.5	117,300	49.0	108,800	92.8	*8,500	7.2
Cognitive or emotional tasks	134,800	56.3	46,200	19.3	58,400	24.4	56,600	97.0	**1,700	3.0
Household chores	102,800	43.0	23,400	9.8	113,100	47.2	109,900	97.2	*3,200	2.8
Home maintenance or gardening	85,100	35.6	23,500	9.8	130,800	54.6	127,000	97.1	*3,700	2.9
Meal preparation	178,200	74.4	*6,800	2.8	54,400	22.7	54,400	100.0	**0	0.0
Paperwork	166,700	69.6	*5,900	2.5	66,800	27.9	63,400	95.0	*3,400	5.0
Private transport	108,200	45.2	*8,200	3.4	123,000	51.4	115,100	93.6	*7,900	6.4

(a) Only people who needed assistance were asked about assistance received.

(b) Percentages calculated as a proportion of those who need assistance.

*Notes*

1. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted with caution.
2. Estimates marked with \*\* have an associated relative standard error (RSE) of more than 50% and should be interpreted with caution.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

These results are consistent with those observed among people with stroke assessed by Aged Care Assessment Teams (ACATs) over the period July 2003 – June 2004. ACATs determine eligibility for formal assistance programs, for more details see section ‘Formal care services in the community’, below. While ACAT clients are expected to have limitations in social activities and participation, ACAT clients with stroke have a much higher level of activity limitations than all ACAT clients. Activity limitations were very common among people with stroke and spanned every area considered, especially transport, domestic work, health care tasks, meals and self care (Table 10).



**Table 10: Activity limitations among ACAT clients**

Limitations	Clients with stroke		All clients	
	Number	Per cent	Number	Per cent
Self care	12,045	72.9	63,612	60.1
Movement activities	6,657	40.3	28,336	26.8
Moving around places at or away from home	9,861	59.7	50,274	47.5
Communication	4,499	27.2	18,780	17.7
Health care tasks	12,370	74.9	68,930	65.1
Transport	13,703	82.9	79,887	75.5
Activities involved in social and community participation	11,852	71.7	67,786	64.0
Domestic work	12,942	78.3	80,048	75.6
Meals	12,150	73.5	70,898	67.0
Home maintenance	9,197	55.7	55,343	52.3
Other	733	4.4	4,709	4.4
None	332	2.0	3,211	3.0
Unable to determine	78	0.5	1,500	1.4
Not stated / inadequately described	131	0.8	1,694	1.6
<b>Total</b>	<b>16,524</b>	<b>100.0</b>	<b>105,856</b>	<b>100.0</b>

*Notes*

1. Data on client activity limitations in this format are available for most of Australia and are shown here. Some jurisdictions have not yet adopted this new format in their reporting and their data have been excluded from this table.
2. The activity limitation categories are not independent as clients may have a number of concurrent limitations.

Source: DoHA unpublished data.

While most people with stroke and disability stayed in touch with family and friends, half went to a restaurant or club in the previous 12 months but only one in ten or less were involved in voluntary work or other organised group activities (Table 11). This compares poorly with rates of voluntary work among older people in the general population – one in three people aged 65–74 years and one in four people aged 75 and over (AIHW 2005c).

**Table 11: Participation in community activities by people with stroke and disability living in households**

	People with stroke and disability	
	Number	Per cent
<b>Activities at home in past 3 months</b>		
Visits from family/friends	208,600	87.2
Telephone calls with family/friends	207,100	86.5
Craftwork for/with other people	25,900	10.8
Church/special community activities	18,800	7.9
Voluntary work (including advocacy)	9,600*	4.0
None of the above	13,100	5.5
<b>Activities away from home in past 12 months</b>		
Visited family/friends	181,500	75.8
Went to a restaurant or club	122,400	51.2
Attended church activities	46,800	19.5
Voluntary work	24,300	10.2
Organised performing arts activities	4,400*	1.8
Organised art/craft activities	12,600	5.3
Other special interest group activities	27,100	11.3
None of the above	31,000	12.9
Does not leave home	5,000*	2.1
<b>Total persons with stroke and disability living in households</b>	<b>239,400</b>	<b>100.0</b>

*Note:* Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted with caution.

*Source:* AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

The majority of people with stroke lived in private dwellings (84%), usually with others, while about 12% lived in cared accommodation which includes hospitals, nursing homes, aged care and disability hostels and other 'homes' (Table 12).

**Table 12: Living arrangements of people with stroke**

Arrangement	Number	Per cent
Cared accommodation <sup>(a)</sup>	43,400	12.5
Private dwelling <sup>(b)</sup>		
Lives with principal carer <sup>(c)</sup>	58,200	16.8
Lives alone	70,400	20.3
Lives with others	162,000	46.7
Subtotal	290,600	83.8
Special dwelling <sup>(d)</sup>		
Lives with principal carer <sup>(c)</sup>	*2,400	0.7
Lives alone or with others	*10,300	3.0
Subtotal	12,700	3.7
<b>Total people with stroke</b>	<b>346,700</b>	<b>100.0</b>

(a) Includes hospitals, nursing homes, aged care and disability hostels and other 'homes'.

(b) Includes houses, flats, home units, townhouses, tents, and other structures used as private places of residence at the time of the survey, including dwellings in retirement villages which had no nursing home or hospital care on site.

(c) Principal carer is the person who provides most informal assistance with core activities, as identified by recipients of care.

(d) Includes hotels, motels, boarding houses, educational and religious institutions, guest houses, construction camps, short-term caravan parks, youth camps and camping grounds, staff quarters, and self care components of retirement villages which had a cared-accommodation component.

Note: Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted with caution.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

## Formal care services in the community

Stroke survivors may be able to live at home but many rely on a range of services without which they would need to move into residential care. Among the programs that provide care to people with disabilities and to older people living in their own homes are Home and Community Care (HACC), Community Aged Care Packages (CACP), Veterans' Home Care (VHC) and Extended Aged Care at Home (EACH). Examples of other programs that support people and their carers are Day Therapy Centres and the National Respite for Carers Program. For details of these programs see AIHW (2003).

The Survey of Disability, Ageing and Carers collected information on assistance for people with disability. Excluding those living in cared accommodation and those who do not need assistance, the majority of people with stroke and disability received a combination of informal and formal care (54%), 32% obtained informal help only, 11% received formal assistance only, while 3% received no assistance (Table 13). About 169,700 people with stroke and disability received assistance from informal providers, around 67,700 obtained

government organised help and 109,500 received assistance from private providers (Table 14).

**Table 13: Type of assistance received by people with stroke and disability**

Type of assistance	People with stroke and disability living in cared accommodation <sup>(a)</sup>		People with stroke and disability living in households		Per cent of those with stroke and disability excluding not applicable
	Number	Per cent of those with stroke and disability	Number	Per cent of those with stroke and disability	
Not applicable	43,300 <sup>(b)</sup>	15.3	41,800 <sup>(c)</sup>	14.8	—
None	—	—	*5,900	2.1	3.0
Informal only	—	—	63,600	22.5	32.2
Formal only	—	—	22,000	7.8	11.1
Informal and formal	—	—	106,000	37.5	53.7

(a) Cared accommodation includes hospitals, nursing homes, aged care and disability hostels and other 'homes'.

(b) It is assumed all people living in cared accommodation receive assistance.

(c) People who do not need assistance with any core or non-core activity.

Note: Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted with caution.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

**Table 14: Assistance providers to people with stroke and disability**

Provider	People with stroke and disability receiving assistance	
	Number	Per cent of people with stroke and disability
Government organised	67,700	24.0
Privately organised and non-profit	28,600	10.1
Privately organised for profit	80,900	28.6
Informal provider	169,700	60.0

Note: Recipients of care may receive assistance from more than one type of provider concurrently.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

Aged Care Assessment Teams (ACATs) determine eligibility for CACP, EACH, some respite care and admission to residential aged care. They also provide advice and referral for services available in the community. In determining eligibility, the teams generate data on the clients they assess. Some of these data have been analysed for this report. Where a client was assessed more than once in the period studied, data from the last assessment were used in this analysis. Only complete assessments were included.

Over the period July 2003 – June 2004, 161,816 clients were assessed by ACATs and 21,424 (13%) of these had a diagnosis of stroke. This figure is likely to underestimate the real number of clients with stroke as some jurisdictions have not yet adopted the new format in their reporting to provide enough detail on diagnosis. Compared with the whole population of ACAT clients, clients with stroke were younger and more often male (Figures A4 and A5). Even so, more than half (54%) of all clients with stroke were female compared with 64% of all ACAT clients.

Those with stroke were more likely to be assessed in hospital and were less likely to live alone than all clients (Tables 15 and 16). The latter might be more related to the greater proportion of clients with stroke being younger and male than to having stroke in itself.

**Table 15: Setting for first face-to-face contact for assessment of ACAT clients**

Setting	Clients with stroke		All clients	
	Number	Per cent	Number	Per cent
Hospital	4,536	27.5	22,751	21.5
Other admitted patient setting	1,209	7.3	5,242	5.0
Residential aged care service	1,619	9.8	10,579	10.0
Other <sup>(a)</sup>	9,074	54.9	65,923	62.3
Not stated / inadequately described	86	0.5	1,361	1.3
<b>Total</b>	<b>16,524</b>	<b>100.0</b>	<b>105,856</b>	<b>100.0</b>

(a) Community settings, usually the client's home.

Note: Data on setting at assessment in this format are available for most of Australia and are shown here. Some jurisdictions have not yet adopted this new format in their reporting and their data have been excluded from this table.

Source: DoHA unpublished data.

**Table 16: ACAT client living arrangements at assessment**

Arrangement	Clients with stroke		All clients	
	Number	Per cent	Number	Per cent
Not applicable <sup>(a)</sup>	2,393	14.5	14,345	13.6
Lives alone	4,965	30.0	39,874	37.7
Lives with family	8,350	50.5	45,166	42.7
Lives with others	542	3.3	3,483	3.3
Not stated / inadequately described	274	1.7	2,988	2.8
<b>Total</b>	<b>16,524</b>	<b>100.0</b>	<b>105,856</b>	<b>100.0</b>

(a) Refers to clients living permanently in residential aged care, hospitals or other institutional settings.

Note: Data on client living arrangement in this format are available for most of Australia and are shown here. Some jurisdictions have not yet adopted this new format in their reporting and their data have been excluded from this table.

Source: DoHA unpublished data.

There were no differences observed in the distribution of usual accommodation setting at the time of assessment between those with stroke and all clients. However, after the ACAT assessment, clients with stroke were recommended for high-level residential care much more often (35% compared with 25%) and more of those recommended for residential aged care were recommended for high care (18% low care : 35% high care among clients with stroke versus 22% low care : 25% high care among all clients) (Table 17). This suggests that compared with all clients, people with stroke have greater care needs and require assistance with activities of daily living.

**Table 17: ACAT client accommodation setting at assessment and recommended after assessment**

Setting	Usual accommodation at assessment				Recommended long-term care setting			
	Clients with stroke		All clients		Clients with stroke		All clients	
	Number	Per cent	Number	Per cent	Number	Per cent	Number	Per cent
Private residence	12,202	73.9	77,598	73.3	6,804	41.2	48,048	45.4
Independent living within a retirement village	1,027	6.2	6,878	6.5	404	2.4	3,116	2.9
Supported community accommodation	233	1.4	1,668	1.6	149	0.9	1,282	1.2
Residential aged care service – low level care	1,779	10.8	10,744	10.1	3,009	18.2	22,986	21.7
Residential aged care service – high level care	241	1.5	1,031	1.0	5,751	34.8	26,821	25.3
Hospital	44	0.3	287	0.3	61	0.4	539	0.5
Other institutional care	52	0.3	374	0.4	15	0.1	109	0.1
Other	748	4.5	4,866	4.6	97	0.6	973	0.9
Not stated / inadequately described	198	1.2	2,410	2.3	234	1.4	1,982	1.9
<b>Total</b>	<b>16,524</b>	<b>100.0</b>	<b>105,856</b>	<b>100.0</b>	<b>16,524</b>	<b>100.0</b>	<b>105,856</b>	<b>100.0</b>

*Note:* Data on client accommodation setting in this format are available for most of Australia and are shown here. Some jurisdictions have not yet adopted this new format in their reporting and their data have been excluded from this table.

*Source:* DoHA unpublished data.

At the time of ACAT assessment, clients with stroke were already receiving assistance with activities at higher rates than all clients in every area considered (Table 18). After assessment, formal assistance was recommended more commonly for those with stroke than for all clients, particularly in the areas of self care, movement and health care tasks. Formal assistance with self care, health care tasks, transport, social and community participation activities, and meals was recommended for about half of people with stroke living in the community.

Note that the information available on ACAT clients relates only to whether they have stroke or other conditions. It does not provide details such as when in the course of the disease the assessment took place, whether the stroke triggered the assessment or whether the clients were already living with stroke at the time of assessment.

**Table 18: Assistance with activities among ACAT clients**

Assistance	Assistance received at assessment				Formal assistance recommended			
	Clients with stroke		All clients		Clients with stroke		All clients	
	Number	Per cent	Number	Per cent	Number	Per cent	Number	Per cent
Not applicable <sup>(a)</sup>	2,957	17.9	16,114	15.2	9,026	54.6	52,006	49.1
Self care	7,444	54.9	39,173	43.7	3,855	51.4	21,303	39.6
Movement activities	3,407	25.1	14,984	16.7	1,132	15.1	5,114	9.5
Moving around places at or away from home	5,979	44.1	32,032	35.7	2,244	29.9	12,287	22.8
Communication	2,440	18.0	10,818	12.1	704	9.4	3,179	5.9
Health care tasks	8,054	59.4	46,630	52.0	3,548	47.3	22,533	41.8
Transport	9,704	71.5	59,097	65.9	3,810	50.8	24,643	45.8
Activities involved in social and community participation	7,664	56.5	46,222	51.5	3,835	51.1	23,985	44.5
Domestic assistance	10,874	80.2	69,183	77.1	5,369	71.6	37,150	69.0
Meals	9,957	73.4	59,672	66.5	3,682	49.1	25,553	47.5
Home maintenance	7,223	53.2	45,128	50.3	2,704	36.1	18,565	34.5
Other	538	4.0	3,426	3.8	560	7.5	4,025	7.5
None	1,146	8.4	6,795	7.6	1,398	18.6	9,402	17.5
Unable to determine	125	0.9	1,554	1.7	91	1.2	1,505	2.8
Not stated / inadequately described	403	3.0	4,288	4.8	104	1.4	1,386	2.6
Subtotal excluding not applicable clients	13,567	—	89,742	—	7,498	—	53,850	—
<b>Total</b>	<b>16,524</b>	<b>(b)</b>	<b>105,856</b>	<b>(b)</b>	<b>16,524</b>	<b>(b)</b>	<b>105,856</b>	<b>(b)</b>

(a) At the time of assessment, refers to clients living permanently in residential aged care, hospitals or other institutional settings. After assessment, refers to clients recommended to living permanently in residential aged care or other institutional settings but who may in fact remain living in the community until a residential care place becomes available.

(b) Percentages have been calculated excluding Not Applicable Clients. The assistance categories are not independent as clients may receive assistance with a number of different types of activities. Therefore, the total exceeds 100%.

Note: Data on assistance with activities in this format are available for most of Australia and are shown here. Some jurisdictions have not yet adopted this new format in their reporting and their data have been excluded from this table.

Source: DoHA unpublished data.

In general, before assessment the extent of government program support was similar for clients with stroke and all clients (Table 19). However, those with stroke were more likely to receive assistance from the National Respite for Carers Program, HACC and Day Therapy Centre support.

**Table 19: Government program support among ACAT clients**

Program	Program support at assessment				Program support recommended			
	Clients with stroke		All clients		Clients with stroke		All clients	
	Number	Per cent	Number	Per cent	Number	Per cent	Number	Per cent
Not applicable <sup>(a)</sup>	3,476	21.0	19,238	18.2	9,065	54.9	52,376	49.5
CACP	1,386	10.6	8,403	9.7	2,841	38.1	19,926	37.3
EACH	80	0.6	368	0.4	227	3.0	949	1.8
HACC	4,942	37.9	32,787	37.9	3,292	44.1	22,217	41.5
Veterans' Home Care	956	7.3	5,610	6.5	626	8.4	3,899	7.3
Day Therapy Centre	450	3.4	2,163	2.5	530	7.1	2,644	4.9
National Respite for Carers Program	784	6.0	3,879	4.5	1,751	23.5	9,795	18.3
Other	869	6.7	5,876	6.8	690	9.3	4,442	8.3
None	5,005	38.4	33,225	38.4	1,688	22.6	12,739	23.8
Unable to determine	141	1.1	907	1.0	79	1.1	745	1.4
Not stated / inadequately described	238	1.8	2,980	3.4	144	1.9	2,103	3.9
Subtotal excluding not applicable clients	13,048	–	86,618	–	7,459	–	53,480	–
<b>Total</b>	<b>16,524</b>	<b>(b)</b>	<b>105,856</b>	<b>(b)</b>	<b>16,524</b>	<b>(b)</b>	<b>105,856</b>	<b>(b)</b>

(a) At the time of assessment, refers to clients living permanently in residential aged care, hospitals or other institutional settings. After assessment, refers to clients recommended to living permanently in residential aged care or other institutional settings but who may in fact remain living in the community until a residential care place becomes available.

(b) Percentages have been calculated excluding Not Applicable Clients. The program categories are not independent as clients may receive support from more than one program concurrently. Therefore, the total exceeds 100%.

*Notes*

1. Data on government program support in this format are available for most of Australia and are shown here. Some jurisdictions have not yet adopted this new format in their reporting and their data have been excluded from this table.
2. ACAT = Aged Care Assessment Team; CACP = Community Aged Care Package; EACH = Extended Aged Care at Home; HACC = Home and Community Care.

Source: DoHA unpublished data.

## Informal care

Informal care refers to the care of a person by family and friends, as opposed to care provided by formal agencies or institutions, trained professionals or paid care. Informal caregivers play an important role in the care of stroke survivors (Dewey 2002). They assist with personal activities of daily living (eating, grooming, bathing, toileting, moving from bed to chair and chair to chair, walking, medication supervision), domestic activities (housework, meal preparation, home maintenance) and other activities (managing financial matters, errands, shopping, identifying needs, organising and accompanying the patient to appointments, transport). Carers also reduce the patient's reliance on formal services for domestic assistance and community access (AIHW 2004c).



This section presents information on carers of people with stroke drawn from the Survey of Disability, Ageing and Carers (SDAC) 2003 and from the Aged Care Assessment Program.

As shown above, an estimated 169,700 stroke survivors with disability (60%) received assistance from an informal carer (see Table 14). About 69,670 people with stroke and disability (25%) had no carer.

The SDAC defines a primary carer as a person who provides most informal assistance, in terms of help or supervision, to a person with one or more disabilities. The assistance has to be ongoing, or likely to be ongoing, for at least 6 months and be provided for one or more of the core activities (communication, mobility and self care). In this survey, primary carers include only persons aged 15 years and over.

Females accounted for about 70% of co-resident primary carers of people with stroke and disability, with the bulk of them aged between 55 and 69 years (Figure A6). Two-thirds of co-resident primary carers of people with stroke and disability were the spouse or partner of the care recipient, and one-quarter were their son or daughter (data not shown).

Of all people with stroke assessed by ACATs, 14% had no carer (Table 20). Compared with all ACAT clients, a higher proportion of clients with stroke had a carer. In most cases carers were the wife/female partner or daughter of the person with stroke (data not shown).

These results are consistent with those observed in the Australian study NEMESIS, where 69% of 3-month survivors of first-ever stroke received informal care from relatives or friends, 66% of primary caregivers being women, most commonly the wife or daughter of the patient, and about half of caregivers lived with the stroke patient (Dewey 2002). In addition, up to six secondary caregivers supported patients.

**Table 20: Carer availability among ACAT clients**

Carer	Clients with stroke		All clients	
	Number	Per cent	Number	Per cent
Not applicable <sup>(a)</sup>	2,811	17.0	17,095	16.1
Has a carer	11,310	68.4	68,295	64.5
Has no carer	2,332	14.1	18,518	17.5
Not stated / inadequately described	71	0.4	1,948	1.8
<b>Total</b>	<b>16,524</b>	<b>100.0</b>	<b>105,856</b>	<b>100.0</b>

(a) Refers to clients living permanently in residential aged care, hospitals or other institutional settings.

Note: Data on client carer availability in this format are available for most of Australia and are shown here. Some jurisdictions have not yet adopted this new format in their reporting and their data have been excluded from this table.

Source: DoHA unpublished data.

Excluding those people living permanently in residential aged care, hospitals or other institutions and those not using help or supervision of others to carry out activities, informal carers (family, friends or neighbours) provided the bulk of assistance with activities to ACAT clients with stroke (data not shown). As stated earlier, this was also the case for all people with stroke and disability (see Table 14). Primary carers of people with stroke and disability provided assistance with a wide range of activities (Table 21).

**Table 21: Assistance provided by co-resident primary carers to people with stroke and disability**

Assistance provided	Co-resident primary carers	
	Number	Per cent
<b>Assists with self care tasks</b>	<b>38,200</b>	<b>69.3</b>
Assists with bathing or showering	25,100	45.5
Assists with dressing	31,300	56.8
Assists with eating or feeding	18,800	34.1
Assists with toileting	*9,800	17.7
Assists with managing incontinence	12,500	22.7
<b>Assists with communication tasks</b>	<b>26,400</b>	<b>47.9</b>
Assists to communicate with strangers	25,700	46.7
Assists to communicate with family and friends	13,300	24.1
<b>Assists with mobility tasks</b>	<b>45,600</b>	<b>82.8</b>
Assists with getting into or out of a bed or chair	25,600	46.5
Assists with moving about the house	20,000	36.2
Assists with moving around away from home	40,000	72.9
Assists with transport tasks	46,500	84.3
Assists with cognitive or emotional tasks	49,400	89.5
Assists with health care tasks	45,000	81.6
Assists with household tasks	50,400	91.3
Assists with property maintenance	38,600	70.0
<b>Total co-resident primary carers</b>	<b>55,100</b>	<b>100.0</b>

*Notes*

1. Carers may provide assistance with more than one task.
2. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted with caution.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

More than half of co-resident primary carers of people with stroke and disability spent 40 hours or more per week in their caring role (Table 22). For about 41% of primary carers the caring role did not affect their income, while 23% said their income had decreased and 21% had extra expenses (Table 23). Most primary carers were not employed but among those who were employed, the majority fitted in their carer responsibilities without changing the hours they worked. In NEMESIS 90% of cases' informal care was provided during family or leisure time (Dewey 2002). The majority of caregivers in paid employment did not change their working arrangements to accommodate their carer role. The number of hours per week spent providing care varied between patients but was substantial for many.

**Table 22: Weekly hours of care provided by co-resident primary carers to people with stroke and disability**

Hours per week	Co-resident primary carers of people with stroke and disability	
	Number	Per cent
Less than 20 hours	11,800	21.5
20 to less than 40 hours	*8,600	15.5
40 hours or more	31,200	56.6
Not stated	*3,500	6.4
<b>Total co-resident primary carers</b>	<b>55,100</b>	<b>100.0</b>

Note: Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted with caution.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

**Table 23: Effect of caring role on co-resident primary carer's income, living costs and work**

	Co-resident primary carers of people with stroke and disability	
	Number	Per cent
<b>Effect on financial situation</b>		
Income not affected	22,500	40.8
Income has increased	*2,800	5.1
Income has decreased	12,800	23.2
Has extra expenses	11,600	21.0
Not stated	*5,400	9.8
<b>Whether has difficulty meeting everyday costs as a result of caring role</b>		
Not applicable (finances have not been negatively affected)	25,300	46.0
Has difficulty meeting everyday living costs	15,400	27.9
Does not have difficulty meeting everyday living costs	10,400	18.9
Not stated	*4,000	7.3
<b>Effect on weekly hours worked since commencing caring role</b>		
Not applicable (not employed)	43,100	78.1
Weekly hours worked are unchanged	*9,000	16.4
Weekly hours worked are changed	*3,000	5.4
<b>Total co-resident primary carers</b>	<b>55,100</b>	<b>100.0</b>

Note: Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted with caution.

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

The physical and psychological demands of the caring role can lead to adverse effects on the physical health and emotional wellbeing of carers, their personal relationships and participation in social activities (AIHW 2004c). Most primary carers of people with stroke and disability (62%) reported that their physical or emotional wellbeing had not changed due to their caring role. However, about 61% said they did not feel satisfied, around 37% reported feeling weary or lacking energy, and 30% said they frequently felt worried or

depressed (Table 24). In the majority of cases, the personal relationships of carers remained unaffected by the caring role (Table 25).

**Table 24: Effects of caring role on co-resident primary carer's health and wellbeing**

	Co-resident primary carers of people with stroke and disability	
	Number	Per cent
<b>Whether physical/emotional wellbeing changed due to caring role</b>		
Physical or emotional wellbeing has changed due to caring role	15,900	28.8
Physical or emotional wellbeing has not changed due to caring role	34,400	62.4
Not stated	*4,900	8.8
<b>Whether feels satisfied due to caring role</b>		
Feels satisfied due to caring role	16,500	29.9
Does not feel satisfied due to caring role	33,800	61.3
Not stated	*4,900	8.8
<b>Whether feels weary or lacks energy due to caring role</b>		
Feels weary or lacks energy due to caring role	20,200	36.7
Does not feel weary or lack energy due to caring role	30,100	54.5
Not stated	*4,900	8.8
<b>Whether frequently feels angry or resentful due to caring role</b>		
Frequently feels angry or resentful due to caring role	*6,900	12.6
Does not frequently feel angry or resentful due to caring role	43,300	78.6
Not stated	*4,900	8.8
<b>Whether frequently feels worried or depressed due to caring role</b>		
Frequently feels worried or depressed due to caring role	16,500	30.0
Does not frequently feel worried or depressed due to caring role	33,800	61.2
Not stated	*4,900	8.8
<b>Whether has had a stress-related illness due to caring role</b>		
Has been diagnosed with a stress-related illness due to caring role	*6,300	11.4
Has not been diagnosed with a stress-related illness due to caring role	44,000	79.8
Not stated	*4,900	8.8
<b>Total co-resident primary carers</b>	<b>55,100</b>	<b>100.0</b>

*Note:* Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted with caution.

*Source:* AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

**Table 25: Effects of caring role on co-resident primary carer's relationships**

	Co-resident primary carers of people with stroke and disability	
	Number	Per cent
<b>Effect on relationship with main recipient of care</b>		
Relationship unaffected	27,700	50.2
Brought closer together	12,300	22.3
Relationship strained	11,600	21.1
Not stated	*3,500	6.4
<b>Effect on relationship with partner</b>		
Not applicable (main recipient is partner)	35,600	64.5
Relationship unaffected	*4,100	7.5
Brought closer together	**800	1.4
Lack time alone together	*2,600	4.8
Relationship strained	*2,800	5.2
Has no spouse or partner	*5,700	10.3
Not stated	*3,500	6.4
<b>Effect on relationship with co-resident family members</b>		
Relationships unaffected	12,700	23.1
Brought closer together	**1,600	2.8
Less time to spend with them	*4,700	8.5
Relationships strained	*4,400	8.0
Has no other co-resident family members	28,200	51.2
Not stated	*3,500	6.4
<b>Effect on friendships</b>		
Friendships unaffected	30,200	54.8
Circle of friends has increased	**600	1.1
Circle of friends has changed	*6,900	12.5
Lost or losing touch with existing friends	13,900	25.1
Not stated	*3,500	6.4
<b>Total co-resident primary carers</b>	<b>55,100</b>	<b>100.0</b>

*Notes*

1. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted with caution.
2. Estimates marked with \*\* have an associated relative standard error (RSE) of more than 50% and should be interpreted with caution

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

Formal services available to people through the programs mentioned in the previous section and other government aged care and disability programs help to reduce the load on carers. These programs also offer services that directly assist carers, such as respite care, counselling, education and information services, and care planning and coordination services. For details of these programs refer to AIHW (2004c).

The majority of co-resident primary carers of people with stroke and disability had never used respite care (84%) and most of them (70%) did not need it or want it (Table 26). However, 14% of carers said they needed it but were not receiving it.

**Table 26: Need for and use of respite care by co-resident primary carers of people with stroke and disability**

	Co-resident primary carers of people with stroke and disability	
	Number	Per cent
Received respite care in last 3 months and does not need it further	3,800*	7.0
Received respite care in last 3 months but needs it further	3,200*	5.7
Did not receive respite care in last 3 months and does not need it	1,400**	2.6
Did not receive respite care in last 3 months but needs it	300**	0.5
Has never received respite care and does not need or want it	38,400	69.7
Has never received respite care but needs it	8,000*	14.5
<b>Total co-resident primary carers</b>	<b>55,100</b>	<b>100.0</b>

*Notes*

1. Estimates marked with \* have an associated relative standard error (RSE) of between 25% and 50% and should be interpreted with caution.
2. Estimates marked with \*\* have an associated relative standard error (RSE) of more than 50% and should be interpreted with caution

Source: AIHW analysis of ABS 2003 Survey of Disability, Ageing and Carers Confidentialised Unit Record File.

At the time of assessment, 75% of ACAT clients with stroke were using no respite care services (Table 27). The increased burden on carers of people with stroke is evident from the fact that after assessment only 20% were recommended no respite care, while residential respite care was recommended for 62% and both residential and non-residential care for 12.7%. This compares with 28% being recommended no respite care, 56% residential care and 9% both residential and non-residential care for all ACAT clients.

**Table 27: Respite care among ACAT clients**

Respite care	Respite care use at assessment				Respite care recommended			
	Clients with stroke		All clients		Clients with stroke		All clients	
	Number	Per cent	Number	Per cent	Number	Per cent	Number	Per cent
Not applicable <sup>(a)</sup>	3,957	23.9	23,212	21.9	7,772	47	45,302	42.8
Residential respite care	1,833	14.6	9,419	11.4	5,428	62.0	34,041	56.2
Non-residential respite care	494	3.9	2,646	3.2	191	2.2	1,355	2.2
Both residential and non-residential respite care	274	2.2	1,122	1.4	1,115	12.7	5,463	9.0
None	9,482	75.5	65,700	79.5	1,719	19.6	16,856	27.8
Unable to determine	223	1.8	1,392	1.7	98	1.1	936	1.5
Not stated / inadequately described	261	2.1	2,365	2.9	201	2.3	1,903	3.1
Subtotal excluding not applicable clients	12,567	100.0	82,644	100.0	8,752	100.0	60,554	100.0
<b>Total</b>	<b>16,524</b>	<b>(b)</b>	<b>105,856</b>	<b>(b)</b>	<b>16,524</b>	<b>(b)</b>	<b>105,856</b>	<b>(b)</b>

(a) At the time of assessment, refers to clients living permanently in residential aged care, hospitals or other institutional settings. After assessment, refers to clients recommended to living permanently in residential aged care or other institutional settings but who may in fact remain living in the community until a residential care place becomes available.

(b) Percentages have been calculated excluding Not Applicable Clients. Therefore if Not Applicable Clients are added, the total exceeds 100%.

Note: Data on respite care in this format are available for most of Australia and are shown here. Some jurisdictions have not yet adopted this new format in their reporting and their data have been excluded from this table.

Source: DoHA unpublished data.

## Cost of stroke care

The AIHW has produced estimates of direct expenditure associated with the care of people with cerebrovascular disease, which includes other conditions apart from stroke (AIHW 2004b). As these figures are not specific to stroke, they are not shown here.

Detailed estimates on the cost of caring for stroke are available from a model based on data from the North East Melbourne Stroke Incidence Study (NEMESIS) conducted in 1997, using a bottom-up approach. Stroke incidence rates and resource use data from NEMESIS used in the model are assumed to be representative of practices in Australia generally. However, the NEMESIS results relate to patients living in inner urban Melbourne, close to a centre of excellence in stroke care and research. It is likely that patterns of care and costs vary throughout Australia. For instance, the average length of stay in hospital for rehabilitation after stroke was 45 days in NEMESIS (Dewey et al. 2003), compared with 28 days Australia-wide (see above section 'Hospital care – Rehabilitation'). However, this difference could also be explained by the likely underestimation of the real length of stay arising from recording in hospital administration collections multiple separations for the same stroke patient.

The total cost during the first year after the event for all first-ever strokes in Australia in 1997 was estimated at \$555 million, including direct and indirect costs (Dewey et al. 2001). The largest components of this total were rehabilitation (admitted patient and outpatient), hospitalisation in the acute period, and nursing home care (Table 28). Note also the substantial time costs for carers of stroke survivors and the out-of-pocket expenses incurred by stroke patients. Most out-of-pocket costs relate to care to reduce disability after the acute period (Dewey et al. 2004).

The average total cost per case during the first year after a first-ever stroke event was \$18,956. By comparison, the average total cost per case during the first year after a recurrent stroke was \$21,786 (Dewey et al. 2001). This is because the average cost of acute hospitalisation for stroke care and the average cost of admitted patient rehabilitation are both greater in cases of recurrent stroke than in first-ever strokes (Dewey et al. 2003).

The lifetime costs of all first-ever stroke cases that occurred in Australia in 1997 were estimated at \$1.3 billion or \$44,000 per case, expressed in 1997 dollar terms (Dewey et al. 2001).



**Table 28: Costs during first year after a first-ever stroke, Australia, 1997**

<b>Resource</b>	<b>Cost per case (\$)</b>	<b>Total cost for all cases (\$million)</b>	<b>% of total first year cost</b>
Acute hospitalisation for stroke care <sup>(a)</sup>	6,651	154	28
Admitted patient rehabilitation	5,122	150	27
Nursing home care	2,173	63	11
Lost production (indirect costs) <sup>(b)</sup>	1,170	34	6
Rehospitalisation for stroke complications	973	28	5
Carer time	741	22	4
Out-of-pocket <sup>(c)</sup>	615	18	3
Non-admitted patient rehabilitation	613	16	3
Hospitalisation for recurrent stroke event	576	17	3
Medications	378	11	2
Ambulance transfers for acute care	280	8	1
Respite care	207	6	1
Investigations <sup>(d)</sup>	196	6	1
Carer out-of-pocket	156	5	1
Specialist medical care	138	4	1
General practitioner care	116	3	1
Ambulance transfers (post-acute)	113	3	1
Private allied health care	67	2	<1
Emergency department care (acute)	50	1	<1
Aged care assessment teams	48	1	<1
Community services	25	1	<1
Emergency department care (post-acute)	22	1	<1
Pre-admission general practitioner care	2	<1	<1
<b>Total</b>	<b>18,956</b>	<b>555</b>	<b>100</b>

(a) Costs as determined for patients admitted to Austin Health.

(b) The value of total indirect costs of stroke are included here because with the frictional approach used, all indirect costs are incurred in the early months after stroke.

(c) Includes aids, equipment, home modifications, alternative and herbal medications, transport, private domestic help, and other out-of-pocket costs not included in other cost categories.

(d) Includes radiology, pathology and other investigations.

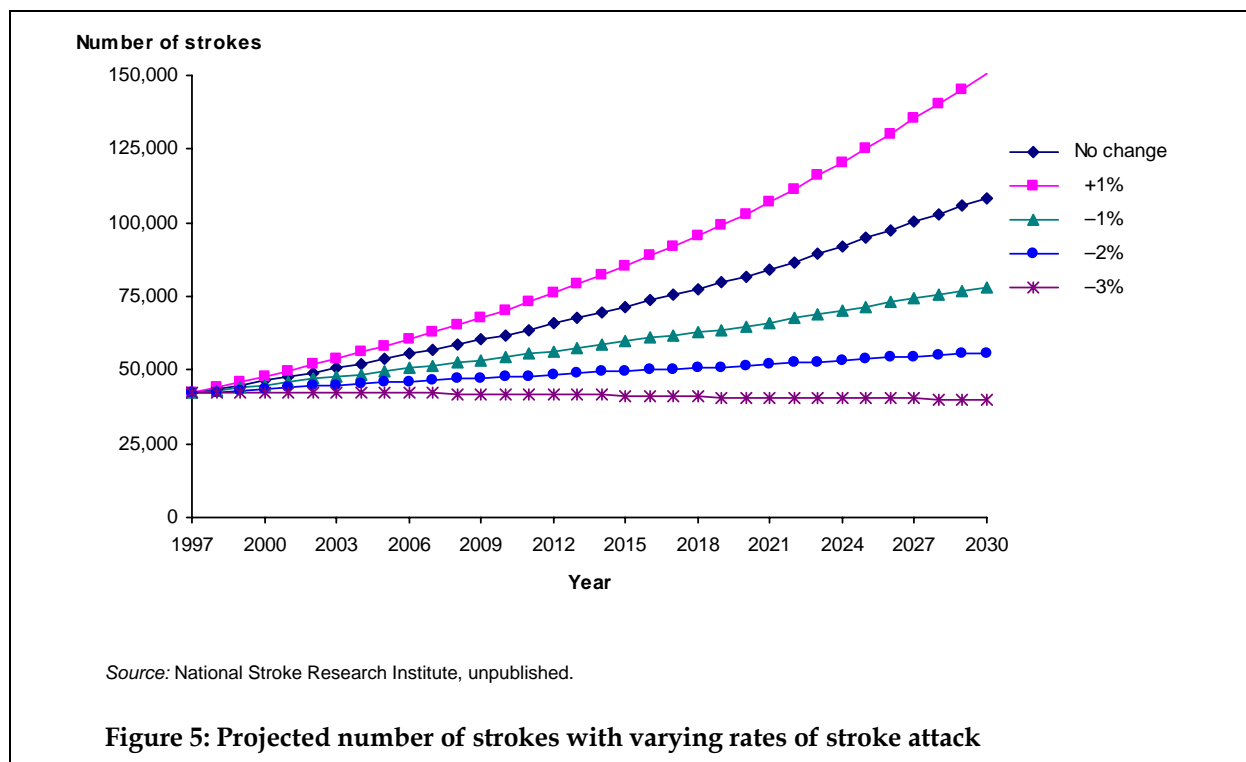
Source: modified from Dewey et al. 2003 and Dewey et al. 2001.

## Future trends

This section presents scenarios for stroke projections into the next decades. The National Stroke Research Institute produced these numbers based on population estimates by the Australian Bureau of Statistics and stroke attack figures from NEMESIS and applied these to annual changes in rates of stroke attack ranging from 3% fall through to 1% increase. These projections are based on the following assumptions:

1. that NEMESIS stroke incidence rates apply to the whole of Australia
2. that differential stroke incidence rates across age groups remain the same as those observed in NEMESIS
3. that the ABS population projections are accurate.

For the case with no change in stroke incidence rates, due to the expected increasing population numbers and the expected change in age structure of the population, the number of strokes would increase from about 42,000 in 1997 to 108,000 in 2030 (Figure 5). If the incidence rates rose by 1% per year, the number of strokes in 2030 would rise to 151,000. Only with an annual reduction in incidence rates of between 2% and 3% would the number of strokes remain the same in 2030 as they were in 1997.



## Discussion: how well do we manage stroke?

Stroke poses a significant burden on patients and their families as well as on the health system and aged care services. It is associated with serious outcomes for patients and their carers. Stroke caused 9,006 deaths in Australia in 2003, almost 7% of all deaths. One in six acute stroke hospital separations ended in death. In 2003 there were an estimated 346,700 survivors of stroke, of whom four in five had a disability, and for two in every five survivors their disability was caused by stroke. People with stroke and a disability were more likely than the average person with a disability to have profound activity limitations relating to self care, movement and communication.

Overall, in 2002–03 there were 68,866 hospital separations with a principal diagnosis of stroke, its sequelae, and rehabilitation for stroke or its sequelae. Importantly, people with stroke stay in hospital much longer than average (the average length of stay excluding same day separations was 12.6 days for initial care for stroke, 16.9 days for initial care for sequelae of stroke and 28.4 days for stroke rehabilitation vs 6.5 days overall). Separations for stroke, its sequelae and subsequent rehabilitation took up 1,073,645 patient days in 2002–03. The effect of this is that, although stroke separations amounted to 1% of all hospital separations for that year, they represented 5% of all patient days. Most of the initial care of patients with stroke presenting as an emergency takes place in public hospitals, as does the initial care of sequelae of stroke. For rehabilitation, about one-third of separations are in private hospitals.

In addition, there were an estimated 269,000 general practice encounters for stroke problems per year over the period April 1998 – March 2004. During these encounters GPs often managed additional conditions likely to impact on the risk of further strokes – most commonly hypertension, diabetes, lipid disorders, atrial fibrillation and ischaemic heart disease. Medications were given very frequently as part of management, and referrals to other professionals and services were common too.

Most stroke survivors live at home, with only 12% in cared accommodation. This is also the case for disabled people with stroke, 15% of whom live in cared accommodation. Many stroke survivors are able to avoid moving into residential care because a range of community services is available to assist them. An estimated 128,000 people with stroke and disability received formal assistance in 2003.

At least one in eight ACAT clients (21,424 people) had a diagnosis of stroke in 2003–04. Compared with the whole population of ACAT clients, people with stroke were younger and much more likely to require high-level residential care, suggesting greater care needs. Formal assistance was recommended more commonly for people with stroke than the average, particularly for self care, movement and health care tasks.

Informal caregivers play an important part in the care of stroke survivors. The vast majority of people with stroke had a carer and, excluding those people who were in institutions, informal carers provided most of the assistance with activities. More than half of primary carers spent 40 hours or more each week in their caring role and for about one in four their caring responsibilities adversely affected their income. Despite the heavy workload of caring for a person with stroke, most primary carers had never used respite care and did not want it. However, one in seven carers who had not received respite care said they needed it. After assessment, respite care was recommended for nearly 80% of ACAT clients with stroke, which is higher than the average, indicating recognition of greater strain on carers of stroke survivors.

In dollar terms, based on a study conducted in Melbourne, the total cost of first-ever strokes in Australia in the first year after the event was estimated at \$555 million in 1997, with most of this attributed to hospitalisation for acute care, rehabilitation and nursing home care. The time costs for carers and out-of-pocket expenses for stroke survivors were also substantial. The lifetime cost of all first-ever strokes that occurred in Australia in 1997 was estimated at \$1.3 billion or \$44,000 per case, expressed in 1997 dollar terms.

Encouragingly, the care of stroke patients seems to be improving...

- The number of stroke care units in public hospitals appears to have increased from 35 to 50 between 1999 and 2004. (Note this is probably an underestimate of the increase, due to differences between the surveys.)
- Those hospitals with stroke care units were more likely to have rapid triage and rapid assessment of patients with acute stroke, on-site access to diagnostic equipment, care protocols in place and rehabilitation services.
- A large proportion of people who had had a stroke reported taking medications to help prevent recurrent strokes, such as blood pressure-lowering drugs, lipid-lowering drugs (statins), warfarin and antidiabetic drugs if they also had diabetes.
- At least 90% of stroke survivors who needed assistance with activities while living at home were receiving it.

However, there is quite a way to go to achieve optimum care...

- In Australia 23% of eligible public hospitals provided organised stroke services in 2004. This compares poorly with some countries like Sweden where 83% of hospitals have stroke units. In Norway and Sweden 60–70% of patients are cared for in stroke care units (Moon et al. 2003; Rudd et al. 2004).
- Although most people in the community recognise stroke is an emergency, and many people know what a stroke is, very few are aware of stroke signs and symptoms. Not being able to identify that a person is having a stroke can lead to delays in presentation for treatment and result in worse outcomes.
- Of concern too is the finding that although guidelines recommend performing CT scan of the brain in all stroke patients within 24 hours of the onset of symptoms, based on hospital statistics this diagnostic procedure was used in the initial care of stroke in only two-thirds of separations. However, this may not accurately reflect whether patients had a scan as the number of procedures may be underestimated due to the limitations of hospital administration data collections.
- Similarly, the prevalence of modifiable risk factors for stroke remains high among people who have had a stroke, putting them at even higher risk of further events.
- Stroke survivors rely heavily on informal carers for assistance with activities. However, only a minority of primary carers access respite care services. In addition, it has been shown that providing carers with training in basic nursing skills, such as moving and handling patients, and facilitating activities of daily living, improves outcomes for disabled stroke survivors and informal carers, as well as reducing costs of care (Kalra et al. 2004; Patel et al. 2004). Such training for carers is currently not given.

There are also gaps in our knowledge...

- For instance, in 2002–03 there were 17,536 hospital separations in which rehabilitation for stroke or its sequelae took place, representing 53% of all separations for initial care of stroke. This might be construed to indicate a low rate of rehabilitation after stroke as almost all patients with stroke would benefit from rehabilitation. However, we must be careful not to infer from these figures that half of all people who were treated in hospital for acute stroke had rehabilitation, as the data refer to hospital separations and not to individual patients. With existing data collections we cannot link records at a national level to track patients and obtain information such as this.
- There is no national information on the time elapsed between onset of stroke symptoms, presentation to hospital and start of emergency care.
- In general, the uptake of clinical guidelines recommendations on appropriate assessments and management is difficult to gauge from available data. Guidelines state that CT scans should be performed within 24 hours of onset of symptoms and rehabilitation for stroke should begin as early as possible but there are no data indicating when this happens in practice. Likewise, although we have some indication of medications being used by people who have had a stroke, we have no national data on medications given in acute care or at discharge from hospital. There is some evidence of wide variation in practices around Australia and suboptimal use of some recommended investigations and treatments (Duffy et al. 2003).
- It is difficult to ascertain the extent of formal care services actually delivered to stroke survivors as there is a myriad of programs, with data held in separate collections and the diagnoses of users are not recorded. Record linkage of these collections would be complex.
- Nor are there regular, up-to-date data on the incidence of stroke that would allow us to determine incidence trends over time.

Despite the lack of actual data on incidence trends, we can expect that the ageing of the Australian population will drive an increase in the number of strokes in the future unless incidence rates fall by 2–3% per year. There is ample scope to intervene to reduce the incidence of stroke with primary and secondary prevention measures.

# Appendix

## Codes used in this report

Data	Disease/problem or procedure	Classification	Code
Deaths	Stroke	ICD-10	I60–I64
Hospital separations	Stroke	ICD-10-AM	I60–I64
	Sequelae of stroke	ICD-10-AM	I69.0–I69.4
	Rehabilitation	ICD-10-AM	Z50
Hospital procedures	Carotid endarterectomy	ICD-10-AM	33500–00, 32703–00
	Chest X-ray	ICD-10-AM	58500–00, 58506–00
	CT scan of the head	ICD-10-AM	56001–00, 56007–00, 56010–02, 56010–03
	Duplex ultrasound of carotid vessels	ICD-10-AM	55274–00
	Echocardiography	ICD-10-AM	55112–00, 55118–00, 55130–00
	MRA of the brain	ICD-10-AM	90902–00
	MRI of the brain	ICD-10-AM	90901–00
	General practice encounters	Stroke/cerebrovascular accident	ICPC-2
Stroke/cerebrovascular accident; old		ICPC-2	K91010
Disability and carers	Stroke	SDAC	923
	Arthritis	SDAC	1301
	Back problems	SDAC	1303
	Dementia	SDAC	511, 605
	Depression	SDAC	513
	Diabetes	SDAC	402
	Heart disease	SDAC	910–914, 919
	High cholesterol	SDAC	404
Aged Care Assessment Program	Hypertension	SDAC	922
	Stroke	ACAP	911–915

## Data sources

**ACAP (Aged Care Assessment Program)**, jointly funded by the Australian Government and states and territories to assess the physical, medical, psychiatric and social needs of older people and facilitate access to appropriate available care services. It operates through a network of regionally based, multidisciplinary Aged Care Assessment Teams (ACATs) across Australia. Assessment by an ACAT is mandatory for admission to residential care, to receive a Community Aged Care Package or for admission to residential respite. ACATs also refer people to community services and to rehabilitation services, both admitted patient and community based.

**AIHW National Hospital Morbidity Database**, contains demographic, diagnosis, procedure and duration of stay information on episodes of care for patients admitted to hospital. The collection is maintained by the AIHW using data supplied by state and territory health authorities.

**BEACH (Bettering the Evaluation and Care of Health) Survey of General Practice**, an ongoing national survey looking at aspects of general practice in Australia, conducted by the General Practice Statistics and Classification Unit (an AIHW collaborating unit within the Family Medicine Research Centre, University of Sydney). BEACH began in April 1998 and involves a random sample of about 1,000 general practitioners per year, each of whom records details on 100 consecutive patient encounters.

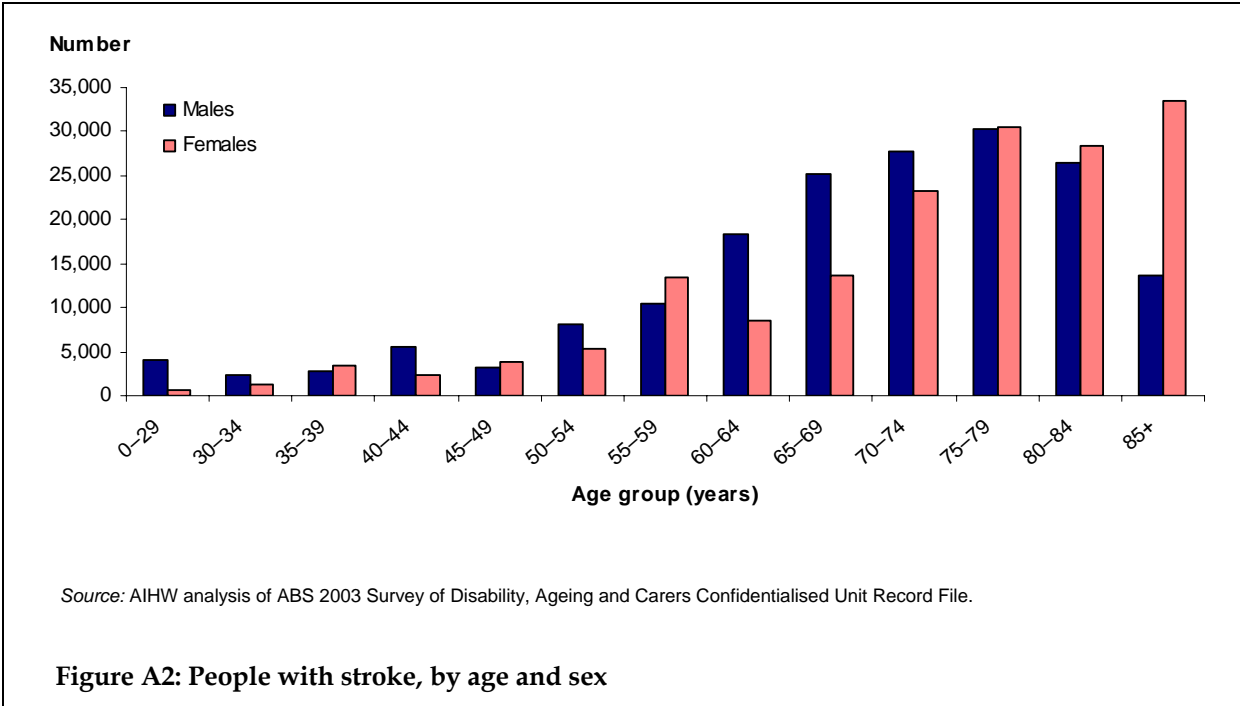
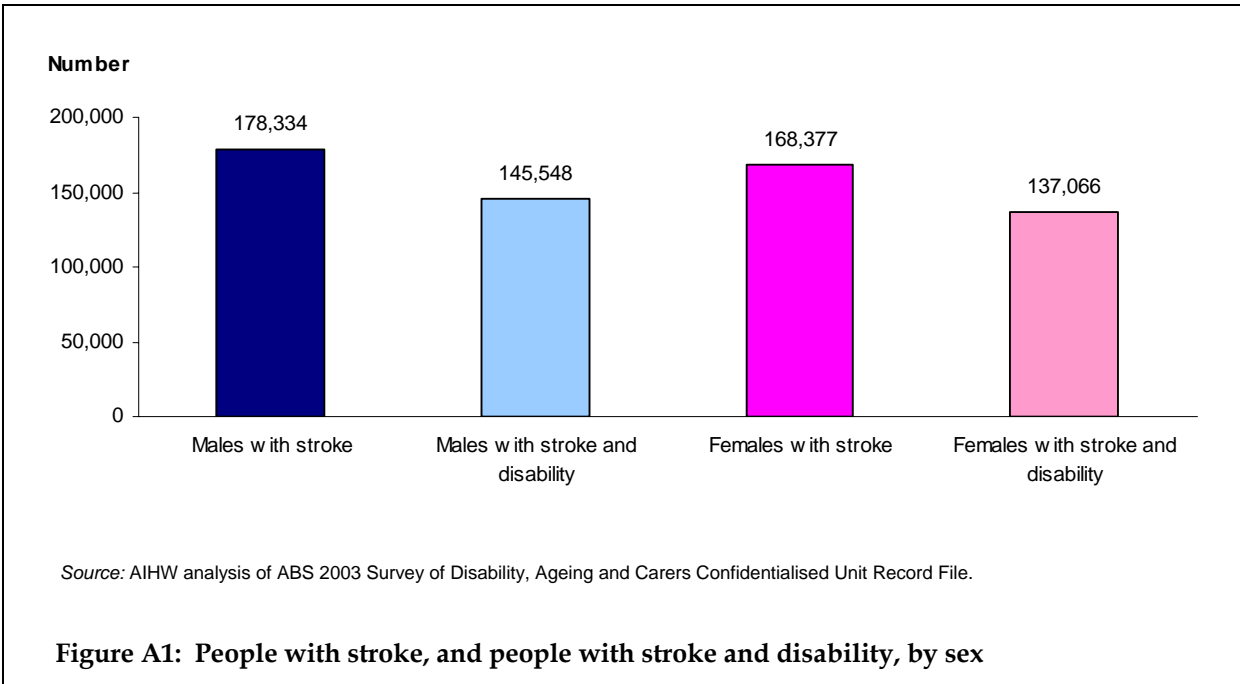
**Disability, Ageing and Carers Survey 2003**, conducted by the ABS, collected national information on people with disabilities, older people and carers of older people and people with disabilities. The survey collected information about people living in households as well as those in cared accommodation (including hospitals, nursing homes, aged care and disability hostels and other 'homes') from a sample of 41,386 people over the period 23 June - 1 November 2003.

**National Health Survey 2001**, conducted by the ABS, to obtain national information on the health status of Australians, their use of health services and facilities, and health-related aspects of their lifestyle. The 2001 survey collected information from a sample of 26,900 people from February to November 2001.

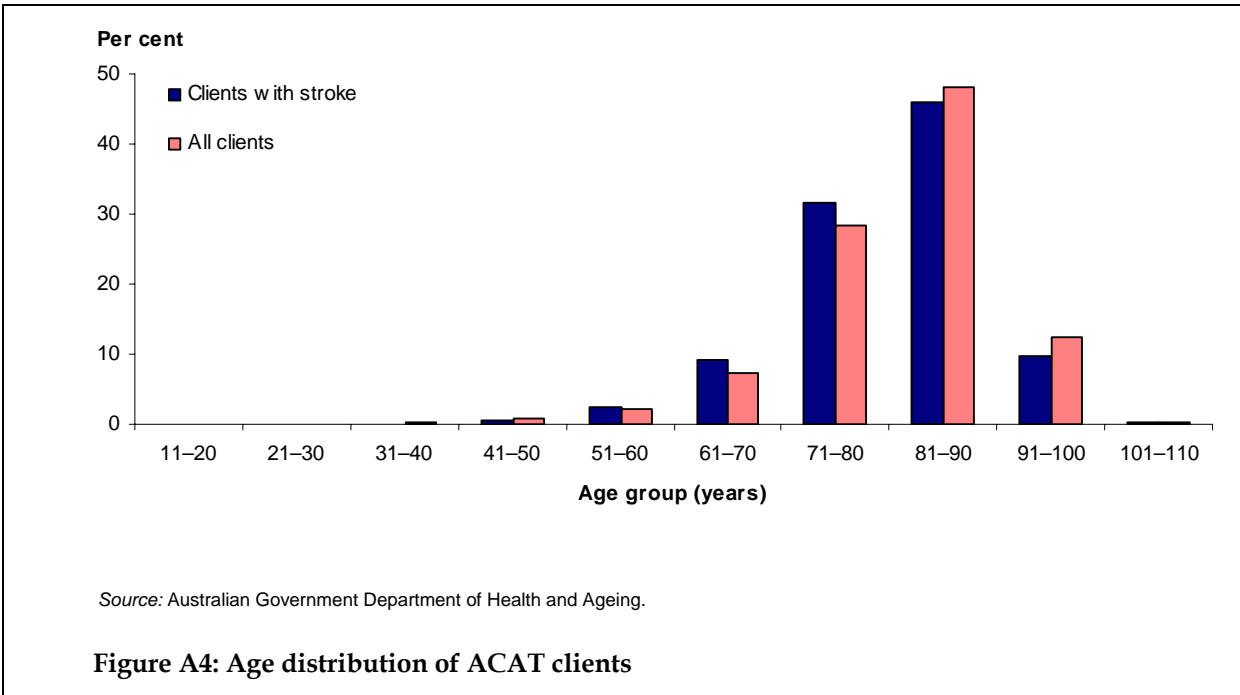
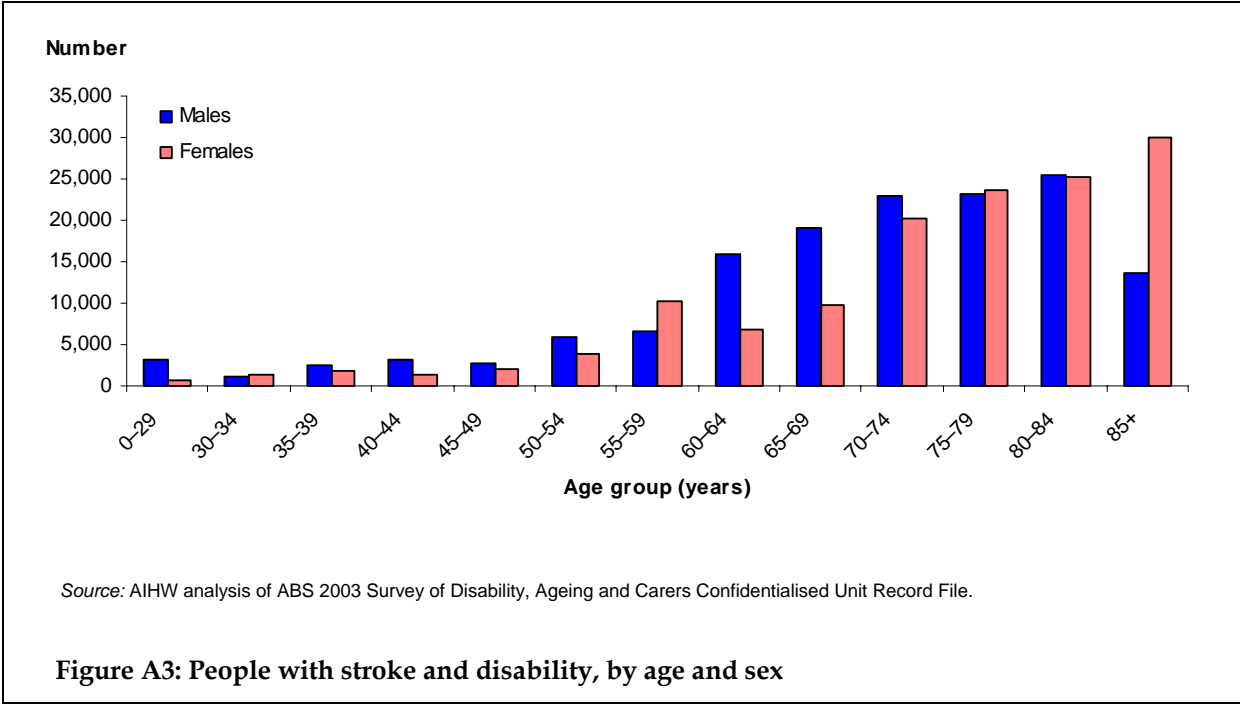
**National Stroke Services Hospital Survey**, conducted by the National Stroke Foundation to determine the number and characteristics of acute stroke services available in Australia. It collected self reported information from eligible acute public hospitals during 2004. A similar survey had been run in 1999 but it sampled both acute and subacute public and private hospitals.

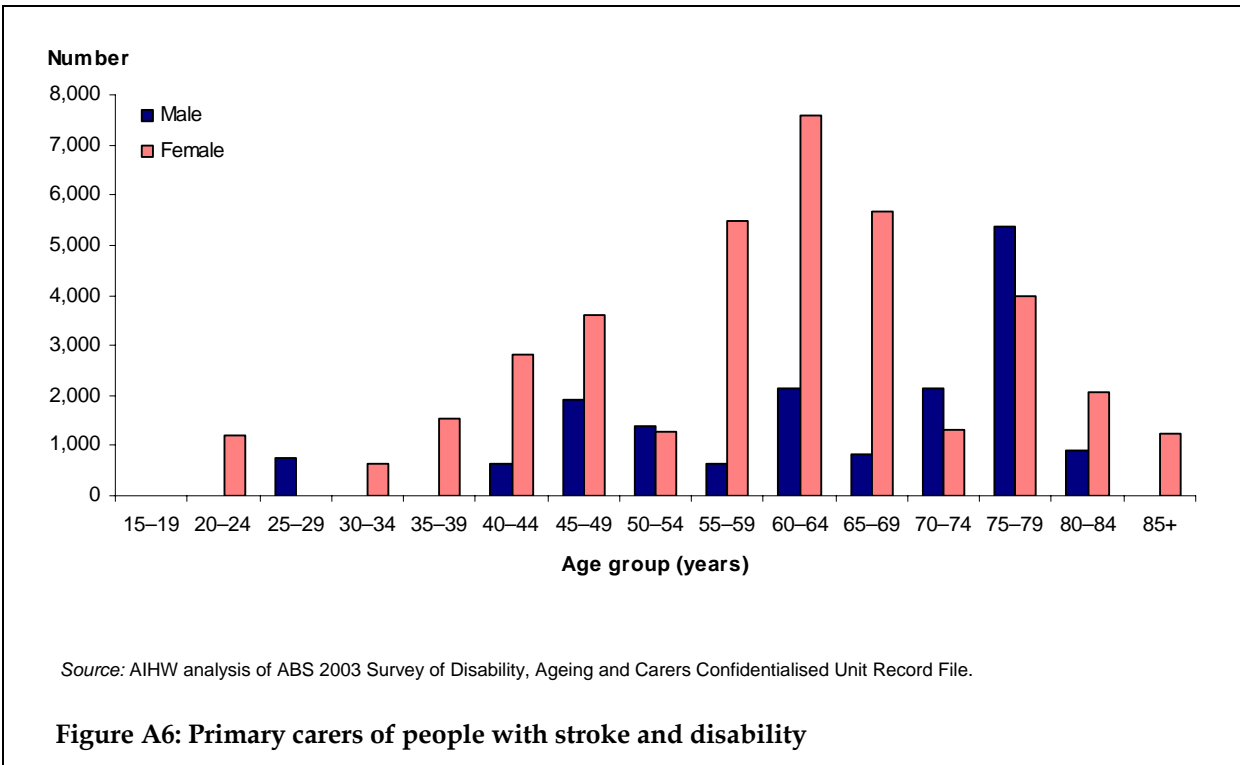
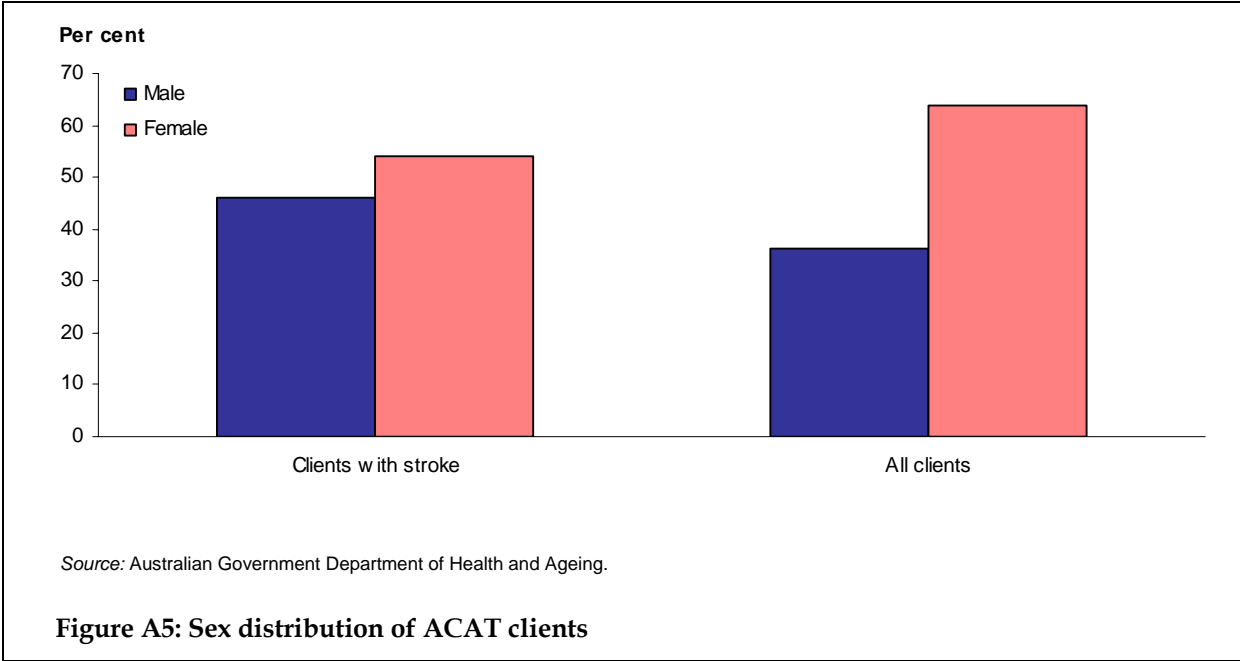
**NEMESIS (North East Melbourne Stroke Incidence Study)**, conducted in a defined area of northeast Melbourne between 1 May 1996 and 30 April 1997, the study ascertained stroke patients from multiple overlapping sources, including 14 major public and 28 private hospitals in the study region and surrounding areas, all nursing homes and hostels in the study region, all medical practitioners potentially able to refer patients to the study, and death records. During the study period a total of 381 strokes occurred in 353 patients from a total population of 133,816.

# Appendix figures









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