Informal carers

In addition to formal services, dementia places a substantial demand on support from informal carers. In 2009, about 9 in 10 (92%) people with dementia living in the community were receiving care from one or more carers.

In 2011, there were an estimated 200,000 carers of people with dementia living in the community.

Around 42% of primary carers of people with dementia were the spouse/partner of the care recipient and 44% were the son or daughter.

When only co-resident primary carers were considered, 57% were the spouse/partner and 36% were the son or daughter. Co-resident primary carers of people with dementia were almost twice as likely as all co-resident primary carers to provide 40 or more hours of care per week (81% versus 42%).

Figure 4: Relationship of primary carer to care recipient with dementia living in the community, by sex and age of co-resident primary carer, 2009

For more information

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Dementia in Australia

Dementia in Australia provides a comprehensive picture of this topic, presenting the latest data and information on trends.

The report covers a broad range of topics including prevalence estimates and projections, mortality, characteristics of people with dementia, and their use of aged care and community services. The report also features information on carers of people with dementia, and on health and aged care system expenditure on dementia.

What is dementia?

Dementia is not a single specific condition. Rather, it is an umbrella term describing a syndrome associated with more than 100 different conditions that are characterised by the impairment of brain functions, including language, memory, perception, personality and cognitive skills.

Despite the variations in the type and severity of symptoms and their pattern of development, dementia is usually of gradual onset, progressive in nature, and irreversible.

The course of dementia is often characterised as occurring in three stages: mild or early-stage dementia, moderate or middle-stage dementia and severe or late-stage dementia (described below).

The most common types of dementia are Alzheimer disease (which accounts for about 55% to 75% of dementia cases worldwide), and vascular dementia (about 20% to 30%).

Mild or early-stage dementia—deficits are evident in a number of areas such as memory and personal care but the person can still function with minimal assistance.

Moderate or middle-stage dementia—deficits become more obvious and severe, and increasing levels of assistance are required to help the person maintain their functioning in the home and community.

Severe or late-stage dementia—characterised by almost total dependence on care and supervision by others.

How many people in Australia have dementia?

An estimated 298,000 Australians had dementia in 2011. Of these, 62% were women, 74% were aged 75 and over, and 70% lived in the community. Dementia was classified as ‘mild’ in 163,900 people (55% of people with dementia), ‘moderate’ in 89,400 (30%) and ‘severe’ in 44,700 (15%).

Fast facts

- Of all Australians, 1 in 77 (1.3%) had dementia.
- Of all Australians aged 65 and over, 1 in 10 (10%) had dementia.
- Of all Australians aged 85 and over, 3 in 10 (30%) had dementia.
A leading cause of death and burden of disease

Causes of death can be grouped in many different ways and the method chosen will affect the ranking of particular causes of death. Using the approach of the Australian Bureau of Statistics, dementia was the third leading cause of death in 2010 (accounting for 6% of all deaths). This means that an average of 25 people died from dementia every day. Twice as many women as men died from dementia (6,083 and 2,920 respectively).

The number of deaths due to dementia more than doubled (2.4 times) between 2001 and 2010 (from 3,740 to 9,003 deaths). Some of this change is due to growth and ageing of the population, while some of the change may be due to changes in the way in which dementia is recorded on death certificates.

Estimates of burden of disease measure the amount of healthy life lost due to premature death and prolonged illness or disability. Estimates for 2011 suggest that dementia was the fourth leading cause of overall burden of disease, and the third leading cause of disability burden. For people aged 65 and over, dementia was the second leading cause of overall burden of disease and the leading cause of disability burden, accounting for a sixth of the total disability burden in older Australians. The burden of disease due to dementia is estimated to have grown by 30% between 2003 and 2011.

How will dementia affect us in the future?

Dementia poses a substantial challenge to health, aged care and social policy, and will continue to do so in the future. Based on projections of population ageing and growth, the number of people with dementia will reach almost 400,000 by 2020, and is projected to triple between 2011 and 2050, to reach around 900,000 by 2050.

Projections suggest that by 2020, dementia will be responsible for the loss of just over 166,000 years of healthy life, increasing from the estimated 121,737 in 2011.

Care needs and services provided

Many people with dementia rely on health and aged care services, and often require a high level of care and support.

In 2009, among those people with dementia who were living in the community, health care (84%), mobility (80%) and private transport (80%) were the three areas in which they were most likely to require assistance.

For those living in cared accommodation, 99% needed help with health care, 98% needed help with self-care, and 91% needed help with mobility. People with dementia living in cared accommodation were twice as likely (80%) as those in the community (39%) to need help with communication.

In 2009–10, 53% of permanent residents in Government-subsidised residential aged care facilities had a diagnosis of dementia. Residents with dementia were more likely than those without dementia to need high care (57% versus 63%), and to have higher care needs in relation to activities of daily living and behaviour, but not in relation to complex health care.

Fast facts

- It is estimated that 552,000 GP attendances in 2010–11 involved the management of dementia.
- In 2009–10, dementia was recorded as a diagnosis for 83,226 (1 in every 100) hospitalisations, and was the principal diagnosis for 12,286 (1 in every 1,000).
- The average length of stay for hospitalisations with a principal diagnosis of dementia in 2009–10 was 18 days, 6 times higher than the average for all hospitalisations.
- 392,796 Government-subsidised dementia-specific prescriptions were dispensed in 2009–10.
- Total direct health and aged care system expenditure on people with dementia was at least $4.9 billion in 2009–10, of which about $2.6 billion was directly attributable to dementia. Of this, $1.1 billion was for permanent residents in residential aged care facilities and $408.0 million was for community aged care services.
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