



Australian Government

Australian Institute of
Health and Welfare

Patterns of health service use by people with dementia in their last year of life

New South Wales and Victoria

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New South Wales and Victoria

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Summary

Dementia is a major health issue in Australia. In 2015, dementia was the fourth-leading cause of burden of disease and injury. For those aged 65 and over, it was the second-leading cause (AIHW 2019a). Furthermore, dementia was the second-leading cause of death overall in Australia in 2018 and the leading cause of death among Australian women (ABS 2019).

Dementia is irreversible and as the condition progresses, health and functional ability decline, leading to increasing care needs. Assessing how health services are used by people in their last year of life, and how this may differ for people with dementia, is important for policy development and health service planning and delivery to ensure all Australians receive appropriate care in their final years of life.

This study examined the use of health services by over 70,000 people in the 12 months before their death in 2013 using linked health administrative data. Both the type and quantity of health services were explored and differences between people with and without dementia were investigated. The health services examined included general practitioner (GP) and specialist services; admitted care in a hospital; and emergency department (ED) care, as well as dispensing of prescription medication. Use of aged care services could not be examined in the study.

Results from this study provide a greater understanding of health service use by people with dementia in their final year of life, but further studies are needed to gain a more comprehensive picture of people with dementia in Australia.

Data source and dementia identification

A key strength of this study is the use of linked administrative data in the National Data Linkage Demonstration Project (NDLDP). This database contains de-identified hospitalisation data from New South Wales and Victoria linked to data from the Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) between July 2010 and June 2015, as well as data from the National Death Index between July 2010 and December 2015. The reference year 2013 was selected as the year of death in this study due to issues with incomplete data in later years.

Analysing linked health administrative data is essential to assess health service utilisation in the last year of life and to identify people with dementia. The number of people identified is greatly increased using linked data as dementia is often under-recorded in administrative data, and not every person with dementia uses each health service in which dementia can be identified. In this study, a person with dementia was identified in the NDLDP database if dementia was recorded on their death certificate, as a diagnosis in any hospital admission between July 2010 and their death, or if they had 1 or more prescriptions for a dementia-specific medication between July 2010 and their death.

Of the people who died in 2013 aged 65 or over with dementia evident in the NDLDP database:

- 67% had dementia recorded on their death certificate
- 66% had dementia recorded in an episode of admitted patient care
- 20% had been prescribed a dementia-specific medication.

Only 36% of people with dementia had dementia recorded in a hospital admission and on their death certificate, and just 8% had dementia evident in all 3 data sources. This is in part because dementia-specific medication is currently subsidised under the PBS only for people diagnosed with Alzheimer's disease. However, these figures reflect the inconsistency in dementia diagnoses coding in health administrative data and the benefits of linking data sets for dementia identification.

Key findings

The study looked at 3 groups of people based on the presence of dementia in the linked data: people who died aged 65 or over with dementia evident; people who died aged 65 or over without dementia evident (referred to as 'people without dementia'); and people who died aged under 65 with dementia evident (younger-onset dementia).

With the exception of GP services, people with dementia who died aged 65 or over used health services less in their last year of life than people without dementia

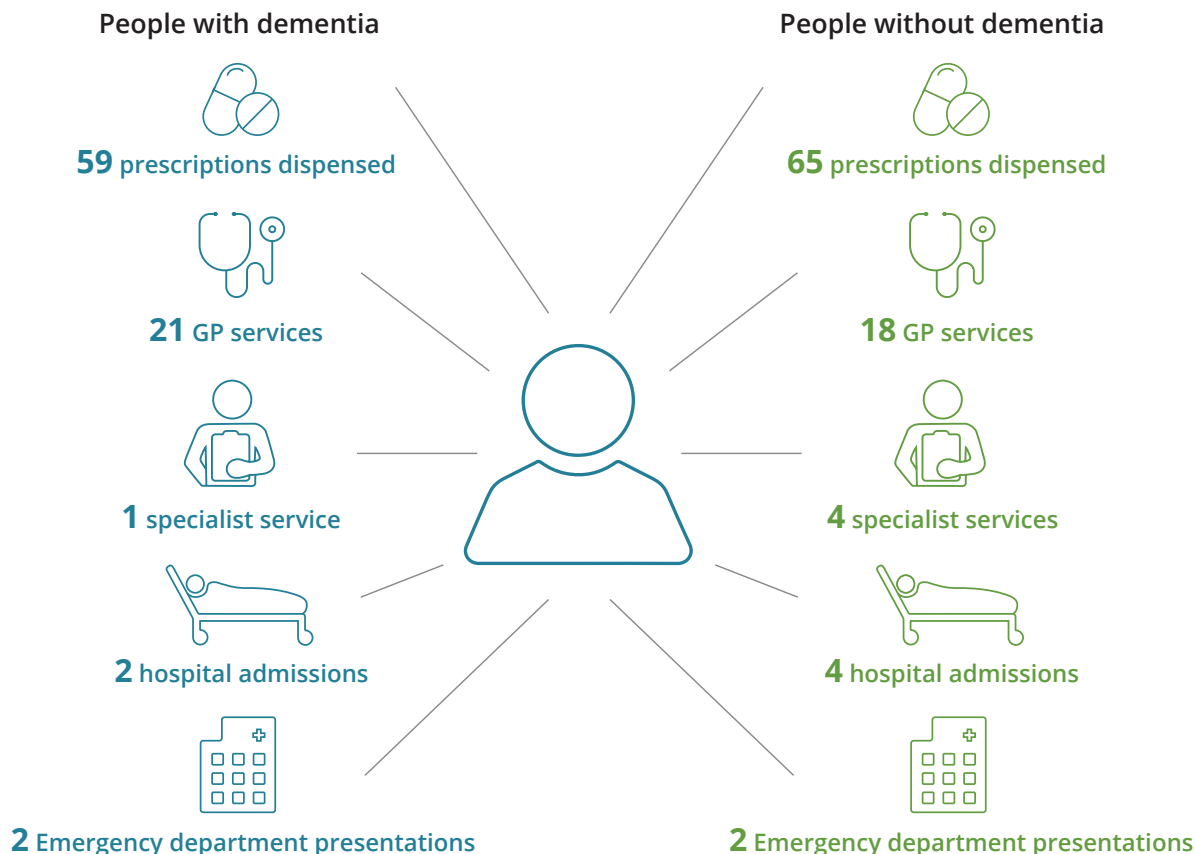
In the last year of life of people who died aged 65 or over:

- GP services were the most common health service type, used by 90% of people with and without dementia
- besides GP services, compared to people without dementia, a smaller percentage of people with dementia used a health service at least once; the greatest difference was seen in the use of specialist services
- women with dementia used health services the least
- it was not possible to directly identify people living in residential aged care facilities, but data from MBS items specific for services in residential aged care facilities suggests that 75% of people with dementia received at least 1 GP service in a residential aged care facility, compared with 30% of people without dementia
- regardless of whether they had dementia or not, the use of each health service decreased with increasing age at death.

Percentage of people who died aged 65 or over who used a health service at least once in their last year of life



Average number of health services used in the last year of life by a person who died aged 65 or over



Regardless of whether they had dementia or not, men used health services more frequently than women. Antipsychotic drugs were dispensed more frequently to people with dementia: 4.7% of all prescriptions dispensed to people with dementia compared with 0.8% dispensed to people without dementia.

Hospital services were used less frequently in the final month of life by people with dementia who died aged 65 or over

- 44% of men and 34% of women with dementia were admitted to hospital at least once in their last month of life. These proportions were lower than for men (58%) and women (52%) without dementia in their final month of life.
- 44% of men and 35% of women with dementia presented to the ED in their final month of life compared with 51% of men and 46% of women without dementia.

People who died with younger-onset dementia used health services in their last year of life more than people with dementia who died aged 65 or over

- The greatest difference was seen in the use of specialist services—51% of people with younger-onset dementia used a specialist service in their last year of life compared with 33% of people with dementia who died aged 65 or over.
- On average, a person with younger-onset dementia had an additional 2 hospital admissions, 1 ED presentation, 1 GP service and 1 specialist service in their last year of life compared with people with dementia who died aged 65 or over. However, they were dispensed 5 fewer prescriptions than people with dementia who died aged 65 or over.

1 Introduction

Dementia is a major health issue in Australia. In 2015, dementia was the fourth-leading cause of burden of disease and injury in Australia overall and the second-leading cause in Australians aged 65 and over (AIHW 2019a). Dementia was the second-leading cause of death in Australia in 2018, accounting for 13,963 deaths (ABS 2019).

Dementia is irreversible and as the condition progresses, health and functional ability decline leading to increasing care needs (refer to Box 1.1 for more information on dementia). The precise number of Australians with dementia is unknown, but prevalence estimates in 2020 range from 400,000 (AIHW 2018) to 459,000 people (Dementia Australia 2020a). As the number of Australians with dementia is projected to more than double between 2020 and 2050, without a significant breakthrough in dementia prevention or treatment, dementia will have an increasing impact on Australia's health and aged care systems (AIHW 2018; Dementia Australia 2018). As they are high users of health care, understanding patterns of health service use by people with dementia—particularly when care needs are greatest—is needed for population health monitoring, policy development and service planning.

This report focuses on health service use in the last year of life by people with dementia using linked administrative data, hereafter referred to as the NDLDP database—National Data Linkage Demonstration Project. The NDLDP database, created under the auspices of the Australian Health Ministers' Advisory Council, includes hospitalisation data from New South Wales and Victoria linked with data from the Medicare Benefits Schedule (MBS), Pharmaceuticals Benefits Scheme (PBS) and National Death Index (NDI). The study included over 70,000 people in New South Wales and Victoria who died in 2013. Of these, 19,222 people who died aged 65 or over and 248 people who died aged under 65 were identified as having dementia using the NDLDP database. Use of aged care services could not be examined in the study.

As no single robust data source exists to derive the prevalence of dementia in Australia, linking existing data sets that contain diagnostic information is important to obtain a more comprehensive picture. Linking data is common practice internationally to obtain epidemiological data for dementia. Furthermore, as administrative data collections centre on service provision, data linkage is needed not only to identify people in the data (rather than services provided) but to understand the use of multiple services over time, or, as in this study, health service use in the last 12 months of life.

Box 1.1: What is dementia?

Dementia is a collection of symptoms—usually progressive in nature—caused by a range of disorders affecting the brain (WHO 2019). The prevalence of dementia increases with age, occurring mainly among those aged 65 or over, and often co-exists with other age-related conditions. It is important to note that dementia is not part of the normal ageing process. Dementia can also occur in people aged under 65, known as 'younger-onset dementia'.

There are many different types of dementia and some are more common than others. The most common types include:

- Alzheimer's disease—a degenerative brain disease caused by nerve cell death resulting in shrinkage of the brain
- vascular dementia—caused mainly by haemodynamic (blood flow to the brain) disorders (for example, strokes), thromboembolism (small blood clots that block small blood vessels in the brain), small blood vessel disease in the brain and bleeding into or around the brain

(Continued)

- dementia with Lewy bodies—caused by the degeneration and death of nerve cells in the brain due to the presence of abnormal spherical structures, called Lewy bodies, which develop inside nerve cells
- frontotemporal dementia—caused by progressive damage to the frontal and/or temporal lobes of the brain (Dementia Australia 2020b; Draper 2013).

An increased risk of developing dementia is also linked to the presence of other conditions (such as Parkinson’s disease, Huntington’s disease and Down syndrome) as well as prolonged substance abuse. It is possible to have multiple types of dementia at once—known as ‘mixed dementia’—the most common combination being Alzheimer’s disease and vascular dementia.

How does dementia affect health service use?

Health service usage by people with dementia is influenced by the progression of their dementia, presence of co-morbid conditions, and their environment (for example, care arrangements and access to health services). People with dementia will experience it differently. Although there is no single universal dementia progression classification system, dementia progression is commonly grouped into 3 stages:

- **Early (or mild) dementia:** the gradual onset of symptoms, which may include confusion, forgetfulness, irritability, appearing more apathetic, poor judgment and decision-making, disinterest in activities, vision or speech problems and behavioural changes, and a decline in higher order or more complex activities of daily living such as understanding finances, planning, organisation. Mild dementia is also defined by cognitive impairment and poor performance on objective cognitive assessments that represents a decline from the past. However, as opposed to more severe forms of dementia, the person retains independence in basic activities of daily living. As signs are subtle, dementia may not be recognised or may be attributed to old age.
- **Moderate dementia:** where symptoms are more distinct and affect instrumental activities of daily living, such as driving and preparing meals. Symptoms may include increased forgetfulness and confusion, inappropriate or uncharacteristic behaviours, and increased fear and paranoia. These experiences often cause distress in the person with dementia.
- **Advanced dementia:** the final stage, in which health and functional ability decline and the person becomes dependent on others for basic activities of daily living (for example, dressing, bathing and toileting). The person may experience severe memory loss, problems with communication, difficulty swallowing, incontinence, decreased mobility or complete immobility in the final months or weeks of life. Most people in advanced stages require extensive care, often by permanent residential care services.

As dementia progresses, individuals have increasing care needs, particularly in their last year of life. Disease progression varies, but on average a person with Alzheimer’s disease is expected to live 8–10 years from diagnosis, an average of 5 years for vascular dementia and 6–12 years for dementia with Lewy bodies (Musicco et al. 2009).

People with dementia often have additional health conditions that may further increase or complicate service needs. In 2016–17, people hospitalised with dementia had an average of 8 health conditions recorded, with Type 2 diabetes the most common co-morbid condition (AIHW 2019b). Furthermore, an international study by Browne and others (2017) found that people with dementia

who had 6 or more co-morbid conditions had significantly greater usage of GP and specialist services, hospital admissions and prescription medication.

Few studies have examined health service usage in Australians with dementia in their last year of life. A recent study based on a cohort of older Australian women found health service utilisation increased in the final months and that dementia as a comorbid condition affected health and aged care service use. Women with dementia used GP services more and specialist services less in the 24 months prior to death compared with women who were still alive, with or without dementia. The study also found women with dementia had a higher probability of having cardiovascular disease, stroke and chronic lung disease (Dobson et al. forthcoming 2020).

Study aims

This study aims to examine health service usage in the last year of life of people with dementia as identified using the NDLDP database. Specifically, the study aims to:

- compare health service usage in the last year of life of people with dementia who died aged 65 or over with people who also died aged 65 or over but who were not identified as having dementia (hereafter referred to as 'people without dementia')
- compare health service usage in the last year of life of people with dementia who died aged 65 or over with people with younger-onset dementia (those aged under 65 when they died).

Health services include hospital admissions, emergency department (ED) presentations, general practitioner (GP) services, specialist services and dispensing of prescriptions.

Report structure

This chapter provides background on dementia in Australia, an overview of the study, and the study aims.

- Chapter 2 details the linked database used in the study, study population definitions and methods used to examine health care service use.
- Chapter 3 presents information on the characteristics of people with dementia who died aged 65 or over examined in the study, and their comparison group.
- Chapter 4 compares overall patterns of health service use in the last year of life of people with dementia who died aged 65 or over examined in the study, and their comparison group.
- Chapter 5 presents detailed information on the use of GP and specialist services in the last year of life by people with dementia who died aged 65 or over examined in the study, and their comparison group.
- Chapter 6 presents detailed information on prescriptions dispensed in the last year of life to people with dementia who died aged 65 or over examined in the study, and their comparison group.
- Chapter 7 presents detailed information on the use of hospital services in the last year of life by people with dementia who died aged 65 or over examined in the study, and their comparison group.
- Chapter 8 summarises the younger-onset dementia study group and their health service use in their last year of life, compared with service use by people with dementia who died aged 65 or over.
- Chapter 9 summarises key findings and discusses strengths, data gaps and future directions.

2 Methods

This chapter provides an overview of the linked database used in the study, criteria used to define the study groups, and the summary measures that defined health service use.

Further detail on the individual data sets included in the linked database and detailed methods can be found in Appendix A.

Data source

The NDLDP database was created under the auspices of the Australian Health Ministers' Advisory Council National Health Information and Performance Principal Committee.

The NDLDP database comprises linked data from Victoria and New South Wales, including public admissions from the National Hospital Morbidity Database and National Non-Admitted Patient Emergency Department Care Database (private hospital data not included) linked to national data from the Pharmaceutical Benefits Scheme database (excluding under co-payment data), Medicare Benefits Schedule database and the National Death Index. The database contains hospital, MBS and PBS data from July 2010 to June 2015, and NDI data from July 2010 to December 2015. Aged care service data was not included in the NDLDP database.

Refer to Appendix A for more information on the individual data sets in the NDLDP database.

Study population

This study is a retrospective examination of health service usage by people who died in 2013. While the NDLDP database contained data for all data sets from July 2010 to June 2015, data was incomplete for some of the individual data sets in later years. Therefore, the year 2013 was selected. All people in this study resided in New South Wales or Victoria at the time of their death.

The study compares people who had dementia with people who did not, based on identification (or lack thereof) of a dementia diagnosis evident in the NDLDP database. The study also examined health service usage by people with younger-onset dementia. As a result, 3 groups are examined in the study:

1 People with dementia, who died aged 65 or over

This study focused on 19,222 people with dementia who died in 2013 aged 65 or over. A person with dementia was identified in the NDLDP database if dementia was evident as:

- an underlying or associated cause of death
- a principal or additional diagnosis in any hospital admission between July 2010 and their death
- they had 1 or more prescriptions for a dementia-specific medication between July 2010 and their death.

Diagnostic codes are based on the International Classification of Diseases, 10th Revision (ICD-10) in mortality data and the ICD 10th Revision, Australian Modification (ICD-10-AM) in hospitals data. PBS drugs are classified according to the Anatomical Therapeutic Chemical (ATC) Classification 2015. All types of dementia were included in this study and the codes used to define dementia by type in each data set are outlined in Table A3.

As dementia is thought to be under-recorded in administrative health data, the number of people with dementia is likely to be underestimated in this study. Furthermore, the NDLDP database does not include aged care data, which if included could have improved dementia identification. In addition, the influence of care settings on health service usage could have been examined with the inclusion of aged care data (see Chapter 9 for further detail on data gaps and future directions).

People with dementia were included in this group if they were aged 65 or over when they died. As it was not possible to identify the age of dementia onset in the NDLDP database, it is acknowledged that a proportion of people in this group may have had younger-onset dementia and died aged 65 or over.

2 People with younger-onset dementia (died aged under 65)

This study included 248 people with dementia who died in 2013 aged under 65. As with people with dementia who died aged 65 or over, people with younger-onset dementia were identified in the NDLDP database if dementia was evident as:

- an underlying or associated cause of death
- a principal or additional diagnosis in any hospital admission between July 2010 and their death
- they had 1 or more prescriptions for a dementia-specific medication between July 2010 and their death.

People with dementia were included in this study group if they were aged under 65 at their time of death. Health service usage for this group was compared with health service usage by people with dementia who died aged 65 or over. This comparison was made due to statistical issues that arise in making comparisons with people who died aged under 65 without identified dementia using the NDLDP database. Age-specific estimates were not calculated due to the small number of people identified with younger-onset dementia in this study, posing confidentiality issues.

3 People without dementia, who died aged 65 or over

In 2013, 50,928 people who were not identified as having dementia using the NDLDP database died aged 65 or over. This group was used as a comparison group for the cohort of people with dementia who died aged 65 or over. People were included in this group if dementia was **not** evident as:

- an underlying or associated cause of death
- a principal or additional diagnosis in any hospital admission between July 2010 and their death
- they did not have a prescription for a dementia-specific medication between July 2010 and their death.

It is important to note that as dementia is thought to be under-recorded in health administrative data, this group may include people with dementia for whom dementia had not been recorded in administrative data associated with their health service use in the NDLDP database in the time that was available prior to their death. People who did not have dementia recorded on their death certificate, and were not prescribed dementia-specific medications and did not have a hospital admission between July 2010 and their death (or did not have dementia recorded in a hospital admission in the same period) would be included in this group.

How was health service use measured?

Health service usage from day of death to 365 days before death was examined for each individual. Health services in this report include use of GP and specialist services, hospital services (hospital admissions and ED presentations) and dispensing of prescriptions.

Summary measures of the use of these health services are reported by sex, age at death and month before death for selected measures. The measures include:

- total number of services provided and prescriptions dispensed
- proportion of people in each group who used a health service at least once
- average number of health services used per person
- total number of specialist services by specialist type
- leading types of prescription medications dispensed
- average length of stay for hospital admissions
- leading principal and additional diagnoses for hospital admissions
- number and type of procedures or interventions during a hospital admission.

Information on co-morbid conditions was available from hospital admissions and deaths data only. Specialist consultations by type of specialist and the type of prescription medication dispensed were also obtained. This information may provide some detail on co-morbid conditions but does not provide a comprehensive picture.

3 Profile of study populations

This chapter describes the age at death and sex profile of people included in the study who died aged 65 or over, their cause of death and the dementia types identified in administrative records for the group of people with dementia.

See Chapter 8 for a profile of people with younger-onset dementia who died in 2013 (dementia in people who died aged under 65).

Age and sex characteristics

Over 70,000 people aged 65 or over in New South Wales and Victoria died in 2013. Of these, 19,222 people (27%) were identified as having dementia and 50,928 (73%) had no record of dementia in the NDLDP database (referred to as 'without dementia').

There were more women with dementia (60% of all people with dementia) than men (40%). By comparison, similar numbers of men and women did not have dementia (Table 3.1).

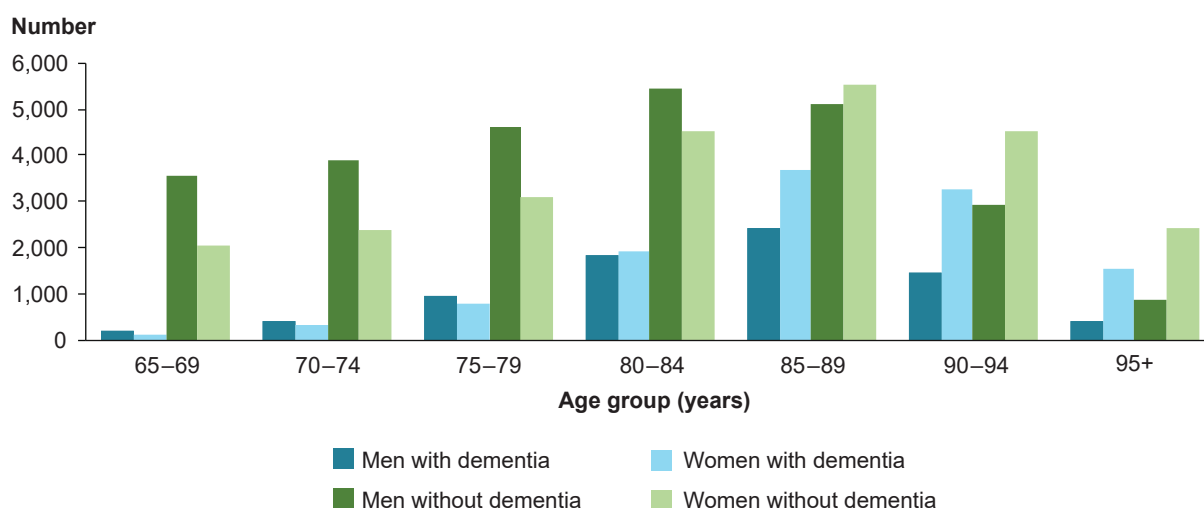
Table 3.1: Study population aged 65 or over at age of death, by dementia status and sex

	With dementia		Without dementia	
	Number	Per cent (%)	Number	Per cent (%)
Men	7,620	39.6	26,397	51.8
Women	11,602	60.4	24,531	48.2
Persons	19,222	100.0	50,928	100.0

Of the people who died aged 65–69 in 2013, 2,174 or 37% were women (Figure 3.1). As age at death increased, so did the proportion of women, reflecting a greater number of women living to older ages. Around 61% of people who died aged 85 or over were women.

As age is the biggest risk factor for dementia, the number of people who died with dementia increased with increasing age at death. Dementia was identified in 5% of people who died in 2013 aged 65–69 but this increased to 37% of people who died aged 85 or over. As more women live to older ages, the number of women who died with dementia was greater than the number of men who died with dementia from age 80 onwards.

Figure 3.1: Study population aged 65 or over at death, by sex, dementia status and age at death



What was their cause of death?

In Australia, cause of death is recorded on a person's death certificate and since 1997, causes of death are classified using the ICD-10. The underlying cause of death is the single disease or condition that initiated the sequence of events resulting in death. Most deaths will also have associated causes of death recorded, which are other diseases or conditions that contributed to the death but were not the underlying cause. Refer to Appendix A for more information on the National Death Index.

On average, 4 causes of death were recorded for people with dementia who died aged 65 or over in 2013. By comparison, 3 causes of death were recorded for the corresponding group without dementia. Dementia was recorded as the underlying cause of death in 45% of people with dementia, as an associated cause of death in 52%, and as both an underlying and associated cause of death in 2.6% of those with dementia.

Underlying cause of death

Unspecified dementia and *Alzheimer's disease, unspecified* were the leading underlying causes of death among men and women with dementia (Table 3.2). *Parkinson's disease* and *Vascular dementia, unspecified* were the sixth- and eighth-leading causes of death among men with dementia. In women with dementia they were the seventh- and sixth-leading causes of death, respectively.

Malignant neoplasms of bronchus or lung, unspecified and *Acute myocardial infarction* were leading causes of death among men without dementia (7.8% and 6.4% of deaths, respectively). *Acute myocardial infarction* and *Chronic ischaemic heart disease, unspecified* were leading causes among women without dementia (6.5% and 5.6%, respectively).

Cardiovascular conditions were more highly ranked in the underlying causes of death in men and women with dementia than in those without dementia, reflecting one of the main risk factors for dementia. In contrast, various cancer types were more frequent underlying causes of death among men and women without dementia than among those with dementia.

Table 3.2: Leading underlying cause of death in study population who died aged 65 or over, by dementia status and sex

Rank	Underlying cause of death in people with dementia	Per cent	Underlying cause of death in people without dementia	Per cent
<i>Males</i>				
1	Unspecified dementia	15.5	Malignant neoplasms of bronchus or lung, unspecified	7.8
2	Alzheimer's disease, unspecified	7.1	Acute myocardial infarction, unspecified	6.4
3	Chronic ischaemic heart disease, unspecified	5.8	Chronic ischaemic heart disease, unspecified	6.0
4	Acute myocardial infarction, unspecified	5.6	Malignant neoplasm of prostate	5.6
5	Stroke, not specified as haemorrhage or infarction	4.3	Chronic obstructive pulmonary disease, unspecified	3.1
6	Parkinson's disease	4.1	Malignant neoplasm of pancreas, unspecified	2.1
7	Malignant neoplasm of prostate	2.9	Stroke not specified as haemorrhage or infarction	2.1
8	Vascular dementia - unspecified	2.7	Atherosclerotic heart disease	1.7
9	Chronic obstructive pulmonary disease, unspecified	1.8	Chronic obstructive pulmonary disease with acute lower respiratory infection	1.5
10	Malignant neoplasm of bronchus or lung, unspecified	1.5	Malignant melanoma of skin, unspecified	1.5

Rank	Underlying cause of death in people with dementia	Per cent	Underlying cause of death in people without dementia	Per cent
<i>Females</i>				
1	Unspecified dementia	21.7	Acute myocardial infarction, unspecified	6.5
2	Alzheimer's disease, unspecified	11.0	Chronic ischaemic heart disease, unspecified	5.6
3	Stroke, not specified as haemorrhage or infarction	6.0	Malignant neoplasms of bronchus or lung, unspecified	5.3
4	Acute myocardial infarction, unspecified	5.6	Stroke not specified as haemorrhage or infarction	4.0
5	Chronic ischaemic heart disease, unspecified	4.7	Malignant neoplasm of breast, unspecified	3.7
6	Vascular dementia - unspecified	2.8	Chronic obstructive pulmonary disease, unspecified	2.9
7	Parkinson's disease	1.7	Malignant neoplasm of pancreas, unspecified	2.2
8	Atrial fibrillation and flutter, unspecified	1.6	Atrial fibrillation and flutter, unspecified	2.0
9	Sepsis, unspecified	1.5	Congestive heart failure	1.9
10	Sequelae of other and unspecified cerebrovascular disease	1.2	Pneumonia, unspecified	1.6

Associated causes of death

Unspecified dementia was also the leading associated cause of death in men and women with dementia who died aged 65 and over (14% of deaths in men and 16% of deaths in women) (Table B1). *Personal history of tobacco use disorder* and *Primary hypertension* were the leading associated causes of death in men and women without dementia, respectively.

A range of cardiovascular conditions, Type 2 diabetes mellitus (with and without complications) and *Acute kidney failure, unspecified* were leading associated causes of death in all people who died aged 65 and over. Sequelae related to advanced dementia (such as *Dysphagia*, *Unspecified urinary incontinence* and *Faecal incontinence*) were leading associated causes in people with dementia, whereas secondary cancers were leading associated causes in people without dementia.

What were the most common dementia types?

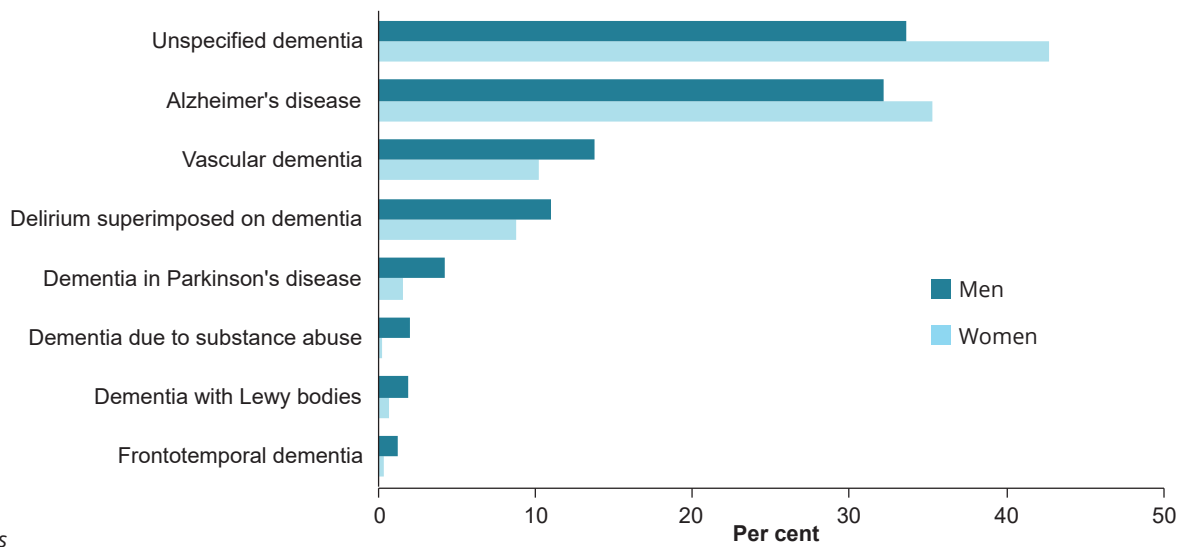
As dementia may not always be recorded on the death certificate for someone with dementia, the number of people with dementia and their diagnosed dementia type/s were also identified from dementia diagnoses recorded in hospital admissions and the dispensing of dementia-specific medications (medications are currently subsidised under the PBS only for people diagnosed with Alzheimer's disease).

When looking at the types of dementia recorded collectively across data sources, *Unspecified dementia* was the most common type recorded in records for people who died aged 65 or over, evident in 34% of men and 43% of women who had a dementia record (Figure 3.2). This was closely followed by *Alzheimer's disease* (32% of records for men and 35% of records for women with dementia evident in the linked data).

With the exception of *Unspecified dementia* and *Alzheimer's disease*, all other dementia types were recorded more frequently in men than in women. This was most notable for *Dementia in Parkinson's disease* and *Dementia due to psychoactive substance use*.

Due to complexities in diagnosing dementia and the possibility of a person having 'mixed dementia', multiple types of dementia may be recorded in a single administrative record as well as across records. Therefore, the number of dementia types will exceed the number of people with dementia and the percentage of dementia types will sum to more than 100%.

Figure 3.2: Dementia types across health service records for people with dementia who died aged 65 or over: proportion of records by type of dementia recorded and sex



Notes

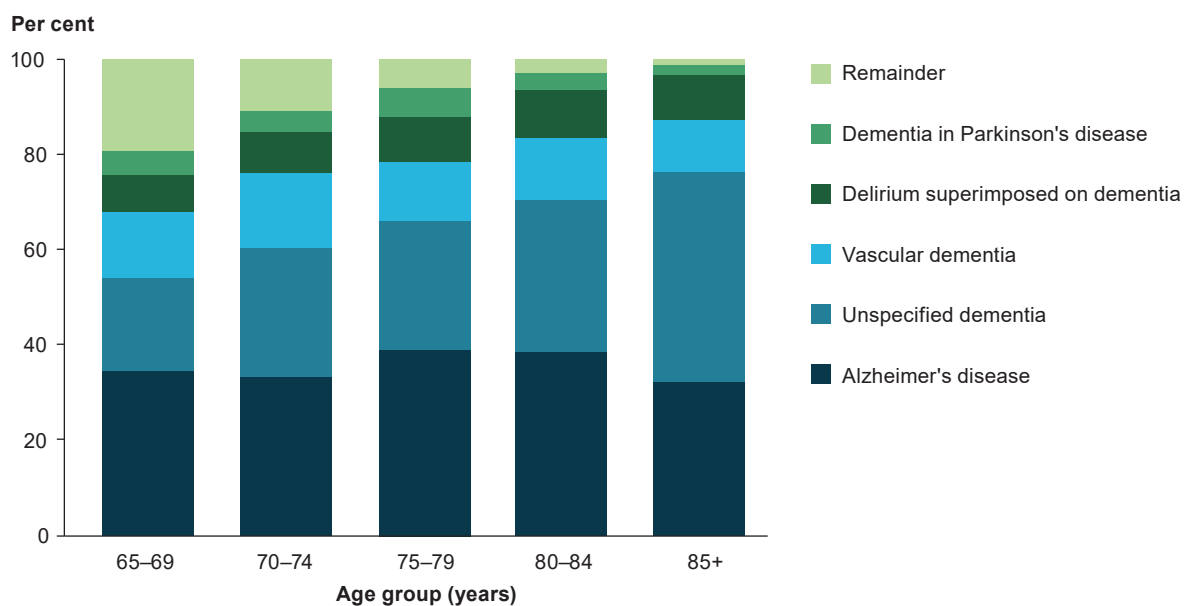
1. The percentage of records with *Dementia in Creutzfeldt-Jakob disease*, *Dementia in Huntington's disease*, *Dementia in Human Immuno-deficiency Virus* and *Dementia in other diseases (remainder)* are not shown due to the small number of cases.
2. As the same person may have multiple dementia types recorded, the percentage of dementia types will sum to greater than 100%.

How did dementia types differ by age at death?

Alzheimer's disease was the most common type of dementia identified in records in each age group except for records for people who died aged 85 or over (Figure 3.3). The number of records with a diagnosis of *Unspecified dementia* increased with increasing age at death. *Unspecified dementia* accounted for 19% of dementia types in records for people who died aged 65–69, increasing to 44% in people who died aged 85 or over.

Records containing a diagnosis for dementia types grouped in 'Remainder' (including *Dementia with Lewy bodies*, *Frontotemporal dementia* and *Dementia in other diseases*) were mostly recorded in people with dementia who died aged 65–69. The number of people with these dementia types as a diagnosis decreased with increasing age at death.

Figure 3.3: Dementia type by age at death for people with dementia aged 65 or over



Note: Remainder includes: *Frontotemporal dementia*, *Dementia in Lewy bodies*, *Dementia in Creutzfeldt-Jakob disease*, *Dementia in Huntington's disease*, *Dementia in Human Immuno-deficiency Virus* and *Dementia in other diseases (remainder)*.

4 Overview of health service usage

This chapter provides an overview of health service usage in the last year of life by people with dementia who died aged 65 or over and how this compares with usage in people who died aged 65 and over without dementia identified in the NDLDP database (referred to as ‘people without dementia’). Health services include hospital admissions (hospitalisations), ED presentations, GP services, specialist services and dispensing of prescriptions.

As aged care data were not included in the NDLDP database, it was not possible to identify people living in residential aged care facilities in this study. Place of residency (such as a residential aged care facility or residing in the community) could help explain observed differences in health-care usage between people with and without dementia and is an important area for future research.

Detailed information on the use of GP and specialist services can be found in Chapter 5, prescriptions dispensed in Chapter 6 and the use of hospital services in Chapter 7. A summary of health service usage in the last year of life by people with younger-onset dementia, compared with people with dementia who died aged 65 or over, is in Chapter 8.

4.1 Health service usage in the last year of life

Almost every person in New South Wales and Victoria who died aged 65 and over in 2013 used at least 1 health service in their last year of life (Table 4.1).

GP services were used by the greatest proportion of people—90% of people with and without dementia who died in 2013. On average, a person with dementia had 21 GP consultations in their last year of life compared with 18 consultations for a person without dementia.

For all other health services, the proportion of people who used the service at least once, and the average number of services used per person was lower for people with dementia than it was for people without dementia. The greatest difference was seen in the use of specialist services—33% of people with dementia used a specialist service with an average of 1.1 specialist consultations, compared with 64% of people without dementia with an average of 4.1 specialist consultations. The proportion of people who were dispensed a prescription at least once and the average number of prescriptions dispensed per person was only slightly less (86% and 59 prescriptions) in people with dementia than in people without dementia (88% and 65 prescriptions).

Table 4.1: Percentage of people using a health service at least once in their last year of life and average number of services used per person, by dementia status

Health service	Per cent (%) of people using a health service at least once		Average number of health services, per person ^(a)	
	With dementia	Without dementia	With dementia	Without dementia
GP services	89.6	89.7	21.2	17.5
Specialist services	32.6	63.9	1.1	4.1
Prescriptions dispensed	85.7	87.8	59.2	65.4
Hospitalisations	65.7	78.3	2.2	3.9
ED presentations	67.9	76.6	1.7	2.1
Any health service	98.4	99.1

(a) Average number of health services per person includes people who did not use a health service in their last year of life.

How did health service use vary by month over the last year of life?

The use of health services by people with dementia varied in each month of the last 12 months of life, reflecting needs for particular services at different end of life stages (Figure 4.1). Variations in health service usage by age and sex for each type of health service are discussed in their relevant chapters (Chapters 5, 6 and 7).

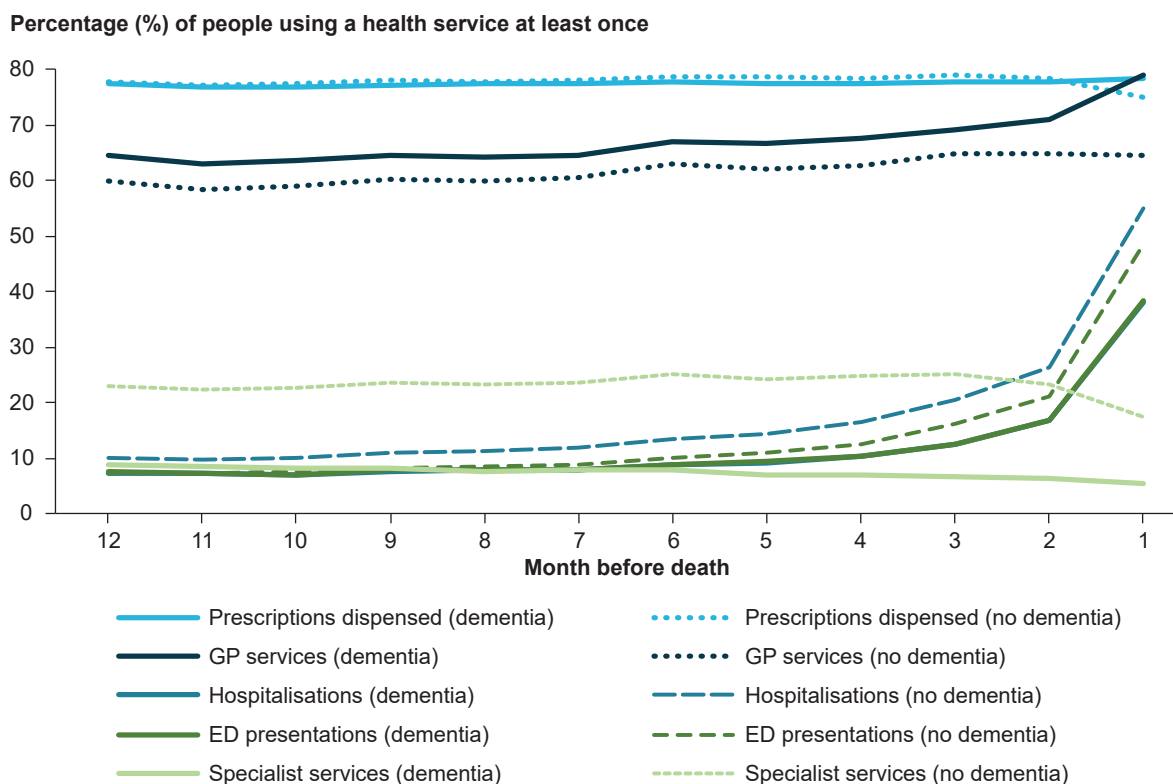
The percentage of people in each month who were dispensed a prescription remained fairly stable over the last year of life, irrespective of dementia status. In each month, a prescription was dispensed to over 75% of people with and without dementia. It is important to note that differences or changes to the types of medication dispensed are an important element of health service usage that is not covered here. Differences in the types of medications dispensed is examined in Chapter 6.

The percentage of people who used a GP service 12 months prior to death was greater in people with dementia (64%) than people without dementia (60%). This increased, notably in the last month of life, to 79% of people with dementia, and more gradually to 65% of people without dementia in the final month of life.

The percentage of people with dementia who used a hospital service (either admitted to hospital or who presented to the ED) increased in the last 6 months of life, particularly in the last month of life. Around 38% of people with dementia used a hospital service in their last month of life, compared with 17% in the second-last month. A greater proportion of people without dementia used hospital services, particularly in the last 6 months of life, than those with dementia.

The percentage of people in each month using a specialist service was consistently less for people with dementia than for people without dementia. Around 8.7% of people with dementia used a specialist service 12 months before death compared with 23% of people without dementia. This decreased to 5.5% of people with dementia and 17% of people without dementia in their last month of life.

Figure 4.1: Percentage of people in each month who used a health service at least once, by dementia status and month before death



Note: The line for 'Hospitalisations' by people with dementia is shown behind the 'ED presentations (dementia)' line, as the percentage of people with dementia who were hospitalised in their last 12 months of life was similar to the percentage of people with dementia who presented to the emergency department in their last 12 months of life.

5 General practitioner and specialist services

This chapter provides detailed information on the use of GP and specialist services in the last year of life by people with dementia who died aged 65 or over, compared with people who died aged 65 or over but were not identified as having dementia using the NDLDP database (referred to as 'people without dementia').

See Chapter 8 for a description of GP and specialist service use by people with younger-onset dementia and how this compares with people with dementia who died aged 65 or over.

5.1 General practitioner services

GP services were used by the greatest percentage of people and were the most frequently used health service in the last year of life by both people with dementia and those without dementia (Table 5.1).

Overall, 408,302 GP services were used in the last year of life by 90% of people with dementia who died aged 65 and over. The percentage who used a GP service at least once was slightly greater in women (91%) than men (88%).

On average, a person with dementia used 21 GP services in their last year of life compared with 18 GP services for a person without dementia. There was little difference in the average number of GP services used between men and women with dementia.

Table 5.1: Use of GP services by people in their last year of life who died aged 65 or over, by dementia status and sex

	With dementia			Without dementia		
	Men	Women	Persons	Men	Women	Persons
<i>People who used a GP service at least once</i>						
Number of people	6,704	10,514	17,218	23,689	21,984	45,673
Percentage of total study population	88.0	90.6	89.6	89.7	89.6	89.7
<i>GP services used</i>						
Average number per person ^(a)	21.2	21.3	21.2	16.9	18.1	17.5
Total number	161,643	246,659	408,302	447,400	444,904	892,304

(a) Average number of GP services used per person includes people who did not use a GP service in their last year of life.

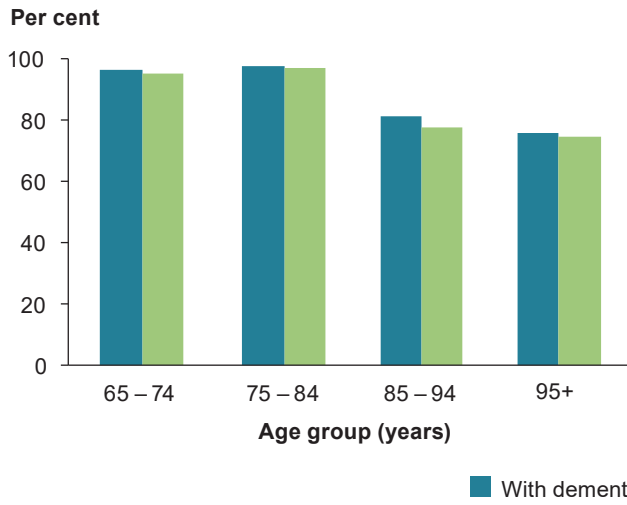
How did GP service use vary by age at death?

The use of GP services in the last year of life decreased with increasing age at death, irrespective of dementia status. Around 96% of men with dementia and 95% of men without dementia who died aged 64–74 used at least 1 GP service in their last year of life, decreasing to 76% of men with dementia and 75% of men without dementia who died aged 95 and over (Figure 5.1a).

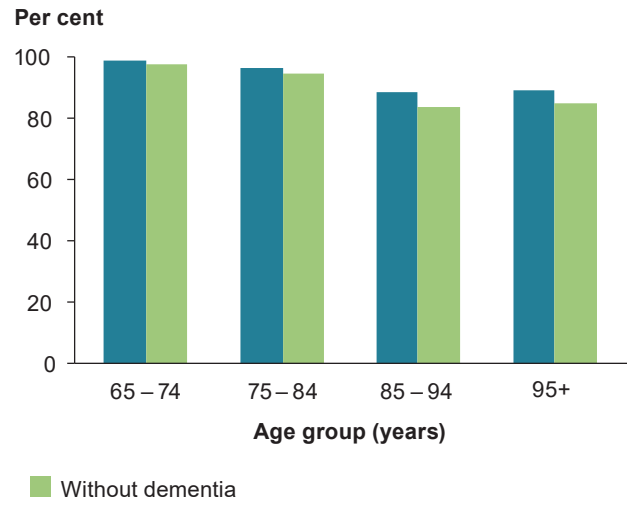
There was a smaller effect of age at death on the use of GP services by women (Figure 5.1b). For women with dementia, 99% of women who died aged 65–74 used a GP service compared with 89% who died aged 95 and over. For women without dementia, this decreased from 97% of those who died aged 65–74 to 85% of those who died aged 95 and over.

Figure 5.1: Percentage of people who died aged 65 or over who used a GP service at least once in their last year of life, by dementia status and age at death, men (a) and women (b)

(a) Men



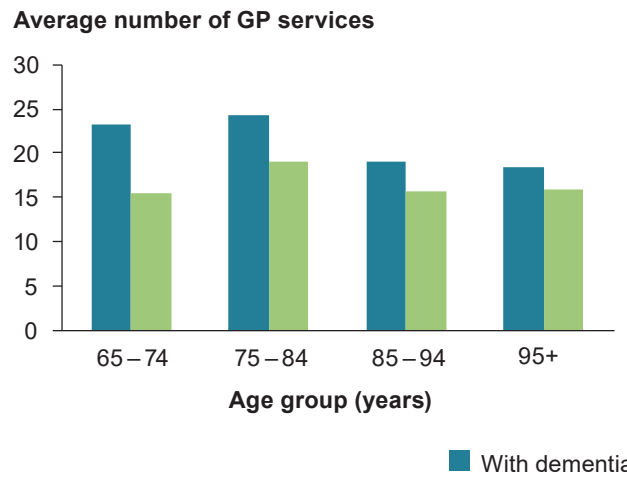
(b) Women



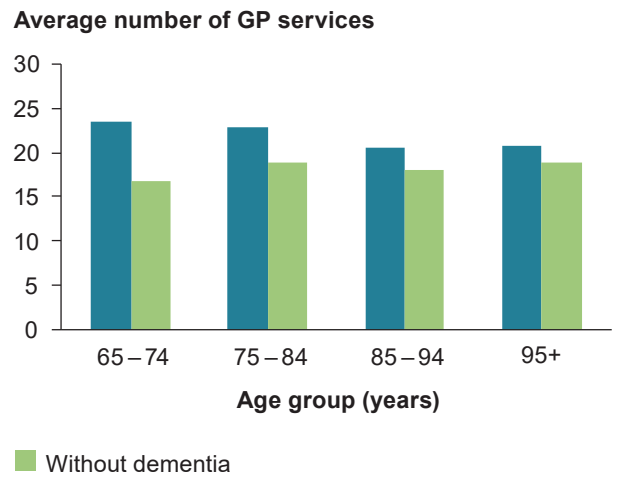
For each age group, people with dementia used GP services more frequently in their last year of life than people without dementia (Figure 5.2). The difference between those with and without dementia in terms of the average number of GP services used decreased with increasing age at death.

Figure 5.2: Average number of GP services used per person in their last year of life, by dementia status and age at death, men (a) and women (b)

(a) Men



(b) Women

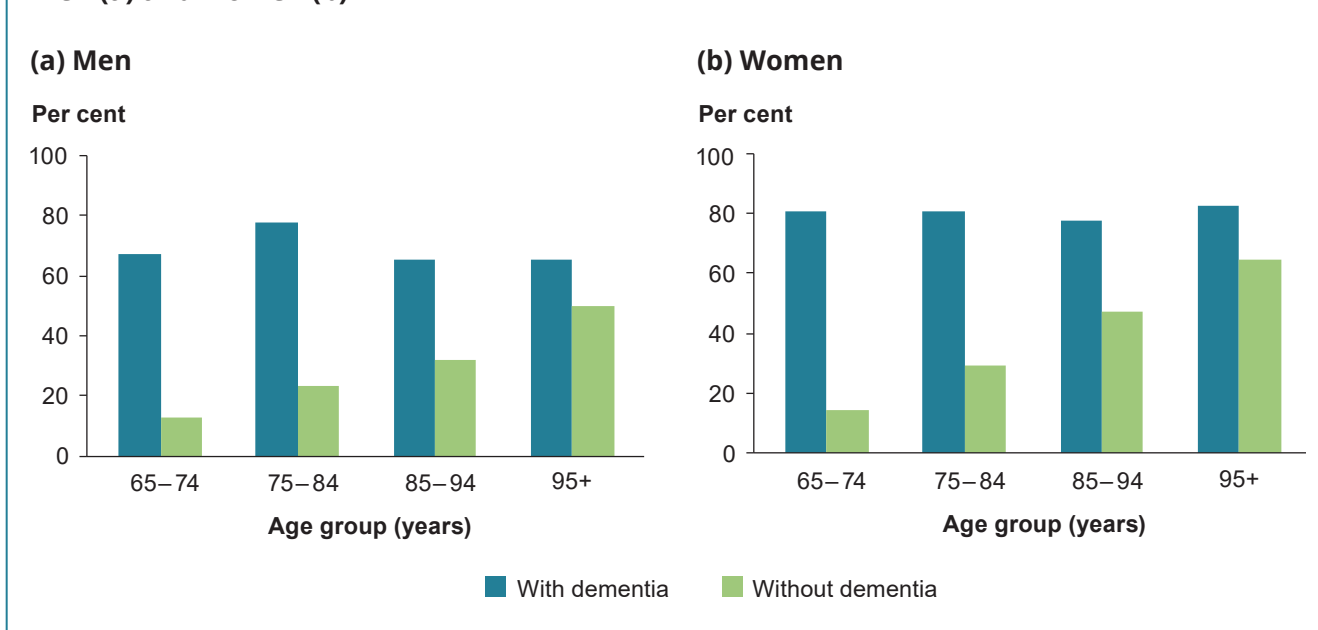


Most people with dementia received a GP service in a residential aged care facility

The majority of people with dementia who died aged 65 or over (75%) received at least 1 GP service in a residential aged care facility. By comparison, only 30% of people without dementia received at least 1 GP service in a residential aged care facility. This could reflect the high level of care required for people with dementia in their final stages of life, often provided by residential aged care services.

In each age group, a greater percentage of men and women with dementia received a GP service in a residential aged care facility in their last year of life than those without dementia (Figure 5.3). The difference was greatest in those who died aged 65–74.

Figure 5.3: Percentage of people who died aged 65 or over who received a GP service in a residential aged care facility in their last year of life, by dementia status and age at death, men (a) and women (b)



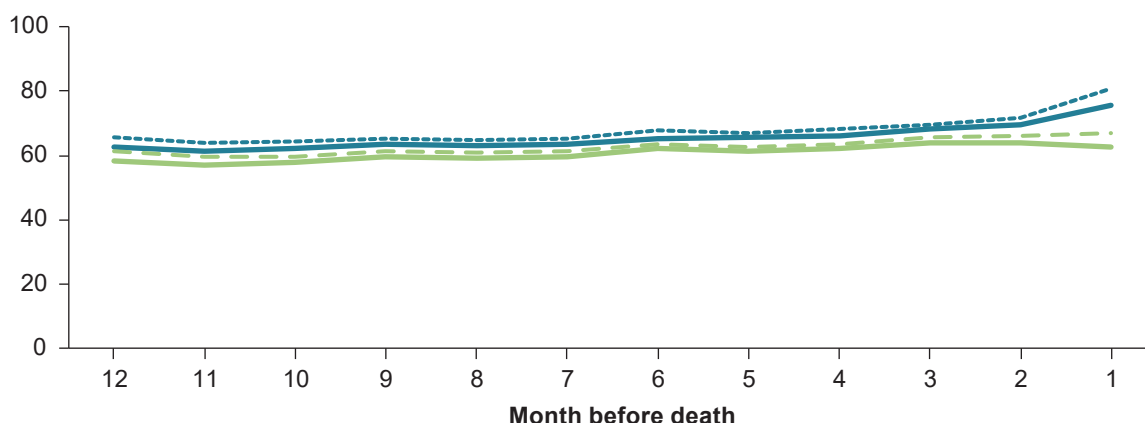
How did use of GP services vary by month over the last year of life?

A greater percentage of people with dementia used a GP service in their last month of life than people without dementia (Figure 5.4a). Around 76% of men and 81% of women with dementia used a GP service in their last month of life, increasing from 63% of men and 66% of women 12 months before. By comparison, 62% of men and 67% of women without dementia used a GP service in their last month of life.

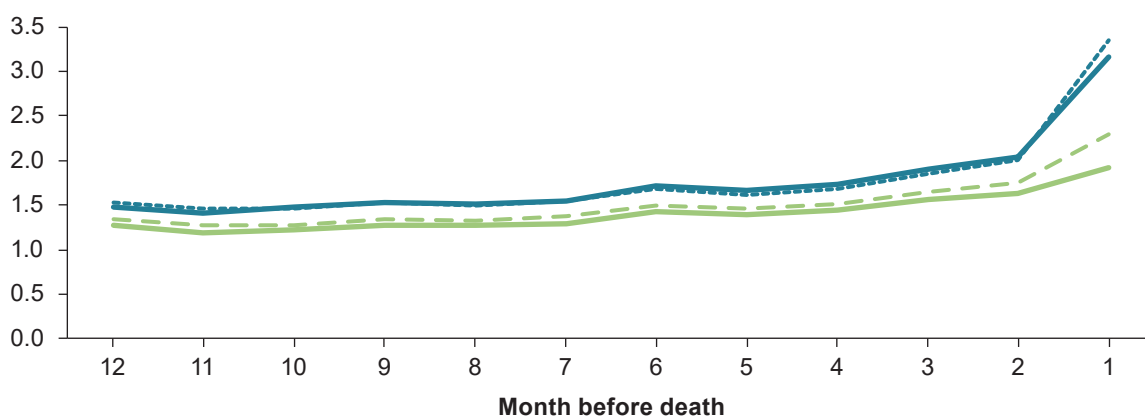
The average number of GP services increased in the months leading to death irrespective of dementia status, and was highest in the last month of life (Figure 5.4b). On average, men and women with dementia had 3 GP services in their last month of life, compared with 2 GP services for men and women without dementia.

Figure 5.4: Percentage of people in each month who used a GP service at least once (a) and average number of services per person (b), by dementia status, sex and month before death

(a) Percentage (%) of people using a GP service at least once



(b) Average number of GP services per person



— Men with dementia — Men without dementia
- - - Women with dementia - - - Women without dementia

Note: Analysis includes men and women who died aged 65 and over in 2013.

5.2 Specialist services

Specialist services were used by the smallest number of people and were the least frequently used health service in the last year of life by people who died aged 65 or over. They were used even less by people with dementia (Table 5.2).

Around 1 in 3 people with dementia who died aged 65 or over (33%) used a specialist service in their last year of life, compared with 2 in 3 people without dementia (64%). Men used specialist services more than women, irrespective of dementia status.

On average, a person with dementia used 1 specialist service in their last year of life compared with 4 specialist services for a person without dementia.

Table 5.2: Use of specialist services in the last year of life by people who died aged 65 or over, by dementia status and sex

	With dementia			Without dementia		
	Men	Women	Persons	Men	Women	Persons
<i>People who used a specialist service at least once</i>						
Number of people	3,137	3,229	6,366	18,197	14,345	32,542
Percentage of total study population	41.2	27.8	33.1	68.9	58.5	63.9
<i>Specialist services used</i>						
Average number per person ^(a)	1.6	0.9	1.1	4.8	3.4	4.1
Total number	11,994	9,968	21,962	126,154	84,089	210,243

(a) Average number of specialist services per person includes people who did not use a specialist service in their last year of life.

Leading specialist types

Ophthalmology was the leading specialist type used by people with dementia who died aged 65 or over—accounting for 13% of specialist services provided in their last year of life (Table 5.3). By comparison, medical oncologists were the leading specialist type used by people without dementia, accounting for 24% of all specialist services in their last year of life. This corroborates the finding that cancer is a leading cause of death among people without dementia in this study.

Consultations with physicians specialising in geriatric medicine (12%), psychiatry (8.2%), and neurology (4.2%)—which are all associated with managing dementia—were among the leading 10 specialist types used by people with dementia in their last year of life, but not by people without dementia.

Table 5.3: Use of leading specialist types in the last year of life by people who died aged 65 or over, by dementia status

Rank	Specialist types used by people with dementia	Per cent	Specialist types used by people without dementia	Per cent
1	Ophthalmology	12.9	Consultant Physician- Medical oncology	24.3
2	Consultant Physician- Geriatric medicine	11.8	Ophthalmology	9.7
3	Consultant Physician- General medicine	8.2	Consultant Physician- General medicine	9.3
4	Consultant Physician- Psychiatry	8.2	General surgery	7.9
5	Consultant Physician- Cardiology	8.0	Consultant Physician- Cardiology	7.7
6	General surgery	7.0	Consultant Physician- Haematology	5.3
7	Consultant Physician- Medical oncology	5.4	Consultant Physician- Respiratory and sleep medicine	3.9
8	Dermatology	5.3	Consultant Physician- Nephrology	3.2
9	Consultant Physician- Neurology	4.2	Urology	3.0
10	Urology	3.4	Dermatology	2.7

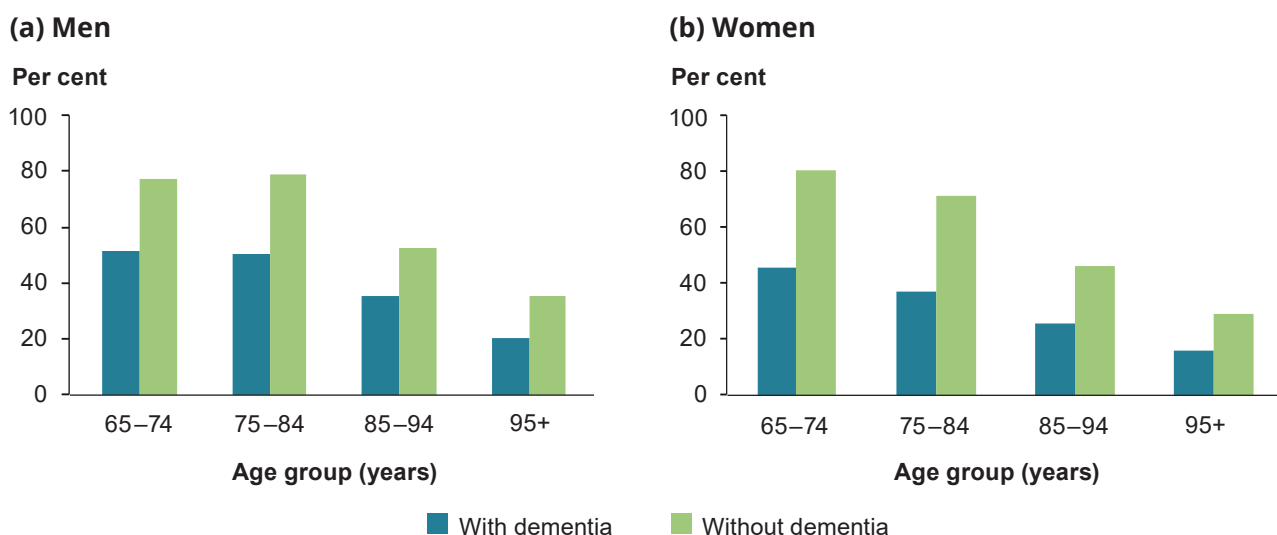
How did use of specialist services vary by age at death?

The proportion of people who used specialist services decreased with increasing age at death, irrespective of sex or dementia status (Figure 5.5).

In each age group, the use of specialist services was substantially lower for people with dementia in their last year of life than people without dementia, with the greatest difference in women aged 65–84 when they died.

Around 52% of men and 45% of women with dementia who died aged 65–74 used at least 1 specialist service in their last year of life, compared with 77% of men and 80% of women without dementia. For people who died aged 95 or over, this decreased to 20% of men and 16% of women with dementia and to 35% of men and 29% of women without dementia.

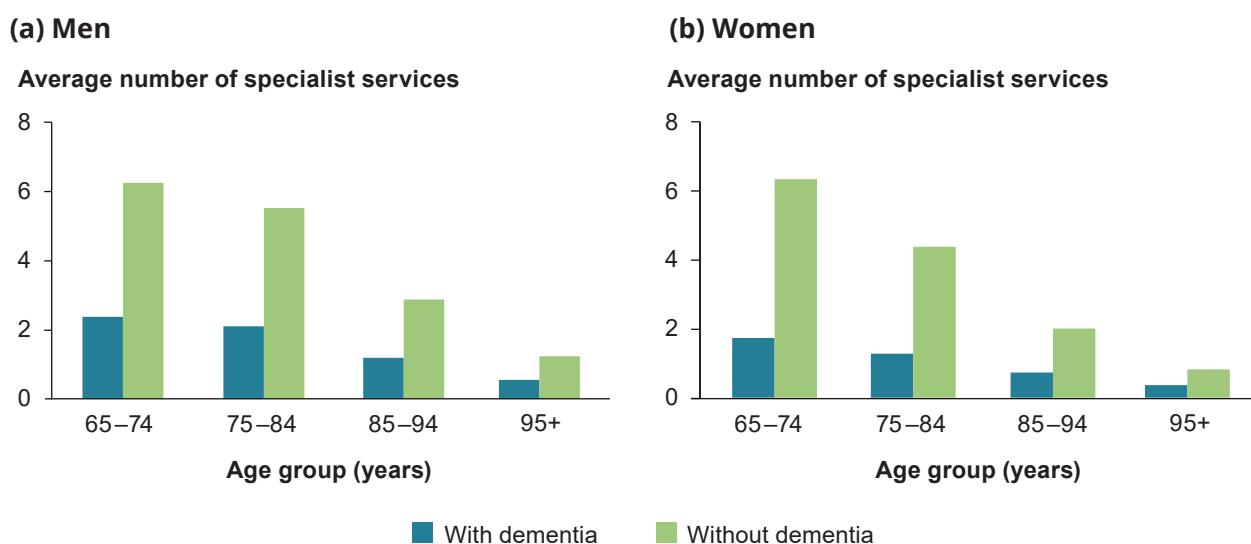
Figure 5.5: Percentage of people who died aged 65 or over who used a specialist service at least once in their last year of life, by dementia status and age at death, men (a) and women (b)



Across all ages at death, men and women with dementia used specialist services less frequently in their last year of life than those without dementia (Figure 5.6). The greatest difference was seen in men and women with dementia who died aged 65–74. As age of death increased, the difference between those with and without dementia in terms of the average number of specialist services used in the last year of life decreased.

Note this is the average number of overall specialist services. A person could have had consultations with specialists across numerous speciality types or could have multiple consultations with the same type of specialist.

Figure 5.6: Average number of specialist services per person used in the last year of life, by dementia status and age at death, men (a) and women (b)



How did specialist service use vary by month over the last year of life?

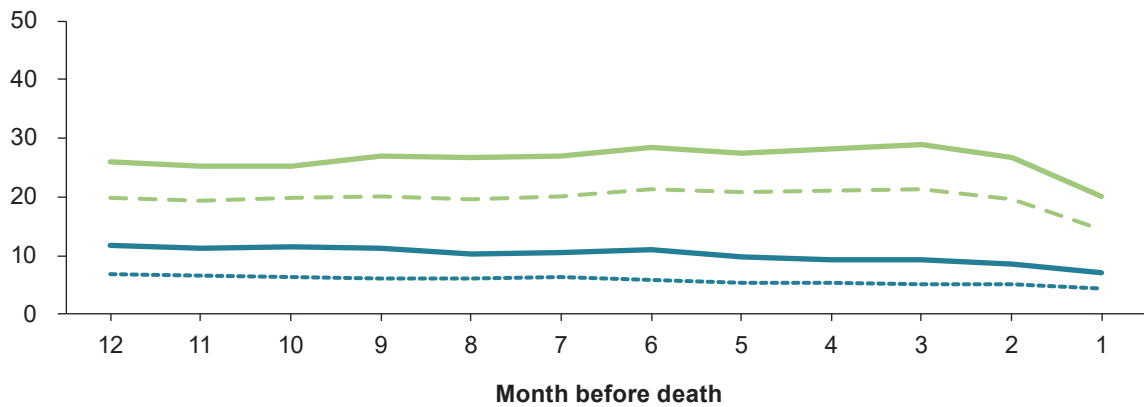
In each month of the last 12 months of life, the proportion of people who used a specialist service was substantially lower for people with dementia than people without dementia (Figure 5.7a).

Around 6.8% of women with dementia used a specialist service 12 months before death, compared with 20% of women without dementia. For men with dementia, 12% used a specialist service 12 months prior to death, compared with 26% of men without dementia. For men and women with dementia, the use of specialist services decreased slightly in the final months of life. For men and women without dementia this decrease was observed only in the last month of life and the decrease was more substantial in men.

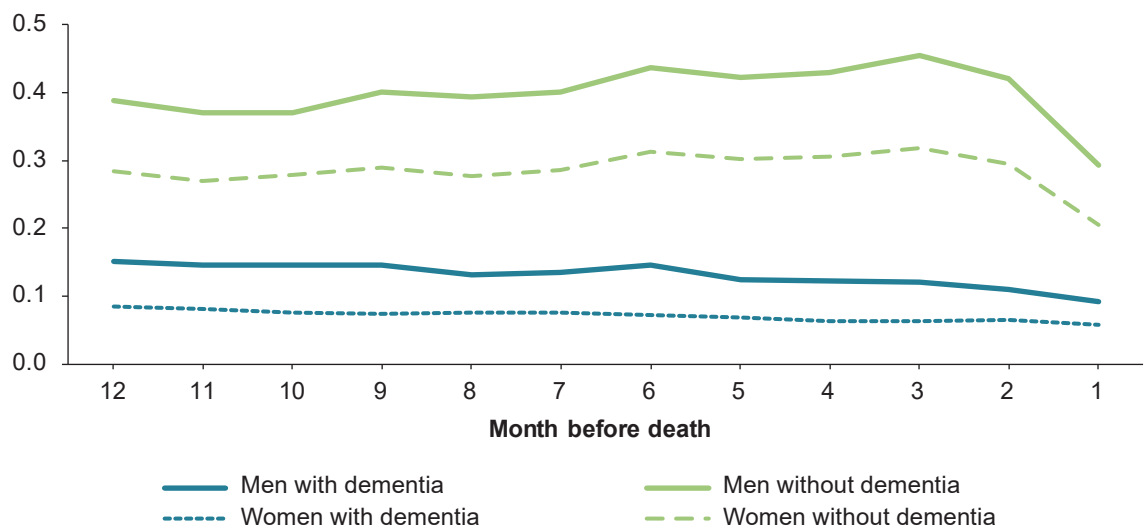
The average number of specialist services used by people with dementia was consistently lower than among people without dementia over the last 12 months of life (Figure 5.7b).

Figure 5.7: Percentage of people in each month who used a specialist service at least once (a) and average number of services per person (b), by dementia status, sex and month before death

(a) Percentage (%) of people using a specialist service at least once



(b) Average number of specialist services per person



Note: Analysis includes men and women who died aged 65 and over in 2013.

6 Prescriptions dispensed

This chapter provides detailed information on prescription dispensing patterns in the last year of life for people with dementia who died aged 65 or over compared with the group who were not identified in the NDLDP database as having dementia (referred to as 'people without dementia').

It is important to note that this analysis focuses on dispensing patterns of prescriptions for medicines supplied under the PBS. Information on the type of drugs dispensed is available, but details on medication intake, adherence and the condition for which the medication was prescribed are not available. The PBS also does not contain data on dispensing of privately prescribed medications, medications to public hospital in-patients and over-the-counter medicines. The NDLDP database does not include medicines subsidised under the Repatriation Pharmaceutical Benefits Scheme (available for eligible veterans, war widows/widowers and their dependants).

Chapter 8 details the prescription dispensing patterns in the last year of life for people with younger-onset dementia and how this differs from patterns for people with dementia who died aged 65 or over.

6.1 Overview of prescriptions dispensed

There were 1.14 million prescriptions dispensed in the last year of life to 86% of people with dementia who died aged 65 and over (Table 6.1). Around 84% of men and 87% of women with dementia had at least 1 prescription dispensed in their last year of life, which was only slightly lower than for men and women without dementia (88% for both).

On average, a person with dementia who died aged 65 or over was dispensed a slightly lower number of prescriptions in their last year of life (59 prescriptions) than a person without dementia (65 prescriptions). This difference was greater for women (60 prescriptions to women with dementia; 69 to women without dementia) than it was for men (57 and 62, respectively).

Table 6.1: Number and percentage of prescriptions dispensed in the last year of life to people who died aged 65 or over, by dementia status and sex

	With dementia			Without dementia		
	Men	Women	Persons	Men	Women	Persons
<i>People who were dispensed a prescription at least once</i>						
Number of people	6,375	10,097	16,472	23,124	21,613	44,737
Percentage of total study population	83.7	87.0	85.7	87.6	88.1	87.8
<i>Prescriptions dispensed</i>						
Average number per person ^(a)	57.4	60.3	59.2	62.2	68.8	65.4
Total number	437,706	699,470	1,137,176	1,641,205	1,688,047	3,329,252

(a) Average number of prescriptions dispensed per person includes people who were not dispensed a prescription in their last year of life.

Opioids were the most common drug type dispensed

Opioids were the most common drug type dispensed to people in their last year of life who died aged 65 or over, responsible for 10% of prescriptions dispensed to people with dementia and 9.4% of prescriptions dispensed to people without dementia (Table 6.2).

Other analgesics and antipyretics (for pain relief—7.4% of prescriptions dispensed) and drugs for peptic ulcer and gastro-oesophageal reflux disease (7.0%) were the next leading drug types dispensed to people with dementia in their last year of life. For people without dementia these were for drugs for peptic ulcer and gastro-oesophageal reflux disease (7.6%) and lipid modifying agents (5.8%).

Notably, antipsychotics were a leading drug type dispensed to people with dementia in their last year of life (4.7% of prescriptions dispensed) but were not featured in the leading drug types dispensed to people without dementia who died in the same year (only 0.8% of all prescriptions dispensed). Information on the condition for which the medication was prescribed was not available in the NDLP database.

Table 6.2: Leading drug types dispensed to people in the last year of life who died aged 65 or over, by dementia status

Rank	Drug type dispensed to people with dementia (ATC3 level)	Per cent	Drug type dispensed to people without dementia (ATC3 level)	Per cent
1	Opioids (N02A)	10.3	Opioids (N02A)	9.4
2	Other analgesics and antipyretics (N02B)	7.4	Drugs for peptic ulcer and gastro-oesophageal reflux disease (A02B)	7.6
3	Drugs for peptic ulcer and gastro-oesophageal reflux disease (A02B)	7.0	Lipid modifying agents, plain (C10A)	5.8
4	Antidepressants (N06A)	6.3	Antithrombotic agents (B01A)	5.3
5	Antipsychotics (N05A)	4.7	Other analgesics and antipyretics (N02B)	4.2
6	Antithrombotic agents (B01A)	4.7	Adrenergics, inhalants (R03A)	4.1
7	Lipid modifying agents, plain (C10A)	4.4	Antidepressants (N06A)	3.9
8	Drugs for constipation (A06A)	3.5	Beta blocking agents (C07A)	3.3
9	Angiotensin-converting enzyme inhibitors, plain (C09A)	2.9	Angiotensin-converting enzyme inhibitors, plain (C09A)	3.2
10	Beta-lactam antibacterials, other (J01D)	2.5	High ceiling diuretics (C03C)	2.5

Note: Medicines are given an ATC classification in the Schedule of Pharmaceutical Benefits according to their main therapeutic use in Australia as registered with the Therapeutic Goods Administration and listed on the PBS. Refer to Table A2 for information on ATC level.

When looking at individual drugs, paracetamol was the leading drug dispensed to people in their last year of life and comprised a greater percentage of prescriptions dispensed to people with dementia (7.3% of all prescriptions) than to those without dementia (4.0%) (Table B2). Paracetamol listed on the PBS is commonly prescribed to people (particularly older people) with chronic pain. However these data may underestimate paracetamol use as paracetamol can also be purchased without a prescription.

The next leading individual drugs dispensed to people with dementia were:

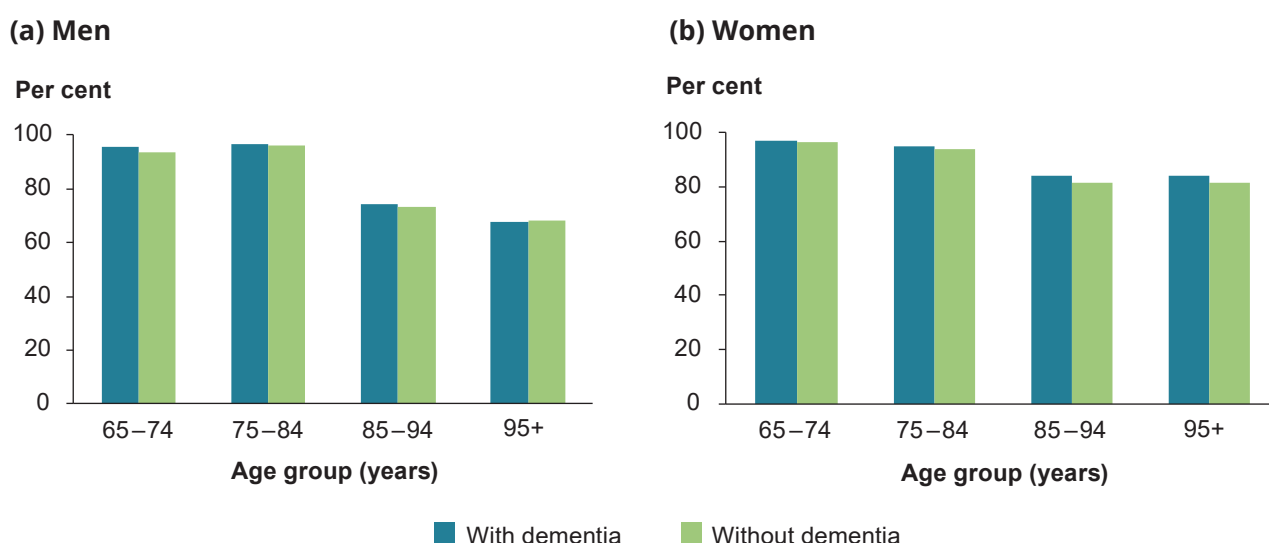
- Buprenorphine (4.2%; for pain relief)
- Pantoprazole (2.7%; for gastro-oesophageal issues)
- Artificial tears (2.5%; for dry eyes)
- Cefalexin (2.3%; for bacterial infections)
- Macrogol (2.3%; for constipation)
- Risperidone (2.2%; for psychosis)

How did dispensing patterns vary by age at death?

In their last year of life, the percentage of men and women dispensed a prescription decreased with increasing age at death (Figure 6.1). In each age group, the percentages of men and women with dementia dispensed a prescription were similar to those for men and women without dementia.

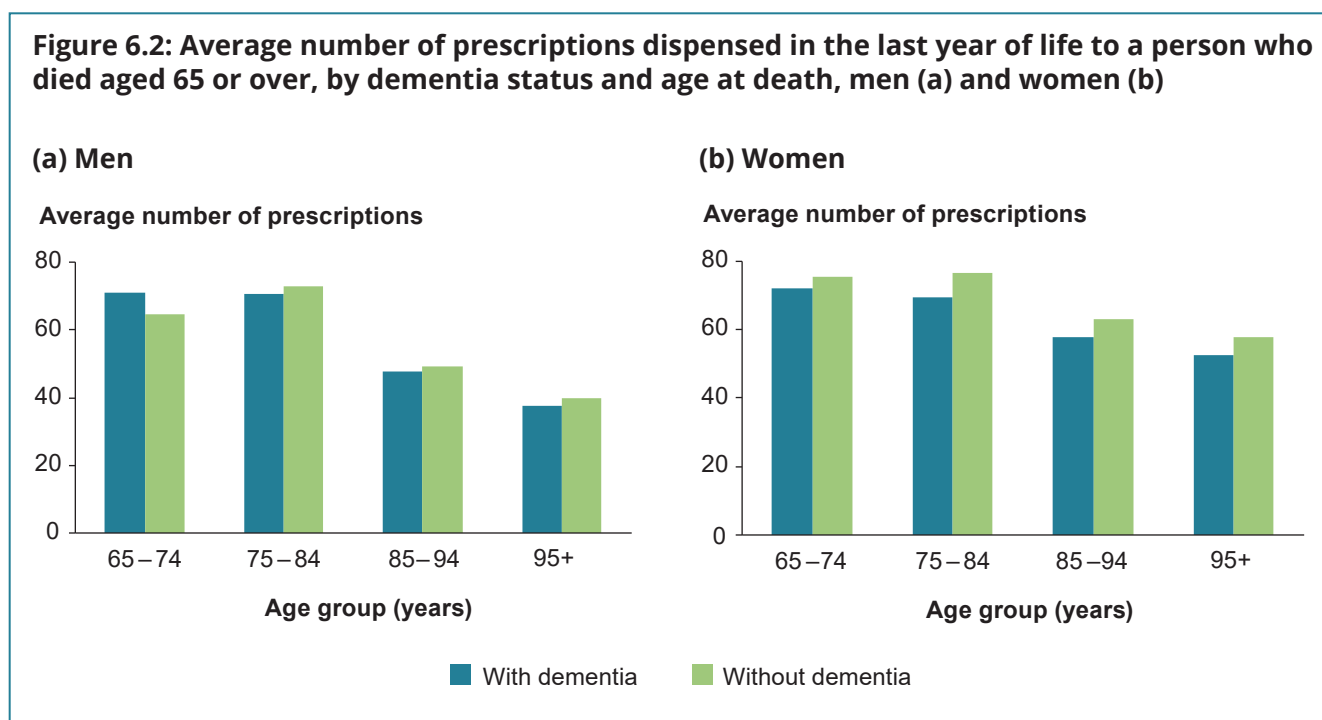
Around 96% of men with dementia and 94% of men without dementia who died aged 65–74 were dispensed at least 1 prescription in their last year of life. This decreased to 67% and 68% respectively for men who died aged 95 and over. For women with dementia this proportion decreased from 97% in those who died aged 65–74 to 84% in those who died aged 95 and over. For women without dementia the corresponding proportions were 97% and 82%.

Figure 6.1: Percentage of people dispensed a prescription at least once in their last year of life who died aged 65 or over, by dementia status and age at death, men (a) and women (b)



Average number of prescriptions dispensed decreased with increasing age at death

The average number of prescriptions dispensed to people in their last year of life decreased with increasing age at death (Figure 6.2). For men with dementia, this was similar to, but slightly less than for men without dementia, except among men who died aged 65–74. The average number of prescriptions dispensed to women with dementia was slightly less than the average number dispensed to those without dementia.

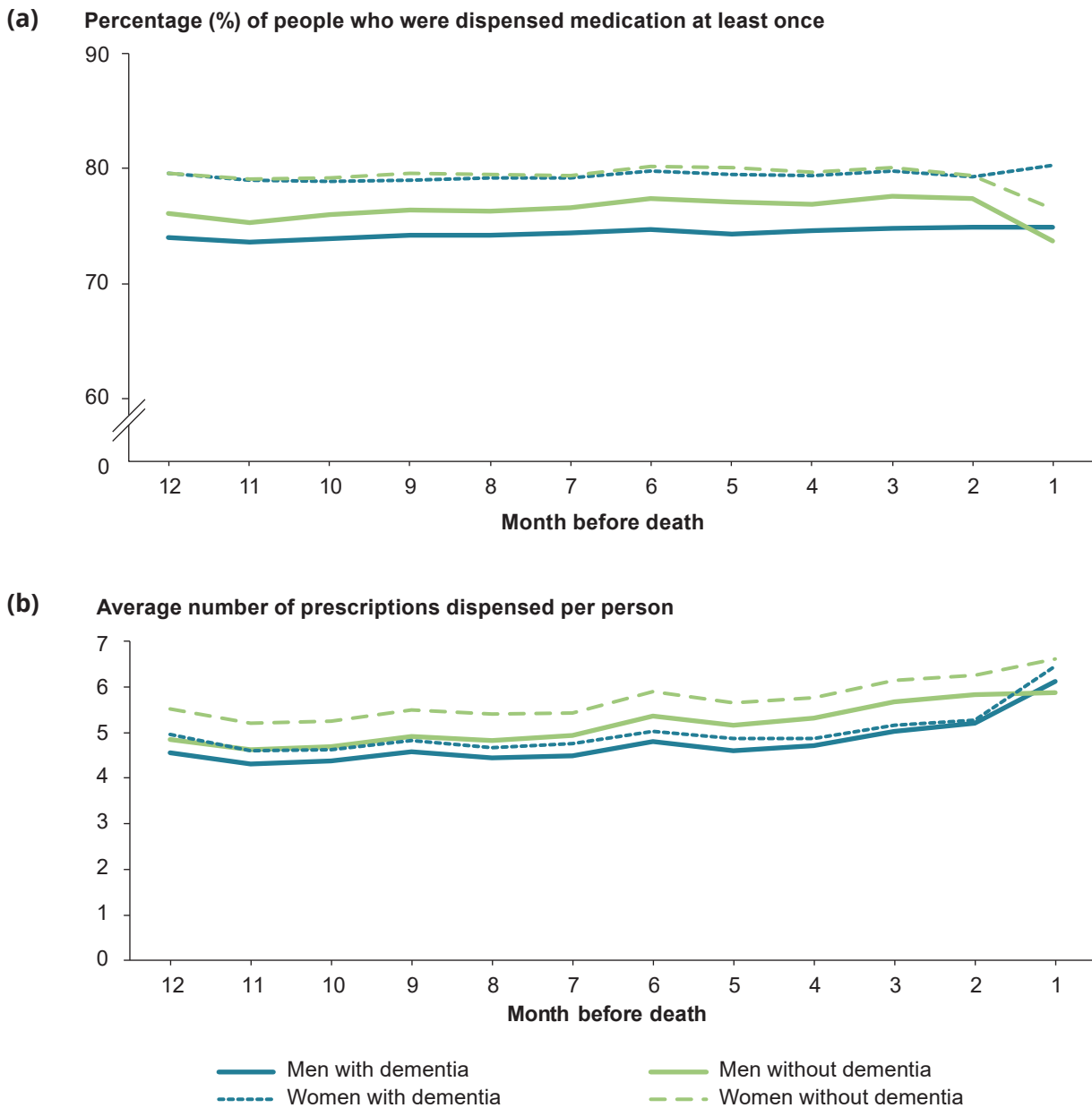


How did dispensing patterns vary by month over the last year of life?

Overall, the percentage of people with a prescription dispensed in their last year of life was higher in women than men, irrespective of dementia status (Figure 6.3a).

While the percentages of men and women with dementia in each month who had a prescription dispensed were consistent over the final 12 months of life, the percentages of men and women without dementia who had a prescription dispensed decreased in the final month of life. However, the average number of prescriptions dispensed increased slightly in the final months of life, with the biggest increases seen in those with dementia in the final month of life (Figure 6.3b).

Figure 6.3: Percentage of people in each month with at least one prescription dispensed (a) and average number of prescriptions dispensed per person (b), by dementia status, sex and month before death



Note: Analysis includes men and women who died aged 65 and over in 2013.

7 Hospital services

This chapter provides detailed information from public hospitals on hospital admissions (referred to as 'hospitalisations') and emergency department (ED) presentations in the last year of life by people with dementia who died aged 65 or over, compared with the corresponding group without a recorded dementia diagnosis in the NDLDP database (referred to as 'people without dementia').

Note, private hospital data were not included in the NDLDP database.

Chapter 8 details the use of hospital services in the last year of life by people who died with younger-onset dementia and how this differs from usage by people with dementia who died aged 65 or over.

7.1 Hospitalisations

Around 2 in 3 people with dementia who died aged 65 or over were admitted to hospital at least once in their last year of life (Table 7.1). This was a total of 41,708 hospitalisations. Men with dementia were more likely to be hospitalised (74% of men with dementia) than women with dementia (60%).

However, people with dementia were less likely to be hospitalised in their last year of life than people without dementia, of whom 78% overall were hospitalised at least once. In addition, people with dementia had on average fewer hospitalisations than people without dementia (2 hospitalisations compared with 4 hospitalisations, respectively). While people with dementia were hospitalised less frequently, their stays were longer than for people without dementia. On average, a person with dementia was hospitalised for 7 days each time, compared with 6 days for a person without dementia.

Men were hospitalised more frequently than women, irrespective of dementia status. When looking at the length of stay, men and women with dementia had the same average number of bed days (7 days), compared with 5 days for men and 6 days for women without dementia.

Table 7.1: Hospitalisations in the last year of life by people who died aged 65 or over, by dementia status and sex

	With dementia			Without dementia		
	Men	Women	Persons	Men	Women	Persons
<i>People who were hospitalised at least once</i>						
Number of people	5,631	7,007	12,638	21,325	18,554	39,879
Percentage of total study population	73.9	60.4	65.7	80.8	75.6	78.3
Hospitalisations						
Average number per person ^(a)	2.8	1.7	2.2	4.5	3.3	3.9
Average number of bed days	7.1	7.1	7.1	5.3	6.3	5.7
Total number	21,566	20,142	41,708	119,526	80,368	199,894

(a) Average number of hospitalisations per person includes people who were not hospitalised in their last year of life.

What were the most common principal diagnoses?

Extracorporeal dialysis was the most common principal diagnosis in people who died aged 65 and over, responsible for 13% of hospitalisations for people with dementia and 24% for people without dementia in their last year of life (Table 7.2). For people with dementia, this was followed by *Pneumonia, unspecified* (3.7% of all hospitalisations) and *Pneumonitis due to food and vomit* (3.6%). *Chemotherapy* (6.1%) and *Congestive heart failure* (3.1%) were the next most common principal diagnoses in hospitalisations for people without dementia.

Pneumonia, unspecified; *Urinary tract infections site, not specified*; and *Sepsis, unspecified* were also leading principal diagnoses, associated with more hospitalisations for people with dementia (3.7%, 3.5% and 1.6% respectively) than people without dementia (2.3%, 1.0% and 0.9%, respectively) in their last year of life. *Unspecified dementia* was recorded as a principal diagnosis in 1.5% of hospitalisations for people with dementia.

As people undergoing dialysis often require a large number of services, further exploration of these data is required to fully understand the impact of dialysis on health service use for people with dementia.

Table 7.2: Leading 10 principal diagnoses for hospitalisations in the last year of life by people who died aged 65 or over, by dementia status

Rank	Principal diagnosis in people with dementia	Per cent	Principal diagnosis in people without dementia	Per cent
1	Extracorporeal dialysis	13.4	Extracorporeal dialysis	23.9
2	Pneumonia, unspecified	3.7	Chemotherapy session for neoplasm	6.1
3	Pneumonitis due to food and vomit	3.6	Congestive heart failure	3.1
4	Urinary tract infection, site not specified	3.5	Care involving use of rehabilitation procedure, unspecified	2.3
5	Care involving use of rehabilitation procedure, unspecified	3.0	Pneumonia, unspecified	2.3
6	Congestive heart failure	2.8	Chronic obstructive pulmonary disease with acute lower respiratory infection	2.0
7	Person awaiting admission to adequate facility elsewhere	2.3	Anaemia, unspecified	1.6
8	Sepsis, unspecified	1.6	Urinary tract infection, site not specified	1.0
9	Unspecified dementia	1.5	Acute sub endocardial myocardial infection	1.0
10	Delirium, unspecified	1.4	Sepsis, unspecified	0.9

Most common principal diagnoses in overnight hospitalisations

As dialysis and chemotherapy were the most common principal diagnoses overall and both are same-day admissions, the most common principal diagnoses among overnight hospitalisations (where a person stayed in hospital at least 1 night) were examined.

Overall, 74% of hospitalisations in the last year of life of people with dementia who died aged 65 and over were overnight admissions. By comparison, a smaller proportion of hospitalisations were overnight admissions (57%) among people without dementia in their last year of life. The average number of bed days for overnight admissions was 9 days in people both with and without dementia in their last year of life (Table B4).

Pneumonia, unspecified and *Pneumonitis due to food and vomit* were the most common principal diagnoses in overnight hospitalisations among people with dementia who died aged 65 or over (responsible for 4.6% of hospitalisations each) (Table 7.3). This was closely followed by *Urinary tract*

infection, site not specified (4.3%). In the group without dementia *Congestive heart failure* (5.2% of hospitalisations); *Care involving use of rehabilitation procedure, unspecified* (4.0%); and *Pneumonia, unspecified* (3.7%) were the most common principal diagnoses in overnight hospitalisations.

Notably, *Awaiting placement to nursing home* was the sixth-leading principal diagnosis for overnight hospitalisations among people with dementia in their last year of life (3.0%), but was not among the leading principal diagnoses in overnight hospitalisations for people without dementia.

Table 7.3: Leading 10 principal diagnoses for overnight hospitalisations in the last year of life by people who died aged 65 or over, by dementia status

Rank	Principal diagnosis in people with dementia	Per cent	Principal diagnosis in people without dementia	Per cent
1	Pneumonia, unspecified	4.6	Congestive heart failure	5.2
2	Pneumonitis due to food and vomit	4.6	Care involving use of rehabilitation procedure, unspecified	4.0
3	Urinary tract infection, site not specified	4.3	Pneumonia, unspecified	3.7
4	Care involving use of rehabilitation procedure, unspecified	3.9	Chronic obstructive pulmonary disease with acute lower respiratory infection	3.3
5	Congestive heart failure	3.5	Urinary tract infection, site not specified	1.6
6	Awaiting placement to nursing home	3.0	Acute sub endocardial myocardial infarction	1.6
7	Sepsis, unspecified	2.0	Secondary malignant neoplasm of bone and bone marrow	1.4
8	Unspecified dementia	1.8	Sepsis, unspecified	1.4
9	Delirium, unspecified	1.8	Acute kidney failure, unspecified	1.4
10	Fracture of subcapital section of femur	1.7	Chronic obstructive pulmonary disease with acute exacerbation, unspecified	1.3

Leading additional diagnoses

Additional diagnoses provide further insight into other health conditions of the patient that may affect a hospital event but do not provide a complete picture of the number of health conditions per person, or at a population level.

On average, there were 5 additional diagnoses per hospitalisation for a person with dementia who died aged 65 or over, compared with 4 additional diagnoses for the corresponding group without dementia. This includes same-day and overnight admissions. The most common additional diagnoses in people with dementia were:

- *Unspecified dementia* (20% of hospitalisations)
- *Unspecified urinary incontinence* (16%)
- *Primary hypertension* (14%) (Table B3).

By comparison, the most common additional diagnoses in hospitalisations for people without dementia were *Personal history of tobacco use disorder* (15% of hospitalisations), *Primary hypertension* (11%) and *Palliative care* (10%).

Conditions associated with significant physical and functional decline (such as incontinence and dysphagia) and urinary tract infections were common additional diagnoses in hospitalisations for people with dementia but not in hospitalisations for people without dementia in their last year of life.

Allied health interventions used more in hospitalisations for people with dementia

Around 3 in 4 hospitalisations for people with dementia in their last year of life (76%) involved at least 1 allied health intervention or procedure (Table 7.4).

Physiotherapy was the most common intervention or procedure involved in hospitalisations for this group (21% of hospitalisations). Other leading allied health services for this group included speech pathology (9.6%), social work (8.1%) and dietetics (6.0%). Each of the leading allied health services were involved in a greater proportion of hospitalisations for people with dementia than in hospitalisations for people without dementia in their last year of life.

Haemodialysis was the most common intervention or procedure in hospitalisations for those without dementia (29%) and second most common for those with dementia (18%).

Notably, procedures involving hip fractures and replacements were among the 10 leading interventions or procedures in hospitalisations of people with dementia (2.2% and 1.4%, respectively) but were not in the 10 leading interventions or procedures for those without dementia.

Table 7.4: Leading interventions or procedures in hospitalisations in the last year of life by people who died aged 65 or over, by dementia status

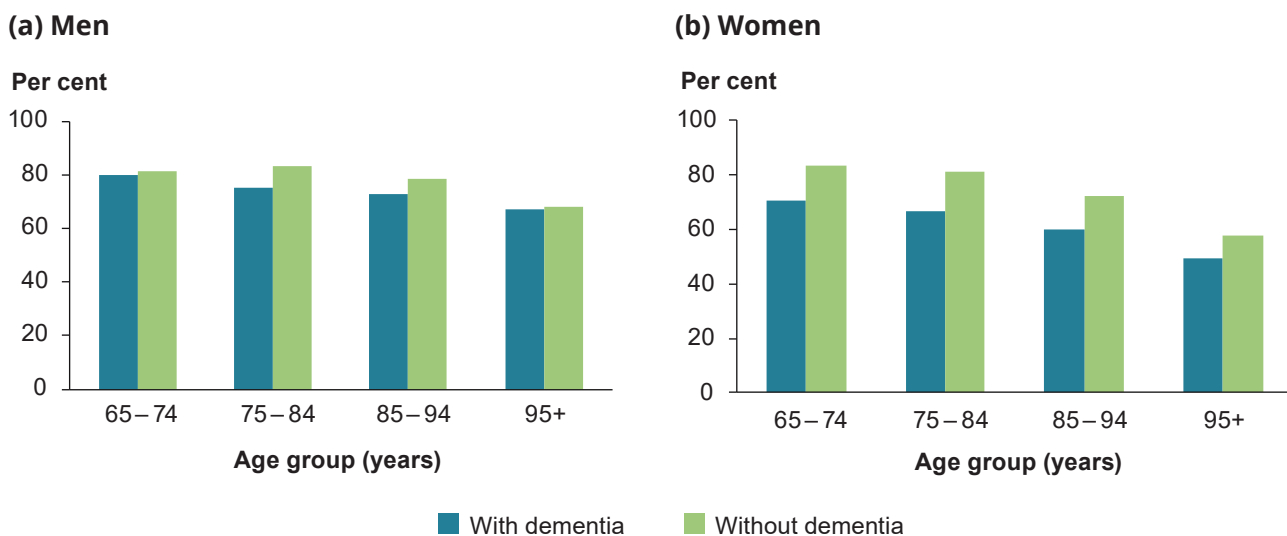
Rank	Intervention/ procedure in people with dementia	Per cent	Intervention/ procedure in people without dementia	Per cent
1	Allied health intervention–physiotherapy	20.7	Haemodialysis	28.7
2	Haemodialysis	17.7	Allied health intervention–physiotherapy	12.4
3	Allied health intervention–speech pathology	9.6	Intravenous administration of pharmacological agent, antineoplastic agent	7.3
4	Allied health intervention–social work	8.1	Administration of packed cells	6.8
5	Allied health intervention–dietetics	6.0	Allied health intervention–dietetics	4.4
6	Allied health intervention–occupational therapy	5.4	Allied health intervention–social work	4.1
7	Allied health intervention–pharmacy	4.2	Allied health intervention–occupational therapy	3.7
8	Administration of packed cells	4.2	Allied health intervention–speech pathology	2.6
9	Internal fixation of fracture of trochanteric or subcapital femur	2.2	Allied health intervention–pharmacy	2.4
10	Hemiarthroplasty of femur	1.4	Abdominal paracentesis	1.2

How did hospitalisations vary by age at death?

The percentage of people who died aged 65 or over with at least 1 hospitalisation in their last year of life decreased with increasing age at death, irrespective of dementia status (Figure 7.1). This decrease was smaller for people with dementia.

Across all relevant ages at death, a greater percentage of men than women with dementia were hospitalised at least once in their last year of life. The percentage of men with dementia who died aged 75–94 with a hospitalisation in their last year of life was lower than for the corresponding group of men without dementia. The percentage of women without dementia who were hospitalised at least once in their last year of life was greater than that of women with dementia.

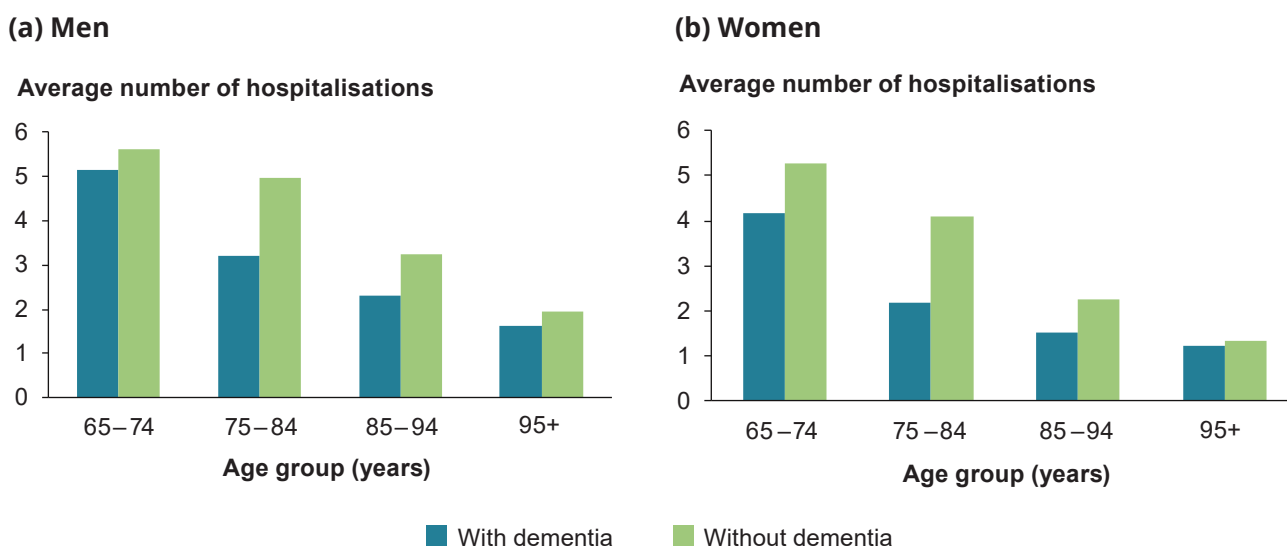
Figure 7.1: Percentage of people with at least 1 hospitalisation in their last year of life who died aged 65 or over, by dementia status and age at death, men (a) and women (b)



The average number of hospitalisations in the last year of life decreased with increasing age at death, irrespective of dementia status (Figure 7.2). For all ages at death, this was lower for men and women with dementia than men and women without dementia.

For men with dementia, the average number of hospitalisations decreased from 5 for men who died aged 65–74 to 2 for men who died aged 95 and over. For men without dementia, the average number of hospitalisations decreased from 6 for men who died aged 65–74 to 2 for men who died aged 95 and over. For women, the numbers decreased from 4 for women with dementia and 5 for those without dementia who died aged 65–74, to 1 for both those with and without dementia who died aged 95 and over.

Figure 7.2: Average number of hospitalisations in the last year of life of people who died aged 65 or over, by dementia status, sex and age at death, men (a) and women (b)

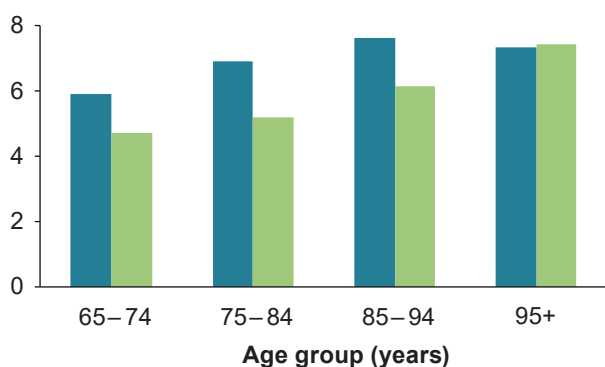


Men with dementia who died aged under 95 had a higher average number of hospital bed days in their last year of life than men without dementia. For men who died aged 95 or over, the average number of days was the same for those with and without dementia. Women with dementia who died aged 75–84 had a slightly higher average number of hospital bed days than women without dementia. For all other ages, the average numbers of days were either similar, or slightly lower for women with dementia (Figure 7.3).

Figure 7.3: Average number of hospital bed days in the last year of life of people who died aged 65 or over, by dementia status and age at death, men (a) and women (b)

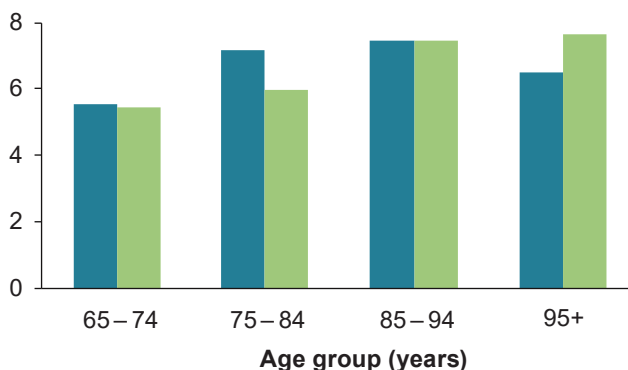
(a) Men

Average number of bed days



(b) Women

Average number of bed days



■ With dementia ■ Without dementia

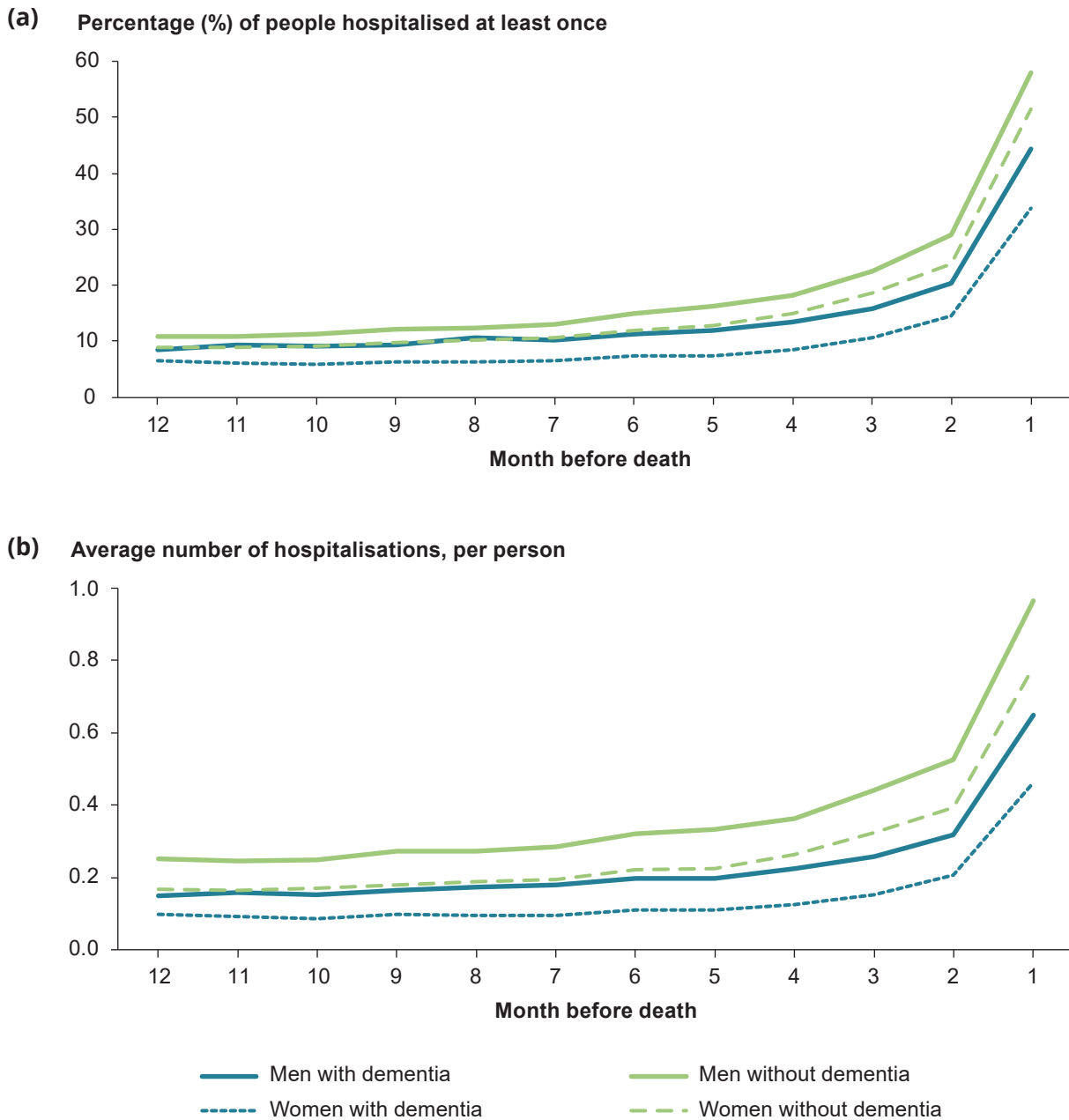
How did hospitalisations vary by month over the last year of life?

Overall, people with dementia who died aged 65 and over were hospitalised less than people without dementia in their last year of life (Figure 7.4a).

Regardless of dementia status, the percentage of people admitted to hospital increased in the months leading to death, with the greatest increase in the last month of life. Around 44% of men and 34% of women with dementia were hospitalised at least once in their last month of life, increasing from 8.5% of men and 6.6% of women 12 months before.

The average number of hospitalisations per person also increased in the final months of life, irrespective of dementia status (Figure 7.4b). The average number of hospitalisations per person in each month was consistently lower in men and women with dementia than in those without dementia.

Figure 7.4: Percentage of people in each month who were hospitalised at least once (a) and average number of hospitalisations per person (b), by dementia status, sex and month before death



Note: Analysis includes men and women who died aged 65 and over in 2013.

7.2 Emergency department presentations

Around 2 in 3 people with dementia who died aged 65 or over presented to the ED in their last year of life (Table 7.5). This was a total of 32,658 presentations.

Men with dementia were more likely to present to the ED than women with dementia (75% of men; 63% of women). Compared with people without dementia, men and women with dementia had fewer ED presentations in their last year of life.

On average, a person with dementia presented to the ED 1.7 times in their last year of life compared with 2.1 times for people without dementia. Men presented to the ED more frequently than women, irrespective of dementia status.

Table 7.5: Emergency department presentations in the last year of life by people who died aged 65 or over, by dementia status and sex

	With dementia			Without dementia		
	Men	Women	Persons	Men	Women	Persons
<i>People who presented to ED at least once</i>						
Number of people	5,697	7,353	13,050	20,880	18,112	38,992
Percentage of total study population	74.7	63.4	67.9	79.1	73.8	76.6
<i>ED presentations</i>						
Average number per person ^(a)	2.0	1.5	1.7	2.2	1.9	2.1
Total number	15,606	17,052	32,658	59,268	45,725	104,993

(a) Average number of ED presentations per person includes people who did not present to the ED in their last year of life.

How did ED presentations vary by age at death?

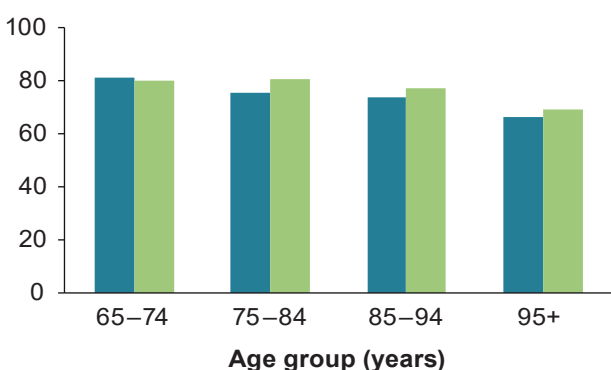
Similarly to hospitalisations, the proportion of people presenting to the ED at least once in their last year of life decreased with increasing age at death, irrespective of dementia status (Figure 7.5). In each age group, men were more likely to present to the ED than women.

As with hospitalisations, in most age groups the percentages of men and women with dementia were lower than those of men and women without dementia.

Figure 7.5: Percentage of people who presented to the ED at least once in their last year of life, by dementia status and age at death, men (a) and women (b)

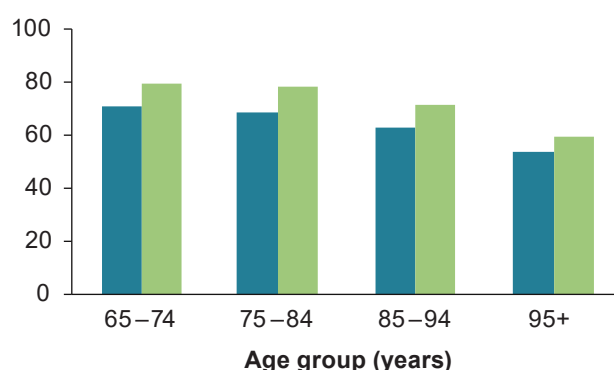
(a) Men

Per cent



(b) Women

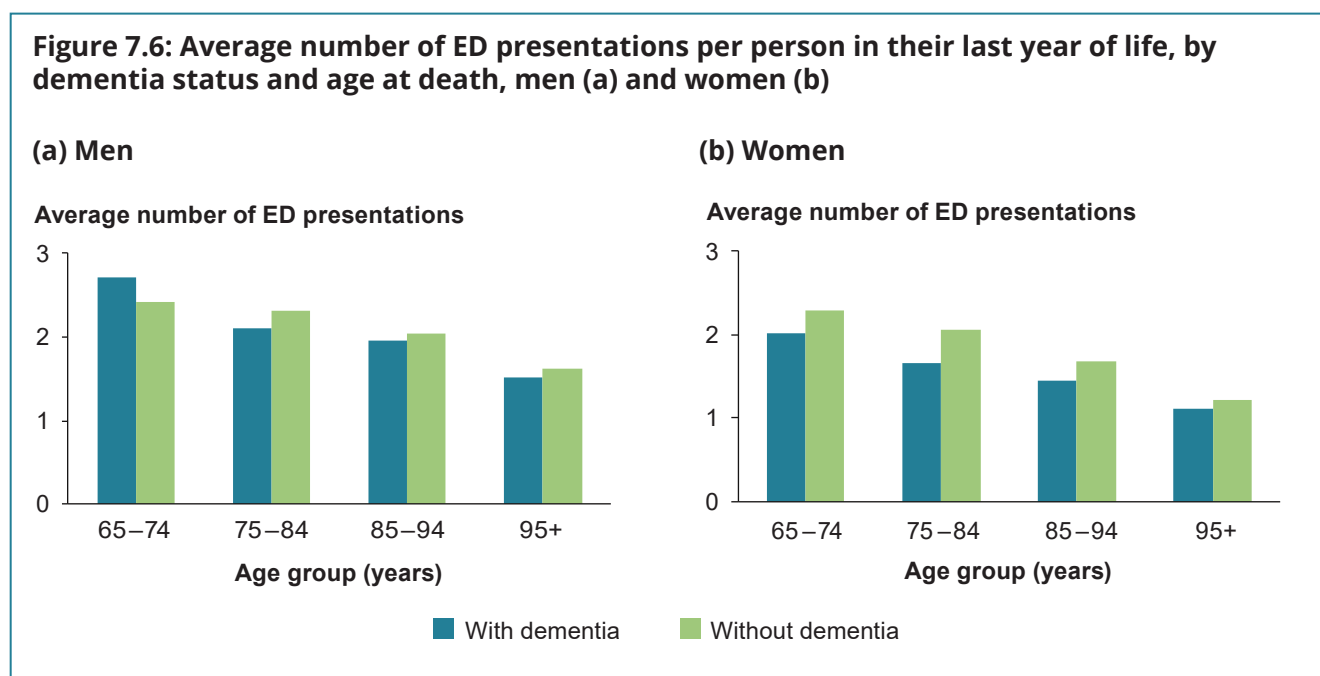
Per cent



■ With dementia ■ Without dementia

The average number of ED presentations in the last year of life decreased with increasing age at death, irrespective of dementia status, but was slightly higher in men than in women (Figure 7.6).

With the exception of men who died aged 65–74, the average number of ED presentations for men with dementia was only slightly lower than for men without dementia. The average number of ED presentations was slightly lower in women with dementia across all age groups at death than for women without dementia.



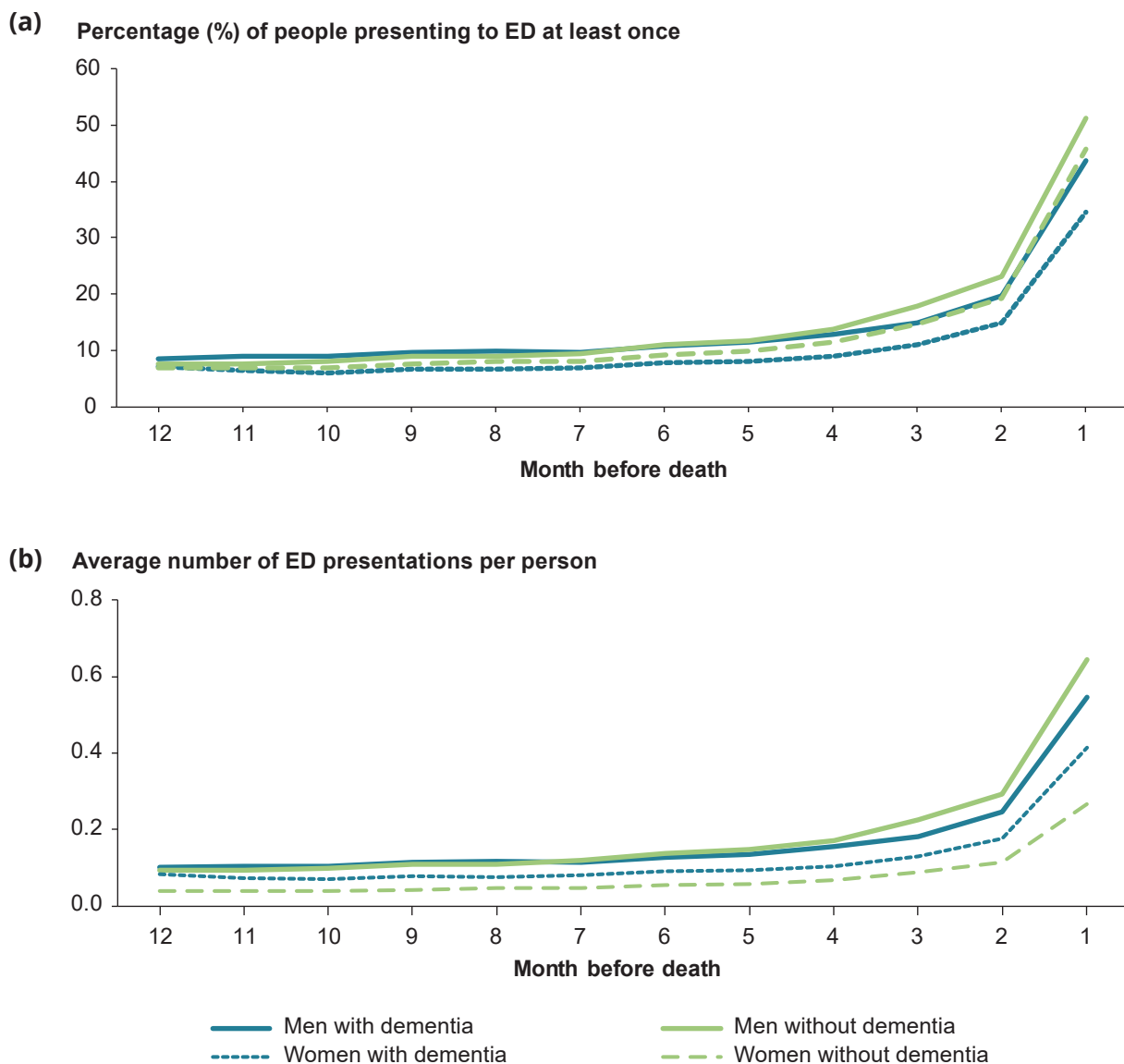
How did ED presentations vary by month over the last year of life?

As with hospitalisations, the percentage of people who presented to the ED at least once increased in the months leading to death, with the greatest increase in the last month of life (Figure 7.7a).

The percentage of men and women with dementia presenting to the ED in each month was similar to the percentages in those without dementia, with the exception of the last 3 months of life. For these final months, men and women with dementia presented to the ED less often than those without dementia. Around 44% of men and 35% of women with dementia presented to the ED in their last month of life, increasing from 8.6% of men and 7.2% of women 12 months before death. By comparison, 51% of men and 46% of women without dementia presented to the ED in their last month of life.

The average number of ED presentations per person also increased in the final months of life, irrespective of dementia status (Figure 7.7b). The average number per person in each month was slightly lower for men with dementia than for men without dementia. However for women, those with dementia had more ED presentations in each month on average than women without dementia.

Figure 7.7: Percentage of people in each month who presented to the ED at least once (a) and average number of ED presentations per person (b), by dementia status, sex and month before death



Note: Analysis includes men and women who died aged 65 and over in 2013.

8 Health service use in people with younger-onset dementia

This chapter provides a profile of people with younger-onset dementia who died (dementia in people who died aged less than 65) and their health service use in their last year of life compared with people with dementia who died aged 65 or over. Due to the small number of people identified with younger-onset dementia, finer disaggregation of the study group and their health service usage was not always possible.

It is important to note that as the age of dementia onset was not identifiable from the NDLDP database, it is acknowledged that people with younger-onset dementia may be included in the group of people with dementia who died aged 65 or over.

8.1 Younger-onset dementia profile

There were 248 people identified with younger-onset dementia who died in 2013 in New South Wales and Victoria (Table 8.1).

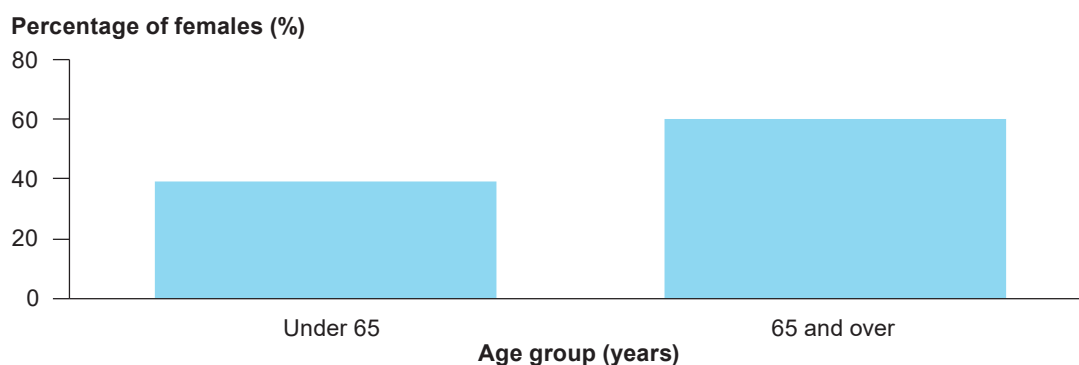
Down syndrome, unspecified was the leading underlying cause of death, responsible for 1 in 10 deaths. This was closely followed by *Unspecified dementia* (9.7% of deaths) and *Alzheimer's disease, unspecified* (8.1%). All remaining causes were responsible for fewer than 10 deaths each and included numerous conditions (such as Huntington's disease, Parkinson's disease, frontotemporal dementia, motor neurone disease, alcoholic cirrhosis of liver, vascular diseases and various cancers).

Table 8.1: Study population with younger-onset dementia, by leading underlying cause of death

Underlying cause of death	Number	Percent (%)
Down syndrome, unspecified	25	10.1
Unspecified dementia	24	9.7
Alzheimer's disease, unspecified	20	8.1
Remainder	179	72.2
Total	248	100.0

There were more males with younger-onset dementia (151 males; 61% of people with younger-onset dementia) than females (97 females; 39%) (Figure 8.1). By comparison, males represented 40% of people with dementia aged 65 and over. This sex distribution for younger-onset dementia was similar to the distribution for people with dementia who died aged 65–69 (64% men; 36% women).

Figure 8.1: Percentage of people with dementia who died in 2013 who were female, by age at death: younger-onset and aged 65 or over



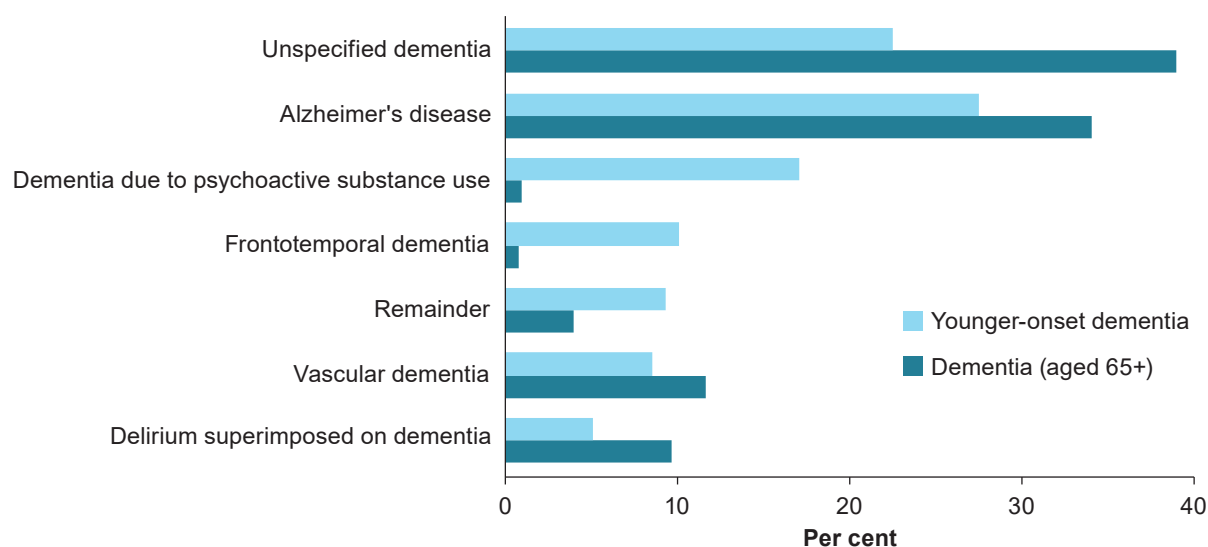
Dementia due to substance use and frontotemporal dementia were more common in people with younger-onset dementia

Unspecified dementia and *Alzheimer's disease* were the most common dementia types in people who died with younger-onset dementia, recorded in half of all the health administrative records with dementia diagnoses evident for this group (Figure 8.2).

Dementia due to psychoactive substance use and *frontotemporal dementia* were more common in records for those with younger-onset dementia than in records for those with dementia who died aged 65 and over. In the younger-onset group these conditions were recorded in 17% and 10% of records with a dementia diagnosis, respectively. By comparison, *dementia due to psychoactive substance use* was associated with only 1.0% of all dementia records in people who died aged 65 and over and for *frontotemporal dementia*, it was just 0.8%.

The less common dementia types (grouped into 'Remainder') were also more common in people with younger-onset dementia (9.3% of dementia diagnoses) than in people with dementia who died aged 65 or over (4.0%). Among people with dementia who died aged 65–69 also, *frontotemporal dementia* and the dementia types grouped in 'Remainder' (of which included *dementia due to psychoactive substance use* for this age group) were more common (see Chapter 3).

Figure 8.2: Dementia types across health service records: proportion of records by type of dementia recorded and age at death (younger onset and 65 or over)



Note: Remainder includes: Dementia with Lewy bodies, Dementia in Creutzfeldt-Jakob disease, Dementia in Huntington's Disease, Dementia in Human Immuno-deficiency Virus and Dementia in other diseases (remainder).

8.2 Health service usage in last year of life

Everyone with younger-onset dementia in the NDLDP database who died in 2013 used at least 1 health service in their last year of life. However the percentage of people using a service and average number of services used differed between those with younger-onset dementia and those with dementia who died aged 65 and over (Table 8.2).

GP services were used most (96% of people with younger-onset dementia) closely followed by dispensing of prescriptions (95%). The average number of prescriptions dispensed to a person with younger-onset dementia in their last year of life was lower than the average number dispensed to a person in the 65 and over group. This may be due to fewer co-morbidities in younger people with dementia; differences in the type of co-morbidities; or to the exclusion of data on prescriptions priced below the general co-payment level (under co-payment) in the NDLDP database. Refer to Appendix A for detailed information on the individual data sources included in the NDLDP database.

On average, a person who died with younger-onset dementia had an additional 2 hospitalisations in their last year of life compared with a person with dementia who died aged 65 or over. The average number of ED presentations and specialist services were also slightly higher for people with younger-onset dementia (3.2 ED presentations and 1.8 specialist services) than for the 65 and over group (1.7 ED presentations and 1.1 specialist service).

Table 8.2: Percentage of people who died with dementia using a health service at least once in their last year of life and average number of health services used per person, by age at death

Health service	Percent (%) of people using a health service at least once		Average number of health services used, per person ^(a)	
	Younger-onset dementia	Dementia in people aged 65+	Younger-onset dementia	Dementia in people aged 65+
GP services	96.0	89.7	22.4	21.2
Specialist services	50.8	32.6	1.8	1.1
Prescriptions dispensed	94.8	85.7	53.9	59.2
Hospitalisations	77.4	65.7	3.8	2.2
ED presentations	76.2	67.9	3.2	1.7
Any health service	100.0	98.4

(a) Average number of health services per person includes people who did not use a health service in their last year of life.

Prescriptions dispensed to people with younger-onset dementia

Opioids were the leading drug type dispensed to people with dementia in their last year of life (Table 8.3). Around 12% of prescriptions dispensed to people with younger-onset dementia in this period were for opioids, compared with 10% of prescriptions dispensed to the group who died aged 65 or over.

For people with younger-onset dementia, other leading drug types dispensed were antiepileptics (8.6), antipsychotics (8.4) and antidepressants (8.0%). These drug types accounted for a greater proportion of prescriptions dispensed to people with younger-onset dementia than to the group who died aged 65 or over. Antiepileptics, anxiolytics (to treat anxiety) and hypnotics and sedatives were leading drug types dispensed to people with younger-onset dementia but were not among the leading types dispensed to those with dementia who died aged 65 or over.

Table 8.3: Leading drug types dispensed to people in the last year of life, younger-onset dementia compared with dementia in people who died aged 65 or over.

Rank	Drug type dispensed to people with younger-onset dementia (ATC3 level)	Per cent	Drug type dispensed to people with dementia who died aged 65 and over (ATC3 level)	Per cent
1	Opioids (N02A)	11.8	Opioids (N02A)	10.3
2	Antiepileptics (N03A)	8.6	Other analgesics and antipyretics (A02B)	7.4
3	Antipsychotics (N05A)	8.4	Drugs for peptic ulcer and GORD (A02B)	7.0
4	Antidepressants (N06A)	8.0	Antidepressants (N06A)	6.3
5	Drugs for peptic ulcer and GORD (A02B)	6.7	Antipsychotics (N05A)	4.7
6	Other analgesics and antipyretics (A02B)	5.4	Antithrombotic agents (B01A)	4.7
7	Drugs for constipation (A06A)	4.5	Lipid modifying agents, plain (C10A)	4.4
8	Anxiolytics (N05B)	3.8	Drugs for constipation (A06A)	3.5
9	Lipid modifying agents, plain (C10A)	3.4	ACE inhibitors, plain (C09A)	2.9
10	Hypnotics and sedatives (N05C)	2.8	Beta-lactam antibacterials, other (J01D)	2.5

Note: GORD refers to gastro-oesophageal reflux disease; ACE refers to angiotensin-converting enzyme.

Similarly to people with dementia who died aged 65 and over, paracetamol was the leading individual medication dispensed to people with younger-onset dementia, responsible for 5.2% of all prescriptions dispensed to them in the last year of life. This was followed by:

- valproic acid (5.0%, for epilepsy and bipolar disorder)
- oxycodone (3.2%, for moderate and severe pain relief)
- pantoprazole (2.8%, for gastro-oesophageal issues)
- diazepam (2.8%, for anxiety and alcohol withdrawals).

With the exception of pantoprazole, each of the medications listed above comprised a greater percentage of prescriptions dispensed to people with younger-onset dementia in their last year of life than of those dispensed to people with dementia who died aged 65 and over.

How did health service use vary by month over the last year of life?

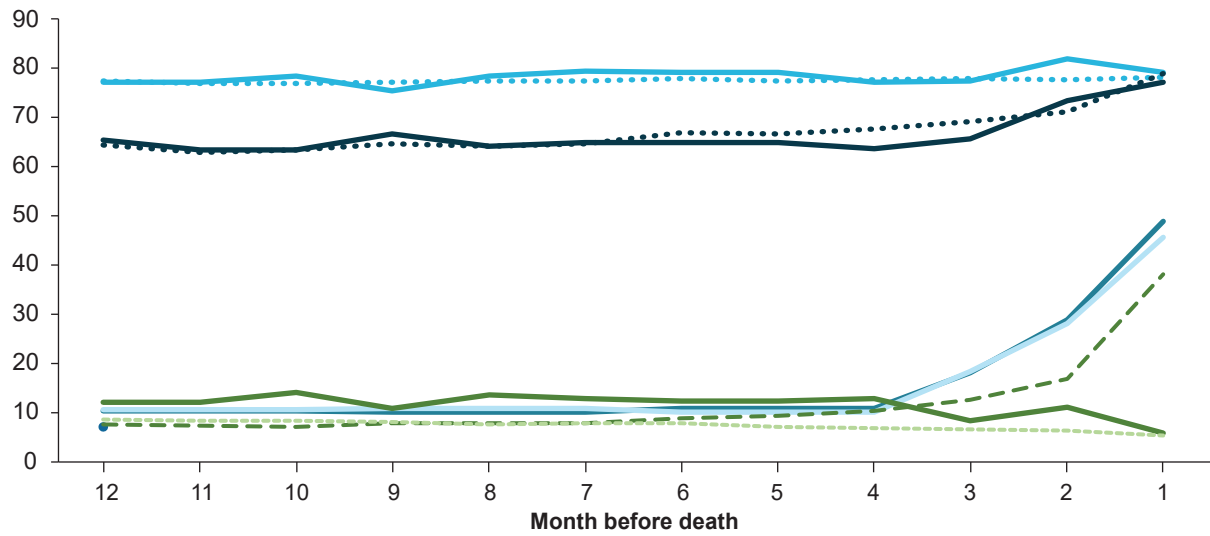
Patterns of health service use over the last 12 months of life for people with younger-onset dementia were mostly similar to the patterns observed in people with dementia who died aged 65 or over (Figure 8.3). Health service usage was generally consistent from 12 to 3 months before death, but was markedly different in the final 3 months of life.

The percentage of people with younger-onset dementia who were admitted to hospital or presented to the ED increased substantially in the final 3 months of life, and was greater than for people with dementia who died aged 65 and over. Almost half of people with younger-onset dementia (49%) were admitted to hospital and 46% presented to the ED in their final month of life, compared with 38% in both hospital services for people with dementia who died aged 65 and over.

The percentage of people using GP services also increased in the final 3 months of life: 77% of people with younger-onset dementia and 79% of people with dementia who died aged 65 and over used this service in their final month of life. Specialist services was the only type of health service where use decreased over the last year of life, from 12% of people with younger-onset dementia at 12 months before death to 6% in the final month of life. The percentage of people who were dispensed a prescription remained stable in both dementia study populations.

Figure 8.3: Percentage of people with dementia who used a health service at least once, by age group at death and month before death

Percentage (%) of people who used a health service at least once



Note: For those aged 65 or over at death, the line for 'Hospitalisations' is shown behind the 'ED presentations' line. The percentage who were hospitalised in their last 12 months of life was similar to the percentage who presented to the emergency department in their last 12 months of life for those with dementia who died aged 65 or over.

9 Discussion

This report describes patterns of health service use in the last year of life by people who died in 2013 in New South Wales and Victoria. Health service usage by people with dementia who died aged 65 and over was compared with usage by people without dementia who died aged 65 and over. In addition, health service usage by people with younger-onset dementia who died in 2013 was compared with usage by people with dementia who died aged 65 and over. Furthermore, this report provides age and sex profiles of the study groups, their leading causes of death and the leading dementia types recorded in people identified from the linked database as having dementia.

It was not possible to examine the factors influencing health service use with the available data. Evidence suggests service use at end of life by people with dementia is influenced by place of care (such as residential aged care facility or in their own home), care needs and quality of care, level of advanced care planning, health-care access and the number and type of co-morbidities (Browne, Edwards & Rhodes 2017; Dyer et al. 2018; Forma et al. 2011). As the NDLDP database did not include aged care data, differences in health service usage by place of residency or by time of entry into a residential aged care facility could not be examined.

In addition, it is important to bear in mind that health service usage is likely to be influenced by personal or family views as well as physician views—particularly as these relate to quality of life.

The lower number of health services used by people with dementia compared with people without dementia is also not indicative of the burden dementia is placing on the health-care system. For example, each hospital episode for people with dementia has been shown to be more costly on average than for those without dementia (AIHW 2013).

9.1 Key findings

Almost every person in this study used at least 1 health service in their last year of life. However, usage varied by age, sex, dementia status and time before death.

People who died aged over 65

Overall, in their last year of life people with dementia who died aged 65 or over used health services less than people without dementia who died aged 65 and over. The greatest difference was in use of specialist services—33% of people with dementia compared with 64% of people without dementia. In their last year of life, men and women with dementia used health services less than those without a record of dementia, however the greatest difference was seen between women with and without dementia.

The use of each health service decreased with age, irrespective of dementia status. With the exception of dispensing of prescription medications, across all ages, a smaller proportion of men and women with dementia used each health service in their last year of life than men and women without dementia.

With the exception of GP services, the average number of health services used in their last year of life was lower for people with dementia than for people without dementia in the same year. GP services were used more frequently by people with dementia in their last year of life, an average of 21 consultations for a person with dementia compared with 18 consultations for a person without dementia. Around 70% of men and 79% of women with dementia received a GP service in a

residential aged care facility, compared with only 24% of men and 37% of women without dementia who died aged 65 and over. This reflects the high level of care required for people with advanced dementia, often provided by residential aged care services.

Overall, hospitalisations and ED presentations increased in the lead-up to death and were most common in the final month of life. Around 45% of men and 34% of women with dementia were hospitalised in the last month of life, compared with 58% of men and 52% of women without dementia in their final month of life. This increased from 8.5% of men and 6.6% of women with dementia, and 10.9% of men and 9.0% of women without dementia 12 months before death. Around 44% of men and 35% of women with dementia presented to the ED in their final month of life compared with 51% of men and 46% of women without dementia in their final month of life.

People with younger-onset dementia

Proportionally more people with younger-onset dementia used a health service at least once in their last year of life than people with dementia who died aged 65 or over. The greatest difference was in the use of specialist services (51% of people with younger-onset dementia compared with 33% of people with dementia who died aged 65 or over).

People with younger-onset dementia who died had on average an additional 2 hospitalisations, 1 ED presentation, 1 GP and 1 specialist service in their last year of life compared with the older group. The average number of prescription medications dispensed to people with younger-onset dementia who died was slightly lower than the number dispensed to people in the older group.

9.2 Strengths, data gaps and future directions

Results from this study provide a greater understanding of health service use by people with dementia in their final year of life. However, further studies are needed to gain a more comprehensive picture of people with dementia and their interaction with Australia's health system.

Use of linked data and need for aged care data to identify dementia

A key strength of this study was the use of linked administrative health data, which was essential to assess health service use by a person (rather than by service), as well to identify people with dementia.

The number of people identified with dementia in this study was greatly increased by using linked data. Of those identified with dementia, 67% were identified from their death record, 66% from a hospital admission prior to death and 20% from a prescription for an anti-dementia medication (Table 9.1). The inclusion of earlier years of hospital and PBS data may have identified more people with dementia.

Around 36% of people with dementia were identified using 2 data sources and only 8.2% were identified in all 3 data sources. The small number of people who had dementia recorded in multiple data sources reflects the inconsistency in the coding of dementia diagnoses in health administrative data. An Australian study which estimated the number of women in Australia living with dementia using longitudinal survey data linked with administrative data found that aged care data identified 79% of women with dementia in their study, 56% were identified in hospitals data, 35% using prescription data and 31% using deaths data (Waller, Mishra & Dobson 2017). Furthermore, coding changes and variations in certification practices have resulted in an increase in deaths coded to dementia, as well as changes to the types of dementia recorded in 2013 as an underlying cause of death (ABS 2015).

Despite this, the group of people who died aged 65 and over who were identified as having dementia had distinct differences in their patterns of health service use compared with the group without dementia. This may indicate that the data linkage approach to identifying cases of dementia is successful and could be adapted and used on national linked data to estimate the prevalence of dementia in Australia. Further work is required to assess how many cases of dementia were missed and the optimum retrospective analysis required to identify the majority of dementia cases.

Table 9.1: People identified with dementia by identifying data set and number of data sets

	Number	Percent of total
<i>Dataset</i>		
Deaths (NDI)	12,906	67.1
Hospitals (NHMD)	12,603	65.6
Prescription (PBS)	3,796	19.7
<i>Number of individual datasets</i>		
1	10,708	55.7
2	6,945	36.1
3	1,569	8.2

Note: The data set percentage adds to greater than 100% as a person may have dementia recorded on more than one data set.

Dementia identification could have been improved with the inclusion of residential and community-based aged care data. A study by Waller, Mishra & Dobson (2017), which estimated dementia prevalence in Australia using linked administrative and survey data, found aged care data was the most robust source for identifying women with dementia. Of the women identified with dementia in their study, 79% were identified using diagnostic information from the Aged Care Assessment Program and Aged Care Funding Instrument. Hospitals data identified 56%, prescription data 35% and deaths data 31% of women with dementia.

Issues with identifying dementia onset in younger-onset group

As the age of dementia onset could not be identified in the NDLD database, people who developed dementia when they were aged under 65 but died when they were 65 or over would not have been included in the younger-onset dementia group. As health service use patterns in people identified with younger-onset dementia in the study were similar to those with dementia who died aged 65–74, it is possible people with dementia who died aged 65–75 had developed dementia before they were 65 and therefore had younger-onset dementia. Future studies should consider the use of GP and specialist clinical data that identifies age of diagnosis (or similar information) if available, to correctly identify people with younger-onset dementia. In addition, studies could factor in the age at which dementia diagnoses first appear in health records. The development of national dementia clinical registries, such as the Australian Dementia Network, Clinical Quality Registry and the state-wide Registry of Senior Australians, could help improve identification of people with dementia—particularly those with younger-onset dementia—and assess their usage of health and aged care services (NHMRC 2019; ROSA 2019).

Comparisons with other studies and factors influencing health service use

Patterns of health service use in women with dementia in their final year of life in this study were similar to those reported in the study by Dobson and others (forthcoming 2020), which examined health service use by older Australian women in their last 2 years of life. The Dobson study linked survey data from the Australian Longitudinal Study on Women's Health (data from a cohort of women born between 1921 and 1926) to PBS, MBS, hospitals, aged care and mortality data. Both studies found GP services were used by a greater proportion of women with dementia and specialist services used by a lower proportion of women with dementia in the lead-up to death. In addition, both studies reported women with dementia towards end of life spent longer in hospital than other women and that hospitalisations increased in the final month of life.

The study by Dobson and others reported a similar proportion of women with dementia were hospitalised (62%), but the proportions using a GP service (99%), specialist service (55%) or who were dispensed prescription medication (99%) were greater than observed in this study (88%, 33% and 86% respectively). This may be due to the differences in the study period (2 years before death compared with 1 year in this study), in the study population age differences (women born between 1921 and 1926 compared with all women who died in 2013 aged 65 or over in this study) and in the identification of dementia in the data sources used.

The greater use of hospital services by men with dementia than women was also observed in a Canadian population-based cohort study of people with advanced dementia in residential aged care facilities. The study used linked administrative data to assess the number of people and sex differences in those with advanced dementia who experienced health care considered burdensome for people with advanced dementia (including ED presentations, hospitalisations and invasive procedures). Men with advanced dementia were significantly more likely to receive a burdensome intervention than women in the last 30 days of life (Stall et al. 2019). A number of factors are believed to contribute to these differences, including men having increased co-morbidities, experiencing more aggressive behavioural symptoms and having a decreased involvement in advanced care planning (Stall et al. 2019; Yu et al. 2019; Perkins et al. 2004; Teixeira et al. 2013)

This study reported principal diagnoses and drug types by number of hospitalisations and prescriptions dispensed, respectively. Analyses could be improved by examining leading principal diagnoses and drug types by the number of people, rather than the number of services. In addition, examination of the diagnoses associated with prescribed medicines would assist in understanding the type and level of co-morbidity among people with dementia.

While this study provides an overall picture of health service use by people with dementia in their last year of life and how this differs from others, it was not possible to assess other contributing factors influencing health service use. Analyses of service use based on the number of co-morbidities in addition to dementia would provide greater insight into health service utilisation by people with the greatest care needs, and how this differs in the final year of life. In a United Kingdom study, people with dementia who also had 6 or more chronic conditions had higher rates of hospitalisation, prescriptions and primary care consultations than those with 3 or fewer conditions (Browne et al. 2017).

People with dementia, particularly in the advanced stages, have high-level care needs—an estimated 52% of people living in aged care facilities in Australia have dementia (AIHW 2019c). Health service use by people with dementia receiving care in residential care facilities may differ from use by people with dementia who do not live in residential care. A recent AIHW study using linked administrative

data found that the patterns of service use by older Australians varied with use of aged care services. People who were in residential aged care were less likely to use a GP or specialist service, or be admitted to hospital than people who used community-based aged care services (AIHW 2019d). This study could not directly identify people living in residential aged care facilities or people receiving community-based aged care services, so could not examine whether or not patterns of health service utilisation were affected by place of residence or care type. Further, it would be beneficial to examine health service usage not only by place of care but by the level of support received in the community. A recent Australian study has shown people with dementia who received support from high-level home care packages had the highest need for assistance upon entry into residential aged care (Welberry et al. 2019).

In addition, health service use by people with dementia may differ depending on the model of care adopted by the residential aged care facility. Australian studies have shown residents who lived in facilities providing a home-like model of care had lower rates of hospitalisation and ED presentation and were less likely to be exposed to potentially inappropriate medications than those living in facilities with a standard care model (Dyer et al. 2018; Harrison et al. 2018).

Future directions

The NDLDP database contained linked administrative data from New South Wales and Victoria, providing data on an estimated 60% of the Australian population (ABS 2018). Linking data from additional states would provide a more comprehensive picture of the number of people with dementia in Australia and their health service use, as well as the capacity to assess variations across geographical areas and population groups.

The AIHW has recently created the National Integrated Health Services Information Analysis Asset (NIHSI AA) Version 0.5 which contains de-identified data from 2010–11 to 2016–17 on admitted patient care services (in all public and, where available, private hospitals); ED services; and outpatient services in public hospitals for all participating states and territories (New South Wales, Victoria, South Australia and Tasmania). It also includes national data for the same period from the MBS, PBS and Repatriation PBS, NDI and residential aged care data. Analyses undertaken using NIHSI AA will be able to expand upon on the work in this study to examine health service usage by people with dementia living in residential aged care facilities, compared to those living in the community.

There are likely to be many underlying causes for the differences in patterns of health service use for people with dementia in their last year of life. With the inclusion of aged care data that contain dementia diagnoses, findings in this report could be expanded not only to identify people with dementia who might have been missed in this study, but also to examine health service use by the care setting provided. Examining influencing factors of service usage, as well as its impact on Australia's health and aged care system, is an important area for future research.

Appendix A: Detailed methods

National Data Linkage Demonstration Project Database

The National Data Linkage Demonstration Project (NDLDP) database was created under the auspices of the Australian Health Ministers' Advisory Council National Health Information and Performance Principal Committee. The de-identified data were made available to selected analysts nominated by the New South Wales Ministry of Health, the Victorian Agency for Health Information, the Australian Government Department of Health and the AIHW.

The linked database contains records of individuals who met any of the following criteria:

- resided in New South Wales and Victoria between July 2010 and June 2015, based on their Medicare records
- received treatment in a public hospital in New South Wales and Victoria between July 2010 and June 2015 (irrespective of their state or territory of residence)—hospital admissions and non-admitted emergency department episodes
- received services provided by the Medicare Benefits Schedule (MBS) and prescriptions dispensed under the Pharmaceutical Benefits Scheme (PBS) from health providers in New South Wales and Victoria between July 2010 and June 2015 (irrespective of their state or territory of residence)
- were provided MBS services and dispensed PBS prescriptions outside New South Wales and Victoria between July 2010 and June 2015 for New South Wales and Victorian residents as recorded on the Medicare Enrolment file at date of service/dispensing
- died between July 2010 and December 2015 (from all states and territories).

The NDLDP database comprises data from the Admitted Patient Care Database, National Non-Admitted Patient Emergency Department Care Database, PBS database, MBS database and the National Death Index.

Hospital admission and emergency department presentation

The NDLDP database contains de-identified extracts from the Admitted Patient Care and Non-admitted Patient Emergency Department Care hospitals data. The Admitted Patient Care data comprise episodes of treatment and/or care provided following admission in hospital and/or in the person's home (for hospital-in-the-home patients). The Non-admitted Patient Emergency Department Care data comprise episodes of care of patients who physically presented to EDs and registered for care in public hospital emergency departments.

In this report, hospital events were limited to episodes of care in New South Wales and Victorian public hospitals only. The analysis does not include interstate hospital services received by New South Wales and Victorian residents (which may be common for people living close to state and territory borders) or services received in private hospitals.

Diagnoses recorded in hospital admissions data are coded using the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM). Procedures are coded using the Australian Classification of Health Interventions. Diagnostic information was not available for the ED presentation data for the years of interest in the study.

Hospital admissions and ED presentations by age, sex, days prior to death and dementia status were analysed in this report. Additional information obtained from hospital admissions data included diagnostic information (principal and additional diagnoses), procedures and length of stay.

Medicare Benefits Schedule

The MBS data collection contains MBS claims data for Medicare services subsidised by the Australian Government. GP and specialist services by age, sex, days prior to death, dementia status and leading specialist types were analysed for this report.

Table A1 outlines the variables used to identify GP and specialist services (by speciality type) reported in the study. For GP services, this includes GP and Vocationally Registered GP attendances, enhanced primary care and other non-referred attendances (including attendances in residential aged care facilities). Data on GP services from the MBS exclude services provided to Department of Veteran Affairs (DVA) card holders where care is reimbursed through the DVA, as well as services provided by salaried GPs in residential aged care or outpatients departments.

Specialty types were classified into subspecialties based on the Derived Major Specialty—used to allocate practitioners to a single specialty each period for statistical purposes. As specialists may have more than 1 registered specialty, service patterns for each specialist are used to classify the most appropriate specialty.

Table A1: GP and specialist service analysis variables and descriptions

Type of service, description and variables used	
<i>GP services</i>	<i>Broad type of service group code</i>
GP and Vocationally Registered GP	A/101
Enhanced primary care	M/102
Other	B/103
<i>GP services</i>	<i>MBS Item</i>
Attendance in a residential aged care facility ^(a)	0020, 0035, 0043, 0051, 0092, 0093, 0095, 0096, 0903, 2125, 2138, 2179, 2220, 5010, 5028, 5049, 5067, 5260, 5263, 5265, 5267
<i>Specialist service</i>	<i>Registered specialty codes</i>
Internal medicine	0001, 0081
General medicine	0002, 0082
Cardiology	0004, 0084
Haematology	0005, 0026, 0085
Nephrology	0008, 0088
Neurology	0009, 0089
Respiratory and sleep medicine	0014, 0094
Geriatric medicine	0016, 0096
Medical oncology ^(b)	0017, 0049, 0097, 0804
General surgery	0031, 0032, 0411
Urology	0038
Dermatology	0052, 0401
Ophthalmology	0054, 0406
Psychiatry	0056, 0099, 0409
Specialist unclassified	..

(a) MBS item numbers for attendances in a residential care facility are also included in Broad type of service group A/101 or B/103

(b) Includes radiation oncology and gynaecological oncology.

Pharmaceutical Benefits Scheme

The PBS database contains all government-subsidised prescriptions dispensed under the PBS. Data for prescriptions that are priced below the general co-payment level (under co-payment) were not included in the NDLD database. As under co-payment data were not available, the total number of prescriptions dispensed as reported in this study is an undercount and the leading types of medicines dispensed may have differed with inclusion of under co-payment data. The PBS also does not contain data on dispensing of privately prescribed medications, medications to public hospital in-patients and over-the-counter medicines.

PBS items were mapped to the Anatomical Therapeutic Chemical (ATC) Classification, a classification system for medicines maintained by the World Health Organization. The ATC classification groups medicines according to the body organ or system on which they act, and their therapeutic and chemical characteristics. Medicines are given an ATC classification in the Schedule of Pharmaceutical Benefits according to their main therapeutic use in Australia as registered with Therapeutic Goods Administration and listed on the PBS.

More information on the ATC classification system can be found at https://www.whooc.no/atc/structure_and_principles/.

Table A2 displays the medications defined in this report by ATC1 level (for example, Alimentary tract and metabolism), ATC2 level (for example, Drugs for acid related disorders), ATC3 level (for example, Drugs for peptic ulcer and GORD) and ATC5 level (for example, pantoprazole).

Table A2: Medications defined in this report, by ATC code.

ATC code	Description
A	Alimentary tract and metabolism
A02	<i>Drugs for acid related disorders</i>
A02B	Drugs for peptic ulcer and GORD
A02BC02	Pantoprazole
A02BC05	Esomeprazole
A06	<i>Drugs for constipation</i>
A06A	Drugs for constipation
A06AD15	Macrogol
B	Blood and blood forming organs
B01	<i>Antithrombotic agents</i>
B01A	Antithrombotic agents
B01AA03	Warfarin
C	Cardiovascular system
C03	<i>Diuretics</i>
C03C	High ceiling diuretics
C03CA01	Furosemide
C07	<i>Beta blocking agents</i>
C07A	Beta blocking agents
C09	<i>Agents acting on the renin-angiotensin system</i>
C09A	ACE inhibitors, plain
C10	<i>Lipid modifying agents</i>
C10A	Lipid modifying agents, plain
C10AA05	Atorvastatin

(Continued)

J	Anti-infectives for systemic use
J01	<i>Antibacterials for systemic use</i>
J01D	Other Beta-lactam antibacterials
J01DB01	Cefalexin
N	Nervous system
N02	<i>Analgesics</i>
N02A	Opioids
N02AA05	Oxycodone
N02AE01	Buprenorphine
N02B	Other analgesics and antipyretics
N02BE01	Paracetamol
N03	<i>Antiepileptics</i>
N03A	Antiepileptics
N03AG01	Valproic acid
N05	<i>Psycholeptics</i>
N05A	Antipsychotics
N05AX08	Risperidone
N05B	Anxiolytics
N05BA01	Diazepam
N05C	Hypnotics and sedatives
N06	<i>Psychoanaleptics</i>
N06A	Antidepressants
R	Respiratory system
R03	<i>Drugs for obstructive airway diseases</i>
R03A	Adrenergics, inhalants
R03AC02	Salbutamol
R03B	Other drugs for obstructive airway diseases, inhalants.
R03BB04	Tiotropium bromide
S	Sensory organs
S01	<i>Ophthalmologicals</i>
S01X	Other ophthalmologicals
S01XA20	Artificial tears and other indifferent preparations

National Death Index

The NDI contains person-level records of deaths registered in Australia since 1980, obtained from the Registry of Births, Deaths and Marriages in each state and territory.

Deaths records from the NDI are supplemented with cause of death information using a once-off linkage with the National Mortality Database. Cause of death data in the NMD are sourced from the Registry of Births, Deaths and Marriages in each state and territory and the National Coronial Information System and compiled and coded by the Australian Bureau of Statistics (ABS). Cause of death information is derived from conditions listed on Part I and Part II of a death certificate and coded using the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10). In this report, the study groups were selected from deaths registered in New South Wales and Victoria in 2013.

Classification of dementia

In this study, a person with dementia was defined as a person from New South Wales or Victoria who died in 2013, where dementia was evident in the NDLDP database as:

- an underlying or associated cause of death
- a principal or additional diagnosis in any hospital admission between 1 July 2010 and their death
- they had 1 or more prescriptions for an anti-dementia medication between 1 July 2010 and their death.

The ICD-10 is used to classify cause of death in the NDI and the ICD-10 Australian Modification (ICD-10-AM) is used to classify principal and additional diagnosis in the Admitted Patient Care data. Table A3 outlines the ICD-10 and ICD-10-AM codes to classify dementia by type in the study. This includes all possible types of dementia.

In addition, supply of 4 different types of anti-dementia medications as recorded in the PBS database was also used to identify people with dementia (Table A3).

Types of dementia

The number of people with dementia and their diagnosed dementia type(s) were identified from dementia diagnoses recorded on their death certificate, in a hospital admission and/ or whether they were prescribed anti-dementia medication (as these medications are subsidised by the Australia Government only for people diagnosed with Alzheimer's disease).

In this study, the number of dementia types recorded for each person was counted once, irrespective of the number of times the diagnosis was recorded in the NDLDP database. For example, if a person had *Alzheimer's disease* and *Vascular dementia* recorded in a hospital admission as well as on their death certificate, this would be counted as a single Alzheimer's disease diagnosis and as a single vascular dementia diagnosis.

Unspecified dementia was counted only when no other dementia type was recorded for that person. For example, if a person had *Alzheimer's disease* recorded in a hospital admission and *Unspecified dementia* recorded on their death certificate, then this person was considered to have only Alzheimer's disease.

It is acknowledged that if additional years of data or additional clinical diagnostic data were available in the NDLDP database, the percentages of dementia types reported in this study might have differed. Further studies on the variation of dementia types recorded across administrative health data are required to inform how this should be managed when reporting on dementia types using linked data.

Table A3: Codes used to identify dementia by data source

Data source	Classification and dementia-specific codes
Mortality	ICD-10 diagnosis code
Dementia (all types)	F00.0, F00.1, F00.2, F00.9, F01.0, F01.1, F01.2, F01.3, F01.8, F01.9, F02.0, F02.1, F02.2, F02.3, F02.4, F02.8, F03, G30.0, G30.1, G30.8, G30.9
Hospitalisations	ICD-10-AM diagnosis code
<i>Dementia type</i>	
Alzheimer's disease	F00.0, F00.1, F00.2, F00.9, G30.0, G30.1, G30.8, G30.9
Vascular dementia	F01.0, F01.1, F01.2, F01.3, F01.8, F01.9
Fronto-temporal dementia	F02.0 <i>and</i> G31.0 ^(a)
Dementia in Creutzfeldt-Jakob disease	F02.1 <i>and</i> A81.0 ^(a)
Dementia in Huntington's disease	F02.2 <i>and</i> G10 ^(a)
Dementia in Parkinson's disease	F02.3 <i>and</i> G20 ^(a)
Dementia in human immunodeficiency virus (HIV) disease	F02.4 <i>and</i> B22 ^(a)
Lewy Body dementia	F02.8 <i>and</i> G31.3 ^(b)
Dementia in other diseases (remainder)	F02.8 <i>and not</i> G31.3
Dementia due to psychoactive substance use	F10.7, F13.7, F18.7
Unspecified dementia	F03
	<i>and not</i>
	F00.0, F00.1, F00.2, F00.9, G30.0, G30.1, G30.8, G30.9, F01.0, F01.1, F01.2, F01.3, F01.8, F01.9, F02.0, F02.1, F02.2, F02.3, F02.4, F02.8, F10.7, F13.7, F18.7
Delirium superimposed on dementia	F05.1
	<i>and not</i>
	F00.0, F00.1, F00.2, F00.9, G30.0, G30.1, G30.8, G30.9, F01.0, F01.1, F01.2, F01.3, F01.8, F01.9, F02.0, F02.1, F02.2, F02.3, F02.4, F02.8, F03, F10.7, F13.7, F18.7
Prescriptions	ATC code
<i>Drug name</i>	
Donepezil	N06DA02
Rivastigmine	N06DA03
Galantamine	N06DA04
Memantine	N06DX01

(a) Indicates that the dementia type is valid regardless of whether the hospitalisation also includes this code.

(b) Indicates that the dementia type is only valid when the hospitalisation also includes this code.

Appendix B: Additional tables

Table B1: Leading associated cause of death in study population who died aged 65 and over, by dementia status and sex

Rank	Associated cause of death in people with dementia	Per cent	Associated cause of death in people without identified dementia	Per cent
<i>Males</i>				
1	Unspecified dementia	13.7	Personal history of tobacco use disorder	15.9
2	Unspecified urinary incontinence	12.6	Primary hypertension	8.5
3	Personal history of tobacco use disorder	12.0	Palliative care	7.8
4	Primary hypertension	10.8	Type 2 diabetes mellitus with established diabetic nephropathy	5.3
5	Dysphagia	8.7	Type 2 diabetes mellitus without complications	5.3
6	Acute kidney failure, unspecified	7.1	Acute kidney failure, unspecified	5.1
7	Faecal incontinence	7.1	Secondary malignant neoplasm of liver and intrahepatic bile duct	4.7
8	Type 2 diabetes mellitus without complications	6.6	Secondary malignant neoplasm of bone and bone marrow	4.6
9	Volume depletion	6.3	Chronic kidney disease, stage 5	3.9
10	Dementia in Alzheimer's disease, unspecified	5.8	Tobacco use, current	3.8
<i>Females</i>				
1	Unspecified dementia	16.0	Primary hypertension	13.2
2	Unspecified urinary incontinence	13.9	Palliative care	9.2
3	Primary hypertension	11.5	Personal history of tobacco use disorder	8.4
4	Urinary tract infection, site not specified	8.6	Secondary malignant neoplasm of liver and intrahepatic bile duct	5.3
5	Faecal incontinence	8.4	Acute kidney failure, unspecified	5.2
6	Volume depletion	7.8	Type 2 diabetes mellitus without complications	5.1
7	Dysphagia	7.2	Congestive heart failure	5.0
8	Acute kidney failure, unspecified	7.2	Urinary tract infection, site not specified	4.3
9	Dementia in Alzheimer's disease, unspecified	7.1	Type 2 diabetes mellitus with established diabetic nephropathy	4.2
10	Type 2 diabetes mellitus without complications	6.6	Volume depletion	3.9

Table B2: Leading 10 medications dispensed to people who died aged 65 and over in the last year of life, by dementia status

Rank	Medication dispensed to people with dementia	Per cent	Medication dispensed to people without dementia	Per cent
1	Paracetamol	7.3	Paracetamol	4.0
2	Buprenorphine	4.2	Oxycodone	3.3
3	Pantoprazole	2.7	Atorvastatin	2.7
4	Artificial tears and other indifferent preparations	2.5	Pantoprazole	2.7
5	Cefalexin	2.3	Furosemide	2.5
6	Macrogol	2.3	Esomeprazole	2.4
7	Risperidone	2.2	Warfarin	2.0
8	Atorvastatin	2.2	Salbutamol	2.0
9	Furosemide	2.0	Tiotropium bromide	1.8
10	Oxycodone	1.9	Cefalexin	1.7

Table B3: Leading 10 additional diagnoses for hospitalisations in the last year of life of people who died aged 65 and over, by dementia status

Rank	Additional diagnosis in people with dementia	Per cent	Additional diagnosis in people without dementia	Per cent
1	Unspecified dementia	19.6	Personal history of tobacco use disorder	15.4
2	Unspecified urinary incontinence	16.5	Primary hypertension	11.4
3	Primary hypertension	14.3	Palliative care	10.3
4	Dysphagia (difficulty swallowing)	10.5	Acute kidney failure, unspecified	7.5
5	Volume depletion	10.4	Type 2 diabetes mellitus without complication	6.3
6	Personal history of tobacco use disorder	10.3	Volume depletion	5.8
7	Urinary tract infection, site not specified	10.2	Type 2 diabetes mellitus with established diabetic nephropathy	5.8
8	Acute kidney failure, unspecified	9.6	Hypotension, unspecified	5.8
9	Faecal incontinence	9.3	Secondary malignant neoplasm of liver	5.7
10	Type 2 diabetes mellitus without complication	7.9	Constipation	5.7

Table B4: Overnight hospitalisations in the last year of life of people who died aged 65 and over, by dementia status

	People with dementia	People without dementia
Number of overnight hospitalisations	30,911	114,728
Average number of bed days, per person	9.2	9.2
Percentage (%) of all hospitalisations	74.1	57.4

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Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ATC	Anatomical Therapeutic Chemical
DVA	Department of Veteran Affairs
ED	Emergency department
GP	General practitioner
ICD-10	International Classification of Diseases 10th Revision
ICD-10-AM	International Classification of Diseases 10th Revision, Australian Modification
MBS	Medicare Benefits Schedule
NDI	National Deaths Index
NDLDP	National Data Linkage Demonstration Project
NHMD	National Hospital Morbidity Database
NIHSI AA	National Integrated Health Service Information Analysis Asset
PBS	Pharmaceutical Benefits Scheme

Symbols

<	less than
—	nil or rounded to zero
..	not applicable
n.a.	not available
%	percentage
+	plus

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Related publications

The following Australian Institute of Health and Welfare publications relating to dementia and/or health service use in people using aged care services might also be of interest:

- AIHW 2012. Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW.
- AIHW 2018. Australia's health 2018. Australia's health series no. 16. Cat. no. AUS 221. Canberra: AIHW.
- AIHW 2019. Hospital care for people with dementia 2016–17. Cat. no. AGE 94. Canberra: AIHW.
- AIHW 2019. Dispensing patterns for anti-dementia medications 2016–17. Cat. no. AGE 95. Canberra: AIHW.
- AIHW 2019. Interfaces between the aged care and health systems in Australia— first results. Cat. no. AGE 99. Canberra: AIHW.



This report examined the health service usage of people with dementia in their last year of life and the findings have important implications for Australia's health and aged care systems. The report shows people with dementia who died aged 65 and over generally used health services less in their last year of life than people without dementia. People with younger-onset dementia used health services more than older people with dementia.

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