Palliative care for people living in residential aged care

The Australian Government subsidises residential aged care services for older Australians whose care needs are such that they can no longer remain in their own homes. Residential aged care services provide accommodation and services to people who require ongoing health and nursing care due to chronic impairments and a reduced degree of independence in activities of daily living. They provide nursing, supervision or other types of personal care required by the residents.

Data downloads

Palliative care in residential aged care tables 2018-19
Palliative care in residential aged care section 2018-19

This section was last updated in June 2020.

Key points

- There were 242,774 people who were permanent aged care residents in Australia in 2018-19, and of these residents, 4,341 (1.8%) had an Aged Care Funding Instrument (ACFI) appraisal indicating the need for palliative care.
- The proportion of ACFI appraisals indicating the need for palliative care for people within aged care facilities increases with the age of the resident.
- The population rate of appraised need for palliative care among people who were permanent residents was highest in Inner regional areas (30.2 per 100,000 population) followed by Outer regional (15.0) and Major cities (14.9).
- Almost 3 in 10 (27.7%) people who were permanent residents with an appraised need for palliative care had been diagnosed with cancer. The types of cancer most often recorded were lung cancer (17.0%) and colorectal (bowel) cancer (14.3%).

The provision of palliative care in residential aged care facilities is complex. Permanent residents often have dementia and/or communication difficulties and complex care needs (AIHW 2019). In addition, there is a high burden of chronic disease and comorbidity in the residential aged care population (Hillen, Vitry & Caughey 2017).
Palliative care provided in a residential aged care service is regulated under the *Aged Care Act 1997*, within the Quality of Care Principles. Under the schedule of specified care and services, an Approved Provider is responsible for providing access to a qualified practitioner from a palliative care team, and the establishment of a palliative care program including monitoring and managing any side effects for any resident that needs it. In addition, under Schedule 2 – Aged Care Quality Standards, an Approved Provider is responsible for ensuring the comfort and dignity of terminally ill care recipients is maintained.

The AIHW's National Aged Care Data Clearinghouse contains information gathered via a number of data collections. Data collected from the Aged Care Funding Instrument (ACFI), which is used to determine the level of Australian Government care subsidies for residential aged care service providers, has been used for the analyses presented here. Funding for palliative care under the ACFI is provided specifically for 'end of life' care, which takes place during the last days or week of a care recipient's life (DoH 2016). Permanent residents who have been appraised as requiring palliative care under the ACFI are included in the 'palliative care' group described in this section. Note that the ACFI is not a care planning tool, but a needs assessment undertaken by services for funding purposes. Comprehensive assessment considers a broader range of care needs than is required in the ACFI.

The number of ACFI claims involving palliative care is inherently lower than the total number of care recipients in residential aged care requiring palliative care. As specified in the ACFI User Guide, funding is provided for a *palliative care program involving end of life care where ongoing care will involve very intensive clinical nursing and/or complex pain management in the residential care setting.* For the purposes of the ACFI, 'end of life' relates to the resident's last week or days of their life. It should be noted that if a resident is already on the maximum ACFI Complex Health Care claim, services may not claim for palliative care as it is not possible to increase the subsidy payable in this situation.

The total number of care recipients in residential aged care requiring palliative care would be higher than the numbers contained in this report. In practice, it is possible to receive palliative care in residential aged care facilities without having received an ACFI appraisal indicating the need for end of life palliative care. Additionally, ACFI only records care required during the last days or week of a resident's life and doesn't take into account that palliative care may be delivered and/or required for a much longer period than this. Also note that the data available to the AIHW cannot confirm the extent or nature of palliative care actually provided for those who were funded for palliative care under the ACFI.

For more information on the data used in this report, refer to the data source section.
Characteristics of residential aged care residents needing palliative care

There were 242,774 people who were permanent residents in residential aged care in Australia in 2018–19, and of these, 4,341 (1.8%) had an ACFI appraisal indicating the need for end of life palliative care. There were 69,923 permanent admissions to residential aged care in 2018–19, of which 2,753 people (3.9%) had an ACFI appraisal indicating the need for end of life palliative care.

In 2018–19, a higher proportion of males who were permanent aged care residents were appraised as requiring palliative care compared with females (2.4% and 1.5% respectively). However, of people requiring palliative care, a higher number were female (2,302 or 53.0%).

The proportion of Indigenous people who were permanent aged care residents appraised as requiring palliative care was lower than that for other Australians (1.6% and 1.8% respectively).

The age profile of permanent residents who required palliative care and of other residents (those not appraised as requiring palliative care) during 2018–19 was very similar. For both groups the number of residents increased with age, and 61.0% of all residents were aged 85 years and older. For permanent admissions during 2018–19, a smaller proportion of people were in the 85 years and older age group (55.2%), indicating the slightly younger age of admissions compared with people who were permanent residents.

The age profile of people who were permanent residents appraised as requiring palliative care in 2018–19 differed slightly by sex (Figure AC.1), with a higher proportion of females aged 85 years and older compared with males (63.0% and 49.7% respectively).
Geographical distribution of palliative care in residential aged care

There were 17.2 people who were permanent residents appraised as requiring palliative care per 100,000 population in Australia in 2018–19, with rates varying across the states and territories. New South Wales had the highest number of people who were permanent residents appraised as requiring palliative care (35.5% of the national total). Tasmania had the highest population rate at 34.6 per 100,000 population, and the Northern Territory had the lowest rate (1.2 per 100,000 population).

The majority (69.8%) of people who were permanent aged care residents in 2018–19 lived in Major cities. Permanent aged care residents who lived in Major cities represented 61.6% of those who were appraised as requiring palliative care, and 70.0% of patients who were not appraised as requiring palliative care through their ACFI appraisal (Figure AC.2). The population rate of people requiring palliative care among permanent residents was highest for those in Inner regional areas (30.2 per 100,000 population) followed by Outer regional (15.0) and Major cities (14.9). The rate of care among other residents (i.e. those permanent residents not appraised as requiring palliative care...
through their ACFI appraisal) was also highest in *Inner regional* (1,168.5) areas, followed by *Major cities* (926.8) and *Outer regional* areas (888.6).

**Figure AC.2: Permanent residential aged care residents by palliative care status, remoteness area, 2018-19**

![Figure AC.2: Permanent residential aged care residents by palliative care status, remoteness area, 2018-19](image)

Source data: Palliative care in residential aged care Table AC.7 (KB XLS)

**Diagnoses**

Almost 3 in 10 (27.7%) people who were permanent residents assessed as requiring palliative care in 2018–19 had been diagnosed with cancer. Conditions recorded at ACFI are not necessarily related to palliative care status. However, differences are apparent in the distribution of cancer diagnosis by ACFI palliative care status. Among aged care residents who were diagnosed with cancer and who were also assessed as requiring palliative care, the most common cancer diagnoses were *lung cancer* (17.0%) and *colorectal (bowel) cancer* (14.3%). Among care residents not appraised as requiring palliative care, the most common cancer diagnoses were *prostate cancer* (18.9%) and *colorectal (bowel) cancer* (16.6%).

The non-cancer disease categories most often recorded among aged care residents requiring palliative care were *circulatory system* (26.5%) and *musculoskeletal* (12.6%). The distribution of non-cancer diseases did not differ greatly across care type, except for *musculoskeletal* disease, which was observed more frequently among residents not appraised as requiring palliative care (23.2%).
Some information on mental and behavioural conditions is also reported through the ACFI. About 2 in 5 (41.0%) residential aged care residents assessed as requiring palliative care in 2018–19 were diagnosed with dementia (including Alzheimer’s disease) compared with half (50.0%) of those not assessed as requiring palliative care. More than one quarter of all ACFI assessed residents were diagnosed with depression, other mood and affective disorders or bipolar disorder (27.0% for those appraised as requiring palliative care and 25.9% for other residents). Delirium was also more common among those assessed as requiring palliative care (4.1%) than other residents (1.5%).

It should be noted that identifying mental health conditions in older people may be difficult. For example, conditions such as dementia and depression are often under-diagnosed and under-treated in residential aged care and in the community. In addition, many mental health conditions share similar symptoms, which can present additional challenges in making a diagnosis. Further information is available from AIHW publications Dementia in Australia and Depression in residential aged care 2008–2012.

**Separation mode**

A separation from residential aged care occurs when a person who is a permanent resident stops receiving residential aged care from a particular facility. The reasons for separation (called the separation mode) indicate the destination of a resident at separation and are categorised as:

- death
- admission to hospital (note that a separation is not counted where the resident is granted hospital leave)
- return to community (such as to family or home)
- move to another residential aged care facility
- other.

Death was the mode of separation for the majority of residents, whether or not they received palliative care (97.4% for those appraised as requiring palliative care and 85.1% for other residents). Those permanent residents assessed as requiring palliative care were less likely than other residents to have a mode of separation of returning to the community (0.2% and 3.8% respectively) or moving to another residential aged care facility (0.4% and 7.6%). A similar proportion for both groups of residents (1.6%) had a mode of separation of going to hospital.

**Length of stay**

Among people who were permanent residents who separated from a residential aged care facility during 2018–19, people appraised as requiring palliative care were more...
likely to have a shorter length of stay than other residents. For permanent residents with a length of stay of less than 8 weeks, the proportion appraised as requiring palliative care during 2018–19 was more than 6 times greater than for other permanent residents (52.4% and 8.0% respectively) (Figure AC.3).

**Figure AC.3: Permanent residential aged care residents by palliative care status, length of stay, 2018-19**

![Pie chart showing the proportion of permanent residents appraised as requiring palliative care by length of stay during 2018-19](source: AIHW. Table AC.13)

Source data: Palliative care in residential aged care Table AC.13 (KB XLS)

**Hospital leave**

A person who is a permanent resident may require hospital leave (a temporary overnight stay in hospital which does not involve permanent discharge from aged care) in order to receive treatment in hospital. In 2018–19, the proportion of permanent residents assessed as requiring palliative care having an episode of hospital leave (31.4%) was similar to other residents (30.9%).

**Residential aged care residents and admissions over time**

The number of people who were permanent aged care residents and admissions appraised as requiring palliative care has trended downwards over the 5 years to 2018–19, with a small rise observed from 2016–17 to 2017–18 (Figure AC.4). Overall, the number of permanent residents appraised by approved providers as requiring ACFI...
funding for end of life palliative care decreased from 8,781 to 4,341 and permanent admissions from 3,716 to 2,753 between 2014–15 and 2018–19. The number of residents and admissions not assessed as requiring palliative care increased over the same period. There have not been any changes to the requirements of the ACFI User Guide since it was introduced in 2008 with regard to palliative care. However, the overall decrease in residential aged care permanent admissions and residents appraised as requiring palliative care is most likely related to changes in the application of the ACFI in recent years, rather than a change in the underlying need for palliative care.

Figure AC.4: Residential aged care permanent admissions and residents appraised as requiring palliative care, 2014-15 to 2018-19

Source data: Palliative care in residential aged care Table AC.15 (KB XLS)

References


Data source

National Aged Care Data Clearinghouse

Data on palliative care in residential aged care come from the AIHW's National Aged Care Data Clearinghouse. This Clearinghouse contains information gathered via a number of data collections. Data collected from the Aged Care Funding Instrument (ACFI) have been used for the analyses presented in this section.

The ACFI is a tool used to assess and provide basic information on the care needs of a person in permanent residential aged care. The results of the assessment are used to determine the level of government subsidy to residential aged care service providers, based on a person's need for care across 3 care domains:

- activities of daily living
- cognition and behaviour
- complex health care (DoH 2016).

ACFI appraisals include:

- relevant mental or behavioural diagnoses
- up to 3 other medical diagnoses relevant to a resident's care needs
- 5 questions relating to a resident's assessed care needs with regard to activities of daily living: nutrition, mobility, personal hygiene, toileting, and continence
- 5 questions relating to a resident's cognition and behaviour: cognitive skills, wandering, verbal behaviour, physical behaviour, and depression
- 2 questions relating to the need for assistance with the use of medication and ongoing complex health care procedures and activities; with the need for palliative care being covered by these questions (DoH 2016).

Responses to ACFI questions are rated on a scale of A to D and are used to determine the level of care a person needs. While mental health or behavioural diagnoses, along with other medical diagnoses, can be recorded, the ACFI is not designed to be a comprehensive assessment tool.

The method used to derive the number of permanent aged care residents in this report differs from the approach used in the AIHW report Older Australia at a glance. In that report, the numbers of permanent aged care residents are presented at 30 June, whereas for this palliative care report, numbers include those who have been resident at any point during the reporting period, and new admissions over that period. This
approach has been taken in this report due to the high proportion of palliative aged care residents who are resident for short periods of time.

Data presented in this report may differ from those published elsewhere due to differences in the preparation and analysis of the source data.

Reference

Key Concepts

**Palliative care in residential aged care**

<table>
<thead>
<tr>
<th>Key Concept</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comorbidity</td>
<td>Comorbidity refers to occurrence of more than one condition/disorder at the same time.</td>
</tr>
<tr>
<td>Hospital leave</td>
<td>A temporary stay in hospital which does not involve permanent discharge from residential aged care.</td>
</tr>
<tr>
<td>Palliative care in residential aged care</td>
<td>Palliative care in residential aged care is ongoing care involving very intense clinical nursing and/or complex pain management in the residential care setting. In the current section, only those aged care residents and admissions who have been appraised by approved providers as requiring ACFI funding for end of life palliative care (i.e. last week or days of life) are included in the group ‘appraised as requiring palliative care’.</td>
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<tr>
<td>Permanent admission</td>
<td>An admission to residential aged care for expected long-term care.</td>
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<tr>
<td>Permanent resident</td>
<td>A person who is receiving long-term (permanent) care in a residential aged care facility.</td>
</tr>
<tr>
<td>Specified care and services</td>
<td>The care and services that all approved providers of residential aged care must provide to any resident as needed, as set out by the Schedule of specified care and services for residential care services (Schedule 1, Quality of Care Principles 2014) within the Aged Care Act 1997.</td>
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