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Pathways of younger people entering permanent residential aged care

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Contents

Summary

Younger people living in permanent residential aged care have one thing in common—they are aged under 65—but beyond this, they can have a range of health conditions and care needs. Some younger people using aged care are people with a disability, but there is no direct way to identify this group in the administrative data, or the reasons people have for entering (or staying in) permanent residential aged care. However, people's activity limitations, care needs and health conditions can provide some context. This report describes some of these characteristics and the patterns of aged care use for people who first entered permanent residential aged care at a younger age.

The number of younger people entering care has been steady over time

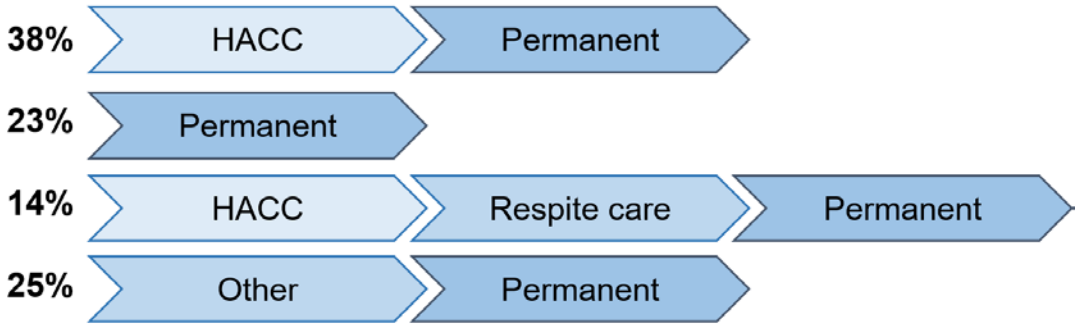
In each year between 2009–10 and 2013–14, around 2,000 people aged under 65 first entered permanent residential aged care. Around half of them were 'older' younger people (aged 60–64). Among the youngest age group (aged under 50), more than 1 in 10 were Indigenous. The overall number of younger people living in permanent care also remained steady through this time: in any year between 2010 and 2014, there were around 6,000 younger people in permanent residential aged care, with a median age of 60.

Around 1 in 4 younger people had an activity limitation in all 4 core activities

Activity limitations—particularly in the core activities of self-care, communication, movement between locations and moving/walking around—are a common way of measuring disability. Most (90%) younger people had an activity limitation in self-care, meaning that they had difficulty with daily tasks such as eating and getting dressed and needed another person's supervision or help. More than 23% of younger people had an activity limitation in all 4 core activities; however, this varied depending on their first-listed or 'main' health condition. The top 3 main health conditions were dementia, cancer and cerebrovascular disease. Dementia was relatively less common among the youngest age group; instead, this group had other progressive neurological conditions.

Most younger people had simple pathways to permanent residential aged care

Almost 1 in 4 younger people who entered permanent care in 2009–10 to 2013–14 had not used any other aged care beforehand. Of those who had used care, the most common program was the entry-level Home and Community Care (HACC).



Time spent living in permanent residential aged care varied considerably

More than 20% of younger people who first entered permanent residential aged care in any year between 2009–10 and 2013–14 spent under 6 months in care. On the other hand, almost 40% of younger people who entered care in 2013–14 were still living in care at 30 June 2018.

1 Introduction

For the purposes of this report, people who entered permanent residential aged care before the age of 65 are considered 'younger'. Aged care is provided on the basis of need, rather than age, and so sometimes even very young people find themselves living in permanent residential aged care. However, this can reflect the lack of availability of other support services, rather than the suitability of permanent residential aged care to meet these people's needs.

Generally, younger people are considered to be better served by other services to provide for their long-term needs. The Younger People in Residential Aged Care (YPIRAC) initiative ran from 2006 to 2011, with the aim of reducing the number of people inappropriately entering permanent care (inappropriate here means in absence of adequate community-based support services or housing), as well as providing better services for those who lived in permanent care (AIHW 2012).

In 2019, the Australian Government announced an initiative to further reduce the number of younger people living in residential aged care. The *Younger People in Residential Aged Care—action plan* (DSS 2019) aims to do this by helping current younger residents to find alternative care arrangements, if that is their goal, and by reducing the number of new entrants through better planning and pathways into alternative arrangements.

The National Disability Insurance Scheme (NDIS) introduced in 2013—and the expansion of its Specialist Disability Accommodation program in 2019 (to address the housing needs of people with disability)—is also progressively altering how support services are provided across Australia for younger people living in permanent residential aged care. In 2017–18, 1,703 younger people living in permanent residential aged care had an NDIS plan approved (NDIS 2018). This represents about 1 in 5 of the 8,304 younger people who used permanent residential aged care during that year (AIHW 2019b). This report relates to an earlier period of time, for which detailed linked data are available, and provides context for measuring future changes in the light of the above changes.

This report contains summary results and commentary on younger people in care and aspects of the care pathway. Most of the charts and tables are expanded in the supplementary tables available online. A summary of the method and data quality issues are presented in the appendix.

Pathways in Aged Care link map

The Pathways in Aged Care (PIAC) link map brings together aged care data from 1997 to 2014 (Box 1). It allows study of people's pathways through the aged care system, from assessment to take-up of care and potentially death. Much of the source data is a by-product of the administrative systems focused on recording activity, and people can be counted multiple times within and across aged care programs. The link map enables reliable person-level analysis.

Box 1: Pathways in Aged Care link map

PIAC connects millions of records of data from different sources. The link map includes the use of any of the following aged care programs between 1 July 1997 and 30 June 2014:

- Permanent and respite residential aged care
- Aged care packages (Home Care Packages Program and its pre-2013 counterparts)
- Home and Community Care
- Transition Care Program.

PIAC also includes comprehensive assessment data collected under the Aged Care Assessment Program (ACAP) from 2003–04 (national collection of person-level data was not established until 2005–06), including for those people who never took up aged care services, and National Death Index (NDI) data for all people who died before September 2015. The extended timeframe ensures that the link map can be used to identify the deaths of people who used aged care up to June 2014.

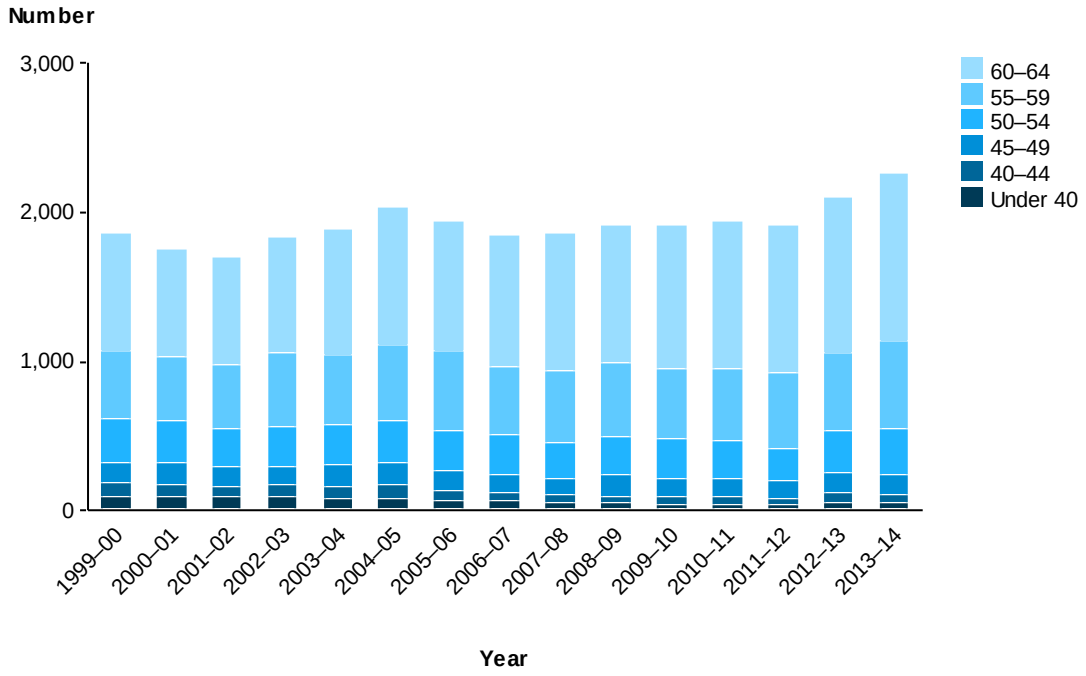
The aged care data are in turn sourced from the National Aged Care Data Clearinghouse (NACDC) housed at the AIHW, forming a central repository of aged care data from 1997 to the present.

Taking a long view

Most of the analysis in this report focuses on the period 2009–10 to 2013–14; while PIAC contains some aged care data from 1997, more comprehensive data are available for these 5 years. However, in this section we look at the longer-term trends to provide greater context for the recent period.

The number of younger people entering permanent residential aged care for the first time fluctuated between 1999–00 and 2013–14 (Figure 1), but averaged around 2,000 people each year.

Figure 1: People who entered permanent residential aged care aged under 65, 1999–00 to 2013–14



Source: Table S1.1.

In the 15 years between 1999–00 and 2013–14, the overall number of younger people first entering permanent residential aged care increased by 22%. However, this differed between age groups: the number of 'younger' younger people (aged under 50) entering permanent care decreased (by 25%) while the number of 'older' younger people (aged 50–64) increased (by 31%).

This reflects trends observed during the YPIRAC initiative, when the number of younger people entering permanent care was reduced more than the number of older people (AIHW 2012). This can suggest that the youngest age groups have different needs that may be met in different ways—for example, through the combination of informal care, community-based aged care and disability services (AIHW 2014). However, it may also reflect underlying attitudes about what is considered a suitable long-term care setting for the youngest age groups compared with the older, who may be seen as more 'suited' to living in permanent residential aged care (and whose needs may be more similar to people aged 65 and over).

Conditions that are commonly associated with older age sometimes affect particular groups of people at earlier ages, leading to earlier entry into permanent residential aged care. For example, while Aboriginal and Torres Strait Islander people are under-represented in permanent care relative to their numbers in the population, compared with non-Indigenous people they are more likely to enter care aged under 65 (and, particularly, aged under 50).

Overall, up to 7% of younger people who entered permanent care in any year between 1999–00 and 2013–14 were Indigenous. The numbers of Indigenous people were small—in 2013–14, 112 people aged 50–64 entering care were Indigenous, and just 36 people aged under 50—but as a proportion of the age group, these represented 6% among people aged 50–64, and 16% among those aged under 50 (Table S1.2).

As a crude measure of whether younger people's functional status changed between 1999–00 and 2013–14, the time between entry to care and the timing of death showed only small changes: the proportion of younger people who died within 6 months of their first entry to permanent residential aged care increased from 16% to 20% over 15 years (Table S1.3).

2 Younger people's characteristics

Circumstances at assessment

Before entering permanent residential aged care, people undergo a comprehensive assessment under the Aged Care Assessment Program. This captures details of their current care and health needs, activity limitations and support requirements, makes recommendations for their future, and provides approval for formal aged care services.

People may have multiple assessments over time as their needs change. The assessment details here refer to the most recent ACAP assessment through which the person was approved for permanent care (and which took place before they entered permanent care).

For younger people who first entered permanent care between 2009–10 and 2013–14, women were more likely to have a carer at the time of assessment, and, in particular, a carer who lived with them (co-resident carer). People aged under 50 were less likely to have a carer than those aged 50–64, and, particularly, less likely to have a co-resident carer (Table S2.1).

People in this youngest age group were also considerably less likely to live alone and somewhat less likely to own their usual accommodation than older age groups (tables S2.2 and S2.3). Around one-quarter of people aged under 50 lived alone (rising to over one-third among those aged 50–64, and fewer than two-fifths owned or had a mortgage on their residence (rising to almost half among those aged 50–64).

The majority of all younger people were assessed in hospital—around two-thirds of people had their first face-to-face contact with the assessment team in either acute care or another inpatient setting (Table 1). The proportions dropped in 2013–14, but this was due to a considerably higher number of missing responses on this item.

Table 1: People who first entered permanent residential aged care aged under 65, first face-to-face contact setting at assessment, 2009–10 to 2013–14 (%)

Year of admission	Hospital (acute care)	Hospital (other inpatient)	*Total hospital*	Residential care	Other setting	Missing	Total
2009–10	39.9	18.6	*58.5*	4.3	32.3	4.8	100.0
2010–11	39.8	21.4	*61.2*	5.6	30.3	2.8	100.0
2011–12	39.7	21.2	*61.0*	4.8	31.2	3.0	100.0
2012–13	41.2	20.3	*61.5*	5.2	31.1	2.2	100.0
2013–14	7.7	4.5	*12.2*	1.1	16.1	70.6	100.0

Source: Table S2.4.

Almost two-thirds of younger people were living in major cities at the time of their ACAP assessment (noting that the location information was missing or of poor quality for many assessment records); on entry to a residential care facility, the proportion was slightly higher (Table 2). Almost all (96%) younger people who had their ACAP assessment in a major city also entered permanent care in a major city (Table S2.5).

Table 2: People who first entered permanent residential aged care aged under 65, remoteness (facility location), 2009–10 to 2013–14 (%)

	Major cities	Inner or outer regional areas within 20km of town of 50,000+	Inner or outer regional areas within 15km of town of 15–50,000	Inner or outer regional areas within 10km of town of 5–15,000	Other inner or outer regional areas	Remote or very remote	Total
2009–10	67.7	9.7	8.2	6.1	5.9	2.5	100.0
2010–11	68.4	9.6	8.9	6.1	4.7	2.3	100.0
2011–12	68.4	9.0	8.6	6.8	5.3	1.9	100.0
2012–13	67.1	9.3	8.9	7.1	6.1	1.4	100.0
2013–14	67.4	9.8	8.9	6.6	5.8	1.5	100.0

Source: Table S2.5.

Functional status and health conditions

Activity limitations

Ten activity limitations are recorded in the ACAP assessment. A person is considered to be limited in a particular activity if they have difficulty carrying out the activity and require another person to assist or supervise.

These activities can be divided into core and other activities. Core activities consist of self-care (daily tasks to do with; for example, eating, dressing and toileting), communication, movement (for example, changing position or moving from chair or bed) and moving around (walking or otherwise moving between places at or away from home). Other activities consist of health-care tasks (for example, taking medications or managing chronic health issues), transport (driving or use of public transport), social and community participation (including shopping, financial management and recreational activities), assistance in domestic activities (managing household chores), meal preparation and home maintenance (such as basic house repairs and gardening). Difficulties in these areas (both individually and combined) can be a significant factor in why people need additional support—and support services or suitable accommodation are not always readily available in the community.

Most younger people who entered permanent residential aged care aged under 65 between 2009–10 and 2013–14 had an activity limitation related to self-care (90%). Limitations in movement were also common (around three-quarters of younger people had a limitation relating to movement activities). Fewer younger people (only around half) had a limitation in their ability to move around, and fewer still had a limitation in communication (around 40%). Limitations relating to health-care tasks, transport, social participation, domestic activities, home maintenance and meal preparation were also common (Table 3).

Table 3: People who first entered permanent residential aged care aged under 65, proportion with limitation in an activity, 2009–10 to 2013–14 (%)

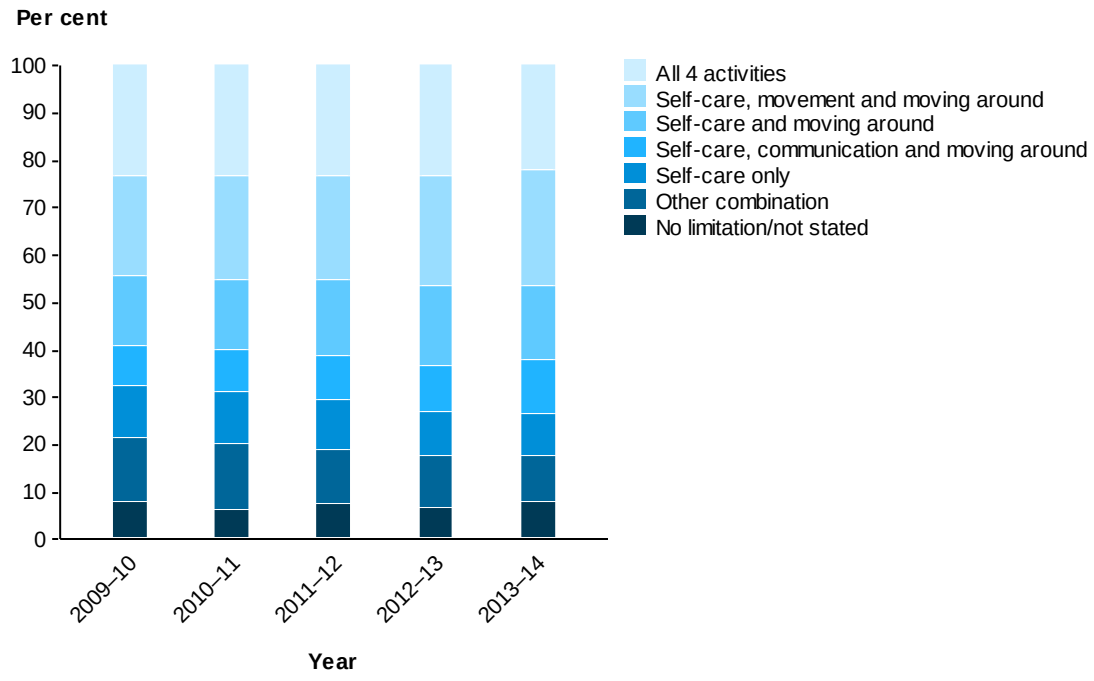
Activity	2009–10	2010–11	2011–12	2012–13	2013–14	All years
Core activities						
Self-care	88.3	90.7	88.0	90.0	88.4	89.1
Communication	41.0	41.8	40.4	40.2	39.3	40.5
Movement	49.1	50.0	47.8	49.7	48.9	49.1
Moving around	70.7	71.4	74.0	76.0	76.9	73.9
All 4 core activities	*23.6*	*23.5*	*23.4*	*23.4*	*22.3*	*23.2*
Other activities						
Health-care tasks	91.3	93.4	93.2	94.1	91.7	92.7
Transport	91.6	94.3	93.9	94.7	93.3	93.6
Social and community participation	89.6	91.5	92.0	93.9	91.8	91.8
Domestic activities	80.5	84.4	86.4	87.6	87.2	85.3
Home maintenance	64.4	67.0	70.8	72.6	72.5	69.6
Meals	80.4	84.3	86.1	87.8	86.5	85.1
All 6 other activities	*56.7*	*60.3*	*64.3*	*66.9*	*65.6*	*62.9*
All 10 activities	**14.7**	**16.4**	**17.3**	**17.4**	**16.3**	**16.4**

Sources: Tables S2.6 and S2.7.

Around 16% of younger people had a limitation in all 10 activities, and 23% had a limitation in all 4 core activities. In both cases, the youngest age group was considerably more likely to have a limitation, with the proportions almost doubling for those aged under 50, compared with the older age groups (Table S2.6).

Other than a limitation in all 4 core activities, the next most common combination was a limitation in self-care, movement and moving around (more than 20% of younger people), followed by self-care and moving around (more than 15%). Some 10% had only a limitation in self-care (Figure 2).

Figure 2: People who first entered permanent residential aged care aged under 65, combinations of core activity limitations, 2009–10 to 2013–14



Source: Table S2.8.

Specific conditions of interest

While people often have multiple medical issues and health conditions affecting their need for care, specific conditions commonly associated with particular care needs can be used to simplify the picture. The ACAP assessment records up to 10 diagnosed health conditions that have an impact on the person's need for assistance with activities of daily living and social participation (the disease or disorder listed first indicates the 'main' condition, that is, the health condition with the greatest impact).

Conditions can be grouped further into higher-level categories. By broad group, mental and behaviour disorders, circulatory system diseases, endocrine and related, and nervous system disorders were common among younger people (Table S2.9). These are not mutually exclusive, as people may have more than 1 condition that affects their care needs. The median number of condition codes recorded was 6 (the maximum possible is 10).

When only the first-listed condition is considered (indicating the 'main' condition, or the condition with the most significant impact on people's care needs), dementia was the most common condition, followed by cancer, cerebrovascular disease, and progressive neurological conditions (such as Huntington disease, Parkinson disease and motor neurone disorder). When any mention of these same conditions was considered, the proportion increased for each (Table 4).

Table 4: People who first entered permanent residential aged care aged under 65, proportion with specific condition (first-listed or any mention), 2009–10 to 2013–14 (all years) (%)

Condition	First-listed	Any mention
Dementia	16.2	24.3
Cancer	12.5	19.0
Cerebrovascular disease	11.2	21.0
Progressive neurological disorder	10.3	14.2
Intellectual, chromosomal or developmental disorder	6.7	12.7
Depression, other mood disorder or psychosis	6.1	34.3
Other nervous system disorder	4.4	17.4
Head injuries	3.3	5.9
Diabetes (any type)	2.0	22.6
Abnormal gait or mobility	1.2	27.1
Kidney or urinary system disorder (not including incontinence)	1.1	8.4
Epilepsy	0.9	10.8
Frequent falls (unknown origin)	0.9	17.6
Anxiety or stress disorder	0.5	9.5
Incontinence	0.1	26.3

Source: Table S2.10.

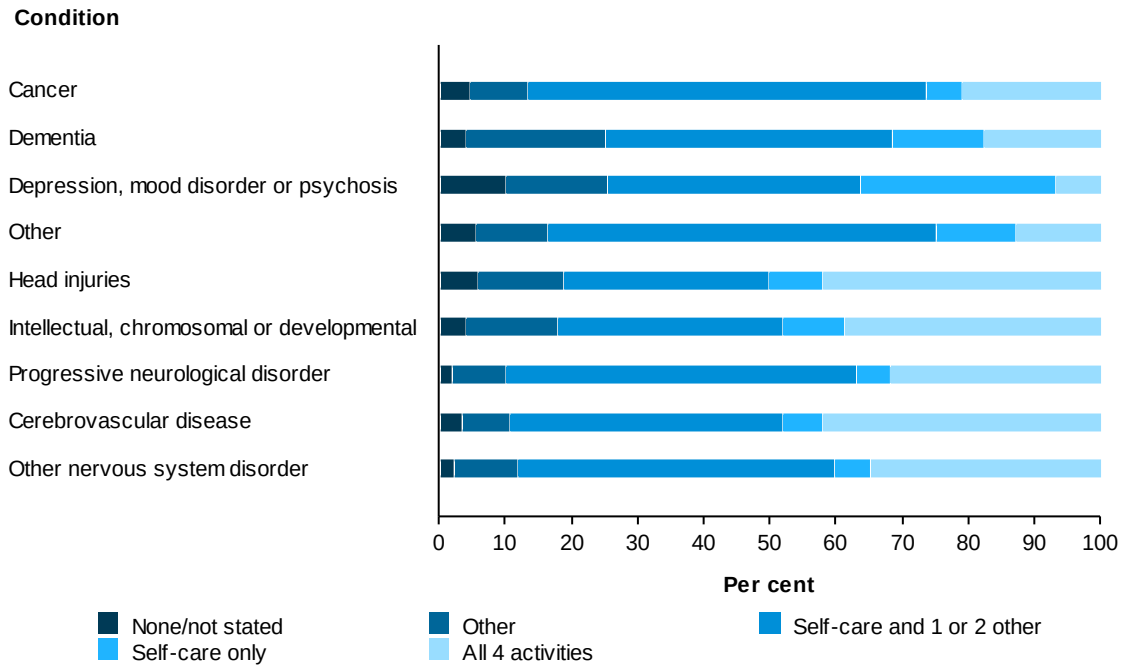
Overall, conditions that affect the brain and nervous system were common among people who entered permanent residential aged care at a younger age, and the proportion of people affected as much as doubled between first-listed and any mention of a condition. This was particularly the case for cerebrovascular disease, intellectual, chromosomal or developmental disorders and head injuries.

Abnormal gait or mobility, incontinence and falls are part of ‘other symptoms and signs’, which consists of a number of disparate conditions that affect people but are not a specific disease or diagnosis classified under the other groups—these were rarely reported as the first-listed or main condition, but were common additional diagnoses.

Combining limitations and first-listed conditions

Different conditions—highlighted here as the first-listed or ‘main’ condition that affected people—can lead people to have very different care needs, and perhaps to different reasons for entering permanent residential aged care. Broadly, limitations in self-care were common, but the exact patterns of combinations varied depending on what condition mainly affected people. For example, people whose first-listed condition was cerebrovascular disease or head injury were twice as likely to have an activity limitation in all 4 core areas as people who had dementia, or people who had cancer (Figure 3).

Figure 3: People who entered permanent residential aged care aged under 65, most common first-listed conditions and combinations of core activity limitation, 2009–10 to 2013–14 (all years)



Source: Table S2.11.

There was relatively little variation in first-listed conditions regardless of whether younger people entered a residential care facility in major cities or in regional areas (Table S2.12). The proportion of people who had some of the most common first-listed conditions decreased as remoteness increased: almost 1 in 3 entrants living in major cities (or near larger towns in inner or outer regional areas) had either dementia or cancer as their first-listed condition, reducing to 1 in 5 for people living in remote or very remote areas or inner or outer regional areas away from larger towns.

3 Patterns of prior aged care use

Pathways

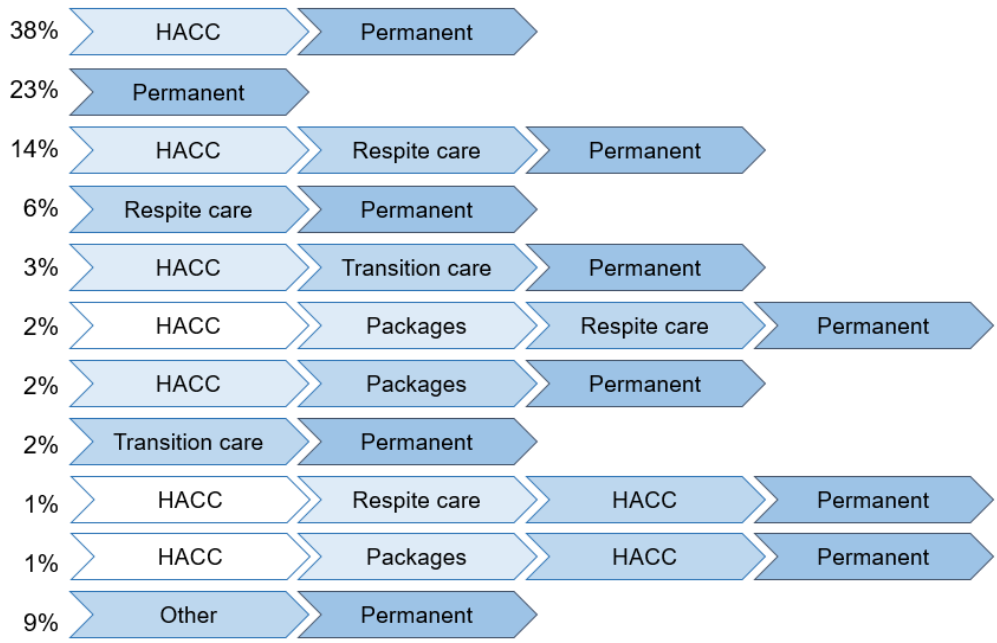
People move through the aged care system as their needs change, but for many younger people in permanent residential aged care, these 'pathways' were relatively straightforward. Around 23% of people who first entered permanent care aged under 65 between 2009–10 and 2013–14 had not used any other aged care beforehand. This proportion was the highest among the youngest age group (those aged under 50), particularly among men (Table S3.1).

Overall, younger people used fewer than 100 different pathways into permanent care, and the pathways were often short (only a handful had 10 or more separate events in their pathway; the longest had 17). Almost half (46%) of younger people had only used 1 other program before permanent care.

Putting aside no previous care, the possible pathways consist of any combination of home care (HACC), community-based aged care packages, respite residential aged care and transition care. Each program is recorded in the order of use, but not taking into account individual repeat episodes of care within the same program, or gaps between programs (this report also does not take into account the use of other supports, such as disability services). The pathways here all end in permanent residential aged care.

The most common patterns of use prior to entry into permanent care were HACC, no prior use of aged care, and HACC followed by respite residential aged care (Figure 4).

Figure 4: People who first entered permanent residential aged care aged under 65, pattern of prior aged care program use (pathways), 2009–10 to 2013–14 (all years)



Source: Table S3.2.

Across the states and territories, the most common pathway was HACC followed by permanent care, except in the Northern Territory where it was only the third most common pathway (S3.3). The Northern Territory also has relatively higher use of aged care services that are not part of the PIAC link map, such as the National Aboriginal and Torres Strait Islander Flexible Aged Care Program (AIHW 2019a).

HACC use followed by permanent care remained the most common pathway when first-listed condition was taken into account, but the proportions varied. Around 25% of people with dementia or cerebrovascular disease used this pathway, while it was taken by over 40% of people with cancer or progressive neurological disorders (Table S3.4).

Last-used program

The program that younger people used last before entering permanent residential aged care was most commonly HACC. HACC was not a straightforward 'aged care' program as such, but provided home-based support to people of various ages, including younger people with disability. Respite was the next most common point of entry into permanent care, and only a small proportion of people last used transition care or community-based packages (Table S3.5).

Compared with older age groups, people in the youngest age group (those under 50) were more likely not to have used any aged care prior to permanent care, and less likely to have last used respite. The patterns also varied depending on people's first-listed condition and combinations of core activity limitations: people whose main condition was cancer, cerebrovascular disease or head injuries were more likely not to have used any aged care prior to permanent care than those with other common conditions, while people who had a limitation in all 4 core activities were more likely not to have prior use than those with any other combination of limitation (Table S3.6).

Time between assessment and entry

For around half of younger people, assessment took place 1 month before their first entry to permanent residential aged care (Table 5).

Table 5: People who first entered permanent residential aged care aged under 65, time between assessment and entry, 2009–10 to 2013–14 (%)

Year	Under 1 month	1 month to under 6 months	6 months and over	No assessment identified	Total
2009–10	47.4	37.2	11.9	3.5	100.0
2010–11	49.2	36.7	11.9	2.2	100.0
2011–12	46.5	36.8	13.7	3.0	100.0
2012–13	49.4	36.8	11.8	2.0	100.0
2013–14	45.0	37.3	14.6	3.2	100.0

Source: Table S3.7.

While the broad patterns remained consistent across the 5 years, the median time (the point at which half of people had entered permanent care) increased slightly from 31 to 35 days (Table S3.8). There was considerable variation depending on people's characteristics: the median time between assessment and entry was just over 2 weeks for those who had not used any other aged care and almost 10 weeks for those who last used respite residential

aged care—this form of respite is commonly used as an entry into permanent care (often in the same facility), which may skew these numbers.

In particular, those younger people who had selected characteristics that might indicate poorer health had shorter median time between assessment and subsequent entry to permanent care. For example, by first-listed condition, the median time for people whose first-listed condition was cancer was under 2 weeks, compared with well over a month for people with dementia.

Assessment for care without take-up

Some people are assessed—and approved—for permanent residential aged care, but never take it up. Between 1 July 2011 and 30 June 2012, more than 3,500 younger people had an ACAP assessment that approved them for permanent care, but over one-third (36%) did not use permanent care before 30 June 2014 (Table S3.9).

The characteristics of younger people who received an assessment approving them for permanent residential aged care and who did not use permanent care differed slightly from those who went on to use permanent care. People in the assessment-only group were:

- somewhat more likely to be older (59% were aged 60–64, compared with 51% among people who used permanent care)
- more likely to have a carer (75% had either a co- or non-resident carer, compared with 64%)
- less likely to have hospital as their first face-to-face contact setting at assessment (43%, compared with 57%)
- less likely to have dementia as their first-listed condition (9%, compared with 16%), but more likely to have cancer (23%, compared with 13%).

A number of factors influence the likelihood of entering permanent residential aged care, such as the formal and informal assistance available to people (people may have used other aged care or disability support services in the community that are not covered here) and the degree and timing of assistance people require. People who were approved for permanent care but did not use it were somewhat less likely to have an activity limitation in all 4 core activities (18%, compared with 22% among people who used permanent care) and more likely to have died within a year of their assessment (38%, compared with 22%).

4 First episode of care

Assessment in care

On entering permanent residential aged care, people's care needs are assessed again via the Aged Care Funding Instrument (ACFI). As the name suggests, it is a funding tool focused on the cost of care, but with this caveat in mind it can be used to identify care needs for people in permanent residential aged care across 3 domains (activities of daily living, cognition and behaviour, and complex health care), as well as people's health conditions.

People can be assigned a rating of high, medium, low or nil for each of the 3 domains. In the first ACFI assessment conducted for younger people entering permanent care each year between 2009–10 and 2013–14, the most common combined rating was 'high' in all 3 domains (7.1% in 2009–10, rising to 14.2% in 2013–14). People can be reassessed as their needs change, and by the latest ACFI assessment on record, the proportion of younger people rated 'high' in all 3 domains was twice as high (rising from 31% to 36% across the period) (Table S4.1).

Younger people whose earlier ACAP assessment indicated that they had limitations in either all 4 core activities or self-care, movement and moving around were twice as likely to be rated 'high' on all 3 ACFI domains at the first assessment as people with other combinations of core activity limitations (Table S4.2). On the other hand, younger people who had earlier been assessed as having a limitation in self-care only were more likely to have some other combination of ACFI ratings, with just 5% rated 'high' across the 3 domains.

Conditions that had been recorded for people at the ACAP assessment prior to entry were generally less likely to be recorded in the first ACFI assessment after entry. These differences are partly accounted for by the different number of conditions recorded, and a different focus on the types of conditions recorded: ACAP captures up to 10 conditions, while ACFI records 3 medical conditions and 3 mental or behavioural conditions, meaning that mental or behavioural conditions are more likely to be captured in the ACFI than in the ACAP. This can be seen most clearly with depression, other mood disorders and psychosis, any mention of which were recorded for half of all younger people at ACFI assessment (Table 6).

Table 6: People who first entered permanent residential aged care aged under 65, proportion with selected condition, by ACAP assessment and ACFI assessment, 2009–10 to 2013–14 (all years) (%)

Condition	Any mention recorded at ACAP assessment	Any mention recorded at ACFI assessment	Any mention recorded at both ACAP and ACFI assessment
Depression, other mood disorder or psychosis	34.3	50.0	31.8
Dementia	24.3	29.3	21.4
Diabetes (any type)	22.6	18.6	17.0
Cerebrovascular disease	21.0	17.8	16.2
Incontinence	26.3	21.5	14.7
Cancer	19.0	15.8	14.5
Intellectual, chromosomal or developmental disorder	12.7	13.6	11.4
Progressive neurological disorder	14.2	12.5	10.9
Abnormal gait or mobility	27.1	11.6	10.3
Other nervous system disorder	17.4	9.6	7.7
Anxiety or stress disorder	9.5	13.0	7.1
Epilepsy	10.8	7.8	6.5
Frequent falls (unknown origin)	17.6	6.6	5.5
Kidney or urinary system disorder (not including incontinence)	8.4	4.4	3.5
Head injuries	5.9	4.3	3.5

Source: Table S4.3.

The type of condition people have can also be associated with details of their stay in permanent residential aged care. Almost half of younger people had at least 1 period of hospital leave during their first stay in permanent residential aged care, but people whose first-listed condition at the earlier ACAP assessment was cancer were least likely to have had any hospital leave (hospital leave applies only for overnight absences from care). The overall time spent on hospital leave varied, with one-third of younger people away for less than 2 weeks in total. As a proportion of time in care, on average hospital leave accounted for just 4% of the days younger people spent in permanent residential aged care (Table S4.4).

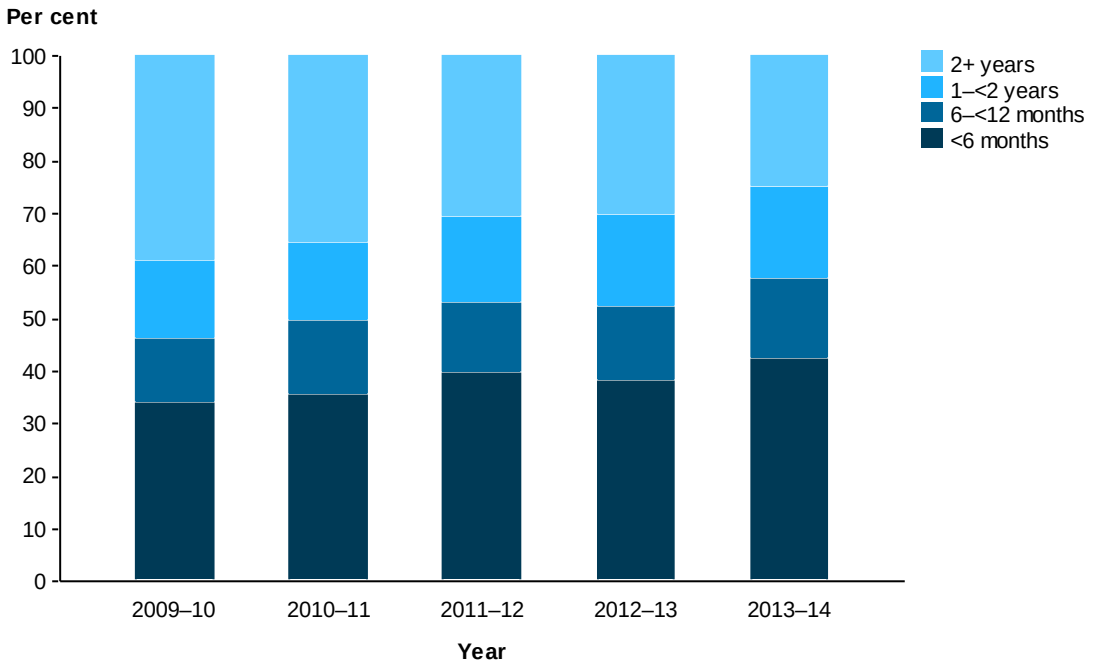
On the other hand, around 11% younger people were assessed as needing palliative care on their first ACFI (Table S4.5). Of this group, almost two-thirds (62%) were people whose first-listed condition was cancer; the next most common condition was progressive neurological disorders (5%).

Exits from care

Some people leave permanent residential aged care soon after entering, while others go on to have considerable lengths of stay in care (using NACDC data, it was possible to identify episodes up to 30 June 2018). The cumulative total length of stay will be examined in more detail in the following section; here, the focus is on the first episode of care after entry. At the completion of an episode of care, the reason for separation is recorded by the facility.

The proportion of younger people whose first episode of care ended within 12 months of entering increased between 2009–10 and 2013–14 (Figure 5).

Figure 5: People who first entered permanent residential aged care aged under 65, first episode length of stay (completed episodes only), 2009–10 to 2013–14



Note: Excluding first episodes that were completed after 30 June 2018.

Source: Table S4.6.

Reflecting this, the median length of stay for the first episode of care for younger people who first entered permanent care in 2009–10 was over 1 year (excluding those episodes that were still ongoing), but reduced to just 9 months for younger people who entered in 2013–14 (Table S4.6).

Overall, the most common separation reason was death (59% of all completed first episodes ended in death), followed by moving to another facility (17%) (Table S4.7). Where the first episode was recorded as having ended in death, the proportion of episodes that ended within 12 months rose between 2009–10 and 2013–14 (from 42% to 53%). In general, however, where younger people left the first residential aged care facility they entered and the reason was recorded as death, they tended to have stayed longer than those who left to move to another facility, hospital, or returned to live at home.

The PIAC 2014 link map also identifies deaths as recorded on the National Death Index up to September 2015, and shows that more than 1 in 4 younger people died within 12 months of their first entry to permanent care (Table S4.8). However, this varied depending on which condition had been listed first (as the ‘main’ condition) at their ACAP assessment prior to entry: younger people whose first-listed condition had been cancer were considerably more likely to have died within 12 months of entering permanent care than those whose first-listed condition was something else (Table 7).

Table 7: People who first entered permanent residential aged care aged under 65, time between first admission and death, by most common first-listed condition, 2009–10 to 2013–14 (all years) (%)

First-listed condition	No death identified	Under 1 year	1+ years	Total
Dementia	58.0	15.4	26.6	100.0
Cancer	10.0	80.8	9.2	100.0
Cerebrovascular disease	69.1	13.3	17.7	100.0
Progressive neurological disorder	59.3	17.6	23.1	100.0
Intellectual, chromosomal or developmental disorder	60.6	16.2	23.2	100.0
Depression, other mood disorder or psychosis	79.3	7.6	13.2	100.0
Other nervous system disorder	57.5	18.3	24.2	100.0
Head injuries	73.8	10.1	16.1	100.0
Other condition	51.9	27.5	20.6	100.0
Total	**53.5**	**26.5**	**20.0**	**100.0**

Source: Table S4.9.

Younger people who had an activity limitation in all 4 core activities, or in self-care, movement and moving around, were more likely to have died within 12 months of first entering permanent residential aged care than people with other combinations of core activity limitations (Table 8).

Table 8: People who first entered permanent residential aged care aged under 65, time between first admission and death, by combinations of core activity limitations, 2009–10 to 2013–14 (all years) (%)

Combination of core activity limitation	No death identified	Under 1 year	1+ years	Total
All 4 activities	49.7	28.4	22.0	100.0
Self-care, movement and moving around	45.1	38.2	16.8	100.0
Self-care and moving around	52.6	27.8	19.6	100.0
Self-care, communication and moving around	60.0	17.4	22.6	100.0
Self-care only	66.0	15.1	18.9	100.0
Another combination	59.3	19.0	21.7	100.0
No limitation	58.6	22.2	19.2	100.0
Total	**53.5**	**26.5**	**20.0**	**100.0**

Source: Table S4.10.

5 Total length of stay in permanent care

This section examines how long younger people stayed in permanent residential aged care. In addition to the duration of the first episode of care, there are other ways of looking at how long people stay in care, each of which presents a slightly different view:

1. **Time in care after first entry:** Cumulative duration of first as well as all subsequent (known-to-date) episodes of care for people who first entered care in each year. This is restricted by the end date to which data are available and does not provide a 'true' end date to people's total length of stay—some people will go on to spend considerable amounts of time in care beyond data availability. This also disproportionately affects later years.
2. **Time in care to 30 June:** Cumulative duration of all episodes of care to 30 June of each year for those who are living in care. As above, calculations of length of stay using this method cannot account for episodes that extend beyond data availability.
3. **Time in care before death:** Cumulative duration of all episodes of care prior to death for people who died in each year. As this excludes people who did not die, it may be relatively more skewed towards shorter lengths of stay.

All 3 cohorts are derived from people who were aged under 65 when they first entered care, and while there is some overlap between them, each cohort is somewhat different and their length of stay varies.

Time in care after first entry

In addition to the first episode of care discussed in the previous section, some people leave care and come back, or leave one facility only to enter another soon after. Considering the full length of stay (the duration of the first episode of care, as well as all subsequent known-to-date episodes of care) captures the person's 'career' in aged care to date. While linked PIAC data are available only to June 2014, for people who entered care in these earlier years it is possible to identify subsequent use of permanent residential aged care in NACDC data to June 2018.

For younger people who entered permanent residential aged care in any of the years 2009–10 to 2013–14, more than 20% spent under 6 months in permanent care. The median time in care was around 3 years, although this varied by age—the younger age groups had shorter median lengths of stay in care than those aged 60–64 (Table 9).

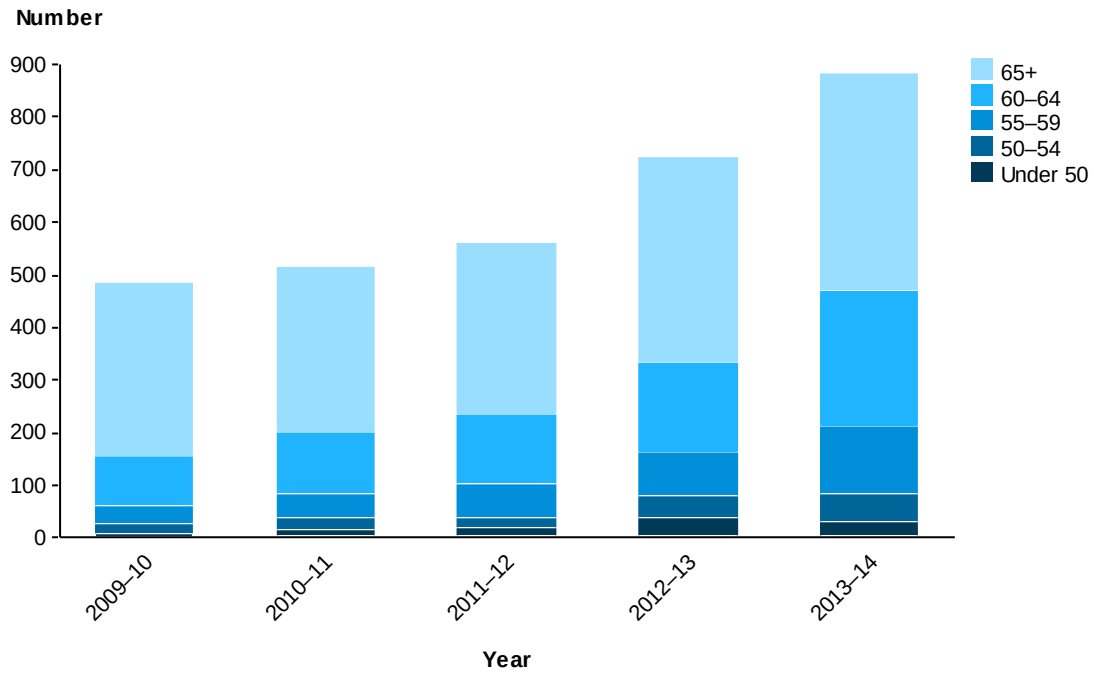
Table 9: Median length of stay in permanent residential aged care (years) for people who had entered care aged under 65 in the year, by age at admission, 2009–10 to 2013–14

Year of admission	Under 50	50–54	54–59	60–64
2009–10	2.5	3.9	3.2	3.2
2010–11	2.1	2.8	3.6	3.1
2011–12	2.1	2.8	2.5	2.9
2012–13	2.3	2.8	2.9	2.8
2013–14	1.8	2.5	2.8	3.0

Source: Table S5.1.

Of the 1,909 younger people who first entered permanent residential aged care in 2009–10, almost 500 (25%) were still in permanent care up to 9 years later at 30 June 2018. This proportion was higher among more recent entrants: almost 900 (39%) of the 2,253 young people who first entered care in 2013–14 were still in care at 30 June 2018, and more than half of this 900 were still aged under 65 at that time (Figure 6).

Figure 6: People who had first entered permanent residential aged care aged under 65 in the years 2009–10 to 2013–14 and were still in care at 30 June 2018, by age at 30 June 2018



Source: Table S5.2.

On the other hand, a small number of people went on to use other aged care services after entering permanent residential aged care. In all, around 5% of people who first entered in any year used other aged care after this point (most commonly HACC)—noting that this information is not available beyond June 2014, the end of PIAC, and so the true proportion may be higher.

Time in care to 30 June

In any year between 2010 and 2014, there were around 6,000 younger people living in permanent residential aged care at 30 June, with a median age of 60.

More than 15% of younger people who were in permanent care at 30 June 2014 had spent under 6 months in care (including the current episode of care to 30 June, as well as any preceding episodes), while a slightly smaller proportion (12%) had spent 10 years or more. The median total length of stay in permanent residential aged care to 30 June was around 3 years (Table 10).

Table 10: Median length of stay in permanent residential aged care to date (years) for people who had entered care aged under 65 and were in care at 30 June, by age at 30 June, 2010 to 2014

Year in care	Under 50	50–54	54–59	60–64
30 June 2010	3.6	3.1	3.5	3.1
30 June 2011	3.3	2.8	3.3	3.0
30 June 2012	3.3	3.0	3.0	3.1
30 June 2013	2.8	2.6	2.9	3.0
30 June 2014	2.1	2.2	2.7	2.7

Source: Table S5.3.

To put this another way, around half of people who were aged under 65 at 30 June had already lived for longer than 3 years in permanent care—and as 30 June represents an artificial end date, many people may go on to stay considerably longer in care and 'age out' of the cohort. For comparison, the median length of stay was over 8 years among people who had entered permanent care at younger ages but were aged 65 and over at 30 June.

The long lengths of stay that some people have make it difficult to identify the circumstances of their assessment, or all details of their prior aged care use. For example, a person-level ACAP data collection was not established nationally until after 2003–04, and ACFI was not used until 2008. Of the people who were aged under 65 and living in permanent care at 30 June 2010, 21% had first entered permanent care before 2004 (Table S5.4).

Time in care before death

Similarly, focusing on people who died during the years 2009–10 to 2013–14 (having entered permanent residential aged care before age 65) can be used to show both those who died at younger ages (aged under 65) and those who entered care young and 'aged out' of the cohort (aged 65 and over).

Around 40% of younger people who died in any 1 of these years had spent under 6 months in permanent care. At the other end of the distribution, only around 5% had spent 10 years or more in permanent care by their death (conversely, these proportions were around 3% and over 40% among people who had entered permanent care at younger ages and died aged 65 and over).

The median length of stay in permanent residential aged care for people who had entered permanent care at younger ages and died aged under 65 was around 1 year, meaning that around half of younger people had a length of stay under 1 year. This was similar for both sexes (Table 11). In contrast, among people who had entered permanent care at younger ages and died aged 65 and over, the median length of stay was around 8 years.

Table 11: Median length of stay in permanent residential aged care (years) for people who had entered care aged under 65 and died, by age at death, 2009–10 to 2013–14

Year of death	Under 50	50–54	54–59	60–64
2009–10	0.9	1.0	1.2	1.0
2010–11	1.0	0.8	1.1	1.0
2011–12	0.9	1.9	0.7	1.0
2012–13	0.8	1.2	0.9	1.0
2013–14	0.6	0.5	0.8	0.9

Source: Table S5.5.

This measure accounts only for the total time spent living in permanent residential aged care, not whether there were breaks in people's episodes of care nor where people were living at the time of their death. Some people might have died while living in permanent residential aged care, while others might have been admitted to hospital or returned home.

Appendix: Methodology and data quality

PIAC link map

The PIAC 2014 link map was used in this report. For more information on the underlying methods used for linking aged care data, the approvals in place, and how dates of service use were determined, please see the related publications *Pathways in Aged Care 2014: technical guide*, *Patterns in use of aged care 2002–03 to 2010–11* and *Pathways to permanent residential aged care in Australia 2013–14.*

Community-based aged care changed during the period to which the link map relates. Community Aged Care Packages, Extended Aged Care at Home and Extended Aged Care at Home—Dementia became the Home Care Packages Program in 2013. HACC has also since become part of the Commonwealth Home Support Program (in 2015).

People's characteristics, health conditions and activity limitations

Any age calculations in this report use a 'master' version of date of birth created as part of the PIAC link map. As the link map draws in date of birth information from different sources, and the NDI is generally considered of the highest quality of the included data sets, this may result in some corrections to what would be reported in the aged care data alone. The resulting calculations differ slightly from numbers reported directly from NACDC data.

The PIAC link map also amalgamates multiple recipient identifiers that apply to the same individual, improving the identification of unique counts of people. Again, the resulting calculations differ slightly from numbers reported directly from NACDC data—for example, the number of people first entering permanent residential aged care aged under 65 is slightly higher in NACDC data than in PIAC, due to identification of repeat entries (sometimes years apart) by the same individual under different aged care identifiers.

Health conditions, activity limitations and selected other demographic details (such as living arrangements and carer availability) were obtained from ACAP assessments; these are further outlined in the ACAP data dictionary that applied at the time. The ACAP assessment determines whether the person needs the help or supervision of another individual in 10 selected activities. Self-care, communication, movement and moving around are considered core activities, with the remaining 6 relating to areas such as household chores, transport and community participation. The ACAP assessment also records up to 10 diagnosed diseases or disorders that have an impact on the person's need for assistance with activities of daily living and social participation (the first-listed condition indicates the 'main' condition). The code list is included in Appendix D of the ACAP data dictionary; the selected conditions used in this report are outlined here (Table A1).

Table A1: Selected conditions used in the report, ACAP codes and their equivalent International Classification of Disease codes

Condition	ACAP health condition code	Equivalent ICD-10-AM code[(a)]
Dementia—includes dementia in Alzheimer disease, vascular dementia and dementia in other diseases	500	—
	501	F00.0, G30
	502	F00.1, G30
	503	F00.2, G30
	504	F00.9, G30
	510	—
	511	F01.0
	512	F01.1
	513	F01.2
	514	F01.3
	515	F01.8
	516	F01.9
	520	—
	521	F02.0
	522	F02.1
	523	F02.2
	524	F02.3
	525	F02.4
	526	F02.8
	530	—
	531	F10.7
	532	F03
Cancer—includes lung cancer, brain cancer and any other tumours	201	C01–14
	202	C16
	203	C18–20
	204	C34
	205	C43–44
	206	C50
	207	C61
	208	C70–71
	209	C82–85
	210	C91–95
	211	C00, C15, C17, C21–33, C37–41, C45–49, C51–60, C62–69, C72–81, C86–90, C96–97, D00–09
	299	D10–48
	605	G45–46
	910	—
	911	I60

Condition	ACAP health condition code	Equivalent ICD-10-AM code[(a)]
Cerebrovascular disease—includes subarachnoid, intracerebral and other intracranial haemorrhage, cerebral infarction, cerebrovascular accidents (stroke) and transient ischaemic attacks (mini-strokes)	912	I61
	913	I62
	914	I63
	915	I64
	916	I65–67, I69
Progressive neurological disorder—includes Huntington and Parkinson diseases, motor neurone disease and muscular dystrophy	602	G10
	603	G12.2
	604	G20–21
	606	G31, G37, G90–93
	607	G35
	609	G71.0
Intellectual, chromosomal or developmental disorder	570	—
	571	F70–79
	572	F80–84, F88–89
	1501	Q05
	1502	Q65–68, Q68–74
	1503	Q90
	1504	Q91–99
	1505	Q00–04
	1599	Q06–64, Q67, Q75–89
Depression, other mood disorder or psychosis	550	—
	551	F20
	552	F30–39
	553	F04, F06, F21–29
Other nervous system disorder	601	G00–09
	610	G80
	611	G81–83
	612	G93.3
	699	G11, G12.0–12.1, G12.8–13, G22–26, G32–34, G36, G43–44, G47–70, G71.1–73, G90–93.2, G93.4–99
Head injuries—includes ear, eye, face, jaw and acquired brain damage	1601	S00–09
Diabetes—includes types 1, 2 and unspecified	402	E1
	403	E11
	404	E13–14
Abnormal of gait or mobility—includes ataxic and spastic gait or difficulty in walking not elsewhere classified	1714	R26
Kidney or urinary system disorder—not including incontinence	1401	N00–37, N39.1–39.2, N39.8

Condition	ACAP health condition code	Equivalent ICD-10-AM code[(a)]
Epilepsy	0608	G40–41
Anxiety or stress disorder—includes panic disorder, stress-related conditions and other neurotic disorders	560	—
	561	F40–41
	562	F43
	563	F42
	564	F44–48
Falls—frequent with unknown aetiology	1715	R29.81
Incontinence—includes stress, faecal and unspecified urinary incontinence	1403	N39.3–39.4
	1707	R32
	1708	R15

(a) International Classification of Diseases, 10th Edition, Australian Modification.

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Abbreviations

ACAP	Aged Care Assessment Program
ACFI	Aged Care Funding Instrument
AIHW	Australian Institute of Health and Welfare
HACC	Home and Community Care
NACDC	National Aged Care Data Clearinghouse
NDI	National Death Index
NDIS	National Disability Insurance Scheme
PIAC	Pathways in Aged Care
YPIRAC	Younger People in Residential Aged Care

Symbols

—	nil or rounded to zero
<	less than

References

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AIHW 2014. People using both Disability Services and Home and Community Care 2010–11. Disability series. Cat. no. DIS 64. Canberra: AIHW.

AIHW 2019a. Aboriginal and Torres Strait Islander people using aged care. Viewed 19 March 2019, https://www.gen-agedcaredata.gov.au/Resources/Dashboards/Aboriginal-and-Torres-Strait-Islander-people-using.

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List of tables

List of figures

Related publications

This report, *Pathways of younger people entering permanent residential aged care*, is part of a series of reports using the PIAC link map. The earlier publications and other ageing and aged care-related releases can be downloaded free from the AIHW website https://www.aihw.gov.au/reports-data/health-welfare-services/aged-care/reports/.

In particular, the following publications might be of interest:

- AIHW 2014. Patterns in use of aged care: 2002–03 to 2010–11. Cat. no. CSI 20. Canberra: AIHW.
- AIHW 2017. Pathways to permanent residential aged care in Australia: a Pathways in Aged Care analysis of people's aged care program use before first entry to permanent residential aged care in 2013–14. Cat. no. AGE 81. Canberra: AIHW.
- AIHW 2018. Cause of death patterns and people's use of aged care: a Pathways in Aged Care analysis of 2012–14 death statistics. Cat. no. AGE 83. Canberra: AIHW.
- AIHW 2019. Insights into vulnerabilities of Aboriginal and Torres Strait Islander people aged 50 and over—in brief. Cat. no. IHW 207. Canberra: AIHW.

The AIHW also hosts a dedicated aged care data website. PIAC data and visualisations are available from the GEN website https://www.gen-agedcaredata.gov.au/Topics/Pathways-in-aged-care/.

Aged care is generally provided on the basis of need, so sometimes it is used by even very young people. In permanent residential aged care, around 2,000 younger people (aged under 65) take up care every year. Their pathways into care are often short, but once in permanent care, their care needs vary considerably—from short stays due to palliative care to long stays due to common older age-related conditions.

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