

Supporting paper 3:

Supporting informal carers of older people

Governments provide a wide range of supports to address the different needs of carers. Yet many carers still report having unmet needs for support. They are also more likely than other Australians to report financial stress and low wellbeing. This suggests that support for carers could be improved.

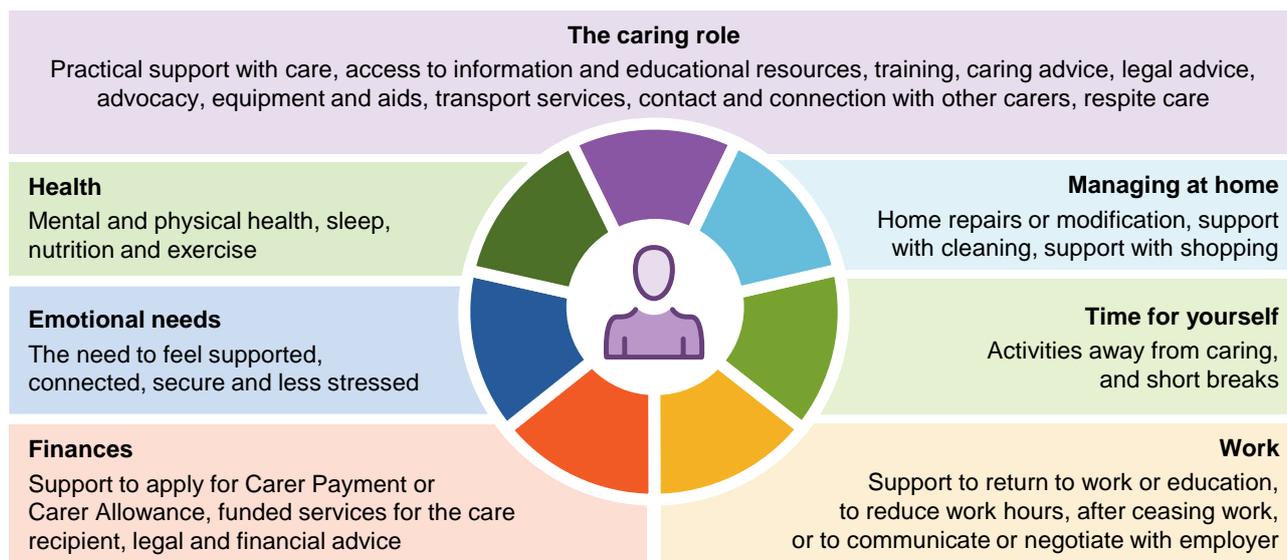
The Commission has been asked to ‘consider alternative ways to support informal carers to support older Australians’ — that is, alternatives to an entitlement to extended unpaid carer leave.

This paper considers ways to support all informal carers of older people, regardless of whether they participate in the paid labour force. It does not go in-depth into all the different types of needs and existing supports for carers. Rather, it focuses on the most significant gaps between existing arrangements and what carers need. The first section outlines what carers say they need. The subsequent sections address gaps in existing supports for carers: section 2 looks at ways to improve the accessibility of income support for carers and section 3 at how improving the availability of quality formal care services will help support informal carers. Services to support carer wellbeing are examined in section 4, and section 5 outlines the importance of ensuring the support system for carers is inclusive, coordinated and responsive to their needs over time.

1 The needs and experiences of informal carers are diverse

The experiences of informal carers are highly diverse. Carers have a range of needs that vary depending on the situation of the carer and the care recipient, and these can change over the course of providing care. For example, a carer who looks after an older person with dementia could need different types and levels of support while providing care, and this will likely differ to the needs of a carer who looks after an older person with a physical disability. The Australian Government Department of Social Services classifies carer needs according to the areas of life in which carers most typically need support (figure 1).

Figure 1 – Carers have a range of support needs



Source: based on DSS (DSS 2019, p. 19).

The Australian Government has committed to meeting the needs of carers in the *Carer Recognition Act 2010* (Cth) Statement for Australia’s Carers (box 1).

Box 1 – Statement for Australia’s Carers

1. All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
2. Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.
3. The valuable social and economic contribution that carers make to society should be recognised and supported.
4. Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
5. Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
6. The relationship between carers and the persons for whom they care should be recognised and respected.
7. Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
8. Carers should be treated with dignity and respect.
9. Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.
10. Support for carers should be timely, responsive, appropriate and accessible.

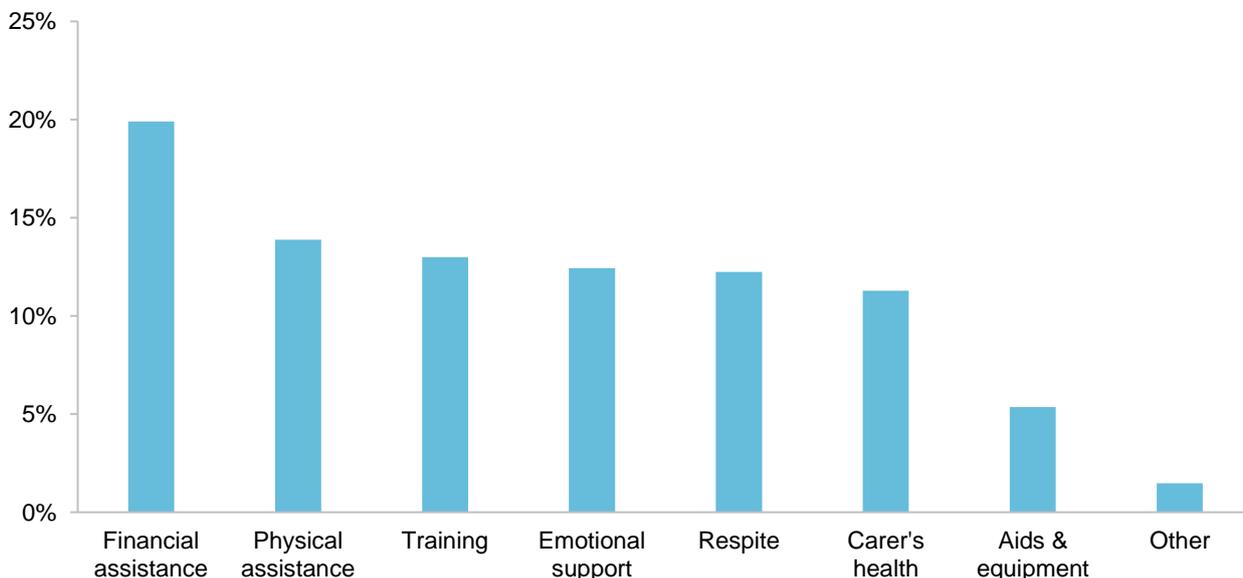
Source: *Carer Recognition Act 2010* (Cth).

The Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) asks primary carers about their situation and needs. In 2018, about 62 per cent of informal primary carers of older Australians (aged 65 and above) reported they did not feel satisfied due to their caring role (ABS 2019a). However, despite this, many did not identify unmet needs for support: 54 per cent reported not needing better or additional support (ABS 2019a).

For the carers reporting unmet needs, the most common were the need for more:

- financial assistance (20 per cent)
- physical assistance (14 per cent)
- training (13 per cent)
- emotional support (12 per cent)
- respite care (12 per cent) (figure 2).

Figure 2 – Common unmet needs of carers of older people^{a,b}



a. This dataset does not ask carers about their need for flexible work or unpaid leave. b. 'Training' includes training on caring for people with disabilities, manual handling and using equipment.

Source: Commission estimates using ABS (*Tablebuilder, Survey of Disability, Ageing and Carers, 2018, Cat. no. 4430.0*).

The COVID-19 pandemic has also likely placed some additional burdens on carers (box 2).

Box 2 – How the COVID-19 pandemic affected informal carers

The COVID-19 pandemic has created additional challenges for informal carers. The 2022 Carer Wellbeing Survey found that, among respondents, the most common impacts were:

- limited social interactions due to care recipient being at high risk from COVID-19 (51 per cent)
- increased intensity or amount of caregiving (50 per cent)
- additional difficulties getting appointments for care recipient (41 per cent) (Schirmer, Mylek and Miranti 2022, p. 11).

Participants to this inquiry also pointed to challenges for informal carers due to the pandemic. Some of the challenges were because of restrictions on travel and movement, which made caregiving and visiting care recipients in aged care facilities during lockdowns more difficult (Australian Psychological Society, sub. 27, p. 2; Carers Tasmania, sub. 37, p. 13).

Others said it became more difficult to access formal aged care services, such as home support and respite, during the pandemic partly due to a shortage of support workers (Carers Tasmania, sub. 37, p. 13). Increased demands on informal carers were also due to a reluctance from some carers and care recipients to use residential aged care in light of COVID-19 outbreaks (Department of Health and Aged Care, sub. 24, p. 7).

Some working carers reported using more leave for their own illnesses, leaving less paid leave to provide care (Carers NSW, sub. 20, p. 20; Carers Tasmania, sub. 37, p. 18; Quality Aged Care Action Group, Aged Care Reform Now and Carers' Circle, sub. 21, pp. 11–12). Others experienced negative effects on

Box 2 – How the COVID-19 pandemic affected informal carers

their wellbeing, including poorer mental health and feelings of isolation (Carers Tasmania, sub. 37, p. 15).

Positive effects of the pandemic on informal carers were also noted. For example, the increased prevalence and acceptability of flexible working arrangements, including working from home, has helped some working carers to balance work and care (Carers Australia, sub. 36, p. 3; Carers NSW, sub. 20, p. 12).

The Government implemented several measures that assisted informal carers, among others, during the pandemic. They included:

- expanding the JobSeeker Payment including to permanent employees who had lost their job, people caring for someone affected by COVID-19, and waiving assets tests and waiting periods. Recipients also received the Coronavirus Supplement worth \$550 per fortnight (Klapdor and Giuliano 2020, p. 5)
- the Pandemic Leave Disaster Payment: a lump sum payment for workers who had to cease work due to self-isolation, quarantine or to care for someone who had to self-isolate or quarantine due to COVID-19
- the COVID-19 Disaster Payment: a lump sum payment for those who had lost work or income due to a COVID-19 lockdown (Klapdor and Lotric 2022, pp. 1–10).

The patterns of unmet needs for support are largely similar between carers who work and carers who do not work. The main difference is that informal carers who work have slightly higher incidences of unmet needs than informal carers who do not work (ABS 2019a) — this reflects that having to balance work with care likely creates more strain for informal carers or makes it more difficult to arrange support services.

Given these similarities, this supporting paper looks at the unmet needs of *all* informal carers of older people.

2 Making income support accessible to carers

The most common reported unmet need among carers is financial support — both the level of support and its accessibility. Carers are more likely than non-carers to experience financial stress events — the 2022 Carer Wellbeing Survey reported that 54 per cent of participating carers had experienced one or more significant financial stress events in the previous year, and 56 per cent of carers regularly feared not having enough money to care for the care recipient (Schirmer, Mylek and Miranti 2022, pp. v, 24, 38). In the 2018 SDAC, 21 per cent of informal carers of older people said they had difficulty meeting everyday living costs (ABS 2019a).

The higher incidence of financial hardship among informal carers can be attributed to several factors.

- Many carers (especially of older people) do not work. Many carers of older people are above retirement age and many carers who do not work rely on Government support payments, such as the Age Pension or Carer Payment.
- Carers tend to earn lower income than non-carers (ABS 2019b), and may reduce their work hours (for example, go from full-time to part-time, or take up a casual role) to allow better flexibility to provide care. In 2018, nearly 20 per cent of carers of older people said the main financial effect of caring was that their income had decreased (ABS 2019a). Additionally, informal carers were twice as likely as non-carers to live in a low-income household (ABS 2019b).

- Carers may have to absorb some of the costs of providing care, such as buying groceries and medications for the care recipient — in 2018, the SDAC found that 10 per cent of carers of older people regularly paid a large part of the care recipient's living costs and 25 per cent said the main financial effect of caring was extra expenses (ABS 2019a).

In the context of an entitlement to extended unpaid leave, Anglicare Australia said a legislated return to work would be helpful, 'but having enough money to live on while carrying out caring responsibilities is far more important' (sub. 6, p. 1).

Some carers are also more likely to experience financial struggles — rates of financial stress are higher for Aboriginal and Torres Strait Islander carers, carers of people with high needs, carers with multiple care responsibilities, and carers of people with terminal illness and/or mental illness, for example (Carers Australia 2021, p. viii).

The Government provides three payments that are targeted at carers. While these payments likely have a significant benefit for some carers, the incidence of financial stress and low income among carers suggests that these payments might not be as effective or accessible as they could be.

What income support is available to carers?

The Australian Government funds three types of income support payment specific to informal carers:

- Carer Payment: a fortnightly pension for carers who leave or reduce work to care
- Carer Allowance: a fortnightly income supplement to offset some of the costs of caring
- Carer Supplement: an annual payment to recipients of Carer Payment and/or Carer Allowance to support carers with the costs of caring.

Some carers receive other government payments that are not specific to carers, such as the Age Pension. In 2018, the most common income support payment received by carers of older people was the Age Pension (30 per cent), followed by the Carer Allowance (28 per cent) and Carer Payment (16 per cent) (ABS 2019a). These payments are summarised in table 1.

While the Carer Payment and Age Pension are paid at the same maximum rate, the greater use of the Age Pension among informal carers of older people likely reflects several factors:

- both payments have the same income and assets limits, but the Carer Payment also imposes income and assets tests and other eligibility requirements on the care recipient
- the Carer Payment will normally stop after the care recipient dies, whereas the carer would normally continue to receive the Age Pension in this situation
- carers can take a break from providing care without it affecting their Age Pension, whereas carers receiving the Carer Payment can take a break for up to 63 days each year (plus an additional 63 days off if the care recipient is temporarily in hospital)
- the Age Pension does not impose any limits on the amount of work, volunteering, studying or other activities undertaken by a carer, whereas there is a 25 hour per week limit on non-caring activities for carers receiving the Carer Payment (Services Australia 2022a).

**Table 1 – Summary of the income supports most used by carers
As at January 2023**

	Maximum rate	Eligibility summary
Age Pension	Per fortnight ^a : • \$936.80 (single) • \$1412.40 (couple)	<ul style="list-style-type: none"> • At or above Age Pension age • Australian resident for at least 10 years • Fortnightly income up to \$2243 (single) or \$3431.20 (couple). The pension is reduced by 50 cents for every dollar earned per fortnight above \$190 (single) and \$336 (couple) • Asset limits of \$280 000 (single homeowner), \$504 500 (single non-homeowner), \$419 000 (homeowner couple) and \$643 500 (non-homeowner couple) (excludes family home)
Carer Payment	Per fortnight ^a : • \$936.80 (single) • \$1412.40 (couple)	<ul style="list-style-type: none"> • Carer and care recipient are Australian residents • Providing constant care in the home of someone with severe disability, severe illness, or frail aged, or to children • Up to 25 hours per week not providing care (e.g. work or study) • Care recipient scores high enough on the ADAT^b, has illness/disability to last at least 6 months, or terminal illness, and need constant care • Carer income and asset limits as per Age Pension • If the care recipient does not receive a pension, their income must be less than \$120 605 per year and assets less than \$744 000 (excludes family home)
Carer Allowance	Per fortnight: • \$144.80	<ul style="list-style-type: none"> • Carer and care recipient are Australian residents • Providing additional daily care and attention to someone because they have a disability, severe illness or are frail aged • Carer and partner's combined income under \$250 000 per year • Care recipient scores high enough on the ADAT, has illness/disability to last at least 12 months or terminal illness, receives care in their home, the carer's home or in hospital
Carer Supplement	Per year: • \$600 per eligible income support payment/each person the carer receives Carer Allowance for	<ul style="list-style-type: none"> • Recipient of Carer Payment and/or Carer Allowance

a. Recipients of the pension may also receive a pension supplement (\$75.60 for a single and \$114 for a couple), and an energy supplement (\$14.10 for a single and \$21.20 for a couple). b. ADAT refers to the Adult Disability Assessment Tool. Sources: Services Australia (2021a, 2021b, 2021d, 2021c, 2022e, 2022k, 2022b, 2022c, 2022i, 2022h, 2022f, 2022j, 2022g, 2023a, 2023c, 2023b).

Income support can be difficult for carers to access

While income support already helps some carers manage the financial strain of caring, the persisting rates of financial hardship among carers suggest that income supports are not fully meeting the needs of carers. Three possible reasons for this are that:

- the level of income support is too low
- the eligibility criteria for payments such as the Carer Payment are overly restrictive
- the process of applying and navigating Centrelink is difficult and time-consuming.

Is the level of income support for carers adequate?

Government income support payments will be reviewed as a result of reforms that are already under way. In November 2022, the Government announced it would establish an Economic Inclusion Advisory Committee to conduct an annual review of the ‘adequacy, effectiveness and sustainability’ of Government income support payments, which is to be published at least a fortnight before each federal budget (Chalmers and Rishworth 2022).

Some inquiry participants argued that the current level of income support provided by the Carer Payment and Carer Allowance is too low to meet the cost of caring (Dementia Australia, sub. 12, p. 14; National Aboriginal Community Controlled Health Organisation, sub. 5, p. 7).

Carer allowance is less restricted [than Carer Payment] ... However the payment is very low — \$136.50 per fortnight, about one seventh of Carer Payment and is not designed for income replacement ... (Women Work and Policy Research Group, sub. 28, p. 7)

The Carer Payment is adjusted at the same rate as other pensions in Australia (such as the Age Pension and Disability Pension). Pensions are adjusted in March and September each year by the greater of the increase in the Consumer Price Index or the Pensioner and Beneficiary Living Cost Index over six months (Klapdor 2022). Pensions are also adjusted to prevent payment rates from falling behind community living standards using a percentage of Male Total Average Weekly Earnings (MTAWE) as a benchmark. Currently, this benchmark sits at about 42 per cent of the MTAWE for the maximum rate of pension for a couple, and about 28 per cent of the MTAWE for the maximum single pension (DSS 2022a). In June 2022, the Melbourne Institute’s quarterly publication of estimated poverty lines in Australia determined the poverty line (including housing costs) per week as follows:

- \$617 for a single person who is working
- \$825 for a couple who are working
- \$500 for a single person who is not working
- \$708 for a couple who are not working (Melbourne Institute 2022, p. 1).

Based on these, the corresponding level of Carer Payment in the June quarter of 2022 of \$450 (single) and \$679 (couple) per week are below the estimated poverty lines for singles and couples who are not working (which may be the case for carers receiving the Carer Payment) (DSS 2022b). However, many recipients of Carer Payment also receive the Carer Allowance and/or rent assistance, which may bring their income to the poverty line or above it. In 2018, about 45 000 carers of older people received both Carer Payment and Carer Allowance, and at June 2022, about 80 000 households received both Carer Payment and Commonwealth Rent Assistance (ABS 2019a; DSS 2022d). Informal carers who receive the Carer Payment are also eligible for a Pensioner Concession Card, which includes access to discounted medications and doctor appointments.

The Carer Allowance is designed to offset some of the costs of providing care, rather than as an income replacement. There is little evidence about the additional costs of care that carers face, which makes it

difficult to judge whether current rates of Carer Allowance are appropriate. The Carer Allowance is intended to offset direct, tangible costs of care, such as the care recipient's food, medications and appointments, but not other costs to carers of caring, such as the cost to the carer's health and wellbeing.

These reviews of income support that will be conducted by the Economic Inclusion Advisory Committee will provide an opportunity to assess the level of Carer Payment and Carer Allowance, with a focus on the appropriateness of the level of these payments for informal carers.

Eligibility requirements

A number of participants raised concerns about the eligibility requirements for income support being overly restrictive, penalising working carers, and preventing them from getting the financial assistance they need. Carers Australia, for example, said:

People are not always aware of the complex eligibility criteria for income support payments until after they have made the decision to cease employment. (sub. 36, p. 28)

One concern is about the income and asset tests to receive Carer Payment. In 2022, the income test reduced the amount of Carer Payment by 50 cents for every dollar where the fortnightly income exceeds \$190 for a single person and \$336 for a couple. Several participants considered these limits overly restrictive for carers needing financial support, especially for carers with a partner.

The carer and their partner must meet an income and assets test, which means that if one member of a couple took unpaid leave, they would only be able to draw on Carer Payment if their partner was on a low income and if they had household assets. Currently a couple may only earn \$336.00 per fortnight before the taper rate begins to reduce the value of the fortnightly payment. (Women Work and Policy Research Group, sub. 28, p. 7)

... partnered carers have less access to the Carer Payment as it is means tested against a spouse or partner's income. (Carers Australia, sub. 36, p. 28)

Another concern was that the Carer Payment provides a disincentive for carers to remain attached to the workforce. To receive the Carer Payment, a carer cannot be away from care (such as to work or study) for more than 25 hours per week, including travel time. Other than these 25 hours, carers are required to be providing 'constant care', which is expected to be 'at least the equivalent of a normal working day', including active care, supervision and monitoring (DSS 2023). Some participants argued that these requirements discourage carers from continuing to work while providing care (Dementia Australia, sub. 12, p. 15; Merri Health, sub. 18, p. 11; NACCHO, sub. 5, p. 7).

The disincentive to work is borne out in the data — in December 2022, only nine per cent of Carer Payment recipients had earnings from employment (DSS 2022e). The Commission's Mental Health inquiry also recommended that, in the context of mental health carers, the 25 hour per week restriction should be replaced with a 100 hour per month restriction on work only (meaning carers could study or volunteer without restriction) (PC 2020, p. 922).

However, the need for more flexibility in Carer Payment eligibility needs to be balanced against ensuring the integrity of the payment to genuine carers. In the 2018 SDAC, about 10 per cent of Carer Payment recipients said they were 'not a carer', while a further 17 per cent said they were 'not a primary carer'. About 9 per cent provided less than 20 hours of care per week. It is possible that some of these carers reporting lower weekly hours of care did not count less-intensive care activities, such as monitoring or social interaction, when asked in the survey. While some carers have asked for changes to the activity requirements for Carer

Payment, it appears that the Department of Social Services could be taking a broader interpretation of the activity tests.

Access requirements

Many participants to this inquiry argued that the Carer Payment and Carer Allowance are difficult to access. Dementia Australia, for example, surveyed 360 former or current carers and 65 per cent reported significant challenges accessing income supports, including 'administrative workload, bureaucratic obstacles, and strict eligibility criteria' (sub. 12, pp. 6, 14).

When carers apply for the Carer Payment or Carer Allowance, they typically have to navigate MyGov and Centrelink, provide documentation for themselves and the care recipient, complete application forms and provide reports from a health professional and from the carer (Services Australia 2022d). Some participants said that the documentation needed for Carer Payment and Carer Allowance are difficult and time-consuming for carers to provide (Dementia Australia, sub. 12, pp. 14–15).

Additionally, carers are time poor and suffer high levels of psychological distress so struggle to navigate the complex and timely process of applying for payments. (NACCHO, sub. 5, p. 7)

The burden of accessing income support can be especially large for particular groups of carers, such as Aboriginal and Torres Strait Islander carers (NACCHO, sub. 5, pp. 7–8) and carers from other culturally and/or linguistically diverse groups, who may need additional help.

Some documentation and evidence requirements are necessary to ensure government payments go to eligible people in need. However, many groups — not just carers — report difficulties navigating Centrelink and accessing income support, suggesting it is a wider issue. For example, a 2022 Senate inquiry found that the process of making a claim for the Disability Support Pension was 'overly complex, difficult to navigate, and results in inequitable outcomes' (Australian Senate 2022, p. 65).

Part of the complexity of accessing income support payments comes from having multiple payments targeted at carers. To access income support, carers have to understand the eligibility requirements and level of support from the Carer Payment, Carer Allowance and Carer Supplement, as well as any other relevant payments such as the Age Pension. Some payments, such as the Carer Payment and Carer Allowance, also require carers to complete separate applications to receive both payments. This contributes to confusion and carer burden when applying for payments and navigating Centrelink. The Commission's 2020 *Mental Health inquiry* made a similar observation:

The existence of a Carer Payment, Carer Allowance and Carer Supplement that all achieve similar objectives, but have some arbitrary differences in eligibility, contributes to an income support system that is complex and not well understood by carers. (PC 2020, p. 921)

As well as reviewing the rate of carer income support payments, the Economic Inclusion Advisory Committee provides an avenue for consideration of the ways in which the complexity of having multiple payments may be contributing to carers' economic disadvantage.

3 Improving the availability of quality formal care

Informal carers often need help from formal services to provide care and manage at home. For example, a carer may need help transporting the person they care for to appointments. And sometimes carers need a break from providing care altogether by using respite services.

Carers NSW noted the importance of formal care, including respite services, to help carers reconcile work and caring.

Access to timely, adequate and appropriate formal care services, including services and supports that provide replacement care while a carer is participating in employment, is a key component of supporting carers to maintain employment and continue caring. (sub. 20, p. 23)

Carers Australia said:

... the support measures needed most by both employed carers and carers not in the workforce is affordable, substitute care of sufficient quality and quantity to enable carers to choose how they spend their time away from caring. (sub. 36, p. 30)

The Australian Nursing and Midwifery Federation argued that investing in formal services should be prioritised over measures to increase informal care.

The sustainability and success of informal care arrangements, whether that be through the use of extended unpaid carers leave or otherwise, is limited without the provision of accessible, timely and appropriate formal supports for both care recipients and carers. At this present time, those supports are not readily available. The ANMF is of a view that investment in formal supports is essential and should be prioritised over steps to increase reliance upon informal care arrangements. (sub. 39, p. 12)

In 2018, about half of carers of older people received help from support services, including formal home support services (ABS 2019a). About 14 per cent of carers of older people said they needed more physical assistance, and 12 per cent more respite care (ABS 2019a). Working carers more frequently reported having unmet needs for physical assistance compared to carers who were not working.

Formal aged care services, including home support, respite and residential aged care, are important to give carers enough time to manage other commitments. They can reduce the burden of caregiving on informal carers and increase the sustainability of informal care. The Royal Commission into Aged Care Quality and Safety (Royal Commission), however, concluded that the aged care system was failing to properly support informal carers, and was providing 'reactive, inadequate and piecemeal support' (RCACQS 2021c, p. 203).

What formal care services are available to carers?

Home support services

The Australian Government subsidises three main types of home support service programs that assist older people and their carers. They are:

- Short-Term Restorative Care
- Commonwealth Home Support Programme (CHSP)
- Home Care Packages (HCPs).

All three programs are intended to provide varying levels of support to the care recipient, but they indirectly support informal carers by assisting with some of the tasks that an informal carer would otherwise provide, as well as some direct supports such as respite (box 3).

Box 3 – Government-subsidised home support services

Short-Term Restorative Care provides support services for up to eight weeks to help reverse or slow down difficulties that the care recipient may have performing daily tasks. It is intended to help delay the need for long-term care and support services, by providing services such as aids and equipment, cooking, home maintenance, nursing, allied health therapies, psychologist or counsellor support, transport and accommodation in residential care (myagedcare 2022b). In 2021-22, about 7400 people received Short-Term Restorative Care, for which the Government contributed about \$75 million (Department of Health and Aged Care 2022a, p. 64).

The Commonwealth Home Support Programme (CHSP) has a similar objective to Short-Term Restorative Care, which is to help older people live safely at home for longer. Recipients can typically access one or two entry level services through Government and/or Government-subsidised service providers, who offer services such as meals, nursing, allied health therapies, cleaning, home modifications and maintenance, transport, social outings and respite. In 2021-22, the Government spent about \$2.9 billion on the CHSP, which was accessed by about 820 000 older people in that year (Department of Health and Aged Care 2022a, p. 32).

Home Care Packages (HCPs) are aimed at helping older people live at home when they require coordinated services to do so. HCPs offer a similar range of services to the CHSP, but are intended for people with more complex needs, to provide access to multiple services. HCPs are offered at four levels: basic, low, intermediate and high, and are delivered through service provider organisations. In 2021-22, the Government spent about \$4.4 billion on HCPs, which were used by about 262 000 older people (with an average age of about 81 years across all users) (Department of Health and Aged Care 2022a, pp. 34, 37; SCRGSP 2023).

The National Aboriginal and Torres Strait Islander Flexible Aged Care Program provides culturally appropriate aged care services at home (and in aged care facilities), for older First Nations people. The services are delivered through local aged care service providers, and are offered according to the needs of the community. The home support services offered can be similar to other home support programs, including care services (such as with bathing, communication and meals), support services (such as cleaning, laundry, medication management, emotional support and social activities) and clinical services. In 2021-22, the program provided about 1300 aged care places, at a cost of about \$118 million (Department of Health and Aged Care 2022a, p. 67).

The Royal Commission recommended the different aged care programs (including residential aged care) be combined. The Australian Government is currently designing a new home aged care program, which it intends to commence on 1 July 2024 (Department of Health and Aged Care 2022b, p. 5)

Respite care

The Government also provides some subsidised access to respite care. Respite care allows the carer to take a break from care for a period of time, which can range from several hours to a day or overnight. It can be provided in an emergency (such as if the carer becomes ill or injured) or planned respite (such as when the carer needs to attend an appointment or goes on holiday). Respite can be provided in the care recipient's home, in a community respite centre or in a residential aged care facility. Carers can access up to 63 days of subsidised residential respite per year through My Aged Care (myagedcare 2023b).

About 2.5 million days of residential respite care were used in Australia in 2021-22, provided to approximately 113 000 recipients, with an average of 1.2 episodes of respite per recipient and an average stay of 30.4 days per episode. The cost of residential respite to taxpayers was \$510 million in 2021-22, and in the same year, the Government provided additional grants of about \$337 million to subsidise the delivery of respite to about 42 000 clients through the CHSP, which offers flexible, centre or home-based respite (Department of Health and Aged Care 2022a, pp. 42–47).

Both the Carer Gateway and My Aged Care sites provide coordinated places for carers to access respite services. To use residential respite, the care recipient must be assessed by an Aged Care Assessment Team (ACAT) to determine the level of respite care needed. Through the CHSP and HCPs, carers can also access respite either in the home, or in a respite centre (such as a day centre or cottage) once they are assessed as eligible for the program (Department of Health 2021a, p. 46).

Residential aged care

Sometimes carers provide care for an older person to ‘fill the gap’ while they wait for residential aged care. In 2021-22, about 246 000 people received permanent residential aged care, at a cost to Government of \$14.6 billion (Department of Health and Aged Care 2022a, pp. 50–52).

Wait times to access formal care services can be long

A common concern relates to wait times to access formal care services, such as HCPs and residential aged care services. In 2022, the My Aged Care site indicated waiting times for a HCP of approximately three to six months, for a person with medium priority (for any of the four levels of package) (myagedcare 2022a). The Commission previously estimated that in 2021-22, the total elapsed time between someone undergoing an ACAT assessment and receiving a HCP ranged from five months for a Level 1 package, to between 8 and 12 months for a Level 3 package (for all priority groups). The total elapsed time was significantly shorter for Level 3 or Level 4 recipients who were additionally designated as high priority — about one month. Wait times tended to be shorter in major cities and inner regional areas, compared with more remote locations (SCRGSP 2023).

Many older people also face wait times to enter residential aged care. In 2021-22, the median elapsed time between a person receiving ACAT approval and entering permanent residential aged care was 153 days. This median elapsed time was shortest in New South Wales (129 days) and longest in the ACT (381 days) (SCRGSP 2023).

Carers note many challenges in accessing formal supports they need. Challenges include long or inconsistent wait times, lack of service access in rural areas, and lack of responsiveness to changing needs. (Merri Health, sub. 18, p. 11)

... waiting lists for higher level care packages means people are struggling at home even before support is provided. (Quality Aged Care Action Group, Aged Care Reform Now and Carers’ Circle, sub. 21, p. 9)

The wait times to access HCPs were also raised in the Royal Commission.

Too many older people are not getting the Home Care Package they need at the time and level they need it. Many people cannot access a package even when they are approved for one because the supply of packages is capped by the Australian Government. ... This is simply too long for older people to wait for care, as many die or have to enter residential care while waiting. (RCACQS 2021b, vol. 2, p. 62)

The wait times for a HCP have manifested in a large number of people waiting to be offered a HCP at the level they have been approved for. At 30 June 2022, there were about 50 000 people waiting for a HCP at their approved level — about 9000 of these had been offered an interim HCP at a lower level (Department of Health and Aged Care 2022c, p. 10).

There are some reforms and additional funding in the pipeline that may relieve some of the current pressure on HCPs. The Royal Commission recommended that the Government increase the number of HCPs available and allocate HCPs to all people on the waiting list, and allocate HCPs at the approved level to any new entrants on the waiting list within a month of their assessment. The Government accepted this recommendation in-principle, and announced in the 2021-22 Budget an additional \$6.5 billion to provide 80 000 extra HCPs over the next two years (Department of Health 2021b, p. 30). More time is needed to assess whether this funding will be adequate in the longer term, given the shift in focus and demand in the aged care sector from residential aged care towards home support.

Access to quality aged care

A lack of quality aged care can result in sustained burden on informal carers. For example, it can require the informal carer to continue to provide support to help ‘fill the gap’ when all the needs of an older person are not being met in a residential aged care home or by home support services. It can also deter informal carers and care recipients from accessing respite care when they need a break.

A number of participants suggested that the poor state of residential care meant informal carers were required to continue caring.

... carers often continue to provide a range of supports to their family members or friends living in residential care and often the tasks are the same as the informal supports provided in home. In part, this reflects the poor state of residential care ... (Carers Tasmania, sub. 37, p. 11)

... it is shameful that they [informal carers] cannot and do not feel confident to reduce their caring responsibilities because of a failure to provide adequate numbers of staff, including registered nurses in residential aged care facilities. (Quality Aged Care Action Group, Aged Care Reform Now and Carers' Circle, sub. 21, p. 17)

A survey conducted by Dementia Australia found that even once a person with dementia had entered residential aged care, informal carers continued to provide a range of support and assistance, including supporting aged care workers due to staff shortages (sub. 12, p. 10). The aged care system can only provide quality residential aged care, including respite, if facilities are adequately staffed.

Quality aged care services must also be able to be tailored to the cultures, languages and identities of carers and care recipients. A number of participants argued that mainstream aged care services often do not cater well for carers and care recipients from diverse groups. The Royal Commission expressed similar sentiments:

The existing aged care system is not well equipped to provide care that is non-discriminatory, culturally safe and appropriate for people's identity and experience. (RCACQS 2021b, p. 75)

People from culturally and/or diverse communities, including Aboriginal and Torres Strait Islander people, need access to culturally safe and appropriate aged care services. One issue is that it can be difficult to find supports for carers and care recipients with a first language other than English. In 2018, about 20 per cent of primary informal carers of older people usually spoke to the care recipient in a language other than English (ABS 2019a). This can compound difficulties in accessing support such as in-home support services, respite and counselling — for example, carers who usually speak a language other than English at home are less

likely to report having good access to information from medical professionals (Schirmer, Mylek and Miranti 2022, p. 55).

The need for advocacy increases with people from CALD [culturally and linguistically diverse] backgrounds because often the carer also acts as an interpreter. While many services in public hospital settings have translation services available, not all health and aged care service providers have this ... (Quality Aged Care Action Group, Aged Care Reform Now and Carers' Circle, sub. 21, p. 9)

Similarly, carers and care recipients can face difficulties accessing formal aged care services that are culturally safe and appropriate. For example, a care recipient may need a residential aged care facility that recognises the significance of the individual's religious, cultural and spiritual practices.

Formal aged care services, including home support and respite care, also may not recognise the diverse relationships and needs of carers and care recipients. In its submission, LGBTIQ+ Health Australia said that many LGBTIQ+ people who are carers or care recipients risk discrimination and not receiving the same level of interest and concern as others when seeking support services (sub. 22, pp. 2–3).

In some First Nations cultures, caregiving is viewed as a part of broader kinship obligations, rather than as a separately defined role (Watarrka Foundation 2023). Mainstream support services do not always recognise the significance of such shared caregiving obligations and duties in different cultures and groups.

The Royal Commission made a number of recommendations to improve the availability of culturally-appropriate formal care services, especially for Aboriginal and Torres Strait Islander people. This included:

- a new Aboriginal and Torres Strait Islander aged care pathway that ensures that First Nations people receive culturally respectful and safe care regardless of where they live, and provides interpreters on the same basis as for other CALD communities when seeking aged care services
- compulsory training on cultural safety and trauma-informed delivery of services for all workers of aged care providers and care finders who are in direct contact with care recipients
- a category under the new aged care program for residential care that, among other things, provides social supports, that include cultural support.

These reforms will help with some of the additional barriers that carers and care recipients from diverse groups face when accessing aged care services and supports. In the position paper, the Commission recommends that the Australian Government review the eligibility restrictions in the National Employment Standards that limit access to carer leave based on the relationship between the employee and the person they care for.

The lack of quality services for carers and older people living outside of metropolitan areas was also raised as a concern.

When providing care, informal carers in rural and remote locations encounter considerable distances to travel and limited access to services. (Royal Australian and New Zealand College of Psychiatrists, sub. 25, p. 3)

There are many challenges faced by older carers, and other informal carers, to access the support they need. These include lack of providers or diversity of providers, especially in rural areas. (Lived Experience Australia, sub. 1, p. 5)

The Royal Commission also found that people in regional, rural and remote areas often experience multiple disadvantages, and have poorer access to primary health care as well as aged care services (RCACQS 2021b, pp. 70–73). It recommended that a System Governor identify areas where the availability

of aged care services is poor and plan for and supplement services to meet the needs of people in non-metropolitan areas.

It can also be difficult for carers and care recipients to find information about the quality of residential aged care facilities (RCACQS 2021b, p. 61). The Royal Commission found that there was a need for a stronger mechanism to ensure the quality and safety of aged care services, including residential aged care. It recommended a variety of measures to improve the quality of aged care services, including:

- a new Aged Care Act that includes objectives to provide high quality, safe and timely support and care and includes a complaint mechanism for people receiving care
- an Australian Aged Care Commission that includes a Complaints Commissioner and a Quality Commissioner
- an independent Aged Care Safety and Quality Authority to enforce compliance of the aged care system with the safety and quality standards
- an independent office of the Inspector General of Aged Care to investigate, monitor and report on the administration and governance of the aged care system
- periodic review of the Aged Care Quality Standards, and development of and reporting on quality indicators
- a star rating system to allow carers and care recipients to compare aged care services and providers, which has since been implemented for residential aged care providers.

The Commission also recommended the Australian Government expedite the broad reform agenda for aged care to enhance the quality of care (PC 2022, p. 112). In the 2022-23 Budget, the Government announced funding for several measures to improve the quality of aged care services, including:

- \$2.5 billion over four years from 2022-23 to require all residential aged care facilities to have a registered nurse onsite at all times, and increasing care minutes to 215 minutes per resident per day from October 2024
- \$23.3 million over four years to improve aged care services that support older First Nations peoples, and older Australians from diverse communities and regional areas
- \$9.9 million over two years to establish the Aged Care Complaints Commissioner (Australian Government 2022, p. 125).

Improving access to respite care

Caregiving can place significant demands on the time and energy of informal carers. Access to respite care that gives carers a break from caregiving can be important to help carers provide care and manage their own wellbeing over time.

The issue of burnout fatigue experienced by informal carers is exacerbated by a lack of quality respite care under the current aged care system. Respite care enhances the sustainability of informal care arrangements. Carers gain the opportunity to manage their own wellbeing and engage in workforce participation, whilst care recipients are given greater opportunities for rehabilitation, reablement or medication review under the supervision of skilled health professionals. (ANMF, sub. 39, p. 11)

But few informal carers use respite care — in 2018, about 87 per cent of informal carers of older people had never used respite care, and most of these carers said they did not want or need respite. The low take-up of respite is not unique to Australia, however — the Organisation for Economic Cooperation and Development found that ‘among OECD countries, respite care remains insufficient, with low uptake due to low compensation, low availability of services and organisational challenges’ (Rocard and Llana-Nozal 2022, p. 5).

The evidence suggests that respite is most effective at improving the wellbeing of carers when it is taken frequently. A study of carers in the United States found that those who received four or more hours of respite

care per week reported a decline in caring burden over time, while carers who did not frequently use respite experienced an increase in perceived burden over time (Avison et al. 2018, p. xix). The effects of temporary residential-based respite are more mixed — there is some evidence that it can improve carer wellbeing during the respite period, but that these benefits are often not sustained beyond the respite period (Vandepitte, Putman and Verhaeghe 2016). Some studies found that respite was generally not effective in improving carer wellbeing (Cheng and Zhang 2020). This suggests that it may be frequent respite, rather than single, infrequent instances of respite, that contribute to improved carer wellbeing. There are several reasons why this may be the case.

- If respite is taken infrequently, respite time may be used to ‘catch up’ on appointments, housework and other demands, rather than for rest (Hussain, Wark and Ryan 2018)
- Infrequent respite may increase the burden on the carer if going to respite causes significant disruptions to the care recipient’s routine. This may increase the likelihood that the carer has to manage increasing challenging behaviours or agitation when the care recipient returns from respite (for example, if the care recipient has dementia) (Alzheimer’s Project 2020). Regular access to respite may help the care recipient ‘get used’ to being cared for by someone else, and possibly in a different place.

Some carers face barriers to accessing frequent respite. The Royal Commission found that some carers were reluctant to use respite even if they needed it, if they had had a previous negative experience, or perceived that formal respite would not provide the same level of care as the informal carer (RCACQS 2021b, p. 66).

Some carers said respite is difficult to access and arrange.

Quite a number of the informal carers would like to be able to continue to work either part-time or full-time, however the availability of services such as in-home respite or social support groups is limited and makes this difficult for the informal carer. (Merri Health, sub. 18, p. 5)

The most common difficulty is access to flexible respite at times that suit the informal carer who may want to attend their own appointments or to just have a break. In the current environment of support worker availability the informal carers have to work around availability of those workers. (Merri Health, sub. 18, p. 12)

Any respite care needs to be flexible, responsive and accessible, not take weeks to set up and require excessive paperwork and processes to establish. (Lived Experience Australia, sub. 1, p. 6)

The Royal Commission also found that:

There are numerous barriers to respite care — services are in short supply, they need to be booked months in advance, or they are only available for periods of several weeks when people and their carers need a shorter time. (RCACQS 2021a, p. 25)

In the 2022 Carer Wellbeing Survey, more participants said they had poor access to different types of respite care than any other support services:

- in-home overnight respite care (81 per cent)
- overnight respite care out of home (74 per cent)
- day respite care out of home (66 per cent)
- in-home day respite care (62 per cent) (Schirmer, Mylek and Miranti 2022, p. 49).

Concerns were also raised about the quality of respite care in residential aged care facilities. For example, the Quality Aged Care Action Group, Aged Care Reform Now and Carers’ Circle said:

The Royal Commission into Aged Care Quality and Safety confirmed what we already knew; residential aged care is severely understaffed and poorly regulated leading to widespread neglect of residents. This means options such as respite (which is already hard to secure) or placing a loved one in residential aged care would be a last resort option resulting in prolonged and intensive informal caring responsibilities in the home. ... More often than not, people receiving high-level care in the home would not cope with a different environment. Some of our members who have availed themselves of this option for respite note that their loved one often declines when placed into residential care – this is particularly the case with people who have dementia. (sub. 21, p. 9)

The Royal Commission recommended several reforms to address deficiencies with respite care. A key recommendation was the creation of a new aged care program, that combines existing programs such as the CHSP, HCPs, residential aged care and respite, with a single assessment process for carers and care recipients. This recommendation was accepted by the then-Government. This program, combined with increased funding for home care, should improve carers' access to respite, and to formal aged care services more broadly.

4 Supports for carers' wellbeing

As well as assistance with providing care, informal carers often need support for their health and wellbeing. Informal carers are at greater risk of experiencing poor health, psychological distress and low wellbeing than the average Australian adult, especially when they do not receive support from friends, family or formal support services (Schirmer, Mylek and Miranti 2022, pp. viii, 8–9).

We are running errands in our lunch breaks, supporting our caree before or after work and taking time off work to manage appointments. We also spend many hours co-ordinating services, appointments and organising the household of our caree. Often at the detriment of our own needs and health. (Merri Health, sub. 18, p. 3)

I worked 10 times harder as a carer for my mother than I did in any of my professional paid jobs. I was exhausted, burnt out and my health was deteriorating. Now I needed the caring! (Merri Health, sub. 18, p. 3)

There is a large body of evidence showing an association between informal caregiving and poor physical and mental health of carers, as outlined in the position paper.

There are a number of existing services, both government and non-government, that help support the health and wellbeing of carers in Australia. As well as the Carer Gateway and formal services such as respite care, a number of services exist to directly support carers' health and wellbeing, including:

- peer support groups, which connect informal carers with one another, either in-person or online
- counselling, so carers can speak with a counsellor in person or over the phone
- self-guided coaching: allows carers to talk with a professional coach
- skills courses: online programs to support carer wellbeing, including dealing with stress, effective communication, self-care, sleep and legal issues (Carer Gateway 2022).

The evidence of the effectiveness of different supports for carers' health and wellbeing is mixed (box 4). However, many carers have suggested that they would like better access to services such as respite, counselling and other emotional support, and training.

Box 4 – How effective are different supports for informal carers?

Psychological interventions

A variety of psychological interventions aim to improve carers' mental health and reduce caring burden and related stress. There is some evidence that psychological supports — such as counselling, emotional support, behaviour management, meditation, mindfulness and acceptance-based interventions — are linked to reduced depression, burden and psychological distress among informal carers (Candy et al. 2011; Cheng and Zhang 2020; Collins and Kishita 2018; Dharmawardene et al. 2016; Díaz-Rodríguez et al. 2021; Huo et al. 2021). The evidence is not as strong for some other types of psychological interventions, such as cognitive behavioural therapy and support groups (Cheng and Zhang 2020; O'Toole et al. 2017).

Education and training programs for carers

Education and training programs can target the development of a range of skills for informal carers, including to improve the health and wellbeing of the carer and care recipient, education about the care recipient's condition (such as dementia) and manual handling courses. There is mixed evidence on the extent to which these programs help with carer burden, quality of life, mental health and transitions to long-term residential care for the care recipient (Jensen et al. 2014; Yesufu-Udechuku et al. 2015). A study in the United States found that education and training for carers lead to increased carer confidence over time (Avison et al. 2018, p. xi). Other studies have found little evidence that information or training programs had significant effects on carer burden, mental health or quality of life (González-Fraile et al. 2021; Treanor et al. 2020).

Other supports

Emerging evidence on some less-studied supports for carers suggests that helping carers manage the demands of care can be beneficial to the carer's wellbeing. For example, early intervention strategies to help a carer feel prepared to provide informal care may offset some of the negative effects of providing care on the mental health of carers (Hebdon et al. 2022). There is also moderate evidence that case management — which refers to a process of assessing, planning, facilitating and advocating for a carer and care recipient to meet their needs — can improve the carer's mental health (Berthelsen and Kristensson 2015, pp. 988–989, 1000; CMSA 2023).

The Government is starting to collect data to assess the effectiveness of the Carer Gateway. From 2022-23, the Department of Social Services will begin reporting on how the wellbeing of informal carers who are registered with Carer Gateway service providers has improved. The aim is to verify whether the supports for carers through the Carer Gateway are effective, and help guide further improvements (DSS 2022c, p. 96).

Some state and territory governments, and local governments, also offer support services for informal carers. For example, the Victorian Government funds the Support for Carers Program, which provides informal carers in Victoria with access to educational programs, health and wellbeing activities, counselling, support groups and information (as well as practical support with care, including domestic assistance, equipment and transport, and respite) (Carers Victoria 2020; Victorian Government 2022).

There are also many non-government service providers in each state and territory that offer support for carers. As well as assistance with care, these providers can also offer services such as support over the phone, counselling and food relief (healthdirect 2022). Some of these services are free.

The range of existing support services for carers' health and wellbeing appears to be reasonably adequate. But services are often difficult for carers to access. This mostly reflects the significant demands that caring

places on an informal carer's time and energy. This is exacerbated by difficulties accessing respite care (ANMF, sub. 39, p. 11).

I don't have the time to join a support group. I basically cannot leave the house except for a three-hour period on Mondays when the housekeeper comes. (Female, aged 62, Caring for a parent and caring for a spouse, Outer Regional). (Hussain, Wark and Ryan 2018)

This makes it more difficult for carers to manage and improve their own health and wellbeing. Measures to improve access to respite, as discussed in section 3, will likely help carers to improve their health and wellbeing, by allowing them more time to access personal support and simply take a break from caregiving.

5 Tailored support for carers

A well-designed system of support services for carers would:

- recognise all caregiving relationships
- be simple to coordinate
- be responsive, as the needs of the care recipient and carer change.

This section looks at the broader system of support for informal carers, how it fits together and how well it works.

Recognising diverse caring relationships

The Commission also heard that some existing arrangements and supports for carers and care recipients do not recognise diverse caring relationships. The National Employment Standards provide an entitlement to carer leave, for carers to care for an 'immediate family or household member'. This excludes many caring relationships and cultural ideas about what constitutes 'family', and non-familial caring relationships.

Sharon describes Noeline as her second mother. Noeline is 70, does not have any children of her own and lives alone. When Sharon got a call at work that Noeline had been taken to hospital after a sudden heart attack ... Sharon travelled to the regional area her aunt lived in and stayed in Noeline's home, looking after the cat and supporting Noeline in hospital. After Noeline was discharged, Sharon stayed another few days to care for her ... On her return to work, Sharon's application for carer leave with a certificate from Noeline's cardiologist was rejected by [Human Resources] as Noeline was not her 'immediate family'. (Carers Australia, sub. 36, pp. 16–17)

In some First Nations cultures, 'family' takes on a broader meaning beyond close biological relatives (NACCHO, sub. 5, pp. 4-5; Watarrka Foundation 2023). Definitions of 'immediate family' also do not cater well to the caring relationships of LGBTI+ people, who often may care for, or be cared for by, someone who is not an immediate family or household member (LGBTIQ+ Health Australia, sub. 22, p. 3). Difficulties accessing culturally appropriate formal care services, as discussed in section 3, are compounded when carers and care recipients have diverse relationships and needs beyond those recognised by mainstream supports. The Government should review the eligibility restrictions in the National Employment Standards that limit access to carer leave based on strictly defined relationships between the employee and the person they care for, in order to better accommodate working carers while they balance caregiving with paid employment.

Coordinating services

Some carers told the Commission that they found it difficult and time consuming to navigate the aged care system to coordinate support for themselves and the care recipient (Carers NSW, sub. 20, pp. 5–6; Merri Health, sub. 18, pp. 3, 12).

This partly reflects the complexity of the aged care system and the network of different supports available to carers and care recipients. The Royal Commission found that ‘irrespective of education levels, means, background or circumstances, it is very difficult for most people to navigate all aspects of the aged care system’ (RCACQS 2021b, p. 62).

There are some existing services that help older people and carers navigate the aged care system. For example, the EnCOMPASS: Multicultural Aged Care Connector program provides case management support to older people, carers and communities who are culturally and/or linguistically diverse, to help them navigate the aged care system and access support services. It is funded by the Government, and provides help through local providers who act in partnership with the Federation of Ethnic Communities’ Councils of Australia (FECCA 2020).

Case management is also used in some other health sectors in Australia and overseas. A case manager may assist with the assessment, planning, coordination, facilitation and advocacy needed for the client to receive timely, coordinated and appropriate services (CMSA 2023). Participants in the National Disability Insurance Scheme can nominate a support coordinator, who helps to coordinate and implement support services for the participant (NDIA 2022). There is some emerging evidence from overseas that case management is associated with improved wellbeing of informal carers (Berthelsen and Kristensson 2015, pp. 988–989, 1000).

Carers and care recipients navigating the aged care system can employ an aged care case manager through a private provider. But this means that carers need to be aware of case management services and reach out to these providers. The Royal Commission recommended that ‘care finders’ should be employed to work with care recipients, their carers and families, to navigate the aged care system and determine the types and timing of services needed, and provide case management assistance if needed. This would include being able to refer the carer to assessment for respite and other support services (2021a, pp. 228–229, 237–238).

While the Government accepted the Royal Commission’s recommendation for care finders, the care finder program that was implemented in January 2023 takes on a narrower role than the Royal Commission recommended. The care finder program is instead directed only at vulnerable older people, who may not have family, friends or a carer to help them access aged care services. It therefore excludes many older people with an informal carer, unless the carer needs ‘intensive support to interact with My Aged Care, access aged care services and/or access other relevant supports in the community’ (Department of Health 2022, p. 6; myagedcare 2023a). The rationale for this exclusion is unclear.

If the role of care finders reflected that envisaged by the Royal Commission — to assist all carers and care recipients who need help accessing and coordinating services and to provide case management — then care finders would also be well placed to provide information to working carers about their right to request flexible work arrangements. Further consideration of the costs and benefits of implementing care finders as envisaged by the Royal Commission appears to be required.

Making support responsive to changing needs

Carers and care recipients need access to timely support that can respond as their needs change over time. Section 3 discussed the wait times that carers and care recipients can face when accessing formal aged care services, such as HCPs and residential aged care.

Aged care package adjustments aren’t agile enough to keep up with the fluctuating care needs of elderly people. If their health slips in such a way that they aren’t able to re-negotiate their supports, they will suffer, whatever those supports may be. (Merri Health, sub. 18, p. 11)

The process for increasing to higher level care packages is lengthy, meaning there is little scope for additional support as and when care needs might increase, temporarily or permanently.

(Quality Aged Care Action Group, Aged Care Reform Now and Carers' Circle, sub. 21, p. 17)

Any respite care needs to be flexible, responsive and accessible, not take weeks to set up and require excessive paperwork and processes to establish. (Lived Experience Australia, sub. 1, p. 6)

As the care needs for an older person increase with age, the effects of unresponsive or delayed access to appropriate support services are compounded. This means that timely access to appropriate support is essential, and by extension, the use of queues to ration the use of aged care services is detrimental to the wellbeing of older people and their carers. Issues with supports being slow to respond to the needs of carers and care recipients will partly be relieved by additional funding, such as the announced funding to increase the number of HCPs offered to older people. However, it also requires a system that can more proactively anticipate how a carer and care recipient's needs might change. For example, a well-designed system would be able to identify and plan for how the care needs of an older person with dementia may increase over time. Care finders who are equipped to undertake case management for carers and care recipients may also be able to assist with this.

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