



Royal Commission
into Aged Care Quality and Safety

CARERS OF OLDER AUSTRALIANS

BACKGROUND PAPER 6

JULY 2019

The Royal Commission into Aged Care Quality and Safety was established on 8 October 2018 by the Governor-General of the Commonwealth of Australia, His Excellency General the Honourable Sir Peter Cosgrove AK MC (Retd). Replacement Letters Patent were issued on 6 December 2018.

The Honourable Richard Tracey AM RFD QC and Ms Lynelle Briggs AO have been appointed as Royal Commissioners. They are required to provide an interim report by 31 October 2019, and a final report by 30 April 2020.

The Royal Commission intends to release consultation, research and background papers. This background paper has been prepared by staff of the Office of the Royal Commission, for the information of Commissioners and the public. The views expressed in this paper are not necessarily the views of the Commissioners.

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Contents

Introduction	1
Who are the carers of older people in Australia?	1
What do carers do for their older family members and friends?	3
What are the impacts of caring?	3
What are the needs of carers and how can they be supported?	5
How are carers assisted in their role currently?	6
Service supports for care recipients	7
Supports for carers	8
Carer diversity	10
Aboriginal and Torres Strait Islander carers	10
Culturally and linguistically diverse carers.....	11
Lesbian, Gay, Bisexual, Transgender and Intersex carers	12
Conclusion	12

Introduction

This paper provides a high-level introduction to the role of family members and friends who provide what is often called informal and unpaid care to older Australians. It has been prepared by staff of the Office of the Royal Commission into Aged Care Quality and Safety but does not represent a direction or position of the Royal Commission in relation to this area. Any views expressed are not necessarily the views of the Commissioners.

Increasingly, older people in Australia are choosing to remain living in their own homes for as long as possible.¹ While not everyone has family members and friends to support them, many older Australians benefit from carers who provide assistance of various forms, ranging from help with domestic work through to personal and health care needs. Caring is often associated with a pre-existing relationship, and can be a positive and rewarding experience for both the person needing care and the carer. Caring can also change the nature of that relationship, and it can become a source of financial, emotional, social and physical strain.²

Carers are critical to the sustainability of the aged care system. They provide support and services that may otherwise be funded by the taxpayer, the estimated value of which is significant.³ Over the past 20 years, the role of carers has been recognised increasingly through various aged care and social policy reforms. However, there remains questions about the extent to which current services help carers to meet the needs of the people that they care for.

This paper provides an overview of the role of carers in supporting older people, the impact of caring and carer needs, and the available supports and services.

The word carer is used in this paper to refer to family members and close friends who provide regular, ongoing assistance to people aged 65 years and older, or 50 years for Aboriginal and Torres Strait Islander people, with everyday personal activities.⁴ It does not include people with employment contracts to provide regular aged care services. Informal carers are still considered unpaid even though they may receive a carer payment or other government allowance.⁵

Who are the carers of older people in Australia?

In 2015, the Australian Bureau of Statistics Survey of Disability, Ageing and Carers reported that there were almost 2.7 million unpaid carers in Australia (12% of the population).⁶ This number represents carers of older Australians and people living with a disability. Of those,

¹ Analysis and Policy Observatory, *Living longer living better aged care reform package*, 2012.

² T Hill, C Thomson, M Raven, M Wong, B Cass, S Yeandle and L Buckner, *Carers and Social Inclusion*, 2016, University of New South Wales, Social Policy Research Centre.

³ Productivity Commission, *Interventions to support carers of people with dementia*, 2018, Steering Committee for the Review of Government Service Provision.

⁴ Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia: Summary of Findings, 2015*, (Catalogue 4430.0), <https://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0>, viewed 9 July 2019.

⁵ Ibid.

⁶ Ibid.

856,100 were identified as primary carers.⁷ Of those primary carers, around 420,700 offered this care to people over the age of 65 years.⁸ There are some indications that the number of carers may be an under-estimate as not everyone chooses to identify themselves in this way.⁹ The 2015 Survey of Disability, Ageing and Carers also reported that the informal carers most likely to provide support to older people with everyday activities were spouses or daughters.¹⁰

Australia has an ageing population. In the last 40 years, the number of Australians aged 85 years and over increased significantly in absolute terms and as a share of the Australian population—from 91,640 in 1978 (0.6% of the Australian population) to 503,685 (2% of the Australian population) in 2018.¹¹ These changes result in more people needing care and more people required to provide care.¹² The number of people available to provide care to older family members and friends is anticipated to rise at a much slower rate for a number of reasons.¹³ They include Australian couples having fewer children, increased rates of divorce, increased participation of women in the labour force and more single-person households.¹⁴

For over a decade, gender inequity has been identified as an issue of concern in caring roles. While there has been some increase in the participation of men in carer roles, caring remains primarily undertaken by women.¹⁵ A 2016 study reported that men may take on caring commitments for an ill or frail female spouse or partner, whereas caring commitments for women may be more broadly spread amongst others including children, partners and parents.¹⁶

The Survey of Disability, Ageing and Carers reported that in 2015, carers were slightly over-represented outside of major cities.¹⁷ Reasons for this include:

- difficulties in accessing formal care services, resulting in greater reliance on family members and friends to provide support
- higher disability and illness rates in males in regional and remote areas, which may necessitate greater provision of informal care
- a higher proportion of Aboriginal and Torres Strait Islander people with poorer health outcomes in regional and remote areas
- declining prosperity in parts of outer regional and remote Australia that may suggest a decline in the capacity to pay for formal care services.¹⁸

⁷ Ibid.

⁸ Australian Bureau of Statistics, above n 4, table 44.1.

⁹ K Eagar, A Owen, K Williams, A Westera, N Marosszeky, R England and D Morris, *Effective Caring: a synthesis of the international evidence on carer needs and interventions*, 2007, Centre for Health Services Development, University of Wollongong, p 21.

¹⁰ Australian Bureau of Statistics, above n 4.

¹¹ Royal Commission into Aged Care Quality and Safety, *Background Paper 2—Medium- and long-term pressures on the system: the changing demographics and dynamics of aged care*, 2019, p 3.

¹² Ibid.

¹³ National Centre for Social and Economic Modelling (NATSEM), *Who's going to care? Informal care and an ageing population*, 2004, report prepared for Carers Australia.

¹⁴ Ibid, p 10.

¹⁵ K Eagar et al, above n 9.

¹⁶ J Schirmer, *Carers in regional Australia*, 2017, Health Research Institute & Institute for Applied Ecology, University of Canberra, p 2.

¹⁷ Australian Bureau of Statistics, above n 4, table 35.3.

¹⁸ Deloitte Access Economics, *The economic value of informal care in Australia in 2015*, Carers Australia, 2015, p 8.

What do carers do for their older family members and friends?

Carers provide a wide range of support for older people in Australia. Some carers provide full-time care, and in other instances formal and informal carers share responsibilities.

Informal or unpaid care can be a substitute for or supplement to domestic, personal care or nursing work.¹⁹ Carers may help their family members or friends in diverse areas, among them mobility, communicating, medication management, caring for wounds, reading, writing, meals and household chores, property maintenance and transport.²⁰ This care can also involve providing support using devices and aids, or responding to challenging psychosocial behaviours associated with dementia. Carers often have to learn about the health conditions of the person they provide care for, support decision-making, and navigate aged and health care systems. They frequently provide emotional, social and financial support.²¹

Informal caring does not end if the older person enters residential aged care. Carers regularly continue to provide personal care and support to the older person, and may also assume an advocacy role. Carers may need to develop new skills to manage the personal and emotional transition that their family members or friends experience when going into residential aged care.

In Australia, the replacement value of all unpaid care (that is, where informal care is replaced with services purchased from formal care providers) for people with a disability, mental illness, chronic condition, terminal illness and older Australians, has been estimated to be around \$60.3b per year (over \$1b a week).²² This figure is based on an estimated 2.86 million carers and on replacing *all* unpaid care.

Given the large number of family members and friends providing care to people over the age of 65 years, it is clear that the replacement value of these services for the aged care system would be significant, critically affecting its current sustainability.

What are the impacts of caring?

While research has generally focussed on the challenges and negative impacts of caring on carers, research evidence also identifies several positive impacts.²³ Caring for family and friends, often a choice, can bring personal rewards. They include the opportunity for personal growth and development of new skills, a chance to meet challenges, satisfaction derived from helping someone, the strengthening of relationships, and receiving the acknowledgement of family members and friends.²⁴ As the level of care increases, carers may experience a renewed sense of meaning in their life which can decrease burden and

¹⁹ F Colombo, A Llana-Nozal, J Mercier and F Tjadens, 'Help Wanted?: Providing and Paying for LongTerm Care' in OECD Health, 2011, *Policy Studies*, OECD Publishing, Paris, <http://dx.doi.org/10.1787/9789264097759-en>, p 136.

²⁰ Australian Bureau Statistics, above n 4.

²¹ Carers Australia, *About carers*, <https://www.carersaustralia.com.au/about-carers/>, viewed 7 June 2019.

²² Carers Australia, *Statistics*, <https://www.carersaustralia.com.au/about-carers/statistics/>, viewed 7 June 2019.

²³ Carers Australia NSW, *Impact of caring*, <https://www.carersnsw.org.au/facts/impact-of-caring>, viewed 9 July 2019.

²⁴ Ibid.

improve care.²⁵ Supporting the positive impacts of caring has the potential to improve the lives of families, governments and society.²⁶

However, the duration and complexity of caring responsibilities can have detrimental effects on the quality of care for the care recipient, and the health and wellbeing of carers. There are reports of carers experiencing psychological distress, strain and deterioration in their health overall.²⁷ In Australia, in 2015, 37.8% of carers reported living with a broadly defined disability that limits or restricts their everyday activities.²⁸ Carers are also reported to experience lower wellbeing than non-carers. They may ignore their own health and experience conditions directly linked to their caring role such as anxiety, depression and back problems.²⁹

Caring can also affect a carer's available time to maintain their social wellbeing, including their ability to participate in their community and interact with their families and friends. Carers may manage strong emotions such as anger, guilt, grief and distress that can cause conflict and frustration.³⁰ The Organisation for Economic Co-operation and Development reported in 2011 that the prevalence of mental health problems among carers was 20% higher than among non-carers.³¹ Similarly, Australian research has shown how people caring for family members and friends with dementia symptoms experience much higher rates of depression and psychological problems.³²

Carers of older people can also suffer significant financial consequences, with their economic security sometimes compromised or impacted upon and accepting responsibility for out-of-pocket costs. Carers often report financial strain associated with their caring roles.³³ For some carers, direct out-of-pocket expenses—medical and pharmaceutical supplies, meals, transport and equipment for the care recipient—may mean drawing on assets, taking on debt or foregoing treatment of their own health concerns.³⁴

The 2015 Survey of Disability, Ageing and Carers indicated that labour force participation rates for those aged 15 to 64 years was 56.3% for primary carers and 77.2% for other carers—lower than that for non-carers, which was 80.3%.³⁵ Carers are also more likely than non-carers to reduce their hours of work and earn less income.³⁶ The loss of income for carers is reported to shift costs from government to private households, and predominantly to

²⁵ R Fauziana, R Sambasivam, J Vaingankar, E Abidin, H Ong, M Tan, S Chong and M Subramaniam, 'Positive caregiving characteristics as a mediator of caregiving burden and satisfaction with life in caregivers of older adults', *Journal of Geriatric Psychiatry and Neurology*, 2018, Vol 31(6), p 332.

²⁶ House of Representatives Committee on Family, Community, Housing and Youth, Parliament of Australia, *Who Cares ...?: Report on the inquiry into better support for carers*, Parliamentary Paper No 100, 2009.

²⁷ F Colombo et al, above n 19, p 97.

²⁸ Australian Bureau of Statistics, above n 4.

²⁹ Carers Australia Victoria, *Impact of caring*, <https://www.carersvictoria.org.au/about-us/impact-of-caring>, viewed 9 July 2019.

³⁰ Ibid.

³¹ F Colombo et al, above n 19, p 98.

³² K Seehera, L Low, S Reppermund and H Brodaty, 'Predictors and outcomes for caregivers of people with mild cognitive impairment: A systematic literature review', *Alzheimer's & Dementia*, 2013, Vol 9(3).

³³ J Wolff, B Spillman, V Freedman and J Kasper, 'A National Profile of Family and Unpaid Caregivers Who Assist Older Adults With Health Care Activities', *JAMA Internal Medicine*, 2016, Vol 176(3).

³⁴ Ibid.

³⁵ Australian Bureau of Statistics, above n 4.

³⁶ M Fine, 'Employment and Informal Care: Sustaining Paid Work and Caregiving in Community and Home-based Care', *Ageing International*, 2012, Vol 37(1), p 62.

women.³⁷ This is illustrated by the fact that the median income of a primary carer is \$520 per week, compared with \$900 per week for non-carers.³⁸ Many carers need to make changes to their working arrangements such as coming in late to work or leaving early, taking time off for carer situations, and reducing work hours or level of responsibility.³⁹ Some carers may choose to exit the workforce entirely to care for a family member. Consequently, carers have reduced or no opportunity to accumulate superannuation or any other savings.

What are the needs of carers and how can they be supported?

Carers can have a range of needs associated with their roles. Addressing them is important because research has shown a clear association between unmet support needs, carer mental health and wellbeing, and the sustainability of the caring relationship.⁴⁰ Of carers that support older Australians, 35% report at least one unmet support need and 64.7% of this group report multiple unmet support needs.⁴¹ The most unmet support needs include financial (18%), physical (13%), and emotional needs (12%), as well as the need for additional respite care and support to improve carer health (12%).⁴²

Carers have described isolation and emotional burden. Up to half of all carers surveyed in New South Wales in 2012 believed that their mental health had been negatively affected by caring, and 40% reported a need for mental health support.⁴³ Some Australian surveys have indicated that social support is associated with better psychological wellbeing.⁴⁴ However, as discussed previously, the caring role can impact on the time a carer has available to participate in their community and interact with family and friends. Carers report a need for more information and accessible, affordable services providing practical and emotional support.⁴⁵

Despite the reported need for support, the overall proportion of carers who utilise available carer supports (including respite) tends to be low and even then, use is often delayed.⁴⁶ For example, the 2015 Survey of Disability, Ageing and Carers reported that 58.9% of carers surveyed did not receive assistance from organised services within the previous six months. Of those surveyed, 35.1% were not satisfied with or were unsure about the range of organised services available to assist with their caring role, and 25.4% were unaware of the range of services available. A proportion of carers (86.2%) were reported to have never used respite. Of those, 55% said they did not need respite and 10.8% said the care recipient did not want respite. Further, formal respite services that are of poor quality may actually increase carer stress.⁴⁷

³⁷ S Hodgkin, 'Intergenerational solidarity: An investigation of attitudes towards the responsibility for formal and informal elder care in Australia', *Health Sociology Review*, 2014, Vol 23(1), p 62.

³⁸ Australian Bureau of Statistics, above n 4.

³⁹ T Hill et al, above n 2.

⁴⁰ J Temple and B Dow, 'The unmet support needs of carers of older Australians: prevalence and mental health', *International Psychogeriatrics*, 2018, Vol 30(12).

⁴¹ Ibid, p 1857.

⁴² Ibid.

⁴³ Carers NSW, *40 Years of Carer Surveys in NSW 1976–2016*, 2016, p 8.

⁴⁴ T Hill and T Broady, *Understanding the social and emotional needs of carers: Final report*, 2019, Social Policy Research Centre, University of New South Wales, p 16.

⁴⁵ Carers NSW, above n 43.

⁴⁶ L Phillipson, S Jones and C Magee, 'A review of the factors associated with the non-use of respite services by carers of people with dementia: Implications for policy and practice', *Health and Social Care in the Community*, 2014, Vol 22(1).

⁴⁷ K Holland, *Carers' perspectives on caring: A qualitative analysis of open-ended responses to the*

In the care of people with dementia, research suggests that timely and appropriate access to formal support services has a positive impact on carers' interaction with and confidence in the aged care system.⁴⁸ Carer supports that have been identified as helpful include training and resilience to build capacity and manage stress levels. Building capacity through education and training for carers may also include administering medicines, manual handling, and accessing and using aids and medical devices.⁴⁹ Psychosocial interventions such as counselling, behavioural management and participation in support groups is reported to reduce carers' stress by changing their beliefs about their responsibilities, as well as their own needs for support and understanding.⁵⁰

Formal support services that have been shown to improve the wellbeing of carers include: respite and breaks from caring; a supportive general practitioner; counselling for carers; advice and information; practical home support; and support from family and friends. Respite has been shown to improve emotional wellbeing and physical health, provide time for carers to look after themselves, enhance autonomy and independence, and provide a period of enhanced 'freedom' or 'choice'.⁵¹

How are carers assisted in their role currently?

There has been a shift in aged care policy over the last 15 years to support older people to remain living in their own homes, and where required, receive formal care assistance there for as long as possible.⁵² A consequence of this has been an increasing reliance on family and friends to provide care at home, as well as supplement formal home support services. The role of family and friends in the aged care system has become more formal and as such, prompted the development of services and supports to assist in their caring role.⁵³ In its 2011 report, *Who Cares ...?: Report on the inquiry into better support for carers*, the House of Representatives Committee on Family, Community, Housing and Youth summarised the importance of supporting informal carers as follows:

... with adequate levels of appropriate support in place, most carers wish to continue to provide care for as long as they feel able to do so. It is therefore in the best interests of all concerned—carers, care receivers, governments and society—to share the responsibility of providing care more evenly. If realised, this will allow carers and their families to participate more fully in society through engagement with education, employment and social activities.⁵⁴

The *Carers Recognition Act 2010* (Cth) was developed to increase recognition and awareness of carers' roles in providing personal care, support and assistance to all people

Carer Health and Wellbeing Index survey 2007, Carer's Australia, 2008.

⁴⁸ P Singh, R Hussain, A Khan, L Irwin and R Foskey, 'Dementia care: Intersecting informal family care and formal care systems', *Journal of Ageing Research*, 2014.

⁴⁹ K Eagar et al, above n 9.

⁵⁰ M Vernooij-Dassen, I Draskovic, J McCleery and M Downs, 'Cognitive reframing for carers of people with dementia', *Cochrane Database of Systematic Reviews*, 2011.

⁵¹ M Hamilton, G Giuntoli, K Johnson and K Fisher, *Transitioning Australian Respite*, 2016, Social Policy Research Centre, University of New South Wales, 2016, p 12.

⁵² House of Representatives Standing Committee on Health and Ageing, Parliament of Australia, *Future Ageing: Report on the inquiry into long-term strategies to address the ageing of the Australian population over the next 40 years*, Parliamentary Paper No 66, March 2005. Australian Institute of Health and Welfare, *Dementia in Australia*, 2012.

⁵³ Productivity Commission, *Caring for Older Australians*, 2011, Inquiry Report, Vol 1, No 53.

⁵⁴ House of Representatives Committee on Family, Community, Housing and Youth, above n 26, p x.

with a disability, medical conditions, a mental illness or who are frail aged.⁵⁵ Unlike legislation in the United Kingdom, this Act did not establish carers' rights or provide legally enforceable obligations.⁵⁶ Rather, it provided a mechanism for recognising carers in the provision and delivery of services that affect them and their role.

Services in Australia designed to support the older person are funded and subsidised through the Australian Government Department of Health, while services aimed at addressing specific carer needs are funded through the Australian Government Department of Social Services.

Service supports for care recipients

A range of aged care programs are funded to provide varying levels of support to older people. These include:

- Commonwealth Home Support Programme for low, entry-level care needs in the home;
- Home Care Packages Program for higher and more complex care needs in the home
- residential care for people who are unable to be supported in their home;
- flexible care including transition care, short-term restorative care, multi-purpose services, national Aboriginal and Torres Strait Islander flexible aged care, and innovative care.

Different types of respite, to support both carers and care recipients, are offered through three Department of Health subsidised programs and services—Commonwealth Home Support, Home Care Packages and residential facilities. In addition, short-term and emergency respite can be currently accessed through the Commonwealth Respite and Carelink Centres. This will reportedly be replaced by the Department of Social Services' Integrated Carer Support Service from September 2019.⁵⁷

However, a recent report by the Aged Care Financing Authority on respite in Australia outlined the concerns of people who access these services.⁵⁸ They included: difficulties in navigating the My Aged Care system; inadequate attention to carer needs; reduced availability of respite; difficulties faced by people with additional needs (e.g. culturally and linguistically diverse people and those living with dementia); and the costs of respite care.⁵⁹

For the programs above, the care-recipient is the focus of eligibility assessment. The carer is considered only in terms of the functional support they provide. For services designed specifically to support carer's own needs, carers may access services provided through a government funded website and contact centre, known as the Carers Gateway.

⁵⁵ Department of Social Services, *Carer Recognition Act 2010 Guidelines*, 2016, <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/carers-recognition-act-2010-guidelines>, viewed 9 July 2019.

⁵⁶ S Yeandle, T Kroger and B Cass, 'Voice and choice for users and carers? Developments in patterns of care for older people in Australia, England and Finland', *Journal of European Social Policy*, 2012, Vol 22(4), p 437.

⁵⁷ Department of Social Services, *New services for carers coming in 2019*, 2019, <https://www.dss.gov.au/disability-and-carers-carers/new-services-for-carers-coming-in-2019>, viewed 24 July 2019.

⁵⁸ Aged Care Financing Authority, *Report on respite for aged care recipients*, 2018.

⁵⁹ Ibid, p 36.

Supports for carers

Policy emphasis on home care has strengthened ‘the voice’ of older people and their carers, resulting in greater public awareness of carer needs.⁶⁰ Government responses to this increased profile have included the implementation of services to assist carers’ wellbeing and resilience, and as a result, assist the person they are caring for.⁶¹ This assistance is not only in terms of the range and quality of supports that are provided by carers, but also the duration of this care being provided at home. To help with this aim, a range of organisations and programs are funded for carers in Australia.⁶² Examples include:

- Carers Australia—this peak national body represents carers of people with a disability, mental illness, chronic condition or those who are frail or aged. Carers Australia provides information, support, education, training and counselling, with support groups organised around some specific conditions.
- Independent Living Centres—these information resource centres display products and equipment to help with day-to-day living activities.
- Dementia Behaviour Management Advisory Service—this 24-hour phone service provides advice and face-to-face support to family carers, primary and acute care staff and aged care providers to improve the quality of life of a person living with dementia. The service provided support for 15,499 cases in 2017–18.⁶³
- National Dementia Support Program—Dementia Australia provides support and education to carers of people with dementia including support groups, training, education and assistance to navigate the system, as well as a national helpline. In 2017–18, the National Dementia Helpline and referral service received over 44,000 contacts.⁶⁴
- National Aged Care Advocacy Program—provided by the Older Persons Advocacy Network, provides advocacy services and training to carers, in the form of consumer education, and support in navigating the aged care system.

Carers may also be entitled to government income support and compensatory payments to support them in their full-time or occasional roles.⁶⁵ These entitlements, delivered through the Department of Human Services (Centrelink) and including Department of Veterans’ Affairs Carer Allowance, can vary according to each carer’s income and assets, the amount of care they provide, which must be full-time, and the number of people with care needs that they assist. In 2017–18, the Australian government spent approximately \$8.5b in direct government payments to carers.⁶⁶

⁶⁰ S Yeandle, T Kroger and B Cass, above n 56, p 442.

⁶¹ K Eagar et al, above n 9.

⁶² MyAgedCare, *Useful contacts for carers*, <https://www.myagedcare.gov.au/caring-someone/useful-contacts-carers>, viewed 9 July 2019.

⁶³ Australian Department of Health, *2017–18 Report on the Operation of the Aged Care Act 1997*, 2018, p 72.

⁶⁴ Ibid, p 18.

⁶⁵ S Hodgkin, above n 37.

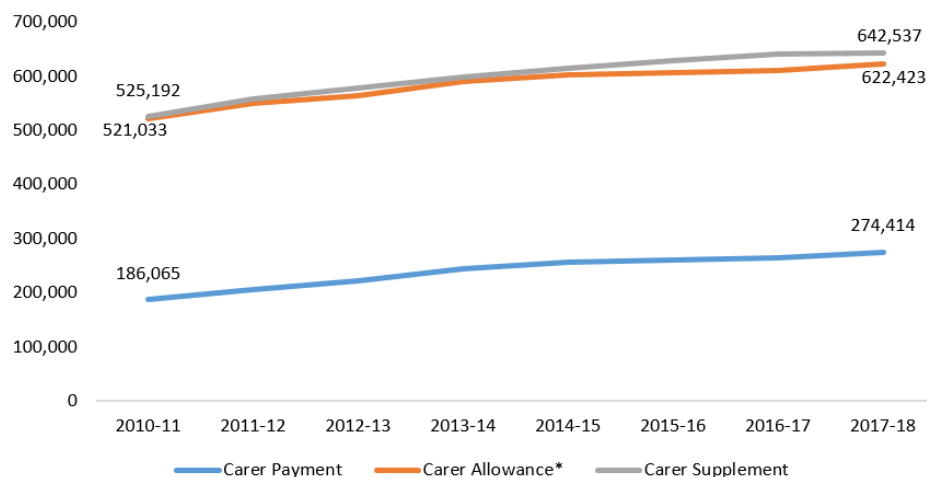
⁶⁶ Department of Social Services, *Portfolio Additional Estimates Statements 2018–19*, 2019, p 39.

Table 1: Summary of carer income support and payments

PAYMENT	HOW MUCH	KEY FEATURES
Carer Payment	\$926.26 (f/n for single) \$698.10 (f/n for couple)	Fortnightly, means tested, income support payment for people who, because of the demands of their caring role, are unable to support themselves through substantial paid employment
Carer Allowance	\$129.80 (f/n)	Fortnightly, income-tested, income supplement for people who provide daily care and attention in a private home to people with a disability or severe medical condition or who are frail and aged
Carer Supplement	\$600 p.a.	Annual lump sum payment intended to assist in alleviating financial pressures experienced by carers

Source: Department of Human Services, *Caring for an older Australian*, 2019, <https://www.humanservices.gov.au/individuals/subjects/caring-older-australian>, viewed 10 July 2019.

As Figure 1 and Figure 2 outline, the number of people receiving carer income support has grown in recent times, as has the total government spending in this area. The number of recipients of the Carers Payment as a share of the total Australian population increased from 0.7% in 2008–09 to 1.1% in 2017–18.⁶⁷ Over the same time period, the proportion of Gross Domestic Product spent on all carer income support increased from 0.36% to 0.45%.⁶⁸

Figure 1: Recipients of Carer Payment, Allowance and Supplement 2010–11 to 2017–18

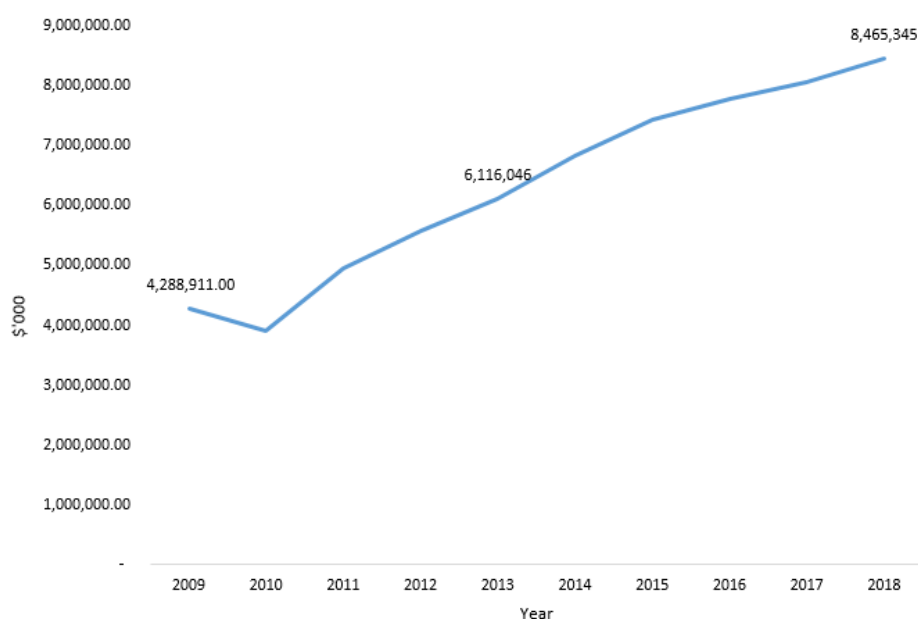
*Adult and child

Source: Data from Australian Government Department of Social Services Annual Reports 2010–11 to 2017–18.

⁶⁷ Calculations based on data from Australian Government Department of Social Services *Annual Reports 2008–2018* and Australian Bureau of Statistics *Population* data.

⁶⁸ Department of Social Services Portfolio Additional Estimates statements. Australian Bureau of Statistics, *Australian National Accounts: National Income, Expenditure and Product*, Mar 2019, (Catalogue 5206.0), <https://www.abs.gov.au/ausstats/abs@.nsf/mf/5206.0>.

Figure 2: Government expenditure on carer income support 2009–2018



Source: Data from Australian Government Department of Social Services Annual Reports—financial statements 2009–2018.

Carer diversity

The impact of caring can increase over time and has different effects for specific groups of carers.⁶⁹ Particular issues arise for carers who identify with some communities. Real and perceived barriers exist for some people to access quality aged care. For example, people who identify as Aboriginal and Torres Strait Islander, from culturally and linguistically diverse backgrounds, and/or lesbian, gay, bisexual, trans and gender diverse and intersex people.⁷⁰

Aboriginal and Torres Strait Islander carers

Around 12.4% of Indigenous Australians are carers, compared with 10.5% of non-Indigenous Australians.⁷¹ Data suggests that Aboriginal and Torres Strait Islander carers are more likely to be younger than non-Indigenous carers.⁷² The average age of Aboriginal and Torres Strait Islander carers is 37 years, 12 years younger than the average age of non-Indigenous carers.⁷³ Aboriginal and Torres Strait Islander carers are also less likely to be employed and to have a lower weekly income than non-Indigenous carers.⁷⁴

⁶⁹ T Hill and T Broady, above n 44, p 1.

⁷⁰ Department of Health, *Aged Care Diversity Framework*, 2018, <https://agedcare.health.gov.au/support-services/people-from-diverse-backgrounds/aged-care-diversity-framework>, viewed 9 July 2019.

⁷¹ Carers Australia, *Aboriginal and Torres Strait Islander carers*, <https://www.carersaustralia.com.au/about-carers/aboriginalandtorresstraitislandercarers/>, viewed 5 June 2019.

⁷² Ibid.

⁷³ Ibid.

⁷⁴ Ibid.

Aged care services have been criticised over a lack of culturally appropriate care for Aboriginal and Torres Strait Islander people.⁷⁵ A lack of cultural appropriateness in services can make it difficult for carers to access and engage in providing formal care for their family member. The importance of the older person remaining in their community, close to family and country, is well documented. Living on country is an integral part of the Aboriginal and Torres Strait Islander cultural identity, and reports of older Indigenous people sometimes choosing conditions of extreme hardship rather than relocating to residential care away from country are not uncommon.⁷⁶ This also affects the ability of Aboriginal and Torres Strait Islander people to access residential respite, which can be a key support for carers. Self-determination and community empowerment are central themes in models of care to support Aboriginal and Torres Strait Islander people, requiring particular consideration of the relationship between mainstream services and community empowerment and traditional family roles.⁷⁷

Culturally and linguistically diverse carers

Carers in culturally and linguistically diverse communities can experience greater difficulty in accessing and navigating the aged care system when compared with other Australians. Many culturally and linguistically diverse carers are 'hidden' carers who are more likely to experience barriers related to differences in language and culture.

Family carers may be unaware of services such as respite, home care and financial support. Cultural resistance to formal aged care services in many communities means that older people from these backgrounds may be a carer for a family member and experience cultural barriers in accessing carer support services. When culturally and linguistically diverse carers need respite services, the support may not be culturally responsive and language barriers make communicating their and their family members' needs difficult.⁷⁸

Literature on the topic suggests that informal care is often the responsibility of family members, despite older migrants in Australia having fewer children or relatives living nearby.⁷⁹ Women in particular can experience pressure to meet the caring needs of family members while also balancing care for their own children and employment.⁸⁰ However, assumptions that people from culturally and linguistically diverse backgrounds are always cared for by family and friends should not override individual preferences and circumstances, and may hide social isolation.⁸¹

⁷⁵ Alzheimer's Australia, *Continuing the conversation: addressing dementia in Aboriginal and Torres Strait Islander communities*, 2015, Alzheimer's Australia and the National Aboriginal and Torres Strait Islander Dementia Advisory Group, 2015 National Workshop Communique.

⁷⁶ D Bell, M Lindeman and J Reid, 'The (mis)matching of resources and assessed need in remote Aboriginal community aged care', *Australasian Journal on Ageing*, 2015, Vol 34(3).

⁷⁷ C Morse and R Lau, 'In care and on call: The endangered system of Australian family-based caregiving' in *Lessons on Aging from Three Nations: The Art of Caring for Older Adults*, 2007. M Linderman, K Smith, D LoGiudice, and M Elliot, 'Innovation and Translation Community care for indigenous older people: an update', *Australasian Journal on Ageing*, 2016, Vol 36(2).

⁷⁸ Department of Social Services, *National Ageing and Aged Care Strategy for people from Culturally and Linguistically Diverse (CALD) backgrounds*, 2015.

⁷⁹ Federation of Ethnic Communities' Councils of Australia, *Review of Australian research on older people from culturally and linguistically diverse backgrounds*, 2015, p 24.

⁸⁰ Ibid.

⁸¹ Ibid.

Lesbian, Gay, Bisexual, Transgender and Intersex carers

There is relatively little research evidence on lesbian gay bisexual transgender and intersex carers in Australia. However, it is generally understood that the needs of carers who identify with the lesbian gay bisexual transgender and intersex communities differ from the needs of other carers.⁸²

Barriers to entering formal care services are often tied to lesbian gay bisexual transgender and intersex carers' expectations, or the actuality, of discrimination from support services and institutions in general. Discrimination can be experienced in terms of carers being blocked from accessing services due to the ethnic diversity of staff and clients, or faith-based values of an organisation.⁸³ In some cases, these carers may be challenged by caring for homophobic family members.⁸⁴ Situations have also often been described where biological family members of the care recipient take control of the supports, essentially denying the validity of an existing partnership.⁸⁵

Conclusion

With the quality of an older person's life greatly assisted by the physical and emotional capacity of their carers, there is significant value in shining a light on carer roles and acknowledging and supporting how they care, support and advocate for their family members and friends. While carers typically report a willingness to continue this care, they also describe compromises or challenges such as reduced health and wellbeing and financial difficulties. These impacts can be significant and have flow-on effects for the person receiving care and the aged care system.

Formal services and supports available to carers of older people in Australia are largely delivered by home care and respite services, subsidised through aged care programs, and complemented by resources such as education and counselling. There is support available from the Carer Gateway, as well as carer payments. Despite research evidence indicating that there are positive outcomes for carers in general, the evidence relating to carers of older people is scarce. The literature that is available tends to indicate that services for this group of people are under-utilised and often delayed. Potential reasons for this may be a lack of carer-awareness and support to link into appropriate services, as well as specific challenges faced by the needs of diverse communities.

Understanding the needs of carers in supporting older Australians to remain at home is challenging. There is a general invisibility of informal caring in available data and literature. Many family and friends supporting older people do not identify as a carer. It is therefore difficult to assess their typical needs in a meaningful way. However, as the population in Australia continues to age, the reliance on carers is set to increase. The need to ensure current services appropriately assist carers to meet the needs of the people that they care for appears greater than ever.

⁸² Carers Australia SA, *LGBTI—Carers: Issues and challenges*, 2017.

⁸³ C Barrett and P Cramer, *An extra degree of difficulty: An evidence based resource exploring the experiences and needs of older LGBTI carers and the carers of older LGBTI people*, 2015, Australian Research Centre in Sex, Health and Society, La Trobe University.

⁸⁴ Ibid, p 7.

⁸⁵ C Cartwright, M Hughes, and T Lienert, 'End-of-life care for gay, lesbian, bisexual and transgender people', *Culture, Health and Sexuality*, 2012, Vol 14(5).