2023-24 Federal Budget Submission January 2023



Introduction

This 2023-24 Federal pre-Budget submission Carers Australia are first and foremost calling on the Albanese Government to confirm the pre-election commitment to develop a National Carer Strategy within its first term:

"Labor recognises that carers have been too often overlooked in policy development and not treated as a vulnerable group in their own right. An Albanese Labor Government will develop a new National Carers Strategy, in consultation with carers, peak bodies and service providers, during its first term of government."

- ALP response to the Carers Australia 2022 Federal Election Survey

While the <u>Carer Recognition Act 2010</u> (Commonwealth) formally acknowledges the valuable social and economic contribution of carers¹ in Australia, the last National Carers Strategy lapsed in 2014. Carers are still not 'recognised', nor their rights and needs adequately embedded within reforms.

Reform across settings and sectors, while well intentioned, has potential to further fragment the provision of supports and services available to carers in all care relationships. With so many processes occurring, Royal Commissions, the NDIS Review, Parliamentary Inquiries, the Productivity Commissions work on carers leave, the development of many other related strategies underway such as the National Autism Strategy, National Dementia Action Plan, Early Years Strategy, Gender Equity Strategy, and the focus on employment following the 2022 Jobs and Skills Summit, there is a need for clear leadership within Government and an absolute awareness of the diversity of caring relationships, the diversity of carers, and the diversity of people being cared for.

In total our asks for the 2023-24 Federal Budget total \$43.9 million over a two-three year period. Consider this within the context that the cost to replace the care provided by unpaid family and friend carers with paid services within aged care and disability support alone would have cost the Australian economy \$77.9 billion in 2020. That was before COVID and the impacts on the community it brought with it.

¹ Carers Australia uses the term 'carer' as defined by the Commonwealth Carer Recognition Act 2010 (the Act), where it should not be used broadly and without context to describe a paid care worker, volunteer, foster carer or a family member or friend who is not a carer. The terms 'informal carer', 'unpaid carer' or 'family and friend carer' are also often used by organisations, government, and the community to describe a carer. Carers Australia may use these terms to assist in providing context and to differentiate between other types of care provision.



Summary of Budget Asks

- 1. Review and strengthen the Carer Recognition Act (2010) (\$1.2 million/2 years)
- 2. Develop a whole-of-government National Carer Strategy (\$2 million/2 years).
- 3. Review of economic and financial security for carers by the Productivity Commission (\$5.2 million/3 years).
- 4. Investigate the barriers to access to respite care across systems (\$2 million/2 years).
- 5. Refund and extend the 'Caring through COVID' project (\$1.6 million/3 years)
- 6. Fund co-designed and local solutions to mental health needs (\$6.9 million/3 years)
- 7. Independent individual advocacy for carers (\$25 million/3 years).

Leadership within government

1. Review and strengthen the Carer Recognition Act

\$1.2 million over 2 years

The importance of robust legislative and policy frameworks to raise the profile of carers and to uphold carer rights is fundamental. We ask that the government review and strengthen the Carer Recognition Act (2010) into a rights-based Act, where the current Act is not binding on any other Act.

This must also consider the introduction or amendment of carer-focused jurisdiction legislation since 2010, as well as updates and development of many other legislative instruments within (but not limited to) aged care, mental health care, disability support, social services, and employment.

In addition, a Carer Impact Statement for cross-portfolio use should be developed, to inform future policies and decisions across health, aged care, disability, mental health and social services, as well as education, training, employment, transport and housing. This would also increase transparency in reporting against the *Act*, noting this is a requirement for all public service agencies per the current *Act*.

2. Develop a whole-of-government National Carer Strategy

\$2 million over 2 years

As a pre-election commitment by the Albanese government, the new National Carer Strategy must involve supported community consultation and extensive engagement with stakeholders during planning, development, and implementation to prepare for the 23% growth in demand for primary informal carers by 2030.²

² Deloitte Access Economics (2020). 'The value of informal care in 2020' for Carers Australia [accessed online]



The Strategy should:

- Have a clear implementation plan that addresses carers' rights and needs, together
 with and separately from the people they care for, including secure employment,
 income and housing.
- Improve responsibility and accountability for carer support, and address diffusion of responsibility and perceptions that carer supports are a Department of Social Services only-role, or primarily focused on carers of people with a disability.
- Monitor implementation, outcome measures and the impact of state/territory jurisdiction-based carer strategies.
- Identify the data needed to monitor the social and economic impact of carer policies and programs.
- Consider the data gaps and limited research on carers and the resultant impact this has on the development of evidence-based health, aged-care, disability support, and social policy and service planning.

Clear leadership within government is essential to address and respond to carer issues that have been clearly and consistently represented to several governments through many reform processes since the <u>2009 House of Representatives Inquiry</u> into better support for carers and subsequent report entitled *Who Cares ...?*

Lack of recognition of the caring role and the impact of not being identified by services they interact with, in addition to limited appropriate and timely respite care and support are critical structural factors to our health, aged care, mental health, disability care and social service systems.

Economic and financial security

3. Review of economic and financial security by the Productivity Commission

\$5.2 million over 3 years

The Government to commission the Productivity Commission to undertake a broad review of economic and financial support for carers. This would underpin a coherent and flexible approach to address the barriers and long-term impacts on carers' financial and economic security and reduce instances of poverty as they maintain and thrive in their caring roles.

Such a review should specifically include:

- Modelling the costs and benefits of providing retirement solutions such as a superannuation guarantee or carer pension credits to people who have had reduced employment opportunities due to providing continuous or long periods of care.
- Reviewing the purpose, intent and adequacy of the Carer Payment and Carer
 Allowance and recommend ways to incentivise carers to participate in the workforce,
 education and training, without affecting carers who cannot work.
- A cost of caring and living analysis to examine implications for short-term and longterm financial security and economic outcomes across caring roles, with a particular



focus on women, single carers, young carers and carers who identify as First Nations or LGBTIQA+.

The right to participate in economic, social and community life is recognised under the <u>Carers Recognition Act 2010</u>. Despite this, carers in Australia experience considerably poorer employment outcomes, with a 52.2% employment to population ratio compared with 75.9% for people without caring responsibilities.³ The prospects for Australia's 235,000 young carers are also poor, as more than 60% of young carers have not studied beyond high school, and on average are expected to receive income support for 43 years over their lifetime.⁴

In the 2022, more than half of carers – 54.4% - reported that they had experienced at least one significant financial stress event in the previous 12 months, such as being unable to pay bills on time, going without meals, or having to ask for financial assistance. This is compared to 32.2% of the broader Australian population.

It is Carers Australia's view that it is an absolute core responsibility of governments to ensure that people living in this country don't have to live in poverty. The <u>Caring Costs Us</u>: <u>The economic impact on lifetime income and retirement savings of informal carers'</u> report demonstrates a significant disparity in governments' willingness to fund formal care services compared to investing in adequate financial assistance for carers to sustainably continue their caring roles and have security at retirement age.

On average, the superannuation balance at age 67 of a person who becomes a primary carer is reduced by about \$17,700 for every year that they are a primary carer. Similarly, their lifetime earnings are reduced by \$39,600 for every year that they are a primary carer.

Further, income support through the Carer Payment is less than 30% of the average weekly earnings, and the value of the Carer Allowance has significantly decreased since its introduction.

Equitable access to respite options

4. Investigate barriers to accessing respite across systems

\$2 million over 2 years

A robust investigation into respite care needs to occur across portfolios, systems, and settings, for Government to appropriately develop future policy and reform decisions for sustainable and equitable access to respite - regardless of location, type of caring role, circumstance, service system accessed or relationship to funding or portfolio.

This should involve

- A demand, needs and supply analysis for respite care, including across different categories of caring, such as aged care, disability, mental health, alcohol and drug services and palliative care programs.
- Attention to cultural appropriateness, availability, accessibility and affordability;
 responsiveness to the needs of both carer and person receiving respite care; and

³ Australian Bureau of Statistics (2018). 2018 Survey of Disability, Ageing and Carers [accessed online]

⁴ Australian Government Department of Social Services (2017). 'Try, Test and Learn Fund: Data Driven Job Opportunities for Young Carers Factsheet' [accessed online].



responsiveness to the needs of carers and people receiving care living in regional, rural and remote areas.

• Journey mapping to better understand the characteristics of carers, the people receiving care and their broader social network that combine to contribute to situations with higher demand for emergency and planned respite.

The importance of respite has been highlighted in the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, the 2020 Productivity Commission Inquiry into Mental Health, and the 2021 Royal Commission into Aged Care Quality and Safety. The findings from these processes consistently note the cessation of funding for previous programs such as Mental Health Carer Respite Services, difficulty accessing respite (particularly community-based cottage respite) through the Carer Gateway, issues with aged care respite pathways (both community and residential) or palliative care-specific respite options, and very limited access to carer respite via the NDIS.

Equitable access and early referral to respite care, both planned and emergency, and across residential and community settings, overnight and day options, is critical to ensure sustainability of care relationships, and the health and wellbeing of carers. In many cases, lack of access to respite care can be the difference between maintaining the caring role or having no alternative but to seek other more costly government-subsidised care and accommodation options, cease or reduce employment, or risk further strain on carer and wider family relationships.

The 2022 Carer Wellbeing Survey revealed that only 27.7% had used respite care services, and of these carers, a high percentage reported 'poor access' to all types of respite provided in community settings, 80.6% for in-home overnight respite, 73.9% for overnight respite out of home, 65.7% for day respite out of home and 61.8% for in-home day respite.

Mental health and wellbeing

5. Refund and extend the 'Caring through COVID' project

\$1.6 million over three years

Caring can at the best of times be a rewarding yet demanding and socially isolating experience however carers have among the lowest levels of wellbeing of any group of Australians and are at a greater risk of negative physical and mental health effects.

We ask for the Carers Australia 'Caring through COVID' project which ceased in 2021, to be re-funded and extended to engage and support the wellbeing needs and experiences of all carers during the ongoing impacts of the pandemic and recovery, and supplement other COVID-19 mental health supports that are not carer-specific. Specific focus would be on the needs of carers of people with intellectual disabilities, people with autism spectrum disorder, and culturally and linguistically diverse carers.

Carers Australia delivered the 'Caring through COVID' project in 2020-21, funded through the COVID-19 National Mental Health and Wellbeing Pandemic Response Plan, with a focus on carers of people with mental ill-health. Independent evaluation determined a positive impact on carers' wellbeing, more people identifying themselves as a carer and high engagement increased social connectedness between participating carers and increased the number of carers accessing support pathways immediately after the program.



Adding to the psychological distress experienced cumulatively since 2020, carers are also providing more care, including more complex care as access to paid services reduced or in some cases ceased for long periods. More than 70% reduced their own social interaction to protect the people they cared for and increased their caregiving responsibilities in 2022, and a majority reported reduced access to support services and to informal support from family and friends.

7. Fund co-designed and local solutions to mental health needs

\$6.9 million over three years

Carers need support for their own mental health, where mental health services often focus on the needs of the person living with a mental illness or psychosocial disability without considering that the person providing care may also require mental health support, and in fact may also be a consumer of mental health services.

Fund Carers Australia and the National Carer Network to co-design, evaluate and deliver locally identified and relevant mental health and wellbeing opportunities for carers across care relationships and settings. The ability to localise and develop activities based on specific needs within communities is essential and has been identified thorough models such as Primary Health Networks.

Specific focus would be put on activities that reach 'hidden carers' such as male carers, carers who identify as LGBTIQ+, culturally and linguistically diverse carers, grandparent carers and former carers, and be designed to complement and support referral into Carer Gateway services.

The <u>2022 Carer Wellbeing Survey</u> revealed carers were three times less likely to have high levels of wellbeing compared to those that do not have a caring role. Carers also continued to be at higher risk of psychological distress, with 48.1% experiencing moderate to high levels of psychological distress – almost twice as many as the 25.0% of Australian adults who experience this.

Young carers are also at increased risk of mental health issues, with many young carers reporting ongoing stress and mental health issues which affects their motivation or ability to get up in the morning or go to school, and that their care responsibilities restrict their ability to achieve their potential, socialise with friends, participate in extra-curricular activities, and to build a sense of belonging.

Advocacy

8. Independent individual advocacy for carers

\$25 million over three years

Carers underpin the sustainability of health, aged care, mental health, and disability support systems and need advocacy for their own needs to continue their significant role as the hidden 'care coordinators' in negotiating and managing care across complex sectors and systems.

Funding is required to establish and provide a rights-based independent and confidential advocacy service for individual carers, involving:



- Family and relationship services which better recognise the role of carers providing individual advocacy on behalf of, and with, people receiving care,
- Assisting carers to understand and exercise their rights,
- Raising and addressing issues relating to accessing and interaction with Commonwealth funded services for themselves and/or the person they are caring for, including health, aged care, disability, mental health, and social services, noting carers may have multiple care relationships and interact with more than one sector,
- Assisting carers with sector navigation, including digital health literacy and access support, and
- Working in partnership with Carer Gateway Providers to improve cross sector and system navigation.

It is a long-standing concern that carers continue to be largely mentioned or considered only in relation to "consumers, their families and carers" without recognition of their specific needs. The provision of evidence-based, culturally sensitive, targeted, accessible information and advocacy is needed to ensure that carers:

- Feel safe and confident in their ability to provide care and navigate complex systems,
- Have the appropriate knowledge to support themselves and the person they care for,
- Are informed of regulatory requirements specific to their situation, and
- Can raise issues related to carer-specific supports and services.

This would be similar to the supports available to older Australians or people living with disability or mental ill-health who can access specific individual advocacy programs. While the Carer Gateway has a focus on tailoring supports, the aim is to give the carer time to balance the caring responsibilities and manage their own wellbeing so that they can continue to be there for those being cared for, not individual advocacy and navigation support.

Having access to support is associated with higher wellbeing⁵. Additional advocacy needs are also required for young carers aged under 25 years, and those carers from culturally and linguistically diverse backgrounds, those who identify as Aboriginal and Torres Strait Islander and who identify as lesbian, gay, bisexual, transgender, or intersex (LGBTIQA+).

⁵ University of Canberra (2022). 'Caring for others and yourself: The 2022 Carer Wellbeing Survey Full Report' on behalf of Carers Australia [accessed online].



About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, alcohol or other drug related condition, terminal illness, or who are frail aged.

In collaboration with our members, the peak carer organisations in each state and territory, we collectively form the National Carer Network and are an established infrastructure that represent the views of carers at the national level.

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment, and education. This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTIQ+)
- Who are living in rural and remote Australia, and
- Who are no longer in a caring role (former carers).

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