



National Carer Network Response to Department of Social Services draft National Carer Strategy

November 2024

About the National Carer Network

The National Carer Network represents the diversity of the three million¹ Australians who provide unpaid care and support to family members and friends living with a disability, chronic or life limiting condition, mental ill health, addiction issue, or who are frail aged.

The peak carer organisations in each state and territory, together with the National Peak body, Carers Australia, collectively form the National Carer Network, an established infrastructure that represents the views of carers at the national level:

- Carers ACT
- Carers Australia
- Carers NSW
- Carers NT
- Carers QLD
- Carers SA
- Carers Tas
- Carers VIC
- Carers WA

Our vision is an Australia that values and supports all carers, where all carers 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.

Australia's carers are diverse and include those who:

- have their own care needs
- live with disability
- are in multiple care relationships
- have employment and/or education commitments
- are 24 years and younger (young carers)
- are 65 years and over
- identify as Aboriginal and/or Torres Strait Islander
- are from culturally and linguistically diverse backgrounds (CALD)
- identify as Lesbian, Gay, Bisexual, Trans and gender diverse, Intersex, Queer, Questioning and Asexual (LGBTIQA+)
- live in regional, rural and remote Australia, and
- are former carers (no longer in a caring role)

¹ Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC) 2022

In alignment with this, the Network endorses the United Nations Universal Declaration of Human Rights (UDHR)² and its relevance to carers, including the right to rest and leisure and to participate in the cultural life of the community (Articles 24 and 27 UDHR). We also recognise the United Nations Convention on the Rights of Persons with Disabilities³ (UNCRPD), acknowledging that carers play an important role in supporting the rights of people living with a disability in line with the CRPD, where they have been nominated to do so.

Acknowledgment of country

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pay our respects to Elders past, present and emerging.



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² United Nations Universal Declaration of Human Rights

³ United Nations Convention on the Rights of Persons with Disabilities

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Introduction

The National Carers Network (Network) is strongly supportive of a National Carer Strategy (Strategy) that will speak to carers and give them confidence that their voices have been heard, that their needs and challenges are understood, their contribution is recognised and that the Australian Government is willing to walk alongside them to create a better system of engagement, recognition and support for the future.

The Network welcomes the opportunity for the Australian Government to more effectively implement and raise awareness of the Carer Recognition Act, 2010 (Cth) and statement for Australia's carers, which set forward a range of specific obligations for public sector agencies, and key, good-practice principles, for the sector and the community. In essence, the Strategy should give effect to the principles and obligations in the Carer Recognition Act, 2010 (Cth).

Unfortunately, the draft Strategy that has been released – and the short timeframe in which carers have been afforded the opportunity to comment – does not reflect what we understand the Government's genuine desire to respect, include and improve the lives of Australians in caring roles.

Indeed, there is significant potential for both the content and the process to disenfranchise carers rather than setting aspirations and tangible actions to give carers hope for the future. The Network sees this as a very real risk for government.

We do, however, believe there is still time to turn things around and make it a document that can place carers at the centre of the Strategy and signal a different future for carers while being alive to the practical constraints within which Government operates.

To that end, this submission sets out some practical solutions for how this can be remedied through:

- adjusting the language used throughout the document to ensure the Strategy is positive, aspirational and reflects the value that the government places on carers. There is a real need to replace some of the language that almost seems to blame carers or assume it is entirely up to them to make the system work
 - Please note **Attachment A** (letter) and **Attachment B** (edits within the draft Strategy) from Carers Australia that provide initial feedback on language within the Strategy document
- directly mapping proposed elements of the strategy to the 22 recommendations of the Federal Inquiry into the Recognition of Unpaid Carers in Australia: *Recognising, valuing and supporting unpaid carers* report released by the House of Representatives Standing Committee on Social Policy and Legal Affairs, adopting those recommendations directly related to the Strategy and Carer Gateway reform. So many carers made submissions to this process and want to see that the time they spent, and the stories they shared were not in vain
- strengthening and rewording the priorities and sub-statements to be more powerful, action-focussed and accountable rather than the current deficit-focussed language which we recently heard one carer describe as 'carer last'

- reflecting carers’ desire to see immediate action that signals Government’s commitment to making a practical difference – while the Network notes the current intent to deliver these separately, it notes that inclusion of some immediate actions would be a powerful show of good intent towards our nation’s carers
- continued consultation and collaboration in design, implementation and monitoring of the Strategy and all associated actions, taking a carer-centred approach
- ensuring that carer representative bodies such as the National Carer Network organisation, Carer Gateway providers and carers themselves are actively engaged in co-designing the proposed outcomes framework and actions, so that those collective and extensive insights on what works can inform successful outcomes for carers
- recognising in the strategy, and our suggested priority actions, the very real financial pressure that many carers are under as a result of their care responsibilities, and making a commitment to act on this, particularly for those carers in receipt of government subsidies directly related to their caring role
- setting a clear commitment to periodic review and measurement of progress, which the Network suggests potentially occur at three, five and seven years into the proposed 10-year timeframe
- ensuring that there is whole-of-government commitment to delivering the Strategy, its objectives and actions, with clear responsibilities, timelines and budgets, and
- reaffirming that carers have the same rights as others under the United Nations Universal Declaration of Human Rights in the Strategy, and ensure associated action plans uphold and promote these rights for carers.

We recommend that the Carer Recognition Act 2010 (Cth) (‘the Act’) be more fully integrated as a foundational component throughout the document. The Act aims to increase recognition and awareness of carers, acknowledging the valuable contribution they make to society. By highlighting the Act in the Strategy’s introduction, motivations, and sections such as Priority Outcome 1, we can ensure that Australia’s carer recognition legislation and policy frameworks work congruently.

The balance of this submission, starting with the Priority Outcome Areas, both expands on the above and aims to assist Government in refining the current draft and prioritising actions for short to medium term action.

These ideas and advice reflect the genuine commitment of our Network to work with Government to ensure our shared aspirations for the future can be realised. We look forward to continuing the conversation.

Priority Outcome Areas

The Network believe that if the Priority Outcome Areas are recrafted with affirmative language and defined actions then this will flow back into opportunities to strengthen the higher order Objectives and Principles (including updating the National Carer Strategy on a page).

Currently the *What we will do* sections appear more as motherhood statements with passive language and no indication or examples of clear and tangible actions. We recommend this be revised to ensure carers to not disengage from the Strategy.

Priority Outcome One

The community, government and those who provide paid care and support recognise and value carers' contributions and expertise and carers are supported to self-identify

Proposed rewording for the outcome

Government, community and those working in the support sector see and value carers, recognising their expertise and contribution, and creating an environment that encourages people to identify as a carer.

Additional inclusions/considerations for 'What we know'

- The value and contribution of carers needs to be actively promoted in the community throughout the year.
- Government, service providers, employers and the community be actively encouraged to recognise and support carers wherever they are in our community.
- Carers must be considered as a central part, including co-design, of decision making in service systems including NDIS, aged care, mental health, health and education and will be recognised as having expertise in the people they care for.
- Service providers must hold carers and the people they care for at the centre of what they do and will actively co-design services, programs, access pathways, policies and procedures with carers and the people they care for.
- Carers need be identified by professionals in the service systems that they interact with and provided with information on the services and supports that are available to them.
- Government must undertake a carer impact assessment of all new policies to avoid unintended negative consequences for carers.
- Carer input must be sought in decision making about the provision of services that affect their lives, including the provision of service to the people they care for.
- Young carers must be supported to manage their caring role, education and wellbeing in the education system.
- Carers must be seen and identified in all services and systems, not just the ones that support the people they care for.

Some proposed actions for inclusion in ‘What we will do’ (noting this is not exclusive or exhaustive)

- The Carer Gateway advertising campaign be continually run throughout the year and expanded to include additional material helping to explain the role of carers and localised content in each State and Territory.
- Internal training in all Government Departments on the role and contribution of carers, and ways to support carers in family, community and the workplace
- Inclusion of people with living or lived experience in carer roles on departmental committees where policy development may impact carers or the people they care for.
- Establishment of an interdepartmental departmental committee (IDC) to ensure that policy development supports and does not inadvertently impact carers.
- Inclusion of a young carer identifier on all school enrolment forms, followed by referrals to support, with a review of this status annually.
- Review of all NDIS and My Aged Care assessment processes to better identify carers and ensure carers are included in decision making and link them to relevant information and support.
- Carer recognition at point of diagnosis to facilitate support for carers
- Revise the definition of a carers to ensure all carers are recognised, including a review the Carer Recognition Act (2010), as recommended by the *Parliamentary Inquiry into the Recognition of Unpaid Carers*.
- Ensure that the definition of carers is replicated consistently across all Commonwealth legislation, government policy and programs.
- Consider implementing a carer card or similar tool for easily and quickly recognising carers.

Priority Outcome Two

Carers can access supports, services and programs at the right time, right place and in the right way across the caring continuum.

Proposed rewording for the outcome

Supports, services and programs are readily available to carers when they need them across the caring experience.

Additional inclusions/considerations for ‘What we know’

We note the current text in this section includes deficit language and propose this language be amended accordingly.

- Services available to carers are not promoted to them.
- Due to system design, carers face challenges with system navigation.

- The demands on carers and the impact on their wellbeing is already significant; system navigation challenges further adds to carer stress.
- Carers have consistently identified the need for local services that are tailored and sensitive to their needs, and are culturally appropriate.
- Complex systems, lack of early identification of carers, lack of information, and carers not self-identifying all result in support being sought for the first time at a point of crisis.
- Whilst Carer Gateway has led to improved access for many carers, carers have a range of support needs not comprehensively addressed by this service model and most carers want to see system improvements.
- Carers want navigation assistance (carer concierge), particularly when seeking emergency supports and respite.
- Respite means different things for different carers, yet commonly all carers report obstacles accessing respite. This includes access to emergency, flexible and fit for purpose respite, particularly in regional and remote geographic locations.

Some proposed actions for inclusion in ‘What we will do’ (noting this is not exclusive or exhaustive)

- Point of Diagnosis recognition - early identification of carers by health and allied health professionals, including provision of information and referral to supports, and the inclusion of check ins with carers.
- Access to programs over the long term that equip carers with the knowledge and skills they need to take up their role in communicating the needs and preferences of the people in their care relationship to secure the support needed training for medical, health professionals and service providers on how to recognise and assist carers. This includes adaptations required for each state and territory and for diverse cohorts.
- Make support available to people transitioning out of long term care roles to assist former carers with their financial, physical and mental health and housing security.
- Improved system functionality, usability and interoperability - recognising that not all carers have same language, knowledge, connectivity or education.
- Provide system navigation support to assist carers to navigate the many, complex, government service systems the engage with.
- Ensure systems and services are providing age appropriate, and culturally safe and inclusive options.
- Ensure respite options and access address provider deserts, including workforce and market shortages, are fit for purpose (including emergency respite), culturally appropriate and flexible for each carer’s unique needs. This means increased access to respite options, including increasing funding for in-home respite and Residential Aged Care Facilities respite beds.

- Recognise that former carers need access to appropriate support post the end of their caring experience for physical and mental wellbeing, financial and housing security.

Priority Outcome Three

Carers can develop the knowledge and skills they need to fulfill their caring role.

Proposed rewording for the outcome

Carers are supported to prioritise their own physical and mental wellbeing.

Additional inclusions/considerations for ‘What we know’

- Carers often take on complex caring roles with no training in providing health care; legal, financial, mobility and behavioural support; or navigating systems, and with different degrees of prior knowledge or education .
- There is a critical need for carers to have practical skills to improve their own lives and the outcomes for those they care for, including training about the conditions, illnesses, medications, or disabilities experienced and legal considerations in providing care.
- It is essential to minimise risks to carers themselves, both in terms of physical health (for example, due to manual lifting) and mental health (for example, due to social isolation – including for former carers).
- Carers want training that is informed by lived experience, is bespoke, that covers the caring experience, and that is flexible in delivery.

Some proposed actions for inclusion in ‘What we will do’ (noting this is not exclusive or exhaustive)

- Increase funding to deliver training and practical skills.
 - Including access to programs about how to provide physical, psychological and behavioural care, maintaining carer mental and physical wellbeing, and legal planning for life and end of life.
 - Consideration of a National Carer Skills Hub, that could provide access to online and in person resources, information and training to provide essential skills for caring.
 - Lived experience will be incorporated in the co-design and implementation of national training programs.
- Review existing training and skills development programs to improve access for carers, for example, modify or adapt existing training for service providers.

Priority Outcome Four

Carers can access, pursue and maintain employment and education, including to improve financial well-being for themselves and those they care for.

Proposed rewording for the outcome

Carers have improved short and long term financial wellbeing, and are supported to access, pursue and maintain their chosen employment and education pathways.

Additional inclusions/considerations for ‘What we know’

- Many carers experience significant levels of financial distress due to reduced income and the additional costs associated with caring, as well as longer term disadvantage through reduced superannuation.
- Carers need support for their short and long-term financial wellbeing. Carers want:
 - review of income support payment levels, eligibility and carer concessions and establishment of superannuation for carers
 - removal of barriers to carer participation in the workforce and/or education system.
 - dedicated job readiness programs
 - transitional support for carers to access or change employment and education, and
 - transitional support when moving to other government support payments (when carer payment ends).
- Carers want improved supports in workplaces and education systems, including increased inclusiveness, recognition and flexibility.
- Carers want increased awareness and recognition in workplaces and education systems.
- Carers want to be valued for their lived experience skills and knowledge, in workplaces and education settings.

Some proposed actions for inclusion in ‘What we will do’ (noting this is not exclusive or exhaustive)

- Prioritise actions to improve short and long-term financial.
 - Review of income support payment levels, eligibility and carer concessions, and introduction of superannuation on the Carer Payment.
Delivering job readiness programs for carers .
 - Transitional support for carers, and former carers to access employment and education.
 - Supporting former carers when transitioning off the Carer Payment.
- Strengthen carer supports.
 - Including within workplace and education system contexts.
 - Continue and expand young carer specific supports such as the Young Carer Bursary Program.

- Simplify and streamline access to carer supports.
- Educational and workplace carer inclusive training and accreditation.
 - Incentivise workplaces and education systems to carer inclusive workplace programs and accreditation and ensure human resource policy reflects carer inclusive practices.
 - In collaboration with carers and carer associations, conduct ongoing carer awareness campaigns to workplaces and education systems.
- Government Department Carer inclusive training and accreditation
 - All government departments and agencies will participate in and report their progress on implementing carer inclusive workplace programs, and undergo accreditation to ensure human resource policies reflect carer inclusive practices, in line with their obligations under the Carer Recognition Act, 2010 (Cth).
 - In collaboration with carers and carer associations, conduct ongoing carer awareness campaigns for all federal and jurisdictional government departments.

Priority Outcome Five

Carers have access to supports that safeguard their psychological, physical and social wellbeing.

Proposed rewording for the outcome

Nil

Additional inclusions/considerations for ‘What we know’

- Psychological distress experienced by carer is compounded by what a carer may have to give up due to their caring role, including social activities and education/work, which negatively impacts wellbeing. Significant financial distress is a further compounding factor.
- Former carers need support when they are no longer in their caring role to assist them with the recovery of the mental and physical health and to ensure they have opportunities to secure their financial future either re-entering the workforce or receiving a different government support.

Some proposed actions for inclusion in ‘What we will do’ (noting this is not exclusive or exhaustive)

- Increase psychological support including:
 - Expanded access to carer counselling through Carer Gateway

- more flexible delivery of mental health/psychological services – for example, consider delivery where a carer can continue with an established psychologist, rather than being required to transfer to a new provider via Carer Gateway, and
- expansion of the number of mental health consults available to carers in the Mental Health Plan
- Utilising Carer Impact Assessments and IDC's to reduce red tape - streamline services and interoperability between them, for example a one-off registration that you are a carer or that a person lives with a disability, rather than this needing to be confirmed multiple times for each service.
- Improve respite availability, appropriateness and flexibility across all respite options – emergency, regular, short and long term
- Develop and implement a family violence strategy (including specialised supports) for carers noting the unique circumstances of carers experiencing violence. For example, contexts may be caring for a child with challenging behaviours, a partner with dementia or a friend with mental ill health who may have episodic violent outbursts.
- Ensure housing security for carers, including carers experiencing rent and mortgage stress, or potential loss of housing if their accommodation is tied to the people they care for.
- Ensure carers maintain their physical health by implementing systems to ensure carers have time, access and funds to maintain this, including respite to attend medical appointments.

Priority Outcome Six

Build the evidence base on carers to better understand who carers are, what are their experiences, what works for them and why.

Proposed rewording for the outcome

Strengthen and gain leverage from the evidence base about carers, to improve the reach and impact of carer policy and service provision, recognising that carers' needs and preferences may change over time.

Additional inclusions/considerations for 'What we know'

- There is a wealth of existing data across fora about carers that can be used to build a better evidence base that promotes a more targeted approach, allowing for sophisticated matching of supports to carers' different needs over time as well as allowing for gaps to be identified and addressed

Many people don't realise they are carers, and we need to explore new strategies to build awareness and knowledge and understanding of the care role to ensure carers are able to connect into information, support and other assistance, as or where they choose to.

For information, the existing evidence base regarding carers in Australia includes, but is not limited to:

- population-level data collected by the Australian Bureau of Statistics (in particular the Census and Survey of Disability, Ageing and Carers, but also a number of other surveys)
- research and evaluation data collected and funded by a range of stakeholders including the Network, other related peak bodies and representative organisations, and academia
- service-level intake, service provision and outcomes data collected by government agencies and government-contracted service providers about carers and/or the people they care for (e.g. Services Australia, Carer Gateway service providers, Commonwealth Home Support Program providers), and
- expertise from carers and the sector collected through extensive government inquiries and reviews (e.g. the Parliamentary inquiry into the recognition of unpaid carers, the Disability Royal Commission).

A high-level overview of published data sources regarding carers can be found in the Carer Knowledge Exchange publication, *Australian carer data sources: A comparative guide*⁴, compiled by Carers NSW in May 2024.

Some proposed actions for inclusion in What we will do (noting this is not exclusive or exhaustive)

- Conduct a comprehensive stocktake of data sources managed and funded by all levels of government that contain information about carers.
 - the Australian Government to work with state, territory and local governments in each jurisdiction, to develop a better understanding of the carer population and who is accessing funded services and support to assist with planning. Focus areas to include:
 - who is / is not included in the ‘carer’ variable for each data source (including the type of care undertaken, the range of conditions included), and what wording is used in questions posed to participants/respondents
 - what data is collected about those identified by the ‘carer’ variable for each data source, and
 - to what extent data collected about carers is used, reported and shared.

⁴ <https://www.carerknowledgeexchange.com.au/research-library/publication/australian-carer-data-sources>

- Strengthen the Survey of Disability, Ageing and Carers - The Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC) together with the Census provide the most reliable population-level estimates about carers in Australia. This will include broadening the definition of ‘carer’ used by the ABS in the SDAC to be consistent with the definition outlined in the *National Carer Recognition Act 2010*. This supports better estimating the prevalence of caring in the community. It could also be expanded further pending a review of the Act.
- Make Carer Gateway data regarding service uptake, unmet demand and effectiveness publicly available, as occurs with NDIS and aged care services.
- Collect carer complaint data to understand and remediate pain points in systems.
- Review the National Carer Act 2010 (Cth), including the definition of ‘carer’ as recommended by the Federal Inquiry into the Recognition of Unpaid Carers in Australia. Since 2010 views on carers and the caring role have evolved. For example, the current Act does not include those caring for someone with alcohol or substance (or other) addiction. A revision of the Act may result in greater inclusion and self-recognition of carers.

Next Steps

Action Plans

As several action plans will be required throughout the life of the Strategy, the Network encourages a commitment be outlined in the Strategy to the ongoing and early design consultation of action plans in co-design with carers including former carers, the Network, and relevant stakeholders.

As several of our recommended actions sit outside the Department of Social Services Portfolio, we also see an opportunity to a whole-of-government commitment to be placed in this section.

Many actions will require collaboration with and commitment from state, territory and local governments, and community stakeholders.

Monitoring, evidence and evaluation

A Strategy is only as successful as the outcomes it delivers. The Network strongly encourages dedicated and robust reviews at three, five, seven and 10 years.

For this to be evidence based, there needs to be clearly articulated actions, timeframes and budgets against which the impact of the actions can be measured and assessed.

The evaluation must include the lived experience of carers and former carers.

Each review should be made publicly available, including any recommendations for improvements to the Strategy and action plans.

Snapshot on Australian carers

The Strategy itself, the associated Discussion Paper and other publications like [Caring for others and yourself: Carer Wellbeing Survey 2024](#) (2024 Survey) has very tangible and sobering facts on the wellbeing of carers. This section would benefit from capturing these in the front of this section. The Network believes this would add weight to the Strategy when engaging with other government departments and jurisdictions, workplaces, educational institutions, service providers and the community (including media).

For example, compared 13% of non-carers, 40% of primary carers and 30% of non-primary carers relied on a government pension or allowance as their main source of income⁵. And the 2024 Survey has identified that compared to the average Australian;

- carers are 2.5 times as likely to report low wellbeing
- are twice as likely to have psychological distress
- half as likely to be in good health, and
- are three times more likely to experience significant financial distress⁶.

Additional background is at **Attachment C**.

Conclusion

The Network looks forward to the launch of a new National Carer Strategy that builds on the extensive feedback from carers about the issues of most importance to them and delivers tangible and concrete actions to improve the wellbeing, inclusion and recognition of Australia's carers and former carers.

Carers and carer representative bodies have genuinely and generously participated in the development of this Strategy. To ensure that carers' lived experience has been heard, and to keep carers and former carers engaged in the implementation of the Strategy, it will be important for the Strategy to provide a firm commitment to embodying lived experience, implement the recommendations in the Inquiry into the recognition of unpaid carers Parliamentary Report, produce considered actions plans and associated budgets and to commit to a public review process.

The Network thanks DSS for the time and effort invested into the Strategy's development and welcomes the opportunity to ongoing participation in its implementation.

⁵ Australian Bureau of Statistics, 2022

⁶ Carers Australia Caring for others and yourself:2024 Carer Wellbeing Survey

Attachments

- Attachment A:** Carers Australia letter – pre-submission National Carer Strategy Draft – 30 Oct 24
- Attachment B:** Carers Australia pre-sub comments National Carer Strategy Draft for Consultation
- Attachment C:** A snapshot of Australia’s carers

A snapshot of Australia's carers

There are three million⁷ carers in Australia, with almost two thirds caring for someone under the age of 65⁵. Women make up 54% of all carers and nearly 67%⁵ of primary carers. Carers can be any age, 13% of carers are under the age of 25⁵, and 25% of carers are 65 years and older⁵. Just over 14% of the Aboriginal and Torres Strait Islander population identify as carers⁸ and more than 27% of carers were born overseas¹. In 2022, approximately 39% of primary carers identified as living with a disability⁵. The LGBTIQ+ community is 3.4%¹ of the caring population and just over 24% of carers live in an area of most socio-economic disadvantage¹.

Being a carer is a constrained choice that impacts many aspects of a carer's life. To better understand and quantify the impact on carers, both Carers Australia, in conjunction with the University of Canberra, and Carers NSW, together with State and Territory Carer Organisations, undertake detailed surveys.

Carer's Australia's conducts an annual [Caring for others and yourself:2024 Carer Wellbeing Survey \(Survey\)](#)⁹. This year's survey had 9,000 respondents. Some key findings identified that compared to the average Australian, carers were 2.5 times as likely to report low wellbeing, are twice as likely to have psychological distress, half as likely to be in good health, and are three times more likely to experience significant financial distress.

More than 10,000 carers responded to Carers NSW 2024 biennial [National Carer Survey](#)¹⁰. Preliminary findings from this survey have identified most carers felt they were not recognised or valued by government, and nearly one in two felt they are not recognised or valued by their community. Most noted they are not asked by service providers about their own needs as a carer and more than six in ten carers feel socially isolated.

While only 13% of Australians rely on a government pension or allowance, 40% of primary carers and 280% of non-primary carers rely on a government pension or allowance as their main source of income⁵. In 2020, a Deloitte Access Economics report on the value of informal care¹¹, identified the economic value provided by carers in 2020 would be \$77.9 billion. The estimated earnings foregone for primary and non-primary carers at \$15.2 billion (\$11.4 billion primary carers, \$3.8 billion secondary carers). In 2022 Australian Bureau of Statistics¹ (ABS) identifies that approximately three in five (60.5%) of the 5.3 million people living with disability in Australia receive assistance with at least one activity of daily living, with 71.6% receiving assistance from informal carers¹², with 42.2% receiving formal assistance daily.

⁷ Australian Bureau of Statistics, Survey of Disability, Ageing and Carers (SDAC) 2022

⁸ Australian Bureau of Statistics, Census 2021

⁹ Carers Australia [Caring for others and yourself:2024 Carer Wellbeing Survey](#)

¹⁰ Carers NSW 2024 [National Carer Survey](#)

¹¹ Deloitte Access Economics (2020), The value of informal care

¹² Australian Bureau of Statistics 2022

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Dear Mr Whitecross and Ms Dennis

Pre-submission response to DSS draft - National Carer Strategy

Further to our discussion on 28 October, we welcome the opportunity to comment on the language used within the National Carer Strategy (Strategy) to ensure the Strategy is empowering and supportive of the future of Australia's three million (and growing) carers.

This letter and the attached comments embedded within the draft Strategy (**Attachment A**) forms only part of the feedback that the National Carer Network will be providing as part of a formal submission (due 3 Nov). This formal submission will address the Strategy in more detail, in particular the language and actions proposed in the Priority Outcomes section (not addressed here).

Our strongest proposed language changes are within the 'What We Heard' section. We believe the current drafting uses deficit language unduly placing the responsibility of the barriers and challenges back on to the carer, for example instead of 'increasing their [carer] awareness and understanding of available support services' we have proposed that there 'needs to be improved provision of information to carers'. As an aside on language, we also note that social isolation has not been discussed in this section yet featured heavily in our consultations across the age continuum.

Carers Australia proposes that the following terminologies be updated throughout the document (note these have not been mocked up within **Attachment A**);

- 'people having a disability' should be updated to 'people living with a disability' – removing the intonation that the disability defines them
- 'mental health conditions' should be amended to 'mental ill health' for similar reasons
- 'drug and substance abuse' should be 'alcohol and substance addiction'. We note there are several variations of this reference with some including alcohol; we propose a consistent approach throughout the document
 - There are also other forms of addiction where carers are providing support particularly in relation to the care recipient's mental ill health

- when referring to ‘wellbeing’, it should be expanded to be ‘physical and mental wellbeing’ to ensure there is a clear understanding of the breadth of the impact, or this should be articulated and defined early in the strategy
- throughout the document, we recommend the inclusion of references to;
 - former carers - as this is part of the carer continuum with carers often still impacted long after their caring journey has ended
 - carers caring for more than one person – as this is more than 30% of all carers
 - carers living with a disability – as this is nearly 39% of all carers, and
 - that caring is a constrained choice and impacts carers Human Rights (text proposed in the Introduction in **Attachment A**), and
- within **Attachment A** we have also provided alternative wording on carer responsibilities to better reflect what we know carers are doing on a regular basis, for example, amending ‘banking’ to ‘financial management assistance’.

Carers Australia proposes that consideration be given to the following;

- we encourage DSS to amend the reference to ‘*sandwiched*’ carers. We do not believe this appropriate for the Strategy as this generally refers to parenting and caring for older parents, however this could be updated to reference those carers with multiple carer relationships (text proposed in **Attachment A**)
- there are some excellent statistics provided in the *Discussion Paper* (to the Strategy) on the projection of the increasing numbers of carers up until 2030, we believe this is worth including in the Strategy along with the valuable insights of the Deloitte Access Economic Report - *the Value of Informal Care in 2020*, including foregone earnings lost by carers, and
- we have proposed some additions to the infographics used throughout the Strategy and propose graphics be identified for easy reference.

Finally, we note an extensive bibliography in Appendix 4, however is there a way to reference publicly available submissions such as [ours](#). We also note that you have referenced our 2023 Carer Wellbeing Survey but wish to highlight that the [2024](#) Survey is now released if you want to provide the most up-to-date findings.

Happy to discuss anything contained within this letter or **Attachment A**, noting a further formal submission will be submitted shortly with additional comments for consideration.

Kind regards,



Annabel Reid
Chief Executive Officer

29 October 2024

Attachment A: Carers Australia’s comments embedded into draft National Carer Strategy

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Australian Government
Department of Social Services

National Carer Strategy 2024-2034

Improving the lives of Australia's unpaid carers

DSS [XXXX.X.XX]



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Acknowledgement of Country

The Australian Government acknowledges Aboriginal and Torres Strait Islander peoples throughout Australia and their continuing connection to land, water, culture and community. We pay our respects to the Elders both past and present.

Content warning

Aboriginal and Torres Strait Islander readers are advised this document may contain images of deceased persons.

Help and support

Please be aware that this document contains information that may be distressing to readers. It **includes information about the experiences of Australia's carers and the challenges they face. If you need support to deal with difficult feelings after reading this paper, there are free services available to help you. These are outlined at Appendix 1, including the [Carer Gateway](#) on 1800 422 737.**

Commented [CA1]: Consideration should be given to moving help and support contacts from Appendix One up to the front of the document. If someone is in distress, the contact numbers for support should be as readily available as possible to access.

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Statement from Australia's carers

From across Australia:

We acknowledge caring as fundamental to life: the essence of our connections.

We honour its many forms, embedded in Aboriginal and Torres Strait Islander kinship and Country, enriched by people of diverse backgrounds and outlooks.

To be a carer is to be a partner, a family member, a neighbour, a mate. Sometimes we don't consider ourselves to be carers. It's something we just do.

Whether it be out of love, tradition or necessity, our contributions are essential to daily life.

*

With ingenuity and resilience, carers keep Australia going.

For us to keep going, we must be recognised and supported as individuals with our own needs, who attend to the needs of others.

This includes:

- *young carers who, out of fear and embarrassment, conceal that we look after our family members and others*
- *lifelong carers who are ageing in anguish, wondering who will watch over our loved ones*
- *carers sandwiched between generations, often forgoing our relationships, income, and wellbeing.*
- *carers in multiple carer relationships, often forgoing our relationships, income, and wellbeing*

Commented [CA2]: This terminology generally is accepted as referring to those who are both parenting and caring. This is not the focus of a National Carer Strategy, acknowledging there are some people caring for children living with a disability and older parents. This could be where the Strategy acknowledges that many carers have multiple care relationships and responsibilities.

Such shortfalls are not ours as carers, but ours as a nation.

*

When our responsibilities are shared, our resolve and our communities grow.

We seek understanding, support and respect from the nation for the impact of caring, in all its forms, on our lives.

We seek to partner with the people we care for and with the organisations that support both them and us. We make this Statement from strength: appreciating the challenges and rewards of caring; knowing that demand for us is rising; believing that when Australians care for one another, we flourish.

Explanatory Note

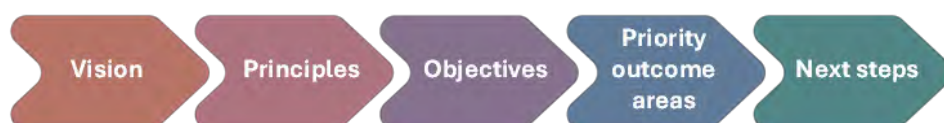
The **Statement from Australia's Carers** above was developed by a dedicated carer working group comprised of members from the National Carer Strategy Advisory Committee, led by Lachlan Rowe. Author and academic Kim Huynh was commissioned to craft it. Valuable input was received from

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carers, the people they care for, artists, scholars, relevant organisations, and members of the Australian public.

Readers guide

The document outlines the Strategy in five parts:



Together these set the scene for what the Strategy wants to achieve, and why.

The Strategy will be delivered through action plans and measured against an outcomes framework. The approach to developing these action plans and outcomes framework is outlined **under 'Next steps'**.

Throughout the Strategy you will read case studies of real-life carers and quotes from carers shared during the Strategy consultation activities.

**

To support your understanding of the foundations and development of the Strategy and how carers were consulted, you can find supporting documents in the appendices.

In addition, you can read the carer consultation reports, and an evidence-base report used to inform the Strategy at [National Carer Strategy \(dss.gov.au\)](https://dss.gov.au) and [National Carer Strategy | engage.dss.gov.au](https://engage.dss.gov.au).

A brief guide on language

The term 'carer' may not be recognised, accepted or acknowledged by some people, including First Nations people and those from culturally and linguistically diverse (CALD) communities. Throughout this document, 'carer' is used as defined in the [Carer Recognition Act 2010](#) as an umbrella term for those who provide unpaid care, support and assistance for someone who has a disability, a medical condition, a mental illness or is frail due to age.

Formal carers and paid support workers are those who provide care, support and assistance as a paid service, as part of a volunteer arrangement or as part of training or education for paid care services. Such formal care arrangements are not in scope for this Strategy. More information on the Australian Government's support for the formal care economy can be found here: [Care and support economy – state of play | PM&C \(pmc.gov.au\)](#).

Please note that people undertaking normal day-to-day care of children, whether a parent or non-parent, kinship, grandparent or in foster care relationships (where the children do not have additional needs for support due to disability, medical conditions, or mental ill health) are not the focus for the

Commented [CA3]: Propose updating to reflect those carers not captured within the Act caring for those with alcohol, other substance and addition issues.

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Strategy. Tailored support for this group of carers can be found by contacting the Grandparent, Foster, and Kinship Carer Adviser at the Department of Social Services on 1800 245 965. Other relevant resources can be located on the [Department of Social Services website](#).

Minister's Foreword

A statement from The Hon Amanda Rishworth MP, Minister for Social Services will be added to the Strategy.

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Introduction

In Australia there are 3 million unpaid carers who provide vital support to family members, friends and loved ones every day.

It is important to recognise the critical role carers play in society and the profound contribution they make to the lives of people they care for.

Caring is a constrained choice that often impacts the physical and mental wellbeing, and financial security of the carer. Carers are often denied equal access to their Human Rights compared to other Australians, including the right to rest and leisure and to participate in the cultural life of community (Articles 24 and 27 UDHR).

The National Carer Strategy (the Strategy) sets the direction and course for our collective efforts to drive positive change for carers.

This is the **Strategy's** vision for carers:

An Australian community in which all carers are recognised, valued and empowered with the support they need to participate fully in society and fulfil their caring role.

The Strategy acknowledges and respects all carers. The Strategy has been shaped by evidence and will support better decision-making on policies and programs that affect carers. The Strategy explains where the Australian Government will prioritise its efforts to support carers and their wellbeing.

At just 9 years old, Layla became a young carer for her mother who suffers from multiple illnesses. Now aged 17, Layla continues to rise above the challenges as a strong advocate for young carers:

"I really want people to know what a young carer is, rather than seeing the words and thinking 'I'm not that.' I want the definition to be widely known." – Layla, young carer

Mariana is a culturally and linguistically diverse (CALD) carer who looks after her husband, who lives with multiple sclerosis. She began caregiving 20 years ago:

"I didn't know how not to be a carer," says Mariana. "I mean, what do you do? You have a child. You have a husband; I loved him so much. It was not something I was thinking, 'am I a carer?' I was the wife, I was the mother, I just was." - Mariana, CALD carer, over 65 years

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Who are carers and why are they important?

Australia's 3 million unpaid carers play a vital role in society, delivering significant social and economic benefits to individuals, their families and the broader community. They play an integral role in the nation's health and social care systems, offering critical, unrecognised contributions.

Carers undertake a caring role for a variety of reasons – family responsibility, emotional obligation and/or to provide better care than anyone else.

The importance of carers cannot be overstated. Carers make significant personal sacrifices – forgoing careers, social lives, ~~and~~ education and financial security and financial security to care for others. This often impacts the carer's mental and physical wellbeing.

Their 'Carers' efforts alleviate pressure on formal health and aged care systems while enhancing the quality of life and independence of those they care for. Moreover, the skills they develop are transferrable to the workforce, underscoring the economic value of their contribution.

However, as Australia's population ages, the number of Australians providing unpaid care is expected to increase dramatically, highlighting the need for a comprehensive approach to recognise and support their efforts. By acknowledging, raising awareness and recognising carers, Australia invests in more than individuals – it strengthens the resilience and sustainability of the entire healthcare system.

The economic contribution of carers has been measured; a 2019 Deloitte Access Economics¹ report identified the economic value provided by carers at \$77.9 billion in 2020. This report also identified that the estimated earnings foregone for primary and non-primary carers was \$11.4 billion and \$3.8 billion respectively. Combined, the opportunity cost for all carers is \$15.2 billion.

These figures will grow with projections that carers are set to increase by 23% between 2020-2030.

Commented [CA4]: Other significant figures include: . Compared to the national average of 16% of Australians, 40% of primary carers and 30% of non-primary carers relied on a government pension or allowance as their main source of income⁵.

¹ Deloitte Access Economics (2020), The value of informal care

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In 2019 Deloitte Access Economics estimated the contribution of unpaid care. These estimates are outlined in the [Value of Informal Care in 2020](#) report.

Commented [CA5]: Propose this is lifted higher.
Ensure all figures are referenced.

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A carer is a person who provides unpaid care and support to another person such as a partner, a family member, friend or neighbour. Most carers are women, ~~but and~~ carers can come from all sections of society, including young people and even children. People become carers in different ways. Sometimes they start helping someone in small ways ~~and the role increases over time~~. Others have a child born with a disability needing additional support. Sometimes it happens suddenly, because of an accident or illness. Carers can be any age. Anyone can become a carer at any time.

The [Survey of Disability, Ageing and Carers \(SDAC\)](#), describes carers by the level of support they provide:

- Primary carers are classified as people aged 15 years and over who provide the most informal assistance with the core activities of mobility, self-care and communication. Their lives are often significantly impacted by their caring role.
- Secondary carers are classified as people aged 15 years and over who provide care with at least one of the core activities, for at least one hour per week, however they do not provide the most care (i.e. they are not the primary carer).
- Other carers are those people of any age who provide any other informal care (i.e. they are not the primary carer and not the secondary carer).

The SDAC found that in 2022, of primary carers, living in households:



Commented [CA6]: Should also reference the number of women in primary caring roles as this is significant and plays in a multitude of ways on female carers well being and financial security.

What does a carer do?

Carers are an essential and important part of the Australian community – supporting, advocating for and empowering the people they provide care for.

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Caring often means assisting someone with their day-to-day activities and supporting their caring needs. Commonly, it is providing physical and personal care like showering, dressing, toileting, feeding and supporting mobility such as lifting and providing transport. It can also involve helping care recipients to manage their affairs, such as organising and attending appointments, social activities, assisting with banking-financial management assistance, and dealing with unexpected situations and emergencies. It may also involve tasks like wound care or medication management. Importantly, it frequently involves providing vital emotional and social support.

Carers provide support complementary to, and often in place of, paid support. They are often involved in securing, coordinating and overseeing the delivery of paid supports. Unpaid carers frequently hold important history and knowledge about the circumstances and experiences of the people they care for, that can be valuable to those delivering paid supports. In many cases, carers' contributions to conveying this information can be vital to ensure appropriate health care, treatment, and support.

Taking on a care role is an important and impactful commitment which is often made in the context of limited alternative options.

What is a care relationship?

Each caring situation is unique. Care relationships can be long-term – such as caring for a person with an intellectual or physical disability, a chronic mental illness; or short term – such as caring for a person requiring end-of-life care, recovering from an accident or experiencing an illness such as cancer. Care relationships can also be episodic – such as caring for a person with sporadic pain symptoms of a chronic illness, or mental ill health.

Nicci became a caregiver as a young person and has remained a carer throughout her adult life. She requires care herself. She currently cares for her ageing father, a partner in palliative care, a partner with neurodivergence, and her adult son who is autistic. She is a member of the LGBTQIA+ community.

“You just carry on,” says Nicci. “Because you have to. And that can be very heavy for some people.”
– Nicci, LGBTQIA+, carer with a disability

People receiving the care may include those who have a live with a disability, chronic medical condition, terminal illness, mental illness including people experiencing drug alcohol and substance abuseadditionaddiction or people who are ageing.

Commented [CA7]: Inconsistent references throughout - drug and alcohol, drugs and substance etc also does not include all additions.

Care relationships vary according to the needs of the person(s) being cared for, and the carer's own individual needs and changing circumstances. There may be multiple care relationships contributing to the support of an individual. Family members may provide different supports or otherwise share responsibility for the wellbeing of a person they are caring for. In other cases, there may be one single unpaid carer filling the role on their own.

According to SDAC, in 2022 the 3 most common reasons primary carers gave for taking on a caring role were:

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Why recognising carers matters

Caring can be a highly rewarding yet challenging responsibility which often goes unseen and **unacknowledged**. Caring can take time away from other aspects of a carer's life. It often requires a carer to learn new information about the person's diagnosis or condition, and to acquire new skills and knowledge to enable them to provide the most informed support for the person they care for. Caring requires commitment and consistency.

"Sometimes, being a carer, you end up losing your own ambitions, job, income, financial security, relationships and your ability to choose what's right for yourself, as your decisions will impact your child and siblings forever." – Kerrie, primary carer for her child with a disability

Taking on a caring role impacts a **carer's own quality of life and freedom of choice**. For some people, it may mean giving up other activities or responsibilities, including work or study opportunities, which **can significantly impact the carer's** life, physically, psychologically and financially. It can also mean adjusting to taking on domestic tasks through complex management of provider packages and responsibilities they have not typically undertaken previously. This can mean that for some carers, ensuring their own needs are met and their wellbeing is maintained can be challenging. Caring responsibilities can impact an entire family, placing relationships under stress and creating unmet needs for other family members, such as siblings and partners.

"I have been caring for 20 years but I didn't know I was a carer because I just saw myself as a son or a husband. It wasn't until a clinician pulled me aside in a hospital and asked, 'how are you doing yourself?' that I started my journey to identify with the term 'carer', and that led me to finding support, education and community." - Anonymous carer

The economic contribution that carers make is significant and supports the effective operation of the health and aged care systems. Additionally, the skills carers gain through caring are valuable and are transferable to the workforce.

Carers are diverse

Carers reflect the diversity of our communities, may be almost any age, are gender diverse, live in various locations, and come from diverse cultural and socio-economic groups. This includes First Nations People, carers from culturally and linguistically diverse communities – including those from multicultural, immigrant, different racial and ethnic backgrounds and refugee backgrounds, carers in rural and remote locations, carers of veterans, carers who identify as members of the LGBTQIA+

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communities, young carers (under 25 years of age) and older carers (65 years and above), and carers with a disability. [Many carers also live with a disability themselves.](#)

The Australian Institute of Family Studies (AIFS, 2024) identified that carers from First Nations, culturally and linguistically diverse communities and LGBTQIA+ are particularly under recognised and under identified in data collections.

Some people who provide care do not always identify themselves as carers. These 'hidden' carers may not be aware of, or seek, support services. AIFS notes that 'existing data on unpaid care may significantly under-estimate the size of the cohort.' There is also a gap in data for carers of people who are affected by trauma, such as veterans, refugees, and first responders (e.g. police, paramedics). [Carers may not identify as carers for a range of reasons, including cultural obligation or real or perceived stigma attached the role of caring or to the person they are caring for.](#)

Intersectionality of carers

The intersectionality of unpaid carers must be acknowledged. The additional barriers, challenges and discrimination carers experience is increased for those with overlapping identities such as ethnicity, culture, religion, age, sexual orientation, gender identity, disability and socioeconomic status.



While each group encompasses a rich tapestry of identities and experiences, it's essential to recognise that many individuals may belong to more than one community, facing unique challenges that arise from the intersection of their multiple overlapping identities. This exploration not only deepens our understanding of their intersecting journeys but also sheds light on the vital importance of inclusion within the carer experience.

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Knowing this it is essential to adopt an intersectional approach to policy and service design. This includes developing inclusive resources collaborating with all communities to ensure that diverse carers feel affirmed in all aspects of their identity. Strategies to recognise and include diverse carers need to be publicly promoted and widely available, to assist all carers to feel confident they can **access supports that are psychologically safe, trauma informed and personalised to the carer's needs.**

We further explore the experiences and challenges of carers in Snapshot: Diversity of Carers.

Why do we need a Strategy

Australia supports those requiring care through substantial funded support systems such as social security, aged care, the NDIS, the health system and veterans' support. As a society, we need to recognise that carers have needs and aspirations of their own, which also require support. Caring is an important and natural part of our lives. The contribution of unpaid carers strengthens the efficiency and effectiveness of these service systems and provides necessary additional support when **funded hours are unable to meet a person's needs. This enables those within our community who** require assistance to live better lives and improve their wellbeing. However, we need to minimise the cost of the caring role on carers.

Carers have told us:

- Low levels of community awareness about carers, and what caring is, contribute to a lack of self-identification of people in caring roles, and a lack of identification in the community. Lack of self-recognition as a carer leads to people either not accessing support or accessing support late, and at a time of crisis.
- Carer supports and services can be difficult to access and navigate and may not be effective or fit for purpose.
- **The caring role impacts carers' health, safety**, financial security and physical and mental wellbeing.

Living in a remote area presents its own obstacles:

"The limited access to services and essential care, the challenge of getting proper schooling and allied health professionals – it all makes the caregiving journey harder" – Cat, carer for her son in a remote area

The previous National Carer Strategy was launched in 2011 and sat alongside the National Disability Strategy 2010–2020 and, in conjunction with the *Carer Recognition Act 2010*, formed part of the **Australian Government's National Carer Recognition Framework. The 2011 Strategy was superseded** in 2015 by the commencement of the Integrated Plan for Carer Support Services (known as Carer Gateway).

Since the release of the previous Strategy, there have been significant reforms to major service systems providing for people with support needs including the roll out of the National Disability Insurance Scheme (NDIS), Australia's Disability Strategy 2021–2031 (ADS), the Disability Royal Commission and aged care reforms following the Aged Care Royal Commission. The increasing focus

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on person-centred planning and service delivery is changing how formal support services interact with the people who use them, their families, friends and carers. This has impacted on unpaid carers who are supporting the person they care for to access services and systems.

The Minister for Social Services referred an inquiry into the recognition of unpaid carers to the House of Representatives Standing Committee on Social Policy and Legal Affairs (the Committee) on 13 June 2023. In March 2024, the Committee tabled its report titled [Recognising, valuing and supporting unpaid carers – Parliament of Australia \(aph.gov.au\)](#). The Committee examined the challenges faced by unpaid carers and options for reform. The report contained 22 recommendations including a need for an increased focus on minority cohorts, including, but not limited to, First Nations carers, culturally and linguistically diverse carers and young carers. The report, including its underpinning data and evidence, and its recommendations have been considered as part of the development of this Strategy.

This Strategy provides an opportunity to review how we currently support carers, what is working and what do we need to better support carers, now and into the future.

By fostering a community that champions mental health, financial sustainability and quality services, Australia is not only investing in the future of its carers but also in the strength and resilience of the nation. Together, we can build a brighter, more inclusive future where every carer's journey is acknowledged and supported.

What we heard

When talking to carers, we heard many perspectives on the caring role and how supports and services are working around Australia.

We heard that identification and recognition of carers is critical:

- There are low levels of community awareness about carers, and what caring is. This contributes to a lack of self-identification of people in caring roles, and a lack of identification in the community (particularly in education and employment settings).
- The expertise of carers should be valued **and recognised** by health care and other professionals, **including service providers**.
- There needs to be recognition of the impacts the caring role has on an unpaid carer.

Carers struggle to access the supports they need:

- They need to know how and where to find information **and to access services**. Carers need access to information from the moment they become carers to build knowledge, and access supports for both them and the person they are caring for. **There needs to be increased improved provision of information to carers, including on support services. This includes increasing their awareness and understanding of available support services**, such as the Carer Gateway. Complex **government systems and lack of interoperability between them (e.g. NDIA, My Aged Care and Centrelink) pose challenges for the carer and is time consuming to manage and resolve**. **Understanding and navigating the different systems carers have to access is time-consuming and complex**.

Carers told us about the impacts caring has on their wellbeing:

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- Carers experience emotional stress, anxiety, depression and compassion fatigue. There is considerable impact of caring on overall psychological wellbeing.
- ~~Carers also experience lower rates of physical wellbeing, often prioritising the person they care for over their own health issues or taking time for physical exercise. Carers also experience lower rates of physical wellbeing, often prioritising the person they care for over their own health issues or taking time for physical exercise.~~
- ~~Lack of access to respite due to provider deserts, complex systems, inappropriate, insensitive and inflexible options has an impact on carers.~~ Barriers to accessing appropriate respite are common, varied and complex. Carer breaks need to accommodate the needs of the carer and the care recipient, as well as the carer. This complicates arrangements, such as the need to link available carer respite to care recipient respite, care recipient refusal and the ability of care replacement services to meet the high needs or cultural requirements of the recipient. This is not helped by variability in understanding of what respite services may comprise of for different cohorts of carers.

We also heard that carer diversity isn't always recognised- carers are diverse:

- ~~Many carers struggle to access services. Services need to be that are culturally safe and informed for carers to be appropriately supported. The lack of culturally safe supports and services create a barrier to access for many carers to be appropriately supported.~~
- Many services do not ~~Services need to~~ recognise the diversity of carers and how this affects them in their caring roles.

Carers need support to build their capacity and to safeguard their future:

- Carers need support to acquire or develop the knowledge and practical skills to provide care while also to maintaining their own physical, psychological, emotional and financial wellbeing, and to ensure their physical and mental wellbeing when providing care to the care recipient. Former carers also need support transitioning back into the workplace and community once their caring responsibilities finish.
- There is a financial impact of providing care, that can have lifelong impacts on the carer. Carers need support to participate in or re-enter the workforce or education (where caring responsibilities to not preclude them).
-

Further detail on the consultation process and evidence summary is at Appendix 2.

Diana's caregiving role evolved into a central part of her identity, impacting her career and personal aspirations.

"You suspend a bit of yourself to serve the role"

Diana believes the future of caregiving depends on tapping into carers' invaluable expertise.

"If we can respect that and access that knowledge, we can spread it. It doesn't just build our capacity—it builds capacity across the board." – Diana, carer of her son with a medical condition

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Who will deliver the Strategy

Carers do not see their role through a lens of which government agency delivers a service and neither should the Australian Government. The Strategy will foster collective efforts for a coordinated approach to holistically supporting carers with via a whole-of government approach: ~~and~~ through working closely with each jurisdiction: and through co-design with carers incorporating their lived experience.

"Lots of options that can pull together to help, but what's missing is the glue to bring them all together for that person" – Anonymous carer

Driving change for carers, and improving outcomes is a shared responsibility across the Australian Government, our carer support partners and all levels of government.

Consultations and other contributions to the development of the Strategy highlight the need to better collaborate and coordinate effort, to invest in, and work more effectively to achieve our vision for carers. The Australian Government will also use this Strategy to guide its work with state and territory governments, complementing state and territory strategies and policies for carers.

"I feel like an octopus having to navigate multiple different organisations or people within the same organisation" – Anonymous carer

More information on the next steps to delivering change for carers is found in the 'Next steps' section of this Strategy.

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National Carer Strategy on a page

Vision
An Australian community in which all carers are recognised, valued and empowered with the support they need to participate fully in society and fulfil their caring role.
Principles
The co-designed principles should guide the coordination and delivery of carer-related and carer-impacting policies, programs and initiatives across Australian Government agencies.
<ul style="list-style-type: none">• Carer-centred: The lived experience of carers will be included in the co-design and co-production of policies, supports and services for carers. Carers' lived experience will be included in evaluation processes.• Evidence-informed: carer policies, supports and services will be informed by evidence, and innovation will be used to address challenges experienced by carers.• Accessible, equitable and inclusive: carer policies, supports and services will be inclusive and tailored to respond to the needs of carers, at all stages of caring, recognising the diversity of carers, and the importance of cultural and psychological safety.• Supports agency: the design of policies, supports and services for carers will enable choices that suit them.• Transparent and accountable: federal government departments will be transparent in their processes to better recognise and value carers.
Objectives
The objectives are the results we want to achieve for carers.
<ul style="list-style-type: none">• Carers are identified, recognised, and valued.• Carers are empowered to fulfil their caring role, whilst still pursuing other aspects of their lives.• Carers' health, safety, wellbeing and financial security are supported.
Priority outcome areas
The priority outcome areas are where we will direct efforts to achieve the objectives and the Strategy's vision.
<ul style="list-style-type: none">• The community, government and those who provide paid care and support recognise and value carers' contributions and expertise and carers are supported to self-identify early.• Carers can access supports, services and programs at the right time, right place and in the right way across the caring continuum.• Carers are able to develop the knowledge and skills they need to fulfill their caring role.• Carers can access, pursue and maintain employment and education, including to improve financial well-being for themselves and those they care for.• Carers have access to supports that safeguard their psychological, physical and social wellbeing.• Build the evidence base on carers to better understand who carers are, what are their experiences, what works for them and why.
Next steps
<ul style="list-style-type: none">• Action – a series of action plans will be developed incorporating the feedback to date and theory of change.• Measuring success - a monitoring, evidence and evaluation approach will be implemented that includes: theory of change; an outcomes framework and a monitoring and evaluation framework.• Co-design - the voices and perspectives of carers will inform and guide the Strategy implementation, monitoring and review to ensure outcomes are delivered and objectives are met.

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Vision

An Australian community in which all carers are recognised, valued and empowered with the support they need to participate fully in society and fulfil their caring role.

Why do we need a vision?

In developing the Strategy, carers shared the key challenges they face.

For many, the lack of recognition of the impacts of their caring role on both their lives and their **families' lives was a significant concern. Carers also highlighted the lack of understanding about the necessity of the care and support they provide to the lives of care recipients and society. The language of 'informal' and 'unpaid' care** implies the care provided is in fact not essential to the safety and wellbeing of care recipients. To keep people living in the community, unpaid care is essential to augment paid care and keep people safe and well. This is the case even when care recipients are in hospital or in residential care, where additional support is required.

Carers consider that the care and support they provide should be as highly regarded as the delivery of formal, paid care services. Carers contribute immensely to both the ability for people needing care to remain in the community, living as independently as possible, and to the economy through their caring role, and they want this contribution to be acknowledged and appreciated.

To continue fulfilling this vital role, carers have expressed the need for effective support and empowerment, with a recognition that their human right to a good life is equal to the rights of those they care for. They want help in balancing their caring role with other important aspects of their lives, including minimising the constraints to participating fully in other aspects of life. They need opportunities to work, access education, social engagement, rest, all which promotes and maintains their wellbeing. Carers seek access to the necessary information, knowledge and skills to perform their caring roles effectively whilst managing their own health and wellbeing, as well as that of the people they care for.

How was the vision created?

In the spirit of carer-centred co-design, the vision statement grew from in-depth consultation between the National Carer Strategy Advisory Committee (the Committee) and the Australian Government, drawing on what we heard from other carers through the consultation process. The Committee is made up of carer sector representatives and carers with lived experience from diverse backgrounds, all selected through an open process to ensure that the experiences and aspirations of carers across the country are reflected in the Strategy and its overarching vision. In crafting the vision statement, the Committee also drew on other evidence sources such as the recent Parliamentary Inquiry into the recognition of unpaid carers, reports and evidence from Australian carer advocacy organisations as well as international carer organisations, strategies and visions.

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Why was our vision created?

The vision is a short over-arching declaration of the aspiration for the **future for Australia's unpaid carers, driving the Government's strategic direction in support of the lives unpaid carers aspire** towards. The vision has already supported the drafting of the new Strategy, by expressing a clear intention about our shared values of inclusion, recognition, co-design, equality, safety and well-being. Carers shared their aspirations to be supported to better balance their caring role with all aspects of their lives such as education, workforce participation and importantly social inclusion.

How will we achieve our vision?

In developing and progressing actions to achieve this vision we will be guided by a set of principles which reflect what we have heard is important to carers. The principles set out in this Strategy will underpin the design, development and implementation of actions.






Actions and their implementation will be shared with the community as they progress.

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Principles

These principles reflect what carers have told us is important to them, when we are co-designing ways to support them to participate fully in society, while also fulfilling their caring roles.

The principles provide a foundation for the coordination of carer policies, programs and initiatives across Australian Government agencies.

Principle	What we will do	How we will do it
<p>Carer-centred</p> 	<p>Include carer lived experiences in the co-design, co-production, monitoring and evaluation of policies, supports and services for carers.</p>	<p>Continue to seek out, listen to and act on carers' perspectives.</p> <p>Focus on what they tell us they need. Be flexible and responsive when circumstances change.</p>
<p>Evidence-informed</p> 	<p>Ensure that carer policies, supports and services are informed by evidence and innovation, to address challenges experienced by carers.</p>	<p>Focus on building and improving an evidence base to better support the development, implementation and monitoring of tailored and responsive supports and services.</p> <p>Enable data sharing and evidence for use by governments and communities to evaluate interventions and resources.</p>
<p>Accessible, equitable and inclusive</p> 	<p>Ensure carer policies, supports and services are inclusive and tailored to reflect the needs of all carers, at all stages of caring, recognising the diversity of carers, and the importance of cultural and psychological safety.</p>	<p>Use evidence-based data and lived experience to codesign innovative, accessible, tailored and inclusive services.</p> <p>Recognise, respect and facilitate the vital role of non-government organisations in providing supports and services.</p>
<p>Supporting agency</p> 	<p>The design of policies, supports and services for carers will enable choices that suit them.</p>	<p>Acknowledge that carers know their needs and aspirations best. All have unique relationships, strengths, capabilities and resources, which may change over time.</p> <p>Co-design policies, supports and services to empower and support carers to find and access the right supports at the right time and to ensure unintended consequences for carers are identified and remediated.</p>
<p>Transparent and accountable</p> 	<p>Federal government departments will be transparent in their processes to better recognise and value carers.</p>	<p>Monitor, measure and evaluate in delivering on the priority outcome areas and achieving the objectives set out in the Strategy.</p> <p>Include carers in the continued development of actions and implementation plans to support realising the vision of the Strategy.</p>

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Objectives

The objectives for the Strategy are grounded in the insights gathered from extensive consultations and supported by robust evidence. Through engaging with carers, service providers and community stakeholders, we have identified key themes and challenges that resonate with the carer community. By aligning our objectives with the voices of those directly impacted, we ensure that our approach is not only relevant but also effective in fostering a more supportive environment for carers across the nation.

Co-developed by carers, these objectives provide the overarching goals carers, and the Australian Government, want to see realised. Through monitoring improvements in these objectives, we will measure our progress toward achieving the Strategy vision.

	Objective	What does this look like?
①	Carers are identified, recognised and valued.	Carers are: <ul style="list-style-type: none">• able to identify they are in a caring role, and can access information of supports available to them• acknowledged by others, and consulted, regarding the person/s for whom they are caring• identified early and are offered information pathways to supports appropriate to their needs• valued equally in their caring role.
②	Carers are empowered to fulfil their caring role, whilst still pursuing other aspects of their lives.	Carers have: <ul style="list-style-type: none">• access to resources and skills training that enhances safe and effective caregiving• access to forms of respite that are most relevant to the circumstances of different carers and those they care for• flexibility and adaptability with learning options and support to accommodate caring responsibilities from educational institutions to support personal and professional development goals• carer-inclusive workplaces that welcome and accommodate their caring responsibilities to support employment goals and financial security.
③	Carers' health, safety, wellbeing and financial security are supported.	Carers can flexibly access the assistance they need to support their: <ul style="list-style-type: none">• physical well-being and safety• psychological health• social connection• cultural and spiritual identity• financial security.

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Priority outcome areas

The priority outcome areas are where the Australian Government will direct efforts to achieve the objectives **and the Strategy's vision**. The **priority** outcome areas encompass recognition and value, support and empowerment, and wellbeing. Through these priority areas, we will consider what actions can improve key challenges faced by carers such as pathways to information, workforce or education participation, access to appropriate respite, carer safety and wellbeing.

Priority outcome area: The community, government and those who provide paid care **and support recognise and value carers' contributions and** expertise and carers are supported to self-identify early.

What we know

Carers are often overlooked by service providers and health professionals. Carers possess valuable history, context and knowledge regarding the person/s they support, which shapes how that person responds to interventions and support services.

Better integration of the role and function of the carer as a critical decision supporter, partnering with treatment and care teams is needed to enable good outcomes.

Carers are under-recognised in the community for a variety of reasons including due to a general lack of community awareness. They may not identify for cultural, relationship or social reasons, or **are 'hidden' due to inadequacies of current data collection** approaches.

Many people providing unpaid care to others do not identify with or use the term 'carer', including many people supporting people with disability or from culturally and linguistically diverse backgrounds and First Nations communities where the word may not translate effectively in their language.

Carers often do not identify or seek support until they are in crisis.

Women are disproportionately represented, often due to gender norms and men are less likely to identify as carers.

What we will do

We will improve awareness of carers, caring roles, the impacts of supporting others, availability of carer supports and services through strategic communications, focussing our efforts on:

- reaching all carers, including those from diverse backgrounds, and those in regional and remote locations
- working to reduce the negative stigma about caring by recognising and raising awareness of **carers' valuable contribution to society**
- focus on addressing gender stereotypes in care
- working with those in care relationships to explore and develop more inclusive language for people providing unpaid care and support to others.
- identify key legislation and policy areas for review and address unintended policy consequences that may impact carers or further constrain their choices.

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We will collaborate across government and the care and support sector to raise awareness of the necessity and value of carer expertise and knowledge and to determine what education other professionals require to improve recognition and integration of unpaid carers as a vital care partner.

We will explore innovative options to transform recognition and support for carers.

Objective supported:

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Priority outcome area: Carers can access supports, services and programs at the right time, right place and in the right way across the caring continuum.

What we know

Carers want better information about services and supports they can access.

Some carers are not aware of the services and supports that may be available to them.

Carers face several key challenges that impact their ability to understand and navigate the systems they need to access. These include:

- The complexity of these systems, including those they need to interact with on behalf of their care recipients, can be overwhelming.
- A lack of clear information and resources tailored specifically for carers often leaves them feeling uninformed and isolated and potentially at risk.
- The demands on carers and their wellbeing in caring roles may limit their capacity to research and engage with available services.

Carers want and need services and support that are easy to find and easy to access.

Carers have consistently identified the importance of engaging with services when and where they need them and in a way that is tailored and responsive to diverse needs.

Supports need to be appropriate and informed to safely deliver services to diverse carers.

Many carers don't seek assistance until they are at a point of crisis. This is often due to not identifying as a carer sooner and/or being unaware of services and supports that may be available.

The introduction of the Carer Gateway has assisted many carers. Feedback from some carers indicates that it has improved access to supports overall, however this hasn't been the case for all carers.

Navigation assistance should be available from a **carer's** first contact with systems and throughout the caring journey, particularly when carers are in crisis and/or burnout and should connect carers to appropriate supports and services available through other systems.

Carers encounter numerous obstacles when trying to access breaks from their caring role via respite options, which are vital for their health and the continuation of their caregiving responsibilities.

Carers need breaks to rest, manage stress or attend to personal tasks. This can mean different things to different carers, this could be short-term alternative care, or assistance with tasks such as cooking, cleaning and running errands. It could mean a retreat or short break to prioritise their own wellbeing to continue providing support to someone else.

Availability of respite care resources are limited in rural and remote regions.

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Respite services are often oversubscribed and have limited availability, which may not be at the time the support is needed.

Some options may not offer the adaptability needed to suit the specific requirements of individual carers or the people they support, complicating the search for a fitting service.

What we will do

We will work with relevant government agencies, carers and the carer support sector to improve information pathways and referrals and streamline processes to access supports and services. This will mean early intervention and support is available to help carers access the information needed to make informed choices.

We will work with carers, the carer support sector and relevant government agencies to explore and co-design navigation assistance options to support carers.

We will promote carer supports to the community.

We will seek to **build on current supports to improve carers' choice of services and providers** and to provide greater choice and flexibility in tailored supports and services.

We will work to improve the appropriateness and competence of services to better support diverse carers to receive supports that are safe, flexible and informed.

In collaboration with carers and the carer support sector, identify, design and implement ongoing solutions for more flexible and accessible respite services and other supports for carers, linked to solutions for care recipients when required.

Work with other service systems, such as aged care and the NDIS, to advocate that services that provide support for the care recipient are designed and delivered in a way that takes account of the needs of carers and the care relationship.

Objectives supported:



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Priority outcome area: Ensure carers are able to develop the knowledge and skills they need to fulfill their caring role.

What we know

Carers may want to increase their knowledge and skills to enable the provision of effective and safe support to their care recipient and to also maintain their own wellbeing. This includes training for manual handling, financial/legal literacy, wound care, medication management and mental health training.

Training and development needs continue across the caring continuum as circumstances change, such as ageing, a reduction in their health and wellbeing or other family members require increased support.

Carers need ongoing access to a library of resources, training opportunities, mental health resources and peer support. In addition, skills in time management and self-care enable carers to prioritise their own well-being while effectively supporting those in their care. By fostering a carer ecosystem that values both their caring role and personal life, carers can achieve a healthier balance and enhance their overall quality of life.

Ongoing access to upskilling to adapt to these changes needs to be available and accessible for all carers.

What we will do

We will identify and expand existing training and practical skills development programs that exist nationally and explore to better ways to connect carers to these resources.

We will support the development of information about pathways to other relevant training and skills development available to unpaid carers.

Objectives supported:



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Priority outcome area: Carers can access, pursue and maintain employment and education, including to improve financial well-being for themselves and those they care for.

What we know

Providing care to another person often means carers need to leave work or education, and for some, this can be for a long period of time.

For many carers, this impacts their ability to find employment. Carers may need support to enhance their capacity to enter or re-enter the workforce or return to education.

Carers want to be supported to reach their own goals and safeguard their futures.

Carers often experience challenges to receiving support and recognition from workplaces and educational institutions, which can significantly impact their ability to balance caregiving responsibilities with work or study.

Employers and educational institutions may not fully understand the unique needs and challenges faced by carers. Workplace and educational policies often lack flexibility, making it difficult for carers to manage their commitments.

What we will do

Taking a multifaceted approach to support carers to achieve financial security, we will:

- support carers to overcome barriers to participating in the workforce or education system
- encourage and support workplaces and educational institutions to better accommodate carers.

Through improved awareness and recognition of carers, support workplaces and education systems to be more inclusive and flexible for carer participation.

We will work with relevant government agencies to improve recognition of carers in the workforce and education systems and value the skills and knowledge they bring from their lived experience.

Objectives supported



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Priority outcome area: Carers have access to supports that safeguard their psychological, physical and social wellbeing.

What we know

The psychological impact of providing care is significant for many carers. For some, it can be a lifelong commitment.

Carers can experience psychological distress because of their caring role. This can be associated with becoming a carer; the cumulative demands of caring; and managing changes in care needs both episodically and over time.

Many carers face living with grief and loss for themselves and the person they are caring for daily. Carers face concerns over the ongoing care of the care recipient as the carer ages - who will take over care when they can no longer provide it.

Some carers face significant concerns for their safety whilst caring for someone. These concerns can arise from the physical demands of caregiving, the behaviours and symptoms of the person they care for, domestic and family violence, and the effects of social isolation on their mental health. Additionally, carers may experience issues related to suicide, including attempts and suicidal thoughts, which can stem from their caregiving situation as well as their own personal history.

Some carers may need support when they are no longer in a caring role, particularly if they were in a long-term caring role and experienced social isolation. This may include accessing supports that enable social participation.

What we will do

In collaboration with relevant stakeholders, including carers and the carer support sector, we will support the psychological wellbeing of carers by improving the responsiveness and appropriateness of carer services

We will work with carers, the sector and across government to better understand and address **social isolation and loneliness for carers and improve services that support carers' social participation.**

We will support carers to improve and maintain their physical wellbeing through training to support their caregiving responsibilities, and information and knowledge that will assist them to protect their wellbeing whilst providing care to others.

We will undertake work to better understand abuse against carers and how to improve the supports they can access.

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Priority outcome area: Build the evidence base on carers to better understand who carers are, what are their experiences, what works for them and why.

What we know

There are significant information gaps about the actual number of carers in Australia and we need a more inclusive demographic picture of the full carer landscape.

Improving data capture to better understand the challenges and contribution of all carers is important to help build improved and integrated services and supports.

What we will do

In collaboration across jurisdictions, we will undertake a stocktake of all data sources relative to carers across the country at all levels of government and the sector with a view to develop a consistent national picture of carers' experiences to inform the development of policies, services and supports

Objective supported:

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Next steps

We will implement the Strategy through action plans. We will measure actions with an outcomes framework to assess progress and effectiveness.

Action plans

A series of action plans will be developed to provide practical steps developed in the context of the vision and priority areas, to achieve outcomes for carers. This allows the Australian Government to be responsive to opportunities while keeping our focus on the overarching vision.

As outcomes of other reforms relevant to carers become realised, new priority areas for carers may emerge. Throughout the life of the Strategy, we will measure and evaluate the impact of actions put in place. This will inform development of future action plans to achieve the Strategy vision.

The first action plan, informed by the views, perspectives, expert advice and evidence collected during the development of the Strategy, will be implemented in the first 2 years.

Monitoring, evidence and evaluation

A robust monitoring, evidence and evaluation approach that aligns data, research and evaluation is integral to the development, implementation and impact of the Strategy.

The core components of the approach include:

- a theory of change
- an outcomes framework
- a monitoring and evaluation framework.

A theory of change tells us why we need change and how our actions will help us meet our objectives.

An outcomes framework will outline how we will measure the outcomes of the Strategy and, where possible, provide measurable indicators.

A monitoring and evaluation framework will support the outcomes framework by tracking the progress and success of the actions taken and monitor progress against the objectives and vision. The voices and perspectives of carers will inform and guide the Strategy implementation, monitoring and review to ensure outcomes are delivered.

We will also undertake a final evaluation of the Strategy.

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SNAPSHOT: Diversity of carers

Carers are diverse. The intersectionality of carers often means some cohorts of carers experience additional challenges and barriers to accessing support. This appendix explores the challenges of carers through evidence gathered from data collection, outcomes of consultations, reports and other related activities described throughout the Strategy.

Young carers

In 2022, there were 391,300 carers under 25 years of age (ABS, 2024). This is likely an under-estimate due to limitations in data collection, social perceptions about what constitutes caregiving as well as a general lack of awareness about the contribution young people make to supporting and caring for family members. The Inquiry indicates young carers may not identify themselves as carers **and may 'see their caring roles as a normal part of family life'**. A young person may be the primary carer or share caring responsibilities with others. They may care for siblings, take on additional responsibilities in the home to support a primary carer or juggle a combination of these roles.

"There've been times when I've said yes to going out to social outings, but then I've had to cancel at the last minute because Mum required my care" – Anonymous young carer

This creates unique challenges for them in relation to participation in education, developing and maintaining meaningful social relationships and workforce participation. Caring responsibilities can contribute to social isolation for young people. Evidence shows that poor mental health in youth increases the risk of adult depression, anxiety and suicidality, and predicts low educational attainment and unemployment (Alfonzo et al 2024). In addition to these risks, many young carers are coping with health conditions and disability themselves. SDAC data indicates that young people with disability are far more likely to be carers than young people without disability (ABS, 2024a).

Addo et al (2021) highlighted the importance of age-appropriate, youth-friendly services and programs that reflect the life stage needs of the carer. Young carer consultations reflected this by raising a need for beneficial practical supports such as financial literacy courses to help manage **household budgets or manage the care recipient's affairs. They highlighted the need for recognition and understanding of young carers' roles in education and employment settings with flexible** arrangements, timelines, or the option to do studies online. Young carers may experience other barriers to accessing support such as requirements for parental consent, stigma and awareness of services available to them.

Young carers discussed their experiences with support and recognition from their education institutions. Social wellbeing initiatives delivered through schools is a welcome support for some, however this is inconsistent. Similarly, some young carers expressed that sometimes what they need is more flexibility for meeting academic deadlines or tailored one-to-one support to stay on top of their studies.

"Sometimes I feel like I am constantly two steps behind everyone else my age. I wish that I were able to have the same opportunities as everyone else my age" – Anonymous young carer

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Participants at the young carer consultations also indicated that connection and networking with other young carers was immensely valuable. This feedback reinforces the importance and value of peer support for carers.

Women who are carers

According to SDAC (ABS, 2024a) just over half (54%) of carers are women and this increases to two-thirds (67.7%) for primary carers. There were a greater number of women who are primary carers than men who are primary carers across all age groups.

Table 1: Number of primary carers by age and sex (ABS, 2024a)

Age	Women	Men
15 to 24	24,300	17,000
25 to 34	70,400	35,100
35 to 44	156,000	38,900
45 to 54	191,200	58,400
55 to 64	150,100	74,500
65 to 74	116,900	91,500
75 and over	66,100	59,500

It is widely acknowledged that the disproportionate levels of unpaid care that women provide as primary carers have significant impacts on their lifelong economic security. This includes negative effects on pay and lifetime earnings, resulting in lower superannuation accumulation and higher risks of poverty in older age. **Unpaid care can also negatively impact women's workforce progress and representation in leadership roles, especially for those who need to work part time and/or flexibility to manage their caring responsibilities.**

Supporting choice and flexibility at all levels in the workplace ensures people are not financially disadvantaged by their carer roles and can help carers balance their work and care commitments. Challenging existing social structures and systems, and rigid gender norms, including through education and awareness raising, representation of carers in leadership positions and in the media, and providing flexible work policies is important to breaking down the gendered norms associated with caring and combatting the gendered impacts on unpaid care.

Working for Women: A Strategy for Gender Equality (Gender Strategy) is the Government's 10-year strategy for advancing gender equality in Australia. Valuing unpaid and paid care is one of five priorities, and directly supports the Gender Strategy's ambitions to balance unpaid work, close the gender pay gap, and close the retirement income gender gap. The Gender Strategy recognizes that unpaid and paid care are linked to each other and to the other priorities of the Gender Strategy: gender-based violence, economic equality and security, health, and leadership, representation and decision making. Addressing negative gender attitudes and stereotypes is a foundation of the Gender Strategy.

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Men who are carers

Men are an important carer cohort, who are under-represented in the service system. SDAC data shows that in 2022, men aged 65 to 74 years and 75 years and over are more likely to provide unpaid care than men at younger ages (ABS, 2024a).

Gendered norms and patterns around care giving have created a persistent stereotype about who cares and what carers look like (WGEA, n.d.) and that stereotype is female. This means that men may not identify what they do as care, may not want to be labelled a carer, be less likely to seek support from the community or their workplace, experience more resistance or discrimination when seeking flexible working arrangements or struggle to be recognised as a legitimate and competent carer.

In the workplace, men who are carers ~~—including parents—~~ are more likely than their non-caring counterparts to feel discriminated against and have their career aspirations dampened (WGEA, n.d.).

Men who are carers are more likely than women who are carers to be employed (74.8% compared to 66.5%) (ABS, 2024a). According to WGEA (n.d.) Australian research 'found that normalising and modelling flexible working arrangements can assist men to balance work with their caring responsibilities'.

Representing caring as 'everyone's job' and as a valued contribution to our community and our economy is important for supporting both to take up more care and to be supported, recognised and respected as carers. More equal sharing of care between men and women is also important for advancing gender equality.

"I started out helping mum manage her appointments, her shopping and stuff. I did not identify I was a carer until I was providing physical care. Now she is in aged care, and I am still managing her affairs, advocating for her and making sure they look after her, it doesn't stop. I am still caring for her." – Anonymous male carer

LGBTQIA+ carers

Note: We use the term LGBTQIA+ in the Strategy. In some cases, terms such as 'LGBTQ+' and 'LGB+' are used in references from a source study or report.

The LGBTQIA+ community has a rich history of caring for both biological and chosen family. Throughout the 1980s and the 1990s, the LGBTQIA+ community and their supporters established large volunteer-run care and support networks across Australia for people living with HIV/AIDS. International research shows that compared to their non-LGBTQIA+ peers, LGBTQIA+ people are 1.2

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times more likely to be primary carers and 3.5 times more likely to provide care for friends and chosen family (Gipson et al., 2023).

Within Australia there is a lack of consistent, national data on LGBTQIA+ people who provide care. Input to date indicates that LGBTQIA+ carers experience additional challenges in their caring role, including experiencing greater social isolation, discrimination (particularly in accessing supports, and services that may not be inclusive), a lack of recognition of identity or experience (Mental Health Carers NSW, 2024), and ongoing declines in wellbeing (Carers Australia, 2023). This is reflective of a broader social context in which people in LGBTQIA+ communities often experience stigma, discrimination, bullying, violence and exclusion (ABS, 2024). This can have significant impact on health and wellbeing, as clearly demonstrated by the ABS report (2024b) on mental health findings for LGBTQ+ Australians.

In their 2024 report, Building the evidence base for the National Carer Strategy, AIFS noted that the 2022 SDAC was the first cycle of this survey to ask carers their LGB+ status. Around 3% of primary carers described their sexual orientation as gay, lesbian, bisexual or who used a different term such as asexual, pansexual or queer (LGB+). The 2022 National Carer Survey found that the average age of LGBTQ+ carers was 47 years, and just under 1 in 3 young carers in the survey (29%) identified as LGBTQ+ (Carers NSW in AIFS, 2024). Furthermore, around 2 in 5 surveyed LGBTQ+ carers were caring for more than one person.

“We want peer led and community-controlled services.” – Anonymous LGBTQIA+ carer

At recent consultations, LGBTQIA+ carers shared the challenges and need to better recognise and support them in their caring roles, and to acknowledge ‘chosen family’.

Carers felt ‘invisible’ to the system due to inadequate data capture and therefore evidence bases to drive improvement do not accurately reflect this cohort of carers. Many carers felt isolated in their roles and that recognition and respect for ‘chosen family’ is lacking.

Peer support is important and effective for wellbeing, information and knowledge sharing. Carers experienced an increased level of initial trust and willingness to share in a group of LGBTQIA+ peers greater than would have been in a non-peer led support group.

“Everybody has done almost everything I’m trying to do before, it’s nice to know you’re not the only one facing a problem.” – Anonymous LGBTQIA+ carer

Peer-led community-controlled services can provide supports that are safe, appropriate and informed. Training and awareness-building for providers is needed to address attitudes and barriers that may prevent LGBTQIA+ carers from being their fully authentic selves in their caring roles and enable them to feel safe and confident to engage.

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First Nations carers

First Nations people may not identify with the term 'carer'. In recent consultations, carers told us that, as it is for other diverse communities, care is seen as an important cultural responsibility.

"It's just part of what being a sister/brother/daughter/son/human comes with, and we value it. We value nurturing and caring as part of our culture." – Anonymous First Nations carer

This means that First Nations carers are likely under-represented in national data collections, with flow-on implications for research and service planning. Noting these limitations, we know from the ABS Census of Population and Housing 2021 that 15% of First Nations people aged 15 years or over provided unpaid care. First Nations people are 1.3 times more likely to engage in unpaid caregiving compared to non-Indigenous Australians and take on caregiving at younger ages (AIHW, 2024b).

We also know that First Nations carers are more likely to be providing multi-generational care. The 2022 National Carer Survey found that 43% of First Nations respondents cared for more than one person, and 17% cared for three or more people (Carers NSW, 2023).

Many First Nations carers undertake their caring roles whilst also dealing with a combination of socio-economic, health and wellbeing gaps, as a result of systemic disadvantage, racism and the impacts of colonisation. Geographic barriers impacting the accessibility and continuity of services is a further challenge for carers, particularly in regional and remote Australia.

"Living remote, you are relying on people, who are relying on people, who are relying on people. It takes one person to leave, and everything falls over." – Anonymous male carer, remote location

There is growing recognition of the critical connection between culture, health and wellbeing. First Nations carers told us that services need to be culturally appropriate and safe for them to be accessible. Carers need to feel trust and confidence in seeking support.

Culturally and linguistically diverse (CALD) carers

It is estimated between 25% and 30% of carers are from CALD backgrounds (Parliament of Australia, 2024). However, this figure is likely under-estimated due to under-reporting and difficulties in identifying caring roles within the CALD community, especially when there can be multiple carers providing different supports. The relatability of these carers to their caring role may not fit into the ABS definitions of 'primary, secondary, and other carers' and therefore be under-represented.

CALD carers often face additional challenges such as limited access to translation services, difficulties navigating online resources, cultural barriers, lack of recognition of identity (MHCN, 2024), and experience of discrimination.

Consultations with carers from culturally diverse backgrounds indicated lower levels of English proficiency and confidence is a significant challenge for some carers and can impact on carers'

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capacity to engage effectively and present their case across the support systems. There was a strong preference to access support through cultural community organisations rather than mainstream organisations. Such organisations are perceived as more understanding and trusted sources.

“Respite for me is having someone from my community back home here to help care for my daughter, so I can continue to work and provide for my family and community as well as contribute to the Australian economy.” – Anonymous CALD carer

Refugee carers raised other challenges. In Victoria, the hidden prevalence of young people with caring responsibilities from refugee and migrant communities was noted in the Centre for **Multicultural Youth’s background paper ‘Who cares,’ highlighting young** carers have unacceptably large caring loads and have low representation when seeking help from support associations (CMY, 2010).

Older carers

Older carers, aged 65 and above, play a crucial role in supporting family members or friends with disabilities, chronic illness or age-related issues. There are an estimated 758,000 carers aged 65 and above (ABS, 2024a). Older carers in Australia face numerous practical challenges related to their caregiving roles, including emotional strain, physical limitations, navigating complex systems as well as **lack of knowledge in digital literacy. Additionally, older carers’ awareness of services such as legal and financial advice, mental health counselling and peer supports may be limited.**

Older carers face the additional issue of who will provide care for the person they are supporting when they are no longer able to. Help is needed to plan the future support of their care recipient. Consultations with older carers revealed a need for additional support for transitioning care, particularly when moving from home-based care to residential care which can be challenging for both the carer and the person they are caring for. This includes not only the direct supports they provide but also the other caring responsibilities such as managing service systems and doing the necessary paperwork and planning for essential supports.

Carers also noted the need for ongoing training and updating of skills as the needs of care recipients **change and specifically, as carers’ physical abilities change as they age.**

*“I’d like to know how to use technology and get more organised, so things work better for me.”
– Anonymous older carer*

Participants at consultations offered insights into programs and initiatives they found valuable, for example intergenerational knowledge sharing. Older carers also reported that their knowledge of supports, services and advocacy organisations often come from each other through peer support avenues.

Carers with disability

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Of the 3 million carers in Australia, almost two in five (39%) had disability and young people with disability were far more likely to be carers than young people without disability. Carers with disability or chronic health conditions report a lack of appropriate, accessible and timely services. This makes it hard to meet their own health-care needs. Many struggle with arranging support across mainstream, Aged Care and NDIS on behalf of the person they care for and for themselves.

"I am a deaf carer who cares for my ageing parents. As a part of my role as a carer I support my parents to access medical appointments. My needs as an NDIS participant are covered such as interpreter when I need it. But If I need to attend an appointment with my parents, I can't access an interpreter when I need to support my parents." – Anonymous carer with disability

Defence family and veterans' carers

The very nature of service in the Australian Defence Force (ADF) can mean that service personnel have a greater likelihood of developing physical and mental health conditions compared to the general community. According to the 2021 Census, one in twenty (5.3%) Australian households (dwellings) had at least one person who had served in the ADF (that is, at least one person who was either currently serving or had previously served in the ADF). The Census found that among the 496,300 people who had previously served in the ADF aged 15 years and over, 13% needed assistance with the core activities of self-care, mobility or communication. Three in five (60%) previous service members had a long-term health condition (ABS 2022).

SDAC data shows that 4.4% of primary carers had, themselves, served in the ADF (ABS, 2024a). Alongside other cohorts of carers, the data regarding defence family carers and carers of veterans is likely under-represented.

Carers may be supporting a veteran, or they may be caring for other family members whilst they or their partner is still employed in the ADF. The number of men who are becoming carers of veterans is also increasing as the number of women serving in the ADF increases. [The Royal Commission into Defence and Veteran Suicide](#) (Royal Commission) considered the impact of service on defence personnel and their families. It aptly noted that when one person joins, the whole family serves. In consultations, we heard from carers a range of unique challenges including the complexity of navigating the various support systems associated with defence veterans and impacts accessing or continuing support because of postings.

"Carers are the primary support, advocate and enabler for their care recipient." - Anonymous carer for a veteran

Defence family carers are dealing with the impacts of separation due to unaccompanied postings or deployments and disruption to work and career due to caring. They navigate relocation impacts to education, services, care resources and support networks for themselves and their families when they do accompany a posting with their serving family member.

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The support role of families and carers extends long after a person transitions from defence service. Veterans often have complex physical and mental health needs. The Royal Commission noted in its final report, that in the context of complex rehabilitation, support included family members attending appointments, participating in rehabilitation planning, remaining in contact with medical or rehabilitation professionals and actively participating in member rehabilitation exercises. Other forms of family involvement **included practical care, emotional support and maintaining the member's** social, domestic and family life. Family members could become socially isolated due to anxiety about stigma and the pressures of the carer role (2024).

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Appendices

Appendix 1: Help and support

Please be aware that this document contains information that may be distressing to readers. It **includes information about the experiences of Australia's carers and the challenges they face**. If you need support to deal with difficult feelings after reading this paper, there are free services available to help you.

Carer Gateway

- Telephone 1800 422 737, Monday to Friday, 8am to 5pm for support and services.
- Visit [Carer Gateway](#)

Beyond Blue Support Service

- Telephone 1300 224 636, 24 hours, 7 days a week or chat online 3pm to 12am AEST, 7 days a week or visit [Beyond Blue](#)

Lifeline Crisis Support

- Provides support if you are feeling overwhelmed, having difficulty coping or thinking about suicide.
- Speak to a crisis support worker by telephone on 13 11 14, 24 hours, 7 days a week.
- Text 0477 13 11 14 or chat online for support, 24/7. Or visit [Lifeline Crisis Support](#).

1800RESPECT

- For support if you are affected by sexual assault or domestic and family violence or abuse.
- Telephone 1800 737 732, 24 hours a day, 7 days a week, chat online 24 hours a day, 7 days a week or visit [1800RESPECT](#)

13YARN

- First Nations service providing culturally safe crisis support. Call 13 92 76, 24 hours a day, 7 days a week or visit [13YARN](#)

QLife

- QLife provides anonymous and free LGBTQIA+ peer support and referral for people in Australia.
- Call 1800 184 527, open 3pm to midnight, every day or visit [QLife - Support and Referrals](#)

Open Arms Veterans and Family Counselling

- As a carer of a veteran, or a veteran who is a carer, you can contact Open Arms to find out what support and services are available for you or your loved ones.
- Call on 1800 011 046 or visit [Open Arms - Veterans & Families Counselling](#)

eheadspace

- eheadspace is a national online and phone support service for young people between 12 and 25. Available 9am – 1pm AEST every day.
- Call 1800 650 890 or visit [Online & phone support | headspace](#)

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Appendix 2: Evidence summary

From April to September 2024, a consultation campaign was undertaken to better understand perspectives of as broad range of carers and other stakeholders as possible about how the Strategy can have the strongest positive impact on the lives of carers. The voices and experiences of carers across the country was critical in the development of the Strategy. Over the 6-month consultation campaign over 100 activities were held, including in-person, online and by telephone. Through these consultations in every state and territory including metropolitan, regional, and remote areas we met and heard from over 1900 carers. Over 700 submissions were received in response to an online discussion paper and questionnaire.

Full consultation reports are available at [National Carer Strategy | engage.dss.gov.au](https://engage.dss.gov.au)

Other evidence used to develop priorities and drive change for carers

Outcomes of these consultations built on an evidence base gathered from previous consultation activities such as the Carer Wellbeing Survey, the House of Representatives Standing Committee on Social Policy and Legal Affairs Inquiry into the recognition of unpaid carers submissions and final report, consultation outcomes from other relevant government processes and previous scoping research conducted in preparation for the development of the Strategy.

The Department of Social Services commissioned AIFS to undertake a scoping literature review of the current evidence base on unpaid carers in Australia. This included who are carers, how are they faring, and the supports available to them and how effective (or not) they are.

Key findings:

- There is relatively good data on unpaid carers and the care they provide. However, the definition of a carer in some key data sets is more restrictive than in the *Carer Recognition Act 2010 (Cwth)*.
- Evidence shows that unpaid carers generally experience poorer wellbeing, income, employment and education outcomes relative to their non-carer peers, and these effects tend to be worse the greater level of caregiving.
- Evidence on what works to support carers is very scant.
- Progress has been slow in addressing the known deficiencies and gaps in the unpaid carer support system. Many of the issues are systemic.

Building the evidence base for the Strategy is available at: [National Carer Strategy | engage.dss.gov.au](https://engage.dss.gov.au)

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Appendix 3: Glossary

These definitions are provided specifically for the Draft Carer Strategy. They are not comprehensive, and variations may be found in literature and across various jurisdictions.

Term	Description
Awareness Raising	Aims to increase community and individual awareness of the vital role carers play in the communities, highlighting the challenges they face and the importance of supporting them through accessible resources and recognition.
Carer Gateway	Carer Gateway is an Australian Government program providing free services and support for carers. It can help if family member or friend with disability, a medical condition, mental illness, or who is frail due to age.
Consultation	the action or process of formally consulting or discussing
Carer - Centred	A carer-centred approach means a policy or program will emphasize individual care, ensuring that services are tailored to the specific needs and preferences of each person. It promotes dignity, autonomy, and holistic well-being, while supporting carers with the necessary resources and training to deliver respectful and effective care.
Community-led	A community-led approach for carers means involving carers directly in the planning, delivery, and evaluation of services and support system that impact them. Their insights and experiences guide decision making to ensure that the solution provided meet their real needs.
Evidence-based	Evidence-based refers to a decision-making process that relies on the best available data and research to shape and implement policies. It involves systematically collecting, analysing, and applying evidence to ensure policies are effective, efficient, and grounded in information.
Empowered	Empowered means allowing carers to make decisions and take actions within specific guidelines to improve care and support, enhancing their ability to respond effectively.
Gender Equality	Gender equality for carers means ensuring that all carers, regardless of gender, have equal access to support, opportunities, and resources. It aims to address and remove gendered barriers that may lead to unequal treatment or outcomes.
Inclusive	Inclusive approach for all cares by ensuring equal access to resources, support, and opportunities. It outlines how to accommodate diverse needs and backgrounds, fostering an environment where every carer can thrive and contribute effectively.
Inquiry	This establishes guidelines for managing inquiries within the organisation. It defines the process for submitting, tracking, and responding to inquiries to ensure time and accurately handling. It

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	specifies responsibilities, response times, and communication methods to maintain transparency and efficiency.
Intersectionality	<p>The interconnected nature of social categorizations such as race, class, and gender as they apply to a given individual or group, regarded as creating overlapping and interdependent systems of discrimination or disadvantage:</p> <p>"Through an awareness of intersectionality, we can better acknowledge and ground the differences among us"</p>
LGBTQIA+	Refers to lesbian, gay, bisexual, transgender, queer, intersex, asexual, and other sexually or gender diverse people.
Recognition	This outlines how the organisation will acknowledge and reward the contributions and achievements of individuals. It defines criteria and processes for recognising and efforts, aiming to motivate and appreciate those who make significant contributions.
Respite Care	Respite care provides temporary relief, allowing carers a break to rest, manage stress, or attend to personal tasks.
Unique needs	This addresses the specific needs of individual carers by recognising and accommodating the unique requirements. It outlines how to identify and address these needs to ensure effective support and care delivery. It aims to tailor assistance to each carer's circumstances, enhancing their ability to provide quality care.
Wellbeing	To support physical, mental, and emotional well-being of carers. Helps carer maintain a healthy balance between their caregiving responsibilities and personal life, aiming to reduce stress and enhance overall quality of life.

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