



**Carers Australia submission to the Department  
of Social Services on the National Carer  
Strategy Discussion Paper**

**SEPTEMBER 2024**

**AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS**

## About Carers Australia

Carers Australia is the national peak body representing the diversity of the three million<sup>1</sup> Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail aged.

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

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.

Our carers are diverse and include those who:

- have their own care needs
- are in multiple care relationships
- have employment and/or education commitments
- are under 25 years (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 rural and remote Australia,
- are former carers (no longer in a caring role), and
- have a disability.

### 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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<sup>1</sup> [Carer's Australia - About Carers - Who is a Carer](#)

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## Introduction

Carers Australia appreciates the opportunity to provide feedback to the Department of Social Services (DSS) in response to the National Carer Strategy Discussion Paper.

Carers Australia supports the efforts made by the Federal Government to ensure a diverse range of carers' lived experience is reflected in the National Carer Strategy. The National Carer Strategy is an opportunity for government to drive meaningful change reforms that will improve the lives of carers. The National Carer Strategy is also an opportunity to engender better identification, recognition and value of carers, and facilitates coordination of policies across Commonwealth portfolios.

Carers Australia endorses the submissions from the National Carer Network; the state and territory peak carer organisations who represent and advocate for carers within their jurisdictions, as well as for carers nationally:

Carers ACT	Carers NT
Carers NSW	Carers Queensland
Carers SA	Carers Tasmania
Carers Victoria	Carers WA

During July and August, Carers Australia organised a range of consultations, with a diverse range of carers (498 in total) across 55 different sessions and locations. Carers Australia has published 8 reports that include dozens of reflections by carers, both challenges and proposed solutions for consideration by government, and for inclusion in the National Carers Strategy. These reports can be reviewed at [Carers Australia - National Carers Strategy](#). This submission is informed by those findings, together with the National Carer Wellbeing Survey (Carers Australia), the National Carer Survey (Carers NSW) and the Survey of Disability, Ageing and Carers (ABS).

Carers Australia endorses the United Nations Universal Declaration of Human Rights and how this relates to carers, including the right to rest and leisure and to participate in the cultural life of community (Articles 24 and 27 –[United Nations Universal Declaration of Human Rights](#))<sup>2</sup>.

For the purposes of this submission, the term 'carer' is defined as per the meaning under the [Carer Recognition Act 2010 \(Cth\)](#)<sup>3</sup>, meaning that a carer is an individual who provides personal care, support and assistance to another individual who is living with a disability, medical condition (including a terminal or chronic illness), mental illness, or who is frail and aged. Carer's Australia also recognises carers supporting those living with addiction. An individual is not a carer if the care, support or assistance provided is under a contract or services or for provision of services, is in the course of voluntary work for a charitable, welfare or community organisation, or is provided as part of an education or training course.

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<sup>2</sup> United Nations Universal Declaration of Human Rights

<sup>3</sup> Carer Recognition Act 2010 (Cth)

## Responses to the discussion paper questions

### Question 1

*What principles to you think should be in the National Carer Strategy?*

The Strategy's Principles provide a starting point for action on better policies. In the context of the Strategy, the Principles can be used to guide how Australian Government departments and agencies will implement the Strategy. The Principles can also be used by people and organisations outside government.

#### **Proposed principles for the strategy:**

1. **Valued:** the role and contributions of carers will be identified, recognised and valued.
2. **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.
3. **Evidence-informed:** carer policies, supports and services will be informed by evidence, noting that at times, innovation will be required to solve previously unsolved challenges for carers.
4. **Accessible, equitable and inclusive:** carer policies, supports and services will be tailored to respond to the diverse needs of all carers, at all stages of caring.
5. **Supporting agency:** the design of policies, supports and services for carers will enable carers to make choices that suit them, and will not unintentionally constrain carers' choices.
6. **Transparency and accountability:** Federal Government Departments will be transparent on their processes to better recognise and value carers and will report on their progress.

Further, the Strategy should have a clear time frame described in the document. Carers Australia proposes 5 years with review dates at 3 and 5 years.

#### ➤ **Proposed actions:**

1. *An external body be created, that includes lived experience and carer peak body representation, to oversee the review of the strategy and progress against it.*
2. *Federal Government departments to report annually on progress against the shared actions such as harmonising the term 'carer' per the Carer Recognition act, and undertake awareness campaigns to department staff and stakeholders.*

## Question 2

What does the caring role involve or look like for carers?

Every carer's journey and experience is unique although many carers experience similar challenges no matter their age, stage of caring or geographic location. Essentially carers want to see better systems in place to ensure they can maintain their own mental health and wellbeing and to ensure financial parity. This can be delivered by government (across several portfolios) in a variety of ways from better carer recognition, better system navigation, better respite options thorough to support for cars to have financial parity.

Carers Australia was engaged by the Department of Social Services (DSS) to assist the department by gathering data, insights and lived experience narratives through coordinated consultation with a diverse range of carers to inform the design of the 2024 National Carers Strategy.

During July and August, Carers Australia organised a range of consultations, with a diverse range of carers (498 in total) across 55 different sessions and locations. Carers Australia has published eight reports that include dozens of reflections by carers, both challenges and proposed solutions for consideration by government, and for inclusion in the National Carers Strategy. These reports can be reviewed at [Carers Australia - National Carers Strategy](#).

## Question 3

*What additional supports and/or skills do carers need or like to develop to assist or support them in their caring role?*

Carers Australia strongly advocates that the focus of the National Carer Strategy should be on carer wellbeing and ensuring the strategy narrative doesn't tip towards 'making cares better carers'.

Improving carer wellbeing in turn allows carers, mentally, physically and financially, to be able to better support themselves and the person they care for. Carer recognition, mental health support, information at point of diagnosis, interoperability between government systems, better system navigation, respite, and flexibility in paid employment are all examples of where the lives of carers can be improved.

Some of this can be delivered via direct support to carers for example IT support, manual lifting training, counselling services whilst others fall to government to deliver such as better system navigation and interoperability, and increased and more flexible respite options.

It is also important that the Strategy includes support and skills training for former carers as they move into a new phase of recovering their own wellbeing, consider re-entering the workforce, or may find themselves in financial duress (government payment changes, loss of social housing – all discussed below).

As to skills, these will often depend to a large extent on the condition of the person being cared for. Some condition-specific organisations, such as Dementia Australia, CarerHelp for

palliative care and Aspect which specialises in autism, do offer skills training. However, this is far from par for the course for other conditions.

➤ **Proposed actions**

3. *Future planning information for carers available via a centralised support for all carers such as the National Carer Network.*
4. *Capability building resources such as learning or signposting to existing learning.*
5. *Education and resources to support carers returning to the workforce.*

## Question 4

*Do carers know what supports or services are available to support them in their caring role?*

Many carers do not know about what supports or services are available to themselves as carers or for the person being cared for, especially at the beginning of their journey.

Many carers informed us that it was months or even many years before they found out about some support options, often through haphazard encounters with other people or peer support groups.

This experience was universal, and identified across all age groups, all cultural and ethnic backgrounds, and regardless of where carers lived. However, some carers struggled more than others. For example, culturally and linguistically diverse ('CALD') carers informed us that they struggled to find support and services, especially culturally appropriate ones. Sometimes carers didn't self-identify as a carer, as caring responsibilities were considered an assumed part of their culture, and other times there can be stigma associated with accessing services and supports.

This highlights the need for government, service providers, community groups and non-profit organisations to have better targeted, cohort specific campaigns for carers including CALD carers, LGBTIQ+ carers, carers with a disability, young carers, carers with lower digital literacy and First Nations carers.

Despite some challenges unique to these cohorts, there are common solutions and improvements that carers have identified, described in the proposed actions.

➤ **Proposed actions:**

6. *A program to encourage health professionals to identify a carer at the point of diagnosis and refer carers to a central point to navigate supports. Carers want information provided at the point of diagnosis by health care practitioners. This includes carer specific information such as where to find carer supports, for example, referral to the Carer Gateway.*
  - a. *Carers particularly want and need the identification of local services.*
  - b. *Delivery of information needs to be location specific, culturally, socially and age appropriate.*



7. *An awareness campaign and training to Federal Government departments to encourage cross referral of carers to the right supports.*
8. *Carer concierge: a central signposting service to help carers navigate complex government systems. Many carers want a single point of entry into the navigation of government systems.*
  - a. *Many carers can find themselves navigating Centrelink, NDIS, and My Aged Carer simultaneously, whilst also trying to navigate multiple providers. Carers valued the concept of having a single point of contact to assist them, such as the National Carer Network, and many noted the impact of system navigation on their own mental health and wellbeing.*

Throughout its consultations, Carers Australia notes that carers also recognised the value of peer support. Whilst peer support is not a substitute for the above actions, many carers value the support and learnings from peer support groups and networks. Many carers do not hear about these groups until they are well into their caring journey, supporting action 7.

## Question 5

*If carers have accessed these services, what has worked for them or and where have they experienced challenges?*

Key areas of concern for carers relating to carer services are:

- system navigation/interoperability; currently it is confusing and time consuming
- respite care options that are currently inflexible and prescriptive, challenging for those in geographically isolated regions, options that aren't always culturally appropriate (CALD, LGBTIQ+), and there is a lack of emergency respite
- carer recognition by health care professionals, paid support workers, within communities (e.g. small towns for cultural groups)
- poor quality and reliability of paid support services; carers citing needing to train paid support workers and described the impact on them when there are provider cancellations, and
- financial parity; is impacted through accessing services including support for medical travel expenses or the cost of assessments through to the ability to purchase a laptop to manage care arrangements

The time lag between identifying a service/assessment through to its approval, then the time subsequently taken to engage a provider is another big concern for carers. Following this process there can be significant time lags in service delivery, assuming there are local services at all. This is a common concern with the provision of respite.

### ➤ **Proposed actions:**

9. *Reform policies, funding contracts, and service provision guidelines to enable carer-driven, innovative respite care options that are consistent across federal systems, offering flexible, culturally appropriate, and peer-informed supports*

10. *Minimum standards of education provided to paid support workers including culturally appropriate care training.*
11. *Training standards and audit of standards for paid support workers' service provision.*
12. *Consultation with paid support worker employers and businesses to drive carers' needs recognition.*
13. *Measure the effectiveness of the Carer Gateway including underspends and thin markets for services provision.*
14. *Clarify objectives for Gateway services to ensure alignment with the National Carer Strategy.*

## Question 6

*We are aware that some carers feel they cannot leave their loved one with others due to the complexity of the care required. What has prevented them from accessing respite and what additional support might relieve their hesitancy to access respite in the future?*

And

## Question 7

*What appropriate alternative carer arrangements have they identified?*

As questions 6 and 7 are interlinked they are answered together.

There are many barriers to a carer accessing respite care, including the person needing care being reluctant or refusing, a fear of placing someone into a new environment (like residential care), general sentiment that service provider staff are untrained and lack empathy (for in home short and long term respite), lack of culturally appropriate care, respite 'deserts' where there are few, if any, respite options available (especially in geographically isolated locations – see questions 11 and 18), lack of flexible respite options in particular emergency respite, and long wait times with subsequent short time frames to accept and prepare for respite opportunities.

Carers often have little choice other than to rely on informal support networks for respite, this can also be fraught with challenges with family/friends/community being volunteers, inexperienced in the care needs, or unable to assist as required due to other commitments. Whilst informal care, like peer support, is valued, it should not be considered a suitable substitute for paid respite care.

Carers identified several solutions and improvements – depending on the type of respite being referred to, a list of solutions is below.

- In-home respite: often this is regular, and for only a few hours to allow the carer time to have a break, socialise etc (sadly however this time is often spent on other related caring responsibilities). Carers have identified that they would be more comfortable with this if they thought paid carers have better training in both delivering care and in

empathy/emotional intelligence, and if support was culturally appropriate. These improvements would also assist with longer in-home support options.

- Trust building/ introduction to respite facilities including community and residential care; it is hard for both the carer and care recipient to feel confident and comfortable entering a respite care option that they have not experienced before. The provision of opportunities to engage with a facility beforehand would assist in overcoming fears and anxiety. For example, an opportunity to join a residential facility for lunch or activities beforehand may be a gentler introduction than the first introduction being for several days or weeks.
- Emergency respite: carers want to know they can access emergency respite when they need it. Many carers have not been able to attend to their own health/wellbeing, or work or other commitments due to a lack of access to flexible-, short-, medium- and long-term emergency respite. This is felt acutely in regional and remote areas of Australia.
- Some carers shared their experience of respite options where they are with the person they care for, for example a dementia retreat where the person living with dementia is also with them. This newer type of respite has received positive feedback and should be further explored as an option they may be preferable for some (not all) carers.

See actions 9, 10, 11 and 12.

## Questions 8

*What carer-inclusive practices could benefit carers' engagement with their workplace or education institution?*

Carers want more respectful, inclusive and flexible workplaces, dedicated carers' leave so they do not have to exhaust their own personal leave allocation (personal and annual leave), and better data capture on carers in the workplace to identify carers who may need flexibility and support.

Carers who had given up work to care, often for many years, wanted assistance to re-enter the workforce. Such assistance might include re-training, additional help with job applications and training on job interview technique, and identification of employment opportunities including those in areas where their caring journey was recognised and included in recognition of prior learning. The additional assistance needed should be considered when seeking work through Workforce Australia. Another suggestion was an employment agency for carers.

### ➤ **Proposed actions:**

15. *Continue and expand existing programs that promote carer inclusive and flexible workplaces. Carers cited the need to accommodate care responsibilities that many occur during regular business hours, the need for absences, and the need for short notice/ emergency leave as care responsibilities require.*
16. *Advocate to Fair Work for an additional week of leave for carers, that is not conflated with personal leave. Carers don't want to require a medical certificate each and every time they take leave as a carer to care for the person they care for. Where some kind of nationally identifying card or proof of care can be supplied annually,*

*this removes an expense and burden of proof to keep demonstrating the caring role. The average length of a caring role is 11.5 years.*

17. *Create payroll tax incentives for employers who are carer inclusive workplaces.*

18. *Recognition of carers' experience counts towards recognition of prior learning.*

## Question 9

*What types of assistance are available to you in your education setting, or in the workplace that you find helpful?*

School aged young carers told us that they received very little compassion, understanding, trust or support from teachers when caring impacted school attendance and delivery of school work within mandated timeframes. School aged carers discussed social isolation due to lost opportunities to participate in school friendships, such as missing lunch breaks to catch up on homework instead of socialising or how caring responsibilities precluded the opportunity to participate in outside school activities or friendships.

Further, the family's drained finances and caring responsibilities often prevented opportunities to participate in educational excursions.

Young carers also cited the guilt associated with taking time to participate in paid employment or further education that negatively impacted their social networks leading to feelings of isolation.

Young carers identified a range of solutions that have either been used by them or they believe would ameliorate this situation:

- Teacher training to include young carer education; understanding what a young carer is, how their caring role may impact them at school and outside of school, and how teachers can support the carer.
- An enrolment process where young carer can to self-identify to then be assisted in balancing their carer role and schooling.
- Personalised learning plans that consider the uncertain nature of caring which makes it difficult to keep to pre-ordained schedules required of students. This can also include recognition of their role as carer and relinquish the requirement for medical certificate (within reason).
- Peer support group for young carers.
- School community education so that their peers better understand their circumstances.

### ➤ **Proposed actions:**

19. *Education department(s) to recognise students who are carers at enrolment, so as to better support young carers throughout their education.*

20. *An awareness campaign to educationalists to further the identification, recognition and value of young carers.*

## 21. Peer supports for young carers.

### Question 10

*How can we best support carers to stay in or re-enter the workforce or education system?*

#### **Re-entering the workforce**

Carers often want to remain in the paid workforce for many reasons including self-worth, social engagement, career satisfaction and financial. Many carers have left their paid employment, reduced their hours or changed profession/vocation (e.g. teachers and chefs) due to inflexible working arrangements, employer pressure or the time commitment required for their caring role.

Carers have identified they could continue in the workplace and therefore contribute to the broader economy and their own financial security if there:

- was better understanding from employers and fellow employees of their situation
- was specific provision of dedicated carer leave
- were better opportunities to flexible working arrangements (where possible)
- were additional supports for carers wanting to re-enter the workforce after an extended absence

#### ➤ **Proposed actions:**

22. *Create education and resources to support carers returning to the workforce.*
23. *Provide targeted tax breaks to encourage carers to return to work.*
24. *Offer return to work incentives such as the Work Bonus, to encourage carers to return to paid employment where they are able to.*

#### **Remaining or re-entering education**

School age carers proposed alternate models to traditional schooling, to assist them stay/re-enter the education system, this included:

#### ➤ **Proposed actions:**

25. *Allow young carers to undertake school certificate or higher school certificate via TAFE*
26. *Facilitate online and hybrid models of schooling where students could access classes both in person and online, accommodating the flexibility young carers need around their caring responsibilities.*
27. *Offer an interest free pause on HECS/ HELP debts for carers while they pause studies to undertake caring duties.*

## Question 11

*What are the top three challenges carers face?*

Caring is a constrained choice and each person is impacted different ways by their unique journey. It is almost impossible to narrow carers' issues to a top three. Carers Australia would like to highlight four issues for carers that are expanded upon below. We also note that many solutions to these issues have been discussed through this submission.

1. **Mental ill health;** results from the [Caring for others and yourself:2022 Carer Wellbeing Survey \(Survey<sup>7</sup>\)](#); identified that carers are 2.5 times more likely to have low wellbeing and are twice as likely to experience psychological distress compared to the rest of Australia. The factors that contribute to this include:
  - a. difficulties navigating complex government support systems (subsequently including provider navigation)
  - b. lack of flexible and emergency respite options
  - c. social isolation due to time spent on caring responsibilities, and the condition of the person being cared resulting in former friends, acquaintances, the community and some family members feeling uncomfortable and withdrawing contact, and financial barriers to participation
  - d. reduced physical health as carers often prioritise the person the over their own health
  - e. anxiety and sadness due to their connection and concern for the person/s they care for
2. **Lack of available, flexible, appropriate and tailored respite;** lack of appropriate respite options was an issue across all the National Carer Consultations. This submission has already discussed the challenges and proposed solutions.

However, there are some caring cohorts that require extra consideration that haven't specifically been addressed above. This includes mental ill health carers, dementia carers, serving ADF members with caring responsibilities and carers of veterans. These carers often experience additional carer responsibilities and challenges, including the need to respond to unexpected and emergency mental ill health and cognitive challenges, potential exposure to physical harm, and societal stigma on conditions like dementia and PTSD.

3. **Navigation of overwhelmingly complex systems;** this has been discussed throughout this submission. The complexity of system navigation, a lack of knowledge about what services and support are available and the time lag for appointments and decisions from 'the system', adds stress and anxiety to the carer and also involves many additional hours of their time.
4. **Lack of financial parity with other non-carers in Australia;** 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 income<sup>9</sup>. Carers not on payments can also struggle with their financial wellbeing and security. There are a range of financial impacts that can impact financial parity:

- a. lack of Superannuation accumulation whilst on carer payments
  - b. caring responsibilities impacting ability to participate fully, or at all within the workforce
  - c. unconscious and conscious bias impacting career progression due to caring responsibilities
  - d. additional costs associated with the provision of care, or for travel/accommodation to appointments especially for those in regional and remote locations
  - e. additional costs associated with the side effects of prescribed medications, for example constipation
  - f. wait time between assessments and access to services leaving the carer to cover the shortfall for provision of care
  - g. housing insecurity
    - a. due to lower income impacting loan options, mortgage repayments or rental tenant suitability
    - b. potential loss of access to social housing if this is linked to the person being cared for and they transition into group housing, residential care or pass away
  - h. sudden loss of payments when no longer a carer, often leaving a gap between government support options while assessment are undertaken by Centrelink
5. **Former carers:** Carers Australia also note that former carers need to be included in the National Carer Strategy and any resulting actions. Former carers need assistance to recover their own wellbeing (physical and mental), to transition back into the workforce or alternate government support and for housing security where applicable.

➤ **Proposed actions:**

- 28. *Create a nationally recognised carer passport (that includes the carer's situation and caring role) and/ or carer ID card (that proves the carer has caring responsibilities per the Act). This streamlines the burden of administration and trauma for carers who constantly have to prove they are a carer or re-explain their situation to a multitude of stakeholders.*
- 29. *GP welfare checks for carers at the end of their caring roles. The check could be triggered by the person they cared for dying or recovering.*
- 30. *Pay superannuation on the Carer Payment to help recover financial parity for carers.*
- 31. *Work to reduce assessment costs and wait times. For example, carers pay less for the assessments required access supports for themselves and the person they care for, to reduce the stress of caring and access to the supports needed.*
- 32. *Increase the Carer Payment and Carer Allowance to better meet the rising costs of caring.*
- 33. *DSS to collect better data on carers and housing issues/ homelessness.*

All other actions in this submission address the issues cited above.

## Question 12

*What are the biggest opportunities to improve the lives of carers and the people they are supporting?*

Carers Australia believes that identifying, recognising and valuing carers is central to all other focuses of the strategy. If carers cannot be identified, including self-identification, and where carers aren't recognised across Commonwealth portfolios, organisations, educational institutions and communities, all other actions recommended in the National Carer Strategy will fail.

Self-identification and recognition are complex; carers don't always identify with the word carer, others simply don't identify the role they take on as a carer or take years to realise how to describe the responsibility they have, how it impacts their lives and subsequently seek supports.

Further, access to formal supports and services can't be provided where a carer isn't identified and recognised. For example, access to the Carer Payment can only be granted where a carer identifies their status then subsequently proves their caring responsibility, or additional carers leave might only be offered in a workplace where the carer's status is known.

Identity and recognition are therefore essential to delivering supports and services to carers.

### ➤ **Proposed actions:**

34. *Education campaign to health and medical professionals and paid support workers, to build understanding and recognition of carers, so that carers can be identified early in their caring journey and referred to supports and information.*
35. *DSS to work with other federal Government departments to try and harmonise the term carer, to support recognition of carers, enabling earlier identification and interventions to prevent carer distress and burnout.*
36. *DSS to work with State and Territory governments to harmonise the term carer to exclude parenting proxies, reducing identity confusion, and enabling earlier identification and early interventions to prevent carer distress and burnout.*

The National Carers Strategy needs to genuinely focus on improving the lives of carers by improving their physical, mental, social and financial wellbeing. This starts with identifying, recognising and valuing carers.

## Question 13

*What do carers find beneficial about peer support and what have they identified as areas for improvement?*

Carers and former carers place a high value on peer support. It helps carers address their loneliness and provides the opportunity to share common concerns in a safe space. It was also considered by many carers as an excellent source of advice. Peer support is frequently the first time some carers find out information about services and support. Carers identified that peer



groups need to be inclusive, and/or specific to particular carer cohorts if they are to be beneficial to all carers.

➤ **Proposed actions:**

37. *Ensure peer support groups can be inclusive of diverse groups of carers, including being respectful of all cultures, sexualities and genders, and are supportive of people where English is not a first language*
38. *Ensure that carers living in regional, rural and remote locations have access to peer support groups, noting these carers value in person engagement where possible*
39. *Ensure that former carers have access to peer support networks, which may include ongoing participation in care groups and mentoring opportunities*

## Question 14

*How would carers like their experiences reflected in the Strategy?*

The 498 carers who participated in the round of consultations organised by Carers Australia devoted considerable time and effort to participate in these consultations, including finding the time and alternative carer arrangements to enable them to do so. They did so in expectation that they would be heard both in terms of the challenges they face and the solutions they proposed – which can't all be reduced to three top priorities.

➤ **Proposed actions:**

40. *Future DSS policy design and creation to be undertaken in collaboration with lived experience carers.*

## Question 15

*If carers belong to a diverse group, what opportunities do they see for the Strategy to improve access to supports and information within their communities?*

Carers Australia believes more investment needs to be made by government to ensure inclusivity for all carers. We have interpreted the word “diversity” in this question to go beyond cultural or gender diversity to embrace other cohorts of carers with particular needs. We also think that further investigation into the lived experience of these cohorts would benefit the development of the Strategy including LGBTIQ+, CALD, geographically isolated, young carers and First Nations carers. With the Priority Reforms to Closing the Gap<sup>10</sup>, DSS should be ensuring there is genuine co-design with First Nation carers on how the Strategy can support them.

**CALD carers** potentially face additional challenges due to cultural norms, language and stigma.

➤ **Proposed actions:**

41. *Culturally and linguistically inclusive information*
42. *Culturally and linguistically inclusive respite and service provider care*

43. *Education within CALD communities to reduce stigma associated with some health conditions and caring responsibilities*

**Young carers** need additional layers of support as they often feel the impacts of social isolation greater than other cohorts and their caring role early in their lives impacts social development, education and future earnings. In addition to action identified earlier for young carers.

➤ **Proposed actions:**

- 44. *Community education on the role of young carers*
- 45. *Health and service provider education on the role of young carers*
- 46. *Employer education on supporting young carer employment*

**Dementia carers** often cite that the stigma of dementia and lack of community understanding of dementia behaviours can lead to the loss social and community interaction and engagement. This can then become a self-perpetuating downward spiral for the dementia carer and person living with dementia.

➤ **Proposed actions:**

- 47. *Community education to promote better understanding and compassion for people living with dementia.*

**Veteran carers** can be supporting a person with complex issues and combinations of physical and mental ill health issues. Veteran carers identified several ways they can be better supported by the Australian Defence Force, Department of Veteran Affairs and within the ADF community. **ADF families** can be providing support for a person with their family who is not the serving member, and face carer challenges imposed by the serving members posting cycle.

➤ **Proposed actions:**

- 48. *A dedicate Veterans Home Care Package*
- 49. *Better recognition by DVA of carers when they are supporting a veteran*
- 50. *Better workplace flexibility and post cycle considerations for those caring for veterans or other family members. These families want earlier notification of posting decision, support navigating new jurisdictional systems and to not continually to 'drop' to the bottom of health care wait lists because of postings.*

**Former carers** are a cohort that has been poorly considered by government, peer support groups, health care professions and non-profit organisations. Many actions to support former carers have been identified above.

➤ **Proposed actions:**

- 51. *Access to bereavement and other health care support via the Carer gateway for a dedicated period of time post the cessation of the caring role.*
- 52. *Establish dedicated, peer support networks.*
- 53. *Support to re-enter the workforce, including recognition of carer skills and a dedicated employment provider specialising in supporting carers. See actions 24 – 26.*

## Question 16

*What are some priorities that might assist or improve the experiences of carers within their community?*

One of the most important priorities for improving carer experiences in the community is much better carer recognition, inclusion and respect. Many actions have already been proposed under questions 8 -13 and 15 and will not be duplicated here.

Many carers throughout the National Carer Consultations suggested and supported government funded campaigns to better educate the Australian public, carers also called for specific campaigns to target subsections within the community – including campaigns to support CALD carers, dementia carers and young carers.

➤ **Proposed actions:**

*54. Fund a campaign to create better awareness of carers in the community. Includes carer stories showing the diversity of carers and care relationships:*

- a. Encourage Australians to better understand the circumstances and value of carers. It should not just be a “one size fits all” campaign. It should be segmented to highlight carers in all their diversity, including different demographics and the different nature of caring for people with different conditions.*
- b. The campaign should also help hidden carers to identify as carers and the supports available to them.*
- c. A separate but related campaign should make Australians aware of aged care support, disability support, mental health support, dementia support, palliative care support and other relevant conditions.*

## Question 17

*Do you have any views on how the assessment process for carer payments in the social security system is working?*

Many carers found the process of applying for the Carer Payment and Carer Allowance daunting, noting some of the following challenges:

- long wait times on the phone to reach a customer service representative
- inconsistent information provided on different calls by different staff
- whilst older carers prefer face-to-face interaction at Centrelink offices (if there is one suitably close by) they are often directed to office computers to deal with their enquiries
- not being informed they could make appointments with a social worker and get financial advice
- difficult application processes, often with repeated paperwork across multiple forms
- long wait times (months) for approval of applications, and

- a number of carers of people on the Aged Pension were not aware they were eligible for the Carer Allowance.

With respect to eligibility assessment, the current Adult Disability Assessment (ADAT) tool was problematic for some carers, especially for those caring for someone with mental health issues and/or episodic conditions which were not well covered in the current tool (Carers Australia acknowledges the ADAT is currently being reviewed).

Some carers struggled with cost of a getting a Treating Health Professional assessment where it involved specialists. Others struggled with their financial assessment requirements.

The actions to address the above issues have been identified in questions 4, 5 and 11.

## Question 18

*Do carers experience any barriers to accessing these emergency support/s due to their role as a carer?*

Carers told us that emergency supports such as respite is almost impossible to access. Most services need to be booked weeks in advance, booked during business hours, assuming there is any availability. Not all carers can call on family or friends to replace them if they experience a personal emergency. Carers' anecdotal evidence illustrates that some carers take the person they care for to hospital with them, when necessary, as no other options were available to the carer.

Further, carers need to plan for emergencies

### ➤ **Proposed actions:**

*55. Many carers wanted a dedicated carer support 24/7 helpline to enable access to services such as emergency respite when it's needed.*

## Question 19

*Issues for carer that weren't addressed in the previous questions.*

### **Language**

The Discussion Paper refers to support workers as 'formal carers'. Paid support workers should not be referred to as 'formal carers' or 'paid carers' as this confuses the role and recognition of carers, thus undermining the objectives within the strategy.

Due to poor self-identification of carers, Carers Australia recommends identifying carers by describing their caring role. For example, rather than 'are you a carer?', Carers Australia recommends, 'Do you provide unpaid care, assistance and support for a family member or friend who is living with a disability, medical condition (including a terminal or chronic illness), mental illness, who is frail and aged or experiencing substance abuse?'

While some carers, and the cared for resent the term ‘carer’. Acknowledging that there is work to do to enable community understanding of the role of carers, and help recognise and value their role, moving away from this term risks losing any recognition already associated with it. A rebrand of carers would distract energy and investment away from uplifting the lives of carers per the National Carer Strategy’s intent. Further:

- Language should not misrepresent the carer role by describing carers as ‘family’ or ‘kin’, as not all family members or kin are carers, and not all carers are family members or kin.
- Language should not misrepresent the carer role through use of already existing terms that have different meanings such as ‘advocate’ or ‘support person’.

The role of the carer becomes invisible if the caring role cannot be identified. Per our comments under question 12; identity and recognition are essential to delivering supports and services to carers.

### **Domestic violence towards carers**

Carers can experience violence and abuse at the hands of those they care for, but this cannot be addressed in the same way as for other women, and has not yet been successfully addressed, leaving female unpaid carers unsafe. We understand that:

Carers who are abused continue to care for the abuser for a number of reasons (Carers ACT 2016):

- there is no alternative care or accommodation
- concern about the wellbeing of the person they care for
- and the stress associated with intervention services

Carer denial, guilt and fear can also contribute to the non-disclosure of abuse (Carers Australia, 2016).

Carers Queensland’s 2015 survey of 571 carers found 26% of participating carers did not feel safe in their caring role and admitted to being abused – physically, financially, emotionally, and/or sexually. Many experienced more than one type of abuse (Carers Queensland, 2015).

Further, current models of managing violent behaviours in people who are cared for, such as those with mental illness, do not acknowledge or recognise the role or rights of unpaid carers. For example, the PACER (Police, Ambulance & Clinician Early Response) model is applied to people with mental illness who commit violent acts, but its model recommends that the cared for is often returned home in response to violent behaviours, meaning that the unpaid carers, mostly women, experience that violence again.

Working for women: a Strategy for Gender Equality's (Department of Prime Minister and Cabinet, 2024) priority actions do not address violence toward female unpaid carers, further illustrating how unpaid carers are overlooked in the design and creation of models and policy affecting them.

➤ **Proposed actions:**

56. *DSS to build better data to understand the unique circumstances of domestic violence towards carers.*

## Carer snapshot

There are 3 million carers in Australia, with approximately 65% caring for someone under the age of 65<sup>4</sup>. Two thirds of primary carers are women, 30% of carers are from multicultural backgrounds<sup>5</sup>, and 12.4% of the Aboriginal and Torres Strait Islander population are carers,<sup>67</sup>. In 2022, 38% of primary carers also identified as living with a disability<sup>8</sup>.

Being a carer is a constrained choice and a significant commitment that impacts many aspects of a carer's life. Results from the [Caring for others and yourself: 2022 Carer Wellbeing Survey \(Survey\)](#); identified approximately 30% of primary carers are providing more than 40 hours of care per week.

The survey identified that compared to other Australians, carers are 2.5 times more likely to have low wellbeing, twice as likely to experience psychological distress, are 2.8 times less likely to have good/excellent health outcomes and are 1.7 times more likely to experience significant financial distress compared to the average Australian. 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 income.

The annual economic value provided by carers has been valued by Deloitte Access Economics at \$77.9 billion per year<sup>9</sup>.

*“So I think it is very important that those in the care system understand that very often we focus a lot of attention on the person who's described as needing the care, but the journey of that person to become in need of care very often brings a bruise on the carer and others involved.”*

**Carer, National Carer Consultations, 2024**

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<sup>4</sup> Carers Australia, Caring for others and yourself, 2022 carer wellbeing survey, 2023

<sup>5</sup> ABS, SDAC, 2022, [CARING FOR YOURSELF AND OTHERS \(carersaustralia.com.au\)](#)

<sup>6</sup> Carers Australia, Aboriginal & Torres Strait Islanders carers, 2024

<sup>7</sup> Carers Australia, Aboriginal & Torres Strait Islander carers, [carersaustralia.com.au/about-carers/aboriginal-torres-strait-islander-carers/](#)

<sup>8</sup> [CARING FOR YOURSELF AND OTHERS \(carersaustralia.com.au\)](#)

<sup>9</sup> (Deloitte Access Economics, 2020)