



**Carers WA**



**Carers WA Policy Submission**  
**National Carer Strategy**  
**September 2024**

## About Carers WA

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Carers WA is the peak body representing the needs and interests of carers in Western Australia and is part of a national network of Carers Associations. Carers provide unpaid care and support to family members and friends with disability, mental health challenges, long term health conditions (including a chronic condition or terminal illness), have an alcohol or drug dependency, or who are frail aged. The person they care for may be a parent, partner, sibling, child, relative, friend or neighbour.

Caring is a significant form of unpaid work in the community and is integral to the maintenance of our aged, disability, health, mental health, and palliative care systems.

Some important facts about carers include:

- There are currently 3.04 million unpaid carers in Australia.
- There are more than 320,000 families and friends in a caring role in Western Australia.
- The replacement value of unpaid care, according to a report undertaken by Deloitte, Access Economics, "The economic value of unpaid care in Australia in 2020" is estimated at \$77.9 billion per annum.

### Acknowledgement of Country

Carers WA acknowledges the Wadjuk Noongar Nation's lands, water, customs, and culture of which the Carers WA Head Office is located. Carers WA recognises our services reach beyond the Perth (Boorlo) region, and so we also acknowledge the cultural diversity of First Nation Peoples across our state and throughout Australia.



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## 2.0 Introduction

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Carers WA (CAWA) appreciates the opportunity to provide feedback to the Department of Social Services in response to its consultation on the National Carer Strategy discussion paper.

CAWA values the efforts made by the Federal Government to ensure carers' voices and their lived experience is strongly represented within the National Carer Strategy. We are also pleased to see strong acknowledgement of the diversity of Australian carers, including (but not limited to) culture, caring experiences, age, gender identity, location, and in the number of people being cared for. Further, CAWA notes the important differentiation which has been made within the discussion paper on the definition of an unpaid carer; difference between an unpaid carer, paid carer and volunteer; and clear collaborative focus on unpaid carers. CAWA is also pleased to see the inclusion within the discussion paper of details on where unpaid carers can get support.

However, whilst CAWA is supportive of the efforts made in the development of the National Carer Strategy thus far, we are keen to ensure that the purpose of the Strategy is realised and that it successfully achieves in practice the vision of what Australia wants to achieve for carers over the next five years. Carers across Western Australia and Australia have invested significant amounts of time and energy to share their feedback and expertise gained through their lived experience, with some carers raising concerns that the prospects the development of the Strategy has placed on the horizon will not be implemented. For carers, the Strategy is representative of hope for change and to be better supported through the significant sacrifices they make every day. This submission is made from this place of hope, for ongoing collaboration and consultation, and an expectation that the National Carer Strategy will bring a much-needed improved quality of life for Australian carers.

This submission has been informed by ongoing feedback from carers, ongoing consultation with WA metropolitan and regional communities, and feedback from four targeted focus group consultations of carers in WA.

For the purposes of this submission, the term 'carer' is defined as per the meaning under the *Carer Recognition Act 2010* (Cth), this being that a carer is an individual who provides personal care, support and assistance to another individual who has disability, a medical condition (including a terminal or chronic illness), a mental illness, or who is frail and aged. 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.<sup>1</sup>

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<sup>1</sup> (Commonwealth of Australia, 2010)

## 3.0 General Feedback

### 3.1 Practical Carer Recognition and Identity

#### 3.1.1 Practical Carer Recognition

*'Recognition sometimes seems like a catch phrase. I find that it has no noticeable impact on my daily carer role to two children with disabilities. Recognition means nothing without action and meaningful support. Too many people find themselves in the role of a full time 24/7 carer at great detriment to themselves. The emotional, social and financial impacts and burden may be acknowledged but it seems to be mostly in the form of "I don't know how you do it". Resources offered via government seem too difficult to access and meet the needs of so few.'* – response from a carer

Inadequate recognition of carers is a common and reoccurring issue, in every setting and industry in which carers are involved. Carers report a lack of carer awareness, identification and recognition; being excluded from discussions of relevance to their caring role; and limited awareness of the significant contributions and sacrifices that carers make. Carers also raise that support is not provided for them to provide adequate care, including health and wellbeing supports, financial support, navigation support, advocacy, education and training.

#### The benefits and meaning of recognition for carers

Where some recognition is given to carers, often this is restricted to a tick of a box or a pat on the back and does not translate to be practical and tangible recognition of the caring role. Practical recognition for carers has a significant direct impact on their wellbeing<sup>2</sup>. The more recognised and valued a carer feels by their community, service providers, family and friends – the higher their wellbeing becomes<sup>3</sup>. In addition, social supports have been determined to have the greatest direct impact on carer wellbeing and have a mediatory effect on the relationship between recognition and wellbeing. In short, improvements in a carer's social supports and levels of recognition in turn reduces the impact of their caring role on their wellbeing<sup>4</sup>.

*'Recognition would mean more support for carers in a tangible way. We are very tired and always have more to do than there are hours in the day.'* – response from a carer

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<sup>2</sup> (SAGE Design & Advisory, 2023)

<sup>3</sup> (SAGE Design & Advisory, 2023)

<sup>4</sup> (SAGE Design & Advisory, 2023)

Feedback from carers has indicated that recognition, for them, would have a significant impact on their lives in all settings. However, the personal meaning of recognition to each carer varied, especially for carers facing significant difficulties in their lives. The themes of what carers would like recognition to look like included: acknowledgement of the difficulties and diversity of the caring role; practical demonstration of this acknowledgement through needed supports and sufficient financial assistance; assistance with service navigation and access; and time to take a break, accompanied with access to respite services.<sup>5</sup>

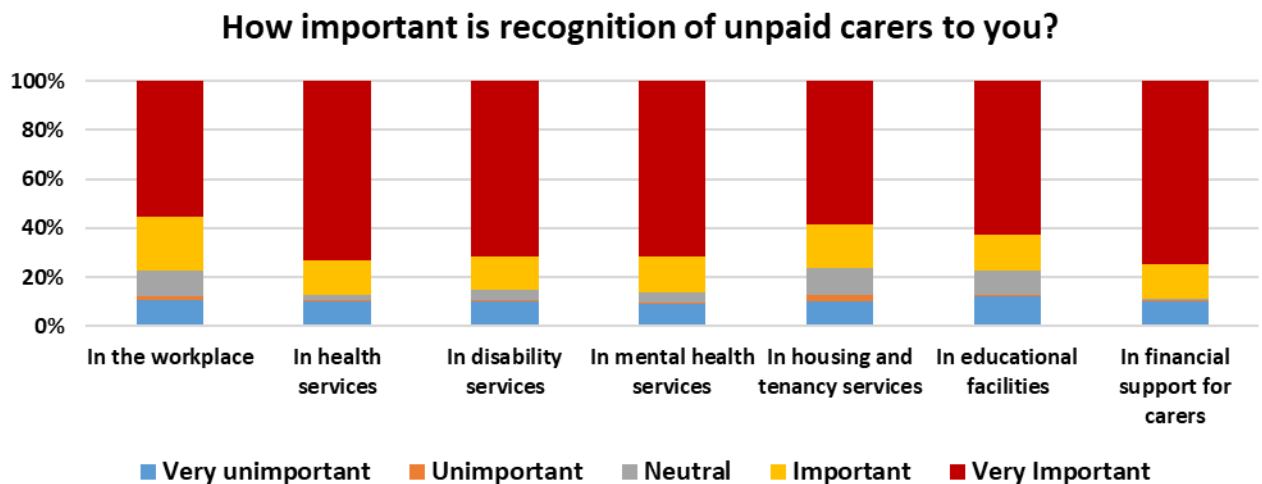


Figure 1 Importance of carer recognition for carers in different settings

#### Carers WA recommends that:

1. Initiatives for practical and consistent recognition of carers be established within every system which carers navigate and utilise, including (but not limited to) the Federal Department of Education; Department of Veterans Affairs; NDIA; Department of Health and Aged Care; Services Australia; and Department of Social Services – as well as their state and territory counterparts. This should include:
  - Identification and recording of carers at intake.
  - Recognition of carers, awareness of the role which carers undertake and carers rights, and inclusion in discussions of relevance to their caring role (where the consumer has given permission for this to occur).
  - Assistance with service navigation and access.
  - Referral of carers to available carer support services; and
  - Referral of carers and consumers to quality respite services.
2. Ongoing awareness campaigns be conducted as part of the National Carer Strategy, to build community practical recognition of carers' rights and the diversity of caring roles, as per Recommendation 22 of the Inquiry into the recognition of unpaid carers, and other sections of this recommendation.

<sup>5</sup> (Carers WA, 2023)

## What does a caring role look like?

*'Carers have a role in the lives of Australians. Carers offer valuable and personal support which is irreplaceable. Carers take on roles which place them at financial and personal disadvantage to be able to care for others.'* – response from a carer

There are 3.04 million carers in Australia<sup>6</sup>, these being someone who provides personal care, support and assistance to another person who has disability, a medical condition (including a terminal or chronic illness), a mental illness, or who is frail and aged<sup>7</sup>. This care provided is unpaid and is not part of a work or voluntary role. A carer can be a friend, family member, neighbour or other person who provides varying levels of support to the person they care for, ranging from 24/7 care, to much less.

Carers themselves are as unique as each caring role is, and it is important that the National Carer Strategy recognise and provide supports for the diversity of each caring role. It is noted in the discussion paper that Australian carers 'are diverse in culture, religion, language, ability, location and family composition, including our LGBTIQ+ community'. The discussion paper also recognises that there is a key distinction between 'young carers' and 'older carers', as well as the acknowledgement that every carer's role will look different and be unique to their personal circumstances and those of the person they care for. Carers WA recommends that the National Carer Strategy also acknowledges these items, but also includes practical recognition of them through ensuring supports are flexible to each carers' unique circumstances, with enhanced choice and control for the carer within these supports.

In addition, while the role of a carer is infinitely diverse, this is not adequately reflected or recognised within the legislation. Across Federal, state and territory carer legislation, the very definition of a carer varies widely. These inconsistencies result in a lack of clarity regarding who is a carer, and lead to increased confusion for people self-identifying as carers and subsequently knowing where to go to access services for carers. Consequently, communities, service providers and other stakeholders are not able to consistently identify carers, be aware of carers rights, and refer carers onto available supports for themselves.

The need for the diversity of caring roles to be reflected and consistently defined in legislation was recognised in the Final Report of the Standing Committee on Social Policy and Legal Affairs, Inquiry into the recognition of unpaid carers. This needs to also be reflected in the National Carer Strategy, with practical initiatives resulting in consistent definitions and understanding of carers and how to practically support and recognise carers.

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<sup>6</sup> (Australian Bureau of Statistics, 2024)

<sup>7</sup> (Commonwealth of Australia, 2010)



Further, a significant barrier to the effectiveness of carer legislation is the lack of enforceability of the rights of carers and the definition of carer stated in such legislation, the limited number of applicable organisations, and limited options of consequences for carers to seek if their rights are breached. The *Carer Recognition Act 2010* (Cth) expressly states that ‘this Act does not create rights or duties that are legally enforceable in judicial or other proceedings’<sup>8</sup>.

This has an impact on the effectiveness on the Act as there is no enforceability or consequence should the rights of carers and obligations on applicable organisations be breached. Further, the limited coverage of the Act to only public service agencies in the Federal Act, further limits the impact of this legislation. While the Inquiry into recognition for unpaid carers makes some recommendations around measures such as seeking legal advice for how to best establish rights for carers, this enforceability of the Act remains an ambiguous area which requires clarity to support any legislative amendments made.

**Hence, Carers WA recommends:**

3. The National Carer Strategy acknowledge the diversity and uniqueness of each carer and carer role, with practical recognition of this through ensuring supports are flexible to each carers’ unique circumstances, with enhanced choice and control for the carer within these supports.
4. The National Carer Strategy include actions to ensure the *Carer Recognition Act 2010* (Cth) is rights-based and enforceable, with clear mechanisms for enforceability and consequences for breaching of the Act. This is also recommended to be extended to carer legislation across all states and territories.
5. The need for the diversity of carers and caring roles to be reflected and consistently defined in legislation and the National Carer Strategy, with practical initiatives to have consistent definition, understanding and practice of carers and how to practically support and recognise carers. This includes:
  - Amendments be made to modernize and clarify the definition of ‘carer’ within the *Carer Recognition Act 2010* (Cth), and address inconsistencies in this definition between Federal, state and territory legislation and practice (as per recommendations 1, 2, 3, & 5 of the Inquiry into the recognition of unpaid carers).

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<sup>8</sup> (Commonwealth of Australia, 2010)

### The cost of caring

Informal care provided by carers offers substantial benefits to Australia's health, disability, aged care and other industries – supporting Australia's strained health system and taking the place of services when systems fail. Indeed, the cost to replace this informal care around Australia was estimated in 2020 to be \$77.9 billion per year<sup>9</sup>. While the demand for carers is projected to increase by 23% by 2030, the number of carers is only projected to increase by 16% over this timeframe<sup>10</sup>. Without improvements to practical recognition and support for carers, this shortfall will result in additional pressure to Australia's already strained health system and formal care.

Being in a caring role comes at a significant cost to a carer's wellbeing, and economic and financial security. Carers have significantly higher rates of psychological distress than the average Australian. Over half of carers have poor wellbeing, compared to 25.4% of adult Australians. Only 17.1% of carers reported having good health, compared to 47.9% for the average Australian<sup>11</sup>. Preventative measures are needed to prevent carer burnout and further pressure on the health system.

Further, on average, by age 67 primary carers will lose \$175,000 in superannuation and \$392,500 in lifetime earnings. Indeed, for every year someone is a primary carer they will lose on average \$17,700 in superannuation and \$39,600 in lifetime earnings<sup>12</sup>. Moreover, 34.4% of carers report not being able to raise \$2,000 in a week if needed and 33.7% report spending more money than they receive in a month<sup>13</sup>. In WA, 24% of carers are in crisis, predominantly in regional areas, and 57% of carers on carer payments are below the poverty line<sup>14</sup>.

Given the above, the prospect of being in a caring role is not a positive one. However, the reality is that everyone will either currently be in a caring role, be in a caring role in the future, or need care themselves. Let's ensure that Australia is a country that cares for its carers and provides them with all the support they may need.

In addition, the cost of caring does not disappear when the caring role ends. Caring has ongoing impacts to the financial, physical and mental wellbeing of a person who used to be a carer, which impact their ability to work, study, be financially stable, and even to have a roof over their heads. Carers WA recommends that the National Carer Strategy recognises and includes former carers in support services and have supports for someone transitioning out of a caring role – including ensuring that former carers are able to access housing. This support is recommended to be extended for two years following the end of the caring role.

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

<sup>10</sup> (Deloitte Access Economics, 2020)

<sup>11</sup> (Schirmer, Mylek, & Miranti, 2022)

<sup>12</sup> (Furnival & Cullen, 2022)

<sup>13</sup> (Carers NSW, 2023)

<sup>14</sup> (SAGE Design & Advisory, 2023)

**Carers WA recommends:**

6. The National Carer Strategy recognises and includes former carers in support services and have supports for someone transitioning out of a caring role – including ensuring that former carers are able to access housing. This support is recommended to be extended for two years after the end of a caring role.
7. Ongoing awareness campaigns be conducted as part of the National Carer Strategy, to build community practical recognition of carers' rights and the diversity of caring roles, as per Recommendation 22 of the Inquiry into the recognition of unpaid carers, and other sections of this recommendation.

## 3.2 Economic Security

Caring has significant negative impacts on carer employment and income opportunities<sup>15</sup>, including on levels of superannuation, lost wages, carer recognition, and time to partake in employment and education. Carers also experience negative economic impacts from time required to navigate multiple complex systems and access necessities such as housing.

Carer recognition is also impacted by economic and financial security. The more financial stress carers experience, the less they feel recognised. Carers who work feel less recognised for their caring role than carers not in paid work. However, carers in receipt of income support such as the carer payment felt more recognised<sup>16</sup>.

In 2022, 57.4% of carers in Australia reported at least on experience of financial stress, up from 50.7% in 2020<sup>17</sup>. Over 2020 to 2022, 18.3% (1 in 5) of carers reported having lost work or significant amounts of income, with economic vulnerability having the largest impact on social outcomes<sup>18</sup>. Moreover, 34.4% of carers report not being able to raise \$2,000 in a week if needed and 33.7% report spending more money than they receive in a month<sup>19</sup>. In WA, 24% of carers are in crisis, predominantly in regional areas, and 57% of carers on carer payments are below the poverty line<sup>20</sup>.

### 3.2.1 Superannuation

*'When working more than a few hours a week decreases your pension that first week there is no incentive to go to work thus NOT giving carers any chance at a "Normal" life experience or future retirement (no superannuation) if the caring position is ever over!' – response from a carer.*

On average, by age 67 primary carers will lose \$175,000 in superannuation. This is an average loss of \$17,700 in superannuation for every year someone is a primary carer. The most impacted 10% of primary carers lose an average of \$444,500 in superannuation by age 67<sup>21</sup>.

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<sup>15</sup> (Carers NSW, 2023)

<sup>16</sup> (Carers NSW, 2023)

<sup>17</sup> (Carers NSW, 2023)

<sup>18</sup> (Carers NSW, 2023)

<sup>19</sup> (Carers NSW, 2023)

<sup>20</sup> (SAGE Design & Advisory, 2023)

<sup>21</sup> (Furnival & Cullen, 2022)

This was a key concern raised by carers in WA in focus groups to inform the National Carer Strategy, including the need to top up carers' superannuation in a manner that is not means tested. Recommendation 19 of the Federal Inquiry into recognition of unpaid carers also raised the need for actions which address the financial disadvantage carers experience over their lifetime<sup>22</sup>. The Inquiry also recommended that an income tax credit be introduced for carers who are returning to the paid workforce, and that other options be considered to incentivise and recognise the impact of caring through the income tax and superannuation systems (Recommendation 21)<sup>23</sup>.

CAWA recommends that, in line with the recommendations of the report *Caring Costs Us*, the Australian Government pays a Superannuation Guarantee Contribution on the Carer Payment. This initiative would include a top-up of carer superannuation in the first year, with the measure costing an estimated \$711.9 million in the first year<sup>24</sup>. This measure would offset 27.8% of the loss in superannuation a carer would suffer because they became a carer. For a person who cared for one year, this initiative would result in a superannuation balance at age 67 that would be \$7,200 higher per year than it would have otherwise been<sup>25</sup>.

This initiative would increase the superannuation balances of over 300,000 Australian carers, and reduce their future reliance on the Aged Pension, delivering savings to government on a lifetime cost basis<sup>26</sup>. This would also deliver savings through ensuring carers are economically and financially supported in the unpaid care work they provide over their lifetime<sup>27</sup> – valued at \$77.9 billion per year for replacement formal services<sup>28</sup>.

**Carers WA recommends:**

8. CAWA recommends that, in line with the recommendations of the report *Caring Costs Us*, the Australian Government pays a Superannuation Guarantee Contribution on the Carer Payment.

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<sup>22</sup> (Parliament of Australia, 2024)

<sup>23</sup> (Parliament of Australia, 2024)

<sup>24</sup> (Furnival & Cullen, 2022)

<sup>25</sup> (Furnival & Cullen, 2022)

<sup>26</sup> (Furnival & Cullen, 2022)

<sup>27</sup> (Furnival & Cullen, 2022)

<sup>28</sup> (Deloitte Access Economics, 2020)

### 3.2.2 Carers Payments

*'Most carers I know have lost fulfilling careers, have limited superannuation, and quite simply cannot afford many of the things that non-carers can. My future and the futures of my carer friends quite frankly look very bleak. Personally, I would love to be in the workforce and I'm currently trying to start my own business to try and generate some income. How I can fit this in alongside my caring role I have no idea but I'm fearful for my future and future security. I certainly won't have children who have any capacity to look after me if I become ill or when I'm old. Words mean very little. Carers don't need words we need support which meaningfully and positively impacts our carer role and provides us with security'. – response from a carer.*

While carers in receipt of the carer payment feel more recognised, a significant proportion of these carers live below the poverty line<sup>29</sup>. Indeed, for every year that someone is a primary carer, they will lose \$39,600 in lifetime earnings. On average by age 67, primary carers will lose \$392,000 in lifetime earnings. The most impacted 10% of primary carers will lose \$940,000 in lifetime earnings by age 67<sup>30</sup>. These significant financial losses were recognised in the Final Report of the Senate Select Committee on Work and Care, which recommended the Australian Government review the level of the Carers Payment and Carers Allowance, in acknowledgement of 'the significant social and economic contribution that carers make'<sup>31</sup>.

In 2021, the maximum income support for carers on the carer payment was equal to only 27.8% of average weekly ordinary time earnings for singles and 21.0% of weekly ordinary time earnings for couples<sup>32</sup>. The carer allowance is equal to only 10% of the basic couple age pension; 6% of the basic care subsidy for a person in an approved care home; or 1.5% of the average amount payable to a person with disability in shared accommodation<sup>33</sup>. The value of the carer allowance has decreased significantly over time.

When the carer allowance was first introduced in 1972 (called the Domiciliary Nursing Care Benefit), the value of this payment was much higher, this being:

- 25% of the income of a couple under the age pension.
- 93% of the Australian Government Personal Care Subsidy.
- 57% of the Australian Government Basic Nursing Home Benefit; and
- 33% of the Australian Government Extensive Nursing Home Benefit<sup>34</sup>.

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<sup>29</sup> (SAGE Design & Advisory, 2023)

<sup>30</sup> (Furnival & Cullen, 2022)

<sup>31</sup> (Commonwealth of Australia, 2023)

<sup>32</sup> (Furnival & Cullen, 2022)

<sup>33</sup> (Furnival & Cullen, 2022)

<sup>34</sup> (Furnival & Cullen, 2022)

Within the Federal Inquiry into recognition of unpaid carers, Recommendation 19 raised that the National Carer Strategy should include gender equality as a key priority, to be addressed by actions including ones which address the financial disadvantage carers experience over their lifetime<sup>35</sup>. It is recommended that one of these initiatives be to increase the Carer Allowance, as the payment which is intended to compensate the primary carer for the financial impact of being a carer<sup>36</sup>. This is recommended to be undertaken in both the following ways, as outlined within the report *Caring Costs Us*

- Increased by 150% for carers receiving the Carer Allowance, but not the Carer Payment, to return the Carer Allowance value to 25% of the income for a couple on the Basic Age Pension; and
- Increased by 475% for carers receiving both the Carer Allowance and the Carer Payment, to return the value of the Carer Allowance to 33% of the value of the average Australian Government Basic Care Subsidy<sup>37</sup>.

These increases to the Carer Allowance would have the effect of offsetting some of the impact of their caring role on their lifetime income: by 31.0% for a 475% increase in the Carer Allowance and by 9.6% for a 150% increase in this payment for the specified groups<sup>38</sup>.

This increase is estimated to lead to an increase of \$9.925 billion in overall expenditure, savings from new informal carers (instead of replacement formal care) of \$4.569 billion – equalling a net cost of \$5.357 billion<sup>39</sup>.

#### **Carers WA recommends:**

9. The Carer Allowance be increased as an action to address the financial disadvantage carers experience over their lifetime. This should include:
  - Increase of 150% for carers receiving the Carer Allowance, but not the Carer Payment; and
  - Increase of 475% for carers receiving both the Carer Allowance and the Carer Payment<sup>40</sup>.

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<sup>35</sup> (Parliament of Australia, 2024)

<sup>36</sup> (Furnival & Cullen, 2022)

<sup>37</sup> (Furnival & Cullen, 2022)

<sup>38</sup> (Furnival & Cullen, 2022)

<sup>39</sup> (Furnival & Cullen, 2022)

<sup>40</sup> (Furnival & Cullen, 2022)

## Reframing carer payments

*'An understanding of the load I carry - impacting on my mental health, physical health, available work time. I want it recognised as a job - to validate the role - even if it's unpaid work. I want recognition of the range of skills you need and or develop as a cadet and advocate.'* – response from a carer.

In addition to the increase in the Carers Allowance, CAWA also recommends that the narrative around receipt of carer payments be reframed to recognise the substantial contribution which carers make, rather than carer payments being viewed as welfare payments, changing to reframe carers as an unpaid workforce. This is recommended to be included as part of the National Carer Strategy within the ongoing awareness campaign on carers as, carer rights and carer supports.

### **Carers WA recommends:**

10. The narrative around carer payments be reframed in recognition of the substantial contribution that carers make, within an ongoing awareness campaign as part of the National Carer Strategy.

CAWA also recommends the inclusion of initiatives which support this recognition of carer roles and the difficulties which carers experience as part of this role, including (but not limited to):

11. Application of 14 weeks of eligibility for the Carers Allowance at the end of a caring role, and the extension of the current 14 weeks of eligibility for the Carers Payment at the end of a caring role.
12. Transitional supports for carers during significant points of change in their caring role, in recognition of the carer's significant contribution, such as:
  - Transitional and grievance counselling (in addition to current counselling services offered through the Carer Gateway); and
  - Transitional support for big changes in a caring role such as a child becoming an adult, the person being cared for permanently entering a residential care facility, etc.
  - Support for carers to plan for when they can no longer care. This includes disaster preparedness; pandemics; emergency planning and preparedness; end-of-life planning for themselves and those they care for; etc.



### 3.2.2 Employment and Education

*While there's more recognition of carers compared to 15 years ago, I think there needs to be more awareness about the role of carers in workplaces and schools not just in service agencies.*

In a survey of WA carers to inform CAWA's response to the Inquiry into Carer Recognition, 77.23% of carers responded that it was important or very important to them to be recognised in the workplace. In the same survey, 77.45% of carers reported it was important or very important to be recognised in educational facilities. In addition to recognition, carers need support and flexibility within these settings to be able to partake in paid work, study or preparing to take on these extra commitments on top of their caring role.

#### Job Readiness/non-workplace focussed employment support

Carer-specific job readiness programs, such as [Carers WA's Be Job Ready Program](#), play a key role in helping carers to upskill, and connect to employment and education opportunities. This is particularly important when carers have been out of the workforce for a long time due to their caring role, during which time job hunting processes have drastically changed, but carers have also gained new skillsets through their caring experience. Job readiness programs can also help carers to identify and utilise these new skills. However, despite the benefits of these programs, funding for them lacks continuity and is only for short periods of time.

The projected average lifetime cost for people on the Carer Payment is \$592,000<sup>41</sup>. This is the saving to government for every carer who returns or enters the workforce and who is no longer on the carer payment. Add to this other savings such as this person's reduced need for the age pension due to having built up superannuation; the increase to their mental and physical wellbeing that participation in paid work brings carers; etc. Continuity of funding and increased capacity for job readiness programs for carers is a measure which makes economic sense.

#### Carers WA recommends:

13. The National Carers Strategy includes actions to ensure continuity of funding for job readiness programs for carers, and increased capacity within these programs.

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<sup>41</sup> (Department of Social Services, 2022)

## Carer friendly workplaces

*'Without the support of my workplace over the past 12 months, I would have had to give up my employment in order to be able to undertake the care I have needed to provide to my 87-year-old parent. The financial value of the caring I provide is enormous and of course this is not taken into account in the tax I pay, or any other financial mechanism available to me. I am effectively having to make a decision between providing less than the level of care needed and holding down a job. I simply cannot do both to the extent that is required.'* – response from a carer.

The Australian Government Productivity Commission's Inquiry into Carers Leave found that flexible working arrangements are highly valued by carers and form a key factor to carers being able to manage their paid work and caring commitments.

When carers are not able to access suitable flexible working arrangements, carers reduce their engagement with the paid workforce, resulting in limited income and opportunities for career advancement. Subsequently, carers' long term financial security, health and wellbeing is impacted<sup>42</sup>. Paid work provides carers with a mechanism to achieve financial security, social connection, and a meaningful activity – with 74.7% of carers finding that paid work provides them with important social connections outside of caring, and 82% reporting it provides a sense of purpose<sup>43</sup>. Hence, reducing barriers to carers maintaining and re-entering paid work are essential to carers' financial security.

The barriers which prevent carers being able to participate in paid work, include care intensity; access to care services; and workplace flexibility. Carers, on average, report spending over 100 hours a week caring, with 48.5% of carers providing 24/7 care<sup>44</sup>. This restricts a carer's ability to work more than part-time, or even work at all. Over half of carers also report being a sole carer for someone and rely heavily on formal services to have the time to work. Carers also often seek to work in flexible jobs and industries to be able to work flexibly, which may include things such as varying start and finish time or working from home<sup>45</sup>. While 57.7% of carers report having access to flexible working arrangements, 1 in 2 carers were not satisfied with their work-life balance and 49.7% of carers did not have enough paid leave required for their caring role<sup>46</sup>. Carers have also reported that their limited ability to engage in paid work has impacted their career progression, leading to lower income potential and superannuation<sup>47</sup>.

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<sup>42</sup> (Carers NSW, 2023)

<sup>43</sup> (Carers NSW, 2023)

<sup>44</sup> (Carers NSW, 2023)

<sup>45</sup> (Carers NSW, 2023)

<sup>46</sup> (Carers NSW, 2023)

<sup>47</sup> (Carers NSW, 2023)

Carers who did participate in paid work have reported on the importance of recognition, understanding and support from managers – all of which have a positive impact on job satisfaction and retention. More than half of carers reported choosing an employer due to being able to access flexible working arrangements<sup>48</sup>.

**Carers WA recommends:**

14. Organisations be encouraged to adopt more carer-friendly workplaces through stronger understanding of how to recognize the valuable contributions of carers in the workplace, and support carers working in their organisations. Organisations are recommended to complete the [Carer-Inclusive Workplace Initiative](#) and/or engage with the [Carer Friendly Employers Program](#) and Accreditation.
15. Organisations be incentivized to become more ‘carer friendly’ through flexible workplace payroll tax incentives.

Carers Leave

*‘Taking carers leave out of someone’s sick leave disadvantageous those carers who have their own health issues - usually resulting in financial disadvantage for the carer’. – response from a carer.*

The majority of carers do not have enough paid leave available and must resort to using unpaid leave for the responsibilities of their caring role<sup>49</sup>. While many workplace cultures are supportive of carers, the time involved in many caring roles exceed the availability of available workplace flexibility and leave arrangements<sup>50</sup>. A bespoke paid carers leave category is needed in legislation to combat this, separate to personal leave allocations. In the Australian Government Productivity Commission’s Inquiry into Carers Leave Final Report, it was recommended that the combining of paid carer leave and sick leave be reviewed, as well as what constitutes eligible occasions of care.

Further, the definition of ‘carer’ in the National Employment Standards is also recommended to be extended to ensure all carers are able to access this leave. At present, this definition only extends carer leave to employees providing care for an immediate family or household member. This definition change forms Recommendation 3 of the Australian Government Productivity Commission’s Inquiry into Carers Leave Final Report.

The model proposed in the Commission’s Final Report also includes an extended unpaid leave period for carers of older people (1-12 months, with access to another 12 months once initial period is used). The Commission also found that the case for an unpaid entitlement for carers is similar for all carers, not just for carers of older people.

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<sup>48</sup> (Carers NSW, 2023)

<sup>49</sup> (Carers NSW, 2023)

<sup>50</sup> (Carers NSW, 2023)

Recommendation 6 of the Commission's Final Report specifically stated that the National Carer Strategy should include:

- a whole-of-government approach to supporting carers to participate in the workforce.
- action to ensure carers' needs are included alongside the needs of the care recipient.
- a commitment to undertake an audit of existing policies to support carers to reconcile paid work and care and actions to resolve gaps.
- a formalised process for undertaking policy evaluations and building the evidence base on effective carer supports, and for incorporating this evidence alongside carers' lived experiences in the development of future policy.

**Therefore, Carers WA recommends the following initiatives be included as part of the National Carer Strategy:**

16. Carers leave adoption form part of the National Carer Strategy, including:
  - The development of a bespoke paid carers leave category in the Fair Work Act 2009 (Cth), separate and equal to personal leave allocations (10 days).
  - Review of the definition of 'carer' in the National Employment Standards, to be consistent with the definition of carer within the *Carer Recognition Act 2010* (Cth).
  - Adoption of the unpaid carers leave model proposed in the Australian Government Productivity Commission's Inquiry into Carers Leave Final Report, but for all carers.

### 3.3.3 Integration and Services Navigation

*'Timely access to services, more efficient and streamlined processes, information in one spot (the amount of times I've had conflicting info or been provided with info on services from other people that is not obvious on any website anywhere), better access to respite care. All of this assists the carer to continue with working as well' – feedback from a carer.*

*'I think Carers need to be paid. There needs to be greater financial assistance to carers; in particular families caring for children with complex medical and intellectual disabilities where the role of caring and navigating through the NDIS is BEYOND a full-time job and a caring role put together!!' – feedback from a carer.*

Carers WA is pleased that the discussion paper has recognised the difficulties and frustration which carers experience when having to navigate multiple complex systems to access services for themselves and those they care for. The National Carer Strategy needs to also recognise this issue, and then go beyond this to include practical solutions to address this issue and its underlying contributors. These include:

- Lack of carer recognition and identification – tools for identification, self-identification, strengthening referral pathways and initiatives to combat ongoing identification fatigue.
- Awareness of available services and which ones to contact and navigate.
- Over-reliance on carers to navigate complex systems, and fill gaps when systems fail.

#### Carer identification

A prominent issue experienced by people in a caring role is identification. Carers are not being identified when they interact with services for themselves and those they care for. Carers also often do not self-identify as carers. This causes a lack of connection to services for the carer themselves and face the stressors of the caring role without supports. Carers WA recommends that a whole-of-government and sector approach is taken to ensuring carers are identified on initial intake for services, building referral pathways to carer supports, and fostering community-wide understanding of carers. This would ensure that carers are identified early in their caring role and wrapped in holistic services to help keep them well and reduce the impact of the role on their wellbeing (physical, mental and financial).

Carers also report ongoing issues with needing to identify themselves as a carer, needing to constantly then explain what a carer is, and limited carer recognition and inclusion in many settings. This is an issue that become especially prevalent during the COVID-19 pandemic, when carers needing to access medical facilities to care for their loved ones were facing barriers to entry due to restrictions and a lack of a tool to be able to identify as a carer. Even after the pandemic, carers call for a tool of carer identification which can alleviate the need to tell their story over and over, causing further exhaustion and adding another task to a carer's already full plate.

Carers WA recommends the establishment of a national Carer Card Program as this tool of carer identification, based on the Carer Card Program model already existing in Victoria. Further, a Carer Card Program would provide carers with a wide range of discounts and benefits on offer from businesses, local government and community organisations.<sup>51</sup> It will also provide carers discounts on products and services, including travel and leisure, education, tourism, health, wellness and retail.<sup>52</sup> This will include concessions on utilities, transport, entry to government leisure facilities, and entry to community events and facilities.

A Carer Card Program would not only achieve increased recognition for Australian carers, it would also offer carers cost of living relief through these discounts, benefits and concessions; as well as provide opportunities for social and community connections whilst utilizing these discounts, benefits and concessions.

The existing Companion Card Program allows individuals with a significant and permanent disability, who may require the assistance of a companion (which may be a carer); to have their companion accompany them at particular events and activities. While this is an excellent initiative and of great benefit to eligible cardholders, this program is very much targeted to the needs of the person being cared for; with use of the card contingent on the card holder being present. The program also has limited scope and eligibility, which does not adequately provide for the 3.04 million carers in Australia.

The Carer Card is not the Companion Card. A Companion Card may be provided to a person who is not able to access a venue or event without assistance or care; whereas the Carer Card is provided to a carer to recognize and reward them for the unpaid care they perform to improve the lives of others.<sup>53</sup> A Carer Card is for the carer in their own right, and they are able to use the card independent of the person they care for.<sup>54</sup>

**Carers WA recommends the National Carer Strategy include:**

17. A whole-of-government and sector approach be taken to ensuring carers are identified on initial intake for services, building referral pathways to carer supports, and fostering community-wide understanding of carers.
18. The establishment of a national Carer Card Program to provide carers with recognition, a tool of identification and access to concessions, discounts and benefits to reduce cost of living impacts and the financial stressors of the caring role.

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<sup>51</sup> Invalid source specified.

<sup>52</sup> Invalid source specified.

<sup>53</sup> Invalid source specified.

<sup>54</sup> Invalid source specified.

## Service navigation

*'Appropriate acknowledgement, which is then practically demonstrated in actual needed support, and not just financially but also in regards to carer health and wellbeing and importantly with navigating the system (as we are dealing with multiple 'households' and everything associated with them - our own and the person we care for). Timely access to services, more efficient and streamlined processes, information in one spot (the amount of times I've had conflicting info or been provided with info on services from other people that is not obvious on any website anywhere), better access to respite care. All of this assists the carer continue with working as well - this for me is my sole income (I have no other family support).'* – response from a carer

Carers report widespread difficulties in trying to navigate the maze of services they must access for themselves and those they care for, with some carers simply giving up trying to traverse services and hoops due to the effort and exhaustion this process causes. In regional WA, this issue is even more pronounced due to limited availability and affordability of services, and ongoing workforce issues. Often, limited awareness of available services further increases the task of being able to find services. This issue has the impact of carers and those they care for either not being able to access services or have the task of accessing services become a full-time job to maintain them. This is a task which carers will often take on, and one which has a significant impact on carers being able to return or enter into paid work due to its time requirements. In addition, the stress of trying to access services has adverse impacts on carers' health and wellbeing.

Regional communities in WA recommended the following solutions to this problem, ones which were also echoed in the focus groups held for the National Carer Strategy:

- One-stop shops or hubs for services (with bulk-billing). i.e. Dementia services.
- Centralisation of systems, access and diagnosis
- Service navigators
- Streamlining services
- Integrated directory of services for carers

### **Carers WA recommends that the National Carer Strategy include:**

19. A commitment from the Australian Government to co-design a simpler process to gain supports when it is most needed and strengthen the supports offered to carers through the Carer Gateway (Recommendation 9, Inquiry into recognition of unpaid carers).
20. A whole-of-government commitment and actions to streamline services, to reduce the administrative burden on carers and consumers.

21. Establishment of initiatives to support carers and consumers with service navigation and access, including service navigators; centralization of systems, access and diagnosis; integrated directory of services for carers; and one-stop shops or hubs for services (with bulk billing).

### 3.2.3 Housing

One in five carers are not satisfied with their housing situation, reporting that their housing situation is not suitable for their caring role. When someone becomes a carer, this can change their housing needs for accessibility requirements, size of the house, other occupants, etc<sup>55</sup>. A carer's financial stability and ability to work can also impact them having stable housing.

Carers have reported the need for the National Carer Strategy to support initiatives for alternative models of home ownership and renting. This included partnerships with government to purchase homes for carers and low interest housing loans for carers.

Carers also raised concerns around retaining their home when the house is under a loved one's name and they go into care.

#### **Carers WA recommends the National Carer Strategy include:**

21. Investigation into alternative models in renting and home ownership for lower income earners.
22. Workshops for carers on housing, tenancy maintenance and homelessness.

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<sup>55</sup> (Carers NSW, 2023)



## 3.3 Carer Health and Wellbeing

### 3.3.1 Respite\*

*'So many people desperately need help, support, and urgent respite which they cannot afford or access (single parents, CALD, etc.). Our carers need very significantly more recognition, more than \$75 a week to recognise our role and contribution to the country, saving massive amounts for the government. It's a sad and frustrating system with no improvement in sight. I feel like I've lost so much in my life as a result of being a carer, and no one other than my husband and elderly parents even acknowledges that, let alone supports it adequately. Feeling despondent...'* – response from a carer

Informal carers experience increased and heightened levels of social isolation, loneliness, psychological distress, as well as ill health and low wellbeing. The impacts of caring have increased during and in the aftermath of the COVID-19 pandemic, particularly in remote and regional areas, as well as for people who provide care for or are part of high-risk groups<sup>56</sup>. Access to respite for an informal carer can help carers to have a healthy level of wellbeing<sup>57</sup>, and better maintain and thrive in their caring role. Despite this, many barriers exist which hinder carers being able to access an appropriate level of respite services. For different types of support, the majority of carers report having poor access to in-home overnight respite care (80.6%); overnight respite care out of home (73.9%); day respite care out of home (65.7%); and in-home day respite care (61.8%).<sup>58</sup>.

This need for respite and for carers to have a break is well recognised. Yet again and again, the results of the many Inquiries, Commissions, and legislative reviews fail to deliver respite which is as diverse as the diversity of caring roles need it to be. Where carers do access respite, often it becomes a break for the carer to be able to do housework, run errands, or to receive treatments for their own health. While it is recognised that the discussion paper acknowledges the need for respite, as well as the positive impacts it can have for carers, respite also needs to be available to carers when there is a need, without restriction, and in a manner so that carers have choice and control about when it can be accessed.

One carer previously described to Carers WA, over time, their experience with accessing respite for their own cancer treatments, for needed house modifications for accessibility for their loved one, and their experiences with poor quality respite – where time away ended with their loved one in hospital with an infection due to poor respite care. This was respite that the carer struggled to acquire, calling service after service and being turned away due to lack of availability and lack of suitable high care options.

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<sup>56</sup> (Schirmer, Mylek, & Miranti, 2022)

<sup>57</sup> (Schirmer, Mylek, & Miranti, 2022)

<sup>58</sup> (Schirmer, Mylek, & Miranti, 2022)

\*The discussion paper defines respite as 'when someone else takes care of the person you care for, so you can have a break.[] Respite care can be given by family or friends or by a respite service. It can be for a short time or for a longer time, including overnight. You may even need to access emergency respite care at short notice if you find you are suddenly unable to provide care.'

This is a snapshot of just some of the barriers that carers face every day just to be able to have some much-needed time to themselves.

This time is not a holiday and should be in addition to time to use for chores or essential medical care for the carer. It is an essential part of maintaining the carer's own well-being, hence high-quality respite care that is local, affordable, flexible to needs and timely needs to be a given for carers.

#### Regional perspectives on respite

*'There needs to be more recognition of carers outside of capital cities. Country families don't have access to the same services, respite, care and facilities that city families do. It makes a stressful situation even more difficult. There needs to be more conversation about the financial burden this places on families. Many carers are forced to leave the workforce to care.'* – a response from a carer.

In regional WA, access to respite and the ability for carers to take a break is even more constrained, leading to increased isolation, burn out and low wellbeing for carers. Indeed, 24% of WA carers are in crisis, with many of these being in regional areas.<sup>59</sup> Given the substantial impact which access to respite and ability for a carer to take a break has on their wellbeing and ability to continue their caring role, it is imperative that respite is available in regional and metropolitan WA.

Carers WA has conducted extensive consultation in regional areas of WA over the past two years, with all regions consulted reporting issues with access to respite and the need for carer retreats.

The Kimberley region reported a severe lack of access to all forms of respite, with one-third of service providers consulted raising concerns about access to respite or opportunities for carers to have a break. Carers in remote communities were particularly flagged as having no access to respite.<sup>60</sup>

In the Great Southern region, lack of respite and carer retreats was identified as the most significant issue for carers in this region. Fifty percent of local service providers consulted identified respite related needs for carers, again for all forms of respite. The impact of this limited availability was reported to be lengthy hospital admissions, as well as some hospital discharges which were described as inappropriate, further resulting in readmission. The main underlying contributing factors for this issue were availability and affordability of respite, as well as workforce issues.<sup>61</sup>

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<sup>59</sup> (SAGE Design & Advisory, 2023)

<sup>60</sup> (Carers WA, 2023)

<sup>61</sup> (Carers WA, 2023)

In the Goldfields region, the ability of carers to access respite was found to be particularly dire. This was compounded by some Kalgoorlie hospital services being discontinued due to funding, which had a domino effect on carers in the region. The community spoke of the existing aged care providers now either not having any respite beds or not taking any more bookings for respite beds due to extensive waitlists. Existing providers also did not have any high-care respite beds. For other forms of respite, extensive waitlists were reported, resulting in there not being any available respite beds or in-home respite in Kalgoorlie.<sup>62</sup>

Respite access in the Esperance region was identified as being limited. Carers described it as frustrating, leading to feelings of burnout and dissatisfaction with their caring role, as well as needing to use the hospital regularly as an emergency respite facility. Nearly one-third of service providers consulted in Esperance identified respite as a significant area of need for carers in the region, whether it be for just an hour a week, in-home respite or residential respite. A need was identified for all forms of respite, as well as accompanying accommodation for staff, due to severe housing shortages in the region.

#### Emergency respite and assistance

Carers raised the need for short-term emergency respite to be available, including in hospitals, as well as a directory of the providers of general emergency and condition-specific respite such as dementia.

Carers of people with dementia particularly raised the need for a 24/7 dementia helpline, as well as an emergency outreach team for dementia. Carers also raised the need for national hotlines to be strengthened, with a 24/7 crisis line for carers and employees with lived experience.

#### Carers WA recommends:

23. The National Carer Strategy include actionable access to high quality respite care that is local, affordable, flexible to needs and timely as an essential part of health and wellbeing initiatives for carers.
24. Carers have choice and control to access respite when and where they need it, without restriction.
25. Establishment of supported respite houses which cater to child, adult and carer needs.

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<sup>62</sup> (Carers WA, 2023)

26. Strengthened services and access to emergency respite and assistance, including:

- A 24/7 dementia helpline.
- Emergency outreach team for dementia
- Strengthened national hotlines
- A 24/7 crisis line for carers, with employees with lived experience.

### 3.3.2 Health and Wellbeing

Carers in WA described the adverse impact which caring had on their health and wellbeing, saying that they had increased psychological strain, physical impacts such as tension, and on their sleeping and eating. Carers described how they felt anxious, depressed and angry, and the adverse impacts of caring on their relationships. Carers also raised their concerns about impacts of caring on siblings, and their experiences with inconsistent access to services.

Carers raised the need for a comprehensive and holistic health and wellbeing package for carers, which could be used however the carer chose to. These were recommended to include:

- Access to respite.
- Carer retreats.
- Self-care activities to maintain both physical and mental health.
- Advocacy.
- At home care for the carer.
- 24 counselling sessions for the carer, outside of mental health plan sessions, through a carer association or other NGO; and
- Flexibility of criteria to access services, to stop people from falling through the gaps.

#### Carers WA recommends:

27. The National Carer Strategy include the development of comprehensive and holistic health and wellbeing packages for carers, which provide the carer choice and control in how they are used.

### 3.4 Diversity of Carers and Caring Roles

Carers WA is pleased that the discussion paper has acknowledged the diversity of carers and caring roles. It is important that this acknowledgement is taken from recognition to action in the National Carer Strategy.

#### 3.4.1 Culturally and Linguistically Diverse Carers

Culturally and linguistically diverse (CALD) carers raised the need to support young CALD carers, with financial support, mentoring and recognition in the education system. CALD carers also raised the need for advocacy, training, navigation support, and interpretation where needed. Feedback from CALD carers also called for the Carer Gateway to be nationally consistent; streamlined; with CALD support for access, reviews and help; and with cross-system navigation support to other services such as allied health, hospitals, NDIS, etc.

#### 3.4.3 Young Carers

Young carers report a lack of understanding of their caring role, including from young carers themselves. They also report barriers faced such as time constraints and additional caring responsibilities, personal identity challenges, a lack of appropriate services, lack of access to transport, not being taken seriously, and the personal impact of the caring role.

Young carers would like to see increased awareness and understanding of their caring role; more recognition and allowances (time and money); being recognised as a priority group; more opportunities and involvement in decision-making and advisory opportunities. Young carers would also like to have more support, whether this be a physical safe place outside of school for young carers to go, young carer peer support groups or services that understand and can support young people in the caring role.

#### Carers WA recommends:

28. The Statement for Australia's Carers is amended to include explicit recognition of: First Nations carers; CALD carers; LGBTQI+ carers; and young carers.
29. The Carer Recognition Act 2010 (Cth) specify that children and young people under the age of 25 who provide care are young carers; and that a person can be in multiple care relationships.
30. The National Carer Strategy tangibly recognize the diversity of carers and include specific actions to identify and support CALD carers, First Nations carers, LGBTQI+ carers and Young Carers.

### 3.5 National Carer Strategy – Principles

Carers WA recommends the following principles are considered for the National Carer Strategy:

- Carers are identified.
- Carers are supported and empowered to manage their caring role.
- Carers are enabled and supported to have a life outside of caring, including social and economic participation in the community.
- Carers are free from disadvantages or discrimination related to their caring role.
- Carers are recognized, acknowledged and valued as partners in care.
- Carers are fully engaged and involved in the planning and shaping of services, policy and legislation design and development.

## 4.0 Conclusion

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Should the Department require any further information regarding the comments included within this submission, or assistance from the perspective of WA carers, Carers WA would be delighted to assist. Please contact the Carers WA Policy Team at [policy@carerswa.asn.au](mailto:policy@carerswa.asn.au).

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