



Carers WA



**Submission to the Australian Government
Department of Health and Aged Care**

A new Aged Care Act: Exposure Draft

March 2024

About Carers WA

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 2.65 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 region, and so we also acknowledge the cultural diversity of First Nation Peoples across our state and throughout Australia.



Enquiries

Carissa Gautam
Systemic Policy Officer

Stuart Jenkinson
Systemic Policy and Strategy Officer

Phone: 1300 227 377

Email: policy@carerswa.asn.au

Website: www.carerswa.asn.au

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Summary of Recommendations

1. Carers be legally recognized within the Act as eligible for support within the aged care system - including adequate, timely and locally based respite for informal carers of older people.
2. Incorporate within the Act carers' right to access supports in accordance with their needs.
3. Incorporate within the Act carers' right to access supports which enable reasonable enjoyment of the right to social participation.
4. Amend the Principles within the Act to:
 - Separate out the Principle 'An aged care system that values workers and carers' to be two separate Principles – 'An aged care system that values workers and volunteers' and 'An aged care system that values carers'. This separation will assist in distinguishing between a carer and an aged care worker or volunteer.
 - Include a section within the 'An aged care system that values carers' that carers of older people should have certainty that they will receive timely and high quality supports in accordance with assessed need (as per Recommendation 3 of the Aged Care Royal Commission Final Report).
5. Specific provision be made in in Section 392 (2) of the Act for:
 - grant purposes that include the provision of timely, local and equitable support for older people and their carers.
6. Specific provision be made in Section 392 (2) of the Act for:
 - grant purposes for rural, regional and remote areas experiencing challenges in the aged care sector and provision of relevant specialist health services to older people and their carers.
7. Clarity and education be provided around:
 - The role of a carer in relation to the roles of supporters and representatives.
 - The responsibilities of supporters and representatives, offences and consequences for committing an offence.
 - Supported decision making education.
8. Section 30, 3d(iii) of the Act be amended to read 'when appropriate, any other person who assists the individual to manage the individual's day-to-day activities or, if there is no such person, any family members, carers, or other persons who have a close continuing relationship with the individual'.
9. Decision making processes be clarified for guardians, representatives, supporters and carers.

10. Older people be encouraged to have an Enduring Power of Attorney, Enduring Power of Guardianship and Advanced Health Directive in place to offer guidance on their wishes to guardians, representatives, supporters and carers.
11. Older people be allowed to have both supporters and representatives.
12. The first review of the new Aged Care Act be undertaken three years after the commencement of the Act, and every five years thereafter.
13. Section 411 (2) of the Act be amended to require the annual report on the operation of the Act to include the reasoning for unmet demand for funded aged care services; how aged care needs are being met in rural, regional and remote areas; and how the aged care sector is supporting carers – i.e. number of referrals to carer support services, etc.

An aerial photograph of a coastal region, possibly a lagoon or wetland, with a semi-transparent blue overlay. The image features several prominent circular patterns overlaid on the landscape. The largest pattern is a multi-layered mandala in the upper center, with a central white dot, surrounded by concentric rings of green, yellow, and blue dots. Another similar pattern is in the lower left, with a central white dot and concentric rings of red, green, and black dots. Other smaller circular patterns are scattered throughout the image. The background shows a mix of light-colored sandy or silty areas and darker, teal-colored water bodies, separated by white lines that could be paths or natural boundaries.

Section 1

1.0 Introduction

1.1 Where are carers in the new Aged Care Act?

Carers WA appreciates the opportunity to provide feedback in response to the Department of Health and Aged Care's consultation on A new Aged Care Act: exposure draft. The Association is supportive of the intent of these much-needed person-centred reforms to the aged care system and legislation. However, we are deeply concerned at the limited consideration of carers within the implementation of these reforms, and at the apparent exclusion of the Aged Care Royal Commission's recommendations in relation to carers within these reforms.

For the purposes of this submission, a carer is defined as per the meaning under the federal *Carer Recognition Act 2010*. This Act states that a carer is an individual who provides personal care, support and assistance to another individual who needs it because that other individual has a disability, a medical condition (including a terminal or chronic illness), mental ill health, or is frail and aged. This definition does not include individuals who provide care under a contract of service, volunteer work or as part of a course of education or training. A carer may be a person's neighbour, friend or family member; and may range in age from 8-25 years (a young carer) and older.¹

While this defined role of a carer in the context of the Australian aged care system was well considered in the final report and recommendations of the Royal Commission into Aged Care Quality and Safety (the Commission), this consideration has not been effectively integrated into the new Aged Care Act. In particular, the Commission recognised the role of the informal carer in the aged care system by building in supports for carers and to ensure carer voices are heard, within its final recommendations².

Support for Australia's carers is essential within the aged care sector, due to the significant and integral contributions which carers make in supporting older people living at home, as well as within aged care services. At home, carers assist in maintaining the independence of older people, out of long-term residential care facilities. The care that carers provide is invaluable and comes at a high personal cost.

Within this submission, Carers WA will detail further from a WA perspective and evidence base, this vital need for integrated and holistic recognition and support of the carer role within the new Aged Care Act.

¹ (Commonwealth of Australia, 2010)

² (Royal Commission into Aged Care Quality and Safety, 2021)

2.0 General Feedback

2.1 Recognition of carers

A significant and prevailing challenge experienced by carers in Australia, is tangible recognition of their caring role, themselves as carers, and appropriate support as part of this recognition. This challenge is well recognised and represented within the Recommendations of the Final Report of the Royal Commission into Aged Care. In reference to the new Aged Care Act and carers, Recommendations 1, 2 and 3 included the need for carers to have access to respite, and to have certainty of timely and high-quality supports. These three recommendations were supported in the Australian Government response to the Royal Commission's Final Report, which also stated that these recommendations would be responded to through the Governance - New Aged Care Act measure. This is represented within the table below.

Royal Commission Recommendation in relation to carers	Australian Government response
<p>Recommendation 1: A new Act</p> <p>2b) The new Act should define aged care as supports, including respite for informal carers of people receiving aged care.³</p>	<p>The Government accepted recommendations 1-3 of the Final Report and stated it would respond through the measure Governance – New Aged Care Act.⁴</p>
<p>Recommendation 2: Rights of older people receiving aged care</p> <p>d) For people providing informal care, the right to reasonable access to supports in accordance with needs and to enable reasonable enjoyment of the right to social participation.⁵</p>	<p>The Government accepted recommendations 1-3 of the Final Report and stated it would respond through the measure Governance – New Aged Care Act.⁶</p>
<p>Recommendation 3: Key Principles</p> <p>3bii) informal carers of older people should have certainty that they will receive timely and high quality supports in accordance with assessed need.⁷</p>	<p>The Government accepted recommendations 1-3 of the Final Report and stated it would respond through the measure Governance – New Aged Care Act.⁸</p>

³ (Royal Commission into Aged Care Quality and Safety, 2021)

⁴ (Australian Government Department of Health, 2021)

⁵ (Royal Commission into Aged Care Quality and Safety, 2021)

⁶ (Australian Government Department of Health, 2021)

⁷ (Royal Commission into Aged Care Quality and Safety, 2021)

⁸ (Australian Government Department of Health, 2021)

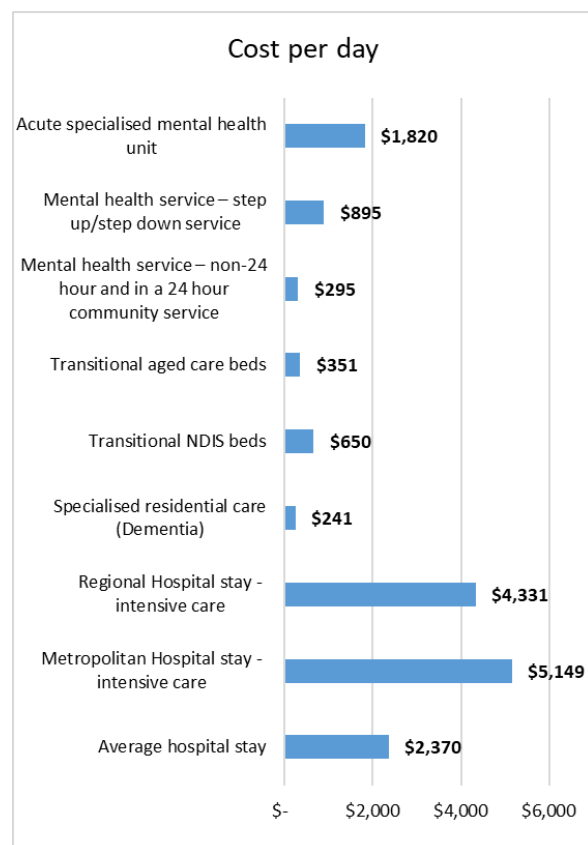
While the New Aged Care Act exposure draft makes reference to needing to ‘recognise’ carers, it fails to acknowledge the need for carers to have their own supports, and certainty of these supports. Through this exclusion, the Act does not give effect to the policy intent and the Royal Commission’s vision for the future of aged care.

In particular, the Act’s direct consideration of carers is limited to the items below. While these are appreciated, there is no mechanism to enforce these items, with even the *Carer Recognition Act 2010* not being enforceable. More is needed to be done to realise the vision of the Royal Commission into Aged Care for carers.

- Section 7 – defining who is a carer and who is not a carer.
- Section 20 (11) – the right of an individual to have persons significant to them, including carers, be acknowledged and respected.
- Section 22 (7) – recognition of the valuable contribution carers make to society, consistent with the *Carer Recognition Act 2010*, and carers should be considered partners with registered providers who deliver funded aged care services.

Tangible recognition of carers is particularly necessary when considering the reliance on carers within the aged care system, particularly when retaining the independence of an older person within their own home. Nationally, the care which carers provide is valued at \$77.9 billion per year and amounts to 2.2 billion hours of unpaid care per year. This is aside from the personal impact of caring on a carer’s general and financial well-being.

Indeed, 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 report having good health, compared to 47.9% for the average Australian⁹. Further, by age 67 primary carers will lose \$175,000 in superannuation and \$392,500 in lifetime earnings. Additionally, for every year someone is a primary carer they will lose on average \$17,700 in superannuation and \$39,600 in lifetime earnings¹⁰.



As demonstrated in the graph ‘Cost per day’, the indicative costs of alternate care arrangements for a person who does not have an informal carer, can be high.

⁹ (Schirmer, Mylek, & Miranti, 2022)

¹⁰ (Furnival & Cullen, 2022)

When considered on an annual basis, the value of carers becomes even more clear, especially in the case of a long stay patient. Recently, the WA Office of the Auditor General estimated 486 patients waiting for NDIS or aged care services had spent about 40,000 days extra in hospital over a 13-month period, with the cost of care for this being approximately \$71.8 million.

In short, initiatives which support carers of older Australians, make economic sense due to the value of informal care provided and savings in comparison to the cost of other forms of care. The recommendations of the Aged Care Royal Commission recognise and reflect this fact, and the Australian Government response indicated that recommendations 1-3 of the Aged Care Royal Commission would be responded to through the Aged Care Act mechanism, including those involving carers.

Therefore, Carers WA recommends that:

1. Carers be legally recognized within the Act as eligible for support within the aged care system - including adequate, timely and locally based respite for informal carers of older people.
2. Incorporate within the Act carers' right to access supports in accordance with their needs.
3. Incorporate within the Act carers' right to access supports which enable reasonable enjoyment of the right to social participation.
4. Amend the Principles within the Act to:
 - Separate out the Principle 'An aged care system that values workers and carers' to be two separate Principles – 'An aged care system that values workers and volunteers' and 'An aged care system that values carers'. This separation will assist in distinguishing between a carer and an aged care worker or volunteer.
 - Include a section within the 'An aged care system that values carers' that carers of older people should have certainty that they will receive timely and high quality supports in accordance with assessed need (as per Recommendation 3 of the Aged Care Royal Commission Final Report).
5. Specific provision be made in in Section 392 (2) of the Act for:
 - grant purposes that include the provision of timely, local and equitable support for older people and their carers.

2.2 Regional, rural and remote

In Australia, about 28% of its population live in regional, rural or remote areas with poor access to specialist health services.¹¹ Australians living in rural and remote areas experience higher rates of hospitalisation, death and injury. However, they also have inferior access to and less use of primary health services – than Australians in major cities.¹²

In WA, carers and older people living in regional, rural and remote areas experience substantial barriers to accessing aged care services and specialist health services. These include extensive waitlists for services and residential care; services not being available locally; and high costs for services.

Albany and the Great Southern region

In Albany and the Great Southern region, the community reported substantial concerns around a lack of access to specialist services in the Great Southern, particularly in remote or outer areas. This was particularly true of CHSP services in remote areas, with some feedback being that clients were being told to relocate as some providers could not service higher level care in remote areas.

Broome and the Kimberley region

Community feedback indicated that there were little to no service providers in remote areas of the Kimberley, and limited access to services even in Broome.

This included support workers, allied health providers, etc. This made accessing supports for those needing them extremely difficult. This is significant for carers as these services reduce their caring responsibilities. Carers end up taking on a bigger role than they otherwise would have. This has contributed to substantial demand for respite and support for carers.

Kalgoorlie and the Goldfields region

Carers and service providers in the WA Goldfields region report being forced to move to metropolitan areas to access healthcare; and accessing occupational therapy, or other allied health services. Where the family moving away works in these allied health services, worker shortages in these vital professions are exacerbated. One service provider aptly termed this as ‘when people get sick, they either move to access healthcare – or they die’.

Health services in the Kalgoorlie and Goldfields region were described as having a lack of availability, extensive waitlists and high costs for services. The community anecdotally provided examples of extreme situations undertaken to ensure access to healthcare, including: doctors needing to be flown in from New Zealand in FIFO arrangements; and where allied health services have been flown in, reports of these costs being added to the cost of the appointment.

¹¹ (Australian Institute of Health and Welfare, 2023)

¹² (Australian Institute of Health and Welfare, 2023)

In particular, carers across all regions of WA are experiencing a lack of access to respite, carer retreats and the ability to take a break from their caring role. This is more pronounced in regional, rural and remote areas of WA. Carers in these areas are in dire need of these services, especially amidst workforce issues in the sector resulting in increased caring responsibilities. These challenges need to be reflected within the new Aged Care Act, with allowances for innovative solutions.

Carers WA recommends:

6. Specific provision be made in Section 392 (2) of the Act for:
 - grant purposes for rural, regional and remote areas experiencing challenges in the aged care sector and provision of relevant specialist health services to older people and their carers.

2.3 Clarity and Education

Within Carers Australia's submission to this consultation, concerns were raised in regard to conflicts which may arise between representatives appointed under the Act, and guardianships under State and Territory law, which result in comparable decision making ability in similar domains. Further prospective conflicts were also raised for if representatives do not agree, resulting in difficulties for all parties involved. There is a need for further clarity and guidance around the decision making processes for guardians, representatives and supporters. This clarity also needs to specifically mention within the 'Duties of the representative', that they take reasonable steps to also consult with carers where appropriate.

It is also not clear as to why an older person can only have one or more supporters, or one or more representatives, when these differing roles working in tandem could offer much benefit to the older person.

Carers WA recommends:

7. Clarity and education be provided around:
 - The role of a carer in relation to the roles of supporters and representatives.
 - The responsibilities of supporters and representatives, offences and consequences for committing an offence.
 - Supported decision making education.
8. Section 30, 3d(iii) of the Act be amended to read 'when appropriate, any other person who assists the individual to manage the individual's day-to-day activities or, if there is no such person, any family members, carers, or other persons who have a close continuing relationship with the individual'.
9. Decision making processes be clarified for guardians, representatives, supporters and carers.

10. Older people be encouraged to have an Enduring Power of Attorney, Enduring Power of Guardianship and Advanced Health Directive in place to offer guidance on their wishes to guardians, representatives, supporters and carers. These are also recommended to give older people the right to:
 - Retain and choose their own doctor when entering residential care.
 - The right to die well, and have information and access to palliative care and end of life care when required.
11. Older people be allowed to have both supporters and representatives.

2.4 Review Period

Carers WA is pleased that a review period has been incorporated into the draft Act. However, a five year wait for a review of the Act and the success of its practical application, is too long – especially for the current and future importance of the aged care sector.

Further, although there will be an annual report on the operation of the Act, the Association believes the report should also include information on the following areas: the reasoning for unmet demand for funded aged care services; how aged care needs are being met in rural, regional and remote areas; and how the aged care sector is supporting carers – i.e. number of referrals to carer support services, etc.

Carers WA recommends that:

12. The first review of the new Aged Care Act be undertaken three years after the commencement of the Act, and every five years thereafter.
13. Section 411 (2) of the Act be amended to require the annual report on the operation of the Act to include the reasoning for unmet demand for funded aged care services; how aged care needs are being met in rural, regional and remote areas; and how the aged care sector is supporting carers – i.e. number of referrals to carer support services, etc.

3.0 Conclusion

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.

4.0 References

- Australian Government Department of Health. (2021). *Australian Government Response to the Final Report of the Royal Commission into Aged Care Quality and Safety*. Canberra: Commonwealth of Australia. Retrieved from <https://www.health.gov.au/sites/default/files/documents/2021/05/australian-government-response-to-the-final-report-of-the-royal-commission-into-aged-care-quality-and-safety.pdf>
- Australian Institute of Health and Welfare. (2023, September 11). Rural and remote health. Australia. Retrieved from <https://www.aihw.gov.au/reports/rural-remote-australians/rural-and-remote-health>
- Commonwealth of Australia. (2010). Carer Recognition Act 2010. Canberra, ACT, Australia. Retrieved from <https://www.legislation.gov.au/Details/C2010A00123>
- Furnival, A., & Cullen, D. (2022). *Caring Costs Us: The economic impact on lifetime income and retirement savings of informal carers*. Canberra: Evaluate and Carers Australia. Retrieved from <https://www.carersaustralia.com.au/wp-content/uploads/2022/04/Final-Economic-impact-income-and-retirement-Evaluate-Report-March-2022.pdf>
- Royal Commission into Aged Care Quality and Safety. (2021). *3. Recommendations*. Canberra: Royal Commission into Aged Care Quality and Safety. Retrieved from <https://www.royalcommission.gov.au/aged-care/final-report>
- Royal Commission into Aged Care Quality and Safety. (2021). *Final Report - 3. Recommendations*. Canberra: Royal Commission into Aged Care Quality and Safety. Retrieved from <https://www.royalcommission.gov.au/aged-care/final-report>
- Schirmer, J., Mylek, M., & Miranti, R. (2022). *Caring for others and yourself: 2022 Carer Wellbeing Survey*. Canberra: Carers Australia & University of Canberra. Retrieved from https://www.carersaustralia.com.au/wp-content/uploads/2022/10/2022-CWS-Full-Report_221010_FINAL.pdf