



**Carers Tasmania Submission on the  
National Inquiry into Carer Recognition**

**August 2023**



## About Carers Tasmania

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers (hereafter carers) in the state.

Carers Tasmania's vision is for an Australia that values and supports carers.

Our mission is to work to improve the health, wellbeing, resilience and financial security of carers and to ensure that caring is a shared responsibility of family, community, and government.

Our values drive everything we think, say, and do.

- **Carers first** – we listen to what carers need, commit to their desired action plan, and deliver results that matter most to carers
- **Care in all we do** – we care for our work, about each other, about Tasmania's family and friend carers, and the bigger world we all share
- **Integrity always** – we are transparent, act ethically, own when things don't go to plan and do what we say we will
- **Quality every time** – we don't accept 'good enough' because carers deserve our very best every time
- **Speed that matters** – we are agile and don't put off what can be done today.

These values represent how we engage with and serve carers, how we work with each other, and our commitment to the broader community. Carers Tasmania encourages partnership with governments and health and community sectors to enhance service provision and improve conditions for family or friend carers through policy development, research and advocacy.

We acknowledge and support people of all genders, sexualities, cultural beliefs, and abilities and understand that carers in Tasmania, whilst sharing the common theme of caring for a family member or friend, are diverse individuals with varying beliefs, experiences, and identities. We value and respect the diversity of carers, their lived and living experiences, and recognise that carers are the experts in their own lives.

Carers Tasmania has offices in Moonah, Launceston and Burnie.

Please direct any enquiries about this report to:

Dr. Samantha Fox  
Chief Executive Officer  
Phone: (03) 6144 3700  
Email: [ceo@carerstasmania.org](mailto:ceo@carerstasmania.org)

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## 1. Background

Carers Tasmania is the Peak Body representing the more than 80,000 informal carers within the state.

A carer is a person who provides unpaid care and support to a family member, or friend, with disability, mental ill health, a chronic or life-limiting condition, alcohol or other drug dependence, or who are frail or aged. Informal kinship carers who care for a child under the age of 18, because the parent is unable to, are also recognised as carers. Carers are predominantly family members, but may also be friends, neighbours, or colleagues. Informal carers are not to be confused with paid support workers who are often called 'carers', with the difference being that support workers are fully employed and remunerated with all the benefits of employment. On the contrary, informal carers perform their caring duties without remuneration, other than minimal carer payments and allowances from the Australian Government.

In addition to representing carers through the Peak Body activities, Carers Tasmania provides support to carers living in Tasmania through its service delivery arm, Care2Serve. The Commonwealth Carer Gateway program is delivered through Care2Serve in Tasmania, as are other supports and services, such as the Tasmanian Government's Home and Community Care program.

The Carer Gateway program provides a range of services and supports for carers which are designed to build resilience, increase wellbeing, improve quality of life, and sustain carers to effectively continue their caring roles. The available supports include the provision of information, advice and referrals, holistic identification of carer strengths and needs through a carer support planning process, professional counselling, peer support, and coaching which aims to support carers in achieving specific goals.

Care2Serve, through the Carer Gateway, has capacity to fund certain instances of planned, practical support services such as in-home respite, personal care, domestic assistance, and meal preparation. Care2Serve may also fund items such as laptops to assist carers who are studying or trying to enter the workforce. Care2Serve also coordinates the provision of emergency support during instances where a carer may be unable to provide the care that they usually do, resulting from unexpected illness or injury of the carer.

## 1. Introduction

Carers Tasmania welcomes the Inquiry into the Recognition of Unpaid Carers by the House of Representative Standing Committee on Social Policy and Legal Affairs.

We note that the Terms of Reference (ToR) are seeking to better understand:

1. The effectiveness of the *Commonwealth Carer Recognition Act 2010 (the 2010 Act (Cth))* and the associated Statement of Australia's Carers in raising recognition and awareness of the unpaid caring role, including its obligations on public service agencies.
2. Developments in the policy landscape at a Commonwealth level since the Act's passage in 2010.
3. The effectiveness of existing state, territory, and international recognition of unpaid care (statutory or other practice).
4. How to better identify the role of unpaid carers in Australian society and the role of a reformed Act, with regard to:
  - a. Understanding the value of unpaid care,
  - b. The needs of specific cohorts such as young carers, First Nations carers, LGBTIQ+ carers, or culturally and linguistically diverse carers,
  - c. The meaningful role that flexible workplaces play in unpaid care, and
  - d. The Government's broad agenda in relation to the care and support economy, the importance of employment participation, and a strong focus on gender equity, and
5. Any other related matters, noting that the adequacy of payments for carers is out of scope for this inquiry.

Given the ten-page limitation per submission for this inquiry, our submission only broadly addresses the ToR. We highlight that to respond effectively to the ToR, ten pages is inadequate, given the large scope of the ToR.

In addition to our response, we seek for consideration to be taken of submissions provided by Carers Australia and the other national state and territory carer organisations. We highlight that across the Carers Australia Network, there is a large, collective body of research and policy knowledge that is relevant to this inquiry.

## 2. What do we continue to hear from carers?

Across Australia, carers continue to go unrecognised, they are often excluded, and despite the significant support contributions to their family members and friends, they are considerably undervalued. As a result of the lack of appropriate recognition and support whilst caring for others, carers face poor health and wellbeing outcomes, social isolation, financial implications, and reduced capacity to undertake or sustain suitable employment or educational options.<sup>1</sup>

Many years have passed since the enactment of the *2010 Act (Cth)* and the associated 2011 Carer Strategy<sup>2</sup>. However, carers continue to report that they face a lack of recognition, that they are not included, and they are unsupported. The following comments were received through surveys by Carers Tasmania, between 2021 and 2023.

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<sup>1</sup> [https://www.carersaustralia.com.au/wp-content/uploads/2022/10/2022-CWS-Full-Report\\_221010\\_FINAL.pdf](https://www.carersaustralia.com.au/wp-content/uploads/2022/10/2022-CWS-Full-Report_221010_FINAL.pdf)

<sup>2</sup> <https://www.carersaustralia.com.au/wp-content/uploads/2020/08/2011-National-Carer-Strategy.pdf>

## **What would good carer recognition and being treated as a valued member of the care team look like to you?**

*"To be provided with a card and be recognised more than we are. It's a full-time job."*

*"Being listened to. Being listened to by medical professionals."*

*"It recognises that the caregiver is an individual who also has needs and wants."*

*"Please include a statement about the value of carers to society. The role of a carer is not recognised or treated with the same respect as a person with a paid full-time job. Carers do not get weekends off or annual leave. It can be a very stressful job, unpaid as it takes a huge toll physically, emotionally on the carer. This creates increased financial cost on the carer as they seek medical/allied health care for their own deteriorating condition."*

*"More communication and respect. More information on services for both the person in care and the carer. More support services. More rights to help those in your care. More information on how to report abuse, complaints etc."*

*"To be included in the conversation, asked to share my perspective and the things I do valued by service providers."*

*"It would be a whole lot different. I would feel more comfortable at not being made to feel like I don't know anything."*

*"Value put on caring role, decision making, and moral support. This work is done out of love care and commitment. It is not for money or glory."*

*"I would be included in decisions relating to significant medication changes. I am not. Ever. I would be interviewed at least once in the annual treatment of a seriously compromised husband with mental health issues. I am not. I would be recognised as vital to his sustainable life. I am not."*

## **Which agencies or service providers would be least likely to identify you as a carer?**

*"Government, i.e., Centrelink, Medicare, etc. I tend to avoid dealing with them as much as possible, it's too hard."*

*"All of them."*

*"Most government agencies but again dependent on who you get."*

*"NDIS."*

## **3. Response to the Terms of Reference**

Carers Tasmania believes that the Commonwealth Act is outdated, not routinely used, and requires amendment. Whilst we propose some initial recommendations in this submission regarding amendments to the 2010 Act (Cth), we believe further and thorough consultation, directly involving carers, should occur across Australia.

### **Definition of carer**

There are discrepancies between who is considered a carer by different Australian states and territories. Tasmania was the last state to pass Carer Recognition legislation, with the *Carer Recognition Act 2023* (Tas) enacted in April 2023. The definition of carer in this legislation is person-centred and inclusive. This inclusive definition aims to reduce stigma and ensure that as many carers as possible can access support.

Tasmania is the only state to formally recognise through legislation, people who are supporting a person with alcohol or other drug dependence. This cohort of carers is not recognised in the *2010 Act* (Cth).

The Tasmanian Act also does not reference specific disability legislation under the carer definition, when referring to caring for people with disability. This was something that Carers Tasmania strongly advocated for within the Tasmanian legislation, as this legislation (refer to list below) excludes people with a disability that is not long-term or permanent.

- *Disability Services Act 1993* (WA)<sup>3</sup>
- *Disability Inclusion Act 2018* (SA)<sup>4</sup>
- *Disability Services Act 1993* (NT)<sup>5</sup>
- *Disability Inclusion Act 2014* (NSW)<sup>6</sup>

Not all people with a disability have a long-term or lifelong disability, but this does not negate the need for support to be provided by carers when a disability is short-term or episodic in nature.

We also emphasise the importance of using best-practice language when referring to people with disability. In providing a response to the Tasmanian Act, we sought guidance from the *People with Disability Language Guide Australia*.<sup>7</sup>

Carers Tasmania also successfully advocated for the use of the wording 'mental ill health' in comparison to 'mental illness' within the Tasmanian Act. This was to acknowledge the sometimes-episodic nature of supporting a person with mental ill health and those without a diagnosis of mental illness. Providing care to someone experiencing mental ill health can, at times, be very complex.

We also highlight that there are discrepancies across the different state and territory legislation around informal kinship carers, grandparent carers, and foster carers. The definition of carer in the *2010 Act* (Cth) does not explicitly recognise informal kinship carers, grandparents, or foster carers who care for a child when their parent is unable to. These carers will only be captured by the definition if the child has a disability, mental illness, a chronic or life-limiting condition, alcohol or other drug dependence. Some state-based legislation supports different types of caring scenarios under carer recognition legislation, for example, Tasmania, the ACT, and QLD (refer to table overleaf).

We also draw attention to young carers. Young carers are people aged under 25 who provide care to a family member or friend. The *2010 Act* (Cth) does not directly exclude young carers, but it does not explicitly refer to them either. We thank the Australian Government for their work to date in supporting young carers, especially recent increases to the Young Carer Bursary. However, we highlight that for a young carer to become aware of available supports, they need to be able to identify themselves as a young carer, or be referred by teachers, wellbeing staff, health professionals, and others in the community. A

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[https://www.legislation.wa.gov.au/legislation/prod/filestore.nsf/FileURL/mrdoc\\_45947.pdf/\\$FILE/Disability%20Services%20Act%201993%20-%20%5B04-g0-00%5D.pdf?OpenElement](https://www.legislation.wa.gov.au/legislation/prod/filestore.nsf/FileURL/mrdoc_45947.pdf/$FILE/Disability%20Services%20Act%201993%20-%20%5B04-g0-00%5D.pdf?OpenElement)

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[https://www.legislation.sa.gov.au/\\_\\_\\_legislation/lz/c/a/disability%20inclusion%20act%202018/current/2018.1.auth.pdf](https://www.legislation.sa.gov.au/___legislation/lz/c/a/disability%20inclusion%20act%202018/current/2018.1.auth.pdf)

<sup>5</sup> <https://legislation.nt.gov.au/en/Bills/Disability-Services-Bill-1993-S-219?format=assented>

<sup>6</sup> <https://legislation.nsw.gov.au/view/pdf/asmade/act-2014-41>

<sup>7</sup> <https://pwd.org.au/wp-content/uploads/2021/12/PWDA-Language-Guide-v2-2021.pdf>

stronger focus is required to raise awareness of young carers, with a strategic aim of reducing the stigma and concern associated with identification.

Jurisdiction	Definition
Commonwealth	(3) To avoid doubt, an individual is not a <b>carer</b> merely because he or she: (a) is the spouse, de facto partner, parent, child or other relative of an individual, or is the guardian of an individual; or (b) lives with an individual who requires care.
Tasmania	Under the definition: (f) is a child, if the person is an informal kinship carer of the child; <b>child</b> means a person under 18 years of age;
Queensland	(2) Also, a grandparent is a carer of his or her grandchild if— (a) the child lives with the grandparent; and (b) the grandparent is the primary care-giver and decision-maker for the child. (3) However, if a child's parent or parents remain the primary care-givers and decision-makers for the child, the child's grandparent is not the child's carer only because— (a) the grandparent cares for the child while the child's parent or parents are working; or (b) the child, together with the child's parent or parents, lives with the grandparent.
Australian Capital Territory	(e) the other person is a child or young person, and the carer is a kinship carer or a foster carer for the child or young person.

### Additional action required

In addition to ensuring that the language used in the definition is consistent, inclusive, and best practice, Carers Tasmania provides the following recommendations based on consultation with carers.

We highlight the Statement of Australia's Carers within the *2010 Act* (Cth) and recommend this be amended to a Carers Charter of Rights. Other Commonwealth documentation that uses a rights-based approach includes the *Aged Care Charter of Rights*<sup>8</sup> and the *Australian Charter of Healthcare Rights*.<sup>9</sup> Implementing a human-rights-based approach is critical to reducing discrimination and upholding the rights of carers, whilst they are trying to support others. When consulting with carers on the Tasmanian carer recognition legislation, our survey found that 75% of carers agreed that the charter should be a charter of rights.

Amendments must be made to the *2010 Act* (Cth) to increase accountability. In Tasmania, the previous Carer Issues Reference Group was elevated to a Minister's Carer Advisory Council (MCAC), which includes five members with lived or living experience as a carer. A function of the MCAC is to monitor the implementation of the Tasmanian Act and progress against the Tasmanian Carer Action Plan. In addition, the Minister must report annually to Parliament on progress towards defined actions. In a survey on the Draft Tasmanian Carer Recognition Bill,<sup>10</sup> 93% of the survey respondents indicated they felt the Minister should report to Parliament about the activities of Government to support carers.

<sup>8</sup> <https://www.agedcarequality.gov.au/sites/default/files/media/charter-of-aged-care-rights-signing-template.pdf>

<sup>9</sup> <https://www.safetyandquality.gov.au/sites/default/files/2019-06/Charter%20of%20Healthcare%20Rights%20A4%20poster%20ACCESSIBLE%20pdf.pdf>

<sup>10</sup> [https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-Submission-on-the-Draft-Carer-Recognition-Act-2022\\_.pdf](https://www.carerstas.org/wp-content/uploads/2017/06/Carers-Tasmania-Submission-on-the-Draft-Carer-Recognition-Act-2022_.pdf)

Carers Tasmania also suggests the inclusion of a review date into the legislation, to ensure regular opportunities to review the legislation, so that it continues to be fit-for-purpose.

An up-to-date National Carer Strategy must be developed. Progress on the previous Strategy should be documented and shared, highlighting items that were not fulfilled or properly implemented. Authentic consultation with carers must also occur as part of this. This must specifically include carers such as:

- Young carers
- First Nations carers
- LGBTIQA+ carers
- Culturally and linguistically diverse carers
- Carers who have disability or health concerns of their own
- Working carers or those trying to enter the workforce.

Consultation should also include carers from other marginalised groups or locations who may not usually be able to participate in more general forms of consultation.

The previous National Carer Strategy from 2011, contained six priority areas for action:

- Recognition and respect
- Information and access
- Economic security
- Services for carers
- Education and training
- Health and wellbeing.<sup>11</sup>

Despite these being defined as priority areas over a decade ago, these continue to be areas of great concern for carers and remain matters of priority.

The updated National Carer Strategy should specifically focus on the policy pillars of the Carers Australia Network:

- The economic security of carers (although the Inquiry states that payment for carers is out of scope, the economic security of carers is a key priority)
- Health and wellbeing of carers
- Carer recognition, representation, and inclusion.

Routine identification, recognition, inclusion, and referral to support must occur across both State and Commonwealth services. Carers repeatedly inform us that this is not occurring. With the introduction of the Tasmanian *Carer Recognition Act*, Carers Tasmania is supporting carers to advocate when utilising state-funded services, using the Carers Charter included in the legislation. Further education and awareness raising will occur to support Tasmanian state service agencies to understand their support obligations. We suggest that a targeted and strategic approach to the education of employees working across the Australian Public Service and Commonwealth-funded services also occurs so that staff are educated on their responsibilities upon engaging with carers.

Progress on the updated National Carer Strategy must be monitored and be visible to the public. Carers Tasmania believes that the Strategy should be mandated as part of the Act, along with a requirement for progress to be monitored and reported on to the public and to Parliament. The previous Strategy was not monitored effectively. The updated National

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<sup>11</sup> <https://www.carersaustralia.com.au/strategic-plan/national-carer-strategy/>

Carer Strategy must set strong obligations on the Australian Public Service about including carers in policy and practice and using clear and consistent language about carers across all policies, programs, and associated documents.

It is further recommended that an 'Office for Carers' is established to oversee amending the legislation, redeveloping the National Carer Strategy, and ensuring carer-inclusive practice across all government departments. This would be led by dedicated staff who are knowledgeable about the history of carer services and policy changes over time.

In addition, public and private hearings should be held on the legislative amendments and updating the Carer Strategy, to provide an opportunity for carers in Tasmania and across Australia to participate and provide feedback, should they wish to do so.

It is imperative that the legislation and associated strategy contain meaningful actions to support carers, that are relevant to carers, and will make positive differences in their lives.

## 4. Summary of Recommendations

Carers Tasmania recommends the following:

- Amend the definition of carer in the Commonwealth legislation to be more inclusive, and to specifically recognise informal kinship carers, carers supporting people who have alcohol or other drug dependence, and carers supporting people experiencing mental ill health.
- Develop and introduce an updated National Carer Strategy, through equitable consultation with carers from a broad range of cohorts, to capture feedback from different caring circumstances. The updated Strategy must recognise and identify actions to better support different carer groups based on the previous strategy priority areas, as well as the policy pillars of the Carers Australia Network.
- Update the Statement of Australia's Carers within the *2010 Act* (Cth) and transform it into a Carer Charter of Rights.
- Ensure full and adequate engagement on the legislative amendments and updating of the National Carer Strategy, including public and private hearings, to provide an opportunity for carers in Tasmania and across Australia to participate and provide feedback.
- Establish an 'Office for Carers' to oversee legislative amendment and related activities, redeveloping the National Carer Strategy, and ensuring carer-inclusive practice across all government departments.
- Develop and implement a targeted approach across the Australian Public Service and Commonwealth-funded agencies to ensure routine identification of carers, recognition, inclusion, and referral to support.
- Increase accountability by introducing a requirement for the Minister to report to Parliament on the implementation of the legislation and updated National Carer Strategy.
- Specify a review date for the legislation, associated Carer Charter of Rights, and National Carer Strategy.