

## Response to the Department of Health and Age Care Consultation on New Aged Care Act: the Foundations (Consultation 1)

September 2023

### Introduction

Carers Australia welcomes the opportunity to respond to the Department of Health and Aged Care [Consultation Paper](#). While we have a strong understanding and focus on the impact of a new Aged Care Act (the 'Act') on older people receiving aged care services, this submission is specifically focused on the inclusion and rights of carers under the Act.

The adequacy of and access to the aged care system, and the way in which it is delivered, is of primary importance to carers of older people, both because they want the best for those they care for and because it has the capacity to alleviate their own caring responsibilities which tend to dwarf the care provided by the aged care workforce.

In 2020, a Deloitte Access Economic analysis of the value of unpaid carer estimated that carers contributed about 2.2 billion hours of care per year, valued at a replacement cost of \$77.9 billion dollars.<sup>1</sup>

The 2018 Australian Bureau of Statistics (ABS) Survey of Disability, Ageing and Carers (SDAC)<sup>2</sup> identified that 35.3% of Australia's 2.8 million family and friend carers cared for someone over the age of 65. Indeed, a quarter of all carers were themselves over the age of 65. Forty five percent of primary carers over the age 65 provided 40 hours per week or more to someone with a profound core activity limitation and 12.5% to someone with a severe core activity limitation. Seventy six percent of carers over 65 provided care to a partner.

In addition to paid support for the person they care for, carers rely on the aged care system for key supports for themselves. This includes respite from caring, education and training in providing care and accessing services, some one-to-one support services such as the Dementia Behaviour Management Advisory Service (DBMAS), and some advocacy services.

According to the 2021 Carer Wellbeing Survey<sup>3</sup>, the carers most likely to have accessed respite services in the past 12 months included those who cared for someone with dementia (41%), carers of the terminally ill (39.9%), and carers of someone with old age frailty (34.6%). Those most likely to have accessed training

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<sup>1</sup> Deloitte Access Economics, Value of Informal Care, 2020, [\[accessed online\]](#)

<sup>2</sup> Australian Bureau of Statistics (ABS), Survey of Disability, Ageing and Carers, 2018, Carers Tables [\[accessed online\]](#)

<sup>3</sup> University of Canberra, 'Caring for Yourself and Others, 20201 Carer Wellbeing Survey Full Data Report', commissioned by Carers Australia [\[accessed online\]](#)

courses or coaching included carers of people with dementia (30.3%), however older carers and those caring for more than 40 hours a week were less likely to access this support than younger carers.

Despite the introduction of the *Carers Recognition Act 2010*<sup>4</sup> and the subsequent introduction of the National Carer Strategy Action Plan (2011-2014)<sup>5</sup>, neither the Act nor the Strategy appeared to have informed the Living Longer, Living Better aged care reforms implemented in 2014. For example, the reforms did not produce discernible improvements in access to respite in either residential care facilities or in the community. The inadequacy of access to respite was commented on in the 2017 Tune Review of Aged Care<sup>6</sup> and resulted in an Aged Care Financing Authority (ACFA) review of respite in 2018 with 19 recommendations for improvements<sup>7</sup>. These were not acted on at the time because they were inter-related with other changes in aged care that were still in development. As in the past, carer needs seemed to fall to the bottom of the list of priorities for aged care.

The need for improved carer recognition and for improved support, including respite, featured in the Final Report and Recommendations of the Royal Commission into Aged Care Quality and Safety<sup>8</sup>.

It is not surprising that the Royal Commission identified that:

*“The Australian Government should ensure that informal carers are properly supported. The current aged care system fails to do so and provides reactive, inadequate support. Supports are often not provided until the strain on a caring relationship has already reached crisis point.”<sup>9</sup>*

## Recommendations of the Royal Commission into Aged Care Quality and Safety with Respect to Carers

In its first recommendation, the Commission provided a definition for a new Aged Care Act which included the entitlements of older people accessing the aged care system and support for carers.

The Commission went on to make a number of recommendations with specific application to a range of respite services, training and education, counselling, and navigation services enabling direct referral and information sharing for informal carers between My Age Care, care finders, assessment services and the Carer Gateway.

**Importantly, the Commission made recommendations in relation to carers’ rights and their inclusion in the key principles to be established in Act.** These are expanded upon below.

**Indeed, the Royal Commission in its Final Report specifically referenced the Statement for Carers in the *Carer Recognition Act* as a foundation for the new Aged Care Act:**

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<sup>4</sup>Federal Register of Legislation, *Carer Recognition Act (2010)* [\[accessed online\]](#)

<sup>5</sup> Department of Social Services, National Carer Strategy: Action Plan (2011-14) [\[accessed online\]](#)

<sup>6</sup> Legislated Review of Aged Care Report (Tune Review), 2017, [\[accessed online\]](#)

<sup>7</sup> Department of Health and Aged Care, ACFA Report on Respite for Aged Care Recipients, 2018, [\[accessed online\]](#)

<sup>8</sup> Royal Commission into Aged Care Quality and Safety, 2021, Final Report: Care, Dignity and Respect, [\[accessed online\]](#)

<sup>9</sup> Ibid., Executive Summary, page 103

*[T]he system of entitlements under the new Act should extend not only to people receiving aged care, but also to those seeking it. They should also extend to family members and friends who undertake significant carer-related responsibilities—people we refer to as ‘informal carers’. **The inclusion of entitlements for informal carers in the new Act is consistent with the principles expressed in the Carer Recognition Act 2010 (Cth). However, unlike the Carer Recognition Act, the new Act should provide means of enforcing those entitlements.***<sup>10</sup>

Particularly significant within the Statement for Australia’s Carers in the aged care context are:

- 4 Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.*
- 5 Carers should be acknowledged as individuals with their own needs within and beyond the caring role.*
- 6 The relationship between carers and the persons for whom they care should be recognised and respected.*
- 7 Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.*
- 8 Carers should be treated with dignity and respect.*
- 10 Support for carers should be timely, responsive, appropriate and accessible.*

**Against this background, we are very disappointed that the Consultation Paper does not embody these recommendations.** Indeed, carers are only mentioned twice in the substance of the paper: once in relation to a broad reference to complaints and feedback mechanisms and again with reference to whistleblower legislation. We find this astonishing against the background where:

- carers are an essential component of the aged care system and economy,
- they access services and supports through that system in order to sustain care, and
- given the commentary and recommendations of the Aged Care Royal Commission.

## The Statement of Rights

The Statement of Rights identified in the Royal Commission’s report included the following:

*2(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*<sup>11</sup>.

As identified in the Consultation Paper, the Commonwealth Government must rely on its ‘external affairs power’ provided in s51 (xxix) of the Constitution and the ratification of international treaties to insert human rights into its legislation. The two treaties relied upon for the new Aged Care Act

<sup>10</sup> Royal Commission into Aged Care Quality and Safety, 2021, Final Report. Vol.3A, page 6 [emphasis added] [\[accessed online\]](#)

<sup>11</sup> Royal Commission into Aged Care Quality and Safety, 2021, Final Report, Recommendations

are United the Nations Convention on the Rights of People with Disability (CRPD)<sup>12</sup> and the International Covenant on Economic, Social and Cultural Rights (ICESCR)<sup>13</sup>.

While the CRPD offers little in the way of specific rights of carers, it does confer some rights on families which can be applicable. For example, in the preamble to the Convention it is stated that:

*The family is the natural and fundamental group unit of society and is entitled to protection by society and the State, and that persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”.*

Then there is Article 28:3 in relation to families living in poverty:

*To ensure access by persons with disabilities and their families living in situations of poverty to assistance from the State with disability-related expenses, including adequate training, counselling, financial assistance and respite care.*

Carers Australia notes the common issue that not all carers are family members in the common meaning of the term. Many carers are friends of the person they are caring for and would not be included in this definition unless the term “family” was intended to include “chosen family”. Article 28.3 does identify the right for carer support which should be applicable to the Aged Care Act, however these supports should be available to carers whether or not they live in situations of poverty.

To the extent that it identifies general rights, the ICESCR may be more applicable to the Royal Commission’s recommendation with respect to the right of carers to access support to facilitate social participation. These rights include:

- self determination and to freely pursue their economic, social and cultural development.<sup>14</sup>
- To take part in cultural life.<sup>15</sup>
- The right to education.<sup>16</sup>
- The right to employment.<sup>17</sup>
- Equal opportunity for everyone to be promoted in his employment to an appropriate higher level, subject to no considerations other than those of seniority and competence.<sup>18</sup>
- The right to the enjoyment of the highest attainable standard of physical and mental health.<sup>19</sup>

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<sup>12</sup> United Nations Convention on the Rights of People with Disabilities [\[accessed online\]](#)

<sup>13</sup>International Covenant on Economic, Social and Cultural Rights (ICESCR) [\[accessed online\]](#)

<sup>14</sup> Ibid. Article 1.1

<sup>15</sup> Ibid. Article 15.1 (a)

<sup>16</sup> Ibid. Article 13:1

<sup>17</sup> Ibid. Part III, Article 6:1

<sup>18</sup> Ibid. Article 7 (c)

<sup>19</sup> Ibid. Article 12.1

**On this basis, Carers Australia sees no reason why the Commission's recommendation in relation to carers' rights should not be included in the Statement of Rights under the new Act.**

At the very least, some reference to the *Carer Recognition Act 2010* could be included in the Act. While it does not bind other acts, it provides guidance as to how carers should be regarded and treated within aged care.

## The Statement of Principles

The Royal Commission also referenced carers in the Key Principles guiding the Act. These included:

*3(bii) informal carers of older people should have certainty that they will receive timely and high quality supports in accordance with assessed need*

*3(bvi) the relationships that older people have with significant people in their lives should be acknowledged, respected and fostered<sup>20</sup>*

These principles reflect articles 6, 8 and 10 in the Statement for Australia's Carers in the *Carer Recognition Act* quoted above. Yet **neither of these principles are included in the fifteen principles underlying the Act identified in the Consultation Paper.**

These principles are not just window dressing. They are important to carers. As matters currently stand, the principles are not currently evident in the way many carers are treated or receive services within the aged care system. Ultimately they can make the difference between the caring relationship being sustained (or not).

Access to timely, high-quality respite has been a perennial problem for carers. Limited availability of either dedicated or residential respite has resulted in long wait times of many weeks or even many months. This is the case even for those who have an urgent need to access respite resulting from a health condition requiring surgery, or a family event a considerable distance away from their home which demands their attendance, or even just because they are so depleted they feel they cannot go on without a break.

We acknowledge that recent aged care reforms, such as more equalised subsidies to providers for permanent and short-term residents and developments in dementia respite, augur well for some carers in the future. However, the growing trend for older people and their carers to use residential respite care to try out the suitability of facilities for permanent care, or to finalise their administrative and contract arrangements with providers while occupying a place in the facility, can continue to block respite places for those carers who just need a break before they go back to caring at home. In 2021-22, 70,993 people received residential respite care, of whom 41,696 (approximately 58.7%) were later admitted to permanent care.<sup>21</sup> In 2019-20, of the 60,674 people who entered permanent residential care for the first

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<sup>20</sup> Royal Commission into Aged Care Quality and Safety, 2021, Final Report, Recommendations, Recommendation [\[accessed online\]](#)

<sup>21</sup> Department of Health and Aged Care, 2021-22 Report on the Operations of the Aged Care Act, page 18 [\[accessed online\]](#)

time, 53% entered permanent care on the same day they exited residential respite.<sup>22</sup> As far as short-term respite offered in dedicated facilities is concerned, such facilities are geographically unevenly distributed and often fail to meet demand. The capping of Home Carer Packages, delays in assessments and further delays in accessing services also impact on carers if respite is included in the package of the person they care for.

Nor are the relationships between older people and their carers routinely acknowledged, respected and fostered. Carers, the challenges they face, the significance of their relationship to those they care for, and their need for support have a very low profile within Australian society. Carers tend to think of themselves as invisible. The social and political lens is on those they care for, and carers tend to be seen as subsidiary background.

The invisibility of carers has been a central theme to emerge from the current [House of Representatives' Social Policy and Legal Affairs Committee Inquiry into the Recognition of Unpaid Carers](#). The need for carers to have their voice heard has too often fallen on deaf ears. The *Carers Recognition Act* itself is unfamiliar to many service providers in the aged care, disability care and health sectors, as it is to many Government departments whose policies directly impact upon them.

**For all these reasons we believe it is important the new Act's Principles reflect the recommendations of the Royal Commission.**

## Supported decision-making arrangements

Carers Australia has a strong interest in supported decision-making arrangements given that many carers perform this role.

We fully support the presumption outlined in the first recommendation of the Consultation Paper with respect to rights. This is that older people have the right to:

*exercise choice and make decisions that affect their lives, be supported to make those decisions where necessary, and have those decisions respected, including where they:*

- *involve personal risk, and*
- *are made in pursuit of quality of life, social participation or intimate relationships,*

This is acknowledging that in some cases they may have reached a stage of cognitive impairment which prevents them from exercising this right or if they want someone else to make these decisions on their behalf.

We agree that the introduction of formal nominee arrangements divided into the role of supporters and the role of representatives is a great improvement on the confusing array of nominee arrangements under the current Act. However, the new arrangements do seem to open their own can of worms in some instances, as identified below.

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<sup>22</sup> Australian Institute of Health and Welfare (AIHW), 2023, GEN Aged Care Data, Respite use on the way to permanent residential aged care

We agree that representatives should be duty bound to refrain from acting or making decisions on a person's behalf unless:

- *they are satisfied that it is not possible for the person to do, or to be supported to do, that act or make that decision themselves*
- *it is possible for the person to do the act or make the decision, but they want the representative to make that decision on their behalf.*

We also agree these arrangements should be confined to providing supported decision-making or, in the case of representatives, substitute decision-making only in relation to aged care. However, we are unclear about what happens if the older person already has a guardian under State or Territory law which confers the power to make decisions which overlap with those of the aged care representative. To take but one example, the NSW Government provides the following information with respect to guardianships<sup>23</sup>:

*A guardian makes healthcare, lifestyle and medical decisions for a set period of time. Their primary role is to ensure the person has access to the same care, treatment and services as the rest of the community. The types of decisions they may need to make for the person can include:*

- *where they live*
- *what services they receive*
- *consenting to their medical and dental treatment.*

As it stands, this description embodies a fair amount of overlap between the decision-making domain of an aged care representative appointed under the new Act and that of the state appointed guardian, unless of course they are the same person.

We are assuming that Powers of Attorney in relation to financial transactions will continue to rely on State and Territory legislation.

We are somewhat confused about the requirement to respect the decisions of older people, even they involve personal risk, and the third decision-making principle in the Consultation Paper which stipulates that:

*If it is not possible to determine what the person would likely want, the representative must act to promote and uphold the person's human rights and act in a way least restrictive of those rights **Note: a representative nominee may override the person's will and preferences only where necessary to prevent harm.***

We believe this principle needs some unpacking, especially with respect to the rather vague and subjective proposition "necessary to prevent harm".

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<sup>23</sup> NSW Trustee and Guardian, Information about Guardianships, [\[accessed online\]](#)

## Recommendations

1. The new Act should embody the recommendations of the Royal Commission into Aged Care Quality and Safety in relation to carers with respect to the Rights and Principles governing the new Aged Care Act.
2. Further clarification and consistency is needed between the roles of guardians and roles of representatives under the Act, and between the presumption of dignity of risk and the duty of guardians to protect the older person from risk.
3. When the draft Act is circulated later this year it should be accompanied by an accessible plain English version to assist the understanding of older people, their families and carers, and this version should be into the major languages spoken by older Australians from culturally diverse backgrounds.



## About Carers Australia

Carers Australia is the national peak body representing the diversity of the 2.65 million Australians who provide unpaid care and support to family members and friends with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness, or who are frail aged.

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

Our vision is an Australia that values and supports all carers, where all carers should have the same rights, choices, and opportunities as other Australians to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment, and education.

This includes carers:

- Who have their own care needs
- Who are in multiple care relationships
- Who have employment and/or education commitments
- Aged under 25 years (young carers)
- Aged over 65 years, including 'grandparent carers'
- From culturally and linguistically diverse backgrounds
- Who identify as Aboriginal and Torres Strait Islander
- Who identify as lesbian, gay, bisexual, transgender, intersex (LGBTI+)
- Who are living in rural and remote Australia, and
- Who are no longer in a caring role (former carers).

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples and communities as the traditional custodians of the land we work on and pay our respects to Elders past, present and emerging. As an inclusive organisation we celebrate people of all backgrounds, genders, sexualities, cultures, bodies, and abilities.

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