

# National Carer Strategy

Executive summary of consultation reports prepared by Carers Australia

Carers Australia is the national, peak body representing Australia’s 3 million carers<sup>1</sup> who provide unpaid or informal care and support to family members and friends with a disability, chronic condition, mental ill health, drug or substance abuse, terminal illness or who are frail and aged.

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

In July and August of 2024, Carers Australia undertook consultations with 486 carers from across Australia, via 55 consultation activities (**Table One**). Consultation activities included roundtables, focus groups, online workshops, in-depth interviews and outreach roundtables held in metropolitan, regional and remote locations in every state and territory. Consultation activities were supported and facilitated by the National Carer Network, Dementia Australia, Mental Health Carers Australia, Partners of Veterans, GLBTI Rights in Ageing (GRAI) and Eating Disorders Families Australia.

Carers Australia also facilitated a roundtable for carer service providers from around the country, to explore how services can be better adapted to meet carers’ needs.

**Table One:** Summary of consultation activities.

Consultation activity	Number of activities completed	Participants by activity type
Roundtables	4	100*
In-depth interviews	9	9
Focus groups	24	265
Online workshops	2	36
Outreach roundtables	4	64
Case study interviews	12	12
<b>Total</b>	<b>55</b>	<b>486</b>

\*Includes 12 carers organisation representatives who attended the Carer Service Providers roundtable.

<sup>1</sup> Australian Bureau of Statistics, Survey of Disability, Ageing and Carers, 2022

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

Carers Australia acknowledges Aboriginal and/or Torres Strait Islander peoples as the traditional custodians of the land on which we work, and pays its respects to Elders past, present and emerging.

Carer participants were from all stages and ages of the caring journey, living in metropolitan to remote locations and caring for people with a range of conditions and situation including mental ill health, veterans, dementia and those in palliative care. Despite the unique caring journey each carer experiences, universal themes identified included **carer fatigue, poor carer wellbeing, social isolation, poor interoperability between government services, system navigation issues** and the need for tailored, flexible **respite**. Carers also highlighted **financial distress**, a lack of **recognition from health professionals**, difficulties retaining **paid employment** and recognition of carers in the **education system** as key impact factors further negatively affected their wellbeing. Support for **former carers** also featured heavily in discussions.

Key issues identified by all carers included:

- the emotional and mental depletion arising from their caring role;
- employment and education challenges;
- financial challenges and stress;
- lack of information at point of diagnosis - struggling to find information about the services available to themselves and care recipients; be they aged care services, the NDIS, medical services, basic income support and assistance with particular expenses or peer support;
- service information and system navigation challenges (once services were identified);
- training in caring for people with particular conditions;
- lack of empathy and training demonstrated by paid support staff, and
- peer support and respite.

#### **Different carer cohorts face additional, or exaggerated challenges.**

In geographically isolated locations, these challenges were exacerbated by:

- additional costs associated with necessary travel to access medical assistance;
- scarcity and uncertainty of health, disability and substitute care in their local areas, especially for respite (provider deserts);
- the impact of provider deserts on carers' ability to participate in the paid workforce; and
- community stigma faced in some smaller communities due a lack of understanding of some health conditions and perceived perceptions in receiving carer payments.

A combination of the above issues often results in financial hardship and poorer mental wellbeing outcomes compared to metropolitan carers.

For young carers under the age of 25 years, who include school students, key issues included social isolation arising from young carers' lack of capacity to engage in social and school activities arising from their caring responsibility and study pressures:

- a lack of understanding by teachers/professors and school/university communities on a young carers' experience and challenges;
- a lack of recognition and support, especially from health professionals and educationalists;
- difficulty balance study, employment and caring responsibilities, affecting the young carers' career trajectory;
- challenging system navigation and access to supports; and
- feeling unsafe.

For carers aged 65 years and over:

- future planning for the person they care for is a concern that isn't well supported by current systems;
- navigating increasingly more complex systems is a key frustration;
- digital literacy can be a challenge;
- difficulty accessing respite has a direct impact on older carers physical and mental wellbeing, especially when supporting people living with dementia; and
- financial security – across a range of issues including future planning and accessing respite.

For culturally and linguistically diverse (CALD) carers:

- lack of provision of information in language;
- lack of provision of culturally appropriate care, including respite;
- a feeling that peer support groups are not always inclusive of all people; and
- stigma within their communities on both the condition of the person they care for and the role of a carer.

In every carer consultation, identity was flagged as a complex issue as not all carers use the term 'carer' or see themselves as carers; instead, carers often see themselves through the lens of the relationship they have with the person they care for. Carers also described how the person they cared for may resent the term carer, creating further barriers to self-identity. The term carer may also not be well received within some communities (for example CALD).

Many carers described a journey of discovery where it took years for them to articulate their caring role, and therefore years before discovering there may be supports available to them as the carer, in addition to supports they seek for the person they care for. It's clear from the consultations that identity is closely linked to access services and supports, and early identification of carers would proactively help prevent carers seeking help when they're in crisis.

Whilst caring is a constrained choice, carers are committed to providing the best possible care to the person they care for; this should not come at a cost to their own human rights including wellbeing, health or financial security. Further, carers living regionally or remotely, approximately 28% of carers, should not be disproportionately impacted by their location, nor should carers struggle to access and navigate supports because of their age, gender, sexuality or cultural identity.

The National Carer Strategy needs to ensure that all carers in Australia have access to supports and services, no matter their location or identity.